

All of us together

UK Health Data Research Alliance Symposium

Tuesday 1 December 2020
09:30 - 17:00

Welcome

Caroline Cake, Chief Executive Officer, HDR UK

HDRUK
Health Data Research UK

UK Health Data
Research Alliance

Health Data Research
Innovation Gateway

→ Join the conversation:
hdruk.ac.uk/HDRAlliance20

@HDR_UK

#HDRAlliance20

Alliance Symposium 4 February 2020!



Health data science has played an extraordinary part in this extraordinary year

Lesson 1: Data is a key resource to help save lives



Lesson 3: The public and patients are enablers, and important advocates



Lesson 2: Getting value from data requires people with a wide range of skills working together



Today we will explore together...

- Health data science lessons from COVID
- Access
- Scale-up
- Federation

@HDR_UK on twitter

Hashtags for today's event:

#HDRAlliance20

#HealthDataTogether



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The importance of health data
for research and innovation

Professor Ottoline Leyser DBE FRS
Chief Executive, UK Research and Innovation

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HDR UK - Black Internship Programme

Caroline Cake, Chief Executive Officer, HDR UK
Martin Levermore, PIONEER Hub

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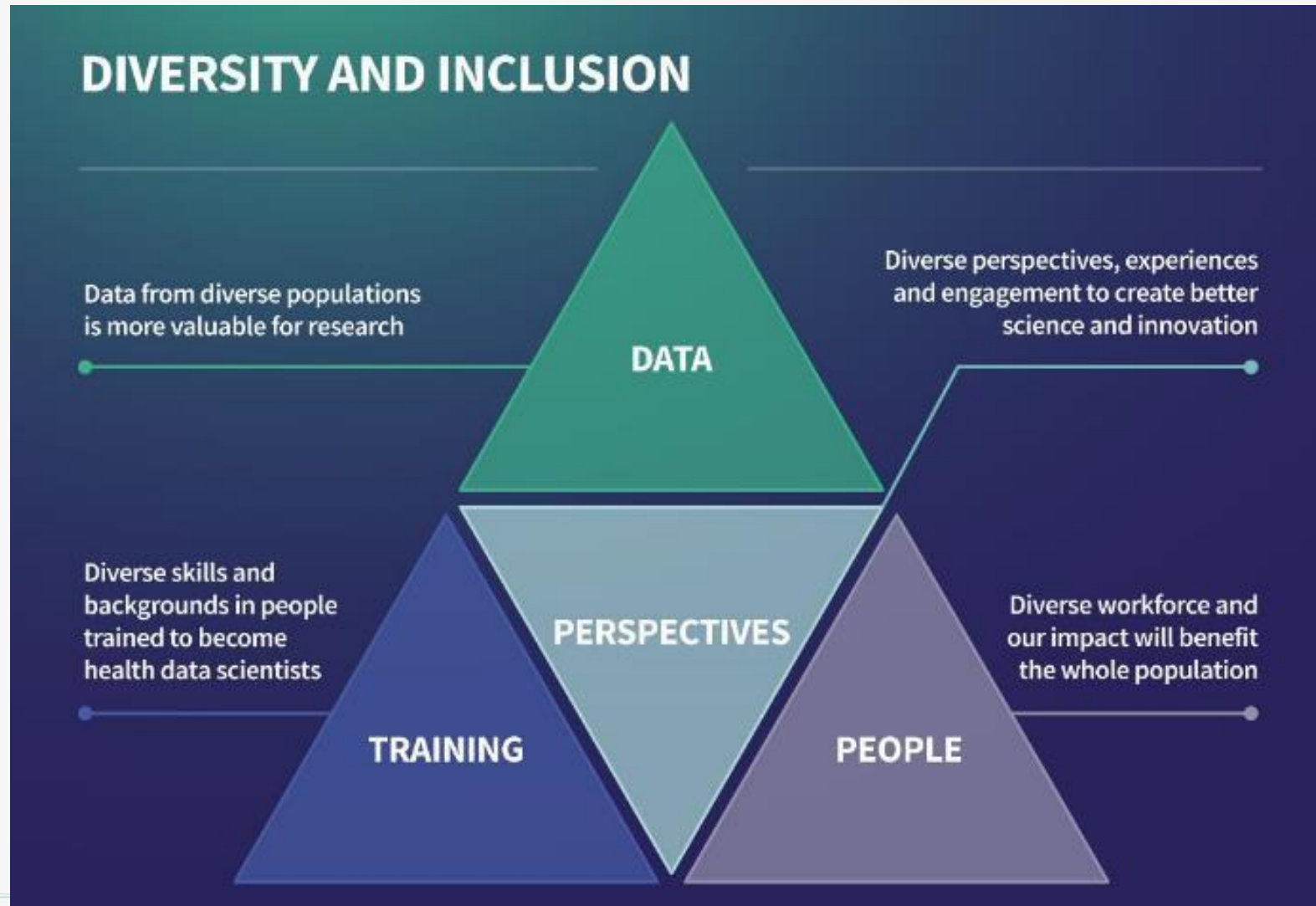
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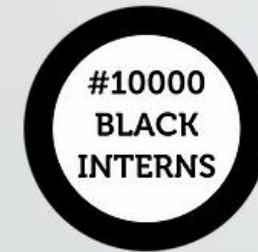
@HDR_UK

#HDRAlliance20

The data science revolution starts now!



Today we are launching the black internship programme for health data scientists partnering with #10,000 Black Interns...



#10000BlackInterns will help transform the horizons and prospects of young Black people in the United Kingdom by offering paid work experience across a wide range of industries, as well as world-class training and development.

With 28 members of the health data community...



Why this matters

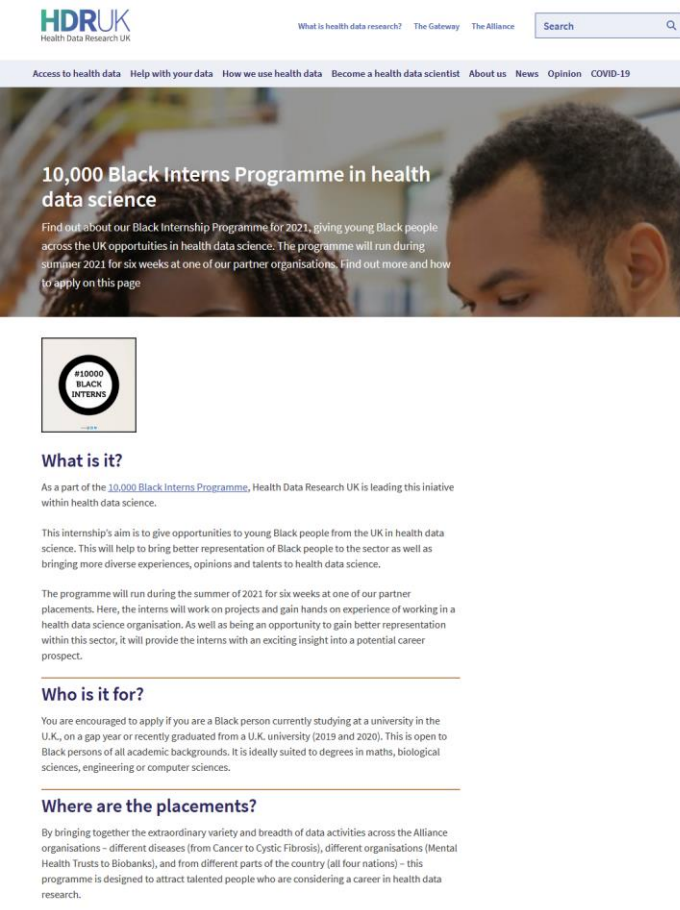
- Start to address under-representation of black health data scientists
- Impacts of COVID-19 for different ethnic groups – and we want to create opportunities for those groups be involved in this work
- Grow diversity of experience, perspectives and talents in our sector



Applications for HDR UK Black Internship programme - open today

- Programme runs for 6 weeks during summer 2021
- Over 50 placements across 28 organisations
- All internships are paid
- Breadth of learning and development opportunities

We will achieve this ambition by working together with you:
Support this vital programme - share link and social posts



The screenshot shows the HDRUK website with a header navigation bar and a search bar. The main content area features a large image of two people looking at a screen, with the title "10,000 Black Interns Programme in health data science". Below the title is a brief description of the programme. A social media-style graphic with the text "#10000 BLACK INTERNS" is also visible. The page is divided into sections: "What is it?", "Who is it for?", and "Where are the placements?", each with detailed text about the programme's goals, eligibility, and structure.

10,000 Black Interns Programme in health data science

Find out about our Black Internship Programme for 2021, giving young Black people across the UK opportunities in health data science. The programme will run during summer 2021 for six weeks at one of our partner organisations. Find out more and how to apply on this page

#10000 BLACK INTERNS

What is it?

As a part of the [10,000 Black Interns Programme](#), Health Data Research UK is leading this initiative within health data science.

This internship's aim is to give opportunities to young Black people from the UK in health data science. This will help to bring better representation of Black people to the sector as well as bringing more diverse experiences, opinions and talents to health data science.

The programme will run during the summer of 2021 for six weeks at one of our partner placements. Here, the interns will work on projects and gain hands on experience of working in a health data science organisation. As well as being an opportunity to gain better representation within this sector, it will provide the interns with an exciting insight into a potential career prospect.

Who is it for?

You are encouraged to apply if you are a Black person currently studying at a university in the U.K., on a gap year or recently graduated from a U.K. university (2019 and 2020). This is open to Black persons of all academic backgrounds. It is ideally suited to degrees in maths, biological sciences, engineering or computer sciences.

Where are the placements?

By bringing together the extraordinary variety and breadth of data activities across the Alliance organisations - different diseases (from Cancer to Cystic Fibrosis), different organisations (Mental Health Trusts to Biobanks), and from different parts of the country (all four nations) - this programme is designed to attract talented people who are considering a career in health data research.

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The story of Health Data Research in the UK
(in the time of COVID)

Chair - Caroline Cake, CEO HDR UK

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**HDR UK's mission is to unite the UK's health data to
enable discoveries that improve people's lives**

**Our 20-year vision is for
large scale data and advanced analytics to benefit every
patient interaction, clinical trial, biomedical discovery
and enhance public health.**

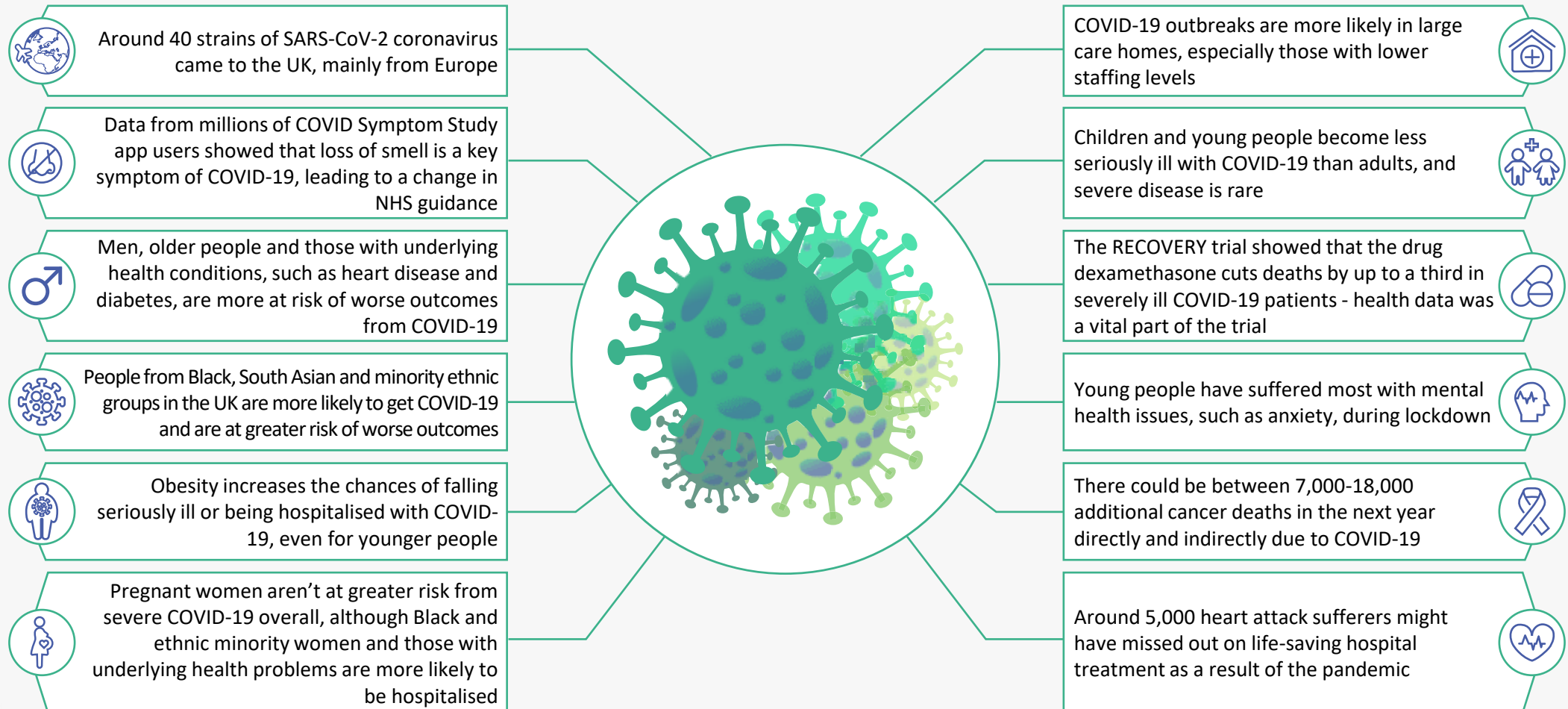
To achieve this vision...we need all of us together

- Diversity in people, skills, sources and use of data
- HDR UK's role in unlocking this potential
- We want to do this together AND with your help.




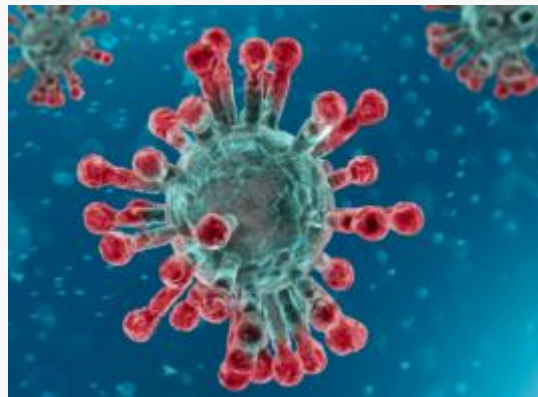


Health data research has responded to one of the biggest challenges in our lifetimes

12 things we have learnt about COVID-19 from health data research



Important discoveries by numerous researchers using data

Understanding Causes of Disease	Better Care	Clinical Trials	Public Health
Genetic sequencing of COVID-19 to track which strains have resulted in different outbreaks	Understanding the impact of COVID-19 on vulnerable people with health conditions, including those with cancer and heart disease	RECOVERY trial used data to establish that dexamethasone reduces death by up to one third in hospitalised patients with severe respiratory complications of COVID-19	High-resolution mapping of COVID cases directly informed public health policy in Wales
			

Inspiring and growing future health data scientists

Over **1,508** health data scientists benefiting from HDR UK training:

- MSc
- PhD
- Summer Schools
- Continuous Professional Development



Building *the* Gateway for researchers and innovators to access data

Health Data Research Innovation Gateway

About Community Dashboard COVID-19 Collections Sign in | Sign up

Explore datasets, tools, papers and related resources used in health research across the UK

Search...

All datasets All tools All papers All courses COVID-19 Cancer

LIVE This is a new service. Your feedback will help us improve it.

523 registered users	533 datasets	126 access requests	143 tools	10,075 searches in last month
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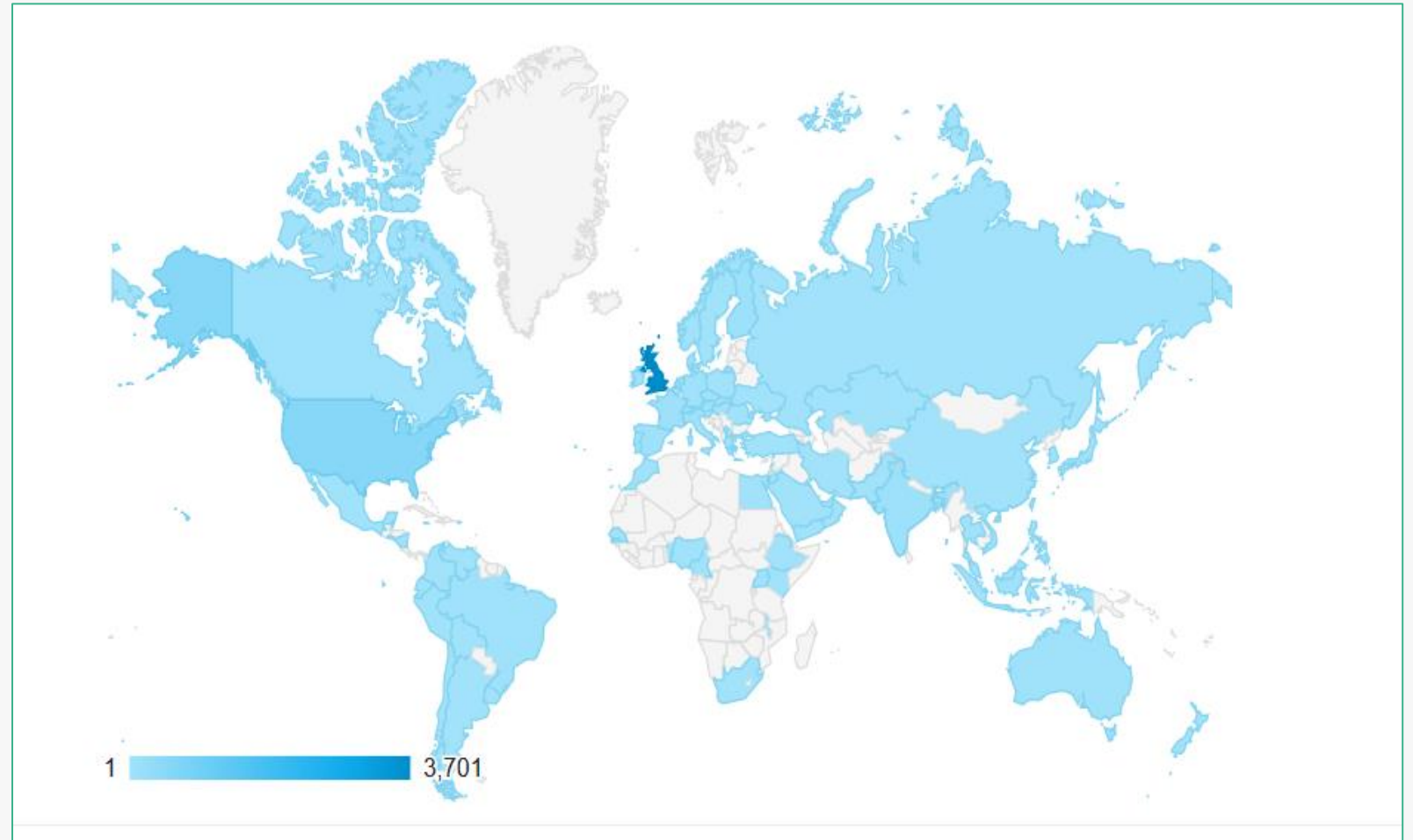
<https://www.healthdatagateway.org/> - a Gateway to datasets, tools, papers, projects and training

UK Health Data Research Alliance members



We are already seeing people discovering UK health data from across the world

**Over 8,300 people, globally,
have been discovering data
through the UK's health data
research Gateway**



A common, transparent approach to data access management based around the Five Safes framework

Health Data Research
Innovation Gateway

Data Access Request

ALLIANCE > SAIL

Save now

About this application

Safe people

Safe project

Safe data

Safe settings

Safe outputs

Files

About this application

Preparation is key to a successful data access request. You need to be able to demonstrate how you will ensure safe use of patient data and the potential for public benefit. The steps below are intended to help you get off to a good start.

1

Select the datasets you need

The datasets you select may impact the questions being asked in this application form. You cannot change this.

4/73 questions answered | 5FC0-31C3-D1E8-1B7C-1E02-BAF7

Contributors

Submit application

Next

Data access request applications

Manage forms and applications

- days

average time from submission to decision

All (6)

Pre-submission (6)

Submitted (0)

In review (0)

Approved (0)

Rejected (0)

ALLIANCE > NHS DIGITAL - Pillar 2 - Covid-19 UK Non-hospital Antigen Testing Results

0 days since start

Pre-submission

Datasets

Pillar 2 - Covid-19 UK Non-hospital Antigen Testing Results

Custodian

ALLIANCE > NHS DIGITAL

Applicants

David Seymour

Submitted

-

Last activity

27 November 2020 19:10

Understanding the value of public donated data to managing a pandemic

0 days since start

Pre-submission

Datasets

COVID-19 Symptom Tracker Dataset

Custodian

ALLIANCE > SAIL

www.hdruk.ac.uk/help-with-your-data/

Data Utility Matrix

Data Quality Tool Evaluation

Metadata completeness



Enabled through services provided by Health Data Research Hubs and the BHF Data Science Centre



BREATHE

Enabling high quality research and innovation to address respiratory conditions such as asthma and COPD.

[Find out more](#)



DATA-CAN

DATA-CAN is a UK-wide partnership that aims to unlock the power of health data to improve cancer care.

[Find out more](#)



NHS DigiTrials

The Hub will focus on the development of a foundation service to improve the assessment of clinical trial feasibility – supporting improved planning and delivery of clinical trials in the UK



PIONEER

By integrating information about how acutely unwell people access and use health services – such as from community health, the ambulance service and hospitals, PIONEER will allow innovative healthcare companies to develop, test and deliver advances in clinical care.



Gut Reaction

Gut Reaction will harness the power of health data to help identify the best treatment for each person with Crohn's Disease or Ulcerative Colitis. Working with patients, academia and industry, it will unite high-quality health data sets from trusted partners and support their use for research.

[Find out more](#)



INSIGHT

INSIGHT is focused on eye disease and its application to wider health, including diabetes and dementia. It will use anonymised large-scale data and advanced analytics, including artificial intelligence, to develop new insights in disease detection, diagnosis, treatments and personalised healthcare.

[Find out more](#)



Discover-NOW

Using NHS data from London and Manchester to support research to find ways to diagnose and treat disease.

[Find out more](#)



BHF Data Science Centre

Promoting the safe and ethical use of data for research into all diseases of the heart and circulation.

[Find out more](#)

Working in partnership to answer priority questions - The National Core Studies

Surveillance & Epidemiology	Longitudinal Health and Wellbeing	Clinical Trials Infrastructure & Support		Transmission & Environment	Immunity
		Vaccines	Therapeutics		
<p>Professor Ian Diamond (ONS)</p> <p>Collecting and analysing data to understand incidence and prevalence broadly and in different settings in order to inform response measures.</p>	<p>Professor Nishi Chaturvedi (UCL)</p> <p>Understanding the impact of Covid-19 on long term health (including long covid) to inform the design of mitigating policies.</p>	<p>Divya Chadha Manek (VTF/NIHR)</p> <p><i>Establishing infrastructure to run large scale trials for Covid-19 drugs and vaccines without disrupting trials for other diseases.</i></p>	<p>Professor Patrick Chinnery (MRC)</p>	<p>Professor Andrew Curran (HSE)</p> <p>Taking samples to aid understanding of transmission of the disease in workplace, transport and public places.</p>	<p>Professor Paul Moss (University of Birmingham)</p> <p>Understanding serology as a useable predictor of immunity against Covid.</p>
<p>Data and Connectivity</p> <p>Professor Andrew Morris (HDR UK working with ONS)</p> <p>Making UK-wide health and administrative data available for linkage and accessible to catalyse Covid-19 research.</p>					

Making data discoverable and safely accessible to support the COVID-19 response

National Trusted Research Environments					
Core COVID-19 Datasets available for linkage	Office for National Statistics Secure Research Service	England (NHS Digital Data Processing Service)	Scotland (National Data Safe Haven)	Wales (SAIL Databank)	Northern Ireland (Honest Broker Service)
Pillar 1 COVID-19 Testing Data	To be linked				
Pillar 2 Testing data (UK Gov)	To be linked				Missing results prior to 26 Apr – Data quality issue
Primary Care	GPES Onboarding underway	GPES extract – 98% practice coverage, large subset of codes (4bn items) Community Prescribing	Albasoft ESCRO GP Extraction* Prescribing Information System	80%+ coverage of full longitudinal record, with 100% coverage for COVID codes	Enhanced Prescribing Database as proxy
Secondary Care	HES – available for internal access only 100% coverage	100% coverage	100% coverage	100% coverage	
Personal Demographic Service	100% coverage	100% coverage	100% coverage	100% coverage	
Death registry	Provisional Monthly Extract & Linked Census and death occurrence	100% coverage	100% coverage	100% coverage	
C-19 Infection Survey (Pillar 4)					
COVID-19 Clinical Information Network (CO-CIN)	To be linked to 2011 census	Data for linkage in Scottish Data Safe Haven agreed	Limited metadata	Awaiting decision on data access	
Census 2011	Household structure				
Covid Opinions Survey					
Business Impact of Covid Survey	c. 5,000 businesses				
Labour Force Survey	40,000 households, 100,000 individuals				
Intensive Care data		ICNARC – internal use only	SICSAG (updated weekly)	ICNARC – internal use only	
Pillar 3 Testing data (NHS labs)		Internal use only			
Pillar 3 Testing data (Thrive)		Internal use only			
Other Pillar 4 Testing data	VIVALDI, REACT II				
ZOE Symptom Study App Data				UK wide (unlinked) Wales (linked)	
COG-UK Viral Genome				Finalising governance	

KEY

1. Custodian engagement

2. Dataset available in secure Trusted Research Environment

3. Linkages established to other priority datasets (within TRE)


4. Datasets available for COVID-19 research via Gateway

This large-scale collaboration is achieving large scale results



25 COVID-19 taskforce calls and SAGE reports
with **167** clinical and health data research leaders engaged



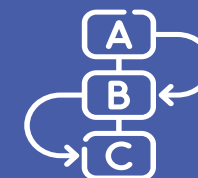
1044 COVID-19 pre-print publications



1474 academic, industry and NHS participants in COVID-19 Slack channel with 10 sub-channels



111 health data research questions identified – 42 prioritised



Involving and engaging patients in health data research in new ways

Strong **Public Advisory Board** providing strategic guidance on all our work

Consultation on COVID work across **7 UK-wide patient and public networks** with **168 responses**.

“

I am glad you're involving me from what seems to be the beginning so that you can actually take my concerns and address them whilst helping the greater good

Patient / Public Voice Rep



92 people consulted to inform decisions on methods and process for clinical trial recruitment

16,500 contacts with patient & public contributors across the institute in 2020

“

It is essential that the public is included in this ground-breaking work.

Margaret Rogers
Member of the HDR UK Public
Advisory Board

Patient input shaping use of data for PRINCIPLE clinical trial



“The creative energy that has gone into making the progress you outline could well be saving lives soon. You are making history.”

Chris Butler, Principle Trial Lead



I'm so pleased you're looking into this as this is something that can actually make a difference.

Patient / Public Voice Rep

Enabled **daily access to positive C-19 test results within 24 hours to increase recruitment.**

Support also included:

- Daily problem solving and management scrums
- In-depth engagement with the ICO
- A public survey with over 90 responses
- Engagement with multiple data custodians
- Review by NHS Digital's IGARD
- NHS Digital's Trial team are now addressing the remaining actions to support data flow

Provides confidence in concept for future trials that require incident COVID cases

International COVID-19 Data Alliance - Advancing open science practice globally



Vision



To unite international health research data to enable discoveries that benefit everyone, everywhere, by reducing the harm of COVID-19; and enable an efficient data response to future pandemics and other health challenges

Mission



To build an open international partnership that demonstrates trustworthiness to support a rapid response to COVID-19 and a long-term alliance for making data accessible to researchers and scientists around the world.

- **Launched on 6 July 2020**
- **Convened by Health Data Research UK**
- **Focus on Lower and Middle-Income Countries**
- **Supported by the COVID-19 Therapeutics Accelerator**
- **Call for Grand Challenge Driver Projects to be launched on 11 December**

Through a broad global Alliance



Our Partners...and growing



Our Therapeutics Accelerator Funders



Convened by

www.icoda-research.org



#ICODAforum

Imagine how far all of us together can go

*If you want to go fast, go alone; but if you want
to go far, go together*

All of us together

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Panel:

Derek Stewart, Patient Representative, Health Data Research UK and PA Consulting

Jill Hopkins, Global Head, Ophthalmology Personalised Care, Roche-Genentech

John Danesh, Research Director, HDR UK Cambridge

**Amitava Banerjee, Associate Professor in Clinical Data Science and Honorary Consultant Cardiologist,
University College London Hospitals NHS Trust**

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Thank you

#HDRAlliance20

#DataSavesLives

