Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS

Listening to Seldom-Heard Groups across Wessex

June 2024

Contents

Foreword ... 3
Executive Summary ... 4
Background ... 6
Objectives ... 7
Methodology ... 9
Results ... 14
Findings ... 22
Analysis ... 28
Recommendations ... 30
Acknowledgements ... 34
Contact ... 35
Appendices ... 36

Foreword

When I first became involved with the Wessex Secure Data Environment (SDE), it was through a series of early outreach meetings specifically aimed at engaging seldom-heard communities in early 2023. At that time, I didn't fully appreciate the significance this initiative would have, not only for my own community in Fareham but also for communities right across Wessex.

My active involvement with the Wessex SDE began as a Digital Critical Friend, a diverse group of public participants that act as a bridge between the SDE team and t and the diverse communities it aims to serve. We provide public scrutiny, fresh perspectives, and help design the SDE's governance, ensuring its inclusive and we are transparent about what we are doing.

This is a role I embraced because I wanted to ensure that the voices of underrepresented groups – often overlooked or marginalised – were not just heard but actively shaped this vital programme. Having worked extensively as a community researcher and advocate within Hampshire, I understand deeply the mistrust and reservations many communities have when it comes to data use and healthcare. That’s precisely why authentic engagement, the kind shown by the Wessex SDE team, is essential.

This report reflects the dedicated, meaningful, and inclusive approach taken by the Wessex SDE programme. It is not just a summary of findings; it is, I believe, a testament to genuine listening and committed co-design. As someone who now proudly serves as a public member on the Wessex Data Access Committee – a group that recommends which research projects should go ahead – I can personally say that these insights are actively guiding the governance, design, and strategic decisions of the Wessex SDE.

Our collective goal remains clear: to build a SDE that safeguards NHS patient data while unlocking its immense potential to save lives, improve health outcomes, reduce inequalities, and accelerate vital medical research. The findings and recommendations set out in this report will help ensure that trust, transparency, inclusion, and accountability remain at the heart of this ambitious programme.

I encourage everyone in Wessex, particularly those from diverse and underrepresented backgrounds, to get involved with the SDE – and with health research more widely. Your voice matters greatly – it is shaping how health data will serve our communities, today and in the future.

Sandra Hall

Wessex SDE Digital Critical Friend
Public Member of the Wessex Data Access Committee

Executive Summary

The Wessex Secure Data Environment (or SDE) is unlocking the potential of our NHS patient data to support research, create life-saving new treatments and medicines, and bring wider benefits to patients and our NHS.

The success of the Wessex SDE is founded on public trust. Trust in turn is built in partnership with the people of Wessex through genuine and meaningful involvement. Listening to under-represented and marginalised groups is critical to ensure that those that have potentially much to gain from research are at the heart of the Wessex SDE, to remove barriers, and ensure research outcomes that genuinely improve lives.

To make sure we spoke to the right people, we used NHS England's Core20PLUS5 framework, reviewed local Joint Strategic Needs Assessments (JSNAs) from councils across Dorset, Hampshire, and the Isle of Wight, and included key groups identified through equalities legislation. This helped us identify and involve 26 distinct groups facing significant health inequalities or who are often under-represented.

From July 2023 to April 2024, the Wessex SDE team listened carefully to over 600 people across Dorset, Hampshire, and the Isle of Wight, focusing especially on communities whose voices often go unheard. Through 37 tailored discussions involving 31 community and voluntary organisations, people generously shared their hopes, concerns, and expectations about how NHS patient data could support better healthcare.

People told us clearly that they see the real benefits of the SDE, such as quicker diagnosis, better treatments, and improved health outcomes. Yet, they also shared honest concerns about data security, transparency around how their information will be used, and fears about data misuse. They urged us to ensure the SDE truly reflects the voices and needs of everyone, especially marginalised groups.

Five themes emerged clearly from these conversations, each closely connected and essential to the success of the Wessex SDE. At the heart is the theme of **'Trust and Transparency'**. People consistently highlighted the importance of knowing exactly how their data would be used and feeling assured that their privacy and personal details were genuinely protected. Closely linked to this was the theme of **'Inclusion and Empowerment'**, emphasising that building trust requires actively involving everyone – particularly those whose voices have often been unheard or marginalised – in shaping decisions and making sure their contributions genuinely influence the design of the Wessex SDE, and the research it supports.

Participants also stressed the importance of ensuring **'Data Accuracy and Security'**, underscoring the need for the NHS to maintain accurate, complete, and up-to-date data, and to safeguard it robustly against misuse or security breaches. At the same time, contributors were thoughtful about broader **'Systemic Challenges and Resource Priorities'**, raising questions about whether investing in an SDE was the best use of NHS resources, particularly given urgent healthcare priorities such as reducing waiting lists or improving primary care. Finally, underpinning all these themes was the essential need for clear **'Accountability and Governance'**, with participants calling for transparent, fair, and ethical oversight of the SDE, ensuring decisions made about data use consistently reflect public expectations and serve the greater good.

Based on these insights, we've committed to developing clear, values-led principles to guide every part of the SDE. We'll use relatable, inspiring examples to explain how NHS data can directly improve lives, and we'll maintain open and transparent dialogue with our communities. We'll also make sure our methods of engagement are accessible, culturally sensitive, and inclusive – relying on trusted local voices to help us reach everyone. These principles and recommendations will continue to evolve, shaped by ongoing conversations, particularly through the Wessex Public Panel on NHS data.

Finally, our heartfelt thanks go out to every person and organisation who contributed. Your honesty, passion, and trust are making the Wessex SDE a truly community-driven initiative that will genuinely improve health and care for everyone in our region.

Background

The Wessex Secure Data Environment (SDE) is a secure cloud-based computing platform designed to enable safe and confidential use of NHS patient data for research and innovation. Part of the national NHS Research SDE Network, the Wessex SDE is hosted by University Hospital Southampton NHS Foundation Trust (UHS) and covers Dorset, Hampshire and the Isle of Wight. This initiative enables approved researchers to access de-identified NHS patient data without it ever leaving a controlled environment, ensuring privacy and enhancing data security.

The development of the Wessex SDE aligns closely with national NHS and Department of Health and Social Care (DHSC) policies. In particular, the DHSC's 'Data Saves Lives' strategy emphasises Secure Data Environments as essential for safe and effective health research. This approach reflects the findings of the Goldacre Review, which stressed the importance of secure, transparent, and trusted data access arrangements. NHS England and the government have invested substantially to develop regional SDEs across England. This strategic investment aims to advance research, improve healthcare outcomes, and maintain public confidence in how patient data is used.

Public trust is central to the success of the Wessex SDE. Recognising this, the Wessex SDE team has placed significant emphasis on public involvement and transparency. Rather than imposing a top-down solution, the programme has committed to co-designing the SDE with local communities. This inclusive approach helps ensure that the platform is built with robust ethical standards and aligns with public expectations. By involving citizens early and regularly, the Wessex SDE demonstrates openness, accountability, and responsiveness to public concerns.

Within this public engagement strategy, the Wessex SDE team has prioritised working with seldom-heard groups as a first step; these groups are often under-represented in health and social care decisions. A literature review undertaken by the Wessex SDE identified a clear gap in existing knowledge: research and consultations on health data use have disproportionately involved mainstream or easily accessible audiences, leaving significant knowledge gaps regarding marginalised communities' concerns and needs. By prioritising these groups from the outset, the Wessex SDE aims to ensure their voices shape its fundamental values and objectives. This targeted engagement provides valuable insights that can guide broader regional conversations and decision-making processes.

Engaging with seldom-heard communities early serves both ethical and practical purposes. Ethically, it ensures fairness and inclusivity, as those most at risk of marginalisation or disadvantage have an opportunity to influence outcomes directly affecting their communities. Practically, it provides essential insights into potential barriers and opportunities that might otherwise be overlooked. Understanding the perspectives and concerns of these groups strengthens the Wessex SDE's foundations, ensures it is culturally sensitive, and ultimately helps build greater trust across all sections of the public. As these relationships take time to develop this engagement activity builds a foundation for future involvement.

Objectives

Objective 1: Ensure meaningful involvement of seldom-heard communities in the design, governance, and communication of the Wessex SDE.

Historically, certain groups have been marginalised or excluded from decisions around NHS data use. Engaging these communities directly ensures their unique concerns and perspectives shape the SDE, creating a trusted platform that genuinely reflects the diversity of the population it serves.

Objective 2: Clearly segment seldom-heard audiences to achieve diverse and representative participation.

Effective segmentation of seldom-heard groups is fundamental to achieving genuinely inclusive participation and capturing critical nuances and intersectional perspectives. This engagement project aims to achieve a meaningful segmentation through the use of established frameworks such as NHS England’s Core20PLUS5, local authority Joint Strategic Needs Assessments, the protected characteristics defined in the Equality Act 2010, and an understanding of the region’s diverse communities and geography.

This deliberate approach ensures that engagement activities capture a richer diversity of lived experiences, strengthening the validity, sensitivity, and representativeness of insights informing the SDE’s design and governance.

Objective 3: Engage communities within their own familiar settings and contexts.

Traditional NHS consultation methods can fail to attract seldom-heard communities, many of whom face barriers such as low trust, low digital literacy, language barriers, or unfamiliarity with formal environments. By proactively visiting groups in their own spaces and contexts, using clear language, tailored communication methods, and trusted local intermediaries, the team overcame these barriers and fostered greater participation, trust, and authentic dialogue.

Objective 4: Adopt flexible methods tailored to the interests and appetite of the groups engaged

Effective PPIE practice requires the use of flexible, responsive engagement approaches that meet seldom-heard groups on their own terms, rather than expecting them to adapt to standard NHS consultation formats.

Evidence from established frameworks such as NIHR INCLUDE and the National Standards for Public Involvement highlights that employing a varied engagement toolkit enables participants to engage according to their own interests, capacities, and comfort levels.

Importantly, even brief or initial interactions have intrinsic value. They are instrumental in beginning to build trust, opening channels of communication, validating community perspectives, and gradually reshaping relationships between marginalised communities and the NHS. Recognising and valuing all levels of engagement, regardless of depth or duration, can foster longer-term confidence, interest, and a sense of genuine partnership.

Objective 5: Provide practical support to ensure inclusive participation and remove barriers to engagement.

Participation can impose practical costs or burdens (e.g., travel expenses, lost time, childcare costs) that disproportionately deter marginalised groups. Offering practical support such as reimbursement of travel expenses and participant compensation ensures equitable access, enabling individuals from all backgrounds to participate without hardship. This should be done in line with NIHR guidelines, whilst ensuring that compensation is relevant and proportionate.

Objective 6: Close the feedback loop by clearly demonstrating to participants how their input has shaped the SDE’s development.

When participants can clearly see how their contributions have informed decision-making, trust and credibility are reinforced. Evidence from established PPIE practice consistently shows that transparency around how feedback is integrated leads to sustained engagement and deeper community relationships. By explicitly communicating back to communities how their input has influenced the Wessex SDE’s design, governance, and communication strategies, the programme will affirm the genuine value of their involvement.

Methodology

Team

University Hospital Southampton

The Patient and Public Involvement and Engagement (PPIE) activity in Hampshire and the Isle of Wight was led by Sarah Knott (Patient and Public Involvement and Engagement Manager) who was assigned from University Hospital Southampton's (UHS) dedicated PPIE function specifically to support this initiative. Sarah's role was underpinned by the wider expertise and established methodologies of the UHS PPIE team, which has a strong track record for embedding patient and community voices into healthcare research, service design, and quality improvement.

Sarah was supported by Heather Parsons, an experienced external PPIE consultant who provided additional specialist advice and facilitation. Together, they delivered focused and flexible engagement activities tailored to the needs of the communities involved, operating with considerable autonomy while maintaining close alignment with UHS's overarching commitment to patient-centred, inclusive, and impactful public involvement.

The PIER Partnership

The PIER (Public Involvement in Education and Research) Partnership at Bournemouth University led engagement across the Dorset region. PIER is a pioneering initiative within the Faculty of Health and Social Sciences, designed to embed public and patient voices at the heart of healthcare education and research. By involving individuals with lived experience, the partnership ensures that teaching and research are shaped by real-world perspectives, fostering a deeper understanding of the challenges and needs faced by service users and their families.

PIER members, who include patients, carers, and members of the public, collaborate with academic staff and students to co-produce curricula, contribute to research design, and deliver lectures and workshops. This inclusive approach enriches learning, challenges assumptions, and promotes person-centred care in healthcare professions.

The partnership also plays a key role in shaping impactful research, offering critical insights to ensure studies address meaningful questions and are ethically sound. This engagement supports more relevant and actionable outcomes, improving healthcare practice and policy.

Rooted in the principles of inclusion, respect, and collaboration, the PIER Partnership exemplifies best practices in public involvement, aligning with national frameworks for participatory education and research. It stands as a leading model of how universities can engage communities to drive positive change in healthcare and social sciences. Find out more at: Public Involvement in Education and Research | Bournemouth University.

Audiences

We used three criteria to identify target demographic groups for the engagement and involvement of seldom-heard groups:

1. NHS England's **Core20PLUS5 criteria** (an approach to healthcare inequalities that includes the most deprived 20% of the population, marginalised groups and clinical areas of focus). The Wessex SDE covers two Integrated Care Boards (ICBs): NHS Dorset and Hampshire & Isle of Wight ICB, both of whom produce their own targets in line with these criteria.
2. Demographic groups identified by local authorities in the Wessex region in their **Joint Strategic Needs Assessments** (JSNA). JSNAs are local assessments of the current and future health and social care needs of the population. They are conducted by local authorities in collaboration with health and social care partners.
3. **Equalities groups** defined by the Equality Act 2010 as people who share a protected characteristic. These characteristics are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.

This approach generated a list of target demographic groups, which are summarised in **Figure 1** below. More than 80 voluntary and community sector organisations were contacted to see if their groups would be interested in participating.

Figure 1: Target demographics identified for engagement

1. 65+
2. Armed Forces
3. Asylum seekers, refugees and unaccompanied minors
4. Coastal communities
5. COPD
6. Core20
7. Disability
8. Domestic Abuse
9. Early cancer diagnosis
10. Ethnic minorities
11. Falls & Frailty
12. Gypsy, Roma and Traveller community
13. Hypertension
14. LGBQT+
15. Long Term Conditions (LTCs)

16. Maternity
17. Minority ethnic communities most affected by Covid-19
18. People experiencing homelessness
19. People in contact with the justice system
20. People with a learning disability and/or autism
21. People with drug & alcohol dependency
22. People with serious mental illness
23. Sex workers
24. Veterans
25. Victims of modern slavery
26. Young people

Strategy

Seldom-heard groups often face barriers to participation due to accessibility, language, and trust issues. Building trust and creating a safe space for open dialogue are essential to capturing meaningful input. Insights show that co-designing sessions with trusted members of the group / group leaders ensures relevance and encourages participation.

Trusted relationships with seldom-heard groups take time to build and it is critical to work with professionals who already have a track record or existing relationships, for this reason the SDE team recruited the PIER partnership to support outreach in Dorset, complementing existing team capabilities in Wessex.

Identified groups were contacted by letter, email or phone with a short overview of the Wessex SDE and a request to engage with their group. The Wessex SDE team worked actively to secure their engagement, where this was possible researchers agreed to meet with groups as part of their existing activities or in small, informal focus groups.

The approach used in these group meetings was tailored to the context. Generally, the approach to the subject matter with the group took the form of a brief overview of the Wessex SDE with the aims of community involvement. It was highlighted that their identifiable patient information (with the safeguards the SDE has in place) will be used to link the data for use within the SDE.

The group were then asked for their thoughts and questions. For some groups, additional materials were used to facilitate the conversations and included a short SDE video prompt, visual prompts and the opportunity and materials to draw a visual representation of an SDE.

Implementation

Outreach and engagement work was carried out in two phases:

1. **July – September 2023**: Wessex SDE and the Wessex Academic Health Science Network undertook a piece of preliminary work; a rapid insight generation. It engaged with four groups, reaching around 30 people whose voices are seldom heard in research. Those initial conversations informed the next stage of the activity.
2. **November 2023 to April 2024:** Public and patient involvement and engagement specialists from University Hospital Southampton, Bournemouth University, and the Public Involvement in Education and Research (PIER) Partnership, organised 37 group engagements across Dorset, Hampshire and the Isle of Wight. Over 600 individuals were involved in these visits, workshops and conversations.

Discussion Guide and Stimulus Materials

To support the outreach and engagement activities across Dorset, Hampshire, and the Isle of Wight, the Wessex SDE team developed a detailed **Discussion Guide** (included as **Appendix 1**). This guide provided facilitators with comprehensive background information on the Wessex SDE, outlining key concepts, intended benefits, and anticipated risks associated with using patient health data for research.

The Discussion Guide included:

- Plain-language explanations of health data, its value for research, and management within the Secure Data Environment.
- Real-world examples of research projects enabled by health data to prompt reflection and discussion among participants.
- Structured activities and prompts to stimulate conversations around participants' hopes, concerns, and ideas related to data privacy, security, consent, and governance.

In addition to the Discussion Guide, facilitators were provided with a set of **supplementary stimulus materials** (see **Appendix 2**) to enhance engagement. These included:

- An "Easy Read" invitation document designed to encourage participation from diverse communities by explaining the format of engagement sessions and offering practical information about time commitments and incentives.
- An "Easy Read" introduction booklet to the Wessex Secure Data Environment, providing accessible explanations about the purpose and

benefits of the Wessex SDE, and clearly outlining the participants' role in shaping the platform.

- An "Easy Read" leaflet and poster titled "Your Information, Your Choice," explaining clearly and simply how personal health data is used, stored, and protected, highlighting individual choice and consent mechanisms.
- A set of visual presentation slides specifically developed to support inclusive and accessible discussions with seldom-heard groups.

In parallel, the BU PIER Partnership employed its tailored materials, including a short informational video, visual prompts, and drawing exercises, designed to facilitate deeper discussions among groups with varying levels of familiarity, literacy, or trust in health services. These materials aimed to foster inclusive engagement by enabling participants to express themselves in ways most comfortable to them, whether visually, verbally, or creatively.

It is important to note that while these materials, including the Wessex SDE Discussion Guide, provided structured and evidence-based support, facilitators were encouraged to adapt their approach flexibly according to the specific needs and interests of each group. Consequently, the actual extent to which these materials guided discussions varied significantly. The findings presented in this report are therefore informed by, but not exclusively derived from, the provided stimulus materials.

*Copies of the Discussion Guide and supplementary stimulus materials used during engagements are provided in **Appendices 1 and 2**.*

Results

Between July 2023 and April 2024, the Wessex Secure Data Environment (SDE) engagement programme carried out targeted engagement activities with seldom-heard communities across Dorset, Hampshire, and the Isle of Wight.

>80 organisations approached → 31 organisations involved → 37 group engagement sessions run → >600 individuals involved

In total, over 80 organisations were approached, either to engage directly, or to assist in convening groups. These initial approaches included an introduction to the Wessex SDE.

As a result, 31 organisations chose to be involved, either directly as participants, or in helping to convene sessions. Convened sessions comprised groups of public participants identified by demographic characteristics and convened by engagement partners. In total 37 group engagement sessions were run, involving more than 600 individuals.

The table below provides an overview of specific engagement activities conducted during this engagement project, highlighting the primary demographic groups involved. In practice, the participant profile within each activity was diverse, reflecting intersectionality and enabling representation across multiple equality and inclusion groups.

A full report produced by the PIER Partnership and covering the groups they convened may be found at **Appendix 3**, whilst a report by Health Innovation Wessex (then known as the Wessex Academic Health Science Network, or AHSN) on their work may be found at **Appendix 4**. Outputs of the activities undertaken by UHS are incorporated directly into the **Findings** section of this report.

Table 1: List of group engagements convened for this engagement project

Organisation or Group Name & Location	Main Demographic Group(s)	No.	Engagem/t Partner
1. 15-17 Year Olds (convened group, Dorset)	**Young people:** participants were aged 15-17 living in a high deprivation area in South Dorset and regularly attending a local youth group.	9	PIER

2. 18-24 Year Olds (convened group, Dorset)	**Young people:** participants were young adults aged 18-24.	12	PIER
3. Alabaré Veterans' Social Group – Boots on the Ground (Salisbury)	**Veterans, Armed Forces, and 65+**: participants were aged 50's – 80's, males and females.	37	UHS
4. Barton Peveril College (Winchester)	Young people: the group was diverse and aged 16-18.	7	UHS
5. Basingstoke Hindu Society	**Ethnic minorities** and **Minority ethnic communities most affected by Covid-19**: participants were from the Hindu population (aged 0-100) in the Basingstoke area.	32	UHS
6. Carers (convened group, Dorset)	**Carers:** participants self-identified as carers currently or recently caring for a parent, son or daughter, or young people with Autism Spectrum Disorder.	12	PIER
7. Chat with Chai (Portsmouth)	**Ethnic minority**: a community group of south Asian women, many with limited English language use.	10	HIW
8. Deprivation (convened group, Dorset)	**Core20:** participants comprised 11 community members and three community volunteers from a high deprivation area in Dorset.	14	PIER
9. DIGS – Disability Interest Group, Salisbury	**Long Term Conditions:** over 40 people with a variety of LTCs.	8	UHS
10. Enableability - Portsmouth Youth Project	**Young people, Disability,** and **People with a learning disability and/or autism**: aged 18-25 with mild to moderate learning difficulties and physical disabilities.	15	UHS

11. Enableability, Portsmouth Teenage Project	**Young people** and **People with a learning disability and/or autism**: participants were aged 13-17 with mild to moderate learning disabilities	16	UHS
12. Hart Young Carers, Fleet	**Young people** and **Carers:** participants comprised aged 7-25 who are active carers for a family member.	10	HIW
13. Headway – Gosport Friday Group	**Long Term Conditions, Disability,** and **Carers:** participants were aged 30-75 with an acquired brain injury, their families and carers.	35	UHS
14. Headway – Gosport Tuesday Group	**Long Term Conditions, Disability,** and **Carers:** participants aged 30-75 with an acquired brain injury, their families and carers.	32	UHS
15. Headway – Ladies Group (Portsmouth)	**Long Term Conditions, Disability,** and **Carers:** participants were women aged 30-75 with an acquired brain injury, their families and carers.	21	UHS
16. Headway – Petersfield Group	**Long Term Conditions, Disability,** and **Carers:** participants were aged 30-75 with an acquired brain injury, their families and carers.	17	UHS
17. HIV Positive (convened group, Dorset)	**Long Term Conditions:** the group comprised men and women with diagnoses ranging from less than 5 years to over 40 years. Only those in the room and healthcare professionals knew about some individuals' diagnoses.	6	PIER
18. Islamic Centre (Bournemouth)	**Ethnic minorities** and **Minority ethnic communities most affected by Covid-19:** participant was a community leader	1	UHS

	representing Asian families of all ages.		
19. LGBTQ+ (convened group, Dorset)	**LGBTQ+:** participants comprised one who identified as transgender, one gay woman, and one bisexual woman.	3	PIER
20. Long Term Health Conditions (convened group, Dorset)	**Long Term Conditions, People with serious mental illness, and People experiencing homelessness:** the group was composed of a self-identified conspiracy theorist, several people with neurodiversity and/or severe and persistent mental health conditions and included some with lived experience of homelessness.	9	PIER
21. Making Friends Group (Lymington)	**65+**: participants were mainly retired women aged 65+.	27	UHS
22. Move Momentum – Gems – over 65's dance group (Winchester)	**65+** and **LTCs:** participants were over 65's, some with LTC's, some couples.	13	UHS
23. Move Momentum – Liberate wheelchair dance group (Winchester)	**Young people, Disability, and Carers:** participants were aged 15-30, wheelchair users, some with family/carers.	10	UHS
24. Move Momentum – Street Dance Academy, Stanmore (Winchester)	**Young people** and **Core20:** participants were 13 -16yrs from an area of social deprivation.	4	UHS
25. New Forest Food Bank (New Milton)	**Core20**: participants were low income/living in poverty, all ages, often vulnerable.	32	UHS
26. Older People (convened group, Dorset)	**65+** and **Long-Term Conditions:** participants were aged 85+.	4	PIER

27. Our Community Café (Salisbury)	**Core20:** participants tended to be vulnerable and low income.	28	UHS
28. Poverty Truth Commission (convened group, Dorset)	**People experiencing homelessness:** participants had lived experience of homelessness, poverty, and high deprivation.	2	PIER
29. Rainbow Island (LGBTQ+, Isle of Wight)	**LGBTQ+:** participants were all over 40’s.	19	UHS
30. Substance Use / Early Recovery (convened group, Dorset)	**People with drug & alcohol dependency:** participants were in early stages of recovery from substance use.	18	PIER
31. Substance Use/Vulnerably Housed (convened group, Dorset)	**People with drug & alcohol dependency,** and **People experiencing homelessness:** participants had a history of substance use including many with experience of being vulnerably housed.	8	PIER
32. Visually Impaired (convened group, Dorset)	**Long Term Conditions:** individuals aged 30-80 with various causes and levels of sight loss and health conditions. Some were guide dog users, some born with visual impairment or blindness, and others experienced sudden or progressive sight loss.	13	PIER
33. Wiltshire Travellers (Travellers’ site, Downton, Salisbury)	**Gypsy, Roma and Traveller community**: Participants were settled travellers ranging from babies to older people.	5	UHS
34. Winchester University	**Young people:** participants four post-grad students attended, aged 21+.	4	UHS

35. Working men (convened group, Dorset)	**General Population (Men aged 18–55):** Working-age men recruited through Weymouth Fire Service and East Dorset Rugby Club, spanning diverse socio-economic backgrounds, not aligning with specific targeted demographics.	10	HIW
36. Yellow Brick Road Project (Young people, Andover)	**Young people**: participants were principally young people aged 13-20.	9	UHS
37. Young Mums Forum (Portsmouth)	**Maternity, Young people**, and **Ethnic minorities**: participants were young parents, their families and supporters and professionals from the African community in Portsmouth.	35	UHS

In total, the detailed engagements summarised in this report reflect conversations with 547 individuals across 37 structured group sessions.

In addition, the Patient and Public Involvement and Engagement (PPIE) practitioners involved in the project also engaged or attended meetings with groups including the **Rushmoor Voluntary Sector Forum, Social Prescribers Network (Southampton)**, and **CLEAR Project (Southampton)**. At these meetings, presentations introducing the Wessex Secure Data Environment (SDE) were delivered, but due to the format or limited participant interest, formal feedback was not collected. While exact attendance at these sessions is not recorded, that these sessions, along with initial outreach discussions held to gauge groups' interest in participation, bring the total number of people engaged in discussions or informed about the Wessex SDE project to over 600.

Demographic analysis of participants

The table below seeks to provide an overview of the proportions of people in different demographic groups. We have chosen to use a smaller set of summary categories for this exercise. This reflects the challenges of categorisation set out in the ‘Note on demographic categorisation’ at the end of this report and the cross-over on certain categories such as “older people” and “long term health conditions”. Attempting to be more specific would mis-represent the diversity and intersectional nature of the groups we spoke to.

Figure 2: Proportions of participants in different demographic groups

GROUP	PERCENTAGE
Digitally excluded	7%
Carers	11%
Veterans	6%
Substance misuse	5%
Settled travellers	≤1%
Refugees	3%
Disabled (learning & physical) and long-term health conditions	28%
Over 65’s	16%
Under 24’s	15%
Ethnic minorities	16%
LGBQT+	4%
Economic deprivation & homeless	6%

Note on demographic categorisation

We have attempted to categorise the groups we engaged with by their demographic characteristics, including in some cases protected characteristics, to ensure we reached a diverse and representative sample of the population and to identify specific needs or preferences among different groups.

We began categorisation based on descriptions from community facilitators and groups. Recognising that categorisation is sensitive and complex due to the intersectional nature of identities, we understand individuals may not identify with our labels. Our categorisation relies on professional judgement and provided or public information, not personal self-identification.

We have followed best practice NHS guidance on public and patient involvement and engagement (PPIE), but we acknowledge that our approach may not fully capture the complexities of intersectionality. We apologise for any errors or omissions in our analysis and welcome feedback or suggestions to improve our engagement with diverse and underrepresented groups in the future.

Findings

In this project, patient and public involvement and engagement practitioners from University hospital Southampton NHS Foundation Trust (UHS), Bournemouth University's PIER Partnership, and Health Innovation Wessex ran 37 group engagement sessions across Wessex.

We have heard from a diverse range of seldom heard and marginalised people from across Dorset. The sample is not representative but does reflect the diversity of the region's communities. Conversations with these groups provide important insights for consideration by the Wessex SDE.

In this section, we have analysed the reports to identify a consolidated list of conversation topics, which summarise the perspectives of the groups involved. As far as possible we have presented the results as distinct and non-overlapping. These are set out in **Figure 3** below.

Figure 3: Perceptions from people who are marginalised and seldom heard in Wessex regarding the Wessex SDE

- Can I trust you?
- The NHS needs to get this right first time
- Data security and control concerns
- Risk of deterring people from engaging with NHS services
- Hopes for the SDE, if it is trusted
- How can we care or trust when we feel powerless?
- Who is safeguarding our data?
- Misunderstanding, discrimination and stigma
- Concerns about privacy and data misuse
- Accuracy and completeness of patient data
- We need clear communication and transparency
- Opt-out system and informed consent
- Prioritisation of NHS spending
- Do I have value? Is my voice heard?
- Culturally sensitive and accessible engagement

In the **Analysis** section of the report that follows we have sought to distil this conversational analysis down into a smaller number of themes capable of more directly influencing the design and governance of the Wessex SDE. Patient health records and research are inherently complex and sensitive, prompting varied emotional and rational responses with some issues naturally overlapping.

Reports providing more detail on the work done by the PIER Partnership and Health Innovation Wessex (then the Wessex AHSN) can be found in **Appendix 3** and **4** respectively; insights from UHS are incorporated directly into this analysis.

Conversation topics

1. Can I trust you?

Trust in the NHS is a critical to engagement with the SDE. Many participants expressed a strong sense of trust in the NHS, especially when it comes to using their data for research. These tend to be people with positive experiences. In contrast, those with past negative experiences are more likely to feel their concerns and needs won’t be addressed. For some, distrust stems from previous trauma, poor care, or stigma, leading to doubts that the SDE will deliver any real benefits. Others worry that personal data might be misused. Trust issues are complex and are discussed in detail within the other themes.

2. The NHS needs to get this right first time

Most groups stressed the critical need for the NHS to get the SDE right the first time, particularly given the perceived precarious state of the NHS. A central concern was that data inaccuracy and incomplete information could undermine its effectiveness. Missteps could also exacerbate health inequalities, particularly for those with complex conditions, making it essential that the SDE addresses these issues through transparency, secure data practices, a strong assurance of data privacy, and that governance is impartial and diverse, reflecting a range of lived experiences.

3. Data security and control concerns

Participants expressed significant concerns about the security of personal data in the SDE, particularly regarding breaches, hacking, and misuse. Past issues with NHS IT systems and the Post Office Fujitsu scandal raised doubts about the NHS's ability to protect sensitive data. There were fears that a centralised system could become a single point of failure, especially if faced with technical challenges or a hack. Concerns were also raised about who could access the data and how effectively personally identifiable information could be removed. Many emphasised the need for robust, multi-layered security to protect against both external and internal threats. Some worried that discussing security risks could inadvertently raise doubts about the system’s safety.

4. Risk of deterring people from engaging with NHS services

The introduction of an SDE could deter individuals from engaging with NHS services, particularly due to fears of data misuse, lack of consent, or perceived profit-driven motives. If these concerns are not addressed, people may avoid or reduce their use of NHS services, which could undermine the success of the SDE initiative.

5. Hopes for the SDE, if it is trusted

There is broad recognition of the potential benefits of an SDE, including more efficient research, faster treatments, and improved diagnoses. However, realising these benefits hinges on two factors: trust in the NHS and trust in its ability to securely implement the SDE. Those with positive healthcare experiences are more likely to contribute to research and see the benefits, with young people particularly optimistic. Participants felt that emotive and relatable use cases – such as personalised cancer treatments – could clearly illustrate the value of the SDE, increasing willingness to share data. Similarly, positioning benefits around a legacy approach, emphasising intergenerational improvements in healthcare, was particularly persuasive for encouraging engagement. In contrast, those with negative experiences or trauma struggle to trust the system, limiting their belief in the SDE's potential. Without addressing these trust issues, some groups may not recognise the benefits, regardless of the SDE's effectiveness.

6. How can we care or trust when we feel powerless?

A sense of disempowerment and distrust drives perceptions of the NHS and SDE for a number of groups. Young people, overwhelmed by global and personal anxieties, felt unable to engage meaningfully, citing fears of conscription, foreign hackers, and government misconduct. Older people expressed resignation, believing SDEs would be implemented regardless of their input, reflecting broader disillusionment with the NHS and societal decline. For those with lived experiences of trauma or addiction, scepticism ran deeper: past deceptions and systemic failures left them questioning the truth behind SDE assurances and doubting the intent of those in power. Across all groups, mistrust—rooted in negative experiences, a lack of transparency, and perceived powerlessness—emerged as a critical barrier to engagement.

7. Who is safeguarding our data?

Ensuring the safeguarding of vulnerable people's data was a key concern, especially for those unable to fully understand or opt out of the system. There were worries about who would oversee this process, emphasising the need for robust governance that protects the most vulnerable from exploitation or inclusion without consent. This was raised by carers, PTC and LTC groups in particular.

8. Misunderstanding, discrimination and stigma

Many contributors expressed concerns that the SDE might fail to meet their specific healthcare needs due to misunderstanding, discrimination or stigma. There were fears that sensitive health information, such as mental health conditions or rare illnesses, could be misused by insurers or employers. Groups with complex conditions, such as acquired brain injuries or autism, felt underrepresented in research. Those affected by autism, HIV, and other stigmatised conditions worried that historical discrimination could be exacerbated by the SDE. Additionally, there were concerns that, if not implemented correctly, the SDE could worsen health inequalities, particularly for those in high-deprivation areas or with complex conditions. Experiences of stigma and trauma created significant barriers to trusting the NHS and engaging with the SDE.

9. Concerns about privacy and data misuse

Participants expressed concerns about how their data might be used outside the NHS, particularly regarding misuse by third parties like insurers or corporations. Fears of discrimination or higher insurance costs due to data misuse were significant, as were worries that research would focus on ‘quick wins’ or profits and so would neglect their needs and underrepresent rare or complex conditions. Data anonymisation is reassuring but there was an understanding that it might not be possible due to requirements for linking and updating patient data. There is broad agreement on the importance of transparency and strong safeguards to prevent misuse and commercial exploitation.

10. Accuracy and completeness of patient data

Concerns about the accuracy and completeness of patient data were prominent, with participants noting that missing or inaccurate information could compromise both patient care and research outcomes. Public contributors highlighted that health data held by the NHS is often incomplete or erroneous, and if this data were used in an SDE, it could undermine potential benefits. The concept of "rubbish in, rubbish out" was emphasised, where inaccuracies, such as incorrect gender data, could skew research findings and affect the quality of care delivered.

11. We need clear communication and transparency

Participants emphasised the need for the NHS to be transparent about how their data will be used, with many calling for simpler, clearer communication to ensure accessibility for all literacy levels. Visual aids and simplified language were suggested to improve understanding. There was also a general preference for traditional communication methods, such as leaflets and direct contact with healthcare providers, with some groups highlighting GPs as a trusted source. While digital methods were also mentioned, concerns about the credibility of information shared via social media were raised. Younger participants said social media shaped their expectations about what good communications and transparency looked like. Strategies that reflect peer influence, convenience, and the norms of social media platforms are therefore especially effective in engaging this demographic.

12. Opt-out system and informed consent

Consent and the opt-out system were big concerns, particularly for those with cognitive impairments or limited understanding. Participants questioned whether people could be fully informed about their choices and if those unable to understand the system could opt out effectively. Many stressed the importance of individuals choosing whether their data is stored in an SDE and controlling its use, while some worried that widespread opt-outs could compromise SDE-enabled research due to incomplete datasets.

13. Prioritisation of NHS Spending

Many participants questioned whether the SDE is the best use of NHS resources, suggesting that funds might be better spent on addressing more urgent issues, such as improving primary care access and reducing waiting times. Some felt that the NHS should focus on improving care and record sharing before investing in data-sharing initiatives like the SDE. For these groups, the priority should be addressing immediate healthcare needs, as they believed resources spent on the SDE for research purposes could be better used to improve existing services. They felt that tackling these basics first would build trust in the NHS and its ability to deliver effective outcomes.

14. Do I have value? Is my voice heard?

For some groups, such as those with a history of substance use, vulnerable housing, older people, and certain LTCs contributors, a key concern was whether their voices had value in research. Public contributors from these groups felt that they are often ignored, because of either their beliefs or their lived experience. They questioned whether there was any point in contributing to research, because their previous experience indicates to them that their voice is valueless.

15. Culturally sensitive and accessible engagement

Some participants emphasised the importance of culturally sensitive and inclusive approaches to engagement, highlighting that trusted community and faith leaders can effectively facilitate conversations about the idea of sharing health data for research. Successful engagement depends on adjusting the approach to groups' needs and practical considerations, such as avoiding overly complex sessions and providing iterative opportunities for feedback, particularly for young people or vulnerable groups who may otherwise feel overwhelmed or excluded. Effective engagement requires culturally appropriate methods, inclusive communication styles, and accessible session designs to ensure meaningful participation from diverse communities.

Analysis

Looking at the conversations from the perspective of SDE design and governance we have identified some cross cutting themes that we believe seldom heard and marginalised groups want to see addressed. This analysis moves us from understanding what these groups are telling us to how we work with public contributors to take action.

Figure 4: Overarching themes emerging from conversations with seldom-heard and marginalised groups

Trust and Transparency	Inclusion and Empowerment	Data Accuracy and Security	Getting It Right First Time	Accountability & Governance
Can I trust you?	Do I have value? Is my voice heard?	Data security and control concerns	The NHS needs to get this right first time	Who is safeguarding our data?
Hopes for the SDE, if it is trusted	Opt-out system and informed consent	Accuracy and completeness of patient data	Prioritisation of NHS spending	Misunderstanding discrimination and stigma
We need clear communication and transparency	How can we care or trust when we feel powerless?	Concerns about privacy and data misuse		
Risk of deterring people from engaging with NHS services	Culturally sensitive and accessible engagement			

We have summarised these five key themes below:

A. Trust and Transparency

Trust in the NHS is foundational to engagement with the SDE. Those with positive healthcare experiences tend to trust the system, while negative experiences breed scepticism and distrust. Transparency in how data will be used, and clear communication are key to overcoming concerns. Many fear misuse of personal data or feel that their voices are disregarded, leading to reluctance to participate in the SDE. Without trust, the SDE’s potential benefits are undermined, particularly among those with prior negative experiences.

B. Inclusion and Empowerment

Concerns about feeling powerless and excluded from the system are prevalent, particularly among vulnerable groups. People with lived experiences of trauma or those in marginalised communities question whether their participation in research is valued. A robust opt-out system and informed consent are essential to empower individuals to control their data. There is a need to address the specific healthcare needs of these groups, ensuring they are not further marginalised by the SDE. Communication of all these matters must be done in a culturally sensitive and accessible way.

C. Data Accuracy and Security

The accuracy and completeness of patient data are critical for the success of the SDE. Many participants raised concerns about how incomplete or erroneous data could skew research findings or compromise patient care. Security of personal data is also a major concern, with fears of breaches, hacking, and misuse. There is a strong demand for multi-layered data protection and safeguards to ensure that data is not misused by third parties, such as insurers or corporations.

D. Systemic Challenges and Prioritisation of Resources

Many participants questioned the allocation of NHS resources to the SDE, suggesting that urgent healthcare needs, such as improving primary care, should take priority. The NHS is expected to address foundational challenges—such as data quality and system capacity—before embarking on large-scale data initiatives like the SDE. Addressing these basic issues would help rebuild trust and demonstrate the NHS's ability to deliver on its promises.

E. Accountability and Governance

Effective governance and accountability are essential to safeguarding the data of vulnerable groups. Participants emphasised the importance of transparent oversight to protect data and ensure it is used ethically. Concerns were raised about whether the data would be safeguarded against misuse, particularly for vulnerable individuals who may not fully understand or be able to opt out of the system. Strong governance structures are needed to ensure trust and mitigate concerns about discrimination or exploitation.

Recommendations

The following recommendations have been developed based on the insights gathered during our engagement activities. These key recommendations aim to address the concerns and aspirations expressed by participants, ensuring that the implementation of the SDE is both inclusive and effective. As the Wessex SDE progresses towards its launch and roll-out, it is imperative to consider these recommendations to enhance communication and patient engagement.

1. **Developing a set of values-led principles for the SDE:** Better understanding seldom-heard groups' concerns gives us a useful starting point for developing a set of 'guard rails' to help shape our culture, guide how we operate, and inform our decision-making. Below we have included a draft of what these might look like – for further discussion and review.

2. **Bringing the Wessex SDE to life:** Groups were interested in how big data health research could benefit them and their communities. There was interest in the use cases, and the potential of the SDE to make gains in treatments and care for health conditions, from addiction to cancer. Younger groups, in particular, were interested in the future possibilities for areas such as diagnostics and genomics.

3. **Creating a positive feedback loop:** There were a lot of questions about how the benefits (of using the data, outcomes of research) would be communicated, and how people would be kept informed about what's been achieved.

   This supports the need to keep an ongoing dialogue with patients and the Wessex public – not just in the lead up to launching the Wessex SDE, but throughout its lifespan.

4. **Addressing accessibility and inclusion needs:** Many groups commented on the need to make the SDE feel relevant to people who lack IT literacy and/or feel digitally excluded.

   People also identified a need for tailored support to help people from vulnerable communities understand the SDE (e.g. people with reduced cognitive capacity, people with low levels of literacy).

5. **Using breadth and creativity in communications:** there were useful discussions in many groups about how and where people might find information about the SDE. There were lots of different suggestions for tactics that individuals felt might or might not work.

   It is clear that what might be popular or useful for some (e.g. social media adverts, or posters in GP surgeries) might not reach others, and therefore the importance of using a variety of methods and thinking creatively about our approach.

6. **Working through trusted messengers:** Groups also provided useful insight into who they like to hear health information from, and who they trust. Reflecting other national research (e.g. Ipsos Veracity Index 2023[1]), many people said that they would not trust politicians or the government.

   Participants discussed the importance of prior trusting relationships and mutual understanding were emphasised, and the benefits of hearing from someone that participants already knew. GPs, district nurses, and community group leaders were therefore suggested in this context, as trusted sources.

7. **Acknowledging the importance of peer influence:** in addition to discussions about who would be trusted in delivering information about the SDE, we also saw examples of where peer influence in the group discussion impacted the direction of the conversation and participants' receptiveness to the idea.

   In a group discussion with young people, one young person gave the example of his dad who has diabetes and said it would be important to know how many people had it in the area. After this conversation, the group said they would be happy for anonymised data to be used to help makes things better.

   In another discussion, with a group of wheelchair users and their carers, one participant said she used to work in research and described what she saw as the benefits of the SDE also said that she had faith in the layers of security in place. The group were receptive to this and, by the end of the session, were generally positive about the benefits, but still cautious about the previous concerns they'd shared (about governance of, and the potential for criminal activity through, the SDE).

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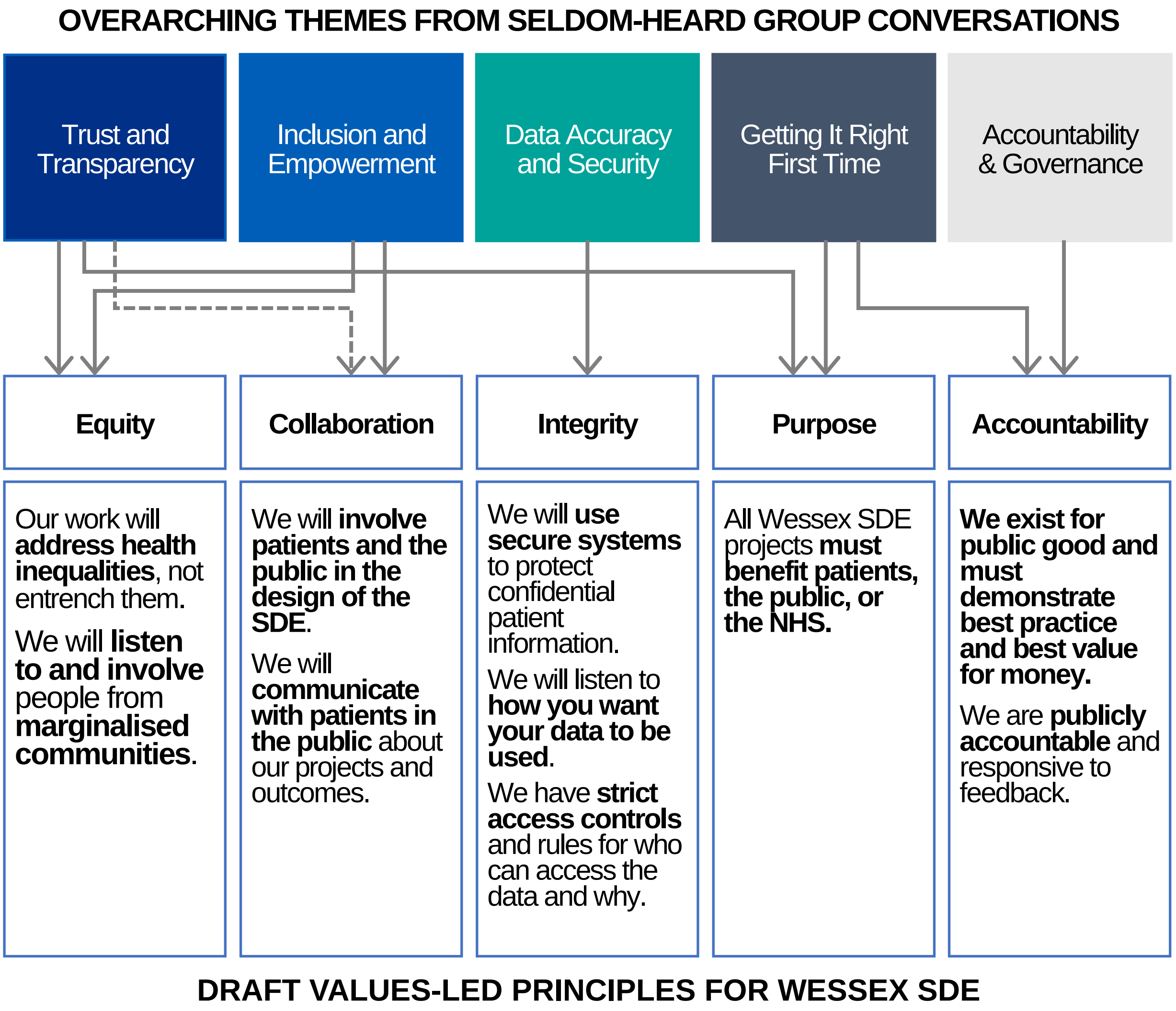
[1] Ipsos, Veracity Index (2023) Trust in professions survey.

Values-led principles to guide the Wessex SDE

The first recommendation from the engagement with seldom heard groups is to develop a set of value-led principles to guide the Wessex SDE. The Wessex SDE team has drafted these principles, which are outlined below. They have been reviewed and validated by the Digital Critical Friends group, consisting of public participants who have received training and are involved in scrutinising all aspects of programme governance and decision-making. They will form part of the feedback to the groups we have engaged in due course.

Figure 5: Draft values-led principles for Wessex SDE, responding to engagement with seldom-heard communities



OVERARCHING THEMES FROM SELDOM-HEARD GROUP CONVERSATIONS

- Trust and Transparency
- Inclusion and Empowerment
- Data Accuracy and Security
- Getting It Right First Time
- Accountability & Governance

Equity

Our work will **address health inequalities**, not entrench them.

We will **listen to and involve** people from **marginalised communities**.

Collaboration

We will **involve patients and the public in the design of the SDE**.

We will **communicate with patients in the public** about our projects and outcomes.

Integrity

We will **use secure systems** to protect confidential patient information.

We will listen to **how you want your data to be used**.

We have **strict access controls** and rules for who can access the data and why.

Purpose

All Wessex SDE projects **must benefit patients, the public, or the NHS.**

Accountability

We exist for public good and must demonstrate best practice and best value for money.

We are **publicly accountable** and responsive to feedback.

DRAFT VALUES-LED PRINCIPLES FOR WESSEX SDE

This set of values led principles will provide the starting point for the next phase of work: the development of a deliberative dialogue process. This is a structured method of engagement that will bring together a diverse group of c.50 public participants, reflective of the geography and demographics of the Wessex region in co-design of the SDE’s governance.

By facilitating in-depth conversations and reflections, the deliberative dialogue process helps to identify and address potential concerns, build trust, and create a shared vision for the SDE's future. The strategic purpose of this process is to guide the Wessex SDE by helping to set core values, strategic research priorities, and policy recommendations on specific aspects of design and governance. The aim is to ensure that the SDE works in a way that optimises the benefits delivered for Wessex and ensures that the process by which it does this is ethical and capable of being trusted by a wider Wessex public that this group reflects.

Public deliberation involves an element of education to give participants a deeper insight into the subject matter. Individuals with lived and learned experience come together, discuss, reflect, and collaborate to identify and address potential concerns, build trust, and create a unified vision for the future of the SDE.

This process will guide the Wessex SDE by setting core values, defining research priorities, and making policy recommendations on design and governance aspects. The goal is to maximise benefits for Wessex and ensure ethical practices and trustworthiness within the community.

Once tested, refined and validated through public deliberation and wider public communication, these principles will be agreed and approved by the Programme Board. They will shape the development of the Wessex SDE and its culture, guide how we operate, and inform our decision-making.

Acknowledgements

Our community contributors and partners

We would like to thank every public contributor to this engagement project. Your openness, passion, and genuine willingness to share their experiences and personal insights has been fundamental in shaping this report and will guide the future development of the Wessex Secure Data Environment.

We promised to place the voices of public contributors, especially those from under-represented and marginalised groups, at the heart of our work—and this remains our guiding principle. By doing so, we aim to build trust, remove barriers, and ensure that the Wessex SDE delivers research and benefits that genuinely improve people's lives. This report clearly sets out what we must do next to honour these public contributions and continue building trust within our diverse communities.

We sincerely thank all voluntary and community organisations who participated for their expertise, time, and commitment either through direct participation or by convening engagement groups. We also appreciate the community workers, volunteers, and group leaders who organised and contributed to the discussions. This project would not have been possible without you.

In addition to the organisations already acknowledged, we would particularly like to thank the following VCSE organisations for their invaluable support and engagement: Body Positive Dorset, Bournemouth Christchurch and Poole Poverty Truth Commission, Bournemouth Heart Club, CLEAR Project (Southampton), Dorset Blind Association, East Dorset Rugby Club, Raising Voices In Research, Rushmoor Voluntary Sector Forum, Social Prescribers Network (Southampton), Steps Youth Club, The Legacy Project, We Are With You, West Howe Community Enterprises, and Weymouth Fire Service.

We would like to thank all participants, group leaders, and facilitators from both University Hospital Southampton (UHS), Bournemouth University's Public Involvement in Education and Research (PIER) Partnership, and Health Innovation Wessex (formerly Wessex Academic Health Science Network, or AHSN) for leading and delivering this programme of work; their experience, commitment and invaluable contributions have been at the centre of shaping this engagement programme and delivering this report.

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Appendices

Appendix 1: Detailed Discussion Guide 37
Appendix 2: Supplementary stimulus materials 82
Appendix 3: PIER Partnership – full engagement report 122
Appendix 4: Health Innovation Wessex – engagement report 182

Appendix 1: Detailed Discussion Guide

Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS

Wessex SDE Toolkit Facilitators’ Guide

The aim of our toolkit is to help people better understand what Wessex Secure Data Environment (SDE) is, how it keeps data secure in line with the ‘Five Safes’ principles, and what kinds of benefits this ‘big health data’ project offers to patients and the public. The toolkit can be downloaded via Dropbox at the following link: https://www.dropbox.com/scl/fo/f7fe9sh9lmhvtk3rzbo0i/h?rlkey=o3f3kw89ieqntmimjqg2ntvn0&dl=0

We developed and designed these toolkit materials using a model of **'data visualisation literacy as empowerment'**. This means making visual materials that help people build technical literacy, improve health literacy, and equip people with the tools to apply this new knowledge. It is not enough to just know what the Wessex SDE project is. We want to do more than just get 'public acceptance of health data sharing for research'. We want to empower the public to talk about, question or even suggest a Wessex SDE data project.

This method is consistent with recent research studies in the field, the results of the literature review by Understanding Patient Data, and other SDE initiatives to consider crowdsourcing research ideas and finding problems to research directly with communities. We think this toolkit can support the slogan, ‘no research about us without us’, meaning, these materials should be able to help communities learn about the Wessex SDE project so that they can participate in the future of health research-- helping us to define the values that inform Wessex SDE, the rules that regulate it, and how it is operated.

This guidebook includes an overview of the Wessex SDE project, an FAQ that provides some more in-depth information, and introduction to our visual materials for PPIE, and a set of suggested activity plans that facilitators can use and adapt.

Contents

I. Key Information 3

Introduction to patient and public involvement 3

The Wessex SDE in a nutshell 3

The benefits in a nutshell 3

How will your involvement help? 4

II. Wessex SDE FAQs 5

What is patient health data? 5

Why patient health data important to research? 5

What is the point of the Wessex SDE? 6

What is wrong with health research today? 6

How will the SDE fix these problems? 7

How will the Wessex SDE work? 7

What kinds of data will be linked in the SDE? 8

How is data linked together in the SDE? 8

Who are the researchers that will use the SDE? 9

How does the SDE work to protect your privacy? 9

What is ‘anonymisation’? 10

What is ‘pseudonymisation’? 10

What is the risk of re-identification? 11

Where can I find more information? 11

PPIE toolkit activities 12

Introduction to toolkit materials 12

Use Case Study Cards 12

Glossary Cards 13

Prompt video (45 sec intro) 13

Introduction to PPIE activities 13

Activity Set A: Key Topics Chats 16

Activity Set B: Creative Activities 20

Activity Set C: Roleplay Scenarios 25

I. Key Information

Introduction to patient and public involvement

You can tailor this introduction to suite your role and the group you are working with.

I work for the NHS / Bournemouth University, supporting researchers with public engagement and involvement. Research is a crucial part of the NHS as it's so important to be looking for new and better treatments and medicines and to improve the way the NHS works.

I'm currently involved in the Wessex SDE project. This stands for the Wessex Secure Data Environment. The aim of this project is to make it easier for researchers to access large amounts of health data by taking existing information, standardising it, anonymising it, and putting it into one place.

We want your help in the development of our Secure Data Environment: setting the values that guide it, the rules that govern it, and in how it is run.

The Wessex SDE in a nutshell

- We are building **an online platform where large amounts of patient health data can be stored, linked together, and accessed by researchers.**
- This is our **'Secure Data Environment'.** The **NHS will own and run it, and it will be** designed to the highest standards of privacy and security for NHS data.
- **Researchers will use it to access data safely and easily** to answer a huge variety of questions and discover life-changing new treatments and medicines for the benefit of all.
- We promise that **people in Wessex will be directly involved** in the development of our Secure Data Environment, the values that guide it, the rules that govern it, and in how it is run.

The benefits in a nutshell

A good way to understand the benefits of the Wessex Secure Data Environment is through the projects it will support. Here are five examples:

1. **Improving pre-hospital emergency care services** by creating a large national dataset for the first time. Other researchers can then use this to find ways to improve the care you get before you get to hospital (PRANA).
2. Using genetic insights to **improve cancer diagnosis and survival** (cancer genomics).
3. Testing new CT and blood screening techniques to **detect lung cancer earlier,** enabling patients to be treated sooner**.** (Lung IDX).
4. Studying early immune problems to help **stop the progression of a specific cancer** called lymphoma (ECRIN).
5. **Gaining new insights into colon and rectal (colorectal) cancers** by using Natural Language Processing, a computer technology that can 'read' through large batches of anonymous tissue and radiology medical reports (HIC).

We have more information about these research projects and the patient health data they need to do their analyses.

Having a chat with public participants about these projects helps to understand how the Secure Data Environment works and the kinds of research it makes possible. We can look at the benefits of this research, as well as at the risks that might exist in using patient health data for research.

Your views on these projects can help us to work out the values that should guide Wessex SDE, the rules that govern it, and in how it is run. Our goal is to make the SDE both as beneficial and trustworthy as possible for people in Wessex.

How will your involvement help?

You can use or adapt to suit your group.

- We take the responsibility of managing people's health data very seriously and want to talk to as many people as possible across Wessex about this project.
- We want to know how you feel about this idea, from how we could communicate better with the public about what the Secure Data Environment is and what it can do, to what you think the rules should be for researchers and their partners that want to use this data.
- We want the public to be involved at every stage of the project.
- What we talk about today will be fed back into the Wessex SDE project, both locally and nationally.
- We will stay in touch with you to let you know the outcomes of your participation, and there will be more opportunities to get involved over the coming months, including participating in workshops and public groups.

II. Wessex SDE FAQs

The series of FAQs that follow should help you introduce the SDE, as well as provide factual responses to participants questions. Depending on the group you are working with, feel free to tailor the amount of detail you provide.

What is patient health data?

Health data is any recorded information about a person’s physical or mental health: in the past, at present, or in the future.

This means that health data may come from any interaction with the healthcare system, for example during an appointment with a GP, or with a nurse or doctor in a hospital. Health data may also be gathered from medical devices and from diagnostic tests (for example, blood tests or genetic tests).

Each NHS or social care service that you use stores its own record about you electronically. This data is stored in many ways and in lots of different places, using many different types of computer systems.

Health data records include personal information. This includes things like your name, NHS number, or your address. These can be used to identify you and to link records from different places together.

Some health data are simple numbers (like your height or weight) or are picked from standardised lists (like information about prescriptions, test results, or vaccinations). Other data are free-text notes (like the comments your GP writes during a visit).

Since patient data is stored in different ways, and scattered across different services, linking data together is key for improving care and advancing medical research.

Why patient health data important to research?

When doctors and researchers look at our health data, they can find new patterns and trends. These can lead to new discoveries that can benefit everyone.

Large datasets are created when the health data of many people and different places are gathered together. When it is stored digitally and organised systematically, huge amounts of data gathered from large numbers of patients can be analysed.

This analysis can be used to improve the understanding of diseases and disability, and to develop new treatments and technologies. It can also be used to plan healthcare services for all our future needs.

What is the point of the Wessex SDE?

The NHS has invested time and money in developing a huge wealth of patient data. But as this data is scattered and recorded in so many different ways, it makes it difficult, slow, and expensive for the NHS to use it for research and for improving care.

By bringing this data together securely and systematically, we can create an opportunity to improve the NHS together, from pre-hospital care to the discovery of life saving treatments or understanding population health.

The Wessex SDE aims to bring data together securely and systematically, speeding up new discoveries for the benefit of people in Wessex and our NHS.

What is wrong with health research today?

Patient health data is already used for research. But as the data is scattered across services and stored in lots of places, it is hard to even know what questions to ask.

Before beginning a project, researchers must work out what data exists, where it is, and apply to each individual place where data is stored to get permission to use it. Each place will have different rules and procedures, creating a timely and costly process.

Today, if permission, is granted then a dataset can be shared, which means it is sent to the researcher in a secure way. The researcher must then translate lots of different datasets into a consistent format and combine them into one large dataset that can be analysed.

Although this system does a good job of ensuring safety and privacy, there are big drawbacks:

1. The current process **lacks transparency**. It is hard for people to understand and ask questions about how their data is being used. The NHS cannot

always see what happens to shared data or the discoveries that are made with it after it is sent.

2. It is **inefficient** and costs the NHS money.
3. Data is **hard to access** as the process is slow and complicated.

How will the SDE fix these problems?

The Wessex Secure Data Environment will give approved researchers rapid and secure access to many different sources of data all in one place, and in standard format, where this data can be easily linked together and analysed.

This means that researchers can access bigger sets of data faster. This will make research easier and open up new research opportunities that do not currently exist. It will accelerate the research process, bringing the benefits of more new discoveries to patients and the NHS, more quickly.

How will the Wessex SDE work?

The NHS owns and runs the Secure Data Environment.

Access to the SDE is granted only to authorised researchers, from approved organisations. Their access is controlled and recorded. They can only work on approved research projects.

Once inside the SDE authorised researchers can see only the data they need for their research. Any information – like your name, date of birth, address, or NHS number – that could be used to identify an individual patient is disguised to protect privacy.

Any new data that researchers want to bring into the SDE also has to be approved, as do the software and tools they can use to analyse the data.

Once the project is complete, researchers will want to take their results out of the SDE. The data they want to take out is reviewed and approved by the NHS before this can happen to further protect privacy.

NHS data in the Wessex SDE is stored on highly secure systems and no identifiable patient health data can be seen by researchers.

As projects take place, all data use in the SDE is monitored for added security and transparency. There is a clear record of everything that happens on the SDE that is available for inspection.

What kinds of data will be linked in the SDE?

Patient data from about 2.7 million people in the Wessex region will be transferred to and linked up inside the SDE.

All this data is de-identified. The aim is to turn data into a form which does not directly identify individuals and where re-identification is not likely to take place. This protects your privacy. We explain in the next section how this happens.

At this early stage of the Wessex SDE projects development, we will be transferring the minimum amount of data needed for the approved research projects that we want to support. As we test and develop the Secure Data Environment system, we will add more data.

Data is collected every time a patient has contact with a health and care organisation so there is a wide range of data that could be transferred to the SDE. The de-identified data transferred to the SDE could therefore include:

- **Medical history:** This includes records of hospital visits, treatments received, allergies, medications, surgeries, and ongoing illness management.
- **Tests and check-ups:** Involves results from lab tests, diabetes checks, X-rays and scans, and other medical tests.
- **Preventative care:** Includes vaccinations and other procedures to stop diseases before they start.
- **Doctor visits:** Covers information from visits to GPs and specialists, and prescriptions.
- **Detailed reports:** Includes reports produced by pathology or radiology services and additional information about the testing process or devices used.

Patients have a choice about sharing their data and can opt-out through the National Opt-Out system or local method for an individual project. Their data will not be used in the Wessex SDE.

How is data linked together in the SDE?

The power of the SDE comes when we can link together lots of different data sets from different places to create a new, large dataset. This allows researchers to see new patterns and make discoveries.

When we are looking at data from several NHS organisations, we need to be able to link all the information about a single patient together. To do this we need to use personal information that can be used to identify you.

For NHS data we use a patient's NHS number, which is unique to them. For some projects, we may also want to link NHS data with other data sets outside the NHS, such as data from other public services. To do this we could use other personal information, like your name, address, or National Insurance number.

This personal information is stored securely and only used to link together data sets inside the SDE. It is kept private and is never shared with researchers.

Who are the researchers that will use the SDE?

The SDE is a valuable resource for a wide range of researchers. We will have full control over which organisations and researchers can have access to the SDE. This may include:

- **NHS analysts** seeking to improve healthcare services
- **University academics** conducting medical studies
- **Pharmaceutical and other private companies** developing new treatments and technologies
- **Voluntary and community organisations** that are supporting public health initiatives.

Each group brings unique perspectives and goals, collectively contributing to the broader understanding and advancement of healthcare and public wellbeing.

How does the SDE work to protect your privacy?

The Wessex Secure Data Environment (SDE) has strict controls to protect your privacy. Researchers only see de-identified data, where personal identifiers – like your name, birth date or address – are removed or disguised. This ensures you cannot be easily identified in a dataset.

The SDE's strength lies in its ability to link together lots of datasets from different places to create new, large datasets. These can reveal new patterns to researchers and help them make discoveries. We need to connect the data from different sources for each patient, without compromising privacy.

Pseudonymisation is the key process used. The organisations that hold your data disguise it and send it securely to the SDE, along with a key to decode it. These are stored separately.

Our team works in a section of the SDE that researchers cannot access. They decode the data and combine datasets using your personal identifiers. This produces a new, big dataset that is pseudonymised again.

The keys that would allow us to re-identify pseudonymised data are always kept private and are never shared with researchers. Even our own team cannot access them without a specific permission.

A further set of checks is then made before the large dataset is available for research. Once the research is complete researchers will want to take their results out of the SDE. Our team reviews and approves this data export before it is allowed to happen.

What is ‘anonymisation’?

Anonymisation is when all personal information – such as your name, address, or NHS number – is completely removed. You cannot be re-linked to the data in any straightforward way. The data is then no longer considered confidential.

Anonymous data helps researchers see the big picture in public health, like spotting trends in diseases across populations. However, it cannot provide details on how health issues affect individuals differently. These more detailed insights are vital to the discovery of new medicines and treatments.

What is ‘pseudonymisation’?

For a basic introduction to pseudonymisation see the glossary card in the toolkit.

Pseudonymisation is when information that is easily attributable to an individual patient is removed and replaced by ‘pseudonym’. This is a unique marker that does not reveal the patient’s ‘real world’ identity but gives them a unique reference number instead.

The process also creates a key, which can be used to link pseudonym back to the individual patient. The pseudonymised data and the key must be stored securely and separately.

What is the risk of re-identification?

While measures are in place to safeguard personal details in the SDE, complete anonymity isn't always guaranteed, especially when data is merged with other sources or focuses on specific traits in small patient groups.

Despite these risks, re-identifying individuals is a complex task and is illegal without consent. Additional security measures within SDEs are also designed to minimise the chances of this happening.

Where can I find more information?

The current NHS national explanation of SDE is available in full here https://transform.england.nhs.uk/key-tools-and-info/data-saves-lives/secure-data-environments/

PPIE toolkit activities

Introduction to toolkit materials

In line with our approach to **data visualisation literacy as empowerment**, we designed these visual toolkit materials to be people centred. The toolkit can be downloaded via Dropbox at the following link: https://www.dropbox.com/scl/fo/f7fe9sh9lmhvtk3rzbo0i/h?rlkey=o3f3kw89ieqntmimjqg2ntvn0&dl=0

We want these materials to feel human and humanising, at the same time as they can capture and explain some of the key technical aspects of data linkage and data security.

In addition to this, these materials were designed in line with three key principles:

- Align to NHS brand guidelines.
- Build on existing visual conceptual logics and representations of the SDE and related linked data projects.
- Incorporate user feedback from PPIE groups and key stakeholders.

Use Case Study Cards

We have created a visual template and public engagement format for sharing information on research projects that have used the Wessex SDE. These ‘Use Case Study’ cards provide accessible information about each project, its benefits, and its secure uses of data.

The user case study cards include:

- **PRANA Improving pre-hospital emergency care services** by creating a large national dataset for the first time. Other researchers can then use this to find ways to improve the care you get before you get to hospital**.**
- **Cancer Genomics** - Using genetic insights to **improve cancer diagnosis and survival.**

- **Lung IDx** - Testing new CT and blood screening techniques to detect lung cancer earlier and **reduce deaths.**

Glossary Cards

In our toolkit there are also some glossary cards that introduce key terms for understanding what the SDE is, how it works, and reflect on the values that guide it, the rules that govern it, and in how it is run. Glossary cards cover the following key topics. These are the included glossary cards:

- **Your health data**. Explains what health data is and how it is used for by the NHS.
- **What is Data?** Introduces the process and value of linking data together from lots of places and how researchers use this to make discoveries.
- **What is an SDE and the Five Safes Framework** Provide an overview of the Secure Data Environment, how it works, and who uses it.
- **Keeping your data safe**. Explains the 'Five Safes' framework that is used to control how the SDE works to keep your data safe.
- **Pseudonymisation** Explains how the SDE uses pseudonymisation to protect privacy.

Prompt video (45 sec intro)

This short introductory video to SDE has been useful in previous PPIE discussions to introduce what SDE is. It can be paired with or replace some of the introductory text at the start of this facilitation guide.

https://youtu.be/qbAAD9UGNCI?si=BPGxGVEWZHT01VV8

Introduction to PPIE activities

Depending on the data literacy level of your group and its levels of familiarity with NHS initiatives, you may want to just have a general chat, or do something more hands-on, or take a playful approach and do an interactive, role play activity.

In this guidebook, we provide an overview for three different types of activities that you can use:

A. **Key topics chats**
B. **Creative activities**
C. **Roleplay scenarios**

Feel free to adapt or mix these up as best suits the group you are working with.

******Please record the method you used in your PPIE notes. ******

Activity Set A: Key Topics Chats

If it makes the most sense for your group to just have a general chat about what health data research and what the Wessex SDE is, you can use the discussion questions provided below to help guide your conversation.

Group Size:

Can be done with smaller or larger groups.

Materials:

Use Case Study and Glossary Cards, sticky notes, and pens for the add-on exercise. If you want to show the video or display any materials on screen, you'll also need A/V set-up.

Make it Virtual:

You can use share screen to share any of these visual materials with the group. Then either read out the questions or put them on the screen.

Activity Plan:

For some groups, a visual aid can help guide and ground discussions.

You may want to start with the **use case study cards** as prompts, or to ask some of the questions below first and then use a prompt to delve into a more detailed discussion.

In our toolkit there are also some **glossary cards** that introduce key terms for understanding what the SDE is, how it works, and reflect on the values that guide it, the rules that govern it, and in how it is run.

We have set out a set of questions for discussion below. These are loosely linked to the glossary cards we have produced but can be used flexibly depending on the interests of your group.

You may also want to show **the prompt video** at the start of your session if you have the appropriate set-up and you feel your group would respond well to video content.

Discussion Questions:

For each question we are keen to understand how participants feel so that we can find themes and identify some values-based principles from the discussion. These can then be used to guide the development of the SDE.

GLOSSARY CARD	QUESTIONS
Your health data and research	1. Did you know that your patient health data is already used for research? How do you feel about this use of your data? 2. What are some good and bad things you think could happen if researchers had easier access to patient health data for studies? 3. What are the good and bad things about specific projects like studying lung diseases, cancer treatments, or emergency care research using linked health data? 4. What do you think about linking your health data from lots of different places together, like GP and hospital records or test results, to study diseases? 5. What are our priorities for research here in Wessex? 6. How do we value NHS data? What do we want from researchers in exchange for giving them access to data?
What is an SDE	7. How do you think the SDE should act to be transparent and accountable? 8. How can we make sure that the decisions that the SDE takes are trusted by the public? 9. What kind of involvement do you think patients and the public should have in the SDE?
Keeping your data safe	10. What do you think about different types of organisations, like universities, charities, or companies, having access to your health data? 11. Do you have any worries or questions about how your health information might be used for research? 12. What do rules should we have to keep your health data safe? 13. (Prompts for this last question could explore the Five Safes: making sure the data doesn't show personal details, only using data where there is a benefit to patients or the NHS, only allowing approved researchers, using a secure system to

	store data, and checking results before sharing to protect privacy.)
Protecting your privacy	14. What are your thoughts about anonymising data – removing names and other personal details – before researchers see it? **15. How do you feel about researchers using your health data without asking you directly for permission, as long as your confidential patient information is always kept private?** *Note that this is the key question that Health Research Authority want us to test with the public.*

Key Topic Discussion Outputs:

Capture answers and discussion themes for your report.

Add-On Activity: ‘Hopes, Fears, and Ideas’ sticky notes exercise

If you want to add a workshop element to your discussion then take a flipchart or suitable wall space and create three areas marked ‘**Hopes**’, ‘**Fears**’ and ‘**Ideas**’.

Give participants some sticky notes and a marker pen to write short sentences or words that capture their response to each question **OR** the facilitator can write these up for the group. Post these up in the relevant area. It’s a good idea for the participants / facilitator to explain the comments as the sticky notes are added.

Thematically sort the sticky notes as you add them to the wall OR at the end of the session after you have worked through some/all of the questions. Work with the group to put related comments together in a group.

Once this is done **write a title for each group** on another sticky note. These are your themes.

Create a **democratic discussion** with the group about how to (1) reduce or remove fears; (2) how to ensure that their hopes for the project actually happen; and (3) how their ideas might be further developed so they work in practice.

Add-on Activity Outputs: Take photos of the completed flipchart or wall space, along with notes from the session.

Activity Set B: Creative Activities

Some PPIE groups enjoy a more hands-on approach to a discussion group or workshop. In this section we present activities for groups that invite them to draw, write or re-design as a means to explore the key values, governance questions, and rules around the Wessex SDE project.

Before you begin any of these creative activities, try to ease any concerns participants' have about their drawing abilities by highlighting that it’s just their ideas that matter – doodles, stick figures, etc. are very welcome! Or for writing, reassure them that full sentences are not needed, stream of thought or jotted down notes are perfectly fine.

Draw or write about the Wessex SDE

This drawing or writing activity can be used with groups that either respond well to more creative prompts, or that already have a base understanding of what health data and data security are.

Group Size: Can be done with smaller or larger groups.

Materials: For this activity you will need everyone to have a pencil (or pen, marker, crayon, etc) and small blank index cards, sticky notes, or squares of blank paper.

Make it Virtual:

- Use **breakout rooms** and enable participants (or facilitators) to share screen. With the new whiteboard features, you can even ask people to mock up text on screen
- Use a **padlet** to help record participants feedback and enable them to upload photos or screenshots of their own drawings.

Activity Plan:

Step 1: Briefing

Provide the group with a more in-depth overview of what the SDE is. This can be either in text form (handed out or read out), or by showing a short video. Allocate time for questions about SDE and then provide participants with a drawing prompt.

This short introductory video to SDE has been useful in previous PPIE discussions to introduce what SDE is. It can be paired with or replace some of the introductory text at the start of this facilitation guide.

https://youtu.be/qbAAD9UGNCI?si=BPGxGVEWZHT01VV8

After the video, don’t lead participants in how to respond. We want to know what their instinctive and immediate thoughts are, particularly if this is the first time they are hearing about SDE.

In the discussion, you might raise some topics covered in the video, particularly if these are not reflected in the drawings/writings. This can help widen the reflection.

Step 2: Drawing or writing

Prompt your participants to draw an icon or visual representation of how they imagine a ‘secure data environment.’ If writing, reflect on your initial response to the ‘secure data environment’.

You might further prompt with questions such as, ‘What does “data security” look like to you?’ Or ‘How could you represent a “secure environment” where people’s health data would be stored for research use?’

Allocate 5-15 minutes for this task. You can see how people are getting along and decide how much time makes sense for your group. If some people finish early, you can ask if they’d like to try to draw another representation.

Step 3: Grouping ideas

Gather everyone’s drawing and/or writing together and lay them out on a table or along a wall. Make sure everyone can see them and that they can be moved around.

Work with the group to cluster together similar drawings. For example, representations that look like houses might be grouped together.

Step 4: Reflecting

Ask the group to comment on how the drawings/writing are similar and different. What metaphors were most used? How did people represent the idea of security? Of data? Do any of the drawings or writings seem different from all the others?

Outputs: Capture this discussion, as well as a digital image of the clustered drawings, for your PPIE report.

Add-On Activity: Re-draw or Re-write

Based on the discussion, now ask participants to redraw or rewrite, focusing on some of the comments and topics raised in the discussion.

For example, if participants talk about benefits or hopes or particular fears, the second round of drawing/writing would follow-up and explore this.

Prompt questions could include: ‘What are you thinking now?’ ‘Would you add or change anything?’ Let participants know that they can amend their original work in a different colour (so we can see the amends) or start fresh.

Then repeat steps 3 and 4.

Outputs: Capture this discussion, as well as a digital image of the clustered drawings, for your PPIE report.

Help us re-design our Wessex SDE toolkit

The aim of this activity is to generate discussion on the values and governance of the Wessex SDE at the same time as getting feedback on our toolkit design materials.

Group Size: Can be done with smaller or larger groups. Depending on group dynamics and group size and, participants can work individually or in pairs. It is a good idea to give each person or pair a single use case study or glossary card to focus on. You can either give everyone the same visual or mix it up.

Materials: For this activity you will need to distribute copies of our toolkit materials (use case studies and/or glossary cards) to participants along with sticky notes, a pen or pencil, a mark-up pen, or emoji stickers.

Make it virtual:

- Use **breakout rooms** and enable participants (or facilitators) to share screen. With the new whiteboard features, you can even ask people to mock up text on screen
- Use a **padlet** to help record participants feedback and enable them to upload photos or screenshots of their own drawings.

Activity Plan

This activity has five steps. If you are short on time, you can choose to do just the ‘deconstruct’ or ‘reconstruct’ parts of the activity or spread them across two. You might also find that people ‘deconstruct’ and ‘reconstruct’ at the same time. If this seems to be happening organically, you can combine steps 2 and 4 and just have a single discussion:

Step 1: Briefing

Provide the group with a more in-depth overview of what the SDE is. This can be handed out or read out. Then provide participants with the visual material (use case study card or glossary card) that they will be ‘deconstructing’ and ‘reconstructing’.

Explain that you would like them to spend some time (around 5 minutes) reading the text and looking at the images. Ask them to reflect on how well they think they understand what the card is about.

Step 2: Deconstruct

Using stick notes and either a mark-up pen or emoji stickers, ask participants to make comments directly on the visual materials. These comments might relate to:

- How well they understand the language used to explain the case study or glossary term. This can include reflections on tone, style, jargon, metaphors, etc.
- How well they understand the visuals used to explain the case study or glossary term. This can include icons, data graphics, colours, layout, etc.
- Anything else that they think might be confusing or difficult to understand.

Step 3: Discuss

Ask participants either to present back to the group, or volunteer to share some of what they did. Try to group together any common concerns and see if any other patterns emerge. Use their comments to guide them onto step 3, where they will take their critiques and turn them into actionable suggestions for improving the materials.

Step 4: Reconstruct

Now ask participants to return to their visual material and the comments they made. Either using a new copy of the material, or another colour of mark-up pen and sticky note, ask them to try and make suggestions to improve or enhance the visual. These suggestions might include:

- A different way of writing or phrasing an explanation. This can include alternative words, metaphors, or tones.
- A different way of representing visually. This can include icons, data graphics or the layout.
- Anything else that they think might help improve or clarify the visual material.

Step 5: Discuss

Ask participants either to present back to the group, or volunteer to share some of what they did. Try to group together any common suggestions and see if any other patterns emerge. To wrap things up, try to recap the major suggestions that people brought forward and let them know that you will share the final versions of the designs with them.

Outputs: Capture this discussion, as well as a digital image of the deconstructed and reconstructed materials, for your PPIE report.

Activity Set C: Roleplay Scenarios

Begin by introducing the SDE using the relevant **Toolkit glossary cards** and **FAQs.** This provides the group with a more in-depth overview of what the SDE is. Then discuss one or more of the following topics using the content and prompts provided, using the activity below.

Roleplaying has lots of benefits. It helps us to understand different viewpoints – in this case campaigners who are critical of what we are doing, different kinds of researchers, and NHS decision makers – by letting us experience these roles first hand. This method also helps us with communication skills and supports cooperative solutions.

Group Size: Will work best with groups of 6-20 people

Materials: For this activity you will need to distribute copies of our toolkit materials (use case studies and/or glossary cards) to participants along with some note paper, post-its and writing materials.

Make it virtual:

- Use **breakout rooms** and enable participants (or facilitators) to share screen. With the new whiteboard features, you can even ask people to mock up text on screen

Data Access Committee game

The SDE's Data Access Committee is the group of people who will take decisions on what research projects are allowed to go ahead and use the SDE. It's a vital role and we want you to step into the roles of the people who are involved.

By roleplaying the Data Access Committee process, we will all get useful insights into the values that should guide the SDE, and the kinds of rules and processes that are needed to meet public needs and expectations. We can think about who should be on it, and what we would expect of them. Moreover, it should be fun.

*****Encourage open and respectful dialogue.*****

STEP 1: Divide Participants

Split your group into three teams:

A. Campaigners (against the project)
B. Researchers (for the project)
C. NHS (making the decision on data access)

Ideally you want to have 2-3 people in each role; enough that they can have a discussion, but not so many that this takes a lot of time or becomes unwieldy. If you more than 12 participants in your session, you can have several separate committee roleplays going on, though each would need its own facilitator.

STEP 2: Brief the Teams

Tell the group in a moment you will hand out a **use case study card**. Each Team will then take a different role. Fix a time limit for the groups to read and discuss the cards. We recommend 10-15 minutes. You can allow the group to go on longer if they are finding the discussion fun and interesting or cut it short if teams quickly come to a view.

At the end of that time the Campaigner and Researcher Teams will put their arguments to the NHS. Each team needs to either nominate a representative to speak or agree to do this as a team.

The NHS will be able to ask team questions after they speak. At the end of presentations and questions the NHS Team will then have a fixed time (we suggest 3-5 minutes) to decide on whether the project on the card can go ahead, based on the arguments they have heard and the rules that they have made up for themselves.

- **Campaigners (concerned about the project).** You are a group that is concerned about this project and have spotted potential problems or risks. Discuss the **use case study card** and agree on any objections you have for the project, or challenges you want to make before it goes ahead.
  Groups can also use the **'Five Safes' glossary card** to help think about what this might be: Does the project lack a public benefit? Is there a risk of data misuse? Is data too sensitive for sharing? Could the research results have unintended consequences?
- **Researchers (for the project)**. You are the researchers applying to access data in the SDE. You need to make the argument for why this should be allowed.
  You need to be clear on the benefits to patients, the public, and the NHS. You might also want to think about what else will persuade the NHS. Or any criticisms that you might need to defend against.
- **NHS (making the decision on data access)**. Your job will be to decide whether the project goes ahead. Before you hear the arguments, agree what tests you will use to decide whether the project can go ahead. Write these down. Short notes or individual words on post-its are fine.
  Be clear that this is a game. There are no right and wrong rules. We are interested in how they would judge the project, not what they think the 'right' answer is.

STEP 3: Case Presentation

Ask the Researcher Team to present their case in support of the project. Keep them to their time limit as far as is reasonable in the circumstances.

The NHS team then has an opportunity to ask questions.

After they have finished the Campaigner Team presents their concerns. Then the NHS Team has an opportunity to ask them questions too.

STEP 4: Decision Making

After the NHS Team has listened to both sides and asked any remaining questions, have them decide if the project should proceed. Ask them to give clear reasons for their decision that are supported by the Five Safes framework.

STEP 5: Reflection

Give everyone involved an opportunity to reflect on how they feel and think about: (1) the decision, (2) their role and what they said; and (3) the other Teams and what they said. You can use the questions below (or those in Activity A) to guide discussion:

- What rules do you think the SDE needs to make the trusted decisions?
- Who should be making the decisions about what research happens? How should the public be involved?
- What are the risks and benefits you see in research using NHS data?

STEP 6: Rotate and repeat

Repeat the exercise with the participants swapping roles and using a new case study.

Outputs:

- Observe discussions and note key arguments and decision factors.

- At the end, facilitate a group discussion to reflect on the exercise and capture insights on how different perspectives influence decision-making in healthcare.

Newspaper Headline game

This is an imaginative game and quite straightforward. Working in groups, participants will brainstorm and create a newspaper headline for a big problem the SDE might face.

We want participants to think about their concerns around health data research and data security. This game asks: If people’s concern turned into a reality what would be the worst-case scenario? How would it be reported by a tabloid newspaper like *The Daily Mail* or *The Sun?*

After participants work to create the crisis, you will then have them look at what could be done to help prevent it. Here, you can use the **toolkit glossary cards** as a prompt for this discussion – looking at the different ways that the SDE can keep data safe.

This game helps people think about safety in a creative way. It's great for the SDE team to hear the problems people are concerned about and their ideas for how we might fix them – it helps us improve. Plus, participants will get a better understanding of data safety. Let's dive in and see what they come up with!

Foster a welcoming environment where everyone feels comfortable sharing their thoughts. Be clear that we at the SDE believe in parity of esteem: that experts and the public should have equal respect and value in this dialogue, acknowledging that each perspective brings crucial insights to the table.

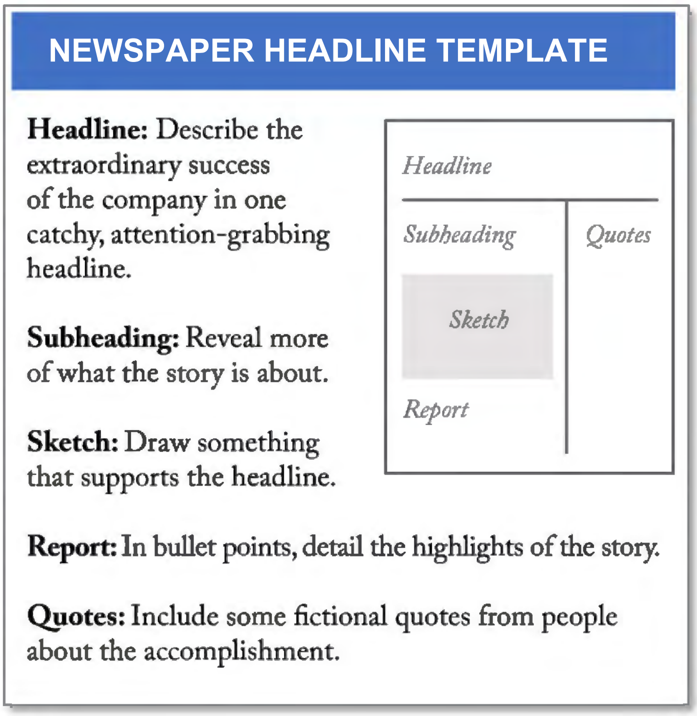
STEP 1: Form Groups

Split everyone into small, manageable groups. Aim for diversity in each group to get a range of perspectives.

STEP 2: Newspaper Headline Story Creation

Each group crafts a headline about a big problem the SDE might face, like a data breach. Encourage them to be creative but realistic, thinking about their own concerns as a starting point.

The groups can just write the headline, or you can give them the option of sketching out the front page using the template shown right.



NEWSPAPER HEADLINE TEMPLATE

Headline: Describe the extraordinary success of the company in one catchy, attention-grabbing headline.

Subheading: Reveal more of what the story is about.

Sketch: Draw something that supports the headline.

Report: In bullet points, detail the highlights of the story.

Quotes: Include some fictional quotes from people about the accomplishment.

STEP 3: Discuss Newspaper Headlines

Groups share their headlines with everyone. This is a chance for open discussion about the potential challenges highlighted by each headline.

STEP 4: Introduce 'Keeping Your Data Safe' Card

Hand out the **toolkit glossary cards** and **a copy of the FAQs** to each group. This will guide them in the next part of the game. Explain that the SDE follows the Five Safes framework that is outlined on the What is the SDE and Five Safes cards.

Each of the Five Safes provides a way of tackling the problems that we have identified. For example, if the problem was misuse of data, then the 'Safe People' principle is the one we should think about.

STEP 5: Solution Brainstorming

Using the card, groups brainstorm solutions and preventative measures for the problems they've identified, guided by the principles of the Five Safes.

STEP 6: Share and Reflect

Each group presents their solutions and preventative ideas. This is a great opportunity for everyone to learn from each other's insights.

Outputs:

- Actively listen and take detailed notes on the concerns raised and solutions proposed.
- Take photos of or keep the newspaper headlines and any other notes / sticky notes that are shared.
- After the session, collate the notes to identify common themes and unique ideas.

‘Make your own research project’ game

For this activity, you are asking participants to step into the shoes of a researcher. As the facilitator, you'll be actively involved, helping participants understand the types of data that might exist to help solve their chosen problem and how to tackle it.

First, you will ask participants to pick a health or social issue that matters to them. Then, they'll create their own research project proposal to tackle this problem. You will work with them to decide what kind of data they'll need and think about any challenges or opportunities their research project proposal might bring up.

This game is designed to for participants to reflect on the kinds of health research that is important to them and to reflect on how they view research. It's also a way to explore the complexities and considerations of real-world research.

STEP 1: Identify a Healthcare Problem

Working as a group, brainstorm a healthcare problem that needs solving. This should be a real problem that relates to health or social care, depending on where the group wants to go. Ideally it is something that the group agrees on and care about, but the value of the task is getting people to think like researchers, then to explore the implications of the study—what concerns or questions people might raise.

You can begin by providing some ideas of what kinds of research that can be done with the SDE. This is a list of the six kinds of project the NHS Research SDE Network is designed to support:

- 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 or technologies 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

STEP 2: Formulate a Research Question

Craft a clear, focused research question that addresses the identified problem. The facilitator should help to guide this activity you to ensure it is specific and researchable. For example, you could use an AIM, WHY, HOW structure.

- Aim (AIM): What are you trying to achieve?
- Rationale (WHY): Why is this important? What gap in knowledge or healthcare does it address?
- Methodology (HOW): In very broad terms how will the research be done?

STEP 3: Define Required Data

Discuss and list the types of data needed to answer your research question. This is an opportunity to discuss what data is, how it is created, how to get hold of it, and what you can do with it.

The facilitator can help explore or imagine the different data sources that could be used. There is no need to be completely accurate with what datasets exist, we can be imaginative about this point.

STEP 4: Design the Research Project

Sketch a very basic plan for your research. Outline steps like data collection, analysis, and expected outcomes, with the facilitators guidance to help make it realistic.

STEP 5: Explore Implications

Reflect on the possible impact of your research. Consider potential challenges and opportunities your project could encounter in the real world. For example:

- Is there a clear benefit to the patients or the NHS?
- Who might support or oppose this, and why?
- What sort of safeguards do you think the public would want to see?
- Are there any unintended consequences from the research?
- Do you think the NHS should allow or refuse this project, and why?
- How would you make sure the benefit of allowing the research to happen is shared fairly?

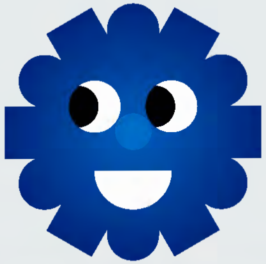
STEP 6: Reflect and Discuss

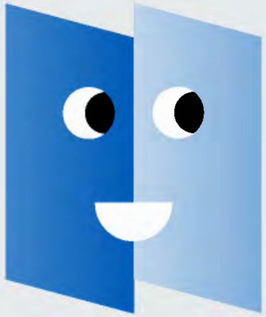
Share your research plan and thoughts on the process. This is a great moment to learn from each other's approaches and insights.

Outputs:

- Write up the research project adopted by the group. You can use the checklist below to help structure this:
    - Problem Identified: [Brief description]
    - Research Question: [Clear, concise question]
    - Required Data: [List of data types/sources]
    - Potential Impacts: [Challenges and opportunities]
    - Research Plan Outline: [Step-by-step approach]
- Observe the issues that they discuss in this context and their reflections on the process.
- Capture any ethical concerns or innovative solutions discussed.
- Compile these observations post-session with a thematic analysis.

Wessex Secure Data Environment Toolkit





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TOOLKIT

Introduction

The aim of our toolkit is to help people better understand what the Wessex Secure Data Environment (SDE) is, how it keeps data secure in line with the 'Five Safes', and what kinds of benefits this 'big health data' project offers to patients and the public.

These toolkit materials are designed based on a model of 'data visualisation literacy as empowerment'. This means creating visual materials that help people gain technical literacy, improve health literacy AND give people the tools to put this 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.

Produced by:
This toolkit has been produced by Bournemouth University for University Hospital Southampton NHS Foundation Trust, who are leading the Wessex Secure Data Environment Project (SDE). The Wessex SDE is part of a national programme funded by the NHS England and the Department of Health and Social Care. Project lead by Professor Anna Feigenbaum. Design by Minute Works.

Use Case Study Cards

We have created Use Case Study Cards 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.

Glossary Cards

What is data?

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.

You and your data

What is my health data?

Anytime you interact with the NHS, for example during an appointment with a GP, or with a nurse in a hospital, they will record information about you. For example, you might discuss how you are feeling, and they will note it down, or you might have your blood pressure measured and the results added to your file.

Why does the NHS have personal data on me?

Each NHS or social care service that you use stores its own record about you electronically. Personal data included in your health records are things like your name, NHS number, or your address. This information is used to identify you, to contact you, and to link records from different places together.

Why is it good to share our health data?

When doctors and researchers bring our health data together, they can find new patterns and trends to improve the understanding of diseases and disability, and to develop new treatments and technologies. This data can also be used to plan healthcare services for all our future needs.

What is data?

Hi I'm **Data**. I represent things in the world, including details about you.

I can represent something small and personal, like the number of cups of tea you drank this week.

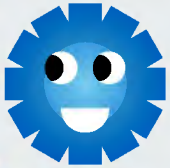
Or I can represent something huge, like the number of cups of tea drunk in the UK each year. (Almost 36 billion!)

By linking different kinds of data together, researchers can ask bigger questions, look at more sides of a problem and gain new insights.

Usually, people think of me as representing numbers or amounts, like 'how many,' 'how much,' 'how often.

But I can also be about describing experiences. For example, if you told me why you drink so much tea—or so little tea--that could be data too.

Health researchers can use data to help improve their knowledge of diseases and illnesses so that society can prevent, treat and care for people better.



By linking different kinds of data together, researchers can ask bigger questions, look at more sides of a problem and gain new insights.

For example, researchers who wanted to know about tea drinking and life expectancy in the UK brought together data on cups of tea drunk and data on mortality rates.

Researchers can also link up data from different kinds of places to discover more about people's health. For example, do places that serve free tea improve mental health by combating loneliness?

Using big data is getting easier and faster with new technologies. This raises important questions about who gets to collect, research and make decisions with data.

The NHS is trying to answer these questions as part of their commitment to use data to improve the health and care of the population--in a safe, trusted and transparent way.

GLOSSARY

What is the SDE and the Five Safes?

Hey, who are you?

Hi, I'm **Secure Data Environment**. They call me this because I'm a platform that provides a safe home for data, a place where it lives and is looked after. If people want to visit my data, they have to have good intentions, to treat it with care and to go through a training process.

Ok, I'm in. Can I wear a lab coat?

You can help come up with new data projects for me. I love a good proposal!

Hi, I'm **Five Safes**! My five principles work together to keep your data safe. Let me introduce you to them:

Safe Projects – Before any research begins, projects are approved by an independent review committee, who check that the reason for using the data is for the benefit of people's health and social care. These committees usually have patients or members of the public on them, too.

Safe People – To keep data safe, all SDE users must receive appropriate training and demonstrate that they have the technical skills needed before they are approved to access data.

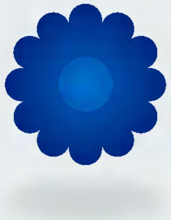
Safe Data – Data is treated before going into the SDE so that personal details and people's identities are kept safe. This can involve a process called pseudonymisation – see 'What is pseudonymisation?' glossary card.

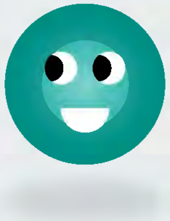
Safe Settings – Access to SDE data is only possible in a secure setting. There are safeguards in place, including the use of technologies, like encryption, to protect data.

Safe Outputs – Before any research findings or statistics are released, these outputs are screened by a controller to make sure that no one can be personally identified from the data. Extra steps are taken where data is about a small group, such as a tiny village, that is more at risk of identification.

GLOSSARY

What is pseudonymisation?





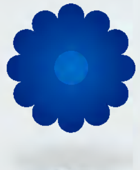
Who are you?

I'm sorry but that's private.

C'mon, you can trust me...

I'm pseudonymised data.

What kind of word is that?



It's simpler than it sounds. While your doctors need to know who you are, you probably don't want everyone reading your medical records. To keep your personal information confidential, when your data is used for research, any information that would identify you is removed and replaced by me, **Pseudonymised Data**.

So I get a secret name like a superhero?

Sort of. It's a way to keep your personal identity safe.

And you are?

I'm **Five Safes**. I put the *Secure* in ***Secure* Data Environment**. To have **Safe Data**, researchers will give patients a name or number, called a unique identifier, that does not reveal their 'real world' identity.

But what if someone figures out who the patients are?

A special code is used, like a key, that locks and unlocks my identifiable personal information.

This special code is called a **project key** and it is held by people that guard the SDE system. The project key is not accessible to the researchers working on the project, ensuring that your confidential data remains secure.

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.

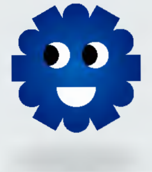
USE CASE STUDY

IDx Lung

Early Cancer Detection in Wessex and Yorkshire

The IDx Lung project is using the SDE to help improve the early diagnosis of lung cancer.

Accessing the SDE, researchers can use me, a linked dataset, made up of blood and nasal swap test results, CT scans and patients' background information like age, gender and illness history.



Lung cancer is the third most common form of cancer. Nearly 50,000 people get diagnosed in the UK each year. GPs in some parts of England and Wales identify people aged 55 to 74 who smoke or who used to smoke and offer them Lung Health Checks…

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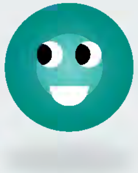
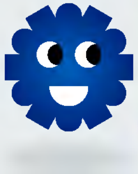
…At the health check, blood and nasal swap samples are taken to help diagnose lung cancer. Then those get sent to partner labs for testing.



I hate putting those sticks up my nose.



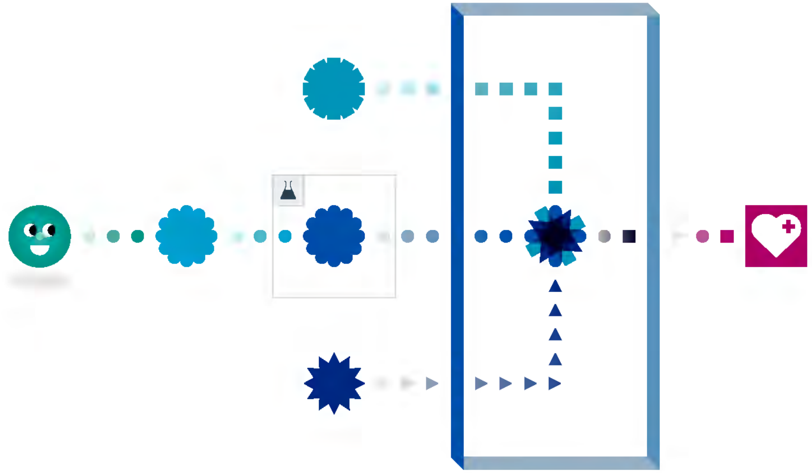
As these people get follow-up checks, including CT scans, this data goes into the SDE, allowing researchers to track what happens over time.

Why do the researchers need to know things like their age and gender?

This information helps researchers find patterns in data that might have to do with gender, age or ethnicity. It can help researchers look for health inequalities.

To make sure these patients cannot be personally identified, all this data is pseudonymised, individual details are removed. IDx Lung researchers have no way to access patient records, instead they are looking for insights that can improve early diagnosis for future patients.

By creating linked datasets like me, the IDx Lung team also helps future researchers. Improvements in early diagnosis can hopefully increase the current 10% survival rate — benefiting patients, as well as their family and friends, like you.



The process starts with ● **you** having ✹ **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

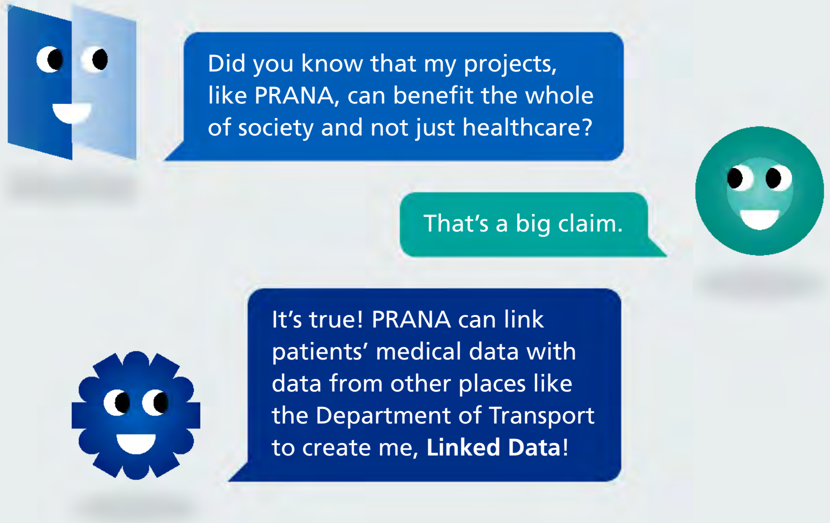
Pre-hospital critical care refers to the specialized medical attention and interventions provided to individuals facing life-threatening illness or injury before they reach a hospital. This care is provided by nurses, paramedics and doctors.

USE CASE STUDY

PRANA

The Pre-hospital Research and Audit Network

Improving how we take care of seriously ill or injured people before they reach hospital and unlocking insights to enhance policies and infrastructures that can save lives.



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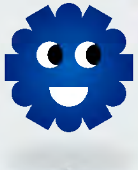


…I am full of new information to answer questions like ‘What affects how fast an ambulance can get to hospital?’ or ‘How does car design impact injuries in a crash?’

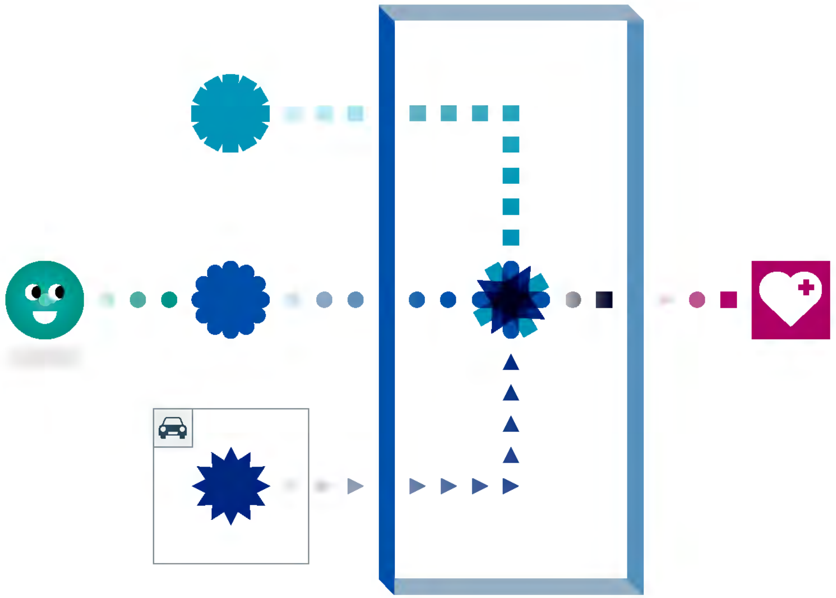
Using linked data, this **safe project** can improve patient care, shape better policies, and make emergency response more efficient and effective…

Can you fix the potholes on my road?

I’m more of a big picture kind of platform. PRANA’s goal is to save people’s lives, improve emergency care, and reduce road collisions--one of the UK’s leading causes of trauma. Did you know that 1,700 people die each year?

Ok, that’s more important than the potholes. So, by using this data you can change things?

I am full of untapped potential. You can analyse me, **Linked Data**, to help improve local ambulance services, look at health inequalities in how patients receive emergency care, develop new training for nurses and paramedics. You could even ask me questions about road quality.



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.

USE CASE STUDY

Cancer Genomics

Using genomic data to improve cancer treatment

Cancer is caused by changes to genes. There are thousands of different changes that cause cancer. To learn more about them, researchers can look at the DNA from cancer patients' tumours.

What do they do with this DNA?

Samples get sent to labs that have special equipment for 'genomic sequencing' that can decode all the detailed information DNA contains. These insights help researchers and doctors better understand and treat patients' cancer.

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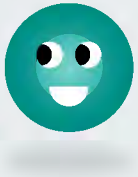


But isn't everyone's experience of cancer different?

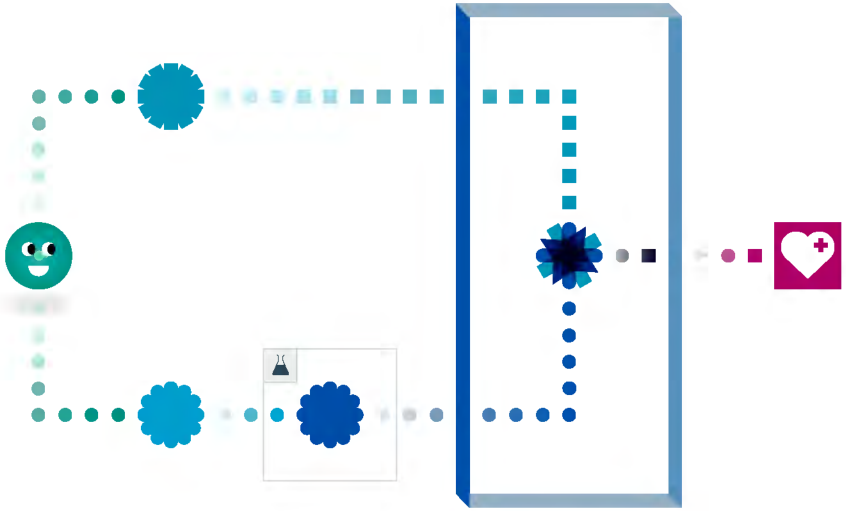
Yes, information about patients' individual journeys is also important for providing more personalised care. If information from patients' medical records can be linked with genetic sequencing data, researchers and doctors will be able to match cancer patients with the best treatments.

But if they have all this data, why aren't they already doing this?

That's a very good question! Partly it is because there is so much data that only some of it gets prioritised and used.

Another challenge is that this data is currently stored in different places. To be able to bring it all together securely in the SDE, we are working to build effective data transfer and storage systems.

Over time, the project's goal is to create a unified system. So, if a patient moves from one hospital to another, insights about their cancer can still be understood and interpreted in the same way 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 2: Supplementary stimulus materials

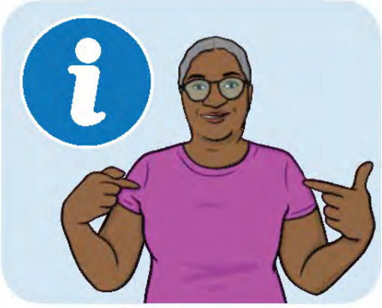
Easy Read

Talk to us about our new project

This booklet is from the NHS in Wessex.

Our services cover Hampshire, Dorset, the Isle of Wight and South Wiltshire.

We would like you to talk to us about our new **Secure Data Environment** project in Wessex.



Data is information about something or someone.

The project

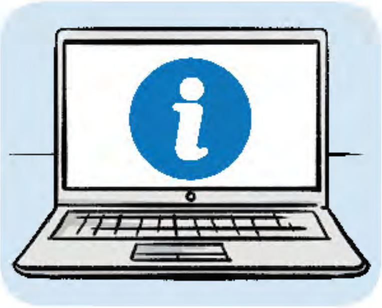
Our project is looking at how we can use data about people’s health to support health **research**.

Research is when a group of experts look into something to find out more information about it.

Health research helps us find new ways of treating patients and improving people’s health.

We think data about people’s health can help health research in Wessex.

Our idea

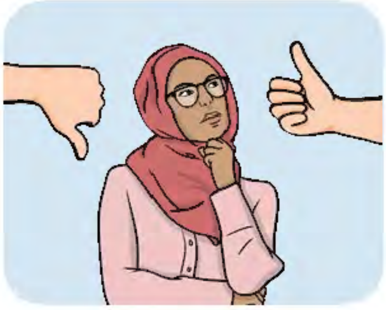


Our idea is to have a website where we can keep data about people's health.

We are calling the website our Secure Data Environment.

People doing health research can use the website to find data.

We will keep data about your health safe on the website.



You will have a choice about whether we can use data about your health or not.

We need your help

There will be rules about:

- Who can use the website.

- How people should use the website.

We want everyone to be happy with the rules.

We would like to talk to you about our project and the rules.

This will help us make sure we have the right rules and that our project will be good for everyone.

The talk will be around 30 minutes long.

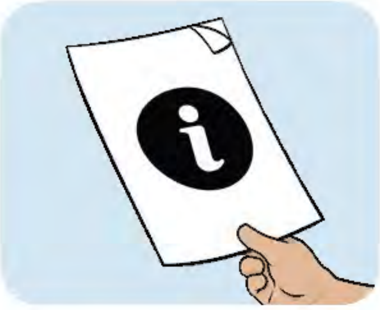
We can meet you at a time and place that suits you.

As a thank you for helping us, we will give you a £50 shopping voucher.

How to talk to us

To set up a meeting with us, please email Sarah Knott at Sarah.Knott@uhs.nhs.uk

Sarah is part of our project team.



You can also email Sarah if you need any more information.

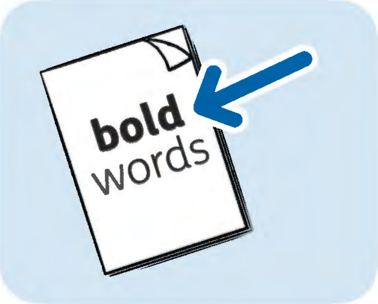
Our Secure Data Environment project

In Wessex

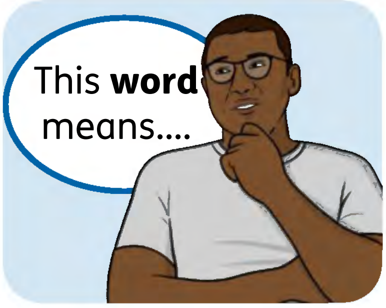
Easy Read

This is an Easy Read version of some information. It may not include all of the information but it will tell you about the important parts.

This Easy Read booklet uses easier words and pictures. You may still want help to read it.



Some words are in **bold** - this means the writing is thicker and darker. These are important words in the booklet.



Sometimes if a bold word is hard to understand, we will explain what it means.

Blue and underlined words show links to websites and email addresses. You can click on these links on a computer.

What is in this booklet

About this booklet 4

The project 5

Data about your health 8

Find out more 10

About this booklet

This booklet is from the NHS in Wessex.

Our services cover Hampshire, Dorset, the Isle of Wight and South Wiltshire.

It is about our **Secure Data Environment** project in Wessex.

Data is information about something or someone.

This booklet will tell you about our project.

The project

Our project is looking at how we can use data about people's health to support health **research**.

Research is when a group of experts look into something to find out more information about it.

Health research helps us find new ways of treating patients and improving people's health.

We think data about people's health can help health research in Wessex.

Our idea

We think we could use data about people's health to:

- Improve emergency care services that people need before they get to a hospital.

- Improve treatments for people with cancer.

Our idea is to have a website where we can keep data about people's health.

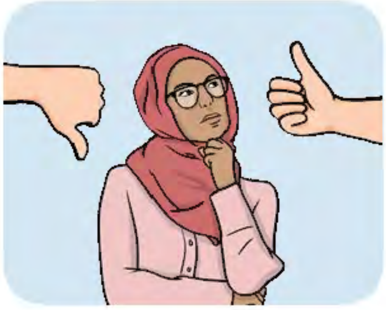
We are calling the website our Secure Data Environment.

People doing health research can use the website to find data.

Data about your health

We will keep data about your health safe on the website.

You will have a choice about:



- Whether we can use data about your health or not.

- How we can use data about your health.

Work with us

Our project will only work if we listen to you.

We want to make decisions about our project with you.

To find out more about working with us on our project, please email Sarah Knott at Sarah.Knott@uhs.nhs.uk

Sarah is part of our project team.

Find out more

To find out more about Secure Data Environments, you can go to this website:
www.transform.england.nhs.uk/key-tools-and-info/data-saves-lives/secure-data-environments/

Wessex
SECURE DATA
ENVIRONMENT

Part of the
**NHS Research Secure Data
Environment Network**

NHS

Your information, your choice

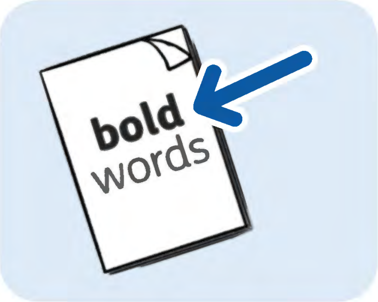
How we look after and use information about your health

Easy Read

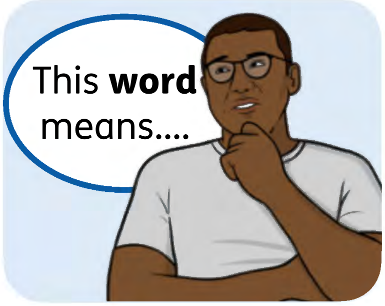
Easy Read

This is an Easy Read version of some information. It may not include all of the information but it will tell you about the important parts.

This Easy Read booklet uses easier words and pictures. Some people may still want help to read it.



Some words are in **bold** - this means the writing is thicker and darker. These are important words in the booklet.



Sometimes if a bold word is hard to understand, we will explain what it means.

Blue and underlined words show links to websites and email addresses. You can click on these links on a computer.

What is in this booklet

About this booklet 4

Our Secure Data Environment 9

Find out more 12

About this booklet

This booklet is from the NHS in Wessex.

Our services cover Hampshire, Dorset, the Isle of Wight and South Wiltshire.

This booklet is about how we look after and use information about your health.

This information is anything that has to do with your health and care, like:

- Illnesses you have.

- Treatment or care you get.

This information also includes:

- Health tests you have had.

- Medicines you are taking.

- Your **allergies**.

  If you have an **allergy**, it means your body reacts to a certain material, like dust.

- When you have been to hospital appointments and what happened at them.

Who can look at my information?

Information about your health is kept by organisations that give you healthcare, like:

- Your hospital.

- Your local doctor’s surgery.

- The NHS.

Only healthcare staff at these organisations can look at your information.

Why do organisations need my information?

The organisations that give you healthcare use information about your health to:

- Give you the right care when you are ill or injured.

- Plan your care and arrange for you to use the right healthcare services.

- Do health **research.**

  Research means collecting information about something to find out more about it.

Health research helps us find new ways of treating patients and improving people's health.

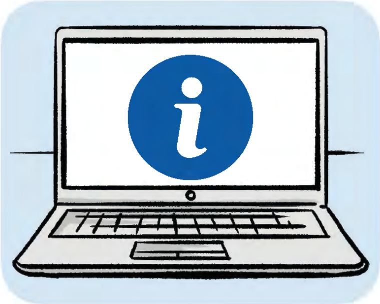
Is my information kept safe?

Information about your health is kept safe by the organisations that give you healthcare.

These organisations follow the law when collecting and keeping people's information.

Our Secure Data Environment

Doing health research can help us to improve our services.



We want to have a website where we can keep information about people's health.

We are calling the website our Secure Data Environment.

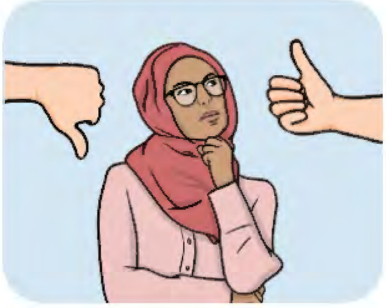
Only people doing health research can use the website to find information.

We are working with lots of different people to plan and set up our website.

If you would like to take part in planning and setting up our website, please visit: wessexSDE.NHS.net

We will keep your information safe on the website.

But you do have a choice about:



- Whether we can use your information and keep it on the website.

- How we use your information.

If you decide that you do not want us to use information about your health, this will **not** affect the care you get.

If you do not want information about your health to be on our Secure Data Environment website, please tell us by:

- Email: contact@wessexSDE.NHS.net

- Phone: 01234 567 890

- Post:
  Wessex SDE
  University Hospital Southampton
  NHS Foundation Trust
  Tremona Road
  Southampton
  SO16 6YD

Find out more

You can look at our website here:
www.nhs.uk/your-nhs-data-matters

Wessex
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Environment Network

NHS

Your information, your choice

Information about your health is kept by organisations that give you healthcare, like your local doctor's surgery.

We may use information about your health to do **health research**.

Health research helps us find new ways of treating patients and improving people's health.

If you do not want your information to be used in health research, please contact us by:

- Email: contact@wessexSDE.NHS.net
- Phone: 01234 567 890

Easy
Read

NHS

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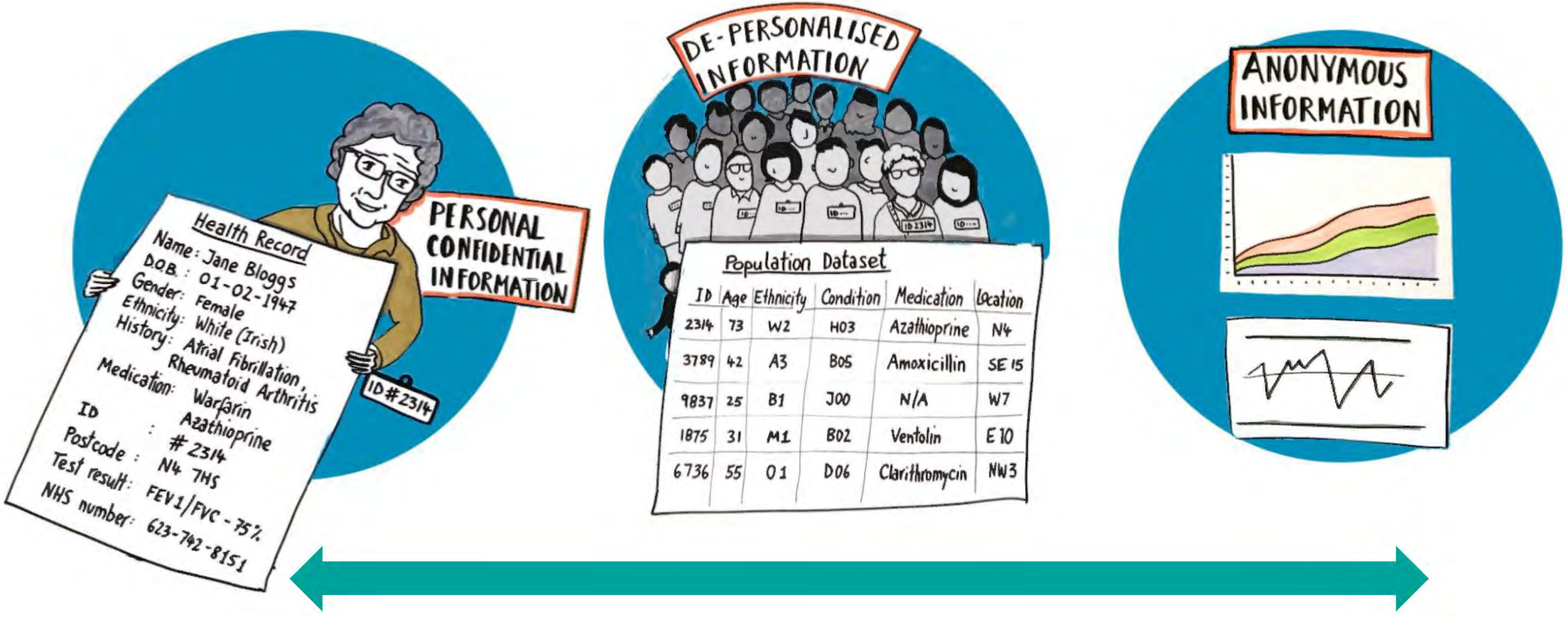
Additional Stimulus material

November 2023



Health Record
Name: Jane Bloggs
D.O.B.: 01-02-1947
Gender: Female
Ethnicity: White (Irish)
History: Atrial Fibrillation, Rheumatoid Arthritis
Medication: Warfarin Azathioprine
ID : # 2314
Postcode : N4 7HS
Test result: FEV1/FVC - 75%
NHS number: 623-742-8151

Population Dataset

ID	Age	Ethnicity	Condition	Medication	Location
2314	73	W2	H03	Azathioprine	N4
3789	42	A3	B05	Amoxicillin	SE 15
9837	25	B1	J00	N/A	W7
1875	31	M1	B02	Ventolin	E 10
6736	55	01	D06	Clarithromycin	NW3

MORE IDENTIFIABLE

LESS IDENTIFIABLE

NHS

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Introduction to the Wessex Secure Data Environment

October 2023

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NHS

The Wessex Secure Data Environment project is looking at how we **unlock the potential of health data to support research and innovation**, for the benefit of patients and our NHS.

There are **six main kinds of research** and innovation that the project would aim 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

Two projects we are looking to support here in Wessex aim to **improve pre-hospital emergency care services** and use data about our genes to **give better cancer treatments**

… to do this we are building **an online place where health data can be stored and accessed by researchers.**

This is our **‘Secure Data Environment’** and it will be designed with the highest standards of privacy and security for NHS data.

Wessex
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data Environment Network

NHS

Your health data will be **kept safe** and you will have **choice** about how it is used.

You can find out more about the national NHS programme that we are part of here.

Community involvement is vital to the project's success. We will work together to ensure important decisions about the project are made with you, and for the benefit of local people and the NHS.

To find out more or arrange a meeting please contact **Sarah Knott** at University Hospital Southampton NHS Foundation Trust.

Sarah.Knott@uhs.nhs.uk

Appendix 3: PIER Partnership – full engagement report

“This is complex and potentially divisive – The NHS needs to get this right.”

Perceptions from people who are marginalised and seldom heard in Dorset regarding the Wessex Secure Data Environment Project

April 2024

BU Bournemouth University | Public Involvement in Education & Research Partnership

CSHV Centre for Seldom Heard Voices Bournemouth University

Report written by:
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PIER Officer
Public Involvement in Education and Research (PIER) Partnership

Christine Vincent
Postgraduate Research Assistant and Faculty of Health and Social Sciences Student

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Project Oversight:
Dr Mel Huges
Professor of Social Work
Academic Lead for Public Involvement in Education and Research (PIER) Partnership
Deputy Director of the BU Research Centre for Seldom Heard Voices
Director of the National Centre for Cross-Disciplinary Social Work
Advance HE National Teaching Fellow

Executive Summary

As part of a larger initiative by the Department of Health and Social Care and the NHS in England, the Wessex Secure Data Environment project aims to improve the way health data supports research and innovation. To do this, a Secure Data Environment, an online location designed to give NHS data more protection, is being developed, where health data is stored for access by researchers.

Community involvement was seen as essential to ensure that marginalised voices contribute to the development of the Wessex Secure Data Environment. The aim of this aspect of the project was to understand the thoughts, questions, fears, concerns, hopes, and dreams of those living in Dorset regarding their health data being stored in a Secure Data Environment for use by researchers.

Community involvement activities took place from January 2024 to March 2024. Twelve groups, made up of 110 people living in Dorset whose voices are seldom heard in research, took part in discussions with one or two facilitators. These groups were carers, people with long-term health conditions, members of a Poverty Truth Commission, people living in an area of high deprivation, young adults (18-24-year-olds), a youth group (15-17-year-olds), people experiencing vulnerable housing, people in early recovery from substance use, people with an HIV positive diagnosis, people with visual impairment, older people (aged 86 and over), and members of the LGBTQ+ community.

Many public contributors initially felt uncertain about the topic and their ability to contribute meaningfully. However, there was also an element of curiosity, which resulted in a willingness to be involved. This, combined with the influence of established trusting relationships with the Bournemouth University Public Involvement in Education and Research (BU PIER) partnership, contributed to enthusiasm for exploring the topic in detail. Public contributors typically left with many questions rooted in curiosity, rather than distress.

From the discussions thirteen themes were identified: “Can I trust you?”, “The NHS needs to get this right”, “How secure is ‘secure’?”, “This is complex and potentially divisive”, “Hopes and dreams, if done right”, “What are my priorities?”, “Will our data be looked after?”, “My needs are misunderstood”, “Do I have value? Is my voice heard?”, “We are too worried about other things to care about this”, “How can I be sure?”, “Resignation”, and “We have no control”.

For each group, emergent themes are represented diagrammatically using a colour coding system. Each diagram consists of the overarching theme – the key driver that shaped the conversation –, 3 sub-themes, and a concluding theme. Many themes recurred across multiple groups, but four themes emerged from single groups.

Each diagram is followed by a narrative summary of the conversations held with the group. These discussions are then comparatively distilled in the ‘Conversations’ section, which concludes with next steps for the project and final remarks.

For many groups, the conversations spanned issues much wider than those directly linked to the Secure Data Environment project. These issues strongly influenced and provided the context for what was most important to the group members with regards to the use of their data for health and social care research and have therefore been included.

1 Introduction

As part of a larger initiative by the Department of Health and Social Care and the NHS in England, the Wessex Secure Data Environment (SDE) project aims to unlock the potential of health data to support research and innovation (Department of Health and Social Care 2022a). To do this, an SDE is being developed, which is an online location designed to give NHS data more protection, where health data is stored and can be accessed by researchers.

Currently, when a researcher or analyst wants to use NHS data, they must go through a rigorous application process known as the Data Access Request Service (DARS) (NHS England 2024a). Whilst the DARS process is considered to effectively protect patient data and privacy (Health and Social Care Information Centre 2016), there are ways that sharing data for research and innovation could be more efficient, secure and support greater collaboration.

SDEs are designed to uphold the highest standards of privacy and security of NHS health and social care data by giving approved users access to relevant health data for research and analysis without the raw data ever leaving the SDE (Department of Health and Social Care 2022b). By removing personal details, SDEs ensure that patient information remains confidential. They aim to improve security, as NHS data will only be hosted on systems that can prove high levels of protection, and efficiency, by ensuring many sources of data can be linked, improving the preparation and easy access of data by researchers (NHS England 2024b). Overall, this will aim to increase the speed at which the NHS can make decisions and the discovery of new treatments, while ensuring the privacy and protection of patients and their health information (NHS England 2024b).

Community involvement was seen as imperative to ensure that the public's most marginalised voices are heard and contribute to the development of the Wessex SDE. The aim of this aspect of the project was to understand the thoughts, questions, fears, concerns, hopes, and dreams of people living in Dorset whose voices are often excluded from research regarding their health data being stored in an SDE for use by researchers.

A key objective of the project was to include public contributors who are most marginalised in society, including those who may have particularly sensitive health data. To identify groups for inclusion, people within NHS England's Core20PLUS5 were asked to take part, as well as several groups outside these criteria who tend to be heavily marginalised and may have most to lose by their health data not being stored and shared securely. The Core20PLUS5 criteria are made up of the most deprived 20% of the population, as identified by the Index of Multiple Deprivation, and five clinical areas, including maternity, severe mental illness, chronic respiratory disease, early cancer diagnosis, and hypertension (NHS England 2023). The following report presents the findings from these community involvement sessions.

2 Engagement Activities

Community involvement activities took place in the 3 months from January 2024 to March 2024. Twelve groups, made up of 110 people living in Dorset whose voices are seldom heard in research participated in discussions with one or two (of two) facilitators.

Table 1 details the groups that participated in community involvement activities.

Table 1. Description of Dorset-based groups included in Community Involvement Activities

Group Type	Group Description
Carers	Twelve self-identified carers currently or recently caring for a parent, son or daughter, or young people with Autism Spectrum Disorder. The group self-identified as “a diverse group made up of a range of ages and lived experiences”.
Long Term Health Conditions	Nine people with long-term health conditions, many with multiple long-term conditions. The group was composed of a self-identified conspiracy theorist, several people with neurodiversity and/or severe and persistent mental health conditions and included some with lived experience of homelessness.
Poverty Truth Commission	Two members of a Poverty Truth Commission based in Dorset, both with lived experience of homelessness, poverty, and high deprivation.
Deprivation	Eleven community members and three community volunteers from a high deprivation area in Dorset.
18-24 Year Olds	Twelve young adults aged 18 to 24. The group was composed of university students, agricultural workers, those working on zero-hour contracts in retail and hospitality, an apprentice at a nursery school, and one who is in the process of completing deckhand sailing training.
15-17 Year Olds	Nine young people aged 15 to 17 living in a high deprivation area in South Dorset and regularly attending a local youth group.
Substance Use/Vulnerably Housed	Eight people with a history of substance use including many with experience of being vulnerably housed. Attended drop-in style sessions on a one-to-one basis.
Substance Use/Early Recovery	Eighteen people (thirteen in a group setting; five one-to-one drop-ins over coffee after group activity) in early stages of recovery from substance use.
HIV Positive	Six people with an HIV Positive diagnosis living in Dorset. The group contained a mix of men and women with a range of length of time since diagnosis (from less than 5 years to more than 40 years). For some, the only people who knew of their diagnosis were those in the room and healthcare professionals.
Visually Impaired	Thirteen people with varying levels of visual impairment. The group included men and women aged 30 to 80 years old, who had a range of cause and degree of sight loss and different associated health conditions. Some were guide dog users, some had been born with visual impairment/blindness, others experienced sudden onset or progressive sight loss.
Older People	Four people aged 86 and older with multiple health conditions and attending a local group designed for people with specific long-term health conditions.

LGBTQ+	Three people from the LGTBQ+ community, one who identifies as transgender, one gay woman, and one bisexual woman.

Drawing on the Bournemouth University Public Involvement in Education and Research (BU PIER) partnership's established and trusted relationships with community partner organisations and individual PIER members, this part of the Wessex SDE public involvement included some of those most marginalised and seldom heard voices from across Dorset.

Where, when, and how the conversations should be held were jointly planned with group leaders. For some groups, several conversations were held with different public contributors. Groups were a combination of in-person or online with one or both facilitators present. Where people chose to contribute on an individual basis, this too was accommodated to enable contributions in the manner that supported inclusion and at the pace of trust. For some groups, additional materials were used to facilitate the conversations and included a short SDE video prompt, visual prompts and the opportunity and materials to draw a visual representation of an SDE. Overwhelmingly, the preference for all groups was the interactive discussions and conversations to explore what was most important to each public contributor. However, having flexibility and choice and a range of materials was helpful to support inclusion, create a 'safe' feel in the workshop, and contribute to deeper exploration of the issues.

Many public contributors initially felt uncertain about the topic and their ability to contribute meaningfully. However, there was also an element of curiosity, which meant people were willing to be involved. This, combined with the influence of established trusted relationships with Bournemouth University Public Involvement and Engagement in Research (BU PIER) and, in many cases, the community partner we were collaborating with, resulted in an enthusiasm for exploring the topic in detail. Public contributors typically left with many questions rooted in curiosity, rather than distress.

Following discussions, themes were identified and mapped to a diagram. The diagrams were colour-coded to allow researchers to identify when and where the same theme was identified from more than one group. While this aided the identification of common themes, it also allowed identification of themes unique to a specific group, reflecting difference.

3 Findings

Across all groups, thirteen themes were identified (Figure 1).

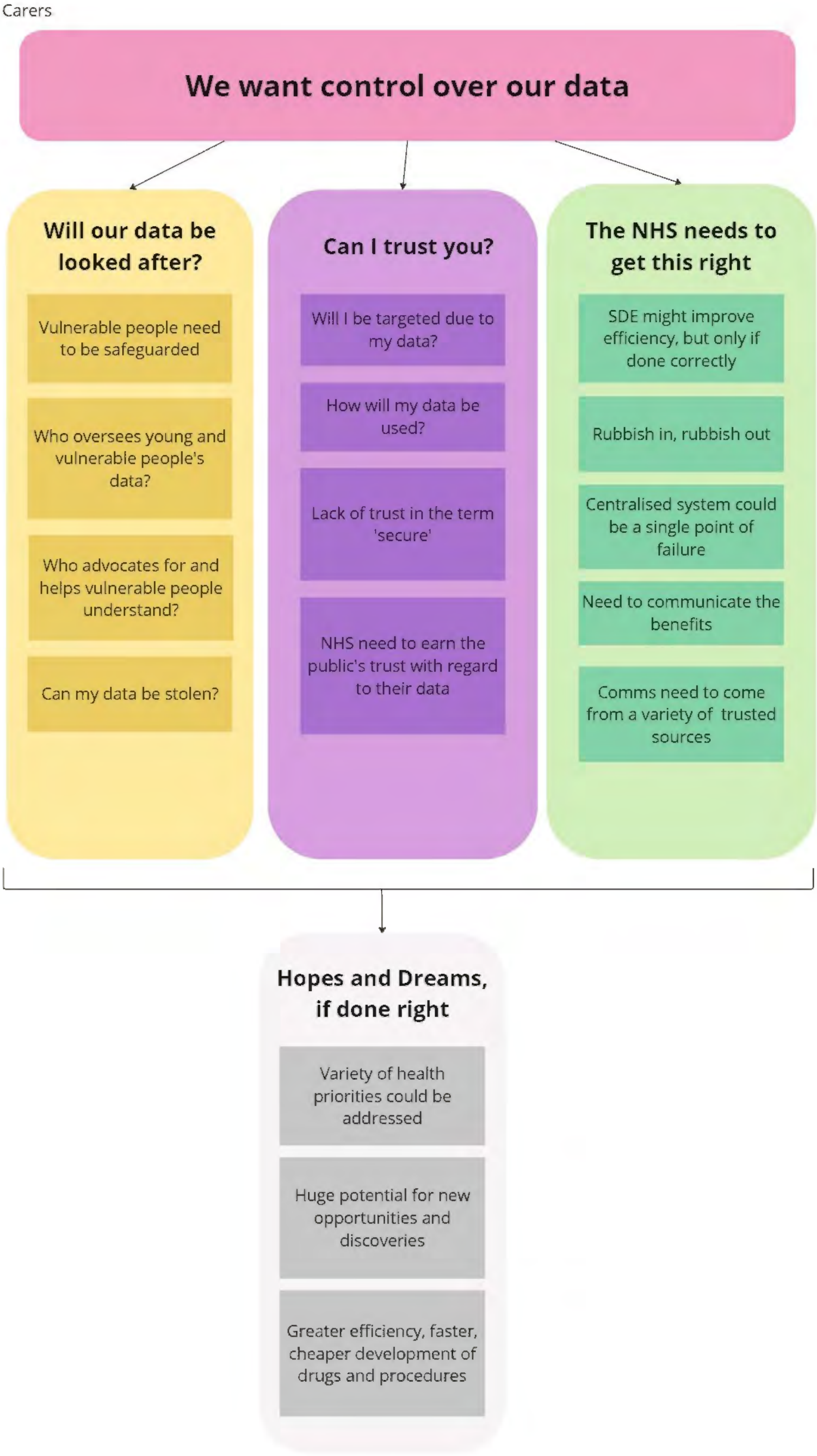
Figure 1. Themes discussed during community involvement activities and how many groups discussed them (grey circles)

Table 2 illustrates which groups discussed each theme.

Table 2. Themes discussed by each group (x = discussed)

Theme	Carers	Long Term Health Conditions	Poverty Truth Commission	Deprivation	18-24 Year Olds	15-17 Year Olds	Substance Use / Vulnerably Housed	Substance Use / Early Recovery	HIV Positive	Visually Impaired	Older People	LGBTQ+	Theme Frequency
Can I trust you?	x	x	x	x	x		x	x	x	x		x	10
The NHS needs to get this right	x	x		x	x				x	x	x	x	8
How secure is ‘secure’?			x			x	x	x	x	x	x	x	8
This is complex and potentially divisive		x		x		x	x	x	x	x		x	8
What are my priorities?	x	x	x	x		x		x					6
Hopes and dreams, if done right	x			x	x	x				x			5
Will our data be looked after?	x	x	x		x							x	5
My needs are misunderstood							x		x	x			3
Do I have value? Is my voice heard?							x				x		2
We are too worried about other things to care about this						x							1
How can I be sure?			x										1
Resignation											x		1
We have no control over this								x					1

3.1 Carers



Carers

We want control over our data

Will our data be looked after?

Vulnerable people need to be safeguarded

Who oversees young and vulnerable people's data?

Who advocates for and helps vulnerable people understand?

Can my data be stolen?

Can I trust you?

Will I be targeted due to my data?

How will my data be used?

Lack of trust in the term 'secure'

NHS need to earn the public's trust with regard to their data

The NHS needs to get this right

SDE might improve efficiency, but only if done correctly

Rubbish in, rubbish out

Centralised system could be a single point of failure

Need to communicate the benefits

Comms need to come from a variety of trusted sources

Hopes and Dreams, if done right

Variety of health priorities could be addressed

Huge potential for new opportunities and discoveries

Greater efficiency, faster, cheaper development of drugs and procedures

Figure 2. Carers’ Theme Diagram

The carers group included 12 self-identified carers, all of whom currently or recently cared for a parent, son or daughter, or for young people with Autism Spectrum Disorder, either in the same home, living locally, or living distantly with episodes of living in parents' home. The group self-identified as a "diverse group made up of a range of ages and lived experiences".

Video prompts were used to generate discussion and facilitators gave an explanation of the Wessex SDE project. One public contributor drew an image to illustrate their thoughts (Appendix A), while others participated in verbal discussions. Two carers participated in in-person, one-to-one discussions with a facilitator. Four attended an in-person discussion with one facilitator. The remaining six participated in an online discussion with both facilitators present.

Following video prompts and initial description from facilitators, carers generally felt an SDE sounded like a good idea, but questions arose very quickly. For example:

"Will there be checks on people that are asking for the information?"

"Are they paying money to get the information?"

"Can we opt out of being on this database?"

There were initial questions around, *"Can people steal my/our data?"*, but carers quickly acknowledged, *"It's probably less risky than the current system".*

The idea that data held within an SDE would have personally identifiable information removed was felt to be a strength:

"This could speed things up and improve and make things easier."

There was a concern that some people, particularly those with certain health conditions, would be targeted for unfavourable purposes:

"Can organisations misuse my/our data to deprecate our lives? For example, by preventing us from getting insurance if we have 'markers' for a disease or illness?"

"Are you going to be targeted by them finding there are lots of certain types of people in a certain area?"

The use of 'secure' in the SDE title and the associated implications of this came into question:

"It's punchy, but 'secure' doesn't make me feel secure, it's all the 'what if's, there's so much other stuff that comes along with it. What's the catch? I love the idea of it all being together and centralised, but I'd want to know more."

"The fact that there's no personal information in the system reassured me, but where it's labelled a 'secure data environment', it makes it sound like it will contain information that I should be worried about."

Worries around the security of the system also arose due to recent events in the media:

"Because of the Post Office thing, I would not ever trust the word 'secure'."

"I would want to know which IT company is involved, due to mistrust relating to the Post Office situation and to know what they have in place for issues that are highlighted."

Carers also wanted to know exactly what information was being shared and to be in control of that, either though the option to opt out or by choosing what information goes in:

"I'd want to opt out and know exactly what I'm sharing."

"I want to read my records before, so I know what's being shared."

"I want to tick a box saying I'm happy to share."

However, there were differences in this perception amongst the group. Some carers felt that as long as their health data was contributing to improving other people's health and wellbeing, they wouldn't mind their data being stored and shared:

"For me personally, I don't have a concern with people using my data if it's for the benefit of the health of other people. I don't have a history of medical difficulties, I'm not a vulnerable person, I have mental capacity. My concerns would be for other people, but I don't have an issue with my personal data being used."

Carers also expressed that clarity is needed regarding what is being consented to:

"What research purposes is my data being used for? 'A researcher' is broad. I would consent to some things, but not everything. If I had a diagnosis and it could inform better healthcare, I'd feel differently than if it was for another purpose. You have to be clear on what you're consenting to. Do we get to opt in and out and pick and choose who we allow our data to go to?"

There were questions for some carers around how the data will be used:

"Would it be open to people who are manufacturing drugs? Could competitors use it for profit generation? Would the private sector be able to access it? It needs a control at the start to prevent this."

Trust in the NHS' ability to deliver this project effectively also came into question, primarily due to a perception that the NHS has a poor record in the way it has previously handled largescale data-related and IT projects and that the NHS currently holds a lot of health data but aren't using it efficiently:

"They've got lots of data, but they're ineffective at using it efficiently already, so if it goes more digital and gets broader, your concerns only grow in some ways."

"The NHS are not paragons of large IT project management. What makes them think it is different this time?"

While most carers recognised that there would be benefits to sharing data nationally *("I have had 20+ procedures and I can see it as a positive that you don't have to re-tell your story, especially if parts of it are traumatic or triggering"*), there were concerns around foreign access *("Is it just researchers from England? If you're on a joint project, would other countries be able to access the data?"*), how far sharing would stretch *("I've recently gone private for some healthcare needs. Are those notes properly shared and where are they stored? … How do we know that the records being stored are accurate if we're accessing private healthcare?"*), and the accuracy of data going in *("If the data is inaccurate or has gaps going in, what's the result of the research?").*

Carers also recognised the concept of *"Rubbish in, rubbish out":*

> *"If my data is going into an SDE to drive research, the research will be flawed because the data is incomplete. No research can be accurate and meaningful if the data is incomplete, inaccurate, or incorrect."*

For some carers, there was concern around the safeguarding of vulnerable people and questions around who would oversee their data:

> *"For young people in care that can't verbalise, authorise, or understand, what's being put in place for them? Does their information just get shared because they don't have the capacity to make a decision? Who advocates and helps them understand?"*

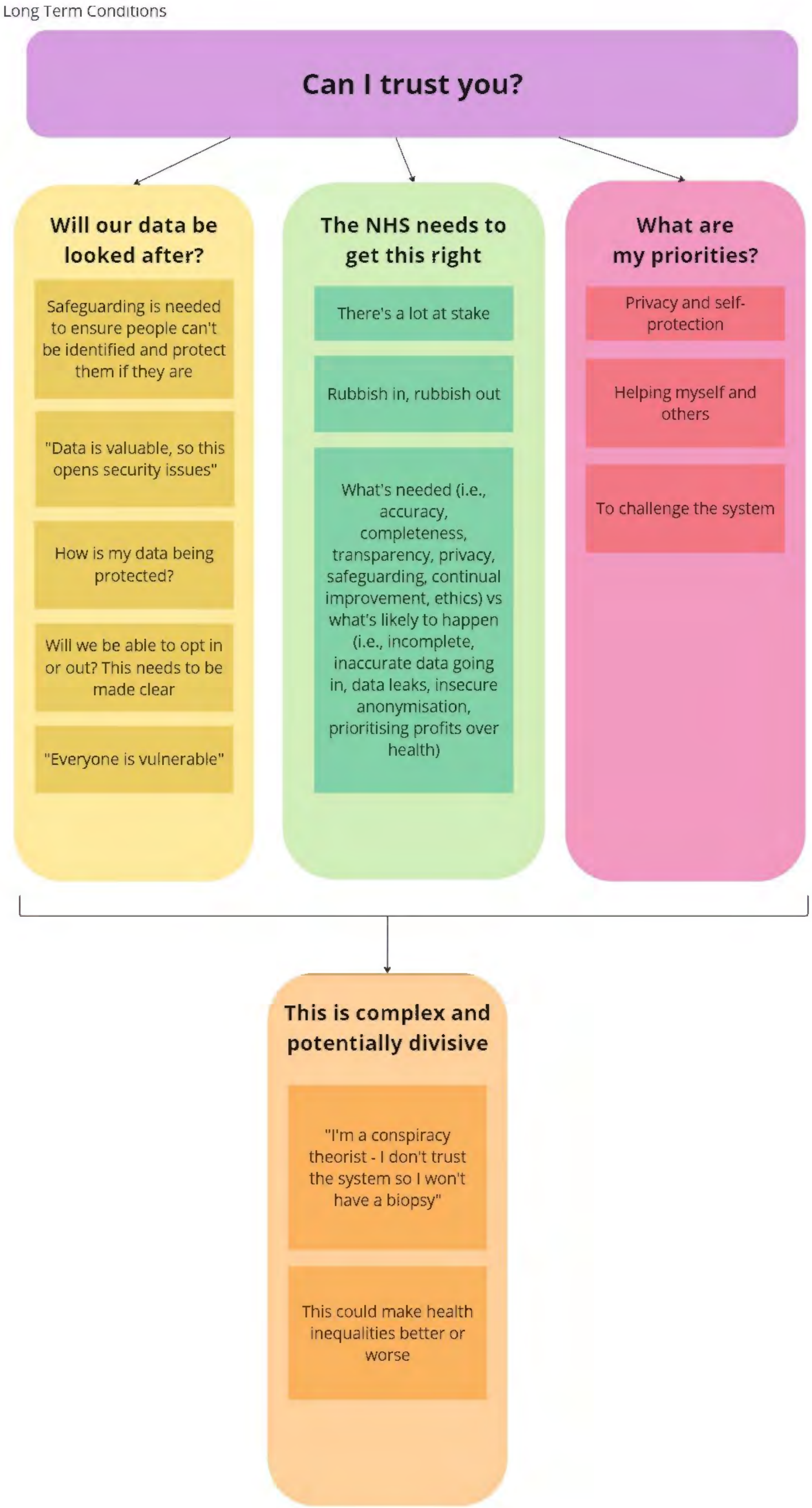
Carers were also concerned that a centralised data system could be a single point of failure:

> *"There's an issue around it being a single point of failure and that the data within it is hugely valuable to the commercial sector. If it's hugely available, there are benefits, but there are risks as well."*

When asked who they would trust to decide what is regarded as 'safe', carers said, *"It can't be anyone who's going to make a profit out of the data, so no one from the NHS. I wouldn't trust politicians or big pharma, so it would have to be a standalone, impartial department made up of general members of the public, volunteers maybe, I don't know how they'd even approach that on a nationwide scale."*

Carers shared that they would trust to hear about SDEs from their General Practitioner (GP), carer groups and organisations, podcasts, social media, the BBC, their regulator (e.g. Care Quality Commission (CQC)), groups like the Women's Institute, but not from the government. It was also recognised that while information should come from trusted sources, *"it's got to be multi-source"* and that this information should be drip-fed, but that *"the drip feeding is not just 'what we are going to do', but also 'what we've done' and 'how it's going'. Positive stories and benefits really need to feed in."*

3.2 Long Term Health Conditions



Long Term Conditions

Can I trust you?

Will our data be looked after?

- Safeguarding is needed to ensure people can't be identified and protect them if they are
- "Data is valuable, so this opens security issues"
- How is my data being protected?
- Will we be able to opt in or out? This needs to be made clear
- "Everyone is vulnerable"

The NHS needs to get this right

- There's a lot at stake
- Rubbish in, rubbish out
- What's needed (i.e., accuracy, completeness, transparency, privacy, safeguarding, continual improvement, ethics) vs what's likely to happen (i.e., incomplete, inaccurate data going in, data leaks, insecure anonymisation, prioritising profits over health)

What are my priorities?

- Privacy and self-protection
- Helping myself and others
- To challenge the system

This is complex and potentially divisive

- "I'm a conspiracy theorist - I don't trust the system so I won't have a biopsy"
- This could make health inequalities better or worse

Figure 3. Long Term Conditions Theme Diagram

The Long Term Conditions (LTCs) group was composed of nine people with long-term health conditions, many with multiple long-term conditions, including a self-identified conspiracy theorist, those with neurodiversity and severe and persistent mental health conditions, previous experience working in public involvement, previous involvement in hospital engagement boards, and lived experience of homelessness.

Two group members met online with one facilitator and seven met in person with both facilitators. Two video prompts were shown at the start of each session, followed by facilitator description of the project, to generate discussion.

Most public contributors liked the idea of an SDE and felt reassured:

"I think it's a good step forward. People worry and are reluctant about their data. This goes some way to addressing that."

Public contributors initially liked the idea that data within an SDE would not contain any identifiable information, but they soon questioned the security, safety and effectiveness of the methods proposed to achieve this:

"Although it's technically anonymised, it's about how it makes people feel. Even if we give them those assurances, there's still a perceived risk."

"Any anonymisation can be breached if you try hard enough."

"The more controls you've got, the more you can hone it down and be able to identify individuals."

Similar to carers, public contributors with LTCs recognised that the centralisation of data into an SDE could act as *"a massive single point of failure if something goes wrong."*

"Who gets access to the data?" was a recurring question throughout both conversations with public contributors with LTCs:

"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?"

"Who are 'they'? Who checks who the researchers are? Who holds the data? Who are the software developers?"

Public contributors felt it was important to know who exactly is involved in the entire process.

Throughout the discussion, markedly opposing views were apparent. Some people said they currently didn't access healthcare services because they don't trust what happens with their data, *"I don't trust the system, so I won't have a biopsy"*, while others said, *"I personally don't care. What's the risk to me? It's not scary to me personally."*

Additionally, some public contributors worried about who the NHS intends to sell their data to:

"It's not about how the health service use it, it's about who they're going to flog it off to."

There were also concerns that if the NHS do ultimately sell data within an SDE or the SDE software itself, that they wouldn't make enough money off it:

"This resource is worth hundreds of billions of pounds, but they won't sell it for that."

Equally, some public contributors felt that *"it's all about profit, not altruism".*

Concerns were also raised about the NHS recognising the value of the data they have access to:

"Historically, the NHS has not been good at recognising the value of the data that it holds. How is data actually used for research purposes? Is it entering the commercial field? This isn't a problem, per se, provided that its true value is recognised and historically it hasn't been."

It was acknowledged that this may be contentious for the NHS:

"What's done now can impact the benefits of this in the future. You can lose the benefits of it if you don't recognise the value of what you've got."

Public contributors also agreed that one of the benefits of an SDE could be duplication reduction:

"There's a lot of duplication. To get the best data, we want to collect it once and get it right the first time. If there's a lot of duplication, what's the public experience of that and are you diluting the project's effectiveness?"

"As a patient, you have to retell your history time and again, it's wearing and there is concern over the accuracy of what is said and done each time. It's highly inefficient and unnecessary time is spent on gathering what should already be there and has been covered so many times."

Following from this conversation, the importance of high-quality data was highlighted:

"With duplication comes inaccuracy. Rubbish in, rubbish back out again. We need to make sure it's quality data that's being centralised."

"Accuracy is key."

This was closely linked to the perceived usefulness of the system:

"If we've got a secure, lovely environment that's full of inaccurate data that has inequalities, is it useful?"

"If we get collection wrong, what good is it?"

A proposed solution to ensuring this is done right was, *"Data collection needs to be given the time it deserves. Time is a scarce resource in the health system, but if we spend more time at those early stages…if we take the time now, we can save time down the road."*

Closely linked to the point of accuracy was completeness. Public contributors felt that, to be effective, data going in needs to be complete, broad, and from everybody. However, they believed that this to be an impossible ask:

"It's never going to be from everyone."

"I never get to speak to a doctor…A lot of data is being missed because people can't get appointments in the first place."

Linked to this point was the concern that the system is *"creating bias"* towards those who regularly access healthcare, therefore potentially exacerbating health inequalities:

"Does this create an inadvertent bias to those engaged with health services in a different way? Be wary of inadvertent health inequalities. The more you're involved, the more data that's collected. What about people with less data put in in the first place?"

Concerns were also expressed that if pharmaceutical companies use the data for drug development, this could further exacerbate health inequalities because they would not be interested in pharmaceutical developments for rarer conditions:

"They're not trustworthy. The drug companies, for instance, will stop making drugs for illnesses with a small cohort."

However, there was also recognition that, if handled appropriately, health inequalities could be addressed:

"Putting trust aside, if you had a national bank of data, they might see local patterns to pick up health inequalities. That can only be good."

Trust was a major point discussed amongst the groups, including trust in those collecting the data, software developers, researchers, the NHS, and whoever holds the data:

"It's also about who is collecting the data and their ability to do that. Have they been shown how to do that accurately and effectively? Soft people skills come into play. You can't just hand someone a form and rush on to something else because then potentially you're not getting the data that you need."

"If there's no trust in the data environment, no one is going to use it."

"If you're truly going to leverage the benefit, the patient needs to know that data is accurate, people inputting it need to know it will be used, and researchers need to know they're getting good data out."

Public contributors expressed that trust is everything and indicated that the NHS needs to earn their trust:

"Without trust, there wouldn't be anything at all."

"Data is valuable, so this opens security issues."

"The NHS was hacked a few years ago, there's a lot that goes on that we don't know about."

"Data is currency."

"When you take a DNA test for ancestry purposes, they take your data and sell it to make money. How do I know the NHS won't do the same?"

Despite doubts expressed, one public contributor said, *"You can't just think of yourself. What will the country need moving forward?"* and, *"I would rather give my information if it would help someone in the future. I'm unimportant and relatively invisible."* This highlighted that some people do not feel as protective over their data as others, prioritising contributing to a greater good over protecting their own data:

"For the public health of the future, it's my role. If I could leave my body to science, I would. This is no different."

There was also a recognition that data can be accessed from a variety of sources, not just the NHS. This resulted in some people trusting the NHS with their data, as they felt it was no less secure than other sources, while others remained sceptical about how safe and secure their NHS data is:

"For me personally, I trust the NHS with my data."

"It scares me. How do you deal with it if your information has been shared inappropriately?"

Some people were willing to accept the risk of their data being used inappropriately if the benefits were seen to outweigh the risks. This idea was related to the use of mobile phones. While people knew that their data was being shared by using a mobile phone, the convenience of having a smartphone outweighed the risks of their data being shared and sold:

"You can say something near your phone and adverts related to that thing will appear."

"Some people will have awareness that this is going on, but it's acceptable to them because the benefits outweigh the risks."

People need to feel that the benefits of an SDE outweigh the risks of their data being lost, stolen, or used inappropriately if they are going to allow their data into the system.

Equally, not all data is perceived as equal. Some health data is sensitive, and some people want aspects of their health to remain private:

"Health data is personal. There are things I don't want other people to know."

Regarding communications around the SDE, there was consensus that the NHS needs to *"share the success stories"*:

"People are more likely to take data discussions more seriously if they know what good is coming out of it."

"Communications need to highlight the positives, both with regard to individuals and saving the NHS time and money."

The importance of transparency was also mentioned. Communications should be clear and transparent about what an SDE involves, whether patients can opt in or opt out, what data is held, how it's used, who accesses it, and other key details:

"Transparency is key."

Additionally, public contributors held the view that communications should be an ongoing conversation, but that *"reassurance needs to be balanced".* They felt that people shouldn't be bombarded with information, especially the risks. Benefits need to be highlighted in addition to any potential risks.

Finally, safeguarding, as discussed in the carers group, was raised towards the end of the conversation:

"Safeguarding people who can't consent is important."

3.3 Poverty Truth Commission

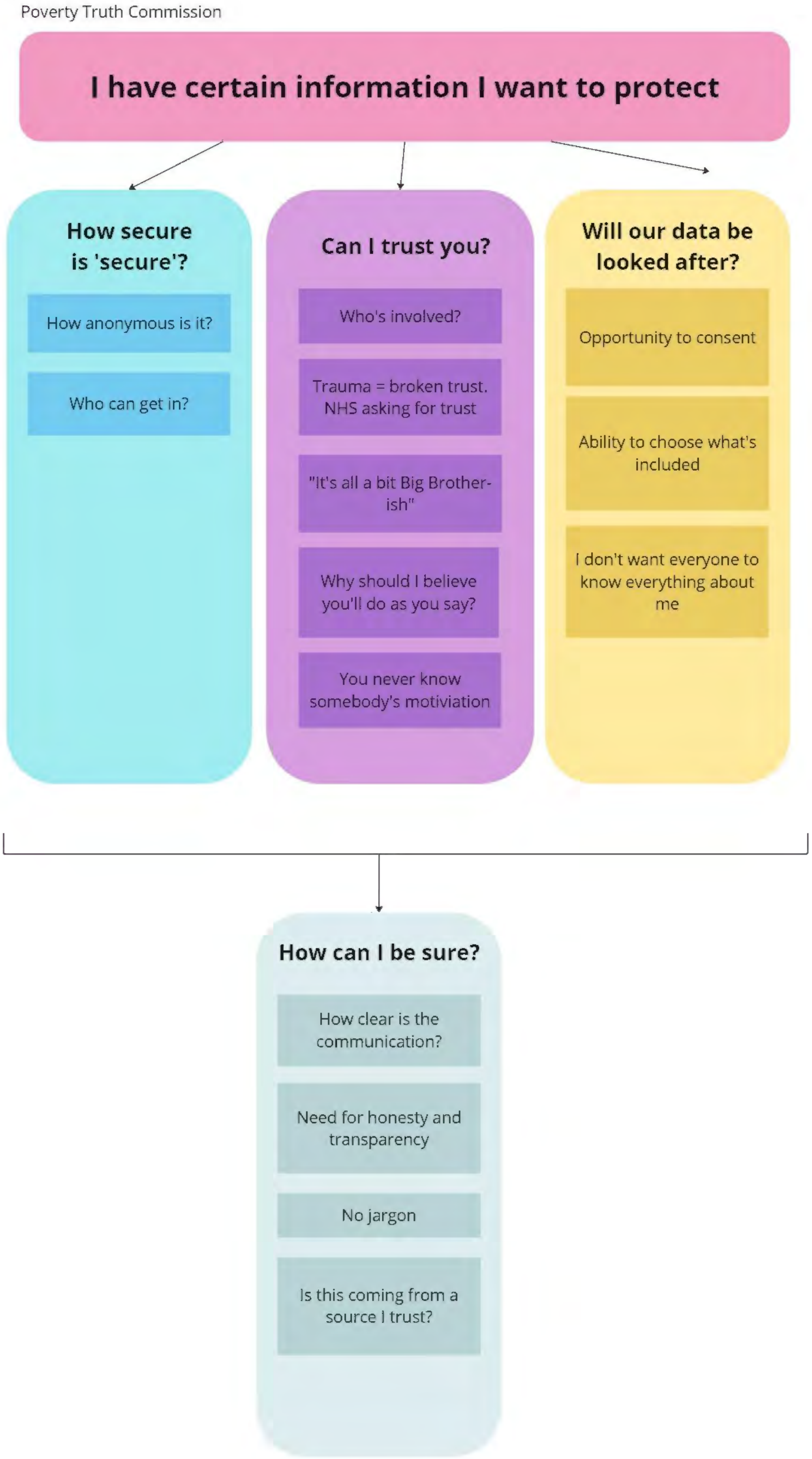


Figure 4. Poverty Truth Commission Theme Diagram

The Poverty Truth Commission (PTC) group was comprised of two members of a PTC based in Dorset. Both members met with two facilitators in person. The conversation began with two video prompts and an introduction to the project from facilitators.

Public contributors shared they had never heard of an SDE. At the beginning of the conversation, one public contributor said, *"I have never been bothered about my data."* This was quickly followed by, *"To be honest, I'm not even sure what 'data' means"*, highlighting that some people may find the terminology confusing and struggle to understand the personal implications of an SDE. For instance, while this public contributor identified that they have never been bothered about their data (for example, they also said, *"Some people are worried about identity theft, I ain't worried about that because I don't think anybody would want to be me."*), as the conversation carried on, they remarked, *"Well, I wasn't worried. Now I am!".*

Public contributors felt that their ability to believe in and trust communications around an SDE would be influenced by who delivers them. Public contributors agreed that they would trust someone with whom they have an established relationship discussing SDEs with them over someone they don't know. Government officials, representatives of the church, and those working in a job centre were all identified as those who could not be trusted. When asked who they trusted, public contributors emphasised the importance of mutual understanding, a shared lived experience, and the need to recognise people's humanity. They also recognised that there are different types of 'expertise' – that which is gained through lived experience, and that which is gained through education. The example that was given was a midwife who has had a child versus one who has read a textbook about delivering a child. Public contributors expressed that both experiential and professional expertise are needed when making decisions around health data.

Regarding identifiable information being removed from the data, there were concerns around what exactly this meant. Public contributors expressed a desire to know exactly how much information will be included in the system:

> *"If someone in our area is looking at that post code and sees a single parent with cancer and this issue and this issue, they can go, 'Oh, I know who that is'."*

> *"How much of the information is there? Can I be identified by the information that's in the system?"*

There was therefore a concern around individuals remaining identifiable despite removal of identifiable information:

> *"I would like to know how anonymised it is. Down to what degree."*

One public contributor suggested this could be mitigated by openness and honesty about what information is available within an SDE. When asked why this was important to them, the public contributor said, *"Well, you don't know what anybody will do nowadays"*, emphasising their lack of trust, not just in the NHS, but much more widely.

There were also concerns around how secure the access-granting process is:

> *"I would like to know; can the general public get access to it as well? Can you just say you're a researcher and get access?"*

Public contributors also questioned the ethics around researchers accessing health data within an SDE without explicit patient consent:

"How come all this research is available and it's accepted that this data could be available, but like if you wanted to look up how many paedophiles were near a school, there's a load of people saying, 'You can't do that, it's against human rights!'?"

A similar example that was discussed related to Clare's Law, which allows police to disclose a person's history of abusive behaviour to those who may be at risk of such behaviour, and the amount of public resistance to its introduction. Ultimately, public contributors had questions around why their health data could be used, potentially without their permission, but they weren't entitled to information about someone else that could directly affect their and/or their children's lives.

Like previous groups, public contributors expressed that the NHS need to get this right:

"The hardest thing is, I get the good intentions of it. The research is needed, but it's got to be done in the right way."

What this public contributor meant by 'the right way' is that the NHS needs to ensure that people can't be identified by their health data and that information they don't want to share isn't shared, that communications are clear and informative and come from trusted sources, and that people with malicious intent will be prevented from accessing the data.

Similar to discussions during the LTCs group, PTC public contributors recognised that not all data holds the same value:

"The first video mentioned social care data. I would like to know what data is included in that."

"My history with social services; I wouldn't want any of it on there."

"And people with mental health issues. If you're having a mental health crisis, do you want people to know about that?"

When asked, "Are there specific aspects of your data that you feel are more precious?", PTC public contributors responded, *"Yes, mental health, being a survivor of domestic violence, for example"* and *"That's why I'd like to know what data is there and to have a choice as to what's included and what's not…Like, I wouldn't mind saying I've had social services in my life, but I wouldn't want to say why or how."*

There was also a recognition that data is valuable and that it could be used against people:

"It's all a bit Big Brother-ish, isn't it?"

"I don't trust easily, I'm cynical and a bit paranoid, but it's so easy for a criminal to use that information for anything."

There was also a discussion around how previous trauma influences one's ability to trust:

"I think it's a case of 'don't trust anyone'."

"Can I trust you?"

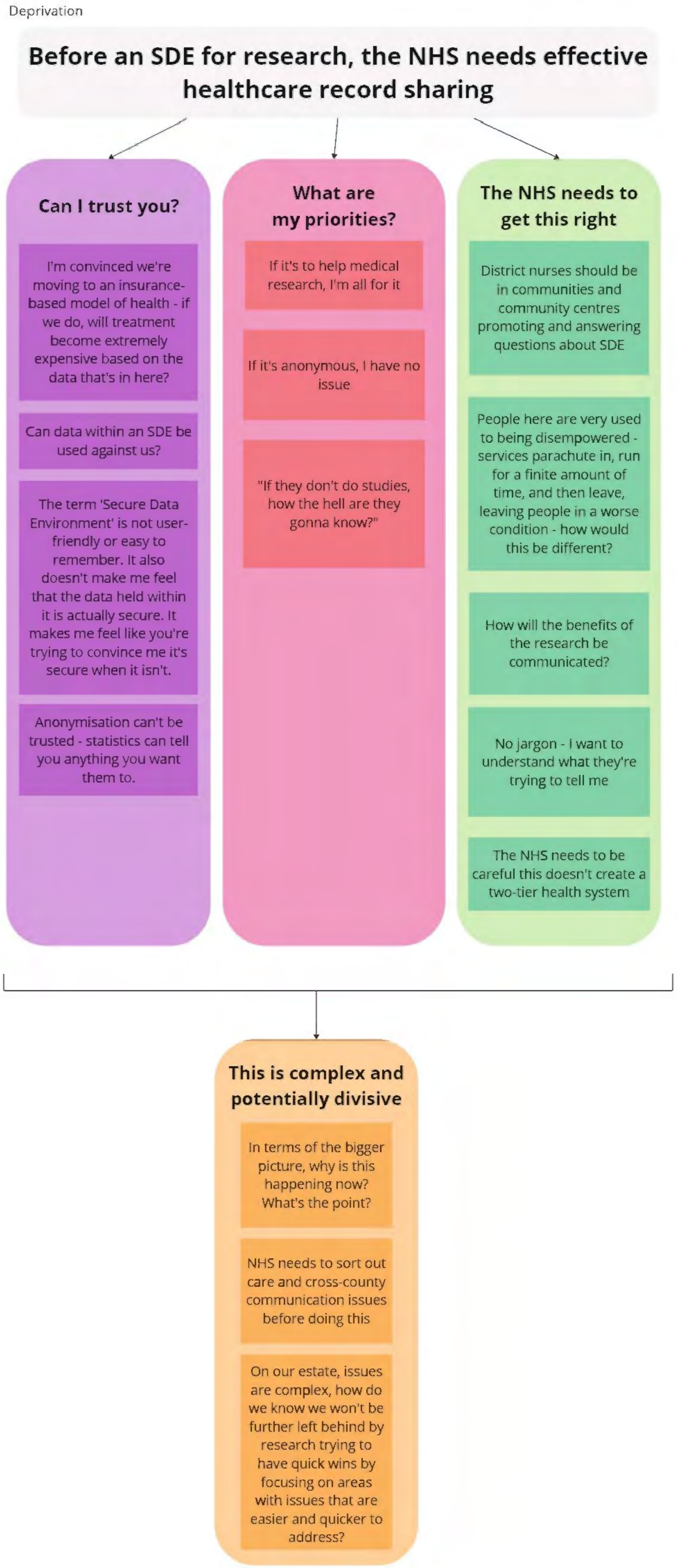
Conversations from this group highlighted that their lived experience informs how communications and new systems in general will be perceived. That trauma is linked to a breaking of trust and trust is the very thing the NHS is asking for, and if someone has lost their trust in the NHS, or never had it in the first place, it can be difficult for this to be established or restored:

"It's like when people ring you up on a scam. They say, 'You can trust me', but I know I can't."

Public contributors, like previous groups, also discussed that there was a concern that some people in society may be less able to protect themselves and that safeguarding these people is imperative:

"Vulnerable people, like the elderly, disabled people, victims of hate crimes, how are they going to feel comfortable with that system and know that they're protected?"

3.4 *Deprivation*



Deprivation

Before an SDE for research, the NHS needs effective healthcare record sharing

Can I trust you?

I'm convinced we're moving to an insurance-based model of health - if we do, will treatment become extremely expensive based on the data that's in here?

Can data within an SDE be used against us?

The term 'Secure Data Environment' is not user-friendly or easy to remember. It also doesn't make me feel that the data held within it is actually secure. It makes me feel like you're trying to convince me it's secure when it isn't.

Anonymisation can't be trusted - statistics can tell you anything you want them to.

What are my priorities?

If it's to help medical research, I'm all for it

If it's anonymous, I have no issue

"If they don't do studies, how the hell are they gonna know?"

The NHS needs to get this right

District nurses should be in communities and community centres promoting and answering questions about SDE

People here are very used to being disempowered - services parachute in, run for a finite amount of time, and then leave, leaving people in a worse condition - how would this be different?

How will the benefits of the research be communicated?

No jargon - I want to understand what they're trying to tell me

The NHS needs to be careful this doesn't create a two-tier health system

This is complex and potentially divisive

In terms of the bigger picture, why is this happening now? What's the point?

NHS needs to sort out care and cross-county communication issues before doing this

On our estate, issues are complex, how do we know we won't be further left behind by research trying to have quick wins by focusing on areas with issues that are easier and quicker to address?

Figure 5. Deprivation Theme Diagram

Discussions were held with two groups from an area of high deprivation in Dorset: one with 11 community members and another comprised of three community volunteers. Both groups met in person with one facilitator. To generate discussion, the facilitator gave a verbal introduction to the project.

Community members' primary concern was the lack of connectivity between NHS systems. They felt that this should be the priority of the NHS, rather than implementing an SDE. Community volunteers expressed similar concerns:

> *"In terms of the bigger picture, why is this happening now? What's the point?"*

Similarly, community volunteers wondered whether an SDE could contribute to improving connectivity:

> *"Health data is accessible anyway, this would just be streamlining it. It's hard enough to get your health records from your GP, would this help with that?"*

Some community members shared, *"it sounds like a secure data environment would be great."* It was recognised that *"The benefit of doing research is great for people with serious conditions and bringing this data together in one place will enable doctors to access research documents and other things."* Initially, community volunteers also recognised the potential benefit of an SDE:

> *"In terms of health tracking, it makes a lot of sense."*

While many community members agreed that *"if they're not taking your identity, I don't see a problem with researchers using your information in that way. If it's to help with medical research, I'm all for it"*, others had concerns around whether and how they would be notified if their data had been used:

> *"Would we be notified? Would they just use it?"*

Some community members expressed that they would like to know the research outcomes:

> *"I want to know what the outcome of the research is and I'm worried that if they just used my information without me knowing, they wouldn't tell me the conclusions."*

Some community members had no problem with their health data being used to support research:

> *"You can have my information and use it willy nilly. I'd rather them use it."*

Community volunteers also recognised the potential research benefits of an SDE, but remained sceptical about the possibility of unintended consequences:

> *"Having centralised health information is so valuable, and it makes a lot more sense, because it means you're not having to jump through hoops to access stuff that's potentially improving the lives of entire populations, but will there be an unintended consequence of that?"*

> *"Statistics can tell you anything you want them to."*

Community volunteers were concerned with who might be able to access their health data, regardless of whether personally identifiable information was included:

> *"Who's seeing the data? I would worry about that."*

They also expressed concerns about whether they could be targeted for details in their data:

“Can the data within it be used against us?”

One community volunteer expressed concerns similar to carers’ concerns about the prospect of data within an SDE limiting access to insurance services:

“I’m convinced we’ll be moving to an insurance-based model of health. I think that our primary care will always be free at point of access, but that secondary care will move into insurance. In terms of data use, if they know that you have lifestyle modifiers, for example being a smoker or overweight, at what point will treatment become very expensive?”

Regarding the term ‘Secure Data Environment’, and like concerns expressed in previous groups, community volunteers said, *“It’s not a user-friendly term and it doesn’t convince me it’s secure. It makes me feel like there’s information in it that I should be worried about.”*

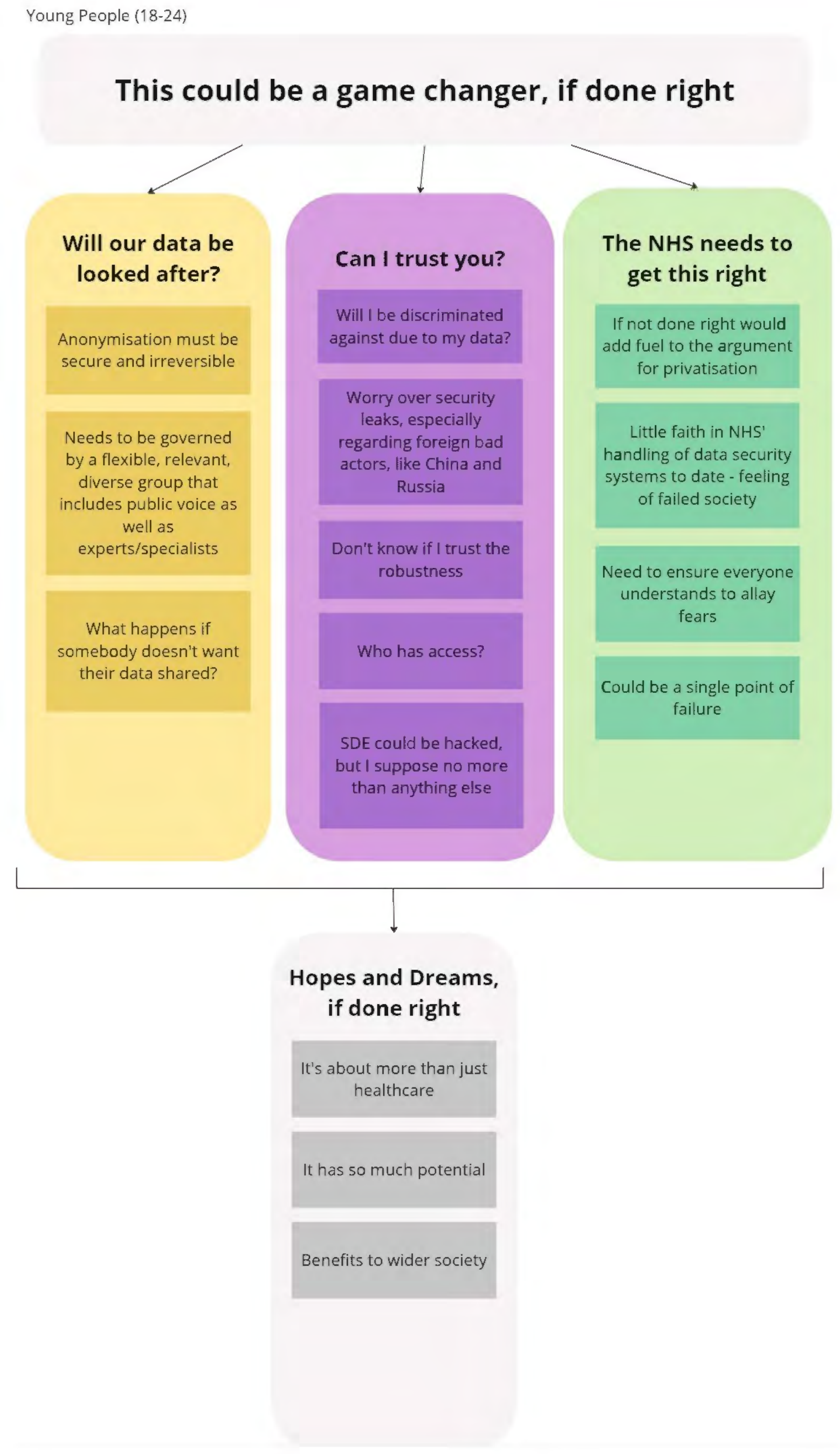
Similar to previous groups, community volunteers expressed concerns that an SDE may exacerbate health inequalities, particularly for people living in high deprivation areas:

“Would it create a two-tier health system?”

“If you’re looking for a ‘quick win’ intervention, it wouldn’t be in this area, so would it contribute to the marginalisation in areas like this?”

Community volunteers also emphasised that because of the government structure and system in the United Kingdom, *“nothing really changes or improves,”* largely reflecting *“governments only work to the next four years, or the next election, so they don’t want to do a 10-year plan, which is more of what would benefit us in this community.”* This closely linked to the feeling by community volunteers that *“people here are very used to being disempowered. Services parachute in, run for a finite amount of time, and then leave, leaving people in a worse position.”* They had fears that an SDE would have a similar impact in high deprivation areas like theirs.

3.5 18-24 Year Olds



Young People (18-24)

This could be a game changer, if done right

Will our data be looked after?

- Anonymisation must be secure and irreversible
- Needs to be governed by a flexible, relevant, diverse group that includes public voice as well as experts/specialists
- What happens if somebody doesn't want their data shared?

Can I trust you?

- Will I be discriminated against due to my data?
- Worry over security leaks, especially regarding foreign bad actors, like China and Russia
- Don't know if I trust the robustness
- Who has access?
- SDE could be hacked, but I suppose no more than anything else

The NHS needs to get this right

- If not done right would add fuel to the argument for privatisation
- Little faith in NHS' handling of data security systems to date - feeling of failed society
- Need to ensure everyone understands to allay fears
- Could be a single point of failure

Hopes and Dreams, if done right

- It's about more than just healthcare
- It has so much potential
- Benefits to wider society

Figure 6. 18-24 Year Olds Theme Diagram

This group was composed of twelve young adults (six male six female) aged 18 to 24. For all, it was their first time being a public contributor to a research project. Six were second year university students at different universities across the UK. Two were agricultural workers, two had temporary jobs on zero-hour contracts in retail and hospitality, one was an apprentice at a nursery school, and another was completing their deckhand sailing training. One of the young adults had heard of NHS SDEs through a conversation with a parent involved in medical research.

Six young adults attended an in-person session with one facilitator, four attended a separate in-person session with one facilitator, and the remaining two participated in online conversations with one facilitator. A short video prompt and facilitator explanation about SDEs was given at the start of all sessions. Seven young adults chose to draw a pictorial representation of an SDE as part of their contribution.

All young adults shared their hopes for the use of an SDE to support research with potential health and wellbeing benefits for individual patients, members of the public, the health system, and society more widely. Potential benefits related to *"more and better research"*, *"improved efficiency of the health service"*, and *"benefits to wider society"*.

The young adults identified multiple areas of research they hoped would benefit from having access to SDEs. Research areas included *"new medical treatments", "genomics", "diagnostic features for early diagnosis", "histological findings", "vaccines", "new diseases", "mass roll out of health interventions", "identifying the main issues that need addressing to improve public health and the advancement of healthcare", "statistical research with big data"*, and *"identifying percentage of the population affected and the number of likely cases"*. Additionally, potential direct benefits to the research process were envisaged, including *"help finding participants for trials as well as being able to identify specific nuances and conditions that make trials better."*

Regarding improved efficiency of the health service and benefits to wider society, the young adults emphasised the potential for *"monitoring of treatments and drugs without having to ask people or doctors individually", "treating diseases earlier and preventing or delaying complications"*, and *"quicker diagnosis".* There was a recognition that SDEs had the potential to influence a current national priority:

"NHS wait times are constantly scrutinised."

Benefits to wider society that young adults identified they would want to see included *"focus where money is best spent", "make comparisons across the country", "identify causalities and health trends with the aim of optimising health and wellbeing", "medical training"*, and *"your health history can be used to improve the care of others in years to come."*

In addition to these hopes and dreams, young adults expressed some fears. For instance, they expressed concerns that, particularly for older people, some may not have sufficient understanding of the safety and security measures being taken and would therefore refuse to participate:

"The older generation may not understand. They may believe anyone can access their data and not want to be a part of it."

Similar to other groups, young adults highlighted the potential for hackers to access large amounts of data:

"If it is hacked, it is not just one area, but the whole country."

> *"A centralised system will cause a more devastating data leak than a smaller, compartmentalised data system if broken into. Security must be rigorously checked and maintained."*

They also questioned the practicalities of implementing an SDE ethically:

> *"How do you get permission from everybody?"*

Young adults also questioned what would be done to people's data if they refused to have it stored in an SDE:

> *"What do you do if someone doesn't agree? Will their data not be stored anywhere?"*

Like other groups, young adults also expressed concerns around the potential for an SDE to exacerbate discrimination:

> *"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?"*

Young adults also had questions around who can access the data within an SDE:

> *"Who has access and why and when?"*

This linked to a later conversation around the potential for security leaks to unauthorised personnel, particularly regarding foreign bad actors like those in China or Russia.

The legitimacy of the removal of identifiable information also came into question, as in other groups. It was mentioned that *"anonymisation of records must be achieved in an irreversible manner."* Young adults felt that if anonymisation is to be used, a specific name must not be able to be found under any circumstances.

Linked to the points regarding government made by the community volunteers in the deprivation group, young adults wondered, *"Would a change in government change how data is treated?"*

Uniquely, young adults also recognised potential behavioural challenges that may occur because of health data being shared:

> *"Sharing one's own personal health issues can lead to feelings of judgement and embarrassment."*

There was also a discussion around the sense of privacy people feel towards their health data and the potential implications of a data leak:

> *"For many people, personal health data is very sensitive and private. If it got leaked, it could cause a big issue."*

> *"The NHS is currently a very respected institute, especially by those who don't live in the UK. If the system got hacked, it could mean losing public trust and respect in the NHS. It would be very bad if people couldn't trust the healthcare system."*

These comments led to a conversation about the rise of an anti-movement, which young adults believed could ultimately add fuel to the argument for privatisation of the NHS.

Regarding who should have access to the data, young adults felt that different levels of access should be granted for different purposes. For example, *"students for research and dissertations should be able to have a level of access"*, as well as *"reliable companies with trustworthy backgrounds"*. Young adults felt that those with access should have some level of data security knowledge or qualifications:

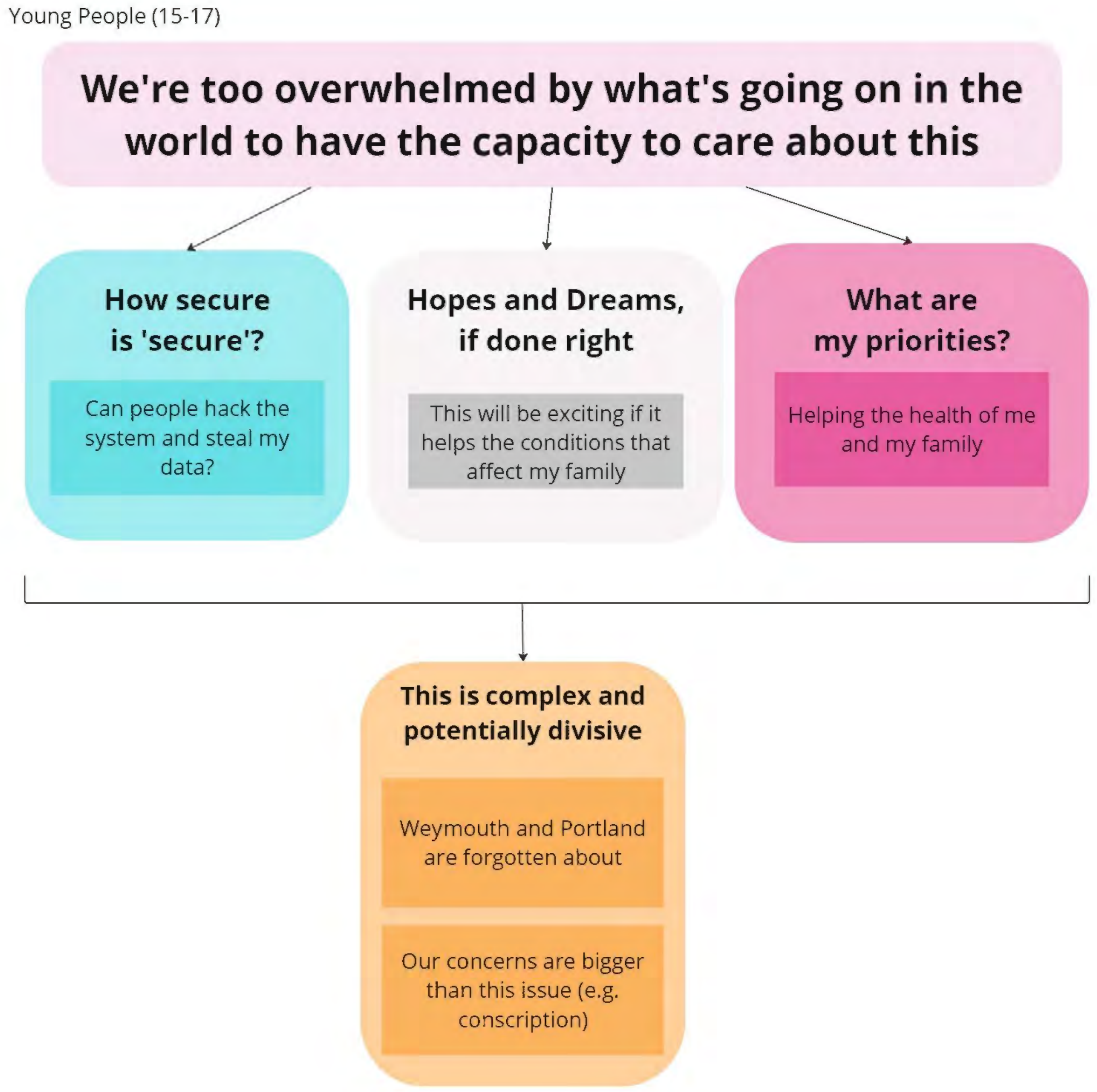
"Why let someone access data if they don't know what they are doing?"

They also suggested that checks should be put in place regarding granting access:

"Those with access need to have some sort of check like the DBS you need for working with kids."

When discussing who should decide who gets access to the data, young people felt there should be a *"diversified and reasonably sized"* specific organisation/committee responsible for this. According to young adults, this committee should not be pre-existing and should be made up of *"high-up medical professionals and software engineers/data scientists with an inside knowledge of the system."* They also emphasised the importance of *"only select experts"* having access to *"the inner code. They need to be very careful about how this code is given because it is associated with the hardware."* Young adults also emphasised that *"members of the public need to have a say".*

3.6 15-17 Year Olds



Young People (15-17)

We're too overwhelmed by what's going on in the world to have the capacity to care about this

How secure is 'secure'?

Can people hack the system and steal my data?

Hopes and Dreams, if done right

This will be exciting if it helps the conditions that affect my family

What are my priorities?

Helping the health of me and my family

This is complex and potentially divisive

Weymouth and Portland are forgotten about

Our concerns are bigger than this issue (e.g. conscription)

Figure 7. 15-17 Year Olds Theme Diagram

Nine young people aged 15 to 17 (mixed genders), attended an in-person workshop with both facilitators. Facilitators explained SDEs and gave an overview of the project to prompt discussions. The workshop was held at their regular youth club, and formed part of their regular session with their trusted youth workers present.

Initially, the young people shared they felt too overwhelmed by things going on in the world and amplified by social media (particularly, the perceived threat of conscription) to be concerned about their health data. However, they shared that they had concerns around their health data being accessed by hackers. Their ultimate priorities for the focus of SDE-enabled research were that those conditions that affect them and their families be addressed. This included various cancers, cognitively degenerative conditions like dementia, neurodiversity, Reynaud’s, mental health conditions, and chronic illnesses like diabetes.

They hoped that, through SDE-supported research, the chances of *“contracting or passing on these various conditions or illnesses”* would be reduced.

Generally, young people were not concerned with who their data is shared with:

> *“I would allow anyone to access the data, because it is anonymous.”*

They appeared confident in the security and reliability of the SDE’s anonymity. They felt it was acceptable for their health information to be used for research, *“only if no researcher knew who I was”* and *“on a ‘need to know’ basis”*, because *“it’s our private information”.*

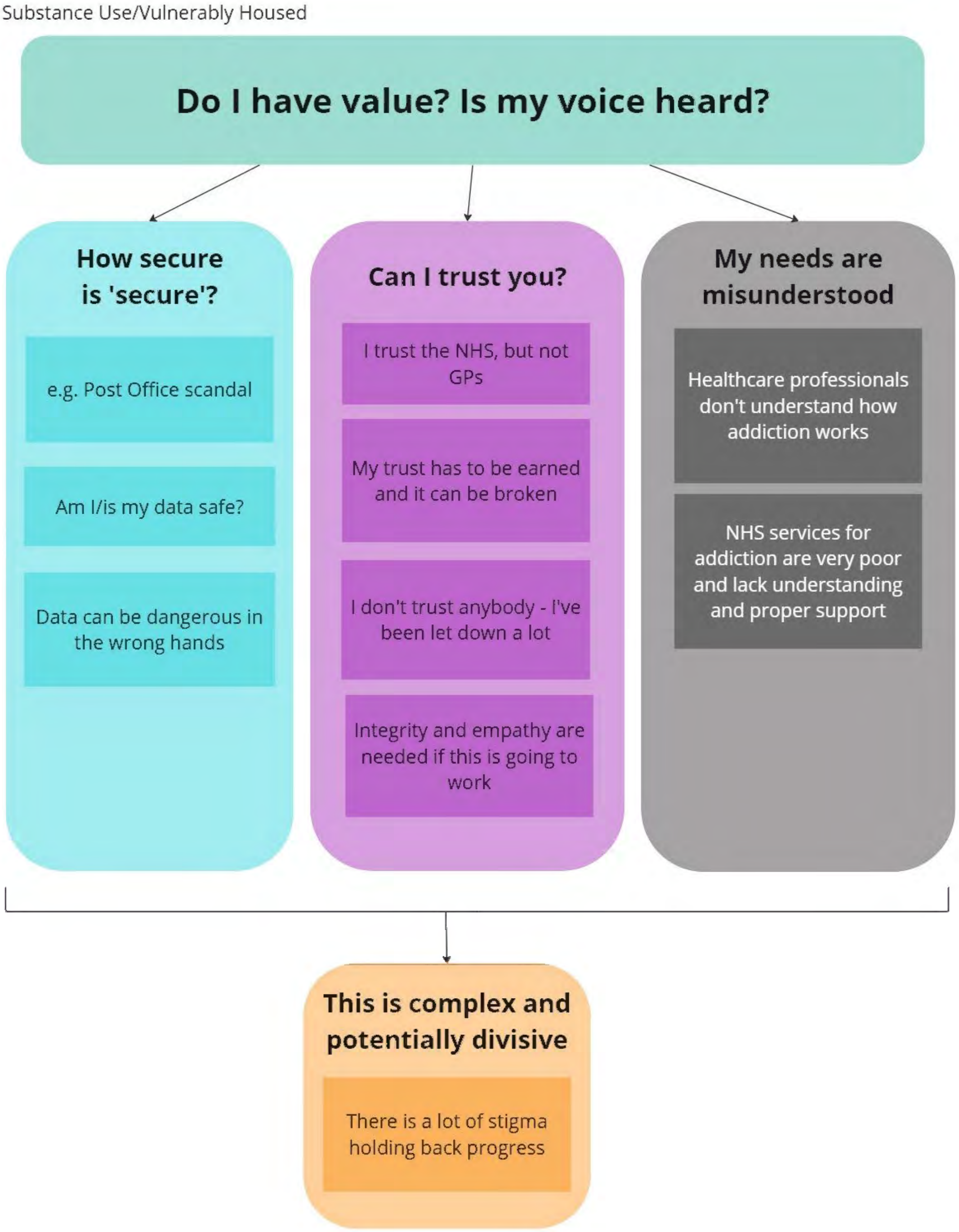
Young people did express concerns about foreign bad actors, stating, *“if it is outside the UK, they are going to scam us”*. This appeared to be linked to personal experiences with scam phone calls.

Largely, young people did not want the government to be involved. They did not trust or like the government and felt that government officials make bad decisions. They likened this to the *“banning of lots of dogs without asking. He never asked anyone.”*

It was also discussed that young people would trust their data being held in an SDE more if the researchers who are using it also allow their and their families’ data to be held within it.

Similar to other groups, young people raised questions such as, *“Will it be used to generate profit?”*, *“Who can look at the data?”*, and *“Who are they selling my data to?”.*

3.7 *Substance Use/Vulnerably Housed*



Substance Use/Vulnerably Housed

Do I have value? Is my voice heard?

How secure is 'secure'?

- e.g. Post Office scandal
- Am I/is my data safe?
- Data can be dangerous in the wrong hands

Can I trust you?

- I trust the NHS, but not GPs
- My trust has to be earned and it can be broken
- I don't trust anybody - I've been let down a lot
- Integrity and empathy are needed if this is going to work

My needs are misunderstood

- Healthcare professionals don't understand how addiction works
- NHS services for addiction are very poor and lack understanding and proper support

This is complex and potentially divisive

- There is a lot of stigma holding back progress

Figure 8. Substance Use/Vulnerably Housed Theme Diagram

Eight public contributors with a history of substance use and experiencing vulnerable housing individually contributed to a conversation with one facilitator in-person. These one-to-one conversations were held in a drop-in style session. No visual prompts were used. Facilitators described the Wessex SDE project to generate discussions.

Overall, public contributors from this group felt that their voice was usually unheard and did not have value in the public domain. This, combined with a feeling that they and their needs are misunderstood by society and healthcare professionals, led to a sense of mistrust in the concept of an SDE and its effective delivery and maintenance.

Generally, public contributors felt the main benefit of an SDE would be better understanding of substance use, which could potentially improve the services available:

"If we're understood better, then hopefully the services we are provided would improve."

"Maybe research that uses my information could help to make the understanding around addiction better, which would help to make the service better."

However, there were some hesitations in believing this would come to fruition:

"But Rome wasn't built in a day."

"There is massive stigma holding back progress, but research can help with that."

Public contributors from this group widely felt that they didn't mind their health data being used, as long as identifiable information was removed:

"I'm fine with my information being used for research, as long as there's no name on it."

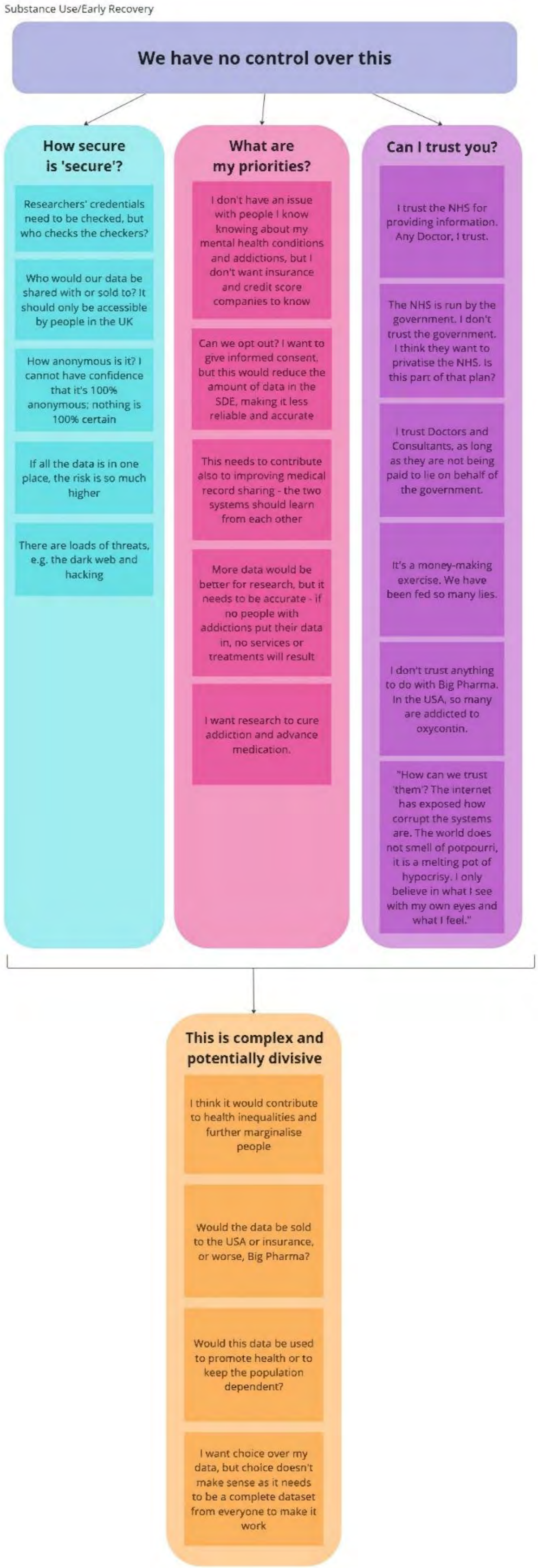
"I don't have an issue with it; they're doing this for a reason. It's for the greater good".

Although some public contributors felt they could trust the NHS with their health data, due to the NHS never previously using data against them, *"I trust the NHS with my data because nothing has ever been used against me from the NHS in the past"*, there were limitations on who they thought should be able to access the data:

"I think only health professionals and researchers should be able to access it, not the public. That's important to me."

While there was a recognition that specific services would need to be able to access the data within an SDE to improve those services, public contributors also felt that *"people should be able to choose which services they consent to having that information"* and by extension, *"people should be able to reject their data going in if they want to; it shouldn't be compulsory".*

3.8 *Substance Use/Early Recovery*



Substance Use/Early Recovery

We have no control over this

How secure is 'secure'?

Researchers' credentials need to be checked, but who checks the checkers?

Who would our data be shared with or sold to? It should only be accessible by people in the UK

How anonymous is it? I cannot have confidence that it's 100% anonymous; nothing is 100% certain

If all the data is in one place, the risk is so much higher

There are loads of threats, e.g. the dark web and hacking

What are my priorities?

I don't have an issue with people I know knowing about my mental health conditions and addictions, but I don't want insurance and credit score companies to know

Can we opt out? I want to give informed consent, but this would reduce the amount of data in the SDE, making it less reliable and accurate

This needs to contribute also to improving medical record sharing - the two systems should learn from each other

More data would be better for research, but it needs to be accurate - if no people with addictions put their data in, no services or treatments will result

I want research to cure addiction and advance medication.

Can I trust you?

I trust the NHS for providing information. Any Doctor, I trust.

The NHS is run by the government. I don't trust the government. I think they want to privatise the NHS. Is this part of that plan?

I trust Doctors and Consultants, as long as they are not being paid to lie on behalf of the government.

It's a money-making exercise. We have been fed so many lies.

I don't trust anything to do with Big Pharma. In the USA, so many are addicted to oxycontin.

"How can we trust 'them'? The internet has exposed how corrupt the systems are. The world does not smell of potpourri, it is a melting pot of hypocrisy. I only believe in what I see with my own eyes and what I feel."

This is complex and potentially divisive

I think it would contribute to health inequalities and further marginalise people

Would the data be sold to the USA or insurance, or worse, Big Pharma?

Would this data be used to promote health or to keep the population dependent?

I want choice over my data, but choice doesn't make sense as it needs to be a complete dataset from everyone to make it work

Figure 9. Substance Use/Early Recovery Theme Diagram

Thirteen public contributors in early recovery from substance use participated in an in-person group discussion with one facilitator. Five participated in one-to-one discussions with the same facilitator over coffee after the group activity.

Overall, the public contributors felt they have no control.

"I thought this was all happening anyway."

"It's not in our control. It's their game. A money-making exercise. We have been fed so many lies – fat versus sugar, that was all false, oxycontin not being addictive, that was false."

They expressed a desire for the data within an SDE to be strictly accessible by health service-related researchers, not Big Pharma, *"who are only in it for profit"*. They were also concerned that if pharmaceutical companies used the data, they could manipulate it to suit their agenda.

Additionally, like other groups, public contributors did not want their health data to be shared outside the UK.

They had questions around, *"Who would the SDE share our data with or sell it to?"* and expressed the importance of checking the researchers. However, they also recognised that this could result in *"an endless chain of checking credentials"* because someone would need to check the credentials of those who check the researchers.

There were also questions regarding security of an SDE, such as *"Can we opt out?"*. Like other groups, the option to opt out and to check what aspects of their data are included in an SDE were important to public contributors. However, they also expressed doubts that allowing every person whose data will be in an SDE to check the data first was a possibility. Equally, if too many people removed certain aspects of their data, public contributors recognised that this *"wouldn't work, as you need all the data for it to make sense".*

"But if we all (people with addictions) did not share our data with the SDE, the data would say there was no addiction and so no services or treatments would be needed."

Public contributors also recognised that if anything went wrong, *"it would be a threat to the NHS".*

The reliability of an SDE's anonymity was brought into question several times.

"I cannot have confidence that it is 100% anonymous. Nothing can be guaranteed. Nothing is 100% certain. That is unrealistic."

"I don't care if you say it is anonymous. That is bullshit. They (hackers and scammers) can work there."

Public contributors also shared concerns expressed by other groups around the risks associated with a centralised system.

"If all the data is in one place, the risks are so much higher."

"Security would be a high risk, as cyber security is a big trend. There are loads of threats: the dark web, hacking…"

Again, like other groups, the public contributors expressed fears around who would be able to access their data. Particularly, they worried that if insurance and credit score companies could access it, they could *"put you in a bracket and deny you access to things or take things away from you".*

Public contributors in this group also shared fears expressed by other groups, such as the fear that an SDE could further marginalise people.

"Systems like this protect the elite and marginalise the poor. That is the tale of history, and it is no different now."

"I think it would increase health inequalities. There is no evidence to the other, as the gap is growing every day."

"If an area is identified as undesirable, it will become blacklisted."

There was also a prominent lack of trust in the government, who fund the NHS. Public contributors felt that, due to the government's history of cover-ups, if something negative were to happen to an SDE, it would be covered up, *"like Hillsborough or COVID".* They also worried that implementing an SDE may be part of the government's plan to privatise the NHS.

"I don't trust the government. I think they want to privatise the NHS. Is this part of the plan?"

This lack of trust appeared linked to anger at the system, including government, big business, and the NHS. Public contributors characterised the system as having *"no empathy",* being *"corrupt",* that *"they don't care",* are *"narcissists",* and *"like to keep everyone quiet and fob them off with sound bites and rhetoric and cliches".* Public contributors also doubted the government's intentions.

"With this data, would it go to promoting health or be used to keep the population dependent?"

"This smells like it would be open to lobbying with the government giving their mates the contracts for the SDE, like Michelle Mone and the crap PPE."

"How can we trust them? The internet has exposed how corrupt the systems are. The world does not smell of potpourri. It is a melting pot of hypocrisy. I only believe in what I see with my own eyes and what I feel."

For many, this lack of trust was linked to perceptions of Big Pharma and was likened to the oxycontin addiction crisis in the USA.

"How immoral is that? The overprescribing is a huge problem."

"Big Pharma has so many fines for the crimes they have committed and keep committing."

Like other groups, the public contributors also doubted the NHS' ability to deliver this effectively, due to the poor state of current digital systems, and expressed that an SDE would need to be secure to be effective.

"Medical records sharing just does not work. Why would this be different?"

"The secure data environment would need to be bullet proof. Horizon was so dodgy."

Regardless of the doubts, lack of trust, and feeling of no control, public contributors shared hopes for an SDE, if managed properly.

"That there is a carryover. That sharing of data also works in terms of sharing medical records. That the two systems can learn from each other."

"If the data remains anonymous, it could be positive. More data would be better for research."

"Cure addiction. Advance medicine."

"Improve cancer treatments and reduce cancer waiting times – these are a disgrace."

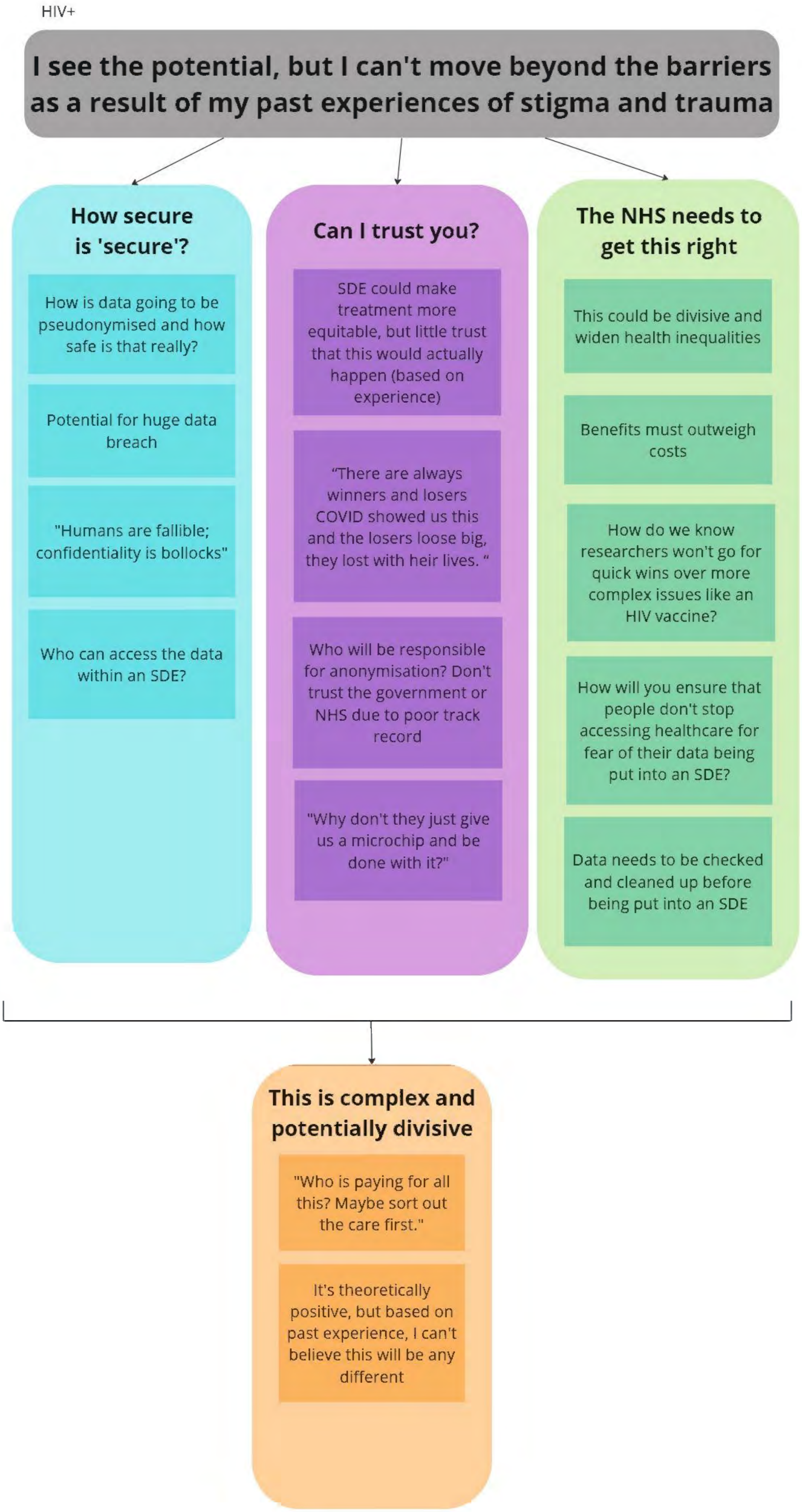
"Reduce NHS costs by making the system and service more efficient and effective."

Regarding communication, public contributors wanted to be told *"where to get more information, where to get progress updates, somewhere to go and be able to ask questions".* They acknowledged that *"people will have lots of questions and concerns. By you (facilitator) doing this exercise, they are acknowledging they know this".*

Some public contributors shared they would trust to hear about SDEs from *"the health service – any doctor would be fine. It doesn't have to be one I know",* and they trust doctors and consultants, *"as long as they are not being paid to lie on behalf of the government".* Others expressed, *"I don't trust anyone with what they say. Only me and what I see or when I have done all my research."*

Ultimately, public contributors in this group appeared to be grappling with their perceptions of SDEs. They wanted choice, but choice didn't make sense, as data is needed from everyone to make an SDE work; they trusted the NHS, but only if they weren't being spurred on by government lies and cover-ups; and they recognised potential benefits of an SDE, but worried that Big Pharma may use their data to suit their agenda.

3.9 *HIV Positive*



HIV+

I see the potential, but I can't move beyond the barriers as a result of my past experiences of stigma and trauma

How secure is 'secure'?

How is data going to be pseudonymised and how safe is that really?

Potential for huge data breach

"Humans are fallible; confidentiality is bollocks"

Who can access the data within an SDE?

Can I trust you?

SDE could make treatment more equitable, but little trust that this would actually happen (based on experience)

"There are always winners and losers COVID showed us this and the losers loose big, they lost with heir lives. "

Who will be responsible for anonymisation? Don't trust the government or NHS due to poor track record

"Why don't they just give us a microchip and be done with it?"

The NHS needs to get this right

This could be divisive and widen health inequalities

Benefits must outweigh costs

How do we know researchers won't go for quick wins over more complex issues like an HIV vaccine?

How will you ensure that people don't stop accessing healthcare for fear of their data being put into an SDE?

Data needs to be checked and cleaned up before being put into an SDE

This is complex and potentially divisive

"Who is paying for all this? Maybe sort out the care first."

It's theoretically positive, but based on past experience, I can't believe this will be any different

Figure 10. HIV Positive Theme Diagram

Six people with an HIV positive diagnosis attended an in-person session with one facilitator. The group was a mix of men and women, with a range of length of time since diagnosis, from less than five years to more than 40 years. For some in the group, only those in the room and medical professionals knew of their diagnosis, and every aspect of their lives was shaped by the fear of their HIV Positive status being discovered by others.

Some public contributors in this group had previous bad experiences with sharing information, which made them reluctant to trust an SDE. They could see potential benefits to an SDE, such as greater efficiency, the possibility of more security, more collaborative and better quality research, with improved results. They said, *"it makes sense, and it will happen"*. The problem, however, is stigma. To them, a diagnosis of HIV should not be associated with shame. This stigma was seen to stem not only from society and peers, but also from General Practitioners (GPs). This experience meant several of the public contributors felt defined by their HIV status and pushed away by stigma:

"We face barrier after barrier."

"I was made to feel like a leper."

While the public contributors recognised that more and better quality research could mean the NHS take greater responsibility for finding a vaccine for HIV, they also feared that the complexity of this subject, which could mean other diseases with quicker wins could be prioritised. This is similar to the fears held by the community volunteers in the deprivation group, who feared their area would be forgotten by researchers who are looking for quick, easy wins.

While public contributors were able to recognise the potential benefits of an SDE, they were hesitant to trust that these benefits would be realised, due to their mistrust in the system:

"Why don't they just give us a microchip and be done with it?"

"It's a slippery slope to government overreach like the China credit rating system. It has an Orwellian nature to it".

For some, their HIV status and the associated stigma prevented them from trusting how their data would be used, which ultimately resulted in an unwillingness to share it:

"I would want to share my data, but I wouldn't because of my HIV status. I just don't have the trust."

In one example, a public contributor's treatment approach was changed by a healthcare professional, but the healthcare professional was unable to explain on what medical grounds the change had been made. The public contributor attributed this to their HIV Positive status:

"I felt puzzled, shocked, and offended, actually. I felt judged and violated."

Like other groups, this group felt that an SDE is unlikely to be totally altruistic. They felt that the public must understand the real motivation for the SDE and how it is going to be used. They also feared that an SDE could be divisive and potentially widen health inequalities. This was largely linked to the government's COVID response and the public's reaction to a virus that they feared, which felt personal to some public contributors with HIV.

Uniquely to this group, there was a long discussion around COVID and its impact on trust, widening the gap in health inequalities, and polarisation:

"There are always winners and losers. COVID showed us this, and the losers lose big, they lost with their lives."

"My trust in the government and with my doctor has been vastly eroded by COVID. COVID polarised people."

"During COVID, people were controlled and demonised. We need to build back trust."

"COVID was really traumatic."

Similar to other groups' fears, public contributors expressed concerns that an SDE could exacerbate health inequalities:

"An SDE could widen the 'them and us', will people that are excluded from healthcare and other non-users not be in the data box?"

As an extension of this fear, and again like other groups, some public contributors expressed concerns that people may refuse to access healthcare out of fear of how their data is being used:

"Would fear of having data in an SDE mean people would reduce or stop accessing healthcare or withhold certain information?"

This was seen to risk the quality of data and individuals' health.

In line with fearful expressions in previous groups, public contributors also feared that they would *"lose"* as a result of an SDE being implemented:

"There are always people like a 'poor Jo' like me who will lose. Like, life insurance will be a no."

This fear that the data contained within an SDE could affect one's ability to obtain insurance, whether that is life insurance or, further down the line, health insurance, resonated across several groups.

Similar to sentiments of the deprivation and substance use groups, public contributors with an HIV positive diagnosis questioned where the money for the SDE was coming from and why it was being done now, as they saw it being instead of addressing other more pressing needs of the NHS:

"Who is paying for all this? Maybe sort out the care first."

"The NHS has no money."

"How much is the whole thing going to cost to set up and keep running?"

This questioning led to an expression of fear that the NHS may need to sell the data within an SDE to make up the cost of the system and its upkeep:

"Would they need to sell the data to re-coup costs?"

"The current funding crisis might mean they were pressurised to sell access to the data to fund the NHS."

Equally like previous groups, there was a recognition that the benefits of the system must outweigh the costs:

“The benefits of sorting and using the data in this way would need to outweigh costs.”

For public contributors to trust the altruism of an SDE’s implementation and continued use, they requested accountability, including regular updates on the benefits :

“This is so important; it shows they care and the intention to do good and improve lives is trust. And also, it is our money.”

Public contributors also raised the *“Rubbish in, rubbish out”* point, stating, *“They need to check data and clean it up before putting it into an SDE. For example, diagnosis of menopause is not agreed, and one GP might diagnose and another not. This might mean inaccurate research.”*

However, public contributors also recognised the potential value of the SDE in improving diagnostic accuracy and making treatment more equitable. Yet, because of previous experiences with the NHS, trauma, and stigma, public contributors felt unable to believe that these benefits would truly be realised.

Public contributors also questioned the way in which their identifiable information would be removed and how safe and secure the process is:

“Who and how is data going to be pseudonymised, and how safe is this really?”

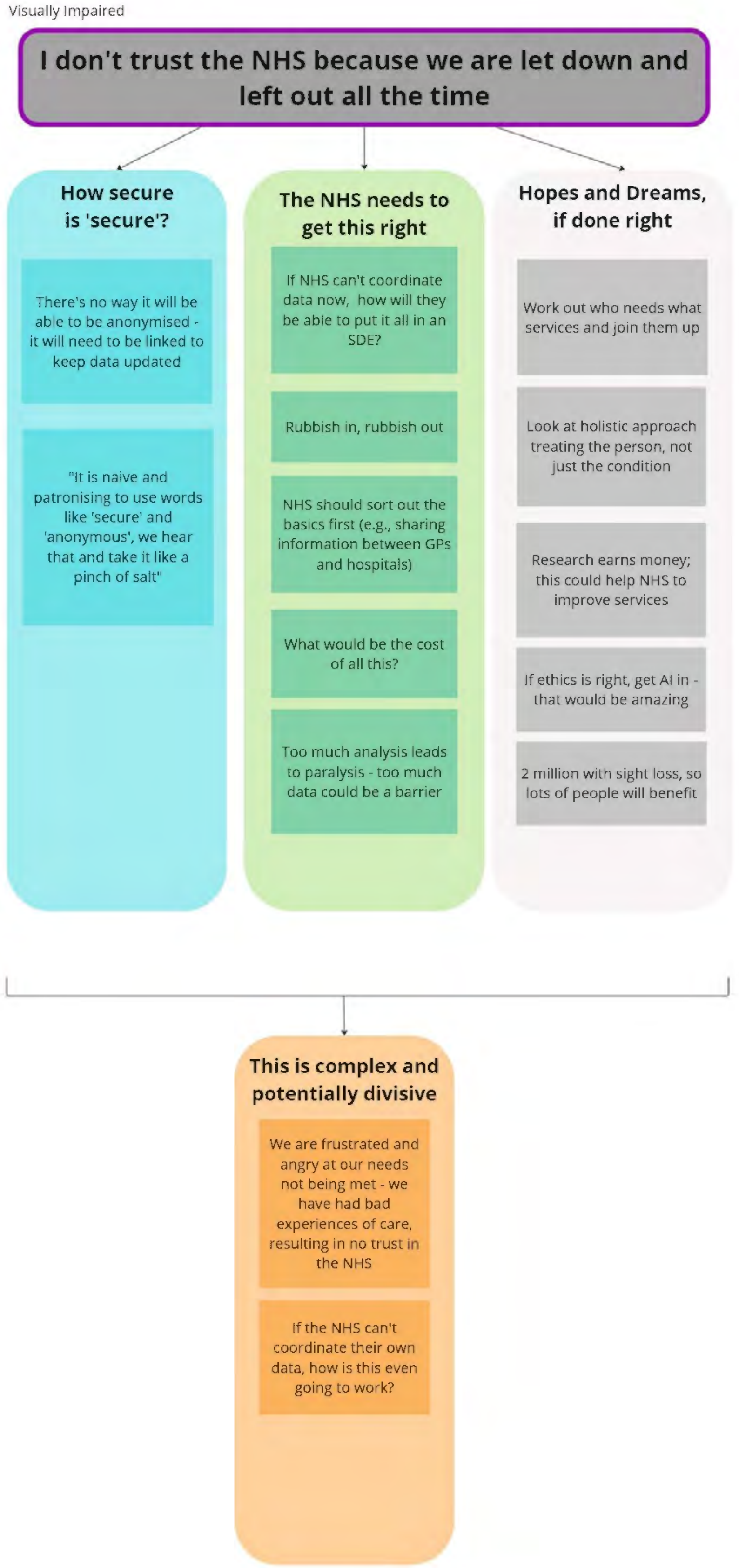
It was recognised within the group that *“data has to be linked back to enable continuity of the health journey to be captured by the SDE”.* This brought into question whether people would be able to be identified.

When discussions began around who could be trusted with their data, public contributors felt they couldn’t trust the government or the NHS due to poor track record. They also didn’t trust ‘Big Tech’, who were seen to be linked to ‘Big Pharma’. Some public contributors didn’t feel they could trust anyone with their data:

“Human beings are fallible. Confidentiality is bollocks.”

Public contributors from this group had many questions around an SDE’s security, the drivers behind its implementation and continued use, costs, accuracy, and potentially unintended negative consequences. Ultimately, though, they were able to continually recognise the potential benefits of an SDE, but struggled to believe it would happen this way, due to past experiences, trauma, and persistent stigma.

3.10 Visually Impaired



Visually Impaired

I don't trust the NHS because we are let down and left out all the time

How secure is 'secure'?

There's no way it will be able to be anonymised - it will need to be linked to keep data updated

"It is naive and patronising to use words like 'secure' and 'anonymous', we hear that and take it like a pinch of salt"

The NHS needs to get this right

If NHS can't coordinate data now, how will they be able to put it all in an SDE?

Rubbish in, rubbish out

NHS should sort out the basics first (e.g., sharing information between GPs and hospitals)

What would be the cost of all this?

Too much analysis leads to paralysis - too much data could be a barrier

Hopes and Dreams, if done right

Work out who needs what services and join them up

Look at holistic approach treating the person, not just the condition

Research earns money; this could help NHS to improve services

If ethics is right, get AI in - that would be amazing

2 million with sight loss, so lots of people will benefit

This is complex and potentially divisive

We are frustrated and angry at our needs not being met - we have had bad experiences of care, resulting in no trust in the NHS

If the NHS can't coordinate their own data, how is this even going to work?

Figure 11. Visually Impaired Theme Diagram

Thirteen public contributors attended an in-person session with one facilitator in a community venue chosen by the public contributors. The group was composed of men and women, aged 30-80. It was a diverse group including range of cause and degree of sight loss, different associated health conditions, guide dog users, and people born with visual impairment/blindness, as well as sudden onset and progressive sight loss.

Initially, public contributors felt frustrated and angry at their health and social care needs not being met, due to bad experiences, resulting in lack of trust:

"It is so frustrating all the time."

"We are left out all the time."

They felt they had been "passed from pillar to post" and that they "constantly have to chase", often resulting in feelings of guilt and that they are a burden.

"I often feel panicky and frightened."

"It can feel soul destroying; I have an active mind."

For some public contributors, previous experiences of poor care made them feel *"a burden of responsibility to manage [their] own health* despite *the NHS."*

Frustration and anger with the NHS were indicated throughout the conversation, with public contributors saying, *"They can cross out the S – the service in NHS is not serving us."* There was a sense that *"you need a sighted person to navigate the system and do your own research to work it out yourself"*, hence a sense of lack of independence and the need to rely on others and to self-advocate due to the poor quality of services available. Regarding this, one public contributor said, *"Since 1997, it is your legal right to get information in a format that is accessible, and this is still not happening."*

There were concerns around the NHS' ability to input accurate data into an SDE, based on how the NHS currently manages data:

"If the NHS can't coordinate their own data, can't get a letter sent, can't see MRI results from Dorchester in Poole – I would be concerned about the accuracy of the data going into the SDE."

"I'd be worried about rubbish in, rubbish out."

"The data would need a very big clean up, there is probably a lot of it that is wrong."

Similar to other groups, public contributors expressed that the NHS needs to *"sort out the basics first"*, for instance, sharing information between NHS trusts, *"then we might have some faith that an SDE might work."*

Like other groups, public contributors did not trust that their data would remain anonymous, largely because it would need to link back to the source of the data *"to keep data updated"*. There was also an expression that *"too much analysis leads to paralysis – too much data, too big, too many steps, this could be a barrier."*

Public contributors also questioned the cost of implementing and maintaining an SDE:

"What would the cost be of all this?"

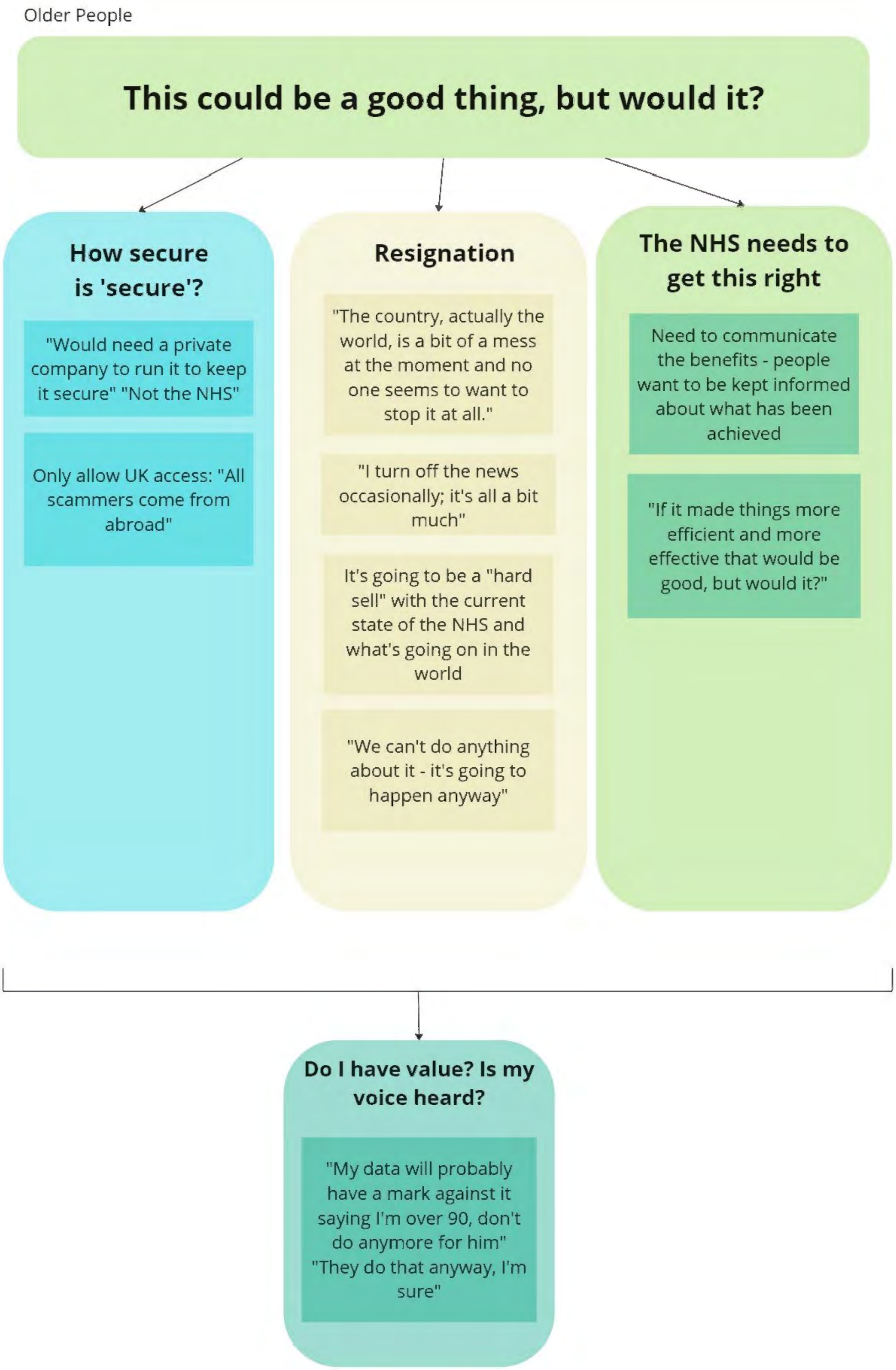
“The NHS is broken, there is no money at all. I can’t see an eye specialist. I can’t get a GP appointment.”

When asked to think about potential benefits, public contributors expressed that there are 2 million people with sight loss, *“so lots of people will want this”*. While some public contributors felt research could be beneficial, they said, *“I would love to see lots of research, if it was genuine.”*

Public contributors had little trust in the NHS’ ability to build a secure system, due to *“past NHS issues”* and *“constantly hearing about ransomware and hackers”*. Public contributors were not only worried about expert hackers, but also human error.

Similar to other groups, public contributors did not trust the term ‘secure’. They felt, *“it is naïve and patronising to use words like ‘secure’ and ‘anonymous’, we hear that and take it like a pinch of salt”.*

3.11 Older People



Older People

This could be a good thing, but would it?

How secure is 'secure'?

"Would need a private company to run it to keep it secure" "Not the NHS"

Only allow UK access: "All scammers come from abroad"

Resignation

"The country, actually the world, is a bit of a mess at the moment and no one seems to want to stop it at all."

"I turn off the news occasionally; it's all a bit much"

It's going to be a "hard sell" with the current state of the NHS and what's going on in the world

"We can't do anything about it - it's going to happen anyway"

The NHS needs to get this right

Need to communicate the benefits - people want to be kept informed about what has been achieved

"If it made things more efficient and more effective that would be good, but would it?"

Do I have value? Is my voice heard?

"My data will probably have a mark against it saying I'm over 90, don't do anymore for him" "They do that anyway, I'm sure"

Figure 12. Older People Theme Diagram

Four public contributors had individual conversations with one facilitator. All were aged over 86 and have multiple health conditions. No visual prompts were used. The facilitator described the Wessex SDE project to generate discussions.

Initially, there appeared to be a level of indifference towards SDEs by public contributors. However, upon further discussion it became clear that this was actually a sense of resignation:

"Surely everyone knows everything about me already. They hold my data anyway; I don't think it would bother me."

"We can't do anything about it. It's going to happen, and I can't see it's going to do too much harm."

"At my age, it is too late. I am too old even to think this would be of any use to me."

For some, this resignation led to fear that they would be discriminated against due to their age:

"My data will probably have a mark against it saying, 'over 90, don't do anything more for him'."

This was followed by a remark from another public contributor, *"They do that anyway, I'm sure."*

This defeatism appeared to be linked to a sense of pessimism regarding the state of the NHS, the country, and the world:

"The country – actually, the world – is a bit of a mess at the moment. It's divisive and no one seems to want to stop it at all."

"I turn the news off occasionally. It's all a bit much."

"There is so much waiting for the NHS and lots of people are getting missed."

This pessimistic view led some public contributors to believe that *"it's going to be a hard sell."*

Despite the overarching pessimism there was a sense of optimism about the potential for an SDE to improve research and contribute towards finding cures for cancers, osteoporosis, and kidney disease – all of which are conditions that affect either the public contributor or someone they know – and improving treatment. However, this was followed by a statement that *"finding more treatments would mean we'd need more hospital beds and there aren't any"* and *"no one does what is recommended"*. The older public contributors indicated that there would be barriers preventing older people from believing that the benefits from an SDE would truly be realised, based on the current state of the NHS, the country, and the world.

This sense of defeatism and pessimism also became apparent when discussing SDE security:

"I know people pick up information about us all the time."

"AI is going to ruin everything."

There were fears around scammers accessing health data within an SDE:

“All scammers come from abroad. That’s a pain in the neck.”

“There is money in data, including health data.”

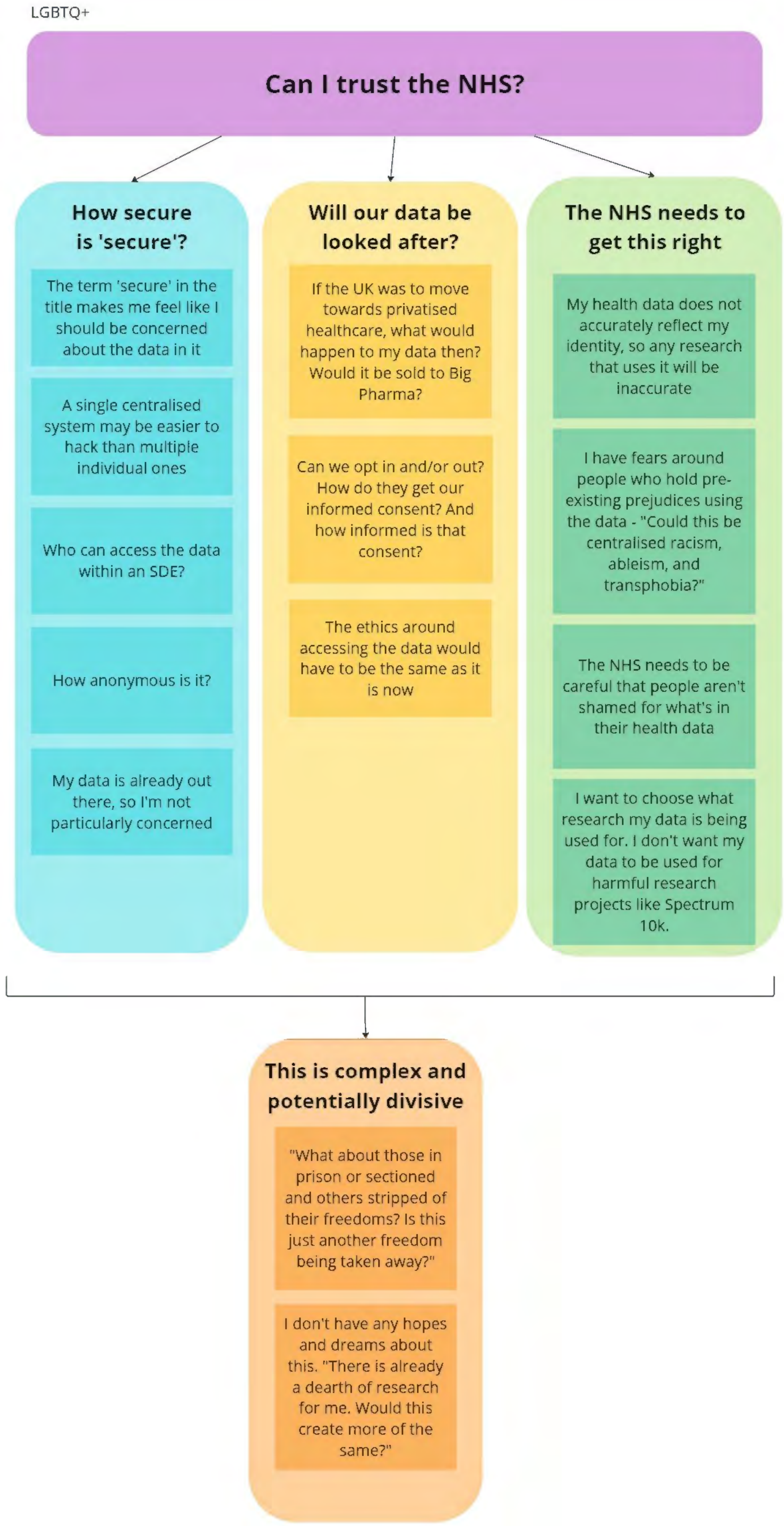
There was also a lack of trust in the NHS to deliver and maintain an SDE effectively:

“Would need a private company to run it to keep it secure.”

“Not the NHS”.

Public contributors felt that trusted sources who they would like to hear about SDEs from were universities, GPs, and, interestingly, the NHS, as they felt they did not have cause not to trust their communications.

3.12 LGBTQ+



LGBTQ+

Can I trust the NHS?

How secure is 'secure'?

The term 'secure' in the title makes me feel like I should be concerned about the data in it

A single centralised system may be easier to hack than multiple individual ones

Who can access the data within an SDE?

How anonymous is it?

My data is already out there, so I'm not particularly concerned

Will our data be looked after?

If the UK was to move towards privatised healthcare, what would happen to my data then? Would it be sold to Big Pharma?

Can we opt in and/or out? How do they get our informed consent? And how informed is that consent?

The ethics around accessing the data would have to be the same as it is now

The NHS needs to get this right

My health data does not accurately reflect my identity, so any research that uses it will be inaccurate

I have fears around people who hold pre-existing prejudices using the data - "Could this be centralised racism, ableism, and transphobia?"

The NHS needs to be careful that people aren't shamed for what's in their health data

I want to choose what research my data is being used for. I don't want my data to be used for harmful research projects like Spectrum 10k.

This is complex and potentially divisive

"What about those in prison or sectioned and others stripped of their freedoms? Is this just another freedom being taken away?"

I don't have any hopes and dreams about this. "There is already a dearth of research for me. Would this create more of the same?"

Figure 13. LGBTQ+ Theme Diagram

This group composed of three members of the LGBTQ+ community, one who identifies as transgender, one who identifies as a gay cisgender woman, and one who identifies as a bisexual cisgender woman. One public contributor met with one facilitator online, while the other two jointly took part in an online conversation with one facilitator. No visual prompts were used. Facilitators described the Wessex SDE project to generate discussion.

All public contributors had established trusted relationships with each of the facilitators hosting the conversations. For one public contributor, this was the only reason they agreed to participate in this research.

Importantly, the thoughts and opinions given by the transgender public contributor, whose gender expression differs from the sex they were assigned at birth, differed from those given by queer cisgender public contributors, whose gender expression aligns with their sex assigned at birth.

Generally, cisgender public contributors acknowledged that they had never thought about how secure their health data is before, and likely would not have been inclined to question its security when moving into an SDE. However, they did, purely because ‘secure’ is in the title:

> “I don’t know how secure our current system is, so I don’t really know how different this would be. I’ve never bothered to think about whether my data is secure in the NHS app before, so if somebody just said, ‘We’re moving to a centralised system’, I wouldn’t have considered if that is secure, but because ‘secure’ is in the title, it makes you question it a bit and makes you feel like you should be concerned.”

They also mentioned that when communicating about SDEs to the public, it may be a mistake to draw too much attention to the ‘security’ aspect, as this may make people question and doubt the security of their health data in ways they haven’t previously:

> *“I don’t think you’d want to point a big finger at it to draw people’s attention to their data, when actually people’s data is already out there.”*

Calling the system a ‘Secure’ Data Environment was likened by one public contributor to a previous untrustworthy employer, *“who used to say, ‘I’m a really nice guy’, but then would do something awful”*. One public contributor said, *“If it means ‘anonymous’, that would make more sense to me. In a way, it’s not that secure because people can find the data, but it is secure in the sense that it can’t be linked back to me. So maybe say that instead of using the word ‘secure’”.*

Cisgender public contributors weren’t overly concerned about how their health data is stored and shared, as long as it’s for research purposes:

> *“I’m not that bothered about my data anyway. I have nothing to hide. Even if my name was attached to it, if it’s for research purposes, then I’m cool with it.”*

However, the transgender public contributor felt concerned about the security and intent of an SDE:

> *“You know, all this confidential stuff you gave to your GP, we are just going to move it over here and have a good rummage around.”*

They also worried that an SDE might contribute to ostracising LGBTQ+ people in research:

"It could create a dataset that could potentially contribute to the 'look at this weird bunch of people' approach to research and innovation."

Cisgender public contributors agreed that they had not previously thought about how their health data is stored and shared, that they use the NHS app freely without questioning its security, and that they willingly give up their health data currently for things like travel insurance, so why should they feel differently about this, especially when it is to be anonymised:

"If it's purely anonymous and there's no way at all that your name is attached to your information, then I'd be like cool okay, but also am I that bothered? Would I care if the current NHS app was hacked? If it is leaked, what can you do about it, you know?"

"I've never even thought about how secure the NHS app is, I just downloaded it. Maybe I'm thinking of potential concerns now because I'm being asked about it directly, but generally I have never really thought about it."

"Thinking about it, when I'm getting a quote for travel insurance, I happily share the medical data they ask for."

Cisgender public contributors tended to trust the NHS, despite recognising that they have a reputation for poorly handling data:

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

The transgender public contributor, however, said, *"So many trans people have such bad experience of the NHS, even if it is not harmful, it is hugely effortful. You have to self-advocate all the time".*

Transgender experiences of healthcare are unique in the LGBTQ+ community. Cisgender queer people did not tend to share the same negative healthcare experiences. This is largely due to their queerness being linked to sexuality, while for a transgender person, their queerness tends to be linked, at least in part, to gender expression. Transgender people also face unique challenges regarding stigma and prejudice that are not always experienced by cisgender queer people. These unique experiences led the transgender public contributor to worry that an SDE could contribute to racism, ableism, and transphobia, which were not concerns that were explicitly voiced by cisgender public contributors:

"What stereotypes are people going to come with to access the data? Could this be centralised racism, ableism, and transphobia?"

Additionally, the transgender public contributor is autistic, which contributed to a unique perspective on the type of research that they would feel comfortable with their health data contributing to. Specifically, they mentioned that they would not want their health data to contribute to projects such as the 'Spectrum 10K' research project, as they perceived this project to be harmful to the autistic community.

Both transgender and cisgender public contributors had concerns about the reliability of an SDE's anonymity. For cisgender public contributors, these were more questions as to how anonymous the system would be, rather than explicit concerns. For the transgender public contributor, however, there were concerns around transgender people being able to be identified by their health data and the potential implications of this:

"People with trans-identifiable markers in their data may have specific concerns. For example, would they be traceable to where they live? There is a huge amount of violence towards trans people. It could be a real issue."

However, they also had concerns that the data going into an SDE would be an inaccurate representation of their identity, which could negatively impact the outcomes of any research that involves their data:

"I would not come up in any way as queer on my health records, they would assume me to be cis[gender] female. The bank of data would be flawed."

While cisgender public contributors raised concerns around security and potential hacking by homophobic foreign bad actors, they also recognised that they had never considered this for their health data as it's currently stored and likely only raised this concern because they were being asked about their thoughts directly:

"This is going to sound far-fetched, but in my doctor's notes I say I'm a gay woman, and if Russia, who are against gay people, could access that data, what would they do with that?"

"There are quite a few different platforms that already hold my information, and I've never thought, 'What if Russia hacks it?', but because I'm now directly being asked, that's why I'm thinking about it. So there are lots of places my data already is, I don't really care about my data being out there and the fact that it's anonymous means it's better than other information I've put elsewhere."

It was apparent that the transgender public contributor had greater concerns around anonymity and security than cisgender public contributors, largely due to fears around violence towards transgender people and the potentially harmful implications of a transgender person being identifiable by their data.

Importantly, while cisgender public contributors could recognise possible hopes and dreams for an SDE, particularly related to reducing strain on NHS workers and therefore improving the likelihood that health data will be shared for research purposes, the transgender public contributor did not recognise any hopes and dreams:

"I don't have any. There is already a dearth of research for me. Would this create more of the same?"

For the transgender public contributor, there was a sense of defeatism:

"It is hard. Trans hate is horrifying. How can we have any impact with the onslaught of shit? We are tired as a community. We are exhausted by life and the hellscape of the modern UK."

Cisgender public contributors were generally optimistic that an SDE could go some way to improving health inequalities compared to the current system:

"If the current system relies on GP surgeries responding to requests for research, there's a chance that the places that have the most strain on them probably have the least amount of time for fulfilling those requests. This could help that."

However, the transgender public contributor expressed concerns that a poorly managed SDE could contribute to exacerbating health inequalities:

"The data would be missing traveller community data, people who are vulnerably housed, there is a risk that health inequalities would become wider."

"What would it mean to be more efficient with poor data that is missing swathes of people? You need everybody's information to make this work."

These variations in expectations and hopes for an SDE may relate to differences in the level of trust transgender and cisgender people have in the NHS. Due to negative past experiences with the NHS, transgender people may be less likely to trust the NHS, their intentions, and their ability to contribute effectively, meaningfully, and ethically to research.

When asked who they would trust to hear about SDEs from, all LGBTQ+ public contributors said, *"Not the government"*. Instead, public contributors wanted to hear about SDEs from the NHS directly, through an email campaign and/or conversations had directly with healthcare professionals; local counsellors and those based in the community who already have established trusted relationships with the public contributors; and GPs and nurses. However, there was a recognition that GPs and nurses *"aren't going to spin it, but they may well be very patronising, and many would feel unsafe to ask or be able to really articulate what they really want to say"*.

4 Conversations

In this project, we heard from a diverse range of seldom heard and marginalised people from across Dorset. The sample is not representative but provides some important insights for consideration by the Wessex SDE project to inform ongoing project development. In this section, we bring together the themes from all groups and the wider context of the discussions and make suggestions to inform project next steps.

The influence of current societal factors and important ongoings in the media and in public contributors' lives was somewhat unexpected but significant. Although a direct link is not obvious, factors such as conscription going viral on young people's social media pages, oxycontin addiction in the USA, and the Post Office scandal were highly influential in shaping and informing perspectives on SDEs.

The following sections discuss each theme identified and the sub-themes within them.

4.1 Can I trust you?

Trust was a key theme discussed in 10 of the 12 groups. Public contributors shared their hesitation to trust the NHS with a largescale data project, due to perceptions of the NHS' poor handling of similar projects in the past. For those with experiences of poor care, trauma, and stigma, lack of trust appeared to be a more prominent barrier and sometimes led to an inability to believe that any potential benefits of an SDE could be realised. Additionally, some public contributors feared that if their data contained information about certain lifestyle factors, pre-existing conditions, or potential predisposition to certain conditions, this could be used against them, for example, when trying to obtain life or health insurance in the future, particularly if the UK were to move to an insurance-based healthcare system. There was also a lack of trust in the term 'secure'. Some public contributors felt that the term 'Secure Data Environment' implies that the data held within it is something they should be concerned about.

Interestingly, while many public contributors expressed lack of trust in the NHS and the wider healthcare system, a minority suggested that they trust the NHS with their data, primarily due to a lack of negative experiences regarding the NHS and their data and a suggestion that they were able to separate data from care. For some, this presented as a willingness to accept the benefits of an SDE, as they were perceived as outweighing the risks. For those who did not feel they could trust the NHS, SDEs, or the healthcare system, risks were largely perceived to outweigh benefits.

4.2 The NHS needs to get this right

Most groups (8 out of 12) felt strongly that there was a need for the NHS to 'get this right' the first time, sharing their sense that NHS is in a relatively precarious state currently. Central to this need was the idea that health data currently held by the NHS is inaccurate, incomplete, or otherwise messy. Public contributors felt that if data in its current state went into an SDE, any potential benefits may not be realised and resulting research may be ineffective, due to the concept of 'rubbish in, rubbish out'. For instance, a transgender public contributor in the LGBTQ+ group highlighted that there may be inaccuracies in the data related to their sex and gender, which would result in any research that uses such data being inaccurate.

There were also discussions amongst several groups that while an SDE could be used to address and reduce health inequalities, if not done correctly, it could have the opposite effect. Public contributors in the deprivation group, as well as those in the LTCs, LGBTQ+, and HIV Positive groups, were concerned that some people, particularly those living in areas of high deprivation, those with complex conditions such as HIV, or those who typically do not access healthcare services, would be left behind by the SDE-enabled research. Specifically, they worried that researchers using the data within an SDE may be more likely to go for ‘quick wins’ and that the issues that concerned them would not fall into this category. This fear was also expressed by the LTCs group, who linked it to pharmaceutical companies’ desire to produce drugs that will generate the most profit, which is not likely to include medications for conditions that occur in small frequencies in the population.

Public contributors also expressed that while they could see the value of the benefit of a centralised data system, they feared this could conversely be a weakness acting as a single point of failure if it were to face technical challenges or be hacked. Particularly for young adults, there was a belief that if an SDE were hacked, it would lead the UK towards a privatised healthcare system, emphasising the importance of the NHS ‘getting it right’.

For some groups, emphasis was placed on the need for the NHS to focus on improving care and record sharing first, rather than spending resources on implementing and maintaining an SDE for research purposes. They lacked capacity to care about their health data being stored and shared via an SDE. Instead, they emphasised the importance of the NHS addressing its issues with continual care. The fact that the NHS are spending so much resource to implement an SDE for research purposes felt misguided by these public contributors, who would see more benefit in that time and money being used to improve current conditions of care. One group suggested that if the NHS could *“sort out the basics first”*, this might improve their faith in an effective SDE.

4.3 How secure is ‘secure’?

Questions regarding the security of an SDE were raised in 8 of the 12 groups. Security was brought into question in relation to who would be able to access the data within an SDE, how effectively personally identifiable information would be removed from the health data (and how this is possible if the data is to be linked back to the data source in order to be kept up-to-date), if and how the system will be protected against hackers and foreign bad actors, and as such whether health data held in an SDE would be safe. This was, in part, driven by media coverage of scandals such as that involving the Fujitsu and the Post Office and the part played by the government, which was brought up in several discussions. There was a recognition amongst many groups that data is extremely valuable and it can be dangerous in the wrong hands, with public contributors emphasising the need for robust security measures with multiple layers of protection against bad actors either side of the firewall (with the risk posed by foreign hackers being felt to be particularly problematic), scammers, others with harmful intentions, and incompetence.

Some groups discussed the potential use of artificial intelligence (AI) in conjunction with an SDE. While some thought AI would be a useful, and even exciting tool for contributing to improved efficiency and effectiveness of treatments, detecting early warning signs, and other benefits, others feared that AI use could have negative effects, with some public contributors fearing it could ruin an SDE.

Others highlighted that it may be unwise for the NHS to draw attention to the security of health data, as this could automatically make people question how secure their data is, even if they hadn’t considered it before.

4.4 This is complex and potentially divisive

The fact that implementing and maintaining an SDE is complex and potentially divisive was brought up in 8 of the 12 discussions. During the LTCs discussion, one public contributor, a self-described conspiracy theorist, expressed that they currently do not access all healthcare services available to them for fear of how their data will be used. Multiple groups discussed that such a mentality may prevent or reduce some people’s access to healthcare services if an SDE was to be introduced, particularly if people’s health data was to be stored in an SDE without their explicit consent. A second public contributor in the LTCs group worried that the NHS would sell their data, potentially to other countries, for less than what it is truly worth. However, others, particularly in the carers and visually impaired groups, liked the idea that the NHS could make money off an SDE, as this was seen to potentially benefit the NHS greatly by improving financial gain.

4.5 What are my priorities?

Public contributors' priorities for an SDE were discussed in 6 of the 12 groups. While some public contributors valued privacy and self-protection, others prioritised helping themselves and others, contributing to a greater good, having control over their data, and protecting certain information. Often, these priorities were linked to past experience. For instance, those who wanted to protect certain information tended to be people with traumatic experiences related to health and social care services, while those who prioritised contributing to a greater good tended to be those who had faith in the NHS and no or few bad health and social care experiences.

4.6 Hopes and dreams, if done right

While there were several concerns and questions raised throughout the community involvement sessions, public contributors in 5 of the 12 groups were able to see potential benefits in the implementation of an SDE. Particularly, these centred around greater efficiency and effectiveness of research, better and faster treatment, improved diagnosis, and faster and cheaper development of medicines. For young adults specifically, this was seen to have benefits much wider than those linked directly to healthcare. They believed, if done properly and effectively, an SDE has potential to provide benefits to wider society. Additionally, several groups recognised that an SDE could improve 'our' lives. Who is included in 'our' differed from group to group, although it typically related to the individual, their loved ones, and others with similar lived experiences.

However, for some groups, the ability to believe that such benefits would be realised was limited by previous negative experiences and a related inability to trust the NHS. This was illustrated particularly in the PTC group, who emphasised questions around how they could be sure that everything that's being said can be trusted; the HIV Positive group, whose previous experiences with stigma and trauma limited their ability to trust that benefits would be seen; the older people group, whose resignation towards SDEs regarding the state of the NHS and the world resulted in an inability to believe in benefits being realised; by the trans public contributor in the LGBTQ+ group, who worried that an SDE could contribute to pathologisation of autism and gender diversity; and in the young people (age 15-17) group, who were concerned with issues such as conscription, which restricted their mental and emotional space to worry about their health data being stored in an SDE.

Conversely, young adults were optimistic about SDEs, claiming they could be *"a game changer",* if done right. To be 'done right', young adults expressed that anonymisation must be secure and irreversible, although they recognised that this may not be possible, and that the implementation and maintenance of an SDE needs to be governed by a flexible, relevant, diverse group that includes a variety of lived experience and professional expertise. Carers also expressed the need for an impartial governance group composed of people who will not make a profit from the data, although they recognised that this would be difficult to achieve on a national scale.

4.7 Will our data be looked after?

This theme was discussed in 5 of the 12 groups and included subthemes such as the importance of secure and irreversible anonymisation; the need to safeguard vulnerable people and their data; and the desire to have the option to opt in or opt out, choose what data is included in an SDE, and provide informed consent.

Several groups discussed anonymisation, whether it could be trusted, and the need for it to be secure and irreversible. However, public contributors also recognised that irreversible anonymisation may not be possible, due to the need for data to be linked to the source for it to be kept updated.

Some groups raised concerns around how vulnerable people's data would be safeguarded. They questioned who will oversee vulnerable people's data and whether their data will be automatically included in an SDE because they're unable to understand and/or have the capacity to opt out. While it may have been expected that carers would have this concern, and indeed they did, it was also raised by other groups, such as the PTC and LTCs groups. This illustrates the importance of safeguarding to the public, not just for those who are directly affected by it.

The topic of consent came up in several groups, which was closely linked to a generally shared view that patients should have the opportunity to opt in or out of having their data stored in an SDE. Some groups suggested that people should have the choice of exactly what data goes into the SDE, while others felt it was important that people can choose how their data is used once it's in an SDE. This point was felt to be extremely important to public contributors. However, it was raised that if too many people opted out, any SDE-enabled research will be meaningless, as the dataset will not be complete.

4.8 My needs are misunderstood

Public contributors in 3 of the 12 groups discussed the ways in which their needs are misunderstood by the healthcare service and society. Those with experience of substance use and vulnerable housing shared that they feel healthcare professionals do not understand how addiction works and that NHS services for addiction are very poor. Those with an HIV positive diagnosis shared that while they can see the potential for an SDE, they struggled to move past the barriers they experience due to experiences of trauma and stigma. For the visually impaired, their sense of being misunderstood, let down, and left out resulted in a lack of trust in the NHS.

4.9 Do I have value? Is my voice heard?

For 3 of the 12 groups (those with a history of substance use and vulnerable housing, older people, and certain public contributors in the LTCs group), the question, 'Does my voice have value?' was a significant issue. Public contributors from these groups felt that they are often ignored, because of either their beliefs or their lived experience. They questioned whether there was any point in contributing to research, because their previous experience indicates to them that their voice is valueless.

4.10 We are too worried about other things to care about this

This theme was discussed exclusively by the young people age (15-17) attending a regular local youth group. For young people, fear of conscription resulted in an inability to feel they had mental and emotional capacity to care about how their health data is stored and shared with researchers. Once discussions began, however, young people shared that they would like an SDE to be used for research related to the conditions that affect them and their families. They also worried about foreign hackers being able to access their data and they expressed that they did not trust the government, due to recent actions by government officials covered in the media.

4.11 How can I be sure?

Public contributors from the PTC had significant experiences of trauma relating to health and social care services. This resulted in them questioning whether they can be sure that what is being said about an SDE is true. They acknowledged that the NHS is asking people to trust them and their ability to deliver and maintain an SDE, but this is difficult for this group, due to their experiences of trauma and the resulting lack of trust they feel towards the NHS and the government.

4.12 Resignation

Older people (age 86 and over) initially appeared to be indifferent to SDEs. However, upon discussion, it became apparent that this indifference was actually a sense of resignation. Older people felt that an SDE was going to be implemented regardless of their wants and needs and that, due to the current poor state of the NHS and the world, it's going to be a *"hard sell"*. This theme is similar but slightly different to the theme 'We are too worried about other things to care about this'. While young people discussing that theme were overwhelmed by other things going on in their lives and the world, older people appeared to lack the sense of overwhelm, and instead indicated that they felt resigned to the fact that an SDE would be implemented whether they wanted it to or not, attributing this to the current state of the NHS and the world.

4.13 We have no control over this

This theme was discussed by public contributors with experience of substance use and in early recovery. During these discussions, there was an overwhelming sense of lack of control and helplessness, primarily due to a lack of trust in the government and, by extension, the NHS. Public contributors in this group felt they had been lied to countless times about their health, relating this particularly to the oxycontin addiction crisis in the USA. This sense of having been lied to and the subsequent lack of control tended to influence perceptions regarding SDEs significantly, resulting in doubts about the government's intent with implementing an SDE.

5 Next Steps

One key discussion point amongst almost all groups was who public contributors would trust to hear about SDEs from. There was a clear lack of trust in the government, as almost every group that had this discussion stated that they would not trust hearing about this from government officials. Additionally, they would not trust representatives of the church, those working in job centres, 'Big Tech', or 'Big Pharma'. They would, however, trust to hear about SDEs from GPs, groups and organisations linked to their employment and/or medical condition, regulators (specifically for carers), and groups like the Women's Institute. Importantly, public contributors valued having conversations about SDEs with people they have pre-existing mutual understandings or relationships with, those with a shared lived experience, and people who value the humanity of others. Public contributors also felt it was important that the information regarding SDEs be given through multiple trusted sources, rather than coming from a single point of contact.

Another common theme was that public contributors wanted to have open conversations about SDEs, either with nurses or GPs or other trusted, community-based sources. Public contributors generally disliked physical materials such as pamphlets when presented with them and felt instead that they would want to hear about this from a real person, who would give them the opportunity to ask questions and voice their concerns. Not only would this allow people to have their questions answered, but it would avoid the issue of jargon use. Some public contributors did not understand the true meaning of 'data', which is an essential aspect of the communications proposed for this project. It is important that any communications that people have access to are clear and easy to understand. People must be met where they are. There cannot be any assumption about a pre-existing level of knowledge because this will vary from person to person and if someone doesn't understand a term such as 'data', there is a potential for them to become disengaged, not only from an SDE, but, as was suggested by public contributors, from healthcare as a whole.

It was equally important to public contributors that information regarding SDEs contains not just a statement of what is being done, but also examples of how it is benefitting individuals, the NHS, and society. Public contributors wanted to hear about the specific benefits and positive outcomes resulting from the SDE project and associated case studies.

Some public contributors, however, remained sceptical that there would be any benefit to individuals and society, as they feared profit would be valued over research benefit and altruism. Several groups discussed that this is not likely to be a purely altruistic endeavour and worried that any opportunity for the NHS to make money off the data held within an SDE would overshadow potential benefits.

It is important that communications about SDEs address the various questions and concerns raised by public contributors during the community involvement activities. Any education around SDEs should also address the specific concern raised by the PTC group around why it is acceptable for their data to be used in this way, potentially without their permission, but they are unable to access data that could directly affect their and their children's lives due to perceptions that this violates civil rights to privacy. Emphasis should be placed on the fact that personally identifiable information will be removed from all data, but the public's general lack of confidence in the ability of the NHS to do this effectively and meaningfully must be considered.

Equally, the varied and relatively extreme views expressed on AI suggests that it is important for appropriate information around the intended use of AI in an SDE to be proposed and managed effectively.

6 Final Remarks

All public contributors involved in this project shared thoughts, opinions, worries, fears, hopes, and dreams based on their lived experience. While some groups raised similar points, sometimes despite vastly different experiences, there were also points raised in each group that were unique to their lived experience. This is important to highlight, as it shows that the way people perceive the NHS' involvement in an SDE and their ability to trust that their health data will be safe, secure, and anonymous cannot be understood in isolation. To understand and be able to communicate effectively and establish trust, people need to be heard, respected, and treated as whole people with a culmination of experiences that contribute to their perceptions. The Wessex SDE project must recognise that different people will feel differently about their health data being stored in and shared with researchers by an SDE, and that to manage expectations and build trust, these feelings, regardless of how they are expressed, must not be ignored.

This aspect of the Wessex SDE project aimed to gather views from a wide range of people whose voices are typically excluded from research. The conversations were rich, passionate, and diverse. Ultimately, public contributors valued being asked their opinions on issues not directly related to the condition that contributes to their marginalisation. They felt that they were valued for their original thoughts, and were seen as whole human beings, with thoughts and opinions outside of their health condition or experiences. Public contributors felt valued in a space where they are usually excluded. This was powerfully influential and significantly contributed to their willingness and enthusiasm to engage with the research. While ongoing project development and wider work may be needed to address reducing health and social care inequalities, the Wessex SDE project must ultimately ensure that people feel heard, valued, and respected to establish trust and enable public acceptance.

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For Further Information

If you have any questions or comments regarding this report, please email Dr Kate Jupp at kejupp@bournemouth.ac.uk or Professor Mel Hughes at mhughes@bournemouth.ac.uk.

For more information regarding the BU PIER Partnership, please visit www.bournemouth.ac.uk/pier.

For comments or questions regarding the wider Wessex Secure Data Environment Project, please email Chantal Chaney at chantal.chaney@opyn.consulting.

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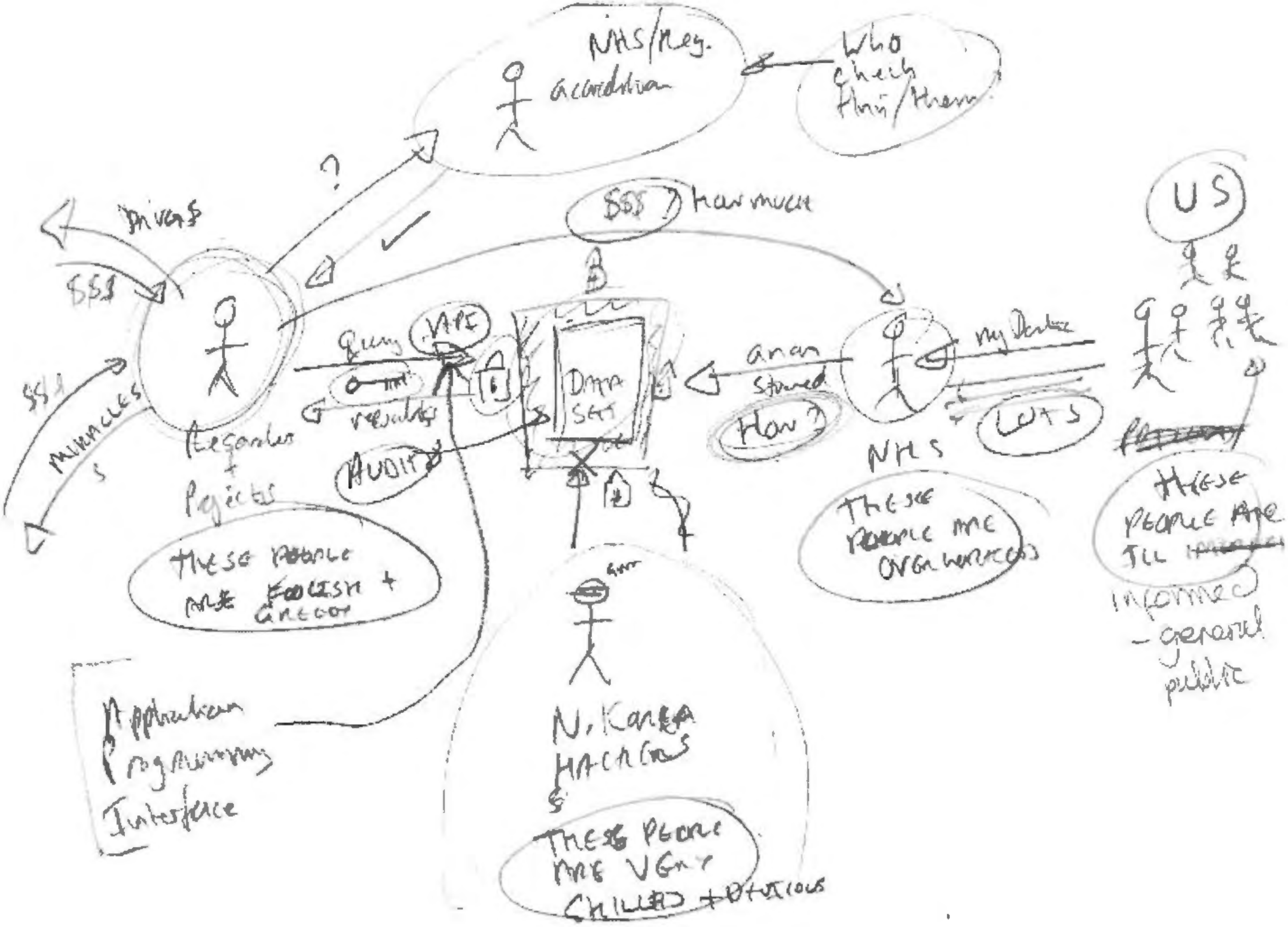
Appendix A: Carer Visual Representation



Appendix 4: Health Innovation Wessex (formerly Wessex Academic Health Science Network, AHSN) – engagement report

Wessex
Academic Health
Science Network

Wessex Secure Data Environment (SDE): Seldom-heard groups early engagement

Findings

David Kryl
Director of Insight, Wessex Academic Health Science Network

Part of
The AHSN Network

Overview and context

A consortium of NHS organisations in the Wessex region has obtained funding to establish a sub-national Secure Data Environment (SDE). An SDE is a digital system that holds and manages access to sensitive data for approved researchers. Data does not leave an SDE and it is managed in such a way to minimise the possibility of re-identification.

The Wessex SNSDE project has workstreams that are developing the technical aspects of an active SDE. In addition, project partners believe that meaningful community engagement is a prerequisite for a successful and impactful SDE.

Several studies have shown that the public is generally supportive of health data being used for research purposes. Their expectations centre on security and privacy, public benefit being the driving factor, and transparency around data processes.

In order for the public to feel confident that their health data is safe, secure and used appropriately to both their immediate benefit and greater societal benefit, the public must join the journey and actively contribute to decisions.

Additionally, the importance and scale of the opportunity around health data use demands that our public contributors come from more diverse backgrounds than traditionally accessed during research-led patient and public involvement and engagement (PPIE) activities. So, there are a wide range of other civil society groups that we want to engage, but it may be difficult to do so due to resource constraints. These additional conversations are critical, not just because they strengthen our licence to operate, but because they bring insights that help us optimise the value proposition; that is, who benefits and how.

This rapid evaluation is a starting point for the discussion about who should benefit and how the SDE will work to do this. In principle everyone in Wessex has a say, but in a resource constrained environment we need to prioritise and to have a clear and publicly acceptable rationale for doing so.

Previous community engagement examples

London:

- OneLondon Citizens' Summit
- 100 Londoners across all 32 boroughs, and from different backgrounds
- Expect health and care data to be accessed and used by those who need information to perform their role, with conditions
- Acceptance for de-personalised data to be used for proactive care, planning and research with specific conditions
- De-personalised health and care data must be shared and used by relevant bodies to plan and improve services and demonstrably benefit health
- Experts to lead detailed decision-making, with the public involved in ongoing policy development.

Wessex:

- Wessex Care Records Citizen Research workstream to inform development of citizen engagement strategy
- Small minority did not think health information is already being shared
- Most willing to share health data (personalised) with NHS, universities and charities; but not with companies
- Trust de-identified information being shared if know who is seeing it, that access is restricted, and with appropriate security measures.

Methodology

In response to managing Covid-19 challenges, Wessex AHSN developed a rapid insight generation and rapid evaluation methodology to capture learning in the local NHS and care systems.

This 'Rapid Insight' approach involves deliberative events with stakeholders to generate insights linked to specific priority areas of interest, followed by rapid analysis and dissemination of the findings.

This project adapted the Wessex AHSN Rapid Insight methodology as described by Jackie Chandler, Philippa Darnton and Andrew Sibley in 'Very rapid insight generation to support UK health and care systems: An AHSN approach. Frontiers in Sociology'. 28 March 2023. DOI 10.3389/fsoc.2023.993342

At the beginning of each session, each group's level of understanding about concepts of data, SDE, use cases, and communications about SDEs were elicited. Time was spent on achieving a shared understanding of the topic before moving to a discussion about governance and participation.

Group makeup

- The three groups involved in five sessions included:
  - ***Hart Young Carers*** *- A north Hampshire group including people from age 7 to 25 who are active carers for a family member*
  - ***Chat with Chai*** *- A Portsmouth community group of south Asian women, many with limited English language use*
  - ***Weymouth Fire Service*** *and* ***East Dorset Rugby Club*** *- Working men between 18-55 years of age belonging to various socio-economic groups according to National Statistics Socio-economic Classifications*
- The discussion questions were developed in partnership with Ralph Scott, SDE workstream lead for Communications and Community Engagement.

Questions

Question 1: *What data should go into the SNSDE?*

Question 2: *What type of research and analysis should be supported?*

Question 3: *Who can access the data?*

Question 4: *Who should be involved in making decisions about how the SNSDE is run?*

Question 5: *What should the boundaries be for data access?*

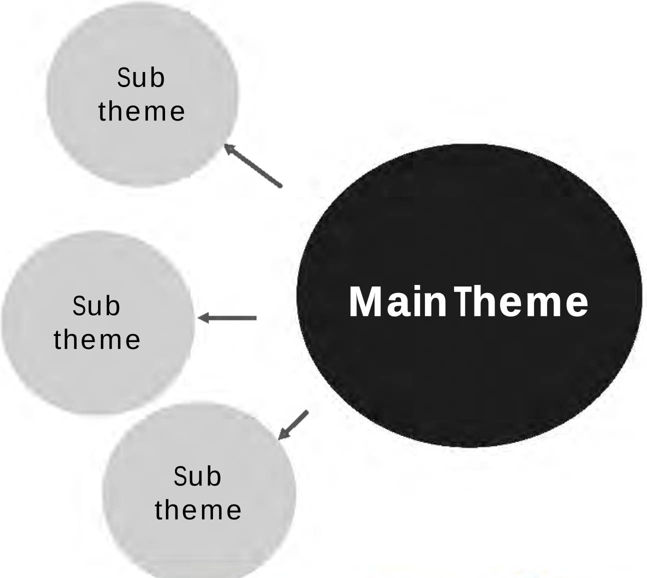
Question 6: *How should the community be involved in these decisions?*

Focus group structure

- Four sessions were face-to-face and one was hosted on Microsoft Teams; both facilitated by Wessex AHSN.
- Structured around six themes.
- All sessions were recorded without participant identification. The recordings are stored as per NHS GDPR guidelines.
- The value of the exercise comes from stakeholder input – attendees did not need to worry about finding the right word, the appropriate terminology or getting the spelling spot on, they simply shared their thoughts about each question.

Analysis and Mind Mapping

- Responses to each of the six themes were collated and broken down into key points.
- These points were then grouped by theme through a simple thematic analysis.
- A theme is defined as the ‘central message or perception’ that is being expressed.
- Themes were broken down further into sub themes, if appropriate.
- Mind Maps were used to present the identified themes, as illustrated.



Sub theme

Sub theme

Main Theme

Sub theme

Limitations of the findings

- This report describes the outputs of short sessions, designed to capture the current experiences of different community members.

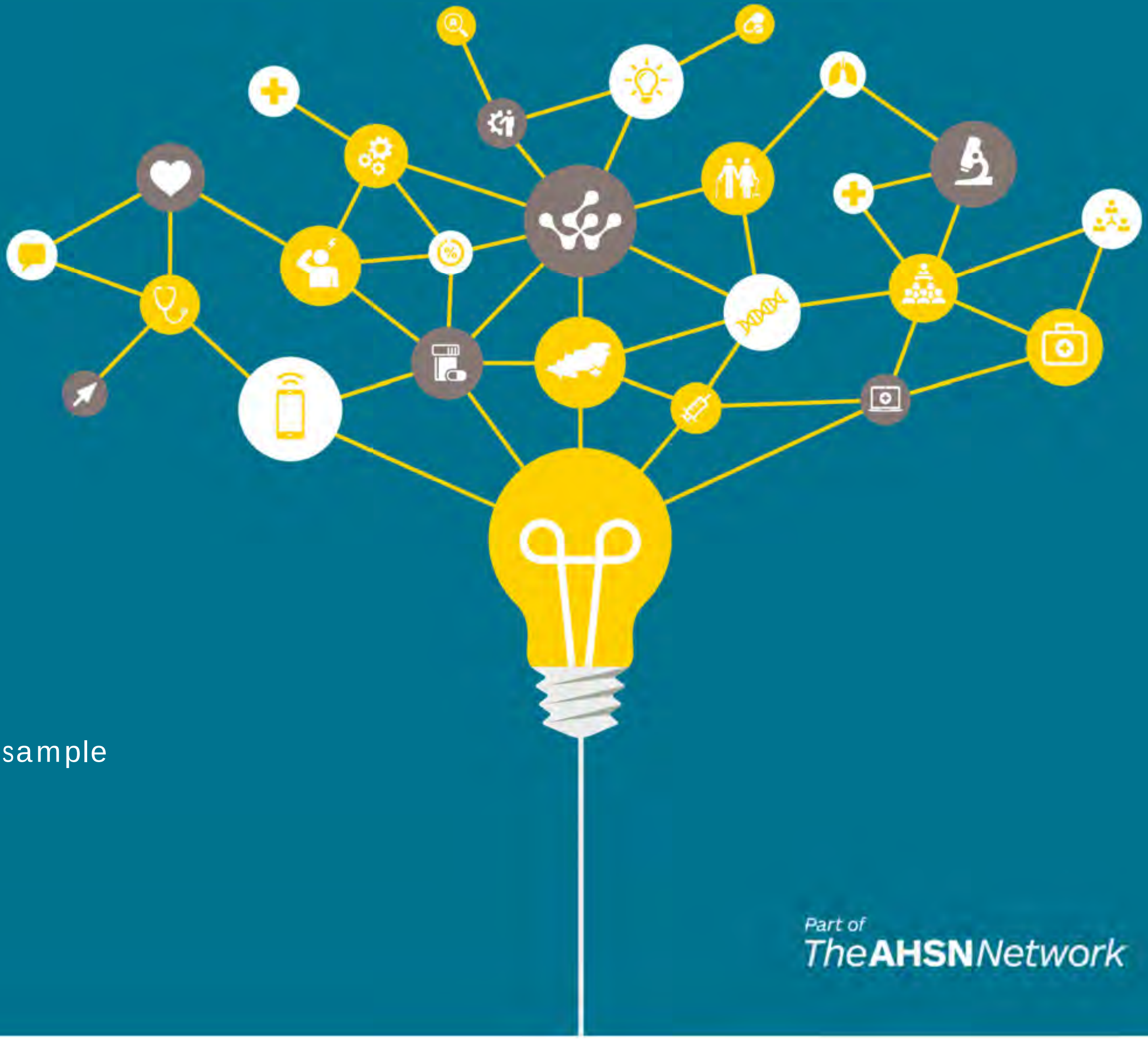
- The outputs are intended to inform Wessex SNSDE planning and delivery.

- Indicative findings are drawn from a limited set of data that was collected and analysed over a short timescale to enable rapid learning (September 2023).

- The findings are not conclusive. The findings cannot be extrapolated to a broader population of users and/or applied to settings or contexts other than that described. Nor can it be assumed that the findings are applicable to a similar setting or context.

- The information presented is derived from personal opinions and represents the perspectives of the individual participants.

- For the purposes of service delivery decisions, these indicative findings should be used alongside other learning obtained through the Wessex SNSDE programme.



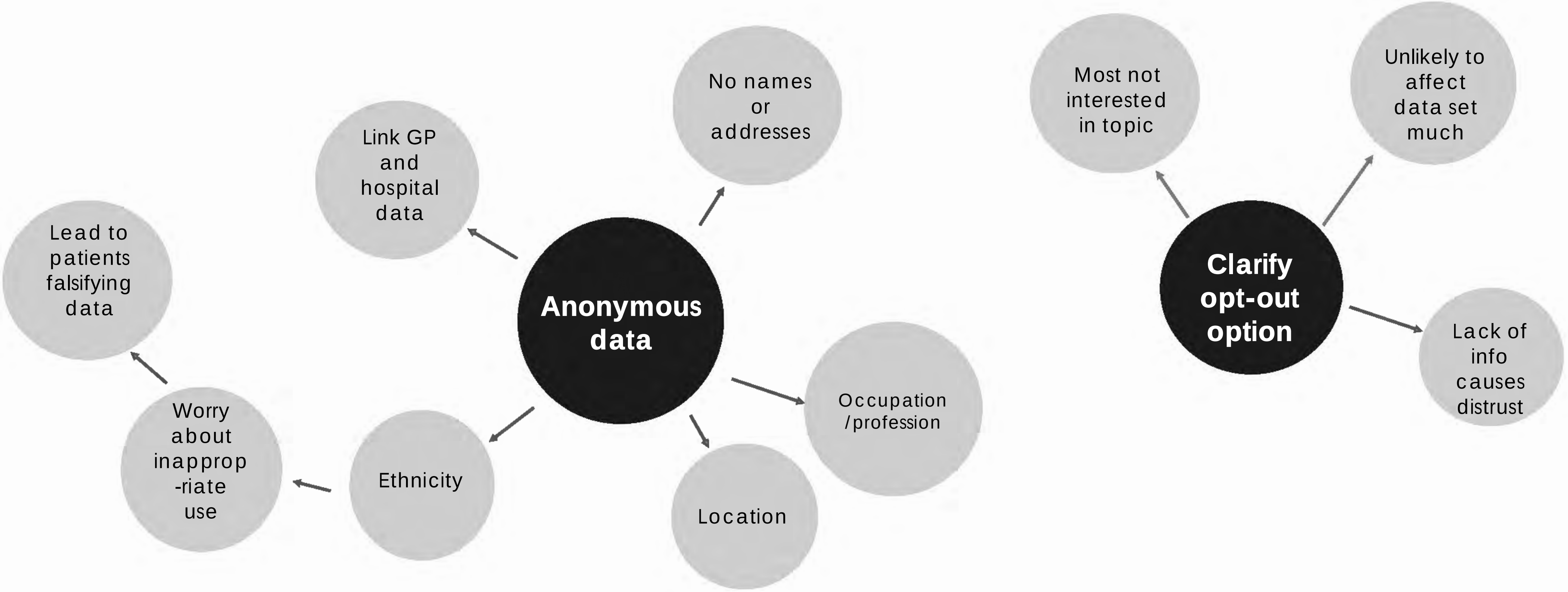
Findings

Mind Maps are presented for each question and sample comments are provided in quotations.

Part of
TheAHSNNetwork

Mind Map 1

What data should go into the SNSDE?

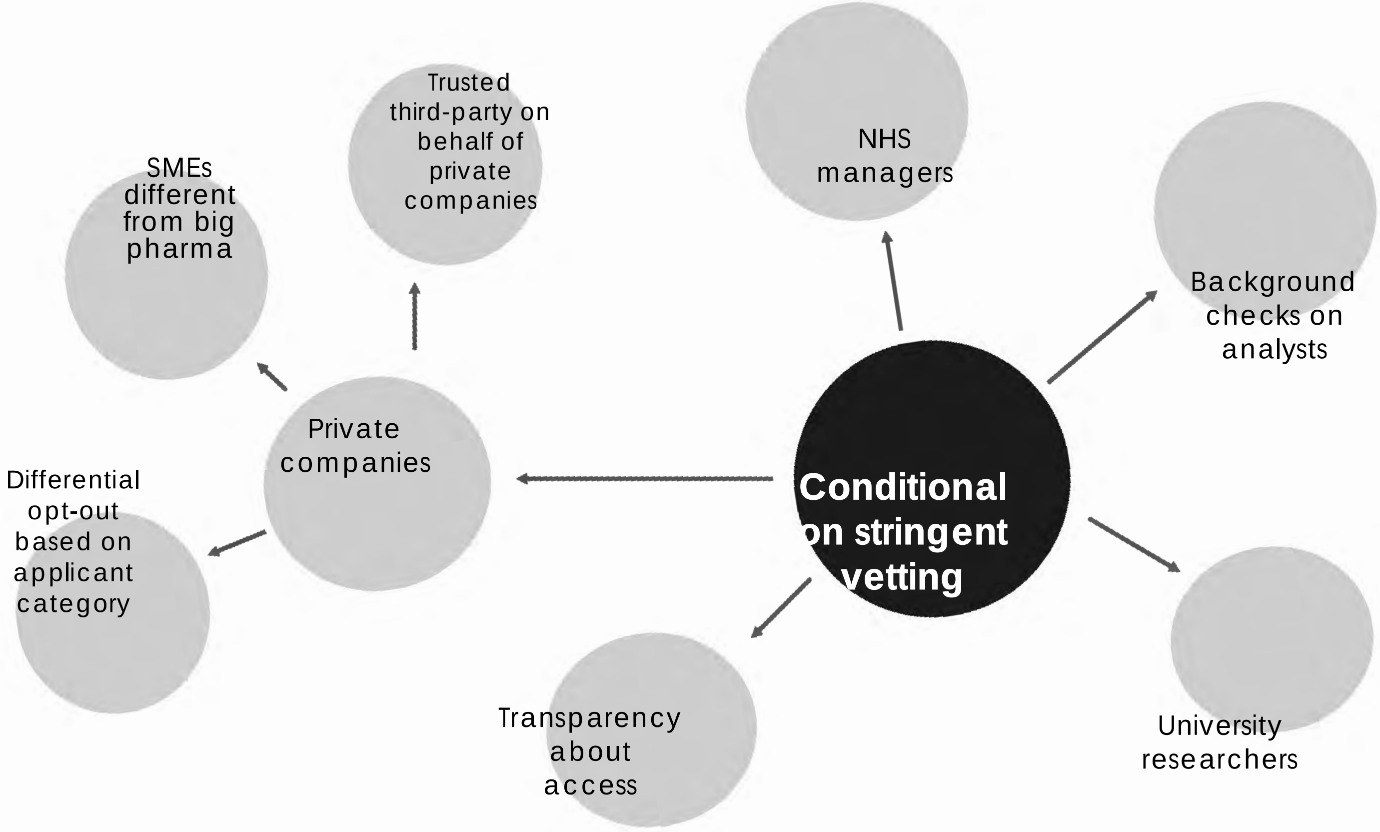


Mind Map 2

What type of research and analysis should be supported?

Mind Map 3

Who can access the data?



Conditional on stringent vetting

NHS managers

Background checks on analysts

University researchers

Transparency about access

Private companies

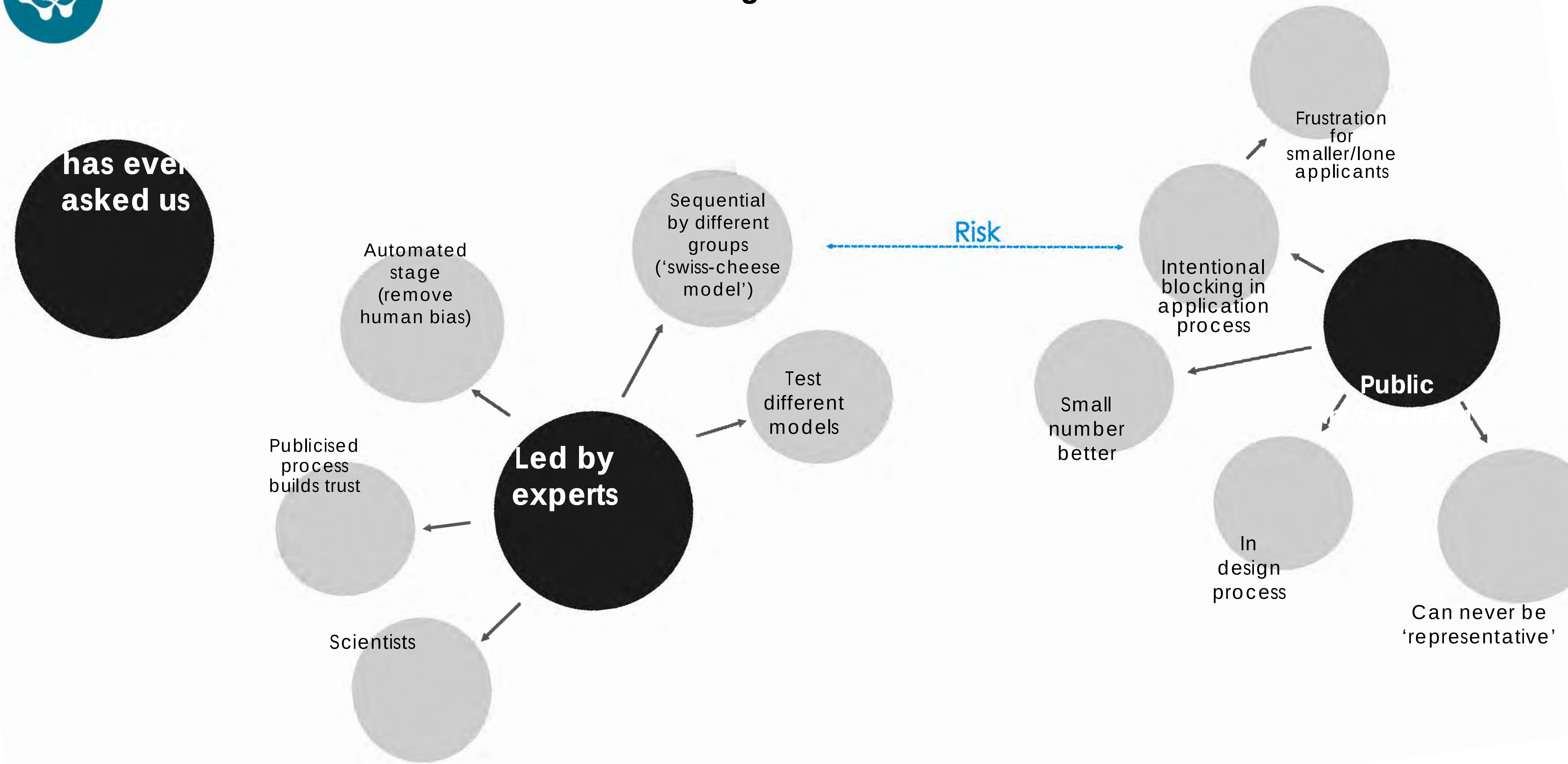
Trusted third-party on behalf of private companies

SMEs different from big pharma

Differential opt-out based on applicant category

Mind Map 4

Who should be involved in making decisions about how the SNSDE is run?



Nobody has ever asked us

Led by experts

Automated stage (remove human bias)

Sequential by different groups (‘swiss-cheese model’)

Test different models

Publicised process builds trust

Scientists

Risk

Public

Intentional blocking in application process

Frustration for smaller/lone applicants

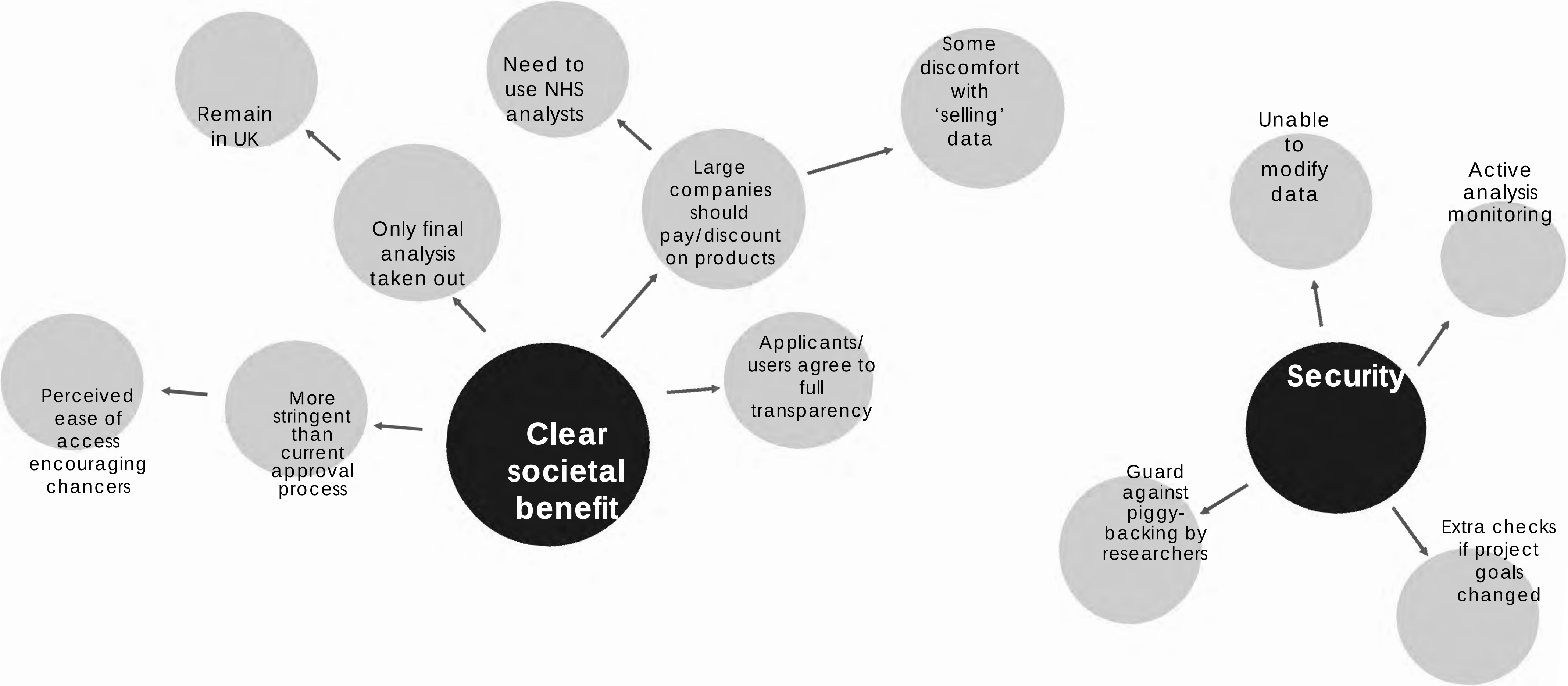
Small number better

In design process

Can never be ‘representative’

Mind Map 5

What should the boundaries be for data access?



Clear societal benefit

Only final analysis taken out

Remain in UK

Large companies should pay/discount on products

Need to use NHS analysts

Some discomfort with ‘selling’ data

Applicants/ users agree to full transparency

More stringent than current approval process

Perceived ease of access encouraging chancers

Security

Unable to modify data

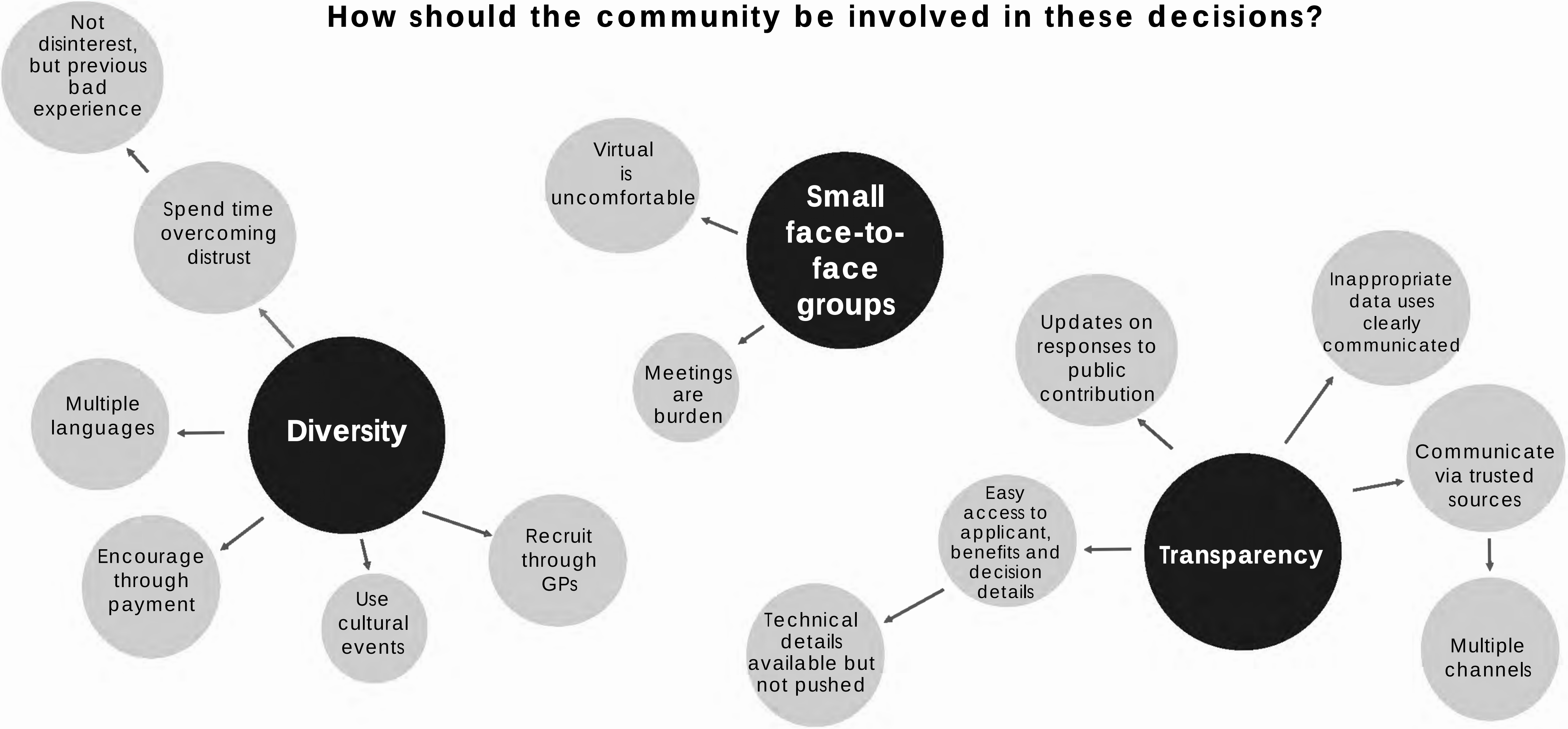
Active analysis monitoring

Extra checks if project goals changed

Guard against piggy-backing by researchers

Mind Map 6

How should the community be involved in these decisions?



Diversity

Spend time overcoming distrust

Not disinterest, but previous bad experience

Multiple languages

Encourage through payment

Use cultural events

Recruit through GPs

Small face-to-face groups

Virtual is uncomfortable

Meetings are burden

Transparency

Updates on responses to public contribution

Inappropriate data uses clearly communicated

Communicate via trusted sources

Multiple channels

Easy access to applicant, benefits and decision details

Technical details available but not pushed

Overarching findings and recommendations

- **No major differences to other studies**
  - 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).
- **Worries**
  - 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.

Overarching findings and recommendations

- **Common views**
  - No one has ever asked them for their opinions!
  - Regular involvement/attendance in formal decision-making not desired
  - ‘Representation’ is not realistic
  - NHS does not communicate enough with people about this subject
  - Information about how and who is accessing the data should be easily available.
- **Recommendations**
  1. *If involved, participants from these groups prefer face-to-face discussion groups, rather than joining formal meetings and virtual set ups, and focus on use case updates*
  2. *Vetting process for data access should focus on data users, potentially as strong as government Security Clearance, and societal benefits*
  3. *Use a third-party (university, Office for National Statistics, or NHS analysts) to do the research on behalf of commercial requests to show independence and build trust.*

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