

MAKING A DIFFERENCE:

A REVIEW OF THE NHS RACE AND HEALTH OBSERVATORY'S FIRST YEAR





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FOREWORD

A little over a year into its existence, the NHS Race and Health Observatory has already had impact far beyond what would be expected of an organisation of its age and size. With a team of fewer than 10 people, the Observatory's work has led to a national review of medical devices, formed groundbreaking international partnerships, and delivered major policy change.

The Observatory was first publicly spoken about in early 2020 after years of quiet planning. The weight of evidence pointing to ethnic health inequalities had become so great that inaction was no longer an option. The leadership of the NHS at the time saw that there was a dire need for a new voice in the system, an independent voice that could cut through the politics, expose the impacts and causes of racial inequity in our health and care system, and provide practical evidence-based solutions.

What happened next is already well known. The COVID-19 pandemic changed the world, shining a light on our vulnerabilities as a nation and, more starkly, our inequities as a society. Black and Asian communities were more likely to catch COVID and to die from the disease. The case for the creation of the Observatory became more urgent still.

And so, we have spent the first year of our existence mobilising evidence, conducting pioneering research, and engaging with leaders across the

system. We have been practically supporting the system to make change through tangible recommendations, the creation of resources, and the provision of direct support to NHS organisations at all levels. We have brought together a board of world-renowned experts and leaders in the field, have established a stakeholder engagement group to ensure that our work speaks to communities, and have drawn upon a group of international academics to drive our work towards global firsts.

We find ourselves at a significant point in history for our health service. When we look back at this moment, we hope it will be seen as the moment when the nation woke up to the scale of inequality embedded in the delivery and experience of healthcare, a moment when we decided the future would be different.

The work is just beginning. This review is not just a look back at what we have done, it is a show of gratitude to the people who have made it possible, and a call to arms to the whole sector.

Our mission at the Observatory is to end racial inequity in the NHS. It will take time, but the tide is starting to turn.

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Marie Gabriel CBE
Chair
NHS Race and Health Observatory

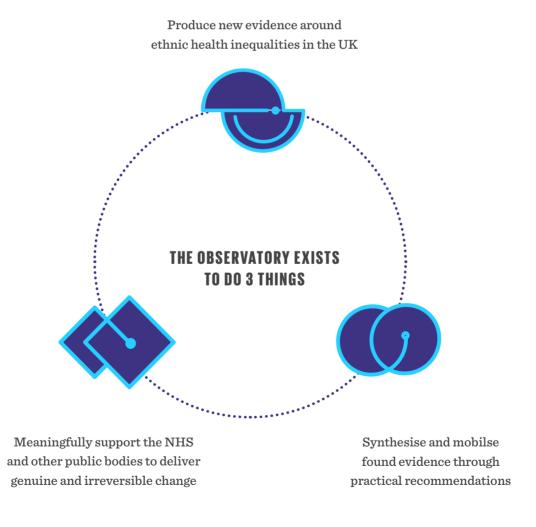
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Dr Habib Naqvi MBE DirectorNHS Race and Health Observatory

INTRODUCTION

The NHS Race and Health Observatory was formally established in April 2021, meaning we are now one year into our mission to reduce ethnic health inequalities across the health and care sector. The Observatory was established at an extraordinary time, one year into a pandemic that has changed the world. And although the Observatory was conceived of before the pandemic struck, the disproportionate impact of COVID-19 on Black, Asian and ethnic minority communities in this country has firmly and repeatedly reestablished the case for the existence of such a body.¹²³

The Observatory exists to do three things: to produce new evidence around ethnic health inequalities in the UK; to synthesise and mobilse this and other evidence through practical



recommendations; and to meaningfully support the NHS and other public bodies to deliver genuine and irreversible change.

As our research has shown, there is still much more to be done to eliminate racial inequity from the health and care system. We know that change takes time, but we are seeing the start of genuine change. We have seen our work receive enormous media attention; have had our recommendations adopted by national institutions; have engaged with many thousands of individuals; have highlighted evidence and best practice; listened to and amplified the experiences of Black and minority ethnic communities; and seen a steady and sustained growth in our following. And despite working in a difficult context, we have seen policymakers make unprecedented commitments to remove racial bias from the healthcare system.

There is, though, a lot more to do. It is important that, as we continue to pursue change, we do not lose sight of the pernicious and continuing influence of racial bias in society today. Racism takes many forms in the health and care system. Structural, in the sense that history and policy drive inequities in living and working conditions and in access to education and other amenities; interpersonal, in the sense that individual biases still inform a person's experience in healthcare settings; and institutional, in the sense that health and care providers represent the meeting point of these two other forms of racism.⁴ In our institutions, beloved though many of them are, we see the impacts of structural and interpersonal racism combine to shape the experiences and outcomes of ethnic minority communities on a daily basis.

The work of the Observatory aims to drive change by starting conversations, presenting irrefutable evidence, leveraging funding and, perhaps most importantly, by removing the excuses that have persisted for many decades.

¹https://coronavirus.data.gov.uk/details/deaths [accessed 17th January 2021]

 $^{{}^2} https://www.ons.gov.uk/people population and community/births deaths and marriages/deaths/articles/upqdating ethnic contrasts in deaths involving the coronavirus covid 19 england and wales/24 january 2020 to 31 march 2021$

³ https://www.gov.uk/government/publications/covid-19-reported-sars-cov-2-deaths-in-england/covid-19-confirmed-deaths-in-england-report#ethnicity

⁴ Nazroo, James Y., Kamaldeep S. Bhui, and James Rhodes. "Where next for understanding race/ethnicinequalities in severe mentalillness?Struc tural, interpersonal and institutional racism." Sociology of health & illness 42.2 (2020): 262-276.



The biggest impact of the RHO has been its ability to mainstream evidence of ethnic health inequality affecting patients and professionals in the NHS. The RHO has provided policymakers a depth of understanding and the solutions that should be taken forward in the journey to equity and inclusion.

PAV AKHTAR

CHIEF DIVERSITY AND INCLUSION OFFICER,
NHS BLOOD & TRANSPLANT
MEMBER OF RHO STAKEHOLDER ENGAGEMENT GROUP



WHO ARE WE?

When we released our strategy last year, we focused on what we wanted to do, the values we held, and the priorities we had set for ourselves. Although this was the right thing to focus on at the time, we did not spotlight the people who would make it happen.

In addition to building a core team of specialists, one the first major achievements of the Observatory was establishing a board of global experts in the fields of race and health. Our board members bring a broad range of professional expertise, lived experience, and political influence to bear in guiding the Observatory.

BOARD MEMBERS





Marie Gabriel CBE

NHS Confederation

Chair





Professor John Appleby Director of Research & Chief EconomistNuffield Trust

Dr Halima Begum Chief ExecutiveRunnymede Trust





Yvonne Coghill CBE Director Excellence in Action

Professor Kevin Fenton Regional Director, LondonOffice for Health Improvement and Disparities





Professor Stephani Hatch Professor of Sociology and Epidemiology King's College London

Dr Adrian James PresidentRoyal College of Psychiatrists













Rt. Hon. Professor the Lord Kakkar PC

Professor of Surgery University College London

Professor Dame Donna Kinnair DBE

Former Chief Executive and **General Secretary** Royal College of Nursing

Professor Sir Michael G Marmot

Professor of Epidemiology University College London

Dr Chaand Nagpaul CBE Chair **British Medical Association**



University of Manchester

Heather Nelson Chief Executive

Black Health Initiative

Professor David R. Williams Florence and Laura Norman Professor of Public Health and Chair Harvard School of Public Health

Patricia Miller **Chief Executive Officer** Dorset Integrated Care System

EXECUTIVE TEAM



Dr Habib Naqvi MBE | Director

Habib oversees the work of the Observatory and leads the organisation's public and political engagement. He draws upon a diverse background in public health and healthcare policy and strategy development. Habib speaks and writes widely on health equity and has experience across the NHS and Civil Service.



Owen Chinembiri | Senior Implementation Lead

Owen is responsible for our digital and data focused workstreams, the development of our online resources, and for driving work on the implementation of our recommendations. Owen has a background in occupational therapy and is an alumnus of the NHS Graduate Management Scheme (Health Informatics Specialism). He has worked in various management and leadership roles for clinical, transformation, performance and informatics teams. As part of his role, Owen oversees commissioning for our Digital and Data workstream.



Ruth Mannion | Business Manager

Ruth is responsible for financial planning, budget management, research contracting, recruitment, and team wellbeing. She also leads on the organisation's governance arrangements and is supporting the delivery of the Observatory's first international conference. Ruth has extensive experience of working in business and administrative roles for local government and in the NHS.



Rose Obianwu | Head of Communications

Rose leads on strategic communications planning and media relations for the Observatory, managing outgoing communications materials, website, and dealing with media enquiries. She is responsible for the Observatory's overall media strategy, stakeholder engagement and mapping exercises and promoting the international conference.



Sam Rodger | Senior Policy and Strategy Lead

Sam is responsible for overseeing strategy and policy at the Race and Health Observatory, making connections across the health and care landscape, and using robust evidence to inform national policy. His role includes overseeing the organisation's research commissioning processes and leading on our Mental Health workstream.



Zarah Mowhabuth | Transformation Manager

Zarah is responsible for organisational programme management as well as managing the organisation's social media output and supporting with digital communications. Zarah also provides support to our Academic Reference Group and International Experts Group and has lead on organizing our international conference.



Arnie Puntis | Research and Policy Manager

Arnie is responsible for oversight of the Observatory's research portfolio and leads a programme of work looking at increasing ethnic diversity in clinical education and biomedical research. As part of her role, Arnie also oversees our Maternity and Neonatal workstream. Arnie has a background in physiotherapy and worked as a Clinical Fellow for Health Education England.



Kumi Takaoka | Senior Business Support Officer

Until March 2022, Kumi was the Observatory's Senior Business Support Officer. Before joining the Observatory, she worked for NHS Employers. She graduated from University of Gloucestershire and has extensive business administrative, PA and communications experience. She comes from a broad background of experience in various sectors, such as education, local government and architecture.

Dr Veline L'Esperance | Clinical Advisor, Genomics

Dr Veline L'Esperance leads the Observatory's projects on ethnic and racial inequalities relating to genomics and precision medicine. Veline is an academic General Practitioner in South London. She holds an NIHR Research Fellowship at King's College London and has expertise in health inequalities, epidemiology and primary care health economics.

Dr Carl Reynolds | Clinical Advisor, Sickle Cell Disease

Dr Carl Reynolds is senior clinical advisor to the Observatory leading on sickle cell inequality. He is a consultant respiratory and general internal medicine physician at North Middlesex University Hospital NHS Trust and an honorary senior clinical lecturer at the National Heart and Lung Institute at Imperial College London.

SPECIAL MENTIONS

Throughout our first year, we have also been supported by several other individuals who have worked with us either in partnership or as part of an elective placement:

Dr Olamide Dada, who led our groundbreaking work on racial bias in Pulse Oximetry and is the Founder and Chief Executive of Melanin Medics.

Tyler Thompson, who worked on community engagement in NHS Blood and Transplant, and on work around ethnicity in the NHS Graduate Management Training Scheme.

Ore Odubiyi, who worked with us during our first year on a range of policy issues.

James Frater, who, at the time of writing, is leading on a project to examine levels of trust in primary care services among Black and minority ethnic communities.



Equity in health outcomes and experiences are front and centre of the RHO ambition. Current programmes of work will improve perinatal outcomes and experiences of women and babies from Black, Asian and ethnic minority backgrounds, whilst contributing to the body of knowledge in this area.

PROFESSOR JACQUELINE DUNKLEY-BENT

CHIEF MIDWIFERY OFFICER,
NHS ENGLAND & NHS IMPROVEMENT
MEMBER OF RHO MATERNITY & NEONATAL WORKING GROUP



THE REST OF THE OBSERVATORY

The Observatory is more than its core team, and it's thanks to the individuals on this page that we have been able to achieve what we have.

STAKEHOLDER ENGAGEMENT GROUP

Meets Quarterly

Oversees and advises on all RHO functions & co-designs research output.

- Heather Nelson (Chair), Chief Executive, Black Health Initiative
- Pav Akhtar, Chief Diversity and Inclusion Officer NHS Blood and Transplant
- Melissa Berry, Diversity Consultant
- Emma Bray, Outreach and Campaigns Officer, Friends, Families & Travellers Jenni Caguioa, CNO Black, Asian, and minority ethnic Nurse Advisor, NHS
- Jacqueline Dyer, Independent Health and Social Care Consultant and Mental Health Equalities Advisor for NHS England
- Simeon Essuman, NHS Service User
- Clenton Farguharson MBE, Director of Community Navigator Services CIC & Skills for Care Ambassador
- Jacynth Ivey, Director of Inspiring Hope and non-executive director at Birmingham Community Health NHS Trust
- Mark Johnson, Emeritus Professor of Diversity in Health and Social Care, De Montfort University.
- Varadarajan Kalidasan, Consultant Paediatric Surgeon and Urologist, Royal Alexandra Children's Hospital, Brighton
- Fatima Khan-Shah, NHS Programme Director, West Yorkshire and Harrogate Health and Care Partnership
- Felicia Kwaku, Associate Director of Nursing, Kings College Hospital NHS Foundation Trust
- Rev Charles Kwaku-Odoi, Chief Officer, Caribbean & African Health Network (CAHN)
- Bren McInerny, Community volunteer, Gloucester Stafford Scott, Director of Tottenham Rights CIC, Associate Consultant at the Kings Fund
- Patrick Vernon, Associate Director for Connected Communities, Centre for Ageing Better
- John Walsh, Organisational Development Lead and Freedom to Speak Up Guardian, Leeds Community Healthcare NHS Trust

NHS RHO

Provides strategic high-level decis

NHS CORI

ACADE REFERENC

Meets Qu

Advises the RHO team on and issues of diver

- Professor Stephani Hatch (Co chair). Profes Institute of Psychiatry, Psychology & Neurosc
- Professor James Nazroo (Co-chair), Professo
- Professor Uduak Archibong, Professor of Div
- Dr Jason Arday, Professor of Sociology and [Durham University
 - Dr David Ashby, National Director of Improve
- Dr Laia Bécares, Senior Lecturer in Applied S
- Professor Jeremy Dawson, Professor of Healt
- Professor Gina Higginbottom, Emeritus Profe Nottingham
- Professor Mark Johnson, Emeritus Professor Montfort University
- Professor Kamlesh Khunti, Professor of Prima University of Leicester
- Professor Azeem Majeed, Professor of Prima Department of Primary Care & Public Health
- Professor Abdul Razaq, Interim Consultant in
- Dr Renee Romeo, Reader in Health Economic Professor Michael West, Professor of Work a Fund

MATERNAL & NEONATAL WORKING GROUP

Meets Bi-Monthly

Provides expert oversight and advises the RHO team on funding decisions.

- Professor Jacqueline Dunkley-Bent (Co-chair), Chief Midwifery Officer, NHS England and
- Christine Ekechi, Consultant Obstetrician and Gynaecologist, Imperial College Healthcare
- Janet Fyle, Advisor, Royal College of Midwifery

- Wendy Olayiwola, National Maternity Lead for Equality, NHS England and NHS

DIGITAL & **WORKING** 0

Meets Bi-Mo

Provides expert overs the RHO team on fur

- Clinical Information Officer, Surrey and Borde
- Dr David Ashby, Director of Improvement Pro

- Yvonne Mhlanga, Head of Mental Health Com
- Eddie Olla, Regional Director for Digital Trans
- Dr Gurprit Singh Pannu, Chief Clinical Inform

- Shella Sandoval, Nursing Information Officer
- Surriya Walters, Digital Inclusion Outreach M

O BOARD

Quarterly

gic direction and cision making.

DRE TEAM

DEMIC NCE GROUP

Quarterly

on academic commissions versity in research.

rofessor of Sociology and Epidemiology at the uroscience, King's College London f Diversity, University of Bradford and Deputy Executive Dean (People and Culture),

rovement Products and Services, NHS England ied Social Science, University of Sussex Health Management, University of Sheffield Professor Ethnicity and Health, University of

ssor of Diversity in Health & Social Care De

Primary Care Diabetes and Vascular Medicine,

rimary Care and Public Health, and Head of the ealth, Imperial College London nt in Public Health, Lancashire County Council omics, King's College London ork and Organisational Psychology, The King's

INTERNATIONAL **ADVISORY GROUP**

Meets Quarterly

Extends RHOs global reach and oversees international activity.

- Professor David R. Williams, (Co-Chair) Professor of Public Health, Harvard University (U.S.A)
- Yvonne Coghill, (Co-chair) Special Advisor, NHS Race and Health Observatory (UK)
- Andy Burness of Burness Communications, a mission-driven global communications firm supporting non-profits and the people they serve (U.S.A)
- Ricci Harris, Public Health Physician and Associate Professor, Eru Pōmare Māori Health Research Centre, Department of Public Health, University of Otago, Wellington (New 7ealand)
- Professor Stephani Hatch, Professor of Sociology and Epidemiology, leading the Health Inequalities Research Group at the Institute of Psychiatry, Psychology & Neuroscience. King's College London (UK)
- Raymond Lovett, Program leader for Aboriginal and Torres Strait Islander Health, National Centre for Epidemiology and Population Health, Australian National University (Australia)
- Anthony Mbewu, Specialist in internal medicine and cardiology (South Africa) Professor James Nazroo, Professor of Sociology, University of Manchester (UK)
- Irma Velásquez Nimatuj, Spokeswoman for Indigenous communities in Central America, journalist, activist and University of Oregon Visiting Professor (Guatemala)
- Professor Naomi Priest, Group Leader of Social-Biological Research, Centre for Social Research and Methods, Australian National University and Murdoch Children's Research Institute (Australia)
- Dr Priscilla Reddy, Visiting Scholar Centre for Critical Research in Race and Identity, University of KwaZulu-Natal (South Africa)
- Dr Janet Smylie, Professor at the Dalla Lana School of Public Health, University of Toronto (Canada)
- Dr Laurie Zephyrin, Vice president

& DATA G GROUP

ersight and advises funding decisions.

gital Health Transformation and Associate Chief orders Partnership NHS Foundation Trust . Products & Services, NHS England and NHS

Commissioning, Berkshire West CCG

NHS Blood and Transplant icer, Royal Free London NHS Foundation Trust th Manager, Good Things Foundation

MENTAL HEALTH WORKING GROUP

Meets Bi-Monthly

Provides expert oversight and advises the RHO team on funding decisions.

- Evelyn Asante-Mensah, Chair, Pennine Care NHS Foundation Trust Paul Farmer, Chief Executive, Mind

- Sarah Hughes, Chief Executive, Centre for Mental Health
 Dr Sri Kalidindi CBE, Psychiatrist, Maudsley; National Clinical Lead for Rehab, NHS
- Jinjer Kandola, CEO, Barnet, Enfield & Haringey NHS Mental Health Trust Saiqa Naz, Cognitive Behavioural Therapist, Sheffield Health and Social Care NHS



It is important to understand the relationship between race, health, and inequality as we work and live in a more diverse society. The RHO is already making an impact with its current work and publications that help raise awareness on these issues.

JENNIFER CAGUIOA

INTERNATIONAL RECRUITMENT AND ETHNIC MINORITIES NURSE ADVISOR, NHS ENGLAND AND NHS IMPROVEMENT MEMBER OF RHO STAKEHOLDER ENGAGEMENT GROUP



MAKING AN IMPACT

Quantifying impact in the world of race equity is not a simple thing. 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, in the short time the Observatory has been operating, we have seen major policy change, directed an unprecedented amount of research funding, and managed a huge amount of public and professional engagement across our workstreams.

This section of the report outlines where we have made an impact in our first year. In our strategy document, we set out five domains in which we expected to see some change in our first year of operation. As you will see over the following pages, we believe we have delivered that impact, and that the stage is set for radical change in the future.



Driving Policy Change

Engaging with ministers and other policymakers to ensure that evidence is digested and acted upon at the highest level, and ensuring that positive change on race equality is both long-term and irreversible.



Shaping research

Identifying gaps in the existing evidence base and, where we cannot fill those gaps with our own work, working alongside other research organisations and funders to help prioritise this research.



Influencing leadership

Engaging directly with local and regional leaders in the system to drive meaningful change, and working with national policymakers to ensure that leaders are both properly equipped and sufficiently accountable.



Engaging the public

Using diverse traditional, social, and community media channels to raise awareness and stimulate debates to bring understanding of ethnic health inequalities into mainstream discourse.



Creating practical tools

Producing resources and evidence to help improve decision making about populations and to empower communities to advocate for change.



It is important to understand the relationship between race, health, and inequality as we work and live in a more diverse society. The RHO is already making an impact with its current work and publications that help raise awareness on these issues.

JENNIFER CAGUIOA

INTERNATIONAL RECRUITMENT AND ETHNIC MINORITIES NURSE ADVISOR, NHS ENGLAND AND NHS IMPROVEMENT MEMBER OF RHO STAKEHOLDER ENGAGEMENT GROUP



DRIVING POLICY CHANGE



Engaging with ministers and other policymakers to ensure that evidence is digested and acted upon at the highest level, and ensuring that positive change on race equality is both long-term and irreversible.

One of the Observatory's primary aims for our first year was to have an impact on policymakers. For a large part, this has meant engaging with officials from across NHS, the Department of Health and Social Care, and beyond. We actively engage on policy with many organisations including the Care Quality Commission, Health Education England, the Office for Health Improvement and Disparities, NHS Confederation, NHS Providers, the General Medical Council, the Nursing and Midwifery Council, the British Medical Association, the Professional Standards Agency, and many more besides. By building relationships across the policy space, we are able to target our recommendations at appropriate individuals, and to ensure that those recommendations are acted upon.

As well as the work we've done promoting policy change around pulse oximetry (see overleaf), the Observatory has:

- contributed evidence to the All-Party Parliamentary Group (APPG) inquiry into sickle cell care;⁵
- held roundtables with key policymakers to drive forward recommendations around better quality ethnicity coding in the NHS;⁶
- provided evidence to government officials on the importance of funding an ethnicity boost to the Adult Psychiatric Morbidity Survey;⁷
- and supported the NHS in its development of the new Core20PLUS5 approach to health inequalities.⁸

Throughout all the above, and most importantly of all, we have sought to include and amplify the voices of those with lived experience of ethnic health inequality. As well as consulting regularly with our own Stakeholder Engagement Group, we have also held consultations and engagement events, and we make genuine community engagement a fundamental pre-requisite of all our funding decisions. We believe that policy changes that do not take account of these voices will never meet the needs of the underserved communities in the UK.

Alongside all the above, we have also begun to influence policy globally. As well as convening a group of international academic experts, we have signed an MoU with the US Centers for Disease Control and Prevention (CDC), agreeing to pool our resources

and intelligence, and to learn from one another about universally applicable responses to health inequalities.

CASE STUDY

Pulse Oximetry

Some of our greatest early progress has come off the back of our first ever major publication, a rapid review into racial bias in pulse oximetry. Released in April 2021, the review looked at evidence gathered over many decades to shine a spotlight on potential inaccuracies in pulse oximeters. These devices fit on a person's finger and use light to measure oxygen levels in the blood. The report explored evidence to suggest that these devices may be less accurate when used on patients with darker skin. These concerns were especially relevant given the large-scale rollout of these devices for home-management of COVID-19, a disease that was already proving to disproportionately affect Black and Asian people.

The report was an example of precisely what the Observatory was designed to do – mobilising evidence to ask questions of the established health and care system. The review did not argue that pulse oximeters were inherently unsafe, but it exposed shortcomings in the process for the design and manufacture of medical devices. Where such life saving devices are tested only on people of certain ethnicities, we cannot be sure of their efficacy for ethnic minority communities.

Since the publication of our review, we have seen policymakers respond quickly to the concerns raised:

- The Medicines and Healthcare products Regulatory Agency updated their guidance to highlight the potential for inaccurate readings.⁹
- The National Institute for Health Research put out a call for new studies looking at the potential diagnostic inaccuracy of pulse oximeters.¹⁰
- The Secretary of State for Health and Care launched a review into the health impact of potential bias in medical devices.¹¹

⁵ https://www.sicklecellsociety.org/no-ones-listening/

⁶ https://www.nhsrho.org/news/ethnicity-coding-in-english-health-service-datasets/

 $^{^7 \} https://www.gov.uk/government/statistics/adult-psychiatric-morbidity-survey-mental-health-and-wellbeing-england-2014$

 $^{^{8}}$ https://www.nhsrho.org/publications/nhs-race-health-observatory-consultation-response-core20plus5/

⁹ https://www.gov.uk/guidance/the-use-and-regulation-of-pulse-oximeters-information-for-healthcare-professionals

¹⁰ https://www.nihr.ac.uk/documents/21608-diagnostic-accuracy-of-pulse-oximeters/29470

¹¹ https://www.gov.uk/government/news/review-launched-into-the-health-impact-of-potential-bias-in-medical-devices

PEOPLE CONSULTED THROUGH SURVEYS AND FOCUS GROUPS

80 MILLION



PEOPLE REACHED THROUGH MEDIA

7400

NEW TWITTER FOLLOWERS

1053

NEW LINKEDIN FOLLOWERS

3100

YOUTUBE VIEWS

593

ARTICLES FEATURED IN MEDIA OUTLETS

PROGRAMMES OF WORK INITIATED

SHAPING RESEARCH



Identifying gaps in the existing evidence base and, where we cannot fill those gaps with our own work, working alongside other research organisations and funders to help prioritise this research.

Our primary function is to mobilse high quality evidence and support tangible evidence-based change in the health and care system. Research and evidence are at the core of everything we do. When we released our most recent report, a rapid evidence review of ethnic inequalities in healthcare, we stressed that research alone is not enough to deliver change. But that, without robust research, policy change will never deliver significant change and, at worst, could cause more damage.¹²

Over the past year we have commissioned research that has sought to plug gaps in existing knowledge, or to create evidence granular enough to promote practical actions. Above all, we have commissioned research that will remove excuses for inaction. The below list covers all of our commissions across our first year:

- A review of ethnicity coding in English health service datasets.¹³
- A review into ethnic health inequalities and the NHS as a whole, looking at the institutional factors embedding racism in the system.¹⁴
- A focused review looking at supporting named leads for health inequalities on NHS boards.¹⁵
- A rapid evidence review looking at ethnic health inequalities across five key priority areas for the Observatory.
- A policy review of the Improving Access to Psychological Therapies (IAPT) programme.
- A mapping exercise of existing policy interventions to tackle ethnic health inequalities in maternity and neonatal health.
- A review of neonatal assessment and practice in Black and Asian newborns.
- A review of Equality Impact Assessments for new treatments and disruptive innovations in the NHS.
- A review of NHS-managed national patient and public mobile apps.
- A study to explore the impacts of Long-COVID on UK healthcare workers. 16

- A study to identify best practice in mental health care for Gypsy, Roma, and Traveller communities.
- A review into factors that contribute towards inequalities in health outcomes faced by people with a learning disability from a minority ethnic community.
- A review into ethnic health inequalities in precision medicine and the future of healthcare.
- A project looking to promote effective and respectful communication with ethnic minority women and pregnant people.
- A review into ethnic health inequalities in the genetic testing and diagnosis of familial hypercholesterolemia.

In addition, we have been working in close partnership with other organisations such as the National Institute for Healthcare Research, Macmillan, the Nuffield Trust, the Kings Fund, and the London School of Hygiene and Tropical Medicine to maximise the impact of our research funding, and to influence the priorities of larger funders. Nowhere is this better evidenced than in the recently NIHR-funded project - a study within a trial to determine the effect of skin tone on the diagnostic accuracy of pulse oximeters - due to produce findings in September 2023.

We will continue to look ahead, and to engage with our stakeholders to ensure that the solutions we develop are always impactful and meet the needs of ethnic minority communities.

¹² https://www.nhsrho.org/publications/ethnic-inequalities-in-healthcare-a-rapid-evidence-review/

 $^{^{13}\,}https://www.nhsrho.org/news/ethnicity-coding-in-english-health-service-datasets/$

¹⁴ https://www.nhsrho.org/publications/ethnic-health-inequalities-and-the-nhs/

 $^{{}^{15}\}text{https://www.nhsrho.org/publications/supporting-named-leads-for-health-inequalities-on-nhs-boards/}\\$

 $^{^{16}}$ https://www.nhsrho.org/press-release/race-and-health-observatory-to-work-with-uk-academic-team-to-explore-impact-of-long-covid-on-uk-health-are-workers/



It is clear the observatory has had a significant impact on race issues in health, but this is only the beginning. Over the next year, through the data, digital, and innovation group, we look forward to providing more research and practical support for the health and care sector to go further to address these issues.

POLLYANNA JONES

HEAD OF DELIVERY AND COLLABORATION,
NHS ENGLAND AND NHS IMPROVEMENT
MEMBER OF RHO DIGITAL & DATA WORKING GROUP



INFLUENCING LEADERSHIP



Engaging directly with regional and system leaders in the system to drive meaningful change, and working with national policymakers to ensure that leaders are both properly equipped and sufficiently accountable.

Our approach to driving policy change means becoming a positive influence and practical resource for decision makers. When we talk about influencing leadership, we do not just mean ministers and national policy makers, but leaders at all levels of the health and care system. It is our belief that the system is full of influential individuals with the power to make meaningful change. We also believe that a combination of bespoke support, constructive challenge, and celebration of success, can drive leaders to make these changes.

Among our first publications was our report, *Ethnic health inequalities and the NHS: Driving progress in a changing system.* It examined the structural factors within the NHS that have meant it historically fails to serve all communities equally. It also examines the levers that are available to health and care leaders and proposes practical steps for leaders to take. In a follow up report, looking at the role of board-level health inequalities leads, we presented a progressive framework of actions for boards to consider (see pg.29).

At national level, we have been engaging with leaders across the system. Our board, many of whom are leaders of national organisations, are advocates for our work. We also engage directly with leaders in the Department of Health and Social Care and the NHS and have been invited by the Secretary of State for Health and Social Care, and the Chief Medical Officer to feed into key policy development, principally around the urgency of increasing vaccine uptake for ethnic minority communities during the pandemic and during the development of the upcoming white paper on health disparities, due to be published later this year.

Beyond those very senior leaders, however, we have also invested significant time in exploring the ambitions, concerns, and support needs of local leaders. Our report on NHS health inequalities leads showed that, even where well meaning, many health inequalities leaders felt they did not have the data, time, or resources to properly make a difference on health inequalities in their area¹⁷ As well as producing education resources based on that research, we are continuing to work with NHS England and NHS Confederation to ensure that this learning is embedded in programmes designed to improve board capability in this space.

We also believe that good leadership needs to be recognised and celebrated, and we were happy this year to sponsor both the HSJ list of the Top 50 Black, Asian and Minority Ethnic Leaders, and the Race Equality Award at the 2021 HSJ awards. Through both, we hope that good practice and influential role models can be highlighted to encourage and inspire other committed individuals and teams across the nation.

We will continue to work alongside national leaders, providing best quality evidence, and robust challenge, in the years to come.

SHORT-TERM FOCUS

LONG-TERM FOCUS

Accountability

- Providing visibility and assurance to the board
- Role modelling, challenging, and advocating for addressing inequalities in the organisation and in systems
- Providing assurance to regulators and ensuring compliance eg, in relation to elective recovery
- Monitoring changes in compliance requirements
- Embedding inequalities into system work

Policy formulation

- Establishing long-term vision, mission, and ambitions, including with system partners (as employers, as care providers, and as anchor institutions)
- Deepening understanding of inequalities and 'causes of causes', including integrating multi-sector data sets
- · Establishing a theory of change
- Establishing governance, frameworks, and standards
- Setting targets, eg, for employment and service provision
- Establishing training and support structures

Supervision

- Championing and enabling work on health inequalities in organisations and systems, including at service level, in designing service provision, and workforce development
- Creating momentum and enthusiasm, and maintaining focus
- Trying to create an inequalities mindset
- Ensuring equity of access, experience, and outcomes for patients and staff, including in response to Covid-19
- Securing and managing resources focussed on inequalities
- Ensuring responsibilities and work areas are clear
- Creating implementation plans, supporting problemsolving, monitoring progress, and measuring impact

Strategic thinking

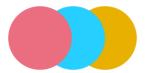
- Providing strategic direction, leadership, and alignment across multiple new and existing programmes, preventing scope creep, within the organisation, in systems and across regions
- Working closely with system partners, especially public health and population health colleagues
- Supporting data collection and analysis to inform decisions
- Navigating policy or political dilemmas about priorities and resource allocation, especially in the context of vested interests in the status quo
- Convening stakeholders, eg, though programme boards or multi-sector stakeholder groups
- Learning from others

INTERNAL FOCUS

EXTERNAL

FOCUS

ENGAGING THE PUBLIC



Using diverse traditional, social, and community media channels to raise awareness and stimulate debates to bring understanding of ethnic health inequalities into mainstream discourse.

The Observatory was set up to serve the public by delivering equity in the health and care system. In achieving this, it is vital that we are engaging with and responding to the public, empowering patients and care users by making high quality evidence available to them and encouraging them to demand greater inclusivity from their local health and care providers.

Community voices are at the core of what we do. We have established a stakeholder engagement group who guide the work that we do, and we make genuine community participation and coproduction a precondition of our research funding. Our approach to community participation is evidence-based and guided by principles of independence, diversity of experience, systematic primacy, and transparency.

We have carried out several engagement exercises, including a broad ranging consultation around the language we use to describe race and ethnicity, and a survey exploring the concept of trust as a social determinant of ethnic health inequality. Most recently, we have announced our international conference on Health, Race and Racism – creating a virtual space in which the public can engage with experts and one another around the world.

We have engaged the public primarily through diverse and traditional media sources. Over the past year, we have been featured in over five hundred mainstream print and online media articles. Our reports have been covered by broadcast TV and Radio channels including BBC, Channel 4, Sky News, LBC, and others.

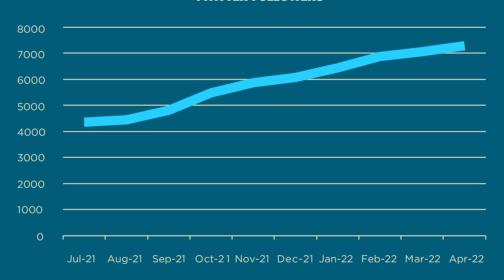
Our work is also targeted at Black, Asian and minority ethnic audiences, here and abroad, across print, broadcast, regional and community radio. Interviews have spanned the BBC Asian Network, Islam Radio, Al Jazeera, The Wire, and BEN Television with publications including The Voice, Muslim News, Eastern Eye, Asian Post, and African, Caribbean community programmes via the BBC's UK Black hub.

Our recent rapid evidence review was featured on the front page of the Guardian and our work has been covered by many international outlets based in Brazil, India, and Turkey

LINKEDIN FOLLOWERS



TWITTER FOLLOWERS



NEWSLETTER SUBSCRIPTIONS



and various global news wires. We have also published blogs from clinicians, activists, and leaders, and have hosted global webinars.¹⁹

We have also engaged extensively through social media. In the past year, we have grown engaged and proactive followings on both Twitter and LinkedIn. We are continuing to see steady growth across both platforms, and in subscribers to our weekly newsletter. These channels allow us to engage in direct dialogue with our stakeholders in almost real time, meaning we can remain engaged with the issues that mean something our stakeholders.

We remain committed to working proactively with communities affected by racial inequity and the wider public.

 $^{^{18}\} https://www.nhsrho.org/publications/nhs-race-health-observatory-terminology-consultation-report/$

¹⁹ https://www.nhsrho.org/blog/

CASE STUDY

The Power of Language

As a new organisation working in race equality, we are acutely aware of the power that language can have to shape public policy. Over the Summer of 2021, we carried out a stakeholder engagement exercise to better understand the views of our stakeholders. We asked how people feel about collective terminology such as 'BME', 'BAME', and 'ethnic minority' and asked people to share their views about language more generally. We engaged with over 5000 people through a combination of a survey and focus groups, and used those insights to inform the creation of principles we will follow when writing and talking about race.

Although we started the process to explore whether there was a single acceptable collective term, what we found was much more nuanced and complex. Rather than adopting a new term, we instead co-designed a set of principles that we have carried forward throughout our writing and engagement.

Our five principles:

- 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.

You can read more about how we arrived at these principles in our report, *The Power of Language*.

CREATING PRACTICAL RESOURCES



Producing resources and evidence to help improve decision making about populations and to empower communities to advocate for change.

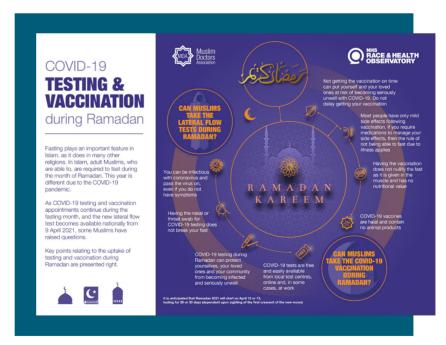
Part of our mission at the Race and Health Observatory is to put research and evidence in the hands of the people who can use it and make it accessible to a diverse audience of service users, healthcare workers, academics, and policymakers. We achieve this by making our research and evidence available in a variety of formats, including infographics that pull on key findings to be shared across social media and beyond.



We have also hosted several webinars on health inequalities, COVID-19 vaccination, and compassionate leadership.²⁰ These events allow us to not only hear from experts in their fields, but also to allow members of the public to directly question and engage with those experts.

Finally, we ensure that all of our research outputs are accompanied by actionable recommendations. We challenge ourselves to ensure that our recommendations are evidence-based and that they can be practically implemented. Where possible, we name individual organisations and teams, and we ensure that the literature and methods required to support implementation are available. We also support organisations to make these changes through bespoke support.





²⁰ https://www.youtube.com/channel/UCcVRKG6jOL_6lmqNyOeZl8g



Since working with the RHO I have felt how the value of my lived experience can help to influence positive longterm change. The stark health inequalities faced by Gypsies and Travellers is being seen with a fresh and determined approach to tackling them head on.

EMMA BRAY

OUTREACH AND CAMPAIGNS OFFICER, FRIENDS, FAMILIES & TRAVELLERS MEMBER OF RHO STAKEHOLDER ENGAGEMENT GROUP



WHAT COMES NEXT?

The contents of this report represent only the start of the work the Observatory has been set up to do. There is a lot more ahead, and we have three key areas of focus for the coming year.



Implementation

If our first year was about mobilising evidence, in our second year we will move towards implementation. This will mean working with national policymakers to ensure that our recommendations are embedded and spread across the system. It will also mean working with emergent integrated care systems to test out novel and experimental new ways to reduce ethnic health inequality. Finally, it will mean putting resources in the hands of patients, service users, and the public.

To that end, this year we will be launching an interactive digital platform, designed to provide public access to data on health inequalities across the country. The data will be localised, and the platform will provide access to case studies and resources to help organisations respond to inequality in their area. The platform will be accessible and intuitive, flexing to the needs of the user.



Innovation

We will of course, continue to produce and mobilse evidence across our priority areas – mental health, maternal and neonatal health, digital inclusion and data capture, genomics and precision medicine, and the health and care workforce. But we will also turn our attention to the research sector itself, exploring how medical research is funded, who is getting the money, and who is involved in the research. We will also consider how racial biases are embedded in the education and continued development of clinicians and other healthcare professionals, and we will look at the power of professional regulation to help reduce inequalities. Finally, we will be looking at the opportunities for learning that we can provide, seeking to give back to the sector through placements and other opportunities.



Engagement

We will continue to foreground the voices of people with lived experience in our work. On top of our existing forms of engagement, we also plan to launch a community engagement framework, designed to direct funding at smaller community-focused and grassroots organisations who might otherwise miss out on central funding, but who provide a vital service in advocating for the least well served communities in the country.

We will also take our engagement to an international level. July 2022 will see our first ever international conference – *Health, Race and Racism* – where people from around the world will come together both physically and virtually to explore the ways in which racism impacts health globally, but also to learn from one another about the steps we can take to turn the tide.

Finally, we will continue to keep our ears and eyes open to the everchanging reality of race and health in this country. We end this report by inviting readers to follow us, engage with us, and challenge us on the way we work. We will only be successful in our mission by engaging in continuous dialogue with our supporters and the public.



The work of the RHO is vital in these difficult times. In the last year, the organisation has brought together people from across the NHS and wider to think, learn and create positive actions together. I am honoured to be part of this work.

JOHN WALSH

ORGANISATIONAL DEVELOPMENT LEAD,
LEEDS COMMUNITY HEALTHCARE NHS TRUST
MEMBER OF RHO STAKEHOLDER ENGAGEMENT GROUP





