UK Health Data Research Alliance

Improving Access to Linked Data for Research

Workshop Summary – 19th October 2022

On 19th October 2022, The Alliance hosted the second workshop on 'Improving access to linked data for research', chaired by Meredith Leston (Nuffield Department of Primary Care Health Sciences, University of Oxford), following on from an informative session summarised here. Key stakeholders were brought together from the health data ecosystem to address several recommendations highlighted in the previous workshop. In particular, this session focused on the need to better understand and streamline the data access processes and data access agreements. The aims of this session were:

1. To identify opportunities for unlocking the potential linkages of consented and routinely collected health data.
2. To map data access processes and identify areas for streamlining.
3. To understand the landscape surrounding data access agreements.

59 representatives from the health-related sector, including research groups, regulators, custodians, and clinicians attended the meeting. The session was opened by Dr Tony Calland, Chair of the Confidentiality Advisory Board (CAG) at the Health Research Authority (HRA), who outlined the role and purpose of CAG, the importance of managing confidential patient data, how to understand the legal basis, common law and GDPR. He also provided useful information and tips to applicants interested to submit applications to CAG.

This was followed by Edel McNamara, Data Protection and Information Governance Lead (Global) and Rachel Brophy, Information and Research Governance Manager at HDR UK, who presented and led breakout sessions on data access processes and data access agreements respectively. They both highlighted work driven by the pan-UK Data Governance Steering Group, a working group of the Alliance representing data custodians and policymakers across the four nations. The Steering Group is focused on simplifying and streamlining data access governance processes.

All presentations from the 'Improving Access to Linked Data for Research' workshop can be found in 'outputs' on the Alliance website.

Below, we outline the key elements of this workshop and the insights, discussions and recommendations for change that emerged from each session.

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Mapping data access processes: The ‘tube map’ of data access

One of the ‘Action Forces’ set up by the pan-UK Governance Steering Group is about mapping data governance processes currently used by data custodians to provide access to data to identify areas of commonalities and opportunities for streamlining. In this session, a visual ‘tube map’ of processes by some major custodians was presented. The map endeavours to illustrate all ethics and governance approvals needed to link health and admin data across the four nations allowing the researchers navigating the process, and the steering group, to visualize the steps in the access process and the interplay between different types of approvals.

An overview of the main discussion points highlighted during breakout sessions is shown below.

Feedback on the map format

- The ‘tube map’ was well received and considered an accessible way to visualise the steps applicants need to go through to access data.
- It was considered a very helpful way to represent all four nations on one page.
- It was also highlighted that the ‘tube map’ already shows the complexities of accessing data and adding more data custodians might show additional differences in processes.
- It was suggested that this map could be part of a toolkit with interactive links to guidance for applicants

Participants also suggested including in the ‘tube map’ the timelines of how long each step is likely to take, relevant security and governance policies related to each nation (e.g. NHS-D DSPT) and guidance from HRA.

Encouraging transparency in data access processes

- Workshop participants suggested that use cases and guidance based on 'real-world' exemplars would be helpful to improve understanding of data access processes.
- Having information upfront, visible, and accessible is very important.
- Transparency of processes and clarity around requirements are important first steps.
- It would be helpful to have a single place where information about data access processes is collated.
- The ‘tube map’ is a good start to building this type of resource.
- The map of data access processes could be a good tool to identify consistencies across organisations.
- It could be helpful to drive harmonisation of processes, e.g. around researcher accreditation.

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Data Access Agreements: a landscape review

The TRE Legal Toolkit Action Force is another sub-group of the pan-UK Data Governance Steering Group. The purpose of this group is to clearly define roles and responsibilities between data custodians, data processors and researchers, as well as to produce a standardised template data access agreement, data sharing agreement and data protection impact assessment (DPIA). This work will potentially benefit researchers by enabling them to fill out a single DPIA form rather than several, speed up contracting within universities and research institutions and provide access to a transparent and easy-to-understand toolkit for all parties involved.
The toolkit will contain four main components: a template data depositing agreement (DDA), data access agreement (DAA), DPIA and associated guidance for all. This will be heavily influenced and steered by comprehensive patient and public involvement and engagement (PPIE), and a cross-custodian collaboration.
An overview of the main discussion points highlighted in this session is shown below.

General feedback on the TRE Legal Toolkit

- The idea of creating a template concept is good, but there is a need to understand buy-in from organisations and how easy or difficult it is to adopt templates.
- It would be helpful to include a standardised glossary in the toolkit.
- It was suggested that standardised tripartite agreements across academia, NHS trusts and large national TREs would also be useful.
- The toolkit should include realistic timelines to help users understand roughly how long the processing may take.
- Participants also suggested that example contracts from joint research organisations (academic/research institutions) would provide clarity around data existing in a TRE rather than with the academic institution.

Potential for the TRE Legal Toolkit to help speed up the contracting process?

- There is an urgent need for standardised templates which could help to underpin trust and trustworthiness.
- Standardised agreements should provide clarity and remove ambiguity amongst researchers, ultimately speeding up the process.
- Workshop participants acknowledged that this is a good opportunity to develop a standard template and that the Alliance could drive adoption of this template.
- The Alliance could facilitate engagement with data custodians to help design and establish the template in standard practice and to ensure buy-in from data-sharing organisations.

Additional considerations

- Data custodian approval is very important.

- Cross-sector and cross-national discussions are essential.
- Having standardised agreements would be useful, especially when engaging with partners who don't have legal teams as it would provide better assurance.
- This will need to align with its technical equivalents (specifications of TRE capabilities and processes) -- it's ultimately all about risk management and that must be holistic.
- Understanding templates that are used in other aspects of health research and the buy-in they currently have from organisations, will be important in helping understand what may need to be done in terms of engagement.

Conclusions and next steps

This was the second of this workshop series on 'Improving access to linked data for research' where we discussed issues around difficulties accessing routinely collected and consented data and proposed opportunities for change. We discussed the importance of communicating the positive value of using this data and the need of being able to use data that participants would like us to use for research and innovation. We also explored the intricacies around inconsistent data access processes across the UK and received feedback on solutions proposed such as the 'tube map' and the TRE Legal toolkit.

As ethical issues and consent were important aspects highlighted by community discussions, we will now convene a third working session to discuss and understand more the type of consent and what researchers should consider when using previously consented data to link to routinely collected data.

Following this third and final workshop, we aim to consolidate input in an opinion paper to be presented at one of the next Alliance Board meetings.