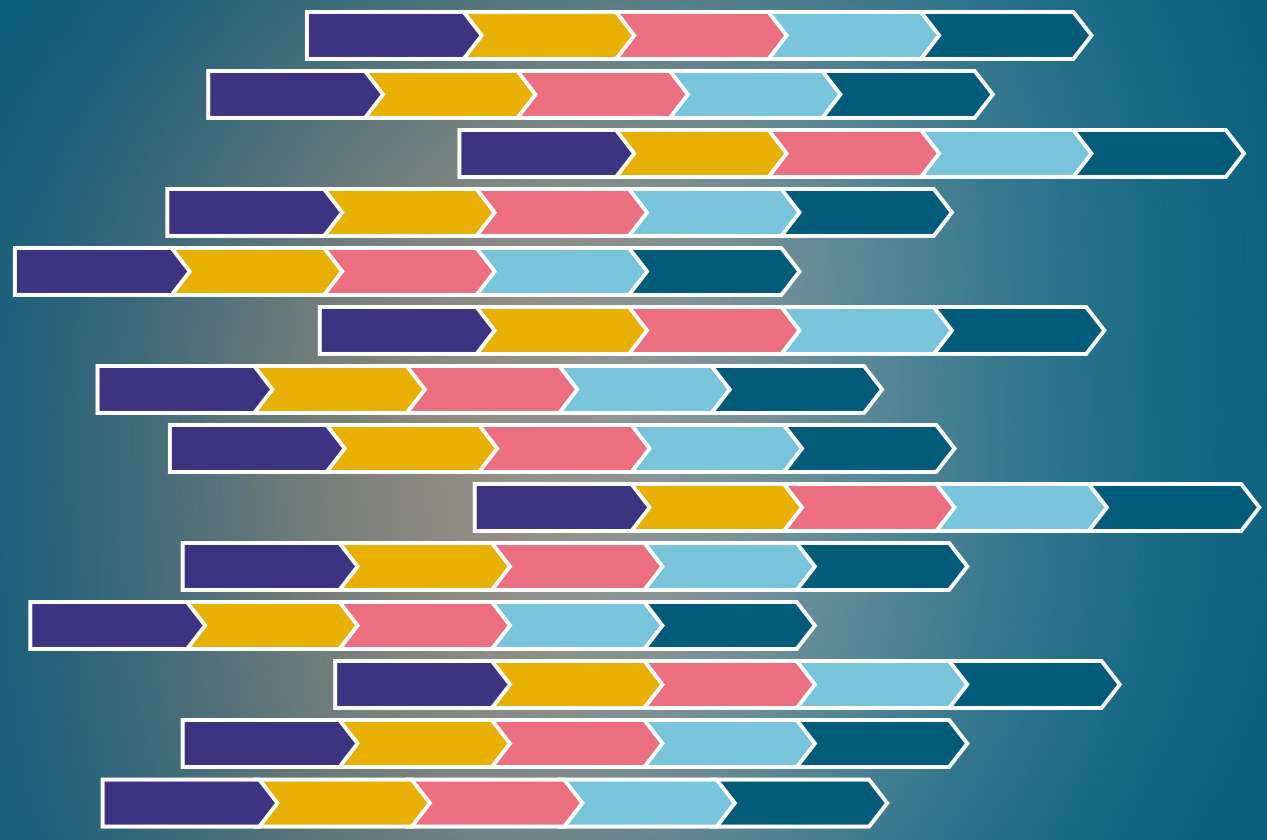
NHS RACE & HEALTH OBSERVATORY

# Implementing recommendations for anti-racism and anti-discrimination in healthcare: A clear path towards anti-racism



## Supplementary report to the Toolkit

NCCMH

Prepared by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the NHS Race and Health Observatory (RHO)

# Content warning

This report contains discussion and accounts of racism and discrimination across healthcare that may be upsetting.

**Resources and support:** If you would like further resources or support, please see our list below. These resources were found in co-production with lived experience researchers. Local areas may also have other organisations not listed here.

**Organisations:***

- Black Health Initiative: Equality of access to education, health and social care (Leeds)
- Black Thrive Global: Reimagining and co-creating a world in which Black people thrive
- Bliss: For babies born premature or sick
- Caribbean & African Health Network: Improving holistic health and wellbeing
- Five X More: Changing Black maternal outcomes in the UK
- Friends, Families and Travellers: Getting a fair deal for Gypsies, Roma and Travellers
- The Ubele Initiative: African diaspora-led organisation, building sustainable communities across the UK

** Several organisations are members of the NHS RHO's Stakeholder Engagement Group or other NHS RHO Advisory Groups.*

**Other organisations and resources:**

- The King's Fund: Inequalities and inclusion in NHS providers project
- Mind: Racism and mental health – Useful contacts
- Race Equality Foundation: Tackling racial inequality in public services
- RISE. Freedom from Abuse and Violence: Anti-racism resources
- The Runnymede Trust: The UK's leading race equality think tank
- Stephen Lawrence Day Foundation: To inspire a more equitable, inclusive society and to foster opportunities for marginalised young people in the UK
- Survivors Network: Anti-racism resources

The NCCMH does not directly endorse any organisation or resource.

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# Abbreviations

| | |
|---|---|
| **CQC** | Care Quality Commission |
| **EAG** | Equality Advisory Group |
| **EIA** | Equality Impact Assessment |
| **IAPT** | Improving Access to Psychological Therapies (now called NHS Talking Therapies) |
| **ICB** | Integrated care board |
| **ICS** | Integrated care system |
| **NCCMH** | National Collaborating Centre for Mental Health |
| **NICE** | National Institute for Health and Care Excellence |
| **PCREF** | Patient and Carer Research Equality Framework |
| **QI** | Quality improvement |
| **RHO** | Race and Health Observatory |
| **RREAL** | Rapid Research Evaluation and Appraisal |
| **SMART** | Specific, Measurable, Achievable, Relevant, and Time-bound objectives |
| **VCSE** | Voluntary, community and social enterprise organisation |

# Contents

# Executive summary

## Introduction

Since its establishment in 2020, the NHS Race and Health Observatory (RHO) has conducted and commissioned work into advancing the evidence base on ethnic inequalities, racism[a] and health. The NHS RHO has identified widespread ethnic inequalities across:

- the NHS workforce
- mental health services
- maternal and neonatal care
- digital inclusion and access to health services
- genetic testing and genomic medicine studies.

Following research, recommendations for improving practice are made. The National Collaborating Centre for Mental Health (NCCMH) was commissioned by the NHS RHO to develop an anti-racism implementation model, to support the implementation of recommendations published by the NHS RHO and commissioned partners.

## The need for an implementation model and strategy

The NHS RHO has started to move towards an implementation phase to ensure the recommendations generated by research are put into practice. The NCCMH therefore conducted research to gather in-depth insights into implementation[a] and interventions that address racism, to support and guide the work. This research comprised qualitative interviews with NHS RHO stakeholders, and focus groups[a] with people with lived and/or learned experience facilitated by lived experience researchers, in which we explored the enablers for and barriers to implementing the NHS RHO recommendations. We also investigated what these enablers and barriers mean for implementation more broadly.

The implementation model, presented as a step-by-step toolkit, was co-produced[a] with subject matter experts, people with lived experience and other stakeholders including NHS RHO Board members, through a series of three design workshops. Our quality improvement (QI) team grounded the model in published literature on implementation. The implementation model offers support to the NHS RHO, and organisations they have commissioned, to develop implementable and trackable recommendations.

a See the Glossary for definitions of the following terms on this page: co-production, focus group, implementation (in research) and racism.

# What this report adds, and our findings

This Supplementary Report should be read alongside the Toolkit that has been developed for the NHS RHO to aid the implementation of recommendations for anti-racism and anti-discrimination in healthcare. This report will also be of interest to people involved in the research component of this project, and wider stakeholders interested in the intersection between racism and health.

In this report, we (the NCCMH research team) present the findings of our research, including examples of individual experiences and good practice in services and organisations. We identified five themes,[b] which were underpinned by the principle of undoing harm:

### 1. The approach to implementation

This includes:

- acknowledging racism
- bringing people along with you
- the methods used for implementation, such as QI
- recognising resource constraints.

### 2. Leadership and buy-in at multiple levels

This can:

- create accountability for implementation
- contribute to a culture change
- ensure stakeholders, including advocates, for anti-racism programmes are engaged and involved.

### 3. An anti-racism approach, throughout

This ensures that organisations are ready to be accountable for undoing harm. It requires:

- healthcare providers building trust with communities
- redirecting services to communities with unmet needs to provide culturally competent[b] care
- workforce training and development
- capacity-building.

### 4. Co-production with people with lived and learned experience

This must be considered from inception and include people with critical voices. Co-production needs sufficient time and resource to increase the power and influence of those involved.

### 5. Experience of racism and discrimination in quality of access, treatment, care and support

This theme acknowledges how our past experiences of harm shape our perceptions and views of the present. Intersectionality[b] (for example, between ethnicity[b] and gender) can also play a significant role for some people who experience racism.

b See the Glossary for definitions of cultural competence, (race and) ethnicity, intersectionality and themes.

# Next steps for the NHS RHO

In Table 1, we suggested some next steps for the NHS RHO, which are mapped to the five building blocks[c] of implementation developed as a basis for the Toolkit[d].

**Table 1: Suggested next steps for the NHS RHO, mapped to the five building blocks of implementation**

| |
|---|
| **Evidence/ interventions** |
| • To be selective and driven by the political landscape (e.g., if there is an upcoming general election) when deciding what evidence is used to influence policymakers.<br>• To advise researchers conducting primary research on which demographic categories to use to help build an evidence base. |
| **Context/the system** |
| • To collaborate with new partners beyond health, to address social inequalities and the social determinants of health.<br>• To understand the context and support organisations in preparing to implement recommendations, by assessing their readiness to bring in anti-racism practices and re-think how they operate to prepare for an anti-racism approach.<br>• To involve networks that have the infrastructure to support the adoption of the recommendation and widespread implementation. |
| **Design** |
| • To ensure that engagement and systems:<br>  ◦ are strategic<br>  ◦ align with existing goals and wider strategies<br>  ◦ consider cycles of change.<br>• To continue to generate recommendations that are modifiable and impactful for organisations responsible for change, in dialogue and consultation with key stakeholders.<br>• To prioritise recommendations to support implementation with all stakeholders, with realistic timelines, milestones and targets.<br>• To develop a more integrated, concurrent approach to evidence generation and implementation. |

c See the Glossary for a definition of building blocks.

d After consultation the Toolkit was structured using a step-by-step approach, with the building blocks woven throughout

**Infrastructure**

- When developing recommendations, to include people who are:
  - closer to delivery
  - closer to receipt of interventions
  - responsible for system change.

  And, to give them time to prepare and engage through support and coaching.
- To explore how to improve the implementation science behind anti-racism, and how this may be applied to the NHS through the role of integrated care systems (ICSs).
- To play a role in lobbying for the introduction of more equitable and anti-racism approaches from:
  - publishers
  - ethics committees
  - funders.

**Evaluation**

- To support the development of an independent evaluation process, reflecting on what does and does not work in specific locations/contexts.
- To ensure clear key performance indicators and metrics are monitored, over time and at the end of a project.
- To celebrate and share success stories of change that has been achieved, including lessons learned.

## Conclusion

Good implementation:

- is iterative
- is impactful
- measures change over time
- involves diverse stakeholders
- is sustained through shared practice and learning.

Our findings emphasise how an anti-racism approach should feature in implementation work.

The NHS RHO should build on its strengths by raising its profile and fostering partnerships with other organisations (for example, integrated care boards [ICBs] and systems, voluntary, community and social enterprise organisations [VCSEs], local authorities and so on) and professional bodies as it enters its implementation phase.

The Toolkit is a starting point for the NHS RHO's next phase.

# Lay summary

The National Collaborating Centre for Mental Health (NCCMH) was asked by the NHS Race and Health Observatory (RHO) to work on a plan to help put into action recommendations from a range of NHS RHO projects. This involves using an anti-racism approach. The NHS RHO asked for this because racism has led to worse outcomes (for example, in health) for some minoritised communities compared with the general population.

This report explains how different groups worked together to develop advice and guidance, which we call a toolkit. The Toolkit offers practical steps for NHS RHO to take to address racism and promote fairness for everyone in the health service.

The NHS RHO can also use the Toolkit to begin working towards creating a more equal healthcare system for all. The Toolkit, and principles within it, may also be a useful tool for other organisations.

# How this report and the Toolkit were developed

## How to put recommendations into action

This is called 'implementation'. The first step was to look at research that has been published on how to develop and implement recommendations in healthcare. From this, five key building blocks were developed as a basis for the Toolkit:

### The five building blocks of implementation

**1. Evidence and interventions:**

- Ensure the evidence used is robust and credible
- Develop adoptable interventions
- Draw upon evidence-based practice

**2. Context and the system:**[e]

Consider the impact of people, organisations or systems, the external environment and organisational culture.

**3. Design:**

Create a learning system to support providers/organisations to adopt the recommendations.

**4. Infrastructure:**

Assess an organisation or system's readiness for implementation, the skills and knowledge needed and try to remove barriers.

**5. Evaluation:**

Evaluate how interventions are being adopted, their effectiveness and what contributed to successful implementation.

e See the Glossary for a definition of system (healthcare).

## Bringing experts and people with experience together

The NCCMH research team, which included topic experts and people with lived experience of racism, brought together the following people to discuss the Toolkit:

- people who have used NHS services and experienced racism
- NHS staff, including leaders and managers
- people who work with or for the NHS RHO
- a representative from local government
- an expert in diversity and inclusion.

It's also important to remember that people working in the NHS staff and other people organisations may have experienced racism themselves.

Over 3 months, this group of people were asked to take part in online discussions. These discussions took place in three workshops made up of about 20 people, in two smaller focus groups of around seven people, or in individual interviews. They talked about their experiences of racism when working in or using the NHS. They mainly talked about their experiences of mental health and maternal health. They also talked about other areas of healthcare, such as primary care (for example, their experiences at a doctor's appointment or pharmacy).

The aim was to record instances of racism and to come up with ideas for improving services and to reduce racism. They talked about what could help or what made it harder to put recommendations from the NHS RHO into practice. People in the group gave examples of good and bad practice, and what happened after both. They were shown the five building blocks of implementation and made suggestions on how to create the Toolkit and handle problems.

People shared some very difficult and painful stories. If they wanted to have a break, they could go to a quiet space away from the group. There, a staff member could listen to them and support them if they wanted.

## After collecting the evidence

After the online meetings, the NCCMH research team took the evidence they had collected in the online meetings and developed five key areas (themes).

**Undoing harm** was spoken about across all five themes, which were:

- **Theme 1:** The first theme is **the approach to implementation,** which includes acknowledging that racism exists, bringing people along with you and the methods used to approach implementation, which includes QI.

One person in a focus group said:

> *'You have to really bring the workforce along with this implementation. Please do not just do it to them, bring them along. And hopefully that way, we get the outcomes that we want to see.'*
>
> **Lived Experience 11, Focus Group 2**

- **Theme 2:** Make sure **leadership and staff at all levels** of an organisation understand why this work is important and needed.
- **Theme 3:** Follow the Toolkit process to remove racism at all levels and use an **anti-racism** approach across the work.

One person in a focus group said:

> *'Basic training for everyone, from the top to the bottom, before their job starts. Some sort of guidelines. Because unless and until the job insists on not being racist, I don't think anyone will take it seriously.'*
>
> **Lived Experience 2, Focus Group 1**

- **Theme 4:** Make sure that the process involves people with experiences of racism, leaders, managers and anyone else interested working together from the start and throughout (this is called '**co-production**').

One person in a focus group said:

> *'It's not [that] these communities are 'hard to reach'. We're not reaching out hard enough on going to the spaces and places that that they frequent.'*
>
> **Lived Experience 6, Focus Group 2**

- **Theme 5: Share examples of how racism leads to unfairness and inequality of treatment**, and so to poor health outcomes, to help understand how to make things better.

In the discussions, people understood that putting the Toolkit into practice might be challenging. Some questions were raised by those taking part in the discussions, such as:

- Will there be enough money and time to do the work?
- Will the staff, including leaders, believe that the programme will be taken seriously?
- Will people have belief in the process if they have seen similar initiatives not be successful?

All these points and more were taken on board by the researchers, and a chart for following progress (the Recommendation Tracker, in MS Excel) was developed with the Toolkit to monitor some of these concerns.

## What happened next?

The Toolkit and the information collected were sent to the people who had been involved in the online meetings. We asked them to read them and check if they reflected the discussions in the meetings. The Toolkit was then tested with two organisations that had previously worked with the RHO, one focused on mental health and the other on neonatal care. Their feedback was used to make changes to the Toolkit.

# 1. Introduction

## 1.1. Background to the project

The NCCMH was commissioned by the NHS RHO to develop an anti-racism implementation strategy and model to support the implementation of recommendations developed by the RHO and the RHO's partners.

The model has been co-produced with subject matter experts, people with lived experience and other stakeholders including NHS RHO Board members through a series of three design workshops.

Our QI team grounded this model in the published literature on implementation (for further detail, see Section 2.1 of this report).

The NCCMH research team also conducted research to gather in-depth insights on implementation and interventions to address racism to support and guide the QI work. The findings of our research are presented in this report.

## 1.2. Evidence and context for this work

There is an expanding body of evidence on the relationship between racism and health, although it is mainly literature from the USA and tends to be descriptive.[1] A rapid evidence review[2] of UK literature, commissioned by the NHS RHO, identified widespread ethnic inequalities across:

- digital inclusion and access to health services
- genetic testing and genomic medicine studies
- maternal and neonatal care
- mental health services
- the NHS workforce.

In that review,[2] the authors listed actions for NHS arm's-length bodies. These actions included:

- enforcing guidelines on monitoring data
- building trust with communities and organisations
- investing in research on racism and healthcare.

Inequalities in access, treatment, experiences and outcomes in maternal and mental health continue to be reported in the UK.[3–6] Racism is also described as being embedded in the UK health research system, with examples found in areas from commissioning to dissemination.[7]

However, steady progress to dismantle racism in healthcare is being made. For example, the Patient and Carer Race Equality Framework (PCREF)[8] is the first mandatory anti-racism framework by NHS England. The PCREF was developed for all NHS mental health trust and service providers to support improvement in leadership, governance, data and feedback mechanisms.

The NHS RHO was established in 2020 in response to The BMJ's special issue on racism in medicine.[9,10] The murder of George Floyd and the global wave of protests that followed, and the impact of the COVID-19 pandemic, also raised public awareness of racism and discrimination.[f, 10] The NHS RHO is now shifting its attention towards implementation, to support the impact of research and make changes to practice.[11]

Implementation models are commonly used to describe and guide the translation of research and recommendations into practice. There are several examples in the literature, with most focusing on the 'who', 'what' and 'how'.[12–14] The 'who', for example, may relate to the people involved or the context of the organisation/system; the 'what' to the evidence used and interventions developed; and the 'how' to the infrastructure available to support implementation.

## 1.3. Aim and research question

Our research aim was to identify the enablers and barriers to implementing the NHS RHO recommendations, highlight evidence practice gaps and record experiences of racism to guide the development of the Toolkit.

Our research question was:

**What are the perceived barriers and enablers to implementing the NHS RHO recommendations to address the impact of structural racism on ethnic inequalities in health outcomes (including maternal and mental health)?**

f See the Glossary for definitions of discrimination.

## 1.4. How to read this report and who this report is for

This report is intended to be read alongside the Toolkit that has been developed for the NHS RHO to aid the implementation of recommendations for anti-racism and anti-discrimination in healthcare. It will also be of interest to:

- people involved in the research component of this project
- wider stakeholders who are interested in the intersection between racism and health.

The model offers support to the NHS RHO, and organisations commissioned by the NHS RHO, to develop implementable and trackable recommendations.

The findings are structured according to the topics[g] covered in focus groups and interviews.

Examples of experiences and of good practice are presented in boxes like this:

▲ Example of experience (dark grey/black box with triangle)

✦ Example of good practice (dark blue/teal box with star)

g See the Glossary for definitions of topics.

# 2. Method

## 2.1. Review of literature

The first step in creating an implementation model was to review the published literature on implementation. In one notable paper, Huybrechts and colleagues[15] reviewed 17 determinant frameworks to identify the main components and constructs of each model, of which there were 90. Our team categorised these 90 components and constructs, and developed five building blocks of implementation:

1. Evidence and interventions
2. Context and the system
3. Design
4. Infrastructure
5. Evaluation.

We took the five building blocks to our design workshops, outlined in Section 2.2, for review. Over the course of three workshops, we started to develop guidance and identify resources to develop an implementation toolkit.

We also conducted research to gather in-depth insights on implementation and on interventions to address racism, to support and guide the QI workstream. The findings from our research are presented in Section 3.

## 2.2. Design workshops

We ran three design workshops in September, October and November 2023, aiming to:

1. Review and discuss the draft building blocks of the implementation model.
2. Review components of the revised implementation model, test out guidance and tools.
3. Walk through[h] applying the implementation model to two sets of the NHS RHO's recommendations, to test validity.

We invited NHS RHO stakeholders to design workshops that included:

- arm's-length bodies
- experts in maternal and mental health
- ICBs and provider trusts
- NHS RHO Board members
- people with lived experience (patients and carers).

h The examples used for the walk through were the Review of Neonatal Assessment and Practice in Black, Asian and Minority Ethnic Newborns[16] and Ethnic Inequalities in Improving Access to Psychological Therapies (IAPT): Full Report.[6]

## 2.3. Qualitative research

We conducted two qualitative studies (semi-structured interviews and focus groups) to explore the perspectives and experiences of, and beliefs about, implementing NHS RHO recommendations for tackling structural racism. This included the gaps between evidence and practice. Both studies ran from June to December 2023.

All participants received an information sheet by email that explained the purpose of the study. They were asked to fill in forms with their demographic information and to give consent for their data to be used, before starting the interviews or focus groups.

We did not seek approval from a research ethics committee because this project was designed to be specific to the NHS RHO as a service evaluation/improvement/development project. This was determined following use of the NHS Health Research Authority ethics decision tool. The findings should not be generalised or transferred to other settings. The conclusions should also not be applied or transferred to other settings.

### 2.3.1. Interviews

Two NCCMH researchers (VP, AR) carried out 14 semi-structured online interviews with NHS RHO stakeholders between August and December 2023. Held over videoconferencing, the interviews were between 22 and 37 minutes long (average 27 minutes). Automatic transcripts were generated by the videoconferencing software. Transcripts were checked for accuracy by both researchers before analysis.

Participants were recruited using convenience sampling, due to the study time restrictions. The NHS RHO identified potential interviewees based on their involvement with the NHS RHO. Interviewees were then invited to participate by email by VP/AR. One person declined to participate because they felt they were too closely affiliated with the field and the NHS RHO.

The aims of the interviews were:

- To explore the barriers and enablers for interventions and mechanisms for change that have used an anti-racism approach.
- To understand the context, enablers and barriers for implementing recommendations developed by work commissioned by the NHS RHO.

Before the interviews, the topic guide (which can be seen in Appendix A) was tested with NHS RHO staff, and then refined as the study progressed. In the interviews, the topics covered included:

- examples of previous interventions and mechanisms for change
- the perceived barriers and enablers of these
- what implementation is
- factors that may impact implementation.

Field notes were taken during interviews. Interview transcripts were analysed by two NCCMH researchers (VP, HG) using the Rapid Research Evaluation and Appraisal (RREAL) approach.[17] This involved drafting and adapting RREAL sheets for the researchers to independently draw key themes and notes from interviews. One researcher (VP) then combined the two RREAL sheets.

Both researchers agreed on the final themes and subthemes, after the themes drawn from the interviews were mapped to those generated by the focus group analysis.

### 2.3.2. Focus group discussions

In November 2023, we ran two 1.5-hour focus groups over videoconferencing, with 15 people with lived and learned experience from across England. The focus groups were suggested by our lived experience researchers (IS, FM), who were recruited by the NCCMH. We were also advised to hold focus groups by the equality impact assessment[i] (EIA) that was conducted internally (Section 2.4).

The focus groups were co-designed and facilitated by lived experience researchers (IS/FM). One lived experience researcher was new to focus group methodology, and so was given training materials and support beforehand. They also shadowed a focus group before facilitating alone. In the focus groups, two NCCMH researchers (VP, AR) took notes of the discussion and gave technical support.

Participants were invited to take part in the focus groups by email. They were recruited using convenience sampling, and were a mix of attendees from this project's QI design workshops.

The aims of the focus groups were to:

- Better understand the needs, preferences and priorities of people with lived and learned experience for tackling structural racism.
- Explore perspectives that may support or challenge the implementation of interventions aimed at tackling structural racism.

i See the Glossary for a definition of equality impact assessment (EIA).

The focus groups covered four topics (see Appendix B for the topic guide):

1. Inequalities and inequities in healthcare
2. Implementation
3. NHS RHO recommendations
4. General reflections.

We sent the focus group questions to the participants by email before the groups took place, to give them time to prepare.

In the online focus groups, we made a virtual 'quiet space' for anyone who wanted to take a break from the discussion. A trained member of staff was in the virtual quiet space to give support. The staff member had a list of resources for support to share with participants, which had been co-developed.

Focus group participants with lived experience were offered an honorarium for taking part, as were our lived experience researchers who were involved throughout the research workstream. Honorariums were in line with the Royal College of Psychiatrists' patient and carer representatives' payment guidelines.

Focus group transcripts were analysed by the team (EC, FM, VP, AR, IS) using the participatory approach DEPICT.[18, j] This involved individual coding of transcripts, comparisons of codes in pairs and then as a group using Microsoft Whiteboard. We finalised the codebook and themes as a group using Microsoft Excel (see Appendix C for the codebook, showing themes, subthemes and codes).

j DEPICT = 'Dynamic reading, Engaged codebook development, Participatory coding, Inclusive reviewing and summarizing of categories, Collaborative analyzing, Translating'.

## 2.4. Equality impact assessment

We conducted several EIAs with the NCCMH Equality Advisory Group (EAG)[k] during project development, during scoping and early development (August 2023), during development (October 2023), and pre-consultation (January 2024). The EIA is designed to comply with the Equality Act 2010[19] and Human Rights Act 1998.[20] It assesses the consideration of equality issues, ensuring that project outputs (for example, documents that are produced, such as this report) do not discriminate against any groups with protected characteristics. EIAs assess that project outputs highlight planned areas of action relevant to equality, or where projects may advance equality of opportunity.

Feedback following the EIA resulted in a second lived experience researcher being recruited to the project team, the addition of focus group discussions led by people with lived experience, and the adoption of a participatory analysis approach.[k] Intersectionality was also raised by the EAG during the EIA and was a topic area explored during focus group discussions. We also adapted the support and engagement in line with findings from the EIA. Specifically, the focus groups included a light icebreaker to welcome people to the discussion, a quiet space for anyone who wanted a break and a resource list for support (for example, organisations and literature) on anti-racism work.

A copy of our finalised EIA can be found in Appendix D.

k See the Glossary for a definitions of the Equality Advisory Group (EAG) and participatory approaches in research.

## 2.5. Positionality statements

The NCCMH research team was made up of people with lived and learned experience in this area. Each produced a personal statement setting out their experience.

VP's statement is as follows:

*VP is a researcher who has a PhD in Public Health. Her background is in participatory approaches in research, and she advocates for co-production where possible in research. VP is a UK-born Greek Cypriot researcher and is aware of the intricacies of growing up in the multicultural city of London and in a community with a strong sense of family and traditions within her culture. Although VP has no direct experiences of racism herself, she is aware of those experienced by family members and has experienced microaggressions of having a non-English sounding name, being asked, 'Where are you really from?', and told that 'Your English is very good.' She acknowledges that these experiences will have shaped how the research was conducted and how the findings were interpreted.*

In the interest of openness and understanding, FM (lived experience representative) wished to state her position in relation to this project:

*FM is a woman from a multiethnic background, a person of colour with a religion that is in the minority. She was born and grew up in the UK. English is her first language. She is a social science and history graduate. She has lived most of her adult life in North Yorkshire. FM is a mother of three adult children. She is semi-retired and has worked as an administrator in education and the adult care sector. She is currently part-time self-employed in the car sales industry. FM sees herself as economically comfortable at this time. FM has regularly accessed the NHS as an unpaid carer looking after both persons of colour and White British. FM has accessed paediatric care when her children were young and has also accessed the NHS as a patient in maternity, general healthcare and cancer care. Throughout her life, FM has experienced racism many times, whether that be overt racism, unconscious bias or microaggressions.*

IS also wanted to share the following statement:

*My journey as a co-producer spans over 2 decades, enriched by a background shaped by overcoming various forms of disadvantage. Throughout my life and career, my focus has been on empowering individuals and communities to confront oppression, particularly related to race,[l] ableism and other factors such as socio-chemistry. I've played a pivotal role in creating platforms for people to share their stories to make positive change, with the goal of bringing about impactful change within support systems and society at large. Racial and social justice is more than a passion for me; it's a deep-seated commitment that guides my actions and what I do in life. As a disabled, non-binary person from a racialised background, I have faced many different types of oppression that have caused much harm. Through the work I do, I want to make sure this doesn't happen to others.*

l See the Glossary for a definition of race (and ethnicity).

# 3. Findings

## 3.1. Participant information and demographics

### 3.1.1. Design workshops

In total, 48 individuals attended the three design workshops. The number of attendees varied across the workshops (September n=37; October n=30; November n=26). This included (where data were available):

- 12 experts by experience[m]
- 11 NCCMH staff
- 6 maternal health experts
- 4 mental health experts
- 4 NHS RHO representatives (including staff and Stakeholder Engagement Group members)
- 3 representatives from arm's-length bodies
- 1 equality, diversity and inclusion expert
- 1 local authority staff
- 1 QI expert
- 5 people whose affiliation was not reported.

m The experts by experience had lived experience of cancer (n=3), maternal health (n=2), mental health (n=5), chronic conditions (n=1) and physical health (n=1).

### 3.1.2. Interviews

We interviewed 14 people, including:

- 4 NHS RHO Board members
- 4 NHS RHO Academic Reference Group members
- 4 Maternal Health Advisory Group members
- 2 Mental Health Advisory Group members
- 2 NHS RHO staff members.

Some interviewees had more than one role within the NHS RHO. The roles and responsibilities of the above stakeholders were explored in interviews. The roles of the NHS RHO Board, and the Reference and Advisory Groups, as well as the responsibilities of their members can be seen in Appendix E.

### 3.1.3. Focus groups

We also conducted two focus groups with people with lived and learned experience, facilitated by people with lived experience. There were six and seven participants in each focus group, all from England.

A summary of participants' demographic information is provided in Table 2.

Table 2: Summary of demographic information of focus group participants

| Demographic factors | Focus group participants (n=10) |
|---|---|
| Gender* | • Female (n=8)<br>• Male (n=3) |
| Ethnicity* | • Black British (n=1)<br>• Black British African (n=1)<br>• Black British Nigerian (n=1)<br>• Asian British (n=1)<br>• Black British/Caribbean (n=1)<br>• Bangladeshi British (n=1)<br>• Nepalese (n=1)<br>• White British (n=1)<br>• Mixed Indian and British (n=1)<br>• Dual ethnicity (n=1) |
| Region | • Yorkshire and Humber (n=3)<br>• London (n=3)<br>• South West (n=2)<br>• South East (n=1)<br>• East Midlands (n=1) |
| Employment status** | • Self-employed (n=4)<br>• Employed part time (n=1)<br>• Employed full time (n=3)<br>• Student full time (n=1)<br>• Unemployed due to disability (n=1)<br>• Homemaker (n=1) |

* Note that gender and ethnicity were both self-describe questions.
** Participants could select more than one.
We no longer have access to interview or design workshop data.

**Note on how we present our data**

In Sections 3.2, 3.3, 3.4 and 3.5, we present our findings from the interviews and focus groups. We refer to the data in the following way:

- Interviewee = interview data only.
- Focus group participant = focus group data only.
- Participants = both interview and focus group data.

## 3.2. What good implementation looks like

### Implementation needs to be iterative and measure change over time

Participants referred to the process of implementation as:

- an action that is adopted in practice
- having a comprehensive and sustainable roadmap
- having a monitoring and evaluation process (metrics, tools, resources and measurable changes).

Implementation tends to focus on the end goal; however, it must be thought through from the conceptualisation or beginning of any projects or initiatives.

Interviewees talked about how models and frameworks used in implementation science have identified the multiple layers and levels that may support or hinder implementation. Implementation must be based on evidence and theory.

> *The issue is, of course, that (...) we don't need to be doing this at the end of a study. Implementation is really vital from (...) conceptualisation...*
>
> **Interviewee A07**

### Implementation is about impact

Discussions also focused on the impact of implementation. For example, the impact can be seen in:

- changes in professional practice
- standards
- ways of working
- service outcomes.

Understanding the physical environment, the societal and political context, the individual motivations and the potential for the work can help identify possible collaborations and disagreements.

### Implementation must involve multiple diverse stakeholders

We also explored who should be involved in the implementation process. Interviewees and focus group participants said that the development of coalitions of willing implementation partners was essential to successful delivery. The partners that are involved would depend on the objectives of the project.

Examples of partners are:

- ICSs
- local authorities
- VCSEs.

Workforce representation and inclusion are also important, to make sure that community engagement is sustained over time.

To maintain anti-racism as a priority, leadership should acknowledge and recognise structural inequalities and discrimination with clear oversight, accountability and responsibility.

> *For me, implementation is how you transfer an intervention from evidence and theory into on-the-ground delivery, and delivery at scale to achieve the population health benefits that you wanted to achieve. Delivery is not just doing the intervention. The question is, are we doing it at the level which is required for it to have the intended impact on population health.*
>
> **Interviewee A03**

### Implementation needs to be sustained over time

Sustainability, embedding practice across levels, sharing good practice and learning were viewed as indicators of good implementation. This can be achieved by supporting leaders and organisations in delivery, and ensuring fidelity of interventions or mechanisms for change (that is, that they are implemented as intended). However, this is often a challenge in project-based work, because it may have funding that restricts sustainability.

## 3.3. Underlying evidence guiding the NHS RHO recommendations

Interviewees could identify various projects commissioned by the NHS RHO and carried out by expert organisation and academics, notably:

- Ethnic Inequalities in Healthcare: A Rapid Evidence Review[2]
- Ethnic Inequalities in Improving Access to Psychological Therapies (IAPT)[6]
- Pulse Oximetry and Racial Bias: Recommendations for National Healthcare Regulatory and Research Bodies[21]
- Review of Neonatal Assessment and Practice in Black, Asian and Minority Ethnic Newborns: Exploring the Apgar Score, the Detection of Cyanosis, and Jaundice[16]
- Sickle Cell Digital Discovery Report: Designing Better Acute Painful Sickle Cell Care[22]
- We Deserve Better: Ethnic Minorities with a Learning Disability and Access to Healthcare[23].

The evidence for the 'Pulse Oximetry and Racial Bias' and the 'Review of Neonatal Assessment and Practice' recommendations largely depended on US literature, due to the limited UK evidence base. Using international evidence can be problematic, however because populations are categorised in different ways.

## The level of evidence for recommendations varies

The evidence for some recommendations was clearer (for example, from randomised controlled trials) than for others. Therefore, there was a suggestion to be pragmatic (that is, practical and realistic) when developing recommendations – particularly when little evidence was available, or when correlations could be drawn rather than causal inferences made (for example, from survey data). One interviewee said there was an 'overwhelming' amount of evidence, whereas others were less certain.

> *The evidence is there, and that evidence shows that patients are disadvantaged, and are more likely to experience mortality, morbidity and [have] poor experiences. So, the evidence is there. It's the health system, those that are providing care, that needs to change. The evidence is overwhelming*
>
> **Interviewee B04**

Interviewees recognised that a range of evidence is used and accepted, such as systematic reviews, qualitative evidence, quantitative evidence and community-based research. They also recognised that recommendations target various stakeholders and parts of society, including:

- academic institutions (to influence funders and so on)
- general public (improving attitudes, awareness and understanding)
- national government.

Interviewees recognised that projects commissioned by the NHS RHO build on partnership networks and connections, for example with Royal Colleges and professional bodies. However, interviewees raised the point that underinvestment persists in research and other evidence, and in the action to address ethnic inequalities in health. This is despite the growing recognition of the importance of research, following George Floyd's murder, the Black Lives Matter protests and movement, and the impact of the COVID-19 pandemic.

> *Even though there's been a greater spotlight placed on tackling racial disparities in the national spotlight, there's still nowhere enough resources (...) allocated towards it.*
>
> **Interviewee A01**

## 3.4. The NHS RHO's role in implementation

The NHS RHO was described by a staff member as having a 'three legs of the stool' model for implementation (Figure 1), in which each of the three components supports the whole.

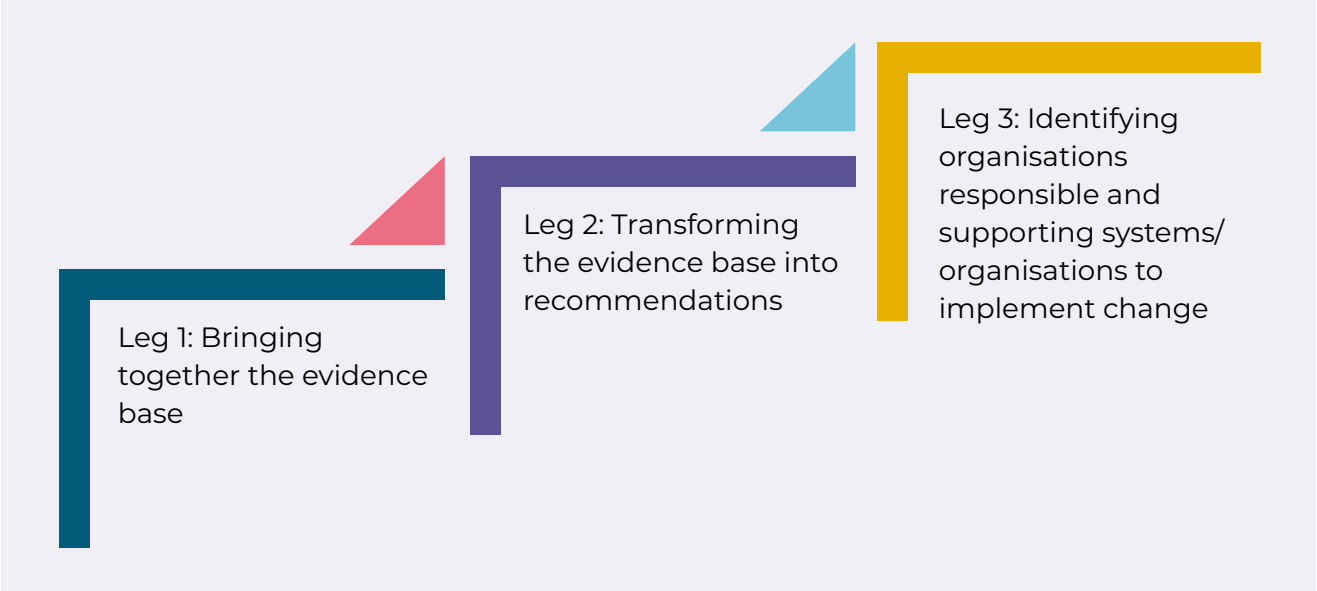


**Figure 1: The 'three legs of the stool' model (NHS RHO)**

Interviewees felt that the NHS RHO had excelled in raising the organisation's profile through publishing reports and reviews, and their presence in national and international media.

However, interviewees acknowledged the need to recognise how systems have cycles of change to ensure that engagement with systems, and what they are being asked to do, are at strategic time points.

> *Some things are not necessarily leadership questions, but questions about how do you get people who are closer to delivery (...) They could be commissioners of services. It could be senior midwives for our maternal recommendations. It could be primary care network leads for primary care related risk recommendations. Or it could be chairs and chief execs of hospital systems in regions, because we're looking for a system change.*
>
> **Interviewee A03**

Interviewees also felt that the NHS RHO plays an important role in bringing together important stakeholders. They felt that this should include those closer to delivery and responsible for system change (for example, chairs and chief executives). The NHS RHO has begun to hold follow-up roundtables after publishing reports, which could be a route to increase their influence and impact. Another example was to use routes and programmes that already have buy-in from the system, such as women's health hubs.[24]

The recommendations generated must be modifiable, impactful and adopted by organisations responsible for change. Therefore, developing recommendations in dialogue and consultation with a range of stakeholders ensures they remain feasible and relevant. It also allows organisations to assess expectations of what the recommendations are aiming to achieve, and the timeframe and process for them.

> *Thinking about other commissioners and service providers who don't obviously have a health 'hat' on, and especially when we're thinking about social determinants, there's a growing understanding in wider sectors (...) for example, poverty, housing organisations. So, there's opportunity to (...) implement some of their asks and collaborate with (...) not [just] the usual suspects in the space.*
>
> **Interviewee A01**

One limitation identified was the size of the NHS RHO and that a consultancy function may support implementation. The NHS RHO began conversations with partner organisations to discuss implementation models in the latter part of 2023.

One interviewee felt that the NHS RHO has a role in improving the implementation science behind anti-racism. The NHS RHO's role includes the application of implementation science to the NHS, and working to support the role of ICSs that focus on:

- anti-racism perspectives
- health inequalities
- productivity
- value for money.

Lastly, one interviewee shared that an ambition would be for there to be self-motivated (rather than mandated) community mobilisation and buy-in from individuals and organisations. They referred to a social movement to 'change hearts and minds' driven by a legal,[19,25] moral ('It is the right thing to do'), economic[26] and fundamental case to improve patient care and safety.

> *Implementation is about change. It's about (...) supporting leaders and organisations to think about and action what they need to do. And for [NHS RHO], it's about how do [they] support that in a holistic way that doesn't just focus on those individual metrics that need to close down (...) to reduce the inequality gap.*
>
> **Interviewee A06**

## 3.5. Enablers and barriers to implementation

We asked participants to reflect on factors that may act as enablers or barriers to the implementation of the NHS RHO recommendations, as well as on interventions more broadly.

Enablers and barriers may work across multiple levels – from system to individual. Through our participatory analysis, we identified five themes, which are underpinned by the principle of undoing harm:

1. The approach to implementation.
2. Leadership and buy-in at multiple levels.
3. An anti-racism approach throughout.
4. Co-production with people with lived and learned experience.
5. Experience of racism and discrimination in quality of access, treatment, care and support.

The themes and subthemes developed through our participatory analysis are included in Appendix C.

Some insights were shared about the development and running of the NHS RHO. They are shown in Table 3 and mapped to the five building blocks of implementation.

The themes can relate to the implementation of recommendations across multiple settings, including policy, research and clinical practice. Clinical practice was covered more than policy and research in focus group discussions with people with lived experience.

**Table 3: Opportunities and challenges for implementing the NHS RHO recommendations mapped to the five building blocks of implementation**

| Building blocks | Opportunities | Challenges |
|---|---|---|
| **Evidence/ interventions** | Focusing on data and evidence when developing actions and recommendations helps avoid entering a 'culture war' | Denial of racism in society and a lack of acknowledgement by leaders or organisations that racism is an issue |
| | Having a role advising researchers who are conducting primary research on which categories to use | Differences in data measurement, categorisation and reporting |
| | More frequent publishing of data on inequalities, to keep it at the top of the agenda | |
| | Being brave and bold in identifying issues for healthcare systems when conceptualising projects | Race intersecting with other protected characteristics (intersectionality) being used as an excuse not to act |
| **Context and the system** | The role of the NHS RHO in bringing together key stakeholders as a network, with a need to implement and collaborate with new partners beyond health and the NHS | External pressures affecting the NHS (e.g., industrial action, winter pressures, efficiency, waiting lists) |
| | Involving networks that already have the infrastructure and opportunities (e.g., Academic Health Science Networks), to support adoption and scalability | Institutions being scared to admit that there is racism within those institutions (e.g., the NHS and academic institutions) |
| | Involving and expanding international partnerships beyond academic to those delivering change on the ground | |
| | The murder of George Floyd and the ensuing protests steering institutions and individuals to want to make change | Lack of investment in research/ different types of evidence addressing ethnic inequalities in health, despite growing recognition (George Floyd's murder, for example, and the COVID-19 pandemic) |

| Building blocks | Opportunities | Challenges |
|---|---|---|
| | Partnering and working with people experiencing racism through building trusted relationships | People with lived experience being disheartened when they do not see any change |
| | Relationship-building with current and future political parties and leaders (e.g., if there is an upcoming general election, to put pressure on the government to prioritise tackling health inequalities) | Political and institutional bodies opposing recommendations |
| | Increasing the time for leaders to focus on and embed the inequalities agenda | |
| | Connecting with grassroots organisations, to enable cultural and societal change | |
| **Design** | Prioritising the recommendations, to support their implementation (phasing recommendations) | Some findings and recommendations being difficult to manage and monitor |
| | Mandating improvement in one or two measures around race and discrimination | Recommendations not being mandated centrally, leading to de-prioritisation or not being seen as important |
| | Exploring implementation and evidence generation concurrently rather than sequentially (taking a more integrated approach) | |

| Building blocks | Opportunities | Challenges |
|---|---|---|
| **Infrastructure** | Improving programme management and resources within the NHS RHO (e.g., creating the role of a director of implementation) | NHS RHO staff needing to be supported and not overstretched or overburdened |
| | External funding and investment on inequalities is growing – the competition may offer opportunities for implementation | Underinvestment in implementation capacity versus evidence generation capacity remaining a problem in the sector |
| | Having demonstrable senior leadership, ownership, problem solving and support for the NHS RHO from the outset (e.g., NHS England executives, strong representation of leaders on the NHS RHO Board) | Having unclear accountability for longer-term recommendations due to funding and sustainability of the NHS RHO |
| | The NHS RHO continuing to do well in raising their profile (e.g., in international and mass media) | People viewing work as 'outsourced to NHS RHO', and therefore not the only agents responsible for action |
| | Lobbying publishers, ethics committees and research funders to introduce more equitable and anti-racism approaches | Organisations focusing on productivity and process rather than quality and equity, and being led by denialism and lack of commitment |
| **Evaluation** | Organisations and individuals, both internal (e.g., individual performance and responsibility) and external (e.g., through regulation and at every stage) being accountable | People becoming apathetic to the cause when no change is seen |

## Theme 1: The approach to implementation

Discussions in focus groups and interviews reflected on the enablers and barriers to implementation. The first theme is the approach to implementation, which includes acknowledging racism exists and the methods used to approach implementation. The enablers and barriers are discussed under the following subtheme headings.

### Acknowledgement of racism

- Organisational readiness to hear the message, acknowledge racism and take anti-racism action (see also Themes 3 and 5). Acknowledgement involves:
  - recognising the different forms of racism that may exist, such as:
    - institutional
    - internalised
    - personally mediated
    - structural
    - systemic
  - acknowledging institutional racism in systems
  - ensuring that organisations are ready to accept and commit to anti-racism plans and actions.

  Acknowledgement is an essential step in undoing harm.

> *The recognition of systems that they may be institutionally racist or institutionally sexist or institutionally ableist. It takes time for organisations to hear and then to understand how they respond, and we've seen this with other organisations, not just the Metropolitan Police or the education system, the probation service etc. But, over time, we are seeing a drumbeat of a greater understanding and awareness.*
>
> **Interviewee A03**

One interviewee said that acknowledgement is about organisations embracing the principles of proportionate universalism.[n] A focus group participant referred to racism as still being a 'taboo topic' for some. Fostering open dialogue can help overcome those reservations, which can potentially have a positive impact on individuals and communities.

Interviewees also spoke about institutions being 'scared' or not ready to admit that racism exists in their organisations.

> *The institution itself is scared. I have this with my own institution, where, doing the work I do, I talk about the institution and racism within the institution. So, institutional racism and what we could do to change it, and the leaders of the institution, who I know well, [they] really don't want to talk about these things. It's too scary...*
>
> **Interviewee A02**

n See the Glossary for a definition of proportionate universalism.

### Data collection, quality and evaluation

- Understanding the problem and factors affecting solutions through good quality research processes and requirements that support implementation using data and theory-based interventions (for example, from evidence reviews). This includes:
    - Understanding the current system. This involves the organisation, current ways of working and the societal and political context. These should be understood before implementation, as well as identifying what will and will not motivate people to change or implement new ideas. This could be achieved by listening to front-line staff and by understanding daily realities; this can help to build trust, buy-in (see also Theme 2) and support to deliver culture change.
    - Understanding the causes of the problem (different forms and levels of racism) and the impact of it, and exploring possible solutions working in partnership with key stakeholders including people with lived experience (see also Theme 4). Often, if interventions address a problem or outcome but do not address the underlying cause, issues will continue to arise in other forms.

> *Particularly where issues of inequality have been addressed, there has been the emotional connection. [It is] based on either immersing yourself in the realities that people living with said inequalities have to go through, [and] having a better sense, and insights into the way that individual organisations can intervene. And the fact that they have agency, because sometimes we just don't talk about it.*
>
> *Interviewee B02*

    - Considering different levels of an intervention and shifting away from individual to structural levels (for example, communities, workforce, institutions, policy and so on).

However, a lack of research on and knowledge about implementation, as well as gaps in evidence and data, were raised as potential challenges to the implementation of anti-racism interventions and mechanisms for change. One interviewee felt that an emotional response is 'no longer suitable' and, instead, commissioners need clarity on the expectations and actions, including training and development for systems (although this view was not shared by all).

Other issues raised included:

- No clear definitions of equity – one interviewee raised that this is a philosophical position, 'not just down to fairness'.
- Inconsistencies in data recording, categorisations, classifications and measurements of race, ethnicity and culture, which can delay processes in research (for example, using religious affiliation rather than ethnicity). This also results in an inability to measure change.
- Variations in social construction of terms can reduce the ability to influence commissioners and the wider public.
- There is a lack of research carried out with people from racially minoritised communities[o] for whom English is a second language.
- Some people argue that using qualitative or 'conversational' data that highlights the impacts of racism and marginalisation makes it difficult to track the impacts and outcomes on health and wellbeing. However, one interviewee said that this reasoning was being used as an excuse to not make changes, with some forms of knowledge being viewed as more important than others.
- Lack of expertise and experience in implementation.
- Being selective and driven by the political landscape when deciding what evidence is used to influence policymakers.

> *Deprivation (...) tells you where the inequality exists, but not necessarily **why** it exists. Therefore it's critical that we focus on these issues (...). I guess we find ourselves at a crossroad on whether (...) commitments [made during the COVID-19 pandemic] will be taken forward and seen through or not. And so it's important that we continue to focus on this agenda and we can continue to (...) support and resource tackling inequalities by focusing on the causes.*
>
> **Interviewee A06**

This enabler relates to how any culture change must be linked with data. The data should show whether interventions are making a difference and whether they have been actioned.

Implementing policy is often steered by people who are already well-informed (for example, members of grassroots or user groups). Interviewees felt this is often at odds with 'lip service' paid in equality programmes as well as concerns about taking resources away from others.

o See the Glossary for a definition of racially minoritised community.

However, the external environment can act as a barrier, for example:

- Financially competitive landscapes hinder collaboration efforts, for example, short-term charity funding hinders charities being able to plan strategically, maintain and grow services (although one interviewee felt that competition could offer opportunities for implementation).
- Political 'turbulence' can challenge implementation objectives relating to policy change. Another example given was of the 'political dissonance' and apathy towards providing resources and funding to causes for racially minoritised communities and refugees.
- Variation in political support (for example, from a political leader or party) shifts the priorities in the work to be undertaken. External political factors, such as austerity, can influence funding, resources and the physical spaces available.

> *The external environment has been massively turbulent and disruptive for the [charity] sector as a whole.*
>
> **Interviewee A01**

- 'Top-down' structures and overstretched staff due to workforce shortages (particularly in the NHS), can challenge the anti-racism priorities of individuals, and result in tokenism. Participants related this to current workforce capacity issues due to industrial action, winter pressures and so on.
- Blaming communities for structural racism, and 'gaslighting' them.
- Lack of acceptance and denial of the existence and impact of racism.
- Reluctance to set targets.

### Managing and setting expectations and direction

From a programme management perspective, enablers for interventions and/or mechanisms for change were described as focusing on QI relating to time, planning and process. These are summarised in Figure 2.


**Figure 2: Components described by participants for managing and setting expectations and direction in QI work**

Participants shared that these components enable projects to gain traction and drive change, and show a commitment to anti-racism work (see also Theme 3), which could then be prioritised by stakeholders. Interviewees emphasised that budgets and milestones should not be the only factors to dictate delivery, as these can challenge the overall goals of the work.

Focus group participants raised the point that the pace and speed for change can affect people involved (for example, people with lived experience, workforce, leadership), particularly when expectations about progress are not met. These people need to have 'bought in' for change to happen (see also Theme 2). Change can also be difficult to navigate in complex systems like the NHS, and systems need to be ready for change to support implementation.

- A more integrated approach to implementation evidence generation (concurrently rather than sequentially) may also overcome issues to implementation.

For example, one interviewee felt that focusing on data and evidence when developing actions and recommendations can help to avoid a 'culture war' and instead justify being led by the data. Additionally, one interviewee described how information is often known intuitively, but without evidence and data this can be difficult to prove to commissioners.

> *Along with that cultural change celebration of when it does work....[it's] actually holding people to account for anti-racism.*
>
> **Interviewee B03**

> *You have to really bring the workforce along with this implementation. Please do not just do it **to** them, bring them along. And hopefully that way, we get the outcomes that we want to see.*
>
> **Lived Experience 11, Focus Group 2**

> *That more integrative approach is more intensive, and it may mean that we do less in terms of evidence generating reports. But we do so with fewer, much more impactful, much more pathway approaches to (...) achieving change, and that would ultimately result in greater impact.*
>
> **Interviewee A03**

## Resources

- Unrestricted funding rather than ringfenced funding, as well as specific funding streams for knowledge translation and implementation, would support efforts.

Traditionally there is an underinvestment in implementation compared with evidence generation capacity. Dissemination is often done in an individual's own time and with no additional funding.

> *Any implementation going forward is going to be a challenge because of the so limited resources that many of the organisations are facing. I just can't get beyond that.*
>
> **Lived Experience 9, Focus Group 2**

✦ **Example of good practice:**

The Canadian Institutes of Health Research (CIHR) has stand-alone funding streams for implementation (or knowledge mobilisation), unlike the UK which focuses on research.

▲ **Example of experience:**

Research conducted by The Ubele Initiative showed that 9 out of 10 Black, Asian and minority ethnic-led charities were likely to be forced to stop operating after the first 3 months of COVID-19 pandemic restrictions due to lack of resource, which would prevent 15,000–20,000 people per week from accessing services.

- Short-term funding disproportionately impacts smaller organisations (for example, charities).

It was discussed that short-term funding cannot deliver change or get to the root of issues, and it can lead to concerns over quality and assurance, and the sustainability of projects. For example, staff turnover and policy changes can affect an organisation's ability to measure change over time. One interviewee felt that larger charities working in anti-racism 'may not have done as well' as smaller charities.

However, one interviewee described that finances were not a barrier but rather 'it is more about human behaviour'.

There were also concerns that limited resource may mean taking resources away from others to address inequity, which people are often reluctant to do.

> *Because they [NGOs, VCSEs, small enterprises] don't have core funding and rely on local government or local NHS to provide them with short term funding, it becomes very difficult to plan strategically and to maintain and grow services.*
>
> **Interviewee A02**

> *The money is there. Where are people choosing to put the money? We have to find ways [...] for [that money] to be spent equitably. Because [...] if we disadvantaged somebody in one area, the need will show up elsewhere, probably multiplied.*
>
> **Interviewee A08**

## Learning community and network

Participants described best practice in model delivery as being place-based, tailored to the setting/region, integrated through outreach and as using an action learning[p] approach.

Specifically:

- Local, place-based approaches shift from national to local community models that have local support. Local support can be targeted and more effective when it has clear ownership and increased sensitivity to questions of racism. However, conscious efforts need to be made to prevent a postcode lottery.
- A tailored, multifaceted, multicomponent, multilevel and integrated approach through outreach across settings and regions can ensure that people are targeted using a whole-system and accessible approach (for example, considering language and wording,[q] literacy levels and so on). This approach takes into account regional and local nuances and provides opportunities to join up related programmes and efforts to remove duplication and wasted resource. Such an approach may also make it more likely that interventions are sustained.
- Action learning approaches: ensure processes are iterative, by working with funders and commissioners to develop a roadmap of actions, which is an ongoing process.

However, one interviewee felt that some models do not address structural drivers (for example, serious youth violence in Chicago).[27] They explained that raising awareness may not necessarily affect change, which can be due to unsuccessful implementation of the model, the model not being focused enough or fit for purpose, or aiming only to raise awareness rather than make a change.

> *I think the model needs to be able to be flexible. It needs to be able to flex to regional differences [...]. The model needs to be able to flex depending on the actual needs of the [...] institution.*
>
> **Lived Experience 5, Focus Group 1**

> *Centrally driven interventions have been ineffective because they haven't focused on the institutions that they were targeted at. So, they offered stuff to institutions without actually thinking about the ways in which institutions functioned.*
>
> **Interviewee A02**

p See the Glossary for a definition of action learning.

q In both focus groups, there was silence when the topic of implementation was first raised. Facilitators offered prompts, to encourage participants to share their perspectives.

## Theme 2: Leadership and buy-in at multiple levels

The roles of leadership and buy-in across multiple levels were described as both barriers and enablers to implementation. The enablers and barriers are discussed under the following subtheme headings.

### Undoing harm

On attitudes and understanding around racism, privilege and inequity, the following examples were shared:

- People's lack of response to the issue, and providing evidence of what works and doesn't work, can make people feel disheartened and apathetic (described as 'learned helplessness' by Interviewee A03).
- Denial of racism in society, challenging narratives that have been reinforced by the media, and a lack of acknowledgement by leaders or organisations that racism is an issue.
- Apathy from people on the ground towards anti-racism work.
- 'Culture wars' and framing the tackling of racial inequalities as 'a good thing for everybody' are political and ideological issues.
- Fear of repercussions from raising concerns about racism, and experiences of microaggressions and moral injury.
- Institutions (for example, the NHS and universities) that are scared of racism need to do groundwork, if racism is part of the institutional processes and norms.
- Stereotypes may be barriers: there is a need to challenge assumptions, stereotypes and bias (for example, CBT was seen to have Eurocentric aspects, such as individualism, which may not be appropriate for people from collectivist cultures).
- Leaders may be driven by their own ego, power and so on, and leaders are not held to account (only personal determination keeps this at the top of the agenda).

> *We still live in a society that denies racism is an issue [...]. We're kind of going against the grain [...] with the work that the Observatory does. Just because [...] people think it's a bit of a non-issue, and they pay lip service to it when there are deaths in the media... how do we win the hearts and minds of society?*
>
> **Interviewee A01**

> *If you're coming from a place of individual privilege to be able to take people along with you on that journey in ways that are meaningful, that challenges but supports change. Then that holds everybody to account to do it. So, although the focus is on the structure of racism and organisations, there's an individual component that we also need to understand how best we do that as well.*
>
> **Interviewee A03**

- 'Watering down' of cultural competence and safety.[r]
- Lack of confidence and the fear of being perceived as racist.
- There is more willingness to tackle and discuss individual than structural racism.
- Individuals and institutions need to keep up to date with the latest research.
- Racism can be a difficult and emotionally charged topic to discuss and work on.

> *Just having a government that doesn't really accept that racism is an issue [...] makes it hard to [...] convince decision makers.*
>
> **Interviewee A01**

### Accountability for implementation

The following were seen as important aspects of being accountable for implementation:

- Oversight and accountability of senior leadership in health services/commissioners with community leaders and political leaders. Examples include:
  - Clear roles and responsibilities of leaders, managers and wider workforce.
  - Identifying and having responses to 'frequently raised objections'.

> *At the moment, implementation is half-hearted because there isn't the resource to follow it, either financially or in terms of human resource. And I think it's half-hearted because not all layers of the system – that's looking at NHSE and senior management, down to director-level, management – have really bought into this being an important agenda.*
>
> **Interviewee B01**

  - Work may become deprioritised when it is not centrally mandated and when there are no consequences if changes are not achieved. Therefore, mandatory standards and performance measures (for example, part of Care Quality Commission [CQC] assessments and ratings) should give a clear reason to prioritise action, with consequences for failure to meet standards and ongoing reporting.
- Clarity on what is expected from leaders and staff including governance and how strategy is to be delivered. One barrier that was shared was:
  - Ethics committees not challenging the relevance of populations in research and the accessibility of the study (for example, relating to language).

r See the Glossary for a definition of cultural safety.

- Enabling a sense of responsibility at all levels of the NHS workforce. This could be achieved by, for example:
  - Motivating clinicians and services to take pride in their service and be competitive about achieving success, by linking the tackling of inequity to a measure of success for individuals and services.

### Culture change

The following points were made in relation to culture change:

- Organisations are productivity- and process-driven rather than quality or equity driven, and are led by denialism and lack of commitment. One barrier shared was:
  - Regulators (such as the CQC and ICBs) focusing on whether there is an issue with assessment processes often overlook or choose not to do anything as this is 'too difficult'. There may be a cycle of denial (for example, denial by regulators who may then be criticised by providers who are also in denial).

> *The NHS is embedded within a broader society, isn't it? While we're constantly bombarded with messages that tell us that migrant and, by association, UK born and bred [...] minorities are not entitled [...]. That's a really dominant narrative everywhere, so it's quite hard for [...] people not to be influenced by that.*
>
> **Interviewee A04**

> *They might say, [...] 'Oh yes, but just because that worked in that context – our context is rather different, so we can't really extrapolate from that evidence over there.' So [...] it's just watching out for these different ways in which people will block.*
>
> **Interviewee A04**

- Values-based and committed leadership that encourages creativity, health and wellbeing and recognises individuals and their skillsets (for example, equality, diversity and inclusion) and a tone of leadership that fosters an environment of safety. Examples include:
  - Role modelling by senior staff to have impact on those more junior.
  - Acknowledging hardship, and accepting and admitting that racism, discrimination and bias exist in an organisation, and that they will affect staff and patients.
  - Taking time to get on-the-ground experience through outreach beyond the boardroom.
  - Building in time to understand the values and beliefs of the workforce and what the challenges are.

There is a moral and emotional argument for this type of leadership. Aligning and framing this work with issues and ideas that people feel strongly about may motivate action (for example, making it a safety concern or emphasising the financial cost of racism).

> *I think the NHS is special, but at the same time it doesn't always behave itself and stand up to its values [...]. That's where my relationship with it is changing.*
>
> **Interviewee A08**

- Ensuring equitable and anti-racist workforce recruitment, training and skills development. Examples include:
  - Raising minimum training standards to tackle structural issues, including encouraging continuing professional development, supporting people to undertake Master's and PhD degrees, and training in equitable recruitment practices.
  - Including anti-racism work in staff appraisals.
  - Giving people mandated time and space to reflect with peers/other staff (for example, managing shame and White fragility)[s] and raise awareness about racism and ethnic inequalities.
  - Equipping individuals with the knowledge and skillsets to lead projects, and creating opportunities for people from racially minoritised backgrounds.

> *If we look at [...] the NHS and [...] who is in the leadership roles, in the higher-paid leadership roles, it isn't equal. When you're leading people that are diverse you need diverse leaders, and [...] diversity [...] improves outcomes and saves lives.*
>
> **Interviewee B04**

### Engagement, empowerment and advocacy

The 'stakeholders' referred to in both interviews and focus groups included senior leaders of organisations (for example, NHS and VCSE), experts with lived experience including carers and loved ones, workforce (for example, VSCE) and broader communities. The following emerged from discussions about engagement, empowerment and advocacy:

- Individual-level advocacy/ influence to raise awareness and general dissemination.
- Using an upcoming general election to influence government to prioritise tackling health inequalities including relationship-building with current and future political parties/ leaders.

> *It's not [that] these communities are 'hard to reach'. We're not reaching out hard enough or going to the spaces and places that they frequent.*
>
> **Lived Experience 6, Focus Group 2**

s See the Glossary for a definition of White fragility.

> *Sometimes [...] the ability to bring about impactful change is governed by [...] what's happening now, and there may be more... direct governmental influence that needs to take place [...] for things to change.*
>
> **Interviewee A07**

## Theme 3: An anti-racism approach throughout

An anti-racism approach was a core theme across interviews and focus group discussions. Principles of anti-racism that emerged from the discussions are organised under the following subtheme headings.

### Undoing harm

The following point was considered to be crucial in adopting an anti-racist approach that undoes harm:

- Understanding organisations' contexts and foundations before implementation to understand if they are realistically ready and, if not, having a more fundamental re-think about how they operate and how they could develop an anti-racism approach.

> *This is in part about leadership of institutions owning the problem and being involved in the design of the solution. Another part of it is the people on the ground... being [...] mobilised. Inspired. Also owning their contribution to the problem and what can be done about it.*
>
> **Interviewee A02**

The first step for any organisation is to admit and acknowledge racism, and to challenge narratives that perpetuate racism. This includes the different forms and definitions of racism.

This approach appreciates and recognises that inequalities that are operationalised are not stand-alone issues but are part of the wider context and practices of an institution. This may relate to the values within an organisation but also to difficult, first-hand experiences (see also Theme 5) of those accessing or providing services.

### Actions by healthcare providers

The following were deemed important actions by healthcare providers to take when developing an anti-racist approach:

- Building trust with communities that have been historically exploited, underserved and oppressed.
- Reorienting services to serve the needs of racially minoritised communities through inspiring and mobilising people on the ground to improve experiences of healthcare. It emerged from discussions that this could be achieved by:
    - Shifting from punishment and coercive mental health care to compassionate care (or cultures of care)
    - Establishing health institutions within a community framework (for example, in Boston, USA)[28]
    - Increasing diversity in the workforce

- Considering the role of other factors such as gender, social class and deprivation and how these may intersect with racism (see also Theme 5).

**▲ Example of experience:**

COVID-19 highlighted inequalities in outcomes among racially minoritised communities related to multigenerational households, front-line racially minoritised staff, comorbidities etc.

- Providing culturally competent, person-centred care that is sensitive to differences across cultures, and demonstrates understanding and an openness to learn. This includes respecting the knowledge of carers who advocate for culturally appropriate care for their loved ones, ultimately ensuring that people have autonomy over their own care. Examples include:
  - For families from racially minoritised communities, offering parents the correct screening tests for their newborns (for example, for sickle cell and thalassaemia).
  - The role of social prescribers in being culturally competent, 'doing their research' and making culturally sensitive,[t] tailored suggestions for social activities for individuals.
  - Ensuring accessibility of services and treatment (for example, where English is not a first language).
  - Equitable treatment options that take into account specific needs of communities (for example, diets suggested for diabetes management).
- Ensuring that workforce training and competences are developed to reflect on biases and resistance to change. This includes people understanding what racism and privilege mean, challenging perceptions, assumptions, prejudices and bias, and identifying how these impact practice. This involves encouraging the workforce to support and sustain a culture change.

**✦ Example of good practice:**

Barbers Round Chair Project by Islington Council – barbers are trained as community mental health ambassadors, 'to support conversation about mental health' and combat stigma.

*I'm changing my position now, which is [it's] not my responsibility to help you manage your shame or fragility because it's not about you. That's a separate space you need. This is about the people in the communities.*

**Interviewee A08**

*Basic training for everyone, from the top to the bottom, before their job starts. Some sort of guidelines. Because unless and until the job insists on not being racist, I don't think anyone will take it seriously.*

**Lived Experience 2, Focus Group 1**

t See the Glossary for definitions of cultural sensitivity and prejudice.

### Accountability for implementation

The following were seen as important aspects of being accountable for implementing an anti-racist approach:

- Campaigning and advocacy work by organisations and individuals to exert pressure and advocate for the demands and unmet needs of racially minoritised communities. Examples of this work include:
  - Individual-level advocacy/ influence to raise awareness (see also Theme 2)
  - General dissemination of best practice (see also Theme 2)
  - Authentic and values-based leadership (see also Theme 2).
- Adapting and staying flexible in one's approach.
  - Sophisticated and nuanced interventions require buy-in from stakeholders but also flexibility to be adapted as and when required.

> *We need organisations and people to focus on this agenda because they want to, not just because they have to as a result of regulation, assurance or contract. [For] changing people's hearts and minds... getting that social movement is absolutely critical, so accountability is important.*
>
> **Interviewee A06**

## Theme 4: Co-production with people with lived and learned experience

The principles of co-production, partnership working and collaboration were core features of interviews and focus group discussions.

Participants recommended that the principles of co-production should be met for true collective ownership by all stakeholders in the development and implementation of an intervention.

The discussions are summarised under the following subtheme headings.

### Who is involved

When thinking about whom to involve, there were the following considerations:

- Foster supportive partnerships and collaborations with all stakeholders from inception: this includes writing bids or grant proposals, intervention design, employing people with lived experience as co-producers to sit on programme management boards to support decision-making (co-production).

> *Having workforce and leadership and community engagement feeding into each other. Having the funding to cover it. Then each of the different sectors flows from [...] that [implementation] framework.*
>
> **Lived Experience 7, Focus Group 2**

This may also include developing coalitions of willing/implementation partners, considering the context and specific objectives of the work (to identify which organisations/ individuals to involve and how), as well as collaborating with the health and other sectors.

- Steering groups should be diverse with a range of partners representing all stakeholders at all levels, rather than be tokenistic in nature (for example, by relying on one person to be the only representative of a population).
- Include those who may have a critical voice.

*The NHS is awful. It gets one person of colour and says, 'This is my/our token person'. And that's it. God forbid they open the space to anybody else, and I've seen that happen.*

**Interviewee A08**

✦ **Example of good practice:**

Good practice example: Integrated Knowledge Users (Canada) who are people who will embed knowledge at the end of a programme including people with lived experience and policymakers. Integrated knowledge users help with implementation as they are involved from the outset of work and contribute to the evolution of a research pipeline. They are a requirement of funding by the Canadian Institute of Health Research.

*Once you have good evidence on the problem and the nature of the problem, and you're willing to explore and redefine the nature of that problem in partnership with other people, and then explore solutions in partnership with other people, then you can begin to implement actions that can produce change.*

**Interviewee A02**

### How they are involved

Involving others requires that there is:

- Enough time for co-production and co-designed solutions, leading to shared decision-making, purposeful actions and community ownership of community responses.

  This is particularly important for communities that are historically underserved and with whom trust and relationship-building are vital. A Delphi exercise[u] may be helpful to build consensus about how issues should be approached.

✦ **Example of good practice:**

The NHS RHO includes people with lived experience as co-chairs on working groups.

*Any good implementation [will] work [if it] isn't centred around your perception of the community [but] for the community's perception of itself.*

**Lived Experience 7, Focus Group 2**

u The Delphi method is a structured way to capture opinions from multiple experts and generate a consensus on a topic using a series of questionnaires.

- An increase in the power and influence of those with lived and learned experience by encouraging their involvement and engagement, which will ultimately inspire people to believe that change will happen and can be the most important legacy.
- Acceptance, accountability, and involvement of senior leaders (for example, clinical directors) who want and are required to see change and those on the front line to understand day-to-day realities – this can drive buy-in and provide support to deliver culture change (see also Theme 2).

## Theme 5: Experiences of racism and discrimination in quality of access, treatment, care and support

Focus group participants shared examples of racism and discrimination in healthcare and beyond. They felt that people with lived experience must be involved in sharing their experiences of racism and discrimination in healthcare and other sectors, for example in education and employment. This theme, however, was spoken about more in focus groups than interviews because it was one of the aims of focus group discussions. The discussions are summarised under the following subtheme headings.

### Causes of structural, institutional and systemic racism in practice

Participants suggested reasons why racism exists in medical practice, including:

- structurally rooted and colonial narratives in medical education, training and resources (for example, using Apgar scores for jaundice)
- environments (for example, regional differences in care) and culture
- individual experiences (for example, biases, perceptions, prejudices and assumptions).

Focus group participants suggested that structural racism could be challenged through the education system. Schools and other places of education could create space for students to practise self-reflection and question their own (implicit) biases, and could use educational materials and open dialogue.

### Experiences of racism, discrimination and oppression in healthcare, from point of entry

In the interviews, examples were shared from the literature, including:

- differences in the length of time to access pain relief[29]
- premature deaths (for example, of people with learning disabilities in East London[30])
- Black women's mortality rate being four times greater than that of White women during pregnancy or within the first 6 weeks after childbirth
- other published findings by M-BRACE.[31]

In the focus groups, an experience relating to pain was also shared:

**Example of experience:**

*When my cousin was in a very serious situation and needed a Caesarean [...] she was denied pain treatment as a result of the colour of her skin, I can only assume. When we as a family tried to intervene [...] we were called aggressive, and security was called. My husband is White, and when he intervened there was such a different response.*

Lived Experience 8, Focus Group 2

One interviewee provided an example from a news article on instances of microaggression whereby Black and Brown people were told to 'adopt a Western work name' so that their colleagues could pronounce it.[32]

One person who was interviewed spoke about ethical dilemmas they had experienced at work, when raising concerns about outreach with minoritised communities had led to them experiencing tension and microaggressions.

*Some don't believe that they are discriminating against anybody. So [...] a barrier is the lack of acknowledgement. And disbelief and racist behaviour. That is a barrier to improvement, because there are some that will never allow – and they can be very covert with their [...] actions – they will never allow there to be equity.*

**Interviewee B04**

One focus group participant shared their negative experiences of primary care and mental health services, where clinicians had made assumptions and judgements about their background and confronted intracommunity racism:

**Example of experience:**

*For me, the most racism I've received has been from South Asian consultants, be it within the mental health system or within the GPs. And other [...] clinical settings. It is almost that they will not leave their vices at the door. So, when I'm explaining what I'm going through, how I'm feeling, etc. [...], everything is dismissed because I'm a person of colour – as are they – and 'as a South Asian', I should just 'suck it up, get on with it... go home...'. That is the experience I have had, many times, especially with the mental health system.*

**Lived Experience 4, Focus Group 1**

### Past experiences shaping current experiences and perceptions (emotional toll)

In focus groups, participants linked past experiences of racism in healthcare with their current emotional responses to healthcare systems and professionals. This had led to people feeling disappointed, frustrated, unheard, undermined and devalued.

Examples shared included experiences of:

- microaggressions
- White privilege[v]
- conscious and unconscious bias.

v See the Glossary for a definition of White privilege.

Here is an example of a microagression experienced by a focus group participant:

**Example of experience:**

*Just 2 to 3 weeks ago, I went to take my father's medicine from the pharmacy. I was in the line, like everybody else, and the line was very long. The pharmacist was handing out the medications for other patients who were well, not my colour, and she was asking them to check [...] the prescription, if the address is correct. She was handing the medications out in that manner – the address was written on the box [...]. I expected [...] that she would ask me a similar question [...]. However, it didn't happen like that. She was asking me to write the address down on paper and give it to her, which I did. And I showed her that I wasn't an invader in my own address. Then, after some time, she handed me my father's prescription medication. There was [a] difference in her way of handling how to give out the medication which [...] I felt was very prominent [...].*

**Lived Experience 2, Focus Group 1**

Another focus group participant with lived experience also shared how a medical professional had made an assumption about their culture and relationship dynamics due to their ethnicity and religion. This had made them feel devalued and othered:

**Example of experience:**

*When I was having my examinations, when I was going through the [...] treatments for cancer, [...] I was in the room with a South Asian registrar and my husband. My husband was the one that was addressed [with] the questions constantly, always. He was even asked permission if he [the registrar] could touch me, to examine me. My husband was absolutely incredulous about it. He couldn't understand why the registrar was talking to him about my health issues. That really struck a chord with me. [...] Being from a Jamaican culture and having been able to strike out for myself and be independent, I was shocked and surprised.*

**Lived Experience 5, Focus Group 1**

There were also concerns raised about people's first interaction with health services being negative and how this may then have longer-term negative implications:

**Example of experience:**

*The first barrier when it comes to healthcare is [...] even stepping into the doctor's reception and trying to get your point heard. And [...] getting the sense and the feeling that because of what you look like or who you are, you're not being listened to in the same way the next person's being listened to. I've had experience of that on multiple occasions [...]. It's not just being what we're doing now, it's what happened in the past and how that influences what happens in the future, and also where we start with [...] accessing our health care.*

**Lived Experience 5, Focus Group 1**

## Intersectionality

Intersectionality acknowledges the complexity of people's individual narratives.

In focus groups, participants spoke of intersecting issues between race, gender, ethnicity, sexuality and religion. Intersectionality was raised in relation to people's experiences, but it could also be related to implementation. However, one interviewee described a perceived tension with intersectionality and felt that this may draw a focus away from race.

*Another thing that people need to be learning [about is] this growth in the focus on intersectionality. Intersectionality is an important conceptual tool, but the problem is it often leads to people arguing [that] 'well, everybody is disadvantaged in some way', and it waters down the focus on race. So, they end up with nothing being tackled properly.*

**Interviewee A04**

# 4. Discussion

## 4.1. Findings

Our findings align with those from the NHS RHO rapid review;[2] however, our findings also emphasise how an anti-racism approach should feature in implementation work. We found that good implementation:

- is iterative
- is impactful
- measures change over time
- involves diverse stakeholders
- is sustained through shared practice and learning
- must be considered from conceptualisation.

Interviewees acknowledged that NHS RHO-commissioned projects built on their networks and their connections with influential stakeholders. Concerns were raised over how evidence and research is prioritised, and over sustainable funding in anti-racism work. Interviewees reflected on the strengths of the NHS RHO in partnership-building and raising its profile. They suggested that the implementation of anti-racism programmes should be developed further. They also suggested that recommendations are developed that consider the cycles of change across systems.

We identified five main themes that influence implementation, all underpinned by the principle of undoing harm:

1. The approach to implementation. In good practice:

- racism is acknowledged
- projects are evidence-based
- projects have a clear vision and realistic milestones
- people are brought along with you
- stakeholder expectations are managed
- methods for implementation, such as QI, are used
- resource constraints are considered
- a learning community and network is created.

2. Leadership and buy-in at multiple levels. This can:

- create accountability for implementation
- contribute to a culture change
- ensure stakeholders, including advocates, for anti-racism programmes are engaged and involved.

3. An anti-racism approach throughout. This ensures that organisations are ready to be accountable for undoing harm. It requires that healthcare providers build trust with communities and redirect services to communities with unmet needs to provide culturally competent care. Workforce training, development and capacity-building are important, as is accountability for implementation (by maintaining flexibility and advocacy work by individuals and organisations). Core training for mental health professionals should embed an anti-racism approach.
4. Co-production with people with lived and learned experience. This includes supportive partnerships and collaborations with all stakeholders from the start, including people with critical voices. Co-production needs sufficient time to increase the power and influence of those involved, and bring in the acceptance, accountability and involvement of senior leaders.
5. Reflecting on experiences of racism and discrimination in quality of access, treatment, care and support. Past experiences shape our perceptions and views of the present, so undoing these harms is an important first step. Intersectionality can also play a significant role for some people who experience racism. Experiences of different forms of racism (for example, structural, institutional, personally mediated/interpersonal) can have long-standing effects and lead to intergenerational trauma. The first step to any anti-racism work is to undo harm by acknowledging racism. It is important to remember that racism leads to oppression, discrimination and inequities, and poorer outcomes including increased morbidity and premature mortality.

## 4.2. Reflections of lived experience researchers

Table 4 shows the reflections of our two lived experience researchers on this project.

## 4.3. Next steps

Throughout this project, we worked as a group of people with lived and learned experience to develop the Toolkit for the NHS RHO to aid the implementation of recommendations for anti-racism and anti-discrimination in healthcare, with research supplementing our project.

The suggested next steps for the implementation phase of the NHS RHO are mapped to the five building blocks, and are shown in Table 1 in the Executive Summary. Co-production is an essential part of these next steps.

Table 4: Reflections of lived experience researchers

| | Reflections |
|---|---|
| **What does it all mean?** | Whole thing has to feel genuine – starting with understanding definition, highlighting this is about racism.<br><br>Making a bold statement and working on a notion of structural ideas in systems and people and history that we need to keep in mind and undo.<br><br>Be clear on the actions across the themes.<br><br>Racism leads to oppression and discrimination – say this up front.<br><br>Buy-in may look different across the contexts – refer to where it is given, e.g., individual buy-in (thoughts and thinking); workforce buy-in (everyday practice/on the ground and leadership); and lived experience/VCSE buy-in. |
| **What were our most important findings?** | Understanding that it is a large project that may need to be broken up – do not try to do the whole thing, doing a good job of little parts rather than the whole thing.<br><br>Quote 'not reaching hard enough' – it took us a long time to get there – this can relate to both co-production and experiences of care.<br><br>We have not reached enough in our experiences, and it denies people care. How are new communities being involved and how interfaces may block them. The onus should be on the implementation model to reach people rather than the other way round. |
| **What do we need to share and with whom?** | All stakeholders – organisations that in the past have not acknowledged racism.<br><br>Other organisations who are not ready to implement anti-racism approaches beyond our original list – how the model can be adapted for others.<br><br>So much work has been and will be done. Using this model, if successful, should help inform other agencies such as local councils, government bodies and so on share the love. |
| **What questions do we still have?** | How is this going to relate to someone who is walking into the NHS? Can users benefit from this or is this only leadership and staff? Users will benefit if the staff are more content and valued for who they are and what they can bring.<br><br>How do we put this into reality? Needs to be made really clear in any instructions for using it and adapting the Toolkit. |

# Glossary

Table 5 contains definitions of terms used in this report and the Toolkit. Many of these terms have been well defined elsewhere, and so are quoted from cited sources.

**Table 5: Glossary of definitions and explanations of terms used in this report**

| Term | Reflections |
|---|---|
| **Action learning** | This is a 'process that involves a small group working on real problems, taking action, and learning as individuals, as a team, and as an organisation. It helps organisations develop creative, flexible and successful strategies to pressing problems'.[33] |
| **Building blocks** | Building blocks are areas of implementation that were identified in our literature review to form a basis for the Toolkit. The five building blocks are:<br>1. Evidence and interventions<br>2. Context and the system<br>3. Design<br>4. Infrastructure<br>5. Evaluation.<br>They are also the primary drivers in the theory of change for implementing NHS RHO recommendations. |
| **Co-production** | 'An approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. The assumption is that those affected by research are best placed to design and deliver it and have skills and knowledge of equal importance'.[34] |
| **Cultural sensitivity, safety and competence** | 'Culturally sensitive care is that which is relevant to service users' needs and expectations while practising cultural safety[35] by considering power relationships and imbalances. This involves considering any attitudes, feelings, experiences or circumstances that may be common to the person's racial, national, religious, linguistic or cultural background. Cultural competence involves responding effectively to all people in a way that preserves their dignity and is respectful, while utilising and valuing differences. It includes being committed to bringing their culture/s into an organisation's policy and practice'.[6] |

| Term | Reflections |
|---|---|
| **Discrimination** | The Equality Act 2010 defines discrimination as treating someone less favourably because of a protected characteristic.[19] There are different forms of discrimination: direct, indirect, indirect, harassment or victimisation, and failure to make reasonable adjustments for protected characteristics. |
| **Equality impact assessment (EIA)** | 'A detailed and systematic analysis [that] determines how a policy, procedure or change to process may disproportionately impact a particular group'.[36] |
| **Equality Advisory Group (EAG)** | A standing group of lived experience experts who work with the NCCMH to ensure its workstreams follow the principles of co-production and equality. Members of the EAG have a diverse range of experiences and backgrounds, and are committed to identifying and highlighting the needs of minoritised groups across NCCMH work outputs. |
| **Focus group** | 'A focus group is a small group of people brought together to talk. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems'.[34] |
| **Implementation (in research)** | 'Implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice'.[37] |
| **Intersectionality** | 'A framework that acknowledges that all people have unique experiences of discrimination and disadvantage exacerbated by the overlap of multiple social identities'.[37] |
| **Participatory approaches in research** | A type of research 'where researchers and people who use services or carers are partners in a research project. The research addresses an issue of importance to service users or carers, who are involved in the design and conduct of the research, and the way the findings are made available. The aim of the research is to improve people's lives. This isn't a research method – it's an approach to research, a philosophy'.[34] |
| **Prejudice** | 'An opinion or attitude about a group or individual…often built on ignorance, fear or hatred'.[38] |
| **Proportionate universalism** | 'The resourcing and delivering of universal services at a scale and intensity proportionate to the degree of need. Services are therefore universally available, not only for the most disadvantaged, and are able to respond to the level of presenting need'.[39,40] |

| Term | Reflections |
|---|---|
| **Race and ethnicity** | 'Race' and 'ethnicity' are often used interchangeably. While there is some overlap, they have different meanings. Race assigns people to 'racial groups' based on perceived shared physical attributes or traits, such as similar facial characteristics and skin colour. Race is a social construct without a biological basis, which has been used throughout history to categorise people and inflict notions of superiority of White over non-White. 'Ethnicity' refers to the experiences of groups of people based on shared culture, national origins, religious practices, traditions, language and other factors. Ethnicity is a preferred and more accurate term because it takes into account the many factors that contribute to a person's sense of identity and community'.[6,19] |
| **Racially minoritised community/ group** | 'When we say "minoritised", it is to recognise that social processes of power and domination have constructed how different groups of people are perceived. Some ethnic groups may be minorities in the demographics of the UK, but are majorities in the global population. From that wider perspective, it is incorrect to say "ethnic minorities".'[6]<br><br>In this report, we use the term racially minoritised.<br><br>Other common terms about ethnicity that are used only when referring to other work, or in direct quotes, are:<br><br>● Ethnic minority<br>● Black, Asian and minority ethnic (abbreviated to BAME or BME)<br>● Person of colour. |

| Term | Reflections |
|---|---|
| Racism | We refer to the forms and levels of racism as defined by Camara Phyllis Jones:[41]<br>• **Institutionalised racism:** '...differential access to goods, services and opportunities of society by race. Institutionalized racism is normative, sometimes legalized, and often manifests as inherited disadvantage. It is structural ..., so there need not be an identifiable perpetrator.' It is 'often evident as inaction in the face of need'.<br>• **Internalised racism:** How people who experience stigmatisation may internalise 'negative messages about their own abilities and intrinsic worth'. 'It manifests as an embracing of "whiteness" ...; self-devaluation ...; and resignation, helplessness, and hopelessness'.<br>• **Personally mediated racism:** 'It can be intentional or unintentional, and 'manifests as lack of respect ..., suspicion ..., devaluation ..., scapegoating ..., and dehumanization.'<br>We also refer to structural and systemic racism as defined by Kapadia and colleagues and NHS England – Midlands, respectively:<br>• **Structural racism:** 'The processes that lead to disadvantage in accessing economic, physical and social resources'.[2]<br>• **Systemic racism:** 'Power and privilege that can offer intrinsic advantages to White people over people from Black and minoritised ethnic backgrounds'.[42] |
| System (healthcare) | '[A] healthcare system comprises different individuals, organisations, workforces, stakeholders, policies, resources, funding, technology, actions, interactions and reactions, working towards meeting the health needs of a particular patient, user, community or population.'[43] |
| Themes | Themes are areas of discussion that came up repeatedly in the interviews and focus groups. They were identified through our analysis of the interviews and focus group data. |

| Term | Reflections |
|---|---|
| **Topics** | Our researchers wrote a topic guide with areas to be focused on in the interviews and focus groups. Topics are areas of focus in the topic guide. |
| **White fragility** | A term coined by Robin DiAngelo,[44] who has defined it as 'the defensive reactions so many White people have when our racial worldviews, positions, or advantages are questioned or challenged. [...] Think of it as a weaponized weakness. [...] But the impact is not weak at all. It's a powerful means of White racial control.'[45] |
| **White privilege** | This term means 'how having White skin gives an individual an advantage in life. White privilege does not mean White people have never struggled, but White people do not experience racial discrimination on an institutional or societal basis in Britain. Having White privilege and recognising it is not racist. But White privilege exists because of historic, enduring racism and biases and is the "power of accumulated power"'.[42] |

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## Conflicts of interest

No conflicts of interest were declared.

# Appendix A: Interview topic guide

Thank you for taking the time to speak to me today. My name is [NAME]. I am one of the Senior Researchers based at the National Collaborating Centre for Mental Health who have been commissioned to undertake this work.

The interview will focus on identifying key areas of focus for the project by gaining insight into the individual experiences and knowledge of the interviewee.

[*Edit: The next statement was added to later interviews*]: The project aim is to develop an anti-racism implementation strategy and model to help RHO implement recommendations.

[Edit: The next statement was added to later interviews]: I have a few things I need to run through before we begin if that's ok?

This interview will take around 30-45 mins. We can stop and take breaks as and when you would like and if you'd prefer not to answer a question, please just let me know.

[Edit: The next statement was added to later interviews]: I'll also be taking notes so if I am not looking at the screen, I am listening but trying to capture everything you are saying.

All your information will be confidentially stored on RCPsych computers. We also will anonymise all transcripts and remove any identifiable information.

Finally, I'll be recording the conversation to help with transcription – is this ok with you?

[Edit: The next statement was added to later interviews]: And do you have any questions before we get started either about the interview itself or relating to the information I shared beforehand?

**[START RECORDING]**

**BACKGROUND – short questions**

1. Can you please tell me a bit about yourself – what is your current position and involvement with the NHS RHO?
2. What do you think the purpose/ use of this project is? [*Edit: Previous question removed after the initial interview*]
3. In your view what are the key issues in racial inequities, in: 1) mental healthcare, 2) maternal healthcare; and 3) any other aspects of healthcare you'd consider particularly important? [*Edit: Previous question removed after the initial interview*]

**INTERVENTIONS**

4. Could you tell me about any previous interventions or mechanisms for change for addressing structural/systemic/ institutional racism and inequity that you have been involved in or are aware of? How would you describe the implementation of this work?

Prompts:

- Global (transferability to UK)/UK context; any health area; RHO or beyond
- What worked well and why?
- What were the challenges/what could be improved and why?
- What was the impact of the work?

**IMPLEMENTATION**

5. How would you describe what implementation is, and what 'good' implementation should look like?

- Prompt: the process, what and who is involved?

**The RHO has identified a series of recommendations for identifying and tackling ethnic inequalities in health and care.**

[Interviewer provides following overarching summary of recommendations]:

The NHS RHO has five strategic priority workstreams. These are: (1) improving health and care, (2) empowering vulnerable communities, (3) innovating for all, (4) creating equitable environments, and (5) collaborating globally. The work programmes so far have looked at 13 different areas: (1) accountability and improvement, (2) community engagement, (3) data and digital, (4) funding, (5) genomics, (6) leadership, (7) learning disabilities, (8) maternal and neonatal, (9) medical devices, (10) mental health, (11) national policy, (12) sickle cell, (13) workforce.

As a result, almost 160 recommendations have been generated.

6. What is the key underlying evidence guiding these recommendations?

Prompts:

- Strength of evidence?
- Level of intervention?

7. What is the RHO already doing in terms of implementation? For example, support/guidance to assist the implementation of RHO recommendations?
8. What do you believe are the key challenges/barriers and enablers to implementing these recommendations? Why?

Prompts:

- Type of barriers/enablers (e.g., political, structural, institutional, psychological, social, etc.)
- Insights into culture change that could aid successful implementation?

**SUMMARY AND FINAL THOUGHTS**

*[Interviewer to summarise discussion and answers. Ask interviewee to interrupt summary if anything is incorrect, inaccurate, or they wish to emphasise/highlight anything they've said]*

Is there anyone who you think is critical or who would be valuable to this work to interview?

Is there anything else you want to mention or talk about, or any questions you wish to ask?

Thank you for your time today.

**[END]**

# Appendix B: Focus group topic guide

**Welcome and introductions**

Welcome everyone. Thank you very much for joining us today. Today's focus group will be led by *[me, Isaac/Faaria]* and supported by Alan and Vas.

Let's start by getting to know each other. Let's go around the group and if you could each briefly say who you are and where you live.

**Purpose of focus groups**

The purpose of this focus group is to discuss your needs, preferences and priorities for tackling structural racism across a variety of health areas.

You will be asked about your opinions on key issues regarding ethnic inequalities and inequities across healthcare and important areas for supporting the implementation of initiatives aimed at addressing these inequities and what barriers may challenge this. You may wish to reflect on your own experiences and how these relate to your cultural needs and expectations, spiritual and/or religious beliefs.

We appreciate that the discussions today may bring up difficult memories and experiences. We have therefore set up an allocated quiet space for people to join if they wish to. You can also dip in and out of the call and we have prepared a list of support services that you may wish to consult with after the discussions.

The session will be around 1 hour 30 minutes, with a 10-minute comfort break around halfway through. You can also take breaks as and when you need to. Please note, you do not need to answer any questions if you do not want to.

We will be here asking a series of questions, but do not feel you have to just address these. You can also ask each other questions if you feel it would benefit the aim of this discussion, and if responses create a discussion amongst yourselves that is great.

We may interrupt if the discussion is going off track, e.g., steering too far away from our aim of today. A reminder:

Today is a focus group where we will discuss your **needs, preferences and priorities** for tackling structural racism and discrimination across a variety of health areas. We appreciate that due to the systemic and structural experiences of racism you may have some experiences outside of healthcare.

**Ground rules:**

1. **Listen with respect and openness**. We seek to value learning from different people and stay open to new ways of doing things.
2. **Everyone is responsible for respecting confidentiality**. People may share something they wish to be kept confidential. We require everyone's agreement not to share anyone's information without their permission.

3. **Collaborate and contribute.** We would like everyone to feel able to participate. If you would prefer to respond to a question privately after the focus group, you can send us an email with your thoughts.
4. **Disagree with the point – not the person.** There are no right or wrong answers, only differing points of view. You do not need to agree with others, but you must listen respectfully as others share their views.
5. **Use plain language.** We seek first to understand, then to be understood. If possible, avoid using jargon and explain acronyms if they must be used.

We will be recording the group to capture everything you have to say. We will not identify anyone by name in our write up. You will remain anonymous with all your information confidentially stored on RCPsych computers. As we are recording, please keep to one person speaking at a time.

Does anyone have any questions before we get started? So, if everyone is ready, we'll start the recording now.

**[START RECORDING]**

**BACKGROUND – Equality versus equity**

Before we get started, we will be referring to the terms 'inequalities' and 'inequities' today. A good way to remember these is the shoe analogy:

- Equality – everyone has access to a pair of shoes
- Equity – everyone has access to a pair of shoes that fit.

A cartoon explaining this is also on the slide.

**TOPIC 1 – INEQUALITIES AND INEQUITIES IN HEALTHCARE**

1. In your view what are the key issues relating to structural or institutional racism and racial inequalities, in:

- Mental healthcare
- Maternal healthcare
- Any other areas of healthcare

Prompts:

- Please feel free to share irrespective of when this happened.
- Examples (other areas of healthcare): primary care (e.g., GP), secondary care (e.g., hospital), tertiary care (e.g., specialist treatment), community health, social care.
- What is your experience of culture, attitudes, perceptions or beliefs within services or systems? Prompt: cultural viewpoints (Western, biomedical approach compared with alternative therapies), past experiences, etc.

- What are your views on the structures and systems themselves?
- How about policies and guidelines?
- Can you give an example of how this has impacted on your own/loved one's experiences of healthcare? Why?
- How important do you feel intersectionality/other additional factors are in terms of health inequalities versus race as a core denominator of physical and mental health inequalities? Intersectionality is about the multiple identities people may hold.

**TOPIC 2 – IMPLEMENTATION**

A large part of the project is to support the implementation of recommendations developed by the NHS RHO. Let's break this down into first thinking about what implementation means to you.

2. How would you describe what implementation is?

Prompts:

- What does implementation mean to you? (Prompt: what – features; who – people; where – context/ system; when – timeframe; how – processes)
- What does implementation look like in your own organisation?
- Process – what, who and how are people involved?
- Any examples of 'good' implementation you can share?

**[BREAK – 10 mins]**

**TOPIC 3 – NHS RHO RECOMMENDATIONS**

Now let's think about the NHS RHO recommendations specifically – NHS RHO want to support organisations to implement these

The NHS RHO's 160 recommendations have been allocated across 13 different work programmes so far, shown on the slide.

3. Given the work programmes just presented, what may impact the implementation of these recommendations? Why?

Prompts:

- What changes would you expect to see from successful implementation of the NHS RHO recommendations or areas requiring change discussed previously?
- Examples: goals/indicators of success; prioritisation of existing areas; levels of implementation (local to national)

**TOPIC 4 – GENERAL REFLECTIONS**

4. What do you think the implementation framework that we develop for NHS RHO ought to include, or be aware of?
5. Of everything discussed today, what is the most important to you?

**SUMMARY AND FINAL THOUGHTS**

Thank you all for participating today. Is there anything else you would like to mention or talk about, or do you have any questions you wish to ask?

**[END]**

# Appendix C: Codebook developed during participatory analysis

| Themes | Sub-themes | Codes |
|---|---|---|
| **1. The approach to implementation** | Accountability | Role of regulators |
| | Acknowledgement of racism | Racism |
| | Managing and setting expectations and direction | Clear purpose, focus and vision |
| | | Pace/speed of change |
| | | Navigating change |
| | | Readiness for change |
| | | Sustaining momentum and priority |
| | Data collection, quality, and evaluation | Measuring and reporting racism |
| | Community involvement and engagement | Meaningful involvement and engagement |
| | | Not tick box/tokenistic |
| | Accessibility | Language, accessibility and understanding of implementation |
| | Learning community and network | Flexibility for iteration |
| | | Sharing best practice |
| | Resources | Finances |
| | Workforce | Time |
| | Research | Funding/commissioning |
| | | Publishing |

| Themes | Sub-themes | Codes |
|---|---|---|
| **2. Leadership and buy-in at multiple levels** | Engagement, empowerment and advocacy | Communities<br>Experts with lived experience<br>Public sector<br>VCSE |
| | Undoing harm | |
| | Culture change | |
| | Accountability for implementation | Roles and responsibilities |
| | Stakeholder engagement and involvement | People with lived experience<br>Workforce |
| **3. An anti-racism approach throughout** | Actions by healthcare providers | Experiences of healthcare |
| | Undoing harm | Acknowledgment of racism<br>Challenging existing narratives |
| | Accountability for implementation | Roles and responsibilities |
| **4. Co-production with people with lived and learned experience** | Who is involved | Diverse representation in patient/public involvement<br>Variety and alignment of stakeholders (e.g., lived experience) |
| | How they are involved | Community response<br>Decision-making<br>Impact of patient/public involvement<br>Level of outreach<br>Purposeful action |

| Themes | Sub-themes | Codes |
|---|---|---|
| **5. Experiences of racism and quality of access, treatment, care and support** | Intersectionality | Ethnicity<br>Gender<br>Religion<br>Sexuality |
| | Past experiences shaping current experiences and perceptions (emotional toll) | Disappointment<br>Frustration<br>Questioning self |
| | Examples of racism, discrimination and oppression in healthcare, from point of entry | Being devalued<br>Being undermined<br>Conscious bias<br>Implicit bias<br>Microaggressions<br>Not being listened to<br>Unconscious bias<br>White privilege |
| | Forms of racism, discrimination and oppression | Individual<br>Institutional |
| | Causes of structural, institutional and systemic racism in practice | Culture<br>Education and training<br>Environments<br>Individual experiences<br>Resources |
| | Anti-racism approaches in healthcare[w] | Accessibility<br>Cultural sensitivity and cultural competency<br>Equitable treatment<br>Person-centred and tailored care<br>Trust in relationships |

w Moved to Theme 3 in the report.

# Appendix D: Equality impact assessment

## NCCMH equality impact assessment information[x]

### Introduction

1. Organisations have a duty to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations between people from different groups. The purpose of this form is to document the consideration of equality issues in each stage of the development process of this project, before reaching the final output that will be approved by the commissioning organisation and stakeholders. This equality analysis is designed to support compliance with obligations under the Equality Act 2010 and Human Rights Act 1998.

2. Table 6 lists the equality characteristics and other equality factors that should be considered, i.e., not just population groups sharing the 'protected characteristics' defined in the Equality Act but also those affected by health inequalities associated with socioeconomic factors or other forms of disadvantage. The table does not attempt to provide further interpretation of the protected characteristics. This is because it is likely to be simpler, and more efficient, to use the evidence underpinning the project to define population groups within the broad protected characteristic categories rather than to start with possibly unsuitable checklists created for other purposes, such as social surveys or HR [human resources] monitoring tools.

3. The form should be used to:

   - confirm that equality issues have been considered and identify any relevant to the topic
   - ensure that the project outputs do not discriminate against any of the equality groups
   - highlight planned action relevant to equality
   - highlight areas where projects may advance equality of opportunity.

x The equality impact assessment (EIA) is derived from a template. It may be edited or adapted as appropriate, to fit the needs of different projects. For example, projects may differ in how many times they need to be reviewed and circulated to the EIA. Or sections may be added or removed, as necessary. Some projects may need to re-work the language used to fit the project.

This form is to be updated by the Project Manager, supported by member of the research team during development of the project and submitted at different stages[y] of the validation process:

- Scoping
- First circulation
- A subsequent circulation (i.e., at one other time point when project documents/drafts are circulated for comment)
- Final draft.

**Table 6: Protected characteristics (Equality Act 2010) and other characteristics that may put a person at risk of experiencing inequalities**

| Protected characteristics |
|---|
| • Age<br>• Disability<br>• Gender reassignment*<br>• Pregnancy and maternity<br>• Race<br>• Religion or belief<br>• Sex<br>• Sexual orientation<br><br>*Note:*<br><br>The characteristic of marriage and civil partnership is protected only from unlawful discrimination. There is no legal requirement to consider the need to advance equality and foster good relations.<br><br>The definition of direct discrimination covers less favourable treatment of someone associated with a person with a protected characteristic, such as the carer of a disabled person.<br><br>* This is the term used in the Equality Act 2010. There, it states that this term includes the protection of any person who is proposing to undergo or is undergoing a process of changing physiological attributes of biological sex. |
| **Other characteristics** |
| **Socioeconomic status**<br><br>Depending on policy or other context, this may cover factors such as social exclusion and deprivation associated with geographical areas or inequalities or variations associated with other geographical distinctions (e.g. the North/South divide, urban versus rural). |

y The frequency of updates to the EIA will depend on the needs of the individual project and, as such, may vary from project to project.

**Other categories**

Other groups in the population experience poor health because of circumstances often affected by, but going beyond, sharing a protected characteristic or socioeconomic status. Whether such groups are identifiable depends on the guidance topic and the evidence. The following are examples of groups covered in National Institute for Health and Care Excellence (NICE) guidance and other notable organisational resources:

- Gypsy, Roma and Traveller communities
- Homeless people and people in unstable housing situations
- Looked after children
- Migrant workers
- Prisoners and young offenders
- Refugees and asylum seekers
- Young and unpaid carers

# Equality impact assessment form

## 1. Early development

**1. Have any equality issues impacting upon groups been identified so far during the development process?**

[Please briefly state any relevant equality issues identified]

**Equality issues identified:**

1. The project itself aims to address racial equality issues in physical health and mental healthcare by developing an implementation framework and strategy to tackle these issues.
2. Intersectionality of race and other factors influencing equality of care.

**Action taken:**

- Project in early stages – consultation (via interviews) with key people within and external to the NHS RHO who can provide various informed perspectives and share knowledge regarding racial health and mental healthcare inequality in the UK, and the current status of implementation efforts.

**Additional considerations raised by the EAG, 30 August 2023:**

- The EAG in itself feels it can support with intersectionality.
- Ageing prison population growth, NHS in-reach into prisons insufficient, dementia, human rights concerns with regard to prisoners (triple intersectionality re. prisoners: disability, race/ethnicity, age) – this is an area of concern.
- Intersectionality, re. people from minoritised groups from lower socioeconomic backgrounds.
- Mind have undertaken some work on socioeconomic status and experiences of minoritised ethnic groups.
- Story sharing of experiences seen as important to this work.
- A suggestion to cross-check this work with the PCREF.
- Capturing experiences from people with lived experience in a trauma-informed way is important – e.g., using quotations from people from workshops is a powerful way to do this.
- A note to use language carefully, re. racism, intersectionality 'intersectional experiences', etc. EAG expressed a wish to be invited to contribute to documents/ resources etc. to check language use.
- There should be clear language and terms as part of the implementation support developed.
- EAG emphasised the importance of engaging with as many people with different experiences as possible given range of issues specific and across different populations.
- Re. maternal care – one barrier may be that they are caring for children before and/or after birth and this can be a barrier (for example, getting that group of people's voices heard in workshops). Ensuring this is family friendly.

**2. Have relevant bodies and stakeholders been consulted, including those with a specific interest in equality?**

Have comments highlighting potential for discrimination or advancing equality been considered?

**Stakeholders consulted/to be consulted:**

NCCMH has reached out to many stakeholders, including but not limited to:

- Birmingham City Council
- Black Equity Organisation
- Calderdale Council
- Cancer Research UK
- CQC

- Caribbean and African Health Network (CAHN)
- NHS England
- NHS RHO members, which include a variety of academic and medical professionals
- NICE
- North London Mental Health Partnership
- OHID
- Race Equality Foundation
- Race on the Agenda
- Royal College of Midwives
- Sands and Tommy's
- Southwest London ICB
- The Runnymede Trust
- The Ubele Initiative

**Additional suggestions for outreach/consultation by the EAG, 30 August 2023:**

- The workforce representative of the communities it is serving.
- The invisibility of some groups from consideration in services (e.g., Black women).
- How will organisations demonstrate meaningful change – this will be something to bring to the QI team.
- Capturing experience alongside data to show meaningful change demonstrative of anti-racism in systems.
- Considerations about research methods (interviews etc.) and research interpretation.
- Are professional bodies and regulators being challenged around their own fitness-to-practice (F2P) cases and processes? A disproportionate number of healthcare professionals from minoritised communities are 'caught in the net' of F2P – In scope?
- Emphasis on equity in this work.
- Implementation science approach, practical guidance dictating how you achieve equity in care as the aim – how to put equity into an implementation model.
- Vulnerable people who may be misunderstood when trying to communicate their needs if they have communication challenges or neurodiversity.

**3. Have any population groups, treatments or settings been excluded from coverage in the project this stage in the process? Are these exclusions legal and justified?**

No groups have been explicitly excluded thus far; rather appropriate groups have been targeted for consultation.

**Additional considerations, EAG, 30 August 2023**

Not discussed

**4. If applicable, does the project make it impossible or unreasonably difficult in practice for a specific group to access a service or element of a service?**

N/A

**Additional considerations, EAG, 30 August 2023:**

Not discussed

**5. If applicable, does the project and framework aim to advance equality?**

Yes – the project aims to produce an implementation framework and strategy designed to advance racial equality in healthcare and mental healthcare.

**Additional considerations, EAG 30 August 2023:**

Not discussed

**Completed by: EAG (notes developed by LLA)**

**Date: 30 August 2023**

## 2. Development

**1. Have the potential equality issues identified during the scoping stage been addressed by the project team, and if so, how?**

**AR (Senior Researcher): update on issues addressed by the project team:**

- Specific populations raised by the EAG last time valid to consider for the project as it develops even though the project is less specific in terms of populations.
- There will be more specific focus on populations as a lot will be captured by way of recommendations.
- The EAG raised concerns about involvement of people with LE [lived experience] taking a role in the development work – AR advised that 2 colleagues with LE have been brought on to lead on focus groups and support with project development.

- LE colleagues to take lead on focus groups (there will be 2 focus groups – EAG discussion on mixing experiences of groups etc. somewhat dependent on the aims of each focus groups, participation).
- LE colleagues will also collaborate with the NCCMH team on topic guides and questions to steer the focus group discussions (6–8 participants for each focus group).
- Composition of focus groups? EB (Project Manager) has been doing the outreach and recruitment – aim to get balance between people with LE and professional experts in mental health, maternal health and other areas. The aim of the focus group is to gain an idea of perceptions and opinions on 'What does good implementation look like?' and 'What are the requirements to ensure implementation of recommendations successfully?'
- Consideration of representation within focus group participants to get rich discussion and address power imbalances etc. (e.g., balancing different types of experiences and giving people opportunity to express their thoughts freely).

**2. Have any other potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the project team addressed them?**

- EB clarified the plan to develop the implementation model for a set of recommendations (e.g., using the Ethnic Inequalities in IAPT review recommendations).
- Intersectionality (raised previously, but reiterated as vitally important) – the EAG is able to help in this regard, but might be beneficial to think about a more concrete method of putting this into action.
- This may be something to be captured via the focus groups.
- Equitable access to focus groups (e.g., considerations about digital access, access to Internet etc, as a limitation of the methods).
- Equitable contributions to focus group discussions – suggestion for an icebreaker at the start of focus groups to support people to engage regardless of background/experience/position and facilitate productive synergy.
- How to ensure a representative sample in focus groups? This is a known challenge.
- Team reaching out to variety of groups, but there are of course practical limitations (e.g., participant numbers etc).
- Starting point for design workshop recruitment aimed for 10 professional and 10 LE experts, for example.
- Aim for the mix of different physical health and mental health experiences within the project.
- There is a limit to how much representation can be varied across different societal experiences – a limitation of the work with small groups and limited time/resources allocated to the project.
- Consideration of jargon/abbreviations when considering engagement in focus groups.

- Accessibility issues associated with focus group facilitation (e.g., icebreaker – what is used should enable participation rather than limit it, this is where the topic/ question needs to be considered carefully).
- Consideration of timing of focus groups to ensure access and availability.
- Contributions provided via chat function (edited for anonymisation):
    - Intergenerational inequalities from minoritised groups? (Accessible communication and reasonable adjustments made for participants and staff – well established practices around this).
    - In the model we need to ensure that recommendations that will be implemented have intersectionality woven into them.
    - Re: power imbalance. Being clear on the topic at the start as well as making clear that there are people from different backgrounds and to be aware of jargon. Having an LE member help run the focus group can help with this. Having a set of housekeeping rules like avoidance of jargon etc. at the start can be helpful in terms of bringing the group back if at points it swerves or is dominated by one individual. Inputting in a variety of ways, e.g. vocal, written, Jamboard (for anonymity). This will all be so variable and dependent on the group dynamics.
    - Can we not offer both online and face-to face focus groups?
    - Digital exclusion especially for those that will be most impacted by inequalities, intersectionality and intergenerational issues.
    - We can perpetuate the artificial divides between clinician and service user (these can often be the same person and this can change over a person's life – being one or both at different times).
    - Contracting around how each focus group will run, between participants, would be another tool to use to mitigate against power imbalances.
    - You can't get a representative sample with such small numbers but you can optimise representation.
    - Important to be transparent about the limitations.

**3. Have the project's considerations of equality issues (including ways to advance equality) been described in any drafts for consultation, and, if so, where?**

N/A – no outputs drafted yet

**Updated by: EAG (notes by LLA)**

**Date: 10 October 2023**

## 3. Pre-consultation

**1. Have any other potential equality and equity issues (in addition to those identified during the scoping and development processes) been identified, and, if so, how has the project team addressed them?**

**Presentation from lived experience advisor to the project and the senior researcher:**

- Members of the research team shared the progress of the NHS RHO implementation work so far.
- Focus groups were facilitated by lived experience experts and interpretation of findings has been co-produced.
- Issues raised from focus groups included:
    - Intersectionality and how this is not consistently considered
    - Unconscious bias
    - Racist assumptions that impact health care
    - Differential treatment based on race and ethnicity.

**Additional EAG considerations via discussion:**

- Query if in scope: courses and training around disciplinary and F2P proceedings, and representative workforce (including those in leadership positions) – one of the areas of focus is around leadership and workforce and the role of senior leaders in representation.
- Using the word 'racism' is considered important as well as focusing on 'trauma' and the role of 'intergenerational trauma'.
- Defensiveness regarding racism on the part of healthcare providers can be a barrier to anti-racist approaches.
- 'You can do harm and add to the pot of harm or do good and add to the pot of good'.
- The team writing up tried to be conscious of their own positions and stances and biases in the interpretation of findings.
- Defensiveness – inclusion in the Toolkit about teams' need to be reflective and conscious of issues of racism, will be drawn out in the introduction to the Toolkit.

| | |
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| 4. | **Have the project's considerations of equality and equity issues (including ways to advance equality) been described in the draft resources for consultation, and, if so, where?** |

- The focus of the work is on advancing equality and achieving equity in healthcare as it pertains to race and ethnicity – an anti-racist approach to intervention implementation.
- The EAG are invited to consult on the Toolkit which is going out for consultation from 29 January 2024.
- Note for research team to add EIA to the report methodology and appendix.

**Additional EAG considerations via discussion**

- N/A

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|---|---|
| 5. | **Any other comments, thoughts and suggestions regarding equality and equity issues and considerations?** |

- N/A

**Updated by: EAG (notes by LLA)**

**Date: 24 January 2024**

## 4. [Optional]

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|---|---|
| 1. | **Have any other potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the project team addressed them?** |

| | |
|---|---|
| 2. | **Have the project's considerations of equality issues (including ways to advance equality) been described in the final draft, and, if so, where?** |

| | |
|---|---|
| 3. | **Has the Equality Impact Assessment been reviewed and signed off by the Director/s?** |

**Completed by:**

**Date:**

# Appendix E: Roles and responsibilities at the NHS RHO

Table 7 outlines the roles of the RHO Board, Academic Reference Group, Maternal Health Advisory Group and Mental Health Advisory Group. It describes the responsibilities of the members. The responsibilities were described by interviewees.

**Table 7: Roles and responsibilities at the NHS RHO**

| | NHS RHO Board | Academic Reference Group | Maternal Health Advisory Group | Mental Health Advisory Group |
|---|---|---|---|---|
| **Membership** | | From disciplines of:<br>• Demography<br>• Epidemiology<br>• Health economy<br>• Maternal health<br>• Mental health<br>• Migration<br>• Psychiatry | • Clinicians<br>• Mainly women<br>• People with lived experience<br>• VCSE staff<br>• Others | |
| **Meetings** | Regular – every quarter | Regular – every 2 months | Fairly regular | |

| | NHS RHO Board | Academic Reference Group | Maternal Health Advisory Group | Mental Health Advisory Group |
|---|---|---|---|---|
| **Roles and responsibilities** | • Conceptualisation of the NHS RHO<br>• Providing strategic advice | • Reviewing commissioned research conducted and proposals<br>• Helping to develop tender documents and advise on recruitment to tenders<br>• Oversight of work as it progresses<br>• Not involved in all work, but members of the group share the responsibility<br>• Reviewing outputs<br>• Receiving updates on the NHS RHO's progress<br>• Involved in interviewing candidates for NHS RHO roles<br>• Supporting how evidence from commissioned research is actioned (includes international) | • Identifying priorities for new evidence generation<br>• Advising on commissions for new work<br>• Commenting on NHS RHO statements and outputs | • Developing activities and work for the NHS RHO relating to mental health<br>• Advising and decision-making in developing new grants and initiatives to be commissioned in future (e.g., co-commissioning: mental health and maternal health working groups)<br>• Implementing the NHS RHO's overarching strategy<br>• Working with stakeholders and experts<br>• Feedback on outputs |