

What are the Clinical Research Networks?

The Clinical Research Networks are part of the National Institute for Health Research and the UK Clinical Research Collaboration. The Collaboration has been set up to establish the UK as a world leader in clinical research. Clinical Research Networks have been put in place to support this to improve patient care and allow access to the best treatment.

The Networks believe that **active patient and public involvement** is needed if it is to encourage research which directly benefits and reflects the needs and views of patients and the public.

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.

How do I find out more?

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

**NIHR Clinical Research Network
Coordinating Centre (NIHR CRN CC)**
Fairbairn House, 71-75 Clarendon Road
Leeds LS2 9PH
Telephone: 0113 343 2314
Email: crncc.info@nhr.ac.uk
www.crncc.nihr.ac.uk/index/patients

This leaflet was originally produced by NIHR CRN CC in collaboration with INVOLVE, a national group that promotes public involvement in NHS, public health and social care research. Visit the website at www.invo.org.uk or email admin@invo.org.uk or Tel: 023 8065 1088. Alternative formats are available.

Direct contacts

Contact the following people if you are interested in getting involved in a specific area:

Comprehensive Clinical Research Network which supports clinical research in all areas of disease and clinical need.
Email: roger.steel@nihr.ac.uk

Primary Care
Sam Taylor, Tel: 0113 343 0403
Email: sam.taylor@nihr.ac.uk

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

Dementias, Parkinson's, Huntington's and Motor Neurone Disease
Terry McGrath, Tel: 020 7676 2121
Email: terry.mcgrath@dendron.org.uk

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

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

Mental Health
Geraldine Mason, Carers (FACTOR)
Coordinator
Tel: 020 7848 0644
Email: factor-mhrn@iop.kcl.ac.uk
Thomas Kabir, Service Users Coordinator
Tel: 020 7848 0644
Email: thomas.kabir@kcl.ac.uk

Stroke
Zena Jones, Tel: 0191 246 4659
Email: zena.jones@ncl.ac.uk

NHS

**National Institute for
Health Research**

Clinical Research Network
Coordinating Centre

Do you want a say in clinical research?

Who is this leaflet for?

Patients

Carers

Members of the public

People using healthcare services

This leaflet tells you:

What clinical research is

Why clinical research is

important

What 'active' involvement in
research is

How you could be involved

How you would benefit

How you can find out more



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.

Why is clinical research important?

Whether clinical research is carried out directly on people, or using other techniques, its **primary aims are to:**

- Provide the best **advice and treatments** for people
- **Increase understanding** about the human body and mind in health and when living with illness
- **Share** knowledge and learning
- **Improve patient care.**

What is 'active' involvement in research?

To most people, involvement means taking part in a study as a voluntary patient, and this is extremely important.

However there are other forms of 'active' involvement in research, such as working **with** researchers and doctors, and **getting involved** in the different stages of research (see below).

How could I be involved?

There will be a range of activities that you may be able to get involved in, with **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.

How does patient and public involvement benefit research?

Getting actively involved can lead to:

- More **relevant** research questions being asked resulting in more **useful** research
- More **sensitive** approaches to people who take part in studies as 'participants'
- Helping to keep the research **on track**
- Greater opportunities to **share research news** with patients and the public.

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.**

Will I get paid?

It depends on what you are doing. Sometimes getting involved is unpaid. This information will always be made clear to you at the beginning. Any expenses you incur will always be reimbursed.

