

## Wessex SDE Transparency Policy, V1

Trust reference	SDE_POL_003	Version number	1
Description	This policy informs how the Wessex SDE will provide transparency about the work that it is doing, how decisions are made and our reporting commitments		
Level and type of document	UHS R&D specific policy – controlled document		
Target audience	All Wessex SDE stakeholders and the public		
List related documents/policies (do not include those listed as appendices)	None		
Author(s) (names and job titles)	Wessex SDE Director of Operations, Mark Heffernan		
Policy sponsor	Wessex SDE SRO, Chris Kipps		

This is a controlled document. Whilst this document may be printed, the electronic version posted on Florence is the controlled copy. Any printed copies of this document are not controlled.

As a controlled document, this document should not be saved onto local or network drives but should always be accessed from Florence.

### 1 Version control

Date	Author(s)	Version created	Approval committee	Date of approval	Date next review due	Key changes made to document
6/8/25	Mark Heffernan PPIE SDE Team	1	Chris Kipps Mikayala King Rachel Chappell James Batchelor	Florence	6/8/26	First Version

## **2 Index**

1	Version control .....	1
2	Index .....	2
3	Introduction .....	3
4	Scope and purpose .....	3
4.1	Legal and Policy Framework .....	3
5	Definitions .....	3
6	Details of policy .....	4
6.1	Transparency Across SDE Programme Phases .....	4
6.2	Publication and Disclosure Commitments.....	4
7	Roles and responsibilities.....	7
8	Equality impact assessment.....	7
9	Document review.....	7
10	Process for monitoring compliance.....	7
11	Appendices .....	8
11.1	Appendix 1: Publication Scheme .....	8
12	References.....	9

### 3 Introduction

Transparency is central to establishing and retaining the public trust which is fundamental to the Wessex SDE. This policy establishes our commitment to openness and accountability in all aspects of the SDE programme. It is designed to meet public expectations for transparency, ensuring that citizens can trust how their de-identified data is used and that we are answerable for our decisions.

It sets out for stakeholders and the public what information will be shared, how, when, and why. In doing so, it aligns with relevant legal requirements and best practices across the NHS and public sector for transparency and information governance.

### 4 Scope and purpose

The SDE's aim is to ensure the best use of research to improve patient outcomes. This Transparency policy establishes our commitment to openness and accountability in all aspects of the SDE programme. It is designed to meet public expectations for transparency, ensuring that citizens can trust how their de-identified data is used and that we are answerable for our decisions. It sets out for stakeholders and the public what information will be shared, how, when, and why. In doing so, it aligns with relevant legal requirements and best practices across the NHS and public sector for transparency and information governance.

All staff and partners involved in the Wessex SDE are expected to be familiar with and adhere to the commitments made in this policy. By following these requirements, the Wessex SDE programme will continue to foster trust through openness, meet its legal obligations, and exemplify best practice in transparency for the benefit of patients, participants, and the public.

#### 4.1 Legal and Policy Framework

Our transparency obligations are underpinned by key legal frameworks and national policies. We adhere to the **Digital Economy Act 2017**, which enables the sharing of de-identified (pseudonymised) data for research in controlled environments, and we operate as a “secure environment” in accordance with those standards.

We also comply fully with the **UK General Data Protection Regulation (GDPR)**, the **Data (Use and Access) Act 2025** and the **Data Protection Act 2018**, which require that personal data be handled lawfully, fairly, and transparently. In addition, we follow **NHS data governance policies** and standards, including the **National Data Guardian's Caldicott Principles**, notably Principle 8, the “no surprises” transparency principle that mandates informing patients and service users how their information is used.

Finally, as an NHS programme, we are subject to the **Freedom of Information Act 2000 (FOI)** which provides the public a right of access to information held by public authorities (including NHS organisations). This policy should be read and applied in conjunction with these laws and guidelines, ensuring legal and regulatory compliance in all transparency and disclosure practices.

### 5 Definitions

Term	Definition
Caldicott Guardian	A senior person within a health or social care organisation who makes sure that the personal information about those who use its services is used legally, ethically, and appropriately, and that confidentiality is maintained
Data Access Committee (DAC)	A group of professional and public members who meet monthly and who review SDE studies for recommendation and approval.

Data Use Register (DUR)	A listing on our SDE website of all studies currently running in the SDE
Personal data	Any information, which directly or indirectly can identify an individual such as name, identification number or contact details
Pseudonymisation	The processing of personal data in a way that it cannot be attributed to a specific data subject without the use of additional information, provided that additional information is kept separate
UK GDPR	Is the retained version of the General Data Protection Regulation ((EU) 2016/679) as it forms part of the law of England and Wales
Wessex SDE	The Wessex Secure Data Environment (or SDE) is a secure, NHS-owned and run platform that stores and links patient data for research and analysis. It is built to the highest standards for privacy and security of NHS health and social care data.

## 6 Details of policy

### 6.1 Transparency Across SDE Programme Phases

We provide public assurance on the governance and technical infrastructure of the Wessex SDE throughout each phase of its development: **Pre-Release, Develop, and Scale**. At every stage, we implement robust safeguards and oversight mechanisms to protect data and uphold privacy, and we communicate these measures openly to maintain public confidence.

During the **Pre-Release** phase, the SDE platform will initially be accessible to a limited group of authorised researchers through a Platform as a Service' (PaaS) model. Researchers will be required to obtain separate governance approvals to use the platform, including NHS Health Research Authority (HRA) approval or equivalent ethical and legal clearances. Interim governance and quality oversight is provided by the Data Access Committee (DAC) at University Hospital Southampton NHS Foundation Trust. As the foundational governance structures and security controls are established and independently evaluated, we will publicly announce key milestones to demonstrate that the SDE meets required security and governance standards.

In the **Develop** phase the SDE is further built out, a new Wessex Data Access Committee (DAC) with public and professional membership begins operation, and research projects commence. The UHS DAC will begin to transfer responsibilities to the Wessex DAC. During this phase we will continue to disclose significant developments, engage with stakeholders and oversight bodies, and give our Digital Critical Friends (public participants group) oversight of our activities. We will share updates on the platform's technical capabilities, governance model, and update the programme's Data Use Register detailing research projects active on the SDE.

By the **Scale** phase (full operational rollout), all final governance arrangements will be in place – including fully constituted oversight committees and approved comprehensive standard operating procedures – and we will maintain ongoing transparency about SDE operations, data usage, and safeguards.

In each phase, any significant changes to how the SDE functions or is governed will be communicated proactively, ensuring that stakeholders and the public remain informed and confident in the system's integrity.

### 6.2 Publication and Disclosure Commitments

To fulfil our transparency objectives, the Wessex SDE programme commits to proactively publishing and disclosing information as outlined below. These measures follow best practices from NHS and public sector transparency policies, ensuring information is presented clearly and accessibly:

1. **Wessex SDE Policy Suite Publication:** We will publish elements of the SDE policy suite that are of public interest, based on public expectations and governance recommendations. Core policies (for example, on data privacy, security, and access) will be made available on our website so that the public and partners understand the rules governing the SDE. Internal procedures or detailed technical documents may be summarised for public consumption if the full texts are too technical, or if their publication might create a security risk, in order to balance transparency with clarity. The main criterion for publication will be public interest, and we will collaborate with our Digital Critical Friends to evaluate such considerations.
2. **Patient and Public Involvement Reporting:** We will publicly report on our website the activities and findings of our Patient and Public Involvement and Engagement (PPIE) programme. This includes publishing summaries of feedback, questions, challenges, or recommendations raised by patient and public representatives, and detailing how the SDE programme has addressed or implemented those recommendations. Such reports will be written in accessible language and updated regularly to show the influence of public input on the SDE's development and changes to operational working.
3. **Wessex Data Access Committee Governance & Decisions:** The decisions of the Wessex Data Access Committee (DAC) on data access requests will be disclosed in a timely manner. The materials to be disclosed will be agreed with the Wessex DAC and at a minimum will include the committee's Terms of Reference, meeting agendas, and minutes of meetings, including decisions. Details of approved requests will be published in due course on the Data Use Register (DUR). Personal or sensitive details (such as researcher identities or proprietary methodologies) may be omitted if necessary for confidentiality or security, but the public will be able to see a clear description of decision-making and the types of projects that are being enabled through the SDE. This disclosure demonstrates that an independent governance body is reviewing requests and only allowing data uses that meet strict criteria.
4. **Data Use Register (DUR):** We will maintain a public Data Use Register of all approved data uses through the Wessex SDE. The register will list each approved project, including the project name, a plain-language summary, unique project identifier, the contracting organisation (trading and legal names), relevant website links for further information, the date of the countersigned Data Sharing Agreement (DSA) or Data Access Agreement (DAA), and the duration of the agreement. Each entry in the Data Use Register will be published or updated within **8 weeks** of data access approval, meeting the timeframe recommended by national transparency standards. The level of detail shared in the DUR entry may be subject to commercial and IP considerations in line with HRA guidance. Maintaining this register enables patients and the public to "see and feel confident in how patient data is being used" through the SDE. It is a key accountability tool and will be accessible via our website (and, if applicable, the HDR UK Innovation Gateway).
5. **Research and Case Studies Web Pages:** We will maintain dedicated research pages on our website up to date. These pages will include case studies highlighting research projects conducted within the SDE and explaining their outcomes or benefits to patients and society. They will also provide resources for researchers (such as information on how to apply to use the SDE, guidance documents, and points of contact for support). Keeping this information current ensures that both the public and the research community have insight into what the SDE is enabling and how to engage with it. Success stories and case studies will be written for a general audience to clearly illustrate the public value derived from the SDE.
6. **Updates to External Platforms:** In addition to our own website, we will update information on external platforms such as the Health Data Research UK (HDR UK) Gateway and relevant NHS England websites (or other relevant platforms developed as the NHS Research SDE Network develops). This includes maintaining up-to-date content about the Wessex SDE on national directories or data hub listings – for example, details of our services, available datasets, access procedures, and contact information. By keeping national platforms current,

we contribute to transparency on a wider scale and help interested parties find accurate information about the Wessex SDE easily.

7. **National Reporting (NHSE Memorandum of Understanding (MoU)):** We will meet all reporting requirements set by the national NHS England team under any MOU or similar agreement. This includes providing regular reports on SDE operations, usage metrics, performance against key indicators, and other governance information that the national programme requires. Where possible (and not restricted by the terms of the MOU), we will also make summaries of these reports public or incorporate key highlights into our own communications – for instance, including statistics about the number of projects supported, types of data accessed, and other aggregate performance data. Fulfilling these national reporting obligations not only ensures accountability to NHS England but also provides additional transparency to the public regarding the SDE's progress and impact.
8. **Media Relations and Communications:** Major developments, research breakthroughs, or public-interest stories emerging from the SDE will be the subject of press releases or media statements, crafted in collaboration with communications professionals to ensure accuracy and clarity. We will coordinate proactive and reactive media communications about the SDE with the University Hospital Southampton NHS Foundation Trust (UHS) communications team (as the host organisation for the Wessex SDE). Likewise, if there are media enquiries or public questions (reactive communications), we will respond openly and factually, working with the UHS press office (as host organisation for the Wessex SDE) to maintain consistency and transparency. Our aim is to promote understanding of the SDE's work and to address any public concerns transparently via the media, while aligning with the broader communications strategy of University Hospital Southampton NHS Foundation Trust.
9. **External Audits:** Should any external audits or independent reviews of the Wessex SDE's processes, security measures, or decision-making be conducted, we commit to publishing the results or a summary of those audits (subject to any operational or confidentiality constraints). For example, if an external body evaluates our compliance with data protection standards or our adherence to the SDE governance framework, we will share the findings publicly along with any actions we are taking in response. This may be done via our website or in an annual report. Publishing audit outcomes demonstrates accountability and a willingness to be scrutinised, reinforcing trust in how the SDE is managed. (If an audit report cannot be fully published due to security sensitivities, we will release as much information as possible – or an overview of the conclusions – to still provide transparency without compromising safety.)
10. **Research Outputs and Public Benefit:** We will report on the research outputs facilitated by the SDE and the resulting impact and public benefit. This may be done through an annual report or periodic impact summary published on our website. We will include information such as the number of studies completed, summaries of key findings or innovations, publications in peer-reviewed journals, and any improvements to healthcare or patient outcomes that arose from research using the SDE. By highlighting these outcomes, we demonstrate the value of allowing controlled use of health data and show the public how such data-driven research leads to tangible health and societal gains.
11. **Freedom of Information Requests:** As noted, the Wessex SDE is subject to the Freedom of Information Act 2000 (FOIA), and we will handle FOI requests in a legally compliant manner and coordination with the UHS Information Governance team. As the host organisation for the Wessex SDE, UHS has statutory responsibility for responding to FOIA requests.

Working with UHS, we will maintain procedures to efficiently log and respond to any FOI inquiries regarding the SDE, ensuring that responses are issued within statutory deadlines and in compliance with FOIA. Where appropriate, we will disclose information requested unless a specific exemption under the Act applies (for example, if releasing certain details would breach data protection laws or patient confidentiality).

We also maintain a **Publication Scheme** (a guide to information routinely published; see **Appendix 1**) in line with FOIA best practice, which means we aim to proactively publish frequently requested or significant information about the SDE so that it is readily available without the need for a formal request. In this way, we seek to uphold not just the letter of FOIA but its spirit, by being as open as possible about the SDE's operation and governance.

## 7 Roles and responsibilities

The SDE Director of Operations is responsible for adhering to the commitments in this Transparency Policy.

The SDE Senior Responsible Officer (SRO) is accountable for adherence to the commitments in this Transparency Policy.

## 8 Equality impact assessment

Equality and diversity are at the heart of Trust values. Throughout the development of the policies we give regard to the need to eliminate discrimination, harassment and victimisation, to advance equality or opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it.

The Policy & Guidance Team hold all equality impact assessments centrally. These are available upon request from [Policy&Guidance@uhs.nhs.uk](mailto:Policy&Guidance@uhs.nhs.uk)

## 9 Document review

All Trust policies will be subject to a specific minimum review period of one year; we do not expect policies to be reviewed more frequently than annually unless changes in legislation occur or new evidence becomes available. The maximum review period for policies is every three years. The author of the policy will decide an appropriate frequency of review between these boundaries.

Where a policy becomes subject to a partial review due to legislative or national guidance, but the majority of the content remains unchanged, the whole document will still need to be taken through the agreed process as described in this policy with highlighted changes.

This Wessex SDE Transparency Policy will be reviewed at least annually or whenever significant changes occur in the SDE programme or relevant legislation) to ensure it remains up-to-date and effective.

## 10 Process for monitoring compliance

The purpose of monitoring is to provide assurance that the agreed approach is being followed. This ensures that we get things right for patients, use resources well and protect our reputation. Our monitoring will therefore be proportionate, achievable and deal with specifics that can be assessed or measured.

Key aspects of this policy will be monitored:

Element to be monitored	All
Lead (name/job title)	Director of Operations
Tool	Website and PPIE activity
Frequency	Monthly
Reporting arrangements	Status report to Board and SLT

Where monitoring identifies deficiencies actions plans will be developed to address them.

## 11 Appendices

### 11.1 Appendix 1: Publication Scheme

The table below summarises the Wessex SDE's commitments to publish information about its activities and operations.

Category	Information Published	Frequency / Timeframe	Where Published
<b>Annual Report</b>	Share operational and financial performance and results in our annual report, or sooner wherever possible.	Annual	Wessex SDE website
<b>Complaints and redress</b>	Publish explicit signposting of complaint and redress routes clearly on the SDE website.	By Q4 2025, with annual updates as required	Wessex SDE website
<b>Data Access Committee (DAC)</b>	Terms of Reference, meeting agendas, minutes, DAC decisions (anonymised as needed)	Published following each DAC meeting	Wessex SDE website
<b>Data Use Register (DUR)</b>	Completed for all projects that use the SDE. It will include: project name, lay summary, unique identifier, contracting organisation details, relevant website links, date of countersigned agreement, duration of agreement	Within 8 weeks of approval	Wessex SDE website; HDR UK Gateway (if applicable)
<b>Incident Reporting</b>	Capture, review, and communicate learnings from security incidents, near-misses, and challenges, sharing anonymised summaries regularly with stakeholders.	Ad-hoc as required, at least annually if applicable	Wessex SDE website, where appropriate
<b>Internal and External Audits</b>	Results or summaries of audits / reviews; actions taken in response	Upon completion of audits; at least annually if applicable	Wessex SDE website
<b>External Platforms</b>	Services, datasets, access procedures, contacts; updates to national directories/platforms	Regularly updated; at least annually	HDR UK Gateway, NHS England websites
<b>Freedom of Information Requests</b>	Routinely requested or significant information; handled via FOI procedures with UHS	Ongoing basis; proactive publication where appropriate	Wessex SDE website where appropriate, e.g. FAQ
<b>Media and Communications</b>	Press releases, statements on major developments, research	Ongoing basis; responsive to events	Media; Wessex SDE website



	breakthroughs, public-interest stories		
<b>National Reporting</b>	Operational reports, usage metrics, performance indicators required by NHS England; public summaries / highlights published proactively where appropriate	As required by national NHS England reporting agreements	Wessex SDE website
<b>Patient and Public Involvement</b>	Summaries of feedback, recommendations from patient / public representatives; responses / actions taken by SDE	Regularly updated; at least annually	Wessex SDE website
<b>Policy Documents</b>	Core SDE policies where appropriate (e.g., data privacy, security, access); summaries of technical / internal policies if highly technical.	Updated as required	Wessex SDE website
<b>Research Outputs and Impact</b>	Number of studies completed, key findings, innovations, peer-reviewed publications, healthcare improvements from research, and case studies	Regular updates; at least annually	Wessex SDE website

## 12 References

None