

International Journal of Population Data Science

Journal Website: www.ijpds.org



A holistic implementation of the Alliance Transparency Standards: Demystifying research governance and sensitive data processing

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Background

To promote transparency for both the public and researchers [1, 2], our objective was to implement all HDRUK Transparency Standards within the Grampian Data Safe Haven (DaSH) [3] website [4]. Particularly, we aimed to clarify sensitive data processing within our Trusted Research Environment (TRE) and improve accessibility of ethics and governance permissions procedures to facilitate public-benefit research.

Methods

Utilising Knowledge Translation [5] and Implementation Science [6] methods, we identified relevant audiences to engage with the website to develop and evaluate digital content. A holistic approach to navigation, content creation and visuality was implemented to improve user experience for diverse audiences [7], leveraging plain language strategies [8] for understanding and transparency.

Results

We addressed Standard 1 by publishing the DaSH Project Initiation Document and clear information on data processing. For Standards 3, 4 and 5, we enhanced user experience through streamlined navigation, dropdowns, signposting, and clear language, ensuring information remains appropriate for diverse audiences. Additionally, we established a quarterly review/update cycle. For Standard 6, we documented our Governance and Security structures alongside ISO27001 certification, a Data Use Register, and an Impact list of DaSH-supported research publications. Our most significant contribution was toward Standard 2, creating detailed permissions pathways guidance documents, including visual aids and permissions application checklists. To our knowledge, we are the first UK TRE to fully document and publish all available permissions pathways [9].

Lessons Learnt

There were three main lessons learnt. (1) A four-month timescale for website redesign incorporating new content, and multi-audience feedback, could prove overly ambitious without a strong procurement team, dedicated staff, and established audience connections. (2) Content management systems may be a significantly limiting component, impacting both visual appeal and the audiences' preferred access (e.g. mobile). Implementing certain recommendations (e.g. Data Use Register; Database register), can lead to potentially dense pages and visually cluttered tabular information that are difficult to navigate. (3) Publishing audit findings or information about breaches presents a communication challenge. The potential exists for misinterpretations of legal, technical, or classification terms, which could erode public trust, even with transparency as the aim.

Conclusions

First, implementing the six HDRUK Transparency Standards simultaneously enables holistic improvements to openness, maximising the benefits of their complementary recommendations. Second, publishing project lifecycle information clarifies TRE and researcher responsibilities, especially during data extraction, pseudonymisation, and linkage stages [10], fostering trust and confidence in sensitive data use and processing. Third, by documenting ethics and governance pathways available in visual, text, and downloadable formats, we have demonstrably improved ethical and research literacy for both researchers and the public. By clearly articulating an easy-to-follow process for each permissions pathway, this initiative has been identified by our audience as the most impactful improvement in making sensitive data research transparent and accessible.

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