

Introduction to... Involving patients and the public in research and research design

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“Patient 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) is an essential element of [research](#) funding applications and ethics. [This guidance](#) is a brief introduction to some of the things you will need to think about as you consider involving patients and the public in research and research design. It is not designed to replace the much more comprehensive guidance provided by:

- [INVOLVE](#) - INVOLVE is national advisory group that supports greater public involvement in NHS, public health and social care research and makes available a large number of relevant resources for both researchers and patients and the public on their site: www.invo.org.uk
- [Research Design Service - Patient and Public Involvement \(PPI\)](#) is an integral component of the advice given to those approaching RDS London. RDS London has a team of PPI experts who can offer support to those developing grant applications to funding bodies. RDS London can facilitate links between research teams and patients / members of the public through its database of individuals and patient groups in London, with an interest in research. To learn more about the support RDS London can offer, see their leaflet [Research Design Service London: our three stages of support for patient and public involvement](#).
- [Biomedical Research Centres - BRCs](#) supports researchers with patient and public involvement (PPI) and often have a dedicated PPI manager. There are 3 in the UCLPartners system – UCL, GOSH, Moorfields. Support includes:
 - [Training](#) – Run workshops on PPI, including introductory sessions and sessions on setting up a patient group. They also run introductory sessions for patients and the public.
 - [Bursaries](#) – they have a PPI bursary fund to help researchers carry out PPI.
 - [Advice](#) – researchers can ask for advice by contacting the PPI manager or by writing to the helpdesk ppihelpdesk@ucl.ac.uk
- [People in Research](#) - People in Research provides information specifically for the public - researchers wanting to find members of the public to get involved in their research also advertise here: <http://www.peopleinresearch.org>

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Who is this relevant to?

~~Although this guidance document~~ is primarily designed to help ~~managers and those~~ researchers who are seeking funding through the NIHR Research for Patient Benefit (RfPB) stream ~~but~~, it ~~also~~ provides lots of useful tips and things to consider to incorporate meaningful PPI into any research study.

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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.

"Researchers and others use different words to describe public involvement, for example words such as engagement and participation. When INVOLVE uses the term 'public involvement' we are not referring to researchers raising awareness of research, sharing knowledge or engaging and creating a dialogue with the public. We are also not referring to the recruitment of patients or members of the public as participants in research. However, these different activities – involvement, engagement and participation – are often linked and, although they are distinct, can complement each other"

Use of the term *'patient and public involvement'* does not indicate that you have to involve patients and the public in your research, but encourages involvement of these groups as appropriate to individual research projects. Those who are conducting research into a particular health condition may find it most appropriate to involve people with that condition in their research, while researchers looking at issues of relevance to large portions of the population (e.g., public health etc.) may find it makes most sense to involve the general public in their research.

Tips

Ideally patients and the public should be involved from the outset of your study. If your research proposal has been developed following patient/public feedback about a particular service, it is important to note this, but there must also be further patient involvement later in the proposal development. We now offer some other points you may wish to consider:

"There is no standard model for appropriate PPI as Programme Grant applications vary immensely. Things to consider when thinking about public involvement in your programme can be found on our PPI pages. You can also visit the INVOLVE website where there is a set of FAQs especially for researchers wanting to find out why and how they might involve the public in research. INVOLVE has also published guidance to applicants about public involvement in research and a guide to payments for PPI."



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Patient and Public Involvement in the planning phases of research and research design

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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.

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

- [Trust patient involvement groups and Involvement Leads](#)
- [Council of Governors and members \(for Foundation Trusts\)](#)
- [Other local or regional advisory groups – relating to local/regional forum. 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 – has a website and e-bulletin where researchers can include opportunities for patients and members of the public to get involved in health research \(see page 4\).](#)
 - [HealthUnlocked](#)
 - [Talk London online – set up by the Greater London Authority](#)
 - [MumsNet](#)
 - [MyHealthLondon – set up by NHS England \(London\)](#)
 - [NHS Citizen](#)

~~— Speak to patient support groups in your area (or nationally if none exist locally) and get their views on your research idea. Ask the Patient Experience team at a hospital in your area whether they have a PPI Forum that might be interested to hear about your study. Make contact with your Local Clinical Research Network (LCRN) who often have local or regional PPI leads. The People in Research Forum has a website and e-bulletin where researchers can include opportunities for patients and members of the public to get involved in health research (see page 4).~~

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Some things to consider:

- ❖ Some patients ~~and members of the~~ and public have a lot of experience reviewing proposals and grant applications, whilst others have none. ~~Either way,~~ Always give clear guidance, ~~pointing out where you could particularly use their help~~ be clear on purpose and giving 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 could use their help and feedback.

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Also take care to pitch your explanations in a clear and accessible way, avoiding jargon and inviting people to ask questions.

- ❖ The application asks 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 the research team has 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 provides small bursaries up to £350 that can be used for refreshments, patient/public time and travel, etc (see page 4). [Reimbursement/payment of expenses and/or time for patients involved needs to be thought through.](#)

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Patient and Public Involvement throughout the research

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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

There is no 'one-size-fits-all' solution to meaningful PPI and you do not need to tick all of the boxes above in order to do PPI successfully. Some things to consider:

- ~~❖ The areas included in Q3 above provide a helpful indication of the various ways in which patients and the public can contribute to health research and even propose some specific examples, e.g., as part of a steering/advisory group or as a member of the research team.~~
- ❖ 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. Consult INVOLVE's guide for making [Payment and recognition for public involvement in research.](#)

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- ❖ Don't forget to consider the logistics of holding meetings that include patients and the public, and incorporate these considerations into the 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).
- ❖ Just like other members of the team, patients and public will require support that is appropriate for their role, e.g., training, mentorship, shadowing, and this support needs to be considered within the budget.
- ❖ 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, ensuring that involvement is well thought through and meaningful.

Information leaflet guidance

Informed consent forms the cornerstone of ethical requirements in healthcare research. In the context of healthcare research, the giving of informed consent signifies that the patient has made an informed and voluntary decision about their participation in a study.

To get there, individuals must be provide with comprehensible information to allow them to make a fully informed decision to take part in a study. 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:

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~~* If the leaflet better in two parts such 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 the study about? What will happen to me in the study? What are the possible benefits and risks? What are the privacy and security risks?
- 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.

Finally don't forget to seek advice from patients and the public before going to the REC.

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For more information

See the websites of the organisations listed on p.1. You may also want to contact your local involvement lead or [Fiona McKenzieChelsea Atherton](#), Patient Insight and Involvement ~~Lead~~**Project Co-ordinator** at UCLPartners – fiona.mckenziechelsea.atherton@uclpartners.com.

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