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## **ONE INSTITUTE STRATEGY 2019/20**

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## Purpose of document

This is an updated edition of the One Institute Strategy published in October 2019.

This document describes Health Data Research UK’s strategy for 2019/20 and how this aligns to our 20-year vision and 5-year priorities. This One Institute Strategy 2019/20 is written with a professional audience in mind and is aimed at colleagues working with Health Data Research UK. It has received input from Health Data Research UK’s Board, Public Advisory Board, Science Strategy Board, research leads, our funders and other key advisors. It is supported by an internal delivery plan, which can be requested by emailing [enquiries@hdruk.ac.uk](mailto:enquiries@hdruk.ac.uk)

We are funded by the Medical Research Council (MRC); the health research departments of England, Scotland, Wales and Northern Ireland (National Institute for Health Research (NIHR), Chief Scientist Office (CSO), Health and Care Research Wales, HSC Research and Development respectively), the Economic and Social Research Council (ESRC), the Engineering and Physical Sciences Research Council (EPSRC), Wellcome, The British Heart Foundation and UK Research and Innovation.

## Executive Summary

**Health Data Research UK is uniting the UK's health data to make discoveries that improve people's lives.** By bringing together the sharpest scientific minds and providing safe and secure access to rich health data, we aim to better understand diseases and discover new ways to prevent, treat and cure them.

**Over the next 20 years**, our 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 are building a data innovation engine for the NHS, academia and industry to make this happen. This includes a set of ambitious priorities that we have set out to deliver **over the next five years**:

- Improving discovery of new diseases and treatments
- Improving evaluation of safe, effective, affordable treatments for patients
- Improving healthy life expectancy for people living with a common disease
- Improving clinical innovations that enhance NHS and social care services
- Developing and applying advanced health data science to address major health challenges
- Creating more than 10,000 health data scientists
- Creating a world-leading data infrastructure and UK-wide approach to secure data services
- Earning public trust by engaging and involving people in all aspects of our research and innovation

Why is this important? Antimicrobial resistance, mental health issues, cardiovascular disease, cancers, and dementia are just some of the extensive healthcare problems facing today's society.

Health Data Research UK can help find solutions to these problems by forging partnerships between researchers, innovators, data scientists, patient groups and the public and empowering them with access to quality, large-scale health data. Insight-driven science is crucial for advances in understanding health and disease and how we can tackle them with life-changing personalised medicines, treatments and technologies.

The UK is home to the NHS, a strong life sciences industry, world-leading academic institutes, and a vibrant tech community. The population's health data will provide the UK's pioneers with an opportunity to drive innovation, grow the industry, and take a holistic view to improving the health of the nation.

We are reinventing healthcare research by championing an open, collaborative culture working towards a common goal – to improve people's lives.



We are delivering our mission by bringing together the following themes underpinned by a culture of transparency, engagement and involvement to earn public trust in the use of health data for research:

### Science

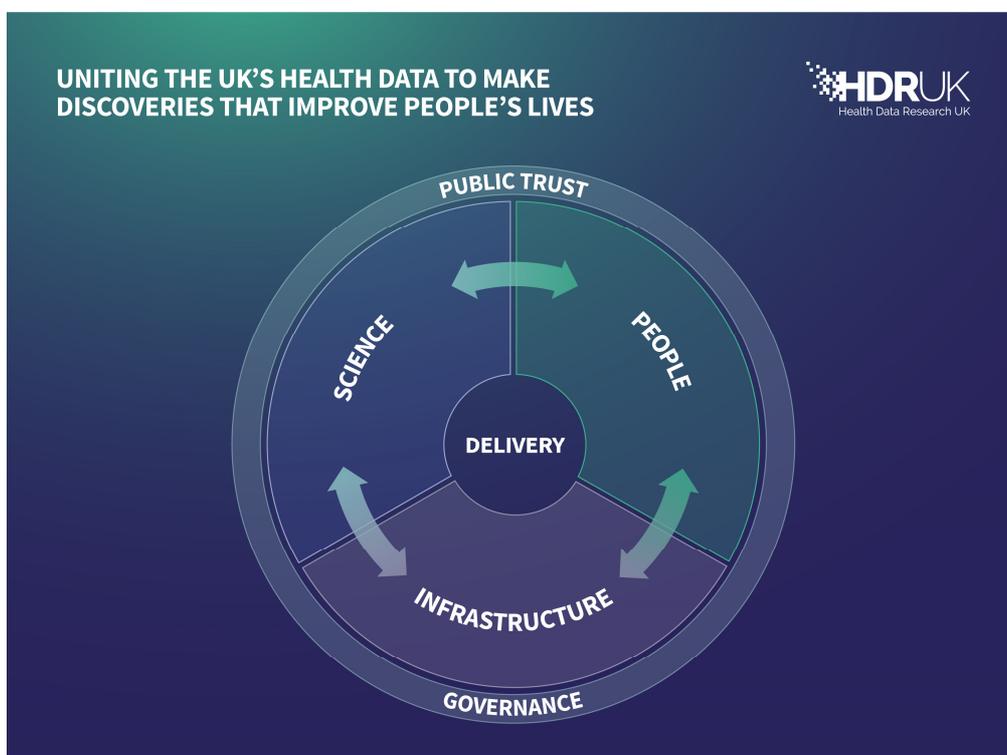
The UK has a rich scientific heritage and holds some of the most robust and diverse health data of anywhere in the world. The stimulation of world-leading scientific research, through the mobilisation of environmental, molecular and clinical data and insight from wearables and NHS routine data will be the catalyst in the discovery of new diseases, an increase in clinical trial participation and delivery of insights into the best treatments, with the elimination of some of the most devastating diseases. We will do this by developing innovative ways of extracting new knowledge from complex and diverse health data and empowering the community of NHS and other healthcare innovators to harness its potential.

### People

We will inspire the next generation of health data scientists; attracting innovative thinkers who will use large-scale data in novel ways to solve health problems facing our society. We are in a bright new world of original ideas, ground-breaking discoveries and high-profile partnerships. Our training programmes will support and empower people from across the world – including mathematicians, scientists, data analysts and engineers – to lead the data science revolution.

### Infrastructure

We are developing cutting-edge infrastructure and a strong governance framework co-created with the public to enable secure, trusted research data services and support improvements in patient care. Research and innovation will flourish when boosted with comprehensive national data from electronic health records, medical images, wearables, genomics, environmental sources and biomedical research.



## Delivery highlights

Health Data Research UK was established in April 2018. In 2018/19 we delivered:

- **Science:** we have established six HDR UK substantive research sites, comprising 22 UK universities, NHS and research institute partners, with a common Institute Agreement. We are transitioning to national programmes and have already: established national implementation projects; developed joint grants, for example a £10 million grant proposal with the British Heart Foundation; played international leadership roles on Alzheimer’s Disease; and developed joint national initiatives with the Alan Turing Institute and Medicines Discovery Catapult.
- **People:** we have created our initial cohort of 180 Principal Investigators (PIs) and co-Investigators, and 46 non-clinical UKRI and Rutherford Fellows. We have built a strong leadership team of Research Directors and Associate Directors across the UK. We are setting up Master’s degree programmes and studentships in health data science and jointly submitted grants for a PhD programme. We have built national partnerships with the NHS, Software Sustainability Institute and Open Data Institute.
- **Infrastructure:** we were commissioned to lead delivery of the UK-wide Digital Innovation Hub Programme. During the year we launched 10 sprint exemplar projects, which will deliver by November 2019; and created the UK Health Data Alliance with national data custodians from all four nations.
- **Engagement:** we established a Public Advisory Board following an application process that attracted 100 members of the public. We engaged over 2,500 people in the design and development of the Digital Innovation Hub Programme from the public, academia, industry, NHS, government and charities.

## One Institute: Our 20-year vision

We will be a world-leading, international health data research institute, distinguishing the UK as the core of the health data science revolution. Over the next 20 years, access to rich, far-reaching data combined with new scientific insights will transform research and innovation, and lead to significant advancements in our understanding, preventing, diagnosing and treating of disease.

To achieve this aspiration, Health Data Research UK is bringing together the NHS, the public, industry and academia as one combined force. A collaboration of this scale has never been seen before and it will significantly transform the future of healthcare by developing and championing the best in *science*, *people* and *infrastructure* underpinned by earning public trust. Each of these elements has a crucial part to play in advancing healthcare improvements and will fuse together to create an unparalleled ecosystem for health data science and innovation to flourish.

Our Strategic Framework outlines how we will develop these three areas and our plan for 2019/20, our five-year big ambitions, and our 20-year vision.

# STRATEGIC FRAMEWORK FOR 1 YEAR, 5 YEARS AND 20 YEARS

**OVER THE NEXT 20 YEARS** our vision is for large scale data and advanced analytics to benefit every patient interaction, clinical trial, biomedical discovery and enhance public health. We are building an innovation engine for the NHS, academia and industry to make this happen.

## 5 YEAR AMBITIONS

- IMPROVING DISCOVERY** of new diseases and treatments
- IMPROVING EVALUATION** of safe, effective, affordable treatments for patients
- IMPROVING HEALTHY LIFE EXPECTANCY** for people living with a common disease
- IMPROVING CLINICAL INNOVATIONS** that enhance NHS and social care services for people

<b>WHAT WE ARE DOING IN 2019/20</b>	SCIENCE			
	<b>Understanding the causes of disease</b> <b>National Project:</b> Understanding disease using multi-omics + local	<b>Better, faster, efficient clinical trials</b> <b>National Project:</b> Building a national trials strategy + local	<b>Improving public health</b> <b>National Project:</b> Measuring and understanding multi-morbidity + local	<b>Better care</b> <b>National Project:</b> Engaging with NHS, research and innovation leaders + local
	<b>Human Phenome Project</b> <b>National Project:</b> Human phenome online library + local			
	<b>Applied Analytics</b> <b>National Project:</b> Reproducibility of Artificial Intelligence and Machine Learning in medicine + local			
	<b>Health data science to tackle disease</b> , including dementia, cardiovascular disease, cancer and rare genetic disorders			
	PEOPLE			
	Data science literacy, NHS analytics community, HDR UK UKRI/Rutherford Fellows, Doctoral research			
	School leavers, postgraduate, post-doctoral and pathways to seniority programmes			
	INFRASTRUCTURE			
	<b>Deliver Hubs</b> <b>Deliver DIH Sprints:</b> Myeyesite; Cloud-based integration of phenotype and genotype data for rare disease research; Developing an integrated data repository and analysis platform to maximise the impact of large-scale cancer cohort studies	<b>Deliver Hubs</b> <b>Deliver DIH Sprints:</b> Using Routine NHS Data to Accelerate Clinical Trial Recruitment	<b>Deliver Hubs</b> <b>Deliver DIH Sprints:</b> Using data to improve care for patients with heart failure	<b>Deliver Hubs</b> <b>Deliver DIH Sprints:</b> PED4PED; Enhancing Clinical Responses through Digital Information Transfer and Alerting by a Hospital-wide Smartphone Application
Infrastructure layer				
UK Health Data Research Alliance				
ONE INSTITUTE				
Public engagement	Communications	Professional leadership		
PUBLIC TRUST				

We will develop and apply advanced health data science to address major health challenges

We will create 10,000+ health data scientists

We will create a world-leading data infrastructure and UK-wide approach to secure data services

We will earn public trust by engaging and involving people in all aspects of our research and innovation

### HORIZON SCANNING

Looking ahead at next 5-20 years: International Advisory Board, scientific discoveries, funder priorities

## Science – activating world-class health data science

**Ambition: We will develop advanced health data science tools and technologies to analyse complex and diverse health data and seize its power to solve health challenges**

We are entering a new era of scientific convergence, where computational, population, social and biomedical research communities come together to tackle complex health questions using large scale health data. HDR UK is combining health and biomedical expertise with new tools and technologies to enable a data-led approach to reduce the time from scientific discovery, to intervention, and through to innovative patient treatments. We aim to revolutionise the ability to understand, prevent, diagnose and treat devastating diseases, such as dementia, cardiovascular disease, cancer and rare genetic disorders.

Underpinned by our Infrastructure Programme, we will attract the leading maths, statistics, computer science and interdisciplinary teams and provide development opportunities, through our talent and training programmes to maximise their strengths. We will challenge them to develop analytical methods and support them to produce and scale tools to shape the future of healthcare.

The power of health data science at scale will be demonstrated by:

- **Scale of population:** we will use the largest health research and patient data available, at a national and international population scale.
- **Scale of data:** we will find new ways to use diverse data from electronic health records, to genomics, imaging, mobile and wearable data, and environmental and other social data.
- **Scale over time:** we will deliver a life-course perspective, from early to adult life and across generations, increasing the duration and frequency of data available for research use.
- **Scale of services:** the tools and technologies we develop will be engineered to be reproducible, reliable and scalable across different datasets, and made available to researchers globally.
- **Scale and speed of impact:** the outcomes of our research will be rapidly applied to frontline decision-making for patients, health providers, populations, policymakers and regulators.

