NIHR | National Institute for Health and Care Research

NHS RACE & HEALTH OBSERVATORY

Equity by Evidence

Improving Health and Care Research Through Better Representation of Black, Asian, and Ethnic Minority Communities

A collaborative approach to reducing health inequalities through inclusive research

Report produced following a cross-sector workshop in June 2025

October 2025

Contents

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- Association of Medical Research Charities
- Cancer Research UK
- Caribbean & African Health Network
- Department for Health and Social Care (DHSC)
- Elsevier
- Health and Care Research Wales
- Health and Social Care Northern Ireland
- Health Research Authority (HRA)
- Imperial College London
- King's College London
- Medicines and Healthcare products Regulatory Agency (MHRA)
- National Institute for Health and Care Excellence (NICE)
- National Institute for Health and Care Research (NIHR)
- NHS Race and Health Observatory
- NIHR Research Support Service
- Nuffield Trust
- Race Equality Foundation
- The George Institute
- The Lancet
- Trial Forge
- UK Research and Innovation (UKRI)
- Understanding Patient Data
- University East London
- Wellcome

Participants at the June 2025 workshop

Participants at the June 2025 workshop

Special thanks to colleagues from the Medical Science Sex and Gender Equity project (MESSAGE) at The George Institute for sharing their methodology, the lessons learned from their work, and for collaborating on the development of the briefing pack for the event. The MESSAGE project has successfully conducted a series of 'policy lab' workshops resulting in a co-designed best practice policy framework for UK research funders to improve consideration of sex and gender in research. This proven methodology provides a template for bringing together stakeholders from across the research landscape to develop solutions collaboratively. Thank you to Ross Pow who worked with the project team to develop the workshop, briefing pack, provided facilitation and supported the writing of this report.

A Note on Terminology

Throughout this report, we use 'Black, Asian, and ethnic minority communities' as our standard term, following current RHO practice. We acknowledge that language in this area continues to evolve, and the workshop recognised that future work may need to explore terminology and definitions further to ensure they are truly inclusive and meaningful.

How to use this report

This report is for everyone with an interest in improving health and care through better research. Whether you are a researcher seeking to understand potential changes to the research landscape, a funder developing policies, a healthcare professional interested in better evidence, or a member of the public wanting to understand how research can better serve your community, you will find relevant information here.

The report takes you from considering current challenges through to the practical solutions that are proposed to improve the impact of research. Each section of the report builds on the previous one but can also be read independently depending on your interests and needs.

Quick Navigation Guide

- **For a rapid overview:** Focus on the Executive Summary and Next Steps sections, which provide the essential findings and immediate actions
- **For understanding the context:** Begin with the Introduction and Challenge sections, which explain why this work is urgently needed
- **For implementation details:** Concentrate on the Building the Framework and Making It Happen sections, which contain practical solutions and approaches
- **For getting involved:** Jump directly to the Get Involved section to understand how you can contribute to this work.

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Executive Summary

When research fails to properly represent Black, Asian, and ethnic minority communities, it produces findings that do not work for everyone and can worsen existing health inequalities.

Pregnancy and childbirth, jaundice in newborns, heart disease, skin conditions, blood disorders and COVID-19 vaccines all provide examples of where slow or missed diagnoses, delayed or ineffective treatments and poor standards of care cause harm and distress to people from Black, Asian and ethnic minority communities. These inequalities often arise as a result of research that does not account for differences related to race and ethnicity.

Black, Asian, and ethnic minority groups are often not properly represented in research, either through under-recruitment of participants or because resulting data is not appropriately disaggregated by ethnicity. Often, the research workforce itself does not reflect the diversity of the communities where research is undertaken, potentially skewing the questions addressed and failing to understand the situation and lived experience of different groups in designing research methods.

The NHS Race and Health Observatory (RHO) and the National Institute for Health and Care Research (NIHR) are working together to tackle this by building a coalition of like-minded organisations across the research sector.

A lot of work has already happened to create guidance and resources for researchers to consider ethnicity. We are looking to build on this good practice to create meaningful change across the whole research system in the UK.

To help develop practical actions, in June 2025 the RHO and NIHR brought together over 40 representatives from academic research groups, public and charitable funders, publishers, regulators, policy makers, and those with lived experience to develop recommendations for how health and care research can better take race and ethnicity into account in order to improve its impact on health outcomes and inequalities.

This work revealed a sector ready for change but needing coordinated support to do so. The recommendations in this report provide a roadmap for transforming how the UK research sector approaches ethnic diversity in health and care research.

By working together, learning from each other, and keeping community needs at the centre of our efforts, we can strengthen the quality of our research system that serves the whole population and reduces - rather than reinforces - health inequalities.

Recommendations for action

- **Coordinated action across the whole sector is essential including** funders, universities, researchers, clinicians, regulators, scientific publishers, patients and advocacy organisations. No single group or organisation can solve this alone. The aim must be to build momentum across the whole research sector by coordinating a collective effort.
- **The motivation for change should be grounded in delivering higher quality research and more research impact.** This emphasises that all science should be fit for purpose as a necessary part of delivering value for money.
- **A unified framework should be co-produced with all stakeholders over the next two years.** This framework will set out the ambition of what we are trying to achieve, along with the principles and actions needed across the research lifecycle, so that better accounting for ethnicity results in positive impacts for everyone.
- **Substantial investment in capacity building is required.** This includes additional funding for recruiting a diverse workforce, training for researchers and reviewers, and support for sustained community participation.
- **Clear, consistent definitions and practical tools must be readily available** to support researchers in implementing these changes effectively.

What this means for different stakeholders

- **Funders** should put in place consistent approaches to ensure race and ethnicity are properly considered in all applications, with flexibility based on the objectives, type and scale of the research.
- **Researchers** should consider how to adequately capture race and ethnicity, and the determinants of ethnic inequalities in health, across the research cycle - designing, delivering and disseminating findings. They should be supported with training, additional funding, and clear guidance.
- **Healthcare providers** should require and use the improved evidence base from the resulting research to implement more effective treatments and services tailored to the diverse populations they serve.
- **Patients and the public** should have access to research findings that genuinely reflect and benefit the diversity of the whole population, leading to reduced health inequalities.

Why race and ethnicity matters in health and care research

Health and care research should generate knowledge that benefits the whole population. Yet in the UK, much of our health and care research fails to reflect our rich ethnic diversity. This is not merely an oversight – it is a critical flaw that undermines the quality, applicability, and value of research findings.

When research ignores ethnic diversity, it risks producing findings that serve some parts of the population more than others. More troublingly, this status quo can entrench existing disparities in health outcomes, creating a vicious cycle where those already experiencing health inequalities are further disadvantaged by research that doesn't consider their needs or circumstances.

What's the harm?

Examples of what happens when research does not sufficiently account for ethnicity

Area	Harms	Reasons
Maternal mortality	Black women are nearly three times more likely to die during pregnancy and childbirth compared to White women, while Asian women are almost twice as likely.[1]	Maternal health data does not reveal causes linked to ethnicity, language, immigration status and socioeconomic status. Black, Asian and ethnic minority communities are underrepresented in maternity-related trials and suffer from systemic racism and generic care protocols and algorithms.[2]
COVID-19	People in Black, Asian and ethnic minority communities were more likely to die or suffer severe health impacts during the pandemic.	Socioeconomic factors linked to ethnicity played a significant role along with lower levels of inclusion in clinical trials and other medical research.[4,5] Medical equipment (such as pulse oximeters) were less effective for people with darker skin tones.[6]
Dermatology	People with darker skin tones have higher rates of missed or delayed dermatological diagnoses	Medical education resources rarely show conditions on darker skin, which risks missing or delayed diagnoses.[7] Ethnicity is not considered sufficiently in dermatology research.[8,9]
Cardiovascular drugs	Some cardiovascular drugs are less effective in Black and British South Asian patients.	Clinical trials for medications used to prevent heart attacks and manage heart failure have included insufficient participants from Black, Asian and ethnic minority communities.[10,11]
Neonatal jaundice	Newborn babies with dark skin tones may not have jaundice detected.[12]	Skin-based assessment tools can be biased because they are not researched or designed with non-White skin tones in mind. Healthcare workers may not have the skills or cultural awareness to pick up and respond to the concerns of parents with Black, Asian, ethnic minority newborns.
Sickle Cell Disease	This genetic condition mostly affects Black African and Caribbean people who often suffer from substandard treatment and poor pain management in a sickle cell crisis. There is also a lack of investment in research and novel treatment.	Research into the disease is relatively underfunded compared to other genetic conditions. Sickle cell disease is not prioritised by healthcare providers and staff can lack the training needed to ensure effective diagnosis and prompt treatment.[13]

1. Felker et al, MBRRACE-UK 2024, 2. Birthrights, 2022, 3. Marmot et al., 2020, 4. Murali, 2023, 5. NHS RHO, 2024, 6. Sjoding et al., 2020, 7. Mineroff et al 2023, 8. Mineroff et al 2023, 9. Wainman, 2025, 10. Magavern, 2023, 11. Johnson, 2008, 12. Fair et al, 2023, 13. NHS RHO, 2025

Change needs every part of the research sector to work together

Recognising these challenges, in July 2023, the NHS Race and Health Observatory (RHO) and the National Institute for Health and Care Research (NIHR) published a **statement of intent** to work together. This commitment aimed to ensure that the research sector plays its role in reducing race and ethnic inequalities in health and care by supporting researchers to use more inclusive approaches to the design, delivery and dissemination of their research.

Left to right: NIHR's Phoebe Wallace (Research Inclusion Manager) & Dr Esther Mukuka (Director of Research Inclusion), RHO's Professor Habib Naqvi (CEO) & Dr Ngozi Kalu (Assistant Director, Research & Evidence)

This partnership recognises that changes in representation and reporting need to be practicable, measurable and rigorous. Critically, working out what these changes need to involve cannot be done by looking at ethnicity or race in isolation. It requires an understanding of how a wide range of factors – social, economic, cultural – intersect with ethnicity and race to affect the commissioning, conduct and communication of research. Agreeing and implementing these changes will also require working with all parties involved in research – funders, researchers, scientific publishers, regulators and the public.

The first step to achieving this was to bring together some of these stakeholders for a workshop discussing three key areas; exploring the barriers to progress and how these might be overcome, setting out a vision for more equitable accounting for race and ethnicity in research, and presenting proposals for next step actions. The findings from the workshop are discussed within the following sections.

The challenges we face

The factors that hold back accounting for race and ethnicity in health and care research are multifaceted and deeply embedded in current practice.

Before solutions can be developed, it is essential to understand the barriers that currently prevent better representation of Black, Asian and ethnic minority communities in research. Challenges exist at every level of the research sector, from the factors affecting individual researchers to societal and institutional barriers.

Overarchingly, accounting for race and ethnicity is not currently consistently mandated in the research pipeline by funders, regulators and research institutions.

For Research Funders

- No unified approach across different funders
- Difficulty assessing whether applications adequately address ethnicity
- Limited resources for supporting researchers to better account for ethnicity
- Differences in experience, capacity, and complexity between larger and smaller funding bodies

For Researchers

- Unclear guidance on when and how ethnicity matters for their research
- Limited ethnic diversity of the workforce and systemic biases
- Lack of training in how to design inclusive studies with ethnic diversity in mind
- Limited confidence in analysing data by ethnicity
- Higher costs and complexity to ensure diverse recruitment and statistically valid results
- Pressure to publish quickly, making thorough recruitment difficult

For Communities

- Limited awareness of research opportunities
- Language, cultural and financial barriers to participation
- The direct and indirect costs of being involved in the research process
- A belief that research does not address community priorities
- Mistrust of research institutions based on historical injustices, previous experiences of under-representation, or limited impacts from research resulting from low participation

Our vision for change

Better accounting for race and ethnicity in health and care research is not about quotas or tick-boxes. It is about ensuring research produces the best possible evidence for everyone by being commissioned, conducted and communicated with race and ethnicity in mind.
The aim should be to build momentum across the whole research sector by organising coordinated action that builds on what can be done at the level of the individual organisation. This relies on having broad-based agreement that accounting for ethnicity is a priority, and a shared vision of the actions necessary to bring that about.

What Needs to Happen?

- **Make the case for change based on 'Quality First'**
  This is not simply a diversity, equality and inclusivity initiative, but an essential change to ensure good science that benefits everyone. Better accounting for ethnicity improves research quality and value for money.
- **Coordinate action across the whole research sector**
  Funders, researchers, publishers, and regulators must work together with shared expectations and aligned policies.
- **Provide practical support to researchers**
  Change must be supported, not just mandated – researchers need training, tools, funding and examples of best practice.
- **Build long-term partnerships with communities**
  Communities should be genuine partners, involved in setting funding priorities, shaping research design, participating in research, disseminating findings and translating research into health and care impacts.
- **A unified framework agreed and adopted across the UK health and care sector.**

Building the framework: A unified approach

A unified approach is needed for the development, launch and adoption of a framework that all organisations can adopt and adapt to their needs. This should be supported by a set of practical tools to assist implementation and educational resources to upskill different elements of the research sector. The aim is to start a roll out of the framework and educational outputs within the next 2 years.

The process of developing and implementing the framework should be fully transparent, so that all stakeholders are clear on what this will involve, and the range of expertise represented in the final outputs. Not all organisations are expected to implement change at the same pace, and a flexible roadmap will allow organisations to make progress according to their particular situation. The following approach reflects the initial areas of focus for this project. Additional supporting actions beyond the current scope of this project, are captured in Appendix 1.

Components of the Framework

The framework will set out:

- Clear requirements from funders, researchers, and publishers
- Standardised definitions and terminology regarding race and ethnicity
- Mandatory questions for research funding applications related to ethnicity considerations
- Principles for ensuring research appropriately reflects the populations it is intended to benefit (rather than setting targets for rates of participation)
- Expectations for recruitment, analysis, and reporting
- Flexibility in the application of its principles depending on the focus, type and scale of research (as well as differences across the 4 nations of the UK)
- Approaches to the monitoring and evaluation of its implementation and impact

Practical Tools

The framework will be supported by practical tools, including:

- Best practice examples of ethnicity consideration and inclusion for different research areas
- Advice and training on inclusive methods in the design, delivery and dissemination of research
- Template text for applications and protocols
- Cost calculators for diverse recruitment into research studies
- Guidance on working with community partners
- Training on personal and systemic biases in research

A Timeline for Implementation

Immediate actions (next 6 months)

- **Form initial coalition** – RHO to lead in forming a 30+ organisation coalition committed to promoting change across the sector
- **Develop roadmap for change** – A detailed timeline and responsibilities for framework development and roll-out
- **Audit resources** – Map existing tools, training, and best practices

Medium-term goals (6-24 months)

- Define terms – Establish consistent terminology and ethnicity categories
- Co-produce the framework through iterative consultation with all stakeholders through the Policy Lab process
- Develop training materials for research funders and researchers, and make them freely available
- Launch the framework with early adopter organisations who can then share learnings with the sector
- Establish evaluation metrics to track progress and impact
- Build public awareness of the benefits of inclusion and promote ways for patients and the public to get involved

Long-term aims (3-5 years)

- Universal adoption of the policy framework across the UK health and care research sector
- Demonstrable improvements in research participation from Black, Asian and ethnic minority communities
- Emerging evidence of reduced health inequalities linked to better research
- UK further embed its reputation as a leader in inclusive health research

Measuring Success

Progress will be tracked through:

- **Number of organisations** adopting the framework
- **Percentage of studies** meeting ethnicity inclusion standards
- **Diversity of research** participants
- **Community feedback** on research relevance and trust
- **Health outcome and care experience** improvements by ethnicity
- **Number of researchers** who engage with our educational materials

Other potential positive outcomes we hope to see but are not currently planning to measure as part of the framework:

- Increased **diversity in research teams**
- Better use of **new and existing data**
- **Growing trust** between research institutions and ethnic minority communities

Participants discussing the overarching question for the day "What is needed for health and care research to account for ethnicity equitably in order to maximise the impact of research outputs in improving outcomes and reducing inequalities?"

Making it happen

This is an important moment in the journey toward more inclusive health and care research in the UK. The consensus is clear: properly accounting for ethnicity is not optional – it is essential for high-quality, scientifically rigorous research that benefits everyone.

Success in this endeavour requires more than good intentions. It demands coordinated action, sustained investment, and genuine partnership with communities. The rewards – better treatments, reduced inequalities, and improved health for all – make this effort not just worthwhile, but urgent. The MESSAGE project's success in relation to accounting for sex and gender in research proves that ambitious system-wide change is possible when all stakeholders unite and organise around a common goal.

The work coordinated so far by RHO and NIHR has demonstrated that the UK research sector is ready for this change. Already many organisations – funders, researchers, regulators, publishers and community groups – are committed to working together. However, the journey towards truly inclusive research will not always be straightforward. There will be challenges, setbacks, and difficult conversations along the way. As this work progresses, terminology, approaches, and recommendations may also evolve based on consultation and emerging evidence.

What will not change is the commitment to ensure health and care research serves everyone in our diverse society. There is no doubt that the UK research sector has the expertise, commitment, and collaborative spirit needed to realise this aim. By working together, learning from each other, and keeping community needs at the centre of our efforts, we can build a health and care research system that improves outcomes for all and reduces rather than reinforces health inequalities.

Get involved

This work needed to better account for ethnicity in research requires active participation from across the research sector and wider society. Everyone can contribute to building more inclusive research.

For Funders, Regulators and Research Organisations

Organisations across the research sector of all sizes can play a vital role. Start by joining the coalition through RHO to connect with others committed to change. Share your existing tools, resources, and examples of best practice – what seems routine to you might be revolutionary for others. Participate actively in the framework development process to ensure what emerges meets your organisational needs. Most importantly, commit to piloting new approaches and sharing your learning, both successes and challenges, with the wider community.

For Researchers

Individual researchers are at the heart of this transformation. Make use of existing resources and guidance, and attend training on inclusive research design to build your skills and confidence. Share your experiences and challenges openly – your insights are vital for

developing practical solutions. Partner with community organisations to understand their priorities and build lasting relationships. Advocate for change within your institution, whether through formal committees or informal networks. Remember that small actions can create ripple effects across teams and departments.

For Communities

Communities must be genuine partners in this transformation, not passive participants. Engage with local research opportunities through free services like Be Part of Research, which make it easy to find and take part in health and care research across the UK. Help shape research priorities to ensure they address real community needs. Provide honest feedback on research approaches – your insights can reshape well-intentioned but ineffective practices. Consider becoming a community research champion to bridge the gap between your community and research institutions. Your voice and experience are essential for creating research that truly serves everyone.

For Healthcare Professionals

Clinical perspectives are invaluable in ensuring research addresses real-world healthcare challenges. Improve ethnicity data recording in clinical settings – accurate data is the foundation of good research. Support research recruitment in diverse populations by discussing opportunities with patients and addressing concerns. Share your insights on the health disparities you observe. Advocate for inclusive research in your field through professional networks and publications.

About the authors

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Appendix 1 - Supporting actions for further consideration

As part of the workshop, further supporting actions at various levels of the sector were highlighted by participants. These actions are included as additional potential areas to explore:

Building skills and capacity in accounting for ethnicity:

- Mandatory training modules for researchers on inclusive research design regarding ethnicity and race
- Specialised courses for collecting and analysing ethnicity data
- Peer mentoring programs connecting experienced and new researchers
- Integration of ethnicity inclusive research and practice into undergraduate and postgraduate curricula
- Increasing the value placed on ethnicity-related data from qualitative methods and lived experience approaches

Diversifying the research workforce:

- Set aspirations for diversity within research teams
- Support career development for researchers from Black, Asian and ethnic minority backgrounds
- Create community 'research champion' roles

Funding costs:

- Seek additional funds to support inclusive research recruitment, translation and interpretation
- Spread funding equitably across a diverse range of research institutions
- Resources for sustained community engagement
- Flexibility in project timelines to allow for the design of inclusive research and thorough recruitment

Tackling biases:

- Training on racism and unconscious bias across the sector
- Review how symptoms may vary according to ethnicity and improve how this is taught in medical education
- Ensure funding panels are diverse and informed and the importance of ethnicity inclusion

Making better use of existing data:

- Re-analyse or disseminate existing datasets to increase the base of data with ethnicity breakdowns
- Publish supplementary data on ethnic differences
- Link datasets to explore intersectional factors
- Create repositories of ethnicity-focused research

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