

2183 UPD Workshops Stage B
Discussion Guide final
2 hours in length

1. INTRODUCTIONS AND EXPLANATIONS (5 MINUTES)

- Re-introduce self and remind 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 is the second of our two sessions about communicating the storage and use of health data. Today we are hoping to create an ideal resource to explain this method of storing and accessing data to the public.
- 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

2. EXPLAINING THE PURPOSE OF THE SESSION (5 MINUTES)

The purpose of this section is to outline what we will cover in the workshop and highlight to participants what we heard in Stage A.

- **Stimulus 1a, 1b and 1c – session purpose and findings from Stage A**
- This is some information about what we'd like to achieve in today's session and what we learnt from our last sessions.
- Do you have any questions after reading this?

3. ONE LINE SUMMARY (10 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 alternatives**

- On this screen are some alternative descriptions for our 1-line summary.
- Which parts of these descriptions do you like? Why?
- Which description is the **clearest**? Why?

- *Probe the preferred terminology between these options:*
 - De-identified health data OR health data that is not identifiable.
 - Approved individuals OR approved users OR a longer list of users.
 - Highly secure OR controlled and safe.
 - Remote access OR ‘without them needing to download the data’. *Moderator note: possible not all SDEs or TREs will involve remote access as some will be accessed on site*
- How important is the statement in option C ‘that can save and improve lives’?

- If we were to write an ideal one-line description, how would that look? *Moderator note down to use later.*
- For the purposes of this exercise we have used an example that **uses de-identified data**, which means it’s extremely difficult to identify you, as is the case with the majority of TREs/SDEs.. As we learnt last time there are a few Secure Data Environments/ Trusted Research Environments that do use identifiable information for example for direct care of a patient. This data is already accessed, but the way it is being accessed is different within a SDE or TRE. How could a 1-line description look in this circumstance? *Moderator note down alternative*

4. MORE DETAILED CONTENT – CHOOSING THE RIGHT MESSAGES (40 MINUTES)

The purpose of this section is to identify the preferred messages under each of the core topics.

Content can be edited to create ‘optimum’ versions.

For each topic, moderators should note down which level of information this should sit under; within the 1-line description, the main resource, or a link to further detail.

How it works – stimulus 3

- **Stimulus 3a – facts about SDEs/TREs.**

- On this screen in front of you are some facts about how a Secure Data Environment/ Trusted Research Environment works.
- Which of these is the **most important point to communicate to the public** do you think? Why?

- Which **level of information** is this detail best suited to? The one-line description, the main resource (video or infographic) or within a link to further information? *Moderator note down in stimulus 8.*

- **Stimulus 3b – describing how it works.**

- Here are some alternative ways you could describe how a Secure Data Environment/ Trusted Research Environment works.
- Do you have any questions after reading these?
- Which do you prefer? Why? Which is clearest, why?
- If we were to create our own description, what words would that use?
- What **level of information** is this best suited to? *Moderator note down in stimulus 8.*

• **Stimulus 3c – descriptions of the differences.**

- We have talked about what all Secure Data Environments and Trusted Research Environments have in common. There are two differences described here; one is that a majority use information that is de-identified and a few use information that is identifiable (for example for direct care). The second difference is that some are storage solutions and some use federated data. This means that some have a single system with all the data in it and others have multiple systems where the data stays in it's original location and questions are asked across the dataset.
- Do you have any questions after seeing this? *Moderator skip to 3e if participants would like a reminder description of federated data at this point. Moderator introduce 3d (de-identification) description at this point.*
- How important do you feel this level of information is? Why?
- Is there any further detail would you need here?
- What **level of information** is this best suited to? *Moderator note down in stimulus 8.*
- Where do you think de-identification needs to be covered? *Prompt if this needs to be described in the main resource or as a link.*

• **Stimulus 3e – diagram explaining process using a de-identified 'storage solution' example.**

- This is an example of a diagram that could be used to describe how a Secure Data Environment or Trusted Research Environment works in the case of an example that is a storage solution that uses de-identified data.
- Do you have any questions after seeing this?
- How does this compare to the text descriptions? Better/worse, why?
- In the case of those which are storage solutions, each Secure Data Environment/ Trusted Research Environment will store data with a different organisation. How important is it to know what organisation is storing the data? What level of detail should that sit within?

• **Stimulus 3f – describing federated data.**

- In front of you are some alternative ways to describe federated data.
- Which do you prefer? Why? Which is clearest? Why?
- If we were to create our own description, what words would we use?

Who accesses it – stimulus 4

• **Stimulus 4a – who accesses the information.**

- The resource could provide one line on who accesses the information, or some more detail. Some examples are included here.
- Which do you prefer? Why?
- What **level of information** is this best suited to? *Moderator note down in stimulus 8.*
- **Stimulus 4b – how they are approved.**
- Do you have any questions after seeing these descriptions?
- Which do you prefer? Why? Which is clearest? Why?
- If we were to create our own description, what words would we use?
- What **level of information** is this best suited to? *Moderator note down in stimulus 8.*

Benefits – stimulus 5

- **Stimulus 5 – benefits**
- In front of you are several benefits that are listed on existing websites related to Secure Data Environments/ Trusted Research Environments.
- Do you have any questions after reading these?
- Which benefit is most **interesting to you?** Why?
- Are there any benefits listed here that do not feel relevant for you? Why?
- What **level of information** is this best suited to? *Moderator note down in stimulus 8.*

The uses of the data – stimulus 6

- **Stimulus 6 – uses.**
- As with the benefits, there are different amounts of detail that can be provided on how the data is used. In front of you are several ways the use of this data can be described. These are based on the NHS England Secure Data Environment.
- Do you have any questions after reading these?
- Which do you **prefer?** Why? Which is clearest? Why?
- *Probe:* Which level of detail are you looking for? Something simple like option C or more specific detail like option D? Why?
- What **level of information** is this best suited to? *Moderator note down in stimulus 8.*

Security – stimulus 7

- **Stimulus 7 – security.**
- In front of you are the five safes that we introduced you to last time. We have discussed further detail on point a (safe people) earlier in the conversation.
- Re-reading these, are there any other security points that you would need more information on? Which?
- **Which of these is most important to you?** Why?
- What **level of information** is this best suited to? *Moderator note down in stimulus 8.*

5. Information prioritisation summary (5 MINUTES)

The purpose of this section is to recap on which information is best suited to each level of detail. Moderator will have allocated each topic to an information 'level' earlier in the conversation.

• Stimulus 8 – prioritising topics

- In front of you are the different pieces of information that we have shared with you today and we have placed each into the 'level' you felt it fit best in.
- What do you think about this prioritisation of messages?
- *Allow discussion and debate.*

6. THE FORMAT (15 MINUTES)

The purpose of this session is to stimulate participants creativity by introducing them to formats that exist now to enable co-creation.

• Stimulus 9 – format

- These are some of the formats in which the main resource could be produced.
- What would be your preference? Why?

• Stimulus 10a,b,c – example formats

- *Moderator show each in turn and discuss*
- What do you think of the resource being produced in this format?
 - What would work well?
 - Is there anything that you think would be more challenging in this format?

5 MINUTE COMFORT BREAK TO ENABLE MODERATOR TO PULL TOGETHER CONTENT

7. CO-CREATE AN IDEAL SPECIFICATION (35 MINUTES)

The purpose of this section is to co-create a resource to describe SDEs/TREs to the public.

- We have decided our key messages that we'd like to communicate, which level of information these should be included within and the best format.
- What we'd like to do for the rest of the session is to create this format together.
- *Moderators use developed sentences and create either a script for an animation or an infographic (as preferred by participants) on screen.*

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.