

# Wessex SDE Communications & PPIE Strategy 2025-26

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This strategy paper explains how the Wessex Secure Data Environment (SDE) will communicate clearly, involve the public meaningfully, and help deliver trusted, high-impact research in 2025–26.

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# Mandate and context

## Why the SDE exists

The Wessex SDE's mission is to speed up health innovation that improves people's lives and the NHS. We enable safe research access to linked NHS patient records within a controlled, audited environment. This delivers public value when data-enabled research leads to better diagnosis, care and policy. Researchers never see confidential patient information.

## Our obligations

### Funders and sponsors

We operate under agreements with our funders and sponsors, including NHS England and NHS Trusts in Dorset, Hampshire and the Isle of Wight. These agreements expect transparent reporting, practical public engagement, and visible value for money. In practice, that means keeping a public Data Use Register up to date, publishing regular programme updates, aligning with national SDE messaging, and showing how our work benefits care and research. We also follow inclusion and accessibility duties, complete equality impact assessments, and use correct funder attribution and approvals.

For the communications and PPIE programme, this translates into a clear publication schedule with named owners, providing a single authoritative source for messages and facts, a searchable transparency area on the SDE website, and a small, focused stakeholder engagement plan linked to the research pipeline.

### Regulators and standards

We work in a tightly regulated space. The NHS Health Research Authority set expectations for our ethics. The Information Commissioner's Office regulates privacy under UK GDPR and the Data Protection Act 2018. We also meet the common law duty of confidentiality and honour the National Data Opt-Out. Our approach also reflects guidance from the National Data Guardian and the Caldicott Principles.

NHS England's SDE policies and the 'Five Safes' framework set operational standards for secure access to data that protects privacy. Freedom of Information rules apply to our host NHS bodies, and public-sector accessibility regulations shape how we publish online.

For communications and PPIE, this means plain-English privacy information, clear explanations of legal bases and safeguards, and "start simple, dig deeper" content that links summaries to detailed pages like the Data Use Register and governance sections. We check case studies and publications against safe-outputs rules, maintain FOI-ready facts and a master Q&A, design for accessibility by default, and make sure we are ready to handle any issues that may arise quickly and accurately.

## **Public mandate (our social licence)**

Through ongoing PPIE we have built a clear picture of what people in Wessex expect from NHS data-enabled research. They want a clear public purpose, fairness, and strong safeguards. They want control and choice, including simple routes to information about opt-outs and complaints. They expect independent lay oversight, for example through our Digital Critical Friends (DCFs) and on the Wessex Data Access Committee (DAC). They want proportional use of data, transparency that shows what changed, and inclusion that reaches seldom-heard groups with fair reward and low barriers to take part. They also want honest, balanced communication about risks and limits.

These expectations shape the design of our programme. We use co-design as standard, publish “you said, we did” updates, and tell story-led accounts of impact that link research to everyday care. We offer multiple ways to get involved, from light-touch feedback to deeper roles, and we pay people fairly. We set clear escalation for sensitive topics, measure reach, diversity and trust, and report progress openly. Above all, we keep the tone respectful and the language plain so there are no surprises.

## **Service reality and focus for 2025-26**

The Wessex SDE is live with secure technology and clear rules. This includes a new Wessex Data Access Committee, with public members, that recommends which research studies can proceed. Our strengths include embedded public involvement and growing partnerships with researchers and NHS teams.

We also know there is more to do: make it easier for researchers and the public to find us; help more early conversations become well-designed, approved studies; and plan for long-term sustainability.

Our communications and PPIE programme will meet these needs by making routes to access simple, nurturing partnerships from first enquiry to study delivery, and showing – through plain-English stories and core metrics – the difference this work makes for patients and services.

# Objectives

Our approach is guided by our social licence: we earn permission to use data for research by being transparent, involving the public in real decisions, and showing clear public benefit. We also need to grow informed demand so high-quality studies choose Wessex, and we must evidence benefits with stories and metrics that stand up to scrutiny. The detailed Objectives and Key Results (OKRs) for 2025–26 are listed in Appendix A.

## **Objective 1 – Strengthen community involvement and advocacy**

Outcome: public voices shape priorities and decisions, and people can see how their input made a difference. Involvement continues to be broad, includes seldom-heard groups, and enables confident public advocates to talk about what we are doing. Success looks like trusted, visible public influence across our governance and communications, with accessible information for those whose data supports the SDE.

## **Objective 2 – Show impact and public value**

Outcome: people can clearly see the difference the SDE makes for patients, services and research. We explain benefits and limits in plain English, and we are open about what went well and what we learned. Success looks like a concise public record that links activities to outcomes and demonstrates value for money and public good.

## **Objective 3 – Strategic stakeholder engagement and outreach**

Outcome: it is straightforward for researchers and NHS partners to plan and deliver responsible studies that align with the SDE's public mandate and national standards. Expectations are clear early on, so good ideas become well-designed, approvable studies quickly. Success looks like fewer, better touchpoints and easier starts, without adding unnecessary burden.

## **Objective 4 – Strengthen channels and content**

Outcome: transparency is predictable, accessible and useful. People can “start simple, dig deeper” to find checkable facts about what we do, what data is used, who can access it and how decisions are made. Success is seen in up-to-date public reporting of the research we do, the data we hold, and clear web content that serve both public readers and specialist users.

## **Objective 5 – Robust issues and crisis communications management**

Outcome: when challenges arise, we respond quickly, openly and consistently to protect trust. Lessons are shared appropriately, and teams are confident in how to communicate. Success looks like timely, accurate responses grounded in agreed facts, with improvements fed back into our programme.

# Audiences

The audiences for our communications and PPIE programme are defined by the objectives above. Priority groups and their needs are set out below, reflecting our 2025-26 focus.

## **Public and patients (including seldom-heard groups)**

First, people need to know the SDE exists; without that awareness they cannot form a view, exercise choices, or decide whether to get involved. The SDE needs to make clear why it matters with short, human, local stories. Once interested, people want a start-simple, dig-deeper path: short, plain-English summaries with clear routes to fuller detail on what data is used, why, who can see it, how it is protected, and how decisions are made. They also want agency: options ranging from light-touch feedback to roles in co-design and decision-making, and visible “you said, we did” proof that their input changes things.

## **Researchers (clinical and academic)**

The public’s mandate to use NHS data only becomes real if researchers know the SDE exists and can use it. Time-poor teams want a clear, credible entry point: a plain “how it works”, proof of delivery, and a named contact. They also want early-stage support (planning, costing, funding) so good ideas become studies. They also value predictability and ethical assurance: simple processes, standard turnaround times, and confidence that using NHS patient data is safe, lawful, and publicly supported.

## **Industry (biopharma, med-tech, data intermediaries)**

Industry partnerships matter because they turn NHS data into new treatments, diagnostics and tools. Partners need to know we exist and what problems we solve, with quick, plain-English overviews, a clear “how to start” path, and a point of contact. They look for similar assurances about delivery as researchers.

## **NHS and NIHR system partners**

They want assurance that governance is sound, that the SDE is delivering value for money, and visible benefits to patient care and research pathways – with a clear simple story and messaging that they can use in their own comms. They want to keep time commitments from their teams limited and manageable, sight of pipeline and results, and alignment with national priorities.

## **Government and regulators**

They need confidence we meet mandated standards, with transparent reporting, credible public engagement, lawful data flows, and proportionate risk management.

## **Media and opinion formers**

They need plain-English explanations, human examples, and checkable facts answering, “what data, who sees it, how is it kept safe, and what does the public gain?” They need timely access to spokespeople and accountability when things go wrong.

# Strategy

We know that public trust and research impact are linked and rise together. We cannot have impact without trust, and trust is strengthened when people see real-world benefits. Our strategy therefore holds two goals at once: sustain our social licence through transparency and involvement, and promote impact through clear, accurate stories and simple routes to collaborate.

## How we will sustain social licence

- **Make transparency routine:** publish simple summaries, link to deeper detail, and maintain the Data Use Register.
- **Embed public voices:** work with our Digital Critical Friends group to ensure that the SDE is behaving in line with public expectations, review our research pipeline, co-author public reports, and shape policy updates.
- **Continue the conversation with seldom-heard groups:** return to communities we engaged, show what changed, and invite involvement that suits their needs.

## How we will promote impact responsibly

- **Lead with powerful research case studies,** show how they are powered by NHS patient data that is securely managed with public support for its use; and enabled by the SDE, which includes public voices in design, governance and delivery.
- **Keep language plain, facts checkable, and messages aligned** with NHS England and Health Research Authority expectations.
- **Support researcher engagement** through outreach, ‘quick start’ information, and a concise toolkit so they can plan studies ethically and efficiently.

## Focus for 2025–26

- **Public assurance through action:** reduce policy talk and show delivery, especially around governance in practice and “you said, we did.”
- **Seldom-heard groups:** continue a flexible, story-led approach; meet people where they are; remove barriers through fair payment and accessible formats.
- **Proactive storytelling:** highlight work that shows clear public value, including service improvement and population health projects with nearer-term benefits.

# Activity programme

The 2025–26 programme turns the strategy into day-to-day practice. It shows how transparency, meaningful involvement and clear stories about public benefit come together to keep trust strong while helping well-designed studies happen.

## 1: Governance and assurance

### DCF scrutiny and assurance

We will embed public scrutiny in how the service runs. Our Digital Critical Friends (DCF) will have a formal role across governance: attending relevant boards, contributing to the Wessex Data Access Committee (DAC) process, and providing lay review when we seek changes to approvals or new permissions (for example, when we amend our NHS Health Research Authority consents). DCF members will complete a quarterly look-through of studies we are talking to about access to the SDE and of the public benefits emerging from supported research. DCF members will co-author an Annual Report so the things that matter to the public are reported publicly. By looking at both what comes in and what goes out, DCF input helps ensure decisions continue to reflect public priorities.

### Transparency policy implementation

We will make transparency routine by implementing the Transparency Policy and its publication scheme. This includes maintaining a Data Use Register that describes, in plain English, the projects using data in the SDE, what they are doing, and the public benefit they seek to deliver. Aligned with this, we will be open about how the Wessex DAC takes decisions and will publish summaries of external audits and other high-interest material on a predictable schedule. Our goal is clear: information about our actions, data access and decision-making should be easy to find. When issues arise, and where it is appropriate to do so, we will share lessons learned openly and in collaboration with public participants to help maintain trust.

### Public impact reporting

We will also report impact in an ongoing, human way. Short, plain-English updates and the Annual Public Report will explain what has happened and why it matters, with a visible “you said, we did” thread that shows how public input has changed priorities, design choices and decisions. These sit alongside the Data Use Register and DAC publications to give a rounded public record.

### How this delivers the objectives

- **Objective 1 (strengthen community involvement and advocacy):** public voices shape priorities and decisions, and people can see how their input made a difference.
- **Objective 2 (show impact and public value):** a concise public record links activities to outcomes and value for patients and services.

- **Objective 4 (strengthen channels and content):** transparency is predictable, accessible and useful.
- **Objective 5 (issues and crisis):** sharing lessons learned appropriately supports fast, open responses that protect trust.

## 2: Public engagement and inclusion

### DCF advocacy and public voices

Beyond providing critical oversight, DCF members will act as credible public advocates. With light training and support, they will help explain the SDE at community events, research forums and media opportunities – leading with powerful research stories and explaining how NHS data and the SDE have enabled progress. They will also support website and newsletter content creation, adding authentic voices and keeping materials accessible. This dual role – scrutiny and advocacy – reflects what the group asked for and helps more people hear directly from peers, not just officials.

### Seldom-heard groups (close the loop and continue the dialogue)

We will continue our work with seldom-heard groups across the region using a “meet people where they are” approach, delivered with trusted partners such as Bournemouth University’s PIER team. Our first task is to close the loop: go back to groups we have already engaged, show what we heard, what we changed and what happens next. This helps people see their time has made a difference, supports informed choices about data use, and keeps participation broad so research reflects our whole population. We will also provide opportunities for individuals to become involved as DCFs, strengthening the diversity of this group and ensuring that we continue to value and promote in-depth engagement of these communities.

### Patient information and practical transparency

To support informed choice at scale, we will look at refreshing patient-facing materials in accessible formats and priority languages, and distributing them with the support of NHS Trusts, GP surgeries, and other partners who are giving secure and private research access to their data through the SDE. This is practical transparency: clear information in places people already use, when it is relevant to them.

### Media and case studies

We will maintain a modest press function focused on local and sector media, promoting short, accurate case studies that connect research to everyday care and value for money. This raises awareness of research and the SDE among the public and helps researchers and NHS colleagues demonstrate the benefit of their work.

### How this delivers the objectives

- **Objective 1:** public involvement remains broad and diverse, includes seldom-heard groups, and enables confident public advocates.

- **Objective 2:** people can clearly see the difference the SDE makes, with stories that explain benefits and limits in plain English.
- **Objective 4 (supporting):** accessible materials and clear routes to information help people “start simple, dig deeper.”
- **Objective 3 (supporting):** DCF voices at research forums create fewer, better touchpoints without adding unnecessary burden.

## 3: Researcher engagement and partnership development

### Researcher toolkit

We are exploring a co-produced ‘researcher toolkit’ that brings public participants and researchers together to make starting research with the SDE easier. The emphasis would be on “how it works”, expected ethics and governance, the public mandate under which the service operates, and practical resources (for example, approved descriptions for funding applications and clear maps of data access steps). We will test the idea with potential users and proceed if it adds real value.

### Events and outreach

We will support a calendar of stakeholder events, focusing on having a presence at existing events where we can reach researchers and prospective partners effectively. We are also considering a quarterly stakeholder newsletter. The goal is simple: a few good touchpoints that help teams plan responsible studies early, with clear routes to advice. Again, these are explored and sized to avoid over-promising and to keep effort on things that work.

### How this delivers the objectives

- **Objective 3 (strategic stakeholder engagement and outreach):** it is straightforward for researchers and NHS partners to plan responsible studies that align with the public mandate and national standards; expectations are clear early, so good ideas become well-designed, approvable studies.
- **Objective 1 & 4 (supporting):** co-produced guidance and clear content help public readers and specialist users find what they need.

## 4: Channels and content

### Website and content development

We will evolve our website to follow a “start simple, dig deeper” structure. People who want an overview get it in one page; those who want detail can click through to registers, policies and governance. We will keep a searchable ‘PPIE & Impact’ area up to date, so it is easy to see how public input has changed things. A quarterly content grid, aligned with programme milestones, will keep updates consistent and useful rather than noisy.

## Equalities Impact Assessment (annual)

We will support the creation of an externally validated Equalities Impact Assessment (EqIA) of the SDE each year, reporting progress on equality, diversity, and inclusion aims and what we will do next. This links to our stories of impact to fair participation and helps us improve where gaps remain.

### How this delivers the objectives

- **Objective 4:** transparency is predictable, accessible and useful, with current registers and clear web content.
- **Objective 2 (supporting):** impact stories are tied to inclusion through the EqIA.

## 5: Risk and issues readiness

### Crisis and issues plan

Our issues and crisis plan sets out clear roles, approvals and timelines, and we test it annually. We recognise that issues arise for many reasons; they often escalate when people do not receive clear, consistent answers. To prevent this, we prioritise timely, accessible and aligned messaging across partners and the SDE Network. Public messaging follows our “start simple, dig deeper” approach so core FAQs are easy to find and understand. For spokespeople and delivery teams, we keep agreed facts and answers up to date so responses are prompt, accurate and consistent – without overloading the public record with detail.

Messaging is integral to risk control: unclear or conflicting answers undermine trust and prolong issues. We aim for responses that are open and factual, prompt and correct, respectful and written in accessible language – not jargon. Where appropriate, and with public participants support, we publish lessons learned and improvements, so accountability is visible.

### How this delivers the objectives

- **Objective 5:** when challenges arise, we respond quickly, openly and consistently to protect trust; lessons are shared appropriately and improvements feed back into the programme.
- **Objective 4 (supporting):** agreed facts and Q&A keep public updates accurate under pressure.

## 6: Keeping it safe and running

### Engine room and coordination

Behind the scenes, we run the engine room that makes the public-facing commitments real. We maintain a single source for facts and messages, review public-facing content for privacy, a further check for ‘safe outputs’ and accessibility, and coordinate approvals with our NHS host so FOI responses and publications are timely and correct.

## **DCF secretariat and system alignment**

We provide the secretariat for the DCF group – scheduling, papers, minutes, action tracking, participant payments, training and pastoral support – and support their contributions to the Wessex DAC and other operational activities. To avoid duplication and make best use of NHS resources, we take part in NHS England’s SDE Communities of Practice and share materials with other SDEs. We also stay aligned with NHS and NIHR system partners so our communications support wider NHS priorities and benefit from local and national learning.

### **How this delivers the objectives**

- **Objective 1:** dependable support enables visible lay influence across governance and communications.
- **Objective 4:** approvals, audit trails and accessibility checks keep channels accurate and useful.
- **Objective 5:** readiness is maintained through agreed lines, records and rapid responses.
- **Objective 3 (supporting):** alignment with national partners helps create fewer, better touchpoints for researchers and NHS teams.

# Reporting

We will track a small set of clear metrics that show whether we are doing the right things well. These measures match our objectives, are practical to collect, and help us learn and improve without publishing unnecessary internal detail.

## Transparency and assurance

1. Transparency disclosures in line with the SDE's transparency scheme and updated at least quarterly.
2. Updates to the SDE's Data Use Register and a high-level Data Capabilities Register within nationally agreed timeframes.
3. Wessex Data Access Committee minutes published online within 4 weeks of meetings.
4. Launch of updated website with tiered transparency so users can "start simple, dig deeper", with tracking and reporting of website engagement statistics.

## Public involvement and inclusion

5. DCF programme delivery tracked: a clear work plan agreed with DCFs and published including active public representation in SDE governance and covered by Quarterly PPIE Impact Updates (see below).
6. DCF scrutiny of all SDE amendments and updates to all NHS Health Research Authority ethics approvals sought.
7. Trained DCF ambassadors supporting 2+ external SDE events, either with researchers or patient and public audiences.
8. Seldom-heard group engagement: numbers reached, diversity of participation, and worked examples published that show "what we heard, what we changed, what next," reviewed quarterly.

## Impact and value

9. Annual Public Report published with endorsement from DCF group.
10. Quarterly PPIE Impact Updates that show progress against recommendations.
11. Media outcomes: number and quality of accurate pieces that explain benefits and safeguards, reviewed quarterly.

## Stakeholder engagement and demand

12. Enquiries from researchers and NHS teams that progress to advice or scoping, tracked quarterly.
13. Use of researcher guidance materials or toolkit (if launched) tracked quarterly.

14. Stakeholder experience: optional annual survey to understand what is working and what to improve.

**Issues readiness**

15. Crisis and issues management plan in place and understood across the SDE service team.

16. Core public briefings and agreed answers kept current so responses remain prompt, accurate and consistent across partners.

Each year we will review this set of measures to keep them meaningful, retire what is not useful, and add only what helps the public see the difference this programme is making.

## Glossary

TERM	DEFINITION
Annual Public Report	A plain-English, annually published account explaining the Secure Data Environment's work, impact and safeguards.
Caldicott Principles	A set of NHS guidelines ensuring patient information is used lawfully, ethically and only when necessary—as defined by the Caldicott Guardian network.
Common law duty of confidentiality	The legal obligation on health professionals to keep patient information confidential unless consent is given or another lawful basis applies.
Data Access Committee (DAC)	An independent body that reviews data-use proposals and assesses whether they meet ethical, legal and public-interest criteria.
Data Capabilities Register	A public inventory describing, in general terms, the datasets held within the Secure Data Environment.
Data minimisation	The principle of using only the minimum amount of personal data necessary to achieve the research or planning objective.
Data Use Register (DUR)	A publicly accessible list of approved projects using the Secure Data Environment, with plain-English summaries of their purposes, data used and public benefits.
Digital Critical Friends (DCF)	A trained, diverse public group who scrutinise the Secure Data Environment, co-design governance and materials, and act as ambassadors.
Equality Impact Assessment (EqIA)	An evaluation of how fairly a programme includes different groups, with actions to improve inclusion.
Five Safes Framework	A set of principles—originating from the Office for National Statistics (ONS) in the early 2000s—used to ensure safe research access to sensitive data through controls over projects, people, data, settings and outputs.
Freedom of Information (FOI)	A statutory right enabling the public to request recorded information from public bodies, including NHS organisations.
Health Research Authority (HRA)	An NHS regulatory body that protects and promotes the interests of patients and the public in health research.
Information Commissioner's Office (ICO)	The UK's independent regulator responsible for enforcing data protection and privacy laws, including UK GDPR and the Data Protection Act 2018.

National Data Guardian (NDG)	An independent adviser and challenger to the health and care system, ensuring patient data are used safely, securely and with public trust.
National Data Opt-Out	The option available to patients to prevent their confidential patient information from being used for research and planning.
Pseudonymisation	The processing of personal data in such a manner that it can no longer be attributed to a specific individual without separate additional information, which is kept under technical and organisational safeguards. This contrasts with anonymisation, which is irreversible.
Secure Data Environment (SDE)	A controlled and audited environment allowing approved researchers secure access to data without exposure to confidential patient identifiers.
Social licence	Public consent for data use in research, earned through multi-level public engagement in the design and governance of the Secure Data Environment, setting and testing acceptable guardrails with a sufficiently large audience.
Transparency Policy	A formal set of commitments and rules ensuring information on data use, governance and decisions is published openly and accessibly.
UK GDPR	The United Kingdom's version of the General Data Protection Regulation—the legal framework governing personal data processing in the UK post-Brexit.