DARE UK

Building a trustworthy national data research infrastructure: A UK-wide public dialogue

Initial workshop agenda, Thursday 13 and Friday 14 January 2022

Google Jamboard was used as an interactive whiteboarding tool for the online workshops. You can access a copy of the Jamboard slides used for the workshop; the relevant pages for each activity are referenced below.

Time	Activity	Room*
09.45	Main room opened for welcomes	M
10.00	Speaker: Introduction and key concepts	M
10.15	Ice breaker Participants introduced themselves and took part in an ice breaker activity in their breakout rooms (*Jamboard pages 1-2*).	B
10.30	Ground rules Participants agreed a set of ground rules for the day together in their breakout rooms *(Jamboard page 3)*.	B
10.40	Speaker: What is a trusted research environment (TRE)?	M
10.55	Whole room TREs Q&A	M
11.05	*Comfort break*	
11.15	Activity: Motivations, concerns and benefits of sensitive data research Participants discussed their own perceptions of the motivations, benefits and concerns related to the use of sensitive data in research, and then discussed the possible views of other stakeholder groups (e.g. researchers, data custodians and governments), and where they agreed and disagreed *(Jamboard pages 6-8)*.	B
11.30	Presentation: The data journey, from collection to use in research Participants were presented with an example of what the sensitive data journey – from data collection to use in research – looks like, including details of the data access and accreditation processes for researchers.	B
11.45	Reflection on data journey Participants were asked to reflect on the data journey presented and share their views on: how well they trusted the process to keep their data safe and secure; how easy they felt the process was for researchers; whether they felt the security processes in place seemed about right, too little or too much; and whether they had any concerns with the process, or views about how it could be improved.	B
12.00	Speaker: Data research case studies, including Q&A with speakers	B/M

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	Participants were presented with a real-life case study of the use of sensitive data in research. On the Thursday, nation-specific case studies were presented in the national breakout rooms; on Friday, a UK-wide case study was presented to all participants in the main room.	
12.15	Reflection Participants were asked to share their reflections on the case study presented.	B
12.25	*Lunch*	
13.15	Welcome back	B
13.20	Activity: Risk/benefit case studies part 1 Participants were presented with three hypothetical data research case studies *(Jamboard page 10)*, including information about the data used and the purpose of the research, and were asked to rank them in terms of their perceived benefit and risk. The purpose of this part of the activity was to explore perceptions regarding the balance of the risks and benefits of data research.	B
13.35	Activity: Risk/benefit case studies part 2 Participants were then told *who* accessed the data in each case (e.g. academic researcher; commercial organisation; government analyst) *(Jamboard page 11)*, and were asked to discuss whether their perception of the risk/benefit of each case study changed on the basis of who had accessed the data. The purpose of this part of the activity was to explore views towards different types of researcher accessing sensitive data for research.	B
13.50	Activity: Data access methods Participants were presented with the existing methods of data access for approved researchers accessing data in a trusted research environment *(Jamboard page 12)* and asked to rank the different methods according to both how secure they felt they were and how easy it was for the researcher to access the data in each case. The purpose of this activity was to explore views towards current data access methods, and whether participants felt the security processes in place were sufficient, too little or too much.	B
14.05	Speaker: [Existing examples of public involvement and engagement in data research](#)	M
14.15	Reflection on current public involvement and engagement Participants were asked to share their views on the current methods of public involvement and engagement in data research as presented, and whether they felt the levels of involvement were sufficient, too little, or too much. They were asked how they think the public should be involved and engaged going forward.	B
14.25	*Comfort break*	
14.35	Activity: safe words/scary words	B

	Participants were asked to share their views on how well they understood certain words or phrases commonly used when describing data research *(Jamboard page 13)*. They were invited to suggest alternatives for the words and phrases they found less clear or easy to understand.	
14.45	Activity: lay concepts Participants were asked to draft definitions for a set of key concepts relating to data research, including: sensitive data; data research; and trusted research environment *(Jamboard page 14)*. They were then shown common definitions for these concepts *(Jamboard page 15)* and asked how clear and understandable they felt these definitions were, and were asked how they felt they could be improved.	B
15.00	Introduce final reflection	B
15.02	Final reflection	B
15.25	Thank you and next steps	M
15:30	*Close*	

*M = main room; B = breakout room