

Paper A: Convenor's Update

29 April 2020

Thank you for your continued support of the UK Health Data Research Alliance during these extraordinary and difficult circumstances. There has been outstanding engagement and leadership from colleagues across the UK, that has built momentum across several priority areas. This update highlights key activities and achievements since the January board meeting, within the context of the Digital Innovation Hub Programme developments. The last six weeks have inevitably been dominated by the COVID-19 pandemic and the activity across Alliance has been pivoted to meet this global emergency.

National health data research capability to support COVID-19 research questions

On 14 April the Scientific Group for Emergencies (SAGE) endorsed all the requirements of an approach to establishing a legally compliant approach to link data and provide access to secure analytical environments for researchers to answer rapid COVID-10 related research questions, across the four nations, using cardiovascular disease as an exemplar.

The approach was developed by NHS Digital (NHSD), Health Data Research UK, National Institute for Cardiovascular Outcomes Research (NICOR) and the British Heart Foundation (BHF) and is generalisable to other conditions. It will be subject to review after the COVID-19 emergency, or after six months, whichever comes first.

The specific requirements were: i) this approach should be operational over the next 1-2 weeks ii) government should ensure that key policy and research questions can be addressed via this approach iii) data custodians need to make their data rapidly accessible through this route iv) funders must facilitate the scale-up and operation of this approach.

There are three parts to the approach: A. Research Question Funnel, B. Linked data via Trusted Research Environments, C. Information Governance and Access. Full details are available in [Paper B](#).

From 20 April the prioritisation process is being fed into the government's Scientific Advisory Group for Emergencies (SAGE) on a weekly basis, with the objective to support rapid research using health data into healthcare outcomes associated with COVID-19 and into potential interventions to reduce the severity of those outcomes. The latest report to SAGE can be accessed [here](#) (Paper C).

Further details of the approach, including how to submit research questions or volunteer capabilities to support research priorities can be found on the HDR UK COVID-19 webpage <https://www.hdruk.ac.uk/covid-19/>. The latest developments will be covered as the main agenda item.

Health Data Research Hubs

In the last six weeks, the Health Data Research Hubs shifted most of their priorities towards COVID-19 related activities. Below we provide a summary of activities for each Hub:

- **BREATHE** have pivoted as much effort as possible to addressing the considerable national and global challenge posed by COVID-19 and have prioritised all work that aims to contribute to management and mitigation of the spread and impact of COVID-19.
- **PIONEER** are heavily involved in DECOVID, a national COVID-19 dataset, with partners including University Hospitals Birmingham NHS Foundation Trust (UHB), University College London Hospitals NHS Foundation Trust (UCLH), Kings College Hospital NHS Foundation Trust (KCH) and The Alan Turing Institute (ATI). Once the dataset has been curated, this will be used both clinically and academically to gain insights into the pandemic and support clinical and government decision making.
- **Digi-Trials** are pivoting to support COVID-19 clinical trials. This includes support for making Outcome data available to the large number of requests now being received. As an example, Digi-Trials are assisting [The Recovery Trial](#) being run by the University of Oxford by providing patient outcomes data from the Secondary Uses Service (SUS+) and from other source for the cohort of patients in the trial.
- **Gut Reaction**'s immediate focus is on linkage of NIHR BioResource (phenotype & genomics), PHE and HES data to answer COVID-19 related research questions. This is particularly important for the IBD BioResource and Gut Reaction Hub, where the medications participants are taking may influence the course of COVID-19 infection.
- **DATA-CAN** have developed core services and are in various negotiations to understand how they could be utilised for COVID-19 activities. They are focusing on leading programmes of work to look at the impact of COVID-19 on cancer diagnosis, treatment and outcomes. It is anticipated that DATA-CAN may become a key disease specialist by supporting activities in the SAGE prioritisation process.
- **Discover-NOW** is keen to support the research challenges presented by the COVID-19 crisis, and are highlighting the opportunity for supporting retrospective, feasibility and prospective studies through various channels with and with partners.
- **INSIGHT** can contribute through health data modelling to rebuilding NHS services and supporting patient care in the post-COVID-19 landscape. In conjunction with Hub partners and the resource agreed and drawn from Roche and AAAMD, INSIGHT are in the early stages of exploring the potential of real-time data to inform advancement of Oculomics research in understanding COVID-19, and in parallel to serve future NHS operational planning to aide getting services back up and running in the period after the immediate crisis.

Health Data Research Innovation Gateway

Minimum Viable Product (MVP)

The Innovation Gateway MVP continues to be accessed by users around the world, who are discovering the metadata from over 400 datasets hosted on the Gateway. This metadata continues to improve as a result of engagement with the data custodians and publishers of the metadata. Further work is taking place across both the Alliance and Hubs to increase the number of datasets discoverable through the Gateway. The functionality of the MVP continues to improve as the development team have been responding to user feedback. Work in the coming weeks will focus on improving the filtering and sorting of search results, as well as enabling additional means of logging in.

To date, 412 datasets are currently listed in the Gateway, including the [COVID19 Symptom Tracker](#) App data, the first COVID-19 relevant dataset to be added. In the coming weeks we aim to onboard more metadata from COVID-19 relevant datasets.

Technology Partnership

Phase 2 of the Innovation Gateway is being developed through a technology partnership. Thank you to colleagues from NHS Digital, NHSX, Public Health England, NHS Scotland, the Office of the National Data Guardian and the HDR UK Public Advisory Board who helped with the selection. Three potential partners undertook an 8-week rapid development task (RDT) as the final stage of the procurement process. The RDT exercise started on 27th January and completed on 2nd April with a final panel interview.

A Technology Partner has been now chosen and will be announced publicly in early May. The Phase 2 specification is currently being developed and will be publicly available once finalised in conjunction with the technology partner.

The components that need to be delivered by the first milestone of the second phase of the Gateway delivery (31 Oct 2020) include:

- A data access request workflow and dashboard
- Integration of user collaboration tooling
- MVP of cohort discovery

UK Health Data Research Alliance

New members

We were delighted to announce publicly three new members of the Alliance at the beginning of April who had signed their letter of intent to join the Alliance. We look forward to their engagement in the Alliance workstreams and to working with them on onboarding metadata for their data assets.

- **Neonatal Data Analysis Unit (NDAU, Imperial College London)**

The NDAU at Imperial College holds the National Neonatal Research Database, a unique resource containing data from over 600,000 babies and 7 million days of care for these babies across all the neonatal units in England and Wales. The NNRD is a very valuable international resource and access to this data has the potential to facilitate research to improve prevention, treatment, and delivery of health services for mothers and babies.

- **Health Informatics Centre (HIC), University of Dundee**

The HIC was the first centre in Scotland to offer a Safe Haven and has been operational for over 10 years. The Safe Haven allows secure collaborative research using sensitive electronic health records. HIC maintains a clinical data repository covering approximately 20 % of the Scottish population, combining routinely collected datasets for the Tayside and Fife population

- **Oxford University Hospitals (OUH) NHS Foundation Trust**

OUH is a renowned centre of clinical excellence and one of the largest NHS teaching trusts in the UK, bringing a wide variety of datasets to the Gateway, and covering areas ranging from emergency and routine care to microbiology and pathology.

The following organisation has also signed their letter of intent but not yet been publicly announced:

- **NIHR Clinical Research Network**

Alliance Workstreams

Promoting participation and improving access

Work is underway on the priority of improving access to health data by addressing some of the difficulties that exist in the UK.

As well supporting both researchers and data custodians in facilitating access and streamlining current processes, we are working to provide a solution for some data custodians through the development of the Health Innovation Gateway.

As part of Phase 2 of the Gateway development, an Access Management module will be developed that enables users to request access to datasets, submit required information and track the progress of applications directly. For data custodians with existing 'in house' solutions, the Access Management module will provide validated inputs to their approvals processes, whilst for data custodians that do not currently have an automated, web-based workflow it would provide a 'best of breed' web-based access management request solution.

We have started by building on the work to date by the NHS Digital Research Advisory Group (RAG) Streamlining and Ethics sub-group. Initial members of this workstream have provided crucial input to inform development of this module and define technology requirements. Thank you to those who already participated in the first two workshops on 2nd and 29th April. The main highlights from the first workshop can be found in this [Report](#).

We are still working with the health data research community including data users, data custodians, health data research hubs, regulators and public and patients, to understand current processes and identify areas of improvement. We encourage all Alliance members to engage with us and the Gateway Technology Partner and provide input at each stage of the Data Access Management module development.

A general overview of the project can be found in paper D and this will be covered as an agenda item.

Data Standards & Quality

This workstream is currently focused on the Data Utility project which aims to provide a common means of articulating the usefulness of a dataset for a given purpose, in order to support user activity through the Gateway, describe the impact of any curation activity by Hubs and to support effective targeting of any future investment around “improving the data”.

There is an engaged community to drive this work through the Hub Data Officers Group, which is chaired by Monica Jones (DATA-CAN Chief Data Officer). This group supports several concurrent workstreams, including evaluating data utility, data standards and metadata. It is worth noting that across the central team and each of the Hubs and Alliance members, work responding to COVID has impacted the ability to devote time to data utility activities. We provide an outline of this project in paper E.

Practitioner, Public & Patient Involvement and Engagement (PPPIE)

Since the last meeting, we have created an aligned strategy and delivery plan for communications, engagement and involvement for HDR UK, which incorporates the key areas of focus for this Alliance workstream. Recent developments include the establishment of a new COVID-19 patient/public advisory group, with over 60 participants, who are available and interested in providing advice and input on data research for coronavirus. HDR UK can provide a co-ordinating role to any Alliance members that wish to consult with this group and we aim to do this via our Slack channel.

Other work has included supporting the Hubs in recruiting and involving lay representatives. We have seen some developments in the Hub PPPIE strategies, with particular reference to the One London citizen engagement work, which provides insights about the trade-offs that the public are willing to take relating to health data use. Recommendations from this are yet to be published, but will inform the work of Discover-NOW and other Hubs including INSIGHT.

Through desk research and working with various members of the HDR UK community, we are looking to identify the key questions and grey areas in which PPPIE can have an impact in addressing.

At HDR UK we are boosting input from patients, the public and practitioners through the following routes:

- Recruitment of three new Public Advisory Board members, representing Scotland and Northern Ireland

- Recruitment of four new lay members to join our two new delivery groups
- Early stages of developing a Practitioner Advisory Board as we feel practitioners are a particularly important group to engage in the discussions.

Questions and input from Alliance members on this workstream are:

- To support the research question prioritisation process that we are reporting to SAGE, we require input from Alliance members' established PPPIE groups. We are working with your communications leads to get this started, but require the help of Board members to mobilise these teams so that we can ensure patients and the public are shaping the way that data is made available in the pandemic response
- We will be seeking input from Alliance members on what the Practitioner Advisory Group should look like and what type of activities it should drive.

Metadata Onboarding (*formally 'Supporting Health Data Research Innovation Gateway development and launch' workstream*)

The focus of this workstream is making datasets discoverable through the Gateway, and improving the quality of the metadata available in the Gateway. An MVP metadata standard has been developed and used for this work, and this is being revised based on the outputs of the first phase of work where the metadata of the 400+ datasets provided a valuable picture of the current state of metadata across the Alliance. An improvement plan at attribute level is being implemented by MetadataWorks and Parity and feedback is continuously gathered from all those participating in the work to date. Many of the Alliance members who engaged in the metadata onboarding process took advantage of the financial investment provided in the past months.

Alliance members who have not yet had capacity to engage with the process are encouraged to do so, with a particular focus on COVID-19 relevant datasets. Alliance Board members are encouraged to review how the metadata for their organisation's datasets are represented on the Gateway and provide feedback.

Aligning approach to Trusted Research Environments

On 12th March 2020 we hosted a workshop to discuss approaches to Trusted Research Environments (TREs) and brought together a community of experts interested in improving the use of data for research in a safe and ethical way. Representatives from the data custodian community, TRE providers, HDR UK Public Advisory Board, and funders attended the workshop either in person or via Zoom videoconferencing.

During interactive breakout sessions, participants discussed three main topic areas:

- Ideal requirements for TREs
- Approaches to federation across TREs
- TRE accreditation

The intention was to stimulate discussions on the importance of TREs and to establish a working group to collaborate on the development of the Alliance TRE workstream.

The outputs from the workshop have been incorporated in a draft green paper which we are sharing widely for consultation and is available [here](#) (Paper F). We invite the Alliance Board to provide input directly in the Google Doc shared.

A workshop report can also be accessed via this [link](#).

Alliance Symposium Tuesday 4th February 2020

On February 4th we held the first UK Health Data Research Alliance Symposium which brought together more than 150 people across the UK Health Data Research Alliance, Health Data research Hubs, Innovation Gateway, sandbox and others working closely with HDR UK in infrastructure. We had the opportunity to showcase achievements to date and ongoing work across the Digital Innovation Hubs programme. Attendees had a chance to learn more about elements of HDR UK strategy, share feedback on challenges and opportunities and propose new ways to work together.

The keynote speaker was Jeni Tennison, the Chief Executive of the Open Data Institute, who shared a cross-sector perspective on trustworthy access to data.

For those who were unable to attend, we livestreamed the plenary sessions and collated key outputs from discussions during the breakouts and World Café sessions. Slides and outputs from the event can be found [here](#).

Upcoming: Health Data Research UK's 'One Institute' Annual Conference, 16th June

Alliance members are invited to attend Health Data Research UK's 'One Institute' Annual Conference on Tuesday 16 June 2020. Given the current coronavirus (COVID-19) situation, the event will be virtual. We shall also use it as an opportunity to focus on the COVID-19 Taskforce, and the research that is being led by colleagues across the HDR UK family.

The meeting is for the whole HDR UK community and is our annual opportunity to come together and to celebrate our achievements. The event will bring together all staff from across the HDR UK regions: our research teams, Fellows, Alliance members, Hub teams and Gateway delivery partners, along with our Public Advisory Board and public and patient representatives, and colleagues from our key partnership organisations.

This year, we will also be joined for the whole day by our distinguished HDR UK International Advisory Board, including the Chair Dr Amy Abernethy, Deputy Commissioner of the FDA in the US. Amy will be participating in a fireside chat, focusing on how data and technology will influence the future of clinical and regulatory science.

Register via [Eventbrite](#).