How your health information improves lives

Your health and care records help us care for you, but also have the power to improve the health of your whole community and future generations.

North East and North Cumbria
SECURE DATA ENVIRONMENT

Did you know?

Your health and care records are held by lots of different places like:

- GPs
- Hospitals
- Mental health services
- Social care services

This helps us care for you. It also helps us care for people in your commuity and future generations.

What is changing?

Researchers contact GP practices or hospitals to ask for information out of patient's records. This might be information like what medicine people take. Access to this information helps them carry out research. Researchers have to ask lots of different places for information which can be hard. It also makes it hard to link information from different places. This means researchers don't always have the best information to work with. This way of sharing will be stopped in the future.

Instead, researchers will come to a Secure Data Environment. This will give them better, linked information which they can't take away or use it again.

Good to know

The information will be kept in a safe place and will also be more up to date and in a more standard format.

How will researchers and planners get access to patient records?

Health and care information will be stored in a space known as a **Secure Data Environment**. Only approved individuals will have access to it the data and only for a specific project.

Approved healthcare planners

Secure Data Environment

Health and care records

Approved researchers
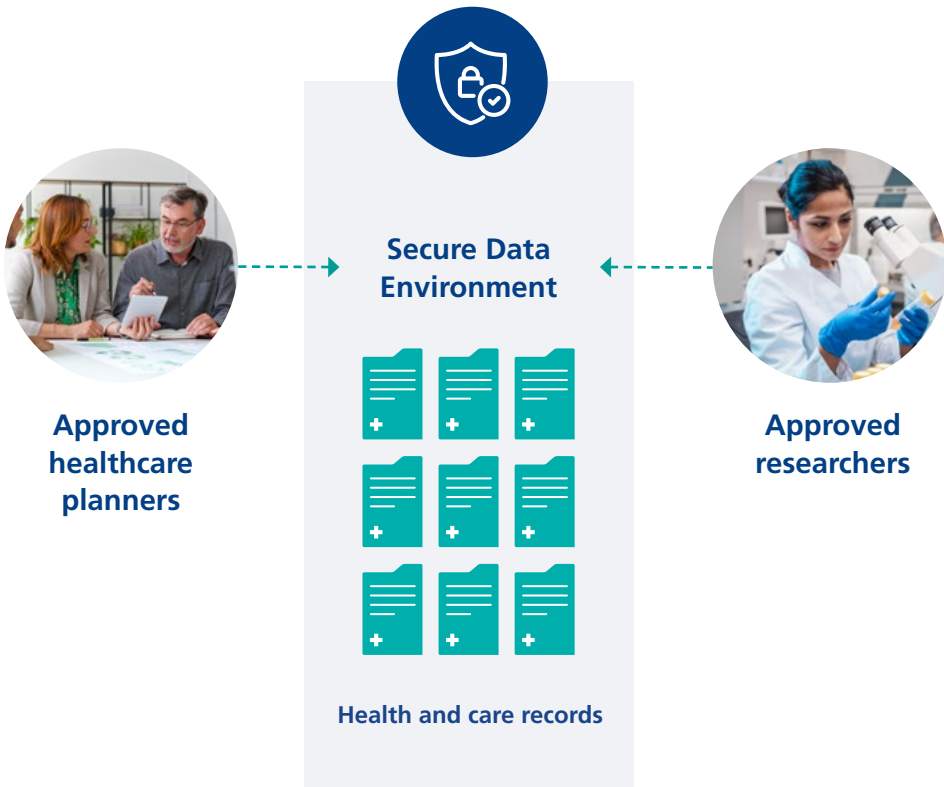
Health and care records are well protected under the law*. Health and care staff and researchers must have very specific permissions to use personal health information and any organisation that holds this, like your GP practice, is the legal controller for that data.

The controller has responsibility for making sure any information they hold about people is kept safe, secure and private.

When health and care information is made available for research, information which could identify you is removed. NHS staff who are not part of your medical care team remove information like your name, NHS Number and address from your record. This is so we can remove or hide your identity, but still link your records together. Your consent for this is not needed.

How we remove your personal details

Name
Address
Tel. No.

Age
Sex
Medical problems
Medications

Removed

Your health records

Age
Sex
Medical problems
Medications

Secure Data Environment

*The Secretary of State for Health and Social Care (for non research purposes) and the Health Research Authority (for research purposes) has supported the application from the North East and North Cumbria Secure Data Environment following advice from the Confidentiality Advisory Group (CAG) under section 251 of the NHS Act 2006.

Health and care information will only be made available to approved researchers and NHS planners for specific projects.
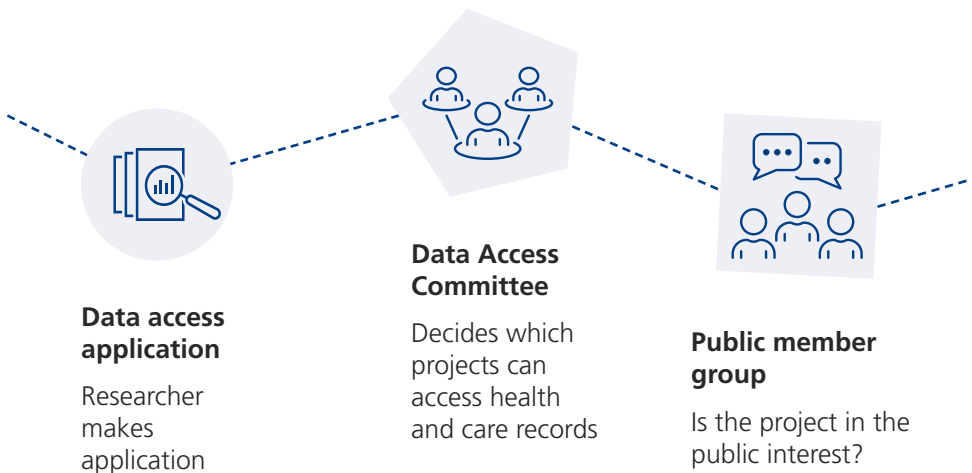
Once their project ends:

✗ **the data cannot be removed or downloaded**

✗ **the data cannot be accessed again**

People who want to access information for research and planning will have to complete a detailed application. A local Data Access Committee oversees this and decides who can access health and care records. This committee includes clinical, security, legal and ethical experts, as well as members of the public.

Once the Data Access Committee has reviewed the project, a group of members of the public assess whether it's in the public interest.

Data access application

Researcher makes application

Data Access Committee

Decides which projects can access health and care records

Public member group

Is the project in the public interest?

Researchers who want to access information on the Secure Data Environment must meet:

Strict legal standards

Strict cyber security standards

Strict ethical standards

How is my information kept safe?

Anyone who wants to access your health and care information for research or planning needs to send an application covering why they want to access it.

They must:

✔ Work in a trusted organisation like the NHS, a university, a charity or pharmaceutical company

✔ Have training in how to use the Secure Data Environment – and how to keep patient information safe

The project must:

✔ Meet legal and ethical standards

✔ Be checked by experts to make sure that only the right people and projects can have access to the Secure Data Environment

Good to know

Your information will not leave the Secure Data Environment so it stays in the NHS.

Good to know

We publish the information about every project which accesses health information on our website: https://northeastnorthcumbria. nhs.uk/here-to-help-you/health-advice-and-support/secure-data-environment-for-patients-and-the-public/data-use-register/

Who will have access to my information and why do they need it?

People working in:

- the NHS
- Universities
- Pharmaceutical or biomedical companies
- Charities
- Local authorities

need access to health and care records. This helps them understand more about health trends in our region, how we provide health and care, and which treatments benefit us the most. They only access information that's relevant to their field of interest – so they don't see your full medical record.

They don't need to see information which identifies you, like your name and address. They want to see what illnesses people have, what treatment they have received – and if that helped.

The more information we have available in the Secure Data Environment, the more it represents our community. This helps to plan new treatments and services that reflect what our region needs and improves everyone's health and wellbeing.

Good to know

Access to information in the Secure Data Environment is tightly controlled so that only approved individuals can see it. They don't need to see information which identifies you, like your name and address.

Here are some of the different types of people who could access the Secure Data Environment:

Hospitals, where a clinical research nurse needs to understand outcomes for all patients taking a particular medication for diabetes, or to help find patients who might be suitable for a new study.

Charities, like the British Heart Foundation who may want to understand more about heart disease in particular groups of people, like women or the elderly.

A biomedical company working with a local university to find out how well a new cancer drug works.

Local authorities who organise services to help people stop smoking may want to access health information about smoking rates in their area.

Can I opt out of the North East and North Cumbria Secure Data Environment?

Health and care records are already used to support research, planning and evaluating health and care services. People do not have to give permission for their health and care records to be used. When health and care information is made available for research, information which could identify you is removed.

You can see which projects have access to the North East and North Cumbria Secure Data Environment on our website. Visit: https://northeastnorthcumbria.nhs.uk/here-to-help-you/health-advice-and-support/secure-data-environment-for-patients-and-the-public/data-use-register/

To opt out of the North East and North Cumbria Secure Data Environment, you can contact us by email, telephone or post. You need to provide us with the following details so we can remove you:

- NHS Number (if known)
- Full name
- Date of birth
- Gender at birth
- Address
- Telephone number (optional)

Email: necsu.sdeoptout@nhs.net

Phone: 0191 916 9353 (available Monday to Friday, 9am to 5pm)

Post:
Governance Team
North East and North Cumbria Integrated Care Board
Pemberton House
Colima Avenue
Sunderland Enterprise Park
Sunderland
SR5 3XB

National Data Opt-Out

The National Data Opt-Out allows people to opt out of their confidential patient information being used for research and planning. Where the National Data Opt-Out applies, it will be respected.

The National Data Opt Out does not apply to data which has already had your identifiable data removed and a new disguise code (known as psdeudonymisation) applied.

Find out more in our privacy statement: https://northeastnorthcumbria.nhs.uk/here-to-help-you/health-advice-and-support/secure-data-environment-for-patients-and-the-public/sde-privacy-policy

Where can I find out more?

Understanding Patient Data

This website has a range of resources and materials which explain how health and care information is used in different ways: https://understandingpatientdata.org.uk/secure-data-environments

The NHS Secure Data Environment

You can also find out more about the Secure Data Environment on: https://northeastnorthcumbria.nhs.uk/our-work/secure-data-environment/

To find out more scan the QR code or call 0191 916 9353

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