

HDR UK COVID-19 Strategy

This is a 'live' strategy and will be continually updated. This is version 1.2

4 April 2020

Introduction

As the national institute for health data science, the Health Data Research UK (HDR UK) community is actively championing the use of health data to address the global COVID-19 challenge. Institute members across our sites and hubs are contributing to this global challenge by forging partnerships with government, NHS, industry and academia. Teams are already working on risk factors, genomics, clinical trials, care pathways and surveillance to help, for example, identifying which retrovirals and which clinical practices have the best outcomes for patients with COVID-19 (see our dynamic [COVID-19 activity log](#) for further examples of current activity).

The rapidly unfolding situation shows the breadth of different challenges that need to be addressed and the diversity of skills and expertise required. It also shows the need for us to be fully supportive of those at the front line of testing, clinical care and policy decision making - so that what we do helps and doesn't distract.

Such is the scale and immediacy of the challenge that we have developed a rapid, collaborative and agile strategic response to deploy our national capability through three priorities:

1. Leverage the best of the UK's health data science capability to **address the wider impact of the COVID-19** pandemic supporting vulnerable groups who will be hardest hit
2. **Accelerate safe access** to UK-wide priority data relevant to COVID-19 for research
3. **Co-ordinate and connect** national data science-driven research efforts related to COVID-19

Priority 1: Leverage the best of the UK's health data science capability to address the wider impact of the COVID-19 pandemic supporting vulnerable groups who will be hardest hit

The HDR UK community includes many of the UK's finest health data researchers and innovators who are already supporting the COVID-19 response: these include clinical trials, surveillance, genome sequencing, dynamic modelling, real-time dashboards and close working with virology and infection control teams, and are outlined in the [COVID-19 activity log](#).

BREATHE, the HDR Hub for respiratory health is focusing all resources and efforts on COVID-19. BREATHE will help navigate respiratory health data sets from across the UK, creating a digital resource where trained, approved experts can access data safely and responsibly, on an unprecedented scale. The HDR Hubs for clinical trials, Real World Evidence and other disease areas: NHS DigiTrials, PIONEER, DATA-CAN, Gut Reaction, Discover-NOW, INSIGHT and the BHF Data Science Centre; are also focusing resources and expertise on COVID-19.

In addition, we are refocusing work across all our nationally coordinated priorities to deploy health data science to the COVID-19 challenge, including our work on Understanding the Causes of Diseases, Improving Public Health, Better Care, the Human Phenome and Applied Analytics.

We have identified opportunities to scale up this existing work to deliver UK wide impact and to accelerate insights. These include:

- Augmenting the clinical trials work on existing and retroviral treatments
- Real-time predictive analytics
- Monitoring whether measures we are introducing are working within the UK and internationally – and knowing when to lift restrictions
- UK wide surveillance building on projects in Scotland, North West London and Wales.

We also recognise the importance of sustaining activities in other disease areas, including cardiovascular disease, cancer, diabetes, eye disease, Alzheimer’s disease and inflammatory bowel disease as people living with these diseases may be the most adversely affected by COVID-19.

Whilst some of these potential projects can be resourced through redeployment, funding and access to data (outlined below) are also required.

Deliverables *[led by Caroline Cake]*

- 1.1.** Coordinate an inventory of HDR UK COVID-19 research questions and activities and publish this on the [HDR UK website](#), questions such as “At the point of peak need, if patient requirements outstrip ventilation capacity, how should hospitals stratify and prioritise patients for ventilation?”. To also act as a ‘shop window’ of opportunities for industry partners wishing to contribute to the challenge. *[coordinated by Melissa Lewis-Brown]*
- 1.2.** Identify, support, accelerate and scale research and innovation projects that address new COVID-19 challenges by *[coordinated by Rhos Walker and Ben Gordon]*:
 - collaborating with funders to shape calls
 - joining up research using longitudinal datasets in, for example, Wales, Scotland, North West London and internationally
 - coordinating different research studies being led by parts of the UK and identifying opportunities to scale through the HDR UK Hubs, Alliance, industry and international partners
- 1.3.** Identify COVID-19 specific deliverables that each HDR Hub and HDR National Priority (including sites) contribute towards. *[coordinated by Rhos Walker and Ben Gordon]*

Priority 2: Accelerate safe access to UK wide priority data relevant to COVID-19 for research

This COVID-19 research endeavour urgently needs access to individual-level, linked data from across the UK. This data must be safely available as near real-time as possible for research. We will work with the 27 members of the **UK Health Data Research Alliance** including national NHS bodies across the UK (NHS Digital, NHSX, NSS, PHE, NWIS and NHSCIC) to improve the speed of access and utility to data. We will achieve this through the linkage of data collections that are already established to produce a national registry of COVID-19 patients (infected and recovered) for research.

Our research community has identified an initial set of priority datasets for this endeavour:

- COVID-19 testing & isolates data
- Primary care data
- NHS 111
- Prescribing data
- Secondary care data
- Critical Care data from Hospital Electronic Health Records
- Genomic data (including international sequence submissions)

We will work with national data custodians and regulators to identify the action required to enable the “priority” datasets to be linked and made available and updated daily (as far as possible) for research. For deeper electronic health record data, we will work with our Better Care Partnership network of digitally mature NHS sites.

We will also support efforts already underway including with [UK Biobank](#), the [Sanger Institute](#), [UKCRC Tissue Directory and Coordination Centre](#) and [PHE](#)’s efforts in the discovery and access of COVID-19-relevant samples and linked data, and the [NIHR Health Informatics Collaborative](#) (HIC) theme on critical care.

Whilst the potential public benefit of accelerating access is immense, it is vital that privacy is protected. We will work with data custodians to agree proportionate governance requirements which reflect the level of emergency and uses the “Five Safes” approach to protecting privacy. We will seek input from HDR UK’s existing national network of patients and members of the public, including members of the HDR UK Public Advisory Board and HDR Hub Public & Patient Advisory Groups, to ensure we are working to our value of transparency and that our work earns public trust. We will accelerate our Innovation Gateway development to build an appropriate environment to facilitate the research, supported by data use agreement templates.

Deliverables *[led by David Seymour]:*

- 2.1. Contribute to an international COVID-19 workbench through the **Innovation Gateway**, building upon existing capability to improve availability, accessibility, interoperability, linkage and findability of data that will move research in COVID-19 farther and faster. This will comprise of integrated access to COVID-19 datasets, community developed tools deployed in a Trusted Research Environment. *[coordinated by Andrew Morris and Gerry Reilly]*
- 2.2. Collaborate with data custodians within the Alliance to agree national data standards associated with COVID-19 *[coordinated by Neil Sebire]*
- 2.3. Engage all 27 Alliance members in adding COVID-19 relevant datasets for research onto the workbench. *[coordinated by David Seymour and Paola Quattroni]*
- 2.4. Engage other data custodians, including industry partners, in making COVID-19 relevant datasets accessible for research through the Gateway, and in line with the [UK Health Data Research Alliance Principles for Participation](#) *[coordinated by David Seymour and Paola Quattroni]*
- 2.5. Launch a coordinated effort across the HDR UK Public Advisory Board, HDR UK Hub and Site Public & Patient Advisory Groups, existing patient and public groups (e.g., useMYdata) and national partners such as Understanding Patient Data to involve patients, vulnerable populations and wider public in shaping the approach to data access. *[coordinated by Sinduja Manohar]*
- 2.6. Put all COVID-19 related **metadata** from existing Alliance members, HDR UK studies (see [COVID-19 activity log](#)), and international sources on the HDR UK COVID-19 Workbench. *[coordinated by Gerry Reilly, Peggy Barthes-Streit and Susheel Varma]*

Priority 3: Co-ordinate and connect national data science-driven research efforts related to COVID-19

The HDR UK One Institute UK-wide model and existing collaborations with over 200 NHS, academia, industry, patient and public groups, enables HDR UK to connect and co-ordinate national COVID-19 data-driven research projects.

Deliverables *[led by Rhos Walker]:*

- 3.1. Lead the **HDR UK COVID-19 Taskforce** with a weekly COVID-19 taskforce summit to support/co-ordinate the research effort. *[coordinated by Melissa Lewis-Brown, chaired by Andrew Morris]*
- 3.2. Provide a single, open SLACK channel ([#covid-19challenge](#)) as a point of information for all HDR UK investigators, collaborators and studies on COVID-19. Provide further channels for more detailed discussions on aspects of COVID-19, which broadly align with World Health Organisation priority areas. *[coordinated by Michael Ingram]*
- 3.3. Leverage HDR UK's GitHub (<https://github.com/hdruk/covid-19>), linked to other endeavours, to provide unrestricted access to open source tools and pipelines and resources relevant to COVID-19 data science research. *[coordinated by Susheel Varma]*

- 3.4.** Publish a weekly communications update on the HDR UK website on progress in partnership with Government, other researchers and national/international partners e.g. International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC) reporting on real-time intelligence on COVID-19 HDR UK research expertise and opportunities to support the COVID-19 data science research effort with relevant industry partners. *[coordinated by Fran Lord and Sinduja Manohar]*
- 3.5.** Collect and collate all relevant pre-print and open-access papers related to COVID-19 research in a central location to allow the HDR UK research community to ‘stand on each other’s shoulders’. *[coordinated by Susheel Varma and Melissa Lewis-Brown]*

Principles of the HDR UK COVID-19 Taskforce

The HDR UK community has subscribed to the following ways of working that are vital to rapid progress on the COVID-19 pandemic:

1. Guided by the HDR UK values: Transparency, Optimism, Respect, Courage and Humility
2. [UK Health Data Research Alliance Principles for Participation](#)
3. [HDR UK Attribution Policy](#)
4. [HDR UK Development Principles](#)

We are heartened by the immediate response from our whole community in rising to this global health challenge and will work together in an agile way over the coming weeks and months to bring the best of HDR UK.