SOCIAL NETWORKS AND ENGAGEMENT WITH
MENTAL HEALTH SERVICES AMONG BLACK AFRICAN
AND CARIBBEAN PEOPLE DIAGNOSED WITH
NON-AFFECTIVE PSYCHOSIS

A thesis submitted to The University of Manchester for the degree of Doctor of
Philosophy in the Faculty of Biology, Medicine and Health

2017

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ABSTRACT

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy

Candidate: Amy Degnan          Date: September 2017

Title: Social networks and engagement with mental health services among Black African and Caribbean people diagnosed with non-affective psychosis

Black African and Caribbean people in the UK have the highest incidence rates of non-affective psychosis and the poorest access to, and experiences and outcomes of mental health services of all ethnic groups. Research and policies, including those written by the Department of Health and the National Institute for Health and Care Excellence, have repeatedly highlighted the need to reduce ethnic inequalities and improve engagement with mental health services among Black people with psychosis. Despite this, there is a current lack of evidence examining social and psychological factors that may facilitate better service engagement in this underserved group. Theories suggest engagement with services in minority ethnic groups may be influenced by social networks, illness beliefs, mental health stigma and perceived ethnic or racial discrimination in services.

The main aims of this thesis were to examine the social network characteristics in Black African and Caribbean people with non-affective psychosis and to develop psychological theories to explain engagement with mental health services in the UK. This thesis includes three separate papers. The first paper is a systematic literature review and meta-analysis examining the nature and strength of the relationships between social network size and symptomatic and functional outcomes in non-affective psychosis. The two succeeding papers report on a sample of Black African and Caribbean service users diagnosed with non-affective psychosis in the UK and include: i) a comprehensive descriptive account of social network characteristics in this sample, drawing comparisons with previous literature in predominately White samples; and ii) a cross-sectional study examining relationships between social networks, illness perceptions, stigma, racial or ethnic discrimination in mental health services and current engagement with mental health services.

Meta-analytic findings in the first paper showed that a larger social network size was related to improved negative and overall psychiatric symptoms. The second paper showed that social network characteristics of Black service users with non-affective psychosis were small, densely interconnected and comprised a disproportionate number of family members. Service users’ social networks also comprised close to zero wider social contacts, mostly connected social ties (few social isolates) and were ethnically homogenous (individuals formed social ties with people of the same ethnic group to their own). Cross-sectional findings in the third paper suggested that a more ethnically homogenous social network was the strongest predictor of engagement with mental health services from both staff and service user perspectives. Specific illness perceptions (greater treatment control, greater identification with symptoms, and higher perceived concern and emotional distress related to problems) were related to better self-reported engagement with services. Higher perceived personal control and racial or ethnic discrimination in services were related to staff-reported engagement and service user reported engagement, respectively. Internalised stigma was not related to engagement.

Findings suggest that social networks are important for outcomes and engagement with mental health services in non-affective psychosis. Psychosocial interventions that aim to build and maintain supportive social networks, enhance personal control over problems and beliefs about the benefits of treatment, and tackle perceived racial or ethnic discrimination in services, may facilitate better engagement, reduce inequalities and improve outcomes for Black African and Caribbean people with non-affective psychosis. Future longitudinal research is required to examine potential causal mechanisms by which social networks, illness perceptions and perceived racial or ethnic discrimination in services relate to engagement with services in this population.
DECLARATION

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ACKNOWLEDGEMENTS

First and foremost, I would like to thank my supervisors, Dr Dawn Edge, Dr Katherine Berry, Prof Nick Crossley and Prof Kathryn Abel, for their continued support, expertise and guidance. A special thank you to Dawn and Katherine for your inspiration and encouragement, and supporting my professional and personal development over the past few years. Thank you also to my academic adviser, Dr Sandra Bucci, for listening and for your sound advice.

I would like to thank all of the service users who donated their time and efforts to take part in the research. Thank you for sharing your experiences.

I would also like to thank the CaFI research advisory group of service user, carer and community consultants; Paul, Daisy, Mary, Yvonne, Natasha, Anthony, Sonia and Michelle. Thank you for your invaluable input and expertise. It has been an absolute pleasure working with you over the past three years.

Thank you to my wonderful friends. Thank you to Eilish Burke and Rebecca Owen for your kindness, support and advice throughout and particularly in the final stages.

Thank you to James Hartley, Lucy Shattock, Sophie Baker and Sam Bard for your friendship, dedication and support with the research. Thank you to my office buddies, especially Chen Zhao, Rebekah Carney and Gemma Stringer. I am very grateful to have worked in such an encouraging and warm environment and shared this PhD journey with you.

Thank you to my inspirational yoga teacher, Andrea Everingham, for teaching me to breathe and be mindful.

Thank you to Mum and Dad and my beautiful sisters, Anna and Beth, for your endless love, support and encouragement. Thank you for your patience and always being there to listen. Thank you to Grandma Grace for your unwavering support and continued interest in my work.

Thank you to Eryn Page for helping me to put things into perspective and for always putting a smile on my face.
CHAPTER 1: Introduction
1.1 Overview

The aim of this Chapter is to provide the context for the thesis, presenting the background literature that informed the research aims and hypotheses for the empirical studies. The Chapter begins with an introduction to psychosis and its incidence among Black African and Caribbean people in the UK, followed by a summary of the literature relating to negative pathways to care and outcomes in this population. The second part of this Chapter provides an overview of the literature on engagement with mental health services in Black African and Caribbean people, before discussing potential social and psychological processes related to engagement, including social networks, illness beliefs, perceived stigma, and discrimination in services. The Chapter will finish with the aims and outline of the current thesis before discussing its methods in Chapter 2.

1.2. Psychosis

Psychosis describes a group of experiences that include hallucinations (i.e. hearing, seeing, tasting, smelling or feeling things that other people do not, e.g. hearing voices), delusions (i.e. holding strong or unusual beliefs that others do not share, e.g. paranoid thoughts about being plotted against, or that people on the television are sending messages to you), and disorganised thinking (e.g. pressured or slowed speech, thought block, disconnected thoughts). Psychosis in the context of distress can manifest in many different psychiatric diagnoses, of which schizophrenia (non-affective psychosis) is the most common. Pooled annual incidence of all psychoses has been reported as 32 cases per 100,000 and schizophrenia 15 per 100,000 (Kirkbride et al., 2012).
Schizophrenia includes *positive symptoms* or psychosis, such as hearing voices and paranoia, and *negative symptoms*, such as reduced emotional expression, lack of motivation, and social withdrawal. There is also cognitive impairment (e.g. poor attention, memory problems) and significant impact in one or more areas of functioning, such as work, interpersonal relations or self-care. Schizophrenia is a severe mental health problem that is experienced by approximately 1% of the population worldwide (The Schizophrenia Commission, 2012).

Peak onset for non-affective psychoses in men and women is in their twenties, declining thereafter, with a smaller secondary peak for women after 45 years of age (Kirkbride et al., 2012). Schizophrenia can lead to severe personal distress and adverse personal and social outcomes, including impaired functioning, poor quality of life, high rates of unemployment and premature mortality (The Schizophrenia Commission, 2012). Schizophrenia and related psychoses place a substantial burden on health and social care services, costing society an estimated £11.8 billion a year (The Schizophrenia Commission, 2012).

Current literature is consistent with a biopsychosocial model of aetiology and treatment in schizophrenia and psychosis. Despite an earlier focus on biological models, there is now strong evidence to show that adverse social contexts and experiences are associated with increased risk of onset (e.g. Morgan et al., 2017; Varese et al., 2012). Current clinical guidelines in the UK (National Institute for Health and Care Excellence, 2014) and USA (Dixon et al., 2010) recommend psychosocial interventions as an adjunct to medication. These include cognitive behavioural therapy (CBT), based on evidence of its effectiveness at reducing symptoms (Morrison et al., 2014; van der Gaag, Valmaggia, & Smit, 2014; Wykes, Steel, Everitt, & Tarrier, 2008), and family intervention, which has been shown to
reduce psychotic relapse and hospital admission (Pharoah, Mari, Rathbone, & Wong, 2010; Pilling et al., 2002). However, despite the National Institute for Health and Care Excellence (NICE) (National Institute for Health and Care Excellence, 2014) guidelines that psychological interventions should be routinely offered to people diagnosed with schizophrenia and psychosis, only ten percent of those who could benefit gain access (The Schizophrenia Commission, 2012).

Over recent years, psychological approaches have increasingly been moving towards a more recovery-focused conceptualisation and treatment of psychosis (The British Psychological Society, 2014). Psychotic experiences are common, can be appraised positively, and may never cause distress for some people (The British Psychological Society, 2014). Numerous studies have now demonstrated that psychosis is experienced by non-clinical populations (e.g. Van Os, Linscott, Myin-Germey, Delespaul, & Krabbendam, 2009). This is consistent with current theories suggesting that psychotic experiences lie on a continuum with normal functioning, rather than existing in separate diagnostic categories (Van Os, Hanssen, Bijl, & Ravelli, 2000; Van Os et al., 2009). Additionally, there is cultural diversity in the ways in which psychotic experiences are understood, with people from some cultures valuing such experiences as hearing voices (The British Psychological Society, 2014). Labelling and pathologising experiences deemed to be psychotic as mental illness or with a psychosis or schizophrenia diagnoses may be helpful for some people but unhelpful for others (The British Psychological Society, 2014).
1.3 Psychosis in the Black African and Caribbean population

1.3.1 Defining ‘Black African’ and ‘Black Caribbean’

The terms ‘Black African’ and ‘Black Caribbean’ refer to Black individuals of African or Caribbean origin who could trace at least part of their heritage to Africa. Black African and Caribbean people in the UK may also choose to be called ‘Black British’ in recognition of their British nationality and identification with British culture. Similarly, Black Caribbean people may prefer ‘African-Caribbean’ in recognition of their African ancestry. Black African and Black Caribbean will be used in this thesis. ‘Black people’ or ‘Black group’ is used when referring generally or to a combined group of Black people of African descent.

1.3.2 Incidence of psychosis

The increased risk of being diagnosed with schizophrenia and other psychoses among migrant and minority ethnic groups is well established (Cantor-Graae & Selten, 2005; Fearon et al., 2006; Kirkbride et al., 2012; Tortelli et al., 2015). This has been described extensively over the past few decades in the UK and internationally, with evidence existing across four continents (Tortelli et al., 2015). Meta-analyses of incidence rates (pooled risk ratio (RR)) in England over a sixty-year period suggest that, compared to the White British population, rates of schizophrenia are 5.6 times higher in Black Caribbean (95% CI: 3.4-9.2, N=5), 4.7 in Black African (95% CI: 3.3-6.8, N=5) and 2.4 in South Asian (95% CI: 1.3-4.5, N=3) groups (Kirkbride et al., 2012). The Aetiology and Ethnicity in Schizophrenia and Other Psychoses (AESOP) study, a multi-site epidemiological study in three UK catchment areas (London, Bristol and Nottingham), reported even higher incidence
rates (Fearon et al., 2006). Using 2001 UK census data as the ethnic denominator, rates for all psychoses (adjusted for age and gender) were between two and seven times greater than White British population for Black Caribbean and Black African (including ‘mixed’) populations. For narrowly-defined schizophrenia, rates were, on average, nine times greater in Black Caribbean and six times greater in Black African people (Fearon et al., 2006).

Recent meta-analytic findings showed a pooled incidence rate ratio (IRR) of 4.7 (95% CI: 3.9-5.7, N=11) in Black Caribbean groups relative to the reference population in England (Tortelli et al., 2015). There was limited evidence from two out of three studies in the review that rates were slightly higher among Black Caribbean women than men (Tortelli et al., 2015). This review focused on Black Caribbean people, as the excess risk was considered to have the largest impact in terms of the mental health burden in England (Kirkbride et al., 2010; Morgan & Hutchinson, 2010).

There has been no evidence for differences in migration status; with few studies examining separate effects for people born in the UK versus migrants (Tortelli et al., 2015). One review found emerging evidence of higher rates in people of mixed ethnicity, which they suggest could be a marker of ‘third-generation’ descendants (Kirkbride et al., 2012). The elevated rates of psychosis remain when adjusting for age or sex (Kirkbride et al., 2012; Tortelli et al., 2015). Methodological variation and study quality over the past 60 years have not influenced higher rates of diagnosis among Black people despite reported diagnostic shifts away from schizophrenia (Kirkbride et al., 2012; Tortelli et al., 2015).
1.3.3 Explanations for high incidence of psychosis

Numerous hypotheses have been put forward to explain the higher rates of psychosis in Black populations in the UK (for reviews, see Bhugra & Bhui, 2001; Fung, Bhugra, & Jones, 2009; Morgan, Charalambides, Hutchinson, & Murray, 2010; Pinto, Ashworth, & Jones, 2008; Sharpley, Hutchinson, Murray, & McKenzie, 2001; Tortelli et al., 2015). Initially, the higher rates were thought to be an artefact of methodological biases such as lack of cultural understanding among Western psychiatrists leading to misdiagnosis (Fernando, 1998; Fung et al., 2009), and poor study quality such as inaccurate ethnic denominators, retrospective case data, and non-standardised diagnostic criteria (Fernando, 1991). Misdiagnosis remains a popular explanation, argued to be the result of clinician bias, culturally insensitive diagnostic tools, and erroneous interpretations of culturally-appropriate distress in response to adversity (Pinto et al., 2008). However, this has been contradicted by review findings of elevated rates upholding across studies with different settings in the UK, denominator calculations (including more accurate population estimates), confounders (i.e. age, gender and socioeconomic status), standardised diagnostic criteria, more rigorous prospective designs, blind raters and ethnically matched psychiatrists (Kirkbride et al., 2012; Tortelli et al., 2015).

Biological theories for raised rates in Black Caribbean groups have been refuted based on evidence of lower incidence in Caribbean countries (Bhugra et al., 1996; Hickling & Rodgers-Johnson, 1995; Mahy, Mallett, Leff, & Bhugra, 1999; Sugarman & Craufurd, 1994). However, there is a lack of corresponding incidence studies in African countries (Kirkbride et al., 2012). Cannabis use has been implicated as a risk factor based on evidence for higher misuse in Black groups than
White groups (Afuwape et al., 2006), and its association with psychosis onset (Henquet, Murray, Linszen, & van Os, 2005). However, the evidence for its more frequent use in minority population and clinical samples is equivocal, and no epidemiological studies have adjusted for cannabis use in the association between minority ethnicity status and psychosis (Tortelli et al., 2015).

Earlier theories relating to selective migration (Odegaard, 1932), or the tendency of those individuals who are predisposed to psychological distress to migrate, have not been supported (Cantor-Graae & Selten, 2005). However, psychosocial stressors related to migration and minority status such as social segregation, social deprivation and acculturative processes may contribute to the higher risk in these populations (Bhugra & Bhui, 2001). Acculturation refers to the process of cultural change over time when exposed to a different culture following relocation (Kent & Bhui, 2003). It has been theorised that exclusion and isolation may lead to internalised distress and paranoia through a reduced sense of belonging and alienation from one’s surrounding environment (Bhugra & Bhui, 2001). Feeling marginalised from the majority culture may also have a negative effect on self-esteem which is a known vulnerability factor for psychosis (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001). Ethnic identification, the extent to which one identifies with their ethnic origin, is one feature of acculturation that has been implicated as a relevant factor in the development of psychosis (Bhugra, Leff, Mallett, Morgan, & Zhao, 2010; Reininghaus et al., 2010). Stronger negative ethnic identity has been associated with excess of psychosis in Black groups (Veling, Hoek, Wiersma, & Mackenbach, 2010). Reininghaus et al. (2010) found that this relationship was mediated by perceived social disadvantage, suggesting strong ethnic identification may not only lead to an increased social distance to the White British majority, but also to a Black
individual’s own ethnic group when it is perceived to be subject to social adversity and discrimination.

Experiences of racism and perceived racial discrimination from the majority culture have both been associated with heightened risk for psychosis in minority and migrant groups, independent of socio-economic status and demographics (Karlsen, Nazroo, McKenzie, Bhui, & Weich, 2005; Veling, Hoek, & Mackenbach, 2008). It has been hypothesised that specific stressors may increase the risk of specific psychotic experiences in minority ethnic groups (Morgan & Fearon, 2007); for example, perceived discrimination might lead to more persecutory delusions through lack of trust in relationships and paranoia (Mallett, Leff, Bhugra, Pang, & Zhao, 2002). Perceived discrimination has been associated with positive symptoms of delusions and paranoia (Bentall, Corcoran, Howard, Blackwood, & Kinderman, 2001; Janssen et al., 2003), and has been shown to mediate psychosis symptom severity amongst African-descended migrants (Berg et al., 2011).

Perhaps the most robust evidence to explain the raised rates of psychosis among Black African and Caribbean people come from the AESOP study, a large multi-centre incidence and case-control study in first episode psychosis, conducted initially over a three year period (Morgan & Fearon, 2007). Findings from the ten year follow up has recently been published (AESOP-10) (Morgan et al., 2017). Most of the work conducted as part of AESOP focused primarily on the experiences of the UK’s Black Caribbean population, given they have the highest incidence, but findings relating to Black African people have also been reported (Morgan & Fearon, 2007). Taken together, findings from AESOP suggest that adverse social experiences such as childhood adversity (Morgan et al., 2007), cumulative social disadvantage (Morgan et al., 2008), and fragmented neighbourhoods (Kirkbride et al., 2007) contribute to
explaining the increased risk of psychosis in Black ethnic groups in the UK (Morgan & Fearon, 2007). These will be considered in turn.

Childhood adversity, including long-term separation from parents and parental death during childhood has been strongly associated with increased risk of psychosis, with the strength of the associations similar in White British and Black Caribbean people (Morgan et al., 2007). However, separation from (but not death of) a parent is more common among Black Caribbean population and therefore may contribute to the excess of psychosis in this population (Mallett et al., 2002; Morgan et al., 2007). Multiple socioenvironmental stressors that increase an individual’s risk for psychosis have been found to be significantly enhanced in Black communities, including unemployment, urbanicity, lower social class, lone parenthood, living alone, and poverty (Bhugra & Bhui, 2001; Brugha et al., 2004; Mallett et al., 2002; Sharpley et al., 2001). There is evidence to suggest the excess risk among minority groups is attenuated when adjusting for socioeconomic status (Kirkbride, Barker, et al., 2008; Tortelli et al., 2015). Reports from the AESOP study using case-control data suggest direct exposure to social stressors is associated with greater risk of schizophrenia independent of ethnicity, but these risk factors are more prevalent among Black Caribbean groups (Morgan et al., 2008; Morgan et al., 2007).

Family breakdown and social isolation may contribute to elevated risk by reducing the amount of economic and social resources available for coping with stressful events in the face of continued adversity and discrimination (Morgan & Fearon, 2007). Reininghaus et al. (2008) report empirical findings to suggest that unemployment leads to higher incidence rates due to the discrepancy between perceived high expectations of success and low employment achievement. It has been proposed that Black Caribbean people are more likely to experience a greater
sense of failure from poor achievement, due to higher expectations and goal striving as a result of their migration history (Mallett, Leff, Bhugra, Takei, & Corridan, 2004; Reininghaus et al., 2008). Bhugra and Bhui (2001) hypothesise that greater social deprivation and limited opportunities for success may contribute to social stress, poor self-esteem and an internalised sense of inferiority, increasing psychosis risk.

Rates of non-affective psychosis have been found to be reduced when people live in neighbourhoods where their ethnic group comprises a larger proportion of the local population (Boydell et al., 2001; Kirkbride, Jones, Ullrich, & Coid, 2014; Kirkbride et al., 2007). This has been termed the ‘ethnic density effect’ (Becares, Nazroo, & Stafford, 2009), and has been observed in Black ethnic urban communities in England (Kirkbride et al., 2014; Schofield, Ashworth, & Jones, 2011). Greater urbanicity (urban living) has been associated with lower rates of psychosis, which could be viewed as consistent with these effects; though there are is no comparable research in rural areas (Tortelli et al., 2015). Neighbourhood-level structural characteristics could be interpreted as objective accounts of the levels of social cohesion and segregation in certain populations (Brugha et al., 2004). Living in more ethnically-dense or cohesive communities may lead to greater levels of social support which help to buffer the deleterious effects of social adversity and discrimination on psychological distress (Broome et al., 2005; Brugha, 2010; Das-Munshi et al., 2012).

McKenzie, Whitley, and Weich (2002) suggest that the ethnic density effect might be explained by higher levels of social capital in ethnically-dense communities. Social capital refers to the social organisation of a community that ‘facilitates coordination and cooperation for mutual benefit’ (Putnam, 1993, p. 36). Reduced social capital has previously been implicated in the aetiology of psychosis (Allardyce
et al., 2005). Participation in cohesive social networks may reaffirm ethnic identity and provide a sense of belonging to Black groups who feel marginalised from the dominant culture (Reynolds, 2006). Moderate levels of social capital and trust have been associated with lower incidence of schizophrenia in urban environments; suggested not to be because low levels of social capital attenuate social stress, but that high levels can be enmeshing and limit access to outside social resources (Kirkbride, Boydell, et al., 2008).

1.3.4 Negative pathways to care

In addition to the high incidence of psychosis, empirical research (Bhui et al., 2003; Morgan et al., 2005a, 2005b; Morgan, Mallett, Hutchinson, & Leff, 2004) and evidence-based policies (Department of Health, 2005; Sainsbury's Centre for Mental Health, 2006) have repeatedly highlighted that Black groups have the greatest inequalities in access, experiences and outcomes of mental health services compared to any other ethnic group in the UK. Their pathways into care are less likely to involve the General Practitioner (GP) than their White British counterparts and often involve multiple help-seeking attempts (Morgan et al., 2004). Delays in access to treatment increases the duration of untreated psychosis (DUP) and the severity of symptoms such that Black people are more likely to make contact with services at crisis point (Bhui, Christie, & Bhugra, 1995; Morgan et al., 2004). This is problematic as prolonged DUP is associated with poorer prognosis and more relapses (Marshall et al., 2005; Perkins, Gu, Boteva, & Lieberman, 2005).

Black African and Caribbean people experience more adverse and coercive care pathways, including high rates of involuntary admission (i.e. sectioning) and involvement of the police (Morgan et al., 2017; Morgan et al., 2005a). Black people
are up to 6.6 times more likely to be admitted as inpatients or detained under the Mental Health Act 2007 than White British people (HM Government, 2007; Mental Health Taskforce, 2016). Once in specialist mental health services, Black people experience higher rates of seclusion and restraint, higher mean doses of psychotropic medication, and are less likely to be offered psychological therapy (Bhui et al., 2003; Morgan et al., 2004). They also experience longer hospitalisations and higher rates of involuntary hospital readmissions following discharge (Morgan et al., 2006). For example, in 2010, Black people spent twice as long in hospital than the average stay (The Schizophrenia Commission, 2012). In light of these marked inequalities, UK policy guidelines conclude that mental health services for people of Black African and Caribbean backgrounds are inadequate (National Institute for Health and Care Excellence, 2009; The Schizophrenia Commission, 2012). The Mental Health Taskforce (2016) recently reported a ‘systemic failure’ of the UK National Health Service (NHS) in providing effective mental health care for Black African and Caribbean groups.

1.3.5 Long-term course and outcome of psychosis

There is now strong evidence to suggest that ethnic disparities in the incidence of psychoses and access to care extend to worse course and outcomes in Black Caribbean and African people (Morgan et al., 2017). The AESOP-10 study has recently reported ten year follow up findings of an ethnically diverse cohort of 532 individuals in first episode psychosis (Morgan et al., 2017). The results showed that, compared with White British people, Black Caribbean and Black African people experienced poorer social and service use outcomes, and Black Caribbean people also experienced poorer clinical outcomes. In line with earlier AESOP findings (e.g.
Morgan et al., 2008; Morgan et al., 2004), Black ethnicity was associated with persistent social disadvantage and social isolation and higher rates of hospital admissions involving the police and compulsory section (Mental Health Taskforce, 2016). The strength of the associations with service use reduced after controlling for clinical and socio-demographics and baseline compulsory admission, which suggests that earlier experiences of services may have partially explained the differences in service use outcomes. There was also evidence for more continuous symptoms and low rates of recovery among Black Caribbean people, but not in Black African people. This contradicts previous studies in Black Caribbean people showing a more benign course (McKenzie et al., 2001; McKenzie et al., 1995), and a systematic review showing no ethnic differences in clinical course and outcome (Chorlton, McKenzie, Morgan, & Doody, 2012). The association between Black Caribbean ethnicity and clinical course in the AESOP-10 study was stronger at later time periods, suggesting that ethnic inequalities in clinical course progressively worsen over time. Morgan and colleagues (2017) proposed this may explain why earlier studies using shorter follow-up periods failed to find worse clinical outcomes in Black Caribbean populations (Kirkbride, Barker, et al., 2008; McKenzie et al., 2001; McKenzie et al., 1995). Baseline social disadvantage and social isolation accounted for the greater likelihood of a continuous clinical course, but not symptomatic recovery. The authors tentatively hypothesise that social disadvantage and psychosis are mutually reinforcing, such that disadvantage exacerbates symptoms (and vice versa) in a vicious cycle leading to a more chronic clinical course and social exclusion (Morgan et al., 2017). Findings to date suggest that the association between Black ethnicity and poorer outcomes over time is similar across first and subsequent generations (McKenzie et al., 1995; Morgan et al., 2017). However, this
is based on two studies and thus further research is needed comparing different
generations before any firm conclusions can be drawn.

1.4 Summary

In summary, there is robust evidence to show that the incidence of psychosis is
elevated in minority ethnic groups in the UK, with the highest rates reported in Black
Caribbean and African people. Research to date, mostly from epidemiological
studies, suggests the raised rates in Black groups are contributed to by cumulative
social and economic disadvantage, including adversity in childhood (e.g. parental
separation) and adulthood (e.g. social stressors such as loneliness, poverty,
unemployment), and socially fragmented communities (i.e. social segregation). Few
studies have examined mechanisms by which early adverse life events and continued
social stressors may lead to increased psychosis risk in Black groups; but current
theories suggest their effects may be exerted via multiple social and psychological
processes such as social capital, perceived social disadvantage, internalised
perceptions of inferiority, low self-esteem and low expectations of success.

There is some evidence to suggest that ethnic disparities in psychosis onset extend to
poorer clinical course in Black Caribbean people, and poorer social and service use
outcomes in Black Caribbean and African people (e.g. Morgan et al., 2017). Further
research is needed to examine factors that lead to worse outcomes among Black
minority ethnic groups to inform psychosocial interventions and key targets for
research policies and healthcare services. Evidence suggests that the ethnic
disparities in course and outcome of psychosis may be influenced by past
experiences of services and pathways into care in Black people in the UK. As such,
there has been a vast amount of literature focusing on help-seeking and engagement
with mental health services among Black with psychosis. This will be the focus of the second part of this Chapter and will provide the rationale for the aims of this thesis.

1.5 Engagement with mental health services

1.5.1 Defining engagement with mental health services

Reviews have highlighted that there is no widely accepted definition of engagement (Kreyenbuhl, Nossel, & Dixon, 2009; O'Brien, Fahmy, & Singh, 2009). Broadly speaking, the term ‘engagement’ in the mental health literature is commonly used to understand the relationships between individuals with mental health problems and mental health services. In their review of the literature, O’Brien et al. (2009) note the measurements and conceptualisations of engagement are often ill-defined and vary widely across studies. The empirical literature commonly examines engagement through attendance, drop-out or contact with services (O'Brien, Fahmy, et al., 2009). For example, studies in individuals with severe mental health problems have measured missed appointments, failed referrals from crisis care and non-adherence with treatment following hospitalisation (Kreyenbuhl et al., 2009). However, O’Brien and colleagues (2009) highlight that most studies examining ‘disengagement’ have not differentiated between those people who dropped out based on their own accord versus in agreement with a mental health professional. Moreover, engagement is likely to vary across different clinical settings, treatments and diagnoses, but few studies have controlled for these confounders (O’Brien et al., 2009).
The review by O’Brien and colleagues highlights that engagement is often conflated with the concept of ‘therapeutic alliance’ (Catty, 2004) or ‘therapeutic engagement’ (Spencer, Birchwood, & McGovern, 2001) rather than the relationship with services as a whole (Goodwin, Holmes, Cochrane, & Mason, 2003; Tait, Birchwood, & Trower, 2002). Examining general perceptions across services is important given that individuals are in contact with a number of professionals and their key mental health professional often changes throughout their contact with services (O’Brien, Fahmy, et al., 2009).

It has been argued that, over the years, research and policies have tended to focus on those who are ‘at risk’ of non-compliance or non-attendance rather than taking into consideration the experiences of people who are in consistent contact with professionals (Chase et al., 2012). Chase et al. (2012) suggest that engagement should not be defined as mere compliance but the ability of service users to be active agents in treatment and communicate their individual needs to listening professionals. Based on their qualitative findings in outpatients with severe mental health problems, they report that regular attendance at appointments is not synonymous with treatment satisfaction and may be masking unmet needs or underlying negative feelings of dissatisfaction or resentment (Chase et al., 2012).

A better understanding of engagement with services is likely to be gained by using more comprehensive measures examine multiple factors. O’Brien and colleagues (O’Brien, Fahmy, et al., 2009; O’Brien, White, Fahmy, & Singh, 2009) describe engagement as a complex phenomenon that includes acceptance of the need for help, satisfaction with treatment, positive therapeutic alliance and working towards agreed goals. Similarly, Tait and colleagues (Tait, Birchwood, & Trower, 2003) have defined engagement as involving multiple components, including availability,
collaboration, help-seeking and adherence to treatment. Subjective and objective accounts of engagement should be used in addition to statistics relating to initial access and service use. Service users and professionals may have different ideas of engagement and it is therefore important to consider both perspectives (O'Brien, White, et al., 2009; Tait et al., 2002). Investigating the views and experiences of individuals who are currently in contact with services and in established relationships with mental health professionals may contribute to a better understanding of ways to engage all individuals in effective treatment (Chase et al., 2012).

1.5.2 Engagement with mental health services in England

Review findings (Kreyenbuhl et al., 2009; O'Brien, Fahmy, et al., 2009) suggest that up to one third of individuals with severe mental health problems disengage from services, with consistent evidence to show that minority ethnic background is associated with greater disengagement from mental health treatment. Younger age, male gender, social deprivation, forensic history, co-occurring substance misuse, more severe psychopathology and first onset psychosis are also associated with higher treatment dropout (Kreyenbuhl et al., 2009; O'Brien, Fahmy, et al., 2009).

Disengagement from services across all ethnic groups is problematic as it often leads to adverse outcomes, including exacerbation of symptoms, repeated hospitalisations, homelessness and suicide (for review, see Kreyenbuhl et al., 2009). Poor adherence to medication and psychosocial treatment is common in individuals diagnosed with schizophrenia, and can increase risk of relapse and hospitalisation (Drake et al., 2015; McCann, Boardman, Clark, & Lu, 2008; Tay, 2007). Service-level changes in the UK over the past few decades, such as the introduction of early intervention
services (EIS) for psychosis, have been informed by evidence highlighting the
detrimental effects of poor and delayed engagement with services (Sainsbury's Centre for Mental Health, 1998). Other UK health related policies (Department of Health, 2005; National Institute for Mental Health, 2003) have outlined strategies to improve engagement and reduce ethnic inequalities in mental health service and outcome. The Delivering Race Equality (DRE) in mental health care programme (Department of Health, 2005) was implemented in response to an independent inquiry into the death of David Bennett, a British born Black Caribbean man, who died following coercive restraint in a medium secure psychiatric hospital in England. The aim was to ‘…improve equality of access, experience and outcomes for Black and minority ethnic mental health service users’ (Department of Health, 2005, p. 3). The action plan included more appropriate and responsive services and strengthening community engagement through the introduction of Community Development Workers (CDWs).

1.5.3 Correlates of engagement with mental health services in England

Two narrative literature reviews have examined correlates of engagement with mental health services in England (Kreyenbuhl et al., 2009; O'Brien, White, et al., 2009). Psychological characteristics previously associated with treatment disengagement in psychosis include lack of insight and hiding or minimising symptoms (O'Brien, Fahmy, et al., 2009; Tait et al., 2003). Medication adherence in first episode psychosis has also been associated with attitudes towards medication, accepting the need for treatment, insight and self-esteem (Drake et al., 2015). Service users have reported dropping out of treatment because they were dissatisfied with services as a result of not being listened to or able to actively participate in decision
making (O’Brien, Fahmy, et al., 2009). Qualitative findings in service users with severe mental health problems have suggested a desire to be independent, a poor therapeutic relationship and a loss of control due to medication effects are most important for disengagement in treatment (Priebe, Watts, Chase, & Matanov, 2005). Difficulties in building a therapeutic alliance has been correlated with poor engagement in early psychosis (Lecomte et al., 2008). People with severe mental health problems have reported not seeking professional help because they feel that treatment would not be effective and because they prefer to manage problems on their own (Kessler et al., 2001; Priebe et al., 2005). Dissatisfaction with treatment due to perceptions of it being unhelpful or not being of benefit has been associated with drop out of community based mental health care (Rossi et al., 2008; Ruggeri et al., 2007). Financial and contextual barriers such as cost, transport, and lack of time have also been reported as reasons for drop out (Rossi et al., 2008; Ruggeri et al., 2007). Most of the empirical literature on treatment adherence and drop out has focused on the experiences of predominately White British people and included mixed diagnostic samples, with no studies focusing solely on the experiences of Black service users.

1.6 Engagement with mental health services in the Black African and Caribbean population

1.6.1 Poor engagement with mental health services – the ‘vicious circle of fear’

Black African and Caribbean people have consistently been reported to have the most difficult relationships and poorest engagement with mental health services of all other ethnic groups in the UK (Sainsbury’s Centre for Mental Health, 2006).
Mistrust of services, perceived stigma and expectations of discrimination and coercive intervention by key professionals are suggested to continue the delay in seeking formal help in the course of psychosis (Morgan et al., 2004). The Sainsbury Centre for Mental Health (since renamed the Centre for Mental Health) suggested that adverse experiences in services lead to fear, mistrust and delayed or non-engagement, which reduces early help-seeking in the event of relapse and results in coercive treatment and poorer outcomes (Keating, Roberson, McCulloch, & Francis, 2002). The resultant ‘circle of fear’ (Keating & Robertson, 2004) is thought to reinforce Black communities’ negative attitudes towards and non- or dis-engagement with mental health services, further exacerbating the vicious cycle (Care Quality Commission, 2011; Keating et al., 2002).

Much of the literature on engagement in minority populations has focused on initial access to care or ‘help-seeking’, which is suggested to include both initiation of, and engagement with, healthcare (Kovandžić et al., 2011). In their review, Morgan et al. (2004) highlighted that research in this area has predominantly been conducted using epidemiological methods, correlating data on police involvement, GP referral and compulsory admissions with sociodemographic and clinical data, and inferring causal mechanisms within observed associations. For example, one earlier hypothesis is that ethnicity causes increased risk for compulsory admission via more severe clinical presentation and challenging behaviour (for review, see Morgan et al., 2004). This has been contradicted by evidence showing that the elevated risk of psychosis does not fully explain why Black people come into contact with services via more negative referral routes (Morgan et al., 2004).

It has been argued that the relationship between Black ethnicity and adversarial access to services may be better explained by sociocultural factors, such as social
networks, beliefs about mental illness, and perceptions of treatment and services (Morgan et al., 2004). However, there is a lack of empirical research that examines potential social and psychological processes that influence help-seeking behaviours and engagement in Black people with psychosis. More qualitative and process-oriented quantitative research is needed to build theoretical models that explain mechanisms between ethnicity and poor engagement with services (Morgan et al., 2004). Research highlighting the importance of social networks for engagement with services will now be considered, followed by psychological theories to explain service engagement including illness perceptions, mental health stigma, and racial or ethnic discrimination.

1.6.2 Social networks and engagement with mental health services

Social networks can be described as the set of social relations or social ties that connect individuals (Crossley et al., 2015). The Network Episode Model (NEM) (Perry & Pescosolido, 2015; Pescosolido & Boyer, 1999) is a social network model of help-seeking in response to health problems. The NEM conceptualises help-seeking as a dynamic social process influenced by contacts in the social network who offer advice, information, support and beliefs about illness and the usefulness of treatment. The NEM suggests that social networks are social structures where members interact and influence one another; for example, exchanging resources, sharing information and culture, and providing support or friendship (Pescosolido & Boyer, 1999). The NEM suggests that help-seeking must be understand and analysed within the context of social relations, as social network members influence the behaviours and attitudes of all individuals in the network (Pescosolido & Boyer, 1999). Recent qualitative evidence in support of the NEM suggested that individuals
with severe mental health problems strategically activated their social networks to manage crisis, which included a core social network (close people) and those with prior mental health experience (Perry & Pescosolido, 2015). Additionally, individuals who reported activating network members who endorsed medical treatment also reported better professional help-seeking and recovery, including better quality of life and social functioning (Perry & Pescosolido, 2015).

The onset of psychosis has previously been suggested to represent a ‘network crisis’ (Lipton, Cohen, Fischer, & Katz, 1981), whereby there is a rapid change to the structure, function and quality of an individual’s social network as families and friends respond to elevated support needs. During this time, network members are called upon for advice and information about where to go for help and how to respond in a crisis (Lipton et al., 1981). There have been a few studies in psychosis highlighting the important role of social networks in facilitating help-seeking. Families have been found to play a crucial role in pathways to care for psychosis, reducing the DUP by encouraging early help-seeking (Del Vecchio et al., 2015).

Empirical findings suggest that the most important determinant of police involvement and compulsory section is the absence of a relative or friend to facilitate formal help-seeking (Cole, Leavey, King, Johnson Sabine, & Hoar, 1995). An earlier study suggested that living away from family among a Black Caribbean group compared to Asian and White ethnic groups was associated with more relapses and readmissions to hospital; with 31% of Black Caribbean people living with their close family compared to 90% of Asians and 70% of Whites (Birchwood et al., 1992). However, increased social contact is not necessarily synonymous with more positive social support and can be harmful (Thoits, 2011). This has been highlighted in research showing that an emotionally over-involved and critical (high expressed
emotion) family environment increases the risk of relapse in schizophrenia (Barrowclough & Hooley, 2003; Butzlaff & Hooley, 1998).

Few studies have examined the relationship between social network characteristics and engagement with services in psychosis, with most focusing on single dimensions of both concepts. For example, there is evidence to show that an increased number of social contacts is associated with decreased likelihood of contacting emergency services in psychosis (Albert, Becker, Mccrone, & Thornicroft, 1998; Becker, Albert, Angermeyer, & Thornicroft, 1997; Bhui, Ullrich, & Coid, 2014) and shorter DUP (Bhui et al., 2014; Jeppesen et al., 2008; Larsen, Johannessen, & Opjordsmoen, 1998). One study by Carpentier and White (2002) found that more cohesive networks (i.e. at least three cooperative network members who knew one another) were related to sustained service use in individuals with severe mental health problems; which they suggest is explained by earlier recognition of the problem, and more informational and practical support to secure access. Together, these quantitative findings suggest that family and friends can facilitate early help-seeking and better engagement with services. Most quantitative research has focused on contact with friends and families or the size of social networks. However, none of these quantitative studies have examined potential mechanisms to explain these relationships and it is unclear whether these findings can be generalised to the experiences of Black African and Caribbean people with psychosis in the UK.

There has been some qualitative work that highlights how social networks may lead to engagement in Black and minority ethnic communities (e.g. Kovandžić et al., 2011; Shefer et al., 2013). Ethnic variations in help-seeking and pathways to care have been viewed a result of interacting social and cultural factors located within a particular social network, alongside beliefs and perceptions about treatment (Morgan
et al., 2004). Kovandžić et al. (2011) described a ‘paradox of demand’ relating to the role of social networks in accessing primary care services among ‘hard to reach’ minority groups. Their qualitative synthesis suggested that the existence of a supportive social network can be a facilitator to seeking help through the provision of information and practical assistance but that it might also act as a barrier due to perceptions that support is already available in the network, perceived stigma, or negative attitudes towards outside help.

Further findings from qualitative research highlight a lack of knowledge about mental health problems in Black and minority ethnic communities (Shefer et al., 2013), and an over-reliance on information in social networks for help-seeking (Kovandžić et al., 2011). Research suggests that Black families often contact services at crisis point as a last resort after multiple help-seeking attempts (Morgan et al., 2004; Shefer et al., 2013). Delays in accessing services lead to more severe problems and changes in behaviour within the home and the local community, which means that significant others in the social networks (relatives, friends and neighbours) of Black people are often involved in calling the police and initiating compulsory admission (Owens, Harrison, & Boot, 1991). The stress experienced by relatives in the periods of untreated psychosis and the confusion about how to seek appropriate help is suggested to facilitate this response when crisis develops (Harrison et al., 1989). Study findings demonstrate that delayed access to treatment negatively affects families’ perceptions of the burden of care (Awad & Voruganti, 2008). Black and minority ethnic service users have reported that calling on the authorities to hospitalise people is common in their community, due to a lack of knowledge about mental illness leading the public to wrongly construe the unwell as ‘dangerous’ (Shefer et al., 2013).
1.6.3 Psychological theories to explain engagement with mental health services

*Illness perceptions*

Illness perceptions have been broadly defined as a collection of beliefs relating to how people make sense of and understand their health problems (Lobban, Barrowclough, & Jones, 2003). The Self-Regulation Model (SRM) (Leventhal, Nerenz, & Steele, 1984) is one of the most widely used socio-cognitive models of illness beliefs. The SRM proposes that an individual develops cognitive representations of their illness which guide their emotional responses and coping behaviours. The SRM suggests that, in order to make sense of and cope with their symptoms, people develop a number of beliefs relating to the cause, identity, timeline, consequences and control over the cure of their illness. The SRM was originally developed to explore illness beliefs in physical health problems but has since been applied to a range of mental health problems, including schizophrenia and psychosis (Lobban, Barrowclough, & Jones, 2005a). There is some support for the SRM model in mental health problems as specific illness perceptions have been associated with outcomes (for comprehensive review, see Baines & Wittkowski, 2013). However, there is limited evidence that coping mediates the relationship between beliefs and outcome appraisal in schizophrenia, as predicted by the SRM. For example, illness beliefs relating to greater perceived negative consequences has been shown to have a direct effect on social functioning, depressive symptoms and quality of life outcomes in psychosis, with coping accounting for little variance in the model (Lobban, Barrowclough, & Jones, 2004).

A relatively recent systematic review (Baines & Wittkowski, 2013) of illness perceptions in mental health problems reported on four studies in psychosis samples,
three of which measured some form of engagement with services (Lobban et al., 2004; Lobban, Barrowclough, & Jones, 2005b; Watson et al., 2006; Williams & Steer, 2011). One of the reviewed studies examined current engagement in specialist mental health services (Williams & Steer, 2011) and found that fewer perceived negative consequences, greater perceived personal and treatment control, and a more coherent understanding of problems was associated with better self-reported engagement. Two studies looked at self-reported medication adherence; better medication adherence was associated with beliefs that treatment was helpful in one study (Lobban et al., 2005a), and greater perceived identity and negative consequences and lower treatment control in the second study (Watson et al., 2006). Another study, not reported in the latter review, found that more negative illness perceptions (i.e. greater emotional distress and concern, having more negative consequences, a greater timeline, and less personal control) were related to greater self-reported unmet needs in service users with a range of mental health problems (Broadbent, Kydd, Sanders, & Vanderpyl, 2008). This study also found that SRM illness perceptions (i.e. higher treatment control and coherence, longer timeline, lower concern and higher personal control) were related to positive attitudes to medication. Together, these findings suggest that the SRM provides a useful theoretical framework for conceptualising how people understand and manage their mental health problems. However, none of these studies have included ethnically diverse samples and therefore it is unclear whether illness perceptions are related to engagement in Black African and Caribbean people with psychosis. If found to be relevant, the SRM may highlight important areas for future psychosocial interventions to improve engagement and related outcomes in this population (Lobban et al., 2004).
Beliefs about the causes of mental health problems, commonly termed ‘causal beliefs’ or ‘causal attributions’, have received some attention in the engagement literature. A recent review reported that biological causal beliefs were associated with better medication adherence and relationships with mental health professionals in psychosis, and these were less likely to be endorsed in minority ethnic groups (Carter, Read, Pyle, & Morrison, 2016). Additionally, across ethnic groups, people with psychosis were more likely to endorse psychosocial causal beliefs and these were related to better engagement with psychotherapeutic approaches (Carter et al., 2016). Negative attitudes towards diagnostic labelling and psychiatric medication have been reported in Black minority communities (Rathod, Kingdon, Phiri, & Gobbi, 2009; Shefer et al., 2013). Common ‘traditional’ causal beliefs reported among Black people include social deviance, or being punished for previous wrongdoings, and spiritual causes such as ‘Obeah’ (black magic) (McCabe & Priebe, 2004; Rathod, Kingdon, Phiri, & Gobbi, 2010; Shefer et al., 2013). Additional qualitative findings indicate that Black Caribbean community members and service users often believe mental illness is directly caused by being misunderstood by arresting police officers (Rathod et al., 2010). Negative beliefs about mental illness and treatment, compounded by the fear, mistrust and stigma outlined above, may increase the likelihood of Black people relying on traditional support networks (e.g. relatives, friends, spiritual advisors) to deal with mental health problems, rather than mainstream mental health services (Obasi & Leong, 2009; Rathod et al., 2009). Spiritual causal attributions may lead to alternative methods of coping such as prayer (Carter et al., 2016; McCabe & Priebe, 2004). Recent findings from an observational study showed that Black people with first episode psychosis were more likely to consult faith-based institutions than White people, but these ethnic differences were
not significantly influenced by culturally mediated illness attributions (Singh et al., 2015). Moreover, compulsory detention was not explained by ethnic differences in illness attributions. The authors highlight qualitative findings to suggest that other factors are at play, such as family and community influences and lack of cultural awareness training in mental health services (Islam, Rabiee, & Singh, 2015).

Mental health stigma

One of the most commonly cited reasons for not seeking help from mental health services is the stigma attached to mental health (Corrigan, 2004; Corrigan & Watson, 2007). Stigma was originally defined as ‘an attribute that is deeply discrediting’ where we ‘believe that the person is not quite human’ (Goffman, 1963, p. 3). There are various types of mental health stigma (for review, see Clement et al., 2015). Corrigan and Watson (2002) defined two key components: public stigma is the negative stereotypes, discrimination and prejudices held by others in society against the stigmatised individual; and internalised stigma (or self-stigma)\(^1\) has been defined as the internalisation of these negative messages or stereotypes and holding stigmatising views of oneself. Internalised stigma is associated with a range of adverse outcomes in individuals with severe mental health problems, including poor self-esteem, hopelessness, increased distress and poor recovery (Corrigan & Watson, 2002; Livingston & Boyd, 2010). Public stigma has been found to significantly predict internalised stigma and high levels of both have been negatively related to willingness to seek professional help for mental health problems (Vogel, Wade, & Hackler, 2007).

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\(^1\) Internalised stigma is often used interchangeably with self-stigma. Internalised stigma will be used in this thesis.
People diagnosed with schizophrenia experience higher internalised stigma compared to other severe mental health problems (Holzinger, Beck, Munk, Weithaas, & Angermeyer, 2003). High expectations of being stigmatised is common for people experiencing psychosis (Wood et al., 2014). Perceptions of stigma may lead to avoidant behaviours, preventing disclosure and help-seeking for psychosis (Harrison et al., 1989; Kovandžić et al., 2011; Pyle & Morrison, 2013). Stronger self-labelling and reduced stigma stress has been shown to predict more positive attitudes towards psychiatric medication and psychotherapy in young people at risk for psychosis (Rüsch et al., 2013). Another study in individuals diagnosed with schizophrenia showed that lower internalised stigma was associated with improved therapist-rated participation in treatment (Tsang, Fung, & Chung, 2010). One recent study found no direct effect of experiences of mental-health related discrimination on poorer engagement with community mental health teams in the UK, but found an indirect effect that was mediated by higher levels of mistrust in services and therapeutic relationships (Clement, Williams, et al., 2015).

Findings from a recent systematic review suggest that higher perceived mental health stigma is significantly associated with help-seeking for mental health problems in the general population (Clement, Schauman, et al., 2015). Subgroup analyses found two types of stigma that showed a small significant negative association; internalised stigma and treatment stigma (stigma associated with seeking or receiving treatment for mental ill-health). Moreover, the effect was enhanced for males, young people and minority ethnic groups (i.e. largest association in Asian American and Arabic, followed by African American). Qualitative syntheses revealed the processes underlying the relationship between stigma and help-seeking which included: dissonance between self-identity and common stereotypes about mental health;
anticipation experience of negative consequences; preference for non-disclosure; stigma-related strategies to enable help-seeking (e.g. normalising problems); and stigma-related aspects of care to facilitate help-seeking (e.g. use of less stigmatising forms of care such as talking treatments and community services). As highlighted in this review, current literature relating to stigma and engagement is limited as it focuses on initial access to care and predominantly White samples (Clement, Schauman, et al., 2015). No work has been carried out to explore stigma experiences and engagement amongst Black people with psychosis in the UK who are already in contact with services.

Research suggests that there are greater levels of stigma related to mental health problems in Black compared to White non-clinical populations (Anglin, Link, & Phelan, 2006; Corrigan & Watson, 2007). High perceived stigma relating to psychosis has been reported by Black ethnic service users and lay persons in the UK (Rathod et al., 2010). Qualitative research indicates that ‘silencing’ of mental health problems due to perceived stigma influences help-seeking responses in African-descended communities (Mantovani, Pizzolati, & Edge, 2017; Shefer et al., 2013). The stigma and taboo surrounding mental health problems mean that they are often not spoken about within minority ethnic families and communities (Rathod et al., 2010). Perceived mental-health related discrimination by the authorities and the medical establishment, and emanating from ethnic communities and families, has been reported as a major barrier to accessing mental health care among minority ethnic groups (Shefer et al., 2013). In a study of Black African American outpatients, perceived stigma relating to mental health problems was not associated with treatment engagement, but stigma concerns related to treatment prompted service users to avoid or delay treatment (Alvidrez, Snowden, & Patel, 2010).
These findings highlight the multidimensional nature of stigma and reflect the ongoing debate relating to the conceptual clarity of the stigma construct, which is often confounded with psychosocial variables such as emotional distress (Livingston & Boyd, 2010). There is a particular need for a greater understanding of stigma and its relationship with engagement in Black populations, where marginalisation and social exclusion are pertinent. Minority ethnic individuals are proposed to experience ‘double stigma’ as they are already faced with prejudice and discrimination related to minority group affiliation (Gary, 2005).

*Racial or ethnic discrimination in services*

The most common explanations for ethnic inequalities in pathways to care and poor engagement experienced by Black groups are reported to be misdiagnosis, cultural insensitivity and institutional racism (McKenzie & Bhui, 2007; Nazroo, 2015; Rüsch et al., 2013; Singh, Greenwood, White, & Churchill, 2007). Cultural stereotypes of Black people as being violent and dangerous have been suggested to fuel more compulsory and coercive powers among police and healthcare professionals (Pipe, Bhat, Matthews, & Hampstead, 1991). Racial discrimination inherent in Western psychiatry and Eurocentric conceptualisations of mental health problems have been argued to translate into the maltreatment of Black individuals in mental health services (Fernando, 1991). A number of UK health-related reports and polices have either directly stated or alleged that NHS mental health services are institutionally discriminatory (Commission for Healthcare Audit and Inspection, 2005; Department of Health, 2005; Keating et al., 2002; National Institute for Mental Health, 2003). However, the use of racism to explain disparities in coercive and adverse treatment has been challenged based on a lack of clear supporting evidence (Singh et al.,
2007), and is suggested to be unhelpful as it reinforces stereotypes and the mistrust of services in Black and minority communities (Singh & Burns, 2006).

Black people have historically been labelled as ‘hard-to-reach’ in the UK but this has been challenged based on literature suggesting that they often have multiple attempts at seeking help before crisis develops (Morgan et al., 2004). This narrative can place blame on Black people for not seeking treatment, when there is evidence to suggest they are less likely to be referred to mental health services by primary care (Islam et al., 2015). Black African and Caribbean peoples’ previous experiences of services have been shown to influence their future help-seeking and engagement for psychosis (Edge & MacKian, 2010; Morgan et al., 2017; Morgan et al., 2004). Ethnic differences and adverse relationships with services have been shown to develop over time and with repeated contact (Burnett et al., 1999). Additionally, an increasing level of dissatisfaction has been associated with greater number admissions to hospital in Black Caribbean people (Parkman, Davies, Leese, Phelan, & Thornicroft, 1997). Black community members have previously reported avoidance of mental health services due expectations of cultural incompetence or racist maltreatment (Callan & Littlewood, 1998; Mclean, Campbell, & Cornish, 2003). Qualitative accounts from minority ethnic communities suggested that help-seeking strategies are often generated through storytelling within social networks, whereby a community member only needs to hear about and internalise the negative experiences of others to disengage with services (Kovandzic et al., 2011). A lack of effective and culturally sensitive information about mental health and available support also deterred help-seeking from primary care (Kovandzic et al., 2011). Most of the published work relating to perceived discrimination in clinical samples has focused on the experiences of Black Caribbean people in the UK, non-UK Black and
minority ethnic people (e.g. African American), or mixed minority ethnic samples. Little work has been carried out in Black African samples in the UK.

1.7 Chapter summary

In summary, Black African and Caribbean people have repeatedly been referred to as ‘hard-to-reach’ and as having the most difficult relationships and poorest engagement with mental health services. This narrative has been challenged by research suggesting that Black people have failed attempts at seeking professional help and that services may not be meeting their needs. Poor engagement with services is problematic as it is associated with adverse outcomes (e.g. suicide). Delayed engagement and prolonged duration of untreated symptoms can impede recovery, leading to poorer prognosis with higher rates of relapse and readmission to hospital.

Research to date highlights the potential importance of social networks in facilitating (and discouraging) help-seeking and engagement in psychosis. There is some evidence, mostly qualitative, to suggest that help-seeking and engagement in psychosis may be influenced by illness beliefs, stigma, and discrimination, with observed differences for minority ethnic groups. However, limited empirical research has been carried out to examine the relationships between these constructs and engagement among Black African and Caribbean people with psychosis in the UK; despite the obvious need. Additionally, there has been a paucity of research investigating current engagement with services, with most studies focusing either on initial access to or disengagement from treatment. More detailed theoretical understanding of social and psychological factors that influence current service engagement in Black African and Caribbean people in the UK is warranted to inform
psychosocial interventions to improve engagement and mental health service provision for these, and other, marginalised groups.

1.8 Aims and outline of the present thesis

Aims of thesis

The overall aims of the current doctoral thesis are twofold. Firstly, the aim is to systematically assess the importance of social networks for outcomes in non-affective psychosis and to provide a detailed account of the social network characteristics in Black African and Caribbean people with non-affective psychosis in the UK. The second aim is to advance current knowledge by developing psychological theories to explain engagement with services in Black African and Caribbean people with psychosis in the UK.

Outline of thesis

This thesis is presented in alternative format. At the time of writing, the first paper (Chapter 3) was under review and the subsequent two papers (Chapters 4-5) were in preparation for submission.

Chapter 2 provides an overview and justification of the methodologies used in the present thesis beyond that which is described in the papers, including the research design, participants and recruitment, measures, analysis methods, and service user and carer involvement.

Chapter 3 presents a systematic literature review and meta-analysis of the nature and extent of the relationship between social networks and outcomes in schizophrenia and non-affective psychosis. An initial search of the literature confirmed that there
was limited research examining social networks in Black African or Caribbean clinical populations. This Chapter therefore provides a comprehensive overview of the available literature on social networks and outcomes in non-affective psychosis across all ethnic groups. A subsidiary aim was to assess study quality, including the conceptualisation and measurement of social networks in the reviewed studies, and to provide recommendations for future social network research in psychosis. The findings of this systematic review helped to inform the hypotheses and social network measure used in the quantitative studies (Chapters 4 and 5).

The empirical study presented in Chapter 4 describes the social network characteristics in a sample of Black African and Caribbean people diagnosed with non-affective psychosis. This paper discusses the findings in relation to previous literature, drawing comparisons with social network characteristics in predominately White British populations. The findings of this paper were used to inform hypotheses relating to the association between network characteristics and engagement for Chapter 5.

The cross-sectional study in Chapter 5 examines the nature of the relationships between social and psychological factors and engagement with services in Black African and Caribbean people diagnosed with non-affective psychosis. This study reports on the same sample as Chapter 4. The relationships between social networks, stigma, discrimination and illness perceptions were examined using correlational and subsequently multiple linear regression analyses, adjusting for psychosis symptoms. Further exploratory mediation analysis was used to explore interactions between predictor variables and to develop a tentative theoretical model to predict service engagement. Given the limited research in this area, this was considered to be theory
building work that aimed to generate hypotheses for future large-scale longitudinal studies.

Chapter 6 presents the general discussion of the thesis, including summaries of findings of the empirical studies, methodological considerations, strengths and limitations, and clinical and research implications.
CHAPTER 2: Methodological considerations
2.1 Overview

The aim of this chapter is to provide an overview and justification of the methodologies used in the thesis, including research design, participant recruitment and engagement, service user and carer involvement, study measures, analysis methods, and ethical considerations. Methodologies and methodological limitations relating to individual studies are described within each of the corresponding papers and in the general discussion.

2.2 Research design

This programme of study used quantitative methods with a cross-sectional design (Chapters 4 and 5) to address individual research aims. Cross-sectional research is a necessary and useful first step to test whether any significant relationships between variables exist, before undertaking more resource heavy longitudinal work. To establish causal associations, experimental and longitudinal designs are needed. However, an experimental design was not appropriate in the current thesis due to ethical issues and difficulties with manipulating complex social and psychological variables such as social networks and discrimination. The two quantitative studies in this thesis therefore used observational designs and self-report measures to assess key variables of interest. A longitudinal follow up was not possible within the scope of this thesis due to insufficient time and resources but is a key recommendation for further work to advance the findings of the included studies (Chapter 6).
2.3 Participants

The same inclusion criterion was used for the clinical samples for both the quantitative studies in this thesis. Participants were eligible if they self-identified as being of Black Caribbean or Black African background (i.e. including Black British and ‘Mixed’ ethnicities with at least one grandparent born in a Caribbean or African country); had a clinical diagnosis of ICD-10 (World Health Organisation, 1992) or DSM-5 (American Psychiatric Association, 2000) schizophrenia or non-affective psychosis (i.e. schizophrenia, schizoaffective disorder, schizophreniform disorder, delusional disorder, psychosis not otherwise specified); were over 18 years of age; and gave written informed consent to participate. Participants were also required to be under the care of a mental health team and key worker who they had known for at least one month. Similar criteria have been used in previous studies to ensure that mental health professionals have sufficient knowledge of the service user to complete measures assessing their relationship (Barrowclough et al., 2001; Berry, Barrowclough, & Wearden, 2008).

In line with previous research, a key worker was defined as a mental health professional who is responsible for managing and implementing the care support plan with the service user (Barrowclough et al., 2001; Berry et al., 2008). In the present thesis, key workers included support workers in rehabilitation units or supported housing, and care coordinators of multidisciplinary teams, such as community psychiatric nurses (CPNs), occupational therapists and mental health social workers.

Exclusion criteria included a primary substance misuse or mood diagnosis and significant cognitive impairment implicated in aetiology. Participants were also
excluded if they were assessed by their key mental health professional as too unwell or lacking capacity to participate. Due to limited resources for translation, participants were required to be English speaking to complete the study measures.

2.4 Recruitment and engagement

The programme of research presented in this thesis was carried out alongside a trial to develop and test the feasibility of a Culturally-adapted Family Intervention (CaFI) for Black Caribbean people diagnosed with schizophrenia and their families. The CaFI study was funded through the National Institute for Health Research (NIHR) Health Service and Delivery Research (HS&DR) programme (project ref: 12/5001/62). The present author’s lead supervisor (DE) was the Chief Investigator for the CaFI trial and the author (AD) was the research trial manager for its entire duration [Sept 2013 – Mar 2017]. Further details of the trial methodology and findings can be found in the published protocol (Edge et al., 2016) and NIHR report (Edge et al., in press). The current author shared recruitment with a CaFI research assistant (SB) and a trainee clinical psychologist (LS), who was also conducting her research thesis at The University of Manchester alongside the CaFI trial. The CaFI trial had similar eligibility criteria as the present research but, unlike the current study, was specific to Black Caribbean people and excluded individuals of Black African ethnicity.

Participants were recruited from acute inpatient wards, rehabilitation units, community mental health teams (CMHTs), and early intervention services (EIS) across three National Health Service (NHS) Trusts in Greater Manchester, UK.

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2 Sophie Baker was a research assistant on the CaFI trial
3 At the time of the study, Lucy Shattock was a Trainee Clinical Psychologist in Greater Manchester who was conducting her research project as part of the CAFI trial at The University of Manchester.
Participants could self-refer or were referred by mental health professionals who provided potentially eligible participants (i.e. on their caseload or in their mental health service) with information about the study and obtained their consent to be contacted by a member of the research team. Mental health professionals were provided with crib sheets detailing a short summary of the research and eligibility criteria, to reduce burden and to facilitate the delivery of study information to service users. Recruitment to the CaFI trial and the current research programme were carried out in parallel using similar recruitment methods. Following screening, eligible service users were informed about both the present study and the CaFI study (depending on their interest) and were given adequate information, choice and as much time as they needed to make a decision about whether to take part in both, one, or neither of the studies.

The researcher contacted referred individuals via their preferred method (usually telephone) to discuss the research and their potential involvement. Service users were posted the participant information sheet [Appendix I], which included detail about the two quantitative studies (Chapters 4 and 5). Self-referrals contacted the researcher directly on a central study number shared via the recruitment methods below. Participants were given at least 24 hours to consider the information and then were contacted again and invited to attend a meeting with the researcher at a convenient time and location of their choice, such as in their home, local community centre or NHS or University building. During the initial visit, the researcher talked through the participant information sheet in detail and addressed any queries or concerns. Participants were subsequently asked to provide written informed consent [Appendix II]. This included consent for their key worker to be approached to complete a questionnaire about their relationship. Key workers were provided
separate participant information sheets [Appendix III] and consent forms [Appendix IV] for their involvement in the study.

Difficulties recruiting minority ethnic groups to clinical research studies have been extensively documented (Brown, Marshall, Bower, Woodham, & Waheed, 2014; Hussain-Gambles, Atkin, & Leese, 2004; Waheed, Woodham, Hughes-Morley, Allen, & Bower, 2015). A variety of recruitment methods were employed due to the anticipated challenges with recruiting a large sample of individuals over a limited time period who met the specific ethnic and diagnostic inclusion criteria. Recruitment methods included placing advertisement posters [Appendix V] in local NHS and community settings and delivering presentations to NHS care teams, third sector mental health organisations and Black-Majority Churches. The CaFI trial received additional support from the NIHR clinical research network (CRN) officers, who passed on study information to NHS staff via email and at regular team meetings and approached service users about the study in inpatient wards. The research was also advertised on the NHS Trust staff intranet and in local radio stations (i.e. BBC Radio Manchester and Peace FM (now Legacy) and newspapers (i.e. Manchester Evening News and The Nubian Times). To engage the local community, the author and lead supervisor of the thesis hosted two community launch events in two local areas in Manchester (Hulme and Moss Side) with a high proportion of Black and minority ethnic communities. The researchers highlighted opportunities to get involved in the studies and interested attendees left their contact details for further information. In total, around 100 people attended the events, including community members, service users, carers, and health and social care professionals. These engagement events and press releases provided a platform for recruitment to the present study by raising awareness of the research and building
relationships with local third sector mental health services, including the African Caribbean Mental Health Services, Just Psychology, Manchester Black and Minority Ethnic (BME) Network, Black Health Agency, Manchester Carers Forum, Rethink Manchester Carers in Action, Self-Help Services, Patient Voices and BlueSCI.

Of the 84 participants referred to the study, 51 (60.71%) consented to participate. Two individuals self-referred into the study and the rest were referred via their mental health professional. Five (9.62%) participants dropped out during the study. No data was available for one participant who withdrew post-consent following a relapse and hospital admission. Four participants completed some measures but were lost to attrition after the first assessment visit; two lost contact, one relapsed and the other was imprisoned, meaning they could not be contacted to participate. Of the 51 individuals who took part in the quantitative studies, 24 participated in the CaFI trial.

2.5 Procedure

Following informed consent, participants conducted the quantitative assessments. Researchers supported participants to complete the measures independently and assistance was provided when needed, such as with clarifying terms, reading out questions and completing consent forms. Participants were given the opportunity to complete the measures in a separate appointment to reduce the level of participant burden. All measures were completed within a two-week period. The order of the measures was determined based on their relative importance to the study aims. Individuals that were also participating in the CaFI trial completed the quantitative

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4 This participant was admitted to hospital and was too unwell to meet with the researcher to complete the measures.
study before they started the therapy sessions to avoid any potential confounds related to taking part in the trial.

2.6 Self-report measures

This subsection describes the self-report measures that were used in the quantitative studies. Methodological detail relating to their use in the empirical studies is reported in the individual papers in Chapters 4 and 5. Copies of self-report measures can be found in the appendices [Appendix VI].

2.6.1 Service engagement

The Service Engagement Scale (SES) (Tait et al., 2002) is a questionnaire measure of service user engagement with mental health services from a staff member perspective. The SES includes 14 items which comprise four subscales: availability; collaboration; help-seeking; and treatment adherence. An example item is ‘The client seeks help to prevent a crisis’. Participants rate the extent to which they agree with each statement on a four-point Likert scale ranging from ‘not at all’ or ‘rarely to most of the time’. Higher total scores represent poorer engagement. The SES has previously demonstrated a high level of test-retest reliability and validity in samples of individuals with psychosis (Tait et al., 2002, 2003).

The Singh O’Brien Level of Engagement Scale (SOLES) (O’Brien, White, et al., 2009) is a 16-item self-reported measure of engagement with mental health services. The SOLES consists of two subscales: acceptance for need of treatment; and perceived benefit of treatment. An example item is ‘I find seeing my key worker helpful’. Endorsement of each statement is rated on a scale from 1 (not at all) to 10.
(entirely). Higher total scores usually relate to a higher level of engagement, but scores were reversed for this study to be consistent with SES scoring.

2.6.2 Internalised stigma

*The Internalised Stigma of Mental Illness (ISMI) scale* (Ritsher, Otilingam, & Grajales, 2003) is a 29-item self-report measure with five subscales: alienation, stereotype endorsement, discrimination experiences, social withdrawal and stigma resistance. An example item is ‘Stereotypes about the mentally ill apply to me’. Participants rate each item on a four-point Likert scale ranging from 1 ‘agree’ to 4 ‘disagree’. Total scores can be calculated by summing the subscale scores, with higher scores indicating higher internalised stigma.

2.6.3 Illness perceptions

*The Brief Illness Perception Questionnaire* (Brief-IPQ) (Broadbent, Petrie, Main, & Weinman, 2006) is a brief self-report measure of illness beliefs derived from the original Illness Perception Questionnaire (IPQ) (Weinman, Petrie, MossMorris, & Horne, 1996). The original lengthier IPQ is based on the Self-Regulation Model (SRM) (Leventhal et al., 1984) which suggests individuals develop specific emotional and cognitive representations about health problems that influence their coping responses. The IPQ can be adapted for mental health problems (Baines & Wittkowski, 2013), and an adapted version has been validated in people diagnosed with schizophrenia (IPQ-S) (Lobban et al., 2004, 2005a). The Brief-IPQ includes nine items representing different illness perceptions: five cognitive representations (consequences, timeline, personal control, treatment control and identity); two emotional representations (concern and emotional representation); and one
comprehensibility item (coherence). An example item is ‘*How concerned are you about your mental health problems?’* Each item is rated on a scale of 0 (e.g. *not concerned*) to 10 (e.g. *very concerned*), with higher scores indicating greater endorsement of the illness perception. Based on feedback from a service user and carer advisory group (section 2.10), the wording on the BIPQ was modified to be more user-friendly (whilst retaining the integrity of the item) and the term ‘illness’ was replaced with ‘mental health problem’.

2.6.4 Racial or ethnic discrimination

A measure of perceived racial or ethnic discrimination in mental health services was developed specifically for the current thesis as existing measures were not deemed to be culturally relevant to the experiences of Black African and Caribbean people receiving treatment under mental health services in the UK. Two reviews of race and ethnicity based discrimination measures have highlighted that additional measures are needed for the assessment of perceived discrimination in healthcare settings, as most measures assessed general dimensions of racism, focused specifically on the experiences of African American patients, and were not psychometrically validated (Bastos, Celeste, Faerstein, & Barros, 2010; Kressin, Raymond, & Manze, 2008). The latter reviews were conducted over five years ago, but a literature search conducted by the author reiterated its conclusions and found no novel or relevant measures since then. The Perceived Discrimination Measure (PDM) was, therefore, developed by the author in collaboration with an advisory group of service users, carers and community members (section 2.10). The PDM includes two items: 1) *NHS mental health services discriminate against people (treat people unfairly) because of their racial/ ethnic background*; and 2) *NHS mental health services*
discriminate against me (treat me unfairly) because of my racial/ethnic background.

Participants are asked to rate these statements on a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).

2.6.5 Psychosis symptom severity

The Positive and Negative Syndrome Scale (PANSS) (Kay, Fiszbein, & Opler, 1987) is a widely used 30-item semi-structured clinical interview designed to provide a standardised assessment of symptoms in schizophrenia during the previous week. It includes three subscales: positive (seven items); negative (seven items); and general psychopathology (16 items). Each item is rated by interviewers on a Likert scale, ranging from 1 (absence) to 7 (extreme). Total scores can be derived by summing items, with higher scores indicating greater symptom severity. Two postgraduate researchers (the author, AD, and a second researcher, LS) were trained to conduct and rate the PANSS. Researchers attended regular supervision with a clinical psychologist and inter-rater reliability was monitored every three months. Intraclass correlation coefficients (ICCs) for the subscales and total scores at the start of the study ranged from .82 to .95.

2.6.6 Sociodemographic data

Service user clinical and sociodemographic information was collected via a self-report questionnaire that was developed specifically for the study. This measured a range of variables, including age, gender, ethnicity, diagnosis, duration of contact with services, service setting, country of origin, employment, education, marital status and living status. All information was verified by the participant’s key worker and clinical case notes.
2.7 Social network analysis

Social network analysis is a method of data collection and analysis that was used in the two quantitative studies (Chapters 4 and 5) to examine the social network characteristics of the participants.

2.7.1 Social network analysis

Social network analysis (SNA) encompasses a collection of theories, models and techniques that focus on relationships among social entities and the patterns and implications of these relationships (Borgatti, Mehra, Brass, & Labianca, 2009; Carrington, Scott, & Wasserman, 2005; Mitchell, 1969). Network analysis has a relatively long history with a wide interdisciplinary reach, finding important applications in anthropology, sociology, social psychology, and economics amongst many other disciplines. SNA provides a tool for describing and analysing relation phenomena and their effects on individual and group behaviour (Berkman, Glass, Brissette, & Seeman, 2000). According to network theory, social networks can be measured and defined as relational concepts and processes between interacting units (Borgatti et al., 2009). Social networks are considered to be social structures that afford opportunities but also place constraints upon the network members (Coleman, 1990). Within these social structures, people interact and influence one another, for example, exchanging resources, sharing information and culture, and providing support or friendship (Crossley et al., 2015). However, this comes at a cost, with expectations and demands from the environment in which they are situated (Crossley et al., 2015). There may be a trade-off between the safety and social support of strong social ties and the flexibility of wider social ties that may be weaker but provide access to novel resources (Granovetter, 1973).
There are two methodological approaches in SNA research; *personal network analysis* (often referred to as ego-network analysis) and *whole network analysis*. Crossley et al. (2015) describe an *ego-net* as a network which forms around a particular social actor [ego]…. it involves all other actors (alters) with whom ego enjoys a specified and relevant relation or set of relations, whatever they might be (e.g. emotional closeness, information sharing, economic exchange etc.), and it involves the pattern of (specified) relations between those ‘alters’” (p. 1). To generate a personal network, one only needs to interview the ‘ego’ to gather information about their relationships with the ‘alters’ (and, if appropriate, between the ‘alters’). In contrast, the whole network approach examines the existence of ties between all individuals in a given population; most often through survey research (Pearson, 2013). People interact and form relations across a number of social circles, with the typical adult having family, community, work and friendship connections relating to the different contexts and activities in which they are involved (e.g. gym, university, church). These interacting social circles can be relatively distinct, and the focal individual often provides the only point of intersection between them. Therefore, if one wishes to study many different social contexts, the size and complexity of the task would be too onerous for whole network analysis (Crossley et al., 2015). Whole network analysis is only feasible in clearly bounded groups, such as those relating to a single social circle or context (Mitchell, 1969).

Ego-net methods are more commonly used in mental health research due to ethical issues and difficulties collecting data relating to all social ties in the networks of clinical samples. Characteristics of the whole social network are often inferred from the participant in ego-net research (Crossley et al., 2015; Pearson, 2013). For these reasons, ego-net research was utilised within the present thesis.
2.7.2 Social network mapping interview

The social network mapping interview [Appendix VII] used in the current thesis collected data relating to the characteristics of the service users’ social networks (*ego-nets*) (Crossley et al., 2015). This study used a modified version of the Personal Wellbeing Network (PWN) interview developed by the McPin Foundation, London, in their recent NIHR-funded Community Health Networks study (Pinfold et al., 2015). The PWN was informed by patient and public involvement (PPI) feedback and piloted in individuals with severe mental health problems with demonstrable face validity (Sweet et al., in press). The modified PWN collects data on three key elements: 1) *alters*: the participants’ (*ego*) network members; 2) *network structure*: the characteristics of social connections between network members; and 3) *alter attributes*: socio-demographic information about network members. Network mapping interviews with similar techniques have been used in previous studies in psychosis and have demonstrated good reliability (Siette, Gulea, & Priebe, 2015).

For each participant, a comprehensive list of people (*alters*) in their social network was generated using the *name generator* approach (Campbell & Lee, 1991) which asks a series of questions focusing on the exchange of interaction between ego and alters. An example question is, ‘*Who are the people that you enjoy seeing or spending time with?*’ The first nine questions include two positive interactions (i.e. enjoy spending time with and share social activities); two negative interactions (i.e. find social contact distressing; would prefer not to see); two involving emotional support (i.e. emotional reassurance; discuss important matters); and three relating to instrumental or practical support (i.e. borrow money or material goods; obtain advice or information; help with everyday tasks). The tenth question asks participants to list
anyone in their social network who they have not recalled, ensuring saturation is reached. Network boundaries were drawn by asking participants to name people with whom they are in regular contact or regard as important or meaningful at the time of the interview. There was no upper limit on the number of people participants could recall. Participants could recall the same person in response to different name generator questions.

For the second part of the interview, participants were asked to place each recalled network member on an *emotional closeness map* on one of six concentric circles in terms of how close they felt to that person, ranging from close (1, inner circle) to not close (6, outer circle). Following this, to gather information on *network structure*, participants were asked to draw lines between those people who knew one another on the closeness map.

In the third part of the interview, for each person listed, participants were provided a name interpreter card with a series of questions to generate information about *alter attributes*: i) gender; ii) age; iii) ethnicity; iv) frequency of contact; v) duration known; vi) type of relationship; vii) whether they used mental health services; viii) whether they know about the service user’s mental health problems; ix) satisfaction with emotional support; and x) satisfaction with instrumental or practical support. For each network member, on each interpreter card, the interviewer jotted the emotional closeness score, along with each name generator question from which the network member was recalled and whether the particular interaction was reciprocal or dependent (i.e. one direction, from the network member to the participant).

Finally, the participant was asked to rate the extent to which they felt satisfied with their overall social network on a scale of 1 (*very dissatisfied*) to 5 (*very satisfied*) and
give their reason for their rating. The interview was conducted by trained researchers (AD and LS). The length of time to complete the interview ranged from 45 to 90 minutes but it was dependent on the number of people recalled by the participant, as well as the participant’s cognitive ability. For this thesis, the following structural, compositional and transactional social network variables were generated from the interview:

**Structural characteristics**

- **Network size:** the total number of individuals recalled in the social network.
- **Network density:** the proportion of network members who know one another, or the ‘interconnectedness’ of the network. This was calculated by dividing the number of actual connections with the number of possible connections in the social network. Density ranges from 0-1, with higher scores indicating greater densities.
- **Network homophily:** the extent to which participants ‘cluster’ or form relationships with people who are similar versus dissimilar to themselves. This study measured two types of homophily: *ethnic homophily* and *gender homophily*. That is, the extent to which participants formed relationships (or social ties) with people of the same ethnic group and gender to their own. This can be measured using the external-internal (EI) index which examines the number of ties within and between groups (Krackhardt & Stern, 1988). Specifically, the index calculates the number of external social ties (different group) minus the number of internal social ties (same group) divided by the total number of social ties. The EI index ranges from -1 (greater homophily,
all social ties belong to the same group) to +1 (greater heterophily, all ties belong in a different group).

- **Isolates**: the number of people that are connected to the participant but are not connected to others in the social network.

- **Components**: a subset of network members all of whom are connected by a path when the participant is removed.

*Compositional characteristics*

- **Relationship type**: the number and proportion of network members recalled for each of the following different types of relationship: immediate family; wider family; partner; friends; colleagues; neighbours; acquaintances; and healthcare professionals. Relationships were categorised into: i) family (immediate, wider and partner); ii) friends; iii) wider contacts (colleagues, neighbours and acquaintances); and iv) health and social care professionals. Participants could choose more than one relationship for each network member but were asked to indicate the priority relationship, which was used for the categorisation. Proportions for compositional variables were calculated by dividing the number of network members per group by the total number of individuals recalled (i.e. network size).

- **Network diversity**: the number of different types of relationships in the participant’s social network, with scores ranging from 1 to 8. This measure counted instances where the same person satisfied more than one relationship type.
• **Mental health service use and knowledge:** the number and proportion of network members that: i) use mental health services; and ii) know the service user has a mental health problem.

**Transactional characteristics**

• **Strength of tie:** the ‘closeness’ or ‘intensity’ of the relationship. This has been suggested to reflect the ability of one individual to exert influence on another (Mitchell, 1969). Measures of the strength of each relationship in the network included: i) emotional closeness, ranging from 1 (*not very close*) to 6 (*very close*); ii) number and proportion of people in the inner circle, i.e. network members rated as very close; iii) frequency of contact, rated on a scale of 1 (*never/no longer*) to 6 (*daily*); and iv) duration known, ranging from 1 (*less than 6 months*) to 4 (*more than 10 years*).

• **Perceived social support:** the participant’s satisfaction with the level of social support provided by each network member, including two items: i) emotional support; and ii) instrumental/practical support. Each item was rated on a Likert scale, ranging from 1 (*very dissatisfied*) to 5 (*very satisfied*).

• **Function/content:** the number and proportion of people recalled in response to each of the ten name generator questions relating to different types of social interactions (e.g. sharing social activities; discussing important matters; stressful interactions; provision of advice or information; borrowing money etc.). These ‘network types’ were not mutually exclusive as participants could recall the same person in response to different name generator questions.
• *Reciprocity*\(^5\): the extent to which the social exchange was reciprocated or not. This study measured the number and proportion of social interactions that were reciprocal (i.e. bidirectional) versus dependent i.e. one direction, from the network member to the service user. Reciprocity was examined per name generator question (or type of social connection) and summed across all social connections.

### 2.8 Quantitative analysis methods

#### 2.8.1 Mediation analysis

Mediation analysis was used in Chapter 5 to examine relationships between social and psychological variables (i.e. social networks, perceived racial or ethnic discrimination in services and illness beliefs) and engagement with services. One of the main goals in psychological research is to *explain* relationships that exist between independent variables (IV) and dependent variables (DV) (Cheung & Lau, 2007). Mediation analysis is one method to examine the mechanisms that may underlie the relationships between variables (Cheung & Lau, 2007; Hayes, 2009, 2013). In a simple mediation model, the independent variable \(X\) exerts an effect on the dependent variable \(Y\) through an intervening or *mediator* variable \(M\) (Hayes, 2009). Figure 1 presents a simple mediation model where \(c'\) is the direct effect of \(X\) on \(Y\) and the product of \(a\) and \(b\) equates to the indirect effect of \(X\) on \(Y\) through \(M\). The total effect \(c\) is the sum of the direct effect \(c'\) and indirect effect \(ab\) \((c = c' + ab)\).

---

\(^5\) Because of the nature of the name generator questions, it was not possible to measure whether the relationship was instrumental, i.e. one direction, from the service user to the network member.
Figure 1.

A simple mediation model

2.8.2 Bootstrapping

Bootstrapping is a statistical re-sampling procedure that provides a non-parametric method of statistical inference (Mooney & Duval, 1993). Bootstrapping works by taking multiple random subsamples from the original sample and then calculating the statistical analysis for each subsample. This analysis results in an empirically derived sampling distribution for the statistic of interest, which is assumed to represent the distribution of that statistic in the population (Mooney & Duval, 1993). Bootstrapping generates confidence intervals to test null hypotheses; with one assumption being that the null hypothesis is accepted if the confidence interval crosses the point of null effect (Mooney & Duval, 1993; Wood, 2005). The minimum number of subsamples recommended for generating accurate confidence interval estimates is 5000 (Efron & Tibshirani, 1994).

Bootstrapping was used in the present thesis to examine the significance of indirect effects in the mediation analysis conducted in Chapter 5. Bootstrapping was considered appropriate as it is a robust method for establishing mediation effects and works well in small samples (Preacher & Hayes, 2004). Bootstrapping is also ideal...
as it can be used alongside parametric tests, such as linear regression, and it does not require the assumption of normality which is often violated in mediation analyses as the indirect effect is often skewed (Cheung & Lau, 2007). This makes it preferable to other methods such as the commonly used Sobel’s test which assumes a normal distribution (Cheung & Lau, 2007).

2.9 Reflexivity

The perspectives and backgrounds of researchers involved in the current programme of work should be acknowledged given their potential influence on the research process and findings. The author (AD) is a White British female with an interest in culture and psychosis. AD completed a BSc in Psychology and an MSc in Clinical and Health Psychology before completing the current PhD in Clinical Psychology. AD grew up in a socio-cultural context that lacked diversity but has since lived in the ethnically and culturally diverse city of Manchester, UK, for over ten years. During this time, the author has worked in clinical and research settings with people from a diverse range of social, ethnic and cultural backgrounds.

The lead supervisor of the thesis (DE) is a Black Caribbean female Senior Lecturer in Psychology and Academic Lead for Equality Diversity and Inclusion, with a passion for work to reduce inequalities in access, care and treatment experienced by undeserved communities. The second supervisor (KB) is a White British female Clinical Psychologist and a Senior Clinical Lecturer specialising in attachment theory and psychosis. The third supervisor (NC) is a White British male Professor of Sociology who co-founded the Mitchell Centre for Social Network Analysis. The fourth supervisor (KA) is a White British female Consultant Psychiatrist and
Professor of Psychological Medicine and Reproductive Psychiatry. All supervisors were working at The University of Manchester at the time the thesis was carried out.

2.10 Service user and carer involvement

The present thesis was carried out with active involvement from service users, carers and community members throughout key stages of the research process, including study design, participant recruitment, data collection and dissemination of findings. The CaFI trial had a research advisory group (RAG) of eight service users, carers and community members of Black Caribbean background who were passionate about improving mental health care for people living with psychosis in their community. RAG meetings were held regularly throughout the three year CaFI trial and chaired by a service user co-applicant (PG) who had over twenty years lived experience of psychosis and expert knowledge relating to the mental health of Black communities. The author of the current thesis organised and co-chaired the meetings. During the meetings, the lead author consulted the RAG about a number of issues relating to the current research to ensure it was carried out in a way that was acceptable and sensitive to the socio-cultural backgrounds of Black mental health service users experiencing psychosis. Feedback was sought on appropriate ways to approach people about the study and carry out the research assessments whilst minimising potential distress or burden. The RAG also reviewed and provided feedback on research materials, including the participant information sheets, advertisement posters, consent forms and network mapping interviews. Changes were made to the content and wording to ensure the study materials and interview questions were appropriate and easy to understand. Their contribution informed decisions relating to the service user reported measures (section 2.6), including
engagement with services (SOLES) (O'Brien, White, et al., 2009) and racial or ethnic discrimination in services (PDM). RAG members selected the SOLES questionnaire (O'Brien, White, et al., 2009) for service user reported engagement as they felt that this was user-friendly and more accurately reflected their experiences than other available measures (i.e. Gillespie, Smith, Meaden, Jones, & Wane, 2004; Goodwin et al., 2003; Hall, 2001; Tait et al., 2002). They also contributed to the development and phrasing of the items for the study-specific perceived discrimination measure (PDM).

2.11 Ethical approval

The studies included in this thesis were approved by the NHS Research Ethics Committee (15/NW/0086), Trust Research and Development Departments and The University of Manchester.
3.1 Abstract

Depleted social networks in schizophrenia are of potential clinical significance. A systematic review was conducted to examine the strength of associations between social network size and outcomes in schizophrenia-spectrum diagnoses. Studies were identified from a systematic search of electronic databases (EMBASE, Medline, PsycINFO, and Web of Science) from January 1970 to June 2016. Eligible studies included peer-reviewed English language articles that examined associations between a quantitative measure of network size and symptomatic and functional outcome in schizophrenia. The search yielded 16 studies with 1,929 participants. Meta-analyses using random effects models to calculate pooled effect sizes (Hedge’s $g$) found that smaller social network size was moderately associated with more severe overall psychiatric symptoms ($g = -0.53$, 95% confidence interval (CI) = -0.88, -0.18) and negative symptoms ($g = -0.75$, 95% CI = -0.10, -0.51). Statistical heterogeneity was observed ($I^2 = 35.75\%$, $I^2 = 63.04\%$) which could not be explained by low quality network measures or sample heterogeneity in sensitivity analyses. There was no effect for positive symptoms ($g = -0.19$, 95% CI = -0.49, -0.11) or social functioning ($g = 0.36$, 95% CI = -0.08, 0.80). Narrative synthesis suggested that larger network size was associated with improved global functioning, but findings for affective symptoms and quality of life were mixed. Psychosocial interventions which support individuals to build and maintain social networks may improve outcomes in schizophrenia. Further research is required to examine temporal associations between network characteristics and outcomes in schizophrenia and test theoretical models relating to explanatory or mediating mechanisms.
3.2 Introduction

Social connections can have positive effects on mental health, for example, by directly increasing self-esteem or buffering the negative effects of socioenvironmental stressors (Brugha, 2010; Cohen & Willis, 1985). Conversely, having fewer social connections is associated with more adverse outcomes, such as poorer physical health and increased risk of early mortality (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). However, social relationships are not always supportive and can be sources of conflict and stress (Thoits, 2011). For example, emotionally over-involved and hostile interactions with significant others can lead to higher rates of relapse in schizophrenia (Barrowclough & Hooley, 2003; Butzlaff & Hooley, 1998). Social withdrawal may be used as a protective mechanism, but this can further limit the availability of social connections and important buffers, thereby potentially increasing the risk of poor long-term outcomes (Gayer-Anderson & Morgan, 2013; Sündermann, Onwumere, Bebbington, & Kuipers, 2013).

Over the past few decades, an abundance of research has shown that social networks are disrupted in schizophrenia (Palumbo, Volpe, Matanov, Priebe, & Giacco, 2015; Randolph, 1998). It is often assumed that the size and quality of social networks diminish as a consequence of the illness, with earlier theories proposing a ‘network crisis’ at first onset (Beels, 1979; Lipton et al., 1981). This has been contradicted by findings that network characteristics are relatively stable over the year following initial hospitalisation (Horan, Subotnik, Snyder, & Nuechterlein, 2006). Recent evidence suggests that social networks and satisfaction with social support deteriorate at first episode and before the onset of psychosis (Gayer-Anderson & Morgan, 2013). It is now generally accepted that the relationship between network
disruption and increasing chronicity is non-linear and network changes occur prior to, and at the later stages of schizophrenia (Gayer-Anderson & Morgan, 2013).

Social network is a multidimensional construct, yet research in schizophrenia tends to use generic measures and focus on functional attributes such as social support (Brugha, 1995). Social network analysis (SNA) (Borgatti et al., 2009; Mitchell, 1969) provides a comprehensive method of describing and analysing social networks, defined as sets of social ties or connections between individuals. SNA draws a distinction between structural characteristics, or the patterns of social connections, and interactional characteristics, such as the content, function or quality of relationships. This approach minimises bias as it delineates the effects of objective characteristics of social relationships from individual-level subjective variables (Horan et al., 2006). Structural features of social networks that have received the most attention in schizophrenia research are size, composition and density (Palumbo et al., 2015; Randolph, 1998). Compared to non-psychotic populations, the social networks of people with schizophrenia and psychosis tend to be smaller and more interconnected, comprising proportionately more family members and fewer friends (Palumbo et al., 2015; Randolph, 1998). However, social network characteristics have been shown to vary substantially across individuals and samples (Palumbo et al., 2015; Pinfold et al., 2015), with research suggesting these differences may be associated with outcomes in schizophrenia (Allison, Harrop, & Ellett, 2013; Horan et al., 2006). In addition to objective symptomatic and functional outcomes, studies have also examined subjective outcomes such as perceived quality of life (QOL) (Becker et al., 1998).

Despite the potential importance of social network characteristics for outcomes in schizophrenia, to date, there has been no systematic review of the magnitude or
nature of these relationships. Previous literature reviews on social networks and mental health outcomes are outdated, not systematic, include mixed diagnostic samples and do not focus specifically on network size and patient-related outcomes (Albert et al., 1998; Buchanan, 1995). Existing reviews also fail to differentiate structural from interactional network characteristics (in their relationship with outcomes) and do not conduct formal quality assessments considering the heterogeneous measurement of social networks in relation to study findings (Siette et al., 2015).

The specific aims of this systematic literature review and meta-analysis were to: 1) carry out a systematic search and narrative synthesis on the nature and strength of the relationship between social network size and symptomatic, functional and QOL outcomes in schizophrenia; 2) examine the quality of both the empirical findings and the measurement of social networks; and 3) conduct a series of meta-analyses to examine the magnitude of the relationship between network size and schizophrenia outcomes. The findings will help to determine whether social networks are important for clinical outcomes in schizophrenia and highlight key targets for psychosocial interventions.

### 3.3 Method

The review was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). The review protocol was registered on PROSPERO [ID= CRD42015020246].
3.3.1 Eligibility criteria

Eligible studies were peer-reviewed journal articles published in English. Studies published after 1970 were included as these were the first empirical studies of social networks in schizophrenia (Sokolovsky, Cohen, Berger, & Geiger, 1978). Eligibility criteria also included a sample of participants who were at least 18 years of age and majority (≥70%) schizophrenia spectrum diagnosis based on: i) ICD (ICD-9 or -10 F20-29) or DSM criteria (i.e. schizophrenia, schizoaffective disorder, delusional disorder, schizophreniform disorder, or psychosis not otherwise specified); or ii) clinical evaluation of non-affective psychosis in early intervention services (EIS). Articles had to be quantitative empirical studies examining associations between social networks and current symptomatic, functional or QOL outcomes in schizophrenia. Eligible designs included cross-sectional and longitudinal studies, with no restriction on the direction of the relationship. However, retrospective measures of premorbid symptoms or functioning were excluded. Studies were required to have included at least one quantitative measure of social network size and current symptomatic, functional or QOL outcome in schizophrenia.

3.3.2 Search strategy

On 1 June 2016, a systematic electronic search was conducted on electronic databases: EMBASE, Medline, PsycINFO and Web of Science. Several combinations of the following and related search words were used and separated by the Boolean operators OR and AND: ‘schizophrenia’ OR ‘psychosis’ OR ‘severe mental illness’ AND ‘social network’ OR ‘personal network’ OR ‘social tie’. Medical Subject Headings (MeSH) and explode functions were used to expand the search and identify all relevant studies. Given that multiple outcomes were being
investigated; outcome-related search terms were not included. This was to ensure no relevant research was mistakenly overlooked by applying too narrow an outcome-related search criterion. The search strategy was adapted for each database [Appendix VIII].

3.3.3 Screening and study selection

Two postgraduate researchers (AD and DS\textsuperscript{6}) independently screened articles for eligibility. Titles and abstracts were examined against the inclusion and exclusion criteria (stage 1). Full texts of potentially relevant articles were retrieved and screened according to the inclusion criteria (stage 2). Level of agreement at stage 1 was 90\% and stage 2 was 89\%. At each stage of screening, discrepancies were resolved via discussion with the clinical supervisor KB\textsuperscript{7} before continuing to the next stage. Additional studies were identified via the reference lists of included articles.

3.3.4 Narrative synthesis

A narrative synthesis (Mays, Roberts, & Popay, 2001) was carried out to summarise and critically appraise the reviewed studies. Empirical findings were combined into a narrative by categorising outcomes into coherent theoretical domains. Effect sizes for all findings were presented in tables where available (in the paper or from the authors) (Table 1).

\textsuperscript{6} Daryl Sweet is a co-author on the paper. Daryl was a PhD student at The University of Manchester at the time the thesis was carried out.

\textsuperscript{7} Katherine Berry is a co-author and was one of the academic supervisors of the current thesis.
3.3.5 Quality assessment

The Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (Thomas, 2003) was used to evaluate study quality. The EPHPP has been applied to healthcare related systematic reviews with demonstrable inter-rater reliability and a high level of content and construct validity (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012; Thomas, Ciliska, Dobbins, & Micucci, 2004). The tool was adapted in order to be consistent with the observational analytic design of the included studies. Components relating to randomised designs, blinding and intervention integrity were omitted. Given the heterogeneity of social network measures in schizophrenia (Siette et al., 2015), it was important to include a separate assessment of their quality. The EPHPP in the current review, therefore, included six components: 1) selection bias; 2) confounders; 3) data collection-outcome; 4) data collection-social network; 5) withdrawals and drop-outs; and 6) analysis. Each component was rated as either ‘strong’, ‘moderate’ or weak’ based on specific criteria (Appendix IX). The lead author (AD) and a postgraduate student conducted the quality assessments. Substantial agreement was found ($k = .610$ to .888). Discrepancies were discussed and resolved with KB.

3.3.6 Meta-analysis

*Eligibility criteria*

Studies that statistically examined associations between social network size and a validated outcome measure were included in the meta-analyses. Studies were excluded if there was insufficient data to calculate effect sizes, despite attempts to contact authors for missing data.
Data extraction and effect size computation

Data were available for separate meta-analyses on the relationship between network size and 1) overall psychiatric symptoms; 2) positive symptoms; 3) negative symptoms; and 4) social functioning. Most studies reported cross-sectional correlational analyses (Pearson’s $r$ or Spearman’s rho) which were converted to Cohen’s d and then the common metric Hedge’s $g$ for meta-analysis. For studies reporting regression, the effect size $r$ was estimated and converted to Hedge’s $g$.

Consistent with previous meta-analyses in the field (Pilton, Varese, Berry, & Bucci, 2015; Varese et al., 2012) a protocol was developed to minimise the potential effects of non-independent data, improve comparability across studies and reduce bias: i) where studies reported cross-sectional and temporal associations, cross-sectional data was used; ii) when longitudinal studies reported cross-sectional results at multiple time points, data from the earliest time point was used (Time 1/baseline); and iii) where studies reported multivariate analyses and adjusted for covariates, the unadjusted data was used.

3.3.7 Statistical analysis

Comprehensive Meta-Analysis version 3.0 (Borenstein, Hedges, Higgins, & Rothstein, 2005; Borenstein, Hedges, Higgins, & Rothstein, 2009) was used to calculate effect sizes and perform meta-analyses. Random effects models were used due to considerable variation across study measures and designs. The model performs better than fixed-effect models and provides more conservative estimates accounting for observed heterogeneity (Brockwell & Gordon, 2001; Kontopantelis & Reeves, 2010). Heterogeneity was examined using Cochran’s Q and $I^2$ statistics to
determine the amount of heterogeneity resulting from variance between studies \((p<.05)\). Visual inspection of funnel plots and Egger’s test of funnel plot asymmetry was applied to examine publication or selection bias. For meta-analyses demonstrating significant effects, the Fail-Safe N was calculated to estimate the number of additional unpublished/missing studies that would be required to nullify the effect.

Sensitivity analyses were conducted removing studies with weak or moderate quality network measures (as indicated from the quality assessment) and samples <100% schizophrenia/non-affective psychosis. ‘One-study-removed’ sensitivity analyses were conducted to assess whether any studies skewed the results.

### 3.4 Results

3.4.1 Study selection

The search across all databases yielded 15 articles for inclusion. One additional article was identified through searching reference lists resulting in a total of 16 articles. The study selection process is summarised in the PRISMA diagram (Figure 2).
Figure 2.

PRISMA Flow Diagram.
3.4.2 Study characteristics

Four of the 16 included articles used overlapping samples. Two studies (Cechnicki, Wojciechowska, & Valdez, 2008; Goldberg, Rollins, & Lehman, 2003) comprised the same sample as two earlier studies (Cechnicki & Wojciechowska, 2008; Dixon, Goldberg, Lehman, & McNary, 2001) but addressed different aims. Of the 14 independent samples, five were conducted in the USA, four in the UK, two in Poland and one in each of Australia, Denmark, and Austria. There were a total of 1,929 independent participants across the included studies at baseline, with sample sizes ranging from 24 to 547. Of these, 1,102 (57%) were male. Of 11 studies reporting it, the mean age ranged from 23 to 63 years. Seven of 12 studies reporting ethnicity were mostly (>60%) Caucasian. Seven studies included multiple ethnic groups (UK - Black-Caribbean, Black-African, Asian; USA - Latino and African American). Ten of the 14 independent samples were 100% schizophrenia-spectrum; including four first episode and seven schizophrenia diagnoses samples. Two samples were mixed (affective and non-affective) psychosis and two included individuals with severe mental health problems (including affective disorders). Seven studies reported mean duration of illness which ranged from 2.3 to 16.7 years. Most studies were cross-sectional, with only three longitudinal studies examining temporal associations (Angell & Test, 2002; Howard, Leese, & Thornicroft, 2000; Thorup et al., 2006); all of which were randomised controlled trials (RCTs). Study characteristics and key findings are presented in Table 1. Sample characteristics can be found in Appendix X.
Table 1

Characteristics and key findings of included studies

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Sample N (M/F)</th>
<th>Social network measure</th>
<th>Outcome measure</th>
<th>Outcome category</th>
<th>Design (time points)</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allison et al. (2013)</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>UK</td>
<td>24 (18/6) 100%</td>
<td>Modified PRQ</td>
<td>PANSS (P, N); HADS</td>
<td>Symptom severity (positive, negative &amp; affective)</td>
<td>Cross-sectional correlational</td>
<td>1. No sig correlations between size of network and positive (rho= -0.15), negative (rho= -0.27), anxiety (rho= -0.09), or depression (rho= 0.01) symptoms.</td>
</tr>
<tr>
<td>Angell &amp; Test (1992)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>87 (62/25) 98%</td>
<td>CAF - study specific</td>
<td>BPRS-18 (P)</td>
<td>Symptom severity (positive)</td>
<td>Cross-sectional correlational + longitudinal (18 + 24 months)</td>
<td>1. N=122 in RCT, but complete data for 87 (71.3%) due to attrition.</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>2. Cross-sectional analyses at T1 showed no sig correlation between positive symptoms and network size (rho= -0.07).</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>3. Cross-sectional analyses at T2 showed no sig correlation between positive symptoms and network size (rho= -0.18).</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>4. OLS regression showed no sig association between T1 positive symptoms and T2 network size (β= -0.11) over six month period, controlling for education, gender, age and treatment allocation.</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td>5. OLS regression found increase in positive symptoms over a six month period (T1 to T2) was sig associated with declines in network reciprocity (β= - 0.23) but not size (β= -0.17).</td>
</tr>
<tr>
<td>Becker et al. (1998)</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>143 (80/63) 83%</td>
<td>SNS</td>
<td>LQoLP</td>
<td>QOL</td>
<td>Cross-sectional correlational (baseline)</td>
<td>1. Sample grouped according to quintiles of network size, from 1 (small network, 1-6 contacts) to 5 (large network, 19-42 contacts)</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td>2. ANOVA showed sig quadric contrast between</td>
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</tbody>
</table>
social network quintiles in terms of average QOL. Average QOL increased up to quintiles 4 and 5; sig contrasts between these two and the lower three quintiles.

3. In multiple linear regression analyses, average QOL was sig positively associated with higher network quintiles, with levelling off at around 20 contacts ($\beta = 0.61, CI= 0.25, 0.96$). This remained after adjusting for age, BPRS anxiety/depression, service satisfaction, & number of unmet needs.

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Data Collection</th>
<th>Measure</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cechnicki &amp; Wojciechowska (2008)</td>
<td>64 (28/36)</td>
<td>BQ</td>
<td>BPRS-24 (G, N, P); DSM-III: social functioning</td>
<td>Cross-sectional correlational (7 years after first admission)</td>
</tr>
<tr>
<td>Poland</td>
<td>100%</td>
<td></td>
<td></td>
<td>1. Larger social networks sig associated with less severe BPRS overall ($\rho = -0.32$), positive ($\rho = -0.42$) and negative symptoms ($\rho = -0.38$) and improved social functioning ($\rho = 0.38$).</td>
</tr>
<tr>
<td>Cechnicki et al. (2008)</td>
<td>64 (28/36)</td>
<td>BQ</td>
<td>LQoLQ</td>
<td>Cross-sectional correlational (7 years after first admission)</td>
</tr>
<tr>
<td>Poland</td>
<td>100%</td>
<td></td>
<td></td>
<td>1. Large social network sig correlated with higher general subjective satisfaction with QOL ($\rho = 0.35$)</td>
</tr>
<tr>
<td>2. Larger extra-familial network did not correlate with general QOL ($\rho = 0.12$).</td>
<td></td>
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</tr>
<tr>
<td>Cohen et al. (1997)</td>
<td>117 (29/88)</td>
<td>Modified NAP</td>
<td>TSC</td>
<td>Cross-sectional correlational</td>
</tr>
<tr>
<td>USA</td>
<td>100%</td>
<td></td>
<td></td>
<td>1. 47% (n=54) satisfied and 53% (n=63) not satisfied with their lives and QOL over the past 30 years.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2. Satisfied group sig more likely to have more network members who could be 'counted on' ($t= -2.52, d= -0.47, CI= -0.84, 0.10$) and greater network density ($t= -2.73, d= -0.51, CI= -0.88, -0.14$).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3. No sig group differences in total network size ($t=0.90, d= 0.17, CI= -0.20, 0.53$).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4. Multivariate logistic regression model showed</td>
</tr>
</tbody>
</table>
Cresswell et al. (1992) UK

| 40 (31/9) | SNIS | BPRS-18 (G); SANS | Symptom severity (overall & negative) |

Cross-sectional, correlational

1. Higher severity of overall symptoms sig related to smaller primary group (family/friends) ($r = -0.36$), secondary group (outside family/friends) ($r = -0.47$) & primary group seen weekly ($r = -0.32$)
2. Higher severity of negative symptoms sig related to smaller network size in primary group ($r = -0.42$) and primary group seen weekly ($r = -0.41$), but not secondary group ($r = -0.21$)

Dixon et al. (2001)

| 218 (123/95) | Study specific | PANSS (T) | Symptom severity (overall) |

Cross-sectional, correlational

1. Hierarchical OLS regression showed that total PANSS symptom severity was inversely associated with the size of social support network ($r = -0.21$), which remained when controlling for demographic covariates (age, education, gender, ethnicity) ($sr^2 = .041$).

Goldberg et al. (2003)

| 218 (123/95) | Modified SSSNI | PANSS (GP, P, N); BQOL | Symptom severity (affective, positive, negative) QOL |

Cross-sectional, correlational

1. Smaller network size was sig correlated with more severe negative symptoms ($r = -0.29$) and general symptoms ($r = -0.19$). Positive symptoms and general satisfaction with QOL were not sig associated with network size (na).
2. Results from ANOVA showed sig differences across five network density categories for PANSS general ($F = 3.30$), positive ($F = 3.14$) and negative ($F = 3.00$) symptoms, with trend for less severe symptoms for low to moderate density and more severe symptoms for no connections. But post-hoc tests only sig for general symptoms. QOL was not sig associated with density (na).

Hamilton et al.

| 39 (39/0) | Modified NSRS & SANS; | Symptom |

Cross-sectional, correlational

1. NSRS total scores sig negative correlated with more reliable social contacts (could be ‘counted on’)

sig predicted greater satisfaction with QOL, adjusting for socio-demographics (AOR= 4.68, CI= 1.36, 16.08). Network density was not a sig predictor of QOL (AOR= 2.94, CI= 0.43, 20.18).
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Country</th>
<th>Total</th>
<th>Sample Size</th>
<th>Measure</th>
<th>Severity</th>
<th>Functioning</th>
<th>Correlation Method</th>
<th>Time 1 Findings</th>
<th>Time 2 Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Horan et al.</td>
<td>2006</td>
<td>USA</td>
<td>T1: 89</td>
<td>75/14</td>
<td>Study specific</td>
<td>BPRS-24 (G, P, N, A)</td>
<td>Symptom severity (overall, positive, negative, affective) Social functioning</td>
<td>Cross-sectional correlational</td>
<td>1. At baseline (T1), total network size did not sig correlate with BPRS overall ($r = 0.01$), BPRS positive ($r = 0.11$), BPRS negative ($r = -0.16$), BPRS anxiety/depression ($r = 0.07$) or current overall social functioning (total SAS) ($r = 0.03$). Higher percent kin was sig associated with lower total SAS scores ($r = -0.28$). Network density and degree did not correlate with BPRS symptoms or functioning.</td>
<td>2. 34/87 participants (38%) completed T2 assessments. At 15 months, smaller total network size correlated with more sig severe BPRS positive symptoms ($r = -0.36$), but did not sig correlate with BPRS overall ($r = -0.19$), BPRS anxiety/depression ($r = 0.05$) or BPRS negative ($r = -0.16$). Higher scores on BPRS positive correlated with greater density ($r = 0.42$) and lower per cent kin ($r = -0.37$), but not degree. BPRS negative and overall symptoms did not correlate with density, percent kin or degree at T2.</td>
</tr>
<tr>
<td>Howard et al.</td>
<td>2000</td>
<td>UK</td>
<td>302</td>
<td>143/159</td>
<td>74%</td>
<td>SNS</td>
<td>GAF (D)</td>
<td>Global functioning</td>
<td>Cross-sectional correlational + longitudinal (baseline, 2 years)</td>
<td>1. Complete data $n=135$ Time 1 and $n=130$ Time 2. 188 (62%) completed SNS T1 and 151 (50%) T2; 230 (76%) completed GAF T1 and 215 (71%) T2. Reasons not reported.</td>
</tr>
</tbody>
</table>
networks T1 and GAF disability T2 controlling for GAF at T1 ($n=107$, $\beta=0.14$, CI= -0.35, 12.36).
5. The best fitting model from SEM ($n=107$) suggested that total social network size at T1 explains some variance in GAF disability at T1 (coefficient= 0.19), and GAF T1 explains some of the variance in GAF over a two year period (T2) (coefficient= 0.34), but insufficient power to detect effects.

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Country</th>
<th>Measures</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macdonald et al. (1998)</td>
<td>46 (34/12)</td>
<td>Australia</td>
<td>SRS – two subscales, SAPS; SANS; BDI;</td>
<td>Symptom severity (positive, negative, affective)</td>
</tr>
<tr>
<td></td>
<td>100%</td>
<td></td>
<td></td>
<td>Cross-sectional, correlational, 1. No sig correlations between network variables and depressive (na) or positive symptoms ($r=0.07$). Size of support network sig correlated with increased negative symptoms ($r=0.34$)</td>
</tr>
<tr>
<td>Sibitz et al. (2011)</td>
<td>157 (85/72)</td>
<td>Austria</td>
<td>WHOQOL-BREF; ADS</td>
<td>QOL Symptom severity (affective)</td>
</tr>
<tr>
<td></td>
<td>100%</td>
<td></td>
<td></td>
<td>Cross-sectional, correlational 1. Increased number of friends sig correlated with lower depressive symptoms ($r=-0.32$) and improved subjective QOL ($r=0.27$). 2. SEM showed that poorer social network (insufficient number friends) negatively influences subjective QOL only if leading to stigma and low empowerment, which resulted in depression and, in turn, impaired QOL (indirect effect= 0.16). There was no direct effect of QOL (direct effect= -0.07) on social network.</td>
</tr>
<tr>
<td>Thorup et al. (2006)</td>
<td>547 (323/224)</td>
<td>Denmark</td>
<td>SNS SANS GAF (S, F)</td>
<td>Symptom severity (positive, negative) Global</td>
</tr>
</tbody>
</table>
functioning onset)

3. Reduction in disorganised symptoms associated with larger network size at 2 years but not baseline

4. Positive symptoms was not sig related to network size at baseline or 2 years

5. Multivariate regression models at 2 years (N=332) included site, treatment, age and number of contacts at entry as sig covariates. Male gender (-0.86), older age (-0.07) and more severe disorganised symptoms (-0.29) were sig predictors of reduced family network size. More severe negative symptoms (-0.26), older age (-0.04) and completed A-level status (0.74) were sig predictors of reduced friendship network size.

Wojciechow et al. (2002)

<table>
<thead>
<tr>
<th>Poland</th>
<th>BQ</th>
<th>BPRS-24 (G, N, P)</th>
<th>DSM-III: social functioning</th>
<th>Symptom severity (overall, positive, negative)</th>
<th>Social functioning</th>
</tr>
</thead>
</table>
| 56 (32/24) | 100% | 113% | Cross-sectional correlational (3 years after first admission) | 1. Smaller total network size sig correlated with greater intensity of BPRS overall (rho=-0.49), negative (rho=-0.48) and positive (rho=-0.29) symptoms. No sig correlations between size of network and social functioning (rho= 0.14).
2. Larger extra-familial network sig correlated with fewer overall (rho=-0.42) and positive symptoms (rho=-0.30) and improved social functioning (rho= 0.55). No sig correlations between extra-familial network and negative symptoms (rho=-0.25)

Note: 1, 2 = studies used the same samples; studies highlighted in bold text are in the meta-analysis.

Social network measures: BQ=Bizon’s Questionnaire (Bizon et al., 2001); CAF=Community Adjustment Form (Test et al., 1991); NAP=Network Analysis Profile (Cohen & Sokolovsky, 1979, 1981); PPKI=Pattison Psychosocial Kinship Inventory (Pattison et al., 1981); PRQ=Peer Relations Questionnaire (Connolly & Johnson, 1996); SNIS=Social Network Interview Schedule (Sheperd, 1984); SNS=Social Network Schedule (Dunn et al., 1990); SSSNI=Social Support and Social Network Interview (Lovell et al., 1984); SRS=Social Relationships Scale (McFarlane et al., 1981).

Outcome measures: ADS=Allgemeine Depressions Skala (Hautzinger & Bailer, 1993), German version of Centre for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1997); BDI= Beck’s Depression Inventory (Beck & Steer, 1987); BPRS-24=Brief Psychiatric Rating Scale (24 items) (Overall & Gorham, 1982).
BPRS-18 (Overall & Klett, 1972); BPRS-P= positive subscale (Mueser et al., 1997b); BPRS G=global scores; N= negative subscale; BQOL= Brief Quality of Life Inventory (Lehman et al., 1995); DSM III= Diagnostic and Statistical Manual of Mental Disorders third edition (American Psychiatric Association, 1980); GAF= Global Assessment of Functioning (Endicott et al., 1976); GAF-D= GAF disability subscale; HADS= Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); LQoLQ= Lehman's Quality of Life Questionnaire (1988); LQoLP= Lancashire Quality of Life Profile (Oliver, 1991; Oliver et al., 1996); NSRS= Negative Symptom Rating Scale (Iager et al., 1985); PANSS= Positive and Negative Syndrome Scale (Kay et al., 1987); PANSS T= total scores; N= negative, P= positive, GP= general psychopathology subscales; SAS= Social Attainment Scale (Goldstein, 1978); SANS= Scale for the Assessment of Negative Symptoms (Andreason, 1984); SAPS= Scale for the Assessment of Positive Symptoms (Andreasen, 1982); SF-36= The 36 item Short Form Survey (Ware & Sherbourne, 1992; Ware et al., 1993); TSC= The SHORT CARE (Gurland et al., 1984); WHOQOL-BREF= World Health Organisation-Quality of Life Assessment-26 item version (WHOQOL Group, 1998).

Abbreviations: ANOVA= analysis of variance; AOR= adjusted odds ratio; CI= 95% confidence intervals; F= female; M= male; na= not reported or not available; OLS= ordinary least squares regression; QOL= quality of life; RCT= randomised controlled trial; SS= schizophrenia spectrum; SEM= structural equation modelling; sig= statistically significant; T1= Time 1; T2= Time 2
3.4.3 Social network characteristics

A broad range of assessments were used to measure the characteristics of social networks. Assessment tools included structured or unstructured interviews, questionnaires, single item measures and rating scales. Network definition and criteria varied in terms of the time period or the level of social contact (e.g. present, past month, contact every month) and the number of network members, with some studies setting an upper limit on the number of people named (e.g. maximum of 10) and others asking for an unrestricted list of all people known. Mean total network size was reported for six independent samples and ranged from 4.18 (Goldberg et al., 2003) to 12.9 (Hamilton, Ponzoha, Cutler, & Weigel, 1989). Characteristics of the social network measures are available in Appendix XI.

3.4.4 Study quality assessment

Quality assessments are presented in Table 2. Selection bias was rated weak for 59% (n=16) of studies due to lack of detail on recruitment and selection procedures, self-referred or convenience sample or less than 60% response rate. Eighteen studies controlled for confounders in the analyses or design (n=5 rated ‘moderate’ as 1+ confounders, and n=12 ‘strong’ as 2+ confounders). Data collection for outcomes was rated ‘strong’ for just over half (n=14) studies reporting valid and reliable outcome measures. The remaining studies were given ‘moderate’ (n=5) and ‘weak’ (n=8) ratings mainly because of poor reporting of service use data collection (e.g. hospital admissions) and no references for translated measures which brought ratings down (despite studies including validated measures for other outcomes). Fifty-nine per cent (n=16) of social network tools were rated as strong. Network tools were rated as ‘weak’ in seven studies due to non-validated assessment tools with
inadequate measure of network size; including lack of detail (n=2), boundaried (capped network size or focus on one type of relation) (n=3), single item measures (n=2), and no measure of size (n=1). ‘Moderate’ ratings were given to four studies (11%) due to lack of detail (n=2) or boundaried networks (n=2). Withdrawals and drop-outs was rated ‘not applicable’ for the vast majority of studies (n=23) due to the cross-sectional design and rated ‘moderate’ for two longitudinal studies with 60-79% follow-up rate and weak for two studies with less than 60% follow-up rate. Most analysis sections (n=24) were appropriate to the research aims and statistical methods appropriate for the design and were marked as ‘strong’ (n=9) or ‘moderate’ (n=15). Fifteen studies were marked as ‘moderate’ for analyses due insufficient detail relating to the management of missing data, distribution and skewness, power analyses and correction for multiple correlations.

3.4.5 Association between social networks and outcomes

A total of 12 studies were included in the meta-analyses on the association between social network size and outcomes. Two studies (Dixon et al., 2001; Goldberg et al., 2003) had overlapping samples but measured different outcomes and were included in separate analyses. See Table 3 for summary statistics and Appendices for forest plots [Appendix XII] and funnel plots [Appendix XIII].
### Table 2

**Methodological quality of included studies**

<table>
<thead>
<tr>
<th>Study reference</th>
<th>Selection bias</th>
<th>Confounders</th>
<th>Data collection - outcome</th>
<th>Data collection - size</th>
<th>Withdrawals and drop-outs</th>
<th>Analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allison et al. (2013)</td>
<td>WEAK</td>
<td>WEAK</td>
<td>STRONG</td>
<td>MOD</td>
<td>N/A</td>
<td>MOD</td>
</tr>
<tr>
<td>Angell &amp; Test, (1992)</td>
<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>WEAK</td>
<td>MOD</td>
<td>MOD</td>
</tr>
<tr>
<td>Becker et al. (1998)</td>
<td>MOD</td>
<td>STRONG</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>STRONG</td>
</tr>
<tr>
<td>Cechnicki &amp; Wojciechowska (2008)ólica</td>
<td>WEAK</td>
<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>MOD</td>
</tr>
<tr>
<td>Cechnicki et al. (2008)</td>
<td>WEAK</td>
<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>MOD</td>
</tr>
<tr>
<td>Cohen et al (1997)</td>
<td>MOD</td>
<td>STRONG</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>STRONG</td>
</tr>
<tr>
<td>Cresswell et al. (1992)</td>
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<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>WEAK</td>
</tr>
<tr>
<td>Dixon et al. (2001)</td>
<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>MOD</td>
</tr>
<tr>
<td>Goldberg et al. (2003)</td>
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<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>STRONG</td>
</tr>
<tr>
<td>Hamilton, et al. (1989)</td>
<td>WEAK</td>
<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>MOD</td>
</tr>
<tr>
<td>Horan et al. (2006)</td>
<td>WEAK</td>
<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>MOD</td>
</tr>
<tr>
<td>Howard, Leese &amp; Thornicroft (2000)</td>
<td>MOD</td>
<td>STRONG</td>
<td>STRONG</td>
<td>WEAK</td>
<td>STRONG</td>
<td></td>
</tr>
<tr>
<td>Macdonald et al. (1998)</td>
<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>MOD</td>
<td>N/A</td>
<td>STRONG</td>
</tr>
<tr>
<td>Sibitz et al. (2011)</td>
<td>MOD</td>
<td>STRONG</td>
<td>STRONG</td>
<td>WEAK</td>
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<td>Thorup et al. (2006)</td>
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<td>MOD</td>
<td>STRONG</td>
<td>MOD</td>
<td>MOD</td>
<td>STRONG</td>
</tr>
<tr>
<td>Wojciechow et al. (2002)</td>
<td>WEAK</td>
<td>STRONG</td>
<td>STRONG</td>
<td>N/A</td>
<td>MOD</td>
<td></td>
</tr>
</tbody>
</table>

*Note:* 1, 2 = overlapping samples; MOD = moderate; N/A = not applicable
Table 3

Summary statistics for meta-analyses and sensitivity analyses: social network size and outcomes in schizophrenia

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Studies</th>
<th>Total N</th>
<th>Random effects meta-analysis</th>
<th>Heterogeneity</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Hedge’s g</td>
<td>95% CI</td>
<td>P Value</td>
<td>Q Value</td>
<td>df</td>
</tr>
<tr>
<td>Overall symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td>467</td>
<td>-0.530</td>
<td>-0.875</td>
<td>-0.184</td>
<td>0.003</td>
<td>10.822 (4)</td>
</tr>
<tr>
<td>100% SS + HQN</td>
<td>4</td>
<td>249</td>
<td>-0.595</td>
<td>-1.111</td>
<td>-0.079</td>
<td>0.024</td>
<td>10.683 (3)</td>
</tr>
<tr>
<td>Positive symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
<td>405</td>
<td>-0.192</td>
<td>0.494</td>
<td>0.110</td>
<td>0.213</td>
<td>12.709 (6)</td>
</tr>
<tr>
<td>100% SS</td>
<td>6</td>
<td>318</td>
<td>-0.206</td>
<td>-0.581</td>
<td>0.169</td>
<td>0.281</td>
<td>12.683 (5)</td>
</tr>
<tr>
<td>HQN</td>
<td>4</td>
<td>248</td>
<td>-0.276</td>
<td>-0.793</td>
<td>0.241</td>
<td>0.296</td>
<td>11.357 (3)</td>
</tr>
<tr>
<td>Negative symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>577</td>
<td>-0.754</td>
<td>-0.997</td>
<td>-0.512</td>
<td>0.000</td>
<td>10.895 (7)</td>
</tr>
<tr>
<td>100% SS</td>
<td>7</td>
<td>358</td>
<td>-0.818</td>
<td>-1.126</td>
<td>-0.509</td>
<td>0.000</td>
<td>10.128 (6)</td>
</tr>
<tr>
<td>HQN</td>
<td>5</td>
<td>288</td>
<td>-0.899</td>
<td>-1.319</td>
<td>-0.480</td>
<td>0.000</td>
<td>9.789 (4)</td>
</tr>
<tr>
<td>Social functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>209</td>
<td>0.361</td>
<td>-0.078</td>
<td>0.801</td>
<td>0.107</td>
<td>4.737 (2)</td>
</tr>
</tbody>
</table>

Note: Bold figures indicate statistically significant association between social network size and outcome; SS=schizophrenia spectrum; HQN=high quality network; CI=confidence interval.
3.4.6 Symptomatic outcomes

Overall psychiatric symptoms

Meta-analyses of five studies with 467 participants showed a significant moderate effect ($g=-0.53$) for the association between smaller network size and overall psychiatric symptoms, with moderate heterogeneity ($I^2=63.04\%$). Egger’s regression test was non-significant ($t=1.06$, SE=2.16, $P=0.365$), indicating no publication or selection bias (Fail-Safe N=28). A sensitivity analysis removing one study (Dixon et al., 2001) with <100% schizophrenia sample and a poor quality network measure slightly increased the effect ($g=-0.60$) and heterogeneity ($I^2=71.92\%$).

The significant results are based on cross-sectional evidence from four studies of samples with longer-term problems (Cechnicki & Wojciechowska, 2008; Cresswell, Kuipers, & Power, 1992; Dixon et al., 2001; Wojciechowska, Walczewski, & Cechnicki, 2000). One recent onset study (Horan et al., 2006) found no cross-sectional associations between size and symptoms at initial hospitalisation or 15-months. However, the disruptions in network characteristics typical of schizophrenia samples (i.e. small, densely interconnected and high proportion kin) were present at initial hospitalisation and remained stable at follow-up. Although this study included strong quality network and outcome measures, it did not examine the association longitudinally nor did it control for potential confounders. Dixon et al. (2001) was the only study to consider the influence of extraneous variables and showed that symptoms contributed to reduced network size when entered into a regression model with demographic covariates (i.e. age, gender, education, ethnicity). However, this
study included affective diagnoses and used a poor quality network measure (i.e. single item).

Positive symptoms

Seven studies with 405 participants were included in the meta-analysis for positive symptoms which found no significant effect of network size ($g=-0.19$) and moderate heterogeneity ($I^2=52.79\%$). Egger’s test indicated no publication bias ($t=0.56$, SE=2.82, $P=0.598$). A sensitivity analysis excluding one study (Angell & Test, 2002) with <100% schizophrenia made little difference to the findings ($g=-0.21$; $I^2=60.58\%$). Removing three studies with weak (Angell & Test, 2002) and moderate (Allison et al., 2013; Macdonald, Jackson, Hayes, Baglioni, & Madden, 1998) quality network measures also had a negligible effect ($g=-0.28$, $I^2=60.58\%$).

Findings for positive symptoms were mixed. Three studies found a significant cross-sectional association between larger size and less severe positive symptoms (Cechnicki et al., 2008; Horan et al., 2006; Wojciechowska et al., 2000), but this was not supported in six studies (Allison et al., 2013; Angell & Test, 2002; Goldberg et al., 2003; Hamilton et al., 1989; Macdonald et al., 1998; Thorup et al., 2006). Two RCTs (Goldberg et al., 2003; Thorup et al., 2006) with non-significant findings were omitted from the meta-analysis due to insufficient data. Only one of these studies (Goldberg et al., 2003) did not suffer from selection bias, though it was also the only study to include a mixed diagnostic sample which may have affected its external validity.

The other omitted study (Thorup et al., 2006) was one of two RCTs in first episode psychosis to report longitudinal analyses and adjust for confounders. Thorup et al.
found that more severe disorganised symptoms were significantly associated with a reduction in family but not friendship network size over a two-year period, adjusting for treatment allocation, age and social network size at baseline. There was no association between positive symptoms and number of social contacts. Angel and Test (2002) showed that an increase in positive symptoms over a six month period was not significantly related to network size, controlling for education, gender and treatment allocation. However, this study had a relatively small sample and may have lacked sufficient power to detect effects. Additionally, the measure of network size only included non-kin and was capped at ten members. Both longitudinal studies were rated as moderate quality for ‘withdrawals and drop-outs’ based on the fact that around 70% of the sample were analysed at follow-up after attrition and missing data. Both studies reported no significant differences between those who were and were not followed up in terms of demographic, network and outcome measures at baseline. However, the selection procedures in both studies were rated low quality as the response rate was not reported.

**Negative symptoms**

Meta-analysis conducted on eight studies (n=577) showed a significant negative association between network size and negative symptoms (g=-0.75) and low heterogeneity ($I^2=35.75\%$). There was no evidence of publication bias as indicated by Egger’s test ($t=1.75$, SE=1.04, $P=0.131$; Fail-Safe N= 123). A sensitivity analysis removing one study (Goldberg et al., 2003) with less than 100% schizophrenia samples found a slight increase in effect (g=-0.82) and heterogeneity ($I^2=40.76\%$). An additional sensitivity analysis removing three studies (Allison et al., 2013;
Goldberg et al., 2003; Macdonald et al., 1998) with low quality social network measures also increased the effect size \((g=-0.90)\) and heterogeneity \((I^2=59.14\%)\).

Seven studies (Cechnicki & Wojciechowska, 2008; Cresswell et al., 1992; Goldberg et al., 2003; Hamilton et al., 1989; Macdonald et al., 1998; Thorup et al., 2006; Wojciechowska et al., 2000) reported a significant association between negative symptoms and network size. Two first episode studies did not find an association; Allison et al. (2013) comprised a small sample with poor quality network measure (i.e. capped at 10), but the study by Horan et al. (2006) was higher quality. All but one study (Goldberg et al., 2003) rated low quality on selection bias, as a result of convenience sampling or lack of detail on recruitment and selection procedures.

Only two studies adjusted for confounders, one of which examined the relationship longitudinally. In their first episode sample, Thorup et al. (2006) suggested that more severe negative symptoms predicted significantly reduced friendship but not family network size over a two year period, adjusting for treatment allocation, age and number of contacts at baseline. Macdonald et al. (1998) explored the influence of social skill in the relationship between negative symptoms and total network size in schizophrenia using structural equation modelling. Cross-sectional analyses supported a tentative model to suggest that negative symptoms have an indirect effect on the size of social networks via social skill, accounting for 15% of the variance in the model.

**Affective symptoms**

Five cross-sectional studies examined affective symptoms. Fewer friends was weakly related to more severe depressive symptoms in a large sample of participants
with schizophrenia (Sibitz et al., 2011). In a large SMI sample (Goldberg et al., 2003), smaller total network size weakly correlated with more severe general psychopathology. However, these findings were not consistently supported by other included studies. Friendship size did not relate to depression or anxiety in a small first episode sample (Allison et al., 2013). Total network size did not correlate with depression in a study of schizophrenia outpatients (Macdonald et al., 1998), or with depression or anxiety in first episode psychosis (Horan et al., 2006). Each study used a different outcome measure, though all were validated (Table 1). Both studies with significant findings (Goldberg et al., 2003; Sibitz et al., 2011) were stronger quality in that they had larger samples and lower selection bias compared to the other studies. However, they did not control for confounders and were cross-sectional in design. Moreover, the network measures were of low quality (i.e. capped at 10 (Goldberg et al., 2003) and single item (Sibitz et al., 2011)).

3.4.7 Functional outcomes

Social functioning

Three studies (n=209) measured social functioning outcomes. Meta-analyses showed no significant effect (g=0.36) and moderate heterogeneity ($I^2=57.77\%$). Egger’s test was non-significant ($t=1.22$, SE=6.67, $P=0.437$), suggesting no selection bias. All studies had 100% schizophrenia samples and high quality social network measures. Sensitivity analyses indicated that the removal of one study (Cechnicki & Wojciechowska, 2008) resulted in a substantial reduction in effect size (g=0.14) and heterogeneity ($I^2=0\%$). This study assessed schizophrenia outpatients seven years
after the initial hospitalisation, whereas the other two included patients in earlier stages of their illness. No studies adjusted for confounders.

*Global functioning*

Two longitudinal RCTs (Howard et al., 2000; Thorup et al., 2006) reported cross-sectional associations between more social contacts and improved global functioning, but no significant temporal relationship. Howard et al. (2000) stated that weak evidence from structural equations may suggest that social networks could affect individuals’ functioning over a two year period. However, the study reportedly lacked sufficient power to detect significant effects. Although the analyses controlled for age and ethnicity, they included a mixed diagnostic sample with patients at different stages of illness but did not adjust for diagnosis or illness duration. Thorup et al. (2006) adjusted for potential confounding variables (treatment group, age and number of contacts) and included a number of covariates in multivariate analyses, but global functioning did not predict family or friendship network size over two years. Both studies had considerable attrition rates at follow-up (33%- 40%); with weak evidence that participants who dropped out were those who had greater difficulties and thus the generalisability of these results is questionable.

*Quality of life*

Five cross-sectional studies examined QOL outcomes (Becker et al., 1998; Cechnicki et al., 2008; Cohen, Talavera, & Hartung, 1997; Goldberg et al., 2003; Sibitz et al., 2011). Higher subjective QOL was associated with having more social network members in two schizophrenia samples (Cechnicki et al., 2008; Sibitz et al., 2011). In one of these, further analyses using structural equation modelling found no
direct effect of social network size on QOL. However, a tentative model showed a small indirect effect of reduced number of friends on QOL through higher perceived stigma and low empowerment, which led to depression and subsequently impaired QOL. This study comprised a large sample of schizophrenia patients with a long duration of illness but did not adjust for variation in symptom severity and included a poor quality network measure (i.e. single item).

One high quality study in a large random sample of people with psychosis (Becker et al., 1998) found that satisfaction with average QOL was positively associated with larger social networks, with a tailoring off at around 20 social contacts. Multivariate analyses showed that age, anxiety and depression, service satisfaction and needs for care were also independently associated with QOL but did not confound its association with network size.

However, findings were mixed and two studies in patients with longer term problems found no relationship between number of social contacts and QOL (Cohen et al., 1997; Goldberg et al., 2003). One of these (Goldberg et al., 2003) was rated poor quality as it did not control for potential confounders and included a poor quality measure of network size (i.e. capped at 10). The other study (Cohen et al., 1997) was of strong quality and included a relatively large sample, but the participants were over 55 years of age and thus unlikely representative of younger people at earlier stages of illness.

3.5 Discussion

This is the first systematic review and meta-analysis on the relationship between social network size and clinical and functional outcomes in schizophrenia. Meta-
analytic pooled effect sizes found that smaller social network size was moderately associated with more severe overall psychiatric symptoms and negative symptoms, but not positive symptoms or social functioning. There was a low level of statistical heterogeneity between studies for negative symptoms and moderate heterogeneity for overall psychiatric symptoms. The narrative review highlighted some empirical evidence which demonstrated that a having more social ties is moderately associated with better global functioning, fewer affective symptoms and improved QOL.

Two of the sixteen studies in this review examined potential mechanisms to explain the processes by which a greater number of social ties is associated with improvements in negative symptoms and QOL in schizophrenia. These mechanisms were social skill (Macdonald et al., 1998), and stigma and empowerment (Sibitz et al., 2011), respectively. However, most of the reviewed studies reported cross-sectional data and thus causal direction cannot be inferred. Larger social networks may lead to improved symptoms by buffering the effects of psychological stress associated with schizophrenia, but negative symptoms such as anhedonia and apathy may also influence individuals’ motivation and social skills and reduce the likelihood they will build and maintain social relationships (Thorup et al., 2006). Only three studies examined temporal associations and, taken together, suggest a bi-directional relationship; with significant results showing that more severe disorganised symptoms predict smaller networks (Thorup et al., 2006) and smaller networks predict poorer global functioning (Howard et al., 2000). It is likely that the relationship is reciprocal and that there is a complex interplay between more disrupted social networks, individual characteristics, such as social skill, stigma and empowerment, and poorer outcomes over time.
There was limited evidence that the relationship between network structure and outcomes may be non-linear. Findings from one study indicated a curvilinear relationship to suggest that patients with around 20 network members experience a better QOL (Becker et al., 1998). This suggests there may be an optimum network size for improved QOL outcome. Larger network structures may allow more resources such as information and support but can also be overwhelming, stressful and come with certain expectations or constraints. Moderately sized networks, with a sufficient number of social contacts, may be more manageable whilst still enabling access to sufficient resources for enhanced coping (Albert et al., 1998; Dozier, Harris, & Bergman, 1987).

There are some methodological issues to consider when interpreting the findings of the present review. Methodological quality can influence effect sizes (Tarrier & Wykes, 2004). Sensitivity analyses were conducted, therefore, removing studies with low quality social network measures and less than 100% schizophrenia spectrum samples; these slightly increased the effect size for overall psychiatric and negative symptoms. However, removal of these studies also increased statistical heterogeneity, suggesting that there were other unmeasured sample or study characteristics that accounted for the observed heterogeneity. In addition to diverse network measures, the quality assessment highlighted variation in methodology such as selection procedures and study design which may have affected the results. One limitation is that potential moderator effects in the meta-analyses could not be explored due to the small number of studies and insufficient data. The meta-analyses included cross-sectional univariate data and, therefore, can only provide information about associations between key variables.
It is plausible that some of the reviewed studies did not find any significant association because they did not consider other unmeasured variables that may be related to network size or outcome. For example, only half of the reviewed studies controlled for the confounding effects of clinical and socio-demographic variables in multivariate analyses (e.g. symptoms, age, ethnicity, gender). Based on current evidence, it is difficult to determine the effects of social network characteristics and outcomes independent of confounders or other explanatory or mediating mechanisms (Sündermann et al., 2013; Thoits, 2011). More sophisticated statistical analyses in larger samples are required to test theoretical models which identify potential mediators, effect moderators and causal pathways. Future controlled trials of interventions that measure changes to networks alongside changes to clinical and functional outcomes, at multiple time points, would allow better inference about causation and the direction of these effects.

There was a tendency for network size to be more strongly related to symptomatic and functional outcomes in patients at later stages of schizophrenia when compared to first episode patients. This was supported by evidence for stronger associations when assessed at lengthier time periods from the previous hospitalisation (Cechnicki et al., 2008; Horan et al., 2006; Thorup et al., 2006). Experiencing a psychotic episode and a period of hospitalisation for the first time is likely to be very stressful and chaotic; during this time, it is likely that people are less able to access or mobilise resources within their social networks to help manage symptoms or engage in social activity (Horan et al., 2006). No studies controlled for illness duration and few controlled for diagnosis (e.g. first episode versus schizophrenia). Future research would benefit from adjusting for and drawing comparisons between subgroups within the schizophrenia spectrum and at different stages of illness.
Social networks were measured using a variety of assessment tools based on different definitions, timescales and criteria, as previously highlighted in schizophrenia research (Anderson, Laxhman, & Priebe, 2015; Gayer-Anderson & Morgan, 2013; Siette et al., 2015). It is often assumed that having more network members is beneficial as this corresponds to greater levels of support (Gayer-Anderson & Morgan, 2013). However, social connections may be appraised negatively and consist of overinvolved, unhelpful or critical interactions. Other features of the network are also likely to interact with the size and structure of the network to influence outcome, such as the function, content and perceived quality of social ties. Focusing on network size may not be the primary goal and it is important to reflect on person-centred formulations to consider what meaningful and resourceful social contact is for the individual (Pinfold et al., 2015). Comprehensive assessment tools should examine the different types of relationships, transactional qualities (e.g. reciprocity, frequency, intensity), and the structure of social networks (e.g. density).

**Clinical implications**

The present findings indicate that larger social networks are significantly associated with better symptomatic and functional outcomes in schizophrenia. Interventions that target social networks may therefore indirectly improve these outcomes. Given that network changes can occur prior to and during the early stages of schizophrenia (Gayer-Anderson & Morgan, 2013), clinicians should intervene early to support individuals to access and mobilise their social connections during a period of stability after initial contact with services. Psychosocial interventions such as peer support, community engagement and social skills training can lead to improvements
in the size of social networks in psychosis (Anderson et al., 2015). Clinical guidelines for the management of schizophrenia and psychosis recommend peer support and self-management interventions for building social support networks (National Institute for Health and Care Excellence, 2014). Supporting individuals to map out their social connections in diagrammatic form may be helpful to provide a better understanding of social networks from their perspective (Pinfold et al., 2015; Sweet et al., in press). These findings suggest a role for the routine use of network mapping tools which could also be used therapeutically to inform more person-centred clinical practice as well as to measure networks as predictors and outcomes in clinical trials.
CHAPTER 4: Social network characteristics of Black African and Caribbean people with non-affective psychosis in the UK
4.1 Abstract

Black African and Caribbean people in the UK have the highest rates of psychosis and the poorest access to, and experiences and outcomes of mental health services of all ethnic groups. Current evidence-based theories suggest social networks may be related to risk, pathways to care and outcomes amongst Black people with experience of psychosis. Social networks are depleted in psychosis but there is limited research in African and Caribbean groups. This study examined the social network characteristics of Black African and Caribbean people diagnosed with non-affective psychosis. Fifty-one participants were recruited from community and inpatient mental health services in the UK using convenience sampling methods. In a cross-sectional design, participants completed semi-structured social network mapping interviews and standardised interviews of psychosis symptoms. Participants’ social network size (mean=12) was comparable to that of other psychosis samples, though varied widely across the sample (range= 3-35). Networks were of moderate density and comprised disproportionately more relatives than other relationship types, with similar proportions of friends and healthcare professionals and close to zero wider contacts. Participants had on average three ‘close’ people in their network. Their social networks comprised more social ties with people of the same ethnicity and gender to their own than different. Greater satisfaction with social support was moderately associated with higher social network satisfaction. Poor network quality (emotional closeness, network satisfaction, social support) was related to more severe psychosis symptoms. The social network approach provides a useful therapeutic tool to assess and deepen our understanding of social networks as part of research and clinical practice. Further research using network mapping tools is required to inform interventions and policies about how to build and sustain social
networks, improve recovery and ultimately reduce inequalities experienced by Black people in the UK.
4.2 Introduction

Minority and migrant ethnic populations have the highest incidence of schizophrenia and psychosis compared to majority populations (Cantor-Graae & Selten, 2005; Fearon et al., 2006; Kirkbride et al., 2012). In the UK, Black Caribbean and Black African people have the highest rates of diagnosis, with incidence of schizophrenia five to six times higher than White British people (Kirkbride et al., 2012). Black people also have marked disparities in pathways to mental health services. Evidence suggests they are up to seven times more likely to experience compulsory hospital admission than White British people (The Schizophrenia Commission, 2012). They also experience more adverse and coercive treatment, higher doses of medication, longer lengths of hospital stay and are less likely to be offered psychological therapy (Bhui et al., 2003; Morgan et al., 2005a, 2005b; Morgan et al., 2004). UK policies have repeatedly highlighted the need to reduce ethnic inequalities in mental health service provision (Department of Health, 2005; National Institute for Mental Health, 2003). Policy programmes have been put forward to introduce more responsive and appropriate services, including community engagement (e.g. Department of Health, 2005).

There has been a growing interest in the role of social networks amongst Black African and Caribbean communities in the UK to explain increased psychosis risk and adverse care pathways and to inform strategies to improve engagement with services. Theories suggest that the fragmented structure of social networks and social isolation and exclusion (within families and the community) contribute to higher incidence of psychosis and inferior access to mental health services (e.g. Bhugra & Bhui, 2001; Pinto et al., 2008). Living in socially fragmented neighbourhoods and
social exclusion have both been found to contribute to the risk of psychosis in Black minority groups (Kirkbride et al., 2007). On the other hand, living in more ethnically dense communities has been shown to reduce psychosis symptoms and it is suggested that the potential for greater network cohesion in ethnically dense communities may buffer the deleterious effects of social adversity on distress (Becares et al., 2009; Das-Munshi et al., 2012). Following the onset of psychosis, the social networks of Black people may be more vulnerable to deterioration because of family burden and breakdown associated with untreated problems and repeated hospital admissions involving the police (Bhui et al., 2003; Keating et al., 2002; Sainsbury's Centre for Mental Health, 2006). Delayed access to adequate treatment increases perceived caregiver burden in psychosis (Awad & Voruganti, 2008).

Research suggests that Black families often contact the police and initiate hospital admission at crisis point after long periods of coping without professional help, despite multiple help-seeking attempts (Morgan et al., 2004; Owens et al., 1991; Shefer et al., 2013). Fear, mistrust and stigma located within Black peoples’ social networks may influence their help-seeking attitudes and disengagement with services (Morgan et al., 2004).

There is reason to believe that the social networks of Black people may be different to those of White British people, more generally. African-descended family networks are traditionally larger and include extended family members, rather than nuclear family units (i.e. two parents and their children) (Arnold, 2012). In the context of family separation during slavery, Caribbean people recreated traditional African family structures by extended family and community networks (Arnold, 2012). Migration has been suggested to weaken family structures and access to supportive social relationships (Mallett et al., 2002). Large scale migration to the UK between
the post-war period and the 1960s may have left behind large extended families and tight-knit communities and replaced them with smaller family units or single person households (Arnold, 2012; Murphy, 1996). The majority of Caribbean-descended people in the UK today are not immigrants but British born (Office for National Statistics, 2011). However, research suggests that Black Caribbeans are more at risk of family breakdown, including being separated from parents during childhood (residing in foster care or children’s homes), and living alone or in single parent families in adulthood (Bhugra & Bhui, 2001; Sharpley et al., 2001). There is some qualitative evidence to suggest the social networks of people from Black Caribbean communities are largely comprised of people from the same ethnic background, and that close family members are relied-upon for support and resources, with limited alternative sources of support (Campbell, Cornish, & McLean, 2004; Eliacin, 2013). Strong ethnic identity has also been reported to be associated with experiences of social exclusion and marginalisation from majority communities (Campbell et al., 2004; Eliacin, 2013). The limited research exploring theories relating to social networks, social capital and cohesion has focused on the experiences of Black Caribbean people, and even less is understood about the social networks of Black Africans in the UK.

Difficulties in developing and maintaining relationships are common experiences in psychosis; and loneliness and social isolation have been identified as significant barriers to recovery (Lim & Gleeson, 2014). A surge of empirical studies on social networks in schizophrenia were carried out in the late 1970s and throughout the 1980s, but these focused on qualitative network features and less on the structural characteristics of networks. Historically, the concept of ‘social support’ and social networks have been conflated (Brugha, 1995). Social support has generally been
conceptualised as a positive construct that serves as a protective factor against mental ill-health, either by directly gratifying affiliative needs or buffering the negative impact of stress (Brugha, 2010). However, social interactions and the family environment can be stressful for people experiencing psychosis and can contribute to adverse outcomes. For example, research suggests that emotionally overinvolved, critical and hostile interactions (high levels of expressed emotion) with relatives can increase risk of relapse in persons with a schizophrenia diagnosis (Barrowclough & Hooley, 2003; Butzlaff & Hooley, 1998). The cross-cultural validity of expressed emotion (EE) has been questioned; with research highlighting the cultural-specificity of EE constructs, including perceived criticism (Tompson et al., 1995) and emotional over-involvement (EOI) (Singh, Harley, & Suhail, 2013). EOI may not necessarily be detrimental in all cultures and may be moderated by warmth and mutual interdependence in familial relationships (Singh et al., 2013).

There has been substantial heterogeneity in the definition and measurement of social networks within psychosis research (for review, see Siette et al., 2015). For example, measures have varied in terms of the definitions used to describe social contacts and in the time periods wherein social contacts are assessed (Palumbo et al., 2015; Siette et al., 2015). More precise methods such as social network analysis (SNA) have emerged to better capture the complexity of the construct (Borgatti et al., 2009; Crossley et al., 2015; Mitchell, 1969). SNA was originally developed by anthropologists (Mitchell, 1969) but has since been applied to a wide range of disciplines, including psychological research. SNA focuses on relationships between individuals and the patterns and implications of these relationships on individual (and group) behaviour (Carrington et al., 2005). SNA differentiates between structural characteristics (e.g. network size and density or interconnectedness),
compositional characteristics (e.g. relationship type, sociodemographic characteristics of network members) and interactional characteristics (e.g. frequency of contact, intensity, content, function) (Mitchell, 1969). These network characteristics can be collected through comprehensive semi-structured network mapping interviews (Crossley et al., 2015; Siette et al., 2015)

There is a considerable amount of research to suggest that the social network characteristics of people diagnosed with schizophrenia and psychosis are different from those in non-clinical populations (for reviews, see Palumbo et al., 2015; Randolph, 1998). On average, their networks have been found to be smaller and more densely interconnected and to comprise less reciprocal and more ‘dependent’ relationships (Randolph, 1998). Social network size, particularly the number of friends (rather than family members), and individuals’ satisfaction with social support have been found to deteriorate at first episode and before the onset of psychosis (Gayer-Anderson & Morgan, 2013). Additionally, with increasing duration of contact with inpatient services, individuals’ networks have a tendency to include more healthcare professionals and fewer wider social contacts, such as colleagues or acquaintances (Randolph, 1998). A systematic review of social networks in psychosis found a weighted mean size of 11.7 persons for whole networks and 3.4 persons for friendship networks (Palumbo et al., 2015). Networks tended to be dominated by family members (43.1%). The total network size was much lower than the general population, which has previously been estimated to be at an average of 25 people (Pattison & Pattison, 1981).

Assessing social networks is important as there is evidence to suggest that variations in network characteristics in psychosis are associated with variation in outcome (e.g. Horan et al., 2006; Howard et al., 2000). Findings from a recent systematic review
and meta-analysis conducted by the current authors (Chapter 3) suggest that, in individuals diagnosed with schizophrenia, a larger social network size is moderately associated with improved negative symptoms (e.g. Macdonald et al., 1998) and social functioning (e.g. Horan et al., 2006). Larger social networks have also been related to fewer hospital admissions (Albert et al., 1998; Bhui et al., 2014) and improved quality of life (Goldberg et al., 2003). Findings were mixed, however, and the review recommended that network size needs to be considered along with other network and psychological characteristics to better understand its relationship with outcomes (Chapter 3).

Most studies examining social networks in psychosis have been carried out in predominately White populations. A recent review reported that social network size and support were more depleted in first episode psychosis among minority ethnic groups compared to majority groups (Gayer-Anderson & Morgan, 2013). However, this was based on three studies using social support measures (Brugha et al., 2004; Chakraborty, McKenzie, Hajat, & Stansfeld, 2010; Das-Munshi et al., 2012). One of these was a UK study and reported that Black African and Caribbean ethnic status was associated with having a primary social support group of less than three close persons (Brugha et al., 2004). Conversely, social network size has been found to be larger in Black service users (mean=15.1) than White service users (mean=11.5) with psychosis in UK community services (Becker et al., 1997). One earlier study using more detailed network mapping interviews found that network characteristics (i.e. size, density, composition) in Black African Americans diagnosed with schizophrenia were similar to that reported in primarily White psychosis samples (Cohen & Kochanowicz, 1989). These findings suggest network patterns may be
cross-cultural in psychosis. However, there have been no studies using comprehensive network assessments in Black UK populations.

The first and main aim of this study was to provide a descriptive account of the social network characteristics of Black African and Caribbean people with non-affective psychosis living in the North of England. This is the first known study to examine social networks in this population. In line with previous research in psychosis, it was hypothesised that the social networks would be smaller, more densely interconnected and contain a higher proportion of family members compared to social networks typically found in non-clinical and non-psychosis samples. A second aim was to examine relationships between social network size and support and network satisfaction. Based on previous literature (Sweet et al., in press), it was hypothesised that larger network size (greater number of total connections and more connections for each relationship type) and greater perceived social support would be related to higher network satisfaction. A third and final aim was to examine associations between social network variables and sociodemographic characteristics and psychosis symptoms.

4.3 Method

4.3.1 Participants

Participants were recruited into the study based on the following criteria: i) primary diagnosis of schizophrenia spectrum disorder or non-affective psychosis based on medical notes; ii) self-ascribed Black Caribbean or Black African background (including Black-British and ‘Mixed’ ethnic background); iii) aged 18 years or above; and iv) English speaking. Participants were excluded if they were clinically
assessed as being too unwell or lacking capacity to participate, or if they had a primary substance abuse diagnosis or significant cognitive impairment implicated in aetiology.

4.3.2 Recruitment

Participants were recruited via care teams or self-referral from a range of National Health Services (NHS) in Greater Manchester, UK, including acute inpatient wards, rehabilitation units, community mental health teams (CMHTs) and early intervention services (EIS), and from local third sector organisations. Participants were additionally recruited as part of a National Institute for Health Research (NIHR) funded feasibility trial to develop and test a Culturally-adapted Family Intervention (CaFI) for African Caribbean people diagnosed with schizophrenia; details of which can be found in the published protocol (Edge et al., 2016)\(^8\). Participants were recruited by trained research assistants and NIHR clinical research network (CRN) staff.

Of 84 participants referred to the study, 51 (60.71%) agreed to participate. Only five (9.62%) participants dropped out after giving their consent to take part leaving 46 participants with complete data for the analysis. Reasons for attrition were two relapses, two lost contacts and one imprisonment.

\(^8\) The full title of the study is ‘Culturally-adapted Family Intervention (CaFI) for African-Caribbeans diagnosed with schizophrenia and their families: a feasibility study of implementation and acceptability’. The study was funded through the NIHR Health Service and Delivery Research (HS&DR) programme (project ref: 12/5001/62).
4.3.3 Measures

*Social network mapping interview*

Network mapping semi-structured interviews were used to collect information regarding participants’ social networks (or ‘ego-nets’) (Crossley et al., 2015). A modified version of the personal wellbeing network (PWN) mapping schedule was used [Appendix VII]. This schedule was developed by researchers at the McPin Foundation, London, as part of their recently published NIHR-funded Community Health Networks study (Pinfold et al., 2015; Sweet et al., in press). The PWN was informed by patient and public involvement (PPI) feedback and piloted in individuals with severe mental health problems, with demonstrable face validity (Sweet et al., in press). Network mapping interviews with similar techniques have been used in previous studies in psychosis and have established good reliability (Siette et al., 2015). Structural, compositional and transactional social network variables can be generated from this network mapping interview.

For each participant, a comprehensive list of people in their social network was generated using the name generator approach (Campbell & Lee, 1991). This included nine open-ended questions focusing on the exchange of interaction between the participant and their network members (e.g. *who are the people you enjoy seeing or spending time with?*), and a tenth question asking the participant to list anyone in their social network who they had not recalled to ensure saturation was reached. Participants were instructed to recall people who they have regular contact with or who they regard as an important or meaningful relationship. There was no upper limit on the number of people the participant could recall. Network size was measured by the total number of contacts recalled. Participants were then asked to
place each person on a concentric circle diagram, or ‘emotional closeness map’, in
terms of how close they felt to that person, ranging from 1 (close, inner circle) to 6
(not close, outer circle). For each network member, the interviewer noted the
emotional closeness score (1>6) along with the name generator question(s) from
which the network member was recalled and whether the particular interaction was
reciprocal (i.e. whether the direction of the exchange was bidirectional or in one
direction from the network member to the participant).

Participants were asked to complete a ‘name interpreter card’ for each network
member to generate sociodemographic data and information about their relationship,
including: i) gender; ii) age; iii) ethnicity; iv) frequency of contact, ranging from 1
(never) to 6 (daily); v) duration known, ranging from 1 (less than 6 months) to 4
(more than 10 years); vi) type of relationship (i.e. immediate family, wider family,
friend, healthcare professional, acquaintance, colleague or neighbour); vii) whether
they used mental health services; viii) whether they knew about the participant’s
mental health problem; and ix) satisfaction with emotional and instrumental support,
ranging from 1 (very dissatisfied) to 5 (very satisfied).

To gather information on network structure, participants were asked to draw lines
between network members who knew one another on the emotional closeness map.

From this information, the following structural characteristics were calculated:

- **Density**: the proportion of network members who know one another, or the
  ‘interconnectedness’ of the network. This was calculated by dividing the
  number of actual connections with the number of possible connections in the
  social network. Density ranges from 0-1, with higher scores indicating higher
densities.
• **Isolates**: the number of people that are connected to the participant but are not connected to other people in the participant’s social network.

• **Components**: a subset of network members all of whom are connected by a path when the participant is removed

• **Homophily**: the extent to which participants ‘cluster’ or form relationships with people who are similar versus dissimilar to themselves. For this study, we examined *ethnic homophily* and *gender homophily*. That is, the extent to which participants formed relationships with people of the same ethnic group and gender to their own. This was measured using the external-internal (EI) index which examines the number of ties within and between groups (Krackhardt & Stern, 1988). Specifically, the index calculates the number of external social ties (different group) minus the number of internal social ties (same group) divided by the total number of social ties. The EI index ranges from -1 (greater homophily, all social ties belong to the same group) to +1 (greater heterophily, all ties belong in a different group).

Finally, the participant was asked to rate their satisfaction with their overall social network on a scale of 1 (*very dissatisfied*) to 5 (*very satisfied*) and explain the reason for their response.

Network mapping interviews took between 45-90 minutes depending upon the number of people recalled and participants’ cognitive abilities. Two trained postgraduate researchers (AD and LS) conducted the interviews.
Psychosis symptom severity

The Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987) is a standardised semi-structured interview that assesses positive, negative and general psychopathological symptoms of schizophrenia and psychosis. The PANSS includes 32 items that are assessed based on symptoms experienced in the previous week and measured on a Likert scale, ranging from 1 (absent) to 7 (extreme). Higher scores reflect more severe symptomatology. The same researchers (AD and LS) who conducted the network mapping interviews also conducted and rated the PANSS interviews. They attended monthly supervision sessions and inter-rater relatability was assessed every three months, with high reliability observed for the subscales and total scores (intraclass correlation coefficients; ICCs= .82 to .95). The alpha coefficient for PANSS total scores in this study was $\alpha= .83$.

Sociodemographic variables

A self-report questionnaire collected sociodemographic information from participants (Table 4). Mental health professionals were asked to verify information and any missing data against clinical case notes.

4.3.4 Procedure

The study received ethical approval from the NHS Research Ethics Committee (15/NW/0086). Service users were invited to meet with the researchers (AD or LS) in a convenient location of their choice (e.g. at home, local community centre, NHS or University building). During the meeting, the researchers went through the participant information sheet [Appendix I], obtained informed consent [Appendix II].
and administered the measures. Service users were given the option to complete the PANSS interviews, network mapping interviews and demographic measures in separate meetings in order to reduce the participant burden involved in participation.

4.3.5 Data Analysis

Data were analysed in SPSS version (IBM Corp, 2015) and UCINET (Borgatti, Everett, & Freeman, 2002). Network data were entered into Microsoft Excel and imported into UCINET in the form of three matrices: i) for each participant (ego), network members (alters) recalled in response to each name generator question; ii) ego-alter connections and alter-alter connections; and iii) ego and alter attributes (i.e. socio-demographic and relationship characteristics) (Crossley et al., 2015) Summary statistics for structural, compositional and transactional network variables were generated in UCINET and input into SPSS for further analyses. Social network diagrams were created in NetDraw in UCINET.

Descriptive statistics were examined for ego-network variables, socio-demographics and PANSS. Skewness and kurtosis z-scores were reviewed for normality, with scores inside of -1.96 and +1.96 indicating a normal distribution. Most network variables were skewed. Attempts were made to transform skewed data for comparison with clinical and socio-demographics, but some were unsuccessful. Correlational analyses examined associations between continuous measures, using Pearson for normally distributed data and Spearman for skewed data. One-way ANOVAs and t-tests were used to examine associations between continuous measures and categorical sociodemographic data (i.e. gender, ethnicity, country of origin, diagnosis). Non-parametric alternatives (Mann-Whitney U and Kruskal-Wallis) were used for skewed data.
Social network and PANSS data were not available for the five participants who dropped out and so these participants were excluded from the analysis (i.e. listwise deletion). One-way ANOVAs and t-tests showed no differences in sociodemographic characteristics of participants who completed all measures, compared to those who dropped out. If participants had ≤20% missing data on a particular measure, the missing item(s) was replaced with the mean score for that measure.

4.4 Results

4.4.1 Sample characteristics

Sociodemographic and clinical characteristics of the total sample are described in Table 4. The mean age of the full sample was 42.38 years (range= 19-81). In total, there were 36 males (70.6%) and 15 females (29.4%). Around one third (n=14) of the sample was Black African and two thirds (n=37) were Black Caribbean. Fifty-five percent (n=26) of participants were born in the UK and the rest were born abroad, either in Africa (25.5%, n=12) or the Caribbean (19.1%, n=9). Clinical diagnoses covered the full schizophrenia spectrum, with most of the sample receiving a schizophrenia (64.7%) or schizoaffective disorder (15.7%) diagnosis. Sixty-five percent (n=33) of the sample were recruited from community services (49.0% CMHTs; 17.8% EIS; 17.8% third sector) and the rest were receiving inpatient care (17.6% acute; 17.6% rehab). Duration of contact with services ranged from one to 55 years with a mean of 17.28 years (SD= 10.65). Most participants (93.6%, n=44) were taking anti-psychotic medication at the time of assessment.
Table 4.

Clinical and sociodemographic characteristics of sample (n=51)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), mean (SD)</td>
<td>42.38 (13.01)</td>
</tr>
<tr>
<td>Gender, Male n (%)</td>
<td>36 (70.6)</td>
</tr>
<tr>
<td>Ethnicity, n (%)</td>
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</tr>
<tr>
<td>Black Caribbean</td>
<td>33 (64.7)</td>
</tr>
<tr>
<td>Black African</td>
<td>12 (23.5)</td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td>4 (7.8)</td>
</tr>
<tr>
<td>White and Black African</td>
<td>2 (3.9)</td>
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<td>Employment, n (%)</td>
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<td>Unemployed/long term sickness or disability</td>
<td>39 (83.0)</td>
</tr>
<tr>
<td>Employed/student/volunteer</td>
<td>8 (17.0)</td>
</tr>
<tr>
<td>Education, n (%)</td>
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</tr>
<tr>
<td>High school education</td>
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<tr>
<td>Other/ no qualifications</td>
<td>20 (42.6)</td>
</tr>
<tr>
<td>Marital status, n (%)</td>
<td></td>
</tr>
<tr>
<td>Married/cohabiting</td>
<td>6 (13.0)</td>
</tr>
<tr>
<td>Single/divorced/separated</td>
<td>40 (87.0)</td>
</tr>
<tr>
<td>Children (yes), n (%)</td>
<td>24 (51.1)</td>
</tr>
<tr>
<td>Living alone (yes), n (%)</td>
<td>24 (51.1)</td>
</tr>
<tr>
<td>Diagnosis, n (%)</td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>17 (33.3)</td>
</tr>
<tr>
<td>Paranoid schizophrenia</td>
<td>16 (31.4)</td>
</tr>
<tr>
<td>Schizoaffective disorder</td>
<td>8 (15.7)</td>
</tr>
<tr>
<td>Delusional disorder</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>Non-affective psychosis</td>
<td>9 (17.6)</td>
</tr>
<tr>
<td>PANSS, mean (SD)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>66.96 (15.92)</td>
</tr>
<tr>
<td>Positive</td>
<td>15.85 (5.72)</td>
</tr>
<tr>
<td>Negative</td>
<td>16.84 (4.60)</td>
</tr>
<tr>
<td>General</td>
<td>34.18 (8.54)</td>
</tr>
<tr>
<td>Duration contact with services (years), mean (SD)^</td>
<td>17.28 (13.61)</td>
</tr>
</tbody>
</table>

Note: PANSS= Positive and Negative Symptom Scale; N=46 due to missing data, other than age, gender and ethnicity where N=51.
4.4.2 Social network characteristics

Social network connections across full sample

A total of 601 alters (social connections) were recalled across the full sample (n=46). Of these social connections, 28.6% (n=172) were with people of Black Caribbean ethnicity, 20.1% (n=121) Black African, 17.1% (n=103) Black British, 23.8% (n=143) White British, 3.2% (n=19) Asian, and 7.1% (n=43) ‘other’ (i.e. Arab, ‘White Irish, White other’, or ‘other mixed ethnic background’). There were fewer social connections with males (53.5%, n=322) than with females (64.9%, n=389). Most network members were between the ages of 25 and 54 years (43.7%, n=163), with almost equal numbers at either end of the spectrum; under 24 (17.7%, n=106) and over 55 years (17.4%, n=104).

Descriptive statistics for the total number of social connections recalled in response to the name generator questions can be found in Table 5. Across the full sample, 83.66% of connections were reported to be reciprocal (i.e. bi-directional exchange). When looking more closely at the percentage of reciprocal ties, most of the positive interactions were reciprocated; these included, sharing social activities, spending time or discussing important matters (mean range= 83-99%). A moderate percentage of interactions (mean range = 48-59%) involving the alters providing emotional or practical support were deemed by participants to be reciprocal. This suggests about half were not reciprocal or may have involved the participant being ‘dependent’ upon alters. Around 4% of total connections were perceived as stressful or difficult and three-percent involved people that participants did not wish to make contact with. However, these ‘negative’ perceptions of social ties were not always
reciprocated; on average, less than half were rated as reciprocal (22.82% and 39.56%, respectively).

Structural characteristics

Structural social network characteristics of the sample are presented in Table 6. The mean number of people recalled was 12 but varied widely across the sample (range= 3-43). Network size had a positive skew, with only around a quarter of participants (24.9%) recalling over 13 contacts. Modal and median values of ten social contacts may, therefore, be more representative of the total sample. On average, social networks were of moderate density (49.8%) (indicating that approximately 49.8% of the alters in an average network had ties to one another) (Crossley et al., 2015). Seventy-two per cent (n=33) of the sample had networks with one or two components (50.0% and 21.7%, respectively), suggesting most networks were made up of a small number of connected groups. Seventy-six percent (n=35) had no socially isolated members, 13% (n=6) had one, and 11% (n=5) had between two and seven isolates. Negative ethnic and gender network homophily scores (E-I index) highlight a tendency for participants’ social networks to comprise a higher number of people of the same ethnic background and gender than of a different ethnic background and gender to their own.

---

9 There was one outlier who reported a network size of 43 people. Removal of this outlier resulted in a mean of 11.4 (SD = 7.12; range= 3-33)
Table 5

Descriptive statistics for number of social ties and proportion of reciprocal ties recalled in response to name generator questions across the sample (n=46)

<table>
<thead>
<tr>
<th>Name generator question</th>
<th>Total N (%)</th>
<th>Mean (SD)</th>
<th>Range</th>
<th>Med, Mod</th>
<th>R% (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Who are the people you currently enjoy seeing or spending time with?</td>
<td>328 (29.02)</td>
<td>7.13 (8.02)</td>
<td>1-37</td>
<td>4.5, 4</td>
<td>99.22 (4.92)</td>
</tr>
<tr>
<td>2 Who do you currently have to see but would prefer not to?</td>
<td>31 (2.74)</td>
<td>0.67 (0.92)</td>
<td>0-4</td>
<td>0, 0</td>
<td>22.82 (40.42)</td>
</tr>
<tr>
<td>3 From time to time, most people discuss important matters with other people.</td>
<td>145 (12.83)</td>
<td>3.15 (2.88)</td>
<td>0-14</td>
<td>2, 2</td>
<td>82.96 (32.75)</td>
</tr>
<tr>
<td>4 If you needed to obtain some advice or information for a mental health problem, who would you approach?</td>
<td>97 (8.58)</td>
<td>2.11 (2.04)</td>
<td>0-9</td>
<td>1, 1</td>
<td>49.67 (44.49)</td>
</tr>
<tr>
<td>5 If you needed some emotional reassurance and comfort for a mental health problem, who would you approach?</td>
<td>88 (7.79)</td>
<td>1.91 (1.80)</td>
<td>0-9</td>
<td>1.5, 1</td>
<td>52.15 (44.49)</td>
</tr>
<tr>
<td>6 Who has recently helped you with everyday tasks such as cooking, cleaning, shopping, filling out forms, and finding out information?</td>
<td>73 (6.46)</td>
<td>1.58 (1.42)</td>
<td>0-6</td>
<td>1, 1</td>
<td>48.37 (47.20)</td>
</tr>
<tr>
<td>7 If you needed to borrow some material goods or money, who would you go to for help?</td>
<td>74 (6.55)</td>
<td>1.54 (0.93)</td>
<td>0-5</td>
<td>1, 1</td>
<td>59.46 (46.87)</td>
</tr>
<tr>
<td>8 Who are the people you attend or share social activities with?</td>
<td>182 (16.10)</td>
<td>3.96 (5.43)</td>
<td>0-34</td>
<td>2, 1</td>
<td>88.89 (31.43)</td>
</tr>
<tr>
<td>9 Who are the people you currently see with whom you find encounters difficult or stressful?</td>
<td>43 (3.80)</td>
<td>0.93 (1.57)</td>
<td>0-9</td>
<td>1, 1</td>
<td>39.56 (49.08)</td>
</tr>
<tr>
<td>10 Please list anyone who you regularly interact with who you have not listed in one of the previous questions.</td>
<td>69 (6.11)</td>
<td>1.5 (2.31)</td>
<td>0-13</td>
<td>1.5, 1</td>
<td>58.33 (49.53)</td>
</tr>
<tr>
<td><strong>Total interactions</strong></td>
<td><strong>1130</strong></td>
<td><strong>24.57 (17.80)</strong></td>
<td><strong>7-110</strong></td>
<td><strong>20, 15</strong></td>
<td><strong>83.66 (12.72)</strong></td>
</tr>
</tbody>
</table>

*Note: Alters recalled in response to network questions are not mutually exclusive. All variables positively skewed.*
Table 6

Structural social network characteristics of the sample (n=46)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean (SD)</th>
<th>Range</th>
<th>Mdn</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>Size*</td>
<td>12.09 (8.43)</td>
<td>3-43</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Density</td>
<td>0.50 (0.25)</td>
<td>0-1</td>
<td>0.48</td>
<td>0.33</td>
</tr>
<tr>
<td>Ethnic homophily+</td>
<td>-0.27 (0.53)</td>
<td>-1-1</td>
<td>-0.37</td>
<td>-0.8</td>
</tr>
<tr>
<td>Gender homophily</td>
<td>-0.28 (0.29)</td>
<td>-0.89-0.64</td>
<td>-0.3</td>
<td>0</td>
</tr>
<tr>
<td>Isolates+</td>
<td>0.53(1.33)</td>
<td>0-7</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Components+</td>
<td>2.13(1.90)</td>
<td>1-12</td>
<td>1.5</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: *Density: higher scores= higher density; Homophily: lower scores= greater tendency to form social ties with people of the same ethnic group or gender; isolates=number of people only connected to ego; components=number of connected groups within network; imputed mean for N=1 missing value for isolates and components; Skewed data: + = positive skew; ^ = negative skew.

Compositional characteristics

Table 7 presents compositional characteristics. On average, participants had approximately four different types of relationships in their social networks. This included disproportionately more relatives, making up almost half (43.1%) of the total number of contacts, followed by just over a quarter (28.2%) friends and just under a quarter (23.2%) healthcare professionals. Participants had very few wider contacts (acquaintances, colleagues, neighbours) with mean values suggesting they comprised only 6% of the total network, though this variable was positively skewed and 69.6% (n=32) of participants reported zero wider contacts and 19.6% (n=9) reported one wider contact\(^{10}\). On average, participants reported that the majority (88.1%) of network members knew about their mental health problems. Mean scores suggest that just under a fifth (17.2%) of participants’ network members also used mental health services.

\(^{10}\) One participant was an outlier and reported 14 wider contacts. Removal of this outlier resulted in a mean of 0.64 (SD=1.63; range= 1-9).
When summed across the full sample, 12.8% of family members, 32.7% friends and 48.8% wider contacts were reported to use mental health services. No professionals were reported to use mental health services (i.e. ‘do not know’ = 43.8%; ‘no’ = 56.1%).

Table 7

Compositional social network characteristics of the sample (n=46)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean (SD)</th>
<th>Range</th>
<th>Mdn</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diversity</td>
<td>3.72 (1.19)*</td>
<td>-</td>
<td>2-8</td>
<td>3.5</td>
</tr>
<tr>
<td>Family</td>
<td>5.59 (6.37)*</td>
<td>43.11 (28.71)</td>
<td>0-28</td>
<td>3.5</td>
</tr>
<tr>
<td>Immediate family</td>
<td>3.37 (3.91)</td>
<td>27.0 (22.16)</td>
<td>0-21</td>
<td>2</td>
</tr>
<tr>
<td>Wider family</td>
<td>1.96 (3.63)</td>
<td>13.94 (19.0)</td>
<td>0-19</td>
<td>0.5</td>
</tr>
<tr>
<td>Partner</td>
<td>0.26 (0.57)</td>
<td>2.21 (5.04)</td>
<td>0-3</td>
<td>0</td>
</tr>
<tr>
<td>Friends</td>
<td>3.39 (3.94)*</td>
<td>28.16 (22.81)</td>
<td>0-20</td>
<td>2.5</td>
</tr>
<tr>
<td>Wider contacts</td>
<td>0.94 (2.54)*</td>
<td>5.51 (10.65)*</td>
<td>0-14</td>
<td>0</td>
</tr>
<tr>
<td>Neighbours</td>
<td>0.09 (0.28)</td>
<td>0.84 (2.84)</td>
<td>0-1</td>
<td>0</td>
</tr>
<tr>
<td>Colleagues</td>
<td>0.11 (0.74)</td>
<td>0.25 (1.71)</td>
<td>0-5</td>
<td>0</td>
</tr>
<tr>
<td>Acquaintances</td>
<td>0.74 (2.04)</td>
<td>4.42 (10.10)</td>
<td>0-9</td>
<td>0</td>
</tr>
<tr>
<td>Professionals</td>
<td>2.15 (1.67)*</td>
<td>23.21 (19.14)*</td>
<td>0-9</td>
<td>2</td>
</tr>
<tr>
<td>Know MH problem N*</td>
<td>10.41 (6.86)*</td>
<td>88.09 (15.38)*</td>
<td>3-31</td>
<td>9</td>
</tr>
<tr>
<td>MH service use N*</td>
<td>2.22 (3.42)*</td>
<td>17.15 (20.17)*</td>
<td>0-15</td>
<td>1</td>
</tr>
</tbody>
</table>

Note. Diversity=number of different types of relationships (1-9); Family=immediate family, wider family and partner; Wider contacts= neighbours, colleagues and acquaintances; MH=mental health; *Not mutually exclusive with other relationship types; Skewed data: + = positive skew; ^= negative skew.

Transactional characteristics

Table 8 presents summary statistics for transactional characteristics. Mean emotional closeness scores suggest that participants’ generally perceived their network members to be close to them. Participants had, on average, three people in their ‘inner circle’ who they rated as ‘very close’; comprising just under a quarter (23.7%) of the total network.
Emotional closeness was associated with relationship type (Welch’s $F(3, 159.32)=17.54$, $p<.001$), with higher emotional closeness ratings found for family ($M=4.40$, $SD=1.82$) compared to wider contacts ($M=3.23$, $SD=1.20$) and professionals ($M=3.21$, $SD=1.49$), and for friends ($M=3.99$, $SD=1.54$) than professionals.

Around two thirds (67.1%) of the network members were reported to have known the participant for more than five years. These long-standing relationships were mostly family members (74.6%); followed by friends (19.5%), professionals (2.6%) and wider social contacts (3.3%). Most network members (75.8%) were seen at least monthly; this regular contact was made with 46.3% family, 29.3% friends, 12.6% professionals, and 9.8% wider connections.

Mean scores show that participants’ satisfaction with both emotional and instrumental support across the total network was generally high (Table 8). Most participants (80%, $n=36$) stated they were satisfied (40%) or very satisfied (40%) with their social networks. Two participants (4.4%) reported feeling dissatisfied and seven (15.6%) were unsure or neither satisfied or dissatisfied. Reasons for satisfaction included: feeling accepted and understood ($n=4$), being able to depend on others when needed ($n=4$), provision of coping strategies and social support ($n=18$), long-standing and close relationships ($n=6$), and enjoy socialising ($n=4$). Reasons for dissatisfaction or neutral feelings included: loneliness ($n=3$), relationship breakdown ($n=2$), inability to talk about problems ($n=2$) or do not wish to disclose ($n=2$).

In line with the study hypotheses, greater satisfaction with social support was associated with higher overall social network satisfaction ($r_{s}(44)=.51$, $p<.001$). However, contrary
to predictions, network satisfaction was not related to total network size ($r(44)= .04, p=.796$), or number of family ($r(44)= .10, p=.508$), friends ($r(44)= .08, p=.604$), wider contacts ($r_s(44)= -.12, p=.435$), or professionals ($r_s(44)= -.09, p=.557$).

Table 8

*Transactional social network characteristics of the sample (n=46)*

<table>
<thead>
<tr>
<th>Characteristic*</th>
<th>Mean (SD)</th>
<th>Range</th>
<th>Mdn</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional closeness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3.88 (1.24)</td>
<td>1.2-6</td>
<td>4</td>
<td>3.5</td>
</tr>
<tr>
<td>Inner circle, N</td>
<td>3.24 (5.33)</td>
<td>0-24</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Inner circle, %</td>
<td>23.70 (28.21)</td>
<td>0-100</td>
<td>13.25</td>
<td>0</td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>8.09 (0.94)</td>
<td>5.2-10</td>
<td>8.12</td>
<td>6.67</td>
</tr>
<tr>
<td>Instrumental</td>
<td>3.98 (1.25)</td>
<td>2.4-5</td>
<td>4.08</td>
<td>4</td>
</tr>
<tr>
<td>Emotional</td>
<td>4.11 (0.48)</td>
<td>2.8-5</td>
<td>4.11</td>
<td>4</td>
</tr>
<tr>
<td><strong>Network satisfaction</strong></td>
<td>4.13 (0.91)</td>
<td>1-5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td><strong>Frequency of contact</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>24.2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monthly</td>
<td>23.8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly</td>
<td>32.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily</td>
<td>19.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Duration of contact</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>8.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 months to 5 years</td>
<td>24.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-10 years</td>
<td>11.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 10 years</td>
<td>55.4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Emotional closeness= 1 (not close – outer circle) to 6 (very close – inner circle); Instrumental support, emotional support and network satisfaction= range 1 (very dissatisfied) to 5 (very satisfied); imputed mean for N=1 missing value for emotional closeness and network satisfaction. Skewed data: + = positive skew; ^ = negative skew.*
4.4.3 Relationships with symptoms and demographics

A greater proportion of wider social contacts ($U=119.00$, $p=.009$) was found among females (Mdn= 0.10) compared to males (Mdn= 0). A higher proportion of friends was reported in participants who were Black African (M=0.39) versus Black Caribbean (M=0.22) ($t(44)=-2.60$, $p=.013$) and in those born abroad (M=0.36) versus in the UK (M=0.22) ($t(44)=-2.27$, $p=.034$). Age and diagnosis were not correlated with network variables ($p <.05$).

Greater severity of positive symptoms (PANSS) was related to higher proportion of service users in the network ($r_s(44)= .32$, $p=.030$), lower emotional closeness ($r(44)=-.33$, $p=.026$), fewer people in the inner circle ($r(44)=-.31$, $p=.039$) and lower perceived social support ($r(44)=-.33$, $p=.026$). More severe negative symptoms (PANSS) was associated with a fewer number of components ($r_s(44)= -.29$, $p=.047$), higher proportion of professionals ($r_s(44)= .32$, $p=.030$), more people who knew about the participant’s mental health problems ($rho(44)= .38$, $p=.008$) and less satisfaction with social support ($r(44)=-.31$, $p=.037$). More general psychopathology symptoms (PANSS) was associated with greater proportion of professionals ($r_s(44)= .29$, $p=.049$), fewer people in the inner circle ($r(44)= -.37$, $p=.010$), and less satisfaction with social support ($r(44)=-.30$, $p=.044$) and less satisfaction with networks as a whole ($r_s(44)= -.39$, $p=.007$). Overall psychiatric symptoms (PANSS total) was related to fewer people in the inner circle ($r(44)=-.36$, $p=.015$) and less satisfaction with social support ($r(44)= -.37$, $p=.012$) and social networks ($r_s(44)= -.33$, $p=.025$).
4.4.4 Network visualisation – case illustration

Figure 3 illustrates a social network of one of the participants with a network structure that is considered to be typical for the current sample. This participant (SU323) has a network size of 11, with moderate density (49.09%), two components and no social isolates. The people in the network are labelled in terms of their relationship with the participant (or ‘ego’). Lines connect the network members who are reported to know one another. The shapes represent gender; females are circles and males are squares. The colour of shapes indicate the ethnic group of the network member; pink is Black Caribbean (including ‘Mixed’), blue is White British and green is ‘unknown’. Emotional closeness scores are represented by the size of the shape, with larger size reflecting higher emotional closeness ratings.

![Social network diagram (SU323)](image)

Figure 3.

Social network diagram (SU323)
4.5 Discussion

This is the first study to examine social network characteristics in Black people diagnosed with non-affective psychosis in the UK. The findings highlight similarities between the network characteristics of the present Black African and Caribbean sample and those found in previous psychosis studies. Previously reported changes to the size, composition and structure of social networks among people diagnosed with psychosis (compared to non-clinical samples) were observed in this study sample of Black people with psychosis, suggesting that these may be cross-cultural (Cohen & Kochanowicz, 1989). Consistent with hypotheses and previous studies in predominately White samples, this study showed that the networks of Black people with psychosis were small and moderately interconnected and comprised disproportionately more family members. Novel findings suggest they also have very few wider social ties and a high number of people of the same ethnicity to their own. These findings also suggest that higher network satisfaction, and perceptions of social support and emotional closeness are related to lower psychological distress in Black people with psychosis.

The mean social network size of 12 in the current sample of Black people with psychosis is lower than the general population (e.g. Cresswell et al., 1992; Hill & Dunbar, 2003; Pattison & Pattison, 1981) and the same as that previously reported for people with psychosis (Palumbo et al., 2015). Additionally, the high proportion of family members in the networks (mean= .43) are similar to previous studies in schizophrenia and psychosis which range between .38 and .64 (Becker et al., 1998; Erickson, Beiser, Iacono, Fleming, & Lin, 1989; Hamilton et al., 1989; Holmes-Eber &
Family relationships in this sample were also reported to be more long-standing (in terms of longer duration known) and ‘emotionally close’ than those with professionals and friends. The greater stability of family relationships was in line with findings in relation to other ethnic groups with psychosis (Gayer-Anderson & Morgan, 2013; Thorup et al., 2006). It also supports qualitative findings in Black communities emphasising the reliance on close family members for support and resources at times of stress (Mclean et al., 2003). The ‘network breakdown’ in the current sample was comparable to other primarily White psychosis samples and involved deterioration in structure and composition, including few friends and wider contacts (i.e. acquaintances, neighbours, colleagues). This suggests that the higher levels of family disruption (e.g. Mallett et al., 2002) does not lead to greater deterioration in the social networks of Black people than White people.

Participants’ lack of contact beyond their primary group contrasts with previous research. The present sample reported very few (0-2) wider social network contacts, smaller than numbers found in predominantly White samples with severe mental health problems (Sweet et al., in press). Many service users were not currently in work and around half were residing in acute or rehab units, which may partially explain the lack of access to wider contacts outside of their families or the mental health system. In this study, participants had been in contact with services for a long period of time (mean=17 years) and many had experienced repeated hospital admissions over the years. This may explain why there were similar proportions of professionals (mean= .23) to friends
(mean= .28) in the social networks. Similar proportions of professionals have been found in previous research in individuals diagnosed with schizophrenia (.20) (Cohen et al., 1997) and severe mental health problems (.19) (Sweet et al., in press). It may also explain why participants reported that most network members (88%) knew that they had a mental health problem; which could be seen as inconsistent with research reporting high level of non-disclosure and mental health stigma in Black communities (Kovandžić et al., 2011; Shefer et al., 2013). The number and proportion of friends reported (mean: N=4, .28) is similar to that reported in other psychosis samples (mean: N=3, .27) (Palumbo et al., 2015) and lower than the general population (N=8-10 friends) (as cited in Palumbo et al., 2015; Wighton, 2007).

The current findings showed that Black African participants had a significantly higher proportion of friends in their social network than Black Caribbean participants, and that those born abroad had more friends than those born in the UK. Having disproportionately more friends is therefore likely to be an artefact of more recent migration to the UK, which changes the composition of the network such that more friendships are formed as family members stay in the home country. There were no other associations between the network characteristics and socio-demographic characteristics of the sample.

The social networks of the current sample were moderately interconnected, with an average density of .50. This suggests that around half of the network members in an average network were connected to one another (Crossley et al., 2015). Previous studies in psychosis have reported similar densities (ranging from .45 to .64) in longer term
schizophrenia samples (Cohen et al., 1997; Dozier et al., 1987; Goldberg et al., 2003; Lipton et al., 1981) and .73 in individuals with recent onset psychosis (Horan et al., 2006). It has been suggested that more densely interconnected network structures can be overwhelming and stressful and limit access to alternative perspectives (Dozier et al., 1987). Social networks with moderate densities may be more beneficial as they offer security and support whilst also including weak social ties that act as bridges to other networks and broaden resources at times of distress (Horan et al., 2006). The moderate social networks in this sample could therefore be viewed as being of optimal density, providing adequate support whilst being manageable. However, there was variation across the present sample, and it is these inter-individual differences in network density that are associated with outcomes. In two studies of individuals with severe mental health problems, moderate density has been related to a reduction in overall psychiatric symptoms (Goldberg et al., 2003) and length of hospital stay (Dozier et al., 1987).

Black people’s social networks in this sample generally comprised connected groups with very few isolated individuals (i.e. persons only connected to the participant and no one else in the network). There is no comparable literature in psychosis. However, these findings are in accordance with the traditional social structures of African-descended people which involve tight-knit communities and extended family networks (Arnold, 2012).

Participants were more likely to report relationships with people of similar ethnicity to their own rather than different (i.e. their networks were more ethnically homogenous). There has been no prior quantitative examination of ethnic composition of individuals’ social networks in Black African and Caribbean people with psychosis. However,
findings from qualitative research suggest that Black Caribbean people form communities with other Black people to facilitate trust and cooperation in the face of inequalities and social exclusion (Mclean et al., 2003). On a macro level, epidemiological studies have found that more ethnically dense minority communities are protective in psychosis and reduce distress (Becares et al., 2009; Das-Munshi et al., 2012), but can have adverse effects when mediated by perceptions of social adversity (Reininghaus et al., 2010). Taken together, previous findings suggest that certain beliefs (i.e. related to being of Black ethnicity) may be interacting with the structure and composition of social networks to influence outcomes in psychosis.

Most (84%) of the total social interactions were reported to be reciprocal. However, there were some observed differences in reciprocity depending on the type of exchange or social interaction. Interactions that involved the provision of emotional or practical support had lower reciprocity scores than interactions that involved sharing social activities, spending time with or discussing important matters with people. This suggests that participants had a tendency towards receiving more support in their relationships and is consistent with previous studies in psychosis (Horan et al., 2006; Lipton et al., 1981; Randolph, 1998). For example, in individuals with recent onset psychosis, Horan et al. (2006) found that 31% of relationships involved receiving more support, 44% were reciprocal an 21% involved providing more support. Often the same network member was reported to involve both positive and negative interactions. This endorses previous findings that significant relationships in people’s lives can be harmful and contradictory (Thoits, 2011). It is therefore important to view social networks as involving both
positive and negative characteristics. It is worth noting that total reciprocity score in this study should be interpreted with caution and not be used as proxy for dependency in relationships, as it included certain interactions that were inherently bidirectional (i.e. sharing activity).

The Community Health Network (CHN) study (Sweet et al., in press) examined personal networks in people with severe mental health problems using the unmodified network mapping interview used in this study. They identified three social network typologies with distinct compositional and structural network features and that were associated with different socio-demographic characteristics: i) ‘Formal and sparse’ networks contained few social ties (mean= 12.4) and a higher proportion of healthcare professionals than the other network types. They were more likely to have diagnoses of schizophrenia and psychosis, and to be older and male, receiving secondary care and on long-term sickness and disability benefits; ii) ‘Family and stable’ networks had higher numbers of family and friends, and more emotionally close and stable social ties. They were more likely to be female and White British and have bipolar diagnoses and be in primary care services and in employment; and iii) ‘Diverse and active’ networks involved more social ties (mean= 23.9) than the other two types, with more diverse relationships and weak ties (colleagues, neighbours, acquaintances). They tended to be younger and to be in higher education, training or volunteering positions. Having a ‘diverse and active’ network type was related to improved self-reported wellbeing and general health compared to the other two types, with ‘formal and sparse’ networks having the lowest scores. However, the ‘family and stable’ networks reported
significantly more access to social support than the other two types. In the present sample, the total network size is the same as that reported for the ‘formal and sparse’ network type (mean= 12), but the proportion of family members more closely reflects the ‘family and stable’ typology (mean= .38 versus .43 in the current sample). These findings highlight, again, the significance of the family in the current sample of Black people experiencing psychosis. It also suggests that the current sample may have poorer quality networks in terms of their influence on health and wellbeing.

The proportion of professionals in the current study was comparable to the total sample in the CHN study (mean total sample=.19; network types mean range= .18 to .32). Discrepancies are evident in that the earlier SMI sample in the CHN study reported a larger proportion of friends (mean= .33, mean range= .27 to .34) and a much larger proportion of wider social ties (mean= .20; mean range= .12 to .26). These observed differences could reflect clinical differences, as their sample included individuals with affective disorders and only 39% were diagnosed with non-affective psychoses. The CHN sample was mostly White British (though it was ethnically diverse: 69% White British and 31% ‘other’) and therefore may reflect ethnic differences between White and Black people with psychosis. However, further studies examining specific clusters or ‘network types’ among different ethnic or cultural groups are required before any conclusions can be drawn.

Most of the sample reported to be ‘satisfied’ with their social networks as a whole; though less than half were ‘very satisfied’. In line with current predictions and with the CHN study in severe mental health problems (Sweet et al., in press), greater satisfaction
with social networks was related to improved social support. However, contrary to
current hypotheses satisfaction was not related to the size or composition of social
networks. This suggests that the function and quality of social relationships may be
more important than the number of persons available in the current sample of Black
people with psychosis. Higher satisfaction with social networks and support and higher
emotional closeness was related to lower psychological distress. Higher social support
has previously been associated with improved symptoms in non-affective psychosis
(Cechnicki & Wojciechowska, 2008; Macdonald et al., 1998). Network size was not
related to symptoms; contradicting findings from the current author’s recent meta-
analysis in predominately White samples with non-affective psychosis (Chapter 3). In
the review, more severe negative and total symptoms were related to smaller network
size, but there was no effect for positive or general symptoms. The current findings
reiterate the conclusions of the review, in recommending that networks be defined as
multifaceted and not reduced to single dimensions such as size.

There are some methodological issues to consider when interpreting the findings. The
network mapping interview can be lengthy (depending on the number of people
recalled) and therefore may be challenging for people who experience psychosis or
cognitive difficulties. Additionally, the number of people recalled may have been
influenced by response bias, including poor memory or social desirability, or
participants’ mood or motivation levels at the time of the interviews. Some participants
reported difficulties in remembering which social network members knew one another
(alter-alter ties) which may have led to an incorrect estimate of network density. It has
previously been suggested that networks in people with severe mental health problems may be smaller than what they report due to difficulties in accurately evaluating their networks (Buchanan, 1995). However, investigating personal accounts of social networks is suggested to be more important than objective accounts as these have been shown to be more positively associated with beneficial health outcomes (Melrose, Brown, & Wood, 2015).

Caution must be taken when generalising these findings beyond the current study due to the small sample size and lack of control group. The small sample meant that the current study was unable to make any detailed and meaningful comparisons of social network characteristics between Black Caribbean and Black African groups or across the schizophrenia-spectrum. Future research would benefit from using larger samples and controlled designs comparing social networks across different ethnic and diagnostic subgroups. A fruitful avenue for further research would be to examine and compare network typologies and their relationships to outcomes in psychosis across different ethnic groups, to advance on the recent CHN study findings, which included mainly White individuals with severe mental health problems (Sweet et al., in press).

The study is cross-sectional and therefore causal direction between networks and psychosis symptoms cannot be inferred. For example, increased levels of distress may lead to greater social withdrawal from close persons and worsen symptoms, or close relationships may serve to protect an individual from distress and prevent worsening symptoms. Evidence to date supports the bi-directional and complex nature of the relationship between social networks, onset, course and outcomes in psychosis (Gayer-
Anderson & Morgan, 2013). There is evidence in primarily White populations to show that networks deteriorate prior to the onset of psychosis (Gayer-Anderson & Morgan, 2013) and limited evidence to show that social networks are generally relatively stable over the period following onset (Horan et al., 2006). It is plausible that differences may be found in the networks of Black people with psychosis over time, however, as they have been shown to have a progressively worse clinical course and outcome than their White counterparts (Morgan et al., 2017). Social networks may also be influenced by participants’ previous contact and experiences with services (e.g. number of admissions) (Albert et al., 1998; Morgan et al., 2017). Further examination of Black people’s networks in longitudinal studies would improve our understanding of which characteristics are amenable to change and important for long-term positive outcomes.

Selection bias relating to the recruitment methods may have favoured those who reported better quality social networks, with which they were more satisfied. Clinicians may have referred into the study individuals that were better engaged, more clinically stable and had improved functioning. Participants took part voluntarily and therefore may have been those who were more likely to have reported more positive relationships than the general clinical population, or their social networks may have been less affected by their experience of psychosis or mental health services. This potentially limits the generalisability of the findings to all Black African and Caribbean service users with psychosis.

Notwithstanding, the current study is novel in that it is the first to provide a detailed account of the social network characteristics in Black people with psychosis. These
findings can be used as a platform to generate theories relating to social network characteristics that may be unique to Black and other marginalised UK populations, including the potential effects of more ethnically cohesive networks on disparities in engagement with services and outcomes. Interventions would benefit from using the network mapping tool to develop individualised shared formulations to gain deeper understanding of the social networks of Black people and resources available to them to improve recovery in psychosis. The authors encourage future large scale social network studies to be carried out in this population to test the reliability of the present findings.

**Clinical implications**

This study provides support for the application of social network analysis (Crossley et al., 2015) in psychological research and its utility in broadening current understanding of the networks of Black people with psychosis in the UK. The social network mapping approach and network diagrams may be a useful therapeutic tool for understanding service users’ social networks from their perspectives and, importantly, how such insights might be used to support their recovery (Pinfold et al., 2015). For example, network mapping assessments can be used as part of individualised formulations in psychosocial interventions and clinical practice (Sweet et al., in press). The current findings highlight the importance of involving the family in psychosocial interventions to enhance the recovery process (Barrowclough & Tarrier, 1992; Claxton, Onumere, & Fornells-Ambrojo, 2017; Pharoah et al., 2010; Pilling et al., 2002). Family interventions are recommended in current evidence-based clinical guidelines for schizophrenia and
psychosis (Dixon et al., 2010; National Institute for Health and Care Excellence, 2014). There has also been increasing interest in adapting psychosocial interventions in psychosis to meet the cultural needs of specific ethnic groups (Degnan et al., 2017), including family therapy for Black Caribbean people (Edge et al., in press; Edge et al., 2016). Although there have been no efforts to adapt interventions for Black African groups in the UK, recent findings indicate that Black people with psychosis may benefit from interventions that engage and build on wider social ties, such as peer support and community based interventions (Anderson et al., 2015; Edge et al., in press). This is in line with current clinical guidelines for schizophrenia and psychosis that recommend peer support and self-management interventions for building a social support network (National Institute for Health and Care Excellence, 2014).
CHAPTER 5: Social and psychological predictors of engagement with services in Black African and Caribbean people with non-affective psychosis
5.1 Abstract

Background: Black African and Caribbean people in the UK have the highest incidence of psychosis and greatest inequalities in access to, experiences and outcomes of mental health services of all ethnic groups. Research and policies have repeatedly highlighted the need to reduce ethnic disparities and improve engagement with services among Black people with psychosis. Despite this, empirical research exploring sociocultural and psychological factors that may influence engagement amongst Black people in the UK is lacking.

Aim: To examine whether social networks and psychological factors are associated with engagement with mental health services in Black people with psychosis.

Method: A cross-sectional study was conducted with 51 Black African and Caribbean adults diagnosed with non-affective psychosis and currently in contact with mental health services in England. Measures were administered to examine relationships between social networks, illness perceptions, perceived racial or ethnic discrimination in mental health services, internalised stigma and current engagement with services from service user and staff perspectives.

Results: Social network composition (greater ethnic homogeneity) moderately correlated with better service user and staff reported engagement. Greater perceived personal control over problems was associated with better staff reported engagement. Lower perceived ethnic or racial discrimination in services, and specific illness perceptions (higher perceived treatment control, greater self-identification with psychosis
symptoms, more concern and greater emotional response related to problems) were 
associated with better service user reported engagement. Internalised stigma was not 
associated with service engagement. Multivariate regression analyses suggested that a 
more ethnically homogenous social network was the strongest predictor of better service 
user and staff reported engagement.

Conclusion: Psychosocial interventions that target social networks, perceived ethnic and 
racial discrimination in services, and illness perceptions may facilitate better 
engagement and improve outcomes. Further longitudinal studies are required to examine 
causal mechanisms between illness perceptions, social networks and future engagement.
5.2 Introduction

Schizophrenia and other psychoses are severe mental health problems associated with substantial personal, economic and social burden (The Schizophrenia Commission, 2012). Black and minority ethnic and migrant populations have the highest incidence rates of schizophrenia and other psychoses compared to majority populations (Cantor-Graae & Selten, 2005). In the UK, rates are highest among Black ethnic groups, with the incidence of narrowly-defined schizophrenia up to nine times greater in Black Caribbean people and up to six times higher in Black African people compared to White British populations (Fearon et al., 2006). Research has consistently reported that Black people have more adverse experiences and poorer outcomes of mental health services, including more involuntary hospital admissions, coercion and restraint, higher doses of medication, reduced access to psychological therapy, longer lengths of hospital stay, and higher rates of relapse and readmission (Bhui et al., 2003; Morgan et al., 2017; Morgan et al., 2004).

Previous negative experiences have been suggested to fuel negative perceptions of mental health services among Black communities, leading to fear and mistrust, and non- or dis- engagement (Keating et al., 2002; Keating & Robertson, 2004; Morgan et al., 2004). Compared to other ethnic groups, Black people are much more likely to come into contact with services at crisis point through compulsory section and the police, with repeated involuntary admissions following discharge (Keating et al., 2002; Mental Health Taskforce, 2016; The Schizophrenia Commission, 2012). Delayed access to evidence-based treatment and longer duration of untreated psychosis symptoms results
in poorer prognosis (Marshall et al., 2005; Perkins et al., 2005). Poor engagement with mental health services and treatment is problematic as it can lead to adverse outcomes, such as increases in relapse and readmission (Kreyenbuhl et al., 2009; McCann et al., 2008; Tay, 2007). Over the past few decades, Government policies have repeatedly highlighted inequalities in access to, and experiences and outcomes of services for Black people (e.g. National Institute for Health and Care Excellence, 2009), and have outlined strategies to improve engagement among minority ethnic communities (e.g. Department of Health, 2005; National Institute for Mental Health, 2003). However, there has been little improvement, as highlighted in a recent report by the Mental Health Task Force (2016) that described the ‘systemic failure’ of mental health care for Black African and Caribbean people in the UK. It is therefore crucial to conduct further work to improve our understanding of factors that are associated with better engagement in Black people to inform psychosocial interventions and improve mental health service provision for this disadvantaged group.

There is a lack of empirical research examining social and psychological processes associated with engagement with services in Black African and Caribbean people with psychosis in the UK. Research investigating predictors of engagement in minority ethnic populations has primarily focused on initial access to care or help-seeking, which is suggested to include first contact and continued engagement with services (Kovandžić et al., 2011; Morgan et al., 2004). Negative pathways to care and help-seeking amongst Black people have been suggested to result from sociocultural processes, rather than ethnic differences in clinical presentation (Keating & Robertson, 2004; Morgan et al.,
It has been proposed that help-seeking should be analysed within the context of social relations, where significant others offer advice, information, beliefs and support that influence how individuals define and respond to mental health problems (Morgan et al., 2004; Perry & Pescosolido, 2015). Observational studies show that family members can facilitate early help-seeking for psychosis (Cole et al., 1995; Del Vecchio et al., 2015). There is also evidence that a larger number of social contacts is associated with a reduced likelihood of accessing care via acute services (Becker et al., 1997; Bhui et al., 2014), and shorter duration of untreated psychosis (Bhui et al., 2014; Jeppesen et al., 2008; Larsen et al., 1998). Social network members are reported to facilitate access through helping to identify problems, recognising the need for formal care, and providing information and practical support to secure access to services (Kovandžić et al., 2011).

Social networks can be defined as a set of social relations that form connections between individuals (Crossley et al., 2015). Recent meta-analytic findings (Chapter 3) suggest that having more people in the social network is associated with improved outcomes in people diagnosed with schizophrenia, including negative symptoms and social functioning. However, consistent with earlier research (Siette et al., 2015), the review highlighted marked heterogeneity relating to the definition and measurement of social networks in psychosis research. For example, many studies conflate the concept of social network with social support and set upper limits when measuring the size of networks (Palumbo et al., 2015; Siette et al., 2015). Moreover, most studies in the review did not consider potential mechanisms by which larger social networks related to
improved symptomatic and functional outcomes in psychosis; with only two of the 16 reviewed studies suggesting relationships may be partially explained by reduced stigma (Sibitz et al., 2011) and improved social skill (Macdonald et al., 1998), respectively.

There has been limited research into social networks and current engagement in psychosis. Findings from a mixed methods study showed that having more cohesive social network (defined as at least three people who are all connected with ‘mutual cooperation’) was related to early referral to services and more sustained service use in severe mental health problems (Carpentier & White, 2002). The authors suggested more cohesive networks allowed for easier recognition of symptoms and access to services. However, larger and more cohesive social networks may not necessarily equate to greater levels of social support (Gayer-Anderson & Morgan, 2013; Thoits, 2011). For example, it is well established that stressful or critical interactions can increase risk of relapse and hospital readmission in schizophrenia (Butzlaff & Hooley, 1998). There is some research to suggest that networks of moderate size and density (or interconnectedness) may be most beneficial for outcome (Becker et al., 1998; Dozier et al., 1987; Goldberg et al., 2003). This is perhaps because they are more manageable whilst providing access to outside resources not available in more densely interconnected networks (Albert et al., 1998).

There has been some qualitative research in Black minority ethnic groups to suggest that stigma, racial or ethnic discrimination, and beliefs about mental illness existing within social networks may influence engagement. Social networks of Black individuals may reduce help-seeking when they involve negative beliefs about mental health treatment or
services, fuelled by previous adverse experiences (Morgan et al., 2017; Morgan et al., 2004). Despite policy initiatives to improve engagement (e.g. National Institute for Mental Health, 2003), increasing reports of unfair treatment and mistrust have been found in people of Black ethnic backgrounds (Henderson et al., 2015). Reports from Black and minority ethnic communities suggest that individuals often internalise the negative experiences of others generated through storytelling in social networks, which prevents future help-seeking for mental health problems (Kovandžić et al., 2011). Black Caribbean people in the UK have reported avoiding services due to perceived discrimination and expectations of racist maltreatment (Mclean et al., 2003). Beliefs relating to mental health problems and professional mistreatment might mean that Black people are more likely to access support from informal social networks (e.g. family, friends, spiritual or community support) rather than mainstream services (Obasi & Leong, 2009).

The most widely cited model of illness beliefs is the social cognitive Self-Regulation Model (Leventhal et al., 1984). The SRM views individuals as active problem solvers in the treatment process whose coping responses are guided by emotional and cognitive representations of their illness. The SRM has been successfully applied to severe mental health problems, with a systematic review showing associations between specific illness perceptions and outcomes (Baines & Wittkowski, 2013). For example, the belief that symptoms have more negative consequences have been shown to independently predict greater depression and lower perceived quality of life over a 6 month period in people with a diagnosis of schizophrenia (Lobban et al., 2004). Only one study has examined
the relationship between illness perceptions and service engagement in psychosis and
found that a more coherent understanding of problems, fewer perceived negative
consequences, perceptions that treatment can help and greater perceived personal
control are related to better self-reported engagement (Williams & Steer, 2011). Similar
SRM illness perceptions have also been related to medication adherence in severe
mental health problems (Broadbent et al., 2008; Watson et al., 2006; Williams & Steer,
2011). It is plausible that people of Black ethnicity have different illness perceptions that
are related to their engagement with mental health services. However, the application of
the SRM in Black people with psychosis is yet to be tested.

There is qualitative evidence to suggest that high levels of stigma and taboo surrounding
mental health problems in Black and minority ethnic communities may be a barrier for
seeking professional help (Kovandžić et al., 2011; Mantovani et al., 2017; Shefer et al.,
2013). Stigma is a common experience in psychosis (The Schizophrenia Commission,
2012; Wood et al., 2014), and has been reported to be higher in Black compared to
White non-clinical populations (Anglin et al., 2006). Public stigma describes the
negative societal messages and stereotypes relating to individuals diagnosed with mental
illness (Corrigan & Watson, 2007). The internalisation of these stigmatising views
(internalised stigma or self-stigma) is related to reduced self-esteem, psychological
distress and can impede recovery (Link, Struening, Neese-Todd, Asmussen, & Phelan,
2001; Livingston & Boyd, 2010). A recent systematic review found that higher
internalised stigma was associated with reduced help-seeking across clinical and non-
clinical samples, and that this effect was enhanced for minority groups (Clement,
Schauman, et al., 2015). Findings from qualitative syntheses in the review suggested that preference for non-disclosure and anticipatory negative consequences were factors underlying the relationship (Clement, Schauman, et al., 2015). However, the review highlighted that further research is needed to better understand the links between stigma and engagement in minority ethnic communities.

The overall aim of the present study was to examine whether social networks and psychological factors are associated with engagement in Black African and Caribbean people diagnosed with non-affective psychosis currently receiving care in UK mental health services. The present study reports on the same sample used in an earlier study conducted by the present authors. The earlier study examined the social network characteristics of Black African and Caribbean people with psychosis (Chapter 4). There has been no previous research examining the ethnic composition of social networks and their relationship with current engagement with services in this population. On a macro-level, ethnically dense minority communities have been found to be protective in psychosis and reduce distress (Becares et al., 2009; Das-Munshi et al., 2012), but can have adverse effects when mediated by perceived social disadvantage (Reininghaus et al., 2010). In line with this view, it was hypothesised that networks with greater ethnic homogeneity may lead to poor engagement when there are negative beliefs about illness and treatment, and high perceived discrimination and stigma related to being part of that particular ethnic group. This study will be the first to assess whether inter-individual variation in size, density and ethnic composition in the social networks of Black people with psychosis, relates to their engagement with mental health services.
The first objective was to examine cross-sectional associations between current engagement with services and social networks, illness perceptions, internalised stigma, and perceived ethnic or racial discrimination in mental health services. Based on previous research, it was hypothesised that higher perceived discrimination and internalised stigma, and specific illness perceptions (i.e. more negative consequences, less coherent understanding, less perceived treatment and personal control, greater identity, concern and emotional distress) would be related to poorer engagement. It was also hypothesised that larger and more interconnected and ethnically homogenous social networks with would be associated with better engagement with mental health services. The second objective was to conduct non-linear comparisons between social networks (size and density) and engagement to determine whether a curvilinear relationship existed. This was based on previous findings suggesting that networks of moderate size and density may be more beneficial for outcome (e.g. Dozier et al., 1987; Goldberg et al., 2003). The third objective was to test two separate models to examine key social and psychological variables that were hypothesised to predict service engagement from the staff and service user perspective, respectively, whilst adjusting for potential clinical or sociodemographic confounders. The fourth and final objective was to explore whether psychological processes (e.g. illness perceptions) mediated the relationships between potential predictor variables (e.g. social networks) and engagement with services.
5.3 Method

5.3.1 Participants

Participants were recruited to the study based on the following eligibility criteria:

i. A primary diagnosis of schizophrenia or non-affective psychosis (ICD-10 F20-29 or DSM-5) according to clinical case notes


iii. Aged 18 years or above

iv. English speaking to complete study measures

v. Currently under the care of a mental health professional for at least one month

Participants were excluded if they had a primary substance abuse diagnosis, a significant cognitive impairment was implicated in aetiology (e.g. organic disorder), or if they were assessed by clinicians being too unwell and lacking capacity to participate.

Participants were recruited by the lead author (AD) via self-referral or through their clinical teams from National Health Service (NHS) inpatient wards, rehabilitation units and community services (early intervention services and community mental health teams) and third sector organisations in Greater Manchester. Participants were also
recruited by trained research staff as part of a National Institute for Health Research (NIHR) feasibility trial led by the senior author (Edge et al., 2016).11

Of the 84 participants referred, 51 (60.71%) consented to participate. Only five (9.62%) participants dropped out during the study. No data was available for one participant who withdrew post-consent due to worsening symptoms. Four participants completed some measures but were lost to attrition after the first assessment visit; two lost contact, one relapsed and the other was imprisoned.

5.3.2 Measures

Service engagement

The Service Engagement Scale (SES) (Tait et al., 2002) is a questionnaire measure of service user engagement from a staff member perspective. The SES includes 14 items which comprise four subscales: availability; collaboration; help-seeking; and treatment adherence. The SES has been validated in psychosis samples (Tait et al., 2002) and the total score showed good internal consistency in the current study (α = .79).

The Singh O’Brien Level of Engagement Scale (SOLES) (O’Brien, White, et al., 2009) is a 16-item self-reported measure of engagement with services. The SOLES comprises two subscales: acceptance for need of treatment; and perceived benefit of treatment.

11 The full title of the study is ‘Culturally-adapted Family Intervention (CaFI) for African-Caribbeans diagnosed with schizophrenia and their families: a feasibility study of implementation and acceptability’. The study was funded through the NIHR Health Service and Delivery Research (HS&DR) programme (project ref: 12/5001/62).
Higher total scores were reversed for this study to be consistent with SES. Cronbach’s alpha coefficient for SOLES total in the present study was $\alpha = .88$.

*Social network mapping interview*

Network mapping semi-structured interviews collected information regarding participants’ social networks (Crossley et al., 2015). This study used a modified version of the personal wellbeing network (PWN) interview which was developed for the NIHR-funded Community Health Networks study conducted at the McPin foundation, London (Pinfold et al., 2015) [Appendix VII]. The PWN has demonstrable face validity (Sweet et al., in press) and similar network mapping interviews have established reliability (Siette et al., 2015). A number of different structural, compositional and transactional social network variables can be generated from this network mapping interview (Chapter 4). For the purpose of this study, three network variables were measured: *network size* (number of people in the network), *network density* (interconnectedness) and *network homophily* (the extent to which one forms relationships with individuals who are similar to themselves). The name generator approach (Campbell & Lee, 1991) was used to obtain an exhaustive list of people in the participant’s social network. This included nine questions that focused on different types of social interaction between the participant and their social network members (e.g. *who are the people you enjoy seeing or spending time with?*), with a final question asking the participant to list anyone in their social network who they have not yet recalled to ensure saturation was reached. Participants were instructed to recall people with whom they
have regular contact or an important or meaningful relationship. There was no upper limit on the number of people participants could recall.

To gather information on the density (or interconnectedness) of the network, participants were supported to draw lines between those people who knew one another. Density is calculated by dividing the number of actual connections between network members by the number of potential connections. Scores range from 0-1, with higher scores indicating higher densities.

The external-internal (EI) index (Krackhardt & Stern, 1988) was used to measure social network ethnic homophily. The EI index calculates the number of social connections in a different group (external social ties) minus the number of connections in the same group (internal social ties) divided by the total number of connections. The EI index ranges from -1 (all social ties in same group) to 1 (all social ties in different group). Negative (or lower) scores indicate greater homophily or a greater tendency for people to form relationships with people of a similar ethnic group to their own (positive (or higher) scores indicate greater ethnic heterophily, tendency for people to form relationships with people of a different ethnic group to their own). Participants were asked to report the ethnic background for each person listed and these were categorised into ‘Black African’, ‘Black Caribbean’ and ‘other’. Lower EI index scores equate to a more ethnically homophilous network (i.e. more social ties of the same ethnic background). The interview takes around 45-90 minutes depending upon the number of people
recalled and the participants’ cognitive abilities. Two trained postgraduate researchers (AD and LS\textsuperscript{12}) conducted the interviews.

*Illness perceptions*

*The Brief Illness Perception Questionnaire* (Brief-IPQ) (Broadbent et al., 2006) is a self-report measure of illness perceptions. The Brief-IPQ is derived from the lengthier Illness Perception Questionnaire (Weinman et al., 1996) which is based on the SRM (Leventhal et al., 1984). The IPQ was originally developed for physical health problems but has been modified for mental health problems, including schizophrenia (IPQ-S) (Lobban et al., 2005a). Items of the IPQ-S have been combined to compute an overall score which gives an idea of how negative the overall illness model is (Lobban, Barrowclough, & Jones, 2006). The Brief-IPQ includes nine items: five cognitive representations (consequences, timeline, personal control, treatment control and identity); two emotional representations (concern and emotional representation); and one comprehensibility (coherence). Higher scores indicate greater perceived negative consequences, a more chronic timeline, greater perceived personal control and belief that treatment can help with problems, greater identity with symptoms, higher levels of concern and emotional representation, and a less coherent understanding of one’s mental health problems (Broadbent et al., 2006; Lobban et al., 2006). Based on feedback from a service user and

\textsuperscript{12} At the time of the study, LS was a Trainee Clinical Psychologist in Greater Manchester who was conducting her research project as part of the CAFI trial at The University of Manchester. AD was the trial manager for the full duration of the study.
carer research advisory group\textsuperscript{13}, the wording on the BIPQ was adapted to be more user-friendly (whilst retaining the integrity of the item) and the term ‘illness’ was replaced with ‘mental health problem’.

\textit{Racial or ethnic discrimination in mental health services}

A measure of perceived racial or ethnic discrimination in NHS mental health services was developed specifically for this study. This was because existing measures focused on African American samples and were not deemed culturally relevant to the experiences of Black people in healthcare settings in the UK (for review of measures, see Bastos et al., 2010; Kressin et al., 2008). The Perceived Discrimination Measure (PDM) was informed by an advisory group of service users, carers and community members. The PDM includes two items: 1) \textit{NHS mental health services discriminate against people (treat people unfairly) because of their racial/ethnic background}; and 2) \textit{NHS mental health services discriminate against me (treat me unfairly) because of my racial/ethnic background}. Participants are asked to rate these statements on a Likert scale ranging from 1 (\textit{strongly disagree}) to 5 (\textit{strongly agree}). The Spearman Brown coefficient for the two items of the PDM in this study was .89.

\textsuperscript{13} AD co-chaired the Research Advisory Group (RAG) with a service user consultant (PG) as part of the CAFI feasibility trial. The CAFI RAG comprised seven additional service user, carer and community members of African-Caribbean background.
Internalised stigma

The Internalised Stigma of Mental Illness (ISMI) scale (Ritsher et al., 2003) is a 29-item self-report measure with five subscales: alienation, stereotype endorsement, discrimination experiences, social withdrawal and stigma resistance. Higher scores indicate higher internalised stigma. Cronbach’s alpha coefficient for the ISMI total score was $\alpha = 0.87$.

Psychosis symptom severity

The Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987) is a widely used 30-item semi-structured clinical interview designed to provide a standardised assessment of positive, negative and general psychopathology symptoms in schizophrenia during the previous week. Higher scores indicate greater symptom severity. Two researchers (AD and LS) were trained to conduct and rate the PANSS; intraclass correlation coefficients (ICCs) for the subscales and total scores ranged from .82 to .95. The PANSS total showed good internal consistency in the present study, with a Chronbach’s alpha coefficient of $\alpha = .83$.

Sociodemographic variables

Service user sociodemographic information (Table 9) was collected via a self-report questionnaire which was verified by their key worker and clinical case notes.
5.3.3 Procedure

Ethical approval was obtained by the NHS Research Ethics Committee (15/NW/0086). Service users were invited to attend an appointment with the study researcher (AD or LS) at a location of their choice (e.g. at home, local community centre or NHS service). During their individual appointments, service users and key workers were supported to go through the participant information sheet [Appendices I and III], provide informed consent [Appendices II and IV] and complete study measures. Key workers met with the researchers no later than two weeks following service user consent. To reduce burden, service users were given the option to complete the PANSS and network interviews in separate assessments within a two-week time interval.

5.3.4 Data analysis

SPSS version 22 (IBM Corp, 2015) was used to analyse the data. UCINET (Borgatti et al., 2002) was used to calculate network ethnic homophily for each participant. Descriptive statistics were calculated for all measures. Skewness and kurtosis z scores were assessed for normality, with a non-normal distribution indicated by scores falling outside the range of -1.96 to 1.96. Data that were skewed were transformed for correlational analyses. Geometric means were calculated for log-transformed data (i.e. network size, network ethnic homophily). Medians are presented for squared data (i.e. SES total) and data that could not be transformed (i.e. BIPQ treatment control, concern, coherence). Pearson correlation coefficients were used for normally distributed continuous data and Spearman for skewed data. One-way ANOVAs and t-tests or non-
parametric alternatives (Kruskal-Wallis and Mann-Whitney U) were used to examine associations between continuous measures and categorical sociodemographic data (Table 9). One participant with no data was excluded from the analysis (i.e. listwise deletion). If participants had \( \leq 20\% \) missing data on a specific measure, the missing item(s) was replaced with the mean score for that measure. One-way ANOVAs and \( t \)-tests showed no differences in clinical and sociodemographic variables between the sample with and without participants with missing data \((p <.05)\).

To analyse the possibility of a non-linear relationship between the structure of social networks and engagement with services, the sample was grouped according to quintiles for network size and density [Appendix XIV]. One-way ANOVAs (\( F \) ratios) followed by linear and quadratic (non-linear) contrasts were conducted in SPSS to examine overall group differences and whether any significant main effects could be explained by differences between specific quintiles.

Multiple linear regression was used to examine whether significant independent variables (IVs) were associated with service user (SOLES total) and staff reported (SES total) engagement. Due to the small sample size (\( n=47 \)), only three IVs were added into the regression model (i.e. adhering to the general rule of thumb of 10 participants per predictor variable (Austin & Steyerberg, 2015; Harrell, Lee, & Mark, 1996; Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996). Two separate models were tested for SOLES and SES, adjusting for potential clinical and sociodemographic confounders that correlated with these variables. Mediation analysis was used to explore potential pathways by which social networks might be related to engagement. To test the
assumptions for a mediational analysis, a number of linear regression analyses were conducted to examine relationships between independent variables (IV) (e.g. social networks), potential mediators (M) (e.g. illness beliefs, stigma) and dependent variables (DV) (i.e. engagement) (Hayes, 2013). Mediation analysis was conducted using the Process macro for SPSS (Hayes, 2013). Bootstrapping with 5,000 random samples was used to examine indirect effects (i.e. the effect of the IV on the DV via the mediator), with significant effects observed when the 95% confidence intervals (CI) does not cross the point of null effect (Hayes, 2013). Bootstrapping is a robust method for detecting effects in small samples and for non-normal distributions (Cheung & Lau, 2007; Preacher & Hayes, 2004).

5.4 Results

5.4.1 Sample characteristics

Clinical and sociodemographic characteristics for the full sample are presented in Table 9. Of the 51 participants, there were 36 males (70.6%) and 15 females (29.4%). The mean age was 42.38 years (range= 19-81). Thirty-seven (72.5%) were of Black Caribbean and 14 (27.5%) of Black African background. Around half (55.3%) of the sample were born in the UK and the other half abroad in a Caribbean (19.1%) or African (25.5%) country. Eighty-four percent had received a formal clinical diagnosis on the schizophrenia spectrum and 17.6% experienced non-affective psychosis. Mean PANSS total scores suggest the present sample was mildly to moderately unwell (PANSS total; mild= 58; moderate= 75) (Leucht et al., 2005). Participants were recruited mostly from
CMHTs (59%), followed by acute inpatient (17.6%) and rehab (17.6%), EIS (4%) and third sector (4%). Nineteen (41.3%) had known their key worker for under 12 months, 15 (32.6%) between one and five years, and 12 (21.1%) over five years.

5.4.2 Descriptive statistics

Descriptive characteristics (means, standard deviations, range) for all measures are presented in Table 10. Higher severity of symptoms (PANSS total) was significantly related to poorer staff reported engagement (SES) (Table 11). No other sociodemographic or clinical confounders significantly related to SOLES or SES ($p < .05$).
<table>
<thead>
<tr>
<th><strong>Characteristics</strong></th>
<th><strong>Counts/Percentages</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years), mean (SD)</strong></td>
<td>42.38(13.01)</td>
</tr>
<tr>
<td><strong>Gender, Female n (%)</strong></td>
<td>15(29.4)</td>
</tr>
<tr>
<td><strong>Ethnicity, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>33(64.7)</td>
</tr>
<tr>
<td>Black African</td>
<td>12(23.5)</td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td>4(7.8)</td>
</tr>
<tr>
<td>White and Black African</td>
<td>2(3.9)</td>
</tr>
<tr>
<td><strong>Employment, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Unemployed/long term sickness or disability</td>
<td>39(83.0)</td>
</tr>
<tr>
<td>Employed/student/volunteer</td>
<td>8(17.0)</td>
</tr>
<tr>
<td><strong>Education, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>High school education</td>
<td>27 (57.4)</td>
</tr>
<tr>
<td>Other/no qualifications</td>
<td>20 (42.6)</td>
</tr>
<tr>
<td><strong>Marital status, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Married/cohabiting</td>
<td>6(13.0)</td>
</tr>
<tr>
<td>Single/divorced/separated</td>
<td>40(87.0)</td>
</tr>
<tr>
<td><strong>Diagnosis, n (%)</strong></td>
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</tr>
<tr>
<td>Schizophrenia</td>
<td>17(33.3)</td>
</tr>
<tr>
<td>Paranoid schizophrenia</td>
<td>16(31.4)</td>
</tr>
<tr>
<td>Schizoaffective disorder</td>
<td>8(15.7)</td>
</tr>
<tr>
<td>Delusional disorder</td>
<td>1(2.0)</td>
</tr>
<tr>
<td>Non-affective psychosis</td>
<td>9(17.6)</td>
</tr>
<tr>
<td><strong>Duration contact with services (years), mean (SD)</strong>^</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>17.28(13.61)</td>
</tr>
<tr>
<td><strong>PANSS, mean (SD)</strong></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>66.96 (15.92)</td>
</tr>
<tr>
<td>Positive</td>
<td>15.85 (5.72)</td>
</tr>
<tr>
<td>Negative</td>
<td>16.84 (4.60)</td>
</tr>
<tr>
<td>General</td>
<td>34.18 (8.54)</td>
</tr>
</tbody>
</table>

*Note: PANSS= Positive and Negative Symptom Scale; N=47 due to missing data, other than age, gender and ethnicity where N=51.*
Table 10.

Descriptive statistics (means, standard deviations and range) for engagement, social networks, racial/ethnic discrimination, internalised stigma, illness perceptions and psychosis symptom measures (n=51)

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>Range</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 SES Total</td>
<td>49</td>
<td>0-30</td>
<td>10.54(7.28)</td>
</tr>
<tr>
<td>2 SOLES Total</td>
<td>49</td>
<td>56-160</td>
<td>119.18(27.76)</td>
</tr>
<tr>
<td>3 SN Size</td>
<td>46</td>
<td>3-43</td>
<td>12.09(8.43)</td>
</tr>
<tr>
<td>4 SN Density</td>
<td>46</td>
<td>0-1</td>
<td>0.50 (0.25)</td>
</tr>
<tr>
<td>5 SN EH</td>
<td>46</td>
<td>-1-1</td>
<td>-0.27 (0.53)</td>
</tr>
<tr>
<td>6 ISMI Total</td>
<td>49</td>
<td>32-103</td>
<td>63.41(16.05)</td>
</tr>
<tr>
<td>7 PDM Total</td>
<td>49</td>
<td>2-10</td>
<td>5.73(2.64)</td>
</tr>
<tr>
<td>8 BIPQ Consequences</td>
<td>47</td>
<td>0-10</td>
<td>6.53(3.18)</td>
</tr>
<tr>
<td>9 BIPQ Timeline</td>
<td>47</td>
<td>0-10</td>
<td>6.02(3.53)</td>
</tr>
<tr>
<td>10 BIPQ Personal Control</td>
<td>47</td>
<td>0-10</td>
<td>5.66(3.27)</td>
</tr>
<tr>
<td>11 BIPQ Treatment Control</td>
<td>47</td>
<td>0-10</td>
<td>7.28(2.91)</td>
</tr>
<tr>
<td>12 BIPQ Identity</td>
<td>47</td>
<td>0-10</td>
<td>5.96(3.34)</td>
</tr>
<tr>
<td>13 BIPQ Concern</td>
<td>47</td>
<td>0-10</td>
<td>6.70(3.77)</td>
</tr>
<tr>
<td>14 BIPQ Coherence</td>
<td>47</td>
<td>0-10</td>
<td>7.04(2.91)</td>
</tr>
<tr>
<td>15 BIPQ Emotional Response</td>
<td>47</td>
<td>0-10</td>
<td>6.09(3.15)</td>
</tr>
</tbody>
</table>

Note: SES= Service Engagement Scale; SOLES= Singh O'Brien Level of Engagement Scale; SN=social network; EH =ethnic homophily; ISMI=Internalised Stigma of Mental Illness Scale; PDM=Perceived Discrimination Measure; BIPQ=Brief Illness Perception Questionnaire; PANSS= Positive and Negative Symptom Scale; Bold italicised values = skewed data; Geometric mean log-transformed variables: size=9.65, network ethnic homophily=0.11; Median scores: SES total=8 (square root transformation); BIPQ treatment control=8, BIPQ concern=8, and BIPQ coherence=8 (slight negative skew).
5.4.3 Relationships between social networks and engagement

Associations between continuous measures can be found in Table 11. Consistent with predictions, greater social network ethnic homophily (i.e. more ethnically homogenous social network) was significantly associated with better engagement on the staff reported SES and service-user reported SOLES. That is, the more people of the same ethnic background in the social network than not, the better the engagement with mental health services. Hypotheses relating to social network size and density were not supported; with no evidence for associations (linear or curvilinear) with engagement with services. Table for non-linear analyses between networks and engagement can be found in the appendices [Appendix XIV]. Non-linear analyses examined differences between five subgroups of social network size and density in terms of service user and staff reported engagement (SOLES and SES). Statistical comparisons were made between five subgroups or (quintiles) of social network size (i.e. number of social contacts: 3-6; 7-9; 10; 11-14; 15-43) and density (i.e. 0-0.25; 0.26-0.39; 0.40-0.56; 0.57-0.73; 0.74-1.0). Contrary to predictions, one-way ANOVAs (with linear and quadric contrasts) showed no overall significant group differences between quintiles of social network size or density in terms of total scores on the SES \(F(4,41)=0.76, p=.557\); \(F(4,41)=0.66, p=.623\), and SOLES \(F(4,41)=0.70, p=.598; F(4,41)=0.88, p=.484\).

5.4.4 Relationships between illness beliefs, stigma, discrimination and engagement

BIPQ illness perceptions were related to engagement in predicted directions. Higher BIPQ perceived personal control was significantly related to better staff reported
engagement (SES), and higher scores on BIPQ treatment control, identity, concern and emotional response were significantly moderately associated with better service-user reported engagement (SOLES). However, BIPQ timeline, negative consequences and coherence were not associated with engagement. In line with hypotheses, there was a significant correlation between higher perceived ethnic or racial discrimination in services (PDM) and poorer service-user reported engagement (SOLES). Contrary to predictions, internalised stigma (ISMI) was not related to staff or service user engagement (SES or SOLES). Scores on SES and SOLES were not significantly correlated.
Table 11

Correlations between engagement, social networks, internalised stigma, racial/ethnic discrimination, illness perceptions and psychosis symptoms (n=47)

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<td>.04</td>
<td>.30*</td>
<td>- .04</td>
<td>.32*</td>
<td>- .13</td>
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<td>.17</td>
<td>- .41**</td>
<td>- .17</td>
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<td>- .23</td>
<td>.02</td>
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<td>- .22</td>
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<td>- .20</td>
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<td>- .31*</td>
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</tbody>
</table>

Note: SES= Service Engagement Scale; SOLES= Singh O’Brien Level of Engagement Scale; Higher scores=poorer engagement; SN= social network; EH= ethnic homophily; ISMI= Internalised Stigma of Mental Illness Scale; PDM= Perceived Discrimination Measure; PANSS= Positive and Negative Symptom Scale; BIPQ= Brief Illness Perception Questionnaire; C= consequence, T= timeline; PC= personal control; TC= treatment control; I= identity; CON= concern; COH= coherence; ER= emotional response; SES total SQRT transformed; Social Network Size and Ethnic Homophily= LOG transformed; Italicised values= Spearman’s correlations for untransformed/skewed data, BIPQ treatment control, concern and coherence; Due to varying missing data across study measures, samples sizes ranged from n=45 to n=47. Bold*= significant at p<.05; Bold** = significant at p<.01.
5.4.5 Models to predict engagement with services

A model to predict service user reported engagement

Based on their significant associations with SOLES, the IVs included in the model to predict service user reported engagement were network ethnic homophily, PDM discrimination in services and BIPQ illness perceptions. Due to the small sample size, BIPQ treatment control was entered into the model, based on previous literature suggesting its importance for engagement and outcomes in psychosis (Baines & Wittkowski, 2013; Williams & Steer, 2011). No clinical or sociodemographic variables were added into the model as none were significantly correlated with engagement. The predictors were entered simultaneously into the model due to limited evidence on the relative importance of these novel measures in predicting engagement. The overall regression model was significant and explained 30% of the variance in service user reported engagement, $F(3, 42)= 6.12$, $p= .001$, $R^2= .30$ (Table 12). Direct effects indicated that network ethnic homophily was independently associated with engagement, but BIPQ treatment control and PDM perceived racial or ethnic discrimination in services did not significantly contribute to the model.
### Table 12

**A model to predict service-user reported engagement with services (SOLES), with social network ethnic homophily, illness perceptions and racial/ethnic discrimination as independent variables (n=46).**

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>CI (95%)</th>
<th>β</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>SN EH</td>
<td>20.33</td>
<td>7.23</td>
<td>5.73</td>
<td>34.92</td>
<td>.39</td>
</tr>
<tr>
<td>BIPQ-TC</td>
<td>-2.50</td>
<td>1.27</td>
<td>-5.05</td>
<td>0.05</td>
<td>-.27</td>
</tr>
<tr>
<td>PDM</td>
<td>0.54</td>
<td>1.52</td>
<td>-2.53</td>
<td>3.61</td>
<td>.05</td>
</tr>
</tbody>
</table>

*Note: SN EH=Social Network Ethnic Homophily LOG transformed; BIPQ-TC= Brief Illness Perception Questionnaire - Treatment Control; PDM= Perceived Discrimination Measure; B=unstandardized regression coefficients; SE B =standard error of B; CI= confidence interval for B; β= standardised coefficient Beta; significant at * p<.01; *p<.001.*

### Table 13

**Linear regression analyses to test assumptions for two hypothesised models for mediation pathways from predictor variables to service user reported engagement (n=46)**

<table>
<thead>
<tr>
<th>Model (path)</th>
<th>Outcome</th>
<th>Variables</th>
<th>B</th>
<th>SE B</th>
<th>CI (95%)</th>
<th>β</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1(c)</td>
<td>SOLES</td>
<td>SN EH</td>
<td>24.61</td>
<td>6.84</td>
<td>10.83</td>
<td>38.38</td>
<td>.48</td>
</tr>
<tr>
<td>1(b)</td>
<td>SOLES</td>
<td>PDM</td>
<td>3.42</td>
<td>1.45</td>
<td>0.47</td>
<td>6.37</td>
<td>.32</td>
</tr>
<tr>
<td>1(a)</td>
<td>PDM</td>
<td>SN EH</td>
<td>0.08</td>
<td>0.03</td>
<td>0.02</td>
<td>0.14</td>
<td>.38</td>
</tr>
<tr>
<td>1(c’)</td>
<td>SOLES</td>
<td>SN EH</td>
<td>22.31</td>
<td>7.40</td>
<td>7.38</td>
<td>37.23</td>
<td>.43</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PDM</td>
<td>1.27</td>
<td>1.53</td>
<td>-1.81</td>
<td>4.34</td>
<td>.12</td>
</tr>
<tr>
<td>2(c)</td>
<td>SOLES</td>
<td>PDM</td>
<td>3.42</td>
<td>1.45</td>
<td>0.47</td>
<td>6.37</td>
<td>.32</td>
</tr>
<tr>
<td>2(b)</td>
<td>SOLES</td>
<td>BIPQ TC</td>
<td>-3.50</td>
<td>1.28</td>
<td>-6.08</td>
<td>-0.93</td>
<td>-.38</td>
</tr>
<tr>
<td>2(a)</td>
<td>BIPQ TC</td>
<td>PDM</td>
<td>-0.35</td>
<td>0.16</td>
<td>-0.68</td>
<td>-0.03</td>
<td>-.31</td>
</tr>
<tr>
<td>2(c’)</td>
<td>SOLES</td>
<td>PDM</td>
<td>1.92</td>
<td>1.53</td>
<td>-1.17</td>
<td>5.01</td>
<td>.18</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BIPQ TC</td>
<td>-2.99</td>
<td>1.34</td>
<td>-5.68</td>
<td>-0.30</td>
<td>-.32</td>
</tr>
</tbody>
</table>

*Note. Model assumptions: path c= x variable predicts y; path b= mediator variable predicts y; path a= x variable predicts mediator; path c’= x variable no longer predicts y or is lessened predicting y. SOLES= Singh O’Brien Level of Engagement Scale; SN EH=Social Network Ethnic Homophily LOG transformed; PDM= Perceived Discrimination Measure; BIPQ TC= Brief Illness Perception Questionnaire, treatment control; B=unstandardized regression coefficients; SE B =standard error of B; CI= confidence interval for B; β= standardised coefficient Beta; significant at * p<.01; *p<.001.*
Exploratory mediational analyses examined potential pathways by which the predictor variables might lead to service user reported engagement (SOLES). A number of separate linear regression analyses were carried out to further explore the relationships between variables in the model that were significantly correlated (Table 11) and to identify potential mediatory pathways.

Model one (Figure 4) suggested that social network ethnic homophily (IV) predicted service user reported engagement (DV) via perceived ethnic or racial discrimination in mental health services (M). Based on the direction of significant associations, model one proposed that a more ethnically diverse network leads to poorer engagement through greater perceived ethnic or racial discrimination in services. As shown in Table 13 network ethnic homophily significantly predicted SOLES engagement ($F(1, 44)= 12.95, p= .001, R^2=.23$) and ethnic or racial discrimination ($F(1, 44)=1.76, p=.010, R^2= 0.14$), and, together, network ethnic homophily and ethnic or racial discrimination significantly predicted SOLES engagement ($F(2, 43)= 6.78, p=.003, R^2=.24$). However, when ethnic or racial discrimination was entered into the model, the effects of network ethnic homophily on SOLES engagement remained significant and did not lessen but, conversely, strengthened. This suggests that the mediational pathway proposed in model one was not present and therefore no further analyses were conducted.
Model two (Figure 5) proposed that perceived ethnic or racial discrimination in mental health services (IV) predicted service user reported engagement (DV) via BIPQ treatment control (M). Based on theoretical assumptions and correlations coefficients (Table 11), greater perceived ethnic or racial discrimination was hypothesised to lead to poorer engagement through lower perceived benefits of treatment. Separate linear regressions suggested mediation may be present (Table 13). Ethnic or racial discrimination significantly predicted SOLES engagement \( F(1, 47) = 5.45, p = .024, R^2 = .10 \) and BIPQ treatment control \( F(1, 45) = 4.67, p = .036, R^2 = .09 \), and BIPQ treatment control predicted SOLES engagement \( F(1, 45) = 7.49, p = .009, R^2 = .14 \). When BIPQ treatment control was included as a predictor, the overall model retained significance but the effects of ethnic or racial discrimination became non-significant \( F(2, 44) = 4.58, p = .016, R^2 = .17 \). Mediation analysis was therefore conducted using the Process macro (Hayes, 2013) to examine the indirect (mediated) pathways between ethnic or racial discrimination, BIPQ treatment control and SOLES engagement. Results suggested no significant mediation of BIPQ treatment control; the indirect effect was not
significant as indicated by the 95% bootstrapped confidence interval (BCa CI) crossing zero ($B=1.05 (SE B=0.78); 95\% \text{ BCa CI}= -0.01 - 3.34$).

**Figure 5.**

*Model 2: proposed mediation model to predict service user engagement*

*A model to predict staff reported engagement*

Social network ethnic homophily and BIPQ personal control were included in the multivariate regression model with staff reported engagement (SES) as the outcome variable. PANSS total was included as a covariate given its significant relationship with SES. Hierarchical regression was used with the control variable, PANSS total, entered in the first block and the predictors BIPQ person control and network ethnic homophily in the second block (Table 14). The overall regression models for both blocks were significant. The first model with PANSS symptoms explained 14% of the variance in staff reported engagement ($F(1, 44)=7.07, p= .011, R^2 = .14$) which increased to 32% of the variance when adding in the two predictors, $F(3, 42)= 6.44, p=.001, R^2 = .32, \Delta R = .18$. In the second model, network ethnic homophily was significantly positively associated with staff reported engagement but BIPQ personal control and PANSS
symptoms were no longer significant. Correlation coefficients between variables in the model suggest assumptions for mediation analyses were not met; network ethnic homophily and personal control were significantly related to PANSS and engagement but not to each other (Table 11) and therefore no further analyses were conducted.

Table 14

A model to predict staff reported engagement with services (SES), with psychosis symptoms, ethnic homophily and BIPQ personal control as independent variables (n=46).

<table>
<thead>
<tr>
<th>Block</th>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>CI (95%)</th>
<th>β</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>PANSS total</td>
<td>0.03</td>
<td>0.01</td>
<td>0.01</td>
<td>0.05</td>
<td>.37</td>
</tr>
<tr>
<td>2</td>
<td>PANSS total</td>
<td>0.02</td>
<td>0.01</td>
<td>-0.00</td>
<td>0.03</td>
<td>.22</td>
</tr>
<tr>
<td>2</td>
<td>SN EH</td>
<td>0.70</td>
<td>0.27</td>
<td>0.16</td>
<td>1.24</td>
<td>.34</td>
</tr>
<tr>
<td>2</td>
<td>BIPQ PC</td>
<td>-0.09</td>
<td>0.04</td>
<td>-0.18</td>
<td>0.00</td>
<td>-.26</td>
</tr>
</tbody>
</table>

Note: PANSS=Positive and Negative Symptom Scale; SN EH=Social Network Ethnic Homophily LOG transformed; BIPQ PC= Brief Illness Perception Questionnaire - personal control; B=unstandardized regression coefficients; SE B =standard error of B; CI= confidence interval for B; β= standardised coefficient Beta; significant at *p<.01

5.5 Discussion

This study is the first to quantitatively examine the relationships between social and psychological factors and current engagement with mental health services in Black people with psychosis in the UK. In line with predictions, social networks, illness perceptions, and perceived ethnic or racial discrimination in mental health services were significantly associated with engagement with services in Black African and Caribbean people with psychosis. However, contrary to hypotheses, internalised stigma was not related to engagement with services in this sample.
The present findings suggest that more ethnically homogenous social networks (i.e. more people of the same ethnic background in participants’ social networks than not) are moderately associated with improved engagement from both staff and service user perspectives. Greater ethnic homogeneity was a strong independent predictor of service user reported engagement. Illness perceptions (i.e. greater treatment control, identity, emotional response and concern related to problems) and higher perceived racial or ethnic discrimination in services were also significantly related to poor self-reported engagement with services. However, illness perceptions (treatment control) and racial or ethnic discrimination were not independent predictors when entered into a model with the ‘ethnic homogeneity’ social network variable. For staff reported engagement, greater ethnic homogeneity was a strong independent predictor of engagement when entered into a multivariate model, adjusting for psychosis symptoms. However, greater perceived personal control was not an independent predictor of staff reported engagement in the model.

There was no evidence that illness perceptions (i.e. personal control) mediated the relationship between ethnic homogeneity and staff reported engagement. Additionally, there was no evidence for mediatory effects of perceived racial or ethnic discrimination in the relationship between ethnic homogeneity and service-user reported engagement, or illness perceptions (i.e. treatment control) in the relationship between racial or ethnic discrimination and service-user reported engagement. These findings suggest that ethnic homogeneity operated independently to influence engagement with services. However,
the potential effects of other unmeasured variables in these relationships cannot be ruled out and additional research is required to determine causality.

It is possible that other untested psychological mechanisms may explain the relationships between ethnically homogenous social networks and service engagement in Black people with psychosis. It is possible that other characteristics potentially related to ethnic homogeneity, such as certain cultural beliefs, resources in the network, or the quality and function of relationships, may be important for engagement. Being surrounded by people who are of a similar ethnic background may facilitate an increased sense of self-identity and self-esteem (Reininghaus et al., 2010), which may improve and individual’s likelihood of engaging effectively in treatment. Although not directly tested, the current findings could be viewed as consistent with the ‘ethnic density effect’ whereby living in more ethnically-dense communities is related to reduced psychological distress (Becares et al., 2009). It has been suggested that the beneficial effects of ethnic density may be a reflection of greater levels of social network cohesion and social support that buffer individuals against the effects of adversity and racism on psychological distress (Becares et al., 2009). Focusing just on composition is suggested to limit knowledge about the social context as it is assumed that the effects of social context are only about the individuals in the network and ignores how they are structured around the individual (Crossley et al., 2015). In the current study, a more ethnically homogenous social network was significantly associated with larger and more densely interconnected networks. However, network size and density were not associated with engagement in this study. This suggests the interaction between social
network structure and ethnic composition does not account for the beneficial effects of ethnic homogeneity on engagement in the current sample.

The findings are inconsistent with previous studies showing that better help-seeking in psychosis is associated with larger and more cohesive networks (Carpentier & White, 2002) and a greater number of social connections (Albert et al., 1998; Becker et al., 1997; Bhui et al., 2014; Cole et al., 1995; Jeppesen et al., 2008; Larsen et al., 1998). Two of the latter studies (Becker et al., 1997; Bhui et al., 2014) were carried out in the UK and used good quality network measures and ethnically diverse samples. However, these two studies focused on initial access to services. Perhaps the positive influence of a larger and more cohesive social network structure on help-seeking does not persist once people have already accessed mental services. In this study, there was also no evidence for a curvilinear relationship between social network size or density and engagement. This is inconsistent with previous study findings highlighting the beneficial effects of having moderately sized and interconnected networks on outcomes (Becker et al., 1998; Dozier et al., 1987; Goldberg et al., 2003).

In line with predictions and in accordance with previous research in psychosis (Watson et al., 2006; Williams & Steer, 2011) and severe mental health problems (Broadbent et al., 2008), specific illness perceptions were related to engagement with services. Better engagement was associated with greater perceived personal control over problems, belief that treatment is helpful in controlling symptoms, and perceptions of greater concern and emotional distress. However, contrary to predictions and previous studies (Broadbent et al., 2008; Watson et al., 2006; Williams & Steer, 2011), fewer perceived
negative consequences and a more coherent understanding were not related to engagement. However, two of the latter studies (Broadbent et al., 2008; Watson et al., 2006) examined medication adherence and only Williams & Steer (2011) measured engagement as a multifaceted construct using a validated questionnaire, the Engagement Measure (Gillespie et al., 2004). The SES (Tait et al., 2002) and SOLES (O’Brien, White, et al., 2009) were used for staff and service users, respectively, in the current study, which could partially explain the discrepant findings. However, they do measure similar concepts (e.g. treatment acceptance and adherence, work alliance). Alternatively, a more coherent understanding of problems and the extent to which there are negative consequences may not be important for engagement in Black people with psychosis. Notwithstanding, these findings provide further support for the application and dimensions of the Self-Regulation Model (Leventhal et al., 1984) and suggest it may be useful in predicting in engagement in Black people with psychosis. Previous research suggests that illness perceptions independently predict outcomes over time in individuals diagnosed with schizophrenia (Lobban et al., 2004). However, the temporal relationship between illness perceptions and engagement cannot be concluded based on the present cross-sectional results and requires testing in longitudinal studies.

Higher perceived ethnic or racial discrimination in services was related to poorer service user reported engagement. This is consistent with previous reports of avoidance of mental health services in Black Caribbean communities due to fear of racist maltreatment (Mclean et al., 2003). The current findings suggest that perceptions of racism continue to effect engagement of Black service users when they are receiving
treatment in services. The significance of institutional racial discrimination in Black African and Caribbean people has been raised repeatedly in relation to their increased risk of psychosis, and coercive and adverse pathways to care (e.g. Commission for Healthcare Audit and Inspection, 2005; Department of Health, 2005; Karlsen et al., 2005; Nazroo, 2015). Others have argued that focusing on racism is unhelpful for addressing ethnic inequalities in mental health services, as this serves to reinforce stereotypes and further mistrust among Black minority groups (Singh & Burns, 2006; Singh et al., 2014; Singh et al., 2007). However, this study suggests Black service users’ perceptions of institutional racism influence how they engage with current treatment and their key mental health professional. Therefore, efforts to tackle perceived discrimination in services could improve engagement in treatment and subsequent clinical outcome.

Perceived discrimination in mental health services was not related staff reported engagement. This may suggest that service users’ perceptions of discrimination are hidden or not spoken about in professional relationships to an extent that staff do not notice changes to the working alliance or engagement in treatment. It is possible that what could be considered as overt engagement, such as attendance at appointments and medication compliance, is masking underlying negative feelings or perceptions towards services or professionals (Chase et al., 2012). On average, service users reported some perceived racial or ethnic discrimination (as indicated by mean scores falling above the middle score). Although the engagement measures were different for staff (SES: Tait et al. (2002)) and service users (SOLES: O'Brien, Fahmy, et al. (2009)), they included
similar concepts and average scores suggested that both staff and service users generally reported good engagement. It is unclear whether this relationship would be different in Black people with psychosis who are not currently engaged or have disengaged with services. It is possible that service users who staff perceived as poorly engaged are those that perceive higher racial or ethnic discrimination.

The current findings suggest that the amount of stigma experienced is not related to current engagement in mental health services in Black African and Caribbean people with psychosis. This is inconsistent with hypotheses and previous studies suggesting that internalised stigma is associated with reduced help-seeking for mental health problems (Clement, Schauman, et al., 2015). Problems with defining the stigma construct and its cultural relevance have previously been highlighted (Semrau, Evans-Lacko, Koschorke, Ashenafi, & Thornicroft, 2015; Wood, Burke, Byrne, Enache, & Morrison, 2016; Wood et al., 2015). The current sample generally reported moderate levels of stigma (indicated by mean scores at the midpoint of the scale) which may not be representative of all Black people who experience psychosis (e.g. Rathod et al., 2010). Most of the current sample had been in services for many years, with only three participants recruited from early intervention services. It is possible that higher stigma would be observed in Black people who are at earlier stages of psychosis where, for example, heightened distress and a lack of knowledge may have reduced the likelihood of disclosure and professional help-seeking (Clement, Schauman, et al., 2015; Kovandžić et al., 2011; Shefer et al., 2013).
Perceived stigma relating to mental health problems may not be relevant in this sample of Black people with psychosis, who had generally been in services for a long time. However, research suggests that experiences of stigma may be problematic if it is affected by perceptions of mental services and treatment. Mistrust of services and poor therapeutic relationships have been found to mediate the effect of experienced mental health discrimination (or received stigma) on poor engagement with community mental health services (Clement, Williams, et al., 2015). Recent theories outline the importance of the cultural context for stigma, and social networks have been suggested to act as a buffer from stigma threats (Wood, Byrne, & Morrison, 2017). It is plausible that resilience or protective factors such as self-esteem, external shame and social rank which have been shown to mediate the relationship between stigma and recovery in psychosis (Wood et al., 2017) buffered the current sample against the effects of any (received or perceived) stigma on engagement with treatment.

The study generated a few methodological considerations and suggested directions for future research. The SES (Tait et al., 2002) and SOLES (O’Brien, White, et al., 2009) were selected because they measure engagement as a multifaceted construct. The finding of no relationship between scores on the staff reported SES (Tait et al., 2002) and service-user reported SOLES (O’Brien, White, et al., 2009) could indicate that they are measuring different constructs. Previous research has found poor concordance between service user and staff reported engagement (O’Brien, Fahmy, et al., 2009; Rothman, Hedrick, Bulcroft, Hickam, & Rubenstein, 1991). Although the SES and SOLES include similar components of engagement (e.g. acceptance of the need for
treatment and working alliance), the individual items and response scales are different. The SOLES was used to measure service user reported engagement because it was deemed to be acceptable by a service user and carer research advisory group. However, future studies that aim to draw direct comparisons between staff and service user reported engagement may benefit from administering the same validated measure to both groups. The study findings suggest that service users and mental health professionals in this study had different ideas on engagement and that these are related to different social and psychological processes. Engagement is a multifaceted construct and is likely to vary according to its measurement and source. Further research would benefit from using validated self-report and observer rated measures of engagement from a range of sources, including service users, family members, community members and mental health professionals.

The sample was small with limited power to detect significant effects and increased risk of Type II error. Regression analyses allowed us to test plausible relationships and propose tentative models that could not be constructed using correlations. Given the small sample in this study and multiple testing, the correlational analysis was considered to be exploratory and generate hypotheses for future large scales studies. The convenience sampling methods may have led to selection bias for individuals that are well engaged or have positive views of mental health services and therefore the results may not generalisable to all Black people who are currently receiving treatment in mental health services. It is unclear to what extent the relationship between illness perceptions, including greater perceived benefits of treatment and personal control, and
better engagement with services may be an artefact of the recruitment pathway. There is limited research on individuals who are not in contact with mental health services (Kreyenbuhl et al., 2009). Future research would benefit from including Black people with psychosis who are not engaging well with services. It would also be useful to conduct qualitative research to examine factors that influence engagement among Black people with psychosis that are not currently accessing services.

The study was cross-sectional and therefore one cannot infer causality or the direction of the relationships between the predictor variables and engagement. It is plausible, for example, that higher perceived discrimination in mental health services leads to poorer engagement in treatment and vice versa. Longitudinal studies are needed to test causal links and whether social networks, illness perceptions and discrimination predict engagement over time in Black people with psychosis. This is particularly important as engagement has been reported to fluctuate over time (Priebe et al., 2005). It would be insightful to examine these relationships at time periods at which they are likely to change, such as at treatment initiation or hospital admission. Intervention studies could examine potential causal mechanisms linking ethnic homogeneity, illness perceptions and discrimination to engagement, and to test whether targeting these factors improves engagement in Black people with psychosis. Further qualitative studies in this population would help to explain relationships between social networks, illness perceptions and discrimination and generate hypotheses relating to potential mechanisms. Qualitative research would better our understanding by providing an in-
depth exploration of facilitators and barriers to engagement from the perspectives of Black people with psychosis and individuals involved in their care.

The use of self-report measures may have led to response bias, including social desirability or recall bias. This study developed and used a specific measure of discrimination that was not validated and included two single items. This was because there was no culturally-appropriate measure of perceived racial or ethnic discrimination for Black people in the UK (Bastos et al., 2010; Kressin et al., 2008). This draws attention to a significant gap in the literature. More comprehensive discrimination measures that are relevant to the experiences of Black people in the UK should be developed and their validity tested. Finally, beliefs about the causes of mental health problems have been associated with treatment adherence and therapeutic alliance in psychosis (for review, see Carter et al., 2016). This is a suggested avenue for future research as causal beliefs have not been examined in relation to current service engagement in Black people with psychosis.

In conclusion, this study was the first to examine the potential social and psychological predictors of engagement with services in a sample of Black individuals diagnosed with non-affective psychosis. The findings suggested that more ethnically homogenous social networks are independently associated with better engagement with services in this population. Results also suggest that specific illness perceptions, including the greater perceived personal control and the belief that treatment can help control problems, and higher perceived ethnic or racial discrimination in mental health services is related to poorer engagement with services. Future longitudinal research using large samples is
needed to test potential causal mechanisms between social networks, illness perceptions, discrimination and engagement. Interventions to improve engagement would benefit from collaborative formulations and shared individualised treatment plans that aim to build and maintain supportive social networks, enhance personal control over problems and beliefs about the benefits of treatment, and reduce perceptions of discrimination. Improving engagement with services may serve to reduce the inequalities in access, outcomes and experiences of services experienced by Black African and Caribbean people with psychosis in the UK.

**Clinical implications**

These findings have potentially important clinical implications. Psychosocial interventions should help service users to build and maintain social networks to facilitate their engagement with services. These findings support policies that aim to build links with communities to improve engagement (Department of Health, 2005). Working with Black African and Caribbean service users, families and community members may help to develop solutions about how best to engage people (Edge et al., 2016). Developing individualised shared formulations and treatment plans may help to build alliance and engagement in treatment. This would provide a platform for mental health professionals to explore service users’ views and concerns about treatment and to ensure services are meeting their needs. Cultural awareness training for mental health professionals would be beneficial to facilitate more open conversations and understanding about ethnicity and culture in services and clinical practice (Edge et al., 2016). These strategies would
help to tackle perceived institutional discrimination and lack of cultural understanding or prejudice existing in services. Given that illness perceptions are related to engagement, psychological interventions may benefit from working with service users to develop more personal control over their mental health problems and enhance their belief that treatment can help to manage their symptoms (Lobban et al., 2004).
CHAPTER 6: Discussion
6.1 Overview

This thesis had two main aims. The first aim was to systematically review the importance of social networks for outcomes in non-affective psychosis and to provide a detailed account of the network characteristics in Black African and Caribbean people diagnosed with non-affective psychosis in the UK. The second aim was to develop psychological theories to explain engagement with mental health services in this population. The Chapters featured in this thesis report on three individual papers that make significant contributions to the literature on social network characteristics and their relationships with outcomes and engagement in Black African and Caribbean people with non-affective psychosis. The present Chapter will provide a summary of the thesis findings and potential clinical implications. Following this, methodological considerations, including strengths and limitations, of the current thesis will be discussed. The Chapter will finish with recommendations for future research.

6.2 Summary of findings

6.2.3 Chapter 3

The first paper in this thesis was a systematic review and meta-analysis to examine the nature and strength of the associations between social network size and symptomatic and functional outcomes in individuals with schizophrenia-spectrum diagnoses. Previous literature reviews have been carried out on social networks and mental health outcomes (e.g. Albert et al., 1998; Buchanan, 1995). However, these were not systematic, did not analyse the strength of the relationship between specific network characteristics and outcomes, and included mixed diagnostic samples. A
comprehensive search strategy yielded 16 studies with 1,929 participants. Meta-analyses using random effects models to calculate pooled effect sizes found that larger social networks were moderately associated with improved outcomes, including lower severity of overall psychiatric symptoms and negative symptoms. There was substantial statistical heterogeneity that could not be fully explained by differences in diagnosis or the quality of social network measures. Meta-analyses found no significant association found between social network size and positive symptoms or social functioning. There was insufficient data to conduct meta-analyses on affective symptoms or quality of life. Narrative syntheses highlighted some evidence to suggest that larger network size was associated with improvements in global functioning, affective symptoms and quality of life but the findings varied across the studies. These findings were discussed in relation to study quality which suggested that differences in methodologies may have explained the discrepant findings.

The review highlighted that most of the literature to date has been cross-sectional and only three of the 16 reviewed studies were longitudinal. There was limited evidence to show that more severe symptoms predicted smaller networks (Thorup et al., 2006), and smaller networks predicted poorer functioning (Howard et al., 2000). Only two studies examined potential mechanisms by which larger social networks were related to better symptomatic and functional outcomes; via increased social skill (Macdonald et al., 1998), and stigma resistance and empowerment (Sibitz et al., 2011). This means that no firm conclusions can be drawn relating to the causal directions between network size and outcomes. The review concluded that the relationship is likely to be dynamic and bi-directional. For example, having more social contacts may reduce symptoms by buffering the effects of stress on the individual, but
symptoms such as social withdrawal may reduce an individual’s ability to maintain a large social network. Based on the findings of this review, it was recommended that longitudinal studies be conducted with more sophisticated analyses to test theoretical models and potential causal mechanisms linking social networks to outcomes. In line with previous research (Siette et al., 2015), the review reported problems with the definition and measurement of social networks in the included studies and recommended the use of more comprehensive assessment tools that measure a range of social network characteristics. Social network analysis (SNA) (Crossley et al., 2015) provides one such method as it delineates between different network characteristics, including structural (e.g. size, density or interconnectedness), compositional (e.g. type of relationship, demographic characteristics of network members), and transactional (e.g. social support, emotional closeness) (see description in methods Chapter 2.7).

6.2.4. Chapter 4

Chapter 4 provided a descriptive account of the social network characteristics of Black African and Caribbean people with non-affective psychosis in the UK. The systematic review in Chapter 3 highlighted the importance of social networks for outcomes in non-affective psychosis. However, it also revealed a lack of social network research in Black people with non-affective psychosis. This gap in knowledge was addressed in Chapter 4. A total of 51 Black African and Caribbean participants diagnosed with non-affective psychosis were recruited from UK National Health Service (NHS) mental health services. This study addressed a key recommendation of the review in Chapter 3 by using a comprehensive network mapping interview tool to examine a range of social network characteristics as
measured in SNA. Participants completed this interview and a standardised measure of psychosis symptoms at a single time point. Social network characteristics of the sample were discussed in relation to previous literature in psychosis, which is based on samples comprising mainly White individuals. Cross-sectional associations were conducted between social network characteristics and psychosis symptoms.

The results showed that the social network characteristics of Black African and Caribbean people with non-affective psychosis closely resembled that found in other psychosis studies (e.g. Horan et al., 2006; Palumbo et al., 2015). The mean network size of 12 persons was the same as that reported in a recent systematic review in psychosis (Palumbo et al., 2015). The social networks were of moderate density (interconnectedness) and comprised a disproportionate number of family members. They also comprised an equal but smaller proportion of friends and professionals, similar to previous psychosis samples (e.g. Cohen et al., 1997).

However, there were some novel findings relating to the network characteristics of the Black service users that warrant further investigation. Their social networks had close to zero wider social ties (i.e. neighbours, acquaintances, colleagues), fewer than previously reported in psychosis samples. Their social networks also comprised mostly connected groups, with very few isolated individuals (i.e. people only connected to the service user). Family members were reported to be the closest and most stable relationships in participants’ social networks. Taken together, these findings are in accordance with the traditional social networks of African-descended people that involve extended family connections and tight-knit communities (Arnold, 2012). Participants also had more ethnically homogenous social networks, suggesting they had a tendency to form social ties with persons of a similar ethnic background to their own. There is some qualitative evidence to suggest that Black people in the UK
form social ties with people of similar ethnicity to facilitate trust and cooperation in the face of perceived inequalities and social exclusion (Mclean et al., 2003).

Cross-sectional results in Chapter 4 also showed that higher perceived emotional closeness, network satisfaction and social support were related to greater severity of psychosis symptoms. Contrary to review findings in Chapter 3, social network size was not related to psychosis symptom severity (including negative, positive, affective or overall psychiatric symptoms). The results in Chapter 4 suggested that structural characteristics, such as the density and number of people in the social network, may not be as important for outcomes as the quality of the relationship among Black people with non-affective psychosis. However, they may also reflect differences in methodologies, such as the more comprehensive social network measure used in the current study compared to previous studies (Siette et al., 2015). This Chapter reiterated the recommendations of Chapter 3, to measure the social network as a multi-faceted construct and delineate the potentially separate effects of individual network characteristics on outcomes in psychosis.

Chapter 4 highlighted potentially important social network characteristics in Black African and Caribbean people with non-affective psychosis. The findings can be used to generate theories relating to social networks and outcomes that may be specific to this group. In the context of this thesis, the findings were used to inform hypotheses relating to specific network characteristics that may be associated with engagement with mental health services in Chapter 5.
6.2.5 Chapter 5

There is limited understanding of the social and psychological factors that may influence engagement with mental health services in Black African and Caribbean people with non-affective psychosis. This is despite repeated calls to improve engagement with services in order to reduce ethnic inequalities in mental health service provision and outcomes for this disadvantaged group (National Institute for Health and Care Excellence, 2009; National Institute for Mental Health, 2003; Sainsbury's Centre for Mental Health, 2006). The aim of Chapter 5 was therefore to advance current literature and develop a theoretical model to explain engagement with mental health services in this population. The cross-sectional study in Chapter 5 reports on the same sample of 51 participants as that reported in Chapter 4. Service user participants completed measures of social networks, symptoms, engagement with services, illness perceptions, internalised stigma and perceived racial or ethnic discrimination in mental health services. Service users’ key mental health professionals also completed measures of service user engagement with services. Social network characteristics hypothesised to be associated with engagement included size, density and ethnic homogeneity (i.e. the tendency for an individual to form social ties with persons of a same ethnic background to their own). This was informed by previous literature highlighting that these characteristics are likely to be theoretically important for engagement in this population (e.g. Carpentier & White, 2002).

The findings in Chapter 5 showed that greater ethnic homogeneity and specific illness perceptions were moderately associated with better service user and staff reported engagement with services. Specifically, illness perceptions of greater perceived personal control over problems was associated with better staff reported
engagement and greater perceived treatment control, identification with symptoms, concern and emotional distress related to problems was associated with better service user reported engagement. Higher perceived ethnic or racial discrimination in services was also related to poorer service user but not staff reported engagement. Two separate models were tested for service user and staff reported engagement. Multivariate regression analyses suggested that a more ethnically homogenous social network was the strongest predictor of better service user reported engagement. Perceived discrimination and illness perceptions (treatment control) did not significantly contribute to the model. This model explained 30% of the variance in service user reported engagement. In a separate model for staff reported engagement, ethnic homogeneity was the strongest predictor, adjusting for severity of psychosis symptoms. Illness perceptions of perceived personal control did not significantly contribute to the model, which explained 32% of the variance in staff reported engagement. Exploratory mediation analysis was used to explore interactions between predictor variables and develop theoretical models to predict staff and service user reported engagement. However, no mediatory effects were observed.

The direct effects of ethnic homogeneity suggest that this variable operated independently to predict engagement with mental health services. The relationship between ethnic homogeneity and engagement was not mediated by illness perceptions or perceived discrimination. It is possible that other untested psychological mechanisms related to being in a social network with people of a similar ethnic background may account for its relationship with engagement. For example, ethnic homogeneity may be associated with increased ethnic identity, self-esteem or social support, which may lead to better engagement through greater
acceptance of problems and the ability to actively engaging in treatment and goal setting.

Chapter 5 findings provide support for the Self-Regulation Model (Leventhal et al., 1984) which suggests that variations in beliefs about illness are associated with variations in outcomes. The SRM states that the relationships between illness perceptions and outcome appraisals are mediated by coping responses. In the current sample, specific illness perceptions were related to service user engagement (perceived treatment control, identity, emotional response and concern) and staff-reported engagement (personal control). This is consistent with a study showing that illness perceptions have direct effects on outcomes both cross-sectionally and longitudinally in individuals diagnosed with schizophrenia (Lobban et al., 2004). However, in this thesis, illness perceptions did not have direct effects on engagement in multivariate analyses. In the former study, the indirect effect of coping was not supported (Lobban et al., 2004). This is line with cognitive models of psychosis where appraisals are proposed to directly affect outcomes (Garety et al., 2001; Morrison, 2001). Coping behaviours were not tested in this study, but it is plausible that beliefs about the controllability of problems guided service users’ coping behaviours which then influenced their engagement in services as reported by staff.

Social network density and size were not related to engagement with services. This contrasts previous findings in psychosis showing that a more cohesive social network may lead to sustained service engagement through greater recognition of the problem and increased social support (Carpentier & White, 2002). Additionally, internalised stigma was not related to engagement, which is inconsistent with research highlighting its negative relationship with help-seeking for mental health problems (e.g. Clement, Schauman, et al., 2015). These findings suggest that social network
structure and internalised stigma may not be important for engagement in Black African and Caribbean people with non-affective psychosis. However, this is the first study to quantitatively test these relationships in Black people with psychosis and therefore requires replication in studies with larger samples and longitudinal designs.

6.3 Clinical implications

The findings of the present thesis indicate that more attention needs to be paid to social networks and the psychological processes existing within these networks that may influence engagement and future clinical outcomes in Black people with psychosis, including beliefs about mental health problems and treatment and perceptions of ethnic or racial discrimination in services.

Findings from the current systematic review (Chapter 3) suggest that psychosocial interventions that target the size of individuals’ social networks may indirectly improve symptomatic and functional outcome in psychosis. An earlier review showed that a diverse range of psychosocial interventions can lead to improvements in the size of social networks in psychosis, including community engagement, social skills training and peer support (Anderson et al., 2015). Current guidelines for psychosis recommend peer support and self-management interventions for building a social support network (National Institute for Health and Care Excellence, 2014). The review highlighted studies to show that social network size was more strongly related to positive symptomatic outcome, the longer the period from initial hospitalisation (Cechnicki et al., 2008; Horan et al., 2006; Thorup et al., 2006). Interventions may be more beneficial when delivered at a time in which service users are able to access or mobilise resources within their social networks to help manage symptoms or engage in social activity (Horan et al., 2006). Given that network
changes can occur prior to and during the early stages of schizophrenia (Gayer-Anderson & Morgan, 2013), mental health professionals may wish to intervene early to support service users to access and mobilise their social connections during a period of stability after initial contact with services.

The current thesis highlights the utility of the social network approach (Crossley et al., 2015) and the importance of assessing a range of social network characteristics in clinical practice. Although an increase in social network size may be beneficial for symptom reduction, it might not be the primary goal for service users. In the current sample of Black service users with psychosis, emotional closeness, network satisfaction and social support were related to reduction in symptoms, but the number of social contacts was not (Chapter 4). It is therefore important to reflect on individual formulations to consider what meaningful and resourceful social contact is for the individual. More focus may be given to the types and quality of relationships within networks, the characteristics of network members, frequency of contact, interdependency and overall structure of networks. Supporting clients to map out their social connections in diagrammatic form would be helpful in providing a better understanding of social networks from their perspective, while a the network mapping approach may be useful in understanding how enhancing specific features of the social network can support recovery (Sweet et al., in press).

Network mapping tools could be used therapeutically as part of clinical practice and to measure social networks in research studies. The social network mapping interview used in this thesis (Sweet et al., in press) is lengthy and can take between 45 and 90 minutes to complete depending on the number of social contacts recalled. This could be time consuming and burdensome when used in clinical practice where resources are stretched. It may be more feasible to generate a clinically appropriate
version and to break down the tool into separate sections for use in therapy (e.g. name generator, emotional closeness map, questions about network members). The social network analysis field is expanding and has an increasingly wide interdisciplinary application (Crossley et al., 2015). There are now electronic versions of network mapping tools available for data collection in research studies (e.g. EgoNet; McCarty, 2003) that could be used in clinical practice. These programmes help you create a questionnaire, collect data and generate network measures that can be used for further analysis on other software such as UCINET (Borgatti et al., 2002) that was used in this thesis. More sophisticated analyses of specific social network features such as density or homogeneity would require training. An avenue for future research would be to create a user-friendly accessible version of network mapping software for use as a self-help resource or to compliment psychosocial interventions.

Delivering psychological interventions online and on mobile phones (i.e. websites and applications) have been shown to be feasible, acceptable and effective among individuals with psychosis (Alvarez-Jimenez et al., 2014; Firth et al., 2017; Van Der Krieke, Wunderink, Emerencia, De Jonge, & Sytema, 2014).

Although the social network features of the current sample of Black people with psychosis closely resembled that of other psychosis samples (Palumbo et al., 2015), there were features that may be specific to Black cultures and benefit from consideration in clinical interventions (Chapter 4). The social networks of the current sample were small, interconnected, and consisted of mostly family members, with few friends and professionals, akin to previous psychosis studies (e.g. Horan et al., 2006). Novel findings showed that the networks of Black participants with psychosis were ethnically homogenous, comprised few contacts outside the extended family, and were made up of mostly connected social circles. Family members were
consistently rated as the closest persons in the social network. The importance of involving the family in psychosocial interventions for psychosis is well recognised (Barrowclough & Tarrier, 1992; Claxton et al., 2017; Pharoah et al., 2010; Pilling et al., 2002), and family approaches are recommended in evidence-based clinical guidelines for psychosis (Dixon et al., 2010; National Institute for Health and Care Excellence, 2014). There has been increasing interest in adapting psychosocial interventions in psychosis to meet the cultural needs of specific ethnic groups (Degnan et al., 2017). Culturally-adapted Family Intervention (CaFI) developed specifically for Black Caribbean people with non-affective psychosis has recently been shown to be both feasible and acceptable (Edge et al., in press; Edge et al., 2016). CaFI is based on a ‘shared learning’ ethos where therapists, acknowledge relatives and service users’ strengths and learn from their experiences, developing individualised formulations that consider their cultural values and explanatory models. Given the findings relating to the importance of close and supportive familial social ties in the present thesis, actively involving the family early on in treatment, such as in EIS, may improve satisfaction and outcomes and offer opportunities for engagement in Black people with psychosis.

The present thesis suggests that specific illness perceptions (i.e. treatment control, personal control, emotional response and concern) are related to engagement with services in Black people with psychosis. Study findings (Chapter 5) suggest that beliefs about the unhelpfulness of treatment and a perceived lack of control over problems may hinder engagement in this population. Assessment and formulation of service users’ beliefs and expectations of services and treatment could be carried out as part of routine clinical practice. Conversations to understand beliefs about mental health problems may highlight client strengths and resources as well as moving
towards mutually-agreed treatment and recovery goals. Psychological interventions may benefit from working with service users to strengthen beliefs about the controllability of problems and that treatment can help to control problems (Lobban & Barrowclough, 2009). Cognitive behavioural therapy (CBT) for psychosis aims to reduce the distress associated with positive symptoms by directly targeting negative appraisals (Morrison, 2001). CBT techniques could be used to develop collaborative explanations for problems, increase a sense of control over experiences and reduce related distress. Interventions with individualised ‘recovery action plans’ have been shown to be effective at challenging unhelpful illness perceptions and improving outcomes in physical health problems (Petrie, Broadbent, & Kydd, 2008; Petrie, Cameron, Ellis, Buick, & Weinman, 2002).

Mental health professionals involved in the care of Black people with psychosis may benefit from a shared understanding of service users’ beliefs about mental health problems and treatment in services (Edge et al., in press). Greater dissonance between service user and staff illness models may lead to culturally insensitive clinical practice (Bhui & Bhugra, 2002; Islam et al., 2015), and reduced satisfaction with treatment (Carter et al., 2016; McCabe & Priebe, 2004). Although the mechanisms by which ethnically homogenous social networks are related to better engagement need to be tested (Chapter 5), the findings suggest that we need to optimise the resources existing within the social networks of Black people with psychosis. It is important to work in partnership and include the perceptions of service users in treatment decision making to enhance sense of personal control and develop shared goals, including what meaningful engagement is for the service user. Working collaboratively with service users and their families to develop individualised formulations and treatment plans may help to build therapeutic
alliance and trust, particularly where there is perceived discrimination in services (Chapter 5). Culturally-adapted interventions would benefit from building links and having conversations with Black African and Caribbean service users, families and community members to develop solutions and strategies to engage people (Edge et al., 2016).

The current finding of a relationship between greater perceived ethnic and racial discrimination in services and poorer engagement (Chapter 5) could be viewed in accordance with social care policies that continue to challenge ethnic disparities and aim to reduce racial discrimination in services (Department of Health, 2005; National Institute for Mental Health, 2003). Mental health professionals should ask service users about their experiences of racial or ethnic discrimination in assessment and build this into individualised formulations. The present thesis focused on discrimination in the NHS, but this may have been influenced by more general perceptions of racism outside the mental health system. Therefore, it may also be beneficial to consider service users’ general experiences and perceptions of racism before they were in contact with services. Mental health professionals often avoid discussions around ethnicity and culture for fear of saying the wrong thing (Keating, 2009). Cultural awareness training may help to facilitate better understanding and confidence in carrying out conversations about ethnicity and culture in services and clinical practice (Edge et al., 2016). Training health professionals in culturally-sensitive practice may improve Black service users’ experiences of care (Bhui et al., 2015), and their subsequent engagement with mental health services and treatment.
6.4 Methodological considerations

The specific methodological considerations of each of the empirical studies can be found in the discussion sections of the relevant Chapters (4-5). This section will provide a summary of overarching limitations and strengths of the thesis.

6.4.1 Study design

The main limitation of the thesis is the cross-sectional design of the quantitative studies in Chapters 4 and 5. Due to insufficient time and resources, a longitudinal follow up was not possible. This meant that the causal direction of the relationships reported between study variables cannot be inferred. As aforementioned, from a theoretical point of view, the relationships between the hypothesised predictor variables (ethnic homogeneity, illness perceptions and racial or ethnic discrimination) and engagement with services are likely to be bi-directional. It is possible that third variables not measured in this study may have influenced the associations between these variables.

There was no control group in Chapter 4 to enable us to draw statistical comparisons between the network characteristics of the current sample and other psychosis or ethnically diverse samples. Comparisons were drawn with previous literature in psychosis and non-clinical samples in the discussion but these were not empirically examined and should therefore be interpreted with caution.

Another consideration is the lack of a qualitative study in this thesis. Qualitative interviews or focus groups could have been carried out to examine subjective experiences of factors that influence engagement from the perspectives of service users and their key workers. In hindsight, it would have been useful to include a
qualitative component at the start of the project to refine hypotheses relating to social and psychological predictors of engagement for the quantitative study (Chapter 5). This may have helped to reduce the number of potential predictor variables in the regression analyses and increased statistical power, given the small sample. However, this was not feasible due to time and resource constraints, particularly seen as recruitment to the quantitative studies was shared with and working within the timescales of the CAFI trial. Moreover, the present thesis is considered to be a substantial body of work and comprised a number of different quantitative methodologies that were considered to be appropriate to address its aims, including a systematic review and meta-analyses, SNA and regression and mediation analyses.

Despite these limitations, this was the first study to provide a comprehensive description of networks in Black people with non-affective psychosis. The empirical studies in this thesis are exploratory and have produced novel findings relating to potential predictors of engagement with services in Black African and Caribbean people with non-affective psychosis. This thesis has conducted the first necessary steps to generate tentative theories relating to engagement before these are tested in more resource heavy longitudinal or intervention-based studies.

6.4.2 Sample size

The sample size included in the quantitative studies (Chapter 4 and 5) was small and may have been underpowered. A total of 51 participants were recruited to the research. Of these, 47 participants (92%) completed all of the assessment measures. As detailed in the relevant Chapters, there was no statistically significant difference in clinical or socio-demographics between those participants that dropped out and those that completed the study. This was considered to be a high recruitment and
response rate; particularly for a minority ethnic group that have historically poor engagement with services (Keating et al., 2003; Keating & Robinson et al., 2004). Minority ethnic groups are less likely to engage in mental health research (Hussain-Gambles et al., 2004); due to barriers such as negative help-seeking attitudes, stigma, fear and mistrust, cultural inappropriateness and practical constraints (Brown et al., 2014). Many of these barriers may have been overcome in the current thesis by the innovative and culturally-sensitive recruitment strategies employed as part of the CAFI trial (Edge et al., 2016).

Formal power calculations were not completed for the quantitative studies in Chapters 4 and 5. The lack of statistical power associated with the small sample size may have led to a Type II error, where potentially significant findings regarding relationships between social networks, illness perceptions, discrimination and stigma and service engagement may have gone undetected. There is also a risk that multiple testing in the correlation analyses may have led to a number of false positives, increasing the risk of Type I error. Adjustments for multiple testing (e.g. Bonferroni) were not undertaken because the limited power associated with the small sample size may have increased the risk of Type II error where potentially significant findings were missed. Notwithstanding, many of the results reported in the correlational and regression analyses in Chapter 5 were highly significant at $p<.01$, despite the small sample and being potentially underpowered. Findings from this thesis are tentative and require further testing in larger samples with adequate power.

6.4.3 Sample characteristics

The main findings in this thesis report on a combined group of Black African and Caribbean people with non-affective psychosis in the UK. The quantitative studies
(Chapters 4 and 5) included more Black Caribbean participants (n=37) than Black African (n=14) participants. The sample also included participants of mixed Black and White ethnic backgrounds (n=6, 12%). Moreover, only two individuals in the Black African sample was born in the UK, and the remaining twelve were born in African countries. The small sample size meant that there was limited power to draw statistical comparisons between Black African and Black Caribbean subgroups. Statistical differences were examined between the African and Caribbean groups in terms of social network characteristics (Chapter 4). However, it was not possible to examine ethnic differences in the relationships between social and psychological factors and engagement in Chapter 5. The thesis included both Black African and Black Caribbean people because of the similar negative experiences and poorer outcomes of mental health services in the UK (Bhui et al., 2003; Morgan et al., 2017). However, it is important not to homogenise these two broad ethnic groups and to note that the findings of this thesis may not be generalisable to the experiences of all Black ethnic subgroups and subcultures in the UK.

There is considerable cultural diversity within African descent populations, though broad labels such as Black African and Black Caribbean are commonplace in health research (Agyemang, Bhopal, & Bruijnzeels, 2005). The inclusion criteria for the present thesis included self-ascribed ethnicity, as an indication that the participants identified with their chosen ethnic group. However, the use of broad ethnic categories can conceal marked heterogeneity within these groups and ultimately reduce the applicability of research findings and provision of culturally-appropriate healthcare (Agyemang et al., 2005). It has been argued that combining African descended populations under a single label of ‘Black’ creates problems when comparing ethnic groups and reinforces the idea that being Black causes ethnic
differences in health outcomes (Agyemang et al., 2005). Unfortunately, due to limited time and resources, the present thesis was unable to recruit a large enough sample to tease out differences between Black ethnic or cultural groups in terms of their social network characteristics (Chapter 4), and social and psychological factors that predict engagement with services (Chapter 5). There may be cultural differences such as spiritual or religious orientation, levels of ethnic identification or acculturation, and degree of interdependency and collectivism between African subcultures in the UK. Cultural variations such as these may have an influence on social network characteristics, perceived stigma and discrimination, beliefs about psychosis and patterns of engaging with services. There may have also been differences in network characteristics and engagement in terms of the length of time living in the UK or country of origin within the Black African and Caribbean groups that could not be examined in this thesis. More recent migrants may have had different experiences in the NHS, in terms of pathways to care and treatment by police and healthcare professionals, to those who were born in or migrated to the UK decades ago. Engagement with services may have changed over time and been influenced by significant changes to UK mental health services over the past thirty years, such as the introduction of EIS and transformation from hospital to multi-disciplinary community-based services (Kreyenbuhl et al., 2009).

Most of the participants were male (70.6%). The average age of the sample for the quantitative studies was 42 years, ranging from 19 to 81 years. The age of the sample could be considered representative but, because of the small sample size, there were few people at either end of the spectrum. This means that the sample may not be generalisable to younger people at first onset or older adults in later life services.
The participants in this thesis were recruited from a variety of NHS community, acute and rehabilitation services. This enabled an examination of Black peoples’ experiences across a range of mental health services for psychosis. However, most of the sample had a long duration of illness (average of 17 years) and were receiving care from community mental health teams (CMHTs) (59%). Only two participants were recruited from early intervention services (EIS). Given there have been major changes to UK mental health services over the past few decades (O'Brien, Fahmy, et al., 2009), including the introduction of EIS, the experiences reported by service users in this thesis may not be representative of more recent experiences of first contact with services. Additionally, this thesis reports on the experiences of Black people receiving service in three NHS Trusts in Greater Manchester, England, and may not be generalisable to experiences in other NHS services.

The sample was recruited using convenience sampling methods and therefore may have been biased to certain sample characteristics such as those who were better engaged, or more motivated or interested in research. The same participants were used in each of the empirical studies (Chapters 4-5) which may have led to participant burnout and influenced their responses in the assessments. This may have been increased by the fact that some were also participating in another trial (for further details see Chapter 2).

The present thesis focused on service users currently engaged in treatment. Moreover, the participants were mild to moderately unwell and levels of engagement were reported to be generally quite high, from both the staff and service user perspective. Therefore, the findings in this thesis may not be generalisable to all Black people with non-affective psychosis receiving care in mental health services. There is some evidence to suggest individuals who poorly engage with services may
have more unmet needs and are more socially and psychologically impaired than those who have better engagement with services (O'Brien, Fahmy, et al., 2009). Nevertheless, examining the perceptions of individuals who were currently engaged in services is deemed to be as equally important, as this provides information that can be used to inform strategies to engage others (Chase et al., 2012).

6.4.4 Measures

Participants were not screened into the empirical studies (Chapters 4-5) using standardised diagnostic screening assessments. This was to reduce participant burden related to the number of measures administered in the research assessments. However, participants were screened for a diagnosis of non-affective psychosis based on a psychiatrist assessment in clinical case notes. The Positive and Negative Symptom Scale (PANSS) (Kay et al., 1987) was deemed to be the most appropriate assessment of psychosis symptoms as it is validated and widely used. This allowed comparisons to be drawn across other studies in psychosis samples. The PANSS was not used as a screening tool because it was deemed to be unethical for participants to complete the full interview (which takes around 45 minutes) and subsequently not be invited to participate in the study. This would potentially create further barriers in a minority group who are difficult-to-engage in research (Hussain-Gambles et al., 2004), and may have been a concern for clinicians who referred service users to the study.

Self-report questionnaire measures can be problematic as they are susceptible to recall bias, including memory and social desirability bias. However, the psychological constructs measured in this study, including perceived stigma, perceived discrimination and illness perceptions, are inherently subjective and thus
self-report measures were deemed to be most appropriate. Validated self-report measures were used in the quantitative studies where available. Internal consistency was good and alpha values have been reported in the thesis (Chapter 5). This is important as unreliable measures can increase the potential of Type II errors and result in important findings being missed. Poor validity can be problematic as it calls into question the integrity of the construct that the measure intends to measure. Two variables were measured using non-validated measures and therefore warrant mention; perceived racial or ethnic discrimination in mental health services and social networks.

A measure of perceived racial or ethnic discrimination in services was developed specifically for this study as there was no measure that was relevant to the experiences of Black people in the UK, as previously highlighted (Bastos et al., 2010; Kressin et al., 2008). This measure had good internal consistency and face validity, informed by service user and carer involvement (Chapter 2.10). However, its construct validity and test-retest reliability have not been assessed and therefore findings relating to discrimination should be interpreted with caution.

Social network characteristics were examined using a modified social network mapping interview that has established face validity in severe mental health problems (Pinfold et al., 2015). The reliability of this measure has not been tested. However, similar network mapping interviews have demonstrable internal consistency and test-retest reliability in psychosis samples (Siette et al., 2015). The social network mapping interview is considered to be one of the main methodological strengths of this thesis and advances many previous social network studies in psychosis. The network approach allows a detailed assessment of a variety of social network characteristics and addresses some of the methodological flaws of other social
network measures (Siette et al., 2015). For example, social networks were not boundaried in terms of size and participants were free to recall an unlimited number of people in their social network. The advantages of this approach have been discussed within the relevant Chapters in this thesis. However, it is worth noting here that the accuracy of the social network characteristics relies on self-report and memory. Anecdotal feedback suggested most participants completed this measure with ease, but occasionally participants reported difficulties remembering information such as the demographic information of the participants and the people who knew one another in the social network (which is used to measure the density or interconnectedness of the network).

It is worth noting here that there is little convergence on reporting of network characteristics such as average network size in the general population (Hill & Dunbar, 2003), as well as psychosis populations (Palumbo et al., 2015). This is primarily related to the difficulties in estimating and defining an individual’s network and due to marked heterogeneity in measurement of networks across empirical research studies (Siette et al., 2015). Additionally, there are likely to be differences between older and more contemporary studies post developments in social media and the evolution of social networking. These issues should be considered when interpreting the findings of the present thesis and drawing comparisons with previous research.

The use of staff and service user reported engagement measures potentially reduced problems with common method variance and allowed the examination of different perspectives of engagement. There were discrepancies in the findings relating to service user and staff perspectives of engagement. However, it was difficult to determine whether this reflected different ideas about engagement or was an artefact
of the different measures. To reduce the risk of recall or reporting bias, studies would need to test engagement using the same measure from self-report and observer viewpoints. This was not carried out in the present thesis as the service user reported engagement measure (SOLES) was selected based on the preferences of an advisory group of service users, carers and community members (Chapter 2.10). Future studies may benefit from including a memory or cognitive assessment tool to control for any variation in reporting that could be attributed to faulty recall, though the additional burden on participants would need to be considered.

6.5 Research recommendations

Future research is warranted to determine whether the current findings can be replicated in larger powered samples of Black people with non-affective psychosis across different settings and NHS services in the UK.

Further studies using longitudinal designs are required to test causal relationships between social networks, illness perceptions, perceived ethnic or racial discrimination and future engagement with services. Review findings suggest that networks deteriorate prior to the onset of psychosis (Gayer-Anderson & Morgan, 2013) and there is limited evidence to show that social network characteristics are relatively stable in the year following the onset of psychosis (Horan et al., 2006). Similarly, research suggests that illness perceptions are stable over a six month period in individuals with schizophrenia diagnoses (Lobban et al., 2004). Perceived racial or ethnic discrimination may change over time, as perceptions of services among Black people have been found to become more negative with increasing contact (Parkman et al., 1997). Engagement is also suggested to fluctuate over time (Priebe et al., 2005). Future research may wish to examine relationships over longer
time periods and at points likely to be related to change, such as treatment initiation, relapse or hospital admission. Longitudinal studies would also benefit from examining the stability of social network characteristics over time to determine whether they fluctuate and if there are certain characteristics that are important for long-term engagement and positive outcomes.

Intervention-based research could test whether targeting illness perceptions and racial or ethnic discrimination in services would improve engagement in Black people with non-affective psychosis. Further work is needed to better understand the mechanisms by which social network ethnic homogeneity, specific illness perceptions and perceived racial or ethnic discrimination are related to engagement with services. This would help to identify key mechanisms to target in psychosocial interventions in order to improve engagement. The final models tested in this study (Chapter 5) accounted for 48% and 32% of the variance in service user and staff reported engagement, respectively. This suggests that there were other unmeasured variables that may have influenced engagement. Future research could examine social and psychological variables that have been highlighted as theoretically relevant but were not tested in the thesis, including mistrust of services, coping behaviours, ethnic identity and self-esteem.

Further studies using matched control designs are required to compare network characteristics and their relationship with engagement with services across different ethnic and diagnostic groups. Network characteristics of Black ethnic groups could be compared with other dominant ethnic groups in the UK, including White British and South Asian. This may also include differences across different Black ethnic subgroups in the UK, including 'mixed' ethnic groups and recently migrated versus British-born individuals. Additionally, comparisons should be made between
individuals with different diagnoses on the schizophrenia-spectrum and duration of symptoms, including first episode versus longer term problems.

There is a lack of knowledge relating to those individuals with severe mental health problems such as psychosis that do not currently access or never come into contact with services (Kreyenbuhl et al., 2009). Most studies in research and clinical settings are conducted on people who are already engaged or have previously engaged in some form of treatment. There has been prospective research to suggest that individuals diagnosed with schizophrenia can experience intervals of recovery and favourable outcomes without long-term medical treatment (Harrow & Jobe, 2007; Harrow & Jobe, 2013). Some individuals may not wish to engage in services or medical treatment. However, given the established relationship between disengagement with services and poorer outcomes (Kreyenbuhl et al., 2009), it is important to offer effective evidence-based interventions to those who are likely to benefit. Perhaps individuals do not wish to engage because services or the treatment offered are not meeting their needs. Individuals diagnosed with schizophrenia receiving mental health services are rarely offered psychological therapies (The Schizophrenia Commission, 2012). Black African and Caribbean people are even less likely to be offered psychological therapy and receive poorer treatment (Bhui et al., 2003). Further research needs to consider what positive engagement with mental health services means for Black people. It would be informative to conduct further work exploring resilience and protective factors in Black African and Caribbean people who are not in services and effectively managing their own recovery for psychosis. Recruiting participants not in services may be challenging and would require novel recruitment methods, including community engagement.
As previously discussed, early onset may be the best time to intervene with strategies to improve engagement (Kreyenbuhl et al., 2009), it would therefore be useful to conduct qualitative and quantitative research with Black people in EIS. It would be useful to interview service users specifically about their experiences of engaging with services, including initial access and pathways to care, treatment provision and relationships with key mental health professionals.

Further qualitative studies with service user, family members or carers and mental health professionals would help to understand facilitators and barriers to engagement from a range of perspectives. Qualitative work may contribute to current understanding of the relationships between social networks, illness perceptions and discrimination and generate further hypotheses relating to potential mechanisms.

6.6 Conclusions

To conclude, this thesis has made a number of noteworthy advancements to the current understanding of social network characteristics and engagement with mental health services in Black African and Caribbean people diagnosed with non-affective psychosis in the UK. Black African and Caribbean people have the highest rates of psychosis and worse access, and experiences and outcomes of services of all ethnic groups in the UK (Bhui et al., 2003; Morgan et al., 2017). The need to improve engagement in order to reduce inequalities in mental health care among Black people has been repeated highlighted in research and health-related policies (e.g. Department of Health, 2005; Mental Health Taskforce, 2016; Sainsbury's Centre for Mental Health, 2006). Despite this, there has been limited work to examine social and psychological factors that may improve engagement in this population. It has been theorised that engagement is a sociocultural process influenced by social
networks and beliefs about illness and treatment existing within those networks (Morgan et al., 2004; Perry & Pescosolido, 2015). Systematic review findings in this thesis suggest that larger social networks are associated with improved symptomatic outcome in psychosis. However, there is a lack of research examining social networks in Black African and Caribbean people with psychosis.

The current thesis presents empirical findings that address these significant gaps in knowledge. Results presented in this thesis suggest that the social networks of Black people with psychosis are generally small and interconnected, more ethnically homogenous and comprise mostly family members, with very few wider social ties. Findings also suggested that greater satisfaction with social networks and more emotionally close and supportive connections are important for Black people with psychosis as they are related to lower symptomatic distress. The present thesis was the first to empirically test theories to explain current engagement with services in this population. Findings suggested that more ethnically homogenous social networks were strongly associated with better engagement with mental health services. Additionally, specific beliefs about psychosis, including perceptions that treatment can help to control problems and lower perceived personal control over problems, and higher perceived racial or ethnic discrimination in mental health services were related to poorer engagement. Taken together, the findings of this thesis emphasise the need to understand and work in partnership with service users and families to ensure current services are meeting their needs and challenge negative perceptions of mental health treatment. Psychosocial interventions that aim to build and maintain supportive social networks, enhance personal control over problems, improve beliefs about the benefits of treatment and tackle discrimination in services may facilitate better engagement and subsequent outcome. The next step
is to conduct qualitative and longitudinal research to explore causal mechanisms linking social networks, illness perceptions and perceived discrimination with engagement with mental health services in Black people with psychosis.


Eliacin, J. (2013). Social capital, narratives of fragmentation, and schizophrenia: an ethnographic exploration of factors shaping African-Caribbeans' social capital and


PARTICIPANT INFORMATION SHEET – service user

Study Title: Social relationships in people from African Caribbean and Black African backgrounds who have experience of psychosis  
REC: 15/NW/0086

You are being invited to take part in our research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. **If you wish, one of our team will go through this information sheet with you and answer any questions you have.** You are also free to talk to others about the study if you wish. Please ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part.

**What is the purpose of the study?**
You are being invited to take part in a study looking at peoples' social relationships. The study will investigate how people from African Caribbean or Black African backgrounds, who have experience of psychosis, relate to their key workers and people in their social networks. The study will also investigate how this group of people seek help and engage with mental health services. This research is being done to help us understand how mental health services can best support African Caribbean and Black African people.

**Why have I been invited to take part?**
You are being invited to participate because:

(a) You have been identified by your key worker as being eligible to take part
(b) You have experience of psychosis
(c) You have identified that you are African Caribbean or Black African

**What will I have to do if I take part?**
This study will be divided into two parts:

**Part one:** You will be asked to take part in two interviews and complete a few short questionnaires. The first interview will ask about your experiences of mental health and psychosis. This should take around 45 minutes. The second interview will focus on your social network and you will be asked questions about the different relationships you may have. One example of a question we might ask is “**Who would you go to for advice or support for mental health or emotional problems?**” This interview should take around 30-60 minutes. The questionnaires will ask your views about using and engaging with mental health services, your relationship with your key worker, your beliefs about psychosis, and if you have had any experiences of stigma to mental health and discrimination in services. These questionnaires should take around 30 minutes to complete. All together, the study will take between 1½ to 2½ hours in total and can be carried out in one meeting or several meetings. We are looking for 50 people to take part in this study.
With your permission, we will inform your key worker of your involvement in the study and ask your key worker to complete two questionnaires about their relationship with you. We may also ask your key worker to look at your case notes to confirm information such as your diagnosis, age and contact with services.

**Part two:** You will also be invited to take part in another interview about one month later to find out about your experience of talking about your social networks. During this follow-up interview, you will also be asked about some of the topics that were covered in the earlier questionnaires such as your views about mental health services, beliefs about psychosis, and experiences of discrimination. This should take around 30-60 minutes. You will be reminded about this follow-up interview immediately after part one and again two weeks before your follow-up appointment.

We are looking for 25 people to take part in the follow-up study (half of the original sample) and will stop recruiting once we have reached this number.

**Where will the research be conducted?**
If you decide to take part, you will meet one of the researchers at a time that is convenient to you. The researcher will visit you in a suitable location on the ward or in the community, depending on where you are staying at the time.

**Do I have to take part?**
No, taking part is entirely your choice. If you prefer to not take part you do not have to give a reason. Staff involved in your care will not be upset and your treatment will not be affected.

**What happens if I change my mind?**
If you take part but later change your mind, you can withdraw at any time from the study. Changing your mind will not affect your standard of care or treatment. In the unlikely event that you lose the capacity to consent during the course of this study, you will be withdrawn from the study but we will continue to use the information we have already collected.

**Will I be paid for taking part?**
As a token of appreciation, you will be given £10.00 worth of shopping vouchers for taking part in the research study.

**Will my taking part be kept confidential?**
Yes. If you agree to take part in the study, any information you give the researcher will be kept strictly confidential. However, we do have a responsibility to inform your key worker if you tell us information that suggests you or someone else might be harmed. With your permission, we would like to inform your psychiatrist/care coordinator if you agree to take part in the study. We will also continue to keep them informed if you decide to take part in the second part of the study. You will be asked if you mind the session being recorded by audio tape, so interviews can be transcribed and rated by the researchers. The recordings will be destroyed after they have been used. Your personal details (e.g. name, address) will not be disclosed.

**What will happen to my data?**
Your anonymised data will be held securely by the research team at The University of Manchester for 5 years after the last publication of the study or for 10 years, after which point it will be destroyed. Personal information (e.g. name, age) will be destroyed as soon as it is no longer needed.

What are the possible risks of taking part?
There are no identified risks to taking part in the research study. However, it is possible that you may become uncomfortable discussing issues relating to your mental health or social relationships. Should this happen, you can speak to researchers and the person in charge of your care (key worker/ care coordinator). If it is out of hours, please contact your local crisis team. The researcher will give you this phone number. Further support is available from the Samaritans (08457 909090), Rethink National Advice Service (020 8974 6814) and SaneLine (0845 767 8000).

What are the possible benefits of taking part?
The study may not benefit you directly in the short term, but we believe that the information we collect will help us improve the future care of people from African Caribbean and Black African backgrounds who have experience of psychosis. The study is planned for 2 years and the findings will be fed back to interested participants at the end of this time period.

What if something goes wrong?
If you have a concern about any aspect of this study, please ask to speak to the lead researcher, Amy Degnan (0161 275 5224), who will do her best to answer your questions. If you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Coordinator on 0161 275 7583 or 0161 275 8093 or by email to research.complaints@manchester.ac.uk.

Who is conducting the research?
The research is organised by The University of Manchester and is being carried out at NHS mental health services in Manchester. It is being conducted by two researchers as part of their doctorate and PhD in Clinical Psychology.

Who has reviewed the study?
This research project has been reviewed by The University of Manchester Research Ethics Committee, the National Research Ethics Service (REF), and your NHS Research & Development Department.

What do I do now?
A researcher from the study or a key worker will have given you this information sheet. If you are interested in taking part, please let your key worker or the researcher know. Your key worker can help you contact the researcher. The researcher can meet with you and answer any questions you have about your involvement in the study. She will give you more time to think about being in the study and, if you are still interested, ask you to sign a consent form to show that you are willing to take part. She will then explain what will happen next.
Thank you very much for considering taking part in our research.

Please discuss this information with your family, friends or key worker if you wish.

Please contact us if you require further information or advice on how to take part:
APPENDIX II: CONSENT FORM QUANT STUDY - SERVICE USERS

CONSENT FORM: ASSESSMENT STAGE 1 - SERVICE USER

Study Title: Social relationships in people from African Caribbean and Black African backgrounds who have experience of psychosis

Name of Researchers: Lucy Shatlock & Amy Degnan

REC Ref: 15/NW/0086

Please initial each box and sign your name to show you agree to the items below:

1) I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

2) I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving a reason, without detriment to myself, and without my medical care or legal rights being affected.

3) I understand that, in the unlikely event that I lose the capacity to consent during the course of this study, I will be withdrawn from the study but information I have already given will be used by the researchers.

4) I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from The University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.

5) I give consent for interviews to be audiotaped for data analysis and reporting purposes.

6) I agree that anonymised quotes from interviews can be used in the reporting of this research. I understand that my personal details will not be used and it will not be possible to identify me from any published information.

7) I agree that information from my interviews and questionnaires in which I participated will be kept for at least 10 years after the current study and that no information that could identify me will be shared or published.
8) I consent to my psychiatrist/care coordinator being informed about my continued involvement in the study.

9) I consent to my key worker/care coordinator being approached and asked to complete questionnaires about our relationship.

10) I agree for the researchers to contact me about taking part in another interview about my experiences in the future.

11) I understand that if I tell the research team anything that indicates a risk of harm to myself or others, they will need to share this information with my key worker and relevant organisations or authorities but that they will discuss this with me first.

12) I agree to take part in the above study.

Name of participant

………………

Date

………………

Signature

Name of person taking consent

………………

Date

………………

Signature
APPENDIX III: PARTICIPANT INFO SHEET – KEY WORKERS

PARTICIPANT INFORMATION SHEET – Key worker

Study Title: Social relationships in people from African Caribbean and Black African backgrounds who have experience of psychosis  
REC: 15/NW/0086

You are being invited to take part in our research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. **If you wish, one of our team will go through this information sheet with you and answer any questions you have.** You are also free to talk to others about the study if you wish. Please ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part.

**What is the purpose of the study?**  
The study will investigate how people from African Caribbean or Black African backgrounds, who have experience of psychosis, relate to their key workers and people in their social networks. The study will also investigate how this group of people seek help and engage with mental health services. This research is being done to help us understand how mental health services can best support African Caribbean and Black African people.

**Who will be invited to take part in the study?**  
Participants will meet the following criteria:
- (d) Identified by key worker as being eligible to take part
- (e) Experience of psychosis
- (f) Self-identify as African Caribbean or Black African
  - Key workers of all participants taking part will be invited to take part in the study.

**Why have I been invited to take part?**  
Because you are a key worker of a participant in the study.

**What will be involved for participants who decide to take part?**  
This study will be divided into two parts:

**Part one:** Participants will be asked to take part in two interviews and complete a few short questionnaires. The first interview will ask about their experiences of mental health and psychosis. This should take around 45 minutes. The second interview will focus on their social network and they will be asked questions about the different relationships they may have. One example of a question we might ask is “Who would you go to for advice or support for mental health or emotional problems?” This interview should take around 30-60 minutes. The questionnaires will ask their views about using and engaging with mental health services, relationship with key worker, beliefs about psychosis, experiences of stigma to mental health and discrimination in services. These questionnaires should take
around 30 minutes to complete. All together, the study will take between 1½ to 2½ hours in total and can be carried out in one meeting or over several meetings. We are looking for 50 people to take part in this study.

**Part two:** Participants will also be invited to take part in another interview about one month later to find out about their experience of talking about social networks in the previous interview. During this follow-up interview, they will also be asked about some of the topics that were covered in the earlier questionnaires such as views about mental health services, beliefs about psychosis, and experiences of discrimination. This should take around 30-60 minutes. Participants will be reminded about this follow-up interview immediately after part one and again two weeks before their follow-up appointment. We are looking for 25 people to take part in the follow-up study (half of the original sample) and will stop recruiting once we have reached this number.

**What will be involved for participants' key workers?**
If you agree to take part, you will be asked to sign a consent form and you will complete two short questionnaires where you rate different aspects of your relationship with your client (engagement with services and working alliance - e.g. ‘the client seeks help when assistance is needed’). This should take no longer than 10 minutes. Key workers will complete these questionnaires when the participant completes Part one measures [above].

**Will participants be informed of their key worker's involvement?**
Participants will be asked permission to keep their key worker informed of their continued involvement in the study. Participants will be informed that we will ask their key worker to complete two questionnaires about their relationship with them. Participants will also be informed that we may ask their key worker to look at their case notes to confirm information such as diagnosis, age and contact with services.

**Where will the research be conducted?**
The researchers will meet participants and key workers separately. The researcher will visit you at a convenient time and in a suitable location, on the ward or in the community.

**Do I have to take part?**
No, taking part is entirely your choice. You may refuse to participate in the study without affecting you client’s ability to participate.

**What happens if I change my mind?**
If you take part but later change your mind, you can withdraw at any time from the study. If you withdraw, we will continue to use the information we have already collected.

**Will my taking part be kept confidential?**
Yes. If you agree to take part in the study, any information you give the researcher will be kept strictly confidential.
What will happen to participant data?
Participant anonymised data will be held securely by the research team at The University of Manchester for 5 years after the last publication of the study or for 10 years, after which point it will be destroyed. Personal information (e.g. name, age) will be destroyed as soon as it is no longer needed.

Will participants be paid for taking part?
Key workers will not be paid for taking part. As a token of our appreciation, participants will be given £10.00 worth of shopping vouchers for taking part in the research study.

What are the possible risks of taking part for participants?
There are no identified risks to taking part in the research study. However, it is possible that participants may become uncomfortable discussing issues relating to their mental health or social relationships. There is a distress policy in place should this happen. They can speak to researchers and/or the person in charge of their care (key worker/ care coordinator). If it is out of hours, participants can contact their local crisis team. The researcher will give participants this phone number. Further support is available from the Samaritans (08457 909090), Rethink National Advice Service (020 8974 6814) and SaneLine (0845 767 8000).

What are the possible benefits of taking part for participants?
We believe that the information we collect will help us improve the future care of people from African Caribbean and Black African backgrounds who have experience of psychosis. The study is planned for 2 years and the findings will be fed back to interested participants at the end of this time period.

What if something goes wrong?
If you have a concern about any aspect of this study, please ask to speak to the lead researcher, Amy Degnan (0161 275 5224), who will do her best to answer your questions. If you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Coordinator on 0161 275 7583 or 0161 275 8093 or by email to research.complaints@manchester.ac.uk.

Who is conducting the research?
The research is organised by The University of Manchester and is being carried out at NHS mental health services in Manchester. It is being conducted by two researchers as part of their doctorate and PhD in Clinical Psychology.

Who has reviewed the study?
This research project has been reviewed by The University of Manchester Research Ethics Committee, the National Research Ethics Service (REF), and your NHS Research & Development Department.

What do I do now?
A researcher from the study will have given you this information sheet. If you are interested in taking part, please let the researcher know. The researcher can meet with you and answer any questions you have about your involvement in the study.
She will give you more time to think about being in the study and, if you are still interested, ask you to sign a consent form to show that you are willing to take part. She will then explain what will happen next.

Thank you very much for considering taking part in our research.

Please contact us if you require further information or advice on how to take part:
APPENDIX IV: CONSENT FORM – KEY WORKERS

CONSENT FORM: Key worker

Study Title: Social relationships in people from African Caribbean and Black African backgrounds who have experienced psychosis

Name of Researchers: Lucy Shattock & Amy Degnan

REC Ref: 15/NW/0086

Please initial each box and sign your name to show you agree to the items below:

13) I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

14) I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving a reason, without detriment to myself.

15) I understand that if I withdraw from the study, the information I have already given will be used by the researchers.

16) I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from The University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

17) I agree that information from my questionnaires in which I participated will be kept for at least 10 years after the current study and that no information that could identify me will be shared or published.

18) I understand that my taking part will be kept confidential.

19) I agree to take part in the above study.

Name of participant: [Name]
Date: [Date]
Signature: [Signature]

Name of person taking consent: [Name]
Date: [Date]
Signature: [Signature]
APPENDIX V: STUDY ADVERTISEMENT

Take part in a research study to explore people’s social relationships

We are looking for people from Black African or African Caribbean backgrounds that have experience of psychosis

This involves completing interviews and short questionnaires that will help us to understand how mental health services can best support people

You will be asked to complete interviews and a series of short questionnaires. You will be given shopping vouchers for your time.
APPENDIX VI: SELF-REPORT MEASURES

Socio-demographic Questionnaire: Service Users

1. What is your date of birth? __________

2. What is your gender? __________

3. What is your ethnic group?
   - Black/ African Caribbean
   - Black African
   - Black-British
   - Any other Black/ African/ Caribbean background, please describe:
     ........................................................................................................
   - White and Black Caribbean
   - White and Black African
   - Any other Mixed/ Multiple ethnic background, please describe:
     ........................................................................................................

4. What is your country of origin (include place of birth if different):
   ........................................................................................................

5. What is your religion?
   - No religion
   - Christian
     (including Church of England, Catholic, Protestant and all other Christian denominations)
   - Jewish
   - Muslim
   - Buddhist
   - Hindu
   - Sikh
   - Any other religion, please describe:
6. What is your current employment status?
   - Full-time work
   - Part-time work
   - Volunteer
   - Student
   - Unemployed
   - Long-term sickness or disability
   - Looking after family or home
   - Retired

7. What is your marital status?
   - Married or in Civil partnership
   - Cohabiting
   - Single
   - Separated/ divorced
   - Widowed

8. Do you have any children?
   - Yes
   - No
   - If yes, how many?

9. What best describes your housing status?
   - Owner occupiers (including with a mortgage)
   - House or flat rented from a housing association/local council
   - House, flat or room rented from a private landlord
   - Residential home or supported housing
   - Hostel
   - Homeless or living on the street
   - Staying with a friend or family but have own bed
   - ‘Sofa surfing’ (staying with friends or family but no bed)
   - Other, please describe:

10. Who do you live with?
    - Alone
    - Partner/ spouse
    - Parent/ parents
    - Other family members
    - Friends
    - Other, please describe:
11. What is your highest level of qualification?
   Degree level or above
   A-levels or equivalent (e.g. Baccalaureate)
   GCSE or equivalent (e.g. O-levels)
   Apprenticeship
   Other qualifications
   No qualifications

12. Which service currently provides your mental health care?
   Inpatient ward
   Community Mental Health Team
   Community (other)
   Rehabilitation ward

   Other, please describe:
   ………………………………………………………………………………………………

13. Please specify name of service:
   ………………………………………………………………………………………………

14. How long have you known your care coordinator/key worker [person completing engagement and alliance measures for study]?
   ………………………………………………………………………………………………

15. Have you been given a mental health diagnosis?
   If yes, please specify:
   ………………………………………………………………………………………………

16. If yes, do you agree with this diagnosis?
   Yes ☐    No ☐

17. At what age did you first get professional help for your mental health problem?
   ………… years

18. Have you ever stayed overnight in a psychiatric inpatient ward?
   Yes ☐    No ☐

19. If yes - Have any of the stays been under section (involuntary admission)?
   ☐    ☐
20. If yes - Have any of the stays not been under section (voluntary admission)?
   Yes ☐  No ☐

   How many stays?
   …………………………………

21. Are you taking any prescribed medications for mental health conditions?
   Yes ☐  No ☐

   If yes, how many?   ☐
   If yes, please specify type:
   …………………………………………………………………………..

22. How is your medication administered?
   Please tick all that apply.
   Oral ☐  Depot injection ☐  Both ☐
Brief Illness Perception Questionnaire (Brief-IPQ)

Here are some general questions about your mental health problem(s).

For each question, please circle the number that best indicates your response.

1. How much do your mental health problems affect your life?
   0  1  2  3  4  5  6  7  8  9  10
   no affect at all
   severely affects my life

2. How long do you think your mental health problems will continue?
   0  1  2  3  4  5  6  7  8  9  10
   a very short time
   forever

3. How much control do you feel you have over your mental health problems (that is, how easy would it be for them to improve by your own efforts)?
   0  1  2  3  4  5  6  7  8  9  10
   absolutely no control
   total control

4. How much do you think your current treatment can help with your mental health problems?
   0  1  2  3  4  5  6  7  8  9  10
   not at all
   extremely helpful

5. How much do you experience symptoms related to your mental health problems?
   0  1  2  3  4  5  6  7  8  9  10
   no symptoms at all
   many symptoms
6. How concerned are you about your mental health problems?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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<tbody>
<tr>
<td>not at all concerned</td>
<td>extremely concerned</td>
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<td></td>
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</table>

7. How well do you feel you understand your mental health problems?

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<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>don't understand at all</td>
<td>understand very clearly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</table>

8. How much do your mental health problems affect you emotionally? (e.g. do they make you angry, scared, upset or depressed?)

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<thead>
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<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all emotionally affected</td>
<td>extremely emotionally affected</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</table>
Internalised Stigma of Mental Illness Scale (ISMI)

We are going to use the term ‘mental illness’ in the rest of this questionnaire, but please think of it as whatever you feel is the best term for your experiences. For each question, please mark whether strongly disagree (1), disagree (2), agree (3) or strongly agree (4).

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel out of place in the world because I have mental illness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Having a mental illness has spoiled my life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. People without mental illness could not possibly understand me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I am embarrassed or ashamed that I have a mental illness</td>
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<td>5. I am disappointed in myself for having a mental illness</td>
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<td>6. I feel inferior to others who don’t have mental illness</td>
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<tr>
<td>7. Stereotypes about the mentally ill apply to me</td>
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<td>8. People can tell that I have a mental illness by the way I look</td>
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<tr>
<td>9. Mentally ill people tend to be violent</td>
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<tr>
<td>10. Because I have a mental illness, I need others to make most decisions for me</td>
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<tr>
<td>11. People with mental illness cannot live a good, rewarding life</td>
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<tr>
<td>12. Mentally ill people shouldn’t get married</td>
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<tr>
<td>13. I can’t contribute anything to society because I have a mental illness*</td>
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<tr>
<td>14. People discriminate against me because I have mental illness</td>
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<tr>
<td>15. Others think that I can’t achieve much in life because I have a mental illness</td>
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<tr>
<td>16. People ignore me or take me less seriously just because I have a mental illness</td>
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<td>17. People often patronize me, or treat me like a child, just because I have a mental illness*</td>
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<td>18. Nobody would be interested in getting close to me because I have a mental illness</td>
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<tr>
<td>19. I don’t talk about myself much because I don’t want to burden others with my mental illness</td>
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<td>20. I don’t socialize as much as I used to because my mental illness might make me look or behave “weird”</td>
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<tr>
<td>21. Negative stereotypes about mental illness keep me isolated from the “normal” world**</td>
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<tr>
<td>22. I stay away from social situations in order to protect my family or friends from embarrassment</td>
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<tr>
<td>23. Being around people who don’t have a mental illness makes me feel out of place or inadequate</td>
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<td>24. I avoid getting close to people who don’t have a mental illness to avoid rejection</td>
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<td>25. I feel comfortable being seen in public with an obviously mentally ill person</td>
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<td>26. In general, I am able to live my life the way I want</td>
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<td>want to</td>
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<td>27. I can have a good, fulfilling life, despite my mental illness</td>
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<tr>
<td>28. People with mental illness make important contributions to society</td>
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<td>29. Living with mental illness has made me a tough su</td>
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**Perceived discrimination measure**

We would like to know how much you agree with the following two statements.

For each statement, please mark whether you strongly disagree (1), disagree (2), neither agree or disagree (3), agree (4) or strongly agree (5).

1) NHS mental health services discriminate against **people** (treat **people** unfairly) because of their racial/ethnic background

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<tr>
<td>1</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree</td>
<td>Agree</td>
<td>Strongly agree or disagree</td>
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2) NHS mental health services discriminate against **me** (treat **me** unfairly) because of my racial/ethnic background

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<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neither agree</td>
<td>Agree</td>
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The SOLES - The Singh O’Brien Level of Engagement Scale

Please rate from 0 to 10 your agreement with the following statements:

1. I attend appointments with my keyworker

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2. I need to see my keyworker regularly

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3. I find seeing my keyworker helpful

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4. I need to be involved with mental health services

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5. I have benefited from mental health services

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6. I have a mental health problem

0 1 2 3 4 5 6 7 8 9 10
not at all  entirely

7. I find my psychiatrist helpful

0 1 2 3 4 5 6 7 8 9 10
not at all  entirely

8. I need to take psychiatric medication

0 1 2 3 4 5 6 7 8 9 10
not at all  entirely

9. I find psychiatric medication helpful

0 1 2 3 4 5 6 7 8 9 10
not at all  entirely

10. I always take my medication

0 1 2 3 4 5 6 7 8 9 10
not at all  entirely

11. I feel I get enough practical support from mental health services

0 1 2 3 4 5 6 7 8 9 10
not at all  entirely
12. I feel I get enough emotional support from mental health services

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13. I can cope by myself without contact from mental health services*

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14. Admissions to hospital have been helpful

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15. I feel listened to by health professionals

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16. I can get help from mental health services when I need it

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# Service Engagement Scale

Please circle the response which best describes your client.

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<tr>
<td>1. The client seems to make it difficult to arrange appointments</td>
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<td>2. When a visit is arranged, the client is available</td>
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<td>3. The client seems to avoid making appointments</td>
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<td>4. If you offer advice, does the client usually resist it?</td>
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<td>5. The client takes an active part in the setting of goals or treatment plans</td>
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<td>6. The client actively participates in managing his/her illness</td>
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<td>7. The client seeks help when assistance is needed</td>
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<td>8. The client finds it difficult to ask for help</td>
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<td>9. The client seeks help to prevent a crisis</td>
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<td>10. The client does not actively seek help</td>
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<td>11. The client agrees to take prescribed medication</td>
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<td>12. The client is clear about what medication he/she is taking and why</td>
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<td>13. The client refuses to co-operate with treatment</td>
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<td>14. The client has difficulty in adhering to the prescribed medication</td>
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APPENDIX VII – SOCIAL NETWORK MAPPING INTERVIEW

Stage 1: Network Mapping Interviews

Interview Procedure and Topic Guide

Interview procedure

Aim of interview

This interview schedule includes the topic guide for the phase one social network mapping interview. The aim of the interview is to map and describe the participant’s social network characteristics (e.g. size, composition, density, frequency, strength).

Format of interview

The interview is structured and covers standard questions to generate the participant’s social network. The questions must be followed in the exact order they are presented in the topic guide. The interviewer must have the following network mapping materials to undertake the interview: a) A2 and A3 paper; b) name interpreter cards; c) emotional closeness map; d) two copies of interview guide (one for participant to look at if they wish); and e) pens and A4 paper.

The name generator technique will be used to collect data on three key elements: 1) alters: names of the respondent’s network members; 2) structure: presence (or not) of relationship between alters; and 3) alter attributes: socio-demographic information about these alters. For each respondent, a comprehensive list of people in their social network (alters) will be generated using a series of 10 questions (e.g. ‘Who are the people you currently enjoy seeing or spending time with?’).

The strength of social tie or the ‘closeness’ of a network member will be measured using an emotional closeness map. The density of the network or ‘interconnectedness’ will be measured by drawing lines on the closeness map between those alters who have a social connection (i.e. who know one another).

The interviewer will subsequently use name interpreter questions to gain socio-demographic information about each named person (e.g. age, gender and ethnic group), the type of relationship, length of time known and frequency of contact. The number of different functions that each social tie provides (Multiplexity) will be measured for each network member by indicating on the card the name generator questions for which person was mentioned. Reciprocity will be measured by noting down on the card whether these functions are reciprocal or not.
Finally, the respondent will be asked to rate the satisfaction of their whole social network on a Likert scale ranging from 1 (very satisfied) to 5 (not satisfied).

The interview will be recorded, transcribed and anonymised by a member of the research team. The interview will be analysed and rated by the lead researcher.

**Information and consent**

Participants will have already received a Participant Information Sheet detailing the nature of the study and their involvement. This will be explained verbally during the informed consent procedure. Participants will be asked to sign a consent form.

**Confidentiality**

At the start of the interview, each participant will be advised that all information they disclose during the interview will remain completely confidential. Participants will be informed that confidentiality will only be broken if the information suggests that they or another person is at risk of harm.

**Distress policy**

Participants will be informed that they have the right to withdraw from the study at any time if they feel uncomfortable or distressed. Participants will be given the opportunity to complete the interviews and questionnaires at their own pace, with regular breaks, and in separate appointments if they wish. If there are any questions that the participant does not wish to answer, the interviewer will move on. If participants become distressed as a result of the interview, they will be advised to contact their care coordinator and when out of hours, their local crisis team. Participants will also be signposted to relevant services, including the Samaritans, Rethink National Advice Service and SaneLine. The researchers will ensure that all participants have their office contact number and phone numbers for the latter support services.

**Conducting the interview**

- Aim to develop a good level of rapport with the participant initially by taking some time to have a general conversation with them and make them feel relaxed before you start. It may be helpful to record (but not transcribe) this too as it can help more anxious service users feel at ease with the recorder.
- Try to adopt an informal conversational style.
- Resist the urge to agree or disagree with the respondent’s statements. Use neutral statements to encourage, e.g. ‘uh-uh’, ‘ok’, and ‘right’.
• Redirecting- Where the subject goes off the point, tactful, respectful attempts should be made to redirect, e.g. ‘Perhaps we could talk about that later, what I’m really interested in here is…’.

• Change language to mirror/paraphrase language used by respondent (e.g. when describing their mental health problems).

**Topic Guide**

**Introduction**

Thank you agreeing to take part in this interview. Everything that we talk about today is private; I won’t share anything we discuss with other people unless I believe that you or anybody else is at risk of harm. Let me know if you need to take a break at any point. Although I am recording the interview I may also want to jot down a few notes, I hope this is OK.

Have you got any questions about this interview before we make a start?

**Name Generator Questions**

[Name Interpreter Card]

• I’m going to ask you a series of questions to find out the names of people you know. The people you name can have a positive or negative influence in your life.

• For each question, you can provide any one known to you in any capacity – family, friend, partner, neighbour, acquaintance, or healthcare professional.

• Please only include people you currently and regularly interact with.

• Please only provide the first names or initials of people you know. We will keep this completely confidential.

• Each name is written on a sticky note in front of and in collaboration with the participant.

• Researcher writes each nameinitials on a Coding Sheet and an ID number is allocated to each individual. Each code is then written on a new Name Interpreter Card.

• The nameinitials are NOT written on the Name Interpreter Card.

• After each question, researcher probes ‘anyone else?’ until participant says no.

• Encourage participant to generate all possible names for each question (to examine multiplexity i.e. of different support functions – emotional, instrumental, tangible, companionship)

• For each question, prompt for reciprocity i.e. ‘this person x who helps you, do you help them too ..?’
• Question number is written on each Name Interpreter Card and whether reciprocal or not.

1. Who are the people you currently enjoy seeing or spending time with? [*positive*]
2. Who do you currently have to see but would prefer not to? [*negative*]
3. From time to time, most people discuss important matters with other people. Who are the people with whom you discuss matters with? [*emotional support*]
4. If you needed to obtain some advice or information for a mental health problem, who would you approach [*informational, problem-solving help*]?
5. If you needed some emotional reassurance and comfort for a mental health problem, who would you approach? [*emotional help*]
6. Who has recently helped you with everyday tasks such as cooking, cleaning, shopping, filling out forms, and finding out information? [*instrumental/informational support*]
7. If you needed to borrow some material goods or money, who would you go to for help? [*instrumental, tangible help*]
8. Who are the people you attend or share social activities with? [*positive*]
9. Who are the people you currently see with whom you find encounters difficult or stressful? [*negative*]
10. Please list anyone who you regularly interact with who you have not listed in one of the previous questions.
   a. Probe: Any other family, friends, neighbours, acquaintances, healthcare professionals

**Network Mapping Tool**

[Emotional Closeness Map]

- Participant is shown the map which will be A2 or A3 depended on network size
- Use A2 for larger networks – over 30 contacts
- Respondent ‘ME’ is in the centre of the map

- I’m now going to ask you to place all the people we’ve generated on this map according to how close you feel they are to you
- Please put those you feel closest to in the inner circles and those you feel less close to in the outer circles (record as 1 (close) > 6 (not close)).

- You can also place people outside the circle completely if you do not feel close to them at all, but please write everyone down somewhere.
- After you’ve placed everyone on the map I will ask you to draw lines between each person who knows each other - so please group people who know each other together in the same zone of the map.
a) All people are placed on map by going through sticky notes one by one — researcher can take lead on this where necessary.

b) Lines are drawn between each person who knows each other — each person is connected to others systematically starting with inner circle. Circles are drawn around groups in which everyone knows each other. Researcher probes to make sure everyone who knows each other is connected by going round each person and asking who they know. Coloured pens used to help keep map readable.

c) Inner circle — participant asked if they can rank inner circle by closeness — score put beside each.

d) Participant asked if anyone is missing — if so, complete a sticky note, Coding Sheet and Name Interpreter Card and add person to map.

Name Interpreter Questions

[Name Interpreter card]

- Researcher goes through the Name Interpreter Card questions one by one with the participant in relation to each person mentioned on the Coding Sheet.
- For each of the people you’ve mentioned, I am going to ask you a series of questions which you can see on the card in front of you.
- Please answer with the category that fits best

Network Satisfaction

- What is your overall satisfaction with your social network we have just mapped?
  [show participant scale below]
- Why is this?

1 2 3 4 5

Very satisfied Satisfied Unsure/Neutral Dissatisfied Very dissatisfied.

Close

Finally, do you have anything else that you would like to add?

Can you tell me how you have found this interview with me today?
Thank you for taking the time to talk with me today.

As we discussed earlier, I will go and transcribe and anonymise this interview and then destroy the recording. I will keep the first names/initials of the people you mentioned separate to the information you provided on the (Name Interpreter) Cards [show cards as prompt]. The (Name Interpreter) cards will be labelled with ID numbers and not names/initials. The Coding Sheet [show as prompt] links the ID numbers to the names/initials. I will not share this information with anyone other than the research team. All the (Name Interpreter) Cards with personal information will be locked away in a filing cabinet and will not be shared with anyone outside the research team. The coding sheet will be locked away in a separate filing cabinet so that the information you provided here [show Name Interpreter Card] cannot be linked to the people in your network.

I will then analyse the information about that we collected today to draw out and describe your social network.

If you are interested in being contacted about the follow-up interview study in one month’s time, I’ll contact you in a couple of weeks to arrange a second appointment. I will share your social network diagram with you at the next appointment.

If you do not wish to be contacted about the follow-up interview, I can send you the diagram of your network and a summary of the findings at the end of the study. Is this something you would be interested in receiving?

If you have any questions about the study, feel free to contact me [make sure they have the contact details].

Notes:

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<table>
<thead>
<tr>
<th>First Name/Initial</th>
<th>Code Number</th>
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<tr>
<td>Name Interpreter Card</td>
<td>Person code:</td>
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<td>-------------</td>
</tr>
<tr>
<td><strong>Gender</strong> [tick one option]</td>
<td><strong>Ethnic group</strong> [choose from list overleaf]</td>
</tr>
<tr>
<td>Male</td>
<td>..................................................</td>
</tr>
<tr>
<td>Female</td>
<td>..................................................</td>
</tr>
<tr>
<td><strong>Age</strong> [tick one option]</td>
<td><strong>What is your relationship to this person?</strong> [choose more than one if applicable but star the priority relationship]</td>
</tr>
<tr>
<td>Under 18</td>
<td>Immediate family member</td>
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<tr>
<td>18 to 24 years</td>
<td>Wider family member</td>
</tr>
<tr>
<td>25 to 34 years</td>
<td>Partner</td>
</tr>
<tr>
<td>35 to 44 years</td>
<td>Friend</td>
</tr>
<tr>
<td>45 to 54 years</td>
<td>Neighbour</td>
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<tr>
<td>55 to 64 years</td>
<td>Colleague</td>
</tr>
<tr>
<td>65 years or older</td>
<td>Healthcare professional</td>
</tr>
<tr>
<td><strong>How often are you in contact (face to face/telephone/internet) with this person?</strong> [tick one]</td>
<td><strong>Do they use mental health services?</strong></td>
</tr>
<tr>
<td>Everyday</td>
<td>Yes / No / Don’t know</td>
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<tr>
<td>At least once a week</td>
<td><strong>Do they know that you experience mental health problems?</strong></td>
</tr>
<tr>
<td>At least once a month</td>
<td>Yes / No / Don’t know</td>
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<tr>
<td>Occasionally</td>
<td><strong>How satisfied are you with the level of emotional support (comfort and reassurance) you receive from this person?</strong> [tick one option]</td>
</tr>
<tr>
<td>Never/ no longer</td>
<td>Very satisfied</td>
</tr>
<tr>
<td><strong>How long have you known this person?</strong> [tick one option]</td>
<td>Satisfied</td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>Unsure/Neutral</td>
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<tr>
<td>6 months to 5 years</td>
<td>Dissatisfied</td>
</tr>
<tr>
<td>5-10 years</td>
<td>Very dissatisfied</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>..................................................</td>
</tr>
<tr>
<td><strong>Name Generator Question</strong> [tick all that apply]</td>
<td><strong>How satisfied are you with the level of instrumental support (offer of help or assistance in tangible way) you receive from this person?</strong> [tick one option]</td>
</tr>
<tr>
<td>1 Reciprocal?</td>
<td>Yes No</td>
</tr>
<tr>
<td>2 Reciprocal?</td>
<td>Yes No</td>
</tr>
<tr>
<td>3 Reciprocal?</td>
<td>Yes No</td>
</tr>
<tr>
<td>4 Reciprocal?</td>
<td>Yes No</td>
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<tr>
<td>5 Reciprocal?</td>
<td>Yes No</td>
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<td>Reciprocal?</td>
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<td>6</td>
<td>Yes</td>
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<td>7</td>
<td>Yes</td>
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<td>8</td>
<td>Yes</td>
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<td>9</td>
<td>Yes</td>
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<td>10</td>
<td>Yes</td>
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</tbody>
</table>

**Ethnic Groups:**

- Black/African Caribbean
- Black African
- Black British
- Black ‘other’
- White British
- White Irish
- White Gypsy/Traveller
- White ‘other’
- Asian - Indian
- Asian - Pakistani
- Asian - Bangladeshi
- Asian - Chinese
- Asian ‘other’
- White and Black Caribbean
- White and Black African
- White and Asian
- Arab
- Other ethnic group
Emotional Closeness Map
APPENDIX VIII – SEARCH STRATEGY

SEARCH STRATEGY

EMBASE

1. exp schizophrenia/
2. exp psychosis/
3. (psychotic or schizo$ or psychosis or psychoses). ti.sh. hw.ab.kw.
4. [title, subject headings, heading words, abstract, key word]
5. ((chronic$ or sever$) adj5 mental$ adj5 (ill$ or disorder$)).ti.hw.ab.kw.sh
6. or/1-4
7. exp social network/
8. (network$) adj5 (social or fami$l or peer or friend$).ti.sh. hw.ab.kw.
9. (Egonet$ or ‘personal net$’ or ‘egocentric net$’). ti.sh. hw.ab.kw.
10. (tie$ or relation$ or contact$ or connect$) adj5 (social). ti.sh. hw.ab.kw.
11. or/ 6-9
12. 5 and 10

PsycINFO

1. exp schizophrenia/
2. exp psychosis/
3. (psychotic or schizo$* or psychosis or psychoses). ab.hw.id.sh.ti [abstract, heading word,
key concepts, subject heading, title]
4. ((chronic* or sever*) adj5 mental* adj5 (ill* or disorder*)). ab.hw.id.sh.ti
5. or/1-4
6. exp social networks/
7. (network*) adj5 (social or fami$l* or peer or friend*). ab.hw.id.sh.ti
8. (Egonet* or “personal net*” or “egocentric net*”). ab.hw.id.sh.ti
9. (tie* or relation* or contact* or connect*) adj5 (social). ab.hw.id.sh.ti
10. or/6-9
11. 5 and 10
12. Limit 11 to yr='1970-current’
MEDLINE

1. exp schizophrenia/
2. exp psychotic disorders/
3. (psychotic or schizo* or psychosis or psychoses).ab.hw.kw.sh.ti [abstract, subject heading word, keyword heading word, keyword heading, MeSH subject heading, title]
4. ((chronic* or sever*) adj5 mental* adj5 (ill* or disorder*)).ab.hw.kw.sh.ti
5. or/1-4
6. (network*) adj5 (social or famil* or peer or friend*). ab.hw.kw.sh.ti
7. (Egonet* or “personal net**” or “egocentric net**”).ab.hw.kw.sh.ti
8. (tie* or relation* or contact* or connect*) adj5 (social). ab.hw.kw.sh.ti
9. or/6-8
10. 5 and 9
11. Limit 11 to yr='1970-current'

WEB OF SCIENCE

1. TS=(psychotic OR schizo* OR psychos$s) [= TOPIC: title, abstract, author key words, key word plus]
2. TS=((chronic* OR sever*) NEAR/5 mental* NEAR/5 (ill* OR disorder*))
3. OR/1-2
4. TS=((network*) NEAR/5 (social OR famil* OR peer OR friend*))
5. TS=(egonet* OR "personal net**" OR "egocentric net**")
6. TS=((tie* OR relation* OR contact* OR connect*) NEAR/5 (social))
7. OR/4-5
8. 3 AND 7
APPENDIX IX – QUALITY ASSESSMENT TOOL

Effective Public Health Practice Project (EPHPP)

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES (ADAPTED*)

Common types of design include: (A) non-randomized controlled trials, and (B-C-D) observational analytic study or component where the intervention/exposure is defined/assessed, but not assigned by researchers.

A. Non-randomized controlled trials
   The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups.

B. Cohort study
   Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal).

C. Case-control study
   Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective).

D. Cross-sectional analytic study
   At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population sub-groups according to the presence/absence (or level) of the intervention/exposure.

*This measure has been adapted for use in a review of studies including cross-sectional and cohort (prospective, longitudinal) analytical designs

*The following subscales have been omitted:

- B – STUDY DESIGN
- D – BLINDING Q1 AND Q2
- G – INTERVENTION INTEGRITY Q1, Q2 AND Q3
- H – ANALYSES Q1, Q2, AND Q4
COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?
Very likely
Somewhat likely
Not likely
Can’t tell

(Q2) What percentage of selected individuals agreed to participate?
1. 80 – 100%
2. 60 – 79%
3. Less than 60% agreement
4. Not applicable
5. Can’t tell

<table>
<thead>
<tr>
<th>RATE SECTION</th>
<th>THIS</th>
<th>STRONG</th>
<th>MODERATE</th>
<th>WEAK</th>
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<tr>
<td>See dictionary</td>
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<td>3</td>
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DICTIONARY: SELECTION BIAS

(Q1) Participants are more likely to be representative of the target population if they are randomly selected from a comprehensive list of individuals in the target population (score very likely). They may not be representative if they are referred from a source (e.g. clinic) in a systematic manner (score somewhat likely) or self-referred (score not likely).

(Q2) Refers to the % of subjects in the control and intervention groups that agreed to participate in the study before they were assigned to intervention or control groups.

STUDY SPECIFIC NOTES: SELECTION BIAS

(Q1) They may not be representative if they are referred from a source (e.g. clinic) in a non-systematic manner (e.g. convenience sample approached based on service such as Early Intervention Services) or subsample selected from an earlier study (score not likely). If there are two groups (e.g. clinical and control) then answer question with relevance to both.

(Q2) This includes declines only and does not include those who were approached but do not meet inclusion criteria.*When papers did not give details of selection procedures, but direct you to another paper/provide reference for further details then rate based on this info but do make a note for discussion
A: SELECTION BIAS SCORING

**Strong:** The selected individuals are very likely to be representative of the target population (Q1 is 1) and there is greater than 80% participation (Q2 is 1).

**Moderate:** The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); and there is 60 - 79% participation (Q2 is 2). ‘Moderate’ may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can’t tell).

**Weak:** The selected individuals are not likely to be representative of the target population (Q1 is 3); or there is less than 60% participation (Q2 is 3) or selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).

B) CONFOUNDERS

(Q1) Were important differences between groups taken into account (controlled for) in the analysis (or design)?

Yes
No
Can’t tell

**STUDY SPECIFIC NOTES: CONFOUNDERS**

The following are examples of confounders in the relationship between social networks and outcomes of interest (i.e. symptoms, relapse/readmission (service use), treatment/service engagement, social functioning, and quality of life).

Ethnic group; Gender; Age; Education/employment; Marital status; Social class/socioeconomic factors/financial strain; Living status/residence Diagnosis; Service (inpatient/outpatient, acute/rehab, community care/CMHT/CPN); Medication use; Substance misuse; Duration/severity of mental health problem General psychopathology factors (e.g. depression, anxiety); Outcomes of interest (e.g. positive/negative symptoms, social/occupational/personal functioning, service use/hospital admission, engagement/alliance, quality of life); Baseline score on follow-up score

(Q2) If yes, indicate the percentage of relevant confounders that were controlled - either in the design (e.g. stratification, matching) or analysis?

80 – 100% (most)
60 – 79% (some)
Less than 60% (few or none)
Can’t Tell
Not applicable
DICTIONARY: CONFOUNDERS

By definition, a confounder is a variable that is associated with both the independent variable and the dependent variable. The authors should indicate if confounders were controlled in the design [by stratification or matching] or in the analysis. There should be no obvious dissimilarities between groups that may account for differences in outcomes.

STUDY SPECIFIC NOTES: CONFOUNDERS

While specific definitions may vary, in essence a confounding variable fits the following four criteria, here given in a hypothetical situation with variable of interest "V", confounding variable "C" and outcome of interest "O":

1. C is associated (inversely or directly) with O
2. C is associated with O, independent of V
3. C is associated (inversely or directly) with V
4. C is not in the causal pathway of V to O (C is not a direct consequence of V, not a way by which V produces O)

*Please note question 1 includes in analysis but we have changed this to also include research design*

Examples of controlling for confounders in analysis include comparing groups (e.g. t-test) to check for differences if one group not included in analysis; partial correlation; controlling for variables in regression; covariates in ANCOVAs

Examples of controlling for confounders in design include restriction (e.g. control for gender and age by including all males over 60 years) and matching (e.g. for age and gender – also have to control for this in analysis as use different stats to unmatched studies) and randomisation (i.e. equal chance of being in each group, so likely similar distribution of confounding factors – success can be examined via statistical comparison of baseline characteristics)

*Focus on ALL analyses relevant to review question and reported in each paper (not just meta-analysis on size and outcome). Rate for all papers, including those not included in the meta-analysis and just in narrative review.*
(Q1) If some attempt to control for confounders in either analysis or design rate as ‘yes’ (NB., where there are more than two analyses in one paper, if control for confounders in only one (e.g. regression but not t-tests) still rate yes – can rate the extent via percentage rating in Q2).

(Q2). Where there are two or more relevant analyses, the rating for percentage of confounders will be analysed across all relevant analyses (e.g. if there are two relevant analyses and a number of confounds are adjusted for but only in one out of the two analyses, then rate across both and reduce the final percentage rating – cannot score higher than ‘60-79%’)

- Rating of 80-100% (most) = 2+ confounders controlled for in analysis or design (where applicable)
- Rating 60-79% (some) = 1+ confounders controlled for in analysis or design (where applicable)
- Rating less than 60% (few or none) = No attempt to control for confounders in analysis or design (where applicable)

*Where Q1 is no, Q2 is not applicable.

B: CONFOUNDERS SCORING

**Strong:** will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); or (Q2 is 1).

**Moderate:** will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) and (Q2 is 2).

**Weak:** will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) and (Q2 is 3) or control of confounders was not described (Q1 is 3) and (Q2 is 4).

C) DATA COLLECTION METHODS

C1: OUTCOME MEASURE

(Q1) Were the data collection tools for outcome measure(s) shown to be valid?

- Yes
- No
- Can’t tell
- Not applicable – service use data*

(Q2) Were the data collection tools for outcome measure(s) shown to be reliable?

- Yes
- No
- Can’t tell
- Not applicable – service use data*
* Service use measures (e.g. hospital admission, length of stay, types of services used etc.) tend to be rated from medical case notes or other clinical records and assessment tools are not typically psychometrically validated. Service use assessment tools are therefore rated as ‘not applicable’ in the questions relating to their validity and reliability and separate scoring criteria has been developed in C1: OUTCOME ASSESSMENTS.

C2: SOCIAL NETWORK MEASURE

(Q1) Were the data collection tools for the social network measure(s) shown to be valid?
Yes
No
Can’t tell

(Q2) Were the data collection tools for the social network measure(s) shown to be reliable?
Yes
No
Can’t tell

(Q3) Was the data collection tool for the measure of social network size deemed to be adequate?

Yes - the tool was adequate i.e. the respondent was asked to provide a list of network members in response to more than one question (e.g. network mapping tool, network schedule)

No – the tool was deemed inadequate i.e. the measure of network size was capped (e.g. maximum number of 10); responses were categorical or made on a Likert scale; only one single study specific item was used; only one type of relationship measured (e.g. friend)

Can’t tell – there is not enough detail to rate as yes or no

Not applicable - no measure of size*

*The study did not measure network size (do not include Q3 in rating if not relevant and follow the scoring procedure detailed in C1: OUTCOME assessments)
DICTIONARY: DATA COLLECTION METHODS

Tools for primary outcome measures must be described as reliable and valid. If ‘face’ validity or ‘content’ validity has been demonstrated, this is acceptable. Some sources from which data may be collected are described below:

Self-reported data includes data that is collected from participants in the study (e.g. completing a questionnaire, survey, answering questions during an interview, etc.). Assessment/Screening includes objective data that is retrieved by the researchers. (e.g. observations by investigators). Medical Records/Vital Statistics refers to the types of formal records used for the extraction of the data.

Reliability and validity can be reported in the study or in a separate study. For example, some standard assessment tools have known reliability and validity.

STUDY SPECIFIC NOTES: DATA COLLECTION METHODS

*Data collection ratings will be made for measures relevant to the review question. For the purpose of this study, the component has been divided into two subcomponents: 1) outcome measure(s); and 2) social network measure(s). Ratings will be conducted in relation to the social network measure(s) and the outcome(s) of interest only (and not in relation to other reported measures).

*For both subcomponents, if there is more than one measure and one is valid/ reliable and the other is not valid/ reliable, rate ‘no’. All measures have to have some indication of validity/reliability to rate ‘yes’.

*If papers have used reliable and validated outcome measures but have translated these into another language or modified them, these modified versions would need to have demonstrable validity/reliability

*For the social network measure, where studies have used network-mapping measures but these are ‘study-specific’ rather than an established tool (e.g. Social Network Schedule, Dunn et al., 1990), you can still rate as valid/ reliable based on theoretical literature relating to that tool (e.g. name generator and name interpreter techniques which are grounded in Social Network Analysis (Mitchell et al., 1969) and have been used in a range of populations and disciplines) and its analysis (e.g. Social Network Analysis; Crossley et al., 2015).

C1: DATA COLLECTION METHODS SCORING – OUTCOME

Strong: The data collection tools have been shown to be valid (Q1 is ‘yes’); and the data collection tools have been shown to be reliable (Q2 is ‘yes’).
*For service use data, a strong rating is given when a validated or published rating scale has been used to extract data from clinical case notes or medical records.

**Moderate:** The data collection tools have been shown to be valid (Q1 is ‘yes’); and the data collection tools have not been shown to be reliable (Q2 is ‘no’) or reliability is not described (Q2 is ‘can’t tell’).

*For service use data, a moderate rating given when data has been extracted from clinical case notes or medical records; or if more than one data source has been used (e.g. case notes and interview) but none of these meet criteria for a strong rating.

**Weak:** The data collection tools have not been shown to be valid (Q1 is no) or both reliability and validity are not described (Q1 and Q2 is ‘can’t tell’).

*For service use data, a weak rating is given when data has been obtained through self-report assessment tools or interviews; or if the assessment tool has not been described.

For studies assessing BOTH service use and other outcomes, score the outcome measure(s) as normal and the service use outcome separately – so you have two ratings. Then create a total score using the following criteria:

**Strong:** two strong ratings

**Moderate:** one strong and one moderate rating (no weak ratings)

**Weak:** at least one weak rating

**C2: DATA COLLECTION METHODS SCORING – SOCIAL NETWORK**

**Strong:** The data collection tools have been shown to be valid (Q1 is ‘yes’) or reliable (Q2 is ‘yes’); **AND** the measure of size is adequate (Q3 is ‘yes’).

**Moderate:** The data collection tools have not been shown to be valid or reliable (Q1 and Q2 is ‘yes’); or both reliability and validity are not described (Q1 and Q2 is ‘can’t tell’); **OR** the measure of size is inadequate or not sufficiently described (Q3 is ‘no’ or ‘can’t tell’).

**Weak:** The data collection tools have not been shown to be valid or reliable (Q1 and Q2 is ‘yes’); or both reliability and validity are not described (Q1 and Q2 is ‘can’t tell’); **AND** the measure of size is inadequate or not sufficiently described (Q3 is ‘no’ or ‘can’t tell’).
D) WITHDRAWALS AND DROP-OUTS (if applicable)

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?
Yes
No
Can’t tell
Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).
80 -100%
60 - 79%
less than 60%
Can’t tell
Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION | STRONG | MODERATE | WEAK | Not Applicable
--- | --- | --- | --- | ---
See dictionary | 1 | 2 | 3 | 

DICTIONARY: WITHDRAWALS AND DROP-OUTS

(Q1) Score YES if the authors describe BOTH the numbers and reasons for withdrawals and drop-outs.
Score NO if either the numbers or reasons for withdrawals and drop-outs are not reported.

(Q2) The percentage of participants completing the study refers to the % of subjects remaining in the study at the final data collection period.

STUDY SPECIFIC NOTES: WITHDRAWALS AND DROP-OUTS

*Rating not applicable for one time point cross-sectional studies – only rate for longitudinal studies

(Q1) If withdrawals are not referred to in the paper, and the ‘n’ included in the analysis is the same as the ‘n’ for the original sample, presume there are no drop outs.

*Consider how many were included in the analysis. If the ‘n’ in the reported results (e.g. tables) is different to the original ‘n’ but the authors do not explicitly report the withdrawals/drop-outs/missing data in the text then rate as ‘no’. If they report the numbers but do not give reasons then also report as ‘no’. Must report both for a rating of ‘yes’.
D: WITHDRAWALS AND DROP-OUTS SCORING

**Strong:** will be assigned when the follow-up rate is 80% or greater (Q2 is 1).
**Moderate:** will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) **OR** Q2 is 5 (N/A).
**Weak:** will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q2 is 4).

**Not applicable** = no follow up (not longitudinal)

E) ANALYSES

(Q1) Was the quantitative analysis appropriate to the research question and the statistical methods appropriate for the study design?

  Yes
  No
  Can’t tell

**STUDY SPECIFIC NOTES: ANALYSES**

* Consider this rating in terms of whether the analysis was appropriate and reported in a way that it is clear how it illuminates the research questions

*Rate yes if some level of clarity. If score yes, can then score strong or moderate depending on extent to which appropriate and reported in such a way that it is clear how answers aims/ research questions (see scoring).

*When assessing whether the analysis was appropriate for the question asked, consider sample size and power analyses, type of statistical test, correcting for Type I error (e.g. conservative p value, using Bonferroni adjustment where multiple comparisons) and handling of skewness (e.g. transformation) and missing data (e.g. listwise deletion, imputation).

*Consider whether the authors report analysis clearly – Is the analysis clearly reported? (I.e. is there an analysis section in the methods or is the analysis sufficiently described in the results?) Are relevant statistics presented? Do the authors report and justify decisions (e.g. power analysis for sample size and p values)? Do the authors report the distribution of data and skewness statistics? Do the authors report missing data?
E. ANALYSES SCORING

**Strong:** will be assigned when the analysis is appropriate and reported in a way that it is clear how it illuminates the research questions (*Q1 is yes*). *The authors provide a clear description of analysis and report relevant information, such as that relating to sample size estimates/power analysis, statistical test, choice of p value, skewness and missing data.*

**Moderate:** will be assigned when the analysis is appropriate but is not reported in a way that it is clear how it illuminates the research questions (*Q1 is yes or can’t tell*). *The analysis is appropriate but it is not reported clearly and/or is missing relevant information relating to sample size estimates/power analysis, statistical test, choice of p value, skewness and missing data.*

**Weak:** will be assigned when the analysis is not appropriate, or it is not clear (*Q1 is no or can’t tell*). *The analysis is not appropriate or the analysis seems appropriate but it is reported in such a way that it is unclear how it relates to the research question and no relevant information relating to the analysis is provided.*

*NB in the original version of the tool, the analysis section was omitted from the global scoring but it is included in our adapted version*

*Additional guidance (italicised text) has been added to the anchor points to aid scoring*
**SCORING**

**COMPONENT RATINGS**

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

<table>
<thead>
<tr>
<th></th>
<th>Selection bias</th>
<th>Strong</th>
<th>Moderate</th>
<th>Weak</th>
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<tbody>
<tr>
<td>A</td>
<td></td>
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<tr>
<td>B</td>
<td>Confounders</td>
<td>Strong</td>
<td>Moderate</td>
<td>Weak</td>
</tr>
<tr>
<td>C</td>
<td>Data collection method</td>
<td>Strong</td>
<td>Moderate</td>
<td>Weak</td>
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<td></td>
<td>C1-Outcome</td>
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<td></td>
<td>C2-Social networks</td>
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<tr>
<td>D</td>
<td>Withdrawals and dropouts</td>
<td>Strong</td>
<td>Moderate</td>
<td>Weak</td>
</tr>
<tr>
<td>E</td>
<td>Analysis</td>
<td>Strong</td>
<td>Moderate</td>
<td>Weak</td>
</tr>
</tbody>
</table>

**GLOBAL RATING FOR THIS PAPER (circle one):**

1 STRONG (no WEAK ratings)
2 MODERATE (one WEAK rating)
3 WEAK (two or more WEAK ratings)

With both reviewers discussing the ratings:
Is there a discrepancy between the two reviewers with respect to the component (A-D) ratings?

If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

**Final decision of both reviewers (circle one):**

1 STRONG
2 MODERATE
3 WEAK
Component Ratings of Study:

For each of the six components A – E, use the following descriptions as a roadmap.

A: SELECTION BIAS SCORING

**Strong:** The selected individuals are very likely to be representative of the target population (Q1 is 1) and there is greater than 80% participation (Q2 is 1).

**Moderate:** The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); and there is 60 - 79% participation (Q2 is 2). ‘Moderate’ may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can’t tell).

**Weak:** The selected individuals are not likely to be representative of the target population (Q1 is 3); or there is less than 60% participation (Q2 is 3) or selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).

B: CONFOUNDERS SCORING

**Strong:** will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); or (Q2 is 1).

**Moderate:** will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) and (Q2 is 2).

**Weak:** will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) and (Q2 is 3) or control of confounders was not described (Q1 is 3) and (Q2 is 4).

C1: DATA COLLECTION METHODS SCORING - OUTCOME

**Strong:** The data collection tools have been shown to be valid (Q1 is ‘yes’); and the data collection tools have been shown to be reliable (Q2 is ‘yes’).

**Moderate:** The data collection tools have been shown to be valid (Q1 is ‘yes’); and the data collection tools have not been shown to be reliable (Q2 is ‘no’) or reliability is not described (Q2 is ‘can’t tell’).

**Weak:** The data collection tools have not been shown to be valid (Q1 is no) or both reliability and validity are not described (Q1 and Q2 is ‘can’t tell’).

C2: DATA COLLECTION METHODS SCORING – SOCIAL NETWORK

**Strong:** The data collection tools have been shown to be valid (Q1 is ‘yes’); and the data collection tools have been shown to be reliable (Q2 is ‘yes’); AND the measure of size is adequate (Q3 is ‘yes’).

**Moderate:** The data collection tools have not been shown to be valid or reliable (Q1 and Q2 is ‘yes’); or both reliability and validity are not described (Q1 and Q2 is ‘can’t tell’);
OR the measure of size is inadequate or not sufficiently described (Q3 is ‘no’ or ‘can’t tell’).

Weak: The data collection tools have not been shown to be valid or reliable (Q1 and Q2 is ‘yes’); or both reliability and validity are not described (Q1 and Q2 is ‘can’t tell’); AND the measure of size is inadequate or not sufficiently described (Q3 is ‘no’ or ‘can’t tell’).

D: WITHDRAWALS AND DROP-OUTS SCORING

Strong: will be assigned when the follow-up rate is 80% or greater (Q2 is 1).
Moderate: will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) OR Q2 is 5 (N/A).
Weak: will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q2 is 4).

Not applicable = no follow up (not longitudinal)

E. ANALYSES SCORING

Strong: will be assigned when the analysis is appropriate and reported in a way that it is clear how it illuminates the research questions (Q1 is yes). The authors provide a clear description of analysis and report relevant information, such as that relating to sample size estimates/power analysis, statistical test, choice of p value, skewness and missing data.

Moderate: will be assigned when the analysis is appropriate but is not reported in a way that it is clear how it illuminates the research questions (Q1 is yes or can’t tell). The analysis is appropriate but it is not reported clearly and/or is missing relevant information relating to sample size estimates/power analysis, statistical test, choice of p value, skewness and missing data.

Weak: will be assigned when the analysis is not appropriate, or it is not clear (Q1 is no or can’t tell). The analysis is not appropriate or the analysis seems appropriate but it is reported in such a way that it is unclear how it relates to the research question and no relevant information relating to the analysis is provided.

*NB in the original version of the tool, the analysis section was omitted from the global scoring but it is included in our adapted version*

*Additional guidance (italicised text) has been added to the anchor points to aid scoring*
## APPENDIX X – SAMPLE CHARACTERISTICS OF INCLUDED STUDIES

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Setting/ sample</th>
<th>Diagnosis (% SS; screening tool)</th>
<th>Duration SS, years (Mean)</th>
<th>Total N (M/F)</th>
<th>Age, years (Mean)</th>
<th>Ethnicity (N/%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allison et al. (2013)</td>
<td>EIP teams</td>
<td>100% ICD-10 F20-29 clinical referral</td>
<td>2.3³</td>
<td>24 (18/6)</td>
<td>23</td>
<td>WB (11/46%), Black (2/8%), Asian (6/25%), Other (4/17%)</td>
</tr>
<tr>
<td>Angell &amp; Test (1992)</td>
<td>Secondary analysis data PACT trial: RCT of assertive community treatment in young adults with early onset schizophrenia</td>
<td>98% (2% schizotypy) clinical referral</td>
<td>na</td>
<td>87 (62/25)</td>
<td>N/% 20-24 (44, 50) 25-29 (26, 30) 30-32 (17, 20)</td>
<td>Caucasian (83/95%), AA (3/4%), Latino (1/1%)</td>
</tr>
<tr>
<td>Becker et al. (1998)</td>
<td>Prospective controlled evaluation study of community mental health services in two inner city areas – baseline data for random sample of psychosis</td>
<td>83% (17% AD) OPCRIT functional psychosis; ICD-10 SCAN</td>
<td>16.2</td>
<td>143 (80/63)</td>
<td>38.6</td>
<td>White (87/61%), BC (41/29%), BA (11/8%)</td>
</tr>
<tr>
<td>Cechnicki &amp; Wojciechowska (2008)</td>
<td>Krakow longitudinal study: community outpatient ward for psychosis rehab – evaluated 7 years after first hospitalisation</td>
<td>100% DSM-III clinical diagnosis</td>
<td>na</td>
<td>64 (28/36)</td>
<td>32</td>
<td>Na</td>
</tr>
<tr>
<td>Cohen et al. (1997)</td>
<td>Older adults (≥55 years) with schizophrenia living in community</td>
<td>100% DSM III-R clinical diagnosis</td>
<td>na</td>
<td>117 (29/88)</td>
<td>63</td>
<td>White (41/35%), Black (47/39%), Latino (29/25%)</td>
</tr>
<tr>
<td>Cresswell et al. (1992)</td>
<td>Day outpatients at rehab centre inner-city hospital</td>
<td>100% Hospital case notes, clinical report</td>
<td>16.7</td>
<td>40 (31/9)</td>
<td>41.7</td>
<td>Caucasian (26/65%); non-Caucasian (14/35%)</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Design/Methodology</td>
<td>Classification</td>
<td>Sample Size</td>
<td>Duration</td>
<td>Ethnicity</td>
</tr>
<tr>
<td>---------------------</td>
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<td>------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Dixon et al. (2001)</td>
<td>USA</td>
<td>Reanalysis data from EIDP: multi-site RCT comparing two vocational interventions for people with SMI</td>
<td>DSM-IV SCID</td>
<td>218(123/95)</td>
<td>41</td>
<td>Caucasian (53/24%), AA (143/65%), Other (11/23%)</td>
</tr>
<tr>
<td>Hamilton et al. (1989)</td>
<td>USA</td>
<td>Veterans mental health clinic (&gt;2 years schizophrenia)</td>
<td>DSM-III clinical diagnosis, research screening interview</td>
<td>11</td>
<td>39 (39/0)</td>
<td>Caucasian (33/85%)</td>
</tr>
<tr>
<td>Horan et al. (2006)</td>
<td>USA</td>
<td>Subsample DPSD project: longitudinal study schizophrenia with first episode psychosis (&lt;2 years)</td>
<td>DSM-III-R, PSE</td>
<td>1.3</td>
<td>T1: 89 (75/14) T2: 34(na)</td>
<td>Caucasian (77/86%)</td>
</tr>
<tr>
<td>Howard et al. (2000)</td>
<td>UK</td>
<td>PRiSM psychosis study; prospective non-randomised controlled trial two community mental health services</td>
<td>DSM-III-R, PSE</td>
<td>302 (143/159)</td>
<td>Med=40 Range=15-89</td>
<td>Caucasian (193/64%), BC (74/24%), BA (17/6%), Other (14/5%), missing (4/1%)</td>
</tr>
<tr>
<td>Macdonald et al. (1998)</td>
<td>Australia</td>
<td>Outpatients three inner-suburban community mental health clinics (≥ 2 months discharged acute episode)</td>
<td>DSM-III-R; psychiatrist report &amp; interview clinical psychologist</td>
<td>5.6</td>
<td>46 (34/12) 34(9.3)</td>
<td>Na</td>
</tr>
<tr>
<td>Sibitz et al. (2011)</td>
<td>Austria</td>
<td>Inpatients &amp; outpatients of medical university &amp; various mental health centres</td>
<td>ICD-10 criteria</td>
<td>13.5</td>
<td>157 (85/72) 37.3</td>
<td>White (100%)</td>
</tr>
<tr>
<td>Thorup et al. (2006)</td>
<td>Denmark</td>
<td>Subsample OPUS trial; RCT integrated versus usual treatment in first episode psychosis - inpatient &amp; outpatient services</td>
<td>ICD-10 SCAN</td>
<td>Na</td>
<td>547(323/224) Range=18-45</td>
<td>Na</td>
</tr>
</tbody>
</table>
**Poland**

outpatient ward for psychosis rehab – evaluated 3 years after first hospitalisation

**Note:**

Studies deleted as same study samples: ¹Cechnicki et al. (2008), Poland; ²Goldberg et al. (2003), USA; ³defined as first contact with services; ⁴mean unless otherwise stated

**Trials/studies**

DPDS=Developmental Processes in Schizophrenia Disorders project (Nuechterlein et al., 1992); EIDP=Employment Intervention Demonstration Program (Lehman et al., 2002); LPD=The Study of Low Prevalence disorders (Jablensky et al., 2000); PACT= Programme of Assertive Community Treatment (Test et al., 1991); PRiSM psychosis study (Thornicroft et al., 1998); OPUS trial (Peterson et al., 2005).

**Diagnostic screening measures**

DSM=Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association: DSM-III,1980; DSM-III-R, 1987; DSM-IV, 1994); ICD-10= International Classification of Disease-10 (WHO, 1992); ICD-9 (WHO, 1978); ICD F20-29= schizophrenia, schizoaffective disorder, delusional disorder, schizophreniform disorder, or psychosis not otherwise specified; LIS=Lifetime Illness Review (Jeste, 1997); PSE=Present State Examination (Wing et al., 1974); OPCRIT=Operational Criteria Checklist (McGuffin et al., 1991); SCAN= Schedules for Clinical Assessment in Neuropsychiatry (World Health Organisation, 1992ab); SCID (First et al., 1994).

**Abbreviations**

AD=affective disorders; AA=African American; AP=affective psychosis; BA=Black African; BC=Black Caribbean; EIP=Early Intervention in Psychosis; F=female; M=male; Med=median; na=not reported or not available; OP=other psychosis; RCT=randomised controlled trial; SMI=serious mental illness; SS=schizophrenia spectrum; T1=Time 1; T2=Time 2; UK; United Kingdom; USA=United States of America; WB=White British

**APPENDIX XI – CHARACTERISTICS OF SOCIAL NETWORK MEASURES**

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Measure Assessment tool</th>
<th>Network criteria</th>
<th>Time period</th>
<th>Network members /composition*</th>
<th>Network size Time 1 M (SD)^</th>
<th>Network size Time 2 M (SD)^</th>
<th>Network variables</th>
</tr>
</thead>
</table>

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<table>
<thead>
<tr>
<th>Study Authors</th>
<th>Year</th>
<th>Country</th>
<th>Instrument</th>
<th>Method</th>
<th>Reference</th>
<th>Sample Size</th>
<th>Measure/Outcome</th>
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</thead>
<tbody>
<tr>
<td>Allison et al.</td>
<td>2013</td>
<td>UK</td>
<td>Modified PRQ</td>
<td>Questionnaire</td>
<td>Present Friends</td>
<td>4.3 (2.91)</td>
<td>-</td>
</tr>
<tr>
<td>Angell &amp; Test</td>
<td>2013</td>
<td>UK</td>
<td>CAF - Semi-structured interview</td>
<td>Questionnaire</td>
<td>Past month Friends</td>
<td>T1: 2.5 (2.94)  T2: 2.7 (2.82)</td>
<td>Size Reciprocity</td>
</tr>
<tr>
<td>Becker et al.</td>
<td>1998</td>
<td>UK</td>
<td>SNS Semi-structured interview</td>
<td>Semi-structured interview</td>
<td>Past month Total</td>
<td>12.8</td>
<td>-</td>
</tr>
<tr>
<td>Cechnicki &amp; Wojciechowska</td>
<td>2008</td>
<td>Poland</td>
<td>BQ Questionnaire</td>
<td>Number of network contacts</td>
<td>Present Total ≤10</td>
<td>24%</td>
<td>Size Composition</td>
</tr>
<tr>
<td>Cohen et al.</td>
<td>1997</td>
<td>USA</td>
<td>Modified NAP Semi-structured interview</td>
<td>Number of people with notable interaction</td>
<td>Past 3 months Total</td>
<td>na</td>
<td>-</td>
</tr>
<tr>
<td>Cresswell et al.</td>
<td>1992</td>
<td>UK</td>
<td>SNIS Semi-structured interview</td>
<td>Number of persons currently in contact</td>
<td>Primary (family and friends) and secondary Seen or in contact past 12 months</td>
<td>Primary 12 months</td>
<td>7</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Question/Method</td>
<td>Sample Description</td>
<td>Present</td>
<td>Support Network</td>
<td>Size</td>
<td>Density</td>
</tr>
<tr>
<td>-------------------------------------------</td>
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<tr>
<td>Dixon et al. (2001) USA</td>
<td>Study specific</td>
<td>Single question</td>
<td>Number of people who meet instrumental and/or affiliative needs and seen weekly</td>
<td>Present</td>
<td>Support network</td>
<td>na</td>
<td>-</td>
</tr>
<tr>
<td>Goldberg et al. (2003) USA</td>
<td>Modified SSSNI</td>
<td>Semi-structured interview</td>
<td>Maximum ten critical members of social network who provide support in some capacity</td>
<td>Present</td>
<td>Total</td>
<td>4.18(2.27)</td>
<td>-</td>
</tr>
<tr>
<td>Hamilton et al. (1989) USA</td>
<td>Modified PPKI</td>
<td>Semi-structured interview (+ verified list via significant other)</td>
<td>Number of kin and non-kin</td>
<td>Present</td>
<td>Total</td>
<td>12.9(9.2)</td>
<td>-</td>
</tr>
<tr>
<td>Horan et al. (2006) USA</td>
<td>Study specific</td>
<td>Semi-structured interview</td>
<td>Number of people in contact with and/or feels close to 12 month period prior to hospitalisation</td>
<td>T1: 8.8(3.8)</td>
<td>T2: 8.7(3.0)</td>
<td>T1: 3.9(2.4)</td>
<td>T2: 3.3(1.5)</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Method</td>
<td>Number of network contacts</td>
<td>Past month</td>
<td>Total</td>
<td>Med(R)</td>
<td>Med(R)</td>
</tr>
<tr>
<td>-----------------------</td>
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</tr>
<tr>
<td>Howard et al. (2000)</td>
<td>UK</td>
<td>SNS Semi-structured interview</td>
<td>Number of network contacts</td>
<td>Past month</td>
<td>Total</td>
<td>Med(R)</td>
<td>Med(R)</td>
</tr>
<tr>
<td>Macdonald et al. (1998)</td>
<td>Australia</td>
<td>SRS – two subscales response</td>
<td>Maximum of six people whom person talks to for six different areas of life (work, money and finances, home and family, personal and social, personal health, societal issues)</td>
<td>Present</td>
<td>Total</td>
<td>6.3(3)</td>
<td>-</td>
</tr>
<tr>
<td>Sibitz et al. (2011)</td>
<td>Austria</td>
<td>Study specific single question</td>
<td>Number of social contacts with four possible answers ('no or little social contacts', 'few acquaintances', 'few close friends', 'sufficient friends and acquaintances')</td>
<td>Present</td>
<td>Number of friends</td>
<td>4.6(5.0)</td>
<td>-</td>
</tr>
<tr>
<td>Thorup et al. (2006)</td>
<td>Denmark</td>
<td>SNS Semi-structured interview</td>
<td>Number of family and friends in contact with (up to maximum of 25)</td>
<td>Previous month</td>
<td>Total</td>
<td>T1=7.6</td>
<td>T2=8.2</td>
</tr>
<tr>
<td>Wojciechow et al. (2002)</td>
<td>BQ</td>
<td>Questionnaire</td>
<td>Number of persons currently in contact</td>
<td>Present</td>
<td>Total</td>
<td>na</td>
<td>-</td>
</tr>
<tr>
<td><strong>Poland</strong></td>
<td>303</td>
<td></td>
<td></td>
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<tr>
<td>with: ≤10=small; 11&gt;20=average; &gt;21=large</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age of network</th>
<th>Type of support system</th>
<th>Amount of support</th>
<th>Localisation of support</th>
</tr>
</thead>
</table>

**Note:**

Description of measures based on information reported in the articles; *only some network types mutually exclusive; ¹Cechnicki et al. (2008) deleted as reports same network characteristics for same study sample; ²report on overlapping samples but different network characteristics; ³M and SD, unless otherwise stated; bold text is structural characteristics that have been examined in relation to outcomes in the studies (some studies described structural characteristics but not did not examine their association with outcomes).**

**Abbreviations**

M=mean; Med=median; MH=mental health; na=not reported or not available; R=range; SD=standard deviation; T1=Time 1; T2=Time 2.

**Social network measures**

BQ=Bizon’s Questionnaire (Bizon et al., 2001); CAF=Community Adjustment Form (Test et al., 1991); NAP=Network Analysis Profile (Cohen & Sokolovsky, 1979, 1981); PPKI=Pattison Psychosocial Kinship Inventory (Pattison et al., 1981); PRQ=Peer Relations Questionnaire (Connolly & Johnson, 1996); SNIS=Social Network Interview Schedule (Sheperd, 1984); SNS=Social Network Schedule (Dunn et al., 1990); SSSNI=Social Support and Social Network Interview (Lovell et al., 1984); SRS=Social Relationships Scale (McFarlane et al., 1981).
S4.1 Forest plot of the association between social network size and overall psychiatric symptoms

S4.2 Forest plot of the association between social network size and negative symptoms
S4.3 Forest plot of the association between social network size and positive symptoms

S4.4 Forest plot of the association between social network size and social functioning

APPENDIX XIII – FUNNEL PLOTS FOR META-ANALYSIS

FUNNEL PLOTS
Funnel plot for the association between social network size and overall psychiatric symptoms

Funnel plot for the association between social network size and negative symptoms
Funnel plot for the association between social network size and positive symptoms

Funnel plot for the association between social network size and social functioning
APPENDIX XIV – RESULTS OF NON-LINEAR ANALYSES FOR SOCIAL NETWORKS AND ENGAGEMENT

NON-LINEAR ANALYSES FOR SIZE

*Differences across social network size subgroups (quintiles) for service user- and staff- reported engagement measures*

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD) [95% CI] for social network subgroups (quintiles)</th>
<th>ANOVA F(df)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SES total</td>
<td>13.27 (8.15) 10.38 (8.55) 10.00 (6.53) 9.25 (6.18) 6.78 (6.20)</td>
<td>.761</td>
</tr>
<tr>
<td></td>
<td>[7.57, 19.23] [3.23, 17.52] [3.96, 16.04] [4.08, 14.42] [2.01, 11.54]</td>
<td>(4, 41)</td>
</tr>
<tr>
<td>SOLES total</td>
<td>112.09 (31.15) 121.70 (31.42) 125.86 (17.73) 113.75 (19.21) 129.10 (29.26)</td>
<td>.698</td>
</tr>
<tr>
<td></td>
<td>[91.17, 133.02] [99.22, 144.18] [109.46, 142.26] [97.69, 129.81] [108.17, 150.03]</td>
<td>(4, 41)</td>
</tr>
</tbody>
</table>

*Note: Imputed means for missing data (≤20%); SES total for combined groups has slight positive skew.*
**NON-LINEAR ANALYSES FOR DENSITY**

*Differences across social network density subgroups (quintiles) service user- and staff- reported engagement measures*

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD) [95% CI] for social network subgroups (quintiles)</th>
<th>ANOVA F(df)</th>
<th>Overall effect</th>
<th>Linear contrast</th>
<th>Quadratic contrast</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1: [0.00- 0.25] 2: [0.26- 0.39] 3: [0.40- 0.56] 4: [0.57- 0.73] 5: [0.74- 1.0]</td>
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</tr>
<tr>
<td>SES total</td>
<td>10.11 (6.09) 10.37 (7.17) 13.60 (8.61) 8.06 (6.16) 9.89 (8.55)</td>
<td>.661</td>
<td>.126</td>
<td>.375</td>
<td></td>
</tr>
<tr>
<td></td>
<td>[5.43, 14.79] [5.24, 15.49] [7.00, 20.22] [3.32, 12.80] [3.32, 16.46]</td>
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<tr>
<td>SOLES total</td>
<td>122.55 (29.34) 124.50 (26.21) 107.00 (26.35) 129.22 (21.27) 117.56 (31.64)</td>
<td>.880</td>
<td>.034</td>
<td>.137</td>
<td></td>
</tr>
<tr>
<td></td>
<td>[100.00, 145.11] [105.75, 143.25] [86.75, 127.25] [112.87, 145.57] [112.24, 128.28]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note:* Imputed means for missing data (≤20%); SES total for combined groups has slight positive skew.