Pan-UK Data Governance Steering Group Second Meeting

04 July 2022

Summary of Key Discussion Points

Introductory comments were given by Andy Boyd and closing comments by Prof Andrew Morris.

Presentation by Andy Boyd and Cassie Smith (copy attached).

Scope and Cross-Discipline Collaboration

- The group needs to be clear about scope and what we mean by "health data". The group is intentionally broad, including representatives from ADR UK and ONS, and this is a key strength. By bringing together cross-sectoral expertise we can learn from one another and start to bring alignment between processes for accessing administrative and health and care service data. This provides a legacy for the cross-sectorial working established in the Data & Connectivity National Core Study which has already led to governance rationalisation and standardisation (e.g., the adoption of 'five safes' framework).
- The discussion highlighted the importance of building on previous work (e.g., alignment with Digital Economy Act) where possible and that there is a considerable amount of work underway in this area.
- The pan-UK element is a strength that can facilitate streamlining across the four nations.
- The group also needs to be clear on what is meant by the terms "research" and "researcher".
- It was suggested that Department of Health involvement in the group would be beneficial and that we need to ensure we are collaborating across other relevant government activities.

Prioritisation Exercise

- There was broad agreement on the three priority actions in the draft Action Plan circulated by the secretariat as a pre-read.

- Three Action Forces will be established to refine and deliver the three priorities, with an HDR UK Information Governance Manager allocated to be the "engine room" for each of the Action Forces.
- An emerging priority was raised relating to the NHS development of a Secure Analysis Environment accreditation scheme (as described in the DHSC Data Saves Lives policy) and how this would fit with other similar accreditation schemes (including UK Statistics Authority's Digital Economy Act accreditation framework). It was identified that some infrastructure providers will seek accreditation to both schemes (and potentially wider four nation approaches). Alignment of accreditation frameworks would bring benefits and efficiencies to the system. It was noted that NHS will soon launch a consultation scheme for the planned accreditation framework.
- The importance of tangible results and promoting innovation was discussed. It was highlighted that the initial three priority actions were chosen as they would be able to produce outputs in the short- to medium- term.
- **"Mapping exercise" priority**: The process for requesting data linkage was highlighted as the greatest challenge and there is great confusion and misunderstanding in this area. Mapping processes for data access (without linkage/federation) will be more straightforward, but both are needed
- **"Trusted Research Environment (TRE) Legal Toolkit" priority**: The toolkit needs to have the flexibility to be used in different scenarios but detailed enough to be useful. It was noted that the toolkit would include standardised agreements/clauses.
- **"Five Safes Form" priority**: It was suggested that the action force should also consider how the five safes can be operationalised.

Next steps: Steering Group members to nominate participants for the three "action forces" by 15 July

Data Minimisation
- HDR UK's Public Advisory Board (PAB) recently discussed the application of data minimisation principles to data access in Trusted Research Environments (TREs).
- PAB members were asked for their perspectives on researchers seeking to conduct analysis on a "hypothesis free" basis having initial broad access to data sets in a TRE for the purposes of determining significant correlations which warrant further investigation and with a more targeted research question and dataset. Overall, the PAB was hesitant to support this type of data access as they felt data minimisation remained an important principle and they didn't see a strong justification for allowing this type of initial broader data access.
- The importance of other safeguards was also noted such as transparent and clear output checking and airlock policies like those in place at Genomics England. Additionally, it was noted that different levels of access for different types of users could be of use here. The availability of high-quality meta data along with a synthetic representation of the data could give researchers a better understanding of the data sets without a disclosure risk.
- It was noted that clear communication and transparent processes are vital to ensure the public are aware of how their data is being used. Any activities would need to be monitored to ensure they are for the public benefit.

- The discussion emphasised that data minimisation is not binary, proportionality is key, and what a researcher needs should always inform what they are given access to.

Next steps: Members of the group to provide specific case studies where broader data access can facilitate better research in the public interest for the PAB to consider this question in more detail

Concluding remarks

- We need to encourage innovative, trustworthy governance and that is what this group can achieve.
- Bringing a variety of disciplines together will be key to making progress in this area.

Attendees

Alex Bailey, MRC Regulatory Support Centre

Alex Newbury, Welsh Govt

Alison Knight, HRA

Alistair Rennie, Research Data Scotland

Andrew Morris, HDR UK

Andy Boyd, Bristol University, HDR UK

Angela Coulter, Public Contributor

Carole Morris, Public Health Scotland

Cassie Smith, HDR UK

David Ford, SAIL Databank

David Seymour, UK Health Data Research Alliance

Dawn Monaghan, NHS England

Declan Bradley, NI PHA

Edel McNamara, HDR UK

Emma Gordon, ADR UK

Fergus McDonald, DARE UK

Hans-Erik Aronson, DARE UK

Jillian Hastings Ward, public contributor

Michael Chapman, NHS Digital

Neena Modi, President of BMA

Paola Quattroni, UK Health Data Research Alliance

Peter Stokes, ONS

Sinduja Manohar, HDR UK

Sue Bateman, CDDO

Tim Hubbard, Genomics England, UK Health Data Research Alliance