INTERNATIONAL COVID-19 DATA RESEARCH ALLIANCE

Launch of the International COVID-19 Data Research Alliance and Workbench

गत, हे, 欢迎, Bem-vinda! Bienvenue! добро пожаловать, أهلا بك
Bienvenidas, স্বাগত, Karibu! Välkommen! Welcome!

08/07/2020

Launch …. Listen … Learn

INTERNATIONAL COVID-19 DATA RESEARCH ALLIANCE

- Why an International Alliance?
- Partnership working
- Principles
  - Trust, Transparency, Respect
- Research questions
- How to get involved
- Q&A

COVID-19 represents an unprecedented public health, social, medical, and economic crisis

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Our challenge

There is an urgent need to enable access to data that can be linked with other data in a safe and secure way, for the world's research community to answer key questions. Those answers are urgently needed to save people's lives now and in the future.

Nigeria's first COVID-19 mobile testing both in Ota, Ogun State, Nigeria.
Photo Source: WHO

International COVID-19 Data Research Alliance and Workbench

The International COVID-19 Data Research Alliance and Workbench provide a coordinated international platform to enable researchers to access global data to derive rapid insights about COVID-19 and speed up the development of interventions, treatments, and vaccines.

The COVID-19 Therapeutics Accelerator donors and partners formed the International COVID-19 Data Research Alliance to accelerate clinical research

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Key challenges relating to COVID-19

Poor understanding of the disease mechanisms

A lack of accurate, early, and accessible diagnostic methods

A therapeutic pipeline that is in its infancy, no vaccine yet available

Poor coordination across clinical trials

Fragmented data

We need a research environment to provide shared datasets, collaborative work spaces, and analytical tools to address these challenges

The Alliance will oversee a trusted research environment to enable global researchers to evaluate research questions

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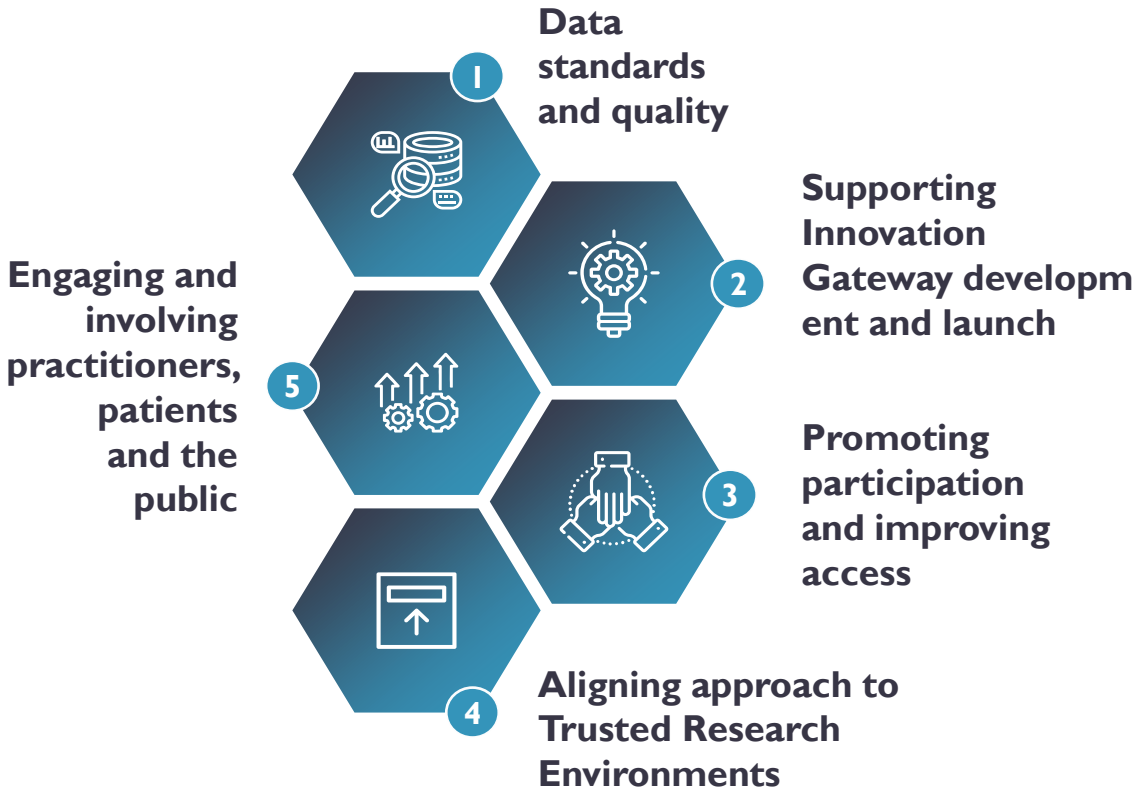
Key capabilities and stance

- Deep network of organizations and senior talent to recruit Alliance members
- Proven track record of delivery
- Building capabilities on foundation of trust
- Deploys the data science infrastructure and capabilities to support researchers
- Creating an environment that supports reciprocity between data providers and analysts



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Vision

To unite data from international clinical trials, biomedical and health research to enable discoveries that benefit all people, everywhere, by reducing the harm of the COVID-19 pandemic.

Mission

To build a trustworthy international partnership and enduring analysis infrastructure to support a rapid response to the current COVID-19 and future pandemics across the world.

Developing a Broad Global Alliance

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Funders

- COVID-19 Therapeutics Accelerator Funders

Initial Alliance Partners

- African Academy of Sciences
- BREATHE Health Data Research Hub
- COVID19 R&D
- Generation Scotland
- GenOMICC (Genetics of Mortality in Critical Care)
- Genomics England
- Global Alliance for Genomic Health
- HDR Network Canada
- Infectious Diseases Data Observatory (IDDO)
- International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC)
- NICE
- SAIL… (as at 30 June 2020)

Technology and data science expertise

- Aridhia
- Cytel
- Mastercard
- Novartis Pharma
- NMD Group
- SeRP (Secure eResearch Platform)

"start small, think big, move fast"

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Quotes from Partners

"We are delighted to be part of this COVID-19 Alliance and it's heartening to see the research community coming together at such a critical time to accelerate the generation of research evidence through data re-use. Having pioneered collaborative data-sharing in resource-limited settings with the global scientific community over the last decade, we know that this is a proven way to translate data into evidence to improve outcomes for patients worldwide."

Professor Philippe Guérin, Director of the Infectious Diseases Data Observatory (IDDO)

"New data being generated from research into COVID-19 are hugely valuable. We have to unlock the full value of these assets by making them findable, accessible and securely usable by researchers around the world working in the public's interest."

Tariq Khokhar, Head of Data for Science and Health at Wellcome,

How the Alliance will realise our vision and complete our mission

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- **Learn** from and bring together existing initiatives

- **Work in partnership** with data stewards, data contributors and data users from across six continents at scale, with a specific emphasis on low and middle income countries

- **Promote and facilitate open research** that allows sharing of data, analysis methods, and results to support knowledge synthesis and dissemination

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Alliance Principles

- **Equity** in developing a global approach
- Adhere to **principles for responsible data sharing** and respect the data sharing and privacy preferences of participants
- **Transparency** of governance and operations
- Use a **proportionate approach to governance** based on the "five safes" and support GDPR-grade safeguards
- **Accountability** to best practices in technology, ethics, and public outreach
- **Inclusivity** by partnering and building trust among stakeholders
- **Collaboration** to share data and information to advance human health
- **Innovation and Agility** in order to develop an ecosystem that accelerates progress
- **Independence** through structures and governance

Demonstrating trustworthiness in everything

The Workbench lies at the heart of the initiative and enables our work

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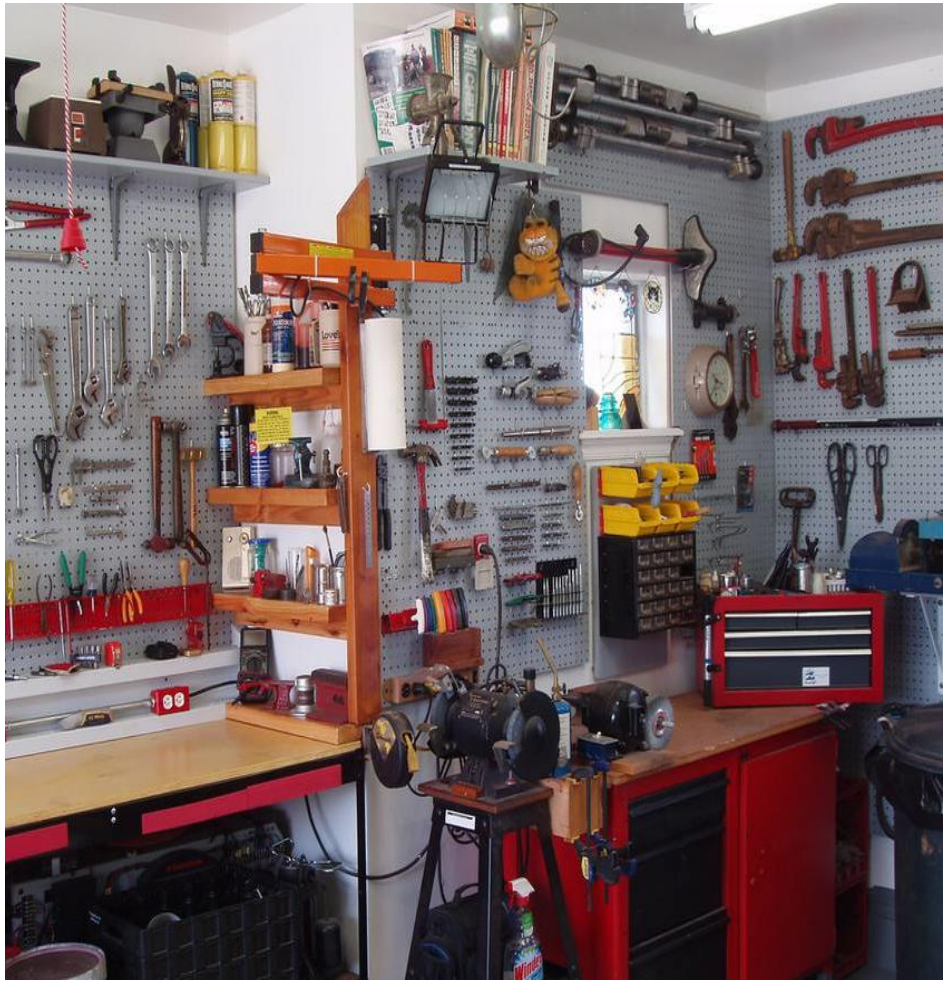
Discover data	• Search relevant data sources from around the world
Request access	• Request data from multiple datasets through a single mechanism
Analyse data	• The Workbench provides a secure environment for analysis with a range of tools available
Federated access	• If data cannot leave a local setting, analysis can be sent via federated compute from the Workbench to the data
Collaborate	• Teams of authorised researchers can work together in dedicated workspaces



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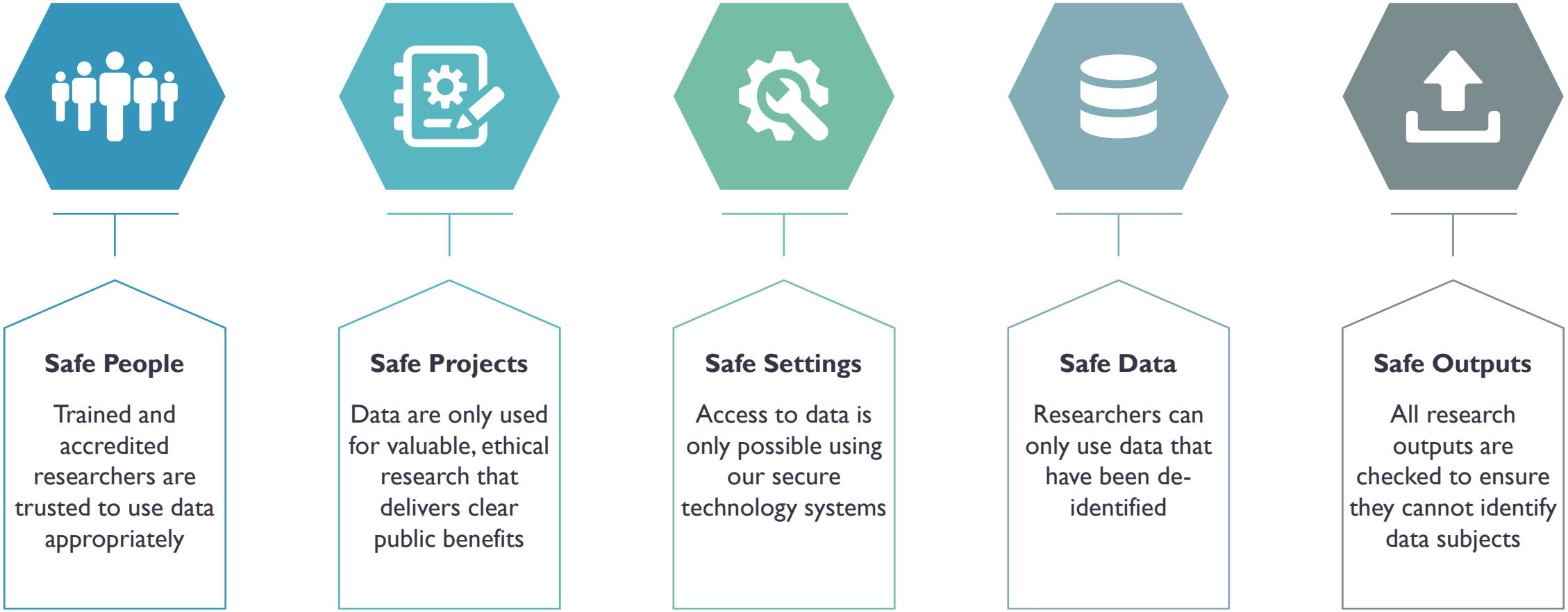
Robust governance – based on the 'Five Safes'



Safe People

Trained and accredited researchers are trusted to use data appropriately

Safe Projects

Data are only used for valuable, ethical research that delivers clear public benefits

Safe Settings

Access to data is only possible using our secure technology systems

Safe Data

Researchers can only use data that have been de-identified

Safe Outputs

All research outputs are checked to ensure they cannot identify data subjects

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Building a trustworthy system

Public and patient involvement

- Input and advice from outset
- Involvement in decision-making structures
- Community engagement
- Clear communication
- Transparency

"Public engagement must not be overlooked in the rapid response to COVID-19"

Patient Advisory Group

"If the systems for engagement are not already in place, then you need to adopt a process of 'learning and adapting' – finding ways of engaging as much as possible, and developing systems as you go."

Dakar Community Engagement Workshop

Organising research questions so we can prioritise, and secure data sources & analytics tools

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Disease and Population	Vaccines and Prophylaxis	Diagnostics	Treatments	Outcomes and residual unmet need	Other?
Transmission patterns	How to measure immunity?	How well do the tests perform?	When should I administer treatment?	What are the risk factors linked to severe outcomes?	Host virus genome interactions?
Can we predict local outbreaks	Speeding up vaccine development		How quickly to treatments work?	Long term health consequences of COVID infection	
What are the risk factors associated with severe outcomes?	Do some vaccines work better than others in patient segments?		Which treatments work best in the elderly? Renally impaired?...		
Evolution of the disease population segments?	Do some vaccines work better than others in patient segments?		Which patients benefit best from a particular treatment		
			How quickly do treatments work?		
			How well do RCT trials translate to real-world setting?		
			RCT results: What is the safety and efficacy of each treatment studied?		
			When should I administer treatment?		

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Driver Projects: Start small, think big, move fast

Goals

- To use data and analysis tools to generate answers to priority questions for tackling COVID-19
- Refine and improve our systems, tools, and processes

Priorities

- Holistic evaluation of the efficacy and safety of treatments for COVID-19
- Understanding the COVID-19 disease and identifying windows of opportunity to intervene to modify disease progression

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Initial Work: Tracking mechanism for all relevant randomized clinical trials. Operational aspects of summary data transfer to workbench (Data Dictionary, timing, process flow and linkage to other data sources)

Deliverables:

- **Data Model** constructed to ensure summary-level analyses are meaningful, and can be bridged to other data sources
- **Standard tools/reports** to describe the trials, to provide meta-analyses, and network meta-analyses
- **Abstracted/digitized** information from published data if not otherwise made available to the Alliance
- **Bespoke aggregated data sets** to conduct modelling involving other data sources or other analytic approaches

Data Commitment: A dozen pharmaceutical companies of the COVID19 R&D Consortium have committed summary-level data from their trials. Other organizations have also indicated they are interested in partnering.

Overview of the Workbench

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Please view webinar recording for video

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Who is the Alliance seeking to serve?

Regulators

Data Scientists

Researchers

Funders of research

Healthcare professionals

Public and patients

Policy makers

We will be seeking ways to engage with all key stakeholders in the community

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How can you participate?

Alliance Partners

Data partners

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

Strategic Partners

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

Inspire and contribute to Driver Projects and harnessing the power of data and the Workbench

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Future Driver Projects will be:

- Sourced from the community
- Evaluated and prioritised by our Scientific Advisory Committee

Beyond Driver projects

- Ultimate goal is to empower the community to be able to identify and research key questions directly via the Workbench

We want to continue to receive your research questions

Timeline

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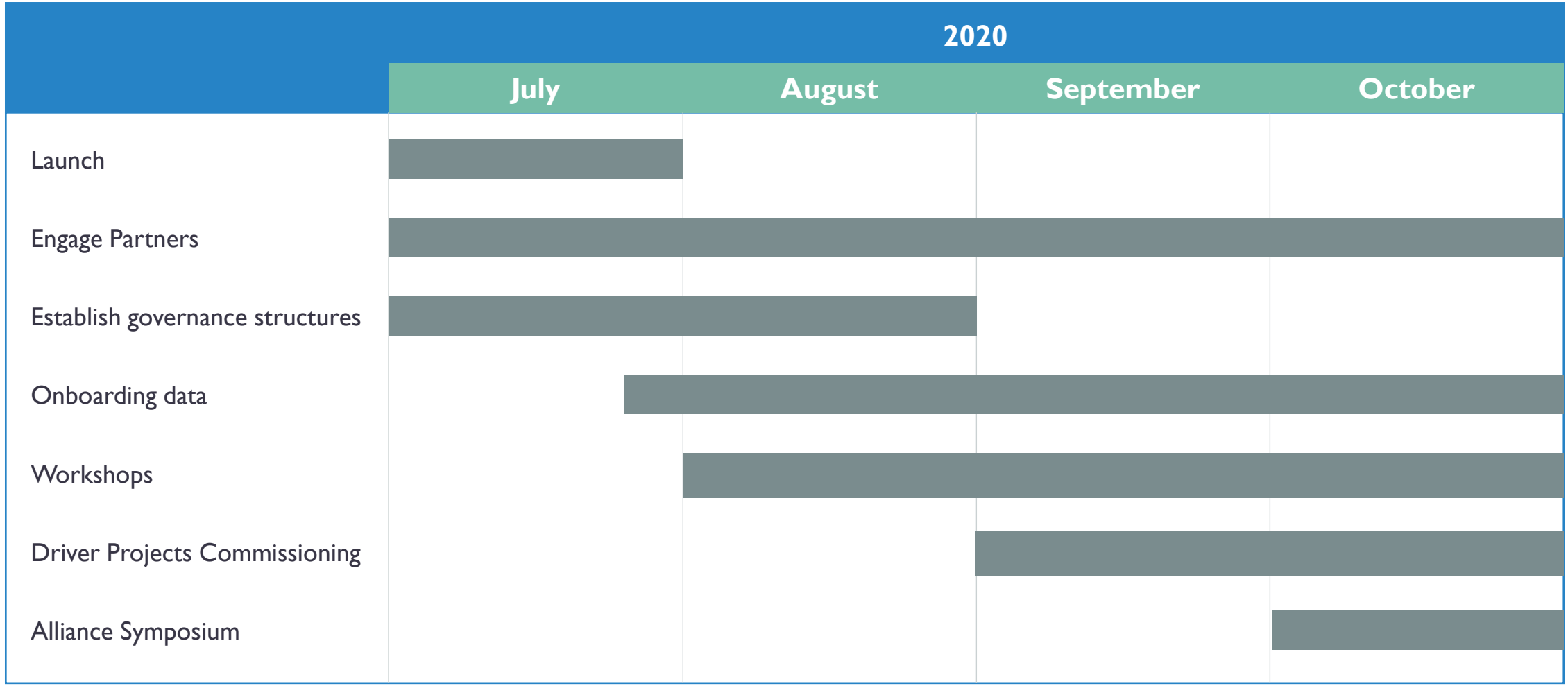

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Q&A

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Questions received so far about the initiative

- Given existing infrastructure in place, how does "workbench“ fit with this, without duplicating existing efforts?
- How can patients get involved?
- Will there be additional PPI opportunities?
- How can Swedish based cardiology researchers get involved?
- What is the way of securing data and accessing the data ?
- Does it need secured access ?

Thank you

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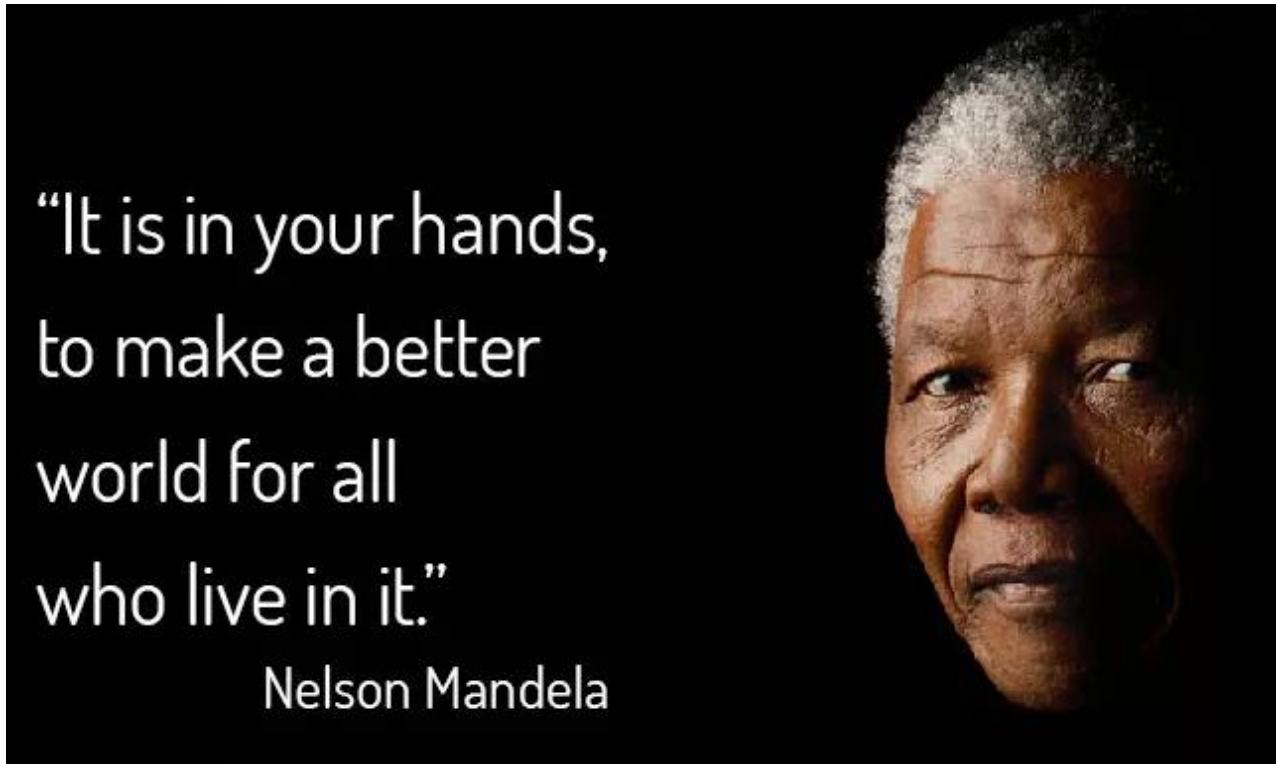

- Get in touch:
  - Website
  - covid@hdruk.ac.uk
  - Slack channel (coming soon)
- Spread the word
- Get involved

https://www.hdruk.ac.uk/covid-19/international-covid-19-data-alliance/

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Backup

Data and data science are critical to addressing priority questions for tackling COVID-19

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Disease and Population	• What are the risk factors associated with severe outcomes? • How can we predict the extent of local outbreaks better (e.g. using approaches like sewage monitoring)? • What does effective data about the disease and its systemic implications look like? • What are the host virus genome interactions? • What are the risk factors for infection and for Developing severe disease, how long will immunity if it does develop ,last? • Do certain disease phenotypes have a greater likelihood of disease progression or successful treatment with different mechanisms of action? • What is the evolution of the disease population segments?
Vaccines and Prophylaxis	• How will immunity be measured? • Will it be supporting vaccine development? • What are the prospects for vaccine development? • Will there be best medicines for each patient subgroup?
Treatments	• When should I administer treatment? • How quickly do treatments work? • Which treatments work best in the elderly and renally impaired? • What are the best combinations of treatments most suited for treating patients at different stages of disease? • Which patients benefit best from a particular treatment? • Will it be identifying and making available patient level data for Covid outcomes and treatments? • How well do RCT trials translate to real-world setting? • RCT results:What is the safety and efficacy of each treatment studied? • Will there be phenotyping severe presentations using data, to understand variable effective pathways of treatment? (more personalised medicine) • What is the best outcome measure to characterize successfully treating different disease severities of the coronavirus?

Data and data science are critical to addressing priority questions for tackling COVID-19

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Data	• Is there a minimum of ethical standards for sharing data in the context of a pandemic? • Can access to the required data be simplified? • How can data sharing and open science assist with the climate crisis? • Will there be Data standardization and structure to enhance interoperability? • Will globally collaborated data about Socio-economic factors and hospital data be used? • In relation to GDPR will there be data safety and cross-border sharing in compliance with national and European legislation? • Will there be comprehensive reporting of infection, symptoms, severity and outcome, short, medium and long term?
Outcomes/residual unmet need	• What are the risk factors linked to severe outcomes? • How to reduce the likelihood of future pandemics, especially of zoonotic origins? • What are the long-term health consequences of COVID infection? • What can we learn from past outbreaks that can assist with managing the current ones? • What is the relationship of cognitive performance, inflammatory immune response and mental illness? • Will the research include mobility and "back to work“ aspects? • What is the impact on health care settings that support other long-term conditions? • What are the insights for prevention, treatment stratification and response? • Do biomarkers exist that accurately predict clinical outcome?
Other?	• What is the sustainability of core resources to continue to offer open data with minimal friction? • Are there clear guidelines on what constitutes de-identified data that is probably safe from de-anonymization? • How to join together existing initiatives to move forward scientific discovery at a rapid pace for COVID. • What opportunities and challenges does the COVID-19 crisis provide with regards to addressing the climate crisis? • Can efforts for data aggregation be aligned with other efforts in the industry? (e.g. Transcelerate) • What are the regional differences and best practices? • What are the insights for prevention, treatment stratification and response?