

5. Public involvement in research

5.1 Background

“Every day, hundreds if not thousands of patients and the public go the extra mile to help make research happen in the UK. Their contribution is many and varied. One of the most important ways in which they make a difference to what we do is by improving the quality of research, how it is designed, conducted and delivered. Within the NIHR, such is the extent to which the public has become involved that research is increasingly becoming a joint venture between patients and the public, researchers, clinicians and health professionals. If we are to meet the health and social challenges of the future then these partners must be empowered, encouraged and supported to work even closer together.”¹

5.2 Definitions

Public Involvement (also known as **Patient and Public Involvement [PPI]** or **Patient and Public Involvement and Engagement [PPIE]**)

The NIHR defines ‘public involvement in health and social care research’ as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.

When using the term ‘public’ we include 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. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services².

Public Engagement

Within NHS research, public involvement is viewed as being different to public engagement, which is when information and knowledge about research is shared with the public³. Read the HRA’s [Transparency Agenda](#) for further information.

It is important to note that ‘public engagement’ is a term that is widely used in a variety of sectors, from arts and heritage to science policy and local government, as well as universities and research funders like UKRI and Wellcome. In these contexts, it “describes the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit.”⁴

Additionally, Queen Mary University of London uses the term ‘public engagement’ to encompass all other terms referred to here.

¹ [NIHR Going the Extra Mile 2014](#)

² [NIHR \(2021\) Briefing Notes for Researchers](#)

³ [NIHR \(2021\) Briefing Notes for Researchers](#)

⁴ [National Coordinating Centre for Public Engagement](#)

For the purpose of this policy, the term 'public involvement' also broadly encompasses 'public engagement', 'co-production', 'user or patient-led research' and 'participatory research' although it is acknowledged that variations in practice exist.

5.3 Why is public involvement in research important?

Public involvement can influence research in many positive ways:

- In the identification and selection of research topics
- Informing project design and research methods
- Improving recruitment and data collection
- In the analysis and dissemination of results
- Informing the translation of research into real-life benefits
- Increasing the likelihood of securing research funding

Other benefits for people who get involved:

- Learning about research and health conditions
- Having more informed control over their health
- Developing new skills and gaining new perspectives

Benefits for the public more broadly:

- Improved trust in science, research and healthcare
- Ensures different ethical issues have been considered
- Ensures research is carried out for the public benefit

Public involvement ensures all communities are included in the research process, helping innovations in healthcare to be meaningful and ethical. The involvement of the public in research can empower individuals, give the research greater credibility and help bring about developments that will lead to more sustainable change. Staff, participants in research, and the public, in general, can help to ensure that standards are understood and met⁵.

The purpose of this policy is to ensure that staff undertaking research, at Barts Health and Queen Mary:

- Are aware of their responsibilities in involving the public in their research.
- Are suitably trained and supported to effectively engage and involve the public in their research.
- Aspire to best practice in the different ways they involve the public in their research.

5.4 Policy

This policy applies to all research that is led by or involves significant input from Queen Mary or Barts Health staff, honorary employees, short term appointees, volunteers and visiting staff using Barts Health patients or the staff, premises or facilities of the two organisations, for their research.

⁵ [UK Policy Framework for Health and Social Care, 2017](#)

- Research, and those pursuing it, should uphold the [principles](#)⁶ and [standards](#)⁷ underpinning public involvement to ensure research is representative of the diversity of human society and conditions and the multicultural nature of society. It should take account of age, disability, gender, sexual orientation, race, culture and religion in its design, undertaking, and reporting. The body of research evidence available to policymakers should reflect the diversity of the population.
- Healthcare research should be pursued with the active and meaningful involvement of patients, service users, families, carers and the public, including where appropriate those from under-served groups. There is no single definition for an under-served group; it will depend on the population, the condition under study, the question being asked by research teams, and the intervention being tested. No single, simple definition can encompass all under-served groups.⁸
- Those undertaking public involvement in research should be suitably trained and supported to engage in meaningful ways with patients, service users, families, carers, community groups and the public.⁹ Further information about PPIE training opportunities is available via local PPIE leads (see below for contact details).
- Patients, service users, families, carers, participants and the public should be involved, where possible, in the design, conduct, analysis and dissemination of research and also in the strategic direction and setting of research priorities.
- Members of the public involved in research should be recompensed or rewarded in line with established good practice. Public involvement activities should be appropriately costed and funding must be secured to ensure that out of expenses and payment for involvement can be met.¹⁰
- Once established, the results of research should be disseminated to the research community, study participants and the general public. Special arrangements should be made to ensure access to information for those with a low level of literacy, English as a second language, or a disability. Members of the public involved in your research will want to ensure that the findings are widely disseminated so they can influence and change practice for the better¹¹. Public involvement can help to identify how research outcomes could be communicated. Public contributors can assist with the production of plain English summaries and facilitate the dissemination of these by providing access to patient and community groups. The results of the study or clinical trial can, therefore, be shared appropriately to ensure that the right people and organisations have been involved.¹² For further information, see Section 7 Dissemination Policy.

Queen Mary and Barts Health researchers should seek input from local Patient and Public Involvement and Engagement (PPIE) leads, patient or interest groups, as well as regional and national advisory bodies. Current guidance should be sought and followed on recruitment, training and involvement of the public in the activities of individual research groups as well as in Queen Mary and Barts Health corporate activities, such as Clinical Governance or Modernisation groups.

⁶ [NIHR Going the Extra Mile, 2014; p13](#)

⁷ [UK Standards for Public Involvement](#)

⁸ [NIHR CRN INCLUDE Guidance, July 2020](#)

⁹ [NIHR Learning for Involvement](#)

¹⁰ [NIHR Payment guidance for researchers, Jul 2021](#)

¹¹ [NIHR \(2021\) Briefing Notes for Researchers](#)

¹² [Health Research Authority, Research Transparency](#)

Further advice and guidance can be obtained from:

Research Engagement Unit, Research Development, Barts Health NHS Trust,
Education Centre, Newham University Hospital, Glen Road, London E13 8SL

T: 020 7363 8923/ 07901 009069

E: patientsinresearch.bartshealth@nhs.net

W: jrmo.org.uk/public-involvement/

Centre for Public Engagement, Queen Mary University of London

CB100, Queens' Building, Mile End Road, London, E1 4NS

T: 020 7882 6115

E: publicengagement@qmul.ac.uk

W: www.qmul.ac.uk/publicengagement/

NIHR Research Design Service, London

E: ppi@rdslondon.co.uk

W: www.rds-london.nihr.ac.uk/patient-public-involvement/

NIHR Centre for Engagement and Dissemination:

E: ced@nihr.ac.uk

T: 020 8843 7117

NIHR website: www.nihr.ac.uk/health-and-care-professionals/engagement-and-participation-in-research/involve-patients.htm

HRA website: www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/

This policy applies to both Barts Health and Queen Mary.