Wessex SDE PPIE Impact Overview

September 2025

Summary

This impact report covers the period from June to September 2025, summarising the impact that patient and public involvement and engagement (PPIE) has had on the Wessex Secure Data Environment (SDE) over this period.

The main areas of work were a review of the SDE policy suite by the Digital Critical Friends Group[1] and the implementation of a new digital Critical Friends working group structure to support the SDE as it starts providing pseudonymised NHS patient data to approved researchers. The milestones within this process are set out in the table below.

Month	Public engaged	Activity	Outcome / Impact
May / June	15 (DCF group)	Policy prioritisation for scrutiny	The DCF group reviewed the SDEs full policy suite and prioritised those policies that felt to be most crticial to public trust, as part of a scrutiny of organisational governance.
June	15 (DCF group)	Policy review	DCFs split into scrutiny sub-groups to review eight individual policies or key SDE documents and made comments and recommendations on individual policies.
June / July	15 (DCF group)	Recommendation setting	DCFs workied with the SDE comms and PPIE team to consolidate recommendations and synthesise

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[1] The **Digital Critical Friends** are a standing group of public participants, recruited to reflect the demographics of the Wessex region, who work closely with the Wessex Secure Data Environment team to ensure NHS data is used safely and for public benefit. They play an active role in the SDE's governance and scrutiny, including serving on the Wessex Data Access Committee, which reviews and advises on which data access requests should be permitted.

			overarching themes across the eight policies reviewed, which were reported to the Wessex SDE Board for action. Responsibility for responding to recommendations was delegated to the SDE Operations team.
August / September	15 (DCF group)	New working group structure	The SDE team and DCFs working together developed a new working group structure to support the SDE as it moves to being an operational service. DCFs from the group were recruited to support these new functions.

Overview

The Wessex SDE isn't just about technology - it's about people and trust. From the outset Wessex patients and the public have been sharing their hopes, concerns, and expectations for how this platform should be run.

In March 2025 the SDE marked a significant milestone as it moved to being a 'live' service. This step reflects the platform's technical maturity, achieving a high level of assurance through internal reviews and external audits, including ISO27001 certification, and robust governance structures.

At the point that it went live, Wessex SDE already had a full set of working policies and procedures in place (referred to as the 'policy suite'), allowing data to be brought into the platform securely and used for approved research. These rules combine processes developed specifically for the SDE with those used by University Hospital Southampton, which hosts the platform.

It is recognised that the SDE's policy suite is necessarily a work in progress as it responds to evolving national governance and regulatory requirements, the practical needs of researchers, and ongoing co-design input from public participants and Wessex stakeholders.

The next stage of development focuses on strengthening and standardising these policies, working with public participants through the Digital Critical Friends group to make sure they reflect public expectations. The two pieces of work detailed in this report are therefore critical to this process and to maintaining public trust.

In addition, it should be noted that over June to Sepotember 2025 the SDE introduced an independent Wessex Data Access Committee, with four public

members, to review and advise on requests to use data – helping to ensure all decisions are fair, transparent, and in the public interest.

Digital Critical Friend Policy Review

The Digital Critical Friend Policy Review was set up to make sure the Wessex SDE is open, trustworthy, and well-run. The review focused on what matters most to the public, ensuring the SDE's processes and governance stand up to scrutiny. Specifically, the review aimed to:

- **Check the SDE's governance from a public perspective**, ensuring its policies, rules and procedures are clear, strong, and meet public expectations.

- **Help DCF members feel confident in the SDE**, giving them reassurance that it operates fairly and honestly, so they feel comfortable explaining and supporting it to others.

- **Focus attention where it matters most**, looking closely at policies that DCF members felt carried the biggest risks for public trust or were of greatest public interest. This made the best use of the group's time and effort.

- **Use detailed reviews of selected policies** to find lessons that apply more widely, so that improvements identified through this targeted work would benefit the whole of the SDE's governance in a practical, straightforward way.

Approach

Initially, 36 policies making up the full policy suite at the point that the SDE went live, were identified for review. As a first step, the DCF group were invited to prioritise these policies using clear, consistent criteria, evaluating each policy based on:

1. **Risk:** Potential financial, legal, operational, reputational, compliance, or strategic impacts.

2. **Public Interest:** Level of stakeholder concern, political sensitivity, media attention, public scrutiny, or regulatory focus.

3. **Complexity and expertise required:** Degree of technical or specialist knowledge needed, indicating the need for additional expert input or external review.

A briefing paper with short descriptions of the policies was circulated to DCFs to prioritise the policies into four categories:

- **High:** Important for public input, visibility and trust

- **Visible:** Transparency only, want to see but not to change

- **External:** Requires third party assurance – expected it is highly technical or legislative in nature.

- **Low:** Trust SDE and/or partners to deliver, no detailed DCF input needed.

This was supported by background reading, to remind them of the outcomes from previous public engagement and what the wider public had reported as their key concerns and areas of interest, including:

- Listening to Seldom-Heard Groups across Wessex (June 2024)
- Wessex Public Panel on NHS Data (July – September 2024) recommendations
- PPIE Insights for the Wessex SDE Data Access Committee (April 2025)

The initial review identified **10 high priority policies**, of which two were already being reviewed by the Wessex DAC and had limited scope for additional input and influence. The scrutiny therefore focused on the remaining eight policy areas.

Members then carefully examined the policies, asking the challenging questions they felt the wider public would want answered using a five-step co-design approach to listening, theming, sensemaking, modelling, and validating.

Over three months the groups completed; desktop reviews, discussed challenges and changes, learnt more about the complex and highly regulated technical and governance environment the SDE is working within, participated in theming of responses, and produced strategic recommendations and policy specific actions.

Implementation

The outcomes and further details about the process have been captured in our ['Digital Critical Friends: Targeted review of the SDE policy suite'](#) (under 'Resources) which includes a foreword from a DCF. The paper was reviewed at our July SDE Board, with responsibility for delivering against the recommendations delegated to our Director of Operations.

Working with our Comms and PPIE team, we have been actively implementing the DCF's recommendations, including updates to:

- Wessex SDE Transparency Policy (under 'Resources')
- Wessex SDE Privacy Policy (awaiting Board sign off)
- Wessex SDE EqIA Policy (awaiting Board sign off)

Additionally, we have been further developing our transparency approach and publication commitments, including:

- [Public attitudes to SDE-to-SDE Data Sharing](#) (under 'Resources')
- [Public attitudes to Clinical Trials re-identification](#) (under 'Resources')
- You said, we did - retrospective and future facing, (currently in progress, to be updated end October)
- Website restructure with layered information and transparency (currently in progress, to be updated end October)

Finally, we have been working with the DCFs to review the ways in which they are engaged in the delivery of the SDE, its governance functions, and designing the next phase of the SDE. We are now recruiting to different roles to ensure that everyone has an equal opportunity to engage in the way that best suits them, their skills and their availability.