

How your health information improves lives

Your health and care records help us care for you.
They also have the power to unlock new treatments,
medicines and devices.



Did you know?

Lots of different places hold parts of your health and care record. GP, hospitals, mental health, voluntary and social care services can all hold a piece.

This information helps healthcare workers care for you. But it can also help researchers make new discoveries. When we can link lots of records together it helps us spot patterns. This knowledge can improve the health of people who live nearby and future generations.

How will my information be accessed?

Researchers and planners contact the NHS to ask for information from patient records. This information is hard to access and share.

In time, this way of sharing will stop. Researchers will need to apply to a Secure Data Environment. This is a specially designed space for health and care research and planning. This keeps the information in the NHS and only approved people can see it.

How is my information kept safe?

Anyone who wants to access the Secure Data Environment needs to send a request. We remove details like your name so the researcher won't know who you are.





They must:

- ✓ Work in a trusted organisation like the NHS, a university, a charity or pharmaceutical company
- ✓ Have training on keeping the information safe

The project must:

- ✓ Meet legal*, security and ethical standards
- ✓ Be in the public interest

The benefits

- ✓ Better planning of health and care services
- ✓ More secure
- ✓ Allows more research to happen

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 pseudonymisation) 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/>

*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.

