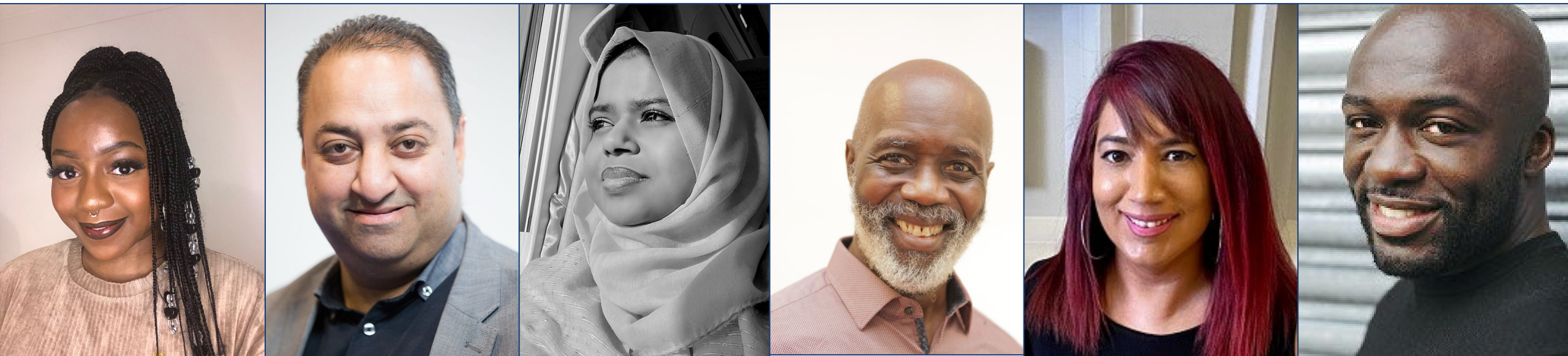


THE RACE EQUALITY FRAMEWORK

A PRACTITIONER'S GUIDE FOR PUBLIC INVOLVEMENT IN RESEARCH



Contents

01 Setting the scene

- 4 Infographic: Unique strengths of the Race Equality Framework
 - 5 Foreword by Fay Scott
 - 6 Foreword by Jeremy Taylor OBE
 - 7 Preface
 - 9 Introduction
-

02 Introducing the Race Equality Framework

- 12 Infographic: Why should organisations use the Framework?
 - 13 What is the Race Equality Framework?
 - 14 Why organisations should adopt the Framework
 - 15 The five domains of the Framework
 - 16 Domain 1: Individual Responsibility
 - 17 Domain 2: Leadership
 - 18 Domain 3: Public Partnerships
 - 19 Domain 4: Recruitment
 - 20 Domain 5: Systems & Processes
-

03 The Framework in action

- 22 Infographic: Summary guide to using the Framework
 - 23 How to use the Framework
 - 25 Stage 1: Establishing your organisational readiness (steps 1 to 8)
 - 26 Stage 2: Carrying out your self-assessment (steps 9 to 12)
 - 27 Stage 3: Using the results to improve your racial competence (steps 13 to 20)
 - 28 What a racially competent organisation looks like
 - 29 Measuring the impact and benefits of change
-

04 Appendices

- 31 Infographic: The Race Equality Public Action Group
 - 32 A: About the NIHR's Race Equality Public Action Group
 - 33 B: People who have made a substantial contribution to the Framework
 - 34 C: Pilot partner organisations and early adopters
 - 35 D: Case study summaries
 - 42 E: Allyship resources
 - 43 F: Sample role profile: Ambassador for public involvement in research
 - 45 G: Glossary of terms
-

Setting the scene

- 4 Infographic: Unique strengths of the Race Equality Framework
- 5 Foreword by Fay Scott
- 6 Foreword by Jeremy Taylor OBE
- 7 Preface
- 9 Introduction

01

Unique strengths of the Race Equality Framework

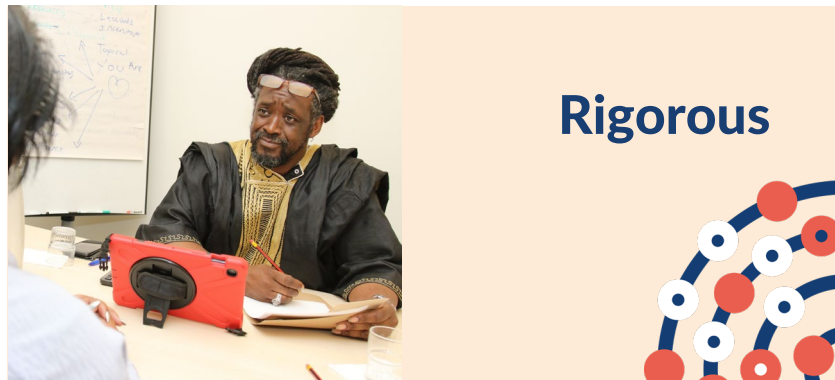
The Race Equality Framework for public involvement in research is a self-assessment tool, conceived by the NIHR's Race Equality Public Action Group (REPAG), to help organisations improve racial equity in health and care research.



The Framework's development is rooted in co-production, led by the public through the REPAG.



The Framework is grounded in REPAG members' cultural and lived experiences and informed, through consultation, by the very communities it is intended to support.



The Framework has been developed with rigour and due diligence, through a continuous cycle of consultation, feedback and revision, in collaboration with Black African-, Asian- and Caribbean-heritage communities and 16 pilot partner organisations.

FOREWORD BY FAY SCOTT

I am thankful to have worked with such dedicated public members and National Institute of Health and Care Research colleagues to co-produce this Framework.

Leading change in health and care research requires us to:

- speak to the voices that are often not heard in the plethora of discussions about race
- hear their trauma and pain, recognising the context in which this operates
- ask them the question: 'What matters most to you?' and
- act on what we hear and challenge ourselves to do better.

The feedback from our consultation events reveals that people from Black African-, Asian- and Caribbean-heritage communities do not expect perfection but also do not want tokenism. What they want to see are organisations doing their best to eradicate racial inequality in a respectful, open and transparent manner. That includes involving Black African-, Asian- and Caribbean-heritage people as equal partners. It also includes increasing the diversity of researchers and public involvement leads who can engage effectively with communities to build trust.

We must, therefore, evaluate our systems and processes to understand where improvements need to be made and

additional support provided. We must be able to have open and challenging conversations without fear of repercussions. We must lead change in an authentic way, recognising our faults and learning from them. It is in this way that organisations will start to earn the trust and confidence of communities.

This Framework is a tool to help organisations deliver the change needed to address systemic inequities in health and care research. The self-assessment questions are probing; they will challenge your thinking, approach and practice.

Research will only be truly inclusive when it is informed by, and focused on, the issues that matter to diverse communities. If their voices are ignored, then we have failed in our duty of care.

There is a time to listen and there is a time to act.



Fay Scott

Founder and Co-Chair, NIHR
Race Equality Public Action
Group



FOREWORD BY JEREMY TAYLOR OBE



I am delighted to introduce the Race Equality Framework, which has been co-produced by members of the Race Equality Public Action Group.

The Race Equality Public Action Group (REPAG) is supporting the National Institute for Health and Care Research (NIHR) to build our understanding and competence in the area of race equity, so that we become more inclusive in our relationships with the public. As Director for Public Voice, I am proud to act as sponsor to the Group.

We know that ethnicity and race have been shown to systematically influence health outcomes, socio-economic status and employment opportunities. Racial inequity continues to damage the lives and health of people who are from Black African-, Asian- and Caribbean-heritage communities; the same communities have also been disproportionately harmed by COVID-19.

Too few of the patients and public members who work with us are of Black African, Asian or Caribbean heritage. They need to have a stronger presence, voice and influence in shaping the health and care research agenda.

The REPAG is therefore focusing its attention on these communities in particular, while looking to generalise its

learning across a wider group of diverse communities. The Race Equality Framework is a key part of the REPAG's response to the inequities they experience.

I look forward to seeing the Framework discussed, applied and developed more widely over time, helping to create a fairer and more inclusive research culture.

A handwritten signature in black ink that reads "Jeremy Taylor". The signature is written in a cursive, flowing style.

Jeremy Taylor OBE

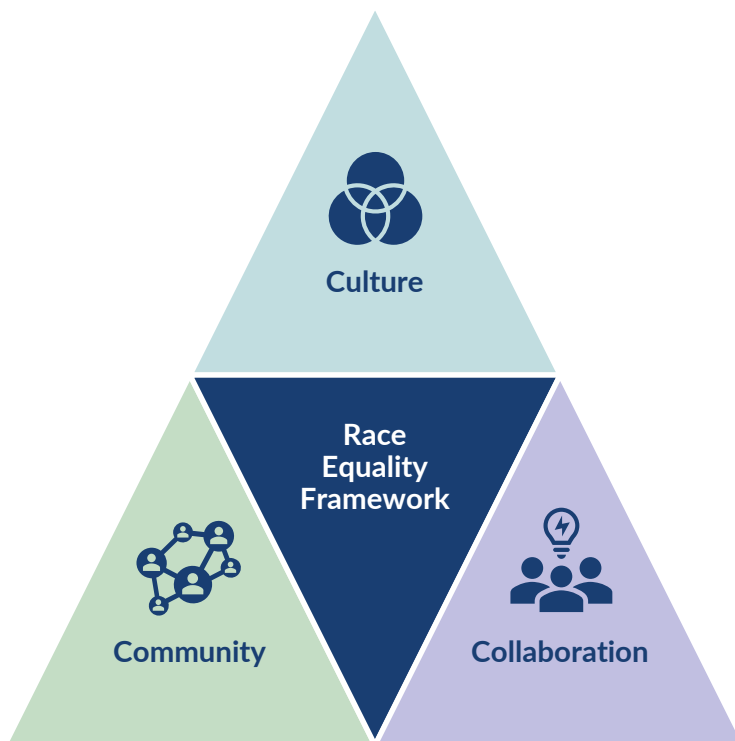
NIHR Director for Public Voice, NIHR Centre for Engagement and Dissemination, National Institute for Health and Care Research

PREFACE

Welcome to the Race Equality Framework for public involvement in research, co-produced by the National Institute for Health and Care Research's Race Equality Public Action Group.

Please read this guide carefully before starting on your self-assessment.

It contains important advice and tips on how to get the best out of the Framework.



Terms used

Although both equality and equity promote fairness, we prefer to use the term 'equity'. That is because it places greater emphasis on treating people according to their needs.

In this document we also use the term 'anti-racist'. For our public contributors it is a familiar term and one that should serve to focus our minds as together we work to improve racial equity in health and care research.

A third term we use is 'racial competence'. In our view, it reflects the complex and multi-faceted nature of racial inequity and the need not just to focus on systems and processes but also to examine what we ourselves can do to bring about positive change. You can find the full definition for this, and for racial equality and racial equity, in our Glossary in [Appendix G](#).

Consulting communities

In May and June 2021, we invited members of the public to three community consultation events. The purpose of these events was to seek Black African-, Asian- and Caribbean-heritage communities' views on the

Framework—how well they think it could help organisations improve their racial equity, how comprehensive it is and what, if any, changes would make it better. Many of those who attended had little or no prior involvement in research.

Several overarching themes emerged, with participants across the three events stressing the need for the following:

- trust and confidence that the self-assessment will not just be a tick-box exercise
- openness to a diversity of perspectives and insights
- accountability and leadership
- a robust and rigorous change management process
- a standard of racial competence to be met
- evidenced change.

¹ In using 'Black African-, Asian- and Caribbean-heritage' as a working definition that may change over time, we recognise that there are other racialised groups that do not fall under this description. Nevertheless, the focus of the Framework and its self-assessment questions can be adapted to support all other racialised groups.

Below, we have summarised the main comments arising from each event separately. We used this feedback to refine the Framework, checking the revised version with our participants to make sure that we had captured their views accurately.

Feedback from the 'Black Men' consultation event, 24 May 2021

Participants in this group stressed the importance of organisations involving diverse communities in the self-assessment process. They further felt that it is for members of their communities to define racial competence, and for organisations then to demonstrate, with evidence, how they meet that definition.

This group was also keen to see more empathy from organisations, believing that empathy-driven actions would lead to more authentic change. Moreover, in their view it should be the responsibility of everyone in organisations, not just a select handful of people, to implement the findings of their self-assessment in order to bring about that change.

Feedback from the 'Black African-, Asian- and Caribbean-heritage People'¹ consultation event, 17 June 2021

This group echoed the need for strong leadership and

a carefully considered approach when organisations come to work through their self-assessment. They also stressed that on completing the self-assessment, having a robust change management process in place will be essential if organisations are to be able to drive through the cultural change needed.

Other points raised by this group included the suggestion that organisations may find it useful to consult clinicians as they work through the questions, and the importance of making sure that the Framework is accessible to everyone.

Feedback from the 'Black African-, Asian- and Caribbean-heritage People' consultation event, 23 June 2021

A lot of comments from this group were directed at the wording of the questions. These included the preference for more personalised language, greater encouragement for organisations to hold themselves to account through SMART objectives, more challenging questions and tighter language where content may be open to interpretation.

This group was also particularly keen to see organisations using what they called external assessors during their self-assessments. Specifically, they suggested that organisations involve members of

the public and/or their peers from other organisations to bring an element of external assessment to the process.

Piloting the Framework

Between September and December 2021, a total of 16 research organisations (see [Appendix C](#)) field-tested the Framework. We were particularly keen to hear their views on the self-assessment process as well as on the usefulness and clarity of the questions.

In response to their feedback, we reduced the number of self-assessment questions from 60 to 50. We also made the questions simpler and more focused while ensuring that they remained probing and challenging. The amended Framework was then put back to our community consultation partners for their final comments and approval.

By testing the Framework in this way, we have ensured that it is robust, rigorous and effective while at the same time respecting and retaining the voice of the public and the integrity of co-production.

INTRODUCTION

Why focus on Black African-, Asian- and Caribbean-heritage communities?

'We stand in solidarity against racism and anti-blackness and we acknowledge that as a research organisation we have more to do. We need more Black voices within our leadership, in our committees, in our institutions and in the cohorts of people we fund.'²

As the research arm of the NHS health and care systems, the NIHR's core mission is 'to improve the health and wealth of the nation'.³ When we say nation, we mean everyone living in the UK.

However, Black African-, Asian- and Caribbean-heritage people remain significantly under-represented in our public involvement community. These same groups are also disproportionately affected by COVID-19,⁴ have a history of mistrust of research⁵ and are more likely to be hesitant about using vaccines.⁶ Thus, as part of the NIHR's core mission, our ambition is for the ethnic diversity of people who are involved or participate in clinical research to reflect the diversity of those in the population affected by the particular aspect of health or care being researched. We are supported in this by the Equality Act 2010. The Act allows organisations to take action that may involve treating one group more favourably, where this is a proportionate way to help members of that group overcome a disadvantage or participate more fully; or to meet needs they have that are different from the population as a whole.⁷

To this end, the NIHR has collaborated with the Centre for Ethnic Health Research at the University of Leicester on a series of videos on how to design and conduct health and care research that is sensitive to and inclusive of Black African-, Asian- and Caribbean-heritage people. In addition, our Clinical Research Network has commissioned research to understand the barriers preventing these same groups from participating in research. We have also published the INCLUDE Ethnicity Framework,⁸ to inspire researchers to be aware of the diversity of health and cultural needs of potential participants when designing clinical trials.

To bring about change and improve race equity requires focused and sustained effort over the long term. A lot of good work has been done but there is a lot more still to do.



² NIHR, June 2020 - <https://www.nihr.ac.uk/news/nihr-stands-by-black-lives-matter/25039>

³ <https://www.nihr.ac.uk/about-us/>

⁴ Public Health England, June 2020 - <https://www.gov.uk/government/publications/covid-19-understanding-the-impact-on-bame-communities>

⁵ Farooqi, A., Jutla, K., Raghavan, R. et al. (2022) 'Developing a toolkit for increasing the participation of black, Asian and minority ethnic communities in health and social care research', BMC Medical Research Methodology - <https://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/s12874-021-01489-2>

⁶ BMA, February 2021 - <https://www.bma.org.uk/news-and-opinion/why-are-we-vaccine-hesitant-in-a-pandemic>

⁷ <https://www.legislation.gov.uk/ukpga/2010/15/contents>

⁸ The INCLUDE Framework (NIHR) - <https://www.trialforge.org/trial-forge-centre/include/>



Why the Framework is important for the NIHR and the organisations we support

The Race Equality Framework has a public-facing outlook that builds on the opening statement overleaf. Its purpose is to bring together patients, the public and research organisations as partners working to understand the needs of Black African-, Asian- and Caribbean-heritage people, overcoming barriers to their participation in research and increasing the number of them directly benefitting from it. In this way, it also supports the UK Standards for Public Involvement.⁹

The Framework's main users will be those working in health and care research. NIHR has a strategic commitment to actively and openly support and promote equality, diversity and inclusion in health and care research. As part of that commitment, we seek to galvanise the sector's efforts to reduce health and care inequalities and to better meet the needs of under-served communities. The Framework, which focuses on race but whose principles can be applied to all the protected characteristics under the Equality Act 2010, will be of considerable help in this respect.

Why we use the term 'Black African-, Asian- and Caribbean-heritage people

There have been numerous debates and public statements on how to refer to

members of groups who have been racialised in UK culture. The public members who worked with us to develop the Framework, and who continue to work to dismantle barriers to involvement and engagement, asked us to place valuing personal identity at the heart of our work. In November 2020 they led discussions on dropping the controversial BAME terminology, which has alienated communities and caused hurt. They went on to propose alternative wording that better reflects the histories, identities and cultures of those communities. The REPAG has since adopted this new collective term, which for its members values the very people they aim to empower and support.¹⁰

Looking ahead

Diverse and inclusive public involvement is essential if research is to be relevant and provide better health outcomes for all. Patient and public involvement has been a cornerstone of NIHR since it was established in 2006. At this pivotal time, in which a spotlight has been shone on the real-world effects of health inequalities linked to race and ethnicity in the UK, we aim to move closer to meeting our Inclusive Opportunities Standard: a standard that requires research to be 'informed by a diversity of public experience and insight'¹¹ so that it leads to treatments and services that reflect the needs of everyone.

'By 2025 we expect all people using health and social care, and increasing numbers of the public, to be aware of and choosing to contribute to research by:

- identifying future research priorities and research questions
- informing the design and development of innovations
- participating in research studies
- advocating for the adoption and implementation of research in the NHS.¹²

⁹ UK Standards for Public Involvement <https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/>

¹⁰ A number of organisations have been moving away from using BAME terminology, including the UK government - <https://www.gov.uk/government/publications/inclusive-britain-action-plan-government-response-to-the-commission-on-race-and-ethnic-disparities/inclusive-britain-government-response-to-the-commission-on-race-and-ethnic-disparities>

¹¹ <https://sites.google.com/nih.ac.uk/pi-standards/standards/inclusive-opportunities>

¹² NIHR (2015) Going the Extra Mile: Improving the nation's health and wellbeing through public involvement in research - <https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf>

Introducing the Race Equality Framework

- 12 Infographic: Why should organisations use the Framework?
- 13 What is the Race Equality Framework?
- 14 Why organisations should adopt the Framework
- 15 The five domains of the Framework
- 16 Domain 1: Individual Responsibility
- 17 Domain 2: Leadership
- 18 Domain 3: Public Partnerships
- 19 Domain 4: Recruitment
- 20 Domain 5: Systems & Processes

02

Why should organisations use the Framework?



Evidence tells us that action is needed

Black African-, Asian- and Caribbean-heritage people have a history of mistrust of research and remain significantly under-represented in our public involvement community.



There are legal and national imperatives

Using the Framework will help organisations meet their obligations under the Equality Act 2010 and the UK Standards for Public Involvement.



Inclusive research is robust research

If our aim is to improve the health of all, then we must learn also to listen and respond to the voices we don't usually hear.



Its applications go beyond race equality

The self-assessment template can be adapted, should organisations wish to assess their competence in other areas, e.g. other racialised/ ethnic groups or protected characteristics.

WHAT IS THE RACE EQUALITY FRAMEWORK?

The Race Equality Framework is a self-assessment tool designed to help organisations improve racial equity in health and care research.

The purpose of the Framework is to guide organisations in health and care research on their path to racial competence. In so doing, it aspires to eliminate racial inequity in health and care research and to improve equity in health and care outcomes for Black African-, Asian- and Caribbean-heritage communities. Its scope is as follows:

- to provide a model for inclusivity in research
- to increase the recruitment, involvement and participation of Black African-, Asian- and Caribbean-heritage people in research
- to hold researchers and organisations accountable for racial equity.

At its core sits a template of 50 self-assessment questions covering the following five critical areas or domains of organisational activity:

1. Individual Responsibility
2. Leadership
3. Public Partnerships

4. Recruitment
5. Systems & Processes

Answering these important and self-defining questions will not be a quick exercise: each requires careful consideration, responses backed up by evidence and, where necessary, well-thought-out plans of action.

Although primarily designed for the health and care research sector, the Framework can be adapted for use by any organisation, department or team that recruits members of the public to its panels, committees or advisory groups, or involves them as collaborators or participants in research.

Although the self-assessment questions are concerned with race, they can be adapted to probe any of the protected characteristics under the Equality Act 2010.¹³

¹³ <https://www.legislation.gov.uk/ukpga/2010/15/contents>



WHY ORGANISATIONS SHOULD ADOPT THIS FRAMEWORK

There are compelling reasons why organisations – and not just those in the field of health and care research but any that use public partnerships in their work – should use this Framework.

A number of those reasons have already been set out in the Introduction (p.9). They include the under-representation of diverse communities in health and care research and their over-representation in health, care and wider inequality and inequity. Completing the self-assessment will also give organisations the information, insight and evidence they need to make informed decisions and meet their obligations under the public sector equality duty.

In addition, it has been found that organisations that promote racial equality and equity are more likely to find it easier to reach, connect and work with diverse communities, be better at managing risks and make



better business decisions—all as a result of the enhanced insight and problem-solving that diversity brings. Not surprisingly, such organisations are also more likely to be high-performing: globally, employers in the top 25% in terms of racial diversity are reported to be 33% more likely than the least diverse companies to exceed their profit margin.¹⁴

Organisations that use diverse public partnerships stand to gain a similar range of benefits. However, in the health and care research sector, Black African-, Asian- and Caribbean-heritage patients continue to face systemic barriers to participation.

Improving this situation requires transformational thinking and new ways of reaching diverse patient groups. This is where the Framework can help. By completing the 50 self-assessment questions, organisations will be able to:

- change the way they think
- create a more inclusive environment for Black African-, Asian and Caribbean-heritage patients, service users and carers
- develop closer ties with these communities
- increase recruitment/involvement among patients and service users from these communities.



A virtuous circle

By sharing the outcomes of their self-assessment, organisations can visibly demonstrate their commitment to supporting diverse communities.

This will act as a beacon to Black African-, Asian- and Caribbean-heritage people, serving in turn as a starting point for developing strong, trusting and mutually advantageous relationships.

¹⁴ Delivering through Diversity (McKinsey Management Consultants, January 2018) - <https://www.mckinsey.com/capabilities/people-and-organizational-performance/our-insights/delivering-through-diversity>

THE FIVE DOMAINS OF THE FRAMEWORK

1. INDIVIDUAL RESPONSIBILITY

DEFINED AS:

Individuals being supported to take responsibility for highlighting, challenging and eliminating inequity, acting as allies to foster good relations.

2. LEADERSHIP

DEFINED AS:

Behaviours that:

- a) Drive improvement.
- b) Empower individuals and harness their talents.
- c) Create a safe environment in which to challenge poor practice, where racial equity is prioritised, well-resourced and leads to tangible change.

3. PUBLIC PARTNERSHIPS

DEFINED AS:

Equal partnerships that:

- a) Are respectful and provide a platform for learning and change.
- b) Instil a co-production ethos in all areas of work.

4. RECRUITMENT

DEFINED AS:

Implementing diversity recruitment strategies that:

- a) Use data to understand how and where to focus efforts to recruit Black African-, Asian- and Caribbean-heritage public contributors.
- b) Are monitored for their effectiveness.

5. SYSTEMS & PROCESSES

DEFINED AS:

- a) Identifying and removing barriers to involvement.
- b) Using flexible models and ways of working that recognise and respect the circumstances and experiences of Black African-, Asian- and Caribbean-heritage people.

DOMAIN 1
INDIVIDUAL
RESPONSIBILITY

What to look for

Individuals are encouraged to reflect on how their attitudes and/or behaviours might disadvantage their Black African-, Asian- and Caribbean-heritage colleagues. They are challenged and supported to take responsibility for/seek opportunities to/set SMART goals for, enhancing their learning and development to improve their racial competence and their understanding of the impact of structural racism on health and care outcomes; and to build diverse networks beyond their own culture. Safe spaces for conversations about race are available, as is reverse mentoring and coaching on race. Teams understand what allyship is and how to be effective in this role. Black African-, Asian- and Caribbean-heritage public contributors are listened to, developed and supported.

Self-assessment questions

1. List all the race equality training (include training in allyship), that your organisation/ department provides (content, frequency, etc.). How does it ensure that all staff receive such training, and what efforts does it make to assess the quality/ impact of the training?
 2. What further opportunities for learning and development in the area of race equality not listed in Q1 does your organisation/department make available to staff? (For example, reverse mentoring, coaching, building diverse networks that go beyond individuals' own culture.)
 3. How does your organisation/department actively encourage staff to pursue race equality training, learning and development, as captured in the questions above? (For example, through individual performance objectives, setting SMART goals.)
 4. How does your organisation/department measure the outcome of race-related training, learning and development in terms of the extent to which staff apply it in their work and day-to-day interactions with Black African-, Asian- and Caribbean-heritage people?
 5. What is your organisation/department's definition of an 'ally'; and what form of allyship does it provide members of the public, as well as public contributors and members of staff of Black African, Asian or Caribbean heritage, in its everyday work and conversations? Give examples.
 6. What support systems does your organisation/department have in place for Black African-, Asian- and Caribbean-heritage public contributors? (For example, a named contact whom they can approach on matters to do with race; a process for raising complaints to do with race.)
 7. What development schemes does your organisation/department provide for Black African-, Asian- and Caribbean-heritage public contributors? (For example, mentoring, buddying scheme and/or shadowing opportunities.) How are they encouraged to use them and what is the uptake of such schemes?
 8. Within your organisation/department, how are Black African-, Asian- and Caribbean-heritage public contributors and staff who experience everyday racism and/or micro-aggressions encouraged to challenge such behaviour?
 9. How does your organisation/department support individuals to call out instances of discrimination or racism against Black African-, Asian- and Caribbean-heritage public contributors and staff, when they see it?
 10. Within your organisation/department, how are individuals encouraged and supported to become advocates for Black African-, Asian- and Caribbean-heritage public contributors, staff and members of the public?
-

DOMAIN 2 LEADERSHIP

What to look for

Senior leaders are aware of the historical and current climate and context of race, as well as their responsibility to pursue solutions in this area. Strategies, plans and SMART goals are in place for engaging with and involving the public in work to improve organisational behaviours and practice. A senior leader executive champion provides visible leadership and accountability for driving organisational improvements and behavioural change. Senior leaders are open to and seek out opportunities for learning, such as reverse mentoring and/or coaching, to improve their racial competence. Initiatives to tackle racial inequity are fully resourced and supported; and examples of good practice are celebrated and shared.

Self-assessment questions

11. Does your organisation/department's vision for its health and care research strategy include becoming an anti-racist organisation? If so, how does this vision translate into organisational/departmental aims and objectives and ultimately into action? If not, how does your organisation/department make clear its commitment to racial equality in health and care research?
 12. What steps have senior leaders taken to create an authentic, inclusive workplace environment that empowers and values the talents of Black African-, Asian- and Caribbean-heritage people?
 13. What steps have senior leaders taken to encourage racial diversity on your organisation/department's advisory groups, committees, and patient and public involvement boards?
 14. Do senior leaders consult the public directly on strategies and policies to do with race? If yes, what examples are there of such consultation being used to shape strategy and policy in your health and care research?
 15. Has your organisation/department appointed any senior champions from its executive team to lead on matters of race? (For example, as the lead on racial equity/equality in health and care research, or as a freedom-to-speak-up guardian or advocate.)
 16. How have senior leaders in your organisation/department demonstrated their commitment to the Race Equality Framework? (For example, how and to whom they have allocated this work, the strategies and resources they have put in place to support them and how they intend to review the process and outcomes.)
 17. What measures does your organisation/department have in place to ensure that it is open about the number and outcome of complaints it receives against managers and senior leaders where racism and/or discrimination appears to be a factor?
 18. How do senior leaders in your organisation/department ensure that the research cycle does not contribute to racial bias and that any bias that is found is eliminated?
 19. How do senior leaders promote the value and importance of building partnerships with the public?
 20. What training, mentoring and coaching on racial equality/equity and anti-racism is provided for senior leaders; and what checks are in place to ensure that everyone eligible receives it?
-

What to look for

Surveys and audits demonstrate efforts to partner with Black African-, Asian- and Caribbean-heritage people and communities. Black African-, Asian- and Caribbean-heritage people are actively involved in co-production work and in informing and shaping priorities. Relationships are established and sustained through continued engagement and dialogue. Black African-, Asian- and Caribbean-heritage people report positive experience of their interactions and colleagues are appreciative and recognise and value the contributions they make.

Self-assessment questions

21. What action has your organisation/department taken, or what evidence has it used, to understand how Black African-, Asian- and Caribbean-heritage communities view their relationship with the healthcare system? (For example, lack of trust, experience of discrimination.)
 22. How does your organisation/department internally encourage the involvement of Black African-, Asian- and Caribbean-heritage communities in its work?
 23. How does your organisation/department go about identifying which communities it is not engaging with?
 24. Does your organisation/department require research leaders to establish long-term links with Black African-, Asian- and Caribbean-heritage community groups to help build the latter's trust and confidence? If so, how does it go about this? What benefits to both the organisation and those communities have those links brought?
 25. What partnerships has your organisation/department built with organisations or individuals of Black African, Asian and Caribbean heritage with a view to:
 - a) being able to inform them of opportunities to participate in research
 - b) understanding barriers to their participation in research
 - c) co-designing research, and
 - d) them informing and shaping research priorities?
 26. Does your organisation/department ever sub-contract/contract Black African-, Asian- or Caribbean-heritage organisations to carry out research? If not, does it have any intentions to do so? If not, please give reasons for your answer.
 27. What opportunities and incentives does your organisation/department offer Black African-, Asian- and Caribbean-heritage public contributors to apply their skills, lived experiences and diversity to other activities not related to research—in particular, to inform or lead on training on race or to sit on selection/interview panels?
 28. How does your organisation/department define and measure improvement in terms of public partnership activities? (For example, number or type of partnerships, diversity profile, outcomes achieved.) How does it recognise and share progress and good practice in this area?
 29. How does your organisation/department monitor how the people with whom it engages, as public contributors, research participants or panel/committee/board members, view their interactions? (For example, the extent to which they feel heard and their contributions are valued by the healthcare system.) Can the results be analysed by race?
 30. How does your organisation/department communicate its appreciation to public contributors and make them feel recognised and valued for their contributions?
-

DOMAIN 4 RECRUITMENT

What to look for

Relationships are established with community groups/organisations to build trust and understand barriers to recruitment. Strategies are based on evidence and best practice. SMART recruitment targets are set and monitored, effectiveness is reviewed and action is taken to tackle shortcomings. Diverse media are used. Information is tailored and culturally sensitive in terms of language. Partnering with Black African-, Asian- and Caribbean-heritage organisations forms a key part of organisational/departmental recruitment efforts.

Self-assessment questions

31. How does your organisation/department use data to understand the demographic profile of local areas, and how does it use this information to inform where to focus its recruitment activities?
 32. How does your organisation/department review its recruitment and selection processes to determine whether they are delivering the organisation/department's desired racial equity outcomes?
 33. What does your organisation/department do to ensure that its recruitment and selection processes (for public contributors, research participants and panel/board/committee members) are not biased against/do not disadvantage people of Black African, Asian or Caribbean heritage?
 34. What does your organisation/department do to ensure that Black African-, Asian- or Caribbean-heritage communities know about opportunities to become public contributors, research participants and panel/board/committee members? (For example, through long-term relationships with patients, service users and carers, information sessions in local venues, outreach work, articles in community newspapers or other diverse media.)
 35. With regard to Q34 above, how does your organisation/department decide what action to take in order to reach communities?
 36. What attempts has your organisation/department made to understand the reasons behind Black African-, Asian- and Caribbean-heritage people not applying for positions as public contributors, research participants or panel/board/committee members? (For example, mistrust of research aims, fear of tokenism.)
 37. With regard to Q36 above, what actions has your organisation/department taken to challenge those reasons and how successful have those actions been?
 38. What attempts does your organisation/department make to encourage applications from Black African-, Asian- and Caribbean-heritage people through its recruitment materials? (For example, materials are published in various languages, contain diverse images, include a statement expressing the desire to recruit from these communities.) How successful have these attempts been?
 39. If not covered in the questions above, what attempts has your organisation/department made to apply recognised best practice to how it recruits Black African-, Asian- and Caribbean-heritage public contributors, research participants or panel/board/committee members? How successful have these attempts been?
 40. Does your organisation/department have a budget for recruiting public contributors (of all backgrounds); if so, what is the process for setting and reviewing it?
-

**DOMAIN 5
SYSTEMS &
PROCESSES**

What to look for

Strategies for public involvement set out clear plans and SMART goals for addressing the under-representation of Black African-, Asian- and Caribbean-heritage public contributors. Public-facing policies on health and care research are impact-assessed and there is evidence of learning from Black African-, Asian- and Caribbean-heritage communities. There are flexible models and ways of working that speak to the circumstances of Black African-, Asian- and Caribbean-heritage people.

Self-assessment questions

41. What systems/processes does your organisation/department have in place to help it understand the health and care needs of the population it serves? How comprehensive is the information they provide?
 42. How regularly does your organisation/department carry out race equality impact assessments on its public-facing policies and projects on health and care research? What processes are in place to ensure that actions falling out of these assessments are carried out in a timely manner?
 43. How often does your organisation/department audit its systems and processes to identify barriers to the public involvement of Black African-, Asian- and Caribbean-heritage people? (For example, the language in which material is written, the use of digital communication tools.) What processes are in place to ensure that actions identified by these audits are carried out in a timely manner?
 44. What models or ways of working has your organisation/department introduced that acknowledge the circumstances of Black African-, Asian- and Caribbean-heritage people? (For example, outreach activity at weekends.)
 45. What is your organisation/department's approach to co-producing research with Black African-, Asian- and Caribbean-heritage people? How does it ensure that its approach is effective?
 46. Within your public involvement work, what systems/processes does your organisation/department have in place to monitor the racial diversity profile of public contributors, research participants and panel/board/committee members?
 47. With regard to Q46 above, how does your organisation/department then use this information? (For example, to identify under- or over-representation amongst certain groups; to set targets for maintaining or increasing representation in certain groups.)
 48. What is your organisation/department's process for deciding what actions it will take in response to suggested changes, benefits and learning identified through Black African-, Asian- and Caribbean-heritage public involvement?
 49. How does your organisation/department record all the learning outcomes (whether favourable or critical) from its public involvement activities and then share these with staff and members of the public?
 50. How does your organisation/department encourage its funded partners (including research collaborators, contractors and other third parties) to demonstrate racial equity in terms of awarding research contracts to Black African-, Asian- and Caribbean-heritage people or to organisations that represent them?
-

The Framework in Action

- 22 Infographic: Summary guide to using the Framework
- 23 How to use the Framework
- 25 Stage 1: Establishing your organisational readiness (steps 1 to 8)
- 26 Stage 2: Carrying out your self-assessment (steps 9 to 12)
- 27 Stage 3: Using the results to improve your racial competence (steps 13 to 20)
- 28 What a racially competent organisation looks like
- 29 Measuring the impact and benefits of change

Summary guide to using the Framework

The Race Equality Framework for public involvement in research comprises 20 steps across three stages.

Stage 1: Establish your organisational readiness

1. Discuss budget and secure agreement
2. Appoint a project lead to oversee the work
3. Identify an executive sponsor
4. Set up your self-assessment team
5. Make sure your team is trained in race equality
6. Recruit allies to support you in this work
7. Establish a self-assessment schedule
8. Choose the assessment scale



Stage 2: Carry out your self-assessment

9. Rate your performance across the questions
10. Consult more widely where relevant
11. Carry out a midpoint review
12. Identify good practice, gaps and action areas

The self-assessment questions span five areas of organisational activity.



Individual responsibility



Leadership



Public partnerships



Recruitment



Systems and processes

Stage 3: Use results to improve racial competence

13. Decide on actions and timescales
14. Celebrate and share current successes
15. Create a SMART action plan for change
16. Finalise the plan with senior management
17. Monitor progress, change and impact
18. Review learning and embed into activities
19. Write and share case studies
20. Continue on the path to racial competence

What is 'racial competence'?

It is the ability to recognise one's bias, positively interact with racial diversity and have open conversations about race that show a willingness to hear, learn and act.

HOW TO USE THE FRAMEWORK

We anticipate that your self-assessment will take anything from between one to three months to complete. Exactly how long will depend on the size of your organisation or department, the resources you have available, how much work you have already done in this area and how much you intend to carry out in one go, e.g. you may choose to concentrate on one domain at a time.

Before starting the process, it may be helpful to think about what support is already available to you and what more you might need to put in place.

Strong leadership will be crucial. Race is a complex and multifaceted area, and for various reasons some individuals may be hostile to this work. Leaders must therefore provide the necessary support and change-management ethos to enable challenging conversations to take place, facilitate learning and growth, and drive suggested improvements and cultural change.

Another vital element and a key partner of leadership

is **allyship** (see [Appendix E](#) for a list of allyship resources). At the same time as promoting the principles of allyship, it will be important to call out behaviours that marginalise and disempower people and to take appropriate action against such behaviours wherever they arise. It is important to recognise that while change itself may be led by a few people, it is everyone's responsibility to hold themselves accountable for it.

A third critical aspect is who you assign to **your self-assessment team**. A broad and diverse range of perspectives will ensure that you get the most out of the process. For that reason, we recommend that you consider appointing the following:

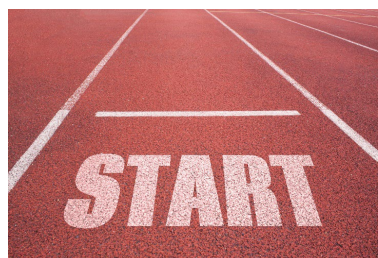
- people with experience of working with the public
- people with experience of conducting self-assessments/audits
- people with specific expertise in race equality/racial equity
- members of the public/service users/research

participants of diverse ethnic backgrounds

- members of external organisations who can act as peer assessors.

Members of your team in these last two categories will be particularly helpful for introducing a degree of independent challenge to your findings. You may also find it helpful to conduct some form of **consultation**, e.g. with staff, health and care professionals, public contributors, patients, service users, carers and/or other members of the public, to capture their views and experiences.

Finally, as your self-assessment gets underway we recommend that you consider producing at least one **case study**. Case studies will allow you to formally chart the improvements you make. By doing so, Black African-, Asian- and Caribbean-heritage communities will be able to see that you are serious about overcoming racial disparities in health and care research. This in turn will help you to build trust and confidence among these communities.



STAGE 1. ESTABLISHING YOUR ORGANISATIONAL READINESS

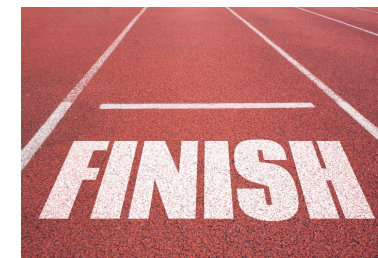
Steps to prepare for your self-assessment.

STAGE 2. CARRYING OUT YOUR SELF-ASSESSMENT

Steps involved in carrying out your self-assessment.

STAGE 3. USING THE RESULTS TO IMPROVE RACIAL COMPETENCE

Steps for getting the most from your findings.



HOW TO USE THE FRAMEWORK (cont.)

Taking the preceding guidance into consideration will ensure that you get the best out of the self-assessment exercise. It will also increase the likelihood that your results will lead to successful outcomes.

Other steps you may find it useful to take before you start on the self-assessment questions are set out on p.25 under Stage 1: Establishing your organisational readiness. It is not mandatory for organisations to complete all the steps in Stage 1—we recognise that you may be at different stages of learning and change—but you may find them helpful as a checklist.

Once you have completed all the necessary groundwork work, you will be ready to proceed to Stage 2: Carrying out your self-assessment (p. 26). The self-assessment questions are deliberately multifaceted to challenge organisations and encourage deeper self-reflection—e.g. Why is this needed? What prevents this from happening now? How will doing this help us to bring about the outcomes we are seeking? Simple yes/no/not applicable answers will not suffice.

This stage is followed by the final one, Stage 3: Using the results to improve your racial competence (p.27). See p.29 for further information on how to measure your progress to becoming racially competent.

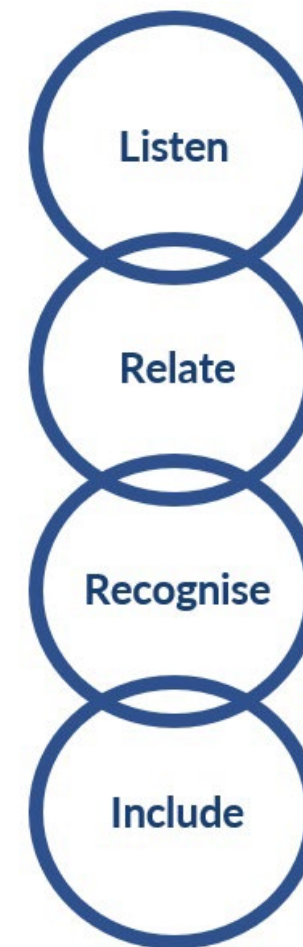
The Patient–Public Partnership Model: a new way of working

At all stages of this work it will be important to acknowledge, and where appropriate be guided by, the patient–public voice. The simple model to the right is intended to help you do this.

How to include the patient–public voice in this work

- ✓ **Listen** to patients and members of the public from Black African-, Asian- and Caribbean-heritage communities and acknowledge their long-standing lack of trust in health and care and research.
- ✓ **Relate** more deeply and strongly to these communities by engaging them in *sustained, open and honest* conversations.
- ✓ **Recognise** what you as an institution are doing that is not inclusive and how that causes harm.
- ✓ **Include** patients and members of the public from these communities by inviting them to be part of this work, giving them credit for their opinions and compensation for their time.

The Patient–Public Partnership Model



Stage 1: ESTABLISHING YOUR ORGANISATIONAL READINESS

STEPS 1 to 8

01 Schedule time in departmental meetings to discuss your rationale for adopting the Framework. This will help secure agreement for this work. Use the discussions to pinpoint what you need to do and the budget you will need to carry out the self-assessment.

02 Appoint a project lead to oversee the self-assessment. (This could be a public involvement lead or researcher, for example.)

03 Identify an executive sponsor who will build the lessons arising from the Framework into wider organisational learning, development plans and strategies.

04 Set up your self-assessment team. The team should be diverse and include experts by experience as well as individuals with experience of working with the public, experience of conducting self-assessments/ audits and specific expertise in racial equality/equity. Make sure that everyone is clear about their roles and responsibilities.

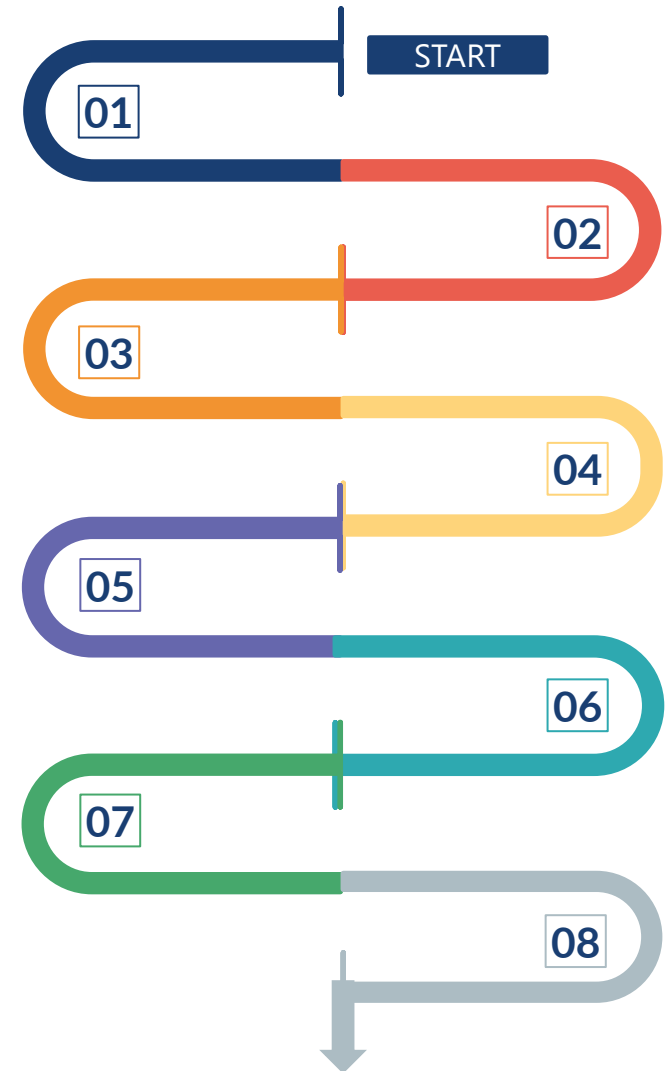
05 Make sure that all members of your self-assessment team have received race equality training.

06 Recruit allies to support and champion this work. (These could be individuals who have expressed an interest in matters pertaining to race.)

07 Establish a schedule for your self-assessment, making sure that you:

- give your project lead enough time and support to oversee the work, and
- factor in midpoint reviews to reflect on early findings.

08 Choose the assessment criteria or scale you will use to evaluate your organisation/department's performance on each question (e.g. very good – good – poor – very poor).



Stage 2: CARRYING OUT YOUR SELF-ASSESSMENT

STEPS 9 to 12

09 Work through the Framework's five sets of self-assessment questions, rating how your organisation /department is performing against your chosen criteria or scale.

You may find it helpful to consult other staff/ departments on certain questions and/or to create a database in which to store answers and supporting documents.

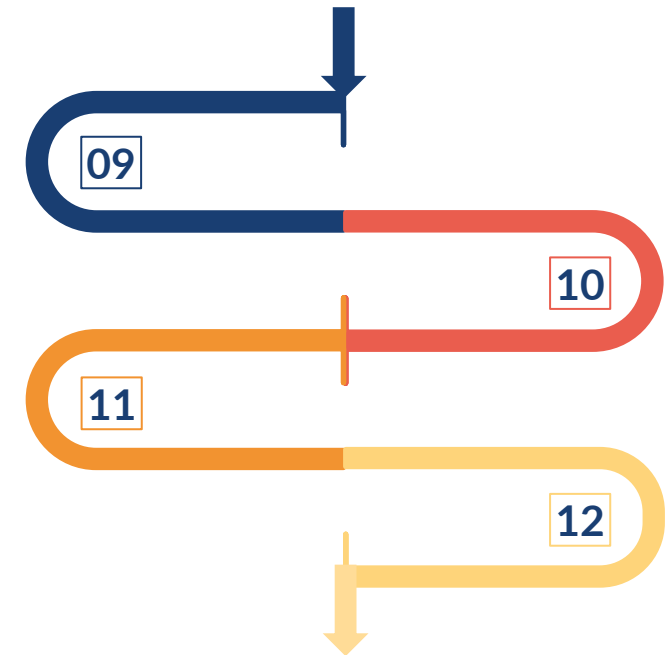
10 Where relevant, consider carrying out some form of consultation, e.g. with staff, health and care professionals, public contributors, patients, service users, carers and/or other members of the public. This could be for the purpose of fact-checking or for obtaining further information.

11 We recommend that you perform a midpoint review, to identify any challenges, share good practice and act on early findings.

It may also be useful to introduce an element of independent challenge to your findings at this stage.

12 Applying your findings to your research cycle (or other area of work that you are assessing), establish the following:

- a. areas of good practice
- b. gaps in research
- c. where you need to take action to improve race equity.



Stage 3: USING THE RESULTS TO IMPROVE YOUR RACIAL COMPETENCE

STEPS 13 to 20

13 Looking at your results from STEP 12, decide what action(s) you are going to take and over what timescale (e.g. short-, medium- or long-term or no action).

14 Celebrate and share any further examples of good practice.

15 Draft a SMART (Specific, Measurable, Achievable, Realistic and Time-Bound) action plan for change, targeting the areas you have identified.

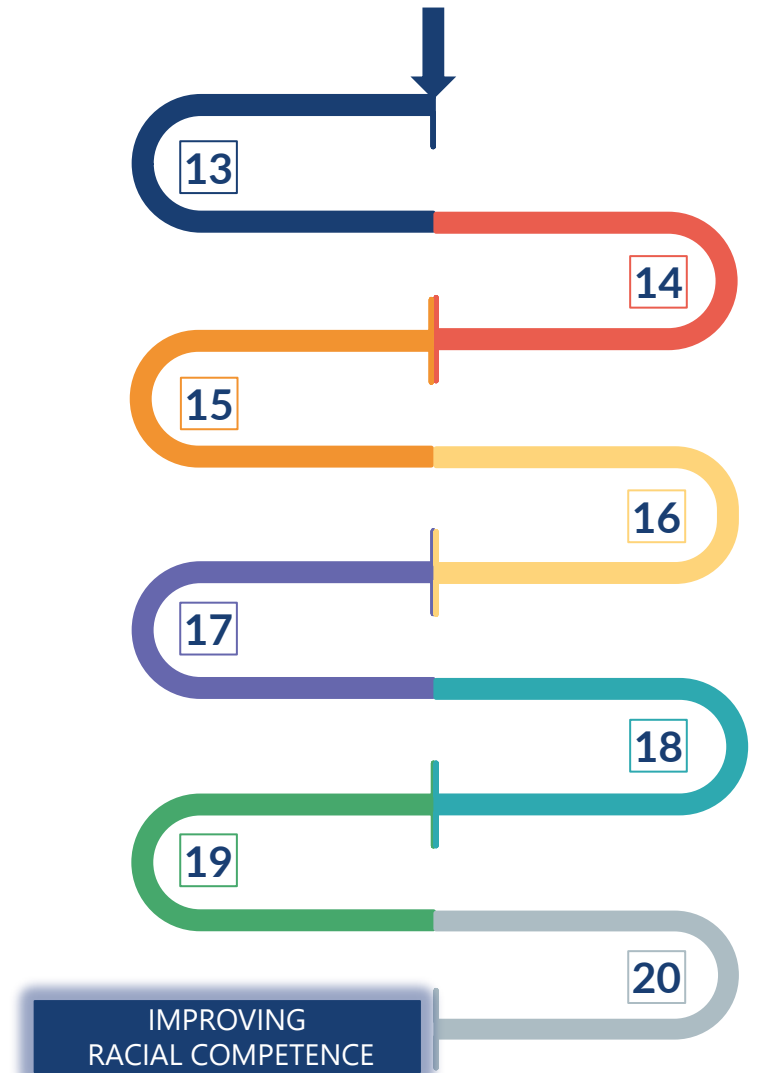
16 Finalise the plan with your senior management team and identify who will be monitoring its implementation – it should not be left to one individual.

17 Chart your progress, impact and change. Consider building these actions into your team-building activities to maintain momentum and focus.

18 Review learning—identify opportunities to build learning into your organisation’s equality, diversity and inclusion (EDI), public involvement and/or customer service strategies, policies, activities or plans.

19 Write up one or more case studies, in order to share your experiences internally and externally.

20 Review your racial competence regularly, incorporating any lessons learnt into the process.



WHAT A RACIALLY COMPETENT ORGANISATION LOOKS LIKE



The Race Equality Public Action Group's definition of racial competence is set out below. It was written by a Black member of the REPAG and subsequently approved by all REPAG members.

Racial competence is:

The ability to recognise and check one's own bias; interact with racial diversity in a positive manner; and have open and honest conversations about race in ways that show a willingness to hear, learn and take action.

Racial competence means understanding the impact of structural racism and fostering a culture of allyship that challenges organisational practices and behaviours that exclude Black African-, Asian- and Caribbean-heritage people and other racialised groups.

Being racially competent means translating our statements into action to promote equity of voice and equality of opportunity.

A racially competent organisation should display the following attributes:

- empathy
- authenticity
- integrity
- transparency
- accountability

Participants in our community consultation events believe that it is not for organisations to define racial competence. Rather, they believe it is for members of their communities (with lived experience) to define it and for organisations then to demonstrate, with clear evidence, how they meet that definition.

Organisations may therefore wish to consult their communities in order to develop their own working definition.

MEASURING THE IMPACT AND BENEFITS OF CHANGE

There are lots of different approaches to measuring the impact and benefits of change.

Which approach you choose will depend largely on the nature of the changes you are making and what impact or benefits you are seeking to achieve.

Nevertheless, as a starting point you may find the following useful:

1. Agree the change, impact or benefits that you wish to bring about.
2. Translate the above into clear goals, using simple and precise language so that everyone is clear about what they are trying to achieve.
3. Draw up an action plan to establish what actions and resources you will need to achieve your goals.
4. Identify one or more SMART (specific, measurable, achievable, realistic and time-bound) indicators or metrics for your activities and goals.

Below, we have set out some quantitative metrics that your organisation may choose to consider. Please note that this list is not intended to be exhaustive or prescriptive.

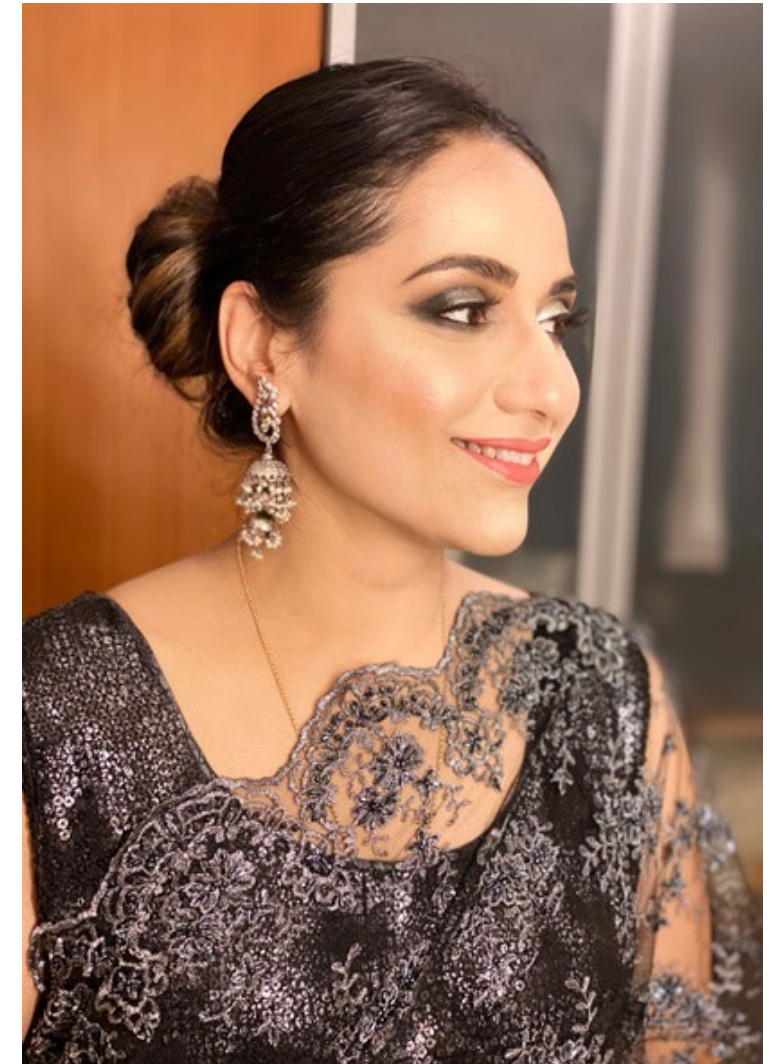
- percentage of people recruited onto trials/ committees/ panels/ advisory groups who are of Black African, Asian or Caribbean heritage
- percentage of public contributors leading on co-

production work within your team/department/ organisation who are of Black African, Asian or Caribbean heritage

- percentage of public contributors providing training on race in your team/department/organisation who are of Black African, Asian or Caribbean heritage
- percentage of staff who have received training in racial competence
- percentage of leaders who have developed personal action plans to improve their racial competence
- percentage of leaders trained in allyship
- mentoring and/or coaching programmes to improve racial competence in place
- number/proportion of researchers motivated to take research projects forward to address racial disparities in health and care.

You may also find it helpful to include qualitative metrics, such as those gathered through consultation exercises. For example:

- quality of medium- to long-term partnerships developed with organisations representing the interests of racialised communities.



Appendices

- 31 Infographic: The Race Equality Public Action Group
- 32 A: About the NIHR's Race Equality Public Action Group
- 33 B: People who have made a substantial contribution to the Framework
- 34 C: Pilot partner organisations and early adopters
- 35 D: Case study summaries
- 42 E: Allyship resources
- 43 F: Sample role profile: Ambassador for public involvement in research
- 45 G: Glossary of terms

The Race Equality Public Action Group

We are Black African-, Asian- and Caribbean-heritage people working alongside the NIHR and health and academic communities.



The REPAG is a public-facing group focused on racial equity in health and care research.

Our purpose

To give Black African-, Asian- and Caribbean-heritage people stronger input in shaping research and putting evidence into practice.



To help the NIHR understand and eliminate racial inequity, and embed racial equity in its work.



Our objectives

Understand barriers to involvement in health and care research



Enable learning by flagging challenges facing public involvement



Develop relationships to amplify public voice and drive improvement



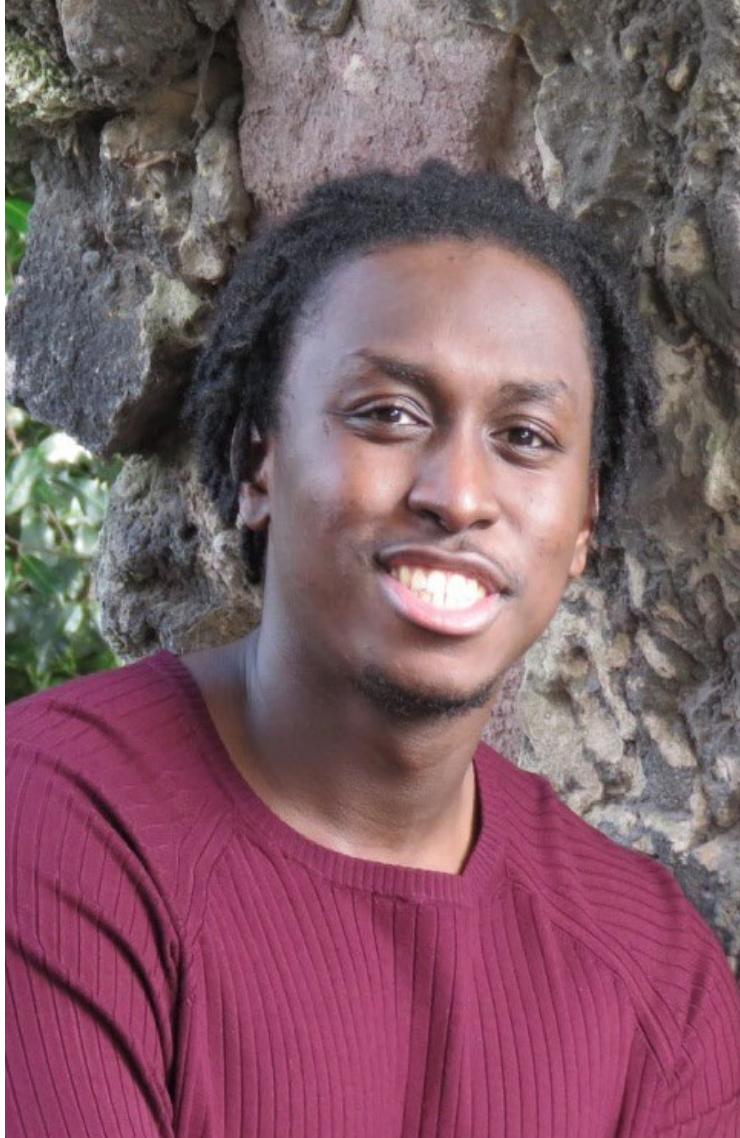
Promote good practice in the health and care system



For more information

Please contact Framework lead co-creators David Faluyi (NIHR Public Contributor) or Fay Scott (Senior Public Involvement Manager, NIHR) at:
repag_enquiries@nihr.ac.uk

A: ABOUT THE NIHR'S RACE EQUALITY PUBLIC ACTION GROUP



The Race Equality Public Action Group (REPAG) is a public-facing group focused on advancing and accelerating racial equity in health and care research through the lens of public involvement, engagement and participation, i.e. public partnerships.

Set up in October 2020, the NIHR's REPAG is a dynamic, public-facing group committed to improving racial equity in health and care research. Its executive sponsor is Jeremy Taylor, Director for Public Voice and of the Centre for Engagement and Dissemination, which hosts the Group.

The REPAG is made up of Black African-, Asian- and Caribbean-heritage public contributors—each of whom brings a range of professional and lived experience—working alongside NIHR colleagues and members of both the health and academic communities. This collaborative approach recognises that, individually, no-one has all the answers. Indeed, it is only by public members and

academics working together that we have been able to co-produce this Framework.

The REPAG's purpose is twofold:

1. To give Black African-, Asian- and Caribbean-heritage people a stronger voice in shaping the research agenda and research design; and to give them a stronger voice in putting evidence into practice.
2. To help the NIHR identify, understand and eliminate racial inequity; and to help it proactively embed racial equity in its day-to-day work and forward planning.

To achieve this it has four objectives, as set out below.

OBJECTIVE 1

To conduct a series of listening exercises in order to understand how to remove the barriers (for individuals and organisations) to getting involved in health and care research, with particular regard to Black men.

OBJECTIVE 2

To act as a conduit for organisational learning, by flagging up challenges facing public involvement in research.

OBJECTIVE 3

To develop stakeholder relationships with organisations that have a common cause, amplify the public voice and drive improvement in health and care research systems, processes and culture.

OBJECTIVE 4

To produce resources to promote learning and good practice in racial equity and racial competence throughout the health and care system.

B: PEOPLE WHO HAVE MADE A SUBSTANTIAL CONTRIBUTION TO THE FRAMEWORK (includes current and former members of the REPAG)

ANDRÉ TULLOCH, NIHR Public Contributor

CAROLINE BARKER, Strategic Lead, Patient and Public Involvement, University Hospital Southampton NHS Foundation Trust and UK Clinical Research Facility Network

CLAIRE WALLACE-WATSON, Project Support Co-ordinator, NIHR Digital Office

DAVID FALUYI, NIHR Public Contributor, Lead Co-creator of the Framework

FAY SCOTT, REPAG co-chair and founding member, Lead co-creator of the Framework, Senior Public Involvement Manager, NIHR

JON COLE, Assistant Director, Public Involvement & External Engagement, NIHR Evaluation, Trials and Studies Commissioning Centre

JOHN CASTLEDINE, Head of Learning, Development and Design, NIHR Clinical Research Network

DR KATE HOLMES, Head of Collaborations, NIHR National Office for Clinical Research Infrastructure

KATIE COOK, Strategic Oversight Lead for the REPAG, Senior Programme Manager, NIHR

KRYSIA DZIEDZIC, Director of Impact Accelerator Unit, NIHR Senior Investigator and Professor of Musculoskeletal Therapies, Keele University

LAURIE OLIVA, formerly Head of Public Engagement and Involvement, NIHR Clinical Research Network Co-ordinating Centre

MARK SLOCOMBE, NIHR Public Contributor

MIKE ROGERS, Assistant Director, Global Health Research, NIHR

NIKKI BENT, Senior Administrator, NIHR

PAVEL OVSEIKO, Senior Research Fellow, University of Oxford and NIHR Oxford Biomedical Research Centre

ROYSTON JOHN, REPAG co-chair, International CEO of the National Coalition Building Institute

SISDR SANDRA RICHARDS, NIHR Public Contributor

DR SARAH KNOWLES, Research Fellow, Knowledge Mobilisation, Centre for Reviews and Dissemination, University of York

ZAHRA KOSAR, NIHR Public Contributor

The REPAG also wishes to acknowledge and thank KATHERINE AXEL-MCKAY. Through her support, which began in the early days of the Group and continues to this day, she has truly epitomised the spirit of allyship.

C: PILOT PARTNER ORGANISATIONS AND EARLY ADOPTERS

Pilot partner organisations

Alder Hey Children's Hospital

Doncaster Council

University Hospitals Birmingham NHS Foundation Trust, in partnership with the University of Birmingham, which includes:

NIHR Birmingham Biomedical Research Centre

NIHR Trauma Management MedTech Co-operative (Trauma MIC)

NIHR/Wellcome Trust Clinical Research Facility Birmingham (CRF)

NIHR Surgical Reconstruction and Microbiology Research Centre (SRMRC)

NIHR Applied Research Collaboration West Midlands (ARC WM)

Manchester University NHS Foundation Trust, which includes:

Vocal

NIHR Manchester Biomedical Research Centre

NIHR Manchester Clinical Research Facility

University Hospitals Southampton NHS Foundation Trust, which includes:

NIHR Applied Research Collaboration (ARC) Wessex

NIHR Southampton Biomedical Research Centre

NIHR Southampton Clinical Research Facility

Institute of Applied Health Sciences, University of Aberdeen

Keele University

Midlands Innovation Health

Midlands Partnership NHS Foundation Trust

Staffordshire and Stoke-on-Trent AHP Council

University of Oxford

NIHR Oxford Biomedical Research Centre

NIHR Oxford Health Biomedical Research Centre

NIHR Applied Research Collaboration for Oxford and the Thames Valley

NIHR Oxford Cognitive Health Clinical Research Facility

The Centre for Reviews and Dissemination, University of York

Roche Products Ltd

NIHR University College London Hospitals Biomedical Research Centre

North Central London Research Consortium

James Lind Alliance

Early adopters[†]

1. National Co-ordinating Centre for Public Engagement (NCCPE)
2. Generation Scotland
3. Division of Psychiatry, University of Edinburgh

[†] Organisations that joined after the testing period but indicated their commitment to undertaking the self-assessment and have signed a Memorandum of Understanding to that effect.

D1: CASE STUDY SUMMARY – Birmingham NIHR infrastructure

The Birmingham Focus on Education—changing hearts and minds to promote racial humility and intelligence, and meaningful culture change

We are proud to be part of the NIHR REF (Race Equality Framework) project. It has given us the opportunity and time to gain a deeper understanding of racial equity/equality and what strategies we need to put in place for meaningful change to happen. We believe we have made significant progress that will benefit both our patients and our staff in the future, and which aligns with our organisations' work on fairness and equality.

The context: Birmingham is a vibrant, culturally rich area. Nevertheless, our research and health care services often fail to reach or target patients and members of the public most in need. Taking part in the REF pilot gave us an opportunity to review and gather data on our current position on race equity; provide feedback on how we could do better; reflect upon the 'transactional', short-term nature of the indicators we were using; and help us to think critically about our aspirations to advance race equality and longer-term change.

The process: First, we secured support at the executive level so that any changes we made would be lasting and meaningful. We were fortunate that our executive teams were already on board prior to the REF exercise. Next, we established our Self-Assessment Oversight Team (SAOT). The team contained a broad cultural mix of people with varied skillsets (clinical, research, academia and management), patients and public representatives from Black African-, Asian- and Caribbean-heritage groups (9/23) and an independent expert advisor in equity from local charity BRAP (www.brap.org.uk).

Before embarking on the self-assessment, the team spent time reviewing the questions and agreeing our approach. We collected data via online questionnaires, focus groups and one-to-one interviews. As we did so, we identified a common thread or shared vision within our SAOT of wanting to promote a meaningful culture of and for change. We believe this begins with education and training, which is required to change hearts and minds and promote racial humility and intelligence; hence our case study is based on the Individual Responsibility domain. In order for the Framework to be meaningful, involving patients and members of the public—who have been instrumental in co-developing this case study—is the key thread running through all the domains. Thus, we were keen to cross-reference our findings and actions with the Public Participation domain.

Data were collected for all the Individual Responsibility questions via an online survey. This was sent to a range of staff members, from clinical to clerical, from both University of Birmingham (UoB) and University Hospitals Birmingham (UHB) and across our NIHR Infrastructure. Because the subject area is sensitive in nature, and in order to empower staff to provide honest answers, we made the survey anonymous.

Our findings: **1) Lack of awareness of race equality training:** Over 50% of respondents did not know that their organisation/department provided race equality training. Levels of awareness differed too, with 64% of UoB respondents but just 42% of UHB respondents aware. **2) Training is not actively encouraged:** While there was some evidence of awareness of training, many respondents indicated that they were not actively encouraged to attend it. **3) The perceived quality of training is low.**

Focus groups with contributors corroborated these findings. Overall, our public/patient partners felt that:

- training is needed for all staff and should be updated and made mandatory
- training should be embedded in governance structures (policies and procedures)
- training policies, e.g. EDI (Equality, Diversity and Inclusion), should be co-produced with public/patient partners and built into training
- patients/public should be part of the training team and should be respected
- training content should be in a format that is accessible to all, i.e. in plain English.

Next steps: We have set ourselves seven objectives, along with success measures and timelines, with the goal of implementing a co-developed programme of transformational education and development that engages on an emotional, intellectual and practical level. 35



D2: CASE STUDY SUMMARY – Greater Manchester NIHR infrastructure

Taking steps towards an anti-racist ecosystem in Greater Manchester

The Framework's process is rigorous and encourages an evidencebased approach. Our pilot gave us the opportunity to self-reflect and a space to ask for support. Importantly, it has also galvanised collaboration and joint action at a strategic level.

The process: Our pilot was sponsored by Manchester University NHS Trust (MFT) Research & Innovation Division (R&I). It involved all NIHR infrastructure hosted by MFT R&I, and the University of Manchester (UoM) Faculty of Biology Medicine & Health.

We took a strategic approach to engage senior leaders across all the above. We engaged public contributors through various forums (e.g. BRAG, GM PCIE Forum). A public contributor of Caribbean heritage co-led the pilot and its implementation group, which included research, academic and operational staff with experience of racial inequality.

Our findings were as follows:

- white individuals wish to move from being non-racist to anti-racist; to understand how to become better allies to those who experience racial inequality; and to understand how to champion inclusive practice and cultural change
- we need to go beyond unconscious bias and/or general Equality, Diversity & Inclusion (EDI) training at *all* levels; to identify personal actions; and to better assess the impact of training and our processes of accountability for progress on EDI
- those with direct experience of racial inequality need to be better represented in the governance functions of our research ecosystem
- systematic approaches and accompanying processes are needed to ensure that race equality and inclusion are addressed at *all* stages of the research cycle
- a lack of workforce diversity, especially at senior levels, remains an issue
- action to tackle race equality (and inclusion) needs to be adequately resourced and embedded', not viewed as an 'extra' or add-on—i.e. no more 'EDI for nothing'
- building and maintaining equitable relationships with marginalised groups remains a priority for research and public involvement; this should go beyond individual projects and programmes and have sustainability built in.

Objectives: To bring about the change we need, we have identified three overarching objectives from suggestions made by a range of constituencies during the pilot:

1. To develop capacity and confidence within the research ecosystem to become anti-racist.
2. To increase the representation of people with living experience of racial inequality within NIHR infrastructure governance and workforce.
3. To develop systems and processes to address race inequality at all stages of research and public involvement.

Good practice: It exists, but would benefit from being extended and/or joined up:

- productive and equitable research and public involvement partnerships established with individuals, community groups and organisations with living experience of racial inequality across different sections of the GM research ecosystem
- emerging examples of embedded and systematic approaches to understanding and addressing health inequalities, demographics of participation and involvement
- existence of good practice around race equality training (e.g. reverse mentoring).
- programmes evolving their focus towards more directly addressing inequalities through research and public involvement
- positive policies in NHS contexts to include those with experience of racial inequality as part of staff recruitment processes
- funding and supporting the capacity of organisations of/for people of Black, Asian and Minority Ethnic backgrounds to undertake research and public involvement.

'What's struck me is just how much the whole research cycle needs to be viewed in relation to race equality—not just the public involvement aspects of it.'

'NIHR—across all its functions—also needs to model change, especially when it comes to resourcing EDI.'

'I've realised that what I'm doing is not enough. I need to become more actively anti-racist and always bring it back to the personal, what I can do differently, and not hide behind organisational barriers and strategies.'

D3: CASE STUDY SUMMARY – James Lind Alliance (JLA)

REPAG case study

So much of the work of the JLA is about relationship building. We have therefore begun to think more clearly about this and to identify groups that we know we would like to work more closely with in a mutually beneficial relationship.

Our challenge: For the purposes of this case study, one question from the self-assessment stood out in particular: What partnerships has the organisation/department built with organisations or people of Black African, Asian, and Caribbean heritage to inform and shape research priorities?

Our focus was on the JLA Executive team, which directs the JLA and is made up of a Secretariat team of four and a team of eight JLA Advisers. Our challenge has been to consider how the JLA Executive can promote racial competence and ensure that we help priority-setting partnerships (PSPs) as best as we can to include the voices and experiences of Black African-, Asian- and Caribbean-heritage groups.

Aims, goals and objectives:

1. To provide racial competence training to the JLA Executive.
2. To scrutinise the racial competence of each stage in our PSP process and to update our Guidebook (a step-by-step guide to the methods and process involved in running a PSP) with what we have learnt. To that end, we have committed to exploring:
 - how we can encourage more representation of Black and African-, Asian-, and Caribbean-heritage people on the steering groups of PSPs
 - how past PSPs have successfully used innovative approaches to reach under-served groups—the findings from which we will share in our Guidebook
 - who responds to our survey and how PSPs can engage with under-served groups to ensure that areas of importance to these groups are not lost from the final priority-setting workshop

- how the final priority-setting workshop can better include marginalised voices and encourage attendance.

Initial actions: We will have discussions with JLA Advisors to explore ways in which we can influence PSPs. JLA Advisers will then be trained and supported to help PSPs widen access and outreach to potential respondents.

Inputs and resources: Secretariat time and funded JLA Adviser time to update the Guidebook.

SMART indicators: Updated Guidebook produced in 2023, in consultation with JLA Advisers.

Key changes, outcomes, impacts and benefits: Making engagement with Black African-, Asian- and Caribbean-heritage people more explicit in the JLA Guidebook.

More on the work of the James Lind Alliance

The James Lind Alliance is an initiative that brings patients, carers, and clinicians together in PSPs. The aim of PSPs is to identify and prioritise the 10 unanswered questions or evidence uncertainties that their community agrees are the most important; their purpose is to make sure that researchers and funders are aware of the subjects that matter most to the people who need to use their research in their everyday lives.

PSPs are condition-specific; there are now over 100 completed PSPs in a range of conditions and settings, such as asthma, type 2 diabetes and palliative and end-of-life care. PSPs are developed with our guidance but operate independently in accordance with an established method. This method is underpinned by our principles of equality, inclusivity, transparency and commitment to using and contributing to the evidence base.

A PSP usually begins when a group of proactive, interested individuals approaches us for advice about setting up a PSP. They source the necessary funding and we then appoint one of our JLA Advisers, who is independently contracted by the PSP and chairs and guides it through the PSP process. A PSP can take about 18 months from start to finish.

D4: CASE STUDY SUMMARY – Keele University

Objective: in-depth introspection

The Race Equality Framework signposts patient and public contributors towards the right questions to ask. It helps us to work with researchers to include people who are seldom heard and hardly ever involved' (Linda Parton, LINK Member).

Our findings: Since completing our Framework pilot, the following three domains have become the focus of our work in 2022 and our 'readiness for change' process:

- 1. Individual responsibility**—The Framework questions highlighted the need for action and acknowledgement of the following: racial competence, allyship and where we are now. 'We only know what we know' was a common theme in our conversations about race equity.
- 2. Recruitment**—Year 1: Appointment of a Race Equality Ambassador with lived experience to co-produce our Framework pilot. Year 2: Addition of a funded support worker with lived experience post within the Impact Accelerator Unit (IAU), to start summer 2022; beginning the journey to true representation within the PPIE department and early career growth of diverse communities in public involvement.
- 3. Public partnerships**—Co-production with communities and members is currently limited and needs strengthening.

IMPACT: At Keele there is a clear vision to scale up this initiative in 2022 and connect with stakeholders—community groups, health and care partners across the NIHR—through our Race Equality Ambassador. We will be supported in this by both emerging integrated care systems in the North-West Midlands. By sharing our research with Black African-, Asian- and Caribbean-heritage communities we will help to improve health literacy. We will also record the gender, age, social deprivation background and ethnicity of our public contributors to assess the diversity of our public involvement in research.

Learning

- examples of best practice have been captured through this process that can be shared with others

- through the action plan, recommendations for embedding racial competency will be identified and implemented in departmental policies and practices
- the action plan will create a sustainable engagement plan for Patient and Public Involvement and Engagement with Black African-, Asian- and Caribbean-heritage community groups across the North-West Midlands region.

Next steps:

- completion of the action plan, outlining diverse and inclusive models of working and partnerships with regional, evidence-based initiatives.
- a Race Equality Framework diverse working group to be formed to steer progress on our action plan
- race competency training, listening events and workshops to be held, with a view to improving community engagement and inclusivity
- future joint working with partners across the West Midlands; growing our work with current partners, including Public Involvement and Lay Accountability for Research (PILAR); supporting new collaborations with the Birmingham Region Research Centre; and establishing a climate in which research priorities and questions are informed by patients, public and communities.

'This is the first time we've taken the "lid off" how we are engaging with communities and to honestly dedicate time and resource to understanding how we can improve our practices to engage a more diverse population in research.'

Helen Duffy, Faculty Operational Manager

'The Framework is inspired by the voices of people of Black African, Asian and Caribbean heritage. Through this Framework, the Race Equality Public Action Group has set out achievable ambitions for NIHR research and its implementation. ...Having funding support from our Clinical Research Network in 2022 will be game-changing and will allow us to continue this important work with Natalie [our race equality ambassador].'

Professor Krysia Dziedzic, NIHR Senior Investigator and Director of the Impact Accelerator Unit, School of Medicine, Keele University

D5: CASE STUDY SUMMARY – Oxford NIHR infrastructure

Developing a diverse Patient and Public Involvement (PPI) group across the NIHR research infrastructure in Oxford

Diverse voices add value to research findings, aid medical decision-making and ultimately save lives.

The context: Research professionals have struggled to establish meaningful and trusting relationships with Black African, Asian and Caribbean communities. Consequently, the latter's involvement and participation in research studies is limited; research professionals remain unaware of what outcomes matter to them; and the development of treatments, technologies and medical devices continues to be skewed towards white groups.

Our process: The research infrastructure in Oxford, together with seven public members (six of Black African or Asian heritage), carried out our self-assessment. Although public members thought that their input was more relevant in the Public Partnerships domain, we discussed all five domains and decided that the Recruitment section was the appropriate starting point. Importantly, our contributors emphasised that we should strive to reach a diverse range of under-represented communities—not just their own—as this would bring about better health outcomes for everyone.

Aims, goals & objectives: Our overall aim is to build long-term, trusting relationships with patients, carers and public members from under-represented communities, to encourage them to apply for advisory and/or research co-production roles and to participate in research.

To achieve this, Oxford Health and Oxford BRC have established a new patient and public involvement advisory group, the 'Diversity in Research group'. The group currently has 15 members, 14 of whom are of Black African, Asian or Caribbean heritage. Members also identify as carers for people with learning and physical disabilities, people with long-term conditions, people from the LGBTQIA community and mothers with young children. The group's purpose is as follows:

- to increase the involvement of under-represented communities in health research
- to advise researchers on bespoke research projects (e.g. give feedback on research questions, reach target audiences, disseminate research opportunities)

- to support/educate the scientific community, highlighting the benefits of involving people with lived experience in research and giving practical examples of how to involve them in a meaningful way.

The group, which meets monthly, has been working on a number of projects, including a demographics survey to help identify which communities are least involved in research, so that we can develop outreach programmes to increase their inclusion; 'Barriers and solutions to involvement', which looks at barriers faced by members and potential solutions to overcome them; feedback to researchers on eight projects; and a learning and networking event attended by 60 research professionals.

Learning points:

- the self-assessment exercise highlighted the value of providing feedback. We now do this, thereby demonstrating how we value our contributors' input
- the group found that people with non-research backgrounds often find scientific presentations difficult to understand. We have therefore established the practice of one or two contributors reviewing presentations before meetings. This has helped significantly in terms of the feedback researchers receive
- lack of confidence speaking in a variety of situations, including focus groups and to wider audiences, was also a challenge identified by our members. We have since put together training in 'soft transferable skills' to help build their confidence in public speaking.

'It is a pleasure to be part of this group, to hear and contribute different perspectives on research projects. The meetings provide a valuable space to challenge how research should be done and can be made more accessible and relevant to the diverse communities across the UK.'

Kiran Kaur Manku

'The meeting was a fun, informal way of discussing future work for 2022. I left the meeting feeling that my opinion matters a lot and I feel like doing even more if I could.'

Rosemary Musesengwa

D6: CASE STUDY SUMMARY – Roche Products Ltd

Current reflections and planned actions

The REF questions raise difficult but also different themes for us to consider as a company. These challenge us on how we think and act internally but more importantly how we think, partner and act externally as a healthcare company in the UK and worldwide. We are proud of these first steps and aim to be the catalyst for change for other organisations partnering with the public to increase equality, diversity & inclusion.

Our process: Our core self-assessment team comprised representatives from clinical operations, HR, public affairs, medical affairs and global patient partnerships, to ensure that a broad range of perspectives was considered. As part of our internal consultation process we sought input from our ED&I network, soliciting direct feedback from a subset of Black African-, Asian- and Caribbean-heritage colleagues.

Our challenge: Our global patient partnership group is responsible for engaging with patients and patient communities across the world when we design our trials and materials. Our 2020 metrics indicate that around just 40% of our trials had patient input prior to completion. Over the last two years we have been working to increase that figure; however, for trials that do have patient engagement we have not actively sought to engage those from under-served communities. We also recognise with greater clarity, the close link between the culture of our organisation around diversity and inclusion (broadly and in particular in terms of race) and how we design and run our clinical trials.

Aims:

Long-term outcome: That we have race equity in our research that is reflective of UK society, to create better access and outcomes for all patients.

Mid-term outcomes:

- that there is increased collaboration with, and participation by, UK communities of Black African, Asian and Caribbean heritage in our research
- that our systems and process enable the participation of UK communities of Black African, Asian and Caribbean heritage in our research, and
- that across the organisation, we increase knowledge and awareness of diversity and inclusion and its impact on our patients and our ability to serve them.

Actions: We are developing an outcomes-based plan to ensure systemic organisation changes across three connected workstreams, each focusing on a specific aspect of this work:

- Individual Responsibility & Leadership
- Public Partnerships, Recruitment & Systems and Processes
- Foundational Activities (to drive awareness of diversity & inclusion and the impact this has on us as Roche employees, on our business and on society).

Alongside this, we have identified a trial in the early planning stage whose team will be committed to embedding the principles of the Race Equality Framework from the start. We have also begun proactively partnering with Black African-, Asian- and Caribbean-heritage patients to co-produce and review our participant-facing materials for new trials running in the UK.

Further changes, outcomes and benefits:

- in a foundational step to increase awareness of the role and importance of diversity in how we serve our patients' needs, we will create learning material for Roche employees; and we will seek creative ways to broaden the reach of this information (e.g. introduce it as part of the induction of new employees)
- we will establish a UK advisory board of public contributors, to collaborate on our research strategies and hold us to account on our commitments
- we will ensure that for all research conducted in the UK, appropriate public and patient involvement is sought either globally or locally.

With all the above, we hope to demonstrate our commitment, improve trust in the research we carry out and break down barriers to participation in our trials.

'Although Roche is early in our Race Equality Framework (REF) action planning, we are fully committed to increasing the diversity of our clinical trial participants across the Roche portfolio in the UK and globally.'

Robin Whittaker, UK Clinical Operations Head

D7: CASE STUDY SUMMARY – University Hospital Southampton NHS Foundation Trust

Changing culture through allyship

Our public members have been involved every step of the way, supporting, advising and learning together with us.

Our challenge: Q5 in the domain of Individual Responsibility returned the lowest score in our self-assessment exercise. The reason for this was that staff had little understanding of what the term ‘ally’ meant, a concept that was also new to our public members. Interviews and focus groups revealed that staff wanted to understand this term and recognised a need for personal development in this regard.

Aims & goals: Our aim, therefore, is to provide all our Research and Development (R&D) staff with training and development in allyship, with a view to achieving 80% compliance (this target takes into account sick leave, maternity leave and people leaving the department) by March 2023:

Goal 1: To have R&D staff, including partners, trained and developed to act as allies and feel confident and empowered to act personally or seek support.

Goal 2: To implement an evaluation strategy for capturing, through demonstrable actions, the learning that has been achieved.

To realise these goals, we have drawn up a nine-point action plan with timelines. Our overarching objective is to ensure that all R&D staff not only understand allyship but also enact its principles, in order ultimately to establish a culture in which inequity is unacceptable and tackled where found. Wider challenges include how to determine training need, secure funding for training and staff-release time, motivate staff to participate and evaluate the impact of this personal development.

Inputs: Since bringing in an external company to provide (Actionable Allyship) training, the REF team has secured internal funding to provide its own course. This work will be co-led by public members and staff. They in turn will be supported by the newly formed Southampton Centre for Research Engagement and Impact—which will be appointing a member of staff to lead the race equality agenda and take forward inclusivity within

R&D. Funding has also been forthcoming to allow public members to attend the Actionable Allyship training—to provide feedback and shape future internal courses—and to put four R&D staff through an external Train the Trainer programme.

Key changes, outcomes, impact and benefits: Staff participation in the self-assessment, the allyship training being offered and feedback to teams on the outcomes of the project have all stimulated awareness and discussion of allyship. As a result, most R&D staff now understand the term and the need for their own personal development in this area. It is anticipated that the impact of this will be a positive change in culture.

The allyship programme is still in the early stages of implementation, and as a starting point we are using an external company to develop the materials. However, we have the opportunity to develop the sessions together with our public partners using their lived experience. For example, one of our public members has identified the need for a more powerful training video on race that presents their lived experience of aggression.

Learning points/good practice: Allyship was selected as a case study because it is the one challenge from undertaking the self-assessment that applies to every member of R&D; and because it serves as a platform from which to promote racial competence. The main learning point here is to ensure that our public members take on a leading role to further develop our training programme.

‘The allyship training was excellent. We had a meaningful discussion in our breakout group. A very good three hours. However, there needs to be a punchier video on race. The video used was a great example, but it needs a powerful video of the really ugly scenarios that are experienced.’
Public Member

‘The Actionable Allyship programme is going well, but there is no doubt that it is more meaningful if there is a diverse group of participants. This adds depth to the session, as people share their lived experiences.’
Trainer

E: ALLYSHIP RESOURCES

There are a number of informative print and video resources available for those interested in learning more about allyship. Below are some links to get you started.

Essential reading and watching

What is Allyship and Why is Allyship Important?:

https://www.youtube.com/watch?v=hmN1_Bsb0FE

How to be a Good Ally – Identity, Privilege, Resistance | Ahsante the Artist:

<https://www.youtube.com/watch?v=q7EIX4GFQpl&t=14s>

Further information

Want to be an Ally? Steps to True Allyship:

https://www.youtube.com/watch?v=59ydGd_E98o

Allyship is the Key to Social Justice | Whitney Parnell | TEDx Herndon:

<https://www.youtube.com/watch?v=xJm7hIAZ3BY>

What if White People Led the Charge to End Racism | Nita Mosby Tyler |

TEDxMileHigh: <https://www.youtube.com/watch?v=VQSW5SFBsOg>

Implicit Bias – how it affects us and how we push through | Melanie

Funchess | TEDxFlourCity:

<https://www.youtube.com/watch?v=Fr8G7MtRNIk>



F: SAMPLE ROLE PROFILE: AMBASSADOR FOR PUBLIC INVOLVEMENT IN RESEARCH

This role profile has been kindly provided by Keele University, one of our pilot partner organisations. The university recently recruited a part-time (0.5 FTE) Race Equality Framework ambassador, an expert by experience, to lead on engaging with people of Black African, South-Asian, East-Asian and Caribbean heritage (not excluding people of mixed heritage) and on piloting and implementing the Framework.

Main duties

With lived experience and an ability to build and manage relationships with a diverse range of stakeholders at both the local and national level, the role-holder will:

- Develop a strong track record of meaningful, inclusive and impact-driven community-led approaches to engaging people, communities, civil society and other stakeholders in decision-making within selected projects.
- Become an embedded member of the Patient and Public Involvement and Engagement (PPIE) team and represent the team on a number of internal and external PPIE platforms, as appropriate.
- Contribute to and lead on a range of PPIE working groups and projects to support people of Black African, South Asian, East Asian and Caribbean heritage in co-production with researchers, academics, external stakeholders, PPIE leads and patients and members of communities who contribute to our work.
- Assess opportunities to provide support to researchers applying for health or social care research grants and ensure public involvement from seldom-heard voices and underserved communities at every stage of the research but particularly at the research design stage.

Further duties include:

PPIE leadership and operational delivery

- Develop and grow the PPIE portfolio in research implementation and education, ensuring synergies in collaboration with other NIHR cross-institution PPIE leads and

other sectors and research funders, leading the way in involving patients and the public of Black African, East Asian, South Asian and Caribbean heritage as equal partners in research and innovation.

- Scope and develop new approaches and innovative models for involving and empowering people from Black African-, East Asian-, South Asian- and Caribbean-heritage communities in setting research priorities, as well as in research design, delivery, dissemination and implementation, working with the PPIE team to embed best practice and models into the full end-to-end process of research management.
- Develop and deliver inclusive learning and support activities and resources to build PPIE capacity development for involving people of Black African, East Asian, South Asian and Caribbean heritage, targeting in the first instance research applicants, award holders and patients and public members, so that PPIE underpins all that we do and leads to equitable community-centred research.
- Build a network and database of people of Black African, South Asian, East Asian and Caribbean heritage interested in being involved in health or social care research, by contacting public/patient groups, individuals or other stakeholder groups.
- Organise events and communications to encourage people of Black African, South Asian, East Asian and Caribbean heritage to contribute to or join the network and get involved in research.
- Advise, support and mentor researchers keen to establish their own public and patient forums with people of Black African, South Asian, East Asian and Caribbean heritage.

F: SAMPLE ROLE PROFILE (cont.)

Partnership development

- Identify and scope opportunities for scaling up our PPIE, forging appropriate partnerships/collaborations with community engagement key opinion leaders and stakeholders from Black African-, South Asian-, East Asian- and Caribbean-heritage communities.

Monitoring, evaluation and learning

- In collaboration with the PPIE team, explore meaningful ways to capture the impact of PPIE in the research with people of Black African, Asian and Caribbean heritage, ensuring that the patient and community voice underpins how we seek to demonstrate and evidence the real difference we have made to improve the health and wealth of the nation through research.
- Embed a culture of shared and collaborative learning across the PPIE landscape, ensuring that the organisation reflects on practice and uses learning to improve PPIE for people of Black African, Asian and Caribbean heritage.

Experience required

- A background in community engagement with people of Black African, Asian and Caribbean heritage in the voluntary and public sectors, with a genuine understanding of the role and importance of patient and public involvement in health and social care research and services.
- Experience of the theory and practical implementation of a wide range of inclusive and diverse engagement and participation techniques, including community development approaches, social movements and digital engagement.
- Experience of approaches to reach communities, particularly under-served communities.
- Knowledge of initiatives with civil society to bring about changes in the policy landscape or in service design and delivery, preferably in the health sector.

- Facilitation skills with the ability to develop, deliver and lead workshops and meetings through a wide range of platforms.
- Excellent writing, editing and verbal communications skills, with the ability to turn PPIE case studies into accessible and engaging formats for a wide range of audiences.
- Excellent interpersonal skills, influencing skills and emotional intelligence, with the ability to command the respect of colleagues and stakeholders at all levels and to exercise influence without authority.
- Comfortable working independently but with a strong team ethic and able to work collaboratively and effectively.
- Bachelor's degree-level qualification or equivalent experience.
- Proficiency in Google and Microsoft Office applications and experience of virtual working.
- Evidence of a commitment to diversity and equality of opportunity.

Candidates may also have:

- Experience of working in health, social care and/or research.
- A relevant professional qualification and/or membership of a relevant professional body.

On the right is Natalie Knight, the Race Equality Framework Ambassador for Public Involvement in Research at Keele. She was appointed by one of the members of the REPAG who is based at the University, who was inspired to recruit Natalie by the work of the Group.

'Joining the IAU as Race Equality Ambassador has taken the Race Equality Framework pilot beyond the self-assessment tool and its pages, to true systemic change. Keele has taken the brave step of doing the introspection.'



G: GLOSSARY OF TERMS

Allyship is about building relationships of trust, consistency and accountability with marginalised individuals and/or groups of people. Although you might not be a member of an under-invested or oppressed group, you can support them, make the effort to understand their struggle and use your voice alongside theirs (taken from NHS England and NHS Improvement¹⁵).

Co-production is a way of working whereby service providers and users work together to reach a collective outcome. The approach recognises that those who are affected by a service are best placed to help design or improve it.

Engagement (in this Framework) is when information or knowledge about research is shared or more widely disseminated.

Involvement (in this Framework) is when members of the public are actively involved in research projects and/or research organisations.

Micro-aggressions are brief, everyday slights, snubs or insults that may be subtle or ambiguous but which communicate a negative message to the recipient based on their membership of a marginalised group.

National Institute for Health and Care Research (NIHR). Established in 2006, the NIHR is the nation's largest funder of health and care research. It works in partnership with the NHS, universities, local government, other research funders, patients and the public, to provide and enable world-class research that transforms people's lives, promotes economic growth and advances science.

Participation (in this Framework) is when members of the public take part in research.

Public contributor is an umbrella term that the NIHR uses to describe members of the public who take part in patient and public involvement activities. We use the [NIHR definition of 'public'](#),¹⁶ which includes 'patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services'. We also include members of the public who are potential recipients of health promotion programmes, public health programmes and social service interventions.

Public partnerships is a term to collectively describe ways in which patients, service users, carers and members of the public work with researchers, and health and

Care professionals in the creation and use of health and care research. The term public partnerships encompasses participation, involvement and engagement: all are important in the process of creating and making use of high-quality research and each can take place in isolation or in parallel. Experience, as well as research, has shown that they are mutually supportive in making research as relevant and impactful as possible. Use of the term Public Partnerships is not intended to replace, or make redundant, any existing terms or preferred ways of describing things.

Racial competence¹⁷ is the ability to recognise and check one's own bias; interact with racial diversity in a positive manner; and have open and honest conversations about race in ways that show a willingness to hear, learn and take action. Racial competence means understanding the impact of structural racism and fostering a culture of allyship that challenges organisational practices and behaviours that exclude Black African-, Asian- and Caribbean-heritage people and other racialised groups. Being racially competent means translating our statements into action to promote equity of voice and equality of opportunity.

Racial equality. The Equality and Human Rights Commission (EHRC) describes equality as: 'Ensuring that every individual has an equal opportunity to make the most of their lives and talents'. Thus, racial equality means making sure that everyone has the same opportunities and receives the same treatment and support, regardless of their race.

Racial equity. Equity is about giving people what they need, in order to make things fair. Thus, racial equity is about giving more to racialised groups who need it, in order to give them the same opportunities that everyone else has.

Reverse mentoring. Whereas traditional mentoring is centred on the development of junior mentees, in reverse mentoring both the mentor and mentee have the opportunity to learn from each other. The focus of reverse mentoring is to increase the mentee's inclusion competencies; however, mentors are simultaneously given the opportunity to learn from their mentee's experience, knowledge and skills. Thus, reverse mentoring can be considered a career development opportunity for both parties.¹⁸

¹⁵ https://midlands.leadershipacademy.nhs.uk/wp-content/uploads/sites/3/2020/12/Allyship-Toolkit_.pdf

¹⁶ NIHR - <https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-help-with-research/>

¹⁷ This definition was written by a black member of the REPAG and duly approved by all REPAG members. ¹⁸ The Prince's Responsible Business Network: <https://www.bitc.org.uk/wp-content/uploads/2021/10/bitc-factsheet-race-what-is-reverse-mentoring-october21.pdf>

© 2022 National Institute for Health and Care Research

All rights reserved. No part of this publication may be reproduced, distributed, or transmitted in any form or by any means, including photocopying, recording or other electronic or mechanical methods, without the prior written permission of the publisher, except by reviewers quoting brief excerpts in a review and for certain other non-commercial uses permitted by copyright law.

NIHR Centre for Engagement and Dissemination
Grange House
15 Church Street
Twickenham TW1 3NL

Please note:

The photographs in this guide are of people who were directly involved in producing this Framework, were involved in the consultation events or have an interest in the work of the REPAG. They have given their explicit consent for their photo to be used for this purpose. It is forbidden to use their images for any other purpose without their explicit consent.

