

## UK Health Data Research Alliance Executive Committee

**Date:** Monday 04 December 2023

**Attendees:** Janet Valentine (ABPI), Nicola Perrin (AMRC), Roger Halliday (RDS), 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), Claire Argent (HDR UK)

**Apologies:** Alex Newberry (Welsh Government), Andrew Morris (HDR UK)

### Welcome and Introductions

- The Alliance Executive Committee welcomed Jan Speechley and Richard Ballerand as its newest members representing the public.

### Major developments in the ecosystem

*Federated Data Platform (FDP) announcement:*

- The [National Data Opt Out Dashboard](#) showed a minor increase in opt-outs after the announcement, but the overall impact was less significant than anticipated. Minimal effects were also observed in Scotland and Northern Ireland.
- Nicola acknowledged the complexity of the issue, seeing the slight increase positively. Credit was given to NHS England (NHSE) for incorporating advice and recommendations.
- A Check and Challenge Group, chaired by Jacob Land and involving healthcare professionals, patient and public groups, offers independent advisory input on the programme. Additionally, there is a Public Involvement and Engagement (PIE) group that will be advising the FDP. The General Practice Data for Planning and Research (GPDfPR) PIE group will now take on a broader function.
- The issue regarding conflicting information on the rules for opting out was raised. Nicola clarified discrepancies between NHSE's explanations and reported information, indicating a need for alignment. The complexity arises from the FDP's multiple purposes. Opting out isn't possible for direct care use, while it does apply for planning and research. Guidance on the various use cases and the application of the national data opt-out is expected soon.
- Jan Speechley stressed the need for more public material and awareness. The [NHS FDP Programme Public Engagement Portal](#) was shared. Michael highlighted ongoing investment into broader engagement with public on how NHS in England uses data, which moves away from project-by-project engagement.
- There was also a question regarding the grounds for the judicial review. A statement from an [NHS Spokesperson](#) was referenced. Nicola highlighted a previous judicial review during the procurement process, which was withdrawn due to a lack of legal basis, possibly indicating a similar outcome for the ongoing review. Another judicial review is expected from Good Law Projects, focusing on the legalities of opt-out.
- The convergence of care and research and the mix of use cases for data should be addressed. Janet Valentine noted that there is a link between direct care and research. The lawful collection of data for direct care enables research that saves people's lives, which in turn enables direct care. The use of the term 'planning' was queried and its potential for misinterpretation. Nicola clarified that this term arose from the analysis of language conducted by Understanding Patient Data (UPD).
- David pointed out the opportunity to learn from both positive and negative experiences.

**ACTION: To continue monitoring the impact of the FDP on opt outs and review how the Alliance can support communication around opt-out rules, the convergence of research and care in the use cases for data, and potential implications for the Devolved Nations.**

*O'Shaughnessy Review Government Response:*

- Nicola highlighted the link to the O'Shaughnessy recommendations and the government response to these. The response includes a Health Research Authority (HRA) review aimed at developing guidance for contacting people to take part in research, which explains where research can be part of care. There may be some types of research explicitly ruled out from this. There is a spectrum between care and research, which is where the opt out discussions have faltered. The more we can be clear about the spectrum the easier it will be to understand where opt outs apply.
- Ian Young was pleased to receive a four-nation response to the O'Shaughnessy recommendations, despite the absence of a Health Minister. He noted that O'Shaughnessy will be visiting Northern Ireland shortly, where the response will be discussed in more detail.

*Devolved Nation Updates:*

- Ian Young shared that a new electronic health and social care record is being rolled out across Northern Ireland, supplied by EPIC. One trust has gone live, and they aim to roll it out across the remaining trusts in the next year.
- Roger Halliday updated on an information governance model in Scotland that focuses on functional anonymisation that is receiving support. Suggesting that this could be presented to the broader Alliance membership for consideration.
- The other development from Scotland is the launching of a new Researcher Access Service in February. It is a first version of a rapid data access for research in the public good service.

**ACTION: Flag new Electronic Patient Record (EPR) system in Northern Ireland and implication for data access and data standards.**

**ACTION: Present functional anonymisation ICO piece in Scotland to wider Alliance.**

**Mapping of coordinating groups involved in health research ecosystem**

- Nada presented a summary of the key insights from the mapping exercise (see Paper 2 for more details).
- Janet is a member of the Life Sciences Council Health Data Sub-Group, which has only convened once thus far. Presently, it's an industry-facing group, whose focus lies in influencing policy to ensure that any implemented policies won't impede commercial innovation. There is no risk of overlap with the Alliance.
- The Council and Alliance concentrate on data, which intersects with various other areas. So, there should be more clarity about the Alliance focus and less concern about others' interests.
- Nicola noted the absence of two groups: the Advisory Group for Data Saves Lives Strategy (National Data Advisory Programme), where Nicola holds a position, and the Clinical Research Vision Data and Digital Subgroup for delivery partners.
- Richard noted that useMYdata has agreed to join as a member of the Research Advisory Group (RAG). Additionally, Richard serves as a European Institute for Innovation and Technology expert evaluator and sits on the Innovators forum.
- Michael shared that NHSE is currently reviewing the structure and membership of RAG, welcoming suggestions for names.
- There is difficulty in finding a single entity representing funders, which needs to be considered.

**ACTION:** More info to be provided by members on missing groups (LSC Health Data Subgroup, Data Saves Lives Strategy Advisory Group, Northern Ireland TRE Strategic Board, Scottish Groups).

**ACTION:** Share alternative names for the Research Advisory Group (RAG) with Michael.

**ACTION:** Consider how best to represent funders and coordination around this.

### Alliance Work Plan

- Paola presented an overview of the Alliance's goals, governance structure, and reported on the current status of workstreams and special interest groups (see Paper 3).
- Roger stressed the importance of maintaining focus on the three primary work areas (technology and data standards; trust and transparency; capacity building) and strongly supports the efficiency measure of a researcher identity service. He also suggested it would be useful to help Alliance members understand how well they've met good practices, and to develop measures that gauge the success of these goals.
- Janet highlighted ongoing efforts to aid data custodians and users within Cassie and Andy's Pan UK Data Gov Steering Group. She recommended addressing barriers to data access and exploring how the Alliance could support progress.
- Michael observed that much of the listed work plan remains unfinished, expressing concern about spreading efforts too thinly. He suggested a quick assessment of Alliance members' engagement. Additionally, he questioned the Alliance's UK-wide focus, considering this to be its unique selling point.

**ACTION:** Report on current level of engagement of Alliance members to better understand where they are in terms of meeting conditions of FAIR and Five Safes, for next Executive Committee.

**ACTION:** Develop measures of success for work plan objectives.

**ACTION:** Ensure the work plan has good UK wide coverage/balance.

**DECISION:** Keep focus on priority areas and ensure we are not spread too thinly.

### New Projects: Researcher Passport Service

- David outlined the approach to funding. Some activities receive funding through HDR UK's core funds. Additional funding may be sourced for priority areas. This could range from small-scale initiatives (e.g., MRC capital funding supporting transparency work) to this Research Passport service, where UKRI funding is potentially available. In this instance, it's key we ensure that funders support meaningful initiatives while also pursuing funding opportunities.
- This proposal, arising from the DARE UK programme and NHS SDE network feedback, aims to establish a unified method to accredit researchers for data use in Trusted Research Environments. Potential funding supports exploring challenges and opportunities, building on existing initiatives like the NIHR research identity service, GA4GH, and HRA's research passport. Scope covers better understanding of the requirements for obtaining a passport, the accreditation process, and deploying an efficient technical solution. This is in early stages as the grant award has not been confirmed but there needs to be tangible benefits to researchers by enabling quicker, more efficient access. Its alignment with the Five Safes framework, particularly the Safe People aspect, remains crucial.
- Janet emphasised the importance of identifying legitimate researchers and clarifying data access and liability. However, she questioned whether this responsibility should lie with the Alliance, considering differing interpretations by data custodians. Even if the Alliance undertakes such a task, ultimate decisions will reside with national initiatives. Addressing information governance and interpreting rules while clarifying the acceptable legal use of data should be a priority.

- Nicola noted that whilst this may not be the rate limiting step, we could reduce duplication by having a streamlined process.
- Jan Speechley inquired whether accreditation will include a record of Public Involvement and Engagement (PIE), and if a history of responsible behaviour could ease future checks.
- Richard acknowledged the need for more work in this area, as from the public's perspective, there are individuals labelled as researchers who might not genuinely fit that role.
- Ian highlighted the importance of country specificity or interoperability for the researcher passport to avoid added complexities.

**ACTION: Paola to provide update on progress of the Research Passport service project at the next meeting.**

#### **New Projects: Public Engagement in Data Research Initiative (PEDRI) Partnership**

- PEDRI, funded by UKRI with involvement from ADR UK, is a sector-wide partnership bringing together organisations who work with data and statistics to generate insights that can inform policy and practice. DARE UK has allocated funding until March 2024 for PEDRI to collaborate with the Alliance, leveraging the existing network and driving adoption of PIE standards across the Alliance, and to explore common issues across sectors. Potential topics to be addressed include, diversity in data, data access, and the commercial use of data.
- This collaboration can serve as a continuation of the previous Alliance's work dedicated to public and patient involvement, which stopped with the arrival of PEDRI.
- Nicola highlighted a growing activity in the PIE health data space. While increased involvement is positive, it raises the risk of confusion regarding roles, duplication, gaps, and unclear accountability. Several aspects need attention in the PIE space:
  - Discussions on use cases
  - Best practice for engagement
  - Active engagement in national deliberation exercises
  - Linking health data with other data assets
  - Thought leadership and policy development
- Clarity on responsibilities among various organisations and activities is crucial.
- Ian supported Nicola's concerns, noting that devolved nations can suffer ripple effect due to unclear media coverage on data access issues in England, which might not be country specific. Ensuring clarity in roles and coordinating activities across different UK regions is key due to differing policy positions.

**ACTION: Nicola to begin mapping of PIE activities and responsibilities in the health data space.**

#### **Agenda for upcoming Alliance Council (17<sup>th</sup> January)**

**ACTION: Committee to review draft agenda for Alliance Council (enclosed in email) and feedback by Wednesday 20<sup>th</sup> December.**

## Decisions & Actions

ID	Key Note / Decision	Date agreed
D001	Work Plan: Keep focus on priority areas and ensure we are not spread too thinly	04-Dec

ID	Action	Owner	Due Date
A001	Website: Executive Committee members to provide brief bio and if willing a photo for Committee page on the Alliance website	NK	31-Jan
A002	FDP: To continue monitoring the impact of the FDP on opt outs and review how the Alliance can support communication around opt-out rules, the convergence of research and care in the use cases for data, and potential implications for the Devolved Nations	ALL	Ongoing
A003	Devolved Nations: Flag new EPR system in Northern Ireland and implication for data access and data standards	IY	17-Jan
A004	Devolved Nations: Present functional anonymisation ICO piece in Scotland to wider Alliance	RH	17-Jan
A005	Membership: Consider how best to represent funders and coordination around this	DS/PQ	28-Feb
A006	Ecosystem Alignment: Janet Valentine to share info on remit and membership of Life Sciences Council Health Data Subgroup	JV	31-Jan
A007	Ecosystem Alignment: Include info on the Data Saves Lives Strategy Advisory Group and the Clinical Research Vision Data and Digital Subgroup for Delivery Partners	NP	31-Jan
A008	Ecosystem Alignment: Ian Young to provide more info on the Northern Ireland group (NI TRE Strategic Board)	IY	31-Jan
A009	Ecosystem Alignment: Feed in Scottish groups via Tom Barlow	RH/TB	31-Jan
A0010	Ecosystem Alignment: Share alternative names for the Research Advisory Group (RAG) with Michael Chapman	All	31-Jan
A0011	Work Plan: Report on current level of engagement of Alliance members to better understand where they are in terms of meeting conditions of FAIR and Five Safes	NK/PQ	28-Feb
A0012	Work Plan: Develop measures of success for the work plan objectives	NK/PQ	28-Feb
A0013	Work Plan: Ensure the work plan has UK wide coverage/balance	DS/PQ	28-Feb
A0014	New Projects: Paola to provide update on progress of the Research Passport service project at the next meeting	PQ	16-Apr
A0015	New Projects: Nicola to begin mapping of PIE activities and responsibilities in this health data PIE space	NP	TBC
A00116	Alliance Council: Committee to review draft agenda for Alliance Council (enclosed in email) and feedback by Wednesday 20 <sup>th</sup> December	All	20-Dec