

Public Attitudes to SDE-to-SDE Sharing of Data

July 2025

This report has been prepared by the Wessex SDE Comms & PPIE team. It summarises insights on public attitudes towards Secure Data Environment (SDE)-to-SDE data sharing, specifically in scenarios where federated research queries are not feasible.

Its purpose is to inform and guide policy for the Wessex SDE in relation to sharing data directly with other accredited NHS SDEs and approved secure environments under controlled conditions.

The analysis brings together evidence from local deliberations with the Wessex Public Panel on NHS Data, review by the Wessex Digital Critical Friends Group, and relevant national insights.

Evidence base

In preparing this note the following sources have been reviewed:

- **Wessex Public Panel on NHS Data (July–September 2024)** – Four-day deliberative dialogue with 50 citizens from across Wessex
- **Wessex SDE Digital Critical Friend’s draft report: ‘Digital Critical Friends: Targeted review of the SDE policy suite’ (June 2025)** – Included scrutiny of the Wessex SDE’s planned amendments to its NHS Health Research Authority S251 consent, which includes SDE-to-SDE sharing.
- **NHS England – National Engagement on Data – Cohort 1 Report (March 2025)** – Deliberation on data use principles and SDE governance
- **NHS England – National Engagement on Data – Cohort 2 Report (June 2025)** – Focus on data access for planning and research.
- **NHS England – National Engagement on Data – Cohort 3 Draft Report (June 2025)** – Focused on public views of opt-out mechanisms.
- **Wessex Secure Data Environment Literature Review (Oct 2023)** – Synthesis of research into public attitudes towards data use

The Wessex Public Panel on NHS Data (the “Public Panel”) conducted in summer 2024 and scrutiny of the Wessex SDE’s policy suite undertaken by Wessex SDE

Digital Critical Friends (DCF) group (2025) directly addressed public attitudes towards SDE-to-SDE data sharing. The DCF scrutiny included review of plans to add SDE-to-SDE sharing and clinical trial re-identification to the Wessex SDE's Health Research Authority consents.

National deliberative dialogues commissioned by NHS England and reviewed for this paper did not directly explore this precise question, they offer relevant contextual insights, integrated into this analysis to strengthen the overall understanding of public attitudes.

Level of public support

There is broad public support for collaboration across NHS SDEs to maximise benefits and avoid duplication.

Participants from the Wessex Public Panel clearly supported SDE collaboration, seeing value in the development of larger, richer datasets that strengthen research quality and scope. Wessex DCFs expressed a clear preference for federated queries as the initial choice for collaboration and supported direct SDE-to-SDE sharing when necessary and with appropriate justification.

Public benefit and value

Delivering clear 'public benefit' is essential for any research using NHS patient data.

Public involvement in Wessex has shown strong support for data sharing between SDEs, as long as the purpose is clear, well-defined, and offers genuine benefit to local people. For instance, research into rare diseases, where local data might be limited, is particularly supported, provided there are strong safeguards and minimal data sharing.

Participants also emphasise that any benefits from data shared with other SDEs should reflect the effort and volume of data contributed by Wessex. They seek clear reassurance about how improvements – such as enhanced data quality or better treatments – will be returned to local healthcare services without creating extra duplication or additional storage costs.

Transparency

Transparency is central to maintaining public trust. Public participants in the Wessex Public Panel and DCFs called explicitly for clear visibility regarding decision-making processes, oversight structures, and responsibilities for multi-SDE projects.

Wessex DCFs made a recommendation that SDEs disclosure of SDE-to-SDE sharing on the Data Use Register (or equivalent transparency measure) whether this is on a project basis or to support the development of new data registries.

DCF members also stressed that transparency should remain straightforward as SDE processes evolve, recommending that SDEs provide clear, accessible information about how patient data is safeguarded during research, regardless of how data is being used.

More broadly, transparency and consistency in applying data use principles, clearly demonstrated and communicated, were key to reassuring the public (NHS England 'National engagement on data' Cohort 1 Report).

Governance

Digital Critical Friends (DCFs) emphasised the importance of robust and consistent governance for SDE-to-SDE sharing, given multiple SDEs would be involved. They queried whether a national body oversees this type of sharing, echoing feedback from Cohort 2 of the NHS England 'National engagement on data', where participants argued that: "Decision making should move to a model that balances the need for national consistency and regional responsiveness," (p.74).

Wessex Public Panel participants asked for clear information on how responsibilities and approvals are divided among SDEs. They suggested that the SDE with the largest or best-quality dataset should take the lead and asked whether each SDE will have its own DAC meetings, how decisions will be delegated, and what role the public plays in setting these rules. The Panel sought assurance that these processes would be transparent and communicated to the public.

When data is shared with other SDEs, participants expect that benefits are be proportional to the effort and volume of data contributed by Wessex. They also want clarity on how learnings and improvements (for example, better data quality or treatment pathways) will be fed back to local services — without creating unnecessary duplication or extra storage costs.

DCFs acknowledged the clear safeguards around SDE-to-SDE transfers, such as the transfer of pseudonymised data only, and found these reassuring. However, they felt that direct SDE-to-SDE sharing may represent a departure from the 'data access by default' approach, which is fundamental to the purpose of building SDEs and aligns with Health Research Authority (HRA) consents. This change could look like the kind of 'data sharing' that current national policy and public expectations are moving away from. As a result, they implied the threshold for approving SDE-to-SDE sharing might need to be set higher.

Overall DCFs were reassured by the current governance approach, including oversight from the National SDE Research Network Board within NHS England, and local review through the Wessex Data Access Committee (DAC). They were also reassured by ongoing national work through Communities of Practice to establish consistent guidance for interoperability between SDEs. Public participants

emphasised that their continued support depends on clear progress in these governance arrangements.

Trust in the quality of data

The Wessex Public Panel highlighted that trust in data sharing is directly linked to perceptions of data quality. This is relevant to SDE-to-SDE sharing because increased collaboration across different SDEs relies on public confidence in the consistency, reliability, and integrity of data shared between them.

Factors influencing trust include data quality (i.e. some kinds of data are more qualitative, subjective, or reliant on self-reporting than others); its source (NHS-collected data being more trusted than commercial sources); the potential for misinterpretation or misrepresentation; and the thoroughness of quality checks.

For example, routinely collected NHS data such as test results and blood samples are widely viewed as reliable and low risk. In contrast, more sensitive or personal data, such as sexual health information, is considered higher risk due to unreliability of self-reporting. Data from outside the NHS - like commercial wearables – is viewed sceptically, as the public is concerned it could be manipulated for commercial rather than public benefit.

We infer that, for SDE-to-SDE sharing, public participants will be interested in where quality checks occur, whether this is done at source or by the lead SDE, and how a robust, consistent and publicly trusted standard is applied.

Data security and risk management

We know public participants are concerned about data breaches and hacking, particularly when data is centralised in one place, as this can increase vulnerability. Wessex DCFs have also highlighted concerns about cyber-attacks when data is moved between systems (for example, 'man-in-the-middle' attacks). Sharing data between SDEs involves further centralisation, increasing the perceived risk and potentially impacting public trust.

The Wessex Public Panel sought assurance that data minimisation principles would be applied to ensure only the necessary data required for research would be shared. Similarly, they expected stricter oversight for projects involving sensitive or high-risk data, as demonstrated by feedback from the Wessex Public Panel. Highlighting these safeguards clearly in decision-making processes and transparency reporting could help address these trust concerns.

Public involvement and accountability

Securing Health Research Authority (HRA) approval for new SDE capabilities like SDE-to-SDE sharing, is usually only the first step. How these capabilities are put into action is equally important.

Wessex DCFs clearly expect public representatives to remain actively involved in – and to have oversight of – the implementation process, including policy, governance, and decision-making. This ensures that public concerns and priorities continue to guide data-sharing activities.