

Wessex SDE PPIE Impact Overview

January 2026

Summary

This report highlights the impact of Patient and Public Involvement and Engagement (PPIE) within the Wessex Secure Data Environment (SDE) between October-December 2026. Through our Digital Critical Friends (DCFs), members of the public have played an active role in shaping how the SDE is governed, how it communicates, and how it builds trust in the responsible use of health data.

Public contributors have provided insight, challenge, and lived experience across a wide range of activities, including Data Access Committee and Board meetings, national events, and the development of public-facing communications. Their feedback has directly informed improvements to transparency, accessibility, and accountability, including changes to our website and how we explain our work to different audiences.

This work demonstrates our commitment to embedding public voices in decision-making and ensuring that the use of health data delivers clear public benefit, is well governed, and remains worthy of public trust.

Month	Public engaged	Activity	Outcome / Impact
October	14 DCFs	Town Hall	Our Town Hall sessions provide overarching views of all the work that is happening across the SDE and how the DCFs can be best engaged to add value and reflect their insights and lived experience.
October	3 DCFs	SETT Conference	DCFs represented the SDE as a panel Chair, Public member on the panel and attendee at this University of Southampton event open to researchers and the public.
November	4 DCFs	Advisors and Explorers	The SDE's Clinical Lead held the first session with this working group to

			explain our HPO Ontology Driver Project. The introduction was followed by a second session to deep dive into Risks, Trust and Value.
November	5 DCFs	Annual Report	DCFs explored the different types of content that we might like to include in the annual report at the end of the financial year. Their insights will help us to ensure that we focus on key areas of interest and information required for public trust and to maintain our social licence.
November	2 DCFs	National SDE PPIE Conference	Our DCFs attended this event in London to share the work that they have been doing with other public members nationally.
November	14 DCFs	Town Hall	DCFs discussed what they had been doing as well as the emerging themes of our SDEs research strengths and convergence.
December	8 DCFs	Year in Review	The group reflected on their individual and group experiences throughout the previous year. We then discussed what worked well, what could work better, and our focus looking ahead.

Overview

PPIE is a core part of how the Wessex SDE operates. It ensures that decisions about the use of health data are informed not only by technical and clinical expertise, but also by public values, expectations, and lived experience.

Our DCFs are embedded across the SDE's governance and engagement activity. They contribute to strategic discussions, review policies and public-facing materials, participate in Data Access Committee and Board meetings, and represent the public voice at regional and national events. This role is not advisory in name only; DCF insight actively shapes how we work and how we improve.

Over the reporting period, DCFs have helped us reflect on public trust, data bias, transparency, and communication. Their challenge has influenced how we explain

complex topics such as data use, artificial intelligence, and governance, ensuring that our messaging is clearer, inclusive, and more accessible.

This ongoing dialogue helps the SDE remain accountable to the communities it serves. By listening to and acting on public feedback, we strengthen confidence in how health data is used, improve the quality of our decisions, and ensure that public benefit remains at the centre of our work.

DCF engagement in detail

October Town Hall

DCFs provided updates on their recent contributions to the SDE governance, and wider SDE activity, including:

- Updates from the DAC about the research projects presented and approved
- Board engagement, maturity of relationships, and stronger, open communication
- SETT Conference
- Website redesign, with recommendations for dashboards, near real-time information and easy understand graphics
- Future research opportunity
- Planned work with Seldom Heard Groups in the new year

SETT Conference

DCFs reflected positively on the SETT Conference, where the Wessex SDE team presented on public trust, data access, and ethical governance.

- Public members felt it was valuable to see how public voices were represented alongside technical and policy discussions.
- The conference helped raise awareness of the Wessex SDE nationally, highlighting its leadership in transparent, citizen-centred data governance.
- Several attendees noted strong public interest in how AI and Secure Data Environments can be used responsibly to improve health outcomes.
- Members agreed that future conferences should include dedicated public engagement sessions and opportunities for DCF members to co-present with researchers, reinforcing the message that the public are equal partners in data governance and innovation.

Advisors and explorers

Our Clinical Lead provided an overview of our HPO Ontology project.

The Aim of the project is: To identify missed diagnoses and patterns from clinical notes.

- Attendees found the session interesting but highly technical and difficult to follow.
- Concerns raised:
 - Pace and complexity of presentation.
 - AI bias, hallucinations, and ethnic name recognition.
 - Clarification needed on whether the LLM was bespoke or adapted ("Pterodactyl" model used, trained locally but not built from scratch).
 - Strong desire for plain-English follow-up session.
- Emphasised importance of hope in research and the public's optimism around AI potential for cures
- Highlighted need for robust safeguards and critical evaluation of AI bias and verification processes.
- Noted importance of patient/public involvement in interpreting free-text medical data.

As this is a complex project with a lot of technical issues, a second session did a deep dive into:

- Risks and Trust exploration: looking at what feels comfortable and safe; what needs more explanation to support the public; what feels risky; and reassurances needed
- Adding value to the project: where are the challenges; what are the communications needs; risk and AI; future activities

Annual report

Led by the SDE's Comms and PPIE, the group reflected on the different types and styles of report that could be used by the SDE and the building blocks that they wanted to see. This included workshop to look at:

- Meeting public expectations
- Minimum viable product: what is essential to a good annual report
- Optional building blocks: where more detail is required
- Best case: definitely need, nice to have
- Appendices and wrap up

The output from the session is being shared with the wider SDE team to ensure that we are capturing and recording the required information to design and deliver the Annual Report at the end of the financial year.

National PPIE Event

DCFs provided their feedback and key reflections from the National PPIE Event hosted by NHS England.

- Wessex seen as being among the national leaders for engagement and technical readiness – ‘Further, Faster’
- Key takeaways:
 - Need for national coordination but maintain regional identity.
 - Example of London DCF having 250 members voting digitally.
 - Plans for a national online forum in December for cross-regional public discussions.
 - Reported 59% national public confidence in data use across SDEs.
 - Discussion on “social licence” and consistent terminology across regions.
 - Potential collaboration opportunities with the Southwest team.

Town Hall

In addition to sharing details of the above work the DCFs also discussed:

- Increasing the role of DCFs to lead these sessions
- Emerging convergence across the South Coast
- Upcoming events
- SDE data strengths
- Early research impact and performance, including Driver and Registry projects

Year in review

As the year comes to an end it provided a good opportunity to reflect on all the work that has been happening across the SDE and the role of the DCFs. Together we considered:

- **What has worked well:** DCF learning and understanding of the SDE; their engagement and contribution to decision making; Comms and PPIE to develop and share information about what we are doing
- **What could work better:** greater public education and awareness of the SDE; surfacing direct outcomes and benefits of the SDE; ensuring that security and safety of the SDE are clearly explained
- **Our focus looking ahead:** public benefit research use cases; use of multi-media approaches; promotion outside clinical environments; trusted partners to share information – community leaders; collaborative working with other

SDEs; view of SDE performance nationally – how do we compare and what can we learn

At the end of the session the feedback was themed and will be used to help shape of Comms and PPIE plans for 2026-27.