

Pan-UK Data Governance Steering Group

Innovative Data Governance Frontiers meeting

4th November 2022

Chair: Professor Sir Ian Diamond, UK National Statistician
Convened by Andy Boyd (Director, Longitudinal Link Collaboration) and Cassie Smith (Head of Legal, Trust & Ethics, HDR UK)

Convening a multidisciplinary group, including academic researchers, scientists, NHS colleagues, representatives from industry, government, media and legal professionals and patient and public representatives, allowed diversity in a shared vision to tackle the challenge of simplifying and streamlining data access governance processes.

Speakers and contributors set the scene of current challenges around processes and times for data access. The meeting conveners provided an update on actions and priorities arising out of the Pan-UK Data Governance Steering Group, working with collaborators across the four nations. The meeting generated a resounding agreement to further the development of robust, transparent and trustworthy streamlined data access governance models to enable data-driven discoveries which will improve people's lives. The challenge was laid down to meet again in 100 days with tangible outputs.

Attendees joined this hybrid event both in person at the Wellcome Trust and online via Zoom.

Agenda

Introduction by Professor Andrew Morris, Director of HDR UK.

"We are going to activate change. We are going to work together"

Welcome Address delivered by Sir Patrick Vallance, UK Government Chief Scientific Adviser

View here: <https://hdruk.box.com/s/b4keh8szhbgcmz3dor5e55i7wk8sbxt8>

Views of members of HDR UK's Public Advisory Board (PAB)

Debbie Keatley, PAB Member

Chris Monk, PAB Member

'Trustworthy Governance: Opportunities and Challenges' [[Slides here](#)]

Michael Chapman, Director of Research and Clinical Trials, NHS Digital

Kirsty Irvine, Chair of Independent Group Advising on the Release of Data (IGARD)

Update of the work of the Pan-UK Data Governance Steering Group [[Slides here](#)]

Cassie Smith, Head of Legal, Trust & Ethics, HDR UK

Andy Boyd, Director of the UK Longitudinal Linkage Collaboration

‘Levelling up health - adventures in data linkage’

Dr Laura Gilbert, Director of Data Science, Cabinet Office, and Head of 10DS

Presentation and discussion points:

Trust & Transparency:

- There is a societal cost when trust is low. When trust is lost, it is expensive. It can be restored but never to the same extent as before.
- A high level of trust comes from character and competence. Communications need to be open, fair, valid, authoritative, and inclusive. Closed off spaces and language that is difficult for the majority to understand are no longer acceptable.
- Patients and public have a role to play in the whole research lifecycle and not just because they will make things better but because they have a right to be there.
- Transparency and trust are not the same thing. Transparency plays a part but is not enough on its own.
- People want to be involved in the conversation, but this must be done early.
- There is a need for those that work with data to prove trustworthiness, to be explicit in everything that is being done.
- The opportunities are immense; however, we must proceed at the right pace to maintain trust, safeguards, and good practice. If we do not build trust through the processes, we will fail. The public voice is vital.
- There are three key areas to build trust. The public should know:
 1. **Where the data is:** This is a data custodian responsibility and needs to be standardised.
 2. **That the data is being looked after correctly:** With assurances provided by Secure Data Environments (SDEs)/Trusted Research Environments (TREs)
 3. **How the data is being used:** Communication and transparency are key.
- As an alternative to a lot of written text, infographics and videos should be considered as communication means with patients and public.

Trusted Research Environment (TRE) operational issues:

- A question was raised around whether TREs/SDEs are always required for trustworthy research. Where consent has been obtained to explicitly cover all activities this might be an instance where TREs/SDEs are not required. However, there is a clear move away from data dissemination.
- A discussion was held around the possibility of relaxing strict application of data minimisation principles when accessing a TRE, to allow hypothesis-generating research and exploration of data sets before applying for further approvals. However, it was noted that data minimisation is still an important safeguard in the public eye.
- Streamlined processes need to reduce the administrative burden on the researcher.
- A discussion was held around how to use data while TREs with governance based on the Five Safes are under development, which can take many months. Data use may be appropriate with safeguards in place. We are following in the footsteps of the economic world so there is confidence that the infrastructure can catch up.

Work of the Pan-UK Data Governance Steering Group:

The pan-UK Data Governance Steering Group is a working group of the UK Health Data Research Alliance which represents data custodians and policymakers across the four nations. The group has a commitment to meaningful patient and public involvement and engagement in all its activities. Three priority areas for simplifying and streamlining data access processed have been determined by the group and are in progress as smaller working groups, or 'Action Forces'

1. Mapping data access governance processes across the four nations with a view to identifying opportunities for harmonisation and definition of principle-based governance mechanisms to enable safe data access
2. Development of a TRE Legal Toolkit
3. Adoption of a streamlined data access form based around the 'five safes', and associated training

Actions:

The group strongly supported the vision of co-creation of trusted governance models with patient and public involvement throughout. The group agreed to

- Draft a consensus statement on trustworthy governance, partnerships and skills required.
- Develop a plan for action with priority deliverables for the next 100 days.

With thanks to all