

# UK Health Data Research Alliance



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## Dear Alliance Member

In this month's Alliance Community Bulletin, we bring you a selection of updates from across the ecosystem, including the recently published initial draft of the DARE UK federated architecture blueprint for sensitive data research, details about how to incorporate more PPIE in your work with the help of HDR UK Voices, upcoming Alliance events, plus much more.

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

### Join the HDR UK Voices partner network



Have you ever wanted to reach out to the public about an involvement opportunity, but not known where to start? Become part of our [HDR UK Voices partner network](#), and we'll share your involvement opportunities with the HDR UK Voices public network. By signing up, we'll also let you know about public involvement opportunities by other partner organisations which you can share with your own public networks.

If you'd like to sign up to the HDR UK Voices partner network, please email Rachel at [Rachel.Edwards@hduk.ac.uk](mailto:Rachel.Edwards@hduk.ac.uk).

[>> Find out more about HDR UK Voices](#)

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## Secure Data Environment Network Market Engagement

NHS England would like to hear from technology vendors, service providers and systems integrators who have expertise (or an interest) in supplying capability to SDEs, and/or contributing to an open-source project for a framework for NHS SDEs.

All industry providers are invited to attend an initial briefing call via MS Teams with NHS England SDE programme leads on **Friday 21st April at 13.30 to 14:15**

[>> More information here](#)

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## HDR UK Black Internship Programme continues to gather pace

The Black Internship programme has experienced significant growth in both applications and internship placements since its inception in 2021. The internships programme for 2023 will get underway on 3rd July, and ahead of the launch we are pleased to share some insights from this years application process.



We received a staggering 660 applications for the 2023 programme, and have already placed 93 interns, with recruitment still ongoing. We would like to thank all of our host organisation for your continued support.

[>> Find out more about the Black Internship Programme](#)

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### In other news

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

#### **Request for comments: Initial draft of the DARE UK federated architecture blueprint for sensitive data research**

The DARE UK programme has designed an initial draft architecture blueprint for its proposed federated network of Trusted Research Environments (TREs) to strengthen research using sensitive data in the UK. This was carried out in consultation with data research experts and following global best practices. The draft is now open for review and comments to gather diverse perspectives from key stakeholders and the public.

Please [read the report](#) and share your thoughts by completing [this survey](#) which will be open until **26 May 2023**. We appreciate your contribution and look forward to your valuable insights.

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#### **Article: Contextualising adverse events of special interest to characterise the baseline incidence rates in 24 million patients with COVID-19 across 26 databases: a multinational retrospective cohort study**

Adverse events of special interest (AESIs) were pre-specified to be monitored for the COVID-19 vaccines. Some AESIs are not only associated with the vaccines, but

with COVID-19. Our aim was to characterise the incidence rates of AESIs following SARS-CoV-2 infection in patients and compare these to historical rates in the general population

[>> Read full article](#)

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## Celebrating the relaunch of Understanding Patient Data

Understanding Patient Data (UPD) has been relaunched today and is now based at the NHS Confederation. UPD is an initiative which aims to make the way patient data is used more visible, understandable and trustworthy, for patients, the public and health professionals. Its new phase will focus on health data policy, data transformation and population health management and use.

[>> Find out more about UPD's plans and how to get involved here](#)

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## Upcoming Events

### 27 April at 10:00 - Improving Access to Linked Data for Research workshop

We aim to convene key stakeholders to address current barriers to linking consented data with routinely collected health data without undermining trust, accuracy, and collaboration. [Register here](#)

### 28 April at 13:00 - Alliance Council Meeting

Senior representatives from all member organisations meet on a quarterly basis to share developments across the landscape, discuss best practice in data use and evaluate outputs produced by current Alliance working groups. If you wish to join the next Alliance Council meeting, please email [ukalliance@hdruk.ac.uk](mailto:ukalliance@hdruk.ac.uk)



Join us at the next [Diversity in Data - Ethnicity coding working group](#).

Based on feedback from previous working group sessions, we have drafted a set of recommendations for key areas of improvement around recording of ethnicity data, which will be discussed and refined in this final meeting. We have a fantastic line-up of expert speakers who will share their insights and perspectives on 6 key themes:

#### 1) The purpose and value of capturing ethnicity data

Speaker: [Sara Khalid](#) (Oxford University)

#### 2) Ethnicity data standardisation

Speakers: [Vahé Nafilyan](#) and [Rose Drummond](#) (ONS)

#### 3) Communication and transparency

Speaker: Della Ogunleye ([STANDING Together](#) subcommittee members)

**4) Training and guidance for ethnicity data collection**

Speaker: [Jonathan Valabhji](#) (NHS England)

**5) Data Linkage to improve data completeness**

Speaker: [Angela Wood](#) (University of Cambridge)

**6) International harmonisation**

Speaker: [Alastair Denniston](#) (INSIGHT Hub)

If you are passionate about creating a more inclusive and equitable future for all, then we encourage you to attend and share your insights and perspectives on this critical issue.

[Register here](#)

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### Thank you for reading!

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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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