

PROGRESS REPORT

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MESSAGE FROM THE CHAIR AND CHIEF EXECUTIVE

As we reflect on the past 12 months, we are increasingly proud of the role that the NHS Race and Health Observatory has played in tackling ethnic inequalities in health and healthcare. We have done so by focussing on the fundamental principles of our operating model: providing evidence-based analyses; outlining clear recommendations for change; and supporting implementation across the wider system.

With a core team of ten people, our work has continued to impact national healthcare policy in areas as diverse as mental healthcare; maternal outcomes and neonatal testing; sickle cell care pathways; and genomics and genetic testing. In achieving these endeavours, we have continued to form groundbreaking and innovative partnerships with organisations within and beyond our geographical borders.

We are very clear in our aims: our work is not just to highlight the scale of the challenge on ethnic inequalities in health and healthcare, but to also provide real world solutions to those challenges. That is why we have been practically supporting the healthcare system in making meaningful changes through resources and implementation support.

But, of course, we cannot achieve more for patients and communities without a workforce that is diverse at all levels, working in organisations and systems that are free from discrimination. Our focus going forward will also support the healthcare system to examine where it is on workforce race equality, so that lessons can be learned to hardwire this agenda in sustainable way in day-to-day work.

The Observatory continues to be as much in demand as ever and we remain highly respected for our independence, our reliance on objective evidence, and for our focus on impact. We are proud of what the Observatory has achieved during its first three years. We want to thank the Observatory Board, its core team, advisory groups, our colleagues at NHS England, and all those we work with, for their hard work and continued commitment to this critical agenda.

In the coming months we will launch our new strategy covering 2024–27. It will build upon the strong foundations that we have built for the Observatory during its initial period following establishment. It will therefore be an evolution rather than a revolution of our work to date and will be squarely aimed at both tackling long-standing challenges and seizing the opportunities we see ahead.



Marie Gabriel

Marie Gabriel CBE
Chair
NHS Race and Health Observatory



Dr Habib Naqvi

Dr Habib Naqvi MBE
Chief Executive
NHS Race and Health Observatory

WHAT DOES IT MEAN TO MAKE A DIFFERENCE?

The NHS Race and Health Observatory was launched in April 2021. We exist to eliminate unjustifiable variations in the quality of care and health outcomes for Black, Asian, and ethnic minority people and communities, as well as ethnic inequalities experienced by the health and care workforce¹. We don't just work to highlight inequalities. Our mission is to actively improve outcomes for patients, service users, and workers, by demonstrating how those inequalities come to exist in the first place, using that insight to drive policy change, and working with the NHS in England to implement our practical evidenced based actions.

Racism and racial inequity persist in our healthcare system because they are ingrained in social norms, policies, assumptions, curricula, and ways of working; this is how structural racism manifests. While awareness of the impact of racism and racial inequity is growing, meaningful change across healthcare continues to prove slow and difficult. Ending inequity is complex and, for the millions of Black and ethnic minority people who use and work in the health service, deeply personal.

The Race and Health Observatory is a fully independent body, founded by the NHS to deliver a concerted focus on racial and ethnic health inequalities. While race equity has been on the agenda in the NHS for many years, the work so far has proved ineffective, and the results only partial. The Observatory is designed as a catalyst, to drive action on delivering equity. We're doing this by mobilising evidence, enabling policy change, and demonstrating practical ways in which health and care organisations, and society as a whole, can work to reduce ethnic and racial inequalities in health and healthcare.

Over the past two years, we've worked to change the conversation about race equity in the NHS and the broader health sector. We're ensuring that leaders can no longer ignore the irrefutable and mounting evidence of racial inequity in our system and in the country. We're showing the system that equalities need to be a consideration in all elements of service improvement and design, never just as a tick box. And we're looking to ensure that the infrastructure that supports the NHS – clinical education, policymaking, research funding – is shaped in a way that embeds race equity for many years to come. More broadly, we're looking across different sectors to better understand the structural determinants of health inequity, and exploring where we might intervene to prevent unequal outcomes earlier.

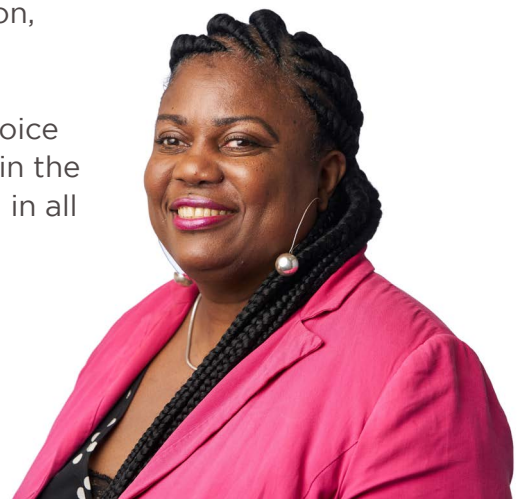
This progress report provides an update on our approach, outlines the impact we've had over the past year, and points towards where we're headed in the future.

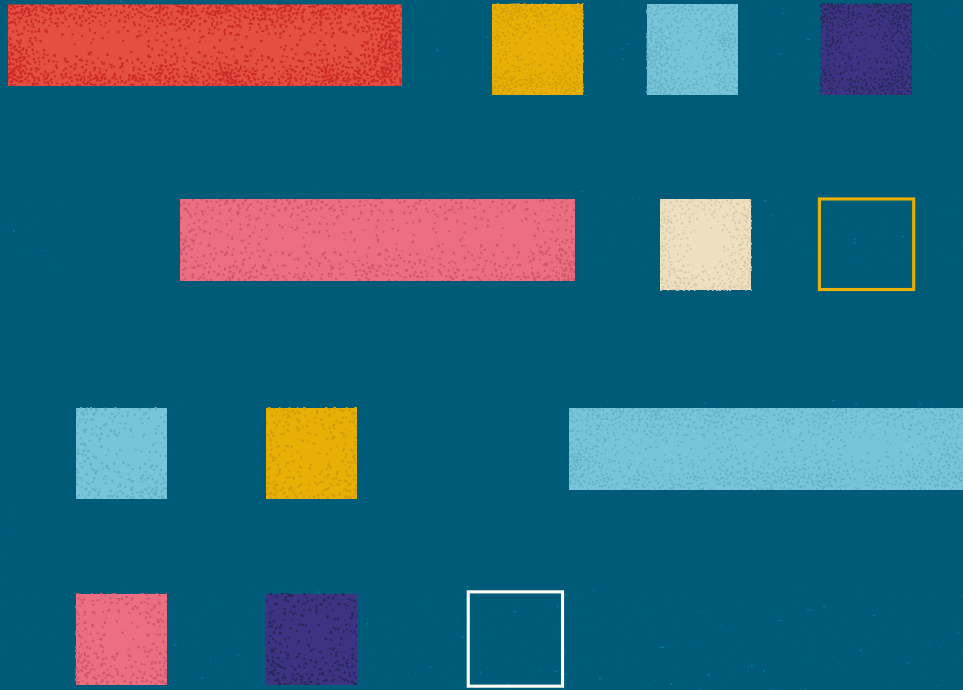
¹ To learn about our approach to terminology, you can read our report, The Power of Language, here: https://www.nhsrho.org/wp-content/uploads/2023/04/NHS_RaceHealthObservatory_Terminology-consultation-report-NOV-21-1.pdf



IN MEMORY OF THE LATE HEATHER NELSON

Heather was a valued board member from 2021 - 2023. Her determination, passion, and knowledge drove her contribution and, Heather was instrumental in ensuring that the voice of the community was embedded in the work of the Observatory team and in all Board deliberations.





**WE'RE SHOWING THE SYSTEM THAT EQUALITIES NEEDS
TO BE A CONSIDERATION IN ALL ELEMENTS OF SERVICE
IMPROVEMENT AND DESIGN, NEVER JUST AS A TICK BOX.**

HOW WE WORK

OUR MODEL

There are three strands to the Observatory's model, all of which are vital in the pursuit of racial equity in health for patients² and workers. At every stage of our operating model, we include the voices of people with lived experience of racism and discrimination to ensure that the work we do meets the needs of the people it is designed to help and empower.



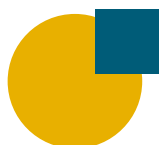
Evidence

We draw on the best quality evidence around racial and ethnic inequality in health and care. This means not only commissioning original research to fill knowledge gaps, but also amplifying existing evidence. We want to put better-quality information in the hands of the people who can use it, whether that be policymakers, healthcare professionals, commissioners, members of the public, or patients. We make evidence accessible through the creation of tools and digital resources.



Engage

We use this evidence to influence leaders through practical recommendations for policy. This means translating complex research into succinct briefings; working collaboratively with government, the NHS, and arms' length bodies to ensure that policymaking is informed by an understanding of race and racism; and working alongside other research organisations to focus greater resource on understanding why and where racial inequity exists. Our recommendations are targeted, actionable, and applicable at every level. We want to make sure that policymaking takes account of human insight and experience, not just crude numbers.



Enable

Based on our recommendations, and in response to the needs of the people and communities we work with, we support the implementation of new practice at the grassroots. We fund and lead innovative anti-racist improvement and implementation practices, and are committed to working in partnership with, and building trusting relationships with, healthcare systems and providers. Our approach to implementation is the result of iterative co-design and is constantly tested and challenged to ensure it is having the intended impact.

² We adopt a broad definition of the word patients, meaning whenever we refer to patients, we also include service users, carers, families, and friends.

COMMUNITY PARTICIPATION

All of our work is co-designed and co-produced. We're supported in this by our Stakeholder Engagement Group, who provide us with grassroots insight and strategic guidance, and help to embed public and patient voices at the heart of our work. The group members are from a diverse range of backgrounds and bring a wealth of lived experience and professional expertise to the work of the Observatory, as well as constructive challenge and critique.

The Group are represented at our Board and are consulted on all major decisions. They are also involved in all aspects of our work from gathering evidence to testing conclusions and recommendations and in working to implement positive change. The group also forms the centre of a much broader network of community, voluntary, and faith-based organisations, and other allies who we work in partnership with to ensure the views and voices of underserved communities are at the centre of everything we do. Through this same network, we amplify the work of the Observatory and work to continuously enhance our coalition in the pursuit of ethnic and racial equity in health.

RACE AND RACISM

Inequalities in health are not just about the experiences people have in hospitals, GP surgeries, or care homes, but also about the broader social factors that dictate a person's level of health risk in the first place. Forces such as racism, discrimination, deprivation, and social segregation influence a person's quality and length of life long before they encounter the health and care system. The challenge facing us, therefore, is not just about equity in access to services, but also about understanding the systemic and unwarranted disadvantage faced by Black and minority ethnic people in this country more broadly.

We are committed to threading a nuanced consideration of racism through all of the work we do at the Observatory. Existing evidence already shows us the impact that racism has on mental and physical health, and the ways in which structural racism drives unequal outcomes through deprivation, discrimination, intergenerational trauma, and embedded cultural assumptions. Our mission is to build upon this evidence base, filling gaps where we find them, and translating that evidence into tangible change.

OUR ORGANISATION

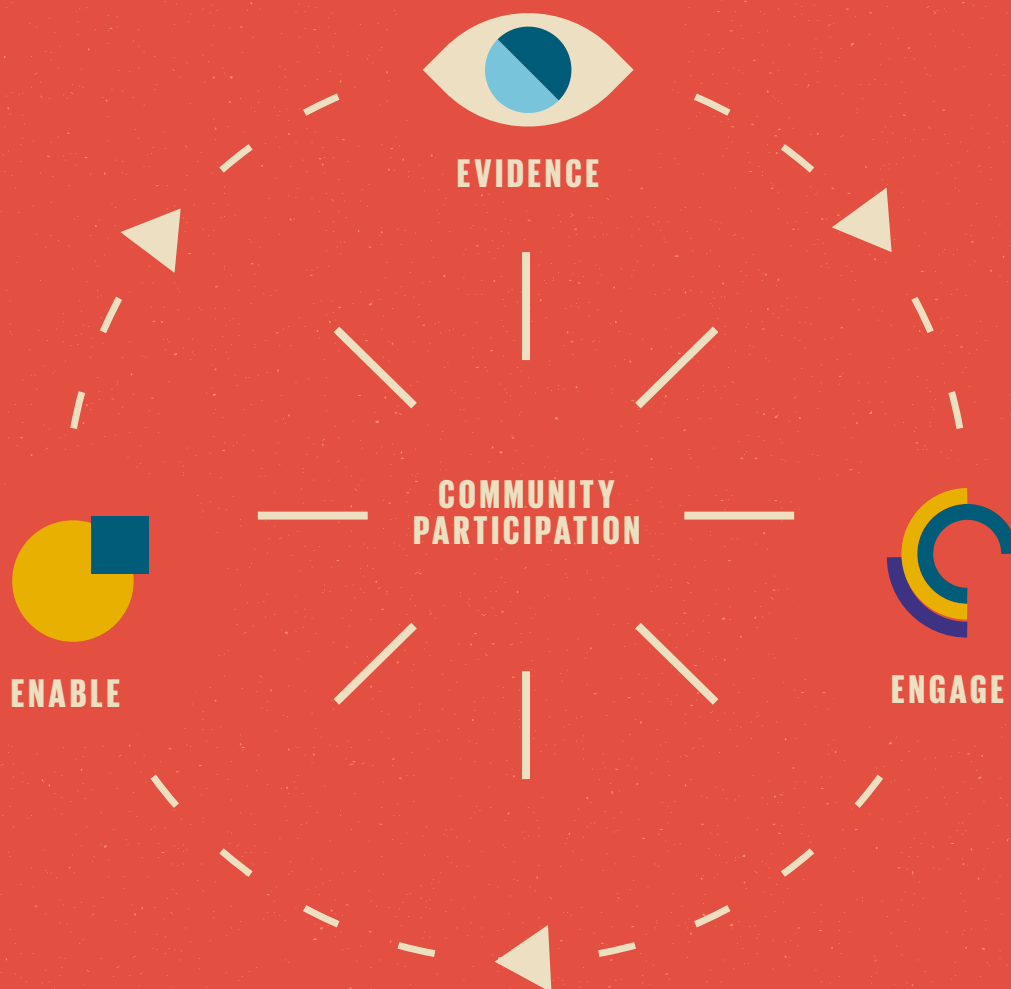
At the Observatory, we've brought together a team of experts in research, policy, implementation, communications, community engagement, and business management to drive forward our work on race equity. As well as being supported by an influential Board, we also work through a dispersed network of experts across several advisory groups:

- Academic Reference Group
- Stakeholder Engagement Group
- Maternal and Neonatal Health Advisory Group
- Mental Health Advisory Group
- International Experts Group

While the rest of this report will highlight impact across our three strands of work, it is important that we also recognise the less visible elements of what we do. Without our business support functions, we wouldn't be able to process contracts and procurement, ensure staff welfare, provide secretariat support to our advisory groups, manage our supply chains, or run recruitment exercises. Without project management support, we wouldn't be able to ensure the timely delivery of work or ensure value for money. And without our communications team, we would be unable to field press enquiries, support members of the public, receive national media coverage, or launch our reports. The work that goes into our reports and output is complex and varied, and we rely on every member of the Observatory's small but effective team in achieving our goals.

OUR IMPACT

Quantifying impact in the pursuit of race equity is not a simple matter. Ethnic health inequality is affected by deeply ingrained systemic inequalities across housing, employment, justice, migration, and inter-generational trauma, to name just a handful of factors. Even so, over the past year, we have achieved major policy change, provided expert advice to organisations across the health sector, enhanced our reach into the public domain, and further embedded ourselves in the system to ensure that race equity in health remains a central priority for leaders.



EVIDENCE

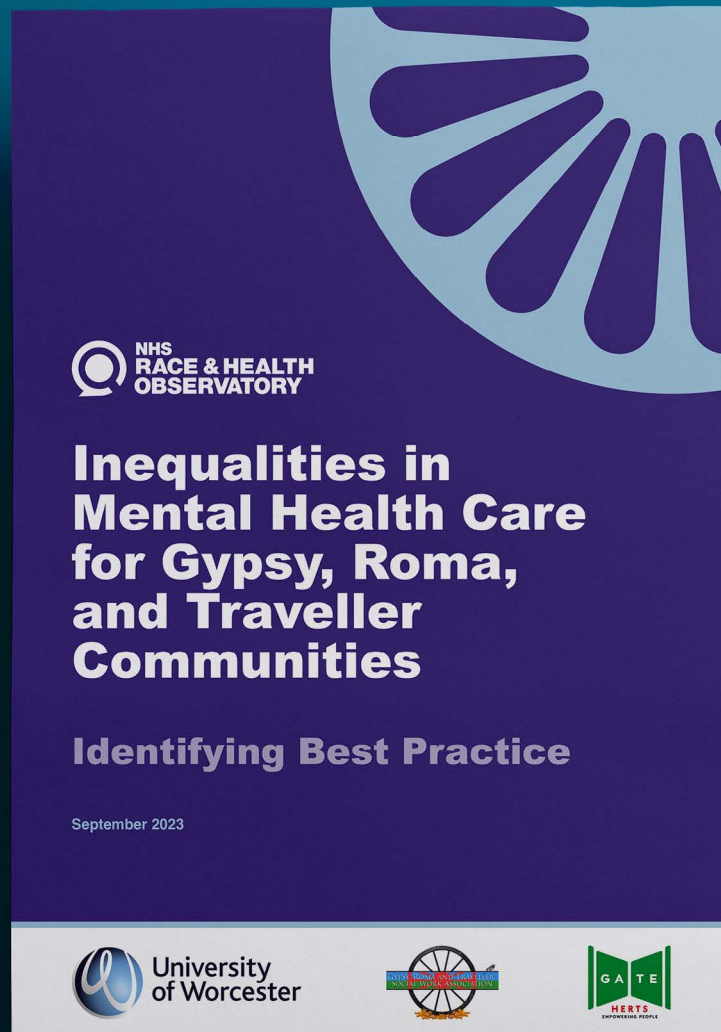


We have a dual ambition with our evidence generation function. Firstly, through producing research outputs and synthesising evidence, we want to enable better and more equitable policy development and decision making at all levels in the healthcare sector. Secondly, by working with partners and leading by example, we aim to make the research sector itself more equitable, pushing for representative sampling, diverse research teams, and enhanced community participation in all publicly funded research.

Our approach to evidence generation includes working in partnership to scope and deliver bespoke research projects, each of them applying an anti-racism lens to explore ethnic health inequity. Over the past year, we have published the following reports, each meaningfully adding to the evidence base in this space:

- Elective backlog and ethnicity: Is there variation in lost activity time to treatment and rates between ethnic groups?
- Mapping of existing policy interventions to tackle ethnic health inequalities in maternal and neonatal health.
- Digital apps and reducing ethnic health inequalities: Driving progress through digital, design, and organisational transformation.
- Sickle cell digital discovery report: Designing better acute painful sickle cell care.
- Review of neonatal assessment and practice in Black, Asian and minority ethnic newborns: Exploring the Apgar score, the detection of cyanosis, and jaundice
- We deserve better: Ethnic minorities with a learning disability and access to healthcare.
- REACH-OUT: Caring for the healthcare workforce post COVID-19 – A longitudinal mixed-methods study of post-COVID-19 outcomes in healthcare workers from diverse ethnicities – Update report.
- Inequalities in Mental Health Care for Gypsy, Roma, and Traveller Communities, Identifying Best Practice.
- Ethnic Inequalities in the Improving Access to Psychological Therapies (IAPT) Programme.

In addition to our own research outputs, we've also signed a significant partnership agreement with the National Institute for Health and Care Research to enhance both organisations' efforts to drive race equity in healthcare research. Elsewhere, we're collaborating with Genomics England on the Identification and assessment of ethnic health inequalities that exist within the Genomic Medicine Service, and working with Department of Health and Social Care and the National Centre for Social Research to ensure that the national Adult Psychiatric Morbidity Survey is representative of the UK population.



INEQUALITIES IN MENTAL HEALTH CARE FOR GYPSY, ROMA, AND TRAVELLER COMMUNITIES

Gypsy, Roma, and Traveller communities face some of the starkest inequalities in access to healthcare in England and experience dire mental health outcomes.

In September 2023, we published a comprehensive review that explores a lack of mental health care provision for these communities; captures first hand insight from members of these communities; and highlights good practice examples from six effective services across England, most of them run by voluntary Gypsy, Roma and Traveller organisations.

The report not only makes far reaching recommendations for change at a national level, but draws out replicable practice from these case study sites, in order to aid the spread of this vital work.

ENGAGE

We bring our evidence generation to life by engaging with ministers and other policymakers to ensure that our insights are digested and acted upon at the highest level, thereby ensuring that positive change on race equality is both long-term and irreversible. Over the past year, we've:

- Acted as a critical friend on the government's upcoming Major Conditions Strategy and other key pieces of national policy.
- Developed meaningful working partnerships with the Care Quality Commission, the Professional Standards Agency, the Healthcare Safety Investigation Branch, in each case providing advice on race equity and furthering the reach of our policy recommendations.
- Helped to inform NHS England's policy approach to acute painful sickle cell episode care and personalised treatment plans.
- Continued to work and spread our policy influence globally, both through our bilateral partnership with the Centers for Disease Control and Prevention in the USA, and through our own international experts group.
- Taken up or continued our membership on several important and influential advisory groups and strategic boards, including:
 - The NHS Assembly
 - National Patient Safety Commissioners' Advisory Board
 - Mayor of London's Structural Racism and Health Equity Review
 - National Genomics Board
 - NHS Advancing Mental Health Equalities Taskforce
 - Health and Social Equity Collective Steering Committee
 - Understanding Patient Data Steering Group
 - Inclusive Pharmacy Practice Advisory Board

We also continue to engage directly with local and regional leaders across healthcare to drive meaningful change, and work with national policymakers to ensure that leaders are both properly equipped and sufficiently accountable.

MORE THAN
1200
ARTICLES IN PRINT
AND ONLINE

12
MAJOR
PUBLICATIONS

MORE THAN
2.2K
ENQUIRIES
ANSWERED

MORE THAN
20
CONTRACTS SIGNED

MORE THAN
423
MILLION PEOPLE
REACHED

7
NEW COMMISSION
AND PARTNERSHIPS
LAUNCHED

Over the past year, we've presented at conferences, summits, webinars, and award ceremonies, and have used our reports and research outputs to equip leaders with the knowledge and resources they need to embed greater race equity in their day-to-day practice. We are expanding the forms our outputs take, including lay summaries and video content to further reinforce our messages and increase our spread. We also continue to write and publish blogs from individuals and thought leaders across the health equity sphere. We're also expanding our own thought leadership, with articles and opinion pieces published in the British Medical Journal, The Lancet, and the Health Services Journal.




We're using diverse traditional, social, and community media channels to raise awareness, stimulate debates, and further public understanding of ethnic health inequalities and racism. Since our last impact report, we've been featured in more than 300 articles across digital and print media have an audience reach of more than 400million through media outlets. We've been featured in the Guardian, the HSJ, The Lancet, the Eastern Eye, the Asian Times, iNews, The Mirror, the BBC, The Voice, and many more outlets. Behind the scenes, we've been engaging with the public through enquiries and social media engagements, with more than 2 thousand enquiries answered over the past year.


← → ↻


Tests to assess newborns' health not effective for BAME babies in UK

Minority ethnic newborns risk late diagnosis and poorer health as guidance was developed for white European babies in 1952

Anna Bawden
Wed 12 Jul 2023 00:01 BST



 A review found guidance on a healthy newborn's skin tone made no reference to descriptions for black, Asian and other skin types. Photograph: Blend Images/Alamy

Tests to assess newborn babies' health are not effective for non-white children and should be replaced, according to the [NHS Race and Health Observatory](#).

In the UK, neonatal death rates among black and Asian newborns are **much higher** than for white babies.

← → ↻ <http://www.yourwebsite.com>

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News

Life expectancy of minority ethnic learning disabled people is half that of white counterparts

BMJ 2023 ; 382 doi: <https://doi.org/10.1136/bmj.p1713> (Published 25 July 2023)
 Cite this as: *BMJ* 2023;382:p1713

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Adrian O'Dowd

[Author affiliations](#) ▾

People with a learning disability from a minority ethnic background have a life expectancy of just 34 years—around half that of their white counterparts who on average live to 62, to a report from the NHS Race and Health Observatory has found.¹

Early mortality among people with a learning disability from a minority ethnic background was triggered by poorer healthcare access, worse experiences of various services, and worse outcomes, found the report which was

Policy Briefing: The Ockenden review

This briefing examines the Ockenden review through the lens of race equality and makes recommendations for best practice in the future.

Background

There is a growing body of evidence showing that ethnic health inequalities exist throughout maternal and neonatal care.^{1,2,3} As argued in our recent [rapid evidence review](#), the NHS Race and Health Observatory is one of many organisations advocating for targeted interventions to improve health outcomes for ethnic minority women, people, and their babies.

Independent reviews have a critical role to play in driving improvement across health and care. The Ockenden review, led by Donna Ockenden, focused on maternity services at the Shrewsbury and Telford Hospital NHS Trust (SaTH). The review looked at 1,592 clinical incidents involving 1,286 families. It conducted clinical and governance reviews and engaged with family and staff voices. The size and scale of this much needed review was unprecedented in the NHS.

The review's report was released in March 2022 and included many key "Immediate and Essential Actions" (IEAs) for the improvement of maternity and neonatal services. As with all reviews that aim to improve the quality of care in the NHS, we believe it is important to examine the review's methods, findings, and IEAs through the lens of ethnic health inequality.

The NHS Race and Health Observatory works to mobilise insights and evidence on ethnic health inequalities; offer evidence-based recommendations for change; and to meaningfully support the NHS and other bodies to deliver that change. As such, this briefing aims to provide future healthcare reviews - including the 2022 review into maternity services at Nottingham University Hospitals NHS Trust - with theoretical and methodological advice to support a sustained and meaningful focus on tackling ethnic health inequalities and inequities.

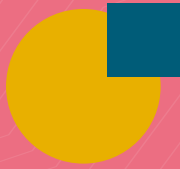
POLICY BRIEFING: THE OCKENDEN REVIEW

In September 2022, we released a policy briefing analysing Donna Ockenden's review into failings of the maternity services at the Shrewsbury and Telford Hospital NHS Trust.

The briefing examined the review through the lens of race equity and made recommendations for future reviews around effective engagement of ethnic minority communities; steps to mitigate poor data quality; and the importance of considering structural factors and workforce culture.

As a result of the briefing, the Observatory has been closely involved in developing the terms of reference for subsequent reviews, including at Nottingham University Hospital NHS Trust.

ENABLE



Over the next year, we want to build upon the impact we've already had, and develop a future-proof implementation model, a pipeline that can be adapted across all of our different areas of focus to translate research findings into practical changes in the NHS and beyond. That's why we're launching two new programmes of work aimed specifically at enhancing improvement and implementation:

ANTI-RACISM AND IMPROVEMENT

An entire discipline has evolved around the concept of 'improvement' in healthcare, where experts from various backgrounds focus on how to improve access, outcomes, and experience in healthcare settings around the world. While these efforts are extremely valuable, we're interested in enhancing the field of anti-racist improvement. This means not just focusing on how to make a service better, but seeking to understand why people from different ethnic backgrounds are having different experiences in the first place and making institutional changes to eliminate that inequality. It will mean considering organisational culture, leadership behaviours, and approaches to community participation.

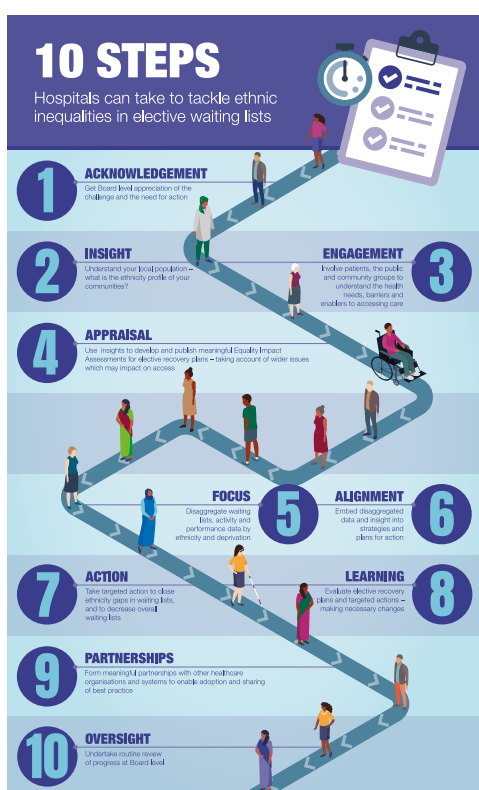
To achieve this, we'll be working with the Institute of Healthcare Improvement to establish a Learning Action Network – a group of healthcare systems who have made a commitment to anti-racist improvement and will work in partnership to reduce inequity in access, outcomes, and experience in maternal and neonatal morbidity and mortality. Their work will be widely shared, so that others can learn from and replicate their progress.

THE OBSERVATORY'S IMPLEMENTATION MODEL

More broadly, we will be developing a model of implementation that will use the same anti-racist principles to drive action across all of our recommendations. We are working in partnership with the National Collaborating Centre for Mental Health and people with lived experience to co-produce this model, and have created a new post – Director of Implementation – to ensure that our work continues to have an impact in a way that is truly felt by patients.

Both pieces of work rely on engaged and passionate leaders, and we're working closely with integrated care systems to ensure that we have a generation of leaders with the integrity and ambition to make eliminating racism among their major focuses. Elsewhere, we will continue to produce resources and evidence to help improve decision making about populations and to empower communities to advocate for change. As in the past,

we have been creating videos, and infographics to ensure that our work can be easily shared and digested, regardless of a person's background or access to technology. Additionally, our International Expert's Group has begun work on a framework to support leadership behaviours on racial equity across the NHS, and our Stakeholder Engagement Group have begun to build a resource that will help the system better engage and involve people and communities from Black, Asian and minority ethnic communities.



Ramadan Mubarak

GET HELP TO STOP SMOKING THIS RAMADAN

- 1** Ramadan is the perfect time to beat bad habits like smoking. Make it a Ramadan resolution to get smoke-free through the blessings of the month.
- 2** All tobacco products should be avoided, including vapes and shisha. Chewing stimulants like khat, along with betel quid, psain, gutkha, zarda and khaini, are also harmful and cause cancer.
- 3** By stopping smoking, you will reduce the risk of developing avoidable cancers. It is estimated to cause around 27% of all cancer deaths in the UK and nearly 20,000 deaths from cardio-vascular disease every year.
- 4** Most smokers successfully reduce their smoking when fasting in Ramadan. You can get help to maintain this behaviour once you've opened your fast, and beyond.
- 5** Make the intention this Ramadan to have a smoke and tobacco free year. Enjoy the benefits in recovering your taste, having better health and improved weight!

RATES OF CARDIOVASCULAR DISEASE ARE HIGHER AMONG SOUTH ASIAN & BLACK COMMUNITIES

Free help and support
Use your local NHS stop smoking, cessation services, free support is readily available all year round. The NHS Quit Smoking app is also free and can be downloaded to help track your progress over 28 days.
Find your local Stop Smoking Service via www.nhs.uk/better-health/quit-smoking

NHS RACE & HEALTH OBSERVATORY
BRITISH ISLAMIC MEDICAL ASSOCIATION

All of this work will find its home online alongside a repository of good practice examples, case studies, and useful research to accelerate positive change at a local level.

BUILDING A COALITION

It is not an easy time to enact change in our healthcare system – lives are being lost, buildings are falling apart, staff are burnt out, and leaders are being forced into a narrow focus on elective backlogs and cost-cutting. The combination of these pressures once again means that inequalities are falling to the bottom of the priority list. The Observatory exists to ensure that this doesn't happen.

We believe that change in the real world must be based on the best possible evidence available and must be based on principles of co-design and co-production. This is especially true in the healthcare sector, where change takes time and lives are at stake. When we make a change, we need to be sure it will improve the lives of Black, Asian, and ethnic minority patients, communities, and members of the workforce.

We cannot do this alone, and it is essential that, across healthcare and beyond, we are building a coalition of willing and passionate individuals and organisations who share a belief in ridding the system of race inequity. We therefore invite all of our stakeholders to join us in achieving this mission. To keep up to date with our progress, and any opportunities to get involved, you can sign up to our newsletter at www.nhsrho.org.

If you want to get in touch with us directly, please do so by contacting us at the details below:

✉ info@nhsrho.org

✕ [@NHS_RHO](https://twitter.com/NHS_RHO)

[in](https://www.linkedin.com/company/nhs-race-and-health-observatory) [NHS Race and Health Observatory](https://www.linkedin.com/company/nhs-race-and-health-observatory)

