

SEHTA 2023 International MedTech Expo & Conference



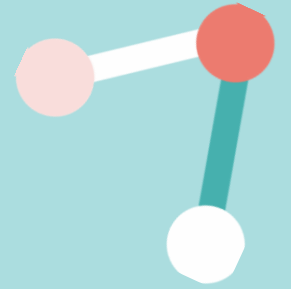
Silvia Bortoli
Senior Public Involvement Manager
National Institute for Health and Care Research

3 November 2023

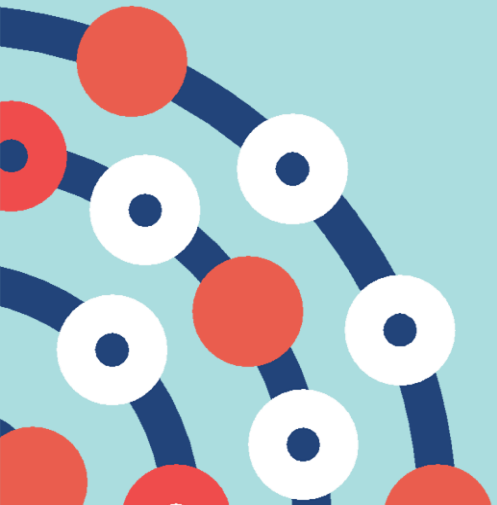


- Introduction
- Getting started
- Equality, diversity and inclusion
- Reward and recognition





Introduction



Definitions

Involvement

Engagement

Community
engagement

Public
involvement

Patient and
public
involvement

PPI

What is involvement

NIHR defines **public involvement** in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an **active partnership** between patients, carers and members of the public with researchers that influences and shapes research.

For example:

- joint grant holders or co-applicants on a research project
- identifying research priorities
- as members of a project advisory or steering group
- commenting on and developing patient information leaflets

What is engagement

Engagement in research is where information and knowledge about research is provided and disseminated.

Examples of engagement are:

- science festivals open to the public with debates and discussions on research
- raising awareness of research through media
- dissemination to research participants, colleagues or members of the public on the findings of a study.

Why involve members of the public in research?



People who are affected by research have a right to have a say in it



Members of the public can provide a different perspective



Involving members of the public can tailor your research to the needs of specific communities



Public involvement can make research more relevant



Funding bodies and ethics committees will ask about your plans for public involvement

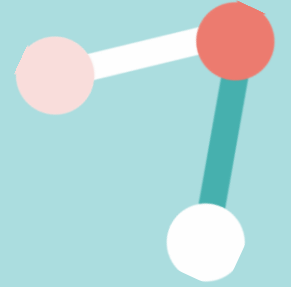
Why people get involved in research

- make a difference to future health and social care research
- make research more relevant, useful and beneficial to everyone
- opportunity to 'give something back'
- to ensure the voice of their community/communities are represented

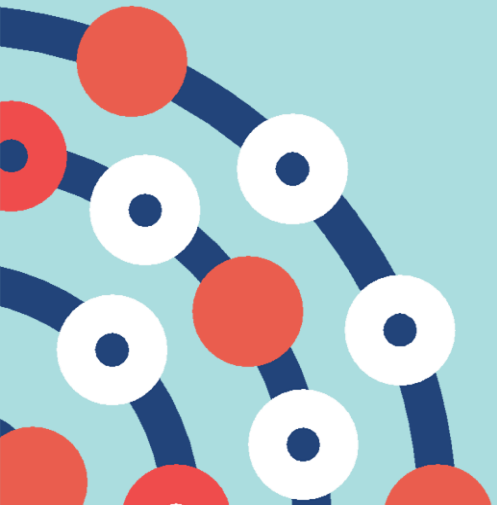
“Getting involved in research is intellectually stimulating, satisfying and interesting”

“My caring role and service user experience means something, my views are listened to and enable research to reflect the needs of others like myself”

“Research needs to be accessible to all. I feel my work is helping to make this more of a reality”



Getting started



UK Standards for Public Involvement



Who to involve

Key points to consider:

- the type of lived experience required will vary depending on the focus of the research
- be clear about the purpose of involving people in research and what experiences and knowledge they can provide
- include a diversity of relevant views and perspectives
- people can wear several hats, and their contributions may be broader because of this range of experiences

From: “Different experiences: A framework for considering who might be involved in research” (2021)

Approaches

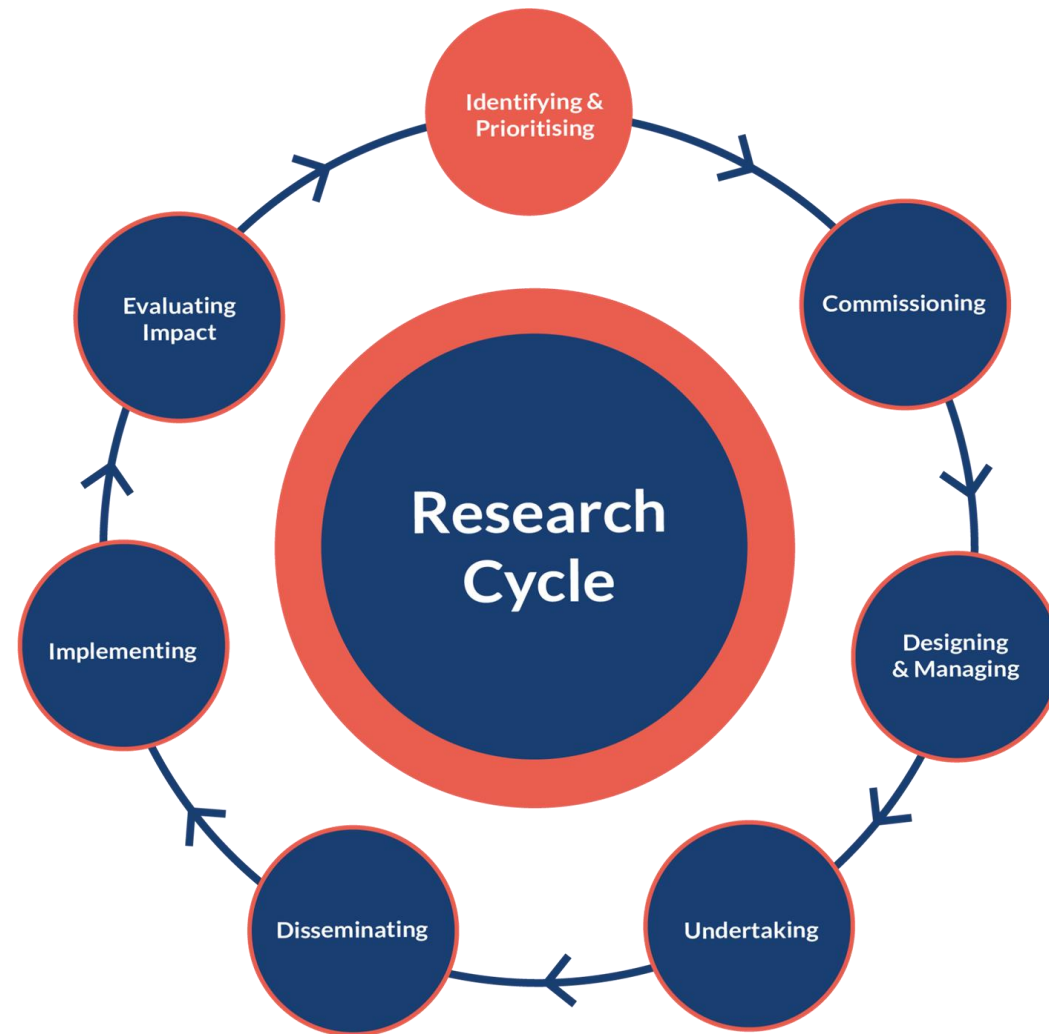
Involvement:

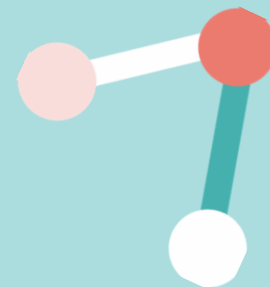
- Consultation
- Collaboration
- Co-production
- User-led/ user-controlled

Engagement:

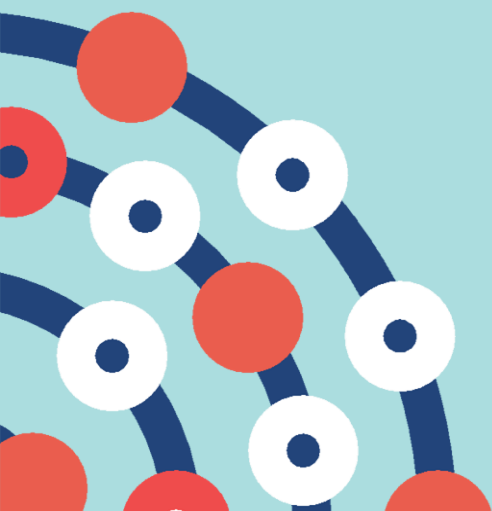
- Media engagement
- Websites
- Social media
- Presentations
- Posters and displays
- Festivals

Involvement and engagement can be done in all stages of the research cycle





Equality, Diversity and Inclusion



Why is it important to consider EDI in involvement?

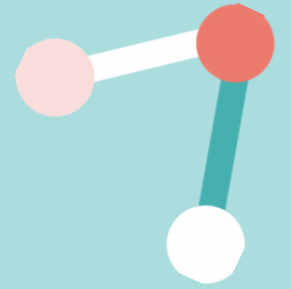
- The diversity of people who get involved in health and care research often does not reflect the diversity of the population who are affected by the issues being researched.
- Relying on one 'type' of member of the public to cover the whole public experience could lead to some perspectives being missed. Including a diversity of views and experiences helps to improve the research.
- If involvement is not inclusive, or if people do not have a genuine opportunity to influence decisions, it undermines the benefits of partnership.

How to incorporate EDI in involvement?

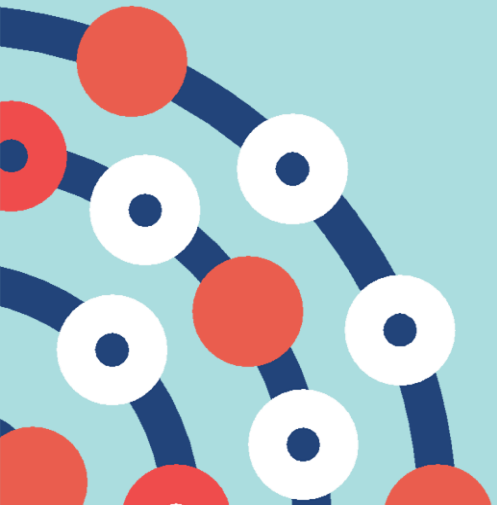
- It is important to offer public involvement opportunities that are accessible and inclusive.
- Involvement opportunities should take into account the needs of different communities and individuals, and anyone who gets involved should be treated equitably.
- We should not expect patients, carers and the public to fit into research systems. Instead, we need to help researchers get closer to communities.

Resources to browse

- [NIHR Equality, Diversity and Inclusion Strategy 2022-2027](#)
- [NIHR Research Design Service - Equality, Diversity and Inclusion Toolkit](#)
- [Being inclusive in public involvement in health and care research guidance document](#)
- [NIHR webinar How to incorporate Equality, Diversity and Inclusion \(EDI\) in Patient and Public Involvement \(PPI\)](#)



Reward and recognition



Principles of reward and recognition

Rewarding and recognising public contributors for sharing their time, knowledge and experience is an important part of ensuring public involvement is **meaningful** and can draw on a **diverse range of perspectives**.

Offering and facilitating payments for involvement needs to take account of a **diverse range of circumstances** including people in receipt of welfare benefits, people on low or uncertain income, or people who may not have bank accounts.

Good practice for reward and recognition

- Agree with public contributors what is the best way for them to be rewarded and recognised for their involvement: monetary and/or non-monetary reward
- Where possible involve the public contributors you'll be working with in the budgeting process
- At the outset, offer clear information for public contributors explaining what they are being offered, how they will be paid, and what actions they need to take
- Do not underestimate your budget for involvement

Good practice for reward and recognition

- Where possible, pay for expenses in advance to avoid members of the public having to wait for reimbursement; reimbursement of expenses should be processed promptly
- Public contributors have the right to decline payment or ask for a lower amount
- Public contributors in receipt of benefits should be careful about understanding how much money they can take home before their benefits could be impacted - NIHR subscribes to the 'Benefits Advice Service'

Payment guidance

[NIHR payment guidance for researchers and professionals](#)

[NIHR payment guidance for members of the public](#)

[Guidance for organisations on employment status and tax](#)

Thank you for listening

silvia.bortoli@nihr.ac.uk

