

UK Health Data Research Alliance Executive Committee

Date: Tuesday 16 April

Attendees: Janet Valentine (ABPI), Nicola Perrin (AMRC), Alex Newberry (Welsh Government), Andrew Morris (HDR UK), Ian Young (HSC NI), Jan Speechley (PAB), Richard Ballerand (useMYdata), David Seymour (HDR UK), Paola Quattroni (HDR UK), Nada Karrar (HDR UK), Stephen Burrows (HDR UK)

Apologies: Roger Halliday (RDS)

Alliance quarterly progress report

- A quarterly status report on the Alliance's progress and delivery against key objectives was [presented](#), which included updates on membership growth and diversity, communities convened, development of standards, and current levels of adoption.
- The adoption rate of transparency standards and in particular the data use register (DUR) was highlighted as an area for improvement, considering this is a key principle for participation.
- A question was raised on whether the Alliance should be more explicit about organisations that are not being transparent, and about what meaningful transparency looks like. There were previously mixed feelings across the Council when it came to reporting this publicly, but this is something to reconsider.
- Showcasing exemplars and organisations that are implementing best practice was also noted.
- In addition to providing funding to enable individual organisations to publish DURs, developing a health data infrastructure to support DURs could be as effective (e.g. a common portal to enable organisations to upload data uses into).
- The Gateway DUR was recognised as a promising model for this, along with development of a widget to push this data back into custodian websites. The question is how we get these things to stick and understand what are the barriers to some of the most basic levels of transparency.

ACTION: Develop an implementation plan for how we can improve transparency with Alliance members that are data custodians. Consider in this plan how we ensure there is meaningful transparency.

ACTION: There are many platforms that may be available for increasing transparency, so think about how we can link technical information from the Gateway to less technical website websites, which may include revisiting the widget concept.

ACTION: Use upcoming transparency showcase event to highlight this issue, in addition to championing organisations doing this well.

Horizon scanning and key interfaces in the ecosystem

Developments / feedback from related groups

Life Science Council (LSC):

- The Health Data Industry Sub-Group, which is a sub-group of the LSC met in February. Three trade associations are working together on a consultation with their respective memberships on how they use data and whether the proposed regional SDE networks will meet the needs of industry. This will be accompanied by interviews with a few companies to capture industry views on how the network could improve and be internationally competitive. The government

has committed to responding to this consultation. A coordinated report will be published on this.

- The upcoming LSC on the 22nd May has been postponed.
- There was a question on the sufficiency of current Alliance engagement with industry, which is through trade bodies. The steer was that while trade associations serve as a key interface for policy issues, direct engagement with users is necessary when deciding on which standards industry adopts. The role of trade associations is to convene their members around specific issues and topics, as exemplified in the joint Roundtable conducted with TechUK to convene system suppliers and others to explore OMOP CDM.

DECISION: When it comes to policy issues, industry is happy for the trade bodies to be the key interface, but trade bodies are the appropriate entities to connect with actual users on particular issues and topics.

ACTION: Paola to coordinate with Janet on using ABPI to reach out to the relevant industry organisations regarding the use of data standards (OMOP CDM).

NHS England Research Advisory Group (RAG):

- The group has been reduced in size and renamed the Data Enabled Research Advisory group. It meets officially for the first time on the 14th May. It will follow on from the wider Stakeholder Research Advisory Group, which will meet biannually.
- The last meeting was productive and included discussions on sharing common data access pitfalls, through to more long-term challenges. The group also discussed planned investments from major government funders (NIHR, MRC, ESRC) in the next few years.
- Hilary Fanning has been appointed as SRO for Data for Research and Development Programme and will be devoting 50% of her time on the programme.

Northern Ireland:

- Currently in a transition phase to a new electronic healthcare record, which will integrate social care data with healthcare data into a single system. Existing data is not being migrated onto the new system, and data access to this existing data still requires support.
- There is a major data strategy in place, and the Health Minister was reinstated several months ago.

Wales:

- Agreement made to continue funding the SAIL Databank and currently negotiating level of funding that they will receive from March 2025 onwards.
- Work being carried out with the Digital Health and Care Wales organisation to improve the collaboration with SAIL. SAIL's recent change to their data access policies, which align more closely with the Alliance recommendations was noted.
- The Welsh government is midway through conducting a deliberative public dialogue focused on using data to support patient recruitment into trials. Understanding Patient Data, use My data and Med confidential have been involved. The findings of the report will have value beyond Wales.

Office for Strategic Coordination of Health Research (OSCHR):

- The group hasn't met since the last Executive Committee meeting, and data is not on the agenda of the upcoming meeting.

Public Involvement:

- Nicola provided a comprehensive update on the different activities ongoing in this space, which fall into the following buckets:
 - Understanding public attitudes
 - Developing explainers and resources.
 - Influencing policy and contributing the patient voice to advisory groups.
 - Championing the benefits of using patient data.
 - How you encourage participants in research studies, which links to work in Wales.
 - Understanding how to reach diverse and underrepresented communities.
 - Developing standards and good practice public engagement.
 - New research and analysis about how to communicate some of these issues
 - Horizon scanning
- There is a need for coordination across the sector. It would be useful to have a forum to share updates about what's happening, identify gaps, establish shared priorities, and align activities rather than initiating new ones.
- There is also discussion about who would be best placed to deliver some of those activities. A complexity arises with both UPD and PEDRI wanting to pursue very similar objectives and both seeking support from the same funders.
- In Wales, a PPI Four Nations group has been established to share knowledge, learn from each other and reduce duplication. However, the coordination of activities is made challenging by PEDRI, UPD, and all the other regional work.
- Andrew Morris and Nicola Hamilton are meeting in a few weeks to discuss the sustainability in business models and funding of PEDRI and UPD. There is a common mission here, so there must be a common path forward.

ACTION: Andrew to report back on outcome of conversation with Nicola Hamilton.

Connecting with data and digital research investments

The following existing and planned investments were flagged:

- [Data for R&D Programme](#): Through Michael Chapman and others there are good connections into this programme.
- [UKRI Digital Research Infrastructure: Dare UK](#) Programme offers good connection into this considerable
- [Smart Data Research UK](#): Health and well-being is one of four sort of domains.
- [Population Research UK](#): Coordinating hub is a £10.8 million investment across MRC and ESRC that is now up and running. It would be worth inviting them to join the Alliance.
- [UKRI/NIHR Enhancing Biomedical and Health related Data and Digital Platform Resources](#): £15million funding call with a closing date in mid-June that a many Alliance Members will be interested in.

The high level of investment but lack of connectivity across those programmes was raised as a major risk. Andrew co-hosted a dinner with Patrick Chinnery, who is the executive chair of the MRC, along with the leaders of all the major research councils to promote more coordination of investments.

ACTION: Invite Population Research UK to become a member of the Alliance.

Reviews and policy developments

- [Unifying Health Data in the UK](#): A brief update was received from Cathie Sudlow, and this report continues to be in draft form but will be moving forward over the next few months.
- [NHS England Data Access Policy](#): The update is essentially complete, subject to final clearance from DHSC and Ministers. The aim is to publish it soon after the pre-election period ends.

International engagement and developments

- [ENTRUST](#): This partnership aims to create a network of trusted research environments (TREs) and federated analytics in Europe by outlining the requirements from both technical and governance perspectives.
- [QUANTUM](#): This focuses on designing and developing data quality labels for secondary use of health data, to contribute to the European Health Data Space. There is some interest from NHS colleagues to align as much as possible.
- [Singapore](#): A meeting was held with colleagues from [TRUST](#), Singapore's national data exchange platform, to discuss the common data models work that the Alliance has been doing.
- [The Netherlands](#): Discussions were held with an organisation in the Netherlands called [Health RI](#), which is setting up a model similar to HDR UK. They were very interested to hear more about the Alliance and the soft incentives and how we engage with stakeholders.
- [ELIXIR](#): The TRE project in Europe is led by ELIXIR, of which Tim Hubbard, who was seconded in HDR UK, is now the Director.

Alliance priorities for 2024/25

- Driving the adoption of best practice is the most important and impactful thing that the Alliance can do and should be the top priority, with a particular focus on transparency standards. It was agreed that members who are data custodians should be brought up to a minimum standard, which may require understanding what the blockers are for not achieving those standards.
- The Alliance Executive Committee presents a great opportunity to steer prioritisation in a way that was not previously possible.
- The Rogers Curve of innovators was an example of improvement methodology shared to support this ambition.
- The Alliance has evolved over time but signing up to the [Principles for Participation](#) remains the minimum requirement to entry. Now that there are over 100 Members, should the bar be raised for becoming an Alliance member?
- It is also worth considering awarding smaller grants to incentivise change as part of that overall approach to driving adoption.

DECISION: Driving the adoption of best practice is the most important and impactful thing that the Alliance can do and should be the top priority, with a particular focus on the transparency standards.

ACTION: Consider development of a Self-Assessment Questionnaire to assess how organisations are measuring up to our key standards. Also consider revising criteria for Alliance membership.

ACTION: Consider incentivising and motivating change through relatively small funding grants.

ACTION: David also flagged Paper 4, which is the Alliance introduction and latest iteration of trying to present the Alliance offer. Committee members to share any thoughts or feedback on [Paper 4](#) (The Alliance introduction).

Agenda for upcoming Alliance Council (22nd May)

- The agenda for the upcoming Council meeting was discussed and it was agreed that the importance of data standards would be a good topic for the panel discussion.
- However, more clarity is required on the signing-off of Alliance papers.

ACTION: Paola to circulate latest draft of the ethnicity coding paper when the chairs are ready.

ACTION: Explore what the Alliance sign-off means for the membership and what the mechanism might be for doing this. Reference points such as the Global Alliance for Genomics and Health and other similar Alliances might be helpful.

ACTION: Frame the panel discussion on the importance of the adoption and implementation of data standards and call it out in the title.

Decisions & Actions

ID	Key Note / Decision	Date agreed
D001	Driving the adoption of best practice is the most important and impactful thing that the Alliance can do and should be the top priority, with a particular focus on the transparency standards.	16-Apr
D002	When it comes to policy issues, industry is happy for the trade bodies to be the key interface but trade bodies are the right place to go to connect with the actual users on particular issues and topics.	16-Apr

ID	Action	Owner	Due Date
A001	Develop an implementation plan for how we can improve transparency with Alliance members, which may include mapping members against the Rogers Curve of innovators. Consider in this plan how we ensure there is meaningful transparency.	PQ/NK	03-Jul
A003	Consider development of a Self-Assessment Questionnaire to assess how organisations are measuring up to the principles for participation and our key standards.	TBC	03-Jul
A004	Consider whether we want to raise the bar for membership and whether a stricter criterion in terms of a minimum threshold is required.	TBC	03-Jul
A005	Consider incentivising and motivating change through relatively small funding grants.	TBC	03-Jul
A006	Use upcoming transparency showcase event to highlight this issue, in addition to championing organisations doing this well.	PQ/NK	22-May
A007	Invite Population Research UK to become a member of the Alliance.	PQ	03-Jul
A008	Committee members to share any thoughts or feedback on Paper 4.	All	30-Apr
A009	Revisit concept of widget for linking technical information from the Gateway to custodian websites/other platforms.	TBC	03-Jul
A010	Paola to coordinate with Janet on using ABPI to reach out to the right industry organisations on use of data standards.	PQ	TBC
A011	Andrew to report back on outcome of conversation with Nicola Hamilton.	AM	TBC
A012	Confirm Research Data Scotland agenda item with Roger Halliday.	PQ/RH	30-Apr
A013	Paola to circulate latest draft of the ethnicity coding paper when the chairs are ready, to have another conversation on it.	PQ	TBC
A014	Explore what the Alliance sign-off means for the membership and what the mechanism might be for doing this.	PQ/DS	03-Jul
A015	Frame Alliance Council panel discussion on the importance of the adoption of data standards and call it out in the title.	PQ	22-May