

Ethnic Inequalities in Healthcare: A Rapid Evidence Review

Summary

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The University of Manchester





The University Of Sheffield.

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

Executive Summary

This summary 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 guality 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

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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 over-represented 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.

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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.

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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

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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 score (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.

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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

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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.
- 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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Academic and Clinician Stakeholders

- **Prof Karl Atkin,** Professor of Sociology, *The University of York*
- Andy Bell, Deputy Chief Executive, *Centre* for Mental Health
- **Yvonne Coghill,** Director, *Excellence in* Action and member of the NHS Race & Health Observatory board
- **Rakhi Chand,** PhD Student, Alliance Manchester Business School, *The University of Manchester*
- Dr Jayati Das-Munshi, Senior Lecturer in Social Epidemiology with King's College London and Honorary Consultant Psychiatrist with South London & Maudsley NHS Trust
- **Prof Dawn Edge,** Professor of Mental Health and Inclusivity, *University of Manchester*
- Dr Mel Haith-Cooper, Reader in Maternity and Migrant Health, *University of Bradford*

- **Prof Flis Henwood,** Professor of Social Informatics, *University of Brighton*
- Dr Hanif Ismail, Research Fellow, University of Bradford
- **Dr Adrian James,** President of the Royal College of Psychiatry and member of the NHS Race & Health Observatory board
- **Dr Saghira Malik Sharif,** Principal Genetic Counsellor, Yorkshire Regional Genetics Service, *Leeds Teaching Hospitals NHS Trust*
- **Dr Shuby Puthussery,** Senior Lecturer in Public Health, Director of the Maternal and Child Health Research Centre, *University* of Bedfordshire
- Dr Shwetha Ramachandrappa, Consultant Clinical Geneticist, *Guy's and St Thomas' Hospital*
- **Dr Tanvi Rai,** Senior Researcher, *University of Oxford*

- **Professor Gurch Randhawa,** Professor of Diversity in Public Health and Director of Institute for Health Research Institute, *University of Bedfordshire*
- **Prof Jane Sandall,** Head of Midwifery and Maternity Research, *NHS England and NHS Improvement*
- Dr Andrew Smart, Reader in Sociology, Bath Spa University
- **Dr Julie Vogt,** Consultant in Clinical Genetics, *Birmingham Women's and Children's NHS Foundation Trust*
- **Dr Ros Williams,** Lecturer in Digital Media & Society, *The University of Sheffield*
- **Jo Wright,** Consultant Midwife, *Walsall Healthcare Trust*

Community Practitioner Stakeholders

- Puja Patel, Acacia Family Support
- Jean Smith, Nilaari
- Zakira Takolia, Nilaari
- Lana Mareno, Wellness Journey
- Jazz Browne, Nubian Life
- Godefroid Seminega, ASHA
- Lydia Mugoyikazi, ASHA
- Tamba Musa, ASHA
- Iyamide Thomas, Sickle Cell Society
- Emma Bray, Friends, Families & Travellers

- Marie Claire Kofi, Plasma of Hope
- Kerry Leeson-Beevers, Alström Syndrome UK
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- **Naailah Rehman,** University Hospital Birmingham
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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 <u>nhsrho.org/publications</u>

