



UK Research
and Innovation

HDRUK
Health Data Research UK



ADRUK
Data-driven change

DARE UK – Early Thinking

Demonstrating Trustworthiness workshop

Tuesday 1 March 2022

DARE UK aims to design and deliver a national data research infrastructure that is **joined-up, demonstrates trustworthiness** and supports **research at scale for public good.**



Why should the focus be on demonstrating trustworthiness?

- We know that, when making use of sensitive data in research, trust is crucial – we are talking about sensitive data about people, so people need to be able to trust their data is being used safely and appropriately
- Demonstrating trustworthiness has widely become the accepted standard when it comes to discussions around trust, rather than attempts to 'build' or 'maintain' trust
- Trust can take years or decades to build, and only a moment to lose when taken for granted

Philosopher Onora O'Neill, [TEDx 2013](#): *“Trust, in the end, is distinctive because it's given by other people. You can't rebuild what other people give you... We need to think much less about trust... much more about being trustworthy, and how you give people adequate, useful and simple evidence that you're trustworthy.”*

Draft recommendations for how to better demonstrate trustworthiness in the use of sensitive data for research

Based on:

- Our initial Landscape Review (October 2021) – involved interviews and workshops with stakeholders from across the sector
- Our Public Dialogue (final report currently in production), involving 46 members of the public from across the four UK nations
- Other recent papers and reports from across the sector
- Other conversations and discussions with stakeholders

Recommendation 1: Proactive transparency

Public dialogue has consistently found **increased understanding = increased support**. **Proactive transparency** should be practiced by those responsible for handling and using sensitive data for research

- **Actively reaching out** to the public to tell them how their data is being used and why
- Reaching out in an accessible and relatable way to different communities and groups to ensure a **diverse and inclusive** public is reached
- With a focus on **public benefit** and **security processes** in place

Recommendation 1: Proactive transparency

Broadly agreed that proactive transparency is an important distinction, and consistency is key

1. Important to decipher which channels, settings and spokespeople are effective at reaching different groups to ensure diversity and inclusion, particularly for those less digitally connected
2. Important to consider who is responsible for proactive transparency, and how researchers can be supported to promote their work so it is not over-burdensome on the research itself
3. Consistent and accessible language should be used across the sector
4. Messaging needs to be proportionate and easy to understand – the right volume of information at the right time – but should also not underestimate public understanding and shy away from presenting complex topics
5. Proactive transparency needs to start at the beginning of the data journey, from data collection right up to research outputs and impact

Recommendation 2: Public information campaign

A **public information campaign** should be conducted as a general awareness raising exercise for data research

- **Centrally coordinated** and appropriately **resourced**
- It should bring data research **into the mainstream** via channels such as newspapers, television and social media
- Reaching out to **different groups** with accessible (in both language and medium) and relatable messaging
- Development of **consistent and accessible messaging and definitions**

Recommendation 2: Public information campaign

Broadly agreed that a public information campaign would be worthwhile to raise general awareness

1. Messaging should be honest and consistent, and relatable for different audiences, with a strong focus on the benefits of data research and the safeguards in place
2. Language should be understandable and accessible, with consistent definitions
3. Approaches should be wide-ranging and innovative; different methods and messages may be needed to reach different groups
4. Consider involving the public in leading the campaign
5. A public campaign should not be rushed, and those leading it should be well prepared for objections and concerns
6. It should be centrally coordinated and align with other campaigns; will require large resource
7. Important to decipher what the call for action is

Recommendation 3: Adoption of data use registers

Data use registers should be adopted by the custodians of all types of sensitive data as a key aspect of maintaining transparency in the use of this data for research

- Including information about who has accessed what data, when and for what purpose
- In a clear and accessible format and regularly updated as and when access is granted

Recommendation 3: Adoption of data use registers

Broadly agreed that data use registers should be adopted by all data custodians, though it was acknowledged that there are challenges to achieving this

1. There should be a standardised approach to data use registers, e.g. what information they include and how often they should be reviewed, and this should be regulated
2. Registers should make research motivations explicit and be linked to research outputs, and should be understandable to a lay audience
3. A public information campaign should involve promotion of data use registers
4. Consider whether it's feasible for the location of data use registers to be centralised alongside further information about what they are and how they work
5. Could be difficult to achieve across the board, and registers could be burdensome to maintain – data custodians will need dedicated resource to ensure longevity
6. Learn from existing best practice where registers are already being maintained

Recommendation 4: A culture shift to recognise the importance of public involvement and engagement

- Public involvement and engagement should be **embedded** across the entire data research lifecycle
- The **necessary resources** should be dedicated to enable it to happen in a meaningful way
- Researchers themselves should be **trained** in public involvement and engagement best practice
- It should be **meaningful and not tokenistic**, giving those involved the time to fully understand and respond to the issues being discussed
- The public should be **involved in decision-making**

Recommendation 4: A culture shift to recognise the importance of public involvement and engagement

Broadly agreed that a culture shift is needed, and that involvement and engagement must not be tokenistic

1. There needs to be support/incentives for researchers to dedicate more time to involvement and engagement
2. The public should be involved throughout the entire data journey/research lifecycle
3. Important to establish the different ways the public want to be involved, and in which decisions
4. There should be mandatory requirements for involvement and engagement within funding applications, data access requests and accreditation processes, and these activities should then be monitored
5. Making it meaningful/avoiding tokenism is a challenge – there is a need to establish best practice for achieving this, working with the public to do so
6. More involvement and engagement training opportunities are needed for researchers
7. Consider how to make the most of digital opportunities to increase involvement, e.g. via online forums

Recommendation 5: An independent, central coordinating function for public involvement and engagement with data research

Responsible for:

- Leading the creation of a **more standardised approach** to public involvement and engagement across the whole UK data research sector
- Leading on **better understanding and documenting of public attitudes**
- Providing a central point of **information sharing and coordination** for public involvement and engagement professionals
- Developing and providing **public involvement and engagement training and resources**

Recommendation 5: An independent, central coordinating function for public involvement and engagement with data research

Generally seen as worthwhile if it fills a gap/doesn't replicate what's already in place

1. Public attitudes evolve and change, so understanding them needs to be an ongoing process
2. Important to explore and better understand variation in public attitudes, and what affects this
3. Such a function would need to be properly funded/resourced in a sustainable way
4. Provision of training for both professionals and members of the public who want to be involved is needed
5. Standardisation must avoid being too restrictive and potentially missing out some members of the public – perhaps establishing and promoting best practice is a better focus
6. A function that is cross-sector (i.e. covering the use of data related to education, welfare, health and more) could be a challenge, but an increase in cross-sector data linkage makes it important to figure out
7. Anything new should be joined-up with and learn from existing programmes, e.g. [NCCPE](#), [Involve](#), [Understanding Patient Data](#), others



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Thank you

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