

# HDR UK Strategic Delivery Plan – 2021/22



**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 to feedback from our colleagues and stakeholders

*COVID-19 has enabled an extraordinary use case that demonstrates the power of health data science. Looking ahead HDR UK needs to maintain a balance between COVID and other diseases*

*HDR UK has a practical and applied approach to public and patient involvement and engagement that is really driving better decision making*

*“You are the gateway to the rich, but distributed and heterogenous, data in the UK”*

*HDR UK is providing co-ordination in a busy landscape: prioritising questions, reporting to SAGE, and the role of the Gateway.*

*HDR UK needs to focus on building trustworthy, efficient access to linked datasets that represent the majority of the population, and helping organisations to use them*

*HDR UK can inspire people (researchers, the public) with what is possible with the scale of health data now available – and why this matters to people*

# We have reviewed our One Institute strategy to focus our 2021/22 delivery plan on what makes HDR UK 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 catalyses and convenes the whole health data community, and positions the UK to play a leading role in **international health data science**



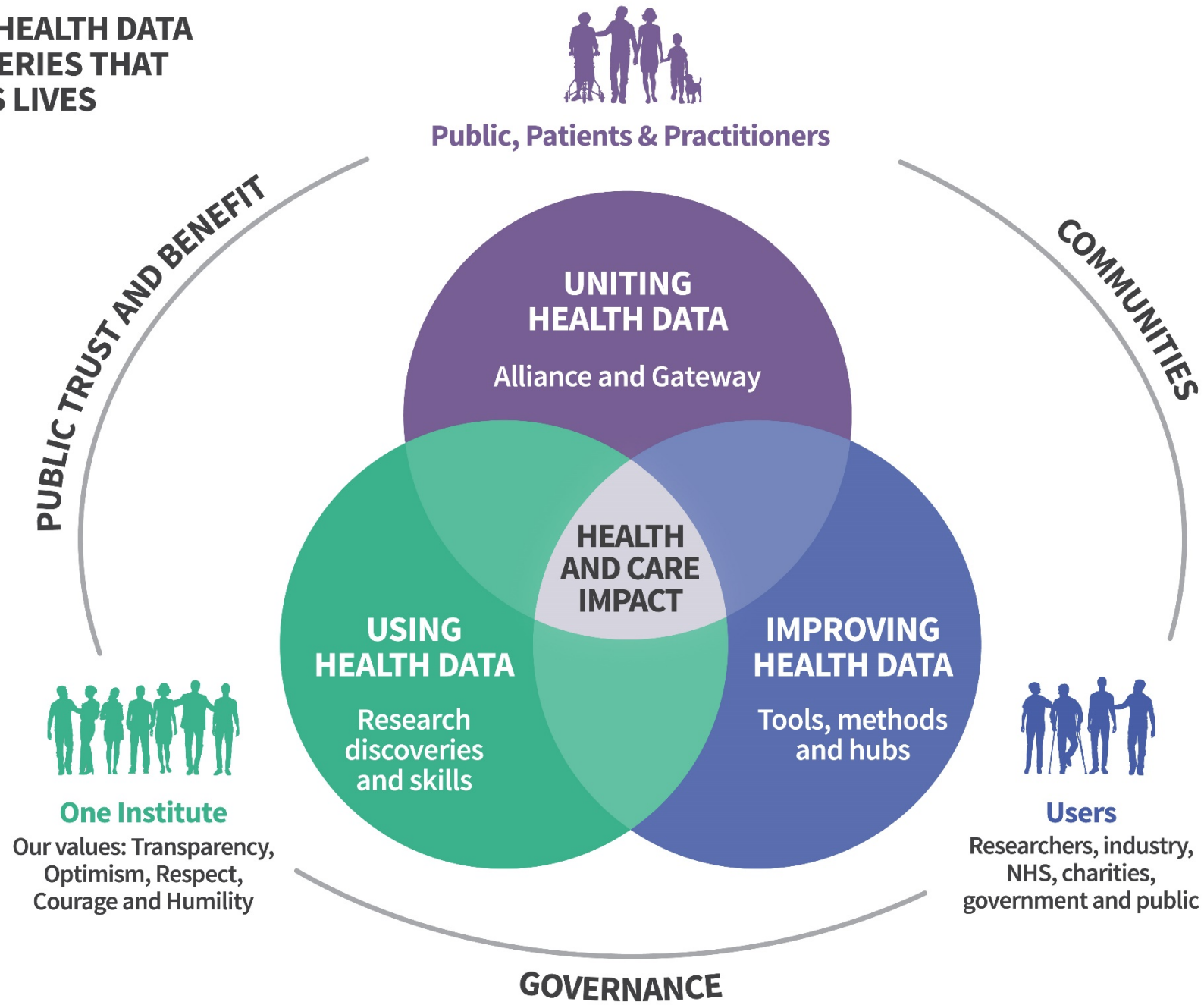
## How we will do it

HDR UK is enabling 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



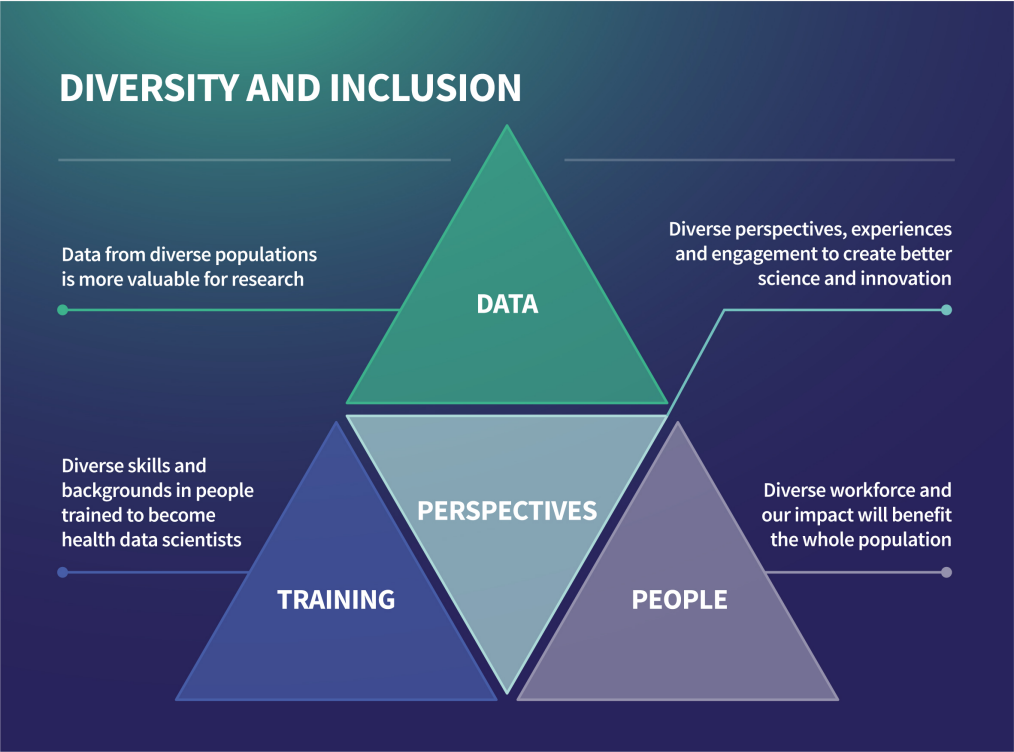
UNITING THE UK'S HEALTH DATA  
TO ENABLE DISCOVERIES THAT  
IMPROVE PEOPLE'S LIVES



## In 2021/22 we will be scaling-up impact through streamlining, innovating and federating

1. Sustaining and building on the health data research progress achieved through COVID-19, in a trustworthy way, to **enable discoveries across more diseases, globally**.
2. Scaling-up a federated approach to **improving data utility**, drawing on deep expertise in specific health and data domains, as exemplified by the [Hubs](#), to support researchers and innovators across academia, industry, NHS and charities in the UK and internationally.
3. Developing and embedding use of the [UK Health Data Research Innovation Gateway](#) to enable more **efficient and effective federated** health data research at scale across different health and biomedical research needs.

# To enable the discoveries that benefit all of us, we need diversity of data, people, skills and perspectives



**Press Release**

**Health Data Research UK Announces Black Internship Programme Starting Summer 2021**

1 December 2020

Today, 1 December 2020, Health Data Research UK and 20 of its partners across the UK, announce the launch of an internship programme for Black health data scientists starting in summer 2021. ...

**HDRUK**  
Health Data Research UK

**Diversity and Inclusion Policy**

25

interventions enacted to improve diversity and inclusion at HDR UK

Governance

Data

Events

Communications

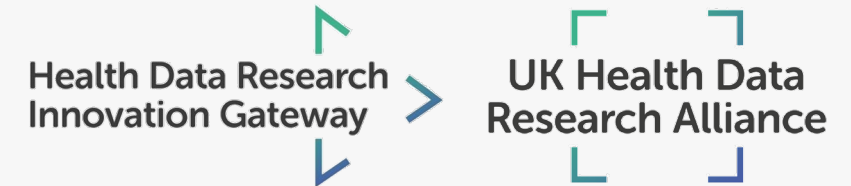
Recruitment



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

### In 2021/22 we are focused on:

**Gateway services** (convenience, speed of access, metadata, concierge) – use of these services, happy customers & a vibrant ecosystem of partners built on patient, public and user involvement

**Federation** across national Trusted Research Environments for specific uses (eg Data & Connectivity)

**Breadth** of relevant datasets (eg more high-use datasets such as the Zoe Symptom Tracker, Population Research UK) and **coverage** (whole UK population). Availability of **Industry** datasets through partnerships (eg Hubs)

**Diversity** of datasets to ensure an appropriate representation of the population.





# 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 data quality in 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 2021/22 we are focused on:

Evidenced **improvements** to data (ie successful Hub Milestone 2 & 3) and more **linked** data assets on the Gateway with accessible descriptions (BHF Data Science Centre, National Core Studies, ICODA) that are being used to meet national priorities and policy.

Developing data engineering **capability** to get data onboard, link it and improve it

Embedding data utility, TRE and federation **standards**



**APPLIED ANALYTICS**

**HUMAN PHENOME**



# 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 2021/22 we are focused on:

New high-impact **outputs** and **innovations** from national priorities, demonstrating our **distinctive** approach, including the impactful **cross-national priority and cross-disease approach**

**Training 5,000 cross-sectoral** health data researchers

2-3 high-impact driver projects that harness the value of **industry**

**International** driver projects (part of ICODA) that guide principles and best practice for international uses of data

# 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

### In 2021/22 we are focused on:

Joined-up **brand strategy** to unite the different components (Alliance, ICODA, Gateway, hubs, training), promote partners and reach public and research communities

**Quinquennial 2** vision, financial strategy and organisation development in place to achieve it

*"One of the things that has impressed me with HDR UK is that as members of the public I feel we are being treated as if we have some intelligence and can contribute with fresh perspectives and are not simply seen as survey 'fodder'. Everyone that I've met at HDR has shown that they care about what we have to say, you show us that you're listening and want to work with us."*

**HDR UK lay member**



Our values continue to be at the heart of our work

**OUR VALUES**

**T**ransparency  
**O**ptimism  
**R**espect  
**C**ourage  
**H**umility





# And we will continue to build our community



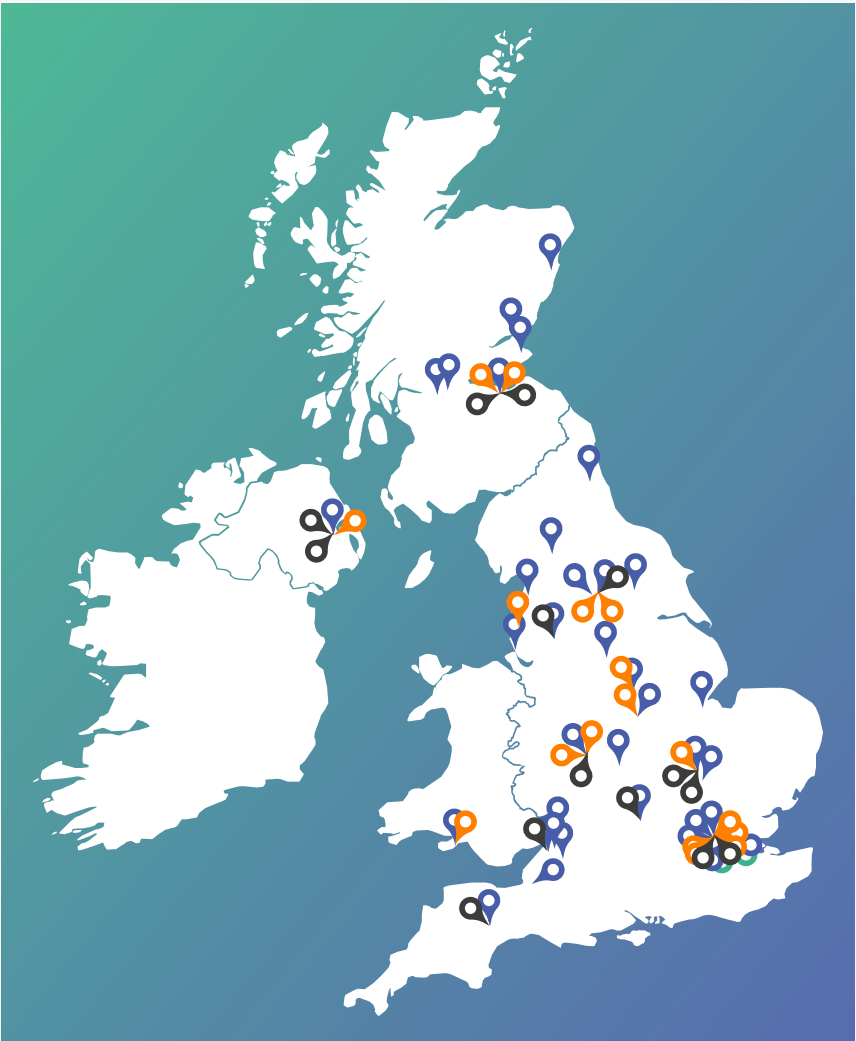
**Wellcome Trust  
Great Ormond Street  
DRIVE Unit**

**CENTRAL TEAM OFFICES**



**HDR UK Cambridge  
HDR UK London  
HDR UK Midlands  
HDR UK North  
HDR UK Oxford  
HDR UK Scotland  
HDR UK South-West  
HDR UK Wales and  
Northern Ireland**

**RESEARCH LOCATIONS**



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

**HEALTH DATA  
RESEARCH HUBS**



**Belfast  
Birmingham  
Bristol  
Cambridge  
Edinburgh  
Exeter  
Leeds  
London  
Manchester  
Oxford**

**TRAINING LOCATIONS  
(Masters and PhD)**



# Who's who at HDR UK



**ICODA Director**  
Julia Levy

Technology Director  
Neil Postlethwaite

Head of Partnerships  
Anne Wozencraft

Communications & Engagement Manager  
Davide Scalenghe

Research Manager  
Adrienne Testa

Programme Officer  
Karen Hunter



**BHF Centre Director**  
Cathie Sudlow

**BHF Operations Director**  
Lynn Morrice

BHF Engagement & Communications Manager  
Debbie Ringham

BHF Research Project Manager  
Rouven Priedon

BHF Research Project Manager  
Jackie MacArthur

BHF Executive Assistant  
Lydia Martin

## Health Data Research Hubs



**Director**  
Aziz Sheikh



**Director**  
Charlie Davie



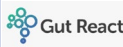
**Director**  
Liz Sapey



**Director**  
Alastair Denniston



**Director**  
Martin Landray



**Director**  
John Bradley



**Director**  
Axel Heitmueller

## Health Data Research National Priorities

**Understanding Causes of Disease R.D.**  
John Danesh (HDR UK Cambridge)

**Clinical Trials Research Director**  
Martin Landray (HDR UK Oxford)

**Public Health Research Director**  
Ronan Lyons (HDR UK Wales & NI)

**Better Care Research Directors**  
Simon Ball (HDR UK Midlands)  
Munir Pirmohamed (HDR UK North)  
Jonathan Sterne (HDR UK South-West)

**Human Phenome Research Director**  
Harry Hemingway (HDR UK London)

**Applied Analytics Research Director**  
David Robertson (HDR UK Scotland)  
Chris Holmes (Alan Turing Institute)

**Public Advisory Board Chair** Angela Coulter  
**Gateway Advisory Group Chair** Tim Hubbard  
**International Advisory Board Chair** Amy Abernethy  
**International Council of Ethics Chair** Effy Vayena  
**Early Career Committee Chair** Jon Kennedy

## Communications & Engagement



**Communications & Engagement Executive Director**  
Amanda White

**Head of Communications & Engagement**  
Joel Beckman

Communications Officer  
Ashleigh Smith

Digital Marketing Manager  
Stephanie Parrott

Events & Engagement Manager  
Francesca Lord

**Public and Patient Engagement Manager**  
Sinduja Manohar

PPIE Officer  
Alice Dowden

PPIE Officer (Data & Connectivity)  
Judy Slape

## Operations



**Executive Director of Business Operations**  
Victoria Platt (maternity leave)  
Dani Breitingen-Blatt (maternity cover)

Learning & Development Manager  
Tammy Palmer

Business Operations Officer  
Kate Sanders-Wilde

Executive Assistants  
Lindsay Cockcroft  
Chris Pianfetti  
Sarah Fullegar

HR Partners  
Gravitate HR

IT Partners  
Microsys

Legal Partners  
Bird & Bird

## Improving data



**Executive Director – Hubs & Data Improvement**  
Ben Gordon

Chief Clinical Data Officer  
Neil Sebire

Hub Development Manager  
James Pickett

**Programme Manager**  
Kay Snowley

Programme Officer  
Clara Fennessy

## Uniting data - Gateway



**Chief Technology Officer**  
Charles Gibbons

**Director of Engineering**  
Susheel Varma

Data Science / Software Engineering Interns  
Jake Barrett  
Kabir Khan

**Technology Partnership Director**  
Peggy Barthes-Streit

Gateway Content & Community Lead  
Vicky Hellon

Technology Partner  
PA Consulting

## Uniting data – UK HDR Alliance



**Alliance Executive Director**  
David Seymour

Alliance Delivery Manager  
Paola Quattroni

**Senior Programme Manager – Data & Connectivity**  
Lara Edwards

Programme Manager – Data & Connectivity  
Sophie Morris

## Using data



**Chief Science Strategy Officer**  
Rhos Walker (maternity leave)  
Melissa Lewis-Brown (maternity cover)

**Director of Health Data Science Training**  
Sarah Cadman

Director of Wellcome PhD Programme  
Peter Diggie

Director of Alliance Learning & Development  
Georgina Moulton

National Programme Manager, Science  
Dani Breitingen-Blatt  
Victoria Effiom (interim)

Research Manager  
Melissa Lewis-Brown  
Hollydawn Murray (interim)

Better Care Programme Director  
Alice Turnbull

## Finance



**Finance Executive Director**  
Amanda Borton

**Head of Finance**  
Georgina Thompson

Financial Controller  
Monica Liljeroth (T)

Management Accountant  
Donna Cullen

Finance Business Partners  
Yvonne Carey (T)  
Jenny White (T)

Finance Consultant  
Jenn Watson (T)

Contracts Manager  
George Lyons

## Director



**Director**  
Andrew Morris

Technologist in Residence  
Gerry Reilly

## CEO



**CEO**  
Caroline Cake

Head of Legal / Sole Legal Counsel  
Cassandra Smith

## Board



**Chair**  
Graham Spittle



**Board Member**  
Sarah Harper



**Board Member**  
Alex Markham



**Board Member**  
Jonathan Montgomery



**Board Member**  
Lucy Neville-Rolfe



**Board Member**  
James O'Shaughnessy



**Board Member**  
Frances Rawle



**Board Member**  
Jim Smith



**Board Member**  
Janet Thornton



**Board Member**  
David Zahn

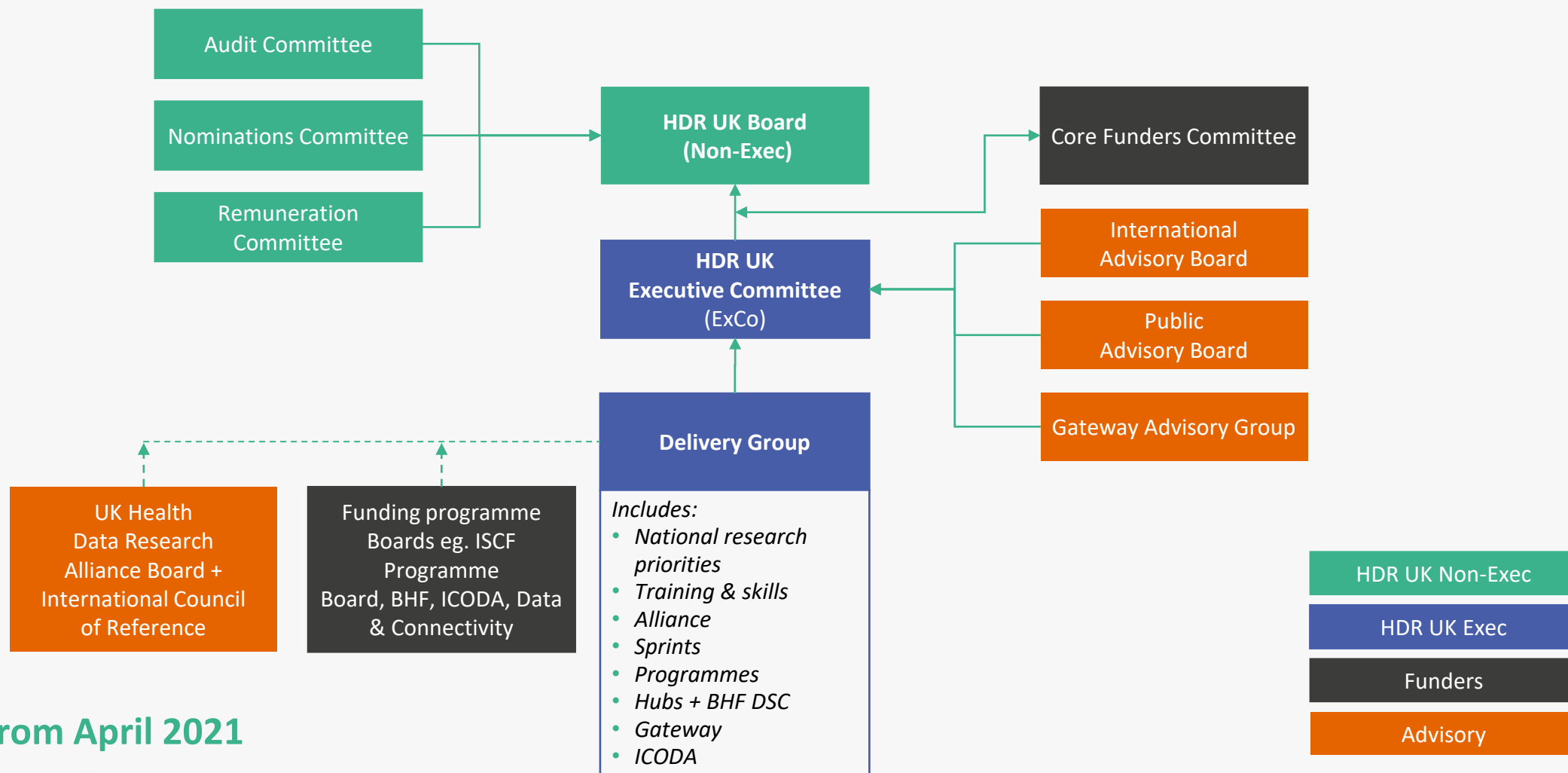
Bill Boa - Audit & Risk Committee

Denotes Executive Committee member  
Denotes Delivery Group member

Bold text: Denotes Line Manager

**HDRUK**  
Health Data Research UK

## Our governance structure



Model From April 2021



# Thank you

## Find out more:

Health Data Research UK  
[hdruk.org](http://hdruk.org)

UK Health Data Research Alliance  
Web: [ukhealthdata.org](http://ukhealthdata.org)

Health Data Research UK Innovation Gateway  
[healthdatagateway.org](http://healthdatagateway.org)

Social: @HDR\_UK

Email: [enquiries@hdruk.ac.uk](mailto:enquiries@hdruk.ac.uk)