



Your health data could save lives

Using routinely collected health data for research is helping others by improving patient experience and outcomes. PIONEER makes this possible by bringing together health data from various hospital and ambulance services.



Find out more about the health projects PIONEER is supporting, how health data is used for research, and what your choices are.

 www.pioneerdatahub.co.uk/your-data-helps-patients

PIONEER is part of a network of health data research hubs, funded by Health Data Research UK and UK Research and Innovation.

Potential to improve lives

Health data is the information that doctors and nurses collect about you when you visit a hospital, GP or other healthcare provider. It allows them to give you the best possible medical care, and is also used for research – to develop new treatments for patients – and to improve services.

When health data is used for research, it is anonymised. This means all parts of the data which can identify you are removed, and there is no way that researchers could find out who you are from your data.

The millions of patient health records held by the NHS have enormous potential for research.

For health data research to improve healthcare for all patients, the data needs to reflect us all - people from different ethnicities, backgrounds and with different health problems. This is why everyone's health data is used for research, unless you choose to opt out.

What data is collected?

Your health records contain information about you and your health, such as:

- ↗ Age
- ↗ Ethnicity
- ↗ Symptoms
- ↗ Other health conditions
- ↗ Any tests you have had, like blood tests
- ↗ Test results
- ↗ Clinical images, including X-rays
- ↗ Diagnosis made
- ↗ Treatments prescribed

While your health records do contain your name, NHS number, date of birth and address, this is never shared for research purposes to protect your privacy.

Who can access it?

Data is only shared with researchers after careful consideration. Researchers and their projects must meet strict legal and ethical requirements to be allowed to access your data.

Your health data will only be shared with:

- Trusted researchers, trained to handle data securely
- Research projects with potential to benefit the public

Researchers will only be allowed access to your health data if:

- Direct identifiers, such as name and address, are removed from the data shared
- That data will be accessed in secure environments that have been thoroughly tested
- Findings will be reported safely, so that no individuals can be identified

What choices do I have?

If you want your data to be used to help answer critical health research questions, or plan better services for you, your family and others, then you do not need to do anything. Your data is automatically used for these purposes.

However, you can choose to stop your patient information being used for research and planning. 'Opt out' applies to anyone over the age of 13 who lives in England. If you live elsewhere in the UK, your data may be handled differently.

Further information is available at

 www.nhs.uk/your-nhs-data-matters

About PIONEER

PIONEER allows researchers to use health data safely and securely, to help improve diagnosis, treatments and services. This has huge potential to improve the lives of patients.

PIONEER's data come from acute care providers such as the ambulance service and accident and emergency departments. Acute care – which is any unplanned medical care – is a huge part of the NHS workload, so research in this area is vital.

Our panel of members of the public help us to make decisions about which projects we support. If this group does not feel comfortable sharing data for a particular research project, for any reason, then data will not be shared.

You can find out more about the research PIONEER supports at

 pioneerdatahub.co.uk/your-data-could-improve-lives

If you, a family member or friend would benefit from this information in a different language, you can find audio versions and downloadable/printable PDFs on our website.

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