Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS

Wessex Public Panel on NHS Data

July – September 2024

CORE REPORT - NO APPENDICES

Contents

Foreword

by Sam Fortune, Member of the Wessex Public Panel on NHS Data

When I was first asked to attend the Wessex Public Panel on NHS Data over the summer of 2024, my wife said to me, “Are you sure you want to give up a Saturday when the weather is this nice?” Looking back, I’m very glad I did. It seemed too important not to have a say in such an interesting and potentially transformative project.

What made the process so compelling was that the heart of the project was tied up with so many different factors: the practical challenges of keeping data safe and secure, the ethics of how it should be governed, and the questions about how it could be used in research. It meant we found ourselves looking at the issue from many different angles at once, and often one discussion would spark another. That mix of perspectives sometimes made it hard to keep sight of the individual, or to step back and see the bigger picture, but it was exactly that richness that made the process so valuable.

What felt so positive about these four workshops, and the outcome of them, was that we, the Wessex public, were the ones making the decisions and shaping the policies and rules that would guide the SDE. I can see those decisions directly reflected in this report. They weren’t diluted. They weren’t changed.

Over the course of the four-day workshops, as we learned more about the Wessex Secure Data Environment (SDE), it became abundantly clear how exciting and transformative it could be. It was up to us, the participants, to frame the discussion and raise the questions and concerns that the wider Wessex public might have. One of the biggest concerns was always around how people’s data would be used. Understandably, we came back to that discussion many times. But by the end, I felt confident that the steps being taken showed the wealth of measures in place to protect people’s information and to maintain public trust.

As we gained a deeper understanding of how the SDE would work, I, along with other participants, became more comfortable not only with how the data would be used but also with how it would be protected, and the clear public benefits it could deliver.

Thinking back to those early meetings, it felt like every question answered opened up another avenue to explore. But as time went on, we became more focused on what was truly important. What stands out most now are the personal stories shared by other panel members about loved ones and their experiences with the NHS. Those stories brought the discussions to life, and you could feel the genuine excitement about the potential of the SDE.

What I feel really shines through in this report is that the essence of those four days has not been lost. On the first day there was apprehension and uncertainty, but also the start of understanding the safeguards in place to secure and pseudonymise people’s data. The second day took us into a deeper discussion about concerns over how third-party industry might access data. By the final days we could see the benefits of research more clearly, and the importance of supporting the SDE with clear, simple rules. The journey is recognisable, and the conclusions feel right.

After the workshops were completed, I realised I wanted to continue being part of this project. That’s why I joined the standing group of public participants who stay closely involved in the governance of the SDE and became one of the public members of the Wessex Data Access Committee, which makes decisions about what research can go ahead. From that vantage point, I can now see how the recommendations we made as a Public Panel are already shaping the design and governance of the SDE.

That is why I believe this report matters. It captures our voices and the seriousness with which we approached the task. It shows that, given the time and space, ordinary people can grapple with difficult questions and set out the conditions under which trust can be earned. Most importantly, it sets out the guardrails for what the public expects from a secure data environment.

I hope readers will see what I saw: a fair reflection of public voices, and a foundation on which the Wessex SDE can continue to build trust and deliver benefits for everyone.

Sam Fortune
Member of the Wessex Public Panel on NHS Data
Wessex SDE Digital Critical Friend

Executive Summary

The Wessex Public Panel on NHS Data brought together approximately 50 people from across Wessex in a deliberative dialogue to help shape how the region's new NHS Secure Data Environment (SDE) should operate. Over four full-day sessions, these randomly selected participants (recruited by the Sortition Foundation) learned about health data use, discussed their aspirations and concerns, and developed a comprehensive set of public recommendations to inform co-design of the SDE.

The panel's outputs include a set of **core values** to guide the SDE's conduct, eight **strategic research priorities** for the Wessex SDE, and numerous **actions to build public trust** through policy and governance changes. Together, these recommendations describe how the SDE should be run to earn public confidence, representing a distillation of the entire deliberation process with the mandate of the whole group.

The Wessex SDE has committed to act on the Public Panel's input. The core values and strategic research priorities will be embedded in SDE strategy and decision-making, and the detailed recommendations are being reviewed by the SDE governance teams for implementation. Going forward, the programme will establish mechanisms (through its Programme Board, working groups, operational functions, and Data Access Committee governance) to ensure these outcomes shape the SDE's design and operations, and to provide feedback to the public on how their recommendations have been taken forward and aligned with best practice and NHS Research SDE Network policy.

The Public Panel's work is a critical milestone in fulfilling the SDE's commitment to co-design and transparency, and it will be followed by broader public engagement (titled the "Improving Tomorrow's Health" campaign) to validate and refine these recommendations with the wider Wessex population. This final report summarises the Public Panel process, key findings, and next steps in integrating the public's voice into a trustworthy Wessex SDE.

Deliberative dialogue overview:

- **Participants:** ~50 residents of Wessex (Dorset, Hampshire, and the Isle of Wight), selected by civic lottery to reflect regional demographics, split into separate Dorset and Hampshire and Isle of Wight cohorts. I
- **Sessions:** 4 full-day deliberative workshops (3 local cohort sessions each in Bournemouth and Southampton, plus 1 combined session).
- **Duration & Format:** Conducted over Summer 2024, featuring expert presentations, facilitated group discussions, and collaborative activities. Participants received £600 each for their time attending all four sessions of their respective cohorts (in line with NIHR public payment rates).

- **Diversity:** Stratified recruitment ensured a mix of ages, genders, ethnicities, socio-economic backgrounds, and localities reflecting the diversity of the Wessex region (with oversampling of the Isle of Wight to ensure inclusion).

Deliberation outcomes:

- **Core Values:** 8 core values identified to guide how the SDE should operate (e.g. “Benefits everyone,” “Privacy and security first” – see **Findings**).
- **Strategic Research Priorities:** 8 public-defined priorities for research and SDE focus (e.g. prevention and health improvement, equitable outcomes, financial sustainability – see **Findings**).
- **Recommendations:** 32 specific actions proposed by the Public Panel to build public trust, spanning transparency measures, governance practices, and data safeguards (all with high levels of public approval – see **Findings**).
- **Public Mandate:** 100% of panel participants contributed to developing and voting on the final recommendations, which achieved strong consensus.
- **Participant Feedback:** Panel members reported a highly positive experience – for example, they overwhelmingly agreed that their views were respected by others (average 4.7 out of 5 agreement).

Introduction

About the Wessex Secure Data Environment

The Wessex Secure Data Environment (SDE) is a new NHS cloud-computing platform that securely stores and links large volumes of patient health data for research, benefiting patients and society. It upholds the highest standards of privacy and security for NHS patient data.

The SDE's mission is to unlock the potential of health data, accelerate the development of life-changing treatments and medicines, and enhance the efficiency, effectiveness, and safety of the health and social care system.

In this system, approved researchers access de-identified[1] data through a secure platform, removing the need for data sharing. The NHS retains full control, ensuring research safety, protecting patient privacy, and accelerating research and discovery.

By linking diverse data types, researchers can address complex questions, examine multiple aspects of health issues, and gain new insights to develop innovative treatments and technologies. This approach holds transformative potential; in the Wessex context this includes examples such as personalised cancer therapies to reducing waiting times.

All research data on the platform is pseudonymised; researchers do not see confidential patient information, and individuals cannot be easily identified. The NHS governs data access, permissible activities, and the results that can be extracted.

Aligned with the national NHS and Department of Health and Social Care policies, the Wessex SDE supports the government's 'Data Saves Lives' strategy, emphasising Secure Data Environments as essential tools for safe, transparent, and effective health research. This approach also reflects key recommendations from the Goldacre Review, which advocates for “trusted research environments” (another name for SDEs) to securely link and analyse NHS data without moving it around, thereby enhancing security, transparency, and public trust.

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[1] At the time of the Wessex Public Panel on NHS Data the term adopted by the Wessex SDE to describe the way in which confidential patient information is removed by the SDE before being provided to approved researchers was “de-identified”. This term was chosen based on discussion with patients and the public, Understanding Patient Data, and other NHS organisations. Recent advice from the Information Commissioner’s Office (April 2025) suggests that it is preferable to use the term “pseudonymised” as this more specifically describes the way that data is treated within the SDE. For the purposes of this report the term “de-identified” is retained for consistency with the original material presented; public participants in the Public Panel had the distinction between anonymised and pseudonymised explained to them as part of the dialogue.

Similarly, the Sudlow Review underlined the importance of robust governance and strong data stewardship to maximise research benefits while safeguarding patient confidentiality. By bringing approved researchers directly into a controlled NHS environment rather than sharing data externally, the Wessex SDE meets these objectives by placing patient privacy and NHS oversight at the core of its operations.

Wessex is one of 11 regional NHS Research SDEs established in England as part of the NHS Research SDE Network, an initiative backed by significant NHS England investment. This strategic network aims to enhance healthcare outcomes nationwide, accelerate life-changing research, and maintain public confidence in how patient data is handled.

The Wessex SDE is hosted by University Hospital Southampton NHS Foundation Trust on behalf of Wessex Health Partners, NHS Dorset Integrated Care Board (ICB), and Hampshire & Isle of Wight ICB. It is a critical element of the region’s strategy to leverage data-driven innovation, reduce health inequalities, and ultimately deliver better care for local communities.

Building a social licence for the Wessex SDE

The success of the Wessex SDE depends heavily on earning public trust and acceptance – often described as a "social licence."

While, in legal terms, NHS patient data is held by healthcare providers, many individuals feel a strong personal connection to their health information and expect to have a say in how it is used. This perception underscores the importance of involving the public in decisions about data use. Meaningful public participation ensures that the use of NHS patient data for research aligns closely with public values, expectations, and concerns. By fostering open, transparent dialogue and shared decision-making, we can build the trust necessary for the SDE to deliver benefits that the public recognises and values.

From the outset, the Wessex SDE programme has therefore **committed to co-design:** putting patients and the public at the heart of decision-making about how the SDE is developed and run. This commitment is both a strategic choice and a response to national expectations: engaging the public is crucial to building trust in the use of health data, and regulators such as the NHS Health Research Authority (HRA) require evidence of meaningful public involvement in such initiatives.

Co-designing a programme like the Wessex SDE presents several key challenges, primarily due to its complexity and the need for meaningful public engagement.

1. **Complexity and Accessibility**

   The Wessex SDE cloud-computing platform and governance involves a wide range of specific technical and regulatory elements. While many people regularly engage with data-sharing through smartphones and online services, the specifics of how health data is used, regulated, and safeguarded often aren’t widely communicated or understood. There is also a prejudice that because it looks complex, it is not something ‘ordinary’ people can easily engage with, and public participants may be deterred from engaging with the issue. It's vital that the programme clearly articulates what is involved in health data research in straightforward, meaningful terms, rather than presuming it is inherently complicated.

2. **Maintaining Relevant and Focused Engagement**

   Public conversations about NHS service changes often highlight personal healthcare experiences, like GP waiting times. While these experiences are important, co-design processes for data-focused initiatives like the SDE must ensure discussions contribute to shaping the SDE. Facilitators must ensure programme design impacts decisions and policies to do justice to the time participants are contributing.

3. **Representation and Inclusion**

   A key principle of co-design is that public contributors develop a clear understanding of the project so that they can engage fully and make informed recommendations. However, this process of education means that participants stop behaving and thinking as much like the population that they are supposed to represent. The more we want the public to engage and grapple with the critical detail of SDE design and governance, the more learning public participants will do, and the less representative they may become.

   Similarly, some seldom-heard groups, particularly individuals and communities who have had negative experiences with the NHS or other public services, might not feel comfortable participating in formal processes. This means that deliberative co-design methods won't suit everyone, cannot ensure a fully representative view, and must form part of a wider programme of public engagement.

   Furthermore, deliberative dialogues require significant resources, which inevitably limits the number of participants involved. While aiming for complete representation is ideal, practical realities mean we aim instead for reflective and inclusive representation. However, we must acknowledge the risk of unintentional bias in these smaller groups and ensure we regularly test insights and recommendations through wider public conversations. This broader, ongoing public dialogue enables us to check, validate, and refine recommendations to better reflect wider public perspectives.

4. **Good use of NHS time and resources**

   The programme's literature review (see **Appendix G**) highlights an existing body of knowledge about what the public think about the use of NHS data for a range of different purposes. There is limited value in investing NHS time and resource in replicating these insights. There are also several other Secure Data Environment programmes that are undertaking similar PPIE activities; again, it does not make sense to duplicate this work. This creates a challenge.
   Other public deliberations have approached the topic of the use of NHS data for research by introducing public participants progressively to the idea, starting with explaining the range of uses to which NHS patient data is put to situate the research

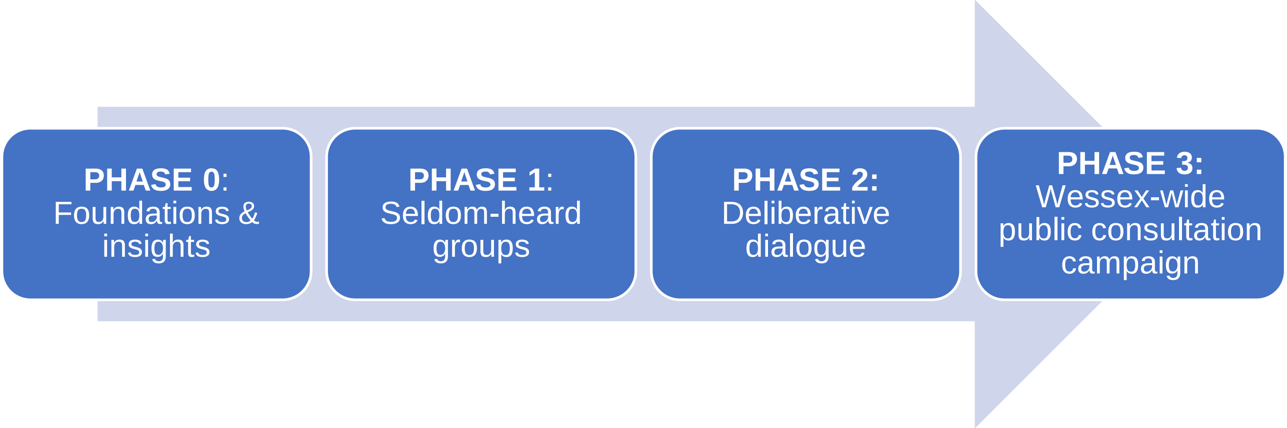
use within this wider context. This takes a considerable amount of time, and whilst it is a good foundation for public participants it does not generate new insights.

The challenge with going directly into the use of NHS patient data for research is that public participants may initially feel under-equipped or lack confidence to engage meaningfully with what they perceive to be complex and specialist topics, such as pseudonymisation, data governance, or the nuances of the scientific method. While most individuals routinely navigate data sharing, consent processes, and interactions with public and private sector services, they do not automatically recognise this experience as relevant to the discussion of NHS research data. Without proper context, participants may therefore underestimate their capacity to contribute or become disengaged. A deliberative approach that begins with inspiring examples of research - highlighting tangible public benefits – can help overcome this barrier by clearly demonstrating the relevance and impact of NHS data use, thereby motivating and empowering participants to engage deeply and confidently in the dialogue.

By clearly acknowledging these challenges and adapting our co-design approaches thoughtfully, we ensure the Wessex SDE is shaped by meaningful, inclusive, and trusted public input.

Strategy

Wessex has adopted a structured, multi-phased public engagement strategy, summarised in the diagram below. It is helpful to understand this strategy to see how the deliberative dialogue fits into the Wessex SDE's wider communications and PPIE programme.



This strategy recognises that earning a robust social licence depends on demonstrating broad public support for the values, principles, and governance underpinning the SDE. Intensive co-design processes, while highly valuable, involve smaller, deeply engaged groups whose outcomes must subsequently be tested with the wider public to avoid potential group bias and ensure fair representation.

Guided by the internationally recognised IAP2 Spectrum of Public Participation[2], the strategy intentionally progresses from intensive co-design (empowerment) towards broader consultation and information sharing. This approach ensures a diverse and inclusive range of perspectives are included, especially from groups typically at risk of exclusion, and builds out the social licence with progressively wider engagement. Continuous scrutiny from the Digital Critical Friends group, established at the outset, ensures ongoing alignment with public values and expectations.

PHASE 0: Foundations & Insights

This phase established an evidence-based foundation, ensuring subsequent public participation added maximum value. Preparatory work included a **literature review** of existing research into public attitudes towards NHS patient data use for research (**Appendix G**), building on significant prior engagement by the **Wessex Care Record**

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[2] The IAP2 Spectrum of Public Participation is an internationally recognised framework developed by the International Association for Public Participation (IAP2). It outlines five distinct levels of public engagement – Inform, Consult, Involve, Collaborate, and Empower – to guide organisations in effectively involving stakeholders and communities in decision-making processes. For more information see: [IAP2 Public Participation Spectrum]().

(WCR) programme. The WCR research identified low public awareness and trust in secondary uses of patient data, highlighting the critical role of clear communication – particularly regarding commercial use, data security, and GP involvement – to build public confidence.

A **Communications and PPIE Working Group**, comprising regional NHS specialists, ensured alignment with existing regional engagement, rigorously testing the multi-phase strategy. Additional **stakeholder engagement** included briefings with NHS patient involvement groups and structured interviews with senior NHS and research stakeholders, ensuring practical robustness and broad support.

Collaboration with the national NHS Research SDE Network ensured alignment with national engagement efforts, distinguishing between regional and national responsibilities for public deliberation. For example, national deliberation should focus on consistent policies across SDEs, like the National Data Opt-Out. Regional deliberation is suited to topics needing local implementation, such as governance structures and tailored access controls. For commercial principles, national guidelines should be set first, followed by regional applications.

The programme also established a standing panel of up to 20 **Digital Critical Friends** (DCFs)[3], recruited to reflect the diverse demographics of Wessex. DCFs have been trained and actively involved in co-designing the PPIE programme itself, providing ongoing challenge and advice throughout the SDE programme.

PHASE 1: Seldom-Heard Groups

This phase specifically engaged marginalised and vulnerable communities, ensuring their voices significantly shaped subsequent dialogue. Over 600 participants from 26 seldom-heard groups across Wessex contributed to tailored discussions, resulting in community-informed, values-led principles for guiding the SDE. This phase generated detailed insights into community-specific concerns regarding data security, transparency, accountability, and inclusion, forming a robust basis for future governance and communication recommendations.

PHASE 2: Deliberative Dialogue

Central to the strategy, Phase 2 involved convening the Wessex Public Panel on NHS Data. Deliberative dialogue – a recognised best practice method – brings together a diverse public cohort, providing time, balanced information, and expert engagement to tackle deeply with complex issues. This allowed participants to develop considered recommendations, shaping shared public expectations around NHS data governance. The

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[3] Numbers of DCFs have varied over the course of the programme from 16 to 20 as individuals have joined and left the panel.

approach demonstrated transparency and openness, fostering legitimacy and directly informing SDE decision-making.

PHASE 3: Wessex-wide Public Consultation Campaign

The final phase, the “Improving Tomorrow’s Health” campaign, will validate the Public Panel’s insights through a broader consultation involving representative polling (approximately 2,000 people) and extensive public information and engagement activities. This ensures findings are robust, broadly supported, and reflective of wider community perspectives.

Objectives

The Public Panel on NHS Data was tasked with addressing the overall research question: **“How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?”**

Within this broad topic, the dialogue was structured to explore several key questions critical to the SDE’s development:

- **Research opportunities:** What types of research uses of the SDE data are seen as most valuable by the public, and where do people draw the line regarding acceptable versus unacceptable uses of NHS patient data?
- **Governance and decision-making:** How should decisions be made about who can access the SDE and for what purposes (for example, what criteria a future Data Access Committee should use, and how to ensure fair, unbiased decisions)?
- **Operational considerations:** How should the SDE work in practice to maintain public trust (including transparency, security measures, and public involvement in oversight)?
- **Public benefit and value:** What principles should guide the SDE to ensure that uses of NHS data deliver tangible benefits to patients, communities, and the NHS, and that any risks or concerns are mitigated?

By the end of the process, the goal was to produce a set of public recommendations in three areas:

1. **Strategic research priorities** for the Wessex SDE (what it should strive to achieve)
2. **Core values** to embed in the SDE’s culture and processes
3. **Specific actions or policies needed to build and maintain public trust** (covering both general policies and research governance).

These outputs would directly inform the SDE’s design, governance framework, and future operations, ensuring that the system reflects what matters most to the people of Wessex.

Methodology

Overview

The Public Panel was delivered as a series of four deliberative workshops between June and August 2024 (three initial sessions in parallel locations, followed by one combined session). The planning was led by the Wessex SDE's Communications and Patient & Public Involvement and Engagement (PPIE) team, with specialist support from the **Sortition Foundation**.

The Sortition Foundation is a not-for-profit organisation that promotes the use of sortition – a democratic lottery-based process of selection – to create representative citizens' assemblies. They ensure participants reflect diverse demographics, enhancing the legitimacy of public decision-making. For more information, visit their website: sortitionfoundation.org.

Throughout the design phase, **Digital Critical Friends** (public representatives already engaged with the SDE programme) were consulted to co-design and test materials, helping to ensure the process was accessible and fair.

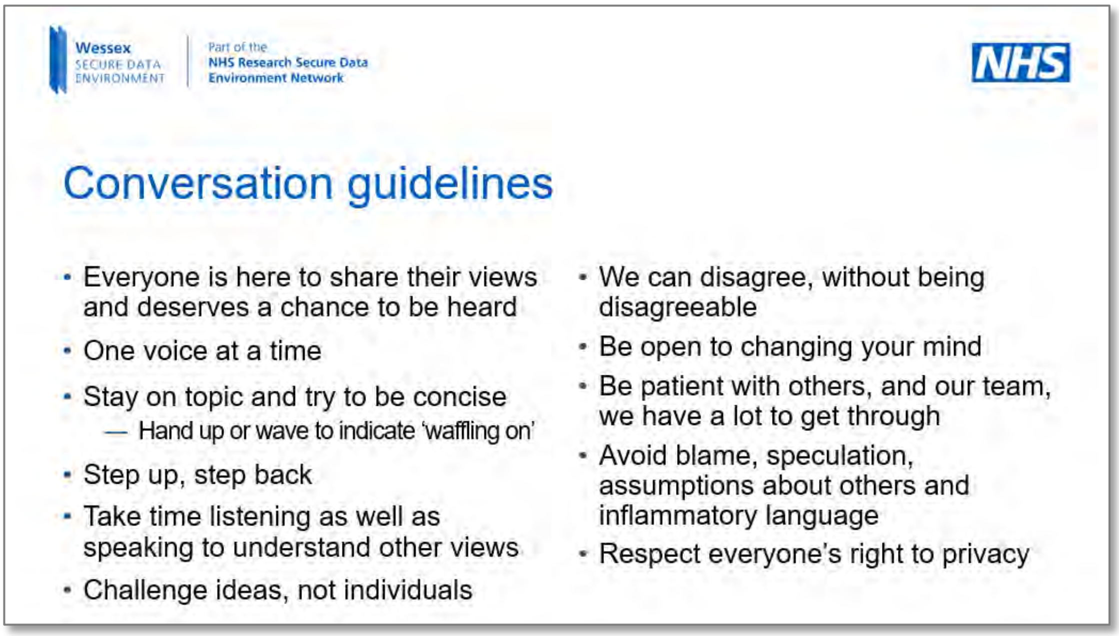
As set out above, the dialogue's **structure** and content were informed by preliminary research and stakeholder input. A discovery phase with internal stakeholders identified the main topics and decisions that required public input: the types of research the SDE might support, the governance and policy framework it would operate under, technical considerations like privacy safeguards, and how the SDE would interface with researchers, industry partners, and other data environments. These themes were woven into an agenda that balanced informative presentations with interactive discussions.

Each session combined **expert presentations, Q&A, and facilitated small-group deliberations**. Participants received foundational information about health data use, the concept of Secure Data Environments, and the Wessex context, both in advance and during the sessions, to ensure they could engage with complex topics.

Professional facilitators at each table used a structured discussion guide to ensure all participants had an equal opportunity to share their perspectives and systematically explore the issues. At the beginning of the dialogue, participants reviewed and agreed upon a set of conversation guidelines, included within all the session materials in **Appendices B-E** and in **Figure 1** below. These guidelines helped foster an inclusive, respectful environment, supporting collaborative and meaningful conversations.

This format follows best practices for deliberation, enabling participants to build knowledge over time and consider diverse perspectives before forming conclusions.

Figure 1: Conversation guidelines adopted by the Public Panel



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Conversation guidelines

- Everyone is here to share their views and deserves a chance to be heard
- One voice at a time
- Stay on topic and try to be concise
  - Hand up or wave to indicate 'waffling on'
- Step up, step back
- Take time listening as well as speaking to understand other views
- Challenge ideas, not individuals
- We can disagree, without being disagreeable
- Be open to changing your mind
- Be patient with others, and our team, we have a lot to get through
- Avoid blame, speculation, assumptions about others and inflammatory language
- Respect everyone's right to privacy

Participant recruitment

Recruitment employed a **sortition** method (a civic lottery). The Sortition Foundation targeted invitations to **17,400** addresses selected by postcode lottery from across Wessex. Participants were selected by sortition to ensure a balanced group, aiming for broad geographic and demographic coverage. Recruitment collateral and demographic balance are set out in **Appendix A**.

Interested respondents were then stratified against target demographics to mirror the Wessex population. Specifically, selection was balanced on age, gender, ethnicity, health status and disability, education, and geography to ensure a reflective sample. An oversampling strategy was used for the Isle of Wight to ensure this smaller community was adequately represented in the final panel.

The result was a broadly representative panel reflecting the diversity of Wessex, including voices from urban and rural areas and from communities often under-represented in such discussions. This random stratified recruitment helped ensure the legitimacy of the panel's conclusions, as they come from a "mini public" that mirrors the make-up of the wider public. In total, **56 individuals** were selected (28 per regional cohort) anticipating a small number might drop out; approximately 50 participants completed the entire process, with minimal attrition.

Appendix A also includes pie charts showing target and confirmed demographics for both cohorts. Specifically, they include: (a) the target demographics for the panel in Dorset and Hampshire & Isle of Wight ICB regions; (b) demographics of respondents to the recruitment process; (c) those then selected, contacted, and asked to participate; and finally, (d) those who confirmed their participation. This illustrates that a representative demographic sample was obtained for both ICB regions.

Co-design approach

To meet the challenges set out in the background and context section above, the decision was taken by the programme team to focus the deliberative dialogue process wholly on the use of NHS patient data for research. This approach avoided duplicating existing PPIE research insights, enabled participants to explore the topic in greater depth, and deliver good value for public money.

We worked on the basis that by inspiring our audiences with powerful research stories they would be motivated to engage with the topic. We led with research examples, made clear the role of NHS patient data in making this possible, and showed the role of the SDE in enabling and adding value to this process, working within the ‘Five Safes’ framework. How we did this is set out in the ‘**Dialogue programme structure’** section of the report.

A key challenge was effectively synthesising extensive outputs from these sessions into clearly recognisable and high-impact recommendations, capable of genuinely influencing the SDE’s design and governance. Given the complexity and volume of deliberations, it was neither practical, appropriate or desirable to expect participants to review and synthesise all prior inputs within a single session. This would not have been the best use of their time or ability to add value through their insights from lived experience.

To address this, the project team followed a structured approach to co-designing the session materials and the recommendations of the dialogue This approach is set out in **Figure 2**. It shows how public participants were included at each stage, and how their input was progressively analysed, organised, and refined to produce recommendations that reflect consensus and guide decision-making.

Figure 2: Co-design approach

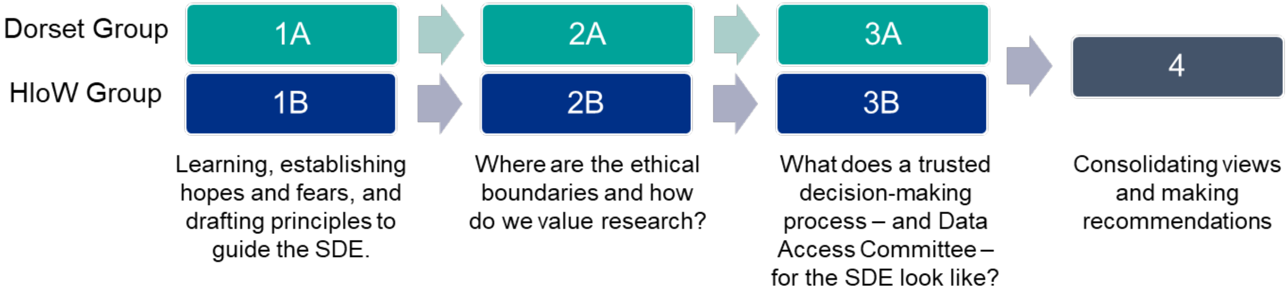
The table below explains the steps set out in **Figure 2**.

STAGE	OWNER	CO-DESIGN APPROACH
Step 1: Listening	SDE Team	Facilitators listened, captured the conversations that formed the dialogue. Sessions were carefully designed to ensure that the most important outputs were captured through workshop activities. These were supplemented by facilitator notes. At the end of each session the facilitation team discussed and shared their insights to ensure that workshop outputs and participant perspectives were understood in context.
Step 2: Theming	SDE Team	Identification, organisation, and categorisation of key ideas and insights from each session into clear, coherent themes. The aim was to give structure, but not to interpret what facilitators heard from public participants.
Step 3: Sensemaking	SDE Team	Interpretation of thematic groupings to work out what was important and what could genuinely influence SDE design decisions or governance actions – and what was important for understanding public sentiment. The aim here was to turn thematic insights into actionable insights.
Step 4: Modelling	Joint (Team & Panel)	Modelling translates sensemaking insights into clear, practical prototypes of potential design solutions or governance frameworks – it produces tangible and readily understood proposals ready for further refinement. Facilitators draft models and worked with public participants to develop, refine and prioritise these ideas – and correct the direction of travel where facilitators had got this wrong or misinterpreted what they had heard. The output was a refined list of recommendations and insights.
Step 5: Validating	Public Panel	Participants collectively reviewed and endorsed the refined recommendations, ensuring they genuinely reflected shared values and priorities. This was facilitated through structured consensus-building activities using participatory decision-making tools (e.g., dot and token voting, visual ranking), clearly highlighting areas of agreement and identifying points for further discussion.

Dialogue programme structure

The diagram below (**Figure 3**) sets out the structure of the dialogue. The first three sessions were delivered in two parallel locations – one in **Hampshire and the Isle of Wight (Southampton)** and one in **Dorset (Bournemouth)** – each with roughly 25 participants, so that travel would be easier and discussions could occur in smaller groups. A final fourth session brought all participants together in a plenary format in Southampton (with around 50 attendees total) to consolidate and validate the outcomes.

Figure 3: Structure of the Wessex Public Panel on NHS Data



All sessions were full-day (6 hours including breaks) and held on weekends to facilitate attendance. Participants were offered payment of **£600** for completing all four days of their cohort's deliberations (equivalent to £150 per day, aligned with National Institute for Health Research public payment guidelines) as both recognition of their time and to reduce barriers to participation.

The four workshop sessions were structured as follows:

DAY 1 – BUILDING UNDERSTANDING, EXPLORING BENEFIT & RISK

The session focused on **introducing data-driven research, the various types of data, and the role of the Secure Data Environment (SDE).** The first day was weighted towards educational components with later sessions becoming more practical. Participants:

- Received introductory presentations explaining health data, its value for research, and how data is securely managed within the Secure Data Environment (SDE).
- Built their understanding of different types and features of NHS patient data (e.g. confidential patient information, the wide range of data collected by health and care organisations, pseudonymised versus anonymised data, etc.), and the concept of the "Five Safes" framework for data security
- Discussed real-world examples of research enabled by NHS data to understand the potential benefits of data-driven health research (such as improving treatments and services) as well as risks and ethical questions (privacy, security, and consent).

- Participated in structured group discussions about hopes, concerns, and expectations related to data privacy, security, consent, and governance.
- Engaged in facilitated conversations to explore participants' initial reactions and questions regarding the use of NHS patient data for research

By the end of Day 1, participants had a basic understanding and raised initial questions and concerns for future sessions. The session's outputs are summarised below. Critical to note is that the reasons behind attitudes, risk rankings, hopes and fears, and principles were equally if not more important and heavily contributed to the analysis in the Findings section. This is also the case with analysis of Days 2 and 3, whilst Day 4 focused on making recommendations so the outputs themselves are of primary value.

All detailed agendas, slide decks, facilitator guides, and participant materials for this session are included in **Appendix B**.

DAY 1 OUTPUTS

1. **Attitudes towards health research:** Panel members discussed their opinions on using personal and Wessex population data for health research purposes.
2. **Safe and risky data:** Assuming the data is de-identified, meaning all personal identifiers are removed, panel members assessed various data types based on their comfort level with their use in the SDE for health research.
3. **Hopes and fears:** Panel members shared their long-term perspectives by creating fictional news stories about the Wessex SDE and its supported research.
4. **Values-based principles**: An initial set of principles to guide the operation of the SDE, which were returned to on Day 4 of the Public Panel.

DAY 2 – ETHICAL BOUNDARIES AND VALUING RESEARCH

The second workshop focused on **where to place the ethical boundaries for acceptable research, considering a range of features, and explored how to value research.**

Participants discussed and developed criteria to define the boundaries of acceptable research. In doing so they were asked to consider whether the research's overall purpose aligned with public values, whether research methods were acceptable, and whether the benefits clearly outweighed potential risks.

To explore these questions in depth, participants reviewed six carefully designed case studies, created by the Wessex SDE team in collaboration with regional clinical and academic experts. These scenarios represented challenging, "edge case" situations intended to test and define the limits of public acceptability for future SDE use:

- **LifeLab:** Improving adolescent health decisions, highlighting consent and young people’s data use.

- **HPV Vaccines:** Handling sensitive health data and pharmaceutical partnerships.
- **MyCOPD:** Patient-generated app data, involving industry collaboration and data moving beyond Wessex.
- **Dementia Clinical Trial:** Re-identifying patients to recruit for clinical research.
- **Sickle Cell Disease:** Balancing significant benefits for a small, underserved group against broader population gains.
- **Sarcoma (Cancer) and AI:** Using artificial intelligence in cancer diagnosis, including equitable sharing of rewards between the NHS and industry.

For each scenario, participants discussed their comfort levels, identified specific risks and benefits, and outlined conditions necessary to ensure acceptability. They also engaged in broader conversations about the range of research activities, types of data, and analytical tools available within the SDE.

Additionally, participants considered scenarios where data might securely leave the SDE, such as for advanced computing resources or patient recruitment into clinical trials. The discussion extended to fair value-sharing practices, emphasising that benefits derived from NHS data should be equitably returned to the NHS and the public.

By the end of the session, key themes had emerged around public priorities and concerns, providing a robust foundation for developing the core values that will guide the SDE.

All detailed agendas, slide decks, facilitator guides, and participant materials for this session are included in **Appendix C**.

Day 2 Outputs

5. **Ranking research:** The panel examined six fictional research examples, ranking them based on their comfort level and drawing out the features of the research, the public benefit they gave back, or other factors influencing their decisions.
6. **Types of value:** The Public Panel examined and ranked the most important benefits of data-driven research for Wessex patients and the public. Importantly they were also clear that value should not be considered only in respect of financial value but wider health and care benefits to both communities and individuals.
7. **Prioritising resources:** Considering that the SDE might have limited resources and research projects will need to be prioritised, Panel members ranked the six research examples using tokens, with additional feedback on their reasons.

DAY 3 – DESIGNING A TRUSTED DECISION-MAKING PROCESS

The third workshop focused on answering the question: **How do we create a decision-making process for the SDE that is trusted by the people of Wessex?**

Participants examined the full end-to-end decision-making process within the SDE, from initial data access requests through research completion and results being taken out of the SDE. They deliberated on where the ‘pinch points’ were – the most sensitive aspects of the process from a perspective of public trust.

The education component of this process introduced to the concept of the Data Access Committee (DAC), an independent body responsible for reviewing and approving data access requests. It was made clear that in the Wessex SDE model, the SDE’s operations team would initially assess the feasibility of data access requests and make recommendations to the DAC. The DAC would consider these recommendations and make decisions primarily on ethical desirability (as opposed to compliance with formal research ethics approvals), public benefit, and priority setting.

Panel members then discussed scenarios ranging from straightforward, low-risk projects to novel and complex proposals, identifying decisions requiring greater deliberation by the DAC and those potentially suitable for delegation to the SDE operational team. Participants then developed decision-making criteria that the DAC could use to assess applications. These should reflect the priorities and expectations of the Wessex public, including the ‘best use’ of SDE resources.

Next, the panel explored the optimal composition of the DAC, discussing the ideal balance between public and professional representatives to ensure effective governance and robust oversight. Finally, participants addressed transparency, identifying critical stages in the decision-making process where openness is most essential and exploring various approaches to transparency that would best ensure public trust.

All detailed agendas, slide decks, facilitator guides, and participant materials for this session are included in **Appendix D.**

Day 3 Outputs

8. **Data access decision making process:** The Panel studied how decisions are made about data access to pinpoint stages whose handling would most affect public trust and understand the reasons behind this.
9. **Data Access Committee decisions, delegation and oversight:** Panel members reviewed and prioritised 10 types of decisions, ranging from those that could be delegated to qualified officials or other SDEs, to those needing complete DAC review. This prioritisation aimed at reflecting Wessex public views and what builds trust in the process.
10. **Project Assessment Criteria:** The panel collaboratively established and prioritised both essential and desirable decision-making criteria for the Wessex DAC to use

when assessing data access requests. These criteria were aimed at fostering public trust in DAC decisions and ensure alignment with Wessex priorities.

11. **Transparency in decision-making:** Participants identified key aspects of the decision-making process where public visibility is crucial for building trust and described what the public would expect to see in terms of transparency.

Figure 4: Sample of outputs produced by the Wessex Public Panel on NHS Data

DAY 4 – CONSOLIDATION AND RECOMMENDATIONS

The final session brought together both regional cohorts of the Public Panel. It began by clearly framing the substantial potential benefits – ‘the size of the prize’ – that a successful SDE could deliver for Wessex. Considering the breadth of opportunities and limited resources, the main challenge was to decide which research goals to focus on. Equally important, is that the SDE pursues this mission guided by a set of values that align with public interests and build trust.

The session's focus was therefore on **the Panel collectively developing and endorsing recommendations** in three core areas, providing both strategic direction and guidance on key aspects of the SDE’s operation:

1. **Core Values:** Defining what matters most to the Wessex public and setting the overall direction for the SDE. These built on the principles drafted at the end of Day 1 (Output 4 above).

2. **Strategic Research Priorities:** Ensuring that research enabled by the SDE aligns with public expectations, reinforcing trust that the SDE is supporting the ‘right’ kinds of research.

3. **Actions to Build Trust:** Identifying critical policy or operational details that, although potentially less visible to the public, were felt to be essential to maintaining trust and confidence in the SDE.

Prototype models of all these three outputs were prepared prior to the meeting. The SDE team conducted detailed preparatory analysis, employing the Listening, Theming, and Sensemaking methodologies as outlined earlier in the report. The team consolidated insights from previous sessions, specifically focusing on safe and risky data, values-based principles, and resource prioritisation to draft prototypes of the ‘Core Values’.

Prototype Strategic Research Priorities emerged from a thematic analysis of previously ranked research areas, identified types of value generated by research, processes for data access decision-making, and criteria for project assessments. Actions to Build Trust drew on outputs of all the sessions.

Having clearly identified these themes, the SDE team created initial draft prototypes, which included **8 core values, 16 strategic research priorities, and 32 actions to build trust.** At the outset of the session, these draft proposals were transparently presented to the Panel, alongside clear explanations of their development process.

Panel participants then engaged actively in structured group activities, thoroughly reviewing, refining, and prioritising the initial drafts in line with the **Modelling** (Step 4) stage of our co-design methodology. Through iterative discussion and collaborative editing, participants significantly improved the initial proposals, resulting in refined recommendations.

At each stage the Panel was asked to **Validate** the final model outputs (in line with Step 5 of our co-design model). The session employed diverse validation methods aligned with the co-design methodology, ensuring recommendations garnered broad consensus across the Panel.

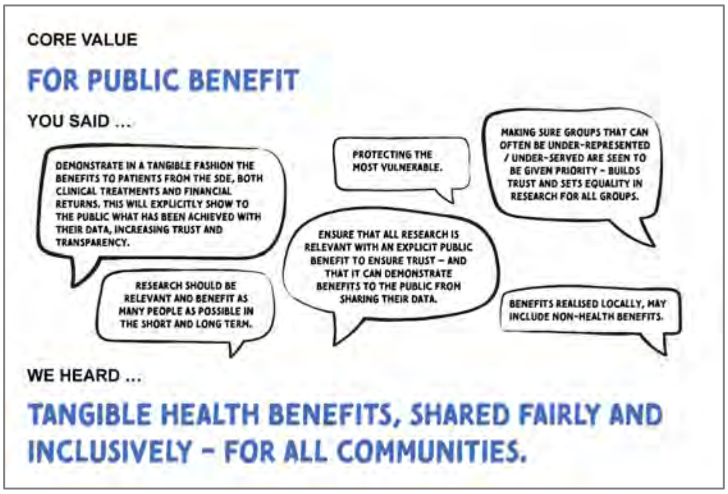
By the end of Day 4, the Public Panel had successfully endorsed a comprehensive and coherent set of recommendations, clearly supported by a majority, providing strategic clarity and a robust set of actions to maintain and build public trust in the SDE.

All detailed agendas, slide decks, facilitator guides, and participant materials for this session are included in **Appendix E**.

Day 4 Outputs

12. **Core Values:** Defining what matters most to the Wessex public and setting the overall direction for the SDE.
13. **Strategic Research Priorities:** Ensuring that research enabled by the SDE aligns with public expectations, reinforcing trust that the SDE is supporting the 'right' kinds of research.
14. **Actions to Build Trust:** Identifying critical policy or operational details that, although potentially less visible to the public, are essential to maintaining trust and confidence in the SDE.

Figure 5: Examples of prototype Core Values, Strategic Research Priorities, and Actions that Build Trust



CORE VALUE

FOR PUBLIC BENEFIT

YOU SAID …

DEMONSTRATE IN A TANGIBLE FASHION THE BENEFITS TO PATIENTS FROM THE SDE, BOTH CLINICAL TREATMENTS AND FINANCIAL RETURNS. THIS WILL EXPLICITLY SHOW TO THE PUBLIC WHAT HAS BEEN ACHIEVED WITH THEIR DATA, INCREASING TRUST AND TRANSPARENCY.

PROTECTING THE MOST VULNERABLE.

MAKING SURE GROUPS THAT CAN OFTEN BE UNDER-REPRESENTED / UNDER-SERVED ARE SEEN TO BE GIVEN PRIORITY – BUILDS TRUST AND SETS EQUALITY IN RESEARCH FOR ALL GROUPS.

RESEARCH SHOULD BE RELEVANT AND BENEFIT AS MANY PEOPLE AS POSSIBLE IN THE SHORT AND LONG TERM.

ENSURE THAT ALL RESEARCH IS RELEVANT WITH AN EXPLICIT PUBLIC BENEFIT TO ENSURE TRUST – AND THAT IT CAN DEMONSTRATE BENEFITS TO THE PUBLIC FROM SHARING THEIR DATA.

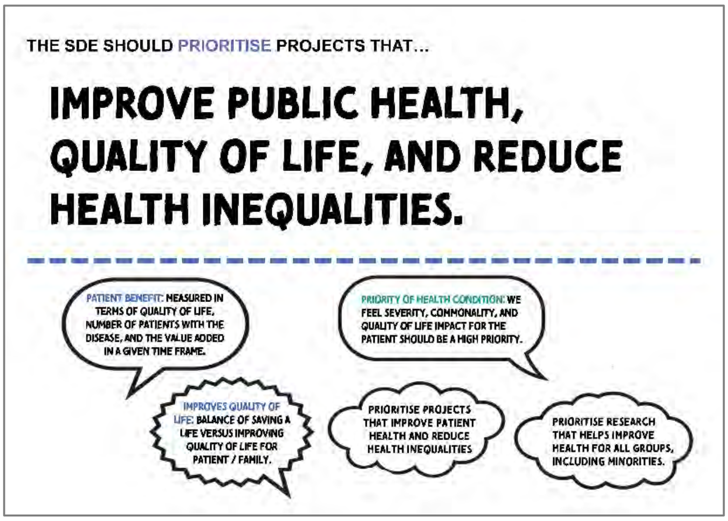
BENEFITS REALISED LOCALLY, MAY INCLUDE NON-HEALTH BENEFITS.

WE HEARD …

TANGIBLE HEALTH BENEFITS, SHARED FAIRLY AND INCLUSIVELY – FOR ALL COMMUNITIES.

The SDE team drafted eight (8) prototype **'Core Values'**, building on the work of the two Public Panel cohorts over three days of dialogue.

These prototypes (and the ones for 'Strategic Research Priorities') included a sample of verbatim quotes and comments from Panel members. These aimed to help explain and justify visually how they had been developed.



THE SDE SHOULD PRIORITISE PROJECTS THAT…

IMPROVE PUBLIC HEALTH, QUALITY OF LIFE, AND REDUCE HEALTH INEQUALITIES.

PATIENT BENEFIT: MEASURED IN TERMS OF QUALITY OF LIFE, NUMBER OF PATIENTS WITH THE DISEASE, AND THE VALUE ADDED IN A GIVEN TIME FRAME.

PRIORITY OF HEALTH CONDITION: WE FEEL SEVERITY, COMMONALITY, AND QUALITY OF LIFE IMPACT FOR THE PATIENT SHOULD BE A HIGH PRIORITY.

IMPROVES QUALITY OF LIFE: BALANCE OF SAVING A LIFE VERSUS IMPROVING QUALITY OF LIFE FOR PATIENT / FAMILY.

PRIORITISE PROJECTS THAT IMPROVE PATIENT HEALTH AND REDUCE HEALTH INEQUALITIES

PRIORITISE RESEARCH THAT HELPS IMPROVE HEALTH FOR ALL GROUPS, INCLUDING MINORITIES.

A long list of 16 prototype **'Strategic Research Priorities'** was reduced to eight refined priorities as a result of dialogue.

THE SDE SHOULD …

ENSURE THE DATA ACCESS COMMITTEE HAS A DIVERSE MIX OF BACKGROUNDS, SKILLS, AND EXPERIENCE – INCLUDING ¼ TO ¾ PUBLIC MEMBERS.

LINKED TO CORE VALUE: DESIGNED TOGETHER

Listening carefully to all aspects of the Public Panel dialogue, the SDE team created 32 prototype **'Actions to Build Trust'** that were further refined and consolidated by the Panel – who also added new Actions. Panel members voted using smiley and frowning face stickers to give a 'Visual Sentiment Vote' as to whether they were supported.

Findings

This section presents the key findings and outputs from the Wessex Public Panel deliberation. It integrates insights from the panel's discussions (the "deliberation process") with the formal recommendations agreed upon by participants. The findings are organised into the following sections:

All recommendations reflect the consensus of the panel and are intended to guide the Wessex SDE's development and operation moving forward. Full details of session plans, presentations, facilitator notes and participant materials can be found in **Appendices A–F**.

Public Perspectives on Data Use and Trust

Over the course of the dialogue, public participants consistently recognised the significant potential benefits of using NHS patient data for research, whilst at the same time voicing clear concerns and conditions for public trust.

In early discussions on Day 1, Public Panel members identified various advantages of health data sharing – for example, enabling medical breakthroughs, improving patient care, and allocating resources more effectively. At the same time, they were mindful of risks such as privacy breaches, misuse of information, and public confusion about how personal data is handled. This balance of hope and caution set the stage for deeper exploration of what would make data use feel acceptable to the public.

Through the Day 2 case studies and subsequent conversations, some common themes emerged. **Participants were more comfortable with data uses that had a well-defined purpose and obvious public benefit, especially when those benefits were tangible and felt locally.** If a research project could clearly demonstrate value for patients or communities in Wessex – for instance, improving an NHS health or care service or addressing a common health issue – and if the data being used was already consented or came from patients who understood its use, it was generally seen as “low risk” and acceptable. Having personal or community familiarity with the health issue also increased comfort (e.g., knowing someone affected by the disease in question).

In contrast, **uses of data involving commercial third parties (industry) or purposes that seemed abstract or distant raised flags of concern.** Many participants were wary of private companies accessing NHS patient data primarily for profit and emphasised that any industry involvement must be tightly controlled and clearly aligned with patient interests. They also worried about the reliability of data originating from outside the NHS and expressed discomfort when they felt they did not have enough knowledge to judge a scenario – highlighting the importance of transparency and education to inform public support.

When asked what they **value most** in decisions about data use, participants repeatedly pointed to **fair, widespread benefits and alignment with NHS values**. They strongly favoured projects that would deliver “tangible and equal benefits for people in Wessex”, improving health outcomes and/or saving NHS resources in a way that is shared across communities. Using data to benefit only a narrow group or something purely academic with no clear real-world impact was less compelling.

The Panel also felt that data initiatives should uphold the ethos of the NHS – serving everyone and prioritising health outcomes over profit. Conversely, they were sceptical of activities that felt detached or “arms-length” from the public: for example, research aiming for benefits far in the future or at an international scale without clear local gains was harder to get excited about.

An underlying thread in discussions was **a mistrust of industry motives, unless there is transparency and accountability in how companies are involved and how any benefits or profits are shared**. These deliberation insights directly informed the development of the Public Panel's Strategic Research Priorities and Core Values for the SDE. They illustrate that the Wessex public is eager to see data used for the common good – improving health and healthcare for all – but only if robust safeguards, transparency, and fairness are in place.

In the later stages of the dialogue (Days 3 and 4), participants showed a pragmatic approach towards decision-making processes for data access in the SDE. They generally recognised research as valuable to society and wanted it to proceed efficiently, without excessive bureaucracy. **Participants emphasised that the level of scrutiny applied should reflect the perceived risks, advocating streamlined and clear decision-making that accelerates worthwhile research while safeguarding public trust.**

Core Values for a Trusted SDE

To build trust and confidence in how the Wessex SDE uses NHS patient data, the project team recognised it was essential for local people to directly shape the organisation's core values. Core values are clear, straightforward statements about what matters most, guiding how an organisation behaves and makes decisions. When developed in partnership with the public, these values establish clear boundaries – setting both positive standards the SDE should pursue, as well as clear limits to its public mandate.

By publicly stating these values, the SDE transparently defines the scope of its social licence and reassures the community that it can be held accountable against these agreed standards. Complementary to the Strategic Research Priorities (see next section), which define what research the SDE should pursue, the core values clarify how it should operate. This collaborative approach to defining the SDE's purpose demonstrates a commitment to openness, transparency, and local priorities.

The Public Panel set out eight Core Values, shown below as written by the public. Each value is followed by commentary on participants' intended goals, drafted by the SDE team.

1. **Benefits everyone**.

   Deliver clear and tangible benefits, shared fairly and inclusively for all communities.

   Commentary: This means the SDE's work, taken in the round, should ideally help everyone, not just specific groups. For instance, there is strong support for improving overall health services or addressing needs in multiple populations. It also implies a focus on equity: historically underserved or overlooked groups should explicitly benefit, ensuring no one is left behind.

   Showing this value in action involves transparency about outcomes – the SDE should publish results and outcomes so the public can see what benefits were achieved and who benefited. Living up to "Benefits Everyone" builds trust by showing the SDE is true to the NHS principle of equity and that the data is being used to create public value for all.

2. **Better together**.

   Involve the public through all stages of the SDE, engaging with all communities through clear communication.

   Commentary: "Better together" reflects a commitment to public involvement and co-production. Participants want the SDE to actively involve lay people – whether through having public members in governance (including on the Data Access Committee), consulting communities on research priorities, or providing updates and education to the public. The Panel felt that involving the public not only builds trust but also improves outcomes by incorporating diverse perspectives. Clear, two-way communication is key: the SDE should explain what it's doing in plain language and listen to public feedback. This value also underscores inclusivity: engaging all communities, including those that might be harder to reach or historically less involved in research. By being “better together,” the SDE allows the public to have a voice and even a sense of ownership in what happens with their data.

3. **Privacy and security first and foremost**.

   Strictly controlled access with independently scrutinised safeguards and limits on authorised users.

   Commentary: Protecting NHS patient data is non-negotiable – the SDE must ensure privacy and security above all else. Data access should be strictly controlled, with robust, independently monitored safeguards and limited access granted only to authorised users. Participants expressed that the public would not tolerate any unnecessary access or sharing of identifiable data, and that even a single breach or misuse could severely damage public confidence. Therefore, this value demands rigorous compliance with best practices, possibly including third-party oversight to audit security (ensuring accountability beyond internal assurances).

   “Privacy and security first” also mean transparency about these protections – the Public Panel wants the SDE to openly communicate what is being done to keep data safe so that people feel safe. In practice, upholding this value might involve measures like regular security audits, strict vetting of who can enter the SDE, the application of data minimisation principles, and clear consequences and penalties for any misuse. It is the foundational value on which trust is built.

4. **Open and honest**.

   Be clear about how the SDE uses your data and what potential benefits this will bring.

   Commentary: The panel insists on full transparency and honesty from the SDE in how it operates and uses data. This core value means the SDE should be clear and upfront about what data it holds, who is using it, for what purposes, and what outcomes are observed. Essentially, “no secrets” – everything the SDE does should be explainable to the public.

   Participants noted that being open builds trust because “it shows nothing is being hidden”. For example, providing public-facing information like project summaries, publishing meeting minutes of decision committees, or proactively communicating any issues or mistakes along with corrective actions. Honesty also entails acknowledging uncertainties or limitations (not over-promising) and giving straight answers to public questions.

   Another aspect raised was that openness invites public involvement – if people see what’s going on, they are more likely to feel part of the process and contribute. In summary, “Open and Honest” means radical transparency as a default, to the greatest extent possible without compromising privacy.

5. **Delivers good value**.

   Supports research that delivers measurable improvement to patient outcomes, making the best use of NHS resources.

   Commentary: The Wessex SDE must make the best use of NHS resources and deliver measurable positive outcomes to justify the investment of public funds. This value is about effectiveness and efficiency. Participants want to see that the SDE is producing results that matter – for instance, improvements in health metrics or cost savings – and not wasting money or effort. Given that the SDE is funded by the NHS (and therefore the public), it needs to show that it is worth what we are putting in.

   One suggestion was to measure performance in terms of population health benefits and long-term NHS efficiency gains. The group also commented that while finances are important, the focus should be on health and community benefits rather than profit. “Delivering good value” might be shown through regular reporting of SDE outcomes (e.g. how many studies led to a change in care, estimated savings achieved, etc.). By being value-driven, the SDE shows respect for public funds and reinforces trust that it exists for public benefit, not bureaucracy or private gain.

6. **Respects people’s choices**.

   Gives you the option to opt out and provides clear information about benefits and risks to inform your decision.

   Commentary: The SDE should respect individuals’ choices about their data and support informed decision-making. This core value emerged from discussions on data consent and the NHS opt-out system. Participants felt strongly that the public’s right to choose whether their data is used must be honoured. In practice, this means the SDE must make it easy for people to opt out of their data being included if they wish, without penalising or pressuring them.

   Moreover, respecting choice requires providing clear, balanced information about the benefits and risks of data use. The panel suggested that the SDE offers “clear options for opting out without influencing people’s decisions” and to explain in plain terms that while data is kept secure, nothing is 100% risk-free. They also emphasised education and inclusivity as part of this value: reaching out to all parts of the community to explain the SDE (so everyone can make an informed choice) and understanding that trust has to be earned to prevent people from opting out. By respecting choices, the SDE acknowledges individual autonomy and builds trust that participation is not coerced but voluntary and valued.

7. **Only positive industry partnerships**.

   Build industry partnerships that are collaborative, transparent, accountable, time-bound, and deliver measurable benefits.

Commentary: If and when the SDE works with industry partners, it must ensure any such partnerships are strictly in the public interest – collaborative, transparent, and yielding measurable benefits to health.

This was a challenging value for public participants to agree and was made to address their caution around private sector involvement. They aren't opposed to industry collaboration per se (indeed, the Panel recognised that pharmaceutical or tech companies can bring innovation and funding), but only under conditions that safeguard the public good.

"Only positive industry partnerships" means: any external partner must be held to high standards of transparency and accountability, with clearly defined projects, key performance indicators (KPIs) for public benefit, and finite time limits, as well as penalties if they fail to deliver on agreed terms. The SDE should always be transparent about how data is shared with or accessed by industry, and critically, data should never leave the SDE or be exploited without oversight. Participants wanted assurances that the presence of industry partners will never compromise data security or the trust the public places in the SDE.

Ideally, partnerships with companies (like pharmaceutical research collaborations) should bring clear value to Wessex – for example, funding for the NHS, access to cutting-edge treatments for local patients, or global recognition that ultimately benefits the region. If these criteria aren't met, such partnerships should not be pursued. This value sets a high bar: industry is welcome only when it aligns with and enhances public benefit, under strict governance.

8. **Good governance and quality assurance**.

Strong and transparent governance, with independent checks on how the SDE is run and the quality of its data.

Commentary: The SDE must have strong, transparent governance and rigorous quality assurance to guarantee that data is used properly and securely. This core value encapsulates the need for ongoing oversight of the SDE's processes.

Participants want to see robust governance structures – for instance, an independent Data Access Committee making decisions, clear policies and standard operating procedures, and oversight by appropriate regulatory or ethical bodies. They also call for quality checks: "accurate, secure data to ensure confidence". That means the data itself should be of high quality (errors or inaccuracies could lead to bad research or even patient harm), and any analysis outputs should be checked. They suggested the SDE's leaders should define how they ensure quality and error-checking and to be open about those methods.

Importantly, the panel linked governance and quality to maintaining trust: if the SDE can show it consistently does what it promised (and catches mistakes), people will continue to trust and not withdraw their data. Additionally, they noted that good governance helps reinforce all the other core values – it is the mechanism by which values like privacy, transparency, and fairness are upheld. Implementing this value might include regular external audits, publishing governance meeting outcomes, and establishing clear accountability for SDE leadership.

These core values are intended to be more than just words on paper; the expectation is that the Wessex SDE programme will integrate them into its ethos and operations. Practical steps discussed by the Panel included developing a public facing “values charter” or code of conduct for the SDE, training staff and researchers on these values, and using them as a checklist for evaluating SDE performance. For example, the programme might report annually on how it has delivered against each core value (such as examples of benefits delivered to all communities, or summaries of privacy audits conducted). By embedding these values, the SDE team will demonstrate accountability to the public input and ensure that as the SDE grows, it remains grounded in what people expect from a trustworthy system.

Strategic Research Priorities for the Wessex SDE

Alongside co-creating the Core Values, the Public Panel was asked to define a set of Strategic Research Priorities for the Wessex SDE. While the values describe how the SDE should behave and make decisions, the priorities set out what kind of research the Wessex public want the SDE to focus its efforts on. Together, the two provide both an ethical framework and strategic guidance for the SDE.

The priorities were developed from prototypes created by the SDE team and synthesised from discussions during earlier stages of the Public Panel. 15 distinct prototypes were presented to the Panel (see **Appendix E** for examples of stimulus materials) from which they prioritised eight through a deliberative and democratic process. These were then further developed and refined through group discussion, with participants also asked to identify why each priority was important for trust and what a good result would look like in practice.

The eight priorities listed below summarize the goals for the SDE to enhance public benefit, support NHS sustainability, and respond to the health needs of communities in Wessex. The titles are directly quoted from participants, while the definitions of outcomes and commentary are provided by the SDE team.

1. **Save the NHS money through prevention and long-term health improvements for everyone.**

   A good result would be research that helps people stay healthier for longer, reducing preventable illness and pressure on NHS services and resources.

   Commentary: Participants saw prevention as the most effective way to protect both health and NHS resources. They wanted research to tackle root causes of disease, with education and early intervention at its core. They explored looking beyond clinical data to environmental and social factors such as air quality or housing. For example, the SDE could prioritise health systems research (studies on how health services are organised and delivered) that test new pathways of care and supports public health programmes to reduce waiting times and deliver more efficient services.
2. **Improve public health, quality of life, and reduce health inequalities.**

   A good result would be research that improves people’s quality of life and ensures all groups, including those historically underserved, benefit equally from better outcomes.

   Commentary: This priority was seen as central to the NHS mission. Participants wanted research that leads to measurable improvements such as higher survival rates, quicker recovery times, or better management of chronic conditions. They stressed the importance of narrowing health inequalities, so no group is left behind. For example, the SDE could enable epidemiological studies (research into health patterns in large populations) that help us understand the role of environment and lifestyle in health outcomes, and design interventions to reduce unfair differences between communities.

This priority was seen as central to the NHS mission. Participants wanted research that delivers measurable improvements such as higher survival rates, quicker recovery times, or better management of chronic conditions. In their discussions, they often converged on the idea that what really matters is not just extending life, but improving the quality of the years lived – in other words, making sure gains in life expectancy are matched by gains in health and wellbeing (i.e. similar to the idea of improving quality-adjusted life years, or QALYs). At the same time, participants were clear that reducing health inequalities must carry equal weight: the benefits of research should reach all groups fairly, especially those who have historically had poorer outcomes. For example, the SDE could enable epidemiological studies (research into health patterns in large populations) that explore the impact of environment and lifestyle on health, and design interventions that both extend quality of life and reduce unfair differences between communities.

3. **Clear aims, measurable outcomes, and alignment with Wessex's health needs.**

   A good result would be research with a clear purpose, measurable impact, and direct relevance to health challenges in Wessex.

   Commentary: Participants said trust depends on research being transparent, accountable and relevant to local priorities. They wanted assurance that projects would deliver outcomes that make a real difference for Wessex residents. For example, the SDE could focus on projects identified with Integrated Care Partnerships (ICPs) and local NHS partners, ensuring that resources go to studies addressing recognised burdens of disease in the region and producing evidence of impact locally.

4. **Create new knowledge and avoid unnecessary repetition.**

   A good result would be research that produces new insights and avoids duplicating studies that add little value.

   Commentary: Participants wanted the SDE to contribute fresh learning that moves health research forward. They felt repeating existing studies wastes scarce resources and undermines confidence. For example, the SDE could ensure every project captures and shares its findings in a way that informs future studies. This would embed knowledge across the system, accelerate innovation, and avoid wasted effort by building on what has already been learned.

5. **Clearly costed, financially sustainable, and delivering value for money.**

   A good result would be research with transparent costs that demonstrates efficiency and delivers clear benefits for the NHS and public.

Commentary: Participants said value for money is essential because the NHS runs on limited resources. They wanted projects to show clearly how funds would be used and what outcomes would result, with open and transparent reporting of the SDE's finances. At the same time, they recognised that research is inherently unpredictable: while a project might not always deliver exactly what it set out to achieve, it can still generate valuable new insights or unexpected benefits. For participants, this was acceptable if the learning was shared openly and contributed to wider improvements. They also stressed that financial considerations should not overshadow patient care and community benefit (this was a recurring theme).

6. **Create financial sustainability for the Wessex SDE to support the NHS in the future.**

   A good result would be research that helps ensure the SDE is financially sustainable and brings fair value back into the NHS.

   Commentary: Participants recognised that the SDE itself needs to be financially viable. They supported models where revenue – such as from industry projects – would be reinvested directly into the local NHS but emphasised that financial return must never outweigh public benefit when prioritising projects. They encouraged the SDE to explore new technologies, such as artificial intelligence (AI), that could help reduce workload pressures and costs, while stressing the need for clear communication about both the benefits and risks. Because AI and machine learning are not widely understood, participants wanted accessible explanations of potential negative as well as positive impacts. In summary, a financially self-sustaining SDE was seen as critical to ensuring it can grow and support more research over the long term.

7. **Quickly deliver results using existing data and resources.**

   A good result would be research that demonstrates early benefits by making use of data and resources already available.

   Commentary: Participants said quick wins are vital for building credibility and trust. Early projects should show visible improvements within a short timeframe, proving the SDE can deliver. For example, the SDE could prioritise projects using existing datasets to answer pressing questions. These early successes would not only reduce burden on the NHS sooner but also build momentum – raising awareness of the SDE, encouraging more researchers to use it, and reassuring the public that their data is being put to good use.

8. **A public benefit that would raise awareness of the SDE and build reputation.**

   A good result would be research that delivers clear and visible benefits to the NHS and public, helping people understand the role of the SDE.

Commentary: Participants wanted the SDE to build its reputation by being outward-facing and celebrating successes. They said visible public benefits are key to strengthening trust and reducing opt-outs, as people are more likely to support data use when they can see positive results. They also recognised that no single SDE can be the best at everything. For Wessex, this meant being clear about its strengths – the areas where local specialist skills and knowledge can deliver the greatest public benefit – and using these to create a competitive edge that attracts investment locally. Publishing and promoting plain-language project summaries and outcomes was seen as an essential way of raising awareness and showing the SDE’s impact directly to the local community.

Taken together, these eight Strategic Research Priorities show that the public want the Wessex SDE to be both ambitious and practical: ambitious in focusing on prevention, innovation, and reducing inequalities, and practical in ensuring research is relevant, cost-effective, and delivers visible results. Participants placed equal weight on long-term impact and short-term credibility, stressing that quick wins are essential for building trust while deeper investments in prevention and sustainability will secure lasting value. Above all, they expect the SDE to operate transparently, reinvest benefits into the NHS, and consistently demonstrate that the use of data delivers real improvements for patients, communities, and the health system as a whole.

At first sight these priorities may appear self-evident – few would argue against prevention, value for money, or reducing inequalities. The risk in presenting them simply, as they are here, is that they could be mistaken for broad aspirations rather than true priorities. In practice, however, the Public Panel developed them through careful deliberation of real choices. Participants examined a series of actual or realistic research case studies and considered different forms of value return, from immediate improvements in patient care to long-term system change. On Day 4, they reflected on why each priority mattered for Wessex and what trade-offs it implied. For example, prioritising prevention may mean giving less weight to treatment; preferring quick results could mean deprioritising slower, larger projects; focusing on benefits for the many can mean fewer resources for rare conditions. In this way, the priorities represent conscious decisions about what the public believe should come first when resources are limited.

Alongside the eight final priorities, the Panel also considered seven other prototypes that had emerged from earlier discussions. The full set of prototype ‘Strategic Research Priorities’ can be found as part of the collateral in **Appendix F**, and in summary these were:

- Wessex gets direct and inclusive health benefits
- Set a higher bar for projects that involve the private sector
- Wider opportunities and national impact
- Aligned with Wessex's strengths in data, research, and clinical skills

- Enforce higher standards for research with low-quality or sensitive data
- Maintain a balanced portfolio, including both commercial and non-commercial projects
- Risks and controversy are clearly considered and steps to address them identified

Together these reflected the Public Panel's concerns about fairness, accountability, and inclusivity, and were important to some participants in shaping the discussion.

In the end, these seven did not progress because some were seen as overlapping with the agreed Core Values – such as privacy, transparency, and fair industry partnerships – or as operational matters best addressed through governance rather than as strategic research priorities; as such these themes are picked up in the 'Actions to Build Trust', detailed in the next section.

By contrast, the eight priorities selected were judged to provide the clearest mandate for the SDE, articulating both the kinds of research the public most wanted to see and the outcomes that would most strongly build and sustain public trust. Looking ahead, while the Panel reached these priorities with a fair understanding of the potential trade-offs involved, there is value in testing them with a broader cross-section of the Wessex population. A future phase of work could use public polling to explore both the priorities and their implied alternatives, helping to confirm how far the Panel's conclusions are shared more widely and to strengthen the legitimacy of the SDE's mandate.

Actions to Build Trust: Public Recommendations

Alongside the high-level priorities and values, the Public Panel developed a set of concrete recommendations for actions and policies to make the SDE trustworthy in practice. Referred to collectively as “Actions to Build Trust,” these are detailed proposals for what the Wessex SDE should do – or avoid doing – to uphold its ‘Core Values’ and meet public expectations. They span a wide range of issues, from transparency and accountability to governance, privacy, industry partnerships, and public inclusion.

To help with understanding of this list, the SDE team has grouped these 32 actions into five themes: (1) Transparency and Accountability; (2) Governance and Oversight; (3) Privacy, Security and Re-identification; (4) Partnerships and Fair Value; and, (5) Public Choice, Inclusion and Education. Together, they show how the Public Panel’s recommended values can be translated into day-to-day practice and policy.

Seven prototype strategic research priorities were not carried forward into the final list recommended by the Public Panel, but their influence is clearly visible here in the ‘Actions to Build Trust’. Participants often reframed these issues as governance safeguards rather than strategic research directions. In this way, the actions and priorities complement each other: the priorities guide what kinds of research the public most want to see, while the actions define the rules and conditions under which that research can take place in ways that uphold public trust.

The actions listed below to build trust are described using wording agreed upon by the Public Panel. The scores shown in brackets after each action represent the net approval score, calculated as the number of positive responses from participants minus the number of negative responses.

A. Transparency and Accountability

1. **Have public accountability mechanisms – so people can give feedback, express concerns, and get their questions answered.** *(+22)*

   Commentary: Participants wanted accessible channels for accountability. They suggested mechanisms such as public forums, online feedback portals, or named contact points. The aim was to create ongoing, accessible dialogue channels for people of all backgrounds, with particular attention to historically marginalised groups.

2. **Have regular external audits and internal reviews – focusing on goals, legal standards, best practice, and public expectations.** *(+21)*

   Commentary: Independent scrutiny was seen as essential. Annual external audits, supported by regular internal reviews, should ideally be published in full, demonstrating both compliance and continuous improvement. This action focused on process and complements action #7 below, which covers outputs.

3. **Measure its performance in delivering good value in terms of population health benefits and long-term NHS efficiency savings.** *(+21)*

   Commentary: Participants wanted clear metrics showing the SDE's contribution to better health and NHS efficiency. Reporting on cost savings, improved outcomes, or lives improved was expected to demonstrate genuine value.

4. **Publish clear, jargon-free summaries of the SDE's operations – focusing on its management, decision-making, and data-handling.** *(+16)*

   Commentary: The panel wanted plain-English explanations of governance and operations. Ideas included online dashboards or annual public reports to demystify how the SDE works.

5. **Promote tangible public benefits – [show] who benefited and how, financial returns, shorter waiting times, or other efficiencies.** *(+15)*

   Commentary: Communication of successes was seen as vital for trust. Participants wanted clear examples of benefits linked to SDE projects, such as shorter waiting times or financial gains.

6. **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.** *(+9)*

   Commentary: Financial transparency was expected. Participants wanted open reporting of funding, expenditure, and any revenues from commercial partnerships.

7. **Carry out regular audits of the outcomes and benefits achieved – both in health and other areas – at least once a year.** *(+9)*

   Commentary: Beyond financial audits, participants wanted outcome audits, independently verifying whether projects delivered what was promised.

8. **Measure public benefit by looking at how much research can improve both health and quality of life for people in Wessex.**

   Commentary: Participants wanted impact measured in terms of peoples' lived experience, not just clinical or academic metrics. Quality of life was considered as important as clinical outcomes. Strategic Research Priority #2 – 'Improve public health, quality of life, and reduce health inequalities' – focuses on SDE research 'inputs'. This action complements it by measuring outputs using the same criteria.

9. **Provide a public list of all research applications and projects, detailing data usage, researchers involved, and the intended outcomes.** *(+6)*

   Commentary: A live public-facing registry of projects was seen as a key transparency measure. Plain-language summaries would help people understand what research was taking place. The score here reflects a balance of positive and negative sentiment (15 in favour, 9 against). While many participants supported transparency, others were mindful of possible issues related to commercial sensitivity, researcher confidentiality, and that there were legitimate constraints and resource implications of doing this at scale.

This action connects closely with the unselected strategic research priority "Risks and controversy are clearly considered and steps to address them identified". Both highlight a public expectation for transparency in research decision-making, even where this may raise challenges around commercial sensitivity or confidentiality. The mixed score here reflects the same tension seen in that priority.

10. **Have continuous monitoring, regular audits, and public reporting of data access and usage by approved researchers.** *(+5)*

    Commentary: Oversight should continue after approval. Monitoring of data access logs, with public reporting of compliance, was expected to reassure that terms of use were followed.

11. **Clearly explain its data security measures, updates on breaches or near-misses, and the steps taken to address them.** *(0)*

    Commentary: Being open about any problems is just as important as sharing good news. People wanted to get clear, timely updates if there were any data breaches and to know what was being done to fix them. The overall score here (zero) reflects that while many valued openness, others were concerned about causing unnecessary worry or giving wrongdoers useful information. Participants agreed updates should be straightforward, honest, and explain what steps are being taken to put things right.

B. Governance and Oversight

12. **Avoid staff holding multiple roles in the SDE where possible (e.g. sitting on the DAC and providing consultancy). Staff must declare conflicts of interest and step back from related decisions.** *(+17)*

    Commentary: Conflicts of interest were seen as a risk to credibility. Participants expected clear policies on declaring and managing conflicts, and separation of roles where possible. This reinforces concerns raised under the unselected strategic research priority "Risks and controversy are clearly considered and steps to address them identified". Both emphasise the importance of visible safeguards to prevent conflicts of interest or bias undermining trust.

13. **Ensure the Data Access Committee (DAC) has a diverse mix of backgrounds, skills, and experience – including ¼ to ¾ public members.** *(+17)*

Commentary: Public representation on the DAC was considered vital. Participants wanted a significant lay presence, ensuring a mix of lived experience and professional expertise.

14. **Set clear rules and protections on data access – e.g. strong contracts, penalties for misuse, and restriction of data re-use.** *(+13)*

    Commentary: Participants wanted firm contracts and penalties to deter misuse. Restrictions on secondary re-use were seen as a necessary safeguard. This highlights how people are worried about private companies getting access to NHS patient data. Many believe the NHS must have strong rules and clear ways to punish anyone who misuses data, so the public can trust the system and feel confident that any problems will be taken seriously.

15. **Have clear guidelines on data retention, secure archiving, and deletion – researchers lose access once a project is finished.** *(+12)*

    Commentary: Clear retention and deletion policies reassured participants that data would not be held unnecessarily once research projects are complete.

16. **Ensure data given to researchers is checked for quality to avoid errors that could harm patient care or research outcomes.** *(+11)*

    Commentary: Poor quality data can lead to mistakes in research, which may result in wrong decisions or wasted NHS resources. Poor-quality data can mean incomplete, inconsistent, or misreported information. The Public Panel focused particularly on self-reported records such as mental health and sexual health data, which they felt were prone to inaccuracies because stigma may lead people to under-report or misreport their circumstances. Alongside this, participants raised concerns about newer data sources, such as wearables, which they feared could be misused or misinterpreted, and whether industry partners could be trusted to share data in full rather than selectively highlighting findings that supported their own interests.

    These issues were seen as particular risks for minority or underserved groups, who might be missed out if their data is incomplete or not recorded properly. For Public Panel members, the solution lay in education and transparency: the SDE should be upfront about these potential risks, explain how data quality will be checked, and show clearly how any risks will be managed or mitigated before life- or service-impacting decisions are made. Taking data quality seriously in this way not only helps the NHS avoid errors and treat everyone fairly but also builds public trust by showing that everyone's information is handled with care and respect.

17. **Ensure researchers can only see de-identified data, and only the minimum required to meet the needs of the approved project.** *(+10)*

    Commentary: The Public Panel strongly supported the principle of "data minimisation," which means limiting access to only the smallest amount of information needed to answer the approved research question. This reduces unnecessary exposure and lowers the risk of misuse or accidental disclosure, helps protect people’s privacy, and builds trust in how health data is used. For the public panel, the combination of data minimisation and de-identification was seen as a complementary safeguard.

Participants also understood that in the context of the SDE, “de-identified” data referred to pseudonymised data (where personal identifiers such as names or NHS numbers are replaced with codes but the data could still, in theory, be re-linked under controlled conditions). This is distinct from fully anonymous data, which can never be traced back to an individual. This type of data can still, in principle, be linked back to the individual in special cases, so strict rules are needed.

18. **Embed public voices in design and governance, ensure their choices shape policy & outcomes – and are treated equally to experts.** *(+10)*

    Commentary: Participants wanted ongoing public involvement in decision-making as well as co-design of the SDE and its governance. Public voices should hold equal weight to expert ones, not be tokenistic.

19. **Ensure more oversight of projects using data deemed “sensitive” or “risky” by the NHS or the Wessex public.** *(+10)*

    Commentary: Projects using especially sensitive data (e.g. mental health or genetics) should face extra scrutiny, such as additional ethics review or tighter conditions. This overlaps directly with the unselected strategic research priority: “Enforce higher standards for research with low-quality or sensitive data.” The good level of support here shows that, although that priority was not carried forward, participants still wanted additional safeguards embedded in governance.

20. **Use proven technologies & meet national standards, NHS best practices, and SDE Network rules to ensure security & patient privacy.** *(+8)*

    Commentary: Participants wanted assurance that the SDE would only use proven tools, meeting national standards and NHS best practice, not experimental or unproven systems. This was an area where private sector involvement was seen as helpful.

21. **Ensure equity and fairness – benefits are shared across all groups, including under-represented and vulnerable communities.** *(+7)*

    Commentary: The panel wanted active monitoring to ensure research benefits reached vulnerable and under-served groups, not just the majority.

22. **Focus on research that helps as many people as possible, benefiting the whole community rather than just individuals.** *(+6)*

    Commentary: Population-level benefit was seen as more valuable than niche projects, unless rare conditions were critically underserved. This aligns with the unselected strategic research priority: “Wessex gets direct and inclusive health benefits.” Both highlight that public benefit should be broad and inclusive, not confined to a small subset of patients.

23. **Ensure research proposals undergo cost-benefit analysis so the SDE's full project portfolio gives more to the NHS than it takes.** *(+5)*

    Commentary: Participants wanted a systematic approach to ensure the NHS gets net benefit from the SDE's research portfolio.

24. **Maximise public benefits by focusing on projects where the Wessex SDE adds most value, referring others to better-suited SDEs.** *(+4)*

    Commentary: Efficiency across the national SDE network was valued. Wessex should focus on projects where it offers unique value and let other SDEs lead when they are better suited. This reflects elements of the unselected strategic research priority: "Wider opportunities and national impact." Both acknowledge Wessex's role in the wider SDE network, with decisions about prioritisation linked to efficiency, collaboration, and maximising added value.

C. Privacy, Security, and Re-identification

25. **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.** *(+20)*

    Commentary: There was good discussion about re-identification across several days of the Public Panel, including use of case studies and exploration of two main situations where it might be needed: finding suitable people for clinical trials and taking action if there was an urgent, clear risk to a patient. Participants agreed this was a tricky topic. While they understood the public benefits, they also worried it could undermine the SDE's promises about privacy and security. These assurances are central to public trust, so it might be difficult to explain how re-identification fits with them.

    Overall, the group agreed that re-identification could be acceptable, but only in specific and well-defined situations, with strict oversight, and only if it clearly benefits the patient. In all cases, they felt that any contact with patients should be made by the patient's own clinical care team, not by researchers, to protect trust and make sure the patient's needs are properly considered.

26. **Explain de-identification of data – what data researchers can see and what they can't, so people can make informed choices.** *(+12)*

    Commentary: Participants asked for clear explanations in plain English of what "de-identified" data means in practice, aiming to enhance public understanding. They recognised that the term refers to 'pseudonymised' data and suggested that simple public explanations should distinguish it from anonymised data.

D. Partnerships and Fair Value

All of the actions to build trust below reflect aspects of the unselected strategic research priority: “Set a higher bar for projects that involve the private sector.” Overall, while participants were cautious about commercial involvement, they also recognised that strict conditions, accountability, and demonstrable NHS benefit could make such partnerships acceptable.

27. **Ensure industry benefits are made clear and are proportionate to the public health and NHS gains they help deliver.** *(+18)*

    Commentary: Partnerships with industry were acceptable only if public benefit was as great as private gain. Full transparency was expected.

28. **Make sure that it gets a fair deal from commercial partnerships – e.g. a share of future profits or intellectual property.** *(+15)*

    Commentary: The panel expected financial returns, such as royalties or IP rights, to flow back into the NHS where public data contributed to profit.

29. **Actively use private sector skills, resources, and funding to boost research, with a laser focus on real health and NHS benefits.** *(+3)*

    Commentary: While cautious, participants acknowledged that the private sector could add value if activities were tightly aligned with NHS benefit and working with strict governance. Views reflected the tension between gaining capability and a general distrust of private sector interests that can be seen across Public Panel recommendations.

E. Public Choice, Inclusion, and Education

30. **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.** *(+16)*

    Commentary: Respect for choice was seen as fundamental. Opt-out mechanisms must be easy to access, neutral, and supported by accessible information. A number of participants talked about the need for public promotion, as people could not access or take decisions about an NHS service they did not know about. This was balanced by a desire to avoid driving opt-outs (which is reflected in action 32 below).

31. **Value insights from people with lived experience – public representatives should reflect Wessex’s diversity to reduce bias.** *(+5)*

    Commentary: Participants wanted the SDE to actively involve people with lived experience, reflecting diverse communities, to shape governance and reduce bias. Once again, parity of esteem between learned and lived experience was seen as vital.

At the same time there was a recognition that it is impossible get a fully representative group, and some communities may not easily engage at all.

32. **Have an education plan about data-driven research to help the public make informed decisions about their health and data.** *(0)*

    Commentary: Participants wanted proactive education efforts, including public campaigns and resources, to explain data-driven research and enable informed decision-making. The net approval score of zero here reflects a balance of positive and negative sentiment, rather than a lack of interest; support for public understanding was balanced by concerns about use of NHS resources and ensuring neutral, non-promotional information.

The recommendations span a broad range of support, with net approval scores from 0 to +22. Importantly, none received a negative net score. All 32 actions were grounded in earlier Panel discussions and prototyped by the SDE team, then refined and validated by the Public Panel. Taken together, they form a comprehensive public blueprint for how to embed trustworthiness into the SDE's everyday operations.

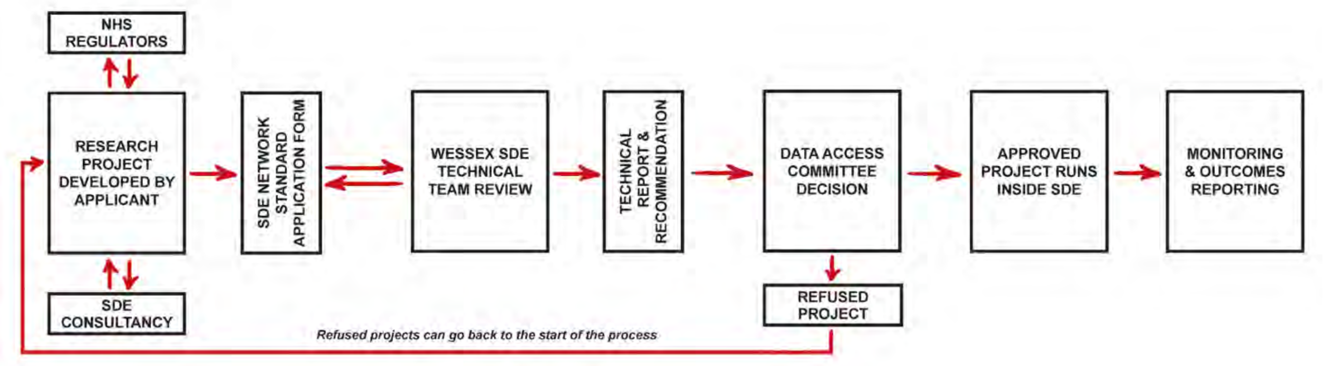
While the majority of actions received near-unanimous support, a handful generated more mixed views, reflecting genuine differences in emphasis across the group. These nuances are valuable: they highlight areas where implementation may need careful balancing of competing considerations.

The next step is for the SDE programme, is to review feasibility, integrate actions into governance documents and policies, and report back openly on progress. Being transparent about which recommendations are adopted, adapted, or deferred – and why – is itself a critical test of the trust these actions were designed to build.

Data Access Process & Governance

The Public Panel spent Session 3 examining the draft end-to-end process for reviewing and approving research projects including both SDE Operations checks and the role of the Wessex Data Access Committee (DAC) as a decision-making body.

Figure 6: A simple model of SDE decision-making



Panel members explored public expectations for each step of the process (see **Figure 6** above showing the model of decision making that was shared). They also looked at the decision-making criteria being used by the DAC and how the principle of transparency should be applied. These insights are compiled below:

1. **Pre-application transparency:** Before formal submission, Panel members felt that the public would want early sight of incoming research ideas. They suggested having “a page for the public to view research projects that are coming into the system and who has submitted them (NHS or commercial)”, as well as an indication of volume. This would raise awareness and potentially invite public comment or interest even before decisions are made. The rationale is that it makes the process accessible and shows openness from the start. It could also help avoid duplicate proposals if they were visible. The public seeing “what’s in the pipeline” builds trust and could spark community engagement or dialogue around certain proposals.

2. **Application stage (submission requirements):** The Panel expected that all proposals clearly state their purpose, data needs, and anticipated benefits (which aligns with requiring a public-friendly summary for the research registry). They also said they would be interested in knowing how many projects are submitted by NHS researchers as opposed to third parties, hinting that the mix of applicants was important and should be transparent.

3. **Technical review stage:** Panel members recommend that roles in the data access decision-making process - such as who assesses feasibility, legality and ethics – should be clearly separated and details of these roles should be published. This transparency prevents any one person or group from holding too much power and

avoids secretive decision-making. Clear job descriptions help prevent conflicts of interest and make sure the public can trust that no one is unfairly influencing decisions.

4. **DAC membership and impartiality:** Echoing earlier recommendations, the Panel insisted the composition of the DAC should be public knowledge: “Public [should] know the composition of the DAC and be aware they are impartially represented by a DCF or similar [public participant]; provide names, titles, etc. of DAC members.”

   Panel members felt that the public would want to know who is making the decisions and that making this information public builds trust – especially if there are regular members of the public involved. They felt it is important to be sure that these public members are truly there to speak up for the public and don’t have any hidden interests. When people can see who is on the committee and what their roles are, it gives them confidence that decisions are fair and made by qualified individuals.
5. **Decision criteria and consistency:** Panel members said they want the Wessex DAC to use a clear and fair set of rules when judging projects. They felt everyone should know what these rules are, such as how public benefit, scientific value, and privacy risks are weighed. The panel suggested having a clear scoring system or criteria, and that these should be made public alongside the decision-making process, so people can see that decisions are made fairly and not left to chance. They believe a standard process helps prevent bias and builds trust in how decisions are made.

6. **Publish decisions and reasons:** A critical ask was that “DAC decisions are published to the public,” along with a “summary of reasons behind decisions”. Once the committee makes a decision on a research application – whether it is approved or rejected – this outcome, along with an explanation, should be shared with the public. Listing these decisions helps everyone understand why certain projects go ahead or are stopped. For example, if a controversial project was allowed, the public can see the justification (e.g. strong safeguards, high public benefit), whilst if something was rejected, people know it was for good reason (e.g. insufficient benefit or too high risk). This is about accountability: the committee’s decisions are open to public view, showing that decisions are made fairly and carefully, not in secret.

7. **Ongoing project transparency:** The Panel wanted transparency across the full research lifecycle, including when a project is running and the impacts after it is complete. For each approved project, people should be able to see that it continues to meet all requirements. The Panel suggested there should be proof that “every project has gone through the process” and is being checked. They want reassurance that approved projects are running as promised, with regular monitoring and updates on progress. When projects are finished, results or at least progress reports should be shared with the public. This keeps things open and shows that projects are delivering the benefits they promised.

8. **Transparency of how NHS resources are used:** Panel members also said the public should see how much the SDE costs and how its resources are used, with open

accounting. They suggested sharing spending details for each project or overall, so people can understand which projects use the most staff time or money and judge if the benefits are worth the costs.

9. **Strong record-keeping:** Good record-keeping at every stage means decisions can be checked and reviewed later. This helps make sure everything is done properly and allows for learning and improvement. The Panel agreed that clear records are essential for transparency.

The Panel was asked to consider which governance decisions about data access could be delegated and which should require direct involvement from the Wessex DAC. Their views were as follows:

10. **Decisions suitable for delegation:** There was support for streamlining the approval process for standard or familiar research projects, recognising the importance of efficiency and minimising bureaucracy. Participants felt routine and low-risk project approvals and technical feasibility checks could be handled by the SDE's operational team as long as there was consistent application of established decision-making principles and clear oversight mechanisms. Similarly, participants were generally comfortable delegating technical assessments and feasibility checks. However, in this context they insisted on clearly defined roles and transparency in job descriptions to prevent conflicts of interest and undue influence.
11. **Decisions requiring direct DAC involvement:** Participants stressed that the DAC should directly handle approvals for: (a) ethically complex, sensitive, or controversial research; (b) projects involving significant privacy risks or potential re-identification of individuals; (c) research with commercial partners; or (d) using highly sensitive data (such as genetic information). Direct DAC oversight was seen as essential to maintaining public trust, ensuring thorough ethical scrutiny, and protecting the public interest.

Conclusions

In summary, several key themes emerge as critical to the Public Panel for building public trust in the governance of the data access.

Transparency emerged as the central theme, emphasising openness at all stages; from the visibility of incoming research proposals and clarity about applicants to clear communication regarding DAC membership, decision-making criteria, approved project outcomes, and resource allocation.

Clearly defined roles and responsibilities were highlighted as essential for maintaining impartiality and trust, particularly in avoiding conflicts of interest during technical assessments and decision-making.

The Panel supported streamlining approvals for routine projects to ensure an efficient process but stressed the necessity of direct DAC oversight for ethically complex or high-risk research involving privacy concerns or commercial partnerships.

These core themes will guide the Wessex Data Access Committee's governance development and support broader actions to build and sustain public trust.

Value return insights

Whilst this topic is to some extent covered by the ‘Strategic Research Priorities’ output of the Public Panel it is helpful to explore deeper how the Panel members ranked different aspects of “value return”.

"Value return" refers to the range of benefits or returns the NHS and broader community might gain from supporting or participating in research within the Wessex Secure Data Environment (SDE). Understanding public attitudes towards value return is important as it ensures that NHS initiatives align with community priorities and expectations, thereby fostering trust and informed support.

The second session of the Public Panel tackled the issue of value return. Public Panel members were asked to evaluate and score a range of potential "value returns" generated by NHS patient data research initiatives. By this stage in the programme, panel participants had engaged extensively with diverse research examples and case studies, gaining a robust understanding of the research ecosystem. Examples explored included scenarios involving early disease diagnosis, technology-driven clinical decision-making, development of new treatments, intellectual property considerations, and the economic impacts of healthcare research investment. As a result, the Public Panel had a shared understanding that "value return" could take a number of forms, including not only direct financial returns but also broader health and social outcomes.

Participants were presented with a list of "types of value" (see Figure 7 below) they were asked to review and discuss them and then rate each on a five-point scale (with 5 representing highest value and 1 representing lowest). They also had the option of adding new kinds of value or not scoring items at all. Alongside the scoring, Panel members provided explanations of their ratings, enabling a deeper understanding of their priorities and concerns.

Figure 7: Examples of different kinds of public value presented to the Public Panel

Lump sum financial benefit	Share in future profits	Intellectual property ownership	Early or discounted access to new treatments	Increased inward investment in Wessex
Improved population health	Reduced NHS costs	New academic insights	Treatments for rare conditions	Greater clinical trial availability
International healthcare impact	Improved clinical decisions (e.g. supported by AI)	Early and accurate diagnoses	New drugs, technologies & treatments	Reducing inequalities

The table below (**Figure 8**) presents the averaged ranking of each type of value return, based on Public Panel members' scores, alongside qualitative reasons drawn from participants' explanations. Scores range from 1 (lowest perceived importance) to 5 (highest importance).

Figure 8: Different kinds of value return ranked by Panel members

Value	Score	Reason
Early and accurate diagnoses	4.9	Early, accurate diagnoses are overwhelmingly prioritised by participants as critical for improving patient outcomes, reflecting a belief that health outcomes should always be the NHS's primary goal. While a minority highlighted cost reductions as essential for effective resource allocation, the consensus clearly places better health above financial considerations.
Improved population health	4.6	Participants strongly agreed that improving population health is beneficial for all and has long-term cost-saving implications for the NHS.
Reducing inequalities	4.3	Reducing healthcare inequalities was broadly supported as a fundamental NHS value essential to ensuring fair and equal healthcare access. A minority questioned its immediate relevance to specific populations, but the overwhelming sentiment affirmed its foundational importance.
New drugs, technologies & treatments	4.3	There was strong consensus that new treatments and technologies significantly improve patient outcomes and help reduce NHS costs over time.
Reduced NHS costs	4.2	Participants viewed cost reduction as crucial for NHS sustainability, enabling resources to be better allocated across health services.
Early or discounted access to new treatments	4.2	Early or discounted access to new treatments was considered valuable as it improves patient outcomes and ensures financial fairness. Participants strongly supported this dual benefit of health improvements and cost-effectiveness.
Improved clinical decisions (e.g. supported by AI)	4.1	Participants generally valued AI-supported clinical decisions due to their potential to improve outcomes, though some expressed reservations rooted in distrust or lack of understanding, slightly moderating overall enthusiasm.
Greater clinical trial availability	3.6	Clinical trials were recognised as offering significant benefits and hope, particularly for patients with limited options. However, their immediate benefits were less

		widely understood by participants without direct personal experiences, which limited broader enthusiasm.
Intellectual property ownership	3.5	Owning intellectual property rights was acknowledged as potentially providing sustainable income for the NHS. However, uncertainty and concerns about how IP rights would be distributed tempered participant enthusiasm.
Increased inward investment in Wessex	3.0	Increased investment was acknowledged as beneficial, but most participants strongly prioritised health outcomes over local economic gains, limiting overall enthusiasm for investment as a priority.
New academic insights	3.0	Participants recognised the foundational importance of academic research but considered it somewhat abstract and less immediately tangible compared to clinical treatments. While valued for future discovery, it was a lower priority overall.
International healthcare impact	2.9	Participants viewed international healthcare impacts positively in principle, but they generally did not consider them immediately relevant or prioritised for the Wessex region specifically.
Treatments for rare conditions	2.8	While recognising the importance of treating rare conditions, participants felt these benefits were limited in broader impact. A minority supported targeted investment in rare diseases, but most preferred prioritising common conditions with wider reach.
Share in future profits	2.2	Participants expressed considerable uncertainty regarding the value of sharing future profits, generally favouring immediate and tangible benefits instead. Though some saw potential value, the prevailing view favoured clarity and immediacy over uncertain long-term financial outcomes.
Lump sum financial benefit	2.1	Lump sum payments were widely viewed as short-term solutions offering no sustainable long-term benefit. While a few participants saw initial lump sums as helpful to support the SDE’s initial viability, most preferred longer-term financial stability strategies.

Interpretation and robustness

At this stage of the deliberative process, panel members had been given a good background on the SDE and data-driven research and had engaged in discussions about aa range of research examples, including both typical and exceptional cases.

Nevertheless, while these scores provide valuable insights, it is important to interpret them with several caveats in mind:

- **Contextual Prioritisation:** Participants consistently emphasised direct health benefits as the foremost priority, often ranking tangible patient outcomes higher than more abstract or longer-term financial gains.
- **Clarity of Benefits:** There was a clear preference for outcomes that were immediately understandable, achievable, and directly related to patient wellbeing or NHS efficiency.
- **Variability and Ambiguity:** Some areas, particularly those relating to financial returns such as profit-sharing or lump sum payments, showed considerable participant uncertainty or ambiguity. These lower scores reflect participants' cautious approach rather than outright rejection.
- **Limited Personal Experience:** Areas such as clinical trial availability or treatments for rare conditions scored moderately, reflecting a general lack of direct personal experience or immediate relevance for many participants.

Conclusion & next steps

This section brings together what the Public Panel has asked of the Wessex SDE and how the programme will respond. The Panel's role went beyond consultation: members worked directly with the SDE team to co-design the values, priorities, and actions that should guide the SDE service. The outputs are therefore co-owned by public participants and the programme team equally, reflecting lived and learned experience working together.

While the outcomes of the Panel are co-owned, responsibility for implementation now rests with the Wessex SDE team. The expectation is that the SDE team will now make best endeavours to implement the recommendations in full wherever possible, adapting them only where legal, contractual, technical or resourcing limits require, and explaining openly what they are doing and why.

Throughout this implementation process it is expected that the SDE's Digital Critical Friends group (a standing group of public participants) will play a continuing role in scrutinising this process, ensuring that delivery remains true to the Public Panel's intent and the spirit of co-design.

A clear public mandate

Overall, the Panel gave clear support and a mandate to the SDE to use NHS patient data for research, on the basis of certain safeguards and limitations. Members supported research that uses de-identified NHS data as a public good and set the conditions for trust: deliver tangible health benefit for people across Wessex; uphold principles of transparency, privacy and inclusion; and embed strong safeguards and governance so data is used ethically and effectively.

Taken together, the Core Values, Strategic Research Priorities, and Actions to Build Trust drafted by the Panel provide a practical blueprint for an SDE that accelerates research while maintaining public confidence. Alongside this, the Panel also expressed a pragmatic instinct: they wanted the SDE to "get on with it" and avoid unnecessary bureaucracy – scrutiny and safeguards should be proportionate to risk – so that good research can proceed at pace.

Interpreting the mandate

Looking across the report, there are some broader lessons that help to explain what the Public Panel's mandate is likely to mean in practice.

First, **trust is not something that can be won through words or promises alone**. For the Panel, trust has to be demonstrated through the way the SDE works every day. This means being transparent about decisions, subjecting the SDE to independent audits and reviews, and reporting openly on the benefits delivered. In other words, trust is an operating model – a set of visible behaviours – rather than a message.

Second, the way the Panel structured its recommendations matters. The Core Values define the boundaries of what is acceptable and unacceptable – the “red lines” of the SDE’s social licence. The Strategic Research Priorities provide direction, identifying the types of research the public wants to see prioritised. The Actions to Build Trust then translate those values and priorities into practical steps that make them real. Together, these three layers explain not just what the SDE should aim to do, but how it should behave in doing it.

Third, **public support is conditional and proportionate**. People expect much stricter rules and safeguards when the risks are higher – for example, where there is sensitive data, any re-identification of individuals (such as for clinical trials), or involvement of commercial partners. By contrast, they were content with lighter-touch processes for routine or low-risk research.

Fourth, **equity must be designed in from the start**. Unless data quality, sampling, and the way outcomes are measured actively include under-represented groups, there is a risk the SDE could deepen existing health inequalities rather than reduce them.

Fifth, the Panel supported **a two-speed approach to delivery**. They wanted to see quick wins that use existing data to produce early benefits and reduce bureaucracy – this helps to build public confidence that the SDE can deliver. At the same time, they stressed the importance of investing in longer-term prevention and NHS system change to secure sustainable benefit over time.

Sixth, the public were **pragmatic about working with industry**. They could see the value of bringing in external skills and funding, but only if such partnerships are clearly in the public interest. For them, this means measurable benefits for the NHS, complete transparency, and safeguards with real sanctions and consequences if agreements are broken.

Finally, the Panel took a **“governance first, technology second” view**. They believed the credibility of the SDE depends as much on clarity of roles, robust conflict-of-interest policies, independent oversight and effective audit, as on the technical features of the data platform itself. They also wanted the SDE to function as a learning system, reporting annually in public on what has been achieved, what has been learned, and how it will continue to improve.

In plain terms, the Panel’s mandate is that the Wessex SDE must prove its value and earn trust through what it does, not what it says – and that is an ongoing process. It should be guided by clear values, focus its research on the areas that matter most to Wessex people, and follow through with concrete actions that make those commitments real.

Safeguards should match the level of risk, equity must be built in from the outset, and delivery should combine quick wins with longer-term improvements. Partnerships with industry are acceptable only on public terms, and strong governance and accountability are at least as important as technical features. Above all, the SDE should be open about its progress, learn from experience, and show in practice how it is acting in the public interest.

From mandate to delivery

Turning the Panel's recommendations into action will follow some general principles.

Whilst recommendations made by the Public Panel are likely to have broad support in the wider community – as they have been developed by a reflective sample of the Wessex population – this is an assumption that needs to be tested. By the end of the four days of deliberation the Public Panel members had absorbed a lot of information and worked hard on understanding and developing their thinking about the SDE. They are therefore less reflective of the general population at the end of the process than they were at the beginning.

It therefore makes sense to test the Public Panel recommendations with a wider audience. Within a reasonable timeframe, the SDE needs to host a "big conversation" with the wider Wessex public to test and validate Panel findings. The aim should be to reach a wide audience through a mix of qualitative and quantitative methods, for example local press, community events, surveys, social media, and potentially a polling a statistically robust sample of the population. This should all aim to test the emerging consensus and gather new perspectives.

The development of the SDE cannot, however, wait for this process to be complete and service design and governance must continue in order to meet funder and sponsor expectations. Implementation of the Panel's findings should therefore continue in parallel; if the wider public conversation challenges or refines these findings then changes can be incorporated as the service evolves.

The Wessex SDE team will use best endeavours to put the Public Panel's findings into practice, making changes only when this is unavoidable and always explaining why. Where recommendations compete or cannot be implemented, the team is expected to be transparent about the trade-offs involved, how the underlying intent has still been addressed, or justifying clearly why recommendations have not been taken forward.

A plain-English "you said, we did" report should be published in due course, showing for each Panel recommendation whether it will be taken forward as is, adapted or deferred, with the reasons, the owner, and the expected timescale.

As implementation is an ongoing and evolving process, continued public involvement is essential. The SDE's Digital Critical Friends (DCF) group will be at the heart of keeping the SDE aligned with the public's expectations, through scrutiny of implementation plans and the detail of emerging policy.

What good looks like at go-live

When the SDE goes live, success will be visible in how it works as much as in what it delivers. Based on the Public Panel's we draw some conclusions about what this might look like. There should be a functioning Wessex Data Access Committee (DAC), making decisions about which research projects go ahead. This committee should include public members alongside experts, and its decisions and decision-making criteria should be clear, consistent and made public.

Alongside this, the SDE should have core governance policies and standard operating procedures (SOPs) in place. These would cover the issues the public has said matter most, for example: transparency in how decisions are made, clear rules on conflicts of interest and separation of roles, and explicit steps to identify and address health inequalities. Together, these measures would show that governance is robust, fair, and trustworthy.

For the wider community, transparency will be just as important. By go-live there should be an initial version of a public project registry, giving people a way to see what kinds of research are being approved, with plain-language summaries accessible to non-specialists. Alongside this, the SDE should start to report publicly on its early benefits and impact in terms that matter to people: for example, how research is contributing to improvements in population health, quality of life, or efficiency in the NHS.

Finally, the SDE should have summaries of what it does and how it does it, alongside opt-out information published in clear, straightforward language. This ensures that members of the public can understand what the SDE does, how their data is safeguarded, and make informed choices about participation.

In short, “good at go-live” means a system that is already demonstrating strong governance, visible accountability, and clear public benefit – laying the foundations of trust from day one.

Future engagement and legacy

The Public Panel made it clear that ongoing involvement of patients and the public is critical to the success of the SDE. This cannot be a one-off exercise. The Panel’s work is therefore the foundation of a continuing partnership with people across Wessex.

A key next step will be a ‘big conversation’ with the wider Wessex public, described earlier in this report. This is needed both to test whether the Panel’s findings reflect the views of the wider Wessex population, and to give more people the chance to hear about the SDE, understand what it will do, and take an informed view on how their data is used. This is a vital part of building a broad public mandate.

Our Digital Critical Friends (DCF) group will also play a central role in carrying this work forward. Their job will be to act as the public’s ongoing representatives, scrutinising the SDE’s activities and ensuring that it continues to meet public expectations and live up to the social licence established through this process. The DCF’s role will be broad – from checking that the programme is delivering on the values and commitments set out here, through to reviewing detailed new policies as the SDE and wider data environment evolve.

Interested Panel members will be invited to join this group to ensure continuity and bring in their experience and perspectives.

As the programme builds experience and capability, there is also potential to use further deliberative panels, citizen juries or other co-design methods to explore specific questions in future. This means that deliberation is not the end of a process, but a tool that can be called on as new issues arise.

Closing the loop will be just as important. The SDE will need to return to the wider Wessex public – including seldom-heard groups engaged in the first phase – to show clearly how their views have influenced the design of the programme and its governance. Just as importantly, the SDE will need to report back on the public benefit it is delivering. For example, enabling new kinds of research, accelerating how quickly studies can be completed, or supporting improvements in patient care and NHS efficiency.

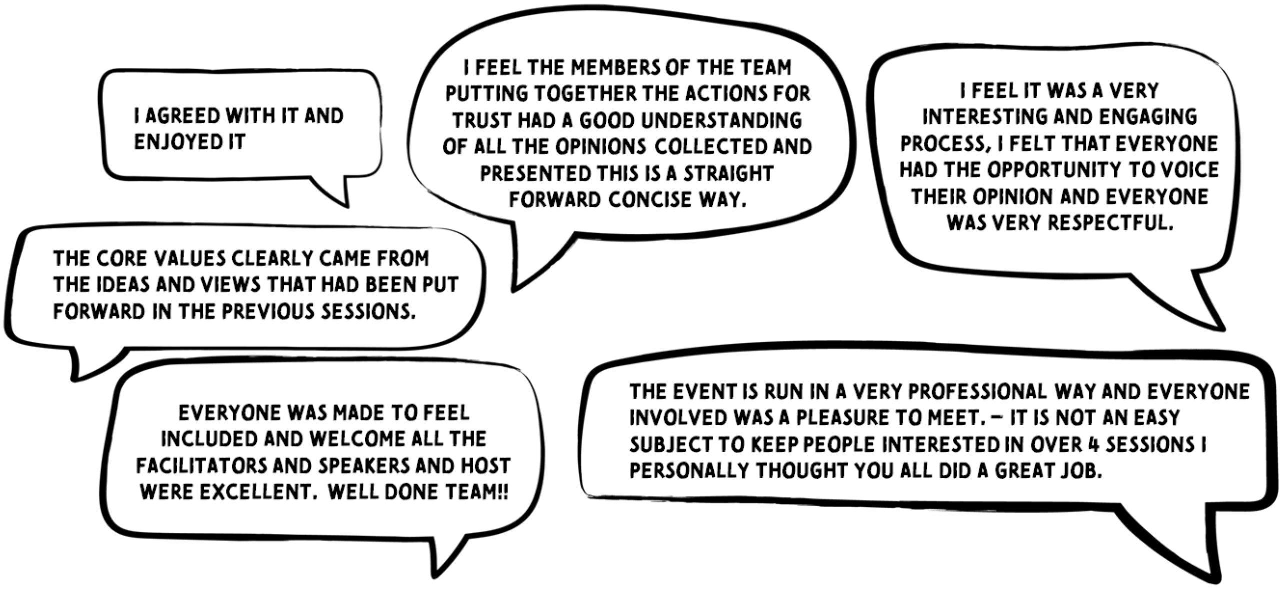
Finally, the programme acknowledges the contribution of all who took part – the public participants, facilitators, clinical and academic contributors, community partners and colleagues. Their combined efforts have shown that it is possible to bring together diverse voices and perspectives to shape a complex programme. The next phase will be demanding, but the reward is a robust and trusted SDE that not only accelerates research and innovation but does so in a way that visibly reflects and respects the values of the people it serves.

Reflections and learnings

Following each deliberative session, the Wessex SDE team gathered structured feedback from both participants and facilitators to understand how well the process was working. This included asking whether the information provided was pitched at the right level, whether there was enough time for discussion and reflection, and whether people felt able to contribute meaningfully and comfortably. Feedback was also sought on the practicalities of the sessions, such as the pace of delivery, opportunities for breaks, and the overall environment for discussion.

Overall, participants found the sessions engaging and informative. **Figure 9** below provides a sample of verbatim feedback from Public Panel members. Almost all enjoyed the experience a lot, valued the opportunity to learn more about research, to share their own views, and to hear perspectives from people with different backgrounds. The respectful and inclusive atmosphere was frequently praised, with survey results showing strong agreement that participants felt listened to and respected, even when views differed. This sense of being heard and valued is a cornerstone of a high-quality deliberative process.

Figure 9: Participant feedback on the Wessex Public Panel on NHS Data



Several recurring themes emerged:

- **Organisation and logistics:** Both participants and facilitators highlighted the strength of the organisation. The events were seen as well run, with good timekeeping and professional facilitation. However, some participants felt that the amount of material sometimes made sessions feel rushed or too tightly packed.

- **Clarity and balance of information:** Information was seen as useful and engaging. Facilitators noted that participants were stimulated by the content, but there were also calls for clearer advance outlines of what each session would cover. Note that this point was addressed in later sessions of the Public Panel with a printed agenda being made available (see **Appendices C-E** for examples of public-facing agendas). Acronyms and technical terms were a common challenge, with requests for plainer language and consistent explanations.
- **Group discussion experience:** Small group work was especially valued by participants, who reported that it created a respectful and safe space for discussion. Facilitators observed that this allowed more balanced contributions. However, in larger groups, some participants noted that a few individuals dominated or took conversations off topic.
- **Usefulness of research examples:** Both participants and facilitators agreed that real-world case studies were a really effective way of grounding the discussion. Examples linked to familiar health issues, such as dementia, resonated strongly with participants, helping abstract ideas about data use feel more relevant and concrete.
- **Time for reflection and depth:** Participants, and facilitators on their behalf, sometimes said they need more time to explore complex or sensitive issues. Some felt that the final sessions in particular were dense and did not allow enough space for reflection or deeper exploration.
- **Atmosphere and overall satisfaction:** Participants consistently described the process as enjoyable, eye-opening, and worthwhile. They appreciated meeting new people, learning about the NHS and research, and contributing to shaping the SDE. Facilitators echoed this, noting the high levels of engagement and positive energy in the room.

From this feedback, a number of learnings can be drawn for future engagement. Clearer advance information and session outlines would help participants feel prepared. More time should be set aside for complex discussions, even if this means simplifying other content. Technical language should be minimised or carefully explained. Group sizes should remain small to give everyone a chance to contribute, and facilitators should actively manage dynamics to avoid any one voice dominating. Using concrete case studies was a powerful tool and should continue. Finally, participants and facilitators alike stressed the importance of a visible feedback loop – what is sometimes described as “you said, we did” – to show how contributions are acted on.

Taken together, these reflections highlight the strengths of the process while also offering practical improvements for the future. They show that when people are given the right environment, information, and support, they are keen and able to contribute meaningfully to decisions about the use of NHS data.

One of the wider lessons from this process is about finding the right balance between making discussions accessible and keeping them challenging. Over four days of deliberation it is natural that, at times, some individuals felt tired, lost focus, or found particular topics difficult. But this was never the same people throughout, and the overall quality of the results reflects how well the group worked together. The Panel was asked to grapple with some demanding subjects, and they rose to the challenge.

The organisers’ view is that this balance was about right: the Panel was supported with clear facilitation and real-world examples, but not over-simplified or patronised. Rather than spending large amounts of time on introductory content, the approach was to inspire participants with engaging stories about research and then invite them to dig deeper. The feedback and outputs suggest this worked – participants tackled complex material and produced thoughtful, practical recommendations.

A final learning here is that in a deliberative process it is natural that not everyone will feel comfortable all of the time, and in fact some level of stretch and challenge is important to ensure the conversations go deep enough to produce meaningful outcomes.