

Research Champion Videoconference

On Wednesday 4 November Research Champions from the NIHR Clinical Research Networks (CRNs) North East and North Cumbria and Yorkshire and Humber came together via zoom for our first collaborative videoconference.

A lot of hard work took place behind the scenes by a group of Research Champions from both CRNs who did a fantastic job in co-designing the event. Organising the videoconference remotely rather than in person meant there were additional challenges to consider, for example making sure the event wasn't too long and ensuring we scheduled a tea break!

Our aim was to learn more about current NIHR guidelines and projects that aim to improve access to research for people from Black, Asian and Minority Ethnic (BAME) backgrounds.

We know that BAME communities are less likely to be represented in health and social care research studies. This makes obtaining good quality research information from, and with, all our communities even more important. The need for more relevant research data to inform health care planning and practice has been highlighted in a number of reports and recommendations. (Department of Health, 2008; Mir et al, 2012).

The reasons for under-representation of BAME communities in research are complex, and include barriers such as language, cultural values, and beliefs between those who conduct research and potential participants, and issues related to general accessibility to research in deprived areas. Poorer engagement of BAME communities can be a relevant factor along any part of the research pathway from developing the research idea through to dissemination and translation of changes into practice:

https://rds-eoe.nihr.ac.uk/rds-ssl-2019/wp-content/uploads/2020/08/Toolkit-for-increasing-participation-of-Black-Asian-and-Minority-Ethnic-BAME-Groups-in-health-and-social-care-research.pdf

However, despite the difficulties, there are examples of excellent practice in this area, and through our videoconference, we wanted to highlight some of these examples and generate a discussion.

Professor Miles Witham opened the event with an excellent talk on the NIHR INCLUDE project and the newly published guidance: www.nihr.ac.uk/documents/ensuring-that-covid-19-research-is-inclusive-guidance-from-the-nihr-crn-include-project/25441

To listen to Professor Miles Witham's talk click here:

Making research inclusive in COVID times: Progress with the NIHR INCLUDE project - Prof Miles Witham

Dr Barabra Czyznikowska then delivered a brilliant talk outlining a toolkit that has been developed with the aim of increasing participation of Black Asian and Minority Ethnic (BAME) communities in health and social care research: https://centreforbmehealth.org.uk/resources/toolkits/

To listen to Dr Barabra Czyznikowska's talk click here:

Centre for BME Health: reducing health inequalities - Dr Barabra Czyznikowska

The final talk was from Aamnah Rahman who delivered a fascinating talk on the Born in Bradford Community Engagement programme. The programme wanted to make sure that all communities were included in the Born in Bradford study: https://borninbradford.nhs.uk/about-us/

To listen to Aamnah Rahman's talk click here:

BIB Community Engagement/Involvement in research - Aamnah Rahman

Following a short break the group was split into smaller groups and each group was tasked with answering one of three questions, which were developed by the Research Champions.

- Q1. How can we engage with BAME communities in a virtual world? What are the barriers?
- Q2. How can we make research more accessible to BAME communities? What are the barriers?

Q3. How do we make the role of Research Champion accessible to people from BAME communities? What are the barriers?

Some fantastic discussions took place and the main points have been captured.

- 1. How can we engage with BAME communities in a virtual world? What are the barriers?
- WhatsApp, which is a free messaging app, is a good way of engaging with community groups and sharing information. This has worked well for Dr Barbara Czyznikowska and some of her groups.
- Engage with younger members of BAME communities i.e. 15-35 year olds. They could help with translation for those not confident in English and could also help in building trust within their communities. This age group is likely to be familiar with Snapchat, Tik Tok, WhatsApp, Twitter, Facebook and other social media platforms.
- Involve Nurses and health professionals from their own communities.
- Make electronic equipment more accessible and offer support to be able to use it.
- Don't give out leaflets especially in the current pandemic.
- We need to be pleasant, approachable, offer trust and be supportive but primarily we need to understand their concerns and act appropriately.

Barriers:

- You have to be IT literate to be able use Zoom and other electronic apps.
- Not everyone has access to zoom and it's hard to get people to commit to attending an online meeting. It's often easier to get people to commit to a face to face meeting.
- The virtual world is very excluding and face to face contact and relationship building has taken a while to build up.
- Language, lack of technical knowledge, fear, trust, religious and cultural differences. Embarrassment of "physical health examinations".
- 2. How can we make research more accessible to BAME communities after the pandemic?

What are the barriers?

- Engage with influencers in the BAME communities such as Imams and other community leaders who are trusted within their communities. They may be able to distribute information impartially and not pressure people.
- Get information out via email as well as on social media.
- Continue to use zoom and other videoconference software but also explore different ways of meeting. This could include focus groups, fun days, food and drink days and shared information days.
- Ensure research is relevant and will be beneficial to the community.
- Ensure that researchers have a Patient and Public Involvement and Engagement budget so that community members who are involved in research are reimbursed for their involvement and are not out of pocket.
- Enable the community to be involved at the idea stage so that they are key in shaping and contributing to the research from the start.
- Ensure that there is clear communication about the project and any time commitments.
- Make sure that research findings are shared with all communities in the appropriate languages.
- Invite other areas of the community to be involved i.e. GP surgeries, housing, schools.
- Researchers could create a database of people from the community who want to be involved.
- Offer training to community members from those who are more experienced, like a mentoring scheme.
- It is important to ensure that underserved groups have access to technology. Provide computers/tablets and training to enable people to get involved.
- It is important to say thank you, to feedback at every point of the research process and to feedback the outcomes and findings of the research project that they had been involved in.
- We should be focussing on how we can make research more accessible now as well as after the pandemic.

Barriers:

- Not having access to a computer. People who are not IT literate could be given training.
- Making assumptions that the communities want to be involved.
- Insufficient funding of the project.
- Involving community members tokenistically.
- Language.
- Lack of feedback.
- People don't use social media.
- Not wanting to attend meetings.
- Misinformation and misunderstanding about what research is.

- Involving patients can become expensive, for example travel costs.
- Age could be a barrier.
- English is not their first language.
- A lot of people use zoom but some people only have access to telephones.

3. How do we make the role of Research Champion accessible to people from BAME communities? What are the barriers?

- Explain the principles of research and how research is important within the community.
- Some people may not be ready to participate in research at this current moment in time as well as after the pandemic. It is important that people feel ready to be involved.
- Involve community leaders and support groups.
- Importance of clear communication and feedback.

Barriers:

- Engaging with communities.
- Equipment accessibility.
- Language barriers.
- Technical knowledge.
- Age.
- Cultural aspects and beliefs.
- Family hierarchies.

Our aim is to take all of this learning forward and to co-design a future event with a working group of Research Champions.

I would like to thank our Research Champions from the NIHR Clinical Research Networks North East and North Cumbria and Yorkshire and Humber for their support in co-designing the videoconference and for all of our Research Champions for their valuable contributions.