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Embedding Public Voices in Data Governance: Insights from the GUARDS Principles Consultation

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Objectives

This project explored public perspectives on the GUARDS Principles, an overarching governance framework for the population data research community, which builds on existing good practice guidance. It evaluated the principles' clarity, relevance, and impact on public trust in the use of data for research, promoting transparency and ethical practices.

Methods

A survey, co-developed with HDR UK's Public Advisory Board, was conducted from 17 June to 1 July 2024 among HDR UK Voices members, a network committed to shaping health data research. 50 participants assessed the six GUARDS Principles—Guided, Understandable, Aligned, Responsible, Deliver, and Stewardship—rating their agreement with each principle's importance on a scale (strongly agree to strongly disagree) and providing qualitative feedback on their reasoning, clarity of language and suggestions for improvement. Respondents received a £25 honorarium. Findings were synthesised to highlight strengths and areas for refinement, ensuring the principles reflect public values and expectations in data governance.

Results

Survey findings showed strong public support for the GUARDS Principles, underscoring their importance in promoting transparency, inclusivity, and trust in data governance. While the principles were generally well understood, participants suggested simplifying language, outlining actionable implementation steps, and improving mechanisms for accountability and public engagement. Respondents also called for clearer definitions of 'public benefit' and emphasised the importance of independent and representative stewardship. These insights informed refinements to the principles, ensuring they align with public expectations whilst complementing existing good practices for safe and secure data access as outlined in the Five Safes framework.

Conclusion

Public consultation on the GUARDS Principles highlighted the importance of public involvement in data governance. Findings reinforce the need for transparency, inclusive frameworks, and actionable measures. Refining the principles will ensure ethical research practices, enhance data accessibility, and foster public trust, improving the responsible use of data for public benefit.

