Do you want a say in clinical research?

Supporting research to make patients, and the NHS, better
We as patients and as members of the public are having more and more of a say in research...what people like me always want to see is research aimed at patients.

How does patient and public involvement benefit research?

In the NIHR Clinical Research Network, we want more successful clinical research studies to be happening in the NHS for the benefit of patients.

If you are a patient or carer, or perhaps a member of public with an interest, you can help research. You could become a participant in a clinical research study that may benefit many people but you could even help shape clinical research by becoming more actively involved and having a say.

Please read through this leaflet to find out how your contribution could benefit others and yourself.

“Our vision at NIHR is that everyone should have access to, and the opportunity to take part in, health research through their local NHS. It’s not simply about people having greater choice over their care and treatment now. It’s also about working with patients to deliver a health service of the highest quality in the future.”

Professor. Dame Sally C. Davies, Chief Medical Officer and Chief Scientific Advisor, Department of Health
Why is clinical research important?

Whether clinical research is carried out directly on people, or by using other techniques, it’s primary aims are to:

- provide the best advice and treatments for people
- increase understanding about human body and mind in health and when living with illness
- share knowledge and learning
- improve patient care

What is active involvement in research?

‘Active involvement’ is different from being a participant in a research study and having tests done on you, for example. Active involvement is where patients have a say in how clinical research is done. This is valuable because it helps make sure research studies are ‘patient friendly’ and relevant to people who use the NHS.

There are different forms of ‘active’ involvement in research, such as working with researchers and doctors, and getting involved in study design and other stages of the research process.

“What is clinical research?

Clinical research helps us understand how to diagnose, treat, cure or prevent health problems.

Some types of clinical research are based on examining and observing people with different conditions, and sometimes comparing them with healthy people.

Other studies may use human samples (blood, tissue and cells) or other existing medical information, or may test medical technologies such as using X-rays.

“Things like patient information notes are now far more likely to have been approved by or even written by a fellow patient.”

“Ade Adebajo, Researcher, Consultant Rheumatologist and member of INVOLVE

“Involving patients in research does work and it does make a difference. It adds value to studies and they provide tremendous insight.”

Ade Adebajo, Researcher, Consultant Rheumatologist and member of INVOLVE
How could I be involved?

There will be a range of activities that you may be able to get involved in, with the opportunity to choose what interests you. Examples include:

- helping to identify research that is important and relevant
- helping researchers to ask the right questions in the best way
- helping researchers to design their research studies
- helping to develop accessible information and research news
- joining a research advisory group
- helping to interpret research results
- helping to support and promote good research
- spreading the word about how people can be a participant in a study by telling them about the following web sites, NHS Choices (www.nhs.uk/conditions/clinical-trials/pages/clinical-trial.aspx) and UK Clinical Trials Gateway (www.ukctg.nihr.ac.uk/default.aspx)

Will I get paid?

It depends on what you are doing. Sometimes active involvement is paid but often it is voluntary. This information will always be made clear to you at the beginning. Any expenses you incur will always be reimbursed.

How would I benefit from being actively involved?

- by having a say in research
- through sharing your experience
- by getting research started that is important to you
- by learning more about research
- through meeting new people - researchers and members of the public
- by gaining confidence and new skills
- by having the chance to make a contribution.

“More and more patients, members of the public and carers are involved in designing trials, in approving trials and sometimes in making strategic decisions about health care.”

Richard Stephens,
Patient, Carer, Research Participant and member of INVOLVE

“My message to patients is, do the trials...get back to your day-to-day life but actually save some time for getting involved (actively) in healthcare research.”
Contact us

Clinical Research Networks have been put in place to support this to improve patient care and allow access to the best treatment. Networks have been established in cancer, dementias and neurodegenerative diseases, diabetes, medicines for children, mental health, primary care and stroke. A Comprehensive Clinical Research Network has also been created to support research in all other areas of health and clinical need.

Comprehensive Clinical Research Network which supports clinical research in all areas of disease and clinical need. Roger Steel, tel: 0113 343 0441 Email: roger.steel@nihr.ac.uk

Primary Care
Marianne Miles, tel: 0113 343 0440 Email: marianne.miles@nihr.ac.uk Tracey Johns, tel: 0203 328 6707 Email: crncc.pcrn@nihr.ac.uk

Cancer
Karen Inns, tel: 0113 343 2254 Email: k.inns@ncrn.org.uk

Diabetes
Martin Lodemore, tel: 020 7594 1796 Email: m.lodemore@imperial.ac.uk

Dementias and Neurodegenerative Diseases
Terry McGrath, tel: 020 7242 3311 Email: terry.mcgrath@dendron.org.uk

Medicines for Children
Jenny Newman, tel: 0151 282 4534 Email: jennifer.newman@liv.ac.uk

Mental Health
Bethan Thomas, tel 020 7848 0644 Email: mhrnppi@klc.ac.uk Thomas Kabir, tel: 020 7848 0644 Email: mhrnppi@klc.ac.uk

Stroke
Zena Jones, tel: 0191 241 8983 Email: zena.jones@ncl.ac.uk

How do I find out more?

If you would like to know more about getting involved, contact:

NIHR Clinical Research Network Coordinating Centre Fairbairn House, 71-75 Clarendon Road Leeds LS2 9PH Tel: 0113 343 0133 Email: crncc.ppi@nihr.ac.uk www.crncc.nihr.ac.uk/ppi

For further information about public involvement in research contact INVOLVE. INVOLVE is a national organisation funded by the NIHR to support involvement in NHS, public health and social care research.

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