

What can I do?



National Institute for Health Research

Your anonymous data is already a great help to health services across the UK. Thank you.

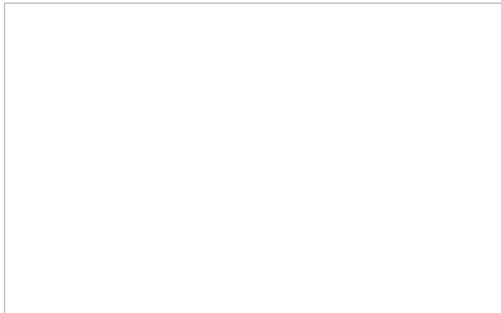
The more detailed data we can use, the more discoveries we can make. There are some simple things you can do to make sure we have the kind of data we need:

- **Encourage your GP to put your data forward** for research studies and trials relevant to your health or particular illness.
- **Give your permission if you are asked to allow data which might identify you to be used for important research** – unless you feel strongly that you do not want your information used in this way.
- **Tell those close to you how important our records are** in research and encourage them to allow the use of their data.

For further information visit:

www.nhs.uk/Conditions/Clinical-trials/Pages/Healthresearch.aspx

For local information please contact:



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Igniting our potential

Your health records save lives

What? How? Why?



What is health research?

Research is an important part of health services in the UK. To most of us research means people in labs or doctors doing trials to test drugs, but there's a whole lot more to health research than that.

Health research benefits everyone whether they're perfectly well, or have been ill for a long time. It helps doctors find out what causes ill-health and develop new medicines and healthcare, which can be used right from the start of an illness.

Research also helps the Health Service improve delivery so that everyone gets the care they need in the best possible way.

The records of your health, lifestyle and health habits (your data) already make a huge contribution to research, just by providing statistics about illness in the UK.

This leaflet tells you how data is used, why it's important and what you can do to help.

There are different types of health research that use people's data. These are sometimes called observational research studies and clinical trials:

Observational research studies look at the records of large numbers of people to see if there are any links between things like diet, or family history, and particular illnesses. They help answer questions about what causes illness and how to treat and prevent it.

Clinical trials are research studies involving people. They test whether treatments are safe and how well they work. They may test new medicines, combinations of existing treatments, or whether giving a treatment in a different way makes it more effective or reduces side-effects. Some trials are designed to find better ways to prevent or diagnose disease or to deliver health services.



Health data played a major part in uncovering the link between smoking and lung cancer

1950s



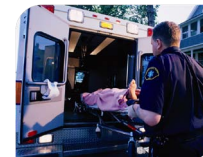
Patient data was used to establish the connection between the prescription of Thalidomide to expectant mothers and children born with birth defects

1960s



Several famous studies, using data, highlighted the increased risk of coronary heart disease and stroke among people with high blood pressure

1970s



Analysis of health data helped researchers identify that the HIV/AIDS virus may be passed from person to person by infected needles, contaminated blood and unprotected sexual intercourse

1980s

Children of the 90s is a long term health research project studying the health and development of the children of over 14,000 pregnant mothers who signed up in 1991 and 1992. Work on the study is continuing, but it has already made some important discoveries, such as showing that putting babies to sleep on their backs reduces the risk of cot death.

'I really can see, how it benefits, especially because of all the research stuff that's come out of it that you see published on the BBC, and stuff. That's quite impressive.'
Polly, Bristol. Child of the 90s.



What is health data?

Health data is all the information recorded about you by anyone looking after your health. This includes GPs, hospital doctors, nurses, physiotherapists and occupational therapists. You may have heard health data talked about as **'patient records'**.

Your data is recorded wherever you get healthcare. It may be kept in several places at once, from the GP surgery to a disease register if you have a particular condition, like cancer.

Data may be recorded on paper or as electronic files on computer. It mainly covers health (such as cholesterol levels, or a diagnosis of diabetes) but also contains other personal details (such as your postcode, job or country of birth).

The UK is the only country in the world where data has been recorded, since the 1940s, for every person registered with the health service – from birth to death. This means there's a huge amount of data that researchers can learn from to help save lives.



The health data of children with autism born since 1979 in eight UK health districts, helped scientists find out that there is no link between the measles, Mumps, Rubella (MMR) vaccination and autism

1990s



Researchers analysed data relating to the first 252 cases of swine flu to identify common symptoms, and the age groups most prone to the virus, helping them take steps to stop it spreading more widely

2000s



The EPIC (European Prospective Investigation of Cancer) study is following the eating and lifestyle habits of over 500,000 people in Europe, over many years, to unravel the link between diet, lifestyle and cancer risk. It has already discovered that alcohol causes at least 13,000 cases of cancer each year in the UK

2010s

How is health data used in research?

Health data is one of the most valuable assets we have. In research, it is brought together from all the different places it is kept and linked to provide the best possible picture of health and what might affect it.

Researchers use data in different forms:

Identifiable data - information that identifies you, like names, addresses and dates of birth. This data is used to find people to take part in trials, or answer extra questions about their health history. For example, it might be used to see if where someone lives increases their chances of getting a particular disease.

Anonymised data – information that cannot be traced back to a person's patient records, making it impossible to identify that person. This data is used when researchers do not need to have any direct contact with you. Sometimes, data is coded so that it can be linked back to an actual person if extra information is needed. This is a very helpful part of research and is strictly controlled.

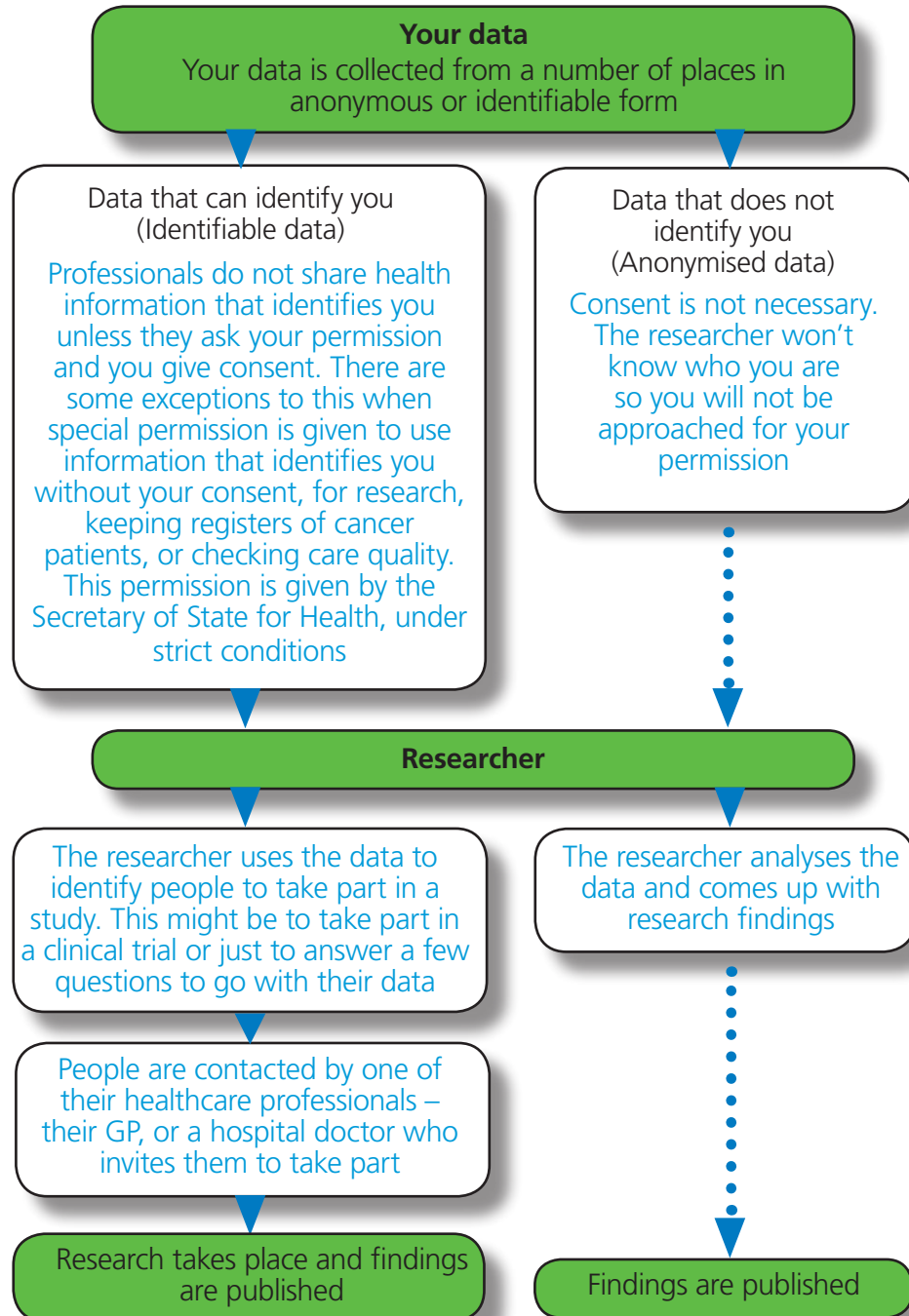
How is data kept safe?

A law (Data Protection Act 1998) has been put in place to make sure that your data cannot be abused. Researchers face disciplinary action, or even prosecution, if they do not use your data responsibly.

An ethics committee, made up of members of the public and professionals, assesses the risks and benefits of individual research studies before they can go ahead.

When people can be recognised by their data, only specific people can see the information and in a secure place.

How data is used



Why me? Why my data?

The use of your data in research is a simple, but vitally important way to make life better for everyone. You're providing vital insight into what causes illness and the steps that can be taken to develop healthcare that works for all of us.

Research using health data helped us discover the link between smoking and lung cancer, has helped women make safe choices about using hormone replacement therapy (HRT) and improved the treatment of cancers, diabetes and asthma.

It has found people for trials of medicines and healthcare and benefitted many people taking part in them. It's also helped us measure how successful our health services are, and continue to improve them.

Without health research we'd still be dying earlier, living with painful and life-threatening illness and leaving a legacy of ill-health for the future. When your data is used in research it helps save lives.

500,000 people aged 40 – 69, from across the UK are taking part in UK Biobank, aimed at improving the prevention, diagnosis and treatment of a wide range of serious and life-threatening illnesses – including cancer, heart diseases, diabetes, arthritis and forms of dementia.

"I answered lots of questions about my health history and lifestyle, and gave samples of my saliva, urine and blood. It was so easy to do. Over the coming years all our data will be regularly analysed to spot trends in illness and how lifestyle might affect health. If studying my history helps prevent people getting Alzheimer's, the way my dad did, or any disease, come to that, I'm all for it."
Philippa, South London. UK Biobank participant.

