UK Health Data Research Alliance

Dear Alliance Member

Welcome to the April edition of the UK Health Data Research Alliance monthly bulletin! In this issue, we shine a light on the three new members who have recently joined our community. We also delve into the latest advancements in health data research with the latest news from existing members, Health Data Research UK (HDR UK) and the wider sector.

News from the UK Health Data Research Alliance

Three new members join the UK Health Data Research Alliance to transform data for public benefit

This month, the UK Health Data Research Alliance welcomes three new members. The new members are: National Institute for Health and Care Excellence (NICE), Data Research Access and Governance Network (DRAGoN) and UK Health Security Agency (UKHSA).

Our recent news announcement provides more information about the work of each of these member organisations.

>> **Read news announcement**

Mapping the world of charity-supported patient registries

More and more medical research charities are harnessing the potential of patient data registries to address the needs of their communities. In this blog, **Liz Perraudin** provides an overview of the recent research study carried out by the Association of Medical Research Charities (AMRC), what's next and how this work will continue to develop over the coming year.

>> **Learn more**

Go behind the scenes at DataLoch

A crucial part of DataLoch's work is making health and care data research-ready. Recently, they have curated a single overview of lifestyle data, started an

exploration of the risks around the sharing of free-text data for research, and are collaborating with researchers to better understand later life through data.

>> **Learn more**

The National Pathology Imaging Co-operative (NPIC) celebrates major milestone

This month, the National Pathology Imaging Co-operative (NPIC) proudly announced that all six NHS Trusts within the West Yorkshire Pathology Network are now live on the NPIC digital pathology platform. Pathology labs in 6 trusts in the region are now fully digital and connected into a shared network, bringing benefits to clinicians and most importantly to patient care.

>> **Read more**

Coming soon: the Scottish Safe Haven Charter 2.0

To meet the demands of Scotland's changing data landscape Research Data Scotland (RDS) recently announced that a new Safe Haven Charter is coming in 2024. This Charter sets out agreed principles and standards for the Scottish Safe Havens to handle data and work as a federation, as well as emphasising the paramount importance of process transparency.

>> **Find out more**

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

The Information Commissioner's Office (ICO) publishes guidance to improve transparency in health and social care

Anne Russell, Head of Regulatory Policy Projects says, "With this bespoke guidance, we want to support health and social care organisations by improving their understanding of effective transparency, ensuring that they are clear, open and honest with everyone whose personal information is being used."

>> **Read more**

Professor Andrew Morris elected as President of the Academy of Medical Sciences

This prestigious appointment not only reflects Andrew's outstanding leadership of Health Data Research UK (HDR UK) but highlights his significant contributions to the medical science community at large. Andrew will formally take up the role from 25 April, succeeding Professor Dame Anne Johnson.

>> **Read news announcement**

Call for funding to establish a Real-World Evidence Network Co-ordination Centre for the UK

HDR UK launched a funding call to establish a co-ordination centre for a pilot real-world evidence network that will utilise data gathered from multiple UK sources. The aim of the Network is to demonstrate the potential of the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) as an enabler of efficient cross-nation research studies. **Apply by 13 May 2024**

>> **Full details here**

Major research and innovation infrastructure investment announced

Five new infrastructure projects are to share £388 million, with additional £85 million to support UK Research and Innovation (UKRI)'s Digital Research Infrastructure Programme. The multimillion pound investments will equip the UK's research and innovation base for the future.

>> **Learn more**

Upcoming Events

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

This meeting will focus on data curation, new functionalities of the Innovation Gateway and outputs from the first Driver Programmes Data Design Authority meeting.

>> Email **ukalliance@hdruk.ac.uk** to join

22.05.24 (10:00 - 13:00) Alliance Council meeting (*online and in-person***)**

Venue: 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**

22.05.24 (13:30 - 17:00) Alliance Data Access Transparency Showcase *(in-person)*

Venue: Wellcome Trust, 215 Euston Road London NW1 2BE

Join us as we celebrate the completion of the **19 projects** that were awarded funding, with the aim of improving the clarity and accessibility of information about data access processes for the public and researchers.

>> **More information and register**

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.