

## CASE STUDY: BETTER INVOLVEMENT AND ENGAGEMENT OF SELDOM-HEARD COMMUNITIES IN BIG DATA RESEARCH

ARC NWC Theme: Care and Health Informatics Theme (CHI)  
NHS Priority Area: Analogue to Digital

### IN SUMMARY

#### This research:

- improved understanding of public trust in big data research
- developed practical tools for inclusive public engagement
- influenced national policy and standards
- supported workforce development and training
- strengthened involvement of seldom-heard communities
- helped organisations work more ethically and inclusively with data
- presented a logic model for consideration in big data research activities to ensure improved engagement and involvement with public contributors, especially those from seldom heard communities.

It demonstrated that meaningful public involvement is not just beneficial – it is essential for responsible, trusted, and sustainable big data research.

#### Public contributor testimony :

*“I enjoyed throughout Piotr’s research journey, where I felt valued, got a better understanding of health research, built links with the community, gained confidence, experienced being working in a team, made friends, had training in literature search, coding, good communication skills and computing skills. I learned so many skills working with Piotr, which I will utilise for the rest of my life.”*

### INTRODUCTION

This project focused on how to better involve and engage the public in big data research. Big data research often uses information that has already been collected for other purposes, such as healthcare records. While this can bring major benefits, many people have concerns about how their data is reused, who controls it, and whether it is used responsibly.

The success of big data initiatives depends on public support. Improved public involvement and engagement could be a way of establishing public support for big data research.

A particular focus of public involvement should be to include seldom heard communities - sometimes also called ‘socially excluded’ or ‘hard-to-reach’ groups. Not incorporating them can make findings ungeneralisable to all parts of society and miss nuance specific to those groups. These are groups whose voices are often missing from research, policy, and decision-making. The research found that meaningful involvement of these communities improves trust, strengthens research quality, and makes research more socially responsible.

This research validated the view that public trust in the management and processes for data management is essential. People are more likely to support big data research when they feel confident that their data will be used fairly, ethically, and transparently. This trust goes beyond what is required by law – it depends on building a strong relationship between researchers and communities.

### NEW UNDERSTANDING OF PUBLIC INVOLVEMENT AND ENGAGEMENT

The research developed a new way of understanding how people can be involved in big data research, especially those from seldom-heard communities. It introduced a practical logic model that helps organisations design better public involvement and engagement strategies.

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## NEW UNDERSTANDING OF PUBLIC INVOLVEMENT AND ENGAGEMENT

This model helps researchers understand:

- what influences public trust
- what affects people's willingness to take part
- how engagement can be made more inclusive
- how to build long-term relationships with communities

The featured logic model includes interconnected sections such as:

- Context: Covers the ethical, legal, social, and public views regarding big data.
- Targeted Population: Identifies who is being engaged (e.g., specific patient groups, the general public).
- Design and Delivery of Activities: Focuses on how involvement occurs (e.g., meetings, workshops, public advisors).
- Outcomes: Measures the impact of involvement on research, such as improved trust, accountability, and better-aligned research goals.

The model helps map how public involvement can move from simple "informing" to "partnership" or "delegation" of control.

## POLICY IMPACT

The research findings directly influenced national policy and standards.

Findings have contributed towards the Public Engagement in Data Research Initiative (PEDRI) working group, which developed Good Practice Standards for Public Engagement in Data for Research and Statistics. These standards are supported by major organisations, including NHS England and Cancer Research UK.

## WORKFORCE DEVELOPMENT AND TRAINING

The research supported the development of skills, training, and inclusive practice across research and public organisations by embedding:

- Equality, Diversity and Inclusion (EDI) training featuring big data
- Patient and Public Involvement and Engagement (PPIE) training featuring big data

The findings were used in:

- national research training programmes
- workshops with public contributors and co-hosted with neighbouring ARCs
- engagement strategies for working with young people
- professional development in non-academic organisations

## COMMUNITY IMPACT

Community Impact

Public contributors were actively involved throughout the research. They received training, support, and opportunities to build new skills in:

- research methods

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### COMMUNITY IMPACT CONTINUED

- teamwork
- digital skills
- confidence building

This approach supported personal development as well as meaningful community participation in research.

### NATIONAL COLLABORATION AND SUPPORT

Support from NIHR Infrastructure made it possible to build national partnerships and collaborations, even during the COVID-19 pandemic. This funding enabled the research to take place and ensured that its impact extended beyond a single region.

### RECOGNITION

The research received national recognition, through the Research Student of the Year Award at the North West Coast Research and Innovation Awards 2023.

### LINKS

Teodorowski P, Jones E, Tahir N, Ahmed S, Rodgers SE, Frith L. Public Involvement and Engagement in [Big Data Research: Scoping Review](#). *J Particip Med*. 2024 Aug 16;16:e56673. doi: 10.2196/56673. PMID: 39150751; PMCID: PMC11364952.

LEARN MORE ABOUT ARC NWC'S IMPACT ON OUR WEBSITE HERE:

