

UK Health Data Research Alliance Board

Wednesday 29th April 2020, 15:00 – 16:30

Immediate actions for Alliance members:

- Agreement from Alliance members to continue work with HDR UK Metadata Onboarding team to prepare data for loading onto the Innovation Gateway over the next months.
- Alliance members to provide contact names and details of their PPIE representatives. We are also seeking input on what a Practitioner Advisory Group should look like and what types of activities it should drive. Please contact Sinduja Manohar Sinduja.Manohar@hdruk.ac.uk to provide suggestions or if you would like to be involved in this work.
- We have opened a public consultation with patients, the public, researchers and innovators to seek feedback on a draft green paper outlining approaches to health data access via Trusted Research Environments. We invite Alliance members to [provide feedback](#) or share the information about the [consultation](#) through their networks. The consultation will remain open until 21 May 2020.
- Alliance Board members are all invited to attend the Health Data Research UK's One Institute Annual Conference on Tuesday 16 June 2020. Registrations via [Eventbrite](#).

Immediate actions for Alliance secretariat:

- Send out latest SAGE prioritisation paper and send regular updates about HDR UK's work on COVID-19.
- Send metadata improvement updates to individual Alliance member organisations.

Next steps for Alliance members and secretariat

- Organise a data utility session at the next Alliance Board meeting. If anyone is interested to join this group, please contact Ben Gordon (Ben.Gordon@hdruk.ac.uk).
- Organise a demo presentation to show new functionalities of the Innovation Gateway (expected in the summer).

Welcome and apologies – Action points from last meeting and questions on Convenor's Update (Paper A)

Caroline Cake (Chair) welcomed everyone to the meeting and set out the agenda. The action points from last meeting were reviewed and an update was given on new Board members joining the Alliance, on recent developments from the Health Data Research Hubs and the recent work by Alliance delivery sub-groups.



Discussion

COVID-19 and prioritisation of research questions

Caroline Cake presented work on the prioritisation process currently being fed into the government's Scientific Advisory Group for emergencies (SAGE) on a weekly basis. This has the objective to support rapid research using health data into healthcare outcomes associated with COVID-19 and into potential interventions to severity of outcomes.

CPRD shared information on their recent work to expedite the data access request process to make data available for research. All approved studies, including those COVID-19 related, are immediately published on the CPRD website: <https://www.cprd.com/protocol-list>. It is important to share information about approved research so that we can avoid duplication of efforts.

Need to streamline prioritisation of access requests e.g., Public Health England has a number of datasets that can support research and surveillance and there is a need for greater coordination with many people trying to answer the same or similar questions and duplication of effort.

Scope for the Alliance to improve communication about datasets relevant to COVID-19 available from data custodians, including linked datasets, and to share which research projects have already been approved. Researchers might not be aware of what datasets are made available, thus making this clear through the Alliance would be helpful.

In Scotland, research questions are prioritised to meet and inform the requirements of the Scottish government. Data access requests answering different questions are not expedited and go through the normal data access request route.

Finally, it was noted that in Northern Ireland there is an additional need compared to other areas of the UK, which is the coordination with the Republic of Ireland, both in relation to data modelling and research data questions.

Innovation Gateway

Updates on the Phase 2 of the Health Data Research Innovation Gateway and introduction to the Innovation Gateway data access module were presented by Peggy Barthes-Streit and Paola Quattroni.

The technology partner has been appointed. Next phase of development work is to end of October. Key modules include: cohort discovery and data access request. To be demonstrated at the next Alliance Board meeting.

It was noted that international data sharing would require different considerations that have not been covered to date. It would be helpful to discuss how we manage international data sharing, how we provide data access across borders and/or allow linking of UK data to international data. This is of particular

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



importance for data coming from rare populations but also international collaborations such as mother/baby data and tackling COVID-19.

The need for standard terminology or legal definitions was also mentioned and how this is approached internationally is also important.

Attendees showed interest in the data utility and data quality improvement work and noted that mapping common data models and looking at how different data users might define 'quality' is of interest. It was proposed that the next Board meeting could cover data quality and utility in a longer session.

Adam Milward (MetadataWorks) presented an update on the metadata onboarding improvements of the past couple of months. He commended the work of those Alliance members who have significantly improved the quality of metadata in the Gateway and have dedicated resources to this work.

Finally, Rebecca Cosgriff from Cystic Fibrosis Trust shared the recently published work on the first 40 cases of cystic fibrosis patients with COVID-19, showing that clinical course of disease in these patients appear similar to the general population.

Next Alliance Board meeting

The next Alliance Board meeting will take place on 23 July 2020 14:00-16:00 via teleconference (Zoom details to be provided). Please save the date, a calendar invite will follow.

Appendix

Attendees via Zoom

| Name | Organisation |
|----------------------|--|
| Brendan O'Brien | NHS National Services Scotland |
| Peter Bradly | Public Health England |
| Janet Valentine | CPRD |
| David Ford | SAIL Databank, Wales |
| Chris Packham | Nottinghamshire NHS Foundation Trust |
| Yvonne Silove | HQIP |
| Marion Bain | NHS Scotland |
| Emily Jefferson | Health Informatics Centre, University of Dundee |
| Chris Hollis | Nottinghamshire Healthcare NHS Foundation Trust |
| Geoff Huggins | NHS Scotland |
| Neena Modi | NDAU Imperial College |
| David Crossman | Scottish Government |
| Tom Denwood | NHS Digital |
| Alistair Weir | Guy's and St Thomas NHS Foundation Trust |
| Kinga Varnai | Oxford University Trust |
| Kate Northstone | ALSPAC |
| Rebecca Cosgriff | Cystic Fibrosis Trust |
| Phil Quinlan | UKCRC Tissue Directory and Coordination Centre |
| Simon Ball | University Hospitals Birmingham NHS Foundation Trust |
| Tim Skelton | University Hospitals Leicester NHS Trust |
| Maria Koufali | Nottinghamshire Healthcare NHS Foundation Trust |
| Ian Young | HSCNI |
| Tom Fowler | Genomics England |
| Neil Sebire | GOSH & HDRUK |
| Mark Howells | Nottinghamshire Healthcare NHS Foundation Trust |
| Charlie Davies | Data-CAN |
| Elizabeth Sapey | PIONEER |
| Alastair Denniston | INISIGHT |
| Martin Landray | NHS Digitrials |
| Axel Heitmueller | Discover-NOW |
| Aziz Sheikh | BREATHE |
| Gerry Reilly | HDR UK |
| Amanda White | HDR UK |
| Peggy Barthes-Streit | HDR UK |
| David Seymour | HDR UK |



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|-----------------|---------------|
| Paola Quattroni | HDR UK |
| Caroline Cake | HDR UK |
| Andrew Morris | HDR UK |
| Susheel Varma | HDR UK |
| Adam Milford | MetadataWorks |