

Effective patient and public involvement: Guide for researchers

This guide aims to tell you more about why and how to involve members of the public in your research. If you would like to discuss anything further, please contact Allison Worth Allison.Worth@ed.ac.uk

“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well”. Professor Dame Sally Davies, Chief Medical Officer for England

“I say do things with people, not to people”. Sir Harry Burns, Chief Medical Officer for Scotland

What are the benefits of involving patients and members of the public in your research?

Involving members of the public in research can help you to ensure that:

- written materials, such as patient information sheets, are unambiguous and easy to understand
- study methods are acceptable to participants
- study recruitment and retention are optimal
- outcomes are relevant to the patient experience
- your interpretation of the study findings includes the patient perspective

Importantly, many funders now expect robust evidence of patient and public involvement in grant applications, so if you can demonstrate effective involvement in designing and conducting your study, it will increase your chance of achieving funding.

Involving patients and the public is also valuable in disseminating your results and can help you to demonstrate the impact of your research.

Principles of patient and public involvement in research

- Value members of the public as full and equal members of the research team
- Treat people as equals, but make sure you communicate in ways that are easily understood by all members of the research team (e.g. avoid the use of detailed scientific or professional language wherever possible)
- Ensure people receive the support they need to be able to contribute as effective team members
- There are also broader democratic principles of citizenship, public accountability and transparency regarding how researchers spend public money.

There is further information about what you can expect of people who get involved in your research and what they should expect from you in the patient and public involvement guide for the public.

What kind of patient and public involvement do you want in your study?

- There are various levels of involvement, including consultation and collaboration. Funders are more likely to look favourably on your application if you demonstrate real collaboration

rather than just telling people what you plan to do and inviting them to comment. It is best to start thinking about involvement as early as possible in the research process so you can involve members of the public in the design of your study.

- You might consider asking one or more members of the public to be co-applicants on your study and sit on the study steering group; in fact some funders now expect this.
- A small project advisory group which meets separately, facilitated by a researcher who communicates between the advisory group and the steering group, is an alternative method, with many advantages. It means you have access to a broader range of public views; people may be more willing to speak up than if they are a single member of the public on a steering group; the group can support each other; their interests receive more time for discussion.
- It might be appropriate for members of the public to be actively involved in data collection, analysis and dissemination.

What value do you expect patient and public involvement to add to your study?

- It is helpful if you can tell people clearly what you want them to bring to your study and how their experience and expertise can complement your own and directly contribute to the research.
- A written role description is often helpful. Allison Worth has some templates you can work with.

Are there particular skills or experiences you want members of the public to bring?

- Do you want people with experience of a particular health condition, either as a patient, parent or carer?
- Do you want people with experience of a specific life event such as adolescence, pregnancy or bereavement?
- Do you want people of particular ages, ethnic groups, sex, or geographical location?
- Do you want people with skills in other fields, such as marketing, web design, social media?

What activities do you want members of the public to undertake and how much time do you expect them to commit?

- You need to be able to explain how exactly you will involve people and estimate what time you want them to give so that people know what they are signing up for. Your grant application will often require a detailed account of your plans for patient and public involvement.
- Pre-funding application: Are you asking for advice on study design before you submit your application?
- Do you want people to be co-applicants, grant holders, members of your steering group?
- If your study is funded: Do you want people to attend meetings, if so how often, what times of day?
- Do you want people to comment on recruitment documents and research findings? Give you ideas about how to enhance recruitment? Help to prepare information for public dissemination? Identify and prioritise topics for research?

- Do you want people to be active researchers e.g. to interview participants, facilitate focus groups, attend workshops or conferences to talk about the research?

It is best if you can negotiate roles and responsibilities for each individual who gets involved, based on their skills, availability and preferences.

Will there be a need to meet regularly and if so will this be face to face?

- If you expect members of the public to attend meetings during the working week, you may be excluding people who work, those with caring responsibilities and people who live at a distance from your workplace. The pool of people is much bigger if they can be located anywhere in the country and your involvement methods are flexible. You could think about phone, Skype, web conferencing, on-line discussion groups and email contacts as alternatives to meeting.
- Give people a choice of how they participate if you can.

How will you communicate with the people you involve?

- It's often helpful to ask members of the public what their preference is for keeping in touch and what times to avoid if phoning.
- Can you identify someone in the team who will be your PPI lead and the main point of contact for the members of the public you involve? Everyone in the team needs to understand why the public is being involved and how to interact with them, but only one person needs to manage the involvement.
- Most people now have internet and email access, but some may not be confident internet users and this should be discussed – you might need to find alternative ways of communicating or give some training.
- If you are asking people to review documents, some people prefer you to print them and send them by post as they find it easier to read a hard copy.
- Can your project support people with different needs, for example motor, visual or cognitive impairment who may wish to be involved?
- Not everyone wants to read reams of documents, particularly complicated/technical protocols, but this shouldn't exclude their involvement. You may need to prepare lay summaries of key documents.
- Ask regularly for feedback from the people you involve to see if it is working for them.

What resources do you have to support public and patient involvement?

- Effective patient and public involvement takes time and requires funds. It is best to think about this during the grant application process so you can add suitable costs to the budget. People must always be offered reimbursement of any expenses they incur, especially travel, subsistence, phone calls, postage and printing.
- You might also think about offering a bursary, honorarium, gift vouchers or funding attendance at a course or conference.
- Can you offer an honorary contract with your organisation as another form of recognition?
- Some people will choose to become involved on a voluntary basis, but you should always budget on the basis that some payment will be offered.

- People on state benefits should get advice about the implications of receiving payment before agreeing to accept any fees. Allison Worth can advise on how to obtain this advice.
- Depending on the nature of the project, you might need to think about childcare costs, cover for carers, or reimbursement for lost work time. Venues and catering for meetings; Disclosure fees; translators and interpreters may also need to be included in budgets.
- Do you (or a member of the research team) have time to offer support, for example giving some one-to-one time to explain the study, discuss your expectations of what the person will do in the project, answer questions?
- INVOLVE has recently produced a guide on budgeting for involvement and an online cost calculator to help you to ensure you have allocated adequate resources to support patient and public involvement – see the resources section of our website for links to these documents.
- Make sure you have a process in place so that, preferably, people are not out of pocket at all or at least are paid promptly for any expenses incurred as a result of their involvement.

Have you thought about training and support needs and how these might be met?

- It's good practice to find out what skills and expertise people can bring to your study, and also what training needs they have. For example, do they understand the clinical/technical language that you might need to use? Do they need pre-meeting briefings and an opportunity to ask questions before the meeting?
- Do you/your research team need training in how to involve the public effectively in research?
- Can you offer or arrange training for people you want to involve in your study?
- Some training courses are available for both researchers and the public to help both develop the necessary skills to work together effectively. Ask Allison Worth for details.

How do you find people to involve in your research?

- The earlier you can start to think about this in the research process the better. You need a brief summary in lay language explaining your research – a paragraph or two will suffice in the first instance.
- The Wellcome Trust CRF in Edinburgh has a patient/public involvement group; Allison Worth can contact them on your behalf.
- People in Research (managed by INVOLVE) <http://www.peopleinresearch.org/> allows you to advertise your research opportunity for free.
- Charities associated with a particular condition (for example Asthma UK, Diabetes UK) often have databases of people interested in helping with research, and will email people with details of your research and ask interested parties to contact you. You can utilise the media, volunteer centres and your own website/social media.
- Ask patients you see in your clinical work if they are interested in helping with research.
- Ask participants in current studies when the study ends if they would like to go onto a database of people interested in helping with research.

How will you measure the impact of involving people?

- Again, thinking early about this - building in regular evaluations to your project is helpful

- Evaluate both the researcher and the patient perspective of involvement
- Can you identify benefits from involving people and lessons learned? It's useful to share this information with the research community.

What ethical issues do you need to consider?

Ethical approval is not usually needed for patient and public involvement in research, even when people are recruited via the NHS. The exception is when the involvement requires direct contact with study participants e.g. conducting interviews. A REC will need to check that the person carrying out the research has adequate training, support and supervision appropriate to the circumstances.

Ethical aspects of involvement that you need to consider:

- the well-being and safety of the people you involve and whether the experience has the potential to cause distress, in which case they may need additional support
- ensuring that data shared is anonymised, that principles of confidentiality are understood
- equal access to information and opportunities to participate in discussions: plain language summaries, meetings are conducted in an inclusive way, induction and training offered if needed
- ensure prompt payment of expenses
- provide adequate support, including at the end of the study

Working with the Patient and Public Involvement Advisor

If in any doubt about what you want from patient and public involvement in your study and how to go about it, get in touch with Allison Worth to discuss your needs. Email Allison.Worth@ed.ac.uk

How can we help you?

Allison's job is to help you to make patient and public involvement in your research useful and enjoyable for you and the people you involve. Working with our own patient and public involvement group, Allison can advise you on any aspect of patient and public involvement in research. This might include:

- Helping you to find people to involve in your research
- Advising you on how to present your research plans to members of the public
- Providing lay reviewers for your study
- Advising you on a range of methods of patient and public involvement to suit your project
- Advising you on budgeting and reimbursement for patient and public involvement
- Advising you on communicating your findings to the public
- Training for patient and public involvement
- Ethical aspects of patient and public involvement
- Any other aspects of patient and public involvement you have questions about
- Troubleshooting/confidential discussion if you encounter problems along the way

Public Engagement in Research

What is the difference between public involvement and public engagement? Involving the public in your research is one method of engagement, but engagement also includes dialogue with the public about research – what it is, how it is done, what it contributes to society - for example by:

- Presentations and talks for the public e.g. PhD in an Hour, Cabaret of Dangerous ideas
- Displays at open days or festivals: e.g. Edinburgh Science Festival
- Working with the media e.g. writing for the non-specialist, broadcast, social media
- Working with community organisations
- Working with arts organisations to present research ideas in different ways
- Lifelong learning courses
- Interactive discussions e.g. taking part in a public debate
- Engaging young people in science: workshops in schools, inviting pupils to open days
- Providing opportunities for volunteering, internships

Opportunities for public engagement

There are considerable opportunities to take part in public engagement events in Edinburgh. For more information about public engagement in science, see the Beltane website <http://www.beltanenetwork.org/>

If you have an idea for an exciting engagement event, contact Allison Worth.