

development of guidelines. Section 5 (p18) has a very clear introduction to research methods, including, 'What are clinical trials?' There are also tips for reviewing research papers and a useful glossary (p40) which includes an explanation of research terms. "SIGN100-A handbook for patient and carer representatives" (2008), is available at:

[www.sign.ac.uk/patients/publications.html](http://www.sign.ac.uk/patients/publications.html)

#### **Getting involved with learning difficulties**

'Let me in I'm a researcher!' was produced in 2006 by a team of researchers with learning difficulties. It gives an insight into how the team received training and support to take control of the whole research process. The researchers were able to investigate 12 research projects about learning difficulties and had the advantage of having expertise in this area. Good involvement led to improved research data and research findings.

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4132916](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132916)

#### **Central Commissioning Facility**

The Central Commissioning Facility of the National Institute for Health Research is looking for members of the public to help commission and review research proposals that have come to it for funding.

[www.nihr-ccf.org.uk/site/consumerinvolvement](http://www.nihr-ccf.org.uk/site/consumerinvolvement)

#### **National Research Ethics Service**

Researchers who want to carry out research studies that involve patients and users of the NHS, or with potential research participants who are patients' relatives or carers, are required to seek ethical advice from an appropriate NHS Research Ethics Committee (REC). RECs exist to protect the rights, safety, dignity and well-being of research participants who are part of clinical trials and other research within the NHS. If you would like to find out more about the role that RECs play in research or think you may be interested in being a member of a REC, the National Research Ethics Service has information.

[www.nres.npsa.nhs.uk/patients-and-the-public/get-involved](http://www.nres.npsa.nhs.uk/patients-and-the-public/get-involved)

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You are free to make copies, but please acknowledge the following:

Produced by Deb Wall, Directorate of Public Health & Health Improvement, NHS Leicester City. A partnership with NHS Leicestershire County & Rutland, LNR Comprehensive Local Research Network, and the Primary Care Research Network (East Midlands and South Yorkshire).



**Get involved...  
in research**

**A brief guide for patients, carers and the public  
who want to find out more about health based research  
and how to become involved in research projects**

**May 2010**



### What is research?

Two simple definitions of research are:

“A step-by-step process that involves collecting and examining information. We do research to improve our knowledge and understanding about the world we live in. It almost always involves finding out something new.”

(Cancer Research UK)

“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, SIGN 100, 2008, p18)

The Department of Health offers a more complex definition, which is used by many researchers who work in the NHS:

“The attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods.”

Researchers use many different methods to collect and analyse information. These include interviews; questionnaires; watching people’s behaviour (observation); asking people to complete diaries of their care; and asking people to participate in trials of new drugs and treatments.

Researchers often call the pieces of research they are working on, studies or projects. Many different types of research take place in the NHS, for example:

- Clinical research
- Scientific research
- Public health research
- Market research
- Social research

Health research is not just about finding out how to treat illness, it may also look at how to prevent illness and keep people well.

**“Research is not just for researchers. The public can be involved too. New research cannot lead to reliable findings unless the right patients agree to join in.”**

(NHS Choices Website)

### People in Research

The People in Research website explains what involvement in clinical research means and what questions to ask organisations about involvement. It also helps you make contact with organisations that would like to involve you in clinical research.

[www.peopleinresearch.org](http://www.peopleinresearch.org)

### Healthtalkonline

In the ‘clinical trials’ section of this site you can read the stories of people who were interviewed about their experiences of participating in clinical trials. 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

The NHS Choices website has a section on clinical trials and medical research where patients and members of the public can find out how to take part. There is also an online video about primary care research.

[www.nhs.uk/conditions/clinical-trials/Pages/Introduction.aspx](http://www.nhs.uk/conditions/clinical-trials/Pages/Introduction.aspx)

### Medical Research Council

It is important that people who volunteer to take part in clinical trials understand what is involved and are able to make an informed choice. You may be able to play an essential role in helping scientists to develop and test treatments for the benefit of everyone in the community. The Medical Research Council, which has a Public Panel, has information on what to do if you would like to take part in research, including clinical trials.

[www.mrc.ac.uk/Sciencesociety/Publicinvolvement/Publicinvolvement/index.htm#P50\\_3919](http://www.mrc.ac.uk/Sciencesociety/Publicinvolvement/Publicinvolvement/index.htm#P50_3919)

### NIHR Clinical Research Network Co-ordinating Centre

A series of leaflets and booklets explaining and answering queries about clinical trials is available from this website.

[www.ukcrn.org.uk/index/patients/publications.html](http://www.ukcrn.org.uk/index/patients/publications.html)

### Cancer Research UK

Cancer Help UK (Cancer Research UK) has online information which explains clinical trials and how to take part in them.

[www.cancerhelp.org.uk/trials/understanding/default.asp?page=51](http://www.cancerhelp.org.uk/trials/understanding/default.asp?page=51)

### SIGN

The Scottish Intercollegiate Guidelines Network (SIGN) has produced a handbook for patient and carer representatives about involvement in the

There are many ways in which public and patient involvement in research is important. It may help to:

- Offer a different perspective of healthcare; the views of those who use the service rather than provide and work in it
- Understand the direct experiences of people who have a particular disease or illness and are experts on it
- Ensure that research issues that are identified and prioritised by others are important and matter to the public
- Ensure that money and resources are not spent on research that has little or no relevance to local people
- Give people a say who may feel their views are not considered when changes to services are made
- Ensure that health professionals become more accountable to their local community
- Ensure that the research findings are shared with the local community and are communicated in user-friendly language
- Generate interest from more people, as 'word gets round'
- Ensure that the health service genuinely responds to the needs of local people.

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### Where can I get more information about involvement?

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If you are interested in becoming involved in health research, including being a participant in clinical trials, these websites all have useful information:

#### **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)

The INVOLVE Public Information Pack (PIP) is for members of the public (including carers and patients) who are interested in getting involved in research and want to know more about it. The pack (four booklets) contains far more detail than we are able to provide in this guide. You can request free hard copies, including a 'jargon buster', or download them at:

[www.invo.org.uk/Members\\_of\\_the\\_Public.asp](http://www.invo.org.uk/Members_of_the_Public.asp)

For example, public health research has shown that living a healthy lifestyle such as drinking alcohol in moderation, not smoking, eating plenty of fruit and vegetables and taking regular exercise can prevent people from becoming overweight, having high blood pressure and heart disease.

You may already have experience of being involved in research in the NHS: You may have answered a researcher's questions about healthcare in your own home, in the community, at your GP surgery or in hospital. You may have been asked to take part in research because a team of researchers wanted to find out whether the health of patients with a particular illness improves with a new treatment or drug.

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### Who does research?

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In health and social care research, a range of people carry out research. They may work alone, or as part of a team. The researchers you are most likely to meet will work in the NHS or in universities:

- Health or social care professionals (e.g. nurses, midwives, doctors, pharmacists, therapists, and social workers)
- Members of university staff (e.g. academic staff, research assistants, associates or fellows)

Some people are full-time research professionals, whereas others carry out research alongside other roles, for example, being a nurse, a doctor, a university lecturer or a student. In future, more patients and members of the public are likely to be trained and supported to carry out health research as part of a team or by themselves. They will be more involved in decisions about what is being researched.

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### Why is research important to the NHS?

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Within health and social care, research is often carried out because researchers want to:

- Find out what people think about the health services they use
- Identify where there are health and social inequalities
- Have a greater understanding of diseases that affect many people
- Improve diagnosis and treatments for patients, and services for the public
- Improve the environment, health and wellbeing of the local population

- Help to prevent illness by identifying people who are at risk of getting ill
- Identify the best use of limited money and resources
- Test treatments to make sure they are safe and effective for patients to use
- Ensure that services and treatments are relevant to those who use them
- Find out better ways of delivering healthcare to patients.

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### What is meant by 'involvement'?

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There are many levels at which the public can be involved in research; from patients or healthy volunteers participating in the trials of new drugs to improve treatments, to patients who are trained to carry out health research themselves.

The involvement of members of the public, patients and carers in research needs to be explained, especially as 'involvement' for some, means sending you a health questionnaire to return in the post. Increasingly, organisations that promote good practice in this area are encouraging researchers to move away from treating people as the subjects of research (research that is done to you, or for you) and encouraging researchers to work in partnership with patients and the public (research that is done with you, or even, by you).

In this way, people who use the NHS will be able to influence decisions on what research takes place; what questions are asked; how research is undertaken; and how results can be used to improve healthcare services.

The amount of involvement that the public, patients and carers have in research studies will depend very much on the type of research being carried out and on whether proper training and support are made available to people who may have no research experience.

Involvement may occur during any of the processes involved in a research project or study. For example:

- Setting the research priorities and agenda
- Identifying relevant research topics
- Helping NHS staff to commission research
- Helping to decide what the research is setting out to achieve
- Choosing the methods used to carry out the research
- Encouraging people to participate in research studies
- Undertaking the research after appropriate training, and with support

- Interpreting the research - understanding what the findings mean for patients and how they can be applied in the health service
- Promoting the research results in the community.

The level of 'being involved' in research may vary:

- As participants - e.g. in clinical trials. Patients with asthma may be asked to test a new treatment
- As researchers - e.g. trained as researchers to gain the views of other patients
- Assisting in the research process - e.g. research meetings, advisory or steering groups
- Reporting and communicating research - e.g. presenting findings in the local community.

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.

The risks of taking part in research should be extremely low, unless you become involved in testing a new treatment for a very serious illness. If you are approached to become involved in a study, the researcher should explain what the study is about, the reasons why they want you to be involved and how you would be involved. You should receive a patient information sheet so you can read about the research in your own time and decide whether you wish to take part.

The researcher should ask for your permission if they want you to participate. You may be asked to sign a consent form after the research study details have been carefully explained to you. Even if you sign the form, you can still withdraw from the research at any time. You should also be told that information you give to the researcher will be stored securely and treated in a confidential manner. If you don't fully understand what the research is about or are having second thoughts, you should know who to contact to get the answers to your questions.

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### Why get involved?

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The National Institute for Health Research (NIHR) is trying to get more people involved in research studies. It says that, "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."