

Research using NHS Data: Your Choice



**Opting out of research in the East of
England Secure Data Environment**

The East of England Secure Data Environment (SDE)

The East of England Secure Data Environment (SDE) is a secure digital platform for research using de-personalised NHS patient data. It is part of a network of regional NHS Research SDEs across the country.

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

Using the East of England SDE, researchers from the NHS, universities, charities or commercial organisations can apply to access data from de-personalised patient records from people treated in NHS settings in the East of England, for research to improve public health. All applications are reviewed against the same strict and consistent set of criteria to ensure they are safe, and that the research is in the public interest.

Research is vital to improve the way that we prevent, predict, diagnose and treat health conditions. The East of England SDE will make research using NHS data safer and easier, while retaining control of that data in the NHS.



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 and has been independently tested
- **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, against consistent and well recognised standards to determine whether they are in the public interest



What are my choices?



If you are happy for your de-personalised NHS data to be used for approved research through the East of England SDE you do not need to take any action.



If you have questions or concerns you are welcome to ask the SDE team. There is more information, including Frequently Asked Questions on our website.

Email us: cu.h.eoe.sde@nhs.net

Visit our website: eoe-securedataenvironment.nhs.uk



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

The next page contains information about the steps you can take to opt out of having your data used for research.

Opting out of the East of England SDE

There are currently **two ways** to opt out of the East of England SDE, depending on what kinds of research you want to opt out of.

You **do not** need to do both opt outs.

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.

The East of England SDE opt out will apply to research projects that occur from the point of opt out, but will not apply to projects that took place before the opt out was registered.

You can make, check or change your choice:

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** 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



By **post:** Print the form from the website and post to:

National Data Opt Out Contact Centre
NHS England
Freepost
PO Box 16738
Redditch
B97 9PT

Our partnering organisations



Please email us at cu.h.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

Get Involved!

People from the East of England have helped to shape how the SDE has developed and how it will function.

You can get involved through our [Public Advisory Group](#) or as a public member of our [Data Access Committee](#)

Visit our website to complete an application form or to find other ways to get involved!



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