

**HDR UK One Institute Strategy
Delivery Plan 2020/21**



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, and biomedical discovery and to enhance public health.

We have listened, reviewed our One Institute strategy and focused our delivery plan on what makes us distinctive



Who we are

Health Data Research UK (HDR UK) is the only national institute for health data that includes England, Wales, Scotland and Northern Ireland



What we do

- HDR UK has been established to work with a **wide range of health data** from the NHS, universities, research institutes and charities, and increasingly from wearables, and private companies
- Over the next 5 years, health research datasets, participants and uses will **grow rapidly**
- HDR UK will position the UK to **lead health data science internationally** with our national, pan-sector approach

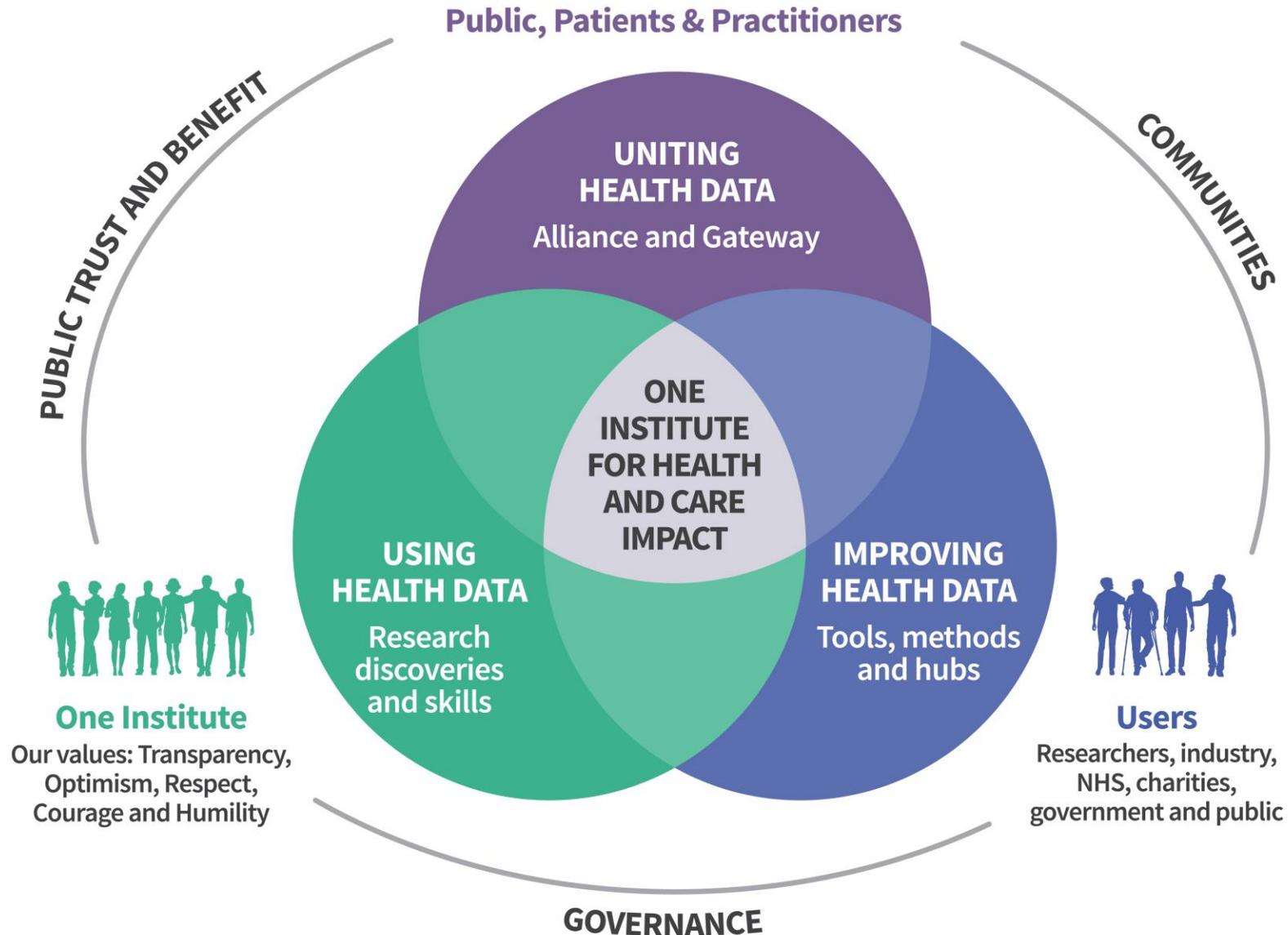


How we will do it

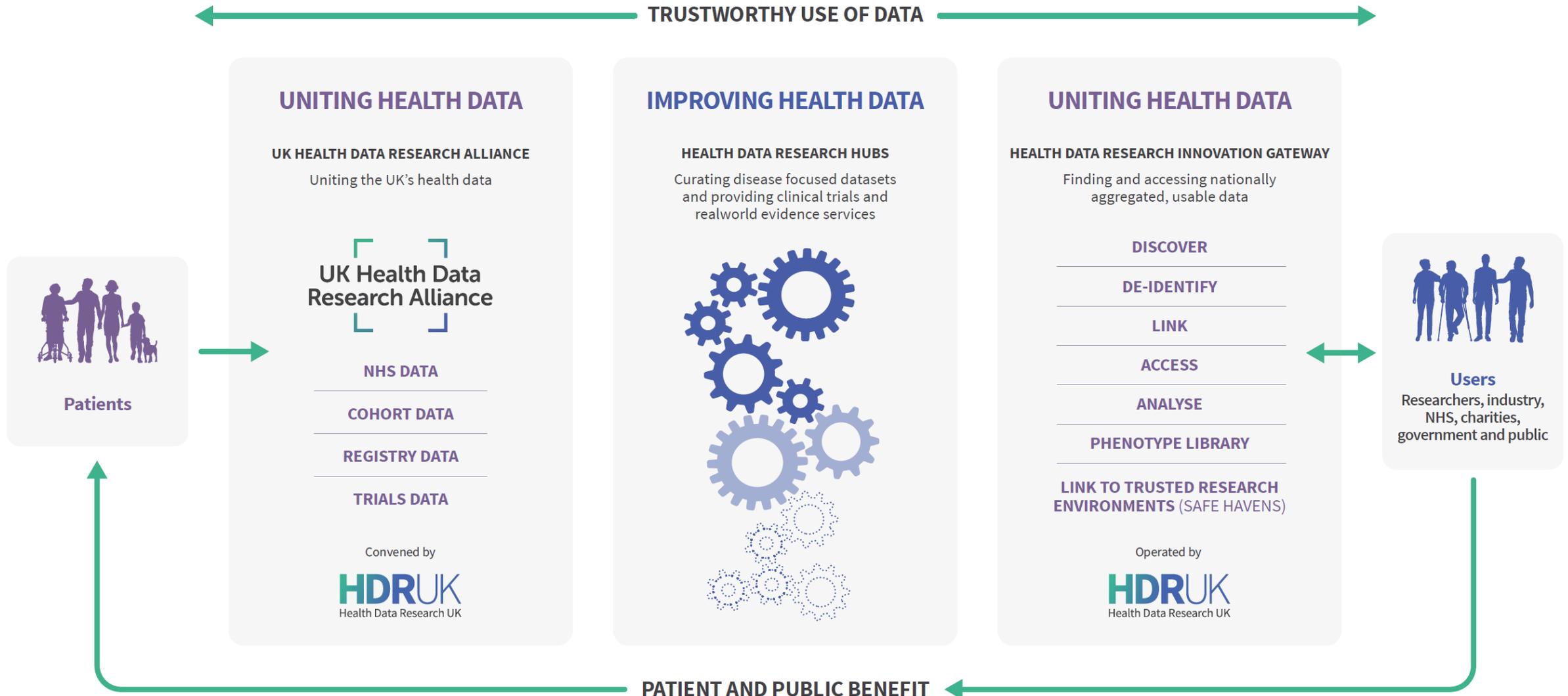
HDR UK is establishing the UK's health data research infrastructure by:

- **Uniting health data** - providing national convenorship through the Alliance and Gateway with open standards, and in a way that earns the trust of patients and the public
- **Improving health data** - providing tools, methods, hubs, and national expertise in health data quality improvement for researchers and innovators
- **Using health data** – enabling research and innovation, demonstrating novel approaches to health data use, impact at scale, and establishing an expert group of national research leaders in health data science

Our strategy



Our strategy will be delivered via the infrastructure we have started to create...



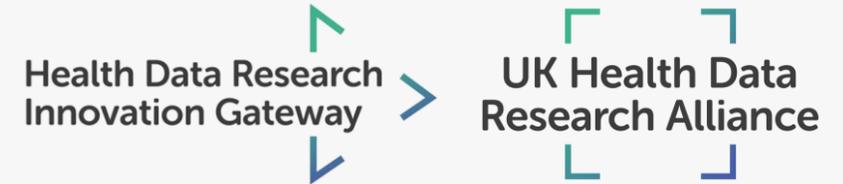


Uniting health data Alliance and Gateway



HDR UK is convening health data custodians across the UK and aims to achieve:

- **Efficient, safe access** to large scale, diverse data for *researchers and innovators*
- **Transparency** of use of data to *patients and the public*



We will achieve our aims through:

- The Gateway: fundamental to the world's health data research, trusted by patients, public and practitioners
- The Alliance with members from all the UK's major health data custodians
- Standards: Participation, Information Governance, Access, benefit sharing, and Trusted Research Environments
- Training for the infrastructure

In 2020/21 we are focused on:

- Creating the Gateway Technology Partnership: To enable secure data access across multiple data controllers, develop concept of Trusted Research Environments and integrate infrastructure developments from core funder investments
- Implementing our Public, patient, practitioner involvement and engagement and talent/workforce strategy: To support and earn trust in the infrastructure
- Increasing scale, depth and transparency of metadata in the Gateway and the Alliance
- Creating Standards for Participation & Sustainability, Access and delivery of Trusted Research Environments

Improving health data

Tools, methods and hubs

HDR UK provides tools, methods, hubs, and national expertise to achieve better data in the Alliance and Gateway for researchers and innovators

We will achieve our aims through:

- Tools and methods to measure and improve the utility of data discoverable through the Gateway, including applied analytics and the human phenome
- 8-10 Health Data Research hubs improving the data, including BREATHE, DATA-CAN, Discover-NOW, PIONEER, INSIGHT, Gut Reaction, NHS DigiTrials, and the BHF Data Science Centre

In 2020/21 we are focused on:

- Developing an approach for evaluating data utility, improving the utility of data in hubs and developing innovative data improvement and measurement approaches
- Establishing the BHF Data Science Centre
- Making discoverable new tools and methods in the Gateway to improve how we describe well-being and disease (the human phenome), using applied analytics (AI) and scoping an approach to integrate social science data



APPLIED ANALYTICS



HUMAN PHENOME



BHF DATA SCIENCE CENTRE

Using health data

Research, discovery and skills

HDR UK enables research and innovation by demonstrating novel approaches to health data use, impact at scale, and establishing an expert group of national research leaders in health data science to achieve:

- **Better, more useful, research** for funders and public – that no single research organisation could achieve alone

We will achieve our aims through:

- UK-wide research programmes: Understanding Causes of Disease, Improving public health, Better Clinical Trials and Better Care
- Health science user community: patients, public, academia, NHS, charities, and government (>10,000 people engaged)
- Major impact use cases
- Training programmes and career pathways for health data scientists

In 2020/21 we are focused on:

- Implementing the One Institute approach to deliver distinctive team science research programmes initially for Understanding Causes of Disease
- High impact use cases: To deliver distinctive team science research programmes in Better Care, Clinical Trials, Public Health and Understanding Causes of Disease areas
- Training and skills development, to develop our Fellows, PhD & MSc programmes



**UNDERSTANDING
THE CAUSES
OF DISEASE**



**BETTER, FASTER,
EFFICIENT
CLINICAL TRIALS**



**IMPROVING
PUBLIC HEALTH**



**BETTER
CARE**



MSc



PHD



FELLOWS

One Institute

Public trust & benefits, governance, team science and communities

HDR UK will bring together the community and earn public trust to build recognition for the UK as the place to do the **most impactful health data science**

We will achieve our aims through:

- International recognition as one of the world's leading health data science institutes
- Scalable, trusted business model
- Inclusive, team-oriented culture built on the values of transparency, optimism, respect, courage and humility
- Successful Quinquennial Review with our core funders and leverage funding secured
- Positioning HDR UK as a trustworthy organisation that has the confidence of patients, the public, practitioners and key stakeholders



"I can see that if researchers had been able to access and use my health data, I might have been offered more effective treatments, quicker."

Roseanna Fennessy, patient representative for Gut Reaction

In 2020/21 we are focused on:

- Successful One Institute Establishment Review
- Developing our international strategy
- Identifying opportunities for greater and financially sustainable impact
- Delivering an integrated strategy for communications, engagement and involvement focused on patients, public, researchers, innovators, practitioners, funders and key stakeholders



"All research is based on data and I want my data to be used to give the most benefit to others and to myself."

Margaret Grayson, patient representative for DATA-CAN

Our big events and milestones for the year

June 2020



One Institute event

August 2020



Summer School

October 2020



Gateway Milestone 2

November 2020



Alliance Symposium

March 2021



Hub Milestone 2

'Green shoots' that give us confidence in our approach

Delivery highlights from 2019/20

100s of people engaging from different communities



>5 high profile global partnerships

6 disease areas prioritised by Hubs



- Cancer
- Diabetes
- Eye health
- Respiratory health
- Acute care
- Inflammatory bowel disease

210 open access publications – starting to make a difference to people's health and care



30 repositories on GitHub



National Projects developing innovative solutions to the UK's biggest health challenges



Smart Hearts – Improving the lives of those with heart failure in Greater Manchester



Linking health data to understand health outcomes of homeless people



Improving child health by optimising the use of clinical data for research

HDR UK is a national federated institute across 31 UK locations



**Welcome Trust
Great Ormond
Street DRIVE Unit**

CENTRAL TEAM OFFICES



**HDR UK Midlands
(Birmingham, Leicester,
Nottingham, Warwick)**

HDR UK London

HDR UK Oxford

**HDR UK Scotland
(Aberdeen, Dundee,
Edinburgh, Glasgow, St
Andrews, Strathclyde)**

HDR UK Cambridge

**HDR UK Wales &
Northern Ireland
(Swansea, Belfast)**

**HDR UK North
(Liverpool)**

**HDR UK South-West
(Bristol)**

RESEARCH LOCATIONS



**BREATHE
DATA-CAN
Discover-NOW
Gut Reaction
INSIGHT
PIONEER
NHS Digitrials
BHF Data Science Centre**

HUBS

**Belfast
Cambridge
London
Bristol
Exeter
Leeds**

**TRAINING LOCATIONS
(MASTERS)**



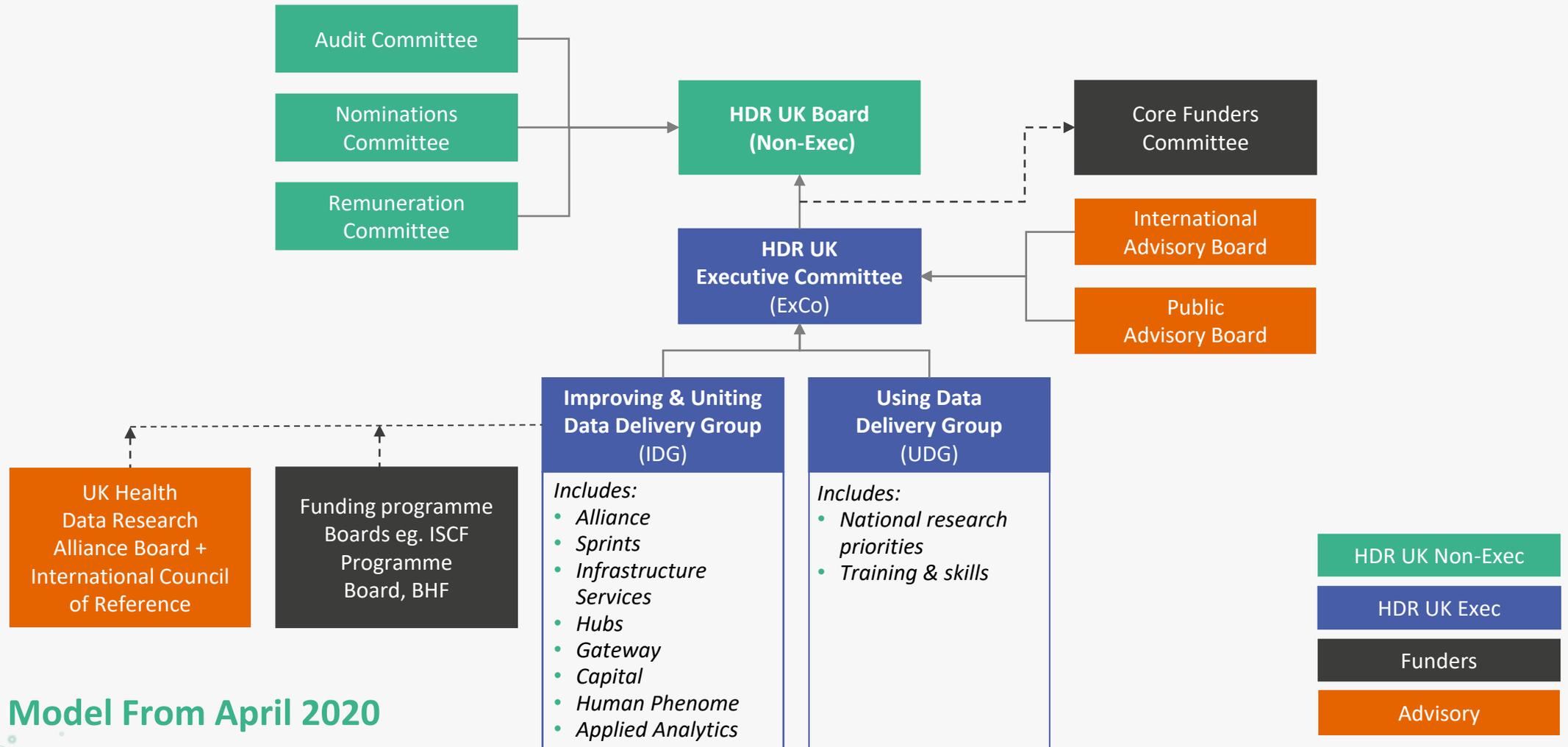
Contact details for our team – please get in touch if you want to be involved (1/2)

 <p>UK Health Data Research Alliance</p>	<p>Director - David Seymour (David.Seymour@hdruk.ac.uk) Alliance Delivery Manager and Access standards – Paola Quattroni (paola.Quattroni@hdruk.ac.uk)</p>	 <p>DATA-CAN The Health Data Research Hub for Cancer</p>	<p>Director: Charlie Davie Operational Lead: Matt Cooper (Matt.cooper@uclpartners.com) Email: datacan@uclpartners.com</p>
 <p>Health Data Research Innovation Gateway</p>	<p>Gateway – Gerry Reilly (Gerry.reilly@hdruk.ac.uk) Gateway Technology Partnership – Peggy Barthes-Streit (Peggy.Barthes-Streit@hdruk.ac.uk) Gateway Technical Direction – Susheel Varma (Susheel.varma@hdruk.ac.uk)</p>	 <p>DIGITRIALS Health Data Research Hub for Clinical Trials</p>	<p>Director: Martin Landray (martin.landray@ndph.ox.ac.uk) Email: nhsdigitrialsboard@nhs.net</p>
 <p>Human Phenome Project</p>	<p>Director – Harry Hemingway (h.hemingway@ucl.ac.uk) Human Phenome Library - Spiros Denaxas (s.denaxas@ucl.ac.uk) Lucy McCloughan (lucy.mccloughan@ed.ac.uk)</p>	 <p>Discover-NOW Health Data Research Hub for Real World Evidence</p>	<p>Director: Axel Heitmueller Operational Lead: Amanda Lucas (Amanda.Lucas@imperialcollegehealthpartners.com)</p>
 <p>Applied Analytics</p>	<p>Director – Chris Holmes (s.denaxas@ucl.ac.uk) Director – Dave Robertson (interim) (D.Robertson@ed.ac.uk) Reproducible Machine Learning – Aiden Doherty (aiden.doherty@dph.ox.ac.uk) Text Analytics - Richard Dobson (richard.j.dobson@kcl.ac.uk)</p>	 <p>Gut Reaction</p>	<p>Director: John Bradley Operational Lead: Mark Avery (mark.avery@eahsn.org)</p>
 <p>BHF Data Science Centre</p>	<p>Director – Cathie Sudlow (cathie.sudlow@hdruk.ac.uk)</p>	 <p>INSIGHT Health Data Research Hub</p>	<p>Director: Alastair Denniston Operational Lead: Manjit Benning (manjit.benning1@nhs.net) Email: enquiries@insight.hdrhub.org</p>
 <p>BREATHE Health Data Research Hub</p>	<p>Director: Aziz Sheikh Operational Lead: Shahid Hanif (shahid.hanif@ed.ac.uk) ; Email: breathe.admin@ed.ac.uk</p>	 <p>PIONEER Health Data Research Hub</p>	<p>Director: Elizabeth Sapey Operational Lead: Claire Potter (c.potter@bham.ac.uk) Email: pioneer@contacts.bham.ac.uk</p>

Contact details for our team – please get in touch if you want to be involved (2/2)

Data Quality Standards	Neil Sebire (neil.Sebire@hdruk.ac.uk) Ben Gordon (ben.gordon@hdruk.ac.uk)	Clinical Trials	Martin Landray (martin.landray@ndph.ox.ac.uk)
Trusted Research Environments	Gerry Reilly (Gerry.reilly@hdruk.ac.uk) Tim Hubbard (tim.Hubbard@hdruk.ac.uk) David Seymour (David.Seymour@hdruk.ac.uk)	Public Health	Ronan Lyons (r.a.lyons@swansea.ac.uk) Alysha Morgan (a.l.morgan@swansea.ac.uk) Colin McCowan (cm434@st-andrews.ac.uk)
Training, skills and development	Georgina Moulton (Georgina.moulton@hdruk.ac.uk)	Public, Patient and Practitioner Involvement	Amanda White (Amanda.white@hdruk.ac.uk) Sinduja Manohar (Sinduja.Manohar@hdruk.ac.uk)
One Institute National Delivery	Dani Blatt (dani.blatt@hdruk.ac.uk)	Communications & Engagement	Amanda White (Amanda.white@hdruk.ac.uk) Fran Lord (Francesca.lord@hdruk.ac.uk) Hettie Williams (Hettie.Williams@hdruk.ac.uk)
High Impact Case Studies and Team Science	Melissa Lewis-Brown (Melissa.lewis-brown@hdruk.ac.uk)	Financial Management and Sustainability	Amanda Borton (Amanda.borton@hdruk.ac.uk)
Understanding Causes of Disease	John Danesh (jd292@medschl.cam.ac.uk) Michael Chapman (mc27@sanger.ac.uk) Richard Houghton (rth29@medschl.cam.ac.uk) Adam Butterworth (asb38@medschl.cam.ac.uk)	Establishment Review	Victoria Platt (Victoria.platt@hdruk.ac.uk)
Better Care	Simon Ball (jd292@medschl.cam.ac.uk) Alastair Denniston (Alastair.denniston@insight.hdrhub.org) Alice Turnbull (Alice.Turnbull@hdruk.ac.uk) Kevin Dunn (K.W.Dunn@bham.ac.uk)		

Our governance structure



Model From April 2020

Thank you

Find out more:

Health Data Research UK
hdruk.org

UK Health Data Research Alliance
Web: ukhealthdata.org

Health Data Research UK Innovation Gateway
healthdatagateway.org

Social: [@HDR_UK](https://twitter.com/HDR_UK)

Email: enquiries@hdruk.ac.uk