



# Your role in NHS research

Information leaflet for patients and carers

## Have you ever thought about taking part in research?

Research is taking place all the time in the NHS – in hospitals, clinics and in the community. This leaflet explains why you or your family or carers may be asked to be involved in research and explains why research is done.

## Why do we do research?

Research:

- Helps us to identify and provide the best possible care for you, your family and community.
- Looks at ways to help prevent illness, and helps us to improve treatments and services, making sure they are safe and effective and make the best use of resources.
- Can increase our knowledge about illnesses and help us to find out what it is like for you to live with a condition.
- Helps us to find out what you and others think about the services you receive.

## Information we get from research may also be used to help us:

- Teach and train our staff.
- Plan for the future.
- Improve the NHS.
- Compare ourselves with the rest of the country.

## How can you help?

Research cannot happen without your help. Taking part in a project may not always help you directly, but you will be helping to develop services and treatments for future generations.

If you are asked to take part in a research project, please consider getting involved.

What you will be asked to do will depend on the project; however it may involve:

- Filling in questionnaires.
- Talking to the researcher about your views.
- Letting the researcher look at your medical notes.
- Trying a new treatment or drug.



## If you are asked to take part in research:

- Your doctor, nurse or researcher will explain what the project is about and what is involved in taking part. They will give you some written information about the project for you to keep.
- You will be given time to think about all the information and to ask questions. If you don't understand anything, please ask. You should only say yes if you fully understand what will be involved and are happy with this.
- If you decide to take part you will be asked to sign a consent form and will be given a copy to keep.

Remember:

- Taking part in research is voluntary. You do not have to take part and you can change your mind at any time - you do not need to give a reason.
- Your care will not be affected if you decide not to take part, or if you say yes and then change your mind.

Before a research project starts it is looked at by various organisations to make sure it is OK for you to take part. These include an NHS Research Ethics Committee and the NHS organisation responsible for your care. They make sure that any risks have been looked at, that the study is of value to patients and the NHS, and that it respects the rights, safety and wellbeing of those taking part. They also review projects regularly after they have started to make sure they continue to be safe.

## Can you be identified?

- No researcher will be given access to your health records for research without your consent.
- Where possible all data collected from you for research purposes will be coded with a number rather than your name.
- Everyone who has access to your records, or any of your details for research, is bound by a strict code of conduct to keep your data confidential.

**We take research very seriously. We are committed to developing our services based on the best research evidence there is so that we can offer the best care and treatment to the people of Norfolk and Suffolk.**



If you would like this leaflet in large print, audio, Braille, alternative format or in a different language please contact the Research & Development Office on 01603 257000 and they will do their best to help.

This leaflet has been produced by the Research and Development Department, NHS Norfolk, December 2010.

Web: [www.norfolk.nhs.uk/research](http://www.norfolk.nhs.uk/research)

