Existing examples of public involvement and engagement in data research

DARE UK Public Dialogue workshops, January 2022

Overview

- No set standards for trusted research environments (TREs) – level of public involvement varies

- However, successfully securing funding for data research often relies on inclusion of public involvement and engagement (e.g. DARE UK funded projects)

Some examples of existing ways the public are involved...

Public representation on decision-making panels

- For example, to assess data research funding applications and data access requests

- Gives members of the public a direct role in the decision-making process

- **Example:** NHS Scotland Public Benefit and Privacy Panel for Health and Social Care, which assesses research applications to access NHS Scotland data

Public panels

- Fully made up of members of the public

- Consulted on issues relating to data research

- May be advisory only (no decision-making power), or be involved in both

- **Example:** SAIL Databank Consumer Panel – involved in all elements of the SAIL process, from developing ideas and advising on bids, to data access approval and dissemination of research findings

Project-specific workshops and focus groups

- More specific, e.g. to give advice to researchers on research projects

- Might involve engaging with specific communities or demographics who's data is used in the research

- **Example:** A Diabetes UK patient and public workshop held in April 2021 to discuss the privacy issues surrounding the use of personal data for research on the links between type 1 diabetes and education

TYPE 1 DIABETES AT SCHOOL & UNIVERSITY: PPI WORKSHOP

Third sector engagement

- To explore the needs and interests of specific communities or demographics

- For example via panels, workshops or meetings

- Input from those working with/for specific groups, and to reach members of the public themselves

- **Example:** Administrative Data Research UK (ADR UK) Community Representative Panels – made up of third sector representatives, practitioners and others working directly with or on behalf of particular groups

What do you think?
Discuss in your breakout rooms.