

Company Registration number: 10887014 (England and Wales)

HEALTH DATA RESEARCH UK
(a company limited by guarantee)

DIRECTOR'S REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

HEALTH DATA RESEARCH UK

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HEALTH DATA RESEARCH UK

LEGAL AND ADMINISTRATIVE INFORMATION

FOR THE YEAR ENDED 31 MARCH 2021

Directors – to 12.5.2021

Trustees and Directors – from 21

Dr Graham Spittle, CBE, Chair
Professor Sir Alex Markham, Chair of Audit and Risk Committee
Professor Sir Jonathan Montgomery, Chair of Nominations Committee – resigned 25.03.2021
David Zahn, Chair of Remuneration Committee
Professor Sir James Smith
Professor Dame Janet Thornton
Professor Sarah Harper CBE, Chair of Nominations Committee
Baroness Lucy Jeanne Neville-Rolfe
Dr Frances Rawle - resigned 12.04.2021
Lord James O'Shaughnessy
Edosa Odara – appointed 14.07.2021
Glenn Wells – appointed 14.07.2021

Company registered number 10887014

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Principal operating office 215 Euston Road
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Company secretary Amanda Borton

Bankers NatWest
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Director's Report

Foreword

The Directors are pleased to present their Strategic report for Health Data Research UK ("HDR UK", the "Company", the "Institute") for the year ended 31 March 2021.

The report provides a review of the activities and business for the HDR UK and outlines its development and performance for the financial year, the financial position at the end of the year and an outline of its plans for the future. The report also describes how the risks facing HDR UK are managed.

Strategic Report

Business and activity review

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

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

To achieve this, our strategic delivery plan, published in June 2020, focuses on our unique strengths and expertise of building a health data research infrastructure for the UK through:

Uniting health data - providing national convenorship through the Alliance and Gateway with open standards, and in a way that earns the trust of patients and the public.

Improving health data - providing tools, methods, hubs, and national expertise in health data quality improvement for researchers and innovators.

Using health data – enabling research and innovation, demonstrating novel approaches to health data use, impact at scale, and establishing an expert group of national research leaders in health data science.

One institute. We are delivering this strategy through our inclusive, team-oriented **One Institute** ethos – bringing together NHS, universities, research institutes, industry and charities – built on our values of transparency, optimism, respect, courage and humility.

Achievements and Performance

Our performance and achievements come from both work we have led and where we have enabled delivery by our colleagues across the Institute and our partner organisations.

Our commitment to Open Science in Health Data Research

We believe that open source is part of a wider open ecosystem approach that encourages open practice in multiple ways – increasing reuse and collaboration

We aim to accelerate reproducible science and maximise limited resources through open practices, such as open standards, data and access. This means we carry out our research in a transparent way, to encourage collaboration and further use of our data for new insights.

Since HDR UK was established as the national institute for health data science in 2018, we have brought together over 150 repositories of open standards, data and source code, tackling some of the most important challenges in wrangling multi-modal data and generating replicable insights. In addition, almost 90% of HDR UK publications are open access.

We believe the HDR UK community has established a strong open practice on which to foster a community of open innovation. Now we are curating the whole into an exciting, living library for the public good.

In the coming year, we will build on our work with our research software engineers, digital research technologists, academics and others to recognise and reward software development and progress our strategy to train 10,000 data scientists by 2023. We will also contribute back to existing open source platforms and investments to improve reuse and foster a community. We will make our work even more discoverable, not just in individual repositories but across cognate groups of standards, papers, code and other research outputs.

Patient and public involvement and engagement

How involving patients and the public improves our work

As a result of the COVID-19 pandemic, the use of data for health research was more visible to the public than ever before - there has rarely been a day when academic and scientific topics have not been headline news.

Involving the public in our work improves the research. It provides a focus on what matter most to patients. It also helps us to demonstrate trustworthiness and build confidence in the use of health data for research and innovation. To really benefit from working with patients, carers and the public, we encourage all teams and projects to be set up in a way that allows for meaningful involvement.

This year we have had over 22,000 patients and public contributors involved in health data research. The work of our Public Advisory Board, lay members in our Governance structure, our COVID-19 Patient and Public Involvement and Engagement Group and groups and panels set up to support the Health Data Research Hubs and research priorities, have all made a significant impact and ensured the work we do has public benefit at its core.

The HDR UK Public Advisory Board (PAB) is our 'critical friend' and has a strategic focus on work related to data access, where we know there are challenging and complex questions to be answered and a potential

risk to public trust. Over the last year members have shaped approaches to involving the public in our programmes on both a national and international scale, helped develop accessible information whilst ensuring transparency on the Innovation Gateway, and influenced the direction of COVID-19 research. Every fortnight, members have provided direct and detailed feedback on our COVID-19 reporting to the government's Scientific Group for Emergencies (SAGE) to demonstrate what is important to patients.

Public involvement and engagement has been embedded in the Health Data Research Hubs since the start, from representation on executive and scientific committees, to reviewing access requests, and involvement in the shaping of research projects. This has helped to make research more relevant, accessible, and transparent. Involving patients and the public in this way improves the validity of the outcomes and conclusions of data science and ensures public benefit.

For our research around COVID-19, the primary focus for patients and the public was to help shape our approach to data access in addition to their role in our research question prioritisation process, developing research projects and our communication. A clear example of their impact was with the development of online risk calculator – called OurRisk.CoV - to estimate the possibility of death based on previous health factors. The initial feedback and input from the group altered the future focus for this work, truly showing the value of involving patients and the public from the beginning of research projects.

The public expect a consistent and higher level of transparency over how health and care data are used and how decisions are made, at a systemic level. Our consultation with the public on vaccine research prioritisation elicited over 800 responses that demonstrated vaccine safety was the primary public concern, and this feedback has been used to inform the work of the National Core Studies.

Our Response to COVID-19

As the national institute for health data science, HDR UK has been a key part of the UK's research response to the COVID-19 pandemic.

Our strategy has been to mobilise talent and partnerships across the UK to coordinate research efforts, accelerate safe and trustworthy access to priority data and leverage the best of the UK's health data science capability to address the wider impact of the COVID-19 pandemic.

These efforts have helped with understanding the virus, clinical trials for treatments (including proving the benefits of dexamethasone for critical COVID-19 patients), symptom trackers, risk calculators and impacts on vulnerable groups, including cancer patients.

We were also able to provide regular updates and recommendations to the government's Strategic Advisory Group for Emergencies (SAGE) on prioritised health data research related to COVID-19.

Our own portfolio of research quickly pivoted to meet the COVID-19 challenge and generated actionable insights. Members of the HDR UK research community had integral roles in:

- The COVID-19 Genomics UK (COG-UK) consortium, which has delivered large-scale and rapid whole-genome virus sequencing to local NHS centres and the UK government of over 170,000 strains; including identifying the new, more virulent strain first identified in SE England.
- Mapping of COVID-19 cases in high-resolution and near real-time, which directly informed public health policy – most notably in Wales.
- Better care of patients: from debunking myths around medicines for pre-existing conditions exacerbating COVID-19 through robust health data research at scale; to understanding the impact of COVID-19 on vulnerable people with health conditions, including those with cancer and heart disease.

Our work to support SAGE

HDR UK has produced 30 concise, regular reports for SAGE to provide recommendations on research projects to prioritise and an overview of data research insights. Each report was reviewed by patient and public advisors and included their comments.

The reports were presented to a fortnightly COVID-19 “taskforce” call which, in total, engaged with 183 clinical and research leaders.

The EAVE II project and BREATHE Health Data Research Hub for Respiratory Health, led by Aziz Sheikh, produced a national data infrastructure which enabled the first whole country estimates of Oxford-AstraZeneca and Pfizer-BioNTech vaccine effectiveness by vaccine type in different age groups. The EAVE II dataset links vaccination, primary care, COVID-19 testing, hospitalisation and mortality records for 99% of the Scottish population - 5.6m people – through the Scottish National Safe Haven.

The infrastructure was developed to allow approved researchers rapid access to and analysis of data in a safe and secure way, with publication of findings within weeks of data collection.

As early as February 2021, analysis from this work showed that the Pfizer-BioNTech and Oxford-AstraZeneca vaccines reduced hospital admissions by 85% and 94% respectively (and this result was maintained for adults >80 years).

The results provided early insights that the COVID-19 vaccination is working on a population-wide level and provided confidence in the continuing roll out.

This was announced by the Prime Minister in February 2021 and influenced national regulatory strategy in the UK, Canada, Denmark, France and Germany (Lancet 2021). Data and Connectivity – supporting the research **Response to COVID-19**

In October 2020, the Data and Connectivity National Core Study was established by the government, led by HDR UK in partnership with the Office for National Statistics to support and accelerate research on COVID-19. Data and Connectivity is a “cross cutting” workstream, supporting the other five National Core Studies into key research questions by enabling streamlined, safe and responsible access to relevant datasets relevant for the pandemic.

The study is the formal continuation of the work we had already started as part of our response to the pandemic; bringing together key assets of the UK data infrastructure by working in partnership with stakeholders from across the four nations to organise health and other data on an unprecedented scale.

Working with partners across the four nations, the programme addresses the existing challenge of bringing together previously fragmented datasets and making them available for researchers to request access via the HDR Innovation Gateway.

Urgent Research Projects

In December 2020, we sponsored 12 urgent research projects following our rapid call for COVID-19 data research initiatives. Among the projects were vital research questions about the effectiveness of COVID-19 vaccines, a study of long-COVID and linked datasets to understand transmission of COVID-19 in schools.

A national linked study to understand socioeconomic inequality in COVID-19 vaccinations among elderly adults in England discovered that those groups most affected by the virus were also most hesitant to be

vaccinated. The study also highlights differences in vaccination rates by deprivation, household composition, and disability status, factors disproportionately associated with infection, providing valuable insights for public health policy and community engagement to promote vaccine uptake.

The projects will complete in Summer 2021 and are expected to leave a legacy for future research studies by enhancing the value of data by, for example, creating additional data linkages, improving the quality of data and following best practice in open science, sharing code and tools.

Impact

The Data and Connectivity National Core Study has supported 885 researchers, working on 323 research projects across a network of five national trusted research environments.

By March 2021, there were 72 COVID-19 priority datasets available on the Gateway, and vaccine data flowing to national Trusted Research Environments for researcher use.

ICODA: A global health data response to COVID-19

In June 2020, the COVID-19 Therapeutics Accelerator announced grants to HDR UK and partners to establish a new International COVID-19 Data Research Alliance (ICODA), and data analysis Workbench to support the rapid development of insights and treatments to combat the global effects of COVID-19.

Working collaboratively to unite and harness the power of health data from around the world, ICODA aims to enable discoveries to treat and prevent COVID-19, as well as co-ordinate an effective global health data response to health challenges of the future.

We offer data contributors a streamlined process to facilitate safe and responsible access to data, with rigorous data governance and access to TREs (such as the SAIL databank in Wales) and a secure workbench environment with a wide range of analytical tools. We have prioritised Driver Projects – specific research questions, bringing together a range of datasets for researchers to analyse to deliver health impact.

Driver Project 1 is a holistic evaluation of the efficacy and safety of treatments for COVID-19. Several thousand clinical COVID-19 trials are in progress globally. As these trials are evaluating the benefit/risk of potential COVID-19 treatment options, it is vital that the scientific community can interrogate this data as it emerges.

The summary level data from the most rigorous of these trials across industry, academia and government is being included in the ICODA Workbench and made available to the community of researchers. With their support, we are strengthening our collective efforts and enabling discoveries to help address this global challenge.

Driver project 2 focuses on the International Perinatal Outcomes in the Pandemic (iPOP) Study, exploring the impact of the pandemic lockdown on preterm births worldwide, including variances across countries.

Whether the pandemic is worsening or unexpectedly improving new-born health, our research is providing critical new information to shape prenatal care strategies throughout (and well beyond) the pandemic.

The iPOP Study and ICODA, recently featured in *Nature*, currently involves over 100 researchers in more than 40 countries, including 22 lower- and middle- income countries (LMICs), with access to data on 2.4m births. Together, they are leveraging the most disruptive and widespread changes of our lifetime to make rapid discoveries about preterm births.

ICODA is funded by the COVID-19 Therapeutics Accelerator, a large-scale initiative started by the Bill & Melinda Gates Foundation, Wellcome, Mastercard with additional support from Minderoo Foundation, and other donors.

Data-enabled clinical trials for profound public benefit

Routinely collected healthcare data holds the key to transforming clinical trials. However, it is estimated that fewer than 5% of UK trials between 2013 and 2018 were accessing data from health care r systems. Work undertaken by HDR UK in 2019 to improve clinical trials has supported two of the most significant scientific breakthroughs of the response to COVID-19 in 2020.

The RECOVERY Trial

In early March 2020, little was known about COVID-19 and there were no effective treatments, with around one in four patients admitted to hospital dying. The RECOVERY Trial, co-led by Martin Landray, HDR UK Research Director, and Peter Horby was set up in just nine days to test drugs against COVID-19, with over 38,000 patients now recruited through 180 hospitals in the largest randomised trial for COVID-19 treatments.

The NHS DigiTrials Hub and HDR UK's clinical trials team, led by Marion Mafham, enabled safe access to linked data from hospital admissions, discharge, treatments, deaths, and COVID-19 test results.

By June 2020, RECOVERY had identified that dexamethasone, a low-cost and widely available drug, reduced death rates. Within hours of the RECOVERY Trial team announcing its findings, England's Chief Medical Officer had recommended its use across the NHS. Its use was soon worldwide. The trial has saved hundreds of thousands of lives by identifying which treatments are effective for hospitalised COVID-19 patients.

Within a year the trial had also discovered tocilizumab as an effective treatment for COVID-19.

RECOVERY has also ruled out 4 drugs - including hydroxychloroquine - as viable treatments (an equally valuable insight).

Many findings from RECOVERY have contradicted the expectations of substantial sections of the medical and scientific community – underlining the value of large-scale randomised tests in providing a clear evidence base.

PRINCIPLE

The PRINCIPLE trial was created to discover COVID-19 treatments for people aged over 50 who are at high risk of complications, which could be taken at home quickly and therefore prevent them from needing to attend hospital. By early October 2020, the trial had registered 1,630 eligible participants; with several barriers impacting the ability to recruit more people due to the nature of the pandemic.

HDR UK enabled the use of linked datasets to identify people with a positive COVID-19 test within 24 hours from the UK's NHS Test and Trace system and Summary Care Record data, massively accelerated recruitment to 4,671 patients by 31 March 2021.

HDR UK also led the crucial public engagement to ensure patients were informed and comfortable with the recruitment process; an exercise which also helped modify and improve the process.

The work undertaken to support the trial demonstrated a new way of enhancing early recruitment to a clinical trial in a community setting and discovered that budesonide, a cheap drug, commonly used to treat asthma, can help people at home recover more quickly from COVID-19.

Using Health Data to provide better care

Our Better Care programme aims to improve people's lives by equipping clinicians and patients in the UK with the best possible data-based information to make decisions about their care.

HDR UK's Better Care National Priority, led by Simon Ball, encompasses a number of partnership programmes across the HDR UK research community, demonstrating the real-world application of the institute's work in clinical settings.

In the last twelve months the programme has expanded geographically to include two new partnership regions in the South-West, led by Jonathan Sterne and North of England led by Munir Pirmohammed.

An innovative partnership with the Health Foundation

In addition to ongoing programmes, a ground-breaking partnership with the Health Foundation has delivered three rapid research "catalyst projects", completed in 12 months.

RADAR (Risk Algorithms for Decision Support and Adverse Outcomes Reduction)

This project in North-West London, which also involved HDR UK's Discover-NOW data hub, resulted in significantly improved prediction accuracy of artificial intelligence (AI) models to provide calculated risk information for patients with diabetes.

This enabled better-informed decisions around treatment and self-management for patients so that hospital admissions are reduced. Feedback also showed a real appetite for the use of these type of tools and the desire for patients to engage more with their own data.

Using diabetes as an exemplar, this project will provide the opportunity to use real-world data for the improvement of outcomes in patients with other long-term conditions.

BREATHE – AI-driven improved clinical decision-making tools to manage a life-long chronic condition (Cystic Fibrosis)

Coordinated by Royal Papworth NHS Foundation Trust across five organisations, this project demonstrated that patients with cystic fibrosis can use a Bluetooth device in the home to frequently monitor their condition and more accurately predict future flare ups.

It also showed the enormous value of empowering patients by providing the tools they need to understand and manage their conditions themselves, creating a tailored approach to care and a reduction in the costly burden of requiring all patients to attend every clinic.

The projects validate the use of artificial intelligence and patient datasets to provide clinicians with new insights that enable improved care; and have the potential to be developed and scaled across other clinical areas.

Understanding the causes of diseases

We use health data in its multiple forms to understand the causes of disease and discover new targeted treatments rather than just addressing symptoms. Our community of experts work to advance understanding of disease prediction, causation and progression.

The overarching hypothesis is that insights into biology and the causes of disease (aetiology) can be revealed by integration of information, at scale, on genomics, other biomolecular traits, and high-resolution electronic health records. Led by John Danesh, our ultimate vision is to create new informatics infrastructures and data science methods that help achieve a deep integration of biology, biomedicine, and population health science.

Among a number of projects this year, using health data at scale, highlight the impact that our team of researchers are having in this field.

Improving public health

In many cases, the data we need to identify what contributes to poor public health already exists in GP surgeries and hospitals - the challenge is to create the infrastructure to link it all together.

Our public health theme, led by Ronan Lyons, enables data science to transform public health research through linking to data beyond health care, for example, to other government sectors, organisations, and data on environments that influence health. By linking data beyond the individual, we can better evaluate risk factors, outcomes and potential for interventions that target related individuals or groups. By enabling whole country comparisons, we inform national policy development for the UK, improving health of all.

Phenomics

Phenomics is the study of how the environment and a person's lifestyle interact with the expression of their genes to influence their health and risk of disease. Led by Harry Hemingway, our phenomics theme aims to connect data, phenomics ontologies and analytics seamlessly across the infrastructure.

The Phenotype Library

In order to study the Phenome, HDR UK researchers tap into the enormous amount of health data contained within Electronic Health Records (EHRs). They develop tools and methods to unlock this data and make it useable and useful, for healthcare professionals and the patients they care for.

These tools include the Phenotype Library, the world's largest open-access library of reproducible phenotyping algorithms for defining disease, behavioural risk factors and biomarkers in EHRs - which now has over 2000 monthly users. We pioneered NLP approaches to convert clinical notes into analysable data and have developed an open-source healthcare analytics platform (COGSTACK MEDCAT) that has been implemented across multiple hospitals internationally.

This work has led to impacts on patient care, service improvement and audit, recruitment to trials, and population research. Using this engineering, we have delivered prognostic research which has informed policy and practice, including a model and online tool for understanding excess mortality over one year during the COVID-19 pandemic.

Other highlights this year include HDR UK researchers being among the first in the world to demonstrate the near shutdown of cancer services in response to COVID-19 and its potential impact on excess mortality, which helped inform the re-start of cancer services by NHS England's National Cancer Director.

An HDR UK-led team of clinicians, epidemiologists, statisticians, data scientists and informaticians also used large-scale samples of NHS patient data to develop a simple risk calculation tool for policymakers, researchers, and the public to estimate excess deaths from COVID-19, ("OurRisk.CoV"). To date, the tool has had over 1.3 million views.

Risk calculator developed to show how underlying health conditions can affect mortality rates in COVID-19 pandemic

Researchers at University College London, University College London NHS Trust, University of Cambridge and HDR UK collaborated to find out how underlying health conditions could affect mortality rates during the COVID-19 pandemic. The study revealed that having an underlying health condition, such as heart disease or diabetes, increases a person's risk of death fivefold over the next year. We developed a prototype online risk calculator – called OurRisk.CoV – showing how age, sex and underlying health conditions can affect mortality rates depending on varying rates of infection within the population and varying overall impact of the COVID-19 pandemic.

CogStack

CogStack is a platform to support open-source healthcare analytics within the NHS and represents a major advance in the capacity to extract and analyse unstructured data from electronic health records (EHRs). It operates in near real-time and is user-friendly, allowing data to be accessed by asking straightforward questions. It can be used for everything from large-scale research and business intelligence to planning patient personalised care.

It has been used for successful projects including: large-scale research investigating the effectiveness of the NEWS2 hospital early warning score system to predict 14-day outcomes for the most seriously ill COVID-19 patients; improving the safety of prescribing Methotrexate for rheumatology patients; improving the use of the antipsychotic medication Clozapine; and identifying outpatient orthopaedic procedures missed by manual coding – leading to annual NHS Trust revenue gain of over £1.25m a year.

Applied Analytics

Through our Applied Analytics theme, led by Dave Robertson, we match knowledge of analytical tools, such as machine learning and artificial intelligence, with large-scale health datasets to show their potential to inform health and care delivery. We help the right people to gain access to the data they need, in a way that protects the data, maintains patient anonymity, and allows innovation.

To date, our Applied Analytics researchers have produced 173 publications, seven open-source software tools and two databases. They have also delivered fundamental national data engineering to support prognostic research, which in turn has informed policy and practice, including through participation the FDA's Clinical Trials Transformation Initiative guidelines on mobile technologies in clinical trials.

An example of how Applied Analytics successfully pivoted to provide insights into COVID-19 is the analysis of text written by doctors being used to find and extract patterns and hidden nuances within medical notes of those who have tested positive for COVID-19.

It found that people taking ACE inhibitors (medicines used to treat high blood pressure or diabetes) were no more likely to experience a severe form of COVID-19 than those who did not take them. This work was also featured in a Statement of Opportunities from UKRI – “Transforming our world with AI”.

National Implementation Projects

Sharing resources such as code and algorithms increases reuse and lends to quicker, more efficient science and collaboration. Our National Implementation Projects are “jewels in the crown”, bringing together leading experts from across the UK to create the tools and technologies needed to generate new knowledge from health datasets.

National Reproducible Machine Learning Project

The project, led by Aiden Doherty, Chris Holmes and Martin Landray, is bringing together data science, machine learning, health data from wearables, and reproducibility with the aim of harnessing their power to provide trustworthy clinical insights.

To improve standards, robustness and reporting of machine learning methods, as well as promote a culture of reproducibility to emerging health data scientists, a draft paper proposing reporting guideline protocols was submitted to BMJ Open.

We are investigating the potential of synthetic datasets as a way of providing research data while protecting patient privacy. In addition to progressing this work on synthetic datasets, the team is also exploring the development of tools to support reproducible machine learning as a way of supporting UK health data scientists working restrictive safe haven environments.

National Phenomics Resource

The project, led by Spiros Denaxas, is developing new tools to help analyse electronic health records (EHRs), maximising their benefits by advancing the creation of phenotype algorithms to identify disease status, onset and progression.

The scoping and prototyping of a phenotype library (a comprehensive, open-access resource providing researchers with information, tools and phenotyping algorithms for UK electronic health records) has made substantial progress. By the end of the year, the HDR UK Caliber phenotype library had 353 phenotype algorithms and another 569 been processed; with more to be added in the coming year.

All of the executable forms of Caliber (and other) phenotypes are now online, can be downloaded and executed against a user's own datasets. This represents major progress towards creating the default phenotype reference point for academia, clinicians, industry and guidelines for community that are trustworthy and transparent.

National Text Analytics Resource

This project, led by Richard Dobson and Angus Roberts, is pioneering the greater use of information stored in electronic health records (EHRs) to help tailor treatment for individual patients and for better, safer healthcare.

Text analytics is already improving research, hospital service planning and clinical decision making in areas such as severe mental illness, multimorbidity and cancer, as well as being used for COVID-19.

One exemplar is a clinician-led project which created dashboards for care teams to use text (and other) analytics for patients on a day-to-day basis. In a mental health trust this would, for example, allow a doctor to gather valuable information ahead of a patient's psychosis medication review, or for a team to liaise with local GPs on patients they share or to look at wider population groups.

To promote sharing and open access, 95 tools have been made available through the HDR UK Innovation Gateway; and a set of GitHub resources, providing more detail on implementation has been made available. Conversations are underway with NHSX for improving data collaboration and on developing the sustainable models for the new technologies.

National Multimorbidity Resource

Led by Colin McCowan, the team is bringing together six datasets with anonymised information on over 10 million people to improve care by discovering more about what illnesses are found together, how they develop as people age and which cause the most problems. This is already yielding results, for example in work to identify clusters of multimorbid conditions that seem to be associated with hospital or care home admission.

Led from Swansea and working closely with the Chief Medical Officer in Wales, analysis has been provided for the Welsh Government Technical Advisory Group (and comparable work has been taking place in Scotland and England).

Addressing a major challenge that multimorbidity is measured in many ways, the team also undertook the largest review of its kind to analyse different definitions and recommend a set of common measures. The paper, published in Lancet Public Health, represents a major milestone in moving to standard definition for research.

National Multi-omics Consortium

The project aims to create a platform that will allow researchers to interrogate the multi-omic data in order to better inform disease aetiology and prediction.

Led by Adam Butterworth the consortium is successfully bringing together a dozen cohorts (c.800,000 participants) from around the UK that have common information – genetic, genomic, linkages to EHRs and multi-omic. This work has contributed to phenome-wide association studies to identify >100 causal effects between 65 proteins and >50 disease phenotypes, with implications for prioritising therapeutic targets. By combining population-based studies across 174 metabolites and 85,000 participants that identified genetic regulators of human metabolism and health, we have provided proof-of-concept for cross-platform 'omics data integration.

So far the work has led to a set of powerful research outputs and insights:

- A paper published in Nature Genetics combining data from several of the cohorts while using different platforms for capturing metabolites.
- A paper in Nature Medicine has resulted from the consortium's work in linking analytes with health outcomes – specifically looking at metabolomics platforms versus hospital derived phenotypes.
- A paper Nature Medicine, following work to use proteomic and transcriptomic data to identify causal factors related to COVID-19 outcomes.

Work has also taken place on using genetic data from two cohorts to predict blood cell traits with the aim of developing a reproducible predictor that could be taken into other cohorts.

HDR UK learning - attracting and developing talent

As the national institute for health data science, a key part of our mandate is to develop the next generation of health data scientists and provide high-level training for those seeking to advance in the sector.

During the year we made substantial progress with our talent and training programmes. To date, we have provided training for **6,074** health data against our target to have trained 10,000 health data scientists in five years.

A key driver of success (especially given the accelerated transition to digital and virtual learning as a result of the pandemic), has been the ability to increase our visibility and reach relevant audiences for through digital marketing, an enhanced web presence, social media promotion, a dedicated newsletter, as well as a new identifiable brand identity for the programme.

Short courses

In June 2020, there were **80 attendees** at our summer school. We anticipate that by the end of our first five years as an institute, over 250 people will have attended our summer schools and other short courses, such as a health information engineering bootcamp for 30 delegates, planned for next year.

Masters

Our seven newly created master's programmes, delivered in partnership with six leading universities across the four nations (Exeter, London School of Hygiene and Tropical Medicine, Leeds, Queens University Belfast, Bristol and Cambridge), commenced in September 2020 with 76 students.

The programmes provide the best possible foundation for careers in health data science and will be delivered across four cohorts (2020-2024), provide over 300 talented students the opportunity to pursue a master's degree and career in health data science.

In addition, we have also funded 10 master's students in Scotland via DataLab, Scotland's Innovation Centre for Data and AI.

PhD programmes

Our flagship HDR UK/Turing Wellcome PhD programme, led by Christopher Yau, delivered in partnership with 7 leading universities will provide studentships for circa **32** people over 8 years (2020-2028). The first cohort of 7 high-calibre students commenced the PhDs in September 2020. The second cohort will comprise 11 PhD students, including 2 funded by the BHF Data Science Centre, our partnership programme with the British Heart Foundation.

Our future focus is enriching the programme through a bespoke industry-led leadership development, growing industry investment in internships, and further embedding the programme within HDR UK strategic priorities.

Fellows

The HDR UK Fellowship Programme concluded in February 2021 and has developed a new generation of 46 leaders in the field. Our 46 UKRI Innovation Fellows and UK HDR Rutherford Fellows, all received expert-led high-level career development through the Fellows Incubator run in partnership with the National Institute for Health Research (NIHR) Academy. They also pursued their own research agendas, built up new networks and established fresh collaborations with other groups or individual researchers.

With the three-year fellowships complete, there is clear evidence of their contribution to advancing knowledge through high quality research, in guiding policy, engaging a wide audience, and increasing recognition. Due to the programme, Fellows have:

- leveraged £3.6 in further funding for every £1 invested – from different sectors and internationally.
- had their publications cited over 9,000 times.
- been recognised for their achievements 39 times - as keynote speakers, through honorary positions, research prizes, and honours such as L'Oréal UNESCO Women in Science fellowship.
- reported over 100 collaborations spanning 20 countries and including representatives from academia, hospitals, industry, and more.
- influenced policy 31 times, both nationally and internationally, including through membership of key advisory committees such as SAGE and SPI-M.
- reported 143 engagements including presentations, working groups, press releases etc., of which 44% were international.

Fellows' publications are typically cited around five times more than others in same field. One paper on the Early dynamics of transmission and control of COVID-19: a mathematical modelling study has been cited over 1,100 times.

A digital learning platform for the health data science community

In May we launched HDR UK Futures – our new virtual learning platform which provides the core infrastructure for all of our training. It is a key enabler for our training portfolio allowing us to build training at scale and to structure, manage, track and deliver learning activities and content both online and face to face. It also supports our commitment to facilitate the community to collaborate regularly, to share information, improve their skills, and actively work on advancing health data science.

To-date **520** people have registered for the platform, which contains a library of carefully curated on-demand online resources that will be regularly refreshed and updated. There are **15 live modules** with a further **100+** in production.

Internships

In addition to the Black Internship Programme HDR UK has also directly provided two year-long internships within the central HDR UK team, supporting the development of the Innovation Gateway, and providing interns with a multitude of new skills and practical experience which will position them well for a permanent job in the sector.

Uniting Health Data

UK Health Data Research Alliance

Collaboration in practice

To help address important health challenges faced in the UK through trustworthy research and innovation, HDR UK convenes the UK Health Data Research Alliance (the "Alliance") to establish best practice and accelerate responsible access and use of health data.

In a year that has united science to deliver some of the greatest collaborative research and discoveries of our lifetime, the Alliance has been a driving force for this approach, bringing together multiple health and research organisations to work in partnership to create a national, federated and co-ordinated approach to health data research infrastructure.

This year has seen continued progress across key workstreams:

- Promoting participation across the sector; encouraging research organisations and custodians to join and build the partnership
- Aligning data standards and quality across the UK, including metadata standards
- Developing a common approach to Trusted Research Environments (TREs) to enhance the researcher experience and provide confidence to data custodians
- Engaging practitioners, patients, and the public (including improving the “plain English” explanations of our work)
- Supporting the development of the Gateway as the platform for researchers to discover and request access to health datasets

Making the case for Trusted Research Environments (TREs)

The UK Health Data Research Alliance (the ‘Alliance’) is committed to an approach to data access based primarily around Trusted Research Environments (TREs); with appropriate robust and independent accreditation, monitoring and auditing.

In July 2020, the Alliance published a comprehensive Green Paper, making the case to use on TREs which, by design, protect the privacy of the individuals’ data they hold, while facilitating the large-scale data analysis which will lead to discoveries and insights that improve healthcare.

Adopting an approach using a network of TREs across the UK would be a way of addressing public concerns and enhancing public confidence in the use of health data for research. The Alliance will continue to make the case for TREs as a vital component of the ecosystem, working on common standards and processes for them to be most effective.

Streamlining data access

The COVID-19 pandemic highlighted the existing need to accelerate access to health data to ensure better and faster research. One solution advanced by the Alliance in the last 12 months has been to work together to standardise and align data access processes across organisations.

In a pilot scheme launched this year, streamlining data access across some data custodian organisations and using a standard data access request form has already made it easier for both researchers and custodians to submit and respond to access requests. Working towards a fully digital, automated end-to-end system has also made the process more efficient for data custodians and researchers.

The universal adoption of the Office for National Statistics’ Five Safe framework provides a gold standard guide for both researchers and custodians to meet the principles of transparency, safety and privacy throughout the data use cycle, from research concept inception to data analysis and insight dissemination. Commitment from all custodians to this common framework is crucial to design standard processes and a proportionate approach.

Building alignment across custodians is helping to enable easier and faster access to UK health and social care data for research in the long term. It also demonstrates the members’ commitment to open access to health data for use in research and ultimately leading to discoveries that will benefit patients.

Growing our Alliance

More than 50 of the UK's NHS, charity and research organisations have joined the Alliance since its formation in February 2019.

During the year, the BHF Data Science Centre, Imperial College [Neonatal Data Analysis Unit](#), [Oxford University Hospitals NHS Foundation Trust](#), COG-UK and Pathlake, [University of Dundee's Health Informatics Centre](#), ICNARC, [Imperial College Healthcare NHS Trust](#), HIC Dundee, [Leeds Teaching Hospitals NHS Trust](#), [QResearch](#), Oxford Health, [The Renal Association](#), [National Consortium of Intelligent Medical Imaging](#), [NIHR Clinical Research Network](#), [Generation Scotland](#), [Public Health Scotland](#), [University Hospitals Bristol](#) and

As Trusted Research Environments become an increasingly important part of our landscape, we will continue to work with partners to develop the common standards necessary for them to be a consistent and effective tool.

12 months of the Gateway – The UK's portal for data discovery and tools for research

Despite progress in technology, the discovery of and safe access to health datasets remains a critical challenge for researchers.

In 2020, the Health Data Research Innovation Gateway (Gateway) was launched as a cornerstone of the UK Life Sciences Industrial Strategy. For the first time, it offers a single front door to discover UK health data, on a journey to streamlined and harmonised access management, across the four nations of the UK.

This year, the Gateway has reached over 1,100 registered users, 16,000 monthly searches and information about over 640 UK and international datasets listed in its 'library'. This covers a breadth of data including primary care, secondary care, palliative care, biobanks and research cohorts. The Gateway is becoming the "go to" place for researchers to discover and request access to UK health datasets, with the added benefit of giving much-needed transparency to the UK public on what data is available and how it is used. The Gateway is at the heart of making open science a reality; so far, 150 tools, 269 projects, and 1146 papers, are available and these are growing daily.

The Gateway has been a key enabler in responding to COVID-19 by providing the UK research community with a single platform to access information about datasets relevant to the pandemic and a means to request access to these. During the year, access to key datasets was accelerated, including those relating to vaccine effectiveness and identifying potential risk factors associated with the vaccines. It also continued to support research on other priority areas, including cancer and heart disease.

Highlights from this year include:

- Launch of a Cohort Discovery Tool with our partnership with CO-CONNECT to enable, for the first time, researchers to search across datasets to find cohorts of patients with specific, defined characteristics; opening up huge potential for increased discovery.
- Integration of a Common Data Access Request form management process that is compliant with the Office for National Statistics' Five Safes framework.
- Rapid onboarding of information about over 70 datasets relevant for COVID-19 research, which are being safely accessed by the Government-led National Core Studies.
- The Gateway became a key part of the fortnightly COVID-19 reports submitted by HDR UK to the government's Scientific Advisory Group for Emergencies ("SAGE").

HDR UK's Public Advisory Board and other patient representatives are involved in the shaping and development of the Gateway. Their input has challenged developments that may cause concern to the public and has helped develop content about the Gateway that is accessible to the public. As with many other organisations, the pandemic also forced a transformation on our ways of working.

It has facilitated 265 requests to access health datasets, in particular actively supporting the government's National Core Studies into COVID-19 ("Data and Connectivity").

BHF Data Science Centre

Launched in January 2020 as a partnership between HDR UK and the British Heart Foundation, the BHF Data Science Centre enables responsible, ethical research that combines the power of advanced analytic methods with the UK's large-scale and diverse cardiovascular data.

The BHF Data Science Centre works with patients, the public, clinicians, researchers and NHS organisations to help them carry out research into the causes, prevention and treatment of all diseases of the heart and circulation.

Creating the UK's largest linked health data research asset

A significant initiative this year has been the CVD-COVID-UK consortium, a NIHR-BHF flagship project which was set up to understand the relationship between COVID-19 and cardiovascular diseases.

Patients with cardiovascular disease are at increased risk of developing COVID-19 and of poor outcomes of COVID-19, such as admission to hospital or intensive care, or of dying. This could be due to cardiovascular conditions themselves, their risk factors, medications, or combinations of these.

At the outset of the pandemic, researchers were unable to access national, linked health data across the whole UK population to carry out analysis that would support healthcare and public health policy.

To solve this challenge, the BHF Data Science Centre developed a new trusted research environment (TRE), in partnership with NHS Digital, providing researchers with secure access to linked health data from primary and secondary care, registered deaths, COVID-19 laboratory and vaccination data and cardiovascular specialist audits.

This data set covers 96% of the population of England (>54m people), with similar linked data made available for Scotland and Wales (>8m people). Through the CVD-COVID-UK consortium, over 200 researchers from 41 UK research organisations, are for the first time analysing linked health data on over 60 million people to address COVID-19 related research questions.

The ability to link different types of health data across the UK population provides a more complete and accurate picture of the impact of the virus on patients with diseases of the heart and circulation than has been possible before now. It also provides the data to understand whether patients with COVID-19 are more likely to go on to develop diseases of the heart and circulation, such as heart attack and stroke.

All protocols, code and analysis is available in the public domain via the BHF Data Science Centre webpages, the Gateway GitHub repository, and open access publications.

Exploring 'False Positive' tests

Testing for COVID-19 infection in populations where active infection is very uncommon will result in some false positive test results. This is where people who do not have infection receive a positive test result, when it should be negative.

In August, Cathie Sudlow, Director of the BHF Data Science Centre, developed a simple interactive tool to help people to understand the problem of incorrect test results.

Improving Health Data

As we work with our partners to unite the vast quantity of health datasets that exist across the UK and make them safely and responsibly available for health research, there becomes a growing need to be able to define, categorise and curate that data.

As the organisation responsible for uniting health data in the UK, we have developed a Data Utility Framework as a way to do this. This is the first time this has been done and represents a huge development in the way we think about datasets. It aims to help researchers from academia, healthcare and industry to make more sense of the increasing data resources available to them.

The new framework shows the usefulness of data for research. It has over 100 datasets evaluated against it and is now integrated into the HDR Innovation Gateway. To support users in identifying in advance whether a dataset would be suitable for their specific purposes, we developed the framework in partnership with users and data custodians.

This year, the framework was used to track the improvements in data of accessible through the Health Data Research Hubs. Throughout the pandemic, the Hubs utilised their rich data sources to support areas of analysis that included infection rates, vaccine roll-out, and to understand the impact of COVID-19 on specific disease areas. Collectively the Hubs drove significant improvements in data, guided by our data utility framework, particularly in the richness of metadata, pathway coverage, and data management processes.

The Hubs were tasked with improving the data that they hold to enhance its research potential. To review the data improvement over the past 18 months, we created the new and innovative data utility framework to gather baseline information at the Hubs' first milestone (December 2019) and compared this with improvements made by the second milestone (March 2021). This was the first opportunity to use the framework not just for guiding users but for reviewing the improvements made to datasets.

Other organisations in the UK, such as NICE and NHSX, are looking to adopt the framework, and it is currently being tested internationally.

Building real-world partnerships through the Health Data Research Hubs

This year, the seven original [Health Data Research Hubs](#) reached their [second milestone](#) – at 18 months since inception – where they were recognised for the quality improvement of their datasets, the impact of their data, and engagement with patients and the public.

Since launching, the Hubs have made 157 datasets - from genomic data to clinical and public health data – discoverable on the Gateway. They have delivered over 300 projects involving hundreds of partners, over 20,000 meaningful patient and public interactions, and 2,300 training activities.

Our report [Improving UK Health Data: Impacts from the Health Data Research Hubs](#) shows how the Hubs have informed UK policy decisions on the effectiveness of COVID-19 vaccines, created tools to improve

clinical decision-making in the management of patients with vascular disease, and supported research in cancer, heart disease and hospital care pathways by linking routinely-collected data.

Highlights from the Hubs include:

- [NHS DigiTrials](#) enabled the RECOVERY trial – the world's largest successful clinical trial on COVID-19 therapeutics to date. They delivered health outcomes datasets and smart trial design to determine the success of [Dexamethasone](#) in reducing mortality for patients with severe COVID.
- [PIONEER](#) led rapid analysis of real time data to discover an increase in venous thromboembolic events (VTE) associated with COVID-19.
- [BREATHE](#), through the citizen science [COVID-19 Symptom Study](#), in partnership with ZOE and Kings College London, urgently provisioned data on COVID-19 symptoms to a range of users, which fed into local and national responses to the pandemic and supports 54 live projects.
- [Discover-NOW](#) linked COVID-19 testing data with all haematology, biochemistry, immunology, microbiology and therapeutic monitoring results for the 2.5m patient records available via their hub
- [DATA-CAN](#)'s analysis of real-time hospital cancer services was shared with the UK's four chief medical officers, the National Clinical Director for Cancer for England and SAGE, contributing to decisions to restart cancer services.
- [INSIGHT](#) provided the first reliable estimates of the scale and severity of the vision loss arising from delays in treatment for newly-diagnosed 'wet AMD' during the COVID-19 period, informing NHS providers on strategies to optimise care of patients during service recovery
- [Gut Reaction](#)'s key partner, the IBD Registry, developed a COVID-19 IBD Risk Tool in just eight days, to allow patients to self-assess their risk of being infected with COVID-19.

One Institute

Tackling the under representation of Black people in the science community

The Black community is heavily underrepresented in the science, technology, engineering and maths (STEM) community, with only 65 Black and 310 mixed and other individuals making up the total of 10,560 science professors in the UK.

The COVID-19 pandemic also highlighted the disparity of COVID-19 infections and its effects on different ethnic groups. In December 2020, we launched an internship programme to create better representation within the health data science communities by creating more opportunities for those groups to be involved in this vital work.

Through partnerships with the UK Health Data Research Alliance and the 10,000 Black Interns initiative – which is designed to transform the prospects of young Black people in the UK – we recruited 54 interns, including over 30 women, to the programme.

The programme is providing paid work experience to future data scientists, with the internships taking place across 25 of our partner organisations. These include the BHF Data Science Centre, Big Data Institute, National Institute for Health Research Clinical Research Network, prominent national charities, data science hubs housed at a number of higher education institutes, university hospitals and NHS trusts such as Guy's and St Thomas', The Royal Wolverhampton and Barts Health.

Starting in Summer 2021, these six-week placements include activities such as conducting research and developing health data analysis, learning about the latest approaches and technologies in the field, collaborating with teams and communicating results and ideas to stakeholders.

Supporting a growing team

In the year to 31 March 2021, the number of staff in the Central Team of the organisation grew rapidly, largely to meet the additional capacity required to support the organisation's phenomenal response to COVID-19.

Through the second and third quarters of the year, this growth was undertaken as a dedicated and intensive recruitment campaign for 45 separate, new roles each recruited through an open competitive process.

In total there were 1,589 anonymised applications for these roles leading to 139 interviews with an acceptance rate of 89%, including three candidates from within the existing Central Team.

To support the growth in new staff, we put in place new initiatives, including:

- Focus on wellbeing and supporting staff and managers throughout the pandemic, all of whom were working from home.
- A bespoke, in-house two-day induction and training programme ("TORCH") for all staff, taking a design based on management consultancy training, to increase overall skills and performance across the organisation.
- Launched a new virtual learning system which hosts a curated curriculum designed to increase skills in project management, leadership, coaching, and builds more technical understanding in health data research areas.

In turn, the Central Team has provided additional support, guidance and capacity to successfully steer the Alliance, our research community and growth in our programmes, as detailed through this report.

As we continue to develop, there will be further focus on putting in place the organisational and operational systems to support this growth, including:

- Enhancing our ways of working as staff return to working in the office.
- An internal secondment programme aimed at supporting employees to grow their careers at HDR UK with opportunities to lead and manage new programmes
- A new management development programme.

Communications and engagement

Activity and impact of the Communications and Engagement team also substantially increased in the year, with a large focus on supporting the organisation's response to the COVID-19 pandemic.

The organisation hosted over 20 of its own conferences and events, including the One Institute event in June 2020, one of the first major scientific conferences of the pandemic, with over 900 registered attendees and featuring Sir Patrick Vallance, the UK government's Chief Scientific Adviser as keynote speaker.

Likewise, our communications output and reach increased because of work on the pandemic, the wider growth in the institute's programme of activities and key role it plays convening and collaborating partnerships across the sector.

In the 12 months to March 2021, the organisation published 25 press releases and news stories and over 50 case studies showcasing the best research from the HDR UK community. There were nearly 2,500 mentions of HDR UK in the media and by the end of the year, there was an average of over 20,000 website users per month.

Reach and engagement on social media has also substantially increased, due to an increased focus on the quality and quantity of content on both Twitter and LinkedIn.

In the coming year, the organisation will continue to use our communication and engagement channels, working with partners, patients, and the public to improve understanding of our role, brand awareness, as well as continue to demonstrate the impact of the institute to key stakeholders.

Funding sources

Financial summary

Our funds support long-term scientific and research studies, training and infrastructure that contribute to data science at scale, support our One Institute approach and deliver long-term impact for the health of patients and populations across the UK.

HDR UK's activity across our strategic priority areas has continued to generate significant interest from funders. We also raised thematic funding to support specific programmes of work, including our work to support the research response to COVID-19.

Funds used for expenditure in 20/21 were awarded by HDR UK Core Funders, Industrial strategy challenge, UKRI Data and Connectivity, Medical Research Council, International funders and others.

In the final part of the year, we concluded the work for Health Data Research UK to become a registered charity (no. 1194431), which came into effect on 12 May 2021.

More information on HDR UK's performance and achievements during 2020/21 can be found in the Annual Review.

Plans for future periods

Using Health Data

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

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

We will achieve our aims through:

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

In 21/22 we are focussed on:

- New high-impact outputs and innovations from national priorities, demonstrating our distinctive approach, including the impactful cross-national priority and cross-disease approach
- Training 5,000 cross-sectoral health data researchers 2-3 high-impact driver projects that harness the value of industry
- International driver projects (part of ICODA) that guide principles and best practice for international uses of data

Uniting Health Data

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

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

We will achieve our aims through:

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

In 2021/22 we are focused on:

- Gateway services (convenience, speed of access, metadata, concierge) – use of these services, happy customers & a vibrant ecosystem of partners built on patient, public and user involvement
- Federation across national Trusted Research Environments for specific uses
- Breadth of relevant datasets.
- Availability of Industry datasets through partnerships
- Diversity of datasets to ensure an appropriate representation of the population.

Improving Health Data

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

We will achieve our aims through:

- Tools and methods to measure and improve the utility of data discoverable through the Gateway, including applied analytics and the human phenome
- 8-10 Health Data Research hubs improving the data

In 21/22 we are focussed on:

- Evidenced improvements to data and more linked data assets on the Gateway with accessible descriptions that are being used to meet national priorities and policy.
- Developing data engineering capability to get data onboard, link it and improve it.
- Embedding data utility, TRE and federation standards

One Institute

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

We will achieve our aims through:

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

In 21/22 we are focussed on:

- Joined-up brand strategy to unite the different components (Alliance, ICODA, Gateway, hubs, training), promote partners and reach public and research communities
- Quinquennial 2 vision, financial strategy and organisation development in place to achieve it

More information on HDR UK's future plans is available in the strategy section of the website

<https://www.hdruk.ac.uk/about-us/our-strategy/>

Financial review

Funding

Core funding

Our founding funders have jointly invested in Health Data Research UK: the Medical Research Council (MRC); the health research departments of England, Scotland, Wales and Northern Ireland (National Institute for Health Research (NIHR), Chief Scientist Office (CSO), Health and Care Research Wales, HSC Research and Development respectively), the Economic and Social Research Council (ESRC), the Engineering and Physical Sciences Research Council (EPSRC), Wellcome, and The British Heart Foundation ("Core Funders").

During 2018/19 the Core Funders agreed in principle to provide £52.7m funding to HDR UK in the 5 years to March 2023. Core (unrestricted) funding received during the year ended 31 March 2021 was £11.5m (2020: £6.2m). In respect of this funding the Company incurred expenditure on staffing, grants and other costs of £11.6m (2020: £6.2m). Core funding cash payments are paid in advance, and £14m is included in income in advance on the balance sheet (2020: £10.0m).

Restricted funding

Restricted funding is received primarily in respect of HDR UK's Uniting Data, Using and Improving Data activities:

- UK Research and Innovation's Industrial Strategy Challenge Fund in support of the Digital Innovation Hub Programme (2021: £5.3m, 2020: £1.3m)
- UK National Core Studies: Data & Connectivity programme funding to support the five National Core Studies established by the government to answer key research questions on COVID-19 (2021: £4.4m, 2020: £nil)
- Medical Research Council funding in respect of capital investments (2021: £4.0m, 2020: £2.0m)
- COVID-19 Therapeutics Accelerator funding in support of the International Covid-19 Data Alliance and data analysis Workbench (2021: £1.3m, 2020: £nil).
- Other charitable expenditure is funded by other funders, or through cost sharing with HDR UK's collaborative partners.

Grants

HDR UK provides long-term awards to research organisations with a track record of excellence in health data science.

Substantive Sites, National Priorities and Health Data Research Hubs

HDR UK has agreements in principle to provide £30.9m funding in the 5 years to March 2023 to the six founding HDR UK sites. Each Substantive Site has a co-ordinating research organisation (RO) and a variable number of associate ROs. The co-ordinating RO is accountable to sub-contract with its associate ROs to ensure delivery of the Institute's objectives.

The Substantive Sites are

- HDR UK Cambridge (Sanger Institute; University of Cambridge, European Bioinformatics Institute),
- HDR UK London (UCL: QMUL, LSHTM, Imperial College, Kings College)
- HDR UK Midlands, University Hospitals Birmingham NHS Foundation Trust: University of Birmingham, University of Leicester, University of Nottingham, University of Warwick
- HDR UK Oxford,
- HDR UK Scotland (University of Edinburgh: Universities of Glasgow, St Andrews, Aberdeen, Strathclyde, Dundee)
- HDR UK Wales & Northern Ireland (University of Swansea: Queen's University Belfast),

Each site contributes to one or more of HDR UK's six National Research Priorities and participates in HDR UK's national implementation projects. These projects are embedded in the national research priorities and delivered by teams across four, five or six sites to deliver research which no single institution would be able to achieve.

HDR UK also has agreements in principle to provide £2.4m funding in the period to from April 2020 to March 2023 to two further HDR UK sites:

- HDR UK North (University of Liverpool: Bradford Teaching Hospitals NHS Foundation Trust, County Durham and Darlington NHS Foundation Trust, Lancaster University, The Leeds Teaching Hospitals NHS Trust, University of Leeds, Liverpool University Hospitals NHS Trust, University of Manchester, Northern Health Science Alliance, Newcastle upon Tyne Hospitals NHS Foundation Trusts, Newcastle University, Salford Royal Foundation Trust, University of Sheffield, South Yorkshire and Bassetlaw Integrated Care System, Wirral University Hospital NHS Foundation Trust)
- HDR UK South-West (University of Bristol; University of Bath)

These sites are focused on HDR UK's Better Care national research priority.

HDR UK has agreements in principle to provide £2.1m to Health Data Research Hubs, PIONEER and NHS Digitrials.

In 2021 HDR UK funded £8.3m site and national implementation project expenditure (2020: £4.4m). £1.5m Health Data Research Hub expenditure was funded (2020: £0.2m).

A further £1.9m (2020: £0.5m) restricted grants were awarded to HDR UK sites and Hubs in relation to capital investments.

Training Programmes

HDR UK has agreements in principle to provide £6m funding in the period to 2024/25 in relation to the HDR UK-Turing Wellcome PhD Programme in Health Data Science, and to provide £2m funding in the period to October 2023 in relation to the HDR UK Masters programmes.

In 2021 HDR UK funded £184k PhD Programme expenditure (2020: £0) and £391k Masters programmes expenditure (2020: £0).

National Core Studies: Data & Connectivity Programme

As part of the National Core Studies: Data & Connectivity programme, in 2021 HDR UK provided £3.1m (2020: £nil) grant funding to four partners to deliver streamlined access to a variety of health and administration data via five secure Trusted Research Environments across the four nations: NHS Digital, SAIL Databank, Scotland National Data Safe Haven and Northern Ireland Honest Broker Service. A further £1.7m of grant funding has been agreed for Data & Connectivity rapid research projects, of which £110k expenditure was funded in 2021 (2020: £nil).

Reserves

The Core Funders are committed to funding costs incurred by the Institute, with regular funding throughout each financial year in advance of expenditure. By the nature of this model, there is no need for significant reserves. However, the Directors are satisfied that there are sufficient arrangements for the provision of funding for the Company to continue to operate for the foreseeable future. This is based on the requirement for the Company to present forecasts to the end of the current funding period so that comfort can be gained that all anticipated costs are manageable with agreed funding

As at 31 March 2021 total unrestricted reserves were £229k (2019/20: £137k) and total restricted reserves were £nil (2019/20: £nil).

Risk management

HDR UK's vision and strategy are ambitious, and there are risks to successfully achieving HDR UK's ambition. Risk management is the responsibility of all members of HDR UK's community and is embedded into the annual strategy planning process. Risks identified are recorded in the risk register which is reviewed and updated monthly by Executive Management.

Our risk management 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; and
- Embedding a continuous improvement and learning culture that ensures we learn from the small incidents and 'near misses' to reduce the likelihood and severity of large-scale incidents.

These risk management processes are part of our ISO9001 certified quality management system.

HDR UK is exposed to risks and uncertainties. These risks, and the actions taken to manage these, are reviewed on a quarterly basis by the Audit and Risk Committee and the Board.

A principal concern of HDR UK is to appropriately respond to the significant growth in health data science activities in response to the COVID-19 pandemic. HDR UK is managing this response through existing and new partnership arrangements, ensuring sufficient and appropriate resourcing is in place, and through exploration of additional funding to support sustained growth.

Structure, Governance and Management

Status

HDR UK is registered as a Company limited by guarantee, set up in July 2017. Registered charity status was awarded on 12 May 2021 (registered charity number 1194431). At this date the directors also became trustees of HDRUK. They have prepared the annual report and financial statements on the basis that charitable status has been awarded.

The Board of Directors govern the Company in accordance with its Memorandum and Articles of Association.

Recruitment of Directors

The Directors make Director appointments for terms of three years, with an extension of up to two further terms subject to open competition at the end of the second term. All Directors give of their time freely, with the Chair receiving a remuneration which was paid during the year. Details of Director expenses and related party transactions are disclosed in note 18 to the accounts.

New Directors are appointed through a public appointment process, depending on the experience and key skills needed. New Directors are recommended by the Nominations Committee and are formally appointed at an HDR UK Board meeting.

Training and Induction

On appointment, new Directors follow a formal induction programme, which includes initial meetings with the Chair and the Director and the provision of key governance documentation. Ongoing training is provided for Directors as relevant throughout their term. Training is in progress to ensure that all board members are aware of their responsibilities as charity trustees.

Organisational structure

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. Day to day management of the Institute is delegated to the Director, Professor Andrew Morris. He is supported by a Chief Executive and executive management team which contains the appropriate range of skills to ensure competent management of HDR UK. The Directors meet at least four times a year.

HDR UK has three Board Committees:

- The Audit and Risk Committee, which was chaired during the year by Professor Sir Alex Markham, is responsible for advising the Board on financial management and reporting, the relationship with external auditors and risk management
- The Nominations Committee, which was chaired until February 21 by Professor Sir Jonathan Montgomery and subsequently by Professor Sarah Harper CBE, is responsible for advising the Board on Board recruitment and skills requirements
- The Remuneration Committee, which was chaired during the year by David Zahn, is responsible for advising the Board on the remuneration of the Institute's key management personnel

Relationships with other organisations

A number of Directors, key management or their close family members hold positions in other organisations with which HDR UK has significant relationships:

Organisation	Relationship to HDR UK	Director involvement
Medical Research Council (part of UK Research and Innovation) Innovate UK (part of UK Research and Innovation)	UK Research and Innovation is a member of the Company. UKRI brings together the seven research councils, Innovate UK and Research England. UKRI provides funding grants to the Company through the Medical Research Council and Innovate UK.	Dr Graham Spittle is a Council Member of the Medical Research Council Dr Frances Rawle is Director of Policy, Ethics and Governance at the Medical Research Council. A close family member of Sir Jim Smith is Executive Chair of the Medical Research Council.

Genome Research Limited	Co-ordinating Research Organisation of the HDR UK Cambridge Substantive Site and lead for HDR UK's Understanding the Causes of Disease national research priority. Genome Research Limited is a wholly owned subsidiary of the Wellcome Trust.	Sir Jim Smith is a Director of Genome Research Limited.
Oxford University Hospitals NHS Foundation Trust	Member of the UK Health Data Research Alliance	Professor Sir Jonathan Montgomery is Chair of Oxford University Hospitals NHS Foundation Trust
The Health Foundation	Partner with HDR UK's Better Care national research priority	David Zahn is a Governor of The Health Foundation
Wellcome Trust	Wellcome Trust provides funding grants to the Company directly for the HDR UK-Turing Wellcome PhD Programme in Health Data Science, through UKRI as a core funder and through the COVID-19 Therapeutics Accelerator. The Company is also a tenant of the Wellcome Trust.	Professor Sir James Smith is Director of Science for the Wellcome Trust
The University of Edinburgh	Co-ordinating Research Organisation of the HDR UK Scotland Substantive Site and lead for HDR UK's Applied Analytics national research priority. Lead organisation for BREATHE - Health Data Research Hub for Respiratory Health. BREATHE is a member of the UK Health Data Research Alliance	Professor Andrew Morris is Vice Principal and Professor of Medicine at The University of Edinburgh

In accordance with the Institute's policy, Directors are required to disclose all relevant interests and register them with the Chair of Directors and to withdraw from decisions where a conflict of interest arises. HDR UK's register of interests is published on the website: https://www.hdruk.ac.uk/wp-content/uploads/2021/05/HDR-UK-Register-of-Interests-21_04-1.pdf.

Full details of Related Party Transactions are included at note 18 of the financial statements

Objective and activity

Objects

HDR UK's main objects, as set out in the Articles of Association, are

- a) to improve, protect, preserve and advance the health of the public in particular but without limitation through the use of health data science by:
 - the development and application of biomedical and health data research.
 - the development of the tools, technologies, skills and partnerships required to transform health informatics research and innovation;
 - the sharing of informationin order to advance the understanding, prevention, diagnosis and treatment of diseases to achieve better health outcomes for the benefit of the public; and
- b) the advancement of medical and health research, in particular but without limitation by undertaking, promoting, disseminating and improving research into biomedical and health informatics.

Aims, objective and strategy to achieve HDR UK's objective

HDR UK has been established to work with a wide range of health data from the NHS, universities, research institutes and charities, and increasingly from wearables, and private companies. Over the next 5 years, health research datasets, participants and uses will grow rapidly HDR UK will position the UK to lead health data science internationally with our national, pan-sector approach. Our strategy will be delivered via the infrastructure we have started to create.

Public benefit

The Directors have referred to the guidance contained on the Charity Commission's general guidance on public benefit and consider HDR UK to be a public benefit entity.

Going Concern

HDR UK has committed funding in place to cover its activities until 31 March 2023. The Directors have therefore been able to satisfy themselves that the Company is able to continue as a going concern.

Audit information

The Directors who were in office at the date of approval of these financial statements have confirmed that, as far as they can reasonably ensure, all relevant audit information has been provided to the auditors; and the Directors have taken all the steps that they ought to have taken as directors in order to make themselves aware of any relevant audit information and to establish that the Company's auditors are aware of that information.

Reserves Policy

The Core Funders are committed to funding costs incurred by the Institute, with regular funding throughout each financial year in advance of expenditure. By the nature of this model, there is no need for significant reserves. However, the Directors are satisfied that there are sufficient arrangements for the provision of funding for the Company to continue to operate for the foreseeable future. This is based on the requirement for the Company to present forecasts to the end of the current funding period so that comfort can be gained that all anticipated costs are manageable with agreed funding.

STATEMENT OF DIRECTORS' RESPONSIBILITIES

The directors are responsible for preparing the Directors' Report and the financial statements in accordance with applicable law and regulations.

Company law requires the directors to prepare financial statements for each financial year. Under that law the directors have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the Company and of the incoming resources and application of resources, including the income and expenditure, of the Company for that year.

In preparing these financial statements, the directors are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Company will continue in operation.

The directors are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the Company. They are also responsible for safeguarding the assets of the Company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Directors' Report, which includes the Strategic Report, was approved by the Board of Directors on 29 September 2021 and signed on its behalf by:



Dr Graham Spittle, CBE
Chair of Directors

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF HEALTH DATA RESEARCH UK FOR THE YEAR ENDED 31 MARCH 2021

Opinion

We have audited the financial statements of Health Data Research UK (the 'company') for the year ended 31 March 2021 which comprise the Statement of Financial Activities, Balance sheet, the statement of cash flows and the related notes to the financial statements. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the company's affairs as at 31 March 2021 and of its net income for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. The directors are responsible for the other information. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF HEALTH DATA RESEARCH UK (Continued)

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the directors' report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of directors' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or

Responsibilities of directors

As explained more fully in the directors' responsibilities statement set out on page 32, the directors are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the directors determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the directors are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the directors either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Explanation as to what extent the audit was considered capable of detecting irregularities, including fraud

Based on our understanding of the company and industry, we identified that the principal risks of non-compliance with laws and regulations related to the law applicable to companies in England and Wales, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006, income tax, and payroll tax.

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF HEALTH DATA RESEARCH UK (Continued)

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to posting inappropriate journal entries to revenue and management bias in accounting estimates. Audit procedures performed by the engagement team included:

- Inspecting correspondence with regulators and tax authorities;
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- Evaluating management's controls designed to prevent and detect irregularities;
- Identifying and testing journals, in particular journal entries with unusual descriptions; and
- Challenging assumptions and judgements made by management in their critical accounting estimates.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Kathryn Burton (Senior Statutory Auditor)
For and on behalf of Haysmacintyre LLP
Statutory Auditors

10 Queen Street Place
London
EC4AR 1AG

Date: 14th October 2021

HEALTH DATA RESEARCH UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 MARCH 2021

	Notes	Unrestricted Funds £	Restricted Funds £	Total 2021 £	Total 2020 £
Income from:					
Donations		11,486,142	15,949,513	27,435,655	9,667,499
Investments		6,026	-	6,026	12,621
Other income		38,095	-	38,095	18,985
Total income		<u>11,530,263</u>	<u>15,949,513</u>	<u>27,479,776</u>	<u>9,699,105</u>
Expenditure on:					
Charitable activities					
Research	2	11,605,159	15,783,410	27,388,569	9,644,027
Total expenditure		<u>11,605,159</u>	<u>15,783,410</u>	<u>27,388,569</u>	<u>9,644,027</u>
Net income/(expenditure) before transfers		(74,896)	166,103	91,207	55,078
Transfers between Funds	13	166,103	(166,103)	-	-
Net movement in funds		91,207	-	91,207	55,078
Reconciliation of funds		137,307	-	137,307	82,229
Total funds brought forward		<u>137,307</u>	<u>-</u>	<u>137,307</u>	<u>82,229</u>
Total funds carried forward		<u>228,514</u>	<u>-</u>	<u>228,514</u>	<u>137,307</u>

All of the above results are from continuing activities

The notes on pages 39 to 54 form part of these financial statements.

HEALTH DATA RESEARCH UK

BALANCE SHEET AS AT 31 MARCH 2021

Company Registration Number: 10887014 (England and Wales)

	Notes	£	2021	£	£	2020	£
FIXED ASSETS							
Intangible assets	8			61,181			96,835
Tangible assets	9			123,213			40,472
				<u>184,394</u>			<u>137,307</u>
CURRENT ASSETS							
Debtors	10	4,937,505			621,878		
Cash at bank and in hand		<u>22,729,593</u>			<u>16,019,025</u>		
		27,667,098			16,640,903		
CREDITORS: amounts falling due within one year	11	<u>(27,622,978)</u>			<u>(16,640,903)</u>		
NET CURRENT ASSETS/ (LIABILITIES)				<u>44,120</u>			<u>-</u>
NET ASSETS/ (LIABILITIES)				<u>228,514</u>			<u>137,307</u>
CHARITY FUNDS							
Unrestricted funds	13			228,514			137,307
Restricted							-
TOTAL FUNDS				<u>228,514</u>			<u>137,307</u>

The financial statements were approved by the Board of Directors and authorised for issue on 29 September 2021 and are signed on its behalf by:

Graham Spittle

Dr Graham Spittle
Director

The notes on pages 39 to 54 form part of these financial statements.

HEALTH DATA RESEARCH UK

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2021

	Notes	2021 £	2020 £
Cash flows from operating activities			
Net cash provided by operating activities	15	6,928,039	8,767,231
Cash flows from investing activities			
Interest received		6,026	12,621
Purchase of tangible fixed assets		(223,497)	(117,115)
		(217,471)	(104,494)
Change in cash and cash equivalents in the year		6,710,568	8,662,737
Cash and cash equivalents brought forward		16,019,025	7,356,288
Cash and cash equivalents carried forward	16	22,729,593	16,019,025

A net debt reconciliation note has not been presented as the charity has no debt.

The notes on pages 39 to 54 form part of these financial statements.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

1. Accounting policies

1.1 General information

Health Data Research is a private company limited by guarantee and is registered in England and Wales. The registered office and the address of the principal place of business is Wellcome Trust, Gibbs Building, 215 Euston Road, London, NW1 2BE.

1.2 Basis of preparation of financial statements

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) – (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006. The Directors have chosen the Charities SORP as a best representation of the Company's circumstances and how to disclose its activities. Registered charitable status was awarded on 12 May 2021.

Health Data Research UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

1.3 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Directors in furtherance of the general objectives of the Company and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Company for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

Investment income, gains and losses are allocated to the appropriate funds.

1.4 Income

Revenue recognised in the year reflects an assessment of the fair value of services provided to the reporting date.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the Company which is the amount the Company would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market, a corresponding amount is then recognised in expenditure in the period of receipt.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

1. Accounting policies (continued)

1.4 Income (continued)

Income tax recoverable in relation to investment income is recognised at the time the investment income is receivable.

Other income is recognised in the period in which it is receivable and to the extent the goods have been provided or on completion of the service.

1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity. HDR UK has one type of activity.

Governance costs are those incurred in connection with administration of the Company and compliance with constitutional and statutory requirements.

Charitable activities and governance costs are costs incurred on the Company's operations, including support costs.

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attaching are fulfilled. Grants offered subject to conditions which have not been met at the year end are noted as a commitment, but not accrued as expenditure.

1.6 Going concern

The Directors consider that there are no material uncertainties about the company's ability to continue as a going concern. The Directors have a reasonable expectation that the Company has adequate resources to continue in operational existence for the foreseeable future with committed funding in place to cover its activities until 31 March 2023. For this reason they continue to adopt the going concern basis in preparing the financial statements.

1.7 Intangible fixed assets and amortisation

Intangible assets costing £1,000 or more are capitalised and recognised when future economic benefits are probable and the cost or value of the assets can be measured reliably. Intangible assets are initially recognised at cost and are subsequently measured at cost net of amortisation and any provision for impairment. Costs relating to assets developed internally are capitalised in accordance with the requirements of FRS 102.

Amortisation is provided on intangible fixed assets at rates calculated to write off the cost of each asset, less their estimated residual value, on a straight-line basis over their expected useful lives:

Purchased software licenses	- The contractual period
Developed software	- Straight line over 3 – 5 years
Websites	- Straight line over 3 – 5 years

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

1. Accounting policies (continued)

1.7 Intangible fixed assets and amortisation (continued)

A full year of amortisation is charged in the year when the asset is ready for use and no amortisation is charged in the year of disposal. The carrying values of intangible fixed assets are reviewed for impairment when events or changes in circumstances indicate that the carrying amount may not be recoverable. Shortfalls between the carrying value and recoverable amounts are recognised as impairments. Impairment losses are recognised in the statement of financial activities incorporating income and expenditure account.

1.8 Tangible fixed assets and depreciation

All assets costing more than £1,000 are capitalised.

Tangible fixed assets are carried at cost, net of depreciation and any provision for impairment. Depreciation is provided at rates calculated to write off the cost of fixed assets, less their estimated residual value, on a straight-line basis over their expected useful lives:

Short-term leasehold improvements	-	Leasehold period
Office equipment	-	5 years
Computer equipment	-	5 years

A full year of amortisation is charged in the year when the asset is ready for use and no amortisation is charged in the year of disposal.

A review for impairment of a fixed asset is carried out if events or changes in circumstances indicate that the carrying value of any asset may not be recoverable. Shortfalls between the carrying value of fixed assets and their recoverable amounts are recognised as impairments. Impairment losses are recognised in the statement of financial activities incorporating income and expenditure account.

1.9 Operating leases

Rents payable under operating leases are charged to the statement of financial activities incorporating income and expenditure account on a straight line basis over the lease of the term.

1.10 Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Company; this is normally upon notification of the interest paid or payable by the bank.

1.11 Debtors

Trade and other debtors are recognised at the settlement amount after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

1.12 Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

1. Accounting policies (continued)

1.13 Liabilities and provisions

Liabilities are recognised when there is an obligation at the balance sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably. Liabilities are recognised at the amount the Company anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide. Provisions are measured at the best estimate of the amounts required to settle the obligation. Where the effect of the time value of money is discount rate that reflects the risk specific to the liability. The unwinding of the discount is recognised within interest payable and similar charges.

1.14 Financial instruments

The Company only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently at amortised cost using the effective interest method, less any impairment losses.

2. ANALYSIS OF EXPENDITURE

Current year	Direct costs	Grant funding of activities	Support costs	Total 2021	Total 2020
	£	£	£	£	£
Charitable activities					
Research	10,256,563	15,758,202	1,373,804	27,388,569	9,644,027
Total 2021	10,256,563	15,758,202	1,373,804	27,388,569	9,644,027

Support Costs	Staff costs	Premises and office costs	Other costs	Total 2021	Total 2020
	£	£	£	£	£
Charitable activities					
Research	698,970	108,481	566,353	1,373,804	536,617
Total 2021	698,970	108,481	566,353	1,373,804	536,617

HDR UK has one type of activity. Support costs have been allocated to that one activity. Governance costs are included within support costs.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

2. ANALYSIS OF EXPENDITURE (continued)

Prior year

	Direct costs £	Grant funding of activities £	Support costs £	Total 2020 £	Total 2019 £
Charitable activities					
Research	3,577,981	5,529,429	536,617	9,644,027	8,105,277
Total 2020	3,577,981	5,529,429	536,617	9,644,027	8,105,277

Support Costs

	Staff costs £	Premises and office costs £	Other costs £	Total 2020 £	Total 2019 £
Charitable activities					
Research	266,321	88,851	181,445	536,617	495,918
Total 2020	266,321	88,851	181,445	536,617	495,918

HDR UK has one type of activity. Support costs have been allocated to that one activity. Governance costs are included within support costs.

3. GOVERNANCE COSTS

	Total 2021 £	Total 2020 £
Chair remuneration	16,430	16,430
Audit fee	16,800	17,800
Non-audit services	7,344	4,000
Legal fees	43,829	-
Board costs	66,966	9,006
	151,369	43,236

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

4. GRANTS PAYABLE

	Total 2021 £	Total 2020 £
Wellcome Sanger Institute (Genome Research Limited)	1,830,212	1,388,141
University College London	2,398,902	1,013,772
University of Birmingham	2,292,187	835,134
University of Oxford	779,081	855,498
University of Dundee	400,000	-
Public Health Agency NI	367,279	-
University of Bristol	216,861	-
University of Edinburgh	1,411,232	705,922
Swansea University	2,181,998	324,612
NHS Digital	1,830,733	-
Government of Scotland	850,500	-
Other	1,199,217	406,350
	<u>15,758,202</u>	<u>5,529,429</u>

The above are the contracting organisations. The full list of fund recipients is listed on our website <https://www.hdruk.ac.uk/about-us/locations/>

5. NET INCOME/ (EXPENDITURE)

This is stated after charging:

	Total 2021 £	Total 2020 £
Depreciation of tangible fixed assets		
- owned by the Company	28,122	15,307
Amortisation of intangible fixed assets	141,600	43,315
Auditor's remuneration – audit	16,800	13,800
Auditors' remuneration – non-audit fees	7,344	4,000
	<u>193,866</u>	<u>76,422</u>

6. STAFF COSTS

Staff costs were as follows:

	Total 2021 £	Total 2020 £
Staff wages and salaries	2,424,460	1,195,969
Social security costs	293,550	142,126
Other pension costs	239,165	110,488
	<u>2,957,175</u>	<u>1,448,583</u>

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

6. STAFF COSTS (continued)

Not included in staff costs were recharged seconded salary costs amounting to £482,568 (2020: £512,284) and temporary staff costs of £796,570 (2020: £252,419).

Including costs incurred from recharged salary costs charged by third parties, the total compensation of key management personnel was £457,420 (2020: £458,677).

The average number of persons employed by the Company during the year was as follows:

	2021 No.	2020 No.
	37	15

The number of members of staff whose emoluments, including benefits in kind, amounted to over £60,000 were as follows:

	2021 No.	2020 No.
£60,000 - £70,000	2	1
£70,001 - £80,000	1	1
£80,001 - £90,000	3	2
£90,001 - £100,000	5	1
£100,001 - £110,000	1	2
£150,001 - £160,000	1	1
£160,000 - £170,000	1	-

No staff costs were capitalised in the year in addition to salaries and wages (2020: £Nil).

During the year, Dr Graham Spittle, a Director, received remuneration for this services as Chair of £16,430 (2020: £16,430) (see note 3). During the period, no other Directors have been paid any remuneration or received any benefits in kind (2020 nil).

7. TAXATION

The Company applied to the Charity Commission for registration as a UK charity. Charitable status was granted on 12 May 2021. All of the Company's income and gains have or will be applied to charitable activities and, as such, no corporation tax liability has been included in these financial statements. The relevant exemptions are included at CTA 2010, Part 11, Chapter 2.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

8. INTANGIBLE FIXED ASSETS

	Total Intangibles £
Cost	
At 1 April 2020	167,204
Additions	112,634
	<hr/>
At 31 March 2021	279,838
	<hr/> <hr/>

8. INTANGIBLE FIXED ASSETS (continued)

	Total Intangibles £
Amortisation	
At 1 April 2020	70,369
Charge for the year	141,600
Impairment	6,688
	<hr/>
At 31 March 2021	218,657
	<hr/> <hr/>
Carrying amount	
At 31 March 2021	61,181
	<hr/>
At 31 March 2020	96,835
	<hr/> <hr/>

At 31 March 2021 the value of capital commitments for intangible fixed assets was £nil (2020: £6,795).

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

9. TANGIBLE FIXED ASSETS

	Short-term Leasehold improvements £	Office equipment £	Computer equipment £	Total £
Cost				
At 1 April 2020	24,883	22,683	33,537	81,103
Additions	-	39,602	71,261	110,863
At 31 March 2021	24,883	62,285	104,798	191,966
Depreciation				
At 1 April 2020	24,883	6,046	9,702	40,631
Charge for the year	-	7,162	20,960	28,122
At 31 March 2021	24,883	13,208	30,662	68,753
Net book value				
At 31 March 2021	-	49,077	74,136	123,213
At 31 March 2020	-	16,637	23,835	40,472

At 31 March 2021 the value of capital commitments for tangible fixed assets was £nil (2020: £78,665).

10. DEBTORS

	2021 £	2020 £
Amounts falling due within one year:		
Trade debtors	2,421,904	93,463
Other debtors	-	6,993
Prepayments and accrued income	2,515,601	521,422
	<u>4,937,505</u>	<u>621,878</u>

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

11. CREDITORS: Amounts falling due within one year

	2021	2020
	£	£
Trade creditors	4,026,657	556,223
Accruals and deferred income (see below)	16,304,186	11,545,671
Accruals for grant payables	7,292,135	4,526,860
Other creditors	-	12,149
	<u>27,622,978</u>	<u>16,640,903</u>
		£
Deferred income		
Deferred income at 1 April 2020		10,742,806
Resources deferred during the year		14,052,205
Amounts released from previous years		<u>(10,742,806)</u>
		<u>14,052,205</u>

During the year, income of £14,052,205 (2020: £10,742,806) was deferred as amounts received were not utilised in the period.

12. FINANCIAL INSTRUMENTS

	2021	2020
	£	Restated* £
Financial assets measured at amortised cost	<u>27,647,005</u>	<u>16,625,781</u>
Financial liabilities measured at amortised cost	<u>13,570,774</u>	<u>(5,898,097)</u>

Financial assets measured at amortised cost comprise cash, trade debtors and other debtors.

Financial liabilities measured at amortised cost comprise trade creditors, other taxation and social security, other creditors and accruals.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

13. STATEMENT OF FUNDS – current year

	Balance at 1 April 2020 £	Movement in funds		Transfers Between Funds £	Balance at 31 March 2021 £
		Income £	Expenditure £		
Unrestricted	137,307	11,530,263	(11,605,159)	166,103	228,514
Restricted					
Digital Innovation Hub Programme Management	-	1,015,363	(1,010,539)	(4,824)	-
Digital Innovation Hub Programme: Phase 3 Capital Programme Phase 2	-	4,279,113	(4,257,129)	(21,984)	-
BHF- Data science Centre	-	2,098,752	(1,972,664)	(126,088)	-
Wellcome Trust - PhD Health Foundation - Better Care	-	626,684	(624,179)	(2,505)	-
Gates Foundation - ICODA	-	104,432	(104,432)	-	-
	-	252,684	(252,684)	-	-
World Class Labs	-	1,314,605	(1,311,328)	(3,277)	-
Population Research UK Data & Connectivity Phase 0	-	1,865,150	(1,865,150)	-	-
	-	13,800	(13,800)	-	-
	-	4,378,930	(4,371,505)	(7,425)	-
Total of funds	<u>137,307</u>	<u>27,479,776</u>	<u>(27,388,569)</u>	<u>-</u>	<u>228,514</u>

Transfers between funds are fixed asset transfers of £166,103.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

13. STATEMENT OF FUNDS (continued)

Details of restricted funds are as follows

Fund	Purpose
Digital Innovation Hub Programme Management	To support the development of the Digital Innovation Hub Programme under the Life Sciences Industrial Strategy.
Digital Innovation Hub Programme: Phase 3	To support business development of the Health Data Research Hubs, support the work of the UK Health Data Research Alliance and the UK Health Data Research Innovation Gateway.
Capital Investment Programme Phase 2	To support HDR UK's capital investment programme in: <ol style="list-style-type: none"> 1. HDR UK Gateway datasets: to ensure Alliance members datasets are onboarded to make them discoverable and accessible through the Gateway for use in scientific research and innovation projects; 2. Trusted Research Environments: to enhance and provide access to Trusted Research Environment capability for current and future Alliance members (including HDR UK sites); 3. Gateway Technology Partnership: To accelerate the development of a common access point for health data assets across the UK; 4. Infrastructure sprints: to develop solutions on curation, data linkage and federated analytics; 5. Collaboration solutions: technology and on-line capabilities that will enable HDR UK to operate efficiently and effectively as One Institute across all priorities, sites and with partners. 6.
British Heart Foundation Data Science Centre	To deliver the BHF Data Science Centre for cardiovascular health
HDR UK – Turing Wellcome Trust PhD Programme	To deliver the HDR UK – Turing Wellcome PhD Programme in Health Data Science
Health Foundation: Better Care Catalyst Programme	To support the Better Care programme catalyst projects, providing exemplar outputs for use of data-driven analytics in clinical practice.
International COVID-19 Data Alliance	To deliver the International Covid-19 Data Alliance to support the rapid development of insights and treatments to combat the global effects of COVID-19.
World Class Labs 20/21	To support HDR UK's capital investments programme and assets, in particular those relating to the national COVID-19 response.
Population Research UK	To support the development of Population Research UK, a research initiative that that maximises the insights, innovations and research efficiency of the UK's world leading social and biomedical data assets, including Longitudinal Population Studies.
Data & Connectivity National Core Study: Phase 0	To support and accelerate research on COVID-19, supporting the other five National Core Studies into key research questions by enabling streamlined, safe and responsible access to relevant datasets relevant for the pandemic.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

13. STATEMENT OF FUNDS (continued)

STATEMENT OF FUNDS – prior year

	Balance at 1 April 2019 £	Movement in funds		Transfers Between Funds £	Balance at 31 March 2020 £
		Income £	Expenditure £		
Unrestricted	82,229	6,266,650	6,328,687	117,115	137,307
Restricted					
Digital Innovation Hub Programme Management	-	932,387	932,387	-	-
Digital Innovation Hub Programme: Phase 3 Capital Programme	-	385,852	385,852	-	-
Phase 1	-	21,153	13,540	(7,613)	-
Capital Programme Phase 2	-	2,039,534	1,930,032	(109,502)	-
British Heart Foundation Data Science Centre	-	51,290	51,290	-	-
HDR UK – Turing Wellcome Trust PhD Programme	-	2,239	2,239	-	-
Total of funds	<u>82,229</u>	<u>9,699,105</u>	<u>9,644,027</u>	<u>-</u>	<u>137,307</u>

Transfers between funds are fixed asset transfers of £117,115.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

14. ANALYSIS OF NET ASSETS BETWEEN FUNDS

Analysis of net funds – current year

	Unrestricted Funds 2021 £	Restricted Funds 2021 £	Total Funds 2021 £
Intangible fixed assets	61,181	-	61,181
Tangible fixed assets	123,213	-	123,213
Current assets	22,970,839	4,696,259	27,667,098
Creditors due within one year	(22,926,719)	(4,696,259)	(27,622,978)
Total of funds	228,514	-	228,514

Analysis of net funds – prior year

	Unrestricted Funds 2020 £	Restricted Funds 2020 £	Total Funds 2020 £
Intangible fixed assets	96,835	-	96,835
Tangible fixed assets	40,472	-	40,472
Current assets	14,401,488	2,239,415	16,640,903
Creditors due within one year	(14,401,488)	(2,239,415)	(16,640,903)
Total of funds	137,307	-	137,307

15. RECONCILIATION OF NET MOVEMENT IN FUNDS TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2021 £	2020 £
Net income for the year (as per Statement of Financial Activities)	91,207	55,078
Adjustment for:		
Depreciation and amortisation charges	176,410	58,622
Net bank interest	(6,026)	(12,621)
Decrease / (increase) in debtors	(4,315,627)	223,603
Increase in creditors	10,982,075	8,442,549
Net cash provided by operating activities	6,928,039	8,767,231

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021

16. ANALYSIS OF CASH AND CASH EQUIVALENTS

	2021 £	2020 £
Cash at bank and in hand	22,729,593	16,019,025
	<u>22,729,593</u>	<u>16,019,025</u>

17. OPERATING LEASE COMMITMENTS

At 31 March the total of the Company's future minimum lease payments under non-cancellable operating leases was:

	2021 £	2020 £
Amounts payable:		
In less than 1 year	1,488	44,650
In two to five years	4,464	2,976
	<u>5,952</u>	<u>47,626</u>

18. RELATED PARTY TRANSACTIONS

During the year, the Company received grants of £19,843k (2020: £9,001k) from The Medical Research Council (part of UK Research and Innovation). £2,049k was owed to HDR UK at 31 March 2021 (2020: £nil). During the year the Company received grants of £5,295k (2020: 1,318) from Innovate UK (part of UK Research and Innovation). UK Research and Innovation is a founding member of the Company.

During the year the Company received grants of £252k (2020: £nil) and other income of £35k (2020: £nil) from The Health Foundation. David Zahn, a Director, is a Governor of The Health Foundation.

During the year the Company received grants of £104k (2020: £2k) and incurred rent expenditure of £84k in relation to Wellcome Trust. Professor Sir James Smith, a Director, is Director of Science for the Wellcome Trust.

During the year the Company awarded grants totalling £1,830k (2020: £1,388k) to Genome Research Limited. Professor Sir James Smith, a Director, is a director of Genome Research Limited.

During the year the Company awarded grants of £1,411k (2020: £706k) and incurred expenditure of £367k in relation to seconded employees at the The University of Edinburgh. £319k was owed at 31 March 2021. Professor Andrew Morris, the Director of HDR UK, is Vice Principal and Professor of Medicine at The University of Edinburgh.

During the year, the Company awarded grants totalling £nil (2020: £13,000) to the Oxford University NHS Foundation Trust. Professor Sir Jonathan Montgomery, a Director, is the Chair of the Oxford University NHS Foundation Trust.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

18. RELATED PARTY TRANSACTIONS (continued)

During the year, the Company incurred expenditure of £nil (2020: £19,525) in relation to Medicines Discovery Catapult Ltd. Professor Sir Alex Markham, a Director, is a director of Medicines Discovery Catapult Ltd.

During the year, Dr Graham Spittle, a Director, was paid £16,430 (2020: £16,430) for his services as Chair. At the year end there was £nil (2020 - £nil) owed to the Director.

During the year, Directors were reimbursed expenses amounting to £nil (2020: £1,178). The nature of the expenses were travel and subsistence.

19. EVENTS AFTER THE REPORTING DATE

HDRUK was registered a charity on 12th May 2021. The registered charity number is 1194431.

20. COMPARATIVE STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

	Notes	Unrestricted Funds £	Restricted Funds £	Total 2020 £
Income from:				
Donations		6,235,044	3,432,455	9,667,499
Investments		12,621	-	12,621
Other income		18,985	-	18,985
Total income		<u>6,266,650</u>	<u>3,432,455</u>	<u>9,699,105</u>
Expenditure on:				
Charitable activities				
Research	2	6,328,687	3,315,340	9,644,027
Total expenditure		<u>6,328,687</u>	<u>3,315,340</u>	<u>9,644,027</u>
Net income/(expenditure) before transfers		(62,037)	117,115	55,078
Transfers between Funds	13	<u>117,115</u>	<u>(117,115)</u>	<u>-</u>
Net movement in funds		55,078	-	55,078
Reconciliation of funds				
Total funds brought forward		<u>82,229</u>	<u>-</u>	<u>82,229</u>
Total funds carried forward		<u>137,307</u>	<u>-</u>	<u>137,307</u>