Diversity in Research Group

https://oxfordbrc.nihr.ac.uk/ppi/diversity-in-research-group/

Achievements in 2021 and next steps
Involving diverse communities in health research

A partnership project, established in 2021, between Oxford and Oxford Health Biomedical Research Centres
Diversity in Research Group

• 16 Group members
  Mahveen Alam, Henri Barrett, Arooj Butt, Corina Cheeks, Shamin Durrani, Farzana Kausir, Hameed Khan, Shamsideen Knowlton, Kiran Manku, Richard Mandunya, Tamanna Miah, Rosemary Musesengwa, Della Ogunleye, Ayath Ullah, Angeli Vaid, Magdalen Wind-Mozley (Chair)

• Facilitators: Alexandra Almeida and Rachel Taylor
Diversity in Research Group

The Group’s purpose:

- To advise and support the Oxford and Oxford Health Biomedical Research Centres
- To increase involvement of under-represented communities in health research
- To advise researchers on specific bespoke projects
This presentation outlines

The group’s key achievements in 2021

The next steps for 2022
Achievements in 2021

Completed projects

1. Feedback to researchers on research projects
2. Group members joined PPI groups
3. ‘Barriers and solutions to involvement’ – the group developed guidance for researchers
4. The Group designed ‘Tell us about you’ demographic survey

Work in progress

Literature review and health inequalities work
1. Feedback to researchers on research projects

- Non-medical interventions for health and well-being (Flourishing)
- Using AI for detecting and treating prostate cancer
- Blood and bone marrow cancers (OxPLORed study)
- Diabetes and the design of diets for non western cultures (DIAMOND study)
- Polygenic Risk Scores – film for the public
Increased budget for PPI in funding applications to enable working with people who face multi-systemic inequalities.

Materials translated so that people who do not speak English can be included.

PPIE contributors involved throughout research cycle (eg. reviewing a variety of materials).

Improvements to research following feedback from the group.
2. Group members joined PPI groups

- Weight Management Panel
- CT scan research project
- NHS App Evaluation
- Diversity seminars
- Psychologically informed physiotherapy
3. Barriers and solutions to involvement

The group identified barriers and solutions to involvement in research and informed new [PPI researcher guidance](#). Some examples are below.

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Solution</th>
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<tbody>
<tr>
<td>Unaware of opportunities for involvement and how valuable their experience is</td>
<td>Hold engagement events and build relationships with the community</td>
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<td></td>
<td>• Be specific to the Community i.e. Caribbean, African, South Asian</td>
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<td>• Get the communities involved with tasks i.e. cooking, invitations</td>
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<td>• Hold events at familiar, supportive community venues</td>
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<td>• Get a health professional to speak on the topics e.g. Diabetes</td>
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<td>Adverts haven't reached them</td>
<td>It’s easier to go through existing community leaders</td>
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<td></td>
<td>• Outreach health workers or support group coordinators who are often the ‘gate keepers’ to communities and trusted figures.</td>
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<td></td>
<td>• Be proactive and build a wider network of community contacts that can then help you reach the most vulnerable and underserved communities.</td>
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3. Barriers and solutions to involvement (cont)

<table>
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<tr>
<th>Lack of time – the requirements are too time consuming</th>
<th>Start building up relationships with the communities before you submit your research application</th>
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<tr>
<td></td>
<td>• Speak to members of a specific community, outreach workers and people with experience of the community before putting together your PPI for research application</td>
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<td>• You need to understand what will need to be in place to meaningfully involve contributors in a research study</td>
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<td></td>
<td>• This work should be started as early as possible to start building up partnerships with the community</td>
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<tr>
<th>Additional costs of parking, travel, childcare, and lost work time to attend meetings – worry them</th>
<th>Communication!</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>• Make sure that you have been in touch with people well in advance of an event to ask about specific requirements</td>
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<td></td>
<td>• Do they need help with transport?</td>
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<td>• Can they only attend at specific times?</td>
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<td></td>
<td>• Offer financial reimbursement such as paying for childcare or a carer’s time</td>
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4. “Tell us about you” survey

The group gave extensive feedback on a survey to collect information about PPIE contributors, making the survey more inclusive for all groups.

This resource has now been distributed to BRC PPI groups, so that researchers can use a survey that is clear and inclusive, allowing them to have a better understanding of who is involved, and where the gaps are etc.
Literature review

• Three members of the group are undertaking a literature review on outreach methods, to understand what is already known about how best to reach particular groups who are not usually involved.

• The knowledge from the literature review will inform our outreach approach.

• We will produce guidance to help researchers involve diverse groups.
The Group is collecting examples of health inequalities to increase our knowledge. A snapshot from the jamboard is below.

**Health inequalities' knowledge - ongoing group project**

- **Only half of women with a learning disability take up breast screen** (Connolly, 2013), compared to 70% of women who do not have a learning disability.

- **Black women are 4 times more likely to die in childbirth and Asian women 2 times more likely to die in childbirth than White women** (Mothers and babies: reducing risk through audits and confidential enquiries in the UK, 2020).

- **Covid Black and South Asian men 2.7 times more likely to die, Black and South Asian women 2 times more likely to die** (Office of National Statistics July 2020).

- **Polycystic Ovary syndrome (PCOS) affects women of colour more severely - US study**

- **Employment worries have negatively affected the mental health of 61 per cent of BAME people, compared to 51 per cent of white people** (MIND, July 2020).

- **A device designed to spot early signs of dangerous falls in oxygen levels in Covid patients works less well in those with darker skin, experts are warning** (BBC, July 2021).

- **In England, Black men are at twice the risk of being diagnosed with, and dying from, prostate cancer compared to White men** (BMC medicine 2015).

- **During Covid, all-cause mortality (ie. for all reasons, including Covid) was 4 times higher than usual for Black men, 3 times higher for Asian men, 2 times higher in White males. For women, 3 times higher for Black, 2 times higher for Asian, for White males, 2 times higher** (Office of National Statistics).

- **Babies from the Black ethnic group have the highest rates of stillbirths and infant deaths, with babies from the Asian ethnic group consistently the second highest**. (Office of National Statistics)

- **Low birthweight is a known risk factor for infant mortality. The Black ethnic group had the highest infant mortality rates for low birthweight babies, with a rate of 43.8 deaths per 1,000 low birthweight live births in 2019**. (ONS)
Next steps

• Annual planning meeting in January 2022
• Widening membership
• Finalise the Terms of Reference
• Identify and address the Group’s training needs
• Diversity workshop for researchers
• Progress health inequalities work
Oxford and Oxford Health BRCs thank the Diversity in Research Group for their commitment and hard work in 2021

Presentation by:

- Alexandra Almeida, Oxford Health BRC
- Rachel Taylor, Oxford BRC
- Angeli Vaid, Oxford BRC
- Magdalen Wind-Mozley, Diversity in Research Group Chair