What is health research?

Research is something that we do when we want to find out new things, understand why and how things work, or test out solutions to problems. When the topic of a research project relates to health and social care, this is known as health research.

Most research aims to answer one or more research questions, e.g.:

- Does using hearing aids to treat hearing loss slow the progression of dementia?
- How do people navigate everyday life after finishing cancer treatment?
- Does having a certain gene increase people's risk of developing diabetes?

What are research methods?

Research methods are the different approaches and techniques that a study uses to collect and analyse data. Not all health research is clinical, and research methods will look different depending on the focus of the study.

Participants are people who take part in a research study. *Data* is information that is collected from participants – it can be *quantitative* if it involves numbers, or *qualitative* if it involves words.

Techniques like surveys, interviews, or measurements of health markers (e.g. blood pressure) are used to collect data. Data is then analysed by comparing different people or groups to answer research questions.

What happens to the research findings?

The results of a research study will usually be turned into reports, academic articles and presentations. The findings will contribute to the body of evidence needed to change something about how healthcare works, for example:

- Introducing a new vaccine, medicine or treatment
- Launching a campaign to improve screening for a health condition
- Increasing funding for a service

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Where can I find out about research opportunities?

I want to participate in a study

Research participation can take many forms and involve different levels of commitment. It might involve things like:

- Sharing your experience in a survey or interview
- Giving a blood or saliva sample
- Trying a new treatment for a health condition you have

Find opportunities:

- National Institute for Health and Care Research Be Part of Research: bepartofresearch.nihr.ac.uk
- NIHR BioResource: bioresource.nihr.ac.uk
- Join Dementia Research: joindementiaresearch.nihr.ac.uk
- Your local NHS Foundation Trust
- Universities, e.g. The University of Essex
- Charities, e.g. Healthwatch Essex
- Speak to your doctor or nurse
- Check your GP surgery website or get in touch with them to ask if they are research active, and ask about what opportunities they have
- Keep an eye out for posters in your GP surgery or local hospital

I want to use my experience to shape what research looks like

Public involvement in research is when researchers consult members of the public on what research looks like. Researchers often want to work with people who have experience of a particular health condition, using a healthcare service or being part of a certain community to improve their project. You might do things like:

- Advise research funders on which projects to prioritise
- Give researchers advice on what questions to ask in an interview or survey
- Supporting the design of information leaflets
- Help spread the word about research
- Carry out interviews with participants

A good place to find out about opportunities is the NIHR's People in Research website.

Find more resources and join the Suffolk and North East Essex Research Engagement Network on our website (scan the QR code to visit our website).

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What to expect when you take part

1. Get in touch with researchers

You'll often need to take the first steps. This may involve sending an email to the researchers, reaching out to your doctor or nurse, or filling out an online form to register your interest. All you need to do is let them know you are interested in taking part and tell them why you think you are eligible.

2. Read the Participant Information Sheet and ask questions

Researchers should give you a Participant Information Sheet. It should tell you:

- What will happen to you when you take part
- What the risks and benefits are
- How to contact the researchers
- Who has given ethical approval for the research

Ask the researchers any questions you have about the research and take time to think about whether you want to take part. If you're not sure what to ask, the Change to National Institute for Health and Care Research Be Part of Research website has a list of questions you might want to consider.

3. Consenting to take part in research

Agreeing to take part in research is called giving 'consent'. Usually, this consent will be given in writing, but sometimes you will only need to consent verbally. For your consent to be valid, you need to:

- Be informed about what the study involves, and any benefits and risks
- Be capable of understanding this information
- Be giving consent voluntarily – without any pressure from anyone else

In some circumstances, a family member, close friend, or doctor can give agreement for someone to take part in research if they lack capacity to consent. The NIHR Be Part of Research website has a page with more information on giving consent to take part in research.

4. Taking part

Every study is different. The best way to understand what taking part will involve is to speak to the researchers of the study you're interested in. You can also read about participants' experiences of taking part in research on the NIHR Website: bepartofresearch.nihr.ac.uk/my-research-story/

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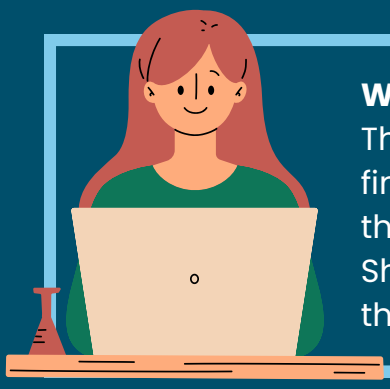
What happens to my contribution to research?

What impact does taking part in research have?

Healthcare systems need evidence to make changes to improve people's health. By taking part, you are helping to create this evidence. Depending on the study, the impact might look like:

- A campaign to encourage people to adopt a lifestyle change or attend a screening for a health condition
- Raising awareness of what it's like to live with a certain health condition
- Recommendations to NHS commissioners on how services should run
- A new treatment being made available

You can read about the findings of previous health research on evidence.nihr.ac.uk.



Where can I find the findings of the study I was part of?

The researchers should provide you with a summary of the study's finding once the research is completed. Alternatively, you can use the contact information provided on the Participant Information Sheet to reach out to the researchers. You can ask them to share the findings and clarify anything you don't understand.

Will the treatment I received in a clinical trial become available?

There is no guarantee that a trial treatment will become available. If it does become available, it may take a long time as the full process can take many years.

After a clinical trial is finished, Change to National Institute for Health and Care Excellence will decide whether to recommend that the NHS buys a new treatment. They base their decisions on:

- If there is enough clinical evidence for the new treatment
- Whether it is cost-effective for the NHS

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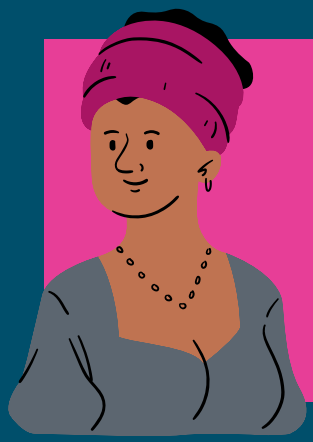

How should researchers support me as a participant?

How do I know if I'll be treated fairly in research?
Research projects that involve human participants are reviewed by a group of experts called Research Ethics Committees to ensure they will treat people who take part fairly. It is their role to assess whether research is ethical, and respects the dignity, rights, safety and wellbeing of those taking part in a study.

Different organisations have their own Research Ethics Committees. If you have any concerns about how a research project is being conducted, you can contact the committee that approved the study.

Should I be worried about risks and side effects?
You should be given information about any possible risks or side effects. Talk to the researchers if you have any concerns. If you take part in a clinical trial, you will be monitored for side effects and your GP should be informed. After taking part in a clinical trial, you will have follow-up appointments for five years to check for long-term effects.

If you're concerned about the risks of taking part, you can get involved in research in other ways - for example, by joining a Patient and Public Involvement and Engagement group.

What are researchers doing to ensure research is inclusive?
Ensuring everyone feels supported to take part in research will help to combat health inequalities. Some things that are being done to ensure research is inclusive include:

- The National Institute for Health and Care Research now only funds research which is designed to address inequalities in health and social care.
- Ethics Committees check that no groups are unfairly excluded from research.
- Patient and Public Involvement and Engagement groups ensure that people who are impacted by research have a say in how it is designed.
- Research Engagement Networks work with communities who are underserved by research to identify barriers to inclusion and increase diversity in research participation.

Join the Suffolk and North East Essex Research Engagement Network at www.letstalksnee.co.uk/health-and-care-research.

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