



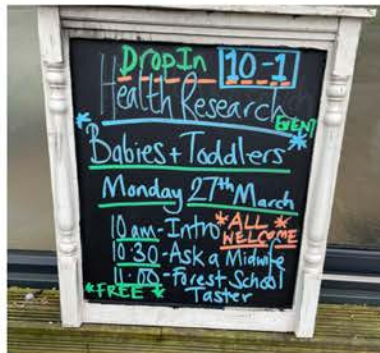
Community Engagement:
Reflections and Recommendations 2022/23

Background

The NIHR Clinical Research Network (CRN) is working with communities to understand current perceptions of health and care research, hear what barriers people face to involvement, and work together to raise awareness of the benefits of participation. In 2022/23 the CRN West of England piloted community engagement projects across the region in partnership with community organisations.

Following an open call, we had conversations with 12 community organisations across the region. We identified 5 to partner with, purposely choosing a range in terms of size, geographical location and the communities they represented. We had conversations with those who were unsuccessful in this round and are looking at how to work with many of them in the future.

We worked together to design projects based on the expertise and cultures of the 5 organisations, aiming to start conversations in the community and build sustainable relationships. Connecting the organisations and building a network was an important part of the process. We offered a half day of training on health and care research as well as bringing organisations together for a celebration and evaluation event.



Community organisations and their projects

Voscur

Voscur is the support and development agency for Bristol's Voluntary, Community and Social Enterprise (VCSE) sector.

They organised a workshop as part of a wider event focusing on the challenges for the VCSE sector in responding to the cost of living crisis. They also ran a follow-up online event to reach those unable to come to the in-person event. 47 people took part in the workshops representing a large and diverse number of voluntary and community organisations in Bristol.



The Ardagh Community Trust (ACT) manages a beautiful site on Horfield Common for the benefit of the local community. Located between Southmead and Horfield/ Bishopston, ACT provides volunteering opportunities, sports, leisure and wellbeing facilities.

ACT ran a series of events focused on 3 different groups; babies and toddlers, children and young people, and adults. They held drop-in sessions on health and care research alongside scheduled taster activities such as Tai-Chi for the over 50s and outdoor play for toddlers. 64 people took part in sessions over the three days.

healthwatch Swindon

Healthwatch Swindon is the independent champion for people who use health and care services. They strive to

understand people's needs, experiences and concerns and speak out on their behalf.

Healthwatch worked with 4 community fridges and cafes in Swindon. They designed a short survey to help start conversations and to better understand perceptions and attitudes to research. They spoke to over 100 people and 52 people completed the paper questionnaire.

Community organisations and their projects



Inclusion Gloucestershire is a user-led organisation, driven by the social model of disability, which sees people as disabled by society rather than by their impairment or difference.

They worked with 2 different communities in Gloucester: The Women's Wellbeing Group at the Friendship Café and the DJ-ing group at Music Works. The Wellbeing Group is made up of Muslim women, most of whom were not born in the UK; the DJ-ing group is a group of people with learning difficulties and autistic people who are passionate about DJ-ing. They ran 2 workshops on user-led research. 19 people took part in the activities.



Diamond's Social Community Hub provides services and activities in communities with high levels of socio-economic inequality in South Bristol. They have developed a unique group therapy method, 'Free Talk', providing an

open floor for people to discuss their feelings and experiences in a safe, non-judgmental environment.

They used the Free Talk method to start conversations around health and care research in the community. They worked with a group of adults, a mixed family group including young children, and a group of young people. 72 people took part in the activities. They created a relaxed atmosphere centred around social eating to support people's wellbeing and tackle social isolation. Participants discussed health inequalities and the role of research in addressing them.



Reflections and learning

All 5 organisations reported a positive response from community members towards the activities. Many people were interested in finding out more about research and a good number of individuals expressed an interest in becoming Research Champions, members of the public who are passionate about research and raise awareness in their communities. People were positive about the face-to-face approach taken by the organisations and felt comfortable having conversations in spaces they were familiar with. Working with trusted organisations was felt to be a very vital aspect of the community engagement projects and connecting the conversations with food, social events and regular activities, helped people feel more open.

Once terminology was clarified, 40% people at the Ardagh felt they had an above average understanding of health and care research. At least 25% had taken part in research or had been invited to by their GP. People reported a gap in knowledge about what research was taking place and how to find out more and participate. There was interest in finding out more about research on specific conditions.

Healthwatch Swindon heard that although people had little knowledge of research, they understood more about how important it is for health as a result of the COVID-19 pandemic. 74% felt research helped health and social care improve.

“I was asked to take part in a survey conducted by the Great Western Hospital... They took the time to explain why they were carrying out the research and how they were going to use it to shape patient delivery.”

“I had cancer when I was young and the treatment of cancers has come a long way, it's all down to research carried out in this area.”

Not all felt so positive about research though. 62% of those Healthwatch spoke to had never taken part in research (most had not been asked) and only 44% felt their views would be heard when taking part in research.

“I feel as though questionnaires I filled in previously have made no difference”

“Need more feedback from the research as you never find out what the end result was and what will become of the research.”



Reflections and learning

Inclusion Gloucestershire found that as a result of the project, people have a better understanding of the fact that they can influence what is researched, that they have a choice to participate and they understand how they can support research. There was interest in creative forms of research and a general fatigue towards surveys. The participants came up with ideas for research into hidden disabilities and the impact on health outcomes of not being listened to by health professionals. 8-10 people are interested in finding out more about the Research Champion programme.

During the Voscur workshop, there was a rich discussion on the benefits of and barriers to participation in health and care research. Individuals and organisations shared their experiences and developed recommendations for increasing engagement and participation in research. 9 of the organisations who attended the Voscur workshop wanted to know more about championing research in their community and the Research Champion programme.

People engaged positively in the Free Talk sessions organised by Diamond's Social Community Hub and were interested to find out more about health and care research. Individuals felt they didn't have much knowledge about research and how to participate and some felt that it was something just for 'rich people'. A few participants responded negatively during the workshops, saying they believe research is like "testing on rats."



Benefits of participating in research: Themes

Communities shared their views on the benefits of participation in research. Many had positive perceptions and could see the advantages it brings to both individuals and the wider community. Organisations identified benefits and highlighted them during their projects.



Better understanding and management of personal health and conditions. Communities highlighted that being more closely monitored by healthcare professionals could reduce anxiety and help people feel more in control of their own health.



Being part of something. People noted that there was a social aspect to participation in research. It gave people the opportunity to meet others with the same condition and connect. They also felt that participating meant others would see their community represented in a positive light.



Contributing to the greater good. Community members felt that doing something that would benefit society as a whole would motivate people to take part and feel good about their contribution.



Economic benefits. People identified far-reaching economic benefits to health and care research. They felt that it could help reduce pressure on the NHS and decrease healthcare costs for society as a whole.



Better care and improved outcomes. Communities felt that research played an important role in informing clinical practice and local healthcare services. They felt that this resulted in better prevention, care and reduction in, or even eradication of, disease.



Increased understanding of how different groups respond to interventions. It was felt that people from different backgrounds taking part in health and care research would help healthcare professionals understand how interventions work for different cohorts.



Increased trust and well-being in the community. Research was felt to improve trust in healthcare through increased and more positive interaction with healthcare professionals.

Barriers to participation in research: Themes

Understanding the barriers to participation in research and listening to people's lived experience is central to our work with community organisations. It helps to build trust and enables us to adapt our approach effectively. Themes emerged during the conversations:



Lack of knowledge and information about health and care research. People were often not aware of the breadth of research taking place or how to participate. Some had little awareness of the benefits of participation in research.



Consultation and engagement fatigue. Communities talked about regularly being approached by researchers on a wide range of issues. There was little knowledge about what had been done with their input and some were reluctant to engage further with research. Others spoke about feeling they had filled in endless surveys and never knew what was done with the information.



Lack of agency and control over research. Some people talked about feeling 'done to' when it came to research. The value and impact of taking part is not always clear, especially when the impact is not seen for years.



Accessibility. Culture and language were identified as barriers to participation, particularly where studies require fluency in English. Finance was also highlighted, lack of access to transport for appointments was felt to be particularly challenging. Some people raised the issue of research being carried out online. This leads to digital exclusion for those without devices, connection or digital skills.



Fear/ Distrust. In some communities there was a clear sense of fear and distrust towards statutory bodies, including the NHS. This distrust was often the result of past experience so is challenging to overcome.



Representation. Community groups talked about not feeling represented by the research community. There was a sense that research is often carried out by 'outsiders', especially if the people asking the questions don't seem or look like the research participants.



Recognition. People felt that involvement in research should be properly recognised and organisations/ individuals should be paid. Vouchers were not felt to go far enough in many cases, people needed to see the impact of research and feel that it would be of benefit to their communities.

Recommendations for community engagement

An important element of the project was to improve our approach to engaging with communities. We met to celebrate, learn and evaluate, looking at where we could build on our experience. The feedback was overwhelmingly positive, organisations felt the process was proportionate and smooth and they valued the connections made with the CRN and each other. Our community partners outlined a series of key considerations that the CRN, health and care organisations and community organisations should bear in mind when collaborating.

Invest in long-term partnerships with trusted organisations

- Develop long-term partnerships supported by long-term investment
- Partner with organisations that have a good track record and support smaller ones
- Collaborate with voluntary sector organisations that have already built trust with communities
- Take the time to build trust rather than having one-off contact.

Make connections

- Connect research with healthcare and tackling health inequalities
- Connect communities with healthcare professionals and researchers
- Make engagement meaningful for each group - tag activities on to other events/ or link to particular conditions
- Ensure relationships are reciprocal
- Have regular drop-in sessions to build relationships and cater to specific interests

Use accessible language and communicate impact

- Communicate in plain English
- Consider if there is a need for interpretation during engagement activities to ensure people feel comfortable expressing themselves.
- Keep questions simple
- Use previous research projects to demonstrate research success
- Make use of personal stories as these are powerful

Prioritise addressing power imbalance

- Be wary of consultation fatigue and the feeling of being powerless and 'done to'
- Ensure people know that they can control their participation and involvement
- Empower people with knowledge about how to influence and how research works
- Co-design future research

Value people and organisations

- Recognise the commitment of organisations and individuals.
- Provide food or social activities to show you value people
- Feedback regularly to communities

Match the approach to the community

- Keep events face-to-face and host them in spaces and settings that are used and trusted by the community
- Use creative and non-traditional approaches to research and engagement (e.g. craft) Avoid standard questionnaires
- Understand barriers like digital exclusion and find ways to overcome them

What next?

In response to the feedback and recommendations received from the 5 organisations, the CRN West of England is committed to building on the learning from 2022/23 and strengthening and improving our community engagement. In particular:

Sustaining and strengthening relationships with organisations

Following the recommendation to build sustainable partnerships with trusted organisations, we will work with each of the organisations to plan next steps for the current year. Initial discussions suggest that these may include:

- A series of drop-in events with researchers and healthcare professionals on specific conditions/ health areas
- Introduction to the Research Champion programme and provision of induction training to interested individuals
- Connection with researchers to ensure communities are able to influence how research is designed

Establishing partnerships with new organisations

In order to expand our reach and strengthen the network, we will use the learning to identify and work with new organisations in the region. We will:

- Continue to foster relationships between organisations and build a network
- Ensure organisations have more time to plan and carry out their projects to best meet the needs of their communities.

In recognition of the importance of community engagement and the need for sustainable funding, the budget allocated to these projects has been doubled for the 2023/ 24 period.

