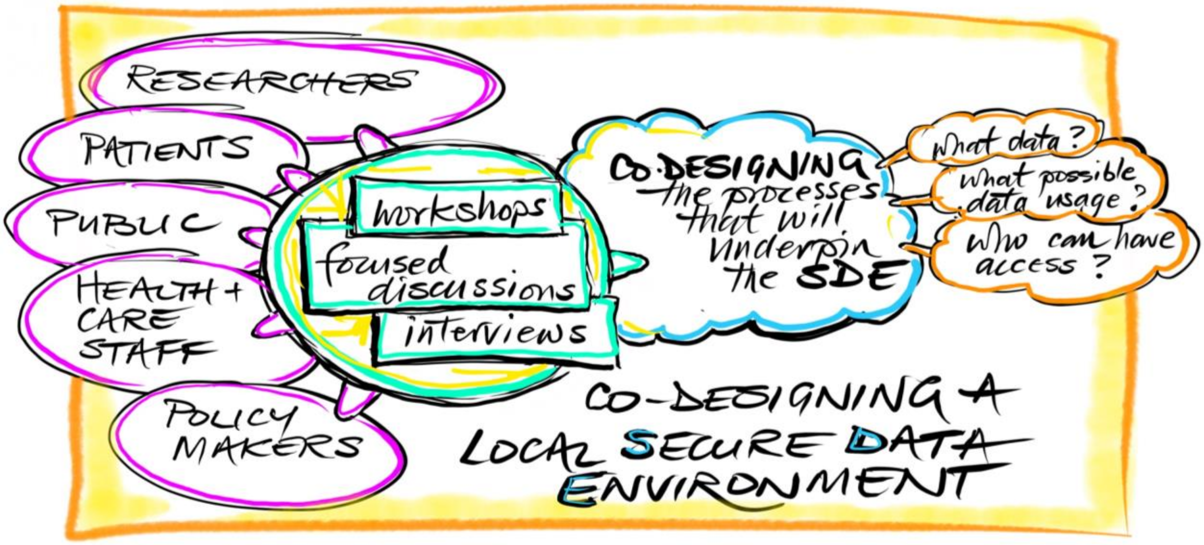
Coproduction and the Thames Valley & Surrey Secure Data Environment: for information



Coproduction is the equal involvement of patients and public, alongside heath & care staff, in the design, delivery, governance and dissemination activities associated with a project

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1: Introduction

From its inception, we have embedded coproduction in the activities of the Thames Valley & Surrey Secure Data Environment (TVS SDE). This is because we want to understand, and act on, the perspectives of a wide range of people so that we create a trustworthy, and trusted, organisation. These perspectives include:

- people whose data it is
- people who generate the data and
- those who are custodians of the data.

We believe that using coproduction will help ensure that the TVS SDE develops structures and processes that are trustworthy, secure and defensible. Specifically, the work informs the following:

- ➢ Governance structures and processes that include an equal place for patients and the public, alongside health and care staff.
- ➢ Legal, ethically informed, data approval and access processes.
- ➢ Communication plans and processes that describe the value of having an SDE for the full range of people that need to know about it.

The following principles have informed how the SDE's coproduction work has been carried out:

- ➢ Involving patients, the public and staff from the start in all aspects of the programme from governance to design, delivery and evaluation.
- ➢ Specific work to ensure input from marginalised, or seldom heard, people and communities.
- ➢ Using what is already known, not duplicating.

This paper outlines some of the coproduction activities that have been undertaken over the past 18 months, focusing on the output of co-design workshops.

2: Coproduction and decision making

Currently, patients and the public are involved in decision making through having a public member and the coproduction lead on the Programme Board. A formal recruitment process to appoint public members to the range of boards and committees has recently taken place. Our approach has been informed by the outputs of codesign workshops (see below).

Further advice to the programme is through:

- The Thames Valley & Surrey Ethics and Engagement Advisory Group, established in 2019, as part of the TVS Care Records Programme. This group has recently become a joint group for the two programmes. The relationship between this group and the proposed SDE clinical advisory group is under discussion.
- The Data Community of Practice (CofP) which has supported development of the SDE through dialogue and workshops. The Data CofP includes health and care staff, patients and public, researchers and data custodians.

3: Co-design workshops

Our workshops are coproduced: the planning group includes a public member and our coproduction lead. Members of the Data CofP also provide additional advice.

The workshops have been run to help with SDE design, rather than to promote, raise awareness of, or create buy-in for, the SDE. To date, we have held five workshops, focusing on:

- Data access and approvals
- Communication and governance
- Value creation
- Raising awareness
- Trust

Our next workshop is on January 30th ’25.

Workshop participants are invited in their own right, not as representatives of organisations. Invitees include patients, public, ethicists, data managers, clinicians, managers, VCSE and public health. We aim to have half patients, public and VCSE, and half health and care staff as participants. We have sought to invite a diverse audience in terms of background, lived experience and ethnicity. We will continue to try to achieve greater diversity.

A briefing paper was sent out before each workshop covering: what is an SDE and highlighting the key questions that will be explored in the workshop. Participants are encouraged to write in with questions before the workshop. On the day, a variety of approaches to engage participants are used, including:

- plenary discussion: context setting, getting on same page, Q&A.
- mixed small groups discussions: table-top writing, voting on ideas, post-its, white boards, Q&A wall, Slido.
- subject experts in audience to draw on if needed.
- visual minutes artist.

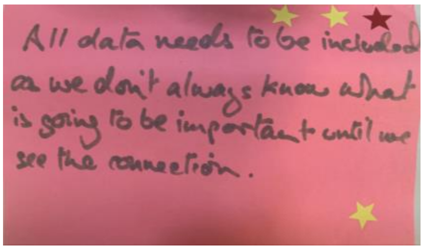
4: Key themes from workshops

Themes have been drawn from across workshops and grouped under the Five Safes Framework.

4.1 Safe data

<u>Data in the SDE should be inclusive</u>

Most participants agreed that all types of data should be included, for some this extended to employment, education and social care. However, there were very clear provisos that the data is not identifiable, is held securely, and is only accessed by *‘trusted’* people with a clear ethical purpose.



All data needs to be included as we don't always know what is going to be important until we see the connection.

[1]

The concerns raised echo much of the existing research with worries that *'I might be identifiable',* that data might be accessed by unethical people, or hacked. Alongside these, there were worries that it might not be possible to truly anonymise some data eg letters or reports, or perhaps once AI has learnt patterns, or when there are small numbers in data sets, and they are combined.

Incomplete data leads to bias

Many people recognised the importance of data quality with concerns that if data was inaccurate, incomplete or biased any ensuing research would be inaccurate. People raised questions about 'missing populations', ie whole communities being absent from data sets as they don't trust sharing their data. This emphasised the need for community conversations so that people can make informed choices about how their data is used. A number of participants raised that they had found out that data held about them was inaccurate. This again emphasised the need for public engagement about data so that people look at their data and, if necessary, get it corrected.

Data processing was also raised as a potential source of bias, AI again being raised.

'Has data already been processed in a bias way before being shared?'

Implications for operation: *need to raise awareness in staff and public about the importance of data accuracy and inclusion. Communications need to highlight security, quality assurance and de-identification processes.*

Sensitivity of data, depends on who you are talking to

It is already known that health data is seen as 'sensitive' compared to other personal data. Within this there are categories of data that people feel are particularly sensitive, although this varies significantly from person-to-person, or group-to-group.

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[1] Post-its from workshops are included throughout this document; stars represent participants' votes for the most important ideas. Participant quotes are in italics and quotation marks. Visual minutes are also included.

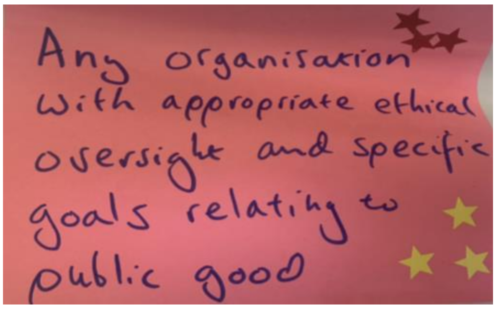
'Worry about data depends on potential for personal or group harms'

The types of data that participants felt merited particular thought included:

- obtained without consent.
- potentially identifiable eg faces or other images.
- beliefs - religious or political.
- gender and sexuality.
- stigmatised conditions such as STIs or mental illness.
- citizenship and immigration status.

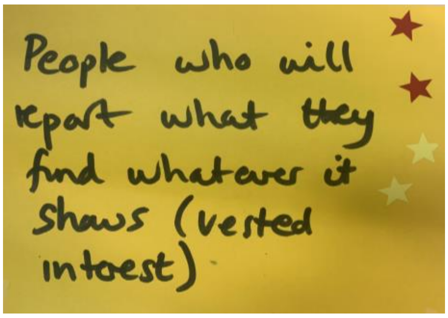
Implications for operation: *a sensitive data approach should be described, and communications include how such data is managed.*

4.2 Safe People



Any organisation with appropriate ethical oversight and specific goals relating to public good

There was a very clear message across conversations that people and organisations who can access data need to be ethical and show their work has public benefit. Part of being ethical includes showing what has been done with the data accessed, and the results of the research. Ideas of equity of access were also raised as important. Participants suggested that access and payment processes need to consider how small charities, or others who do not have much money, can access the SDE.



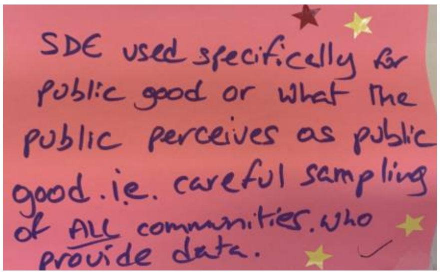
People who will report what they find whatever it shows (vested interest)

Implications for operation:

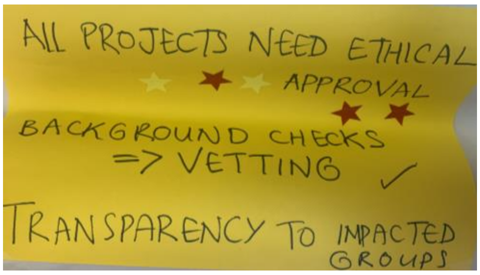
- *approval of people and organisations need to include how public benefit is shown; commitment to openness about use of data accessed; assessment of ethics.*
- *payment policy needs to consider how small organisations can be supported to access.*

4.3 Safe projects

In relation to the sorts of projects that are approved for access to SDE data, participants brought up the repeating themes of public good, equity and transparency. It really mattered to the majority of participants that these values were embedded in the operation of the SDE.



SDE used specifically for public good or what the public perceives as public good. ie. careful sampling of ALL communities. who provide data. ✓



ALL PROJECTS NEED ETHICAL APPROVAL

BACKGROUND CHECKS => VETTING ✓

TRANSPARENCY TO IMPACTED GROUPS

Other things raised in relation to research appropriate for approval included:

- building on what is already known.
- knowing what matters to patients.
- including patients/the public in the proposal.
- taking account of/addressing inequalities.
- aligning with NHS values or priorities.
- having ethics approval.
- having a clear goal or outcome that the research contributes to.
- describing next steps.
- sharing the results publicly.

Implications for operation: *public good, ethics, equity and transparency need to be included in the criteria for assessing research submissions.*

4.4 Safe Outputs (with links to Settings)

Public benefit is a fundamental requirement for most people to feel ok with their data being used for reasons other than their own care. This has also been, unsurprisingly, a recuring theme within our co-design conversations, prompting discussion about what public benefit means in practice. How can we operationalise the importance of public benefit, and how does benefit relate to value generation?

Initial conversations in the value workshop highlighted the distinction between values and generating value. Values are what matters to us, they are both personal and, often, shared. The values that came out of codesign conversations in relation to the SDE were transparency, inclusivity, equity, and the values of the NHS[2]. These mirrored themes of earlier codesign conversations.

With respect to value, or benefit, generated by data from the SDE the things that were discussed included value for the following groups:

- patients

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[2] NHS Core Values: respect and dignity; commitment to quality of care; compassion; improving lives; working together for patients; everyone counts.

- communities
- the health and care system and
- society

The generation of economic value was seen as a benefit that was important, however an explicit link to patient, society and NHS value was seen as more important.

Out of conversations came a series of questions that were important for assessment. These are outlined below in relation to each domain (inevitably there isn't perfect categorisation here as there is overlap between domains).

Creating value for patients

- Does this research address what matters to patients?

Does this research improve:

- knowledge about disease, such as aetiology, prevalence, incidence, morbidity, mortality etc?
- care and treatment?
- outcomes: health, quality of life, 'happiness' and/or experience?

Creating value for the community

Ideas of equity, ie is the whole population likely to benefit, were important for value generation for the community. In conversation participants thought it was important to understand who was included and excluded from research and why. Similarly, people felt that knowing whether research addressed health inequalities and whether specific local benefit might be generated was important. For example, whether there might be a reduction in demand or pressure on local health services.

Creating NHS or system value

Key questions generated by participants were is this research likely to make an impact on:

- quality - effectiveness, safety and/or experience
- efficiency - including productivity
- investment or resource allocation
- workforce eg experience, training and development
- pathway design and delivery
- standards of care

Creating societal value

"Context is important: understanding the research and its impacts in a wider setting"

Key questions generated include:

- Is this research likely to increase trust or confidence in the NHS, in research or in public services more generally?
- Does this research describe:
    - how it fits into what is known already?
    - potential long-term benefit or impact?
    - next steps?

- broad society benefits eg improvement in healthy living or quality of life
- potential non-health benefits eg on crime or education?

Creating economic value
As mentioned, participants stated that this should not be the most important value generated by the SDE. Raising money was seen as important, however patient/public/NHS value should strongly dictate pricing. Similarly, pure commercial research where the value generated is mainly to the organisation requesting access with little or no value to patients/public/NHS was not valued. In a similar vein, there was discomfort with projects that brough only cash value to the SDE/system, without discernible benefits to patients or the NHS.

Other things raised in terms of how access is priced included wanting to ensure smaller research outfits, eg charities, are valued and that this is reflected in pricing. Or wondering if we should charge less if benefit is likely for our local communities.

The value of simply having an SDE
Participants brought up the idea of the 'value' of the SDE itself. For example, potential for reinvestment in 'our region'; enriching the data available to researchers - analysed data becoming part of the overall SDE data; providing services such as help for smaller organisations to manage and curate their data.

Overall our findings on value and benefit are supported by others' research. For example, Faulkner and Kaufman[3] suggest these domains for public value: outcomes that are valued by the public; trust & legitimacy in public services; people's experience of service delivery quality; efficiency.

Implications for operation: *These values should be included in assessment criteria for research submissions and communications should highlight value generated.*

4.5 Safe settings

Technical aspects of how the SDE platform operates were not the subject of codesign conversations; the importance of security, de-identification and the management of sensitive data have already been highlighted. However, communications about the operation of the SDE featured regularly. Key messages included the following:

More communication is needed
It is very clear that most participants across workshops felt that there was a significant communications challenge, as shown in polling during workshop 2.

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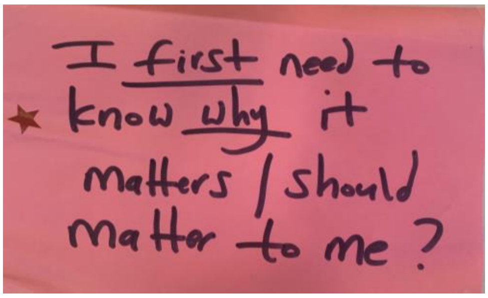
[3] Faulkner N & Kaufman S, 2018

How do you feel the way in which communication about health & care data and research is managed?

This variation in how people viewed current communications was reflected in how they felt about health and care data more generally, as depicted here.

Communicate why data matters



I first need to know why it matters / should matter to me?

Most participants thought that the public (and some staff) were generally unaware of the benefits of using health and care data beyond their own care. So, generating stories about how ‘data saves lives’ was seen to be important.

Understanding data ownership matters

Across workshops there were many references to what happens to ‘my data’. It emerged that there was wide variation in understanding what ‘my data’ meant in practice. It became clear that it is important to distinguish between ‘my data’ meaning data that is about me, as opposed to data that is owned by, or controlled by, me. The legal controllership of data and the rights of the individual need to be clearly communicated.

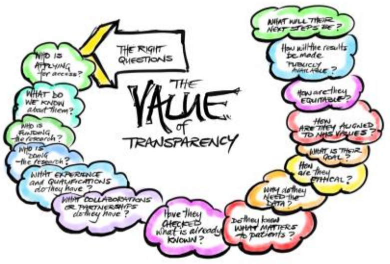
Use multiple messages and channels

Participants thought that the level of health and data literacy amongst many people was low. People need to understand – *'what is health and care data and what is it needed for'* - before messages about the SDE specifically. Then messages about *'how the SDE works and its security, being clear about unknowns and gaps in knowledge'* can be crafted. Last, but not least, messages about the specific uses that SDE data will be put to are needed.

Multiple types of communication resources were suggested - infographics, animations, interviews with differing levels of detail eg 1 min, 5 min and 10 min reads, with registration for the Data community of practice for deeper information.

Implications for operation: *a comprehensive approach to communications is needed for multiple audiences. Our awareness raising course needs to address the ideas raised in codesign conversations.*

4.6. Transparency is paramount



Throughout conversations transparency came up time and time again. People want to know that they are being told what is planned, what happens, and how. Transparency is a key value that the SDE needs to adopt and show, and needs to operate throughout its processes, being explicit about:

- Which data, held where and how?
- Who is applying for, and being granted access?
- What are they using the data for?
- How will the results/outcomes of data use be made available publicly?

4.7: Be trustworthy

"What training? Regulations? Monitoring? Transparency! What is the quality control?"

The distinction between being trusted and trustworthiness was important in conversations. The SDE will need to show that it is deserving of trust, ie is trustworthy. Key attributes that would make the organisation trustworthy included:

- Does what it says it will do, and does it well
- Is transparent about what:
    - processes are used
    - decisions are made
    - what checks are in place
    - value/public benefit is created
- The SDE is a good place to work, good people want to come and want to stay, compassion is a value within the organisation.

Many of the same ideas came out of conversations when discussing what would make SDE to SDE sharing of data acceptable and trusted:

- alignment of security, governance, ethics and processes
- accurate integration
- transparency
- standardisation of processes
- one application process
- shared assurance processes
- accreditation.

4.8 Composition of approvals committee

Many conversations touched on what people thought important in relation to the committee for reviewing proposals for accessing data. For example, how members are recruited should be transparent and there should be a requirement for the committee to have at least 30% public members. There should be a range of representation and diversity in the members appointed: age, lived experience, people who may have low levels of trust, NHS and non-NHS staff NHS - strategic and on the ground. Representation from those who will be accessing the data, and legal input were also mentioned. The importance of including different professional groups and communities, as interests and knowledge about types of data varies, was highlighted. Social work, for example, has different research focus and uses different data types than health research.

How the group should operate

Ideas brought-up by participants included:

- members should be appointed with a fixed term.
- steps should be taken to avoid barriers and hierarchy.
- allow for sensitivities and safeguard against conflicts.
- members need to be equipped and supported to contribute equally.
- conflicts of interest should be considered.
- would paid roles make people more responsible?

Appendix: questions asked at codesign workshops

Data approval and access: codesign workshop 1

What goes into the SDE?
- Does it matter to you what data is included?
- If it does, then which data might be of concern?

What can the SDE data be used for?
- What sort of research and analysis should be supported?
- What benefit should this research and analysis be trying to show?

Who can access data in the SDE?
- What do we need to know about them?
- What checks are needed?

Governance and communications: codesign workshop 2
- Who should be involved in making decisions about how the SDE is run once it is established?
- Which people/organisations can apply to access data?
- How should we involve people in these decisions?

Creating value: codesign workshop 3
- What do we mean by value when we talk about the uses of health and care data ?
- If you sit on the You are the SDE Approval Committee, what questions do you want answers to in order to judge the value of the proposal in front of you?

Questions generated and discussed
- What does patient or NHS benefit mean in practice?
- What do we put in place to make transparency a reality?
- How do we balance different types of value against each other?

Raising awareness: codesign workshop 4
- How do you feel about your health and care data?
- What do you want/need to know?
- How to find out?
- Design a campaign

Trust: codesign workshop 5
- What and why do you trust?
- What makes things trustworthy?