

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



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Objectives

- To implement all six Transparency Standards to the Grampian Data Safe Haven (DaSH) website in collaboration with multiple audiences.
- To improve transparency about ethics and governance requirements for and data processing of unconsented health and social care data provided for research to deliver public benefit.

Methods

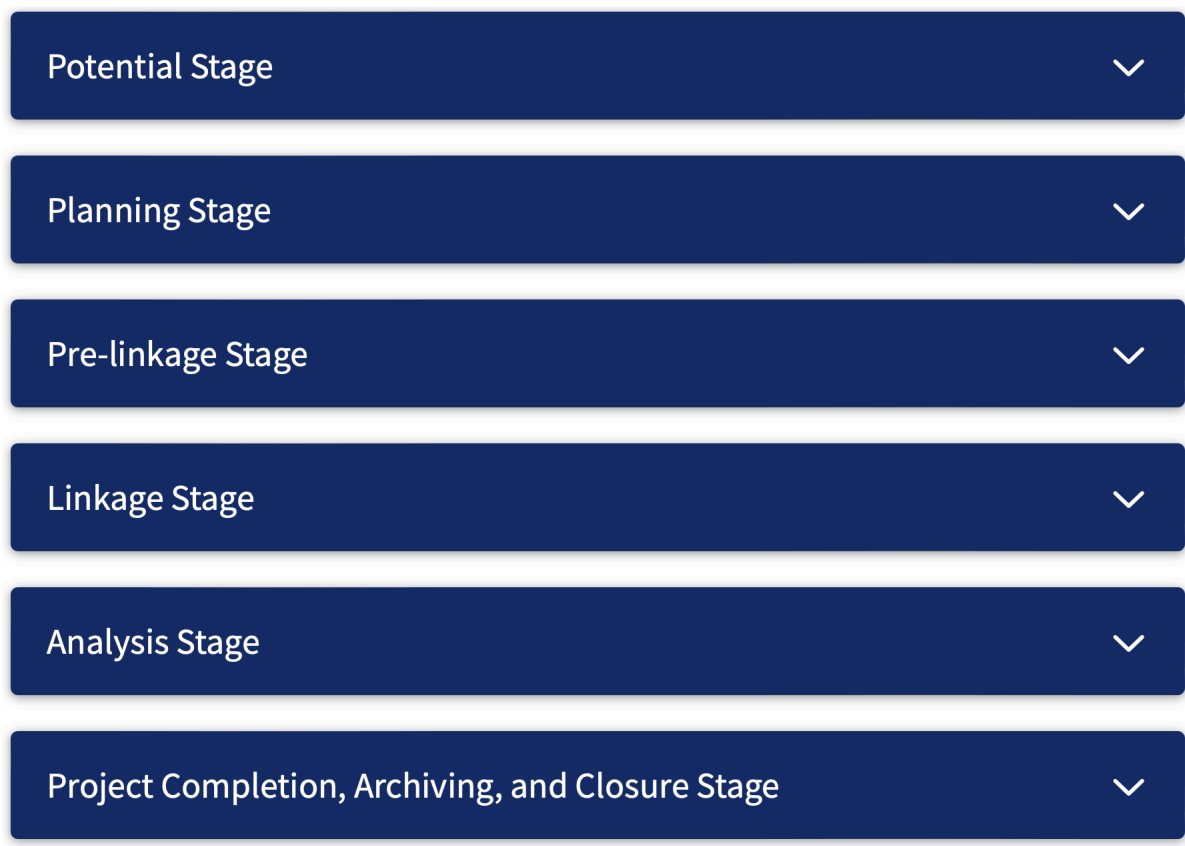
- Applying Knowledge Translation (KT) [1] and Implementation Science (IS) [2] frameworks, we identified relevant audiences that would engage with the website to develop and evaluate digital content.
- Holistic approach across navigation, text and visuality to improve user experience. Plain language strategies [3] were applied to increase clarity, openness and accessibility for multiple audiences to increase understandability and access [4].

Results

STANDARD 1

Open Access Application Form and Guidance:

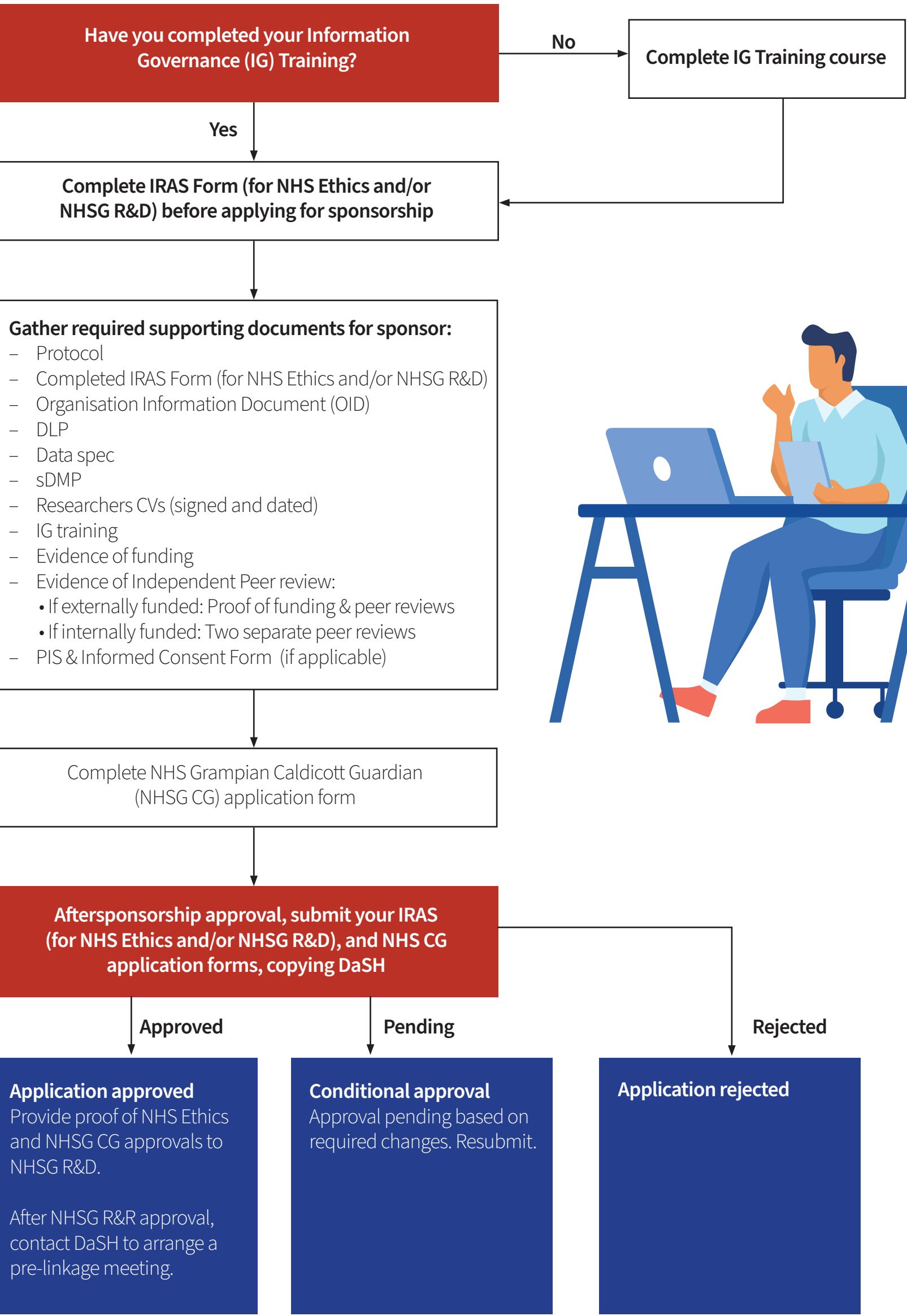
- DaSH Project Initiation Document made available on website, along with clear information about project stages and data processing.



STANDARD 2

Transparent Application Process and Criteria:

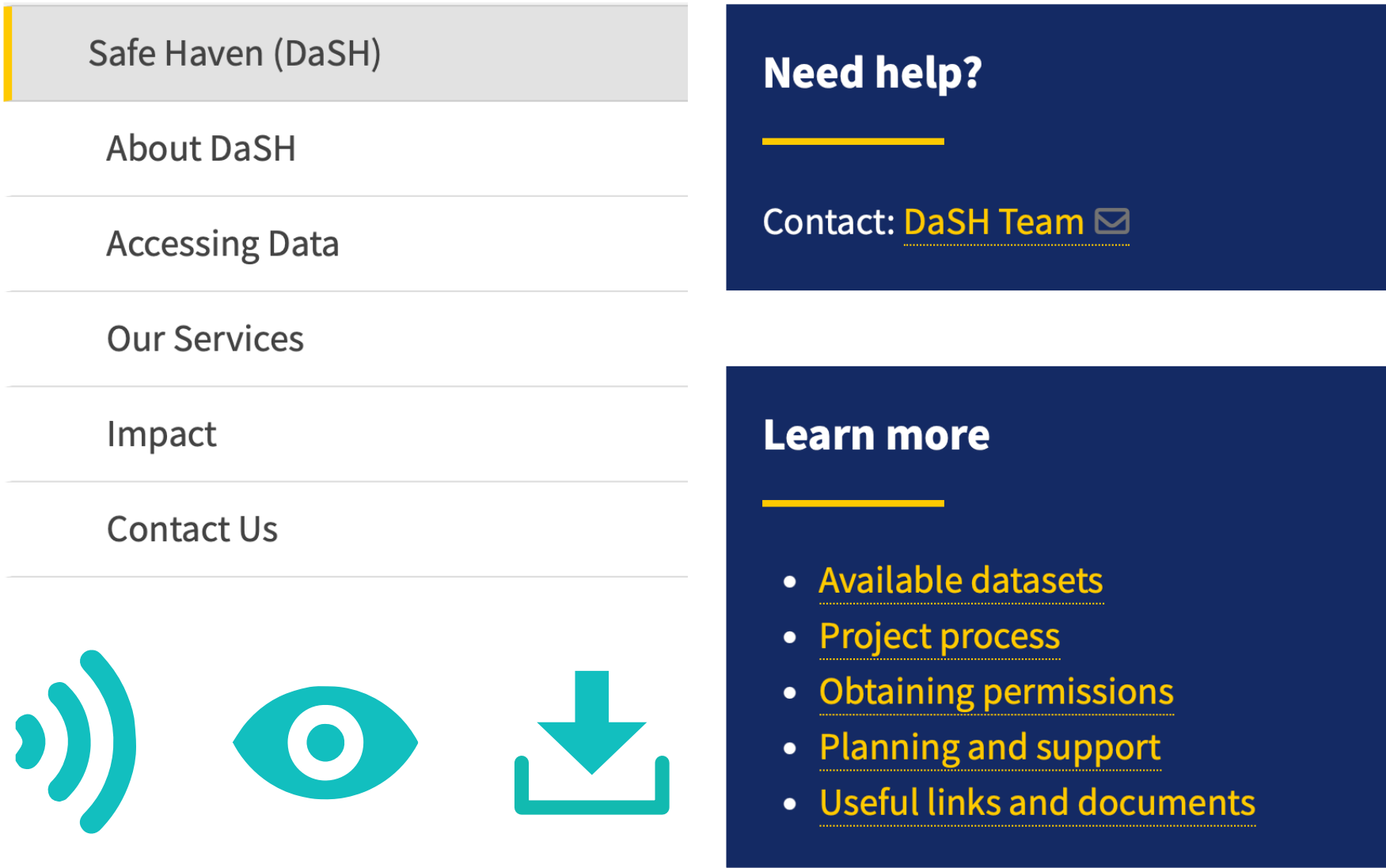
- Detailed permissions pathways guidance provided, researcher checklist provided, visual swimlanes of guidance created.



STANDARD 3

Clear Website Navigation:

- Streamlined user experience and navigation making information easily accessible, including dropdown menus and signposting boxes to easily identify key information, next steps and downloadable documents.



STANDARD 4

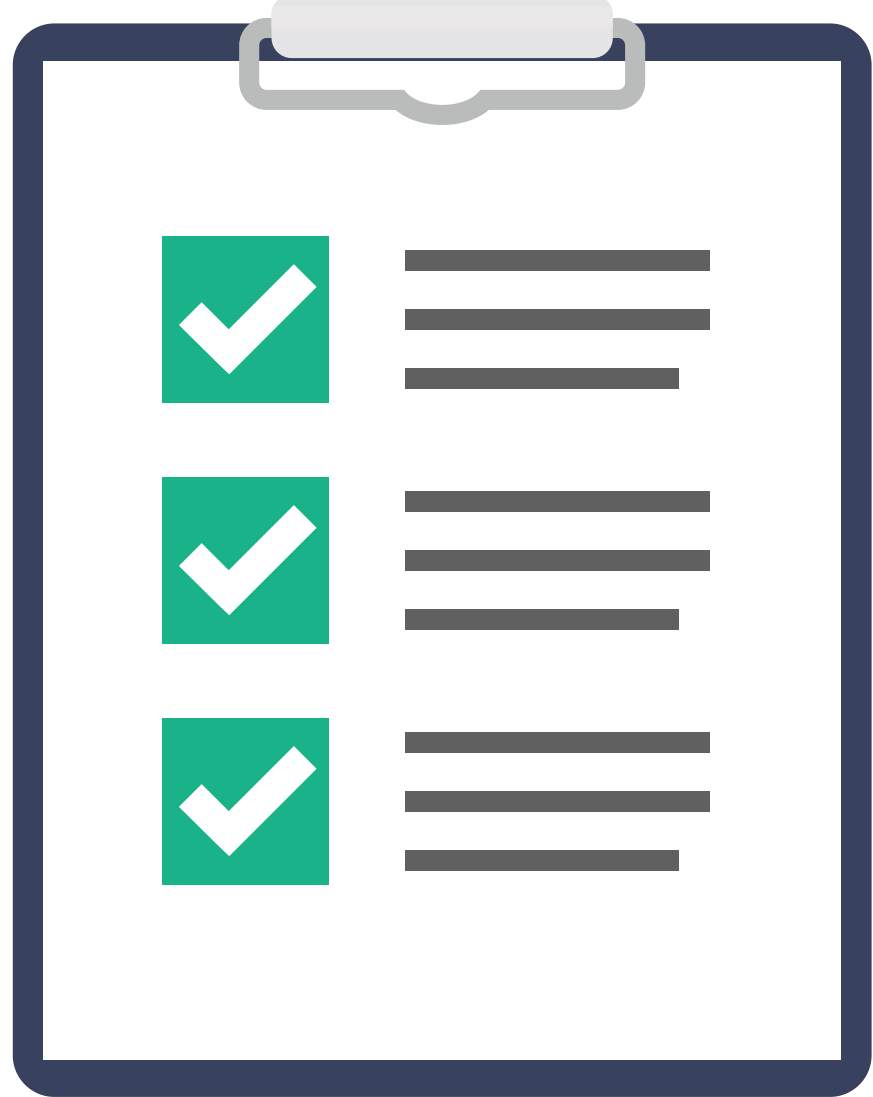
Target audience:

- Target multiple audiences (researcher, public) simultaneously while maintaining information clarity. Audiences provided feedback to improve comprehension and accessibility.

STANDARD 5

Regular Review of Website Content:

- Established quarterly review tasks for Dataset register, Data Use Register; Impact, downloadable document version updates and content expansion.



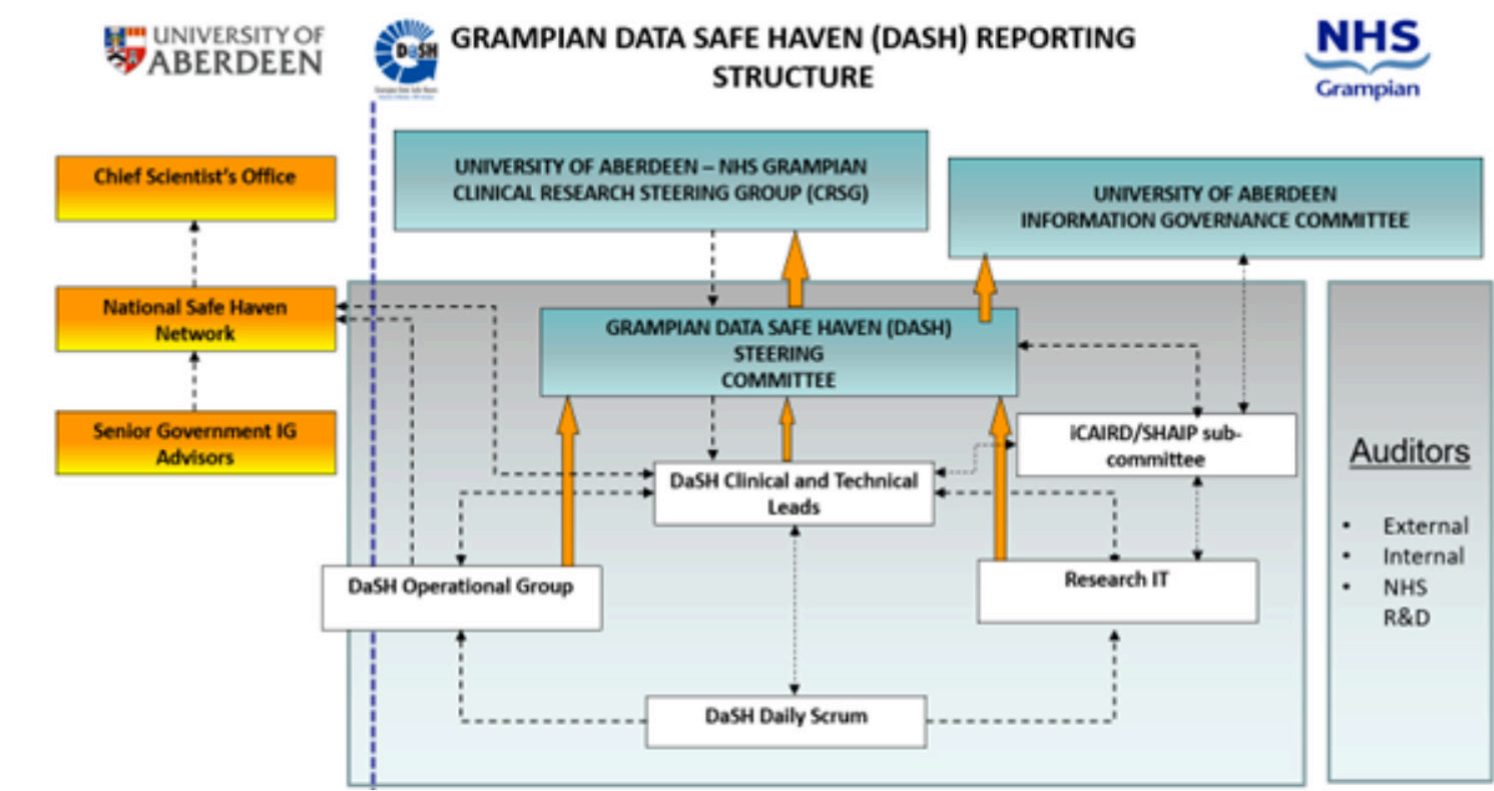
STANDARD 6

Transparency of Data Use and Auditing:

- Information about DaSH Steering Committee, membership, governance and security (covering security incident/breach reporting processes); and audit (ISO27001) information published.
- Data Use Register and Impact of research and benefit to public published.

Governance and Security

The relationship between the DaSH Steering Committee and wider Research Governance structures both locally and nationally demonstrates the wider regulatory and compliance context that DaSH operates within. Information Security requirements are one aspect of this environment; compliance with research ethics and data protection legislation are also necessary.



Lessons learnt

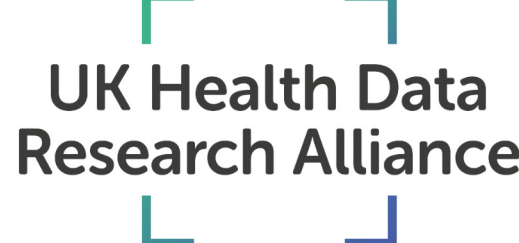
- 4-month timescale can be unrealistic to redesign a website.
- Web content management system may be a significantly limiting component, impacting both visual appeal and where audiences are mobile-first.
- Breach or audit findings are more challenging to implement and could potentially erode public trust even if they meet Transparency principles.

Benefits

- Publishing ethics and governance pathways in multiple formats improves ethical and research literacy for both researchers and the public.
- Documenting the project lifecycle promotes clarity on researcher and trusted research environment responsibilities to ensure adherence to the Five Safes Framework.
- Implementing the six Transparency Standards simultaneously enables holistic improvements, and fully engages with openness and transparency principles.

References

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