BUILDING FOR TOMORROW:
HEALTH DATA RESEARCH UK’S ESTABLISHMENT REVIEW
June 2020
## Contents

**INTRODUCTION**  
ANDREW MORRIS (DIRECTOR) AND CAROLINE CAKE (CEO)  
3

**SECTION A: INSTITUTE OVERVIEW**  
4

**SECTION B: PROGRESS REPORT**  
14

**SECTION B.1: VISION AND STRATEGY**  
15

**SECTION B.2: INFRASTRUCTURE**  
20

**SECTION B.3: TRANSLATION**  
26

**SECTION B.4: ADMINISTRATION, MANAGEMENT & FINANCIAL PLANNING**  
30

**SECTION B.5: PEOPLE – RECRUITMENT, SKILLS AND CAREERS**  
34

**SECTION B.6: COMMUNICATIONS AND ENGAGEMENT**  
39

**SECTION B.7: DEMONSTRATING SUCCESS**  
44

**SECTION B.8: OPPORTUNITIES, CHALLENGES, RISKS AND GAPS AND EXPECTED EVOLUTION TO OUR QQR**  
46
Introduction

We are delighted to be sharing with you the Establishment Review for Health Data Research UK (HDR UK). The purpose of the review is to provide assurance to the Funders of progress in establishing effective governance and processes to achieve the Institute’s mission and strategy.

As the national institute for health data science, HDR UK has been established in a period of unprecedented interest and growth in the field, further accelerated by the outbreak of COVID-19. The prescient investment by Core Funders in the institute is for an initial five-year period from April 2018 until March 2023. As of June 2020, HDR UK has worked in partnership with four additional funders and now has direct or indirect responsibility for £218m of Government, Charity, industry and philanthropic funds.

As this is a new investment, this Establishment Review is of the Institute structures that have been put in place to deliver the funders investment mission and strategy. This is not a review of the science and it should be read in conjunction with HDR UK’s annual reviews 2019/20 and 2020/21, which communicate the science results and impacts.

The fast-moving nature of health data science and its increasingly global nature means that the Institute needs to combine major strategic decisions, and a robust governance structure, with agility. Agility is key to HDR UK becoming recognised internationally as one of the World’s leading health data science institutes and for the UK becoming the most impactful place to do health data science.

This document is structured around the Core Funder Establishment Review Guidance and is an input to an Independent Expert Review Panel in September 2020 which will provide an assessment of and recommendations on strategic delivery, governance and operational matters to increase the likelihood of a positive first Quinquennial Review (QQR) in 2023.

We feel privileged to be leading this exciting endeavour that is uniting the UK’s health data to enable discoveries that improve people’s lives. We welcome recommendations from the Panel to enable us to achieve our mission with the greatest possible scientific and societal impact.

Andrew Morris
Director

Caroline Cake
CEO
HDR UK is the national Institute for health data research that includes England, Wales, Scotland and Northern Ireland. Here, we provide an overview of funder expectations and our vision, strategy and organising structures to achieve these expectations.

SECTION A

Institute overview

Our mission is to unite the UK’s health data to enable discoveries that improve people’s lives.

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

A.1. Funders expectations

The Funders’ expectations are that HDR UK will:

- accelerate the pace and scale of health and biomedical data science to improve health and care for patients and the public and grow capability and economic opportunity in the UK
- provide UK-wide co-ordination of relevant informatics infrastructures, skills, capacity, methods and analytical tools
- work in partnership with key stakeholders across government, academia, the healthcare sector, research charities, industry and the public

The HDR UK Core Award aims to create a multi-disciplinary, geographically distributed and UK wide health and biomedical research Institute “Health Data Research UK” through:

- establishing an integrated network to provide the Institute’s core capability and research capacity
- developing aligned Partnership Sites and other strategic investments
- capacity building and career development programmes
- advising on and collaborating with complementary initiatives in data science taken by the Funders.

The guiding principles for the Institute as proposed by the MRC Council (July 2016) were:

**Institutionally agnostic:** the Institute will not be an exclusive club, but an ‘honest broker’ beyond personal, institutional or geographical interests.

**Team science:** with a significant proportion of the Core Funding for the provision of technical services.

**Open science:** working towards goals in the national interest for the benefit of the wider research community, with a focus on interoperability, and with clear principles for collaboration with data controllers, academia and industry.

**Data ownership:** The Institute will not be a data owner but will work in partnerships with data controllers.

**Public Trust and participation:** An active programme of public engagement and involvement will underpin all the activities of the institute.

Interim funding was provided by the Medical Research Council (MRC) between 1 August 2017 and 31 July 2018 ahead of the award of £53.75m provided by our Core Funders from 1 August 2018.

HDR UK was incorporated in July 2017 as a company limited by guarantee.

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1. Medical Research Council (MRC), Engineering and Physical Sciences Research Council, Economic and Social Research Council, Department of Health and Social Care, Health and Care Research Wales, Chief Scientists Office (Scotland), Public Health Agency (Northern Ireland), Wellcome and British Heart Foundation, together known as the Core Funders.
A.2. Director’s vision and overarching strategy

At launch, the Director’s vision was:

“to exploit the extraordinary capability of informatics to create a national medical research and innovation Institute that leads the international agenda in health data science. The Institute will create a thriving, high-energy UK-wide network of interdisciplinary research expertise. This will disrupt traditional science and transcend disciplines, enable knowledge and predictions from large multi-dimensional datasets and harness cutting-edge technologies to catalyse scientific discovery at scale, accelerate solutions to UK and global health challenges, drive the creation of business opportunities and support informed policy making. The ambition is to transform science, practice and health globally.”

This 20-year vision and our One Institute Strategy for our first five years (Table 1), provide us with a clear and ambitious direction of travel.

<table>
<thead>
<tr>
<th>Vision</th>
<th>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</th>
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</thead>
<tbody>
<tr>
<td>Area of focus</td>
<td>Goals (April 2018 to March 2023)</td>
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</tbody>
</table>
| **Uniting health data** Alliance and Gateway | • Delivering the Gateway; fundamental to the world’s health data research, trusted by patients, public and practitioners  
• Creating the Alliance with members from all the UK’s major health data custodians*  
• Establishing standards: Participation, Information Governance, Access, benefit sharing and Trusted Research Environments  
• Providing training for infrastructure | 1 **Efficient, safe access** to large scale, diverse data for researchers and innovators  
2 **Transparency** of use of health data to patients and the public |
| **Improving health data** Tools, methods and hubs | Creating better quality data in the Alliance and Gateway through:  
• Tools and methods to measure and improve the data quality in the Gateway, including applied analytics and the human phenome  
• 8-10 hubs improving the data | 3 **Better data** for researchers and innovators |
| **Using health data** Research discoveries and skills | • Delivering UK-wide research programmes: Understanding Causes of Disease, Improving Public Health, Better Clinical Trials and Better Care  
• Building health science user community: patients, public, academia, NHS, charities and government at scale  
• Demonstrating major impact cases  
• Delivering training programmes and career pathways for health data scientists | 4 **Better, more useful research** for funders and public - that no single research organisation could achieve alone |
| **One Institute** Public trust & benefits, governance, team science and communities | • Recognised internationally 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 QQR and leverage funding secured | 5 **UK recognised as the most impactful place** to do health data science |

Table 1: HDR UK’s 20-year vision, five-year goals and outcomes
A.3. One Institute Strategy evolution

Establishing a new Institute in the complex and rapidly moving field of health data science has required an agile strategic approach. The Director’s initial five-year plan (July 2018) described six areas of focus:

- **A virtual Institute:** Establishing an independent organisation, initially a Company Limited by Guarantee, with a strong independent Board, and a lean central team providing leadership and expertise based at the Wellcome in London.

- **Six Substantive Sites:** An extensive national network of research organisations – selected as part of a funding call in August 2017 - for health data scientists to collaborate around a number of high impact research programmes.

- **National Implementation Projects:** Led by teams of researchers, scientists and technologists at the Substantive Sites, these projects were introduced to develop innovative solutions to tackle major health data science challenges. The overall aim is to exemplify our mission of research at scale across the UK.

- **Capacity Building:** As part of our commitment to the health data science skills agenda, we committed to developing a careers framework for technology specialists, including mapping the national skills landscape, identifying gaps in provision, opportunities for intervention and partnership delivery solutions, and leveraging additional external resource in this key area.

- **Partnership Sites:** To recognise truly national excellence in research, set against the constraints of the Substantive Site model, we aimed to augment our Institute with new partners. For example, in response to a disease-specific challenge, or to offer a new collaborative dimension, a new test bed for applied research, or the opportunity to engage with scientific excellence in geographic regions poorly represented in the initial Substantive Sites.

- **Director's Investments:** As health data science is an emerging discipline and is subject to rapid and ongoing change, the requirements in 2022 would inevitably be different from those in 2017. Therefore, it was our intention to reserve funding for investment at the Director’s discretion. Opportunities identified at the time included a potential cardiovascular data science centre with the British Heart Foundation or a Digital and Data research call with Asthma UK.
The success of the initial phase resulted in the award of major new funding streams to HDR UK, including the £37.5m for the UKRI Industrial Strategy Challenge Fund Digital Innovation Hub Programme. Such funding streams acted as an accelerator for an even more ambitious strategy to develop the national capability for health data science: our One Institute Strategy published in April 2019 and our annual strategy delivery plan, most recently published in March 2020. The evolution is set out in the timeline in figure 1.

Figure 1: Timeline of HDR UK activities and achievements to date
Key senior leadership appointments made in February – December 2018

Founding partner of UK Health Data Research Alliance announced in December 2018

HDR UK incorporated as a company limited by guarantee in July 2017

BHF and HDR UK start work in partnership to develop BHF Data Science Centre in August 2018

Substantive Site call launched to form HDR UK’s research base in August 2017

Successful applicants announced forming our first six Substantive Sites in February 2018

Interim funding received and six Substantive Sites start in April 2018

First appointments made to the Board in November 2017

HDR UK chosen to lead development of 4-year Digital Innovation Hubs programme in July 2018

DIH Programme Design & dialogue September 2018 – April 2019

Core Funding starts and Call for National Implementation Projects launched in August 2018

Further appointments made to the Board in November 2018

Collaboration with KQ Labs announced November 2018

Andrew Morris announced as Director in March 2017

New Masters programmes announced June 2019

One Institute Strategy launched – April 2019

HDR UK Public Advisory Board announced – January 2019

11 Sprint Exemplars operational January 2019 – December 2019

2019

UK Health Data Research Alliance launched with nine member in February 2019

DIH prospectus launched May 2019

2018/19 Annual Review launched July 2019

HDR UK’s 100th Open Access output published in September 2019

7 Hubs launched in September 2019 and started October 2019

First round of National Implementation Projects announced June 2019

Successful Wellcome PhD Programme announced in September 2019

Chair of International Advisory Board announced in October 2019

BHF Data Science Centre and inaugural Director announced in October 2019

Call for new Substantive Sites and Better Care Catalysts launched in December 2019

Chair of International Advisory Board announced in October 2019

HDR UK implements research question prioritisation process to support COVID-19 response in April 2020

New Substantive Sites and Better Care Catalysts announced in April 2020

2020

Alliance grows to 27 members January 2020

Gateway MVP launched with >400 datasets February 2020

First phase of fully functional Gateway delivered in June 2020

Milestone 1 met by all Hubs December 2019

2020 /21 strategic delivery plan and governance structures announced in March 2020

2020

Gateway MVP developed October 2019 - January 2020

2019

Gateway Rapid Development Task January – March 2020

DIH prospectus launched May 2019

First round of National Implementation Projects announced June 2019

Successful Wellcome PhD Programme announced in September 2019

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Figure 1: Timeline of HDR UK activities and achievements to date
Through our One Institute Strategy, we have established three key capabilities for the UK’s health data research infrastructure which work together in a mutually supportive way as described in Figure 2:

- **Uniting health data** – providing national convenorship through the UK Health Data Research Alliance and Innovation Gateway with open standards, and in a way that earns the trust of patients and the public, and working with a wide range of health and social data generated by the NHS, universities, research Institutes, charities, and increasingly from wearables, and private companies.

- **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.

The strategy is being delivered through an inclusive, team-oriented One Institute ethos - bringing together NHS, universities, research Institutes and charities - built on our values of transparency, optimism, respect, courage and humility.

![Figure 2: One Institute Strategy Schematic](image-url)
A.4. Key organisational structures

A.4.1 THE BOARD

HDR UK is governed by an independent Board, chaired by Dr Graham Spittle CBE. The Board is responsible for the effective governance and development of the Institute, supports the Director in overseeing the delivery of our strategy, monitors key risks, and ensures resources are managed effectively. The Board is supported in its role by three sub-committees: Audit and Risk, Nominations and Remuneration.

A.4.2 THE EXECUTIVE COMMITTEE

The organisation is led by the Director, Professor Andrew Morris, the Chief Executive, Caroline Cake and the Executive Committee (ExCo). The central team enables successful delivery of the Institute mission and strategy through Institute leadership, strategic development and oversight, communications, operations, finance, scientific strategy, technology strategy and programme delivery.

A.4.3. FEDERATED DELIVERY MODEL

HDR UK is a federated Institute with partnerships across universities, NHS organisations, charities, industry, patient groups and research Institutes. Within our community, we have 86 organisations within 56 offices at 32 locations across the UK (figure 3). Our federated approach makes us distinctive, enabling us to operate at scale, and in partnership with government, NHS bodies, industry and charities across the UK.

Figure 3: A national, federated institute across 32 UK locations
Using Health Data

A.4.3.1. RESEARCH SITES

Our six founding core Research Sites (initially called Substantive Sites) brought together 22 research organisations, clustered around geographies in Cambridge, London, Midlands, Oxford, Scotland, and Wales and Northern Ireland. These were selected in 2018, following a competition for research capacity across the UK coordinated by the MRC on behalf of the funders. A further competition was held in 2020 for additional research capacity, focused on our Better Care National Research Priority. This added two more Research Sites—North and South West. HDR UK now comprises 32 leading research organisations, located across all regions of the UK.

A.4.3.2. NATIONAL RESEARCH PRIORITIES

Each Research Site contributes to one or more of HDR UK’s six National Research Priorities (figure 4). Each priority is led by an HDR UK Research Director and supports research that individual research organisations are unable to tackle alone. The priorities leverage the interdisciplinary skills, expertise and partnerships across our research Sites, breaking down geographic and disciplinary boundaries. In December 2019 we made the National Research Priorities the primary organising structure for our research to emphasise the importance of national collaboration in achieving our mission.

Figure 4: Six National Research Priorities
A.4.3.3. NATIONAL IMPLEMENTATION PROJECTS

To further encourage collaboration and research at scale across the UK we introduced National Implementation Projects within the national priorities. These are led by teams of researchers, scientists and technologists from HDR UK’s Sites and develop innovative solutions to tackle some of the UK’s biggest health challenges. Following matchmaking and a rigorous selection process the five projects are:

- **National Multimorbidity Resource** (part of the Public Health national research priority)
- **National Phenomics Resource** (part of the Human Phenome Project)
- **National Text Analytics Resource** (part of the Human Phenome Project)
- **National Multi-omics Consortium** (part of the Understanding the Causes of Disease national research priority)
- **National Reproducible Machine Learning** (part of the Applied Analytics national priority)

Following the initiation of these projects, we continue to focus on building national delivery programmes across each priority area. Providing the structures and ways of working needed to deliver novel insights from interdisciplinary teams.

A.4.3.4. HEALTH DATA RESEARCH TRAINING SITES

HDR UK’s aim is to develop great scientific talent by identifying those with curious minds, technological appetites, and a keenness to be at the forefront of revolutionising health and care, by defining health data skills needs and supporting interdisciplinary training from Masters and doctoral training to research leaders, to address health data science needs of the 21st Century.

Three major programmes have been launched focused on advanced skills:

- **Master’s degree programmes and studentships in health data science** – six new programmes have been developed across UK universities delivering scientifically excellent and innovative postgraduate skills training.
- **Wellcome PhD Programme** to develop future leaders in health data science – in partnership with the Alan Turing Institute – this £7m highly innovative four-year programme will focus on bringing students with quantitative scientific backgrounds to deploy their skills within the health and biomedical communities undertaking ground-breaking research.
- **HDR UK Fellows Programme** – we have supported and provided opportunities for our 46 HDR UK UKRI Innovation and Rutherford Fellows to build their skills and form a network with fellows from the NIHR incubator in health data science.
A.4.3.5. UK HEALTH DATA RESEARCH ALLIANCE

In 2019, HDR UK convened the UK Health Data Research Alliance (the ‘Alliance’), an independent, not-for-profit alliance of health data custodians from 30 of the UK’s leading health and research organisations. The purpose of the Alliance is to facilitate partnership working across NHS organisations and other health data custodians, leading to an ethical, consistent approach to the use of data for research and public engagement. Through the development and sharing of best practice, and by earning trust in health data use, the Alliance aims to develop and maintain the integrity of a trustworthy UK health data research ecosystem.

The Alliance Board is composed of senior leaders from these organisations and an International Council of Reference advises the Alliance Board in relation to ethics and information governance.

A.4.3.5. HEALTH DATA RESEARCH INNOVATION GATEWAY

The purpose of the Health Data Research Innovation Gateway (the ‘Gateway’) is to provide a common entry point to discover and enquire about access to UK health datasets for research and innovation. Launched in January 2020, it provides detailed information about the datasets, which are held by members of the Alliance, such as a description, size of the population, and the legal basis for access.

The Gateway includes the ability to search for research projects, publications and health data tools. It does not hold or store any datasets or patient or health data but rather acts as a portal to allow discovery of datasets and to request access to them for health research. The Gateway currently has metadata discoverable from over 450 datasets. Further detail on the Gateway is provided in section B.2.

A.4.3.6. HEALTH DATA RESEARCH HUBS

In September 2019, HDR UK launched seven Health Data Research Hubs (‘Hubs’). The purpose of the Hubs is to focus on data curation and create international centres of excellence with expertise, tools, knowledge and ways of working to maximise the insights and innovations developed from health data.

In 2020, the £10m BHF Data Science Centre was established, led by HDR UK and funded by the British Heart Foundation (BHF).

Further detail on the hubs and centre is provided in section B.2.

Through the development and sharing of best practice, and by earning trust in health data use, the Alliance aims to develop and maintain the integrity of a trustworthy UK health data research ecosystem.
In the first two years HDR UK has established governance and leadership, clarity of vision, and the UK health data research infrastructure and translation approach. The Institute has also developed administrative, management and financial plans; defined recruitment, skills and careers structures, and established a robust and vibrant communications and engagement capability.

Here, we set out our current position in each of these areas, the supporting structures in place, and how we anticipate these will evolve in the period leading up to the QQR. There is still however much to be done as we are operating in a dynamic research environment with many interdependencies from a political, economic, technological, social, legal and ethical perspective. We highlight the gaps, challenges and risks that we are encountering or anticipating prior to the QQR and beyond.
Vision and strategy

Developing our strategy and setting priorities, taking into account the wider context of the UK Government, funder, regulatory and wider stakeholder landscape.

B1.1. HOW HDR UK’S STRATEGY IS DEVELOPED AND PRIORITIES SET

The health data science opportunity is vast. With finite resources HDR UK must focus to deliver on our mission and vision. This is achieved through our strategy development and delivery planning process.

The annual planning process draws together expertise from across HDR UK and is overseen by the HDR UK Board and led by ExCo, covering all areas of HDR UK’s operations. Delivery plans are led by the two delivery groups: Improving & Uniting Data Delivery Group (IDG) and Using Data Delivery Group (UDG).

HDR UK’s Quality Management System was independently certified to ISO 9001, following an external audit process in August 2019 (figure 5). We are one of only two research Institutes in the UK to achieve this internationally leading quality management standard, used in over 170 countries.

We therefore use our ISO 9001 certified annual planning process (see the appendices). In March 2020, following widespread consultation with Institute members, the Funders, and a series of 43 stakeholder interviews we published our strategic delivery plan for 2020/21, focusing on; (i) what makes us distinctive; (ii) our strategy for responding to the COVID-19 pandemic; and (iii) how teams distributed across the UK are working together for the collective effort.

The COVID-19 pandemic has highlighted the power of our agile, federated strategy, allowing a rapid and galvanising response to the UK research effort at scale in partnership with NHS, academia, industry and patients.

Figure 5: Certificate of registration for HDR UK’s ISO 9001 certification
**B.1.2. INTERNAL PROGRAMME AND PROJECT REVIEW PROCESSES**

Programme and project review processes are fully integrated into our ISO 9001-certified Grants and Contracting process (see appendices), which is audited annually and includes:

- Only supporting bids for new funded activities that are aligned with HDR UK strategy objectives
- Setting up programme and project opportunities with well-defined deliverables and milestones. This ensures that expectations are aligned for all successful programmes and projects
- Managing programmes and projects using our contract management processes which include regular programme and project reviews across all of our objectives

All programmes and projects have assigned central team leads responsible for ensuring reviews are regularly taking place, for example:

- The DIH sprint programme in 2019, had three interim review points and a final end of programme report
- The Health Data Research Hub programme was established with three distinct milestones and the first milestone report has been published on our website here
- The Gateway Minimum Viable Product programme included fortnightly sprint reviews, where the development team were required to demonstrate the stage of development.

Our rigorous approach has been well-received by delivery partners. The teams report that it enables them to rapidly overcome new project start up challenges by having a clear and urgent deadline to collectively work towards. New funding partners, such as The Health Foundation, with whom we are jointly running the Better Care catalyst programme, have asked us to run programmes on their behalf as they value the pace and rigour that we have established.

We have refined our approach with the most recent Gateway Technology Partnership contract by introducing an eight-week Rapid Development Task “bake off” for the three short-listed suppliers to review skills and capabilities in an applied setting.

We also replicate this process with smaller projects to ensure this discipline is embedded throughout our organisation. An example is how we run our events management process, with regular reviews with the chair and organising committee, attendee feedback and running After Action Reviews (AARs) to reflect on and learn from each event.

**B.1.3. MECHANISMS TO DEVELOP COLLABORATION AND COOPERATION INTERNALLY AND EXTERNALLY**

Our mission is dependent on internal and external collaboration and cooperation, with funders, research organisations, data custodians, training organisations, industry partners, NHS organisations, charities, regulators and patient and public representatives and groups. We actively engage with over 2,000 people, recorded in our Customer Relationship Management (CRM) system, across more than 650 organisations.

Our collaborative activities were specifically highlighted during our 2019 stakeholder interviews as an important role of HDR UK within the health data science ecosystem. This has most recently been demonstrated in the COVID-19 crisis, where our community structures and trusted ways of working meant that we were rapidly seen as the go-to organisation for health data research to support the crisis. We:

- rapidly mustered an active research community of over 660 members on SLACK
- published a strategy that pivoted our existing assets, resources and activities to support the national efforts
- captured and prioritised >100 research questions, matching them to resources and activities.
- coordinated data pipelines across four nations and contributed to over 100 pre-print publications
This approach was immediately valuable to national policy submitted weekly to the UK Government Scientific Advisory Group on Emergencies (SAGE), NHS leaders in NHSX and NHS Digital and the devolved nations, as well as to funders such as National Institute for Health Research (NIHR) and UK Research and Innovation (UKRI) to help them with the coordination effort.

Figure 7 shows the evolution of collaborations since the inception of HDR UK and how these have been formalised and focused.

2017
INCEPTION:
- 10 funders

2018
SUBSTANTIVE SITES:
- 6 Research sites with
  20 research organisations

2019
GROWTH:
- > 20 Alliance members
- 7 hubs with over 100 organisations
- 5 training sites and public advisory group

2020
FOCUS:
- One Institute Strategy
Given the importance of effective stakeholder engagement and partnership working we have ISO 9001-certified processes to help us to do these effectively.

**B1.3.1. Key Stakeholder process:**

The Key Stakeholder process is supported by our CRM system which uses vTiger software. The stakeholder process is integrated with our annual planning process and ensures we are actively identifying key stakeholders, listening and understanding their requirements, influencing and informing stakeholder decisions related to our mission and strategy, and reporting and informing stakeholders of our progress.

In the 2020/21 strategy development process we spoke with 43 stakeholders across 33 organisations during the focussed listening and learning stage to inform our 2020/21 delivery plan priorities.

In addition to our formal listening processes, we use our governance processes to receive feedback and understand our operating environment throughout the year. Insights are gained via our core communication and collaboration channels (section B6) from our Non-Executive Board, International Advisory Board, Using Data Delivery Group, Improving and Uniting Data Delivery Group, and Alliance Board.

**B1.3.2. Collaboration/partnership between HDR UK Central team, Sites and similar major investments, and their respective host institutions:**

The Institute Agreement with each of the Sites provides a structure for funding and collaboration, and One Institute ways of working. The National Priorities, Hubs and BHF Centre are each led by a Research or Hub Director responsible for the strategic development and delivery of the priority. These Directors form the UDG and IDG which meet monthly and are responsible for effective partnership, collaboration and delivery across the host institutions. Collaboration is further encouraged through Implementation Projects, the annual Institute Conference, annual Alliance symposia, bimonthly Institute webinars, early career researcher committee, Summer school and annual rewards for “team of the year” and “impact of the year”.

**B1.3.3. Interactions within/between HDR UK Sites, operation of cross-cutting themes and approaches to science, data and tool sharing:**

HDR UK has established policies, principles and ways of working with our research community to encourage collaboration and ‘team science’ within and between Sites and Hubs. The Alliance was developed to build standards among health data custodians and has developed principles and ways of working that further support data and tool sharing through the Gateway. These standards and principles are embedded into HDR UK contract relationships and they are all available on the HDR UK website to encourage these behaviours across the wider health data science community:

- HDR UK Open Access and Attribution Policies
- UK Health Data Research Alliance Principles of Participation (for all data custodians)
- HDR UK Branding Guidelines
- HDR UK Development Principles

**B1.3.4. HDR UK’s strategy for external collaboration (UK-wide, internationally and with the NHS and industry) and engagement with other relevant major strategic investments in the data science field and beyond**

We work in partnership around common strategic goals, including:

- Partnership with NHS Digital to establish the Alliance, that now includes >30 major data controllers from NHS (including NHS X, Scotland, Wales, Northern Ireland) research studies (ALSPAC, UK Biobank) and other major data controllers, including CPRD and Genomics England.
Industry partnerships through the Hub programme where 22 companies (large to SMEs) are supporting the development of disease-specific data assets, (i) providing tools and strategies for data curation, patient engagement and involvement; (ii) enabling real-time anonymised data access for research to improve cancer care; (iii) Cloud-based environments for storage and analysis.

International partnership with the Bill and Melinda Gates Foundation to create an International COVID-19 Health Data Research Alliance to bring together global datasets for trustworthy analysis and meta-analysis.

Partnership with other major existing UK policy making and Alliance organisations; for example, being invited to co-lead a Gap Analysis for the Global Alliance for Genomic Health, participation in the WHO Expert Working Group on AI/Health; member of OLS Innovation and Research Data Group, and NIHR/MRC Research Advisory Group.

The ‘Health Data Science Incubator’ partnership with NIHR and the UKRI National Productivity Investment Fund (NPIF) fellowship scheme, a programme that supports a mix of clinical and non-clinical researchers from across the UK who want to develop their career in health data science.

Formal partnerships with the NICE and the Health Foundation with a focus on the Better Care programme, as well as the Alan Turing Institute to develop joint strategy on applied advanced analytics.

We meet monthly with the ISCF programme board and through these meetings keep close engagement with key stakeholders. We actively contribute to other investments, in particular the digital imaging and pathology centres.

As part of our ISO 9001-certified Partnership process, we have established Memoranda of Understanding with strategic partners. These ensure we have aligned expectations and programmes of work and help to reduce the complexity of the landscape. Our strategic partnerships are monitored through our CRM tool, with a weekly automated report to ExCo on partnership status and developments.

B1.3.5. HDR UK’s assessment of the strategic relationship with funders’ and with funders’ other relevant major strategic investments in the data science field and beyond:

The Annual Core Funders Review, as defined by the Strategic Alliance Agreement, informs, engages and builds the strategic relationship with Funders and with Funders’ other relevant strategic investments. We hold monthly reviews between HDR UK Chief Executive and the Core Funder lead representative from the MRC to maintain close engagement.

Our funders are included in our annual stakeholder interviews that inform our annual planning process. We also have regular meetings with leadership at the NIHR, BHF, Wellcome, the National Data Guardian, Director of the ABPI, Director of UKRI and MRC to review and align with other strategic investments. We also meet regularly other funder partnerships and investments, including ADR UK and UK DRI.

Despite these excellent links there is an opportunity to do more in partnership with our funders and this is described in section B.8.
SECTION B.2.

Infrastructure

HDR UK works in partnership to create a world-leading, robust health data research infrastructure and a four-nations approach to secure data services. Through this rich, robust and reliable infrastructure, we are improving health data access underpinned by a strong governance framework, standards, clarity of leadership, responsibility and engagement with the public.

B.2.1. HDR UK’s role in providing enabling infrastructure for UK health data science

In September 2018, the UKRI and ISCF awarded £37.5m to HDR UK to lead the Digital Innovation Hubs programme to enable the development of infrastructure that supports health data research. The ISCF investment commenced with a six-month Design and Dialogue Phase. We solicited comments from over 2,700 individuals across academia, government, NHS, the public and industry to ask what the attributes of a world-leading health data research ecosystem would be. Through this engagement process, which included partnership with the ABPI and Pistoia Alliance, the original brief to develop interoperable digital innovation hubs was expanded to include the Alliance and Gateway. Each is a key enabling element of the national data infrastructure.

Figure 8: The infrastructure
Our infrastructure strategy set out in August 2019 (see appendices), describes the exciting vision we have for the UK’s health data research infrastructure. This strategy integrates the development of the Alliance, Gateway, and Hubs, and supported by infrastructure investments made within the research Sites. The core features of the infrastructure are:

1. Engaged and informed patients and volunteers providing their data

2. Trusted Research Environments hosting the data in secure, interoperable and sustained ways (safe havens) and enabling reproducible and scalable analysis (e.g. federated analytics)

3. Shared and transparent governance, ethics and access principles, benefits sharing across an Alliance of health data custodians and regulators that embed public confidence and make the data better to use

4. Service-focused innovation Hubs that are enhancing the quality of the UK’s health data and supporting users

5. One common Innovation Gateway so that users can easily discover and access the breadth of UK health data

6. Diversity of innovators and researchers from different industries with the tools and skills to use the UK’s healthcare data to innovate and make discoveries that improve people’s lives

7. Alignment with common, open data standards

HDR UK is on track with the ambitious infrastructure roadmap:

**Development**
**Sept 18 - Jan 20**
- ✓ Engage public, current and future health data community in the vision
- ✓ Create the Alliance and principles of working together
- ✓ Build Innovation Gateway MVP
- ✓ Initiate hubs
- ✓ On-board existing datasets
- ➤ Initial deployment of the UK’s health data research infrastructure

**Growth & Consolidation**
**Feb 20 - Mar 22**
- Build out the Innovation Gateway with federated analytics and linkage capability
- Organisations consolidate around their areas of expertise and outsource other areas
- Develop strategy for international datasets
- ➤ Significant increase in data quality, availability and use

**Mature & Globalise**
**Apr 22 - onwards**
- Further enhancements with functionality that accelerates discoveries
- Expand model to international datasets
- Organisations within the value chain expand their services internationally (eg global governance & standards, global Trusted Research Environments, global data curation services...)
- ➤ Globally leading health data research and innovation infrastructure that has enabled discoveries that improve people’s lives

Figure 9: Infrastructure development roadmap
B.2.2. Overview of HDR UK’s infrastructure capabilities

B.2.2.1. Sprint Exemplars

Alongside the design and dialogue engagement process in 2018, a competition was launched for demonstrator projects (Sprint Exemplars) to provide proof-of-concept activity to inform the longer-term infrastructure work.

Of the £37.5m, £2.7m, alongside £0.3m from HDR UK core funding, was invested in a series of 11-month projects. These projects covered a range of different areas, including adopting digital technology in care setting, building underlying databases to support research, and providing confidence in concept of specific technologies. They have been pivotal to the infrastructure strategy by generating early momentum and engagement with partners from industry, academia and the NHS; providing information about current market and idea generation; sharing early lessons with the wider programme; and starting to build the community. The participants delivered more than their projects – they helped to shape the future of health data science in the UK. Case studies highlight the immediate impact these projects have achieved.

B.2.2.2. The Human Phenome Project

The Human Phenome Project is redefining how we describe all human diseases in a data-driven way. We have more ways of measuring disease than ever before, beyond symptoms, including images (e.g. x-rays), continuous measurements (e.g. physical activity via wearable devices such as a ‘FitBit’), a person’s genetic make-up (e.g. through genome sequencing) etc. Much of this is captured in NHS electronic health records, which make them a valuable resource for studying human disease. We are developing new, more detailed and consistent descriptions of all human diseases, which will facilitate a deeper understanding of disease and how to treat patients. This national priority has two major national projects: the National Phenomics Resource and the National Text Analytics Resource (see section A.4.2).

B.2.2.3. Applied Analytics

This matches expert knowledge of new analytical tools such as machine learning and artificial intelligence with large-scale health datasets to demonstrate the power of these approaches to inform health and care delivery. This national priority is bolstered with the national reproducible machine learning project national implementation project (see section A.4.2.)

B.2.2.4. UK Health Data Research Alliance

Formed in February 2019, the Alliance was inspired by collaborative partnerships such as the Global Alliance for Genomics and Health.

The Alliance has experienced a rapid increase in members – growing from eight founding members in February 2019 to 30 members in April 2020, covering all four nations of the UK, including some of the UK’s largest NHS trusts, national bodies, charities and disease registries.

The Alliance supports five key workstreams, with input from the member organisations to drive the UK’s health data science agenda forward (figure 10).

Figure 10: UK Health Data Research UK Alliance workstreams

1. Data standards and quality
2. Supporting innovation gateway development and launch
3. Promoting participation and improving access
4. Aligning approach to trusted research environments
5. Engaging and involving practitioners, patients and the public
In February 2020, members of the Alliance came together for the first Alliance symposium. This event was attended by over 140 people from the NHS, academia and industry and included workshops and a world café session to stimulate new connections across disciplines.

The Alliance has been pivotal in making data accessible for research in response to COVID-19.

B.2.2.5. Health Data Research Innovation Gateway

Improving access to data for research and innovation is central to our mission. The Gateway is a web portal to enable researchers and innovators to discover which datasets are held by individual healthcare and research organisations across the UK. It aims be a one-stop-shop for researchers and innovators to share, manage and drive the ethical and safe use of data, exploiting cutting-edge analytics and big data technologies to improve health outcomes.

The team builds upon existing infrastructure where possible, rather than starting from scratch, enabling the acceleration of the Gateway and delivering a Minimum Viable Product (MVP) in January 2020 and launching the next phase in June 2020.

The MVP provided researchers and innovators with the ability to discover and make access requests to datasets. It was developed using teams across seven organisations working in partnership with HDR UK.

The MVP development allowed us to invest time to identify a lead supplier to develop the fully functional Gateway. Beginning in October 2019, the procurement involved multiple stages of increasing complexity and scrutiny, initially with expressions of interest, moving into detailed proposals, then panel interviews and finally a Rapid Development Task (RDT). The RDT has been a novel approach to the procurement, which involved the three highest rated suppliers working in parallel to develop a specific component of the Gateway over eight weeks and culminated in a panel interview and technical demonstration. Members of the HDR UK Public Advisory Board have been involved at each stage; partners from the Alliance, including NHS Scotland, NHS Digital, and NHSX were involved in the selection process; and the National Data Guardian was involved as an observer in the process.

Following selection of the new technology partner, the next phase of the Gateway was launched with 457 datasets, tools, projects and community resources for researchers and

Figure 11: Participants at the first UK Health Data Research UK Alliance symposium held in February 2020 at Wellcome
innovators. Through this process, researchers, innovators, patients and members of the public were engaged through workshops, testing sessions and direct interviews.

The COVID-19 response has already demonstrated the utility of a single place to source health data. Even in these early stages of its development the Gateway accounts for 14% of all COVID-19 related research access requests across the UK’s national data custodians.

B.2.2.6. Health Data Research Hubs

Health Data Research Hubs are centres of excellence with expertise, tools, knowledge and ways of working to maximise the insights and innovations developed from health data.

Following the Grants and Contracting process, an interdisciplinary panel in August 2019, chaired by Lord Darzi, identified seven fundable bids. This was beyond the ISCF investment envelope. Recognising the value of all fundable bids HDR UK invested Core funds to enable the establishment of all seven Hubs:

- **INSIGHT**
  The Health Data Research Hub for Eye Health

- **DATA-CAN**
  The Health Data Research Hub for Cancer

- **Discover-NOW**
  The Health Data Research Hub for Real World Evidence

- **BREATHE**
  The Health Data Research Hub for Respiratory Health

- **Gut Reaction**
  The Health Data Research Hub for Inflammatory Bowel Disease

- **PIONEER**
  The Health Data Research Hub for Acute Care

- **NHS DigiTrials**
  The Health Data Research Hub for Clinical Trials

The Hubs were announced in September 2019, with a high-profile launch supported by Ministers, DHSC, NHSX and groups representing patients’ interests including Understanding Patient Data and UseMyData. All Hubs were operational on 1 October 2019.

The Hubs, supported by £22m of ISCF funds and £2m of HDR UK core funds that leveraged £42m of direct or indirect contributions, are formal collaborations between over 100 NHS, academic organisations, patients, charities and industry.

The Hubs all subscribe to the Alliance’s Principles of Participation on information governance, ethics, intellectual property rights and commercial models as a data controller, and to the set of services in the Gateway. Four cross-cutting workstreams have been developed to streamline work and create a shared understanding of issues and approaches across all Hubs:

- Data standards and quality
- Participation and sustainability
- Communications, engagement and involvement
- Financial/KPI reporting

All Hubs are on-track, achieving their first milestone in December 2019.

In 2020, the £10m **BHF Data Science Centre** was established, led by HDR UK and funded by the British Heart Foundation (BHF). The Centre enables responsible, ethical research that combines the power of advanced analytic methods with the UK’s large-scale and diverse cardiovascular data. High impact outputs will help to shape better cardiovascular health services, provide patients and health professionals with the tools to make better decisions, and bring the latest medical discoveries to patients across the UK faster than ever before.

Collectively, the Hubs and the Centre (along with the Gateway and the Alliance) have played a pivotal role in enabling research to support the UK’s COVID-19 response, including the BREATHE Hub’s role with the COVID symptom tracker, one of the most utilised UK research datasets. The BHF Centre is providing leadership on the prioritisation of research questions selected for action during
this COVID-19 period. People with cardiovascular disease are one of the groups most likely to be directly and indirectly adversely affected by COVID-19 as a result of reduced presentation of suspected heart attacks in hospital. In the light of this, a number of partners across the clinical cardiovascular community, led by the BHF, have worked together to create a linked dataset accessible for research.

The Hub model is scalable, and we are in conversations with diabetes, dementia, asthma, pregnancy & child health, longitudinal population studies and primary care communities about establishing and integrating more Hubs.

B.2.2.7. Site infrastructure programme

Funding for infrastructure across the research Sites is supported through the HDR UK Core Award and focused on specific research projects. Additionally, the MRC invested a further £5m capital funding in 2018-19 to support:

- Cohort & trials platform services in partnership with NHS Digital (Oxford)
- Advanced computing infrastructure for development of reproducible machine learning (Oxford)
- Pump-priming of HDR-UK Cloud Based Analysis Platform (Cambridge)
- Creation of an open, standards-based infrastructure to enable UK biobanks and cohorts to be integrated into an information commons-based network to support health data research (Midlands)
- Proposal for a National HDR UK Data Access platform, building on the MRC-supported UKSeRP infrastructure (Wales/NI)
- Establishing a single data sharing platform & extending the life of existing MRC funded HPC (London)
- Sustaining current activity (established by past MRC investment) to support provision of health imaging data for research (Scotland)

As described in the infrastructure strategy (see appendices) these investments are all being integrated into the joined-up national infrastructure programme.

B.2.3. Governance and Cyber Security

HDR UK is not a data custodian. We do not store, hold or process any patient or health data. HDR UK’s cyber security approach is addressed through its IT & Communications Systems Policy and through its Data Protection Policy.

Development of each of the infrastructure activities have followed our ISO 9001-certified processes, including the Grants and Contracting and Partnership processes.

The infrastructure programme is overseen by the IDG which ensures milestones are met, and the strategy delivery plan is on target and in budget. In addition, HDR UK reports monthly on progress against the infrastructure strategy to the ISCF Board. These monthly papers are shared with MRC and provide a detailed log of the infrastructure development.

We are building alignment across the community around this strategy through our policies and ways of working.
SECTION B.3.

Translation

HDR UK’s mission depends on translation of health data research into benefits for patient care, clinical trials, biomedical advancements and public health. It relies on effective partnerships with the NHS and front-line clinical teams, clinical trials organisations, pharmaceutical companies and Government.

Our translation strategy is structured around four health data use priorities:

- **Understanding Causes of Disease**
- **Clinical Trials**
- **Better Care**
- **Public Health**

B.3.1. Understanding Causes of Disease:

The Understanding Causes of Disease national priority aims to take a “molecule to health record” approach to transform scientific understanding of the causes of disease, its progression, and consequently disease prevention and treatment. A key challenge is accessing and analysing this complex genetic and other molecular information at scale. The initiation of HDR UK’s National Multi-omics Consortium, aims to address this challenge by bringing together nine of the UK’s leading research cohorts.

Conducting these analyses requires a trusted research environment (TRE), in which EHR data can be safely processed, alongside access to high performance computing (HPC) facilities. In February 2020, we announced a partnership to link into Cambridge Services for Data Driven Discovery (CSD3) – a national data intensive science cloud for converged simulation, AI and analytics as part of a £10m investment recently announced by the Engineering and Physical Sciences Research Council (EPSRC) to support secure analysis of multi-omics datasets.”

The Understanding Causes of Disease team have also played an important role in supporting Public Health England, playing a pivotal role within the COVID-19 Genomics UK Consortium. The project aims to decode all the genetic information in samples from patients with confirmed cases of COVID-19, enabling scientists to monitor changes at a national scale.
B.3.2. Clinical Trials:

HDR UK’s Clinical Trial’s priority has spearheaded two major industry-sponsored trials, showcased within the Life Sciences Industrial Strategy. The NHS DigiTrials Hub also supports the UK wide RECOVERY trial that is testing seven existing medicines in the context of COVID-19. Currently there are no known treatments for COVID-19, so this is vital work.

The development of good practice guidelines for clinical trial regulation is also being tackled, working in close collaboration with the Wellcome, and partners including the Gates Foundation and the African Academy of Sciences. This work is crucial to inform the scale-up of data-led innovations, such as those delivered by the NHS DigiTrials Hub.

B.3.3. Better Care:

We have adopted a learning health system approach that integrates clinical practice, large scale data and advanced analytics in a cycle of continuous improvement (Figure 13)

We have developed this programme in close partnership with The Health Foundation, NHS Improvement and NHSX as well as input from industry leaders. We continue to expand our Better Care partnerships across the UK, including the integration of a further two Substantive Sites – HDR UK North and HDR UK South West - and four Catalyst projects, including one developing an AI-driven clinical decision-making tool to manage cystic fibrosis and one focused on reducing the health burden of diabetes with AI-powered clinical decision tools, co-led with an SME. These new capabilities significantly increase our direct partnerships with NHS, Local Authority, and care providers across the UK.
B.3.4. Public Health:

We have built close partnerships with public health providers in all four nations, which have been rapidly deployed to support during the COVID-19 crisis. In Wales, the HDR UK team supported the Welsh Government COVID-19 response, working in close partnership with Public Health Wales, the All Wales Critical Care Network, NHS Wales Informatics Service and Cardiff University.

We have established a national project, the National Multimorbidity Resource which aims to bringing together multiple routine datasets representing up to 10 million people across the UK and established new national working groups in maternal and child health, mental health and environment and health to build new interdisciplinary research opportunities.

B.3.5. Governance and operational processes supporting translation

In March 2020, the Board agreed to pursue an application for HDR UK to achieve charitable status. A strong driver in that decision was the ability of HDR UK to credibly engage with the public in a trustworthy way.

Our ISO 9001-certified Partnership process provides the cornerstone of our engagement. Through this we identify organisations with which we can work to achieve our strategy priorities and cultivate our relationship for mutual benefit that will deliver health and care benefits.

All commercialisation activities are done with the support and guidance of our Public Advisory Board to ensure that they are done in a way that builds public trust and achieves outcomes that benefit patients and the public. We are transparent about what we are doing, for example, we held an event on Realising patient and NHS benefits from health and care data – from policy to practice, in partnership with the Academy of Medical Sciences and the Collaboration for the Advancement of Sustainable Medical Innovation (CASMI). This event was about building trustworthy commercial partners, for which we provided a live, open broadcast so that members of the public could participate and have published a report of the event. Through the Alliance, we are developing a commercial strategy and framework that provides a transparent structure for commercial arrangements.

**Intellectual property (IP):**

We have evolved our approach to IP into three distinct models. This enables us to clearly communicate how we work with funded parties from the outset and allows us to ensure health and care benefit can be exploited through outputs available on the Gateway (Table 2).

<table>
<thead>
<tr>
<th>Investment type</th>
<th>Delivery mechanism</th>
<th>IP approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long term research investments</td>
<td>Substantive Sites</td>
<td>Owned by the organisation which generates it</td>
</tr>
<tr>
<td>Project-based research and infrastructure investments</td>
<td>Health Data Research Hubs Better Care catalysts</td>
<td>Owned by the organisation which generates it with automatic license to HDR UK to deliver health and care benefits and use in the Gateway</td>
</tr>
<tr>
<td>Technology development and consultancy support</td>
<td>Health Data Research Gateway</td>
<td>Owned by HDR UK</td>
</tr>
</tbody>
</table>

Table 2: HDR UK IP position
**Influencing Government policy:**
As well as building close partnerships with industry, we have built strong working partnerships with policy makers in Government and the NHS to enable large scale benefits from health data science. As an example of this, our Better Care Partnership Network is being used by the NHS Accelerated Access Collaborative as the starting approach for site selection for Phase IV of the AI Health and Care Award programme.

Developing industry partnerships to achieve health and care benefits: As part of the Design and Dialogue phase of the ISCF Programme we engaged over 1,200 people across 200 industry partners, working in close partnership with the Office of Life Sciences, Innovate UK and the MRC as well as industry organisations included the ABPI and Pistoia Alliance. The Hubs include 60 industry co-applicants and/or collaborators, with several companies stating that their Hub partnership was one of their top global priorities or one of their most exciting initiatives internationally (this included AstraZeneca, Roche, Microsoft & IQVIA).

HDR UK has provided a vital role in deriving benefits from these partnerships, while also maintaining public trust. Our Principles for participation have provided a standard across all activities. We have fully embedded PPPIE throughout and provided transparent leadership to an important dialogue on building trustworthy commercial partnerships.

Within our Gateway programme, we have taken an industry-led approach, at both MVP and full implementation stage. We have effectively managed delivery across multiple partners (including established technology providers, SMEs and academic providers) as well as establishing clear design and development principles. This has been developed in the open throughout – with all code available within the HDR UK GitHub Repository. Our innovative RDT approach enabled a true partnership approach.

**SMEs:**
HDR UK is collaborating with a number of SMEs including through KQ Labs – an accelerator programme led by the Francis Crick Institute to support start-ups at the interface between biomedical and data science. We, together with Genomics England, guide the companies through issues relating to data access. The ten start-ups identified as having the potential to make a global impact on health outcomes, included a scanner for portable diagnosis of brain injuries and an AI system to help guide the treatment of preventable sight loss, have benefited from our shared knowledge and expertise via workshops and training.

**Developing partnerships with national health bodies to achieve health and care benefits:**
Engaging with national health bodies is vital for us to achieve our mission. In addition to the close working partnerships already mentioned with NHSD, NHSX and NHSE, in July 2019 HDR UK and the National Institute for Clinical Excellence (NICE) announced a formal partnership. Through this partnership, we identify and act on opportunities where health data can be better used to support the health and care service to improve outcomes for patients and to do this more efficiently, most recently demonstrated through NICE’s engagement with the COVID-19 research question prioritisation process, where they have submitted detailed questions for consideration by SAGE.

Together, we also support training in health data science to ensure that health and care professionals have knowledge and skills to be able to use and apply health data and technologies and we involve patients and the public in these joint initiatives, ensuring that data is used responsibly and ethically.
SECTION B.4.

Administration, management & financial planning

To ensure that HDR UK runs smoothly, we have robust administrative, management, and financial planning and control structures in place. Here, we set out how we operate as a single, coherent and integrated ecosystem through the administrative, governance, management, operational structures of the Institute.

B.4.1. HDR UK Board, Legal Structure and Executive Governance

HDR UK is a company limited by guarantee (company number: 10887014). HDR UK’s Articles of Association can be found on Companies House. It is governed by a Board of Non-Executive Directors.

The Board is responsible for the effective governance and development of the Institute, supports the Director and Chief Executive in overseeing the delivery of our strategy, monitors key risks, and ensures resources are managed effectively. The Board meets quarterly and is supported in its role by three sub-committees: Audit and Risk, Nominations and Remuneration.

HDR UK’s Executive Committee (ExCo) meets monthly and is jointly chaired by the Director and CEO. ExCo sets, develops and monitors strategic direction across uniting/improving/using/one institute. It is responsible for keeping us on track with our core delivery plan, KPIs and all operational issues (including people development). It has the major delivery and capital programmes reporting to it.

ExCo has two delivery groups reporting to it, which also meet monthly:

- Improving & Uniting Delivery Group (IDG), responsible for delivery of all aspects of the Infrastructure strategy including DIH programme, implementation projects and capital investments, and ensuring that the approach is fully joined up
- Using Data Delivery Group (UDG), responsible for ensuring we are using health data by performing research that individual Institutions cannot do themselves, encouraging early adoption & demonstrating impact at scale, and by training outstanding people

The progress and impact review framework that supports Board, ExCo, IDG and UDG is described in section B.7.

The relationships between the Board, Executive, Funder and Advisory groups is described in Figure 14. Further detail on our governance structure is in the appendices.
B.4.2. Risk Management

Our vision and strategy are ambitious, and there are risks to successfully achieving that ambition. Risk management is everybody’s responsibility and is embedded into the annual planning process. Risks identified are recorded in the risk register (see appendices), which is reviewed monthly as part of our ExCo and each quarter by the Audit and Risk Committee. This includes:

- identifying key risks to our strategy, evaluating their potential impact and assessing their likelihood
- evaluating the effectiveness of relevant mitigating controls
- agreeing, implementing and monitoring controls and actions to mitigate risks.

Risks can be raised by any member of the community and are evaluated by the ExCo and captured in the risk register. We actively review the top 10 risks on the register to ensure attention and resources are focused on the highest impact and likelihood risks. For example, in September 2019, having identified the lack of capacity within the Central team as the top risk that would impede the delivery of our strategic goals, we undertook a recruitment campaign and successfully added 10 new roles to the team. The residual risk score has now been reduced and it is no longer our top risk.

Our continuous improvement culture means we learn from what has gone well and what has not gone well. This is underpinned by our core value of ‘transparency’ – we are committed to sharing information, insights and innovations so that
we learn faster together. Our risk management processes are strengthened through three key components of our Incident and Learning Policy, which enable us to anticipate and be well prepared for significant challenges.

**Incident reporting and escalation:**
Using the learning approach developed in sectors such as the chemicals industry, we learn from small incidents and ‘near misses’ to reduce the likelihood and severity of large-scale incidents. To help with this, we encourage staff to share incidents as they happen and to escalate any issues that they are uncomfortable about to a member of ExCo. These include incidents ranging from health and safety to information security. Incidents are shared via our Slack #incidentlog channel for others to learn from.

**After Action Review (AAR):**
An AAR is a structured review process for analysing what happened, why it happened, and how it could be done better. Any team member can request an AAR and the essence is to bring together the relevant group to think about a project, activity, event or task, using structured questions. Recommendations from the AAR are recorded and circulated to attendees and the wider team, where appropriate.

As a large and complex organisation, it is important that we are able to remain agile and for our governance processes to be robust but not onerous or cumbersome. We have steered away from over bureaucratising our structures; however, this is reliant on excellent communication and a transparent approach to working together. This approach places significance on our ways of working and values.

We will continue to embed our approaches to governance, risk management and dealing with significant challenges. Where necessary, we will evolve our governance structures to ensure they enable HDR UK to operate at its most effective.

**B.4.3. Financial structures and decision making**
HDR UK has increased funds under direct or indirect management by over £100m since August 2018 (Table 2) through direct funds and partnership contributions. Each year, the Board approves an annual budget which is delegated to HDR UK’s budget holders (ExCo, Research Directors, and Hub Directors). Financial information is reported to and reviewed by HDR UK’s governance structures. See appendices.

**Financial planning:**
HDR UK’s budgeting process is integrated with our annual planning process. This process clearly links the detailed budget to the strategic delivery plan. It takes into consideration financial results to date, actions taken as part of the above review processes, fund use and new planned activities.

The annual budget is reviewed and approved by the Audit & Risk Committee, which also reviews the mid-term financial projections on an annual basis.

**New funding and investments:**
All HDR UK expenditure and investments are aligned with our strategic plans and all new funding is managed through our Grants & Contracting process. We carefully consider requests for applications from funders, and where appropriate, act as a convenor/mediator to direct the approach to the most relevant skill sets within our community, for example, with the recent award of the Canada-UK AI Initiative. HDR UK Core Funding allows us to leverage skills and provide valuable in-kind contributions for these projects.

**Financial management:**
As a federated Institute, HDR UK draws on the finance and administrative structures in each of its partner organisations, including their financial and other control frameworks.

Each partner organisation has a named professional leader who is responsible for the collation, review, submission, and explanation of local financial information and reports financial information on a quarterly basis.

HDR UK’s central finance team coordinates and monitors financial information centrally, including budgets, forecasts, actuals, and matched, leveraged and other contributions in-kind.

The central finance team also run medium- and long-term projections of expenditure, income and fund use.
Management accounts are consolidated quarterly and enable us to take a detailed view of financial results, assessing them against budget. This allows us to identify root causes of variations and to forecast results for the full year against budget.

Our identification of actual and expected over/underspends at an early stage through this financial management approach has enabled us to take mitigating actions to bring activity back on track, as demonstrated through our National Priorities, or to reallocate funds where appropriate, for example with our capital investment programme.

The expenditure trajectory for the funding streams in place before our ISO 9001 processes (core funding, capital funding, BHF Centre) are behind the original plan expectations. This has been due to:

- Speed of set up and recruitment within Sites and partnerships
- Robust competitions for appropriate long-term partners for additional scientific research capacity
- Speed of set up and changes to anticipated length of major training programmes.

This establishment period has been characterised by:

- Careful planning, scoping and launch of partnerships and major programmes using funding allocated to support Partnership Sites and Director’s Investments. These investments address strategic gaps and deliver high impact, whilst being integrated within HDR UK, for example the new Sites in South West and North, and the Hubs.
- Re-alignment of existing financial and administrative structures from siloed, geographic base to integrated national programmes to support the One Institute strategy.
- New funding income aligned with and necessary to our strategic ambitions. The activity supported by each new income stream has been carefully scoped with detailed design requirements to ensure funding is additional and complementary to our core funding.

<table>
<thead>
<tr>
<th>Funder</th>
<th>HDR UK direct funding</th>
<th>Partner contribution commitments</th>
<th>Total resource</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>MRC</td>
<td>£10.0m</td>
<td>£2.5m</td>
<td>£12.5m</td>
<td>Supporting the HDR UK capital investment programme</td>
</tr>
<tr>
<td>British Heart Foundation</td>
<td>£10.0m</td>
<td>-</td>
<td>£10.0m</td>
<td>BHF Data Science Centre establishment and delivery</td>
</tr>
<tr>
<td>Industrial Strategy Challenge Fund</td>
<td>£13.0m</td>
<td>£60.4m</td>
<td>£73.4m</td>
<td>Design, delivery and implementation of the Alliance, Gateway and Hubs, as part of the Digital Innovation Hub Programme</td>
</tr>
<tr>
<td>Wellcome Trust</td>
<td>£6.0m</td>
<td>-</td>
<td>£6.0m</td>
<td>HDR UK / Alan Turing Institute PhD programme creation and delivery</td>
</tr>
<tr>
<td>The Gates Foundation</td>
<td>£2.4m</td>
<td>-</td>
<td>£2.4m</td>
<td>International COVID-19 Data Research Alliance creation, and COVID-19 Data Analysis Platform development</td>
</tr>
<tr>
<td>The Health Foundation</td>
<td>£0.5m</td>
<td>£0.5m</td>
<td>£1.0m</td>
<td>Supporting the Better Care Catalyst Project Programme</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£41.9m</strong></td>
<td><strong>£63.4m</strong></td>
<td><strong>£105.3m</strong></td>
<td></td>
</tr>
</tbody>
</table>

Table 2: New funding streams developed since 1st August 2018.
SECTION B.5.

People - recruitment, skills and careers

We are developing our One Institute culture through training, recruitment, development, and policies

HDR UK is made up of a central team, research sites, hub and training teams around the UK that bring deep domain knowledge and skills to deliver our strategic objectives. We also have a team of expert outsourced partners in communications, IT, HR, legal.

Our HDR UK community is described by our Attribution policy. We have three groups within our community:

1. Institute Members: those directly supported by HDR UK funds, directly or in-kind (including professional services teams). We have over 450 Institute Members.

2. Affiliate Members: those who collaborate or partner on HDR UK supported projects or activities by are not directly supported by HDR UK funds.

3. Users and beneficiaries: those who use and benefit from HDR UK outputs but are not funded by HDR UK and not involved in developing them.
The following organigram shows leadership responsibilities for each area of the strategy, Executive and Institute leadership (figure 15).

<table>
<thead>
<tr>
<th>Desired outcomes</th>
<th>Priority Leadership (reporting to UDG and IDG)</th>
<th>Enabling Team</th>
<th>Executive Leadership (reporting to ExCo)</th>
<th>Institute Leadership (reporting to Board)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>One Institute</strong></td>
<td>International strategy <strong>Melissa Lewis-Brown (interim)</strong></td>
<td>Rhos Walker, Melissa Lewis-Brown</td>
<td>Andrew Morris</td>
<td>Andrew Morris</td>
</tr>
<tr>
<td>UK recognised as the place to do health data science</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Uniting</strong></td>
<td>Develop the Alliance &amp; Gateway standards <strong>David Seymour</strong></td>
<td>David Seymour</td>
<td></td>
<td>Caroline Cake</td>
</tr>
<tr>
<td>Efficient, safe access to large scale, diverse data for researchers and innovators</td>
<td><strong>Access Paola Quattroni</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transparency of use for patients and the public</td>
<td><strong>Delivery of TRE: David Seymour + Tim Hubbard + Gerry Reilly</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gateway:</strong></td>
<td><strong>Talent / workforce strategy George Moulton</strong></td>
<td></td>
<td></td>
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<tr>
<td><strong>Technology Partnership Peggy Barthes-Streit</strong></td>
<td><strong>Technical direction Susheel Varma</strong></td>
<td></td>
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</tr>
<tr>
<td><strong>Improving</strong></td>
<td>Data quality standards <strong>Neil Sebire &amp; Ben Gordon</strong></td>
<td>Kay Snowley, Clara Fennessy, Professional Leaders</td>
<td></td>
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<tr>
<td>Better data for researchers and innovators</td>
<td><strong>Establish BHF Centre Cathie Sudlow</strong></td>
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<tr>
<td></td>
<td><strong>New tools, methods and hubs in Gateway</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td><strong>Human phenome (Phenome Library) Harry Hemingway (Spiros Denaxas)</strong></td>
<td></td>
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<tr>
<td></td>
<td><strong>Applied Analytics (Reproducible Machine Learning, Text Analytics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Dave Robertson (interim) (Aiden Doherty, Richard Dobson)</strong></td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td><strong>Population Cohort Hub Rhos Walker</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Using</strong></td>
<td>One Institute national delivery (Dani Blatt) &amp; high impact case studies and team science</td>
<td>Peter Diggle, Professional Leaders</td>
<td>Rhos Walker</td>
<td>Andrew Morris</td>
</tr>
<tr>
<td>Better research for funders and public - that no single research organisation could achieve alone</td>
<td><strong>Melissa Lewis-Brown</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Understanding Causes of Disease John Danesh</strong></td>
<td><strong>Better Care Simon Ball and Alice Turnbull</strong></td>
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<td></td>
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<tr>
<td></td>
<td><strong>Clinical Trials Martin Landray</strong></td>
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<td></td>
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<td></td>
<td><strong>Public Health Ronan Lyons</strong></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td><strong>Applied Analytics Chris Holmes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Training skills &amp; Development George Moulton</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>One Institute</strong></td>
<td>Successful One Institute Establishment Review <strong>Victoria Platt</strong></td>
<td>Kate Sanders, Wilde, Kate Humphries (B&amp;B), Karen Dawson, Lindsay Cockcroft</td>
<td>Victoria Platt</td>
<td>Caroline Cake</td>
</tr>
<tr>
<td>UK recognised as the place to do health data science</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>**Financial management &amp; sustainability strategy <strong>Amanda Borton</strong></td>
<td></td>
<td>Stephanie Gou, Donna Cullen</td>
<td>Amanda Borton</td>
<td></td>
</tr>
<tr>
<td>Communications</td>
<td><strong>Amanda White</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fran Lord, Hettie Williams</td>
<td>Amanda White</td>
<td></td>
</tr>
</tbody>
</table>

The Central team is small unit of 33 permanent staff (employees and secondees) covering a range of skills from strategic development and oversight, communications, operations, finance, scientific strategy, technology strategy and programme delivery. Broadly, they provide four key functions across the Institute:

1. Institute leadership and seeding medium-to long-term opportunities
2. Cross-Institute operations, finance and communications
3. Joining up strategy delivery mechanisms to ensure they are strategically aligned and operationally efficient

4. Delivering key aspects of the HDR UK strategy by leading the development of the Gateway, Alliance and Hubs

**B.5.1. Developing our team culture**

HDR UK’s values form the nucleus from which our team-oriented culture grows. These are shared widely throughout our community and those working with us to support their development, and they guide our decision making and inform our strategy.

The Substantive Site international review panel recognised that enabling cross-Site collaboration would be vital to HDR UK successfully becoming an integrated Institute. As such we have developed
National Implementation Projects, with teams that span four, five and sometimes all six operational Substantive Sites. They have provided new leadership opportunities and enabled delivery of research which no single institution would be able to achieve. We support the learning and development of the National Implementation Projects researchers by sharing research outcomes through our Insight Sharing days. This approach is already bearing fruit, with many publications co-produced across Site boundaries. See Figure 16.

We have implemented a coaching culture, enabling leaders to facilitate learning and build more effective, independent and resilient teams. To support the development of our coaching culture, we are investing in the training of our leaders to become certified coaches. The first cohort of nine is due to complete their training in July 2020 and we will be recruiting the second cohort in summer 2020. This programme is open to all leaders within the HDR UK community, including those at mid-management levels.
B.5.2. Equality, diversity and inclusion

We published our position statement on equality, diversity and inclusion on our website in 2019. We have actively improved representation by: ensuring our events panellists and presenters exhibit gender diversity, supporting our central team with unconscious bias training, learning more about the diversity of our community through staff surveys, growing the range of data custodians within the Alliance to ensure there is broader representation of health data available on the Gateway, supporting research programmes that focus on health outcomes in BAME communities and those underrepresented in current health datasets, and ensuring our community includes people from a range of industries, organisations and bodies.

We are developing our position statement into a full diversity and inclusion policy which will be published in summer 2020.

B.5.3. Staff, HR Policies and Career Development

Launched in January 2019, these cover the full suite of human resources policies from recruitment, induction, professional development, leave entitlement to flexible working and beyond. All staff are required to read these policies, which is captured on our HR system. Our policies are ISO 9001 certified and are internally and externally audited to ensure they are meet our statutory requirements and are competitive.

All members of staff have a named career manager whom they meet with every six weeks to review their career development. Six months after joining HDR UK, each staff member has a probation review, led by their career manager and informed by 360-degree feedback from colleagues and external stakeholders. Thereafter each person has an annual appraisal, with 360-degree feedback and a personal development plan to guide their development over the year ahead. HDR UK's performance improvement processes are deployed where necessary to address performance issues and support staff.

B.5.4. Community policies

We have published position statements on each of our key research policies and have a programme of activity in 2020/21 to evolve these into full policies. Our aim is to be at the forefront of open policy development and we are actively monitoring changes in areas such as open access with Plan S. For example, our 2019/20 Researchfish submission has demonstrated that the vast majority of publications are open access (see figure 17).

Many of our community are also employees of other legal entities and subject to their local institutional policies.

---

Figure 17: Accessibility of publications by National Priority

<table>
<thead>
<tr>
<th>National Priority</th>
<th>Closed</th>
<th>Bronze</th>
<th>Hybrid</th>
<th>Pure Gold</th>
<th>Green</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding Causes of Disease (n=160)</td>
<td>10.0%</td>
<td>13.8%</td>
<td>23.8%</td>
<td>32.5%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Improving Public Health (n=139)</td>
<td>13.7%</td>
<td>9.4%</td>
<td>22.3%</td>
<td>45.3%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Human Phenome (n=138)</td>
<td>13.8%</td>
<td>9.4%</td>
<td>23.9%</td>
<td>39.9%</td>
<td>13.0%</td>
</tr>
<tr>
<td>Clinical Trials (n=2)</td>
<td></td>
<td>50.0%</td>
<td></td>
<td>50.0%</td>
<td></td>
</tr>
<tr>
<td>Better Care (n=127)</td>
<td>14.3%</td>
<td>9.4%</td>
<td>24.4%</td>
<td>38.6%</td>
<td>13.4%</td>
</tr>
<tr>
<td>Applied Analytics (n=83)</td>
<td>16.9%</td>
<td>7.2%</td>
<td>18.1%</td>
<td>32.5%</td>
<td>25.3%</td>
</tr>
</tbody>
</table>

*Bronze: Freely available on publisher page, but without an open licence*
*Hybrid: Version Of Record (VOR) is free under an open licence in a paid-access journal*
*Pure Gold: Version Of Record (VOR) is free under an open licence from a full OA journal*
*Green: Free copy available in an OA repository*

Source: Dimensions (April 2020)
**B.5.6. Training strategy**

HDR UK is developing the next generation of leaders in their field through a community of UKRI Innovation and Rutherford Fellows and NIHR clinical fellows. In 2019, we delivered funding for six Masters programmes, and through a co-investment with the Wellcome, created the Wellcome-HDR UK PhD Programme in health data science, in partnership with the Alan Turing Institute. Both programmes will admit their first students in Autumn 2020. These programmes are overseen by the UDG and supported by a training sub-group within the Sites. The Institute training strategy provides:

- Provision of innovative interdisciplinary training from Masters to Research Leaders
- Build sustainable capability and capacity through leveraging the skills and expertise across all HDR UK partners
- Influence and enable new career pathways across academia, NHS and industry

**B.5.7. Recruitment strategies**

HDR UK has grown rapidly and we have developed a robust recruitment process to ensure we draw on the widest pool and deploy effective selection processes to identify the best talent. The success of our approach is reflected in the diversity of skills and expertise within our central team (see appendices). The HDR UK brand is a strong attractor of high-quality candidates. We use a range of recruitment strategies including advertising on our (and institutional) websites, promoting opportunities via social media (Twitter and Linkedin), reaching learned communities such as the Royal Statistical Society, and online such as via One HealthTech. We support each new team member with a thorough induction to ensure they are well equipped for success within HDR UK.

Recruitment to roles in Sites, Hubs and partners are subject to their own local practices. Common types of staff/skills recruited include PhD students, researchers, data analysts, project management, technical experts (artificial intelligence/bioinformatics etc.). Experiences in recruitment across these organisations during this set up phase include:

- Favouring the use of standard job board websites, local institution websites and social media
- Staff are often recruited internally or from within partner institutions, secondments etc.
- Challenges and delays have sometimes been due to local recruitment bureaucracy (i.e. with University procedures)
- Very small pools of applicants for specialised technical role including data scientists has been challenging

**B.5.8. Institute experience**

We interview each of our leaders and our public advisory board annually to gather feedback on their experiences and inform our strategic plan. We collect survey feedback from groups including fellows, our central team and members of our communities attending events. We are extending our annual listening exercise in 2020 to include a survey for all members of the community on their HDR UK experience.
Communications and engagement

Here, we explore how we communicate within and beyond the Institute, engage with stakeholders, and engage and involve patients and the public.

The primary aim of our strategy for communications, engagement and involvement (CEI) is to position HDR UK as a leading international Institute for health data research, that has the trust and confidence of patients, the public, practitioners and key stakeholders, by:

- **Involvement** of people – patients, public and practitioners – in key design and decision making
- **Communications and engagement** with people – patients, public, practitioners, researchers and innovators, funders and key stakeholders – to demonstrate our progress and impact
- **Supporting and convening communications, engagement and involvement activities at a local level** (Hubs, Sites, Alliance members) – including application of the HDR UK brand identity, use of broadcast channels, providing high quality tools for collaboration, and opportunities for sharing ideas.

B.6.1. Communications channels

In April 2020, we published our strategy for communication, engagement and involvement that outlines how we will achieve our strategic aim. We have implemented a range of channels and opportunities for people to come together, collaborate, contribute, and share ideas. In addition, we have established a network of over 60 communications professionals who support, share and promote our work, which expands our reach using existing communications channels within our member organisations. Our own channels include:

**Website**

The HDR UK website is a core communication channel and is an important source of information for the HDR UK community, which many of our members contribute content to. It contains the latest news and events, project updates, HDR UK publications, and biographies of our 340 members. The website receives an average of 8,500 unique visits a month, which rises sharply when we have a major announcement (e.g. the recent Better Care competition).

We also launched a website for the UK Health Data Research Alliance in September 2019 to promote the important work of uniting health data.

**Weekly COVID-19 weekly taskforce calls**

During COVID these have been held every week, structured around the weekly SAGE report, with 67 clinical and health data research leaders engaged. These calls have triggered many of the health data research collaborations that have taken place during the COVID period.

**Weekly blog**

These are published every Tuesday, since November 2018, and cover news and views from people in our community – such as what it’s like to work as a **clinician in urgent care during the COVID-19 pandemic** through to views on **how to build the skills of data scientists**.
Slack
We use Slack as a channel for internal collaboration with members of the Substantive Sites. This quickly expanded through COVID and we now have 1306 academic, industry and NHS participants in COVID-19 Slack channel with 10 sub-channels. It is used for conversations and discussions on particular research topics. All our main news announcements, events and other updates are posted on Slack for all members to view and share, enabling us to expand our reach and increase visits to the website.

Events
Opportunities for members of our community to get together to co-create and collaborate are vital to the delivery of our strategy. Since HDR UK was established we have run 75 events, including conferences, seminars, symposia and webinars. Our main events are now live-streamed so that they are open to all. From 2020, we have identified three key events that will be run each year, providing a more focused event strategy with clearer outputs. These include:

- One Institute Conference
  This event is for everyone in the HDR UK community to focus on the One Institute strategy, celebrate impact and progress, and build towards the UK being recognised as the place to do health data science. The event also aims to build our inclusive, team-oriented culture that is aligned to our values. To date, we have run two of these events (April 2018 with 87 attendees and in June 2019 with 200 attendees). The next is planned as a virtual conference in June 2020 and we are expecting 400 attendees.

- Summer School
  Our summer school is aimed at early career researchers, including those in our fellowship scheme and others in HDR UK community. Its purpose is to enhance skills in support of our training strategy and to provide an opportunity for people to come together and collaborate on projects. Our first summer school took place in August 2019 with 62 attendees and the next is planned for September 2020 in Nottingham and we are expecting 80 attendees.

- Alliance Symposium
  This annual event shares the latest developments of our Uniting and Improving programmes with Alliance members and
colleagues in the HDR UK community. The first Alliance symposium took place in February 2020, celebrating the Gateway MVP launch and Hub first milestone with 140 attendees, and the next is planned for December 2020, where we are expecting around 250 attendees.

**Insight sharing days**
Our National Priority teams run bi-monthly updates to share detailed progress and updates on research initiatives, held at one of the Substantive Sites.

**Webinars**
We use webinars to broadcast information on a variety of topics, including the launch of new opportunities (e.g. Better Care, Sprint Exemplar projects), and to share bi-monthly updates on our research activities to the HDR UK community. The webinars provide a tool for people to receive consistent and timely information and an opportunity to ask questions.

**Podcasts**
To share the impact of our research with a wider audience, we produce podcasts, for example the podcast to draw out themes of the first 100 HDR UK publications.

**Newsletter**
Our monthly newsletter for the HDR UK community, HIVE, provides updates on our latest news, events and updates during the month. 1,992 people subscribe to HIVE. In the interests of transparency, anyone can sign up to receive HIVE via our website.

**Video-conferencing**
Realising the challenges of working as a federated Institute, we established Zoom as our video conferencing solution in December 2018. We provide licences for everyone in the central team, and one for each Substantive Site, National Implementation Project and Health Data Research Hub. We use 59 licences, with 220 meetings involving over 1200 participants which culminates in 780 hours taking place each week.

**B.6.2. Local stakeholder engagement and outreach**
Our Sites, Hubs and other major activities use the HDR UK brand and the communications and engagement channels, messages and updates led by the central team. All of our local stakeholders are actively engaged through the communications channels described in B.6.1.

Each Site and Hub also has its own local activity, such as websites for Hubs, local newsletters, social media channels and events, for stakeholder engagement and outreach activity. Patient and public engagement activity is reported monthly as part of our key performance indicators. Updates on other types of stakeholder engagement and outreach is shared during regular meetings with the communications leads of the Sites and Hubs.

Discussions on local stakeholder engagement – where relevant to the national strategy – also take place at a senior level at the monthly IDG and UDG meetings.

We use an online planner to schedule key events and activities, including stakeholder engagement and outreach, across HDR UK. This is shared monthly with colleagues across the Institute with a reminder to add any important activities that may be relevant to others across HDR UK. For example, events that are being organised locally or presentations at key meetings.

**B.6.3. UK-wide stakeholder engagement and visibility**
HDR UK’s leadership team are actively engaged in strategic fora for UK health data research. This is reflected in the key strategic roles that members of our community have played in national groups associated with the COVID response, including SAGE and the UKRI/DHSC rolling call panel.

As we are not associated, or located in any single research organisation, we often play an independent convening role across academic, NHS, charity and industry organisations, for example in our leadership of the development of the national health data research capability to support COVID for SAGE (described here).

We work closely with UK system leaders, for example, jointly chairing with Lord Prior, the Chair of NHSE round tables on lessons from COVID and the use health and care datasets to put the UK at the forefront of health data science.
Our key stakeholder process enables us to identify those best placed to support our mission and allows our ExCo to take a lead in developing and maintaining these relationships.

We use our CRM to log contact with people and organisations and a partnership process to report on our interactions with our strategic partners.

Examples include:

- Working closely with government departments, in particular the OLS, to ensure that ministers are kept updated and aware of the importance of health data research
- Contributing thought leadership and updates in the development of the Life Sciences Sector Deal
- Strategic partnership with NHSX to ensure that our work is aligned and complementary

In this establishment review period, while we have been setting up our research and infrastructure, we have not pursued a mainstream media campaign. Despite this, HDR UK is increasingly being seen by the mainstream media as a ‘go to’ voice on health data science.

B.6.4. International stakeholder engagement and visibility

Although established in the UK, the Institute has global ambition. Specifically, with our international engagements HDR UK aims to:

- Access the best ideas, approaches and people globally.
- Mobilise datasets at the scale needed to make discoveries.
- Enhance diversity of participants represented in datasets.
- Magnify the impact of our work and disseminate excellence to areas with pressing public health needs.
- Provide economies of scale through international participation in the Gateway and Alliance, positioning them and the UK as the leading place for health data research.
- Attract investment.

Our first venture to engage internationally is to work in partnership with the Bill and Melinda
Gates Foundation (June 2020) to develop an inclusive International COVID-19 Data Research Alliance that will work with funders, academia, industry, Governments to maintain the integrity of a trustworthy ecosystem for data sharing of COVID-19 data internationally. The primary purpose of the International Alliance is not to control data, but to provide expertise and stewardship of a trusted governance and data infrastructure that will facilitate a rapid response to COVID-19 and future Zoonotic Disease outbreaks.

B.6.4. Involvement of practitioners, public and patients

We encourage involvement and transparency across all our work programmes, to earn and build the trust and confidence of the people that will benefit from health data research. Our progress in this area includes:

- **Public Advisory Board** (PAB) – set up in January 2019, PAB is a group of patient and public representatives that provide strategic advice on our strategy and operational delivery. With almost 100 applications to the PAB, we selected members from a variety of backgrounds. Our 8 members have provided substantial contributions that have influenced and changed process, content and criteria of our work. See appendices.

- **COVID-19 advisory group** – in March 2020 we set up a virtual group of 60 patients and members of the public to advise our work on the COVID-19 response. This was promoted via existing patient groups and networks, including Use My Data, and members were attracted by the opportunity to contribute to this global challenge and working with HDR UK. In just the first week of establishing the group, 37 people provided comments on the development of an app to estimate the possibility of death based on previous health factors and this initial feedback and input has significantly altered the future focus for this piece of work.

- **Development of standards for public and patient involvement** - with input from the PAB, and 50 members of the HDR UK community at an event in November 2019, a set of draft standards were written to establish our commitment to involving and engaging patients and the public in our work. As part of our 2020/21 delivery plan these will be rolled out across HDR UK, ensuring a common commitment to public and patient involvement.

- **Practitioner involvement in Infrastructure Programme** – the importance of gaining knowledge and input from health and care practitioners in the Infrastructure programme was recognised as an important element from the start. The design and dialogue phase included a roadshow of eight events across the UK, targeted at colleagues working in health, care and academia. Following this, we have established a clinical data officers’ group to advise the Infrastructure programme on issues and potential solutions to data quality.

- **Events** – health data used for research and innovation comes from a variety of sources, but all relates to peoples’ interaction with the health and care system in some way. Our values guide our organisation of events to always question how we can involve patients, the public and practitioners.

B.6.5. HDR UK policy on attracting new funding streams

HDR UK has been very successful in attracting new funding as described in section B.2.3. This reflects the rapid development the health data science sector and the trust in our delivery approaches by these funders.
**SECTION B.7.**

**Demonstrating success**

*Over the past 18 months we have been developing how we demonstrate success, learning from others.*

HDR UK’s progress and impact review framework (PIRF) provides a balanced view of the organisation’s progress against the **vision, goals and outcomes agreed with the Core Funders and HDR UK Board**.

The PIRF provides a view of performance through three lenses:

- **Measure 1**: Outcome assessment - can the organisation show qualitative progress towards each of its desired outcomes?
- **Measure 2**: Deliverables - has the organisation delivered the tangible aspects of the agreed goals?
- **Measure 3**: Quantitative metrics (Key Performance Indicators) - can the organisation demonstrate quantified progress against its goals and desired outcomes?

This approach was developed by learning from other organisations, in particular ADR UK. The tools used to conduct these three assessments are summarised in the appendices.

HDR UK uses the PIRF to help the Institute to continually improve and increase its likelihood of achieving its goals, outcomes and vision. The PIRF is used monthly, quarterly, annually and as part of the QQR process.

**Measure 1: Outcome Assessment**

This helps us to understand how well the Institute is progressing against each of its target outcomes. The framework describes five different levels of maturity for each outcome. The Institute self-assesses against the maturity description for each outcome. HDR UK also plans to engage its International Advisory Board and Core Funders to conduct a third-party assessment using the same criteria.

This assessment helps us to describe where we currently are in our progress towards each outcome, which activities to prioritise for the year ahead, and how to align views across the Institute on what success looks like during the QQR. The outcome assessment maturity levels are described in the appendices.

**Measure 2: Deliverables**

This helps us to understand whether we have done the tangible activities that we set out to do. Each March we prioritise our deliverables for the year ahead and set these out in our delivery plan. These deliverables are selected to help us to get towards our outcomes and goals.

We use our delivery plan to plan resources, delegate activities among our team, and keep informed on what each other is working on. They are reviewed monthly and at the end of each quarter we record which deliverables we achieved during that quarter, what we didn’t achieve, and the things we achieved that we hadn’t expected to.

The delivery focus for 2020/21 and links to the QQR goals is shown in the appendices.
Measure 3: Key Performance Indicators

These provide us with a quantified indication of how well we are progressing against each of our goals. They combine ‘leading’ indicators which give us a sense of whether we are on track with future objectives and ‘lagging’ indicators which tell us whether an objective was achieved.

The appendices show the KPIs that are shared with the ExCo, IDG, UDG, Core Funders and HDR UK Board.

Using the Progress and Impact Review Framework

Performance is reported using the PIRF to the following meetings, providing a shared and objective evidence base:

- **Monthly**: KPIs to IDG, UDG and ExCo
- **Quarterly**: KPIs + Deliverables + Outcome Assessment to IDG, UDG, ExCo and Board
- **Annually**: KPIs + Deliverables + Outcome Assessment to IDG, UDG, ExCo, Board and Core Funders

Our PIRF is in its infancy. It was launched in April 2020 and we are embedding it into our governance processes. We review it quarterly and make suitable adjustments to the process to ensure it streamlined and effective. We are currently developing targets for KPIs to help us use our PIRF to its best effect. The PIRF will develop over the coming two years and we expect it to form a vital part of our QQR response.
Opportunities, challenges, risks and gaps and expected evolution to our QQR

A lot has been achieved in two years. The rapidly evolving nature of health data science, particularly in the context of COVID-19, means that there are many opportunities, challenges, risks and gaps to address that will shape our evolution to our QQR.

There are six key opportunities to draw to the attention of our funders.

1. **Sustainability of the Infrastructure in the long term**
2. **Enabling trustworthy access to data at scale for research**
3. **Scope and Scalability**
4. **National collaboration**
5. **Training and leadership development**
6. **International Impact**

**B.8.1. Sustainability of the Infrastructure in the long term**

The Alliance, Gateway and Hubs model is designed to be scalable, reliable, interoperable, secure and sustainable. Our infrastructure strategy is ambitious – it involves many partners, is fast paced, uses new technology solutions, and is striving for impact in a rapidly changing external environment. It is high risk. We have established a capable team and agile, responsive development approach to mitigate this risk. We have developed innovative methods of working including MVPs and sprints to achieve pace and responsiveness.

We see an opportunity to do even more, by working with funders to coalesce around the Gateway to enable rapid access and analysis of massive genomic and other molecular datasets, social datasets, imaging datasets and linkage to cross-UKRI and industry large-scale data research infrastructures, servicing 1000s of researchers.

**This infrastructure requires sustained support, by:**

**Funders mandating use of the existing model:**

We need funders and organisations to unite around the model to realise benefits such as more robust and streamlined data access. Funders could implement incentives, such as funder investments being conditional on participation in the UK Health Data Research infrastructure. We would welcome a discussion with funders around how these incentives can be made more explicit.

**Sustained funding for the existing infrastructure:**

The infrastructure strategy has been transformed by the ISCF investment, enabling a national, and inclusive rather than Institutional approach. However, this funding is time limited and modest in real terms. The funding completes before the end of the QQR period and so there is a funding gap.
Investment in infrastructure to meet future needs:

Whilst the value of the infrastructure is already being demonstrated, for it to become an enduring national capability, funding is needed to maintain and grow the infrastructure beyond 2022. Other national infrastructures that have received commitments of long-term investments, such as UK Biobank and the European Bioinformatics Institute are now international exemplars of best practice.

B.8.2. Enabling trustworthy access to data at scale for research and innovation

Earning public trust in the purpose and processes of accessing health data for research remains a fundamental priority for the Institute. HDR UK has positioned itself as the trustworthy independent organisation that maintains the integrity of the UK health data research ecosystem, connecting data controllers with researchers and innovators. Public engagement and involvement are essential particularly with regard to working with industry partners. We also have a dependency on policy development in this area, including health and care, digital and information governance policy set by Government and NHS organisations as well as the Information Commissioner’s Office, the National Data Guardian and organisations such as Understanding Patient Data. We need support from funders to continue to make the case to the NHS, policy makers and treasury to enable access to data for researchers and commercial organisations. This includes creating the patient and public ‘pull’ for health data research and innovation at scale. It involves aligning the research community, NHS, industry, funders and policy makers on TRE standards, Principles for Participation and other best practices that enable trustworthy access to data for research and innovation.

B.8.3. Scope and Scalability

There is an increasing availability of data at scale, and an increasing emphasis on data from sensors, wearables, social datasets and industry curated datasets. The HDR UK model is purposefully scalable and extensible and we are encouraging participation in the ecosystem according to the Principles for Participation. This includes considering participation from international and industry data custodians. We are achieving this through our ‘HDR UK in a box’ concept, with standardised components for new datasets being onboarded into the Gateway, for new Sites and Hubs joining the HDR UK community, and for new members of the UK Health Data Research Alliance. This concept will integrate into our ISO-9001 Quality Management System, allowing us to scale up and enhance our quality.

From a scope perspective, COVID-19 highlighted the absence of infectious disease as a priority in our portfolio. This was a strategic decision made on establishment of HDR UK. However, we were able to rapidly apply health data capabilities developed for non-communicable diseases to the COVID-19 response. During COVID-19, and the impacts on people as powerfully highlighted through ‘Black Lives Matter’, we saw the need for diverse data to answer urgent research questions, for example, more representative data from different ethnic groups, social care data from care homes, educational data and data from surveys and wearables. Our support in making the COVID Symptom Tracker dataset (the Zoe App) discoverable through the Gateway and securely accessible through the SAIL Databank, enabled by the Breathe Hub, has made it one of the most utilised datasets for research.

There are divergent views among key leaders, policymakers and stakeholders in government departments, NHS and Funders about HDR UK’s scope and role. This created challenges in the Hub call and is evident in the UK strategic plans for significant investment in data quality and curation, which are not as joined up with the existing significant UK Government investments (eg the Hubs) as they could be.

HDR UK acts as an independent, institutionally agnostic not-for-profit organisation to define the policies and support the development of a trusted and open health data research ecosystem. We see an opportunity for funders to build support for HDR UK’s purpose across Government and to increase the scale and scope of HDR UK to enable international leadership in health data science.
B.8.4. National collaboration

HDR UK now works with 32 research organisations across the UK. Some of the original Sites were slow to start, typically due to issues with hiring resource, and this has required us to manage a substantial underspend. This has been less of an issue for the Hubs, despite the scale and complexity of their work being similar. We believe that much of that difference was enabled in part by the structure created by the ISO 9001 Grants & Contracting process, put in place after the original Site projects were established.

Establishing National Implementation Projects and transitioning to National Priorities has helped create greater structure, and pace. And importantly, ensured that we can deliver distinctive research insights, that cannot be achieved by a single research organisation alone. However, it is more challenging to retrospectively create the delivery rigour for our original projects when expectations were not articulated at the outset of the award. Contracting structures of the original investments have made this transition and cross-Site collaboration operationally challenging to achieve:

- **FEC/non-FEC:**
  Our expenditure model is based on direct expenditure (i.e. non-FEC), however the level of understanding of this direct expenditure model amongst our higher education institution partners is low. This is compounded by the relatively small scale of investment made into each organisation leading to a limited impetus to modify local practices to accommodate our ways of working.

- **Pace:**
  We leverage the finance, operational structures and controls in our partner organisations, which are robust and well-established. Our professional leads are key to expediting local processes, however the speed of decision-making and financial data sharing is driven by institutional limits. This mismatch in agility requires active management and affects the speed at which consolidated financial and other management information is available to inform key decision making.

- **New ways of working:**
  The amount of administration resource available to HDR UK – particularly to support financial and non-financial reporting - in each organisation is limited. The re-alignment of research portfolios, financial records and systems to National Priorities has required a significant amount of goodwill to achieve and maintain.

- **Sustainability of funding:**
  The understanding that HDR UK core funding is on-going, renewable, and provides more flexibility than standard grants has been a challenge to cultural norms and requires continual reinforcement. Particularly as this way of working is almost unique when compared to most research awards that our partners manage.

- **Limitations of “Co-ordinating Research Organisation Model”:**
  We rely on the co-ordinating research organisation of each partnership, Site and Hub
to co-ordinate and communicate financial and management information across their consortia to ensure a mutual understanding. This arms-length relationship with the vast majority of our partners means the amount of direct influence that can be exerted by the central team is diminished. Moving to national priorities has exposed the rigidity of this model as all contracting and financial flows need to be directed through the Co-ordinating Research Organisations even when they are not directly involved in the projects.

**We will position our QQR around national priorities rather than geographies. To enable this the original Institute agreement needs to be reviewed to enable HDR UK to be more agile in terms of resource allocation across national priorities for greater impact.**

**B.8.5. Training and leadership development**

Our training and talent strategy aims to identify the distinctive value of HDR UK in creating the next generation of health data scientists, without trying to do it all. This is a complex environment with many stakeholders. We are learning from the experiences of our PPPIE team and the work of the Alliance and Gateway in identifying how our small central team can make focused contributions to the training landscape that builds on the work of our diverse partners. To go beyond the successful establishment the MSc, PhD and Fellowship programmes identifying the right high-impact interventions is essential.

We see leadership development in our growing community of Sites and Hubs as an important priority in the lead up to QQR. Alongside our coaching programme, we are exploring a leadership development programme to support the next generations of leaders. Our ability to scale is reliant on having leaders across all levels of the Institute that can operate in support of HDR UK values. The HDR UK Fellows have currently provide an exceptional cadre of diverse future leaders. However, the £12.5m funding for this programme completes in spring 2021, which presents a significant sustainability challenge.

**HDR UK is yet to achieve the most effective and scalable model for training and are working to refine this. We are currently exploring options to sustain the productivity and career development opportunities of future leader fellowships, however the absence of renewable funding is a significant constraint. We see this as a risk in the lead up to the QQR.**

**B.8.6 Internationalisation**

We are expanding from a national to international infrastructure model. This will involve:

- Building an international patient and public engagement approach that engenders trust
- Developing an International Alliance to align information governance, data access and data quality across international data custodians
- Developing international standards and approaches around TREs and federated analytics
- Making discoverable international metadata and capabilities through the Gateway and integrating international TREs
- Growing the Hub capabilities to enhance the quality and utility of data, we anticipate that this will involve adding new Hubs and new capabilities within the Hubs
- Capitalising on existing international partnerships throughout the HDR UK national research programmes

We have already established partnerships with high-profile global charities, research organisations and industry organisations to develop this approach. Achievement will be measured by health data research use cases that enable discoveries across international datasets.

**The strategic approach is to build a strong foundation of health data research in the UK, and then look outwards for global impact. We anticipate making significant in-roads in developing our international capability post-Establishment Review and prior to the QQR. This will increase our impact and also diversify our funding base.**