

Pan-UK Data Governance Steering Group

24 February 2023

Chairs: Cassie Smith and Andy Boyd

Summary of Key Discussion Points

Introduction

- Introductory comments reflected on the progress over the last ten months and the group's continued focus on solving the challenges in data access and the opportunities to streamline governance processes on a Pan-UK basis. The Chairs thanked everyone, especially the members of the public, for their hard work and commitment to a clear consensus and urgent action on data access governance.
- At the Frontiers Meeting, Sir Ian Diamond and Prof Andrew Morris had challenged the group to deliver action in the next 100-days, this meeting will present the progress on this challenge. It was noted that the Actions Forces have been the mechanism to take forward the work of this group and to produce tangible outputs.

Transparency in Data Access

- Members of the Health Data Research Alliance (Alliance) are committed to being transparent about how their data sets are accessed and used.
- As a follow-up to the 2021 report by HDR UK's Public Advisory Board (PAB) on public involvement in data access processes, the PAB has investigated how well these processes are currently being communicated to a wider public. Angela Coulter (public contributor, former chair of PAB) presented the results of the transparency survey and the PAB's subsequent recommendations.
- HDR UK presented results of a deeper analysis, building on the work of the PAB, into how findable, accessible and transparent data access processes are, including public availability of application forms for data.
- The results showed many Alliance members did not have clear, accessible information available on their websites about data access and there was an impression that the public audience was not always considered when designing the pages.
- The PAB report has made some specific recommendations which advise on a transparency minimum standard and more advanced options to enhance trust and transparency. In summary, information should be clear and comprehensive, involve lay persons and a clear public benefit should be shown.
- It was noted that transparency is key before we can streamline data access processes across custodians.
- The group discussed the complexity; data access processes often have layers of complex procedures behind them, opening up and providing clarity on these processes is essential. It is important to have transparency in all aspects including data access processes, uses of data, registers of breaches etc.
- It was noted that different audiences need to be catered to, researchers and the public have different levels of understanding and requirements.
- The group acknowledged the challenges on this including a lack of consistency in questions being asked, historic use of complex legal language, difficulty accessing application forms, and interoperability with other systems. Transparency is more than just publication and details need to be in an accessible plain English format. There is also a need for consistency of information e.g. a standardised framework for lay summaries, there is so much variation in processes.

- **Next steps** for this group include working through the Alliance to encourage adoption of the transparency recommendations.

Streamlined Governance Models

- Members of the Alliance have signed up to the Principles of Participation, which include commitments to working towards harmonised governance and to meaningful public and patient involvement and engagement (PPIE). The Pan-UK Data Governance Steering Group is supporting the Alliance in delivering these commitments.
- Andy Boyd presented a proposed extension to the Alliance Principles of Participation to set out in more detail how we propose to:
 - Achieve fair, open, authoritative and inclusive public communication
 - Promote privacy, data security and a system of accreditation of TREs/ SDES
 - Streamline data access governance processes with meaningful PPIE
- The group discussed how can we galvanise around a set of core principles that are built as community. An academic article could help articulate this.
- The group noted that there is no common lexicon of terms, this is needed to ensure all parties (data custodians, regulators, researchers and the public) have a shared view.
- The groups noted the importance of PPIE being embedded into the design of processes. This can be challenging with some aspects of process e.g. large number of applications so we need to ensure the right people and processes are in place.
- Transparency needs to be balanced with efficiency and done so in a practical and affordable manner. Consideration is needed on whether these are proportionate, acceptable, inclusive of our broad needs and agendas. Additionally, there is a need to be clear on the principles and to have a public facing version.
- The discussion highlighted need for clarity on roles and responsibilities, the expectations of data custodians, and demonstrating expectations have been met. Additionally, we should explore the role of funders and other stakeholders that need to be included in this discussion.
- A library of good practice could help lower the burden on users however this needs to be managed carefully to avoid a copy and paste mentality.
- It was noted that engagement with the ICO may be beneficial.

Next steps: The Chairs to lead the action to prepare an academic article.

Update on Action Forces

- Edel McNamara presented on the progress of the “Data Access Tube Map” and gave a demonstration of the companion tool to this.
 - **Next steps** include focus groups (public members and researchers) as well as another Action Force meeting to discuss dissemination of the map and tool.
- Rachel Brophy highlighted the progress of the TRE Legal Toolkit Action Force.
- The group has developed a Data Access Agreement specific to data access in TREs/SDEs, mapped against the Fives Safes Framework and built on a common set of data access principles developed by the Action Force.
- This group has worked collaboratively with a contract’s subgroup, a patient and public group, and has also had commercial input.

Open Forum

- An open forum enabled attendees to raise hot topics and emerging issues.
- HDRUK's Public Advisory Board have requested case studies on data minimisation.
- Commercial principles for data access and the use of data by commercial bodies was discussed.
- **Action:** HDR UK to schedule a follow up meeting of the Steering Group on this topic.

Attendees:

Name	Organisation
Emma Gordon	Administrative Data Research UK (ADR UK)
Liam Hart	Bennett Institute for Applied Data Science
John Latham-Mollart	Clinical Practice Research Datalink (CPRD)
Hans-Erik Aronson Fergus McDonald	Data and Analytics Research Environments UK (DARE)
Elena Beratarbide	Digital Health and Care Directorate
Tim Hubbard	Genomics England
Cassie Smith Edel McNamara Rachel Brophy Yemi Macaulay Andrew Morris Cathie Sudlow Ester Bellavia Eilidh Ferguson Crysta Kaczmarek	HDR UK
Paola Quattroni Stephen Burrows	Health Data Research Alliance, HDR UK
Alison Knight	Health Research Authority
Andy Boyd	UK Longitudinal Linkage Collaboration
Alex Bailey	Medical Research Council (MRC)
Vicky Chicco Carl Beesley	National Data Guardian Office (NDG)
Sir Ian Diamond	National Statistician - ONS
Amy Ogborne	NHS E
Kirsty Irvine	NHS E- AGD



Bill South	ONS
Angela Coulter Jillian Hastings Ward	Public Advisory Board, HDR UK
Carole Morris	Public Health Scotland
Roger Halliday Kate McBay	Research Data Scotland
Richard Welpton	UKRI