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# UK Health Data Research Alliance



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**Dear Alliance Member**

February 2024 marks a significant milestone for the UK Health Data Research Alliance as we celebrate 5 years of this influential programme. Below, read more about our incredible journey and join us as we celebrate our past accomplishments and look ahead to the future!

Also in this edition, we share updates on our latest projects and showcase the inspiring work of our members as we reaffirm our commitment to leveraging data for better health outcomes.

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

## **Celebrating 5 Years of the UK Health Data Research Alliance**

As we mark this significant milestone we reflect on the incredible journey of collaboration, discovery, and innovation that brings us closer to delivering the

Alliance's mission. Some of the standout moments from the past 5 years include: Expanding our membership, accelerating data discovery and access, recognising the potential of TRE's, improving transparency, and embracing international standards.

>> [Read news announcement](#)

>> [Read blog](#)

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### **Swansea University receives Queen's Anniversary Prize for work of world-leading SAIL databank**

The award was presented to Swansea University at a ceremony held at Buckingham Palace, in recognition of the contribution for harnessing public data to improve population health and wellbeing through its world-renowned [Secure Anonymised Information Linkage Databank \(SAIL databank\)](#). Swansea University is among a small group of institutions to have won the award with consecutive submissions.

>> [Read more](#)

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### **ELIXIR, the European infrastructure for biological data, celebrates its 10-year jubilee**

Over the past ten years, ELIXIR has facilitated access to life sciences data for researchers in ELIXIR member states and beyond, accelerating research in this field. With this [Scientific Programme for 2024–2028](#) and under the new directorship of Prof. Tim Hubbard from March '24, ELIXIR moves closer to societal challenges.

>> [Read more](#)

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### **Research Data Scotland welcomes Dr Emma Gordon as advisor to board**

The Research Data Scotland (RDS) board is responsible for the effective governance and development of Research Data Scotland. Dr Gordon brings valuable insights into the administrative data landscape across the UK and will work with other Board members to support delivery of the RDS strategy.

>> [Read full news announcement](#)

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**In other news**

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

### **Aridhia adopts Alliance's Data Access Agreement Template**

Last month, Aridhia shared the news that they had integrated the UK Health Data Research Alliance template data access agreement (DAA) into Aridhia Digital Research Environment (DRE), ensuring that data is used in a safe and secure manner.

>> [Read more](#)

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### **Ethnicity data resource in population-wide health records: completeness, coverage and granularity of diversity**

Intersectional social determinants including ethnicity are vital in health research. [Sara Khalid](#) from the University of Oxford, recently led on the first in-depth study of patient ethnicity data collected in the NHS. This study highlights gaps in ethnicity data collection and its impacts on health AI.

>> [Read full paper](#)

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### **The role of the Confidentiality Advisory Group (CAG) in 2024**

Dr Tony Calland MBE reflects on the role of CAG, outlines its achievements in 2023 and provides an overview of the key themes for CAG in 2024, which include patient and public involvement, application uncertainty, AI processing and improving public trust in the use of confidential data through Secure Data Environments.

>> [Read full blog](#)

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## **Upcoming Events**

### **13.03.24 (13:00 - 14:30) PEDRI/Alliance workshop**

The Alliance is partnering with PEDRI (Public Engagement in Data Research Initiative) to discuss public involvement and engagement priorities of Alliance members, partner organisations, and others. The workshop will also explore ways to reduce complexities and drive adoption of best practice.

>> [Register here](#)

### **18.04.24 (14:00 - 15:30) Alliance Clinical Trials Stakeholder Prioritisation Forum**

Alliance members in the trials community are invited to this Alliance special interest group meeting to discuss the barriers to effective use of healthcare systems data in clinical trials.

>> [Register here](#)

### **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](mailto: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](#)

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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](mailto:ukalliance@hdruk.ac.uk) and we will look to include this in the next community bulletin.

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