

How can community organisations support clinical research?

For the health of society, and the integrity of science, we expect medical research to reflect the diversity of human society. For numerous reasons, this is not always the case. But community organisations could hold the solution this.

Research has shown that some groups in society are less likely to be involved in research due to issues around:

- Communication on the commitment required, and the benefits of, research
- Awareness of, and referrals to research
- Trust and reciprocity

Historically, participants have been gathered through traditional methods of GP / Consultant referrals and advertisements in GPs and hospitals. However, it is recognised that these methods often attract 'the usual suspects', who are predominantly white and middle class. To engage a broader range of participants, we need to address the issues above, and this change needs to come from within the research community.

However, it is not easy as a researcher to address the issues above. Particularly when budget and timings are tight, as they nearly always are. It is fair to say that effectively connecting with groups of people, be that South Asian millennials or African-Caribbean grandparents, requires a different type of knowledge, experience, and skill-set.

These can be found in abundance in community and grass root organisations across the UK, who work daily to build relationships and trust, and inspire action to improve people's lives. Unfortunately, many of these organisations are struggling to survive in an environment where government funding is being cut.

Is there a way to foster working between community / grass roots organisations and clinical researchers to make our research system more inclusive, and provide some sustainability and security for these organisations?

Social Action for Health is a charity based in North East London who empower communities to live healthier lives. As an example of their work involving communities in research - the team are currently conducting outreach amongst Pakistani and Bangladeshi populations across East London, raising awareness and collecting DNA samples to support research that aims to fight heart disease, diabetes, and other conditions which are predominant in the South Asian population in London.

The organisation also delivers smaller projects, like their Maternity Voices Partnership, which brings together women across communities who have recently given birth to understand how the maternity services in the area could be improved, which then informs local commissioning and service design.

Across the UK there are many organisations like Social Action for Health, examples include [Community Links](#) in London, the [BAME cancer communities](#) in Nottingham, and the Basil Skyers Myleoma Foundation. In the US, diversity in clinical research has become a more prominent issue over the last few years, and groups like the [MS Minority Research Engagement Partnership Network](#) are driving forward inclusive research, along with platforms like [Savvy Cooperative](#) and [Antidote](#) who are using technology to reach a broader range of participants.

What sets organisations like these apart is their acute awareness of cultural nuances, and their ability to connect with different groups of people, engage them in their health and research, and build lasting trust and relationships.

It is likely that the pressure on UK researchers to diversify their participant pool will only mount in the coming years. Today, more than 40 million patients are needed in around 300,000 clinical trials worldwide every year, but 85% of trials are discontinued because of patient retention. Community organisations could provide vital support here, but they are massively under-utilised in this space.

So how can researchers work with community organisations to strengthen and broaden participation in research, and in turn provide more opportunity for these organisations to utilise and deliver their skills? These organisations could provide support including:

- Communicating the benefits of being involved in research, through co-creating specifications and materials with different groups
- Raising awareness of clinical research projects, reaching a broad range of participants through community networks, and small focus groups in appropriate settings
- Building trust by engaging with different groups in a way that is respectful and reciprocal

But what are the practical steps that researchers and community organisations can take to start working together? Is this something both sides would value?

We are interested in exploring this further and would really value your time, either through an email with your thoughts, at jackannette0@gmail.com. If you would like to speak in more detail about your experience, or what you would find useful, please don't hesitate to contact me. @NIHRINVOLVE are planning to host a Twitter poll on this topic in the near future.