



# Get involved in research...

for patients, families and carers who want to find out about health based research and how to become involved

“ Involving patients and members of the public leads to research that meets their needs, is more reliable and more likely to be put into practice ”

*National Institute for Health Research*

## What is research?

You may already have been involved in research in the NHS. Different methods are used to collect research information. These include: interviews, questionnaires, observing people, and trials of new drugs or treatments.

Many different types of projects called research take place. For example, market researchers may ask for your views of the NHS or services you use. However, this short guide is about how you can play a part in supporting clinical and social sciences research.

**“Research is about investigating new ideas and finding new information that could lead to changes to treatments, policies or care.”**

**The Scottish  
Intercollegiate  
Guidelines Network**

Research is not always about finding out how to treat illness or test new drugs, it may also look at how to diagnose or prevent illness and keep people well. For example, investigating whether regular exercise can stop people from getting Type 2 diabetes.

The [NHS Constitution](#) commits to inform you of research studies in which you may be able to take part. The three clinical commissioning groups in Leicester, Leicestershire and Rutland are all committed to promoting your involvement in research.

## Why get involved?

Patient and Public Involvement (known as PPI) in research is important. It may help:

- Identify whether there is any unfairness in health and social care treatment
- Ensure any research issues identified are important and matter to you
- Ensure that funding is not spent on research that has little or no relevance to you and your community
- Researchers to understand your experiences if you have a particular condition or illness
- Develop new diagnosis methods and treatments for you and other patients
- Test treatments to make sure they are safe and effective for you to use
- Find better ways of delivering healthcare
- Make sure research findings are shared with you and others who take part
- Ensure that research is communicated in user - friendly ways

# What ways can I get involved?

The amount of involvement you have in research studies will depend on the type of research carried out and what interests you. You can be involved as a:

**Participant** - e.g. in clinical trials; testing a new treatment or drug; being interviewed about your experiences of healthcare.

You don't have to get involved in research unless you want to.  
If you decide not to, you will still receive normal treatment and care.

## If you become a participant in clinical research what can you expect?

- The researcher will explain what the study is about, why they want you to be involved and how you could be involved
- You should receive an information sheet so you can read about the research and decide if you wish to take part
- You can discuss your involvement with your family, friends or a carer
- The researcher should ask for your permission if they want you to take part and you may be asked to sign a consent form

Even if you sign a consent form, you can still change your mind and withdraw from the research at any time.



**Researcher** – e.g. helping to identify research topics which are most important to you; attending research meetings; choosing the methods used in the research; carrying out the research.

## If you become involved as a member of a research team what can you expect?

- Getting involved may be paid or unpaid but this will be made clear to you
- Your expenses should be reimbursed
- You should receive the training you need
- You should receive information to help you understand your role

**Communicator** - e.g. understanding the research findings and presenting them in your local community in a language that can be understood; promoting research; encouraging other people to take part in studies. It would be great if you could spread the word about research and encourage others to take part.

## Where can I find out more about taking part in research?

### INVOLVE

INVOLVE promotes and supports public involvement in NHS, public health and social care research and development. [www.invo.org.uk](http://www.invo.org.uk)

### People in Research

This website explains what involvement in clinical research means and how you can get involved. [www.peopleinresearch.org](http://www.peopleinresearch.org)

### Healthtalkonline

You can find out what clinical trials are all about and the reasons why you may want to participate. [www.healthtalkonline.org/medical\\_research/clinical\\_trials](http://www.healthtalkonline.org/medical_research/clinical_trials)

### NHS Choices

A section on clinical trials and medical research where you can find out how to take part. [www.nhs.uk/conditions/clinical-trials/Pages/Introduction.aspx](http://www.nhs.uk/conditions/clinical-trials/Pages/Introduction.aspx)

### Medical Research Council

The Medical Research Council has information on taking part in research. <http://www.mrc.ac.uk/Sciencesociety/Publicinvolvement/index.htm>

### NIHR Clinical Research Network Co-ordinating Centre

Leaflets and booklets explaining and answering queries about clinical trials are available from: <http://www.crncc.nihr.ac.uk/ppi>

### The UK Clinical Trials Gateway

The Gateway provides easy to understand information about clinical research trials running in the UK <http://www.ukctg.nihr.ac.uk/>

### The James Lind Alliance

Bringing patients and healthcare workers together to identify and agree which research questions are most important <http://www.lindalliance.org/>

## It's OK to ask



We want you to feel you are able to ask about getting involved in research. That's why the National Institute for Health Research is saying to you **It's OK to ask**. If you have a medical condition and are undergoing treatment, you can ask your doctor, nurse or consultant about research, and whether it might be right for you. More information can be found at [www.crncc.nihr.ac.uk/oktoask](http://www.crncc.nihr.ac.uk/oktoask)

**To find out about local research contact:** [debbie.wall@leicestercityccg.nhs.uk](mailto:debbie.wall@leicestercityccg.nhs.uk)

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