

Consultation on a pilot Race Equality Framework



Draft themes and selected participant quotes

As circulated for community feedback (Aug 2021)



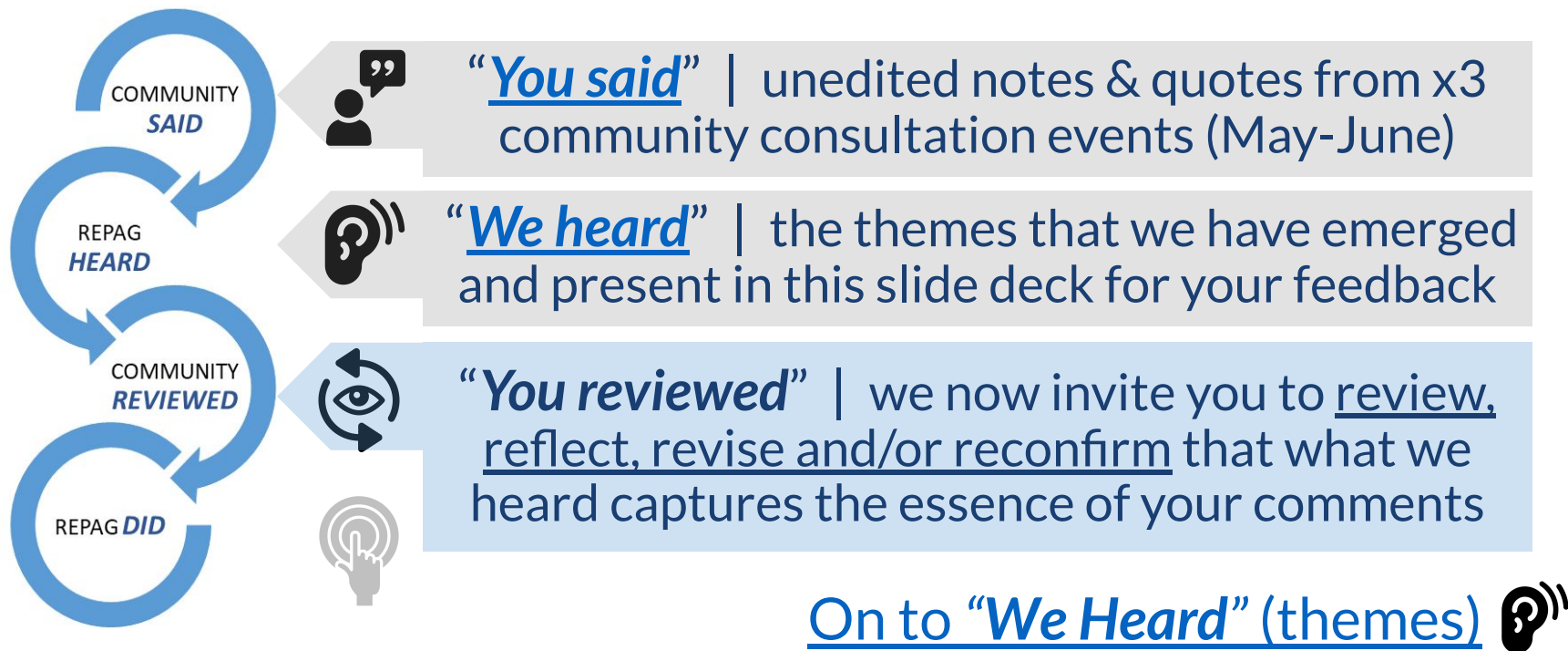
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About this document

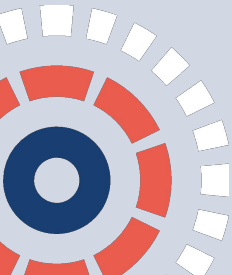
This slide deck contains draft themes and selected participant quotes from a series of consultation events that took place with Black British and African, Asian and African-Caribbean heritage community members, as part of the development of NIHR's Race Equality Framework for health and care research.

The content in these slides and feedback from participants in the community consultation events formed the basis for a Report (available [via NIHR Open Research](#)) which we would encourage all readers to reflect and act on.

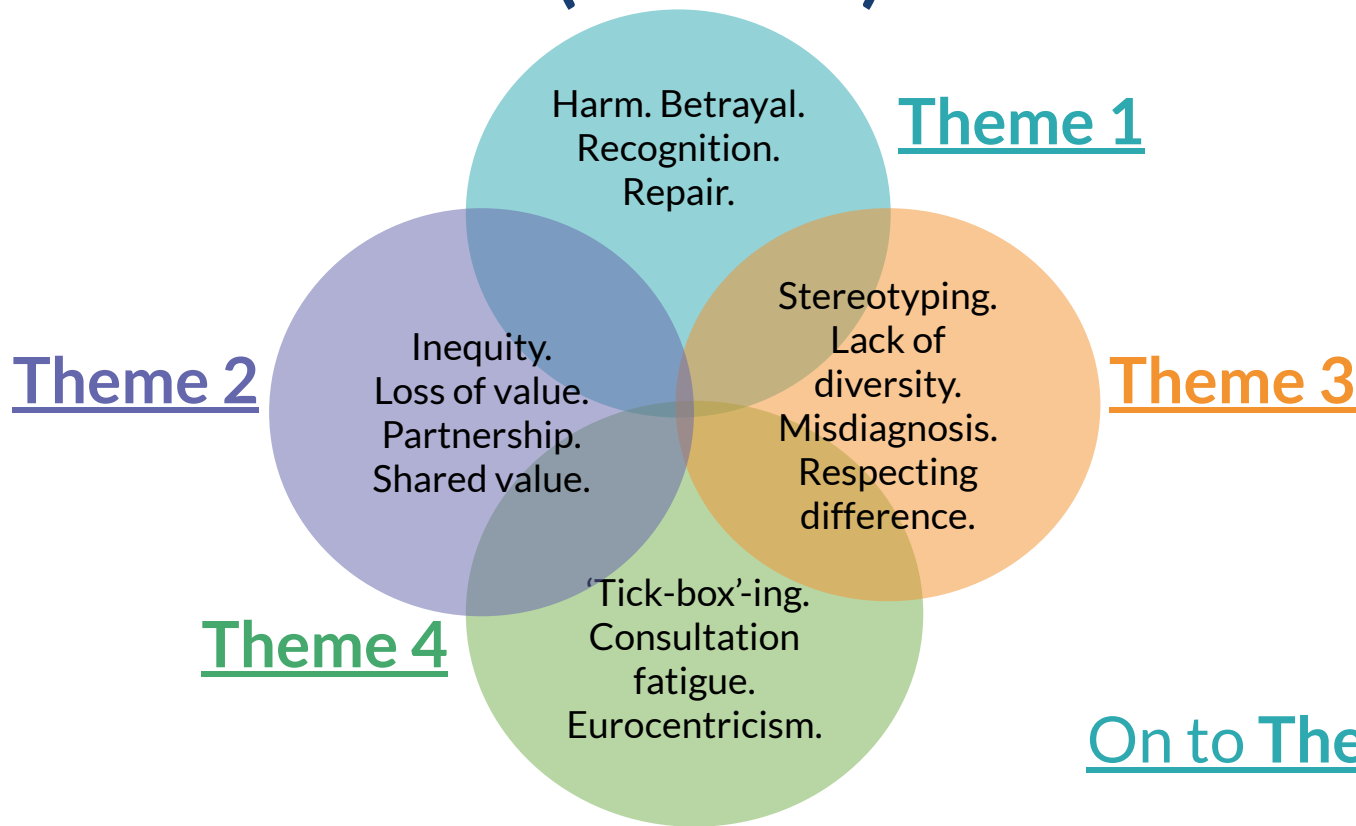
Summary of the thematic review process



“We Heard” (themes)



What “We Heard” (themes)



Theme 1

Enduring issues of harm, betrayal and trauma 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.

What “*You Said*” (quotes) 

On to Theme 2 

Theme 2

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 “*You Said*” (quotes) 

On to Theme 3 

Theme 3

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.

What “*You Said*” (quotes) 

On to Theme 4 

Theme 4

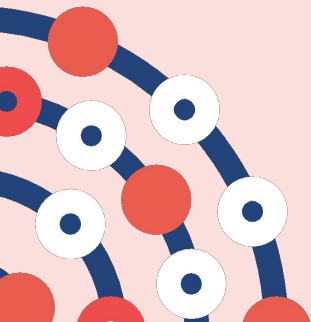
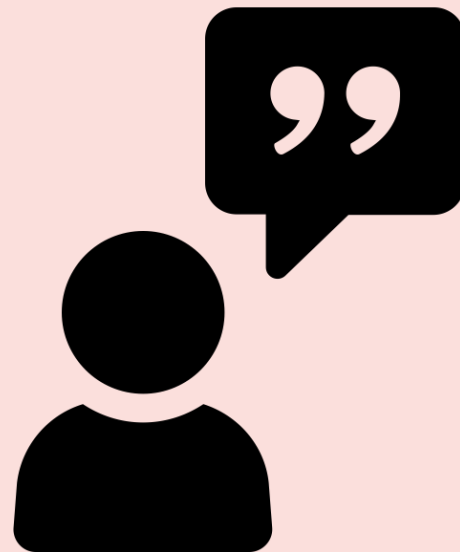
Community members experience collective ‘consultation fatigue’ and are sceptical of research consultations and ‘tick box’ exercises, with little meaningful action or outcomes that benefit the community consulted. Value diverse sources of knowledge and reduce the Eurocentrism.

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

What “*You Said*” (quotes) 

On to “*You Said*” 

“You Said” (quotes)



Quotes 1

"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."

"I don't participate because I don't trust any of it. The only reason I'm here today is because I trust the person who asked me to be involved. ... Anyone else I'm not sure what they're going to use it for, could be for propaganda, against my community."

"An acknowledgement of history and trauma for AAC heritage people when it comes to medical research (e.g. Tuskegee, Henrietta Lacks, etc.)"

"There needs to be acknowledgement by government and within society of the effects of the wrongs of the past - slavery, colonialism, racism and colourism - in a way that is not about guilt and shame but about ownership."

"Show that the history of trauma and pain have really been listened to by organisations"

Back to “We Heard” (themes) 

On to Quotes 2 

Quotes 2

“If I can be sure research will benefit men from our community: that the research will help us not be used against us. Research into black issues is typically done in a way that collates the issues and puts them on the shelf. For example in the research I have participated in I never found out what happened as a result.”

“Ways to help people take on research is by helping them to create a narrative of their own. Right now what we’re doing is taking on what research is done on us as a community - but if we can take this on - getting right information and knowledge that’s suited to communities.”

“There are many public, community consultations of our voices, but they’re not really listened to or used as a contribution. What guarantees do we have that our responses we’re giving you are going to be listened to and implemented into wider healthcare.”

“What discourages people is they do not see impact of their contribution. people are not taken along what is going to happen next.”

[Back to “We Heard” \(themes\)](#) 

[Quotes 2 \(continued\)](#) 

Quotes 2 (continued)

"People wanting to communicate with people that are similar to them or that they can resonate to. I think that's really important when you go into a setting and if there isn't anyone like you, you feel alienated and you don't know how to approach, what to say and you try to change yourself to fit in but you shouldn't need to do that. You shouldn't have to cater for others in their settings. You are who you are any everything about you your colour the way you speak your accent, this is what makes you, you. So when you see somebody else like you it's such a nice feeling you automatically can communicate and people allowing that space for you to actually to approach them.... it's really important to break those barriers and say you're just as human as I am. Yes you might be more talented or educated but we're in it together and we need your helpyou can't do anything without the participation contribution of a patient and a patient can't do anything without the contribution of a Consultant and so it works hand in hand and that's really important."

"Having intermediaries who are from that background who can make the communities aware of these benefits or at least advocate for them or at least be the person to go to. Having more representative people in these areas."

[Back to "We Heard" \(themes\)](#) 

[On to Quotes 3](#) 

Quotes 3

"If the researcher is mindful of if there are disproportionate effects on ethnic minorities that helps. To acknowledge that rather than sweep it under the carpet."

"With people from different cultures, if there is an effort to try to change things, not one treatment for all. Active listening. Active engagement. Make me feel comfortable enough to open up."

"Need to take into consideration the needs of those who are disadvantaged in gaining access and good service. People doing research need to understand how people express themselves relates to their disadvantages and why they are saying the things they are saying or not."

"Vaccine hesitation – being seen as ignorance and lack of education. But actually, reasons structural and educational – didn't address fundamental reasons. All research starts with the assumption Black people ignorant – rather than addressing the real reasons why."

"Need to think about what experience needs to be represented - just because we look alike does not mean we have necessarily had the same experience."

Back to **"We Heard"** (themes) 

Quotes 3 (continued) 

Quotes 3 (continued)

"I realised that the diagnoses are incorrect and I had to go on my own journey to overcome it. I encountered all kinds of abuse. I encountered consultants who were happy to throw out all kinds of diagnoses. One of them diagnosed me with schizophrenia, and just because of how I reacted, I reacted so strongly, he said no. Maybe if I hadn't then I'd be walking round with a diagnosis."

"Mental health, sickle cell, obesity all raised. Because NHS does not work in a holistically culturally competent manner, people may be misdiagnosed."

"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."

[Back to "We Heard" \(themes\)](#) 

[On to Quotes 4](#) 

Quotes 4

“Wanted to be invited as a whole human being, listened to. Need to not be treated like a tick box for the sake of showing a person like me has been consulted and is present in this space, and then afterwards sending me ‘back into your corner”

“It’s important to actively engage the public to make demands. We’ve seen all this before. Change is a promise and they don’t come. It’s about mobilising the communities to demand where change is. People I engage with, they don’t want to hear about the system. They’ve seen repeatedly “we’re gonna do this we’re gonna do this” and it never happens.”

“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.”

“I know people in my community who don’t want to get involved because they’re being asked the same questions again and again.”

“We have had a number of quality systems over the years to improve race equality in the NHS, such as the workforce race equality standards, and care has to be taken as to how this framework is implemented to avoid them to be used as tick box exercises without real change.”

Back to “*We Heard*” (themes) 

Quotes 4 (continued) 

Quotes 4 (continued)

“Lack of empathy and cultural competence needs to be addressed through training. Improving diversity at all levels including senior levels of organisation. Not enough amplification of (grassroots?). Decolonialisation.”

“Advancement of decolonial thought, wide scrutiny about western medical practices and elevation of non-western medicine.”

“The first thing that comes to mind is the boy who died in hospital, he had sickle cell and the nurses didn’t believe him and he had to call 999.”

“Not having a tick-box exercise - making people feel valued and in a forum where they have an equal voice. ”

“Raise awareness of conditions related to genetics.”

“People did not take the time to listen and consider the issues that were particular to her and reflecting her Jamaican lifestyle.”

“If you do say something to get your point of view across it can be perceived as being aggressive, and linked by the professionals to the angry black woman stereotype, when all you are trying to do is be assertive and this is misread.”

Back to “*We Heard*” (themes) 

On to Next Steps



Next steps

- we welcome your **reflections, comments and feedback**: please email repag_enquiries@nihr.ac.uk
- we will incorporate all feedback into a report to share with REPAG and materials for wider public engagement **to inform NIHR's development of REF**
- we **thank you** for your ongoing engagement and honest reflections to ensure that **together we can make progress**

