

Patient and public involvement: Guide for the public

This guide aims to tell you more about why and how you might want to get involved in research. Hopefully it will answer some of your questions.

Want to discuss something? - get in touch with Allison Worth Allison.Worth@ed.ac.uk

If I get involved what will I be doing?

You won't be taking part in a study. You're part of the research team getting actively involved in the research process itself. You're a volunteer, giving your time to contribute to something interesting and useful. Healthcare researchers often want the 'patient' view of a topic and want your practical suggestions about how to improve their studies and the information they produce. Members of the public can have their say on things like:

- Are researchers asking the questions which matter most to patients and carers?
- Have they understood how the patient experiences a treatment or illness?
- Have they thought about practical problems like access, transport and support needs when planning a project?
- Have researchers thought about how their project and new treatments affect the normal daily routines of patients, their families and carers?
- Are they talking about what they do in a way that people can readily understand?
- Will people want to take part in the study or will it be too much for them?
- What could researchers do to make their work more accessible or meaningful to the public?
- How convincing is their plan for patient and public involvement in their research?
- How will patients and the wider public get to know about the results of the research?

There are a variety of different ways to get involved. For example:

- Suggesting new areas for research
- Advising a research team on the design of their study when they are applying for the funding to do the work
- Being part of a research advisory group or steering group for a specific project
- Helping the team collect information, for example interviewing people
- Helping the research team interpret their research results
- Helping the research team to report their research results
- Helping to write information for the public about research.

It's often good to go to meetings so you can meet the team face-to-face, but you may not be able to if you are working, have childcare commitments or live far away, so researchers can often keep in touch with you by email and phone.

What kind of research can I get involved in?

You can get involved in a range of healthcare research studies, all aiming to improve the lives of people with particular illnesses, improve services and improve public health. These include clinical trials of new drugs and procedures; hospital or community-based studies about specific health conditions; studies of health in the course of normal life, such as childhood, pregnancy, ageing and bereavement. Most of the researchers we work with are based in and around Edinburgh, but studies

may be local, national or international. Here are some examples of recent studies where researchers have involved members of the public:

- A study of the new shingles vaccine in Scotland
- A bid to bring a new asthma research centre to Scotland
- A study to see if women who follow the Mediterranean diet in pregnancy lower their risk of having a child who develops asthma
- A study of delirium in patients with dementia
- A study of empathy in medical students

As well as giving advice on specific studies, members of our patient and public involvement group help with training for researchers and advise us at the Wellcome Trust Clinical Research Facility on our work. See the 'About the Wellcome Trust Clinical Research Facility Involvement Group' page on our website for more on what we do.

How do I find out about opportunities for getting involved in research?

If you become a member of our patient and public involvement group, we'll let you know about any new opportunities. Researchers often get in touch with Allison when they are looking for someone to get involved in their research. Allison then emails the group members with a short summary of the planned study and asks if anyone's interested in getting involved.

We also post information about new studies on our website. You can find other research opportunities across the UK through the People in Research website: www.peopleinresearch.org/

What skills do I need?

You do need to have an interest in healthcare research, enthusiasm, a bit of spare time and be willing to speak up about your views. You might have experience of a particular health condition, either as a patient or as a family member of someone with a health condition, but this isn't essential. You don't need medical or scientific expertise – other members of the team have that. What you bring to a research team is a member of the public's point of view, for example what it's like to live with a health problem. If you have particular skills, such as web design, marketing, writing, or scientific knowledge, we'd be delighted to hear about them. The aim is to make sure that research is carried out with the patient's best interests at heart, and that it meets the needs of the public who then get a proper chance to hear about the results.

If a researcher asks me to help with their research, what questions should I ask?

First of all, you need to see a short summary of the research, an outline of what the researcher is looking for from you and how long the project will last. You might want more information on what the study is for, who is doing it and who is funding it. Here are some other questions you might want to ask:

- What do you want from me? For example, do you want me to come to meetings – if so, how often and where? Do you want my thoughts on documents – if so what kind of documents?

How will you send them to me? If I can't get to meetings, can I still contribute and if so, how?

- What kind of skills are you looking for?
- How much of my time will it take? How long will the study last?
- Is there any training needed and if so, who will give it?
- Will I be paid and will you refund my expenses?

If you have any particular needs, let the researcher know e.g. if you have visual or hearing impairments; if your computer skills are limited; if you prefer to be sent information in a particular format.

You can find out more about the sorts of questions you might want to ask in the INVOLVE Public Information Pack (PIP) Booklet 2: Getting started – see below to find out how to get it.

Who can tell me if involvement will affect my benefits?

Individual circumstances mean it is difficult to give specific advice but there is some useful information on the DWP website and the Inland Revenue site

www.dwp.gov.uk/docs/dwp1023.pdf

www.gov.uk/volunteering

What you can expect from involvement

- Negotiate a role that suits you – don't agree to do anything you're not comfortable with or don't feel you can deliver.
- You can step down at any time.
- Get information in a form that is easy for you to understand, in plenty of time before meetings or for you to comment on.
- If you are going to a meeting, you'll get a chance beforehand to find out what the meeting is for and what's on the agenda. You'll also find out who will be there and what is expected of you. After the meeting, someone should ask you what the experience was like and whether anything could be improved.
- You can claim for travel and other agreed out of pocket expenses for your attendance.
- You will be offered training and support if you need it.
- When the study ends, you'll be asked to comment on your experience of involvement.
- You'll get to hear about the difference your involvement has made
- If your experience of involvement wasn't good, let someone in the research team know.

What a researcher expects from you

- Play an active role in discussions.
- Respect the confidentiality of information discussed.
- Communicate effectively, whether in person or by email
- Meet deadlines
- Let the researcher know as soon as possible if you can't do something you're asked to do

Further information

INVOLVE have detailed guides to patient and public involvement, including quotes from people who have been involved in research about their experience. If you want to know more, have a look at these public information packs. You can download them from the INVOLVE website:

Public Information Pack (PIP) Booklet 1: So what is it all about?

<http://www.invo.org.uk/posttypepublication/the-public-information-pack-pip/>

Public Information Pack (PIP) Booklet 2: Getting started

<http://www.invo.org.uk/posttypepublication/the-public-information-pack-pip-2/>

Public Information Pack (PIP) Booklet 3: Finding out more

<http://www.invo.org.uk/posttypepublication/pip-3-finding-out-more/>

The INVOLVE Jargon Buster defines some of the terms commonly used in public involvement in research <http://www.invo.org.uk/resource-centre/jargon-buster/>