

# Sharing NHS patient data between Secure Data Environments

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## What is SDE-to-SDE data sharing

Secure Data Environments (SDEs) are NHS systems that allow approved researchers to study health data safely. There are 12 SDEs that make up the NHS Research SDE Network, which covers the whole of England.

Sometimes research needs information from more than one region of England. In these cases, SDEs may securely combine data from several NHS regions to create research databases that cover several regions, sometimes called **research registries**.

For example, the Connect-D dementia programme is creating a dementia research registry by securely bringing together data from several NHS regions. This will help researchers study dementia across larger populations and improve future care.

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## Why this happens

Health information about the same patient may be recorded by different NHS organisations across the country. Some types of research require more data than is available in a single region. Securely combining data from several regions allows researchers to:

- **Study enough patients to produce reliable results.** This is not always possible using data from one region alone.
- **Understand a patient's full care journey.** People often receive treatment from different NHS organisations during their lives.
- **Research rare diseases and treatments,** where only a small number of patients may be recorded in any one region.
- **Avoid repeating the same work in multiple places,** by preparing one secure dataset that can support approved studies.

This helps researchers answer important health questions more quickly. It keeps NHS data under strict control.

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## How SDE-to-SDE sharing works

Before any data is shared between SDEs, **national and local data opt-outs are applied**. This removes information from patients who have chosen not to take part in research and planning.

1. **One SDE looks after the data.** One Secure Data Environment is chosen as the **host**. It stores and manages the combined research registry.
2. **Other SDEs send coded data.** Each participating SDE prepares its data inside its own NHS system. Personal identifiers – like names, addresses and NHS numbers – are replaced with secure codes before the data leaves the SDE. This process is called **pseudonymisation**.
3. **Everyone uses the same coding method.** The host SDE creates a secret coding method and shares it securely with the other SDEs. Each SDE uses this method to create the codes before sharing its data.
4. **Codes are used to match records.** As every SDE uses the same method, the same patient receives the same code in each dataset. This allows records from different regions to be matched inside the host SDE **without using personal identifiers**.
5. **The host SDE cannot unlock the data.** The host SDE only receives coded data. It cannot turn the codes back into personal identifiers such as names or NHS numbers. The codes are created using a one-way method called **hashing**.

The SDEs that provided the data still hold the link between the codes and the original identifiers. This means they can update the data, apply new opt-outs, or support new approved studies in the future.

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## How your data is kept safe and private

Secure Data Environments protect data using rules called the **Five Safes**. These rules apply to all research. When data is combined across SDEs, **extra protections** are added.

- **Independent approval.** Each new registry must be approved by the Health Research Authority (HRA). Each study using that registry must also be approved by an independent Data Access Committee (DAC).
- **Data is de-identified before it is shared.** Names and NHS numbers are replaced with secure codes before the data leaves the SDE that holds it.
- **The host SDE cannot see personal information.** The SDE that holds the combined data only sees the codes. It cannot see names, NHS numbers, or other personal details from the SDEs that shared the data.
- **Your choices are applied first.** National and local opt-outs are checked before any data is shared.
- **Secure transfer.** Only coded data is sent between SDEs using secure NHS systems.

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## Transparency

All the SDEs involved will publish information about approved projects in a **Data Use Register**. This allows the public to see how NHS data is being used for research.

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## Your data and your choice

Your health data means the NHS records created about you when you receive care. This can include information about your health, appointments, hospital visits, test results and treatments.

If you are happy for your data to be used for approved research and planning, you do not need to do anything.

**You have the right to opt out at any time. Your choice will not affect your care.**

To opt out:

- **Across England:**  
[www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters)
- **From the Wessex SDE only:**  
Email: [optout@wessexsde.nhs.uk](mailto:optout@wessexsde.nhs.uk)  
Phone: 02381 205 314

## Find out more

Visit [wessexsde.nhs.uk](http://wessexsde.nhs.uk) for more information.

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