

Charities Research Involvement Group and Equality

Talking about involvement in research: How can we do this in an accessible way to ensure we encourage a range of people to get involved?

The [Charities Research Involvement Group](#) (CRIG) brings together charities with a commitment to actively involving people with lived experience in the research they fund and support. [Equality](#) is a community engagement agency focused on improving diversity in research.

In August 2021 Equality organised a workshop for CRIG members to discuss how to increase the diversity of people we involve in research. One of the discussion points at this workshop was about how challenging it is to explain what involvement in research is, especially to people who might be new to research as well as to involvement.

In March 2022 Equality community connectors and staff came together with CRIG members to share our experience of talking about involvement in research to different communities of people. This short guide summarises our discussions. We know that there is no one 'right' way to do this, and that what you communicate and how you do this will be at least partly dictated by who you are communicating with. And we note that many of the learning listed below is good involvement practice, regardless of who you want to involve. But we feel that there are useful things to share from our discussion. Here are the lessons we have learned so far:

Prepare well

- **Cultural perceptions:** Understand different cultural perceptions to the condition your charity focuses on – e.g. for some communities there is stigma around particular conditions.
- **Past histories:** Understand that some communities have had a bad experience of research in the past – take the time to understand past histories, and always include space in your planning to openly discuss any concerns with people.
- **On-going relationships:** Try to build relationships with specific groups - don't wait until you have a piece of research you want them to get involved in. Be prepared to invest time to build links with specific groups. For example, Bowel Research UK has spent three years building a relationship with a bowel cancer survivor group which mainly includes people of Asian origin. Guts UK ran a 'science of digestion' event in Ealing and invited a range of organisations and community groups, including mosques and schools, to join.

Think about how you communicate

- **Language:** Ensure you use plain language in all of your communication and help researchers to use plain language to talk about their research – both in writing and verbally. Make sure you and the researchers you work with can talk about the research in a way that is understandable to other people, before you tell anyone about opportunities to be involved. If you have a communications specialist in your

organisation, work with them to ensure your communications are clear and stand-out.

- **Involvement:** Don't use the term 'involvement' in an initial invitation – try phrases like 'help to shape research', 'share your views with researchers', 'tell us what you think about...'
- **Diverse input:** Where possible, review communications with a diverse group of people with lived experience of the condition or the communities you are looking to reach, so they can feedback on the language, whether it is understandable and whether it resonates.
- **Methods:** Think about the methods you use to communicate. For example, Bowel Research UK has worked with people affected by bowel conditions to develop an animation about what involvement in research is – see [here](#)
- **Privacy:** Allowing people privacy can be critical. This means not asking people for too much information when they join an event. For example, one member charity works with a contributor who remains anonymous in committee meetings, but still provides great insights.
- **Listening:** Ask people – what stops you getting involved in research? Really take time to listen and understand their reasons and concerns.

Think about who communicates

- Someone with lived experience who has a link with the community you want to reach and who can talk about how they have been involved, what it has done for them and what impact their involvement has had on research may be more powerful than you or a researcher talking in the abstract about this.

Think about what to communicate

- **Benefits:** Really focus on the benefits of being involved in an activity. What will it mean for the person, their family, their community? Will it impact their lives, or the lives of others with their condition in the future?
- **Personal connection:** If you are meeting people face-to-face or virtually, find a personal connection. Personal stories are important to help build relationships. Remember that some researchers are studying certain subjects because it affects them personally – it's helpful if they can talk about this when they meet people.
- **Specific opportunities and examples:** Tell people about specific opportunities to get involved, not about involvement in research in general. Have plenty of examples ready about people who have already got involved and what they gained from it, as well as what their contribution added.
- **Training:** Once you've linked with people, think about offering training that gives an introduction to what research is and what involvement is – MS Society, Parkinson's UK and many other CRIG members do this. Think creatively about ways to do this so it's not too burdensome on the person.

- **Phases of research:** Think about how to explain that research has different phases and that it can take a long time. Be ready to talk about how people have been involved at all stages, and what difference this has made.

We'd love to hear how others explain what involvement in research is, especially to people who may not have had any contact with research before. Please contact us by email – bec.hanley@gmail.com or annette@equality.health – we'll put together an updated version of this paper later in 2022.

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