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Co-development and Adoption of Transparency in Data Access Standards: Process, Implementation, and Impact

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Objectives

This initiative aimed to enhance transparency in health data access processes by co-developing and implementing clear standards. The goal was to improve public trust and understanding, streamline governance, and promote meaningful public involvement. The project engaged multiple stakeholders, ensuring inclusivity, accountability, and alignment with ethical and governance best practices.

Methods

The project was co-produced through a multi-stakeholder collaboration involving HDR UK's Public Advisory Board and the Pan-UK Data Governance Steering Group. It began with an assessment of transparency issues in data access procedures across the (UK Health Data Research) Alliance. Findings informed the co-development of Transparency Standards, published in 2023. The Alliance then facilitated the implementation of these standards by funding 19 projects to enable real-world application and evaluation. The initiative incorporated public involvement at every stage, ensuring that the standards addressed key concerns around accessibility, governance, and ethical data use while fostering alignment with national data governance frameworks.

Results

The adoption of the standards has led to improvements in accessibility and consistency of data access processes. The funded projects demonstrated (a) improved clarity in application procedures, (b) enhanced public trust through inclusive decision-making, (c) increased engagement with data custodians, and (d) expanded capacity-building opportunities. Data custodians implementing the standards improved their governance frameworks, providing clearer information on data access and ethical considerations. Additionally, the initiative fostered a culture of transparency, with participating organisations publicly sharing information on data access requests and decisions. A dedicated event was held to explore the experiences and impacts of implementing the standards, featuring

poster presentations and the publication of abstracts in a peer-reviewed journal.

Conclusion

This initiative advanced transparency in health data governance by co-developing and implementing standards and funding projects that have improved accessibility, public trust, and engagement. By integrating public perspectives, this project has set a strong precedent for inclusive research practices. However, more work is needed to ensure ongoing adoption and sustainability.



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