

Ethnic Inequalities in Healthcare: A Rapid **Evidence** Review

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Foreword

The NHS Race and Health
Observatory is, first and foremost,
a health research body. We exist
to ensure that the best possible
evidence is available to support
the NHS to tackle ethnic health
inequity. But when we speak about
what we do, we're sometimes met
with a challenge: that we already
know what the problem is, that more
reports and research won't help, and
that what we need now is action.

In many ways I agree with this challenge. There has long been evidence of the stark health inequalities faced by ethnic minority communities in this country. But we must also accept that existing evidence hasn't led to significant change. This is why the Observatory exists. Not just to produce more evidence, but to synthesise what already exists, translate it into actionable policy recommendations, and challenge leaders to act. By drawing together the evidence, and plugging the gaps where we find them, we intend to make clear the overwhelming case for radical action on race inequity in our health service. Put another way, we exist to remove excuses.

This report represents a foundational step in our development. Early on, we spoke to our stakeholders to determine our priorities. There are many areas that require attention, but some rose above the others – mental health, maternal and neonatal health, digital inclusion, genomics and precision medicine, the health and care workforce. But perhaps more importantly than these individual priorities was the need for the Observatory to engage with the forces that create and reinforce these inequalities in the first place, including structural, institutional and interpersonal racism.

This report is the first of its kind to analyse the overwhelming evidence of ethnic health inequality through the lens of racism. A process that, until recently, our leaders have shied away from. I believe, however, that we are living through a time of change, where racism and racial inequality are on the agenda like never before for leaders in our health service. This report should be a tool for them; highlighting the best quality evidence across our priority areas, and making concrete recommendations for change.

There is no excuse for inaction.

Dr Habib Naqvi

Director, NHS Race and Health Observatory

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Our approach to language

Language has power, and the terminology we use when talking about race and ethnicity can have real world policy impact. At the Observatory, we are guided by five principles when talking and writing about race and ethnicity:

- We will always be specific where possible about the ethnic groups we are referring to, only using collective terminology where there is a legitimate need to do so.
- We will not use acronyms or initialisms such as BME or BAME.
- Where collective terminology is needed, we will always be guided by context, and will not adopt a blanket term. In the event that the context is not decisive, we will use collective terms such as 'Black and minority ethnic', 'ethnic minority', 'Black, Asian and minority ethnic' interchangeably. This is to reflect the fact that no one term is suitable to all of our stakeholders and to respect individual and community dignity.

- We will always be transparent about our approach to language.
- We will always be adaptable and remain open to changing our approach to language in the future.

Although this will always be our approach in our own writing, some of our research is commissioned and may directly quote pre-existing research that uses terms we otherwise would not use.

These principles were arrived at following a stakeholder consultation process carried out in Summer 2021. To find out more about it, visit our website at

nhsrho.org/publications

Executive Summary

This report presents the findings and recommendations of a rapid review of ethnic inequalities in healthcare and within the NHS workforce, conducted by academics at The University of Manchester, The University of Sheffield and The University of Sussex.

Ethnic inequalities in access to, experiences of, and outcomes of healthcare are longstanding problems in the NHS, and are rooted in experiences of structural, institutional and interpersonal racism. For too many years, the health of ethnic minority people has been negatively impacted by: lack of appropriate treatment for health problems by the NHS; poor quality or discriminatory treatment from healthcare staff; a lack of high quality ethnic monitoring data recorded in NHS systems; lack of appropriate interpreting services for people who do not speak English confidently and delays in, or avoidance of, seeking help for health problems due to fear of racist treatment from NHS healthcare professionals.

The rapid review focussed on priorities set by the NHS Race and Health Observatory (RHO), relating to ethnic inequalities in:

- access to, experiences of, and outcomes of, mental healthcare;
- access to, experiences of, and outcomes of, maternal and neonatal healthcare;
- digital access to healthcare;
- genetic testing and genomic medicine;
- the NHS workforce.

We searched UK academic and grey literature from 1st January 2011 to 25th October 2021. In total, we screened 13,161 references (titles and abstracts), identifying 178 studies included in our review. We also conducted a stakeholder engagement survey with academics and clinicians (with expertise across the areas of focus) and discussion groups with people working with ethnic minority people in the community (the latter were facilitated by the Race Equality Foundation and The Ubele Initiative). We found that ethnic inequalities were evident in each of the areas reviewed, but found variation in both the quality of evidence and the ethnic minority groups represented in research studies. There were also differences between ethnic minority groups suggesting that some groups have particularly poor access, experiences and outcomes. Findings and recommendations are summarised by topic area.

Ethnic Inequalities in Mental Health Services



Main Findings

The review found evidence to suggest clear barriers to seeking help for mental health problems rooted in a distrust of both primary care and mental health care providers, as well as a fear of being discriminated against in healthcare. The review found this to be the case for many ethnic minority groups but with less evidence about the experiences of Roma, Gypsy and Irish Traveller and Chinese groups, although evidence from our stakeholder engagement groups suggests that these groups may also be reluctant to seek help from services that they do not trust. Evidence from qualitative research suggests that the lack of appropriate interpreting services acted as a deterrent to seeking help.

Ethnic minority groups experienced clear inequalities in access to Improving Access to Psychological Therapies (IAPT); overall, ethnic minority groups were less likely to refer themselves to IAPT and less likely to be referred by their GPs, compared with White British people. Evidence was identified for inequalities in the receipt of cognitive behavioural therapy (CBT) with ethnic minority people with psychosis less likely to be referred for CBT, and less likely to attend as many sessions as their White counterparts. The evidence on ethnic differences in community services was less clear-cut, with some evidence to suggest differences in services such as Assertive Outreach and the use of crisis teams but no evidence for ethnic differences in engagement with home treatment teams. The review provided strong evidence of clear, very large and persisting ethnic inequalities in compulsory admission to psychiatric wards, particularly affecting Black groups, but also Mixed Black & White groups and South Asian groups. There was also evidence of harsher treatment for Black groups in inpatients wards, e.g., more likely to be restrained in the prone position or put into seclusion.

Evidence from the review affirms that some inequalities present for adult populations were replicated in younger populations. Parents reported their children facing the same barriers to accessing services as reported for adult mental health services. Two studies of young Black men showed that they were deterred from seeking help by their knowledge of injustices in mental health services relating to Black Caribbean and Black African populations. Two large national studies found that ethnic minority children were more likely to be referred to CAMHS via social services, education or criminal justice pathways. This was particularly stark for Black children who were 10 times more likely to be referred to CAMHS via social services (rather than through the GP) relative to White British children.

Overall, the review found few national datasets with sufficiently high quality ethnic monitoring data to allow for robust analysis to investigate ethnic inequalities. Many recent reports from NHS Digital (on IAPT, for example) did not report differences in referral rates by ethnic group. National community survey datasets to allow population level analysis were also lacking. Similarly, many of the studies in this review that used clinical data focused on South London (particularly South London and Maudsley NHS Trust) where the linkage of data from clinical systems is more advanced.



Recommendations for Research

- Conduct primary research on the direct and indirect impacts of racial discrimination by NHS staff and institutional processes on access to, experiences of, and outcomes of mental health services.
- Establish repeated cross-sectional national community survey datasets
 of psychiatric morbidity and service use to provide high quality national
 data on the ethnic minority people's attitudes to, and experiences of, using
 mental health services.
- Conduct a process and outcome review of interventions to address ethnic
 inequalities in both the NHS and VCSE organisations to establish 'what
 works', why and for whom. This should extend beyond simply reviewing
 studies that test the effectiveness of 'culturally appropriate/adapted therapy
 interventions' (where there is already a review) to consider systemic
 changes across levels of psychiatric care.



Recommendations for Practice & Policy

- Enforce statutory guidelines on inclusion of national ethnic monitoring data in all NHS mental health clinical data that allows robust statistical Trust-level, regional and national analysis (including data linkage between clinical datasets) to establish where the inequalities are, and for which ethnic groups. This recommendation will require a dedicated drive by NHS England and NHS Digital to emphasise the importance of collecting and reporting these data, as well as providing the infrastructure to collect, analyse and interpret them. An online learning module on recording ethnicity data on the Health Education England, or equivalent, website should be made accessible to all NHS staff, to ensure staff are trained in routine collection of ethnicity data.
- Establish relationships between ethnic minority VCSE organisations and NHS provider services in order to provide the high quality services for ethnic minority patients. NHS England and NHS Trusts need to work with partners across public service, the voluntary sector and community organisations in order to demonstrate commitment to tackling racial inequality in mental health services.

Ethnic Inequalities in Maternal and Neonatal Healthcare



Main Findings

The review suggested the central importance of women's relationships with care-providers, particularly midwives and heath visitors, during pregnancy and beyond. And, while some positive relationships, particularly with some midwives, are documented, the evidence suggests that this is far from the norm. Poor communication between women and providers was a prevalent theme. For women without English language skills, the lack of accessible and high quality interpreting services seems to be a common issue. But communication can also be compromised for British-born ethnic minority women, and migrant women who can speak English. A lack of trust, insensitive behaviour, lack of active listening by providers, and failure to bridge cultural differences, can also impact negatively on communication for these women.

A consistent theme was women's experiences of negative interactions, stereotyping, disrespect, discrimination and cultural insensitivity. System-level factors, as well as the attitudes, knowledge and behaviours of healthcare staff, contribute to some ethnic minority women feeling 'othered', unwelcome, and poorly cared-for. These factors appear to undermine trust and feed fear, which in turn are described as resulting in poorer access to, and engagement with, services. Immigrant women may face particular issues in navigating unfamiliar services and accommodating NHS healthcare information and practices alongside their own and their families' ideas of what is appropriate.

Quantitative data on ethnic inequalities in access to, and receipt of, particular NHS services or treatments, such as timely antenatal booking appointments, Caesarean delivery, or breastfeeding support, is patchy and inconsistent. Qualitative studies reported that ethnic minority women feel underserved by community-based services that could offer support to pregnant women and new parents. Studies highlighted the intersection of additional aspects of social disadvantage with minoritised ethnic identities that can further compromise women's access to, and positive experiences of, maternity care. Groups of women of particular concern include Roma, Gypsy and Traveller women, those seeking asylum or with recent refugee status, those with mental health conditions, and teenage women and young mothers.

We only identified one study that focused on ethnic inequalities in specific aspects of care of the newborn. This study showed that Asian babies were overrepresented in admissions to neonatal units for jaundice.



Recommendations for Research

- Sophisticated quantitative analyses are needed in order to describe and understand patterns of maternity care and outcomes across a wider range of ethnic groups, as well as intersectional inequalities and spatial and temporal trends. Research is particularly needed to identify inequalities in care that contribute to differential perinatal and infant outcomes by ethnicity.
- Complementary research that engages closely with women and families
 to foreground their perspectives and experiences, especially for those in
 very vulnerable circumstances, is also needed. Stakeholders called for coproduced research to develop interventions and make services appropriate
 to the needs and priorities of under-served groups.
- Mixed method and theory-informed research is needed to completely understand the ways in which healthcare providers and patients develop their understandings of one another and how positive relationships between healthcare providers and ethnic minority women can be achieved consistently. There is a need to interrogate the complexity of racialisation processes and how these are inflected by other markers of social status and difference alongside ethnicity. This work should include attention to understanding the institutional and system-level factors structures, procedures and cultures that undermine good quality care and how these can be recognised, resisted and transformed.



Recommendations for Practice & Policy

- Data linkage is required across routine NHS maternity and neonatal datasets
 to allow analyses of patient journeys and outcomes, across mothers and
 their babies, and across service areas. Work is needed to ensure recording
 of ethnicity is complete and accurate. There is also a need to develop
 systems for the routine collection of data relating to key mechanisms and
 exposures, particularly experiences of racism and discrimination.
- Renewed and serious efforts are needed to ensure ready access to high quality interpreting services and translated and audio format health promotion materials.
- There needs to be a serious commitment from NHS England and NHS
 Improvement to tackle racist attitudes and behaviours among healthcare
 staff, and address structural dimensions of NHS systems that discriminate
 against ethnic minority women and their babies.

Ethnic Inequalities in Digital Inclusion and Access to Health Services



Main Findings

There were very few documented ethnic differences in attitudes towards using digital health apps; ethnic minority and White participants were generally equally comfortable using these apps, but with some evidence that ethnic minority participants might use apps less frequently. The studies indicated how this may, to some extent, be borne out of mistrust of intended uses of data by government agencies. There was also evidence to suggest particular issues affecting older ethnic minority people due to a lack of access to digital devices, a lack of digital literacy or due to digital applications not being made available in languages other than English. There were some ethnic differences in the use of NHS telephone services with lower use of NHS Direct services by most ethnic minority groups compared to the White British group. There was evidence of ethnic inequality in referral to urgent and emergency care services by NHS Direct for Bangladeshi people, particularly for those living in deprived areas, but there were no inequalities found for other ethnic minority groups. There was also evidence to suggest that, compared with their White counterparts, ethnic minority people were less satisfied with telephone triage systems in GP surgeries, were less likely to use online services for STI testing and were less likely to have used electronic health records to check their diabetes results.



Recommendations for Research

- A systematic review of ethnic inequalities in access to, experiences of, and outcomes of digital healthcare (using a broad definition to include remote and digital appointments, the use of healthcare apps) is required to ascertain the extent of evidence in the field. The recommended review could be extended to cover the rollout of other digital services (in the public and private sector) to obtain evidence that the NHS could incorporate.
- Research in this area should ensure that the ethnic categories employed are
 disaggregated as far as possible so that the experiences of different ethnic
 groups can be identified, as suggested by our stakeholder input. Further,
 where possible, there should be a specific breakdown of results by age, as
 our review indicated that ethnic minority older people particularly, may find
 digital healthcare inaccessible.



Recommendations for Practice & Policy

- There needs to be digital literacy support (perhaps in the form of community digital hubs) for those who struggle with basic digital access. This should be in various mediums and languages taking into account different styles of learning and understanding. For example, health services could use audio and video messages in local public places and spaces, for a targeted approach, as well as using WhatsApp video and audio messaging to communicate directly with patients. Options to receive digital devices should be offered to patients where needed.
- Undertake thorough evaluations of projects funded under the Adoption Fund by NHS X which are making use of digital technologies for patient care.
 For example, Cambridgeshire and Peterborough Integrated Care Service (ICS) are undertaking Empowering Digital Access in Maternity Services (EDAMS) to identify what the main barriers and blockers are to accessing digital services within the maternity pathway, and North West London CCG are undertaking a comprehensive review on patients receiving or needing community or mental health treatment to understand the scale of digital exclusion across North West London.
- NHS England should make mandatory equality assessments which are recommended under the Public Sector Equality Duty (PSED) for any services moving from in person to digital appointments in order to assess the extent to which ethnic minority groups would be affected by such a move.

Ethnic Inequalities in Genetic Testing and Genomic Medicine Studies



Main Findings

The review found some evidence of ethnic inequalities in attitudes towards accessing, and access to, genetic services, but some of the qualitative and quantitative studies were of low quality, and did not adequately report differences for each ethnic group represented in the studies. Most of the information on genetic services was around antenatal screening and testing. There was relatively little information on experiences of genetic counselling.

The review found that ethnic minority people are not well represented in large genomic wide association (GWA) studies, although there are smaller local studies that have much larger proportions of ethnic minority participants. Results from large survey datasets showed that older ethnic minority people were less likely to donate DNA in studies where they were already participants; but it is possible that attitudes and behaviours of younger ethnic minority people towards participation in genomic studies may differ. However, Skyers' study of

Black African and Black Caribbean people towards participation in the 100,000 Genomes Project suggests that apprehension about participation may also be present for younger Black people.

There was a lack of basic reporting of sample sizes and which data sources had been used in some GWA studies, and many GWA studies only used 'European ancestry' participants in their analysis, making it impossible to investigate the role of ethnicity. However, the review found that developing polygenic risk scores (PRS) in multiethnic cohorts may give greater predictive power within and across ethnic groups, suggesting that the expansion of research beyond European ancestry cohorts will be very valuable. The review did not identify any studies that were using precision medicine in clinical practice.



Recommendations for Research

- Research is required to understand at what points in the care and referral
 pathway in genetic testing and counselling services, ethnic inequalities
 are apparent, and what the nature of these inequalities are. Particularly,
 quantitative and qualitative research is required to understand ethnic
 minority patients' experiences of genetic counselling. Many identified
 studies were concerned with antenatal screening and testing with very little
 research evidence on ethnic inequalities in access to other genetic services
 and technologies.
- Ensure research studies of ethnic minority groups are designed to address gaps in knowledge and to inform service provision and ensure a range of ethnic minority groups are represented. This should particularly be actioned by large funders of health research such as NHS organisations, UK Research Innovation (UKRI), National Institute of Health Research (NIHR) and The Wellcome Trust. Our review found that there was a substantial proportion of studies that focussed on Pakistani populations but none that focussed on for example, Gypsy, Roma or Irish Traveller groups despite previous evidence that these groups are particularly disadvantaged in access to health care.
- Increase the ethnic diversity of genomic studies. This is imperative if these
 studies are to be used in the future for personalised or precision medicine.
 Current initiatives by Genomics England, such as the Diverse Data Initiative
 are likely to benefit from using recruitment methods designed and run in
 partnership with the voluntary, community and social enterprise (VCSE)
 sector and via community settings, many of which have already established
 trust in ethnic minority populations.
- Genomics England should develop a scientific framework within which to conduct genomic studies that includes clear reporting on samples used, and consensus descriptions of ethnic and ancestral groups.



Recommendations for Practice & Policy

For ethnic minority people who do not speak English, interpreters must be
provided at the main points at which routine genetic screening and possible
referral to genetic counselling and testing are likely to be discussed, in
particular for phone appointments, GP consultations and maternity contacts.

Ethnic Inequalities in the NHS Workforce



Main Findings

The review found evidence of ethnic inequalities across a range of professions and settings in the NHS. Two large studies showed that Covid-19 infection was higher in ethnic minority staff in the NHS, particularly for Black and Asian staff. There was also evidence to suggest that the Covid-19 pandemic has disproportionately affected ethnic minority healthcare workers' working environment, in terms of access to adequate PPE and the greater negative effect of the pandemic on ethnic minority staff mental health.

The review found evidence of NHS ethnic minority staff enduring racist abuse from other staff and patients and this was particularly stark for Black groups. Most of the qualitative studies on experiences of racist abuse in the NHS workforce have been undertaken with nurses (and particularly Black African nurses or those that have been internationally recruited), indicating a lack of research on the experiences of other ethnic minority groups working in the NHS.

The review found limited and mixed evidence on ethnic inequalities in NHS staff mental health and wellbeing. Notably, there was very limited evidence connecting the racist experiences endured by staff and their mental health, wellbeing and likelihood of burnout, and indeed other health outcomes. The studies on career progression were largely qualitative and conducted mainly with women; these studies showed how racism played out in the workplace to hamper ethnic minority staff's career progression and professional development. There was also evidence for an ethnic pay gap in most staff sectors in the NHS and which was evident for Black, Asian, Mixed and Other groups, but less so for Chinese groups.



Recommendations for Research

- Conduct a systematic review of racist experiences in the workforce to see for which specific professions and settings there is evidence of racial abuse.
- Conduct a systematic review (of global literature) of what interventions work
 to improve racial inequality in large institutions. The review should be theorydriven, using a conceptual model which centres institutional racism. Reviews
 have been completed on a smaller scale already and there are examples
 of smaller scale initiatives, but there would be considerable added value of
 bringing these together with findings from international settings.
- Research needs to investigate how experiences of institutional, structural
 and interpersonal racism impact on both the mental health and career
 outcomes of NHS ethnic minority staff. Most of the evidence in our review
 treated mental health outcomes (broadly defined) and career progression as
 separate but the two are likely to be interlinked.



Recommendations for Practice & Policy

- National datasets such as WRES need to ensure that all NHS staff
 in all sectors, including casually employed staff and those working
 in subcontracted services, are represented in order to present a
 comprehensive and accurate picture of workplace inequalities facing ethnic
 minority staff within the NHS.
- NHS England and NHS Improvement should review recruitment and staff development procedures to understand where the greatest barriers to ethnic minority staff's progression (promotion, career development, pay) lie.

Conclusions

The review found that there were widespread ethnic inequalities in the areas reviewed, although some of the evidence that was reviewed was poor quality and for some ethic minority groups there was no research conducted on their experiences. There are five major areas where NHS England, NHS Improvement and NHS Digital should take critical action to improve access, experiences and outcomes for ethnic minority groups.

- Enforce Guidelines on Ethnic
 Monitoring Data: Ensure that patients'
 ethnicity is (1) recorded and (2) recorded
 accurately (i.e., self-reported ethnicity) in
 all interactions with NHS staff. Our review
 found that research studies using clinical
 data often had substantial amounts of
 missing ethnicity data.
- Produce better NHS Statistics: NHS Digital should provide national NHS statistics on service use by ethnic group, age and gender (at a minimum) and allow for clinical data to be linked across datasets in order to improve the monitoring of clinical outcomes for ethnic minority populations and to enhance the quality of research that can be undertaken with ethnic minority populations.

- Invest in Interpreter Services: Greater resource needs to be allocated to the provision of interpreters in NHS Trusts; we found that high quality interpreters were not being provided in mental healthcare, in GP surgeries and at various points along the maternal health care pathway. Interpreter services need to be readily available for in person, telephone and digital appointments.
- groups and key VCSE organisations:
 Produce and implement a plan of work to build trust with ethnic minority groups and voluntary, community and social enterprise (VCSE) organisations that work with ethnic minority populations. Our review found that some ethnic minority people delayed or avoided help seeking for health problems due to past experiences of racist treatment by healthcare professionals or due to similar experiences of their friends and family. Improving ethnic minority people's

trust in NHS services will, subsequently,

improve health outcomes through increased access to these services.

Work to build trust with ethnic minority

• Invest in research to understand the impact of racism on healthcare:
Finally, greater investment in research understanding the mechanisms that underpin and drive ethnic inequalities in healthcare is imperative if the mechanisms and systems that give rise to ethnic inequalities are to be disrupted.

Introduction

Ethnic inequalities in health outcomes are evident at every stage throughout the life course, from birth to death. Since the introduction of the Race Relations (Amendment) Act in 2000, the reduction of inequalities has figured prominently as a priority for the Department of Health and Social Care (DHSC) and for the National Health Service (NHS). Reduction of these inequalities requires that the needs of ethnic minority groups are considered within health inequalities policies; that appropriate services are delivered to meet their needs: and that these needs are considered when planning and allocating resources. All of these actions require an understanding of the patterns and mechanisms behind ethnic inequalities in health and healthcare. Although a longstanding body of evidence has documented ethnic inequalities in health and healthcare, a concerted exercise is needed to critically synthesise and appraise that evidence, provide high level conclusions on where gaps exist in the evidence, and produce a clear set of recommendations. This report discusses findings from a rapid review of the evidence on ethnic inequalities in healthcare focusing on the topic priorities set by the NHS Race and Health Observatory (RHO), which included mental healthcare, maternal and neonatal healthcare; digital inclusion; genetic testing and genomics; and NHS workplace inequalities.

It is important to place ethnic inequalities in healthcare within a broader context that acknowledges that these outcomes are both within and beyond the healthcare system. There are growing concerns that significant ethnic inequalities in access to, and experiences of, health services are playing an important part in persistent inequalities in health outcomes. However, a fundamental cause of the ethnic inequalities we see in healthcare services and health outcomes, which is often not mentioned in research and

policy debates, is racism. The evidence on the damaging role of experiences of racism on both health and healthcare inequalities is well established¹⁻³, and acknowledging and understanding the central role of racism and racial discrimination in leading to ethnic inequalities in health and healthcare is central to redressing these inequalities. For example, with regards to mental health, the psychiatric system has been identified by academics, practitioners, patients and activists, of having institutional racism deeply embedded in its structures and processes⁴, a term that was brought into mainstream use in the UK after the McPherson inquiry into the racially motivated murder of Stephen Lawrence, a young Black man who was killed in London⁵. Despite the overwhelming research evidence of racist treatment of Black populations by the UK mental health care system, the recent White Paper on the Reform of the Mental Health Act⁶ gave only cursory attention to race inequalities, thereby neglecting a real opportunity to address the institutional racism evident in the psychiatric care system⁷. The lack of acknowledgment of racism as a key driver of healthcare inequalities faced by ethnic minority people is a dangerous omission, and without which, inequalities cannot be adequately addressed. Additionally, healthcare research must acknowledge that ethnic minority patients and ethnic minority staff working in the NHS are subject to different forms of racism which lead to inequalities. Racism can be structural, institutional or interpersonal in nature8: structural racism refers to the processes that lead to disadvantage in accessing economic, physical and social resources; institutional racism is legitimated by discriminatory policies and norms embedded in large institutions (such as the NHS), and captures a broad range of practices that perpetuate differential access to services, and opportunities within institutions⁹; interpersonal racism refers to discriminatory treatment during personal interactions, such as verbal or physical abuse

but also refers to acts of ignoring or avoiding people due their ethnic background.

Mental illness is, arguably, the health problem for which there are the most unjust and stark inequities for ethnic minority populations. In this illness context, racism (both interpersonal and institutional), socioeconomic inequalities and disadvantage over the life course, and at key junctures in life, can be observed in interplay, resulting in dire health outcomes for ethnic minority people. In the UK context, the over-use of coercive mental health treatment under the mental health act for Black Caribbean and Black African groups¹⁰ and the under-use of specialist mental health services by South Asian (Indian, Pakistani and Bangladeshi) groups¹¹ have been two of the main concerns articulated by health policy commentators, clinicians, and health researchers. The first of these concerns is perhaps the more stark, with findings from numerous studies showing both increased rates of mental illness for Black Caribbean and Black African men¹², and systematic persecution from psychiatric services and criminal justice systems, with these groups much more likely to be subjected to coercive treatments such as involuntary admission to mental health wards, Community Treatment Orders and violence from state systems¹³. Black patients in the UK are also subject to more intrusive treatments, such as injectable anti-psychotics, and are less likely to be offered talking therapy for severe mental illness14.

Maternal and neonatal health is another area where decades of evidence document ethnic inequalities in access to, and experiences of, health services. In pregnancy, many ethnic minority women are more at risk from death in childbirth; Black women are four times as likely to die in childbirth, Asian women are twice as likely to die in childbirth, and women living in the most deprived areas (where many ethnic minority people live) are three times as likely to die in childbirth¹⁵. In the UK, low birthweight, a known risk factor for poor physical, cognitive and emotional development, and chronic disease later in life, occurs more frequently in ethnic minority groups¹⁶ with Pakistani, Bangladeshi, Indian, Black Caribbean and

Black African mothers 2.5 times as likely to birth babies that are deemed to be low birthweight, compared with White mothers¹⁷.

An area of interest to RHO where evidence on ethnic inequalities in scarce is digital inclusion and access to health services. In recent years there has been a shift towards providing healthcare remotely, which has been rapidly accelerated by the Covid-19 pandemic. Despite this, there has been relatively little research on how this shift may have affected ethnic minority people's access to healthcare compared with the general population. There have been concerns that some ethnic minority people may be both less well digitally connected18 (for example, have poorer, or no, connectivity to the internet, or have a digital device with poorer quality hardware) and be less literate with digital technologies, which may impact on their ability to access online services (such as AskmyGP, video appointments, digital healthcare apps).

More recently, there have been concerns that genetic testing and counselling services are not as accessible for ethnic minority patients as they are for the White majority population in the UK¹⁹. Although we are beginning to see some national initiatives to improve access to genetic services, for example, for families practising customary consanguineous marriage, which is being led by the NHS England and NHS Improvement Maternity Transformation Programme, questions remain as to the equity of service provision in genetic testing and counselling for different health conditions. It has also been established that many large genome wide association (GWA) studies lack ethnic diversity and relatedly, this has called into question the utility and validity of conclusions that can be drawn from these datasets.²⁰⁻²² In the UK, we have seen the recent launch of the Diverse Data Initiative (September 2021), in order to address some of these concerns by increasing the representation of ethnic minority people in genomic datasets, but the existing GWA datasets from which conclusions are drawn to make plans for deploying personalised medicine, are thought not to sufficiently represent ethnic minority groups.

Workplace inequalities as experienced by ethnic minority groups among the health workforce is an important area to focus on when addressing ethnic inequalities in healthcare, as previous research has shown that the greater the proportion of ethnic minority NHS staff who report experiencing discrimination at work, the lower the levels of patient satisfaction23. Racism and discrimination towards ethnic minority NHS staff is evident in training and recruitment processes and negatively impacts on career progression and levels of pay. Among medics, ethnic minority doctors are three times less likely to secure a hospital job than White doctors²⁴ a situation that has changed little in 20 years²⁵. Inequities also exist for clinical excellence awards (performance related bonuses for consultant staff) and career progression opportunities, with evidence of substantial under-representation of ethnic minority staff in senior leadership positions^{26,27}. Rates of discrimination, bullying, and harassment are higher among ethnic minority NHS staff than among White staff, and the behaviour may be perpetrated by managers, team leaders, colleagues, or patients and relatives²⁸. In addition, employers are less aware of bullying and harassment problems experienced by minority staff than they are of incidents among White employees.

Despite the evidence presented in this introduction, questions remain around the nature and extent of ethnic health inequalities in NHS healthcare services of those experienced by NHS staff, hence the Race and Health Observatory's desire to commission this review to synthesise evidence in the key topic areas. This report is structured in seven chapters: one reporting on methods and one chapter on each of the topic areas prioritised by the Race and Health Observatory and a concluding. Each chapter begins with a concise introduction of the background of the topic area, followed by a narrative synthesis of the evidence and ending with recommendations for future research and policy. A PRISMA diagram and a table of included studies along with relevant metadata were completed for each topic area and are presented as appendices. The last chapter provides a conclusion, drawing together issues from across the five topics reviewed.

Methods

Aims and Objectives

Our objective was to conduct a rapid review of ethnic inequalities in healthcare and in the NHS workforce and to map the literature against the following priority areas of the NHS Race and Health Observatory (RHO):

- Mental healthcare considering differences in access, experience, and outcomes for service users
- Maternal and neonatal healthcare, considering differences in access, experience, and outcomes for service users
- Digital inclusion, including evidence of differences in the uptake of online appointments, consultations and other digital health applications by reference to availability, accessibility and appropriateness.
- Genomics and genetic testing, including a consideration of representation of ethnic minority groups (aggregated and disaggregated) in genome mapping, and the deployment of genomic medicine services.
- Workplace inequalities, as experienced by ethnic minority groups (both aggregated and disaggregated) among the NHS workforce.

Within this overall scope, the review also describes the various ways in which 'ethnicity' and 'race' have been used, understood and operationalised by researchers, and the consequences of these conceptualisations for interpretation of these studies. Specifically, for all of the above areas, we aimed to:

- Critically evaluate the quantity and study designs for each subset of evidence,
- Synthesise and summarise what each subset of evidence indicates,
- Develop and apply appropriate conceptual models to make sense of the evidence,
- Provide high level conclusions on where gaps exist in the evidence
- Identify clear and evidence-supported recommendations for where RHO could usefully focus its efforts.

Methodological Approach

We conducted a rapid review of studies for each topic area. A rapid review is a "brief synthesis and judgement of available research evidence related to a specific questions", which is appropriate for studies aiming to identify the trends and patterns in the relevant literature²⁹. We streamlined the review process, particularly in assessing quality at a study design level, allowing us to provide RHO with timely information to support policy making. We developed a review protocol to guide the overall review process but with the flexibility to modify specific stages to better meet RHO's needs (e.g., search strategy was adjusted to improve retrieval of literature). Unless otherwise indicated, the review process was aligned to state of the art, evidence-based methods guidance as proposed by the Cochrane Rapid Review Methods Group³⁰.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria for the rapid review are shown in Tables 2.1 and 2.2 respectively. We searched literature from the past 10 years (1st January 2011 to 25th October 2021) in order to provide conclusions and recommendations using the most up to date literature. We focussed on UK literature but there were some systematic reviews included in our review that synthesised data from a range of countries. We excluded studies that focused on health outcomes (e.g., morbidity, mortality) and we also excluded intervention studies that aimed to improve equality of health services for ethnic minority groups.

Table 2.1: Inclusion Criteria for the Rapid Review

Criteria	Details
Date	Published from 1st January 2011 to 25th October 2021
Setting	Any healthcare-related setting, such as primary, secondary or tertiary care in the four constituent countries of the UK ¹
Population	 For all topic areas, include at least one ethnic minority group (whether aggregated or disaggregated) Health service users [mental health, maternal and neonatal health, digital inclusion, and genomics and genetic testing]²; Health workforce [NHS workforce inequality];
Study type	Randomised controlled trials (RCTs), observational studies, case control studies, systematic reviews, qualitative studies, mixed-methods studies.
Publication type	Academic journal articles, reports from statutory bodies, consultation exercise reports (with staff and patients but these must include quantitative or qualitative outcome data)
Exposure	 Ethnicity (ethnic/racial groups) Ethnicity can be self-ascribed, classified based on census categorisation, reported by third party (e.g., clinicians, health administrative system), or based on place of birth, nationality, or migration status (whether aggregated or disaggregated). Outcome should be specified by ethnicity. The results should facilitate comparison by ethnicity. However, for studies containing one ethnic minority group, the results will be included in order to understand experiences for particular ethnic minority groups.
Outcomes	 Focus on service use/access/experience/outcomes [maternity and neonatal health, mental health, digital and genetic/genomic services]; Mental health was defined as emotional, psychological, and social well-being of an individual or group. Mental disorders include depression, bipolar disorder, schizophrenia and other psychoses, and other formally diagnosed mental disorders. Digital health services focus on telemedicine, healthcare smartphone/web apps, remote monitoring and consultation. Genomics and genetic services focus on the development and application of genomics advances in diagnosis, treatment of illness and predictive and preventative care. Experiences of workplace inequality in the NHS workforce (including career progression, mental health effects of racism, pay gap, racism in the workforce, Covid-19's impact on the health outcomes and workplace inequalities).
Language	English Language

Table 2.2: Exclusion Criteria for the Rapid Review

Date	Evidence published before January 1st 2011
Setting	Studies conducted outside the UK; Not related to healthcare settings
Population	 Studies only focussing on the experience or views of health professionals or healthcare providers without reporting the experiences or views from service users, [mental health, maternity and neonatal health, digital inclusion, and genomics and genetic testing]; Studies without explicit identification of any ethnic minority subgroups. Cross-country ethnic group comparison without comparing ethnic groups within the UK.
Study type	Case studies; intervention and evaluation studies ¹ ; studies without empirical data
Publication type	Conference papers; book reviews; book; letters; editorial; book chapters; guidelines; commentaries
Outcomes	 Studies focusing on health outcomes with no healthcare services experience/outcomes. Studies about interventions to improve equality of access to services for ethnic minority people. Maternity and neonatal health service: studies on sex-selected abortion; (recent) pregnant women's admission to ICU or neonatal units; neonatal vaccination; contraception; antenatal screening for genetic diseases (included in genomics and genetic testing topic). Mental health: studies on intellectual or learning disability; dementia or memory problems; substance use disorder; maternal depression (included in maternity and neonatal health topic). Digital health: studies on general digital use among health service users with no focus on digital health services; electronic health records. NHS workforce inequality: studies focusing on disciplinary differences; medical speciality differences; medical students' academic achievement; ethnic minority representation in the workforce
Other	Studies conducted in countries other than the UK. Papers not published in English.

Information Sources

We conducted our searches using four electronic databases (MEDLINE (via Ovid), PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Applied Social Sciences Index & Abstracts (ASSIA)) to identify literature focused on ethnic inequalities in healthcare in the UK within the five areas listed in the objectives. Targeted 'grey' literature searches were carried out using the following databases and websites: Health Management Information Consortium [HMIC] and Social Care Institute for Excellence (SCIE). We also utilised the expertise of our stakeholders (academics and clinicians working in the NHS) to provide literature for the review. The management (screening, full text review and data extraction) of these references are reported separately to the management of references resulting from the searches. The PRISMA³¹ diagrams in the appendices (and referenced in each of the topic chapters) summarise the management of both types of references.

Search Strategy

The search strategy included thesaurus and free-text terms and relevant synonyms for the population (NHS health workforce and (potential) service users including at least one ethnic minority group), main exposure (ethnicity/disaggregated ethnic groups), relevant region (UK) and outcome terms (listed in inclusion criteria) and used proximity operators where appropriate. The search terms were combined using appropriate Boolean operators. Methodological search filters were not utilised in the scoping search to keep it broad and ensure all relevant study types were retrieved. A publication type filter was used to exclude dissertation and conference papers given that they do not share the same peer review procedure as published articles. An example of the detailed search strategy for each topic is shown in the Appendix 1.

Study selection

Search results were downloaded to a bibliographic management software (Mendeley) and imported to systematic review software (Covidence) to facilitate the process of duplicate removal, screening and the organisation of references. A pilot exercise involved 10% of abstracts of all studies being independently screened by two members of the review team (DK, JZ or NW). Verdicts were compared and the inter-rater reliability varied from 81.3% to 96.7% for different topic areas. Given the acceptable level of agreement, the remaining records were distributed between the review team, and were single screened. Studies which did not meet the inclusion criteria were excluded. Full-text articles of relevant studies were obtained and reviewed by one reviewer. A sample of excluded records were reviewed by both reviewers to reduce the likelihood of records being excluded in error. In both the screening and full text review stages, where a verdict of 'unsure' had been recorded (in Covidence) by one reviewer these records were passed on to a second reviewer with agreement to be resolved by consensus. In the event of continued disagreement, a third reviewer was asked to arbitrate on eventual inclusion (LB).

After all eligible studies for data extraction were obtained, we identified all the systematic reviews and meta-analyses and any primary studies included within these reviews. All systematic reviews entered the data extraction stage. Primary studies included in these systematic reviews were eliminated to prevent double-counting. Reports of these primary studies were only consulted when the information in the systematic review was unclear or incomplete. The review followed the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) 2020 statement ³².

Data Extraction

Following piloting of a data extraction form, a user-friendly Google Forms interface was used to input data into a Google Sheet. One reviewer extracted the data independently (DK, JZ or NW). Summary tables were cut and pasted into the final report and frequency counts and aggregated responses were produced for the summary report. Data items extracted include: year and location of study, the related topic area, aim of the study, sample size (age in years), number and percentage of ethnic minority participants, target population, the study population and ethnic groups represented (as labelled by the authors), study design, NHS services covered and outcomes measured (for empirical studies), covariates (for quantitative studies), main findings, key messages including author-reported limitations and review team assessment of limitations. We assessed the quality of each selected study qualitatively against the completeness, accuracy, relevance and timeliness (CART) criteria³³. Limitations of eligible studies were noted, following data extraction by one reviewer. This qualitative assessment further facilitated the data synthesis process, enabling us to draw conclusions in a more critical and cautious way. In the presentation of results in this report, we have indicated where the evidence is weak or there are limitations to the statistical analysis conducted.

Data Synthesis

Considering the heterogeneity in the outcomes, sample and study designs of the studies reviewed, a narrative synthesis was regarded as most appropriate approach for this study³⁴. The literature was synthesised within topic areas, ensuring that results relating to outcomes and experiences were disaggregated as far as possible for ethnic minority groups (i.e., using disaggregated groups such as Pakistani, Bangladeshi, Indian, Chinese rather than the overarching category

of Asian). The extent to which we could do this was limited by the ethnic categories used and analysis performed in the included studies. For this reason, we use the ethnic category descriptions used by authors of the primary studies; hence there is not a consistent terminology to refer to ethnic minority groups throughout the report, and we have reported these in quotation marks to signify that these are ethnicity descriptors used by the authors of the included studies, and are not necessarily the terms that would be used by the authors of this report. We organised the results by service types and sub-themes within each topic.

Stakeholder Engagement

Academics and Clinicians/ Professionals working in NHS health and social care

In order to inform the review, we conducted a survey and online interviews with key academic experts, clinicians and professionals to 1) identify key literature in the substantive topic areas, and 2) ascertain areas where experts, clinicians and professionals consider research and practical solutions should be targeted. The lists of academics and clinicians were compiled using the review team's own knowledge of academics working in the field. A total of 46 experts in the five topic areas were identified and contacted by the review team via email. A survey link was attached to the email for academics and clinicians to complete (see Appendix 2 for the survey). For those preferring to meet online, the review lead (DK) conducted one-to-one interviews via videoconference. From August to October 2021, we received 23 responses from the identified academics and clinicians, of which 20 were collected via Google Forms or email and three were collected via online interviews.

Key literature provided by stakeholders was used to inform the design of search strategy. For recommended articles not captured by database searches, we conducted additional

screening, full-text review and data extraction, as reported in the PRISMA diagrams for each topic area. All the eligible studies obtained were included in the final data synthesis. Future areas for research and practical solutions highlighted by the academics and clinicians were integrated within the recommendations of the report.

Community Practitioners

We also conducted two stakeholder engagement groups consisting of community practitioners working with ethnic minority people with health problems, or more generally, in a community setting (e.g., peer supporters, community development workers). The aim of these stakeholder groups was to engage individuals working in the field to ascertain their views on what needs to happen on a practical level to ensure ethnic health inequalities are addressed.

These groups were conducted by two voluntary, community and social enterprise (VCSE) organisations: The Ubele Initiative, and Race Equality Foundation (REF). In total, six focus group sessions and one structured interview were conducted during September and October 2021 with a total of 40 participants. Participants held varied job roles working directly with ethnic minority communities. These stakeholder groups had good representation in terms of ethnicity, region and age. The group led by the REF included five Black Caribbean people, five Black African people, one Mixed White and Black Caribbean person, one Indian person, one White British person, one Roma person and one Gypsy/Irish Traveller person. The engagement group conducted by The Ubele Initiative recruited 13 Asian people, eight Black people, three people of Mixed ethnic background and one White British person. A focus group guide was developed by the review lead (DK), which facilitated the discussion in relation to the five topic areas of this review. The experiences and views of the community stakeholders were used to draft recommendations for the report.

Ethnic Inequalities in Mental Health Services

Introduction

This chapter reviews literature on ethnic inequalities in mental health services. There has been decades of research that has shown ethnic inequalities in access to, and experiences of, mental health services^{8,35}, although the quantity and quality of evidence is not the same across ethnic minority groups, or across different services of the NHS. The recent independent review of the Mental Health Act³⁶ and the subsequent White Paper, Reforming the Mental Health Act⁶ did not sufficiently acknowledge nor provide targeted solutions to the mental health service inequalities created by institutional racism⁷. Hence, there remains a vacuum in national policies concerning mental health services, with respect to race equality with no sight of anything similar to past mental health race equality initiatives such as Delivering Race Equality³⁷ and the associated Count Me In Census of psychiatric inpatients.³⁸ One potentially important current initiative drafted

as part of the national Advancing Mental Health Equalities Strategy, is the Patient and Carers Race Equality Framework (PCREF), which seeks to develop and implement a competency based framework to ensure services are equitable for ethnic minority groups. This is currently taking place in four pilot sites in the UK, in consultation with ethnic minority people with lived experience.

The review identified a large amount of literature in this area and the results were organised into the following areas: attitudes to help-seeking for mental health problems, ethnic inequalities in access to, and receipt of primary and secondary care mental health services (including talking therapies), inequalities in psychiatric admission rates and processes, and inequalities among youth populations. This section does not review literature pertaining to services provided outside of the NHS (prison, by charities).

Results

The searches identified a total of 7,474 papers from electronic databases and grey literature databases covering the period 1st January 2011 to 25th October 2021 (see Methods chapter for full details of databases used). A total of 2,098 duplicates were removed, leaving 5,376 records to be screened by title and abstract. Of these, 4,718 were excluded at the abstract screening stage, leaving 658 studies. The full text articles were sourced for these 658 studies, apart from for one study where the full text could not be retrieved³⁹. At this stage, 586 studies were excluded. About 40% of studies (n=229) were excluded because they were published before 2011. There was also a substantial number of studies (n=112) that did not relate to mental health services. We identified 49 references from stakeholders; we assessed the full texts of these and included three in the review (a large proportion were excluded as they were duplicates). One paper recommended to us from a stakeholder could not be retrieved as it was still under review with a journal. A total of 74 studies were included in the review for this topic area. As there was a vast amount of literature for this topic area, we focussed on extracting data from systematic reviews (n=8) first and did not extract data for primary studies (n=13, not shown in PRISMA)⁴⁰⁻⁵¹ that were included in these systematic reviews. Appendix 3 summarises the flow of studies in the rapid review process in a PRISMA diagram31.

The main characteristics of the included studies are shown in a table in Appendix 4. The studies were published between 2011 and 2021. The 74 studies were categorised into six broad categories relating to the mental health care pathway (and a separate category for youth services). However, it must be noted that a substantial number of papers reported results for more than one type of service (e.g., community treatment and inpatients admissions). Where this was the case, papers were categorised to the area of services that most of the results related to. The six categories of papers were: (1)

attitudes to help-seeking and experiences of general mental health services, (2) primary and secondary care mental health services, (3) psychological and talking therapies, including Improving Access to Psychological Therapy (IAPT) services, (4) secondary care mental health services (mainly outpatient services), (5) inpatient services and (6) youth (children, adolescents and young people) mental health services.

Attitudes to help-seeking and experiences of general mental health services

There were 12 papers related to attitudes to help-seeking and experiences of general mental health services. One paper was a systematic review conducted on studies from England. One study was a cross-sectional survey conducted in London. The remainder of the papers in this category were qualitative (n=10), using either interviews or focus groups to collect data. Out of these 10 studies, four were conducted in London, three in England, two in the UK, one in Birmingham, one in Bristol and one in Brighton and Hove. Most of the studies reviewed in this section used data from ethnic minority participants only and therefore did not allow for a comparison with White majority groups. The ethnic minority groups that were most sampled across these studies were Black Caribbean, Black African (including Somali people), Pakistani, Indian, Bangladeshi and Chinese groups. There was only one study that allowed a comparison of White British and Black African women in help-seeking behaviours for mental health problems, but this was a low quality survey using convenience sampling and basic statistical analyses.

There were recurring themes across these studies. Four studies^{52–55} reported a lack of trust in healthcare professionals as a reason why people would not seek help from mental health services. Bailey and Tribe⁵² showed this to be the case for older (aged 65 to 79 years) Black Caribbean people living in the UK using qualitative interviews, although it must be noted that the sample size was

small (n=8). Linney and colleagues⁵³ found that Somali people sampled from Bristol (n=23) were also reluctant to seek help for mental health problems (and general medical problems) due to the perception of the GP as an authority figure and a distrust of people in positions of authority. One of the reasons cited for this lack of trust in health professionals and its subsequent impact on avoiding or delaying seeking help was patients' views that healthcare professionals (GPs and mental healthcare professionals) did not either 1) understand what racism was or 2) understand how racist experiences and other individual experiences impacted both their experiences of mental health services and the outcome of the receipt of services. Memon and colleagues'54 qualitative study with Black, Asian and Mixed groups (n=26) in Brighton and Hove provided evidence for this, with one participant stating their annoyance with having to explain 'the Black experience' (p.5) to therapists which then interfered with effective therapy. Similarly, Kalathil and colleagues' qualitative study55 with women (n=27) from a large variety of ethnic backgrounds (Mixed (or other), Black British, Black African, Black Caribbean, Bangladeshi, Indian (Gujarati, East African Indian), Pakistani, African (Liberian, Nigerian, Ethiopian, Angolan, South African)) showed that many participants felt that mental health services and recovery frameworks did not account for their experiences of racism and other discrimination, failing to account for a significant part of their distress.

Five studies⁵⁶⁻⁶⁰ reported dissatisfaction with the experiences of navigating the health system which were rooted in systemic problems with the way mental health services are organised and operate. Shefer and colleagues'56 study of Black African, Black Caribbean, Indian, Kenyan-Asian and Somali people (n=103) living in London concluded that participants were critical about both the psychiatric system and psychiatric staff with participants stating that the aim of psychiatric medication was 'to neutralize patients (rather than cure them)' (p.540). Patients also felt that psychiatrists disregarded their concerns about the side effects of psychiatric medications. Sisley and colleagues'57 study of Black Caribbean women living in London found

that although women generally found GPs to be sympathetic to mental health problems. they felt that what they could offer for mental health problems was limited. For example, patients stated that health professionals failed to provide information about a local (outside of the NHS) 'Black Caribbean and African service', due to lack of knowledge about these services. Women in this study also reported that mental health professionals could be 'patronising and judgemental' (p.400) which deterred help-seeking. Islam and colleagues'59 study of Black African, Black Caribbean, Pakistani, Arab and British Bengali people (n=22) who were current or past Early Intervention Service (EIS) users also concluded that there was a failure by GPs to listen to and address their mental health concerns. Garett and colleagues' synthesis of studies⁶⁰ that reported on problems with accessing primary care health services by South Asian people concluded that there were problems navigating the health system to gain help for mental health problems; however, there was very little specific information in this synthesis and most of the studies focussed only on South Asian women. Brown and colleagues'58 quantitative survey of Black African and White British women living in London showed that there were no differences in the proportion of women citing GP consultation difficulties as a reason for not seeking help for mental health problems (Black African women 20.0% vs White women: 25.3% (Chi squared test statistic= 0.037, p > 0.05). However, this study was a convenience sample in one area of London and did not take into account important covariates in the analyses (age, previous experiences of mental health services).

There were four studies^{54,61-63} that cited language barriers and lack of access to official interpreters as impeding access to mental health services. Hussain and colleagues'⁶¹ qualitative study that interviewed Pakistani people in the UK (n=8) concluded that mental health services were not meeting the needs of Pakistani people, and one of the reasons for this was the lack of interpreters available to people who did not speak English, for example, on admission to psychiatric wards. This was also shown in Yeung and

colleagues'63 study (n=7) of Chinese people's experiences of seeking help for severe mental illness, with one participant stating he felt miserable on a psychiatric ward because he didn't speak English and his psychiatrist didn't understand him. Similarly, Loewenthal and colleagues'62 focus group study of Bengali, Urdu, Tamil and Somali speaking people in the UK showed that patients felt anxious when GPs did not understand their mental health problems due to the former's lack of English speaking skills, but felt that interpreter services were unreliable and sometimes there was a perception that some interpreters may break confidentiality. Participants felt there was a need for more professionally trained interpreters. Memon and colleagues'54 study highlighted that language barriers were particularly a problem for recent migrants of Somali background.

Primary and secondary care mental health services

Four papers contained data relating to ethnic inequalities in both primary and secondary care mental health services. Of these, one was a systematic review of UK studies. The remaining three studies used cross-sectional surveys; one study used an English dataset, Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC)64 and the other two studies used a London dataset, the South East London Community Health Study (SELCOH)65. All of the papers in this section allowed comparison between White majority groups and a range of ethnic minority groups. Twomey and colleagues'66 systematic review of UK studies that predicted health service use for people with mental disorders stated that two studies in their review showed that people from non-White ethnic backgrounds were more likely to seek help from primary care services and one study showed that there was no difference in help-seeking for mental health problems between White groups and ethnic minority groups.

The evidence was also inconclusive for specialist mental health care services with two studies showing ethnic minority people were more likely to seek help from specialist mental health services and one study showing no difference between White and ethnic minority groups. Kapadia and colleagues'67 quantitative analysis of survey data (n=2,260) of ethnic inequality in women's usage of mental health services in England (defined as seeing a GP for mental health problems or seeing a counsellor or psychologist), showed that Pakistani (Odds Ratio (OR)=0.23 (Confidence Interval (CI)=0.08-0.65) and Bangladeshi (OR= 0.25 (CI=0.07-0.86)) women were less likely to use mental health services compared with White women. There was no evidence of differences in usage between White women and White Irish, Black Caribbean or Indian women. The analysis adjusted for a range of covariates (age, mental illness, household income and social support variables) but the analysis used outdated data (from 2000). The remaining two studies by Gazard and colleagues^{68,69} used the South East London Community Health Study (SELCOH) to investigate differences in seeing a GP or counsellor for mental health problems. The first study published in 201568 aimed to investigate differences in migrants' and non-migrants' access to mental health services. The study showed that there were largely no differences in seeing a GP or counsellor for mental health problems between migrant and non-migrants within ethnic groups, but people who were recent migrants (migrated to the UK less than 5 years ago) identifying as 'Other' ethnic background were less likely than non-migrants in this broad ethnic category to see a GP for a mental health problem (OR=0.29, CI=0.09-0.88, p<0.05). However, this result tells us very little about migrants from which specific ethnic group may face these particular difficulties. The second study published in 2018⁶⁹ found that anticipated discrimination was associated with increased service use for mental disorder. There was no evidence from this study to suggest that discrimination experiences were acting as a barrier to health service use.

Psychological and talking therapies, including Improving Access to Psychological Therapy (IAPT) services

Thirteen papers discussed ethnic inequalities in access to, and experiences of, talking therapies or psychological therapies, including Improving Access to Psychological Therapies (IAPT) services. Most of these (n=11) were cross-sectional quantitative studies (surveys, audit of clinical data, cohort studies), one was a mixed methods study (a survey and focus groups) and one was a qualitative survey (used open ended questions). Seven of these studies used data from participants in London (most used clinical data but one study used SELCOH), four used English data, one used UK-wide data (the National Audit of Schizophrenia datasets) and one used data from England & Wales.

Four of the studies⁷⁰⁻⁷³ in this section were related to ethnic differences in Improving Access to Psychological Therapy (IAPT) services. The report from the Health and Social Care Information Centre⁷³ published in 2014 showed that rates of access to IAPT in England were ~1,300 per 100,000 population for White British people; (this was calculated using 2011 England and Wales census data to estimate the size of the population (IAPT data collected 2012-2013). Access rates were lower for all ethnic groups compared to White British people, except for the White & Black Caribbean group, Black Caribbean and Any other Black background (all ~1,700/100K), any other Mixed background and any other background (over 2,500/100K). The estimates were not adjusted for need (mental illness), nor broken down by age or gender. Furthermore, ethnicity was not recorded for 30% of people in the dataset. It must also be noted that our searches identified the most recent report from NHS Digital on rates of access to IAPT74 but this report was excluded from our review as it did not present IAPT referral rates by ethnic group. The other two studies on IAPT were London-specific. Bhavsar and colleagues'70 study of almost 1,500 survey participants whose data were linked to IAPT records found no evidence of ethnic differences in rates of psychological

treatment use. However, Harwood and colleagues'72 larger study (n=85,800) using more recent data (collected 2013-2016) found that compared to the White British group, Black African (OR=0.67, CI=0.63-0.71), Asian (OR=0.65, CI=0.61-0.69) and Mixed ethnic groups (OR=0.80, CI=0.76-0.84) were less likely to self-refer to IAPT than be referred through their GP. The study also found that compared to the White British group, Asian (OR=1.24, CI=1.08-1.41) and Black Caribbean (OR=1.16, CI=1.01-1.33) groups were more likely to be referred to IAPT via secondary care than their GP. Black Caribbean (OR=1.92, CI=1.65-2.24), Black African (OR=1.77, CI=1.43-2.19), Asian (OR=1.64, CI=1.38-1.94), Black Other (OR=2.62, CI=2.03-3.38) and White Other (OR=1.85, CI=1.52-2.24) groups were more likely to be referred through community services (e.g., statutory services like Job Centre Plus, voluntary organisations, education providers and prison and probation services). Finally, the study also found that all ethnic minority groups were less likely than the White British group to receive an assessment following referral.

Five studies^{75–79} reported on access to cognitive behavioural therapy (CBT). Das-Munshi and colleagues'75 large UK-wide quantitative study of ethnic differences in access to pharmacological treatments, psychological interventions and shared decision making and care planning in people with a clinical diagnosis of schizophrenia or schizoaffective disorders, found that relative to the White British group, Asian (OR=0.73, 95% CI=0.61, 0.86), Black (OR=0.74, 95% CI=0.63, 0.88) and Chinese or Other [combined ethnic group] (OR=0.69, 95% CI=0.49, 0.97) groups were less likely to have ever been offered CBT. Morris and colleagues' study of over 20,000 patients with bipolar disorder or psychosis in South London, found that relative to White British people, Black African people were less likely to receive a single session of CBT (OR 0.73, 95% CI 0.66 to 0.82, p<0.001); Black Caribbean people were less likely to receive a minimum of 16 sessions of CBT (OR 0.83, 95% CI 0.71 to 0.98, p=0.03) and both Black African and Black Caribbean people were significantly less likely to receive CBT whilst inpatients (respectively, OR 0.76, 95% CI

0.65 to 0.89, p=0.001; OR 0.83, 95% CI 0.73 to 0.94, p=0.003). Mansour and colleagues'78 study of older people in London (aged >=65) diagnosed with depression found that relative to White British people, Black African older people were less likely to receive CBT (OR=0.53, 95%CI=0.28-0.96), but there were no differences found for other ethnic groups. Byrne and colleagues'79 study of people at ultra high risk (UHR) of psychosis (aged 14 to 35) in London found some evidence that White British people attended more CBT sessions than Black people (Mann-Whitney U post hoc test, z=-2.20, p=0.03). Johns and colleagues'76 study evaluating CBT for psychosis found that there were no ethnic differences in therapy engagement (attended ≥5 sessions, Chi-squared test statistic=0.16, p=0.69).

Three studies reported on psychological or talking therapies more generally. Mercer and colleagues'80 study of South London and Maudsley NHS Trust patients receiving psychological therapy between 2010 and 2015 found that of those accessing psychological therapy, there were significantly fewer Black/Black British patients (p < .05). For schizophrenia diagnoses, there were significantly fewer Black/ Black British and 'other ethnic group' patients accessing psychological therapy (p < .05). The statistical analyses were basic and did not adjust for age, gender or diagnoses. Mind's⁸¹ mixedmethods study investigating access to talking therapies found that people from ethnic minority groups talked about therapists not taking account of how therapy interacted with their religion and spirituality. They also raised issues with language barriers due to lack of interpreters. However, there were no illustrative quotes in the authors' report that were identified by ethnic group nor were the survey results broken down by ethnic group, limiting its usefulness. Moller and colleagues'82 study which aimed to explore the attitudes and beliefs of second-generation South Asian women living in Britain about counselling, used a qualitative survey to sample 82 women. Women in the study reported that White counsellors could be 'culturally ignorant' and Asian counsellors who albeit may demonstrate an 'understanding of cultural issues' could be 'untrustworthy' (p.205).

Two studies reported on ethnic inequalities in outcomes of psychological treatment. Crawford and colleagues'83 large quantitative study (n=14,004) of England and Wales patient data found that most ethnic minority groups were more likely to report negative effects of receiving psychological therapy (experiencing lasting bad effects of treatment), compared with the White group (Asian OR= 2.61, CI=1.85-3.67; Black OR=2.16, CI=1.27-3.67; Mixed OR=1.65, CI=1.00-2.74; Chinese/ Other OR= 2.86, CI=1.73-4.69). Green and colleagues'84 study of over 4,000 records of patients who attended community or psychological therapy services found ethnicity to be an important predictor in recovery outcomes, but it was not clearly reported whether ethnic minority people recover better or worse than White British people.

Secondary care mental health services

Twenty papers contained data on access to ethnic inequalities in a variety of secondary care mental health services (inpatient services were largely categorised separately). The papers included data about crisis services, specialist psychosis services, assertive outreach, community treatment orders, obsessive compulsive disorder services and eating disorder services. Twelve of the papers were cross-sectional studies of survey or clinical data, six studies were qualitative in nature and there were two systematic reviews. Eight studies used English data, six used data from participants or patients in London, three studies were conducted in Birmingham and one study was multi-city in nature. One systematic review included only UK studies and the other incorporated mainly UK and US studies.

Four of the reports⁸⁵⁻⁸⁸ identified were authored by NHS Digital (or the Health and Social Care Information Centre for older reports) and provided rates of use of secondary care mental health services in the UK by ethnic group. These four reports together show that Black groups (Black British, Black Caribbean, Black African and Black Other) are more likely to use specialist mental health services

(outpatient and inpatient services) than the White British group. The most recent of these reports showed that the Chinese, Indian, and Mixed White & Asian ethnic groups were the three ethnic groups with the lowest rate of mental health service use. However, each of these reports used crude rates, and did not adjust for mental illness need. Further, the more recent the report, the less likely the estimates were to be accurate as they use 2011 census population estimates which are now outdated. Therefore, the rates of use in these reports are not accurate (they are likely to be over-estimates of mental health service use, particularly for ethnic minority groups that have grown considerably in population size between 2011 and the date of the reports).

Six papers reported on ethnic differences related to specific community services and the management of mental health problems^{89–94}. Weich and colleagues'89 study of use of community treatment orders (CTOs) of almost 70,000 patients in England found that compared with White patients, Black patients (OR=1.43, CI=1.33 to 1.53) and Mixed ethnicity patients (OR=1.27, CI=1.13 to 1.43) were more likely to be subject to CTOs. There was no difference in the rates between Asian and White people (OR=1.06, CI=0.98 to 1.15). Werbeloff and colleagues'90 study found that one year after contact with crisis resolution and home treatment teams (CRHTs), in the London boroughs of Camden and Islington, Black people (Hazards Ratio [HR]=1.52, 95% CI=1.33-1.74) were more likely to be admitted to acute mental health services (crisis teams, crisis houses, and inpatient wards) compared with White people. There was no difference in admission for Other, Mixed or unknown ethnic groups (HR=1.12, 95% CI =0.96-1.31). In South London and Maudsley NHS Trust there were no differences found for Black groups but patients from Other, Mixed or unknown ethnic background were less likely to be admitted to acute services (HR=0.85, 95% CI=0.75-0.96). Jeraj and colleagues' study93 of ethnic minority peoples' experiences of crisis care in five areas across England found that service users were dissatisfied with many aspects of the services. Participants reported that police lacked empathy when dealing with people in crisis, and accident and emergency

treatment for a mental health crisis is varied. Often, hospital and police services are not joined up. Service users felt that they can often become trapped in a cycle of services and highlighted that there was too much reliance on medication by professionals. There were no ethnic inequalities identified in access to home treatment mental health services in Bookle and Webber's⁹¹ study of inpatient admission in London. Weich and colleagues' qualitative study⁹⁴ of service users' experiences of home treatment found that this service was rated highly, irrespective of ethnic background. Brugha and colleagues'92 study found that characteristics of Assertive Outreach (AO) teams predict ethnic minority patients' outcomes; for the ethnic minority sample only, clients were less than half as likely to receive an intervention (psychological therapy) in teams with a high caseload per team member. Sizmur and McCulloch's study⁹⁵ showed that respondents in most ethnic minority groups (particularly Black African and Mixed White & Black Caribbean groups) were more likely to be on a care programme approach (CPA) than White British respondents.

Five studies reported on racist or unfair treatment within secondary care services⁹⁶⁻¹⁰⁰. Henderson and colleagues'96 study of 200 patients of secondary mental health services found that Black and Mixed White & Black groups reported greater levels of unfair treatment from mental health services and staff compared with their White counterparts. Schofield and colleagues'97 focus group study of Black African and Black Caribbean mental health service users diagnosed with a psychotic illness in South London found that these participants experienced discrimination in mental health services. Patients felt they were more likely to be diagnosed with psychosis, but they also reported that staff fears around stereotyping Black patients due to their ethnic background, may lead to under-diagnosis. Participants in Rabiee and Smith's study98 (25 service users of Black Caribbean or Black African backgrounds) felt that they were being put into the mental health treatment system, being put on medication, but not being offered counselling or talking therapies. Carers also commented negatively on the way that mental health services are

perceived to criminalise Black people. One participant talked about 'how the police had tried to handcuff her daughter'; another participant talked about 'a neighbour who had been dragged out of the bath with no clothes on' (p.169). Participants also recounted incidents of abuse by staff on inpatient wards. The other study in the review by Rabiee and Smith99 showed that some Black Caribbean service users and carers were positive about the accessibility and responsiveness of services but they felt there was a lack of referral to secondary care. Tang's study¹⁰⁰ of people who used mental health services with a psychiatric diagnosis who self-identified as Chinese reported that participants felt disempowered due to a lack of choice in treatment (often only medication was offered). Participants also reported feeling forced to admit themselves 'voluntarily' to psychiatric wards when threatened with a section by health professionals.

One study (Oduola and colleagues'101) reported on ethnic differences in the duration of untreated psychosis (DUP); they found no evidence for ethnic differences in DUP in a sample of over 500 adults (aged 18 -64) in London. One systematic review of access to eating disorder services¹⁰² found that Asian groups were less likely than White people to be diagnosed with anorexia nervosa and less likely to be referred for treatment. One study relating to specialist OCD services¹⁰³ found that ethnic minority groups were underrepresented in secondary and tertiary specialist OCD services and this was the case for adults and adolescents. One systematic review¹⁰⁴ of ethnic differences in mental health service use for Pakistani women in the UK. found that this group was less likely to use specialist mental health services than White women.

Inpatient services

The review found 12 papers relating to inpatient admissions, services or treatment whilst in these settings. Eight of these were cross-sectional quantitative studies of clinical or survey data (six took place in London, one in Wales and one in Leicestershire), two were

systematic reviews (one with a UK focus and one with an international focus) and two were qualitative studies (both reporting on the same dataset that was collected in London and Nottingham).

Five of the studies^{105–109} in this section showed increased rates of compulsory admission to psychiatric units for ethnic minority groups, with the greatest inequalities evident for Black Caribbean and Black African groups. Halvorsrud and colleagues'105 systematic review and meta-analysis of 40 UK studies showed strong evidence that Black groups and Other White groups were more likely to be admitted compulsorily to inpatient wards (Black OR=3.13, 95% CI=2.61-3.76, n=33 [number of studies in the systematic review that this statistic is based on], Other White OR=1.51, 95% CI=0.99-2.30, n=6). This study also showed that Black groups particularly were more likely to have police or criminal justice system involvement prior to admission (police contact: Black African OR=3.60, 95% CI=2.15 to 6.05, n=2; Black Caribbean OR=2.64, 95% CI=1.88 to 3.72, n=8; Black British (OR=1.56, 95% CI=0.98 to 2.48, n=1) and criminal justice system involvement: Black Caribbean OR=2.76, 95% CI=2.02 to 3.78, n=5; Black African OR=1.92, 95% CI=1.32 to 2.78, n=3). Eleven studies in Halvorsrud and colleagues study also showed that Black groups were less likely to be admitted to inpatient wards after contact with the GP (OR=0.68, 95% CI=0.52-0.89, n=11). The study showed that these inequalities have persisted over time. Barnett and colleagues'110 systematic review of international literature (67 studies) showed similar patterns, and is likely to have included some of the same literature. In addition, Barnett and colleagues' study showed that Black Caribbean groups were at increased risk of compulsory inpatient readmission (Black Caribbean: OR=2.30 (95% CI=1.22-4.34)). Bruce and colleagues'109 study of 165 men admitted to one of 10 inpatient wards in London showed that Black Caribbean and Black African men were more likely to be sectioned under the Mental Health Act (2007) compared to White British participants (Black Caribbean OR=2.92, 95% CI=1.14-7.50, p=0.03; Black African OR=8.03, 95% CI=2.69-23.69, p< 0.001). This study also reported

that White British men were more likely to report both more needs and unmet needs in inpatient setting; the authors conclude that ethnic minority men may not be reporting what they need from services. Watson and Daley's¹¹¹ study of use of Section 135 of the Mental Health Act in London (n=63) showed that use was higher in Black Caribbean, and Other Black groups (simple statistical analysis [T-test] performed, not adjusted for covariates). Saltus and colleagues'108 descriptive analysis of the ethnic background of inpatients admitted to psychiatric wards in Wales between 2005 and 2010 showed that a higher proportion of ethnic minority patients were referred from the criminal justice system compared with White inpatients, and there was a consistently higher proportion of White inpatients referred from the GP compared with ethnic minority inpatients. One study (Polling and colleagues'112) reported a different pattern for general hospital admission (not psychiatric wards) following self-harm specifically: their study of London patients admitted or readmitted to hospital following an episode of self-harm, showed lower rates of admission and readmission for self-harm for Black and Asian ethnic groups, compared with White groups.

Two studies reported on the use of seclusion or physical restraint in inpatient settings. Cullen and colleagues'113 study of almost 4,000 inpatient episodes in London found that there were no ethnic inequalities in rates of referral from acute wards to psychiatric intensive care wards (PICU, non-forensic), nor were there ethnic differences in the use of seclusion (patient isolated in a locked room). Payne-Gil and colleagues'114 London study of use of physical restraint found that there were no ethnic differences in the use of physical restraint without prone position (patient lying face and chest down). But Black Caribbean people were more likely to be restrained in the prone position than White counterparts (OR=1.45, CI=1.02-1.07, p=0.04), as were participants that did not have their ethnicity recorded (OR=2.09, CI=1.36-3.22, p=0.001). The study also found ethnic differences in the odds of being secluded; Black African (OR=1.96, 95% CI=1.36-2.83, p < 0.001),Black Caribbean (OR=1.76, 95% CI=1.082.85, p=0.022), Black Other (OR=1.76, 95% Cl=1.27–2.44, p=0.001) and Mixed ethnic background (OR=1.89, 95% Cl=1.11–3.20 p=0.019) patients had nearly twice the odds of being secluded compared with White patients. There were no ethnic differences found in rapid tranquilisation except for participants who did not have their ethnicity recorded – they had an increased chance of rapid tranquilisation (OR=1.56, Cl=1.02-2.40, p=0.04).

Bruce & Smith's study¹¹⁵ of patients with severe mental illness in London (n=11,617) found that Black Caribbean (OR=1.47, CI=1.30-1.66), Black African (OR=1.38, CI=1.23-1.54) and Asian (OR=1.33, CI=1.08-1.64) groups were more likely to stay longer on psychiatric wards than their White counterparts (OR= 1.47, CI=1.30-1.66). In terms of discharge, a quantitative study by Ahmed and colleagues¹¹⁶ of patients discharged from the Psychosis Intervention and Early Recovery service (PIER) in Leicestershire NHS between January 2005 and December 2013, found that there was no difference between ethnic groups as to whether they were discharged to primary or secondary care.

Two qualitative studies by Lawrence and colleagues^{117,118} (n=35, both papers use the same data) reported on the long term experiences of living with psychosis and navigating the mental health system, as well as aiming to understand the journey through mental health services for Black Caribbean, White Other and White British patients. Every Black Caribbean woman in the study commented upon the absence of Black doctors in the health system (and in inpatient wards) who would be more likely to understand their perspective and concerns. Many participants reported feeling powerless, forced to take medication against their will, and unable to make their concerns heard. Some Black Caribbean participants reported being unable to break the cycle of service use, with many having repeat admissions.

Youth mental health services

Finally, there were 12 studies that reported on youth services; 'youth' here is a broad definition encompassing services for children (0-16 years), adolescents (11-18 years) and young people (12 to 29 years). Of these 12 studies, one was a scoping literature review of barriers to accessing child and adolescent mental health services (CAMHS) (incorporating data from the UK and 'developing countries'). There were six cross-sectional quantitative studies using clinical or survey data, three of which were conducted in London, one using English data, one using UK-wide data and one using data from school children in London and a school in one unspecified English city. The remainder (n=5) were qualitative studies taking place in London (n=2), England, Manchester and Birmingham.

There was evidence from six studies about mental health services in youth populations^{119–124} in our review to suggest that some of the same barriers to accessing services that were highlighted for adult populations in section 3.2.1 above, were also present for youth populations. These were: lack of trust in the mental health system, discriminatory racist treatment from services affecting (delaying) decisions to seek help for mental health problems, and language barriers. Anderson and colleagues'123 scoping literature review of barriers to accessing CAMHS services found that the perception that mental health services were not 'culturally appropriate' acted as a barrier to access for children and families from ethnic minority groups. However, the authors do not expand on what is meant by the term 'culturally appropriate', which limits the usefulness of this scoping review. This review also found that for people who do not speak English, this acted as a barrier to accessing mental health services, but it does not state whether this was an issue for young people themselves or for parents seeking help on behalf of their children. The review also found that providing youth mental health services at easily accessible locations (schools, local primary care clinics or community walk-in clinics) or via self-referral mental health service, increased accessibility of services for ethnic minority children and their families.

Two qualitative studies of Black boys' and young men's attitudes towards seeking help for mental health problems showed that the fear of unfair treatment from health professionals could be a factor in delaying help-seeking. Dada and colleagues'119 focus groups with 78 Black boys and young men (aged 13 to 24 years) in Manchester concluded there was a 'general fear that going into statutory mental health services for help, would result in being permanently labelled, locked in, and medicated on strong drugs without hope of getting better or getting out again' (p.9). Young men in this study also believed that they would be treated differently by mental health services based on colour or race. Similarly, Meechan and colleagues'122 study which interviewed 10 Black (identifying as Black African, Black Caribbean or Black Other) male teenagers (aged 16 to 18 years) in one South London school, showed that there was a reluctance to seek help from formal mental health services and this was related to boys perceiving that most mental health professionals were White and would not understand their problems or 'world' (p.4). Sancho & Larkin's study¹²⁰ of 17 Black Caribbean undergraduates (aged 18 to 25) in Birmingham showed that a lack of trust in the mental health system and anticipated racist treatment from services would deter students from seeking help for mental health problems. Kolvenbach and colleagues'121 study of 20 parents in London (10 of whom were from ethnic minority backgrounds including Black African, Black Caribbean, Indian, Pakistani, Iranian, and Malaysian backgrounds) showed that parents also felt a lack of trust in mental health systems when accessing specialist services for obsessivecompulsive disorder (OCD) for their children, with some parents citing discrimination by health services because of their children's ethnic background as a reason. Fernandez de la Cruz and colleagues'124 survey of 293 parents in London which aimed to explore help-seeking attitudes for OCD amongst parents showed that there were small differences between the proportion of parents in the ethnic groups sampled in terms of seeking help from a GP for a child's OCD (White British: 98.6%, Black African: 98.3%, Black Caribbean: 93.5%, Indian: 91.3% (Chisquared statistic=7.289, p<0.01). However, the statistical analysis was not adjusted for other variables (e.g., age, socioeconomic status), and the study used a convenience sample in one city, limiting its generalisability. Black African parents in the study were the most likely to say they would not seek help at all (from any source) for a child's problems (White British: 4.7%, Black African: 31.3%, Black Caribbean: 12.8%, Indian: 7.3% (Chi-squared statistic =25.520, p<0.01)), and the reasons cited for this were previous bad experiences with health services, and not wanting to be discriminated or judged by services due to their ethnic background.

Four youth studies^{125–128} reported on ethnic inequalities in referral into, and experiences of, specialist mental health services. Two studies by Edbrooke-Childs and colleagues using large routine service datasets (n > 10,000) showed that there were ethnic inequalities in referral routes to CAMHS. The most recent of these two studies¹²⁶ showed young people from ethnic minority backgrounds were less likely to be referred through routes that are voluntary. The authors used UK-wide data for 0 to 25 year olds to show that compared to White British young people, Black young people were more likely to be referred through education, mental health services, social care/ youth justice (OR=2.90, 95% CI=2.07-4.06), and 'other' routes, and less likely to be selfreferred, relative to primary care. Asian young people were more likely to be referred through education, social care/youth justice (OR= 1.85, 95% CI = 1.34-2.54), and less likely through mental health services or to be self-referred, relative to primary care. Young people from Mixed ethnic backgrounds were more likely to be referred through education, social care/ youth justice (OR=2.66, 95% CI=1.91-3.72), and other routes relative to primary care. The older of these two studies¹²⁵ showed similar results using data from 26 CAMHS in England; Black, Asian and Mixed ethnic background children were more likely to be referred to CAMHS via education, social services or other services rather than through the GP, compared with White British children. The largest inequality was seen for Black children who were almost 10 times as likely to be referred to CAMHS via social services compared with White British children. This study also showed

that compared with White British children, ethnic minority children were more likely to have their cases closed because they stopped attending rather than it being closed due to mutual agreement between therapist and children's families. Vostanis and colleagues'128 study of 13 to 15 year old Indian and White British children in schools found no evidence of a difference in the use of CAMHS between these two groups. The study was conducted in London and one other English city, with a sample size of 1,087.

There was only one study (by Gurpinar-Morgan and colleagues)¹²⁹ that reported on young people's experiences of therapy. This was a small interview study (n=5) of ethnic minority young people aged 16 to 18 years who had received cognitive behavioural therapy (CBT) which concluded that therapists and patients do not need to share the same ethnic background to work effectively with clients. There was one study by Dominguez and colleagues'130 that found greater treatment delays (as measured by duration of untreated psychosis [DUP]) for adolescent onset psychosis in White adolescents in the study, compared with Black and Asian adolescents. The authors of this study suggest that DUP is lower for ethnic minority groups as they are more likely to be referred to CAMHS via social services, education or criminal justice pathways and hence are likely to start taking anti-psychotic medication sooner after first symptoms of psychosis compared to their White counterparts.

Stakeholder Engagement

Five stakeholders responded to our survey for academics and clinicians, providing references in the area of ethnic inequalities in mental health services, as well as providing details about ongoing research studies that are important in this field. There were two ongoing research projects, Tackling Inequalities and Discrimination in Health Services (TIDES) and the Synergi Collaborative Project that have already produced substantial evidence on ethnic inequalities in mental health services (some of which were included in this review). Both of these research projects will continue

to produce important evidence for the next 2-5 years; this evidence should be consulted when producing plans to address ethnic inequalities in NHS mental health services. The stakeholder survey also yielded information about two important interventions or initiatives to improve outcomes for ethnic minority people using mental health services. One is the Culturally-Adapted Family Intervention (CaFI) study led by the University of Manchester which aims to test the effectiveness of a new talking therapy for Black Caribbean and Black African people. The second is the Ethnicity and Mental Health Improvement Project (EMHIP), a collaboration to attempt to reduce ethnic inequalities in access, experience and outcome of mental health care. EMHIP is a collaborative project between South West London and St Georges Mental Health NHS Trust, South West London Clinical Commissioning Group, Merton & Wandsworth Locality, and networks of ethnic minority voluntary, faith and community groups, convened by the Wandsworth Community Empowerment Network.

In the stakeholder engagement groups that were carried out by our partners, Race Equality Foundation (REF) and The Ubele Initiative, the views of the community practitioners that were involved in these groups were largely consistent with the findings of the review. The issues around the lack of adequate interpreting services in primary and secondary mental health services was more pronounced in the stakeholder groups than in the review, perhaps reflecting both the review's limitations of focusing on ethnic minority groups (rather than specifically migrants) and the relative lack of research on newer migrant populations in the UK. For some groups including people seeking asylum and those from the Roma community, access to a GP is the initial hurdle, which is then compounded by language barriers and a lack of interpreters. A practitioner working with the Roma community said it is extremely rare for there to be interpreting services for their traditional languages and some people have limited understanding of the language of the country of their origin, for example Poland, Slovakia or Czech Republic, so when there are interpreting services available it is difficult to communicate healthcare issues. They also said that often the interpreters carry their own

stereotypes about the Roma community which can impact how they communicate with them. Stakeholders reported that people seeking asylum have been told by healthcare staff to bring a friend who can translate for them. These issues negatively affect being referred to mental health services in a timely manner.

In line with the findings of the literature in this review, many of the stakeholder group participants expressed both a distrust of statutory services and fear of racist treatment from health professionals (as well as recounting previous racist treatment), which affected help seeking for mental health problems. The ongoing stereotypes portrayed in the media about, and the discrimination faced by, ethnic minority groups, perpetuates the distrust for statutory services. There was also concern about ethnic minority patients' safety, particularly whilst staying in inpatient psychiatric units. One practitioner had been to an inquest where a young Black male who was admitted to a psychiatric hospital experienced extreme excessive force which led to his death. These incidents permeate through communities and create fear and distrust. Another practitioner who represents people seeking asylum and refugees said,

"it's more about fear of safety in mental health services; people have reported not only being discriminated but been badly physically abused in mental health services by health professionals or other mental health patients in hospitals and because they are forgotten people who don't have any rights, so nobody will take this forward." People representing different ethnic minority groups reported that minoritised communities do not feel mental health services are for them. There was a clear consensus across practitioners representing different ethnic minority groups that health care services were detached from the communities they are supposed to serve and have failed to properly engage with them in order to understand their needs. This was felt across the Black African, Black Caribbean, Asian, Gypsy and Traveller and Roma communities. One person commented that it can feel like,

"a them and us and that, I think, is a huge problem, so there are the services that are over there that never connect with, never come out to meet the community and understand the communities which they serve."

For Gypsy and Traveller communities the need to access mental health services was surpassed by a fear of social services involvement, and this fear directly prohibited them from seeking the care they need. This fear was also noted amongst South Asian groups. For some people the lack of clear, accessible pathways to much needed mental health services meant that some people gave up (i.e.didn't seek any help; practitioners gave examples of patients with multiple suicide attempts due to lack of engagement from services).

There were also concerns that ethnic inequalities in mental health services were longstanding and that they were not going to be addressed by any current policies, nor did it seem there would be future policies to fix a systemic problem. One practitioner commented.

"I think that it is systematic in terms of there not being sufficient community led non-clinical services and so people from the Black community tend to present in a crisis and then more likely to be diagnosed with schizophrenia than their White counterparts. They're more likely once they're in the system to be discharged and have to re-enter and they're more likely to be sectioned than our White peers, so for me there is that historical context in terms of how the mental health service, well mental health institutions came in to be[ing] and how they're still operating and that's why the picture remains very bleak for Black communities trying to access mental health services."

Summary

The review found that ethnic inequalities are apparent in many different mental health services, but the quantity and strength of evidence varies across services and is more established for some ethnic groups than others. There was evidence to suggest that there are clear barriers to seeking help for mental health problems rooted in a distrust of both primary care and mental health care providers, as well as a fear of being discriminated against in healthcare. The review found evidence that this was the case for many ethnic groups but there was less evidence about the experiences of Roma, Gypsy and Irish Traveller and Chinese groups, although evidence from our stakeholder engagement groups suggest that some of these groups may also be reluctant to seek help from services that they do not trust. There was also evidence from qualitative work that the lack of appropriate interpreting services acted as a deterrent to seeking help.

There were clear ethnic inequalities in access to IAPT, although this could not be reliably ascertained from NHS Digital national data, due to the use of basic descriptive analyses of referral data (e.g., crude referral rates with no adjustment for mental illness need). Based on other data sources, the review found that overall, ethnic minority groups were less likely to refer themselves to IAPT and less likely to be referred by their GPs, compared with White British people. There was also evidence of inequalities in the receipt of CBT with ethnic minority people with psychosis less likely to be referred for CBT, and less likely to attend as many sessions as their White counterparts. The ethnic differences in community services were less clear cut, with some evidence to suggest there were differences in services such as Assertive Outreach and the use of crisis teams but no evidence for ethnic inequalities in engagement with home treatment teams. There were relatively few studies that allowed an assessment of ethnic inequalities in community services. The review provided strong evidence that there were clear and persisting ethnic inequalities in compulsory admission to psychiatric wards, particularly affecting Black groups, but also Mixed Black and White groups and South Asian groups. There was also evidence of harsher treatment for Black groups in inpatients wards from quantitative studies (more likely to be restrained in the prone position or put into seclusion), qualitative studies (beaten on wards) and our stakeholder engagement groups (Black patients feeling unsafe on wards due to abuse from staff and patients).

There was evidence in the review that some of the inequalities present for adult populations were being replicated in younger populations. Parents reported the same barriers to accessing services as reported for adult mental health services. Two studies of young Black men showed that the injustices they knew of in mental health services relating to Black Caribbean and Black African populations, deterred them from seeking help. Two large national studies found that ethnic minority children were more likely to be referred to CAMHS via social services, education or criminal justice pathways and this was particularly stark for Black children

who were 10 times more likely to be referred to CAMHS via social services (rather than through the GP) relative to White British children.

Overall, the review found few national datasets with good ethnic monitoring data which allowed robust data analysis to investigate ethnic inequalities (e.g., National Audit of Schizophrenia dataset). Many of the more recent reports from NHS Digital (on IAPT, for example) did not report differences in referral rates by ethnic group. There was also a lack of national community survey datasets to allow population level analysis. The SELCOH dataset is representative of South London but the last phase of data collection was in 2013 which means the data are now becoming out of date. Relatedly, many of the studies in this review that used clinical data were conducted in South London (particularly South London and Maudsley NHS Trust) where it seems there are more advanced joined up clinical systems that allow data linkage for research purposes.

The review did not include studies of the mental health services provided by the voluntary, community and social enterprise (VCSE) sector, but there are many ethnic minority-led services provided in this sector that may be deemed more acceptable and trustworthy by ethnic minority people than NHS services (e.g., Mary Seacole House in Liverpool, African and Caribbean Mental Health Services, Manchester). However, many of these services tend to be provided in local areas only, can be subject to short term funding from charities or local authorities and perhaps most importantly, they do not provide inpatient services, which is the service for which there are some of the greatest mental and physical harms to ethnic minority service users, particularly those from Black backgrounds.

Recommendations

Research

- Conduct primary research on the direct and indirect impacts of racial discrimination by NHS staff and institutional processes on access to, experiences of, and outcomes of mental health services.
- Establish repeated cross-sectional national community survey datasets of psychiatric morbidity and service use to provide high quality national data on ethnic minority people's attitudes to, and experiences of, using mental health services.
- of interventions to address ethnic inequalities in both the NHS and VCSE organisations to establish 'what works', why and for whom. This should extend beyond simply reviewing studies that test the effectiveness of 'culturally appropriate/ adapted therapy interventions' (where there is already a review¹³¹) to consider systemic changes across levels of psychiatric care. A recent systematic map of interventions to improve equality in mental health services (but not just related to race) shows that there are few interventions targeted at a system level¹³².

Practice & Policy

• Enforce statutory guidelines on inclusion of national ethnic monitoring data in all NHS mental health clinical data that allows robust statistical Trust-level, regional and national analysis (including data linkage between clinical datasets) to establish where the inequalities are, and for which ethnic groups. Recent work supported by the NHS RHO¹³³ has shown that ethnicity recording remains poor in many services in the NHS, including for Hospital Episode Statistics (which records admissions and outpatient appointments). This recommendation will require a dedicated drive by NHS England and NHS Digital to

- emphasise the importance of collecting and reporting these data, as well as providing the infrastructure to collect, analyse and interpret them. An online learning module on recording ethnicity data on the Health Education England, or equivalent, website should be made accessible to all NHS staff, to ensure staff are trained in routine collection of ethnicity data.
- Establish relationships between ethnic minority VCSE organisations and NHS provider services in order to provide the high quality services for ethnic minority patients. NHS England and NHS Trusts need to work with partners across public service, the voluntary sector and community organisations in order to demonstrate commitment to tackling racial inequality in mental health services. One way in which this is already being done to an extent is through the Patient and Carer Race Equality Forum (PCREF), which seeks to develop a competency outcome framework to ensure services are equitable for ethnic minority groups. PCREF is currently being piloted in four Trusts in England (South London and Maudsley NHS Foundation Trust, East London NHS Foundation Trust, Birmingham and Solihull Mental Health NHS Foundation Trust and Greater Manchester Mental Health NHS Foundation Trust) before it is rolled out nationally. The results of these pilots, and the way in which they are used by NHS England and NHS Improvement as part of the Advancing Mental Health Equalities Strategy, have the potential to improve ethnic minority people's trust in NHS mental health services.

Ethnic Inequalities in Maternal and Neonatal Healthcare

Introduction

This chapter provides a review of the available evidence relating to ethnic inequalities in maternal and neonatal healthcare, with a focus on both access and experiences. Large ethnic inequalities in maternal, perinatal and infant mortality have been documented in the UK over more than a decade^{134–139}. While many factors beyond the healthcare system impact upon the risks to pregnant people and their babies, there is increasing recognition of the role that sub-optimal healthcare can play. Better Births, Improving Outcomes of Maternity Services in England 140 and the establishment of the Maternity Transformation Programme were intended to provide the vision and operational structure to achieve safer, more personalised, and more family friendly maternity care. This strategy includes an important focus on enhancing choice and personalisation, ensuring continuity of carer for women (particularly those with additional social needs), and improving access to perinatal mental health services.

Within this national level policy, there has been a spotlight on the need to improve clinical outcomes, and healthcare experiences, for ethnic minority women. Saving Lives, Improving Mothers' Care – the Confidential Enquiries into Maternal Deaths and Morbidity for UK and Ireland, published in November 2018 raised concerns about variation in care for different ethnic groups, and highlighted the need for research to identify the factors underlying the persistent elevated risk of maternal mortality among Black and Asian women when compared to White women. Tackling poorer care and outcomes among ethnic minority women and babies continues to be a focus within the new NHS England and NHS Improvement Maternity Transformation Programme Equity Strategy 141, which includes pledges to improve equity for mothers and babies and race equality for staff.

Results

The searches identified a total of 1,201 papers from journal article databases and grey literature databases covering the period 1st January 2011 to 25th October 2021 (see Methods chapter for full details of databases used). A total of 664 duplicates were removed, leaving 537 records to be screened by title and abstract. Of these, 361 were excluded at the abstract screening stage, leaving 176 studies. The full text articles were sourced for 174 of these studies; we could not find the full text of two references 142,143. At this stage, 141 studies were excluded. Studies were mainly excluded because they did not report on healthcare service access or experiences. Fourteen studies were identified as meeting inclusion criteria but as their data was synthesised as part of systematic reviews already included in the review, data extraction was not carried out for these 14 studies. We also identified 19 references from stakeholders; we assessed the full texts of these and included 3 in the review. A total of 36 studies were included in the review for this topic area. Appendix 5 summarises the flow of study identification and selection in the rapid review process in a PRISMA diagram³¹.

The main characteristics of the included studies are shown in a table in Appendix 6. The studies were published between 2011 and 2021. The 36 studies have been grouped into six clusters: access and experiences in general; antenatal care; intrapartum care; postnatal care; perinatal mental healthcare; and miscellaneous.

Access to, and experiences of, maternity services in general

Thirteen studies provided evidence relating to women's access to and experiences of maternity care in general, rather than focusing on a particular part of the care pathway; two of these were conducted during the Covid-19 pandemic. Six of these were systematic reviews; 144–149 five were qualitative interview

studies; 150-154 one study 155 undertook two online engagement discussions; and another study 156 employed Q methodology, which involves a sequenced approach that proceeds from semi-structured interviews and discussions, through statement identification and sorting, to factor analysis, resulting in a set of factors representing women's experiences of maternity services.

Four of the reviews in this general cluster included primary studies relating to women reporting a range of ethnic identities: Firdous and colleagues¹⁴⁴ focused on studies of Muslim women from different ethnic backgrounds; Higginbottom et al. 148 included studies of immigrant women from various ethnic backgrounds; Khan¹⁴⁹ included studies of 'BAME' women (with included studies reporting on Black African, Pakistani, Palestinian, and West African women); and Rayment-Jones and colleagues¹⁴⁶ included studies of women exposed to 'social risk factors', which included ethnic minority women from a range of ethnic backgrounds and vulnerable migration statuses. In contrast, McFadden and colleagues'145 review focused on Roma, Gypsy or Irish Traveller populations, while Watson & Downe¹⁴⁷ synthesised evidence relating to women identified as Roma or Romani. Among the primary, qualitative studies, Bawadi and colleagues¹⁵⁰ examined Arab Muslim women's experiences of accessing care, while Binder and colleagues¹⁵¹ included immigrant women born in either Somalia or Ghana, and Crowther and Lau's 152 study focused on migrant Polish women. Mantovani & Thomas¹⁵³ included young Black mothers, most of whom were seeking asylum or were migrants. Fernandez Turienzo and colleagues'155 participants identified as Black, White, Asian or Mixed ethnicity. Cross-Sudworth and colleagues¹⁵⁶ included both migrant and British-born women who identified as Pakistani. John and colleagues¹⁵⁴ include women with a range of ethnic minority identities. The geographic location of studies was not always clear, particularly in relation to the primary studies included within the systematic reviews. A majority took place in England, with just two studies including a Scottish sample and one a Welsh sample. Not all studies involved comparative analyses

across ethnic minority and White British groups, and some did not provide evidence on the mechanisms underlying observed patterns of care access or experience.

Access, engagement and quality of relationships with healthcare providers

Higginbottom and colleagues'148 review usefully synthesised evidence relating to maternity care relationships between immigrant women and health-care professionals. From the perspective of immigrant women, a good relationship was established when the midwife was caring, kind and responsive to the women's needs. However, the review found evidence of important variability in the quality of, and satisfaction with, the relationships between midwives and immigrant women across maternity care settings. There was also evidence to suggest a lack of clarity among some immigrant women regarding the role of the midwife (versus other professionals) in meeting their maternity care needs. Higginbottom and colleagues'148 review concluded that open, comfortable and safe relationships with midwives enabled immigrant women to discuss sensitive issues such as female genital mutilation (FGM) and immigration status. The review also identified some positive examples of midwifery care and provision, particularly where midwives demonstrated cultural safety, effective provision of information on pregnancy and labour, good quality of communication during labour, and attention to women's social circumstances. They concluded that, "rather than receiving 'orders' from midwives, the women understandably wanted to be actively involved, have choices and receive explanations of procedures" (p.41).

Fernandez Turienzo and colleagues' participants¹⁵⁵ identified similar factors for ethnic minority women in South London. They valued continuity of care, but felt that in reality care was often fragmented and it was a 'postcode lottery' as to whether a woman received high quality, compassionate care or not. Rayment-Jones and colleagues'¹⁴⁶ review concluded that continuity of care is particularly relevant for women who are unfamiliar with

the NHS system and those living difficult lives, experiencing multiple disadvantages.

John and colleagues' Scottish study¹⁵⁴ found that most women reported good continuity of care despite the Covid-19 pandemic situation. However, unsurprisingly, most women had had telephone calls in place of some routine face-to-face appointments. Most felt that virtual appointments were not as effective, with concerns expressed around effective communication. This was especially the case for unscheduled care. Where women wanted to have an in-person consultation, they found these difficult to arrange. The study was unable to explore whether these issues disproportionately affected ethnic minority women.

For some groups of women, poor communication with health professionals is linked to lack of English language skills and inadequate provision of interpreter services. Watson and Downe's 147 review of evidence relating to Romani women highlighted poor communication and lack of provision of information in a language they could understand as a significant issue. Firdous and colleagues'144 review of Muslim women's experiences highlighted communication issues and inadequate access to information as concerns across all six studies. Similarly, Higginbottom and colleagues' review¹⁴⁸ focusing on immigrant women identified language and communication issues as a major concern. Language was the main factor undermining communication between women and their providers, particularly for Somali women in the study by Binder and colleagues¹⁵¹. Cross-Sudworth and colleagues¹⁵⁶ found that women felt speaking English was important in gaining the care you need. Crowther & Lau¹⁵² found that Polish women faced challenges of not being able to speak in English and found the experience embarrassing. Not understanding what midwives were saying in labour and delivery meant women felt unsafe and vulnerable, and needs were not met.

Suboptimal use of interpreter services was a consistent theme across papers. Bawadi and colleagues¹⁵⁰ reported that the

Arab women in their study, who were not proficient English speakers, had inadequate access to professional interpreters and use of family members in lieu was common. Cross-Sudworth and colleagues¹⁵⁶ reported similar findings in their study of Pakistani women. Firdous and colleagues'144 review also highlighted inadequate interpretation. Binder and colleagues¹⁵¹ found that distrust meant some Somali women were unwilling to speak via an interpreter, regardless of their identity. Crowther & Lau¹⁵² found that some Polish women were unaware that they could ask for an interpreter, and others opted for a friend acting as interpreter during labour due to an impractical phone interpretation service being the only option. Reviews by Khan¹⁴⁹ and Rayment-Jones and colleagues¹⁴⁶ also found evidence of a lack of flexibility and accessibility of interpreting services, especially in urgent situations, which meant family members, had to interpret in their place.

Receipt of written materials during antenatal and postnatal period was also unhelpful for some women as it was all in English^{144,150}. Practice in this regard is, however, clearly variable as a study included in Higginbottom and colleagues' review¹⁴⁸ highlighted how Polish women found leaflets in the Polish language provided by midwives to be very helpful.

Importantly, poor communication was also a consistent theme among ethnic minority women who do speak English, particularly those who are migrants to the UK. Bawadi and colleagues¹⁵⁰ reported that women who spoke English found it difficult to comprehend information provided by healthcare professionals due to unfamiliar medical terminology and the accent of providers. John and colleagues¹⁵⁴ found that some women felt their 'non-British' accents negatively affected how they were perceived by professionals, and, despite the women's good grasp of English, communication was not effective and decision-making could be impaired. Firdous and colleagues¹⁴⁴ and Khan¹⁴⁹ also highlighted medical terminology as impeding understanding. Different ways of expressing symptoms and the use of unfamiliar non-verbal communication cues can also be an issue for migrant women¹⁴⁴.

Khan's¹⁴⁹ review also highlighted poor active listening skills among some healthcare providers which undermined communication and left women feeling uninvolved, dismissed and unsafe. Concerns that this reduces the ability of women to make informed choices and has important implications for their care, e.g., less pain relief and sub-optimal positioning during labour, were highlighted in two papers included in this review.

The reviews by Khan¹⁴⁹ and McFadden and colleagues¹⁴⁵ highlighted the recursive nature of women's experiences with maternity care. Past negative experiences with midwives undermined women's ability to form positive relationships with care-givers in subsequent pregnancies. Women felt that midwives were 'condescending' and 'dismissive' (p.4) and this contributed to feelings of isolation and a perceived lack of care¹⁴⁹. Previous positive encounters with a midwife were linked to current positive pregnancy and labour experiences¹⁴⁹. McFadden and colleagues¹⁴⁵ found evidence from several studies that some Travellers prefer to rely on themselves or others in their communities rather than health services, and that those who had felt intimidated by service experiences wanted to delay any further involvement in maternity care.

System-level factors can also act to undermine the establishment of positive relationships between women and providers, and constrain access to good care. Time pressures leading to rushed interactions were identified by Khan and colleagues¹⁴⁹; a theme reiterated in some of the papers discussed below.

Racism, discrimination and cultural insensitivity

Despite evidence of varied experiences, and of the establishment of positive relationships with healthcare providers for some ethnic minority women, a consistent theme was women's experiences of negative interactions, stereotyping, disrespect, discrimination and cultural insensitivity.

Firdous and colleagues'144 review found consistent evidence that Arab women identified a link between insensitive care and racism, feeling that their Muslim clothing put them at risk of discrimination, including from healthcare providers, a finding also reported by Bawadi and colleagues¹⁵⁰ in their primary study of the experiences of Arab women. Respondents identified mistreatment and poor care particularly on the postpartum ward, feeling ignored and frightened by the unfamiliar care on offer. Unmet needs prompted women to seek check-ups in their home country with doctors they felt they could trust. Firdous and colleagues¹⁴⁴ reviewed a study by Hassan and colleagues¹⁵⁷ in which Arab women's birth plan choices were not acknowledged by providers.

Higginbottom and colleagues'¹⁴⁸ review focused on immigrant women found that 12 out of 40 included studies provided evidence of discrimination, racism, disrespect, and inaction. They state:

"discrimination in maternity care services mitigates the delivery of good-quality maternity care. The discrimination was often subtle and difficult to specify, but direct and blatant discrimination was also documented in some cases. Subtle discrimination included the staff responding to women's questions or requests in rigid and inappropriate manners. Evidence from one study reports that immigrant women were often not welcomed or greeted in a friendly manner and not made to feel safe. Some women suffered acute negative feelings when they were treated differently by maternity care staff. Direct discrimination included health-care staff uttering stereotypical and racist comments"

(p.53).

However, not all studies reported overtly discriminatory behaviour. Cross-Sudworth and colleagues' respondents did not believe care was discriminatory, though they did acknowledge that being educated increased a woman's chances of getting the care they need.

Importantly, Higginbottom and colleagues¹⁴⁸ also point to structural and system-wide issues that shape the care provided to migrant women. They argue that poor relationships and experiences of rudeness, disrespect, powerlessness and coercion "suggest that more systemic dynamics may be at play, which are less to do with the insensitivities of some, but not all, individual members of staff and more indicative of a systemwide framing of service delivery and care for immigrant women" (p.39). John and colleagues¹⁵⁴ reported that institutional racism was highlighted as a significant issue in pregnancy care by most of their ethnic minority participants. Some participants had concerns that medical research is tailored to White people, and therefore expressed distrust in treatments. Participants also perceived that they had greater barriers to accessing healthcare compared to White women.

Cultural insensitivity and lack of accommodation of cultural and religious needs was a further dimension of women's negative experiences highlighted across several papers, manifesting within both the inadequate knowledge and behaviours of individual healthcare provider and systemlevel structures and processes. Firdous and colleagues' review¹⁴⁴ of Muslim women's experiences highlighted consistent evidence of the lack of awareness from healthcare professionals of religious-related requirements and factors influencing women's decisionmaking, and a need for women to rely on friends and others sources of information. Similarly, Khan's review¹⁴⁹ and Higginbottom and colleagues'148 review both highlighted concerns that ethnic minority, and immigrant, women's cultural and religious needs were disregarded, resulting in care that is neither sensitive nor responsive to individual needs. McFadden and colleagues'145 review of evidence relating to Roma, Gypsy or Irish

Traveller women also found some evidence of lack of cultural and lifestyle understanding and awareness among health professionals. This could affect care, for example cultural beliefs, including those around purity, can be a barrier to some Roma women engaging with pregnancy-related care. Fernandez Turienzo and colleagues'155 respondents reported that many women are fearful of service encounters and lack trust in healthcare providers, leading to a reluctance to seek prompt care from services that they perceive as 'other' and culturally insensitive. However, Cross-Sudworth and colleagues¹⁵⁶ concluded from their Q methodology study that some Pakistani women preferred to have an English midwife rather than an Asian one, with whom they would feel more 'ashamed', alerting us to the complex insider-outsider dynamics that can be at play, and the need to ensure cultural competency of all healthcare providers. The importance of gender concordance between patient and provider was identified by McFadden and colleagues'145 review of evidence relating to Roma, Gypsy or Irish Traveller women women attending appointments with male health providers being noted. In contrast, however, Binder and colleagues¹⁵¹ concluded that for Somali and Ghanaian women in their study gender concordance of providers was less important than receiving a professional and respectful encounter.

There were also concerns that maternity wards were not providing an environment that was suitable for some ethnic minority women's needs. Access to appropriate, halal food during hospital stays was highlighted as an issue for Muslim women in Bawadi and colleagues' primary study¹⁵⁰ and the review by Firdous and colleagues¹⁴⁴. Firdous and colleagues¹⁴⁴ also found concerns that medications may not be halal. McFadden and colleagues'145 review of evidence relating to Roma, Gypsy or Irish Traveller women identified evidence of tensions between health service rules and service users concerning who is allowed to visit on the maternity ward, with members of the Traveller community often preferring larger numbers of visitors and no restrictions to family and friends.

Higginbottom and colleagues'¹⁴⁸ review identified the dangers of conflicting medical advice for some immigrant women as cultural practices and the established medical and maternity care systems differ in the UK from those in the women's home countries. Fernandez Turienzo and colleagues'¹⁵⁵ participants also perceived there to be little or no representation of Black, Asian and other ethnic minority and disadvantaged groups in wider networks and facilities beyond the NHS to support pregnant women and new parents. The lack of safe spaces was felt to reduce engagement in services, education and social support.

Antenatal care

Six papers focused on aspects of care in the antenatal period, and some of the general reviews^{148,149} also included some relevant information related to the antenatal period. Four studies employed quantitative analysis of routine service data,158-161 and two used qualitative interviews^{162,163}. The ethnic categories employed were various, with Kapaya and colleagues¹⁵⁹ and Stacey¹⁶³ using the aggregated non-White category, the broad groupings White, Black and Asian being used by Baker & Rajasingham¹⁵⁸, and more specific categories being used in the remaining studies. All studies in this cluster were conducted in England, with four in London and two in the north of the country.

Four papers addressed the issue of late booking which has been identified by professionals as a concern among socially disadvantaged women, including those from ethnic minority communities. Clinical definitions of "late booking" vary, as did the way this was operationalised in the included studies reported below. Nevertheless, presenting at antenatal services at an advanced stage of pregnancy may mean that women do not have the opportunity to benefit from: early identification of pregnancy complications; antenatal information and advice; screening tests; and supported decision making regarding delivery choices.

Baker & Rajasingham¹⁵⁸ analysed retrospective routine data from a London teaching hospital using a model adjusted for age and number of previous births. They found no evidence that women in the Black and Asian ethnic groups were more likely to book late (beyond 18 weeks' gestation) than those women identified as 'Caucasian'. Meanwhile, those women in the combined ethnic group 'other' (which included women labelled as Chinese, Arab, Latin American and 'other') were 1.4 times (OR=1.38, 95% CI=1.06-1.81) more likely to book late (p= 0.016). Kapaya and colleagues¹⁵⁹ analysed retrospective routine data from a Sheffield teaching hospital. They used a combined 'non-White ethnic background' group and found that the odds of booking late for pregnancy care (beyond 20 weeks' gestation) was three times higher for non-White groups compared with the White ethnic group (OR=3.07, 95% CI=2.9-3.28, p< 0.001). McDonald and colleagues¹⁶⁰ analysed retrospective routine data across several London hospitals using univariate statistics. They reported that late booking of first antenatal appointments (more than or equal to 10 weeks' gestation) was more likely for all ethnic minority groups compared with the White British group, apart from for Mixed White & Asian and Mixed White & Black Caribbean women. The greatest difference in late booking compared to White British women was for Bangladeshi and Black African women (OR=2.05, CI=1.91-2.19 and OR=1.9, CI=1.8-2.0, respectively). Examining patterns for migrant women, authors reported that late bookings were more common than for Britishborn women for all apart from those born in Pakistan or India. The highest odds for late bookings were for Somalian and Romanian women. Women who had a first language other than English were also reported to be more likely to book late than those for whom English was their first language (OR=1.32, CI=1.28-1.37). This study also examined patterns of referral to antenatal services. Authors reported evidence to suggest that some groups of ethnic minority women were more likely to be referred late to antenatal services (greater than 8 weeks' gestation), particularly Black African women (OR=1.55, CI=1.46-1.65). However, this was not the case for Black Caribbean, Indian, or the Mixed White & Asian, White

& Black Caribbean, White & Black African groups. The authors concluded that both late referrals and post-referral delays in seeking care contribute to late booking appointments for some groups of women.

Shah and colleagues¹⁶¹ used a retrospective 'case-control' design to compare patterns of antenatal care and obstetric outcomes for a group of immigrant Chinese women with a group of 'British Caucasian' women matched for age and parity, using routine service data and patient notes, and employing univariate statistics. They reported that the immigrant Chinese women – 74% of whom had little or no understanding of English - attended on average one fewer antenatal appointment than the 'British Caucasian' group, and also booked on average seven weeks later (21.01 vs 15.35 weeks, p<0.001, Chi-squared test). Six of the Chinese women (4.80%) received no antenatal care prior to their admission for labour, in comparison to only two of the 'British Caucasian' women (1.60%).

Some evidence was available from primary studies in this cluster, as well as from the general reviews, on the possible reasons behind late booking. Khan's review¹⁴⁹ identified that delays in the booking appointment (first antenatal appointment) can be due to some women being unaware of the importance of the early booking appointment. Immigration status - and unfamiliarity with the UK system is reported to be associated with later booking and presentation to maternity services 148,149,162. Hatherall and colleagues¹⁶² found that ethnic minority women in London may not regard early booking as important for pregnancies with no apparent complications or unusual symptoms. But, studies also identified a lack of information in GP surgeries and community settings to flag up to women the importance of registering with a midwife¹⁴⁹. Access to antenatal care appointments is also delayed by language issues and lack of easy access to interpreter services 148,149,162. Further, for some immigrant women, the presence of female genital mutilation (FGM), differences between the maternity care systems of their countries of origin and the UK, arrival in the UK late in the pregnancy, frequent relocations after arrival, and misgivings about the benefits of antenatal

care, can deter uptake¹⁴⁸. Importantly, reasons for a late booking may also often be structural, for instance due to transport or childcare difficulties^{149,162,163}.

Higginbottom and colleagues¹⁴⁸ also draw attention to the ways in which Home Office rules and treatment of women without documentation and those seeking asylum can severely impact upon their receipt of timely antenatal care. The quote below comes from a study by Phillimore included in Higginbottom and colleagues¹⁴⁸

"The Home Office put me in detention centre so I could not attend my appointments. There were no maternity services there for me for the two months I was there. I was offered appointments, but they were cancelled at short notice without anyone telling me why."

African woman seeking asylum (p.35).

Antenatal group classes can also be a useful service during pregnancy, providing access to information and advice, and the potential to develop a peer-support network. Henderson and Redshaw¹⁶⁴ collected data via post questionnaires sent to an ethnically mixed sample of 347 women in 2014. They reported evidence that the aggregate group 'BME' women were significantly less likely to attend antenatal classes than the White group, due to not being offered them or them being fully booked up.

Ongoing attendance at antenatal care appointments during pregnancy can be compromised by the same factors that delay initial access. Disruption can be caused by language issues and lack of easy access to interpreter services 148,149. Evidence that poor reputations of antenatal services in specific communities and perceptions of antenatal care as a facet of the medicalisation of childbirth, can deter attendance was reported by Higginbottom and colleagues 148. Importantly, reasons for non-attendance at an appointment or a late booking may be due to social difficulties 149,162,163 or indeed

past poor experiences or miscommunication. However, Khan's review¹⁴⁹ suggests that non-attendance can be misinterpreted by midwives as deliberate avoidance of care, thereby contributing to poor relationships between women and care-givers. In some cases, low attendance at antenatal classes by some ethnic minority women has been linked to the fact that men were in attendance, and this was culturally inappropriate for them¹⁴⁹. Men from the Roma, Gypsy and Traveller communities may find attendance at antenatal classes culturally incongruent¹⁴⁵.

Stacey and colleagues¹⁶³ undertook a qualitative study in the North of England to explore the awareness of pregnancy related health messages, particularly related to risks of stillbirth, among migrant women from a wide range of countries. Authors reported that women were frequently familiar with key messages including being aware of the baby's movements and sleeping on their side, despite the term 'stillbirth' being unfamiliar. However, it was less clear that the importance of seeking care urgently in the event of decreased foetal movement had been effectively conveyed by health professionals. Respondents felt that information about healthy pregnancy should come from health professionals, from whom they currently received advice that they perceived to be trustworthy. Women emphasised the importance of trust in their relationship with health professionals, particularly in the absence of friends and family in the UK. They felt it was the responsibility of the midwife to develop this trust so that advice is conveyed effectively. There were mixed views on the utility of written information to communicate key messages about reducing stillbirth, since many did not, or could not, read.

Intrapartum care (labour and delivery)

Four papers reported on aspects of intrapartum care, three employing quantitative analyses, - two of routine data^{165,166} and one of a cross-sectional survey¹⁶⁴ - and one using qualitative interviews¹⁶⁷. Again, ethnic categorisation was varied. Gorman and

colleagues¹⁶⁶ focused on women categorised as Polish migrants, while Essen and colleagues¹⁶⁷ explored experiences of Black Somali women. Aughey and colleagues¹⁶⁵ employed broad groups – White, Black, Asian, Other – in their quantitative analysis, while Hendersen & Redshaw¹⁶⁴ used the aggregated 'Black or minority ethnic' group. Three of these studies took place in England and one in Scotland. In addition, Higginbottom and colleagues'¹⁴⁸ review included some relevant information.

Henderson and Redshaw¹⁶⁴ collected data via postal questionnaires to explore women's access to early labour care among an ethnically mixed sample of 347 women in 2014. They reported no evidence for ethnic inequalities in likelihood of contacting a midwife or the hospital at start of labour or in receiving appropriate advice from this source. They found no evidence in support of there being ethnic inequalities in being asked to stay at home or come to hospital during early labour. And, while there was some evidence of ethnic inequalities in access to antenatal classes (reported above), no evidence was found in support of differential experiences between the two broad ethnic groups in early labour care.

Gorman and colleagues¹⁶⁶ examined rates of Caesarean section (CS) among primiparous women in Scotland and compared CS rates for immigrant women from Poland with women born in Scotland using a linked dataset of routinely-collected administrative data from 2004 to 2009. The study quality was limited by high levels of missing data and only a small number of covariates. Authors reported lower rates of CS for the immigrant Polish group than for Scotland-born women. Shah and colleagues' comparative 'case control' study¹⁶¹ also looked at Caesarean section (CS). They reported that 'British Caucasian' women were twice as likely to deliver by CS as women in the immigrant Chinese group (22/125 vs 13/125, p=0.035, Chi-squared test), but reported no evidence of difference in the rate of assisted vaginal deliveries (involving the use of forceps or ventouse instruments). Four (3%) of the 'British Caucasian' women had home births, while no women in the immigrant

Chinese group delivered at home. Women in the immigrant Chinese group were more likely to experience a perineal tear (53.6% vs 36.8%, p<0.01, chi-squared-test), with 85% of these being second degree tears. There was no evidence to suggest differences across a range of other intervention and outcome measures - including epidural rate, duration of labour, episiotomy, low birth weight, mean five-minute Apgar scores, and infant mortality. Given that immigrant Chinese women may experience the kinds of communication difficulties reported above as impeding good quality care for other immigrant women, these findings resonate with the common finding of communication barriers resulting in unequal outcomes.

Aughey and colleagues¹⁶⁵ undertook a retrospective cohort study using linked routine data from the Maternity Information Systems (MISs), the Hospital Episode Statistics (HES), and the National Neonatal Research Dataset for the period 1st April 2015 to 31st March 2016. They looked at women having a singleton birth via spontaneous vaginal delivery to examine the characteristics of those who had a waterbirth. Logistic regression results, adjusted for potential confounders, showed that waterbirth was less likely to be recorded for women of Black (5.9%, adjusted OR=0.42 (CI=0.36-0.51)) or Asian (4.2%, adjusted OR=0.26 (CI=0.23-0.30)) ethnicity compared to White women in the sample (15.4%). A recorded waterbirth was also negatively associated with socio-economic deprivation. The authors concluded a need to ensure equitable access to waterbirth, though recognised limitations of poor data quality and completeness.

Essen and colleagues¹⁶⁷ investigated understandings of Caesarean section (CS) among immigrant Somali women in London through a qualitative interview study involving 39 women and 41 healthcare providers. The study revealed some important differences in understandings and perspectives between the two groups. Fear and anxiety towards CS was prominent among the women, while providers experienced Somali women's avoidance and refusal to undergo CS as stressful and risky. The study found that discussions with a

care provider about CS before birth was very uncommon among respondents, suggesting the need to develop opportunities for sensitive, routine conversations about the procedure and when it may be indicated. Furthermore, authors suggest that healthcare providers need to do more to understand, and respond to, the social context within which understandings of CS, and other aspects of pregnancy and childbirth, are shaped at community level for immigrant Somali women. This appreciation of wider socio-cultural context is important since critical decisions may be influenced by social actors beyond the woman and her immediate family. Two papers reviewed by Higginbottom and colleagues¹⁴⁸ reported similar findings, with fear of adverse outcomes and potential delays in seeking care once in labour being documented among immigrant Somali women.

Higginbottom and colleagues'148 useful synthesis of evidence relating to maternity care relationships between immigrant women and health-care professionals includes some material that relates to labour and delivery. They found evidence in several qualitative studies that immigrant women experienced midwives to be "unkind, unfriendly and uncaring". Further, they cited work by McLeish¹⁶⁸ that provided evidence that some asylum-seeking Black women experience healthcare practices as coercive, for example, in relation to decisions around hospital stays, induction or a Caesarean section.

Postnatal care & neonatal care

Four papers, all conducted in England, focused on aspects of postnatal (postpartum) and neonatal care. Three of the general reviews^{145,148,149} also included relevant information related to the postnatal period as did one of the more general primary papers¹⁵⁰. Three of the postnatal-focused papers employed qualitative interviews and focused on just one ethnic group, with Abdu and colleagues¹⁶⁹ exploring South Asian women's experiences of health visiting (n=15), Lam and colleagues¹⁷⁰ examining postnatal experiences of Chinese women (n=8), and McFadden and colleagues¹⁷¹ focusing on Bangladeshi women's experiences of breastfeeding (n=23).

The fourth, a low quality paper, employed a cross-sectional analysis of routine data to examine risk factors for admissions to neonatal units (n=133,691)¹⁷².

There was evidence across a number of studies to suggest that access to care in the postpartum period may be poorer among ethnic minority women than among White British women, but the studies were largely small-scale and the full range of ethnic groups were not included. Higginbottom and colleagues' general review¹⁴⁸ was the only source to comment on the immediate postpartum period. These authors identified some limited evidence that immigrant women may be poorly informed of the facilities available in hospital to support the immediate postpartum period. More studies raised concerns regarding poor access to services beyond the hospital period. Khan's general review¹⁴⁹ reported on two studies that indicated expectations of postnatal support were not met because 'BAME' women were less likely than White women to see a midwife post-discharge from the hospital.

Higginbottom and colleagues' review¹⁴⁸ that was focused on immigrant women identified evidence that a lack of money, particularly among women seeking asylum, limits opportunities to access postnatal services. The inability to buy clothes and pushchairs and to cover transport costs can mean women do not attend baby health-check appointments with health visitors. This review also reported on one study evaluating bilingual peer support for breastfeeding which found that the support worker did not inform immigrant women about available breastfeeding classes and none attended such classes.

McFadden and colleagues' review¹⁴⁵ of evidence relating to Gypsy, Roma or Traveller women identified evidence from two studies of poor access to health visiting, and that a high turnover of staff reduced availability of this service. Abdu and colleagues'¹⁶⁹ study found uncertainty among the South Asian women interviewed about how and when to access the health visiting service and confusion regarding their role in relation to other healthcare professionals. Participants felt they had

been reprimanded when they tried to access support at a time that was considered 'wrong' by professionals in the system. The small-scale study by Lam and colleagues¹⁷⁰ in Manchester provided evidence that Chinese mothers do not readily access postnatal support, and that a combination of communication difficulties due to limited English language skills and a perception that services are culturally inappropriate to their needs, deter engagement with mainstream services.

A further study¹⁷² used a retrospective observational design analysing neonatal unit admission data from the National Neonatal Research Database and data on live births in England from the ONS. The primary motivation for this study was the importance of keeping mother and baby together in the neonatal period, and the need to examine whether admissions to hospital of term babies could be appropriately managed in an alternative caresetting, thereby avoiding the separation of the mother-baby pair. Jaundice is a common neonatal condition that can be managed in a transitional care setting if identified early. The study concluded that jaundice was the most common reason for admission to the neonatal unit from home, and that Asian babies were over-represented among babies admitted to a neonatal unit for jaundice. The authors raise the question of whether babies could have been identified and referred earlier, given anecdotal evidence of patchy implementation of transcutaneous bilirubinometers and variable postnatal visit frequency nationally. Though not explicitly highlighted by the authors, it is worth noting that visual estimation of jaundice in babies is highly inaccurate, and may be particularly unreliable for babies with darker skin tones, raising the possibility that routine postnatal care practices may systematically disadvantage non-White babies by delaying access to care.

Evidence suggests mixed opinions among ethnic minority women of the immediate postnatal care they receive on the postpartum ward, but a consistent pattern for migrant women of unfamiliar care practices. Bawadi and colleagues' 150 study of Arab women identified the immediate postpartum period as the time when women felt particularly

poorly cared-for. Some respondents felt that midwives perceived them as demanding and complaining and failed to provide the help they needed at that time. Women felt mistreated, ignored and frightened by the unfamiliar care context. Similarly, McFadden and colleagues¹⁷¹ found that some, though not all, of the Bangladeshi women in their study felt poorly supported after birth, and contrasted the care with what they would have received in Bangladesh. The authors linked this inadequate care with many women struggling to establish breastfeeding, and noted that staff complied with women's request to introduce formula feeds without explaining the negative implications for breastfeeding.

"When this one was born, if I asked them to help me they would get angry with me, making an angry face. I just had the baby and I asked the midwife - I mean the nurse - to hold me to get up and she did not hold me."

Translated, McFadden¹⁷¹ (p.e128)

Higginbottom and colleagues' review¹⁴⁸ focused on immigrant women cited evidence from one study that hospital stays were longer than immigrant women had expected. Longer stays were required to address needs of mother and child, e.g., baby requiring antibiotics or the mother recovering from a Caesarean section. Firdous and colleagues' review¹⁴⁴ found evidence that the presence of men within hospital wards can impact negatively on some women's engagement with breastfeeding. In contrast to these negative hospital experiences, Higginbottom and colleagues' review¹⁴⁸ also reported a study in which migrant women of Middle Eastern and European origin rated the baby support received in the UK more positively than that in their home country. Women noted receiving appropriate information, and practical demonstrations from hospital staff, on a wide range of issues relating to caring for their new baby. In contrast, another study included in the same review reported that immigrant women can become confused

by conflicting information coming from NHS literature, health visitors, and from their own social network. Experiences of support beyond the hospital, and of health visitors, also appear to be very mixed. McFadden's review¹⁴⁵ of evidence relating to Gypsy, Roma or Traveller women highlighted one study in which Traveller women found postnatal care to be "interfering and unnecessary" (p.27) and reported on another that found a lack of trust in health visitors unless a previous relationship had already been established. In contrast, two studies in McFadden's review reported particularly positive experiences of health visitors among Gypsy and Traveller women.

Abdu and colleagues'169 study of South Asian women also found evidence that the individual support on offer from a health visitor is valued, particularly when suffering emotional distress. However, half of the participants seemed to lack confidence to engage in discussion with the health visitor to get the information they needed, despite being able to converse in English. Telephone contact was avoided by women due to fears of not being able to communicate effectively. Half the participants felt that their health visitor prioritised standardised advice, and this could leave women facing a tension between the advice given by health visitors and that provided by their family members.

McFadden and colleagues¹⁷¹ reported that the Bangladeshi women in their study were generally satisfied with the support from health professionals for breast-feeding received at home in the early postnatal period. However, seven out of 23 women felt that visits were rushed and too few.

Perinatal mental healthcare

Six papers were identified in the perinatal mental healthcare cluster. Two systematic reviews were included. Watson and colleagues¹⁰⁷ synthesised evidence relating to ethnic minority women's experiences of perinatal mental ill health, help-seeking and perinatal mental health services; while Prady and colleagues¹⁷³ synthesised evidence on ethnic (in)equity in the implementation

of guidance for the identification and management of perinatal mental health problems. One very small-scale qualitative interview study (n=6) involving White British, Pakistani and Bangladeshi women focused on experiences of bereavement support. 174 Watson & Soltani¹⁷⁵ fielded a small-scale online and face-to-face survey (n=51) to investigate women's experiences and opinions of perinatal mental health problems and services. Two quantitative papers were included. Jankovic and colleagues¹⁷⁶ analysed linked data from the Acute Inpatient Dataset and the Mental Health Services Dataset to explore access rates to secondary mental health services. Prady and colleagues¹⁷⁷ analysed data from the Born in Bradford birth cohort study to investigate associations between ethnicity and treatment for common mental disorders. These quantitative papers varied in their ethnic categorisations, with specific ethnic groups being used by Jankovic and colleagues. 176 but the aggregated 'minority ethnic' being employed in analyses by Prady and colleagues¹⁷⁷. All of the primary studies in this cluster were conducted in England. A small amount of information relating to perinatal mental health was also reported in one of the general review papers¹⁴⁹ and one general primary paper Fernandez Turienzo, and colleagues¹⁵⁵.

Five included studies provided evidence of ethnic inequalities in rates of access to perinatal mental health support. Jankovic and colleagues¹⁷⁶ concluded that access to mental health services during the perinatal period varies significantly between women from different ethnic groups. Findings suggested that women identified as Black African, Asian (including all sub-groups) and White Other had significantly lower access to community mental health services than the White British group. Large differences in the percentages of involuntary admissions were also found with White Other women, Asian women (all subgroups), Black African women and Other groups having statistically significantly higher percentages of involuntary admissions than White British women though small numbers meant that standardised rates could not be compared. Women in the Black African, Asian and White Other groups had a higher

number of attended community contacts and fewer non-attendances/cancellations of appointments than White British women, which suggests that observed ethnic inequalities in access are not likely to be explained by lower uptake among the ethnic minority groups. However, the study did not include any measure of mental ill-health so conclusions cannot be drawn about differential receipt of services in relation to need.

Prady and colleagues' study¹⁷⁷ employed multivariate regression with a range of covariates adjusted for, including presence of anxiety or depression, to examine treatment received by women in an aggregated ethnic minority group compared to White women. They reported that ethnic minority women were more likely than White women to receive no treatment (pharmacological or non-pharmacological) for a common mental disorder in both the antenatal period (Relative Risk (RR)=1.96, CI=1.14,-3.37), and in the first year postpartum (RR=1.74, CI=1.14-2.69 [compared with reference category 'pharmacological treatment']. Postnatally, ethnic minority women were also less likely to be receiving both types of treatment (pharmacological and non-pharmacological) compared with White women (RR=0.42, CI=0.26-0.68).

Prady and colleagues' review¹⁷³ concluded that there is evidence of inequitable implementation of the current UK guidance for the detection and management of mental health problems in perinatal women, with the most consistent evidence of disparity being for ethnic minority women. Differences in detection levels were reported in studies of both the antenatal and postnatal period. Healthcare professionals were less likely to ask ethnic minority women the case-finding questions included in current guidance. The authors found evidence that this disparity was apparent for both women who speak English, and those who do not. Watson & Soltani's 175 small-scale survey (n=51) in a northern city employed univariate statistics and provided evidence of access problems among ethnic minority women (though no comparison with White British women). Almost 60% of respondents reported that accessing mental health support during pregnancy or

shortly after birth was very difficult. Watson and colleagues'¹⁷⁵ review provided further evidence of poor access to perinatal mental health services for ethnic minority women. In addition to these studies, the qualitative study reported by John and colleagues¹⁵⁴ (included in the general cluster above), found that the majority of pregnant or early postpartum ethnic minority women interviewed said that they had not been routinely asked about their mental health in relation to the pandemic by healthcare professionals. This study included no comparator White group.

The included studies also provided evidence (of variable quality and volume) of a wide range of factors acting to impede access to care. Language barriers was a common theme, understood as impacting on women's ability to express their symptoms and seek services. Respondents in Watson & Soltani's¹⁷⁵ small-scale survey (n=51) identified language barriers as obstacles to access. Prady and colleagues' review¹⁷³ noted that provider concerns about communication difficulties, interpreter use and associated time-pressures was a prominent theme underpinning lower detection rates.

Low awareness of services among ethnic minority women was a further factor identified. In Watson & Soltani's small-scale survey (n=51), 67% of respondents could not name any sources of support for women with perinatal mental health problems. In Watson and colleagues'107 review, five of 15 included studies identified lack of awareness of services among ethnic minority women as a key issue. Watson and colleagues' review¹⁰⁷ also noted a range of other factors interplaying to reduce access, including: fear of being labelled an unfit mother and children being removed; fear of stigma; and perception that services on offer were not culturally appropriate nor compassionate. Practical and structural obstacles were also mentioned in some of the reviewed studies, including travel costs and competing childcare and household responsibility. Participants in Fernandez Turienzo and colleagues' study¹⁵⁵ (included above in the general cluster of papers), echoed some of these factors, highlighting stigma as well as the varied ways in which

mental ill-health is expressed and experienced across communities, which can discourage open discussion and engagement with services.

This review also highlighted negative provider attitudes and behaviours (both past experiences and/or expectations of) that have been found to discourage women from seeking support¹⁰⁷. Similarly, Watson & Soltani's¹⁷⁵ survey respondents identified health professional prejudice as an obstacle:

'(the) ingrained prejudices of healthcare professionals...play a huge role in the experiences of pregnant ethnic [minority] women. Unfortunately, racism does also play a role.'

(P51, Indian woman 'cited in Watson & Soltani¹⁷⁵')

The general review by Khan¹⁴⁹ included evidence from a primary study by McLeish and Redshaw¹⁷⁸ that suggested additional provider-related obstacles to the identification of mental illness and accessing of services by ethnic minority women. In this study, women reported that midwives appeared to be uninterested in the women's emotional wellbeing, often due to a busy workload. Women also felt stereotyped if they had a diagnosed mental health problem and felt they were being observed for signs of failure, which generated feelings of vulnerability. These findings were mirrored in the discussions in Fernandez Turienzo and colleagues' study¹⁵⁵.

Only two studies provided evidence on ethnic minority women's experiences of services in this cluster. Garcia and colleagues'¹⁷⁴ small-scale qualitative study (n=6) suggested similarities in the experiences of bereavement among Bangladeshi, Pakistani and White British mothers, including the offer of bereavement support being too early and not feeling comfortable with a male counsellor. However, inadequate responsiveness to religious views and needs was also identified as an issue for the Muslim women. Watson

& Soltani's¹⁷⁵ small-scale survey (n=51) in a northern city generated some limited textual data on experiences of care from women who had accessed support for their perinatal mental health problems. Women described care as culturally inappropriate, inaccessible and White-dominated, and expressed the need for staff education and service redesign.

Miscellaneous papers

Finally, three papers did not fit neatly into any of the clusters above. Deepa and colleagues¹⁷⁹ analysed routine data from one London hospital to assess women's satisfaction with care related to surgical intervention for ectopic pregnancy (n=324). The authors employed basic bivariate analyses and found no evidence of a statistically significant difference in the percentage of women who were satisfied with care across three broad ethnic group categories (Caucasian 86%, Black 75%, Asian 86%, p=0.48, Chi-squared statistic not reported).

Forde and colleagues¹⁸⁰ conducted a qualitative study in which they interviewed women in London who were living with type 2 diabetes (n=30) (and a sample of healthcare professionals) about their experiences of prepregnancy care. The authors did not report comparative findings by ethnicity, though the majority of the participants identified with an ethnic minority group. The authors reported a lack of awareness about the pre-pregnancy care needs, unhelpful communication between women and providers in relation to pregnancy intentions, and a lack of systemic incorporation of pre-pregnancy considerations into the care of women with Type 2 diabetes. Among the few respondents who had experienced prepregnancy care, experiences were positive.

Evans and colleagues¹⁸¹ undertook a systematic review to synthesise evidence relating to the healthcare experiences of women and girls who have undergone female genital mutilation (FGM) or female genital cutting (FGC). This international review included 18 UK studies, and some of these included information relating to maternity care. A positive finding from the review was that

women's accounts included many instances of good care and of being satisfied with their care. Narratives of satisfaction with a warm welcome and caring staff within maternity services, and responsiveness to language barriers, were found in six UK studies. At the same time, however, there was evidence of missed opportunities by healthcare professionals to raise the issue, and a lack of provision of information to women, even during pregnancy-related check-ups, with one UK study documenting women who had had no discussion of FGM/FGC prior to presenting in labour. Furthermore, some UK studies in this review found that women felt judged and discriminated against by those providing their pregnancy care; feeling that they were treated simplistically as victims and their culture was looked down upon. The review therefore concluded that there are very mixed experiences of care.

Stakeholder Engagement

Five stakeholders responded to our survey for academics and clinicians. Ongoing research of relevance within the NIHR Applied Research Collaboration for South London was highlighted. This includes analyses of linked data created via the eLIXIR partnership¹⁸², and a series of recent intervention studies assessing the effectiveness, and mechanisms of effect, of community-based antenatal care and continuity of carer for socially disadvantaged, including ethnic minority, women^{155,183-185}. Two further ongoing studies of relevance were identified: Enhancing antenatal care uptake in an ethnically diverse socially disadvantaged maternal cohort (EnhANCe Project) and Ethnic minority women's experiences of accessing antenatal care in high income European countries: a metasynthesis of qualitative studies¹⁸⁶.

These stakeholders identified areas where they felt maternity services required improvement for ethnic minority women including: higher quality and readily accessible interpreting services; enhanced cultural competence among staff; increased ethnic diversity of staff; more community outreach; identification of missed opportunities for referrals or early

intervention; and patient ambassadors to advocate for families in health settings. They also highlighted the CQC survey of maternity services that reported in January 2020 and identified the ongoing need for improvements in continuity of carer (CoC), access to midwives after giving birth, and perinatal mental healthcare. Currently, ongoing efforts to enhance CoC are underway, with 11 of the poorest areas in England having been given additional resource and support. Stakeholders also emphasised the importance of identifying examples of good practice at service level, sharing and evaluating these initiatives, so that local innovation can be built on elsewhere. More generally, stakeholders emphasised the importance of open conversations about how healthcare professionals view ethnic minority women and the areas of persistent poor practice, as well as increased awareness and acknowledgement of where NHS services are creating inequalities.

In addition, stakeholders drew attention to areas where they felt more research evidence is needed. They highlighted the importance of both more sophisticated quantitative analyses, and research that engages more closely with women and families to foreground their perspectives and experiences, especially those that are in very vulnerable circumstances. Better data linkage is needed at a national level to allow analyses of patient journeys and outcomes over the life-course and across service areas, and datasets that link mothers' and babies' data. More work is needed to ensure recording of ethnicity is complete and accurate in all NHS datasets. Stakeholders identified the need for sophisticated analyses that can elucidate the mechanisms of effect of initiatives that seem promising, as well as analyses that can examine intersectional inequalities, spatial and temporal patterns in maternity outcomes. Research that seeks to understand and inform action on system-level factors – structures, procedures and cultures of care - that prevent receipt of good quality care is also needed. Stakeholders advocated for co-produced research to develop interventions and make services more appropriate to the needs and priorities of under-served groups.

Stakeholder discussion groups organised by The Ubele Initiative and Race Equality Foundation reiterated some of the key messages from the published research, but also raised a number of other important issues that require attention. Both groups identified mistrust of services and fear as a barrier to accessing maternity care and other support. This was thought to be a particular issue among Gypsy and Traveller women and those seeking asylum or with refugee status, but was also believed to affect many other ethnic minority women. Participants talked of 'selfprotection tactics' - including hyper-vigilance over what is disclosed to professionals and avoidance of help seeking unless in an urgent situation - as ways to safeguard themselves and their children. Fear of being deemed 'unfit' and children being taken away was identified as a particular barrier to seeking mental health support. Other obstacles to timely perinatal mental healthcare included the limited responsiveness within services to cultural diversity in how mental distress is experience and expressed as well as persistent community-level stigma around mental ill-health. Both groups emphasised the value women place on continuity of carer during pregnancy, delivery and postpartum to enable trust-building, but felt that in practice care continued to be fragmented for many women.

Poor communication, language barriers and inadequate interpreting services were also prominent themes. Both groups described how language barriers could lead to misunderstandings and seriously impact upon the quality of care received, as well as unnecessary intervention. Lack of culturally appropriate services and limited cultural awareness among maternity staff were also raised as issues. Examples included antenatal classes that are White-dominated and result in ethnic minority women feeling excluded, unwelcome and 'othered', lack of accommodation of some women's cultural expectation of a doula during labour, and staff not appreciating the cultural reasons why women may not disclose a pregnancy early on. Racial stereotyping, discrimination and differential care were felt to be commonplace. Examples given included: Black women being called 'aggressive'; Black and White women being asked different questions reflecting assumptions about their circumstances and 'risk'; not being believed; and the 'Black people don't feel pain' trope. One participant also drew attention to the way in which medical practice based on the normative White body excludes and puts non-White bodies at risk e.g., hypoxemia in babies being recognised by the baby looking blue.

Other issues raised by these stakeholders that were not so evident in the published literature we reviewed, included the importance of community-based grass-roots initiatives that can better meet the needs of ethnic minority women, such as Gypsy and Traveller support organisations that liaise with NHS maternity services on behalf of women. The need for health navigation and support in understanding the NHS was also important for new arrivals. However, many of these community-based organisations lack funding and stability. Participants also raised the importance of diversifying the workforce across the country, and making complaints procedures easy and free of stress for women and families. One group also emphasised the persistently much higher rates of infant mortality among Gypsy and Traveller populations which they felt was not being addressed.

In terms of recommendations for improvement, these very much mirrored those from the academic and clinical stakeholders, with a strong focus on working closely with poorly served women, families and communities. Participants wanted healthcare practitioners to get out into communities, to build trust and learn more about the women they serve. This, as well as training, can help to build cultural competence and reduce fear and improve engagement.

Summary

The review suggested the central importance of women's relationships with care-providers, particularly midwives and heath visitors, during pregnancy and beyond. And, while positive relationships, particularly with some midwives, are documented, the evidence suggests that this is far from the norm. However, poor communication between women and providers was a prevalent theme. For women without English language skills, the lack of accessible and high quality interpreting services seems to be a common issue. But communication can also be compromised for British-born ethnic minority women, and migrant women who can speak English. A lack of trust, insensitive behaviour, lack of active listening by providers, and failure to bridge cultural differences, can impact negatively on communication for these women too.

A consistent theme across the review was women's experiences of negative interactions, stereotyping, disrespect, discrimination and cultural insensitivity. System-level factors, as well as the attitudes, knowledge and behaviours of healthcare staff, contribute to ethnic minority women feeling 'othered', unwelcome, and poorly cared-for. These factors appear to undermine trust and feed fear, which in turn are described as resulting in poorer access to, and engagement with, services. Immigrant women may face particular issues in navigating unfamiliar services and accommodating NHS healthcare information and practices alongside their own and their families' ideas of what is appropriate.

Quantitative data on ethnic inequalities in access to, and receipt of, particular NHS services or treatments, such as timely antenatal booking appointments, Caesarean delivery, or breastfeeding support, is patchy and inconsistent. A number of qualitative studies report ethnic minority women feeling underserved by community-based services that could offer support to pregnant women and new parents. Several studies highlighted the intersection of additional aspects of social disadvantage with minority ethnicity that

can further compromise women's access to, and positive experiences of, maternity care. Groups of women of particular concern include Roma, Gypsy and Traveller women, those seeking asylum or with recent refugee status, those with mental health conditions, and teenage women and young mothers.

We only identified one study that focused on ethnic inequalities in specific aspects of care of the newborn. This study showed that Asian babies were over-represented in admissions to neonatal units for jaundice.

Recommendations

Research

- Sophisticated quantitative analyses are needed in order to describe and understand patterns of maternity care and outcomes across a wider range of ethnic groups, as well as intersectional inequalities and spatial and temporal trends. Research is particularly needed to identify inequalities in care that contribute to differential perinatal and infant outcomes by ethnicity.
- Complementary research that engages closely with women and families to foreground their perspectives and experiences, especially for those in very vulnerable circumstances, is also needed. Stakeholders called for co-produced research to develop interventions and make services appropriate to the needs and priorities of under-served groups.
- Mixed method and theory-informed research is needed to completely understand the ways in which healthcare providers and patients develop their understandings of one another and how positive relationships between healthcare providers and ethnic minority women can be achieved consistently. There is a need to interrogate the complexity of racialisation processes and how these

are inflected by other markers of social status and difference alongside ethnicity. This work should include attention to understanding the institutional and system-level factors – structures, procedures and cultures – that undermine good quality care and how these can be recognised, resisted and transformed.

Policy & Practice

- Data linkage is required across routine NHS maternity and neonatal datasets to allow analyses of patient journeys and outcomes, across mothers and their babies, and across service areas.
 Work is needed to ensure recording of ethnicity is complete and accurate. There is also a need to develop systems for the routine collection of data relating to key mechanisms and exposures, particularly experiences of racism and discrimination.
- Renewed and serious efforts are needed to ensure ready access to high quality interpreting services and translated and audio format health promotion materials.
- There needs to be a serious commitment from NHS England and NHS Improvement to tackle racist attitudes and behaviours among healthcare staff, and address structural dimensions of NHS systems that discriminate against ethnic minority women and their babies.

Inequalities in Digital Inclusion and Access to Health Services

Introduction

In recent years, there has been a shift towards providing healthcare remotely, which has been rapidly accelerated by the Covid-19 pandemic. Despite this, there has been relatively little research on how this shift may have affected ethnic minority people's access to healthcare compared with the majority White British population. The recent Topol Review¹⁸⁷ stated that "digital health technologies should redress not reinforce inequalities, with particular attention given to vulnerable and marginalised groups" (p.10). But there have been concerns that some ethnic minority people may be both

less well digitally connected ^{18,188} (for example, have poorer, or no, connectivity to the internet, have poorer quality hardware) and less familiar with digital technologies, which may impact on their ability to access online services (such as AskmyGP, video appointments, digital healthcare apps) ¹⁸⁹. In this review, we focussed on ethnic inequalities in accessing online healthcare appointments and ethnic inequalities in the use of digital health applications, as this is where our searches identified literature.

Results

The searches identified a total of 615 papers from journal article databases and grey literature databases covering the period 1st January 2011 to 25th October 2021 (see Methods chapter for full details of databases used). A total of 283 duplicates were removed, leaving 332 records to be screened by title and abstract. Of these, 276 were excluded at the abstract screening stage, leaving 56 studies. The full text articles were sourced for these 56 studies, apart from for one study where the full text could not be retrieved¹⁹⁰. At this stage, 44 studies were excluded; the majority of these were excluded because they did not contain any ethnic minority specific data (n=26). A total of 12 studies were included in the review for this topic area. Appendix 7 summarises the flow of studies in the rapid review process in a PRISMA diagram³¹.

The main characteristics of the included studies are shown in a table in Appendix 8. The studies were published between 2014 and 2021. Nine studies contained data on adult populations only, and three harnessed data from child and adult populations. In terms of geographical spread, four studies were conducted in, and were representative of, the UK; two were conducted in England and one in Scotland. The remaining five studies were conducted in specific localities of England (Leicester, Enfield, Hampshire and South London). Nine studies were quantitative in nature, one was a mixed methods study, one was qualitative, and one was a randomised controlled trial (RCT). The level of reporting of ethnic categories varied in the included studies: two studies reported results by 16 ethnic categories as used in the 2011 census, one study reported nine categories, two reported aggregated categories within ethnic subgroups (i.e. White, Black, Asian, Mixed, Other), six studies reported only White and 'BAME'/ Non-White groups, and one study included South Asian groups only within which results were reported for six different ethnoreligious groups e.g. Pakistani Muslim (see Table 1). Out of the 12 studies, there were four related to the usage and acceptability of digital health apps and information; three related to ethnic inequalities in NHS services provided by telephone, and five regarding ethnic inequalities in the provision of online primary, secondary or tertiary NHS care services (see Table 1). Although services accessed by telephone are not digital services, they are a form of remote service which do not contain face to face contact and therefore are included here in order to provide a fuller picture of ethnic inequalities in services that lack face to face contact.

Digital Health Applications and Digital Information

All four studies in this section were conducted in 2020 or 2021. The first study, an online survey conducted by the Ada Lovelace Institute¹⁹¹ found no evidence in support of statistically significant differences between the broad categories 'White' and 'BAME' that were employed in the percentages of people using apps for: 1) contact tracing 2) medical consultation services or 3) symptom tracking apps. There were also no statistically significant differences between 'White' and 'BAME' groups in the percentages of people who reported being comfortable in using these apps. The study did not make any adjustments for age therefore it is not possible to see if the lack of difference reflected the on average age profile of 'BAME' groups, or if ethnic inequalities would be apparent, for example, for older groups. Similar patterns were found in the second study in this section¹⁹², an online survey of the UK YouGov panel, which found that there were no ethnic inequalities in how comfortable people were in using healthbased online tools or apps. However, in this study 'BAME' groups reported using online or app-based health resources less frequently. There were also no ethnic inequalities in how comfortable people were in sharing personal data via Covid-19 contract tracing apps either with the government or industry-led tracing apps, although 'BAME' groups were less likely to be comfortable sharing location data via these apps than White people. Dowthwaite and colleagues'193 study of the use of the NHS Covid-19 mobile phone apps found

that significantly fewer 'BAME' participants than White participants had downloaded the app (Chi-squared test statistic=4.7, p<.05) and more had deleted the app (Chi-squared test statistic =4.5, p<.05). Their study also found that ethnic minority participants were more concerned about how their data would be used compared with White participants. The study used basic statistical analyses without adjustment for covariates such as age or gender. Prinjha and colleagues'194 study of South Asian people in Leicester qualitatively explored their views on SMS text messaging to support medication adherence for Type 2 diabetes. Patients were positive about receiving short messages to help with adherence but also commented that messages could be sent in other digital formats (e.g., audio messages sent via apps such as WhatsApp) in English for people who can understand English but not read it, and audio messages in languages other than English for people who cannot read or understand English), and there should be face to face groups for people who do not use digital devices.

NHS Telephone Services

Warren and colleagues' RCT195 of patients' satisfaction with telephone GP triage vs nurse telephone triage vs usual care in order to get a same day GP appointment found that ethnic minority patients reported lower satisfaction scores compared with White patients (mean difference in scores=5.00, 95% CI=2.96-7.04) for all arms of the trial. Data for the ethnic minority patients indicated that GP triage was associated with greatest satisfaction, followed by usual care and then nurse triage. Ethnic minority patients reported greater ease of getting medical help in the GP triage arm (versus usual care) compared with White patients (p=0.025), although again, ethnic minority patients appeared to report poorer absolute scores than White patients across all three trial arms (e.g. in the nurse triage arm, the mean score for White patients was 19.9 (95% CI 18.3 to 21.5) compared with 26.0 (95% CI 22.1 to 30.0) for ethnic minority patients (higher score indicates greater dissatisfaction).

Cook and colleagues' study 196 analysed over 1.3 million calls to NHS Direct in England and Wales over the period 2010 to 2011 to assess uptake of this telephonebased service compared to what would be expected based on the 2001 census population data. Chi-squared tests were performed to assess under-use/over-use of NHS Direct. Residuals were standardised to 0; in the results below, scores less than 0 indicate less than expected use of NHS Direct, scores greater than 0 indicate greater than expected use of NHS Direct. There was lower than expected uptake across many ethnic minority groups (Bangladeshi, Indian, Pakistani, Black Caribbean, Black African and Chinese) at most age groups. However, there was a higher than expected uptake rate for Bangladeshi and Indian patients aged 60 years and older, with an uptake rate of 0.82 and 0.94 respectively (p < 0.001). A pattern emerged for Pakistani patients, whereby the older the patient the higher the uptake rate. For example, uptake rate for children aged 0-4 years was 0.66, which subsequently increased for patients aged 5–19 years (0.76), 20–29 years (0.80), and 30-39 years (0.86). However, the sample was compared to 2001 census population estimates, which is problematic as the study was conducted between 2010 and 2011 and evidence from the Census shows that the ethnic minority population grew considerably between 2001 and 2011, meaning that the population denominators used will be underestimates. Therefore, the usage rates reported by the authors are likely to be underestimates. Further, the estimates were not adjusted for health need, so it cannot be ascertained use of NHS Direct relates to differing levels of poor health by ethnic group.

In a subsequent study by Cook and colleagues¹⁹⁷ which looked at ethnic inequalities in referral patterns from calls to NHS Direct, the authors found that White British and Bangladeshi children living in the most deprived areas were most likely to be referred to urgent and emergency care, at younger ages. However, children characterised as Indian and Other White were least likely to be referred to urgent and emergency care. For older patients (60 years+), those who were characterised as

Bangladeshi were most likely to be signposted to urgent and emergency care, Other White were least likely to be referred to urgent and emergency services. However, regression analyses were not used to test the effects of all the relevant variables in one model, therefore it is not clear what the reasons for the reported ethnic inequalities were.

Online NHS Services for primary, secondary or tertiary care

Healthwatch Enfield¹⁹⁸ consulted with 1,071 residents in Enfield, London, via an online survey and face to face engagement sessions to ascertain their views on digital appointments in primary care. Differences were reported between ethnic groups in awareness of GP online services, such as booking appointments and ordering repeat prescriptions online, with awareness for the Black group being lowest out of all ethnic groups [White (79%), Other (74%), Mixed (74%), Black (64%), Asian (76%)]. The uptake of GP online services was found to be similar for most ethnic groups apart from those identifying with the 'Other' ethnic group (White (31%), Other (24%), Mixed (37%), Black (31%), Asian (33%)). Ethnic minority groups were more likely than the White group to say they would use an online symptom checker (White (58%), Other (68%), Mixed (62%), Black (68%), Asian (66%)), and the Asian group was most likely to say they would e-mail a GP to seek medical advice (White (65%), Other (65%), Mixed (68%), Black (61%), Asian (75%)). Statistical testing was not carried out on the data to ascertain if the differences were statistically significant. Further, the survey was not representative of the local or national populations, and reasons for ethnic inequalities were not explored by the authors, despite some qualitative comments being collected by the study. Further it must be noted that two of the questions (using an online symptom checker and e-mailing a GP for advice) asked about future intention rather than past behaviour. The report also comments that people who lived in more deprived areas of Enfield were less likely to use video calling for appointments, in part because they preferred

to see a GP or nurse in person, but also due to a lack of computer literacy and lack of access to the right equipment. However, no explicit link was made between this observation and the findings of the survey. An analysis of usage of the My Diabetes My Way electronic patient health records (EPHR)199 in Scotland found that there was a less than expected usage of this resource by ethnic minority patients when compared with estimates of Scotland's diabetic population (chi-squared statistic not reported, p<0.001). The analysis also showed that users of this service were less likely to live in deprived areas and tended to be younger. The authors comment that the lower usage by ethnic minority groups might be partially explained by the service being available in English only.

One study²⁰⁰ conducted in South London compared online and in person sexual health clinic users and found that all ethnic minority groups were less likely to use online services to order self-sample test kits for sexually transmitted infections (STI) compared with the White British group. One further study²⁰¹ explored the acceptability of three digital services as potential platforms for sexual reproductive (SRH) health advice, (1) video consultations via Skype, (2) live webchats with a health advisor, and (3) artificial intelligence (AI) enabled chatbots. White people were more likely to find a webchat acceptable compared with a combined ethnic minority group (OR=2.87, 95%CI (1.30, 6.34)), but there were no differences in the acceptability of the other two digital services. One study of pregnant women attending a virtual antenatal clinic at a UK tertiary care obstetric care centre²⁰² found no evidence of ethnic difference in reported preference for virtual versus face to face clinic type between White and combined ethnic minority groups (p=.93).

Stakeholder Engagement

In our consultation with academics and clinicians, we received only one response from an expert on digital inequalities in healthcare, but this person did not work on ethnic inequalities specifically. They commented that they did not know of any review articles that

examine race or ethnic inequalities in relation to digital health, but a review in this area was needed. The review would bring together research on (i) digital health inequalities, pulling out relevant work on ethnic inequalities, specifically and (ii) ethnic inequalities in health and health care.

In the stakeholder engagement workshops with community and health practitioners working in the field, conducted by our research partners, Race Equality Foundation and The Ubele Initiative, there was acknowledgement that digital appointments (with the GP for example) benefited people at the height of the pandemic, and some advantages of digital healthcare were identified. Participants acknowledged that digital appointments can save time, meaning individuals do not have to take time off work, as well as stating that younger service users, with good digital literacy and access to appropriate devices, would find healthcare access easier and more convenient. There was also acknowledgement that digital access can be beneficial for parents unable to arrange childcare, and for those who have to travel long distances to access care.

Overwhelmingly, participants in the stakeholder engagement groups felt that digital access brought more problems than advantages. As was highlighted in the review of the literature summarised in this chapter, participants felt that low digital literacy levels, limited digital skills (e.g., lack of access to an email address), and differential access to equipment produced barriers to the implementation of successful digital appointments. This was discussed with regards to Gypsy and Traveller communities, Roma communities, and older ethnic minority populations, particularly those in sheltered housing. One community practitioner commented:

"we were successful in applying for funding to be able to buy tablets that we could give to some clients but they needed the support of a relative or carer to be able to help them log on to online activities or to log on services, and so I just really think we're pushing towards a digital era but there will always be people that it won't be appropriate for".

People were worried that a move towards digital healthcare would further increase difficulties in accessing health appointments and add to stress. Participants cited an increase in time to obtain appointments with healthcare staff as well as an increased tendency for miscommunication in digital appointments, due to non-verbal cues being missed in some appointments, with people who did not speak English particularly concerned about digital appointments and digital communication. For some people who do not speak English, there was an increased reliance on family members to translate e-mails and text messages from health service providers. Practitioners in the groups also felt that safeguarding issues were also less likely to be picked up in digital consultations. Some participants reported that ethnic minority patients expressed distrust and concerns over the sharing of their data in a digital form as they are concerned about where the information will go; this was particularly the concerns of some migrant communities where some may have uncertain immigration status.

There were also concerns that a move towards digital appointments has led to the disengagement with health services for some. Disengagement was said to be an issue for people leaving specific types of hospital care, (e.g., substance misuse and addiction services), who need a lot of support and perhaps are not in the right frame of mind to be able to cope with online appointments. The issue around not being comfortable with digital appointments was shared by a practitioner working with Gypsy and Traveller communities, who raised a number of issues including people feeling uncomfortable sharing photos

of body parts with a GP via the internet. For some people, especially older people, the lack of intimacy in an online interaction was said to be off-putting. Further, systems can fail during virtual appointments or there may be poor internet connectivity, both of which affect the quality of interaction and assessment. It can also add further anxiety and delays. Practitioners stated that many older ethnic minority patients and patients who did not speak English had a strong preference for in person face to face appointments. One practitioner commented:

"having a conversation with this person on screen is just not working...and to show a body part too, as part of an examination. No, it's just disastrous".

Many felt that digital access was widening health inequalities, rather than reducing them, and affecting those already most vulnerable. Practitioners commented that often in ethnic minority communities, individuals can delay attending care due to mistrust of health services. A move to digital healthcare is likely to delay access to care further, as some ethnic minority patients (particularly older patients and those who do not read and/or speak English) are unable book appointments via email or on apps so they have long waiting times on the telephone, leading to appointments being booked much later than those who are able to use digital systems.

Summary

The review found evidence of ethnic inequalities in digital access to services, but these were not uniform across services, settings or groups. There were very few documented ethnic inequalities in attitudes towards using digital health apps; ethnic minority and White participants were generally equally comfortable using these apps, but with some evidence that ethnic minority participants might use apps less frequently. The studies indicated to some extent that this may be borne out of mistrust of intended

uses of data by government agencies. There was also evidence to suggest that there may be particular issues affecting older ethnic minority people due to a lack of access to digital devices, a lack of digital literacy or due to digital applications not being made available in languages other than English. There were some ethnic inequalities in the use of NHS telephone services with lower use of NHS Direct services by most ethnic minority groups compared to the White British group. There was evidence of ethnic inequality in referral to urgent and emergency care services by NHS Direct for Bangladeshi people, and this was particularly the case for those living in deprived areas, but there were no inequalities found for other ethnic minority groups. There was also evidence to suggest that ethnic minority people were less satisfied with telephone triage systems in GP surgeries compared with their White counterparts, were less likely to use online services for STI testing and were less likely to have used electronic health records to check their diabetes results. There may be some ethnic differences in the awareness of GP online services and willingness to e-mail a GP for medical advice for Black ethnic groups compared with the White group, but these differences were not statistically tested (only percentages reported). There were no ethnic differences in women's preference for the format of antenatal clinic (virtual vs. face to face).

Recommendations

Research

 A systematic review of ethnic inequalities in access to, experiences of, and outcomes of digital healthcare (using a broad definition to include remote and digital appointments, the use of healthcare apps) is required to ascertain the extent of evidence in the field. The recommended review could be extended to cover the rollout of other digital services (in the public and private sector) to obtain evidence that the NHS could incorporate. • Research in this area should ensure that the ethnic categories employed are disaggregated as far as possible so that the experiences of different ethnic groups can be identified, as suggested by our stakeholder input. Further, where possible, there should be a specific breakdown of results by age, as our review indicated that ethnic minority older people particularly, may find digital healthcare inaccessible.

Policy & Practice

- There needs to be digital literacy support (perhaps in the form of community digital hubs) for those who struggle with basic digital access. This should be in various mediums and languages taking into account different styles of learning and understanding. For example, health services could use audio and video messages in local public places and spaces, for a targeted approach, as well as using WhatsApp video and audio messaging to communicate directly with patients. Options to receive digital devices should be offered to patients where needed.
- Undertake thorough evaluations of projects funded under the Adoption Fund by NHS X which are making use of digital technologies for patient care. For example, Cambridgeshire and Peterborough Integrated Care Service (ICS) are undertaking Empowering Digital Access in Maternity Services (EDAMS) to identify what the main barriers and blockers are to accessing digital services within the maternity pathway, and North West London CCG are undertaking a comprehensive review on patients receiving or needing community or mental health treatment to understand the scale of digital exclusion across North West London.
- NHS England should make mandatory equality assessments which are recommended under the Public Sector Equality Duty (PSED) for any services moving from in person to digital appointments in order to assess the extent to which ethnic minority groups would be affected by such a move.

Inequalities in Genetic Testing and Genomic Medicine Studies

Introduction

This chapter provides a review of three related areas: ethnic inequalities in access to genetic services, the representation of ethnic minority groups in genomic studies, and ethnic differences in risk scores demonstrated in genome wide association (GWA) studies. In terms of genetic testing and counselling services, there have been concerns that these services are not equally accessible for ethnic minority patients as they are for the White majority population in the UK¹⁹. Although we are now beginning to see some national initiatives to now improve access to genetic services, for example, for families practising customary consanguineous marriage, which is being led by the NHS England and NHS

Improvement Maternity Transformation Programme.

It has also been established that many large genome wide association (GWA) studies lack ethnic diversity and relatedly, this has called into question the utility and validity of conclusions that can be drawn from these datasets. ^{20–22} In the UK, we have seen the recent launch of the Diverse Data Initiative (September 2021), in order to address some of these concerns by increasing the representation of ethnic minority people in genomic datasets. Finally, this chapter reviews studies that attempt to understand the ways in which GWA studies are used to establish differences in genetic risk for different conditions, by ethnic group.

Results

The searches identified a total of 1,219 papers from journal article databases and grey literature databases covering the period 1st January 2011 to 25th October 2021 (see Methods chapter for full details of databases used). A total of 375 duplicates were removed, leaving 843 records to be screened by title and abstract. Of these, 739 were excluded at the abstract screening stage, leaving 105 studies. The full text articles were sourced for these 104 studies, apart from for one study where the full text could not be retrieved²⁰³. At this stage, 80 studies were excluded. Over half of these studies were excluded because they did not contain any ethnic minority specific data or did not report data by ethnic group (n=46). We also identified 30 references from stakeholders; we assessed the full texts of these and included two in the review. A total of 26 studies were included in the review for this topic area. Appendix 9 summarises the flow of studies in the rapid review process in a PRISMA diagram³¹.

The main characteristics of the included studies are shown in a table in Appendix 10. The studies were published between 2011 and 2021. Out of the 26 studies, nine were related to experiences of genetic testing, screening or counselling (in antenatal or prenatal services, cancer screening, inherited eye disorders or general attitudes towards genetic testing). Two of these were systematic reviews (comprising mainly UK and US data), three were conducted in the UK, one was conducted in England, one in High Wycombe, one in Yorkshire, and one in the areas of Bradford, Blackburn and Derby. Three studies provided information about the ethnic diversity of samples in genomic wide association (GWA) studies or studies that collect genetic material from participants; of these one was conducted in England, one in South London, and one was a scientometric review (scientific analysis of literature in the field) of diversity in GWA studies. There was only one study that was able to provide data about ethnic minority people's attitudes towards being involved in genomic research studies; this was carried

out in the areas of Bradford, Manchester, Sheffield, Nottingham, West Bromwich, and Ipswich. The remaining 13 studies were from GWA studies (some in the UK but some using global data) to show differences in polygenic risk scores (PRS) for diseases or conditions by ethnic group. Although the focus of this review was UK-specific, it was important to include these studies as many GWA studies use samples from different countries to either increase sample size or replicate findings.

All the studies reported here were conducted in adult populations. Eighteen studies were quantitative in nature, four were qualitative, two were systematic reviews and one was a scientometric review. The level of reporting of ethnic categories varied in the included studies. The studies on genetic testing and counselling which were mainly qualitative tended to be of experiences within particular ethnic groups, and there were more studies in this area focussed on Pakistani people in the UK. The genome wide association (GWA) studies often did not report ethnic groups (using UK customary terminology) but tended to report results by ancestry groups e.g., European, non-European, South Asian, African/ African-American.

Genetic testing and counselling

Nine studies were identified in this area. Five studies focussed specifically on prenatal or antenatal genetic testing and diagnosis. Yu's²⁰⁴ systematic review of issues around antenatal screening and prenatal diagnostic testing for genetic disorders among women of Asian descent in Western countries found evidence that South Asian (Pakistani, Indian and Bangladeshi) women were less likely to be offered prenatal diagnostic testing for thalassaemia. Two studies in Yu's review focussed on Pakistani women's views towards prenatal diagnosis (for genetic conditions); one study (n=138, quantitative survey) found that Pakistani women were more likely to be in favour of this testing compared with White women and the other study (n=19, qualitative)found that there were very few differences in attitudes to prenatal diagnostic testing between Pakistani and White women. A further study of Pakistani women in Yu's review found that the majority (88%) of women sampled had not been asked for their consent for thalassaemia testing. However, most of the studies in Yu's review were more than 10 years old and some were more than 20 years old.

Alsulaiman and colleagues'205 survey of White and Pakistani women found that White women in the UK had significantly less favourable attitudes towards prenatal testing for 30 different genetic conditions than Pakistani women (Chi-squared statistic=46.8, p<0.001) i.e. White women were less likely to say they wanted testing for a variety of conditions compared with Pakistani women. However, the study was of low quality with authors failing to report on sampling strategy of the survey and which geographical areas the survey was distributed. Further the analyses were basic without any statistical adjustment for confounders such as age. Lewis and colleagues'206 UK survey of 585 women who had been offered non-invasive prenatal testing (NIPT) for Down's Syndrome found some evidence of ethnic inequalities in making informed choices (conceptualised by the authors as whether women had good knowledge about NIPT, whether they evaluated the pros and cons of the test, and if their eventual decision about the test matched their attitudes) about NIPT. Multivariate regression showed that White women had almost three times the odds of making an informed choice about NIPT than other ethnic groups (all ethnic minority groups combined: Black, Asian, Mixed and Other) (OR=2.78, 95% CI=1.42-5.46, p=0.003). Tsianakas and colleagues'207 study of 21 women from White and different ethnic minority backgrounds examined the acceptability of being offered antenatal sickle cell and thalassaemia (SC&T) screening. The study found that women who did not speak English fluently found it especially difficult to access and communicate their needs to GPs, often not being aware that they had actually undergone SC&T screening. However, this study reports that there were very few differences between ethnic groups, but the authors do not report results to justify their answer; the qualitative results are not presented by ethnic group. Ahmed and colleagues'208 study of 98 women's

attitudes towards prenatal screening found that participants were concerned about health professionals imposing their own values on women and equated health professionals expressing their personal opinions with potentially forcing women to make a certain decision. Participants who did not understand the NHS system (because they had relatively recently migrated to the UK) reported finding it difficult to make a decision on antenatal genetic screening. However, this study was limited in its findings as many of the results were not presented separately for ethnic minority groups sampled by the study (Black African, Black Caribbean, Chinese, Pakistani groups as well as a White British group).

Two studies (Darr and colleagues²⁰⁹ and Shaw²¹⁰) were qualitative studies with Pakistani people examining attitudes towards the delivery of genetic services (counselling and testing). Both studies identified that some Pakistani people reported that they were assumed to be in cousin marriages by health professionals (e.g., GPs) when asking for information and advice about their children's disability and genetic testing. There was very little other information in these studies about participants' interactions with health services. Allford et al's²¹¹ systematic review of what affects ethnic minority (Black African, White Irish, and South Asian) people's access to genetic cancer services found that there was low awareness of these services amongst these groups. Additionally, White patients were more likely to be referred to genetic services and this may have been due to variation in the use of family history screening questionnaires in primary care. In Allford's review, it was found that South Asian people who did not speak English felt interpreters were making decisions on their behalf, or selectively choosing what information to translate for them. There was not much data on direct patient experience presented in Allford's review and those that were available from quantitative studies were limited and heterogeneous, mostly from observational surveys, with small or convenience samples limiting generalisability. Willis and colleagues'212 study of 200 people (in Yorkshire) to examine ethnic differences in attitudes to genetic testing for inherited retinal disease, and views on the availability of testing

found evidence of greater support for carrier testing for retinal disease in ethnic minority groups (Asian, Mixed and Other combined) compared with the White group (Chi-squared test statistic=11.69, p=0.003). However, most of the questions asked of participants on genetic testing were not reported by ethnic group. There were some longer answers (because the study was conducted over the telephone) which were not separated by ethnic group either.

Representation in genetic databases and involvement in genetic research

This review only identified one study of ethnic minority people's views towards taking part in genetic research - Skyers' study²¹³ conducted in 2018 which qualitatively explored Black Caribbean and Black African people's views and knowledge of the 100,000 Genomes Project (a now-completed initiative to sequence 100,000 genomes from NHS patients with rare disease including rare forms of cancer). A key finding of the study was that Black Caribbean and Black African people have concerns about participating in studies collecting genetic data due to historical experiences of racism; the experiences cited were both personal experiences of racism endured by participants and major racist studies in health e.g., the Tuskegee syphilis study. Participants had little knowledge about the 100,000 Genomes Project and on review of the project advertising materials, found them to be uninviting and too technical. They also expressed fears about the abuse of their genetic data being used for harm, and had concerns about the future privacy of the data and if it could be used by third parties outside of the NHS. However, there was acknowledgement by participants that non-participation in genetic studies would mean knowledge about diseases that disproportionately impact Black people would be limited. But participants felt that those running genetic studies needed to be build a trusting relationship with Black groups in the UK in order to encourage participation.

Three studies provided information on the representation of ethnic minority groups in genetic studies or studies that collect genetic material. Mills and Rahal's²¹⁴ scientometric review of genome wide association (GWA) studies found a lack of ethnic diversity in GWA studies across the globe. Studies published between 2005 and 2018, aiming to discover new genetic pathways, have been highly dominated by participants of European ancestry (86.03% of total samples). The analysis also showed that the percentage of European people in GWA studies fluctuates considerably (as high as 90.76% in 2016 and as low as 71.98% in 2012). Further, the way in which ancestry descriptors are used in GWA studies were ambiguous in a fifth of reviewed studies e.g., there were 26 terms to describe participants of African ancestry. Saifuddin and colleagues'215 aimed to assess the representativeness of the King's College Prostate Cancer Biobank compared with the population that it serves (Guys and St Thomas' NHS Foundation Trust, London). The study found no differences in the distribution of ethnicity between the Prostate Cancer Biobank and the clinical population from which it was taken (Chi-squared test performed, p=0.507). However, ethnicity data were missing for 35.7% of patients in the Prostate Cancer Biobank calling into question the accuracy of these findings. Finally, Meisel and colleagues'216 study of consent to collect DNA in the English Longitudinal Study of Ageing (ELSA) and the Whitehall II Study of civil servants found that ethnic minority people were more likely than White participants to decline giving a DNA sample (8.2% vs. 2.2% in ELSA, p=0.012; 22.4% vs. 7.9% in Whitehall II, p<0.001). In ELSA, logistic regression showed that ethnic minority people were less likely to consent to DNA samples being taken compared with ethnic minority groups (OR=0.195, CI=0.058-0.652, p=0.008). The same statistical method yielded similar results in the Whitehall II study showing that White participants were three times as likely to consent to DNA samples being taken compared with ethnic minority groups (OR=3.428, CI=1.621-7.251, p=0.001).

Genome Wide Association (GWA) studies demonstrating ethnic differences (or lack of) in polygenic risk scores (PRS) or similar measures of risk

The review did not find any studies reporting on precision medicine being used in clinical practice in the NHS, tailored for ethnic minority people. However, we did identify thirteen GWA studies that provide evidence of similarities or differences in polygenic risk scores (PRS) or other measures of gene expression between ethnic groups. Although this review was focussed on the UK, some of the studies in this section were conducted using global samples (as is often the case for GWA studies), although we did not set out to search international literature.

Two studies in this section found that predictive power of genetic samples is improved when ethnically heterogenous samples are used. Marquez-Luna and colleagues'217 study empirically illustrates that developing a PRS to predict type 2 diabetes in more than one ethnic group greatly improves its predictive accuracy, even if used in a test cohort of only one ethnic group. Similarly, Gettler and colleagues'218 study showed that combining PRS scores from ethnically heterogenous populations produced a better predictive model for Irritable Bowel Disorder (IBD), and does so even for a White population. However, the predictive power of the PRS varied across ethnic groups, with lower predictive value for non-Europeans.

Six studies demonstrated ethnic differences in PRS or a similar measure. Bosch and colleagues²¹⁹ showed that tests used to diagnose cystic fibrosis, including genetic screening of newborn children, vary across Non-Asian (unspecified but probably predominantly White) and Asian (covering a heterogenous group of countries of origin including South Asia and South East Asia) populations. Cherny and colleagues'²²⁰ study using the UK Biobank to estimate genetic contributions to age-related hearing impairment found that PRS developed in a White sample were not as effective when

applied to a non-White sample (compared with a White confirmatory sample). Karunamani and colleagues'221 study using the Prostate Cancer Association Group to Investigate Cancer Associated Alterations in the Genome (PRACTICAL) dataset showed that polygenic hazard scores developed for risk of prostate cancer in European men were less useful for African men, and that by including additional single nucleotide polymorphisms (SNPs), the model for African men was improved substantially. Li and colleagues²²² applied PRS for ankylosing spondylitis (AS) in European and East Asian populations and showed good predictive value for a PRS developed for use in each specific ethnic group, but the study did not compare the utility of these different PRS for different ethnic groups. Sarnowski and colleagues²²³ provide evidence that levels of HbA1c are in part related to genetic variation, and that the strength of this genetic influence varies across European, African, Hispanic and East Asian populations. Hence, the utility of the HbA1c measure as an indicator of glycaemic control (and diagnosis) will vary, with a possible under-identification of cases of diabetes or poor glycaemic control for African and Hispanic populations. Finally, McInnes and colleagues²²⁴ identified significant variation in genetic predictors of drug response across people. They also found that the frequency of functionally deleterious genetic variants is greater in 'non-European' populations compared with European populations, and that many of the variants found in 'non-European' populations are not included in the currently used definitions.

Three studies did not find ethnic differences in PRS in predicting likelihood of having a health condition. Moll and colleagues²²⁵ found no difference in a PRS that was associated with chronic obstructive pulmonary disease (COPD) in European (OR per standard deviation (SD)=1.81, 95% CI=1.74–1.88) and non-European (OR=1.42, CI=1.34–1.51) populations. This study demonstrates the potential utility of a PRS, but, unlike other studies, does not identify ethnic differences in its utility. Perhaps this is because genetic prediction of COPD is often small in effect. Traylor and colleagues²²⁶ found that geneenvironment risk factors for rheumatoid arthritis

(RA) identified in European and Asian ancestry populations are relevant in African ancestry individuals. Strawbridge and colleagues²²⁷ identified SNPs associated with risk taking and provide evidence for consistency in their performance across ethnic groups; this was the only study identified by the review which was related to a behavioural trait rather than a physical health condition.

Two studies were conducted in monoancestral samples. Barfield and colleagues²²⁸ found methylation sites associated with daytime sleepiness that are unique to African American populations and Wang and colleagues²²⁹ derived a new genome wide polygenic risk score (GPS) for coronary artery disease (CAD) in South Asian populations. Neither of these studies made comparisons with European ancestry populations.

International Literature

In order to assess if we had missed important international studies, we conducted an additional search of the literature, using search terms to identify international studies. We screened 100 of the studies that we identified and found that: many of these papers covered a single ethnic group, defining their sample as White/Caucasian, or of European ancestry (this was also the reason for excluding a large number of UK studies); many of the studies used Mendelian Randomisation, using genetic measures (such as PRS scores) as an instrument to ascertain causality; many studies were not about examining genetic effects, or precision medicine more broadly but were instead qualitative or mixed methods studies examining the provision or tailoring of care to different groups, or interventions comparing treatments that are not medicine (for example, behaviour change, or psychological therapies). There were some studies (n<5 out of the 100 reviewed) that compared ethnic groups, but these were largely concerned with investigating genetic effects, rather than precision medicine. Overall, these studies had small sample sizes for non-White groups (and consequent reduced statistical power), but often (not always) they found ethnic differences, with genetic effects found for the

White population not replicated in the ethnic minority population. They did not offer clear interpretations of these ethnic differences, but suggested that they result from underlying ethnic differences in genetic architecture, and do not consider the possibility that they might result from very different environmental contexts.

Stakeholder Engagement

Four stakeholders responded to our survey for academics and clinicians, providing references in the area of genetic testing and precision medicine, as well as providing details about ongoing studies that are important in this field. In terms of genetic studies aiming to recruit sufficient sample sizes of ethnic minority groups, the Genes and Health study²³⁰ is one example of a UK-based genetic study recruiting people from East London, Bradford and Manchester with particular emphasis on recruiting large numbers of Pakistani and Bangladeshi people. Between April 2015 and June 2019, this study recruited 38,999 volunteers (all of whom are of Pakistani or Bangladeshi origin) but has an aim of recruiting 100,000 volunteers. Since the publication of Finer and colleagues' report on the Genes and Health study sample characteristics, the study team commenced recruitment of participants in Bradford and most recently, in Manchester. The success of the large number of volunteers may be due to the recruitment strategy used; it is mainly undertaken by bilingual health researchers in community settings, e.g., mosques, markets and libraries, as well as health care settings, e.g., GP surgeries, outpatient clinics. Stakeholders also identified the Genetics of Mortality in Critical Care (GenOMICC) Consortium which seeks to identify genetic markers of what predicts the need for critical care. The study aims to recruit 20,000 Covid-19 patients requiring critical care and 15,000 control cases (those who tested positive with mild symptoms). However, given the disproportionate impact of Covid-19 on ethnic minority groups²³¹, it is disappointing that there does not appear to have been a dedicated recruitment drive for this study to ensure sufficient numbers of ethnic minority

people to ensure a diverse sample. The only results that have been published by the study²³² used only the individuals of European descent for the primary analysis of genetic risk for critical care for Covid-19.

In the stakeholder engagement groups that were carried out by our partners, Race Equality Foundation (REF) and Ubele Initiative, the community practitioners that were involved in these groups echoed many of the findings of the review. In maternity services there is a lack of communication from health professionals about what genetic screening and testing are, with particular difficulties in communication and understanding for women who do not speak English fluently. Community practitioners stated that there were particular inequalities for Gypsy, Irish Traveller and Roma groups where knowledge of genetic screening, testing and services was very limited. Stereotypical and inaccurate views were held by some health professionals (e.g., GPs) assuming that genetic conditions were a result of close relative marriages (mirroring what was found in the published literature). In addition, there was a lack of knowledge amongst GPs of different genetic conditions that are most likely to affect ethnic minority groups, as well as reluctance to refer to genetic services, even when ethnic minority people asked to be referred. Participants across both stakeholder groups stated there was a lack of access to genetic healthcare specialists, not just at the diagnosis stage, but throughout the process of living with a genetic condition. The Sickle Cell Society has been involved in training sickle cell counsellors, and the development of counselling competencies, but they also mentioned the lack of genetic counsellors.

In terms of participating in genetic research, the two groups reported that ethnic minority participants may feel mistrustful of researchers' agendas, and there was misinformation amongst some ethnic minority groups that they would be 'experimented on' as 'guinea pigs'. However, this was balanced with views from many participants that this misinformation needed to be challenged in order that those affected by genetic conditions could reap the benefits of research.

The stakeholder engagement groups also identified some areas of good practice to increase knowledge around genetic testing. One participant in the REF stakeholder group that worked with the NHS screening programme to inform communities and address myths about sickle cell anaemia, reported that a family legacy DVD was developed and showed to ethnic minority communities most at risk of this condition. This included showing the film at Black film festivals, speaking about the issue on Black radio programmes and attending events throughout Black History Month. Another participant mentioned community-based best practice working with Gypsy, Irish Traveller, Roma and Asian communities to help them understand genetic conditions and how these are passed on to children. This included an organisation in Leeds that is developing cultural competence guidance for genetic counsellors. Alstrom Syndrome UK have also worked with ethnic minority families to develop information about genetic testing. Other work includes community-based practice by Lancashire community genetics team, and work funded by Alstrom Syndrome UK

"to develop a 'train the trainer' package to train midwives and health visitors who are working families where there is an increased chance of having a child with a genetic condition".

Summary

The review found some evidence of ethnic inequalities in attitudes towards accessing, and access to, genetic services, but some of the qualitative and quantitative studies were of low quality, and did not adequately report differences for each ethnic group represented in the studies. Most of the information on genetic services was around antenatal screening and testing. There was relatively little information on experiences of genetic counselling (studies only reported that it was difficult to access counselling but not on the quality of that counselling and whether there were ethnic inequalities in genetic counselling experiences).

The review found that ethnic minority people are not well represented in large GWA studies, although there are smaller local studies (King's College Prostate Cancer Biobank, Genes and Health Study) that have much larger proportions of ethnic minority participants. Results for large survey datasets showed that ethnic minority people were less likely to donate DNA in studies where they were already participants, but both of these studies (ELSA and Whitehall II) had relatively small samples of ethnic minority people and were samples of older people; it is possible that attitudes and behaviours of younger ethnic minority people towards participation in genomic studies may differ. However, Skyers'²¹³ study of Black African and Black Caribbean people towards participation in the 100,000 Genomes Project suggests that apprehension about participation may also be present for younger Black people.

There was a lack of basic reporting of sample sizes and which data sources had been used in some GWA studies, making it difficult to ascertain which countries studies had been undertaken in. The review found that developing polygenic risk scores (PRS) in multiethnic cohorts may give greater predictive power within and across ethnic groups. The review did not identify any studies that were using precision medicine in clinical practice.

Recommendations

Research

- Research is required to understand at what points in the care and referral pathway in genetic testing and counselling services, ethnic inequalities are apparent, and what the nature of these inequalities are. Particularly, quantitative and qualitative research is required to understand ethnic minority patients' experiences of genetic counselling. Many identified studies were concerned with antenatal screening and testing with very little research evidence on ethnic inequalities in access to other genetic services and technologies. A systematic review of ethnic inequalities in genetic testing and counselling should also be undertaken especially since research from the United States suggest that there are clear ethnic inequalities in relation to, for example, breast cancer genetic testing and screening²³³.
- Ensure research studies of ethnic minority groups are designed to address gaps in knowledge and to inform service provision and ensure a range of ethnic minority groups are represented. This should particularly be actioned by large funders of health research such as NHS organisations, UK Research Innovation (UKRI), National Institute of Health Research (NIHR) and The Wellcome Trust. Our review found that there was a substantial proportion of studies that focussed on Pakistani populations but none that focussed on for example, Gypsy, Roma or Irish Traveller groups despite previous evidence that these groups are particularly disadvantaged in access to health care¹⁴⁵.

- Increase the ethnic diversity of genomic studies. This is imperative if these studies are to be used in the future for personalised or precision medicine.
 Current initiatives by Genomics England, such as the Diverse Data Initiative are likely to benefit from using recruitment methods designed and run in partnership with the voluntary, community and social enterprise (VCSE) sector and via community settings, many of which have already established trust in ethnic minority populations.
- Genomics England should develop a scientific framework within which to conduct genomic studies that includes clear reporting on samples used, consensus descriptions of ethnic and ancestral groups.

Policy & Practice

 For ethnic minority people who do not speak English, interpreters must be provided for phone appointments, in GP consultation and maternity contacts in particular; the main points at which routine genetic screening and possible referral to genetic counselling and testing are likely to be discussed.

Ethnic Inequalities in the NHS Workforce

Introduction

Discrimination against ethnic minority staff within the NHS is a reflection of wider discrimination, racism, and health inequalities in the UK and globally. Data from the Workforce Race Equality Standard (WRES) in NHS England has shown that inequalities exist in NHS workforce for ethnic minority staff e.g., they are less likely than White counterparts to be shortlisted for jobs, they are more likely to report harassment, bullying or abuse from patients and only 40% of ethnic minority staff believe that their organisation provides equal opportunities compared with 88% of White staff^{234,235}. The Covid-19 pandemic has created additional ethnic inequalities in the NHS workforce (as well as exacerbating existing inequalities), with evidence that ethnic minority staff are more likely to die from Covid-19 than White staff²³⁶, as well as being in more exposed, frontline situations with poorer access to PPE.

This chapter provides a review of five areas of NHS workplace inequality for ethnic minority staff, that were identified in partnership with the Race and Health Observatory: (1) Covid-19 outcomes (e.g., infection, mortality) (2) the impact of Covid-19 on the NHS working environment, (3) racism in the workplace, (4) staff mental health and wellbeing and (5) career progression and pay gap.

Results

The searches identified a total of 2,488 papers from journal article databases and grey literature databases covering the period 1st January 2011 to 25th October 2021 (see Methods chapter for full details of databases used). A total of 1,081 duplicates were removed, leaving 1,407 records to be screened by title and abstract. Of these, 1,257 were excluded at the abstract screening stage, leaving 150 studies. The full text articles were sourced for these 150 studies, apart from for one study where the full text could not be retrieved²³⁷. At this stage, 124 studies were excluded. We also identified 67 references from stakeholders and other sources; we assessed the full texts of these and included four in the review. During the full text screening stage, we consulted with the NHS Race and Health Observatory to ensure the scope of the review on this topic met the needs of the RHO. In light of this consultation, we further narrowed the scope of the review and excluded full texts that we had identified pertaining to the topics of WRES, representation in the NHS workforce, barriers to staff recruitment, bullying and inequalities in disciplinary procedures. The references for these studies are provided in the reference list^{238–256}. However, it must be noted that we did not move these studies

to the data extraction phase, hence without examining them closely, we cannot definitively say that they usefully comment on ethnic inequalities in the NHS workforce although our full text screening suggested that they did.

A total of 30 studies were included in the review for this topic area. Appendix 11 summarises the flow of studies in the rapid review process in a PRISMA diagram³¹.The main characteristics of the included studies are shown in a table in Appendix 12. The studies were published between 2011 and 2021. The 31 studies were categorised into five areas (1) Covid-19 outcomes (e.g., infection, mortality) (2) the impact of Covid-19 on the NHS working environment, (3) racism in the workplace, (4) staff mental health and wellbeing and (5) career progression and pay gap. Ten of the studies sampled healthcare workers (broad definition), and two of these also included nonpatient facing staff, eleven studies sampled nurses, nurse managers or midwives, four studies were about doctors (including trainee doctors), two studies were specifically about psychologists, two related to pharmacists and one study was about inequalities faced by obstetricians and gynaecologists.

There were two papers reporting on ethnic inequalities in Covid-19 outcomes in healthcare workers, both of which were crosssectional quantitative studies. One paper used data from the UK, and one paper used data from both the UK and US. Eight papers contained data relating to ethnic inequalities in the workplace due to the Covid-19 pandemic. Of these, six used UK-wide data and one was a study conducted in London; they all used quantitative cross-sectional data. There were ten papers concerned with experiences of racism in the workplace. Four of these were cross sectional surveys (one conducted in the UK, two in England and one in London) and there was one systematic review that synthesised UK data on international nurses' experiences of working in the UK. There were four qualitative studies with two taking place in England, one in the UK and one in the North West of England. There was one mixed methods study that took place in two neighbouring cities of the UK, but only the qualitative results were extracted as the

quantitative results were not presented by ethnic group. There were five studies related to staff mental health and wellbeing (all cross-sectional quantitative studies); three of these took place in the UK, one covered England, Wales and Scotland and one took place in London and the South East of England. Finally, there were six studies related to career progression and the pay gap. Three of these were conducted with cross-sectional quantitative data (two in England and one in the UK) and three were qualitative studies (two conducted in England and one in the UK).

Ethnic inequalities in Covid 19 outcomes for the NHS workforce

Of the two studies in this section, one reported on ethnic inequalities in positive Covid-19 tests and one on antibody tests. Nguyen and colleagues'257 study of over 2 million frontline health care workers in the UK and US found that ethnic minority frontline workers were nearly five times as likely to report a positive Covid-19 test compared with a White general population reference group (Hazard Ratio (HR)=4.88, 95% CI=4.76-5.01). The risk for ethnic minority frontline healthcare workers was also higher than for White frontline healthcare workers who had a risk of three and half times that of the White general population (HR=3.52, 95% Cl=3.48-3.56). When reporting the results, the authors did not separate the UK and US samples. However, very few participants (6.5% of sample) were from the US. Shorten and colleagues'258 study of over 4,000 staff members in diverse clinical and non-patient facing roles who volunteered for SARS-CoV-2 antibody testing in England found that Black (OR= 2.08, 95% CI=1.25 to 3.45, p=0.005) and Asian (OR=1.61, 95%CI=1.27 to 2.04, p<0.001) staff were more likely to test positive for antibodies than White staff. There were no differences found for Mixed, White Other or Chinese ethnic groups, when compared with White staff.

Impact of Covid-19 on the NHS working environment

There were seven studies that reported on ethnic inequalities in the NHS working environment^{259–265}. Three studies contained information about inequalities in the provision of PPE. Ali and colleagues'259 rapid online survey of attitudes of healthcare workers (HCWs) in the UK about Covid-19 related deaths among healthcare staff found ethnic differences in a range of attitudes. Using Chi-squared tests, the authors found that ethnic minority workers were more likely to: be worried about Covid-19 related deaths in HCWs ('BAME': 76%, 'Non-BAME:' 63% (p<0.001)); to say that Covid-19 related worry affects their ability to care for patients ('BAME': 57%, 'Non-BAME': 31% (p<0.001)); and to have PPE concerns that were not resolved ('BAME': 60%, 'Non-BAME': 42% (p<0.001)). Norton and colleagues'264 study of over 2,000 trainee doctors reached found similar results. In their study, 47% of those identifying as White reported receiving sufficient information on PPE, compared with 33% of those identifying as 'BAME/mixed ethnicity' (Chi-squared test performed, p< 0.001). There was one study in the review by Carvalho and colleagues²⁶⁰ which described ethnic differences in success rates of suitable fit of respiratory protective equipment (RPE). By sampling over 1,000 HCWs in London, they found that successful fit of protective equipment was less likely in all ethnic minority groups compared with White HCWs (Asian OR=0.47, CI=0.38-0.58, p<0.001; Black OR=0.54, CI=0.41-0.71, p<0.001; Mixed OR=0.50, CI=0.31-0.80, p=0.004; Other OR=0.53, CI=0.29-0.99, p=0.043).

Three studies were related to the effect of working during the Covid-19 pandemic on staff wellbeing and working responsibilities. Gilleen and colleagues'²⁶² study of HCWs working in the NHS during the pandemic found that ethnic minority HCWs (OR=1.52, CI=1.04–2.23, p=0.0319) were more likely to report post-traumatic stress disorder (PTSD) symptoms compared with White HCWs. Although the study had a large sample size (n=2,773), it did not cover all NHS trusts (only

19.8% of Trusts (52 of 262 UK NHS Trusts) responded. McFadden and colleagues'265 study of HCWs' wellbeing during the pandemic found a significant difference in mean total wellbeing scores across ethnic groups, with Black people reporting the highest scores [better wellbeing] (F=8.303, df=3, p<0.001). No overall differences were observed in Work Related Quality of Life (WRQoL) scores when compared by age, gender, occupational group or ethnicity. However, there were details missing in the statistical reporting of this study; the coefficients for the regression models were not reported so the effect of ethnic group (and whether it is significant or not) is not available for readers. Further, ethnic minority HCWs constituted only 6.5% of the sample. Kapilashrami and colleagues'263 study of over 500 HCWS in the UK indicated that ethnic minority staff in senior roles were nearly four times as likely to be working in patient-facing roles as their White counterparts (OR = 3.83, 95% CI=1.05 to 13.77, p=0.04), suggesting that White HCWs in senior roles were less exposed than senior ethnic minority HCWs. Ethnic minority ethnic HCWs were twice as likely as White HCWs to work in areas with Covid-19 cases (OR = 2.68, 95% CI=1.77-4.06, p<0.01). The study also found that while ethnic minority HCWs overall were no more likely than White HCWs to be redeployed, ethnic minority staff in nursing roles were three times as likely to be redeployed than White nursing staff (OR=3.33, 95% CI=1.23-9.02, p=0.02). Ethnic minority HCWs were also more likely to be involved in service level implementation and planning (OR=2.19, 95% CI=1.42-3.37, p< 0.001), than White HCWs, and held more staffing and redeployment responsibilities compared to White HCWs (OR=2.63, 95% CI=1.13-6.07, p=0.02).

One report by the General Medical Council²⁶¹ which surveyed over 3,000 medical doctors found that during the Covid-19 pandemic, ethnic minority doctors were less likely to report that there had been positive impact in a range of work-related areas, compared with White doctors. However, only percentages were reported and there was no statistical analysis performed to see if the differences were statistically significant.

Racism in the workplace

There were ten studies categorised in this area and six of them²⁶⁶⁻²⁷¹ were undertaken with nurses (or student nurses and one sampled both nurses and midwives). Bond and colleagues'267 systematic review of qualitative research exploring the experiences of international nurses and midwives reported that international nurses described feeling distressed and confused and humiliated because of the covert and overt discrimination they experienced whilst working in the UK. The incidents of discrimination reported by participants included: 'patients who exhibited racist behaviours', 'refusing care from international or Black nurses', 'staff who would undermine the work of their international colleagues, or draw unfair conclusions about work ethic, motivation or character', 'managers who were seen to apply more scrutiny to Black international nurses working in their team' (p.5).

Likupe and colleagues'269 study of Black African nurses in the NHS found that racism was not only experienced from White British nurses, but also from other overseas nurses, as well as patients and managers. Black African nurses felt that their experience and knowledge in nursing were not respected. Some nurses spoke of how they were made to look stupid if they asked for help with new procedures and believed that this was a result of racism. Black African nurses in the study also identified elderly patients as having the most racist attitudes. Nurses perceived being ignoring by patients and their relatives as racism as they thought that it implied that Black nurses were incompetent. They also reported being prohibited from performing certain procedures and that the responsibilities they were allocated were a reflection of managers' lack of confidence in Black African nurses. Black African nurses were prevented from performing some procedures even when they were competent. In some cases, the nurses felt that their experience was not recognised, and if they voiced this to their managers, they were labelled as confrontational. Nurses said that allocation of responsibilities reflected managers' lack of confidence in Black African nurses.

Some of these findings were also reported in O'Brien and colleagues'270 study of overseas nurses from India, Philippines and Spain conducted in North West England. The authors found that overseas nurses were exposed to overt hostility and racism from patients in the workplace, there was exclusionary treatment of overseas nurses in work allocation (e.g., being allocated direct care rather than higher status tasks). There was also some evidence of discriminatory treatment from students nurses towards internationally recruited nurses who acted as their mentors in Scammell & Olumide's study²⁷¹. Hallett and colleagues'²⁶⁸ qualitative focus group study of student nurses' experiences of racism conducted in two neighbouring cities in the UK found that student nurses accepted the practice of not reporting verbal aggression as this is 'not what students do' (p.4). All the nurses in the study who reported verbal racist abuse reported that this was from patients, not staff. Alexis and colleagues' study of internationally recruited nurses' perception of discrimination, support, and their adjustment to a new environment sampled from 15 NHS hospitals found evidence that internationally recruited nurses from Africa, in particular, perceived discrimination to be evident in the workplace and perceived the support they received to be limited. The sample size was relatively small (n=188), and only basic statistical analyses were undertaken.

There were four studies that reported on racist experiences in the workplace for HCWs other than nurses. West and colleagues'272 report on the levels of reported discrimination for a sample of over 25,000 HCWs across 284 NHS organisations, found that discrimination is reported far more by people in non-White groups (25.6%) than by White staff (9.5%). The highest level of discrimination was reported by staff from Black groups (30.9%). The differences were particularly pronounced in relation to discrimination from patients, relatives and members of the public (21.7% for Black staff, 16.6% for all ethnic minority staff and 4.1% for White staff). Once other factors are controlled for (such as gender, age, occupational group), ethnic minority staff still report much more discrimination on the basis of ethnic background, with the rates for

Black staff 12 times higher than for White staff. Rhead and colleagues'273 quantitative survey of London-based healthcare practitioners (doctors, nurses, healthcare assistants and Improving Access to Psychological Therapy (IAPT) workers) found that Black (OR=3.08, 95% CI=2.00-4.74) and Asian (OR=1.95, 95% CI=1.23-3.08) staff were more likely to say they had experienced discrimination compared to their White counterparts. However, there were no ethnic inequalities found for staff from Mixed ethnic backgrounds. Johnson and colleagues'274 study of over 500 nurses and midwives from four hospitals in the United Kingdom found that ethnic minority nurses and midwives were three times as likely to have experienced discrimination in the workplace (OR=3.04, 95% CI=1.68-5.54). Odusanya and colleagues'275 qualitative study focussed on the experiences of Black and Asian female psychologists working in the NHS. Psychologists in the study reported that they felt like they stood out due to their ethnic background. One psychologist reported:

'When I work in quite an affluent part of town ... there are families who will just say, "I don't think you'll understand my family. I don't think you get us ... you're not like us enough, so can I see somebody else?"

(Farida) (p.279).

Staff mental health and wellbeing

There were five studies in the review that reported on ethnic inequalities in staff mental health, wellbeing or burnout. Three studies reported on burnout specifically^{276–278}. Deery and colleagues'²⁷⁶ London study of over 2,000 nurses found that experiences of verbal harassment were higher among ethnic minority nurses compared to White nurses (but only for experiences of verbal harassment from managers and colleagues, not patients). However, there was no difference in the effect of harassment on the outcomes. Nurses from ethnic minority backgrounds did not differ

from White nurses in terms of the impact of harassment on job burnout or intention to leave. Further, statistical tests for interactions between ethnicity and the different forms of harassment showed no differential effect on measures of wellbeing. The study did find evidence to support the view that effective anti-harassment policies are important for employee wellbeing. Employees were significantly less likely to experience job burnout or indicate an intention to guit their jobs if they believed that their organisation had effective policies in place to tackle harassment. Importantly, the perceived effectiveness of the policies had a greater effect on reducing intentions to leave for nurses from ethnic minority backgrounds than for White nurses. Bourne and colleagues'277 UK-wide study of burnout in obstetricians and gynaecologists found that rates of burnout were lower for the Asian Group (OR=0.74, 95% CI=0.60-0.91) but higher for staff reporting their ethnic background as 'Other' (OR=2.19, 95% CI=1.37-3.52, although there were no further details in the paper about which specific ethnic groups comprise this group. Graham-Brown and colleagues'278 study of renal speciality trainee doctors found that rates of burnout were higher for ethnic minority trainees compared with White trainees, and this pattern was more pronounced than for other medical specialties. However, the authors do not provide the figures to support their claim; the supporting evidence could not be found in the supplementary material to the article, which is where the authors stated it could be found.

One study (Summers and colleagues²⁷⁹) reported on ethnic inequalities in staff wellbeing for psychologists in the NHS, and found that on average, Asian psychologists reported higher wellbeing scores (as measured by the Psychological Practitioner Workplace Well-being Measure (PPWWM) and Short Warwick–Edinburgh Mental Well-being Scale (SWEMWBS)) relative to all other ethnic groups. However, the sample of Asian psychologists was small (n=66) compared with the total sample size (n=1,678) and the analysis was not adjusted for important demographic factors (age, gender, socioeconomic variables). Seston

and Hassell's²⁸⁰ study of work life balance in a nationally representative sample of pharmacists in Great Britain found that, relative to the White group, Indian, Pakistani, Asian Other and Mixed and Other (combined category) ethnic groups had greater problems maintaining a work life balance. There were no ethnic inequalities for Black and Chinese groups.

Career progression and pay gap

There were four studies reporting on career progression^{281–284}. Johnson and colleagues'²⁸³ survey of nurses and midwives in England found that ethnic minority staff had spent longer working at the entry-level grade (Band 5) over the previous 10 years and less time working at more senior grades (Bands 6 and 7). In terms of the barriers to career progression the study found that ethnic minority nurses and midwives were significantly less likely to have received professional training in the previous year (White rate=66.6%, ethnic minority rate=53.0% (Chi squared test statistic=5.90, p=0.015)). They also had to apply for a higher number of posts before gaining their first post at their current grade (White mean=0.81, ethnic minority mean=1.22 (t=-2.28, p=0.026)). However, there were no ethnic inequalities in the perceived level of managerial support for progression and ethnic minority staff were as likely to have applied for promotion in the previous year as White nurses and midwives. For those who had applied for promotion in the previous year, there was no significant ethnic difference in their success rate. The other three studies on career progression were qualitative in nature. Hatzidimitriadou and Psoinos'281 study of the professional development of doctors and nurses recruited from overseas found that participants with a temporary migration status experienced barriers and delays as they tried to develop professionally, whereas those with a more permanent status progressed more quickly. Howell and colleagues²⁸² study of female pharmacists' career choices which sampled 28 women in England found that most ethnic minority pharmacists in the sample did not

report barriers to their career progression. However, the few women who did report this, stated that career progression was based on personal connections with senior management. One participant commented:

'Well I was ready for a management position much earlier than I got one....I felt that the area manager at that time wasn't taking me seriously, but when the area manager changed, and another very good brown faced friend of mine put a good word in for me and that's how I feel I got my first management position faster... somebody I knew, who was also a brown face, who was high up and was in with that 'crowd' put a good word in for me and that's how I got my first management position'

(P13, British Pakistani cited in 'Howell and colleagues²⁸²').

Likupe and colleagues'284 study was the only one in the review that explored barriers to career progression for Black African nurses from the point of view of nurse managers. Some managers in the study admitted that they did not discuss any professional development plans with Black African nurses. One nurse manager (who the authors state was Black) expressed that Black nurses had to prove themselves if they wanted to move up the career ladder, including gaining extra qualifications, and even then, they did not gain the recognition they deserved.

Two studies reported on the ethnic pay gap. Appleby and colleagues'²⁸⁵ briefing report on the ethnic pay gap in the English NHS using over 1 million pay records of NHS staff found that overall, there was a pay gap in favour of ethnic minority staff (5.2%). However, more detailed analysis provided by the authors revealed that this advantage for ethnic minority was restricted to a few occupations and was driven to a substantial extent by the concentration of Chinese staff in

high paying positions, although it is not clear from the report which particular specialties they were concentrated in. For four major staff groups (staff supporting doctors and nurses (such as secretaries and ward clerks), nurses and health visitors, managers and senior managers, and consultants) pay gaps favoured White staff. It is important to note that the analysis does not take into consideration GPs, dentists (and the staff employed at their practices) or other 'contracted' staff, although the authors do not expand on this definition. Morris and colleagues'286 quantitative study of ethnic inequalities in GP wages found that ethnic minority GPs had lower income (6.9% less) but similar hours to White GPs. However, it must be noted that this was a convenience sample so may not be representative of all GPs in England.

Stakeholder engagement

We received four responses to our stakeholder engagement exercise with academics, clinicians and experts working in the field. Two stakeholders responded to our survey for academics and clinicians, providing references in the area of NHS workforce inequality, as well as providing details about ongoing studies that are important in this field. A further two interviews were undertaken via video call (by DK, lead author) with two policy and practice experts in inequalities in the NHS and social care workforce. Overall, the stakeholders' opinions were that there was a substantial amount of evidence that ethnic minority staff in the NHS were treated worse than their White counterparts, but the specifics of this treatment was not available for disaggregated ethnic groups (apart from for Black African nurses, where a number of qualitative studies^{269,287} have provided clear evidence of racial discrimination from staff and patients). Although this review focused only on the NHS workforce, the stakeholders we consulted stated that the inequalities faced by ethnic minority staff in the social care work force may be even greater. However, there are no national data collection mechanisms in place to assess these inequalities (such

as the WRES in the NHS). The Equality and Human Rights Commission (EHRC), at the time of writing, are undertaking an independent inquiry into racial inequality in the health and social care workplaces in England, Scotland and Wales, which is due to be published this year (2022). Our stakeholders also commented on the limitations of WRES in assessing workforce inequalities i.e., WRES only covers England, and it does not cover bank workers and outsourced workers (where more ethnic minority workers may be concentrated).

Summary

The review found evidence of ethnic inequalities across a range of professions and settings in the NHS. Two large studies showed that Covid-19 infection was higher in ethnic minority staff in the NHS, particularly for Black and Asian staff. There was also evidence to suggest that the Covid-19 pandemic has disproportionately affected ethnic minority HCWs working environment, in terms of access to adequate PPE and the greater negative effect of the pandemic on ethnic minority staff mental health. The UK-REACH study of healthcare workers^{288,289} will be important in the future for providing further national evidence on how ethnic minority workers have been affected both in terms of clinical outcome and their experiences of working in the NHS during the pandemic. The UK-REACH study group have published one preprint article²⁹⁰ stating that Asian HCWs were less likely to report access to adequate PPE. However, this paper has not yet been peer-reviewed and hence was not included in our report.

The review found evidence of NHS ethnic minority staff enduring racist abuse from other staff and patients and this was particularly stark for Black groups. Most of the qualitative studies on experiences of racist abuse in the NHS workforce have been undertaken with nurses (and particularly Black African nurses or those that have been internationally recruited), indicating a lack of research on the lived experience of other ethnic minority

groups working in the NHS. The review found limited and mixed evidence on ethnic inequalities in NHS staff mental health and wellbeing. Notably, there was very limited evidence connecting the racist experiences endured by staff and how this affects their mental health, wellbeing and likelihood of burnout, and indeed other health outcomes. The studies on career progression were largely qualitative and conducted mainly with women; these studies showed how racism played out in the workplace to hamper ethnic minority staff's career progression and professional development. There was also evidence for an ethnic pay gap in most staff sectors in the NHS, which was evident for Black, Asian, Mixed and Other groups and less so for Chinese groups. The review found evidence for an ethnic pay gap for GPs (although the data used for the study in question is now over 13 years old).

Recommendations

Research

- Conduct a systematic review of racist experiences in the workforce to see for which specific professions and settings there is evidence of racial abuse.
- literature) of what interventions work to improve racial inequality in large institutions. The review should be theory-driven, using a conceptual model which centres institutional racism. Reviews have been completed on a smaller scale^{291–293} already and there are examples of smaller scale initiatives^{294,295}, but there would be considerable added value of bringing these together with findings from international settings.

- Research needs to investigate how experiences of institutional, structural and interpersonal racism impact on both the mental health and career outcomes of NHS ethnic minority staff. Most of the evidence in our review treated mental health outcomes (broadly defined) and career progression as separate but the two are likely to be interlinked.
- More research is needed that investigates the impact of experiences of institutional, structural and interpersonal racism on both the mental health and career outcomes of NHS ethnic minority staff. Most of the evidence in our review treat mental health outcomes (broadly defined) and career progression as separate but the two are likely to be interlinked.

Policy & Practice

- National datasets such as WRES need to ensure that all NHS staff in all sectors, including casually employed staff and those working in subcontracted services, are represented in order to present a comprehensive and accurate picture of workplace inequalities facing ethnic minority staff within the NHS.
- NHS England and Improvement should review recruitment and staff development procedures to understand where the greatest barriers to ethnic minority staff's progression (promotion, career development, pay) lie.

Conclusions

The review found that there were widespread ethnic inequalities in healthcare in the areas reviewed, as well as ethnic inequalities present for the NHS workforce. Across the five areas reviewed, there were commonalities in the experiences of ethnic minority people within NHS services, and similar issues with the availability and quality of clinical data, NHS minimum datasets and data collected for research purposes. Some of the evidence that was reviewed was poor quality and there were some ethic minority groups for whom there was no research conducted on their experiences. One limitation of the rapid review, due to its nature of being 'rapid' was that there may have been some relevant studies that were not retrieved by our searches. We mitigated this, to an extent, by undertaking the stakeholder survey with academics and clinicians to identify important literature.

In this concluding chapter, we present the main findings of each of the topics reviewed and end the report with a list of critical actions (to be implemented by NHS organisations) to address ethnic inequalities in healthcare, based on the common issues we found across the topics reviewed.

Ethnic Inequalities in Mental Health Services

The review found evidence to suggest clear barriers to seeking help for mental health problems rooted in a distrust of both primary care and mental health care providers, as well as a fear of being discriminated against in healthcare. The review found this to be the case for many ethnic minority groups but with less evidence about the experiences of Roma, Gypsy and Irish Traveller and Chinese groups,

although evidence from our stakeholder engagement groups suggests that these groups may also be reluctant to seek help from services that they do not trust. Evidence from qualitative research suggests that the lack of appropriate interpreting services acted as a deterrent to seeking help.

Ethnic minority groups experienced clear inequalities in access to Improving Access to Psychological Therapies (IAPT); overall, ethnic minority groups were less likely to refer themselves to IAPT and less likely to be referred by their GPs, compared with White British people. Evidence was identified for inequalities in the receipt of cognitive behavioural therapy (CBT) with ethnic minority people with psychosis less likely to be referred for CBT, and less likely to attend as many sessions as their White counterparts. The evidence on ethnic differences in community services was less clear-cut, with some evidence to suggest differences in services such as Assertive Outreach and the use of crisis teams but no evidence for ethnic differences in engagement with home treatment teams. The review provided strong evidence of clear, very large and persisting ethnic inequalities in compulsory admission to psychiatric wards, particularly affecting Black groups, but also Mixed Black & White groups and South Asian groups. There was also evidence of harsher treatment for Black groups in inpatients wards, e.g., more likely to be restrained in the prone position or put into seclusion.

Evidence from the review affirms that some inequalities present for adult populations were replicated in younger populations. Parents reported their children facing the same barriers to accessing services as reported for adult mental health services. Two studies of young Black men showed that they were deterred from seeking help by their knowledge of injustices in mental health services relating

to Black Caribbean and Black African populations. Two large national studies found that ethnic minority children were more likely to be referred to CAMHS via social services, education or criminal justice pathways. This was particularly stark for Black children who were 10 times more likely to be referred to CAMHS via social services (rather than through the GP) relative to White British children.

Overall, the review found few national datasets with sufficiently high quality ethnic monitoring data to allow for robust analysis to investigate ethnic inequalities. Many recent reports from NHS Digital (on IAPT, for example) did not report differences in referral rates by ethnic group. National community survey datasets to allow population level analysis were also lacking. Similarly, many of the studies in this review that used clinical data originate from South London (particularly South London and Maudsley NHS Trust) where the linkage of data from clinical systems is more advanced.

Ethnic Inequalities in Maternal and Neonatal Healthcare

The review suggested the central importance of women's relationships with care-providers, particularly midwives and heath visitors, during pregnancy and beyond. And, while some positive relationships, particularly with some midwives, are documented, the evidence suggests that this is far from the norm. Poor communication between women and providers was a prevalent theme. For women without English language skills, the lack of accessible and high quality interpreting services seems to be a common issue. But communication can also be compromised for British-born ethnic minority women, and migrant women who can speak English. A lack of trust, insensitive behaviour, lack of active listening by providers, and failure to bridge cultural differences, can also impact negatively on communication for these women.

A consistent theme was women's experiences of negative interactions, stereotyping, disrespect, discrimination and cultural insensitivity. System-level factors, as well as the attitudes, knowledge and behaviours of healthcare staff, contribute to some ethnic minority women feeling 'othered', unwelcome, and poorly cared-for. These factors appear to undermine trust and feed fear, which in turn are described as resulting in poorer access to, and engagement with, services. Immigrant women may face particular issues in navigating unfamiliar services and accommodating NHS healthcare information and practices alongside their own and their families' ideas of what is appropriate.

Quantitative data on ethnic inequalities in access to, and receipt of, particular NHS services or treatments, such as timely antenatal booking appointments, Caesarean delivery, or breastfeeding support, is patchy and inconsistent. Qualitative studies reported that ethnic minority women feel underserved by community-based services that could offer support to pregnant women and new parents. Studies highlighted the intersection of additional aspects of social disadvantage with minoritised ethnic identities that can further compromise women's access to, and positive experiences of, maternity care. Groups of women of particular concern include Roma, Gypsy and Traveller women, those seeking asylum or with recent refugee status, those with mental health conditions, and teenage women and young mothers.

We only identified one study that focused on ethnic inequalities in specific aspects of care of the newborn. This study showed that Asian babies were over-represented in admissions to neonatal units for jaundice.

Ethnic Inequalities in Digital Inclusion and Access to Health Services

There were very few documented ethnic differences in attitudes towards using digital health apps; ethnic minority and White participants were generally equally comfortable using these apps, but with some evidence that ethnic minority participants might use apps less frequently. The studies indicated how this may, to some extent, be borne out of mistrust of intended uses of data by government agencies. There was also evidence to suggest particular issues affecting older ethnic minority people due to a lack of access to digital devices, a lack of digital literacy or due to digital applications not being made available in languages other than English. There were some ethnic differences in the use of NHS telephone services with lower use of NHS Direct services by most ethnic minority groups compared to the White British group. There was evidence of ethnic inequality in referral to urgent and emergency care services by NHS Direct for Bangladeshi people, particularly for those living in deprived areas, but there were no inequalities found for other ethnic minority groups. There was also evidence to suggest that, compared with their White counterparts, ethnic minority people were less satisfied with telephone triage systems in GP surgeries, were less likely to use online services for STI testing and were less likely to have used electronic health records to check their diabetes results.

Ethnic Inequalities in Genetic Testing and Genomic Medicine Studies

The review found some evidence of ethnic inequalities in attitudes towards accessing, and access to, genetic services, but some of the qualitative and quantitative studies were of low quality, and did not adequately report differences for each ethnic group represented in the studies. Most of the information on genetic services was around antenatal screening and testing. There was relatively little information on experiences of genetic counselling.

The review found that ethnic minority people are not well represented in large genomic wide association (GWA) studies, although there are smaller local studies that have much larger proportions of ethnic minority participants. Results from large survey datasets showed that older ethnic minority people were less likely to donate DNA in studies where they were already participants; but it is possible that attitudes and behaviours of younger ethnic minority people towards participation in genomic studies may differ. However, Skyers' study of Black African and Black Caribbean people towards participation in the 100,000 Genomes Project suggests that apprehension about participation may also be present for younger Black people.

There was a lack of basic reporting of sample sizes and which data sources had been used in some GWA studies, and many GWA studies only used 'European ancestry' participants in their analysis, making it impossible to investigate the role of ethnicity. However, the review found that developing PRS in multiethnic cohorts may give greater predictive power within and across ethnic groups, suggesting that the expansion of research beyond European ancestry cohorts will be very valuable. The review did not identify any studies that were using precision medicine in clinical practice.

Ethnic Inequalities in the NHS Workforce

The review found evidence of ethnic inequalities across a range of professions and settings in the NHS. Two large studies showed that Covid-19 infection was higher in ethnic minority staff in the NHS, particularly for Black and Asian staff. There was also evidence to suggest that the Covid-19 pandemic has disproportionately affected ethnic minority healthcare workers' working environment, in terms of access to adequate PPE and the greater negative effect of the pandemic on ethnic minority staff mental health.

The review found evidence of NHS ethnic minority staff enduring racist abuse from other staff and patients and this was particularly stark for Black groups. Most of the qualitative studies on experiences of racist abuse in the NHS workforce have been undertaken with nurses (and particularly Black African nurses or those that have been internationally recruited), indicating a lack of research on the experiences of other ethnic minority groups working in the NHS. The review found limited and mixed evidence on ethnic inequalities in NHS staff mental health and wellbeing. Notably, there was very limited evidence connecting the racist experiences endured by staff and their mental health, wellbeing and likelihood of burnout, and indeed other health outcomes. The studies on career progression were largely qualitative and conducted mainly with women: these studies showed how racism played out in the workplace to hamper ethnic minority staff's career progression and professional development. There was also evidence for an ethnic pay gap in most staff sectors in the NHS and which was evident for Black, Asian, Mixed and Other groups, but less so for Chinese groups.

Critical Actions for NHS England, NHS Improvement and NHS Digital

During the process of our review, there were certain themes that recurred both within topic area, and across the five topics reviewed. We found that there was: poor ethnicity data recording in NHS clinical records as well as a lack of infrastructure to allow data linkage across clinical datasets at a national level; a lack of good quality national data on the use of NHS services disaggregated by ethnic group, age, gender and other important demographic and socioeconomic variables, and adjusted for level of ill health; a severe lack of high quality interpreting services; deep distrust of NHS services and professionals (rooted in experiences of racism) by many different ethnic minority groups that deterred helpseeking; and a lack of high quality research studies that theorised ethnicity appropriately, used disaggregated ethnic groups in analysis and were designed to investigate the mechanisms underpinning ethnic inequalities in healthcare. In light of these common problems across topics, we recommend five major areas where NHS England, NHS Improvement and NHS Digital should take critical action to improve access to, experiences of, and outcomes of, healthcare for ethnic minority groups:

- Enforce Guidelines on Ethnic Monitoring Data: Ensure that patients' ethnicity is (1) recorded and (2) recorded accurately (i.e., self-reported ethnicity) in all interactions with NHS staff. Our review found that research studies using clinical data often had substantial amounts of missing ethnicity data.
- Produce better NHS Statistics: NHS
 Digital should provide national NHS
 statistics on service use by ethnic group,
 age and gender (at a minimum) and
 allow for clinical data to be linked across
 datasets in order to improve the monitoring

of clinical outcomes for ethnic minority populations and to enhance the quality of research that can be undertaken with ethnic minority populations.

• Invest in Interpreter Services: Greater resource needs to be allocated to the provision of interpreters in NHS Trusts; we found that high quality interpreters were not being provided in mental healthcare, in GP surgeries and at various points along the maternal health care pathway. Interpreter services need to be readily available for in person, telephone and digital appointments.

Work to build trust with ethnic minority groups and key VCSE organisations:

Produce and implement a plan of work to build trust with ethnic minority groups and voluntary, community and social enterprise (VCSE) organisations that work with ethnic minority populations. Our review found that some ethnic minority people delayed or avoided help seeking for health problems due to past experiences of racist treatment by healthcare professionals or due to similar experiences of their friends and family. Improving ethnic minority people's trust in NHS services will, subsequently, improve health outcomes through increased access to these services.

Invest in research to understand the impact of racism on healthcare:

Finally, greater investment in research understanding the mechanisms that underpin and drive ethnic inequalities in healthcare is imperative if the mechanisms and systems that give rise to ethnic inequalities are to be disrupted.

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- 294. **Ashraf F.** Black and Minority Ethnic Leaders in the Health Sector. *J Psychol Issues Organ Cult*. 2013;3(S1):104-114.
- 295. **Reeves P, Naqvi H.** Enabling BME Nurse and Midwife Progression into Senior Leadership Positions December 2017. 2017;(December):1-22.

Appendix 1: Search strategy (MEDLINE via Ovid)

Mental He	ealth
1	exp Health Services Accessibility/
2	exp Help Seeking Behavior/
3	exp healthcare disparities/
4	care path*.ti,ab,kf,hw.
5	help seek*.ti,ab,kf,hw.
6	(uptake* or use* or usage* or utili*ation or experience* or barrier* or facilitat* or access* or obstacle* or enabler*).ti,ab,kf,hw.
7	(service* or healthcare or care or treat* or prevent*).ti,ab,kf,hw.
8	exp Health services/
9	7 or 8
10	6 and 9
11	1 or 2 or 3 or 4 or 5 or 10
12	exp Mental Health/
13	mental illness.mp.
14	("mental wellbeing" or "mental well-being").mp.

15	Mental health.mp.
16	exp mental disorder/
17	exp depression/ or exp anxiety/ or exp suicide/ or exp eating disorder/ or exp psychosis/ or exp schizophrenia/ or exp stress/ or exp mood disorder/ or exp Stress Disorders, Post-Traumatic/
18	("mental disorder*" or depress* or anxiety or suicide* or eating disorder* or psychosis or schizophrenia or stress or distress or mood disorder* or "post-traumatic stress disorder" or PTSD).mp.
19	Psycholog*.mp.
20	exp Substance-Related Disorders/
21	exp Mental Health Services/
22	exp Community Mental Health Services/
23	exp psychiatric services/
24	counsel*.mp.
25	(IAPT or " psychological therapies service").mp.
26	exp Psychiatry/
27	Psychiatri*.mp.
28	or/12-27
29	exp United Kingdom/ or exp Great Britain/
30	("national health service*" or nhs*).ti,ab,in.
31	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scotlish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab.

32	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or "st asaph" or "st asaph's" or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") or (birmingham not alabama*) or (birmingham's not alabama*) or bradford or bradford's or brighton or brighton's or bristol or bristol's or carlisle* or carlisle's or (cambridge not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or (canterbury's not zealand*) or chelmsford or chelmsford's or chester or chester's or chichester or chichester's or coventry or coventry's or derby or derby's or (durham not (carolina* or nc)) or (durham's not (carolina* or nc)) or ely or ely's or exeter or exeter's or gloucester or gloucester's or hereford or hereford's or hull or hull's or lancaster or lancaster's or leeds* or leicester or leicester's or (lincoln not nebraska*) or (liverpool not (new south wales* or nsw)) or (london not (ontario* or ont or toronto*)) or (london's not (ontario* or ont or toronto*)) or manchester or manchester's or (newcastle not (new south wales* or nsw)) or (newcastle's not (new south wales* or peterborough or peterborough's or plymouth or plymouth's or portsmouth or portsmouth's or preston or preston's or ripon or ripon's or salford or salford's or salisbury or salisbury's or sheffield or sheffield's or southampton or southampton's or st albans or stoke or stoke's or sunderland or sunderland's or truro or truro's or wakefield or wakefield's or westminster or westminster's or winchester or winchester's or wolverhampton or wolverhampton's or ont or toronto*)) or (york's not (new york* or ny or ontario* or ont or toronto*))) or (york's not (new york* or ny or ontario* or ont or tor
33	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
34	29 or 30 or 31 or 32
35	34 not 33
36	exp culturally competent care/
37	(("cultur* competen* care" or "cultur* care" or "transcultural nursing" or (transculturalism or "cultural awareness" or "cultural sensitivity" or "cultural knowledge" or "cultural sensitivity")) adj2 (care or healthcare or nursing)).ab,ti.
38	(Ethnic* or racial or race or racis* or POC or "BME" or "BAME").ab,ti.
39	(Arab or Africa* or Afro* or Asian or Bangladesh* or Black or Caribbean or Chinese or India* or Irish or (Mixed adj other) or Multi*rac* or Pakistan* or Roma or traveller* or Gyps* or Gips*).ab,ti.
40	(Sikh* or Hindu* or Muslim* or Islam* or jew*).ab,ti.
41	36 or 37 or 38 or 39 or 40

42	35 and 41
43	11 and 28 and 42
44	limit 43 to (comment or editorial or letter or newspaper article or published erratum)
45	43 not 44
46	limit 45 to (abstracts and english language and yr="2011 -Current")

Maternal health	
1	exp Maternal Welfare/
2	(matern* adj3 welfare*).ti,ab,kf,hw.
3	(matern* adj3 health).ti,ab,kf,hw.
4	exp Maternal Health Services/
5	(matern* adj3 servic*).ti,ab,kf,hw.
6	(matern* adj3 (care or healthcare)).ti,ab,kf,hw.
7	exp Pregnancy/
8	pregnan*.ti,ab,kf,hw.
9	exp Pregnancy Outcome/
10	exp Pregnancy Complications/
11	(complicat* adj3 pregnan*).ti,ab,kf,hw.
12	(complicat* adj3 birth*).ti,ab,kf,hw.
13	exp Parturition/
14	parturition.ti,ab,kf,hw.
15	(childbirth* or child birth* or child- birth*).ti,ab,kf,hw.
16	exp Delivery, Obstetric/
17	exp Obstetrics/
18	obstetric*.ti,ab,kf,hw.
19	exp Obstetric Labor Complications/
20	exp Labor, Obstetric/
21	(obstetric* adj3 care).ti,ab,kf,hw.
22	exp Postnatal Care/
23	exp Postpartum Period/
24	exp Depression, Postpartum/

25	((postpartum or post-partum) adj3 depress*).ti,ab,kf,hw.
26	(postpartum or intrapartum or post-partum).ti,ab,kf,hw.
27	(eclampsia or pre-eclampsia).ti,ab,kf,hw.
28	Reproductive Health/
29	(reproduc* adj3 health).ti,ab,kf,hw.
30	((antenatal or ante-natal) adj3 care).ti,ab,kf,hw.
31	(skill* adj3 birth adj3 attend*).ti,ab,kf,hw.
32	(institut* adj3 deliver*).ti,ab,kf,hw.
33	(facilit* adj3 deliver*).ti,ab,kf,hw.
34	(facilit* adj3 birth*).ti,ab,kf,hw.
35	(hospital* adj3 birth*).ti,ab,kf,hw.
36	(hospital* adj3 (birth* or born)).ti,ab,kf,hw.
37	Infertility*.ti,ab,kf,hw.
38	exp infertility/
39	"birth weight".ti,ab,kf,hw.
40	exp Maternal Mortality/
41	(matern* adj3 (mortal* or death* or morbid*)).ti,ab,kf,hw.
42	(midwifery or midwiv*).ti,ab,kf,hw.
43	exp maternal-child nursing/
44	exp midwifery/
45	(health adj visit*).ti,ab,kf,hw.
46	((postnatal or post-natal or newborn* or antenatal or prenatal or perinatal or neonatal) adj3 (care or service*)).ti,ab,kf,hw.
47	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46
48	exp Health Services Accessibility/
49	exp Help Seeking Behavior/
50	exp healthcare disparities/
51	care path*.ti,ab,kf,hw.
52	help seek*.ti,ab,kf,hw.
53	(uptake* or use* or usage* or utili*ation or experience* or barrier* or facilitat* or access* or obstacle* or enabler*).ti,ab,kf,hw.
54	(service* or healthcare or care or treat* or prevent*).ti,ab,kf,hw.
55	exp Health services/
56	54 or 55

or hull or hull's or lancaster or lancaster's or leeds* or leicester or leicester's or (lincoln not nebraska*) or (lincoln's not nebraska*) or (liverpool not (new south wales* or nsw)) or (liverpool's not (new south wales* or nsw)) or (london not (ontario* or ont or toronto*)) or (london's not (ontario* or ont or toronto*)) or manchester or manchester's or (newcastle not (new south wales* or nsw)) or	57	53 and 56
60 ("national health service" or nhs").ti,ab,in. 61 (gb or "g.b." or britain" or (british" not "british columbia") or uk or "u.k." or united kingdom" or (england" not "new england") or northern ireland" or northern irish" or scotland" or scottish" or ((wales or "south wales") not "new south wales") or weish").ti,ab. 62 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or "st asaph" or "st asaph's "or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh's "or glasgow or "glasgow's" or inverness or (perth not australia") or ("perth's" not australia") or stirling or "stirling's") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") or (birmingham not alabama") or (birmingham's not alabama") or bradford or bradford's or brighton or brighton's or bristol or bristol's or carlisles or carlisles or (cambridge not (massachusetts" or boston or harvard")) or (cambridge's not (massachusetts" or boston or harvard")) or (cambridge's not (massachusetts" or boston or harvard")) or or derby's or chethester or chichester's or coventry or coventry or derby's or derby or derby's or derby or (durham not (carolina" or no.)) or (durham's not (carolina" or no.)) or ely or ely's or exeter or exeter's or gloucester or gloucester's or hereford or hereford's or hull or hull's or lancaster or lancaster's or leeds" or leicester or leicester's or licioster or leicester's or (lincoln not nebraska") or (lincoln's not nebraska") or (liverpool not (new south wales" or nsw)) or (london not (ontario" or ont or toronto")) or (london's not (ontario" or ont or toronto")) or (newcastle not (new south wales" or nsw)) or (newcastle's not (new south ampton or southampton's or wakefield or wakefield's or westminster or westminster's or winchester's or winchester's or wolverhampton or wolverhampton's or sor salford or salford's or salisbury or salisbury's or sheffield or sheffield'	58	48 or 49 or 50 or 51 or 52 or 57
(gb or "g.b." or britain" or (british" not "british columbia") or uk or "u.k." or united kingdom" or (england" not "new england") or northern ireland" or northern irish" or scotland" or scottish" or ((wales or "south wales") not "new south wales") or welsh"), it, ab. 62 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or "st asaph" or "st asaph" or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen or "dundee or "dundee"s" or delinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia") or ("perth's" not australia") or stirling or "stirling s") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "stirling's") or (birmingham not alabama") or (birmingham's not alabama") or bradford or bradford's or brighton or brighton's or bristol or bristol's or cardisles or cardisle's or (cambridge not (massachusetts" or boston" or boston" or harvard")) or (cambridge's not (massachusetts" or boston" or harvard")) or (canterbury not zealand") or (canterbury's not zealand") or chelmsford or chelmsford's or chester or chester's or chichester's or coventry or coventry or or derby or derby's or exeter or exeter's or gloucester or gloucester's or hereford or hereford's or hull or hull's or lancaster or lancaster's or leeds" or leicester or leicester or bull or hull's or lancaster or lancaster's or leeds" or leicester or leicester's or (lincoln not ebraska") or (liverpool's not (new south wales" or nsw)) or (nodon not (ontario" or ont or toronto")) or (london's not ontario" or ont or toronto")) or (nodon's not ontario" or ont or toronto")) or manchester or manchester's or (newcastle not (new south wales" or nsw)) or (newcastle's or or southampton's or salisbury or salisbury's or shelfield or shelfield's or oxiderland's or rutor or truro's or wakefield or wakefield's or westminster or westminster or oxideriand's or rutor or truro's or wakefield or wakefield's or westminster or ont or toronto")) or (york's not (new york" or ny or ontario" or ont or toron	59	exp United Kingdom/ or exp Great Britain/
kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scotlish* or ((wales or "south wales") not "new south wales") or welsh").ti,ab. 62 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or "st asaph" or "st asaph" or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia") or ("perths" not australia") or stirling or "stirling's") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") or (birmingham not alabama") or (birmingham's not alabama") or bradford or bradford's or brighton or brighton's or bristol or bristol's or carlisle" or carlisle's or (cambridge not (massachusetts* or boston* or harvard")) or (canterbury not zealand*) or (canterbury sont zealand*) or chelmsford or chelmsford's or chester or chester's or chichester or chichester's or coventry or coventry's or derby or derby's or (durham not (carolina* or no:)) or (durham's not (carolina* or no:)) or ely or ely's or exeter or exeter's or gloucester or gloucester's or hereford or hereford's or hull or hull's or lancaster or lancaster's or leeds or leicester or leicester's or (lincoln not nebraska*) or (lincoln's not nebraska*) or (lincoln not (ontario* or ont or toronto*)) or (london's not (ontario* or ont or toronto*)) or (london's not (ontario* or ont or toronto*)) or (london's not onterborugh's or newly) or (lindon's not nebraska*) or pereborough's or peterborough's or plymouth or plymouth's or portsmouth or portsmouth's or preston or preston's or ripon's or salford or salford or salford's or salisbury or salisbury's or sheffield or sheffield or southampton or southampton's or wherefield or wakefield's or westminster or westminster's or winchester's or wolverhampton or wolverhampton or ont or toronto*))), i.b. 63 (exp africa/ or exp americas/ or exp antar	60	("national health service*" or nhs*).ti,ab,in.
asaph" or "st asaph's" or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inveness or (perth not australia") or ("perth's" not australia") or stirling or "stirling's") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "iisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") or (birmingham not alabama") or (birmingham's not alabama") or bradford or bradford's or brighton or brighton's or bristol or bristol's or carlisles or carlisle's or (cambridge not (massachusetts" or boston" or harvard")) or (cambridge's not (massachusetts" or boston" or harvard")) or (cambridge's not (massachusetts" or boston" or harvard")) or (canterbury not zealand") or (canterbury's not zealand") or coventry or coventry's or derby or derby's or durham not (carolina" or nc)) or (durham's not (carolina" or nc)) or ely or ely's or exeter or exeter's or gloucester or gloucester or leicester or leicester's or hull or hull's or lancaster or lancaster's or leeds or leicester or leicester's or (lincoln not nebraska") or (lincoln's not nebraska") or (liverpool not (new south wales" or nsw)) or (london not (ontario" or ont or toronto")) or (london's not (ontario" or ont or toronto")) or manchester or manchester's or (newcastle not (new south wales" or nsw)) or (newcastle's not (new south wales" or nsw)) or or polymouth or plymouth's or portsmouth or portsmouth or norwich's or rottingham or nottingham's or oxford or oxford's or peterborough or peterborough's or plymouth or plymouth's or portsmouth or portsmouth's or preston or preston's or sheffield or sheffield's or sulfarnghon or southampton or southampton's or wakefield or wakefield's or westminster's or winchester or winchester's or wolverhampton or wolverhampton's or (massachusetts' or boston" or harvard')) or (worcester's not (massachusetts' or boston" or harvard')) or (york not (new york' or not or 10 fo 62 64 An t 63 65 Exp culturally compe	61	kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or
exp asia/ or exp oceania/) not (exp great britain/ or europe/) 59 or 60 or 61 or 62 64 not 63 66 exp culturally competent care/ (("cultur* competen* care" or "cultur* care" or "transcultural nursing" or (transculturalism or "cultural awareness" or "cultural sensitivity" or "cultural knowledge" or "cultural sensitivity")) adj2 (care or healthcare or nursing)).ab,ti.	62	asaph" or "st asaph's" or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") or (birmingham not alabama*) or (birmingham's not alabama*) or bradford or bradford's or brighton or brighton's or bristol or bristol's or carlisle* or carlisle's or (cambridge not (massachusetts* or boston* or harvard*)) or (cambridge's not (massachusetts* or boston* or harvard*)) or (cambridge's not (massachusetts* or boston* or harvard*)) or chelmsford's or chester or chester's or chichester or chichester's or coventry or coventry's or derby or derby's or (durham not (carolina* or nc)) or (durham's not (carolina* or nc)) or ely or ely's or exeter or exeter's or gloucester or gloucester's or hereford or hereford's or hull or hull's or lancaster or lancaster's or leeds* or leicester or leicester's or (lincoln not nebraska*) or (lincoln's not nebraska*) or (liverpool not (new south wales* or nsw)) or (london not (ontario* or ont or toronto*)) or (london's not (ontario* or ont or toronto*)) or manchester or manchester's or (newcastle not (new south wales* or nsw)) or (newcastle's not (new south wales* or nsw)) or plymouth or plymouth's or portsmouth or portsmouth's or preston or preston's or ripon or ripon's or salford or salford's or salisbury or salisbury's or sheffield or sheffield's or southampton or southampton's or stalbans or stoke or stoke's or sunderland or sunderland's or truro or truro's or wakefield or wakefield's or westminster or westminster's or winchester or winchester's or harvard*)) or (worcester's not (massachusetts* or boston* or harvard*)) or (worcester's not (or ont or toronto*)) or (york's not (new york* or ny or ontario* or
65 64 not 63 66 exp culturally competent care/ 67 (("cultur* competen* care" or "cultur* care" or "transcultural nursing" or (transculturalism or "cultural awareness" or "cultural sensitivity" or "cultural knowledge" or "cultural sensitivity")) adj2 (care or healthcare or nursing)).ab,ti.		exp asia/ or exp oceania/) not (exp great britain/ or europe/)
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(("cultur* competen* care" or "cultur* care" or "transcultural nursing" or (transculturalism or "cultural awareness" or "cultural sensitivity" or "cultural knowledge" or "cultural sensitivity")) adj2 (care or healthcare or nursing)).ab,ti.		
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(Ethnic* or racial or race or racis* or POC or "BME" or "BAME").ab,ti.	67	(transculturalism or "cultural awareness" or "cultural sensitivity" or "cultural knowledge" or "cultural sensitivity")) adj2 (care or healthcare or nursing)).ab,ti.
	68	(Ethnic* or racial or race or racis* or POC or "BME" or "BAME").ab,ti.

69	(Arab or Africa* or Afro* or Asian or Bangladesh* or Black or Caribbean or Chinese or India* or Irish or (Mixed adj other) or Multi*rac* or Pakistan* or Roma or traveller* or Gyps* or Gips*).ab,ti.
70	(Sikh* or Hindu* or Muslim* or Islam* or jew*).ab,ti.
71	66 or 67 or 68 or 69 or 70
72	65 and 71
73	47 and 58 and 72
74	limit 73 to (comment or editorial or letter or newspaper article or published erratum)
75	73 not 74
76	limit 75 to (abstracts and english language and yr="2011 -Current")

Digital i	nclusion
1	exp telemedicine/
2	exp remote consultation/
3	(telemedicine or telehealth or telehealthcare or telemonitoring or telecare or telediagnosis or teleconsult* or telepsychiatry or telepsychology or teletherapy or "remote monitoring" or "remote diagnosis" or mhealth or "Remote Consultation"). mp.
4	((online or digital or virtual or VR or mobile or internet or tele or Al or "artificial intelligen*" or algorithm or "machine learning" or Apps or telephone or phone or zoom or video or "Social Media" or comput*) adj6 (therap* or prevent* or program* or psychotherap* or rehab* or interven* or treat* or triage or assistant or care or consult* or health or medicine or mental* or psychology or psychiatry or appointment or consultation or care or screening or drug* or medicine or healthcare)).mp.
5	(ediar* or ehealth or emediat* or elearn* or etherap* or (e adj2 (diar* or learn or health or mediat* or therap* or consult* or visit*))).mp.
6	exp hotline/
7	(help line* or hotline or helpline* or hot line).mp.
8	(digital adj3 (divide or inclusion or inequality or gap)).mp.
9	1 or 2 or 3 or 4 or 5 or 6 or 7
10	exp Health Services Accessibility/
11	exp Help Seeking Behavior/
12	exp healthcare disparities/
13	care path*.ti,ab,kf,hw.
14	help seek*.ti,ab,kf,hw.
15	(uptake* or use* or usage* or utili*ation or experience* or barrier* or facilitat* or access* or obstacle* or enabler*).ti,ab,kf,hw.
16	exp United Kingdom/ or exp Great Britain/

17	("national health service*" or nhs*).ti,ab,in.
18	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scotlish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab.
19	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or "st asaph" or "st asaph" or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") or (birmingham not alabama*) or (birmingham's not alabama*) or bradford or bradford's or brighton or brighton's or bristol or bristol's or carlisle* or carlisle's or (cambridge not (massachusetts* or boston* or harvard*)) or (cambridge's not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or (canterbury's not zealand*) or chelmsford or chelmsford's or chester or chester's or chichester or chichester's or coventry or coventry's or derby or derby's or (durham not (carolina* or nc)) or (durham's not (carolina* or nc)) or ely or ely's or exeter or exeter's or gloucester or gloucester's or hereford or hereford's or hull or hull's or lancaster or lancaster's or leeds* or leicester or leicester's or (lincoln not nebraska*) or (lincoln's not nebraska*) or (liverpool not (new south wales* or nsw)) or (london not (notario* or ont or toronto*)) or (london's not (ontario* or ont or toronto*)) or (newcastle not (new south wales* or nsw)) or (newcastle's not (new south wales* or nsw)) or or or plymouth or plymouth's or portsmouth or portsmouth's or preston or preston's or ripon or ripon's or salford or salford's or salisbury or salisbury's or sheffield or sheffield's or southampton or southampton's or salisbury or salisbury's or sheffield or sheffield's or southampton or southampton's or wakefield or wakefield's or westminster or westminster's or winchester or winchester's or wolverhampton or wolverhampton's or (worcester not (massachusetts* or boston* or harvard*)) or (york not (new york* or not or toronto
20	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
21	16 or 17 or 18 or 19
22	21 not 20
23	exp culturally competent care/
24	(("cultur* competen* care" or "cultur* care" or "transcultural nursing" or (transculturalism or "cultural awareness" or "cultural sensitivity" or "cultural knowledge" or "cultural sensitivity")) adj2 (care or healthcare or nursing)).ab,ti.
25	(Ethnic* or racial or race or racis* or POC or "BME" or "BAME").ab,ti.
26	(Arab or Africa* or Afro* or Asian or Bangladesh* or Black or Caribbean or Chinese or India* or Irish or (Mixed adj other) or Multi*rac* or Pakistan* or Roma or traveller* or Gyps* or Gips*).ab,ti.
27	(Sikh* or Hindu* or Muslim* or Islam*).ab,ti.
28	23 or 24 or 25 or 26 or 27

29	22 and 28
30	or/10-15
31	(9 and 30) or 8
32	29 and 31
33	limit 32 to (editorial or letter or comment or newspaper article)
34	32 not 33
35	limit 34 to (abstracts and english language and yr="2011 -Current")

Genom	ics and genetic testing
1	(Ethnic* or racial or race or racis* or "BME" or "BAME" or ancestr* or interethnic or multi-ethnic or multi*rac*).ti,kf,ab,hw.
2	(Arab or Africa* or Afro* or Asian or Bangladesh* or Black or Caribbean or Chinese or India* or Irish or (Mixed adj other) or Pakistan* or Roma or traveller* or Gyps* or Gips* or Sikh* or Hindu* or Muslim* or Islam* or jew* or Hispanic or Latin or Caucasian or European).kf,hw,ti,ab.
3	1 or 2
4	exp precision medicine/
5	exp genetic testing/
6	exp genetic services/
7	exp genetic counseling/
8	((genetic or genom* or personal* or precision or pharmacogenetic* or pharmacogenomic* or bioinformatic*) adj3 (medicine or test* or counsel* or service* or intervention* or diagno* or treatment* or therap* or prevent* or sceen* or drug* or prescri* or (risk adj3 (prediction or assessment or score)))).ti,ab,kf,hw.
9	((Target* adj2 screen*) or (tailor* adj3 therapy*) or ((polygen* adj2 risk) or PRS)). ti,ab,kf,hw.
10	4 or 5 or 6 or 7 or 8 or 9
11	exp genomics/ or exp pharmacogenetics/
12	(pharmacogenetic* or pharmacogenomic* or bioinformatic* or genom* or Biobank or GWAS).ti,ab,kf,hw.
13	11 or 12
14	(diversity or inclusion or under-represent* or under-served or equity or disparit* or equality or inequality or representation).ti,ab,kf,hw.
15	exp United Kingdom/ or exp Great Britain/
16	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or "welsh* national health service*" or nhs).ti,ab,in.

17	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or "st asaph" or "st asaph's" or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") or (birmingham not alabama*) or (birmingham's not alabama*) or bradford or bradford's or brighton or brighton's or bristol or bristol's or carlisle* or carlisle's or (cambridge not (massachusetts* or boston* or harvard*)) or (cambridge's not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or (canterbury's not zealand*) or chelmsford or chelmsford's or chester or chester's or chichester or chichester's or coventry or coventry's or derby or derby's or (durham not (carolina* or nc)) or (durham's not (carolina* or nc)) or ely or ely's or exeter or exeter's or gloucester or gloucester's or hereford or hereford's or hull or hull's or lancaster or lancaster's or leeds* or leicester or leicester's or (lincoln not nebraska*) or (lirocln's not (new south wales* or nsw)) or (london not (ontario* or ont or toronto*)) or (london's not (ontario* or ont or toronto*)) or (newcastle's not (new south wales* or nsw)) or or or toronto*) or or or plymouth or plymouth's or portsmouth or portsmouth's or peterborough's or plymouth or plymouth's or portsmouth or portsmouth's or stoke or stoke's or sinderland or sunderland's or truro or truro's or wakefield or wakefield's or westminster or westminster's or winchester or winchester's or wolverhampton or wolverhampton's or (worcester not (massachusetts* or boston* or harvard*)) or (york not (new york* or not or ontoro*))).ti,ab.
18	15 or 16 or 17
19	exp Humans/
20	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scotlish* or ((wales or "south wales") not "new south wales") or "welsh* national health service*" or nhs).ti,ab.
21	15 or 17 or 20
22	3 and 10 and 21 and 19
23	3 and 13 and 14 and 19 and 21
24	3 and 10 and 18 and 19
25	3 and 13 and 14 and 19 and 18
26	22 or 23
27	24 or 25
28	limit 26 to (editorial or letter or comment or newspaper article)
29	26 not 28
30	limit 29 to (abstracts and english language and yr="2011 -Current")

NHS work	cforce inequality
1	exp United Kingdom/ or exp Great Britain/
2	("national health service*" or nhs*).ti,ab,in.
3	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab.
4	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or "st asaph" or "st asaph's" or "st davids" or swansea or "swansea's" or (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") or (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") or (birmingham not alabama*) or (birmingham's not alabama*) or bradford or bradford's or brighton or brighton's or bristol or bristol's or carlisle* or carlisle's or (cambridge not (massachusetts* or boston* or harvard*)) or (cambridge's not (massachusetts* or boston* or harvard*)) or (cambridge's not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or (canterbury's not zealand*) or chelmsford or chelmsford's or chester or chester's or chichester or chichester's or coventry or coventry's or derby or derby's or (durham not (carolina* or nc)) or (durham's not (carolina* or nc)) or ely or ely's or exeter or exeter's or gloucester or gloucester's or hereford or hereford's or hull or hull's or lancaster or lancaster or leicester's or leicester's or licester's or (lincoln not nebraska*) or (lincoln's not nebraska*) or (liverpool not (new south wales* or nsw)) or (london not (ontario* or ont or toronto*)) or (london's not (ontario* or ont or toronto*)) or manchester or manchester's or (newcastle not (new south wales* or nsw)) or (newcastle's not (new south wales* or nsw)) or norwich or norwich's or nottingham or nottingham's or oxford or oxford's or peterborough or peterborough's or plymouth or plymouth's or portsmouth or portsmouth's or preston or preston's or ripon or ripon's or salford or salford's or salisbury or salisbury's or sheffield or sheffield or southampton or southampton's or salford or salford's or or salbans or stoke or stoke's or sunderland or sunderland's or truro or truro's or wake
5	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
6	1 or 2 or 3 or 4
7	6 not 5
8	exp culturally competent care/
9	(("cultur* competen* care" or "cultur* care" or "transcultural nursing" or (transculturalism or "cultural awareness" or "cultural sensitivity" or "cultural knowledge" or "cultural sensitivity")) adj2 (care or healthcare or nursing)).ab,ti.

10	(Ethnic* or racial or race or racis* or POC or "BME" or "BAME").ab,ti.
11	(Arab or Africa* or Afro* or Asian or Bangladesh* or Black or Caribbean or Chinese or India* or Irish or (Mixed adj other) or Multi*rac* or Pakistan* or Roma or traveller* or Gyps* or Gips*).ab,ti.
12	(Sikh* or Hindu* or Muslim* or Islam* or jew*).ab,ti.
13	8 or 9 or 10 or 11 or 12
14	7 and 13
15	(abus* or harass* or discriminat* or assault* or maltreat* or mistreat* or mistreat* or "ill treat*" or ill-treat* or cruel* or hostil* or harm* or hurt* or agress* or brutal*or bully* or injur* or intimidat* or persecut* or aggravat* or violen* or bias* or prejudice* or intolerance* or favo?ritism* or inequit* or unfairness* or coerc* or bigotr* or injustice* or marginali* or insensitiv* or exploit*).ti,ab,kf,hw.
16	(career or promotion or progress* or advanc* or hiring or recruit* or train* or select* or assess* or retention or "intention to leave" or employ* or "intention to quit" or "intention to stay" or "staff turnover" or retain* or representation or pay or leader* or "middle manager*" or manager or management).ti,ab,kf,hw.
17	Safety/
18	Sexual Harassment/
19	Violence/
20	Prejudice/
21	Aggression/
22	Bullying/
23	Coercion/
24	15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25	("health care provider*" or "community health worker*" or nurse* or "nursing personnel" or "nursing staff" or doctor* or "clinical officer*" or "medical officer*" or "health personnel" or "health staff" or "diverse workforce" or "health care personnel" or "health auxiliary").ti,ab,kf,hw.
26	exp health personnel/
27	exp nurses/
28	("health sector*" or "health management" or "health leadership").ti,ab,kf,hw.
29	25 or 26 or 27 or 28
30	24 and 29
31	14 and 30
32	limit 31 to (editorial or letter or comment or newspaper article)
33	31 not 32
34	limit 33 to (abstracts and english language and yr="2011 -Current")

Appendix 2: Stakeholder Engagement Survey

Rapid Evidence Review of Ethnic Inequalities in Healthcare & Health Services in the UK: Stakeholder Engagement Survey

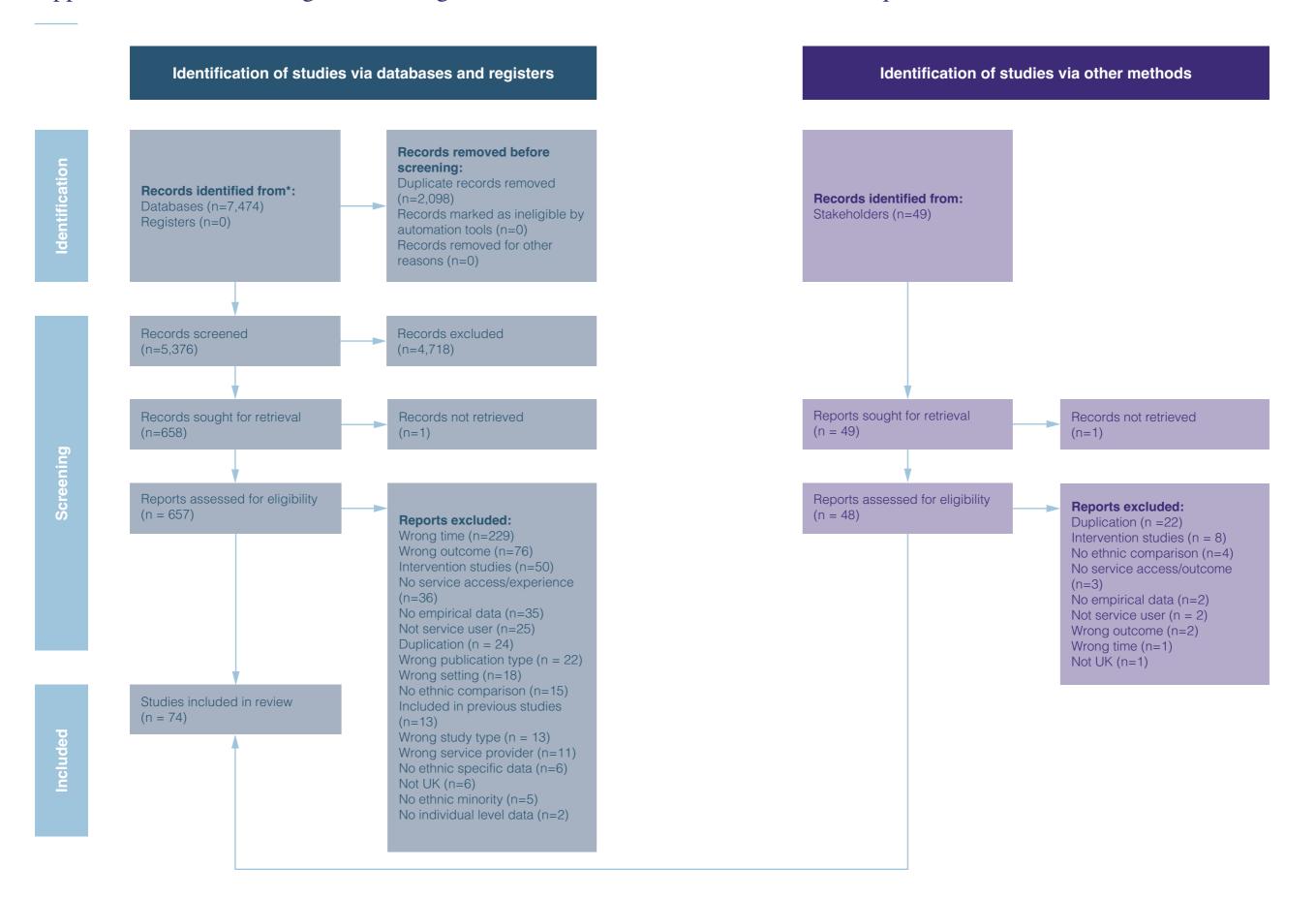
Thank you for your interest in contributing to this rapid review as a stakeholder. This short stakeholder engagement survey aims to collect information about current research in the area, key literature and references and your opinions on ethnic inequalities in healthcare and health services based on your expertise.

The references that you provide will be added to the references that we have found via our search strategies, and your opinions on future research and practice will be used in both the synthesis of the evidence in the review, as well as in the formulation of recommendations that we make to the NHS Race and Health Observatory.

If you have any questions about this stakeholder engagement survey, please contact Dr. Dharmi Kapadia (Dharmi.Kapadia@manchester.ac.uk).

Please provide your full name
Please provide the name of the organisation where you are currently working
Please provide literature or references to key research in the area
Please provide information (weblinks if possible) to ongoing research in this area
What future research is needed in this field in order to ensure ethnic inequalities are addressed?
How does practice within the NHS need to change in order to ensure ethnic inequalities in this area are addressed?
Would you like to be named as a contributing stakeholder in the final report of this review? Yes
No
Many thanks for taking the time to fill in this stakeholder engagement survey

Appendix 3: PRISMA diagram showing the identification of studies on ethnic inequalities in mental health services



Appendix 4: Summary of studies providing data on ethnic inequalities in mental health service

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Attitudes to help	-seeking and experi	iences of general	mental health se	ervices			
Bailey & Tribe (2021)	8 (65-79) [Not reported]	8 (100%)	UK	To understand the experiences and beliefs that underlie help-seeking behaviour among ethnic minority older adults to deliver effective, culturally appropriate, and accessible services.	Mental health services	Qualitative interviews; Black Caribbean older adults identified through day centres and lunch clubs	Black Caribbean
Brown et al. (2011)	145 (18-45) [Not reported]	73 (50.3%)	London	To examine factors that may influence the help-seeking behaviour of Black Africans.	Help-seeking for depression	Cross-sectional survey; women aged between 18 and 45 years, who were Black African or White British and had previously experienced depression.	White British, Black African
Garrett et al. (2012)	4 articles [systematic review] (>=18)) [2011]	Not reported	England	To develop an explanatory framework of the problems accessing primary care health services experienced by British South Asian patients with a long-term condition or mental health problem.	Primary care services	Systematic review (meta-ethnography); British South Asian adult patients with coronary heart disease, diabetes and/or mental health problems.	South Asian
Hussain et al (2021)	8 (33-50+) [not reported]	8 (100%)	England	To investigate how British Pakistani people talk about their social identity, in the context of mental health, and how this shapes their experiences and perceptions of care delivered by the National Health Service (NHS), UK.	General mental health services	Qualitative interviews; people of Pakistani origin living in the catchment area of the study	Pakistani
Islam et al. (2015)	22 (18-35) [Not reported]	22 (100%)	Birmingham	To examine the cultural appropriateness, accessibility, and acceptability of the Early Intervention (EI) for Psychosis Services in Birmingham, UK, in improving the experience of care and outcomes for BME patients.	Early Intervention Service	Qualitative focus groups; current or past early Intervention Service (EIS) users from a BME background.	Black African, Black Caribbean, Pakistani, Arab, British Bengali
Kalathil et al., (2011)	27 (mid 20s- mid 60s) [Not reported]	27 (100%)	London	To explore distress and recovery based on the experience and understandings of African, African Caribbean and South Asian women.	General mental health services	Qualitative interviews; women who identified as Black and South Asian who defined themselves as recovering or having recovered from mental distress or mental health problems	Black, Asian, Mixed (or other), Black British, Black African, Black Caribbean, Bangladeshi, Indian, Pakistani, African (Liberian, Nigerian, Ethiopian, Angolan, South African); migrant; Asian (South Indian, Gujarati, East African Indian)

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Linney et al. (2020)	23 (>=18) [2019]	23 (100%)	Bristol	To explore community beliefs and views about the causes of mental illness, treatment for mental illness, and access to medical services in general.	General mental health services	Qualitative focus groups; Somali people recruited from South West of England	Somali
Loewenthal (2012)	77 (>=40) [Not reported]	77 (100%):	UK	To investigate the feasibility of achieving Improving Access to Psychological Therapies (IAPT) for people from BAME communities living in the UK	Help-seeking and psychological therapies	Qualitative focus groups; people from Bengali, Urdu, Tamil and Somali speaking communities in the UK	Bengali, Urdu, Tamil and Somali speaking people
Memon et al (2016)	26 (18+) [June 2010]	13 (50%) although the remainder did not respond to the question on ethnicity	Brighton & Hove	To determine perceived barriers to accessing mental health services among people from ethnic minority backgrounds to inform the development of effective and culturally acceptable services to improve equity in healthcare	General mental health services	Qualitative focus group; BME individuals, aged 18+ years, resident in the city of Brighton and Hove	Black, Asian, Mixed
Shefer et al (2013)	103 (22-69 years) [not reported]	103 (100%)	London	To extend knowledge about cultural beliefs surrounding mental illness held by the predominant BME communities in London to analyse how these beliefs influence experiences of stigma and relationships with family for individuals with mental illness in these communities	General mental health services	Qualitative focus groups; individuals identifying as being from an ethnic minority background living in London	South Asian, Asian, Black African, Black Caribbean, Indian, Kenyan- Asian, Somali
Sisley et al. (2011)	7 (30s-50s) [2009]	7 (100%)	London	To explore individual explanatory models of experiences of distress, coping and help-seeking choices, with a view to improving cultural relevance of services.	General mental health services	Qualitative interviews; women who self- referred to inner-city community self-help workshops on self-confidence, sleep, anger or stress over a 3-year-period and who identified as African Caribbean	Black Caribbean
Yeung et al (2013)	7 (39-62 years) [not reported]	7 (100%)	England	To examine the role of social networks in the help-seeking process of Chinese people suffering from severe mental illness in England.	General mental health services	Qualitative interviews; Chinese people living in England suffering from severe mental illness (SMI) and their network contacts	Chinese

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Primary and seco	ondary care mental	health services					
Gazard et al., (2015)	1698 (>=16, mean age 43.5) [2008-2010]	659 (52.0%)	England, Lambeth and Southwark boroughs in South East London	To investigate the associations between migration status and health-related outcomes and to examine whether and how the effect of migration status changes when it is disaggregated by length of residence, first language, reason for migration and combined with ethnicity.	General mental health services	Cross-sectional survey; participants of the South East London Community Health (SELCoH) study, randomly selected households from two boroughs in South East London, Lambeth and Southwark.	White, Other, Black African, Black Caribbean
Gazard et al., (2018)	1052 (>=16) [2008-2010]	516 (49.1%)	England, Lambeth and Southwark boroughs in South East London	To investigate differences in health service use and examine the role of discrimination experiences.	General mental health services	Cross-sectional survey; participants in the South East London Community Health (SELCoH) Study	Mixed (or other), Others, White British, White Other, Black African, Black Caribbean
Kapadia et al., (2018)	2260 (16–74) [2000]	1,822 (80.6%)	England	To ascertain: ethnic differences in women's usage of mental health services, if social networks are independently associated with service use, and if the association between women's social networks and service use varies between ethnic groups.	General mental health services	Cross-sectional survey; female participants from the survey, Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC)	White, White Irish, Black Caribbean, Indian, Pakistani, Bangladeshi
Twomey (2015)	28 studies [2000- 2014]	Not reported	UK	To identify variables that predict health service utilisation (HSU) by adults with mental disorders in the UK, and to determine the evidence level for these predictors.	General mental health services	Systematic review; observational and intervention studies that predicted health service use by adults with mental disorders in the UK	White, Non-White
Psychological an	nd talking therapies,	including Improv	ing Access to Psy	chological Therapy (IAPT) services			
Bhavsar et al (2021)	1455 (17-55+) [2008 - 2010]	521 (37.3%)	London	To examine ethnic and migration-related differences in use of IAPT-based psychological treatment using a novel epidemiological dataset with linkage to de-identified IAPT records	IAPT	Cross-sectional studies; participants to The South East London Community Health Study, (SELCoH) who had consented for their data to be linked to IAPT records	
Byrne et al (2019)	228 (14-34 years) [2001-2010]	137 (60%)	Southwark & Lambeth	To examine the influence of ethnicity on service access, treatment uptake and incidence of psychosis	Early psychosis services	Cross-sectional studies; young people at ultra high risk (UHR) of psychosis, attending an early detection clinic.	White, Black, Other, White Other

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Crawford et al (2016)	14,004 (18-75+) [2012-2013]	870 (6.2%)	England & Wales	To determine the prevalence of and risk factors for perceived negative effects of psychological treatment for common mental disorders.	Psychological therapies	Cross-sectional survey; all those aged 18 years or older who were on the case-load of participating services and receiving out-patient treatment for anxiety and/or depression on an agreed census date within the period 1 July to 31 October 2012	White, Black, Asian, Mixed, Chinese/ Other
Das-Munshi et al., (2018)	10,512 (>=18) [2011, 2013]	2,136 (20.4%)	UK	To assess ethnic minority inequalities in access to pharmacological treatments, psychological interventions, shared decision making and care planning, taking into account a range of potential confounders	Psychological and pharmacological treatments	Cross-sectional audit data; people with a clinical diagnosis of schizophrenia or schizoaffective disorders	White, Black, Asian, Mixed, Other, Chinese
Green et al (2015)	4,393 (12-100) [2009-2012]	2,214 (50.4%)	London	To identify patient and treatment factors that affect clinical outcomes of community psychological therapy through the development of a predictive model using historic data from 2 services in London.	IAPT	Cross-sectional study (retrospective observational study); patients who attended community psychological therapy services	White British, BME
Harwood et al (2021)	85,800 (16+) [2013-2016]	33,245 (47.6%)	South London	To examine variation by ethnicity in (i) source of referral to IAPT services, (ii) receipt of assessment session, (iii) receipt of at least one treatment session. Routine	IAPT	Cross-sectional study; South London and Maudsley Trust IAPT service users from 2013 to 2016 over the age of 16	Asian, Mixed, Other, White British, White Other, Black African, Black Caribbean
Health & Social Care Information Centre (2014)	883,968 referrals (18+) [2012- 2013]	Not reported	England	To present rates of access to IAPT	IAPT	Cross-sectional study; people referred to IAPT services during the reporting period	White British, White Irish, White Other, Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Mixed Other, Black African, Black Caribbean, Black Other, Indian, Pakistani, Bangladeshi, Chinese, Asian Other, Other
Johns et al., (2019)	342 (mean age=38.1) [2011- 2015]	85 (55%)	England	To evaluate whether existing services could improve access to cognitive behavioural therapy for psychosis and demonstrate effectiveness using a systematic approach to therapy provision and outcome monitoring.	Evidence- based cognitive behavioural therapy for psychosis (CBTp)	Cross-sectional study; service users of Improving Access to Psychological Therapies for people with Severe Mental Illness (IAPT-SMI).	BME, non-BME

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Mansour et al., (2020)	5,546 (>=65) [2006-2017]	1,615 (29.9%)	London	To compare symptoms and types of treatment between ethnic groups in patients with late-life depression.	Treatment for late- life depression	Cohort study; patients diagnosed with late-life depression (aged 65 years or older at diagnosis) were identified from Clinical Record Interactive Search (CRIS) system in the window between 1st January 2006 and 30th June 2017.	South Asian, Other, White British, White Irish, White Other, Black African, Black Caribbean
Mercer et al (2019)	2,760 (not reported) [January 2010 to December 2015]	1,040 (37.7%)	South London	To explore the proportions of ethnic groups accessing psychological therapy as a proportion of all patients supported by the Trust, as well as their outcomes within broad diagnostic clusters	Psychological therapies	Cross-sectional studies; data from adult and older adult outpatient services which deliver formal psychological therapies within South London and Maudsley NHS Foundation Trust.	White, Black, Other
Mind (2013)	Focus group n=10; Survey: n=1,639 (not reported) [2010]	Focus group: 10 (100%); Survey 98 (6%)	England	To investigate the access to talking therapies in the UK	Talking therapies	Mixed-methods study; people with mental health problems, who have used psychological therapies	White, BME
Moller et al., (2016)	82 (18-42) [Not reported]	82(100%):	England	To explore the attitudes and beliefs that second- generation South Asian women living in Britain hold about counselling, with a particular focus on how these beliefs may impact on the process of help-seeking for psychological distress.	Counselling	Qualitative survey (open ended questions); second-generation British South Asian women, the majority of whom (92%) had no experience of counselling	South Asian, Mixed, Other, Indian, Pakistani, Bangladeshi
Morris et al., (2020)	20,010 (>=15) [2007-2017]	9,617 (48.1%)	London	To explore the role of ethnicity in receiving cognitive–behavioural therapy (CBT) for people with psychosis or bipolar disorder while adjusting for differences in risk profiles and symptom severity. To assess whether context of treatment (inpatient vs community) impacts on the relationship between ethnicity and access to CBT	Cognitive— behavioural therapy (CBT) in people with psychosis or bipolar disorder	Cohort study; records of people who had diagnoses of bipolar disorder (International Classification of Diseases (ICD) code F30-1) or psychosis (F20–F29 excluding F21).	South Asian, White British, White Irish, Black African, Black Caribbean, Indian, Pakistani, Bangladeshi

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Secondary care	mental health servic	ces (including cris	sis services, spe	cialist psychosis services and other outpatient service	es)		
Brugha et al (2012)	1,096 (16 - 60+) [2002-2004]	383 (18%)	England	To examine how characteristics of assertive outreach (AO) teams influence care and outcomes	Assertive Outreach	Cross-sectional studies; Sample of 100 out of 186 Assertive Outreach teams in England. 12 patients systematically sampled from each of the 100 teams, and included a sampling ratio of 2.5 for ethnic minority groups to ensure representativeness.	White British, all other ethnic groups (combined)
Bookle &Webber (2011)	240 inpatient episodes; 77 home treatment episodes (18-65) [2008-2009]	128 (40.4%)	An inner London Borough	To establish whether people of Black ethnic origin had equal access to home treatment in a mental health crisis.	Home treatment of mental health problems	Case control study; cases were people receiving home treatment and controls were all inpatient psychiatric admissions in the borough	Asian, Others, White British, Black British, Black African, Black Caribbean
Community and Mental Health Team: Health & Social Care Information Centre (2011)	1.25 million contacts with specialist mental health services (<15 – 100+) [2009-2010]	Not reported	England	To report on NHS adult specialist mental health services and the people who use them.	Adult specialist mental health services	Cross-sectional study; people using specialist mental health services in England 2009-10	White, Black, Asian, Mixed, Other
Community and Mental Health Team: Health and Social Care Information Centre (2013)	1.5 million contacts with specialist mental health services (>16 – 65+) [2011-2012]	Not reported	England	To provide a more comprehensive picture of people using adult specialist mental health services than	Adult specialist mental health services	Cross-sectional study; people using specialist mental health services in England 2011-2012	White British, White Irish, White Other, Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Mixed Other, Black African, Black Caribbean, Black Other, Indian, Pakistani, Bangladeshi, Chinese, Other
Community and Mental Health Team: Health and Social Care Information Centre (2015)	1.5 million contacts with specialist mental health services (>15 – 90+) [2014-2015]	Not reported	England	To provide a comprehensive picture of people who used adult secondary mental health and learning disability services.	Adult specialist mental health services	Cross-sectional study; people using specialist mental health services in England 2013-2014	White, Black, Asian, Mixed, Other

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Dominguez et al., (2013)	940 (14-35) [2003-2009]	617 (65.6%)	London	This study compared Duration of Untreated Psychosis (DUP) between adolescent and adult-onset individuals in the UK and explored whether the adolescent-onset group showed variations in DUP that could be accounted for by sociodemographic and selected risk factors.	Psychosis treatment	Cohort studies (retrospective); patients referred to nine Early Intervention Services for Psychosis (EIS) in London (UK) between 2003 and 2009	White, Black, Asian, Mixed
Fernández De la Cruz er al., (2015)	24,244 (not reported) [1999- 2013]	6,439 (26.6%)	South London	To explore whether ethnic minorities with OCD are underrepresented in secondary and tertiary mental health services in the South London and Maudsley NHS Foundation Trust.	Secondary & tertiary OCD services	Case control study; cases were 1528 patients with OCD; controls were 22,716 patients with depression	White, Black, Asian, Mixed (or other), Others
Henderson et al (2015)	202 (White participants mean age 43.2 (SD-11.9), Black or ethnic minority participants mean age=40.3 (SD=9.8)). [Sep 2011 to Oct 2012]	94 (47%)	London	To explore the role of psychiatric admission, diagnosis and reported unfair treatment in the relationship between ethnicity and mistrust of mental health services	Secondary mental health services (some focus on those who have had an inpatient admission)	Cross-sectional studies; Participants were patients using secondary mental health services in London aged at least 18 years; a clinical diagnosis of either Major Depression, Bipolar or Schizophrenia spectrum disorders (ICD-10 F32, F21 and F20-F29 respectively); self-defined Black, White or Mixed (either Black and/or White mixed) ethnicity; current treatment with a community mental health team.	White, Black/Mixed
Jeraj et al (2015)	76 (20 - 90+) [August and November 2014]	65 (86%)	Ealing, Lambeth, Northampton, Sandwell, Southampton	To conduct a series of interviews and focus groups with Black and minority ethnic people, in specific areas, who had experience of crisis care.	Crisis services	Qualitative focus groups; people who had experience of mental health crisis care living in the areas where the study was conducted	Black, Asian, White British, White Irish
Kapadia et al. (2017)	21 studies (not reported) [1960- 2014]	Not reported	UK	To clarify usage rates, and describe the nature of Pakistani women's social networks and how they may influence mental health service use.	General mental health services	Systematic review; studies published from 1960 up to the end of March 2014, pertaining to Pakistani or South Asian women, on the subject of either access to, or usage of, mental health services or the nature of social networks	Pakistani

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
NHS Digital (2021)	Not reported (not reported – adult population) [Apr 2017 – Mar 2020]	Not reported	England	-	NHS mental health, learning disability and autism services	Cross-sectional study; people using specialist mental health services 2017 to 2020	White, Black, Asian, Mixed (or other), Others, White British, White Irish, White Other, Black African, Black Caribbean, Black Other, Bangladeshi, Chinese, Indian, Pakistani, Asian Other, Mixed White/Asian, Mixed White/Black African, Mixed White/Black Caribbean, Mixed Other
Oduola et al., (2021)	558 (18–64) [2010-2012]	425 (76.2%)	London boroughs of Lambeth or Southwark	To investigate ethnic differences in DUP in a large epidemiological dataset of first episode psychosis patients in an inner city area of south London	Psychosis treatment	Cross-sectional study; first episode psychosis patients at the South London and Maudsley NHS Trust	Asian, Mixed (or other), Others, White British, Black African, Black Caribbean, White non-British
Rabiee & Smith (2014)	49 (not reported) [not reported]	49 (100%)	Birmingham	To examine understandings of mental health and the extent to which statutory and voluntary mental health services in Birmingham are meeting the needs of members of a range of Black African and African Caribbean communities	General mental health services	Qualitative interviews and focus groups; Black African and Black Caribbean service user and carers living in the Birmingham area with experience of using mental health services	Black African, Black Caribbean
Rabiee and Smith (2013)	25 service users (not reported) [Not reported]	25 (100%)	Birmingham	To examine the views and experiences of using and providing mental health services from the perspectives of Black African and Black African Caribbean mental health service users, their carers, voluntary services and a range of statutory mental health professionals and commissioners in Birmingham	General mental health services	Qualitative focus groups; Black African and Black African Caribbean mental health service users (14 female, 11 male)	Black African, Black Caribbean
Schofield et al., (2019)	35 (>=18) [2014- 2015]	35 (100%)	England, London	To determine how Black African and Caribbean service users perceive and explain these apparent ethnic differences in the rates of psychosis diagnosed.	Mental health services for psychosis	Qualitative focus groups; People from the Black African and Black Caribbean community in Lambeth and Southwark, South East London, diagnosed with a psychotic illness.	Black African, Black Caribbean

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Sinha & Warfa (2013)	12 studies (age>=16) [Not reported]	Not reported	UK, US (Western countries)	To look at the utilisation of treatment, access to treatment and referral of ethnic minorities for treatment of eating disorders in western settings. It also aimed to explore the barriers in access and utilisation of treatment including the role of acculturation.	Eating disorder services	Systematic review; papers published in English language that studied the referrals, treatment seeking and treatment utilisation of eating disorders in ethnic minorities in western settings. It also included papers that studied barriers to treatment seeking and treatment utilisation of eating disorders among ethnic minorities in western countries, people aged 16+.	White, Black, Asian, Hispanic
Sizmur &McCulloch (2016)	13,787 (>=17) [2013]	1,770 (12.8%)	England	To analyse survey variables describing treatments offered to respondents for evidence of differential access or treatment experiences associated with ethnicity.	Secondary care mental health services	Cross-sectional surveys; the population comprised people aged over 17 years seen between 1 September and 30 November 2013 for specialist care or treatment for a mental health condition	White British, White Irish, White Gypsy or Irish Traveller, White Other, Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Mixed Other, Black African, Black Caribbean, Black Other, Indian, Pakistani, Bangladeshi, Chinese, Asian Other, Arab, Other
Tang (2019)	22 (<30 - >71 years) [not reported]	22 (100%)	Birmingham, Manchester & London	To contribute to the discussion of recovery- oriented service with a study on the experience of Chinese people using UK mental health services.	General mental health services	Qualitative interviews; people who used mental health services with a psychiatric diagnosis who self-identified as Chinese	Chinese
Weich et al., (2012)	40 (18-65) [Not reported]	26 (40%)	Birmingham	To explore service users' and carers' accounts of recent episodes of severe mental illness and of the care received in a multi-cultural inner city. To examine factors impacting on these experiences, including whether and how users and carers felt that their experiences were mediated by ethnicity.	Acute mental health care	Qualitative interviews; people who (1) were accepted by one of three Home Treatment teams covered by a single Primary Care Trust in central Birmingham, UK; (2) were aged 18–65 years; and (3) had a clinical diagnosis of a psychotic disorder, predominantly schizophrenia.	White, Black, South Asian, Mixed, White British, White Irish, White Other, Black African, Black Caribbean, Indian, Pakistani, Bangladeshi, Black British
Weich et al (2020)	69,832 patients (>18 - >=65 yrs) [1 April 2011 and 31 March 2015]	16,946 (24%)	England	To examine variation in the use of community treatment orders and their associations with patient outcomes and health-care costs	Community Treatment Orders	Cross-sectional study; patients eligible to be subject to a community treatment order in England	White, Black, Asian, Other
Werbeloff et al. (2017)	17,666 (mean age 39.6) [2008- 2014]	7,269 (41.1%)	London	To examine predictors of admissions to acute mental health services after contact with Crisis resolution and home treatment teams.	Community mental health treatment/ inpatient admissions	Cross-sectional study; patients who have previously received or are receiving mental health care from the Camden and Islington NHS Foundation Trust and South London and Maudsley trust.	White, Black, Other

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Inpatient Services							
Ahmed et al., (2019)	508 (15-42) [2005-2013]	198 (39.0%)	Leicestershire	To determine the influence of demographic and clinical features on the likelihood of patients being discharged to primary vs secondary care	Early intervention in psychosis service	Cross-sectional studies (retrospective observational study); patients discharged from the Psychosis Intervention and Early Recovery service (PIER) (Leicestershire NHS) between January 2005 and December 2013	Mixed, Other, White British, Black African, Black Caribbean, Indian, Pakistani, Bangladeshi
Barnett et al., (2019)	67 studies (not reported) [inception to 2018]	Not reported	UK, International	To examined compulsory detention in BAME and migrant groups in the UK and internationally	Compulsory detention (involuntary psychiatric care)	Systematic review; quantitative studies comparing involuntary admission, readmission, and inpatient bed days between BAME or migrant groups and majority or native groups	White, Black, Asian, Others, Black African, Black Caribbean, Black Other, South Asian, East Asian
Bruce (2012)	165 (mean age=38.5) [2008- 2010]	119 (72%)	South London	To explore differences in the nature and frequency of reported met and unmet needs across African, African-Caribbean and White British heritage groups; and what can explain these ethnic differences.	Inpatient wards	Cross-sectional study; male mental health service users from 10 acute inpatient wards across four South London boroughs.	White British, Black African, African- Caribbean
Bruce and Smith (2020)	11,617 (>=18, mean age=43.69) [2008-2015]	5,214 (44.9%)	London	To examine the impact of multiple variables, across numerous domains (demographic, clinical and behavioural) on longer periods of psychiatric hospitalisation and whether any observed variations in length of stay (LOS) across ethnic groups could be fully or partially explained by the association.	Inpatient wards	Quasi-experimental retrospective between- subject cohort design; all eligible cases met an ICD-10 diagnosis of major mood disorders (without psychotic features), psychotic disorders, or manic disorders (without psychotic features) and must have been an adult at the first referral date (over 18 years of age).	Asian, White British, Black African, Black Caribbean

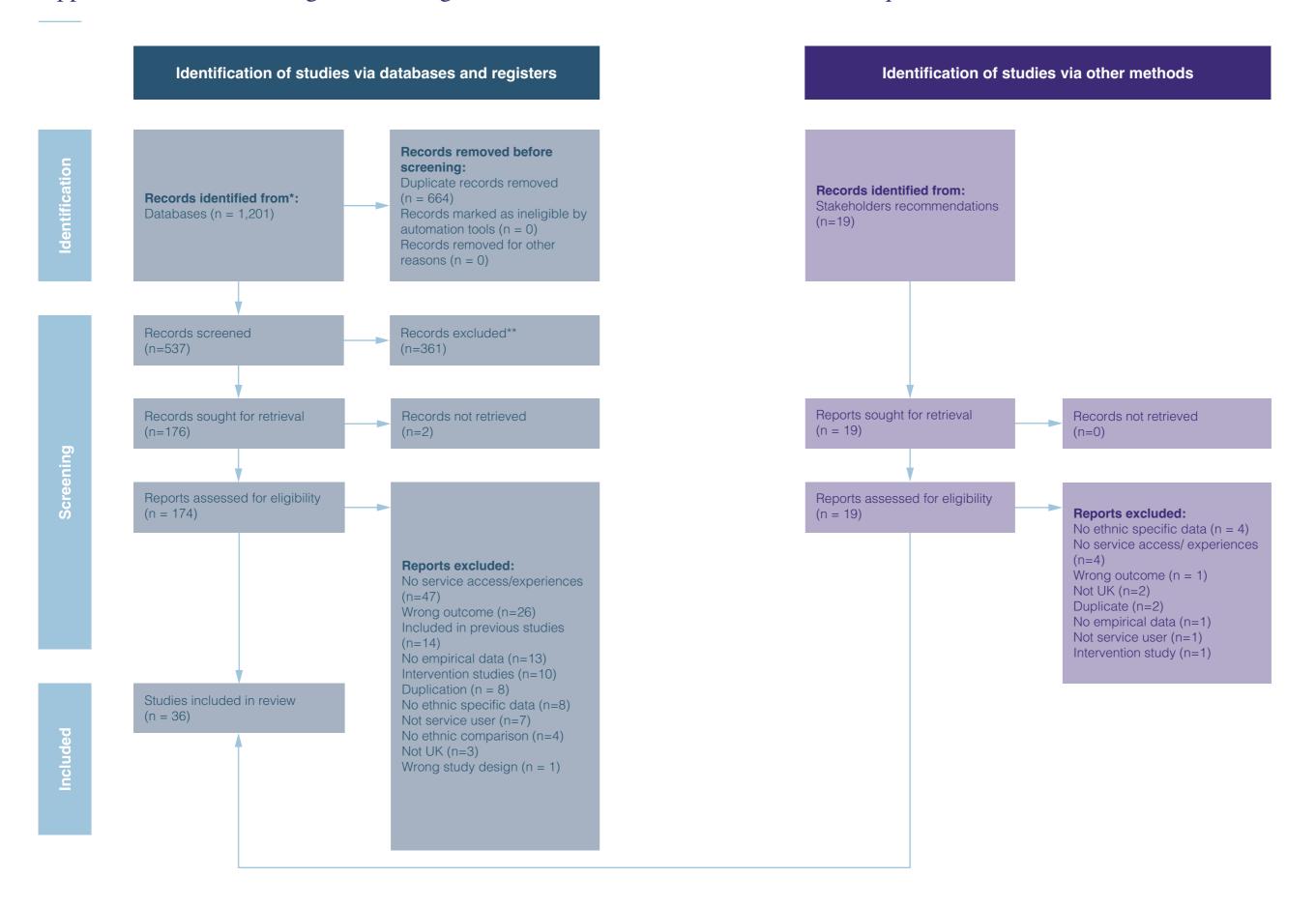
Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Cullen et al., (2018)	4,002 (Not reported) [2008- 2013]	2,854 (71.3%)	London	To determine the demographic, clinical and behavioural predictors of both psychiatric intensive care unit (PICU) and seclusion	Acute psychiatric inpatient services/ psychiatric intensive care unit (PICU)	Case control studies; (1) a psychiatric intensive care unit (PICU) cohort comprising all patients transferred from general adult acute wards to a non-forensic PICU ward between April 2008 and April 2013 (N= 986) and a randomly selected group of patients admitted to general adult wards within this period who were not transferred to PICU (N= 994), and (2) a seclusion cohort comprising all seclusion episodes occurring in nonforensic PICU wards within the study period (N= 990) and a randomly selected group of patients treated in these wards who were not secluded (N= 1032)	White, Black African/Black Caribbean (combined), Other
Halvorsrud et al. (2018)	40 studies (not reported) [inception to 2017]	Not reported	UK	To conduct a systematic review and meta- analysis of research on ethnic inequalities in pathways to care for adults with psychosis living in England and/or Wales	Pathways to psychosis care	Systematic review and meta-analysis; included systematic reviews and meta analyses (for the review of reviews); only quantitative studies for updated search (2012-2017), for adults or children with mental disorders as classified by standardised measures or clinical evaluation	White, Black, Asian, White British, White Other, Black British, Black African, Black Caribbean
Lawrence et al (2021)	35 (21-50 years) [not reported]	20 (57%)	London and Nottingham	To explore the journey through mental health services from the perspective of individuals from the Black Caribbean and majority White British population to help understand variation in the use of mental health services.	Navigating mental health system (including inpatient services)	•	White British, White Other, Black Caribbean
Lawrence et al., (2021)	35 (21-50) [Not reported]	20 (57%)	London and Nottingham	To investigate the long-term experience of living with psychosis and navigating mental health services within different ethnic groups.	Navigating mental health system (including inpatient services)	Qualitative interviews; Qualitative study embedded in AESOP-10, a follow up study at 10 years of 532 individuals with first-episode psychosis that sought to investigate the course and outcome of psychosis across ethnic groups in the UK	White British, White Other, Black Caribbean

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Payne-Gill et al (2021)	10,515 incidents of restrictive practices; 2,350 service users (<18 - 65+) [1 April 2017 and 31 March 2020]	1,317 (56.1%)	South London	To analyse the relationship between ethnicity and the use of restrictive practices to manage incidents of violence or aggression in inpatient settings across an NHS Mental Health Trust	Inpatient wards	Cross-sectional observational study; all incidents of restraint taking place over a three year period in one South London Mental Health Trust	White, Asian, Mixed, Black African, Black Caribbean, Black Other, Other
Polling et al., (2021)	56,117 (>=11) [2008-2018]	24,961 (44.5%)	London	To compare sex-specific rates of hospital admission and repeat admission following self-harm between ethnic groups in London and test whether differences persist after adjustment for socio-economic deprivation.	Inpatient services/ self-harm	Cross-sectional study; a population-based cohort of all individuals aged over 11 admitted to a general hospital for physical health treatment following self-harm between 2008 and 2018	White, Black, Asian, Mixed, Other, White British, White Irish, White Other, Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Mixed Other, Black African, Black Caribbean, Black Other, Indian, Pakistani, Bangladeshi, Chinese, Asian Other, Other
Saltus et al., (2013)	15455 (not reported) [pooled data from 6 datasets 2005- 2010]	433 (2.8%)	Wales	A secondary analysis of the census data, with a focus on mental health inpatients from Black and minority ethnic (BME) backgrounds in Wales.	Mental health inpatient service	Cross-sectional study; mental health inpatients based in Wales	White, Black, Asian, Mixed, Other, White British, White Irish, White Other, Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Mixed Other, Black African, Black Caribbean, Black Other, Indian, Pakistani, Bangladeshi, Chinese, Asian Other, Other
Watson and Daley (2015)	63 uses of section (20-69) [2012-2013]	50 (79.4%)	London	To determine the incidence of the use of section 135(1) of the Mental Health Act 1983 in a London borough and describe the main features of the population subject to that section.	Compulsory detention/ inpatient wards	Cross-sectional study; section 135(1) of the Mental Health Act warrants, considered to be executed (used) in a one-year-period	Others, White Other, Black African, Black Caribbean, Black Other, Asian Other, Mixed Other, British

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Youth mental he	alth services (childre	en, adolescents &	& young people)				
Anderson et al., (2017)	47 studies on service- level barriers for access to CAMHS; 25 on strategies to improve access and engagement (not reported) [1990-2017]	Not reported	UK, developing countries	To identify and aggregate evidence relating to key service development priorities highlighted in the consensus study. It reports barriers children, young people and families encounter when accessing and engaging with Children and Adolescent Mental Health Services (CAMHS), and effective strategies to overcome them.	Mental health services for children and adolescents	Systematic review; children, young people and families in developed countries; papers published after 1990	White, ethnic minority groups
Chui et al., (2021)	18,931 (12-29) [2008-2016]	10,915 (57.7%)	London	To examine inequalities in pathways into care by ethnicity and migration status in 12–29 years old accessing health services in south east London.	Secondary mental health services for young people	Cross-sectional survey; 12–29 year olds who access health services in South East London	Asian, Mixed, Other, White British, White Other, Black African, Black Caribbean, Black British
Dada et al., (2017)	78 (13-24) [Sep 2013 and June 2016]	78 (100%)	Manchester	To find out what young Black men think about mental health and how services should be run	General mental health services	Qualitative focus groups; young Black men living in Manchester	Black
Edbrooke- Childs & Patalay (2019)	145,88 (0-25) [Not reported]	2985 (21%)	UK	To examine whether there are ethnic differences in referral route to youth mental health services.	Mental health services for young people	Cross-sectional study; young mental health service users recorded in routinely collected national data.	Black, Asian, Mixed, Other, White British, White Other
Edbrooke- Childs et al (2016)	11,592 (0-25 years) [2007 -2013]	4,289 (37%)	England	To explore the association between ethnicity and care pathway through child and adolescent mental health services (CAMHS), in terms of reason for referral and case closure, in children presenting with emotional problems.	CAMHS	Cross-sectional study; episodes of care from 26 CAMHS in England submitting data between 2007 and 2013	Black, Asian, Mixed, Other, White British, White Other
Fernandez de la Cruz et al., (2016)	293 (36.9) [Not reported]	154 (64.4%)	London	To explore potential differences in illness perception, help-seeking attitudes, illness knowledge, and causal attributions that could help explain the lower uptake of treatment for OCD amongst ethnic minorities.	Youth services for obsessive– compulsive disorder (OCD)	Cross-sectional survey; self-identifies as belonging to one of the following ethnic groups: White British, Black African, Black Caribbean, or Indian, as these are the four most prevalent ethnic groups in the SLaM catchment area and has children under 18 years of age of their own.	White British, Black African, Black Caribbean, Indian

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Gurpinar- Morgan et al., (2014)	5 (16-18) [Not reported]	5 (100%)	England	To examine BME adolescent service users' perceptions of how ethnicity featured in the therapeutic relationship and its relevance to their presenting difficulties.	Cognitive behavioural therapy (CBT) for young people	Qualitative interviews; adolescent BME service users of cognitive behavioural therapy (CBT)	BME
Kolvenbach et al (2018)	20 (36 to 57 years) parents to children aged 13 to 17 [not reported]	10 (50%)	London	To identify and compare barriers that parents from different ethnic groups face when accessing specialist services for obsessive—compulsive disorder (OCD) for their children	Help-seeking for OCD	Qualitative interviews; a convenience sample of parents of children and adolescents from White and ethnic minority backgrounds were recruited from the National and Specialist OCD, Body Dysmorphic Disorder (BDD), and Related Disorders Clinic for Young People, South London and Maudsley NHS Foundation Trust, London	White, Black African, Black Caribbean, Indian, Pakistani, Iranian, Malaysian
Meechan et al (2021)	10 (16-18 years) [Jan 2019]	10 (100%)	South London	To examine the way in which young Black males in the UK make sense of mental health and associated systems of support	General mental health services	Qualitative interviews; young Black males attending one school in South London	Black, Black African, Black Caribbean, Black Other
Sancho & Larkin (2020)	17 (18-25) [Not reported]	17 (100%)	Birmingham	To understand the barriers and facilitators that Afro-Caribbean undergraduates perceive towards accessing mental health services in the UK.	General mental health services	Qualitative focus groups; Afro-Caribbean undergraduates at Aston University that had lived in the UK for a minimum of five years.	Black Caribbean
Vostanis et al (2013)	2,900 (13-15 years) [not reported]	1,087 (37%)	An English city and London	To establish whether adolescents of Indian and White British ethnicity reported different patterns of contacts with specialist and mental health services and informal supports, accounting for their levels of mental health need	General mental health services	Cross-sectional survey; 13-15 year olds in two schools in England of Indian or White British background	White British, Indian

Appendix 5: PRISMA diagram showing the identification of studies on ethnic inequalities in maternal and neonatal healthcare



Appendix 6: Summary of studies providing data on ethnic inequalities in maternal and neonatal care

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)		
Access and expe	Access and experiences (general)								
Bawadi et al. (2020)	24 (23-36); [not reported]	8 (100%)	East Midlands	To examine the challenges faced by migrant Arab Muslim women in accessing maternity services and to suggest ways to improve.	Maternity services - general access	Qualitative study: interviews; Arab Muslim women who had given birth	Arab		
Binder et al. (2012)	23 (18-48); [2005-6]	50 women (83%)	Greater London	To address the postulates that immigrant women experience sensitive care through the use of an ethnically congruent interpreter and that such women prefer to meet health providers of the same ethnic and gender profile when in a multiethnic obstetrics care setting.	Maternity services - general experiences of care	Qualitative study: interviews and focus groups; immigrant women of Somali and Ghanaian descent and White British women	Place of birth: Somalia, Ghana; White British		
Cross- Sudworth et al. (2011)	16 (not reported); [not reported]	16 (100%)	West Midlands	To explore and compare first- and second- generation Pakistani women's experiences of maternity services.	Maternity services - general experiences of care	Q-methodology; self-identifying Pakistani mothers less than 18 months post-partum and had used NHS maternity services in the inner city area	Pakistani		
Crowther & Lau (2019)	9 (25-39); [2017- 18]	9 (100%)	Scotland	To explore Polish migrant women's experiences of language and communication concerns when accessing UK maternity services.	Maternity services - experiences of language and communication	Qualitative study: interviews; Polish women who recently had experience of local maternity services in a city in Scotland	Polish		
Firdous et al. (2020)	Six studies (age not reported) [dates of publication 2000- 2019]	Not reported	Merseyside, Manchester	To synthesise thematically qualitative evidence on Muslim women's experiences of UK maternity services (regardless of obstetric or medical history).	Maternity services - general experiences of care	Systematic review; Muslim women accessing NHS maternity services	Indian, Pakistani, Bangladeshi, Palestinian, Iraqi, European, Somali		
Higginbottom et al. (2020)	40 studies [dates of publication Jan 1990-Jan 2018]	Not reported	UK: varied locations	To synthesise evidence on access to maternity care for immigrant women, including qualitative, quantitative and mixed-methods studies. *evidence on intervention aspects not included here.	Maternity services: general access and experiences	Systematic review; immigrant women accessing NHS maternity services	Immigrant women, varied countries of birth.		

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
John et al. (2021)	16 (25 - >41 years) [Dec 2020 - Jan 2021]	16 (100%)	Scotland	To explore the experiences of pregnancy, childbirth, antenatal and postnatal care in women belonging to ethnic minorities and to identify any specific challenges that these women faced during the SARS- CoV-2 pandemic.	COVID-19: general experiences of maternity care pathway	Qualitative study: interviews; pregnant women or those who were 6 weeks postnatal in a predominantly urban Scottish health board area	Black African, Black Caribbean, Indian, Pakistani, Bangladeshi, Chinese, Arab
Khan (2021)	Eight studies (24,645 women) (age not reported); [dates of publication 2013-2018]	Not reported	South Wales, Manchester, London, varied locations UK	To explore the maternal health inequalities encountered by BAME women in the UK in relation to their experiences and use of services.	Maternity services - general experiences of care	Systematic review; BAME women in maternity services	Aggregated term 'BAME' used; studies included Black African, Pakistani, Palestinian, West African, and multiethnic samples
Mantovani & Thomas (2014)	15 (16-19 years); [2005-7]	15 (100%)	London	To explore the experience of discovery of pregnancy, professional help-seeking and decision to continue with the pregnancy among young Black teenage mothers looked after by the State.	Maternity services - general experiences of care	Qualitative study: interviews; young Black mothers with a history of care currently pregnant and/or with a child no older than 2 years, living in London	Black African, Black Caribbean, Black British, Mixed Heritage; most either migrants or asylum seekers.
McFadden et al. (2018)	23 studies on maternity, unclear how many from UK; [not reported]	Not reported	UK (no further detail)	To investigate which approaches to community engagement are likely to enhance trust between GRT people and mainstream health services (including maternity services). *Note findings from professional consultation exercises not reported on here.	Maternity services - general access	Systematic review; Gypsy, Roma or Traveller communities	Roma, Gypsy or Irish Traveller
Rayment- Jones et al. (2019)	22 studies; [date of publication up to 2010]	N/A	UK (no further detail)	To uncover the mechanisms that affect women's experiences of maternity care.	Maternity services - experiences	Systematic review (Realist synthesis); women with social risk factors	Most included studies focused on Black and minority ethnicity; asylum seeker /refugee status (no more specific detail given)
Turienzo et al. (2021)	13	Not reported	South London	To explore experiences and insights of service user representatives into maternal and perinatal mental health and related research priorities.	Maternity services - general experiences of care	Qualitative: Public and patient involvement via two online engagement events	Black, White, Asian, Mixed
Watson & Downe (2017)	10 studies (age not reported); [dates of publication 2001 to 2014]	Not reported	Data from 25 European countries, including England, although majority of data from Central and Eastern European regions	To review the published evidence on discrimination against Romani women in maternity care in Europe, and on interventions to address this.	Maternity services - general experiences of care	Systematic review; Romani women in Europe accessing maternity care	Roma or Romani

Appendices

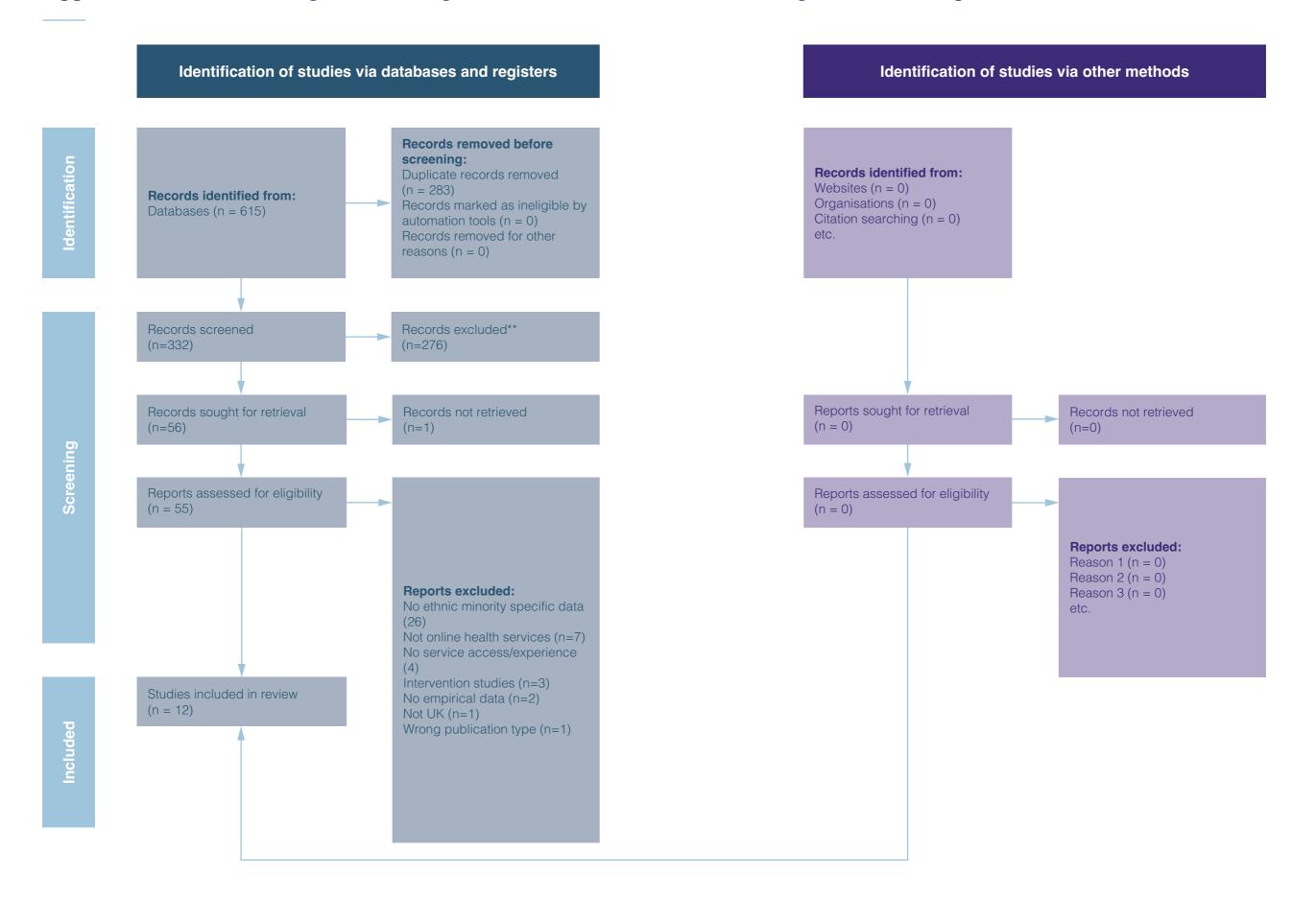
Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Antenatal							
Baker & Rajasingham (2011)	5,629 women were included in the study (Mean age 31) [2007-8]	2,814 (50%)	London	To identify predictors of late booking for antenatal care.	Antenatal care	Retrospective cohort study routine data analysis; women delivering their baby in a London teaching hospital	White, Black, Asian, Other
Hatherall et al. (2016)	21 interviewees + 32 focus group participants [2010-11]	Not fully reported (32 focused group participants were all ethnic minority)	London	To explore the factors which influence the timing of the initiation of a package of publicly-funded antenatal care for pregnant women living in a diverse urban setting	Antenatal care	Qualitative study: interviews and focus groups; pregnant and postnatal women; focus group: women in ethnic minority communities	Bangladeshi, Somali, Lithuanian and Polish
Kapaya et al. (2015)	34,384 (13-52 years) [Jan 2002 - Dec 2010]	6,418 (19%)	Sheffield	To explore the socio-demographic factors that influence late pregnancy booking, and then prospectively compare the stress and social support status of early and late-booking women.	Antenatal care: booking appointments	Retrospective routine data analysis; women with singleton births at a hospital in Sheffield	Aggregated - non-White ethnic background
McDonald et al. (2019)	122,275 bookings antenatal bookings (<20 to >40 years) [Apr 2015 to Mar 2016]	72,947 bookings (60%)	London	To describe late referral and antenatal booking across according to maternal characteristics.	Antenatal care: booking appointments	Cross-sectional routine data analysis; all antenatal bookings in London	White British, White Irish, White Other, Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Mixed Other, Black African, Black Caribbean, Black Other, Indian, Pakistani, Bangladeshi, Chinese, Asian Other, Other
Shah et al. (2011)	250 (cases [Chinese women mean age 26.4, British Caucasian women mean age 28.0 [Jan 2006 to June 2008]	125 (50%)	North London	To compare obstetric outcomes for British Chinese women and British Caucasian women. Patterns of antenatal care are examined.	Antenatal care: booking appointments [*some information also on Labour & Delivery reported in the text]	Case control study; first generation Chinese immigrant women (born in China), who delivered at a teaching hospital in North London	White British, Chinese
Stacey et al. (2021)	30 (22-40 years) [Nov 2019 - May 2020]	30 (100%)	North of England	To explore migrant women's awareness of health messages to reduce stillbirth risk, and how key public health messages can be made more accessible	Antenatal care: health literacy	Qualitative study: interviews and focus groups; migrant women from an ethnic minority background who were aged 18+, with a child under the age of 5	Aggregated term 'BAME' used; all migrants, 'home country' identified as: Pakistan, Bangladesh, Hong Kong, Ethiopia, Guinea, Somalia, Tunisia, Congo, Saudi Arabia, Egypt, Yemen, Russia, Albania, Sudan, Iran, Uganda, Senegal, Eritrea.

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Intrapartum (Lab	oour & Delivery)						
Aughey et al. (2021)	46,088 (age 18- 44) [Apr 2015- Mar 2016]	6,988 (15%)	England	To describe the proportion of births in England that were recorded as having occurred in water, the characteristics of women recorded as giving birth in water; and associated defined maternal and neonatal outcomes.	Labour and delivery care - water birth	Retrospective cohort study routine data; singleton term spontaneous vaginal births	White, Black, Asian, Other
Essen et al. (2011)	39 Somali women (age 18-48) [2005 to 2006]	39 (100%)	Greater London	To explore the perceptions of Somali women in relation to caesarean birth. *Note findings relating to providers not reported on here.	Labour and delivery care - Caesarean	Qualitative studies: interviews; immigrant Somali women, who had had at least one child within the British health care system	Black, Somali
Gorman et al., (2014)	122,803 (median age 29) [2004 to 2009]	3105 (2.5%)	Scotland	To explore the relative explanatory influence of obstetric practice among immigrants (Polish) in origin and destination countries.	Labour and delivery care	Cross-sectional study; primiparous women in Scotland	Polish
Henderson & Redshaw (2017)	3,099 (16+) [2014]	347 (17%)	England	To explore women's experiences of early labour care focusing on sociodemographic differences, and to examine the effect of antenatal education.	Labour and delivery care: experiences	Cross-sectional survey; women who had given birth to a baby; random sampling.	Aggregated BME group
Postnatal & Neo	natal						
Abdu et al. (2016)	15 (20-37) [Mar and June 2013]	15 (100%)	South of England	To explore the perspectives of South Asians regarding their experiences with the Health Visiting Service.	Postnatal: health visiting service	Qualitative study: interviews; South Asian women identified from caseloads of health visitors and from weekly health visitor clinics	South Asian
Battersby et al.(2017)	133 691 babies [2011-2013]	Not reported	England	To identify the primary reasons for term admissions to neonatal units, to determine risk factors for admissions for jaundice and to estimate the proportion who can be cared for in a transitional setting without separation of mother and baby.	Postnatal: neonatal units	Cross-sectional study routine data; babies born at term and admitted to neonatal unit for jaundice	Asian
Lam et al. (2012)	8 (24 - 34); [Not reported]	8 (100%)	Manchester	To explore the postnatal experiences of Chinese women.	Postnatal: experiences	Qualitative study: interviews; Chinese/ British Chinese with child <= 12 months old	Chinese, British Chinese
McFadden et al. (2013)	23 women (27- 40); [Feb - Dec 2008]	23 (100%)	West Yorkshire & North East	To explore the extent to which cultural context makes a difference to experiences of breast-feeding support for women of Bangladeshi origin and to consider the implications for the provision of culturally appropriate care.	Postnatal: breastfeeding	Qualitative study: interviews; women identifying as Bangladeshi who had breastfed in the past 5 years	Bangladeshi

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Perinatal Menta	l Healthcare						
Garcia et al., (2020)	6 (>=18); [2014- 2016]	4 (66.6%)	England	To explore the experiences of bereavement after stillbirth of Pakistani, Bangladeshi and White British mothers in a multi-ethnic town.	Perinatal mental health: Bereavement support	Qualitative study: interview; women who gave birth in the previous 6 to 24 months to a stillborn baby or baby who died within seven days of being in the neonatal intensive care unit	White British, Pakistani, Bangladeshi
Jankovic et al. (2020)	615,092 (18+); [2017]	189,942 (31%)	England	To explore access rates to secondary mental health services, including involuntary admissions to psychiatric inpatient care and patterns of engagement for ethnic minority women.	Perinatal mental health: secondary services	Cross-sectional study, routine data; all women giving birth in England	White British, White Irish, White Other, Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Mixed Other, Black African, Black Caribbean, Black Other, Indian, Pakistani, Bangladeshi, Chinese, Asian Other, Other
Prady et al. (2016)	2,234 (mean age 26.8, SD5.9); [2007-2010]	983 (44%)	Bradford	To investigate the associations between ethnic background and treatment of common mental disorders (CMD) during pregnancy.	Perinatal mental health: treatment for CMD	Cohort study; women recruited to the Born in Bradford cohort study between 2007 and 2010	Aggregated 'minority ethnic'; Black, Mixed, White British, White non-British, Indian, Pakistani, Bangladeshi, Other
Prady et al. (2021)	5 studies reported differences by ethnic group (age not reported); [dates of publication 2013-2016]	Not reported	UK: England, Northwest England, Bradford, Bristol, UK-wide	To examine, from an ethnic equity perspective, the implementation of current guidance for the identification and management of perinatal mental health problems.	Perinatal mental health: general access	Systematic review; studies reporting disparities in identification and management of perinatal mental health problems	Varied across included studies; White, Black, Asian, Mixed, Other, White British, Pakistani
Watson & Soltani (2019)	51 (25-41+); [Nov-Dec 2017]	51 (100%)	Large city in North of England	To investigate ethnic minority women's experiences and opinions of perinatal mental health problems and the provision of support services.	Perinatal mental health: experiences	Cross-sectional: online and face to face survey; ethnic minority women in a city in the North of England who had used or were using maternity services	Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Black African, Black Caribbean, Indian, Pakistani, Arab
Watson et al. (2019)	15 studies, 4,970 [from all studies] (age not reported); [All studies but one published 2003- 2016]	Not reported	England, Wales	To explore ethnic minority women's experiences of perinatal mental ill health, help-seeking and perinatal mental health services in Europe (but all eligible studies were conducted in the UK)	Perinatal mental health: experiences	Systematic review; studies including ethnic minority women living in Europe	Black, South Asian, Asian, White Other, Mixed White & Asian, Black African, Black Caribbean, Indian, Pakistani, Bangladeshi, Asian Other, Other, Pathan, Nigerian, Ghanaian, Portuguese, White American, White Australian

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Miscellaneous							
Deepa et al. (2014)	324 (17-50 years) [Jan 2009–Dec 2012]	130 (34%)	London	To identify characteristics associated with satisfaction after surgery for ectopic pregnancy	Surgery for ectopic pregnancy	Prospective cohort study routine data; women treated surgically for EP in a single centre	White, Black, Asian
Forde et al. (2020)	30 (25-44) [not reported]	24(80%)	England, South London	To elicit the views and experiences of women with Type 2 diabetes and healthcare professionals relating to the pregnancy and prepregnancy care they have received or provided.	Pre-pregnancy care: women with diabetes	Qualitative study: interviews; women with Type 2 diabetes	White, Black, Asian
Evans et al. (2019)	57 papers (18 from the UK)	100%	International including UK	To illuminate the experiences, needs, barriers and facilitators around seeking and providing female genital mutilation-/cutting-related health care from the perspectives of women and girls who have experienced female genital mutilation/cutting.	Care for people who have undergone FGM/C (including maternity care)	Systematic review	Country of origin: Somalia, Middle East, Kenya, South Africa, Gambia, Sudan, Nigeria, Zimbabwe, Sierra Leone, Ethiopia

Appendix 7: PRISMA diagram showing the identification of studies on digital ethnic inequalities



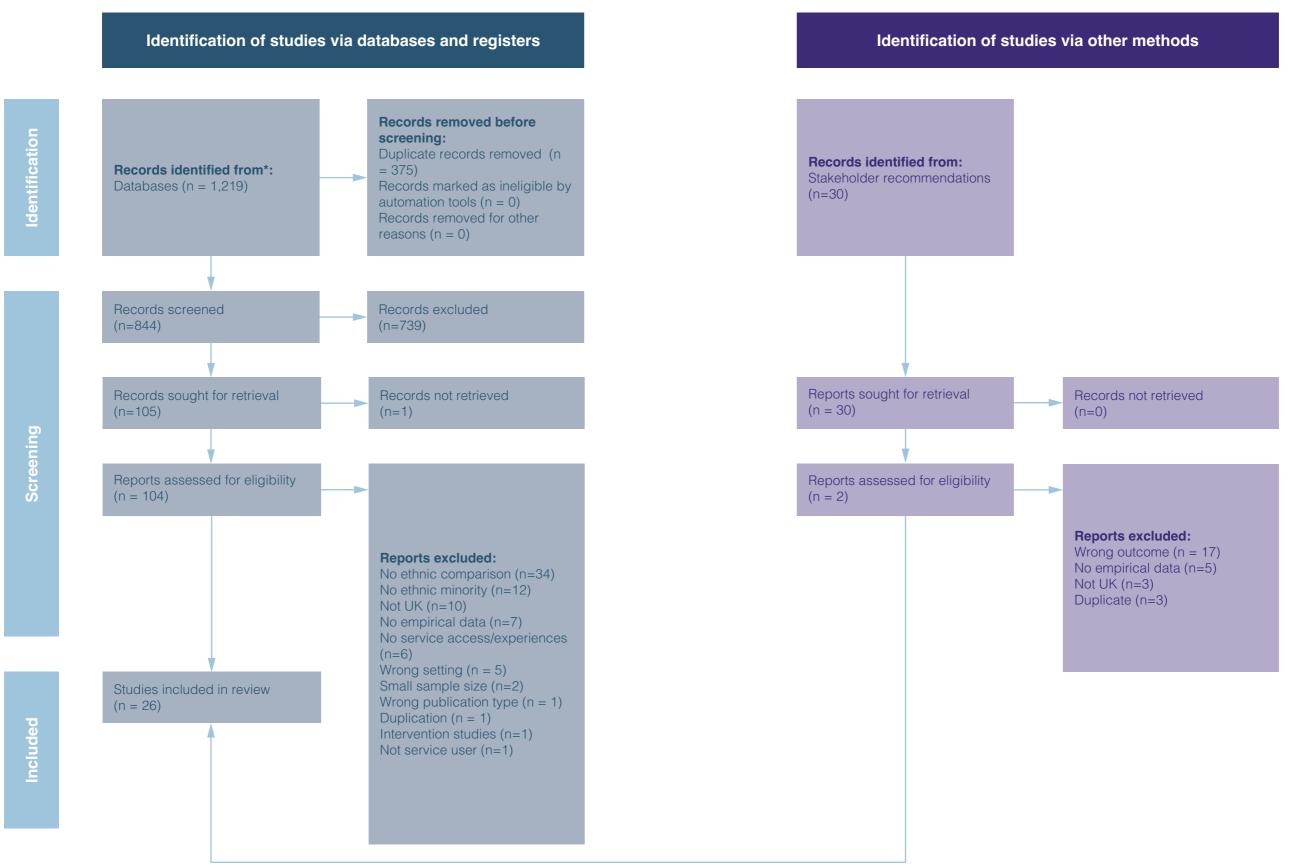
Appendix 8: Summary of studies providing data on ethnic inequalities in access to digital health services

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Usage and acce	ptability of digital he	alth apps and info	ormation				
Ada Lovelace Institute (2021)	2,023 (18-75+) [Jan-Feb 2021]	465 (27%)	UK	To understand public attitudes in the UK to a range of pandemic technologies seeking to engender health outcomes	Use of digital health apps	Cross-sectional online survey; UK general population	White, BAME
Dowthwaite et al (2021)	1,001 (16-75) [December 11 and 21, 2020)	125 (12.5%)	UK	To investigate adoption of and attitudes toward the NHS COVID-19 smartphone app, the digital contact tracing solution in the United Kingdom.	Use of digital apps	Cross-sectional online survey; UK general population	White, BAME
Prinjha et al. (2020)	67 (18-84) [Sep 2017-Mar 2018]	67 (100%)	Leicester	To explore the perceptions and views of British South Asian patients with Type 2 Diabetes on mobile health SMS text messaging to support medication adherence	Mobile Health Text Messaging to Support Medication Adherence for Type 2 Diabetes	Qualitative focus groups; South Asian adults with Type 2 diabetes	Indian Punjabi Sikh, Pakistani Muslim, Indian Gujarati Hindu, Bangladeshi Muslim, Indian Gujarati Muslim
Sounderajah et al. (2021)	2040 (>=18) [June 2020]	286 (14%)	UK	To assess people in the UK at risk of digital exclusion (older people, ethnic minorities) reported their preparedness for digital health strategies.	Digital service (general)	Cross-sectional online survey; adults in the UK registered with YouGov panel	White, BAME
NHS Telephone	Services						
Cook et al. (2014)	1,342,245 telephone calls (0 - 60+) [July 2010-Apr 2011]	357,436 (27%)	England	To determine how the diverse population in England have engaged with NHS Direct	NHS Direct	Cross-sectional analysis of call data; telephone calls to NHS Direct core service	Census 2011 16 ethnic categories [White British, White Irish, White Other, Mixed White & Asian, Mixed White & Black African, Mixed White & Black Caribbean, Mixed Other, Bangladeshi, Indian, Pakistani, Asian Other, Black African, Black Caribbean, Black Other, Chinese, Other]
Cook et al. (2015)	1,415,472 phone calls (0-60+) [July 2010-Apr 2011]	Not reported	UK	To explore referral patterns of National Health Service (NHS) Direct to determine how patients engage with telephone-based healthcare and how telephone-based healthcare can manage urgent and emergency care	NHS Direct	Cross-sectional analysis of call data; telephone calls to NHS Direct core service	Census 2011 16 ethnic categories
Warren et al (2015)	12,132 (0-11 and 16-75+) [May 2011-Dec 2012]	476 (4%)	England	RCT to assess satisfaction with GP triage, compared with nurse triage and usual care, in request for same day GP consultation	Same day appointment with GP	Randomised controlled trial (RCT); patients attending one of 42 GP practices in England	White, Other Ethnic Group

Appendices

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Online NHS serv	rices in primary, sec	ondary or tertiary	care care				
Barnard et al. (2018)	6,456 (>=16) [Jan-Mar 2016]		Lambeth and Southwark, London	To describe the characteristics of users of online sexually transmitted infection (STI) services and compare them with users of in person clinic STI services	Online and in person STI testing	Cross-sectional analysis of routinely collected STI data; users of STI services that were tested for HIV, gonorrhea, chlamydia or syphilis	White British, White Other, Mixed White & Black African, Mixed White & Black Caribbean, South Asian, Black African, Black Caribbean, Black Other, Other
Cunningham et al. (2019)	101,382 page accesses (20- 85+) [2016]	Not reported	Scotland	To analyse the demographic characteristics of use activity of the My Diabetes My Way website that has access to diabetic electronic patient health records, by patients	Access to diabetic electronic patient health records	Cross-sectional analysis of user activity and webpage accesses; electronic person health record (ePHR) registrants accessing My Diabetes My Way (MDMW)	White, Black, Asian, Mixed, Other
Healthwatch Enfield (2019)	1,071 (18-70+) [Aug-Sep 2018]	268 (25%)	Enfield, London	Consultation with residents of Enfield to garner views on digital appointments in primary care	Primary care consultations (GP)	Cross-sectional – online survey and in person engagement sessions; patients in Enfield	White, Black, Asian, Other. The other group in this study comprised of people from Turkish, Greek Cypriot, Turkish Cypriot and Greek communities
Nadarzynski et al. (2020)	257 (16-64+) [May 2017-Mar 2018]	31 (12%)	Hampshire	To explore the acceptability of three digital services, (i) video consultations via Skype, (ii) live webchats with a health advisor and (iii) artificial intelligence (AI)- enabled chatbots, as potential platforms for sexual and reproductive health sexual and reproductive health (SRH) advice	SRH services: video consultation, Webchat, Al chatbot	Cross-sectional survey; patients attending SRH clinics	White, Non-White
Quinn et al (2021)	148 (Mean=31, SD=5.8: Age range not reported) [May-July 2021]	32 (22%)	Leicester	To evaluate patients' and professionals' experiences with virtual antenatal clinic appointments during the COVID-19 pandemic to determine satisfaction and inquire into the safety and quality of care received.	Antenatal virtual care	Cross-sectional survey of pregnant women attending a virtual antenatal clinic at a UK tertiary care obstetric care centre	White, Ethnic minorities

Appendix 9: PRISMA diagram showing the identification of studies on ethnic inequalities in genetic services (including testing and counselling) and genomic databases and medicine



Appendix 10: Summary of studies providing data on ethnic inequalities in genetic testing and counselling and genomic databases and medicine

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Genetic testing a	and counselling						
Ahmed et al (2012)	98 (African women mean age (SD)=26 (4.6); Caribbean women mean age (SD)=30 (7.2) Chinese women mean age (SD)=31 (4.2); White British women mean age (SD)=32 (4.2), Pakistani women mean age (SD)=29 (5.4)	75 (77%)	UK	To explore diversity in the value attached to autonomous informed choice in antenatal screening, and to explore the similarities and differences in this value in women from different ethnic origins.	Antenatal screening	Qualitative interviews; women attending antenatal appointments with midwives	White British, Black African, Black Caribbean, Pakistani, Chinese
Allford et al (2014)	11 studies (age not reported) [studies published 2000- 2009]	Not reported	Studies from UK and US	To review available research to explore what may hinder or facilitate minority ethnic access to cancer genetics services	Genetic cancer testing	Systematic review; South Asian, African or Irish origin at risk of familial breast, ovarian, colorectal and prostate cancers in the UK	South Asian, White Irish, Black African
Alsulaiman et al (2012)	520 (not reported) [not reported]	198 (38%)	UK	The aim of this research was to compare attitudes between women from different cultural and/or religious backgrounds toward prenatal diagnosis (PND) and termination of pregnancy for 30 different conditions	Prenatal testing	Questionnaire; not reported	White British, Pakistani
Darr et al (2013)	50 (20-60+) [not reported]	50 (100%)	Bradford, Blackburn and Derby	To examine the perspectives of the community, of families and of health professionals, in relation to genetic service delivery	Genetic testing and counselling	Qualitative focus groups; lay people of Pakistani origin in three cities in England	Pakistani

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Lewis et al (2016)	585 (mean age=35 years, interquartile range 32-39 years) [Dec 2013 to Feb 2015]	147 (25%)	UK	To validate a modified Multidimensional Measure of Informed Choice (MMIC) instrument for non-invasive prenatal testing (NIPT) and measure informed choice among women offered NIPT following Down's Syndrome Screening (DSS) in a public health service	Prenatal testing	Questionnaire; women who had accepted Down's Syndrome Screening (DSS) as part of routine care, were older than 16 years, had a singleton pregnancy and able to read and understand English, at one of 8 antenatal clinics in the UK	White, Black, Asian, Mixed, Other
Shaw (2011)	62 (20-64 years) [2000-2004]	62 (100%)	High Wycombe, England	To examine British Pakistani-origin couples' responses to counselling about the recurrence risk of genetic problems in children	Genetic testing and counselling	Qualitative interviews; people of Pakistani origin referred to an NHS genetics clinic in High Wycombe, in Southern England	Pakistani
Tsianakas et al 2012	21 (25-32 years) [not reported]	13 (62%)	England	To describe the acceptability to women of being offered antenatal Sickle cell and Thalassaemia (SC&T) screening in primary and secondary care at the visit to confirm pregnancy	Antenatal screening for sickle cell and thalassaemia	Qualitative semi-structured interviews; women recruited from a trial (Screening for Haemoglobinopathies in the First Trimester Trial) being conducted in two Primary Care Trusts (PCTs) in inner city areas of England (2 of the most deprived PCTs in England).	White, South Asian, Black African, Black Caribbean, Chinese, White European
Willis et al 2013	200 (16+) [not reported]	33 (16.5%)	Yorkshire	To record levels of understanding of, and attitudes to, genetic testing for inherited retinal disease, and views on the availability of testing	Genetic testing for inherited eye disorders	Semi-structured interviews via telephone; patients who had previously attended eye clinics in Yorkshire aged 16+	White, Asian, Mixed, Other
Yu (2012)	Not reported [Studies published 1995 -2008]	Not reported	UK	To identify and describe the literature on issues around antenatal screening and prenatal diagnostic testing for genetic disorders among women of Asian descent in western countries.	Prenatal testing	Systematic review; Asian women in Western countries	White, South Asian, Asian, Indian, Pakistani, Bangladeshi, Chinese

Appendices

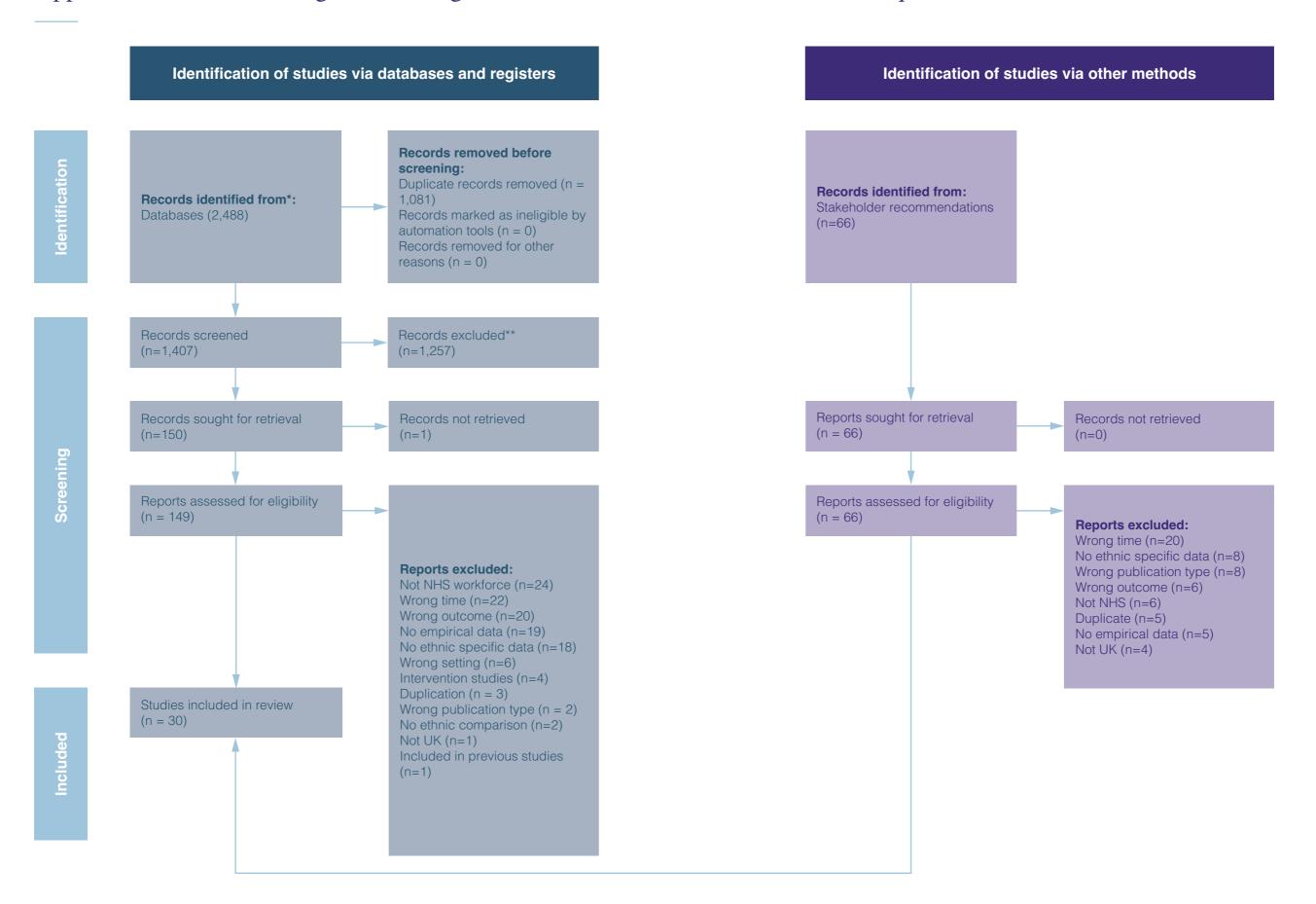
Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Representation i	in genetic databases	s/ involvement in	genetic research				
Meisel et al (2012)	ELSA: 6,618, mean age (SD)= 66.9 (10.5). Whitehall: 6,870, mean age (SD)= 61.2 (5.99) [2003-2004]	712 (5.3%)	England	This analysis explored socio- demographic (age, gender, religion, and education), health-related, and psychological predictors of participation in genetic data collection in two large epidemiological studies: the Whitehall II cohort and the English Longitudinal Study of Ageing (ELSA).	N/A: representation in genetic databases	Survey; respondents to Whitehall study or ELSA	Aggregated (Ethnic minorities, BAME, etc)
Mills & Rahal (2019)	3639 studies [Dates of publication: 2005 - 2018]	Not reported	Global	To review genome-wide association studies (GWAS) from 2005 to 2018 to investigate sample sizes, rates of discovery and traits studied	N/A: representation in genetic databases	Scientometric review; genome wide association studies that have been reported in on scientific published articles	Ancestry: European, Asian, African, Hispanic/ Latin American, Other/ Mixed, African-American/Afro- Caribbean
Saifuddin et al (2017)	549 (<50 to >90) [Jan 2013-Dec 2015]	107 (19.5%)	Guy's and St Thomas' NHS Foundation Trust (GSTT), London	To assess representativeness of the King's College Cancer Biobank	N/A: representation in genetic databases	Comparison of clinical data with population data; prostate cancer patients seen at urology or oncology departments Guy's hospital who gave consent to biobank their samples (blood, tissue)	White, Black, Asian, Mixed, Other
Skyers (2018)	55 (25-65+) [March to June 2018]	55 (100%)	Bradford, Manchester, Sheffield, Nottingham, West Bromwich, and Ipswich	To explore views about the 100,000 Genomes Project, and levels of awareness in Black African and Black Caribbean communities.	Involvement in genetic research	Qualitative focus groups; Black Caribbean and Black African people living in one of 6 localities	Black African, Black Caribbean

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Genome Wide A	Association (GWA) st	udies demonstra	ting ethnic differei	nces (or lack of) in polygenic risk scores (PRS) or sin	nilar		
Barfield et al (2019)	Multi-Ethnic Study of Atherosclerosis (MESA; n = 619, mean age (SD)=68.72 (9.24)) and the Cardiovascular Health Study (n = 483) mean age (SD)=74.03 (5.3) [not reported]	572 (52%)	UK, USA	To explore the association between DNAm and daytime sleepiness quantified by the Epworth Sleepiness Scale (ESS)	GWA	Cross-sectional GWA study; participants in the Multi-Ethnic Study of Atherosclerosis (MESA; n = 619) and the Cardiovascular Health Study (n = 483) using the UK Biobank for cross-study replication and meta-analysis	European, African American, Hispanic American
Bosch et al (2017)	86,979 (Asian mean age (SD)=16 (12), non-Asian mean (SD)=21 (13) [not reported]	563 (0.6%)	UK	To elucidate the impact of Asian descent on the diagnosis of CF	GWA	Cross-sectional GWA study; CFTR2 (Cystic Fibrosis Transmembrane conductance Regulator) and UK Cystic Fibrosis (CF) databases	White, Asian
Cherny et al (2020)	96,576 (21- 89 years) [not reported]	24,471 (25%)	UK	To estimate heritability and environmental contributions to liability of age related hearing impairment (ARHI) and the extent to which a polygenic risk score (PRS) derived from a recent genome-wide association study of questionnaire items regarding hearing loss using the UK Biobank is predictive of hearing loss in other samples	GWA	Case control study; people in the UK Biobank or TwinsUK study with hearing impairment or use of hearing aid, with matched case controls	European Ancestry, African American Ancestry, Southeast Asian Ancestry, Other South Asian Ancestry
Gettler et al (2021)	29,358 (not reported) [not reported]	22,104 (75%)	UK, USA	To define effects of common and rare irritable bowel disease (IBD) variants on disease prediction and pathophysiology	GWA	Case control; participants in BioMe (US GWA) and UK Biobank with IBD and matched controls	European, Ashkenazi Jewish, African American, Hispanic
Karunamuni (2021)	3,013 men with (cases, mean age=62.1) and 3,240 men (mean age=61.8) without (controls) prostate cancer [not reported]	6,253 (100%)	Global	To use machine learning to identify three single nucleotide polymorphism (SNPs) that significantly improved the performance of an established polygenic-hazard model of prostate-cancer risk vs age at diagnosis, specifically tailored to men of African genetic ancestry.	GWA study	Case control study; cases taken from Prostate Cancer Association Group to Investigate Cancer Associated Alterations in the Genome (PRACTICAL) consortium	Ancestry: African American

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Li et al (2021)	15,585 cases and 20,452 controls (not reported) [not reported]	6,001 cases and 4,493 controls of East Asian (Chinese) descent; and 1340 cases and 1685 controls of Turkish and Iranian origin, respectively	Global	To test the hypothesis that polygenic risk scores (PRSs) have strong capacity to discriminate cases of ankylosing spondylitis (AS) from healthy controls and individuals in the community with chronic back pain	GWA study	Case control study; participants in genome wide association studies in UK, New Zealand, France, Australia, USA	Ancestry (European, East Asian, Iranian, Turkish)
Marquez-Luna et al (2017)	~48,000 (not reported) [not reported]	Not reported	Global	To predict type 2 diabetes (T2D) in a Latino cohort using both publicly available European summary statistics in a large sample and Latino training data in a small sample	GWA study	Cross-sectional GWA study; participants in multiethnic GWA studies	Latinos, European, African American, South Asian
McInnes et al (2021)	~500,000 (not reported) [not reported]	Not reported	UK	To determine pharmacogenetic allele frequencies in 14 genes among 500,000 participants in the UK Biobank.	GWA study	Cross-sectional GWA study; participants in the UK Biobank	European, non-European
Moll et al (2020)	27,879 participants (Mean age (SD) varied between the GWAs used e.g. from mean=47.1 (SD=10.47) to mean age =80.34 (SD=4.99)) [not reported]	Not reported	Global	To construct a polygenic risk score (PRS) using additional variants to predict COPD and associated phenotypes	GWA study	Case control study; people with Inflammatory Bowel Disease (IBD) in GWA studies and matched case controls	European and non-European ancestry
Sarnowski et al (2019)	10,338 TOPMed participants; 5,311 Africanancestry, 398,122 European-ancestry, and 1,331 Asian-ancestry non-diabetic UK Biobank participants for replication (40-69 years) [not reported]	TOPMed 4,180 (40%); UK Biobank 6,642 (1.6%)	UK, USA	To identify common, low frequency, and rare genetic variants (single-nucleotide variants [SNVs] and structural variations) associated with HbA1c through association analyses in diabetesfree individuals from four ancestries by using whole-genome sequencing (WGS) data	GWA study	Cross-sectional GWA study; participants in (Trans-omics for Precision Medicine) TOPmed study without diabetes from five cohorts: the Old Order Amish study, the Atherosclerosis Risk in Communities Study (ARIC), the Framingham Heart Study (FHS), the Jackson Heart Study (JHS), and the Multi-Ethnic Study of Atherosclerosis (MESA), and UK Biobank participants	European, African American, Hispanics/Latinos, East Asians

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Strawbridge et al (2018)	72,348 (not reported) [2005- 2010]	72,348 (100%)	UK	To assess sex-specific effects, trans-ethnic heterogeneity and genetic overlap with psychiatric traits	GWA study	Cross-sectional GWA study; UK Biobank participants	South Asian, Other, White Other, African-Caribbean
Traylor et al (2017)	197 cases (mean age=56.3 (SD=14.9), 868 controls (mean age= 58.7 (SD=12.0)) [January 2011 to February 2015]	1,065 (100%)	South London	To evaluate whether genetic and environmental factors associated with Rheumatoid Arthritis (RA) in European and Asian ancestry populations are also associated with RA in African ancestry individuals	GWA study	Case control study; cases were taken from the GENetics of RA in individuals of African ancestry (GENRA) study and controls were from the South London Ethnicity and Stroke Study (SLESS)	Black African, Black Caribbean
Wang et al (2020)	7,244 from UK Biobank, 491 from Bangladesh study, 1800 cases and 1163 controls from India (not reported) [not reported]	10,698 (100%)	UK, India, Bangladesh	To derive a new genome wide polygenic risk score (GPS) for coronary artery disease (CAD) in South Asians	GWA study	Cross-sectional GWA study; cases and controls with CAD in UK Biobank and studies in India and Bangladesh	South Asian

Appendix 11: PRISMA diagram showing the identification of studies on ethnic inequalities in the NHS Workforce



Appendix 12: Summary of studies providing data on ethnic inequalities in the NHS workforce

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Inequalities in Co	ovid-19 outcomes						
Nguyen et al., (2020)	2,135,190 (front-line health-care workers: mean=42; General community: mean= 44) [2020]	Front-line healthcare workers: 9,080 (9.1%); general community: 126,194 (6.2%)	UK, US	To assess the risk of COVID-19 among front-line health-care workers compared with the general community and the effect of personal protective equipment (PPE) on risk	General HCWs	Cross-sectional studies; consecutive users of the COVID Symptom Study app - both front-line health-care worker and people from general community are included.	Black, Asian, Non-Hispanic White, Hispanic White, More than one race or other race
Shorten et al., (2021)	4,474 (mean (SD)=42.5 (13.2)) [29 May to 4 July 2020]	781 (17.4%)	England	To assess the extent of infection in staff working in our healthcare setting.	General HCWs and non-patient facing staff	Cohort studies; staff in diverse clinical and non-patient facing roles who volunteered for SARS- CoV-2 antibody testing by the Roche Elecsys assay between.	Black, Asian, Mixed, White Other, Chinese, White UK and ROI
Impact of Covid-	19 on working envir	onment					
Ali et al., (2021)	1,119 (mean (SD)=45 (9.5)) [2020]	749 (71%)	UK	To explore the views of an ethnically diverse sample of Healthcare Practitioners (HCPs) in the UK about COVID-19- related deaths among HCPs in general and BAME HCPs in particular.	General HCWs	Cross-sectional studies; All Healthcare Practitioners (HCPs) working in the UK	White, BAME
Carvalho et al., (2021)	1,182 (not reported) [2020]	625 (52.9%)	London	To describe success rates of respiratory protective equipment (RPE) fit testing and factors associated with achieving suitable fit.	General HCWs	Cross-sectional studies; healthcare workers who worked in a central London teaching hospital and designated COVID-19 centre and underwent quantitative fit tests (QNFT) during the study period	White, Black, Asian, Mixed, Other
General Medical Council (2020)	3,693 (not reported) [2020]	not reported	UK	To assess how doctors have fared during the Covid-19 pandemic	Doctors	Cross-sectional studies; Doctors in the UK that responded to the GMC's Barometer survey	White, ethnic minorities
Gilleen et al (2021)	2,773 (<25 - 65+) [22 April and 10 May 2020]	393 (14%)	UK	To understand the risk and protective factors associated with poor mental well-being of UK HCWs working during the COVID-19 pandemic	General HCWs	Cross-sectional studies; all UK healthcare workers in the NHS	White, ethnic minorities

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Kapilashrami et al (2021)	456 (not reported) [July– August 2020]	136 (29.8%)	UK	To examine determinants of ethnic disparities in workplace risks of COVID-19 among health and social care workers (HCWs) in the UK.	General HCWs	Cross-sectional studies; Health and social care workers across the UK	White, ethnic minorities
Mcfadden et al., (2020)	3,290 [2020]	220 (6.7%)	UK	To explore the impact of providing health and social care during the COVID-19 pandemic on nurses, midwives, Allied Health Professionals (AHPs), social care workers and social workers working in the UK	Nurses, midwives, Allied Health Professionals (AHPs), social care	Cross-sectional studies; Nurses, midwives, AHPS, social care workers and social workers at any band who are currently employed or self-employed (including agency workers), within any area of health and social care in the UK during the COVID-19 Pandemic.	White, Black, Asian, Mixed
Norton et al., (2020)	2,075 (18-59, mean=22.2, sd=3.36) [2020]	641 (32.2%)	UK	To explore training and perceptions of PPE and infection prevention and control (IPC) in UK medical students and FiY1 doctors during the COVID-19 pandemic.	Trainee doctors	Cross-sectional studies; current medical students and FiY1 doctors in the UK	White, BAME
Racism in the w	orkplace						
Alexis (2015)	188 (>=21) [Not reported]	188 (100%)	England	To determine internationally recruited nurses' perception of discrimination, support, and their adjustment to a new environment in the NHS in England.	Nurses	Cross-sectional studies; Internationally recruited nurses from 15 National Health Service hospitals in England	Philippines, Australia, Botswana, China, Ghana, Guyana, India, Jamaica, Kenya, Malawi, Malaysia, New Zealand, Nigeria, Pakistan, Sierra Leone, Singapore, South Africa, Thailand, Trinidad, Zambia, Zimbabwe
Bond et al., (2020)	6 studies (Not all studies reported age) [2010-2019]	N/A	UK	To synthesise the most recent qualitative research exploring the experiences of international nurses and midwives as they transition and adapt to living and working in the UK.	Nurses, midwives	Systematic reviews; full-text academic articles, detailing primary qualitative research focussed on the experiences of international nurses and midwives, written in English and post-2010	Jordanian, Jamaican, Filipino, Nepalese, Sub-Saharan African, Indian, Ghanaian,
Hallett et al (2021)	129 (survey), 36 (focus groups) (not reported) [the review extracted data for the focus groups only] [May 2018 and December 2018]	Not reported for focus groups	Two neighbouring cities in UK	To identify the prevalence of aggression experienced by nursing students whilst on clinical placement in one UK city, and rates and experiences of reporting of aggression	Student nurses	Mixed methods studies; preregistration nursing students at one of the two universities, in any year of study and field of practice, who had completed at least one clinical placement. All	White, ethnic minorities

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Johnson et al., (2019)	538 (mean age=43.55) [2017]	104 (19.3%)	UK	To investigate the relationships between workplace bullying, perceived discrimination, levels of burnout and patient safety perceptions in nurses and midwives and to assess whether bullying and discrimination were more frequently experienced by Black, Asian and minority ethnic than White nurses and midwives.	Nurses, midwives	Cross-sectional studies; Nurses and midwives from four hospitals in the United Kingdom	White, ethnic minorities
Likupe et al., (2013)	30 (mean age=35) [2006- 2008]	30 (100%)	England	To explore Black African nurses' experiences of equal opportunities, racism, and discrimination in four NHS trusts in North Eastern England.	Nurses	Qualitative studies; Black African nurses in the United Kingdom	Black African
O'Brien et al (2012)	55 (not reported) interviews. There was also observations of 7 different cohorts of overseas nurses on hospital wards but the n was not reported [not reported]	40 overseas nurses (72%)	North West England	To improve our understanding of the processes involved in the assimilation of overseas nurses (OSN) into the salient long-term workforce of the National Health Service (NHS) hospitals in the UK	Nurses	Qualitative studies; Seven cohorts of overseas nurses from India, Philippines and Spain and Home nurse working alongside them in three North West NHS Hospitals in England	Place of Birth: India, Philippines and Spain
Odusanya et al (2018)	6 (34-46) [Not reported]	6 (100%)	UK	To explore the lived experience of Black and minority ethnic (BME) clinical psychologists employed in the U.K. National Health Service (NHS).	Psychologists	Qualitative studies; ethnic minority psychologist working in the NHS	Black, Asian
Rhead et al., (2021)	931 (>=19) [2019]	510 (54.8%)	London	To examine the impact of harassment and discrimination on NHS staff working in London trusts.	General HCWs	Cross-sectional studies; London-based healthcare practitioners (doctors, nurses, healthcare assistants and Improving Access to Psychological Therapy (IAPT) workers)	Black, Asian, Mixed, White British, White Other

Author (year)	Sample size (age in years) [dates of data collection]	Ethnic minority participants N (% of total sample)	Location	Aim of the study	NHS Services covered	Study design; population	Ethnic categories used for analysis (N.B. categories used in data collection may be different due to combining of categories during analysis)
Scammell and Olumide (2012)	33 (not reported) [23 students; 10 IRN mentors] [Not reported]	Student: 1 (4.3%); IRN mentor: 10 (100%)	England	To analyse mentorship relationships between Internationally Recruited Nurse (IRN) mentors and White students, focusing on interaction in which perceptions of difference were in play.	Nurses	Qualitative studies; IRNs were experienced registered practitioners, having worked as nurses in the UK for a minimum of 3 years, on average having mentored five students each. Students are nursing students in England.	Asian, White British, Black African, Black Zimbabwean; White American
West et al., (2015)	255,150 (>=16) [2014]	35,721(14%)	England	The analysis sought to answer the following questions: (1) What are the differences in reported levels of discrimination between NHS staff from different demographic and work backgrounds? (2) Do these differences persist when controlling for other background variables?	General HCWs	Cross-sectional studies; NHS staff across 284 organisations (including 157 acute trusts, 57 mental health/learning disability trusts, 40 clinical commissioning groups (CCGs), 19 community trusts and 11 ambulance trusts)	White, Black, Asian, Mixed, Other
Staff mental heal	lth and wellbeing ou	tcomes					
Bourne et al., (2019)	5,661 (25-74) [2017-2018]	1,335 (43.0%)	UK	To determine the prevalence of burnout in doctors practising obstetrics and gynaecology, and assess the association with defensive medical practice and self- reported well-being	Obstetricians, gynaecologists	Cross-sectional studies; practising obstetrics and gynaecology consultants, specialty and associate specialist doctors and trainees registered with the Royal College of Obstetricians and Gynaecologists	White, Black, Asian, Mixed, Other
Deery et (al)	2,221 (mean=37.98, SD=9.5) [2003]	444 (20%)	London & South East England	To analyse the impact of harassment on job burnout and turnover intentions among a large sample of hospital nurses in Britain	Nurses	Cross-sectional studies; All employees at 6 NHS hospital trusts in London/ South East London	White, ethnic minorities
Graham-Brown et al., (2021)	672 (median age: around 37) [2012-2019]	292 (46.6%)	UK	To understand the impacts of changing workforce demographics on trainee outcomes and wellbeing	Renal speciality trainee doctors	Cross-sectional studies; renal medicine trainees who completed General Medical Council (GMC) national training survey	White, ethnic minorities
Seston and Hassell (2014)	12,364 (mean age =43.8) [2008]	1,632(13.2%)	England, Scotland, Wales	To explore pharmacists' experiences of maintaining work/life balance in a large, nationally representative sample of pharmacists in Great Britain (GB)	Pharmacists	Cross-sectional studies; All GB-domiciled pharmacists who were registered with their regulatory body, the Royal Pharmaceutical Society of Great Britain	White, Black, Indian, Pakistani, Chinese, Asian Other, Mixed and other
Summers et al., (2020)	1,678 (>=18) [Not reported]	222 (11%) [It does not distinguish White British and Other White ethnicity]	UK	To explore the determination of averages for workplace well-being of psychological practitioner subgroups in the United Kingdom.	Psychologists	Cross-sectional studies; Psychological practitioners from a range of psychological subprofessions with a focus on those delivering talking-based therapies.	White, Black, Asian, Mixed, Other

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Career progress	ion and pay gap						
Appleby et al (2021)	1,143,507 (not reported) [December 2017]	225,218 (19.7%)	England	To report on the ethnic pay gap for staff working in the English NHS	General HCWs and non-patient facing staff	Cross sectional study; analysis of pay information for all staff registered as employees in NHS on a census data in December 2017 (excluding GPs, dentists and their staff)	White, Black, Asian, Chinese, Mixed or Other
Hatzidimitri- adou and Pso- inos (2014)	10 (28-52) [Not reported]	10 (100%)	UK	To explore the experiences of overseas health and social care professionals before and after migrating to the UK, and the relevance of cultural capital for their professional development.	General HCWs	Qualitative studies; Overseas doctors and nurses in the UK	South Asian, South Africa, South Asia, South-East Asia, East Africa, Central Asia, Central Europe, South Europe
Howells et al., (2017)	28 (21-60) [Not reported]	18 (64.3%)	England	To explore the employment choices of White and BAME women pharmacists to see whether their diverse work patterns are the product of individual choices or other organisational factors.	Pharmacists	Qualitative studies; registered women pharmacists currently working in the community or hospital sector	White, Mixed, Black African, Black Caribbean, Pakistani, Bangladeshi, Chinese, Asian Other, Middle Eastern
Johnson et al., (2021)	538 (mean age=43.3) [2017]	104 (20.3%)	England	To explore the presence and nature of career progression delays for Black, Asian and Minority Ethnic nurses and midwives and investigated where the barriers to progression were.	Nurses, midwives	Cross-sectional studies; registered nurses and midwives employed by an NHS Trust	White, ethnic minorities
Likupe et al., (2014)	7 (not reported) [2009]	1 (14.3%)	England	To explore the experiences of the nurses from their managers' perspectives in the various settings in which they were employed.	Nurses, nurse managers	Qualitative studies; managers who were supervising Black African nurses	Black African
Morris et al., (2011)	2,271 (not reported) [2008]	277 (11.2%)	England	To analyse the determinants of annual net income and wages (net income/hours) of general practitioners (GPs)	GPs	Cross-sectional studies; GPs in England	White, ethnic minorities



