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Understanding mistrust in research

Roundtable Dialogue
Black History Month – 2022

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On 18th October 2022, the **National Institute for Health and Care Research (NIHR) Birmingham Biomedical Research Centre (BRC)** convened an online roundtable dialogue on understanding mistrust in research.

The panel consisted of leaders from the NIHR Birmingham BRC, University Hospitals Birmingham NHS Foundation Trust (UHB), Global Talent Compass and the University of Birmingham (UoB) with academic researchers, clinicians, a racial justice expert, a midwife researcher, a senior nurse, and a patient partner, in an event that was part of a series of conversations held during Black History Month last year.

The panel of experts was convened to examine the underlying causes of mistrust that restrict medical, clinical, and research engagement. The group explored the historical factors contributing to mistrust in clinical research and the challenges of marginalised Black, Asian, and minority ethnic communities receiving suboptimal medical care. The panel discussed developing strategies to implement structural change that would increase research participation and promote greater workforce diversity to reduce health disparities in underprivileged communities.

The session was chaired by Byron Batten in his role as Head of Inclusion-Improvement, and Chair of the NIHR Race Equality Framework Pilot at UHB.

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> **Research participants**

Table participants

Byron Batten
(Chair) Head of Inclusion-Improvement, Communications and Engagement, Chair of NIHR Race Equality Framework (REF), University Hospitals Birmingham NHS Foundation Trust

Joyce Yeung
Honorary Consultant in Critical Care, Deputy Clinical Director of Research, Research & Development, University Hospital Birmingham NHS Foundation Trust

Victoria Day
Head of NIHR Birmingham Biomedical Research Centre (BRC) Infrastructure, University Hospitals Birmingham NHS Foundation Trust

Carlton Murdoch
Deputy Director of Nursing, University Hospitals Birmingham NHS Foundation Trust

Siddhartha Bandyopadhyay
Professor of Economics, University of Birmingham

Sobia Shaw
Patient Representative of the Birmingham Biomedical Research Centre’s Liver and GI Patient and Public Involvement and Engagement group, Patient Partner of the NIHR Race Equality Framework (REF) pilot project

Carol Cooper
Head of Equality, Diversity and Human Rights, Birmingham Community Healthcare NHS Trust, CEO of Global Talent Compass

Dhruv Parekh
Associate Professor in Critical Care and Respiratory Medicine at The University of Birmingham, Consultant in Intensive Care Medicine and Respiratory, and Director of the Adult NIHR Wellcome Clinical Research Facility, University Hospital Birmingham NHS Foundation Trust

Amie Wilson
Research Fellow in Global Maternal Health and Midwife, University of Birmingham

A legacy of misplaced trust

Participating in research for Black, Asian, and African ethnic minority communities is complicated due to a deep-rooted mistrust of clinical research. While researchers work to establish trust and rapport with patients and their families before conducting research, there is still a lack of understanding about the complexities and nuances of underserved and disadvantaged communities. These communities often feel that research is being 'done to them,' with researchers holding all the power. This suspicion stems from a history of violence and persecution of ethnic minorities, causing them to distance themselves from medical research, healthcare provision, and organised government institutions.

Health equity assessments reveal the painful experiences of racism and marginalisation faced by underserved ethnic minoritised groups. These communities are often excluded from participating in research due to deep-seated biases. Additionally, despite being disproportionately affected by COVID-19, these communities showed poor uptake of the COVID-19 vaccine.

A call for racial empathy and allyship

It is important to revisit historical facts that may create doubt. This can lead to better understanding and empathy. Looking into these facts can help us see the context in which racial trauma occurs, especially for those from minoritised backgrounds. Additionally, exploring history can prevent situations where individuals from underserved communities are limited in their choices.

The Tuskegee study is one such historical trauma; 600 black men were studied between 1932 and 1972, and were repeatedly deceived by the Public Health Service in the United States about their syphilis diagnosis and available treatments, leading to hundreds of deaths, complications and affected wives and children.

One of the most significant scientific discoveries of the last century was the identification of the first immortal human cell line, HeLa. In 1951, Dr George Gey of Johns Hopkins University obtained this resilient and prolific cell line from an African American woman, Henrietta Lacks, without her consent, as it was not required to culture cells from her cancer treatment. Unethically, in today's modern era, these cells went on to inform research on the effects of zero gravity in outer space, the development of polio, COVID-19 vaccines to study leukaemia, the AIDS virus, cancer and in vitro fertilisation worldwide.

Although the Tuskegee study and HeLa cell line happened before modern ethical protocols, a study in the 1990s was even more shocking, as it looked at the aggressive behaviour of mainly African American males. Parents were incentivised with money to enrol their sons in a study where medications and water were withheld while boys were subjected to hourly blood draws and other inhumane research procedures.

Trust in anything but modern healthcare and big pharma

Lack of trust in institutions and governments, particularly around medicine and medical care, is a barrier to research participation and healthcare engagement. During the discussion, some panellists noted that some ethnic minority communities rely on traditional medicines specific to their culture. These remedies include Chinese medicine, ayurvedic practices, and other cultural treatments believed to promote overall health and cure various illnesses rather than relying solely on pharmaceutical drugs.

Dr Wilson described how Eight 'Millennium Development Goals' were established by the United Nations to be accomplished by 2015. Reducing infant mortality and enhancing maternal health were two of these objectives. To reach these goals, policy makers imposed a change from traditional birthing practices, such as family and midwife led birthing attendance, to a medical and institutional mode. Mistrust grew as a result of the exclusion of birth attendants. Poorer outcomes for maternal health and child mortality were seen as a result of this mistrust. Improvements were shown once medical institutions started to integrate traditional childbirth methods and improve communication. This is a great illustration of how to develop trust.

Building trust in research will require cultural safety about who is behind the research. Sobia Shaw, a public contributor, commented, 'Trust happens when we see answers to our questions. Often, the research community is not in charge, whether they look like us or not. They are responding to something in their careers as part of their career journey. It's not necessarily about us. If we were more involved and had more power, agency and influence, we would be lightyears ahead because our health cannot wait for the research community to catch up with what we already know about ourselves.'

Exploiting vulnerabilities and underestimating the depth of colour

Research must begin with an open mind, that acknowledges and accepts differences while being aware of personal biases and striving to treat all individuals equitably. Unfortunately, people tend to be exploited when they are most vulnerable. During the discussion, one panellist pointed out that the issue goes beyond skin colour and background and involves deep-seated societal interpretations of race and colour. 'We should not underestimate the impact of colour and prejudiced beliefs about colourism. The depth of colour has played a significant role in shaping racism over centuries, and it is a systemic problem that cannot be eliminated overnight. It has created mistrust that has persisted for generations.'

Going beyond exploitation, what more needs to be considered?

Minoritised communities often experience unfair treatment in healthcare systems, leading to unequal access and quality of care. Prejudices, cultural differences, and economic disparities fuel this issue. Limited resources, language barriers, and distrust make navigating the healthcare system difficult. Additionally, a lack of clear health information complicates the underrepresentation of minority groups in healthcare and research initiatives exacerbate the challenge.

In response, a multifaceted approach is imperative, encompassing policy reforms, cultural intelligence development programmes, active community engagement, enhanced representation, and the patient cultivation of trust. These interconnected challenges demand holistic strategies to establish fairness in healthcare provision and research endeavours, ultimately improving patient outcomes.

Spiritual beliefs can sometime shape individual attitudes toward the healthcare system, giving rise to varying degrees of mistrust. A panellist shared an instance recounting a conversation with a Muslim nurse. In this example, the nurse conveyed their inner conflict, expressing concerns that receiving the COVID-19 vaccine might undermine their deep-seated faith. This anecdote is not an isolated occurrence; instead, it highlights a broader theme wherein spirituality and the act of worship are intricately woven into perceptions of well-being.

Spiritual practices, like prayer, have long been intertwined with notions of vitality, influencing perspectives on healing and well-being. Recognising the multidimensional nature of ethnic minority communities becomes pivotal in fostering trust within the research system. This imperative underscores the necessity to delve beyond surface impressions, seeking a comprehensive grasp of the diverse layers that constitute individuals' identities.

Asking the right questions

It's important to understand current levels of participation to improve further engagement. However, collecting demographic data can raise concerns about trust. It's essential to explain the purpose of collecting data and ensure participants that it will be anonymised. Educating participants on the benefits of demographic data and using validated and culturally sensitive questionnaires that offer multiple response options and address participants' concerns will encourage more engagement.

Doing more research that affects ethnic minorities

Conducting more research in disease areas that affect ethnic minoritised groups is one way to build trust, as participants can open up to their communities about their experiences and spread the word about the positive experiences. *'One of the things I feel is that we can build trust in people, black and brown people, if we do more research into conditions that affect black and brown people. I'm talking about sickle cell and thalassemia here, fibroids and certain types of diabetes. That way, we engage.'* It can be beneficial to actively involve and encourage people from other backgrounds to participate in research design to gain a new perspective on the goals and objectives of the study. Diverse participation can also influence how the research can aid people whose quality of life is most negatively impacted.

Can you see me?

It is essential to both see and hear patients, as their voices matter.

> Patients need to understand and know that you see them as individuals. When I approach patients who participate in research, irrespective of their nationality, I will try to discuss the study with them, respect them and listen to them while answering any questions.

Patient visibility is essential to ensure that rapport with researchers is built. Researchers should be aware of and knowledgeable about their diverse characteristics to serve patients better. This attention would result in greater recruitment into studies.

Keep the dialogue going

To increase research participation among ethnic minorities and establish a safe research environment, a multifaceted approach is necessary.

Building trust requires open and honest dialogue that addresses historical mistrust. These conversations should not be limited to Black History Month but brought to a broader stage. We must work to prevent future generations from experiencing the same mistrust. This should involve creating a research design framework that actively involves the diaspora for a more culturally sensitive approach.

Secondly, approaching this effort with an open mind, free from preconceived notions, is crucial. Conversations with patients and communities should be characterised by curiosity and respect, acknowledging the diversity of experiences within these groups.

A multi-pronged strategy is necessary, recognising that a one-size-fits-all solution is insufficient. This approach should involve the research community, policymakers, healthcare institutions, and community leaders. Transparency and accountability must be central to this effort, with those in positions of influence promoting and monitoring progress.

In summary, enhancing research participation and fostering cultural safety and trust within Black, Asian, and minoritised ethnic communities requires a comprehensive, inclusive, health and care research-informed approach beyond designated heritage months and that actively involves the affected communities.

What have we learnt?

- Conducting in-depth conversations in our communities with key influencers is essential to creating and developing trust between researchers, wider health services and the community.
- For genuine involvement and true co-production, cultural competence of researchers and the wider health and social care infrastructure is a prerequisite for change.
- Research engagement must be led with an empathic and compassionate lens.
- Research participation is intrinsically linked to experiences and interactions of the broader health and social care sector and wider government institutions. It is essential to understand how those interactions may impact those from racialised and underserved communities.
- It's crucial to use statistics to comprehend where we stand in relation to our engagement and where our initial efforts should be concentrated. An in-depth evaluation should be established to measure and survey mistrust.
- Understanding the historical and lived experiences of underserved groups will add essential context to leading research empathically and help to nurture relationships and rapport building with communities we want to engage with.

What are the next steps?

- We will use evidence based interventions that involve Patient, Public Involvement and Engagement (PPIE) groups to help shape the design of research studies.
- We will continuously improve research models for participation and engagement in clinical research.
- We will develop masterclasses or development sessions for researchers to improve their understanding on how to positively engage and recruit patients that are underrepresented in research or from underserved groups.
- We will host a yearly webinar to debate improving research participation and representation in health and care research, building on current knowledge and creating actionable changes for equity.