

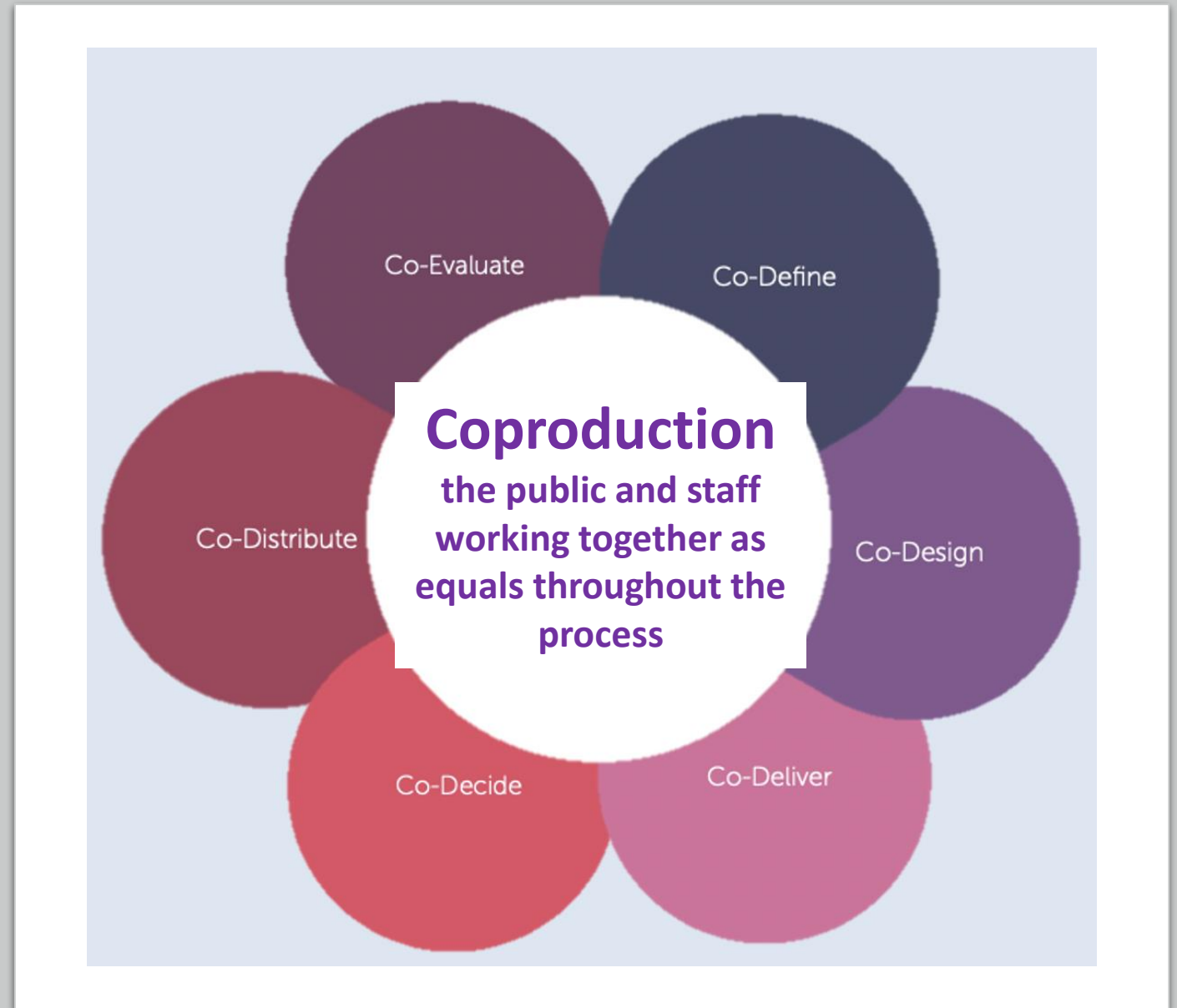
Coproduction: public and staff involvement in the Thames Valley and Surrey Secure Data Environment

Why Coproduction?

To understand, and act on, the range of essential perspectives:

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

This will help ensure that our SDE develops structures and processes that are trustworthy, secure and defensible



Our coproduction principles

- Patients, the public and staff will be involved 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 will be undertaken
- We will use what is already known from the literature and others practice

Coproduction: outputs

1: Legal, and ethically informed, data approval and access processes are developed and used:

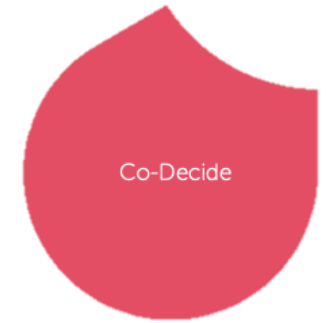
- Which data is included in the SDE: what type, from whom and for how long
- What can data in the SDE be used for?
- Who can access the data: what checks on purpose, funding etc. are needed?

2: Governance structures and processes that include an equal place for patients, the public, health and care staff

3: Communication plans and processes that:

- describe the value of having an SDE for patients, the public, health and care staff, academic and commercial researchers using a range of approaches
- provide assurance to all that data is kept securely and used appropriately ie in line with co-produced approval and access processes

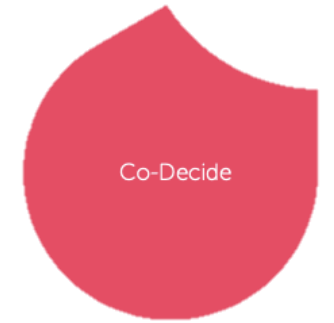
Governance and advice



Governance

- SDE Board: public member and PPI methodologist are members
- Other boards will have public members, informed by our co-design process
- Public and staff involvement will be a standing agenda item and part of risk log

Governance and advice



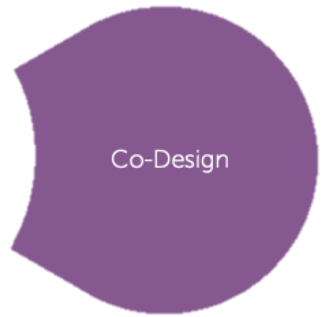
Advisory groups

- Thames Valley and Surrey Care Records Programme Ethics and Engagement Advisory Group will be used for advice: this has staff and public members
- A Data Community of Practice (CofP) will be developed to support development of awareness and champion's work, drawing initially on the TVS SCR Ethics and Engagement Group

“We want to help people understand their health and care data and what happens to it”

Statement of purpose from initial CofP meetings

Co-design workshops



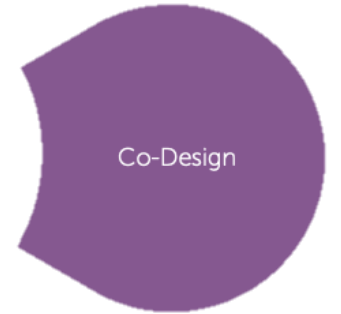
Workshop planning

Planning group includes public member and PPI methodologist and draws on advice from our Data CofP

Participants

- Invited in their own right, not as representatives from organisations or specific communities.
- Invitees to include patients, public, ethicists, data managers, clinicians/managers, VCSE, public health
- Aim to have half patients, public, VCSE and half health and care staff

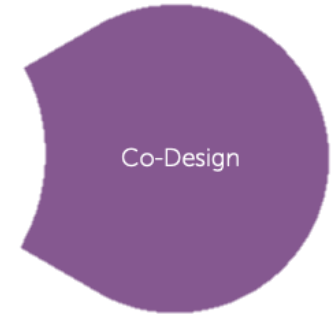
Co-design workshops



Purpose

Design workshops to support design and delivery of the SDE, not for raising awareness or generating buy-in

- Briefing paper sent out beforehand
 - what are SDEs, key challenges and questions that will be explored in workshops
 - allow people to write in with questions they have before the workshop – either answered beforehand or utilised on the day



Marginalised and seldom hard groups

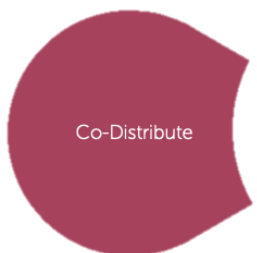
To help ensure a breadth of views are heard and acted on we will run a series of discussions, working through community connectors. We will probably initially seek the views of:

- People who have experienced homelessness
- Gypsy, Roma and Traveler communities
- Refugees and asylum seekers

Creating transparency and awareness



- Working with our CofP and drawing on our previous Data PPI workshop outputs, co-design community and staff engagement for the coming two years
- Explore and build on a digital champions model to create local conversations
- Co-develop and co-deliver training for staff and community champions to support understanding and awareness of health and care data: what it is; how it is used and what rights people have



Further work to develop this coproduction plan will be informed and built on through our workshops and Data Community of Practice

