

Research using NHS patient data in the East of England Secure Data Environment



Stakeholders

The East of England SDE project brings together organisations across the region that use or hold NHS patient data, provide technical expertise in data science and innovation and who work with patients and members of the public. The organisations partnering to deliver this project include...



Your NHS data: Supporting your treatment

Each time you visit your doctor or have tests or treatment in hospital, the details are added to your health records. This information is collected to help take care of you.

Your patient records contain information such as:

- Medicines or treatments you have had
- Blood and other test results
- Images such as X-rays and scans
- Any health conditions you have or previously had



It also contains information about you such as your name, birthdate, address, ethnicity and your NHS number.

The information in your NHS record is your NHS data - the information the NHS holds about you and your health.

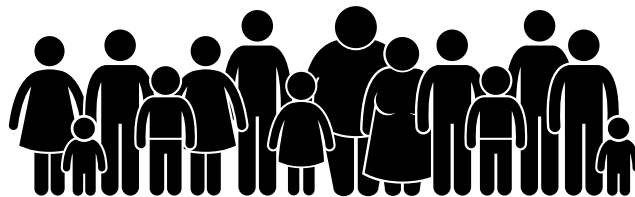
GPs, NHS hospitals and other health services such as the Ambulance service all record this information separately on their own systems, so you may have NHS records held by different organisations, depending on what kind of treatment and care you need.

Your NHS data: Supporting research for everyone

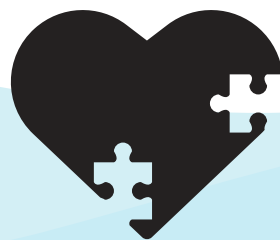
On its own, your NHS data is used to help healthcare professionals give you the best possible care.



However, when your NHS data is combined with the NHS data from other people across the country, it can be used to support research to create better treatments and healthcare for everyone.



Researchers can look for patterns and clues in the combined data from thousands of people to help improve care for people with heart disease, cancer and other common health conditions.



Because the NHS has data from so many people, it can even be used for research into less common conditions and illnesses that are harder to research. And the research is more likely to include information from people who might otherwise find it more difficult to take part in research.

Together, health data has the power to save lives through research!

The East of England Secure Data Environment

The East of England Secure Data Environment (SDE) is a digital platform that allows approved researchers to securely access de-personalised patient data for health research.

It has been built in partnership with NHS organisations across the East of England, with state-of-the-art cyber security measures, controlled access and robust oversight of data usage.

The East of England SDE protects the **privacy, security and integrity** of NHS patient data during research use by:

Anonymisation – all directly identifying information is removed from the data before researchers use it

Security testing and accreditation – the SDE has been built to industry-leading standards of cybersecurity, with ISO 27001 accreditation

Minimisation – researchers will only receive access to the specific data required for their approved research

Environment controls – researchers can only access the approved data within the controlled environment of the SDE, where they cannot copy, delete, remove or change the data

Exit control - research outputs are manually checked to ensure that no information that could be re-identified is removed from the SDE

Verification – researcher and organisation credentials and experience are verified before access

Contractual controls – researcher organisations agree to legally-binding terms and conditions for use of the data

Benefit to public health – all applications for data access are assessed by an independent panel, which includes members of the public, to determine whether they are in the public interest

How do researchers access data in the SDE?

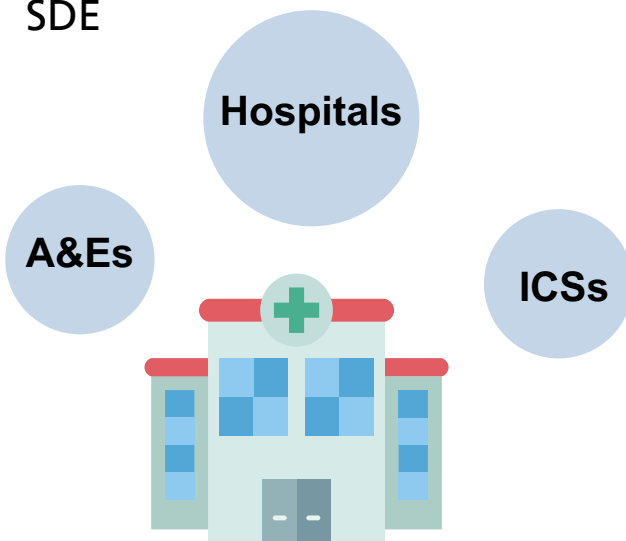
- 1 A researcher, who may be from the NHS, a university, a charity or a commercial organisation, **applies for permission** to use the SDE for a specific project



- 2 A committee decides whether the researcher is **safe** and the project has the potential to **improve public health**

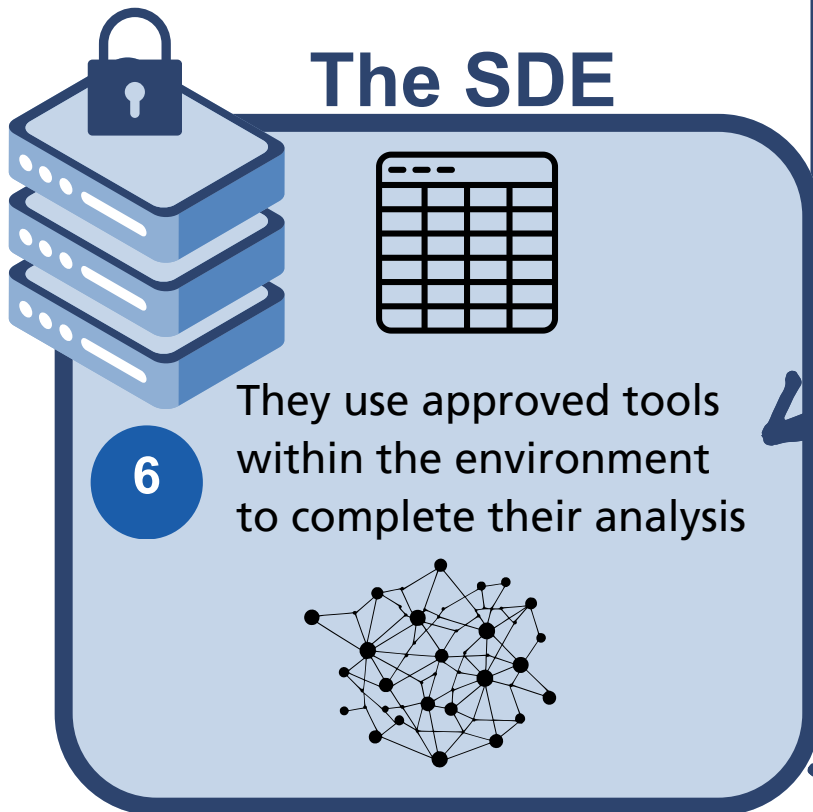
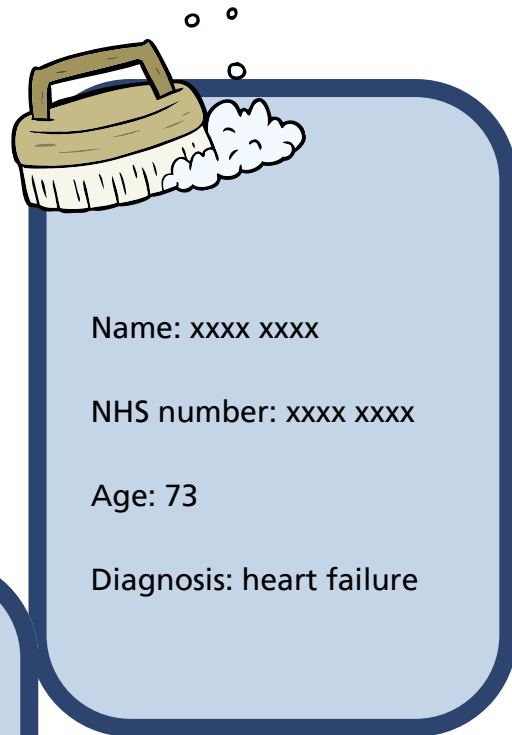


- 3 NHS organisations which have agreed to contribute patient data **share a copy** of data for that **specific research project** with the SDE



How do researchers access data in the SDE?

- 4 Data from organisations enters the scrubbing area, where identifying information, such as names and NHS numbers are removed



- 6 They use approved tools within the environment to complete their analysis

- 5 Only de-personalised data enters the SDE, and researchers are only given access to the specific data they require

- 8 Once the study is complete, the researcher can no longer access the data

- 7 The researcher can only take an **anonymous summary** of their results out of the SDE, which is manually checked



Who decides who can access the data?

Every researcher who would like to access patient data using the SDE will need to make an application that states who they are, what they are researching and what data they need. All applications, whether they are from NHS, university, charity or commercial researchers, are assessed against the same criteria for safety, security and public interest.

The Data Access Committee

The East of England SDE Data Access Committee (DAC) will assess every application against a consistent set of criteria to decide whether the researcher will be allowed to access the requested data in the SDE.

The DAC is made up of data, health, research and privacy experts from NHS and research organisations and, crucially, patients and members of the public. The DAC can also request additional expertise (including from people with lived experience) to help support decisions about specific projects.

How does the committee decide each project?

The committee assesses each application against an agreed set of criteria that has been developed with our public advisory group, aligned with national best practice.

The criteria are based on the 'Five Safes' framework developed by the Office for National Statistics. The Five Safes are a set of standards which enable data services to provide safe research access to data.

The principles are:

1. Safe Data
2. Safe Research
3. Safe People
4. Safe Settings
5. Safe Outputs



Opting out

If you do not want to have your data used for research through the East of England SDE you can opt out.

The East of England SDE opt out

If you choose this opt-out, your data will not be used in any research that takes place within the East of England SDE, but may still be used for other applicable research. For example, research using your data through an SDE in another region. Your choice will apply to all applicable research applications made after you opt out.

You can make, check or change your choice by phone or email:



By phone: Call **01223 348 490**



By email: **cuh.eoe.sde@nhs.net**

The National Data opt out (NDOO)

If you choose this opt-out, NHS England and other health and care organisations will not be able to share any of your personal data with other organisations for research and planning, except in certain situations. For example, when required by law.

Visit **nhs.uk/your-nhs-data-matters/** for more information.

You can make, check or change your choice:



Visit the [website](https://nhs.uk/your-nhs-data-matters/) at nhs.uk/your-nhs-data-matters/



NHS App: Select 'Your Health', then 'Your Health Choices', then 'Choose about your health records data'



By phone: 0300 303 5678



By email: **enquiries@nhsdigital.nhs.uk**

Reducing avoidable hospital readmission for heart failure

Researchers are using the East of England Secure Data Environment to help people in the East of England stay out of hospital after treatment for heart failure.

Heart disease is a chronic problem which affects many people in the East of England. When people are hospitalised for heart failure, about 20% of them need to be re-admitted within 8 weeks of returning home.

Researchers suspect there are patterns and similarities in the patients that need to be readmitted, which could be used to help doctors predict who might need additional support or a different treatment plan.

Professor Angela Wood from the University of Cambridge is using the East of England SDE to analyse de-personalised data from people with heart failure who have been treated in hospitals across the East of England. Her research team is developing a tool that will help doctors to calculate whether a patient being treated for heart failure is at risk of needing readmission.



This will help doctors to personalise care by keeping people in hospital a little longer or providing additional preventative treatment.

Get Involved

People from across the East of England have been involved in the East of England Secure Data Environment since the early planning phase. There will always be opportunities to get involved in the East of England Secure Data Environment and to have your say.

Core Public Advisory Group (CPAG)

We've been working with a small group of people from across the East of England who meet with the SDE team about every 2 months to provide a public perspective on the project and to advise on its development.

You can express an interest in [joining the CPAG](#) by completing this online form, which is also on the [East of England SDE website](#).

Data Access Committee Public Members

Are you interested in helping to decide which projects should be approved through the SDE? People with lived experience of a health condition (including as a carer or community advocate) can apply to be a public data access committee member.

Public DAC committee members can either be 'regulars' who attend meetings approximately every month, or 'specialists' who are invited to review occasional projects where their lived experience is important in making a decision about that project.

You can express an interest in becoming a public DAC committee member using the form here: [APPLY NOW](#) 



Keep in touch

Our website is the best place to find out about the research taking place through the SDE, to look for vacancies on the CPAG, apply to be a public DAC member or to read about how public input has shaped our work. Visit us at eoe-securedataenvironment.nhs.uk/

You can also sign up to our newsletter, to receive updates about the SDE direct to your inbox.



Please email us at cuh.eoe.sde@nhs.net if:

- You would like more information about the [East of England Secure Data Environment](#)
- You have questions about Opting out or in
- You would like this information in another format or language