UK Health Data Research Alliance

Dear Alliance Member

In case you missed it, last month the UK Health Data Research Alliance celebrated its 5th anniversary and we published a [news piece](#) and [blog](#) to mark this significant milestone. Alliance members united at the HDR UK Annual Conference to celebrate the latest advances in health data science and many have taken part in Alliance working group sessions, which we share outputs from below. Finally, make sure you check out the 'upcoming events' where we share details of key Alliance events happening in April.

News from the [UK Health Data Research Alliance](#)

Alliance Members receive recognition for their work at the 2024 HDR UK Annual Awards

We were delighted to see many familiar faces at the 2024 HDR UK Conference in Leeds earlier this month, and huge congratulations to Alliance members Lancashire Teaching Hospitals who won the prize for Team of the Year and Understanding Patient Data (UPD) who took home the Public and Patient Involvement and Engagement prize at the HDR UK 2024 Annual Awards. Also special mention to the Trusted Research Environment Data Access Agreement Template which received an award recognising reproducibility.

>> **Find out more**

use MY data - Bring your voice to our patient movement.

use MY data is the only independent patient movement in the UK focused on promoting the responsible, accountable use of patient data. If you are a patient, relative or carer who cares about your patient data being used to save lives and improve outcomes, please join us. Membership of use MY data is free.

>> **Find out more**

The Alliance establish a regular forum to discuss the barriers to effective use of healthcare systems data in clinical trials.

Chaired by Prof [Matthew Sydes](#) (UCL) and Associate Prof [Marion Mafham](#) (University of Oxford), this sub-group of the Alliance aims to facilitate an exchange of ideas between data providers, consumers of trial results and the wider trials community, covering how challenges can be addressed and to prioritise the necessary actions to realise the potential benefits.

>> **[Read meeting report](#)**

Outputs from the latest Alliance Data Officers group meeting.

This first Data Officers Group meeting of 2024 was chaired by [Geoff Hall](#), with presentations from Tim Beck (University of Nottingham) on the GA4GH Beacon v2 standard for genomic and clinical data discovery and [Monica Jones](#) (Leeds University) on priorities for data standards.

>> **[Read meeting report](#)**

In other news
What's been happening across the ecosystem....

Support us with the development of the HDR UK Patient and Public Involvement and Engagement Strategy.

HDR UK have launched our draft Public and Patient Involvement and Engagement (PPIE) strategy and we are seeking input from patients, carers, the public, and wider stakeholders to make sure our strategy accurately reflects the needs and preferences of our diverse communities. Read about our goals and objectives and share your views by completing our short online survey. This public consultation closes on **12 April 2024.**

>> **[Find out more about our consultation](#)**

Health Research Authority (HRA) launch their Make it Public campaign.

#MakeitPublic is a campaign dedicated to research transparency. HRA's vision is for trusted information from health and social care research to be publicly available for the benefit of all. For #MakeitPublic Week 2024 (18 - 22 March), the focus is on increasing research registration rates and on Thursday 21 March they're holding a free online workshop to address the barriers to registering research.

>> **[Find out more](#)**

Launch of EOSC-ENTRUST - driving European interoperability for sensitive data access and analysis.

EOSC-ENTRUST, an EU-funded project led by ELIXIR and the EUDAT Collaborative Data Infrastructure (CDI), aims to build a European network of Trusted Research Environments (TREs) for sensitive data and develop a common blueprint, or reference architecture, for federated data access and analysis.

>> **Find out more**

Launch of QUANTUM: "Developing a Data Quality and Utility Label."

Funded by Horizon Europe, the objective of the QUANTUM project is to create a common label system for Europe that will allow its use in all countries for scientific and health innovation purposes. These labels will enable researchers to use data with a notion of the quality and utility that will ensure that their research and innovations are effective and provide value to society.

>> **Learn more**

Upcoming Alliance Events

18.04.24 (14:00 - 15:30) Clinical Trials Prioritisation Forum meeting #2

This meeting will put a spotlight on the perspective of data custodians regarding access to data for clinical trials and consented cohorts, as well as the challenges faced by researchers and the costs and impacts associated with addressing them.
>> **Register here**

08.05.24 (11:00 - 12:30) Alliance Data Officer Group meeting

Topics covered in this meeting will include data formation-cohort discovery tool functionality, data curation and drivers programme-data quality.
>> Email **ukalliance@hdruk.ac.uk** to join

22.05.24 (10:00 - 13:00) Alliance Council meeting and Transparency Showcase (*online and in-person*) at Wellcome Trust, 215 Euston Road London

NW1 2BE.

Join us at the quarterly Council meeting where we will share developments across the landscape, discuss best practice in data use and evaluate outputs produced by current Alliance working groups.
>> To join online, please email **ukalliance@hdruk.ac.uk**
>> To join this event *in-person,* please **register here**

This meeting will be followed by the **Alliance Data Access Transparency Showcase** in-person event (13:30 - 17:00) **More information**

Other Events

24.04.24 (10:00 - 15:30) HDR UK Advanced Computer Science Summit: AI and Healthcare

Hear about the future of advanced computation in healthcare and discuss the impact these may have on our research. We have a great line-up of speakers including Frank van Harmelen, Alessandra Russo, Mark Parsons, Elham Kashefi, Honghan Wu, William Whiteley and Mobuolafoluwa Onayade.
>> **Register here**