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

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**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

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**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

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**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

Public, Patients & Practitioners

UNITING HEALTH DATA
Alliance and Gateway

PUBLIC TRUST AND BENEFIT

One Institute
Our values: Transparency, Optimism, Respect, Courage and Humility

USING HEALTH DATA
Research discoveries and skills

ONE INSTITUTE FOR HEALTH AND CARE IMPACT

IMPROVING HEALTH DATA
Tools, methods and hubs

COMMUNITIES

Users
Researchers, industry, NHS, charities, government and public

GOVERNANCE
Our strategy will be delivered via the infrastructure we have started to create...
...and is responsive to the COVID-19 crisis

Our strategy in responding to the COVID-19 pandemic is to mobilise talent and partnerships across the UK to:

- Co-ordinate and connect national data science driven research efforts related to COVID-19
- Accelerate access to UK-wide priority data relevant to COVID-19 for research
- Leverage the best of the UK’s health data science capability to address the wider impact of the COVID-19 pandemic, supporting vulnerable groups that will be hardest hit

To ensure that the most promising research questions are supported, and to limit distraction of the NHS, we are using a process to prioritise research efforts and report these to the Scientific Advisory Group for Emergencies (SAGE).
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**

<table>
<thead>
<tr>
<th>We will achieve our aims through:</th>
<th>In 2020/21 we are focused on:</th>
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<tbody>
<tr>
<td>• Tools and methods to measure and improve the utility of data discoverable through the Gateway,</td>
<td>• Developing an approach for evaluating data utility, improving the utility of data in hubs and</td>
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<tr>
<td>including applied analytics and the human phenome</td>
<td>developing innovative data improvement and measurement approaches</td>
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<tr>
<td>• 8-10 Health Data Research hubs improving the data, including BREATHE, DATA-CAN, Discover-NOW,</td>
<td>• Establishing the BHF Data Science Centre</td>
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<tr>
<td>PIONEER, INSIGHT, Gut Reaction, NHS DigiTrials, and the BHF Data Science Centre</td>
<td>• Making discoverable new tools and methods in the Gateway to improve how we describe well-being</td>
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<td></td>
<td>and disease (the human phenome), using applied analytics (AI) and scoping an approach to</td>
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<td>integrate social science data</td>
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![Gut Reaction](image1)

**Gut Reaction**

The Health Data Research Hub for Cancer

![DATA-CAN](image2)

**DATA-CAN**

Health Data Research Hub for Real World Evidence

![Discover-NOW](image3)

**Discover-NOW**

Health Data Research Hub for Clinical Trials

![INSIGHT](image4)

**INSIGHT**

Health Data Research Hub

![PIONEER](image5)

**PIONEER**

Health Data Research Hub

![APPLIED ANALYTICS](image6)

APPLIED ANALYTICS

![HUMAN PHENOME](image7)

HUMAN PHENOME

![BHF DATA SCIENCE CENTRE](image8)

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

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<tr>
<td>• UK-wide research programmes: Understanding Causes of Disease, Improving public health, Better Clinical Trials and Better Care</td>
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<tr>
<td>• Health science user community: patients, public, academia, NHS, charities, and government (&gt;10,000 people engaged)</td>
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<td>• Major impact use cases</td>
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<tr>
<td>• Training programmes and career pathways for health data scientists</td>
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<tr>
<td>• Implementing the One Institute approach to deliver distinctive team science research programmes initially for Understanding Causes of Disease</td>
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<tr>
<td>• High impact use cases: To deliver distinctive team science research programmes in Better Care, Clinical Trials, Public Health and Understanding Causes of Disease areas</td>
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</tr>
<tr>
<td>• Training and skills development, to develop our Fellows, PhD &amp; MSc programmes</td>
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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

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

"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

"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

**CENTRAL TEAM OFFICES**
- Welcome Trust
- Great Ormond Street DRIVE Unit

**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)

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

**TRAINING LOCATIONS**
- Belfast
- Cambridge
- London
- Bristol
- Exeter
- Leeds
Contact details for our team – please get in touch if you want to be involved (1/2)

| UK Health Data Research Alliance | Director - David Seymour (David.Seymour@hdruk.ac.uk)  
|  | Alliance Delivery Manager and Access standards – Paola Quattrooni (paola.Quattrooni@hdruk.ac.uk) |
| Health Data Research Innovation Gateway | 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) |
| Human Phenome Project | 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) |
| Applied Analytics | 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) |
| BHF Data Science Centre | Director – Cathie Sudlow (cathie.sudlow@hdruk.ac.uk) |
| BREATHE | Director: Aziz Sheikh  
|  | Operational Lead: Shahid Hanif (shahid.hanif@ed.ac.uk)  
|  | Email: breathe.admin@ed.ac.uk |
| BREATHE | Director: Cathie Sudlow (cathie.sudlow@hdruk.ac.uk) |
| DATA-CAN | Director: Charlie Davie  
|  | Operational Lead: Matt Cooper (Matt.cooper@uclpartners.com)  
|  | Email: datacan@uclpartners.com |
| DIGITRIALS | Director: Martin Landray (martin.landray@ndph.ox.ac.uk)  
|  | Email: nhsdigitrialsboard@nhs.net |
| Discover-NOW | Director: Axel Heitmueller  
|  | Operational Lead: Amanda Lucas (Amanda.Lucas@imperialcollegehealthpartners.com) |
| Gut Reaction | Director: John Bradley  
|  | Operational Lead: Mark Avery (mark.avery@eahsn.org) |
| INSIGHT | Director: Alastair Dennistion  
|  | Operational Lead: Manjit Benning (manjit.benning1@nhs.net)  
|  | Email: enquiries@insight.hdrhub.org |
| PIONEER | Director: Elizabeth Sapey  
|  | Operational Lead: Claire Potter (c.potter@bham.ac.uk)  
|  | Email: pioneer@contacts.bham.ac.uk |

|
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) |
| Trusted Research Environments | Gerry Reilly (Gerry.reilly@hdruk.ac.uk)  
| Tim Hubbard (tim.hubbard@hdruk.ac.uk)  
| David Seymour (David.Seymour@hdruk.ac.uk) |
| Training, skills and development | Georgina Moulton (Georgina.moulton@hdruk.ac.uk) |
| One Institute National Delivery | Dani Blatt (dani.blatt@hdruk.ac.uk) |
| High Impact Case Studies and Team Science | Melissa Lewis-Brown (Melissa.lewis-brown@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) |
| 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) |
| Clinical Trials | Martin Landray (martin.landray@ndph.ox.ac.uk) |
| Public Health | Ronan Lyons (r.a.lyons@swansea.ac.uk)  
| Alysha Morgan (a.l.morgan@swansea.ac.uk)  
| Colin McCowan (cm343@st-andrews.ac.uk) |
| Public, Patient and Practitioner Involvement | Amanda White (Amanda.white@hdruk.ac.uk)  
| Sinduja Manohar (Sinduja.Manohar@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) |
| Financial Management and Sustainability | Amanda Borton (Amanda.borton@hdruk.ac.uk) |
| Establishment Review | Victoria Platt (Victoria.platt@hdruk.ac.uk) |
Our governance structure

- Audit Committee
- Nominations Committee
- Remuneration Committee
- HDR UK Board (Non-Exec)
- HDR UK Executive Committee (ExCo)
- Core Funders Committee
- International Advisory Board
- Public Advisory Board
- Improving & Uniting Data Delivery Group (IDG)
  - Includes: Alliance, Sprints, Infrastructure Services, Hubs, Gateway, Capital, Human Phenome, Applied Analytics
- Using Data Delivery Group (UDG)
  - Includes: National research priorities, Training & skills

UK Health Data Research Alliance Board + International Council of Reference

Funding programme Boards eg. ISCF Programme Board, BHF

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
Email: enquiries@hdruk.ac.uk