Reaching Out: Building relationships to increase research impact

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1.0 Introduction

1.1 **Background**

A Public Health England Review found that 'the highest age standardised diagnosis rates of COVID-19 per 100,000 population were in people of Black ethnic groups (486 in females and 649 in males) and the lowest were in people of White ethnic groups (220 in females and 224 in males).'[1] Already well documented is the under-representation of people from these groups in the participation and involvement in research. In light of this, the NIHR partners, Research Design Service (RDS), Clinical Research Network (CRN) and Applied Research Collaboration (ARC) in the South East have, over the past 18 months, responded by establishing links with various organisations from the Black ethnic group as a whole and the Asian ethnic group as a whole in the region. So far, the focus has been on developing relationships, occasionally bringing researchers into the group to showcase and discuss research that the partners think may be of relevance and general discussions about the need to develop relationships and build trust between the organisations that are part of the 'research infrastructure' in the region and our various communities. The NIHR partners have sought to move away from short term, 'transactional' relationship between researcher and community toward the development of an ongoing trusting relationship. NIHR partners and the people, with whom we meet, from the Black ethnic group as a whole and the Asian ethnic group as a whole, now want to build on these relationships.

Below is a description of our Reaching Out event. This is followed by key findings from the day and next steps.

1.2 Purpose of the Reaching Out event

This Reaching Out project gave NIHR partners and the public an opportunity to further consolidate these relationships, identify what they might collectively do to better work with the public in the future (the public for the purposes of this paper includes community leaders, community connectors, community development professionals and individuals from ethnic minority groups). This project was an opportunity to capture what needs to change at both a local and national level; to ensure an ongoing partnership between NIHR and the public, which NIHR partners believe is the foundation stone for ensuring greater representation and involvement in research and ensuring that research activity reflects the needs of all. The intention is to co-produce a way forward for the partnership, including defining the purpose of the partnership and activities that could be undertaken within this partnership. This report has intentionally avoided developing a 'how to' guide or a 'top tips' as a range of such tools already exist e.g. Cowan 2021.

This event was funded by the NIHR Centre for Engagement and Dissemination (CED) programme, as part of a wider Reaching Out programme to influence NIHR to:

- further embrace and invest in relationships with communities in shaping and delivering research
- review and adapt its culture, funding and contracting systems, policies and processes to enable this

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[1] Public Health England (2020) Beyond the data: Understanding the impact of COVID-19 on BAME groups

The work from this event will feed into a second stage National Conversation on Community Engagement, ideally fronted/led by CED and RDS, which focuses on generating positive action and change within NIHR, based on the event findings and outcomes.

The overall purpose of our event was to help us co-produce a plan that would identify the purpose, aims and activities of an ongoing partnership between NIHR organisations, organisations from various ethnic minority groups and researchers in the South East region.

More specifically the aims of our event were to:

- identify barriers, at a local and national level, to engagement, involvement and participation in research and how these might be addressed;
- identify what changes the NIHR, at a national and local level, may need to make to ensure more effective engagement;
- identify opportunities for, and benefits of, working in partnership.

It was acknowledged that this event would provide information that is needed to develop a way forward for an ongoing partnership. Following this event, an action plan will be developed with participants in an iterative way, partly through sharing progress online and partly via ongoing meetings.

1.3 The online event

The NIHR partnership held an online consensus event, using a modified nominal group technique (a further explanation of, and justification for this underpinning approach is provided below).

Agenda for the day.

- Welcome/Introduction (15 minutes)
- Breakout session 1 (20 minutes)
- Breakout session 2 (20 minutes)
- Comfort break (10 minutes)
- Breakout session 3 (20 minutes)
- Feedback from each of the groups (5 minutes feedback from each group plus whole group discussion) (30 minutes)
- Comfort break (10 minutes)
- Breakout session 4 (20 minutes)
- Feedback from each of the groups and whole group discussion (20 minutes)
- Next steps (15 minutes)

How the breakout sessions worked

There were three breakout sessions and three key questions:

Q1 **For public**: What are your experiences, if any, of participating or getting involved in health/social care research?

For researchers: What are your experiences, if any, of people from ethnic minority groups getting involved/participating in research?

Positive and negative

What, if anything, would you like to see change?

Prioritise up to five key points

Q2 What might be the benefits and outcomes of working together in partnership?
Prioritise up to five key benefits or outcomes

Q3 What are the challenges/barriers and opportunities to developing an ongoing partnership?

How might barriers be overcome?

What resources would be needed?

What could NIHR do/change to help – local/national?

Prioritise up to five key points

- There were six groups and three sessions
- Each break out session had two groups addressing each one of three questions
- Each group had the chance to address each of the three questions
  There was a facilitator and scribe for each group who remained with the same question across the three breakout sessions. The facilitator was there to lead the discussion and keep the session to time and topic.
- Each group included a mixture of six or seven participants (e.g. two members of the public, two from NIHR/other organisations, two researchers)

Breakout session 4

Having teased out and discussed key issues, challenges, barriers, opportunities etc in the first three breakout sessions each of the six groups addressed the same question.

Q4 What should be the purpose, aims and activities of an ongoing partnership?
What should our vision and mission be?
What is the appetite for an ongoing partnership?
What activities should the partnership undertake?
Are they realistic and achievable?
Identify up to five priorities

1.4 Where is the public involvement in our approach?

In the first instance ideas for a Reaching Out project was discussed and debated with the established ethnic minorities group. The NIHR partnership worked with a public member on writing drafts of the proposal. Then, using an iterative approach, the project proposal was sent to the ethnic minorities group for comment, feedback and sign off. A member of the ethnic minorities group was the lead author of this report and another member of the group acted as a reviewer.

The plan for the day was also reviewed by, and revised following input from the Kent, Surrey and Sussex Regional Patient and Public Involvement (PPI) Forum – a Forum that includes various NIHR partners and members of the public that seeks to ensure PPI activity is co-ordinated across the region.

1.5 The method underpinning NIHR partnership approach

A modified nominal group technique (NGT) was used. NGT is an approach to decision-making where the goal is to achieve consensus among participants, in this case the development of a plan for an ongoing relationship. It is an approach that has been successfully used by one member of the NIHR partnership to inform the development of a standard of education and training for the Health and Care Professions Council (Hickey and Chambers 2014).

Typically, NGT involves five stages:

- Introduction and explanation of the meeting/event
- Silent generation of ideas – participants are provided with the nominal questions and asked to consider them
- Sharing of ideas – participants share their views with a facilitator (but don't debate them)
- Group discussions – participants debate the various issues
- Voting and ranking – the ideas and issues that are developed are prioritised via voting and ranking

There are some ingredients that can influence the success or otherwise of an NGT. Good facilitation is crucial; with the facilitator, ensuring everyone is able to have their voice heard. The nominal questions should be clear. Finally, the participants should be those who will be affected by the outcome.

In NGT there is the opportunity for equal input from all participants and so it is a particularly good approach when involving public members. In addition, the desired outcome is change and so it is useful to include those individuals who will be affected by the changes contributing to decision-making.

In what way was our proposed event 'modified'?

Our event was structured with open questions that attendees considered. However, there were several differences:

1. There was not a silent generation of ideas.
2. Rather than then simply sharing ideas we had breakout groups in which participants shared AND discussed ideas – we believe that this enables a more creative process as individuals can share, discuss, and build on the thoughts of each other.
3. The numbers involved in our event meant that discussions took place in break out groups.
4. It was necessary to have four break out group discussions rather than one – the first three breakout sessions enabled a discussion of issues that then informed the final session.

These differences are captured in the table below.

Traditional	Modified
Introduction and explanation	Introduction and explanation
Silent generation of ideas	
Sharing ideas	Sharing ideas in six break-out groups x 3
Group discussion	Group discussion
Voting or ranking	Voting or ranking in break out groups
	Group discussion

2.0 Experience of ethnic minority community connectors and development leaders

> **“There is little room to change activities to accommodate the needs or nature of the communities, if this was not identified at application stage”**

2.1 Powerlessness of the researched

The majority of comments from the public described a frustration and a powerlessness of the ‘researched’ and those who represented the community groups and organisations. Some of the public described research topics developed by researchers as being motivated by “self-interest” and not for the benefit of the community. There was a sense that research was abstract and needed “to be measurable and tangible” with benefits and/or measurable targets for the community. Public members described a sense that communities were not enabled to be “authors of their own fate”.

They described feelings of distrust towards researchers, sometimes due to research fatigue, not receiving feedback at the end of research projects and not being understood as an ethnic minority group. There was also a sense that the diversity of and between different ethnic minority groups was not understood.

2.2 Problematic framing of ethnic minority people

Members of the public also reflected on researchers’ definitions of communities, which they believed were often framed through problematic terms such as “vulnerable” or “hard to reach”. Researchers often spoke of them in terms of deficit based research – where they were referred to as having ‘poorer health outcomes’, ‘barriers’, ‘language deficits’ and ‘not having an ability to articulate their points’. These views were problematic as they perpetuated negative narratives that contribute to stigmatisation and stereotyping.

Research questions sometimes were not relevant to communities involved. Public attendees did not feel “ownership of the research.” Public attendees expressed having little to no input into research questions and the framing of ethnic minority people gave them very little sense of self-determination or in control of their own narrative. Public attendees at the event expressed how they were often obliged to work within these negative narratives and constructs as researchers were the curators of the research.

Public attendees noted that researchers needed to align their priorities with community goals and concerns. Public attendees suggested “better ways of working” through more asset-based approaches that could build on existing resources. Asset based community development (ABCD) is a process which focusses on community assets and strengths rather than focusing on needs and problems which can have a tendency to blame and have a top-down approach. ABCD looks to find strengths, capacities and assets within a community. The Marmot Review (Marmot, 2010) recognises that the development of healthy and sustainable communities, who may be impacted by socio-economic inequality, requires using local assets and empowering communities.

2.3 Transactional relationships

Public attendees suggested moves away from an over reliance on transactional relationships; researchers zooming in and out of communities as and when they need something from them. They described a sense of disconnect with the researchers who did not follow up with the results of their research; the researched ended up feeling used. There was also a wish to have an equal relationship where they were seen as partners. Such partnerships would involve compatible goals, where there was mutual benefit, and a reciprocated interdependence.

2.4 Research fatigue

Continuously being researched and not seeing a positive impact was difficult for community members and leaders. The need for researchers to feedback, manage expectations, explain the outcomes and impact of the research was important.

2.5 Acknowledging skills of community connectors `

Public attendees commented how their skills and time required for community development, mobilising and organising were not always valued or remunerated. Public attendees described how they were often expected to bring together groups, share contacts or do engagement work without acknowledgement. There was frustration that research proposals did not cost-in community connector costs.

It was also felt that the time it took community groups to build links and relationship were not valued and not often acknowledged, compensated or considered at the design stage, at inception of the research idea. One member of the public reflected that the lack of resource allocated to community development, “limits involvement of key people in society who would otherwise add value in research”. This included providing local intelligence and links into different communities.

2.6 No ongoing relationship with community development connectors

As a consequence of the transactional relationships, referred to earlier, public attendees spoke of the absence of meaningful and trusting relationships with researchers. Often researchers came to community connectors only to access groups of people to research when they needed something. The public attendees were looking for more ongoing engagement, which provided long term more detailed and nuanced research that could help researchers better identify study topics, to make them more meaningful to the people they wish to research. Public attendees felt that involving them and the researched at earlier stages would help the disconnect between researchers from the researched. In the excerpt below a community connector describes how research is currently designed and how it could or should be designed:

> “ . . . designed and decided by a different party to the communities, it is important to involve the community at the early stages . . . before institutions commission research, it is important to have relevant

> stakeholders and have any questions/issues answered by the community. A balance of power is required."

2.7 Lack of resources allocated to community development connectors

There were few resources allocated to the actual community connectors. Whilst there may be money/vouchers allocated to participants – the work of the connectors were largely unacknowledged. The work of community development connectors can involve the assembling of groups, the managing of ongoing relationships with the researched, the marketing of the research interpreting and/or translating materials and managing the expectations of individuals.

2.8 Importance of cultural competence

There were requests for researchers to have training in cultural competence so that they would be better able to work with ethnic minority people. It was felt that there was often a lack of connection which could make approaches to reducing health disparities problematic (see 1.2 problematic framing of ethnic minority people). It was felt that academics may lack a conceptual clarity of the issues that surround ethnic groups, which could result in cultural insensitivity, implicit biases and/or stereotyping. This was reflected in community connector impressions that researchers were often uninterested to understand frustrations of communities that did not fit with their research plans. There was some concern that research teams were not keen to engage with systemic racism or "issues around racism" when examining negative health outcomes of people from ethnic minority communities.

2.9 Researchers not being representative of community members

Researchers were described by some as not reflecting the community that they were researching. Subsequently the community felt a sense of detachment from researchers. This could also lead to research questions and approaches not reflecting the concerns and issues of different communities.

3.0 Experience of researchers of ethnic minority people

“Need to be more culturally competent and have better knowledge of the different communities.”

“Being more comfortable around the different communities rather than studying the ‘other’

Researchers’ observations often chimed with the concerns of the community.

3.1 Low recruitment

Researchers acknowledged that there was very low recruitment of participants from ethnic minority groups into clinical trials and research. One researcher reflected that this was:

> “. . . possibly because there are not many in the geographical area or within the clinical area that my research is focused. I simply don’t see them coming to the clinic (which is my usual means of contact with potential participants). I could meet with may be two out of thousands of patients”

However, there are other structural or cultural factors such as inequities in referral pathways and destinations[2] or lower attendance to services that may be less accessible to some groups[3] . Other researchers commented that, translation services, “language, and culturally relevant communications” were needed. While still others noted that researchers had not done enough to reach out to different communities. .

3.2 Getting buy-in and cultural competence

Researchers felt it was difficult to get access, buy-in and trust from community groups. Researchers also admitted how they found “going in cold” in research projects difficult and one researcher reflected how as a result of the complexity that they chose not to get involved with ethnic minority groups as they found it “too difficult to develop relationship and trust”.

Researchers expressed a genuine wish to engage with people from ethnic minority groups but were not sure how to create a safe, open and comfortable space for community groups. There was a lot of uncertainty how to communicate with the groups, one researcher said that they wished ‘to be more comfortable around studying the ‘other’ and be more 'culturally competent’. There was acknowledgement that a two-way learning process may be valuable in researching people from ethnic minority groups.

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[2] Chui, Z., Gazard, B., MacCrimmon, S. *et al.* Inequalities in referral pathways for young people accessing secondary mental health services in south east London. *Eur Child Adolescence Psychiatry* **30,** 1113–1128 (2021).
Bhui K, Stansfeld S, Hull S, Priebe S, Mole F, Feder G (2003) Ethnic variations in pathways to and use of specialist mental health services in the UK: systematic review. Br J Psychiatry 182(2):105–116
Ayo Y, Morley D, Steven W (2020) Delivering culturally competent services. In: Theodosiou L, Knightsmith P, Lavis P, Bailey S (eds) Children and young people’s mental health: early intervention, ongoing support and flexible evidence-based care 2nd edn. Pavilion Publishing and Media Ltd, pp 57–67.

[3] British Heart Foundation (2017) National Audit of Cardiac Rehabilitation (NACR) Annual Statistical Report. file:///C:/Users/sasid/Downloads/bhf_nacr_report_2017---digital.pdf

3.3 Working beyond the library

Researchers said that they were not currently working with communities on an ongoing basis. Some researchers identified that they needed to “better understand what needed to be done in terms of research – with success in recruitment and asking the right questions”. That is, they need to ‘get out of the library’ and engage with communities. Some researchers reflected on the need to “create relevance” in their research and to “look at individuals and get a sense of their lifestyles and what impacts them” and the importance of “gather[ing] people’s experiences”.

There were two camps of researchers, one group expressed an appreciation of the need to look out of the “lab or corporate office” otherwise their research would have limited relevance to communities. The other camp of researchers were more cautious, whilst valuing honest and open relationships, and that while the public could contribute to research they felt dialogue with the community could have potential limitations. For example, there was the view that researchers and professionals had the expertise in terms of ‘what issues were facing communities and the world’ and that “people don’t know what they don’t know”.

3.5 Role of community connectors/partners

Some researchers, whilst identifying the value of having conversations with the “communities”, argued that funders provided little time or resource for this.

One researcher suggested that it was important to make sure that researchers identified the ‘right’ community partners. She relayed her experience of working with Roma communities and the benefits of working together in partnership with groups that are already well established and have strong links with different communities:

“The importance of the right person engaging with the communities, someone who understands different invested interests and power dynamics within them. If you’re employing someone to engage with communities then it’d be helpful if it was someone who was already trusted and respected within the community. Or have links with a body that has already established trust and loyalty. Both of these will lead to a better chance of the possibility of implementing change during the research rather than at the end.”

4.0 Researchers being responsive to the community needs

At the event attendees reflected on how they could move forward towards an authentic, equitable and meaningful partnerships.

4.1 Earlier and ongoing involvement and relationships

Developing relationships prior to the start of a research project was identified as an important part of creating a more equitable relationship. This would enable groups and organisations to have input into and shape research ideas earlier in the process than hitherto. Research questions would likely be more meaningful, better defined, more targeted and feel more relevant to communities. It could also enable community organisations and researchers to co-produce research proposals.

Building relationships, would mean that both parties would have a better understanding of each other, but in particular, would allow researchers to understand how communities work, and better understand community priorities, assets and strengths. Researchers working in this way have also developed trust amongst communities. Positive relationships between researchers and communities could lead to co-producing and co-designing research, as one participant said, with “a shared focus which builds a stepping block and you can then build the relationship.”

There is, however, a resource issue – for the time that community development takes and the skills and learning that community connectors bring to enhancing research.

4.2 Asset based research

There were requests from community groups to reframe the way that ethnic minority c groups are researched, away from deficit-based research, which characterises ethnic minority people with stigmatising health issues, which feeds into stereotyping of deficit-based narratives of lack of exercise, bad diet, alcoholism, obesity, etc.

Researchers building asset based approaches into their research may look to consider opportunities of amplifying voices and capacity building in communities, and consider taking interdisciplinary approaches to health research to understand the challenges of inequality

4.3 Sharing skills and experience

A key theme to emerge from the event was the desire for mutual learning and active participation to build trust and long-term relationships between researchers and community groups. One of the major themes amongst public and researchers alike was to build cultural competence of researchers, so they can grow their awareness and understanding of communities that they may not be familiar. Likewise, communities wanted to learn from researchers to gain greater awareness and understanding of research. One idea was creating buddying systems between researchers and community development leads to upskilling both groups -researchers could better understand community development and community group leads could better understand the research process.

4.4 Authentic and equal partnerships

Community groups were particularly keen to build genuine partnerships with researchers, which they hope would develop into a shared vision of meaningful research where they could co-produce research that was solution focussed and have a positive impact on local communities. There were hopes that collaboration would bring capacity building, ongoing dialogue, resources, entering joint funding opportunities, identifying new areas of research and addressing power differentials.

4.5 Representation

Community members felt they would like to have more ownership over research so they could learn to be community researchers and be better able to have get to the heart of matter and work to finding their own solutions. There was a sense that the “Global South are well capable to research local issues” as one public attendee put it i.e. there was a wish from community groups to see more researchers from ethnic minority groups undertaking research into their communities.

5.0 Next steps

Below is a list of activities that a Forum – consisting of members of minority ethnic communities, representatives from NIHR bodies in the region and possibly researchers - could collectively work on. The Forum will continue to meet and discuss, develop and prioritise these activities. Each of these steps would need to be explored and scoped further.

5.1 Possible next steps for the Forum:

- **Develop an engagement charter:** Develop a charter, drawing on findings of the Reaching Out event, that look to criteria that researchers need to meet when working with communities and prior to them going out to communities. The charter would cover ‘what does ‘good’ like when working with different communities?’ They could be required to answer a set of questions to enable a panel to assess if they are addressing issues concerning communities.
- **Assessing engagement plans:** Creating a panel that is able to assess if researchers are considering how they are working with communities they are studying and embedding central research questions (see draft questions 5.3) that consider the role of the communities they are researching. Alternatively, a member of the public from the ethnic minority community lens could sit on the ethics approval panel for researchers to ensure good practice is embedded within research. It may be that the engagement charter could form the basis of any assessment.
- **Training for researchers:** Develop a list of principles/responsibilities/ ethics/guidelines in working with ethnic minority communities – to be used as a training/learning guide for researchers. The Forum could seek to engage with research institutions to discuss how they can use guidelines as a way to benchmark research ethics. It may be that the engagement charter could form the basis of any training.
- **Training in research for community organisations**: to be enable them to co-produce with researchers and end up with transferable skills so they can use them for individual progression and organisational development/growth.
- **Buddying for researchers:** Community connectors could support researchers to better work with communities.
- **Match making service:** The Forum could be a mechanism for matching communities with researchers/academic institutions.
- **Advising on research plans:** Organisations and groups who have a research idea could attend a Forum meeting to discuss, and get feedback on, their research ideas/plans.
- **Develop the Forum into a true partnership between researchers and community**: We want to build stronger, trusting relationships between researchers and community groups. This would involve members from community groups being involved in, for example, chairing and facilitating meetings and overall governance.
- **Reach out further:** The Forum could reach out to other community groups in the region.

> **“**Researchers need to be comfortable with dealing with uncomfortableness.”

5.2 Resources needed

- Time and resource to establish meaningful and trusting relationships with enabling community organisations
- Engagement with community stakeholders who act as a conduit
- Commitment needed by researchers
- Engagement with communities at the earliest stages of any research project
- Remuneration to both recognise and value community time, skills and expertise
- Adequate resource allocated to meaningful engagement with minority groups (i.e acknowledging community groups, the diversity between and within ‘community groups’ who may be more fragmented rather than a group; cultural differences; addressing language differences; addressing digital exclusion; addressing issues that impact groups
- Time and resource allocated to dissemination/sharing results with communities and sustaining the relationships when the study is completed. As one participant of the conference captures, “Communities need to be involved throughout the cycle of research.”

5.3 Potential questions for researchers to consider prior to meeting with the Forum:

- What current links do you have with the community/groups/individuals you are looking to study (formal and informal)?

- How have you involved the community/groups/individuals you are looking to study?

- How have you involved the community/groups/individuals you are looking to study in the research questions?

- Can you explain why you are taking this asset/deficit based response?

- How are you involving community connectors in conducting this research?

- Has your research come from a specific request from the community/group or individuals?

- How are you resourcing communities/groups or individuals in the research?