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Improving transparency in data access processes: Developing best practice standards and promoting system-wide change through a competitive funding call

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Abstract

Introduction
Transparency in the use of data for research benefits the public and researchers by fostering trust and enabling efficient data sharing. Public support for access to their data for research depends on robust data security, the absence of conflicting interests, and a clear demonstration of public benefit, all of which must be evident through transparent practices. A lack of clarity in data access processes can delay research, highlighting the need for clear and streamlined approval procedures. To maintain what is often referred to as a 'social license to operate', organisations must meet and uphold societal expectations, with transparency being a key dimension of that responsibility.

Objective
To develop and foster adoption of a set of transparency standards for the data science community, supporting trustworthy and streamlined data use for health and socio-economic research and planning.

Methods
A multi-stakeholder deliberation was undertaken, informed by two reviews of existing data access procedures across participating organisations. Stakeholders included healthcare and research organisations, data custodians, regulators, industry representatives, academic experts, and members of the public.

Results
The review and deliberation identified missed opportunities to inform and involve the public in data access procedures, along with inconsistencies in data access processes and supporting materials across the organisations. In response, we developed the Transparency Standards, comprising 28 recommended actions grouped into four themes: provision of clear data access guidance; clear website navigation designed to meet the needs of public and research users; regular review and iterative improvement of processes; and reporting of data access outcomes and information security findings. A targeted funding call facilitated the adoption of standards in 19 organisations, resulting in reusable transparency materials and transferable knowledge to support wider implementation.

Conclusion
The Transparency Standards support data custodians in strengthening openness and accountability in data access processes, helping to build public trust while simplifying procedures for researchers. Their broad adoption demonstrates a shared commitment to the ethical use of data. However, varying levels of implementation point to the need for continued investment to sustain progress and respond to public and researcher expectations.

Keywords
transparency; social licence; patient and public involvement and engagement [PPIE]; trusted research environment [TRE]; secure data environment [SDE]; data safe haven [DSH]; five safes; FAIR; CARE; data access; UK health data research alliance; alliance; Pan-UK data governance steering group

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Introduction

Data access processes can be unclear, difficult to find, and hard to interpret. This creates challenges for researchers, who may struggle to apply for access to data, and for the public, who may lack information about the criteria researchers must meet to access sensitive data for research. Well-communicated procedures for requesting access to data and explaining data governance can significantly impact the public and the researcher community, though in different ways. For the public, transparent data access processes foster trust by ensuring that their interests and values are respected [1, 2]. For researchers, transparency provides clarity on application and approval processes, leading to efficient and timely data access and discovery sharing. However, efforts to promote transparency have been inconsistent and rarely meets the needs of either group.

Although public attitudes towards data access for health research are complex, there is widespread support for data-intensive research under certain conditions [3, 4]. These conditions include proven competence in data security, mechanisms to de-identify data, absence of conflicting private interests [1, 5], and clear benefits to patients and the wider public [6]. Additionally, participation must be non-exploitative, voluntary, and aligned with the public good [2]. Therefore, data stewards have a responsibility to meet these societal expectations, extending beyond compliance with law and governance regulations – a concept known as the 'social license to operate' [2, 7]. In some areas there are additional requirements to uphold the social licence, such as longitudinal consented studies which have long-term responsibilities to maintain transparency of data use [8], and where commercial organisations are involved, the purposes and justification for data access must be well communicated. [9]. One way to address these issues is to publish data access mechanisms, decision-making criteria, and outcomes of data access requests, supporting the conditions necessary for public trust. Fulfilling these responsibilities requires both action at the individual organisational level and coordinated, system-wide efforts to build and sustain public trust.

The benefits of using data for research are well-documented, from disease surveillance to the initiation of clinical trials with appropriate participants. However, these benefits are often delayed by legal complexities, a lack of transparency in the requirements for data access [2, 10, 11], and multiple approval mechanisms from various data custodians, which increase administrative burden and delay data access [12]. These barriers, shaped by legal requirements and their interpretation, organisational strategies, and political contexts [12], contribute to inefficiencies and missed research opportunities. This underscores the need for more transparent and inclusive data access processes, with clear criteria, decision-making steps, outcomes, and timelines [13]. Greater transparency not only encourages the need to streamline procedures but also aligns research with public interests and values [1, 2], encouraging greater trust in the system.

In response to this evidence, key stakeholders, including the UK Health Data Research Alliance (the 'Alliance') [14], Health Data Research UK's (HDR UK's) Public Advisory Board (PAB) [15], and the Alliance's Pan-UK Data Governance Steering Group (the 'Steering Group') [16], collaborated to develop and launch a set of Transparency Standards designed for widespread adoption across the sector.

This paper outlines the development of the Transparency Standards, documents their implementation through a dedicated funding call, and shares insights gained from the process. It also highlights the importance of public involvement and the need for further refinement to ensure ongoing improvements and broader adoption.

Methods

Stakeholders involved

The Alliance is a partnership of over 100 leading healthcare and research organisations, including the National Health Service, academia, regulators, and industry bodies. As a subgroup of this partnership, the Steering Group [16] aims to facilitate harmonised and transparent data governance for trustworthy data science across the UK. It does so by delivering programmes of work on priority areas, sharing best practice, and facilitating the development and adoption of common standards.

The Steering Group has convened the 'Five Safes Action Force' to promote the practical implementation of the 'Five Safes' framework [17] among data custodians. This framework enables organisations to evaluate whether data use can be deemed "safe" by carefully weighing a range of relevant contextual factors [18]. The Action Force is tasked with delivering system-wide tools and infrastructure enhancements to encourage trustworthy data use and to support upholding a social licence for population data science.

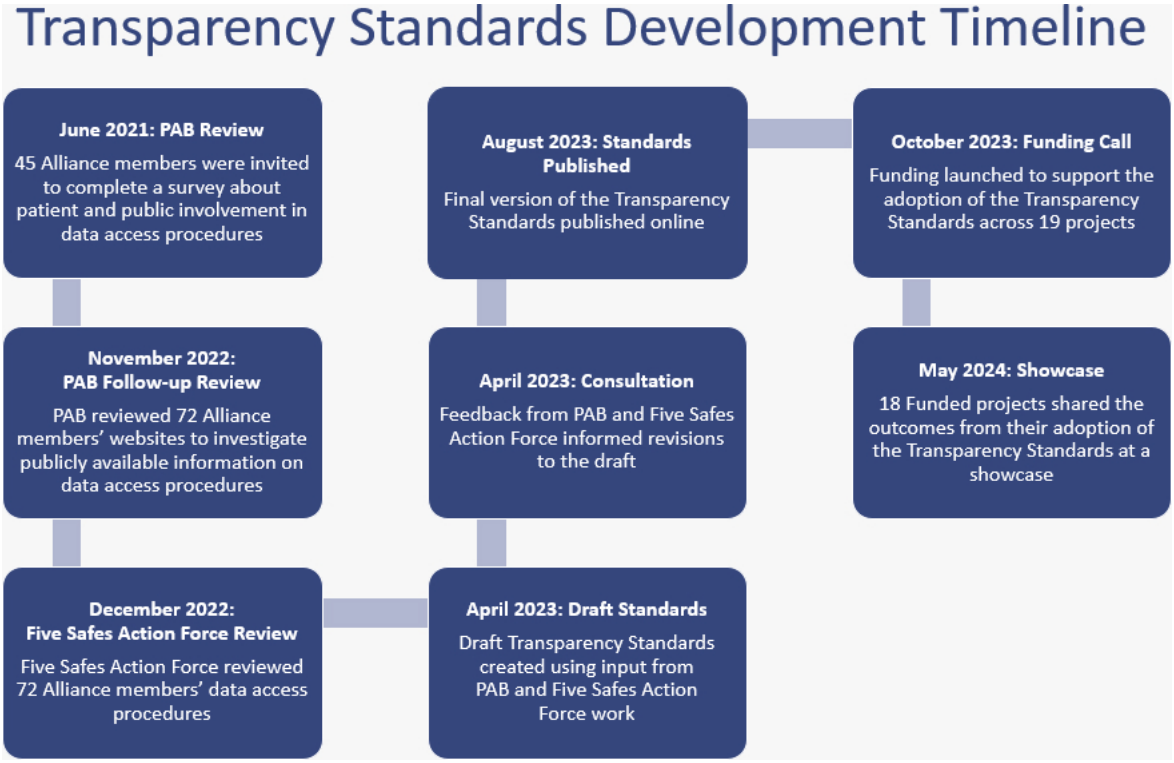
The PAB [15] is a diverse group of public members, appointed for a 2-year term, who serve in an advisory capacity within the governance structure of HDR UK. The PAB meet on a monthly basis and are reimbursed for their time according to HDR UK's Honoraria and Expenses Policy. They provide valuable insights into public perceptions surrounding health data, its access and use in research. They play a key role in offering both strategic and operational support to HDR UK, ensuring that patients and the public remain central to HDR UK's mission and work.

Figure 1 provides an overview of the deliberation process, which was carried out with the involvement of the stakeholders outlined above and is further detailed in the following sections.

Review of existing data access procedures by the Public Advisory Board

In June 2021, members of the PAB invited all 45 Alliance member organisations to complete a survey about patient and public involvement in reviewing data access requests and monitoring data use and outcomes [19]. The survey focused on three main areas: (i) data custodian access processes and decision-making criteria; (ii) public involvement in Secure Data Environment (SDE) data governance; and (iii) transparency of outputs arising from approved research. In November 2022, the PAB conducted a follow-up review of the data access information available on the websites of all the Alliance members which had increased to 72 by that time. This assessed how clear and understandable the language

Figure 1: Transparency standards development timeline



was [20]. Findings from these exercises (summarised in the Results section) were shared with the Alliance and the Steering Group, and they were published online [19, 20].

Review of existing data access procedures by the Five Safes Action Force

Between October and December 2022, the Five Safes Action Force reviewed the clarity of 72 Alliance members' public-facing information on data access processes, including (i) the accessibility and transparency of the application process, including whether a data access application form was readily available; (ii) whether the standardised data access form developed by the Alliance was being used [21, 22]; and (iii) whether all aspects of the Five Safes framework were respected in the data access process. Findings (summarised in the Results section) were presented to the wider Steering Group to help identify barriers and enablers to transparency and suggest ways to drive improvement.

Transparency Standards development and adoption through a funding call

Building on these efforts, the Steering Group recommended developing a set of Transparency Standards. PAB members welcomed this proposal and chose to contribute to the process. In April 2023, PAB reviewed an initial draft to ensure it aligned with findings from their earlier review, identify any necessary changes, and assess the clarity of the language. Feedback from this session informed a revised version, which was reviewed again by both groups before the final version was published in August 2023 [23].

An overview of the Transparency Standards is provided in Table 1. A detailed description of each standard, including how

Table 1: Overview of transparency standards

Standard	What it covers
1 Open access application form and guidance	Ensure data access forms and guidance are publicly available and understandable
2 Transparent application process and criteria	Explain each step of the application process, criteria, and public involvement
3 Clear website navigation	Help users find relevant access information quickly and easily
4 Audience-focused content and language	Use accessible language for researchers and the public, with dedicated content for each group.
5 Regular website content reviews	Commit to keeping website content accurate, up to date, and helpful.
6 Transparency of data use and auditing	Share how data is used, decisions made, and lessons learned, including audit outcomes.

it addresses specific gaps and supports greater transparency, is provided in Table 3.

Following publication, HDR UK sought support from the Medical Research Council (MRC) to launch a funding call offering grants of up to £15,000 to successful organisations to support adoption of the standards [24]. Each project was expected to implement one or more of the Transparency Standards.

Eligible applicants included organisations that provide access to their datasets for research purposes and were either existing Alliance members or those working towards becoming one. Applications were evaluated against specific criteria, including prior efforts to improve transparency for data access in their respective organisations, public engagement initiatives, and clarity of information published on their data access processes [25]. Reviewers from HDR UK and the PAB assigned a score (0, 3, 7 or 10) to each project based on these criteria, as well as on project plans, alignment with the standards, number of recommendations addressed, feasibility of completion by 31st March 2024, and appropriate use of funds [25]. A detailed plan on how the organisation would complete the project and utilise the funding was requested along with a high-level proposed budget.

Successful applicants were notified in late October 2023 and were asked to present a brief report on implementation of the standards in the form of a poster [25] for presentation at the Alliance Transparency Showcase in May 2024. There was also an opportunity to publish the posters and abstracts in the International Journal of Population Data Science (IJPDS) [26].

Results

Findings from the Public Advisory Board's review

The 2021 survey conducted by PAB members revealed missed opportunities to inform and involve the public regarding policies on health data access and use, as well as inconsistencies in how data access requests were handled and reported [19]. For example, less than half (9 out of 22 respondents) had public representatives as members of the Data Access Committee. Only half (11 of 22) provided clear lay-accessible criteria for data access decision making. Just eight organisations provided links to their data use registers, and around half were able to provide policies for audit, monitoring and sanctions for data misuse.

A follow-up discussion of the findings among PAB members underscored the critical importance of clearly communicating the conditions under which sensitive data is made available to researchers. Consequently, the group undertook a review of Alliance member organisations' public websites to assess their accessibility (i.e., how easy was it to find the information?) and the clarity of their content for non-technical audiences (i.e., is the clarity of language used accessible?). This assessment, conducted in 2022, revealed several additional shortcomings, including a lack of user-friendly language, frequent use of academic jargon, and lack of clarity about the involvement of patients and the public in data access processes. Websites were hard to navigate, sometimes out of date, and not designed with a public audience in mind [27].

As a result, PAB developed an initial set of core and enhanced standards to inform good practices in communication of data access processes [28], including exemplar cases (Table 2).

Findings from the Five Safes Action Force's review

The review conducted in 2022 by the Five Safes Action Force found that Alliance members' websites lacked clear and easily accessible information on data access processes. In particular, information was fragmented and did not direct researchers or public members to their respective areas of interest. Of the websites reviewed between October and December 2022, approximately 80% did not provide a downloadable open access application form or detailed information about how data applications were assessed. A comprehensive list of available datasets for research and linkage was not always apparent or clear. When linkage was offered, the websites were not often clear on how this would be achieved or whether additional approvals were required. Websites were hard to navigate and many failed to include a list of previously approved projects. Many lacked up-to-date UK General Data Protection Regulation compliant privacy notice information and some still referred to expired Health Services (Control of Patient Information) notices.

Transparency standards

Findings from the reviews described above helped establish a set of principles for transparency. Data access procedures and outputs should be open, clear, and understandable to all stakeholders, particularly the public. These principles go beyond merely sharing information; they require that the information be easily accessible, presented in straightforward language, relevant to diverse audiences, and regularly updated for accuracy.

These principles, along with content already developed by the PAB (Table 2), and consultations with both the PAB and the Five Safes Action Force conducted between April and July 2023, contributed to the creation of the Transparency Standards (Table 3). These Standards were published online and introduced to a broader audience through a blog published in August 2023 [23, 29].

The Transparency Standards (Table 3) provide practical guidance to improve transparency in the access and use of data for research. They begin with core requirements for data access (Standards 1 and 2), such as the availability of application forms and associated guidance, and set expectations for how this information should be presented to all stakeholders (e.g., researchers, public members and information governance leads). The Standards also highlight the importance of tailoring language, content, and format to suit specific audiences (Standards 3 and 4), and they call for regular updates and review cycles to ensure information remains accessible and relevant (Standard 5). In addition, they encourage clear communication of data access approval processes, publication of a list of approved studies, and

Table 2: Clear communication on data access procedures standards

Topics	How to ensure clear communications	Some good examples
Core standards		
Making the information clear and comprehensible	Involve lay people in writing and checking all materials intended for the public to ensure that the web design and its contents is comprehensible and accessible.	Use of plain English https://www.pioneerdatahub.co.uk/about/partnering-with-patients/
Making the information readily accessible and easy to navigate	Make it clear on the home page where relevant information about data security and access can be found on the site.	Use of clear navigation https://www.pioneerdatahub.co.uk/about/partnering-with-patients/
Purpose of data research and potential for public benefit	Studies have repeatedly found that people want and expect their data to be used for public benefit purposes only, so the benefits should be made clear.	Videos on purpose and benefits https://ourfuturehealth.org.uk/research-programme/ https://ukllc.ac.uk/the-public/
Data sources and how data are used	Information about what data is held, how it was obtained, and how it will be used is a necessary requirement.	Description of data sources and security processes https://www.insight.hdrhub.org/about-your-data Diagrams of data flows https://cprd.com/safeguarding-patient-data
Criteria for granting access	The criteria that must be met before data is made available to researchers is central to public interest in how their data are used.	Video and text explaining the Five Safes https://dataloch.org/data/data-securityhttps://dataloch.org/data/data-security
Finding out about approved studies, results and publications	Lists of approved studies and, where possible, the outputs of these should be publicly available and accessible.	Data use registers https://ukllc.ac.uk/how-we-use-your-data/ https://bioresource.nihr.ac.uk/using-our-bioresource/
Enhanced standards		
Who is responsible for data governance and security	How the organisation is structured and who is responsible for dealing with data access requests is potentially useful information for the public.	Description of governance structure with diagrams https://ourfuturehealth.org.uk/about-us/

Continued

Table 2: Continued

Topics	How to ensure clear communications	Some good examples
How data access requests are dealt with	Our previous report recommended that data access requests should be reviewed by independent data access committees with clearly explained procedures. To be truly transparent minutes of committee deliberations should be published and available on data controllers' websites.	Video covering many aspects of data access https://www.pioneerdatahub.co.uk/about/partnering-with-patients/ Minutes of data access committee meetings https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/independent-group-advising-on-the-release-of-data/meetings
Who reviews data access requests	Involvement of members of the public in data access committees helps to build trust, so providing names and biographical details is good practice.	Names and bios of data access committee members https://www.insight.hdrhub.org/data-trust-advisory-board
How conditions of data use are monitored and actions taken when breaches are detected	Information about how data use and compliance with contractual obligations is audited and sanctions that are applied if breaches are detected is of interest to some members of the public.	Data use audits https://cprd.com/data-use-audits

articulation of the public benefit resulting from those studies (Standard 6).

Adoption of the Transparency Standards through a funding call

A total of 23 organisations applied for funding, of which 19 were successful (Table 3). The organisations funded are listed in Table 4, along with information about which Transparency Standards each one addressed. For clarity, the organisations are grouped according to the Alliance membership categories: Academic Centres, Charities, Healthcare Providers, Research Data Services, and Public and/or Patient Advocacy Groups.

All funded projects apart from one adopted more than one standard and addressed multiple recommendations within each standard (Table 4). It was noted by some projects that the process of applying the standards in a real-world setting provided important feedback which could lead to iterative evolution of the standards. For example, the University of Aberdeen project enhancing the Grampian Data Safe Haven (DaSH) website (Table 4) decided not to develop a separate website section targeting the public (as recommended in the standard) and instead used plain language suited for a lay audience across all web content for the benefit of both the public and research users.

All projects involved patient and public involvement in implementing each standard. This was achieved through mechanisms such as consultations with the public on existing data access information, systematic involvement of public members and researchers in creating and reviewing data access information and embedding public members in data access review panels. Some organisations collaborated with internal patient and public advisory groups to create materials that enhance stakeholders' understanding of the lawful use of data for research.

Twelve projects committed to regularly reviewing and updating the content created, regardless of the main standard adopted. Review periods ranged from 3-6 months to annually, or as needed based on feedback. Activities included uploading case studies or Data Use Registers (DUR), reviewing forms, developing guidance, updating web content, and inclusion of research summaries/abstracts.

Fourteen projects adopted Standard 6 (Table 3), implementing it by collating and improving the visibility of summaries of approved studies. Thirteen of the fourteen projects published committee decisions on their websites, including, in some cases, types of projects approved, and decisions to deny access. Two projects specifically mentioned use of Alliance DUR templates [30].

The work required to adopt and implement some standards often overlapped, allowing projects to address relevant recommendations from multiple standards. For instance, reviewing website content, forms, and guidance related to the access process often incorporated elements of Standards 1, 2, 3, and 4 (Table 3) and implementing these meant that websites had to be adjusted to accommodate and increase transparency. All projects adopted Standards 3 and 4 (Table 3) to improve navigation, language, structure and content for researchers and public members. They aimed to make web pages more interactive and engaging, tailoring content and structure to the target audience to improve user experience and search engine optimisation, guided by focus groups consisting of researchers, members of the public and advisory panels.

Anecdotal feedback highlighted the importance of funding to enable dedicated staff time to focus on the project and specific deliverables. Some organisations hired short-term contractors or allocated staff time to lead content production, create infographics, manage projects, and develop websites. This enabled them to run focus groups, review content and identify areas for improvement. Additionally, they conducted user experience testing and analysed how users search their systems to identify content gaps for researchers, patients, and the public.

Discussion

Our reviews identified numerous shortcomings in the transparency of data access processes, decision-making, and subsequent use of data. To address these challenges, we adopted a multi-stakeholder deliberative approach to develop generalisable Transparency Standards for data access and use. This approach drew on contributions from a broad range of stakeholders across the UK, including the NHS, health research institutions, national statistical agencies, and research organisations of varying sizes and remits, operating at national, regional, and devolved levels. The active involvement of a public advisory group—who contributed meaningfully and held leadership roles throughout—further strengthened both the development and credibility of these Standards.

The Transparency Standards outlined in Table 3 offer a clear set of publicly co-developed principles for data custodians to adopt. They aim to promote streamlined, trustworthy, and accessible information about data access across various organisations. A key reason to promote these Standards is to ensure consistency in communicating information about data access, use and public benefit. This consistency enables key information to be presented in a predictable, comparable, and accessible manner, which is critical for enabling public understanding, supporting accountability, driving research outputs, and building trust. Without a consistent application, transparency efforts risk becoming fragmented or ad hoc, potentially undermining their effectiveness and the public's confidence in data stewardship.

A recurrent theme across the different projects adopting the Transparency Standards was the central role of public contributors in each initiative. All awardees developed and updated materials for both members of the public and researchers, aiming to ensure public representation in data access processes and to embed mechanisms for public scrutiny throughout the administration, review, and approval of applications. By involving public members at every stage, organisations not only improved the quality of their outputs, but also began to shift their ways of working—a change reflected in findings presented at the showcase [26]. This approach fosters accountability, both in operational practices and in engagement with the public.

The specific focus on Standard 6 (Table 3), related to data use and auditing, including the creation of lay summaries and the publication of decisions, demonstrates a proactive approach to accountability. By sharing the outcomes of

Table 3: Transparency standards and related recommendations**

Standard 1: Open access application form and guidance	
Custodians should have a copy of the data access application form and accompanying guidance notes on their website which are openly available.	• Publish the data access application form that can be accessed without the need for registration or any other additional requirements. • Publish guidance notes, including details as to why the information in the form is being requested (e.g. for compliance with national standards or legislation), as well as examples of completed forms, including successful or unsuccessful submissions.
Standard 2: Transparent application process and criteria	
Custodians should provide clear information on every step of the data access process, including the criteria for granting access and how members of the public are involved in the process.	• Clearly set out each step in the data access process in a transparent format with appropriate structure and language (e.g., through diagrams, videos, animations, swim lane diagrams or process flows) understandable to both researchers and the public, indicating timescales for each step where possible and defining where responsibility lies. • Provide clear guidance notes and requirements for the application process. • Include a description on the website on how the data access process incorporates the Five Safes Framework and explain what this means in a transparent way. • Explain how applications are assessed, including how members of the public are involved in assessing applications and in developing the criteria used to assess applications. • Terminology for secure data platforms, such as Trusted Research Environment (TRE), Secure Data Environment (SDE), and Data Safe Haven (DSH), varies across data custodians despite describing similar systems for managing sensitive data. In the absence of standardised terms, clear definitions should be provided.
Standard 3: Clear website navigation	
Information about data access processes should be easily discoverable and comprehensive.	• Ensure information about the data access process is easy to locate and clearly communicated from the homepage. If including it directly on the homepage is not feasible, use clear signposting, such as drop-down menus, to guide users to the relevant information. Include clear information about how public benefit is assessed. • Have separate website sections for information about clinical trials and for the re-use of data in research (where applicable). • Where the data custodian supports different types of data access with distinct processes (e.g., service improvement versus research), have separate sections of the website with the required information. • For linked data sets with multiple controllers, provide clear and detailed information on requirements for data access, with a clear pathway setting out what the researcher should expect in terms of approvals, timescales, access, and information about the role of relevant data controllers.
Standard 4: Audience-focused content and language	
Website should use appropriate language for the audience and should include content specifically developed for members of the public in readily understandable terms.	• Consider accessibility when creating website content to suit different audiences. • Consider having separate website sections for researchers and members of the public, in each case using appropriate language for the target audience. • Involve researchers, information governance professionals and members of the public in writing and checking of all materials to ensure that the web design and its contents are accurate, accessible, and transparent. • Provide a mechanism for members of the public and researchers to provide feedback on the language, structure, and content. • Consider how to provide information in an appropriate language to members of the public who may not have access to the internet.

Continued

Table 3: Continued

Standard 5: Regular website content reviews	
Website content should be periodically reviewed and updated as appropriate.	• Commit to regular review cycles, for example every six or twelve months, to assess and update website content, ensuring the information remains accurate, current, and aligned with operational and policy changes. • Where there are downloadable application forms and guidance notes, custodians should include the last review date and the next review date to ensure researchers, and the public know they have the current version. • Have a "frequently asked questions" section and or equivalent on the website and keep this regularly updated.
Standard 6: Transparency of data use and auditing	

Custodians should be transparent about how data is used for research.	• Publish a summary of approved studies/protocols (lay summary, technical summary, public benefit etc) and resulting research outputs for full transparency within 3 months of approval. Where data controllers set precedents, these should be openly shared to drive continuous improvement across the sector and to encourage consistency of decision-making.
	• Publish minutes and/or core decisions made in Data Access Committee meetings (noting that redaction of sensitive information may be appropriate).
	• Publish case studies each year, particularly those that highlight public benefit and examples of how lives are improved by use of data for research.
	• Publish a data use register that is updated at regular intervals.
	• Publish decisions on data access requests that have been rejected, with consideration for the level of detail that is appropriate to share publicly (e.g., it may not be appropriate to publish names of organisations or researchers). Publishing the reason why certain types of requests are rejected may give the public reassurance that standards are being upheld and encourage consistency of decision making. The reasons do not have to be sensitive or give details around a specific researcher; they could be summaries such as data sensitivity, type of organisation requesting access, public perspective, etc.
	• Consider publishing how changes in areas such as governance, transparency, regulation, access mechanisms, and data or technology issues have affected certain projects, to show how these improvements support better use of data endorsed by the public.
	• Publish an up-to-date and clear privacy notice in compliance with data protection legislation.
	• Publish:
	  ◦ A short summary of audit findings and sanctions that are applied if breaches are detected (noting that redaction of sensitive information may be appropriate).
	  ◦ A general overview of the number and type of sanctions that have been applied and some examples or case studies illustrating how to improve on these.

*Please note that the content of this table has been updated from the original version used in the funding call to reflect recent feedback and improve clarity and accessibility.

data access decisions and the real-world impact of research, organisations reinforce their dedication to ethical data use and to delivering value for the public. This transparency is essential for building trust and ensuring that data research continues to reflect and respect societal values.

Beyond supporting accountability, the Transparency Standards can help maintain the social license to operate with the public. Social license represents the ongoing approval and trust of the public, which is essential for organisations handling sensitive data. Earning and sustaining this licence requires transparent practices, meaningful public involvement, and a clear demonstration of public benefit. By embedding these principles into data governance through the Transparency Standards, organisations can better align with public expectations and sustain the trust needed to operate responsibly.

Resource limitations were recognised as a barrier to adoption. We found that relatively small financial awards

Table 4: Awarded organisations categorised by the type, how much was awarded for the project and the standard adopted

Awarded organisation	Organisation type*	Value of award	Standard addressed*	Reference
HSC Business Services Organisation – Honest Broker Service (HSCNI)	National agency/ public body	15, 000	1, 2, 3, 4, 5, 6	HSC Honest Broker Service, Applying the Health Data Research UK Transparency Guidelines in Northern Ireland – International Journal of Population Data Science (ijpds.org)
University College London (ECHILD)	Non-Alliance member	15, 000	1, 2, 3, 4, 5, 6	Implementing Transparency Standards: The ECHILD Project in Action | International Journal of Population Data Science (ijpds.org)
SAIL Databank (Swansea University Medical School)	Research Data service	6, 456	1, 2, 3, 5	An audio-visual resource to improve transparency in SAIL Databank's data access process. – International Journal of Population Data Science (ijpds.org)
UK Cystic Fibrosis Registry, Cystic Fibrosis Trust	Charity/ social enterprise, Research funder	15, 000	1, 2, 3, 4, 5, 6	UK Cystic Fibrosis Registry Website Enhancements: A User-Centred Approach to the Data Access Transparency – International Journal of Population Data Science (ijpds.org)
Healthcare Quality Improvement Partnership (HQIP)	Charity/ social enterprise, programme investment	14, 987	1, 2, 3, 4	Developing meaningful public involvement in HQIP's data access processes and Data Access Request Group (DARG) – International Journal of Population Data Science (ijpds.org)
UCL- MRC Unit – Lifelong Health and Ageing	Academic Centre, Cohort/ biobank	14, 062	1, 2, 3, 4, 5, 6	Skylark Wiki: Accessing research data of the MRC National Survey of Health and Development – International Journal of Population Data Science (ijpds.org)
Royal Marsden NHS Foundation Trust	Healthcare Provider	1, 000	1, 2, 3, 4, 5, 6	The Royal Marsden BRIDgE TRE Transparency Project | International Journal of Population Data Science (ijpds.org)
Manchester University NHS Foundation Trust	Healthcare Provider	15, 133	1, 2, 3, 4, 5, 6	Improving Transparency of NHS Trust uses of data for Research Purposes | International Journal of Population Data Science (ijpds.org)
Imperial College Healthcare NHS Trust ICHT iCARE	Healthcare Provider	14, 963	2, 3, 4, 5, 6	Enhancing Transparency, Awareness, Accessibility of Healthcare Data Access for Research: the iCARE website redesign project | International Journal of Population Data Science (ijpds.org)
Generation Scotland – University of Edinburgh	Cohort/ biobanks	14,976	1, 2, 3, 4, 5, 6	Generation Scotland – Transparency in the data access process | International Journal of Population Data Science (ijpds.org)
South London and Maudsley NHS Foundation Trust	Healthcare Provider	6, 597	1, 2, 3, 4	Lay review of the South London and Maudsley NHS Foundation Trust's (SLaM) Clinical Records Interactive Search (CRIS) system website to better meet UK Heath Data Research Alliance Transparency Standards. | International Journal of Population Data Science (ijpds.org)
UK Longitudinal Linkage Collaboration (UK LLC)	Research Data service	12, 365	4	Understanding Longitudinal Population Study Data and the Law | International Journal of Population Data Science (ijpds.org)
"Cambridge University Hospitals NHS Foundation Trust and NIHR-Cambridge Biomedical Research Centre"	Healthcare Provider	11, 500	1, 2, 3, 4, 5, 6	**
DATAMIND The Health Data Research Hub for Mental Health	Research Data service	14, 626	1, 2, 3, 4, 5, 6	Improving transparency of longitudinal health research: glossary, infographic and accessible study summaries | International Journal of Population Data Science
University of Aberdeen – Grampian Data Safe Haven (DaSH)	Research Data Service	14, 513	1, 2, 3, 4, 5, 6	A holistic implementation of the Alliance Transparency Standards: Demystifying research governance and sensitive data processing – International Journal of Population Data Science (ijpds.org)

Continued

Table 4: Continued

Awarded organisation	Organisation type*	Value of award	Standard addressed*	Reference
Research Data Scotland	Cohort/ Biobank, Research Data service	14, 000	2, 4,	Transparency Animations: Trusted Research Environments, Data Linkage and Synthetic Data – International Journal of Population Data Science (ijpds.org)
Intensive Care National Audit and Research Centre (ICNARC)	Charity/ social enterprise, Research Data service	14, 996	1, 2, 4, 6	Improving transparency of processes for accessing ICNARC data for research purposes | International Journal of Population Data Science (ijpds.org)
Optimum Patient Care Limited	Charity/ social enterprise	15, 000	2, 4, 6,	Enhancing Transparency in Optimum Patient Care Research Database Access Procedures: A Multifaceted Approach Addressing Improvements in Transparency Standards | International Journal of Population Data Science (ijpds.org)
Our Future Health	Cohort/ Biobank	15, 000	1, 2, 3, 4, 5, 6	***

*There are recommendations within each headline standard and organisations were not expected to adopt all aspect of a specific standard for their project.
**Organisations did not participate in the provision of a poster and or abstract for the Alliance Transparency Standards Showcase.
***Organisations provided a poster not for publication on the IJPDS journal.

enabled rapid transparency improvements and fostered innovation in developing transparency materials [26]. The strong response to the funding call demonstrated significant demand for these standards, with implementation showing such improvements can be achieved quickly across diverse organisations.

However, this one-off funding call could not assess the sustainability of improvements or whether it fostered a cultural shift toward prioritising transparency in the design of websites and other public-facing media and materials. While relatively small amounts of funding and short deadline generated significant interest, such resources are not consistently available. Given the importance of transparency and trust for sustaining public engagement with data, ongoing funding opportunities and periodic review are crucial. The latter would allow standards to evolve, incorporating lessons from initiatives like the Grampian project, which demonstrated benefits of lay-oriented website content.

The funding was restricted to UK-based data custodians operating SDEs, predominantly well-resourced infrastructures. Nevertheless, we believe the standards and lessons from their implementation in the UK context has relevance to the international context.

A key limitation to the funding call was the five-month delivery timeframe, which influenced review criteria and restricted applicants to those with fully developed plans. This tight schedule also introduced scientific constraints, as exemplified by one project's inability to obtain ethics approval for public involvement within the period [31].

While these constraints highlight important implementation challenges, the demonstrated appetite for transparency improvements—evidenced by the response to funding calls and rapid organisational adoption—suggests substantial potential for broader uptake. The project revealed that while flexibility in interpreting the Transparency Standards fostered innovation and context-specific solutions, it also underscored the value of supplementary approaches to strengthen standardisation. Periodic collaborative reviews among organisations could further refine transparency materials, share best practices, and streamline data access protocols. System-wide accreditation requirements for SDEs (e.g., the system administered by the UK Statistics Authority), coupled with independent audits, may also promote alignment without compromising adaptability

The successes achieved within tight timeframes confirm both the feasibility of such interventions and the returns on investing in transparency infrastructure. These findings provide a foundation for advancing data governance practices nationally, and potentially internationally, particularly through initiatives that combine sustained funding with structured opportunities for iterative improvement and cross-institutional learning.

Conclusion

The development and implementation of the Transparency Standards across various organisations has led to significant advancements in creating more open, accountable, and inclusive data access processes. Their broad adoption reflects a shared commitment among academia, healthcare providers, and other stakeholders to align with regulatory and public expectations. However, varying levels of adoption of the standards across different organisations highlights the challenges of achieving uniformity, suggesting potential value in formalising these standards within regulatory frameworks to drive continued improvements.

The role of collaboration cannot be overstated. The Alliance and Steering Group have already laid the groundwork for collective progress, but sustaining momentum will require structured mechanisms—periodic reviews to track adoption, shared platforms for refining transparency materials, and perhaps most critically, the formal inclusion of the public in the design of SDEs and broader data-sharing infrastructures. This proactive embedding of transparency, rather than treating it as a 'tick-box exercise', could catalyse the cultural shift

needed to move beyond compliance and toward genuine accountability.

Looking ahead, it will be important to establish clear metrics to evaluate the effectiveness of the Transparency Standards and guide improvements over time. Measuring adherence and progress could include monitoring the frequency and quality of updates to data-sharing practices, the extent of stakeholder engagement, and the impact of transparency on research outcomes. Additionally, assessing the potential benefits, such as increased trust, better collaboration, and improved public involvement, may help demonstrate the full value of the Transparency Standards. These evaluation efforts may help build the evidence base needed to justify sustained funding and wider implementation.

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Statement on conflicts of interest

None declared.

Ethics statement

This paper reports no original population data and is therefore exempt from ethical review.

Data availability statement

No new data were created or analysed in this study. For further information about the materials supporting the findings, please contact the authors: Yemi Macaulay (yemi.macaulay@hdruk.ac.uk) or Ester Bellavia (ester.bellavia@hdruk.ac.uk).

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