

People want trustworthy researchers to have better access to their data. But only if they're told about it

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The UK Research and Innovation (UKRI) DARE UK (Data and Analytics Research Environments UK) program has today published the findings of a UK-wide public dialogue exploring views towards data research practices, and where improvements need to be made to increase public confidence.

We know from over a decade of previous research that the public broadly support the use of their [sensitive data](#) in research—data about their education, health, welfare, employment and more. But we also know that this support is conditional on the safe storage and appropriate use of that data, and trustworthiness is crucial. The importance of continuing to understand what the public want—particularly since the beginning of the COVID-19 pandemic and associated developments in how data is accessed and used for research—and meeting their expectations, cannot be underestimated when making use of sensitive data.

In January and February this year, DARE UK and Kohlrabi Consulting delivered a series of deliberative workshops with 44 members of the public from a diversity of backgrounds and identities from across England, Northern Ireland, Scotland and Wales. Participants had low existing awareness of how sensitive data is used in research, but showed widespread support for data research and were reassured by processes currently in place to protect their data. They wanted all types of researchers—including commercial organizations—to have access to their data when the proposed research is in the public benefit.

However, participants were surprised by how long and hard it can be to access data and wanted to see these processes improved, so that public benefit can be realized more quickly. They also felt the public are currently left in the dark about data research. For it to be more trustworthy, they saw a clear need for data custodians and researchers to more proactively reach out and tell the public about what is being done with their data, how and why; and to meaningfully involve an inclusive public in their work. The dialogue's findings resonate with those of other recent conversations with the public.

The DARE UK program, which is currently in its first Phase, led by Health Data Research UK (HDR UK) and ADR UK (Administrative

Data Research UK), will now take the dialogue's findings and recommendations forward in partnership with key stakeholders, including public representatives, to design and deliver a more joined-up, efficient and trustworthy national data research infrastructure. The report is also a useful addition to the [evidence base](#) for others who want to make sure they are handling and using sensitive data for research in a trustworthy way.

Hans-Erik G. Aronson, director of DARE UK Phase 1, says that "trustworthiness is at the core of everything DARE UK aims to achieve in the design and delivery of a more coordinated national data research infrastructure. When we speak of sensitive data, this is often data about people, and it is therefore essential that this data is stored and used in ways that people feel confident in."

"The findings of this public dialogue are vital for informing our ongoing work to improve the systems and processes supporting the use of sensitive data in research across the UK. I look forward to taking them forward to make sure DARE UK's work aligns with public expectations at every level."

Justin O'Byrne, Co-Director of Digital Research Infrastructure at UKRI, says that "building trust into our thinking has been at the heart of what UKRI has been doing for a long time, and through the UKRI Digital Research Infrastructure program—of which DARE UK Phase 1 forms a key element—we have an opportunity to build on that legacy and inform our longer term thinking in this area. We cannot take the support of the public for granted and we have to work hard to make sure we continue to be trustworthy. The findings of the DARE UK public dialogue will be valuable for helping us achieve this."

Professor Andrew Morris, director of Health Data Research UK (HDR UK), says that "to fully realize the benefits of health data research at

scale, we must create a data ecosystem that puts the public's trust at its heart and invites them to contribute to it in a meaningful way. We're pleased to see the recommendations from DARE UK's public dialogue, and look forward to seeing them taken forward to deliver a trustworthy national data research infrastructure that supports research at scale for public good."

Dr. Emma Gordon, director of ADR UK (Administrative Data Research UK), says that "DARE UK provides a crucial opportunity to reflect and consider how to draw on the strengths that exist across different research sectors and involve the public in that conversation. ADR UK is pleased to see the findings of this public dialogue, which build on the literature review on 'Trust, Security and Public Interest: Striking the Balance' we published in 2020."

More information: Full dialogue report and recommendations:
[www.dareuk.org.uk/wp-content/u ... ialogue_May-2022.pdf](http://www.dareuk.org.uk/wp-content/uploads/2022/05/DARE-UK-Dialogue-May-2022.pdf)

Provided by Health Data Research UK

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