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Using public engagement to promote data transparency and build public trust in a new UK-wide birth cohort

Lisa Calderwood¹, Alyce Raybould¹, Erica Wong¹, Karen Dennison¹, Alissa Goodman¹, and Pasco Fearon²

¹University College London, London, United Kingdom

²University College London, London, United Kingdom; University of Cambridge, Cambridge, United Kingdom

Public engagement is an important mechanism for ensuring that the voices of the public are integrated into study design and data use. However, engaging with the public around data use and data privacy can be challenging, due to the complex and specialist nature of the topic. Building on previous work (Raybould, IJPDS 2025), this paper showcases the findings and outputs from a range of public engagement work carried out for Generation New Era, a new UK-wide birth cohort study, funded by the Economic and Social Research Council. A key aim for Generation New Era is to build public trust through clear communication about benefits and data safeguards and use the Five Safes Framework to help shape these commu-

nications. To help develop and test these communications, we are carrying out in-depth public engagement work to test the main study's privacy information and explanations of data use, security and privacy with members of the public, to better understand lay interpretations of technical language and to further improve how we communicate these. We are working with a specialist public dialogue team at Verian carry out testing of these materials using small in-person focus groups with a diverse group of parents from across the UK in late 2025. We also plan to use specialist public panels on data use (e.g. ADR-UK) in all four UK nations as part of this work, to review the more technical aspects of the privacy information.

