NIHR | National Institute for Health and Care Research

"You've ignored our needs...
...but now you need our involvement."

Report of themes from community consultations on a pilot
Race Equality Framework for health and care research organisations.

Contents

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Executive summary

The National Institute for Health and Care Research (NIHR) is committed to actively and openly supporting and promoting equality, diversity and inclusion. A core part of this commitment is to improve opportunities for under-served and unheard communities to be involved in and engage with health and care research. This Report forms part of the activities of NIHR's Race Equality Public Action Group to develop a Race Equality Framework for Public Involvement in Research, as a means to strengthen racial and cultural competencies, encourage allyship, and reduce the barriers to equitable inclusion of diverse patient and public communities across the health and care research system.

The Report captures the authentic voices and views of the Black African, Asian and Caribbean heritage community members who participated in three consultation events held in May and June 2021, which informed and shaped the co-design of the Race Equality Framework. It presents themes representing complex and deep-rooted institutional, societal and human issues.

The Report, and the themes and voices presented within it, knowingly and deliberately *'draw a straight line to the truth'*, to communicate community members' collective experiences and their expert insights. NIHR recognises that its content may make some readers feel uncomfortable or even distressed. Nonetheless, readers are encouraged to give themselves the time and space to engage with its content, and stop, listen and think before contemplating action.

This action may appropriately focus around - and we would encourage - engagement with and adoption of NIHR's Race Equality Framework, as a self-assessment tool to help organisations improve racial equality in public involvement in health and care research. Or, action may take other forms.

Regardless, we hope that the Report's content provides both a catalyst for and evidence to support constructive conversations and further activities that champion the voices of the under-served and the unheard. These issues need to be addressed by any individuals and organisations seeking to improve their racial competency, allyship and collaboration, and who seek to address the injustices these individuals and communities face.

Setting the scene for NIHR’s Race Equality Framework

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 the National Institute for Health and Care Research (NIHR) since it was established in 2006. In this pivotal era, in which a spotlight has been shone on the real-world effects of health inequalities linked to race and ethnicity in the UK, collectively 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’* so that it leads to treatments and services that reflect the needs of everyone.

Evidence shows us that ethnicity and race systematically influence health outcomes, and socio-economic status. 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 been disproportionately harmed by COVID-19.

Efforts to recruit a diverse range of public contributors, too few of the patients and public members who work with NIHR are Black African, Asian and African Caribbean heritage people. NIHR Centre for Engagement and Dissemination (CED) recognised that these communities needed to have a stronger presence, voice and influence in shaping the health and care research agenda. Complementing work being overseen by the NIHR’s Head of Equality, Diversity and Inclusion, the Race Equality Public Action Group (REPAG) has focused on actions that relate directly to public and patient involvement and engagement. REPAG is an expert advisory group comprising public contributors, senior NIHR staff and members of the health and academic community.

The Race Equality Framework is a key part of REPAG’s response to the inequities these communities experience. The Race Equality Framework is a self-assessment tool designed to help organisations improve racial equity in public involvement in health and care research. This Framework has been designed to serve as a guide for constructive conversations in research organisations, to put in place the building blocks for meaningful change through sustained effort and commitment.

Echoing REPAG’s role in championing the voices of the under-served and the unheard, and co-production as a cornerstone of REPAG’s ethos and values, three community consultation events took place from May to June 2021 to seek the views of Black African, Asian and African Caribbean heritage individuals on the Race Equality Framework. This report is a synthesis of their experiences and views on how to reduce barriers to health and care research for these communities.

From August to December 2021, sixteen organisations were trialling the Race Equality Framework to assess how their current policies, practices and organisational culture could be changed to better serve diverse communities, foster improved race relations and ultimately improve healthcare delivery. This pilot is ahead of a wider rollout of the final Framework in Spring 2022, which all research organisations will be encouraged to adopt.

We encourage all communities involved in health and care research to read and reflect on the content of this Report, which surfaces the lived experiences that led to the co-production of the NIHR’s Race Equality Framework and - we hope - will encourage everyone to consider how they can act to improve racial and cultural competencies.

Introduction to the Report and its approach: a plea to reflect and act

Our activities as authors of this Report form part of a groundbreaking initiative to improve the cultural competencies of researchers and research organisations, informed by a diversity of public experience and insight, and provide better outcomes for all, as part of the development of a Race Equality Framework for public involvement in health and social care research. This Report has sought to capture and preserve the authentic voices and views of Black African, Asian and Caribbean heritage community members who participated in three consultation events held in May and June 2021 (hereafter, ‘participants’).

The messages captured within this Report reflect people’s lived experiences as revealed in those discussions. These lived experiences resonate with the legacy of negative societal interactions, which have resulted in the research enterprise being flawed in many instances and tarnished by documented instances of racial injustices. We have derived themes through a rigorous process that is consistent with qualitative research methodology and grounded in best practice standards for public involvement, to ensure that participants were rightly afforded ethical and respectful engagement.

The themes are fundamentally linked and represent complex and deep-rooted institutional, societal and human issues. We urge readers to consider the issues reported as a whole, taking into account the wider contexts within which they are reported.

Engaging meaningfully with the findings of this Report may make some readers feel uncomfortable or even distressed. This may be because the Report seeks to *‘draw a straight line to the truth’* (in the words of one of the participants), to communicate participants’ collective truths and their expert insights. Participants’ voices articulate the need for this engagement to take place not as a punitive objective, but instead as recognition that there are underlying, unresolved issues affecting this population. Until these issues are addressed, they will continue to hamper necessary and progressive adjustments that are in alignment with the philosophy of equal human rights and universal access to health and social care.

This Report is not based on a premise of false evidence appearing real (F.E.A.R.); indeed the methodology employed in this process has ensured that the voices and associated meanings have not been lost. The themes do not show merely perceptions or anticipated anxieties, but reflect the individual and collective direct experiences of real problems. We recognise through the sharing of lived experiences and documented evidence of historical events, what exists now is a strong sense of betrayal, injustice and inequity based on a series of documented events. As a result there is trauma we all have to work to heal, and relationships and trust that need to be repaired. We therefore once again urge readers to please stop, listen, think and begin to contemplate the required actions in a meaningful way so you can contribute in a significant way to eliminating or at the very least lessening the inequalities that systematically impact these communities. In so doing, we individually and collectively reduce the barriers to accessing adequately the health and social care that all people are entitled to.

We share this depth and breadth of feeling and expertise with the wider community and as NIHR and partner research organisations pilot the Race Equality Framework as the primary route to improve race equity in public involvement in research. We hope the Report will inform, educate and help those with an interest in the health and wellbeing of all communities, to improve racial competencies, allyship and collaborations.

We invite you to connect with, reflect, and act on the realities of the community participants who have generously shared their lived experiences.

The Report is presented in the following structure:

What we did | REPAG's process to retain authenticity in what was said, heard, reviewed and done throughout the community consultation events and the analysis underpinning this Report.

What we found | Authors' report of the themes that represent the key points communicated and subsequently reviewed by participants in the community consultation events.

What happens next | REPAG's commitments to further work, and reflections on the learning to share with the wider research community, to encourage inclusive action.

What we did: retaining authenticity in what was said, heard, reviewed, and done

In this section we describe the methods REPAG used to gather feedback, and what the authors did with that feedback to produce the Report.

Stage 1: How was feedback gathered? | describes the community consultation events that took place, and how these were run by REPAG.

Stage 2: What did we do with the feedback? | describes how the authors of this Report (SK, SR and AK) dealt with feedback, which was a collective and inclusive process that checked back with participants in the consultation events.

We followed a model of 'Said: Heard: Reviewed: Did' (detailed below) developed during the early conceptualising of the process. This model is a departure from the typical research data collection and analysis approach. What the model requires is an engaged and inclusive approach which involves returning to the participants who gave voice to their experiences, to verify these 'data' and emerging themes; in so doing misguided researcher interpretations are avoided. This approach also means the process of creating themes is shared, jointly understood and endorsed and we approach this as work which is about sharing understanding - what has been shared with us (the authors), and how do we share what we have learned? With this model, the authenticity of the voice is preserved.

Stage 1: How was feedback gathered?

REPAG sought to capture community members' views on their participation in health and care research, the challenges facing Black African, Asian and Caribbean heritage people, and their views on the pilot Race Equality Framework, by conducting three consultation events.

How were community members reached?

REPAG asked members of Black African, Asian and Caribbean heritage communities to share invitations through their own professional and personal networks. Information was tailored for professional networks, for patient and public groups, and for individual outreach (via WhatsApp).

How was the event described?

The NIHR's Race Equality Public Action Group (REPAG) brings together members of the public and research professionals to take action on race equity in health and care research. The group has developed a Race Equality Framework to support research teams in promoting race equality. REPAG is holding three community consultation events where we are inviting Black African, Asian and Caribbean heritage individuals aged over 18, living in the UK to come along and share their experiences and views to help us shape the Race Equality Framework and reduce barriers to research for these communities.

How were the events made accessible?

In recognition of the time involved, contributors were reimbursed £50 for their time. They could opt to receive this into a bank account, as a voucher, or make a donation to an organisation. REPAG asked those invited to contact the team directly about any accessibility issues, so they could make individual arrangements to suit their needs. One attendee reported a visual impairment and asked to have a one-to-one call prior to the event to talk through the written material that was provided. Two attendees requested visual information in large font. REPAG held the consultations in the evening so that attendees were not expected to miss work. While the online events may have limited access for those who struggle with digital access, it opened up accessibility to those that would have faced geographical limitations requiring attendees to travel.

How were the events run?

All the events were run online via Zoom.

Recognising that these events focused on sensitive and challenging topics, REPAG ensured that a counsellor was present in each consultation Zoom meeting. The counsellor provided their mobile number at the beginning of the event so that anyone who wished to could contact them directly.

Each session began with a brief introduction to NIHR and to the work of REPAG. The co-Chairs described REPAG's ethos and working contract, and Zoom protocols for the event, to clearly communicate why the attendees were being asked to contribute, how attendees would work together during the event, and how their feedback would be acted upon.

The Facilitators observed after the first session that attendees tended to view them or refer to them as representatives of NIHR. While this was true to an extent, Facilitators wanted to better acknowledge that they and REPAG's co-Chairs were members of the community and had themselves experienced the impact of racial inequality. For the remaining two sessions, the co-Chairs took extra time at the beginning of the event to discuss their shared experiences, and to express to the attendees that they were among people who understood them.

Each event was supported by:

- REPAG co-Chairs, Royston John and Fay Scott.
- Event Facilitators: four external Facilitators, two REPAG members, and one NIHR Facilitator were recruited. All Facilitators were of Black African, Asian and Caribbean heritage. Their role was to enable focused discussion in the break-out rooms and report back in the main session.
- Main note-takers: four main note-takers from the NIHR attended. All main note-takers were also of Black African, Asian and Caribbean heritage. They were also present in the break-out rooms to support the relevant Facilitator. They captured the discussion live on google jamboards, enabling attendees to see what was being recorded. They also took notes throughout the session.
- Note-takers: additional note-takers were members of REPAG including the authors of this Report (SK, SR and AK). Only one of the note-takers (SR) is of Black British, African Caribbean heritage. Note-takers were present in the main session and each present in one of the breakout rooms to provide additional recording of the discussion. The sessions were not audio-recorded, and instead written notes were taken. Attendees were informed that the note-takers were present so they were fully aware of who was involved. After the initial introduction, note-takers were asked to turn off their cameras and not contribute directly to the session. This was in recognition that the event was not an academic or research space to contribute to, but a space for public attendees of Black African, Asian and Caribbean heritage. Prior to the meeting the note-takers had been instructed to suspend their own interpretation of what was being said, listen and note the matters raised by the community in a way that was as verbatim as possible. All the written notes from both the main and supporting note-takers were provided to the event attendees within four days of each consultation event (see 'Said: Heard: Reviewed: Did' model, described below).

What were participants asked to talk about?

The events were split into two halves. Firstly, participants were asked for general reflections about health and care research. Secondly, participants were asked for specific reflections on the draft Race Equality Framework.

In this Report, we focus on the general reflections provided, which give us insight into perceptions of health and care research more broadly, and have wider relevance across the academic community. The specific feedback about the Framework was reviewed and acted upon by the Race Equality Framework development team. A similar inclusive process of engagement with participants was undertaken to check and respond to this specific feedback, with participants provided with a rationale for which aspects of their feedback were included (or not included, in the very few cases where these were out of the framework's scope) in future iterations of the Race Equality Framework.

In the events, attendees were asked the following general reflection questions:

1. What would encourage you to participate in health and care research?
2. What health challenges do you believe are currently facing Black African, Asian and Caribbean heritage people?
3. What do you think needs to be done to address at least one of the areas above?

Who attended the events?

General Data Protection Regulation rules and our lack of a secure data repository for registered applicants informed the decision not to gather detailed demographic information. However, all participants were of Black African, Asian or Caribbean heritage. The first event was specifically for Black African or Caribbean heritage men (including those of mixed heritage), who REPAG had identified as particularly under-represented in research and as a focus for the first year of REPAG activity.

A total of 59 participants were involved. The participants were asked to report if they had been involved with NIHR previously, and to rate their knowledge of health and care research. The majority (82%), had not worked with the NIHR previously, 71% rated themselves as either having limited (34%) or some (37%) knowledge of health and care research. This indicates that the events succeeded in recruiting potentially new contributors rather than being limited to consulting with those who were already aware of, or contributing to, NIHR activities. REPAG carried out a degree of vetting to ensure that only participants meeting the heritage criteria of the groups we sought to hear from were included in the events.

Event	**Attendees**
Consultation Event #1 May 2021	20 men of Black African and Caribbean heritage
Consultation Event #2 June 2021	5 men and 15 women of Black African, Asian and Caribbean heritage
Consultation Event #3 June 2021	3 men and 16 women of Black African, Asian and Caribbean heritage

Stage 2: What did we do with the feedback?

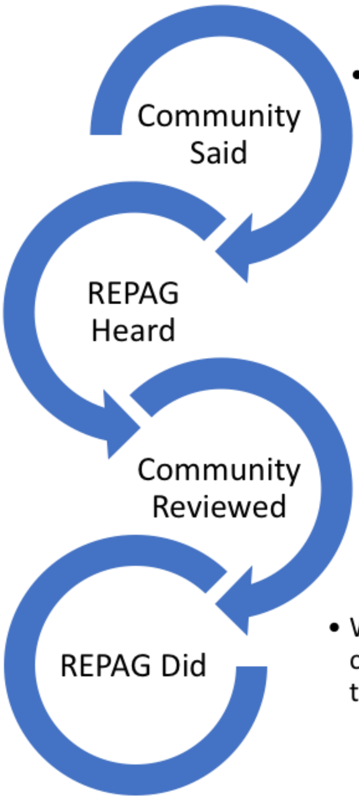
We agreed at the beginning of the process of planning the thematic review underpinning this Report that we wanted to be guided by three principles:

1. ***Authenticity***: We wanted to ensure the analysis was rooted in the original meaning of the attendees to avoid inaccurate interpretations. So, notes taken during the events were sent to the attendees in their raw form (without any editing or revision) to enable attendees to check what we had captured and to provide edits if they wished. We agreed that the final themes should be written, as much as possible, in the language used by the attendees. We did not begin analysis until after all the events were completed. We wanted to remain open minded to what was being expressed in each event, without beginning to layer our own understanding over them. In this way, each event was treated as unique and provided discrete data..
2. ***Transparency:*** We wanted to acknowledge our own role in the analysis, and particularly recognise that typical academic analyses can be hidden from the participants. We therefore introduced a participatory stage to the process, where developing themes were shared with the attendees and we invited them to add, edit or revise our early understanding.
3. ***Collaboration:*** To ensure authenticity and transparency, our process was therefore critically collaborative with the attendees. Attendees had the opportunity at two

stages (after the notes were collated, and after themes were produced) to edit or add to the analysis, and to challenge our recording or interpretation.

The ‘Said: Heard: Reviewed: Did’ model

We achieved the intended authenticity, transparency and collaboration aspects through a four-stage approach referred to earlier as the ‘Said: Heard: Reviewed: Did’ model. This approach recognises that seeking and achieving understanding between researchers and participants in research is an ongoing interactive process that occurs between us.



- Verbatim quotes from the attendees. Unedited notes recorded by each note-taker were used, after they had been shared back with attendees to check we had recorded these adequately.
- Our initial thematic analysis, what we (the analysis team) think was being communicated in the events. Recognising that what we hear is influenced by our perspective, and needs to be checked again with the attendees.
- We presented the initial themes and supporting quotes back to the attendees, to seek confirmation, clarification and challenge. This is included in the report.
- What we commit to doing in response to the confirmed themes. Recognising the ongoing work, that this analysis and report are not a full stop.

The analysis team consisted of SK (White British woman), AK (White British man) and SR (Black British woman of African Caribbean heritage). The team held five reflective meetings between July and August 2021 to work through the feedback and create summary themes. The aim of the themes was for them to be:

- Comprehensive: they would, between them, address all the issues raised across the three workshops.
- Communicative: they would communicate the key issues raised, succinctly but without losing complexity, to audiences of the Report who had not attended the events themselves.

The analysis team each brought different lenses to the analysis process, based both on cultural as well as professional backgrounds. Through close collaboration together and exploring our different understandings we were able to reach a consensus about what we felt we had most strongly heard during the events.

To produce the themes, all the notes were pooled in an online repository. We first read through the raw notes individually and recorded our own comments about what we felt were key points. We met up and compared these first impressions, considering what aspects we had noted had been emphasised, what was the same and where we picked up things that were different. We discussed our further impressions, having heard each other's thoughts. We went back to the raw notes frequently, to keep checking in with the original comments. We also kept returning to our goals, of authenticity, transparency and collaboration, to keep these in mind as we considered how to summarise the key issues that we heard. We also returned regularly to the specific brief we were given by REPAG. We provide a technical summary of this process, reporting how this mapped onto established qualitative methodological approaches, in Box 1, below.

Box 1: Qualitative Technical Summary

The analysis we performed can best be described as a reflexive thematic analysis (Braun and Clarke, 2019). Reflexive thematic analysis recognises that researchers bring their own interpretations to the data to construct *familiar* meaning. We felt this an important aspect of the process acknowledged by our Said, Heard, Reviewed, Did model, which recognised the need to check our interpretation with the attendees to preserve *their* voice and their meaning. Themes in this approach to analysis aim to reflect shared meaning, rather than just summarise topics, and we again felt this was consistent with our focus on authenticity and communicating what the attendees were expressing as important, rather than us just summarising issues that were discussed.

We conducted the following stages with the feedback itself:

1. Familiarisation: All three members of the team reviewed all of the collated notes from the three events.
2. Open Coding: All three members generated their own codes to consider the key issues being expressed. We met as a group to compare our initial coding, discuss differences, and agree on preliminary themes which we would return to the original notes to consider.
3. Axial coding: We met several more times as a group to discuss what overarching thematic categories could be described that would adequately reflect the diversity of codes we had created.
4. Selective Coding: To present our understanding back to the attendees, we created a google slide deck which summarised the themes and provided selected quotations from the notes documents.

We did not conduct this activity as typical academic research, but as a community consultation. We were mindful however of the need for this work to be robust, and to be legitimate in the eyes of our intended research audience. To achieve this, we draw on the COREQ qualitative reporting checklist, and would argue that we have fulfilled the criteria of fully reporting and reflecting on the research team composition, the consultation setting and attendees, the analysis process undertaken, and demonstrate, with reference to original quotations, how the themes were produced.

What we found: themes from community consultation events

The themes that we presented back to the attendees are available as a supplementary document, which contains a fuller series of illustrative quotes. We provide a summary of each theme below.

The themes speak to distinct yet closely interrelated categories. They are deliberately not suggested to be independent from each other, but overlap and interact to give a complete picture. After much discussion, we chose not to try to summarise each theme as one word or phrase, as this would misrepresent the complexity of what was being expressed. The themes are numbered for reporting purposes, but these numbers do not represent an ordering or priority.

Theme 1 speaks to enduring harm being persistently caused in complete contradiction to apparent reason for medical research e.g. Hippocratic oath. Theme 2 reveals concerns about equity which is overshadowed by the concept of equality. There needs to be equity to achieve equality. Theme 3 captures concerns that point to misunderstandings, which can lead to misdiagnosis and result in prolonged and unnecessary lack of appropriate treatment. Theme 4 indicates that community wisdom is repeatedly overlooked and preferred interpretations dismiss cultural awareness in preference for Eurocentric biases.

Theme 1: Harm, betrayal, recognition, repair

Enduring issues of harm, betrayal, trauma and loss of confidence caused by racial injustices and cultural incompetencies must be acknowledged and respected.

Researchers actively seeking to improve their cultural competencies must recognise and take responsibility for how to repair trust among communities.

‘On the issue of mistrust, some of that is historical, us [Black community] feeling ignored since time immemorial… You’ve ignored our needs, our housing, but now you need our involvement.’

Link to further quotes.

What we include in this theme:

- There is a legacy of enduring harm which still negatively impacts us.
- We have [documented] evidence of harm historically and continually, from those who had a duty of care to us.
- When we trusted medical and other health professionals in the past in research, this was betrayed.
- Understand why we are suspicious, and empathise with the harm we have suffered.
- Researchers should understand this historical and social context before they seek to work with us, or they risk unintentionally causing further harm.
- Researchers should recognise they are from a community that has inflicted harm.
- This is not a fear of possible harm. This is rooted in our experience.

Theme 2: Inequity, loss of value, partnership, shared value

Community participants in research have neither been treated equitably, nor have derived value from the benefits of their involvement.

Authentic, equal, open and transparent partnerships and relationships with community members must recognise contributions from and bring value to all contributors, and not continue to dehumanise or extract value from participants, exploitatively.

‘What discourages people is they do not see the impact of their contribution. People are not taken along to what is going to happen next.’

Link to further quotes.

What we include in this theme:
- Who is the research for?
- Partnership – value us, and make research that is valuable for us.
- What would authentic partnership look like? Will ‘power’ inequalities be addressed?
- Nothing about us without us.
- Work with us and with our community, see our strengths, make spaces where we can work with people who are like us.
- Recognise exclusive and exclusionary practices in research.
- Feedback to us – be transparent and accountable when we have contributed.

Theme 3: Stereotyping, lack of diversity, misdiagnosis, respecting difference

Diversity among and between communities is routinely ignored, misrepresented, or stereotyped leading to misdiagnosis.

Cultural competency must be built on active consideration, understanding and respect of cultural differences.

‘Research seems to be based on the majority population and is missing all the colour of the tapestry. If research is more colourful, the true gist of the topic and the issues that need to be addressed will be understood.’

Link to further quotes.

What we include in this theme:
- Respect and understand differences, within and between different communities.
- Do not pathologise or ‘other’ us.
- Understand how our health is misunderstood leading to misdiagnosis or neglect because of the ignorance of difference. How the issues cause frustration; there must be recognition of our frustration at this inequity.
- Act in ways that are culturally competent and sensitive.
- Do not assume one size fits all or stereotype.

Theme 4: Tickboxing, consultation fatigue, eurocentrism

Community members experience collective ‘consultation fatigue’ and are sceptical of research consultations and ‘tick box’ exercises, with little meaningful action or outcomes that benefit the community consulted. Value diverse sources of knowledge and reduce Eurocentrism.

We must learn from those failures and ensure that the wisdom of the multicultural community is acknowledged and the application of collective knowledge is our primary call to action.

‘More community relations, getting people in charge to speak to people in the community to understand who we are as people, what works, what doesn’t.’

Link to further quotes.

What we include in this theme:

- We are not ‘hard to reach’. We have been involved many times before. But there is not evidence that we have been listened to.
- Change initiatives are too often performative or superficial. When interventions are introduced they can be grudgingly applied. They are too often done without our direct involvement or without accountability to us.
- As a community we have a great deal of experience, from our own lives, our individual and collective history, the lives of those around us, and our professional roles. We have contributed considerably for the advancement of others medically and academically but don’t get anything back but rhetoric.
- Culturally we have ways of knowing that places the collective experience as important. The culturally appropriate concept of Ubuntu is important here - loosely translated it means ‘I am because we are’ There is a preference for the collective rather than the individualised human experience. We bring our collective identity and experience to these discussions, we want change to make things better for all, not just some of us.
- We have relevant knowledge and experience to inform this work.
- The concept of Sankofa is important here - that to move forward, we must look back, learn from the lessons of the past and apply the wisdom gained to the present.
- Change needs to be assessed, evaluated and validated by the community it affects.

The next stage of our process was ‘Community Review’. The slide deck of themes and quotes was sent to all attendees and we invited them to reflect on the themes we had heard and provide feedback. Eleven attendees in total provided feedback by email.

Overall there was a positive response to the themes, and confirmation that they communicated the discussions that were had in the events. None of the themes or suggestions were challenged as inaccurate or inappropriate.

‘*I am quite pleased with the outcome and data collected from the panel. I especially love one of the points on Theme 4 which states that the wisdom of the community should be acknowledged.’*

‘I believe it is an accurate capture of patient perspectives. It is a very holistic review and well documented.’

Comments tended to relate to suggestions for emphasis, agreement on content, and queries about how the themes would or could be communicated.

On communication, one attendee commented ‘*the themes are strong on “glass half empty” but there is a need to recognise the balance for constructive focus would involve “glass half full”’*. There was a request to explicitly acknowledge or communicate the ongoing nature of the work, to communicate *‘flow’* or *‘a movement of more to come. When we put a full stop on something people it's fine where it is, when true it's to be continued*.*’* The limitations of a written report for communicating and exploring these issues was described: *‘Felt easier talking this through than reflecting on the written material. Maybe that is to do with a lack of images, visual stimuli and sound. I think the image of the “ear” is great and maybe the image and quality of listening/being heard can itself be expanded.’*

There was a request to carefully consider language used, how some words can be perceived as coded or jargon, and should be more fully explained, especially when they are crucial to understanding. *‘I am blessed to see included the terms- “Sankofa” and “Ubuntu”... I think it wise and helpful (best practice- in my humble opinion) for the sake of clarity, that they are discussed/ clearly defined, so that everyone involved in consuming this document knows what is meant/ is in agreement with the meaning of these words used, as they appear under theme 4. It is skilful use of language and word choice that holds the key to clarity of communication in the sharing of ideas, towards trust building, based upon truth and knowledge of what is true.’*

What happens next: reflection, inclusive engagement, shared learning, action

The final stage of the shared model - ‘REPAG did’ - is work to be completed, and this section is therefore ‘to be continued’. We do not suggest this means the Report is unfinished, but rather that the Report deliberately acknowledges that the work itself must be ongoing. The Report cannot be, in the words of one contributor, *‘a full stop’*, but must be understood as one part of a continued process. This will include its influence on the ongoing work of REPAG, and also the work involved in further sharing the themes beyond REPAG with external stakeholders and NIHR’s own staff. We draw on the themes themselves to recognise our responsibility to widely share this Report and to engage with the research community with this learning. To draw again on a contributor’s own words, the report must be *‘more than “please see attached”’*, and we commit to actively sharing and promoting the findings, and to finding ways to further reflect on them together with the communities themselves. We in REPAG commit to revisiting this Report in 12 months’ time, to transparently update what has been done since its publication. We hope that other researchers similarly see the value in explicitly framing reports as dynamic outputs to be revisited as part of ongoing partnership work.

We carefully considered whether we should make discrete recommendations about ‘What Happens Next’ for the wider research community. Our main recommendation is to ask readers of this Report to sit with and reflect on the problems highlighted within it. We recognise the urge to move to ‘recommendations’ that offer a way forward, and we do think there are indications from the analysis about what needs to be done, but these should not be rushed into before engaging with the weight of the trauma experienced and reported by participants. This is reflected in the Theme headings, where we deliberately resisted a framing of ‘positives and negatives’, or ‘barriers and facilitators’. The issues raised in the consultations could not be separated cleanly into these categories. Rather, we encourage researchers to engage with how the themes express both the harms experienced and the hope that things can be improved as entwined. It is not possible to engage in one without the other.

Similarly, when the wider REPAG team reviewed the analysis, some members queried whether the theme headings could be better distilled into single overarching labels or summary terms. Again, while we recognise the motivation here is to improve the communication by making the themes more accessible on first sight, we wanted to resist this as an effort to simplify the multi-factorial insights that emerged. We ask researchers reading the Report to spend time reflecting on the themes and their complexity, rather than wanting to understand them quickly through being able to summarise or conveniently define and subsume them under existing definitions and practices. There is a strong, clear and undeniable request for the relevant and key stakeholders to genuinely ‘listen’ and ‘hear’ what is actually being ‘said’ and the meaning thereof and then ‘act’ accordingly.

While we therefore felt it was important not to claim we could condense the findings into straight-forward ‘recommendations’ of exactly what could be done, we do think that the themes themselves firmly indicate *how* any further work *must* be done. The themes express the need for future work to be conducted that authentically and transparently engages with members of these communities. Researchers should be prepared to acknowledge the history of harm and exclusion, acknowledge the expertise and wisdom of the communities themselves, and negotiate what makes research valuable and what commitments are necessary to realise this value in practice.

The themes demonstrate that progress in this area must be judged by the communities themselves, and both researchers and funders should consider how they can involve community contributors and networks to define measures of success, monitor progress, share learning and understand and evaluate impact, in an inclusive, properly collaborative and equally valued fashion.

We offer the following reflections on the process of working , which we hope are useful to researchers considering their own work:

- Although at least one of the analysis team has a background in qualitative research (SK), we deliberately began our discussions openly, thinking about what we wanted to achieve and what we wanted to avoid, rather than choosing a specific method to follow. The Said: Heard: Reviewed: Did’ model was the result of these discussions. While we do think the model is more than a method, there are qualitative methods which similarly focus on participatory analysis. We recommend researchers consider these in future research and consultation work. Doing so would recognise and align with the issues raised in the Themes, for example acknowledging that assumptions can be made about these communities which they can challenge, that they have collective wisdom and insight which can valuably inform research work, and that given the history of exclusion and neglect, it is vital to do **work '*with*'** such communities and **not simply '*about*'** them. This is considered by these communities to be an unethical and exploitative practice.

- As important as the sharing of preliminary themes with the consultation attendees, was the composition of the analysis team and the relationships between us. It was through openly reflecting on our ideas, questioning and challenging each other, that we were able to produce themes of depth which were then validated by consultation attendees themselves. This was not achieved through a specific technical method but through trust and willingness to challenge and be challenged. This process was made possible by the unwavering commitment and willingness of each team member to be open to learning from the other team members' perspective, position and recognise the considerable responsibility we were charged with. We constantly reminded ourselves of the trust placed in us by the REPAG and by the communities that the participants represented. It provided a valuable learning opportunity that has provided huge insight and reward. It is undoubtedly the case that if the white team members had completed this by themselves, our work would have looked very different and likely would not have resonated with the attendees. One specific example of how this made the analysis different was the inclusion of the concepts of Ubuntu and Sankofa (which attendees remarked they were especially pleased to see). We acknowledge that these concepts may be unfamiliar to white audiences, and we encourage them to take this as an opportunity to seek out the work of African-centred scholars and thinkers.
- The resource needed to conduct this kind of inclusive and equitable monitoring, evaluation and learning is a serious consideration, and potentially a serious risk to continuing the work done to date. We observe that inclusive work of this kind is not the norm either in academia or in research funder practices, and needs to be supported. We must be very mindful of losing the trust gained in doing this work in an inclusive way, if we revert to traditional or 'feasible' academic ends (ie. publish the report and do nothing further) or 'standard' (i.e. centrally-determined and easy to measure) monitoring and metrics. This is a call for a relationship between researchers and the community members. We have begun this investment and need to sustain it.
- We remain enormously grateful to the Consultation attendees for sharing their experiences and their insights. We thank REPAG for supporting us to spend time with what those attendees shared, to reflect on and consider what was heard and what was meant. We hope that the Report - our '*straight line to the truth*' - can support and inspire researchers to try, as we have here, to be authentic, transparent and collaborative in their efforts to address race inequality and inequity in health and care research.

From NIHR's perspective, the Report content and themes within it will directly inform and influence how REPAG delivers its strategic action plans.

- Firstly during the internal NIHR equality, diversity and inclusion week, building on themes raised in the community consultation event, we have worked with a number of participants in the community consultation event to deliver a webinar to a wider NIHR audience - so that the needs expressed by black men about their health and well being directly reached the ears of NIHR's staff and research community and hopefully triggered reflection and a reshaping of research agendas to be inclusive.

- There has been continued engagement with the community consultation participants, through a ‘Share and Learn event’ in December 2021, in which they witnessed the progress made with piloting and testing the Race Equality Framework.
- NIHR is working towards launching the Race Equality Framework for Public Involvement in Research in Spring 2022, and the themes raised will shape and influence the planning of engagement activities and communications.
- REPAG will be recruiting eight further community members to train as action learning set Facilitators, working alongside pilot Race Equality Framework partners to conduct action learning sets both before and after the launch of the Framework in Spring 2022.
- As REPAG moves into strategic planning for 2022/23, the themes will directly influence work to develop and support a network of organisations actively seeking to improve racial equity in patient involvement in research.

Annex 1: how we met the UK standards for public involvement

Inclusive Opportunities: Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

We made use of our REPAG members' networks to reach members of communities who have in the past been described as 'hard to reach'. We offered reimbursement and asked about accessibility concerns, to make sure people were not excluded from accessing the events. Within the sessions, there was flexibility to feedback through discussion or chat, and attendees could also email reflections after the events

Working together: Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

We clearly communicated the purpose of the events to attendees, and revisited this at the beginning of each session to orient attendees to what we hoped to achieve and why their contributions were essential. We established respectful ways of working together during the event, and had facilitated breakout sessions in smaller groups to help people contribute. We communicated the role of the different note takers, and confirmed that the unedited notes would be made available so that attendees could check if their views had been recorded and represented properly.

Support and Learning: Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

The events were discrete and specific to this stage of REPAG's work, and so providing ongoing learning opportunities was not the focus here. We did provide support for the Facilitators and note-takers to undertake their roles, including a debriefing at the end of the events to reflect on what went well and what we could do differently. We invited all attendees to contribute to the analysis process, which we hope could contribute to building confidence for those who may wish to get involved in research in the future. We also explicitly recognise and recommend that this is not viewed as a 'full stop' but as part of an ongoing process of working with these communities.

Communications: Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

This report forms an early part of our communications plan, and the primary intended audience for the report is the academic community. We recognise the need for reporting to patients, carers and the public and this will be addressed in our further communications. We intend to act upon feedback from the events about more active dissemination of work, for example exploring different formats (such as a video presentation) and creating a dissemination plan for sharing the report across different networks, including community and patient networks.

Impact: Seek improvement by identifying and sharing the difference that public involvement makes to research.

We hope that this report makes clear how essential it is to listen to individuals and communities, in order to improve the research that is done, by exposing assumptions, highlighting challenges and suggesting solutions. We have reported who was involved in the events and thematic review and how, and reflected on what we gained from this participatory way of working. We have described our commitment to acting upon the findings and revisiting the report to add what has been achieved. The report will be publicly available, to share this openly.

Governance: Involve the public in research management, regulation, leadership and decision making

Public members are a core part of the REPAG team and one of the report co-authors is a public member. This will continue to be central to our work, and we have invited new public members to join REPAG since this work was done. Specific to this piece of work, public members were part of the REPAG team who reviewed and approved the report.