

Company Registration number: 10887014 (England and Wales)

Charity number: 1194431

HEALTH DATA RESEARCH UK
(a company limited by guarantee)

ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

HEALTH DATA RESEARCH UK
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LEGAL AND ADMINISTRATIVE INFORMATION

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Trustees and Directors

Dr Graham Spittle, CBE, Chair
Professor Sir Alex Markham, Chair of Audit and Risk Committee
David Zahn, Chair of Remuneration Committee – resigned 04. 03.2022
Professor Sir James Smith
Professor Dame Janet Thornton
Professor Sarah Harper CBE, Chair of Nominations Committee
Baroness Lucy Jeanne Neville-Rolfe - resigned 12.12.2021
Dr Frances Rawle - resigned 12.04.2021
Lord James O'Shaughnessy
Edosa Odara – appointed 14.07.2021
Glenn Wells – appointed 14.07.2021, resigned 26.11.2021
William Boa, Chair of Remuneration Committee – appointed 16.12.2021

Company registered number 10887014

Registered office Wellcome Trust
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NW1 2BE

Principal operating office 215 Euston Road
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NW1 2BE

Auditor Haysmacintyre LLP
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EC4R 1AG

Company secretary Amanda Borton - resigned 29.09.2021
Elemental Company Secretary Limited - appointed on 29.09.2021

Bankers NatWest
250 Bishopsgate
London
EC2M 4AA

Solicitors Bird & Bird LLP
12 New Fetter Lane
London
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TRUSTEES' REPORT

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Foreword

The Trustees are pleased to present their Strategic report for Health Data Research UK ("HDR UK", the "Company", the "Institute") for the year ended 31 March 2022.

Registered charity status was awarded on 12 May 2021 (registered charity number 1194431). At this date the Directors also became Trustees of HDR UK. The Trustees continue to present the Company's information in line with the Charities SORP, previously chosen as the best representation of the Company's circumstances and how to disclose its activities.

This report provides a review of the activities and business for 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.

Overview

In the year that the word data hit international headlines, Health Data Research UK strengthened its leadership and demonstrated impact as the national institute for health data science.

2021/22 was a pivotal year for HDR UK. We are approaching the end of the first five years since establishment and have taken time to work with colleagues, partners, funders and advisors to reflect on and review progress and create an ambitious new strategy for our next five years starting in 2023. This strategy will be defining for HDR UK and will pave the way for the UK to harness the value of data in the most trustworthy way to transform knowledge and understanding of disease and boost medical innovation to benefit us all.

In our report we highlight the significant research achievements made across the Institute, with over 2,600 research papers published and 66,000 citations in these first five years. Many have directly informed policy decisions and healthcare practice during the pandemic where our research has delivered discoveries about the virus, its prevention, causes and management and provided insights into vaccine efficacy and safety. We have enabled data discovery, access and linkage that have underpinned the UK's pandemic response through our joint leadership with the Office of National Statistics of the Data and Connectivity National Core Study. Our leadership of the International COVID-19 Research Alliance, led by our new Global Research Director Trudie Lang and delivered with partners across the world, has enabled actionable insights on the pandemic for global ministries of health and populations.

Our partnerships have continued to grow and flourish during the year and demonstrated the value of combining expertise to deliver further and faster on joint ambitions. Strategic partnerships with the British Heart Foundation and NHS Digital, under the leadership of Cathie Sudlow, has enabled – for the first time ever – secure access to the largest linked health data resource covering 54.4 million people in England. This year we joined forces with Diabetes UK to create a Diabetes Data Science Catalyst, which we hope will be a model for collaboration with other charities.

HDR UK's leadership of the UK Health Data Research Alliance has delivered some of the greatest collaborative efforts to drive forward best practice and inform policy in health data research. This included white papers on

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Trusted Research Environments in partnership with NHS England, data standards, and recommendations on building transparency in data research through standards on data use registers.

This year marked the second anniversary of the Health Data Research Innovation Gateway, our platform for researchers to discover and request access to UK health datasets, which lists over 750 datasets from more than 60 data custodians. A new Cohort Discovery tool was launched to enable researchers to search by specific population criteria across multiple datasets, widening the data discovery capabilities of the Gateway even further and facilitating a faster pathway to impactful research.

Our network of Health Data Research Hubs continued to grow with the addition of two new Hubs; DATAMIND for mental health research and Alleviate to advance research into chronic pain. As a network, the hubs are pioneering and informing the development of health data research in the UK, demonstrating how insights from data are improving people's lives. To date they have secured over 400 contracts for health data science projects.

Our commitment to working with the public and patients as partners as a key part of our strategy has continued through the year with our leadership across the sector in demonstrating transparency and building trustworthiness in data initiatives. HDR UK's innovative approaches to bring public views in quickly and effectively has shaped research and improved outcomes and, this year, over 14,700 patient and public members contributed to our work. We have widened our public engagement and reach through social media, press campaigns, and events showcasing the benefits and impact of data.

To support the future generation of data scientists we launched HDR UK Futures, a new virtual learning environment, to provide bitesize training from UK's experts on areas including phenomics, data engineering and data access. In response to the significant underrepresentation of Black people in data science, this year saw the launch of the Black Internship Programme with 48 interns matched to data roles in 23 of our Alliance partner organisations, many going onto secure roles in the field.

The achievements highlighted in this report are a result of the commitment and dedication of the many teams across HDR UK's federated national Institute, our partners and our patient and public advisors. It is a testament to their focus on our values of transparency, optimism, respect, courage and humility that we have made such progress.

As we transition to our future strategy, we look forward to working with our partners and community, strengthening our connections and to focus on delivering novel insights and innovative data research and services to enable discoveries that improve people's lives.

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Strategic Report

Business and activity review

HDR UK is the national institute for health data that includes England, Scotland, Wales and Northern Ireland with a mission 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 2021, focused on our unique strengths and expertise of building a health data research infrastructure for the UK through three strategic areas:

- **Uniting health data** - providing national convenorship through the UK Health Data Research Alliance and Health Data Research Innovation 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.

We have delivered this plan with our inclusive, team-oriented **One Institute** ethos – bringing together experts across the UK to collaborate and achieve more together than they would alone – all built upon values of transparency, optimism, respect, courage and humility.

Achievements and Performance

During the year, we worked across the Institute and with our partners to review our impact to date and to develop a strategy for the future five years (2023-2028). This work forms part of our [five-year \('quinquennial'\) review](#) by our core funders and, following significant collaboration with colleagues across academia, healthcare, charities, industry and patient groups, we published an overview of our impact and future strategy in February 2022. Further details of the future strategy are outlined in the Plans for Future Periods section of this report.

This report provides the highlights of key achievements and performance across HDR UK during 2021/22 and includes work that HDR UK has led and activities that HDR UK has enabled and delivered in partnership.

Accelerating the pace and scale of health and biomedical data science

National Research Priorities

HDR UK's six National Research Priorities on Applied Analytics, Human Phenome, Understanding Causes of Disease, Clinical Trials Improving Public Health and Better Care have produced UK-wide research that no single research organisation could achieve alone. Between April 2018 and March 2022, HDR UK researchers published

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>2,600 papers with >66,000 citations and have delivered research that has directly informed policy decisions and clinical practice during the COVID-19 pandemic.

Highlights of HDR UK's research impact during the year are provided below. Further examples can be viewed on [our website](#).

Better Care - the value of triage during periods of intense COVID-19 demand ([Wood et al 2021](#)).

Very little work has previously been done on the triage of patients who might need intensive care support. As COVID-19 cases mounted, scientific evidence was needed about which approaches for rational decision-making on the use of limited resources would yield the best outcomes. HDR UK created an open-source computer simulation model using records of 9,505 patients to assess the life years saved for triage strategies under different scenarios. This research can provide a basis for policymakers and care providers to start preparing protocols for future health emergencies.

Collaboration across the clinical trials landscape ([Cake et al 2022](#))

Currently only a very small proportion of clinical trials access and use routinely-collected data – despite its potential to make trials more efficient across finding, recruiting and following up patients. HDR UK established multidisciplinary partnerships to address the technical, ethical and logistical requirements of providing clinical trial researchers with rapid access to large, linked datasets and integrated patient engagement. These novel collaborative approaches have helped researchers significantly enhance recruitment and subsequent delivery of trials – including RECOVERY, PRINCIPLE and TACKLE - for research into COVID-19.

HDR UK programmes responding to COVID ([Lyons et al 2021](#))

During the pandemic, the Welsh Government needed to understand COVID-19 in the population – from its spread to the effectiveness of control policies. A means was needed to track the pandemic and answer new research questions as they arose. The HDR UK Multimorbidity project was rapidly pivoted to create a TRE linking population-level data for all 3.1 million people in Wales to rapidly analyse COVID-19 and discover what works to prevent and treat the infection. The findings (e.g. identifying vectors of transmission and assessing vaccine effectiveness by socioeconomic group) were used by the Welsh Government, the Government's Scientific Advisory Group for Emergencies (SAGE) and the New and Emerging Respiratory Virus Threats Advisory Group (NERVTAG) to inform national policy and save lives.

Polygenic Score Catalog ([Lambert et al 2021](#))

Polygenic risk scores (PGSs) have immense potential for helping predict people's likelihood of developing many serious illnesses. However, progress is hindered by a lack of common standards or best practice. HDR UK co-developed the new Polygenic Score Catalog – an open resource of published PGSs that includes full scoring information annotated with expertly curated metadata. It allows PGSs to be re-used and evaluated so their

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accuracy and clinical value can be fully assessed. The catalogue has transformative potential to help a nascent area of research become of real clinical value. It is already extensively used and holds >2,100 PGSs from >260 papers for >500 different traits, demonstrating its capacity to harmonise and unify them in one database.

Multi-omics consortium to inform disease aetiology and prediction (National Implementation Project); ([Butterworth et al 2021](#))

Studies that combine genetic information with other blood-based factors – including proteins, metabolites and lipids – and health records, have the potential to provide more direct insight into disease causes and prediction. A key challenge, however, has been accessing this information at sufficient scale. HDR UK convened the Multi-omics Cohorts Consortium to bring together molecular research cohorts from across the UK nations, comprising over 800,000 participants, to test the feasibility of integrating the extensive molecular measurements across cohorts. The consortium has improved the scale and statistical power of research into the cause and prediction of disease – e.g. the use of proteomic and transcriptomic data to identify causal factors related to COVID-19 outcomes – and laid foundations for infrastructural innovation to improve future research and outcomes for patients.

A new method to link health records of mothers and babies ([Harron et al 2021](#))

Targeted support for women before and during pregnancy has the potential to improve outcomes at and after birth, through promoting preconception health and reproductive choices and mitigating the adverse effects of maternal stress. Understanding which women are most vulnerable, and how to identify them in time for intervention, is the first step to the effective development of early health and social support programmes. But existing studies evaluating the association between maternal risk factors and specific infant outcomes have mostly focused on single risk factors. Led by HDR UK researchers developed a probabilistic linkage technique to analyse the association between multiple maternal psychosocial risk factors that can be identified routinely and early in pregnancy and key birth and infant outcomes for 2,137,103 births. The study identified multiple risk factors that were associated with poor infant outcomes. It clearly shows the need for risk-factor informed interventions before, during, and after pregnancy – and is expected to influence the current update of the Healthy Child Programme (HCP).

Response to COVID-19

During the year, health data research continued to provide enormous value to people across the UK in response to the COVID-19 pandemic. HDR UK's strategy enabled us to mobilise expertise 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.

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These efforts have delivered scientific discoveries about the virus, its prevention, causes and management. Our portfolio of research and studies supported by HDR UK and have generated actionable insights about COVID-19 including:

- Over 20 papers demonstrating the effectiveness and safety of COVID-19 vaccines through the EAVEII studies led by HDR UK BREATHE Hub Director Aziz Sheikh. These include the benefits of the vaccine outweighing the risks of COVID-19, including the risk of heart complications and blood clots; research on the vaccines' effectiveness of preventing deaths from the delta variant of COVID-19; and insights demonstrating that protection from the COVID-19 vaccine wanes after three months
- Identification of treatments for COVID-19 to speed recovery via the PRINCIPLE trial and increase survival via the RECOVERY trial
- Implications for other healthcare services including in mental health and cancer care.

Data and Connectivity National Core Study

HDR UK's joint leadership with the Office for National Statistics (ONS) of the Data and Connectivity National Core Study continued during the year. One of six National Core Studies Programmes, the study works with policymakers, data custodians, providers of Trusted Research Environments, researchers and the public to make COVID-19-relevant data available for research with greater speed, efficiency and scale.

Over the last 12 months, the programme has continued to underpin the UK's COVID-19 response and contribute to future pandemic preparedness. Notable outputs include deepening our understanding of the Omicron variant, which became dominant throughout 2021 and 2022. Data and Connectivity-enabled research has demonstrated that Omicron is usually milder than the Delta variant, but more likely to break through immune protection due to changes in its spike protein and cell-entry mechanisms (Sheikh et al., 2022) (Willett et al., 2022).

The programme has also provided valuable insights into vaccine efficacy and safety that are important for the UK's ongoing pandemic response, using large-scale data to show vaccines offer high protection against infection for 6-months, and that this persists for people of all body weights (Horne et al., 2022) (Piernas et al., 2022).

As well as enabling key scientific insights, an important objective of the programme is to support the development of data infrastructure and address unmet data linkage needs that will strengthen future health threat responses.

In the last year, the programme has continued to convene multi-organisation groups to drive progress in this area, including continuing to develop a national UK Trusted Research Environment network across the four nations for the first time. NHS Digital, ONS, SAIL Databank, Northern Ireland Honest Broker Service and Public Health Scotland/Edinburgh Parallel Computing Centre have now collaborated as a single UK-wide team to enable access and linkage to 91 UK priority datasets for urgent COVID-19 research.

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The Outbreak Data Analysis Platform (ODAP) led by Kenny Baillie, University of Edinburgh and Sharon Peacock, COG-UK, and supported by Data and Connectivity is providing an accessible data resource to enable research relevant to pandemics. It brings together outbreak-relevant data from clinical records, research studies and audit data and a streamlined data access process is in development which will allow a UK-wide, single panel of data custodians to provide a transparent information governance process, adhering to the Five Safes principle.

In September 2021, the COVID-19 Data and Connectivity National Core Study (NCS), partnered with The Turing Institute to fund nine projects focused on both using advanced analytics to contribute to our understanding of COVID-19, and leaving a legacy for future research studies by enhancing the value of data and following best practice in open science, sharing code and tools.

The selected projects are being delivered by 16 collaborating universities across the four nations, and are using the health data research infrastructure and network of TREs established and supported by the Data and Connectivity NCS.

All the datasets are being made discoverable and available to request access to via Health Data Research Innovation Gateway.

ICODA – A global health data response to COVID-19

Work undertaken by HDR UK to convene the International COVID-19 Data Alliance (ICODA), which was announced in June 2020 has come to fruition in the last 12 months. The ICODA initiative, funded by the COVID-19 Therapeutics Accelerator, a large scale initiative supported by the Bill & Melinda Gates Foundation and Minderoo Foundation and other donors, now has twelve driver projects – specific research questions bringing together a range of datasets for analysis, all approaching completion. Ten of these were selected from a Grand Challenges ICODA pilot funding call announced at the end of 2020 which resulted in 418 applications from 69 countries.

Across the twelve ICODA driver projects we have an active cohort of 135 researchers from 19 countries working in our trusted research environment, the ICODA Workbench. This provides them with a wide range of analytical tools, wrapped with rigorous data governance processes and a mechanism to share meta data for secondary data use through our ICODA Gateway. Our researchers are working with a broad range of data types including data from health systems, clinical trials, electronic health records, population data, hospital admissions, birth and vaccine data.

Driver Project REHCORD which is working on understanding the Impact of COVID-19 on health service delivery and institutional mortality across multiple countries used an interrupted time series design to assess the immediate effect of the pandemic on 31 health services in 10 low to middle income settings. Despite efforts to maintain health services, disruptions of varying magnitude and duration were found in every country, with no clear patterns by country income group or pandemic intensity. They found that often the disruptions in health services preceded COVID-19 waves. (C. Arsenault, Nature Medicine, Mar 22).

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Overall the ICODA driver project cohort continue to have a strong impact, with 21 publications, articles and pre-prints to-date, in journals including BMJ Global Health, The Lancet and Nature Magazine, and dashboards informing ministries of health and populations, all of which are featured on the ICODA website.

There is an active ICODA researcher community of practice with teams now contributing to the development of a wider global health data science community and cohort, hosting regular webinars and presentations. Working in partnership with The Global Health Network, and pivoting to focus on community enablement, we have launched the Global Health Data Science Hub, now with over 1000 members. The Hub working group meets monthly with members from across the globe, encouraging collaboration and knowledge exchange across health data scientists on a global scale.

In September 2021, Professor Trudie Lang joined HDR UK as the Global Research Director. Professor Lang is responsible for leading a new programme, HDR Global. This builds on the ICODA initiative, with the objective of improving health data science practices globally, using learnings acquired from HDR UK and ICODA. HDR Global, alongside The Global Health Network and partners in Africa, Asia and Latin America, has been awarded a five-year grant from the Bill & Melinda Gates Foundation to take forward HDR UK's Global work.

As the ICODA initiative comes to a close in the second half of 2022, we are sharing open data governance processes, tools and best practices and infrastructure lessons learned to ensure we are better positioned for future global health challenges.

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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 work of the BHF Data Science Centre has grown substantially over the year, with impacts presented at our [Research Showcase](#) event in March 2022. Over 500 people registered to join the event to hear key speakers who included Professor Nilesh Samani, Medical Director of the BHF, and Kelvin Pitman, patient contributor to our Oversight Committee. The virtual event highlighted activities, such as enabling linked health data research across the UK, pioneering large-scale cardiovascular imaging, and advancing data-enabled clinical trials.

The CVD-COVID-UK consortium, a NIHR-BHF flagship project which was set up in 2021 to understand the relationship between COVID-19 and cardiovascular diseases has enabled secure access to a linked health data resource covering 54.4 million people in England. The data is available to UK researchers to collaborate in NHS Digital's secure trusted research environment and has contributed to research including a [study](#) that suggested that blood-thinning medications in patients with cardiovascular disease is associated with lower risk of death from COVID-19.

Several workshops during the year have informed our plans for our thematic areas including [cardiovascular imaging](#), [wearables](#), and [data enabled clinical trials](#). These workshops have involved representatives from the NHS, academia, policy groups and the public.

In the summer of 2021, we joined forces with Diabetes UK and the British Heart Foundation to co-produce a strategic partnership that has evolved into the Diabetes Data Science Catalyst. This strategic partnership is a model for collaboration with other charities.

Research outputs from the centre during the year included:

- A [study](#) in PLoS Medicine led by the CVD-COVID-Consortium showing elevated risk of thrombosis following vaccination with the AstraZeneca COVID vaccine, although lower than that with infection. This study was widely cited in the mainstream press.
- A study published in [BMJ](#) on establishment of a TRE enabling safe and secure whole population research on Covid-19 and cardiovascular disease (Wood and Sudlow)

We host a series of monthly webinar [series](#) showcasing our work or stimulating new ideas by hosting invited external speakers. These events often generate insightful discussion. We also engage regularly with our Public and Patient representatives and a member of the CVD-COVID-UK Approvals and Oversight Board has written an [opinion piece](#) on using health data.

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Assembly of a UK-wide data infrastructure and services for health research

UK Health Data Research Alliance

HDR UK is delivering not only technology, but the underpinning governance, ethics, standards, public engagement and data curation to enable health data research. HDR UK has created the [UK Health Data Research Alliance](#), the [Health Data Research Innovation Gateway](#) and has convened a network of Trusted Research Environments (TREs) across the UK. This has enabled discovery and safe research access to over 720 datasets held by 60 data custodians (out of an estimated 5,000 UK health datasets currently in research use). For the first time ever, research is now possible using linked, UK-wide data on a population of more than 65 million people.

Funded by UK Research and Innovation's Industrial Strategy Challenge Fund, Health Data Research UK is working in partnership to unite UK health data through the creation of a national health data research infrastructure since 2019. Our convenorship of the [UK Health Data Research Alliance](#) (the 'Alliance'), our improvements across the [Health Data Research Innovation Gateway](#) (the 'Gateway') and our management of the network of [Health Data Research Hubs](#) has delivered impact for industry, the NHS and patients across the UK who are benefiting from medical discoveries and breakthroughs resulting from research using health data.

The Alliance is a growing partnership of leading healthcare and research organisations who have united to establish best practice for the ethical use of large-scale health data for research. During 2021/22 membership of the Alliance grew to 67 members with new members announced in [May 2021](#), [November 2021](#) and [January 2022](#). In a year that has delivered some of the greatest collaborative efforts to respond to the pandemic, 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 coordinated approach to health data research infrastructure. Together the Alliance members are making significant progress to establish best practice and inform policy in health data research.

In December 2021, the Alliance published a [White Paper on principles, approaches and guidelines for data sharing and linking Trusted Research Environments \(TREs\)](#), as well as examples of best practice drawing on the experiences of Alliance members and their colleagues across the world. The guidelines are for UK data custodians and other organisations involved in data sharing and information governance both within and beyond the health sectors and are structured around the 'Five Safes' framework for the access of health data. The paper also sets out principles for the federation of Trusted Research Environments - how they can be linked, to substantially enhance the scale of secure and trustworthy data linkage and research.

A data use register – also known as a data release register or list of approved projects – is a public record of how data is being used for research, by whom and most importantly for what purpose, and it offers a clear demonstration of the benefit and value of using health data. In January 2022, the [Alliance published recommendations](#) for a data use register standard to be adopted by organisations responsible for the safe sharing of data used for research and innovation, following consultations and workshops with health data research organisations, universities, data custodians, patients and the public. The Alliance is now working with data custodians to support adoption of this standard and improve transparency in data use.

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Health data research to improve people's lives relies on a set of common standards for healthcare data and metadata. The Alliance has carried out data user and custodian surveys with academic researchers, charities, data custodians, healthcare providers, life science companies and AI and technology companies to understand the current use of health data standards and opportunities for greater alignment. These identified a higher level of data standards expertise in industry compared with academia, that two thirds of health data users had basic or no data standards expertise and that almost 90% of users were in support of a core set of data standards to enable health data research. Data custodians and data users were also discovered to be using a wide range of data standard and data models. Based on this work, in November 2021 the [Alliance published a White Paper](#) making recommendations for data standards. The paper encourages improvements in data usefulness and usability and was developed with input from the health data community, patients and the public.

Health Data Research Innovation Gateway

The [Health Data Research Innovation Gateway](#) (the 'Gateway') was established in 2020 and is the UK's only unified platform to search, discover and request access to health datasets for research and innovation. Since then, over 750 datasets from more than 60 data custodians have been made available for researchers to search and request access to, in addition to over 3,000 other health data resources including publications, data uses, tools and educational courses.

The Gateway is not limited to being a metadata registry, but forms an entire ecosystem for fostering the curation, quality improvement, access, and ethical use of health data. To date, the Gateway has over 2,000 registered users from across the health data community who are making more than 10,000 searches a month.

Throughout 2021, COVID-19 resources continued to be added to the Gateway which inevitably shifted towards vaccine-related datasets including [vaccination status](#) and [adverse reaction data](#) from NHS Digital. The [COVID-19 Symptom Tracker Dataset](#) remains the most viewed resource on the Gateway and continues to support scientific discovery, including this recent [publication](#) in Nature Communications.

In April 2021, the [Cohort Discovery Tool](#) was launched. Delivered in partnership with [CO-CONNECT](#) and funded by UK Research and Innovation, the tool enables researchers to search by specific population criteria across multiple datasets, widening the data discovery capabilities of the Gateway even further and facilitating a faster pathway to impactful research. 11 Gateway datasets covering over 70,000 subjects are now available for researchers to discover using Cohort Discovery – the latest being the [COVIDsortium study](#) from University College London.

In October 2021, additional improvements were made on the Gateway to support data discovery with the release of the [Data Utility Wizard](#). The tool allows researchers to search for and discover datasets listed on the Gateway using specific criteria and filters, using a simple, user-friendly interface to help evaluate the likely utility of specific healthcare datasets via a series of simple questions. The development of the tool is based on HDR UK's [Data Utility Framework](#), transforming it into a practical tool that supports the research experience.

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More recently, the focus has been on the development of a [data use register](#) to publicly show how datasets published on the Gateway are being used, by whom and for what purpose. The functionality implements a [national standard for data use registers](#) created by the Alliance. It aims to improve transparency in the use of health data for research and provide a best practice example of how information about approved data uses is shared and managed. More than 800 data uses have been uploaded to the Gateway since its release in early 2022.

Two years after its creation, the Gateway is now a recognised platform for researchers to discover and request access to UK health datasets, offering a simplified and standardised approach to data access management and supporting transparency and trustworthiness in the use of health data for research across the wider community.

Health Data Research Hubs

The [Health Data Research Hubs](#) provide a rich toolkit of healthcare datasets, infrastructure and capabilities that enable users to identify, access, understand and use data to improve people's lives. Working in partnership with HDR UK, each Hub is the product of strong collaboration between the NHS, academia, industry and the public and forms an integral part of the vibrant UK research data ecosystem. Our network of Hubs are pioneering and informing the development of health data research in the UK, and globally, and is demonstrating how insights from data are improving people's lives. Since establishment, the Hubs have delivered remarkable work, including:

- Making over 200 datasets available via the Gateway
- Delivering over 500 projects involving hundreds of partners
- Carrying out over 30,000 meaningful patient and public interactions
- Delivering over 2,300 training activities
- Reducing the time to access data to 26 days (median time to get a decision on a data access request)

During the year we announced two new Hubs joining the network. The DATAMIND Hub aims to improve the use of big data for mental health research by providing expert data services, tools and expertise to a wide range of users. Mental health affects almost everyone at some point in their lives and, to varying degrees, is the biggest cause of ill-health for people living in the UK. People living with a mental illness are less likely to take part in or to remain in usual types of research studies and may also be actively excluded. This means that much of what we know about mental health is not based on the very people who are worst affected. However, the UK has some of the best data in the world, which can be used in research to understand how to prevent mental ill-health and maintain and improve people's lives. DATAMIND will maximise the value of this data by safely and securely bringing together data from diverse sources, including health records, schools and administrative data, charity data, research trials, genomics, longitudinal studies and cohort data.

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In partnership with the Medical Research Council (MRC) and Versus Arthritis, HDR UK is leading the Alleviate: APDP Pain Research Data Hub (Alleviate Hub) to advance necessary research into chronic pain. Chronic pain is a major unmet public health challenge, with little known about its exact cause. Many pain-related datasets from research studies already exist across the UK; however, prior to now, there has been no national approach to coordinating and managing this data. The Alleviate Hub will address this challenge by safely and ethically bringing together pain-related data from diverse UK research cohorts, providing researchers and innovators with the ability to link pain-related health data.

The DARE UK (Data and Analytics Research Environments UK) programme

DARE UK (Data and Analytics Research Environments UK) is a UK Research and Innovation (UKRI) programme which aims to design and deliver a more joined-up, efficient and trustworthy national data research infrastructure. This is to support safe and secure cross-domain analysis of sensitive data at scale for public good.

Phase 1 of the DARE UK programme, which began in July 2021 and is jointly led by HDR UK and ADR UK (Administrative Data Research UK), has been an extensive listening exercise with stakeholders across the UK, including researchers, technologists, the public and others. The goal has been to understand, through open dialogue, what's needed to enable more efficient, coordinated and trustworthy data research. The aim is to ensure that subsequent phases of DARE UK work to address the needs of the UK in making the best use of data at scale for public benefit.

Engagement so far during DARE UK Phase 1 has included several key complementary activities. An initial landscape review, published in October 2021, engaged broadly across the UK research and innovation ecosystem to establish an initial, broad framing of the key focus areas for the landscape that could be taken forward into further investigation, analysis and engagement. The review involved 60 interviews with a total of 79 stakeholders selected from across the spectrum of research disciplines, as well as two open workshops with approximately 100 researchers and technologists.

In January 2022, a portfolio of nine Sprint Exemplar Projects was initiated, having been competitively selected at the end of 2021, with a total award of over £2 million from UKRI. The projects are focused on uncovering and testing early thinking in the development of a coordinated national data research infrastructure to inform future directions of DARE UK. Delivery of project outputs is scheduled for the end of August 2022.

In January and February 2022, a UK-wide public dialogue was held via a series of deliberative workshops with 44 members of the public. The aim was to deepen public conversation around data research practices and capture tangible actions that could be taken forward to better address public views. The dialogue found people want trustworthy researchers to have better access to their sensitive data for research in the public interest, but that more proactive transparency is needed around who is accessing sensitive data, how and why.

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In March 2022 a series of six virtual workshops was held to seek further input and feedback on a set of emerging recommendations shaped around six thematic areas of focus in the context of a coordinated national data research infrastructure. The input from the workshops has informed the further development of the recommendations.

The findings of DARE UK Phase 1 activities are now being incorporated into a findings report – a draft version of which went out to public consultation in July 2022 – with a comprehensive set of recommendations for the delivery of a coordinated national data research infrastructure. The final report is due to be published at the end of August 2022.

Working in partnership as One Institute

HDR UK is a multi-disciplinary, geographically distributed, UK-wide Institute of over 1500 researchers across >39 organisations. During the year, the Institute has engaged a broader UK and increasingly global community spanning the National Health Service (NHS), research institutes, industry, charities, government and regulators with >500 organisations collaborating on programmes of health data research initiated and enabled by the Institute.

Communications and engagement

During the year, HDR UK's work with the media (broadcast, radio, press journalists) around key activities, events and campaigns, has significantly increased HDR UK's reach. It has raised awareness and boosted engagement in research projects, training and public engagement.

In Autumn 2020 HDR UK ran a public-facing campaign to share examples of the impact of data on the research response to COVID-19, identifying stories and case studies that resonated with the public. Stories were pitched to journalists and achieved strong reach across social media channels and press coverage, including a story published on the HDR UK website *12 things we've learned about COVID-19 from health data research*.

The campaign culminated in a briefing with the Medical Journalists' Association chaired by Tom Whipple, Health Editor of the Times, with a panel including Tim Spector (COVID-19 Symptom Study, King's College) and senior researchers from the HDR UK community.

In June 2021, HDR UK further enhanced its reputation as the leading voice in the health research community in response to debate around the implementation of General Practice Data for Planning and Research (GPDPR). The communications team successfully built on an existing #DataSavesLives mini campaign to support the case for GP data use in research, built around a Joint Statement that was signed by over 250 leading health researchers, as well as maintaining a drumbeat of increasing activity around key HDR UK and national moments. The campaign also included a briefing hosted by the Science Media Centre, attended by 19 journalists, resulting in national broadcast (BBC, Channel 4) and print coverage with quotes from Cathie Sudlow and Martin Landray.

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The campaign received overwhelming positive feedback from members of the UK health research community, for helping to redress the balance of the debate in the national media and put forward the positive case for the secure, trustworthy use of health data for research in the face of negative headlines.

The HDR UK website receives an average of 28,000 users a month, a 106% increase on 2020 and a 349% increase on 2019. The HDR UK website links to the [Alliance website](#), the [HDR UK Futures](#) training platform and the Gateway to provide users with a clear route to discover more detailed, tailored information in response to their user need. The quality and quantity of social media output has increased throughout the year, improving since the start of 2021 with the recruitment of dedicated digital communications expertise into the team. As at the end of January 2022, HDR UK has over 9,000 followers on Twitter, with an average of 326,000 impressions per month, and over 4,500 followers on LinkedIn. The monthly institute newsletter, *HIVE*, which provides a concise update on key activities and developments across the organisation. Some 4,900 people subscribe to HIVE, the main HDR UK newsletter.

HDR UK's annual scientific conference in June 2021 – [Data Insights in a Pandemic](#) – demonstrated the insights and value that a data-led approach has delivered during the pandemic; and showcased the scientific discoveries that establish a strong foundation for the future. The conference took place alongside the [COVID-19 National Core Studies Symposium](#), which showcased the progress on each of the six National Core Studies and their impact on UK COVID science, life sciences industry, and policy. Both events attracted over 2,300 people to register to attend.

Patient and public involvement and engagement

HDR UK has shown leadership across the sector in demonstrating transparency and trustworthiness to patients and by embedding public and patient involvement and engagement (PPIE) in research, infrastructure developments and governance. HDR UK's innovative approaches to bring public views in quickly and effectively has shaped research and improved outcomes, for example enabling agreement on national standards for data use registers – which are now visible through the Gateway, and coordinated public and patient engagement across data custodians. This year over 14,700 patients and public contributors were involved and engaged in health data research.

During the year we held a campaign to recruit new members to our Public Advisory Board, which provides strategic guidance to HDR UK. [Seven members were appointed](#), bringing new voices and expertise to the Board. The work of our Public Advisory Board, public advisors 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. During the year our PPIE has been influential across the Institute's work, driving forward a range of activities including:

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- Proactively getting involved to help shape our strategy for HDR UK's next five years, including having a public advisor as a co-lead for our PPIE approach
- Key members of funding and/or review panels, including the Health Data Research Hub Milestones, Data and Connectivity Rapid Funding Calls and the Grand Challenges ICODA COVID-19 Data Science pilot initiative
- Shaping the direction of COVID-19-specific research and communications, and providing their valuable insights to HDR UK's COVID-19 response, including through regular reports to SAGE
- Making recommendations to the Goldacre Review on the need for meaningful PPIE in the efficient and safe use of health data for research
- Leading on the development of guidance for public involvement in data access processes across the Alliance and wider health data organisations
- Co-developing guidance, including templates, for public involvement in funding calls which can be adapted used beyond HDR UK and sector-wide organisations
- Running our #AtoZHealthData twitter campaign to raise awareness and understanding of health data science whilst engaging the wider public

HDR UK learning - attracting and developing talent

Over the past year, the HDR UK Talent and Training team has taken major steps towards our goal of building a vibrant and diverse health data science workforce and responding to the UK's health data science skills shortage.

HDR UK Futures

Launched in 2021, our virtual learning environment HDR UK Futures now has over 1,700 users and houses circa 100 bitesize videos, over 12 learning pathways in topics such as Health Information Engineering, Phenomics and Accessing Health Data and gives users access to a range of online events. A subsequent refresh has added features to make playlists, track training records and earn badges. Success is monitored via user behaviour metrics and feedback, currently averaging at 5 stars. More developments are underway with a signposting feature launching in 2022.

Workshops and webinars

A successful series of workshops and webinars has been run over this period. A fully subscribed health information engineering workshop will be repeated in 2022 following extremely positive feedback. Online webinars have included topics such as Reproducibility and what it means to work in a Trusted Research Environment.

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Outreach

To increase visibility of health data science careers, we profiled diverse health data scientists on our website and bitesize videos and in February 2022 signed the [Technician Commitment](#). A LinkedIn alumni group has been set up to nurture this community and a careers event is planned for summer of 2022. We maintain a strong online presence; our monthly training E-bulletin has over 1,000 subscribers and digital marketing attracts new Futures users and the careers and training pages are among the most visited on the HDR UK website.

Partnerships

We have continued to develop our partnerships with Health Education England, the European Bioinformatics Institute, NHS Digital Leadership Academy and more, and in March 2022 we joined the Turing's Data Skills Taskforce. We sit on the NHSX's Developing Data and Analysis as a Profession Board and have commenced resource-sharing, for example EMBL-EBI now host our bitesize videos.

Masters

Our seven master's programmes, delivered in partnership with six leading universities across the four nations, is now in its second cohort and is successful at side-skilling students with quantitative skills. A third of students came from non-biomedical backgrounds and circa 25% from the first cohort went on to a PhD, 20% into graduate research positions, 30% into industry, 10% into NHS-based careers, and 5% are intercalating medical students.

HDR UK/Turing Wellcome PhD programme

Our flagship programme is now in its second cohort with nine students and seven universities. The first cohort demonstrated their value through student-led collaborations leading to accepted research papers at leading international conferences in 2021 and development of unique PhD proposals. With diversity and inclusion considerations at its core, over half of accepted students identify as either female, BAME or having a disability.

Biomedical Vacation Scholarships

Launched in 2022 this programme gives six undergraduates in the middle of quantitative degrees the chance to undertake health data research projects. Promoting diversity, priority has been given to candidates from backgrounds currently under-represented within health data science. Two-thirds of the successful candidates met widening access criteria.

Building diversity in data science

Run by HDR UK and the Alliance in partnership with [10,000 Black Interns initiative](#), our Health Data Science [Black Internship Programme](#) continues an exciting endeavour for early career Black data scientists who are currently heavily under-represented within the health data science sector. Our Health Data Science Black Internship Programme is just one of several steps that we are taking to start to address this

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underrepresentation. In 2021 we recruited 54 interns (including 30 women) to work in placements at 25 of HDR UK's partner organisations including members of the Alliance. This pioneering programme opened the door to significant opportunities for the interns, with many going on to full-time employment or more education in health data science. The programme positively and disproportionately impacted diversity in the health data science landscape not only by providing opportunity for the 50 but creating new future role models that many more can aspire to. HDR UK is now repeating the programme in 2022, which is bigger and more impactful than the Institute's first programme.

Plans for future periods

In 2022/23 HDR UK will transition to its second five-year strategy in an increasingly uncertain economic environment. HDR UK's long-term mission, to **unite the UK's data to make discoveries that improve people's lives**, remains unchanged as it moves forward into its second five years. The Institute will continue to work with its partners and funders towards a future vision in which 'large-scale data and advanced analytics benefits every patient interaction, clinical trial, biomedical discovery and enhances public health'.

HDR UK will convene partners across different geographies and sectors to unite diverse health-related data. The breadth of support for the Institute's vision and strategy is clearly demonstrated by the 59 letters of support received during a stakeholder engagement process in 2021 from a wide range of NHS, industry, academic, charity and international partners. The Institute will continue to assemble and deliver user-led health data research infrastructure and services. By bringing together diverse health data science, engineering and delivery expertise HDR UK will advance research discoveries and accelerate insights that benefit patients and the public across the UK and globally.

The Institute will narrow the gap between new research discoveries and direct impacts for patients and the public. Across pandemics and infectious diseases, non-communicable diseases - including cardiovascular disease, cancer and dementia, common and rare conditions - patients and the public will have safer, better and faster answers to causes, treatment and prevention of disease to deliver equality in health outcomes.

In the second five years, HDR UK will focus on **three integrated areas of activity** to deliver this ambition.

Research Data Infrastructure and Services: Providing the UK-wide and global co-ordination and leadership of health data infrastructure and services required to make health-relevant data FAIR. This will be built on the convening, collaborative and co-ordinating role of the **UK Health Data Research Alliance** and will comprise four **Pillars of activity**:

- Assembling the technology services ecosystem
- Trust and transparency
- Developing the tools required to make data useable
- Building skills and capacity.

Research Driver Programmes: Advancing research discoveries through high impact UK-wide programmes that:

- Address major health and societal challenges

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- Guide the development of the infrastructure and services for the benefit of other researchers
- Are outward-looking with global reach.

One Institute Partnerships: Through national leadership with a clear vision and ambition to assemble an ambitious health data research ecosystem with enduring benefits for all researchers

- As an innovative distributed UK-wide and increasingly global Institute, HDR UK will act as a flagship for team science, drawing on skills, resources, and expertise from academic, NHS, industry and government partners.

Our approach for this ambitious five-year strategy is set out in the [overview of the quinquennial review](#) and our [strategic delivery plan for 2022/23](#) are both published on our website.

Financial review

Funding

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.

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. Following the adoption of charitable status in May 2022, the remaining balance of Core (unrestricted) funding of £33m has been recognized in 2022 as required by the Charities SORP (FRS102), (2021: £11.5m). In respect of this funding the Company incurred expenditure on staffing, grants and other costs of £13.3m (2021: £11.6m).

Due to the adoption of charitable status no core funds are held as income in advance in 2022 (2021: £14m)

Restricted funding

Restricted funding is received primarily in respect of HDR UK's Uniting Data, Using and Improving Data. In 2022 income has been recognized in line with Charities SORP requirements.

- UK Research and Innovation's Industrial Strategy Challenge Fund in support of the Digital Innovation Hub Programme (2022: £ 5.7m, 2021: £5.3m)

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- 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 (2022: £10.2m, 2021: £4.4m)
- Medical Research Council funding in respect of capital investments (2022: £0.8m, 2021: £4.0m)
- COVID-19 Therapeutics Accelerator funding in support of the International Covid-19 Data Alliance and data analysis Workbench (2022 £3.5m, 2021: £1.3m)
- BHF – Data Science Centre established to carry out research using health data into the causes, prevention, and treatment of all diseases of the heart and circulation (2022 £9.4m, 2021 £0.6m)
- DARE – The UK Trusted and Connected Data and Analytics Research Environments programme aiming to deliver a national federated digital infrastructure (2022: £1.1m, 2021: 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),
- From April 2020 - 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)
- From April 2020- HDR UK South-West (University of Bristol; University of Bath)

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.

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HDR UK has also supported the establishment of two Health Data Research Hubs, PIONEER and NHS Digital.

In 2022 HDR UK funded £9.2m site and national implementation project expenditure (2021: £8.3m). £472k Health Data Research Hub expenditure was funded (2021: £1.5m).

£nil (2021: £1.9m) 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 £417k PhD Programme expenditure (2021: £184k) and £971k Masters programmes expenditure (2021: £391k).

National Core Studies: Data & Connectivity Programme

As part of the National Core Studies: Data & Connectivity programme, in 2022 HDR UK provided £5.1m (2021: £3.1m) grant funding to five 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. £1.5m was spent on rapid research projects (2021: £0.1m) and a further £1.5m was spent on additional activities with five partner organisations and cohorts (Outbreak Data Analysis Platform, Intensive Care National Audit and Research Centre, Acute Admissions, REACT, Qresearch) (2021: nil).

Reserves Policy

The Core Funders are committed to funding costs incurred by the Institute, with regular funding throughout each financial year. By the nature of this model, there is no need for significant reserves. However, the Trustees 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 2022 total unrestricted reserves were £20.0m (2021: £229k) and total restricted reserves were £12m (2021: £nil).

Risk management

HDR UK's vision and strategy are ambitious and there are risks that may impact our ability to successfully achieve our ambition. HDR UK considers risk management to be fundamental to good management practice and a significant aspect of good charity governance.

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HDR UK's risk management policies and processes make the effective management of risk an integral part of day-to-day operations at HDR UK and provide a framework to:

- Define risk governance
- Identify key risks
- Assess risks
- Develop mitigating strategies and actions
- Monitor and review risk activities
- Communicate and report risks

Risk management is an ongoing and dynamic process and HDR UK regularly reviews the risks we face and mitigation strategies. HDR UK has a Risk Register, which is structured in line with Charity Commission guidance. The Risk Register is reviewed and updated by the Executive Committee monthly, reviewed and discussed by Audit & Risk Committee (ARC) quarterly and reviewed by the full Board quarterly. As a charity, the Board of HDR UK are responsible for total risk exposure.

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

A principal concern for HDR UK is ongoing sustainable funding. HDR UK is managing this through ongoing engagement with funders, in particular with our core funders as part of our five-year quinquennial review. HDR UK has a written guarantee from MRC for future funding at a sustainable level.

Structure, Governance and Management

Status

HDR UK is registered as a Company limited by guarantee, incorporated 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 HDR UK.

The Board of Trustees govern the Company in accordance with its Memorandum and Articles of Association. The Trustees have the benefit of a qualifying third-party indemnity provision as defined by section 234 of the Companies Act 2006.

Recruitment of Trustees

The Board makes Trustee appointments for terms of three years, with an extension of up to two further terms. All Trustees give of their time freely, with the Chair receiving a remuneration which was paid during the year. Details of Trustee expenses and related party transactions are disclosed in note 17 to the accounts.

New Trustees are appointed through an open public appointment process, depending on the experience and key skills needed. New Trustees are recommended by the Nominations Committee and are formally appointed in accordance with the Articles.

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Training and Induction

On appointment, new Trustees follow a formal induction programme, which includes initial meetings with the Chair and the Trustee, provision of training via an online learning system and the provision of key governance documentation. Ongoing training is provided for Trustees as relevant throughout their term. Training has been provided to ensure Trustees are aware of their responsibilities as both company directors and charity trustees.

Organisational structure

The Board provides leadership and governance to the HDR UK. This is a strategic role that involves ensuring oversight, compliance and performance management. The Board meets at least four times per year. Day-to-day responsibility for the running of HDR UK is delegated to the Director. The Director is supported by an executive management team which contains the appropriate range of skills to ensure competent management of HDR UK.

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 during the year by Professor Sarah Harper CBE, is responsible for advising the Board on Board recruitment and skills requirement.
- The Remuneration Committee, which was chaired during the year by David Zahn followed by William Boa from 16 December 2021, is responsible for advising the Board on the remuneration of the Institute's key management personnel in the context of appropriate comparators and sector benchmarks.

Relationships with other organisations

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

Organisation	Relationship to HDR UK	Trustee 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 was Director of Policy, Ethics and Governance at the Medical Research Council until April 2021. Professor Sir James Smith's spouse was Executive Chair of the Medical Research Council from April 2018 to January 2022

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Genome Research Limited	<p>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.</p> <p>Genome Research Limited is a wholly owned subsidiary of the Wellcome Trust.</p>	Professor Sir James Smith was a Director of Genome Research Limited until July 21.
The Health Foundation	Partner with HDR UK's Better Care national research priority	David Zahn is a Governor of The Health Foundation, Chair of Investment Committee and Remuneration Committee
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. HDR UK is also a Tenant of the Wellcome trust	Professor Sir James Smith was a Director of Science for the Wellcome trust, resigned May 21
The University of Edinburgh	<p>Co-ordinating Research Organisation of the HDR UK Scotland Substantive Site and lead for HDR UK's Applied Analytics national research priority.</p> <p>Lead organisation for BREATHE - Health Data Research Hub for Respiratory Health. BREATHE is a member of the UK Health Data Research Alliance</p>	<p>Professor Andrew Morris is Vice Principal and Professor of Medicine at The University of Edinburgh</p> <p>Graham Spittle is Dean of Innovation</p>
Scottish Government	Scottish Government members are represented on the Alliance board	Professor Andrew Morris is Chair of the Scottish Government Standing Committee on Pandemics and of the Scottish Government COVID-19 CMO advisory Group

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In accordance with the Institute's policy, Trustees are required to disclose all relevant interests and register them with the Chair of Trustees 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/2022/08/HDR-UK-Register-of-Interests-07_22.pdf.

Full details of Related Party Transactions are included at note 17 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 Trustees 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 and has a written guarantee from MRC for future funding at a sustainable level. The Trustees have therefore been able to satisfy themselves that the Company is able to continue as a going concern.

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FOR THE YEAR ENDED 31 MARCH 2022

Audit information

The Trustees 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 Trustees have taken all the steps that they ought to have taken as trustees in order to make themselves aware of any relevant audit information and to establish that the Company's auditors are aware of that information.

Statement of Trustees' Responsibilities

The Trustees (who are also directors of HDRUK for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees 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 charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

So far as each of the Trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company's auditors are unaware;
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information; and
- there were no serious incidents during the previous financial year that should have been reported to the Charity Commission but were not.

HEALTH DATA RESEARCH UK
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FOR THE YEAR ENDED 31 MARCH 2022

Approval

This Trustees' report including the Strategic report was approved by the Board of Trustees on 22nd September 2022 and signed on their behalf by:



Dr Graham Spittle, CBE
Chair of the Board of Trustees
22 September 2022

INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES OF HEALTH DATA RESEARCH UK FOR THE YEAR ENDED 31 MARCH 2022

Opinion

We have audited the financial statements of Heath Data Research UK for the year ended 31 March 2022 which comprise the Statement of Financial Activities, Balance sheet, the statement of cash flows and the related notes to the financial statements, including a summary of significant accounting policies. 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 charitable company's affairs as at 31 March 2022 and of the charitable company's net movement in funds, including the income and expenditure, 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 charity 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 trustees' 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 charitable 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 trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Trustees' Annual Report. 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

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

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.

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 Trustees' Annual Report (which includes the strategic report and the directors' report prepared for the purposes of company law) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the strategic report and the directors' report included within the Trustees' Annual Report have 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 charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report (which incorporates the strategic report and 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 by the charitable company; or
- the charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement set out on page 28, the trustees (who are also the directors of the charitable company for the purposes of company law) 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 trustees 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 trustees are responsible for assessing the charitable 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 trustees either intend to liquidate the charitable 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.

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

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:

Based on our understanding of the charitable company and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to Charity and Company Law applicable 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 and the Charities Act 2011, and consider other factors such as payroll tax and income tax.

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:

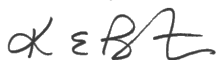
- Inspecting correspondence with regulators and tax authorities;
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- Evaluating management's controls designed to prevent and detect irregularities;
- Identifying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

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

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 charitable 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 charitable 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 charitable company and the charitable 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 Auditor

10 Queen Street Place
London
EC4R 1AG

Date: 12th October 2022

HEALTH DATA RESEARCH UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2022

	Notes	Unrestricted Funds £	Restricted Funds £	Total 2022 £	Total 2021 £
Income from:					
Donations		33,040,548	31,595,723	64,636,271	27,435,655
Investments		-	-	-	6,026
Other income		11,370	4,029	15,399	38,095
Total income		<u>33,051,918</u>	<u>31,599,752</u>	<u>64,651,670</u>	<u>27,479,776</u>
Expenditure on:					
Charitable activities					
Research	2	13,319,767	19,579,970	32,899,737	27,388,569
Total expenditure		<u>13,319,767</u>	<u>19,579,970</u>	<u>32,899,737</u>	<u>27,388,569</u>
Net income/(expenditure) before transfers		<u>19,732,151</u>	<u>12,019,782</u>	<u>31,751,933</u>	<u>91,207</u>
Transfers between Funds	12	39,565	(39,565)	-	-
Net movement in funds		<u>19,771,716</u>	<u>11,980,217</u>	<u>31,751,933</u>	<u>91,207</u>
Reconciliation of funds					
Total funds brought forward		228,514	-	228,514	137,307
Total funds carried forward		<u>20,000,230</u>	<u>11,980,217</u>	<u>31,980,447</u>	<u>228,514</u>

All of the above results are from continuing activities

The notes on pages 37 to 54 form part of these financial statements.

HEALTH DATA RESEARCH UK**BALANCE SHEET AS AT 31 MARCH 2022**

Company Registration Number: 10887014 (England and Wales)

Registered Charity Number: 1194431

	Notes	£	2022	£	£	2021	£
FIXED ASSETS							
Intangible assets	7			76,490			61,181
Tangible assets	8			122,716			123,213
				<u>199,206</u>			<u>184,394</u>
CURRENT ASSETS							
Debtors	9	33,174,251			4,937,505		
Cash at bank and in hand	15	14,618,944			22,729,593		
		<u>47,793,195</u>			<u>27,667,098</u>		
CREDITORS: amounts falling due within one year	10	(16,011,954)			(27,622,978)		
NET CURRENT ASSETS/ (LIABILITIES)				31,781,241			44,120
NET ASSETS/ (LIABILITIES)				<u>31,980,447</u>			<u>228,514</u>
CHARITY FUNDS							
Unrestricted funds	12			20,000,230			228,514
Restricted				11,980,217			-
TOTAL FUNDS				<u>31,980,447</u>			<u>228,514</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 22nd September 2022 and are signed on its behalf by:



Dr Graham Spittle, CBE
Chair of the Board of Trustees
22nd September 2022

The notes on pages 37 to 54 form part of these financial statements.

HEALTH DATA RESEARCH UK**STATEMENT OF CASH FLOWS****FOR THE YEAR ENDED 31 MARCH 2022**

	Notes	2022 £	2021 £
Cash flows from operating activities			
Net cash provided by operating activities	14	(7,991,186)	6,928,039
Cash flows from investing activities			
Interest received		-	6,026
Purchase of tangible fixed assets		(119,463)	(223,497)
		(119,463)	(217,471)
Change in cash and cash equivalents in the year		(8,110,649)	6,710,568
Cash and cash equivalents brought forward		22,729,593	16,019,025
Cash and cash equivalents carried forward	15	14,618,944	22,729,593

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

The notes on pages 37 to 54 form part of these financial statements.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

1. Accounting policies

1.1 General information

Health Data Research is a Charity and 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 Charitable Status

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

1.3 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 Trustees had previously 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.

Following the award of Charitable status on 12 May 2022, HDR UK's income recognition policy was updated to fully comply with the Charities SORP (see note 1.5, Income) A review was undertaken of all grants previously recognised under the FRS102 accruals model. Following this review £53.8m has been recognised as income in the financial year to March 2022. Had HDR UK been awarded charitable status in 2021 an additional £51.6m of income would have been recognised in that year. Total income would have been £79m in 2021 and £13m in 2022. There were no other changes to accounting policies.

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.

1.4 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees 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.

1.5 Income

All income is recognised once the Company has entitlement to the income, it is probable that the income will be received, and the amount of income receivable can be measured reliably. Income not meeting these criteria is deferred.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

1. Accounting policies (continued)

1.5 Income (continued)

Income from grants containing performance conditions is recognised as performance occurs, with all funding received in advance or in arrears of performance deferred or accrued accordingly. Otherwise income is recognised in full as soon as any other relevant conditions are satisfied.

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.

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.

1.6 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 and is analysed between grant funding and the cost of activities performed directly by HDR UK together with the associated support costs including governance costs. The staff cost element of support costs is attributed to grant making activities in proportion to grant expenditure and direct expenditure. Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

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

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.

1.7 Going concern

The Trustees have a reasonable expectation that the Company has adequate resources to continue in operational existence for the foreseeable future. For this reason they continue to adopt the going concern basis in preparing the financial statements.

1.8 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.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

1. Accounting policies (continued)

1.8 Intangible fixed assets and amortisation (continued)

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

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.

1.9 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 depreciation is charged in the year when the asset is ready for use and no depreciation 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.

1.10 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.

1.11 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.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

1.12 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.

1.13 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.

1.14 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 significant, a discount rate is applied. The discount rate that reflects the risk specific to the liability. The unwinding of the discount is recognised within interest payable and similar charges.

1.15 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.

1.16 Critical accounting judgements and estimates

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for revenues and expenses during the year. However, the nature of estimation means that actual outcomes could differ from those estimates.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

2. ANALYSIS OF EXPENDITURE - Current year

	Direct costs £	Grant funding of activities £	Support costs £	Total 2022 £	Total 2021 £
Charitable activities					
Research	10,353,726	19,837,037	2,708,974	32,899,737	27,388,569
Total 2022	<u>10,353,726</u>	<u>19,837,037</u>	<u>2,708,974</u>	<u>32,899,737</u>	<u>27,388,569</u>

Support Costs

	Staff costs £	Premises and office costs £	Other costs £	Total 2022 £	Total 2021 £
Charitable activities					
Research	1,814,063	170,974	723,937	2,708,974	1,373,804
Total 2022	<u>1,814,063</u>	<u>170,974</u>	<u>723,937</u>	<u>2,708,974</u>	<u>1,373,804</u>

HDR UK has one type of activity. Support costs have been allocated to that one activity. Governance costs are included within support costs. Support costs related to grant funding activities included in total support costs above are £1,197,609.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

2. ANALYSIS OF EXPENDITURE - Prior year

	Direct costs £	Grant funding of activities £	Support costs £	Total 2022 £	Total 2021 £
Charitable activities Research	10,256,563	15,758,202	1,373,804	27,388,569	9,644,027
Total 2022	<u>10,256,563</u>	<u>15,758,202</u>	<u>1,373,804</u>	<u>27,388,569</u>	<u>9,644,027</u>

Support Costs

	Staff costs £	Premises and office costs £	Other costs £	Total 2022 £	Total 2021 £
Charitable activities Research	698,970	108,481	566,353	1,373,804	536,617
Total 2022	<u>698,970</u>	<u>108,481</u>	<u>566,353</u>	<u>1,373,804</u>	<u>536,617</u>

HDR UK has one type of activity. Support costs have been allocated to that one activity. Governance costs are included within support costs. Support costs related to grant funding activities included in total support costs above are £419,939.

3. GOVERNANCE COSTS

	Total 2022 £	Total 2021 £
Chair remuneration	16,430	16,430
Audit fee	20,340	16,800
Non-audit services	9,150	7,344
Legal fees	-	43,829
Board costs	107,201	66,966
	<u>153,121</u>	<u>151,369</u>

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

4. GRANTS PAYABLE

Organisation	Total 2022 £	Total 2021 £
Oxford (University)	2,804,886	779,081
Edinburgh (University)	2,656,837	1,411,232
UCL	2,478,118	2,398,902
Swansea (University)	2,081,478	2,181,998
NHS Digital	1,474,221	1,830,733
Wellcome Sanger Institute (Genome Research Ltd)	1,437,073	1,830,212
Birmingham (University)	1,223,897	2,292,187
Scottish Government	1,067,210	850,500
ICL	918,160	26,428
Bristol (University)	606,216	216,861
Other	3,089,063	1,940,068
	19,837,159	15,758,202

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/> act

In 2022 11.2% of grants payable related to Improving Data (2021: 31.3%); 6.1% of grants payable related to Training (2021: 0.9%); 38.3% related to Uniting Data (2021: 22.1%) and 44.4% related to Using Data (2021: 45.8%).

5. STAFF COSTS

Staff costs were as follows:	Total 2022 £	Total 2021 £
Staff wages and salaries	4,738,433	2,424,460
Social security costs	571,174	293,550
Other pension costs	473,262	239,165
	5,782,869	2,957,175

Not included in staff costs were recharged seconded salary costs amounting to £764,691 (2021: £482,568) and temporary staff costs of £935,861 (2021: £796,570).

Including costs incurred from recharged salary costs charged by third parties, the total compensation of key management personnel was 2022: £638,806 (2021: £457,420).

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

5. STAFF COSTS (Continued)

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

2022 No.	2021 No.
74	37
<u>74</u>	<u>37</u>

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

	2022 No	2021 No
£60,000 - £70,000	11	2
£70,001 - £80,000	7	1
£80,001 - £90,000	2	3
£90,001- £100,000	3	5
£100,001,-£110,000	2	1
£110,001-£120,000	-	-
£120,001-£130,000	1	-
£130,001-£140,000	1	-
£140,001-£150,000	1	-
£150,001- £160,000	-	1
£160,000 - £170,000	-	1
	<u>28</u>	<u>14</u>

No staff costs were capitalised in the year in addition to salaries and wages (2021: £Nil).

During the year, Dr Graham Spittle, a Trustee, received remuneration for his services as Chair of £16,430 (2021: £16,430) (see note 3). During the period, no other Trustees have been paid any remuneration or received any benefits in kind (2021: nil).

6. 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 been 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 2022

7. INTANGIBLE FIXED ASSETS

	Total Intangibles £
Cost	
At 1 April 2021	279,838
Additions	78,313
	<u>358,151</u>
At 31 March 2022	<u><u>358,151</u></u>
	Total Intangibles £
Amortisation	
At 1 April 2021	218,657
Charge for the year	63,004
	<u>281,661</u>
At 31 March 2022	<u><u>281,661</u></u>
Carrying amount	
At 31 March 2022	76,490
At 31 March 2021	<u><u>61,181</u></u>

At 31 March 2022 the value of capital commitments for intangible fixed assets was £nil (2021: £nil).

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

8. TANGIBLE FIXED ASSETS

	Short-term Leasehold improvements £	Office equipment £	Computer equipment £	Total £
Cost				
At 1 April 2021	24,883	62,285	104,798	191,966
Additions	-	-	41,150	41,150
	<u>24,883</u>	<u>62,285</u>	<u>145,948</u>	<u>233,116</u>
At 31 March 2022	24,883	62,285	145,948	233,116
	<u>24,883</u>	<u>62,285</u>	<u>145,948</u>	<u>233,116</u>
				-
Depreciation				
At 1 April 2021	24,883	13,208	30,662	68,753
Charge for the year	-	12,457	29,190	41,647
	<u>24,883</u>	<u>25,665</u>	<u>59,852</u>	<u>110,400</u>
At 31 March 2022	24,883	25,665	59,852	110,400
	<u>24,883</u>	<u>25,665</u>	<u>59,852</u>	<u>110,400</u>
Net book value				
At 31 March 2022	-	36,620	86,096	122,716
	<u>-</u>	<u>36,620</u>	<u>86,096</u>	<u>122,716</u>
				-
At 31 March 2021	-	49,077	74,136	123,213
	<u>-</u>	<u>49,077</u>	<u>74,136</u>	<u>123,213</u>

At 31 March 2022 the value of capital commitments for tangible fixed assets was £nil (2021: £nil).

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

9. DEBTORS

	2022	2021
	£	£
Trade debtors	4,819,074	2,421,904
Prepayments and accrued income	28,339,245	2,515,601
Grants Receivable	15,932	-
	<u>33,174,251</u>	<u>4,937,505</u>

10. CREDITORS: Amounts falling due within one year

	2022	2021
	£	£
Trade creditors	2,277,110	4,026,657
Accruals and deferred income (see below)	1,493,369	16,304,186
Accruals for grant payables	12,011,647	7,292,135
Other creditors	229,828	-
	<u>16,011,954</u>	<u>27,622,978</u>

	£
Deferred income	
Deferred income at 1 April 2021	14,052,205
Resources deferred during the year	(26,727)
Amounts released from previous years	(14,052,205)
	<u>(26,727)</u>
Deferred income at 31 March 2022	<u>(26,727)</u>

During the year £26.7k has been deferred as this has not met the SORP criteria for income recognition. In 2021 £14,052,205 was deferred as amounts received were not utilised in the period.

11. FINANCIAL INSTRUMENTS

	2022	2021
	£	£
Financial assets measured at amortised cost	<u>47,793,195</u>	<u>27,647,005</u>
Financial liabilities measured at amortised cost	<u>16,038,682</u>	<u>13,570,774</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 2022

12. STATEMENT OF FUNDS – current year

	Balance at 1 April 2021 £	Movement in funds		Transfers Between Funds £	Balance at 31 March 2022 £
		Income £	Expenditure £		
Unrestricted	228,514	33,051,918	(13,319,767)	39,565	20,000,230
Restricted					
Digital Innovation Hub Programme Management	-	1,114,408	(831,381)	(1,631)	281,396
Digital Innovation Hub Programme: Phase 3	-	4,628,518	(3,040,078)	(10,521)	1,577,919
Capital Investment Programme Phase 2	-	783,464	(764,197)	-	19,267
British Heart Foundation Data Science Centre	-	9,356,722	(872,629)	(1,866)	8,482,227
Wellcome Trust PhD Programme	-	190,644	(190,644)	-	-
Health Foundation – Better Care	-	75,926	(75,926)	-	-
ICODA & Grand Challenges	-	2,568,922	(1,290,232)	(8,349)	1,270,341
ICODA & Global Health Network Planning	-	970,893	(970,736)	(157)	-
World Class Labs 20/21	-	(15,489)	15,489	-	-
Population Research UK	-	460,642	(460,417)	(225)	-
Data & Connectivity Phase 0	-	1,557,000	(1,557,000)	-	-
Data & Connectivity Phase 1	-	8,694,096	(8,689,785)	(4,311)	-
DARE Phase 1	-	1,062,754	(701,339)	(12,348)	349,067
CO-CONNECT	-	151,252	(151,095)	(157)	-
Total of funds	228,514	64,651,670	(32,899,737)	-	31,980,447

Transfers between funds are fixed asset transfers of £39,565.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

12. 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 1	To support HDR UK's capital investment programme, in particular development of platforms, advance compute infrastructure and support of critical existing health data research infrastructure investments.
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.
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 ("ICODA") & Grand Challenges	To deliver the International Covid-19 Data Alliance and data analysis Workbench to support the rapid development of insights and treatments to combat the global effects of COVID-19.
ICODA & Global Health Network: Planning Grant	To enable the expansion of the ICODA workbench for COVID data analysis to low and middle income country partners
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.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

12. STATEMENT OF FUNDS (continued)

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.
Data & Connectivity National Core Study: Phase 1	To continue to respond to emerging COVID-19 research priorities, mapping key data sets required by the National Core Studies, NIHR UPH Studies and SAGE sub-groups to allow research which can inform policy and operational decision making across the UK. To further develop the data infrastructure and services across the UK to allow faster access to high priority health, administrative, molecular, and behavioural data assets for researchers working on the most important COVID-related studies, ensuring priority research questions can be answered efficiently, in a transparent and trustworthy way. To strengthen and extend the existing national Trusted Research Environments (TRE) and UK Health Data Research Innovation Gateway infrastructure through inclusive four nations approach ensuring the priority datasets for COVID-19 research are findable, accessible, inter-operable and reusable (FAIR).
DARE – Data and Analytics Research Environments UK	To scope out the delivery of a national federated digital research infrastructure to establish the next generation of secure, flexible and interoperable environments for connecting and analysing complex and sensitive multi- disciplinary data at UK scale.
CO-CONNECT – COvid Curated and Open aNalysis aNd rEsearCh plaTform	To build the data infrastructure to ensure researchers have the necessary information to answer fundamental questions around how immunity may help prevent future spread of the virus spreads in schools and workplaces, how best to treat it in hospitals, and generally how long immunity lasts.

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

12. STATEMENT OF FUNDS (continued)

STATEMENT OF FUNDS – prior 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	-	4,279,113	(4,257,129)	(21,984)	-
Capital Programme Phase 2	-	2,098,752	(1,972,664)	(126,088)	-
BHF Data science Centre	-	626,684	(624,179)	(2,505)	-
Wellcome Trust PhD Programme	-	104,432	(104,432)	-	-
Health Foundation - Better Care	-	252,684	(252,684)	-	-
ICODA and Grand Challenges	-	1,314,605	(1,311,328)	(3,277)	-
World Class Labs 20/21	-	1,865,150	(1,865,150)	-	-
Population Research UK	-	13,800	(13,800)	-	-
Data & Connectivity Phase 0	-	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 2022

13. ANALYSIS OF NET ASSETS BETWEEN FUNDS

Analysis of net funds – current year

	Unrestricted Funds 2022 £	Restricted Funds 2022 £	Total Funds 2022 £
Intangible fixed assets	76,490	-	76,490
Tangible fixed assets	122,716	-	122,716
Current assets	27,514,683	20,278,512	47,793,195
Creditors due within one year	(7,713,659)	(8,298,295)	(16,011,954)
Total of funds	20,000,230	11,980,217	31,980,447

Analysis of net funds – Prior 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

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

	2022 £	2021 £
Net income for the year (as per Statement of Financial Activities)	31,751,933	91,207
Adjustment for:		
Depreciation and amortisation charges	104,651	176,410
Net bank interest	-	(6,026)
Decrease / (increase) in debtors	(28,236,746)	(4,315,627)
(Decrease)/Increase in creditors	(11,611,024)	10,982,075
Net cash provided by operating activities	(7,991,186)	6,928,039

HEALTH DATA RESEARCH UK
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

15. ANALYSIS OF CASH AND CASH EQUIVALENTS

	2022 £	2021 £
Cash at bank and in hand	14,618,944	22,729,593
	<u>14,618,944</u>	<u>22,729,593</u>

16. OPERATING LEASE COMMITMENTS

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

	2022 £	2021 £
Amounts payable:		
In less than 1 year	1,626	1,488
In two to five years	-	4,464
	<u>1,626</u>	<u>5,952</u>

17. RELATED PARTY TRANSACTIONS

During the year, the Company received grants of £45,504k (2021: £19,843k) from The Medical Research Council (part of UK Research and Innovation). £4,502k was owed to HDR UK at 31 March 2022 (2021: £2,049k). During the year the Company received grants of £5,743k (2021: £5,295k) 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 £76k (2021: £252k) and other income of £11k (2021: £35k) from The Health Foundation. David Zahn, a Director, is a Governor of The Health Foundation.

During the year the Company received grants of £191k (2021: £104k) and incurred rent expenditure of £110k (2021: £84k) in relation to Wellcome Trust. Professor Sir James Smith, a Director, was Director of Science for the Wellcome Trust.

During the year the Company awarded grants totalling £719k (2021: £1,830k) to Genome Research Limited. £246k was owed at 31 March 2022 (2021: £nil). Professor Sir James Smith, a Director, was a director of Genome Research Limited.

During the Year the company awarded grants of £429k (2021: £425k) to Scottish government. £194k was owed at 31 March 2022 (2021: £nil). Andrew Morris is Chairman of The Scottish Government COVID-19 CMO advisory Group and Chair of the Scottish Government Standing Committee on Pandemics.

During the year the Company awarded grants of £1,676k (2021: £1,411k) and incurred expenditure of £393k (2021: £367k) in relation to seconded employees at The University of Edinburgh. £393k was owed at 31 March 2022 (2021: £319k). Professor Andrew Morris, the Director of HDR UK, is Vice Principal and Professor of Medicine at The University of Edinburgh.

HEALTH DATA RESEARCH UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

17. RELATED PARTY TRANSACTIONS (continued)

During the year, Dr Graham Spittle, a Trustee, was paid £16,430 (2021: £16,430) for his services as Chair.

During the year, Trustees were reimbursed expenses amounting to £nil (2021: £nil).

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

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