

Alliance & Hub Data Officers Group (DOG)

Notes and Actions

7 February 2023

This is a summary of the key outcomes and actions from the agenda items in the quarterly HDR UK Alliance & Hubs Data Officers Group (DOG).

Summary of Actions

Action #	Action	Lead	Deadline
20230207/01	Field level metadata - - HDR schema inclusion to be resolved between HDR and the NHS D HRD team.	AE	
20230207/02	Send a generalised version of the letter to data providers inviting conversation relating to data integrity process and clinical trials.	AE	16/03/2023

1. Welcome:

The Chair (Alison Elderfield) welcomed all, especially new members to the first DOG meeting of 2023.

2. Alliance update

Review of UK HDR Alliance (the 'Alliance') governance as we transition to QQ2:

- Background of the Alliance given, including recap of principles, aims and impacts.
- Overview of the Alliance governance review being carried out due to growth, changes in the ecosystem and funding changes.
- Alliance shift to play key role in shaping health data research for infrastructure and services, with a focus for this group specifically on data standards
- Alliance membership will be extended to non data custodians to involve policy makers and there will be a focus on industry engagement. An alliance Executive Committee will be formed to represent and steer the group.

3. EHDEN call update:

- There will be a focus on driving adoption of existing standards. E.g. Adoption of OMOP common data model.

- Detail was given about the final EHDEN partnership call, including awards and data harmonisation through OMOP. Twenty-three EHDEN partners in the UK open the opportunity for data standards partnerships. This includes work around Co-Connect and Cohort Discovery on the Gateway.

4. Metadata update: Metadata specification and Federated catalogues

- A survey has been sent to specific organisations to help gauge the current landscape of metadata and data standards used for health datasets in organisations.
- Updates on federated metadata automation work includes a drive towards Phase 2 with a focus on: small bug fixes, self-onboarding for pull system, push API's, automated push onboarding and federating assets such as data use registers. This includes ongoing conversations with custodians and flexibility because there is no one standard for every custodian.

5. NHS Digital Health Research Data Catalogue API in public health beta

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- Laura Sato, Rachel Brown and Sridhar Shanmugam were introduced.
- An overview of the data catalogue includes list of available datasets and details. The catalogue is aligned to the HDR UK dataset metadata schema standard v2.0.2. Breakdown of high-level architecture was given including technology platforms, security and the onboarding process that enables use of the API to access the datasets.
- This catalogue was developed to contribute to HDR UK's federated catalogue and can be aligned with other organisations for similar use cases. This is the first use case and catalogue built and new API's can be configured if required. The catalogue will include datasets from national disease registration service.

6. Use of UK Clinical Trials healthcare datasets

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- Matt Sydes introduced. David Seymour gave background and sought input from the Data Officer's group to add value and influence.
- An overview on clinical trials, and improving clinical trials was given. Simplification of data use and high-quality evidence is a key stepping stone to improving outcomes. MHRA real-world data guidance on data quality recognises it is essential that process are established to ensure the integrity of data, this aligns with views from HDRUK, NIHR and CPRD
- This piece of work is now being expanded to other data providers and the data integrity process is being shared. Through the Alliance, letters have been sent out inviting conversation.

7. QQ2 update and discussion.

- The QQ2 strategy includes aligning geographies and sectors to bring together the health data ecosystem and unleash the power of diverse health related data. This will include moving from 1-1 trusted relationships to many-many trustworthy ecosystems and will work in partnership with NHS Data for R&D programme, DARE UK and European organisations such as TEHDAS.
- Impact will be enhanced through interactions between research driver programmes such as: Molecules to health records, Inflammation and immunity, medicines in acute and chronic care, social and environmental determinants of health, pandemics and outbreaks and big data for complex disease.

8. AOB

- Paola Quattroni raised the current role being advertised for the Data Standards Project Manager at HDR UK
- Next DOG Meeting: to be confirmed.