

Pan-UK Data Governance Steering Group Inaugural Meeting

21 April 2022

Summary of Key Discussion Points

Introductory and closing comments were given by Prof Andrew Morris and Sir Ian Diamond.

Presentation by Andy Boyd and Cassie Smith (copy attached)

<https://hdruk.box.com/s/kp9xr8en9e2t61s8bc51w4tc3yxohh1i>

Introduction

- Introductory comments highlighted that access to data for research and statistical analysis by researchers is a significant issue because of lack of standardisation, duplication, inconsistency, and delay.
- There is a need to move forward at pace with processes to enable faster and more predictable routes to data access with “good, safe, accessible, trustworthy” governance processes.
- The opportunity is for the group members to work in partnership with the aim of simultaneously protecting individual rights, promoting the public good potential of data in the UK for research and innovation, and building a culture of data justice and equity.

Trust and Public & Patient Involvement and Engagement (PPIE)

- The importance of public and patient trust is central to the group’s work and will be brought into all the group’s activities
- The discussion highlighted that the group must also carry the profession with us, the governance processes we build must be trusted and understood by healthcare professionals to overcome concerns about “selling data”.
- HDR UK has recruited three public contributors to join the Steering Group and help us build our shared vision of robust, streamlined, transparent governance processes built on a foundation of deserved public trust.
- Our public contributors were unable to attend the inaugural meeting due to illness, however they will be separately briefed on this meeting and will join future meetings.

Purpose of the group and objectives

- The discussion highlighted the importance of framing the primary challenges accurately and understanding the purpose, scope and mechanics of the Steering Group.
- In closing comments, it was noted that the Steering Group's purpose is coordination and connection of principles and best practice, not "command and control." The aim is to produce useful outputs and not to duplicate the work of others.

UK-wide approach

- The challenges of streamlined governance were discussed, and it was suggested that a layered approach might be preferable in simplifying governance issues, starting with the basics.
- The complexities of different legal systems may make pan-UK progress challenging although much of the underpinning legal regime (GDPR) applies pan-UK.

Sharing precedents

- The group discussed the need to understand the different decision-making processes across data custodians and make those processes publicly available as currently inconsistent decisions are being made by different data custodians.
- There was strong support for creating a library of data access precedents as a first step to encouraging consistency of decision making across data controllers.
- As a longer term step the Steering Group could agree some common principles that data custodians should apply when assessing data access requests.

Data Minimisation

- The group discussed the appropriateness of strictly applying data minimisation principles when data is accessed within a secure setting (e.g. Trusted Research Environments; TREs) and subject to output checks to prevent reidentification.
- Concern was raised that strict application of the GDPR data minimisation principles inhibits hypothesis-free research and exploratory access to data, as well as adding a burdensome step to project-specific data provision, and that proportionality was needed.
- HDR UK has not taken a position on this issue to date. However, the topic is being explored at HDR UK's next Public Advisory Board (PAB) meeting with the aim of understanding public attitudes to this issue, for example whether the public would be comfortable with researchers having initially broader access to data within a TRE for the purposes of establishing which datasets are needed to answer their research question and what safeguards/guardrails the public would like to see implemented in this scenario.

Action: HDR UK to report back on the conclusions of the PAB discussion on data minimisation at the next Steering Group meeting.

Actions

- The discussion highlighted the need to prioritise and commit to around three achievable outputs, selected from the 'low hanging fruit'.
- If even one process or form is standardised that would be an incredibly powerful impact. Streamlining processes for accessing data to answer complicated research questions across multiple TREs is an important target, but it is not easy and would need to be tackled in stages.
- HDR UK will hire additional resource to support as the "engine room" of the group.
- Participants noted that even when there is consensus for streamlining processes, there are still significant challenges in implementation and there is a need for Steering Group members to be committed to implementing change.
- In closing comments, it was noted that the power of the Steering Group in bringing together data custodians to tackle these challenges should not be underestimated.

Action: HDR UK to prepare draft action plan setting out around three potential key high priority achievable actions for comment and discussion.

Action: HDR UK to schedule second Steering Group meeting. This has now been scheduled for 4 July.

Attendees

Alex Bailey, MRC

Alison Knight, HRA

Alistair Rennie, Research Data Scotland

Andrew Morris, HDR UK

Andy Boyd, Bristol University, HDR UK

Cassie Smith, HDR UK

David Ford, SAIL Databank

Declan Bradley, NI PHA

Edel McNamara, HDR UK

Emma Gordon, ADR UK

Ian Diamond, ONS

Jennifer Boon, NHSTD

Kevin Willis, NHSD

Michael Chapman, NHSD

Neena Modi, President of BMA

Paola Quattroni, HDR UK

Peter Stokes, ONS

Tim Hubbard, Genomics England