

# UK Health Data Research Alliance



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**Dear Alliance Member**

This month, we provide you with an update on three of the Alliance Special Interest Groups; Diversity in Data, OMOP CDM and Using Linked Data for Research. We also invite Alliance Members to provide feedback on the DHSC "Data access policy update: proposed draft" and the PEDRI draft Public Involvement and Engagement Best Practice Standards. Finally, don't forget to check out the upcoming events section at the bottom of the page.

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

**UK Health Data Research Alliance calls for action to improve coding of ethnicity data**



The Alliance and its members have a key interest in tackling health inequalities and meeting the needs of underserved groups in the UK. This opinion piece outlines the work of the Alliance Diversity in Data Ethnicity coding special interest group to-date and the next steps to carry this work forwards.

[>> Read full article](#)

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### **Mapping the UK landscape of data standards adoption**

The Alliance is undertaking a survey of the UK landscape in health data standards, particularly the OMOP Common Data Model. We're very keen to hear from data custodians, data users and researchers about their use of the CDM and other standards – or their reasons for not adopting them! Please complete our questionnaire using [this link](#), or scan the QR code. The survey will close on **Friday 30th June**.



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### **Using Linked Data for Research: Challenges and Opportunities within the UK Health Ecosystem**

The Alliance recently conducted a series of working group sessions to address the challenges and opportunities associated with utilising linked data for health research in the UK. [Read more](#) about this Special Interest Group, and next steps.

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### **World's largest imaging study begins exciting second stage to re-scan 60,000 UK Biobank volunteers**

UK Biobank's biomedical database is already the most comprehensive database in the world for scientific and health related research. The repeat imaging of thousands of volunteers will enable many more fundamental discoveries, better understanding of early disease stages, accelerate research into early diagnosis and support the development of new treatments.

[>> Learn more about it](#)

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### **In other news**

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

#### **Open consultation - Data access policy update: proposed draft**

The Department for Health and Social Care (DHSC) has launched a consultation on "[Data access policy update: proposed draft](#)". This policy proposes a system of 'data access as default' for the secondary uses of NHS health and social care data under the [Data Saves Lives Strategy](#). This change will be supported by the implementation of secure data environments (SDE's) across the NHS in England.

You can send your feedback by emailing [dataaccesspolicy@dhsc.gov.uk](mailto:dataaccesspolicy@dhsc.gov.uk). The consultation deadline is **Friday 23 June**.

[>> Read the full proposal here](#)

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### **Commercial clinical trials in the UK: the Lord O'Shaughnessy review**

This review was commissioned to offer recommendations on how commercial clinical trials can help the life sciences sector unlock UK health, growth and investment opportunities. This publication provided 27 recommendations to the UK government for action.

[>> Final report](#)

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## Public Involvement and Engagement Best Practice Standards Open Consultation



The Public Engagement in Data Research Initiative (PEDRI) have launched an open public consultation on their draft Public Involvement and Engagement Best Practice Standards for the use of data for Research and Statistics. PEDRI welcome feedback from Alliance Members on these [draft standards](#) via [this survey](#). The deadline for submitting feedback is **Friday 30th June**.

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### Upcoming Events

#### **27.06.23 - Alliance Special Interest Group on the OMOP Common Data Model**

The inaugural meeting of this Special Interest Group devoted to the OMOP CDM will be chaired by Dani Prieto-Alhambra and Geoff Hall. We hope that the group will provide a forum for users to share knowledge, experience, and tools when mapping data to OMOP and using transformed data. [Register here](#) for this online event.

#### **28.06.23 - UK TRE Community Meeting**

The online event is hosted by the UK TRE Community and is aimed at Research Software Engineers (RSEs), researchers, Trusted Research Environment (TRE) users, developers and enthusiasts to collaborate on and communicate about open-source TRE infrastructure. For more information and to register [click here](#).

#### **04.07.23 - HDR UK Midlands Regional Community Event**

This in-person event is to celebrate the successes of the region in QQ1 and discuss the future activities of the region and collaboration for QQ2. All are welcome to attend. [Click here](#) to view the agenda. [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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