

Opening the door to research



“Research and clinical trials are an everyday part of the work done in the NHS. The people who carry out research are mostly the same doctors and healthcare professionals who treat people. Their aim is to find better ways of looking after patients and keeping people healthy” From NHS Choices.

As a member of the public or as a patient or carer, there are **TWO** ways you can help: by **taking part** in a study or by **getting involved** in the design and set-up of a research study

Taking part

You can take an active part as a participant, in studies covering topics researched through your doctor or local health advisors; such studies might be looking into illnesses like Alzheimer’s, Diabetes, Cancer, Blood Pressure, Stroke.

We are talking here about studies that can benefit you, your family and others. The more we find out about certain conditions, the more informed we are and the better choices we can make for everyone’s future.

You can look for research studies yourself, you can ask your doctor or a patient organization, or by looking on the internet (see the back page). Alternatively, you may be invited to take part in research. Be cautious and don’t be afraid to ask questions.



“When I joined the study, I felt like I owned my condition. I was able to change”.

“I met others in my study group and we found support”.

“My GP had suggested changes but I was unable to make those changes till I took part in a study”

Getting Involved—by sharing your expertise

You can have your say in how studies are set-up as well as in other activities.

Patient and Public Involvement (PPI) encourages the active involvement of patients, carers and the public in a range of research activities e.g. study design and information; study progress. You can help design and monitor studies adding your wisdom to influence and reshape future study strategies.

Researchers are always looking for people to help with decisions around the design of their studies. PPI members can provide a quality check for relevance, understanding and accuracy. PPI is crucial in supporting many different types of research, including health research focusing on the cause and cures of illnesses, and social care research investigating the needs of carers for disabled, elderly and vulnerable people.

"No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights"

As a PPI member you might be asked to help with:

- Deciding what is going to be researched (prioritising)
- How the research should be carried out (designing)
- What is done with the research at the end of the study (progress and outcomes)

“Patients are at the centre of our work. We ensure that the research we support is relevant to and benefits those who use primary care services by involving patients and the public at all stages of the research process.” From NIHR website



National Institute for Health Research

The National Institute for Health Research is the research arm of the NHS. Its role is to improve the health and wealth of the nation through research. The Primary Care Research Network helps General Practitioners (GPs) and community services to be involved.

Have you been invited to take part in a study?

Have you been given a patient information leaflet to read?

Have you seen an opportunity to have your say about research?

Remember you can always ask questions and you don't have to take part if you don't want to.

To find out more ...

Look out for the leaflet: “Your health records save lives” which will help you to see what contribution data/information about you can make.

Look on the PCRN website: www.crncc.nihr.ac.uk/about_us/pcrn/primary_care_patients/pc_participation.htm



Get in touch with INVOLVE, a national group supporting public involvement in research: www.invo.org.uk/

There is also a website for *People in Research*. This site has a searchable database of involvement opportunities: www.peopleinresearch.org/

For more general information on patient participation at practice level please look at: www.napp.org.uk

Some hospitals and universities run patient panels that help researchers with the design of the studies. Addenbrooke's Research & Development (R&D), in Cambridgeshire has a page for patients and the public: www.cuh.org.uk/research/public/public_index.html