Inside Research: Participatory and community-based approaches to tackle health inequalities, 2 November 2021.

Summary of discussion in the breakout sessions

In the breakout sessions of this Inside Research seminar (see programme) each group was invited to explore the following questions:

Q: What practical actions can we all take to support participatory ways of collaborating in research or in developing services?
Q: What more do we need to do in our own organisations/research areas?
Q: What general support is needed for this?
Q: Who are the groups we most need to target to include them? How can we make this happen?

Here is a summary of the discussion from the breakout groups around these questions:

Q: What practical actions can we all take to support participatory ways of collaborating in research or in developing services?

- Researchers need to focus on the key needs and challenges that communities and service users are facing and how can we develop a research programme to address these problems. Participatory research will help understand what the need is today, how we can address that and will help get the right service users involved from the start.
- Ensure community and patients are involved from the very earliest stages of research. Too often researchers come with a preconceived idea, which they try to bend to co-production – rather than letting involvement shape and provide nuance to the questions being explored.
- Researchers are not the experts in peoples' problems. Top-down professionalised expertise cannot deal with the problems of inequality. Researchers must work with community organisations and work with people to bring them into the room.
- Researchers should be clear about knowing what they don't know and letting that shape the involvement in and co-production of research.
- Equally bringing stakeholders together once a precise research goal and research method has been planned, could lead to fruitful research and enthusiasm from stakeholders.
- If you want to engage with communities, you need to take an "asset-based community development approach". The premise of this approach is that communities can drive the development process themselves by identifying and mobilising existing, but often unrecognised assets. Thereby responding to challenges and creating local social and health improvement.
- When engaging with groups, make sure there is an incentive (eg financial). Ensure they receive feedback on how the research has been done and what the results are, and how taking part in research benefits them.

Q: What more do we need to do in our own organisations/research areas?

- Organisations must be open to undetermined questions when entering dialogue with lived experience members. Researchers should also be encouraged to approach service users before

they have a clear plan for their research, in order to develop a culture where research is informed by service users' experiences.

- As researchers we are encouraged to present ourselves in a polished-clear coherent way, so it feels uncomfortable to say we don't know the answers.
- Researchers need to think about how they can bring a person in to be a long-standing supporter. This could mean finding money to invite them along to meetings. Help people to be actively involved (eg to help design a flyer, to give advice and information, to be on a steering group).
- Do more work to promote the ARC's public research panels to internal research audiences.
- Train researchers in cultural safety/competency and equality, diversity and inclusion (EDI) principles and recruit researchers from diverse backgrounds which reflect the local community.
- The ending of research projects should be more systematically planned, so that researchers don't just drop communities and people involved. It's important to follow up and disseminate findings and share how their input was used.

Q: What general support is needed for this?

- Better funding advice can be sought.
- Funding bodies should be more flexible to support and sustain participatory research.
- There should be more budget planned in from the beginning of research projects/ethics on making study information available in more languages and thereby making it more inclusive.
- Fund more dedicated roles to support community-based engagement in research – this is something that has become established in the charity sector, and it needs to be mirrored in the world of research. Then you can segment your work to reach particular groups.

Q: Who are the groups we most need to target to include them? How can we make this happen?

- We need to get marginalised people engaged, not just working with people who are easier to engage. So, for example, doing more work with people who do not speak fluent English.
- Practical actions that would facilitate having marginalised communities at the table/participating in research include asking why meetings are always in the office hours and in NHS buildings – a local mosque, church, synagogue or community centre could be more appropriate.
- People who have been excluded because of physical, mental and cognitive disabilities are empowered by being online, so a hybrid system is inclusive and accommodating to everyone.
- Support inclusive online engagement – for example, giving people internet cards and extra funding for laptops, electricity, as well as training on Zoom or MS Teams.
- But don't overlook the importance of face-to-face meetings and reaching people where they are receiving services (eg GP surgeries, routine hospital appointments).
- Engage with local authority social care and primary care contacts, and service users' groups, such as carers' support groups, mental health service groups or parents' support groups.
- Some people can't access the health system let alone take part in research. But we can amplify these marginalised voices if this is facilitated face to face. This is where community champions come in – someone who is trusted, speaks English and can help make research more accessible.