

2183 UPD Workshops Stage C
Discussion Guide Final
2 hours in length

1. INTRODUCTIONS AND EXPLANATIONS (10 MINUTES)

- Introduce self and explain to participants that we work for RWL, an independent market research company and are conducting research on behalf of a charity called Understanding Patient Data (UPD).
- This session is about communicating the storage and use of health data. Today we are going to introduce a resource that explains a method of storing and accessing data and we are interested in hearing your views on it.
- 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.

- Remind participants about their personal details:
- 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. FIRST REACTIONS TO THE NEW RESOURCE (25 MINUTES)

The purpose of this section is to introduce the test resource describing SDEs/TREs to and capture first reactions.

- The purpose of our session today is to look at an early draft of a resource that explains a new method of accessing and storing health data to the public. This resource will be an animated video with a voiceover. For the purpose of this session today we have text (instead of a voiceover) and descriptions of what images could be shown.

- **Stimulus 1 – Resource one line description, script, and images**

- **Moderators show the whole of resource**

- What are your initial thoughts?
- How do you feel about this method of storing and accessing data having seen this?

- Thinking now about the way this is communicated – what did you like about this approach?
- Was there anything you didn't like?
- Do you have any questions after seeing this?
- Are there any parts of this that were not clear? Which and why?
- *Moderators take notes of any points of confusion or elements that were not liked to probe further in later sections.*

3. ONE LINE SUMMARY (15 MINUTES)

The purpose of this section is to determine the optimum 1-line summary of a Secure Data Environment/ Trusted Research Environment.

- **Stimulus 2 – One line description alternatives**

- At the top of this screen is the 1-line summary that you were shown a moment ago at the start of the animated video script.
- Which parts of this description did you like? Was there anything you didn't like?

- *Moderators show two alternative descriptions.* On the screen now I have two alternative one-line descriptions, which description do you like best? Why?
- What do you think of using the phrase '**NHS data**' rather than '**health data**'?
- If we were to write an ideal one-line description, how would that look?

4. VIDEO SCRIPT AND DESCRIPTORS (25 MINUTES)

The purpose of this section is to explore the content of the video script in more depth and identify any areas that would need tweaking.

- We are going to take each part of the video script in turn now and explore your opinions in more detail.

- **Stimulus 1 – resource script and images**

- *Moderators: taking each slide in turn ask the following general questions alongside specific prompts for each scene listed below.*
 - How did this content make you feel about this method of storing and accessing data?
 - Which parts of this did you like? Was there anything you didn't like?
 - Did this raise any questions for you? What were they?
 - If we were to write an ideal script/ design ideal images for this section, how would that look?

- **Stimulus 1b specific prompts – Scene 1: introduction to the use of patient data**

- How important was this introduction up-front?

- *Probe:* could this be removed and the resource start at scene 2? What would be the benefits of this? Any drawbacks?
- How would you feel about this information being provided in extra links rather than in this main resource?

- **Stimulus 1d specific prompts – Scene 3: how accessed**

- What do you think of the mention of an ‘**access review committee**’? *Prompt: do they understand what this is?*
- **Stimulus 3 – alternatives for 1d**
- What do you think of the mention of the ‘**five safes**’? *Prompt if participants feel they need any further information.*

- **Stimulus 1e specific prompts – Scene 4: what data**

- This description could include mention that different **data sets can be linked together** within the SDE; for example health data with local authority data. What do you think of including that information?
- This description could include detail about the **analysis and results being checked before they are released**. What do you think of including this information?

- **Stimulus 1f specific prompts – Scene 5: benefits**

- Of all the benefits listed here, which is of most interest to you? Why? *Probe importance of ‘cost effective’ and ‘collaboration’ benefits.*

5. ‘THIRD’ LEVEL OF INFORMATION AND DETAIL (30 MINUTES)

The purpose of this section is to explore the further details on SDEs/TREs that might be provided as ‘links to further information’.

- Having seen the resource explaining SDEs/TREs, do you have any unanswered questions? *Moderators note down.*
- What would be the best way to provide this further information do you think? *Probe: within the animated video, or as extra detail provided separately.*
- We are now going to share with you some examples of the wording of further information to see what you think.
- **Stimulus 4 a,b,c,d,e,f,g,h,i – further details**
- *Taking each in turn ask the following questions:*
- How do you feel about this method of storing and accessing data having read this?
- Do you have any questions after reading that?
- Is there anything that is not clear?
- How important is this information to you personally?
- Thinking about these pieces of further information we have just shared with you, where do you think this information should be? *Prompt: a link to further information, further down the web page that contains the video.*

6. SHARING OPEN SAFELY VIDEO (10 MINUTES)

The purpose of this section is to share the new Open Safely video as a prompt for participants to see how this video could look and what learnings could be taken for this one.

- We are now going to share with you an example of an animated video that exists for another topic called Open Safely.
- **Stimulus 5 – Open Safely video**
- What did you think of this approach?
- What did you like about the video? What could be learnt for the resource we have been looking at today?
- What didn't you like about the video? Anything to avoid for the resource?

8. CONCLUSIONS (5 MINUTES)

- Are there any other points that UPD should think about when producing a resource to explain Secure Data Environments/ Trusted Research Environments that we have not considered?

Thank and close.