Wessex SDE: How We Have Responded to Public and Patient Feedback

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Status Code	Status Description	Explanation
1	Critical Failure	No action taken; significant risk or stakeholder dissatisfaction.
2	Failure	Acknowledged but inadequately addressed; ongoing concerns.
3	Partially Implemented	Action initiated but incomplete; further steps needed.
4	Implemented	Successfully addressed; meets expectations.
X	Not Adopted (Justified)	Deliberate decision not to implement, with documented rationale.

#	PPIE Activity	Recommendation	Detail	Response	Status	Closed	Justifcation
1	SHG	Developing a set of values-led principles for the SDE	Formally adopt and integrate clear, values-led principles into the SDE governance framework and decision-making processes, ensuring regular review and updates informed by ongoing community engagement. This ensures the SDE remains aligned with community expectations, and works within acceptable 'guard rails' that shape SDE culture, guide how the organisation operates, and informs decision-making. These should be published to support public trust.	The SDE has adopted "Core Values" Codesigned by the Wessex Public Panel on NHS Data. These are published on the SDE website and form part of the Terms of Reference for the Wessex DAC.	4	Yes	N/A
2	SHG	Bringing the Wessex SDE to life	Develop detailed, relatable, and engaging public-facing case studies showcasing the potential benefits of the SDE across diverse medical and community contexts. This makes the benefits tangible and relatable to a wide range of people, thereby increasing public understanding and support for the SDE. Younger groups, in particular, were interested in the future possibilities for areas such as diagnostics and genomics.	SDE has developed and actively promoted public-facing case studies as part of the 'Improving Tomorrow's Health' campaign to effectively communicate SDE research use cases and outcomes.	4	Ongoing	
3	SHG	Creating a positive feedback loop	Establish and maintain an ongoing and transparent feedback mechanism that clearly communicates research outcomes and community benefits to stakeholders regularly. Regular communication reinforces transparency and trust, showing communities that their contributions have real, measurable impacts.	Feedback to HIOW SHG groups is complete and feedback via the Improving Tomorrow's Health campaign has reached over 0.5M people.	4	Ongoing	
4	SHG	Addressing accessibility and inclusion needs	Ensure all communication and engagement materials are accessible and inclusive, specifically tailored for groups with lower digital literacy, cognitive impairments, and literacy challenges, providing targeted support. This approach ensures equitable participation, enabling diverse communities to fully engage with and benefit from the SDE.	Easy Read materials were produced as part of the SHG programme; the SDE website is fully accessible.	4	Ongoing	

5	SHG	Using breadth and creativity in communications	Adopt a varied and innovative communication strategy employing multiple channels and creative methods to effectively reach and engage diverse community groups. Diversifying communication methods ensures maximum reach and effectiveness, particularly among groups not easily accessed through traditional NHS communication methods.	The SDE's 'Improving Tomorrow's Health' campaign used a wide range of channels and content including: websites, newspapers, radio, social media, leaflets and posters, and community magazines, as well as via NHS channels.	4	Ongoing
6	SHG	Working through trusted messengers	DCFs keen to enage with all areas of the SDE development and governance arrangements, particularly with regards to oversight and decision making.	The design of the SDE's 'Improving Tomorrow's Health' campaign was directly influenced by the the insights from seldom heard groups: e.g. patient, public and VCSE advocates and a grassroots-driven communications campaign.	4	Ongoing
7	SHG	Acknowledging peer influence	Proactively leverage peer influence by training and empowering SDE public participants to act as community ambassadors, enhancing local understanding and acceptance of the SDE. Peer-to-peer communication is highly influential and effective in overcoming barriers related to trust and engagement, especially in sceptical communities.	Public participants recruited to become Digital Critical Frends (DCFs) to the Wessex SDE. Provided 4x training and onboarding sessions to allow them to contribute theor lived experience and present a public voice within the SDE programme. Additional DCFs recruited following the Public Panel to address gaps in representation. Public participants were actively involved in the SDE's 'Improving Tomorrow's Health' campaign.	4	Ongoing
8	DCF Website Pre-launch Review	Addressing accessibility and inclusion needs in creation of SDE website	DCFs provided feedback on approach, copy, and content of the website. Key themes emerging from this feedback were: accessibility, ease of navigation; priority of materials presented, tone and laungauge, and evidence of delivery. These varied from high level strategic suggestions to specific edits. A full record of these comments was made.	July 2024: Website comments log created with feedback from all public and internal stakeholders. Details captured on what changes were made and implemented as a result, plus explanation of what wasn't adopted and why. January 2026: External accessibility review completed by Blackspike (www.blackspike.com), confirming conformance with WCAG 2.2 Level AA across the site and alignment with the NHS Accessibility Checklist. We have adopted the NHS Accessible Information Standard and use it to guide how we identify and respond to the information and communication needs of users.	4	Yes
9	DCF PP Co-design	DCF input to design and delivery of Public Panel	Use insights from the SHG work completed and support of the DCF Group to help define the scope of the Public Panel and support its delivery.	Group work with all DCFs to review plans for the public panel. Recruitment of 4x DCFs to present at the first event and share their experience. 1x DCF to act as a facilitator. All DCFs invited to join the final full day session to support the final capture of outcomes and hear feedback first hand from the public panel. All DCFs completed a desktop review of the PP Report and findings to confirm alignment with what they heard. 1x DCF provided foreword to the report to share their experience and thoughts	4	Yes

10	DCF PP Co-design	Broaden representativeness of the Digital Critical Friend group	Consider the recruitment of additonal DCFs following the Public Panel to ensure that the group is repreesentative of the make up of Wessex	4x new DCFs recruited to join the DCF group with a focus on younger representation and under-respresented demographics	4	Yes	
11	DCF PP Co-design	Public members integrated into SDE Governance	DCFs keen to enage with all areas of the SDE development and governance arrangements, particularly with regards to oversight and decision making.	2x DCFs recruited through application to the Wessex SDE Programme Board. 4 DCFs engaged on the Wessex Data Access Committee (DAC). Members are supported with pre-meets to review the documentation, discuss any gaps in knowledge or understanding of what is being presented, and to air initial questions or concerns before the meeting ensuring they are comfortable to raise challenge. DCFs also actively engaged in other working groups to support operational delivery of the SDE	4	Yes	
12	Public Panel: Strategic	Strategic priorities for SDE research	Formally adopt and implement the 'Strategic Research Priorities' identified by the Public Panel as explicit decision-making criteria within the SDE framework. Clearly defined research priorities ensure alignment with public expectations and enhance accountability and strategic coherence within the SDE.	Adopted as part of the Wessex DAC Terms of Reference.	4	Yes	
13	Public Panel: Strategic	Core values for SDE	Formally integrate and adopt the 'Core Values' identified by the Public Panel as guiding principles across all SDE Programme, Operations, and DAC team activities. Embedding clear core values supports consistent, ethical decision-making and helps build enduring trust among stakeholders and the wider community.	Core Values' are embedded in the Wessex DAC Terms of Reference.	4	Yes	
14	Public Panel: Strategic	Transparency policy	Establish a formal transparency policy detailing public reporting requirements, including, for example, regular publication of SDE accounts, Data Access Committee (DAC) decisions, and annual reports. This responds directly to public demands for openness and accountability in SDE operations, ensuring consistent public oversight and trust.	Transparency Policy is being reviewed by Digital Critical Friends to ensure that it meets public expectations.	4	Yes	
15	Public Panel: Strategic	Independent audit	Implement an independent audit or externally accountable scrutiny process for ongoing review of the SDE's operational compliance with legal standards, ethical guidelines, and public expectations. Regular external audits address a number of direct requests as well as wider public concerns about potential conflicts of interest, commercial partner involvement, delivery of public benefits, and enhances transparency and credibility.	NHS England, DHSC, Kerv and ISO 27001 audits all demonstrate a commitment to external audit. We are also committed to publish and annual report, including information about audits	4	Ongoing	

16	Public Panel: Strategic	Equalities Impact Assessment	Carry out a comprehensive Equalities Impact Assessment (EqIA) covering all aspects of the SDE programme including DAC composition, decision-making processes, and public involvement mechanisms. This ensures fairness, equity, and inclusivity, addressing public concerns about representation and equal access to benefits.	EqIA has been reviewed by Digital Critical Friends to ensure that it meets public expectations and formally adopted by the SDE	4	Yes	
17	Public Panel: Strategic	Local and national opt-out options	Develop and actively promote a clear, accessible local opt-out option alongside the national opt-out, supported by transparent, balanced communication about data use risks and benefits. This meets NHS HRA commitments and ensures that individuals' data choices are respected, addressing public concerns around autonomy and informed consent.	Local Opt-Out (LOO) and Patient Notification (PN) information have been published on the SDE website and communicated to all partners.	4	Yes	
18	Public Panel: Strategic	DAC decision-making co-design	Engage public representatives directly in the co-design process for the DAC decision-making framework, clearly defining criteria, governance roles, and transparency mechanisms. This collaborative approach ensures that DAC processes reflect public priorities and enhance legitimacy and trust.	Four DCFs are involved as public members of the Wessex DAC. The Wessex DAC TOR was also subject to DCF scrutiny.	4	Ongoing	
19	Public Panel: Strategic	Public voice in DAC	Actively co-design the public representation component within the DAC to ensure effective inclusion and meaningful representation of seldom-heard groups. This approach addresses public concerns around equity and inclusivity, ensuring DAC decisions represent the full diversity of the community.	As above. One of the DCFs included on the DAC initially came through our SHG engagement work.	3	Ongoing	Direct involvement of SHGs in the DAC is not practical and will not be taken forward. However the Wessex DAC should consider outreach activities to meet the spirit of this recommendation and ensure that it is assessed as part of future EqIA updates.
20	Public Panel: Strategic	Commercial model co-design	Engage public participants in co-designing the SDE's commercial model, explicitly defining principles for financial transparency, pricing strategies, and equitable benefit-sharing. Regular financial reviews and public reporting ensure the commercial approach aligns transparently with public interests and NHS values.	The SDE recognises the importance of transparency in relation to the use of public funds. The service operates within the parameters set by the NHS Research SDE Network, which shapes and significantly limits the scope for local discretion; public contributors can shape the commercial model is communicated to the public . To support transparency and public accountability, the SDE will include a clear statement on how it delivers value to the NHS and to the public within its Annual Report.	3	Action required	The SDE recognises the recommendation made by the Digital Critical Friends regarding greater direct influence over financial decisions. However, the operating and funding model is set within the framework of the NHS Research SDE Network, which limits the scope for local variation or direct amendment. Within these parameters, the SDE will strengthen transparency by setting out clearly how it delivers value to the NHS and to the public in its Annual Report. Action: Complete Annual Report by end March 2026.
21	Public Panel: Detail	Transparent Public Feedback	Have public accountability mechanisms – so people can give feedback, express concerns, and get their questions answered.	The SDE has established a point of contact and communications handling protocol. The SDEs transparency policy sets out further how it will make itself accountable.	4	Yes	

22	Public Panel: Detail	Regular Standards Compliance Audits	Have regular external audits and internal reviews – focusing on goals, legal standards, best practice, and public expectations.	See Recommendation #15 above.	4	Ongoing	
23	Public Panel: Detail	Track Population Health & NHS Savings Impacts	Measure its performance in delivering good value in terms of population health benefits and long-term NHS efficiency savings.	Participants asked the SDE to track and report its impact on population health outcomes and long term NHS efficiency savings. This work is underway and will be progressed through three linked strands. The SDE is developing a value return framework to set out how value is returned to data controllers, including NHS Trusts and General Practitioners across Wessex. In parallel, NHS England is developing a national benefits realisation framework that will define how SDEs measure benefits to patients, the public and the NHS; the SDE will adopt this framework once finalised to ensure alignment with national requirements. In addition, the SDE will report progress, both qualitatively and quantitatively where feasible, in its Annual Report, including case studies to illustrate impact in practice.	2	Action required	This work is in development. Further detail will be published in due course and reported through the Annual Report.
24	Public Panel: Detail	Strict Re-identification Rules	Only allow re-identification of individuals when it delivers clear health benefits, under strict NHS oversight, and with involvement of the patient's clinical care team.	Fully covered by existing legal protections, and implemented in SDE governance, and operating procedures.	4	Ongoing	
25	Public Panel: Detail	Clear Industry Benefit Balance	Ensure industry benefits are made clear and are proportionate to the public health and NHS gains they help deliver.	See Recommendations #20 and #23 above.	4	Ongoing	
26	Public Panel: Detail	Manage Staff Conflicts Transparently	Avoid staff holding multiple roles in the SDE where possible (e.g. sitting on DAC and providing consultancy). Staff must declare conflicts of interest and step back from related decisions.	Covered by host organisation (UHS) policies. The SDE is committed to ensuring that where staff are required to hold multiple roles and functions that these are regularly reviewed to minimise conflicts of interest. As appropriate and proportional to the possible risks all staff are required to highlight potential conflicts of interest and follow UHS policy and best practice.	3	Ongoing	The SDE is subject to the policies and operational guidance of UHS as the host organisation. Resourcing levels and requirements also require members of the SDE to hold multiple roles and positions for efficiency.
27	Public Panel: Detail	Diverse DAC Membership	Ensure the Data Access Committee (DAC) has a diverse mix of backgrounds, skills, and experience – including ¼ to ¾ public members.	Achieved by current DAC membership.	4	Yes	
28	Public Panel: Detail	Clear Opt-Out Choices	Give clear options for opting out without influencing people's decisions - Explain the risks (E.G. nothing is 100% secure) and the real benefits the SDE could bring.	Local Opt-Out (LOO) and Patient Notification (PN) information have been published on the SDE website and communicated to all partners.	4	Yes	
29	Public Panel: Detail	Jargon-Free SDE Summaries	Publish clear, jargon-free summaries of the SDE's operations – focusing on its management, decision-making, and data-handling.	The current website provides accessible and public participant -reviewed content. SDE Governance framework is clearly defined on SDE website, including outlining decision-making processes and ensuring transparency about operational procedures	4	Ongoing	
30	Public Panel: Detail	Fair Commercial Partnership Terms	Make sure that it gets a fair deal from commercial partnerships – e.g. a share of future profits or intellectual property.	SDE commercial model has been developed with this as a priority. See Recommendation #16 above	4	Ongoing	

31	Public Panel: Detail	Highlight Tangible Public Gains	Promote tangible public benefits – who benefited and how, financial returns, shorter waiting times, or other efficiencies.	The Wessex Sde's Data Use Register and it's 'Improving Tomorrow's Health' campaign have both covered this recommendation. SDE will continue to promote public benefits through ad hoc case studies media relations, outreach, and an annual report.	4	Ongoing	
32	Public Panel: Detail	Strong Data Access Protections	Set clear rules and protections on data access – e.g. strong contracts, penalties for misuse, and restriction of data re-use.	Fully covered by SDE governance and SOPs, with the exception of penalties; transparency on penalties was a priority for Public participants.	3	Ongoing	Penalties for misuse of data are explictly owned and managed by the national guidance and direction on this topic. Wessex inputs into these discussions at a national level.
33	Public Panel: Detail	Explain Data De-identification Clearly	Explain de-identification of data – what data researchers can see and what they can't, so people can make informed choices.	SDE has provided clear online explanations or references (such as ICO guidance) regarding data pseudonymisation, anonymisation, and de-identification processes used within the SDE.	4	Yes	
34	Public Panel: Detail	Clear Data Retention Policies	Have clear guidelines on data retention, secure archiving, and deletion – researchers lose access once a project is finished.	This work is in progress and is being developed by the Wessex SDE Operations team as part of the technical operating model. Once finalised, the Communications and PPIE function will publish an appropriate level of detail on the website setting out guidelines and procedures for data retention, secure archiving and deletion following the conclusion of research projects, subject to security requirements.	3	Action required	This is currently being developed as part of the Wessex SDE technical operating model and will be published once finalised, subject to security requirements.
35	Public Panel: Detail	Rigorous Data Quality Checks	Ensure data given to researchers is checked for quality to avoid errors that could harm patient care or research outcomes.	Fully covered by SDE governance, SOPs, And working practices.	4	Ongoing	
36	Public Panel: Detail	Minimal Data Access Principle	Ensure researchers can only see de-identified data, and only the minimum required to meet the needs of the approved project.	Fully covered by SDE governance, SOPs, and working practices.	4	Ongoing	
37	Public Panel: Detail	Embed Public in Governance	Embed public voices in design and governance, ensure their choices shape policy & outcomes - and are treated equally to experts.	Digital Critical Friends group is embedded in all aspects of Programme governance, including the programme board and working groups.	4	Ongoing	
38	Public Panel: Detail	Oversight for Sensitive Data	Ensure more oversight of projects using data deemed 'sensitive' or 'risky' by the NHS or the Wessex public.	All projects are independently reviewed by the Wessex Data Access Committee before access is granted. The Committee assesses public benefit, proportionality and sensitivity, and can require additional safeguards where needed. The SDE operates a risk-based model. Projects involving more sensitive data or novel use cases can be subject to enhanced scrutiny and additional operational controls, including separation of duties, audit checks and strengthened monitoring. The current control framework is proportionate to the nature of the data and use cases being supported. Where higher-risk or more sensitive use cases arise, the SDE will introduce additional safeguards as required. At present, the Data Access Committee has not identified a need for controls beyond those already in place.	3	Yes	The current governance and technical controls are proportionate to the risk profile of the projects we are supporting, and the Data Access Committee retains the authority to require additional safeguards if and when higher-risk or more sensitive use cases arise.

39	Public Panel: Detail	Publish Financial Transparency	Publish the SDE's income and spending clearly so the public can see the costs, since it is run by the NHS with public money.	SDE is commited to publish comprehensive financial transparency reports annually, clearly detailing SDE income, expenditures, and financial performance.	4	Ongoing	
40	Public Panel: Detail	Audit Real-World Research Impact	Carry out regular audits of the outcomes and benefits achieved – both in health and other areas – at least once a year.	SDE currently meets this through MI reporting to NHSE. SDE is committed to develop an annual impact reporting process clearly documenting the real-world health and research impacts of SDE activities, aligned with best practice standards, for example is part of an annual report.	4	Ongoing	
41	Public Panel: Detail	Proven Security Standards	Use proven technologies & meet national standards, NHS best practices, and SDE Network rules to ensure security & patient privacy.	See Recommendation #15 above. We have a proven platform provider and technology, and full implementation has been verified. DCF's have also been satisfied as part of their SDE Policy Review scrutiny activity.	4	Yes	
42	Public Panel: Detail	Equitable Community Benefits	Ensure equity and fairness - benefits are shared across all groups, including under-represented and vulnerable communities.	See Recommendation #16 above.	4	Ongoing	
43	Public Panel: Detail	Assess Research Public Impact	Measure public benefit by looking at how much research can improve both health and quality of life for people in Wessex.	A Required fields in the Data Access Request Form (DARF) and is part of the SDE Operations Pre-Check and Wessex DAC decision making process (inc. the latter's Terms of Reference). Reporting is incorporate reporting on this into our annual report.	4	Ongoing	
44	Public Panel: Detail	Public Research Transparency	Provide a public list of all research applications and projects, detailing data usage, researchers involved, and the intended outcomes.	Covered by the SDE Data Use Register.	4	Ongoing	
45	Public Panel: Detail	Maximise Community-wide Benefits	Focus on research that helps as many people as possible, benefiting the whole community rather than just individuals.	The Wessex SDE has embedded community-wide benefit as one of its Strategic Research Criteria, applied throughout the approval process. Each application is assessed by the Data Access Committee against its likely public and population-level benefit, alongside other governance and scientific considerations. Delivered benefits are evidenced through published research outputs, case studies and the SDE Annual Report. The SDE supports a broad range of health research, and not every study will deliver benefit at scale. However, all approved projects must demonstrate a clear public benefit and alignment with NHS priorities. Within this remit, the SDE seeks to maximise overall community-wide impact while maintaining support for clinically important and innovative research.	3	Yes	The SDE supports a balanced research portfolio, and while maximising community-wide benefit is a guiding criterion, not every clinically valuable or innovative study will deliver population-scale impact on its own.
46	Public Panel: Detail	Ongoing Data Access Reporting	Have continuous monitoring, regular audits, and public reporting of data access and usage by approved researchers	See Recommendation #44 above. SDE also has live monitoring of researchers in the SDE and safeguards to protect against misuse. Information is published on how this works, as part of the annual report and on the SDE website	4	Ongoing	
47	Public Panel: Detail	Research Cost-Benefit Analysis	Ensure research proposals undergo cost-benefit analysis, so the SDE's full project portfolio gives more to the NHS than it takes.	See Recommendation #30 above.	4	Ongoing	

48	Public Panel: Detail	Value Lived Experience Insights	Value insights from people with lived experience – public representatives should reflect Wessex's diversity to reduce bias.	See Recommendation #37 above.	4	Ongoing	
49	Public Panel: Detail	Focus on SDE Strengths	Maximise public benefits by focusing on projects where our SDE adds most value, referring others to better-suited SDEs.	The Wessex SDE is working on a number of 'Driver projects' with funding from NHS England to develop national resources and insights based on our local knowledge and skills bases around Pre-hospital care, Cancer, and Dementia. We are similarly collaborating on other Driver Projects where another SDE is acting as lead. We will continue to update the public about the progress of these and future projects through our website and enaggement work.	4	Ongoing	
50	Public Panel: Detail	Leverage Private Sector Skills	Actively use private sector skills, resources, and funding to boost research – with a laser focus on real health & NHS benefits.	The SDE uses a number of private sector consultants and regularly engages with commercial stakeholders to ensure that their perspectives are reflected. This is profiled on the SDE website.	4	Ongoing	
51	Public Panel: Detail	Public Data Education Plan	Have an education plan about data-driven research to help the public make informed decisions about their health and data.	Education and information provision has been a central part of the SDE's work engaging with Selden heard groups, the deliberative dialogue process, and its 'Improving Tomorrow's Health' campaign. **SDE has** an ongoing commitment to establish and implement a comprehensive public education plan focused on data-driven research, leveraging science communication best practices.	4	Ongoing	
52	Public Panel: Detail	Explain Security Measures Clearly	Clearly explain its data security measures, updates on breaches or near-misses, and the steps taken to address them.	There are clear limits on what it is sensible to publish to ensure that this does not open the SDE up to security threats. To the extent that the SDE agrees with this approach which is covered by the transparency policy.	3	Ongoing	Ongoing development and implementation of a detailed critical incident management and crisis communication plan to transparently manage and communicate any security breaches or near-misses.
53	Public Panel: DAC & Transparency	Pre-application transparency	Transparency around types of applicants and projects applying use the SDE (e.g., NHS versus commercial), alongside proactive public engagement opportunities. This ensures early transparency, building public trust and enabling meaningful community input and oversight.	See Recommendation #44 above.	4	Ongoing	
54	Public Panel: DAC & Transparency	Technical review transparency	Ensure clearly defined roles and public visibility in the technical review (i.e., SDE Operations Pre-Check) stage, explicitly avoiding any role duplication to eliminate conflicts of interest. Clear, publicly documented roles ensure impartiality, safeguard integrity, and maintain public confidence in the fairness of the review process.	See Recommendation #26 above.	4	Ongoing	
55	Public Panel: DAC & Transparency	DAC decision-making transparency	Regularly publish detailed information about DAC composition, clearly stating member identities, roles, backgrounds, and impartiality assurances. Publicly accessible profiles enhance transparency, foster accountability, and reassure the public about fairness and representation in the decision-making process.	Covered by Transparent Policy. SDE has created and published detailed DAC member profiles on the website, clearly stating member composition and ensuring transparency regarding impartiality. Minutes from DAC meetings are also published on website.	4	Ongoing	

56	Public Panel: DAC & Transparency	Projects and outcomes transparency	Provide public reporting on all approved projects, including selection criteria, costs, measurable outcomes, and project effectiveness, supported by robust record-keeping. Detailed transparency on project operations and results demonstrates accountability and clearly evidences the public value delivered by the SDE.	See Recommendations #31 and #40. This is covered by the SDE's Data Use Register and public communication activities.	4	Ongoing	Establish and implement a structured impact reporting system for the DAC covering all approved SDE projects, clearly communicating outcomes and benefits. Outcomes could be published in an annual report .
57	Public Panel and DCF	Public members integrated into SDE Governance - Data Access Committee (DAC)	Public panel keen to have public representation on the SDE DAC and recognised the value of this being done by DCFs to reduce addition training and onboarding time. DCFs keen to enage with all areas of the SDE development and governance arrangements, particularly with regards to oversight and decision making.	4x DCFs recruited through application and interview to the Wessex SDE DAC alongside 6x professional members. The DAC members have been trained to understand the full research and application journey from application through to outputs and impact. Using test cases and study examples they are developing and testing the decision making processes required by the SDE. Additonal aspects of decision making continue to also be tested with the full DCF Group to ensure that it is fair and representative of the public opinion in Wessex	4	Ongoing	
58	DCF Policy Review	Using surveys to monitor culture and diversity	Regularly (ideally at least annually) use stakeholder surveys (including public representatives and Digital Critical Friends) to check if openness, honesty, and inclusivity are embedded in everyday work practices.	A full annual stakeholder culture and diversity survey was identified as a potential work package for 2025–26 but has not yet been implemented due to capacity constraints. As a first step, we will undertake a structured survey of Digital Critical Friends this year to assess openness, honesty and inclusivity in practice. We will use the findings to inform whether a broader stakeholder survey should be introduced in future years.	2	Action required	Complete Digital Critical Friend survey within 2025-26 year.
59	DCF Policy Review	Transparent incident reporting	Establish a clear policy and robust process by 2026 to capture, review, and communicate learnings from security incidents, near-misses, and challenges, sharing anonymised summaries regularly with stakeholders.	Commitment delivered in SDE Transparency Policy; this is supported by the SDE's indicident management policy but this document is not shared publicly for security reasons.	4	Yes	
60	DCF Policy Review	Clear governance structures	Publish and regularly update an organisational chart and share at least internally with Digital Critical Friends a clear scheme of delegation (or equivalent) detailing roles, responsibilities, and decision-making authorities.	Operations Director has delegation from SDE Board and is currently developing the Operational Organisational structure for the SDE. This is an ongoing process and will be shared with DCFs via Town Hall. Operational governance is explained on the SDE website, including Terms of Reference for each of the key operational boards.	4	Yes	
61	DCF Policy Review	Clear lines of accountability	Clearly communicate to stakeholders via the SDE website how the SDE is held accountable, providing named points of contact for queries or concerns where possible.	SDE Comms and PPIE team has completed a refresh of the SDE website to ensure that it provides the ability for the public to a) quickly access and view key information about the SDE, b) provided tiered information to 'scratch the surface' including signposting to accountability and redress measures	4	Yes	

62	DCF Policy Review	Transparent decision-making processes	Develop and publish clear, detailed decision-making process maps or frameworks covering Pre-Check, Data Access Committee decisions, approvals, appeals, and precedent setting, with annual reviews involving public input, by Q2 2026 or as these policies and procedures develop. Ideally provide worked examples to make these easy to understand.	The SDE's Equalities Impact Assessment Policy specifically addresses key commitments in relation to the decision making of the DAC and wider SDE governance to ensure that we are not only transparent but also proactively consider the potential impact of the SDE. The policy also includes specific requirements around the composition of DAC membership, decisions, approvals, appeals and precedent. December 2025: Fully addressed in SDE website re-fresh.	4		
63	DCF Policy Review	Structured Transparency Portal	Develop and implement a tiered transparency framework by Q1 2026, offering tiered information (from plain-English summaries to detailed reports and organograms) to suit different levels of public interest and engagement.	SDE Comms and PPIE team has completed a refresh of the SDE website to ensure that it provides the ability for the public to a) quickly access and view key information about the SDE, b) provided tiered information to 'scratch the surface' including signposting to accountability and redress measures Fully addressed in SDE website re-fresh.	4		
64	DCF Policy Review	Accessible and inclusive communications	Provide clearly accessible, easy-read, and non-digital communication materials on key SDE policies and processes through patient notification materials and on the SDE website (such as opt-out options and routes for raising concerns) by Q1 2026.	The Wessex SDE is in the process of updating our Public and Patient Notification Materials. This will include easy read versions of key documents in line with the NHS Accessible Information Standards	2	Action required	Public notification materials update to be completed covering this action.
65	DCF Policy Review	Equality and representation	Complete an annual review of the DCF group to identify possible changes and potential recruitment of new DCF members to meet the needs of the SDE and reflects the local demographics.	The SDE has committed in it's EqIA Policy to complete annual reviews of othe DCF membership to ensure that it is reflective of local demographics and diversity. January 2026: The SDE has committed to a further round of recruitment as part of engagment with minority and under-represented groups in Dorset planned for Q1 2026.	3	Action required	Further DCF recruitment as part of the seldom heard groups engagment Programme commissioned from Bournemouth University's PIER Partnership in Q1 2026
66	DCF Policy Review	Regular updates for Digital Critical Friends	Provide quarterly updates specifically to Digital Critical Friends on project pipeline and active research, policy changes, outcomes, and emerging issues, starting by Q1 2026.	SDE provides regular updates via the DCF meetings to review pipeline, key projects and other activities of the SDE. Commitment is captured in DCF Work Plans for 2025-26. Quarterly updates will be provided by SDE Director of Operations	3	Action required	Director of Operations to provide quarterly updates at DCF Town Hall meetings.
67	DCF Policy Review	Regular and timely updates to website and public comms	1. Share operational results and performance in our annual report, or sooner wherever possible. 2. Provide regular updates to our website and Data Use Register to ensure that the Wessex public have visibility of all live projects using the SDE in no more than 8 weeks from the researchers accessing data. 3. Ensure that key information is provided through regular website reviews and policy updates.	1. Commitment to Annual Report captured in WSDE Transparency Policy 2. DUR regularly updated on WSDE with new projects 3. Commitment to Annual Report captured in WSDE Transparency Policy	4	Ongoing	

68	DCF Policy Review	User and organisation validation	Clearly publish on the SDE website transparent user and organisational validation processes aligned to SDE Network policy once these are agreed internally, ensuring that implementation (including roles and responsibilities) is captured in relevant Standard Operating Procedures.	SDE follows national guidance from SDE Network in relation to the checks and approvals required for User and Organisation validation. Process is outlined in the Researcher Toolkit and will be made publicly availbable once approved. Longer term the SDE Network will be moving towards a centralised approval process to reduce complexity and duplication. Information about this will be shared in line with NHSE guidance.	3	Action required	Researcher toolkit to be made available on website once approved. Future updates on the national position on organisation and user validation will follow SDE Network guidance.
69	DCF Policy Review	Security and oversight controls	Show clearly to DCF members how the SDE is making sure two people oversee all important administrative tasks, and confirm that thorough background checks (like enhanced DBS) have been completed for everyone who has system administrator access.	The Wessex SDE operates within the governance and information security frameworks of University Hospital Southampton NHS Foundation Trust, and staff with privileged access are subject to appropriate NHS employment and information governance requirements. Contracted partners are bound by formal agreements and NHS security standards. Responsibilities are separated across project approval, data preparation and technical administration, providing layered oversight at key stages. A formal dual sign-off requirement for all administrative actions has not been adopted, as existing controls are considered proportionate to current activity.	X	Yes	Additional controls have not been introduced because the current layered governance and security arrangements are proportionate to the risk profile of the SDE's existing activities.
70	DCF Policy Review	Network security assurance	Explain to DCF members exactly how data moving between researchers' computers and the SDE is protected from being intercepted or accessed without permission.	Process was explained during the DCF policy review snd DCFs were satisifed with the explanation. Details are not provided more widely to ensure that it does not create a potential vulnerability in line with our ISO27001 commitments	4	Yes	
71	DCF Policy Review	Physical data access environment controls	Operations team to consider extra ways – like legal agreements or practical safeguards (e.g., webcam monitoring, limiting access to specific locations or countries, or restricting access hours) – to clearly define and control where and how researchers can access data.	Researchers access data within a secure, controlled technical environment that operates under NHS security standards and contractual restrictions. The SDE does not currently apply additional physical monitoring controls, such as webcam recording or location-based access limits, as these have not been required for the current risk profile of approved projects. The SDE retains the ability to introduce enhanced safeguards should higher-risk use cases arise.	X	Yes	Enhanced physical access controls have not been introduced because current projects do not present a level of risk that would justify more intrusive measures.
72	DCF Policy Review	Technical skills and technology risks	Clearly identify, measure, and report the risks around recruiting and keeping skilled technical staff, dealing with technology becoming outdated, and maintaining good long-term relationships with suppliers – proportionate to the SDE's current maturity level.	The SDE has a contractual relationship with the Clinical Informatics and Research Unit (CIRU) at University of Southampton (UoS) to deliver the technical delivery of the SDE. The responisbility for recutment and retaining of skilled staff is therefore contractually passed to UoS and CIRU. The SDE continually audits CIRU's performance against the agreed Key Performance Indicators to ensure that skilled staff are retained in key positions and that the service agreement has been fulfilled.	X	Yes	This is a commercial position agreed between the SDE and our Technical delivery partner, CIRU, and is montiored and managed on a commercial basis.

73	DCF Policy Review	Quality Assurance	Provide regular updates that independent checks and assessments have been made on all aspects of information security to ensure that the agreed policies and processes are being followed and are working effectively.	The SDE's technical environment is internationally accredited to ISO27001 standards. This is audited on an annual baiss by ISO. Updates regarding relevant audits and assurances are shared on the governance pages of the SDE website in line with our Transparency commitments	4	Ongoing	
74	DCF Policy Review	Accessibility of accountability process	Enhance the accessibility and transparency of the routes to redress.	SDE Comms and PPIE team has completed a refresh of the SDE website to ensure that it provides the ability for the public to a) quickly access and view key information about the SDE, b) provided tiered information to 'scratch the surface' including signposting to accountability and redress measures	4	Yes	
75	DCF Policy Review	Document ownership and management	Establish a robust document ownership and management system detailing authorship, approval, and review dates prominently on policy documents.	SDE has adopted UHS protocols and templates for all SDE Policies which includes the information requested in the review	4	Yes	
76	DCF Policy Review	Literacy levels in comms	Tailor all communications to average literacy levels to ensure accessibility and clear understanding across diverse community groups.	SDE Comms and PPIE team has reviewed the WSDE website to ensure that it meets accessibility standards for NHS and public sector.	4	Yes	
77	DCF Policy Review	Clear decision-making criteria	Publish an explanation of how the SDE makes decisions on data access, addressing both the Pre-Check and Data Access Committee processes – favouring a flexible approach that incorporates scorecard and principles-based criteria, and distinguishes between commercial, clinical, and academic research projects based on their risk levels and public interest.	Further information about our approvals processes and decision making has been made available as part of the WSDE website refresh	4	Yes	
78	DCF Policy Review	A clear precedent-setting policy and process	Have a policy and clear process for how the SDE sets precedents in its decision-making, favouring a flexible approach that reflects on the merits of both the prescribed-list approach (clear, upfront rules that make things straightforward), and a case-history approach (giving more flexibility).	It is not anticipated that the SDE will be adopting a precedent process or policy at this time.	4	Ongoing	The SDE will continue to monitor the need for precedent setting and address with support of DCFs/public at the appropriate time
79	DCF Policy Review	Clear delegation and oversight	Publish an organogram (or similar) showing who is responsible for different decisions and processes within the SDE, including for the Pre-Check process.	Further information has been made available as part of the WSDE website refresh	4	Yes	
80	DCF Policy Review	Accessible communication	Clearly set out guidelines on what "easy-to-understand" means for different groups, making sure communication works for everyone, especially those who might struggle, by early 2026.	The Wessex SDE follows the Accessible Information Standards as used by the NHS. Implementation includes easy read versions of key documents, infographics, audio and other mixed media to share information and updates about the SDE	4	Yes	
81	DCF Policy Review	Intersectionality and inclusivity	Explicitly acknowledge intersectionality in the EqIA and clearly describe how overlapping identities and needs will be addressed by early 2026.	Specific wording has been added to the EqIA Policy to acknowledge intersectionality and how it will be addressed	4	Yes	

82	DCF Policy Review	Real-life impact for marginalised groups	Demonstrate clearly, through practical examples and real-life stories which are representative of marginalised communities, to show how the SDE's equality and inclusion activities specifically benefit marginalised or underrepresented communities by late 2025.	We are currently in the process of developing case studies to evidence the work that the SDE is delivering and how these deliver benefit. Case studies will be included and shared in our Annual Report and updated on the SDE website	3	Action required	Annual Report and case studies on website
83	DCF Policy Review	Mandatory staff inclusion training	Ensure all SDE staff and decision makers complete mandatory diversity and inclusion training, reinforcing commitments within the EqIA and visibly embedding inclusive practices by Q1 2026.	Commitment is captured in SDE EqIA policy, section 6.4.2. Implementation will be delivered by University Hospital Southampton in line with their current staffing and HR processes.	4	Yes	
84	DCF Policy Review	Transparent appeals process	Clearly define and communicate a transparent appeals process for decisions made by the Data Access Committee, specifying clear grounds and criteria by early 2026.	Not currently in place. DAC chair has been tasked with developing and sharing the appeals process. Once the process is developed and refined it will be included within the SDE's Researcher Toolkit and made available.	2	Action required	Action with Data Access Committee Chair to develop and share appeals process.
85	DCF Policy Review	DCF visibility and involvement in future HRA submissions	Ensure DCFs get to see any new or amended HRA submissions planned by the SDE Operations team. Involve DCFs in co-design when this would add value to the process.	The 2025–26 work plan anticipated DCF review of the HRA update prior to submission. Owing to operational timing constraints, this did not take place for the current submission. The SDE will share the submitted materials with DCFs and will schedule earlier engagement for future submissions to ensure meaningful involvement.	3	Action required	DCFs to review HRA update post-submission in March 2026. Future updates to be shared with DCFs in a timely fashion.
86	DCF Policy Review	DCF involvement in clinical trials re-identification, federated data analysis, and future capability changes	Involve DCFs in implementing clinical trials re-identification processes and federated data analysis across multiple SDEs, in particular around governance and transparency arrangements for these and other new SDE capabilities.	The Wessex SDE is not currently operating clinical trials re-identification or federated data analysis. Digital Critical Friends are embedded within relevant governance and working groups and will be engaged as part of the design and implementation of any future capability changes in these areas. Any such developments will align with national policy and regulatory frameworks and will be subject to Data Access Committee scrutiny and established public engagement processes.	X	Yes	No implementation is currently underway. Should these capabilities be introduced, DCF involvement is built into the SDE's governance structure.
87	DCF Policy Review	Managing workload implications for clinical teams from clinical trials	Be clear about whether clinical trials re-identification will create additional work for GPs and clinical teams, and confirm that they are happy with how this process will be managed to avoid placing extra pressure on already overstretched NHS resources.	To be addressed once there is further clarity regarding clinical trials re-identification and in line with National guidance	3	Ongoing	The SDE is not currrently operating any clinical trials work. Further review and assessment to be completed and aligned with National processes and policies
88	DCF Policy Review	Safeguards and oversight for re-identification	Make sure re-identification is only done via trusted clinical teams, with clear and open oversight, so patients know exactly what's happening with their data.	The Wessex SDE does not currently operate any clinical trials re-identification. Any future re-identification would require appropriate HRA and ethics approval, be undertaken solely by authorised NHS clinical teams, and be subject to established governance oversight. Digital Critical Friends are embedded within this governance structure and would be involved as part of that process.	4	Yes	As the SDE is not currently undertaking any re-identification activity, there is no live process requiring implementation; if introduced in future, it would be designed to ensure re-identification is undertaken only by authorised NHS clinical teams under appropriate regulatory oversight.

89	DCF Policy Review	Multi-SDE data sharing governance	Provide clear, simple information explaining how the SDE looks after patient data, which is true for all kinds of research whether it is another SDE or an individual researcher. If more detailed is needed on specific situations, such as federated queries, provide that detail clearly but separately, so it's available if people want it as part of a tiered approach to transparency.	The Wessex SDE provides clear, accessible information on its website explaining how patient data is safeguarded across all types of research, whether access is requested by another SDE or an individual research team. This core explanation sets out the consistent governance, security and approval processes that apply in all cases. Where more detailed information is appropriate, this is provided separately through the Data Use Register, project summaries and published documentation, allowing a tiered approach to transparency for those who wish to explore further.	4	Yes	
90	DCF Policy Review	Accessible content and explaining acronyms	Publish a glossary on the SDE website and create an easy-read version of the Transparency Policy by October 2025.	The Wessex SDE is in the process of updating our Public and Patient Notification Materials. This will include easy read versions of key documents in line with the NHS Accessible Information Standards	2	Action required	Public notification materials update should cover this requirement.
91	DCF Policy Review	Financial transparency	Adopt open book accounting and include clear, simplified financial information in the annual report from 2025-26 onwards.	Commitment captured in SDE Transparency Policy under its publication scheme. This explains that there will be financial reporting in the SDE's Annual Report	3	Action required	Action: complete Annual Report - end March 2026
92	DCF Policy Review	Lessons learned reporting	Publish summaries of audit outcomes, clearly including lessons learned and improvement areas, starting with audits completed in 2026.	Commitment captured in SDE Transparency Policy under publication scheme: internal and external audit	4	Ongoing	
93	DCF Policy Review	Complaints and redress	Publish explicit signposting of complaint and redress routes clearly on the SDE website by Q4 2025.	Commitment captured in SDE Transparency Policy under publication scheme: Complaints and redress Additional information has been provided on the SDE website to make the process for raising concers or complaints more obvious and transparent	4	Yes	