

# The Importance of Public Involvement in your research design



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# NIHR and Public Involvement

- **NIHR ‘Going the Extra Mile’ 2015 -2025**
- **UK Public Involvement Standards 2019** – developed by Chief Scientist Office (Scotland), Health and Care Research Wales, the Public Health Agency (NI) and the NIHR (England)

**“Our vision is for a population actively involved in and engaged with research to improve health and wellbeing for themselves, their family and communities”** (NIHR Going the Extra Mile)

**“... creating a research culture that welcomes the public into research, and helps researchers and organisations work with the public**  
(UK Public Involvement Standards)

# What Public Involvement Is and Is Not

- Research carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them.
- Patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.

## What it's not:

- Participation e.g. participants recruited into a research study
- Engagement e.g. events where public find out about research
- Professional, academic, researcher perspectives

# Public Involvement and Your NIHR Application

- Patient and public involvement plans assessed by funding committees, including patient and public members.
- Plans for public involvement necessary both for stage 1 and 2 applications.
- A PPI Lead is a designated and required role within the research team.

Applications should demonstrate evidence of both:

- Public involvement in **developing** the research application
- Public involvement **plans** as part of the research

# Key Areas to Consider in Public Involvement

- Equality, Diversity, and Inclusion.
- Building and sustaining working relationships.
- Opportunities (WIIFY) What's In It For You (public contributors)?
- Payment and recognition.

# Public Involvement Recognition Payments

## Examples:

- setting up meetings with groups e.g. venue hire, refreshments
- reimburse patients, carers etc. for their time e.g. thank you vouchers
- fees for a public collaborator e.g. involved in writing a grant proposal
- out-of-pocket expenses e.g. travel, subsistence, carer costs
- not to be used for the research itself

# Examples of Public Involvement Opportunities

- Identifying research priorities e.g. for a specific disease condition or service use.
- Commenting and developing research materials e.g. patient information leaflets or other sections of the study protocol.
- Being a co-applicant on a research project.
- Carrying out research, with appropriate training and support e.g. undertaking interviews with research participants.
- Co-producing research outputs e.g. short films of research findings.
- Participating in research dissemination and knowledge transfer e.g. joint conference presentations and writing for publication.

# How RDS NW can help – support for public involvement

- RDS Advisers/case managers provide public involvement advice.
- Specialist Public Involvement Advisers can provide additional help with complex issues or innovative approaches.
- Public contributors on ‘mock’ RDS review panels provide detailed feedback on public involvement.
- Resources on RDS Resource - [www.rdsresources.org.uk](http://www.rdsresources.org.uk)



# Public Involvement During Pandemic Restrictions

- Public involvement continues to be an integral element of research proposal development and is assessed by review panels.
- Resource hosted on the RDS NW website - [www.rds-nw.nihr.ac.uk/public-involvement/guidance-for-planning-virtual-ppi](http://www.rds-nw.nihr.ac.uk/public-involvement/guidance-for-planning-virtual-ppi)
- Advice on working remotely in public involvement:
  - adapting the public involvement approach during physical distancing
  - what platforms are available and enabling participation in remote and online PI activity
  - how to make sure public involvement is appropriate and not burdensome on those that are invited to be involved

# Your Public Involvement Checklist:

- ✓ Can you demonstrate sufficient public involvement in the development of the application?
- ✓ Have you considered plans for public involvement during the research?
- ✓ Are you being authentic and will the language you use reflect this?
- ✓ How have you addressed equality, diversity and inclusivity in the selection of public contributors?
- ✓ Have you identified a public involvement lead in your research team?
- ✓ Has a budget been included for public involvement during the research?
- ✓ Is your plain English summary understandable?

# Links to resources for further information

## UK Standards for Public Involvement

<https://sites.google.com/nihr.ac.uk/pi-standards/home>

## RDS Equality Diversity and Inclusion Toolkit

<https://www.rdsresources.org.uk/edi-toolkit>

## Be Part of Research

<https://bepartofresearch.nihr.ac.uk/>

## People in Research

<https://www.peopleinresearch.org/public-involvement/>