Yorkshire
& Humber
SECURE DATA
ENVIRONMENT

Part of the **NHS Research Secure Data Environment Network**

NHS

Secure Data Environment Professional Engagement Report

June 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.

GP Involvement and Engagement

Engaging with professionals is important part of the SDE planning and delivery, varying those who are data providers, data controllers, users of the SDE etc. Within this report we have listen to GP trainees who will be the future of our GPs across Y&H and the potential future data controllers who will have a say on how patient data will be used for research and planning. These conversations help shape the SDE programme to ensure they have the information they need to make an informed decision and are able to easily support patients and their communities when asked about how data is used for research and planning.

Below are some key examples of how GP’s play a vital role in the SDE.

- **Shaping the SDE**: Their clinical insights help guide how the environment can be effectively integrated into practice.
- **Supporting research**: Many studies recruit participants through GP practices, making their involvement essential.
- **Public communication**: GP surgeries are key locations for informing patients about changes in how their health data is accessed and used.

New research from Understanding Patient Data has been published looking at public attitudes around GP records and how data is used. The findings revealed that people trust their GPs as a source of information about data use and so they want to hear directly from them about how their health records are handled. Their findings particularly in the *Public Attitudes and Information Needs About GP Record Data* highlight that GPs are uniquely positioned to help patients make informed decisions, increasing transparency and trust.

For example, of the people spoken to, “78% would prefer information about their GP record to come from GPs, highlighting the importance of supporting practices in delivering consistent messaging”.

We are therefore working closely with GP trainees and professionals to build long-term awareness and engagement around the Secure Data Environment (SDE). For example, during a recent GP session held within the Y&H region, participants raised important concerns related to data confidentiality, patient consent, and inconsistent coding practices. It was said that clinical codes used in practice are not always applied consistently, which can impact the quality of research data potentially skewing results. Additionally, there were general questions particularly around issues such as privacy, cybersecurity, and patient autonomy.

These insights highlight the critical importance of involving GPs in the development and communication of the SDE. Their clinical knowledge and trusted relationship with the public, position them as key partners in helping patients understand the purpose of the SDE, building trust, and addressing concerns.

Purpose

A workshop was held on June 20 2025 with General Practitioner trainees from South Yorkshire to understand their knowledge of data being used for research and planning and their opinions on impact to their day to day roles in a General Practice.

Demographics

We collect demographic data from GP trainees and practitioners during workshops and this is done for several reasons. Personal information is however not collected unless an individual consents to this and wants to be involved in future opportunities. For the data collected, it helps us develop a comprehensive understanding of the distribution and diversity of GP professionals across the Yorkshire & Humber Secure Data Environment (SDE), including characteristics such as age, gender, employment status, and ethnicity.
By gathering this information, we are better positioned to engage effectively with the full range of demographic groups within local communities, ensuring that communication is easily understood and inclusive. It also enables us to assess the level of awareness among GPs regarding the SDE, identify area-specific challenges such as capacity to communicate data use to patients and support research and planning priorities on a local and regional level. As well as this, collecting this data allows us to capture the experiences of GPs in working with the wider research community. Ensuring that the dataset reflects a diverse and representative mix of practices from deprived urban areas to more affluent rural settings. All data collected is stored in line with IG and GDPR guidance.

Below is a summary of the demographic data gathered at the South Yorkshire GP workshop held on May 20 2025.

Category	**Details**
Location	South Yorkshire
Most Common Age Range	25–34 years old
Gender	Mixed, majority female
Sexual Orientation	Majority heterosexual; some bisexual
Ethnic Backgrounds	White British, Asian or Asian British, African, Arab-Middle Eastern
Education Level	Mostly Level 6/Bachelor’s degrees; some with Master’s or PhDs
Employment Status	Majority full-time; others part-time or not currently working
Household Income	Mostly within £35,000–£74,999
Disabilities Reported	Few (e.g. dyslexia); most reported no disabilities
Caring Responsibilities Reported	Mostly reported none

Method:

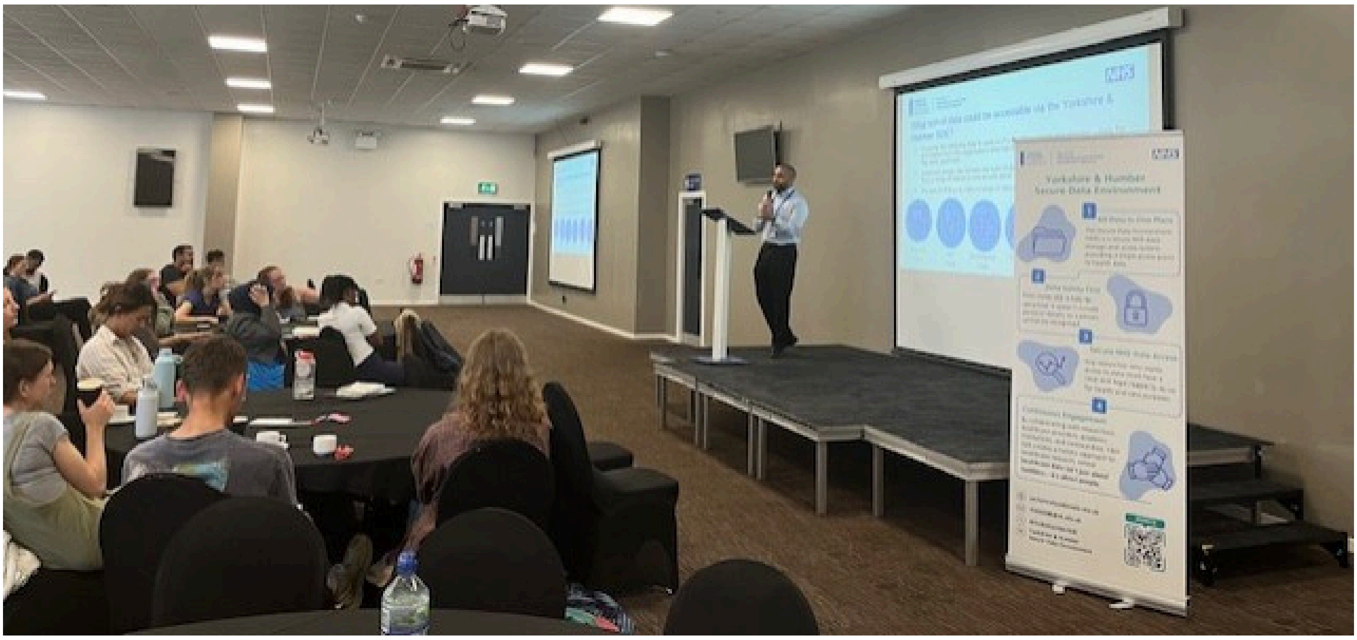
The workshop was delivered to over 70 GP trainees from across South Yorkshire. During the workshop, the aim was to inform them about the SDE and why the SDEs have been set up to improve research and planning and data linkage across all sectors. The participants were given the following three questions to discuss with floating facilitators to support and experts to answer any questions that came up throughout.

- **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?**

The tables were asked to think about their roles within General Practice and as members of the public to discuss each of these questions and feedback one or two points agreed by the table that they wanted to raise or ask about.

Key findings:

At the beginning of the session, the participants were asked if they knew about the SDE, 0% of the participants knew or had heard about the Secure Data Environments and what they were expected to achieve. This showed that communication and education across the professional landscape at all levels needs to be improved and worked on, which is being built in through Y&H Communication and PPPIE strategies for 25-26.
Capacity in GP Practices is stretched, they have a lot to do within a limited time, which is why it is important to understand the best way for the SDE programme to support questions they may get from the public about how data is being accessed for research and planning. The GP trainees offered many ideas on how the SDE presents opportunities for those working in general practice and what opportunities they could see the SDE bringing to their work and the communities. These included: Data Access and Infrastructure, Cross-sector Integration, Equity & Inclusion, Research & Academic Potential and System and Economic Benefits.



Opportunities for the SDE

Data Infrastructure and Research Capability

Participants emphasised the ease of access to large, rich datasets as a key advantage of the Secure Data Environment. This accessibility was seen as a valuable for conducting high-quality, large-scale research with greater efficiency and depth.
Another significant benefit highlighted was the ability to trace findings back to the original data sources. This feature was recognised as essential for maintaining transparency and ensuring the integrity of research, allowing for verification and validation of results.

The creation of "dummy" or synthetic databases for training purposes was also encouraged. Participants noted that these would provide a safe and effective way for users to develop their skills and familiarity with data structures and analytical tools, without compromising patient confidentiality.
Finally, the importance of using up-to-date and accurate patient data was strongly emphasised. Participants agreed that timely and reliable data is critical for generating relevant insights that can inform evidence-based decision-making and drive improvements in healthcare delivery.

Linking Data

A major strength identified by participants was the potential for data integration across multiple sectors, including health, education, police, and social services. This capability was seen as a powerful tool for enabling a more holistic and coordinated approach to population health.
Participants noted that linking outcomes across these sectors could provide valuable insights into the complex social determinants of health. By understanding how factors such as education, housing, and public safety intersect with health outcomes, researchers and policymakers can develop more targeted, effective interventions to improve overall wellbeing and reduce inequalities.

Equity and Inclusion

Many participants highlighted the importance of using the Secure Data Environment to improve the inclusion of underrepresented groups particularly ethnic minorities and individuals from deprived communities in research.
They recognised that greater representation in data-driven studies is essential for producing more equitable evidence, addressing disparities in health outcomes, and ultimately supporting efforts to reduce long-standing health inequalities. By ensuring that these populations are accurately reflected in research, the SDE can help inform more inclusive policies and services that meet the needs of diverse communities.

Research and Academic Growth

The SDE was widely recognised as a valuable asset for academic institutions and research professionals. Participants highlighted its potential to support a broad range of academic activities, including opportunities for postgraduate students such as those undertaking PhD and MRes programmes.
The SDE was also seen as a strong platform for fostering collaborations with industry partners, particularly in the pharmaceutical and technology sectors. Notably, the potential for AI-driven research and training was emphasised, with participants acknowledging the SDE's capacity to support innovation and skill development in this rapidly evolving field. AI-driven research and training was particularly noted.

System and Economic Benefits

Participants expressed optimism that research-led prevention strategies could contribute to reducing long-term NHS costs by enabling earlier interventions and more efficient service delivery.
It was also suggested that GP practices could be financially compensated for the time and resources spent on research recruitment activities. Such support would help ensure the sustainability of practice involvement in research initiatives.
Additionally, some participants highlighted the ethical value of using patient data to generate insights that directly benefit the communities from which the data originates. This was seen as a meaningful way to give back and reinforce public trust in the responsible use of health data.

Challenges and concerns of SDE:

The challenges raised included awareness, consent & opt-out, trust, safety & ethical considerations, data management & access, commercial & financial concerns, security & technical risk, communication & literacy, operational & administrative impact.

Awareness, consent & opt-out

GPs mentioned that many patients are unaware that their data may be used in research, and there are concerns about the lack of explicit consent. It is important to ensure individuals are given the opportunity to make an informed choice and understand their rights.

Healthcare professionals need clear guidance on how to explain the use of data to patient especially why they were not consulted initially—and how patients can opt out if they choose. Accessible information and communication tools are essential for supporting these conversations.

In the event of a data breach, patients and the public need to know what actions will be taken beyond issuing an apology. Clear protocols for accountability, remediation, and ongoing protection are critical to maintaining public trust.

Trust, Ethical and Safety Considerations

Participants highlighted concerns around data safety, transparency, and the processes for obtaining informed consent. These elements are seen as foundational to maintaining public trust and upholding ethical integrity in data use.
There is a clear need for robust safeguards and transparent systems to monitor and control access to patient data. Ensuring accountability and clearly communicating these protections are essential steps to building trust and addressing concerns about misuse or unintended consequences.

Data Management & Access

It is important for the public to understand who access to the data will have, how access is granted, and whether only the minimum necessary data will be made available for each project. GP’s therefore highlighted of the importance of transparency around these processes being essential for maintaining trust.

Information should be shared on how data will be presented and analysed such as whether it will be grouped by geography or other demographic factors. This helps stakeholders assess the relevance and implications of the data use.

Clear explanations are needed on how the data will be used, including examples of previous or potential research studies conducted within Secure Data Environments. Highlighting the specific health challenges or risks these studies address can illustrate the public value and intended outcomes of such projects.

Commercial & Financial Concerns

There is concern about whether the initiative is NHS-contracted or involves commercial entities. If financial or commercial interests are involved, this may raise concerns around motives of data use.
With setup and ongoing costs (e.g., £400 initial fee and £435 per month), there is a need for transparency around how these funds are used and where the money goes. Clarifying the financial structure is essential for accountability.

Questions remain about whether there are shareholders involved and what incentives, if any, are offered to GP practices. Understanding any monetary benefits or financial relationships can help assess potential conflicts of interest.

Security & Technical Risk

Cybersecurity is a key concern, particularly regarding the risk of hacking and potential breaches within GP systems. Clear information is needed about the safeguards currently in place and how data will be effectively protected to ensure patient confidentiality and maintain trust in the system.

Concerns were also raised about technical aspects of implementation, such as whether inconsistent clinical coding might impact the quality of research findings. While many participants viewed AI as a promising tool, some expressed apprehension that increased automation could diminish the human element in care and decision-making.

Communication & Literacy

To effectively engage participants, it was said that is important to provide accessible online information through QR codes, links, or SMS messages. All materials need to be presented in a way that supports health literacy, using clear and understandable language.

Offering information in multiple languages was seen as essential to promoting inclusivity and ensuring comprehension across the region's diverse communities. Providing accessible materials in a variety of formats helps ensure that all individuals, regardless of linguistic background, can engage meaningfully with research-related information.

Participants also emphasised the need for adequate time and support to help individuals understand the purpose and implications of research. The presence of a dedicated research coordinator was identified as a valuable resource for answering questions and providing tailored explanations.

Finally, participants underscored the importance of acknowledging and addressing research hesitancy. Building trust through clear, transparent communication was seen as critical to overcoming concerns and fostering informed participation in research initiatives.

Operational & Administrative Impact

Participants raised several concerns related to the operational and administrative impact of implementing the Secure Data Environment.

One key issue was the cost of recruitment, particularly when practices are expected to support research without dedicated funding. Many expressed concern about the increase in unfunded workload for GPs, which could place additional strain on already stretched resources.

There were also questions about whether individual practices or Primary Care Networks (PCNs) have access to in-house researchers or resources to manage data requests and conduct analyses.

Participants highlighted the need for additional support and infrastructure to ensure research activities can be integrated into daily practice without compromising patient care.

Other practical considerations included the implications of not having access to the SDE and how this might affect equity between practices. Finally, questions were raised around insurance coverage and liability when handling patient data within the SDE, pointing to a need for clear guidance and protections.

Conclusion:

The South Yorkshire GP trainee workshop revealed strong support for the concept of Secure Data Environments, particularly in advancing equity, data-driven research, and integrated public health strategy. However, trust, transparency, and implementation logistics remain pressing challenges. Participants underscored the need for patient education, ethical clarity, and financial support to ensure long-term success. This feedback will inform future engagement and development activities across the Y&H SDE network.