

2183 UPD Workshops Stage A
Discussion Guide final
1.5 hours in length

1. INTRODUCTIONS AND EXPLANATIONS (10 MINUTES)

- Introduce self and RWL, an independent market research company.
- Explain that we are conducting research on behalf of a charity called Understanding Patient Data (UPD).
- This session will be about how to communicate the storage and use of health data. It is the first of two sessions we have on this topic.
- Please be open and honest with your feedback today, we want to hear what you really think! The research session is confidential and all the feedback you give today will be shared on an anonymous basis with the UPD team – you will not be identifiable within the report and none of the comments you make will be attributed to you.

- Your personal data will be held securely by Research Works Limited for 6 months, then deleted.
- Your personal data will not be shared with any other third party, including our client UPD in any way that would allow you to be individually identified.
- You are also consenting to UPD processing aggregated data from which you cannot be individually identified – in the form of the report we supply for research purposes.

- Ask permission to record the session.
 - RWL will use and store the audio or video for the purposes of this research project only;
 - All audio/video data is kept securely for up to 12 months after project completion, it is then deleted from our systems.

SWITCH ON RECORDING

- Participant introductions – first name, region of the UK where you live and what you do for a living.

2. EXPLORING KEY TERMINOLOGY (15 MINUTES)

The purpose of this section is to identify understanding of the common terms relating to health data amongst these research participants.

- What do you think the term **‘health data’** refers to?
 - *If needed moderator explain:* When we think about ‘health data’ we mean data relating to the physical or mental health of an individual including the provision of health services which reveals information about their health status.¹

¹ [Health data | ICO](#)

- When I say the term ‘**access to health data**’ what do you think that means? How do you imagine this differs from **data sharing**?
- Thinking about your personal health data, who do you think would have access to this data?
- What would you imagine they use the data for?
 - *Probe awareness of the following usage types: Direct Care, Research and Development, clinical trials, Population Health management*

• **Stimulus 1 – UPD public guide to what happens to health data and de-identifying health data**

- This is some information about the way that health data can be used.
- Do you have any questions after reading this?
- How do you imagine **health data is stored**?
- How do you imagine health data is **accessed**?
- **Workshop 5 only:** *Moderator note: If participants raise further questions or concerns about data usage or data access in this group then the document ‘Black South Asian and Invisible Why Patient Data Matters Infographic’² may be helpful and can be shared at this point.*

3. UNDERSTANDING OF TREs (20 MINUTES)

The purpose of this section is to explore how to describe TREs to members of the public.

The aim of this session and the one we will run with you in early February is to help develop a way to communicate a new method of storage and access to health data. By the end of our second session, we should have identified the optimum way of doing this.

- Have you heard the phrase **trusted research environment** before today?
- What do you imagine this means?
- Have you heard the phrase **secure data environment** before today?
- What do you imagine this means?

For the rest of this group, we will refer to trusted research environments and Secure Data Environments. Trusted Research Environment and Secure Data Environment are both phrases used to describe the same thing. The NHS and the Department of Health and Social Care use the term Secure Data Environment (SDE) but other organisations and groups use the phrase Trusted Research Environment (TRE). We are going to share some information with you about that now.

STIMULUS 2a, b, c, d – short descriptions of TREs/SDEs

Moderator: show one sentence at a time and vary the order in which each sentence is shown in the groups.

- What are your thoughts after reading this?

² Developed by UPD.

- Do you have any questions? Is there anything you think is unclear?
- What do you think **approved researchers** means?
- What do you think the phrase '**remote access**' means?
- Which of these four descriptions **do you prefer?** Why? Which is clearest? Why?

STIMULUS 3a and 3b – further detail on TREs/SDEs and benefits of them

- What are your thoughts after reading this?
- Do you have any questions? Is there anything you think is unclear?
- Which phrases and sentences **are most helpful?**
- Is there anything in this description that you find **reassuring about this method of storing and accessing health data?** What?
- Are there any phrases or sentences that are **not helpful or not clear?**
- Have you heard the phrase **data federation?** Where? What do you think this means?

STIMULUS 0 – description of data federation

- What are your thoughts after reading this?
- Do you have any questions? Is there anything you think is unclear?
- Is it important to know that some TREs/SDEs use data federation do you think? Why/why not?

4. PRIVACY AND SECURITY (10 MINUTES)

The purpose of this section is to explore how participants feel about the five safes.

- When thinking about the storage and use of health data, what is important to you?
Prompt: security and privacy
- What would you want and need to know about the **security and privacy of your health data?** *Moderator note down ideas.*

STIMULUS 4a – Five safes description by HDRUK

This is a list of five principles which trusted research environments/secure data environments should follow.

- What are your thoughts after reading this?
- Do you have any questions? Is there anything you think is unclear?
- Is there anything **missing from these principles do you think?** What?
- Thinking back to what you felt was important [*moderator refer to notes taken at start of section 4*], does this cover all those factors of importance? Why/why not?
- *Moderators note: If participants have any questions that are unanswered or would like more detail share this stimulus from ONS:*

• STIMULUS 4b – ONS descriptions of the 5 safes

5. REVIEW OF INFORMATION SHARED SO FAR AND DISCUSSION OF NAME (15 MINUTES)

The purpose of this section is to identify any gaps in the information shown to date and to explore the name options.

STIMULUS 5a, b – HDRUK 1 PAGE DESCRIPTION and Will Dixon video summary

Moderator show video and 1 page description which summarises information given.

Moderator note: 1 page description does repeat information given so far so can be left out if participants have grasped this. The video was helpful at this point.

Both of these are summaries of the information we have given you so far.

- What are your thoughts after seeing these?
- Do you have any questions? Is there anything you think is unclear?
- Is there anything **missing from either of these do you think?** What? *Moderator take notes to use in section 6 below.*
- Which do you prefer? The one-page summary or the video? Why?

STIMULUS 6 – NAME OPTIONS (Note: ensure this is covered very briefly)

Trusted research environments and Secure Data Environments can be given different names by different organisations and some of these are on the page in front of you.

- Which name best describes the model we have described to you? Why?
- Do you prefer the word 'secure' or the word 'trusted'? Why?
- What does the word 'research' in the first two titles mean to you? *Probe any assumptions that the environment will only be used for research and not for other purposes such as planning.*

6. MORE DETAILED DESCRIPTIONS OF TRE (15 MINUTES)

The purpose of this section is to identify what further detail or technical information is useful and understandable.

I'm going to share with you some further detail about how trusted research environments or secure data environments work and I'd like you to tell me how helpful you find this.

STIMULUS 7,b,c, – Process diagrams

Moderators vary the order in which the process diagrams are shown in each group and ask the following questions of each:

- What are your thoughts after reading this?
- Do you have any questions? Is there anything you think is unclear?
- What is helpful within this description/diagram? *Probe:* What elements do they think should be included within any public communication.
- Is there anything in this description/ diagram that you feel is unhelpful or unclear? What? Why?
 - How could this be improved?
- After reviewing this detail is there anything that is still not clear? What?

- Is there any more information you would need? What? Does this cover all the additional questions you had in section 5?

STIMULUS 8a and 8b – list of TREs/SDEs that exist

This is a list of some of the TREs/SDEs that exist currently.

- Is it helpful to know some specific examples? Why/why not?
- As this information shows there are several examples of TREs/SDEs. What would you want to know about each of them individually? *Prompt: any expectation that they would follow the same standards/ be consistent.*
- *Probe any mentions of streamlining the system or number of TREs/SDEs.*

6. CONCLUSIONS (5 MINUTES)

- What are the most important points to communicate about trusted research environments/ secure data environments?

Thank and remind participants about the reconvened group w/c 5th or w/c 12th February.