

UK Health Data Research Alliance Council

Actions and meeting notes

Friday 28th April 2023 (13:00 – 15:00)

Immediate actions for Alliance members:

- Contact us via ukalliance@hdruk.ac.uk if you would like to input on the CMO commissioned review on data flows by Professor Cathie Sudlow.
- Register for the upcoming [workshop on diversity in data](#) on 24th May, if you would like to actively shape recommendations on recording of ethnicity data. Registration will close on Monday 15th May 2023 at 8pm.

Actions for HDR UK secretariat:

- Circulate slides presented at the meeting to all attendees.

Meeting notes:

Welcome, introductions and opening remarks

Andrew Morris, Alliance Chair and Director of HDR UK welcomed the attendees and highlighted key points within the Convenor's paper.

Andrew welcomed [three new members to the Alliance](#), including:

- MRC Unit for Lifelong Health and Ageing
- UK Dementia Research Institute (UKDRI)
- British Regional Heart Study (BRHS) UCL

Action points from the last meeting update on governance and workstreams

Paola Quattroni, Head of Alliance Engagement and Strategy, HDR UK, updated on previous action points from the last Alliance Board meeting and Alliance workstreams, thanking relevant contributors.

- Progress has been made on development of an Alliance Executive Committee, to provide input on Alliance strategy and prioritisation. To date, Roger Hallyday, (Research Data Scotland), Ian Young (Health and Social Care Northern Ireland), Alex Newberry (Welsh government) and Janet Valentine (ABPII) have agreed to join the Committee.
- The 'Improving Access to Linked Data' working group held the third working group session on 27th April 2023. Outputs and summary will be shared on the [Alliance website](#).
- The 'Diversity in Data' working group have now held 3 working sessions on Ethnicity Coding standards and will be writing a recommendations paper on best practice for the collection of



ethnicity data. The final in-person working group will be held 24th May 2023. For more details, see the [Alliance website](#).

CMO commissioned review on data flows

The Chief Medical Officer for England Professor Chris Whitty, NHS England's National Director of Transformation Dr Timothy Ferris and the UK's National Statistician Professor Ian Diamond have commissioned Professor Cathie Sudlow, Chief Scientist, Deputy Director of HDR UK and Director of BHF Data Science Centre, to conduct a review of flows of health data.

Cathie shared her slides on the [Review of UK health data flows and how they can be improved](#). [Paper F](#) includes the Terms of Reference for the review.

Cathie invited Alliance members to contribute by reaching out via ukalliance@hdruk.ac.uk.

Panel presentations: Industrial Strategy Challenge Fund (ISCF) Data to Early Diagnosis and Precision Medicine retrospective and plans for commercial access to data:

- Ian McKay, Deputy Challenge Director at Innovate UK, John Nolan, Senior Health Data Scientist at BHF Data Science Centre and Jonathan Cook, University Lecturer & Deputy Director of OCTRU at University of Oxford, presented slides on [Data to Early Diagnosis and Precision Medicine Challenge](#).
- Dal Bansal, Operations Director, National Pathology Imaging Cooperative, presented slides on [National Pathology Imaging Co-operative: Overview](#).
- Amanda Lucas, Director of Information, DISCOVER-Now presented slides on [Key impacts of DISCOVER-Now](#).
- Janet Valentine, Director of Health Data and Digital Policy, ABPI, shared her reflections on the ISCF investment in the Digital Innovation Hubs programme and considerations around industry needs.
 - The outstanding contribution of the Health Data Research Hubs was acknowledged, despite the challenges presented by COVID-19, leading to re-prioritisation of activity, and the difficulty in establishing sustainable centres that bring together data from various sources.
 - Regarding industry needs, there are many differences to academia, in particular their drivers and the need of predictability around timescales, services being provided, contractual terms and deliverables.
 - Many ABPI members were very pleased with their experiences with the Hubs and felt very engaged.
 - However, among members, there was an overall feeling that Hubs set up was more appropriate for academia and that industry access to data required is still an issue.
 - A deeper understanding of the pharmaceutical industry is required as the drivers of industry and academia are not always the same.
 - The pharmaceutical industry is a heavy user of data. This needs to be appreciated more widely.
- Chris Carrigan, Expert Data Advisor, useMYdata, presented slides on [Perspective from public representatives on effective involvement and engagement](#).



- Chris Russell, Programme Director (Data for R&D) NHSE presented slides on the [Data for R&D Programme](#).

Panel Presentations: Towards efficient, transparent, reproducible and scalable research – data harmonisation and standardised methods

- Ed Burn, University of Oxford, presented slides [generating evidence from routinely collected healthcare data from across Europe using the OMOP common data model](#).
- Sue Mason, Professor of Emergency Medicine, The University of Sheffield and Will Whiteley, Clinical Epidemiologist, The University of Edinburgh presented slides on [Insights from harmonising regional hospital admission data](#)
- Rob Baxter, Technical Lead, DARE UK presented slides on [DARE UK 'A Sensitive Data Research Network: Where Next?'](#).

Panel discussion and close

David Seymour, Director of Infrastructure & Services at HDR UK chaired the panel discussions and invited members to contact us via ukalliance@hdruk.ac.uk if interested in contributing to OMOP discussions. Plans are ongoing to set up a Special Interest Group on OMOP common data model and facilitate development of a UK OHDSI (Observational Health Data Sciences and Informatics) Node.

The need of sharing resources for researchers and information around OMOP mapping and ethical approvals was highlighted.

David closed the meeting by thanking all the speakers and attendees for their contribution to the first Alliance Council meeting.

Appendix

UK Health Data Research Alliance Gibbs Building, 215 Euston Road, London NW1 2BE
enquiries@hdruk.ac.uk | [@HDR_UK](#) | ukhealthdata.org



Attendees

Name	Organisation
Alex Knight	HDR UK
Alex Newberry	Health and Care Research Wales
Amanda Lucas	DISCOVER Now / Imperial College Health Partners
Andrew Morris	HDR UK
Andy Boyd	UK LLC
Andy Wong	MRC Unit for Lifelong Health and Ageing
Ann John	Swansea University
Archie Campbell	The University of Edinburgh
Ben Crosby	HDR UK
Cathie Sudlow	HDR UK
Chris Carrigan	useMYdata
Chris Orton	SAIL Databank
Chris Russell	NHS England Transformation Directorate
Claire Argent	HDR UK
Claire Harrison	MHRA
Claire MacDonald	Manchester University NHS Foundation Trust
Dal Bansal	National Pathology Imaging Co-operative
Dale Kirkwood	Lancashire Teaching Hospitals NHS Trust (LTHTR)
Danielle Fisher	Royal College of General Practitioners
Dave Chuter	useMYdata
David Harrison	iCAIRD
David Jenkinson	The Brain Tumour Charity
David Seymour	HDR UK
Ed Burn	University of Oxford
Edel McNamara	HDR UK
Elliot Bridges	Human Fertilisation and Embryology Authority
Emily Jefferson	HDR UK
Erik Mayer	Imperial College London
Fergus McDonald	DARE UK
Garry Coleman	NHS England
Guy Smallman	University Hospitals Coventry and Warwickshire
Hans-Erik Aronson	DARE UK
Ian McKay	UKRI
Janet Valentine	ABPI
John Nolan	HDR UK
Jonathan Cook	University of Oxford

UK Health Data Research Alliance Gibbs Building, 215 Euston Road, London NW1 2BE
 enquiries@hdruk.ac.uk | @HDR_UK | ukhealthdata.org

Katherine O'Sullivan	University of Aberdeen
Kay Snowley	HDR UK
Lara Edwards	HDR UK
Laura Cocking	NIHR BioResource
Lisa Scerri	The Royal Marsden NHS Foundation Trust
Lucy Lennon	University College London
Lynn Morrice	HDR UK
Matthew Hoare	UKRI
Melissa Lewis-Brown	CRUK
Michael Ball	MRC UKRI
Michael Cook	Our Future Health
Nathalie Kingston	NIHR BioResource
Nay Aung	Queen Mary University of London
Nick Kennedy	Royal Devon University Healthcare NHS Foundation Trust
Nicola Armstrong	HSCNI
Paola Quattroni	HDR UK
Rachel Brophy	HDR UK
Richard lee	The Royal Marsden NHS Foundation Trust
Richard Walls	Health Informatics Centre, University of Dundee
Rob Baxter	DARE UK
Robert Stewart	King's College London
Roger Halliday	Research Data Scotland
Sallie Lamb	University of Exeter
Sion Parry	University Hospitals Coventry and Warwickshire
Sophie Williams	Barts Health NHS Foundation Trust
Stephen Burrows	HDR UK
Stephen Lock	NIHR Clinical Research Network
Sue Mason	The University of Sheffield
Susan Hodgson	MHRA
Tim Robbins	University Hospitals Coventry and Warwickshire
Tom Barlow	Scottish Government
Will Whiteley	The University of Edinburgh
Yemi Macaulay	HDR UK
Zoe Plummer	UK Renal Registry