Wessex SECURE DATA ENVIRONMENT | Part of the NHS Research Secure Data Environment Network

NHS

Wessex SDE PPIE Impact Overview

July to September 2026

Overview

Patients and members of the public continued to play a central role in shaping the Wessex Secure Data Environment (SDE) between July and September 2026.

During this quarter, public contributors helped us examine proposals to share information between NHS organisations, scrutinised plans to link health and council records, and helped strengthen how we assess risks and protect patients. They also shaped research involving artificial intelligence (AI), supported new patient advisory groups and helped us improve how we explain our work.

This quarter showed how public challenge continues to help improve decisions. Our contributors did not simply support everything proposed. They raised difficult questions, identified risks and made practical recommendations. Their advice is helping us develop clearer standards for deciding when and how information should be used.

Public involvement at a glance

Month	Public engaged	Activity	Outcome / impact
July–September	Digital Critical Friends	Ongoing review of SDE research, governance, strategy and public benefit	Public perspectives continued to inform Board and Data Access Committee discussions, including research safeguards and the benefits expected from using NHS data.
July–August	Digital Critical Friends	Review of proposals for sharing information between NHS Secure Data Environments	Public feedback informed the evidence provided to national regulators and the safeguards considered for sharing information securely between NHS research settings.

August–September	Digital Critical Friends	Two Town Halls on linking NHS and council data, held on 17 August and 23 September	Public contributors identified risks, challenged assumptions and developed advisory recommendations to strengthen how future research requests are assessed.
July–September	Digital Critical Friends	Review of GP data-processing plans, information security risks and the SDE's Value Return Policy	Helped identify the safeguards and assurances needed to protect information, use NHS resources responsibly and explain how research should benefit patients.
August–September	REAL-DERM applicants and Patient Advisory Group	Recruitment and establishment of a patient group to support research into AI and skin cancer	65 initial expressions of interest led to a 12-member group bringing different experiences and skin tones into the research.
September	Young people through LifeLab	Exploring AI in healthcare research	Young people raised questions about safety, fairness and accountability, helping shape further discussions and engagement.
July–September	GP patients and Patient Participation Groups	Community engagement, including an event at Lyme Bay	Gave patients opportunities to learn about the SDE, ask questions and share views on the use of GP information for research.
July–September	Digital Critical Friends	Public involvement in the Wessex Health Partners Data Access Scheme	A public contributor helped assess applications for research support. Nine research teams were selected, with up to £225,000 of support available.
July–September	Patients and wider public	Improvements to patient information, website content and	Made it easier to understand how health information is used, what research has

		public research records	been approved and what findings have been published.

1. Public challenge influenced important decisions about data use

One of the strongest examples of public influence this quarter concerned proposed changes to the SDE's HRA approvals.

DCFs considered proposals to enable appropriately governed sharing of data between NHS Secure Data Environments. They recognised the potential research benefits and **supported the principle of SDE-to-SDE sharing**, provided appropriate safeguards were in place. Their feedback contributed to the public involvement evidence prepared for the HRA.

DCFs also considered proposals relating to the use of local authority data. While recognising its potential research value, they raised significant concerns about the breadth of the proposal, the safeguards required and whether sufficient public involvement had taken place.

Impact: DCFs did not support progressing the local authority data proposal in its initial form. Their challenge led to further consideration of the proposal and practical recommendations for strengthening how future uses of local authority data should be assessed.

These included ensuring researchers can explain why specific information is necessary, what risks its use could create and how those risks will be managed.

This demonstrated an important principle of the SDE's approach to public involvement: **public contributors are there to influence and challenge decisions, not simply endorse proposals.**

2. Public perspectives strengthened safeguards and governance

DCFs continued to contribute directly to the SDE's formal governance through representation on the SDE Board and Data Access Committee.

They also provided public perspectives on areas including GP data processing, information security, free-text health records and the SDE's approach to defining the benefits expected from research.

For example, DCFs contributed to development and review of the **Value Return Policy**, helping consider how benefits such as better treatments, new knowledge,

improved patient experience and more effective NHS services should be recognised alongside financial value.

Impact: Public perspectives are increasingly embedded in routine SDE decision-making, helping the SDE consider not only whether something can be done, but whether it is appropriate, adequately safeguarded and likely to deliver worthwhile public benefit.

The HRA discussions also highlighted the importance of involving public contributors **early enough to influence significant proposals**, rather than seeking their views once an approach has already been developed.

3. Lived experience is becoming more closely connected to research

This quarter saw significant progress in bringing public involvement closer to individual research programmes.

For **REAL-DERM,** which is investigating AI in NHS skin cancer services, earlier public feedback highlighted questions about fairness, patient safety, transparency and performance across different skin tones.

Building on this, a dedicated **12-member Patient Advisory Group** was established. Recruitment through external partners and the wider NHS SDE Network generated **65 initial expressions of interest**, with particular emphasis placed on including people with different skin tones, backgrounds and experiences of skin conditions.

Impact: The group will provide an ongoing patient perspective as the research develops, helping keep fairness, safety, patient experience and trust central to the study.

Plans also progressed to strengthen lived-experience involvement in two other major programmes:

- **Connect-D**: involving people living with dementia, carers and organisations representing those affected to help shape how the programme develops and how information and benefits are explained.
- **PRANA**: developing a dedicated advisory group involving people with experience of major trauma, helping identify important research questions and outcomes that matter to patients and families.

Together, this represents a shift towards embedding relevant lived experience within major research programmes rather than relying only on general public involvement.

4. We broadened the voices informing the SDE

Alongside our established DCFs, we continued to broaden the range of people and perspectives informing the SDE.

We reviewed findings from Bournemouth University's PIER research involving **108 contributors across 12 groups** whose perspectives can be underrepresented in health research and public engagement. The findings are informing how we explain data sharing and approach engagement with communities that may have different experiences of the NHS.

Through the University of Southampton's **LifeLab** programme, young people also explored the use of AI in healthcare. They raised questions about missed diagnoses, unfair results, accountability when AI makes mistakes and whether patients should know when AI is being used.

Impact: These questions are helping shape the next stages of engagement around AI, particularly around safety, fairness, transparency and accountability.

We also began taking conversations about health data into local communities through GP practices and Patient Participation Groups. An initial session with the **Lyme Bay Patient Participation Group** followed by attending their **Annual General Meeting** gave patients an opportunity to hear about the SDE, the importance of sharing GP data for research, ask questions and share their views.

5. Public involvement helped make research benefits more visible

Public contributors continued to challenge the SDE to demonstrate not only how information is protected, but **what worthwhile research using NHS data achieves for patients and the public**.

A DCF participated in the Wessex Health Partners Data Access Scheme, helping assess applications for research support. Nine research teams were selected, with up to **£225,000 of support** available. This brought a public perspective alongside scientific considerations when assessing which projects should be supported.

We also continued improving public-facing information about SDE-supported research. This included developing clearer, layered case studies, strengthening explanations of safeguards and public benefit, and making it easier to distinguish between research that is still underway and studies that have produced findings.

The new **Publications Register** also provides a clearer way for people to see research outputs and, where possible, connect them with the projects recorded in the Data Use Register.

Impact: Patients and the public have clearer ways to see not just which research has been approved, but what it is finding and why the use of NHS data matters.

As the SDE develops, we will continue working with patients and the public to shape decisions, strengthen safeguards and demonstrate the benefits of research. Research using people's health information should be shaped with them, not simply carried out on their behalf.