

Secure Data Environment Professional Engagement Workshop Report

January 2025

Introduction and Background:

Secure Data Environments (SDEs) are built as a safe space for authorised researchers to access NHS and healthcare related data for their approved projects. However, protecting people's privacy is vital and therefore all personal details like names, addresses, and NHS numbers are changed to so called artificial identifiers, or pseudonyms, through a process called pseudonymisation. This means that researchers can study data without seeing any real details that show who the patients are.

SDEs are a significant step forward in the delivery of the Data Saves Lives strategy, which puts data at the heart of transforming services, improving outcomes, and saving lives.

Yorkshire & Humber Secure Data Environment (Y&H SDE) is part of a bigger National SDE Network looking to create safe and secure data linkage that is underpinned with strong public involvement to influence policy and decision making. It follows strict rules to make sure the data is used safely, transparently and correctly. It pools the home-grown talent of researchers and analysts across every corner of the region in an unprecedented and seamless way – ensuring that the whole is greater than the sum of its parts.

Our SDE brings together all three Integrated Care Boards (West Yorkshire, Humber & North Yorkshire and South Yorkshire) with local universities and a widening range of partners from schools, the community and industry.

Purpose:

A workshop was held on the 17th of December 2024 and sought to gather the perspectives of General Practitioner trainees in Bradford regarding the SDE.

Method:

Around 30 GP Trainees took part in two focus groups, facilitated by members of the Y&H SDE. They were asked three questions:

Question 1: What do you think are the opportunities and challenges around the implementation of Secure Data Environments?

Question 2: What information would you need as a healthcare professional when talking to patients about Secure Data Environments and the use of data for research?

Question 3: Based on everything you have heard, do you think the implementation of Secure Data Environments is a good or bad idea, and why?



Key findings:

Generally, trainee GPs perceived the adoption of SDEs to be a good idea, there were some reservations, and these are subsequently discussed. Key findings from the workshop are broken down into two areas: Opportunities for the SDE and Challenges of the SDE with additional focus on where Trainee GPs perceived additional support would be beneficial.

Opportunities for the SDE

GP trainees identified several potential opportunities with the SDE, with the primary focus on its impact for patients. The SDE was seen as a valuable tool for generating critical insights to enhance patient care through research. For example, they believed that awareness of the SDE among patients, particularly those from "under-represented groups," could increase research participation of such public groups. GP trainees felt that the SDE would simplify the process of identifying eligible individuals for more niche studies, making it easier to enroll participants in research.

Additional opportunities were considered to be:

- The ability to track and link health, social, housing data etc.
- More research opportunities.
- Supports research and development.
- Provide secure access to data for research purposes.
- Easy access to data, enabling efficient data search and acquisition, processing and insights.
- Sharing of data on a wider scale.

Improving population health was viewed as a key opportunity for the SDE, as its broad reach to diverse patient groups could enable access to a larger pool of individuals for research. This would facilitate comparative research across different age groups and geographic regions. A further opportunity perceived was the easy and timely access to data, ensuring that researchers can retrieve the information they need when required, thus improving patient care outcomes.

Most importantly, it was noted that the Y&H SDE had the opportunity to **improve patient understanding and trust** to the wider NHS. GP trainees described that due to the confidentiality of data that patients' may be more comfortable and open to participate in research.

Perceived Challenges of SDE:

The primary challenge of the SDE was around the question: “How secure is the SDE?” GP trainees worried about the confidentiality of patient data and the potential risks of breaches, not only for data providers but also for patients. Many believed that patients would share similar concerns, and as such, there is a pressing need for transparency regarding the security of the platform. Moreover, it was noted that patients might be anxious about their data being used in research without their explicit consent, reinforcing the need for clear and patient-friendly communication about how their data will be handled.

GP trainees expressed that patients may feel uncertain about their ability to opt in or out of the programme, especially when the process is unclear or lacks sufficient options for voluntary participation. This suggests that patient education sessions would be crucial in alleviating anxiety and providing a clearer understanding of the SDE for both patients and clinicians.

Furthermore, different general practices code patients records in different ways. Thus, one option could be to raise awareness on coding specific data. For example, some practices only code big things such as long-term health condition, therefore suggesting a unified approach to coding is needed. To add to this, different care places use different data management systems, for example primary care will use a different operating system to secondary care, likely posing a challenge.

GP trainees also expressed broader anxieties about the role of artificial intelligence in the SDE, questioning how Y&H SDE team can ensure that the data used is not manipulated. They also highlighted concerns about determining which data is truly important, as well as issues related to compliance with data protection regulations. These issues add to the overall sense of uncertainty and caution regarding the implementation and use of the SDE in healthcare.

What could help with the perceived challenges?

In order to effectively address the concerns surrounding the SDE, GP trainees emphasised the importance of using a variety of resources to **educate both patients and the public.**

General feedback:

The general feedback regarding the SDE reveals that, while there is broad support for the initiative; however, several concerns and considerations need to be addressed for it to be fully accepted and successfully implemented. Many participants recognised the immense potential benefits of the SDE, particularly in advancing future research, improving medical outcomes, and enhancing medication management. However, there is a clear emphasis on the need for more work on how data is utilised within research, ensuring that it is handled securely and appropriately.

A key factor for acceptance is patient confidentiality. Several responses highlighted that the success of the SDE centres on the guarantee that patient data remains secure. Ensuring that information is protected from unauthorised access, including potential hacking threats or data breaches, is a critical concern. Additionally, there are questions around who would have access to datasets and whether it would be shared with third parties. These concerns suggest a need for clear policies and transparency regarding data access and sharing practices.

Another significant point raised is the ability for patients to opt-out individually. While the concept of a secure, accessible research database is widely supported, many respondents believe it is essential that patients fully understand how their data will be used before they are asked to consent. This highlights the importance of clear communication and patient education in alleviating scepticism about the system. Ultimately, the feedback shows that while the SDE is viewed as a good idea with the potential to improve research accuracy and have a broader understanding of population health. The success of the initiative depends on addressing privacy concerns, ensuring transparency across the programme, and giving patients the autonomy to make informed decisions about their data.