Data Access and Discovery

Improving transparency in the use of health data for research: Recommendations for a data use register standard

14/02/2022 | Paola Quattroni & Nada Karrar, HDR UK
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We are the national institute for health data science.

Our mission is to unite the UK’s health data to enable discoveries that improve people’s lives.
Working in partnership with patients, the NHS, universities, business & charities to create a world-leading and robust health data infrastructure

We are an independent legal entity, a charity, with 86 organisations across 32 locations in the UK, working in partnership to deliver core platform, interoperability, standards, governance and metadata dictionaries.

Uniting health data
By convening community of custodians and researchers

Improving health data
By working in partnership to provide services to researchers

Using health data
By enabling data science and innovation
The **UK Health Data Research Alliance** is an independent alliance of leading healthcare and research organisations united to establish best practice for the ethical use of UK health data for research at scale.
The Alliance approach to convening community, developing and implementing standards

CONVENE:
Engage with patients and public, data custodians, researchers and funders to develop recommendations for a standard

e.g. More than 100 people and 50 organisations contributed to development of a data use register standard

DEVELOP:
Publication and refinement of the standard

e.g. Trusted Research Environments, Data standards

IMPLEMENT:
Implementation of the standard by Alliance member organisations

Establishe best practice for the ethical use of UK health data for research at scale

Implementation via the Innovation Gateway, a portal for data discovery and access
A data use register is a list of approved projects or a public record of data an organisation has shared with other organisations and for what purpose.

The challenge we face is that this information is not always made public. As well as, lack of consistency or standardisation when it comes to the content, functionality and purpose of these registers.
What do we want to achieve?

• By establishing a core set of standards on data use registers, we hope to
  • increase transparency in the use of health data for research and innovation – Alliance members also agree to transparency of governance and operations when the signing the Letter of Intent
  • demonstrate the value and benefit of using health data - National Data Guardian and Understanding Patient Data highlight that ‘transparency cannot be separated from public benefit’
  • develop a culture of openness amongst data custodians
  • generate better insight into data use and data access
  • build public trust and advocacy for data use

“Being clear how data is used a vital step to ensure the whole process is meaningful and trusted, in terms of outcomes, cost effectiveness and public trust.”
- Public contributor-
The public perspective

We call on senior leaders within Alliance organisations to acknowledge the importance of patient/public involvement in data access processes and take a lead on this. Specifically to:

✓ Enable public involvement in all data access procedures, both researcher and custodian work.

✓ Standardise data access processes, as far as possible based on the Five Safes model.

✓ Demonstrate transparency in data access and use through a publicly available register, in line with the principles and recommendations set out above. Purpose for data use is key.

✓ Establish an Alliance forum to encourage shared learning across organisations, drawing on the views and experiences of patient/public members involved in existing approval processes.

What have we done so far?

Widespread community involvement and engagement:
• Collaborative approach with input from public and lay representatives, data custodians, researchers, policy makers and funders (more than 100 people and 50 orgs contributed to the standard)

Preprint analyses published in May 2021:
• Analysis conducted on 48 data custodians (reviewing content, format, update frequency and accessibility of data use registers)
• Key takeaway: nearly 50% of data custodians reviewed do not publish information about data use

Public consultation on green paper recommendations in July 2021
• Green Paper has been downloaded 1,263 times
• Recommendations were supported by 93% of respondents

Publication of White Paper on data use register standard in Jan 2022
• Recommendations presenting a minimum standard for data use registers

Development of a Gateway data use register underway
• To provide transparency of data uses approved for datasets published on the Innovation Gateway, a portal for data discovery and access

Data use register standards white paper https://doi.org/10.5281/zenodo.5902743
What have we recommended in the standard?

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<td><strong>Recommendation 1:</strong> Transparency</td>
<td>All data custodians and controllers responsible for the collection, storage and sharing of data for the purpose of research, innovation and service evaluation should <em>publish and actively promote a public record (data use register) of approved research studies</em>, projects and other data uses.</td>
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<td><strong>Recommendation 2:</strong> Frequency</td>
<td>Data use registers should, as far as possible, be <em>populated in near real time</em> directly from information provided through the Data Access Request process to improve timeliness and accuracy of entries.</td>
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<td><strong>Recommendation 3:</strong> Format</td>
<td>Data use registers should be made available in both <em>human-readable and machine-readable formats</em>.</td>
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<td><strong>Recommendation 4:</strong> Content</td>
<td>Data use registers should have a <em>consistency of format and content based on the Five Safes framework</em> and an agreed specification to enable ease of understanding and aggregation of registers.</td>
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<td><strong>Recommendation 5:</strong> Link to outputs</td>
<td>Researchers, data custodians and funders should use data use registers to close the loop on the impact of data use by including, where possible, <em>links to research findings and other outputs</em> as these become available.</td>
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What is the added value of these recommendations?

Confidence, reliability, trust in the data/information accuracy and authenticity

- Alignment to the **Five Safes Framework***
- Data custodians can demonstrate that access is only granted to appropriately qualified individuals, in secure settings, and for purposes with a clear legal and ethical basis that serves the public interest.

Demonstrating impact of research: linking data use to research outputs

Recognised by many of our contributors as an ambitious target but essential step in demonstrating impact and value of data use

Requires a system wide effort involving researchers, data custodians, funders, and regulators.

Data use registers can help researchers and data custodians demonstrate trustworthy access to and use of data by being transparent about the purpose of research and the impact on public benefit

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*<https://www2.uwe.ac.uk/faculties/bbs/Documents/1601.pdf>
Office for National Statistics
Guest speakers

Angela Coulter
Chair of HDR UK Public Advisory Board

Victoria Yorke-Edwards
Research Fellow in Trial Conduct Methodology, MRC Clinical Trials Unit at UCL

https://www.hdruk.ac.uk/people/angela-coulter/

Twitter: @VickiYE
https://www.mrcctu.ucl.ac.uk/
Related resources and upcoming events

Useful links:

• Read our White Paper on a data use register standard: https://zenodo.org/record/5902743#.YgOz0urP1Pa

• Read the preprint: Analysis of data use registers: https://www.medrxiv.org/content/10.1101/2021.05.25.21257785v1.article-metrics

• Access the Health Data Research Innovation Gateway: https://www.healthdatagateway.org/

• Learn more about our work on improving transparency in data use: https://ukhealthdata.org/projects/improving-transparency-in-data-use/

Hear more from us:

• Signup to our monthly Gateway Newsletter: https://www.hdruk.ac.uk/access-to-health-data/health-data-research-innovation-gateway/

• Follow HDR UK on Twitter: @HDR_UK https://twitter.com/HDR_UK

• Contact Ruth: ruth.milne@hdruk.ac.uk

• Next Data and Discovery Event: Thursday 14 April https://www.eventbrite.co.uk/e/265211363327
Data Access & Discovery

11:00 - 11:45
Thursday, 14 April 2022

#HealthDataGateway
Thank you