Involving patients and the public in research

“Inpatient and public involvement in research means that members of the public and/or patients are active partners in the research process”

NIHR Research for Patient Benefit

*Patient and Public Involvement* (PPI) in research means research which is done with and by patients and the public, rather than to, for or about them. It is an essential element of research funding applications and ethics. We recognise there is no ‘one size fits all’ for PPI and to help you incorporate meaningful PPI into your research study, we offer the following tips which builds on [NIHR](https://www.nihr.ac.uk) and [INVOLVE](https://www.involve.org.uk) guidance, to help you get off to a flying start.

**Definitions**

*patients and public* includes: patients and potential patients, people who use health and social care services, informal (unpaid) carers, parents/guardians, disabled people, members of the public who are potential recipients of health promotion programmes, public health programmes, and organisations that represent people who use services.

*Involvement* refers to an active partnership between patients and the public and researchers in the research process, rather than the use of people as ‘subjects’ of, or ‘participants’ in research. Patient and public involvement in research is often defined as doing research ‘with’ or ‘by’ people who use services rather than ‘to’, ‘about’ or ‘for’ them. This would include, for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.

**Tips**

There is a wealth of very good guidance available to applicants planning research for example:

- **Population:** involve the right mix of people.
- **Get early help:** INVOLVE’s website has FAQs, which are specifically aimed at those wanting to find out why and how they might involve the public in research.
- **Plan** ahead and allow enough time to secure funding, venues, partners, etc. and also coordinate and promote your research successfully. Take a look at TwoCan Associates route map, which aims to help organisations that commission or fund research who wish to involve service users in their work. There are examples of forms, policies and strategies which you can download and adapt for your own use.
- **Ethics:** Don’t forget the range of ethical issues that you will need to consider when involving patients and the public
- **Communication, Communication, Communication:** Provide information about why you are doing the study, the subject of your study, what you would like participants to do, and what you plan to do with the information they give you.
Patient and Public Involvement in the planning phases of research and research design

Q1. Were patients and the public actively involved?

Q2. Please further describe how patient and public involvement has informed and/or influenced the development of the application and how patients and the public have been actively involved.

Some things to consider:

- Some patients and public have a lot of experience reviewing proposals and grant applications, whilst others have none. Always give guidance, be clear on purpose and give an example of the type of feedback you are expecting.

- If you present your research to a group of patients and/or members of the public, use this opportunity for active dialogue and go along with a number of specific questions or areas where you are seeking their help and feedback. Pitch your explanations in a clear and accessible way, avoiding jargon and inviting people to ask questions.

- Some research applications ask not just whether but how patients and the public have been involved in the design or development of the proposal; therefore it is important to include examples of advice that has been received and any consequent changes that have been made.

- Where relevant, mention PPI in other sections of the application to indicate you have taken PPI seriously by embedding it fully into the study.

- PPI in the early stages of a study may incur costs, so it is worth noting that the RDS London may be able to provide a small bursary that can be used for refreshments, patient/public time and travel, etc. Reimbursement/payment of expenses and/or time for patients involved needs to be thought through.

Ways of finding and involving patients/public in the early stages of your research:

- NHS Trust patient involvement groups and Involvement Leads
- Council of Governors and members (for Foundation Trusts)
- Local or regional advisory groups. Make contact with your Local Clinical Research Network (LCRN).
- Recruitment in clinics and through clinicians
- GP Practice Patient Participation Groups
- Community organisations and groups
- Healthwatch
- Health and Wellbeing Boards
- Clinical Commissioning Groups
- Online communities
- People in Research forum – a website and e-bulletin where researchers can include opportunities for patients and members of the public to get involved in health research.
- HealthUnlocked
- Talk London online – set up by the Greater London Authority
- MumsNet
- NHS Citizen

Patient and Public Involvement throughout research

Q3. Please indicate the ways in which the public will be actively involved in the proposed research, by ticking all of the relevant boxes
  - Design of the research
  - Management of the research (e.g. steering/advisory group)
  - Developing participant information resources
  - Undertaking/analysing the research (e.g. part of research team)
  - Contributing to the reporting of the study report
  - Dissemination of research findings

Q4. Please give more details, including how patient and public involvement will benefit the research, the reasons for taking this approach and arrangements for training and support

Some things to consider to help you do PPI successfully:

- Set aside time to consider ways in which the experience and expertise of patients and the public could improve your research, e.g., ensuring information sheets are clear and readable, or thinking about research results and helping to determine what they mean for patients in practice.
- If an advisory group is considered to be the best way of involving patients and the public in your research, think about what type of advice you want to ask of them, how you will act on it, how you will integrate the group into the wider team and at what points during the study it might meet.
- If you will be involving one or more patients or members of the public as full co-applicants or members of the research team, think about putting together a role description, and consider how you will ensure that they are consulted and listened to in meetings. Just like other members of the team, they will also require support that is appropriate for their role, e.g., training, mentorship, shadowing, and this support needs to be built into your budget. There is some excellent guidance developed for the East Midlands AHSN about patients as co-applicants.
- Don’t forget to consider the logistics of holding meetings that include patients and the public, and incorporate these considerations into your budget (e.g., in addition to travel expenses, add costs for child minders and carers so that patients and members of the public who have those responsibilities can attend meetings).
Consult UCLPartners policy on reimbursement and recognition for involvement and INVOLVE’s guide for making payment and recognition for public involvement in research.

- The patients and members of the public who will be involved with your research will be giving their time and expertise to the study and should be treated as valued members of the team. The application should reflect this, demonstrating that involvement is well thought through and meaningful.

**Information leaflet guidance**

Informed consent is one of the cornerstones of ethical requirements in healthcare research and signifies that the patient has made an informed and voluntary decision about their participation in your study.

To get there, individuals must be provided with comprehensible information to allow them to make a fully informed decision to take part in a study. You should tell the participant how their confidentiality will be safeguarded during and after the study. Make it clear if information will be treated as confidential or anonymous and explain any circumstances in which exceptions may need to be made. You may wish to tell the participants how your procedures for handling, processing, storage and destruction of their data meets the NHS Caldicott principles and the Data Protection Act 1998.

A well designed information leaflet could help not only to recruit more individuals into your study but possibly retain them in that study.

Here are some tips for designing information leaflets.

- Think about whether the leaflet is better in two parts e.g. Part 1 – summary of the study, which invites the person to read part 2 if they are interested in the study. Part 2 – further information about the study which incorporates the following five W’s:
  - **What** – what is your study about? What will happen to them in the study? What are the possible benefits and risks? What personal data are you processing and what mechanisms will you put in place to safely handle that data?
  - **Why** – why is the study being done?
  - **Where** – where will the study take place and if so how much time
  - **When** – when will the study begin and possibly finish?
  - **Who** – who’s leading the study

**Remember:** Presentation is essential: Keep it simple and easy to understand, don’t put too many scientific words in. Don’t forget to seek feedback from patients and the public before submitting your application to your Research Ethics Committee.

**Local Help and Advice**

Contact your local involvement lead or Fiona McKenzie, Patient Insight and Involvement Lead at UCLPartners for help to develop your research ideas, proposals and plans which engage with, and are led by, patients and/or the public.