



equality

diversity in research
equality in health

Agenda

Item	Timings
Introduction to Equality: Why we need to improve diversity in research •Improving diversity working with BME community leaders	(13.30-13.35)
Current barriers to diversity and inclusion in research •Findings from our focus groups •Charles Kwaku-Odoi, CEO at CAHN, speaks to his experience	(13.35-13.45)
Available guidance and tools	(13.45-13.50)
The role of the sponsor in improving diversity in research Questions to the group	(13.50-14.10)

Definitions

The NHS INCLUDE framework definition of under-served groups:

The work of the INCLUDE project shows that there is no single definition for an under-served group. Some key characteristics that are common to several under-served groups are:

- Lower inclusion in research than one would expect from population estimates
- High healthcare burden that is not matched by the volume of research designed for the group
- Important differences in how a group responds to or engages with healthcare interventions compared to other groups, with research neglecting to address these factors

“Failing to include a broad range of participants means that results may not be generalisable to a broad population”

Why we're here today

14% of UK population BME

5% participate in medical research

In UK, 5.5% in diabetes trials despite accounting for 11.2% of population

In US, 3% of trial participants for prostate cancer are African men despite being twice as likely to die

Around 30% of critically ill people with COVID-19 are BME – of 1077 in the Oxford COVID-19 vaccine trial, 6 are Black and 35 South Asian

BUT 37% and 30% in US Moderna and Pfizer trials

“If research fails to engage all those who could benefit, there is no guarantee that results will apply to populations not included in the research”¹

“Diversity in clinical research is a prerequisite for equity in health”²



¹ Access at: <https://www.leicesterdiabetescentre.org.uk/news-blog/bame-individuals-must-not-be-under-represented-in-covid-19-research>

² Access at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3689626/>

Vision and Mission

Vision

A UK research sector based on **trust, transparency, and respect**. Where there are no socio-economic barriers to being involved in research

Mission

All health research and clinical trials in the UK **represent the population of the UK**, or those most impacted by the condition.



Advisory Board

BME Community Organisation Leaders from across the UK



Hanif Bobat
Ethnic Health Forum
Manchester



Vicki Harris
HAREF
Newcastle



Charles Kwaku-Odoi
CAHN
Manchester



Kye Lockwood
Social Action for Health
North East London



Davine Forde
Manchester BME
Network



Caribbean and African Health Network – case study

CAHN undertook a number of initiatives to support their local communities during COVID

Collective Community Response Meetings – Education and prevention activities, stakeholder engagement and collaborative approaches

Mental Health and Wellbeing support – disseminated in partnership with local health and social care organisations

Virtual event on vaccine safety and uptake – Including health professionals connecting with the community on the safety and efficacy of the vaccine

Survey and report - A picture of inequality: The impact of COVID-19 on the Caribbean & African Community in Greater Manchester

COVID-19 videos – covering a range of information and ‘myth-busting’ on coronavirus with local people from the community

Friday 4th December
Time: 09:30 – 11:00

Greater Manchester BAME COVID-19 Men's Health Collaboration Dissemination Event

What to discuss?

- What activities were undertaken
- How many people have received support?
- What support was provided
- How volunteers were trained to support the delivery
- How multi-agencies worked together via a seamless referral process

Please come along and learn more by booking a place via <https://gmbamecovid-19mhevent.eventbrite.co.uk>
For further information please contact lorraine@cahn.org.uk or 07853 888888

#BlackHealthMattersGM

A PICTURE OF INEQUALITY:
The Impact of COVID-19 on the Caribbean & African Community in Greater Manchester

Survey Findings
June 2020

Logos: YABSI, MANCHESTER BME NETWORK, JAMH, T4SE, Wai Yin Society, CAHN

Barriers to being involved in research



Fair reimbursement of time and expertise	Engagement from beginning to end	Engagement methods
<ul style="list-style-type: none"> • Time and money are critical for us all (increase in requests during COVID-19) <ul style="list-style-type: none"> • Community organisations are severely stretched • There must be fair distribution of resources for expertise and delivery • How do we value this, and open up the right funding channels? 	<ul style="list-style-type: none"> • True co-production of research programmes, not tick box accreditation for proposals • Asking communities what they want from research / what they want to be researched • Bringing findings back to participants and communities, what is the benefit and the impact? 	<ul style="list-style-type: none"> • True co-production of communications materials • Materials and methods must be translated and culturally appropriate • Put the participant at the centre of the research • Awareness of the benefits of being involved in research, focused on individual / community perspectives

TRUST



Where engagement has worked



Sandpit session in Manchester	Collaborative proposal	Virtual feedback sessions
Academic researcher going to the community organisation three times to develop the proposal with their input	Bringing together researchers and community organisations to discuss research priorities	Virtual sessions to feedback on research findings – ahead of publication

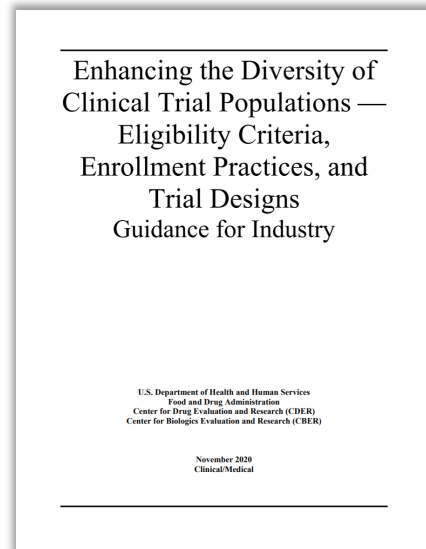
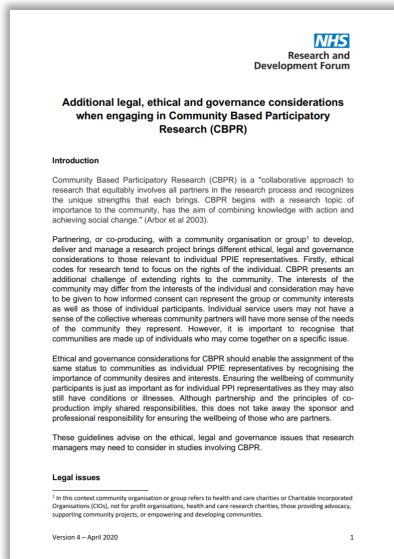
**MANCHESTER
BMENETWORK**
Strengthening Our Future



ActWELL

Existing guidance and tools

A range of guidance and tools available, but we know they're not translating into practice consistently.



Questions to the audience

Polling questions via Slido:

- Are you already doing something to improve diversity in research participation in your role as Sponsor? (e.g. strategy, SOPs, community outreach)
- If you said yes, what are you doing?
- If you said no, what are the practical challenges as Sponsor of ensuring ethnic diversity is a consideration at every stage of the research (e.g design, undertaking research, dissemination)
- Do you think we should require inclusion as part of the Sponsor's assessment of a study?
- Would you be interested in taking part in a workshop next year to discuss this further?



Next Steps

- Contact annette@equality.health
- Focus group / workshop
- Website forum for comment



Thank you

