

International COVID-19 Data Research Alliance and Workbench

Launch Event Report

8 July 2020

Introduction and overview

This report reflects the key themes discussed at the launch of the International COVID-19 Data Research Alliance and Workbench on 8 July 2020. The event was open to all and was delivered as a virtual webinar. It provided a forum to share the vision for this initiative, introduce its aims and principles, and demonstrate the functionality of the Workbench. This is a key platform to help the Alliance deliver on its mission to build a trustworthy international partnerships and enduring analysis infrastructure to support a rapid response to the current COVID-19 and future pandemics across the world.

Importantly, the event was also an opportunity to listen to and learn from the research community and other stakeholders, and to invite them to join the partnership and play an active role in helping shape the programme.

The live webinar, attended by more than 200 people from 26 countries, was an opportunity for us to “launch, listen and learn” - to present the aims and principles of the initiative, the technical scope of the Workbench to the community and to learn from and involve others. The ultimate goal of this initiative is to develop solutions that last beyond this pandemic and can help us act faster in future crises.

We were delighted with the level of engagement in this event and look forward to building on this momentum, engaging fully with the broader global community and helping build solutions that make a difference both during this COVID-19 crisis and in future pandemics.

Speakers

The speakers at the launch were representatives from the Alliance partners and collaborating organisations:

Speakers	Job Title & Organisation
Steve Burnell	Director, COVID-19 Response, Minderoo Foundation; Chief Executive Officer, Collaborate Against Cancer, Minderoo Foundation
Peter Goodhand	Chief Executive Officer, Global Alliance for Genomics and Health (GA4GH)
Steve Kern	Deputy Director, Quantitative Sciences, Global Health – Integrated Development, Bill and Melinda Gates Foundation
Julia Levy	Interim Director, International COVID-19 Data Research Alliance and Workbench, Health Data Research UK
Andrew Morris	Director, Health Data Research UK
Nicola Perrin	Strategic Advisor, International COVID-19 Data Research Alliance and Workbench, Health Data Research UK
Gerry Reilly	Chief Technology Officer, Health Data Research UK
Aziz Sheikh	Professor of Primary Care Research & Development and Director of the Usher Institute, The University of Edinburgh; Director, Asthma UK Centre for Applied Research, NIHR RESPIRE Unit and BREATHE, the Health Data Research Hub for Respiratory Health, and Co-Director, NHS Digital Academy
David Sibbald	CEO and Co-Founder, Aridhia Informatics Ltd
Névine Zariffa	Founder, NMD Group LLC

Bringing data together is vital to accelerate insights into COVID-19

Many organisations across the world are conducting studies into COVID-19 and generating data that, when aggregated and reanalysed, can lead to powerful insights that help accelerate discovery of interventions. However, the data are often siloed meaning it is difficult for researchers to share and collaborate quickly to leverage the expertise and capabilities of 21st century research and analysis.

“What we don’t know about COVID-19 is striking. Data will be crucial in our quest to understand immunology, transmission, how can we harness genomics, and importantly the role of therapeutics and clinical trials to combat this pandemic. To do that we need not only good data sources but the ability to integrate data sources at scale.” **Andrew Morris, Health Data Research UK**

However, bringing data together effectively, safely, and securely, and encouraging collaboration, pose substantial challenges. Developing and maintaining trust with the research community, patients and the public is the most important of these challenges.

In this context, the International COVID-19 Data Research Alliance and Workbench initiative is designed to work in partnership across the world to accelerate the discovery and development of insights and treatments to combat COVID-19. Our mission is to build a trustworthy international partnership and enduring analysis infrastructure to support a rapid response to the current COVID-19 pandemic and future pandemics across the world.

“There is enthusiasm and an unprecedented response from the research world to work on solving problems related to COVID-19 but it is challenging to do as isolated groups. Bringing people together at the Workbench provides the opportunity to learn from each other, to collaborate in analysis and in understanding questions that are important across the globe to address the pandemic.” **Steve Kern, Bill and Melinda Gates Foundation**

Building trust is a central pillar of the initiative

For collaborations to work effectively, trust is essential.

Transparency is a key component of building trust and one of our guiding principles. We are committed to being transparent in what we say, what we do, the decisions we take and the results we obtain. We are also committed to responsible data sharing and to ensuring the data is brought together in a way that respects the privacy of participants and the data sharing preferences of the custodians.

“People must feel that the data they collected or that came from sovereign entities is used in a respectful way, along the guidelines for which it was intended/collected.” **Steve Kern, Bill and Melinda Gates Foundation**

Importantly, we do not want to create a mega-repository of data. Instead we will be building a trusted research environment where data can be shared safely and securely. If transferring data to the Workbench is not feasible, we want to facilitate access to the data at the original location, provided it is also a safe and secure setting, with the right auditing processes.

To ensure the data is safe and secure we will implement the “Five Safes”, as well as support GDPR-grade safeguards. The “Five Safes” is a recognised and trusted framework that allows the risks associated with access to sensitive data to be assessed and managed. It considers the people, projects, settings, data, and outputs involved.

Equity is another key component of trust. To ensure equality, access to the platform will be inclusive, fair, and clear. Data custodians can retain control of the data and be able to use their own decision and approval processes. Researchers will be given autonomy within the data analysis projects they lead. It is imperative there is reciprocity between the data collectors and the data analysers, and we want to ensure that everyone’s work is attributed fairly.

Importantly, patients and the public will be involved in all stages of development and delivery of the initiative. How to do this will require careful consideration to accommodate the different needs and formats of public involvement and community engagement across the globe.

“We do not want to control data. That is not our job. [Our job] is to think through the policies, the tools, the standards, the governance, and the public engagement that enable collaboration and interoperability, which we define as the ability to work across organisational boundaries with no additional effort.” **Andrew Morris, Health Data Research UK**

Collaborating and expanding the network of partners to achieve more

The International Alliance is a consortium of life science, philanthropic and research organisations, convened by Health Data Research UK (HDR UK) and including the Bill & Melinda Gates Foundation, Minderoo Foundation, Wellcome, African Academy of Sciences, HDR Network Canada, Genomics England, and the Infectious Diseases Data Observatory. These organisations bring data assets, expertise and/or funding to the Alliance.

“There is this underlying tenet that everything we do is based on equality, collaboration, and open access to data and information...in this case information about COVID-19. So, it was obvious for the Mindaroo Foundation to understand the context of this [initiative]. We were impressed by the partners involved on the funder side and with HDR UK as the convener, so it seemed appropriate to support this [Alliance].” **Steve Burnell, Mindaroo Foundation**

We will work in partnership with data stewards, data contributors and data users from across the world, with a specific emphasis on low and middle-income countries. We will also learn from, and bring together, existing initiatives with complementary goals, as well as establish strategic partnerships that can help us inform and shape governance, assist with technical challenges, support public engagement activities, and reach networks and communities. Lastly, we will promote and facilitate open research that allows the sharing of data, analytical tools and methods and supports knowledge synthesis and dissemination. We are particularly focused on ensuring equality of access and recognition for all including those from low- and middle-income countries.

We are seeking to establish a wide range of formal partnerships with both data and strategic partners:

Data partners who can:

- Contribute datasets
- Make data discoverable
- Authorise access requests
- Demonstrate transparency
- Collaborate to harmonise standards
- Conduct analyses in the workbench

Strategic Partners who can:

- Provide technical expertise
- Identify research questions
- Help inform and shape governance
- Support public engagement activities
- Reach networks and communities
- Conduct analyses in the workbench

Creating the Workbench, a space for collaborative data analysis

We have set up the Workbench as a platform to support a wide range of data management and data science needs. It will allow users to search for and discover relevant datasets anywhere in the world, with the help of metadata. When the data is located, the process of accessing the data will be streamlined, with a single mechanism to request access from multiple datasets. Once the data access has been approved, researchers will be able to work collaboratively to analyse the data using a range of tools within the safe setting of the Workbench.

The Workbench also addresses a frequent concern among data collectors that their data are being used by others without proper attribution or even consideration of the intent with which the data was collected. The Workbench allows those who collect the data to collaborate with those who are analysing the data, and for both groups to have their work recognised. It is being designed to support and enable high quality, reproducible science.

The launch included a short demonstration of the Workbench, which can be viewed in the recording of the event (at time 40:20) here: https://www.youtube.com/watch?v=CESn1_gFRJO

“The Workbench adopts an ecosystem approach, supporting open science to tackle COVID-19. This means we want to enable people to form dedicated teams, bring data, code, expertise, and have freedom to operate within the domain of their driver project. And [we want to] do this while ensuring appropriate use and governance of the data.” **David Sibbald, Aridhia Informatics.**

Research questions underpin the work of the initiative

This is a complex initiative, so we need an anchor to help us decide what we tackle first. For us, the anchor is the research questions that matter to the community that we serve. This helps us to prioritise and focus our efforts as we seek data sources and we refine our systems, processes and tools. It also ensures that the initiative generates meaningful insights with a high level of impact.

Research teams will be authorised into the Workbench via a careful but light touch approval process.

We have undertaken an initial consultation with the research community and identified treatments, vaccines and prophylaxis, and disease and population, as the top three priorities based on the level of interest. Data for vaccines and prophylaxis is still emerging, so we have chosen treatments as our number one priority, and disease and population as the second.

In order to help us start building a platform that is fit for purpose, we have already selected two driver projects along those two priorities. Driver projects are developed to ensure clear and concrete deliverables can be obtained from the initiative, while also helping to inform that the initiative is fit for purpose. We are therefore using them to generate answers and evidence for the research question, as well as to evaluate the first phase of the Alliance and Workbench.

The first driver project, which is more advanced, focuses on the holistic evaluation of the efficacy and safety of treatments for COVID-19. The second driver project will help understand the COVID-19 disease and identify windows of opportunity to intervene to modify disease progression. The variety of research questions means that each driver project will have its own characteristics and specific requirements. We will make all the outputs and tools that we co-create publicly available in the spirit of open science.

“While we [deliver the driver projects], we also test ourselves, we test our tools, we test our governance, processes, we get feedback from all as collaborators and contributors of data. We don’t have all the answers, so if you have any concrete suggestions, thoughts or ideas you want to send to us, we would be appreciative of that.” **Névine Zariffa, Founder, NMD Group LLC**

Question and answer session

The event included an extensive question and answer session that brought together many queries and suggestions from the attendees. These included questions on the best ways to involve the public and patients in the different stages of the initiative, how does the Alliance’s work complement, and could integrate with, other COVID-19 data initiatives, and options for future funding, among others.

Moving forward

This launch was the first public step in our journey. If you are interested in learning more, contributing to and helping shape our work, please get in touch via covid@hdruk.ac.uk – we would love to hear from you and discuss how you can get involved.