Improving Diversity in Health Research and Trials, A Conversation with Medical Research Charities

egality

Acknowledgements

Egality are a start-up focused on improving diversity in health research and clinical trials.

This is a complex issue, so we focus on a very specific *'piece of the puzzle'*. We connect culturally diverse community organisations with the research sector to share expertise, improve communications, and conduct outreach to improve diversity in health research and trials.

Introduction

The coronavirus pandemic and Black Lives Matter movement has focused more public attention on persisting health inequalities, and raised more awareness about representation of ethnic minority communities in health research.

Through our work with the **Charities Research Involvement Group** (CRIG) we heard that members (policy, PPI, and research professionals) wanted to increase the diversity of people actively involved in research, but were unsure how to do so.

To explore this, we ran three focus groups with 17 medical research charities in November/December 2020. The purpose of the groups was to facilitate a conversation between members, share experiences, and understand what guidance and support individuals needed.

We've summarised discussions into six key areas, and included recommendations and resources for the national bodies, organisations and individuals.

We hope the report sparks conversations across the sector about what can be done to improve diversity in research.

We hope it supports organisations and individuals to take one action to improve diversity today.

What if – Everyone who read this took one action today to improve diversity in research?

Our focus groups a year on *(December 2021)* would be filled with discussions on learnings, experience and progress.

1. Standards, guidance, and best practice on diversity in research

We heard that there are no universally recognised standards for diversity in research. Guidance and best practice examples on how to improve diversity are also limited. Given this is a complex area with ethical implications, participants said that they are hesitant to take action without standards and guidance. This is understandable, but means progress to improve diversity could be stalled.

One of the first questions we were asked in each focus group was what does good diversity look like? Is there a percentage I should be meeting? Should it correlate with the prevalence in my disease area? Participants were unsure how to measure *'success'* and were hesitant to ask researchers to improve diversity without a clear standard.

The next question was usually, do you have any examples of best practice, any guidance on how to this? Participants in all focus groups recognised that the usual way of doing things wasn't reaching a diverse range of people. People often referred to the *'usual suspects'* i.e. white and middle class, who were consistently involved in research.

We heard examples of projects that had gone well, and things that hadn't worked. Those that went well usually involved working with a new group of people, for example community organisations or local services, who bought in a new perspective. Those that didn't work were often small alterations on the usual methods, e.g. altered job descriptions for traditional working group structures. A number of participants commented that the most useful part of the discussion was listening to others' experiences.

Recommendations:

National Bodies - Work together to develop standards and guidance on improving diversity in research, so organisations and individuals feel supported and can make progress.

Organisations and Individuals - Use resources available to take the first step, for example, the eight principles on PPI with ethnic minority communities released in the recent Journal of the Royal Society of Medicine editorial. PPI guidance like the UK Standards for Patient Involvement also provide a framework for all public engagement.

Egality will be also be starting a webpage showcasing case studies from medical research charities and community organisations delivering projects to improve diversity in research. Please submit examples to the team, details at the end.

2. Budgets to improve diversity in research, and evidence to support investment

Improving diversity in research requires investment of time and money, which is limited. Especially now, when the sector, the wider industry, and the economy, are facing unprecedented pressures.

We heard that internal budgets don't usually include money to improve diversity in research, which restricts the time and resources a researcher can commit. We discussed examples where organisations were including allocations in 2021/22 budgets, in line with ED&I strategies, participants saw this long-term approach to improving diversity as the ideal.

"We had an Equality and Diversity officer a few years ago, but they left. The person responsible was not given many resources. After Black Lives Matter one of directors is leading a diversity working group to look at where we are, what we are doing, and what resources we need."

Participants also wanted to see guidance from funders on whether applications should include a budget to improve diversity. Similar to discussions on standards and guidance, people wanted to be clear how this would impact researchers, and if they would be penalised for not including it.

Participants said that it would be useful to have evidence on how improving diversity will result in better research and outcomes. This would support conversations with budget holders, who must make difficult decisions with restricted budgets. It was recognised that evidence is currently limited because research has not been diverse in the past.

Recommendations:

National Bodies - Work together to build the evidence for diversity in research and the impact on research and health outcomes. We hope national funders will also develop guidance for research and applications. Like the Wellcome Trust guidance on clinical trials which includes a section on underrepresented groups.

Organisations - Include allocations for improving diversity in annual budgets, in line with organisational strategies on ED&I that support change across the organisation.

Individuals - Use resources available to take the first step at no cost. For example, the NIHR INCLUDE framework provides free guidance including a roadmap to improving diversity, and potential challenges you might face.

3. Standardised methods and inclusive categories to record ethnicity

Ethnicity data is not routinely collected, which means organisations and the sector don't know the diversity of partipants currently involved in research, and don't have a benchmark to measure improvement. The lack of standardised methods and inclusive categories means researchers don't feel equipped to record ethnicity.

"We discussed this with our grants team and have started to ask researchers to report on ethnicity. We've realised ... that we don't understand the landscape of our research area and who is participating"

We heard that there are no universal methods for recording ethnicity data that are used consistently in the sector. Participants were also concerned about ethical issues, meeting GDPR requirements, and being clear on the purpose of this data. Linked to the discussions on standards, there was concern about putting additional pressure on researchers, without clarity on how to record and report ethnicity appropriately. Would researchers be penalised for not recording/or not having a diverse enough sample?

"When I was doing my research, I didn't really think about ethnicity, but when you see the stats and the majority are white or from the same groups, it does hit you."

Participants also commented that the ethnicity categories commonly used do not reflect the range of diversity in the UK, and how people identify. For example, conflating African and Caribbean as *'Black British'.* We heard researchers can feel uncomfortable asking participants about their ethnicity, for fear of causing offence.

Recommendations:

National Bodies - Work together to develop standardised methods and inclusive categories so researchers feel equipped to record and report ethnicity. There is already positive progress, like Understanding Patient Data's upcoming research programme on Engaging with Black & South Asian people on equitable data collection.

Organisations and Individuals - Start recording where you can, so you have a benchmark and can measure progress. There are resources like the NIHR INCLUDE ethnicity framework which provides guidance and worksheets to help you consider who should be involved in your research. The Government have also released guidance on writing about ethnicity, including words and phrases to use and avoid.

4. Improved diversity in the workforce, boards and working groups

The medical research charity workforce is predominantly white British[1]. Research shows that more diverse organisations prevent groupthink, and are more innovative[1], which will help solve challenges like diversity in research.

We heard that workforce diversity is a concern, and participants recognised the impact this could have on organisational culture, and the ability to engage diverse people and groups in research, and working groups. Participants also recognised the need for diversity in senior leadership and boards, and the need for buy in at the top to increase diversity in the workplace.

> *"I wonder if it's a big issue that the organisation is predominantly white—so maybe when reaching out to communities, they might not relate to me… We and senior leadership need to think about this."*

We heard that PPI and patient working groups and steering groups are also made up of predominantly white, middle class, participants. Participants asked for guidance on how to improve recruitment to these roles. It was recognised that time commitments, and role expectations could be exclusive. Again, participants noted that it was useful to hear other experiences, and would like to see more examples of best practice in this area.

> *"We have a sitting community of sorts of 480 people, and I think 5% come from a Black and ethnic minority background."*

Recommendations:

National Bodies - Work together to conduct a system review of current routes into charity roles, and how these could be diversified. Working with advocacy organisations like Charity So White.

Organisations - The ACEVO report on racial diversity in the charity sector provides leadership principles and practical recruitment advice. Organisations are also developing ED&I strategies which include a focus on workforce and working group diversity, for example Cancer Research UK. The EDIS Network also aims to inspire and encourage the UK scientific community to make equality and diversity a top priority, you can access resources and tools on their website.

Individuals - On steering/working groups, practical considerations include, the timing of meetings, the job descriptions and expectations, and your recruitment networks. If there are participants you want to reach, consider why they might want to be involved, and what could be stopping them. You can, hold workshops with people outside your organisation, like community leaders to explore how to make groups more appealing and accessible.

5. Improved relationships and new ways of working with community organisations

Community organisations have been engaging culturally diverse communities in health programmes and research for years. At the moment, they are not often involved in UK-wide research programmes that define the medicines and health services society receives. There is an opportunity for medical research charities and community organisations to build new relationships and work together to improve diversity in research.

We heard that some participants had previously tried, but struggled to identify organisations, and make contact, with limited information available online. Some participants felt like they didn't truly understand how community organisations operate, or their priorities, so were hesitant about reaching out.

> *"I think we should think of new ways to engage with these groups and look towards voices they trust (community leaders)."*

There were a few questions on establishing ways of working. Are you working with another charity who are doing this out of good will, or is it more of a transactional relationship? Participants discussed examples of projects falling through, because there were not clear expectations on both sides. Participants were also interested to understand how priorities could be aligned, and what research community organisations would like to see.

We heard that people were conscious of needing to maintain on-going relationships, but found this difficult given time and capacity restraints on both sides. It was recognised that COVID-19 has intensified pressure, and impacted face to face community outreach and engagement.

> *"We think we started strong but lost the engagement and are not sure why"*

Egality have also conducted similar focus groups with community organisations, from these discussions, and with our Advisory Board community organisation representatives we developed Egality's Principles for Engagement, which you can use to guide your work.

Recommendations:

National Bodies - Support new ways of working and funding for building relationships and working with community organisations.

Organisations and Individuals -
- Build relationships so community organisations can be actively involved from the start in discussions about research priorities
- Reimburse organisations for their time and expertise, and set up scopes of work and contracts between both parties so each side know what to expect
- Ensure that there is engagement throughout the process, and the outputs of the research are shared with all parties and those who participated

Egality's offer, and how we can support, is set out on page 10

6. Translation and interpretation

Participants were conscious of language barriers, and the time and resources required to do this well. Participants spoke about being unsure on which languages to use, and where to set the scope. Especially when research materials were used on multiple platforms and owned by different parties. They recognised that some research materials may not land with communities in formal English or translations, and the need for layman terms to be used in any language.

> *"Communities are really interested in the research, but English is not their primary language. All our material is in English, but we also have control over what we say about research and the language used. We did a big piece of work to translate some of the work in different languages – it's a big task. How do we translate research we support or are part of our platform? How can we make the research accessible?"*

Recommendations:

Organisations and Individuals - Work with communities to identify which language and dialects will be most appropriate to translate materials to. Some community organisations offer translation and interpretation services in local dialects. Organisations like English Unlocked also provide training and consultancy on working with interpreters.

Examples of good practice in community engagement

A charity engaged ethnically diverse participants, specifically from the South Asian community and in deprived areas through working with community organisations. This was from a social research perspective, and included:

- Creating long-term partnerships with local community organisations, including immersion with the local communities by joining events and networking
- Recruiting individuals through community organisation partnerships or direct contact after seeing a brief or survey marketing
- Phone interview option in place of face-to-face focus groups, helping to navigate issues of sensitivity, time restrictions, and digital exclusion
- Providing vouchers as incentives for participation
- Some of their researchers could speak a community language, i.e. Urdu and Punjabi and had cultural understanding which allowed for easier direct communication in focus groups and interviews, as well as in recruitment stages to explain the research

Stroke Association recognise that South Asian and African and Caribbean communities are disproportionately affected by stroke due to higher prevalence of associated risk factors.

The Stroke Priority Setting Partnership (PSP) had planned to engage with these groups through face-to-face interactions via relevant partners. The PSP first survey was launched in late February 2020, and with everything moving online due to the COVID-19 pandemic, the plans had to change.

To increase engagement, the team worked with the localised stroke services their organisation provided. These services were more imbedded within local communities. This increased the number of people from ethnic minority groups participating. The team are now working with Egality Health to increase engagement in these communities in the second survey.

Tenovus Cancer Care funded a research project to engage the local traveller community. The investigator involved members of the community as fellow researchers to conduct interviews. She equipped them with recording tools, recognising the importance of the spoken word in the Traveller community. This gained participants' trust, and helped overcome stigma against institutions.

Egality's offer

Egality are a start-up enterprise focused on improving diversity in health research and clinical trials.

Improving diversity in research is a complex issue, so we focus on one very specific piece of the puzzle. We connect culturally diverse community organisations with the research sector to improve diversity in research.

- Workshops with community organisation leaders to explore research priorities and develop research communications that are focused on the benefits to people and the community

- Outreach with community organisations, sharing information to networks of local organisations and people via social media, email, WhatsApp, community meetings and events.

We work with our [Advisory Board](#) of community organisations and representatives from the research industry who guide the organisation strategically.

If you'd like support to improve diversity in your research, get in [contact](#) today.

Egality's commitments

- **Start a webpage of best practice on our [website](#)**

- **Organise a workshop for CRIG members and community organisations to meet, share experiences, and explore ways of working together**

- **Support the CRIG through a working group to look at a specific cross-sector challenges where guidance/templates/research would be valuable**

What will your commitment be?

Available Resources

INCLUDE Ethnicity Framework
Aims to help trial teams think carefully about which ethnic groups should be included in their trial for its results to be widely applicable, and what challenges there may be to making this possible.

NIHR INCLUDE Guidance
Guidance to improve inclusion of under-served groups in clinical research. Includes roadmap suggesting intervention points and a framework of questions to guide the design and assessment of clinical research proposals.

Patient and public involvement for ethnic minority research: an urgent need for improvement
Editorial, including recommendations for increased engagement and evidence of ethnic minority contribution in patient and public involvement (PPI).

Demand Diversity
Campaign website with resources including reports on attitudes towards clinical research among people from ethnic groups, a literature review on diversity in clinical research, and a podcast with insights from the public.

FDA Guidance - Enhancing the Diversity of Clinical Trial Populations — Eligibility Criteria, Enrolment Practices, and Trial Designs Guidance for Industry
Includes guidance on eligibility criteria, and study design to improve diversity in enrolment.

PhRMA Principle of Conduct of clinical trials communication of clinical trial results
Chapter six is focused on their commitment to enhancing diversity in clinical trial participation.

Wellcome Trust Clinical Trials Policy
Includes section on including people from under-served groups.

UK Standards on Public Involvement
A description of what good public involvement looks like and approaches and behaviours that are the hallmark of good public involvement.

Charity so white
A POC led campaign group seeking to tackle institutional racism in the charity sector.

EDIS Group
A coalition of organisations working to improve equality, diversity and inclusion within the science and health research sector. Resources and practical tools available on the website.

Government Guidance on writing about ethnicity
Guidance on how the Government writes about ethnicity, including words and phrases they use and avoid, and how they describe ethnic minorities and different ethnic groups.

Egality – Principles for Engagement
Developed with community leaders to guide your work when building relationships and working with community organisations.

Contact us

If you'd like support to improve diversity in your research, get in contact today.

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