

UK Health Data Research Alliance Executive Committee

Date: Tuesday 30 July

Attendees: Janet Valentine (ABPI), Roger Halliday (RDS), Alex Newberry (Welsh Government), Jan Speechley (PAB), Richard Ballerand (useMYdata), David Seymour (HDR UK), Paola Quattroni (HDR UK), Nada Karrar (HDR UK), Stephen Burrows (HDR UK), Claire Argent (HDR UK)

Apologies: Nicola Perrin (AMRC), Andrew Morris (HDR UK), Ian Young (HSC NI), Michael Chapman (NHSE)

Actions Log

- The key actions and decisions from the last Alliance Executive Committee meeting were shared. Several of the open actions arose from a discussion on improving transparency and are being addressed in the implementation plan (Paper C).
- It was noted that ongoing discussions are taking place to address the coordination of public involvement and engagement activities, particularly regarding PEDRI and Understanding Patient Data (UPD).
- Five actions were closed.

ACTION: Revisit the Alliance sign-off process at the next committee meeting.

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, standards in development, activities to support adoption, metrics on communications and engagement, and a spotlight on the recent Transparency Showcase.
- *Researcher Registry IG and Policy working group:*
 - It was queried whether industry or pharmacy was represented at the recent workshop. There are still many unanswered questions regarding this project, and it was advised that the standard should be set to meet the expectations of an international pharma community, even if this might be difficult.
- *Communications benchmarking data:*
 - To help better understand whether current engagement data on the Alliance website and newsletter are in line with peers, it was suggested that data could be shared from analogous organisations to provide benchmarks for these metrics.
 - It was also noted that most Alliance website visitors are new users rather than returning users, so there is an opportunity to remind members of all the great content on the website and to encourage co-promotion.
- *Membership types:*
 - As part of the membership strategy, priority organisations already involved with Alliance working groups are being targeted for membership, including regulatory and advisory bodies. This raised the question of whether different membership categories should be considered.
 - It was agreed that segmenting the membership into different categories will be helpful.
 - A suggested approach to applying this categorisation could be by developing slightly different principles for the agreed organisation types. However, in the interest of transparency, there is a need to minimise the changes to the Principles for Participation, while ensuring that they are relevant to all organisations. This could be achieved by

developing differing guidance outlining what membership and the principles mean for each category and how they apply to organisations.

- The AMRC was shared as a notable example, as they have two categories of membership (one given immediately and the other achieved if you meet a set of criteria). Thus, there is an expectation of how members progress to meet certain principles.
- *Self-Assessment Questionnaire:*
 - There is an opportunity to capture how well organisations are meeting the principles as they join the Alliance through a self-assessment questionnaire. This could provide a baseline for an annual self-assessment survey.

ACTION: Roger to share benchmarking data on RDS communications metrics.

ACTION: Communications data benchmarking to be picked up with the HDR UK Central Comms Team.

ACTION: Invite Janet Valentine to upcoming Researcher Registry IG and Policy workshops.

ACTION: Develop proposals on different membership types and the possible impact this will have on the Letter of Intent and Principles for Participation.

ACTION: Develop a self-assessment form as part of the onboarding process to capture maturity and progress against the Alliance Principles for Participation. To understand impact, this should be followed up by an annual self-assessment survey.

Horizon scanning and key interfaces in the ecosystem

- With the recent changes in government, how can the Alliance better shape and influence the new priorities it presents? This includes developments in AI and understanding the impact of emerging initiatives like the National Data Library. There are also a few new bills on cybersecurity and resilience, digital information, and smart data to consider.
- It was reflected that while this is a fantastic opportunity, the diversity of the Alliance makes having a shared lobbying and influencing position very difficult. So, how can the Alliance Council be used to build understanding around new initiatives and positioned as a useful audience for policymakers (like the Office for Strategic Coordination of Health Research (OSCHR) Health Informatics Subgroup)?
- It could also be more helpful for the Alliance to act as a 'distiller' of key policies and initiatives, providing a deeper understanding of this information to its members. 'Distillations' the Alliance has done in the past have been very helpful.

DECISION: The Alliance can lobby to influence policy to a limited extent due to size and diversity of the membership, but there is significant value in the Alliance synthesising and sharing knowledge and information with the membership as it becomes available. The Alliance membership can also be positioned as a diverse and expert group for policymakers and developers to consult.

Implementation plan for improving transparency

- A plan was presented exploring how the influence model framework would be used to drive meaningful improvement in the transparency of data use within the membership. This includes a focus on fostering understanding through updated principles for participation that better reflect the importance of transparency and more frequent communications that signpost resources and technology available to facilitate change. This will involve better guidance and training on the Enhanced Gateway. Exemplary organisations will also be highlighted through a series of spotlight blogs on the Alliance website to role model best practice across the membership. Financial incentives are being explored but are unlikely to be available this financial year.

- For some organisations, the barrier to adoption will be the lack of financial resources; however, there will be members who do not respond to any funding calls due to a lack of capacity. Therefore, it is crucial to consider how the Alliance supports these hard-to-reach organisations.
- There is a need to segment and better understand non-compliance, particularly for NHS trusts (as the SDE network could be a key influence and channel for this group). Understanding the resources required for those that have changed, alongside the barriers to adoption, could help shape communications.
- Regarding reinforcing systems and processes, there is an opportunity to consider how the Alliance can work better with the HRA and funders to embed transparency in data use, which has broadly been achieved in transparency around clinical trials.

ACTION: Develop a better understanding of the root causes for organisations not adopting transparency standards and use this information to shape the communications strategy.

Principles for Participation

- Paper A was shared with the committee in advance of the meeting, outlining several options for updating the principles to better highlight transparency. The second option, to create a 10th Principle specifically dedicated to upholding transparency, was selected by several committee members as the most favoured. The updated paper will be shared with the Alliance Council for final comments.

DECISION: The Principle for Participation will be updated to include a 10th Principle specifically dedicated to upholding transparency (second option). This draft paper will be shared with the Alliance Council for final comments.

Alliance Council agenda

- A panel discussion on implementing the FAIR guiding principles is being planned for the upcoming Alliance Council meeting on 14th August. Three speakers have been confirmed.

AOB: Thank you to Paola Quattroni

- This was Paola Quattroni, the Head of Alliance Strategy and Engagement's, last Alliance Executive Committee meeting. Appreciation and thanks were expressed for the phenomenal contribution she has made to the Alliance over the past four and a half years. Paola has been instrumental in the growth and development of the Alliance, and the team will work hard to build on the legacy she leaves behind.
- The committee has been invited to her leaving drinks on Thursday 29th August.

ACTION: Committee members are invited to Paola's leaving drinks at 6pm on Thursday 29th August, at 31 Marchmont St, Greater, London WC1N 1AP (a short walk from the Wellcome Trust).

Decisions & Actions

ID	Key Note / Decision	Date agreed
D005	The Alliance can lobby to influence policy to a limited extent due to size and diversity of the membership, but there is significant value in the Alliance synthesising and sharing knowledge and information with the membership as it becomes available. The Alliance membership can also be positioned as a diverse and expert group for policymakers and developers to consult.	30-Jul
D006	The Principle for Participation will be updated to include a 10th Principle specifically dedicated to upholding transparency (second option). This draft paper will be shared with the Alliance Council for final comments.	30-Jul

ID	Action	Owner	Due Date
A028	Revisit the Alliance sign-off process at the next committee meeting.	NK	30-Sep
A029	Roger to share benchmarking data on RDS communications metrics.	RH	30-Aug
A030	Communications data benchmarking to be picked up with the HDR UK Central Comms Team.	DS/NK	
A031	Invite Janet Valentine to upcoming Researcher Registry IG and Policy workshops.	NK	01-Aug
A032	Develop proposals on different membership types and the possible impact this will have on the Letter of Intent and Principles for Participation.	NK/DS	30-Sep
A033	Develop a self-assessment form as part of the onboarding process to capture maturity and progress against the Alliance Principles for Participation. To understand impact, this should be followed up by an annual survey.	NK/SB	30-Aug
A034	Develop a better understanding of the root causes for organisations not adopting transparency standards and use this information to shape the communications strategy.	NK	30-Sep
A035	Committee members are invited to Paola's leaving drinks at 6pm on Thursday 29th August, at 31 Marchmont St, Greater, London WC1N 1AP (a short walk from the Wellcome Trust).	All	29-Aug