

Alliance Data Officers' Group Meeting

Wednesday 8th May 2024, 11:00am to 12:30pm

This is a summary of the key outcomes and actions from the UK Health Data Research Alliance Data Officers' Group (DOG).

Summary of Actions

Action	Lead
The HDR UK website will be updated with information on the data design authority including blog activities.	Alliance Team
Call for participation in the data design authority (as a member or working group) and in the federated metadata working group by interested individuals.	Interest individuals to contact Alex knight or Monica Jones

Welcome

The Chair (Geoff Hall¹) Welcomed all to the Data Officers' Group meeting. He introduced himself and encouraged everyone to introduce themselves via the chat.

1. Alliance update (Geoff Hall)

The chair described the work of the Alliance and provided an update on recent developments. He explained the aim of the data officers' group and its focus to bring about solutions to issues with data curation, quality, and data standards.

The chair invited **Paola Quattroni (Head of Alliance Strategy and Engagement)** to provide a brief update:

- In the past few months, the Alliance has welcomed five more members which include; The National Institute of Health and Care Excellence (NICE), Data Research Access and Governance Network (DRAGoN), UK Health Security Agency (UKHSA), NIHR Yorkshire and Humber Patient Safety Collaboration (PRSC) and National PET Imaging Platform.
- The Next Alliance council meeting is due to be held on the 22nd of May, followed by a Transparency Showcase celebrating 19 successful Trust and Transparency projects.

¹ Professor of Digital Health, University of Leeds; Honorary Consultant in Medical Oncology, Leeds Cancer Centre; Chief Clinical Information Officer, LTHT; and Chief Clinical Data Officer, HDR UK.

2. openEHR Why it Matters for Health and Care Data-Rachel Dunscombe (CEO-openEHR).

[Link to slides: [OpenEHR why it matters for health & care data](#)]

This presentation discussed the role and activities of openEHR for health and care data. Key points are highlighted below:

- openEHR is a membership organization established to ensure high-quality data engineering and integration. Originating from the WHO's guide to international standards, openEHR aims to provide a solid foundation for the interoperability of healthcare data.
- A recent paper titled: [Converge or Collide? Making Sense of a Plethora of Open Data Standards in Health Care](#) was published, discussing the synergy between openEHR, FHIR, and OMOP. The paper advocates for a complementary rather than competitive approach among standards bodies.
- An economic analysis commissioned by the Treasury highlighted the value of standardized data to the UK economy and the NHS. This led to collaboration with EY UK to explore the global standardization of data and economic benefits to social healthcare systems like the NHS.
- openEHR has expanded its membership, working with affiliates in countries such as Germany, Finland, Switzerland, and the USA. The organization is governed by various committees, including the Specification Committee, Clinical Program Board, Software Board, and Education Program Board, which provide updated documentation and support to the community.

3. Clinically Led APP development- John Meredith (Programme director at openEHR)

[Link to slides: [clinically led app development](#)]

This presentation explored the potential of using openEHR to support the Wales Cardiac Network, specifically focusing on the acute coronary syndrome (ACS) as a use case.

- The inefficient process of data collection by the method of collating national audit data involves filling out spreadsheets and sending them via email, without direct access to the data stored in physical files and highlighted the need for a more integrated and accessible data management system.
- The development of the openEHR model included analysing the existing openEHR framework to determine its applicability, designing specific models tailored for the ACS use case, and validating the results. The aim was to create models that support clinical knowledge managers. These involved; Analysing and designing models specific to the

ACS pathway, validating results and publishing components within the openEHR framework and iteratively refining models to ensure accuracy and relevance.

- The ACS pathway covers various types of data, including demographic information, referral pathways, medical history, and treatment details, spanning seven different care boundaries. Early challenges included relying on audit data for clinical applications, which proved to be inadequate. The detailed representation of clinical models in openEHR provides a robust blueprint for health data, ensuring comprehensive and interoperable electronic health records.
- openEHR supports interoperability by providing a detailed and flexible data structure. However, HL7 FHIR operates in an aggregated data space, which complements openEHR detailed approach. While openEHR can serve as a single source of truth, its applicability depends on the specific use case.
- Challenges in reusing and modifying data models were discussed, particularly the risk of system disruptions and the need for careful API management.
- The Wales Cardiac Network has embraced openEHR for quality improvement. An ACS pathway using openEHR is set to be published and rolled out in Wales, with the potential for national implementation. This initiative aims to enhance the accuracy and usability of clinical data, ultimately improving patient care and outcomes.

4. OpenEHR Tech Overview Ian McNicoll (Consultant at openEHR)

[Link to slide: [openEHR tech overview](#)]

This presentation highlights the challenges of managing and standardizing diverse data types, and how openEHR addresses these challenges by providing a technical framework that ensures interoperability and vendor neutrality.

- Digitizing healthcare involves managing complex data types, with significant challenges in handling and standardizing this data. openEHR addresses these challenges by providing a technical framework that separates applications from data, allowing for interoperability and vendor neutrality.
- One of the key features of the openEHR clinical data repository is a no code/low code data source, Vendor-Neutral Information Model; as it enables various vendors to interact with a standardized clinical data repository, and its composition-based data submission; where data is submitted form of compositions, which are structured documents that can be individually queried and accessed at a granular level.
- In terms of Querying and data management: It has Archetype Query Language (AQL) which is similar to SQL but path-based. AQL allows for detailed querying of data, with the ability to exclude specific sectors. While AQL does not support population queries and may impact performance, data can be exported to traditional databases for extensive research queries. To support population query for research purposes, openEHR data can be exported to traditional databases to facilitate complex queries and analyses.

- We are also working on a second model; re platforming openEHR in Sweden, allowing data scientists to run the set of AQL, run the raw data and tidy it up into their registry format to allow more granularity.

5. Data design Authority (Monica Jones, Associate Director for Data Standards & National Strategic Lead. HDR UK)

[Link to slide: [Data Standards and Data Design Authority](#)]

This presentation discussed the newly established Data Design Authority, its aim and updates from the first meeting held on the 29th of April. Key points are highlighted below:

- The Data Design Authority (DDA) was established to provide a convergence with the Driver Programmes to support colleagues in terms of data standards.
- The first meeting was held on the 29th of April. The meeting was well-attended, and terms of reference were agreed upon, allowing the group to start its work.
- The first use case emerged from the Information and Immunity Driver Programme, led by Chris Orton at Swansea University. This initiative focuses on systematic data curation across five driver programmes, enhancing national-scale research-ready data assets. It emphasizes efficient implementation and integration within existing infrastructure and technical goals. Specifically, the project aims to curate respiratory datasets for COPD, asthma, and ILD across the four UK nations, ensuring standardized data collection and usage.
- The second use case is from the Medicines in Acute and Chronic Care Driver Program, led by Tony Brookes (Leicester University) and Suzy Gallier (University hospital Birmingham NHS foundation Trust). This involves creating a consistent metadata catalogue for each project, building on work from Leicester, and aligning it with the HDRUK gateway metadata model for improved data management and discovery.
- The DDA will identify and address challenges across all of the driver programs, including molecules to health records, social environmental determinants of health, and big data for complex diseases. The DDA will also liaise with external advisory bodies and will consider restarting the Federated Metadata Working Group to enhance collaboration and standardization efforts.
- The next meeting is scheduled for July 1st. The DDA invites participation from interested parties and will update the HDRUK website with details. Blogs and other communications will share ongoing activities and progress.

6. New Gateway Metadata-Isaac Odiase (Chief Product Owner, HDRUK).

[Link to slide: [New Gateway Metadata and Demo](#)]

This presentation delved into the current development and future plans of the gateway which was established in 2021. Key points noted are highlighted below;

- The primary focus is to evolve the gateway beyond just data discovery to support researchers throughout their entire research journey. Additionally, we aim to integrate



community aspects into the gateway, fostering collaboration and incorporating solutions from the wider community, aligning with the principles of our enhanced gateway development.

- The current gateway includes a robust search function, with over 850 metadata descriptions and a data access model created in collaboration with the UK and Alliance Group. It also features a data use register and more than 300 tools and publications. Recognizing the evolving needs, we conducted numerous user workshops and requirements-gathering sessions to develop the Enhanced Gateway, set to be released in summer 2024.
- The Enhanced Gateway aims to support researchers throughout their entire journey, not just in data discovery. We are emphasizing automation, community involvement, and scalability. Key improvements include handling multiple metadata schemas, automating metadata onboarding, and enhancing search functionality with natural language processing and ontology mapping. These enhancements will address current limitations and improve user experience.
- We seek support from the data officers' group to enhance metadata quality and assist in testing the preproduction environment and also gateway data custodians to improve metadata quality on the gateway. Contact: Ping.Yu@hdruk.ac.uk.

Discussions

During the meeting, there was a discussion about the involvement of healthcare practitioners with openEHR amid the dominance of US-based commercial EHR providers. It was acknowledged that promoting open and standardized data with these vendors is challenging, particularly in the UK, which is a secondary market compared to the USA. Despite these challenges, other countries are also advocating for open standards, which may help facilitate broader adoption of openEHR.

The applicability of openEHR in clinical trials was also discussed, with a notable example being its use in stage four cancer trials in the USA. Additionally, a life science affiliate has been established to support global life sciences initiatives, focusing on developing an open-source trial system. This represents a significant move towards utilising openEHR for comprehensive and accessible clinical trial management.

There was also a brief discussion on federating metadata within the SDE network and the HDR gateway. The importance of coordinating these efforts was emphasized to prevent collaboration issues arising from uncoordinated datasets. This suggests potential collaboration if the work of the DDA aligns with the goal of federating metadata, especially considering the existence of sub-national SDEs.

While the impact of the new gateway was welcomed/anticipated, concerns were expressed about maintaining ease of use for data controllers and providers. The importance of balancing the needs of researchers with those of data providers to ensure continued dataset uploads was stressed. In response, it was highlighted that efforts are underway to automate data onboarding and that continuous engagement with data controllers and researchers will be prioritized.

Funding Call for Real World Evidence Network Coordinating Centre: A reminder was issued regarding the HDRUK funding call for the Real-World Evidence Network Coordinating Centre.

OHDSI UK Meeting: Scheduled for September 27th at the Wellcome Trust in London. Due to the high interest, a waiting list has been initiated.

OHDSI Europe Meeting: Alex Knight (Project Manager-Data Standards) will attend this event in Rotterdam at 1-3rd of June and will present on the adoption of OMOP across the UK.

OMOP Special Interest Group Meeting: Scheduled to take place 28th June 2:30pm-4pm. **Next Data Officers Group Meeting:** Scheduled for September 3rd, 2024

Attending Organisations

- Cancer Research UK
- Cystic Fibrosis Trust
- Department of health and social care
- Discover Now
- Ethical Healthcare
- Genomics England
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Health Data Research UK
- Health and Social Care Northern Ireland
- Healthcare Quality Improvement Partnership
- Imperial College London
- Imperial College Healthcare NHS Trust
- Intensive Care National Audit and Research Centre
- National Joint Registry
- National institute for Health and care research
- NHS England
- Optimum patient care
- openEHR
- Research data Scotland
- Royal College of General Practitioners
- Smart Data Research
- techUK
- The Brain Tumour Charity
- The National Institute for Health and Care excellence
- The Royal Marsden NHS Foundation Trust
- The University of Edinburgh
- University of Bristol
- University of Dundee
- University of Leeds
- University Teaching Hospital Leeds
- UK Research and Innovation- Economic and Social Research Council
- UK Health Security Agency