

A quick guide to getting involved in health research for members of the public

Patient and Public Involvement in health research

Whether you have a health condition, have cared for someone who has, or have never needed medical treatment, your opinion on how we can create better medications and treatments for the NHS is valuable.

Patient and public involvement in research means that the public have a role in influencing, designing and carrying out research. Some examples of ways to be involved are reviewing lay summaries, participating in discussions with researchers and providing advice.



We have put together some basic information for the public to find out more about what **'Involvement'** means in health research and how to go about getting started.

Researchers use several phrases to describe taking part in research, such as **'Involvement'**, **'Engagement'** and **'Participation'** and it can be confusing what they actually mean.

Research needs you to get **involved!**

Most people or their families will have experience of using healthcare services in the NHS at some point in their lives.



We need as many voices from all backgrounds to make sure we are doing the right research to benefit everyone.

Those **involved** in research can help researchers



- ✓ shape the research trial to suit patients
- ✓ find and reach out to the best audiences
- ✓ communicate in the right way
- ✓ identify ways to measure outcomes
- ✓ provide the best solutions for patients
- ✓ share results, including influencers

Taking part in health research

Taking part, or participating, in a trial means that researchers will study you and other study participants, to learn more about health and disease.

Data from information you provide, for example by answering a questionnaire, providing a blood sample or testing a new treatment, help to answer researchers' questions.



Patient and Public Engagement

Patient and Public Engagement (PPE) is where information about research is shared with the public.

For example: an article in the media, a webinar talk, tour, public lecture or providing information at a public event.



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What kind of research can I get involved in?

There are lots of different kinds of research that you can get involved in, and you don't need to have a specific health condition to contribute.

Examples might include hospital or community-based studies about specific health conditions, or studies of health in the course of normal life, such as childhood, pregnancy, ageing and bereavement.

What are the benefits of being involved?

- Opportunity to create positive change
- Learn more about a health condition
- Discover more about research and healthcare
- Develop new skills and increase confidence
- A chance to 'give something back' to the NHS
- The prospect of meeting new people
- Satisfaction from making a difference

What would I be expected to do?

Healthcare researchers need your thoughts about their research, and how they could improve their studies and the information they produce. Your questions and concerns about research can also be really valuable.

Most involvement activities ask you to provide your feedback in some way - either in person at a meeting or discussion group, or via email or phone.

Don't just take our word for it, ask one of our public contributors:



"Being part of the PPI group has proved an extremely rewarding experience and provides a sense of contributing something of real value, no matter how small that might be. It is a very positive and socially stimulating experience"

Barbara, Cambridge University Hospitals
Panel member

Interested in joining the Cambridge University Hospitals Patient and Public Involvement Panel?

Our PPI panel provides feedback and ideas to researchers to make sure their research is more accessible and it meets the needs of patients and the public. A lot of PPI activities can be done from home.



If you are interested in joining or like to find out more information send an email to ppi@addenbrookes.nhs.uk

Where can I find out more?

- ★ Contact the PPI team at your local hospital
- ★ Ask your clinician if they are undertaking research
- ★ Many health charities and patient support groups have PPI opportunities
- ★ Suggest a research topic on the NIHR website
- ★ Contact the Patient Led Research Hub with an idea

Useful websites

Opportunities for getting involved in research
www.peopleinresearch.org

NIHR INVOLVE www.invo.org.uk/

Learning and support for PPI (NIHR)
www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-learn-about-research/

Clinical Research Network
www.ukcrc.org/patients-and-public/

Applied Research Collaboration
www.arc-oe.nihr.ac.uk/patient-public-involvement

Healthtalk www.healthtalk.org/

Charity Involvement Directory www.slginvolvement.org.uk/

UK Clinical Research Facility
www.ukcrfnetwork.co.uk/patients-public/

Association of Medical Research Charities
www.amrc.org.uk/

Patient Led Research Hub
www.plrh.org



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