



Ensuring clinical research reflects the UK's diverse population



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Participants

• (Chair) Byron Batten, Head of Inclusion-Improvement, Communications and Engagement; University Hospitals Birmingham NHS Foundation Trust

• (Co-Chair) Dr Kanta Kumar, Patient and Public Involvement and Engagement Lead, College of Medical and Dental Sciences, University of Birmingham

• Professor Phil Newsome, Deputy Director of the NIHR Birmingham Biomedical Research Centre; Director of Research and Knowledge Transfer, College of Medical and Dental Sciences, University of Birmingham

• Professor Wasim Hanif, Trustee, South Asian Health Foundation

• Tom Gidlow, Birmingham Co-ordinator, In2Science

• Sobia Shaw, Patient Partner, Member of the BRC Liver & GI PPIE group

• Tony Kelly, Patient Partner, Member of the BRC Muscle Health Group PPIE group and Diabetes champion

• Professor Supratik Basu, Royal Wolverhampton NHS Trust, CRN West Midlands

• Professor Dagmar Scheel-Toellner, University of Birmingham EDI Committee Representative; University of Birmingham Lead for the Birmingham pilot of NIHR Race Equality Framework

• Dr Ameeta Retzer, Research Fellow, University of Birmingham

• Dr Claire Ray, Reader, University of Birmingham; Lead for Outreach and Widening Participation, College of Medical and Dental Sciences, University of Birmingham

• Dr Rowena Sharpe – Director of Precision Medicine Trials at the Cancer Clinical Trials Unit.

On 16 February 2022, the National Institute of Health Research (NIHR) Birmingham Biomedical Research Centre (BRC) convened a roundtable on how to ensure clinical research reflects the UK's diverse population.

The roundtable brought together leaders within the BRC, University Hospitals Birmingham NHS Foundation Trust (UHB) and the University of Birmingham (UoB) with researchers, clinicians, patients, volunteers and relevant charities in the West Midlands. The participants all had the required academic, clinical and/or lived experience of inequalities to enable them to conduct a rich and honest conversation on this important topic.

The session was chaired by Byron Batten in his role as Head of Inclusion-Improvement, Communications and Engagement at UHB and Dr Kanta Kumar in her role as Academic Lead for Patient and Public Involvement and Engagement for the College of Medical and Dental Sciences (UoB).

Which groups of people are not currently reflected in clinical research?

As the NHS Race & Health Observatory revealed overwhelming evidence of ethnic health inequality in healthcare in its recently published Rapid Evidence Review¹, it is clear that ensuring all

people are included in clinical research is a priority.

There are many groups of people who are under-served in clinical research and this has been well documented in a number of studies and reports, with some examples clearly summarised in the NIHR INCLUDE project². Populations that are under-served were discussed, and although the INCLUDE project outlines overarching descriptors of under-served groups, such as age extremes, language barriers and physical health conditions, these were not broken down further or described in detail. An example of a group raised in the discussion that may be under-served included people experiencing violence and abuse.

Why are certain groups under-served?

The reasons why certain groups have been under-served have been well documented and are again well summarised in the NIHR INCLUDE project. These reasons, or barriers, would be helpful to understand in a more local context, and once we understand the barriers, we can start to address them.

Under-served groups are not always aware of opportunities to be involved in clinical research. They may not understand what research is and how it can benefit them or their community. They don't feel valued and included by healthcare professionals and research teams. Many people feel uncomfortable



when asked intrusive questions or are concerned of how their data is stored and used. There are also issues around remuneration and lack of payment.

What can we do to overcome barriers?

Birmingham is more ethnically diverse than most British cities³ and has a high level of deprivation⁴. The city is home to many under-served groups and there are local barriers to being included in research. Local barriers may be as diverse as the city's population, but there are themes which are common throughout.

More diverse institutions

Our universities, healthcare institutions and research teams need to be more diverse and inclusive. Under-served people will trust trials when they see research teams who look and sound like them.

We need to find opportunities to recruit across the whole population, and plan for the longer term when considering

recruitment strategies. Paid internships and mentorships will help more under-served people into universities and research career paths while educating healthcare professionals to understand the importance of inclusion will be reflected in the individuals recruited and the teams built.

More inclusive culture

Inclusivity should be at the heart of our institutions so that everyone we engage with feels welcome and involved.

Research facilities are unfamiliar environments for people that have not had the opportunity to engage with research

before. Research teams need to be out in the community to engage with our population and establish trust and build meaningful relationships. At the same time, our doors need to be open to all.

We need to find opportunities to recruit across the whole population.

Ask the right questions

Trials should be relevant to under-served groups. Involving people early in the development of trials will support engagement. It's important to ask what people are interested in and what they would like to talk about.

The focus should be on genuinely valuing under-served people's ideas and contributions. If they help to shape clinical research, they'll be far more likely to get involved.

Talk in plain English

There is not as much demand for materials and literature in different languages as the research community thinks. The bigger barrier lies in the jargon, acronyms and medical terms used when communicating with under-served groups.

Using plain English and communication methods that consider people who don't read or write is important. Where we communicate also needs to change. Promoting trials in publications and on radio and social media that is used by

under-served groups helps reach the right people and shows understanding of their communities. Infographics and animation can overcome language and reading-level barriers.

Feedback

Engagement with under-served groups should not be tokenistic but should be considered in the long-term to build and strengthen relationships and trust. If people receive feedback from their input and are thanked for their participation or involvement in research, they will be more likely to continue providing support.

What tools and resources are needed?

Education and training are at the heart of overcoming barriers. This starts from the very top of institutions (where under-served people are not making decisions) through to research teams and students. Student equality groups help equip

students with knowledge and cultural competency to build an inclusive approach to clinical research. Universities need to free student time to support this.

We also need to recruit people from under-served groups to reach out to their community and help lead Patient and Public Involvement and Engagement. We must also be conscious of burnout among patient and public contributors from under-served groups. Increasing

the number of representatives from different communities can help to support this.

Building more strategic partnerships with industry supports involvement of under-served groups in the earliest stages of developing industry-led clinical research.

Partnership with voluntary groups is another way to reach people who are often excluded.

Ultimately, we need to create system-wide cultural change based on trust, respect and understanding.

It's up to us to ensure everyone feels they belong.

Engagement with under-served groups should not be tokenistic.

This was our first roundtable event on clinical research reflecting the UK's diverse population. As we are aware that we won't be able to solve these problems from a single session, this was intended as an introduction into the area. The NIHR Birmingham BRC plans to host a further series of roundtable events to explore topics that have arisen from this initial session.

Endnotes

The NHS Race & Health Observatory's Ethnic Inequalities in Healthcare: A Rapid Evidence Review is available at <https://www.nhs.uk/publications/ethnic-inequalities-in-healthcare-a-rapid-evidence-review/>

Details of the NIHR INCLUDE project including examples of under-served groups and barriers to inclusion is available at <https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435>

Captured in 2011 Census. Data is available at <https://www.ons.gov.uk/>

According to the Indices of Deprivation (IOD) 2019 available at https://www.birmingham.gov.uk/downloads/file/2533/index_of_deprivation_2019

