

UK Health Data Research Alliance Executive Committee

Date: Monday 07 October 2024

Attendees: Janet Valentine (ABPI), Roger Halliday (RDS), Michael Chapman (NHSE), Claire Bond (Welsh Government), Richard Ballerand (useMYdata), Nicola Perrin (AMRC), David Seymour (HDR UK), Doreen Tembo (HDR UK), Nada Karrar (HDR UK), Stephen Burrows (HDR UK), Claire Argent (HDR UK)
Apologies: Andrew Morris (HDR UK), Ian Young (HSC NI), Jan Speechley (PAB)

Welcome and introductions:

- Doreen Tembo, Interim Head of the Alliance was welcomed to the Committee. Doreen is also the Head of Public Involvement and Engagement (PIE) at HDR UK and the strategic lead for PEDRI (Public Engagement in Data and Research Initiatives).
- Claire Bond, who works within the Research and Development Division of the Welsh Government, also attended the meeting for the first time.

Actions Log

- The key actions and decisions from the last Alliance Executive Committee meeting were shared.
- The issue of understanding why members have not adopted the transparency standard was investigated through desk-based research by the Secretariat, which identified NHS Trusts as the primary group to focus on. Ongoing efforts, in collaboration with the Secure Data Environment (SDE) network, aim to streamline the adoption process, particularly for Trusts already involved with the SDE, to make compliance easier.
- Discussions with the new NIHR data team leadership are underway to ensure proper NIHR representation at the Alliance Executive Committee.
- Three actions were closed.

ACTION: [Update on status of NIHR representation on the Committee at future meetings.](#)

Alliance quarterly progress report

- A quarterly status report on the Alliance's progress and delivery against key objectives was shared, which included updates on membership growth and diversity, communities convened, standards in development, activities to support adoption, metrics on communications and engagement, and a spotlight on the recent OHDSI UK event.
- *Enhancing the diversity and quality of health data:*
 - Efforts to improve the diversity and quality of health data are progressing, with new clinical trials legislation set to enforce stricter requirements for more representative trial populations, particularly regarding ethnicity. Pharmaceutical organisations will need to create detailed diversity plans, though the absence of universal standards across the industry poses challenges for regulatory compliance.
 - The Health Research Authority is actively engaged, recognising that addressing diversity requires ongoing development of standards and systems to measure progress.
 - Additionally, NHS England is working to improve the collection and standardisation of ethnicity data, which has suffered since the COVID-19 pandemic due to restricted access to GP data. Accurate data is crucial for addressing health inequalities, and discussions are ongoing to ensure more robust and consistent data collection, not just in times of crisis but for long-term NHS use.

ACTION: Consider how the Alliance standards on ethnicity coding data can be adopted, and more broadly how the work on Diversity in Data can be taken forward to address other key areas such as diversity in trials recruitment and how success in this area can be measured.

- *Alliance Membership and Representation*:
 - The discussion on Alliance growth highlighted the increase in membership to 107 organisations, but raised questions about whether all relevant groups are represented. A suggestion was made to conduct a "census" to assess current membership and identify gaps. It was noted that the landscape is constantly evolving, with some programmes becoming dormant or merging, while new initiatives arise.
 - Ensuring broad representation, particularly among key "aggregators" like Population Research UK, was discussed. There may still be organisations, especially those managing clinical and population cohorts, that need to be encouraged to join, though participation should remain voluntary unless their absence is disruptive.
 - A question was raised about mapping key stakeholders in the data ecosystem. While no formal mapping exists, assessments have been made to ensure broad representation, including four-nation involvement and major data service providers. However, with emerging groups like Smart Data Research UK, ongoing efforts will be needed to incorporate new stakeholders.

ACTION: Incorporate Alliance membership gap analysis into the Alliance strategic review, identifying key "aggregators" and emerging programmes and services.

Key interfaces in the ecosystem

- *OSCHAR (Office for Strategic Coordination of Health Research)*:
 - The next OSCHAR meeting is set for next week, featuring a presentation by Becca Cosgriff on the Data for R&D programme. The last meeting took place after the July election, focusing on university sustainability.
- *NHS England RAG (Research Advisory Group)*:
 - The recent stakeholder RAG meeting was merged with the Health Data User Group as part of a broader strategy to streamline NHS England's stakeholder engagement. This aims to focus discussions and reduce fragmentation by consolidating various groups into more centralised forums.
- *Life Sciences Council*:
 - The next Life Sciences Council meeting will take place on 22 October, but changes in membership and structure are anticipated following the new government. The future of the Health Data Industry Sub-Group, with over 50 members, is uncertain due to concerns about its size and effectiveness as an advisory body.
- *UseMyData*:
 - UseMyData has applied for charity registration with the Charity Commission, which will affect its funding streams but not its day-to-day operations.
 - Additionally, a new English national platform is being established under the European Patients Academy on Therapeutic Innovation (EUPATI), with support from the NIHR. This initiative aims to enhance participant diversity in clinical trials, aligning with wider efforts to improve inclusivity across clinical research.

Reviews and policy developments:

- *Pandemic Preparedness Review*:
 - Research Data Scotland (RDS) is reviewing the UK's pandemic preparedness post-COVID, with a publication expected in November. The review will focus on leveraging data

systems developed during the pandemic to enhance future responses, and the findings may influence upcoming health data strategies.

- *Sudlow Review:*
 - The Unifying Health Data Review, led by Prof. Cathie Sudlow, will launch on 8 November. Pre-launch briefings have highlighted key recommendations for improving health data integration and accessibility, with contributions from figures like Ian Diamond and Chris Whitty. The final report aims to provide a roadmap for unifying health data sources.
- *Darzi Review:*
 - The Darzi Review illustrates the critical role of data in evaluating the healthcare landscape. It highlights how data has been utilised to identify challenges and opportunities within the system and stresses the necessity for a robust data infrastructure to enhance health outcomes.
- *GP Data for Consented Studies:*
 - The Health Secretary recently announced improvements to GP data access for consented research studies. This development allows NHSE to centralise the process of checking patient consents and security measures, removing the need for researchers to engage with GP practices individually. This is a major step forward for data access, potentially enabling faster and more efficient clinical studies.
 - Additionally, there was a brief mention of a move towards creating a single patient record as part of a 10-year plan, though further details on this aspiration are yet to emerge.
 - The Committee recognised the need to swiftly implement these improvements in practice. The initiative is expected to progress in stages, with the first phase being rolled out soon.
- *Association of the British Pharmaceutical Industry (ABPI) Consultation:*
 - The ABPI, alongside health tech associations ABHI (Association of British HealthTech Industries) and BIA (BioIndustry Association), consulted members on their experiences with the sub-national Secure Data Environment (SDE) network. The consultation aimed to gather feedback on how the SDE network could be improved to better meet industry needs, particularly in relation to data access for research.
 - The report with recommendations has been shared with the government, and there is hope that a government response will be issued alongside the report's publication before the next executive committee meeting.

ACTION: Update on outcomes of RDS's review into the UK's pandemic preparedness post-COVID.

ACTION: Update on recommendations and government response to ABPI report on snSDE industry needs.

- *Bigger picture:*
 - It was noted that the broader context, including the spending review, national data library proposals, and the 10-year plan, had been somewhat overlooked. The group recognised they were focusing on minor issues without addressing the central, unknown factors that connect them. This underscored a larger issue: fragmented discussions occurring across various programmes and committees, lacking a cohesive strategic dialogue.
 - A key challenge is finding a way to unify these conversations, with uncertainty about which body should lead the coordination.
 - Emerging recommendations from the Sudlow Review may provide clarity, and NHSE is addressing these concerns, but coordination among government departments continues to be a challenge.

KEY NOTE: There was consensus on the need for a joined-up approach across government and stakeholders regarding the broader issues impacting the health data research ecosystem. However the mechanism to achieve this remains unresolved.

International collaborations:

- The discussion highlighted recent international collaborations, including visits from the French Health Data Hub, the Singapore Health Ministry, and an upcoming visit from Health Rhode Island in the Netherlands, all aiming to learn from the UK's developments in health data.

Public Involvement Initiatives:

- There have been ongoing efforts to align work plans with Understanding Patient Data (UPD), focusing on better coordination and explanation of roles within the health ecosystem.
- A recent roundtable, convened by Janet Valentine, focused on public trust and how central coordination of initiatives could be beneficial. UPD has taken on the responsibility for this coordination, working closely with other organisations to ensure roles and responsibilities are clear.
- Concerns were raised about avoiding duplication of efforts. It was noted that members of various groups, including useMYData and the Health Research Authority (HRA) participated in the roundtable and supportive of the proposed steps forward.
- Overall, the public involvement efforts seem to be moving in a positive direction, but there is still a need to ensure effective coordination across the UK and to minimise duplicated efforts.

ACTION: Continue to highlight and address key issues and future developments in the coordination of public involvement initiatives.

Alliance membership models proposal:

- A paper was presented outlining options for potential new membership models for the Alliance to enhance adoption and engagement with the Principles for Participation.
- The AMRC's approach served as a case study, featuring three membership categories: full members, introductory members, and supporters.
 - *Full members*: Must meet stringent criteria, including being a UK charity funding research, adhering to expert review principles, having a defined research strategy, and implementing a conflicts of interest policy. Benefits include opportunities, such as eligibility for specific funding streams, with audits every five years to maintain standards.
 - *Introductory members*: Charities working towards full membership criteria within a two-year support period, expected to demonstrate progress.
 - *Supporters*: Organisations that do not fund research but support the goals of full members. Charities failing to meet necessary standards cannot become supporters, maintaining the quality mark associated with membership.
- There is a need to clearly differentiate between data custodians and non-data custodians within membership categories. While data custodians are expected to comply with specific principles, some organisations may not have the capacity to meet these requirements but can still engage meaningfully in the conversation.
- Concerns were expressed regarding the potential confusion that might arise from introducing additional membership categories and the importance of ensuring that membership reflects an organisation's capability and engagement level.
- A tiered membership was supported, but it was emphasised that categories should be clearly defined and relevant to each organisation's role in research.
- A self-assessment form would allow organisations to evaluate their progress against established standards. This could lead to a system of recognition through "badges" that indicate the level of compliance, such as bronze, silver, and gold, which could motivate organisations to improve their practices.

- The importance of balancing accessibility and exclusivity in membership benefits was underscored, as limiting access might reduce engagement from key stakeholders and undermine the collective output of the alliance.

ACTION: Share an updated proposal outlining clearer categorisations for each approach, defined membership benefits, and careful consideration of the potential unintended consequences.

Alliance Strategic Review:

- A review will be undertaken to evaluate the Alliance’s role for the 2025–26 period, with input from members encouraged to enrich the process. The goal is to align strategies effectively and improve understanding of membership models to maximise impact and benefits for the UK ecosystem moving forward. This review aims to create a cohesive framework that supports the Alliance’s objectives and ensures its continued relevance in an evolving landscape.

ACTION: Keep Committee informed and involved in the development of the Alliance Strategic review and its outcomes.

Alliance Council agenda

ACTION: Committee members are invited to review and comment on the agenda offline but due to short timescales, any comments should be shared by Friday.

Decisions & Actions

ID	Key Note / Decision	Date agreed
D007	There was consensus on the need for a joined-up approach across government and stakeholders regarding broader issues impacting the health data research ecosystem, such as spending reviews, national data libraries and 10-year plan. However, the mechanism to achieve this remains unresolved.	07-Oct

ID	Action	Owner	Due Date
A036	Update on status of NIHR representation on the Committee at future meetings.	DS	04-Dec
A037	Consider how the Alliance standards on ethnicity coding data can be adopted, and more generally how the work on Diversity in Data can be taken forward to address other key areas such as diversity in trials recruitment.	TBC	TBC
A038	Incorporate Alliance membership gap analysis into the Alliance strategic review, identifying key “aggregators” and emerging programmes and services.	DT	04-Dec
A039	Update on outcomes of RDS’s review into the UK’s pandemic preparedness post-COVID.	RH	04-Dec
A040	Update on recommendations and government response to ABPI report on in snSDE industry needs.	JV	04-Dec
A041	Continue to highlight and address key issues and future developments across the coordination of public involvement initiatives.	NP/DT	Ongoing
A042	Share an updated proposal on membership models outlining clearer categorisations for each approach, defined membership benefits, and careful consideration of the potential unintended consequences.	NK	04-Dec
A043	Keep Committee informed and involved in the development of the Alliance Strategic review and its outcomes.	DT	04-Dec
A044	Committee members are invited to review and comment on the agenda offline but due to short timescales, any comments should be shared by Friday.	All	11-Oct