

2183 UPD Stage C stakeholder depths and triads
Discussion Guide Final
Depth interviews 45 minutes to 1 hour

1. INTRODUCTIONS AND EXPLANATIONS

Thank you for taking the time to talk to us today. I'd like to discuss the best way to provide members of the public with information on Secure Data Environments and Trusted Research Environments. This forms part of a large public engagement project for **Understanding Patient Data (UPD)** centred around pinning down some clear information about TREs and SDEs, what they are, how people feel about them, and the language that should be used in communicating about them.

Before we begin, there are a few points I need to explain to you:

Your personal data (i.e. your name, job title, and work email address) will be held securely by Research Works Limited (the data processor) for the purposes of this research project only. Your personal data will be held by us for 6 months, then deleted. It will not be shared with any other third party.

Please be open and honest with your feedback today. The research session is confidential and all the feedback you give today will be shared on an anonymous basis with the Understanding Patient Data team – you and your individual organisation will not be identifiable within the report and none of the comments you make will be attributed to you or your organisation. Aggregated and anonymous findings will be used and shared where relevant with partners including NHS England and will be published. If, instead of remaining completely anonymous, you wish to be acknowledged as a contributor in the final report, we are also happy to do that. Please just let us know at the end of our conversation.

We would like to ask your permission to record this interview:

- Your audio data will be used and stored securely for the purposes of this research project only.
- It will be analysed (non-digitally) and the findings will be reported back to UPD in a way that means you are anonymous to them.
- It will be held by us securely for 12 months, then deleted. It will not be shared with any third party.
- You have the option to request earlier destruction of your information, or to see the information we have recorded about you, by getting in touch with us directly.

SWITCH ON RECORDING

Please start by giving us a brief introduction to your job role and responsibilities.

The purpose of this conversation today is to inform a resource UPD will develop to explain SDEs and TREs to members of the public. We will begin by thinking about considerations for

this resource before we share the findings from the research so far and the draft resource to capture your input.

2. CONSIDERATIONS AND USE OF A RESOURCE DESCRIBING SDEs/TREs

The purpose of this section is to understand the likely use cases of a resource describing SDEs and TREs to members of the public and any considerations for the development of the resource.

- Tell me about your **experiences with Secure Data Environments and Trusted Research Environments?** *Probe how they work with SDEs and TREs.*
- UPD are keen to provide clear communication about SDEs and TREs to members of the public. What, in your view would be **important to consider** when communicating SDEs and TREs to members of the public?
- How could this resource be **used**? *Prompt:*
 - Where could it be signposted from?
 - In what context could it be introduced to members of the public?
- Do you know of any examples of specific SDEs or TREs that would have a need to communicate the details of how health data is stored or accessed with members of the public? Which?

3. FINDINGS OF RESEARCH TO DATE

In this section we will introduce an overview of the findings to date from the workshops with members of the public.

- To date we have run 14 workshops with members of the public from a range of demographic groups who live in England, Wales, Scotland, and Northern Ireland. In front of you is a summary of the findings so far.
- **Stimulus 1 – summary of research to date**
- What do you think of these results? Is there anything surprising in here?

4. THE RESOURCE CO-CREATED BY MEMBERS OF THE PUBLIC

The purpose of this section is to invite input on the draft resource development.

- During the workshops with the public, we asked them to co-create ideas for a resource describing SDEs and TREs. We have turned these ideas into two draft resources to test in further workshops and we would value your input on the content.
- The first resource is referring to de-identified data, and the second to identifiable data.
- **Stimulus 2 & 3 – draft resources Moderator show each in turn**
- What do you think of this?
- Which aspects do you feel work well?
- Is there anything you feel doesn't work well?

- This resource should be **balanced** and **transparent**. Do you think it delivers on that in its current form or not? Why?
- This resource should provide information that is transparent **without seeking to reassure or convince** the public. It should leave them to draw their own conclusions. Do you think it delivers on that in its current form or not? Why?
- What do you think of the **terminology used**?
- What do you think of the **tone of voice**?
- Does this resource cover all the **topics related to SDEs and TREs that are important?** *If not probe what is missing*
- What do you think of an **animated video as the format of this resource?**
- *Moderators prompt any improvements in detail.*
- **Stimulus 4 – extra information**
- This is some of the information that could be provided to the public as links from the main resource.
- What do you think of this description? *Probe: accuracy, terminology, tone of voice.*
- What do you think of the way this describes the differences between SDEs and TREs?

5. INFORMING NEXT STEPS

In this section we will consider how to ensure the resource is valuable.

- Having seen the resource, how do you think it could be useful once developed? *Prompt specific use-cases and contexts.*
- What does UPD need to consider when they produce a final version?
- Thinking now about the final report we produce, what information would be useful to those organisations looking to develop their own SDE/TRE resource?

Confirm if participant wants to remain anonymous or would like to be acknowledged in the report.

Thank and close.