Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS

Wessex Public Panel on NHS Data

July – September 2024

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

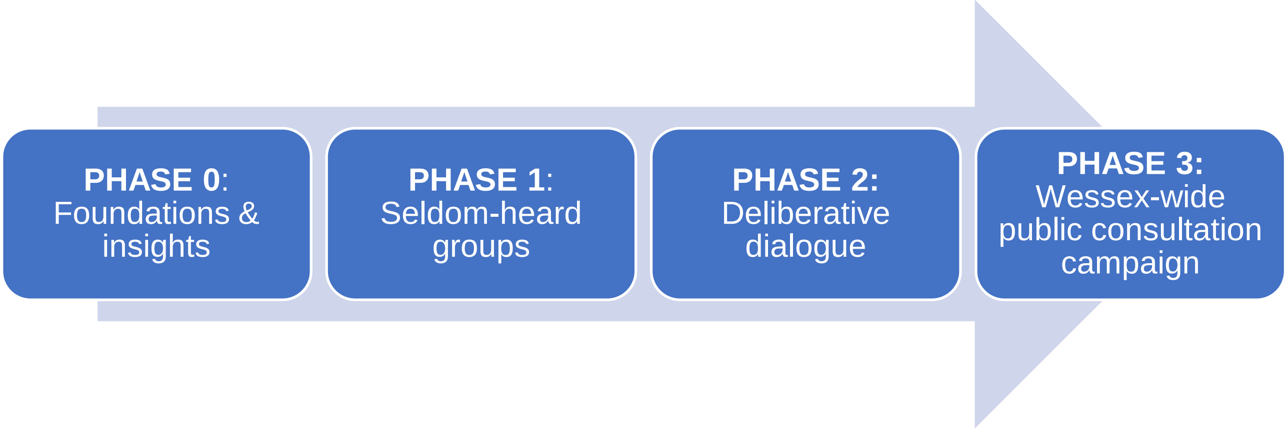
use within this wider context. This takes a considerable amount of time, and whilst it is a good foundation for public participants it does not generate new insights.

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.

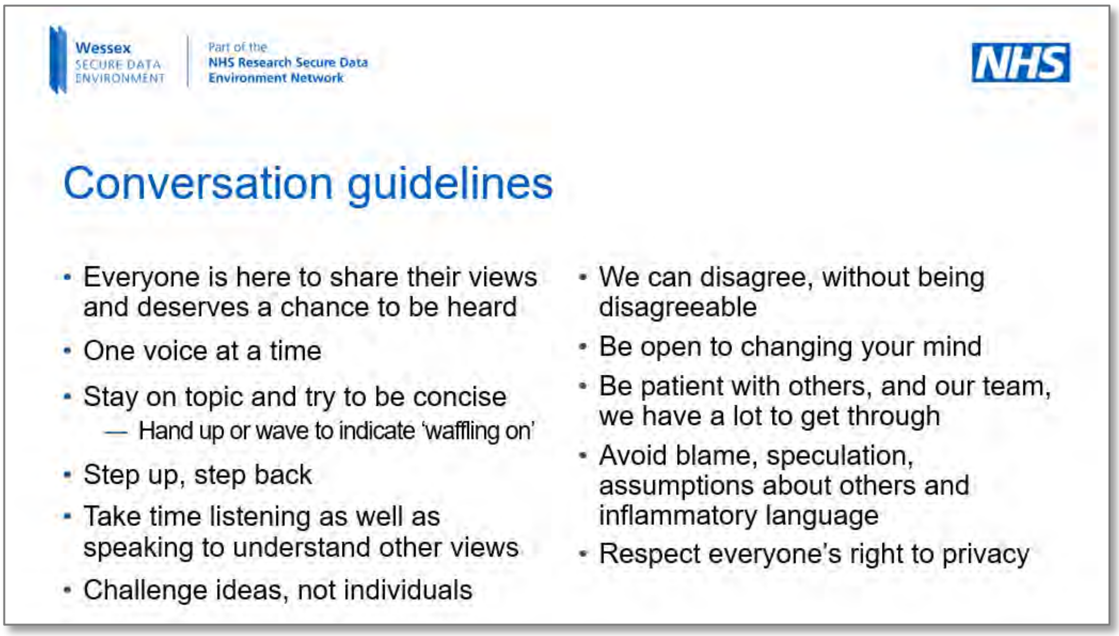
As set out above, the dialogue's **structure** and content were informed by preliminary research and stakeholder input. A discovery phase with internal stakeholders identified the main topics and decisions that required public input: the types of research the SDE might support, the governance and policy 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

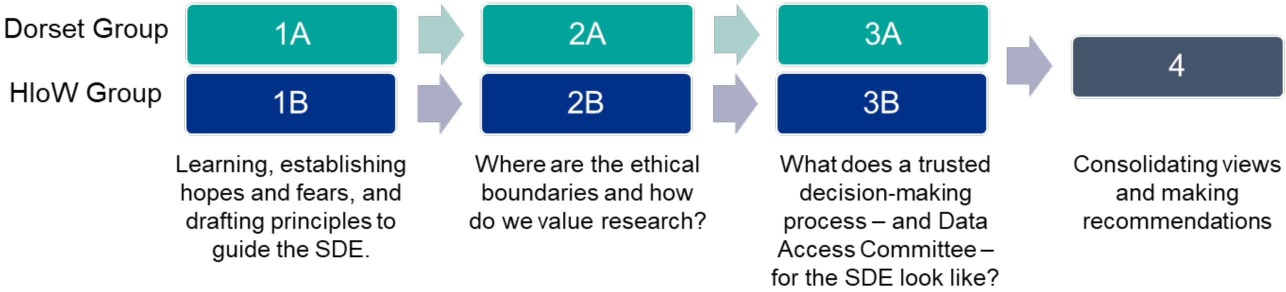
The table below explains the steps set out in **Figure 2**.

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.

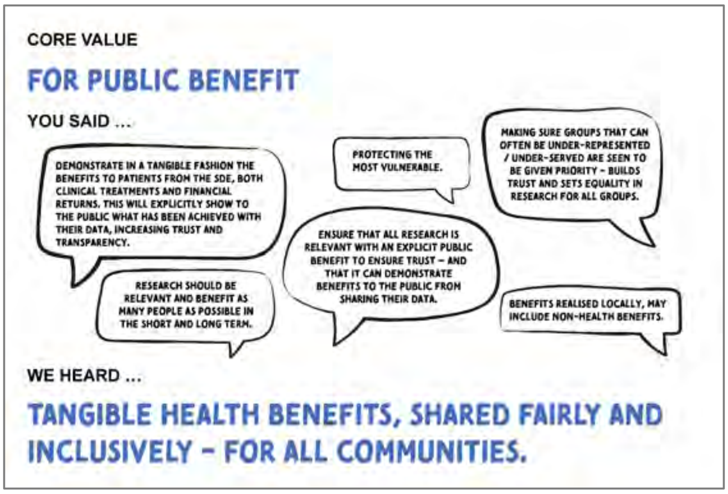
By the end of Day 4, the Public Panel had successfully endorsed a comprehensive and coherent set of recommendations, clearly supported by a majority, providing strategic clarity and a robust set of actions to maintain and build public trust in the SDE.

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.

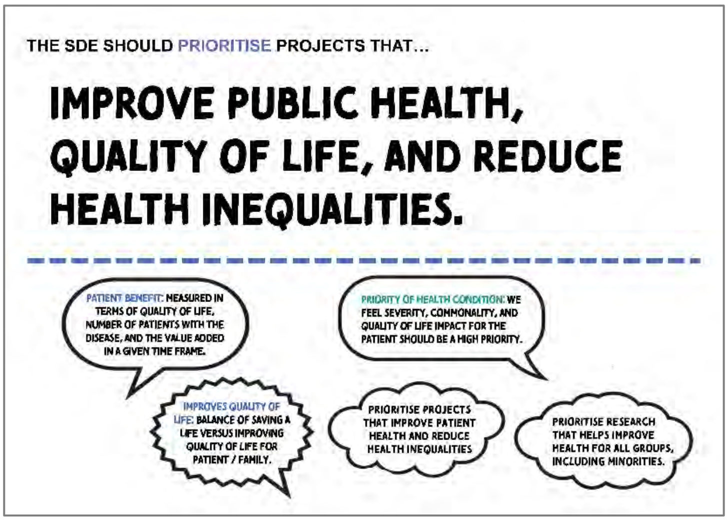
BENEFITS REALISED LOCALLY, MAY INCLUDE NON-HEALTH BENEFITS.

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.

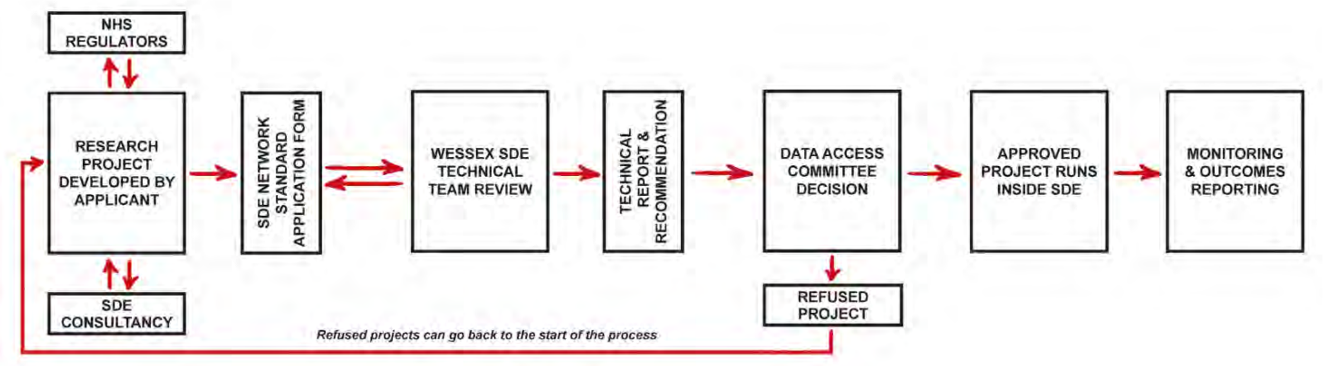
While the majority of actions received near-unanimous support, a handful generated more mixed views, reflecting genuine differences in emphasis across the group. These nuances are valuable: they highlight areas where implementation may need careful balancing of competing considerations.

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.

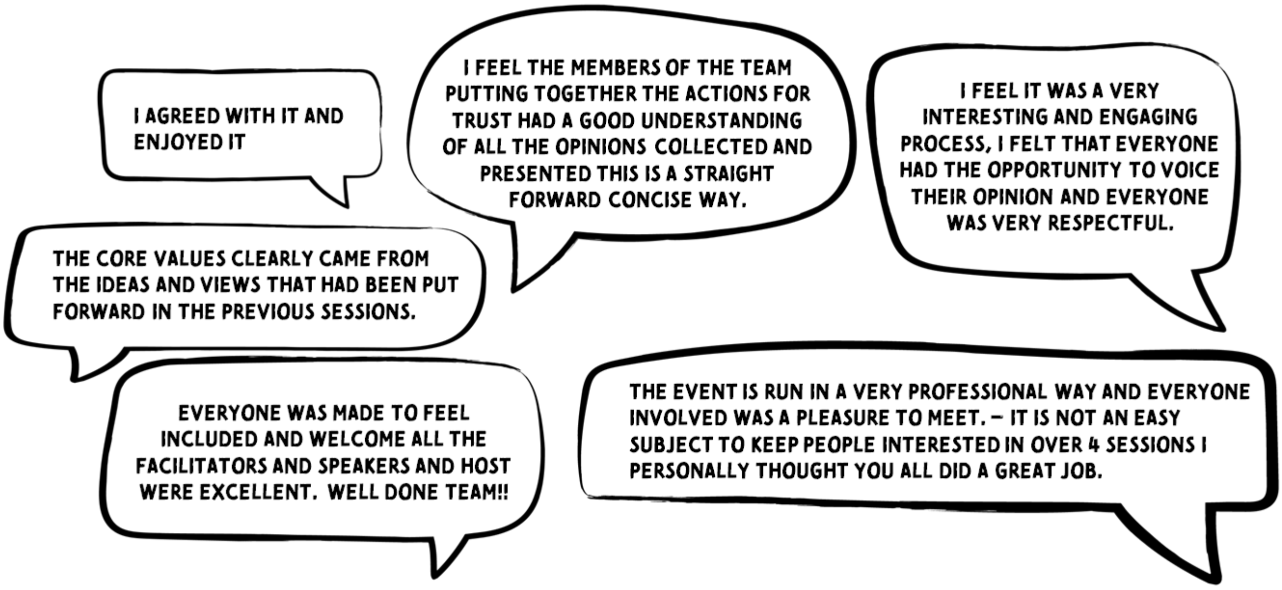
Finally, the programme acknowledges the contribution of all who took part – the public participants, facilitators, clinical and academic contributors, community partners and colleagues. Their combined efforts have shown that it is possible to bring together diverse voices and perspectives to shape a 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.

Appendices

Appendix 1: Recruitment and onboarding materials

Guide

This appendix sets out how participants were recruited and onboarded for the Wessex Public Panel on NHS Data.

To make sure the Public Panel reflected the diversity of people who live in Wessex, recruitment was carried out by the independent Sortition Foundation. They specialise in running civic lotteries that are fair and inclusive.

People were invited to take part through a random selection process, and from those who responded, a panel was chosen to be broadly **reflective of the local population**. This meant carefully balancing the final group so that it included people of different:

- Ages – from younger adults to older residents
- Genders
- Ethnic backgrounds
- Levels of education
- Health status and disability
- Places of residence – with participants drawn from both Dorset and Hampshire & the Isle of Wight

The Sortition Foundation also took account of areas of deprivation, so that the voices of people who are often under-represented in public discussions were included. This process gave us a panel of local residents who could bring a wide range of experiences and perspectives, helping to ensure that the Wessex SDE is designed in a way that works for everyone.

The process was split into two parts:

1. **Recruitment by the Sortition Foundation** – undertaken on the basis of the agreed *Scope of Work* (January 2024). The Sortition Foundation managed the design, printing and distribution of invitation packs, and selection of participants by lottery to achieve a reflective sample of the Wessex population.

    - Invitation letter with FAQs
    - Envelope and design proofs
    - Invitation card
    - Recruitment demographics (pie charts showing target, respondents, selected, confirmed) for Dorset and Hampshire/Isle of Wight

2. **Onboarding by the Wessex SDE team** – once the Sortition Foundation handed over the confirmed list of 58 participants, the SDE team managed onboarding. Each participant received a tailored Welcome Pack, which set out:

    - Event dates, times, and locations
    - What taking part would involve
    - Travel, accessibility, and payment arrangements
    - Pre-read glossary and briefing materials introducing the Wessex Secure Data Environment and NHS data use

Attachments in this appendix:

A. Invitation card, letter, envelope and FAQs

B. Recruitment demographics (Dorset and Hampshire and Isle of Wight cohorts) showing performance against recruitment targets

C. Dorset Welcome Pack (with glossary and briefing materials, a similar tailored pack was prepared for participants from Hampshire and the Isle of Wight)

A: Invitation card, letter, envelope and FAQs

You are invited to register your interest in the

Wessex Public Panel on NHS Data

How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?

Taking place over four days from July to September

Deadline for registering your interest in this event is **Sunday 23 June 2024**

Register at **www.sortition.uk/dorset**
or by phone on Freephone **0800 009 6486** (8am-10pm Monday to Friday, 9am-6pm Saturday, Sunday and bank holidays)

Take part and receive £600

Return address
Sortition Foundation,
32 Gilbert Close,
Cambridge, CB4 3HR

SCAN ME

“How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?”

Your address has been selected to receive this invitation to take part in the Wessex Public Panel on NHS Data.

Take part and receive £600.

Respond by **Sunday 23 June** to take part

NHS

3rd June 2024

Dear Resident,

You could be **one of 50 people** selected to take part in **Wessex Public Panel on NHS Data**, answering the important question:

How should we make the most of NHS data for research
to improve lives and health outcomes in Wessex?

NHS organisations in Wessex are building a secure online platform called the Wessex Secure Data Environment. Researchers will use it to access data safely, quickly, and easily to answer a huge variety of questions and discover life-changing new treatments and medicines for the benefit of all. We are organising this Public Panel so that local people are directly involved in its development, the values that guide it, and in how it is run.

The **Public Panel** will run across four Saturdays: 13 July, 10 August, 7 September in Bournemouth, and a final session on 28 September in Southampton. You need to attend all the sessions. **If you take part we will give you £600 to thank you for your time.**

You don't need any prior knowledge to take part in the Public Panel. All we ask of you is to listen to the information presented and share your opinions with us and the other people taking part like yourself. We want to hear from a real cross-section of people from Dorset. If your household has received this letter and you are aged 16 and over then you are the right person to take part!

Register your interest by visiting **www.sortition.uk/dorset** or by calling Freephone **0800 009 6486**. The deadline to register is **Sunday 23rd June**. The participants will then be selected by lottery. More details are available overleaf.

This is a fantastic opportunity to help to shape how the NHS uses data for research. We hope that you will be interested in joining the Public Panel and we look forward to hearing from you.

Yours faithfully,

Signature file needed

Dr Christopher Kipps
Wessex Secure Data Environment Project Lead and Professor of Clinical Neurology & Dementia
University Hospital Southampton NHS Foundation Trust

FREQUENTLY ASKED QUESTIONS: EVENT NAME

What is a Public Panel?

This event will follow an established democratic process that is used all over the world. It brings together a group of people selected by lottery, who broadly represent the entire community. The people who attend learn about issues, discuss them with one another, and then make recommendations about what should happen and how things should change.

Who is running the event?

University Hospital Southampton NHS Foundation Trust (UHS) is leading the Wessex Secure Data Environment on behalf of NHS organisations in Wessex. The Trust is a major centre for teaching and research, providing clinical care to nearly 4m people across the south of England and beyond. UHS is commissioning facilitation experts and partners across Wessex to deliver the project.

The Sortition Foundation is a not-for-profit organisation that specialises in recruiting and selecting people by lottery to take part in these kinds of events, in a way that is broadly representative of the wider population. www.sortitionfoundation.org

What will taking part involve?

If you are selected to take part you will have the opportunity to meet with individuals from all walks of life who live in Dorset. You will hear from engaging speakers, and you will discuss the issues involved in small groups, with facilitators to make sure everyone has their voice heard. You do not need to have any prior knowledge of the topics – all the information you need will be provided during the day.

When and where are the sessions?

- Bournemouth:
    - Saturday 13 July, 10am-4pm,
    - Saturday 10 August, 10am-4pm
    - Saturday 7 September, 10am-4pm
- Southampton:
    - Saturday 28 September, 10am-4pm

How will you ensure that the event is accessible?

The in-person meetings will be held at accessible venues with disabled parking available. Lunch will be provided, and transport expenses will be covered.

We are committed to accommodating the needs of all participants - please ask if you have any questions about accessibility and support services.

There is no dress code. Please wear whatever feels comfortable for you.

The information provided during the event will be as jargon-free as possible. There will be opportunities to ask speakers to explain what they mean if what they are saying is not clear.

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https://www.qr-code-generator.com/
QR CODE TO REGISTRATION PAGE HERE

To register your interest visit:
www.sortition.uk/dorset
or call Freephone **0800 009 6486**
(8am–10pm Monday to Friday, 9am–6pm on Saturday, Sunday and bank holidays)
by **Sunday 23rd June**

FREQUENTLY ASKED QUESTIONS: EVENT NAME

If you require any form of additional support, for example translation, or support with accessibility issues, childcare, or other caring responsibilities, then every attempt will be made to provide this. If you are selected please just let us know about your specific requirements when we contact you.

If you are selected to take part, you will receive **£600** to compensate you for your time. The stipend is optional and can alternatively be received in vouchers.

Who can apply?

Anyone aged 16 and over by the close of registrations, who is normally resident in the area and who lives full or part time at an address that has received this invitation can apply, with a few exceptions set out below. Please note that a maximum of one person from any single household will be selected to participate.

The following people cannot apply: Elected representatives from any level of government; paid employees of any political party; or local government or NHS employees working in any politically restricted post.

How was I selected to receive this invitation?

Your household was one of 17,400 addresses in Wessex that were selected by lottery from the Royal Mail address database.

After I register my interest, what happens next?

Once registration has closed, 50 people will be selected by lottery from those who registered their interest, to take part in the event.
The lottery process is done in a particular way to make sure that there are people from all across the community attending.

If you are selected, we will contact you by phone and email from Monday 24th June to let you know. We will then arrange a call with you to confirm that you can attend, discuss any requirements you may have to make it possible for you to attend, and explain what happens next.

What will happen after the event?

A report on recommendations from the Public Panel will be presented to the Wessex public through in person events, on our website, and through NHS partners across Wessex. It will be used to develop the design and operation of the Wessex Secure Data Environment.

Where can I get more information?

If you would like more information about the Public Panel before registering, please call the Freephone number below, or email wessex@sortitionfoundation.org. More information about the event will also be available from the registration page below.

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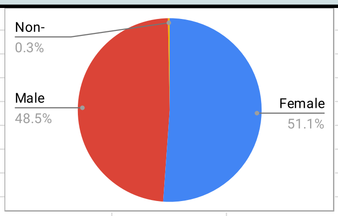
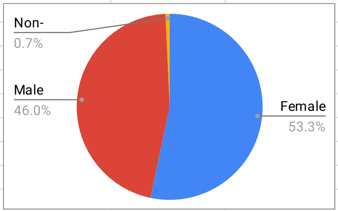
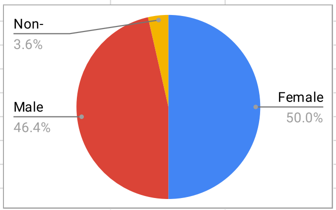
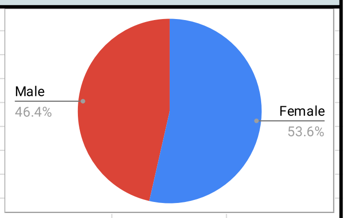
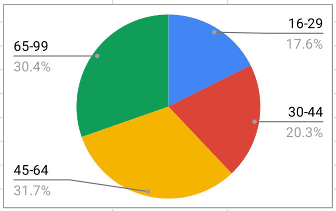
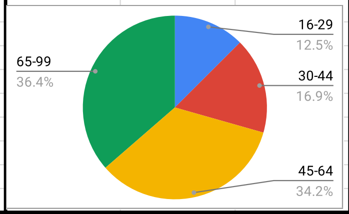
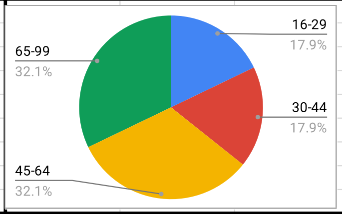
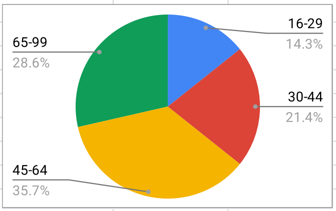
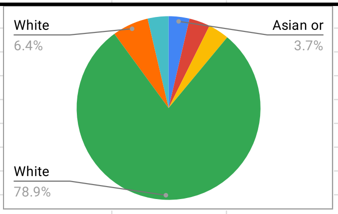
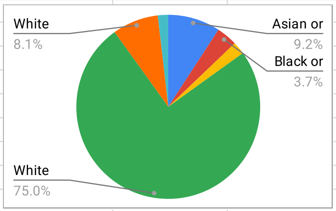
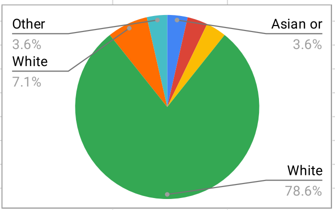
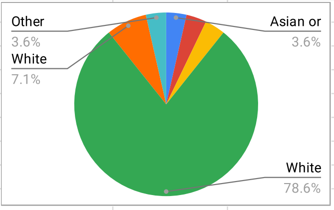
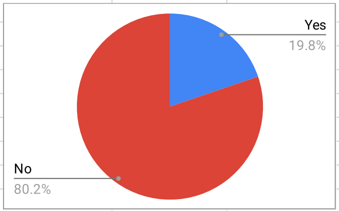
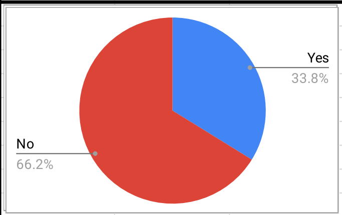
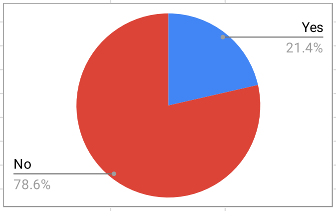
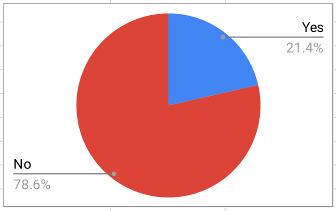
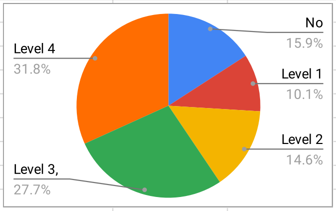
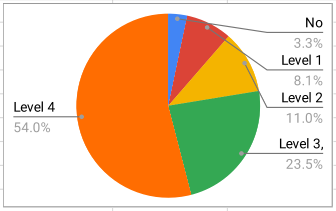
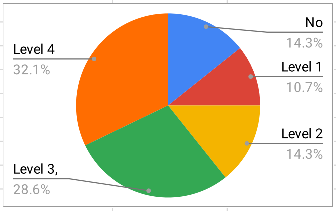
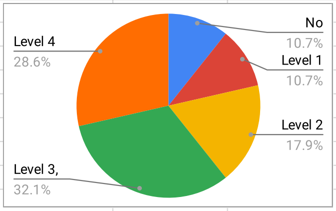
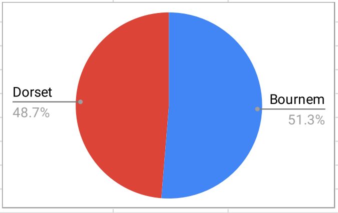
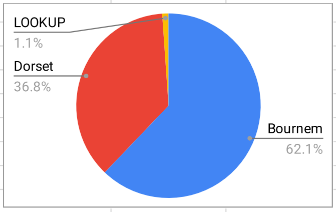
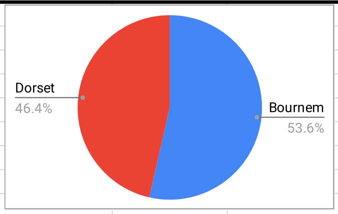
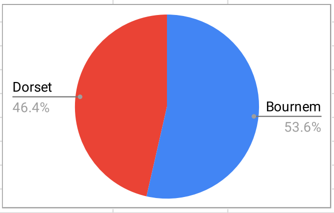
https://www.qr-code-generator.com/
QR CODE TO REGISTRATION PAGE HERE

To register your interest visit:
www.sortition.uk/dorset
or call Freephone **0800 009 6486**
(8am–10pm Monday to Friday, 9am–6pm on Saturday, Sunday and bank holidays)
by **Sunday 23rd June**

B: Recruitment demographics

Hampshire & Isle of Wight Cohort: Reflective target vs. confirmed attendees

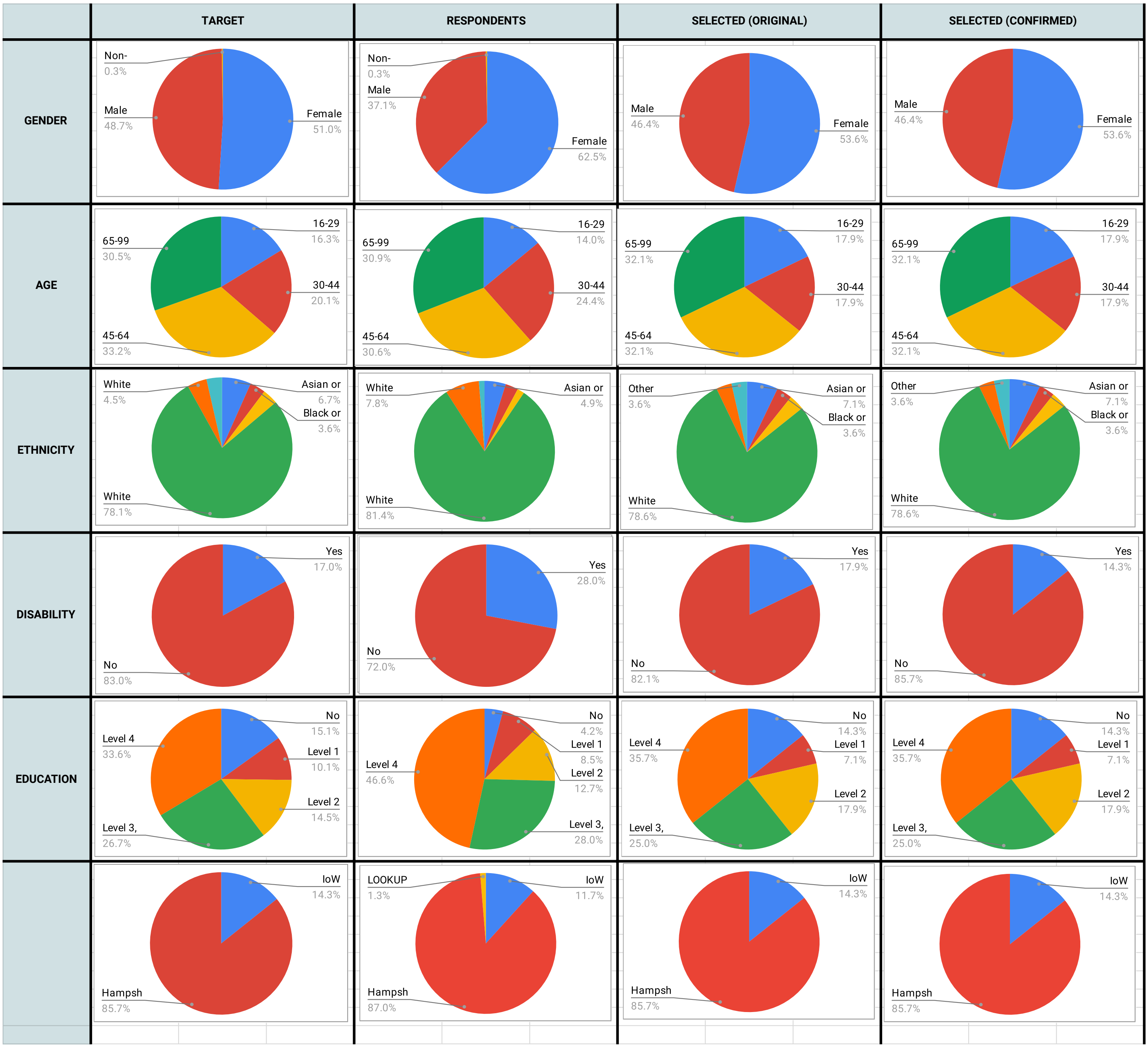
	TARGET	RESPONDENTS	SELECTED (ORIGINAL)	SELECTED (CONFIRMED)
GENDER				
AGE				
ETHNICITY				
DISABILITY				
				
				

Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data Environment Network

NHS

Dorset Cohort: Reflective target vs. confirmed attendees



C: Dorset Welcome Pack

Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS

Wessex Public Panel on NHS Data

Dorset Participant Welcome Pack

1 July 2024

Contents

Welcome

This welcome pack provides all the information you need to join the Wessex Secure Data Environment's Public Panel events for Hampshire and the Isle of Wight and get the most out of the experience.

It includes details about the venue and a questionnaire about you to help us meet your needs and pay you for your attendance and reasonable expenses.

If you have any questions or would like to discuss any concerns, we would be happy to hear from you. Contact details are provided below, we're also happy to call you back if you would like.

Dates, times and location

The first three events will take place at Bournemouth University's Gateway Building, 12 St Paul's Ln, Bournemouth BH8 8GP on the following dates:

- Saturday 13 July
- Saturday 10 August
- Saturday 7 September

The final event will take place at Southampton Football Club, St Mary's Stadium, Britannia Road, Southampton, Hampshire, SO14 5FP

- Saturday 28 September

All events will run from 10am to 4pm. The venue will be open from 9:30am, please arrive in time to find your way to the event and get a tea or coffee ready to start at 10am.

What will taking part involve

NHS organisations in Wessex are building a secure online platform called the Wessex Secure Data Environment, or SDE. This will enable researchers to access data safely, quickly, and easily to answer a huge variety of questions and discover life-changing new treatments and medicines for the benefit of all.

We are organising this Public Panel so that local people like you are directly involved in its development, the values that guide it, and in how it is run. Your voice is essential in shaping a transparent and trustworthy process.

We have two groups of about 25 people each. One recruited from Dorset and the other from Hampshire and the Isle of Wight.

Over the course of four sessions, we will provide you with information about how NHS patient data can be used for research – and how this is done safely and securely – so don't worry if you feel like this is all new to you and you don't yet understand the topic, the presentations at the meetings will give you all the information you'll need and there will be plenty of opportunities to ask questions.

We will also share examples of research projects that might want to use our Secure Data Environment – and get your views on what the benefits and risks these projects may bring.

A lot of the time in the meetings we will be working in small groups to discuss with you how we decide what research can happen in the future. Who should be taking these decisions? What should they be thinking about? How do we ensure that this process is transparent and trustworthy for the public? And sharing your conclusions with each other.

At the end of the Public Panel, we will bring together the two groups to share their ideas and together make recommendations. The SDE team has made a promise that these recommendations will be at the heart of how our secure data environment is designed and run.

There is also some reading material that will help you understand a little more about the Wessex Secure Data Environment. You don't have to read this if you are short on time - everything will be explained when you get to the first event, but it might make you feel a bit more prepared!

Pre-read materials

A selection of pre-read materials is provided at the end of this document that will help you understand a little more about the Wessex Secure Data Environment. You don't have to read this if you are short on time - everything will be explained when you get to the first event, but it might make you feel a bit more prepared!

Dietary requirements

Please fill in the on-line form if you have not done so already or contact Sarah with your dietary needs including allergies and intolerances.

Tel: 07796 274731

Email: sarah.knott@uhs.nhs.uk

Accessibility requirements

It is vital that everyone can fully participate in these events and we will do our best to accommodate your needs. This could include you needing extra space for your wheelchair, carer or assistance dog, large print documents, particular seating arrangements, financial support to cover your caring responsibilities, an interpreter or signer.

These can be entered into the online form if you have not done so already or please contact Sarah to discuss your needs.

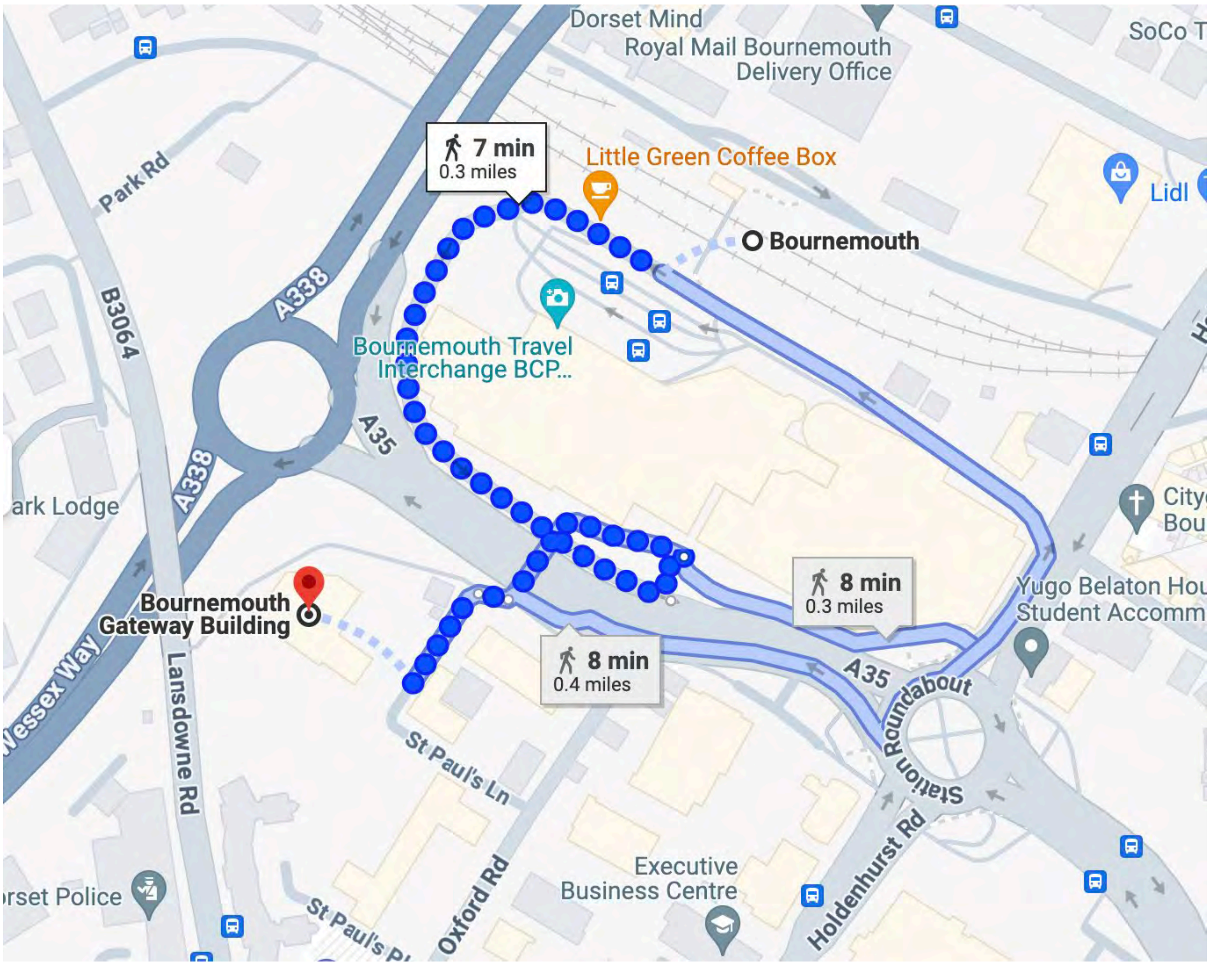
Tel: 07796 274731

Email: sarah.knott@uhs.nhs.uk

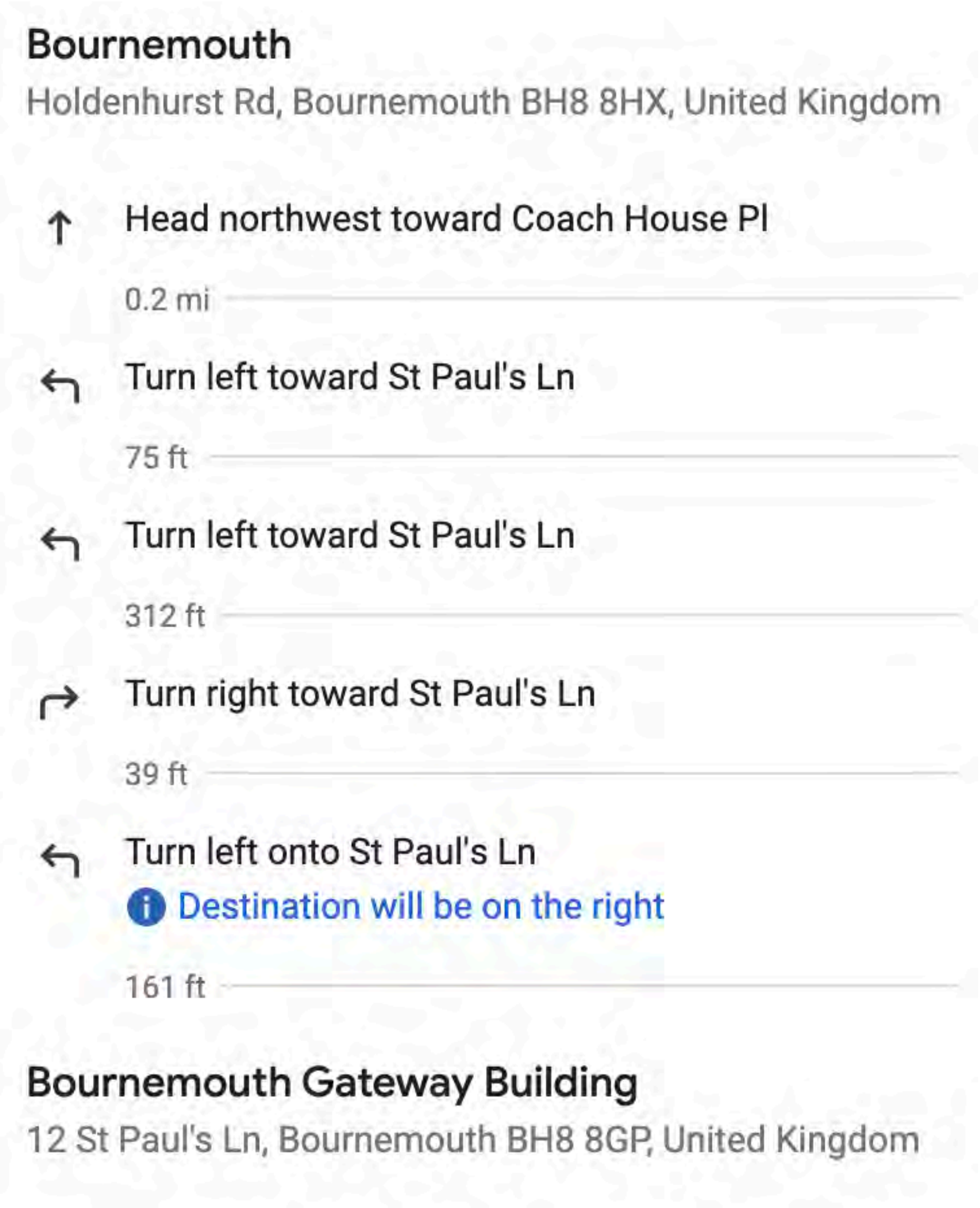
Your personal information will be kept confidential. We appreciate it can be difficult talking about your personal circumstances but we want to support you to attend these events and have the most enjoyable experience you can.

Directions to the venue

The map below shows the walking route from **Bournemouth Railway Station:**



Walking directions from **Bournemouth Railway Station**:



Bournemouth
Holdenhurst Rd, Bournemouth BH8 8HX, United Kingdom

↑ Head northwest toward Coach House Pl

0.2 mi

↰ Turn left toward St Paul's Ln

75 ft

↰ Turn left toward St Paul's Ln

312 ft

↱ Turn right toward St Paul's Ln

39 ft

↰ Turn left onto St Paul's Ln
ⓘ Destination will be on the right

161 ft

Bournemouth Gateway Building
12 St Paul's Ln, Bournemouth BH8 8GP, United Kingdom

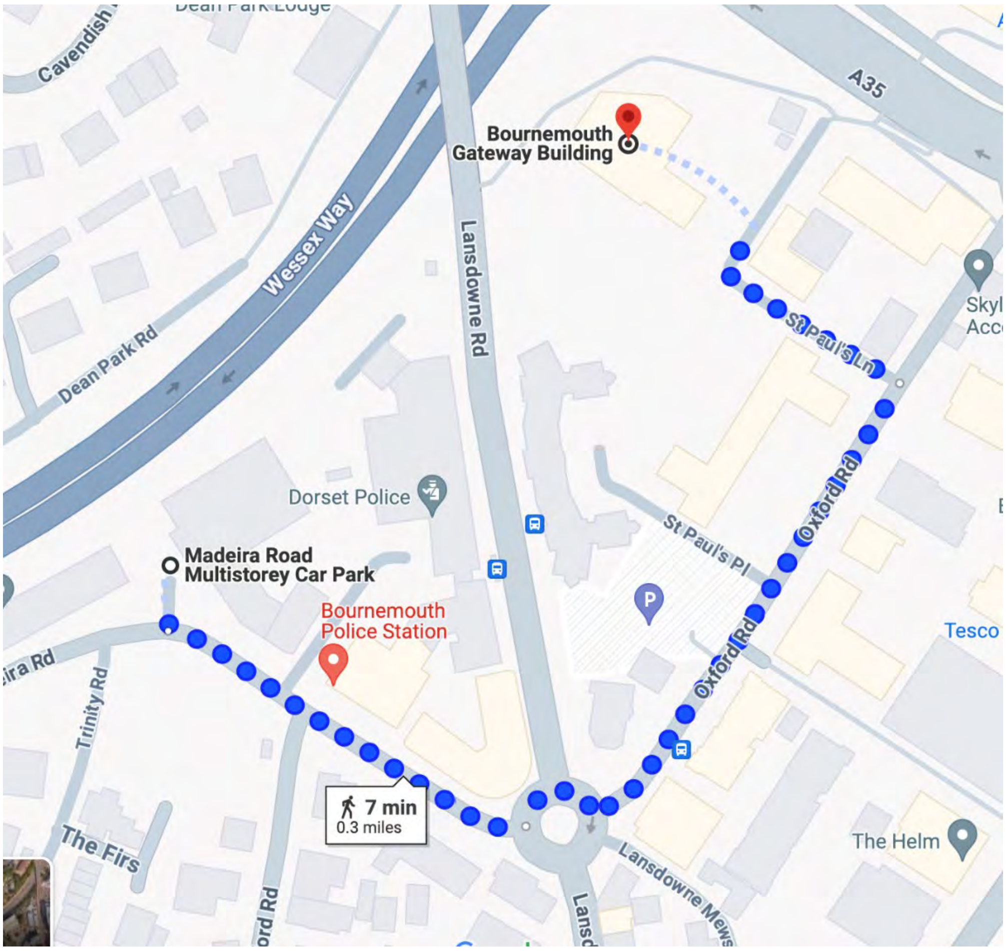
Venue parking

There is no parking available onsite, however there is a public car park nearby (approximately 200m). The name of the car park is Madeira Road Multistorey Car Park and is on the A338 Wessex Way, BH1 1QQ. The cost for the parking is £6.10 and will be covered by your expenses. If you have any questions about this or need additional support, please contact Sarah.

Tel: 07796 274731

Email: sarah.knott@uhs.nhs.uk

[Parking website]



Additional travel information

Further information on how to get to the Gateway building is available on the Bournemouth University site - [https://www.accessable.co.uk/bournemouth-university/access-guides/bournemouth-gateway#acff56cc-5a26-f040-8643-cc72e12e1f93]

Southampton Football Club

The final event on 28 September will be held at a different venue to the previous sessions. Details on how to get to the football club are available using [this link].

What to wear

There is no dress code. Please wear whatever feels comfortable for you.

Payments and attendance

You will be paid for attending these events and any reasonable expenses, so keep any receipts/tickets etc where possible. After the final event on the 28th September, you will be sent a claims form from University Hospital Southampton admin team to complete and return. You will be paid directly into your bank, usually within 2-3 weeks of us receiving your form.

Please contact Sarah if you have any questions, concerns or require additional support with payments or expenses.

What to do if you can't attend

We know that sometimes the unexpected happens and you might be unable to attend an event. Please notify Sarah if you can't attend an event or would like to withdraw from the Public Panel.

Tel: 07796 274731

Email: sarah.knott@uhs.nhs.uk

Pre-read: Background briefing notes

Over the next few pages we have provided some background information, introducing some important ideas across of brief and easy-to-understand briefing notes.

These notes will help you get familiar with some of the big ideas that will be discussed at the Wessex Public Panel on NHS data. They explain what data is and what data the NHS holds about you. It looks at how your data is managed by the NHS and how researchers can be given access to it safely, whilst protecting your privacy.

You can browse through the cards at your own pace and in any order. If you do have time to read them then that will help you to get the most out of the events. If you don't have time that is absolutely OK too – we will explain everything at the first event you attend.

We hope you find them useful and enjoyable. If you have any questions or feedback, please contact Sarah Knott at sarah.knott@uhs.nhs.uk.

Note that the 'Pre-read' referred to above is part of the Welcome Pack is reproduced at 'Appendix Z: Wessex SDE Toolkit'.

Appendix 2: Day 1 – Building understanding, exploring benefit & risk

Guide

This appendix contains all materials used in the first Public Panel session (20 July 2024, HIOW cohort; 13 July 2024, Dorset cohort).

Purpose of the day

The first session of the Public Panel focused on:

- Introduce participants to the Wessex Secure Data Environment (SDE) and the overarching question of the panel.
- Build understanding of how NHS data is currently used for research, and the opportunities and challenges of moving to an SDE model.
- Explore participants' initial hopes, fears, and principles for how a trusted data environment should operate.

The session combined expert presentations, small group discussion, and participatory exercises to make sure participants had the knowledge and confidence to contribute.

Key activities included:

- Learning about NHS patient data and the role of SDEs.
- Exploring attitudes towards health research and data-driven projects.
- Considering different data types and what feels "safe" or "risky" to use.
- Generating early hopes and fears for the SDE, captured as "newspaper headlines."
- Beginning to define values-based principles that should guide governance of the Wessex SDE.

Attachments in this appendix:

D. **Session 1 Facilitation Plan** – full agenda, timings, facilitator instructions, exercises, and materials required.

E. **Session 1 Master Deck** – participant slide deck, covering agenda, background to the SDE, case studies, exercises, and panel discussion prompts.

D: Session 1 Facilitation Plan

Wessex Public Panel on NHS Data: Session 1 Plan – HIOW Cohort

20 July 2024

#	Start	End	Time	Title	Description of the process	Materials & running notes
-	09:00	09:30	00:30	**Team check-in**	An opportunity for the team to check-in regarding the plans for the day and for facilitators to clarify any process concerns. Actions include: • Preparing flipcharts (note that pre-prepared materials are available if required; please ask Sarah Knott): — For session 5 – divide sheet into the 3 dimensions - positive, negative, neutral / unsure (suggest using a face rather than words) — For session 8 – Data types – agreed data types on rectangular Post-it notes on a titled flipchart — For session 8 - Line presenting a scale from 1-5 – where 1= 'very comfortable' and 5 = 'very uncomfortable" — For session 10 - Divided flipchart with the titles 'Hopes' (exciting and opportunities) and 'Fears' (risks and concerns) • Organising tables. *Note that participants will be asked to wait outside the event room until 09:30.*	Flipchart and stand for each table Sharpies – at least 1 per person Pens and note paper- for each person Flipchart markers – big sharpies and at least 2 coloured markers Glossaries etc. at each table Blank name badges
0	09:30	10:00	00:30	**Participants arriving**	**Table Facilitators** • At tables welcoming participants. • Handing out name badges for participants to write their own name. • Referring early participants to the information materials available at the tables.	**-**
1	10:00	10:10	00:10	**Introduction and welcome** Setting the scene, context, and tone of the day.	**Lead Facilitator - Kaela** Welcome and who is in the room • Facilitation team, speakers and DCFs • Cover housekeeping Set out the purpose of the Panel • The role of the panel in determining HOW (not IF) the SDE will be implemented to support health research.	Parking Place slides

					- Overview of the agenda for the day including outputs from the morning and afternoon sessions. - Summary of what will happen over the whole Public Panel (4 days). - **Introduce 'Parking Place.'** - Cover social media. - Propose conversation guidelines.	
2	10:10	10:20	00:10	**Table Exercise 1: Introductions**	**Table Facilitators** **Topic: Make introductions between members and review proposed conversation guidelines.** **Process:** **Stage1 (2 mins) – Introductions** Call on each member of your table, in turn, to introduce themselves: - Their name. - Where they are from. - Why they decided to join the Panel. **Stage 2 (8 mins) – Review conversation guidelines** - Are they clear? - How would you see that working in practice? - Are there any additions you want to propose? If there are additions Table Facilitators should be prepared to feed these back in plenary to close the session. Please note: *This is not about creating a big list of rules, but rather ensuring everyone is comfortable with what is expected of them during the discussions.* **Outputs:** To close the session **Lead Facilitator Kaela** will call on each group in turn for any proposed additions to the conversation guidelines. If agreed, she will add them to the flipchart.	Consolidated conversation guidelines document, which will be written on a flipchart in the room

3	10:20	10:32	00:12	**Learning Presentation 1: Objective setting** Provide an overview of what an SDE is and sets the big question for the Public Panel	**Lead Facilitator Kaela** will prepare members for the presentation and encourage them to take notes, before introducing the first speaker. (1 min) **Speaker: Chris Kipps** (Wessex Secure Data Environment SRO, University Hospital Southampton) Topic: **How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?** (8 min) • Explains that the aim of the day is to get alignment between people with lived and learned experience on what the prize is and what we need to do to achieve it. • Emphasises focus on Data Access rather than Data Sharing. **Lead Facilitator Kaela** will call for 1 minute of reflection / notetaking before introducing the next speaker. (2 min)	Ralph Scott will be recording speakers from this point onwards.
4	10:32	10:45	00:13	**Learning Presentation 2: Understanding data-driven research** To help members understand what is driving the shift to SDEs	**Speaker: Sarah Ennis** (Professor of Genomics, University of Southampton) Topic: **What is data-driven research? Example: Using genetic data to improve outcomes for cancer patients** (up to 12 mins). Sarah Ennis will present the cancer genomics project and explain: (1) What research means in this context (e.g., discovering patterns that can help us develop a new personalised treatment). (2) What are the different kinds of data-driven research that participants might want to think about. (3) How research is done without the SDE. (4) The problems with the current system. **Lead Facilitator Kaela** will call for 1 minute of reflection / notetaking before introducing the first group task.	**-**
5	10:45	11:05	00:20	**Table Exercise 2: Attitudes towards health research** To explore initial understandings and responses to the idea of data being used for health research (rational and emotional)	**Table facilitators to lead** Topic: **How do you feel about data about you, and the rest of the Wessex population, being used to enable health research?** Purpose – to host a reasonably open discussion with your group to generate initial responses to the question above. The aim of this session is to gauge group's emotional and rational responses to the health research and create an initial mood board that we can revisit later in the Public Panel sessions to see how people's attitudes have moved. **Prompt Questions** (to help get your group going)**:** • Was anything particularly surprising in what you've heard? (And is that a good, bad, or neutral thing?)	Pre-prepared flipchart with positive, neutral, and negative sections to it Note to facilitators: *This exercise is part of creating a bigger 'mood board' capturing the initial reactions* concerns, attitudes, and visions *(rational and emotional) of the Panel as a whole at the beginning of the process. Your individual table results will be*

					• What if anything from what you've heard seems particularly exciting? • What, if anything particularly concerns or worries you? • What are you unsure about? • Are there any types of health research that you are most positive or negative about? **Outputs:** • Use Post-it notes to capture responses and display on a flipchart. • While you are responsible for ensuring points are captured do encourage public participants to write their own Post-its too. • Visually theme and group results as positive / negative / neutral on a pre-prepared flipchart.	*consolidated onto a whole group board.* *Speaker(s) available to be called to tables to answer questions.*
6	11:05	11:20	00:15	**BREAK**	-	-
7	11:20	11:35	00:15	**Learning Presentation 3: What is health and social care data?** Increase members' understanding of the range of data that could be held in the SDE	**Lead Facilitator Kaela** will prepare members for the presentation and encourage them to take notes, before introducing the speaker. (1 min) **Speaker - Phil Hyde** (Director of children's major trauma, University Hospital Southampton) **Topic: What types of data could be held in the SDE and how might they be used? Example: Using pre-hospital care data to improve outcomes** Present the PRANA research case study with a focus on the data it uses and to explore: (1) The range of data that could flow into the SDE (c.435 datasets). (2) The challenges and opportunities that this presents to researchers; and (3) The general principle that researchers do not get to see confidential patient information. *Note that Day 2 of the Public Panel will explore acceptability of including specific NHS and non-NHS datasets in much greater depth. Participants should be asked to focus on NHS data types today.*	
8	11:35	12:00	00:25	**Table Exercise 3: What is safe and risky data?** Exploring members concerns about different types of data being stored and used	**Table facilitators to lead** **Topic: What is safe and risky data?** Purpose of this session is to understand what types of data panellists might feel is more sensitive / more private and what types of data they are more comfortable with being used for health research. **Process:**	• Pre-prepared flipchart with 10 – 15 types of data sets on Post-its • Pre-prepared flipchart page – scale from 1= 'very comfortable' to 5 = 'very uncomfortable"

					Stage 1 – Review data types (5 min): Using the presentation as a ‘jumping off’ point begin by reviewing the pre-prepared list of types of data to ensure understanding. • Give participants the opportunity to add any other types of data that the NHS may hold about them that they feel is particularly sensitive / private when considering its use for potential health research (adding these as new Post-its to the flipchart). **Stage 2 – Ranking data types (20 min)** **Key question: Assuming that the data is de-identified, meaning that any personal identifiers are removed, which, if any, of the data types listed here would you be more or less comfortable with being used in the SDE for health research?** • Place pre-prepared scale on the table and explain it to members. • Take the Post-it from the pre-prepared list and position it on the scale as directed by the participants. • Explore reasons why they have placed that kind of data where they have – noting these alongside the original Post-it (NOTE - this reason, more than the ranking, is what we are interested in). • If members disagree the data type can be duplicated and positioned at a different point of the scale as well – ideally with clear reasons for the different positioning. • Continue the same process – asking for data types that people are comfortable with / uncomfortable with until all examples are positioned (or time runs out). • If time, ask if there are any additional data types that members would be particularly uncomfortable with. • Add to scale along with reasons. **Outputs required:** • Visual representation of what types of personal data members identify as most sensitive and clear reasons why • Note that the point of this exercise is to explore reasons for ranking more than the ranking itself. A rich conversation about why participants see specific data types as more or less risky is more valuable than covering all data types.	• *Speaker available to be called to tables to answer questions*
9	12:00	12:15	00:15	**Learning Presentation 4: How the SDE solves research problems?** Informing members about what a Secure Data Environment is and how it can help	**Lead Facilitator Kaela** will prepare members for the presentation and encourage them to take notes, before introducing the speaker. (1 min) **Speaker - Chris Kipps** (Wessex Secure Data Environment SRO, University Hospital Southampton) **Topic: How the Wessex SDE solves research problems** • Recap the problems the current way of doing research creates (i.e. slow, expensive, hard)	

				overcome current challenges	- Explains the change that the SDE makes to how research is done and the benefits to researchers. - Explains what this means for how data is managed from a patient's perspective in the form of a user journey story - Explain how data privacy and security are protected by the SDE focusing on the 'Five Safes' - Explaining three key aspects of the SDE: (1) we need to be able to access data without individual consent (using S251 permission from the Health Research Authority); (2) we will ensure privacy through pseudonymisation of patient data; and (3) ensuring data security through design of the platform.	
10	12:15	12:40	00:25	**Table Exercise 4: Our hopes fears and aspirations for the Secure Data Environment** Exploring people's hopes and fears about what they have heard	**Lead facilitator Kaela will introduce the two stages of the session** Purpose of this session is to explore participants initial reactions to the idea of the SDE AND distil these down into some specific events / outcomes that sum up the best- and worst-case scenarios for the SDE – in the form of newspaper headlines. **First, thinking about what you've heard so far, what are your hopes** (the biggest positives, exciting opportunities) **and fears** (negatives – concerns, fears and risks) **for the way the SDE might operate?** - Take 3 Post-its each, and a sharpie, and take a moment to yourself to respond – 1 idea per Post-it. - Once you have had a minute your facilitators will manage the process of sharing these with the group. **Table facilitators to lead** **Topic: What are our hopes, fears, and aspirations for the SDE?** **Process:** **Stage 1 – Hopes and fears (15 min)** - Check each member has 3 Post-its and a Sharpie pen. - Wait while members to take a minute to note (1 response per Post-it) what seems to them the biggest positives (exciting opportunities) and negatives (concerns, fears, and risks) about the proposals for the SDE. - Ask one participant to share 1 of their ideas, briefly explaining their thinking / reasons - add their Post-it to the pre-prepared flipchart. - Ask if others at the table have the same / very similar point – collect them and add to the flipchart to form a cluster – inviting comments from others handing up their Post-its	- Pre-prepared flipchart with the titles 'Hopes' (exciting and opportunities) and 'Fears' (risks and concerns) - 'Newspaper headlines' templates at each table (6-8) – which will be collected up and displayed - *Speaker available to be called to tables to answer questions*

- Ask a different person to share 1 of their ideas and repeat the process of collecting in Post-its
- Continue until all Post-its have been collected and themed/ grouped (but resist the urge to overgroup)
- Once all Post-its are up and grouped add theme titles to each group and any notes needed to aid understanding of individual Post-its.

Stage 2 (10 min) – Newspaper headlines – Kaela will introduce

This is about capturing a snapshot of the Panel's homes and fears.

Ask groups to look at the themes they have identified and imaging the 'best' and 'worst' scenarios they can imagine when the SDE is launched / live in the future – and write a newspaper headline and story to tell us about it.

This will help us all focus on the key things we want to avoid, and enable, when we start looking at the principles that should guide how the SDE operates, after lunch.

Table facilitators

- Work with the group to look back at the hopes and fears and ask themselves the question: "What is the best thing I can see the SDE doing and what would be the worst thing that could happen."
- Break the table group into groups of 2-3 people – with each group creating up to 2 newspaper headlines.
- If necessary, prompt the group to think about other stories they might have heard about involving the NHS, medicines and treatments, data and technology and think about what their hopes and fears might look like in practice.
- Each group of 2-3 people work together to write their headlines for the event they have thought of; illustrate it; and write the first 1-2 lines of the story (using the template provided)
- Collect all these newspaper headlines and pass to the Lead Facilitator

Outputs required:

- Flipchart pages with Hopes and Fears sections, with the group's Post-it notes placed in the relevant section, grouped and themes identified.
- 6 newspaper headlines per table (based on three groups per table); ideally 3 positives and 3 negatives.

Lead Facilitator – introduction to what we are going to be doing in the afternoon session and some things to think and chat about over lunch (slide to be left on screen over lunch as prompt).

Before sending the group to lunch introduce the **consent forms,** we would like them to consider and sign.

11	12:40	13:20	00:40	**LUNCH**	-	Facilitators to put up headlines around the room. Participants have the opportunity to review 'headlines' over lunch. **Chantal** available to answer questions re the consent forms.
12	13:20	13:55	00:35	**Learning Presentation 5 (Panel): Defining trust and governance** Presenting different perspectives on 'What makes for public trust in health research?'	**Lead Facilitator -** reconvenes the group and re-introduces the afternoon (3 mins). Reminds participants about the purpose of the afternoon session, which is to set principles that will act as (1) guardrails to stop bad outcomes; and (2) help ensure the benefits we want are realised. Gets participants thinking about what they need to know from the Panel Discussion to help them with this task. **Topic: What makes for public trust in health research?** The purpose of this panel session is to introduce a range of perspectives on what the public need in order to put their trust in the Wessex Secure Data Environment, its design, and its governance. This then sets up a discussion to establish some broad principles are that should govern the Secure Data Environment in order to achieve trust. **Presentations by:** 1. **Chris Kipps** (Wessex Secure Data Environment SRO) - Health research in a highly regulated environment (5 mins) • **Lead Facilitator Kaela** will call for 1 minute of reflection / notetaking before introducing the next speaker. (1 min) 2. **Prof Will Jennings** (Professor of Political Science and Public Policy, University of Southampton) - The foundations of trust in public bodies (14 mins) • **Lead Facilitator Kaela** will call for 1 minute of reflection / notetaking before introducing the next speaker. (1 min) 3. **Digital Critical Friend representative -** Presenting what we know about public attitudes towards data-driven research nationally and in Wessex, with a focus on what seldom-heard groups say (10 mins) • **Lead Facilitator Kaela** will call for 1 minute of reflection / notetaking before introducing the next speaker. (1 min)	
13	13:55	14:05	00:10	**Table Exercise 5: Consolidating**	**Table Facilitators to lead** **Topic: Identify and prioritise questions for the panel**	`

				questions for the Panel To focus and democratise the Q&A process	The purpose of this exercise is for tables to identify questions that they want to put to the panel and prioritise which ones get asked. The aim is to ensure everyone in your group has an opportunity to propose questions for the panel. **Process:** • Ask for questions from the group – what information would help you to decide where to put the guardrails and how to ensure the benefits happen? • Note each on a Post-it. • Let members of the group know that it is OK if they don't have a question! • Pass these questions to **Chantal.** **Required outputs**: • One or more questions for the panel	
14	14:05	14:30	00:25	**Q&A with the Panel**	**Lead Facilitator** to host the Q&A session with the panel speakers • Lead Facilitator to work through the questions and curate the Q&A session • Questions that are off topic will be put in the **Parking Place** and addressed later. • Lead facilitator to remind participants what we will be doing for the final session so they can think about it in the break.	Ralph Scott to record panel responses. Note that the Lead Facilitator will have a lapel microphone and there will be a roving microphone for the panellists.
15	14:30	14:45	00:15	**BREAK**	-	-
16	14:45	15:25	00:40	**Table Exercise 6: Values-based principles** Exploring what governance principles members believe are needed to ensure public trust	**Table facilitators to lead after introduction from the Lead Facilitator** **Topic: What principles should guide the SDE?** Purpose is to identify and capture what people think the values / principles are that the SDE should work to. • Values - the qualities or standards of behaviour which all involved should seek to live up to. • Principles - the rules or beliefs governing the behaviour and actions of all involved. **Process:** **Stage 1 – Brainstorming principles (20 mins)** • Start by asking members to think back to the Newspaper headlines and the good and bad outcomes we identified. And take a moment to think about what principles and values did the speakers talk about that would help prevent bad newspaper headlines – and ensure we get the good ones. • Including anything that might be missing from what you have heard? Encourage reflection on their own hopes, fears, and aspirations from the morning session.	Feedback templates for principles.

- **<u>Open ‘brainstorm’</u>** - using flipchart and Post-its to record all ideas from the table – grouping them as appropriate.
- Ask for 1 idea from the group – note it on the flipchart and explore further with the group.
    - What would this look like in practice? (What would this mean Chris and his team actually be doing?)
    - What would it hope to achieve / prevent?
    - Why would it be important?
- Move on to the next idea and repeat the process
- for ensuring public trust and confidence in the SDE and how the data held within it is used.

<u>Stage 2 – Prioritising values or concerns (10 mins)</u>

- Ask participants to begin by choosing from their list the principles that seem most important to them - and why? [max 7 mins]
    - Host as a reasonably open conversation among the members at this point to begin negotiating common priorities.
- Agree the group’s top 3. [max 3 mins]
    - If there is not a clear consensus, use sticky dots to vote – with each member getting 3 votes

Lead Facilitator Kaela will introduce the last stage of the process, explaining the purpose and why it’s important, and calling for **1minutes of quiet reflection** before we move on to writing the principles. She will put some examples of principles up on the screen.

- Principles are the rules or beliefs that demonstrate how a value is delivered, e.g. If we value public participation in decision making the rule (or principle) to make this happen might be that we have public members on our decision-making boards.
- Participants should understand that these are <u>guidelines rather than hard rules</u>, because we will need to be implemented in a wider context that we do not fully know yet.

<u>Stage 3 – Writing our principles (10 mins)</u>

Use the pre-prepared template to work with your group to write ‘principles’ that present your groups’ top 3priorities for how the SDE should operate in ways that for ensuring public trust and confidence in the SDE and how the data held within it is used.

These will be fed back in plenary (identify a member to feedback each one).

					Table facilitators explain that we are looking for a list of core beliefs that can guides how the organisation should act, and what it should avoid, to build public trust and confidence in the SDE. • Use the template to write a principle for each of their group's top 3 priorities (1 on each page) o *You can work with the group as a whole to draft these, or ask the group to split them between themselves, do a first draft, share, and finalise.* • This will take the form: ***The SDE should [INSERT PRINCIPLE].*** *The idea is that this will not just be 1 word, but an 'action'* *For example, 'ensure transparency by creating a way for members of the public to be able to see the types of research it is being used for'* ***Because [INSERT REASON FOR HAVING THE PRINCIPLE** – why is it important to the group?].* *Note that we are as interested in the reasons for the principles as the principles themselves.* **Required outputs:** • Long list of values-based principles on Post-its and the flipchart board with any notes. • Shortlist of most important principles on pre-prepared templates. • 1 or more members from the group identified to feedback on top 3 principles.	
17	15:25	15:45	00:20	**Plenary: Bringing together the principles**	**Lead Facilitator** **Topic: What principles should guide the behaviour of the SDE?** Purpose of this final plenary session is to invite members from each group to share their prioritised principles, explain why each was important, and get a high-level vote on which principles are most important. **Stage 1 – Sharing our principles (15 mins)** • Invite representatives from each table to share their top principles • Lead Facilitator collects and displays pre-prepared cards, consolidating the list if any are repeated • Lead Facilitator **(with support from table facilitators)** adds numbers to the principles as they are listed aid with voting and puts the principles up around the room ready for voting **Stage 2 – Voting on principles (5 mins)**	

					- Lead Facilitator explains that everyone has 5 votes to cast on the principles that they think are most important using red sticky dots. - Participants get up and go around the room placing dots on the principles they support. **Required outputs:** - Shared list of value-based principles with red-sticky dots on to show how these are ranked by importance.	
18	15:45	15:55	00:10	**Plenary: Voting results and member reflection** To end the meeting with an understanding of where members currently stand	**Lead Facilitator** **Topic: Results of the poll** Lead Facilitator reveals the results of the ranking based on which principles appear to have the most red dots. Invites comments from participants in relation to a selection of the principles – a mix of the top priority principles or those that are less obvious – to explain their thoughts and feelings.	Table facilitators support the vote count
19	15:55	16:00	00:05	**Ending the day** Closes the meeting, with reminders of what is next.	**Lead Facilitator** - to recap what has been achieved today and what comes next - Thank everyone on behalf of the project team.	*People are welcome to stay on and chat to the team.*

E: Session 1 Master Deck

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Wessex Public Panel on NHS data

WELCOME

Overarching question for the Public Panel

How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?

Agenda for the day

- Why are we here?
- Introduction to research

BREAK

- Introduction to data
- Role of the Wessex Secure Data Environment

LUNCH

- What makes for public trust in health research?

BREAK

- Identifying our guiding principles

Future Public Panel meetings

2nd meeting

- What kinds of research are we comfortable with and what public benefits to we value most?

3rd meeting

- How should decisions be made and who should make them?

4th meeting – bringing the two Public Panels together

- Coming together and making recommendations

Proposed 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
- 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

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How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?

Prof. Chris Kipps

Objectives

1. Why health and care research is important
2. The role of NHS data in making research possible
3. Your role in unlocking this opportunity

What is NHS patient data?

- Whenever you interact with the health and care services they collect data about you, your health and your lifestyle.
- This is recorded and stored in your patient record, whether that be a physical paper copy or digitally.

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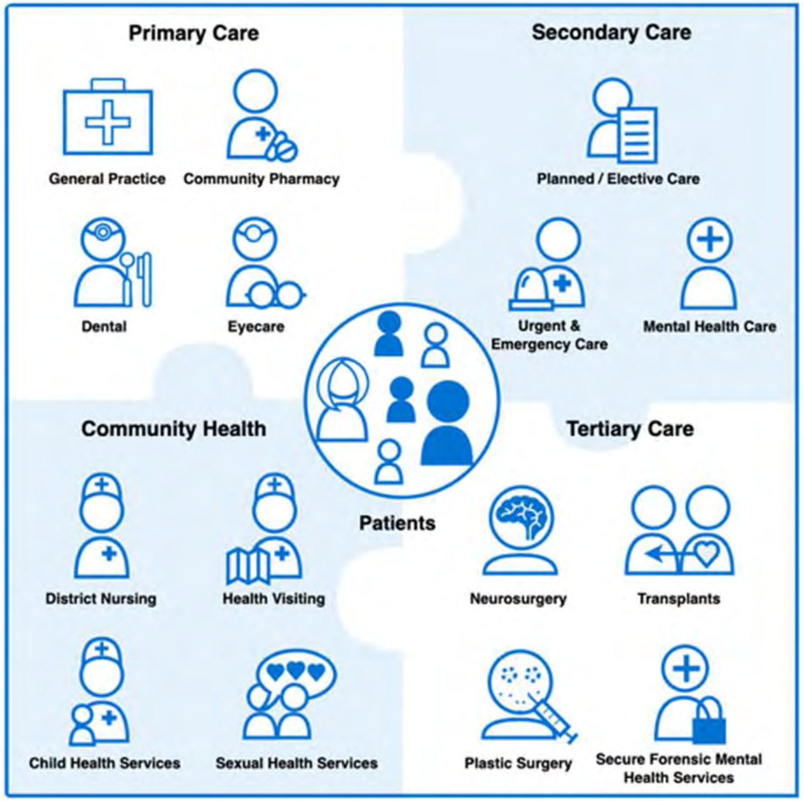
What data is collected in the health and care system

- Huge amount of data collected about you by the NHS
- A lot is left in the digital equivalent of dusty filing cabinets
- It is not linked together and so we can’t do research

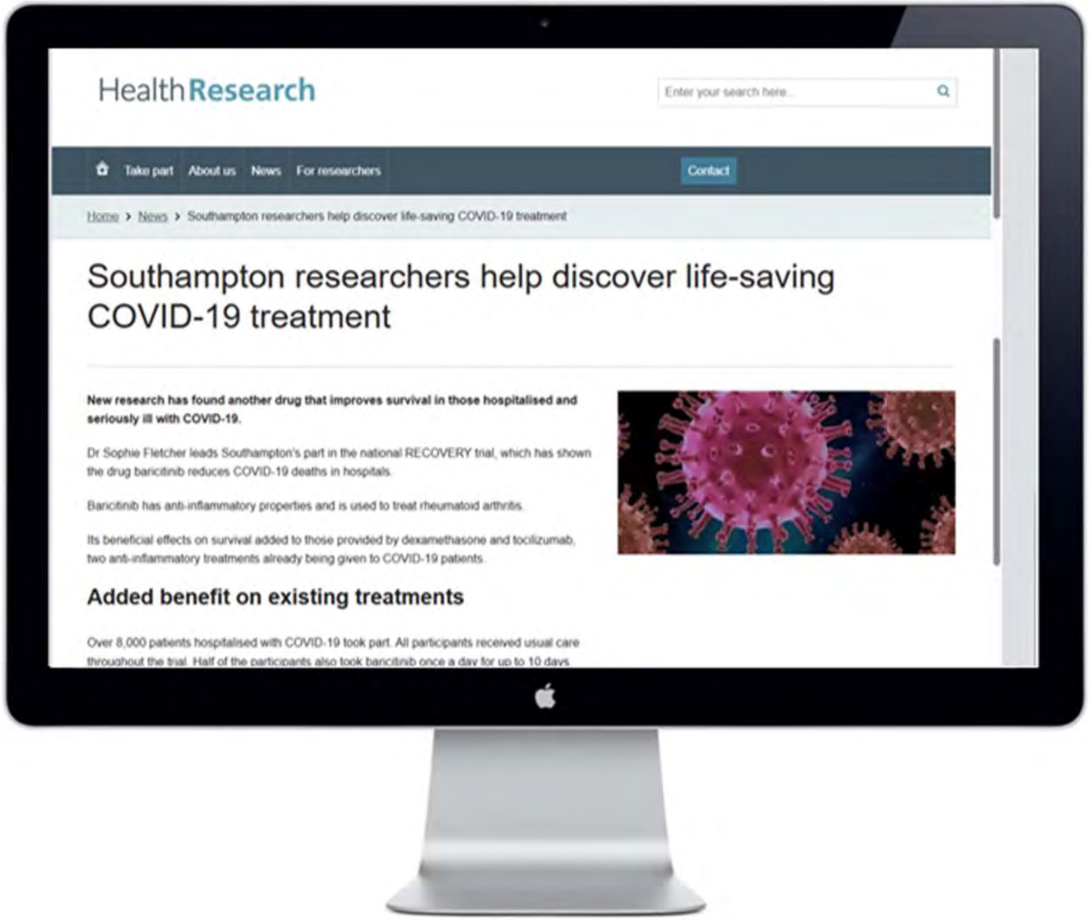


Mental Health

Care Providers
(Social Care)

NHS data and the pandemic

- NHS data is a valuable resource
- Research using this data put the UK at the forefront of the global fight against coronavirus



Southampton researchers help discover life-saving COVID-19 treatment

New research has found another drug that improves survival in those hospitalised and seriously ill with COVID-19.

Dr Sophie Fletcher leads Southampton's part in the national RECOVERY trial, which has shown the drug baricitinib reduces COVID-19 deaths in hospitals.

Baricitinib has anti-inflammatory properties and is used to treat rheumatoid arthritis.

Its beneficial effects on survival added to those provided by dexamethasone and tocilizumab, two anti-inflammatory treatments already being given to COVID-19 patients.

Added benefit on existing treatments

Over 8,000 patients hospitalised with COVID-19 took part. All participants received usual care throughout the trial. Half of the participants also took baricitinib once a day for up to 10 days

Looking ahead - Data Saves Lives

Data Saves Lives

- Recognise that **NHS data is underused for research**
- **Maintain momentum** we achieved during the pandemic
- **Tackle the long-term challenges** ahead of us – like cancer, dementia and mental health
- Improving public understanding of **how data is used**
- Create **a dialogue involving everyone** who is interested in health data
- **Empowering** patients and healthcare professionals
- Showing **real life examples**

The global opportunity

- **Life science businesses are worth £2.26 trillion** each year across the world – the same as ¾ of the UK economy.
- **UK gets 5% of this benefit** – we're ranked 3rd after the US (who get nearly 80%) and China.

Bringing benefits for Wessex

Growing our share of £2.8bn of research funding

Tackle our local health and care priorities

Improve NHS services

Grow investment and job creation

The Wessex SDE is **a highly secure computing environment** that provides **remote access to your NHS data** for approved researchers working on projects that bring a clear public benefit.

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EE	East of England
EM	East Midlands
GW	Great Western
KMS	Kent, Medway & Sussex
L	London
NENC	NENC
NW	North West
TVS	Thames Valley & Surrey
W	Wessex
WM	West Midlands
YH	Yorkshire & Humber

We are **one of 12 SDEs** in England with **shared rules** and able to work together on research projects

What can the SDE Network achieve together?

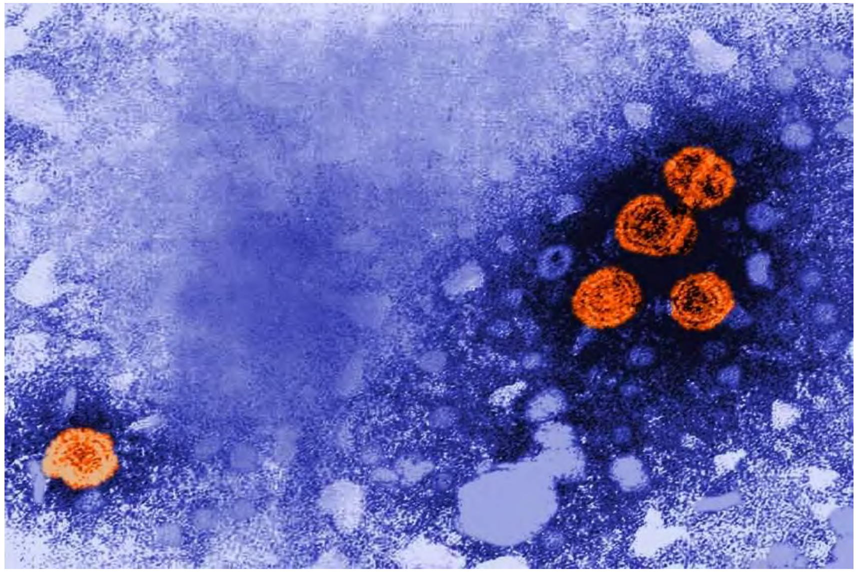
Tackling liver disease and Hepatitis using data captured as standard by the NHS

- Locally Wessex has data on c. 4,500 patients
- In the South we have data from over 30k patients' data
- Industry says this is the **"best longitudinal dataset of its kind in in Europe"**

This is helping us to:

- Better understand hepatitis in the UK and globally to achieve the WHO ambition to…

Eliminate Hepatitis by 2030!



Why hasn’t this been done already?

- The public is concerned about:
  - The **data security** environment
  - The role of **industry and business partners** that are being involved in NHS projects
- It is **complicated** to do
- The **data is fragmented**, not easily located, and doesn't always fit together
- The **public has not been sufficiently involved**

Securing public trust is a top priority for the SDE

Listening to NHS staff and our community – locally and nationally

Wessex Public Panel on NHS Data

Wessex
'Big Conversation'

How we will work together

The Public Panel will:

- Explore your **hopes, fears and ideas**
- **Make recommendations** that will be at the heart of how the SDE is designed and run

Our promise:

- Patients and the public will be at the heart of the SDE’s decision making
- We will work together to set the values that guide it, the rules that govern it, and agree how it is run.

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The work of this panel is essential to building a public mandate for the SDE.

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What is data-driven research?

Prof. Sarah Ennis

What is data-driven research?

- We are looking for patterns in lots of data
- New patterns can be turned into new ways to treat patients and improve NHS services

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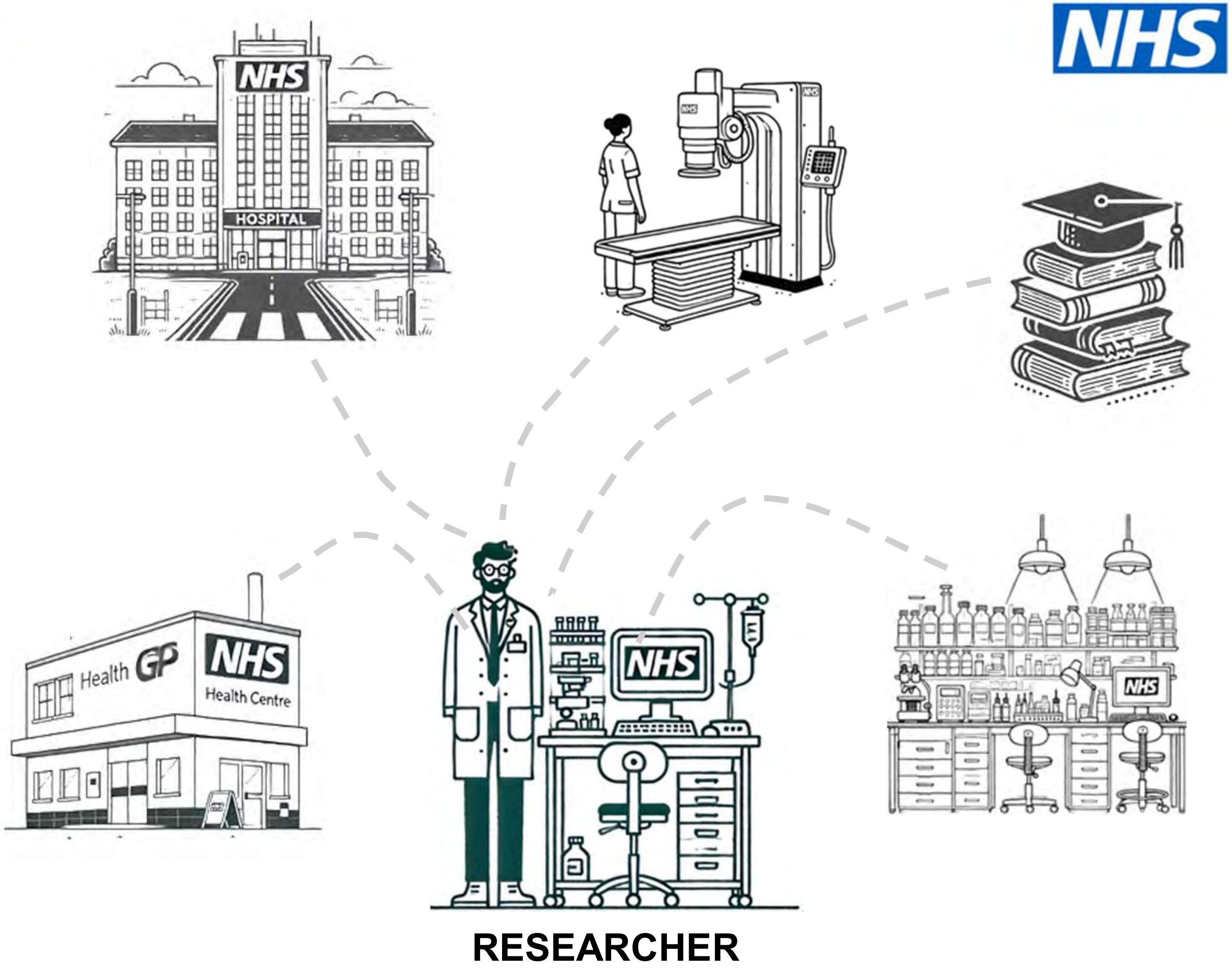
Where do we get the data from?

NHS data is stored in lots of different places and in many different formats



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There are **six main kinds of research** that the SDE aims to help:

Artificial intelligence

Testing, training, and checking AI technologies for use in healthcare

Clinical trial activities

Finding and recruiting people to help test new treatments, and looking at the effects over the short and long term

Real world studies

Looking at the safety and effectiveness of treatments and technologies

Translational research

Discovering new treatments and putting them into practice in a health setting

Epidemiological studies

Looking at large groups of people to understand what affects population health

Health systems research

Researching and testing how well healthcare systems and processes work

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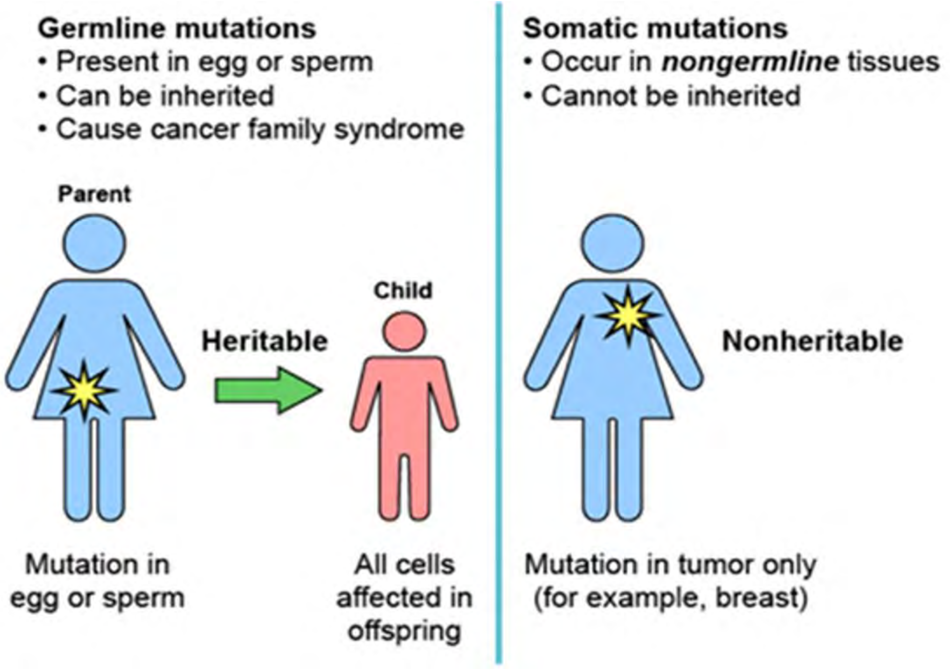
Case study

What is genomic data and how can it improve outcomes for patients?

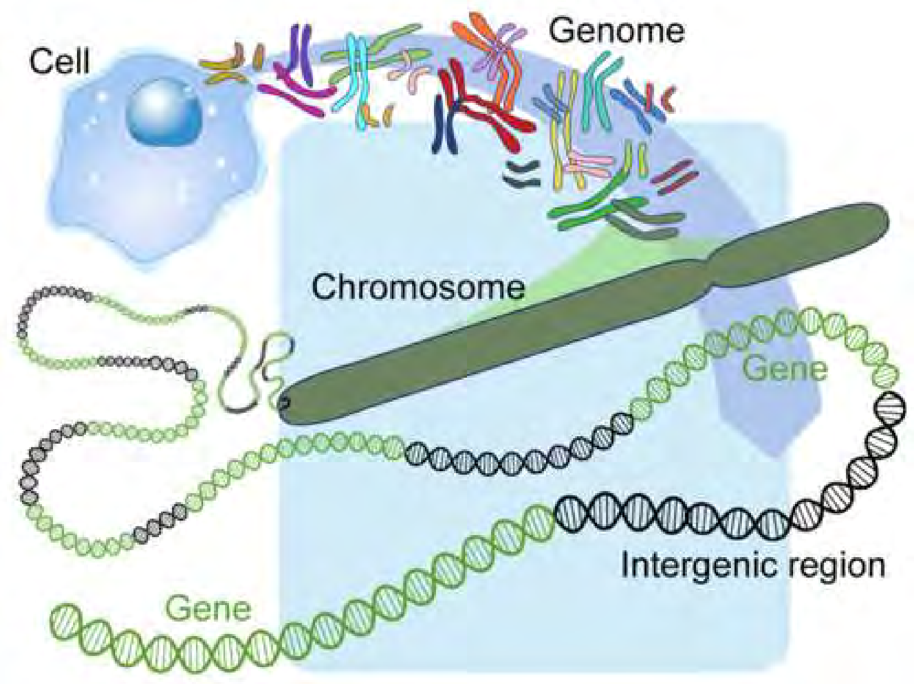
What is cancer?

- Cancer is a genetic disease **caused by changes to your genes** or ‘genomic variants’
- Variants can either be **inherited** or **only exist in a tumour**



What is genomic data?

- Our genome encodes the “recipes” to make (healthy) humans
- Inherited differences encode things like natural variation, disease risk, and drug response
- Acquired changes cause diseases like cancer

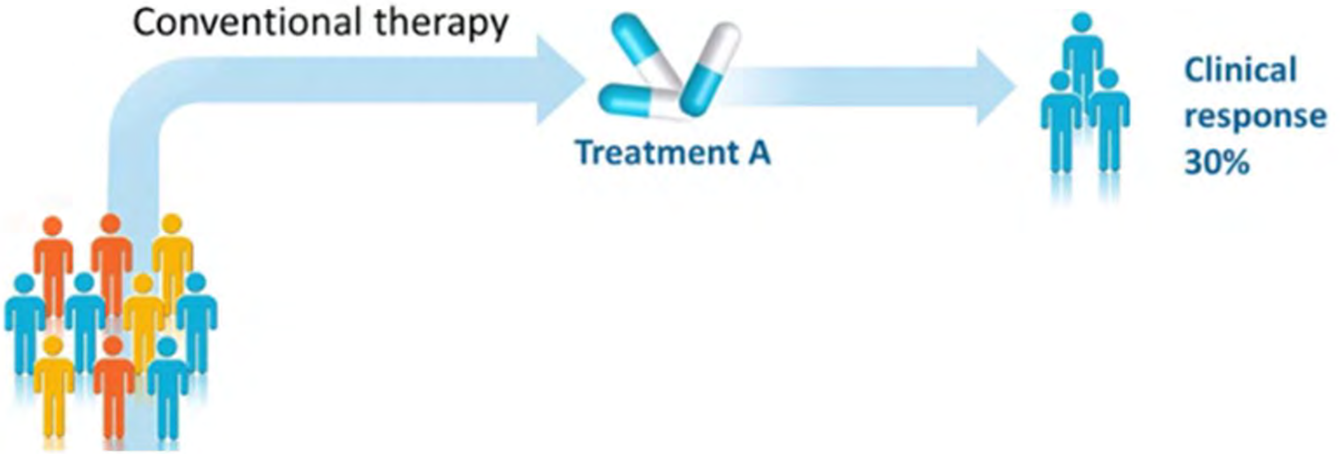


How do we collect genomic data?

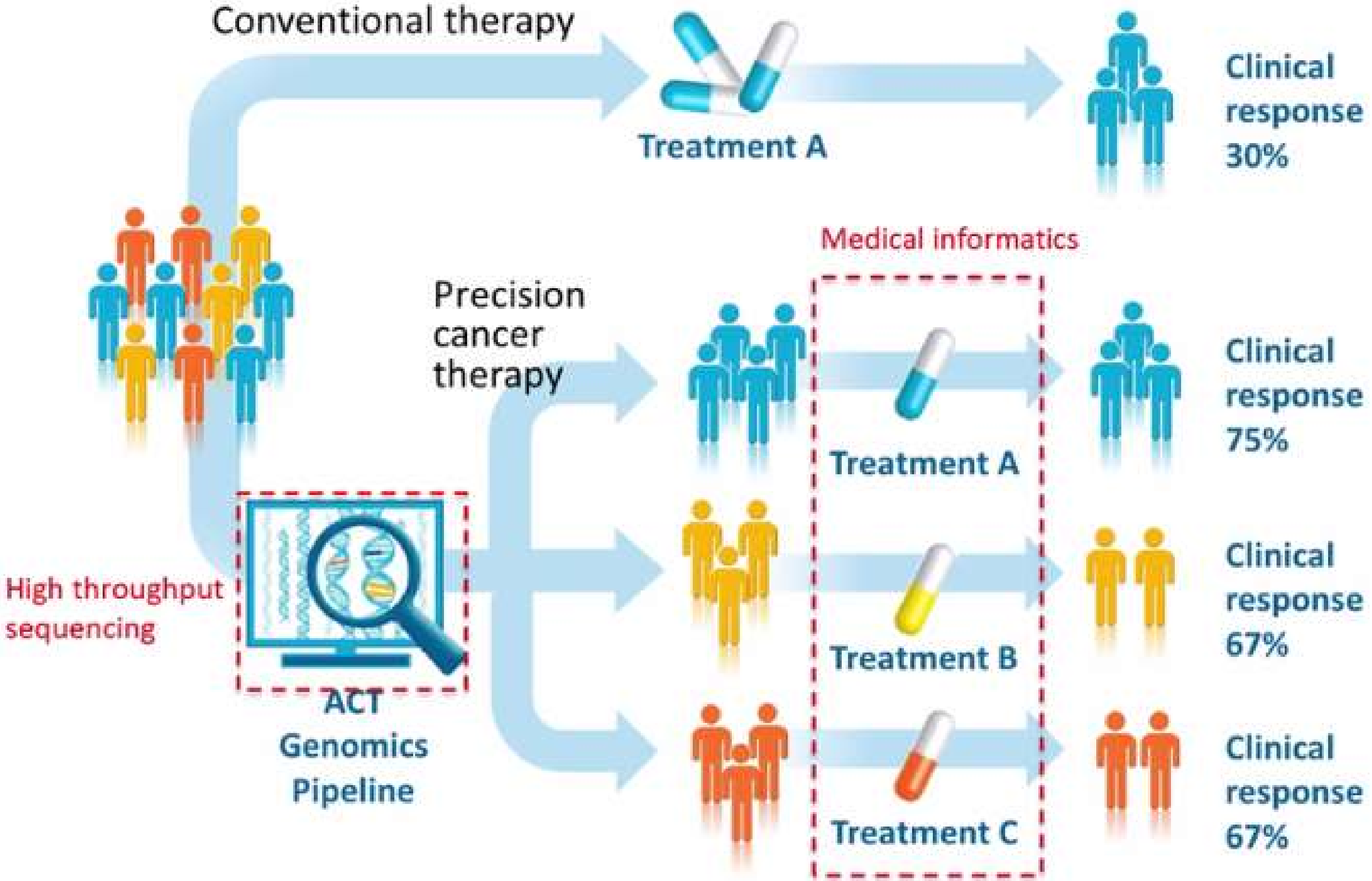
What are we trying to achieve?

- Learning about genetic variants can help us **better treat patients** and **improve outcomes**
- Exploring ways to **better integrate genetic and clinical data** so it helps identify optimal treatments **more treatable** to **save more lives**

Where have we come from?



Where are we going?



Conventional therapy

Treatment A

Clinical response 30%

Medical informatics

Precision cancer therapy

Treatment A

Clinical response 75%

High throughput sequencing

ACT Genomics Pipeline

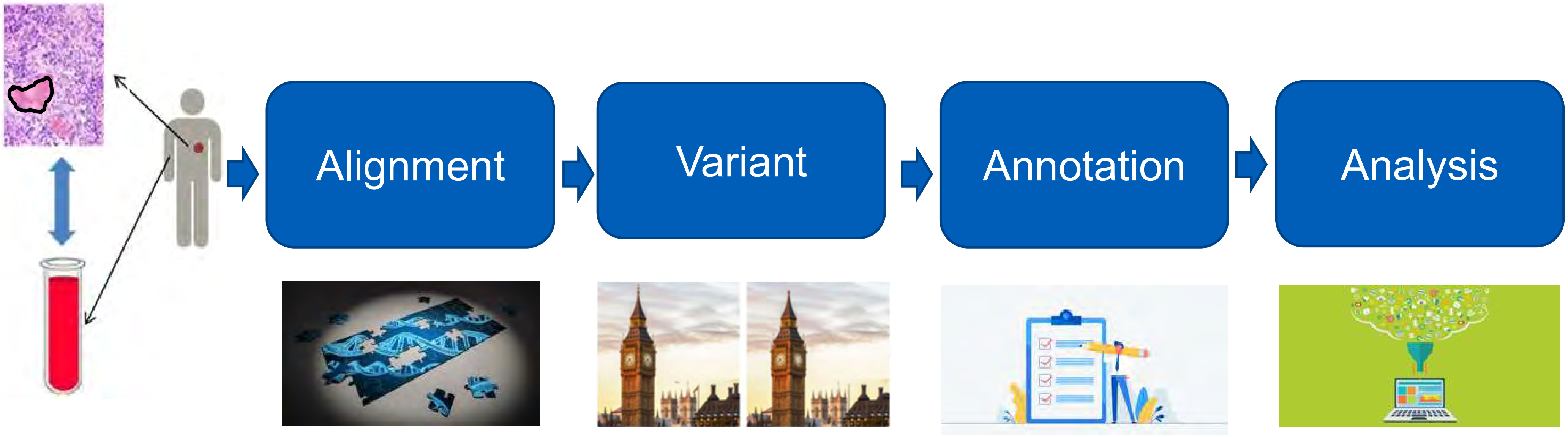
Treatment B

Clinical response 67%

Treatment C

Clinical response 67%

How are we doing the research?



Alignment

Variant

Annotation

Analysis

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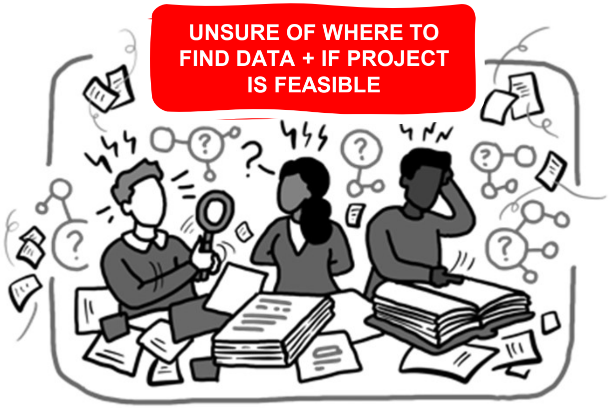
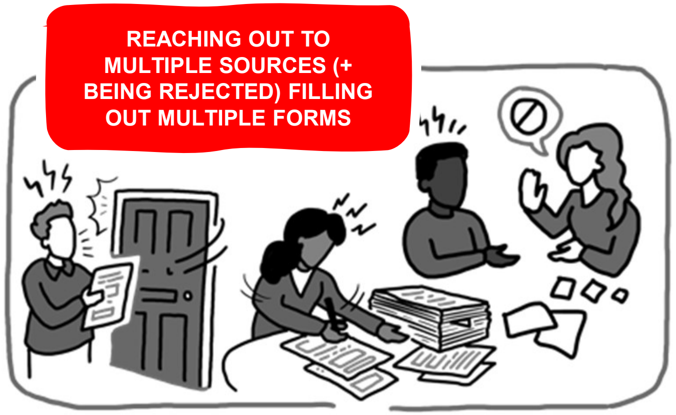
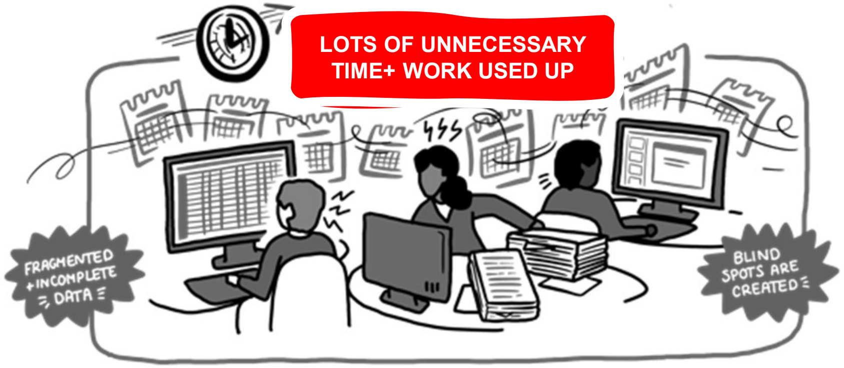
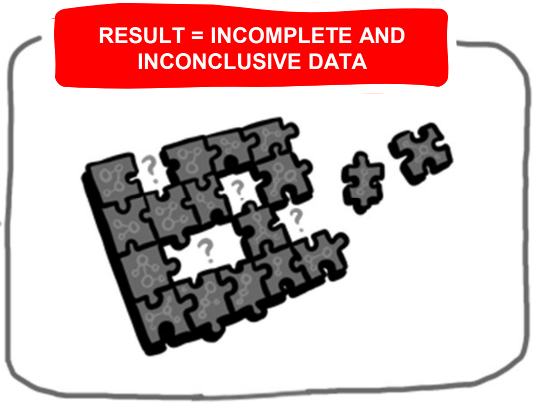
The big challenge is how research works today.


UNSURE OF WHERE TO FIND DATA + IF PROJECT IS FEASIBLE


REACHING OUT TO MULTIPLE SOURCES (+ BEING REJECTED) FILLING OUT MULTIPLE FORMS


LOTS OF UNNECESSARY TIME+ WORK USED UP


DATA IS SENT TO THE RESEARCHER


RESULT = INCOMPLETE AND INCONCLUSIVE DATA

Thank you!

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Exercise 2:

How do you feel about data about you – and the rest of the Wessex population – being used to enable health research?

Break

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What types of data could be held in the SDE and how might they be used?

Example: Using pre-hospital care data to improve outcomes

Dr. Phil Hyde

Objectives

- Providing an example of the types of complex projects that use large datasets which the SDE makes possible
- What other kinds of data could end up on the SDE?

What is Pre-hospital care?

Care provided to patients before they are admitted to hospital.
This may include:

- Emergency medical services including paramedics, critical care teams, search and rescue, Lifeboats, air ambulance
- Other emergency services such as police, fire, road traffic

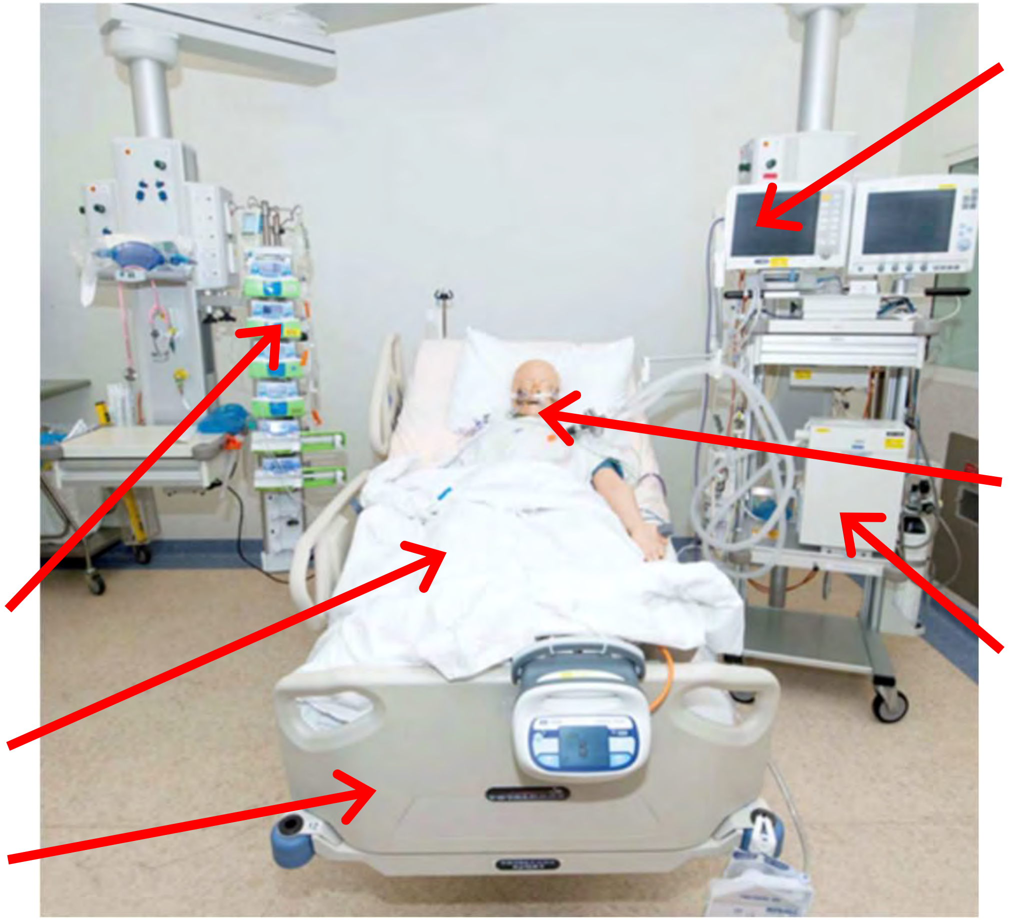
University of
Southampton

NHS
University Hospital
Southampton
NHS Foundation Trust

BRITISH ASSOCIATION FOR IMMEDIATE CARE

AIR AMBULANCES UK
SUPPORTING AIR AMBULANCE CHARITIES

Critical care: The provision of organ support for critically ill and injured patients



Patient Monitor
Blood pressure trace
Oxygen levels
Heart electricity trace
Heart rate
Breathing rate
Carbon dioxide level
Temperature

Breathing tube

Breathing machine

Medicine syringe drivers

Temperature management

Bed / trolley / stretcher

Pre-hospital critical care: provision of organ support for critically ill and injured patients

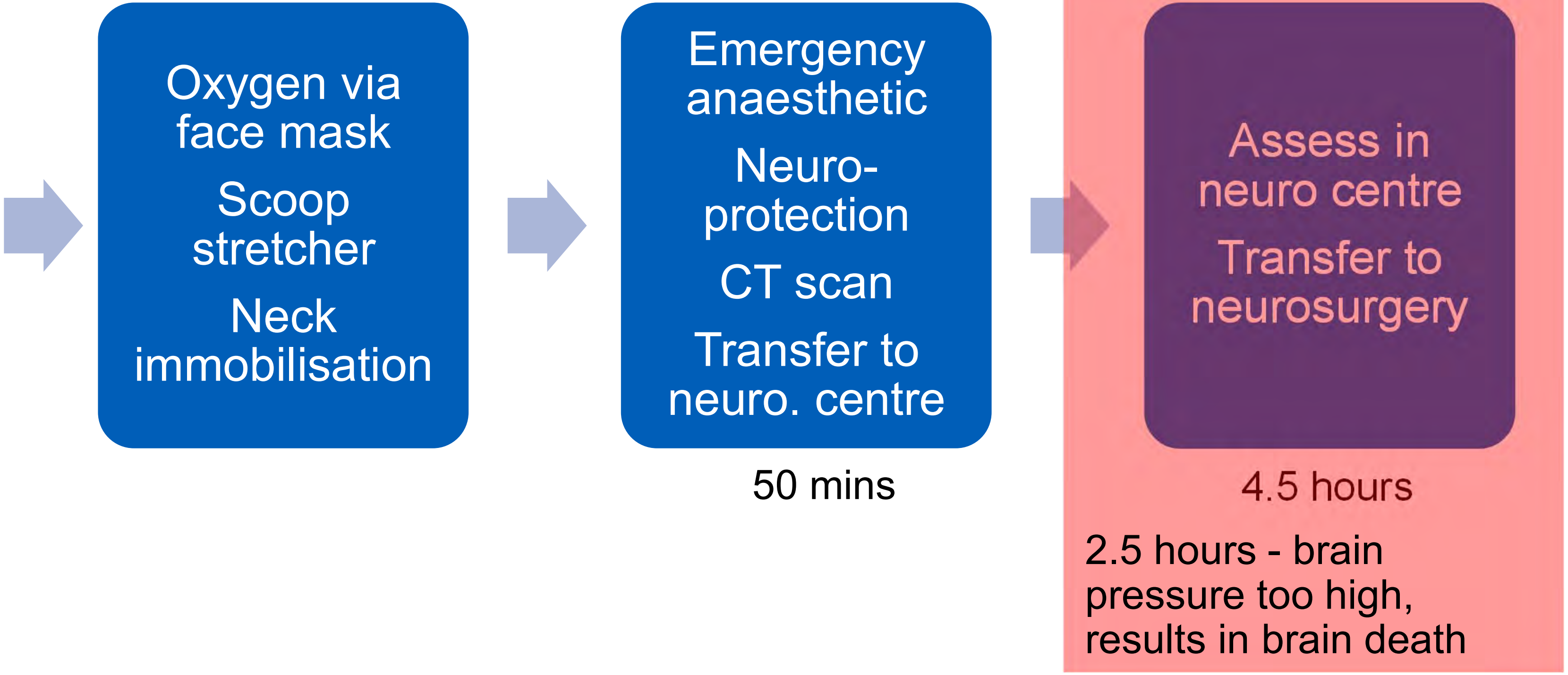
How do we do it?

Example of pre-hospital critical care:

- 14-year-old boy
- Hit by car at high speed
- Head injury
- Bleeding on his brain and pressure rising

Pathway **without** pre-hospital critical care

14-year-old boy, hit by car, deeply unconscious, with raised brain pressure



Oxygen via face mask

Scoop stretcher

Neck immobilisation

Emergency anaesthetic

Neuro-protection

CT scan

Transfer to neuro. centre

50 mins

Assess in neuro centre

Transfer to neurosurgery

4.5 hours

2.5 hours - brain pressure too high, results in brain death

Pathway **with** pre-hospital critical care

14-year-old boy, hit by car, deeply unconscious, with raised brain pressure

Oxygen via face mask
Scoop stretcher
Neck immobilization
Emergency anaesthetic
Transfer to neuro. Centre
Neuro-protection
Invasive blood pressure

Assess in neuro. Centre
CT scan
Transfer to neurosurgery

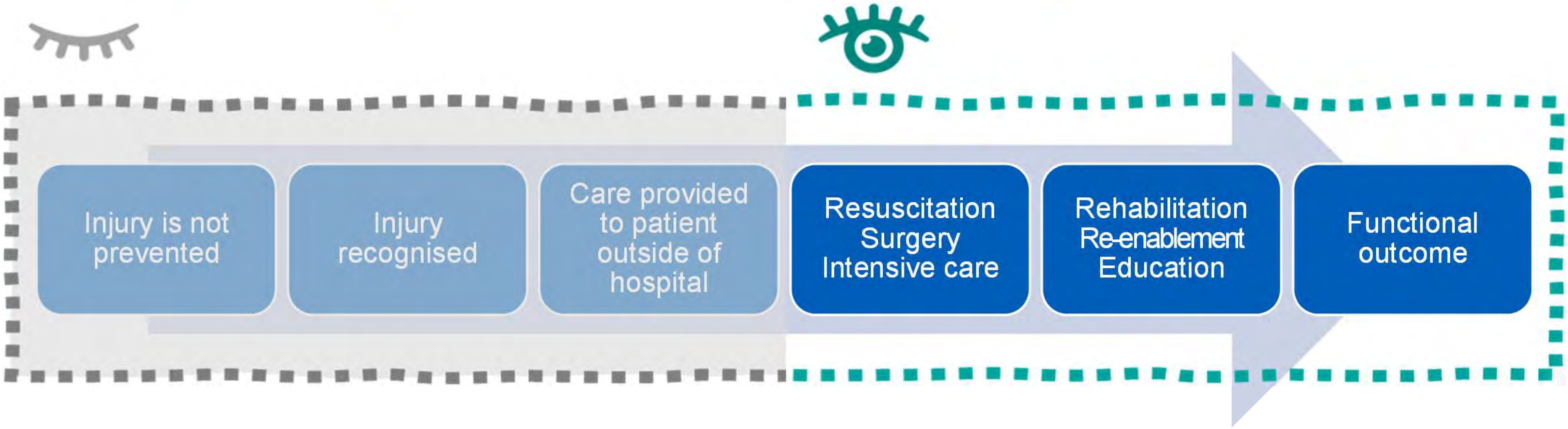
80 mins

2.5 hours - brain pressure too high.

Pre-hospital critical care **cuts the odds of dying by between a third to nearly a half** within 30 days and resulted in **3 unexpected survivors for every 100 patients**.

We know that **data saves lives**, but …

The NHS collects the data but we don’t link it up so there is no overall picture of what is happening in pre-hospital critical care – so **researchers are blind to an important part of the care pathway**



Injury is not prevented

Injury recognised

Care provided to patient outside of hospital

Resuscitation
Surgery
Intensive care

Rehabilitation
Re-enablement
Education

Functional outcome

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PRANA (Pre-hospital Research and Audit Network) aims to **improve pre-hospital emergency care** services by creating a national dataset for the first time

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We are collecting **435 separate bits of information** about patients to create our PRANA large dataset

- Confidential patient information like your name and NHS number
- Similar confidential information from non-NHS partners to allow us to link records together
- Data is de-identified to protect privacy before approved researchers can see it

Incident details	Team members involved	Transport logistics	Rescue and extrication management
Airway and ventilation management	Anaesthesia	Blood component transfusion	Cardiac arrest
Medications	Point of care ultrasound	Near Patient testing	Other interventions
Critical incidents	Patient and family liaison	Major incident	Organ donation

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Police

Coroner's Office


Hospital A&E


Pre-hospital
critical care

Dept for Transport

Ambulance
service

Identifiable data

De-identified data

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PRANA registry

PRANA
PRE-HOSPITAL RESEARCH AND AUDIT NETWORK

Research
dataset


Researcher
restricted
workspace

Identifiable datasets combined inside the SDE using patients' unique personal identifiers – researchers never see this

The new PRANA dataset is pseudonymised before being made available to approved researchers – inside a restricted workspace

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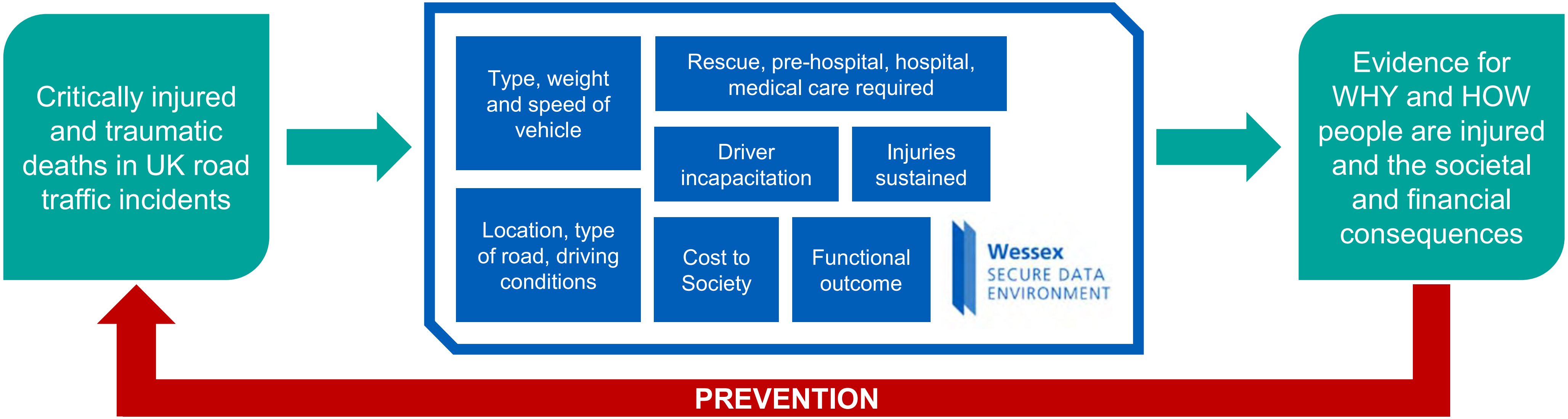
The PRANA large dataset would support a wide range of research – like how best to prevent and deal with road traffic accidents



Critically injured and traumatic deaths in UK road traffic incidents

Type, weight and speed of vehicle

Rescue, pre-hospital, hospital, medical care required

Driver incapacitation

Injuries sustained

Location, type of road, driving conditions

Cost to Society

Functional outcome

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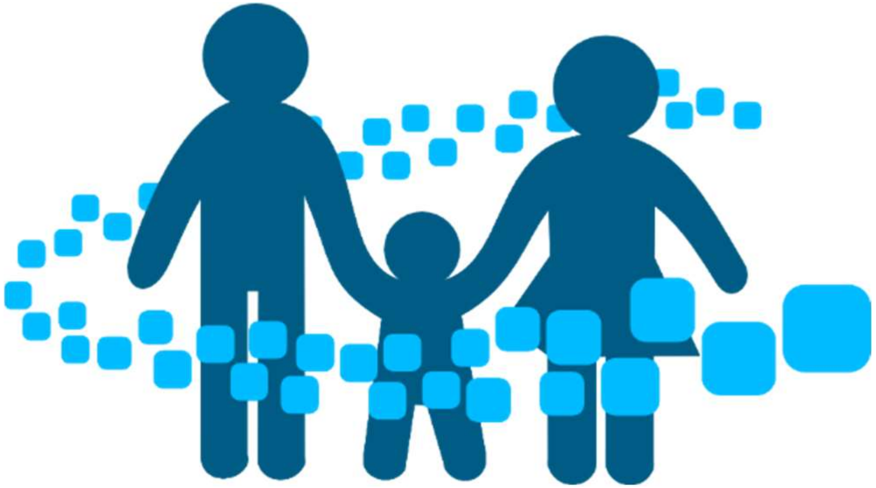
Evidence for WHY and HOW people are injured and the societal and financial consequences

PREVENTION

PRANA is one example of **research that needs access to 100s of near real-time datasets** – all held by different NHS and non-NHS organisations in many different formats and places



What other kinds of data could the SDE access?

Demographic

Information that identifies you like your name, address, NHS number – **used to link datasets but never visible to researchers**

Other personal information that does not identify you like ethnicity, age group and location

Health

Medical records like details of health conditions – including mental health – appointments and treatments

Social Care

Records for any social services provided to those receiving social care as adults or children – including those with reduced capacity

Non-NHS

Data collected by university or private sector researchers

Records held by public bodies like fire and rescue or police

Data collected by the private sector for other purposes – e.g. from wearables

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Demographic or location information

Medical records from your GP or hospital

Mental health records

Laboratory data like blood test or biopsy

Audio and video recordings

Scans & imaging like X-ray, MRI or ultrasound

Monitoring and vital signs records

Prescriptions from your pharmacy

Free text (e.g. GP notes on lifestyle)

Administrative data like appointments

Non-NHS data

Genomic data

Social care **capability assessments**

Sexual health data

Vaccination records

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Exercise 3:

Assuming that the data is de-identified – so any personal identifiers are removed – **which of the data types listed here would you be more or less comfortable with being used in the SDE for health research?**

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How the Wessex SDE solves research problems

Chris Kipps

Objectives

1. Explain how the research works today and the changes as a result of the SDE
2. Understand consent and opt-out
3. See how your data is kept private and secure

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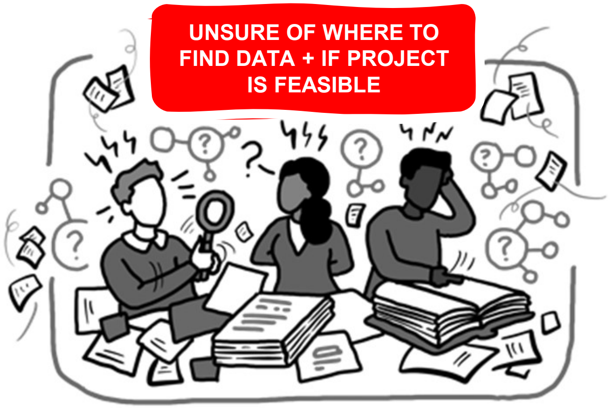
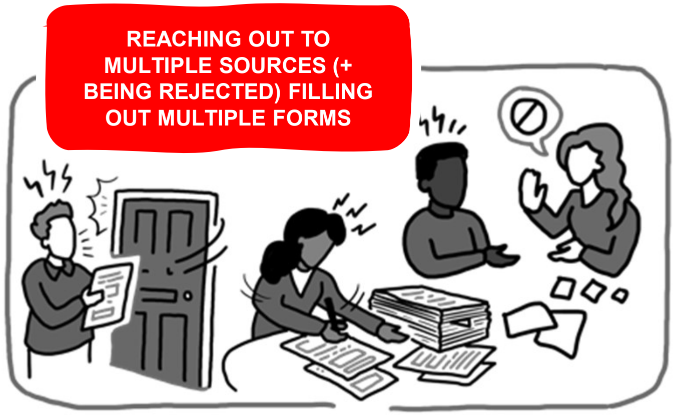
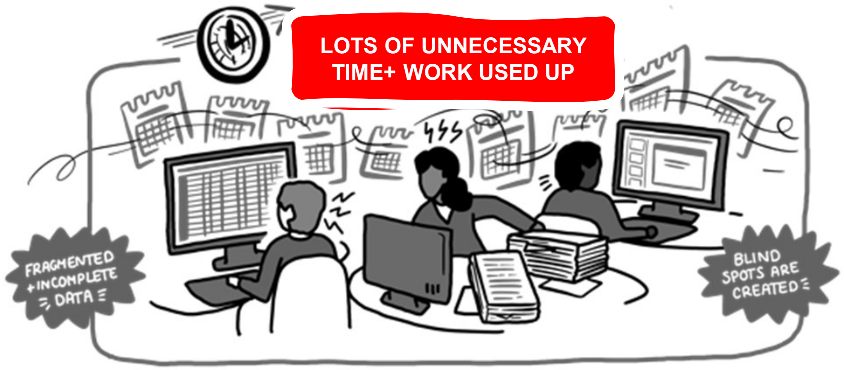
The big challenge is how research works today.



UNSURE OF WHERE TO FIND DATA + IF PROJECT IS FEASIBLE

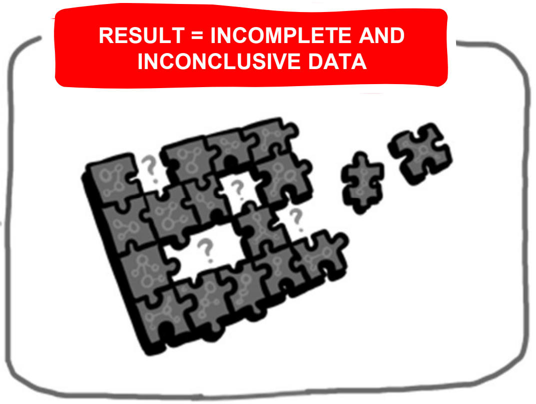


REACHING OUT TO MULTIPLE SOURCES (+ BEING REJECTED) FILLING OUT MULTIPLE FORMS



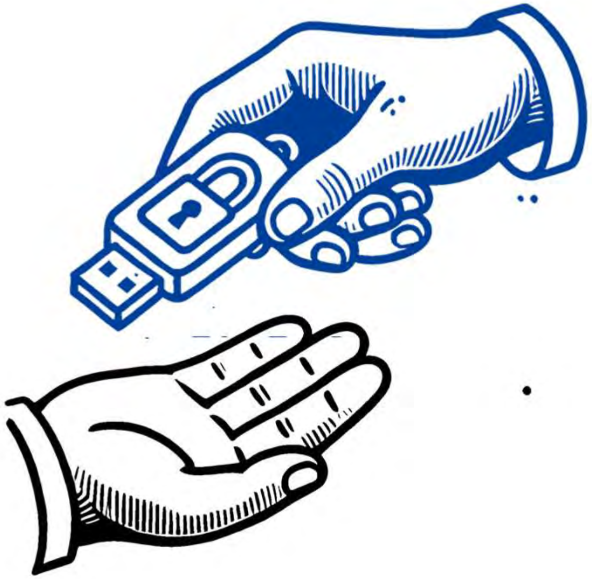
LOTS OF UNNECESSARY TIME+ WORK USED UP

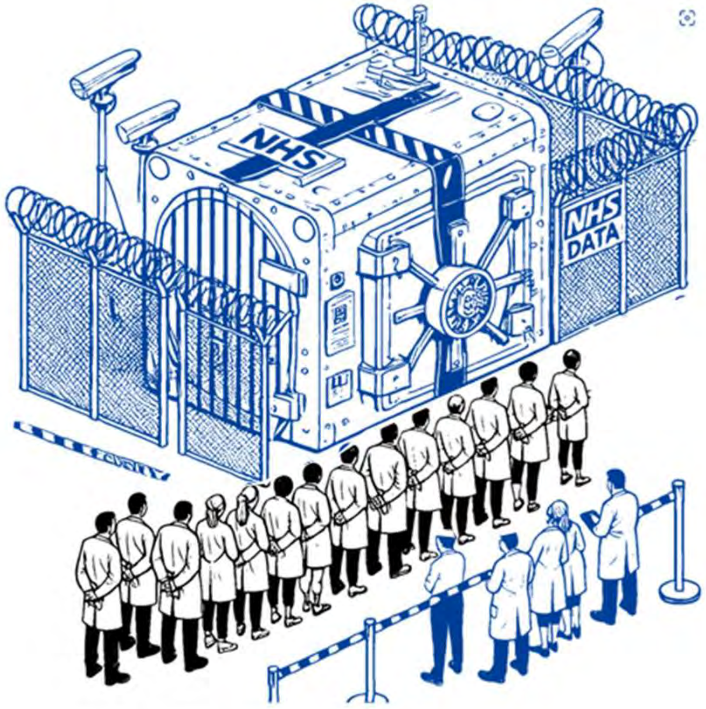
DATA IS SENT TO THE RESEARCHER



RESULT = INCOMPLETE AND INCONCLUSIVE DATA

What is the big change that SDEs bring?





The NHS is moving
from giving data to
researchers – to
making researchers
come to the data

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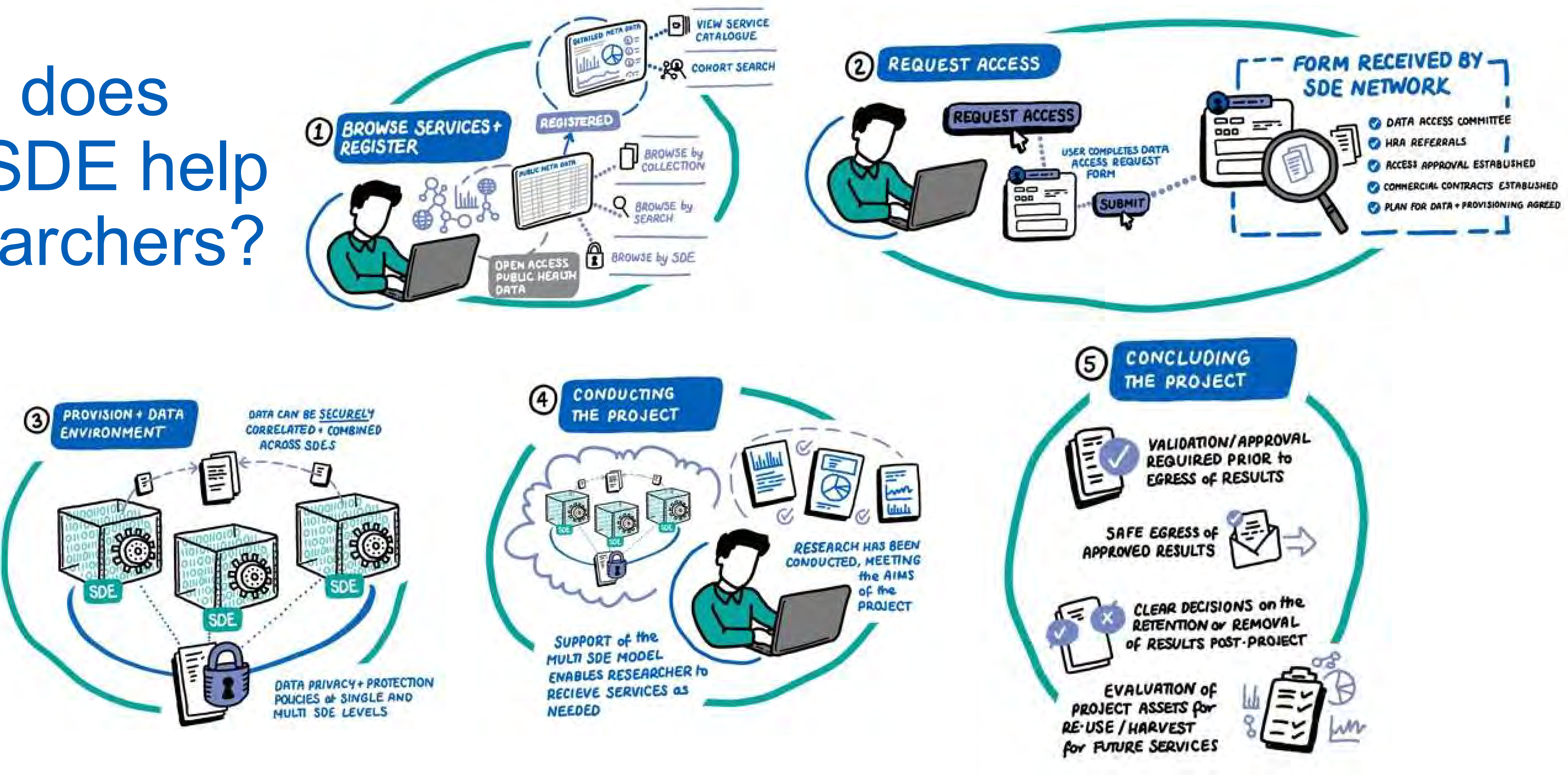
How does the SDE help researchers?



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(1) Data collected by the NHS and **copied into the SDE when needed**

(2) Datasets are linked using your personal information

(3) The new dataset is de-identified – personal information is removed

(4) The de-identified dataset is put in **a secure workspace** for the approved researcher

(5) Only approved tools can be used to analyse the data

(6) Outputs are reviewed and approved before they can be exported from the SDE

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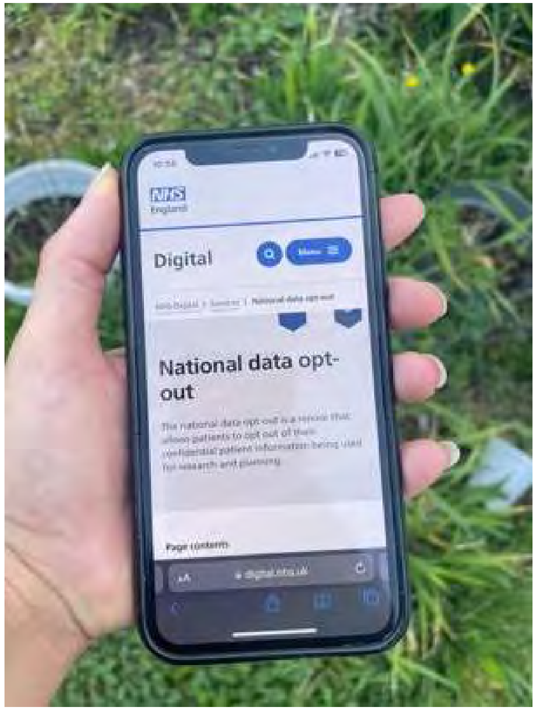
Why can’t you just ask me for consent?

Asking everyone individually every time would be **too slow and difficult** – we need a lot of data!

We ask the NHS Health Research Authority for special permission (called a Section 251 exemption) to use your data.

They have strict rules that we must stick to about when we can use this data – including the need for a clear public benefit

… but you can opt-out



- There is a **National data opt-out** and we will be developing and offering a **local data opt-out**
- **Opting-out will not effect your care** and does not stop you from getting involved in a specific research project – like a clinical trial
- There is a **national debate about the opt-out** and we will follow any changes that come out of this

How does the SDE look after my data?

- **Five Safes:** ONS standard for data handling
- **Public panel:** helps define necessary questions
- **Good answers:** establishes what good answers are
- **Secure use:** ensures data use is secure

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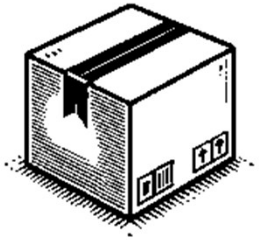
Safe settings:
A highly secure computing environment



A closed box

The fewest physical connections between the SDE and the outside world

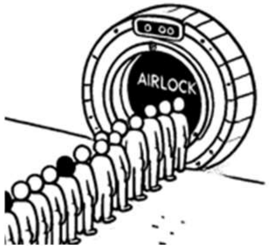
No access to the Internet

Direct data tunnel

No access to data as it moves between the SDE and NHS

ISO 27001 standard

International standard for information security management systems



Airlock system

All data entering or leaving checked by an administrator

Restricted workspaces

Researchers only see data for their project

Penetration tested

Regular external testing of the system and software to find and fix weaknesses

Safe data: De-identified to protect privacy

- We protect your privacy using a process called **pseudonymisation.**
- **We remove personal information that identifies you** – like your name, address and NHS number – **and replace it with a code.**
- We can link the data back to you using a **code key.**
- **Code keys are stored separately and securely – researchers never have access to them.**

PERSONALLY IDENTIFIABLE

PATIENT DATA:

Jordan Thompson

12 Oakwood Drive
Alton
SO34 1AB

18/07/1997

Male, aged 24
Type 1 Diabetes
Chronic severe headaches

DE-IDENTIFIED PSEUDONYMISED

PATIENT DATA:

ID number = 7492076

Location = Hampshire

Male, aged 24
Type 1 Diabetes
Chronic severe headaches

ANONYMISED

PATIENT DATA:

Location = Hampshire

Male, aged 24
Type 1 Diabetes
Chronic severe headaches

Safe Projects: Independent committee

- **Public benefit:** clear benefit to the public or the NHS
- **Independent decisions:** by an independent committee
- **Public involvement:** public members on the committee

Safe People: Only approved researchers

Only approved researchers from approved organisations would be allowed. This could include:

- **Medical staff**, e.g. Doctors, nurses, allied health professionals
- **University researchers**
- **Medical and Social Care Charities**
- **Industry**, e.g. pharma and biotech

Safe outputs: No personally identifiable data

- **Result export:** researchers need to take results out of the SDE
- **No identifiable data:** no personal data taken out
- **Checks:** Automatic and human checks before export
- **Legal controls:** agreements with researchers
- **Monitoring:** Record and monitor SDE activity
- **Transparency:** Transparent reporting on research

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Thank you!

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Exercise 4A:

What are our hopes, fears and aspirations for the Wessex SDE?

Exercise 4B:

Headline News!

Money Mail

Daily Mail

£1 80p to subscribers

Why the heat pump hard sell is a load of hot air

Inheritance tax bombshell facing 500,000 families

STARTS PAGE 27

TWO DATA BREACHES THAT JUST DEFY BELIEF

1. Details of more than 40 MILLION voters exposed in cyber attack on electoral roll

2. Security fears as name of EVERY North
polic
publis

Holly's summer holiday

Simple test to detect cancer spread to hit market in Sept

Startup Gets Licence To Manufacture & Sell Kits

FOR PROPER MEDICAL CARE

THE Sun

40p

LESS THAN THE DAILY MIRROR

FOR A GREATER BRITAIN

STARTS TODAY HOLS FROM £15

CHELSEA ARE CHAMPIONS

BAT'S WAY TO DO IT!

WEST BROM...0 CHELSEA...1

SEE SUNSPORT

OLA-LA!

Sexy star's Strictly Sun Dancin

UK'S BIGGEST CYBER BREACH

NATIONAL HACKED SERVICE

Scores o
hospitals h
Attacke
want ranso

How AI is making diagnosis faster and more accurate

The P&J

INVERNESS, HIGHLANDS & ISLANDS

The Press and Journal

UK REGIONAL DAILY NEWSPAPER OF THE YEAR

Protests could
workers' pay p
– Union boss w

Data leak probe as HIV patients' names revealed

NHS Highland apologises after email blunder identifies sufferers

YOUR HOME INSIDE

STOKES MEMORIALS

DAILY NEWS

Monday
SPORTS p.32
WEATHER p.4

50 cents

Business - Politics - Editorial - Obituaries - TV and radio - Horoscope - Food - City life

New York

Stock market

California

Discovery

State news

Elections

City news

Industry

Healthcare

Europe

Football

Australia

News stories that capture our **hopes and fears** for the Wessex SDE and the data-driven research it helps!

'New era' for Alzheimer's after drug slows decline

NHS in talks over treatment amid hopes it could be approved for patients by end of the year

Brian Monteith: The independence movement is beginning to crumble

THE SCOTSMAN

SCOTLAND'S NATIONAL NEWSPAPER

Alex McLeish: My players stood tall and proud in the Azteca

Kirsty Gunn: Why a letter says so much more than an email

Breast cancer breakthrough will spare thousands the trauma of chemotherapy

Gene test will have immediate impact on how disease is treated

Leaked Brexit doomsday report

Learners allowed on motorway

THE TIMES

Why Bruce Willis is quitting acting

Deborah Ross
Who's the real Elena Ferrante?
Me. Honestly

Childbirth 'is not safe for women in England'

Mothers and babies died avoidably in NHS scandal

Putin faces revolt over blunders in Ukraine

Mr Shane Warne

BBC NEWS

Lunch break:

Re-start at 1.30PM

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After lunch we will be **creating principles to guide how the SDE works** – to stop the bad outcomes we fear and ensure we get the good ones we hope for

Our **Guiding Principles**

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What makes for public trust in health research?

Panel discussion

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Chris Kipps

Health research in a highly regulated environment

We are **building on strong foundations**

- **Research using NHS Data already happens**
- The Wessex SDE will **improve how we do it** – and make new kinds of research possible
- **We have a duty to protect NHS Data** – this is all happening within an existing system of laws and controls

Lawful use of data

Strict national regulatory and policy environment (including data protection laws)

Respecting public choice

We ensure that local and national opt-outs are recorded and implemented

Data owners & controllers

Each NHS organisation has people responsible for ensuring use of your data meets strict policies

Ethical use of data

With dedicated NHS bodies ensuring that the research is support of the public good

We are working to meet **national policy aims**

- **Meeting national objectives** – set out in ‘Data Saves Lives’
- **Learning from past mistakes** – e.g. Care.Data in c.2013
- **Building SDEs locally** – ensuring they are co-designed with local people

Data
Saves
Lives

And, within a **highly regulated environment**

- Caldicott Principles
- Data Protection Act (2018)
- General Data Protection Regulation (GDPR)
- Common Law Duty of Confidentiality
- NHS Constitution
- Health and Social Care Act
- Freedom of Information Act
- Equality impact assessment
- Data impact assessment
- ICO data sharing code of practice
- Data sharing agreements
- Etc.

Department
of Health &
Social Care

NHS
England

NHS
Health Research
Authority

Research
Secure Data
Environment
NETWORK

Building **public trust** is critical to success

- **Complex issues** – with real risks and real benefits
- **Lots of ways for us to get it wrong OR explain it badly** so people to misunderstand
- This Public Panel is vital for us to **set the guardrails** in the right place
- … **AND** make sure we **secure the benefits** Wessex people want

Thank you!

The foundations of trust in public bodies

Will Jennings

Professor of Political Science and Public Policy

Background

- Professor of Political Science and Public Policy – interested in how people form their values/attitudes, and how this impacts behaviour (from elections to public policy).
- Recently led the ‘TrustGov’ project funded by the UK Economic and Social Research Council (2019-2023).
  - Cross-national surveys of citizens about trust (in about 20 countries)
  - Cross-national focus groups of how people make judgements about trustworthiness of political actors and institutions
  - Studies of the effects of trust on a range of attitudes and behaviours (e.g. vaccine hesitancy, ‘pro-social’ behaviours, participation)

Defining trust

- **Trust:** there is a longstanding view that a 'reservoir' of trust is required to sustain societies, economies and democracies
- Much controversy about what social/political trust is.
  - "…Trust is not one thing and it does not have one source; it has a variety of forms and causes" (Levi 1998, p. 79).
  - **But minimal consensus about meaning of the term.**
  - "Trust is **relational**; it involves an individual making herself vulnerable to another individual, group, or institution that has the capacity to do her harm or to betray her." (Levi & Stoker 2005, p. 476).
- ***A* trusts *B* to do *X***

Defining trust

- Social (interpersonal) vs political (institutional) trust
- ‘Thick’ (particularised) vs ‘thin’ (generalised) trust
  - **Particularised trust:** based on first-hand knowledge of individuals or groups (e.g. trust in a friend or neighbour).
  - **Generalised trust:** based on more general information about social groups and situations not directly known to me. We extrapolate from knowledge of how society generally works (e.g. whether it is safe to walk around in ‘this kind of area’ after dark).

Drivers of trust

- Evaluations of trust in public institutions rest upon multiple dimensions. One framework highlights **evaluations of trustworthiness** relating to competence, benevolence and integrity (‘CBI’).

Competence

The ability of the trusted, either in general or to fulfil a specific objective.

Benevolence

Whether the trusted would look after the truster’s interests and well-being, particularly without oversight.

Integrity

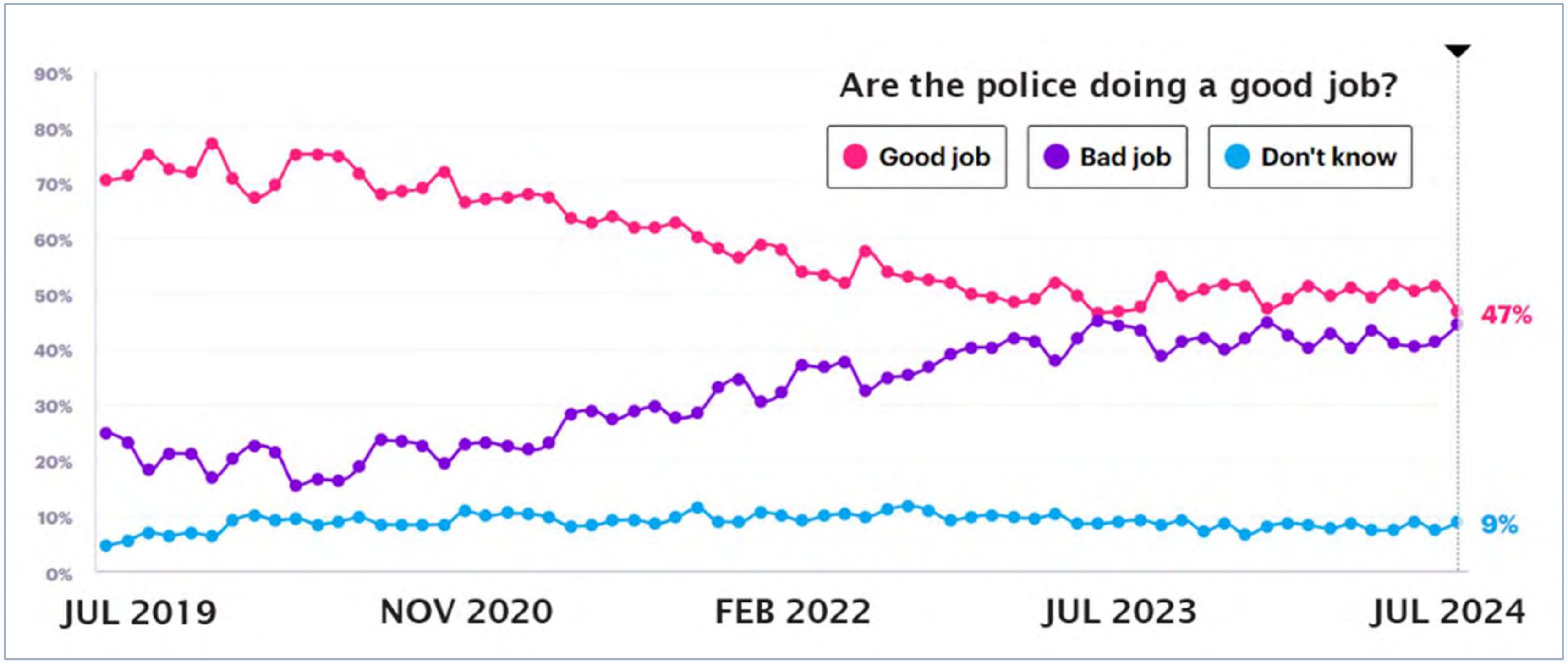
Whether the trusted is open, honest and likely to be consistent in its application.

Trust in political and scientific messengers

- Evidence from **survey experiments**: offered choice of who to trust of a pair of scientists/politicians: random assignment of attributes.
- **Competence** and **independence** matter most for trust in scientists (more than for politicians).
- Communication, honesty, benevolence: Being easy to **understand, admitting mistakes, caring** about ordinary people, being **in touch**, being **transparent** – all matter for trust in scientists/ministers.
- **Values** (balance decisions with needs of business) matter for politicians, not scientists.

How to get it wrong: MET Police

Decline of public trust in **police** – from 75% to 50% confidence in police doing a ‘good job’



How the MET Police got it wrong

- **A series of high-profile cases of serious failings**, misconduct and illegal behaviour by serving police officers (especially during the 2020-22 period).
- **Systemic failures in recruitment and disciplinary system** (Casey review in 2023 found institutional racisms, sexism and homophobia in the MPS) – not just 'bad apples'.
- Poor communications (e.g. botched responses to protests).
- Need independent misconduct systems.
- Need to tackle 'toxic' cultures.

How to get it right: Corporate governance

- Trust is easily lost but hard to rebuild … Rebuilding of trust in **corporate governance** after a series of high-profile scandals and global financial crisis during 2000s (e.g. Goldman Sachs, Northern Rock).
- Reckless trading practices of financial institutions and regulatory failures. Loss of trust in bankers and big business.
- Response: strengthening the **UK's audit, corporate reporting** and **corporate governance systems**.
- Requirements of more **robust stress-testing** of banks, **greater transparency** and more **robust audit**.
- Trust in financial services has recovered (according to the Edelman trust barometer).

Thank you!

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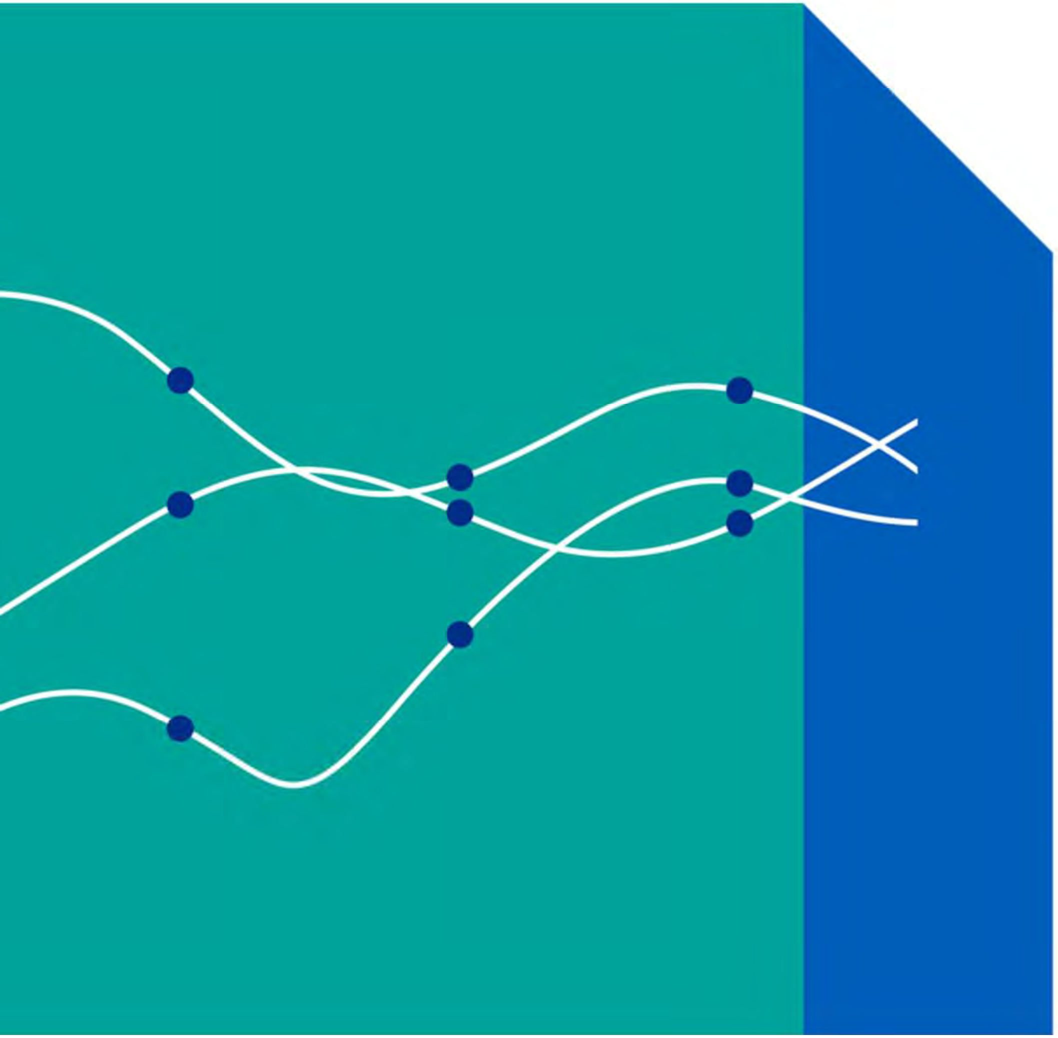


Sandra Hall

Digital Critical Friend

What is a Digital Critical Friend?

Our role would be to help to ensure that the data that is being collected would be going through stringent checks to ensure anonymity for the public whose data is being collected.

We are there to challenge and support the work that is being done, we will also be part of programme boards, co- creating being part of a working group.

Helping out at various events.

Why I decided to join the DCFs

Growing older means more health challenges, I’m currently Pre - Diabetic, I also have many friends facing this challenge.

SDE - will be away researchers will have access to confidential information that may determine a better outcome for patients in the future.

So I hope that through my involvement and participation the research that is being collated might have good future outcomes for patients living with health conditions like Diabetes.

I also enjoy the flexible working hours and being able to do some online work.

Being a voice for underrepresented groups.

The importance of PPIE

Patients and Public involvement is at the heart of SDE.

Over the last few years I've been privileged to be involved in a number of different research projects, both as a researcher interviewing respondents to get their views or being interviewed. Being part of core- leadership providing oversight in various projects.

Having patients and public involvement means a more honest representation of public opinions.

Working together in a partnership- helping to shape the rules and governance of the way the research is being carried out and to challenge ideas that may not be ethically conducive to public opinion.

Listening to Seldom Heard Groups

Seldom heard groups are groups who use our health and social care systems but are less likely to be heard by professionals, health services, research and decision makers.

Over 600 groups, community leaders and services were approached, groups that were selected came from Ethnic Minorities, Young people, Veterans, Maternity(BAME) Armed Forces etc

I was privileged to be part of and to also set -up a group that Sarah could come and visit. In one of the meetings we had a researcher come to chat about his research, something that one of the respondents said has stuck with me ever since.

The SDE team spoke to 560+ people from 40+ groups across Dorset, Hampshire & Isle of Wight

Barton Peveril
Sixth Form College

Basingstoke Hindu Society

Alabaré

clear
citylife

SALISBURY
CITY COUNCIL

DISABILITY
INTEREST
GROUP
SALISBURY

Headway
PORTSMOUTH &
SOUTH EAST HAMPSHIRE

50
Southampton Voluntary Services

lymington baptist
church
Making Friends Group

Move Momentum

NEW FOREST
Food
Bank
BASICS BANK

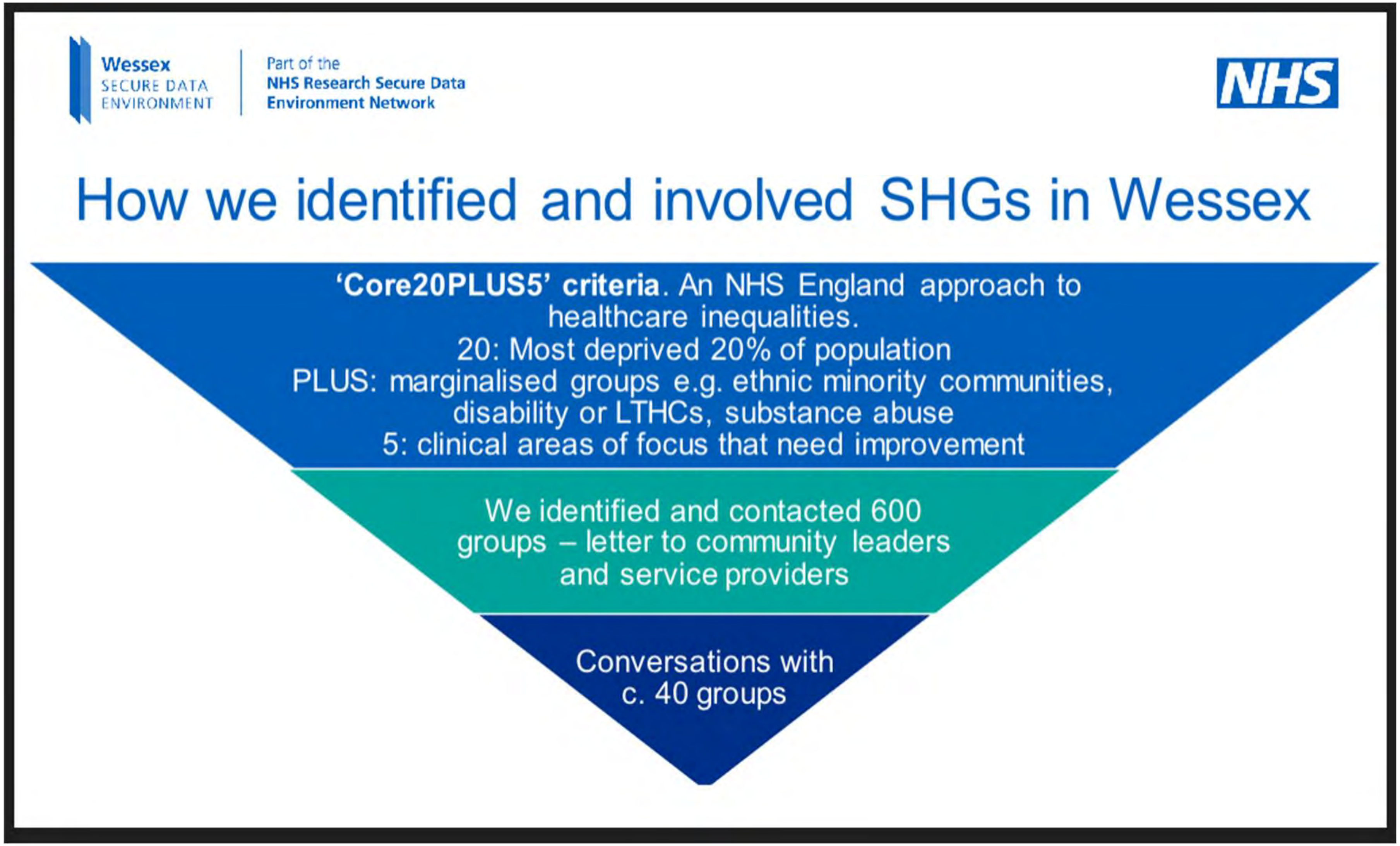
enable
ability
working with disabled people

Rainbow Island

RUSHMOOR
Voluntary Services
Local support for local people

YELLOW
BRICK
ROAD
PROJECTS
HELPING YOUNG PEOPLE
FIND THEIR SEAM OF GOLD

YOUNG
MOTHERS'
FORUM



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How we identified and involved SHGs in Wessex

'Core20PLUS5' criteria. An NHS England approach to healthcare inequalities.
20: Most deprived 20% of population
PLUS: marginalised groups e.g. ethnic minority communities, disability or LTHCs, substance abuse
5: clinical areas of focus that need improvement

We identified and contacted 600 groups – letter to community leaders and service providers

Conversations with c. 40 groups

“*No one has ever asked me for my opinion*”

For me, this quote sums up everything.

It’s the reason why it’s so important to get feedback from groups of people who are under-represented and would otherwise not have their voices heard.

What the Seldom Heard Groups told us

Bringing Projects to life - How big data health research could benefit communities

Creating Positive Feedback - Having an ongoing dialogue with patients and the Wessex public

Accessibility and Inclusion - Making the project accessible to those who have limited IT skills

Information Open to Public - use a variety of methods to let public know about the SDE, eg GP surgeries, social media

Trusted ‘Messengers’ - Establishing links with community leaders and trusted sources, e.g GP surgeries, district nurses, health care workers

Peer Influence - Working alongside people in the community who have health care issues and whose involvement in research, could highlight the importance of research

Where it’s led …….

From the conversations with the Seldom Heard Groups, a report was compiled to capture people’s questions concerns, hopes and fears for the SDE. The DCFs have worked with the SDE team to identify themes.

Purpose - SDE projects must benefit patients

Integrity - Secure systems to project confidentiality
Listening how we would like data to be stored

Equity - Address inequalities, get more involvement in marginalised groups

Accountability - Demonstrate best use of money and are accountable and responsive to feedback.

Collaborations - Involving patients and public in the design of the SDE and communicate the outcomes

Hopes

- Research = good
- Data is beneficial for research

Concerns

- Anonymity
- Inequality
- Security
- Control

Considerations

- NHS capacity to do this
- Who is involved?
- Who decides?

What people said they were concerned about …

“Could people be **discriminated against** based on their health status? For example, those who are chronically ill, HIV positive, disadvantaged socially? How would this affect things like job applications, loans, and insurance?”

“I know you can go in and access without being able to take data out, but how does that work in practice? **Who are the gatekeepers?** Is the patient involved in that decision?”

“In terms of the bigger picture, why is this happening now? **What’s the point**?”

"There’s **better things for the NHS to spend their money on**"

“I would want to share my data, but I wouldn’t because of my [condition]. **I just don’t have the trust**.”

“Because of the Post Office thing, **I would not ever trust the word ‘secure**’.”

"**I trust the NHS**…but **they don’t have a great reputation with handling data**. The app is trash.”

“My history with social services; I wouldn’t want any of it on there.”

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Exercise 5:

Work together to identify and prioritise questions for the panel

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Q&A with panel

Break

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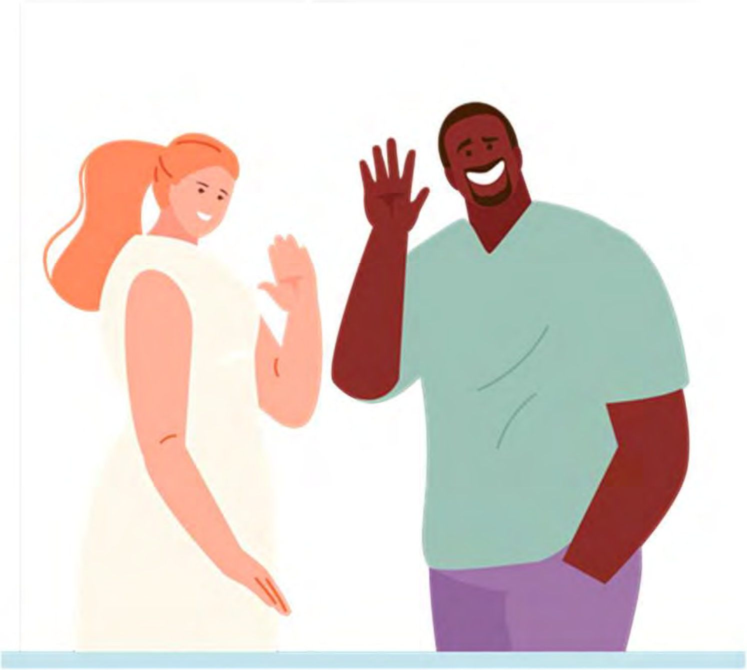
Exercise 6:

What principles should guide the Wessex SDE?



What have we achieved today and what is next?

Appendix 3: Day 2 – Ethical boundaries and valuing research

Guide

This appendix contains all materials used in the second Public Panel session (10 August 2024, Dorset cohort; and 17 August 2024, HIOW cohort).

Purpose of the day

Day 2 was designed to move beyond building understanding amongst participants, and focus on two key questions:

1. **Where do we place boundaries for research?** – testing how comfortable participants felt with different types of projects, and identifying “red lines” or areas needing extra safeguards.

2. **How do we value research?** – exploring different forms of public benefit (from improved care and reduced costs to financial return and international impact), and helping the SDE team prioritise limited resources.

Changes in response to feedback

After Day 1, participants asked for greater clarity on what the day would involve. In response, a **public-facing agenda** was created and shared with participants at the start of the session.

Attachments in this appendix

Session planning

F. **Session 2 Public Agenda** – the version provided directly to participants, outlining the day’s structure.

G. **Session 2 Facilitation Plan** – full agenda, timings, facilitator instructions, exercises, and materials required.

H. **Session 2 Master Deck** – presentation slides, including framing of “safe vs risky” research, case studies, value models, and prompts for discussion.

I. **Session 2 Facilitator Guide** – preparation guide with top tips, flipchart setups, and guidance on capturing outputs (risks, benefits, key factors, rankings, and values).

Collateral

J. **Session 2 Use Case Cards** – single-page case study summaries used in group work (LifeLab, HPV, MyCOPD, Dementia, Sickle Cell, Sarcoma).

F: Session 2 Public Agenda

Wessex Public Panel on NHS Data: Session 2 Agenda

TIME	ACTIVITY	DETAIL
09:45	**Public Panel members arrive for tea and coffee**	
10:00	Introduction and welcome	Explaining the purpose of the day. **In the morning** – we will be discussing where and how we place the boundaries for research that can use the Wessex SDE. **In the afternoon** – we will be looking at different kinds of public benefit that research using the SDE can create and exploring what kinds of value are most important to us.
10:20	Where do we place boundaries for research? – Presentations	Explaining who sets boundaries for research, the role of the Public Panel, and how we have selected the Research Examples we will be discussing today.
10:40	Research Examples 1 and 2 – Presentations and table activity	Presentations of 2 realistic Research Examples and evaluation by Public Panel members.
11:35	**BREAK**	
11:50	Research Examples 3 and 4 – Presentations and table activity	Research Examples 3 and 4 – presentations of 2 realistic Research Examples and evaluation by Public Panel members, followed by ranking the 4 examples we have evaluated.
13:20	**LUNCH**	
14:00	How do we value research? – Presentations	Explaining how the SDE creates value, who it creates value for, and the different kinds of value that it can create. We will then look at what we know about public attitudes towards value exchange between the NHS and different kinds of researchers.
14:20	What kinds of value are most important to us? – Table activity	Panel Members discuss different kinds of public value and then rank these from low to high value.
14:50	**BREAK**	
15:05	Research Examples 5 and 6 – Presentations and table activity	Presentations of 2 realistic Research Examples and evaluation by Public Panel members, focusing on the different kinds of value they create and then adding them to our ranking of other research examples.
15:40	Prioritising SDE resources – Table activity	Panel Members will help the SDE team understand how the 6 research examples should be prioritised with an activity where you decide how to allocate limited resources to support our six research examples.
15:55	Closing the meeting	Lead facilitator summarises what we have achieved today and adds closing comments.
16:00	**END OF DAY**	

Note that exact timings may vary. The session will finish promptly at 4:00PM.

G: Session 2 Facilitation Plan

Wessex Public Panel on NHS Data: Session 2 Plan

10 & 17 August 2024

#	Start	End	Min.	Title	Description of the process	Outputs / materials / running notes
-	09:00	09:30	00:30	**Facilitator check-in**	An opportunity for the team to check-in regarding the plans for the day and for facilitators to clarify any process concerns. Actions include: • Preparing flipcharts (details to be added) • Organising tables Note that participants will be asked to wait outside the event room until at least 09:30.	Flipchart and stand for each table Sharpies – at least 1 per person Pens and note paper- for each person Flipchart markers – big sharpies and at least 2 coloured markers Glossaries etc. at each table Blank name badges
0	09:30	10:00	00:30	**Participants arriving**	**Keira –** Welcomes participants and registers their attendance outside the room **Table Facilitators** • At tables welcoming participants. • Handing out name badges for participants to write their own name. Referring early participants to the information materials available at the tables	**-**
1	10:00	10:10	00:10	**Introduction and welcome** Setting the scene, context and tone of the day.	**Lead facilitator – Kaela** Welcome and who is in the room • Facilitation team, speakers and DCFs • Cover housekeeping	**Introductory PowerPoint presentation**

					- 'Parking Place' - conversation guidelines Remind members of the purpose of the Panel - The role of the panel in determining how (not IF) the SDE will be implemented to support health research - Reminder of what was covered day 1 - Overview of the agenda for the day including outputs from the morning and afternoon sessions - Summary of what will happen over the whole Public Panel **Playback to the Panel the Principles they created Day 1**	
2	10:10	10:20	00:10	**Table Exercise 1: Icebreaker**	**Table Facilitators** Purpose – to give all panellists an opportunity to introduce themselves to the people they will be working with that day and get back into the SDE mindset Process: Call on each member of your table, in turn, to introduce themselves, asking for: 1. Their Name 2. Where they are from. 3. One thing that has stuck with them from the first meeting Once the 'go-around' is completed open up the conversation to wider reflections from day 1 and the Principles they drafted	-
3	10:20	10:40	00:20	**Opening presentation - scene setting**	**Lead Facilitator Kaela** will prepare members for the presentation and encourage them to take notes, before introducing the first speaker. (1 min) **Speaker: SDE Team – Mark Heffernan** - Explaining that most of the research that wants to use the SDE is likely to be uncontroversial – but it is the stuff that tests the boundaries that will tell us where to put the guardrails	**PowerPoint presentation**

					- Sets out how the SDE team has identified some research examples that test the limits of what the public are likely to find acceptable **<u>Speaker: DCF – Angus / Andy</u>** - DCF explaining their group view on the features of research that people might be concerned about – i.e. that went on to help us choose the hypothetical research examples	
4	10:40	10:50	00:10	**Hypothetical Research Example 1**	**Lead facilitator** - sets context re hypothetical examples - created for this process but also realistic and potentially the exact type of thing the SDE's Data Access Committee might be asked to consider. (3 min) - Reminder about the key criteria for health research proposals to use the SDE being to deliver PUBLIC BENEFIT - Reminder about the 2 key case studies we heard about in Meeting 1 – which most people agreed had clear benefits relating to treatment and health outcomes for patients - Notes that these are 'edge use' examples designed to ask Panellists to explore the boundaries of what seem 'comfortable' uses of the SDE and where potential uses start to feel uncomfortable / risky and where they, as representatives of the public, might want to see 'red lines'. **Mark Heffernan** (7 min) - Presents Research example 1 – LifeLab – exploring links with education and non-NHS data	Slide deck pack Summary of research examples at tables
5	10:50	11:10	00:20	**Table Exercise: Evaluation Research Example 1** <u>Outputs:</u> flipchart record of brainstorm – benefits, risks/discomforts, concerns - that group can refer back to when ranking	**Table Facilitators** <u>Purpose</u>: - To collect initial responses and embed understanding of the research example - To explore key aspects of the example that may provoke feelings of risk and/or discomfort <u>Process</u>: **Stage 1** (5 min)	Pre-prepared flip chart Slide deck pack Summary of research example at tables

					Invite members to do quick-fire brainstorm • No judgement, all ideas recorded onto the pre- prepared flipchart (with 3 segments - benefits / risks / key factors). • *Write responses in large print directly onto the flipchart so that all group can see them (supplementing with more detail from members on post-its if needed)* <u>Key questions</u>: 1. What do you see as the biggest 'public benefits' of this project? 2. Is there anything that jumps out to you as risky or discomforting with what is being proposed? **Stage 2** (15 min) Exploring aspects of the particular example in more detail 3. How do you feel about linking all of these data types? 4. Which, if any, feel more risky and why? 5. What safeguarding considerations might we want to consider to ensure that the project feels safe? 6. Any other key considerations / potential concerns regarding this proposal?	
6	11:10	11:15	00:05	**Hypothetical Research Example 2**	**Lead facilitator** – reconvenes group **Mark Heffernan** (5 min) • Presents Research Example 2 – **HPV Vaccines** – Sexual health data and safeguarding	Slide deck pack Summary of research example at tables
7	11:15	11:35	00:20	**Table Exercise: Evaluation Research Case Study 2** <u>Outputs:</u> flipchart record of brainstorm – benefits,	**Table Facilitators** <u>Purpose</u>: • To collect initial responses and embed understanding of the research example	Pre-prepared flip chart Slide deck pack Summary of Case Study at tables

				risks/discomforts, concerns - that group can refer back to when ranking	• To explore key aspects of the example that may provoke feelings of risk and/or discomfort Process: **Stage 1** (5 min) Invite members to do quick-fire brainstorm • No judgement, all ideas recorded onto the pre- prepared flipchart (with 3 segments - benefits / risks / key factors). • *Write responses in large print directly onto the flipchart so that all group can see them (supplementing with more detail from members on post-its if needed)* Key questions: 1. What do you see as the biggest 'public benefits' of this project? 2. Is there anything that jumps out to you as risky or discomforting with what is being proposed? **Stage 2** (15 min) Exploring aspects of the particular example in more detail 3. How do you feel about linking these datasets? (positive, negative neutral) and **why**? 4. How do you feel about the outcomes data being used by non-NHS partners? *[Is there anything that you would want them to use it for/not for? Are there any reasons you might not want them to use it?]* 5. What concerns, if any, are there that this may lead to the industry partner selling more vaccines as a direct result of the research?	
8	11:35	11:50	00:15	**BREAK**		
9	11:50	12:00	00:10	**Hypothetical Research Example 3**	**Lead facilitator** – reconvenes group **Mark Heffernan** (5 min) • Presents Research Example 3 – MyCOPD – Moving data outside the SDE to train an AI model	Slide deck pack

10	12:00	12:20	00:20	**Table Exercise: Evaluation Research example 3** Outputs: flipchart record of brainstorm – benefits, risks/discomforts, concerns - that group can refer back to when ranking	**Table Facilitators** Purpose: • to collect initial responses and embed understanding of the research example • to explore key aspects of the example that may provoke feelings of risk and/or discomfort Process: **Stage 1** (5 min) Invite members to do quick-fire brainstorm • No judgement, all ideas recorded onto the pre- prepared flipchart (with 3 segments - benefits / risks / key factors). • *Write responses in large print directly onto the flipchart so that all group can see them (supplementing with more detail from members on post-its if needed)* Key questions: 1. What do you see as the biggest 'public benefits' of this project? 2. Is there anything that jumps out to you as risky or discomforting with what is being proposed? **Stage 2** (15 min) Exploring aspects of the particular example in more detail 3. How do you feel about data being linked with data from other SDEs? 4. What, if anything, would need to be place to make you more comfortable with it? 5. How do you feel about the deidentified data being taken out of the SDE for crunching by a super-computer? Does this raise any new concerns or risks? 6. How do you feel about the mix of benefits between patients, NHS and industry? Does it feel well balanced? 7. Any other key considerations / potential concerns regarding this proposal?	Pre-prepared flip chart Slide deck pack Summary of Case Study at tables

11	12:20	12:25	00:05	**Hypothetical Research example 4**	**Lead facilitator** – reconvenes group **Mark Heffernan** (5 min) • Presents Research Example 4 – Dementia Clinical Trials re-discovery	Slide deck pack
12	12:25	12:45	00:20	**Table Exercise: Evaluation Research example 4** Outputs: flipchart record of brainstorm – benefits, risks / discomforts, concerns - that group can refer back to when ranking	**Table Facilitators** Purpose: • To collect initial responses and embed understanding of the research example • To explore key aspects of the example that may provoke feelings of risk and/or discomfort Process: **Stage 1** (5 min) Invite members to do quick-fire brainstorm • No judgement, all ideas recorded onto the pre- prepared flipchart (with 3 segments - benefits / risks / key factors). • *Write responses in large print directly onto the flipchart so that all group can see them (supplementing with more detail from members on post-its if needed)* Key questions: 1. What do you see as the biggest 'public benefits' of this project? 2. Is there anything that jumps out to you as risky or discomforting with what is being proposed? **Stage 2** (15 min) Exploring aspects of the particular example in more detail 3. Assuming all data and research is already approved by the NHS Health Research Authority, should the SDE be happy to let the research go ahead? *[yes/no - if not why?]* 4. Is it ok in principle to reidentify people for clinical trials? *[yes/no - if not why?]*	Pre-prepared flip chart Slide deck pack Summary of research example at tables

					5. **Who** do you think should be **contacting people** about clinical trials? Is there anyone that you wouldn't want to do this and **why**? 6. Are there any other things we should consider when reidentifying and/or contacting patients?	
13	12:45	13:20	00:35	**Table Exercise: Risk ranking of the 4 examples** Outputs: a visual map positioning each of the 4 research examples on a 'risk ranking' scale from 1 – 5 with details of the reasons why	**Lead facilitator** (5 min) • Introduces the next exercise – to explore when, if ever, the benefits from using the SDE for a particular type of research may (or may not) outweigh the risks i.e. is it a 'good' use of the SDE resource • Reminder about the 5 safes • Ask group to consider which, if any of these, they might be particularly worried about in relation to each of the case studies **Table facilitators** Purpose: to understand Panellists assessment of relative risk / discomfort relating to the research examples presented and identify which 'edge use' aspects of how the SDE could be used they perceive as most problematic. Process: **Stage 1** (20 min) • Present the prepared scale to participants, placing it in the middle of the table. • Choose 1 research example to begin with (approx. 5 min per case study) o *The order is not important, and you might want to choose the one that elicited the strongest feelings from your group* • Review the group's initial responses to the example • Call for suggestions from the group about where on the scale the particular example should be positioned o *Actively ask clarifying questions to **explore reasons why***	A5 card for each case study Flipchart scale 1- 5 (where 1 = very uncomfortable / very risky use of the SDE and 5 = Very comfortable with this use of the SDE

					o *Record reasons on post-its that can be attached to the A5 example card* • Negotiate and agree a position (interim position) on the scale – using BluTak to stick it on. o *If agreement cannot be reached, choose a position supported by the majority, but record objections as minority views* • Repeat the process for the remining 3 examples – framing the initial question as ‘<u>Does this one seem more, or less, comfortable than the first?</u>’ o *At this point initial positions might shift and cards / reasons can be repositioned along the scale* **Stage 2** (10 min) 1. Ask panellists to ‘step back’ from the specifics of each example and consider: a. Are there cross-cutting issues associated with the risks / discomforts they have identified? - *For example, the involvement of private industry partners, data moving outside the Wessex SDE or concerns about biased/weighted data* b. Are there very specific aspects of concern that have resulted in examples being placed at the risky/uncomfortable end of the scale? - *This could include, for example, the use of AI outside the SDE, the risk of re-identification from small data sets identification.* *c. Capture cross-cutting and the most significant concerns on a different coloured post-it and place these on the scale alongside the examples* - *Where possible associate each with one of the ‘5 safes’*	
14	13:20	14:00	00:40	**LUNCH**		

15	14:00	14:20	00:20	**What we know about the public's attitudes towards value sharing models?**	**Lead facilitator** (2 min) – Reconvenes the panel and explains that we are now switching focus to broader considerations of value and value exchange, for health research using the SDE. We will consider the different types of value coming from research using the SDE, and which might be most valued by the public. We will also be considering how SDE resources should be prioritised to ensure the value most important to Wessex people is delivered. **SPEAKER – Mark Heffernan** (5 mins) Explains how the SDE creates value and the different kinds of value for patients, the community, the NHS, and third parties. All projects must deliver public value. We want to understand what kinds of value are prioritised by people in Wessex. • Short term direct benefits to health and care VS long term breakthroughs • Benefits to clinical care VS efficiencies and prevention savings for the NHS • Financial rewards that can be used to enable further research VS early access or discounts on new treatments **SPEAKER – Joanna Stapley video** (5 min) • National deliberative research • Existing NHS models and best practice • What are the national rules about commercial arrangements – including touching on revenue options like deferred payments, royalties, in-kind benefits, etc. **SPEAKER Ralph Scott** (5 min) – What we know about public attitudes from seldom heard groups and the national literature review	
16	14:20	14:50	00:30	**Table Exercise: Exploring different types of value** Outputs: a visual map positioning the importance of different	**Lead facilitator** – Reconvenes group and introduces the task Purpose: • To explore the overarching question – **"What kinds of public value are most important to us."**	Pre-prepared large post-its with different types of value Flipchart scale 1- 5 (where 1 = very low value

				aspects of value in relation to each other	**Table facilitators – Stage 1** (5 min) • Ask members to review the pre-prepared list of potential aspects of public value / benefits research could deliver • Consider whether there are any other kinds of value they have identified in their discussions that are missing – use Post-it notes to add these to the existing list **Stage 2** (20 min) Task: • Rate the benefits we have identified by positioning them on a scale of 1-5 relating to public value, using a vertical scale (1= low overall public value to the people of Wessex and 5= high public value) Process: Positioning the potential benefits in order of importance to the population of Wessex: • Ask members to choose one of the potential benefits and suggest a for it on the scale – with reasons why. • Seek agreement or divergence from the rest of the table – focusing on reasons why. • Agree (at least provisionally) a position 1. Continue to position all potential aspects of value along the scale – actively probing and noting reasons why **Lead facilitator – Stage 3** (5 min) Seek feedback from each table (ideally from members) about top and bottom ranked aspects of public value	to the Wessex public and 5 = Very high value to the Wessex public
17	14:50	15:05	00:15	**Break**		
18	15:05	15:20	00:15	**Hypothetical Research Examples 5 and 6**	**SDE Presenter – Mark Heffernan** (c.7 min for each research example) • Presents Research examples 5 and 6 - • 5 – Sickle Cell Disease – Low numbers locally, national/international benefit [draw comparison with HPV vaccine example – local high numbers]	

					Lead facilitator calls for 1 min quiet reflection o 6 - Sarcoma – Value exchange between SDE and industry [draw comparison with LifeLab benefits and no industry involvement]	
19	14:20	14:40	00:20	**Table Exercise: Evaluation of Research Examples 5 and 6**	**Table facilitators** Purpose: • Consider the different types of value that these examples create in the context of balancing risk Process: • Write the names of the two Research Examples on the flipchart • Invite Panel members to consider each example in turn for 10 mins total • Add responses to the flipchart on large Post-Its so that all of the group can see them (members can add Post-its too) • In the last few minutes place the research example on the risk scale (rated from 1-5) with the other research examples – this should be a quick rough-and-ready placement Key questions: • What kinds of value does this Research Example create? • Do they also generate new / additional risks? What are they? • How comfortable / uncomfortable are we with these examples?	
20	15:40	15:55	00:20	**Table Exercise: Prioritise SDE resources** Outputs: resources vote Followed by flipchart notes about the main considerations when casting votes	**Lead Facilitator** – introduces the task • All projects must deliver public value. The SDE team wants to understand what kinds of value are prioritised by people in Wessex. • Big question: Where do you think Mark and the SDE team should focus their time to best deliver research outputs that are valued by – and valuable to – the people of Wessex? **Table facilitators** Process:	6 large cups (or other voting receptacles) Blue plastic tokens A3 print of each case study - clearly labelled Additional people resources in the room count the votes as quickly as possible.

					Each member to be given **9 tokens** (5 min) • Question is where they would allocate SDE resources across the 6 case studies considered (with the option of putting multiple tokens towards each example) • Members get up and cast their votes, without the visual influence of where earlier respondees resources were cast. **As members return to tables** (10 min) • Encourage and note reflections on what were their ‘biggest deciding factors’ relating to where to allocate resources o Specifically prompt members to consider whether ‘financial value’ to the SDE played a part in their decisions **Lead Facilitator** (5 min) • Reveals the results of the resource allocation • Invites reflections from the panel	
21	15:55	16:00	00:05	**Closing the meeting**	**Lead Facilitator** • Thanks • Flag the evaluation survey coming • What next	-

H: Session 2 Master Deck

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WELCOME TO SESSION 2

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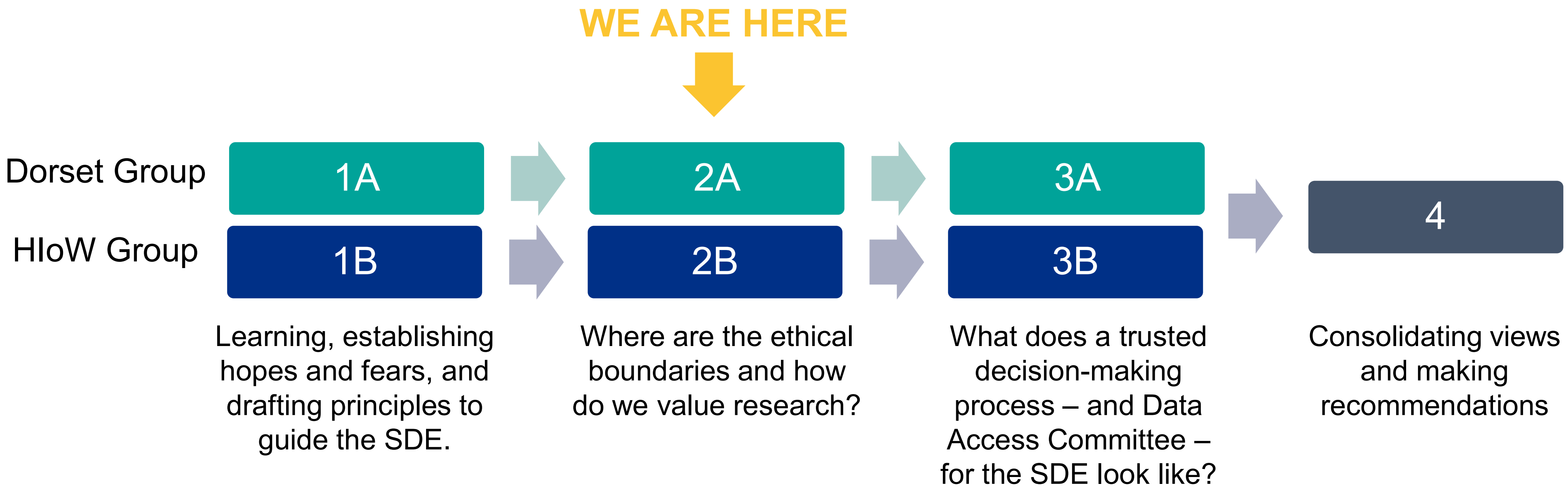
Overarching question for the Public Panel

How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?

Overview of Public Panel meetings



WE ARE HERE

Dorset Group: 1A → 2A → 3A

HIoW Group: 1B → 2B → 3B

→ 4

1A / 1B: Learning, establishing hopes and fears, and drafting principles to guide the SDE.

2A / 2B: Where are the ethical boundaries and how do we value research?

3A / 3B: What does a trusted decision-making process – and Data Access Committee – for the SDE look like?

4: Consolidating views and making recommendations

Overview of Public Panel meetings

Learning, establishing hopes and fears, and drafting principles to guide the SDE.

Where are the ethical boundaries and how do we value research?

What does a trusted decision-making process – and Data Access Committee – for the SDE look like?

Consolidating views and making recommendations

What we achieved in Session 1

- We talked about data-driven research, the kinds of NHS data that might be involved, heard about examples of research, and how the SDE supports researchers.
- We talked about our **hopes and fears** and **rated how risky we thought different kinds of data** are – we have used your rankings to choose the research examples we will share today.
- In the afternoon we heard about how we build **the foundations of public trust** in projects like the Wessex SDE – and **wrote principles to guide the SDE**, which we will return to in Meeting 4.

You told us about the principles that should guide the SDE overall:

- Good communication
- Honesty and openness
- Show tangible benefits
- Show value for money
- Private by design
- Transparency
- Decentralised – to prevent corruption
- Accountable – with external audit
- Educate the public
- Reporting of activity and results
- Accuracy of data
- Clearly stated ethics
- Sustainable commercial model
- …

Agenda for the day

- Why are we here today?
- Introducing how we **guide the boundaries** for research
- Exploring research examples #1 and #2

BREAK

- Exploring research examples #3 and #4
- Risk ranking the four case studies we have discussed

LUNCH

- Understanding how we **value research**?
- Exploring what we value most from research

BREAK

- Exploring how we **prioritise SDE resources**

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

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Where do we **place boundaries** for research?

Mark Heffernan

We need clear and consistent boundaries about the kinds of research that are supported by Wessex

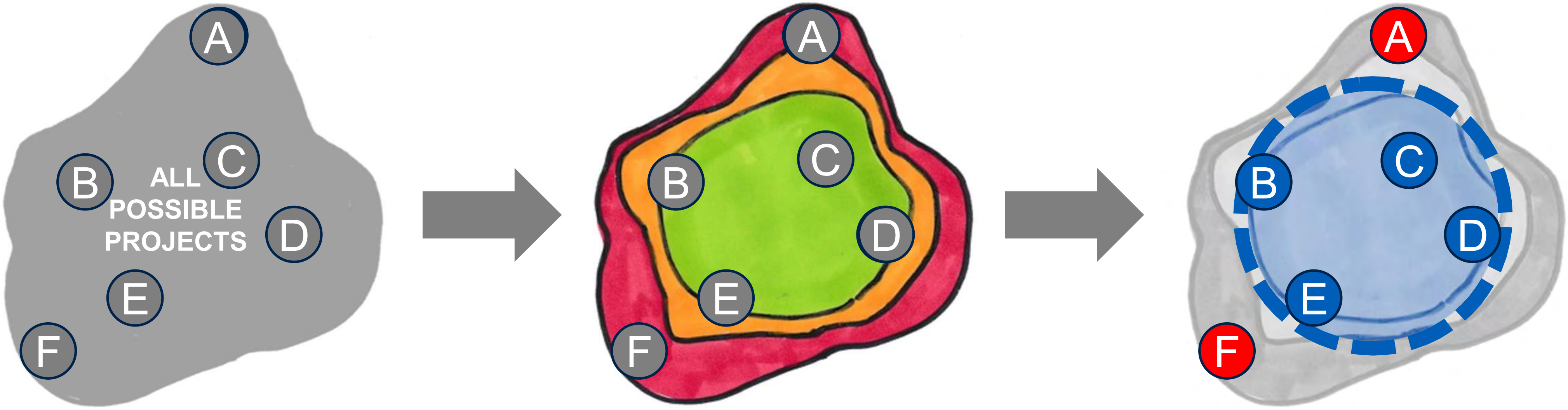
This Public Panel is vital for us to **place the guardrails in the right place** – and make sure we **secure the benefits Wessex people want**. We need to ask:

Is the **overall purpose** of research something people in Wessex would support?

Does the research use **methods** that people in Wessex would support?

Do the **public benefits outweigh any risks**?

How do we find these boundaries?



Find **example research projects** that that could use the SDE

Explore out **how risky** the Public Panel feels these research projects are

Set the guardrails that stop research we don’t want whilst allowing what we do

What research projects are we interested in?

- **Our starting point is the Five Safes**: Data, People, Projects, Settings and Outputs
- We are interested in **projects that challenge these principles**
- With a clear **public benefit that may or may not balance the risks**

How we found research projects to test with you

- Worked with the SDE team, clinical academic researchers, and our Digital Critical Friends
- **Created 4 example projects** that test features that our SDE team and DCFs think are important for future projects, but could be worrying

Talked to researchers about data-driven research they want to do

SDE team identified features of these projects that challenge the Five Safes principles

Discuss and refine this list of features with Digital Critical Friends

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Thank you!

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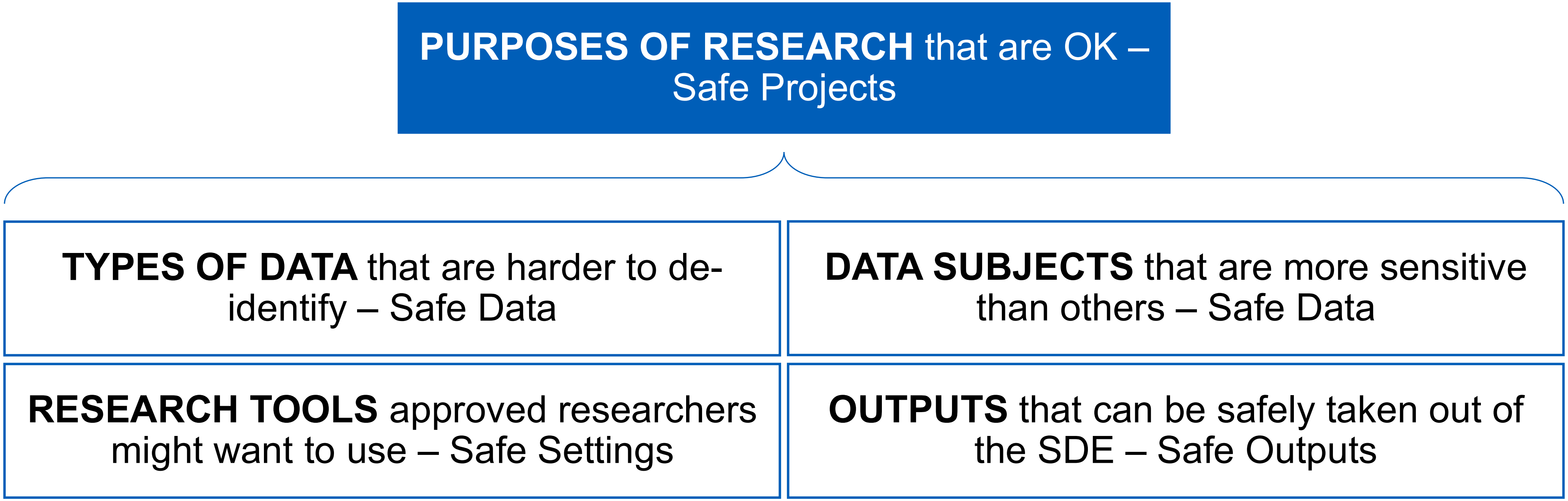
Exploring the details of research – what matters?

Digital Critical Friends

What bits of these research projects will we be talking about?



PURPOSES OF RESEARCH that are OK – Safe Projects

TYPES OF DATA that are harder to de-identify – Safe Data

DATA SUBJECTS that are more sensitive than others – Safe Data

RESEARCH TOOLS approved researchers might want to use – Safe Settings

OUTPUTS that can be safely taken out of the SDE – Safe Outputs

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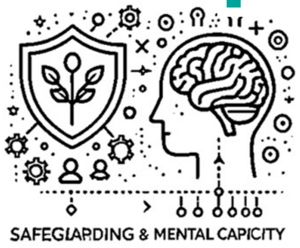
Data subjects

Mental health and social care – esp. where data is more subjective / less certain



Safeguarding and mental capacity inc. temporary loss

GP records

Population Health

Rare conditions

Minority communities (e.g. biased or discrimination)

Data types

+

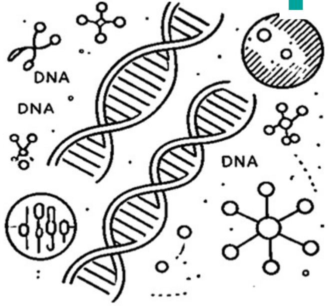

Prescriptions

++


Sexual health

+


Vaccinations

+


Genomic data

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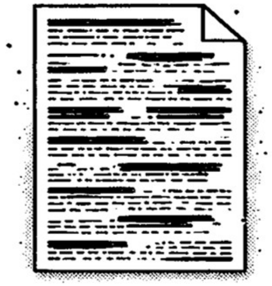

Free text and data privacy

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Photos, sound and video

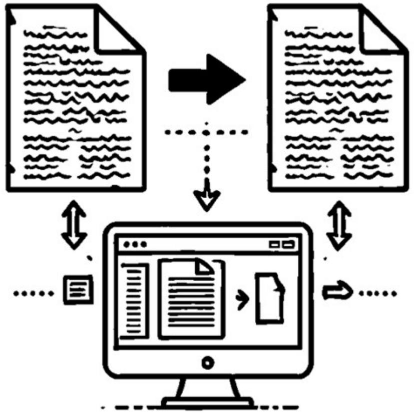
Multi-modal data

+

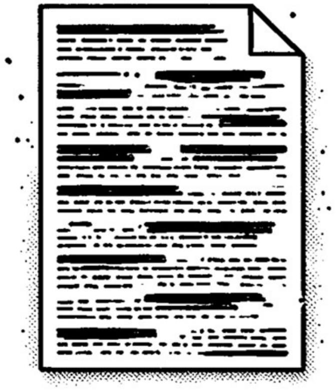

Non-NHS data

Research tools

Basic analytics



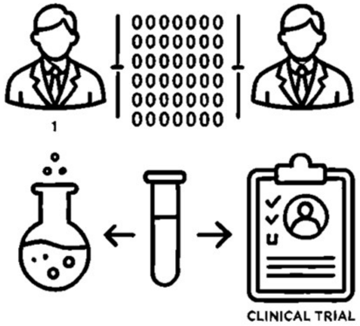
Converting free
text to print



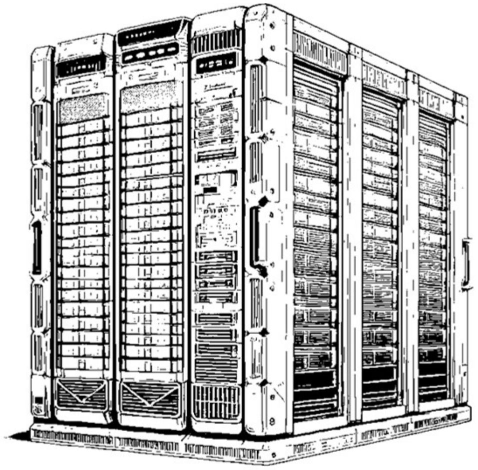
Converting and
redacting free text

AI and
machine learning

Safe Outputs



Clinical trial reidentification



High performance computer cluster (super-computer)

Thank you!

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Exploring examples of research that test the boundaries of what is acceptable

Mark Heffernan

Who decides what? Local vs. national issues

WESSEX SDE (WORKING WITH LOCAL PEOPLE)

- Decides on ethical issues raised by research using the SDE – **where not already reviewed by NHS Regulators**
- Provides **extra scrutiny and guardrails** for issues that people in Wessex see as sensitive

NHS REGULATORS

- NHS Health Research Authority usually **decides whether research projects are ethical** and can go ahead
- Decides when researchers get **special permission to use your de-identified data without consent** (Section 251 exemption)
- Individual data controllers in NHS organisations decide if their data can be used for research

Who decides what? Public Panel vs. SDE Team

PUBLIC PANEL ROLE

- **Identify areas and issues of concern** – and benefits we want to capture
- **Give reasons** – so the SDE team can understand where these concerns are coming from

SDE TEAM ROLE

- **Sets rules** for the platform and its governance that address the issues raised by the public panel
- **Gives reasons** when we depart from the Public Panel’s recommendations

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What should the Panel be looking out for in these research examples?

Safe Data

Data is de-identified to protect privacy.

Safe People

Only trained and authorised researchers from approved organisations.

Safe Projects

Approving research that is ethical and for public benefit.

Safe Settings

Protecting data within secure, controlled environments.

Safe Outputs

Ensuring that released research results cannot identify individuals.

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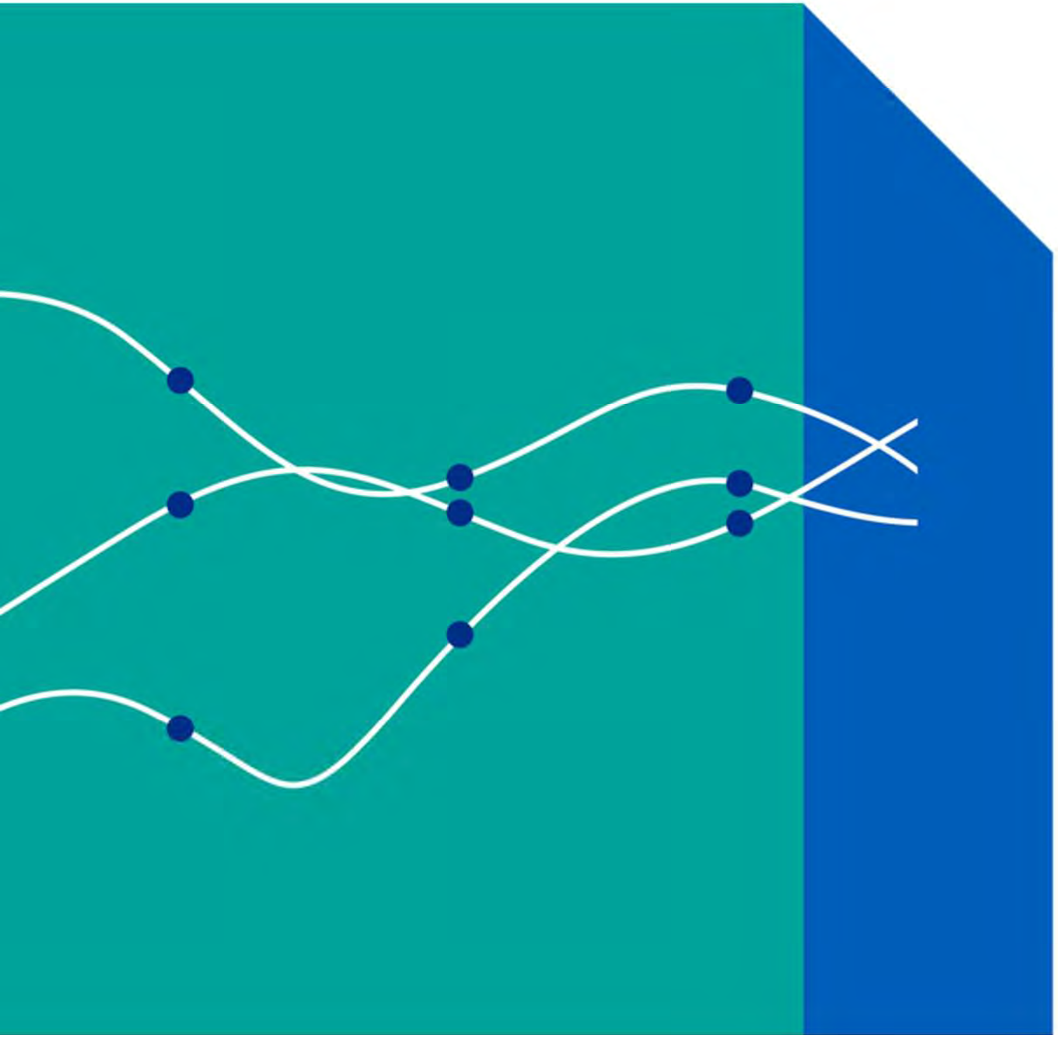


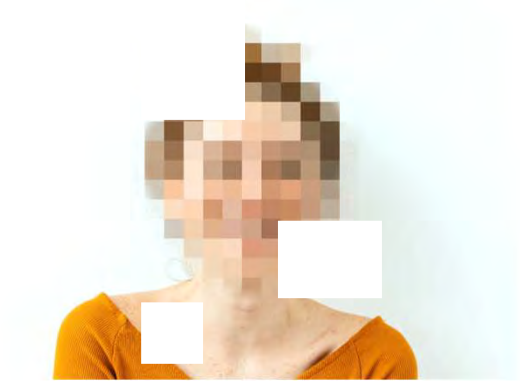
LifeLab Research Example #1

Improving adolescent health using education and non-NHS data

Mission: Improving adolescent health choices

This 10-year study by LifeLab will create real world evidence to **attract funding for local interventions** and new ways of engaging with adolescents about their health and lifestyle choices by **demonstrating links between increased awareness and long-term health and educational success measures**.

Whose data is in the study?



YOUNG VOLUNTEER PATIENT DATA (RECRUITED FROM LOCAL SCHOOLS)

Sarah Bennett

103 High Street
Bournemouth
BH1 1AA

5/7/2010

Female, aged 14
Attainment = B
FSM = Yes
Attendance = 95%

Police record = No
Social care = Fostered
GP = ADHD
LifeLab = Vaping

COMPARISON GROUP PATIENT DATA (SELECTED FROM SDE DATASET)

Location = Hampshire

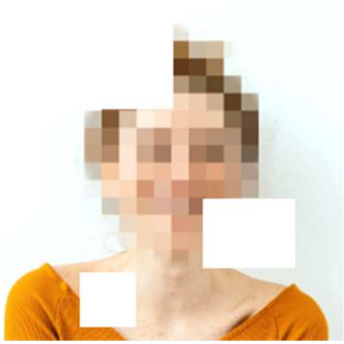
Female, aged 13
Attainment = C
FSM = No
Attendance = 91%

Police record = Yes
Social care = N/A
GP = No data

What is the difference between the two groups?

VOLUNTEERS

- Recruited through local schools – with their assent and consent from parents or guardians
- All data linked together for the study has direct consent
- Volunteers get educational interventions aimed at changing their behaviour



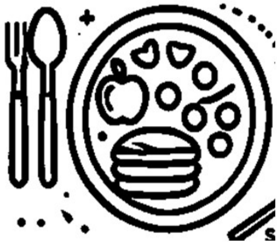
COMPARISON GROUP

- Similar mix of age, gender, and background
- Selected at from the SDE database semi-randomly
- Individuals in the dataset do not give direct consent – but data is de-identified and minimised (only what is specifically needed for the research question is retrieved)

What data is being used?

Education:

Attainment



Free School Meals

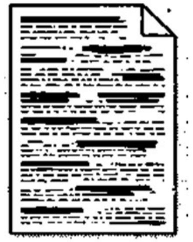
Attendance

Other:

Social care

Police

NHS / LifeLab:



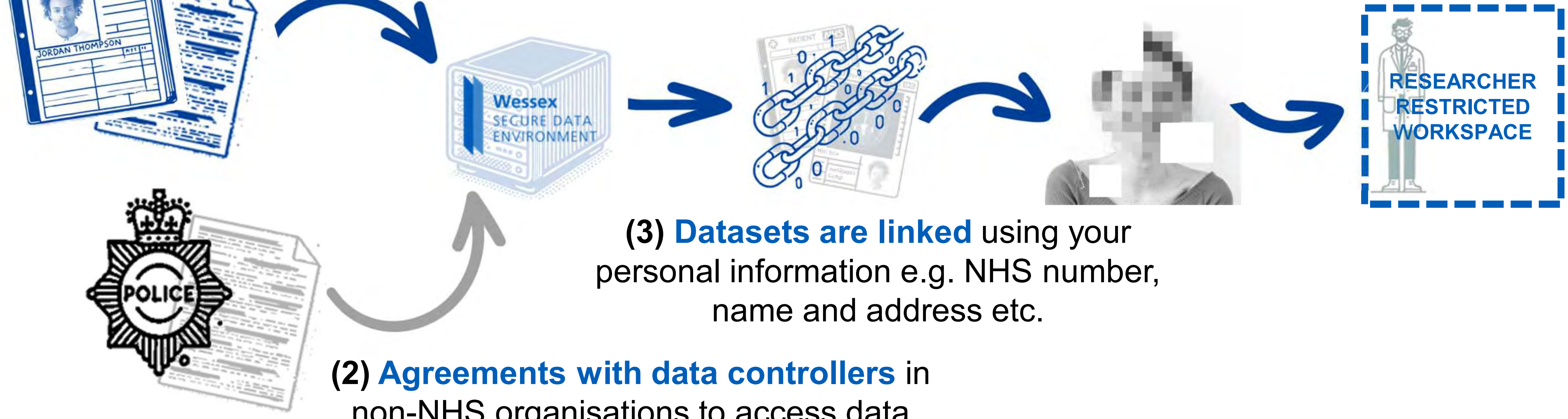
GP record

Self-assessment

How do we protect privacy in free text data?

University Hospital Southampton has developed its own tools to convert notes into text – and then permanently redact personal data

How do we connect non-NHS and NHS data?



(1) Data collected by the NHS and **copied into the SDE when needed**

(2) Agreements with data controllers in non-NHS organisations to access data

(3) Datasets are linked using your personal information e.g. NHS number, name and address etc.

(4) The new dataset is de-identified and minimised– personal information is removed

RESEARCHER
RESTRICTED
WORKSPACE

What are we then doing with the data?

RESEARCH

Volunteers complete annual self-assessments to capture their learnings and the health choices they make

Kath and her team at **LifeLab add this to the new linked dataset** in the SDE

OUTPUTS

A **new dataset** combining nutrition, socio-economics, home and community environments, wellbeing, attainment and health records

Fresh insights into how LifeLab interventions help children to positively change behaviours and:

1. Improve services
2. Attract funding for new initiatives
3. Help children make better choices that improve health and successful outcomes in later life

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How do you feel about linking these data types?

Attainment

Free School Meals

Attendance

Social care

Police

GP record

LifeLab Self-assessment

Consider issues with assent (<16) or consent?

YOUNG VOLUNTEER PATIENT DATA

Children under 16 = with their assent and consent from a parent or guardian

Aged 16+ = can give consent on their own behalf

COMPARISON GROUP PATIENT DATA

No consent BUT data is de-identified and minimised

National data opt-out requires parent or guardian under the age of 13

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Exercise 1:

Evaluate the LifeLab research example

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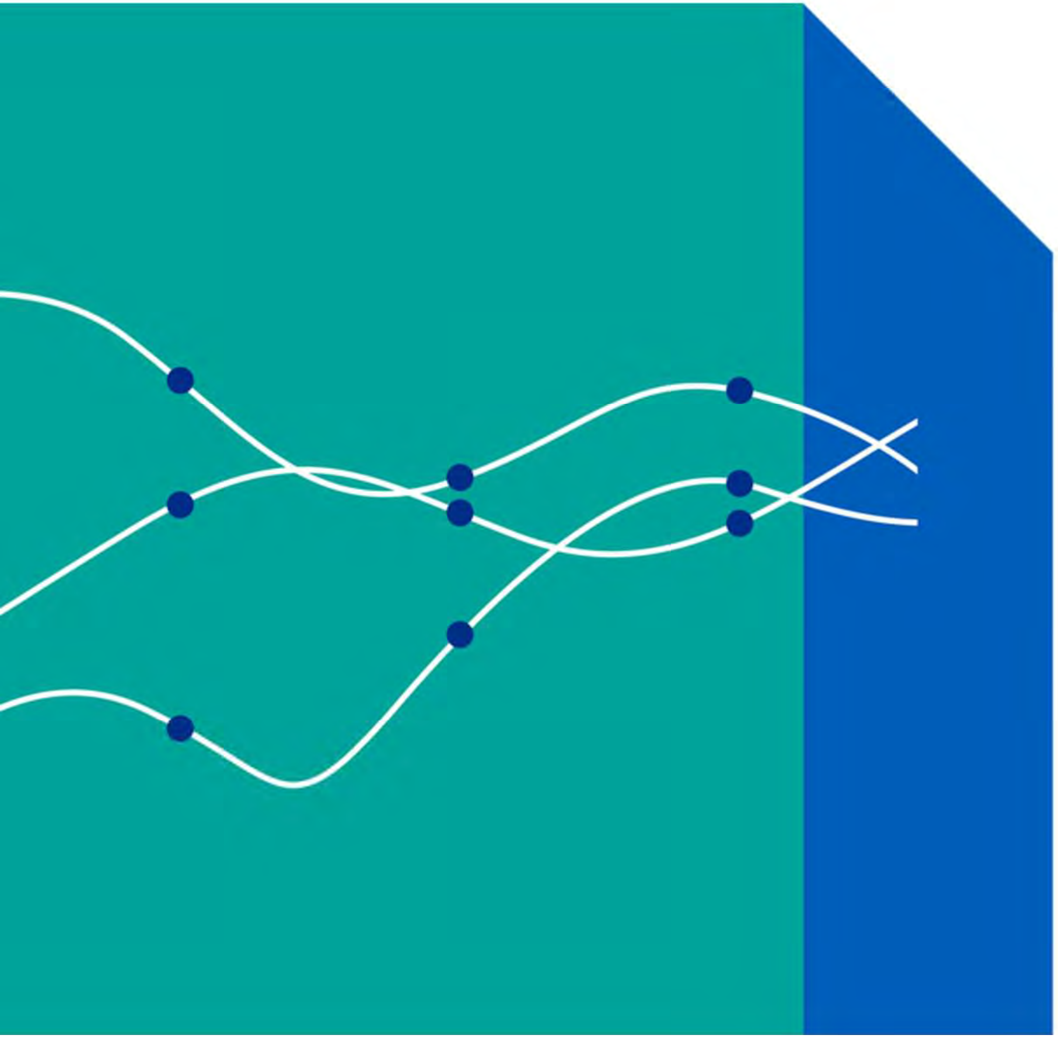


HPV Vaccine Uptake Research Example #2

Using sexual health data to help large numbers of patients in Wessex

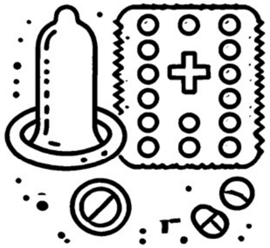
Mission: Targeting population health communication to increase HPV vaccination

- Reduce stigma and target communities and young people who may have missed out on the vaccine when at school
- Improve vaccine coverage
- Reduce risks of cervical and other HPV related cancers.

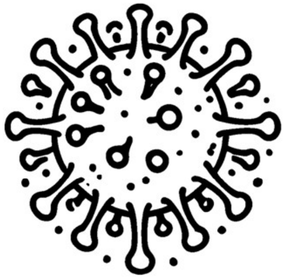
How does HPV vaccination work?

- Around **3,300 people are diagnosed with cervical cancer** in the UK a year.
- HPV vaccine programme started in 2008 and given to girls, and now, boys
- **Up to 70-90% reduction in cancers** – cervical, anal, penal and oral
- **Lower vaccine uptake in minority ethnic and disadvantaged groups** – reasons include vaccine hesitancy and perceptions about sexual health
- **Good communication is critical** to increasing uptake

What data is the HPV research project using?



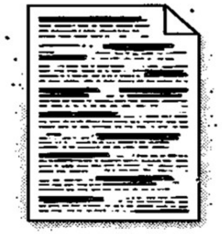
Contraceptives



STI history

Reproductive history

Sexual health record



Free text

Demographics

GP record

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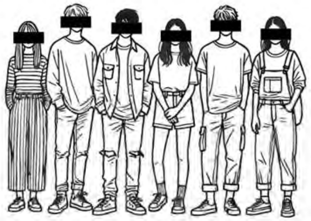
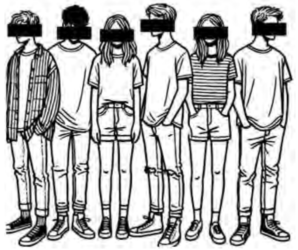
Group 1 - Volunteers
Patients we are vaccinating for the first time at a range of ages



Group 2 – SDE data
Patients vaccinated at age 12-13

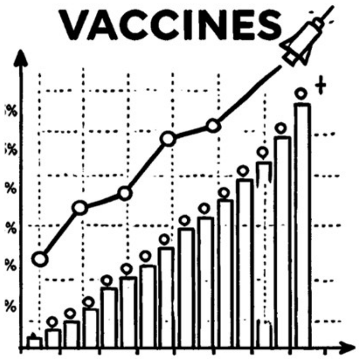


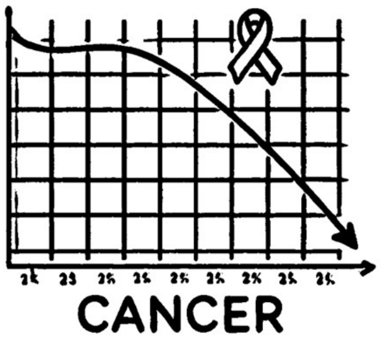
Group 3 – SDE data
Patients never vaccinated

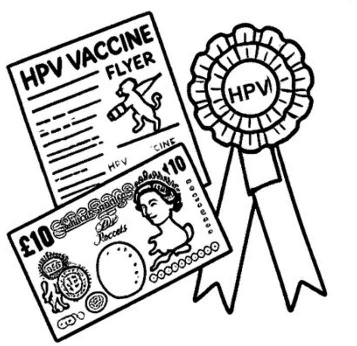
Outcome A: Lifelong study - looking at how timing of vaccine impacts on cancer rates

Outcome B: Behavioural insights study – Looking at GP record extracts, sexual health records, self-assessments and demographic data to understand factors linked to vaccine hesitancy

What are the expected outcomes / benefits?







Improve understanding of vaccine hesitancy in minority ethnic and disadvantaged groups

Increase uptake of the HPV vaccine in groups that were missed during the national vaccine programme (aged 12-13 years) and therefore **reduce avoidable HPV related cancers** in this group

Inform local and national public and **population health communications and spending**

Key considerations

- Lots of people in Wessex could benefit
- Results in **targeting** certain **minority community and disadvantaged groups**
- **Sexual health data sets** - profiling people based on sexual behaviours and other risk factors
- **Industry partner sells more vaccines** – that work – and saving NHS resources treating avoidable cancers
- **Sharing insights with non-NHS public sector partners** – e.g. politicians and media - to inform population and public health communications

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Exercise 2:

Evaluate the HPV vaccines research example

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Break

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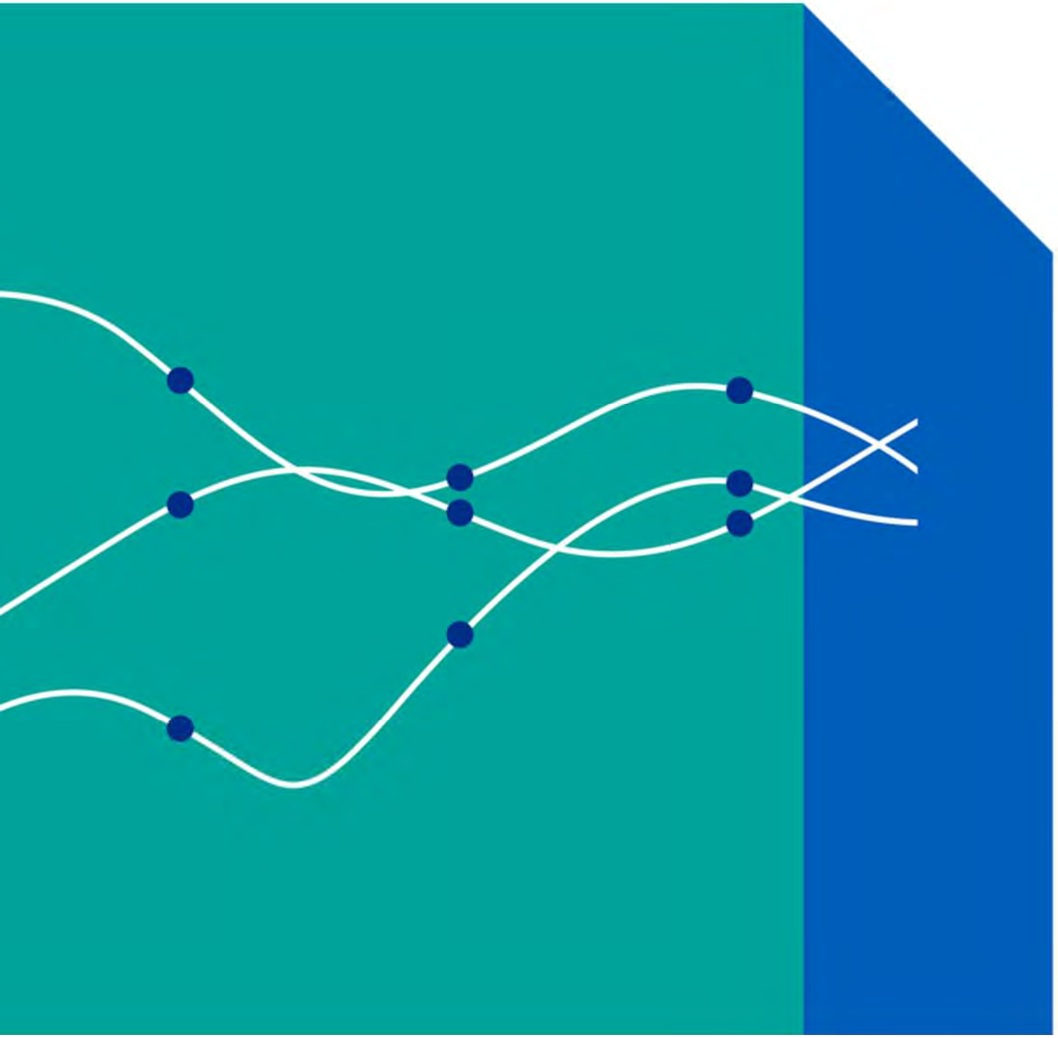

MyCOPD app Research Example #3

Taking large datasets outside the SDE to train an AI algorithm

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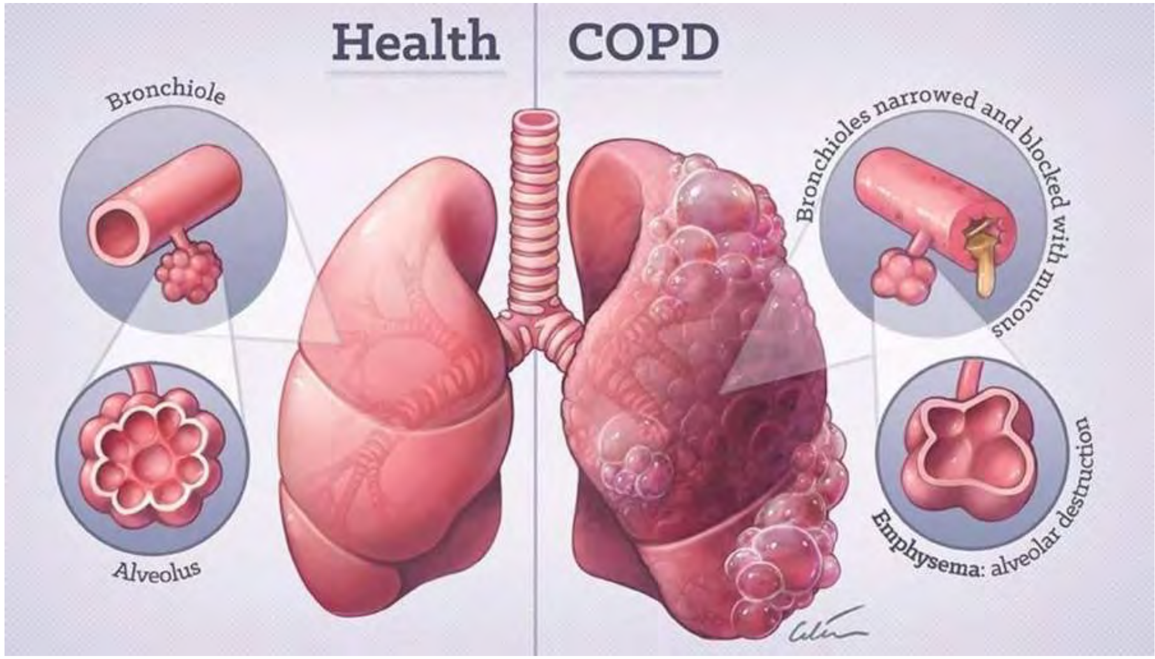
Mission: Patients managing their COPD better and avoiding hospital admissions



Working with industry and other SDEs we will improve the ability of COPD patients to live healthier, better manage their symptoms and reduce hospital admissions.

Chronic obstructive pulmonary disease (COPD) affects over 3 million people in the UK and often leads to hospital admissions.

Whose data is in the study?

Maria Lazaro – mid-50s

Diagnosed with COPD – affects her lungs and breathing

Her GP in Southampton referred her to the research study

Run by Great Western SDE as **a joint project between industry and NHS**

Uses MyCOPD app on her phone and smart watch to manage her condition

What is the Southern Consortium?

Four SDEs representing most of the south of England – working closely and collaboratively together – sharing research work, insights, policy, costs, etc.

What data is being used

App

Exercise

Reports

O2 stats

Location

Air pollution

Weather

- Consented in the MyCOPD app

NHS

Medication

GP record

Patient
self-assessment

Mental
health

- Consented by GP to share and link NHS data and referred to app
- Data from 4 SDEs is de-identified – the 4 local datasets are brought together by Great Western SDE

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Crunching the numbers: What do we do when there is too much data?

(1) Dataset too large to analyse in the SDE

(2) Data is encrypted as it moves between the SDE and the super-computer

(3) outcomes are then returned securely to the SDE for interpretation by the researcher (and data in the super-computer is deleted)

What are the benefits?

PATIENT

- Improved MyCOPD app = better self-care
- Fewer GP and hospital visits

NHS

- Fewer GP and hospital visits reduces strain on NHS
- New insights into effective COPD management
- £££ - lump sum or share in industry partner's future profits

INDUSTRY PARTNER

- Improved MyCOPD app can be sold to more NHS Trusts
- Industry ownership of algorithm trained on NHS dataset – potential other uses such as developing new drugs and diagnostics

Key considerations

- **Taking data outside the SDE** and sending it to a super-computer
- **Combining data** from across the wider **SDE Network/Southern Consortium** – what needs to be in place for you to be comfortable with this data sharing?
- Are there any **datasets** which industry is collecting that feel **more risky** than others and why?

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Exercise 3:

Evaluate the MyCOPD app research example

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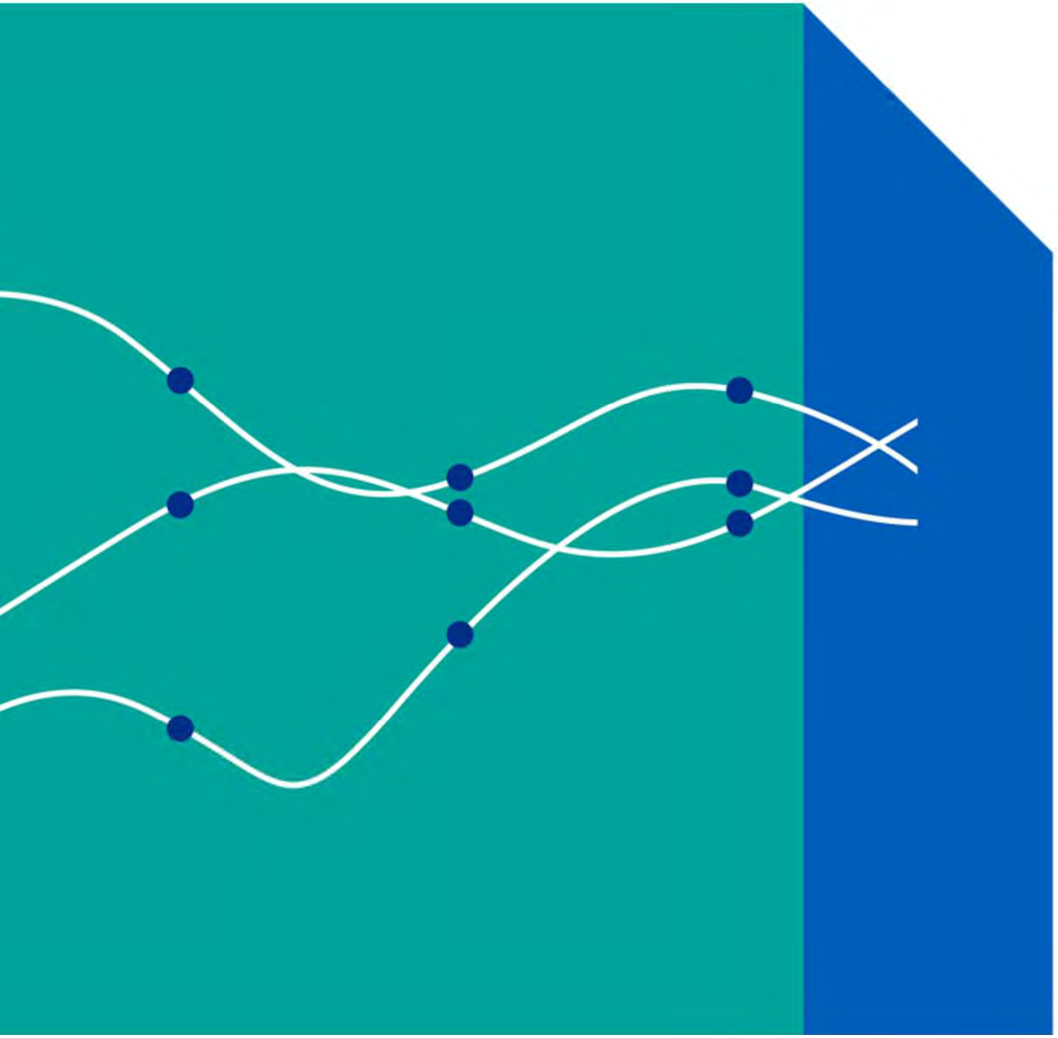

Dementia Clinical Trials Recruitment Research Example #4

Exploring when and how the SDE can re-identify patients

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Mission: Testing new treatments to slow or stop Alzheimer’s disease early

This clinical trial led by University Hospital Southampton aims to **test new treatments that target Alzheimer’s disease at an early stage** – aiming to treat or slow the disease

NHS
University Hospital Southampton
NHS Foundation Trust

How does this clinical trial work?

Industry funded research – led by NHS and University of Southampton

NHS has found new biomarkers (clues) in blood tests that may show early onset Alzheimer’s

NHS researchers already have **NHS approval to do a clinical trial** to test new drugs

Build a de-identified target group of people likely to be at risk **using GP and hospital datasets in the SDE**

Re-identify the target group – using code key – so that they can be contacted

Contact the target group to ask them to be involved – **whilst protecting privacy**

Who should contact participants?

Patient has given consent

- For example, when the patient has registered with NHS DigiTrials or a similar database / service to say they want to be involved in clinical trials

Clinical care team

- Current way we do this and legal
- Clinical team is allowed to see personal info for providing care
- But extra job for clinicians

NHS research team

- Would it be OK for NHS researchers **not** involved in providing care to contact patients?
- Legal grey area

Industry or intermediary

- Would it be OK for industry or other businesses working for them to contact patients directly?
- Not currently legal

When is it OK to re-identify and contact people?

- Identify something that requires referral for urgent clinical care
- Offer participation in clinical trial
- Does offering the trial tell the patient something they may not want to know?
- For example, by being offered a dementia trial does it automatically mean that someone thinks you have dementia (or a high chance of it)?
- Does the nature of the trial affect who should make contact?

Key considerations

- Assuming all data and research is already approved by the NHS Health Research Authority should the SDE let the research go ahead?
- **Is it OK in principle to re-identify people** for clinical trials?
- **Who** should be responsible for contacting people to see if they want to be involved?
- **When** should we re-identify people – are there other cases?
- **What else** effects if and how we re-identify and contact people?

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Exercise 4:

Evaluate the dementia treatment research example

Exercise 5:

Risk ranking the four case studies we have discussed.

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Lunch break:

Re-start at 2.00 PM

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How do we value research?

Mark Heffernan

How does the SDE create value?

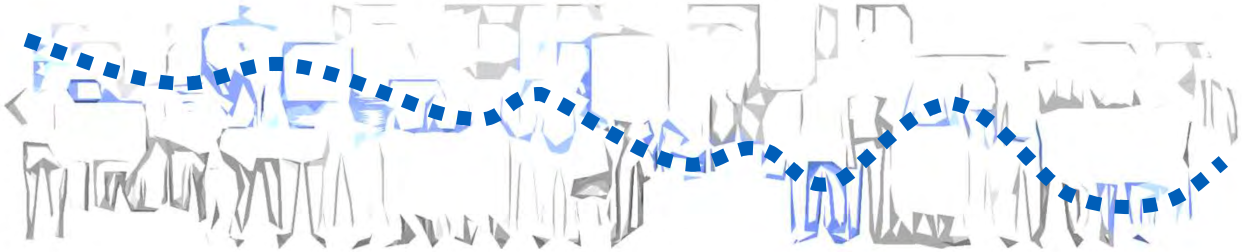
Researchers are only interested in your individual data so that:

- We can **create a unique list of people with linked data from many NHS organisations** (but de-identified)
- **Ensure the list is complete** and does not have duplications or mismatches.
- Beyond that there is **very little need to know identifiable information**
- Unless there is a need to contact someone – e.g. for clinical trials

(1) **Data from lots of people gives us the chance to spot new patterns** – but identifiable personal information is not legal to use for research

(2) De-identified and secure data **protects privacy and builds trust** = legal to use by researchers

(3) **Data is minimised** so researchers only get what they need – **'whole people' are not usually visible**



(4) **Researchers focus on finding patterns in large datasets** – which can be used to develop new treatments and medicines for public benefit

What kinds of value and for whom?

PATIENT

- Improved treatment, outcomes, and personalised medicine
- Early detection of diseases
- Access to cutting-edge therapies in clinical trials
- Better and quicker access to healthcare – e.g. shorter waiting times

COMMUNITY

- Population health insights for targeted interventions
- Better resource allocation to meet health needs
- Improved health equity for different groups

NHS

- Better decision-making about care provision
- Better use of resources and cost savings

THIRD PARTIES

- Quicker pharmaceutical research and drug development
- Testing new treatments and technologies
- Commercial opportunities from developing and selling new innovations
- Attracting research and investment into the NHS and UK

What choices will the SDE have to make?

All projects must deliver public value. We want to understand what kinds of value are prioritised by people in Wessex. For example:

Short term direct benefits to healthcare
VS
Long term breakthroughs

Benefits to clinical care
VS
Efficiencies and savings to the NHS

Financial rewards that can be used to enable further research
VS
Early access or discounts on new treatments

Key considerations

- What are the **different kinds of public value** that projects should be expected to deliver?
- How do we **balance** financial value with other kinds of public value?
- Are some kinds of public value more important than others?

Thank you!

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Public attitudes towards value exchange

Joanna Stapley (NHSE) & Ralph Scott (Wessex SDE)

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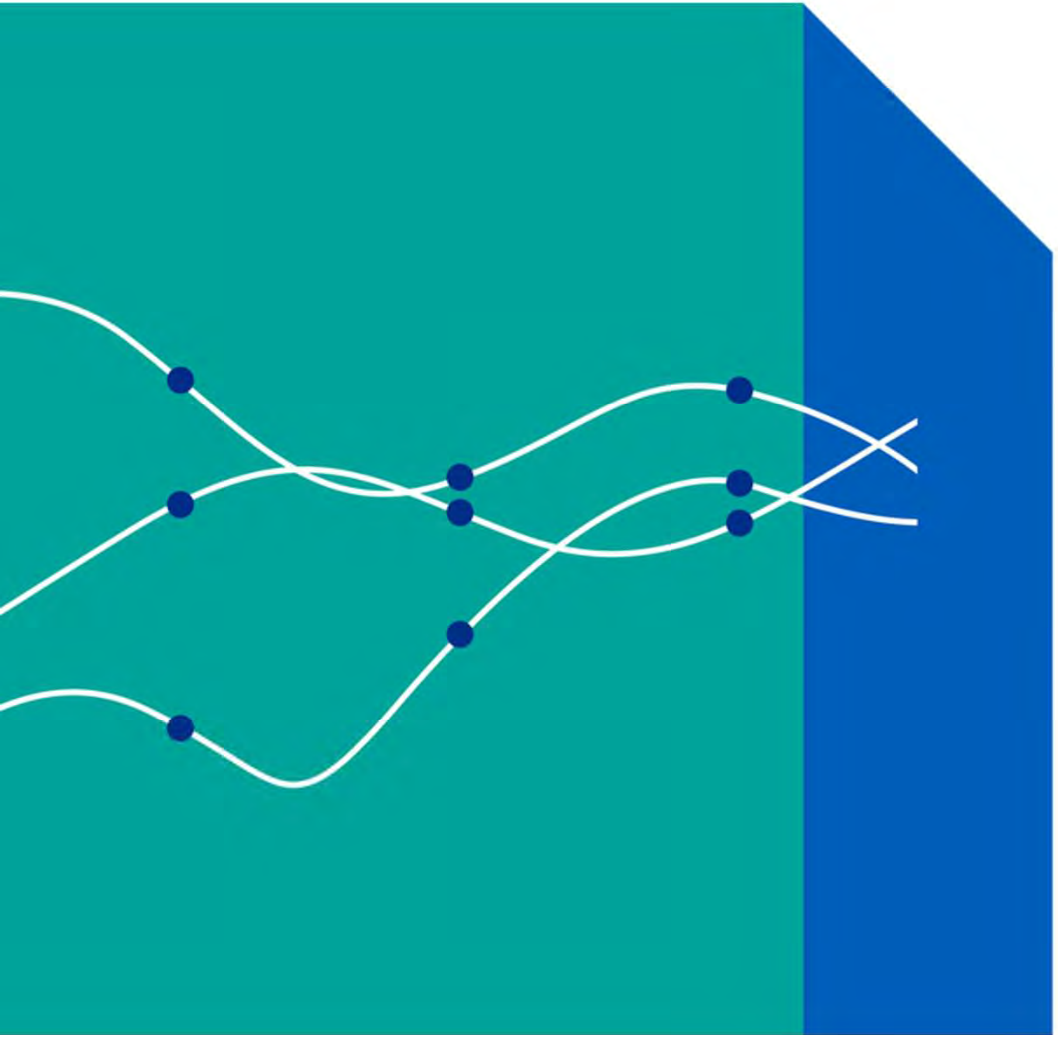
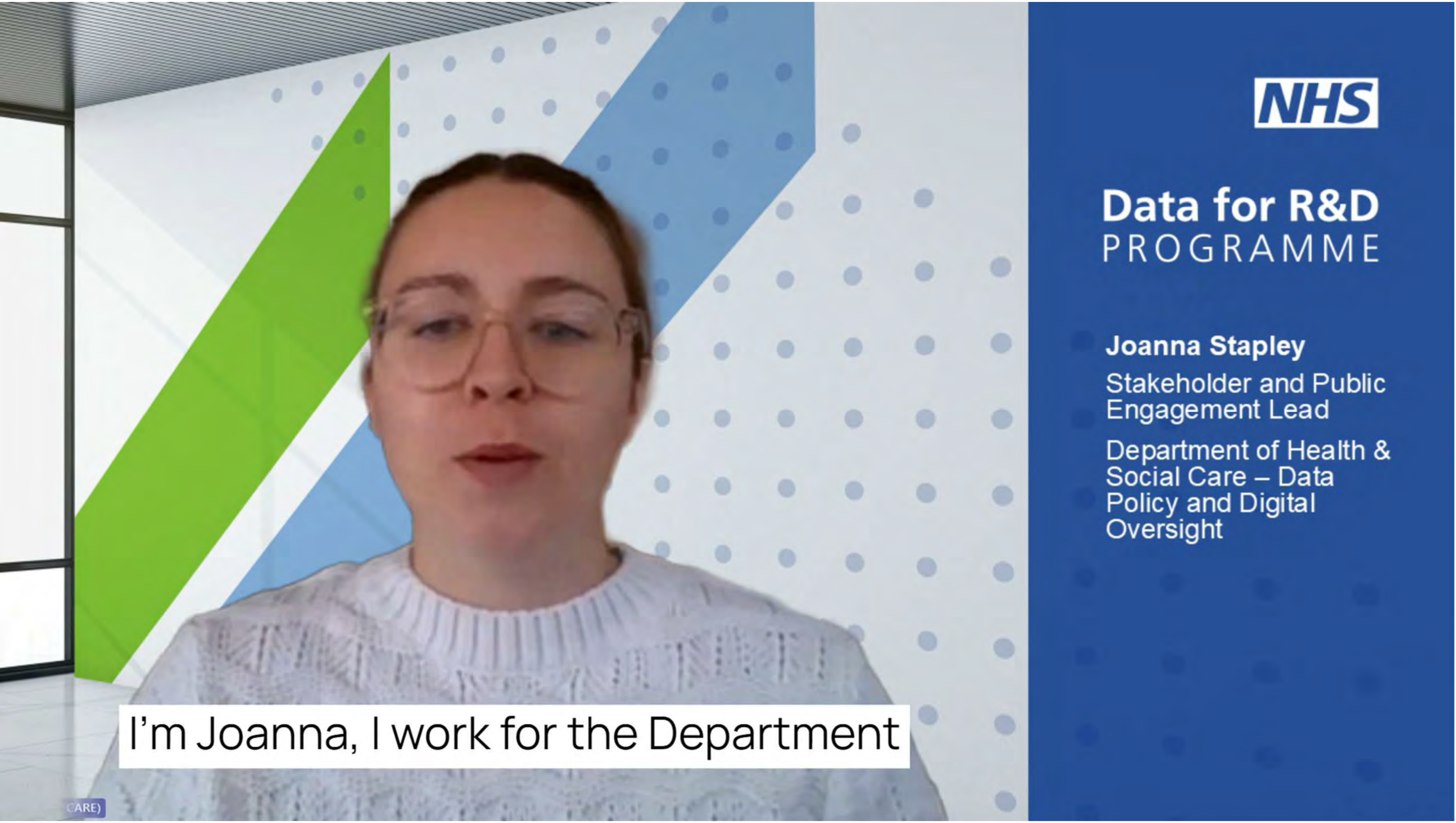


NHS national public engagement insights

Joanna Stapley (NHS England)



Data for R&D
PROGRAMME

Joanna Stapley

Stakeholder and Public Engagement Lead

Department of Health & Social Care – Data Policy and Digital Oversight

I’m Joanna, I work for the Department

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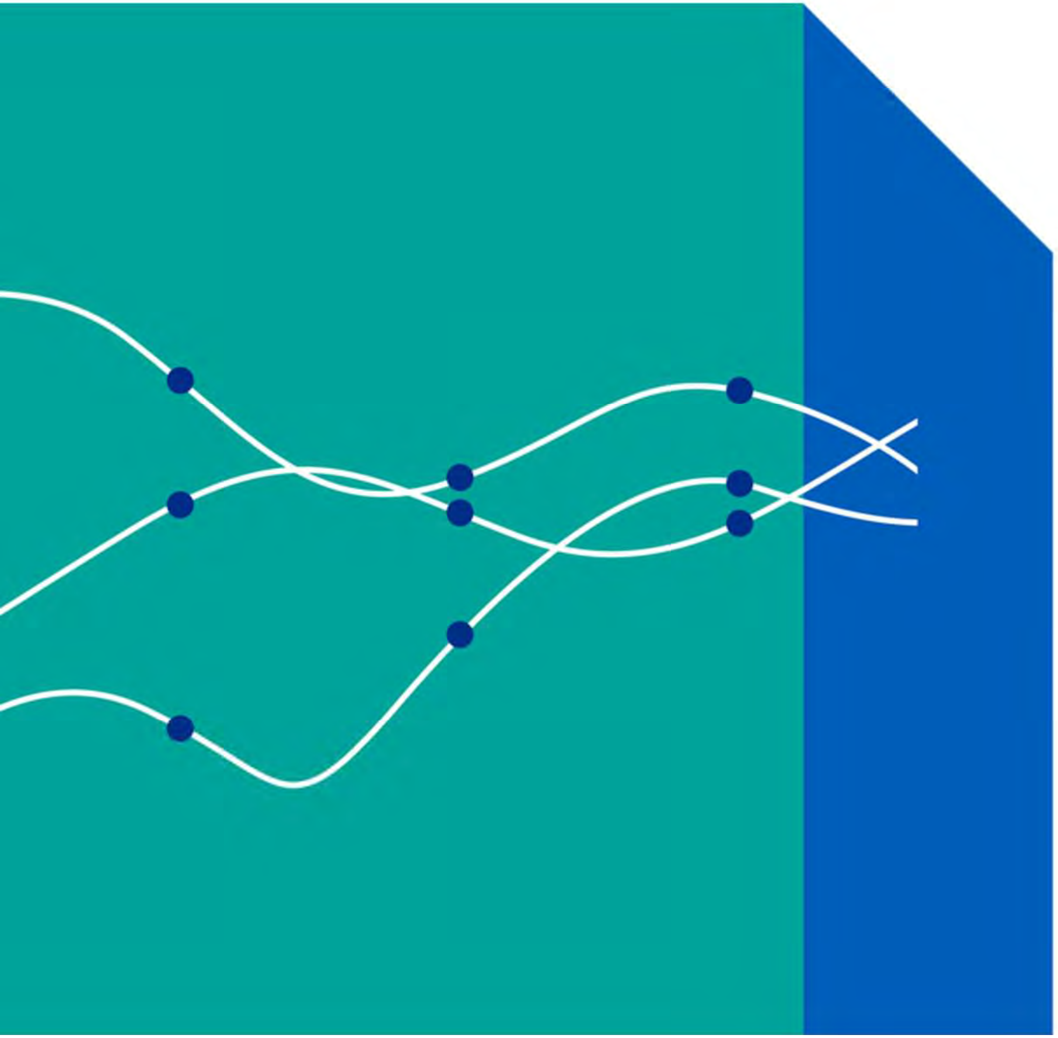

What we know about public attitudes to the value of NHS data

Ralph Scott
(Wessex SDE)

Essential

- **Transparency cannot be separated from public benefit**
- Transparency through the whole data life cycle
- Authentic public engagement

Public priorities

- **Fair distribution** of benefits
- **Sensitive data** treated with utmost care
- Safeguards to protect society from data manipulation
- Public **benefit must outweigh profit**
- Be **ambitious**

Wessex issues

- Mixed views on sharing with drug companies, with concerns about ethics and uses
- Risk of **commercial users focusing on profitable subjects** rather than need
- How is the SDE funded – is it a good use of NHS money

Not important

- Purpose of use does not have to be the same as purpose of collection
- **Scale of benefits is not important** – there is value even if it affects a small number of people

Pricing

- **No selling of NHS data** – but NHS should recover the costs of access
- Costs should reflect purpose, benefits and who the researcher is
- Seek benefits in-kind, intellectual property, and profit sharing
- **Surplus yes** - but shouldn't be excessive or stifle innovation

Thank you!

Exercise 6:

What kinds of public value are most important?

Examples of different kinds of public value

- 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

Break

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Research examples exploring different kinds of value to the NHS

Mark Heffernan

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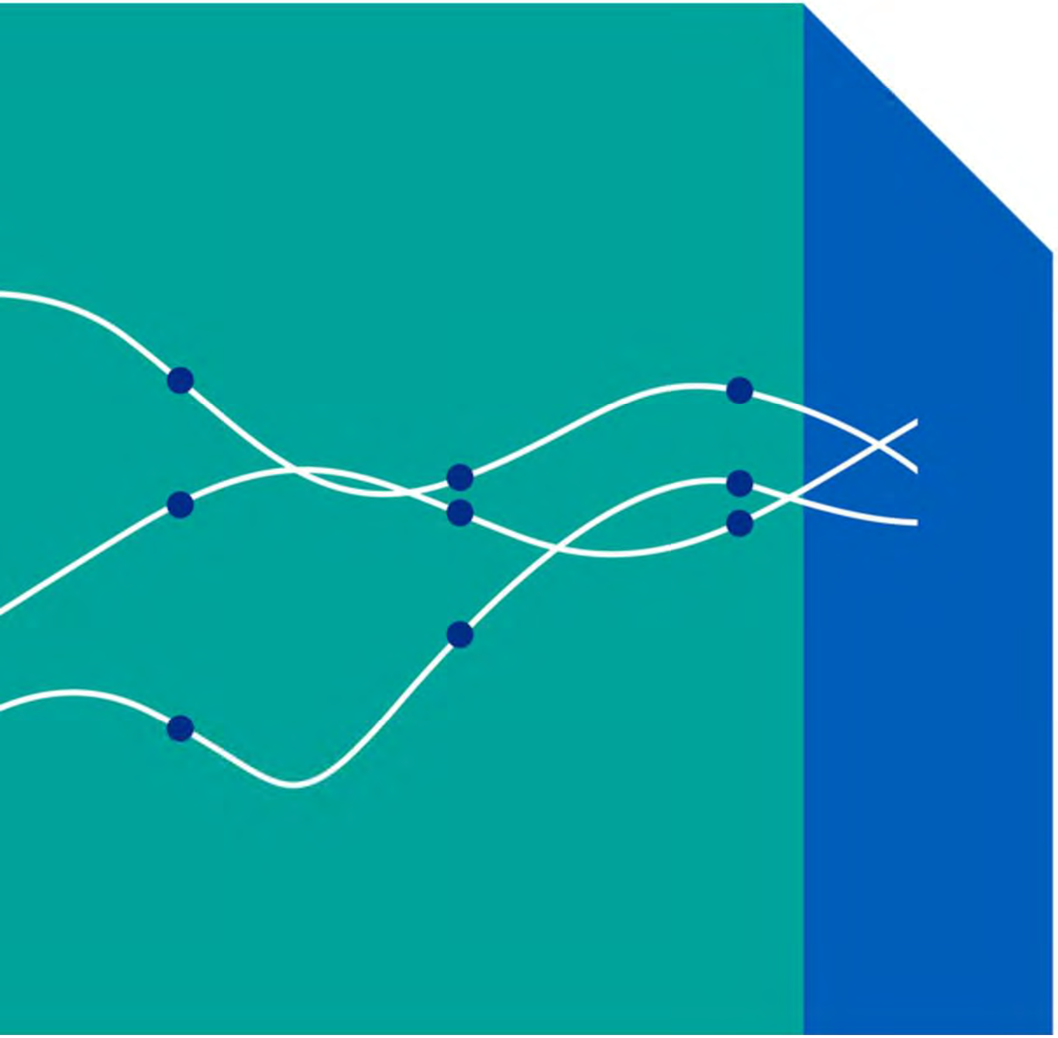


Sickle Cell Disease Research Example #5

Small numbers locally but large numbers internationally

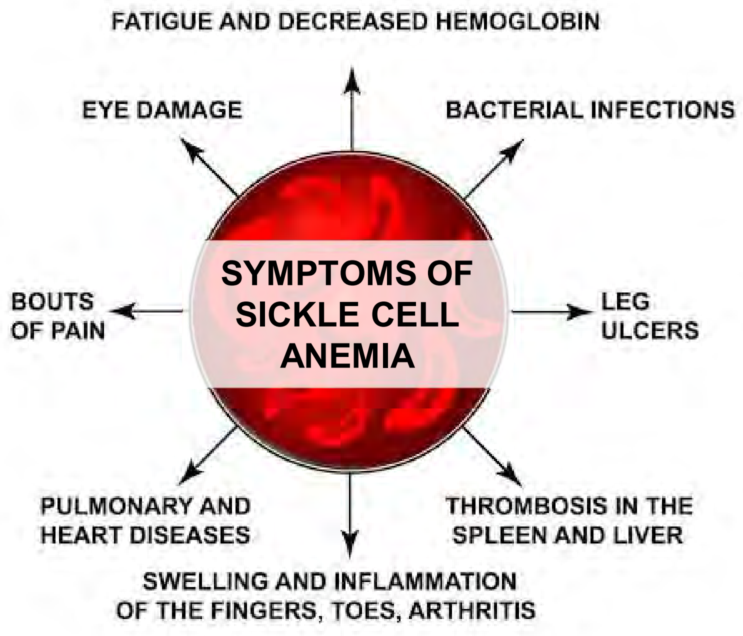
Mission: A cure for sickle cell disease – rare in Wessex but common internationally

Using **gene editing** the research team hopes to **bring ground-breaking new therapies** to patients – via clinical trials – within five years

This highly complex project would be a demonstration of Wessex SDE's strength in running clinical trials – success **could attract other globally significant research trials**

What is Sickle Cell Disease?

- A **blood disease** that particularly affects people from an **African or Caribbean background**
- Caused by a small gene mutation, which reduces cells' ability to carry oxygen around the body
- Patients often require blood transfusions and hospitalisation
- Sickle Cell Anaemia is a specific type of the disease which is highly life limiting, **reducing life expectancy by as much as half**



SYMPTOMS OF SICKLE CELL ANEMIA

FATIGUE AND DECREASED HEMOGLOBIN

EYE DAMAGE

BACTERIAL INFECTIONS

BOUTS OF PAIN

LEG ULCERS

PULMONARY AND HEART DISEASES

THROMBOSIS IN THE SPLEEN AND LIVER

SWELLING AND INFLAMMATION OF THE FINGERS, TOES, ARTHRITIS

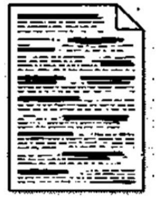
Who and what data?

- Relatively **rare disease in Wessex** so patients could be **more easily identified** from the de-identified datasets
- Outputs from the Wessex would likely need to have numbers removed (lower than 8) or be **combined with larger datasets** to protect privacy


Blood tests


Gene sequencing


Demographics


GP record


Mental health

What are the benefits?

PATIENT

- Success would be lifechanging for a very small number of patients in Wessex

WESSEX SDE

- A highly complex challenge – would prove Wessex SDE’s strength in clinical trials
- Success could attract other businesses looking to run globally significant clinical trials

INDUSTRY PARTNER

- Accelerate development of new gene editing treatments
- Sell effective treatments to the NHS

INTERNATIONAL PARTNERS

- Working with shared international teams
- Contribute to international research and global issues/targets
- Accelerate eradication or cure of key global health issues

Key considerations

- **Low numbers in Wessex** – so little impact locally - but higher numbers nationally and **very high internationally**
- Research would support a minority group who have **traditionally** been **under-represented** in healthcare with **life-changing impact**
- Working with industry to compare effectiveness of drugs – may **sell more** as a result BUT does that matter if it **saves lives**?
- Due to small sample size, there is greater chance that **participants could be reidentified**

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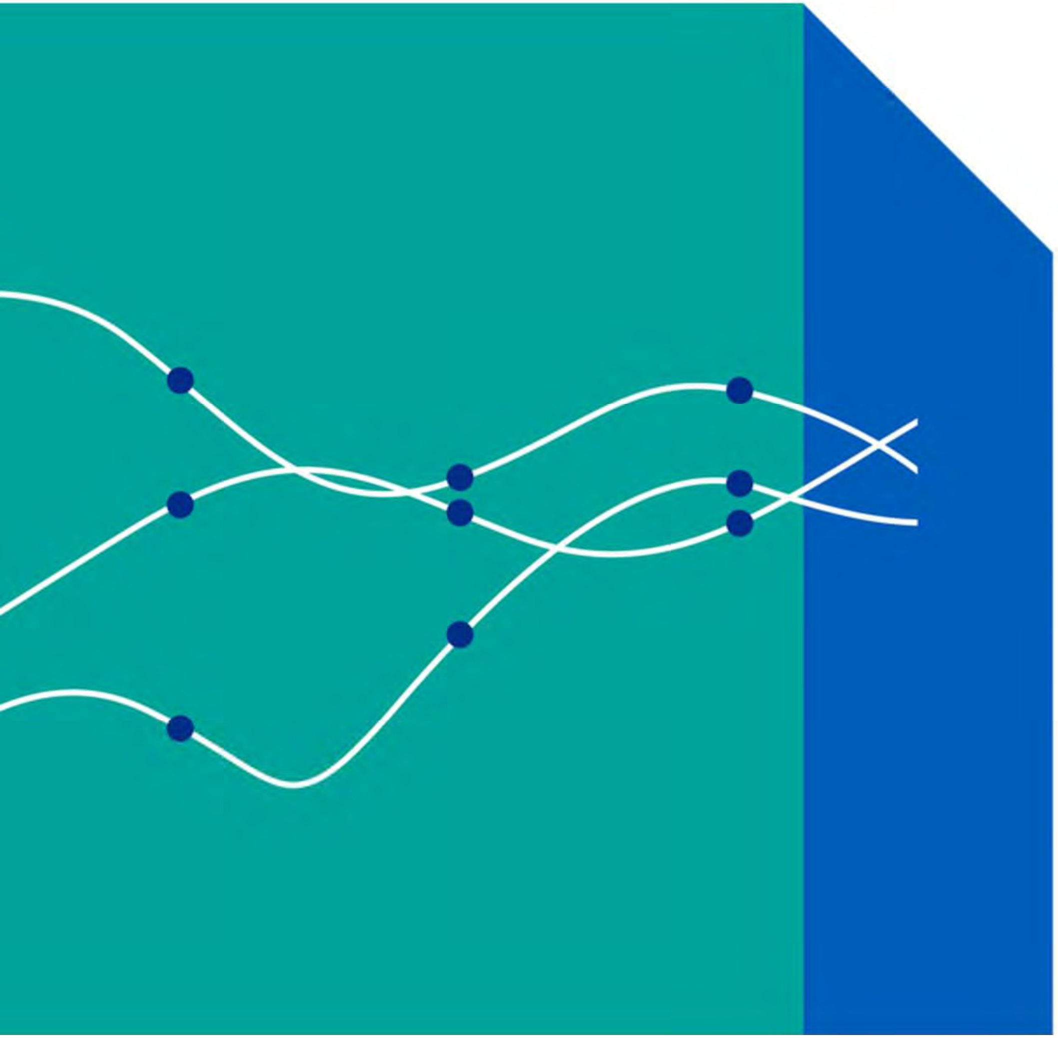
NHS



Sarcoma Treatment Research Example #6

Working with industry to improve NHS diagnosis and treatment

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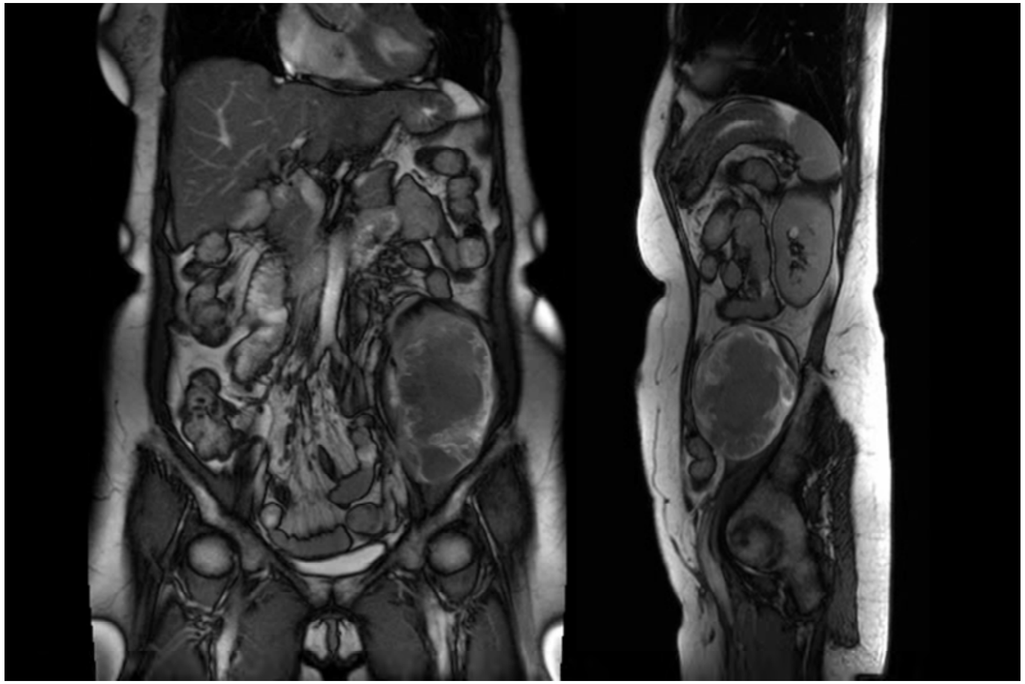
Mission: Better diagnosis and treatment for sarcoma (specific cancerous tumours)

Working with industry and other SDEs we will test a new **AI decision support tool** to improve decision making by multi-disciplinary NHS teams – and testing new care options for sarcoma (cancer) patients.

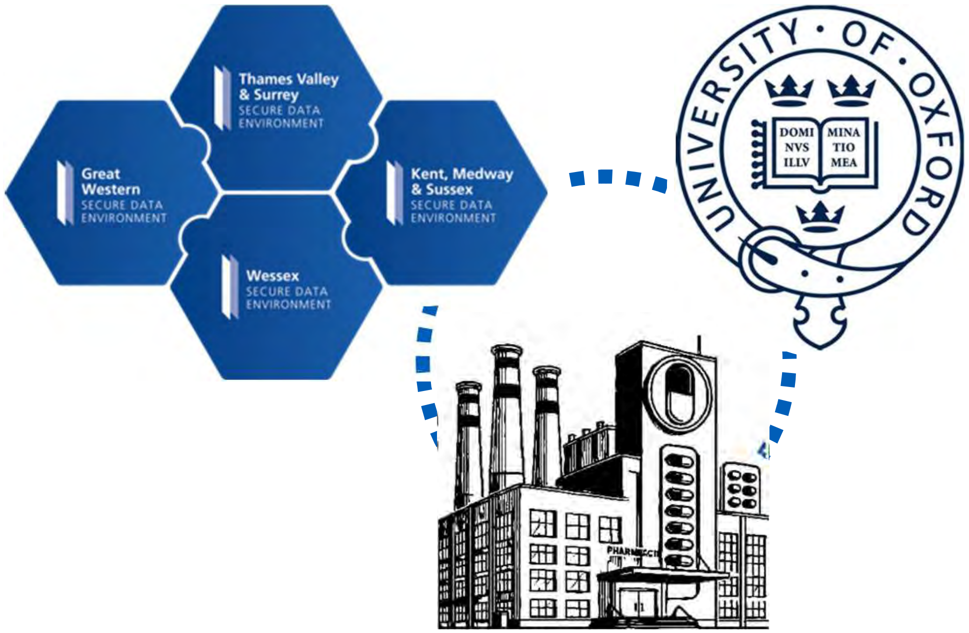
What is sarcoma?

- **A specific type of cancerous tumour** – patients are often critically ill and have few or no treatment options
- Less than 1 in 50 of all cancers each year – but **even the rarest sarcoma subtypes have 100s of new cases each year**
- Often very life-limiting and **treatment is often part of patients' end-of-life care**



How does this research project work?

- Already **has NHS Health Research Authority approval** for the clinical trial
- Involves University of Oxford, Southern Consortium SDEs, and a business
- **Funded by business** – a global BioPharma company
- **Company has developed a new AI decision support tool** to help NHS clinical teams with diagnosis and decisions



What is this new **AI decision support tool**?

- **AI decision support tool** – helps multi-disciplinary NHS teams manage large amounts of info
- **Better visibility of info = better decision-making**
- Tool **adds data to the SDE which is used by the global BioPharma company for research**
- **Data used to train AI model in the SDE** – that suggests new care options the NHS might not normally use
- **The research team use the AI tool to identify new treatment options** and suggest them to the patient's clinical team – who decides on the best care option

What are the benefits?

PATIENT

- Helping NHS research and future patients like them – they are unlikely to benefit directly

NHS

- Improved clinical decision making reduces NHS resources needed
- Better or earlier diagnostic and treatment options for sarcoma

INDUSTRY PARTNER

- Train their AI decision support tool on NHS data
- Test effectiveness of AI tool in real world with NHS clinicians
- Sell tool to NHS Trusts
- Use insights to sell new treatments and drugs?

Key considerations

1. **Balance between benefits** going to the individual, the NHS, and the global BioPharma company
2. Potential for global BioPharma company identify a drug – that works – and sell it into the NHS care pathway
3. Concerns about global BioPharma company biasing the AI tool's decision-making support – so it favours their products

Note: The AI tool would be treated as a "medical device" by NHS Regulators – they have to approve it. Plus, the clinician needs to know how the AI algorithm works. But in a fast-changing world this is an area of concern for regulators.

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Thank you!

Exercise 7:

Evaluation of Research Examples 5 and 6.

Sickle Cell Disease: A gene therapy cure

- **Low numbers in Wessex** – so little impact locally but higher numbers nationally and very high internationally
- **Research would support a minority group** who have traditionally been under-represented in healthcare with life-changing impact
- **Working with industry** to compare effectiveness of drugs – may sell more as a result but does that matter if it saves a life?
- Due to small sample size, there is greater chance that **participants could be reidentified**

Sarcoma: Better diagnosis and treatment

- **Balance between who benefits go to** – the individual, the NHS, and the global BioPharma company
- **Potential for global BioPharma company identify a drug – that works – and sell it** into the NHS care pathway
- Concerns about global BioPharma company **biasing the AI tool's decision-making support** – so it favours their products

Note: AI tool would regulated and the clinician needs to know how the AI algorithm works.

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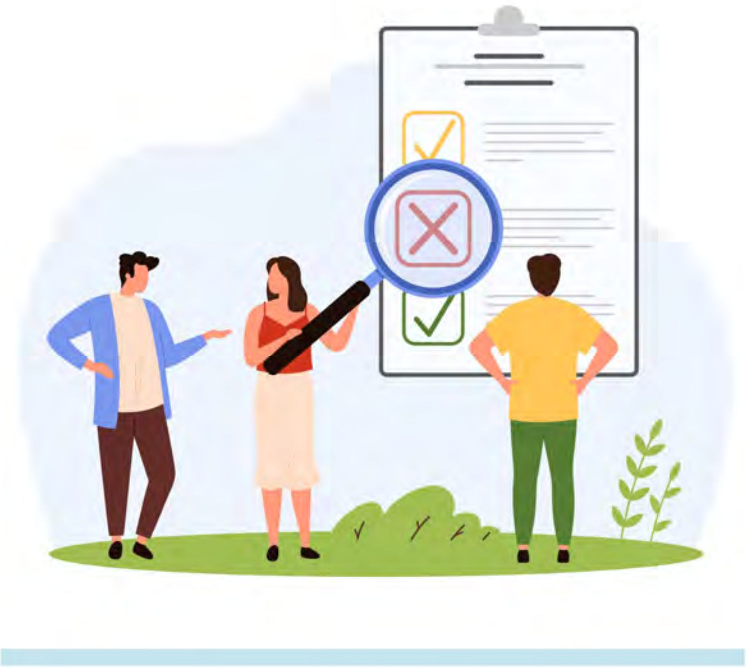

Exercise 8:

Prioritising how we would use SDE resources to support our six research examples

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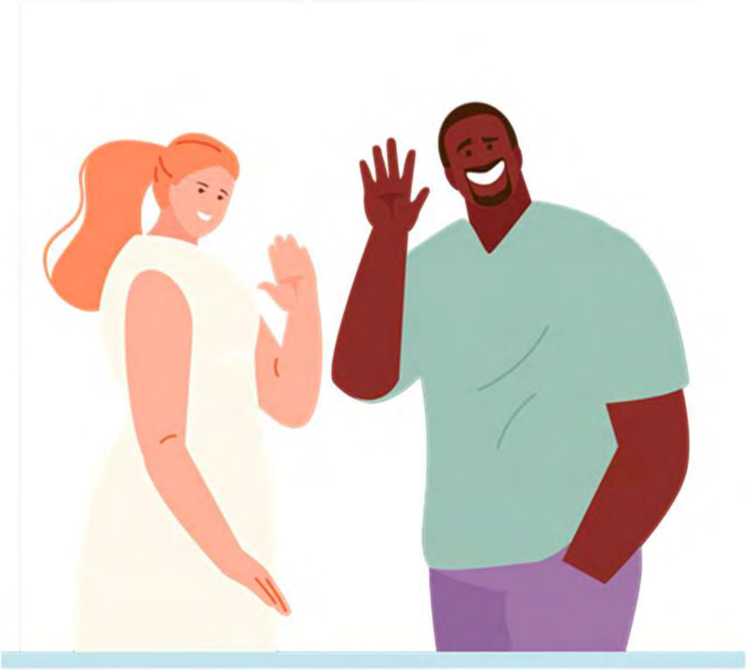

What have we achieved today and what is next?

I: Session 2 Facilitator Guide

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Wessex Public Panel on NHS data

Facilitator's Preparation Guide

Facilitation top tips for Session 2

1. **Encourage Public Panel members to write Post-It notes** – rather than facilitators doing this. We get more feedback this way. Facilitators get more time!
2. **Remember the WHY** – this is as, if not more valuable, than the ranking
3. **Turn questions around** – back to participants. If people ask questions that go into detail we can't supply or is likely to be a 'rabbit hole', ask them why they have these questions. Most likely this will surface a guardrail they want to see or a concern they want to surface.
4. **Remember that the Research Examples are there to highlight principles or features of research** – don't get side-tracked by (1) issues that are outside the SDE's control; or (2) individual bias about the case study as a whole.
5. **Explore other scenarios** – "So you are OK with this feature of research in these circumstances – BUT are there any where you would not be? (And vice versa.)

Top tips

- **Encourage Public Panel members to write Post-It notes** – rather than facilitators doing this. We get more feedback this way. Facilitators get more time!
- **Remember that the WHY is as – if not more valuable** – than the ranking
- **Turn questions around** – back to participants. If people ask questions that go into detail we can't supply or is likely to be a 'rabbit hole', ask them why they have these questions. Most likely this will surface a guardrail they want to see or a concern they want to surface.
- **Remember that the Research Examples are there to highlight principles or features of research** – don't get sidetracked by (1) issues that are outside the SDE's control; or (2) individual bias about the case study as a whole.
- **Explore other scenarios** – "So you are OK with this feature of research in these circumstances – BUT are there any where you would not be? (And vice versa.)
- **Don't overlap Post-It notes** – as this makes it hard to photograph and capture the outputs at the end of the day.

Steps 5, 7, 10 & 12: Research example feedback format

Flipchart setup

Benefits

Risks

Key factors

Expected output from Steps 5, 7, 10 & 12.

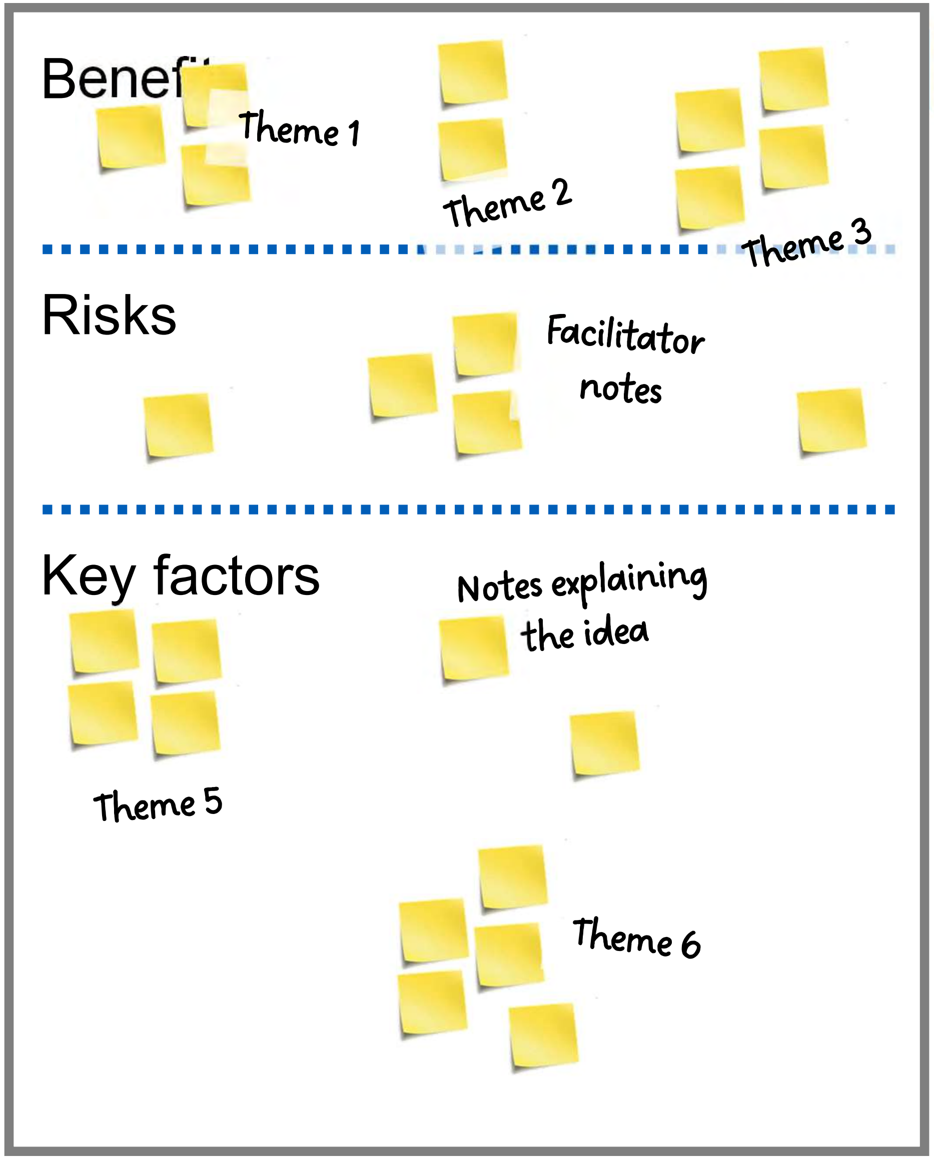
Stage 1 of discussion is about capturing immediate reactions to the research examples in terms of **Benefits** and **Risks**.

Stage 2 is about diving into the specific aspects of the research example that we (SDE team and DCFs) felt were likely to be sensitive.

This second part of the discussion may not fit as neatly into risks and benefits. In this case capture responses in **Key Factors**.

Try to organise **Key Factors** into groups of ideas / themes where possible

Explore the ideas shared by Panel Members and **capture reasons why** on the flipcharts – these are as or more important to us that the ideas themselves.



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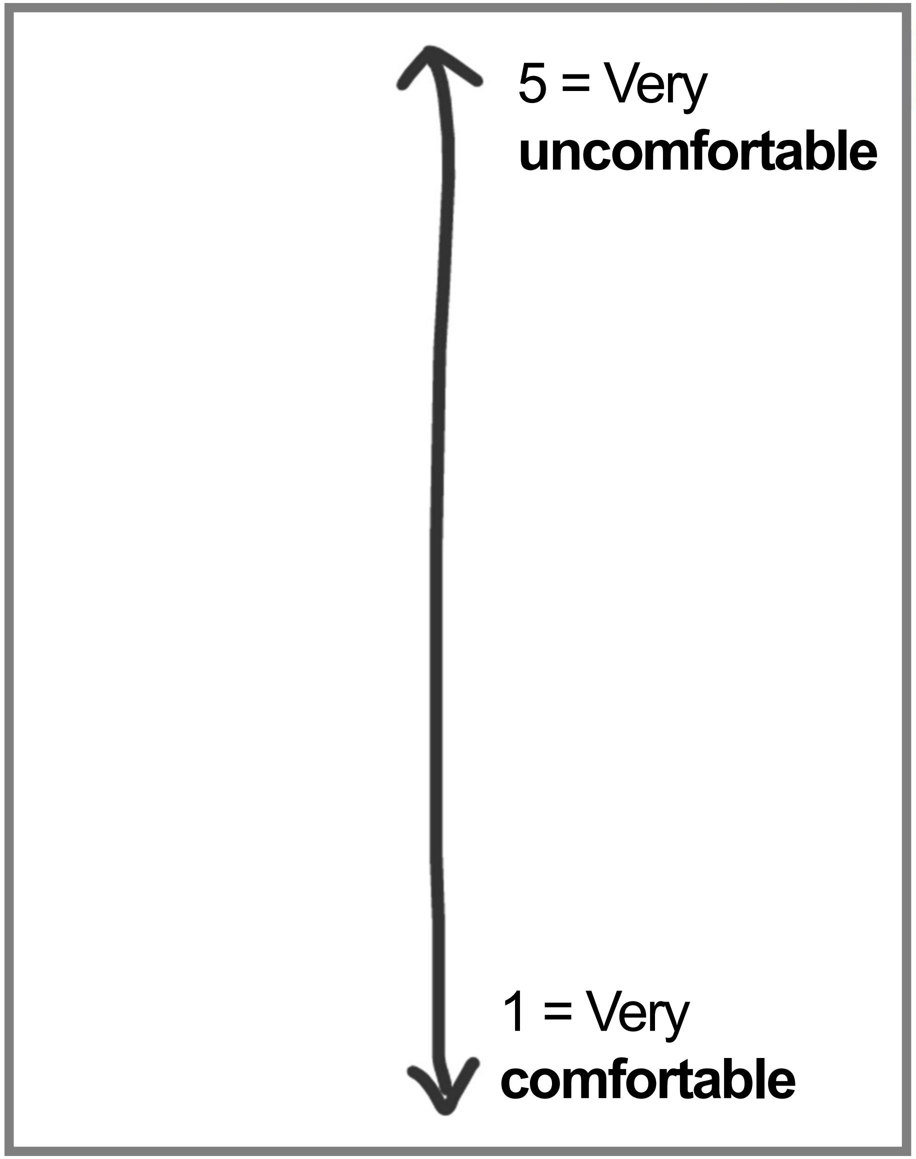
Step 13: Risk ranking the Research Examples

Flipchart setup



5 = Very **uncomfortable**

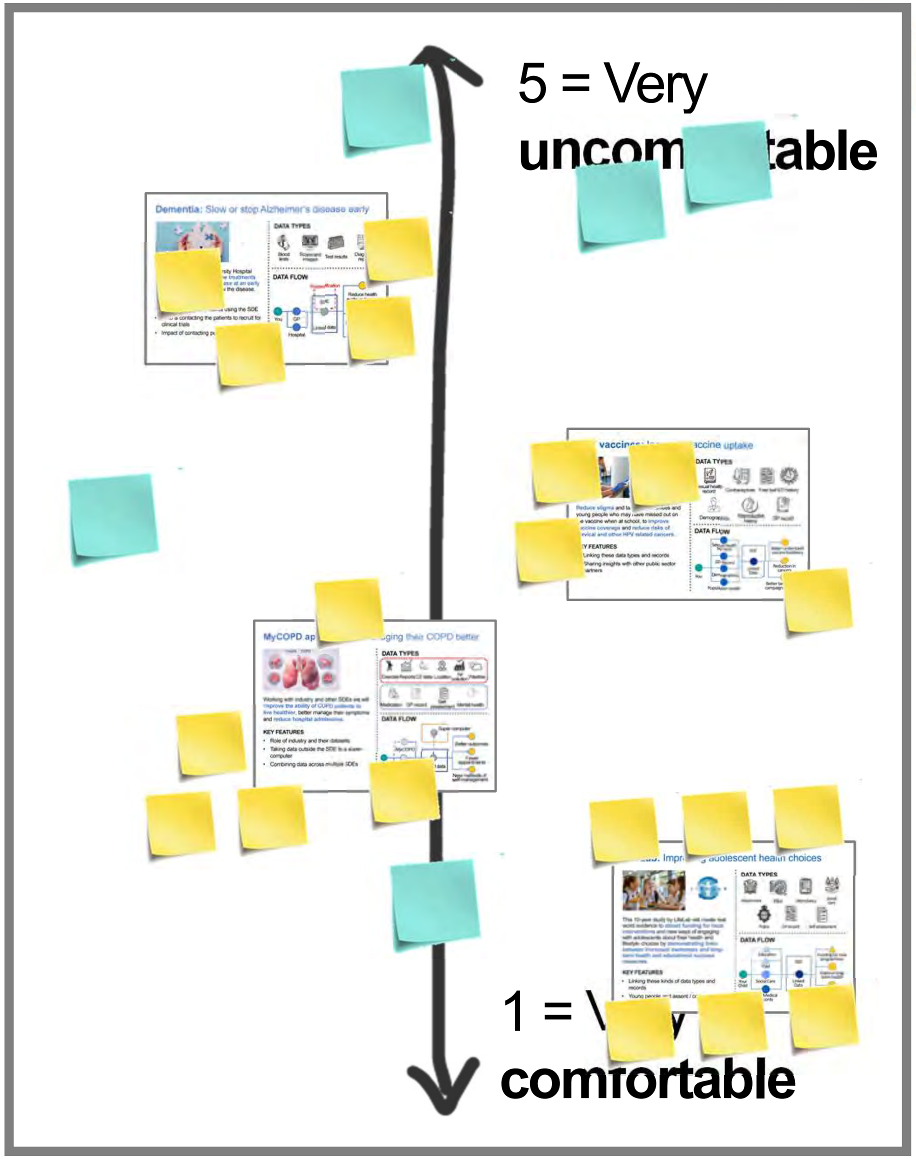
1 = Very **comfortable**

Expected output from Step 13. Note that participants may have different views about what high and low risk means. We suggest:

1. **Very Low Risk**: Minimal concerns; clear and straightforward approval expected.
2. **Low Risk:** Minor issues; likely to be approved with minimal adjustments.
3. **Moderate Risk:** Balanced; clear risks exist but are offset by significant public benefits.
4. **High Risk:** Serious concerns; approval uncertain and would require substantial mitigations.
5. **Very High Risk:** Major risks; approval highly unlikely due to significant concerns.

We don't really want everything rated at 1 or 5 – if Panel Members want to do this that is OK – but please ask Kaela or Ralph to come over and discuss as there are options to avoid this outcome.

Note that the yellow Post-Its here represent the **reasons why** the Panel Members put the Research Examples where they have in **Stage 1** of the exercise. Whilst the green ones represent the **cross-cutting issues** that they identify and place in **Stage 2**.



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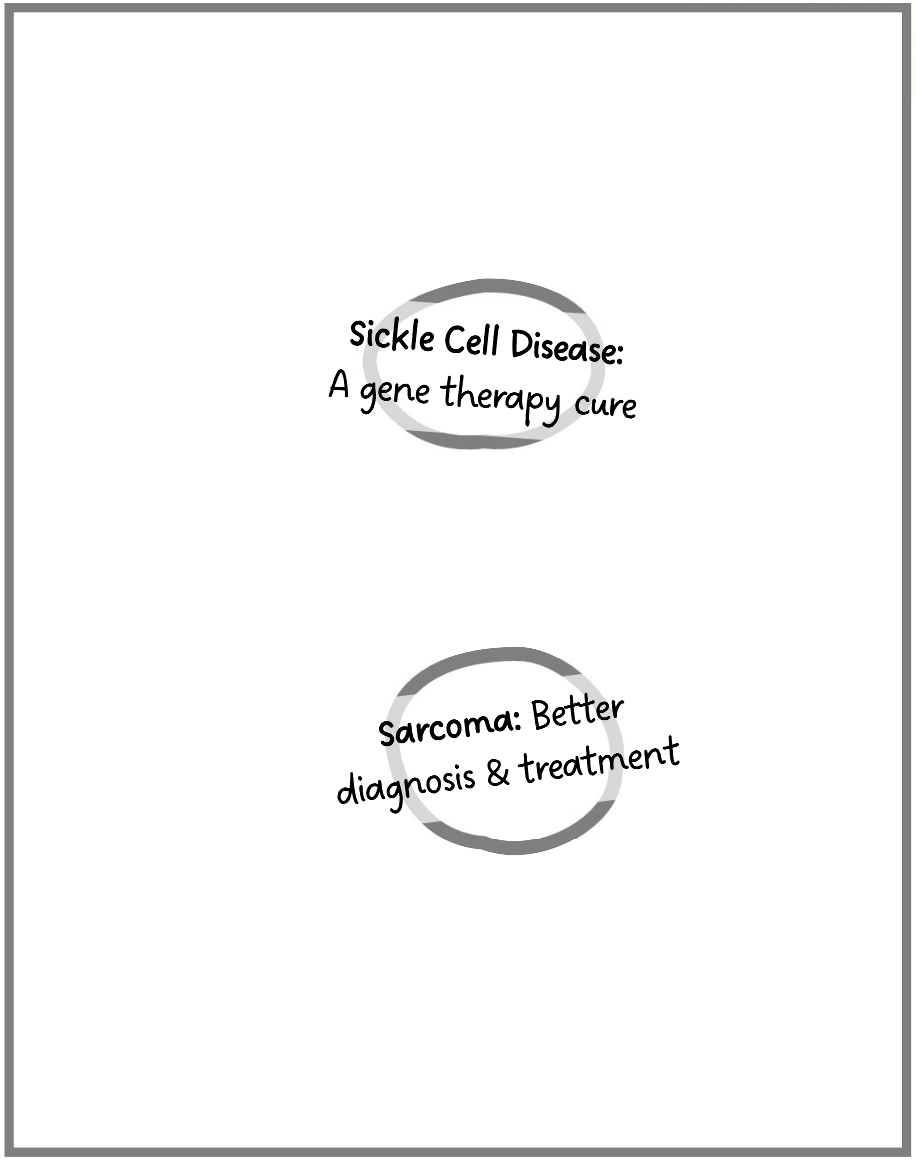
Step 17: Evaluation of Research Examples 5 & 6

Flipchart setup



Expected output from Step 17.

As we only have 15 mins for this exercise the aim is to get quick, rough and ready responses, rather than spend lots of time discussing the case studies.

Ask participants to write their ideas and reactions to the prompt questions on Post-It notes and add these directly to the board. This will allow us to get the most feedback in the short time available.

Facilitators can still write and add some Post-Its – but ideally focus on spotting the themes that emerge and group the Post-Its, adding commentary or notes with your Sharpie pen.

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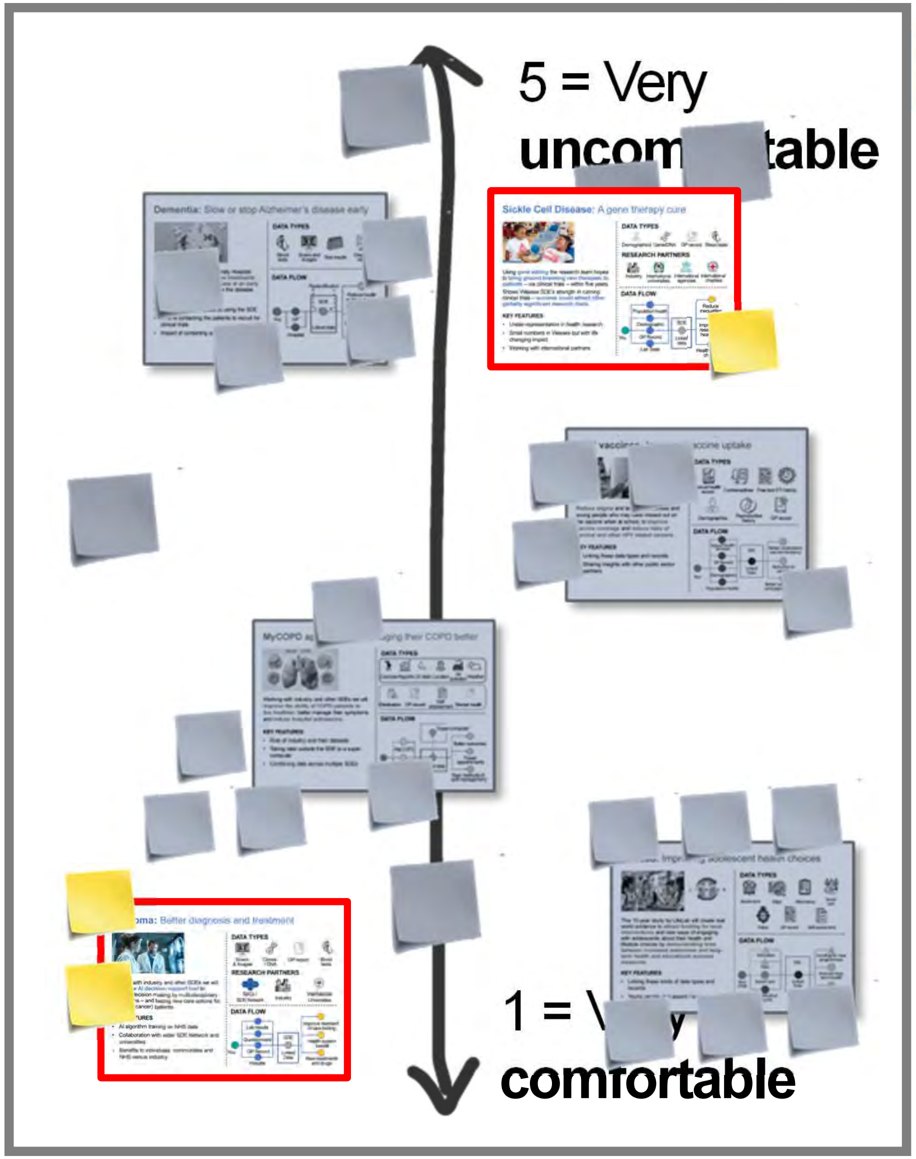
Expected output from Step 17.

At the end of Step 17 we want the tables to add the last two Research Examples to the board.

No need to add reasons as these should be captured on the previous flipchart – but feel free to do so if time allows and Panel Members want to.



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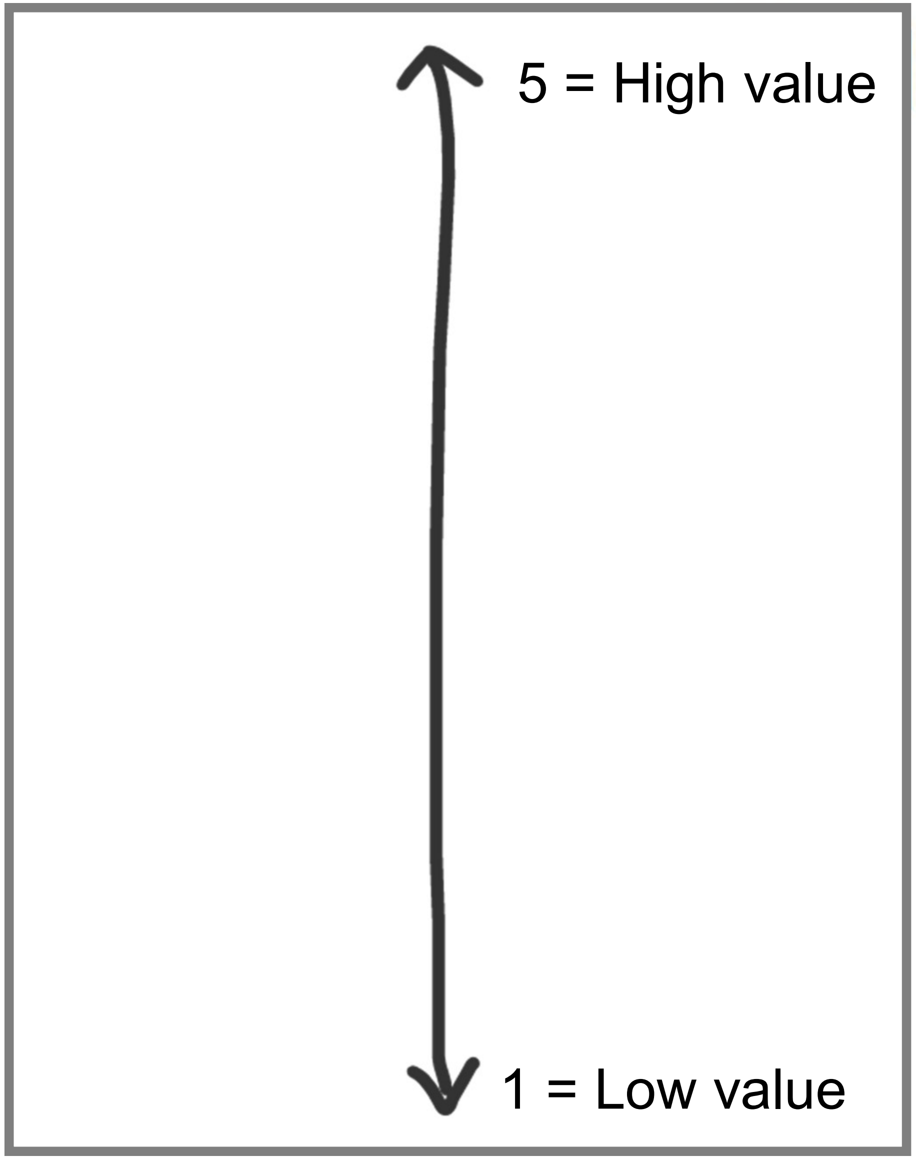
Step 19: What kinds of public value are most important to us?

Flipchart setup



5 = High value

1 = Low value

Expected output from Step 19.

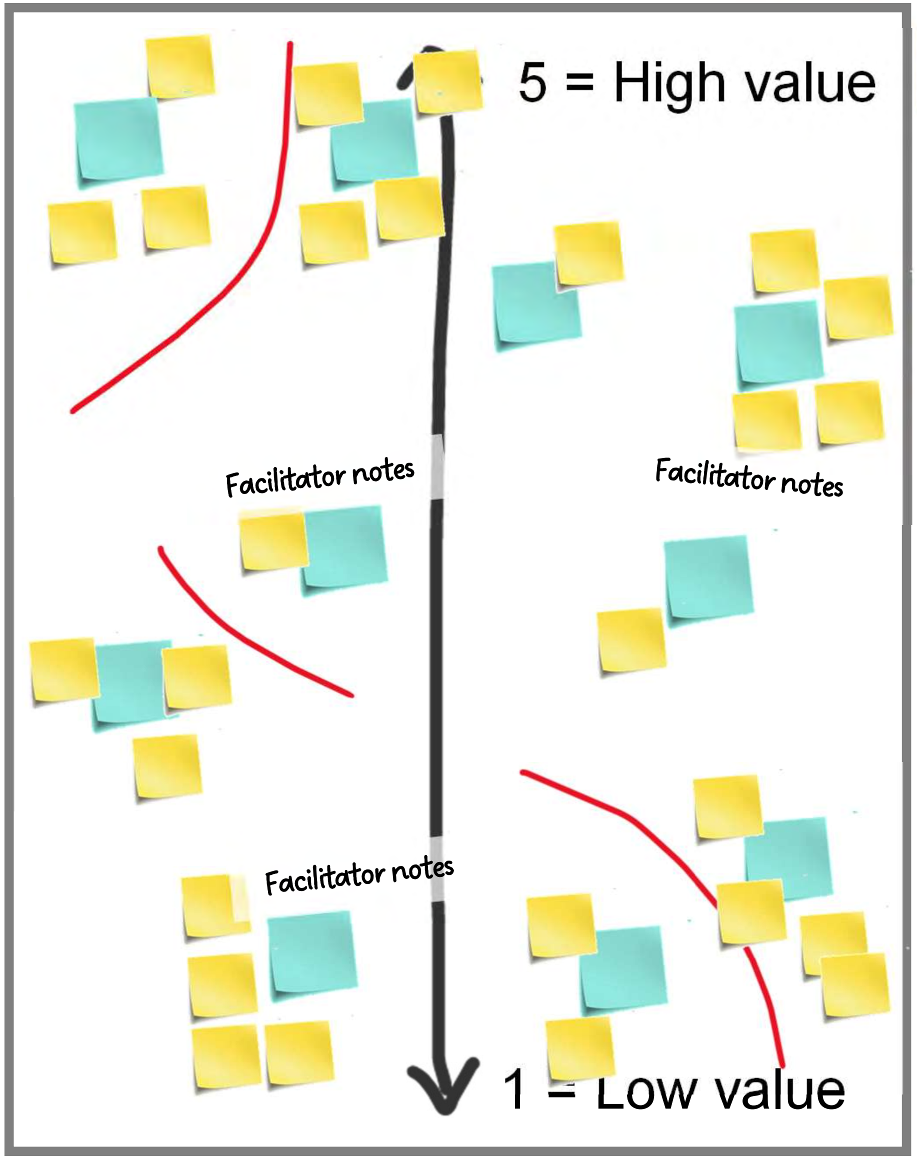
You will have pre-prepared Post-Its for all the kinds of value listed in the slide overleaf. Put these on a blank flipchart page on the middle of your table.

In **Stage 1** we want Public Panel members to think about these, add any they feel are missing, and pull out more specific versions of the ones they have. Use the large rectangular Post-Its as these are easier to read. (Green Post-Its represent these values.)

In Stage 2 ask members to choose one of the potential benefits and position it on the scale – add reasons why (shown here in yellow).

Seek agreement or divergence from the rest of the table – focusing on reasons why. You can duplicate the value and put in two places – with reasons – if there are strong disagreements.

Continue to position aspects of value along the scale – actively probing and noting reasons why. You don't need to get through all of the Post-Its. It is more important that we capture the ones that Panel members feel strongly about and their reasons – these are likely to be these that are more towards 1s or 5s.



Examples of different kinds of public value

- 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

J: Session 2 Use Case Cards

LifeLab: Improving adolescent health choices

This 10-year study by LifeLab will create real world evidence to **attract funding for local interventions** and new ways of engaging with adolescents about their health and lifestyle choices by **demonstrating links between increased awareness and long-term health and educational success measures**.

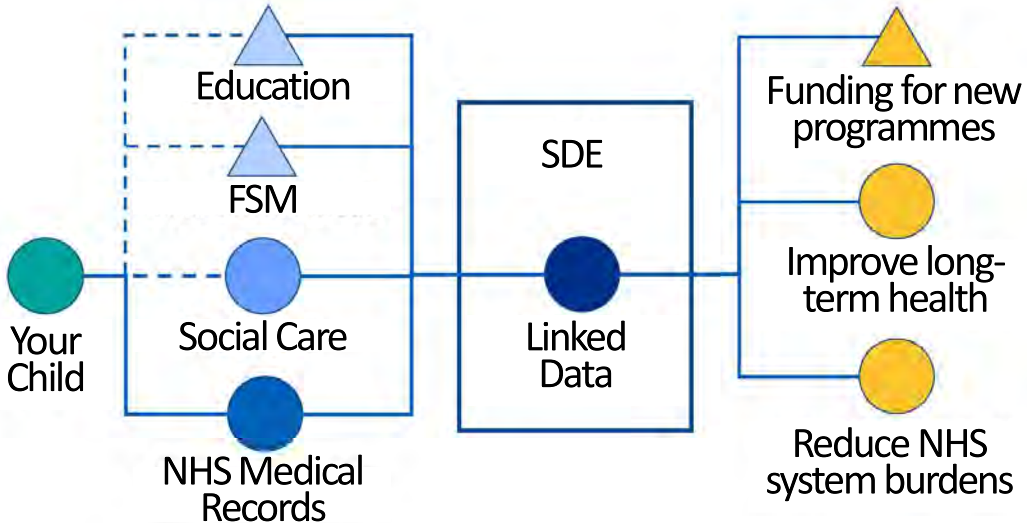
KEY FEATURES

- Linking these kinds of data types and records
- Young people and assent / consent issues

DATA TYPES

Attainment FSM Attendance Social care Police GP Record Self assessment

DATA FLOW



Education

FSM

Social Care

NHS Medical Records

Your Child

SDE

Linked Data

Funding for new programmes

Improve long-term health

Reduce NHS system burdens

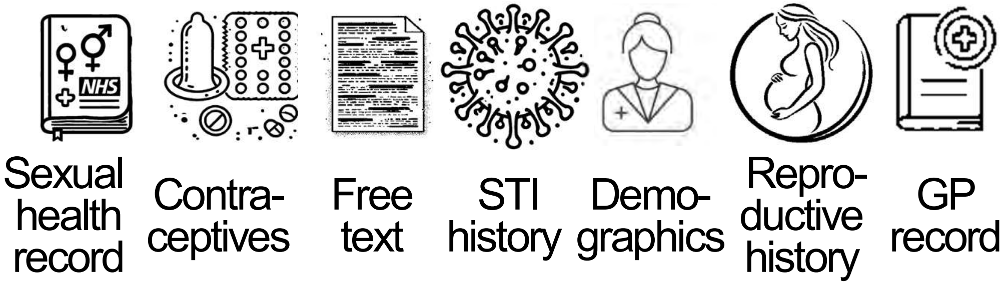
HPV vaccines: Increase vaccine uptake

Reduce stigma and target communities and young people who may have missed out on the vaccine when at school, to **improve vaccine coverage** and **reduce risks of cervical and other HPV related cancers**.

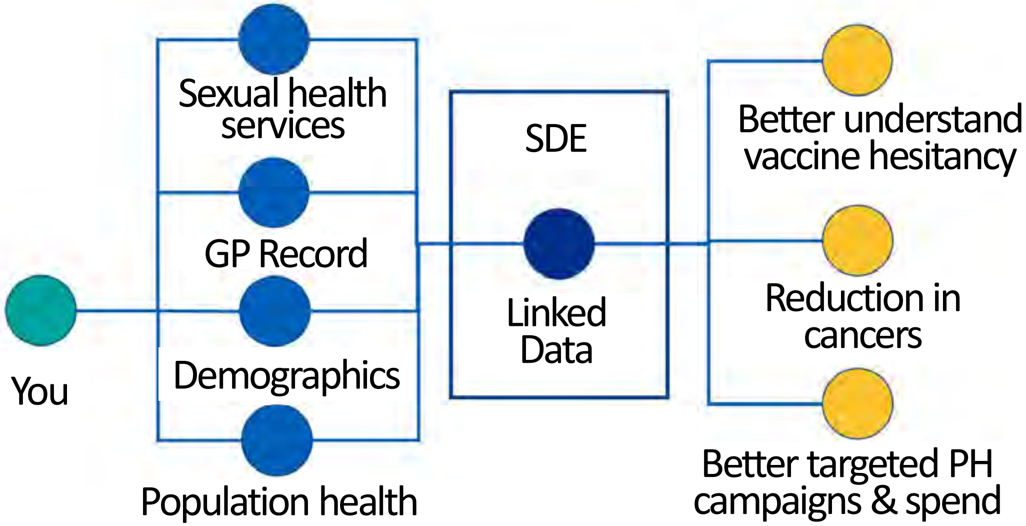
KEY FEATURES

- Linking these data types and records
- Sharing insights with other public sector partners

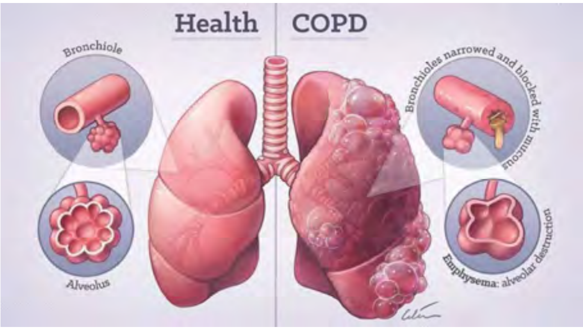
DATA TYPES



DATA FLOW



MyCOPD app: Patients managing their COPD better



Working with industry and other SDEs we will **improve the ability of COPD patients to live healthier**, better manage their symptoms and **reduce hospital admissions**.

KEY FEATURES

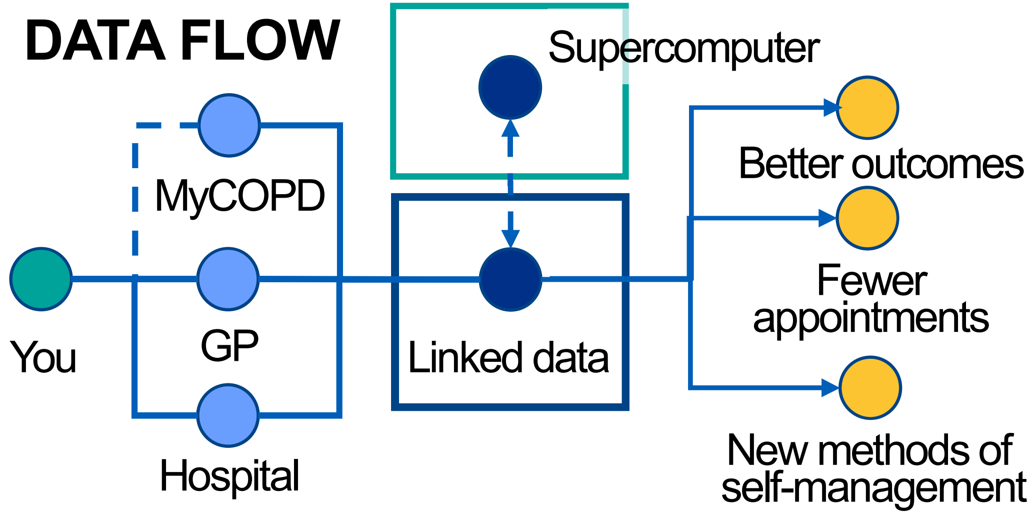
- Role of industry and their datasets
- Taking data outside the SDE to a super-computer
- Combining data across multiple SDEs

DATA TYPES

Exercise
Reports
O2 stats
Location
Air pollution
Weather

Medication
GP Record
Self assessment
Mental health

DATA FLOW



Supercomputer
MyCOPD
You
GP
Hospital
Linked data
Better outcomes
Fewer appointments
New methods of self-management

Dementia: Slow or stop Alzheimer’s disease early

This clinical trial led by University Hospital Southampton aims to **test new treatments that target Alzheimer’s disease at an early stage** – aiming to treat or slow the disease

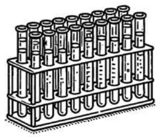
KEY FEATURES

- Reidentification of patients using the SDE
- Who is contacting the patients to recruit for clinical trials
- Impact of contacting people for clinical trials

DATA TYPES

Blood tests

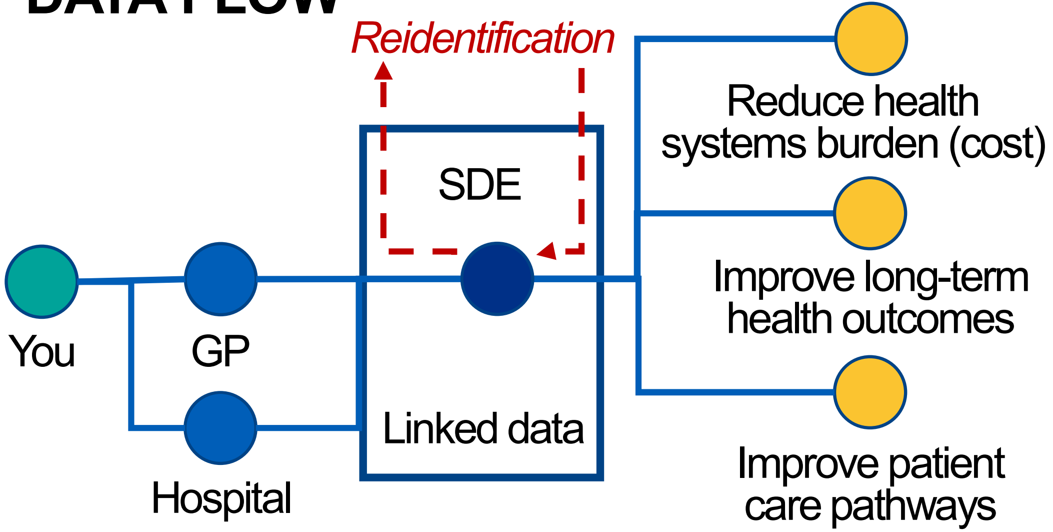
Scans and images



Test results

Diagnostic reports

DATA FLOW



Reidentification

SDE

Linked data

You

GP

Hospital

Reduce health systems burden (cost)

Improve long-term health outcomes

Improve patient care pathways

Sickle Cell Disease: A gene therapy cure

Using **gene editing** the research team hopes to **bring ground-breaking new therapies to patients** – via clinical trials – within five years.

Shows Wessex SDE's strength in running clinical trials – **success could attract other globally significant research trials**.

KEY FEATURES

- Under-representation in health research
- Small numbers but with life changing impact
- Working with international partners

DATA TYPES

Demographics

Genes/DNA

GP Record

Blood tests

RESEARCH PARTNERS

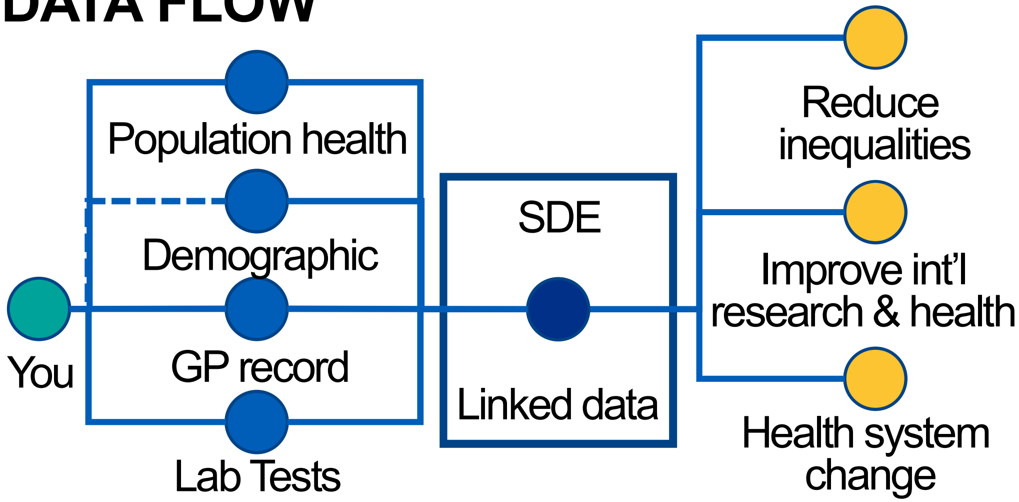
Industry

International Universities

International Agencies

International charities

DATA FLOW



You

Population health

Demographic

GP record

Lab Tests

SDE

Linked data

Reduce inequalities

Improve int'l research & health

Health system change

LifeLab: Improving adolescent health choices

Working with industry and other SDEs we will test **a new AI decision support tool** to improve decision making by multi-disciplinary NHS teams – and testing new care options for sarcoma (cancer) patients.

KEY FEATURES

- Collaboration with wider SDE Network and universities
- Benefits to individuals, communities and NHS versus industry

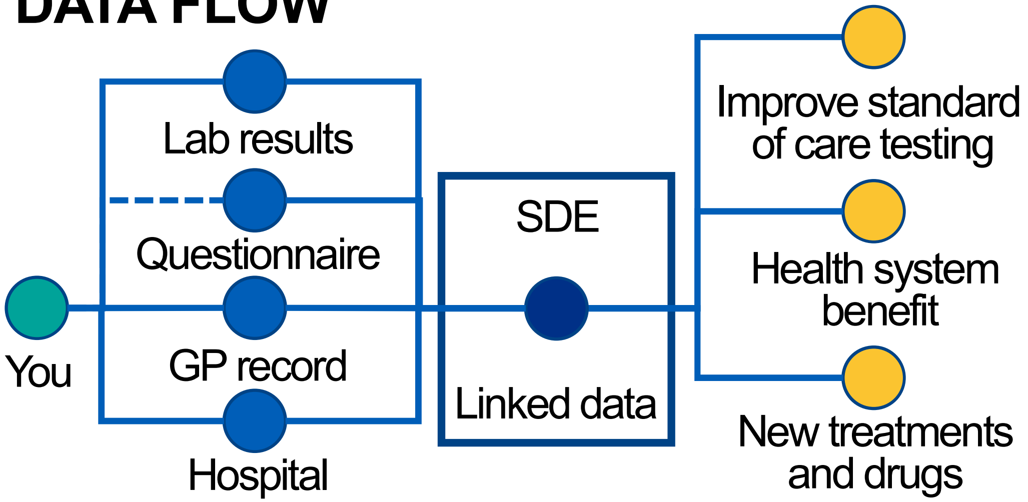
DATA TYPES

Scans & Images
Genes / DNA
GP Record
Blood tests

RESEARCH PARTNERS

SoCo / SDE Network
Industry
International Universities

DATA FLOW



You

Lab results
Questionnaire
GP record
Hospital

SDE
Linked data

Improve standard of care testing
Health system benefit
New treatments and drugs

Appendix 4: Day 3 – Designing a trusted decision-making process

Guide

This appendix contains all materials used in the third Public Panel session (7 September 2024, Dorset cohort; 14 September 2024, HIOW cohort).

Purpose of the day

Day 3 focused on **governance and decision-making**. Participants explored how the Wessex Secure Data Environment (SDE) should make decisions about data access, and how transparency can build public trust. The session tested ideas around delegation, evaluation criteria, committee composition, and expectations of openness.

Key themes

- **Decision-making processes** – understanding the stages from application to monitoring.
- **Delegation of authority** – which types of decisions can be handled by staff, and which require full Data Access Committee (DAC) scrutiny.
- **Evaluation criteria** – treating research proposals like job applications to identify what makes for the "best use" of SDE resources.
- **Committee composition** – discussing the ideal mix of professional and public members, and recruitment models for public members.
- **Transparency** – identifying when and how the public should be able to "see in" to decision-making.

Attachments in this appendix

Session planning

K. **Session 3 Public Agenda** – short agenda provided to participants, outlining the purpose and structure of the day.

L. **Session 3 Facilitation Plan** – full facilitator instructions, timings, and activities.

M. **Session 3 Master Slide Deck** – presentation slides covering DAC role, types of decisions, evaluation criteria, committee composition, and transparency.

Collateral

N. **Decision type cards** – categorising different decision contexts (e.g. Straightforward, Sweet Spot, Hot Debates, Support Role) to help participants judge which decisions could be delegated and which needed full DAC scrutiny. These cards included more detail than the slide deck, defining the nature of each decision category.

O. **Research evaluation criteria materials** – **group worksheets** used at table level for participants to identify essential and desirable criteria for assessing research proposals, and to discuss what “good” and “bad” would look like. There were also similar tools provided to bring together and prioritise criteria in plenary when the tables came together.

K: Session 3 Public Agenda

Wessex Public Panel on NHS Data: Session 3 Agenda

TIME	ACTIVITY	DETAIL
09:45	**Public Panel members arrive for tea and coffee**	
10:00	Introduction and welcome	Explaining the purpose of the day. **In the morning** – we will be discussing how we create a decision-making process and Data Access Committee (DAC) for the SDE that is trusted by the people of Wessex. **In the afternoon** – we will be looking at what transparency means for the Wessex SDE.
10:20	The role of the Wessex Data Access Committee – Presentation	Explaining how decision-making is expected to work from the point that a researcher has an idea, through the approvals process, to implementation, and outcomes.
10:35	Where are the biggest challenges / 'pinch points' for creating a decision-making process? – Table activity	Public Panel members will be invited to review a large-scale map of the decision-making process and add their views on what they see as the key challenges or barriers for developing a trusted decision-making process.
11:10	What kind of decisions does the DAC face? – Presentation	Explaining the different kinds of decisions the DAC has to take and the particular challenges that come with them.
11:20	**BREAK**	
11:35	When are we comfortable with the DAC handing over its decision-making powers to other people? – Table activity	Public Panel members will work together to rank the different kinds of decisions. We will look at how comfortable we feel about these being delegated or handed-over – and where we want the Wessex DAC to focus its time and resources.
12:20	What does a DAC decision involve? - Presentation	Explaining what is involved in a DAC meeting – and what kinds of criteria are used for decisions.
12:30	What are the key criteria research applications should be judged against? – Table activity	Public Panel members will be asked to think about projects as if they were job applications. What are criteria we would want to see them evaluated against (and what would 'good' and 'bad' look like).
13:20	**LUNCH**	
14:00	Who decides? Creating a trusted DAC for Wessex – Presentation	Exploring the mix of people who are needed on a DAC to ensure that it is capable of taking effective decisions and is trusted by the public to do so.
14:10	Ideal make-up of the new SDE DCA and the role of the 'public' –Table activity	Public Panel members are invited to think about the professionals and public representatives that should sit on the Wessex DAC.
14:45	**BREAK**	
15:00	Defining what transparency means for the Wessex SDE – Presentations	Exploring what transparency means in general and in the specific context of the Wessex Secure Data Environment.
15:15	Where are the most important points for transparency? – Table activity	We discuss what the public should expect to 'see' at each stage of the decision-making process for the SDE to be trusted.
15:55	Closing the meeting	Lead facilitator summarises what we have achieved today and adds closing comments.
16:00	**END OF DAY**	

Note that exact timings may vary. The session will finish promptly at 4:00PM.

L: Session 3 Facilitation Plan

Wessex Public Panel on NHS Data: Session 3 Plan

7 Sept in Bournemouth & 14 Sept in Southampton

#	Start	End	Dur.	Title	Description of the process	Materials / running notes
	09:00	09:30	00:30	**Facilitator check-in**	An opportunity for the team to check-in regarding the plans for the day and for facilitators to clarify any process concerns. Actions include: • Preparing flipcharts o Block 8 – a scale from 1 – 6 horizontally on a flipchart (where 1 = completely delegated and 6 = full consideration by the DCA (with a clear red line between 3 and 4) o Block 11 – What criteria should be used to assess potential research proposals to be 'best use' of SDE resources? o Block 15 – 2 flipcharts covering key skills and qualities and the recruitment of DCA public members • Familiarising yourselves with the large templates / worksheets etc. o 2 X A1 copies of SDE decision making process map (Block 4 and block 18) o 4 Decision type handouts (for pairs work Block 8) o Set of decision type cards (for group work Block 8) o 3 large 'position' templates (for prioritising Block 8) o 1 X A1 copy of Evaluation Criteria template (Block 11) o 1 X A1 'who is round the table' illustration (Block 15) o 1 large and 2 small 'windows' (Block 18) • Organising tables – important for this session to minimise the material in the middle of the tables • <u>Note that participants will be asked to wait outside the event room until at least 9:30.</u>	Flipchart and stand - 1 for each table Sharpies – at least 1 per person Pens and note paper- for each person Flipchart markers – big sharpies and at least 2 coloured markers Copies of the slide deck Blank name badges Rectangular and square post-its Whitetack Sets of sticky dots for ranking

	09:30	10:00	00:30	**Participants arriving**	**Keira –** Welcomes participants and registers their attendance outside the room **As participants arrive, they will be asked to choose 1 Lego Card that gives 'an insight into something we may not know about you'** **Table Facilitators** - At tables welcoming participants. - Checking / Handing out name badges for participants to write their own name. - Checking they have selected a lego card - Referring early participants to the information materials available at the tables	Lego Cards (provided by Kaela)
1	10:00	10:10	00:10	**Introduction and welcome** Setting the scene, context and tone of the day.	**Lead facilitator – Kaela** • Welcome and who is in the room • Facilitation team, speakers etc • Cover housekeeping, 'Parking Place', conversation guidelines • Remind members of the purpose of the Panel • The role of the panel in determining how (not IF) the SDE should be implemented to support making the best use of NHS data for health research to provide public benefits • Reminder of what was covered so far and the focus today on governance • Overview of the agenda for the day including outputs from the morning and afternoon sessions • Different way of working today – much more time in plenary – and not just giving answers to facilitators, but really entering into dialogue with each other	

2	10:10	10:20	00:10	**Table Exercise 1: Icebreaker**	**Table Facilitators** Process: Call on each member of your table, in turn, to introduce themselves: a. Their Name b. share the Lego Card they have chosen with the group - what it is and why they chose it.	Lego cards to be collected in at the end
3	10:20	10:35	00:15	**Presentation A: Role of the Wessex DAC (Data Access Committee)**	**Lead facilitator** – introduces the topic and explains how the presentation is going to work **Speaker - Matt Stammers – UHS doctor and member of the existing UHS DAC** - using minimal slides and large boards to lay out the process of research approval, implementation and monitoring - adding large post-its to highlight key points, opportunities for change and deficits when considering the SDE DAC	4 A1 sheets mapping the application and approval process Pre-prepared large post-its
4	10:35	11:00	00:25	**Table Exercise 2: Adding key challenges to the process map** Outputs - A table sized version of the process map identifying key challenges and pressure points	**Table Facilitators** Key Question: **Where along this process do you see the biggest challenges, or barriers for developing a trusted DAC and decision-making process for the SDE? What are they and why?** Process: Place the A1 process map in the center of the table – *facing participants, so it is upside down to you* Stage 1 - Ask each participant to take 3 rectangular post-its and a sharpie to record their responses to the key question - Ask for a volunteer to share their point, and reasons why – placing their post-it on the process map - BELOW the relevant step	A1 version of the process map (as used above) at each table LARGE post-its (3-4)

				for a trusted SDE DAC - 3 large post-its summarising the biggest challenges	• Ask if anyone else has the same / very similar point and encourage them to share their reasoning o cluster these post-its together on the map • Repeat process of calling for a volunteer – *perhaps asking for something at a different point on the map* – until all post-its have been placed and explained. Stage 2 • Review the clusters and negotiate agreement on the 3 BIGGEST/ MOST IMPORTANT challenges according to the group *(this will not necessarily be the ones with the most post-its)* • Record these ABOVE the relevant step – with reasons why Stage 3 • Summarise these on 3 LARGE post-its to be collected in plenary – *large print to be readable across the room* - Table number - The challenge - Why it is particularly important to overcome for a trusted SDE DAC?	
5	11:00	11:10	00:10	**Plenary Feedback - adding to the big process map** Output: a collective map of key challenges	**Lead Facilitator** manages feedback and collation • Asks a member of each group to bring up their 3 and stick them directly onto the boards o *Noting that if they spot others very similar, they should stick them as a group* • Reviews the boards from the left – reading out the post-it, and calling for additional feedback from the relevant group	

6	11:10	11:20	00:10	**Presentation B: What kind of decisions does the DAC face?**	**Speaker - Matt in Conversation with Kaela:** Discuss the range of and types of decisions that the SDE DAC would have to make - from procedural to complex and proposing that some may be able to be delegated to officers while some need to be made by the full SDE DAC (including public representatives) Kaela linking to examples from session 2	Question 'script'
7	11:20	11:35	00:15	**BREAK**		
8	11:35	12:05	00:30	**Table Exercise 3: Considering delegated decisions** Outputs: a table scale positioning who needs to be involved and to what level in different types of decisions	**Lead Facilitator** – introduces the decision types and the scale to be used **Table facilitators** Process: Using pre-prepared scale placed on the table facing participants - from 1-6- where 1 = handed over and 6 = full DAC scrutiny (with a clear red line between 3 and 4) Stage 1 (up to 10 minutes) Ask members to work in pairs using the worksheet to give a score to each decision type i.e. where they believe it should be on the scale Stage 2 (10 – 15 mins) • Ask one pair to share a decision type they scored a '1= handed over' and why o Ask other pairs for their score and compare, including reasons why – Capturing the range of initial positionings on the scale o Negotiate an agreed position (if necessary) and stick the small 'Decision type' card onto the scale (capturing the reasoning) – this could include statements like 'But only if....' • Ask another pair to share a decision type they scored 5 or 6 o Ask other pairs for their score and compare, including reasons why – Capturing the range of initial positionings on the scale	Flipchart scale **1-6** at tables Worksheet handout of decision types - 4 per table - Small (A6) Cards for each decision type X 2 each per table - And some blanks Larger 'positions' template – 3 per table

					o Negotiate an agreed position (if necessary) and stick the small ‘Decision type’ card onto the scale (capturing the reasoning) • Ask the final pair to share a decision type they scored in the middle o Ask other pairs for their score and compare, including reasons why – Capturing the range of initial positionings on the scale o Negotiate an agreed position (if necessary) and stick the small ‘Decision type’ card onto the scale (capturing the reasoning) • Continue to work through the decision types – focusing on the ones that seem most important to the participants to position o There is also the opportunity to add additional ‘decision types’ that participants believe need to be considered (using the blank cards) Stage 3 (last 5 mins) • Work with the group to identify the 3 decision types that they believe it is most important to have a clear, agreed ‘position’ on to be presented in plenary • Complete the 3 ‘position’ template cards for collation in plenary o *For example, this could be that they feel it is important to delegate procedural decisions so that the DAC time can better be used on determining ethical or financial value questions OR that decisions relating to multi-SDE projects don’t need the DAC input because we trust the other SDE’s DAC OR that decisions that have limited direct clinical benefit to the people of Wessex should not be the focus of the DAC*	
9	12:05	12:20	00:15	**Plenary Feedback - creating a collective decision scale** Output: a collective scale created in the	**Lead Facilitator** • Ask one group to share 1 of their prioritised decision types, where they have placed it and why (bringing it up to stick on the large scale) o Ask if other groups prioritised this decision type and where – collect these up for display • Continue mapping and calling for reflections from participants until all 12 are displayed	Using 3 flipchart stands at front of the room - scale of 1-6

				room focusing on important types of decisions and Why?		
10	12:20	12:30	00:10	**Presentation C: What does a DAC decision involve**	**Speaker 3: Dr Mikayala King** How does the DAC take a decision – how do they score applications What are the key attributes that a project needs to have? Introduce idea of a scoring matrix and explain how it works Explain different kinds of scoring – Y/N versus quantitative and qualitative	Pre-record for Dorset, Live HIOW

11	12:30	13:00	00:30	**Table Exercise 4: If projects were job applications, how would we assess them to be 'best use' of SDE resources?**
				
				Output: large template presenting prioritised selection criteria, why and what good and bad would look like
					Lead Facilitator: Introduce the exercise (drawing on the key considerations for research allocations from day 2)
					Explain the exercise (5 min)
					- Presents 'Table Facilitator' as an example of key specifications - Essential and Desirable
					- Now imagine the projects applying to use the SDE were like job applications - what are the Essential and Desirable criteria we would want to see them evaluated against (and what would 'good' and 'bad look like')
					  - Assuming that the proposal has been assessed as technically viable and meeting national ethical standards
					  - noting that the broad concept of delivering public benefit is a 'given' but that tables may want to focus on aspects of that, and other notions of value, that are most important
					
					Table Facilitators:
					Stage 1: (5 min)
					- Begin with an open verbal brainstorm in response to the question - 'What criteria should be used to assess potential research proposals to be 'best use' of SDE resources?'
					  o Capture responses directly onto the flipchart
						Pre-populated template for the job of table facilitator
						
						1 large template sheet for each table - 3 essential criteria and 2 desirable

					(forming the ‘long-list) Stage 2: (10 min) • Review the long list and agree among the table 6-8 from the long-list that seem particularly important criteria for ensuring the DAC decisions make the best use of the SDE for Wessex o Highlight these with a different coloured marker, adding reasons why (creating the short-list) Stage 3: (5 min) • Review the short-list to identify criteria to be added to the A1 template (adding them to it as you go) - 3 Essential Criteria - 2 Desirable Criteria Stage 4:(10 min) • Discuss and add to the template o What would ‘good’ look like for this criteria? o What would ‘bad / fail’ look like for this criteria?	
12	13:00	13:20	00:20	**Plenary: collation and ranking** Output: ranked prioritised selection criteria	**Lead Facilitator** Using duplicate templates to collect and collate the criteria from each table to create a master list Process (Stage 5): • Ask 1 group to present their 3 Essential Criteria - what it is and what good / bad would look like from a research proposal • Summarise the main concept on the blank template • Repeat for each group - noting but not repeating duplicate criteria • Ask 1 group to present their 2 Desirable Criteria - what it is and what good / bad would look like from a research proposal • Summarise the main concept on the blank template • Repeat for each group - noting but not repeating duplicate criteria	Up to 4 blank criteria templates for use in plenary (displayed on stands at the front)

					STAGE 6 - Ranking Key question - If there are multiple 'good candidates' (and limited resources) which criteria should be given the most attention? - Members allocate priorities (each given 5 big red dots for Essential, 5 small red dots for Desirable) - Asked to distribute their votes, rather than putting multiple votes on a single criteria	
13	13:20	14:00	00:40	**LUNCH**		Depending on time the votes may need to be counted over lunch.
14	14:00	14:10	00:10	**Presentation D: Who decides? – the composition of the DAC**	**Lead Facilitator** - reconvenes the group and sets the context for the afternoon **Speaker - Mark Heffernan** (10 min) - Ensure people know what the constraints are on the DAC make-up. - Must be one DAC - Limited talent pool - Public representation - People with learned experience - Indicative size limits - Role of the DAC versus the technical team – i.e. what it is NOT doing	
15	14:10	14:45	00:35	**Table Exercise 5: Ideal make-up of the new SDE DCA and the role of the 'public'** Outputs:	**Table Facilitators:** Process Initiate a table discussion between members, recording key points / conclusions on pre-prepared flipcharts - *Please note this section is not about getting as many ideas up as possible. Instead it is about identifying a preferred, collective, forward looking model.* Stage 1	Pre-prepared flip charts 'Who is round the table' template

				- Flip chart notes on the questions in Stage 1 - Completed ‘who is round the table’ template	1. Thinking about the professional / expert members that will be on the new SDE DAC – what types of background / experience do you think it is **particularly important** for them to have? - Where, if anywhere, might conflicts of interest occur? 2. Thinking specifically about the public members of the DAC, What skills and qualities will they need? - How is value added to the DAC by having members of the public involved? 3. How should public members be selected? Consider each of the potential recruitment models listed below and what might be the strengths and weaknesses of each approach: a. An open recruitment process where anyone can apply and be selected on merit b. By lottery to reflect the make-up of Wessex population c. Invited from groups already engaged with or volunteering with the NHS Public Patient involvement Engagement (PPIE) programmes d. Selected to represent the interests of different groups/communities across Wessex - particularly minority or seldom heard groups (e.g. BAME communities, disability groups, young people, faith groups) Stage 2 – **What should be the characteristics of individuals and the group as a whole?** Place the ‘’who’s round the table’ template in the center of the table facing the group • Work with the group to identify 3-4 core guiding principles that should inform the make-up of the group and record these in the center of the illustration o *These could be things like:* - *Equal balance of men and women*	

					- *75% professional and 25% public* - *Reflect the ethnic diversity of Wessex* • Use post-its to add more details about the specific types of individuals you'd like to see making up the DAC in an <u>ideal scenario</u> o *Here individual members around the table can contribute directly to create small 'PEN portraits' to be stuck next to the different individual images* *– including what they hope each character will bring to the decision-making process* <u>If there is time:</u> Consider what additional support may be needed to help members of the public contribute to the decision-making process on an equal footing to the professionals	
16	14:45	15:00	00:15	**Break**		
17	15:00	15:15	00:15	**Presentation E: Transparency in Decision-Making**	**Lead Facilitator** - reconvenes the group and sets the context for the session - unpacking the idea of transparency **Speaker - tbc** Transparency cannot be separated from public benefit Not about publishing everything – it's about curating the info to ensure that interested parties can find the info they want easily – or understand why they cannot have it Overall, there is a balance between transparency overload and too little information Some principles of transparency	
18	15:15	15:45	00:30	**Table Exercise 6: Where do the main windows of**	**Table Facilitators:** <u>Key question</u>: **For the SDE to be trusted by the people of Wessex what should the public expect to be able to 'see' at each stage of the process?** <u>Stage 1</u>: (15 min)	2nd copy of the A1 process map 1 A4 'big window' per group

				transparency need to be?	• Ask each member to take a few post-its and consider what it would be important for the wider public to be able to see / find out at different stages of the SDE delivery and decision process? o Invite members to stick these directly onto the process map • Review responses and discuss with the group (beginning with the step of the process that has the most post-its associated with it) o Focusing on the balance between what do interested members of the public most need to know vs information overload o Why might we want different levels of transparency at different steps of the process? Stage 2: - introduced by lead facilitator - Where is it most important for the SDE to proactively deliver transparency? ... and what would you expect to see? **Table facilitators** - Each table will have 1 'big window' template and 2 'small windows' to distribute across the process map o What would you want to see? o Why is this important? - Work with the table group to agree where these should be positioned and complete the template questions - Add table number	2 (or 3) smaller windows
19	15:45	15:55	00:10	**Plenary Feedback on key stages for enhanced transparency** **Output:** Group map showing the priority stages for transparency	**Lead Facilitator** • Asks for location and content of the first groups' 'Big Window' - sticks it to the process map o Did other groups have this as a big, or small window? – gives an opportunity to explain why and then bring it up to stick on the main map. • Continues to build overall map in plenary	

				and what the public should expect to see		
20	15:55	16:00	00:05	**Ending the day**	**Lead Facilitator** Thanks Arrangements for the final session	

M: Session 3 Master Slide Deck

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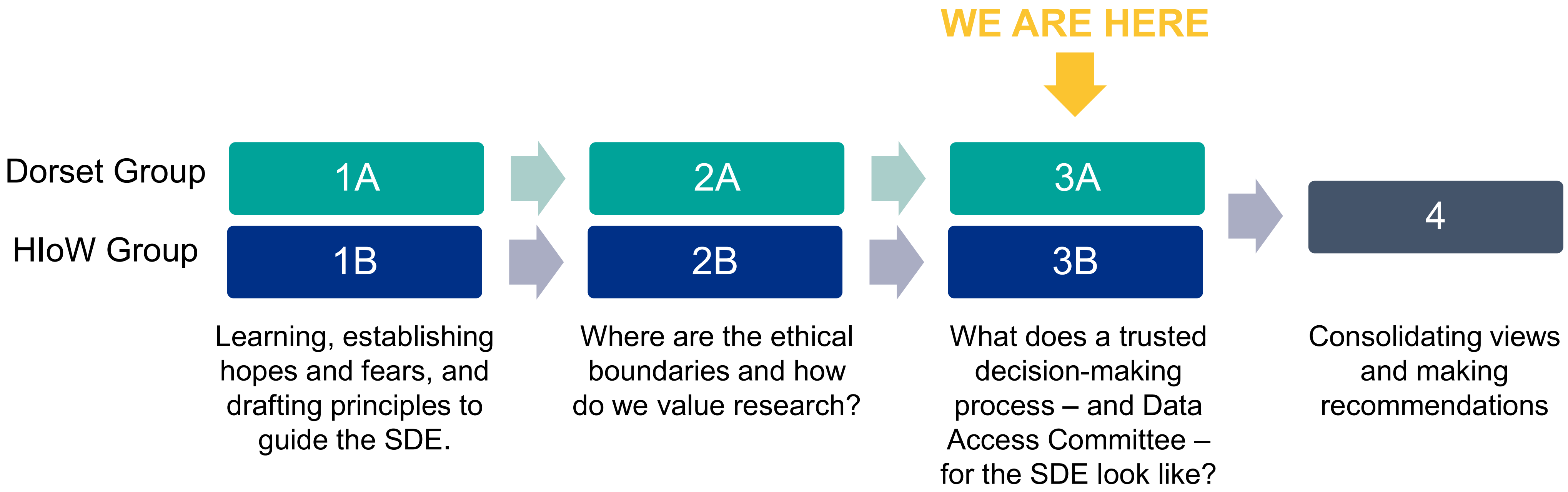
Wessex Public Panel on NHS data

WELCOME TO SESSION 3

Overarching question for the Public Panel

How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?

Overview of Public Panel meetings



WE ARE HERE

Dorset Group	1A	2A	3A	4
HIoW Group	1B	2B	3B	
	Learning, establishing hopes and fears, and drafting principles to guide the SDE.	Where are the ethical boundaries and how do we value research?	What does a trusted decision-making process – and Data Access Committee – for the SDE look like?	Consolidating views and making recommendations

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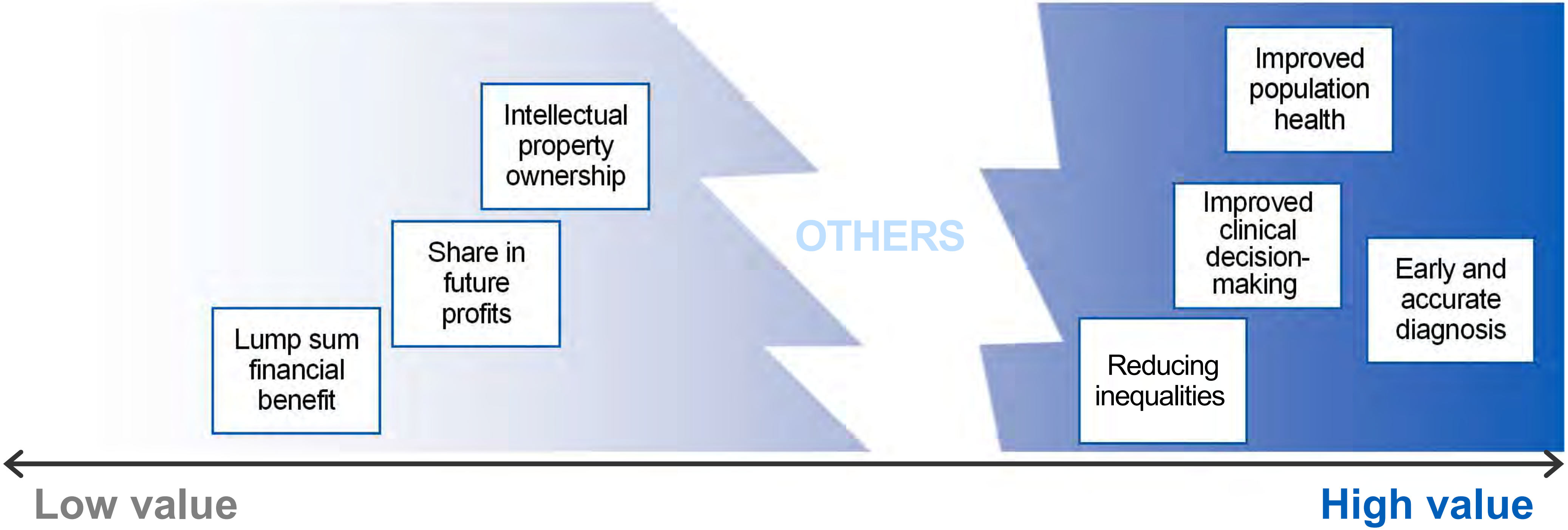
What we achieved in Session 2

How HIOW rated different value types



Lump sum financial benefit

Share in future profits

Intellectual property ownership

OTHERS

Reducing inequalities

Improved clinical decision-making

Improved population health

Early and accurate diagnosis

Low value

High value

How HIoW rated our research examples

HPV vaccines: Increase vaccine uptake

Dementia: Slow or stop Alzheimer's disease early

LifeLab: Improving adolescent health choices

Sarcoma: Better diagnosis and treatment

MyCOPD: Patients managing their COPD better

Sickle Cell Disease: A gene therapy cure

Very **comfortable**

Very **uncomfortable**

How HIoW prioritised SDE resources

HPV vaccines: Increase vaccine uptake

42

Dementia: Slow or stop Alzheimer's disease early

38

Sickle Cell Disease: A gene therapy cure

37

LifeLab: Improving adolescent health choices

34

Sarcoma: Better diagnosis and treatment

33

MyCOPD: Patients managing their COPD better

22

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Question for the day

How do we create a decision-making process for the SDE that is trusted by the people of Wessex?

Agenda for the day

- Introduction and purpose of the day
- The **role** of the Data Access Committee (DAC)

BREAK

- **Types of decisions** to be made by the DAC

LUNCH

- **Decision-making criteria** for the DAC

BREAK

- What **mix of people** do we want on the DAC
- **Key issues** to build trust in decision-making

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

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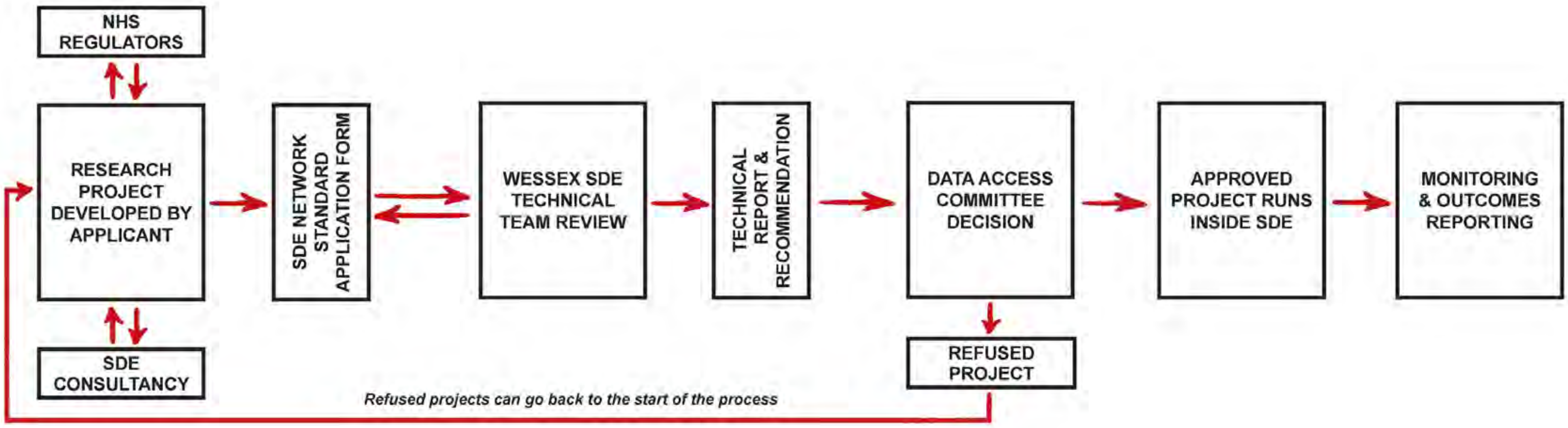
The role of the Wessex Data Access Committee

Dr Matt Stammers

Consultant Gastroenterologist and SETT Centre Theme Lead for Data & AI at University Hospital Southampton NHS Foundation Trust

A simple model of SDE decision-making



NHS REGULATORS

RESEARCH PROJECT DEVELOPED BY APPLICANT

SDE CONSULTANCY

SDE NETWORK STANDARD APPLICATION FORM

WESSEX SDE TECHNICAL TEAM REVIEW

TECHNICAL REPORT & RECOMMENDATION

DATA ACCESS COMMITTEE DECISION

REFUSED PROJECT

APPROVED PROJECT RUNS INSIDE SDE

MONITORING & OUTCOMES REPORTING

Refused projects can go back to the start of the process

Exercise 2:

Where are the biggest challenges / ‘pinch points’ for creating a decision-making process for the SDE that is trusted by the people of Wessex?

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Break

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What kind of decisions does the DAC face?

Dr Matt Stammers & Kaela Scott

Different types of decision for the DAC

Straight-forward	Sweet Spot	Tough Sells	Hot Debates	Careful Balances
Support Role	Leading the Charge	Tried and Tested	Expert Assist	Appeal process

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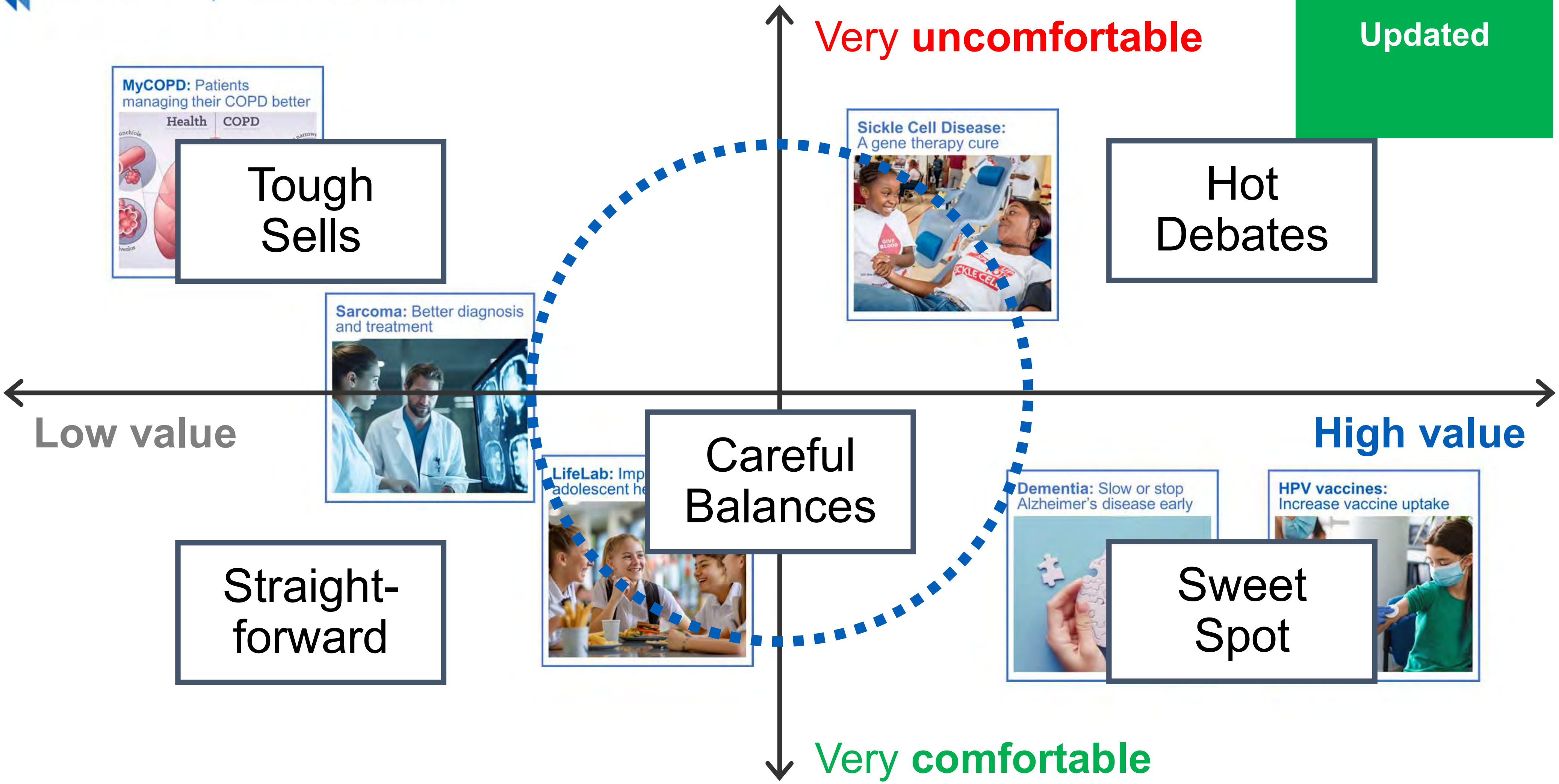
Updated



Very **uncomfortable**

Very **comfortable**

Low value

High value

Tough Sells

Hot Debates

Careful Balances

Straight-forward

Sweet Spot

MyCOPD: Patients managing their COPD better

Sarcoma: Better diagnosis and treatment

Sickle Cell Disease: A gene therapy cure

LifeLab: Imp
adolescent he

Dementia: Slow or stop Alzheimer's disease early

HPV vaccines: Increase vaccine uptake

Our role within the SDE Network

Support Role

This involves several SDEs and we are in a supporting role – another SDE DAC has already decided on this

Leading the Charge

This involves several SDEs and Wessex is the leader and our DAC is the first to take a decision

Our level of experience or expertise

Tried and Tested

We have seen and approved this sort of research before

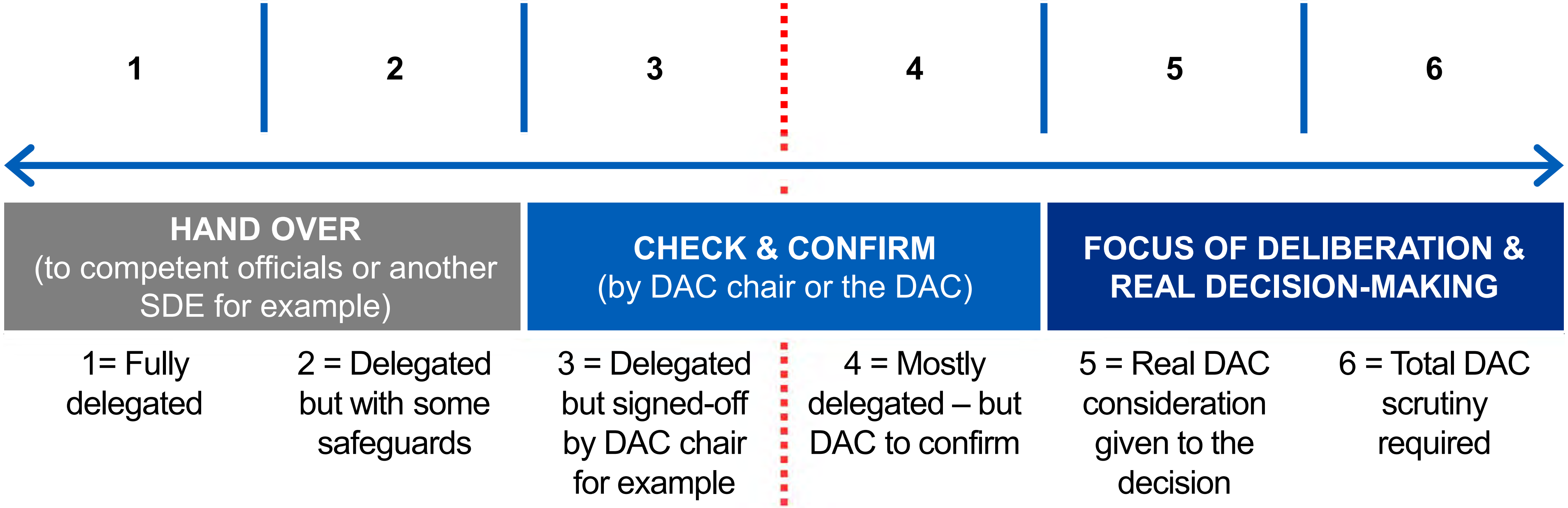
Expert Assist

This is new and outside the expertise of our DAC members

Exercise 3:

When are we comfortable with the DAC handing over its decision-making powers to other people?

Consider handing-over decisions



HAND OVER
(to competent officials or another SDE for example)

CHECK & CONFIRM
(by DAC chair or the DAC)

FOCUS OF DELIBERATION & REAL DECISION-MAKING

1= Fully delegated

2 = Delegated but with some safeguards

3 = Delegated but signed-off by DAC chair for example

4 = Mostly delegated – but DAC to confirm

5 = Real DAC consideration given to the decision

6 = Total DAC scrutiny required

Lunch break:

Ready to start
at 1.10 PM

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What does a DAC decision involve?

Dr Mikayala King

Research & Development Quality Assurance Manager for University Hospital Southampton NHS Foundation Trust

What does the technical team deal with?

Answers procedural questions to ensure that all projects being reported to the Data Access Committee meet the ‘Five Safes’ and could be approved.

COMPLIANCE

- Legal
- Meets regulatory requirements
- Follows NHS rules
- Data controllers are happy to share

TECHNICAL FEASIBILITY

- Peer reviewed = appropriate, relevant, and answers a real research question
- Can be delivered – based on expected time, cost and available SDE capacity
- Secure infrastructure

DATA QUALITY

- Available and complete
- De-identified

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Exercise 4:

If research projects were job applications, how would we assess them to be ‘best use’ of SDE resources?

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Break

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Who decides? Recruiting a trusted Data Access Committee for Wessex

Mark Heffernan
Director of Operations, Wessex NHS SDE

Key considerations

- **A single committee** with clear responsibilities and guidelines.
- **DAC should be focused on substantive decisions**, whilst the technical team handles procedural issues
- **Public representation is essential** for transparency and trust.
- Ensure **public members are well-trained** to support them contributing to discussions.
- **Limited professional talent pool** for skills, availability, and willingness to serve.
- DAC must **include diverse perspectives** = key to trust amongst seldom-heard groups most vulnerable to discrimination.
- There is likely to be **some form of central oversight, including enforcement.**
- **An efficient process builds trust** - with swift decision making, that minimises bureaucracy.
- **There will be a code of conduct for DAC members** – like our conversation guidelines – but that is outside the scope of this discussion.

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Exercise 5:

Ideal make-up of the new Wessex SDE Data Access Committee and the role of the ‘public’

How should public members be selected?

Consider each of the potential recruitment models listed below and what might be the strengths and weaknesses of each approach:

a) An open recruitment process where anyone can apply and be selected on merit

b) By lottery to reflect the make-up of Wessex population

c) Invited from groups already engaged with or volunteering with the NHS Public Patient involvement Engagement (PPIE) programmes

d) Selected to represent the interests of different groups/communities across Wessex - particularly minority or seldom heard groups (e.g. BAME communities, disability groups, young people, faith groups)

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Question for the day

How do we create a decision-making process for the SDE that is trusted by the people of Wessex?

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Exercise 6:

For the SDE, the DAC and the whole governance and decision-making process to be trusted by the people of Wessex

- **What would you expect to see in place at different stages of the process?**

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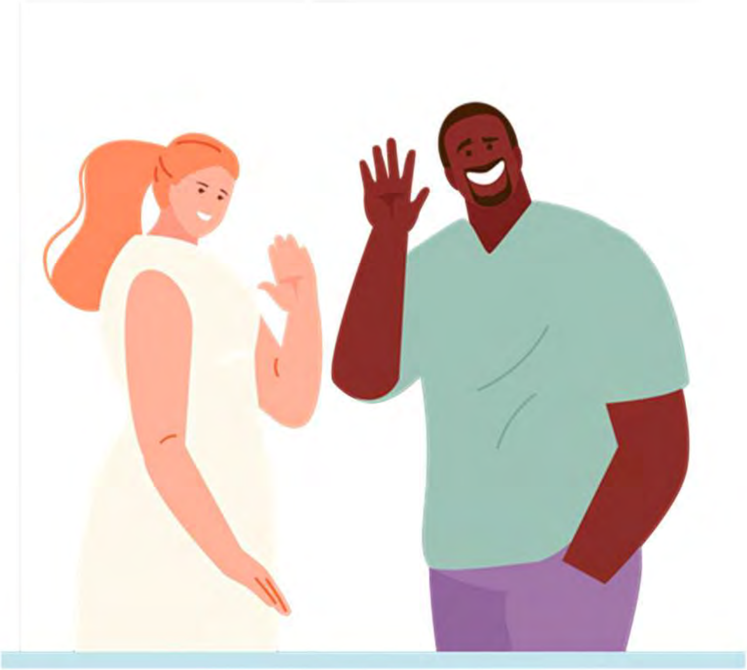
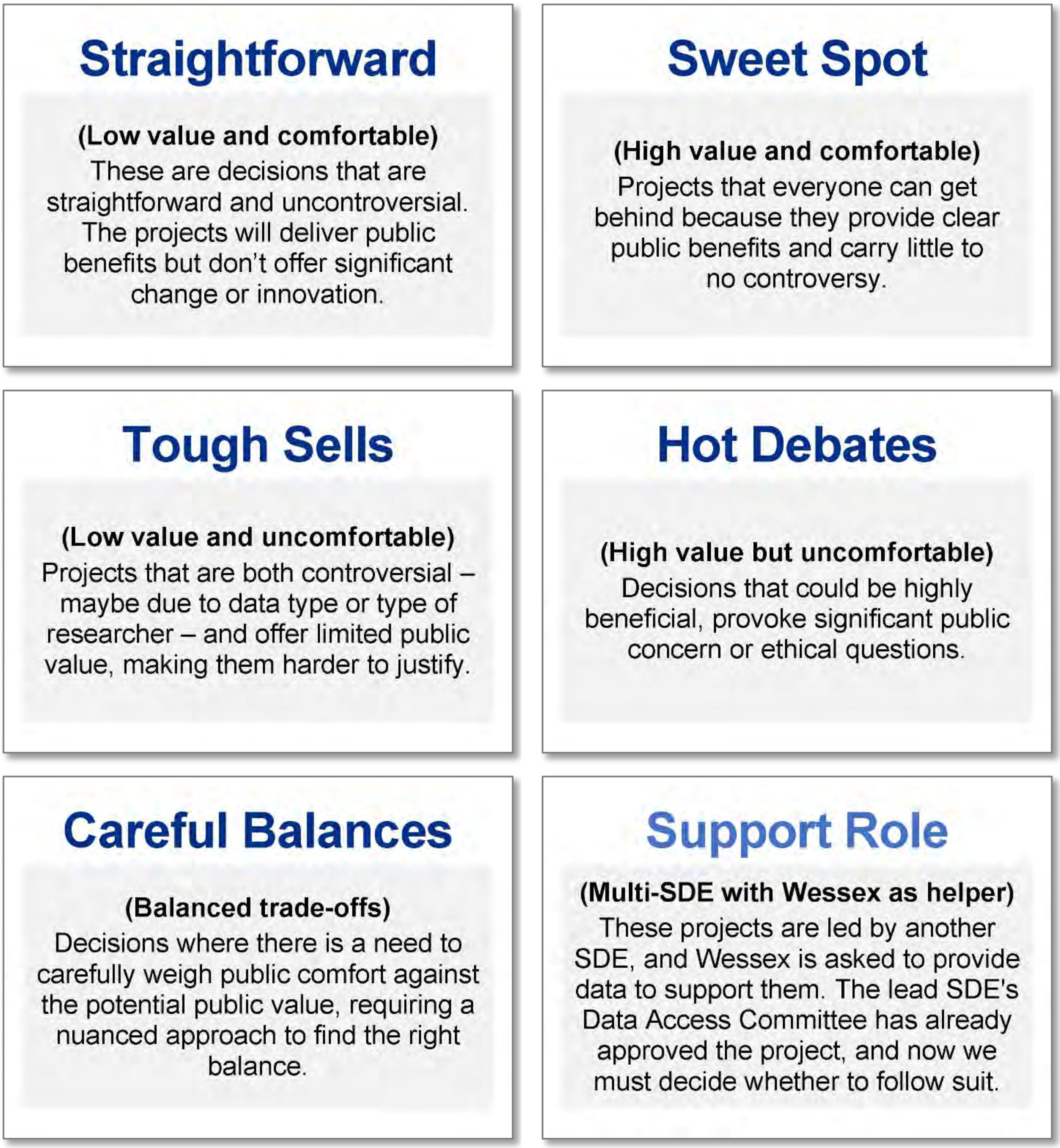


What have we achieved today and what is next?

N: Decision type cards



Straightforward

(Low value and comfortable)
These are decisions that are straightforward and uncontroversial. The projects will deliver public benefits but don't offer significant change or innovation.

Sweet Spot

(High value and comfortable)
Projects that everyone can get behind because they provide clear public benefits and carry little to no controversy.

Tough Sells

(Low value and uncomfortable)
Projects that are both controversial – maybe due to data type or type of researcher – and offer limited public value, making them harder to justify.

Hot Debates

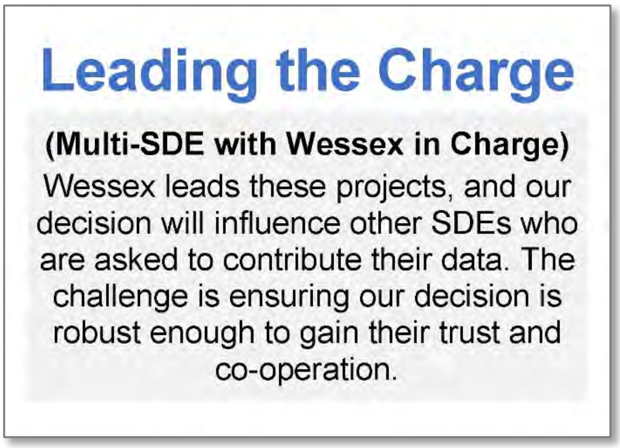
(High value but uncomfortable)
Decisions that could be highly beneficial, provoke significant public concern or ethical questions.

Careful Balances

(Balanced trade-offs)
Decisions where there is a need to carefully weigh public comfort against the potential public value, requiring a nuanced approach to find the right balance.

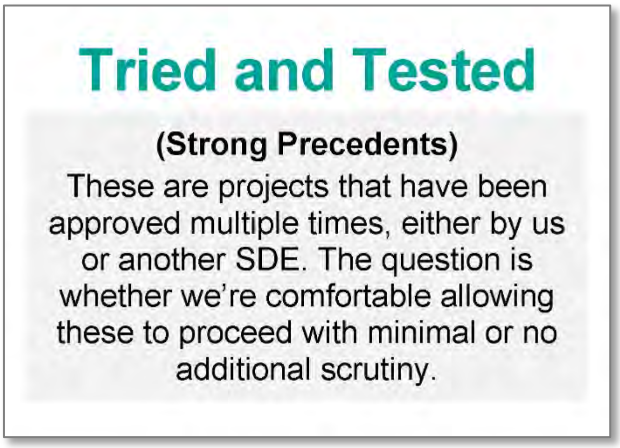
Support Role

(Multi-SDE with Wessex as helper)
These projects are led by another SDE, and Wessex is asked to provide data to support them. The lead SDE's Data Access Committee has already approved the project, and now we must decide whether to follow suit.



Leading the Charge

(Multi-SDE with Wessex in Charge)
Wessex leads these projects, and our decision will influence other SDEs who are asked to contribute their data. The challenge is ensuring our decision is robust enough to gain their trust and co-operation.



Tried and Tested

(Strong Precedents)
These are projects that have been approved multiple times, either by us or another SDE. The question is whether we're comfortable allowing these to proceed with minimal or no additional scrutiny.

Expert Assist

(Requires specialist expertise)
These are complex or novel projects that exceed our DAC's expertise. We either bring in external experts or hand the decision to another SDE with the necessary knowledge.

O: Research evaluation criteria materials

RESEARCH EVALUATION CRITERIA

What criteria should be used to assess potential research proposals as being the 'best use' of SDE resources?

ESSENTIAL	**WHAT WOULD GOOD / BAD LOOK LIKE?**
1 WHY?	
2 WHY?	
3 WHY?	
DESIRABLE	
4 WHY?	
5 WHY?	

Appendix 5: Day 4 – Consolidation and recommendations

Guide

This appendix contains all materials used in the fourth Public Panel session (28 September 2024, both cohorts together).

Purpose of the day

Day 4 brought the Dorset and Hampshire & Isle of Wight cohorts together to consolidate the Panel's work. The session focused on finalising Core Values, agreeing a set of Actions to Build Trust, and refining the Strategic Priorities that will guide the Wessex SDE.

Key outcomes

- A shared set of **Core Values** reflecting what is most important to the public.
- A sahred set of **Strategic Research Priorities** to guide future decision-making.
- A shared set of **Actions to build trust**, which are practical or policy commitments that the public can use to hold the SDE accountable.

Attachments in this appendix

Session planning

P. **Session 4 Facilitation Plan** – detailed timings, facilitator instructions, and running notes.

Q. **Session 4 Master Slide Deck** – full set of presentation materials (agenda, framing inputs, plenary exercises, and summary slides).

R. **Session 4 Practical Guide to Collateral** – facilitator pack showing how each worksheet and board was to be used across the day.

Collateral

S. **Core Values Stimulus Boards (A1)** – visual boards showing the draft Core Values and summarising the "you said / we heard" analysis.

T. **Core Values Worksheets (A1)** – blank templates used by participants to draft Core Value names, principles, and statements of importance.

U. **Strategic Priorities Worksheets (A2)** – blank templates used by groups to define each Strategic Priority, answering "Why?" and "So that …".

V. **Actions to Build Trust Cards (A5)** – a pack of pre-drafted and blank cards capturing “The SDE should…” and “The SDE will…” commitments, refined and finalised by participants.

P: Session 4 Facilitation Plan

Wessex Public Panel on NHS Data: Day 4 Plan

28 September 2024, Southampton

#	Start	End	Min.	Title	Description of the process	Outputs / materials / running notes
-	09:00	09:30	00:30	**Facilitator check-in**	An opportunity for the team to check-in regarding the plans for the day and for facilitators to clarify any process concerns. Actions include: • Familiarising facilitators with the printed templates etc to be used during the day. • Organising tables. • Note that participants will be asked to wait outside the event room until at least 09:30.	Flipchart and stand for each table Sharpies – at least 1 per person Pens and note paper- for each person Flipchart markers – big sharpies and at least 2 coloured markers Blank name badges
-	09:30	10:00	00:30	**Participants arriving**	**Keira –** Welcomes participants and registers their attendance outside the room and gives them their table number • Asks everyone to choose a postcard that reflects how they are feeling about today and the task ahead. **Table Facilitators** • At tables welcoming participants. • Handing out name badges for participants to write their own name if they have not brought theirs • Checking everyone has a postcard and asks them to leave it face down on the table for now.	100+ postcards (Kaela)
1	10:00	10:10	00:10	**Introduction and welcome**	**Lead Facilitator** • Welcome and who is in the room – including the role of the DCFs • the purpose of bringing the 2 panels together • Reminder of the Conversation Guidelines • Overview of the agenda for the day.	**-**

2	10:10	10:20	00:10	**Table Exercise 1: Introductions**	**Table Facilitators** Initiate a ‘go-around’ asking each participant in turn to share: a. Their name. b. Where they are from. c. The postcard they have chosen to reflect how they are feeling about today and the task ahead.	*Please collect in the post-cards at the end of the exercise.*
3	10:20	10:40	00:20	**Presentation of the boards holding Core Values**	**Lead Facilitator** invites **Chris Kipps and Ralph Scott** to present the boards. • Sets out the ‘size of the prize’ and expectations regarding the timing of the next stages of the SDE development, including delivery of benefits back to the SDE, NHS, and Wessex. • Notes that the Wessex SDE will need to be aligned with the national SDE Network programme and policies. • Explains the process of analysis; how we got to the content provided. • Summarises the content of the top half of the boards displayed. • a value as the title of the board and below that a space within which we've summarised the ingredients that go into that core value. • How the SDE will use the outputs	Core value boards displayed around the room.
4	10:40	10:55	00:15	**Table Exercise 2: Does this feel right?** <u>Outputs required:</u> • No specific outputs	**Lead Facilitator** Explains that we will shortly be randomly allocating one board to each table to focus on this morning (and built in opportunities to contribute to all Core Values) but, before that, an opportunity to reflect on what you’ve just heard. **Table Facilitators** Host a reasonably open discussion with the members reflecting on what they have just heard. <u>Prompt questions</u>: • Does this ‘feel’ like it reflects the discussions you have been part of?	

					- Does anything here surprise you? - Do you see any areas where it feels there have been differences of focus between the Dorset and the HIoW groups?	
5	10:55	11:25	00:30	**Table Exercise 3: Developing a statement of principle** <u>Outputs required:</u> - A draft name/title - A draft statement of principle	**Lead Facilitator** Reconvenes the group and allocates 1 board to each table (randomly allocated through a transparent lottery draw). - 1 member from each table invited up to the front (to form a line). - Each draws a board title from the 'hat' and takes the board back to the table with them. <u>Task</u>: to turn the material covered at the top of the allocated board into: - A title / name members feel sums up the core value (this could be as presented or might be changed – we are looking for 3-5 word titles, not long descriptive ones). - A concise, high-level, focused statement of principle about how they would expect the SDE to demonstrate this <u>Process: STEP 1</u> a. Review the material presented at the top of the board to ensure a common understanding of the scope and focus of the topic – seek clarification from the wider team present if needed b. Use a blank flipchart sheet to begin identifying the aspects of the topic that seem most important to be included in the statement of principle. - Work with the group to draft and agree the statement of principle building on the 'sentence starter' on the template: - *For the Wessex SDE to be trusted to make the most of NHS data for research it will …* c. Agree wording of the "Core value name" d. Complete the first two sections of the template and display.	'Hat' with the name of each board on a slip of paper
6	11:25	11:40	00:15	**BREAK**		

7	11:40	12:00	00:20	**Plenary exercise: Why is this important?**	**Lead facilitator** Invites all members to take sharpie and a pad of Post-its and rotate around the 8 boards. STEP 2 • At each board address the question “Demonstrating this Core Value is important for public trust in the SDE because …” – Question will be displayed on the screen **Table Facilitators** – stay with your board to answer any questions from panellists as they rotate and note any additional feedback or comments offered.	• Sharpies and Post-its for everyone
8	12:00	12:20	00:20	**Table Exercise 4: Defining why these values are important for public trust** Outputs required: • Completed Core Value worksheet with a ‘core value name’, a statement of principle, and a 3-4 sentence reason.	**Table facilitators** STEP 3 As your group returns to the table remove the Post-its to a new flipchart page on the centre of the table. a. Work with the members to group and theme the suggestions, noting key themes and phrases on the flipchart page. b. Agree with the group the key points that need to be made in the statement of importance c. Divide the points between members to work in pairs to draft the 3-4 sentences that will fill the next block of the template. - Invite them to share their drafts and work together to finalise the text d. Copy the agreed 3-4 sentences on to the template building from the ‘sentence starter’: *“Demonstrating this is important for public trust because …”* Your table should now have a completed Core Value worksheet with a ‘core value name’, a statement of principle, and a 3-4 sentence reason. Fold this sheet in half and stick it over the top of the original ‘Core Value’ board.	

9	12:20	12:40	00:20	**Plenary exercise: What would 'good' look like in practice?**	**Lead facilitator** Invites facilitators to return the 4-5 ‘actions that build trust’ cards to the bottom of the board; these will have been explained at the start of the day. — *These will be key actions identified during previous meetings.* — *In most cases they will read “The SDE should...”* — *In a few cases cards will read “The SDE will...” (where there have already been commitments made).* — *Also add 1 blank card.* **Table facilitators** • Review the cards with the group for broad understanding of content (5 min) before rotation – seek clarification from the team as necessary. - Consider broad level of agreement across the table **Lead facilitator** Explain the 3 parts of the exercise: 1. To work in pairs to rotate and review the proposed ‘actions that build trust’ cards on the 8 boards: — Using smiley faces to indicate actions that you think are particularly good/important and frowning faces to indicate any that you think would have no impact on building public trust. — Add Post-it notes to add reasons why and/or any suggestions for improvement / to strengthen the action. (Note that frowning faces without reasons will be treated as “can’t be improved”.) 2. To use a Post-it add suggestions of any important additional ‘Actions to build trust’ that seem to be missing (sticking them on the blank card). 3. To individually endorse (or not) each of the Core Values using the bag of 8 tokens: • Ask them to use the boxes to vote for the Core Values they support – only 1 token per box.	• ‘Actions that build trust’ cards and blanks • Bag of 8 tokens per participant • 9 voting boxes

					• No token = I don't endorse the Core Value. • Any tokens that they choose not to use should be placed in the 9th box. The lead facilitator will explain the reasons for these exercises: o *That when the outputs from these meetings are published, we want to be able to show the levels of support for the Core Values from the Panel as a whole.* o *But we also acknowledge that there may be specific values developed here that you personally do not agree with.* o *Acknowledge that prior to publication there may be the need to do small wording 'tweaks' to ensure consistent use of language across the 8 values.* o *Asks members to consider endorsing the essence of each Core Value, even if they do not entirely agree with every aspect of the wording* **Table Facilitators** – stay with your board to answer any questions from panellists as they rotate and ensure you understand the suggestions and feedback being offered	
10	12:40	13:25	00:45	**LUNCH**		
11	13:25	13:50	00:25	**Table Exercise 5: Finalising the boards** Outputs required: • Up to 6 'Actions that build trust' displayed on your completed board • Member identified to feedback	**Lead Facilitator** Reconvenes the group and explains the next stage: • That the SDE team will address comments on the pre-drafted 'Actions to build trust' and revise them. Panellists will review comments in the round and on the blank card. • That it is the responsibility of the group 'holding' the core value to give due and conscientious consideration to the suggestions. • However, they now have a mandate to complete the 'Actions to build trust' on behalf of the Panel as a whole. **Table Facilitators** 1. Support the group to systematically review the 'crowd sourced' suggestions for an additional action covering anything missing	• Crowdsourced comments and suggestions • Preprinted 'Actions that build trust cards' • Blank 'Actions that build trust cards'

					– use a clean flipchart sheet in the centre of the table to theme and group the comments that your blank card has received. – leave other comments and suggestions on the cards on which they were placed. 2. Identify up to 2 additional actions to propose and create cards for them. – *Please note these need to be specific and actionable ‘asks’.* 3. Identify a member of the group to present the board in plenary – Each group will have up to 2 minutes to present.	
12	13:50	14:10	00:20	**Plenary presentation by members of their completed board**	**Lead Facilitator** - Reconvenes the panel The boards are put back on display and a member of the group who has been working on each is invited to present back their work to the wider room (up to 2 minutes per group)	- Boards on display at the front of the room
13	14:10	14:20	00:10	**Plenary presentation**	**Lead facilitator and team** **Mark Heffernan** and **Ralph Scott** will introduce the next activity: - Playback the collated range of 15 'Strategic Priorities' that have been identified from weekends 2 and 3 (particularly from the exercises looking at Data Access Committee decision-making criteria; the types of value prioritisation; and the criteria for prioritising research examples). - Notes that these are ‘Strategic Priorities’ for the SDE as a whole – including but not limited to the Data Access Committee’s decision-making. - A pre-prepared summary of each of these Strategic Priorities will be displayed at the front of the room.	- 15 Strategic Priorities displayed at the front of the room

14	14:20	14:30	00:10	**Plenary exercise: Ranking the Strategic Priorities**	**Lead Facilitator** Explains the ranking process • That each person has 8 sticky dots to distribute across the 8 Strategic Priorities that they believe are most important to consider when deciding which potential research projects should be considered the best use of the SDE’s resources o Only 1 vote per priority o 20 minutes to do this (including most of the break) The 8 Strategic Priorities receiving the most votes will be the focus of the next exercise.	• 8 sticky dots per member
15	14:30	14:45	00:15	**Break**		
16	14:45	15:10	00:25	**Table Exercise 6: Defining the Strategic Priorities** Outputs required: • Completed worksheet with draft responses to template questions – Why? and “So that …”	**Lead Facilitator** Explains that each group has been allocated a priority to work on – based on the order they were ranked. (Group 1 gets the board ranked #1, Group 2 gets the one ranked #2, etc.). **Table Facilitators** a. Review the content outlining the Strategic Priority you have been assigned with the group to ensure a common understanding of the scope and focus of the topic – seek clarification from the wider team present if needed. b. Use a blank flipchart sheet to begin identifying the aspects of the topic that seem most important to be included in the definition of this Strategic Priority and why it is important. c. Work with the group to draft responses that build on the ‘sentence starters’ on the template: — Strategic Priority Name – preferably use the existing title, but your table can re-title it if necessary. — Why? “This is important because...” – explain why this is important; how does it help the SDE make the right decision about which research projects to approve and prioritise. (Note that these are criteria for the SDE as a whole, not just the Data Access Committee.)	• The notes on the Strategic Priority for the group • Flipchart for drafting

					— So that… “A good result for Wessex, the NHS, or the SDE is …” – we want participants to tell us what success looks like for people in Wessex, for the NHS or for the SDE. • Use bullet points to capture key points. • Numbering each point made here so that it can be easily referred to in comments during the plenary session.	
17	15:10	15:20	00:10	**Plenary exercise: Opportunity to review proposed text**	**Lead Facilitator** Invites all members to take a sharpie, a pad of Post-its, and some smiley face stickers to rotate around the 8 boards. The role is to act as a critical friend to the group working on each Strategic Priority. — Acknowledging the ideas / parts of statements that you particularly like (by adding smileys and/or notes) — Making constructive suggestions for improvement to actions and wordings (but not suggesting wholescale change) — Suggest success factors missing from the “So that …” section.	
18	15:20	15:45	00:25	**Table Exercise 7: Finalise the Strategic Priorities**	**Lead Facilitator** Reconvenes the group and asks for each draft template to be passed to a different table. — Table 1 passes to Table 2, Table 2 to Table 3, etc,) **Table Facilitators** • Work with your group to review the draft from the first group working on this Strategic Priority and the crowd-sourced comments • Complete the final template o Remaining true to the intent of the original group o Integrating suggestions where useful **Lead Facilitator** If time allows we will do a quick read out in the last few minutes.	
19	15:45	16:00	00:15	**Closing**	**Chris Kipps to close the session**	

					The Lead Facilitator will hand back to Chris, who will give an address of thanks and outline how we will take the project forward. • Thank attendees for all the hard work that they have put in across the day and the previous sessions • Call for a moment of reflection and for participants to look around the room at what they have achieved today – and the journey they have been on to get here – how they might have changed their minds through the process or the things they have learnt along the way • Summarise next steps: — Team will consolidate the learning and inputs from all the sessions into a formal report (Nov) — Copy of the detailed Report to be made available on the website along with easy read headlines and Exec summary — Wessex Big Conversation to be held in the Autumn/Winter, promoting the report headlines and SDE across Wessex more broadly - will be using multiple types of media etc to ensure good reach — Embedding the recommendation in the evolving design and operation of the SDE • Hope that participants have really enjoyed being part of this process. They will be receiving a follow up email which will allow them to sign up to get further information about what the SDE is doing and how they can be involved in future events if they wish to. • Wish them a safe journey home	

Q: Session 4 Master Slide Deck

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Wessex Public Panel on NHS data

WELCOME TO DAY 4

Wessex
SECURE DATA
ENVIRONMENT

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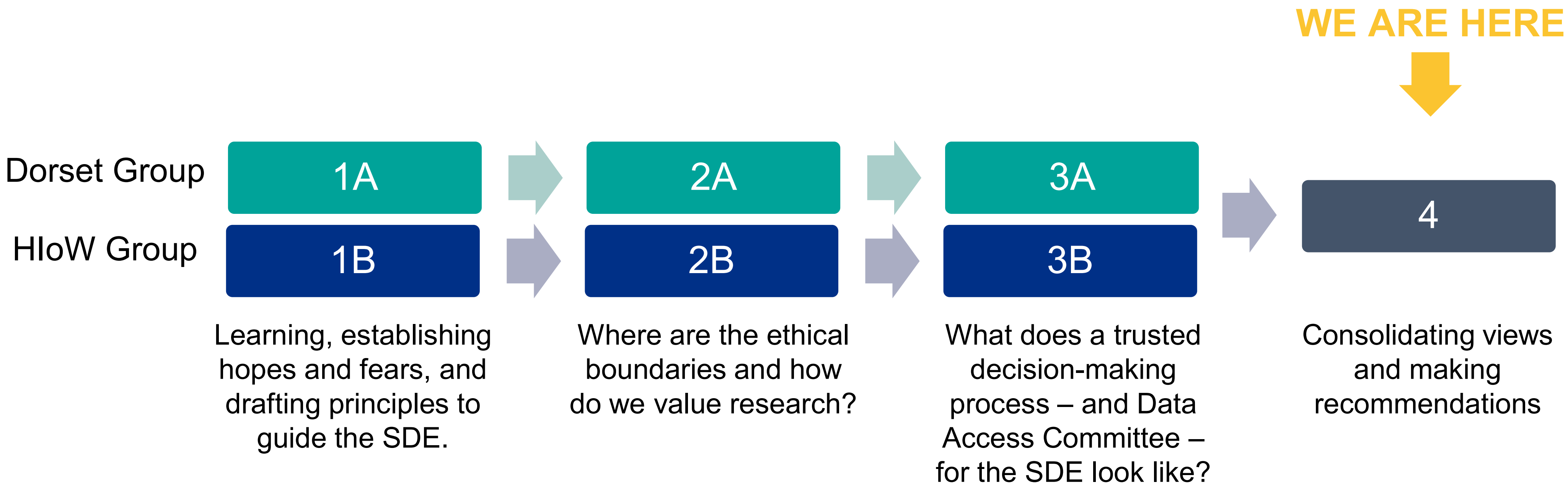
NHS

Overarching question for the Public Panel

How should we make the most of NHS data for research to improve lives and health outcomes in Wessex?

Overview of Public Panel meetings



WE ARE HERE

Dorset Group	1A	2A	3A	4
HIoW Group	1B	2B	3B	
	Learning, establishing hopes and fears, and drafting principles to guide the SDE.	Where are the ethical boundaries and how do we value research?	What does a trusted decision-making process – and Data Access Committee – for the SDE look like?	Consolidating views and making recommendations

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

Agenda for the day

- Why are we here today?
- Review what you told us and start drafting Core Values to guide for the SDE

BREAK

- Explore why the Core Values are important for trust
- Define what 'good' looks like

LUNCH

- Finalise the Core Values
- Rank Strategic Priorities for the SDE

BREAK

- Define and finalise Strategic Priorities

We are aiming for **3** key outcomes

- **Core Values**: what is most important to the Wessex public
- **Actions to Build Trust**: what the public needs to see to trust the SDE
- **Strategic Priorities**: how the SDE can make trusted decisions

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The big win – and how we secure it

Chris Kipps
Ralph Scott

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Our ambitions for the Wessex SDE

The global opportunity

- **Life science businesses are worth £2.26 trillion** each year across the world – the same as ¾ of the UK economy.
- **UK gets 5% of this benefit** – we're ranked 3rd after the US (who get nearly 80%) and China.

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Bringing benefits for Wessex

Growing our share of £2.8bn of research funding

Tackle our local health and care priorities

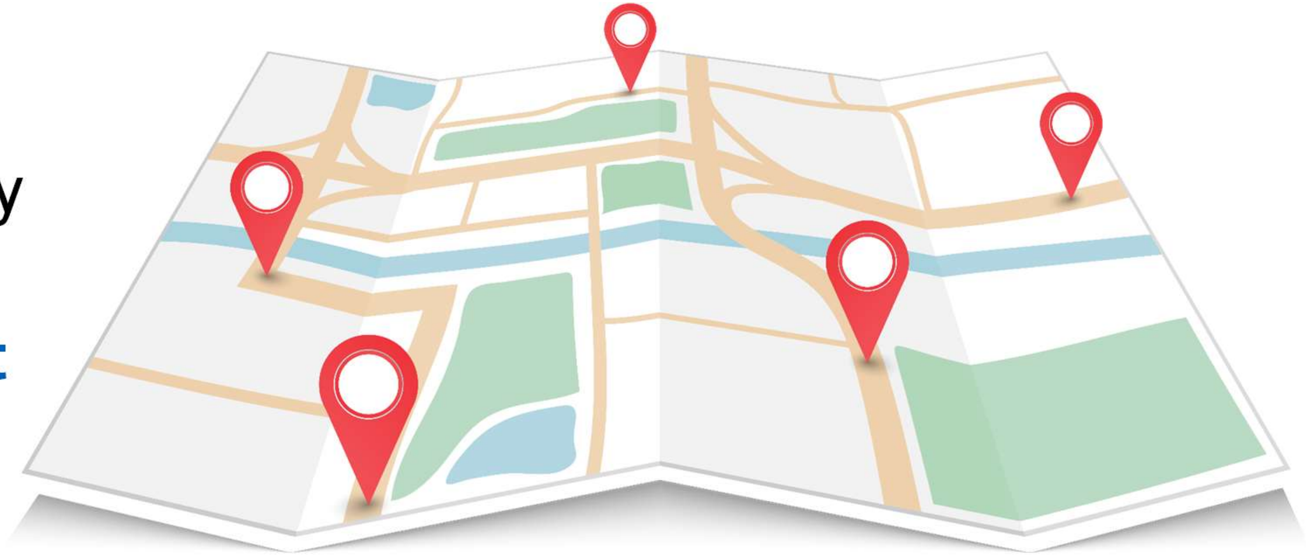
Improve NHS services

Grow investment and job creation

What is the ‘size of the prize’ for Wessex?

There is **a huge range of public benefits we could secure** for Wessex – many destinations to travel to.

We can’t – and shouldn’t try to do everything – what is the right destination for us?



What does the journey to securing these benefits for Wessex look like?

THE RIGHT VEHICLE & DRIVER

RULES OF THE ROAD

… but what does good look like?

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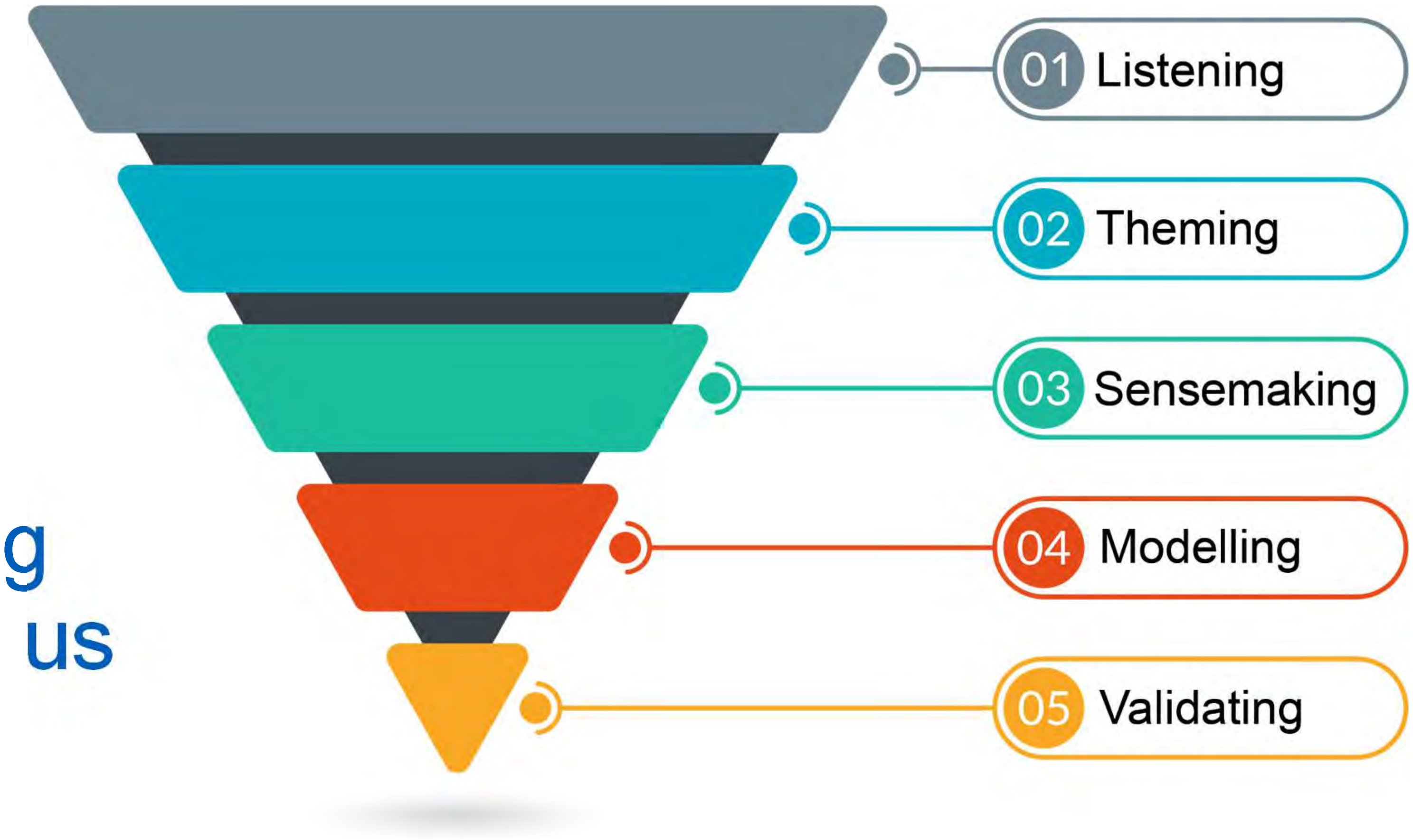
Understanding what you told us


01 Listening

02 Theming

03 Sensemaking

04 Modelling

05 Validating

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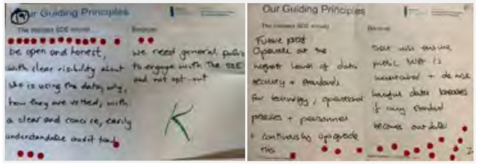
Day 1

Attitudes to health research

Safe and risky data

Hopes and fears

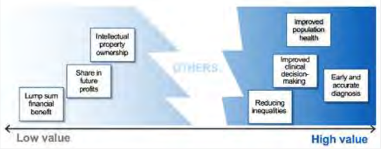
Values based principles



Day 2

Ranking research

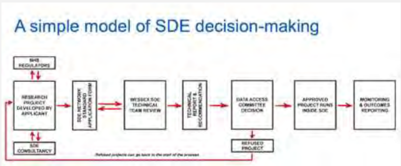
Types of value



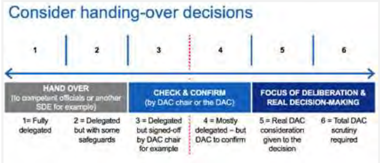
Prioritising resources

Day 3

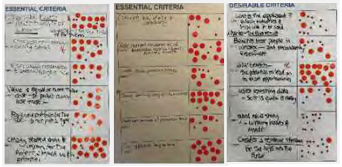
DAC Process


A simple model of SDE decision-making

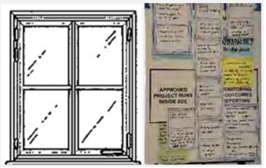
Decision types


Consider handing-over decisions

Project criteria



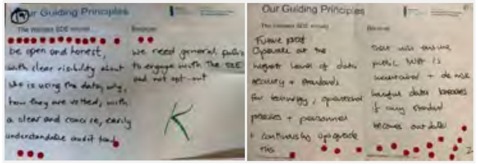
Transparency



CORE VALUES

STRATEGIC PRIORITIES

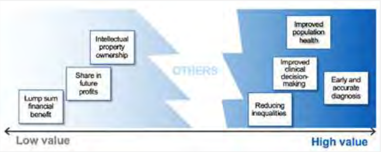
Values based principles



Attitudes to health research

Hopes and fears

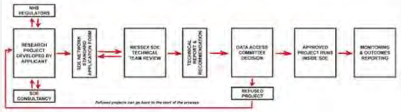
Types of value



Prioritising resources

DAC Process

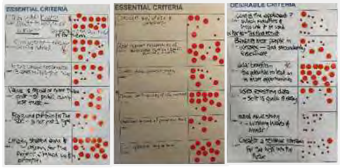
A simple model of SDE decision-making



Ranking research

Safe and risky data

Project criteria



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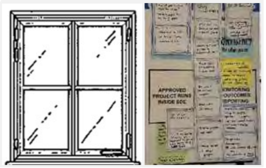
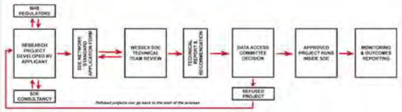
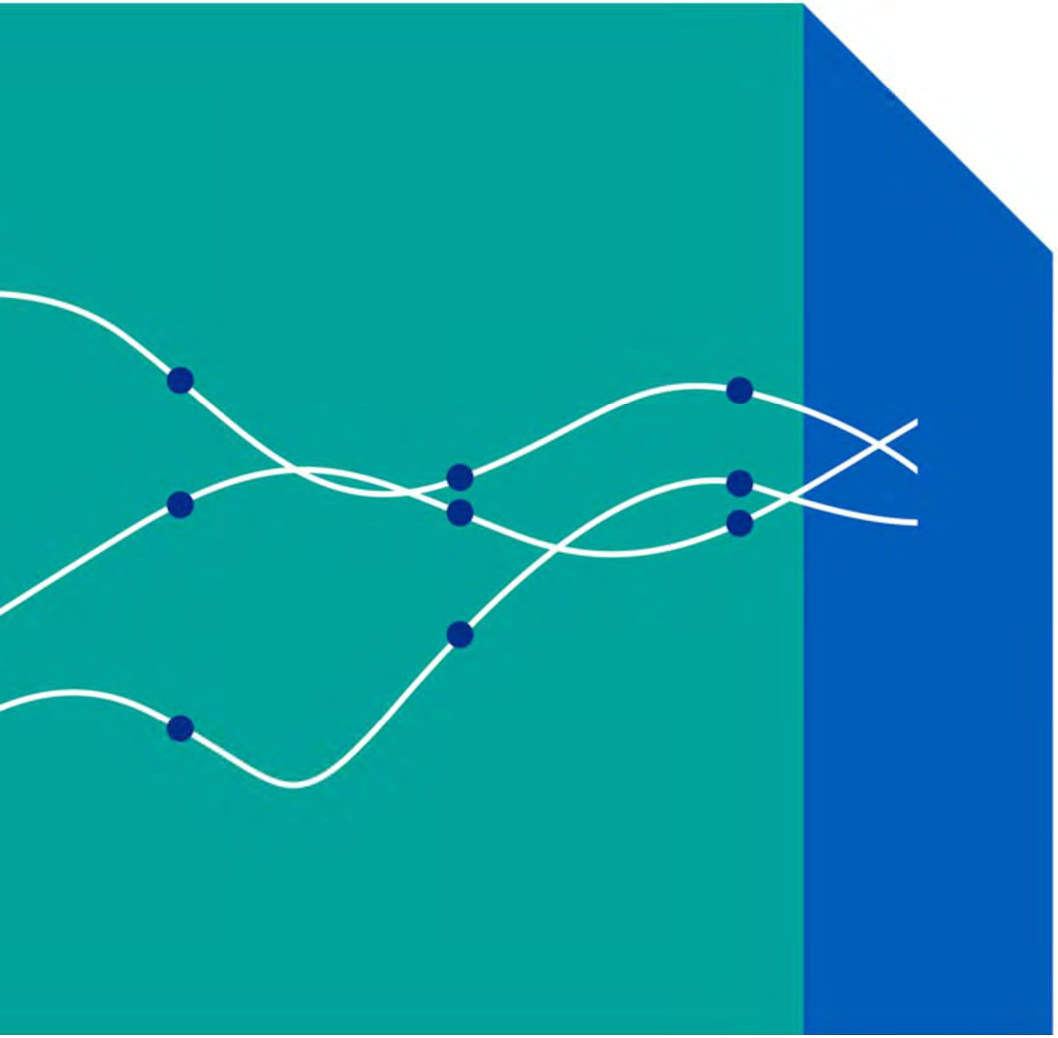


DAC Process

A simple model of SDE decision-making



ACTIONS TO BUILD TRUST



Core values

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.

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

PROTECTING THE MOST VULNERABLE.

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.

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.

BENEFITS REALISED LOCALLY, MAY INCLUDE NON-HEALTH BENEFITS.

WE HEARD …

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

CORE VALUE

DESIGNED TOGETHER

YOU SAID …

PUBLIC TRUST AND BUY-IN.

EASILY UNDERSTOOD BY EVERYONE - ESPECIALLY LAY PEOPLE ON THE DATA ACCESS COMMITTEE.

APPEAL TO ALL GENERATIONS, E.G. USE TIKTOK.

EFFECTIVE COMMUNICATION OF THE COMPLETE PICTURE USING VARIOUS MEDIA.

CLEAR MESSAGING IN A SIMPLE FORMAT THAT WILL REACH THE MOST PEOPLE.

A NEED FOR THE INVOLVEMENT OF SPECIFIC PUBLIC REPRESENTATIVES DRAWN FROM THE DEMOGRAPHICS / AREA TARGETED BY RESEARCH.

PUBLIC INVOLVEMENT: MORE INVOLVED EARLIER IN PROCESS, AND A RANGE OF DIFFERENT PEOPLE AND BACKGROUNDS.

PUBLIC HELP TO DEFINE AND PRIORITISE BENEFITS.

EDUCATING THE PUBLIC SO THEY KNOW WHY WE WANT THEIR DATA TO IMPROVE (SOCIETY) HEALTH.

MINIMISE USE OF ACRONYMS, JARGON, ABBREVIATIONS AS IT CAN GET CONFUSING.

WE HEARD …

CO-DESIGN, PUBLIC INVOLVEMENT, AND CLEAR, JARGON-FREE COMMUNICATION.

CORE VALUE

PRIVATE BY DESIGN

YOU SAID …

DE-IDENTIFY PATIENT DATA.

SAFEGUARD AGAINST BREACH OR LOSS OF DATA.

PREVENT UNAUTHORISED ACCESS.

INFO MUST BE DEIDENTIFIED. POSSIBILITY THAT 'FRESH EYES' OUTSIDE THE NHS PICK UP SOMETHING THAT MIGHT HAVE BEEN MISSED.

ROBUST APPLICATION OF THE FIVE SAFES.

WHERE THERE IS SHARING / USE OF DATA OUTSIDE THE UK ARE THE SAFEGUARDS / CONTROLS EQUALLY SECURE?

HAVE ACCOUNTABLE SECURITY CHECKS.

WE HEARD …

PRIVACY FIRST, RESEARCHERS MUST ONLY SEE DE-IDENTIFIED DATA – WITH STRICT SAFEGUARDS.

CORE VALUE

OPEN AND HONEST

YOU SAID …

HAVE A CLEAR MISSION STATEMENT THAT EXPLAINS THE SDE'S MAIN GOALS AND PURPOSE.

VISIBILITY ABOUT WHO IS USING THE DATA, WHY, HOW THEY WERE VETTED, AND AUDIT OF THE PROCESS.

BE HONEST ABOUT INTENTIONS, FUTURE PLANS, SECURITY, DATA FLOWS AND FUNDING/INCOME.

AVOID SDE STAFF HAVING MULTIPLE ROLES WHEN POSSIBLE. STAFF MUST DECLARE ANY CONFLICTS OF INTEREST AND STEP AWAY FROM RELATED DECISIONS.

SHARE LINKS TO THE RESULTS AND BENEFITS OF SDE PROJECTS. THIS WILL SHOW WHAT WORKED, WHAT DIDN'T, AND THE VALUE GAINED.

MAKE THE DECISION-MAKING AND SCORING PROCESS AVAILABLE ON THE WEBSITE.

PROVIDE INDEPENDENT OVERSIGHT AND AUDIT. PROVIDE VISIBILITY OF WHO IS USING THE DATA, WHY AND HOW THEY ARE VETTED.

MAINTAINING ETHICS (FUTURE PROOFING INTENTION) SO CORE PURPOSE DOES NOT GET LOST / STAYS ON TARGET.

WE HEARD …

BE CLEAR ABOUT HOW DATA IS USED, WHO IS USING IT, AND WHY.

CORE VALUE

DELIVERS GOOD VALUE

YOU SAID …

MAKING SURE THAT THE NHS GETS A GOOD DEAL OUT OF THE COMPANIES USING DATA.

ENSURE IMPROVED QUALITY OF LIFE, NOT JUST YEARS LIVED – QUALITY VS. QUANTITY.

BE VALUE FOR MONEY – EFFICIENT, COST EFFECTIVE, COST V BENEFITS BECAUSE IT IS PUBLICLY FUNDED AND TO MAXIMISE THE SCHEME.

REINVESTMENT OF RESEARCH FUNDS INTO NHS/SDE AND BENEFITS FOR WESSEX.

VALUE IS NOT JUST MONEY BUT BENEFITS TO THE NHS, PATIENTS AND WIDER PARTNERS – E.G. SOCIAL CARE.

INCREASES BENEFITS AND OPPORTUNITIES FOR EVERYONE, NOT JUST SPECIFIC GROUPS.

WIDE IMPACT AND BENEFITS PROVIDE CLEAR VALUE, LOW NUMBERS NEED MORE CONSIDERATION

DRIVE EFFICIENCY BY SHARING KNOWLEDGE ACROSS SDES TO SOLVE SHARED CHALLENGES AND ENSURING RESEARCHERS CAPTURE ALL LEARNING AND FEED THIS BACK – BECAUSE THIS WILL ENABLE MORE RESOURCES TO BE FOCUSED ON THE HIGH VALUE RESEARCH OUTCOMES AND DEMONSTRATES A COMMITMENT TO LEARNING AND SHARING.

WE HEARD …

BE EFFICIENT AND SAVE NHS MONEY – BE GOOD VALUE FOR THE PUBLIC AND NHS.

CORE VALUE

RESPECTS PEOPLE'S CHOICES

YOU SAID …

INFORMATION ABOUT THE SDE IS ACCESSIBLE, EVERYONE CAN READ IT, UNDERSTAND IT AND BUY-IN / OPT OUT.

CLEAR ROUTE TO OPT-OUT.

EXPLAIN WHAT ISN'T GOING TO BE SHARED. IT GIVES THE PUBLIC ASSURANCES THAT PRIVATE AND CONFIDENTIAL INFORMATION ISN'T SHARED, REDUCING THE AMOUNT OF OPT-OUTS, MEANING MORE INFO/DATA TO REVIEW, HELPING WITH RESEARCH.

'DUTY OF CARE' - INFORMATION PROVIDED IF PEOPLE WANT IT.

PUBLICISE OPT-OUT OPTIONS.

COMMUNICATE THE OPTIONS IN AN ACCESSIBLE, CLEAR, CONCISE AND SIMPLE WAY TO EMPHASISE CHOICE AND BENEFITS TO WESSEX AND BEYOND. BECAUSE PEOPLE NEED TO BE ABLE TO MAKE AN INFORMED AND POSITIVE CHOICE TO OPT-IN.

WE HEARD …

OPT-OUT CHOICES AND CLEAR INFORMATION TO INFORM PERSONAL DECISION MAKING.

CORE VALUE

POSITIVE PARTNERSHIPS

YOU SAID …

SHOULDN'T DEMONISE PHARMA COMPANIES.

RESULTS COULD BE MANIPULATED TO INCREASE PROFITS.

MAKING SURE THAT THE NHS GET A 'GOOD DEAL' OUT OF COMPANIES USING DATA.

HOW MUCH BENEFIT IS GOING TO A PROFIT-MAKING ORGANISATION VS INTERESTS OF COMMUNITY.

INDUSTRY BRINGS REVENUE TO THE NHS AND SDE.

DEIDENTIFIED DATA CAN BE MOVED EXTERNALLY FOR ANALYSIS – AS LONG AS THE COMPANY / EXTERNAL MEETS CERTAIN CRITERIA.

INDUSTRY PROVIDES TECHNOLOGY AND SERVICES NOT AVAILABLE FROM THE NHS.

ABILITY TO HELP BRING GLOBAL RECOGNITION AND INVESTMENT.

MAY BE DRIVEN BY MONEY NOT PATIENT BENEFIT.

WE HEARD …

FAIR CHARGING, RETURNS, AND BENEFITS FROM USE OF NHS DATA & RESOURCES BY NON-NHS PARTNERS.

CORE VALUE

QUALITY ASSURANCE

YOU SAID ...

CONTEXT OF USE IS IMPORTANT FOR WHAT DATA SHOULD BE USED. THE BETTER THE CAUSE THE MORE WE WOULD BE HAPPY WITH 'RISKY' DATA.

DATA CAN ONLY BE USED FOR THE REASON THAT WAS STATED BY THE PROJECT – WITH SEVERE PUNISHMENTS FOR BREACH.

THE SYSTEM NEEDS TO BE MANAGED EFFICIENTLY TO ENSURE THAT DATA PROVIDED IS ACCURATE AND IS OF VALUE.

IF THE HEALTH RESEARCH AUTHORITY HAS APPROVED THE PROJECT, THEN WE'RE BROADLY IN AGREEMENT THAT THE SDE CAN DO THE PROJECT.

MUST BE REVIEWED REGULARLY (AUDITED).

INDEPENDENT AUDITOR (OVERSIGHT).

THE SDE SHOULD TRY TO BE DECENTRALISED, NON-COMPARTMENTALISED, WITH AS LITTLE HIERARCHICAL OVERSIGHT AS IS NEEDED. THIS ALLOWS THE FLOW OF INFORMATION WITHIN RELEVANT RESEARCH PROGRAMMES, REMOVES UNNECESSARY INTERVENTIONS, AND HELPS STOP ANY CORRUPTION.

ASSURANCE MUST BE EMPIRICAL AND NOT SUBJECTIVE.

WE HEARD ...

INDEPENDENTLY AUDITED AND ACCOUNTABLE, GOOD QUALITY DATA, AND STRONG GOVERNANCE.

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Exercise 2:

Does this feel right?

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Break

Plenary Exercise:

Why is are these Core Values important?

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Exercise 4:

Defining why these Core Values are important for public trust in the Wessex SDE.

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Plenary Exercise:

What would ‘good’ look like in practice?

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Lunch break:

Ready to start
at 1.25 PM

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Exercise 5:

Finalising the Core Values boards.

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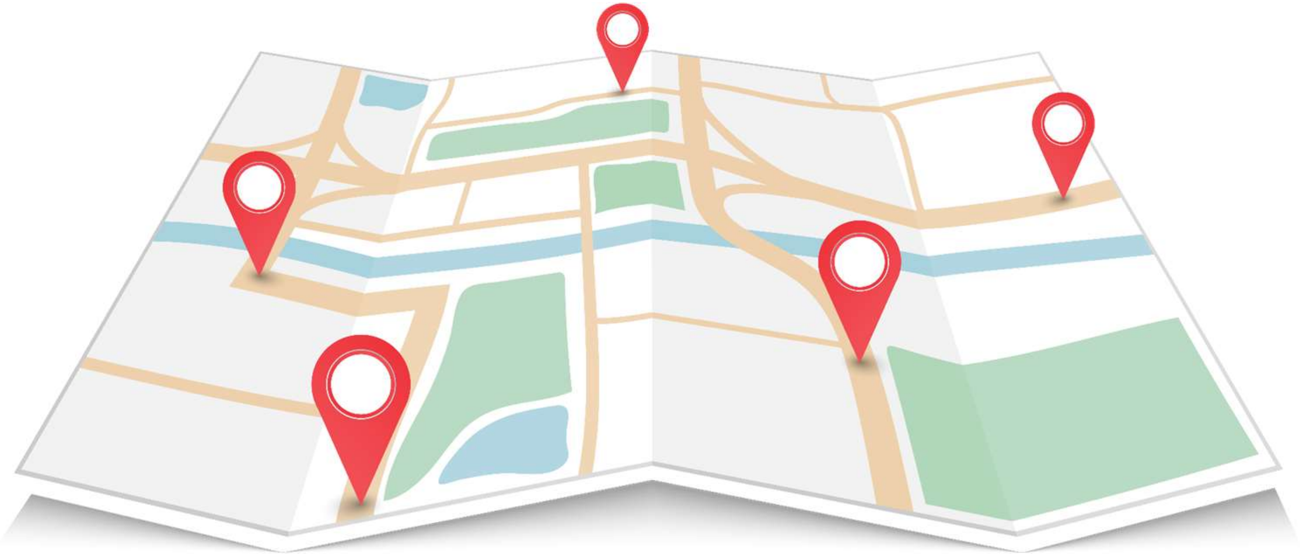
Agreeing the research priorities for Wessex

Mark Heffernan

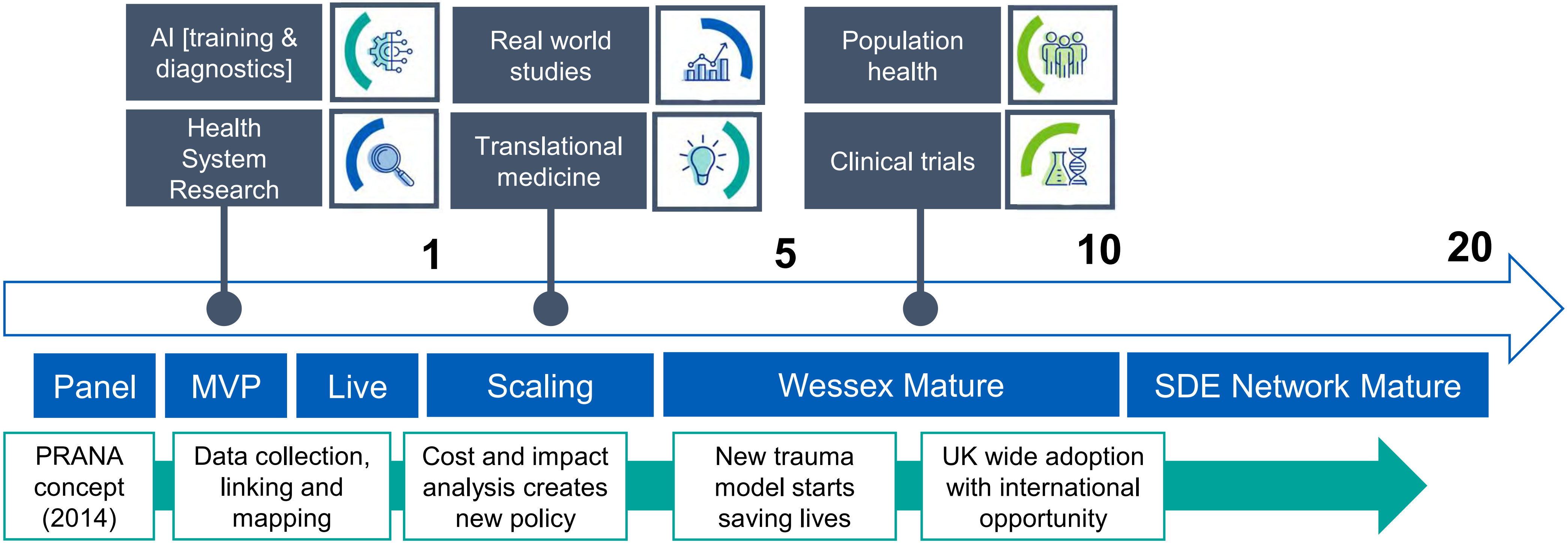
Why do we need strategic priorities?

Strategic Priorities tell us what **YOU** want the SDE to achieve.

They help us navigate to the ‘right destination’ for the Wessex SDE.



Results will take time to deliver



Today our focus is on getting the SDE live

Objectives and key results by March 2025

- 10 studies contracted and delivered or in process
- 40 studies in pipeline
- Data Sharing Agreements and Data Catalogue exercise for all data controllers
- Wessex website and ongoing PPIE including an SDE wide DAC

SDE Operations Functions

- Industry and academic partnerships
- Data partnerships
- Contracts and governance
- Delivery (Data and services)
- Delivery (Technical platform)
- Operations management

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How will Strategic Priorities work in practice?

Strategic Priorities give the SDE clear guidance about what the destination should look like.

They are a decision-making tool, helping us prioritise what is important.

THE SDE SHOULD PRIORITISE PROJECTS THAT DELIVER ...

WIDER OPPORTUNITIES AND NATIONAL IMPACT.

POSSIBILITY OF FURTHER WIDER BENEFIT: DESIRABLE PROJECTS TO ATTRACT RESEARCHERS TO WESSEX.

HAVE WIDER NATIONAL IMPACT: ATTRACTING GOVERNMENT MONEY, SAVING MORE LIVES, HAS A MULTIPLIER EFFECT IF OTHER SDES PICK IT UP, AND THIS BOOSTS A CULTURE OF COLLABORATION.

WIDER APPLICATION: OFFERS ADDITIONAL BENEFITS, RESEARCH, OR COMMERCIAL OPPORTUNITIES.

The **NOT JUST HEALTH** one

THE SDE SHOULD PRIORITISE PROJECTS THAT HAVE ...

CLEAR AIMS, MEASURABLE RESEARCH OUTCOMES, AND ALIGN WITH WESSEX'S NEEDS.

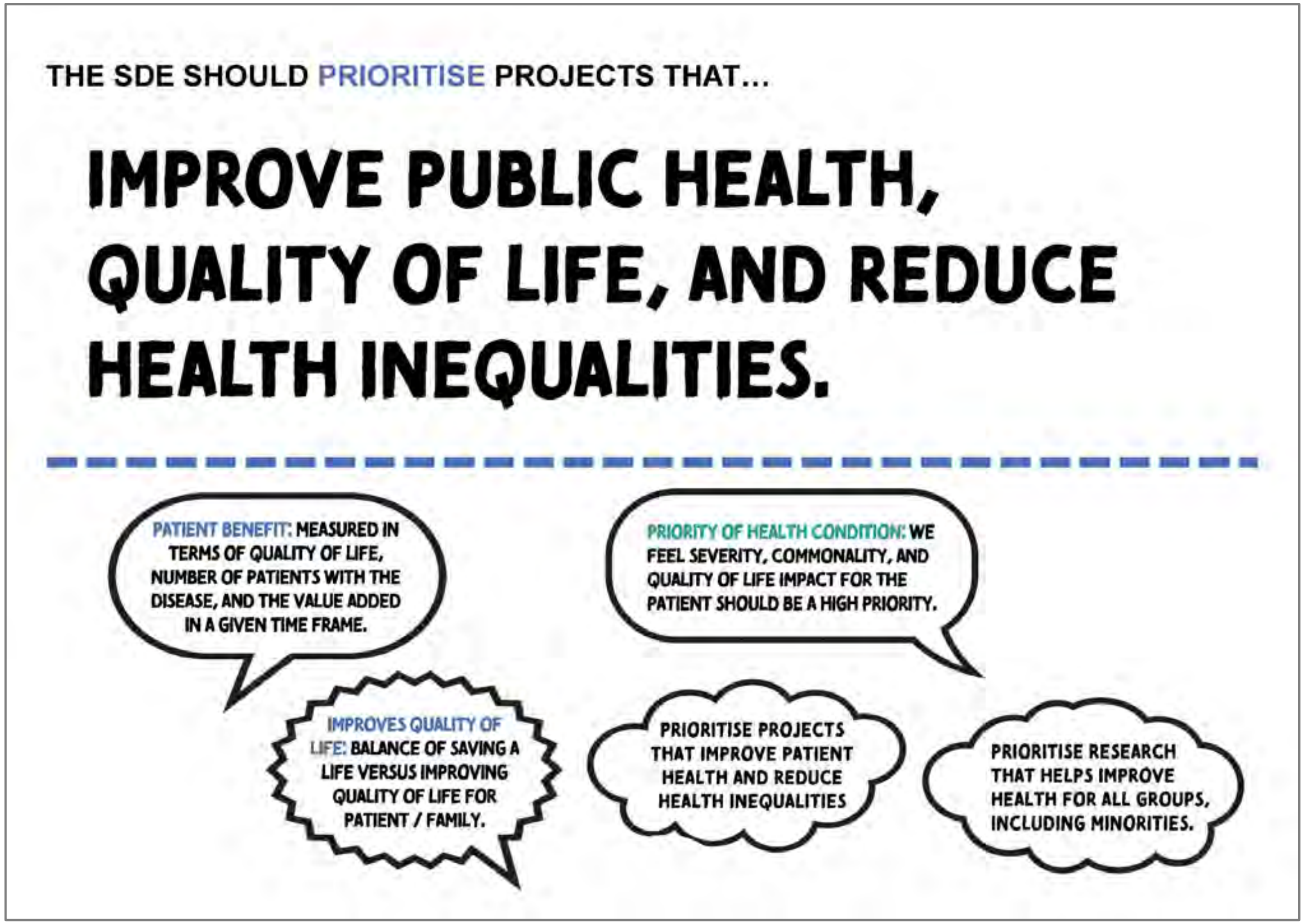
EVIDENTLY BENEFITS POPULATION: IN WESSEX AND NATIONWIDE, IF POSSIBLE. FOR EXAMPLE, WE SHOULD FOCUS ON THE AGEING POPULATION IN WESSEX.

CLEAR RESEARCH OBJECTIVE AND BENEFIT TO WESSEX: ENSURING POSITIVE OUTCOMES FOR LOCAL PEOPLE.

CLEAR RESEARCH QUESTION THAT HAS RELEVANCE: SOMETHING IS CLEARLY ARTICULATED AND MEASURABLE TO WESSEX IN TERMS OF SOCIAL, ECONOMIC, AND HEALTH IMPACTS.

CLEAR PROJECT VISION AND STATED AIM: PRIORITISE WELL-STRUCTURED PROJECTS WITH CLEARLY DEFINED GOALS AND MEASURABLE OUTCOMES

The **MEASURABLE** one



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.

The **QUALITY OF LIFE** one

THE SDE SHOULD PRIORITISE PROJECTS WHERE…

WESSEX GETS DIRECT AND INCLUSIVE HEALTH BENEFITS.

BENEFITS MOST PEOPLE IN WESSEX: GOOD PROJECTS ARE INCLUSIVE, COVER ALL DEMOGRAPHICS INCLUDING MINORITY GROUPS.

INCLUSIVE BENEFITS TO WESSEX: RIGHT BALANCE OF PROJECTS ACROSS WESSEX POPULATION THAT REFLECTS DIVERSITY.

DIRECT POSITIVE HEALTH BENEFITS TO WESSEX: IMPROVES POPULATION HEALTH AND REDUCES NHS COSTS.

BENEFIT TO PEOPLE OF WESSEX: WESSEX POPULATION NEEDS TO SEE THE BENEFIT (E.G. ACCURATE & EARLY DIAGNOSES) TO THEN FORM THEIR DATA TRUST.

The **EVERYONE WINS** one

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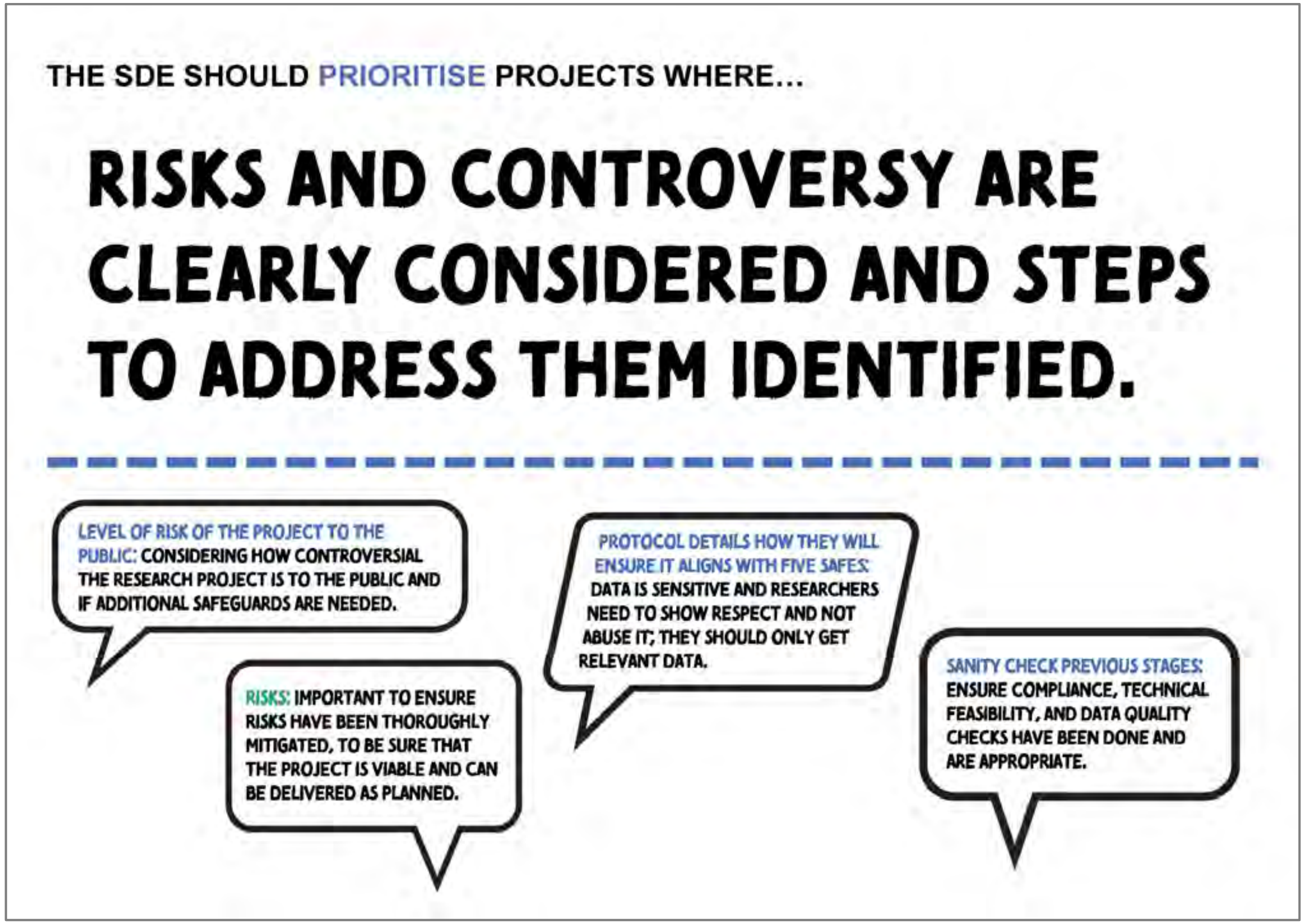

THE SDE SHOULD PRIORITISE PROJECTS WHERE...

RISKS AND CONTROVERSY ARE CLEARLY CONSIDERED AND STEPS TO ADDRESS THEM IDENTIFIED.

LEVEL OF RISK OF THE PROJECT TO THE PUBLIC: CONSIDERING HOW CONTROVERSIAL THE RESEARCH PROJECT IS TO THE PUBLIC AND IF ADDITIONAL SAFEGUARDS ARE NEEDED.

RISKS: IMPORTANT TO ENSURE RISKS HAVE BEEN THOROUGHLY MITIGATED, TO BE SURE THAT THE PROJECT IS VIABLE AND CAN BE DELIVERED AS PLANNED.

PROTOCOL DETAILS HOW THEY WILL ENSURE IT ALIGNS WITH FIVE SAFES: DATA IS SENSITIVE AND RESEARCHERS NEED TO SHOW RESPECT AND NOT ABUSE IT; THEY SHOULD ONLY GET RELEVANT DATA.

SANITY CHECK PREVIOUS STAGES: ENSURE COMPLIANCE, TECHNICAL FEASIBILITY, AND DATA QUALITY CHECKS HAVE BEEN DONE AND ARE APPROPRIATE.

The **RISKY** one

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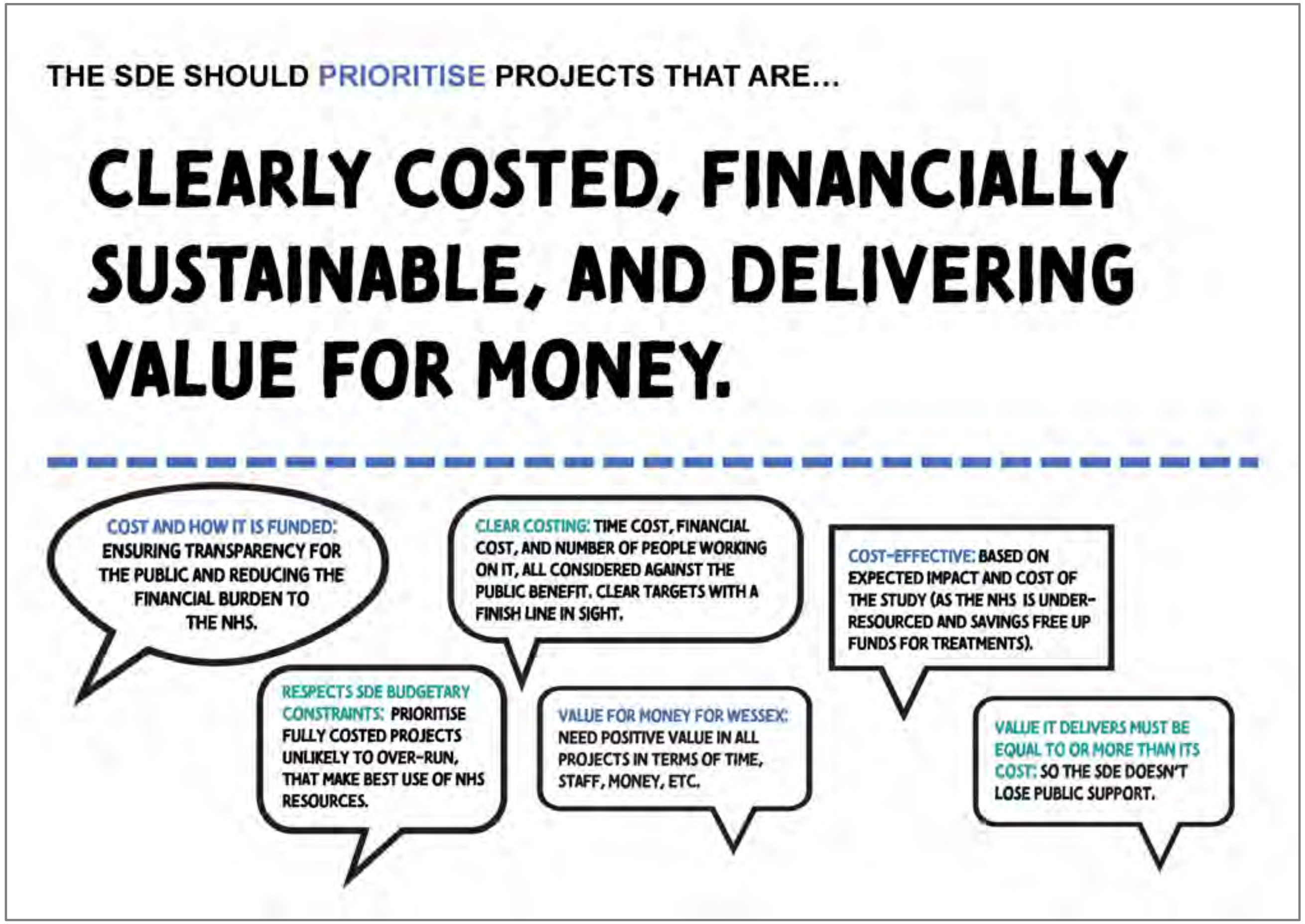


THE SDE SHOULD PRIORITISE PROJECTS THAT ARE...

CLEARLY COSTED, FINANCIALLY SUSTAINABLE, AND DELIVERING VALUE FOR MONEY.

COST AND HOW IT IS FUNDED: ENSURING TRANSPARENCY FOR THE PUBLIC AND REDUCING THE FINANCIAL BURDEN TO THE NHS.

CLEAR COSTING: TIME COST, FINANCIAL COST, AND NUMBER OF PEOPLE WORKING ON IT, ALL CONSIDERED AGAINST THE PUBLIC BENEFIT. CLEAR TARGETS WITH A FINISH LINE IN SIGHT.

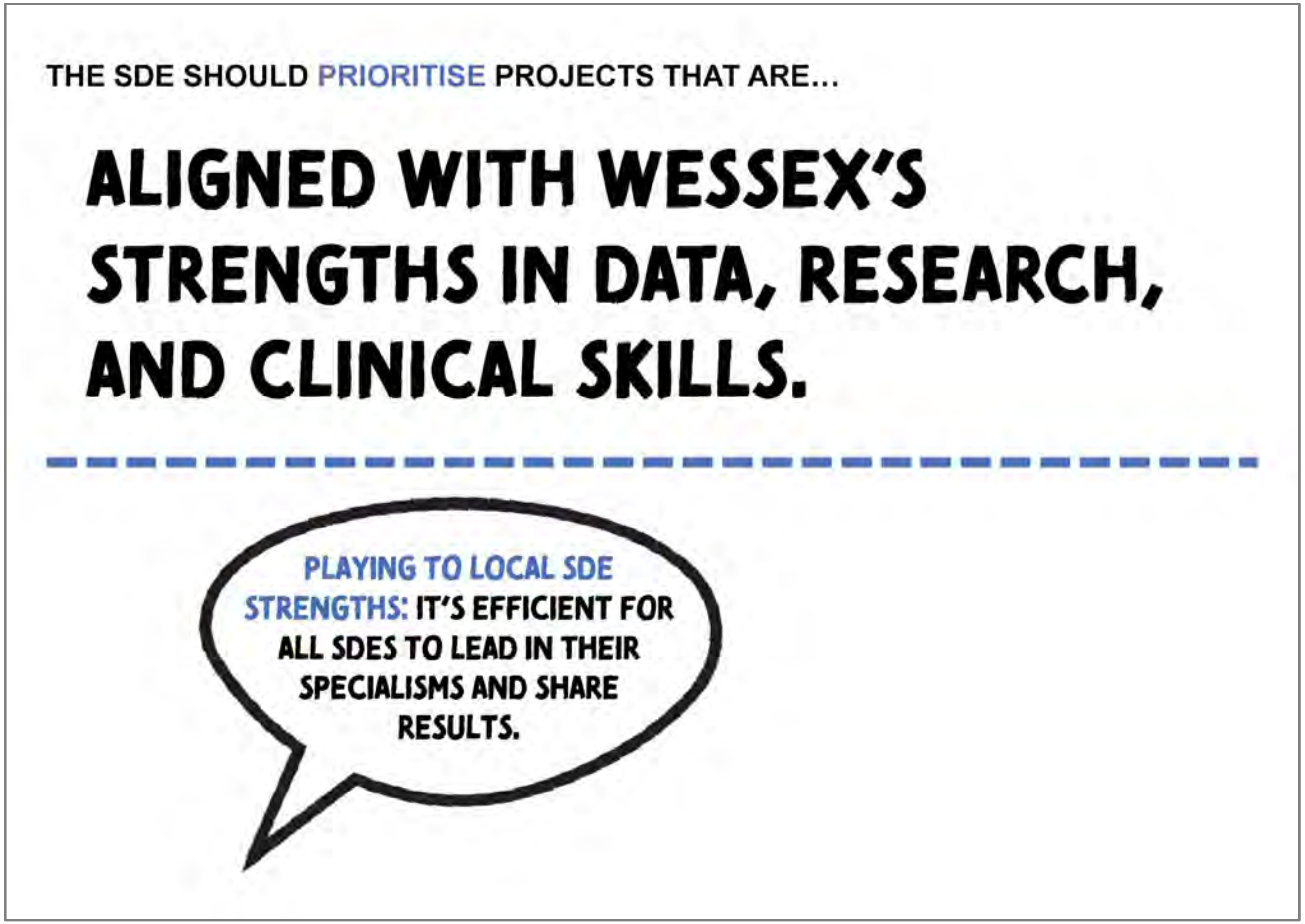
COST-EFFECTIVE: BASED ON EXPECTED IMPACT AND COST OF THE STUDY (AS THE NHS IS UNDER-RESOURCED AND SAVINGS FREE UP FUNDS FOR TREATMENTS).

RESPECTS SDE BUDGETARY CONSTRAINTS: PRIORITISE FULLY COSTED PROJECTS UNLIKELY TO OVER-RUN, THAT MAKE BEST USE OF NHS RESOURCES.

VALUE FOR MONEY FOR WESSEX: NEED POSITIVE VALUE IN ALL PROJECTS IN TERMS OF TIME, STAFF, MONEY, ETC.

VALUE IT DELIVERS MUST BE EQUAL TO OR MORE THAN ITS COST: SO THE SDE DOESN'T LOSE PUBLIC SUPPORT.

The **FINANCE** one



THE SDE SHOULD PRIORITISE PROJECTS THAT ARE...

ALIGNED WITH WESSEX'S STRENGTHS IN DATA, RESEARCH, AND CLINICAL SKILLS.

PLAYING TO LOCAL SDE STRENGTHS: IT'S EFFICIENT FOR ALL SDES TO LEAD IN THEIR SPECIALISMS AND SHARE RESULTS.

The **PLAY TO OUR STRENGTHS** one

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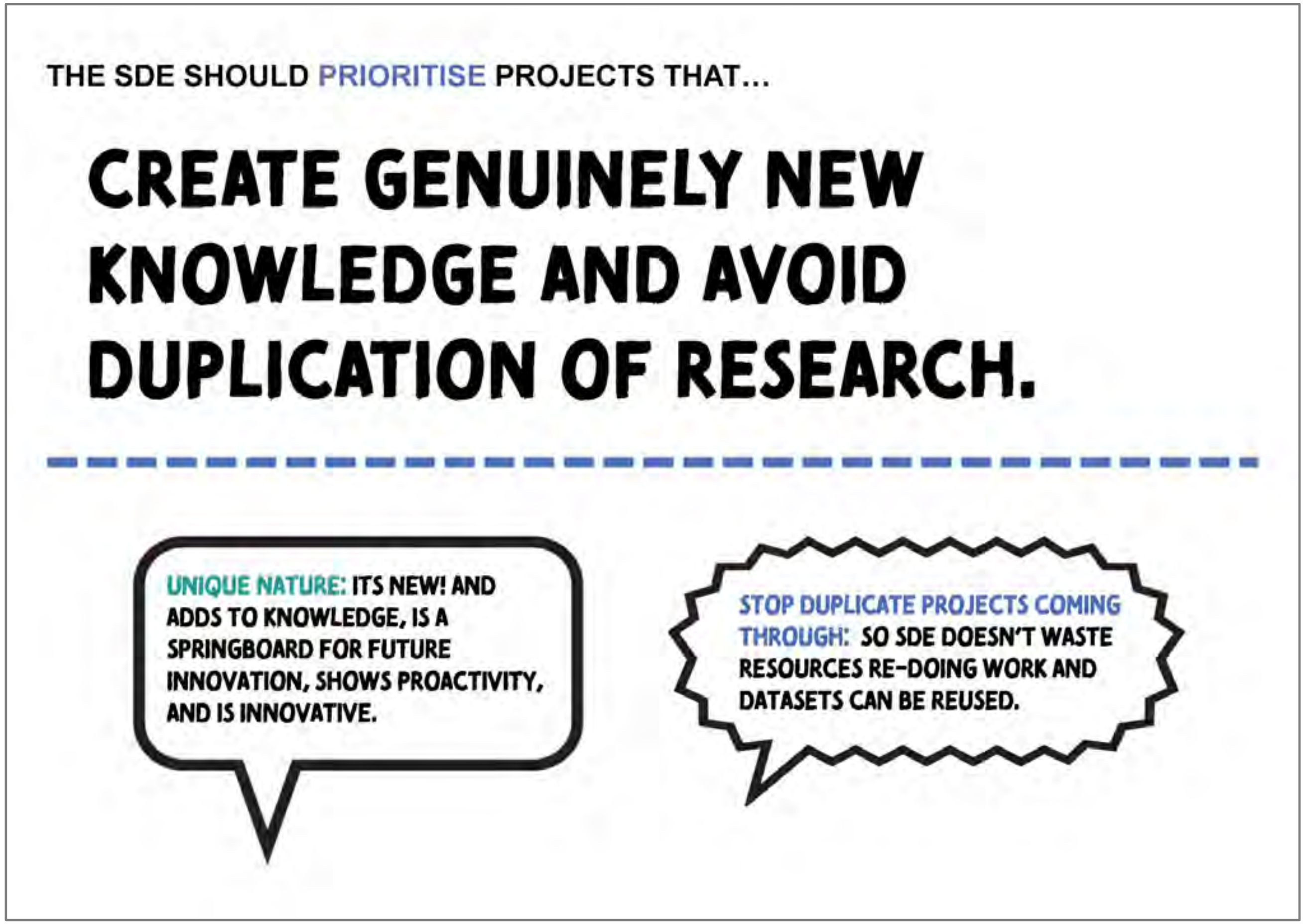


THE SDE SHOULD PRIORITISE PROJECTS THAT…

CREATE GENUINELY NEW KNOWLEDGE AND AVOID DUPLICATION OF RESEARCH.

UNIQUE NATURE: ITS NEW! AND ADDS TO KNOWLEDGE, IS A SPRINGBOARD FOR FUTURE INNOVATION, SHOWS PROACTIVITY, AND IS INNOVATIVE.

STOP DUPLICATE PROJECTS COMING THROUGH: SO SDE DOESN'T WASTE RESOURCES RE-DOING WORK AND DATASETS CAN BE REUSED.

The **INNOVATIVE** one

THE SDE SHOULD PRIORITISE PROJECTS THAT...

CREATE A REVENUE STREAM FOR THE NHS INTO THE FUTURE.

CREATES A REVENUE STREAM: HELPS IMPROVE THE NHS IN THE FUTURE.

The **MONEY MAKING** one

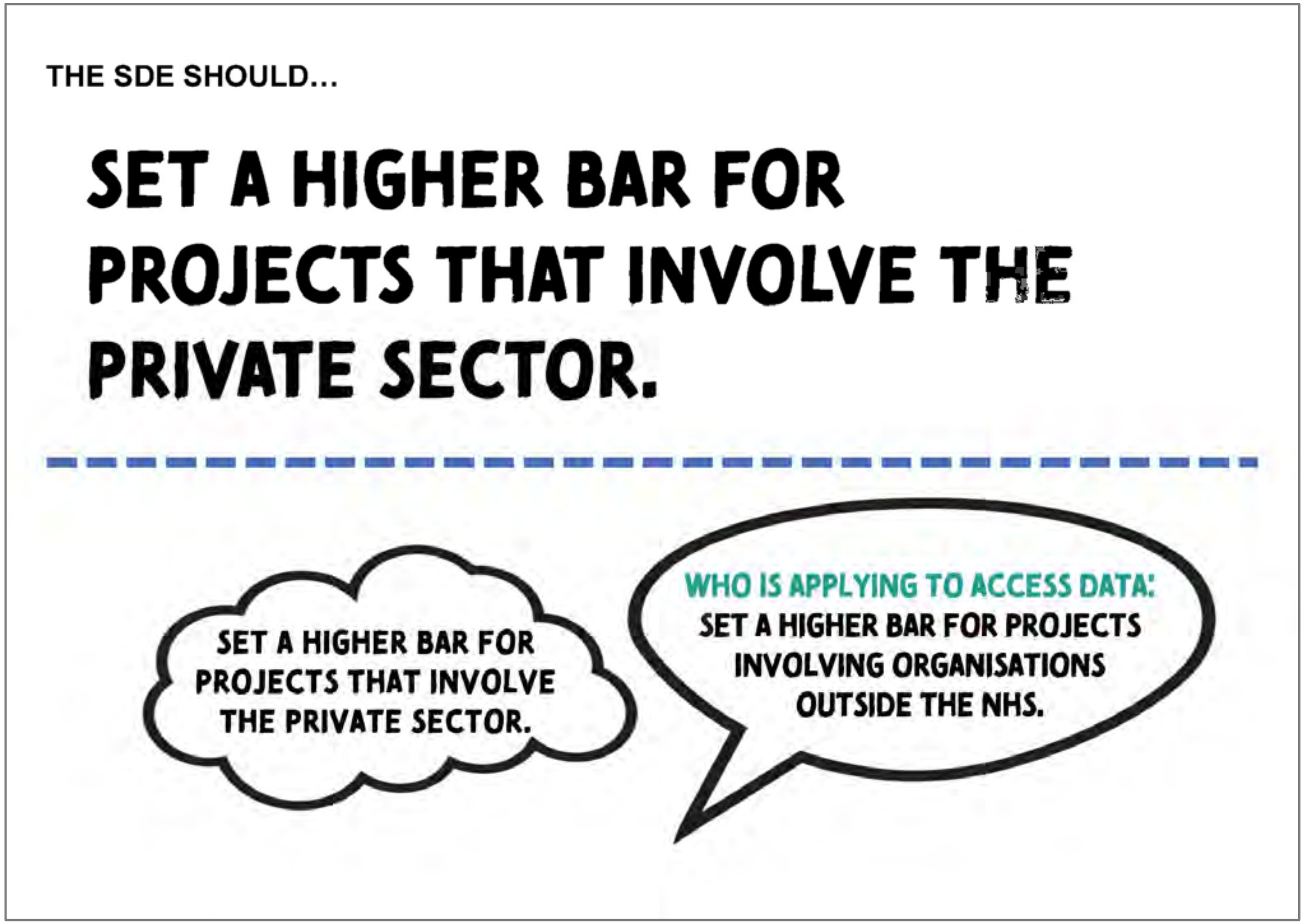
THE SDE SHOULD…

ENFORCE HIGHER STANDARDS FOR RESEARCH WITH LOW-QUALITY OR SENSITIVE DATA.

SENSITIVITY & RESOURCE NEEDS OF THE PROJECT: THE SDE HAS ENOUGH GOOD QUALITY DATA AND RESOURCES TO GET GOOD RESULTS.

ENFORCE HIGHER STANDARDS FOR RESEARCH WITH LOW-QUALITY OR SENSITIVE DATA.

The **SENSITIVE** one



THE SDE SHOULD...

SET A HIGHER BAR FOR PROJECTS THAT INVOLVE THE PRIVATE SECTOR.

SET A HIGHER BAR FOR PROJECTS THAT INVOLVE THE PRIVATE SECTOR.

WHO IS APPLYING TO ACCESS DATA:
SET A HIGHER BAR FOR PROJECTS INVOLVING ORGANISATIONS OUTSIDE THE NHS.

The **PRIVATE SECTOR** one

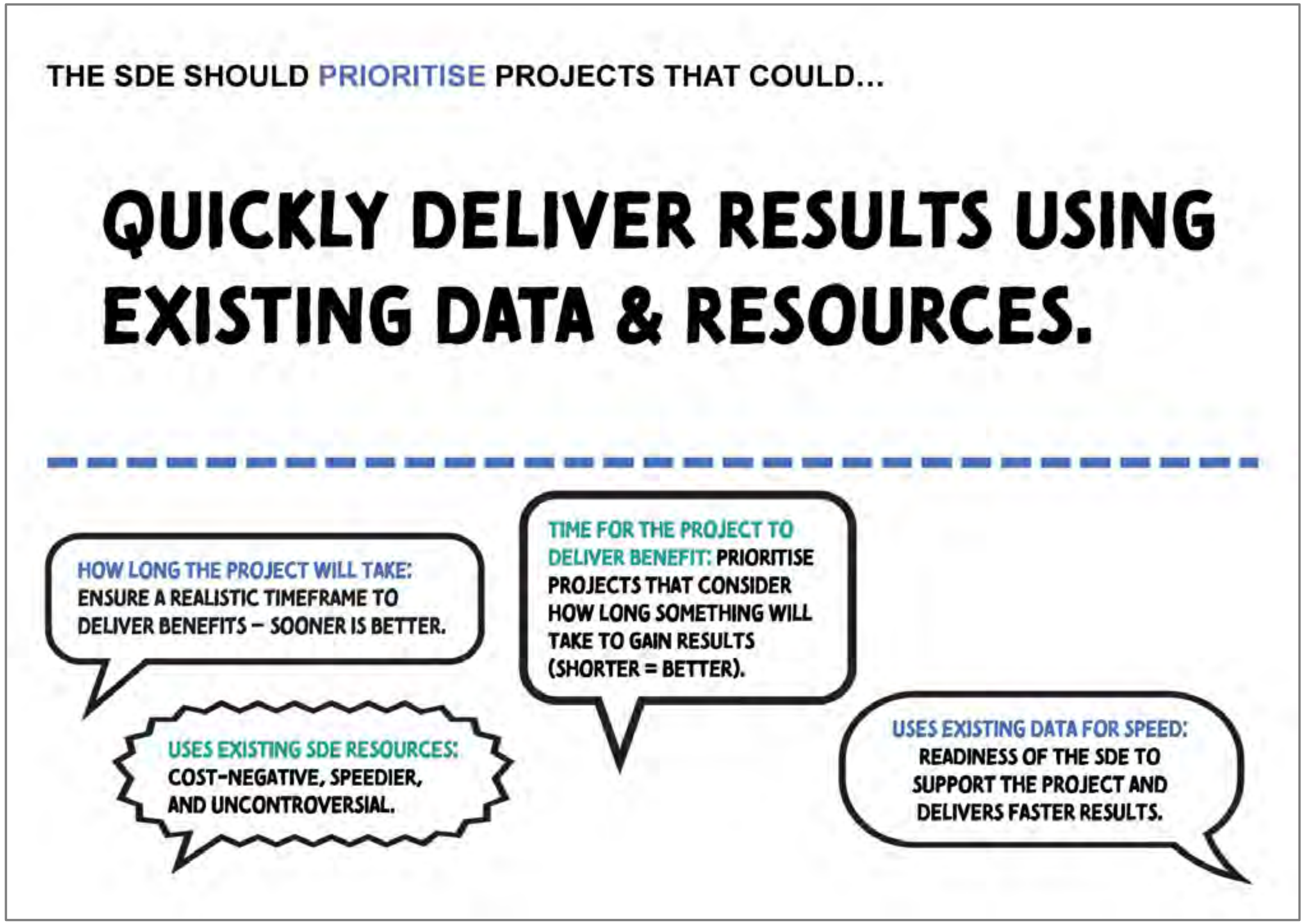
THE SDE SHOULD PRIORITISE PROJECTS THAT OFFER…

A PUBLIC BENEFIT THAT WOULD RAISE AWARENESS OF THE SDE AND WIN HEARTS AND MINDS.

BENEFITS A LARGE AMOUNT OF THE POPULATION: REDUCE HOSPITAL ADMISSIONS AND RAISE AWARENESS – MORE PEOPLE WILL BE IMPRESSED.

CREATE A GOOD NEWS STORY: WINNING HEARTS AND MINDS.

The **GOOD NEWS** one



THE SDE SHOULD PRIORITISE PROJECTS THAT COULD…

QUICKLY DELIVER RESULTS USING EXISTING DATA & RESOURCES.

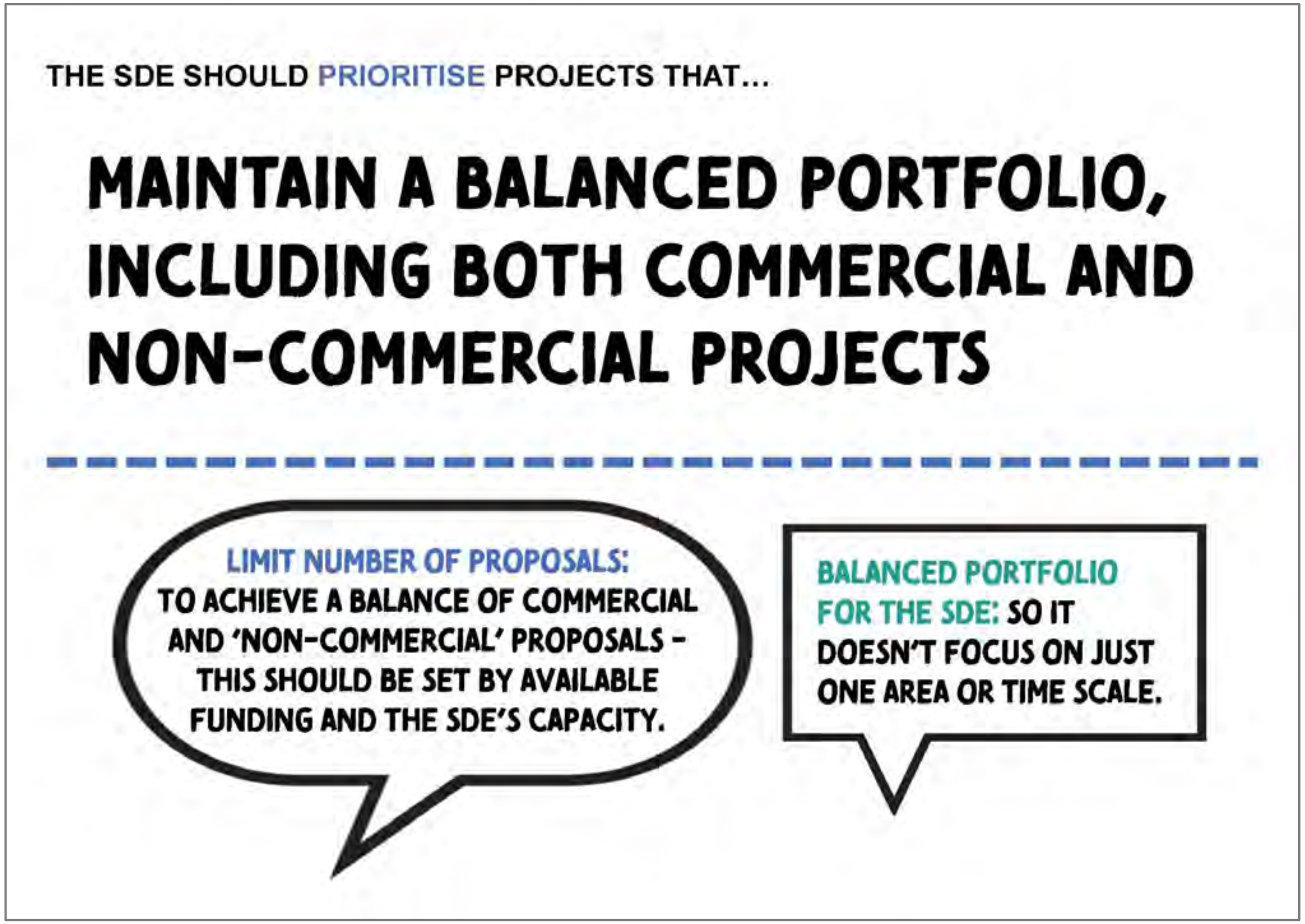
HOW LONG THE PROJECT WILL TAKE: ENSURE A REALISTIC TIMEFRAME TO DELIVER BENEFITS – SOONER IS BETTER.

TIME FOR THE PROJECT TO DELIVER BENEFIT: PRIORITISE PROJECTS THAT CONSIDER HOW LONG SOMETHING WILL TAKE TO GAIN RESULTS (SHORTER = BETTER).

USES EXISTING SDE RESOURCES: COST-NEGATIVE, SPEEDIER, AND UNCONTROVERSIAL.

USES EXISTING DATA FOR SPEED: READINESS OF THE SDE TO SUPPORT THE PROJECT AND DELIVERS FASTER RESULTS.

The **QUICK** one



THE SDE SHOULD PRIORITISE PROJECTS THAT…

MAINTAIN A BALANCED PORTFOLIO, INCLUDING BOTH COMMERCIAL AND NON-COMMERCIAL PROJECTS

LIMIT NUMBER OF PROPOSALS: TO ACHIEVE A BALANCE OF COMMERCIAL AND 'NON-COMMERCIAL' PROPOSALS - THIS SHOULD BE SET BY AVAILABLE FUNDING AND THE SDE'S CAPACITY.

BALANCED PORTFOLIO FOR THE SDE: SO IT DOESN'T FOCUS ON JUST ONE AREA OR TIME SCALE.

The **BALANCED** one

THE SDE SHOULD PRIORITISE PROJECTS THAT...

SAVE THE NHS MONEY THROUGH PREVENTION AND LONG-TERM HEALTH IMPROVEMENTS.

EXPECTED OUTCOMES WITH PREVENTATIVE FOCUS: THIS IS COST EFFECTIVE FOR THE NHS, HAS ECONOMIC IMPACT, AND HAS BIG POTENTIAL TO SAVE LIVES (E.G. VACCINES).

PRIORITISE PROJECTS THAT SAVE NHS MONEY WHILE MAINTAINING QUALITY CARE.

PRIORITISE PROJECTS WITH LONG-TERM PUBLIC HEALTH BENEFITS.

The **MONEY SAVING**
one

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Plenary Exercise:

Ranking the Strategic Priorities.

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Break

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Exercise 6:

Defining the Strategic Priorities.

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Plenary Exercise:

Opportunity to review the proposed Strategic Priorities text.

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Exercise 7:

Finalise the Strategic Priorities.

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What happens next?

Chris Kipps

Next steps

- Team will consolidate the learnings from the Public Panel into a formal report (est. November).
- Report available on the website along with easy read headlines and an executive summary – we will send to you if you would like.
- Wessex Big Conversation to be held in the Autumn / Winter 2024.
- Recommendations embedded in the design and operation of the SDE.
- Future opportunities to be involved – watch for the post-event email!

R: Session 4 Practical Guide to Collateral

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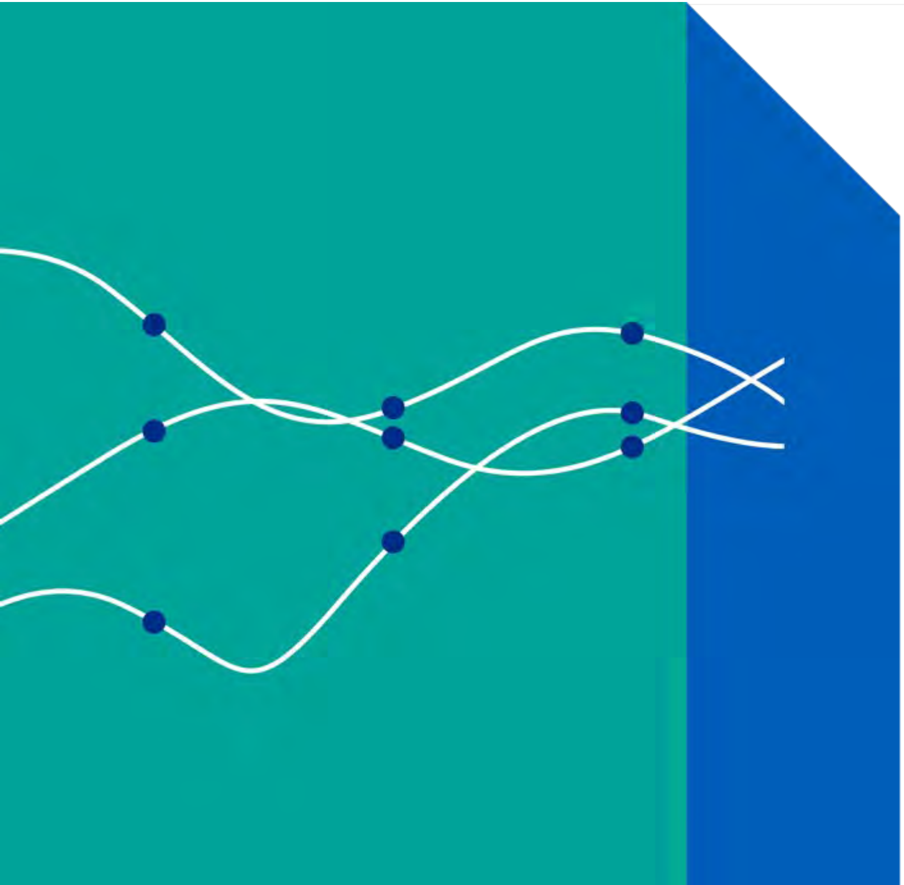
Practical guide to collateral

Wessex Public Panel on NHS Data: Day 4



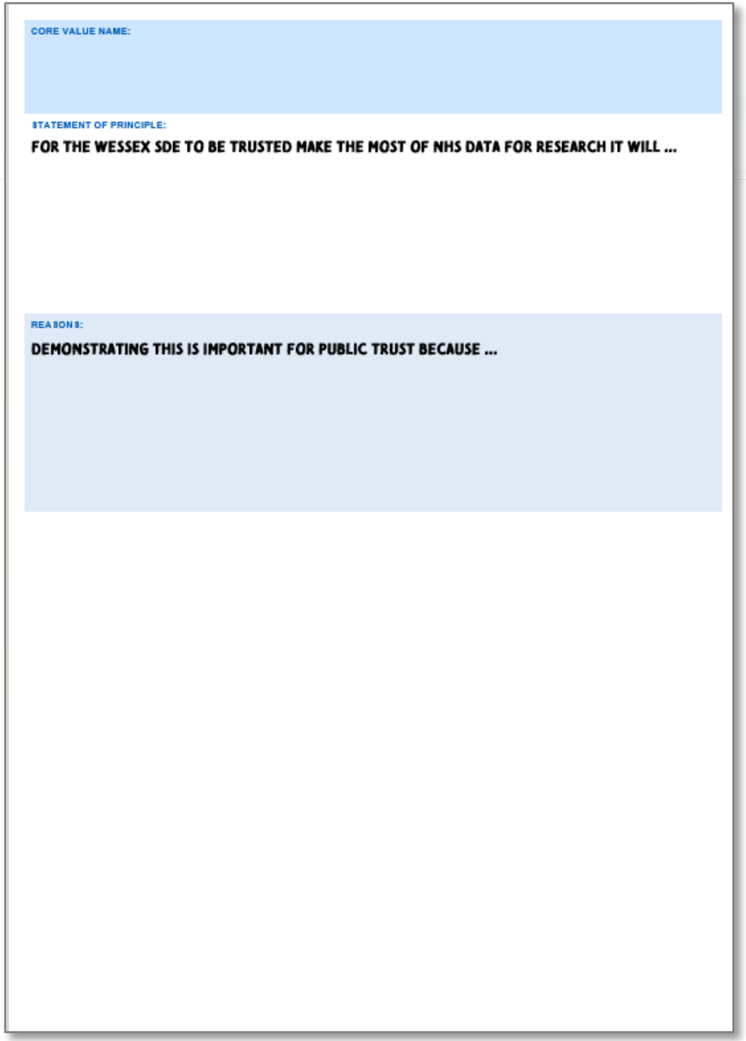
Core values exercises

Day 4

Facilitation preparation

All tables will be given an A1 sheet of paper that looks like this (see right)

The aim is to replace the top half of the “Core values” boards we will supply participants with this the top-half of this sheet once complete.



CORE VALUE NAME:

STATEMENT OF PRINCIPLE:

FOR THE WESSEX SDE TO BE TRUSTED MAKE THE MOST OF NHS DATA FOR RESEARCH IT WILL ...

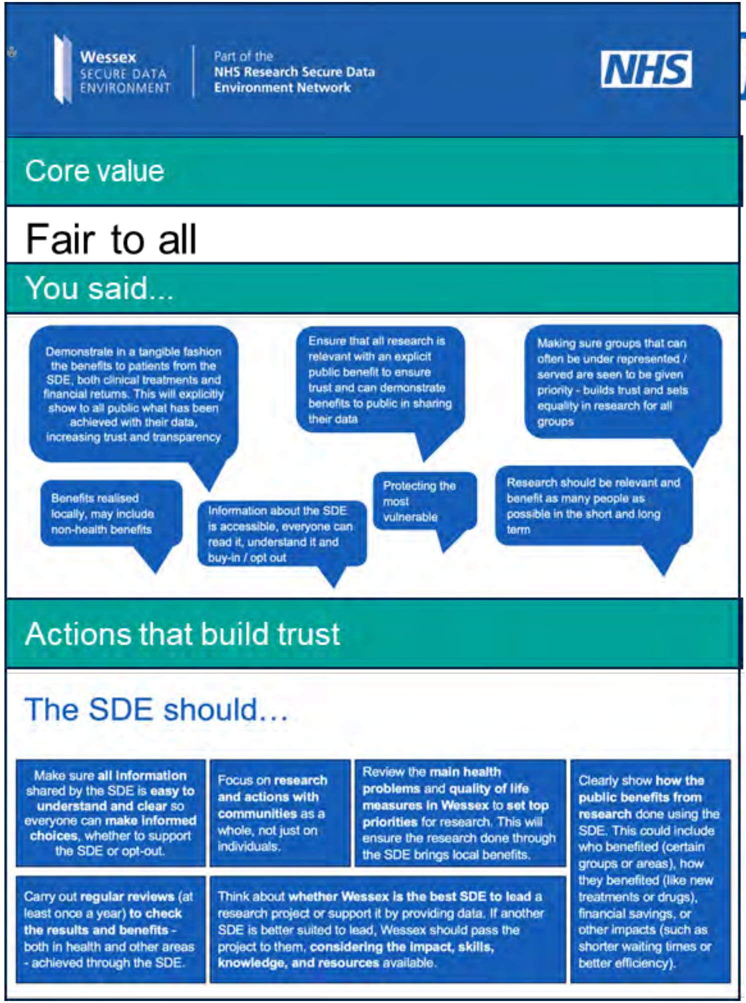
REASONS:

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Step 0: Activity stimulus

Each group will be allocated one the core values stimulus boards.

[15 mins]



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Core value

Fair to all

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 all public what has been achieved with their data, increasing trust and transparency
- Ensure that all research is relevant with an explicit public benefit to ensure trust and can demonstrate benefits to public in sharing their data
- Making sure groups that can often be under represented / served are seen to be given priority - builds trust and sets equality in research for all groups
- Benefits realised locally, may include non-health benefits
- Information about the SDE is accessible, everyone can read it, understand it and buy-in / opt out
- Protecting the most vulnerable
- Research should be relevant and benefit as many people as possible in the short and long term

Actions that build trust

The SDE should…

- Make sure **all information** shared by the SDE is **easy to understand and clear** so everyone can **make informed choices**, whether to support the SDE or opt-out.
- Focus on **research and actions with communities** as a whole, not just on individuals.
- Review the **main health problems** and **quality of life measures in Wessex** to **set top priorities** for research. This will ensure the research done through the SDE brings local benefits.
- Clearly show **how the public benefits from research** done using the SDE. This could include who benefited (certain groups or areas), how they benefited (like new treatments or drugs), financial savings, or other impacts (such as shorter waiting times or better efficiency).
- Carry out **regular reviews** (at least once a year) **to check the results and benefits** - both in health and other areas - achieved through the SDE.
- Think about **whether Wessex is the best SDE to lead** a research project or support it by providing data. If another SDE is better suited to lead, Wessex should pass the project to them, **considering the impact, skills, knowledge, and resources** available.

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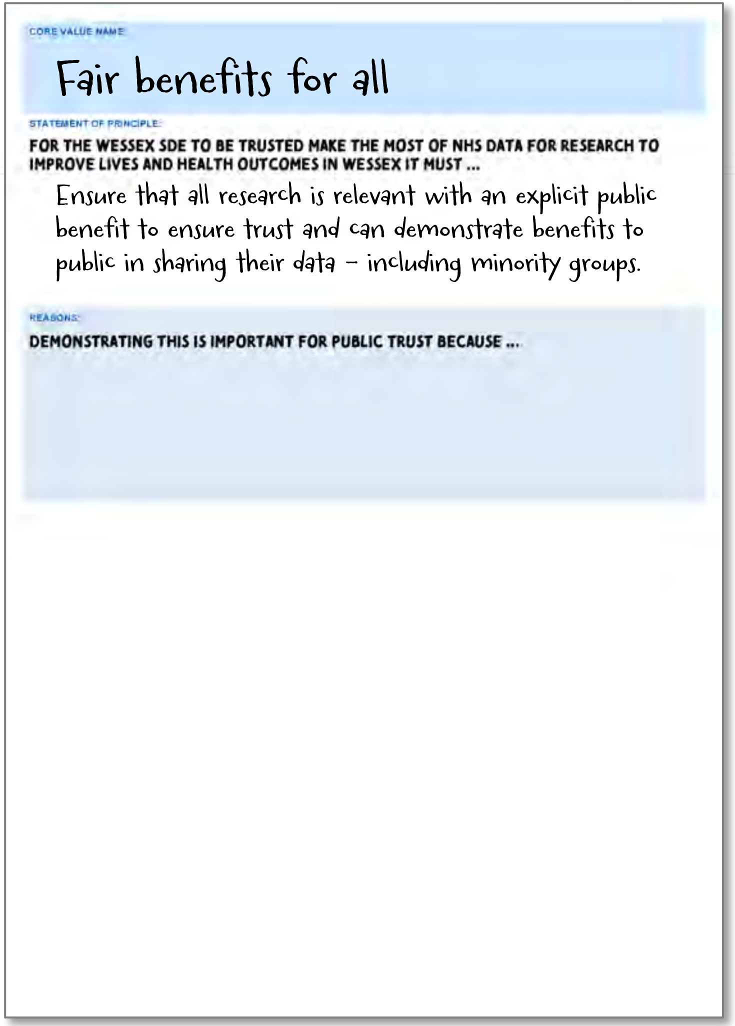
Step 1: Writing a title and a statement of principle

Participants will work on their tables with some rough paper and once they are happy with what they have got, they will write up a "Core value name" and complete the sentence started in the "Statement of principle" box.



CORE VALUE NAME:

Fair benefits for all

STATEMENT OF PRINCIPLE:

FOR THE WESSEX SDE TO BE TRUSTED MAKE THE MOST OF NHS DATA FOR RESEARCH TO IMPROVE LIVES AND HEALTH OUTCOMES IN WESSEX IT MUST ...

Ensure that all research is relevant with an explicit public benefit to ensure trust and can demonstrate benefits to public in sharing their data – including minority groups.

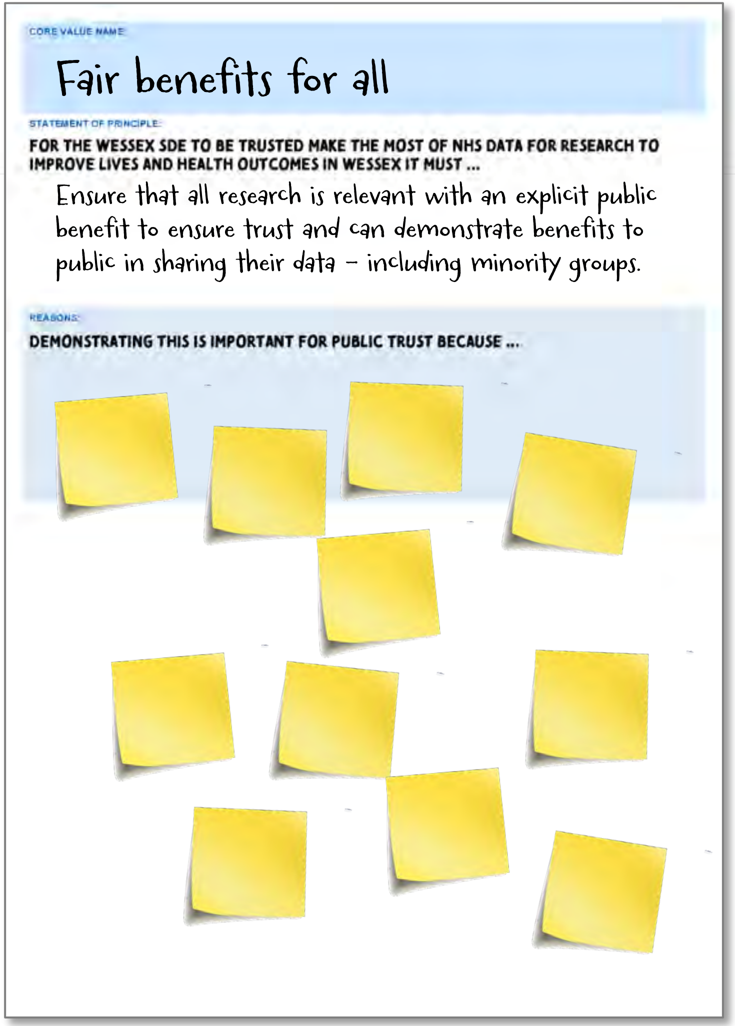
REASONS:

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Step 2: Plenary exercise – Why is this important?

Members will be invited to move between the boards and, using post-it notes, share their ideas with the group that is 'holding' that board.

These can be added anywhere on the bottom ¾ of the board.



CORE VALUE NAME:

Fair benefits for all

STATEMENT OF PRINCIPLE:

FOR THE WESSEX SDE TO BE TRUSTED MAKE THE MOST OF NHS DATA FOR RESEARCH TO IMPROVE LIVES AND HEALTH OUTCOMES IN WESSEX IT MUST ...

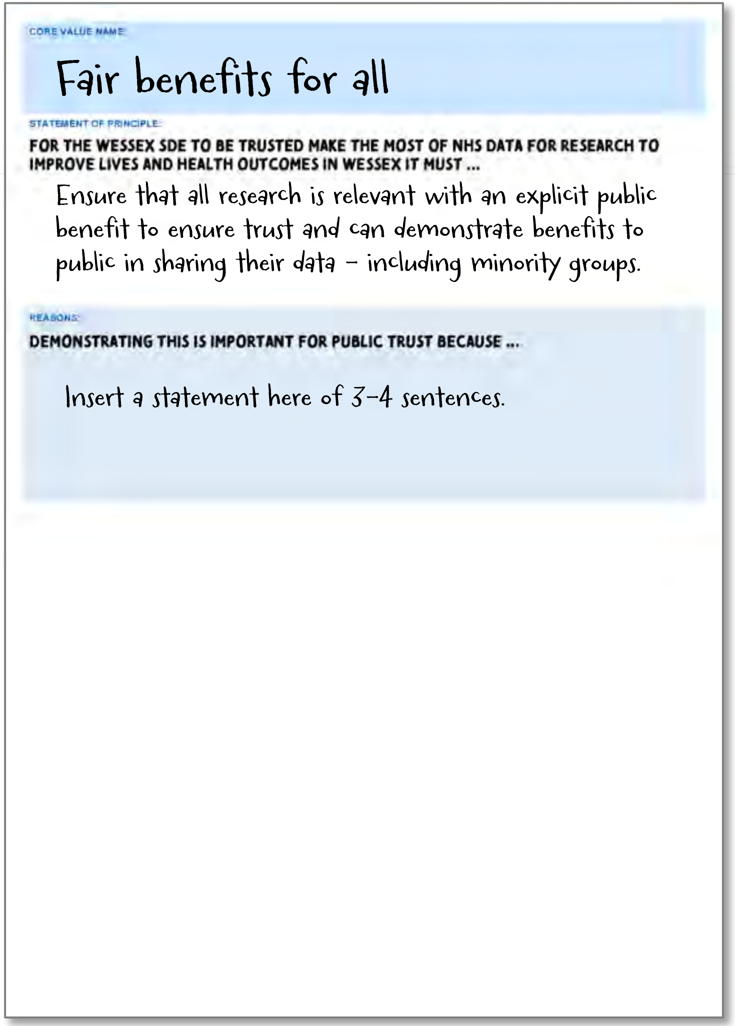
Ensure that all research is relevant with an explicit public benefit to ensure trust and can demonstrate benefits to public in sharing their data – including minority groups.

REASONS:

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Step 3: Group owning the board theme sorts post-its

The group allocated to each board will collect and review the suggestions, grouping and theming them – and organising this content **on a separate sheet.**



CORE VALUE NAME:

Fair benefits for all

STATEMENT OF PRINCIPLE:

FOR THE WESSEX SDE TO BE TRUSTED MAKE THE MOST OF NHS DATA FOR RESEARCH TO IMPROVE LIVES AND HEALTH OUTCOMES IN WESSEX IT MUST ...

Ensure that all research is relevant with an explicit public benefit to ensure trust and can demonstrate benefits to public in sharing their data – including minority groups.

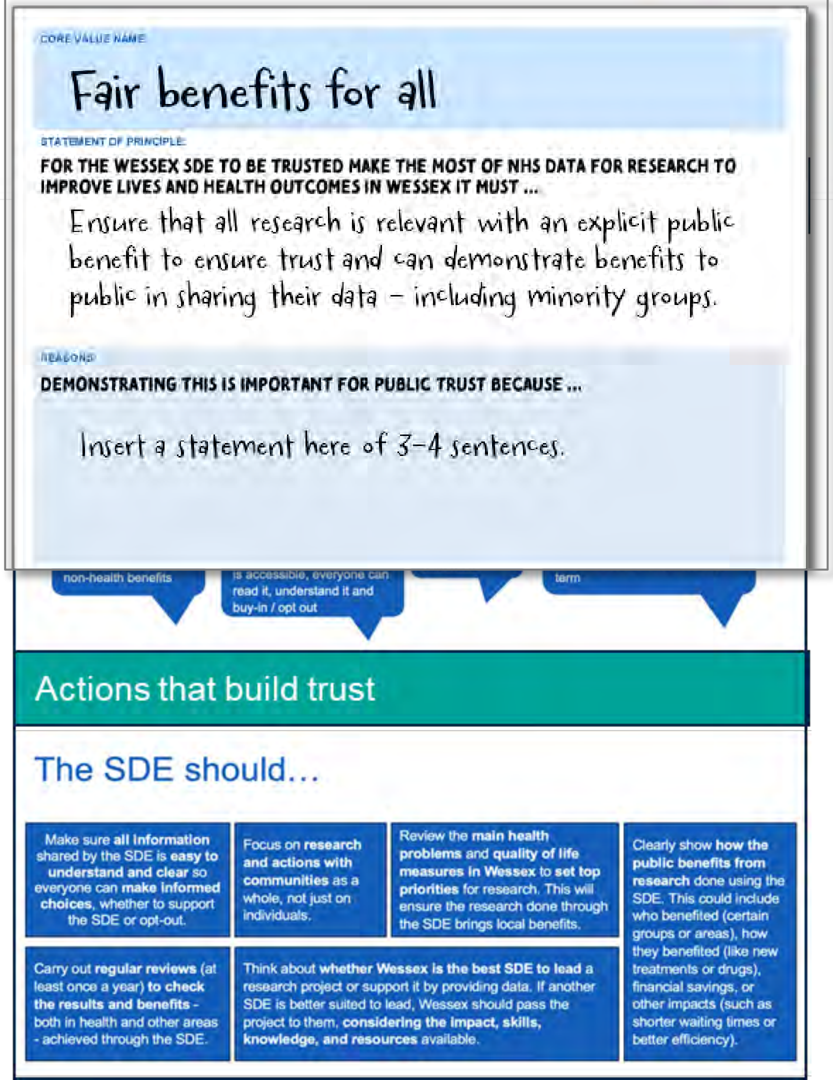
REASONS:

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Insert a statement here of 3-4 sentences.

Step 5: Update the core values boards

Groups fold the A1 sheet in half and stick the top half over the top of the foam boards.



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REASONS:

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Insert a statement here of 3–4 sentences.

non-health benefits

is accessible, everyone can read it, understand it and buy-in / opt out

term

Actions that build trust

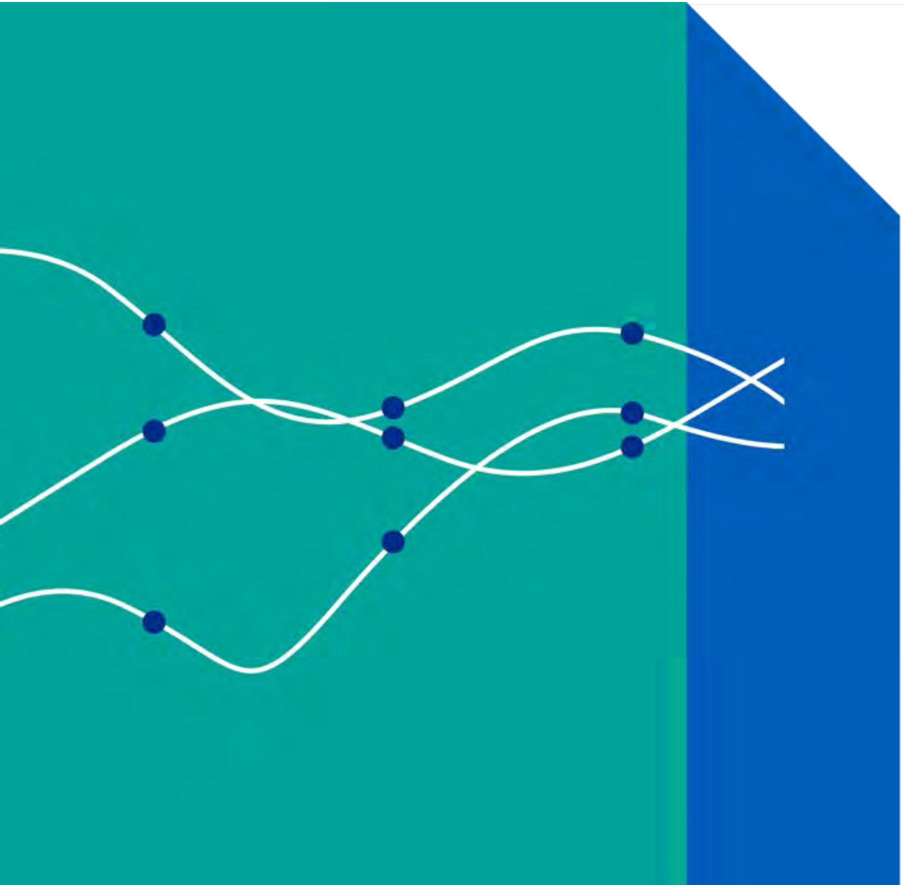
The SDE should…

- Make sure **all information** shared by the SDE is **easy to understand and clear** so everyone can **make informed choices**, whether to support the SDE or opt-out.
- Focus on **research and actions with communities** as a whole, not just on individuals.
- Review the **main health problems** and **quality of life measures in Wessex** to **set top priorities** for research. This will ensure the research done through the SDE brings local benefits.
- Clearly show **how the public benefits from research** done using the SDE. This could include who benefited (certain groups or areas), how they benefited (like new treatments or drugs), financial savings, or other impacts (such as shorter waiting times or better efficiency).
- Carry out **regular reviews** (at least once a year) **to check the results and benefits** - both in health and other areas - achieved through the SDE.
- Think about **whether Wessex is the best SDE to lead** a research project or support it by providing data. If another SDE is better suited to lead, Wessex should pass the project to them, **considering the impact, skills, knowledge, and resources** available.

Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS



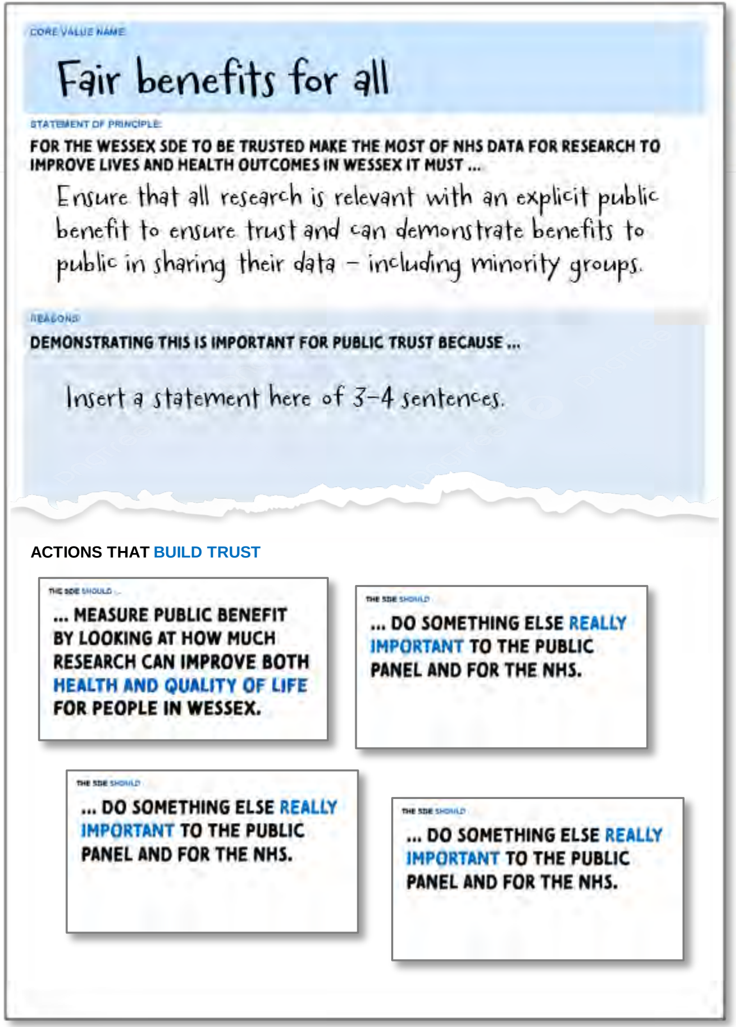
Actions to build trust exercises

Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

Facilitator preparation

By the end of the previous exercise facilitators should have a board that looks like this.



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Ensure that all research is relevant with an explicit public benefit to ensure trust and can demonstrate benefits to public in sharing their data – including minority groups.

REASONS:

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Insert a statement here of 3-4 sentences.

ACTIONS THAT BUILD TRUST

THE SDE SHOULD ...

... MEASURE PUBLIC BENEFIT BY LOOKING AT HOW MUCH RESEARCH CAN IMPROVE BOTH HEALTH AND QUALITY OF LIFE FOR PEOPLE IN WESSEX.

THE SDE SHOULD

... DO SOMETHING ELSE REALLY IMPORTANT TO THE PUBLIC PANEL AND FOR THE NHS.

THE SDE SHOULD

... DO SOMETHING ELSE REALLY IMPORTANT TO THE PUBLIC PANEL AND FOR THE NHS.

THE SDE SHOULD

... DO SOMETHING ELSE REALLY IMPORTANT TO THE PUBLIC PANEL AND FOR THE NHS.

Step 0: Stimulus materials

The bottom half of each of the core principles boards will have a series of three to four A5 cards with statements like those shown right. These will have been drafted by the PPIE team having reviewed the Public Panel events so far.

The reverse side of each card will be a blank version, so that if participants wish to revise the wording in response to feedback from the rest of the group they can do so.

Additional cards that are blank on both sides will be provided.

FRONT

THE SDE SHOULD ...

... MEASURE PUBLIC BENEFIT BY LOOKING AT HOW MUCH RESEARCH CAN IMPROVE BOTH HEALTH AND QUALITY OF LIFE FOR PEOPLE IN WESSEX.

BACK

THE SDE SHOULD ...

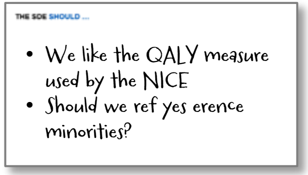
[30 mins]

Step 1: What would 'good' look like in practice?

Public participants will consider the actions that build trust on the bottom of their allocated board.

They consider whether what is already agreed is enough to demonstrate delivering on this value and/or what else should be added (the 3-4 'should' cards).

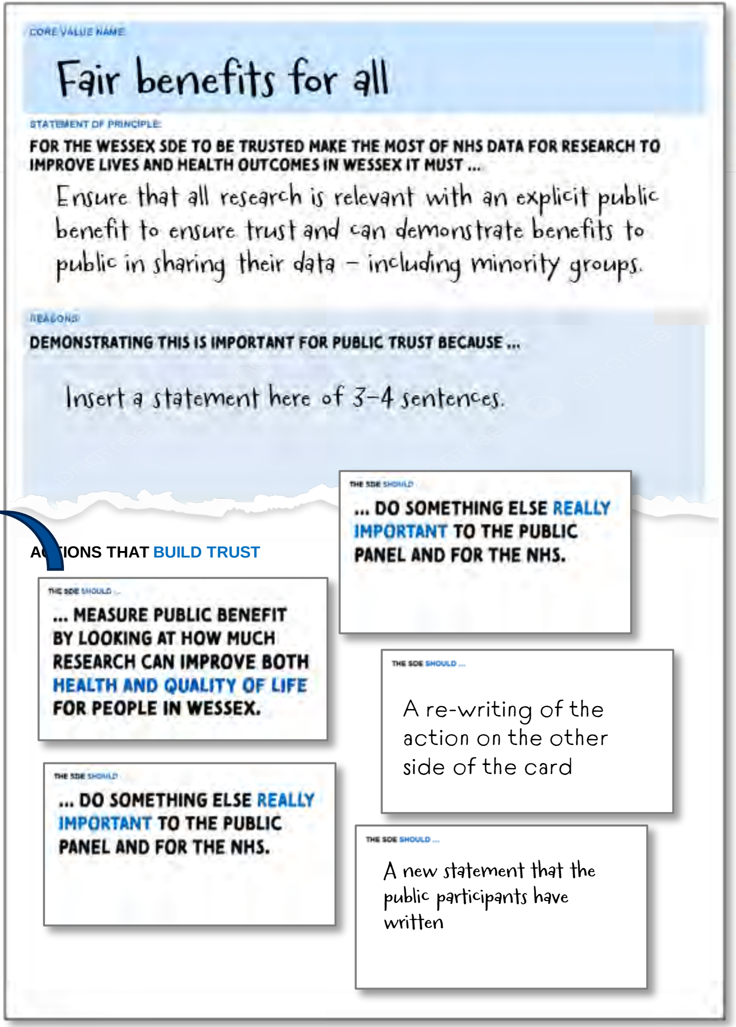
They can either (1) leave the cards as they are; (2) leave them – as expressing the action they want – and add their own comments on the back; (3) rewrite the cards on a new blank one; or (4) add a new card.



THE SDE SHOULD ...

- We like the QALY measure used by the NICE
- Should we ref yes erence minorities?

REVERSE



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REASONS

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Insert a statement here of 3-4 sentences.

ACTIONS THAT BUILD TRUST

THE SDE SHOULD

... DO SOMETHING ELSE REALLY IMPORTANT TO THE PUBLIC PANEL AND FOR THE NHS.

THE SDE SHOULD ...

... MEASURE PUBLIC BENEFIT BY LOOKING AT HOW MUCH RESEARCH CAN IMPROVE BOTH HEALTH AND QUALITY OF LIFE FOR PEOPLE IN WESSEX.

THE SDE SHOULD ...

A re-writing of the action on the other side of the card

THE SDE SHOULD

... DO SOMETHING ELSE REALLY IMPORTANT TO THE PUBLIC PANEL AND FOR THE NHS.

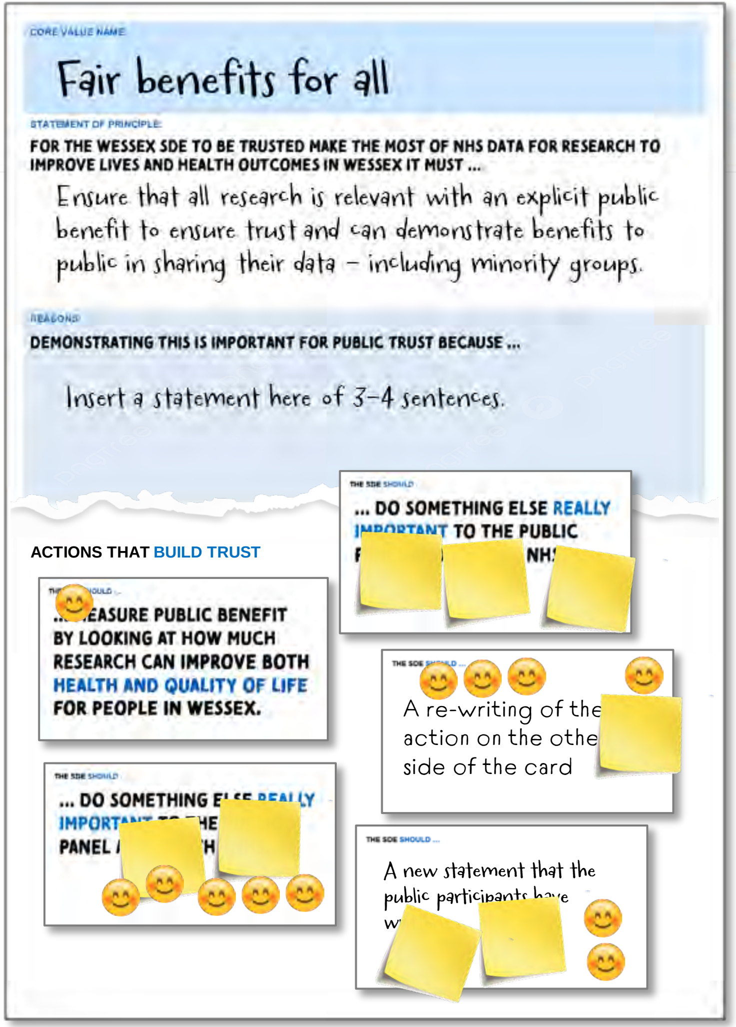
THE SDE SHOULD ...

A new statement that the public participants have written

Step 2: Plenary – Suggestions for improvement or addition?

Members will again move between the boards adding 'smiley faces' to parts of the text they really like and post-its making constructive suggestions for refinement or anything missing (but not substantive change).

[25 mins]



CORE VALUE NAME

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STATEMENT OF PRINCIPLE

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Ensure that all research is relevant with an explicit public benefit to ensure trust and can demonstrate benefits to public in sharing their data – including minority groups.

REASONS

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Insert a statement here of 3-4 sentences.

ACTIONS THAT **BUILD TRUST**

THE SDE SHOULD ...
... DO SOMETHING ELSE REALLY IMPORTANT TO THE PUBLIC
NHS

...EASURE PUBLIC BENEFIT BY LOOKING AT HOW MUCH RESEARCH CAN IMPROVE BOTH HEALTH AND QUALITY OF LIFE FOR PEOPLE IN WESSEX.

THE SDE SHOULD ...
A re-writing of the action on the othe side of the card

THE SDE SHOULD ...
... DO SOMETHING E LY
IMPORT HE
PANEL H

THE SDE SHOULD ...
A new statement that the public participants have

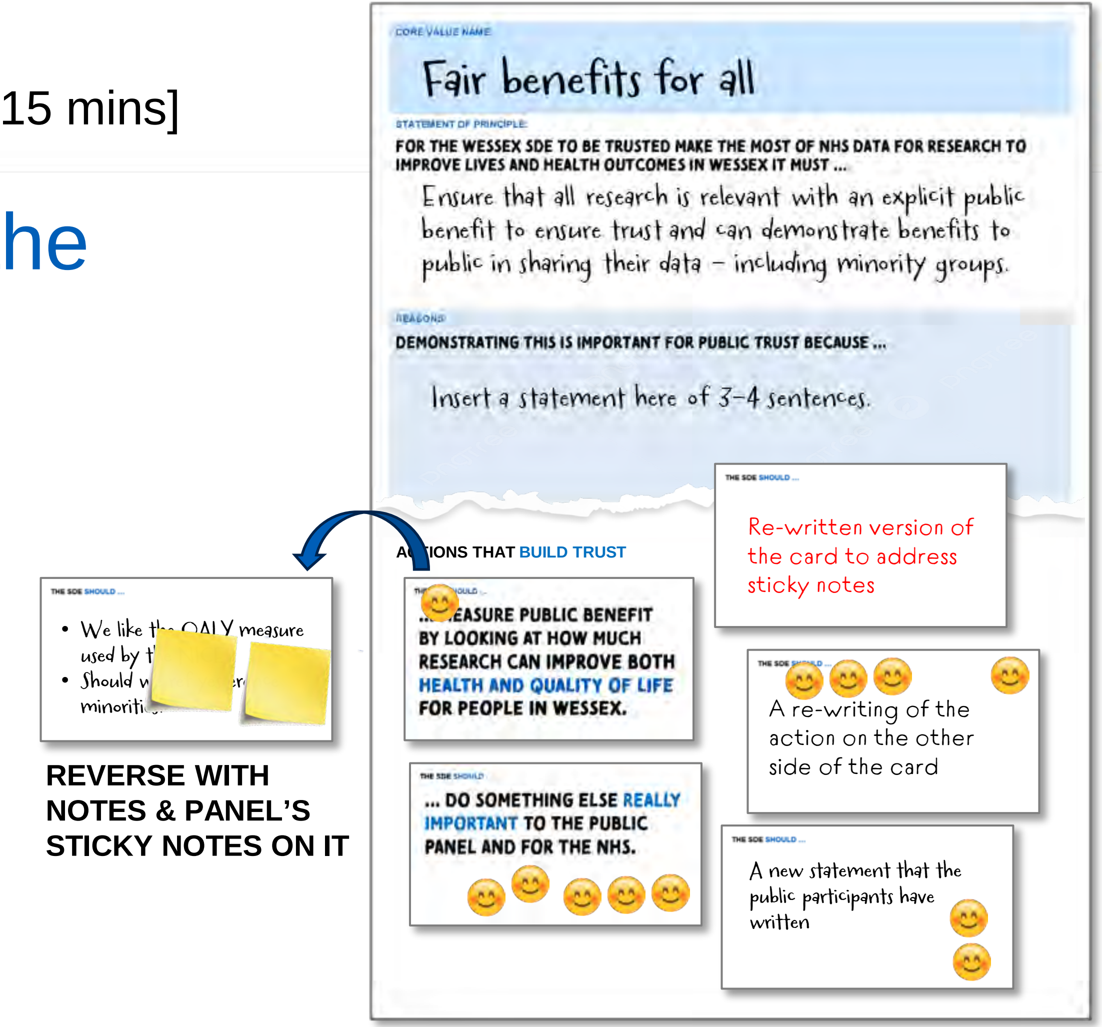
[15 mins]

Step 3: Finalising the boards

The group owning the board reviews the comments and smileys and finalises the cards to reflect these comments where necessary.

Whether or not the table feels that the comment sticky notes require addressing they should be moved to the back of finished card so they are kept together for processing.

The finished product will look something like this.



THE SDE SHOULD ...

- We like th QALY measure used by t
- Should w er minoriti

REVERSE WITH NOTES & PANEL'S STICKY NOTES ON IT

CORE VALUE NAME

Fair benefits for all

STATEMENT OF PRINCIPLE:

FOR THE WESSEX SDE TO BE TRUSTED MAKE THE MOST OF NHS DATA FOR RESEARCH TO IMPROVE LIVES AND HEALTH OUTCOMES IN WESSEX IT MUST ...

Ensure that all research is relevant with an explicit public benefit to ensure trust and can demonstrate benefits to public in sharing their data – including minority groups.

REASONS

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

Insert a statement here of 3-4 sentences.

AC IONS THAT BUILD TRUST

THE SDE SHOULD ...

Re-written version of the card to address sticky notes

TH OULD ...

..EASURE PUBLIC BENEFIT BY LOOKING AT HOW MUCH RESEARCH CAN IMPROVE BOTH HEALTH AND QUALITY OF LIFE FOR PEOPLE IN WESSEX.

THE SDE SHOULD ...

A re-writing of the action on the other side of the card

THE SDE SHOULD

... DO SOMETHING ELSE REALLY IMPORTANT TO THE PUBLIC PANEL AND FOR THE NHS.

THE SDE SHOULD ...

A new statement that the public participants have written

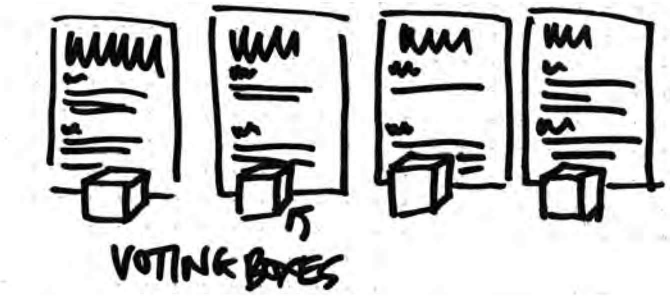
Step 4: Plenary presentation & voting

Plenary presentation

The boards are put back on display and a member of the group who has been working on each presents back to the wider room.

Endorsement and prioritising (by vote)

Each participant will be given 8 voting tokens to use to vote for the principles they support (1 vote each and any unused tokens deposited in a separate box)



Wessex
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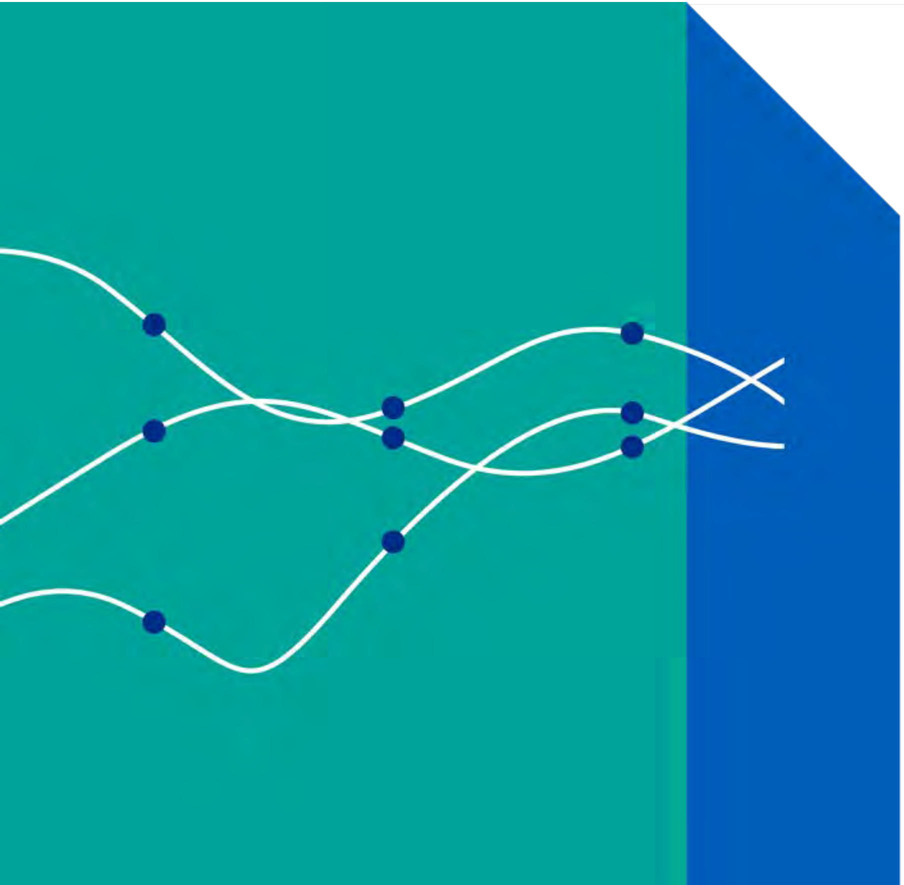
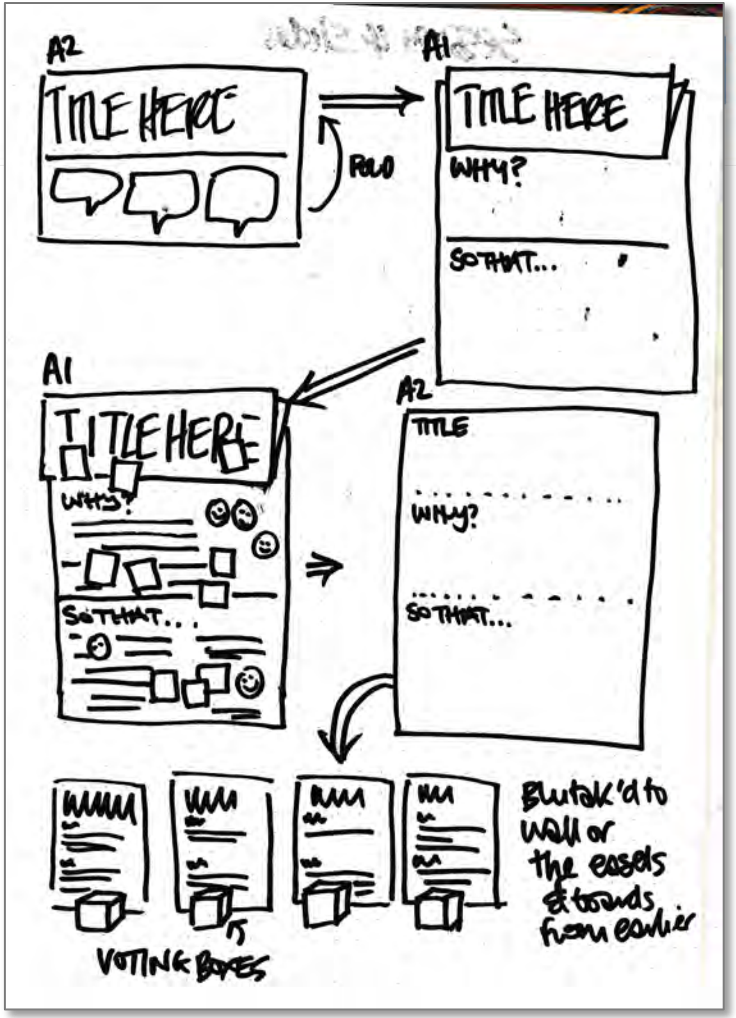


Strategic priorities exercises

Day 4

Overview

The diagram shows an overview of the process for this exercise.



Step 0: Activity stimulus

There will be 4x boards with 15 priorities across them. Each will have equal space on the boards.

There will be a title for the priority and then speech bubbles with the source material in.

Voting is done in the area below the line.

THE SDE SHOULD PRIORITISE PROJECTS THAT DELIVER ...

WIDER OPPORTUNITIES AND NATIONAL IMPACT

HAVE WIDER NATIONAL IMPACT – SUCCESS BREEDS SUCCESS
HIOW

WIDER BENEFITS – THE POTENTIAL TO LEAD ON TO MORE OPPORTUNITIES
DORSET

Step 1: Plenary exercise – Endorsement and prioritising

Using sticky dots members will be asked to vote for the 8 that they personally feel are most important to be used as criteria for evaluating whether a research proposal should go ahead (only one vote allowed for each).

The 8 receiving the most votes will be the focus of the next exercise.

[10 mins]

THE SDE SHOULD PRIORITISE PROJECTS THAT DELIVER ...

WIDER OPPORTUNITIES AND NATIONAL IMPACT

HAVE WIDER NATIONAL IMPA
– SUCCESS BREEDS SUCCESS

WIDER BENEFITS – THE
OTENTIAL TO LEAD ON
TO MORE OPP INITIES

DORSET

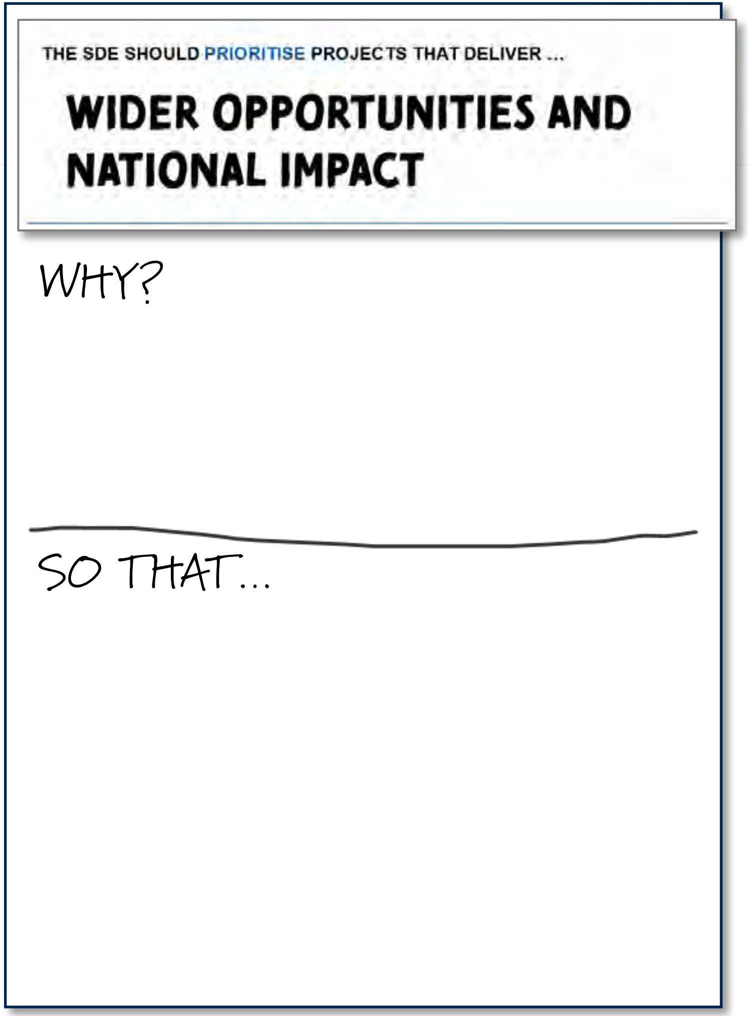
[20 mins]

Step 2: Allocate priorities and develop them further

Each group will be randomly allocated a priority to work on to define why it is important.

Facilitators fold the priority in half and stick it at the top of their flip chart. Underneath that they write the titles for the two parts of the exercise:

- WHY?
- SO THAT…



THE SDE SHOULD PRIORITISE PROJECTS THAT DELIVER ...

WIDER OPPORTUNITIES AND NATIONAL IMPACT

WHY?

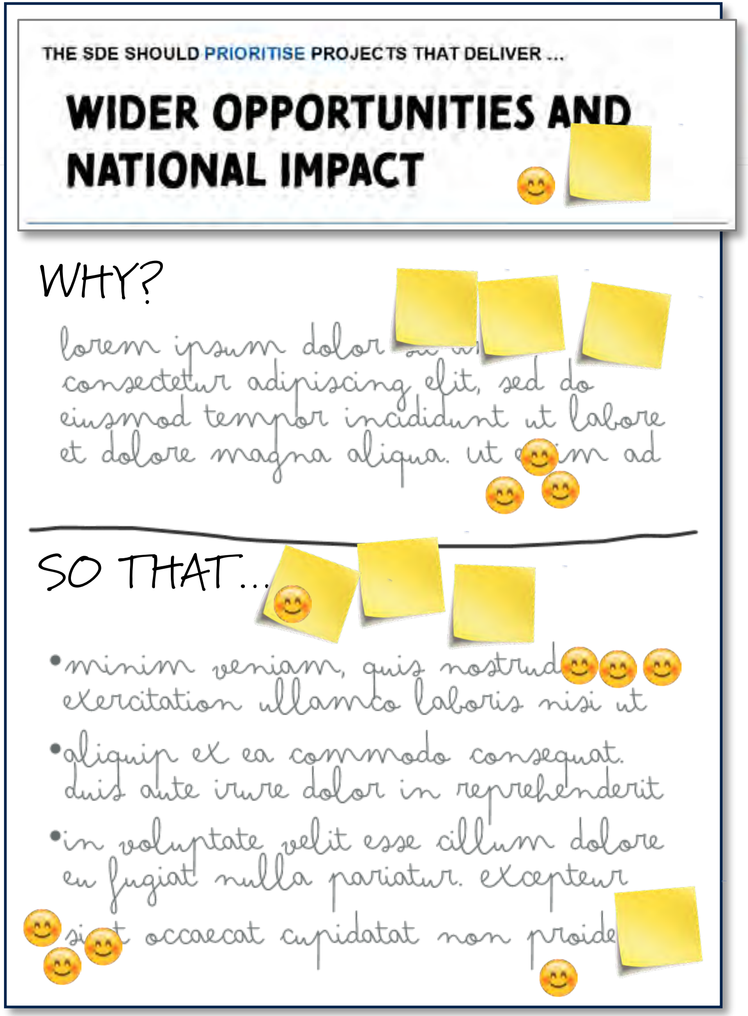
SO THAT...

[10 mins]

Step 3: Plenary exercise – Review proposed text

Members will again move between the boards adding 'smiley faces' to parts of the text they really like and post-its making constructive suggestions for refinement or anything missing (but not substantive change).

Number the “SO THAT…” reasons, so that it’s easier for people to refer to them on Post-its.



THE SDE SHOULD PRIORITISE PROJECTS THAT DELIVER ...

WIDER OPPORTUNITIES AND NATIONAL IMPACT

WHY?

lorem ipsum dolor
consectetur adipiscing elit, sed do
eiusmod tempor incididunt ut labore
et dolore magna aliqua. ut enim ad

SO THAT...

- minim veniam, quis nostrud
exercitation ullamco laboris nisi ut
- aliquip ex ea commodo consequat.
duis aute irure dolor in reprehenderit
- in voluptate velit esse cillum dolore
eu fugiat nulla pariatur. excepteur
sint occaecat cupidatat non proide

[15 mins]

Step 4: Swap boards

Each table swaps their board with another table.

The new table and reviews the suggestions and works to finalise the priority on a new sheet of A2 paper.

They hand this into the front once complete.

STRATEGIC PRIORITY NAME:

WHY?

THIS IS IMPORTANT BECAUSE ...

SO THAT ...:

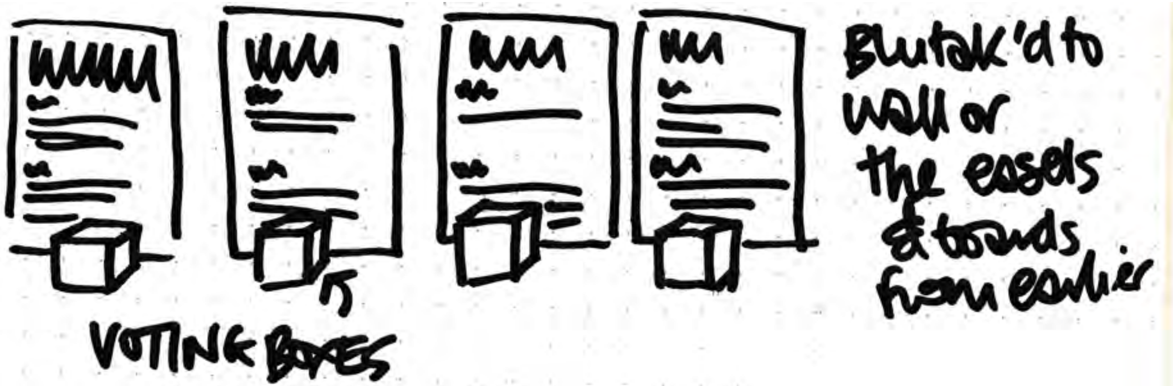
A GOOD RESULT FOR THE WESSEX SDE IS ...

[5 mins]

Step 5: Voting

A2 sheets will be set up round the room with ballot boxes under them.

Each participant will be given 12 voting tokens to use to spread across the 'Strategic Priorities' they feel should be given most weight by the DAC.



S: Core Values Stimulus Boards

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.

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

PROTECTING THE MOST VULNERABLE.

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.

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.

BENEFITS REALISED LOCALLY, MAY INCLUDE NON-HEALTH BENEFITS.

WE HEARD …

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

ACTIONS TO BUILD TRUST …

CORE VALUE

DESIGNED TOGETHER

YOU SAID …

PUBLIC TRUST AND BUY-IN.

EASILY UNDERSTOOD BY EVERYONE - ESPECIALLY LAY PEOPLE ON THE DATA ACCESS COMMITTEE.

APPEAL TO ALL GENERATIONS, E.G. USE TIKTOK.

EFFECTIVE COMMUNICATION OF THE COMPLETE PICTURE USING VARIOUS MEDIA.

CLEAR MESSAGING IN A SIMPLE FORMAT THAT WILL REACH THE MOST PEOPLE.

A NEED FOR THE INVOLVEMENT OF SPECIFIC PUBLIC REPRESENTATIVES DRAWN FROM THE DEMOGRAPHICS / AREA TARGETED BY RESEARCH.

PUBLIC INVOLVEMENT: MORE INVOLVED EARLIER IN PROCESS, AND A RANGE OF DIFFERENT PEOPLE AND BACKGROUNDS.

PUBLIC HELP TO DEFINE AND PRIORITISE BENEFITS.

EDUCATING THE PUBLIC SO THEY KNOW WHY WE WANT THEIR DATA TO IMPROVE (SOCIETY) HEALTH.

MINIMISE USE OF ACRONYMS, JARGON, ABBREVIATIONS AS IT CAN GET CONFUSING.

WE HEARD …

CO-DESIGN, PUBLIC INVOLVEMENT, AND CLEAR, JARGON-FREE COMMUNICATION.

ACTIONS TO BUILD TRUST …

CORE VALUE

PRIVATE BY DESIGN

YOU SAID …

DE-IDENTIFY PATIENT DATA.

SAFEGUARD AGAINST BREACH OR LOSS OF DATA.

PREVENT UNAUTHORISED ACCESS.

INFO MUST BE DEIDENTIFIED. POSSIBILITY THAT 'FRESH EYES' OUTSIDE THE NHS PICK UP SOMETHING THAT MIGHT HAVE BEEN MISSED.

ROBUST APPLICATION OF THE FIVE SAFES.

WHERE THERE IS SHARING / USE OF DATA OUTSIDE THE UK ARE THE SAFEGUARDS / CONTROLS EQUALLY SECURE?

HAVE ACCOUNTABLE SECURITY CHECKS.

WE HEARD …

PRIVACY FIRST, RESEARCHERS MUST ONLY SEE DE-IDENTIFIED DATA – WITH STRICT SAFEGUARDS.

ACTIONS TO BUILD TRUST …

CORE VALUE

OPEN AND HONEST

YOU SAID …

HAVE A CLEAR MISSION STATEMENT THAT EXPLAINS THE SDE'S MAIN GOALS AND PURPOSE.

VISIBILITY ABOUT WHO IS USING THE DATA, WHY, HOW THEY WERE VETTED, AND AUDIT OF THE PROCESS.

BE HONEST ABOUT INTENTIONS, FUTURE PLANS, SECURITY, DATA FLOWS AND FUNDING/INCOME.

AVOID SDE STAFF HAVING MULTIPLE ROLES WHEN POSSIBLE. STAFF MUST DECLARE ANY CONFLICTS OF INTEREST AND STEP AWAY FROM RELATED DECISIONS.

SHARE LINKS TO THE RESULTS AND BENEFITS OF SDE PROJECTS. THIS WILL SHOW WHAT WORKED, WHAT DIDN'T, AND THE VALUE GAINED.

MAKE THE DECISION-MAKING AND SCORING PROCESS AVAILABLE ON THE WEBSITE.

PROVIDE INDEPENDENT OVERSIGHT AND AUDIT. PROVIDE VISIBILITY OF WHO IS USING THE DATA, WHY AND HOW THEY ARE VETTED.

MAINTAINING ETHICS (FUTURE PROOFING INTENTION) SO CORE PURPOSE DOES NOT GET LOST / STAYS ON TARGET.

WE HEARD …

BE CLEAR ABOUT HOW DATA IS USED, WHO IS USING IT, AND WHY.

ACTIONS TO BUILD TRUST …

CORE VALUE

DELIVERS GOOD VALUE

YOU SAID …

MAKING SURE THAT THE NHS GETS A GOOD DEAL OUT OF THE COMPANIES USING DATA.

ENSURE IMPROVED QUALITY OF LIFE, NOT JUST YEARS LIVED – QUALITY VS. QUANTITY.

BE VALUE FOR MONEY – EFFICIENT, COST EFFECTIVE, COST V BENEFITS BECAUSE IT IS PUBLICLY FUNDED AND TO MAXIMISE THE SCHEME.

REINVESTMENT OF RESEARCH FUNDS INTO NHS/SDE AND BENEFITS FOR WESSEX.

VALUE IS NOT JUST MONEY BUT BENEFITS TO THE NHS, PATIENTS AND WIDER PARTNERS – E.G. SOCIAL CARE.

INCREASES BENEFITS AND OPPORTUNITIES FOR EVERYONE, NOT JUST SPECIFIC GROUPS.

WIDE IMPACT AND BENEFITS PROVIDE CLEAR VALUE, LOW NUMBERS NEED MORE CONSIDERATION

DRIVE EFFICIENCY BY SHARING KNOWLEDGE ACROSS SDES TO SOLVE SHARED CHALLENGES AND ENSURING RESEARCHERS CAPTURE ALL LEARNING AND FEED THIS BACK – BECAUSE THIS WILL ENABLE MORE RESOURCES TO BE FOCUSED ON THE HIGH VALUE RESEARCH OUTCOMES AND DEMONSTRATES A COMMITMENT TO LEARNING AND SHARING.

WE HEARD …

BE EFFICIENT AND SAVE NHS MONEY – BE GOOD VALUE FOR THE PUBLIC AND NHS.

ACTIONS TO BUILD TRUST …

CORE VALUE

RESPECTS PEOPLE'S CHOICES

YOU SAID ...

INFORMATION ABOUT THE SDE IS ACCESSIBLE, EVERYONE CAN READ IT, UNDERSTAND IT AND BUY-IN / OPT OUT.

CLEAR ROUTE TO OPT-OUT.

EXPLAIN WHAT ISN'T GOING TO BE SHARED. IT GIVES THE PUBLIC ASSURANCES THAT PRIVATE AND CONFIDENTIAL INFORMATION ISN'T SHARED, REDUCING THE AMOUNT OF OPT-OUTS, MEANING MORE INFO/DATA TO REVIEW, HELPING WITH RESEARCH.

'DUTY OF CARE' - INFORMATION PROVIDED IF PEOPLE WANT IT.

PUBLICISE OPT-OUT OPTIONS.

COMMUNICATE THE OPTIONS IN AN ACCESSIBLE, CLEAR, CONCISE AND SIMPLE WAY TO EMPHASISE CHOICE AND BENEFITS TO WESSEX AND BEYOND. BECAUSE PEOPLE NEED TO BE ABLE TO MAKE AN INFORMED AND POSITIVE CHOICE TO OPT-IN.

WE HEARD ...

OPT-OUT CHOICES AND CLEAR INFORMATION TO INFORM PERSONAL DECISION MAKING.

ACTIONS TO BUILD TRUST ...

CORE VALUE

POSITIVE PARTNERSHIPS

YOU SAID …

SHOULDN'T DEMONISE PHARMA COMPANIES.

RESULTS COULD BE MANIPULATED TO INCREASE PROFITS.

MAKING SURE THAT THE NHS GET A 'GOOD DEAL' OUT OF COMPANIES USING DATA.

HOW MUCH BENEFIT IS GOING TO A PROFIT-MAKING ORGANISATION VS INTERESTS OF COMMUNITY.

INDUSTRY BRINGS REVENUE TO THE NHS AND SDE.

DEIDENTIFIED DATA CAN BE MOVED EXTERNALLY FOR ANALYSIS – AS LONG AS THE COMPANY / EXTERNAL MEETS CERTAIN CRITERIA.

INDUSTRY PROVIDES TECHNOLOGY AND SERVICES NOT AVAILABLE FROM THE NHS.

ABILITY TO HELP BRING GLOBAL RECOGNITION AND INVESTMENT.

MAY BE DRIVEN BY MONEY NOT PATIENT BENEFIT.

WE HEARD …

FAIR CHARGING, RETURNS, AND BENEFITS FROM USE OF NHS DATA & RESOURCES BY NON-NHS PARTNERS.

ACTIONS TO BUILD TRUST …

CORE VALUE

QUALITY ASSURANCE

YOU SAID …

CONTEXT OF USE IS IMPORTANT FOR WHAT DATA SHOULD BE USED. THE BETTER THE CAUSE THE MORE WE WOULD BE HAPPY WITH 'RISKY' DATA.

DATA CAN ONLY BE USED FOR THE REASON THAT WAS STATED BY THE PROJECT – WITH SEVERE PUNISHMENTS FOR BREACH.

THE SYSTEM NEEDS TO BE MANAGED EFFICIENTLY TO ENSURE THAT DATA PROVIDED IS ACCURATE AND IS OF VALUE.

IF THE HEALTH RESEARCH AUTHORITY HAS APPROVED THE PROJECT, THEN WE'RE BROADLY IN AGREEMENT THAT THE SDE CAN DO THE PROJECT.

MUST BE REVIEWED REGULARLY (AUDITED).

INDEPENDENT AUDITOR (OVERSIGHT).

THE SDE SHOULD TRY TO BE DECENTRALISED, NON-COMPARTMENTALISED, WITH AS LITTLE HIERARCHICAL OVERSIGHT AS IS NEEDED. THIS ALLOWS THE FLOW OF INFORMATION WITHIN RELEVANT RESEARCH PROGRAMMES, REMOVES UNNECESSARY INTERVENTIONS, AND HELPS STOP ANY CORRUPTION.

ASSURANCE MUST BE EMPIRICAL AND NOT SUBJECTIVE.

WE HEARD …

INDEPENDENTLY AUDITED AND ACCOUNTABLE, GOOD QUALITY DATA, AND STRONG GOVERNANCE.

ACTIONS TO BUILD TRUST …

T: Core Values Worksheets

CORE VALUE NAME:

STATEMENT OF PRINCIPLE:

FOR THE WESSEX SDE TO BE TRUSTED TO MAKE THE MOST OF NHS DATA FOR RESEARCH IT WILL ...

REASONS:

DEMONSTRATING THIS IS IMPORTANT FOR PUBLIC TRUST BECAUSE ...

U: Strategic Priorities Worksheets

STRATEGIC PRIORITY NAME:

WHY?

THIS IS IMPORTANT TO PRIORITISING WHAT RESEARCH HAPPENS BECAUSE ...

SO THAT ...

A GOOD RESULT FOR WESSEX, THE NHS, OR THE SDE IS ...

V: Actions to Build Trust Cards

THE SDE SHOULD …

MEASURE PUBLIC BENEFIT BY LOOKING AT HOW MUCH RESEARCH CAN IMPROVE BOTH HEALTH AND QUALITY OF LIFE FOR PEOPLE IN WESSEX.

LINKED TO CORE VALUE: FOR PUBLIC BENEFIT

1

THE SDE SHOULD …

CARRY OUT REGULAR AUDITS OF THE OUTCOMES AND BENEFITS ACHIEVED – BOTH IN HEALTH AND OTHER AREAS – AT LEAST ONCE A YEAR.

LINKED TO CORE VALUE: FOR PUBLIC BENEFIT

2

THE SDE **SHOULD …**

PROMOTE TANGIBLE PUBLIC BENEFITS – WHO BENEFITED AND HOW, FINANCIAL RETURNS, SHORTER WAITING TIMES, OR OTHER EFFICIENCIES.

LINKED TO CORE VALUE: **FOR PUBLIC BENEFIT**

THE SDE **SHOULD …**

MAXIMISE PUBLIC BENEFITS BY FOCUSING ON PROJECTS WHERE OUR SDE ADDS MOST VALUE, REFERRING OTHERS TO BETTER-SUITED SDES.

LINKED TO CORE VALUE: **FOR PUBLIC BENEFIT**

THE SDE SHOULD …

FOCUS ON RESEARCH THAT HELPS AS MANY PEOPLE AS POSSIBLE, BENEFITING THE WHOLE COMMUNITY RATHER THAN JUST INDIVIDUALS.

LINKED TO CORE VALUE: FOR PUBLIC BENEFIT

THE SDE SHOULD …

HAVE AN EDUCATION AND PR PLAN ABOUT DATA-DRIVEN RESEARCH TO HELP THE PUBLIC MAKE INFORMED DECISIONS ABOUT THEIR HEALTH AND DATA.

LINKED TO CORE VALUE: DESIGNED TOGETHER

THE SDE SHOULD ...

VALUE INSIGHTS FROM PEOPLE WITH LIVED EXPERIENCE – PUBLIC REPRESENTATIVES SHOULD REFLECT WESSEX'S DIVERSITY TO REDUCE BIAS.

LINKED TO CORE VALUE: DESIGNED TOGETHER

7

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

8

THE SDE WILL …

USE PROVEN TECHNOLOGIES & MEET NATIONAL STANDARDS, NHS BEST PRACTICES, AND SDE NETWORK RULES TO ENSURE SECURITY & PATIENT PRIVACY.

LINKED TO CORE VALUE: PRIVATE BY DESIGN

9

THE SDE SHOULD …

HAVE CONTINUOUS MONITORING, REGULAR AUDITS, AND PUBLIC REPORTING OF DATA ACCESS AND USAGE BY APPROVED RESEARCHERS.

LINKED TO CORE VALUE: PRIVATE BY DESIGN

10

THE SDE SHOULD …

ENSURE RESEARCHERS CAN ONLY SEE DE-IDENTIFIED DATA, AND ONLY THE MINIMUM REQUIRED TO MEET THE NEEDS OF THE APPROVED PROJECT.

LINKED TO CORE VALUE: PRIVATE BY DESIGN

11

THE SDE SHOULD …

HAVE CLEAR GUIDELINES ON DATA RETENTION, SECURE ARCHIVING, AND DELETION – RESEARCHERS LOSE ACCESS ONCE A PROJECT IS FINISHED.

LINKED TO CORE VALUE: PRIVATE BY DESIGN

12

THE SDE SHOULD …

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.

LINKED TO CORE VALUE: PRIVATE BY DESIGN

THE SDE SHOULD …

PUBLISH CLEAR, JARGON-FREE SUMMARIES OF THE SDE'S OPERATIONS – FOCUSING ON ITS MANAGEMENT, DECISION-MAKING, AND DATA-HANDLING.

LINKED TO CORE VALUE: OPEN AND HONEST

THE SDE SHOULD …

PROVIDE A PUBLIC LIST OF ALL RESEARCH APPLICATIONS AND PROJECTS, DETAILING DATA USAGE, RESEARCHERS INVOLVED, AND THE INTENDED OUTCOMES.

LINKED TO CORE VALUE: OPEN AND HONEST

15

THE SDE SHOULD …

CLEARLY EXPLAIN ITS DATA SECURITY MEASURES, UPDATES ON BREACHES OR NEAR-MISSES, AND THE STEPS TAKEN TO ADDRESS THEM.

LINKED TO CORE VALUE: OPEN AND HONEST

16

THE SDE SHOULD …

HAVE PUBLIC ACCOUNTABILITY MECHANISMS – SO PEOPLE CAN GIVE FEEDBACK, EXPRESS CONCERNS, AND GET THEIR QUESTIONS ANSWERED.

LINKED TO CORE VALUE: OPEN AND HONEST

17

THE SDE SHOULD …

ENSURE RESEARCH PROPOSALS UNDERGO COST-BENEFIT ANALYSIS, SO THE SDE'S FULL PROJECT PORTFOLIO GIVES MORE TO THE NHS THAN IT TAKES.

LINKED TO CORE VALUE: DELIVERS GOOD VALUE

18

THE SDE SHOULD …

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.

LINKED TO CORE VALUE: DELIVERS GOOD VALUE

THE SDE SHOULD …

MEASURE ITS PERFORMANCE IN DELIVERING GOOD VALUE IN TERMS OF POPULATION HEALTH BENEFITS AND LONG-TERM NHS EFFICIENCY SAVINGS.

LINKED TO CORE VALUE: DELIVERS GOOD VALUE

THE SDE SHOULD …

ENSURE EQUITY AND FAIRNESS – BENEFITS ARE SHARED ACROSS ALL GROUPS, INCLUDING UNDER-REPRESENTED AND VULNERABLE COMMUNITIES.

LINKED TO CORE VALUE: DELIVERS GOOD VALUE

THE SDE SHOULD …

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.

LINKED TO CORE VALUE: RESPECTS PEOPLE’S CHOICES

THE SDE SHOULD …

EMBED PUBLIC VOICES IN DESIGN AND GOVERNANCE, ENSURE THEIR CHOICES SHAPE POLICY & OUTCOMES – AND ARE TREATED EQUALLY TO EXPERTS.

LINKED TO CORE VALUE: RESPECTS PEOPLE'S CHOICES

THE SDE SHOULD …

EXPLAIN DE-IDENTIFICATION OF DATA: WHAT DATA RESEARCHERS CAN SEE AND WHAT THEY CAN'T, SO PEOPLE CAN MAKE INFORMED CHOICES.

LINKED TO CORE VALUE: RESPECTS PEOPLE'S CHOICES

THE SDE **SHOULD …**

ACTIVELY USE PRIVATE SECTOR SKILLS, RESOURCES, AND FUNDING TO BOOST RESEARCH – WITH A LASER FOCUS ON REAL HEALTH AND NHS BENEFITS.

LINKED TO CORE VALUE: POSITIVE PARTNERSHIPS

THE SDE **SHOULD …**

MAKE SURE THAT IT GETS A FAIR DEAL FROM COMMERCIAL PARTNERSHIPS – E.G. A SHARE OF FUTURE PROFITS OR INTELLECTUAL PROPERTY.

LINKED TO CORE VALUE: POSITIVE PARTNERSHIPS

THE SDE SHOULD ...

ENSURE INDUSTRY BENEFITS ARE MADE CLEAR AND ARE PROPORTIONATE TO THE PUBLIC HEALTH AND NHS GAINS THEY HELP DELIVER.

LINKED TO CORE VALUE: POSITIVE PARTNERSHIPS

THE SDE SHOULD ...

SET CLEAR RULES AND PROTECTIONS ON DATA ACCESS – E.G. STRONG CONTRACTS, PENALTIES FOR MISUSE, AND RESTRICTION OF DATA RE-USE.

LINKED TO CORE VALUE: POSITIVE PARTNERSHIPS

THE SDE SHOULD …

ENSURE DATA GIVEN TO RESEARCHERS IS CHECKED FOR QUALITY TO AVOID ERRORS THAT COULD HARM PATIENT CARE OR RESEARCH OUTCOMES.

LINKED TO CORE VALUE: QUALITY ASSURANCE

THE SDE SHOULD …

HAVE REGULAR EXTERNAL AUDITS AND INTERNAL REVIEWS – FOCUSING ON GOALS, LEGAL STANDARDS, BEST PRACTICE, AND PUBLIC EXPECTATIONS.

LINKED TO CORE VALUE: QUALITY ASSURANCE

THE SDE SHOULD ...

ENSURE MORE OVERSIGHT OF PROJECTS USING DATA DEEMED 'SENSITIVE' OR 'RISKY' BY THE NHS OR THE WESSEX PUBLIC.

LINKED TO CORE VALUE: QUALITY ASSURANCE

THE SDE SHOULD ...

AVOID STAFF HOLDING MULTIPLE ROLES IN THE SDE WHERE POSSIBLE (E.G. SITTING ON DAC AND PROVIDING CONSULTANCY). STAFF MUST DECLARE CONFLICTS OF INTEREST AND STEP BACK FROM RELATED DECISIONS.

LINKED TO CORE VALUE: QUALITY ASSURANCE

THE SDE SHOULD …

LINKED TO CORE VALUE:

Appendix 6: Communications Toolkit

Guide

This appendix contains the **Wessex SDE Toolkit**, a set of materials made available throughout all four Public Panel sessions. Its purpose was to give participants clear, accessible information about the Secure Data Environment, and to provide case studies they could return to when reflecting on values, principles, and priorities.

The toolkit was designed to help participants:

- **Understand what "health data" means** and how the NHS uses it.
- Learn how the **Five Safes** protect privacy in a Secure Data Environment.
- Explore key terms through short **glossary cards**.
- See real-world examples of how linked NHS data can be used for research, through illustrated **case studies**.

Case studies included in the toolkit

- **IDx Lung** – using blood tests, nasal swabs, and CT scans to improve early diagnosis of lung cancer.
- **PRANA (Pre-hospital Research and Audit Network)** – linking ambulance and transport data to improve emergency response and road safety.
- **Cancer Genomics** – combining genomic data with cancer patient records to personalise treatments.

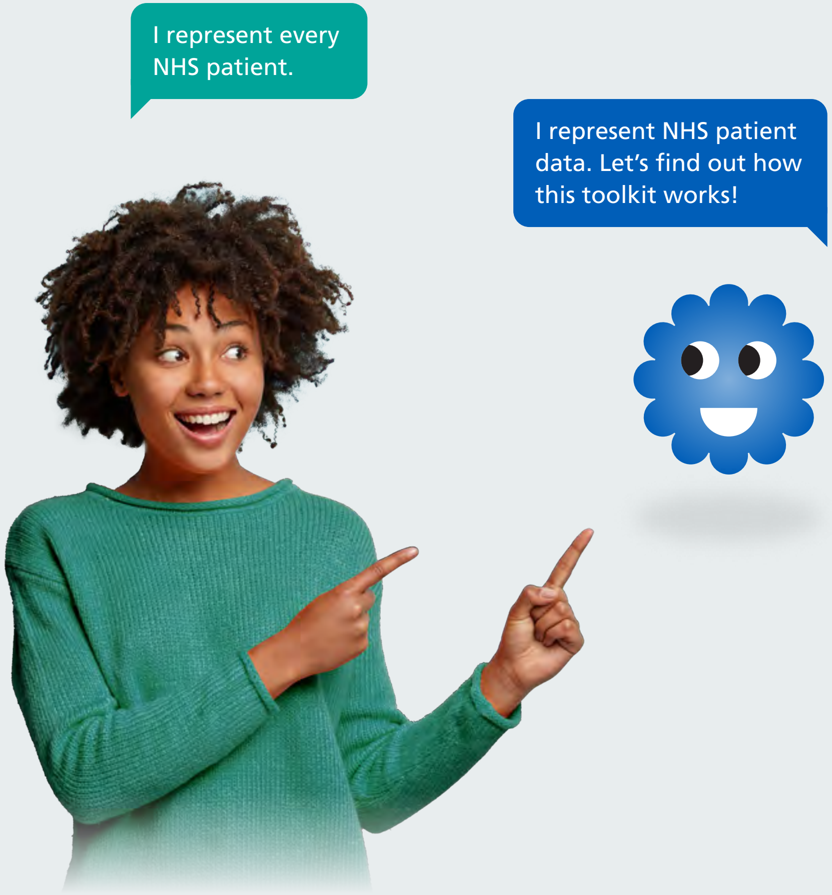
All toolkit materials were created to make complex topics easy to understand, while equipping the public to engage critically and confidently in discussions about data use.

Attachments in this appendix

W. **Wessex SDE Toolkit** – full set of spreads, including glossary cards and case studies.

W: Wessex SDE Toolkit

Wessex Secure Data Environment Toolkit



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TOOLKIT

Introduction

This toolkit aims to help people better understand the Wessex Secure Data Environment (SDE), how it uses the Five Safes to keep data secure, and the benefits this 'big health data' project offers patients and the public.

All toolkit materials are designed based on a model of 'data visualisation literacy as empowerment', which advises creating visual materials that improve technical and health literacy whilst giving people the tools to put their new knowledge into action. Going beyond 'the public acceptance of data,' we want the public to feel empowered to discuss, debate, or even propose a Wessex SDE data project.

Credits:
Bournemouth University has produced these toolkit materials for the University Hospital Southampton NHS Foundation Trust, who lead the Wessex Secure Data Environment (SDE) project, part of a national programme funded by the NHS England and the Department of Health and Social Care.

Project led by Professor Anna Feigenbaum.

Design by Open & Honest.

Case Studies

We have created Case Study leaflets for sharing information on research projects that have used the Wessex SDE. There are two cards for each case study. The first provides an accessible introduction to each research project and its benefits. The second provides more details on the project and a datagraphic that shows how different types of data are brought together in the SDE, enabling research for patient and public benefits.

Glossaries

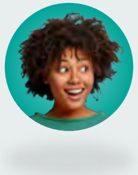
The toolkit also contains Glossary cards that introduce key terms related to the Secure Data Environment initiative. These glossary cards were designed to help people understand how the SDE works, reflect on the values that guide it, the rules that govern it, and how it will be run.

GLOSSARY

You and your data

Oh, my health data, where did you come from!?

From your NHS records! Let's find out what good we can do.



What is my health data?

Anytime you interact with the NHS, for example, when you visit your GP, they record information about you. You might discuss how you are feeling, and they'll note it down, or you might have your blood pressure measured, and someone will add the results to your file. This information is your health data.

Why does the NHS keep my data?

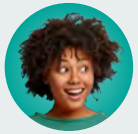
Your data, represented by me, can be used to identify you, contact you, and link records together.

Should I share my health data?

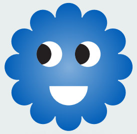
When doctors and researchers bring health data together, they can improve our understanding of diseases, develop new treatments, and plan healthcare services for our future needs.

GLOSSARY

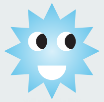
What is data?



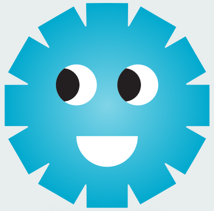
You’re my health data, but what is that?



I represent information about you.



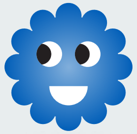
I can symbolise a small detail, like how many cups of tea you drank this week.



Or I can sum up big data, like the number of cups of tea drunk in the UK each year (almost 36 billion!).

Researchers can use linked data to gain new insights. For example, those who wanted to know if tea drinking impacts life expectancy related the number of cups drunk to mortality rates.

Do you always represent a number?



I can represent experiences, feelings, places, people, numbers—you name it.

That sounds powerful. Is linked data safe?

New technologies are making big data use simple and fast, raising questions about who gets to collect, research, and make decisions with data. The NHS is trying to answer these questions as part of its commitment to use data to improve everyone’s health—in a safe, trusted, and transparent way.

GLOSSARY

What is an SDE and how does it keep data safe?

How does the NHS keep my health data safe?

They use a Secure Data Environment, or SDE for short. Let's find out what that is!

The SDE uses the five safes to keep data secure:

Safe Data – See how I'm hidden behind a shield now? That's because data, like me, gets de-identified inside the SDE.

Safe Projects – An independent committee must approve SDE projects. They check research benefits people's health and social care. Committees can include patients or members of the public, like you.

Safe People – Researchers who access the SDE receive appropriate training and must demonstrate the technical skills needed before their access is approved.

Safe Settings – Access to data is only possible in a secure setting. Safeguards, like encryption, protect me.

Safe Outputs – Research findings are screened before release, ensuring nobody is identifiable from data.

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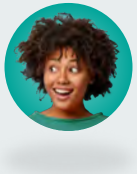
How does the SDE de-identify data?

How is my data kept safe?

While your doctors need to know who you are, you probably don't want everyone to have access to your personal information. That's where the SDE comes in!

Whenever researchers use your data, the SDE removes information that identifies you and replaces it with de-identified data. For example, the SDE replaces patient names with numbers called unique identifiers, which hide real names.

What if someone works out who the patients are?



A code acts as a key that locks and unlocks identifiable personal information. Researchers can't access it. So, I'm Safe Data.

Patient and Public Benefits of this research
Our team wants to find out if using tests on blood and tissue samples, as well as the CT scan results, can help to improve the diagnosis of lung cancer. This research can help patients and the public in the future by improving early cancer diagnosis and intervention. This can enhance care and save lives.

NHS Data to be used: low dose CT scan results, cancer diagnosis outcome data, demographic data and medical history (age, smoking history, education, previous cancer, etc.)

Additional Data: Results of the blood samples and nasal swabs (clinical trial data)

Background

For this project researchers worked with industry partners to trial tests for early cancer detection that uses blood samples and tissue samples taken from inside your nose (called a nose swab). To gather these samples, people undergoing a Lung Health Check were approached and asked if they were willing to participate in a study to help identify lung cancers earlier. Consenting participants provided a nasal swab and blood sample and agreed that the research team could access their CT scan results and their medical records.

What's Next?

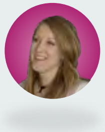
The iDx project is looking to expand their trial to 10 more sites, recruiting another 10,000 participants from across the county for iDx Lung 2. In IDx 2 researchers are working with new partners to assess the usefulness of new tests for early diagnosis. More participants will mean more data can be collected, improving the quality and detail of the researchers' findings. Data from test results can be requested for other research users, and after the team has had time to collect follow up data, results from this long-term research study will also be made available through the SDE.

Research led by: University of Southampton Clinical Trials Unit with the iDx Lung Consortium

Test kits provided by:
Oncimmune (now Freenome), Innovate (now Neogenomics), J&J and Roche

Database developed by:
BC Platforms

NHS Lung Health Check is a service offered through GPs in some parts of England and Wales. It aims to help diagnose lung cancer at an earlier stage when treatment may be more successful.



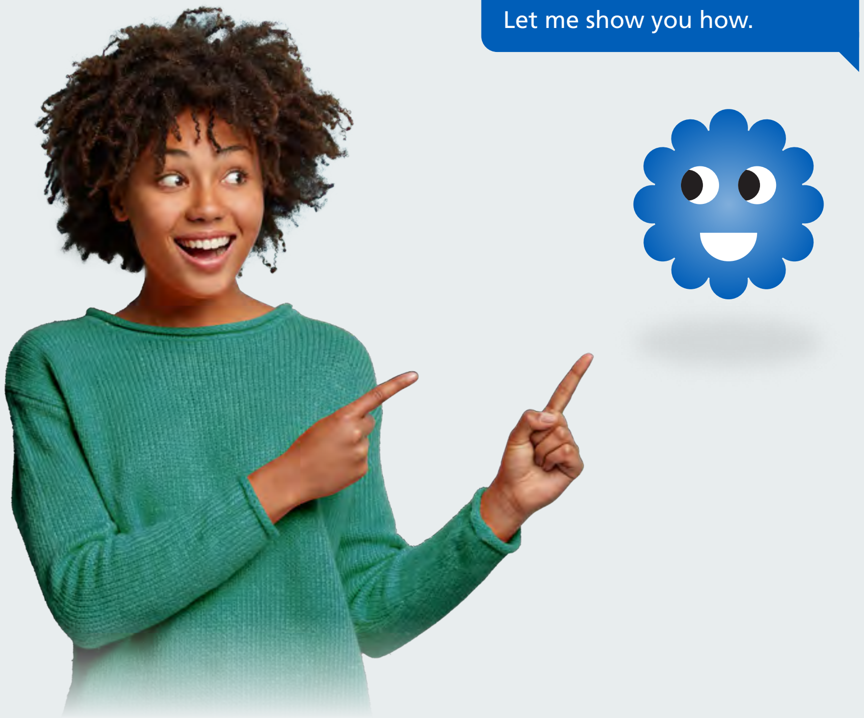
CASE STUDY

IDx Lung

Using the SDE to improve early lung cancer detection

How can linking my health data help the fight against lung cancer?

Linked data helps researchers improve early diagnosis and patient care, benefitting our families, friends and future. Let me show you how.



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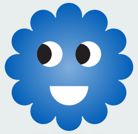
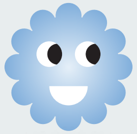
I'm Dr Victoria Goss. My research team work to improve early lung cancer detection. Nearly 50,000 people are diagnosed in the UK each year. It's the third most common form.

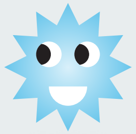
For Dr Goss' project, GPs identified patients aged 55 to 74 who smoke (or used to) and offered lung checks; their blood and nasal swab samples went to partner labs for testing.





Here, I'm data representing their new results from the lab.

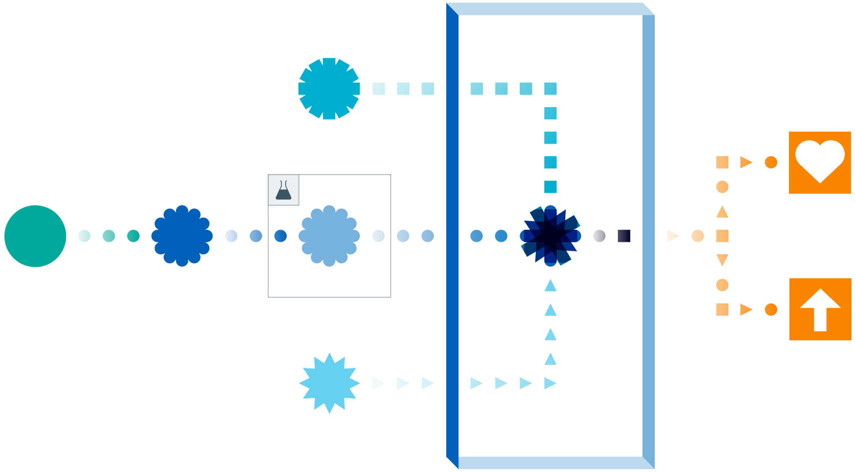
Here, I'm data representing the patients' prior records.



Both data types became linked inside the SDE. Researchers working there used it to gain new insights that improved early diagnosis and increased the 10% survival rate.

Why did the researchers need to know about age and gender?

Linked data in the SDE helped us find and recognise patterns in cancer cases related to age, ethnicity, or gender—information that can improve health inequalities in prevention, diagnosis, and treatment.



The process starts with ● **you** having a ✺ **blood and nasal swab** at the testing station. Your sample results are sent for testing in the ⚗ **industry partners' labs.** ✺ **Results** are then uploaded to the ◥ **SDE**. To be able to link datasets together securely, the NHS research team also uploads ✹ **demographic data** (age, smoking history, education, previous cancer, etc.) and the low dose ✺ **CT scan results** (negative, indeterminate or positive scan) to the SDE. To see if these early detection tests are useful, the clinical outcome data (lung cancer, other cancer, no cancer) will later be uploaded to the SDE in intervals for three years. The ✱ **combined data created a large dataset to work with in the future** and vitally supported early diagnosis, ♡ **improving care**, and ⇧ **saving lives**.

Patient and Public Benefits of this research
Our team uses data to improve the care of critically ill and injured patients who need emergency medical attention. Insights from this data also help to better plan for patient care, including having the right staff and equipment at the right times. Beyond healthcare, insights from this data can be used to improve road safety policy and infrastructure to prevent people from becoming patients. This means less deaths from road collisions — a leading cause of major trauma in our society.

NHS Data to be used: NHS Ambulances Services, Air Ambulance Services, NHS England Hospital Event Statistics, adult and children's intensive care data, Major Trauma System data, out of hospital cardiac arrest data, national transplant data

Additional Data: Department for Transport, Coroners' data, road traffic investigation data

Background
Each day in the UK, people become unwell or get injured and require emergency response. Some face life-threatening illnesses or injuries and need what is called 'pre-hospital critical care'. At present, there is no national data collection of pre-hospital critical care. There is also currently no way of linking NHS data to other relevant data outside of the NHS, for example, Department for Transport data on road collisions. This means we are missing out on making improvements in how we care for people. And we are unable to unlock the insights we need to enhance injury and disease prevention. To address this knowledge gap, we have brought together a research team to establish PRANA, The Pre-hospital Research and Audit Network. PRANA is part of the Wessex SDE.

What's Next?
We would additionally like to see these data insights get used to improve policies and everyday infrastructure to help keep people safer. For example, the Department for Transport could use this data to help minimise road traffic accidents and improve road safety, preventing injuries and saving lives.

Research Collaboration:
Wessex Subnational Secure Data Environment and Clinical Informatics Research Unit at University of Southampton and University Hospital Southampton, NHS England

Partners include:
Department for Transport, Transport Research Laboratory, Air Ambulances UK, Faculty of Pre-Hospital Care of the Royal College of Surgeons of Edinburgh, British Association of Immediate Care Schemes, Intercollegiate Board for training in Pre-Hospital Emergency Medicine

Pre-hospital critical care refers to the specialized medical attention and interventions provided to individuals facing life-threatening illness or injury before they reach a hospital. This care is provided by nurses, paramedics and doctors.

CASE STUDY

PRANA

The Pre-hospital Research and Audit Network (PRANA) are using the SDE to improve how we care for people before they reach the hospital by unlocking insights that save lives.

Give me an example of what researchers can achieve with linked data in the SDE.

PRANA has linked patients' medical details with data from the Department of Transport to improve patient care, shape better policies, and make emergency response more efficient. Let's find out how.

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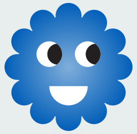
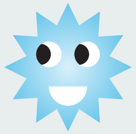
I'm Dr Phil Hyde, working with PRANA. Our team aim to save lives, improve emergency care, and reduce road collisions—one of the UK's leading causes of trauma. We ask questions like, 'What factors impact how fast ambulances get to hospitals?' and 'How does car design affect injuries sustained during a crash?'.

What role does health data play?



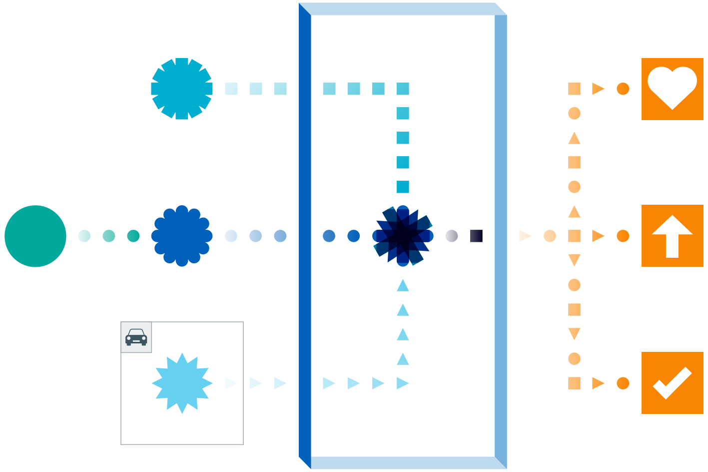
Here, I'm data representing inequalities in how patients receive emergency care.



Here, I'm data gathered from transport organisations.

The SDE can link this data and reveal its untapped potential.

We analyse linked data to discover how it can help to improve ambulance services, uncover inequalities in emergency care, and inform new training for nurses and paramedics. With it, we ask questions about road quality and car safety, seeking to improve infrastructure and road safety policies.



The process starts with **you**. Using Wessex **SDE**, our PRANA researchers bring together data from **different emergency care organisations** and **data** from **transport organisations**, linking this to patients' **medical data**. From the **linked data, we can then look at the full critical care journey**, from patients' initial emergency response (such as a heart attack or severe injury) to their quality of life after treatment. Taking a systematic approach to collecting and analysing this data helps us see patterns and trends that can help **improve patient care**, **enhance medical services**, and **contribute to transport design, road safety policy and infrastructures that prevent injuries and deaths**.

Patient and Public Benefits of this research

Our research team wants to capture and record **genomic variants** in DNA from cancer patients' tumours. Looking at this data, along with other medical information about patients' cancer journeys, will enable us to match exact cancer variants to the drugs that best target them, speeding up the time it takes to find the most effective treatment for patients, and this can help save lives.

NHS Data to be used: DNA from tumour biopsy, information from cancer patients' medical records.

Additional Data: Genomic sequencing data (from the genomics lab).

Background

Cancer is a genetic disease—it is caused by changes to genes. Sometimes these changes, called genomic variants, are inherited by our parents, and other times they only exist in a tumour. Tumours can be caused by thousands of variants. Learning more about these variants and comparing this data to information on cancer patients' journeys, can help us better understand how to target and treat patients' different cancers more efficiently and effectively.

However, right now, even though we have a lot of data on patients' cancer journeys and a lot of data from genomic sequencing, this data is not meeting up. Only a trickle of information gets looked at, the rest is left behind in databases. This means opportunities to help patients are being missed.

What's Next?

In 2024 the team will be working to test and secure the processes we will use to bring together files and create links in the SDE between genomic sequencing data and data from patients' NHS records.

Research Partners:
University Hospital Southampton, University of Southampton, Central and South Genomic Medicine Service

The human genome is the entire collection of genetic information that makes up a person. A person's set of **genomic variants** is what makes them unique from another person.

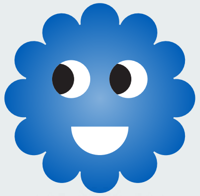
CASE STUDY

Cancer Genomics

Using genomic data to improve cancer treatment

What's 'genomic data', and how can it improve cancer treatment?

Let's ask Sarah Ennis, Professor of Genomics at the University of Southampton.



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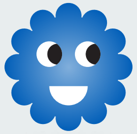
Genes are segments of our DNA—the information in our bodies that makes us who we are. Gene mutations cause cancer. Researchers can learn more about these mutations by looking at DNA.

What do researchers do with this DNA?

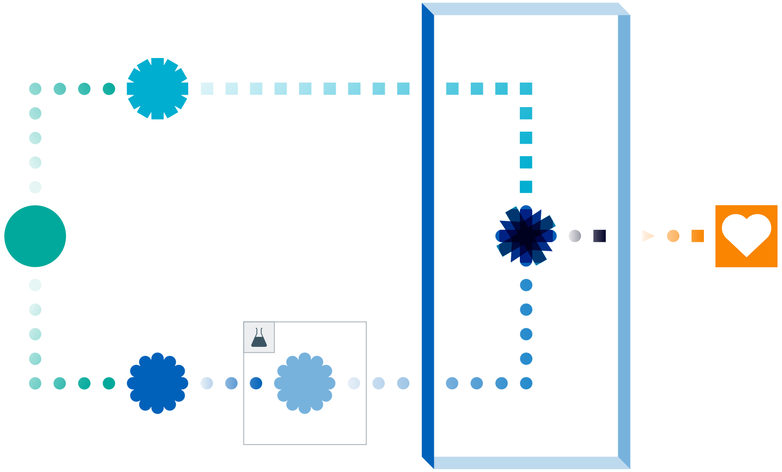


DNA samples taken from patients' tumours are sent to labs using special equipment for 'genomic sequencing', a process that decodes all the detailed information DNA contains. These insights help researchers and doctors better understand and treat cancer.

Linking information about specific patient journeys to genomic data in the SDE can improve personalised care and help doctors and researchers match cancer patients with the best treatments.

If we already have this data, why aren't we doing this now?

Good question. There's so much data stored in different places! Only small amounts get prioritised. Over time, our project's goal is to create a unified system. So, if a patient changes hospitals, insights about their cancer can still be understood by different people in different places.



The process starts with ● **you**. Cancer patients regularly have medical tests to help monitor their cancer. ✹ **Data from these tests is stored in NHS patients' records**. Cancer patients also have ✹ **DNA samples taken from their tumours** so doctors can better monitor and treat them. These tumour DNA samples get sent to ⚗ **genomics labs** where ✹ **genomic sequencing data** is generated. This genomic sequencing data helps decode information about specific cancers and the patients who have them. If ✹ **genomic sequencing data is brought together with data on cancer patients' journeys** in the **SDE**, it can lead to ♡ **more personalised, effective and efficient cancer treatment**.

Appendix 7: Literature Review

Guide

This appendix includes the preparatory literature review conducted ahead of the Wessex Public Panel on NHS Data. The review provided an evidence-based foundation for the deliberative dialogue and helped ensure that the Panel's time was spent generating new insights rather than repeating what is already known.

Attachments in this appendix

X. Use of health data for R&I: A literature review of audience insights research

Y. Health data for R&I audience insights – Summary report

X: Use of health data for R&I: A literature review of audience insights research

Wessex SECURE DATA ENVIRONMENT

Part of the NHS Research Secure Data Environment Network

NHS

Use of health data for R&I: A literature review of audience insights research

October 2023

Contents

Britain Thinks (2023). Commercial Principles for NHS data access.

Research by Britain Thinks to test public opinion on clarity and acceptability of a set of draft commercial principles for the SDE network. The aim is to inform development of these principles as well as the way in which they are communicated. (The objective was not to test whether commercial use of NHS data should happen at all, but the terms under which this happens.) Research comprised a literature review, quantitative research through a nationally representative survey (n=2,000), and three online deliberative workshops with 26 members of the public.

Principles (all received positively and achieved 70-75% clarity and acceptance scores, but require simplification and clarification):

1. Costs of access should not be prohibitive to good uses of data
2. The NHS will always charge a fee for accessing health data
3. The cost of access should depend on how the data is being used
4. On top of costs for access, the NHS intends to share in the value created by its data

Insights from the research are:

- Public assumes that their data (not just health) is already accessible to many organisations.
- 68% of the public know little or nothing about how health data is collected and used.
- Many express unease about sharing health data but struggle to articulate why.
- Only a small minority want to learn more about data access.
- Majority trust the NHS with their healthcare data, are comfortable with various data uses, but the public desires more information and control.
- Healthcare data for research and innovation is seen as beneficial, with some concerns about commercial use and data security. (E.g., 74% support using NHS data to recruit participants for clinical trials.)
- Public believe health data should be more secure, already is more secure, and that it is anonymised.
- Public is comfortable with NHS partnerships, with highest comfort for non-profit organisations and charities.
- 80% comfortable with NFP and charity, 71% with academic researchers, 66% with large pharmaceutical companies, 51% with SMEs, and 45% with large technology companies.

- Framing the move to Secure Data Environments (SDEs) as an improvement in security reassures the public.
- 59% are more comfortable with SDEs compared to the current system, with a slight increase (c.4%) in comfort with commercial partnerships.
- Concerns exist about data access, commercial aspects, and NHS dependency on data income.
- Recommendations for communication include explaining benefits, security, and opt-out options in clear language, using analogies, and be cost-effective.
- Majority support value sharing but seek clarity on income distribution and value definition.
- Cost of access should vary based on data use and type of organisation (i.e., commercial organisations charged more and an additional charge for successful commercial products).

Ipsos (2023). Supporting PPIE across England's SNSDEs - Discovery Phase Report.

Review of stakeholder attitudes and existing research across the 11 SNSDEs.

- SNSDEs may not be seen as core infrastructure by ICS for their activities, and local stakeholders may unclear about their utility.
- Engagement with data controllers like GPs is key to securing support.
- Local policies need to be framed by a clear central policy framework, especially in areas like access, commercial models, and NHS-non-NHS data linkage.
- Standardised national pricing structure/guidance is desired by a number of SNSDEs.
- The commercial model should go beyond cost recovery; it involves value transfer and integration.
- Limited public engagement to date on specific SNSDE areas and AI, but some progress in access controls, governance, and commercial principles.
- Public expects public benefit, transparency, accuracy, de-identification, opt-out/consent, data security, and limited commercial use.
- Trust decreases as data sharing extends beyond direct care within the NHS.
- Public concerns about data security, hacking, unauthorised access, excessive commercial profits, and NHS return on benefits.

PEDRI (2023). Public Involvement and Engagement Best Practice Draft Standards for the use of data for Research and Statistics.

The Public Engagement in Data Research Initiative has created draft standards to guide best practices for involvement and engagement activities in data research and statistics. Provides a set of principles capable of guiding / framing SDE PPIE activity, and that can be used to support early citizen engagement and co-creation of the programme.

Research Works (2023). NHS Digital - GPDPR public survey results

A quantitative survey with three sample groups: 1,703 nationally representative; 309 boost sample of those less engaged online; 50 offline sample of those who do not use the internet.

- Over half were aware of GPDPR, awareness related to online usage
- Around a third of opt-out respondents got information from social media
- Opt-out and local NHS service improvement messages were most recalled and provide a strong basis for future messaging
- Majority aware of opt-out but low understanding of different types
- High trust in NHS use of patient data, lower for external access
- Trust levels: 34% for medical research charities, 23% for academic researchers, 16% for pharmaceutical companies accessing pseudonymised data
- About half reassured by data storage messages, 20% were not
- Higher self-reported opt-out rates in males, <44 years old, socio-economic group A, London, Black Caribbean/Black African/Black British, carers, LTC patients
- Trust in NHS sources for GPDPR information
- Data security reassurance most likely to influence future opt-out decisions
- Broader benefits more compelling than specific ones
- Public requires 'push' comms as they will not actively seek information on data security and access.

Understanding Patient Data (2023). Characteristics of trustworthy use of data

Understanding Patient Data has provided a long list of qualities that the SDE might adopt. From these it is worth highlighting:

- Emphasise the use of patient data for improving health and care.
- Highlight the expertise and competencies of your team to handle data securely.
- Develop strong communication and engagement skills within your team.
- Ensure transparency by openly acknowledging risks and uncertainties.
- Emphasise clear and consistent rules for data use.
- Highlight public involvement in setting rules and deciding permissible data uses.
- Communicate the mechanisms for individual preference, such as opt-outs, clearly.
- Promote collective mechanisms of oversight and public input in communications.
- Use public input to identify potential questions or concerns regarding data sharing.

Wessex AHSN (2023). Wessex Secure Data Environment (SDE): Seldom-heard groups early engagement.

AHSN research using its ‘Rapid Insight’ approach comprising deliberative events with stakeholders to generate insights linked to specific priority areas of interest. Three groups were involved in five sessions: Hart Young Carers (people from age 7 to 25 who are active carers), Chat with Chai (south Asian women), and Weymouth Fire Service and East Dorset Rugby Club (working men between 18-55 years).

- All groups favourable to use of anonymised data.
- NHS is trusted to manage data properly.
- All groups support NHS and university researchers’ access to data.
- All groups open to commercial access to data, subject to appropriate checks and benefits (e.g., discounts for NHS).

- Potential for deeper inequalities based on data interpretation (including data quality and bad research questions).

- Strength of data access controls (verification of applicants and users).

- Commercial users potentially focusing on profitable subjects, not need.

- Regular involvement/attendance in formal decision-making not desired and ‘representation’ is not realistic.

- Information about how and who is accessing the data should be easily available.

Wessex Care Record (2022-23). Engaging HIOW citizens in their data use

The first tranche of research in 2022 comprised an online survey conducted between June and August 2022. This survey received responses from 382 individuals, with 250 responses from HIOW and 132 from Dorset.

A second tranche of research conducted in 2023, included survey with younger people (aged 18-40) using Prolific online platform (377 replies 254 HIOW/123 Dorset). Plus, focus groups with respondents to original survey; patient volunteers; ethnic minority community; Sight for Wight charity; and Gypsy and traveller community.

The bullets below summarise the overall takeaways. Differences between the results of the two surveys are limited, so the most conservative statistics have been used.

- 27% believe their health and care records are shared for developing new medicines and treatments.

- 55% think their records should be shared with universities or charities conducting research, and 38% are open to sharing with companies developing cures and treatments.

- Key concerns: data sale (71%), correcting errors (67%); data security (64%), decisions not benefiting me (55%), and identification risk (46%).

- Trust is built by communicating: Restricted access to only those who need the information; anonymisation of shared data; security assurances; and transparency about who can access the data and how it will be used.

- GPs and NHS domain name websites are sources of trusted information.

- Willingness to share data depends on patient benefit.

- Mixed views on sharing with drug companies, with concerns about ethics and uses.
- Opposition to selling information for profit.
- Comms recommendations: videos/animations; info through GP channels; recruit community champions; use social media; presence at community events; cater to those not digitally enabled

Boniface et al, UHS (2022). DARE PRiAM Project - Public Engagement Report

This report summarises the results from research into public attitudes towards a standard privacy risk assessment framework for those seeking to operate a secure, trusted infrastructure handling sensitive data for research purposes. The research comprised four virtual workshops and a questionnaire securing 500 responses from members of the public.

Workshops covered: (1) language used by the general public when discussing privacy and privacy concerns; (2) the public's ability to manage their own privacy; (3) who is responsible for protection of private information; and (4) review and test a proposed online survey.

- Individuals have a limited understanding of practical consequences and their own rights regarding data protection legislation.
- Privacy decisions are influenced by context, trust, responsibility, and affect.
- Concern about privacy does not always predict data sharing behaviours; other specific goals may trump concern about privacy.
- Transparency and simplicity in data protection practices are desired.
- People are concerned about onward sharing of their data and loss of control.
- Individuals may feel overwhelmed by the amount of information they need to process to make privacy decisions.

GM Care Record (2022). Comms and Engagement Campaign Report

The GM Care Record is a shared care record used by health and social care organisations in Greater Manchester. It played a crucial role in the region's fight against COVID-19. Efforts were made to inform the public about the record and their rights regarding data sharing. At least 10% of the population of Greater Manchester were reached through the campaign.

Campaign deliverables:

- Outdoor advertising on trams and major transport interchanges.
- Social media advertising reaching over 133k views in Greater Manchester.
- Website with over 31k unique visitors.
- Engagement activity targeting diverse communities.
- 6 focus groups conducted with over 80 participants.
- Public campaign with a microsite, media release, and toolkit.
- Second phase with paid-for advertising and community engagement.
- Influencer engagement and support on social media (e.g., Instagram).
- Media coverage secured.
- Toolkit of communication materials shared.

Actionable insights from the campaign:

- Limited prior knowledge of the GM Care Record.
- General support for sharing patient information for direct care.
- Concerns about data accuracy and research use.
- Assurances about data protection and research use effectively address concerns.
- Importance of patients being able to access their data.
- Emphasis on data accuracy and transparency in research data use.
- Ongoing communication and engagement are crucial as the GM Care Record evolves.

Goldacre et al (2022). Better, broader, safer: using health data for research and analysis

The NHS Goldacre Review, led by Dr Ben Goldacre, aimed to address issues related to data access, usage, and transparency within the National Health Service (NHS) in the UK. In a nutshell, the review made recommendations to streamline and improve the process for researchers to access and use NHS data for research while ensuring patient privacy and transparency. Recommendations and insights relevant to the Wessex SNSDE project are summarised below:

- Create a single map of all required approvals to simplify the process for navigation, and to help the public understand research governance.
- Ensure researchers' presence at meetings – e.g., at DAC – to promptly clarify misunderstandings or provide clarifications.
- Establish an arbitrator for disagreements over specific access requests, especially concerning data outside NHS control.
- Have appropriate sanctions for individuals caught deliberately / maliciously attempting to re-identify individuals in patient records.
- Be clear about the definitions of anonymous, pseudonymised but re-identifiable, identifiable, and linked data.
- Disclose all data flows leaving NHS organisations. Goldacre recommends one central, public place to enhance transparency; it is currently unclear where national policy is on this.
- Goldacre recommends negotiating co-ownership of claimed commercial innovations from NHS data to ensure that the value derived from NHS datasets is shared between the NHS and commercial users.
- Promote open code and data practices; test where this applies within the SNSDE environment.
- Establish PPIE expectations for use cases operating on the SNSDE, recognising that one-size-fits-all PPIE requirements can be unrealistic.
- Prioritise equity, inclusivity, and diverse voices in citizen engagement. Assess baseline knowledge and provide training for meaningful participation. Foster ongoing dialogue for mutual benefits and create a culture of citizen involvement within the organisation.

Ipsos (2022). A deliberation on London's health & care data

This deliberation builds upon the work of the OneLondon Citizens’ Summit. Over four three-hour deliberative workshops in February 2022 with 59 Londoners, selected to be reflective of London’s diverse population, participants learnt about how depersonalised data is used in research, planning and improvement. The report sets out a set of expectations which were codesigned by members of the public who took part.

- No selling of data but applying tiered charges for access.
- Prohibition on using data for marketing or insurance purposes.
- Establish Data Access Groups with diverse voices to scrutinise and challenge data access requests.
- Data access contracts should include proportionate financial penalties and sanctions for breaches.
- Promote the National Data Opt-Out transparently to build trust.
- Highlight the Five Safes framework for data security.
- Stress the advantages of health and care data use for public health and NHS financial sustainability.
- Suggested communication channels include offline methods like leaflets at GP surgeries and train station adverts, as well as online platforms such as social media and text messages.

Ipsos (2022). NHS AI Lab Public Dialogue on Data Stewardship

This public dialogue aimed to understand participants' attitudes towards data stewardship for AI research in healthcare, involving four online workshops with 47 members of the public and specialists providing additional information on different decision-making approaches. Workshops introduced participants to health data for AI research, National Data Opt-Out, and Five Safes framework.

- Initially, participants favoured delegated decision-making due to specialist knowledge and perceived speed.
- Concerns arose about the lack of individual choice in delegated approaches.

- Importance of who is involved in delegated decision-making emerged; expected skills, patient/public interest focus, and accountability.

Atkin et al (2021). Perceptions of anonymised data use and awareness of the NHS data opt-out amongst patients, carers and healthcare staff.

Explores public awareness and support for the secondary use of health data and the national Data Opt-Out, focusing on the impact of demography and healthcare experience. Includes co-development of recommendations on sharing unconsented health data for research. Activity included a patient and public engagement program, workshops, questionnaires, and discussion groups. There were 350 participants in total.

- The majority of respondents are willing to allow their anonymised health data to be used for NHS research and academic research.
- 94% of respondents were happy for their data to be used for NHS research, 85% for academic research and 68% by health companies, but less than 50% for non-healthcare companies.
- Awareness of the National Data Opt-Out (NDOO) system is low, highlighting the need for improved education. (32% awareness overall, 53% of NHS staff and 29% of all patients.)
- Concerns about health data use include unauthorised data reuse, discrimination, and data sharing without clear patient benefit.
- Recommended access requirements for unconsented secondary health data use are: ensuring patient benefit, involving patients in data sharing decisions, data retention by NHS, data minimisation, and transparency.
- The NHS is consistently seen as the most trusted partner to hold data or make decisions on health data use.
- People believe the public should be involved in decisions about how NHS data is used and that benefits should be shared across the NHS.

Discover-NOW (2021). Citizens Advisory Group Deliberations 1 & 2 - Reports

The Discover-NOW Board committed to establishing a Citizens Advisory Group to involve the public in the oversight and development of health and care data policies. Ipsos MORI, working in partnership with Imperial College Health Partners, was commissioned to design and deliver two deliberations over the course of 2021.

The first deliberation focused on public expectations for non-NHS partners accessing data in a trusted research environment. Participants were positive about the potential for research advancements but discussed trade-offs between anonymised aggregate data and linking de-personalised data with other Trusted Research Environments.

Attitudes towards sharing health data for R&I:

- General lack of awareness that data ‘about me’ is used in research and development.
- Trust in universities for data access, concerns about commercial organisations and international companies (due to data protection standards).
- Specific concerns expressed about insurance-based healthcare models, employer access to health data, and data security.
- Support for working with commercial partners where there are strong access control criteria.
- Support for a diverse and independent Data Access Committee. Key challenges being bias from ‘uninformed’ members of the public, versus laypeople being ‘railroaded’ by specialists, or competing voices failing to agree.
- Conditions and controls for trusted research access: time limited, legal penalties, only approved researchers, a real evidence gap, data minimisation, contracts, access restrictions, audit trails, secure data deletion, and peer review. (At the same time concerns that this could restrict vital research by non-medical experts.)
- Majority support for linking de-personalised data with other Trusted Research Environments with conditions: additional approval, clear research rationale, criminal penalties, and parity of security in receiving TRE.

Value exchange models:

- Incorporate an upfront access fee as a standard part of value exchange models. This could be refundable where royalties or profit share, IP or equity share, etc. were part of the contract.
- A tiered pricing model should be adopted, accommodating smaller organisations and maintaining inclusivity.
- Utilize a range of value exchange models as one size does not fit all, allowing flexibility for different arrangements and organisations.
- When entering into arrangements, prioritise realistic options such as sharing royalties, which are more tangible and less risky compared to sharing equity.

Commercial surplus investment:

- In situations with a significant surplus, reinvest some into maintaining and improving the Trusted Research Environment (TRE) for data storage, security, and technology.
- Allocate a portion of the surplus back into the NHS as a financial return for its initial investment, recognising it might be a relatively small contribution.
- Consider investing some surplus into a research fund aligned with local needs, promoting long-term benefits to the NHS and the community.
- Distribute smaller surpluses to areas in need, focusing on a research fund and community groups or charities to benefit vulnerable populations.

In deciding how any future surplus should be distributed, three clear and consistent underlying principles emerged.

1. **Greatest impact.** Any future surplus should be allocated to the areas where there is potential for the greatest impact.
2. **Robust, transparent process.** In deciding where any surplus should go (based on the principle of greatest impact), there must be a robust and transparent process, which involves the right people (including patients).
3. **Address local issues.** In allocating future surplus, the driving factor for how the funds will be used should be the ability to address local issues.

Greater Manchester ARC (2021). Data Sharing in a Pandemic: Three Citizens' Juries' Report.

This is a report of three online citizens' juries about data sharing in a pandemic. All three juries were in favour of each of the three data initiatives and the two sub-case studies continuing 'as long as it is valuable'. Jurors considered OpenSAFELY to be the most transparent, trustworthy, and secure. The juries supported the decisions to introduce the initiatives in spring 2020. A majority were in favour of all the data sharing initiatives continuing for as long as they were valuable. Support ranged from 58% for the NHS COVID-19 Data Store and Platform to 87% for OpenSAFELY across the three juries.

- Identifies the need for good public engagement, secure data storage, and clear governance.

Ada Lovelace Institute (2020). Confidence in a crisis? Building public trust in a contact tracing app.

In May 2020, the Ada Lovelace Institute, Traverse, Involve and Bang the Table convened a rapid online discussion with 28 members of the public – the ‘Lockdown Debate’ – to explore attitudes to the use of COVID-19 related technologies for transitioning out of lockdown. The project was deliberative, bringing together participants from a range of backgrounds. The core question posed to the cohort was: ‘Under what circumstances do citizens think that technological solutions like the COVID-19 contact tracing app are appropriate?’. Their recommendations are:

- Provide a transparent evidence base (esp. on benefits and commercial relationships)
- Include independent third-party review
- Clearly define boundaries on data use and justifications.
- Proactively address the needs of, and risks relating to, vulnerable groups
- Proportionality in sharing data for the greater good is emphasised.
- Anonymisation of data and limited data retention are essential for longer-term storage.
- Users should have the right to know their data categorisation and challenge incorrect data.
- Ethical considerations and the values embedded in technology should be consciously addressed.
- The whole system, not just technology, needs to be trustworthy for public confidence.

OneLondon & Ipsos (2020). Public deliberation in the use of health and care data.

Report on the OneLondon Citizens’ Summit held in early 2020. The research comprised 100 demographically representative Londoners, from across all 32 boroughs, and reflecting a range of attitudes towards data sharing (positive, neutral and cautious). They participated in a four-day Citizens’ Summit held over two weekends. The design of the deliberation, including format and content, was informed by insights work and social research with marginalised and vulnerable communities.

- An overwhelming majority of participants support joining up health and care data for individual care and using de-personalised data for planning, research, and development.
- Public acceptability and trustworthiness are shaped by features such as privacy, safety, and transparency.
- People prioritise patient safety and high-quality care over privacy concerns.
- Conditions for accessing and using health and care data should include authorisation, need-to-know basis, safeguards, accountability, serious consequences for misuse, and transparency.
- Data must not be shared with, or sold to, insurance companies or for marketing purposes.
- The process for de-personalising data needs to be clearly communicated: who is involved and how is this done.
- Roles Based Access Control (RBAC) is considered an acceptable way of managing access to health and care data.
- Commercial organisations working with NHS analysts to use de-personalised data for research have potential benefits but require caution.
- Public involvement in ongoing policy development should include a diverse Citizens' Advisory Group.
- Two or three citizen representatives should also sit on decision-making boards with people who work in health and care as well as experts. These roles should be time-limited (and replaced every three years).
- Convenience is seen as an acceptable reason for data to be shared more widely.

Commercial partnerships:

- Benefits should be shared with the NHS, including shared Intellectual Property, royalties, stake (in companies), profits, and outputs (e.g., discount on new drugs).
- Benefits should be shared across the NHS to avoid inequalities, maintain British values, and the principle of the NHS.
- Charges for data access should include recovering maintenance/usage costs as a minimum.
- NHS should charge for access to data (not selling data) for a time-limited period and/or license access to data.
- Differential charging should be implemented, with tiered charges based on turnover and profit-making.
- Public reporting of who has accessed and uses the data, the impact of the research undertaken, and distribution of any financial benefits to the NHS.
- NHS should publish criteria for vetting potential partners, outlining the process they need to go through to obtain access (e.g., for charities, commercial companies, universities).
- Access to data should not be granted to insurance companies.
- All accepted research proposals should demonstrate that they are in the public interest.

Sheehan et al (2020). Trust, trustworthiness and sharing patient data for research

The UK government emphasises the importance of building and maintaining public trust in healthcare. Transparency and accountability are key principles in the use of patient data for research in the National Health Service (NHS). Reports on a co-production workshop with a group of 11 members of the public and two academic ethicists to collectively consider how philosophical accounts of trust might apply within the context of data sharing in the NHS.

- Trust and reliance are separate qualities. Reliance is ‘dependence based on the likely prediction of the other’s behaviour’. Trust comprises reliance, plus commitments and values.
- Trusting is associated with gratitude when it is vindicated and betrayal when it is not.

- Trust and trustworthiness can, and often do, come apart. Being trustworthy does not guarantee that trust will be granted, and when trust is placed, it is not always in trustworthy individuals or institutions.

- The leadership of the project must be demonstrably trustworthy, not merely reliable. They must have the right commitments and values.

- The public should not be required to trust corporate partners but should be confident relying on them or the structures which govern them.

TigTech (2020). Trust and Tech Governance

Discusses the importance of trust in tech governance and the need to incorporate trustworthiness into governance institutions and design. It highlights the drivers of trust and sources of distrust, such as concerns about algorithm impacts, data privacy, and facial recognition. The paper emphasises the importance of building trusted environments and the role of regulation in earning trust. It also covers the need for collaboration and involvement of citizens in governance design. It concludes by discussing the complexity of values and ethical decisions in emerging technologies and the importance of aligning governance with shifting ethics and beliefs.

- Traditional regulation is generally trusted, but relies on effectiveness and enforcement

- Governance must prioritise the public interest

- Focus on ethics, values, and societal impact

The paper identifies 7 Trust Drivers, which show how involving and taking seriously the views of citizens is important for trust:

- **Intent** – It brings greater depth to understanding of what constitutes the Public Interest

- **Competence** – It helps understand expectation and the issues that citizens consider important for governance to deliver

- **Respect** – It demonstrates respect; citizens can see that their views have been taken seriously

- **Integrity** – It helps ensure that one single stakeholder group does not have undue influence on a decision

- **Inclusion** – It gives agency to citizens to shape the technologies that are in turn shaping their lives

- **Fairness** – It demonstrates a commitment to fairness and 'procedural justice'
- **Openness** – It opens up processes to wider scrutiny, incorporates a broader spectrum of views and helps provide evidence of trustworthiness

It also provides a succinct rationale for involving citizens in governance:

1. To access their diverse expertise
2. To spot real world gaps
3. Because 'more of us' are wiser than 'some of us'
4. It gives greater legitimacy to decisions
5. People deserve and may wish to have a say over issues that affect them

Web Science Institute (2020). A Blueprint for a Social Data Foundation.

- Position the SDE as a third-party intermediary to facilitate shared data analysis projects, ensuring governance, agreement brokerage, and shared data management services.
- Rigorously evaluate and mitigate the risk of re-identification.
- Avoiding sharing entire datasets.
- Risk assess each project on the basis of clear criteria.
- Share only deidentified data
- Establish clear and robust agreements governing relationships among all stakeholders
- Ensure compliance with legal, ethical, and cybersecurity requirements.

Understanding Patient Data (2020). Foundations of Fairness - Where next for NHS health data partnerships?

In June 2019 Understanding Patient Data and NHS England in association with the Ada Lovelace Institute, commissioned Hopkins Van Mil to carry out a mixed methods public engagement process, exploring the question: 'What constitutes a fair partnership between the NHS and researchers, charities and industry on the uses of NHS patients' data and NHS operational data?'

- 63% unaware of NHS data access
- 81% support nationwide benefits, not just the partnership area
- Estimated NHS data value: £9.6bn
- 72% interested in how researchers use NHS data
- 74% believe the public should decide on NHS data use
- Local/regional communication preferred for trust
- Need for a governing body / national governance / joined-up approach to overseeing NHS data partnerships
- Governance should include ongoing citizen evaluation of effectiveness / previous decisions
- Health and Wellbeing Boards could provide an established route to public involvement
- Partnerships should focus on improving health outcomes and reducing inequalities; share benefits across the NHS in a defined timeframe; with transparency and accountability; and continual review of data sharing policies considering political and technological changes like Brexit and GDPR.

Chico et al (for the HRA) (2019). Public views on sharing anonymised patient-level data where there is a mixed public and private benefit.

Research comprised workshops with 55 demographically representative participants from the South Yorkshire. The research explored public acceptance of commercial access to anonymous patient health.

- 18% of people support sharing anonymised patient-level data with commercial organisations.
- Education about the role of commercial organisations in healthcare increases acceptance. After deliberative workshops support was 45%.
- Conditions for commercial data access were unanimously agreed upon:
    1. People strongly believe that the NHS should benefit from products or services developed using patient data.

2. Preferred benefits include preferential rates for products and unlimited access to new knowledge or insights.
3. NHS involvement should be seen as an end-to-end partnership, providing assurance to the public.

- People are more accepting of sharing data with pharmaceutical and data analytics companies compared to insurance or marketing firms.
- Trust in commercial organisations accessing patient data is influenced by factors like company size, conflict of interest, services portfolio, track record, and international status.
- Assurance of data protection, commitment to public benefit, regulation, and quality assurance are crucial for building trust.

Fiona Fylan, Brainbox Research (2019). Joined Up (Yorkshire & Humber Care Record research).

This report summarises insight research commissioned to inform the Yorkshire and Humber Care Record. It aims to explore the beliefs that people have about how their health and care records could and should be used, their boundaries for what they are willing for their data to be used for, their concerns around how their data could be used, and the reassurances they want about how their data is safe.

- Public is generally willing to share data beyond direct care for planning services, staying healthy, and research. Support varies depending on the perceived benefits and safeguards in place.
- High trust in GP practices and the NHS.
- Requirement that data sharing for R&I is for the public good.
- Generally positive attitudes toward the use of anonymous health and care records for research.
- 56% support general research for the public good, and >70% support for NHS to research disease treatment, risk factors, and genetics of disease.
- 16% support commercial research
- 46% support using health data to invite people to take part in medical research
- Desire for control over who accesses their records and what they do with them.
- Key concerns are data sale, security, and service cuts.

— Support for opt-in or opt-out mechanisms for data sharing.

The research identified five personas (NB. Sam was not observed in the research but is inferred, and considered important):

1. **Chris.** I am proud of the NHS and social care services, and I trust them with my information. I am happy for my information to be shared with people who care for me as well as with people who plan services and undertake research. I haven’t thought much about data security in the past and I don’t think it’s a problem if I could be identified from my health and care records.

2. **Jordan.** I have had relatively little contact with the NHS and social care, and I assume that my records are available to anybody involved in my care. I often share my personal information on social media sites. I know that personal data is valuable, but I’m not worried about what might happen to my health and care information.

3. **Ali.** I have experienced previous problems with poor communication or connectivity in the NHS and local authority, so I know that my health and care records aren’t easily accessed by people who are involved in my care. I am keen for this to change, and I know it will require more data sharing. I am happy for my information to be used for planning services and for research, although I want to be able to opt out.

4. **Alex.** I am happy for my information to be shared with people involved in my care, but I am wary of who might see what. I want access beyond staff treating me to be restricted and I want to be able to track who has accessed my records. I don’t want my health and care information to be used by commercial organisations without my consent. I am sceptical that the healthcare system can keep my data secure.

5. **Sam.** I have complicated health or social needs which make me vulnerable, and I face many barriers to accessing healthcare. I am not too concerned about who can access my health and care records because I have more pressing needs. I may have problems that make it more difficult to access or use technology that others take for granted.

Kalkman et al (2019). Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence.

A review of 27 papers on patients' and public views on health data use for research. The majority of participants expressed support for data sharing, but also had concerns and conditions. The authors suggest the need for a value-based governance framework to address these concerns and strengthen the social license for Big Data health research. Trust in researchers and institutions is crucial for successful data sharing initiatives.

- A value-based governance framework that includes diverse patient and public values is needed for data-intensive health research. This is the basis of a social licence.
- Majority support data sharing for health research, motivated by contributing to healthcare advancements.
- Conditions for data sharing include public value, privacy, risk minimisation, data security, transparency, control, information, trust, responsibility, and accountability.
- Participants want involvement, notification, and information about data use.
- Accountability and consequences for data misuse are essential.

Academy of Medical Sciences (2018). Our data-driven future in healthcare.

This report outlines a set of principles based on dialogues with patients, the public and healthcare professionals, for the development, evaluation, and deployment of data-driven technologies in healthcare. These principles are:

1. Support clearly defined purposes that uphold the social values of the NHS and benefit individuals, the NHS, or society.
2. Respect and protect the privacy, rights and choices of patients and the public.
3. Include patients and the public as active and meaningful partners.
4. Maintain trustworthiness in the responsible and effective stewardship of patient data within the NHS.

5. Incorporate mechanisms for evaluation and regulation that build public understanding, confidence and trust in these technologies, and guide their use in the NHS.

Aitken et al (2018). Who benefits and how? Public expectations of public benefits from data-intensive health research

Research to identify what public expectations of ‘‘public benefits’’ from data-driven health research are. 3 workshops with 69 members of the public were held across Scotland in May and June 2017. Workshop participants’ preference was clearly for the widest possible public benefit to be felt by all, but they also acknowledged the value in research aiming to primarily benefit vulnerable groups within society. A key focus of discussions was the extent to which workshop participants were confident that potential public benefits would be realised.

- Demonstrating public benefits is essential for maintaining a social license for research practices.
- People prefer a wide public benefit and recognise the importance of benefiting vulnerable groups. Economic benefit was not raised as important by participants.
- Broad conceptualisations of public benefits emerged, including cures, improved lifestyles, and knowledge dissemination.
- There must be commitment and confidence that direct benefits of research will be realised, and findings actioned.
- Involvement of private companies or funding raises public concerns.

Stockdale et al (2018). “Giving something back”: A systematic review and ethical enquiry of public opinions on the use of patient data for research in the United Kingdom and the Republic of Ireland

A systematically review the literature on UK and Irish public opinions of medical data use in research, critically analysing such opinions though an established biomedical ethics framework, to draw out potential strategies for future good practice guidance and inform ethical and privacy debates.

13,472 peer-reviewed papers were reviewed, 20 met the inclusion criteria, covering research from 2004 to 2016. Audiences included Service-users, lay persons, those living with chronic conditions, and the general public ranging from 16 years of age to over 75. Five of the studies included the views of health researchers, health professionals, industry experts, NHS managers and other key stakeholders.

- Public knowledge of the content and collection of patient data in EHRs was reasonably high, but knowledge about the secondary uses, such as data sharing for research, was low.
- People are generally willing to share their data for the “common good”, subject to safeguards and concerns about privacy. Privacy is closely tied to the idea of control over their information.
- Older people (35-65) are more likely to be worried about security than younger people (25-34).
- Older people are more likely to support research by commercial organisations using patient data.
- Lower educational qualifications lead to a preference for explicit consent but less worry about security.
- Lower socioeconomic status is associated with greater privacy concerns and less trust in data handling.
- Non-White British individuals are more concerned about privacy and expect explicit consent.
- Transparency, fairness, and data security are essential in patient data research.
- Research objectives should contribute to the public good and have scientific value.
- Ethical principles such as respect for autonomy, transparency, and harm minimisation should guide decision-making.
- A social license is necessary for data-sharing initiatives, rooted in public core values.

Tully et al (2018). Investigating the Extent to Which Patients Should Control Access to Patient Records for Research: A Deliberative Process Using Citizens' Juries.

The secondary use of health data for research raises complex questions of privacy and governance. The aim of this project was to extend knowledge about what control informed citizens would seek over the use of health records for research after participating in a deliberative process using citizens' juries. Two 3-day citizens' juries of 17 citizens each, were convened to reflect UK national demographics from 355 eligible applicants. Each jury addressed the mission “To what extent should patients control access to patient records for secondary use?” Jurors heard from and questioned 5 expert witnesses.

- Majority support use of health data for research, indicating public acceptance.
- Public believes individual privacy should not prevent research for overall patient benefit.
- Patients should be notified and have the right to opt out.
- Public benefit was a crucial justification for accessing patient records.
- Education about benefits and risks resulted in reduced scepticism.
- Witnesses in citizens' juries should present diverse viewpoints and allow time for questioning.

Y: Health data for R&I audience insights – Summary report

NHS

Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data Environment Network

Health data for R&I audience insights

October 2023

Web Science Institute
University of Southampton

BMJ
British Medical Journal

Sources

Ipsos

Wessex Care Records

DARE UK

NHS
Digital

Goldacre Review

TIGTech
Earning Trust in Tech Governance

Understanding Patient Data

ONE LONDON

The Academy *of* Medical Sciences

NHS
Health Research Authority

Ada Lovelace Institute

NIH
National Institutes of Health

GM Care Record
We are better together

NHSX
AI MED
The NHS AI Lab
Accelerating the safe adoption of AI

NIHR | Applied Research Collaboration Greater Manchester

NHS
England

Discover-NOW
Health Data Research Hub for Real World Evidence

Yorkshire & Humber Care Record

Local and national feedback themes

Concerns & risks

- Data security
- Access controls
- Lack of sanctions
- Sale of data
- Bias / discrimination
- Errors in data
- Identification risk
- Loss of control / opt-outs

Support & value

- Patient benefit
- NHS benefit
- Use in Direct Care
- Public involvement
- Anonymisation
- Enhanced security
- Cost recovery
- Transparency

Public attitudes to health data sharing

- **63%** unaware of NHS data access
- Many uneasy but struggle to say why
- Small minority want to learn more
- Majority trust the NHS with their data
- **55%** support general research for public good
- **>70%** support NHS research to tackle disease
- **16%** trust big pharma accessing pseudonymised data
- Deliberative dialogue increases trust (+27%)
- NHS partnerships increase trust (66% with big pharma)
- **74%** say the public should decide on NHS data use

Demographic insights

Several demographic groups come up as either more likely to distrust or as having specific expectations:

- <44 age, socio-economic group A, Black Caribbean/Black African/Black British, carers, and LTC patients are more likely to opt out
- Older people worry about security but support commercial research
- Lower education prefers explicit consent, fewer security worries
- Lower SES means more privacy concern, less trust
- Non-White British more privacy concerns, expect explicit consent

Governance recommendations

- Requirement for **values-based governance framework** reflecting diverse views
- Patients should be able to access their data and challenge errors
- Establish arbitrator for disagreements
- Appropriate sanctions (criminal and financial)
- Disclose all data flows leaving NHS
- Open code and data practices
- PPIE standard for use cases operating on the SNSDE
- Prohibition on marketing and insurance uses
- Public favour delegated decision making
- Citizens' Advisory Group plus 2-3 reps on decision-making boards

Access criteria

Across the literature review several criteria were identified as necessary conditions of access to health data:

- Public interest test
- Approved researchers
- Access restrictions
- Time limited
- Data minimisation
- Secure data deletion
- Peer review
- Audit trails
- Clear accountability
- Contracts
- Serious sanctions
- Transparency

Commercial model

There is public consensus on aspects of the commercial model:

- A range of models as one size does not fit all
- Tiered pricing based on data use and type of organisation
- Include an upfront access fee, potentially refundable in certain contract arrangements
- NHS co-ownership of claimed commercial innovations / IP – prioritise lower risk options like sharing royalties
- Surplus reinvestment split between SDE, NHS, a research fund aligned with local needs, and VCSE orgs supporting vulnerable populations