

UK Health Data Research Alliance Executive Committee – Inaugural meeting

Date: Thursday 14 September 2023

Attendees: Nicola Perrin (AMRC), Roger Halliday (RDS), Alex Newberry (Welsh Government), Ian Young (HSC NI), Andrew Morris (HDR UK), David Seymour (HDR UK), Paola Quattroni (HDR UK), Nada Karrar (HDR UK), Stephen Burrows (HDR UK)

Apologies: Janet Valentine (ABPI), Michael Chapman (NHSE)

Terms of Reference Sign-off

- Following feedback, the Terms of Reference (ToR) have been updated, with minor changes made to the purpose and remit, membership and Chair.
- The committee agreed that, while the ToR are at a high level, the most important consideration is how this initiative aligns with the broader UK infrastructure, given the level of uncoordinated activities in this field.

Decision: The Terms of Reference (ToR) can be signed-off but will be subject to review in one year's time, along with the Chairmanship. Both new members and existing members are encouraged to review and suggest improvements within the year.

Committee membership

- An offer has been made to a public contributor from the HDR UK Public Advisory Board (PAB) to join the committee. Recruitment for a second public contributor from useMYdata is also in progress, with both expected to be in place for the next meeting.
- Committee currently lacks representation from key areas within the Alliance and the committee discussed whether we need input from major investments like Our Future Health (OFH), UK Biobank, and Genomics England. It was agreed that for this Committee to be effective, it should have no more than 12 members. Therefore, the focus should be on individuals who can leave their institutional affiliations behind, to serve and represent a growing Alliance membership.
- David will be meeting with Marian Knight, who was recently nominated as the NIHR Director of Infrastructure. Another potential nomination is Chair of the Biomedical Research Centres (BRC) Health Informatics Working Group.

ACTION: Invite group to provide suggestions for potential Committee members.

Coordination with other reference groups and advisory boards (OSCHR & Life Sciences Sub-Council)

- The July OSCHR meeting postponed the discussion on data, with Cathie Sudlow expected to provide an update at the next meeting, which could be an opportunity for recommendations on better coordination.
- Concerns were raised about the governance of the NHS England Data for R&D Programme and the Life Sciences Sub-Group, especially regarding the Sub-Group's industry focus and a lack of representation from devolved administrations (DAs). Nicola offered to address these issues at the upcoming OSCHR meeting and act as a conduit for this Committee.
- There is a central issue of complexity and a need of visualising the UK health data ecosystem, as well as the Alliance key areas of work and ongoing projects. It was agreed that the Committee could help provide Alliance members with a roadmap that clearly outlines the tools, standards, and public engagement methods currently in progress under each

workstream (technology, trust and transparency, data quality and standards, capacity building). This will ensure that members are informed about the unique offerings of the Alliance.

ACTION: Cathie and Nicola to compare notes ahead of OSCHR October meeting and to query whether Sudlow review can influence coordination.

ACTION: Nicola to update Committee on October OSCHR meeting.

ACTION: Visualization or schematic of all known reference groups and advisory boards to be shared with wider group for updates (including membership and types of agenda for groups).

ACTION: Articulate Alliance role, roadmap and distinctive offer to members.

Alliance workstream updates from last few months

- **Data standards:** Alliance is driving adoption of the Observational Medical Outcome Partnership (OMOP) common data model (CDM), focusing on technology tools, funding new UK data partners through EHDEN, partnering with NHSE to facilitate transformation of data across sub-national Secure Data Environments (snSDEs), and building communities like the OMOP Special Interest Group (SIG). Upcoming events include the Data Officers Group (DOG) on 28th of September and the OMOP SIG in November.
- **Data Access Transparency:** Building on previous work of the PAB and the Alliance, the Pan- UK Data Governance Steering Group published the [Data Access Transparency Standards](#), alongside a funding call offering custodians up to £15K for implementation of these standards.
- **Training and Capacity Building:** The Black Internship Programme has expanded, involving 93 interns and 54 organisations this year, including about 20 Alliance host organisations, with noted success and value.

Hot Topics: Federated Data Platform, primary care data and potential impact on devolved nations

- The NHS England Federated Data Platform (FDP) is in the procurement phase, with the supplier to be announced soon. Concerns have arisen about a potential controversial supplier, leading to actions like a petition by Foxglove and an [article in The Guardian by Cori Cider](#).
- A coordinated group (including HDR UK, National Data Guardian (NDG), Association of Medical Research Charities (AMRC), National Voices, and Understanding Patient Data (UPD)) is providing input on NHSE's communication plans and advises a proactive campaign to explain safeguards and benefits.
- There's confusion about opt-outs. FDP primarily serves care and operational uses, not research. NHSE needs to clarify that opt-outs don't apply to FDP to prevent significant risks to research.
- Whilst this is an England issue, there is a risk that this could also impact the DAs. So, clear communication is crucial to prevent nationwide issues caused by unclear reports. This could be considered as a topic for the next Alliance Council meeting.

- Alex also shared recent discussions held with special advisors to the Health Secretary, where access to GP data was revisited. Similar concerns have arisen in this context, with no clear timeframe for actions. This is another thing on the horizon that may have implications for devolved nations.

ACTION: Nicola and David to discuss how best to signpost Alliance members to the best resources for explaining opt-outs and other useful resources regarding FDP.

Agenda for upcoming Alliance Council (10th October)

ACTION: Committee to review draft agenda for Alliance Council (enclosed in email) and feedback by Friday 29th September

Decisions & Actions

ID	Key Note / Decision	Date agreed
D001	The Terms of Reference (ToR) can be signed off but will be subject to review in one year's time, along with the Chairmanship. Both new members and existing members are encouraged to review and suggest improvements within the year	14-Sep

ID	Action	Owner	Due Date
A001	Invite group to provide suggestions for potential Committee members	David	18-Sep
A002	Cathie and Nicola to compare notes ahead of OSCHR October meeting and to query whether Sudlow review can influence coordination	Nicola	TBC
A003	Visualization or schematic of all known groups to be shared with wider group for updates, including membership and types of agenda for groups (ahead of October OSCHR meeting and Alliance Council)	Paola/ Nada	02-Oct
A004	Nicola to update Committee on October OSCHR meeting	Nicola	TBC
A005	Articulate Alliance role, roadmap and distinctive offer to members. By visualising the building blocks of trustworthy health data ecosystem and include the specific goals within the blocks. Be clear on what we are aiming for, how will we get there and who is going to do it and by when	Paola/ Nada	30-Sep
A006	Following announcement, invite the new Deputy Chair of HDR UK (who has with expertise in data ecosystems) to speak at the Alliance Council	David/ Paola	TBC
A007	Nicola and David to discuss how best to sign-post Alliance members to the best resources for explaining opt-outs and other useful resources regarding FDP	David & Nicola	30-Sep
A008	Committee to review and feedback on Alliance Council agenda by Friday 29 th September	Paola	29-Sept

A009	Confirm date of next Alliance Executive Committee meeting (early December)	Stephen	29-Sep
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