Diversity and inclusivity in public involvement: Considerations for designing authentic involvement across your study lifecycle

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Contents

- What is public involvement?
- The standards & principles for public involvement
- Public involvement support
- Involving underserved community groups in research
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What is public involvement?

NHS Health Research Authority (2020) defines public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.

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<tr>
<th>Involvement</th>
<th>Participation</th>
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<tr>
<td>Where members of the public are actively involved in research projects and in research organisations. Advising during several stages of the research cycle</td>
<td>Where people take part in a research study. E.g. People being recruited to a clinical trial or other research study to take part in the research.</td>
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**Engagement**

Public engagement is telling people about your research, why it is important, what it found out and the impact and implications of the results.

**Public involvement & qualitative research**

Difference between the two – you will require ethical approval for qualitative research. Public involvement you do not.
Four principles for meaningful public involvement

**Principle 1**: Involve the right people – people with relevant lived experience (patients, services users, or carers)

**Principle 2**: Involve enough people – to provide a reasonable breadth and depth of views (depends on the scope of the study, but always more than 1 person)

**Principle 3**: Involve those people enough – feasible, productive, and appropriate to the research, and at the right times.

**Principle 4**: Describe how it helps – the impact of public contributors, why their experience is relevant and how their involvement will help
UK Standards For Public Involvement

- Working Together
- Communications
- Inclusive Opportunities
- Governance
- Impact
- Support and Learning
How we work

Researchers

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Current opportunities
Support you can access for public involvement

- Public Involvement Opportunities
- Enabling Involvement Fund
- Training and Guidance
- Public Involvement Forum
### Strategies to involving under-served community groups

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<th>Push not pull</th>
<th>User experience design</th>
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<tr>
<td>Go to where groups congregate</td>
<td>Make it easy for groups to participate – what needs to change?</td>
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<th>Influencer engagement</th>
<th>Trusted intermediary engagement</th>
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<td>Link with community leaders</td>
<td>Partner with other organisations</td>
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Identifying under-served communities

It is important to know and map who you need to reach. Be clear about who you want to talk to and get to know your different audiences. Some key consideration to be aware of:

**Build Trust**

Find a form of involvement that works for different groups

Strive for representation  
Go beyond digital engagement

Learn about the groups  
Make it beneficial to community groups

Feedback
Talking Trials: participatory approaches to creating community dialogue

Martina Svobodova & Nina Jacob
Talking Trials Phase 1

- 3 co-production workshops during the spring and summer 2021 using participatory arts methodologies

- We introduced clinical trials, what they are and why they are important. We explored perceptions and views on clinical trials amongst the group.

- In August 2021 we took the exhibition at the Riverside Festival where we had the opportunity to engage with the wider Riverside community (close to 200 people visited our tent)
Talking Trials Phase 1

What we learnt in phase 1:

- Partnership with the South Riverside Community Development Centre (SRCDC) to establish a project delivery group essential for co-researcher recruitment
- Participatory art methodologies proved useful in overcoming any language barriers and helped cement the group as a cohesive unit from the outset
- The focus on co-production helped foster a group of individuals new to research to become involved as co-researchers (rather than research participants) and democratise research
- Projects like Talking Trials can help diversify the research process itself as two of our co-researchers have commenced lay research partner roles within the Centre for Trials Research.
FEARS AND HOPE

- We need a lot of support, love, care and understanding.
- Building trust is important.

THE HEAD AND THE HEART

- We need to talk and share our feelings.
- Reflecting in the sea of the unconscious.

WE NEED TO TALK

- We need to listen to each other.
- We need to understand each other.
- We need to support each other.
- We need to be kind to each other.

What now?

- We need to listen to each other.
- We need to share our feelings.
- We need to support each other.
- We need to be kind to each other.
- We need to understand each other.

Querencia

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CONNECTED COMMUNITIES AND THE FUTURE

The different branches represent the different people and cultures

A Medical Trial is a Gift - A Helping Hand

ACKNOWLEDGEMENTS

We would like to thank those who helped make this project happen:

- [List of names]

Jynhun African South Wales has helped make this possible:

- [List of names]
“I have been involved with the Talking Trials project during the pandemic of COVID-19. It was first time in my entire life to be involved actively talking about medical trials. It has given me a depth insight about what is involved and how community members can have their say and be part of a bigger picture. I find the research project very useful, interesting and rewarding in terms of how the whole process worked. I have been asked if I would like to become a research partner for another study in the Centre for Trials Research. I am delighted to have this opportunity and be able to give my opinion and ideas which may represent the BME communities in Cardiff.”

Mashmooma Din
Project worker, South Riverside Community Development Centre

Research Partner, Talking Trials and Panoramic-PEP studies
“In 2012, my daughter was born and diagnosed with Tetralogy of Fallots (ToF), a congenital heart condition. I am very keen to improve the outcome of families going through a similar phase, by sharing my observations and experiences. So as part of Talking Trials, I was delighted to contribute to discussions on how more people from minority ethnic communities could be encouraged to join clinical trials. I found the discussions very interesting and rewarding. It was exciting to learn how people perceive trials, the hinderances and issues like trust and impact of the community that influence decision making in an individual. I especially enjoyed the concept of people expressing themselves through the medium of art.

I have been recently invited to join the Panoramic PEP trial as a Research Partner, which is another exciting initiative. It will be a steep learning curve, but I am delighted to be able to get involved in this way.”

**Sudipta Bandyopadhyay**

Research Partner, Talking Trials and Panoramic-PEP studies
Our next steps

- Paper to be submitted to Health Expectations Wiley journal
- Further funding from the ‘Rethinking public Dialogue UKRI experimentation fund’ run in partnership with RSA (Royal Society for Arts, manufactures and commerce)
- The 9 months pilot project started October 2022
Talking Trials pilot design

Hypothesis:

A deliberative democratic approach to public dialogue combined with participatory art methodologies can provide clinical trials units with practical recommendations to address underrepresentation of people from minority ethnic communities in clinical trials and change practices within the clinical trials unit.
Talking Trials pilot design

- Further developing our partnership with SRCDC to form a co-researcher group
- **8 co-production workshops** (Learning Stage - 3 meetings, Deliberation Stage – 5 meetings) with the use of participatory arts
- **Community Connectors** (our artist will work with some of the co-researchers to develop a session content to allow them to present their learning and journey through the project to other community groups via the SRCDC ongoing community groups)
- **Co-researchers will present recommendations** on how to make research more inclusive for people from minority ethnic communities’ perspective to the CTR PPI&E Hub, the wider CTR community and stakeholders within Health and Care Research Wales
Talking Trials 2 evaluation

The study will adopt a mixed methods approach using data from various sources. The following evaluation methods will be used:

- **Ethnographic data** will be produced to gain a deeper understanding on the purpose, relevance and benefits of the project as seen by different stakeholders. This will be achieved through **qualitative interviews with the co-researchers & observations of all meetings**
- Co-researchers group **evaluation meeting**
- Talking Trials project delivery group members reflections
Include Roadmap

4 key points:

- Ensure eligibility criteria and recruitment pathway do not limit participation in ways you do not intend.
- Make sure your trial materials are developed with inclusion in mind.
- Ensure staff are culturally competent.
- Build trusting partnerships with community organisations that work with ethnic minority groups.
For more information and support – please email us on research-involvement@wales.nhs.uk