UK Health Data Research Alliance

Dear Alliance Member

This month, we shine a spotlight on the newest members who have recently come onboard. We also provide news and updates from existing members, a brief overview of the key topics covered at the Alliance Council meeting, updates on the adoption of standards and the OMOP common data model, plus much more.

News from the UK Health Data Research Alliance

UK Health Data Research Alliance sees steady growth in membership

Last month we were delighted to welcome three new members to the Alliance;

- **UK Dementia Research Institute (UKDRI)** – the UK's leading biomedical institute dedicated to neurodegenerative disease, and to changing the lives of the millions affected by dementia worldwide.
- **Medical Research Council (MRC) National Survey of Health and Development (NSHD)** – the oldest and longest running of the British birth cohort studies.
- **British Regional Heart Study (BRHS)** – a long-term cohort study investigating the causes of cardiovascular disease (CVD) in men and seeking to understand the effect of co-morbidities on CVD and ageing.

>> Read full announcement

Highlights from the first Alliance Council

On Friday 28th April we held the first Alliance Council Meeting, bringing together all Alliance Members.

Guest speakers presented a series of lightening talks on:

- Industrial Strategy Challenge Fund (ISCF) Data to Early Diagnosis and Precision Medicine retrospective and plans for commercial access to data.
- Data harmonisation and standardised methods, through efficient, transparent, reproducible and scalable research.

DataLoch enhancements

Since the full launch of the DataLoch service in August 2022, support for researchers has further expanded. For example, new demographics and observation tables substantially improve the reliability and coverage of these data and enable more intuitive access to data such as ethnicity, sex, smoking status, and blood pressure.

In addition, the new DataLoch Respiratory Registry improves support for respiratory-related research and aligns with existing registries in England and Wales, offering significant opportunities for research across the three nations. The DataLoch team will add further registries in the future, with the next focused on cardiology.

>> Discover the latest DataLoch updates

Improving data standardisation through implementation of OMOP CDM

The Alliance will convene the community of OMOP users through the creation of a Special Interest Group for the **OMOP Common Data Model**. The Group will support this community, including those who are (or would like to be) engaged in transforming data to the CDM, and also those using it for research. It will provide a forum to share knowledge, experience, and tools.

The first meeting of the Special interest Group is scheduled for 27th June 2023. To express an interest in joining, email **ukalliance@hdruk.ac.uk**

>> For more information, see the Alliance **Data Standards** web page.

In other news

What's been happening across the ecosystem....

Professor Cathie Sudlow to lead CMO commissioned review on data flows

The Chief Medical Officer for England Professor Chris Whitty, NHS England's National Director of Transformation Dr Timothy Ferris and the UK's National Statistician Professor Ian Diamond have commissioned a review of UK wide data flows of health data aiming to address barriers and find solutions to these in England. Professor **Cathie Sudlow**, Chief Scientist, Deputy Director of HDR UK and Director of BHF Data Science Centre who is leading the review, presented the ask and approach at the Alliance Council Meeting. Terms of Reference for the review are available **here**. Alliance members are invited to contribute by contacting **ukalliance@hdruk.ac.uk**.

STANDING Together - Public consultation on draft recommendations for healthcare dataset standards supporting diversity, inclusivity, and generalisability.

The **STANDING Together** initiative proposes that health datasets should be developed and reported with inclusivity and diversity in mind. Its recommendations aim to ensure that AI healthcare technologies can be built and tested on adequately representative data. It is essential that the recommendations are 'sense-checked' by as many people as possible, who can bring their diverse experiences and knowledge to challenge and improve them.

>> Find out more and respond to the consultation

Thank you for reading!

If you have any news or updates from across your organisation, that you'd like us to share with other Alliance Members please send details to **ukalliance@hdruk.ac.uk** and we will look to include this in the next community bulletin.