Exploring Black Experts by Experience views (and experiences) on the concept of using co-production in projects to address racial inequalities in mental healthcare and recommendations for using co-production in future projects.

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DClinPsy thesis (Volume 1), 2023

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Research shows that there are longstanding inequalities within the access to and experiences of National Health Service (NHS) mental healthcare for Black populations. There have been a few interventions aimed at addressing racial inequalities, however, they have mostly been developed by professionals and have not had service user involvement. Within health and social care domains, co-production is becoming increasingly popular in engaging service users from minority groups to participate in improving service provision and interventions aimed at addressing inequalities. However, there has been limited evaluation of co-production, in terms of service users' perspectives and experiences. In parallel, studies have been evaluating the contribution and impact of co-production to mental health services, professionals, service users and wider society. Therefore, this thesis 1) outlines the contribution and impact of co-production on improving healthcare inequalities for Black populations, and 2) used qualitative methodology to explore Black service users' perspectives and experiences of co-production projects aimed at addressing racial inequalities in the care of Black people with psychosis.

Part one is a conceptual introduction. This first identifies the racial inequalities in mental healthcare for psychosis, followed by exploration of the contextual factors underlying these inequalities. Subsequently, this introduction examines the role of co-production in addressing racial inequalities, specifically the application, principles and benefits and challenges. Finally, this introduction discusses three ways that co-production could reduce inequalities, which focused on the impact on knowledge production, improving and empowering professional-service user relationships and social benefits.

Part two is a qualitative study exploring Black Experts by Experience (EbE) perspectives on engaging with and participating in co-production projects aimed at reducing racial inequalities in the care of Black people with psychosis. Eight participants were interviewed; three participants were involved in a co-production project and five participants were not involved in any co-production. The findings suggest that participants engagement in co-production was linked to trusted relationships with professionals helping with the invitation and acting as a bridge to engagement, acknowledging past lived experiences, and motivations to helping one's community. These were all factors relevant to participants' relationship to help. For those who participated the following were facilitators to engagement: the atmosphere created by professionals and other EbEs which fostered feelings of psychological safety. There were also unintended benefits participants did not initially foresee, such as learning more about mental health and ways to maintain this, which improved wellbeing and sustained social connection. Finally, participants reported their hopes for future engagement, which was proactive communication from professionals about next steps and maintaining feedback loops as these supported participants to hope for actionable change in the future.

This empirical study is part of a wider project which co-developed the ‘See Me’ training with EbEs and Experts by Profession. This training was a staff intervention aimed at addressing inequalities and improving the care provided to Black service users, which was comprised of EbEs video testimonials and various reflective tasks for professionals to think about their clinical practice. The three other DClinPsy research projects had the following aims:

- A.1. NHS Mental Health Staff interviews: To understand staff perspectives on engaging with initiatives to address racial inequalities, specifically for Black service users with psychosis.
- B1. Quantitative evaluation: To evaluate the immediate impact of ‘See Me’ training on hypothesised mechanisms of change, which include NHS mental health professionals’ clinical decision-making, cultural competence, trauma-informed care, unconscious bias and mentalisation.
- B.2. Qualitative evaluation: To explore the experience and impact of attending the ‘See Me’ training intervention on NHS mental health professionals in Early Intervention in Psychosis (EIP) services.

Part three comprises a critical appraisal of the research undertaken in Part two. It encompasses reflections on several key aspects, such as motivations to conduct this research, researcher reflexivity and bracketing, the implications of being involved in developing and delivering the co-produced intervention, challenges encountered throughout this research, and the impact of the research on my perspectives and continued professional approach.

Impact Statement

There are well-documented racial inequalities for Black populations in the access, experience, and outcomes within mental health services. There have been a few interventions aimed at addressing racial inequalities, and within health and social care domains, co-production is becoming increasingly popular in engaging service users, although interventions aimed to address these inequalities have typically not involved Black populations. The literature outlined in the conceptual introduction suggests involving Black populations to work alongside mental health professionals, for example in co-production, could significantly enhance the ways that professionals develop and implement interventions and could contribute to reducing inequalities. Furthermore, involving Black populations could impact positively on their experience and relationships with services, which improves their access to services and experience of them, and has the potential to contribute to wider social and psychological factors, such as social networks, employability, and stigma. Therefore, this introduction indicated the various new possibilities of approaching, engaging, and addressing racial inequalities within mental health care, to support improved provision.

The empirical paper is a qualitative account of Black Experts by Experience (EbE) perspectives about engaging with and participating in co-production projects aimed at reducing racial inequalities in the care of Black people with psychosis. Considering the well-documented inequalities in the care of Black service users within the NHS, and the growing recognition of service user involvement in improving service provision, this research offers valuable insights into service users' perspectives on co-production addressing inequalities, where EbE lived experience is two-fold (based on mental health and ethnicity). Service users with and without co-production experience discussed the value of trusted relationships with professionals as a bridge to engaging in co-production; their motivations to participate to help their community within the context of past distressing experiences within services; professionals and EbEs input in fostering psychological safety; unforeseen benefit of social connection and hopes for actionable change in future co-production. Based on these findings, there are recommendations for future co-production projects such as services acknowledging and making efforts to repair populations relationship to help; training for professionals on co-production and their role in bridging engagement; fostering social connection for EbEs within co-production, and considering EbEs community-centred motivations within engagement to projects whilst not exploiting their sense of duty. Future exploration of Black EbEs perspectives on co-production more broadly across services can help to reduce inequalities for Black populations within mental healthcare.

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Acknowledgements

I would firstly like to thank the Experts by Experience who so generously offered their time to share their views with me. I hope that you will feel I have captured your views and experiences in a meaningful way. I would also like to thank the Experts by Experience who generously shared their time and stories in the creation of the ‘See Me’ training film. I hope that we can make all our efforts in this project have the impact that is needed!

I would also like to thank my clinical tutor, Dr Kat Alcock, for your generous support throughout this project and my entire DClinPsy journey. When things on the course have felt overwhelming, you have always been there for practical, emotional, and joyous support.

To my ‘THESISters’, Mishka, Lori, and Michaela, we did it! I could not have had better partners to go through this incredibly important and huge thesis project with! It's been amazing to be in a team with you in (and out of) this project, and I am so proud of what we have achieved together.

To my friends and family for being there to comfort, distract (when I needed a break) and motivate me throughout this project. To Jess, Salisha, Natalie, Janki, and Sarah, thank you for consistently understanding when I have been inconsistent and unavailable, and for always just being there (and always with lots of humour and love).

To Billy, my fiancée, thank you for being there every step of the way, for being patient when I was stressed, consoling my unnecessary tears, being an incredible sounding board, and listening to me talk about the NHS ethics process more than I’m sure you wanted to.

To my Mum and Dad for their unconditional love, unwavering support, and patience. Mum, thank you for the 24/7 support, reassurance, continued words of encouragement and wisdom, and dropping anything to give me a much-needed hug. Dad, thank you for always telling me that I could do whatever I set my mind to, and your terrible but perfectly timed jokes about the wordcount along the way. I hope I can continue to make you both proud.

And last but certainly not least, I would first like to thank my research supervisors, Dr Miriam Fornells-Ambrojo and Dr Chelsea Gardener, for their continued support, supervision, and well-timed bursts of non-thesis related check-ins. This has been an amazing project to be involved in, and I’m grateful to you both that I was a part of it!

Part 1: Literature Review

How can co-production contribute to addressing racial inequalities within healthcare settings?

Abstract

Despite longstanding observations that Black populations have been significantly more likely to have worse pathways to psychiatric settings, compulsory detentions, restrictive practices, and less access to NICE recommended care than White British populations, government initiatives have not been able to reduce these inequalities. This may be because there have been limited interventions reporting practical steps to addressing inequalities, and existing interventions have not involved Black populations in their design and implementation. Therefore, the lived experience of Black people using mental health services and their views on how to progress have been missed.

This conceptual introduction discussed the process of knowledge production and how co-production of Black Experts by Experience (EbE) and professionals can enhance existing knowledge of improving healthcare experiences. The review also discussed how co-production in service development or research can empower EbE populations and improve their relationships with services. Subsequently this review discussed the small-scale social benefits of co-production which have the potential for more widespread benefits for populations. Finally, the review discussed factors to consider for meaningful and useful co-production. Implications for services, policymakers and suggestions for further research are proposed.

1. Racial Inequalities in Mental Healthcare for Psychosis

Mental healthcare disparities between Black and White ethnic groups have been persistent and pervasive for decades (Busfield, 1999; Hussain, Hui, Timmons, & Nkhoma, 2022). There is a disproportionate overrepresentation of Black populations in mental health services, compared to their White counterparts, and this disparity widens for Black populations with additional oppressed/marginalised identities (Crenshaw, 2017; Sattler & Zeyen, 2021). Disparities between the incidence rates for schizophrenia for different ethnic groups is well-known (Halvorsrud, Nazroo, Otis, Hajdukova & Bhui, 2019; Hussain, Hui, Timmons & Nkhoma, 2022). Black and Minority Ethnic ('BME') groups have been diagnosed with schizophrenia or other psychoses disorders more frequently in Western countries compared to their White counterparts (Morgan et al., 2006). Internationally, there have also been increased incidence rates of psychoses disorders among 'BME' and migrant populations, compared with the native majority populations (Alexandre, Riberio & Cardoso, 2010; Al-Saffar, Borga, Wicks & Hallstrom, 2004; Selten et al., 2005; Vinkers, de Beurs, Barendregt, Rinne & Hoek, 2010). Within 'BME' and migrant populations, Black migrants in European countries had the highest risk of schizophrenia or psychoses diagnoses (Cantor-Graae & Selten, 2005; Morgan et al., 2006).

The overrepresentation of Black people with psychosis in mental health services has been linked with increased rates of misdiagnoses (NIMHE, 2003) or overdiagnoses of psychosis in this group. International studies have reported that Black populations and migrants receiving mental health treatment were more frequently diagnosed with a psychotic disorder compared to native majority populations (Schwartz & Blankenship, 2014). Overdiagnosis has been associated with clinicians' biases in attributing symptoms to a psychosis disorder more frequently in Black American populations compared to White populations (Eack, Bahorik, Newhill, Neighbors & Davis, 2012; Minsky, Vega, Miskimen, Gara & Escobar, 2003). Additionally, patient's ethnicity may have contributed to the diagnostic process by influencing the information that professionals obtained from them, which may have contributed to the differences between Black and White populations meeting diagnostic criteria (Strakowski et al., 1997). This may have contributed to consistent reporting in the UK that the incidence rates of schizophrenia and psychoses disorders range between two to eighteen times higher for Black ethnic groups compared to White ethnic groups (Sharpley, Hutchinson, Murray & McKenzie, 2001).

In addition to disparities in diagnosis, disparities in the access to and experience of mental healthcare for Black populations with psychosis compared with White populations are well known. Black patients with psychosis are less likely to be offered a range of evidence-based treatments, for example, they are more likely to be prescribed medication such as depots/injectable antipsychotics (HM Government, 1999) and less likely to be offered National Institute of Clinical Excellence (NICE) recommended psychological therapies such as Cognitive Behaviour Therapy or Family Therapy compared to White patients (Das-Munshi, Bhugra & Crawford, 2018). Furthermore, Black patients have been consistently excluded from decision-making opportunities about their care and treatment options (HM Government, 2018) and have more frequently reported not feeling understood or heard by professionals due to professionals' lack of cultural sensitivity and cultural competence (Cook, McGuire & Miranda, 2007; Wang, Berglund & Kessler, 2000). These disparities have existed beyond mental healthcare for psychosis (Dovidio, Eggly, Albrecht, Hagiwara & Penner, 2016), and Black patients who have had negative or distressing experiences of mental healthcare have reported fear of services, mistrust of treatment/medication advice from professionals and felt discouraged from accessing mental healthcare in the future (McGuire & Miranda, 2008; Sussman, Robins & Earls, 1987).

Several factors contribute to these disparities, and previously genetic and neurodevelopmental factors were being used as explanations for these disparities (Morgan, Charalambides, Hutchinson & Murray, 2010). In countries where populations were predominantly Black ethnicity, such as Trinidad (Bhugra et al., 1996), Jamaica (Hickling &

Rodgers-Johnson, 1995) and Barbados (Mahy, Mallett, Leff & Bhugra, 1999), there had not been an increased risk of psychosis. This indicates that genes alone do not explain the increased psychosis rates and imply an environmental influence in the UK and internationally (Stilo & Murray, 2010). Recent research has suggested social factors significantly contribute to the higher diagnoses rates among ‘BME’ and migrant populations (Morgan et al., 2010). For example, migration across first- and second-generation migrants (Bourque, van der Ven & Malla, 2011; Stilo & Murray, 2022), denser geographical areas or urbanicity (Allardyce et al., 2001; Kirkbride et al., 2012; Pederson & Mortensen, 2001), and strong ethnic identification influenced by perceived disadvantage in society (Reininghaus et al., 2010). Other social factors that are receiving increasing attention are racism and experience of discrimination (Paradies et al., 2015; Penner et al., 2014), which has an indirect impact on health via socioeconomic factors and direct impact on health by creating chronic levels of stress (Brondolo, 2015; Brondolo, ver Halen, Libby & Pencille, 2011; Major, Mendes & Dovidio, 2013). Based on the disparities for Black populations and multiple factors contributing to these inequalities, it may be necessary to separately research disparities within ethnic groups and subgroups rather than as one ‘BME’ group (Kalathil, Bhakta, Danile & Joseph, 2011; Morgan & Hutchinson, 2010b). Contributing factors will be discussed in this review.

The mental healthcare disparities are still present for Black populations with psychosis and within psychiatric settings despite the development of Early Intervention in Psychosis (EIP) services, and within these settings the largest disparities occur for people experiencing First Episode Psychosis (FEP) internationally and in the UK (Cantor-Graae & Selten, 2005; Morgan et al., 2005; Morgan, Mallett, Hutchinson, & Leff, 2004; Tortelli et al., 2015). Black people with psychosis have adverse pathways within psychiatric services, increased rates of compulsory detention, increased rates of restrictive practices during and after compulsory detention, and less access to NICE recommended care (Cantor-Graae & Selten, 2005; Morgan et al., 2005). A review of the evidence is presented next with a preamble about terminology used to report observed differences.

1.1 A Note on Terminology

Differences in health and healthcare have been referred to by different terms. This review will use the terms ‘disparity’ and ‘inequality’. Disparity refers to differences in, and impact of, health outcomes between different populations as defined by social, demographic, environmental and geographical attributes (Truman et al., 2011). Health disparity does not imply something avoidable or unfair, though reductions in health disparities typically show progress towards health equity (Penman-Aguilar et al., 2016; Truman et al., 2011). Inequity and inequality refer to a difference in health outcomes that are systematic, unfair, and avoidable (Penman-Aguilar et al., 2016). International research uses ‘inequalities’ to describe differences across groups, therefore, this review will use this term.

The terms ‘ethnicity’ and ‘race’ are often used interchangeably but have different connotations (Beck, 2016). Ethnicity refers to categories of people based on shared cultural, religious, spiritual, language or geographical backgrounds and race refers to categories of people based on physical characteristics such as skin colour or nationality origins (Bhopal, 2004; Blakemore, 2019). Though both concepts are arguably socially constructed, ethnicity will be used in this review because this is a broader social construct to capture the complexities and nuances of categorisation (Afshari & Bhopal, 2002; Naz, Gregory & Bahu, 2019). Furthermore, in literature ethnicity is often self-defined by individuals (Smith & Silva, 2011). This review referred to Black populations and respective subgroups. According to the Census 2021 data’s (Office for National Statistics, 2022) definition of ethnicity, this review considered individuals who identified as Black or mixed-Black, Black British, Caribbean or African and Other Background within the UK and United States (US).

Individuals with mental health difficulties or disorders have been referred to by different terms, such as patients and service users, which can signify differing relationships and power dynamics between them and services and professionals (McDonald, 2006). This review will use the terms ‘patients’, ‘service users’, and in the section on co-production, ‘Expert by Experience’. Service user has been increasingly used to describe individuals in mental healthcare and used in NICE guidelines (NICE, 2011). Whilst the term patient has connotations with services ‘holding’ more power than individuals, this term continues to be used within the evidence-base about psychosis and used by professionals within inpatient or psychiatric settings, therefore this review used this term accordingly (Simmons, Hawley, Gale & Sivakumaran. 2018). The term Expert by Experience refers to shared power between individuals and professionals, and has been introduced and defined in section 3.2.

1.2 Literature Search

The literature was identified through an initial search on online databases for mental, physical and social care research using keywords relevant to racial inequalities and co-production, which highlighted key concepts and topic areas for enquiry. Following this initial search, citation chaining methodology was used to search the references and citations of these key journals to identify other relevant material (Cribbin, 2011). The key concepts and journals identified were reviewed with the research supervisors to ensure relevant topics had been included and appropriately reviewed, and exclude less relevant topics. This led to further searches on online databases for relevant concepts and topic areas in order to provide as comprehensive and substantiative review of the literature as was possible. This review included peer-reviewed journals and grey literature (evidence that has not been peer-reviewed and published in commercial publications, such as academic papers, research and committee reports, government reports and conference papers (Pappas & Williams, 2011)). Grey literature has been included due to limited commercial publications presenting real world examples of co-production and grey literature disseminating publications with undesirable results, which reduces publication bias (Adams et al., 2016).

1.3 Pathways into Psychiatric Settings

Pathways into psychiatric services differ across ethnicities. Black populations diagnosed with schizophrenia or psychosis are over twice as likely to have Criminal Justice System (CJS) involvement when entering psychiatric settings (OR = 2.49, 95% CI = 2.06 to 3.00, k = 17) (Anderson, Flora, Archie, Morgan, & McKenzie, 2014; Halvorsrud et al., 2018; Singh, Islam, & Brown, 2013), and are almost three times as likely to have police contact (OR = 2.96, 95% CI = 2.10 to 4.17, k = 10). Within the Black ethnicity subgroups entering psychiatric settings, Black African and Black Caribbean populations are similarly as likely to have police contact and CJS involvement, though the rates are more marked for Black British people who are seven times as likely to have CJS involvement than their White counterparts (Halvorsrud et al., 2018). This systematic review and meta-analysis included medium- and high-quality designed studies between 1991 and 2017, and these disproportionate rates of police or CJS involvement remained consistent when study design quality or sample size were controlled. Therefore, the evidence for these disparities could be considered robust.

This ethnic disparity for Black populations' pathways into psychiatric services has been linked to less GP involvement (Bhui et al., 2003). For example, Black people are less likely to have visited their GP before being admitted to psychiatric settings compared to White populations (Morgan, Mallett, Hutchinson & Leff, 2004). Analyses of GP involvement by ethnicity subgroups are similar for Black Caribbean and Black African populations (Ghali et al., 2013; Halvorsrud et al., 2018; Snowden & Yamada, 2005). Though GP visits have been less likely, when Black populations have sought GP support, they have been less likely to be offered treatment or be referred to specialist services or psychiatric settings compared to White and

South Asian populations (Memon et al., 2016). This can increase the duration of psychosis symptoms; Black people have psychosis for up to eight months longer than White populations (Oluwoye, Davis, Kuhney & Anglin, 2021). Longer durations of psychosis can lead to poorer clinical outcomes (Birchwood, Todd & Jackson, 1998; Marshall et al., 2005; Singh, 2007), having a long-term impact on prognosis from not accessing the early detection and intervention model recommended by NICE (McGorry & Killackey, 2002; Singh & Fisher, 2007). Longer durations of psychosis, specifically longer durations of untreated psychosis (DUP), may lead to symptoms becoming more severe over time and increase the likelihood that police or CJS involvement is deemed essential in being admitted to hospital (Ferrari et al., 2015). Furthermore, involuntary practices, such as compulsory detention, may be deemed more essential once admitted (Lawrence, McCombie, Nikolakopoulos & Morgan, 2021).

In addition to societal-level factors, adverse pathways into psychiatric settings have also been associated with individual-level factors such as delayed help-seeking and less self-referrals amongst Black populations (Rennalls, 2020). Delayed help-seeking amongst Black African and Black Caribbean populations with psychosis has been associated with lower: personal awareness of symptoms, family members' knowledge of symptoms and knowledge about mental health services (Ferrari et al., 2015). Additionally, Black populations had higher levels of internalised stigma and guilt, and fear of lifelong discrimination which can dissuade them from disclosing symptoms to others and seeking professional help (Ferrari et al., 2015). Furthermore, when Black populations have sought help, they have reported feeling not listened to, understood, or taken seriously by GP's and healthcare professionals which discouraged them from seeking further support (Islam, Rabiee & Singh, 2015). There may be additional factors contributing to Black populations experiences of accessing care through GPs such as complexities or discrepancies in how either group conveys information to, or receives information from, the other group, and practical factors such as time-pressured GPs appointments (Morgan et al., 2005). Therefore, to improve pathways to psychiatric settings for

Black populations, they need to continue being encouraged to seek professional help as early as possible to increase GP involvement. Additionally, GPs may need further support to engage with Black populations during appointments, and training on psychosis and EIP in order to offer appropriate treatment and onward referrals (Lester, Birchwood, Freemantle, Michail & Tait, 2009; Reynolds et al., 2015).

1.4 Compulsory Detention Rates

Another disparity for Black populations with psychosis is increased rates of compulsory detention compared with other ethnicities. Compulsory detention refers to using the Mental Health Act (MHA) to detain a person in a ‘secure’ setting, such as a psychiatric hospital, due to mental health concerns (Singh, Greenwood, White, & Churchill, 2007). Compulsory detentions can happen within the community (civil detentions) or via CJS involvement (forensic detentions) (Galappathie, Khan & Hussain, 2017). Forensic detentions are the more common pathway for Black populations into psychiatric settings, as described above (see section 1.2). In the UK, the number of people detained in hospital under the MHA has steadily increased; from 29,593 detentions being recorded in 1990/1991 compared to 63,622 detentions in 2015/2016, and a 40% increase on the number of detentions recorded in 2005/2006 (Care Quality Commission, 2018). Within these increasing rates of detention, research has consistently reported disproportionate rates of Black people being compulsorily detained under the MHA by mental health professionals (1983) (Barnett et al., 2019; Busfield, 1999).

In 2021-2022 in England, Black people were four times more likely to be compulsory detained under the MHA than their White counterparts (Audini & Lelliott, 2002; Halvorsrud et al., 2018; NHS Digital, 2023; Singh et al., 2007; Wall et al., 1999;). Conservative research reported Black people were twice as likely to be detained (Barnett et al., 2019), however, when only studies rated as having a high-quality ethnicity subgrouping checklist or high-quality study design were included, reported rates were higher. Separating out Black ethnicity subgroups, in

2021/2022, nearly four times as many Black African and Black Caribbean people were compulsory detained and over ten times as many Black Other people were compulsory detained under the MHA (NHS Digital, 2023). Migrant groups were one-and-a-half times more likely to be compulsory detained in hospital compared with native groups (Barnett et al., 2019). Black Caribbean men are more than three times and Black African men are four times more likely, respectively, to be detained compared to their White counterparts (Morgan et al, 2005). The differences for females are even more pronounced due to the intersection of two inequalities (Roberston, Akre & Gonzales, 2021), such as female gender and Black ethnicity, exacerbating detention rates. For example, being a Black female was a significant predictor of detention to hospital (Barnett et al., 2019) and Black African females are seven times more likely to be detained compared to their White counterparts (Lawlor, Johnson, Cole & Howard, 2012; Mann et al., 2014).

In addition to disproportionate detention rates, Black patients stay longer in psychiatric settings (Mohan et al., 2006), are twice as likely to be readmitted to hospital (Priebe et al., 2009), and are placed on a Community Treatment Order (CTO) between eight to ten times more often than their White British counterparts (NHS Digital, 2019; NHS Digital, 2021). CTO in the UK refers to supervised treatment orders with conditions to maintain care in the community after discharge from psychiatric settings (Swartz & Swanson, 2004). These disparities can have long-lasting, devastating and traumatic impacts for patients. Patients have described being compulsory detained as frightening, distressing, negatively impacting on self-worth (Akther et al., 2019), violating and humiliating (Lu et al., 2017). Patients admitted and re-admitted to hospitals are at risk of harm from institutionalisation, potential harm from staff or other patients, and the loss of employment or housing (Bowers, Chaplin, Quirk & Lelliott, 2009; Lloyd-Evans & Johnson, 2019). Furthermore, five and ten year follow-up studies of Black African and Black Caribbean patients showed persistent periods of illness that included more: frequent hospital admissions, involuntary admissions, police involvement, and longer periods of admission compared with White patients (Ajnakina et al., 2017; Morgan et al., 2017).

In the first meta-analysis that examined compulsory detention in 'BME' and migrant groups in the UK and internationally, 48% of studies provided either no explanation or untested explanations for the ethnic disparities in risk of detention (Barnett et al., 2019). Of the studies that hypothesized about possible explanations, the most frequent were increased prevalence of psychosis, increased risk of violence, increased police contact and poorer levels of social support (Barnett et al., 2019; Gajwani, Parsons, Birchwood & Singh, 2016). However, further information to support or justify these explanations did not appear to be present, which may be a barrier to developing effective policies to prevent and reduce well-documented inequalities in detention rates.

1.5 Restrictive Practices in Inpatient Settings

Furthermore, to the pathways into psychiatric settings and compulsory detention rates, racial disparities exist in how populations are treated by some healthcare professionals within psychiatric settings. Black people experience disproportionate rates of coercive (or restrictive) treatment practices by professionals (Bowers et al., 2005; Gudjonsson, Rabe-Hesketh & Szmukler, 2004), such as physical restraint, seclusion, segregation, and involuntary medication (Abdelghaffar, Ouali, Jomli, Zgueb & Nacef, 2018; Berry et al., 2015; Hui, 2017). Black patients are significantly more likely to be subjected to seclusion and physical restraint than White patients: 56.2 per 100,000 population for Black Caribbean compared to 16.2 per 100,000 population for White patients (Mind, 2019). These increased rates of seclusion for Black patients may be part of a complex vicious cycle of being acutely unwell and then further traumatised by being in seclusion which is an adverse experience. Furthermore, Black patients have longer stays in hospital overall (Mohan et al., 2006), and seclusion remained a significant predictor of longer inpatient stay (McLaughlin, Giacco & Priebe, 2016). Black females are most likely to be physically restrained than White females (HM Government, 2018; Hussain, Hiu, Timmons & Nkhoma, 2022).

Qualitative research has suggested that restraint can produce high levels of distress, fear and anxiety in both patients and staff (Faschingbauer, Peden-McAlpine & Tempel, 2013; Vedana et al., 2018). Restraint and exclusion can also be re-traumatising for those who have experienced physical or sexual abuse (Wynn, 2004). In 2019, a systematic review reported a 25% to 47% post-traumatic stress disorder (PTSD) rate among psychiatric patients after restraint (Chieze, Hurst, Kaiser & Sentissi, 2019). A systematic review and thematic synthesis of restrictive practices (Butterworth, Wood & Rowe, 2022) found that all participants across the studies described losing their human rights, feeling powerless, imprisoned, and dehumanised. Patients' perception of being treated unfairly and coercively could negatively impact treatment adherence, therapeutic relationship and may be a barrier to using mental health services (Jaeger & Rossler, 2010; Rodrigues et al., 2019).

Restrictive practices should only be employed as a last resort (Power, Baker & Jackson, 2020). However, these practices can be used excessively or unnecessarily with patients (National Collaborating Centre for Mental Health, 2019). Increased use of these practices has been attributed to widespread challenges and pressures of professionals working in psychiatric settings, such as a lack of effective alternative strategies (Sequeira & Halstead, 2004; Vedana et al., 2018), significant staff shortages and an insufficient number of professionals trained in de-escalation of challenging behaviours (Marangos-Frost & Wells, 2000; Vedana et al., 2018).

1.6 Reduced Access to NICE Recommended Care

Patients with psychosis should be offered NICE recommended care, such as antipsychotic medications and CBT or Family Intervention for psychosis (NICE, 2014). However, ethnic minority groups are less likely to be offered this range of evidence-based treatments

(Das-Munshi et al., 2018). A systematic review of studies, mostly from the United States, reported that ethnic minority groups are more likely to be prescribed typical (first-generation) antipsychotics over atypical (second-generation) antipsychotics (Puyat et al., 2013), and the latter have fewer and less severe side effects (Geddes, Freemantle, Harrison, & Bebbington, 2000). Black patients in the UK and US with treatment-resistant schizophrenia-spectrum disorders are significantly less likely to be prescribed Clozapine than White patients, after controlling for multiple potential demographic and clinical confounders (Ventura, Hayes & Fonseca de Freitas, 2022; Williams, Harowitz, Glover, Tek & Srihari, 2020). Currently Clozapine is the only licensed medication to treat treatment-resistant schizophrenia-spectrum disorders (Farooq, Choudry, Cohen, Naeem & Ayub, 2019). Interestingly in New Zealand, Maori patients are more likely to be prescribed Clozapine than White European patients (Wheeler, Humberstone & Robinson, 2008) which may suggest that populations who have migrated to another country are less likely to receive this medication than the native majority populations.

Black patients are more likely to be prescribed depot or injectable antipsychotic medications whilst on CTOs rather than oral medications, which felt more coercive and less empowering for this cohort (Patel, De Zoysa, Bernadt, Bindman & David, 2010). Though there may be higher prescriptions for depot medications as has been found to reduce the risk of relapse compared to oral medication (Leucht et al., 2012). Additionally, it has been argued that depot medication administered in the context of CTOs might improve adherence, prognosis and potentially re-admissions for people (Patel et al., 2011), which is important given the various reasons Black populations have reduced treatment adherence, such as mistrust or lack of information shared. However, the lack of choice patients on CTO often experience, raised potential concerns about whether patients' opinions are satisfactorily included in treatment planning and these should be considered against the potential benefits of a depot (Das-Munshi et al., 2018).

Black populations have also had less access to psychological therapies (Glover & Evison, 2009), and healthcare professionals have reportedly not been meeting the recommended guidelines for managing schizophrenia-spectrum disorders in ethnic minority groups (Kuipers, Yesufu-Udechuku, Taylor & Kendall, 2014). CBT is the most widely used and recommended psychological treatment for psychosis (NICE, 2014). Whilst CBT acknowledged the individual's social context of illness, CBT was underpinned by European-American values and developed on WEIRD (western, educated, industrialised, rich and democratic) populations (Hays and Iwamasa, 2006; Naeem, Phiri, P., Rathod, S., & Ayub, 2019; Stone, Beck, Hashempour & Thwaites, 2018). Therefore, there had been concerns that CBT lacked cultural sensitivity and had not competently/adeptly integrated factors such as ethnicity, culture and religion (Summerfield & Veale, 2008). However, when CBT has been culturally adapted it has been beneficial in reducing positive psychosis symptoms and improving mood (Rathod et al., 2013) and including culture within psychological therapy increases completion of therapy (Friskney, Branney, Iqbal, Edwards & Wem, 2023). Edge et al. (2016) co-created a culturally adapted Family Intervention with Black Caribbean patients with psychoses and their families which had the potential to improve this cohort's engagement in services, access to evidence-based interventions and clinical outcomes. Given the growing evidence-base on the efficacy of culturally adapted CBT and psychosocial interventions for psychoses disorders (Degnan et al., 2018; Habib, Dawood, Kingdon & Naeem, 2015; Phiri, 2012), it prompts the question about why service providers offer CBT and Family Therapy less and whether they believe CBT could be suitable for different ethnicities (Rathod et al., 2013).

2. Context to Racial Inequalities

Until recently, most explanations for racial inequalities (Barnett et al., 2019) had primarily been assumptions about Black people's lifestyles, cultural health beliefs, community stigma of mental ill-health, differing help-seeking behaviours, increased drug use, and increased paranoia and “aggressive” behaviour (Chorlton, McKenzie, Morgan, & Doody, 2012; Lawlor et al., 2012; Morgan et al., 2010a). Whilst some of these individual level factors may be relevant, they did not acknowledge the wider contextual factors such as intersectionality of socioeconomic deprivation that contributed to these inequalities (Hankivsky, Cormier & De Merich, 2009). Furthermore, these assumptions perpetuate historical and current institutional racism within UK psychiatry at interpersonal and societal levels (Morgan et al., 2010a; Nazroo, 2003; Paradies, Truong, & Priest, 2014). More recent reviews have acknowledged the role of structural violence (Morgan, Knowles & Hutchinson, 2019) and institutional racism (Nazroo, Bhui & Rhodes, 2020) in relation to the inequalities for Black populations (Zahid, Hosang, Fonseca de Freitas, Mooney & Bhui, 2023).

2.1 Socioeconomic Deprivation, Exclusion and Poverty

In the UK, Black people are disproportionately impacted by deprivation, social exclusion, and poverty (Vernon, 2020). Black people are more likely to be living in poverty due to employment in lower paid work (Henehan & Rose, 2018), higher rates of part-time working and unemployment (Office for National Statistics, 2016) and relatively low levels of overall income (Khan, 2020). Changes to fiscal policies that reduced income from benefits and cut public services disproportionally affected minoritised ethnic groups thereby exacerbating racial inequalities in the economy (Khan, 2015; Women’s Budget Group, 2017). Social deprivation, exclusion, and poverty place unfair limits on access to resources and opportunities, resulting in adverse socioeconomic experiences such as housing instability, exposure to violence, proximity to crime, longstanding unemployment, and environmental neglect (Shim & Compton, 2020). These outcomes are important to acknowledge because they are associated with increased severity of psychological distress, increased severity of mental health symptoms, risk of psychosis (Kirkbride, Jones, Ullrich & Coid, 2014) and increased rates of compulsory detention

(Bindman, Tighe, Thornicroft & Leese, 2002). Having complex social needs may exacerbate mental health symptoms and may impact Black people's help-seeking behaviours. Additionally, complex social needs such as housing instability or poor-quality housing, financial instability and exposure to violence may impact on healthcare professionals (HCP's) perception of risk; they may be more likely to determine a person's social environment is unsafe, risky or exacerbating health symptoms and potentially determine that hospital admission is needed (Sundquist & Ahlen, 2006).

One explanation posed for Black populations experiencing social deprivation more than White populations was their migration history into the UK. Black Caribbean populations settled in the UK post-World War II and populations with Black African heritage has steadily increased since the second wave of migration in the late 1980s (McDowell, 2018). Whilst studies have reported that migrants and ethnic minorities have increased prevalence rates for psychosis diagnoses, migration alone cannot account for the racial inequalities for Black populations (Jongsma, Karlsen, Kirkbride & Jones, 2021). Pre-migratory exposure to stressors and the process of migration can contribute to excess risk of psychosis in migrants (Hollander et al., 2016). However, descendants/first or second generation of migrants who have never migrated have shown excess psychosis risks (Selten, Van der Ven & Termorshuizen, 2020). In these cases/situations, studies have reported that ethnic minority populations, such as descendants of migrants, are more likely to be socioeconomically disadvantaged compared to majority populations who have accrued socioeconomical advantaged positions over time (Jongsma et al., 2021). This disadvantage contributes to health inequalities, specifically increased probability of experiencing stressors and vulnerability to adverse health effects (Jongsma et al., 2021). Individual characteristics such as control, self-efficacy, resilience, and trust can mitigate the negative effects of socioeconomic disadvantage (Public Health England, 2017), however the opportunities and capacities for people who are disadvantaged to make use of these characteristics is limited (Public Health England, 2017). Therefore, migration may contribute to the complexity of ethnic disparities in psychosis across Black subgroup populations in the UK, whether patients have migrated themselves or are the descendants/first or second generations.

Related to social deprivation and migration was social networks. After migrating, some Black Caribbean and Black African populations may have been more acculturated into British culture and had a more established social network and greater opportunities to accrue wealth (Bhugra, 2005; Khan, 2020; Oduola et al., 2019a; Oduola et al., 2019b), whereas others may have been without these social relationships. The absence of social relationships is associated with increased psychological distress (Boydell et al., 2013; Morgan et al., 2009); smaller social networks or less supportive networks have pre-dated early onset of psychosis (Allardyce et al., 2005; Gayer-Anderson & Morgan, 2013; Zammit et al., 2010) and have been associated with more severe psychotic symptoms and negative symptoms among men and those from minority ethnic populations (Degnan et al., 2018). It should also be noted that in contrast, there would have been Black Caribbean or African populations who had become well-established in the UK, for example establishing wealth and social networks, and this may have been an increasing protective factor over time (Rennalls, 2020).

In addition to the impact of social and economic factors on the risk of psychosis, social deprivation is also associated with a longer duration of untreated psychosis (DUP). People living in more deprived neighbourhoods face up to a 36 day longer DUP than those in the least deprived areas of England (Reichert & Jacobs, 2018). There were likely several contributing factors to this relationship, but employment status appears the most significant; Morgan et al. (2006) reported the median DUP for unemployed people was 13 weeks compared to 5 weeks for those employed or in higher education. An explanation might be that being unemployed reduced the visibility of the disruption caused by symptoms of psychosis (Morgan et al., 2006), reducing the likelihood of the person with symptoms seeking help or others seeking help on their behalf. Additionally, a longer DUP might result in longer periods of unemployment due to reduced social functioning and increased social withdrawal (Morgan et al., 2006), and over time longer DUP may lead to symptoms worsening to a crisis point, increasing the likelihood of compulsory detention.

2.2 History of Medicine and Psychiatry

In addition to the societal-level factors discussed above, inequalities for Black populations may be impacted by the professional history of Medicine and Psychiatry mistreating Black populations through coercion and unethical practice. Examples include medical theories that Black populations had thicker skin and a less sensitive nervous system were used to justify maltreatment of enslaved Africans (Gamble, 1993), experimental gynaecological surgical procedures carried out on enslaved women without anaesthesia (Sartin, 2004), medical research being carried out on Black people without their full informed consent such as Henrietta Lacks (Butanis, 2020) and the Tuskegee Syphilis Study (Gamble, 1993). These racist roots have left a legacy of mistrust of health services in the Black community and taught Black populations that the principle of ‘first do no harm’ does not apply to them. Recent reports of Black populations being more than four times more likely to die from Coronavirus (Office for National Statistics, 2020) and Black women being over five times more likely to die during childbirth than White women (Knight et al., 2019) provides further recent evidence that Black people’s lives are still less valued by the UK healthcare system.

Discrimination against, and assumptions about, Black populations exist in the history of psychosis. In 1968 two psychiatrists suggested that the Civil Rights Movement drove Black men to ‘insanity’, coining the term “protest psychosis” (Bromberg & Simon, 1968). Psychosis then transformed from a docile disorder about White middle class women’s roles as mothers and housewives into a condition about ‘angry Black masculinity’ (Johnson, 2012; Metzl, 2010). The Angiolini Report (2017) argued that the decades of racist tropes and stereotypes of Black populations as ‘dangerous, violent and volatile’ may have influenced the perception of Black populations within mental illnesses, particularly Black men, as more threatening (Cummins, 2015). This can be supported by the reported deaths of Michael Martin in 1984, Joseph Watts in 1988 and Orville Blackwood in 1991 in Broadmoor Hospital due to restrictive practices (Prins et al., 1993). Black populations have been dehumanised in psychiatric settings and received less compassion and empathy from professionals, despite them being vulnerable, unwell and in need of care (Walker, 2020). Professionals are exposed to social narratives about racialised and minoritised groups of people, and some professionals may implicitly endorse commonly held unhelpful and discriminative beliefs and biases (FitzGerald & Hurst, 2017). This could influence clinical decision making, particularly during times of high pressure where risk averse responses are more likely to be elicited (Jefferies-Sewell et al., 2015). This perception may impact professionals' treatment decisions, such as using restrictive practices to protect other patients and/or themselves from harm (Penner, Phelan, Earnshaw, Albrech & Dovidio, 2017). Research has supported this idea; Black people are significantly more likely to be detained and experience restrictive practices following involvement in a violent incident, more likely to be perceived as threatening by others (Morgan et al., 2005) or perceived as being at higher risk of 'violent acting out' (Singh et al., 1998). Therefore, it could be understood why healthcare systems can be fear-provoking for Black populations, particularly when restrictive/coercive treatment is a possibility. The fears amongst Black populations about the mental health services are not unfounded but based on actual historical and current inequalities in healthcare treatment.

2.3 Mental Health Act

"Since the MHA was last updated in 2007, there have been longstanding calls for reform - including by parliamentary committees - amidst criticism of increasing detentions and Community Treatment Orders (CTOs) and ethnic disparities" (UK Parliament Office of Science and Technology, 2022, p.3). Within the UK, psychiatric mental health services are embedded in a highly risk-averse culture where the powers outlined in the MHA are used (Markham, 2021).

The MHA's stated aims are to (1) help those who would benefit from treatment for their mental health difficulties or perceived lack of capacity whilst (2) protecting the patient and public from risk of harm (Department of Health and Social Care, 2015). Whilst these are the MHA aims, using the MHA to detain an individual imposes on their freedom and liberty and their families, which can be traumatic and distressing (Akther et al., 2019).

Since the introduction of the MHA, the detention rates in England have at least tripled over the last forty years and this was mostly due to the increase in civil detentions (i.e., involuntary admissions from the community) (Keown, Murphy, McKenna & McKinnon, 2018). In 2018, the Race Disparity Audit (Cabinet Office, 2017) reported that the MHA 2007 would be redrafted in response to increased detention rates for ethnic minoritised individuals, though the new Act is currently in draft form (Department of Health and Social Care, 2021). Concurrently, guidelines/safeguards have been in place to support the MHA being used equitably with populations, such as requiring multiple healthcare professionals to agree on a detention and with sufficient cause/reason to detain people. However, the disproportionate detention rates for Black populations under the MHA should be considered within the context of the historical legacy of Black populations perceived as posing a threat and the risk-averse culture of the UK mental health system, which may provide insight into how the MHA has been used in practice. The aims of the MHA remain a contentious issue (Smith et al., 2023), and it is beyond the scope of this review to comment further. Further discussion about the MHA use and reported experiences of detentions amongst Black African or African-Caribbean patients were included in a recent review (Wessely, Gilbert, Hedley & Neuberger, 2018).

2.4 Expectations and Experiences of Help-seeking

In addition to the societal-level and historical factors discussed above, inequalities for Black populations may be impacted by individual-level and community-level factors. Research using the Theory of Planned Behaviour model (Azjen, 1991) with Black American people hospitalised for psychosis, reported that various factors contribute to Black people's intentions or reluctance help-seek: for example, cultural perceptions and mistrust, and negative perceptions and experiences of help-seeking (Compton & Esterberg, 2005; Taylor & Kuo, 2019). Cultural beliefs and expectations can shape people's awareness and understanding of mental illness and psychological distress, which in turn can influence familial assistance in help-seeking (Singh et al., 2015). Family assistance in help-seeking can be pivotal for accessing support (Cauce et al., 2002; Jones, Heflinger & Saunders, 2007); for example, young adolescents with FEP relied on others and families to access help (Cadario et al., 2011). Family assistance in help-seeking has been associated with a shorter DUP and ameliorates negative pathways to care (Anderson, Fuhrer & Malla, 2013; Morgan et al., 2005). In contrast, stigma about mental health within Black populations and families can impact attitudes to and actions towards help-seeking (Morgan, Mallett, Hutchinson & Leff, 2004); though stigma is not only relevant at a familial-level, but also at individual- and community-levels (Murry, Heflinger, Suiter & Brody, 2011). Stigma about mental health has been conceptualised as stereotypes, prejudice, and discrimination from being labelled “mentally ill” (Corrigan, Druss & Perlick, 2014). Black American populations who sought mental healthcare support reported being treated as outsiders and felt socially distant from family (Conner et al., 2010). However, there are complex nuances in how stigma exists between Black subgroups (Upthegrove, Atulomah, Brunet & Chawla, 2013). In a series of focus groups, Black African patients reported feeling mental health stigma from their community when becoming unwell, and this stigma negatively impacted their wellbeing and increased psychological distress (Shefer et al., 2013). In contrast, Black Caribbean patients reported more significant impact of stigma and racial inequalities in mental health treatment from professionals (Shefer et al., 2013). This highlights that cultural beliefs and understandings of mental health within families and communities can be both a barrier and facilitator to family's involvement in help-seeking (Friskney et al., 2023).

In addition to family's beliefs about mental health, individual's own understandings of mental illness and psychological distress impact on their help-seeking behaviours. There is variation in Black populations, and the subgroups, understandings of illness and wellness. For example, a subsection of Black African and Black Caribbean migrants in the UK at risk of developing psychosis, attributed mental illness to different cultural explanations (Codjoe, Byrne, Lister, McGuire & Valmaggia, 2013), such as connection to society, surviving God's test, active acts of spirituality, (presence or absence of) witchcraft and supernatural forces, and avoidance of adverse environment (Codjoe et al., 2013). This variation in cultural beliefs and illness attributions, which does not apply to everyone within Black populations (Singh et al., 2015), adds to the complexity in understanding their help-seeking behaviours, and consequently how help-seeking behaviours may contribute to wider disparities in incidence rates and outcomes for psychosis.

Black populations are less likely to seek mental health support than other ethnicities (Taylor & Kuo, 2018), potentially influenced by previous experiences of mental healthcare, including admission to and restrictive practices within psychiatric settings (Joseph, 2010; Knight, Jarvis, Ryder, Lashley & Rousseau, 2023; Njiwaji, 2012). Women who had been compulsory admitted to psychiatric settings reported staff's actions during the sectioning process were unnecessary, abusive, and racist, which increased their expectations of further adverse treatment and decreased future help-seeking behaviours (Nicholas, 2020). During help-seeking or in psychological treatment ethnic minorities have reportedly experienced at least one microaggression (Hook et al., 2016). Within psychological treatment, microaggressions against Black people commonly occurred when professionals denied service user-therapist differences, minimised or dismissed discussions about racial or ethnicity issues related to mental health, and/or made assumptions based on service users' ethnicity (Constantine, 2007; Hook et al., 2016; Sue, Capodilupo, & Holder, 2008). Experiencing microaggressions can lead to poorer therapeutic relationships, lower perceived professional competence and understanding, and less satisfaction with psychological treatment (Constantine, 2007). Similarly, expectations of professionals unacknowledging the relevance of cultural and spiritual beliefs around mental health (Islam et al., 2015) and mental health services not being culturally sensitive, can deter help-seeking (Mirza, Birtel, Pyle & Morrison, 2019). Black populations have found meaning and value in consulting faith-based practitioners during their care pathways to psychiatric settings/mental health services (Singh et al., 2015); expectations and experiences of cultural insensitivity from mental health services might be an additional contributor to seeking support from faith-based practitioners. Additionally, these experiences and expectations can prompt Black people to prematurely terminate treatment (Sue et al., 2007; Taylor & Kuo, 2018) and create mistrust of mental health services, which may deter or delay future help-seeking (Friskney et al., 2023). Delayed help-seeking can result in longer DUP, which is reportedly associated with mental health deterioration (Campbell & Long, 2014) and more severe and chronic presentation of psychosis symptoms at contact with services (Mantovani, Pizzolati & Edge, 2017). Black African and Black Caribbean patients were more likely to be in contact with services with chronic and severe presentations than earlier in the disorder (Morgan, Mallett & Hutchinson, 2005).

Thus far, this introduction has outlined the inequalities faced by Black populations within mental health services and the various contextual factors contributing to these inequalities. The remaining sections discuss addressing these inequalities within mental healthcare services and research.

3. Addressing Racial Inequalities: How to?

The ethnic inequalities in healthcare for Black populations have been of major concern to patients, healthcare providers and policy makers (Oduola et al., 2019b). Until the last two decades, there had been few significant improvements in inequalities. More recently, there have been publications about improving these inequalities, such as the UK Government’s Race

Equality Action Plan (Department of Health, 2004), Care Quality Commission's (CQC) National Mental Health Development Unit, NHS Five Year Forward View (2016), and the NHS Advancing Mental Health Inequalities Strategy (2020). Despite these publications acknowledging inequalities and stating aims to address them, they had not stated practical or actionable steps to achieve changes (Hussain, Hui, Timmons & Nkhoma, 2022). There have been exceptions, such as practical guidance on developing anti-racist practice for minority ethic nurses and midwives in the NHS (Jieman, Onwumere, Woodhead, Stanley & Hatch, 2022).

A recent scoping review on implementing anti-racist interventions in healthcare settings for patients concluded that interventions needed: leadership buy-in, a multi-level approach starting at policy- and organisational-level, transparent accountability for all those involved, long-term meaningful partnerships between services and marginalised communities, and ongoing staff education and training (Hassen et al., 2021). This review included thirty-seven peer-reviewed studies and six grey literature documents, and overall, interventions had focused on change at an individual-level (targeting professionals' knowledge, attitudes, and behaviours with self-reflection tools), interpersonal-level (targeting healthcare provider to service user relationship) and community-level (establishing ongoing and meaningful relationships with populations) (Hassen et al., 2021). Practical interventions focused on trainings and workshops for professionals on cultural competence and unconscious biases (Papadopoulos, Tilki & Lees, 2004; Rocke, 2015; Steed, 2010), institutional racism within mental healthcare and anti-racist practice (Malott & Schaefle, 2015; Signal et al., 2007) or recognising professionals' privileges (Fitzgerald et al., 2019; Holm et al., 2017). These reviews attempted to develop practical steps towards anti-racist practice with staff (as in Jieman et al., 2022) and in healthcare settings for patients (as in Hassen et al., 2021), however, all the interventions had been limited in their application and evaluation. Only five of the thirty-seven studies focused on Black populations as the patient group. Additionally, the interventions in Hassen et al. (2021) were based on professionals and organisation's perspectives on how to create change (Gillard, Turner, Neffgen, Griggs & Demetriou, 2010) and had not included the perspectives of populations experiencing the inequalities. The value of involving patients and populations with lived experience into the provision of healthcare has been reported in health and social care domains (Brett et al., 2014; Crocker, Boylan, Bostock & Locock, 2016; Domecq et al., 2014; Shippee et al., 2014; Staley, 2009) and is referred to as Patient and Public Involvement.

3.1 Patient and Public Involvement

The inclusion of service users and carer's perspectives into healthcare and social care domains (INVOLVE, 2015) is commonly referred to as Patient and Public Involvement (PPI), and also known as Participatory Action Research (PAR) or Community-Based Participatory Research (CBPR) (Bergold & Thomas, 2012; Mosavel et al., 2005; Tew et al., 2006). INVOLVE (2017), the UK's national advisory group supporting active public involvement in health and social care services and research, defined PPI as research being carried out 'with' or 'by' members of the public, rather than 'to' 'about' or 'for' them. PPI in healthcare services and research has become increasingly common internationally (Freil & Knudsen, 2009; Holmes, Stewart, Garrow, Anderson, & Thorpe, 2002; Kim & Ross, 2008; Mosavel et al., 2005; Schneider et al., 2004) and is now a requirement in most publicly funded UK research (Department of Health, 2006). This requirement of involving the public has gained more prominence due to clinical and service failings in the UK (Department of Health, 2001; Francis, 2013) and internationally (Walshe & Shortell, 2004; World Health Organisation, 2008). Campaigns of patients, and their families, who have experienced harm have contributed to a new focus of PPI on improving quality and safety within healthcare (Ocloo, Garfield, Franklin & Dawson, 2021). In addition to the mandate, PPI is important in increasing the acceptability, quality and relevance of healthcare services and research to service users', which in turn can increase the likelihood that services and research better cater to the public (Department of

Health, 1990; Department of Health, 2007; Department of Health, 2012). The importance of PPI as a policy has been reported by service users and professionals (Omeni, Barnes, MacDonald, Crawford & Rose, 2014).

Approaches to PPI have differed across healthcare studies and reports due to the breadth of the definition and different terminology (Gibson, Britten & Lynch, 2012), which added to difficulty about what PPI looked like in practice in the NHS (Williams, Robert, Martin, Hanna & O'Hara, 2020). Based on a systematic review of PPI in NHS healthcare (Mockford, Staniszewska, Griffiths & Herron-Marx, 2012), PPI can take many forms: planning or conducting research studies, membership on managerial boards, providing routine feedback to services, and developing healthcare services with a specific aim (Mockford et al., 2012). The impact of PPI on NHS services and research has broadly been divided into the following two areas: service planning and development, and information development and dissemination, which are detailed in Table 1.

Table 1

Impact of PPI on NHS Services and Research

Service Planning and Development	Information Development and Dissemination
Designing or improving: 1. New healthcare buildings (Anderson & Florin, 2001a; Cotterell, Sitzia & Richardson 2004; Perkins & Goddard, 2004), 2. Accessibility to services (Milewa, Harrison, Ahmad & Tovey, 2002; Murie & Douglas-Scott, 2004; Richardson, Sitzia & Cotterell, 2005; Challans, 2006), 3. Current practical systems such as booking appointments (Mountford & Anderson, 2001), 4. Dialogue and interactivity between professionals and service users (Murie et al., 2004), and 5. Dialogue between service users (Fudge, Wolfe & McKevitt, 2008).	Developing and sharing: 1. Information newsletters or booklets for local community on mental health (Robert, Hardacre, Locock, Bate & Glasby, 2003) and physical health services (Stewart & Oliver, 2007; Fudge et al., 2008; Pickles, Hide & Maher, 2008; Cotterell et al., 2004; Richardson et al., 2005; Carney, Jones, Braddon, Pullybank & Dixon, 2006), 2. Information to raise awareness of specific health conditions (Anderson & Florin, 2001b; Ripley, Sullivan & Evans, 2007; Fudge et al., 2008), and 3. Information about co-developing training sessions either for other service users about certain health conditions (Fudge et al., 2008) and for professionals about service users' perspectives (Dearden-Phillips & Fountain, 2005).

The concept of PPI has been overall valued by service users and researchers (Brett et al., 2014): benefits have included improved wellbeing for some service users within their communities (Brett et al., 2010; Minogue, Boness, Brow & Girdlestone, 2005) though challenges have included them feeling not valued or feeling overlooked (Wyatt et al., 2008). Further challenges for PPI included criticisms about: not addressing power inequalities and discrimination (Ocloo & Fulop, 2012), difficulties creating genuine partnerships between healthcare providers and service users, not involving a diversity of people (Bereford, 2013; Denegri et al., 2015; Ocloo, 2020) and exclusivity and tokenism (Ocloo & Matthews, 2016). These criticisms suggested a narrow model of the use of PPI in practice (Brown & Zavestoki, 2004; Ocloo et al., 2021). Participants in PPI should ideally represent the demographic diversity of the general population or the prevalence of a condition (Bitting, Goodman & George, 2020; Clark et al., 2019) though PPI participation has not often involved diverse or racially marginalised populations in improving healthcare provision (Howe, MacDonald, Barrett & Little, 2006; Tarpey, 2006). There may be a bias in those who volunteer for PPI projects (Shea et al., 2022); those who are self-motivated to participate may not have been systemically let down, such as Black populations. Improving the diversity of participation is a key area of improvement for PPI and all involvement approaches.

3.2 The Role of Co-production in Addressing Racial Inequalities

3.2.1 What is Co-Production?

Within PPI approaches, i.e., approaches to improve healthcare provision ‘with’ members of the public, there is a specific type of involvement where service users and professionals share power and responsibilities in an equal and reciprocal relationship (Rose & Kalathil, 2019). This is known as co-production, and this equal partnership approach has been increasingly regarded as the gold-standard for improving healthcare engagement from marginalised groups

(Beresford, 2013; Martin, 2008; Mulvale & Robert, 2021; National Institute for Health Research, 2015).

In mental health literature, the concept of co-production is relatively new and was defined in the 1970's (Realpe and Wallace, 2010), and its relevance has increased significantly within the past twenty years (Ramon, 2018). Co-production is an active participatory approach where people with lived experiences of/with mental health services, which could include, families, carers, and professionals with lived experiences, work in a partnership with service providers to improve services and research during their life cycles (Norton, 2023). Co-production encourages patients and carers to make use of their personal lived experiences, which are viewed as resources crucial for the enhancement of more relevant and higher quality services and research (Horgan et al., 2018). I.e., co-production joins 'expertise by experience' and 'expertise by profession' (Faulkner & Thomas, 2002; Fox, et al., 2018; Gordon & O'Brien, 2018). Co-productions characteristics of service users being actively involved and having an equal relationship with professionals were important distinctions from other involvement concepts (Prahalad & Ramaswamy, 2000), and therefore, co-production was expected to be a paradigm shift in how service users and professionals worked together in service development and in research (Brandsen, Steen & Verschuere, 2018).

3.2.2 A Note on Terminology

Co-production refers to involvement across any stage of the health service cycle or research cycle: commissioning, design, delivery, and evaluation (Brandsen & Honingh, 2016; Needham & Carr, 2009). Co-production has been interchangeably used in mental healthcare literature with participatory approaches with broader definitions, and differences in who and how service users are involved (Gebauer, Johnson & Enquist, 2010; Vargo & Lusch, 2004). Therefore, this review will continue to use the term co-production.

The characteristic of co-production being an active participatory approach has been described in Arnstein's Ladder of Participation as 'doing with' service users (Arnstein, 1969; Arstein, 2019). According to this model, involvement approaches range from professionals and services 'doing to' (passive involvement), 'doing for' or 'doing with' (active involvement) service users. 'Doing to' service users refer to traditional services perhaps with paternalistic views of medicine (Szmukler & Holloway, 2000) and 'doing for' service users can include slightly more involvement such as providing feedback. 'Doing with' service users refer to sharing the roles, responsibilities and power with professionals to improve service provision or research.

Service users have been recognised and valued as having specific expertise or expert knowledge (Happell et al., 2019; Noorani, 2016), and have been increasingly referred to as Experts by Experience (EbEs). EbEs are defined as individuals with lived experience of 1) having, 2) living with and/or 3) caring for someone with mental illness and/or using mental health services (McLaughlin, 2009). Accordingly, individuals with lived experiences, including those who are and are not involved in co-production, will be referred to as EbEs herein.

3.2.3 Where has Co-production been applied?

In a recent scoping review of co-production in applied health research and service development in the UK (Smith et al., 2022), co-production occurred across a range of health conditions, population-specific services, and healthcare domains. Among the healthcare domains, co-production occurred most frequently in the mental health domain, such as EIP services and Improving Access to Psychological Therapies (IAPT) (Slay & Stephens, 2013). In mental health service development, EbEs and professionals jointly improve provision of care, and access to and experience of services (Durose, Beebeejaun, Rees, Richardson & Richardson, 2012). The application of co-production has led to a range of outcomes, for example conceptual (e.g., defining or explaining a subject/topic), methodological (e.g., designing or carrying out a specific task), impact (e.g., barriers and facilitators, acceptability, effectiveness of subject/topic) and knowledge dissemination (e.g., toolkits, leaflets) (Smith et al., 2022).

Despite the application of co-production, there has been limited research or service development reports/publications presenting real world examples (Bell et al., 2023; Filipe, Renedo & Marston, 2017). This is due to contextual factors that shape and limit its implementation (Gheduzzi, Masella & Segato, 2019) and co-production only becoming more common in mental health within the last five to ten years (Lambert & Carr, 2018). Notable advancements have been the Centre for Co-production in Mental Health at Middlesex University in 2016, the annual Australasian Service User Academia symposium, Slay and Stephens (2013) literature review, Carr and Patel's (2016) practical guide and Roper, Grey and Cadogan's (2018) practical guide. Given the sparse publications available, this conceptual introduction used publications across mental and physical health, and social care contexts to discuss how co-production can contribute to addressing racial inequalities for Black populations within healthcare settings. It should be noted that co-production would not solely address these inequalities but should be considered as one of many strategies that prioritise Black populations and their lived experiences.

3.2.4 Principles of Co-production

To aid co-production between professionals and EbEs, Slay and Stephens' (2013) literature review reported six principles, which are detailed in Table 2. However, there have been challenges with co-production projects aligning to principles 5 and 6 which may suggest some professionals are less keen on co-production. There has been a movement to reduce distinction between healthcare provider and EbEs through an increase of Peer Support Workers within services (people with lived experiences of mental health difficulties who join mental health services to help provide support and inspiration for recovery) (Shalaby & Agyapong, 2020). In addition to the principles, Carr and Patel’s (2016) practical guide reported three steps to co-production in mental health services, which are detailed in Table 3.

Table 2

Slay & Stephens (2013): Principles of Co-Production

1. Assets-based approach that transforms the perception of service users from passive recipients of services to equal partners;
2. Building on people’s capabilities and actively supporting these at an individual or community level;
3. Mutual responsibilities and expectations between professionals and service users;
4. Engaging peer and personal support networks to share knowledge, alongside professional working relationships;
5. Removing the boundaries and distinction between professionals and recipients;
6. Enabling the public to be facilitators for change in addition to generating ideas.

Table 3

Carr & Patel (2016): A Practical Guide for Co-Production in Mental Health Services

1.Setting the scene (understanding the context and environment that co-production is going to take place in);
2. Coming together (creating the right conditions for co-production to work); and
3.Working together (achieving parity and genuine collaboration).

3.2.5 Benefits & Challenges of Co-Production

The benefits of co-production in planning and delivering services and in research have been reported via positive outcomes for EbEs at an individual-level and organisation-level (Ewalds-Mulliez, et al., 2018). For example, improved health and wellbeing (Agha, et al., 2018; Bee, et al., 2015; Gillard, et al., 2016), improved satisfaction with services (Burns, et al., 2014), improved quality of services (Cepiku & Giordano, 2014; Henderson, et al., 2004; Palumbo, 2016), and reduced readmission rates, levels of stigma and prejudices (Thornicroft and Tansella, 2005). Co-production has benefitted organisations/services by reducing costs in the long-term despite initial to set-up costs (Nikcevic & Jatta, 2014), and challenging the biomedical/psychosocial/psychological model where each stakeholder could be viewed equally (Rethink Mental Illness, 2015).

In contrast, challenges for professionals involved in co-production have included adjustment to treating EbEs as co-producers rather than as patients (Lambert & Carr 2018; Mayes 2009; Rose 2014), and attitudes and willingness to share power with EbEs during co-production (Norton, 2023). The impact of professionals' attitudes has significantly influenced how integrated and collaborative co-production has been (Davis & Ruddle, 2012; Gebauer et al., 2010; Leone et al., 2012). Challenges for services included co-production being time-consuming and having expensive set-up costs in the short-term (Kara, 2013; Trivedi & Wykes, 2002), lack of guidance available about creating opportunities for co-production (Tuurnas et al., 2015) and difficulties engaging new participants resulting in reliance on the same pool of people (Shortall, 2008).

3.2.6 The Status of Co-production involving Black EbEs

Though co-production has been regarded as the gold-standard method for engaging ethnic minority populations, Black populations have been less engaged. A systematic review of factors impacting Black, Latinos/Hispanic, East Asian and Pacific Islanders participation in research (George, Duran & Norris, 2014), stated that the ability of services to meet the needs of *all* populations is dependent on diverse participants involvement. Black populations may need substantial and additional efforts prior to co-production to help them engage (Banda, Germain, McCaskill-Stevens, Ford & Swain, 2012), such as long-term efforts that shift power, resources and relationships between organisations and populations by recognising power asymmetries and histories of oppression conceptualised as ‘Phase Zero’ (Burgess & Choudary, 2021). Creary, Okoroji, Ibison, Kogbara and Dyer (2023) argued that without these efforts or if services relied on the same few Black EbEs, co-production may be complicit in maintaining power differentials by engaging Black populations symbolically and not meaningfully.

3.3 Co-Production can Produce Different Knowledge

Co-production can contribute to addressing inequalities by challenging how and what knowledge has been produced, specifically knowledge that informs healthcare treatment, research, and service development (Vindrola-Padros et al., 2017; Vindrola-Padros et al., 2019). The concept of knowledge co-production is that there are numerous and coexisting forms of knowledge, and they are all important to improve the health sector (Greenhalgh, 2010; Greenhalgh & Wieringa, 2011). The production of knowledge has historically been by White academics and professionals or dominated by Western Eurocentric epistemologies and perspectives. Current participation in co-production within services or research teams has been predominantly run by White healthcare professionals (Rose & Kalathil, 2019). Consequently, this White Gaze and Eurocentric epistemologies may impact the challenges chosen to be addressed and solutions suggested, which may implicitly set parameters about who has been perceived as ‘suitable’ or as bringing value to the process, such as already privileged populations (Steen, Brandsen & Verschuere, 2018). This may exclude marginalised populations and those most in need of sharing their experiences of inequalities (Steen et al., 2018; Williams et al., 2020), limiting the knowledge learnt which could help to address racial inequalities. Genuine sharing of control and power with people with lived experiences of a subject, is crucial to challenging the dominance of the academic voices and Eurocentric perspectives in mental health research (Beresford and Croft, 2012).

Co-production emphasises a shift in power differentials; from ‘knowing’ professionals and researchers and ‘known’ patients, to equal stakeholders/contributors in improving service provision or conducting research (Karnieli-Miller et al., 2008; Newnes, 2001; Trivedi & Wykes, 2002). In this shifted power dynamic, each stakeholder brings a different cognitive and emotional representation on topics, shaped by different experiences and interests (Rycroft-Malone et al., 2016) which can provide insights into these topics affecting certain groups (Chew, Armstrong & Martin, 2013; Graham & Tetroe, 2007; Ward, House & Hamer, 2009). An example is Edge and Grey’s (2018) co-production of a culturally appropriate Family Intervention (FI) for African and Caribbean populations with schizophrenia. The involvement of EbEs sharing their opinions and experiential knowledge about FI’s advanced the knowledge production in two ways: specific modifications to the intervention (around discrimination and different illness models) to produce a more culturally appropriate intervention and more knowledge for professionals about offering more useful treatments to this population (Edge & Grey, 2018). Another benefit was meaningfully engaging this group of African and Caribbean EbEs, which was significant based on these populations' relationships with mental health services and historically poorer engagement with service development (Keating, Robertson, McCulloch & Francis, 2002).

Co-production has also produced different knowledge in research, for example, in research about the experiences of detention in psychiatric settings for service users with Personality Disorder (PD) (Gillard et al., 2010). EbE and academic researchers' joint data collection and analysis led to a more well-rounded understanding of PD recovery that integrated theoretical, clinical, research knowledge with subjective individual experience (Gillard et al., 2010). Other studies have reported that research data can be enriched and expanded by reflecting on the emotional impact of EbEs lived experiences, which can increase credibility of the findings amongst EbE stakeholders (Elliot, Watson & Harries, 2002) and brings an ecological or real-world validity to the objectivities offered by typical academic research (Faulker & Thomas, 2002). Furthermore, different knowledge can be produced when stakeholders have shared their views on what’s important about the research and why it’s important in relation to their identities (EbE, professional and academic), which has been described as increasing social accountability of science acknowledging that *who you are* shapes *what you know* (Gibbons et al., 1996). Co-production producing different knowledge has been demonstrated in other healthcare research or service development projects, such as improved design and recruitment rate from 40% to 70% in prostate cancer trial (Donovan et al., 2002) and improved richness and quality of the interview data on substance use (Coupland et al., 2005).

Black populations contributing to producing different knowledge could reform our approaches to addressing inequalities in healthcare by sharing their contributions and varied potential solutions (Rycroft-Malone e al., 2016), which would be situated within their experiences and knowledge of mental healthcare. It should be noted that EbEs should not be expected to solely ‘fix’ inequalities that impact their populations, but the co-production principles would argue they should be included equally. Including the experiences and knowledge of populations who have faced inequalities, alongside professionals’ knowledge, may progress to developing more relevant and useful interventions to target inequalities (Vindrola-Padros et al., 2017). Additionally, co-production that is thoughtfully executed and where knowledge is truly co-produced by EbEs and professionals may increase the likelihood that services and research projects will understand and meet the needs of the Black populations they are designed to serve (Gillard et al., 2012; Parveen et al., 2018). Furthermore, EbEs should be included across all aspects of the research process and treatment planning to improve the breadth of producing different knowledge. Further research should focus on understanding more about Black population's experience of co-production, to shape the co-production process in research and service development projects and enhance knowledge production.

3.4 Co-production can Empower and Improve Relationship with Services

Co-production can address racial inequalities by giving Black populations opportunities to be heard in contexts where they had been previously ignored, which assists their own recovery process (Happell et al. 2018; Kara 2013; Syrett 2011). Additionally, EbEs reported that sharing their experiences can contribute to the lives of other mental health service users, which was the strongest motive for getting involved in co-production (Mayes 2009; Syrett 2011; Telford & Faulkner 2004; Trivedi & Wykes 2002). EbEs invited to co-produce mental health research felt valued and proud in sharing their lived experiences (Miceli, Castelfranchi & Pocobello, 2017). They were valued that services recognised and respected their experiences as important to service development and to reduce the likelihood of future EbEs experiencing similar treatment (Pinfold et al., 2015). These findings have been corroborated by a cross-sectional study comparing co-produced mental health services to traditional services (Pocobello et al., 2020) and a literature review on co-production examples in mental health (Slay & Stephens, 2013). EbEs who took part in co-production and felt valued by professionals reported making progress in their healing recovery after experiencing unequal treatment (Pinfold et al., 2015). Additionally, co-production principles and practices can empower the EbEs involved which can have a wider systemic impact (Fairlie, 2015).

EbEs feeling valued from co-production impacted on their relationship with mental health services (Simpson & House, 2002), such as increased sense of empowerment in themselves, and in their communication with healthcare professionals. EbEs felt empowered to share suggestions for service development that may be more relevant to, and valued by, others from similar populations (Baxter, Thorne & Mitchell, 2001; Faulkner, 2004; Turner & Beresford, 2005). There could be significant implications for Black populations and services from better relationships, such as increased willingness of individuals to help-seek earlier during their psychosis, increased contact with services which may foster possibilities of rebuilding trust in services, and more autonomy and decision-making powers in their treatment and care (Slay & Stephens, 2013). For example, EbEs with Holy Cross Centre Trust (HCCT) (who co-designed and co-delivered activity sessions) and Mosaic Clubhouse (who co-produced peer-support an employment programme) were supported to take responsibility for how the service ran and the types of support offered to people, which they valued (Lachmund, 1998) and which altered EbEs views on their autonomy and decision-making capabilities in the long-term (Slay & Stephens, 2013).

The impact of co-production on improving relationships to services has been reported in research about a novel community centre mental health group co-produced and co-facilitated by Black EbEs and Black professionals (Lwembe, Green, Chigwende, Ojwang & Dennis, 2017). EbEs highly valued working with a diverse ethnic team, as evidenced elsewhere (Improving Access to Psychological Therapies, 2009), which resulted in group members reporting positive experiences, a shift in views on mental health services, and a 75% completion rate for the group, which could be considered a high completion rate for service users from minority ethnic backgrounds (Lawton, McRae & Gordon, 2021). This co-produced group has been commissioned to continue, has increasing uptake by EbEs, has been scaled to neighbouring boroughs to improve the racial inequality of access (Lwembe et al., 2017), and has trained service users as mental health champions and group facilitators (Green et al., 2015). This study, and the examples mentioned, have highlighted how co-production can lead to the creation and delivery of more relevant person-centred services (Barker, 2010; Boyle, Coote, Sherwood & Slay, 2010) which can improve access to and experiences of mental health services. This can be applied broadly to other services, for example, psychosis services.

3.5 Co-Production can have Social Benefits

Co-production has the potential to contribute to addressing racial inequalities for Black populations via secondary social benefits. Based on the small amount of quantitative research and Social Return on Investment (SROI) analyses, co-production can impact socioeconomic factors, such as (1) improved social networks and social inclusion, (2) improved skills and employability, and psychological factors, such as (3) addressing stigma (Slay & Stephens, 2013). These benefits are based on a small percentage of the population, but there is potential for more widespread benefits if populations are supported to engage in co-production.

Outcome-focused evaluations of EbEs involved in co-production in the Retain Regain project (supporting people with common mental health difficulties to stay in work or regain work at the earliest chance) reported that 90% percent of participants felt less isolated and 28% of participants made or sustained new friendships. EbEs who coproduced (HCCT) were encouraged to meet peers and try new things, which led to improved confidence in social situations, developing and maintaining relationships in the medium-term, and greater sense of community cohesion in the longer-term. Research has reported the benefit of social connection and networks on continued mental health recovery, reducing risk factors for further mental health difficulties and additional use of services (Tew et al., 2012). EbEs within Croydon Service User Network (co-designed network of psychiatrists and EbEs participating in the running of the service and co-facilitating groups) reported a 30% reduction in use of Accident and Emergency services after six months of members remaining in their co-production network, and the Recovery Innovations (co-produced peer-employment-training for those who have accessed psychiatric services) reported hospitalisations had reduced by 15% at one centre. A co-produced Mental Health Centre, compared with a traditional mental health service, reported hospitalisations decreased by 63% compared to traditional services, and 39% of EbEs reduced or withdrew from psychiatric medications (with professional guidance) compared to 22% of those in traditional services (Pocobello et al., 2020).

EbEs new skills and networks may improve their employability by further promoting their capabilities and self-efficacy to engage in formal learning and training opportunities, and longer-term employment. Sickness absence costs the UK £100 billion annually (Department for Works & Pensions, 2016) and unemployment benefits in the UK were £1.23 billion in 2021/2022 (HM Treasury, 2022). Therefore, there are estimated savings made by preventing more acute mental health needs arising, resultant hospital visits and admissions, and impact on sickness absence and unemployment (Stevens, 2008). Furthermore, in relation to EbEs improved skills and employability, mental health services reported that increased confidence and self-esteem were the most significant outcomes across all co-production projects (Slay & Stephens, 2013). Additional outcomes across all co-production projects were improved resilience, physical health, problem solving, negotiation and communication.

Regarding the third outcome of addressing stigma, EbEs involved in co-production reported experiencing less stigma from professionals. One principle of co-production that aimed to address stigma was breaking down boundaries between ‘patients’ and professionals. For example, co-production within a mental health service about ‘living well’ with dementia helped EbEs feel more equal to healthcare providers, for example, in sharing power about decision-making, than they had experienced in other services (West, Birt, Wilson, Mathie & Poland, 2022). Stigma was reduced when EbEs were included in decisions about the locations of co-production activities; Wandsworth IAPT invited community-based organisations to host co-production projects and provided mental health support via local faith centres, which addressed inequalities in access to mental health services (Slay & Stephens, 2013). Stigma amongst professionals towards service users was also challenged via an EbE-led training programme that aimed to share information and reflections about inequalities (Slay & Stephens, 2013), which was also shared with local communities. Co-production activities have reduced community stigma of accessing mental health services and mental illness (Lwembe et al., 2017). A second co-production principle that aimed to address stigma was developing peer support networks, which reduced stigma associated with mental health conditions and increased belonging to local groups and communities.

3.6 What are the Factors to Consider for Co-Production?

The section reviews the factors that facilitate and inhibit meaningful co-production in mental healthcare within the context of structural barriers that challenge whether and/or how meaningfully ethnic minority groups, such as Black populations can participate in co-production activities (Fotaki, 2015; Williams, Kang & Johnson, 2016; Williams et al., 2020). These barriers included limited awareness of opportunities to participate, fears about changes to their care, breaking cultural norms/stigma and mistrust of services and research (Shea et al., 2022). Furthermore, the first international systematic review on ethnic minority groups in co-production reported when they have taken part in co-production they were included in selective stages of research and not throughout the research process (Dawson et al., 2017). It has been argued that genuine involvement in co-production should occur in all stages of a research or service development project (Rose, 2014). This research is useful for a broader understanding of co-production in practice and reflections/insights on co-production best practice across ethnic minority groups, however, to understand and improve co-production experiences for Black populations in mental health services and research, Black populations need to be encouraged to engage in significantly more co-production projects.

Co-production has the potential to contribute to addressing inequalities, however, a challenge of co-production would be more successful engagement of Black populations than have engaged in other participation approaches. One approach to increasing engagement could be a foundational phase (‘Phase Zero’) prior to co-production that focused on shifting power and relationships between services and populations, by acknowledging and addressing social and power differences, and histories of oppression for marginalised populations (Burgess & Choudary, 2021). The principles of Trauma Informed Care may also be useful within this phase because this in part offers a framework to understanding how services at the bare minimum need to be for Black people with psychosis (Wood, Babusci, Bendall, Sarpal & Jones, 2023). Subsequently, this phase could allow future co-production to be viewed as more meaningful by populations and increase their engagement (Bovaird & Loeffler, 2013; Burgess et al., 2021). For example, deliberate and slow engagement with marginalised groups around Sickle Cell disease has led to increased engagement with co-production activities/projects (Miles, Renedo & Marston, 2018), which highlighted the potential benefit of addressing longstanding differences between groups before inviting them to take part in co-production. Furthermore, for co-production projects to involve more diverse groups, more understanding and research is needed on identifying the best methods of recruitment and engaging people (Bench, Eassom & Poursanidou, 2018; Metz, Boaz & Robert, 2019), to identify which engagement strategies work best and whether different strategies were needed to engage different population groups (Smith et al., 2022).

In addition to improving engagement with co-production, there are practical factors to consider for co-production. For example, a systematic review of co-production (Voorberg, Bekkers & Tummers, 2015) reported that professionals working in a risk-averse organisational culture did not consider EbEs as a reliable resource for improving services (Baars, 2011; Talsma & Molenbroek, 2012). Consultant psychiatrists, in interviews about their attitudes to co-production, expressed support for the theoretical idea of shared decision making in antipsychotic prescribing rather than doing this in practice (Shepherd, Shorthouse & Gask, 2014). Such examples within organisations can maintain the traditional perspectives of EbEs as non-contributors or ‘patients to be researched’, which reinforces a concept of no ‘institutional space’ to invite them as equals (Maiello et al., 2013). Institutional space in this context referred to lack of space or tools within an organisation for EbE involvement practices (Maiello et al., 2013). The perception of institutional space for EbEs could be improved with clearer incentives of co-production for professionals and organisations (Fuglsang, 2008), such as the extent and range of benefits for services from EbEs input (Evans, Hills & Orme, 2012; Sangill, Buus, Hybholt & Berring, 2019), including budgetary benefits (Abers, 1998) or increased service user interest in accessing services (Lam, 1996).

Additionally, clear explanations and agreements about roles and responsibilities within co-production are essential for stakeholders because misalignment in expectations can be a barrier to co-production. For example, without this clarity of expectations, EbEs had felt a power imbalance with professionals, that they were not treated as equal contributors and their contributions were either not listened to or used as a symbolic and tokenistic appendix to the project (Glover, 2009). This could be damaging to EbEs and add to their experiences of being ignored. This could be improved with stakeholders receiving training and having regular meetings about expectations in co-production (Moltu, Stefansen, Svisdahl & Veseth, 2012; Moule & Davies, 2016). A co-produced research project in a psychiatric setting reported that involving EbEs across the research cycle/process helped to clarify expectations between stakeholders and share power, which helped to develop a good collaborative and genuine relationship (MacInnes, Beer, Keeble, Rees & Reid, 2011).

Another factor to consider for co-production would be buy-in or lack thereof from senior management and organisational leaders (O’Dwyer & Kinsley, 2012). Organisational buy-in was more likely if there were existing presence of organisational structures (Andrews & Brewer, 2013; Bovaird & Loeffler, 2012; Meijer, 2012) and the presence of infrastructure to communicate with EbEs (Davidsen & Reventlow, 2011). Where co-production was most well-integrated and adopted within teams, there had been a top-down culture shift from organisation and service leaders. Furthermore, these leaders modelled support for co-production and willingness to share power, which led to a new vision and communication model that enabled most professionals to adopt co-production in many organisational activities. In contrast, leaders who preferred to retain their culture and adopt co-production principles for a specific project or initiative limited in time, co-production was viewed as an ‘add-on’ to existing activities by team members. Sharing power and knowledge is critical for implementing co-production, which includes informing professionals to avoid using jargon to ensure all stakeholders can understand (Stomski & Morrison, 2017). Co-production activities where EbEs were also financially paid for their contributions reinforced the value of their involvement and that services recognised this value (Pinfold et al., 2015), and likewise a barrier was EbEs being paid nominal rates or unpaid which they felt did not match their time or effort (Lemonsky 2015).

There may be an ethical dilemma about whether people who have been traumatised or suffered unequal treatment by services should be the people to ‘fix’ services (Rose & Kalathil, 2019). There is no research about the impact of co-producing research and services aimed to address health inequalities on Black populations (Smith et al., 2023). Furthermore, based on anecdotal evidence during the 2020 international Black Lives Matter (BLM) movement, Black people were exhausted from experiences of institutional racism and from longstanding racial fatigue from trying to tackle inequalities, therefore allies actively participating in the movement was strongly encouraged (Kinouani, 2021; Winters, 2020). Therefore, it is currently unknown how Black populations would view taking part in co-production projects that are aimed to addressing inequalities, for example, whether such research would be distressing and risking Black populations having further racial fatigue. Research is needed to understand Black populations views on and impact of getting involved in co-production projects, especially regarding projects that aimed to address inequalities.

3.7 Conclusion

This review has reported the disproportionate health inequalities that Black populations experience in mental health services (Hussain et al., 2022). Inequalities for Black populations in psychosis services include higher rates of adverse pathways (Halvorsrud et al., 2018), higher compulsory detention rates (Barnett et al., 2019), increased use of restrictive treatment practices (Gudjonsson et al., 2004), and less access to NICE recommended treatments (Das-Munshi et al., 2018). The contextual factors to these inequalities for Black populations, which are vast and interact to create a complicated context, include a history of Medicine, deprivation of liberties in MHA, and help-seeking behaviours. These equalities can be traumatic and fear-inducing for Black populations when they need mental healthcare (Akther et al., 2019). In addition, these inequalities have been a concern for healthcare providers and policy makers, and recent publications aimed to address these (Oduola et al., 2019). However, there was a lack of progress which may be due to the limited guidance on practical interventions or strategies (Hussain et al., 2022). Furthermore, within this limited practical guidance, which was designed by professionals, there was an absence of involvement from service users and populations with lived experiences.

It is essential to involve Black populations in improving healthcare provision to create relevant services that address their needs (Department of Health, 2012), which has been lacking in spite of recent PPI and co-production movements. With the research and service development reports available, this review has described the importance and benefit of including the voices of Black populations in co-production projects, specifically in producing different knowledge about mental healthcare and improving disparities (Edge & Grey, 2018; Gillard et al., 2010), empowering EbEs and improving their relationships with services (Happell et al., 2018), and social benefits (Slay & Stephens, 2013). It is important to include the voices of Black populations to address racial inequalities, in order for co-production practices to be done well. As previously stated, Black populations voices about and experiences of mental healthcare should also be included in other ways to reduce healthcare inequalities, such as reforming the MHA, cultural competence training for mental health professionals, and trauma informed care given overlap with racial trauma. Further, Black populations should be included in improving healthcare inequalities beyond co-production, for example, increased representation in the professions, research led by Black professionals.

There may be an ethical dilemma of involving Black populations in addressing issues that they experienced, for example, they might be reluctant to work with professionals or services that have repeatedly failed them; and/or feel mistrust at working with professionals (Shea et al., 2022). With policies such as ‘no decision about me, without me’, services should prioritise service users' perspectives and their decision-making abilities throughout their mental healthcare journey (Charlton, 1998; Rahman, Nawaz, Khan & Islam, 2022). Black populations should be supported to take part in co-production projects, however, currently their views on taking part in co-production and any impact on them is unknown. As stated above, to increase diversity of populations in co-production projects, future research should focus on identifying the best methods of involving and engaging different populations as this may vary between different groups (Bench et al., 2018; Metz et al., 2019). Likewise, UK policies stipulate that services should explore the impact of involvement practices on service development in health and social care and on EbEs themselves (Carr, 2007; Doel, Carroll, Chambers & Cooke, 2007), and further research in this area is needed. Therefore, Part 2 will be exploring Black EbEs perspectives on co-production research or service development projects aimed at addressing inequalities, specifically perspectives on factors relevant to inviting EbEs and the impact of involvement for those who have taken part.

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Part 2: Empirical Paper

Exploring Black Experts by Experience views (and experiences) on the concept of using co-production in projects to address racial inequalities in mental healthcare and recommendations for using co-production in future projects.

Abstract

Background: In the UK, Black people are more likely to experience racial inequalities in access, experience and outcomes in mental health services compared to their White British counterparts, such as adverse pathways into psychiatric settings, disproportionate rates of compulsory detention, and disproportionate rates of restrictive or coercive practices. While studies and policies have reported these differences and intentions to tackle them, there are limited direct interventions aimed at addressing these disparities. The NHS has highlighted the importance of service user involvement in service design and improvement, and one approach to this is the use of co-production with communities who experience marginalization.

Aim: This study aimed to understand Black people's perspectives on engaging with and being involved in co-production projects aimed at addressing racial inequalities in EIP services.

Method: This study used semi-structured interviews to explore eight Black Experts by Experience (EbE) perspectives and experiences of co-production projects; and recommendations for engagement in future co-production projects. The interview data were analysed using Thematic Analysis (TA) approach.

Results: The analysis resulted in ten subordinate themes and five superordinate themes which highlighted the importance of acknowledging EbEs relationship to help, listening to and valuing EbEs, ensuring psychological safety in co-production, the benefits of connection and learning, and EbEs future hopes for co-production projects on racial inequalities. Recommendations for future co-production projects were discussed.

Conclusion: This is the first study that has qualitatively explored the perspectives of engaging with and being involved in co-production projects aimed at addressing racial inequalities in EIP services. It provides valuable insight into the subjective experiences of EbEs who were and were not involved in co-production projects. This can aid in the development of future co-production aimed at addressing racial inequalities in mental healthcare.

1. Introduction

Inequalities within the access and experience of mental healthcare for Black people with psychosis compared to their White counterparts, has been observed internationally and within the United Kingdom (Mann et al., 2014). Compared to their White counterparts, Black populations with psychosis have a greater risk of adverse pathways into psychiatric services; are over twice as likely to have been involved with the Criminal Justice System (CJS) during their pathway into mental health services (Halvorsud et al., 2018) and in 2021-2022 were four times more likely to be compulsory detained or hospitalised under the Mental Health Act (MHA) (Audini & Lelliott, 2022). Black populations have experienced compulsory detentions as negative more frequently than their White counterparts (42.9% and 29.7% of patients, respectively; Katsakou et al., 2012). Within psychiatric settings, Black patients are significantly more likely to be subjected to coercive or restrictive practices, such as seclusion and physical restraint than White patients (56.2 per 100,000 population for Black Caribbean compared to 16.2 per 100,000 population for White patients; Mind, 2019). Furthermore, in psychiatric settings, Black patients stay longer in hospital than their White British counterparts (Mohan et al., 2006), are twice as likely to be readmitted to hospital (Priebe et al., 2009) and are eight to ten times more likely to be placed on a Community Treatment Order (CTO) (NHS Digital, 2019; NHS Digital, 2021). Regarding treatment for psychosis, Black populations have less access to NICE recommended psychological therapies (Glover et al., 2009), and are less likely to be offered evidence-based treatments for psychosis such as Cognitive Behaviour therapy (CBT) or Family Therapy (Das-Munshi et al., 2018).

Moreover, inequalities exist within access to and experience of Early Intervention for Psychosis (EIP) services (Friskney, Branney, Iqbal, Edwards & Wem, 2023). EIP services are National Institute of Clinical Excellence (NICE) recommended community services developed with the aims to prevent an episode of psychosis or support recovery of individuals experiencing a FEP (Murphy & Brewer, 2011). Preventing a first episode or mitigating symptoms can improve long-term outcomes for individuals at risk of psychosis and prevent any further episodes (Chung et al., 2013; Fusar-Poli et al., 2017). However, the largest disparities between Black and White populations experiencing First Episode Psychosis (FEP) occurs within psychiatric settings (Cantor-Graae & Selten, 2005; Morgan et al., 2005; Morgan, Mallett, Hutchinson, & Leff, 2004; Tortelli et al., 2015). During help-seeking to or receiving support from EIP services, some racial ethnic minorities have reported experiencing at least one microaggression, such as professionals denying differences between them and clients, minimising the importance of racial or ethnicity beliefs relating to their mental health, and making assumptions about them based on their ethnicity (Constantine, 2007; Hook et al., 2016; Sue et al., 2008). Black service users and carers reported a sense of powerlessness and insensitivity to their needs in EIP services (Lawrence et al., 2021), and Black patients experiences in EIP have been associated with poorer therapeutic relationships, lower perceived professional competence and understanding, less satisfaction with psychological treatment (Constantine, 2007) and increased likelihood of prematurely terminating treatment (Sue et al., 2007; Taylor & Kuo, 2018).

These inequalities for Black populations have impacted their psychological wellbeing, duration and prognosis of psychosis symptoms and help-seeking behaviours. Negative experiences of detention, for example via the CJS, can be highly distressing, and have been associated with humiliation, loss of dignity and respect, and a sense of violation (Burnett et al., 1999; Chambers et al., 2014; Lu et al., 2017; Nyttingnes et al., 2016). Individuals can feel traumatised or in some cases can develop psychosis-related post-traumatic stress disorder from the experiences of involuntary and forceful treatment practices whilst experiencing psychotic symptoms (Berry et al., 2013; Rodrigues & Anderson, 2017). Additionally, adverse pathways have been also associated with longer durations of untreated psychosis (DUP), which can delay early detection and intervention of the symptoms impacting the prognosis (Birchwood et al., 1998; Marshall et al., 2005; Singh, 2001). At first presentation and at 10-year follow-up (Morgan et al., 2008; Morgan et al., 2017), Black Caribbean populations with FEP had worse clinical prognosis (overt symptoms), social prognosis (markers of social disadvantages and isolation) and service use outcomes (contact with mental health services and treatment adherence) than the White British counterparts. Furthermore, these inequalities have been associated with delayed help-seeking behaviours in mental healthcare, which can prolong the duration of symptoms and increase their severity (Devonport et al., 2022).

Explanations for these inequalities are complex. As described in Part 1, analyses over the past few decades have often reported individual-level factors to explain these inequalities in mental healthcare and mental health outcomes (Barnett et al., 2019). Factors such as Black people’s lifestyles, cultural health beliefs, community stigma of mental ill-health, differing help-seeking behaviours, increased drug use and aggressive behaviour (Chorlton, McKenzie, Morgan, & Doody, 2012; Lawlor et al., 2012; Morgan et al., 2010a) have been frequently identified as explanations for racial inequalities (Barnett et al., 2019). However, these explanations ‘locate the issue’ within a population and do not acknowledge the impact of institutional racisms within organisations (Nazroo, Bhui & Rhodes, 2019) or the impact of contextual factors in relation to the inequalities (Zahid, Hosang, Fonseca de Freitas, Mooney & Bhui, 2023).

Institutional racisms have a long history with Black populations, including experimental procedures and research conducted without anaesthesia (Sartin, 2004) or without informed consent (Butanis, 2020; John Hopkins Medicine, n.d.), and Government reports bolstering Black men’s perception as threatening (Prins et al., 1993). Institutional racisms have impacted on inequalities for Black populations within psychosis services; Black women have reported that mental health professionals' actions during their compulsory admission to psychiatric settings were (at best) unnecessary and (at worst) abusive and racist (Nicholas, 2020). Experiences and expectations of racist mistreatment by mental health services have impacted on the degree of trust Black populations have felt able to develop in mental health services, which discourages future voluntary help-seeking and discourages future engagement with services (McClean, Campbell & Cornish, 2003). Additionally, inequalities have been associated with contextual factors. For example, socioeconomic deprivation (Vernon, 2020), longstanding unemployment and environmental neglect and social deprivation (Shim & Compton, 2020) and migration (Boydell et al., 2013) are associated with increased severity of psychological distress, increased severity of mental health symptoms, risk of psychosis (Kirkbride et al., 2014) and rates of compulsory detention (Bindman et al., 2002). Considering all these factors (individual-level, institutional and contextual) contribute to inequalities for Black populations, it is important to understand how these factors interact and maintain inequalities in society (Lawrence, McCombie, Nikolakopoulos & Morgan, 2020).

Attempts have been made to theorise and understand the complex interaction of these factors in relation to racial inequalities in society, and specifically within healthcare services. The 'Circles of Fear' model, which explains the cyclical and pervasive nature of racial inequalities in mental healthcare (Keating et al., 2002), suggests that Black populations have mistrust and fear towards accessing mental health services because they perceive services will replicate the racist and discriminatory experiences they had within society. For example, exclusion from schools, contact with police and CJS. In addition to fears about experiencing racism or discrimination, there are fears that accessing mental health services could eventually lead to their death (Keating et al., 2002). Accordingly, individuals, families and carers are reluctant to be involved in mental health services because they fear the outcome (Keating et al., 2002), which perpetuates a cyclical pattern of racism, fear, and inequalities. Equally, professionals and services fear, weariness, and uncertainty about how to support and respond to Black populations can lead to difficult experiences, which reinforces service users' perceptions and fear and reluctance to seek help.

Although this study is based in the UK, there are similar inequalities internationally for Black people with psychosis in the access, experience, and outcomes of mental healthcare (Cenat et al., 2023; Chung, Jiang, Milham, Merikangas & Paksarian, 2023). In addition, there have been increased incidence rates of psychoses disorders among Black and migrant populations internationally compared with the native majority populations (Alexandre, Riberio & Cardoso, 2010; Al-Saffar, Borga, Wicks & Hallstrom, 2004; Selten et al., 2001; Vinkers, de Beurs, Barendregt, Rinne & Hoek, 2010). Other countries, for example in Western Europe and the United States, reported these inequalities were a major social and public health concern and acknowledged that these inequalities need to be addressed at multiple levels, such as social policy, mental health service reform and community initiatives (Anglin et al., 2021; Morgan, Knowles & Hutchinson, 2019).

The UK Government acknowledged these inequalities were concerning healthcare providers and policy makers (Oduola et al., 2019) and therefore, a priority for UK health systems was on implementing interventions to address inequalities and address the mistrust within Black populations. Several Government and National Health Service (NHS) England publications were released and aimed to address pathways into care, detention rates, and access to and acceptance of psychological treatments (Bhui et al., 2003; Fisher et al., 2014). For example, the Race Equality Action Plan (Department of Health, 2004), Care Quality Commission's (CQC) National Mental Health Development Unit, NHS Five Year Forward View (2016), the Race Disparity Audit (Cabinet Office, 2017) and in 2020 the NHS Advancing Mental Health Inequalities Strategy (2020). This latter publication was released in the context of wider disparities for Black populations, such as being four times more likely to die from the 2020 Coronavirus pandemic (Office for National Statistics, 2020) and the resurgence of the Black Lives Matter protests due to another death of a Black man by police in the United States. As a result, this added further focus on the NHS to address disparities for Black populations, which led to the development of NHS England's Patient and Carer Race Equality Framework (PCREF) to eliminate racial inequalities in access, experience and outcomes faced by Black and Minority Ethnic ('BME') particularly Black populations and improve their confidence and trust in services (Smith et al., 2023).

Researchers reviewed the Government's and NHS' publications and the existing interventions within mental health services which aimed to address racial inequalities. In a summary, Hassen et al. (2021) indicated that these interventions included trainings and workshops on: cultural competence (e.g., improving professionals' awareness of racism, unconscious biases and reflections on clinical practice) (Papadopoulos, Tilki & Lees, 2004; Rocke, 2015; Steed, 2010), institutional racism within mental healthcare (e.g., improving professionals knowledge and expertise in using anti-racist practices) (Malott & Schaefle, 2015; Signal et al., 2007) and recognising privilege and implicit bias amongst mental health professionals (e.g., using self-reflection exercises and teachings) (Fitzgerald et al., 2019; Holm et al., 2017). These interventions have been limited in their application to Black populations, for example, five of the thirty-seven peer reviewed studies focused on this cohort, and they were limited in their evaluation of the impact or outcome of the interventions on racial inequalities (Hassen et al., 2021). In addition, the majority of the existing interventions aimed to address racial inequalities in mental health services were developed by mental health professionals (Gillard, Turner, Neffgen, Griggs & Demetriou, 2010). Given the complexity and systemic nature of inequalities, 'one' intervention will not address it all, but Hassen et al.'s (2021) review highlights that there are very few interventions developed and evaluated, which are aimed at addressing inequalities for Black populations in practice.

One direction that health and social care domains are developing in their service provision is with service user involvement. It has been seen as valuable for services to include those with lived experience, also termed as Experts by Experience (EbE), to improve service provision (Gradinger et al., 2015). In a systematic review (Dawson, Campbell, Giles, Morris & Cheraghi-Sohi, 2018), researchers reported that if the specific needs and views from 'BME' groups about service provision were not considered during research or design of interventions, the product or service might not reflect their specific needs and would be ineffective. This is pertinent for the area of inequalities, as it calls for services to engage with communities who experience marginalisation or disparities in care, to be able to understand their experiences, needs and recommendations for improving services (Solanki, Wood & McPherson, 2023), which has been previously lacking. One model for doing this is Co-production, which has been increasingly regarded as the gold-standard for engaging communities, particularly minority groups, into developing service provision (Mulvale & Robert, 2021).

Co-production is an active participatory approach where EbEs work in partnership with professionals on research or service development projects (Prahalad & Ramaswamy, 2000; Vargo & Lusch, 2004). The ethos of co-production is that EbEs and mental health professionals both have pertinent knowledge and expertise that could inform service provision, i.e., co-production joins ‘expertise by experience’ and ‘expertise by profession’ (Faulkner & Thomas, 2002; Fox, et al., 2018; Gordon & O’Brien, 2018). Therefore, co-production stipulates that EbEs and professionals share the responsibilities and power in a reciprocal relationship, and equally contribute to the project processes and tasks. The emphasis on mutuality and equality between all stakeholders sets co-production apart from other service user involvement approaches (Rose & Kalathil, 2019). There are challenges for all stakeholders to engage in co-production (Norton, 2023), however, there have been positive individual- and organisational-level benefits for EbEs such as improved wellbeing and satisfaction with services (Ewalds Mulliez et al., 2018), and organisational-level benefits for services, such as reduced long-term costs (Nikcevic & Jatta, 2014). Importantly, co-production aims to prioritise the valid and real-world expertise of EbEs, alongside professionals’ expertise, which has been shown to produce different academic knowledge in research (Faulkner & Thomas, 2002) and bring new insights into improving mental healthcare provision (Durose, Beebeejaun, Rees, Richardson & Richardson, 2012). Therefore, including the first-hand perspectives of EbEs are key because they are at the centre of healthcare services and they can provide an important, unique, and invested perspectives on what does and doesn’t work well, and why (Tapp et al., 2013). This has led to efforts to include Black people’s experiences and perspectives in interventions aimed at addressing racial inequalities. For example, qualitative research involving EbEs provided valuable insights and changes in detention under the MHA, whereby patients in psychiatric settings can now contribute to the decision about who has rights in making treatment decision on their behalf (Akther et al., 2019; Hussain, Hui, Timmons & Nkhoma, 2022). Furthermore, initiatives within NHS Trusts, such as North East London NHS Foundation Trust (NELFT), to address racial inequalities for BME populations within EIP services led to the commissioning of a staff training intervention; which was co-produced by EIP professionals and Black EbEs.

EbE involvement and co-production is increasingly regarded as the gold-standard for improving health engagement with minority groups (Mulvale & Robert, 2021). Though, literature has indicated that involvement of service users within healthcare development occurred at selective stages of the research or service development (e.g., design) rather than throughout the process and service users were rarely included in the early stages of intervention development, or at phases of funding, data collection, analysis and interpretation, and dissemination (Dawson et al., 2018). A move towards having more genuine involvement and co-production will include various system shifts and factors, but one area is understanding the facilitators and inhibitors to involvement in service development for EbEs. There is little research in this area, but some inhibitors included a lack of understanding about the positive impact of involvement on EbEs and challenges for EbEs in trusting services (Isler et al., 2014). Facilitators included financial payment to recognise EbEs contribution (Mott & Crawford, 2008), allocating time to listen and discuss health problems with the group (Burrus, Liburd & Burroughs, 1998) and sense of contribution to current and future service users lives (Mayes 2009; Syrett 2011; Telford & Faulkner 2004; Trivedi & Wykes 2002). Although these studies provide insights into the potential experiences of ‘BME’ service users involved in health interventions, there is considerable space to highlight the perspectives of Black EbEs involved in co-production interventions, especially those focused on addressing inequalities in mental health services, where their ‘lived-experience’ is two-fold. For example, exploring whether lived experiences of racial inequalities compound participation in mental healthcare co-production and understanding perspectives of taking part in co-production within a context of mistrust in services, or within the context of an ‘ethical dilemma of fixing services that hurt Black EbEs. Moreover, there is considerable space to understand Black EbEs perspectives and recommendations on how to improve engagement, support required in co-production projects. This highlights a gap within the literature, at a time where there is importance of co-production and service involvement in NHS service development, coupled with increased focus on improving and addressing the inequalities experienced by Black service users. Therefore, this study will explore the experiences and impact of co-production on Black EbEs with psychosis, specifically related to projects targeting racial inequalities. To the researcher’s knowledge this is a novel study, with the focus on qualitatively exploring Black EbEs perspectives on co-production aimed at addressing racial inequalities to ascertain how the NHS can support this cohort to engage in developing service provision in this area.

The three main aims of the study were:

1. To explore perspectives of being invited and engaging with co-production;
2. To explore experiences and impact of being involved in co-production and;
3. To obtain feedback and recommendations for engaging Black populations in future co-production projects that address racial inequalities in mental healthcare.

2. Method

This study refers to the constructs of ‘ethnicity’ and ‘race’. Ethnicity refers to categories of people based on shared cultural, religious, spiritual, language or geographical backgrounds and race refers to categories of people based on physical characteristics such as skin colour or nationality origins (Bhopal, 2004; Blakemore, 2019). Both concepts are socially constructed, though this study will use the term ethnicity because this is a broader social construct to capture the complexities and nuances of categorisation (Afshari & Bhopal, 2002; Naz, Gregory & Bahu, 2019) and is often self-defined by individuals (Smith & Silva, 2011).

Ethnicity was defined in this study by the Census 2021 data (Office for National Statistics, 2022) and refers to individuals who identified as Black or mixed-Black, Black British, Caribbean or African and Other Background.

Setting & Contextualising the Study

The context for this study was to include service users who had and had not taken part in co-production projects in order to gather a breadth of information about using co-production in projects about racial inequalities. The ethics application for this study, specifically the inclusion criteria, was deliberately broad and inclusive whereby participants might have contributed to the development of any co-production project about racial inequalities or never contributed to a co-production project (i.e. not been approached or aware of the project). This broad criteria within the ethics application enabled the researcher to approach and recruit both groups of individuals for this study, and gather information about using co-production from a broader sample of participants.

North East London Foundation Trust (NELFT) is an NHS Trust in England. NELFT had an initiative to focus on addressing racial inequalities as with other NHS Trusts (e.g., The NHS Long term Plan (NHS, 2019)). Within their Early Intervention in Psychosis (EIP) services, there was a forum of projects aimed at engaging service users and addressing inequalities which led a BME EbE Group where EbEs could influence various projects within their EIP. One project was a staff training, titled ‘See Me’, which was influenced by recommendations from the EbE Group about the importance of co-production and involvement of service users in addressing inequalities and improving healthcare provided to Black service users. The ‘See Me’ training was co-produced with EbEs (Black service users with psychosis) and mental health professionals. The ‘See Me’ co-production involved four EbEs attending an all-day workshop with mental health professionals and several filming days to share their personal experiences with EIP services, discussing their rich stories, values, and strengths that define their experiences. This was a narrative framework approach to thicken stories of Black populations that are less dominant and to counter dominant narratives and stereotypes. EbEs video testimonials were compiled into a 20-minute film, followed by reflective tasks for professionals to think about their clinical practice.

EIP services are multi-disciplinary teams (MDT) which includes professionals such as nurses, clinical psychologists, care coordinators, support workers, psychiatrists, and occupational therapists. Their aims are to identify and reduce delays to treatment at the onset of psychosis and offer continued support during recovery to reduce the likelihood of relapse following a first episode of psychosis (Murphy & Brewer, 2011). EIP services in the UK are measured against a criterion, National Clinical Audit of Psychosis (NCAP), to ensure their quality of care offered to individuals with psychosis (Addington, French & Smith, 2021).

This study is connected to three other projects about: two projects directly qualitatively and quantitatively evaluated the ‘See Me’ intervention amongst professionals, and one project qualitatively explored professionals needs and experiences of working on projects in the Trust more widely. This was the context of recruitment for this study, whereby professionals within NELFT EIP services were also interested in how they were supporting EbEs, and supporting development of service user involvement and co-production within their Trust. Participants for this study were recruited from services linked to NELFT that support individuals with psychosis.

Design

Inclusion criteria

Participants were recruited based on the following inclusion criteria:

- Adults aged 18 years and over.

- All genders.
- Adults who racially identified as Black, or mixed-Black, British, African, Caribbean and Other Background.
- Adults who are service users under the care of NELFT EIP.
- Participants might have:
    i. Contributed to the development/ co-production of any addressing inequalities intervention (i.e., the 'See Me' training), or
    ii. Never contributed to the development of any addressing inequalities intervention (i.e., not been approached or aware of co-production projects, declined co-production projects)
- Not currently in crisis. This was determined in the first instance by the referring clinician, and by the researcher during the initial contact.
- Not currently in hospital either voluntarily or under the section of the Mental Health Act under section 136, section 2, or section 3. (Please note outpatients under a CTO could take part as long as they were not in crisis, which was determined by the referring clinician).
- Able to read and speak English to provide informed consent, complete the demographic questionnaire and complete the interview.
- Had capacity to provide informed consent.

Interview Schedule

In accordance with TA methodology (Braun & Clarke, 2006), the research team devised a semi-structured interview schedule (see Appendix A) to facilitate the researcher and participants to discuss the research questions. The semi-structured interview was designed to be flexible and responsive to the conversations that unfolded from participants' responses. With this structure, the researcher could generate follow up questions to sufficiently explore topics, while using the schedule to remain connected with the aims of the interview.

Development of the interview schedule. The interview schedule was co-produced by the research team and EbEs (Black people with a diagnosis of psychosis who had worked on projects addressing racial inequalities), and in consultation with Experts by Profession. The first draft included questions proposed by the research team based on recommendations from previous studies of racial inequalities in the care of Black people with psychosis. The research team and EbEs also considered which questions would be important to generate information relevant to the aims of the study. The research team and EbEs identified key sections of the interview schedule including questions exploring demographic characteristics, views on the concept of co-production, views, and experiences of being invited to co-production projects, experiences taking part in co-production projects, and perspectives on the impact of ethnicity on taking part in projects about racial inequalities.

This co-production and consultation were sought to ensure the questions aligned with the aims of the study, to identify whether any important topics were missing, and to ensure that questions were asked in a meaningful, accessible, and sensitive manner. This took place in three stages: (1) meeting with experts in qualitative research and EDI practice to ensure questions about ethnicity and racial inequalities were included and advise on the styles of questions to address the research questions, (2) meeting with five Experts by Experience, all of whom were Black people who accessed NELFT EIP, to refine the questions and ensure they were relevant, and (3) meeting with three Experts by Experience, all of whom were Black people who accessed NELFT EIP, to ensure the questions were clear and sensitively addressed difficult topics. The wording of the interview questions and structure of the schedule was refined based on these consultations. Further details of the consultations are reported in Appendix B.

Format of the interview schedule. At the beginning of the interview schedule there was a form to gather participants' demographics information and contextualise the data based on their contact with EIP services. The interview schedule was comprised of three sections. The first section asked all participants about their experiences of being invited to co-production projects addressing racial inequalities, whether or not they participated in co-production projects. In section two, only participants who had participated in co-production projects were asked about their experiences of this and the impact on them. Participants who had not taken part in co-production proceeded to the third section, where all participants were asked about views on co-production and recommendations for improving involvement in future co-production projects aimed at addressing racial inequalities.

The term ‘co-production’ is not often used in layperson’s spoken language, and this is reflected in the interview transcripts where ‘co-developing’, ‘video’ or ‘project’ are used by participants. Throughout the write-up of this study, the term ‘co-production’ is used by the researcher.

Recruitment

These NELFT services were the four Early Intervention Psychosis (EIP) services across the four boroughs in NELFT and affiliated community wellbeing projects, such as Coping Through Football.

Purposive sampling was used. The researcher recruited participants who were or were not involved in co-production. The aim was to gather views from participants who did contribute to a co-production project or did not contribute (e.g., not been approached to contribute) to hear broader perspectives.

The researcher contacted a Clinical Psychologist from each of the five NELFT sites via an email containing the study description, eligibility criteria, research advert (see Appendix C) and participant information sheet (see Appendix D). The Clinical Psychologists circulated the study with their teams, and the professionals within the teams shared the study with EbEs who met the inclusion criteria. The Clinical Psychologists circulated the study to the NELFT BME

EbE Group to identify EbEs who had taken part in co-production projects and met the inclusion criteria. EbEs who were eligible to take part received the research advert and participant information sheet containing details of the study.

At least 24 hours after receiving an information sheet, the Clinical Psychologist contacted participants to ask if they were interested in taking part in the study. The Clinical Psychologist asked if potential participants consented to be contacted by the researcher or preferred to contact the researcher by email or phone (on a study-specific telephone number). The researcher discussed the study with potential participants and gave them an opportunity to ask any questions. Potential participants that were willing to take part in the study were provided with the written consent form (see Appendix E) and asked to read through and sign two copies: one copy for the participant and one copy for the researcher. The researcher informed the Clinical Psychologist that the client they were caring for was taking part in the study. Once the consent form was completed and returned by the participant, the researcher arranged a date and time to meet with potential participants to conduct the interview. Interviews were conducted online via Microsoft Teams, via telephone or if permitted face-to-face at a NELFT site, depending on participant preference.

Procedure

Based on participant preference, all interviews were carried out online via Microsoft Teams video call except for one participant who preferred to have the interview at their usual NELFT site.

Before the interview started, the researcher reviewed the information sheet with participants and answered any questions or concerns raised. Following this, participants were reminded of their right to withdraw from the study at any point prior to data collection and that doing so would not affect their care in any way. The researcher asked participants to complete a demographics form for descriptive sample purposes and contextualise the data based on their contact with EIP services. The demographic characteristics were as follows: age range, gender, ethnicity, whether they experienced racial inequalities in EIP including but not limited to hospital admission, referral route to mental health services, and any previous involvement in co-production projects in the following areas: addressing inequalities, mental health (see Appendix F).

At the beginning of the semi-structured interview, participants were reminded that all of their information would remain anonymous and confidential, and the researcher encouraged participants to be open and honest. The researcher reminded participants that the interview would be audio recorded. Face-to-face interviews were audio recorded using an encrypted device and online interviews were audio recorded using Microsoft Teams recording feature. The interviews lasted between 30-90 minutes. Upon completion, participants were thanked for their participation. Participants were given a standardised written debrief at the end according to BPS guidelines (British Psychological Society, 2010) for the ethical treatment of research participants, provided with an opportunity to ask questions, and provided with information about support services if further support was required at the time or in future. Participants were informed that the researcher would contact them in a week to check-in on how they were after the interview.

During the interview, the interview schedule was used as a guide to ensure all areas of interest were covered in the discussion; however, the researcher was flexible and adaptive regarding the order that questions were asked and asked follow-up questions if a participant raised a topic not covered by the prepared interview schedule.

Sample

Seventeen people were identified as eligible for the study by Clinical Psychologists using purposive sampling. Nine people declined participation; two were too busy to take part, four people agreed to take part and then cancelled, and three did not respond to the invitation. The remaining eight people identified as eligible agreed to participate in the study and attended interviews. Three participants were involved in co-production to address racial inequalities and five participants were not involved in co-production (i.e., had not been approached to co-produce).

Ethical Considerations

This study was granted full ethical Health Research Authority (HRA) approval by the London Social Care REC (Reference number: 23/IEC08/0016) (see Appendix G). Approval was also granted by NELFT R&D from where participants were recruited (see Appendix H).

Confidentiality and anonymity of all personal data was maintained throughout the entire study. The researcher generated numerical identification codes for participants to replace names and personal identifiable data were removed during transcription. Once transcribed, audio recordings of the interview were immediately deleted. Personal data was stored in a password protected file on the university computer system and files were only accessible to the researcher.

It was anticipated that physical harm from study participation was unlikely, though the researcher was mindful that participants in the study would be asked to discuss events that may have been upsetting. Before commencing the study, participants were reminded that they may withdraw at any time, without their care being affected in any way. During the interview, the researcher monitored the participant for signs of distress and asked participants for feedback about their experience regularly throughout the conversation to allow the researcher to assess any negative reactions. The researcher ensured sufficient time was spent building rapport early in the interview, and participants' experiences and emotions were validated and normalised throughout the conversation.

Following the interview, the researcher thanked participants for taking part. The researcher asked participants how they experienced the interview and if they had found the interview upsetting. None of the participants had reported experiencing the interview as upsetting or distressing. During the debrief (see Appendix I), the researcher offered participants the opportunity to complete a mindful breathing or progressive muscle relaxation exercise and reminded participants of the list of support resources and services to access, if needed. The researcher offered participants to have a debrief call one week after the interview. Finally, participants received £15 for their time.

Data Analysis

TA was used to analyse interviews on participants' experiences. TA is not confined within a particular epistemology and allows for guiding the discovery of data related to the research questions (Braun & Clarke, 2006).

The following steps were recommended by Braun and Clarke (2006) and were taken to analyse the data:

Step 1: Familiarisation of Data

Each transcript was read at least twice by the researcher. Whilst reading and re-reading the researcher noted any thoughts and ideas that came to mind to identify and bracket off the readers own reactions. The researcher noted any possible patterns across the data.

Step 2: Generate Codes

The researcher systematically coded each transcript using NVivo 11 (see Appendix J), giving full and equal attention to each item, attempting to ensure that codes were generated directly from the data which was an inductive approach.

Step 3: Checking Codes

A peer researcher independently coded a transcript using the same procedure outlined above, and any discrepancies were resolved through discussion.

Step 4: Creating Themes

The researcher created a visual map (see Appendix K) of the data (thematic map) to search for initial themes across, and subthemes within, the data.

Step 5: Reviewing Themes

The researcher reviewed the themes with the research team to discuss whether these themes accurately depicted the data.

Step 6: Refining Themes

Based on the discussions with the research team, the researcher refined the themes, and some themes were renamed and anonymised.

Researcher's Background and Perspective

The researcher is currently employed as a Trainee Clinical Psychologist working within the NHS. The researcher worked in EIP services supporting individuals with psychosis and their families and hopes to return working in EIP services after qualifying. The researcher has worked in services that serve ethnically diverse populations. The researcher identifies as Black Caribbean woman in their late twenties and is committed to supporting service users' receiving equitable healthcare with their voices being at the centre of their healthcare. The researcher's positions influenced her interest in this research area as she is invested in improving the experiences of ethnic minority service users. The researcher was also directly involved in the development of the co-produced 'See Me' training. The researcher was mindful to consider how these experiences and motivations may impact her views on and relationship with the interview data and data analysis. The researcher adopted a critical realist approach when analysing the data, which used an inductive experiential framework. This approach supposes that the interviews would have allowed access to the participants' subjective realities and experiences. The researcher used bracketing and a reflective journal to remain aware of her views and position when conducting the interviews (see Sensitivity to Context section below). Key topics considered were 1) having a personal investment in the co-produced training that is being studied, 2) having a personal commitment to service user-centred healthcare practice, and 3) having a personal interest in working within EIP services.

It has been argued that qualitative researchers are not 'neutral' scientific observers who can dismiss scrutiny of their values, experiences, or assumptions. Therefore, it is important for researchers to take a reflective approach about their context underpinning the data collection and analysis (Charmaz, 2014) which can enhance the quality of research (Primeau, 2003). The researcher is transparent about her epistemology because it influences how research is framed in its attempts to 'discover' knowledge (Moon & Blackman, 2004). The researcher believes that how people construct meaning and make sense of experiences is socially constructed (Charmaz, 2014). All descriptions of these experiences are mediated through the filters of language, meaning-making, and social context (Houston, 2010). The researcher accepts that these social constructions can constitute what we know as the reality of our social worlds (Haigh et al., 2019). Therefore, this approach allowed the researcher to contextualise participants' understanding of their social worlds.

Sensitivity to Context

The researcher took several steps to explore and engage with topics that could come up during the research process to support the credibility of the research. Firstly, the researcher conducted a bracketing interview before and after data analysis with a peer doctoral researcher to understand the impact of her pre-conceived biases and ideas on interpreting the data. The bracketing interview helped the researcher to be aware of her biases and is a tool to acknowledge, understand and try to put aside these preconceived biases or ideas which could influence the research process and results (Olmos-Vega et al., 2022). Each bracketing interview lasted approximately 25 minutes each, and the researcher was asked probing questions related to the then current stage of the research. Specifically, during the first interview before data analysis, the researcher explored what drew her to the research topic, and how her background, experiences and prior knowledge about the research topic could influence how she engaged with the data. During the second interview after data analysis, the researcher discussed her experiences and beliefs about the topic, the importance of the topic and assumptions that participants might have made about her. This process would highlight the researcher's relationship with the data which allows for a more transparent research process (Tufford & Newman, 2012). For example, the researcher explored hypotheses about how participants experienced co-producing the 'See Me' training and was able to reflect on how her involvement in the development of the training could impact the information that she would attend to. i.e., would she be more likely to ask follow-up questions about positive experiences and opinions of the co-production? The researcher also kept a reflective journal to remain aware of her biases and assumptions in order to ensure biases were less intrusive during data analysis and interpretation; this helped to preserve the integrity of the research. The peer doctoral researcher made notes during both bracketing interviews, and shared these notes with the researcher. The researcher reviewed these notes after each bracketing interview and incorporated them into the reflective journal.

Secondly, when designing the study, the researcher ensured that Black people with psychosis and with experiences of racial inequalities informed the wording and structure of the interview to ensure that it was sensitively constructed and would explore the participants' perspectives respectfully. The researcher used the reflective journal to hold in mind how she would want to be interviewed about difficult experiences, and how grateful she would have been to be consulted on the interview questions. The researcher was mindful of, and used the journal to discuss her emotions towards, EbEs experiences of inequalities and how it might have felt to have less autonomy and have your voice about your own care be secondary to others.

Finally, the research supervisor reviewed the initial theme structure that was proposed by the researcher, which allowed the researcher to amend discrepancies in the analysis procedure and refine the themes. One transcript was selected at random and underwent independent analysis by a peer doctoral researcher independent of the project. The peer researcher reflected how well the themes discussed the raw interview data and whether the themes missed key information about participants perspectives.

3. Results

Participants

A range of demographic information was gathered from participants, detailed in Table 1 below. The participants were all self-identified Black people under the care of NELFT EIP services. The age of participants ranged between 18-34 years at the time of the interview, most participants were male, and all participants had experiences of racial inequalities in EIP services. Participants length of time with EIP services or community services for continued care for psychosis ranged between 1-12 years, with the average time of five years and three months. Three participants were involved in co-production projects aimed at addressing inequalities (i.e., ‘See Me’ training) and five participants were not involved in any co-production projects (i.e., had not been approached to co-produce). Names and potential personal identifiable information (e.g., EIP service accessed, and hospital(s) admitted to) were anonymised to ensure participant confidentiality.

Table 1

Participant Demographics

Demographic	Description	N=8
Age	Range	18-34 years
	Average age	29.5 years
Gender	Female	1 (12.5%)
	Male	7 (87.5%)
Ethnicity	Black African	5 (62.5%)
	Black British	1 (12.5%)
	Black Caribbean	1 (12.5%)
	Mixed Black Caribbean & White	1 (12.5%)
Experienced racial inequalities in EIP including but not limited to hospital admission	Yes	8 (100%)
	No	
Referral route to mental health services	A&E	1 (12.5%)
	Involuntary hospital admission	3 (37.5%)
	Voluntary hospital admission	4 (50%)
Length of time with EIP services or community services		Range 1yr – 12yrs Mean = 5.3yrs
Any involvement in co-production projects in the following areas: addressing inequalities, mental health access	Yes	3 (37.5%)
	No	5 (62.5%)

Thematic Analysis

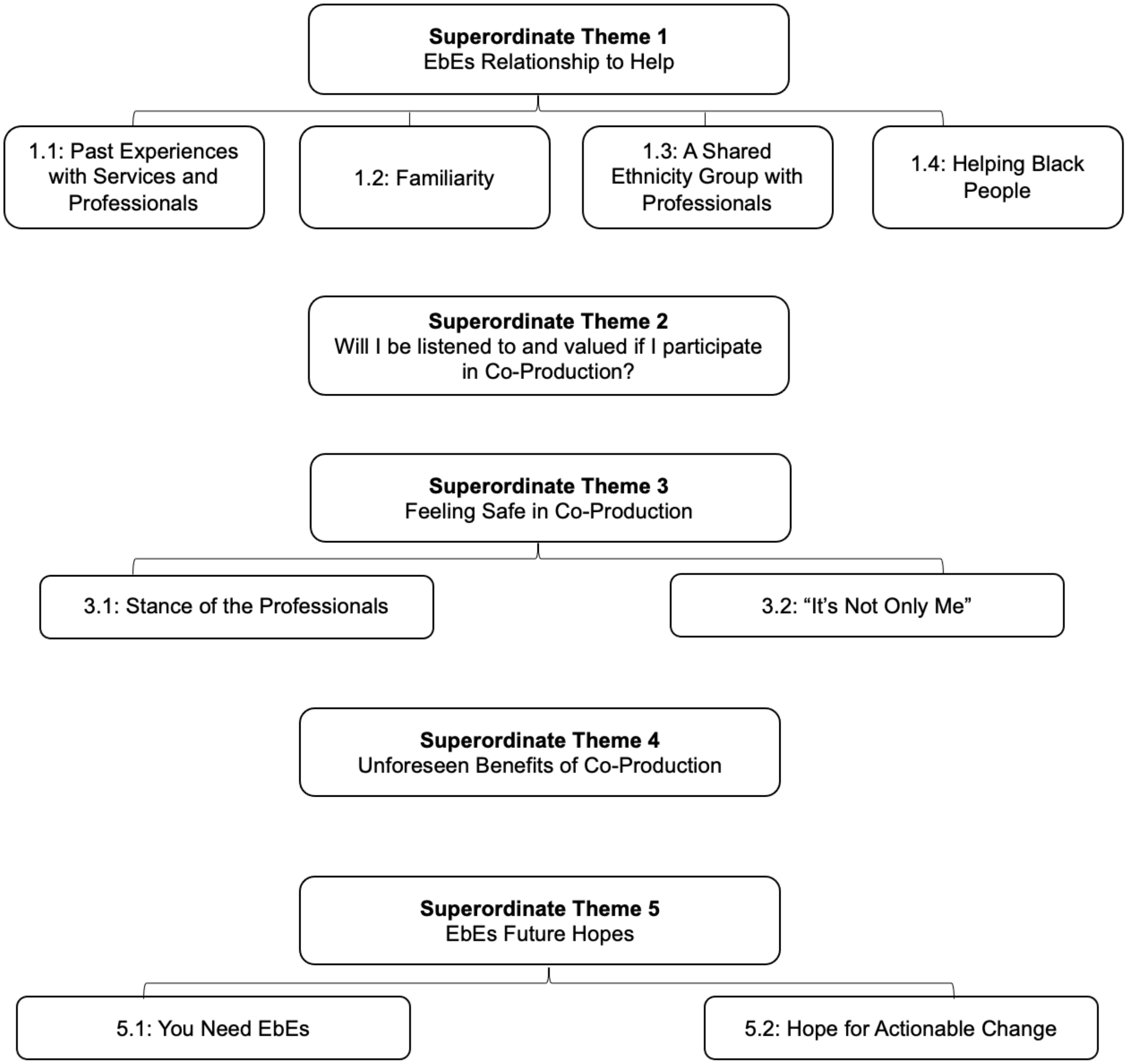
The qualitative study implemented the Braun and Clarke Thematic Analysis (TA) (Braun & Clarke, 2006) approach. The study aimed to explore the perspectives of Black Experts by Experience on co-production aimed at addressing racial inequalities within psychosis services. Another aim was to identify recommendations to improve engagement amongst Black populations with co-production projects aimed at addressing racial inequalities.

Initial examination of the data produced 159 codes which were reviewed and refined resulting in 65 codes. The codes were collated into ten subordinate themes and five superordinate themes; 1) relationship to help, 2) will I be listened to and valued?, 3) feeling safe in co-production, 4) unforeseen benefits of co-production, and 5) EbEs future hopes. Figure 1 is a thematic map illustrating this process. See Appendix J for an illustration of how the codes were collated into superordinate and subordinate themes.

Most of the five themes included quotes from all participants. However, themes about involvement in co-production, specifically 3) feeling safe in co-production, only included quotes from the three relevant participants.

Figure 1

A Thematic Map Illustrating how the Superordinate and Subordinate Themes Were Derived



Superordinate Theme 1 – EbEs Relationship to Help

This theme described participants' relationships to receiving help and their motivations for giving help to others. There were four subthemes: 1) past experiences with services and professionals, 2) familiarity, 3) a shared ethnicity group with professionals and 4) helping Black people. These subthemes impacted on participants engaging with co-production projects.

1.1 Past Experiences with Services and Professionals

Participants' relationship to help was informed by their past experiences with services and professionals. All participants described that Black populations are treated differently to other ethnicities in the UK especially compared to White populations. Participants described that these differences between White and Black populations have existed within mental health services and the wider NHS, and have led Black populations to have additional worries about accessing mental healthcare. These additional worries were about experiencing discrimination or racism from professionals *"professionals work within a racist system and they will inflict pain on people based on their biases…when professionals in are uniform they don't care about you and are willing to hurt or traumatise you"* P07 or worries about how well they communicated with and presented themselves to professionals *"not speaking clearly"* P06. These past experiences increased apprehension about accessing NHS services in general and influenced their feelings of fear and uncertainty about being with new professionals.

> *"Especially for Black people in this country dealing with the service, they do get discriminated against. Obviously, I'm Black and I've done enough history on being Black in the UK and America and stuff like that. So, I do know that there's a big difference and I think that's an issue that there's definitely a difference in how Black people are treated in England, in the NHS system, yeah there's definitely exists"* (P07).
>
> *"They [the racial majorities] might not have as many worries like- because they don't- I mean they have worries don't get me wrong, but their worries are different because they-*

> *as far as racism and things like that, they're experience is much different to racial minorities I feel like"* (P04).

In addition to wider worries about experiencing racism and discrimination, participants reported first-hand accounts of this within NHS mental health services. Participants consistently reported trauma from past experiences with NHS, which had mostly occurred with some professionals during their admission to, or stay in, psychiatric hospitals. In addition to the hospital admission feeling distressing, participants felt that the manner in which they were treated by some professionals during admission was disrespectful, unfair and traumatic. Participants reported being locked in rooms by professionals with limited communication from them about what was happening or why, and stated that professionals did not look at them, which made them feel worthless. The impact of these experiences was that participants felt traumatised, changed as people and would "never be normal" because of being treated in this way by some professionals. This left a legacy of trauma, such as fear of some professionals, and anger and disbelief about how professionals had treated them, which informed participants' relationship to help and view of some NHS professionals.

> *"They can lock you in a room and that's not going to help. It's strange- just being locked in this strange room and it was a very strange time. For me it's not that normal at all. They don't be looking at you, they don't know what is the reason why they put yourself in there. They make an attitude, they misjudge you. So then after that, most of them [patients] will end up in that system and they will never be normal anymore, because of what happened- of what they have been put through"* (P06).
>
> *"Understand that everyone has gone through- these people have gone through trauma. And it's not just mental health, it's trauma. That's when it starts, it's from a trauma"* (P02).

Secondly, past experiences with services and professionals left a legacy of feeling judged based on assumptions about the Black community. Participants felt that professionals were making negative assumptions about them rather than curiously gathering information about them. For example, participants reported that professionals assumed details of their mental health history, such as misusing drugs triggering their psychosis and hospital admission. In addition, professionals assumed the reasons for participants’ fear or anxiety at admission was effects of drug misuse rather than the alternative explanation that they feared hospitals. These incorrect assumptions led participants to feel misjudged and saddened because they felt that these professionals had placed them in categories based on stereotypes.

> *“They're thinking that this guy's done this an enormous amount of drugs and he's mentally not OK. And I'm like, “what the hell? I haven't done that before. I'm just scared of hospitals. I don't like those hospitals”. That is quite, quite sad that in the Black community that we do get assumed that we do certain things that can lead to mental health, it’s not that. And then then the EIP or the home treatment team to check up on me, they were always, they were asking if I touched cocaine or those type of stuff which is something I've not done before. And they have to understand that it’s not everyone that’s entered mental health or everyone Black that’s come through this type of situation that’s done those type of harmful things before”* (P02).

Thirdly, participants' past experiences with services and professionals left a legacy of mistrust. Past experiences informed how participants expected to be treated in the future by some professionals, and reduced their trust that future experiences might be different. Even participants who took part in co-production reported not trusting services and professionals completely because of their past experiences of mental healthcare, and reported that the NHS had a long road to building trust amongst Black populations. Participants' lack of trust in the NHS might be one of the biggest factors impacting on their willingness to engage in NHS co-production projects and work with NHS professionals.

> *“Trust. Ohh. Ohh that's tough. That one is tough. I mean, even for me, I I thought I wouldn't say I'm 100% trusted in NHS, like at all, and even though I've done all of this*

> *over the past year, it doesn't mean I'm 100% trust in NHS. It doesn't mean I'm - I don't know, from my experience I'm fine with working with anybody but there will be people out there who generally do not want to work if anyone in the NHS from their past experiences so I think that would be the biggest biggest problems anyway. ... It's it's a long road for NHS to build that trust with people"* (P01).
>
> *"A lot of these people, if they've had an experience with the service and it's not been a good one, in all likeliness they're not inclined to be involved because of the negativity."* (P07).

Overall, these past experiences within NHS mental health services and with inequality experienced in wider society left a legacy of the help in mental health services. For participants who had some negative past experiences with professionals, there was a legacy of trauma, feeling judged and mistrust in NHS professionals. This type of legacy led to barriers to Black populations engaging in any service user involvement project, including co-production projects, due to apprehension about services, and fear and uncertainty about past experiences repeating with new professionals.

1.2 Familiarity

Participants' relationship to help was impacted by their 'familiarity' with certain professionals which was an important factor for EbEs engaging in co-production. Familiarity with professionals was described in different ways by participants, such as professionals 'knowing and understanding' them, participants 'somewhat knowing' the professional, and participants having a good working relationship with the professional. These professionals were noted as either Care Coordinators or Clinical Psychologists. The interviews clearly indicated that if participants had good existing relationships with professionals involved in their care, who then introduced the co-production initiatives, participants felt they could trust in the project and trust in working with other professionals because of the trust they had in their Care Coordinator or

Clinical Psychologist. Additionally, participants who had not been involved in co-production also stated they may trust or be more interested in taking part in projects if they were introduced by trusted professionals. Participants also reflected on the idea that their existing relationships with trusted professionals also meant that these professionals had insight into their lives and specific current contexts, such as current stressors and the 'impact of stressors on their mental health' and their interests. This was said to be useful for engaging with the offer of co-production for two reasons, which was related to framing invitations to initiatives and relational trust. Participants described that as professionals knew about their contexts (e.g., 'how they were doing mentally'), they were more likely to have additional knowledge about when to offer initiatives at an 'appropriate or convenient' time and be able to make the offer/invitation in a way that felt genuine and connected to participants. Additionally, professionals could offer initiatives that participants 'had knowledge in' and 'might have wanted to take part in' based on their knowledge of participants (e.g., their interests and personal development goals) and participants felt these invitations showed professionals held them in mind. Secondly, a sign of relational trust with professionals was described as participants knowing 'they could share details of their personal lives' with these individuals (as described above in the above examples), and this relational trust created a bridge to accepting invitations to co-production projects.

> *"Yeah, yeah, yeah. That was very helpful to have someone I already knew and already had a relationship with, it was important. I know this person and I know it's a mental health professional so they're gonna hear what I've been talking about and if they hear what I've been talking about, what I talk about they're gonna understand me more"* (P02).
>
> *"I agreed to do it because it came about from my Care Coordinator at the time, her name was [Care Coordinator name] who asked me about would you be interested in being a part this project"* (P01).

> *"...making sure the person's therapist or professional had a personal relationship. Because they're more likely to say yes to that person they know rather than someone randomly because you don't know what the person's going through. The person may not be able to do it [co-production] because you don't know what's going on mentally. The person may not understand because of what they're going through mentally but if it's someone who they can trust in, they might be more likely to say yeah because it's more like hearing it from to a friend"* (P03).
>
> *"how I got involved in the register was just [Clinical Psychologist name] understanding that I know a lot of this stuff and she thinks I can help"* (P07).

Familiarity with professionals also led to the possibility of engagement in overcoming barriers to taking part in co-production projects. Familiarity and trust with professionals as described above, led participants and professionals to discuss, plan and overcome personal barriers to getting involved in initiatives with other EbEs. For example, one participant described overcoming their paranoid thoughts about others with their Clinical Psychologist, and without trusting their psychologist to overcome this barrier, they would not have engaged in the project. Examples of other barriers that participants felt comfortable to talk with trusted professionals about included thoughts about being able to speak clearly and be understood due to the side effects of their medication, worries about how accessible or easy to understand the project would be for EbE, and thoughts about being 'well enough' to take part.

> *"it's only because I had a psychologist and someone that I kind of knew. Someone that I kind of knew that ok yeah, I want to join this. And the psychologist helped me mentally on how to kind of tackle the paranoid paranoid thoughts, and maybe the paranoid thoughts were getting a hold of me and without that I would not have joined the Single Story project"* (P03).

All participants described the importance of trusted relationships, highlighting that it would be 'important for services to know the 'right' professional' to help support EbE in engaging with offers to co-produce. They described that EbE can have different relationships with all types of professionals within their networks or types of services they were involved in. For example, one participant described attending a mental health sports charity, where EbEs 'behaved more like themselves' with the coaches they saw frequently, compared to other professionals they saw less frequently 'in the clinic' and therefore professionals within the coaching context would be better placed to offer the co-production initiatives. Participants were clear that it would be useful for services to speak to different professionals in EbEs networks to understand who knows them well so that the 'right' professional can invite them and increase the likelihood of engaging in co-production projects.

> *"so basically, talk to the key worker that's important first. Like everything you heard from [coach's name], he could give you information different from what a keyworker would give you. And that's important because the people with mental health go in that room and they are different than when they're out of the room. So, when they come out to [football club] they're different to how they are in the room so it's important to speak to a lot of people whose around that person in different environments to find the right person. So that includes me as well so if it was me, speak to my keyworker"* (P08).

1.3 A Shared Ethnicity Group with Professionals

Seven out of eight participants reported that having a shared ethnicity group in common with healthcare professionals involved with co-production projects would positively impact on their engagement with projects related to ethnicity. Participants who had not taken part in co-production projects stated that they would be more inclined to take part if the professionals involved in co-producing were also of Black ethnicity. The interviews described various reasons for this which included participants having similarities with professionals, these similarities increasing the likelihood that both participants and professionals could relate to each other, and sharing something in common might initially aid cooperation between individuals in co-production. Sharing ethnicity made ‘professionals appear relatable’ – in regards, to potentially increasing the likelihood that professionals may have their own similar lived experience and would be more understanding of EbE contributions during projects about racial inequalities. In addition, participants described that it can be difficult to discuss experiences related to ethnicity and race, and there would be differences in the experiences and level of detail shared with professionals who shared or did not share their ethnicity group. They described sharing an ethnicity group with professionals would aid their connection and ease in talking openly in discussions about race and inequality. Participants stated these reasons facilitated their decision to take part in co-production and the current research project. Although the majority of participants shared this sentiment, one participant said that during the co-production project they would contribute similarly regardless of a shared ethnicity group with professionals, and a wide range of ethnicities amongst professionals would be the best way to engage in co-production.

> *“I kind of have to change it a bit, do you know what I mean. But like how you and me are speaking right now, it's kind of easier for me to tell you certain things, but let's say there's another staff person there who's not Black I'd have to explain it in a certain way do you know what I mean”* (P02).
>
> *“I think it helps if there is a Black person also in the group. Not to say that if there was a White person interviewing me I would be completely different, but I think it can help with just the connection, knowing there was someone in the group that’s also Black so perhaps has also experienced the stuff that happens to minorities, whether that’s racially or whatnot. So, I think that can help”* (P04).
>
> *“No offence but if- see you're Black yeah so, it’s easier for me to talk to you because they’re similarities. If it was a White person, I don’t know how much I would do this. Like I took part in this [interview] because you're Black and it was easier to talk to someone like that. But I wouldn’t have taken part, I only took part because of that reason, because*

> *it's not easy to talk to White people … So, I think it's important to get people who are from a certain environment that helps, not just people whose got degrees and went to college and uni for all these years. No. we need relatable people, especially Black people whose relatable"* (P08).
>
> *"There was quite a wide range of issues, ethnicities, which is probably the best way to go, so none at all"* (P01).

1.4 Helping Black People

Participants' relationship to help was also impacted by their want and value to give help to others. All participants reported that they 'had been or would be' motivated to engage in co-production projects about racial inequalities to help other Black people or the Black community as a whole. Participants had varying motivations for helping Black people. One motivation was based on a strong sense of community to do what they could to help even one person via sharing knowledge, experiences, stories and lessons learnt. Participants described that taking part in initiatives to reduce inequalities for Black populations, such as co-production or the current research project, felt important to them and felt like they made a positive contribution to their community. Helping people based on a sense of community was also expressed as a 'duty of care' or responsibility to help others. Participants felt there was a duty of care for EbEs and professionals to better understand what Black service users had gone through in psychosis services in order to produce useful options to improving racial inequalities in these services. One participant believed so strongly in a duty to help Black people that they could not see any other option than taking part in the co-production project or see any negatives to acting on this duty to their community. Another motivation for participants to help Black people was based on their personal connection to topics or projects, which meant they had certain 'knowledge' that could help others. For example, seeing opportunities that linked to participants personal experience of being a 'Black person who accessed psychosis services' or sharing learning based on one's experience of having 'strong social support during their staying well journey'. These lived experiences or personal connections made participants feel connected to topics and therefore intrinsically motivated to share their knowledge to help others when opportunities arose. Participants also wanted to help others learn from their own past experiences in order to make service improvements. Participants felt passionate about using their experiences of psychosis services, specifically their difficult or negative experiences, as opportunities for learning for service users and professionals. They felt passionate that improvements for Black people in psychiatric hospitals, such as mitigating similar experiences of admission for others, would come from them sharing their experiences and insights. Though participants were motivated to use their past experiences for learning purposes, these same experiences were one of the reasons why participants were apprehensive and fearful to engage in co-production with NHS professionals (see subordinate theme 1.1). Therefore, there could be direct tension for participants between wanting to help people via co-production but concerns about working with professionals, which was also directly acknowledged by one participant.

> *"I was like you know what, I can help [Black] people, I can use whatever I've learned or whatever's happened to me, in order to benefit others"* (P02).
>
> *"I think we can really help each other. I think mainly talking, talking to each other. I think I could help [Black people] a great amount by explaining my story, my points, my opinions, everything about me really"* (P05).
>
> *"You have a duty of care for yourself as the patient and you as the experienced worker who's trying to help that patient. Don't you wanna understand the experience that these patients are going through? When wouldn't that pretty much help you as the experienced worker and as the patient to be better experienced of 'what useful options or solutions are there?' from hearing and understanding better in terms of what patients go through? Can't really see any negatives in this, really can't. Shouldn't have to say any more than that, duty of care"* (P01).

“I’m a Black person and it’s talking about mental health, it made sense to involve myself in this” (P03).

“I was crying, pleading with them, I’m saying, ‘I don’t know why I’m here’. Next thing I know, I get my bag delivered and I realised when they put me into a room, I’m pretty much in it. … Going forward I’d love to avoid people going through what I’ve been through because for me it's more for a learning experience, and to really see if I can help. Or if there are any insights that might help on this, especially where your angle is to help Black groups more so they can avoid having these situations” (P07).

Table 2

Illustrative quotes for the subthemes under superordinate theme 1

Subtheme	Illustrative Quote
Familiarity	*“I find it difficult to communicate sometimes because I've found that the side effects on the medication I'm taking, but sometimes it makes it hard to speak, it makes my teeth a bit- feels like its vibrating almost sensitive. Sensitive is the word, makes my teeth sensitive. That's one of the main problems I had [in participating], how would I communicate?”* (P01). *“It'd be one of those things, I’d be thinking. I’d be thinking will they be trying to explain it in easily digestible ways, not to complex because a lot of people with mental health issues they’re capabilities of understanding or their attention span may be limited because of what's going on in their head and stuff. So just easily digestible erm as much as you can. Not too basic, but basic enough*” (P04).

	"Yes, I would like to be a part, I would. In time, in time, if I recover well enough in time. And we [Clinical Psychologist] talked about what's well enough meaning" (P05).
Helping Black people	*"I'd be happy to do it and share my experiences and see if it helps maybe one [Black] person, two people, maybe. I got through that. Let's see if I can help somebody else"* (P01). *"I feel like other [Black] people would benefit from it, so it makes sense just to, just to try and help, I guess. So doing this interview helps me feel that I'm doing something and contributing in a way, contributing in a positive way erm yeah"* (P04). *"Just that people, the other [Black] people who don't have support, you wish that you can help out the other people who don't have support"* (P06).

Superordinate Theme 2 - Will I be listened to and valued if I participate in Co-Production?

Participants reported that their engagement in co-production projects would be impacted by whether they would be listened to or valued by the professionals involved in the project. Participants described being listened to and being valued in three ways: 1) will what EbEs say matter, 2) how will EbEs be viewed by professionals and 3) will professionals' actions show they value EbEs.

Firstly, participants were concerned whether EbE voices would actually matter, be heard and taken on board by professionals, or would their contributions be tokenistic. Participants were concerned about whether their voices would be respected and hold the same weight as the professionals who held power via their expertise and education status. Participants' concerns about being listened to and their voices mattering may have been informed by their past experiences of ‘not’ being listened to by professionals in mental health settings. Therefore, there was genuine concern and uncertainty from participants about whether their opinions would be valued in co-production projects, and they carried this wariness when being invited to projects as well as when they were involved in co-production.

> *“I think the most difficult thing for me personally anyway was- will anyone listen to what I'm saying? You know. Like, are you gonna listen to what I'm saying? What would you take anything from it? You know? Would anyone take the situations that I've been through to heart to say? So that was probably the only reason I had as to why I probably wouldn't say anything at the time”* (P01).
>
> *“If you bring people in that have mental health, it’s like- is there opinion, is their voice actually going to get heard or are they just going to get looked at this like token like “why are you here for? Like we’ve got the degree, the profession, we’ve done the studying, what do you know”* (P08).
>
> *“It’s understanding people are in this context as well and understanding they have probably never been listened to, never been made to feel like whatever they have to say matters”* (P07).

Secondly, participants reported that they wondered how they would be viewed by professionals and how they would be treated. Whilst co-production emphasises shared power and responsibility within projects, participants wondered if in reality they would have mutual and reciprocal working relationships with professionals, or whether they would still be classed as ‘patients’. It appeared that underlying these concerns were thoughts about whether professionals would respect EbEs, their efforts and expertise to help in a project as equal to their own (e.g., would professionals invite participants to ‘speak freely’ and then actively ‘listen to and affirm’ what they said rather than dismiss it). Participants reported that if mutual respect was important to professionals, then engaging in co-production projects would be important for them.

> *“I think the concern might come from if you're attached to a project like what are you- who are you, are you a mental health patient? Or are you someone who’s coming to help, or like what are you going to be classed as coming in to help? Like what are you going to be classed as, coming in and helping”* (P05).

> *“It depends if it’s about working and being mutual that would be nice. But if they’re not willing to do that then that is fine. If being mutual is important to them really then it [working with them] can be important to me”* (P06).

Thirdly, participants wondered whether professionals’ actions would show that they valued EbEs. Participants reflected on concerns about whether their opinions in co-production projects would be heard and how professionals would show this. Participants described that actions such as communication about how EbEs opinions would be used in general and in relation to the project aims, the next steps in the project, updates on the project's progress and being financially paid, indicate they are valued, and that it was worthwhile taking part. Participants reported that financial payments incentivised participants to take part in the current research. Additionally, these actions were tokens of appreciation and showed forethought from professionals, which further symbolised how valuable EbEs were to professionals.

> *“erm I’d say probably just the fact that it would mean that your opinions, your opinions have been considered, that your experiences have been considered and taken into account when they're trying to improve the services”* (P04).

> *“Communication is so key and the lack of communication that is probably between NHS and say your general patient is fairly lacking in my opinion, and I've been nice and saying fairly. I think that part of it that needs to be improved before you do anything else. You improve the communication between yourself - sorry the NHS - and the patient. If*

you can do that, then you can build on the little trust issues about what patients mean to NHS" (P05).

"maybe something more organised like schedule or something that says how long everything is going to take, what is going to be next. I would rather just see a schedule for the whole of it [project]" (P03).

"People should get paid for their service...because obviously my opinion is valuable, my work is valuable. Like people in all sorts of industries, like people making movies get used a lot and it's only a certain part that benefits from it, so I think that getting paid is probably a small token of showing like appreciation, even if it's not a lot. Because a lot of times even if people get credit for helping, that credit's not going to do nothing to benefit them. So at least if they paid, they can be like 'oh ok, I got a little something, a little something of appreciation for the work or whatever' or stuff like that. So, it makes people feel more valuable" (P08).

"I wasn't sure about the interview - I wasn't sure but then you said that you'd give me £15 so then I thought well I'll take it" (P04).

Superordinate Theme 3 - Feeling Safe in Co-Production

This theme described participants' perspectives on being involved with co-production projects, specifically the 'See Me' project, therefore only quotes from those 3 participants who took part were included. This theme described experiences of feeling safe during the co-production project and has been reported under two subthemes: 1) stance of the professionals and 2) "it's not only me". Brief details about the co-production project were detailed at the beginning of the methods section in 'Setting & Contextualising the Study'.

3.1 Stance of the Professionals

All three participants reported feeling safe with the mental health professionals during the workshop because of the stance of the professionals towards them. During the co-production workshop and filming days, participants were invited to share their experiences and perspectives on psychosis services in group tasks in order to outline the video content and video structure. Participants felt comfortable to be vulnerable and share personal experiences with the other EbEs and professionals in the group due to professionals making them feel that it was a safe enough space to be honest in. Professionals showed participants they could be honest in the workshop through their words and actions, e.g., by not forcing them to say anything that they didn’t want to, stating that there were no right or wrong responses, and consistently encouraging participants to share their honest opinions in each group task rather than giving responses they perceived professionals wanted to hear. Participants felt comfort from the pacing of the workshop activities and from being able to take their time to speak, e.g., not being rushed by professionals whilst speaking. Professionals created an atmosphere where participants felt safe and comfortable enough, and this led to participants feeling able to be open to share any views, including their honest views about the Black community, the NHS or former professionals. Participants continued to feel safe after being honest because professionals remained friendly in their non-verbal behaviours e.g., their demeanor and ‘vibe’. Professionals being friendly throughout the workshop was significant because it modelled positive experiences with them in contrast to past negative experiences, and if professionals were being friendly, it was thought that they would not bring participants any harm.

> *“they made sure I was legit comfortable. Literally made sure I was in my own comfort zone. They made sure that I was really comfortable. I was happy. They made sure I was happy to speak about what I wanted to say. They made sure that they didn't force me to say anything I didn't wanna say. I can speak however I want to speak. Didn't make it like, ‘say this right now’. It's not forced”* (P02).

> *"It wasn't like you had to speak strenuously in your mind about what you have to say and what they wanted the answer to be. It was more of a case of, rightly or wrongly, just say how you feel"* (P01).
>
> *"It was really safe. It was comfortable, it was easy. It was. There was no issues. Everyone- You know, when you're speaking, everyone else would listen. So it was cool. Yeah. It was really good. … It's very, very safe, and you're and you're allowed to be very open with any views you may have, whether it be about the black community, be the NHS, staff members"* (P03).
>
> *"The people that I was speaking to, they were friendly, they didn't look like they will bring me any kind of harm. You are going to get on and I thought- I have felt like friendly, friendly, friendly vibes from them. So just make sure that the people who are doing it, offering it are friendly, nice, someone you can talk to, matching your values and your vibes"* (P03).

3.2 "It's Not Only Me"

All participants felt safe in the co-production workshop because they learnt that it was 'not only them' with experiences of mental health difficulties, which was described as the 'best part' of being involved in the project. Participants felt they did not feel alone in relation to two aspects of their identity: 1) being Black and accessing mental health services, and 2) continuing to stay well following their psychosis episode.

Participants described feeling safety and comfort being in the workshop with other EbEs from the same ethnicity. Participants were discussing their own difficulties and difficulties within the Black community regarding mental health, and they reported that being in a room with other Black people who had experiences of mental health difficulties made them feel less alone. Participants stated experiences of stigma from their community "*That's was my biggest concern, will people judge me because when I when I first got my diagnosis I was like "ohh people gonna* *think I'm this the the the disabled person I'm incapable of doing certain things" which was completely false*" P02. For most participants, the workshop was one of the first times they had openly discussed their experiences of mental health and of accessing services with a group of Black people. Participants were grateful to be with others they shared ethnicity and mental health difficulties with because they recognised how few opportunities there were to hear and learn from Black people who accessed services, and how difficult it still was to have open discussions within the community.

> *"Probably the best part of it. Pretty easily the best part of it was that I got to meet some really cool people, because it's not only you that's going through it, it's not only you that has the similar like experiences of the NHS"* (P01).
>
> *"all the people there were Black. So, it was like ideally we could speak a bit more easily, well except the other mental professionals, but everyone there was Black and we could speak confidentially about issues in the Black community, if that makes sense, we could speak more privately about it. Cause let's see if they were a White person sitting next to us. I mean, we're speaking about it, it will be a bit awkward"* (P02).

Participants also described feeling safe and supported being with other people who were managing staying well following their episode and provided a sense of being around 'likeminded individuals'. This allowed them to learn from others in the group and for the first time made participants feel less lonely and as not though it was only them inside a 'bubble'. The 'bubble' represented this group who had a shared understanding of psychosis and continually putting in effort to stay well, and being in the workshop was a visible indication that other people were 'inside the bubble with them' which fostered feelings of safety and support. For some participants this felt like permission to 'take up room' which meant freedom to express themselves and no longer hide themselves or their experiences.

> *"just from their experiences, experiences, what they've been through, how they're similar to mine and what I've been through. And how I'm not the only one inside this bubble.*

> *There’s other people inside this bubble and going through the same thing. And it was very insightful and showed you know that we’re allowed to take up room”* (P03).
>
> *“It was a bunch of likeminded people in terms of- cause obviously we've been through the same experience. So obviously at the time of my situation- when I first came out with my first episode, I was quite lonely. I don't have much people to talk to. So going through my therapy and ohh my other home treatment teams, they obviously they found a place for me to find likeminded people and that's where I first met them was through my first focus group”* (P02).

Superordinate Theme 4 - Unforeseen Benefits of Co-Production

This theme described participants' perspectives on the benefits of being involved in co-production. Participants reported some unforeseen benefits from taking part in co-production such as continued social connection with group members and learning more about mental health for themselves and others.

Participants stated that the social connections they formed with other EbEs, based on sharing and listening to each other's stories and insights, made them want to stay connected with each other. Participants valued meeting others who they had shared identities with, as discussed in the above themes, and they made efforts to stay connected by exchanging contact details. Whilst co-production projects facilitated social connection during the workshop to help group members work together, it was an unexpected benefit that participants wanted to maintain this. Participants had stated that being with each other was the ‘best part’ (as discussed in subordinate theme 3.2), which may explain their motivation to maintain these connections.

> *“I remember [Expert by Experience name] she was great as well. I just remember [Expert by Experience name] cause I took her number to connect, and I remember her because her story really touched me”* (P02).

Another unforeseen benefit of co-production was participants learning from each other, such as gaining a better understanding of mental health and learning about alternative ways to manage their mental health. Participants shared that they did not really understand mental health before taking part in co-production, despite their experiences of psychosis, and from speaking with the other EbEs during the workshop they engaged with ideas about mental health from a different perspective e.g., as peers rather than as patients. Participants described hearing new ideas about maintaining wellbeing, as well as being reminded of ideas from trusted professionals which they had implemented, such as healthier keto diet, going to the gym more and engaging more with friends, then setting goals to maintain these behaviours. There were also actions participants described doing after being involved in co-production, which was linked to their improved confidence in understanding and reflecting on mental health – such as, sharing knowledge with friends and family, and checking in on others' mental health. One participant explained how they have been more attuned to their Dad's mental health, specifically when it looked like their Dad may have been struggling, so they checked in with him more regularly.

> *"We also talked about what to what happens when you go through mental health and there's all these little things that we talked about, which made me get a bigger understanding of mental health myself because me, I didn't really understand it. … But yeah, in terms of the focus groups and projects, it is really let let me understand a lot about mental health. It's legit broadened my understanding and made me see now- and I can visually see when other people are going through something. Like my own Dad works every single day and obviously sometimes when I see him he's quite like this [rests head to the side]. He's just tired and I'm like that, 'are you OK? Have you ate today?' Do you know what I mean, that's sometimes where mental health can start from, even just being tired"* (P02).

> *“I've learned a lot from. I've learned a lot from the experience. I’ll be honest with you so it’s been good, I’ve learnt a lot. … just taking those stories on board and reflecting on them and learning from them, especially in terms of like the end goal of each of those stories were and how they reacted to their situation they were in. You could take something out from that”* (P01).

Superordinate Theme 5 – EbEs Future Hopes

All participants shared their perspectives on co-production and their hopes for the future regarding racial inequalities in mental health services. Participants hoped to be involved in co-production more because it felt essential to them that people who had used mental health services were part of co-production projects that aimed to address racial inequalities within services. Participants also hoped that Black populations getting more involved in co-production would lead to actionable change. This theme has been reported under two subthemes: 1) you need EbEs and 2) hope for actionable change.

5.1 You Need EbEs

Participants stated that services needed EbEs to be part of addressing racial inequalities because they have different knowledge and expertise to professionals. Participants feel they would have unique perspective on how to improve services because of their lived experiences of mental health and racial inequalities, and have been in receipt of the services. The importance of including EbEs in co-production projects was described as an ‘undercover police officer’, where services need people who have been on the ‘inside’ and lived through situations to tell you about it first-hand. Participants reported that services needed this ‘inside’ information in order to address issues that are inside the mental health system, and this could complement professionals’ knowledge and clinical expertise on reducing inequalities in services (e.g., from reports or from third-person accounts of service users). Additionally, participants were not perturbed about being included in resolving issues they did not create or feel imposed on for being asked, instead they felt it was imperative to be included. Participants however, also described the necessity of Black EbEs being part of co-production about racial inequalities as a double-edged sword; co-production projects would affect less change without Black EbEs being a part of it, although there are challenges in engaging Black EbEs in NHS projects and also Black populations/communities experience challenges to participation. For example, awareness of opportunities to participate in projects (e.g., 5 participants were unaware of the co-production project) and apprehension and fear of being in contact with professionals.

> *"I feel like they'll definitely benefit from having people that are going through the mental health struggles and just being able to share those experiences and have their input, so I think it's a really good idea. And I think working together can be very fruitful if done right yeah"* (P04).
>
> *"I don't know why that [co-production] hasn't been thought of before. You need people who've been through it and came out of it to tell you what they've seen from the inside. Just like just like police when they go undercover, you need someone to tell you what it's like on the inside"* (P08).
>
> *"That's the double-edged sword that its [co-production projects on racial inequalities] less likely to go further without people who've been through it being a part of it"* (P07).

5.2 Hope for Actionable Change

Participants' engagement in co-production projects was impacted by hope for change, specifically actionable steps to reduce inequalities. When participants engaged in co-production projects or considered taking part they did not know if, or, how change would be made, but they engaged in the project because they hoped for change. Essentially participants had an element of trust in professionals and trust in their own hopes for change which drove them to engage in projects. Participants also hoped that co-production projects lead to more activities and research about improving the experience of service users in mental health services e.g., more films showcasing how Black service users are being treated and the effect on them, and more research projects on initiatives that involve service users in improving services. Participants would feel more hopeful for change if involvement or co-production projects included feedback loops, hearing how feedback was actioned, and professionals being clear and proactive about providing information on next steps. These actions would show that professionals in co-production projects were determined about making actual changes, and not just talking about making changes.

> *"I just hope that somebody just like listen to this and thinks to themselves this is what needs to be changed. You know, that's what I'm hoping for, whether it be one person or 100 people, it doesn't really matter the number for me, it's just somebody. Just say something and something gets done, that's all like I really care about more than anything"* (P01).

> *"I just hope that this project is the start of many, many, many other projects out there that we could do not just to help the Black community, but everybody that needs help as well"* (P06).

Participants felt that they had to hope for change rather than having certainty that change could occur given the long history of racial inequalities for Black populations in mental health and lack of systemic change. A few participants were skeptical of how this approach (co-production) could produce change because these projects alone would not be sufficient to create change. Participants described that professionals in management positions need to listen to the outputs of co-production to support changes, and although some participants were hopeful management would listen to co-production initiatives, others were uncertain of management support. These few participants were balancing their hope for and skepticism of change which was influencing their decisions about potential future participation.

> *"I'm not sure if saying any of this to anyone inside the organisation is going to make any real change. It needs to advance the conversation, to see change and not just talk about it"* (P07).
>
> *"I think what you're doing is quite good, you're helping a lot of people, and it will hopefully helpful a lot of people from your research that you're doing. I mean you're working with the NHS so hopefully the NHS might take something onboard from the results of your research and stuff is done"* (P04).

Table 3

Illustrative quotes for the subthemes under superordinate theme 5

Subtheme	Illustrative Quote
You need EbEs	*"I think it's a very good idea to be honest because er psychologists by themselves are very knowledgeable, but they don't know everything, certainly its nature that you can't know everything. … a psychologist has a report or a third person kind of view of what's happened. So, it's a bit different when it's coming from someone personally, when they're sharing their experienced emotions and stuff, they have more personalised views on everything that's happened, so it's very raw and fresh. Erm whereas you guys reading from reports, it can be good don't get me wrong but it's much different, it's not as personalised and tailored"* (P04). *"I think the co-production will be more detailed and more than sufficient, it will have much more detail in it than a service just run by professionals that might be just more standard and not as entwined with the views of regular patients"* (P05).

Hope for Actionable Change	*"It would have to be a whole leadership change, leadership shift, mindset shift within leadership to cascade all those behavioural competencies down to the organisation to the people who are managing people, because its embedding behaviour change and culture within an organisation. It's hard to do it but you need buy-in, but its efforts like this to start the conversation"* (P07).

4. Discussion

This study aimed to explore Black EbEs perspectives on engaging in co-production projects that were aimed at addressing racial inequalities experienced by Black people with psychosis and recommendations for supporting EbEs in future co-production projects within this area. A thematic analysis was completed on the interview data from eight participants. The analysis resulted in five superordinate themes and ten subordinate themes. The main sentiments from these themes appeared to be about the importance of psychological safety throughout co-production, added benefits of social connection, and the importance of actions, such as involving EbEs who have used services in reducing inequalities within them. This section discusses these sentiments within the themes and suggests recommendations for practice and future research.

Safe Enough Spaces

All participants felt difficulties in trusting mental health professionals and services due to past experiences, which were 'distressing and even traumatic', and this led to a hesitancy in engaging with co-production projects due to concern of having similar experiences. Pertinently, several concerns were anticipated by participants about taking part in co-production, such as being heard and valued by professionals, trusting professionals and safety during co-production.

The finding mirrors previous literature, which has also found that past experiences of abuses by professionals, historical experiences of discrimination and racism in healthcare, and experiences of being dismissed have contributed to mistrust from service users and hesitancy to participate in service development or research projects (George, Duran & Norris, 2014; Groot, Haveman & Abma, 2022; Shea et al., 2022). According to the Circles of Fear model, past experiences of abuses with various institutions within individuals' lives can further perpetuate mistrust and fears of engaging in services for fear of the outcome (Keating et al., 2002). Professionals and services need to engage with and address areas of mistrust and concern amongst Black populations and consider these factors when introducing co-production initiatives to these populations.

Even within the context of participants hesitancy and concerns, those who had participated in co-production experienced various factors which helped them feel safe and trusting enough to take the risk of participating. Psychological safety is the belief that individuals will not be humiliated or punished for speaking up with ideas, concerns, or mistakes, and that there is safety in risk-taking with others (Edmonson, 1999). One factor which contributed to psychological safety was professionals' familiarity with participants, which was described differently by participants but meant that they had insights into participants' current contexts. This helped professionals to frame invitations to initiatives and signified relational trust which created a bridge to participants accepting the invitations. This type of trust and psychological safety that developed might have mirrored trusted relationships with members of their communities. Wider research has shown that trusted relationships in communities can support participants to take part in projects because communities have and can share information about populations that support their engagement (Burgess & Choudary, 2021; Mills et al., 2006; Schmotzer, 2012). These are important to consider if services want to have co-production projects with individuals who experience both mental health and racial inequalities.

Another factor which continued to build psychological safety during co-production was professional's stance towards participants. Professionals' stance was characterised by their words and actions, such as encouraging honesty from participants and affirming this, not forcing participants to say certain things, not rushing the pace of the workshop or participants whilst they spoke and maintaining a friendly 'vibe'. From the data this enabled participants to feel safe throughout co-production, comfortable enough to contribute their honest views and feel valued by professionals, despite their initial hesitancy linked to past negative experiences. Literature has reported that professionals conveying, via verbal and non-verbal behaviours, they can be trusted and that they value service users feeling comfortable and safe encouraged EbEs participation throughout projects (Palumbo, 2016). This is important to consider for encouraging and supporting co-production with individuals who had past negative experiences with professionals and experienced racial inequalities.

Moreover, there was significance in EbEs being with others who shared experiences and identities, which made them feel safe and less alone. From hearing other EbEs sharing their experiences in mental health settings or staying well, participants felt validation about their own experiences, which gave people a sense of acceptance and comfort in the co-production workshop. Additionally, participants perceiving that they shared an ethnicity group with professionals provided safety due to professionals appearing more relatable and understanding of participants contributions during co-production, and this similarity eased them talking about difficulties related to ethnicity and race. Participants feeling comfortable to speak about difficult topics suggests that creating an environment in co-production of trust and openness can lead to participants feeling they will not be humiliated for what they share and that there is safety in risk-taking with others, which helps to build safe enough spaces so that co-production can be more useful (Burgess & Choudary, 2021; Edmonson, 1999; Ortega, Sánchez-Manzanares, Gil & Rico, 2013). It would be important for services, when trying to engage participants, to consider the potential stakeholders (EbEs and professionals) taking part in projects on sensitive topics, such as topics like racial inequalities in mental health.

Altruism and Connecting with Community

A strong theme in the literature was the role of altruism – construed as helping community – in engaging with co-production projects. Participants had either been or would be motivated to take part in co-production projects about racial inequalities to help other Black people based on a strong sense of community, personal connection to topics or projects giving them certain knowledge to impart, and opportunities for service users and professionals to learn from past experiences and mitigate future experiences of inequalities. These motivations enabled participants to engage in co-production due to a sense of purpose that they could help future generations or others in their community with mental health difficulties benefit from their lived experiences, even in a context of their past experiences making participants fearful and mistrusting of professionals. Participants with lived experiences of inequalities and wanting service users and professionals to learn from them could mean that co-production could be a useful framework for ethnic minorities with different lived experiences to help tackle inequalities. Research findings have found that participants linked their motivations and beliefs, for example, about their community, responsibility for contributing to the common good, and feeling 'moral' obligations with participating in service development or co-production projects (George et al., 2014; Van Eijk & Steen, 2016; Wang, Witteloostuijn & Heine, 2020). Considering this, community-centred motivation is important for services trying to engage Black individuals who have faced racial inequalities within their mental healthcare to take part in projects to reduce these inequalities amongst their own communities.

In addition to sense of community as a motivator to engagement, participants felt a sense of community from building social connections with other EbEs during the co-production workshops, which also went beyond the project. This was an unforeseen benefit. Participants valued meeting others who they had shared identities with, and whom they could listen to and learn from, for example, about mental health and alternative ways to manage their mental health. The findings show that how participants were held and fostered to connect with each other during the workshop enabled their connections to continue. Social connections and social support are protective factors for mental health and are important within the field of psychosis because of the isolation this cohort experience. These findings suggest that co-production can be interventive and include benefits for service users beyond the outputs to improve service provision. Therefore, it would be important for services to acknowledge this benefit and consider their role in supporting and scaffolding connections to build trust with and amongst service users. In turn this could lead to unintended effects of social connection and target isolation amongst individuals, in addition to working towards the aims of the co-production project. This benefit could be explained by Need to Belong Theory, which suggests that individuals form and maintain social connections to fulfil a need for belongingness, because forming new bonds improves their wellbeing and mental health (Leary & Baumeister, 1995). Participants in the current study expressed feeling less alone having learnt that others were ‘inside the bubble’ with them, which may have felt like a sense of belonging and motivating participants to maintain this. It could also be useful for services to advertise connection as a benefit for individuals if social connection will be an aim within the project.

‘Nothing About Us Without Us’

Participants reported that co-production projects could not occur without their input, reporting that services needed EbEs. Participants felt that their insider knowledge, for example of mental health services and/or racial inequalities, gave them additional knowledge that could complement professionals' knowledge and expertise. There were concerns about service users with lived experience of racial inequalities in mental healthcare being involved in ‘fixing’ these issues in services. However, participants clearly stated that despite their challenges to participation their involvement was needed because they had unique perspectives on improving them. This was mirrored in the healthcare literature via the sentiment that services need marginalised populations within service development or research projects, termed ‘nothing about us without us’ which started in the disability sector (Bell et al, 2023). To the researcher's knowledge, until this study, little research had reported Black EbEs perspectives on taking part in projects on addressing racial inequalities for Black populations, particularly not within mental health services. As a result, this is a significant finding that Black EbEs feel it is imperative to engage them in these projects and that inequalities could not be addressed for Black people without that groups input. This finding means that services should reiterate moving towards co-production and genuine service user involvement, especially for populations who have been marginalised. Taken together with other themes, it's important to be transparent about challenges faced within Black populations to participate, and consider the setup/introduction and facilitators to engaging Black populations in co-production to ensure services do not take advantage of, exploit, or reproduce inequalities for Black populations.

Recommendations

Implications for Practice

Future co-production projects should acknowledge populations’ relationship to help with professionals and consider how they may invite or offer the work to populations. NHS services would need to be involved in these efforts to support/facilitate trust of services and acknowledge long standing differences and tensions between marginalised populations in their work, which could enable populations to feel more able to eventually participate in co-production initiatives. These systemic efforts to repair relationship to help have been described as the phase zero model (Burgess & Choudary, 2021). Future co-production can aim to provide experiences that do not reproduce harms or repeat negative experiences, and aim to rebuild trust via professionals remaining transparent and communicating openly throughout projects (Barnett et al., 2019). Additionally, professionals, such as those who are familiar with and trusted by EbEs they support, could proactively ask about and validate EbEs experiences of racism, discrimination, trauma or not being valued or listened to. Moreover, professionals who are trusted by EbEs or within co-production networks (but not involved in facilitating projects) could enquire about individuals' hesitations or concerns about working with professionals in service development projects, to start understanding and overcoming these barriers. This proactive approach can help individuals add additional, hopefully positive, experiences to their relationship help with professionals and services. In turn this could help EbEs to become more comfortable with the concept of working with professionals on addressing racial inequalities as that inherently involves sharing distressing experiences or difficult opinions. This sets a foundation of EbEs being heard, which could make individuals more susceptible to accepting invitations about working with professionals in co-production projects.

Future co-production projects should consider the importance of trusted and familiar professionals in setting up and introducing projects to populations. Services more widely should run training for professionals on the importance of co-production and educate professionals via 1) quantifiable data/outputs about the benefits of co-production to services (for example Pocobello et al., 2020) and research (for example Gillard, Turner, Neffgen, Griggs & Demetriou, 2010), 2) hearing accounts from professionals and 3) hearing accounts from EbEs who have engaged in co-production projects about its value and impact on service development or research. This training will support professionals to connect with the wider values, principles, and practical steps of co-production, and to become aware they can be bridges to helping service users engage with projects in services. This training can also help services and professionals' think about EbEs ‘expert’ or ‘co-contributor/stakeholder’ status and not just their ‘patient’ status in relation to improving inequalities. In addition, any professionals developing specific co-production projects should be clear about the aims, understand the benefits of these bridges (such as trusted professionals) to identifying and inviting service users, and help make genuine offers/invitations to projects. This study’s findings highlight the importance of professionals engaging service users in co-production projects, therefore services would need to understand and reduce barriers, such as time, workload demands or motivation, for professionals in order to attend the above recommended trainings (Tuurnas, 2021).

As well as achieving their project aims, any future co-production project should also look to bolster social connection amongst EbE stakeholders. This can improve the quality of the co-production outputs and can also target isolation and increasing relationships among EbEs. Services and professionals could foster social connection at invitation to projects by arranging for service users with shared experiences or identities to be invited together. During co-production projects, the recommendation would be scaffolding activities and spaces for EbEs to enable social connection and get to know each other, which may aid stakeholders in working together towards the aims of the project and provides a basis for potential continued connection. Additionally, services who have service user involvement could have forums or activities to keep people connected and aware of the different involvement options which are available. Moreover, services could consider creating spaces for connection between those who are on registers to bolster a network of service users involved in co-production within a Trust.

The concept of participants feeling less alone and like they were not the only one who experienced mental health difficulties can be generalised to other EbE population groups and diverse health difficulties. The experience of connecting with individuals who also have shared experiences can apply across demographic populations, and physical and mental health disorders as it refers to a human experience of feeling safety and support amongst others based on a commonality (Martino, Pegg & Frates, 2015; Holt-Lunstad, 2022). This finding within the current study could suggest the importance of facilitating opportunities for EbEs with lived experiences of varied healthcare difficulties to have opportunities to connect with each other.

Given participants’ altruistic or community-centred motivations to take part in co-production projects, services could tap into these motivations during invitations to projects. From the findings all participants said they would take part in projects because of their connection to community i.e., helping other Black people and value in sharing learning from their negative experiences, and participants beliefs that services need them to take part in co-production. This shows services that there are captive audiences for this co-production but taken with other findings from this research there are certain things to be done to support engagement in projects and address concerns to also support engagement. Notwithstanding, it would be important for services to be aware of the emotional and/or practical ask on participants of engaging in projects and put in place structures to acknowledge their contributions, to ensure services are not exploiting their sense of duty. This included things such as financial payment, support structures in co-production, and transparent and proactive communication following projects such as providing feedback, hearing how feedback was actioned and information on next steps.

In summary, it is evident from data that there is a captive audience for co-production projects, as participants said they had or would participate in order to help and support Black people, and said services needed them to make improvements. Therefore, it is important for services to identify and action things to help scaffold engagement which may support individuals with lived experience of racial inequalities in mental healthcare in participating. The recommendations for co-production in practice are services acknowledging populations relationship to help and services making efforts repair this, training for professionals on the importance of co-production and awareness of trusted professionals as bridges to engagement, co-production creating spaces for social connection for EbEs which may have unintended continued benefits, and tapping into service users' community-centred motivations whilst not exploiting their sense of duty.

This study was conducted within a UK NHS Trust; however, the findings and implications could apply similarly to Black populations in other European and Western countries. This study prioritised hearing the voices of people who were marginalised; therefore, the findings and recommendations can translate to marginalised groups accessing mental health services beyond the UK to other Western countries. This study's recommendations for using co-production in future projects (services acknowledgment and efforts to repair populations relationship to help, importance of training professionals and having trusted professionals, building opportunities for social connection, and engaging in community-centred motivations) are applicable to Black populations healthcare engagement internationally.

Limitations and Implications for Future Research

There are several limitations to the current study. Firstly, the sample was predominantly male, and all participants were between eighteen to thirty-five years of age. It would have been beneficial for the researcher to explore the gender and age compositions of the total sampling pool to determine whether the sample was representative of the general population, service user's within EIP services or the whole Trust. EIP services are more likely to have people in this age group.

Secondly the study had a small sample size. Given the detail required to identify themes in the TA methodology, the appropriate sample size for a professional doctorate research project is identified as being between six and ten interviews (Clarke & Braun, 2013). In addition, theoretical data saturation can occur and themes can be apparent after as few as six interviews (Fugard & Potts, 2015; Guest, Bunce & Johnson, 2006), though a larger sample would have more generalisable themes and help consider the importance of themes amongst more people. A larger sample of Black EbEs who had or had not engaged in co-production projects would be required in order to develop the themes further or explore additional themes pertinent to the co-production. Whilst three (out of five) EbEs who had taken part in the 'See Me' project had taken part in the current study, which is a high attendance rate, it would be beneficial to explore perspectives/themes on involvement, such as feeling safe within co-production and unforeseen benefits, with more participants who took part in co-production to inform how service users are supported. Future research is required to capture the voices of those who had been invited to take part in co-production projects but declined. It could be useful to provide these EbEs with an opportunity to provide in-depth, anonymous feedback (I.e., using an online forum) to understand whether this cohort of people have different perspectives on engaging with co-production. Additionally, given this cohort have declined participation, it could be invaluable for future research to explore the perceived barriers to co-production for Black EbEs in psychosis services. Whilst this study had a small sample size, it was the first of its kind and future research could have an open criterion more widely in NELFT to get a wider pool of participants and variety of experience of co-production to further inform support and recommendations for co-production in context of people with lived experience of mental health services and racial inequalities.

Thirdly, some interviews were conducted months after co-production projects and perhaps this influenced retrospective recall. Time since an event can impact recalling the event (Coughlin, 1990). However, it should be noted that people's experiences in projects may have resonated with them long-term, so it was still valuable to consider and interview participants whose co-production experiences were months prior to participating in research.

Furthermore, purposive sampling was used so there may have been a bias in who professionals invited to take part in the study. Those who participated in the study are likely to differ in some way from non-participants. For example, participants who took part in the current research study might have had more positive experiences of co-production or might have less negative past experiences with services. The researcher was unable to compare the demographics of those who chose to participate versus those who did not within the services. Therefore, the amount of variation between participants and non-participants remains unclear. This questions the external validity of the results and how possible it is to generalise from the sample to the target population (Mujere, 2016).

Additionally, the researcher considered whether there may have been challenges in recruiting participants who had not taken part in ‘See Me’, because these participants would have been less familiar with the researcher and not had the opportunities to build trust with the researcher. The researcher considered that participants who had not taken part in co-production projects may have been apprehensive or distrusting about taking part in a project with an unfamiliar staff member. In addition, the researcher was aware of the importance of establishing trust and connection with potential participants, in order to provide an environment where participants felt comfortable enough to honestly share their opinions during an interview. The researcher tried to build trust with this group of participants by being transparent about what was involved in participating, offering autonomy and flexibility to accommodate participants preference for the interview, and continually reminding participants they could withdraw at any point.

Finally, whilst not explicitly stated during the interviews, participants who took part in the ‘See Me’ co-produced intervention may have been aware of the researcher’s involvement in the development and creation of this. The researcher tried to mitigate this, by purposefully not attending the co-production workshop or filming days, however their earlier involvement in creating the concept of the project with participants may have had an impact. Whilst participants stated feeling comfortable with the researcher, the researcher’s prior involvement with this project might conceivably question how able the participants (who took part) were to provide honest and unfiltered feedback in their interviews. Any future research evaluating the perspectives of co-production projects might benefit from being conducted by an impartial researcher, I.e., a researcher who is viewed by the participants as independent from the co-production project. Furthermore, the researcher’s impartiality could have potentially influenced the results. For example, the researcher might have had a bias towards emphasising and inquiring further about favourable perspectives on co-production. The researcher tried to mitigate this by continuously returning to the interview schedule as a prompt to ask about positive and negative perspectives on co-production, and after interviews using the reflective log to explore this bias and why it was coming up during data collection. Additionally, given the nature of the topic, participants may have felt pressure to say yes to this study because they knew the co-production would eventually be linked to research and so maybe also provided socially desirable answers. Additionally, participants were all from one type of co-production project. Therefore, future research should explore perspectives on co-production amongst a wider group of participants who had taken part in more projects to see if similar themes emerge.

5. Conclusions

To conclude, this is the only study that has qualitatively explored the perspectives of engaging with and being involved in co-production projects aimed at addressing racial inequalities. This research offers valuable insights into the subjective experiences of Black EbEs who have and have not participated in co-production projects, and perspectives about Black EbEs participation in projects about racial inequalities. This study emphasised the complex interaction of factors involved in EbEs engaging in co-production, such as participants relationship to help being in tension with their community-centred motivations and beliefs that services needed them. Additionally, safety with and trust in professionals helped participants engage with co-production, and participants feeling less alone led to the unforeseen benefit of continued connection. Future research may wish to explore the perspectives about co-production from larger samples of Black EbEs, as well as perspectives across psychosis and mental health services within other NHS Trusts.

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Part 3: Critical Appraisal

Overview

This critical appraisal outlines my role as researcher and the process and experiences of conducting the empirical study within this thesis (Part 2). I reflect on my motivations for conducting research on co-production and racial inequalities, the research process and significance of researcher reflexivity and bracketing, the co-produced intervention (my personal investment in the co-production, and delivering the co-produced intervention), challenges encountered (ethical approval, impact of ethical approval on recruitment and recruiting Black populations), and the personal and professional impact of this research.

Motivations to Study this Topic

The research topic, exploring the perspectives of Black people with psychosis co-producing interventions aimed to address racial inequalities, stood out to me for two main reasons. Firstly, I started the doctorate within the context of global attention to the stark inequalities for Black populations within society, reignited by the Black Lives Matter protest and disproportionate deaths of ethnic minority populations during Coronavirus 19 pandemic. As part of my identity as a Black female, I was saddened by global feelings of hopelessness, but I had acute determination to be helpful, so I tried to actively engage in activities to reduce racial inequalities. I was a mentor to aspiring Clinical Psychologists from marginalised or ethnic minority backgrounds, with the aim to help increase the diversity of the profession. I was highlighting the inequalities I saw in my personal and professional contexts to my networks, and within mental health services, I wondered how I could be active. Therefore, I was keen to be part of this project that was actively co-creating something to reduce inequalities.

Secondly, being one of few self-defined Black trainees within my cohort, when this project was proposed for someone to take up, I somewhat felt a sense of responsibility to ensure this project happened, likely due to my ethnicity. I recall being aware that if I did not take this project, it was possible that others may not have felt able to for various reasons. For example, discomfort talking about ethnicity and racial inequalities, the project not standing out for others, and/or the enormity of creating an intervention from scratch. These two reasons kept me connected and motivated to conduct this study.

Reflexivity and Bracketing

Researchers are part of the social world that they study, and reflexivity refers to researchers examining the values, preconceptions and interests that may interact with research (Shaffir & Stebbins, 1990; Palaganas, Sanchez, Molintas & Caricativo, 2017). As a result of this, researchers engage in bracketing processes to productively understand their own experiences, preconceptions, and biases in relation to the research rather than attempting to ignore or get rid of them (Porter, 1993). Bracketing is an iterative and ongoing process which can take different forms such as reflective journal or interviews with a peer (Ahern 1999). Given my motivations to the topic area, I chose to use both methods. I have, personally, used journals to reflect on my personal experiences, thoughts, and concerns. Therefore, it felt like a natural choice to use this trusted and cathartic format to reflect on this project, without any fear of judgement from others. This journal was an important tool which helped to uphold the integrity of the research by keeping me aware of my biases and views. Documenting my reflections ensured that my biases had minimal influence during the data analysis and interpretation phase, and this practice was a safeguard for the credibility of the research (Ortlipp, 2015). I engaged in the bracketing interviews because it made sense for me to separate my views, personal experiences and preconceptions from the research, for the sake of this research. Furthermore, given that I would be interviewing participants about reducing inequalities, and inevitably holding power as the interviewer, I felt it was important to put myself in the position of being interviewed. I share some of the reflections and comments from using these tools throughout this critical appraisal.

Considering my identity as a Black British Caribbean female, along with my role as Trainee Clinical Psychologist employed by the NHS, it was essential for me to acknowledge and examine how these aspects of my identity would influence my approach to and active involvement in the research. Working within the area of racial inequalities had the potential to trigger strong emotional responses throughout the project, and it was important to consider the impact this may have on me. Immersing myself in this project, I learnt in greater detail about the stark statistics and distressing subjective accounts of Black Experts by Experience (EbE) within the NHS, which led me to reflect on how the project would shape my perspectives and my clinical practice within the NHS. Therefore, I was mindful throughout the research process to pay attention to my emotional responses when discussing ethnicity, racial inequalities, and the NHS.

I had feelings of sadness, frustration and disappointment when continuously learning about the inequalities faced by Black EbEs. Immersing myself with the research about inequalities heightened my awareness for these inequalities in my everyday interactions. For example, in my clinical role, I became acutely aware about healthcare professionals' language about Black and Minority Ethnic ('BME') patients and how language about service users may create perceptions/misconceptions of them within services. One of my clinical roles was in an Early Intervention for Psychosis (EIP) service, and whilst I was clinically supporting service users following their First Episode of Psychosis (FEP) I was wondering about their experiences predating our interactions, such as experiences of inequalities. I was acutely mindful during my interactions with service users and with professionals in the team of the language I was using and not adding to misconceptions about them. My clinical supervisor was aware of the research project, and within supervision invited me to discuss my emotional responses and invited the EIP psychology team to reflect and be curious about the language we used within the service. Whilst these clinical examples of addressing racial inequalities helped to keep my motivation to conduct this research aflame, it was also somewhat emotionally draining and evoked feelings of sadness. I felt the weight of these emotions during the research process, for example feeling flat when reviewing the literature on inequalities and trying to synthesise it and feeling 'heavy' but grateful after some of the interviews. To support myself after experiencing these emotions in clinical or research settings, I discussed them with peers in the research team, used sections of research supervision meetings to acknowledge these feelings, bracketing interviews, and research reflective logs/journal to help process my emotional experiences. Using these tools allowed me to gain a deeper awareness of my specific views and beliefs, and the internal processes that I was unaware of. This was important because it helped me try to set aside my views, perspectives, and biases throughout the research process, which gave me a consistent 'place' to take my views and experiences. In turn this helped to maintain my momentum throughout the research process.

The 'See Me' Intervention

Personal Investment in Co-Production influencing the Interviews

The 'See Me intervention' was a film of EbEs testimonials followed by individual and group reflective tasks for staff. This intervention was delivered to staff within each NELFT EIP services on five occasions and aimed to address racial inequalities in EIP services for Black populations. The intervention was co-produced by five Black EbEs and Experts by Profession. I was involved in development of the concept and the film itself, along with three peer trainee Clinical psychologists, two research supervisors, and five Black EbEs. Given my project focussed on EbEs experiences of co-production, I did not attend the co-production workshop so that I could maintain my 'researcher' identity to the participants, who were part of the sampling pool for my research project.

Although I did not attend the co-production workshop, I actively participated in the initial stages of the films development to gain insights into the desired content and structure, and I attended NELFT EbE Involvement meetings to promote the 'See Me' intervention and recruit interested participants, which may have made participants who took part in 'See Me' aware of my involvement. Although I explicitly communicated my role as a researcher tasked with exploring their perspectives on co-production at the beginning of the interviews, participants may have been aware of my involvement in the development and creation of the film. I wonder how comfortable and willing participants who took part in co-production felt to express their experiences candidly, especially if they held unfavourable opinions about co-production. I wondered whether my involvement with developing the film could potentially have biased me towards asking more about favourable perspectives of co-production, therefore, I tried to mitigate this by explicitly assuring participants at the start of the interview's that there would not be negative consequences to expressing negative opinions about co-production. I also tried to mitigate possible bias by using my reflective log after interviews to consider how I conducted the interviews and asked participants about co-production, to help ensure that I asked about negative and positive perspectives in subsequent interviews. Furthermore, given the sensitive nature of the topic, participants may have felt pressure to say yes to this study because they knew the co-production project would eventually be linked to research and so maybe also provided socially desirable answers. Any future research evaluating the perspectives of co-production projects might benefit from being conducted by a researcher who is viewed by the participants as independent from the co-production project to maintain impartiality.

Facilitating the ‘See Me’ Intervention

My peer Trainee Clinical Psychologist researchers were evaluating the ‘See Me’ intervention for their research projects, therefore, I delivered two of the five interventions to staff and my supervisors delivered the remainder. I was personally invested in the success of the intervention, specifically how staff viewed and valued the ‘See Me’ film, and in turn how they viewed the overall intervention. I was conscious that I wanted to present the film as well as possible to staff and highlight how much of EbEs lives and time had gone into the film. It was useful for me to be aware of and bracket these views about the film prior to delivering the interventions, in order for me to deliver the interventions having tried to set my biases aside.

Reflecting on the intervention, I noticed the position of staff in relation to co-production. Until delivering the interventions, my focus had been on the experiences and benefits of co-production for service users, however, the interventions focussed my attention to how staff engaged in the intervention, and how we could improve subsequent intervention sessions. Anecdotally, during the interventions I delivered, staff seemed to find the film very emotive: perhaps distressing at being confronted with direct accounts of racial inequalities, and discomfort and anxiety about engaging in tasks with colleagues. Despite these strong emotions being palpable in the intervention, staff seemed to, and reported afterwards they had, tolerated their emotions in order to facilitate meaningful engagement and change. Staff's ability to tolerate these emotions appeared to show their connection and resonance to the EbEs stories and experiences, and a demonstration of their willingness to support tackling inequalities first over their personal comfort. Staff connecting with the film was essential for the intervention, because discussing difficult topics, such as racial inequalities, can lead staff to defensiveness and disengagement likely resulting from fear or shame. From delivering the interventions, I learnt some of the ingredients of sensitively engaging staff in tasks related to racial inequalities, such as a story that connects to individuals' humanity and empathy, and opportunities for staff to reflect and process on material individually before being asked to reflect with colleagues. I plan to use these insights and skills in tackling racial inequalities in my future clinical practice and research projects.

Facilitating the interventions filled me with hope that these EIP professionals acknowledged how vital and powerful it can be to include service user's voices within healthcare and improving the service provision, especially in projects about racial inequalities. Additionally, developing the idea of the film to delivering the interventions gave me a full-circle experience and sense of an important ending and a hopeful beginning/continuation. Furthermore, I have learnt how to meaningfully engage service users, and the associated challenges of this, throughout the research or service development process. Moreover, I can carry this into my clinical practice and research, for example, by prioritising the voices and experiences of service users within their mental healthcare.

Challenges of Conducting this Research

Ethical Approval

There were two specific areas that come to mind when thinking about the challenges faced in this research project: ethical approval and recruitment.

My project involved interviewing Black people with psychosis about their perspectives on co-production, and the experiences of those involved in ‘See Me’ intervention. This project was part of a wider project addressing racial inequalities for Black people in psychosis, therefore, the three peer Trainee Clinical Psychologist researchers had their own projects related to the ‘See Me’ intervention. Two of the projects were about the perspectives on co-production from staff and service users' perspectives (my project being the latter), and two projects were about evaluating the ‘See Me’ intervention. As a result, we created one NHS ethical approval application that subsumed all our projects. Whilst it made sense to write a joint application for our respective projects, this was a huge and very time-consuming endeavour and incredibly taxing. It required all four trainees to coherently write one narrative about the slightly separate contexts to our projects, and our separate research questions and aims. Initially, I underestimated the time this would take; deciphering my own project question, aim and methods and then working with three trainees to produce the coherent narrative. Additionally, given the nature and size of our application, there were delays in our application being reviewed by our supervisors and significant delays from the reviewers in NHS ethical approval department. There was a further delay when we learned that the reviewers suggested that my project should be resubmitted as a standalone NHS ethics application, and the other three trainees should submit a briefer UCL application. This was incredibly disheartening to learn. However, I recognised the reviewers' role was to make suggestions and advise us on our application where necessary. I restarted the process of rewriting my NHS application, however, it was confusing to understand the criteria for NHS ethics applications.

I deviate briefly to discuss the history of ethical approval in research, before returning to my application. The National Research Act was passed in 1974 to protect the rights, dignity, safety and wellbeing of participants and researchers (Akpan, 2012). This Act came after decades of unethical research on people, with one notable example (and relevant to the health inequalities of Black people) being the Tuskegee study which investigated the effects of untreated syphilis in 400 African American men (Gamble, 1993). Returning to my ethics application, I understood the need to protect the safety of participants, however, there appeared to be a discrepancy is needing NHS ethics for my research project and not needing NHS ethics to create the 'See Me' film. It was anticipated within the research team that service users' co-producing the intervention (about views on and experiences of racial inequalities) had more potential to be distressing or upsetting compared to my research interviews (about views on and involvement in co-production). From the position of a Trainee Clinical Psychologist and as a Black person, as I was interviewing service users I understood; the importance of having safeguards to protect them to engage safely in research and avoid risk of harm, and that ethical approval helps to enforce safeguards. However, given participating in developing and filming the 'See Me' film had more potential to distress service users than my project, but did not require NHS ethics because it was a commissioned as a service development project, I struggled to understand purpose of NHS ethics in practice. Specifically, there would have been considerations made about my project and the service development project, which would have informed the reviewers decision that my project required NHS ethical. I tried to hypothesise these considerations, for example, the NHS Trust commissioning their own project as part of service development and my project was gathering data outside of general service delivery. Perhaps there are distinctions about what can be classed as service development audit, and though my project would explore service users' participation in an activity to develop the service, my project could not be classed as such. Unfortunately, I did not receive clarity about the difference between projects and I felt was confused about how ethical approval was applied to conducting research. However, at the time, I recall just being keen for the project to progress, so I focussed on rewriting my application and on doing what was required to push ethics through rather than identifying the exact distinctions between my project and the wider service development project.

Rewriting our four-project application as a solo application added significant delays to my research project and impacted on my timeline for completing different stages of the research. I rewrote and submitted my NHS ethics application five months into my final year of the DClinPsy (February 2023), and though my supervisors tried to expedite my application being reviewed, we received ethical approval at the end of my final year (June 2023). During this ethical approval process, it was challenging and stressful to create and polish numerous documents to a meticulous standard, and unfortunately the process predominantly involved frequent follow-up emails to different ethics reviewers who were responsible for reviewing various aspects of the application. I recall that whilst being detailed-oriented to write the application, I was also trying to synthesise literature for the project, so I felt like I was either slightly detached from the project or very present, respectively, during this time.

The Impact of Ethical Approval on Recruitment

In addition to the practical time taken to progress the application, the delays within the ethical approval process may have impacted on participants 1) taking part in the study and 2) recalling the co-production project. At the time of the co-production, the five EbEs expressed interest and excitement in staying connected to the film and further opportunities to participate in efforts to reduce racial inequalities. I was keen to capitalise on this momentum and invite participants to my research project. However, the delays throughout the ethical approval process meant that it was nine months from creating the film to interviewing EbEs. During recruitment, I was curious to how this delay impacted on participants willingness to get involved and whether the initial excitement from co-production would be sufficient for them to get involved. Reflecting on this then concern now that I have conducted the research, I am aware that within wider research on service users' involvement projects it would be difficult to determine how long ago someone had taken part and base exclusion criteria on this, and delays from participation in projects to interviews are common. Though three of the five participants who had taken part in the co-production participated in my research, which was a good rate, overall recruiting participants to take part in my project was very challenging. For the two participants who declined participating in my research, I was curious about their reasons and hypothesised plausible explanations. For example, the time that lapsed between co-production and the interviews, less excitement about co-production, or more broadly barriers within people's everyday lives or their relationships with services impacting on participation. Given these challenges, the supervisors and I considered widening the sampling pool earlier to other samples, such as those with wider service user involvement experience in EIP and those who had not participated in any service user involvement or co-production projects. As such, I was able to recruit participants with and without co-production experience, which may have led to findings which are more generalisable to Black populations across mental health services. Recruiting participants who had not taken part in co-production also brought challenges; unlike recruiting EbEs from 'See Me', I was recruiting service users whom I had no prior contact or relationship with, which I have reflected on below.

Recruiting Black Populations

There are systemic issues which influence co-developing service provision with minority groups. Minority groups, particularly Black populations, have experienced discriminative practices within their access to and experience of mental healthcare. Past experiences of discrimination impact on expectations of future discrimination with services and creates fear of accessing mental healthcare, which is often reinforced by experiences and responses from other institutions in society, which continues a cycle of broken trust between populations and services. Moreover, given populations lack of trust in accessing services, it is understandable that there are factors impacting on their engagement to develop mental health service provision. This lack of trust of services appeared to be a barrier to recruit Black populations to participate in my research project; whilst I was coming in as a researcher, I may have been viewed as part of the NHS ‘system’. Therefore, given my association with the NHS it may have been difficult for them to trust me and by association trust participating in the research, leading participants to decline taking part.

Building relationships with populations over time is important for building trust. Recruiting for previous NHS research projects, I have learnt that embedding yourself in services significantly helps with building trust in service users and professionals due to increased visibility. Throughout recruitment for the current research project, I was reflecting on how visible I was to potential participants and whether I had given them opportunities for me to build trust with them. I also considered how my position, specifically as a Black person, impacted on recruitment and may have fostered trust; for some participants, being interviewed by a Black professional impacted their willingness to take part. In addition, though I was part of the wider project and familiar to the service users involved in the co-production project, I reflected on how embedded or familiar I was with participants who had not been involved in co-production. My capacity to be embedded with services was limited by being a Trainee Clinical Psychologist; working part-time clinically and attending university or conducting research part-time. These reflections highlighted the potential impact of professionals within the wider project embedding themselves within the services in the service development process, and whether this might have facilitated opportunities to build trust earlier within the project.

Personal Takeaways

I found conducting this research project to be a personally and professionally enriching experience. I felt privileged for the opportunity to hear about and learn from the lived experiences of Black EbEs. Moreover, I was grateful to have been part of a project that took action based on these lived experiences, and aimed to improve the everyday and systemic interactions that Black populations have with mental health services. This project was a substantial but immensely rewarding piece of the work, and the benefits of our collective (research team and EbEs) hard work and action has already been seen. This project has shown me the scope that Clinical Psychologists have with their service users to create and execute opportunities to improve the healthcare their receive. Furthermore, this project has highlighted the value of genuine partnership and collaboration for all stakeholders involved. I have learnt the significance, power, and freedom of including EbEs voices within mental health care. Throughout our clinical training, we are taught to value and prioritise service users' views, strengths and interests in their mental healthcare, and this project reaffirmed my belief that this is vital to working with any service users. Whilst this wider project was a large-scale project that involved creating a film, I have learnt that co-production principles can be brought into all work with service users and everyday interactions with them. As a Clinical Psychologist, I plan to use a person-centred and empathetic approach that situates service users' voices and experiences alongside my own, for example, within their mental health treatment and/or decision-making processes. I hope my practice will continue to contribute to reducing racial inequalities for marginalised populations.

Personally, I have experientially learnt the need for continued spaces to reflect on my biases and perceptions based on my personal experiences, and to reflect on and bracket the emotional responses to addressing racial inequalities. At the beginning of this project, I was protective of criticism about the purpose or value in service users' involvement and I was unaware of my internal processes underpinning these views. In addition, I was unfamiliar with the rationale for and experience of being reflexive in relation to research. At the end of this project, I notice how important bracketing a researcher's views are to helping to maintain the integrity and validity of qualitative research. Being aware and engaging with how my views and position could interact with the data collection and data analysis, has helped me remain focussed on participants perspectives about addressing inequalities. Given the history of Black populations seldom being heard, I have learnt how crucial reflexivity and bracketing is helping *their* voices to be heard.

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Appendices

Appendix A: Interview Schedule

Title:
Exploring the perspectives of Black Experts by Experience who co-produced a staff intervention addressing racial inequalities in mental healthcare for Black people with psychosis.

Aims of the study:

The study is exploring the experiences of Black Experts by Experience who were invited to co-produce an addressing inequalities intervention, such as ‘The Danger of a Single Story’ (DoSS) project. The aims of this study are to explore and improve:

- How participants were invited to co-produce the wider project
- The experiences, perspectives, and impact of co-producing (in NHS Trust’s)
- Co-production in future projects

Interview Schedule:

Please see below how the researcher will set the scene of the interview and manage any sensitivities that might arise.

Thank you for meeting with me today and agreeing to take part in my study.

What name do you prefer to be called by?

Ok, thank you [preferred name].

Explain information about the study, as provided on the study information sheet, giving opportunities for the participant to ask questions.

As explained in the information sheet, I will be asking you questions about your experiences of and perspectives on co-production. Co-production means asking people their opinions on mental health services and inviting people to work jointly with professionals to improve services. During this interview, we will be having a conversation about coproducing interventions to address racial inequalities, such as ‘The Danger of a Single Story’ project, and to generally understand the views of Black people with psychosis about getting involved in such initiatives.
[For people who were not invited to DoSS]: You do not need to have participated in any co-production projects to take part in this interview – all views and levels of experience in this area will be valuable to the study.
[For people who were invited to DoSS]: As a reminder the wider project was to develop a staff intervention to improve racial inequalities for Black people with psychosis. The

wider project was co-produced with Black Experts by Experience (EbE). The wider project and this study have defined co-production as participation in any or all of the following: the initial focus groups, the workshop day, and/or providing feedback to finalise the intervention.

The researcher will sensitively ask the participant about their understanding of co-production before proceeding, to reassess mental capacity. The researcher will ask:

"Can you confirm your understanding of co-production?"

If the participant's response indicates they may not understand the term 'co-production', the researcher will elaborate using the participant information sheet. The researcher will then proceed with explaining the below information.

The aims of this study are to explore and improve:

- *How participants were invited to co-production*
- *The experiences, perspectives, and impact of co-production*
- *Co-production in future projects*

This interview should last around 45 to 60 minutes and you are free to finish the interview and take breaks at any time. The interview includes three sections, based on the aims of this study. For EbE's who chose to participate in co-production, I will ask them questions from all 3 sections. For EbE's who were not involved in co-production (neither in DoSS nor other co-production projects), I will ask them questions from sections 1 and 3. Please let me know if there are any questions that you would prefer not to answer so I can move on to the next question.

We hope to understand your experiences of the wider 'The Dangers of a Single Story' project aimed at addressing inequalities. We really value your feedback which will allow us to shape and improve the co-production process in the future. We understand that it can be difficult to talk and think about issues of race and inequalities and some of the questions may evoke strong emotions and anxieties in people. Therefore, if you become distressed at any part during the interview, please do let me know.

As you might remember, this interview will be recorded so that I can revisit the conversation later. We would like to emphasise that all responses will be kept confidential, so please try to answer openly and honestly.

Are you happy to continue with the interview today?

Section 1: questions exploring the experiences of being invited to participate in 'The Danger of a Single Story' project.

Please see below how the researcher will introduce Section 1 of the interview to all participants.

Thank you for completing the demographics questionnaire. Can I confirm whether you did or did not agree to be involved in co-producing the staff intervention? Thank you for confirming.

Research has shown the importance of including EbE's voices in projects about their own healthcare. Unfortunately, there has been little research on how EbE's have found being involved in co-production projects. Therefore, I will be asking questions about your experiences and perspectives of co-production projects, including 'The Danger of a Single Story' video project.

1. How did you find out about 'The Dangers of a Single Story' video project?
Prompts: did you attend a coffee morning?
Prompts: did a person (e.g., healthcare professional, EbE) introduce this project to you? If so, how was it explained to you?
Prompts: did you find out about the project from a poster or leaflet?

2. How did you find being invited to the wider project?
Prompts: what first came to your mind when you were asked?
Prompts: how did you feel being asked to participate in a project about racial inequalities?

3. What motivated you to accept or decline [delete as appropriate] participating in the wider project?
Prompts: what factors influenced (helped and hindered) your decision to accept/decline this invitation?
Prompts: how did your identity influence your decision?
Prompts: how did your lived experience (e.g., ethnicity, racial inequalities) influence your decision?

4. Even if you participated, what concerns or reservations did you have about getting involved e.g., concerns about co-producing within an NHS Trust?
Prompts: can you tell me if you had any other concerns about the project?

Please see below how the researcher will introduce additional Section 1 questions. The following questions will only be asked to participants who chose not to participate in the co-production.

Thank you for sharing your experiences of being invited to co-produce this project. I will now be asking you for any thoughts and recommendations on how to improve the invitations to future co-production projects.

5. How would you have improved the invitation to this specific co-production project?
Prompts: what could have been done to improve the invitation?
Prompts: what could have been removed to improve the invitation?
Prompts: what, if any, are your recommendations for inviting people with lived experiences to co-production projects?

6. If you had taken part in this co-production project, how would you have wanted to be involved?
Prompts: what would have helped you to contribute e.g., in focus groups, meetings?
Prompts: what would have made it difficult for you to contribute?
Prompts: what recommendations would you have for how researchers/facilitators could have helped you contribute to meetings?

Section 2: questions exploring the experiences, perspectives, and impact of co-producing 'The Danger of a Single Story' project.

Please see below how the researcher will introduce Section 2 of the interview to participants who chose to participate in co-production.

Thank you for answering questions about your experience of being invited to participate in co-production. I will now be asking you questions about your experiences of the actual co-production, and any impact that this may or may not have had on you.

1. How would you describe your experience of co-producing the intervention?
Prompts: how did you think and feel, and what did you do?
Prompts: were there any issues with co-producing?
Prompts: were there any positives about co-producing?

2. How would you describe taking part in an NHS Trust co-production project?
Prompts: what were your issues or concerns about co-producing a project within an NHS Trust?
Prompts: what were your hopes about co-producing a project within an NHS Trust?

3. What helped you to contribute during the co-production meetings?
Prompts: how did you find talking in the meetings?
Prompts: how did you experience doing the exercises during the meetings?

4. What made it difficult to contribute during the co-production meetings?
Prompts: how did you find talking in the meetings?
Prompts: how did you experience doing the exercises during the meeting?

5. What impact did co-producing the intervention have on you?
Prompts: how would you describe the impact on you personally, emotionally, mentally, socially?
Prompts: what impact has participating had on your identity? e.g., your identity with others, your support network?

6. How were you supported during the co-production meetings?
Prompts: where did your support come from? I.e., other participants, facilitators, personal methods.
Prompts: how were you emotionally supported?
Prompts: how were you practically supported?

7. What was it like to be part of a project about addressing racial inequalities for Black people in psychosis services?
Prompts: how would you describe the safety of the meetings i.e.; did you feel safe enough to contribute?
Prompts: how did you personally manage/cope in a group which talked about racial inequalities?

8. What was it like to be with other Black people during the co-production meetings?
Prompts: what impact did the Black EbE's have on you/your experience?
Prompts: how did the researchers/facilitator's ethnicities impact on you?

Section 3: questions about recommendations for improving co-production in future projects.

Please see below how the researcher will introduce Section 3 of the interview to <u>all</u> participants.

In this section, I will be asking you for any recommendations to improve co-production for future projects. These questions are important to ask people who did and did not participate in the co-production, so that more people may feel able to participate in future.

I would like us to consider all we have talked about today and come up with some ideas that could help more people participate in co-production and also help people during the co-production meetings.

1. What do you think about co-production projects overall?
Prompts: what are the strengths of co-production projects?
Prompts: what are the difficulties of co-production projects?

2. What are your recommendations for encouraging service users to get involved in co-production?
Prompts: is there anything the NHS could do to support people to get involved in co-production?
Prompts: is there anything that wider structures could do to support people with being involved in co-production?

3. Even if you did not participate, what are your recommendations for supporting service users once they are involved in co-production?
Prompts: how might you have been better supported, given your lived experiences of racial inequalities?

4. Do you have any other specific recommendations for service users taking part in psychosis co-production projects?

Ending

We have now finished the interview. Before we finish today, is there anything else about your experiences of co-production that we haven't spoken about, and you would like to talk about?

Do you have any questions for me about the interview, or the research in general?

How did you find taking part in this interview? Is there anything that you would have liked to have been different in this interview?

Would you like to hear about the results of this study once it is completed?

I have a list of resources to support you if you are feeling upset or would like further support. I have already shared this with you, but I can share this again today. Please let me know if this would be helpful to you.

Thank you for your time today and for answering these questions. I really value your responses and time.

Appendix B: Interview schedule consultation process

Step 1: Interview schedule development

The research team derived questions based on recommendations for further research from previous studies of racial inequalities in the care of Black people with psychosis. Experts by Experience's were consulted in the development of the interview schedule.

Step 2: Expert opinion with qualitative researcher

Dr Chelsea Gardener and Dr Miriam Fornells-Ambrojo, experts in qualitative research, were consulted to provide feedback and guidance on the styles of questions used to meet the aims of the study and address the research questions. Dr Chelsea Gardener has expertise as an EDI lead in the DClinPsy programme at UCL and has been involved in devising training, intervention and reflective practice for mental health professionals. Based on their comments, wording, question order, and interview style, changes were made to the interview schedule.

Step 3: Further refining the interview schedule with the target populations

Consultations with Experts by Experience's were used to refine the interview schedule. Specifically, the feedback helped to ensure that the topics discussed in the interview were relevant and fully addressed the aims of the study. This feedback was incorporated to generate the next version of the interview schedule.

Step 4: Consultation with Experts-by-Experience

Three Experts-by-Experiences were consulted for the final stages of the interview schedule. All the individuals who took part in the consultation would have been eligible to take part in the study. Experts by Experience's provided feedback on the recruitment poster, information sheet, consent form, and interview schedule. Their feedback helped shape the final wording of questions, to ensure that they were clear, felt relevant, and sensitively addressed difficult topics.

Step 5- post-analysis validity check of extracted themes.

The researcher will conduct a post-analysis validity check of the extracted themes. To do this, the researcher will invite one participant from the study to review the final superordinate themes extracted from their individual interviews to ensure that there is a good fit with their understanding of the experiences that they described.

Appendix C: Research Advert

IRAS: 325675, Version 2.0, Version Date 17.05.23

UCL

RESEARCH PROJECT

NELFT NHS

NHS Foundation Trust

EXPLORING THE PERSPECTIVES OF BLACK EXPERTS-BY-EXPERIENCE ON A CO-PRODUCTION PROJECT ADDRESSING RACIAL INEQUALITIES IN EARLY INTERVENTION FOR PSYCHOSIS SERVICES.

- Aged 18 years & over?
- Do you racially identify as Black, or mixed-Black, British, African, Caribbean & Other Background?
- Are you a service-user or carer for someone under the care of NELFT Early Intervention in Psychosis (EIP) Services?

If you answered 'YES' to all the questions above and would like to share your experiences, we would like to hear from you.

WHO CAN TAKE PART?

Anyone who has used - or has cared for someone using - NELFT Early Intervention for Psychosis services.

You DO NOT need to have taken part in the coproduction project.

WHAT IS THIS RESEARCH ABOUT?

We want to hear Black service-users' views and experiences of a co-production project addressing racial inequalities in Early Intervention for Psychosis services. We want to explore what has facilitated and/ or gotten in the way of participating in this kind of work, in order to identify ways in which services can effectively support efforts to improve equality in care.

WHAT IS INVOLVED?

A single interview (lasting about 1 hour) about your views and experiences. The interview will take place online, or face-to-face, at a NELFT site that is convenient for you.

ALL PARTICIPANTS WILL RECEIVE £15 (CASH OR VOUCHER) FOR TAKING PART IN THE RESEARCH.

We will be recruiting until August 2023.

CONTACT INFORMATION

If you are interested in participating or would like to find out more, please contact Alaina Husbands (researcher) at alaina.husbands.20@ucl.ac.uk; *study tel. number, or Dr Miriam Fornells-Ambrojo (Chief Investigator) at miriam.fornells-ambrojo@ucl.ac.uk; 020 7679 1897. Address: Research Department of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB.

Appendix D: Participant Information Sheet

Study title: Exploring the perspectives of Black Experts-by-Experience on a co-production project addressing racial inequalities in Early Intervention for Psychosis Services

We would like to invite you to take part in this clinical psychology doctorate student project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, please read this information sheet carefully and discuss it with others if you wish, so you understand why the research is being done and what your participation would involve. Part 1 tells you the purpose of this study and what will happen if you choose to take part. Part 2 gives you more detailed information about how the study is managed. Please ask us if there is anything that is not clear or if you would like more information.

Part 1

What is the purpose of the study?

Following wider government policies, NHS trusts in England have been developing strategies for addressing well-known health inequalities in care for Black service-users.

In mental health services, including Early Intervention in Psychosis (EIP) services, there are some examples of the way that teams and staff engage with initiatives to promote equal care for Black service-users including (but are not limited to):

Taking part in team discussions about improving Black service-users experience of care.
Considering cultural factors/needs in everyday clinical practice
Participating in 'Equality, Diversity & Inclusion' projects
Engaging with relevant training (e.g., cultural competency) or educational resources

Little research has directly included Black service-users in co-developing these initiatives and/or being involved in the execution of initiatives. Therefore, little research has looked at what would help or hinder service-users and carers to take on this type of work, and the impact that this has on them.

Therefore, this study aims to:

Gain insight into Black service-users views and experiences of co-developing a project about addressing inequalities, specifically the experiences of being invited to the study, experiences as a co-producer, and recommendations for co-production in future projects.
Understand what facilitators and/or barriers exist for service-users in being involved with type of work.

Explore how this type of work impacts on service-users and carers personally.

We hope that this will inform recommendations for services to meaningfully engage in efforts to improve equality in care.

Why have I been invited to take part?

We have invited people to take part in this research who are:

Adults aged 18 years and over.
All genders
Adults who will racially identify as Black, or mixed-Black, British, African, Caribbean and Other Background
Adults who are service users under the care of NELFT EIS
Black (or mixed Black) adults who care for a Black (or mixed Black) service user under NELFT EIS (carer is defined as anyone who provides any type of care or support (emotional, practical, financial) for the service user. A carer might be a family member of someone from the person social network)
Participants might have:
Contributed to the development/co-production of any addressing inequalities intervention (the 'Danger of a Single Story' training or other), or
Never contributed to development of any addressing inequalities intervention (i.e., refused to or not been approached to contribute)

Do I have to participate?

You do not have to take part in this study. It is up to you to decide whether you wish to participate or not. If you decide to take part, we will ask your permission to use your anonymised responses in my doctoral thesis. We also plan to share our findings in research publications and/or presentations. You are free to withdraw at any time, without having to give a reason. This would not affect your current or future care.

What will happen if I decide to take part in the study?

After you have had time to read this information sheet, which will be at least 24 hours, a Clinical Psychologist from the Early Intervention Service will contact you. If after reading this information sheet you are interested in taking part in the study, please let the Clinical Psychologist know and they will ask if you consent to the researcher contacting you. If you consent, the researcher will contact you and you will have an opportunity to ask any questions about the study before deciding if you want to take part. If you are still interested in participating in the study, you will be given a consent form to complete. Following this, the researcher will arrange a date and time to meet with you for the session. The session will take place online via MS Teams/Zoom, phone or face-to-face at a convenient site in the North East London NHS Foundation Trust (depending on your preference). You will also be able to ask any questions about the study before deciding whether you would like to take part.

You will meet with the researcher for one session lasting approximately 45-60 minutes. During this time, you will complete a demographics form and you will complete an audio-recorded interview lasting between 45-60 minutes where the researcher will ask about your views and experiences of being involved in the addressing inequalities project. There are no right or wrong answers to any of these questions, so we ask that you respond as honestly and openly as possible.

The interview session is audio recorded so that the researcher can transcribe the conversation after you have finished talking. The audio recording will be stored on an encrypted device and will be deleted as soon as the interview is transcribed. Transcriptions will be written by the researcher that conducted your interview and the researcher will remove any personal identifiable information so that the conversation will be completely anonymised. The researcher will identify key themes that arise during the interview and will choose some direct quotations to show examples of these themes in the final report.

Additional opportunity to offer consultation to the research team:

We will also invite participants to meet with the researcher to comment on their interpretation of the main themes emerging from your interview, including any anonymised quotations used. If you are interested in being involved in this additional part of the project, you will be invited to attend a second meeting once we have completed analysing the data (this will likely be around September 2023), when the researcher will show you the summary of themes that have been identified and you will be asked about your feedback to ensure you feel they accurately represent your view.

Will I be compensated?

Yes. You will receive £15 in cash or vouchers as a token of thanks for your time in taking part of the main study and reasonable expenses. Reimbursement of reasonable expenses will be in addition to the cash or voucher given as a thank you for taking part. Additionally, if you also are interested in contributing to checking the credibility of my analysis you will be contacted to review the themes emerging from our interview and will receive an additional £10 in cash or vouchers for your time.

How will we use information about you?

We will need to use information from your healthcare record for this research project. This information will be your name, your date of birth, ethnic identity, telephone number and email address. The research team will use this information to do the research, such as checking you meet the inclusion criteria, or to check your research records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study. The data saved would be name and contact details.

Where can you find out more about how your information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/, our leaflet available by asking one of the research team, by sending an email to miriam.fornells-ambrojo@ucl.ac.uk, or by ringing us on 0207 679 1218 or by sending an email to data-protection@ucl.ac.uk

The data custodian for this study is the Dr Miriam Fornells-Ambrojo.

What will happen to the results of the research study?

You will be offered the opportunity to receive a summary of the findings of the study. The results of the study will contribute to part of a dissertation thesis and be sent to an academic journal for publication, but you will not be identifiable. Your participation in the study will, of course, not be disclosed.

What are the possible disadvantages and risks of participating in this study?

Talking and thinking about racial inequalities in healthcare can, understandably, evoke challenging emotions in some people. This may be particularly difficult as you have lived experience of being a service-user or carer. Please be assured that any information you provide will be handled in the strictest confidence, and that you will be able to answer questions at your own pace.

The researcher is training to be a clinical psychologist so has experience in managing distress. If any time you feel upset, you can let the researcher know so that you can be supported. You can ask the researcher to move on to another subject or terminate the interview altogether. You do not need to discuss anything that you do not want to, and you should discuss only the things which you feel comfortable sharing.

In the event that you experience distress, at the end of the interview, the researcher will remain with you until you feel better and will discuss with you where you can get additional support.

What are the possible benefits of taking part?

We hope that you will find it a positive experience to share your views and experiences. By understanding how service users and carers experience the range of efforts intended to reduce racial inequalities for Black service-users, we can learn how to improve these endeavours and tailor the support that is needed for service-users and carers to participate in this type of work. We aim to share important and relevant information with key stakeholders to enable many people to learn from the feedback that you have provided. We hope that this research can contribute to the improvement in care for Black service users who have been diagnosed with psychosis.

What if there is a problem?

If you wish to complain or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask the researcher if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) negligence, then you may be able to claim compensation. Please make the claim in writing to Dr Miriam Fornells-Ambrojo who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions, contact details are at the end of the document.
If you remain unhappy and wish to complain formally, you can do this from the NHS Complaints Procedure. Details can be obtained from the NELFT, Patient Advice and Liaison Service (PALS). PALS can be contacted online nelftpals@nelft.nhs.uk or by telephone 0300 300 1711.

This is the end of Part 1 of the information sheet.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making a decision.

Part 2

What will happen if I don't want to carry on with the study?

If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

Will my participation be kept confidential? (Privacy notice)

The controller for this project will be University College London (UCL). This means that we are responsible for looking after your information and using it properly. UCL will keep identifiable information about you for 10 years after the study has finished. The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk. This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, please visit this web page for further information https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies. The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data is: 'Public task' for personal data and 'research purposes' will be the lawful basis for processing special category data. Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide, we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk

We follow ethical and legal practices and all information about you will be handled in confidence. The information about your participation in this study will usually be kept confidential. The only exception is if you tell us something that leads us to believe that you may be at risk of harming yourself or somebody else, or that you are at risk of harm from somebody. We will only use your personal information to contact you if you have agreed to be contacted for participation in this study.

Only the lead researchers on the project will have access to your personal information and this will be kept separate from the data collected. Only researchers involved in this study and regulatory authorities will have access to the data. Data will be stored in locked offices and on password-protected databases at University College London. All information that is collected during the course of the research will be kept strictly confidential according to the General Data Protection Regulation (GDPR) and Data Protection Act 2018.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

North East London Foundation Trust will keep your name and contact details confidential and will not pass this information to UCL. North East London Foundation Trust will use this information as needed to contact you about the research study. Certain individuals from UCL and regulatory organisations may look at your research records to check the accuracy of the research study. UCL will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

UCL will collect information about you for this research study from NELFT. NELFT will not provide any identifying information about you to UCL.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by the Social Care REC (*Reference number: 23/IEC08/0016).*

Who is organising and funding this study?

This study has been organised by UCL and funded by UCL DClinPsy.

How have patients and the public been involved in this study?

Service user involvement was an important part of the study preparation, particularly in developing the interview schedule. Three Experts-by-Experience were consulted for the development of the interview schedule. The Experts-by-Experience were Black service users and carers within NELFT. They provided feedback on the recruitment poster, information sheet, consent form, and interview schedule. Their feedback helped shape the final wordings of questions, to ensure that they were clear, felt relevant, and sensitively addressed difficult topics.

You may find the following resources/services helpful in relation to obtaining information and support:

The Samaritans: 116 123. A free 24/7 helpline for anybody experiencing distress.
Support line for NHS staff: 0800 06 96 222 (7am to 11pm, 7 days a week).
Shout Text service: NHS and other health and social care staff can text ‘frontline’ to 85258 for support.
Project5: provides NHS staff free access to support sessions via an online booking system: www.project5.org.
Black Minds Matter UK – a charity supporting Black people to access mental health care services. www.blackmindsmatter.com

The Black, African and Asian Therapy Network – a network offering resources relating to wellbeing and mental health. www.baatn.org.uk
You can access mental health and wellbeing apps such as Headspace, Unmind, Sleepio, Daylight and Liberate for free.
Your General Practitioner (GP) can signpost you to additional services if you experience emotional distress.

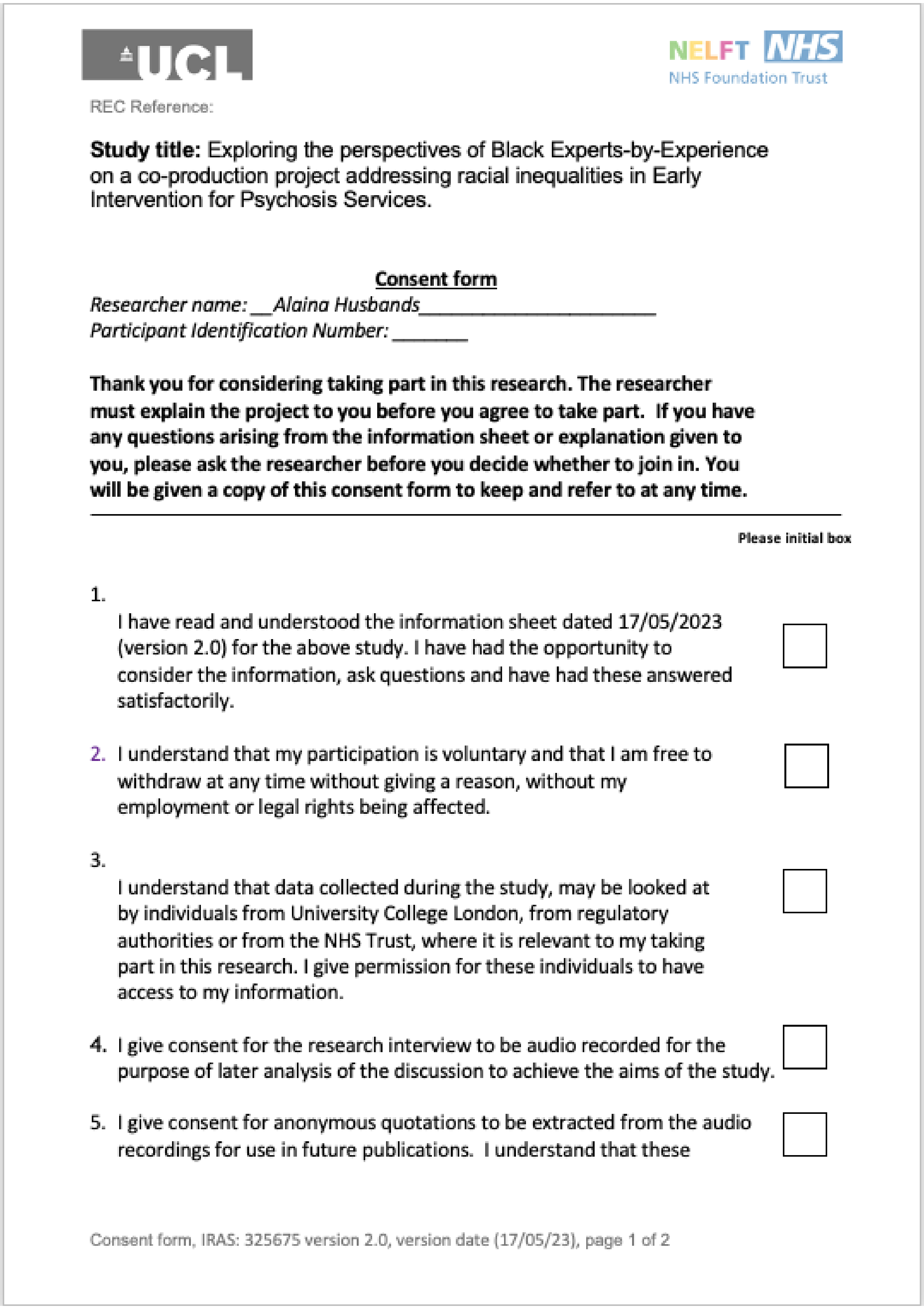
Contact details:

General information about this research project can be obtained from Alaina Husbands, Researcher:
Email: alaina.husbands.20@ucl.ac.uk
Tel: 07958411823
Address: Research Department of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB), and

Dr Miriam Fornells-Ambrojo, Chief Investigator:
Email: miriam.fornells-ambrojo@ucl.ac.uk
Tel: 020 7679 1897
Address: Research Department of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB).

Thank you for your interest in this study and for taking the time to read this information.
If you agree to part in the study, you will be given a copy of this information sheet and a copy of the signed consent form to keep.

Appendix E: Consent Form



UCL

NELFT NHS
NHS Foundation Trust

REC Reference:

Study title: Exploring the perspectives of Black Experts-by-Experience on a co-production project addressing racial inequalities in Early Intervention for Psychosis Services.

Consent form

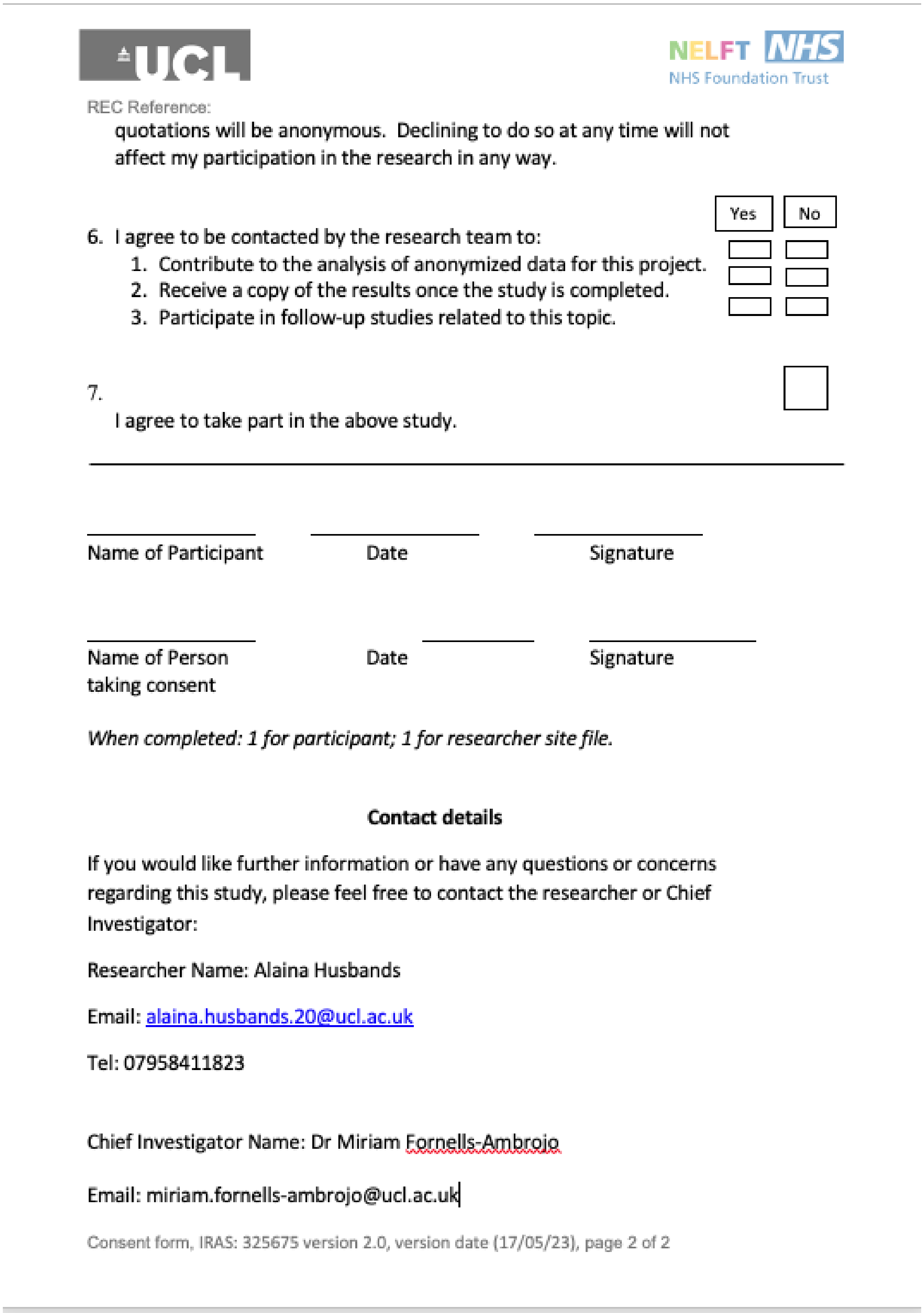
Researcher name: __Alaina Husbands_______________________
Participant Identification Number: _______

Thank you for considering taking part in this research. The researcher must explain the project to you before you agree to take part. If you have any questions arising from the information sheet or explanation given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this consent form to keep and refer to at any time.

Please initial box

1. I have read and understood the information sheet dated 17/05/2023 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my employment or legal rights being affected. ☐
3. I understand that data collected during the study, may be looked at by individuals from University College London, 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 information. ☐
4. I give consent for the research interview to be audio recorded for the purpose of later analysis of the discussion to achieve the aims of the study. ☐
5. I give consent for anonymous quotations to be extracted from the audio recordings for use in future publications. I understand that these ☐

Consent form, IRAS: 325675 version 2.0, version date (17/05/23), page 1 of 2



UCL

NELFT NHS
NHS Foundation Trust

REC Reference:

quotations will be anonymous. Declining to do so at any time will not affect my participation in the research in any way.

6. I agree to be contacted by the research team to: Yes No
   1. Contribute to the analysis of anonymized data for this project. ☐ ☐
   2. Receive a copy of the results once the study is completed. ☐ ☐
   3. Participate in follow-up studies related to this topic. ☐ ☐

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

Name of Participant ____________ Date ____________ Signature ____________

Name of Person taking consent ____________ Date ____________ Signature ____________

When completed: 1 for participant; 1 for researcher site file.

Contact details

If you would like further information or have any questions or concerns regarding this study, please feel free to contact the researcher or Chief Investigator:

Researcher Name: Alaina Husbands

Email: alaina.husbands.20@ucl.ac.uk

Tel: 07958411823

Chief Investigator Name: Dr Miriam Fornells-Ambrojo

Email: miriam.fornells-ambrojo@ucl.ac.uk

Consent form, IRAS: 325675 version 2.0, version date (17/05/23), page 2 of 2

Appendix F: Demographic Characteristics Form

Study title: Exploring the perspectives of Black Experts by Experience who co-produced a staff intervention addressing racial inequalities in mental healthcare for Black people with psychosis.

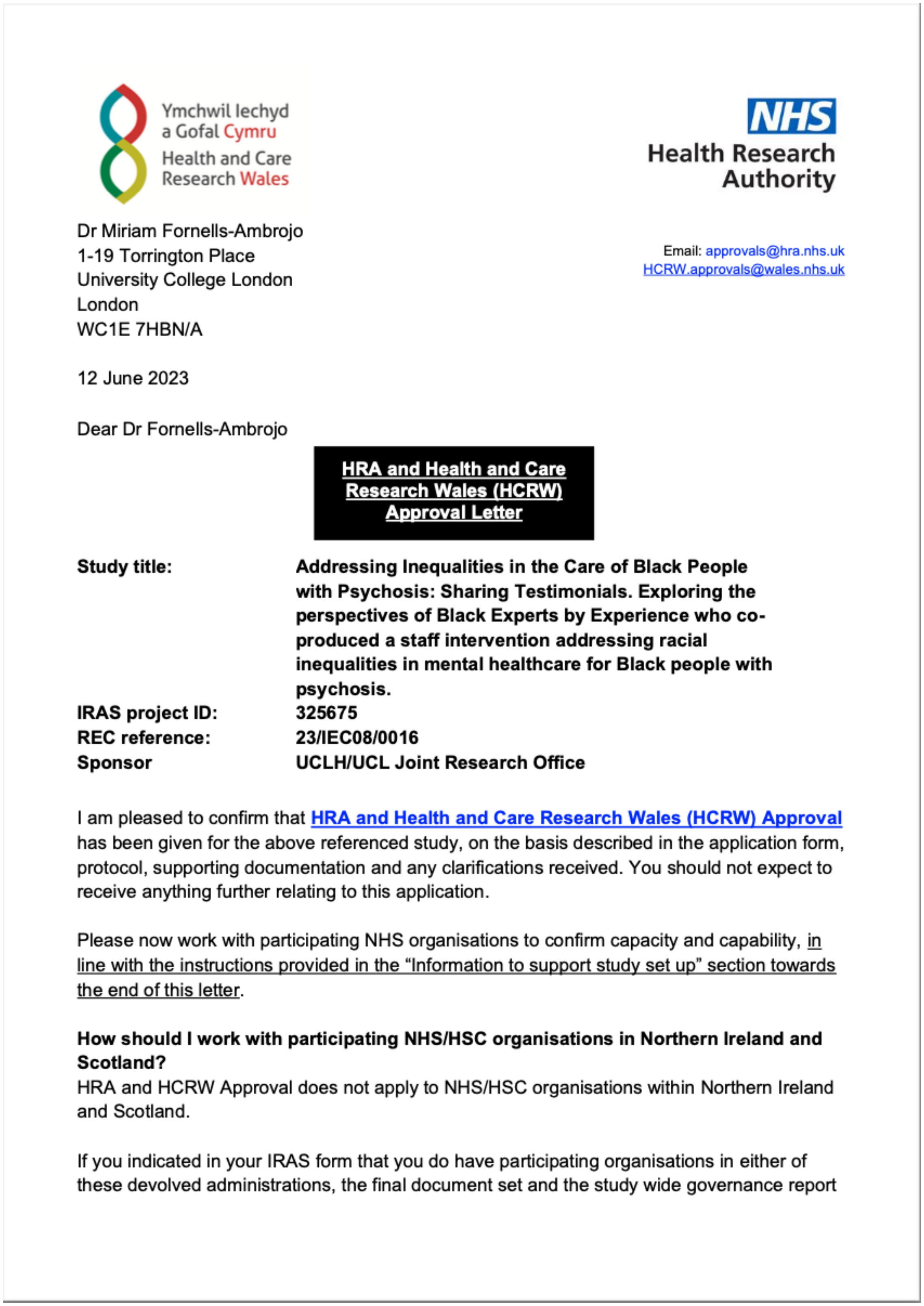
Demographic characteristics

1. **What is your age?**

☐ **18-24**
☐ **25-29**
☐ **30-34**
☐ **35-39**
☐ **40-44**
☐ **45-49**
☐ **50-54**
☐ **55-59**
☐ **60-64**
☐ **65-69**
☐ **70+**

2. **What is your gender identity?**
3. **What ethnicity do you identify as?** (e.g., Black, or mixed-Black, African, Caribbean, British, Any Other Background)
4. **Have you, or someone you have been a carer for, experienced restrictive practices in mental health services?**
5. **What was your referral route into mental health services?**
6. **How long have you accessed Early Intervention Services?**
7. **Have you valued anything from accessing Early Intervention Services?**
8. **Do you have any previous experience of or involvement in projects that aimed to address racial inequalities?** If yes, what was the name and duration of the project(s)?
9. **Do you have any previous experience of or involvement in projects that aimed to improve how Black people have accessed mental health services?** If yes, what was the name and duration of the project(s)?
10. **Were you invited to participate in 'The Dangers of a Single Story' project?**
11. **Did you accept or decline the invitation to participate in 'The Dangers of a Single Story' project?**

Appendix G: HRA Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Dr Miriam Fornells-Ambrojo
1-19 Torrington Place
University College London
London
WC1E 7HBN/A

12 June 2023

Dear Dr Fornells-Ambrojo

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

Study title:	**Addressing Inequalities in the Care of Black People with Psychosis: Sharing Testimonials. Exploring the perspectives of Black Experts by Experience who co-produced a staff intervention addressing racial inequalities in mental healthcare for Black people with psychosis.**
IRAS project ID:	**325675**
REC reference:	**23/IEC08/0016**
Sponsor	**UCLH/UCL Joint Research Office**

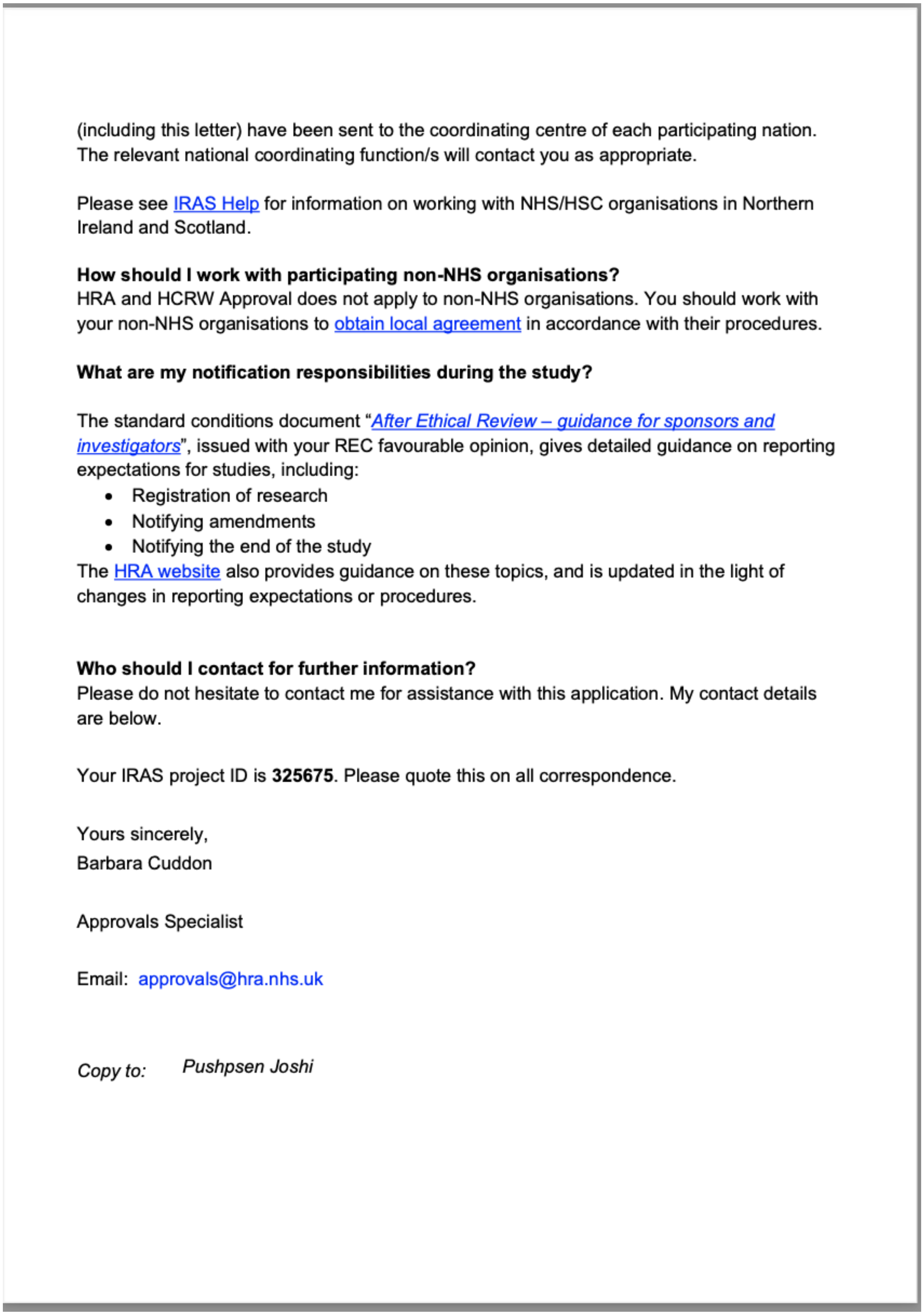
I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further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

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report



(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

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

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

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

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

Your IRAS project ID is **325675**. Please quote this on all correspondence.

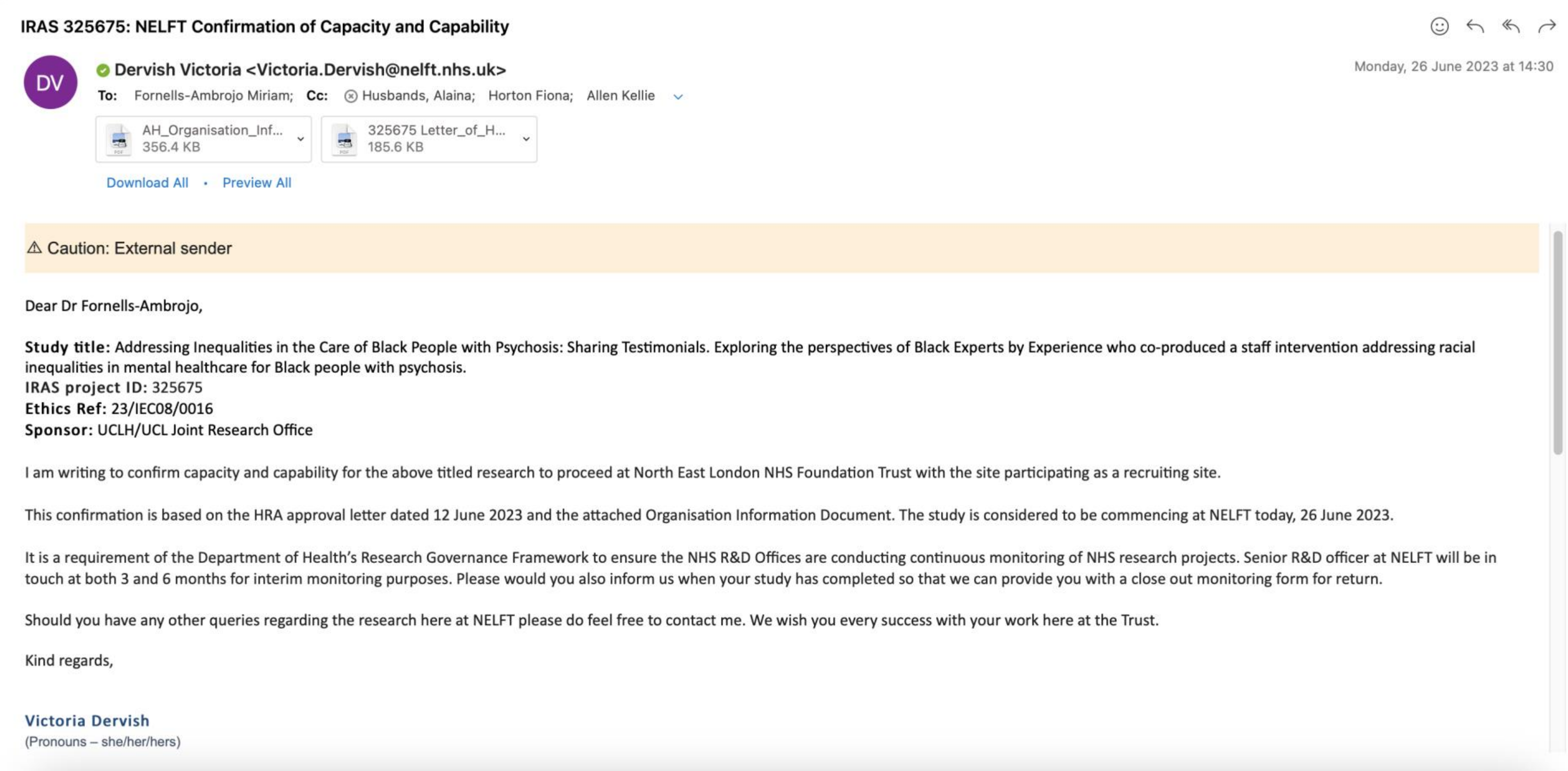
Yours sincerely,
Barbara Cuddon

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Pushpsen Joshi*

Appendix H: NELFT R&D Approval



IRAS 325675: NELFT Confirmation of Capacity and Capability

Dervish Victoria <Victoria.Dervish@nelft.nhs.uk>

Monday, 26 June 2023 at 14:30

To: Fornells-Ambrojo Miriam; **Cc:** Husbands, Alaina; Horton Fiona; Allen Kellie

⚠ Caution: External sender

Dear Dr Fornells-Ambrojo,

Study title: Addressing Inequalities in the Care of Black People with Psychosis: Sharing Testimonials. Exploring the perspectives of Black Experts by Experience who co-produced a staff intervention addressing racial inequalities in mental healthcare for Black people with psychosis.
IRAS project ID: 325675
Ethics Ref: 23/IEC08/0016
Sponsor: UCLH/UCL Joint Research Office

I am writing to confirm capacity and capability for the above titled research to proceed at North East London NHS Foundation Trust with the site participating as a recruiting site.

This confirmation is based on the HRA approval letter dated 12 June 2023 and the attached Organisation Information Document. The study is considered to be commencing at NELFT today, 26 June 2023.

It is a requirement of the Department of Health's Research Governance Framework to ensure the NHS R&D Offices are conducting continuous monitoring of NHS research projects. Senior R&D officer at NELFT will be in touch at both 3 and 6 months for interim monitoring purposes. Please would you also inform us when your study has completed so that we can provide you with a close out monitoring form for return.

Should you have any other queries regarding the research here at NELFT please do feel free to contact me. We wish you every success with your work here at the Trust.

Kind regards,

Victoria Dervish
(Pronouns – she/her/hers)

Appendix I: Debrief Sheet

Study title: Exploring the perspectives of Black Experts-by-Experience on a co-production project addressing racial inequalities in Early Intervention for Psychosis Services

Debrief sheet

Thank you for taking part in this study. This document explains why we set up the study and what we hope to achieve from the data that we collect during the interviews.

If you know of anyone that will be participating in this study, we request that you not discuss it with them until after they have had the opportunity to participate. Prior knowledge of questions asked during the study can invalidate the results. We greatly appreciate your cooperation.

Study rationale

Following wider government policies, NHS trusts in England have been developing strategies for addressing well-known health inequalities in care for Black service-users.

In mental health services, including Early Intervention in Psychosis (EIP) services, there are some examples of the way that teams and staff engage with initiatives to promote equal care for Black service-users including (but are not limited to):

- *Taking part in team discussions about improving Black service-users experience of care*
- *Considering cultural factors/needs in everyday clinical practice*
- *Participating in 'Equality, Diversity & Inclusion' projects*
- *Engaging with relevant training (e.g., cultural competency) or educational resources*

Little research has directly included Black service-users in co-developing these initiatives and/or being involved in the execution of initiatives. Therefore, little research has looked at what would help or hinder service-users and carers to take on this type of work, and the impact that this has on them.

Therefore, this study aimed to:

- Gain insight into Black service-users views and experiences of co-developing a project about addressing inequalities, specifically the experiences of being invited to the study, experiences as a co-producer, and recommendations for co-production in future projects
- Understand what facilitators and/or barriers exist for service-users in being involved with type of work
- Explore how this type of work impacts on service-users and carers personally

We hope that this will inform recommendations for services to meaningfully engage in efforts to improve equality in care.

Contact details

If you would like further information or have any questions or concerns regarding this study, please feel free to contact the researcher or Chief Investigator:

Researcher Name: Alaina Husbands

Email: alaina.husbands.20@ucl.ac.uk

Tel: **STUDY MOBILE ADD HERE**)

Chief Investigator Name: Dr Miriam Fornells-Ambrojo

Email: miriam.fornells-ambrojo@ucl.ac.uk

What if you have been adversely affected by taking part?

The research was not designed to cause distress and reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation, or its after-effects, may have been distressing or challenging in some way. If you have been affected in anyway, you may find the following resources/ services to be helpful in terms of obtaining support and information:

- The Samaritans: 116 123. A free 24/7 helpline for anybody experiencing distress.
- Support line for NHS staff: 0800 06 96 222 (7am to 11pm, 7 days a week).
- Shout Text service: NHS and other health and social care staff can text 'frontline' to 85258 for support.
- Project5: provides NHS staff free access to support sessions via an online booking system: www.project5.org.
- Black Minds Matter UK – a charity supporting Black people to access mental health care services. www.blackmindsmatter.com
- The Black, African and Asian Therapy Network – a network offering resources relating to wellbeing and mental health. www.baatn.org.uk
- You can access mental health and wellbeing apps such as Headspace, Unmind, Sleepio, Daylight and Liberate for free.
- Your General Practitioner (GP) can signpost you to additional services if you experience emotional distress.

Debrief relaxation exercise options.

1. Mindful Breathing Exercise

During this breathing meditation, you will focus on your breath. This will calm your mind and relax your body. There is no right or wrong way to meditate. Whatever you experience during this breathing meditation is right for you. Don't try to make anything happen, just observe.
Begin by finding a comfortable position, but one in which you will not fall asleep. Sitting on the floor with your legs crossed is a good position to try.
Close your eyes or focus on one spot in the room.
Roll your shoulders slowly forward and then slowly back.
Lean your head from side to side, lowering your left ear toward your left shoulder, and then your right ear toward your right shoulder.
Relax your muscles.
Your body will continue to relax as you meditate.
Observe your breathing. Notice how your breath flows in and out. Make no effort to change your breathing in any way, simply notice how your body breathes. Your body knows how much air it needs.
Sit quietly, seeing in your mind's eye your breath flowing gently in and out of your body.
When your attention wanders, as it will, just focus back again on your breathing. Notice any stray thoughts, but don't dwell on them. Simply let the thoughts pass.

See how your breath continues to flow...deeply... calmly.
Notice the stages of a complete breath... from the in breath... to the pause that follows... the exhale... and the pause before taking another breath...
See the slight breaks between each breath.
Feel the air entering through your nose...picture the breath flowing through the cavities in your sinuses and then down to your lungs...
As thoughts intrude, allow them to pass, and return your attention to your breathing.
(Pause)
See the air inside your body after you inhale, filling your body gently.
Notice how the space inside your lungs becomes smaller after you exhale and the air leaves your body.
Feel your chest and stomach gently rise and fall with each breath.
Now as you inhale, count silently... one
As you exhale, count...one
Wait for the next breath, and count again... one
Exhale...one Inhale...one Exhale...one
Continue to count each inhalation and exhalation as "one."
(Pause)
Notice now how your body feels.
See how calm and gentle your breathing is, and how relaxed your body feels.
Now it is time to gently reawaken your body and mind.
Keeping your eyes closed, notice the sounds around you. Feel the floor beneath you. Feel your clothes against your body.
Wiggle your fingers and toes. Shrug your shoulders.
Open your eyes, and remain sitting for a few moments longer.
Straighten out your legs, and stretch your arms and legs gently.
Sit for a few moments more, enjoying how relaxed you feel, and experiencing your body reawaken and your mind returning to its usual level of alertness.
Slowly return to a standing position, and continue with the rest of your day, feeling re-energized.

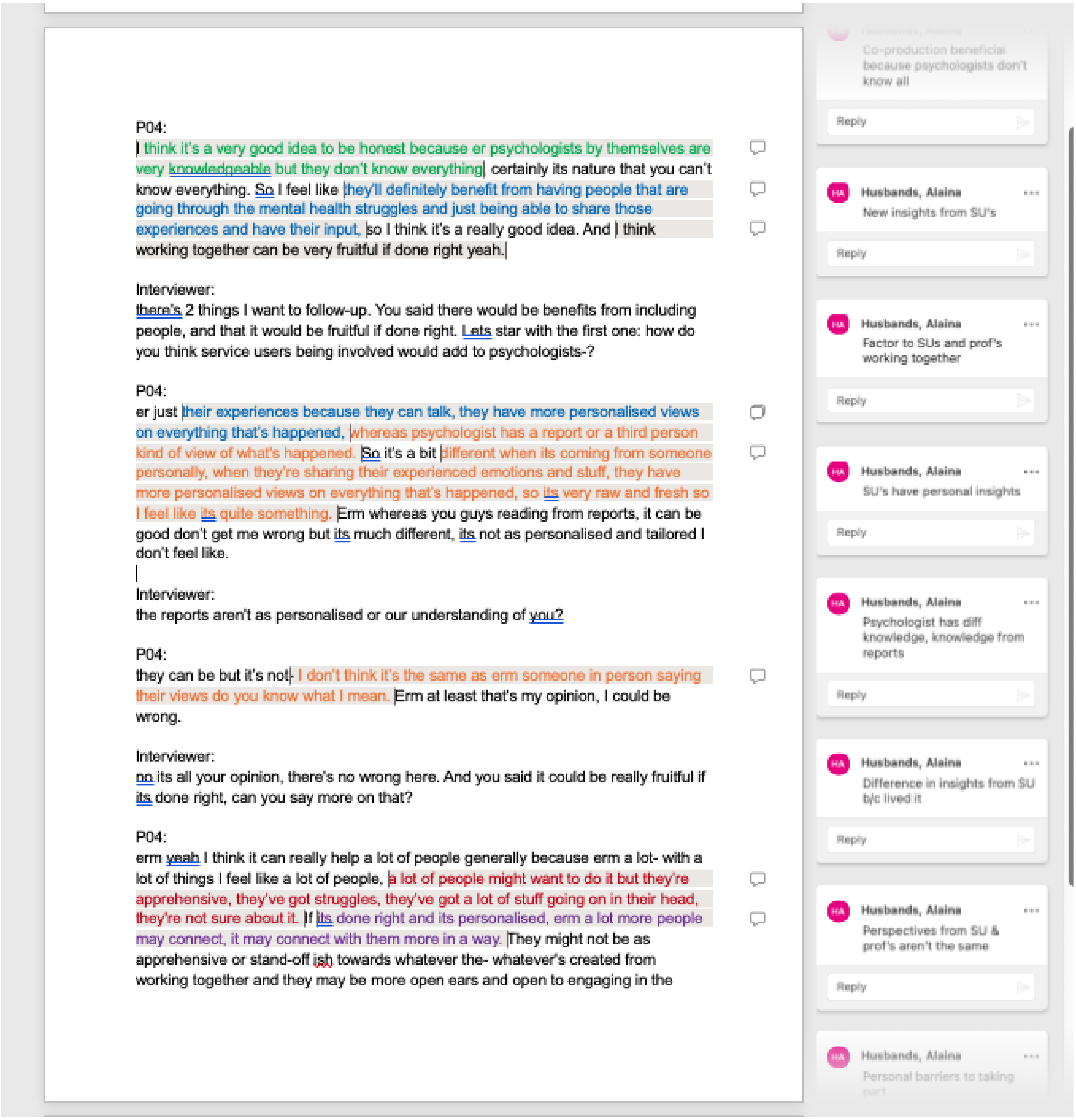
2. **Mindful Progressive Muscle Relaxation Exercise**

Progressive muscle relaxation is an exercise that relaxes your mind and body by progressively tensing and relaxation muscle groups throughout your entire body. You will tense each muscle group vigorously, but without straining, and then suddenly release the tension and feel the muscle relax. You will tense each muscle for about 5 seconds. If you have any pain or discomfort at any of the targeted muscle groups feel free to omit that step. Throughout this exercise you may visualize the muscles tensing and a wave of relaxation flowing over them as you release that tension. It is important that you keep breathing throughout the exercise. Now let's begin. Begin by finding a comfortable position either sitting or lying down in a location where you will not be interrupted. Allow your attention to focus only on your body. If you begin to notice your mind wandering, bring it back to the muscle you are working on. Take a deep breath through your abdomen, hold for a few second, and exhale slowly. Again, as you breathe notice your stomach rising and your lungs filling with air. As you exhale, imagine the tension in your body being released and flowing out of your body. And again inhale…..and exhale. Feel your body already relaxing. As you go through each step, remember to keep breathing . Now let's begin. Tighten the muscles in your forehead by raising your eyebrows as high as you can. Hold for about five seconds. And abruptly release feeling that tension fall away. Pause for about 10 seconds. Now smile widely, feeling your mouth and cheeks tense. Hold for about 5 seconds, and release, appreciating the softness in your face. Pause for about 10 seconds. Next, tighten your eye muscles by squinting your eyelids tightly shut. Hold for about 5 seconds, and release. Pause for about 10 seconds.

Gently pull your head back as if to look at the ceiling. Hold for about 5 seconds, and release, feeling the tension melting away. Pause for about 10 seconds. Now feel the weight of your relaxed head and neck sink. Breath in…and out. In…and out. Let go of all the stress In…and out. Now, tightly, but without straining, clench your fists and hold this position until I say stop. Hold for about 5 seconds, and release. Pause for about 10 seconds. Now, flex your biceps. Feel that buildup of tension. You may even visualize that muscle tightening. Hold for about 5 seconds, and release, enjoying that feeling of limpness. Breath in...and out. Now tighten your triceps by extending your arms out and locking your elbows. Hold for about 5 seconds, and release. Pause for about 10 seconds. Now lift your shoulders up as if they could touch your ears. Hold for about 5 seconds, and quickly release, feeling their heaviness. Pause for about 10 seconds. Tense your upper back by pulling your shoulders back trying to make your shoulder blades touch. Hold for about 5 seconds, and release. Pause for about 10 seconds. Tighten your chest by taking a deep breath in, hold for about 5 seconds, and exhale, blowing out all the tension.

Now tighten the muscles in your stomach by sucking in. Hold for about 5 seconds, and release. Pause for about 10 seconds. Gently arch your lower back. Hold for about 5 seconds, relax. Pause for about 10 seconds. Feel the limpness in your upper body letting go of the tension and stress, hold for about 5 seconds, and relax. Tighten your buttocks. Hold for about 5 seconds…, release, imagine your hips falling loose. Pause for about 10 seconds. Tighten your thighs by pressing your knees together, as if you were holding a penny between them. Hold for about 5 seconds…and release. Pause for about 10 seconds. Now flex your feet, pulling your toes towards you and feeling the tension in your calves. Hold for about 5 seconds, and relax, feel the weight of your legs sinking down. Pause for about 10 seconds. Curl your toes under tensing your feet. Hold for about 5 seconds, release. Pause for about 10 seconds. Now imagine a wave of relaxation slowly spreading through your body beginning at your head and going all the way down to your feet. Feel the weight of your relaxed body. Breathe in…and out…in…out….in…out.

Appendix J: Example of generating codes (step 2)



P04:
I think it's a very good idea to be honest because er psychologists by themselves are very knowledgeable but they don't know everything certainly its nature that you can't know everything. So I feel like they'll definitely benefit from having people that are going through the mental health struggles and just being able to share those experiences and have their input, so I think it's a really good idea. And I think working together can be very fruitful if done right yeah.

Interviewer:
there's 2 things I want to follow-up. You said there would be benefits from including people, and that it would be fruitful if done right. Lets star with the first one: how do you think service users being involved would add to psychologists-?

P04:
er just their experiences because they can talk, they have more personalised views on everything that's happened, whereas psychologist has a report or a third person kind of view of what's happened. So it's a bit different when its coming from someone personally, when they're sharing their experienced emotions and stuff, they have more personalised views on everything that's happened, so its very raw and fresh so I feel like its quite something. Erm whereas you guys reading from reports, it can be good don't get me wrong but its much different, its not as personalised and tailored I don't feel like.

Interviewer:
the reports aren't as personalised or our understanding of you?

P04:
they can be but it's not- I don't think it's the same as erm someone in person saying their views do you know what I mean. Erm at least that's my opinion, I could be wrong.

Interviewer:
no its all your opinion, there's no wrong here. And you said it could be really fruitful if its done right, can you say more on that?

P04:
erm yeah I think it can really help a lot of people generally because erm a lot- with a lot of things I feel like a lot of people, a lot of people might want to do it but they're apprehensive, they've got struggles, they've got a lot of stuff going on in their head, they're not sure about it. If its done right and its personalised, erm a lot more people may connect, it may connect with them more in a way. They might not be as apprehensive or stand-off ish towards whatever the- whatever's created from working together and they may be more open ears and open to engaging in the

Husbands, Alaina
Co-production beneficial because psychologists don't know all

Husbands, Alaina
New insights from SU's

Husbands, Alaina
Factor to SUs and prof's working together

Husbands, Alaina
SU's have personal insights

Husbands, Alaina
Psychologist has diff knowledge, knowledge from reports

Husbands, Alaina
Difference in insights from SU b/c lived it

Husbands, Alaina
Perspectives from SU & prof's aren't the same

Husbands, Alaina
Personal barriers to taking part

Appendix K: Example of visual maps to create themes (step 4)

Data Analysis

1. **Perspectives about Co-P**

Cluster 1	Cluster 2	Cluster 3	Cluster 4	Cluster 5
Hopes things change from co-production Hopes for race equality from co-production Hopes of showcasing treatment, care of Black people & improving this Black people treated differently in England, NHS Black people are put into categories Hopes HCPs taken something away from Co-P	Hopes financial	Invitation said yes as about Black people Invitation said yes to be around like minded, Ebes in similar position, not lonely Invitation said yes to be in group with similar problems, situations Not taken part but would want to say yes to help people Said yes to invitation to help people Support got something from reflecting & learning from others	Invitation said yes as beneficial for their own and others mental health Not taken part but would say yes as aligns with values Not taken part but yes to bettering self Said yes to invitation to learn	Barrier to Co-P may be apprehension, personal struggles, things going on in their head Accepting invitation impacted by recovery & feeling well enough Contributing difficulty medication side effects

2. Engagement & inviting to Co-P

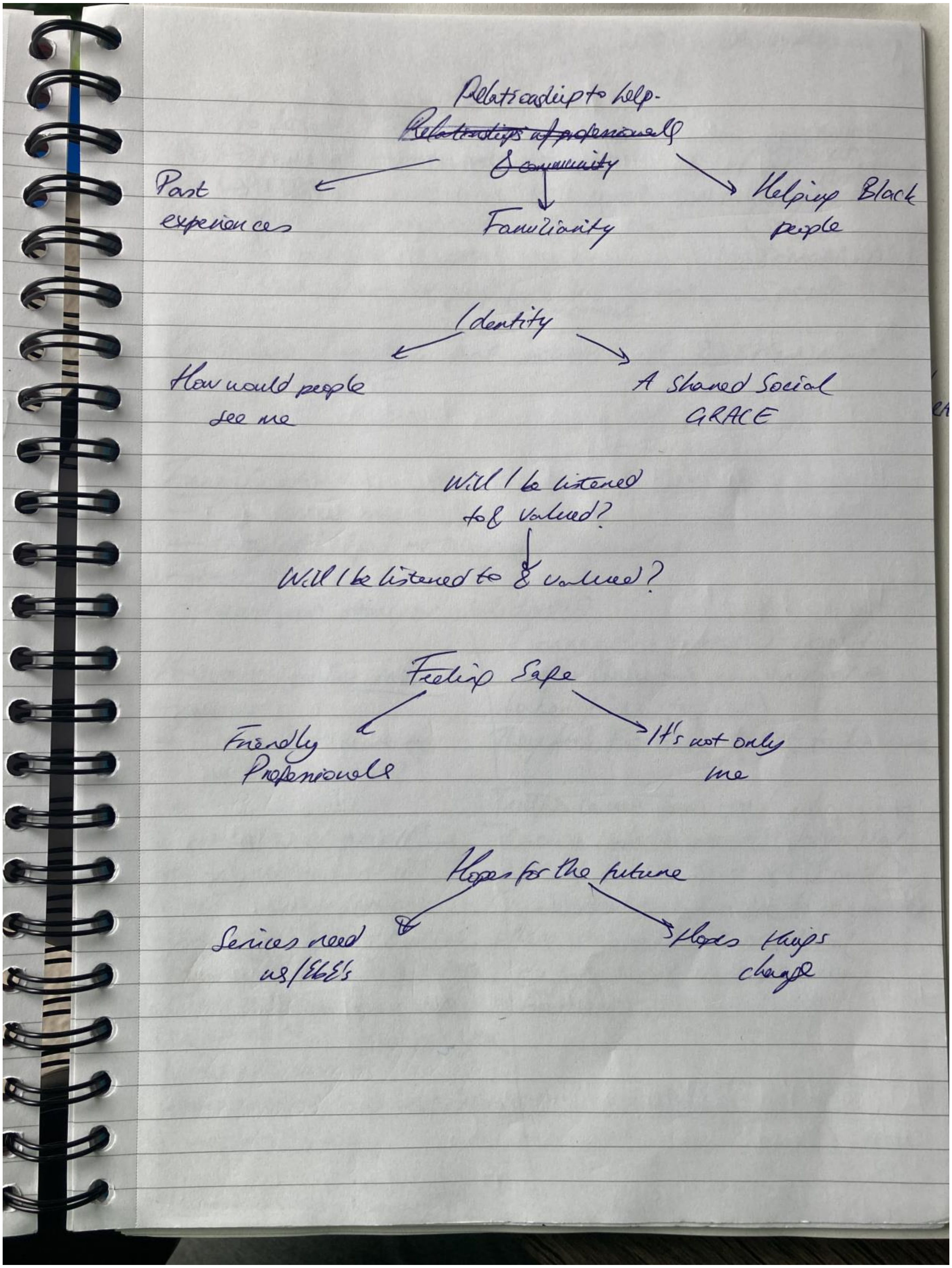
Cluster 1	Cluster 2: history > existing relationships?	Cluster 3: history > previous relationships?	Cluster 4	Cluster 5
Contributing_safe & comfortable to talk in workshop Contributing_want to feel like talking to a friend Recs for engagement_feeling valued and comfortable Contributing_depends on psychological safety to be honest	Conversation with family impacted answer to invitation Great r'ship with Care Co Introduction given about project from psychologist Invitation from Care Co Invitation from psychologist Invitation made sense as already r'ship w psychologist Invitation recs_invited by someone whose had difficulties Recs for engagement_personal r'ship fro invitation	Difficulty saying yes to Co-P may be past NHS experiences Barrier_EbEs may feel obligation to say certain thing, not be honest Barrier_pressure and daunting working with HCPs Concerns about NHS impacted answer to invitation Previous experiences of MH services Trust (inc lack of) in NHS	Said yes to invitation but barrier being judged Contributing difficulty_will anyone listen to what I'm saying Accepting invitation is abuot type of work and mutual_equal Not interested in invitation because views didnt matter	Recs_accessibility Recs_invitation written down and talked about

3. Impact of involvement in Co-P

Cluster 1	Cluster 2: benefit of difference?	Cluster 3	Cluster 4: credibility?	Cluster 5
Impact_feel capable of doing more things Impact_on the person ie on mental health and feeling stronger Impact_social impact of doig more things with life & being better version of self Co-production helps you Hopes_improving abilities and being best version of myself Impact_for self ie others are going through it too Co-P beneficial as can learn from MH experiences	Impact_wide range of HCP ethnicities Co-P beneficial because psycholgists dont know everything Co-P beneficial with mixture of EbE experiences Co-P beneficial_could help EbEs and staff from hearing MH stories Co-P beneficial_jointly EbEs experience & HCPs can gather it together	Experience_best part was hearing EbE's experiences & being with EbE's Experience_EbE's were really good people Experience_uplifting, talk honestly, not taxing Impact_learnt about MH which helps others MH Impact_learnt from others	Co-P beneficial_need to hear from someone whose been inside Co-P beneficial_with credible people Co-P beneficial as can resonate with other patients	Co-P brings personalised stories which brings connection which brings more engagement

Engagement

Being heard			Relating		
Will I be heard?	I haven't been heard	Will I feel safe/comfortable enough?	To Others OR familiarity	With information OR modes of relating	To self?
Said yes to invitation but barrier being judged Contributing difficulty will anyone listen to what I'm saying Accepting invitation is abuot type of work and mutual equal Not interested in invitation because views didnt matter	Difficulty saying yes to Co-P may be past NHS experiences Concerns about NHS impacted answer to invitation Previous experiences of MH services Trust (inc lack of) in NHS	Contributing safe & comfortable to talk in workshop Barrier pressure and daunting working with HCPs Barrier EbEs may feel obligation to say certain thing, not be honest Contributing depends on psychological safety to be honest ~~Recs for engagement feeling valued and comfortable~~ HCP ethnicity?? EbE ethnicity??	Conversation with family impacted answer to invitation Great r'ship with Care Co Introduction given about project from psychologist Invitation from Care Co Invitation from psychologist Invitation made sense as already r'ship w psychologist Recs for engagement personal r'ship fro invitation	Recs accessibility Recs invitation written down and talked about	



Relationship to help.
~~Relationships of professionals & community~~

Past experiences

Familiarity

Helping Black people

Identity

How would people see me

A Shared Social GRACE

Will I be listened to & valued?

Will I be listened to & valued?

Feeling Safe

Friendly Professionals

It's not only me

Hopes for the future

Services need us/EbE's

Hopes things change