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 2023

ANNUAL REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

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LEGAL AND ADMINISTRATIVE INFORMATION

FOR THE YEAR ENDED 31 MARCH 2023

Trustees and Directors

Dr Graham Spittle, CBE, Chair – resigned 26.07.2023 Dame Julie Moore, Chair – appointed 26.07.2023

Professor Sir Alex Markham, resigned as Chair of Audit and

Risk Committee 15.12.2022, completed tenure as trustee 8.11.2023
Professor Sir James Smith completed tenure as trustee 8.11.2023
Professor Dame Janet Thornton completed tenure as trustee 8.11.2023

Professor Sarah Harper CBE, resigned as Chair of Nominations

Committee 15.12.2022

Lord James O'Shaughnessy – reappointed 1.12.2022

William Boa, resigned as Chair of Remuneration Committee and

appointed Chair of Audit and Risk Committee 15.12.2022

Alison Wilcox – appointed 22.09.2022, appointed Chair of Nominations

Committee 15.12.2022

Dr Andrew Elder – appointed 22.09.2022, appointed Chair of

Remuneration Committee 15.12.2022

Professor The Lord Ara Darzi – appointed 22.09.2022

Dr Claire Bithell – appointed 22.09.2022 Sir Mark Walport – appointed 22.09.2022 Dr Claire Newland – appointed 15.12.2022 Edosa Odara – resigned 31.01.2023

Patsy Wilkinson – appointed 5.10.2023

Company registered number 10887014

Registered office Wellcome Trust

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12 New Fetter Lane

London EC4A 1JP

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FOR THE YEAR ENDED 31 MARCH 2023

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 2023.

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. The report also describes how the risks facing HDR UK are managed.

Overview

At the start of this financial year, HDR UK was in the middle of an in-depth review by its main funders to assess its first five years since it was established in 2018 and consider proposed plans for a further five years.

Following completion of the in-depth international review, the Institute was judged as internationally competitive and leading edge in most areas. The International Panel chaired by Dame Muffy Calder concluded that:

- 1. "HDR UK had made impressive progress, establishing itself as an international leader in the health data research field."
- 2. "HDR UK's distinctive success and service to the community, playing a unique convening role was commendable."
- 3. "The cohesive interaction of infrastructure and research has enabled significant progress."
- 4. "HDR UK has developed a highly successful, world leading national resource, promoting collaborative team science and tackling important challenges in health data science."

With this very positive review of the institute's achievements, our core funders – nine of the largest government and charity research funders in the UK – awarded us £71.3 million for the years 2023 to 2028. This increase in funding for the next five years places the institute in prime position to build on its success.

In 2022-23 the institute also announced HDR Global, a new partnership programme to share data science approaches to better collaborate and help address major public health challenges in low- and middle-income countries.

It is a partnership with The Global Health Network (TGHN) and its network of partner organisations in Africa, Asia and South America to support health data science studies across a wide range of disease areas and health challenges, to improve health outcomes for all. HDR Global will assist with sharing data science skills and connecting best practice across this network to enable trustworthy use of data in regions and communities where evidence to tackle threats to public health is lacking.

The Digital Innovation Hub (DIH) Programme ended in March 2023 having achieved a step change in improving the quality of research-ready data and making it easier for researchers to discover, as well as developing services to support the effective and trustworthy use of that data.

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Alongside the data curation and services provided by the Health Data Research Hubs set up under this programme, the Innovation Gateway has improved discoverability of data assets and the UK Health Data Research Alliance has achieved consensus and convergence in key areas of data custodianship.

As the DIH Programme funding ends, HDR UK and NHS England have announced a joint workplan to continue working together on many of the areas started in the DIH Programme which are being continued through the NHS England Data for R&D programme.

In April 2023, twelve Core funded Director's Innovation Fund projects were launched with the objective of propelling the Institute's progress towards QQ2 activity. With a total budget of £2.5 million allocated across the HDR community, the projects accelerated activity across the Driver Programmes, Trust and Transparency, Capacity Building, and the Trials workstream.

In another development, a programme of rapid research projects was set up at the beginning of 2023 to examine how to ease winter pressures faced by the NHS. The 16 research projects, funded by the National Institute for Health and Care Research (NIHR), used data-driven approaches to pin-point pressures in the health care system, understand their causes and develop ways to overcome or avoid them.

The projects include studies aiming to ease pressures on emergency services by using hospital data to speed up patient flow through and out of emergency departments, as well as a project using an analysis approach called 'machine learning' to predict peaks of infection with the common bug, Respiratory Syncytial Virus (RSV), that can cause serious illness in young children and put pressure on paediatric intensive care units. Other projects will investigate the impact of cold and damp homes on people's health with the aim of informing policies to protect the most vulnerable and avoid knock-on impacts on the NHS. The results of these rapid projects will be published from Summer 2023.

These achievements, and those highlighted in this report below, are a result of the commitment and dedication of the many teams across HDR UK's distributed 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.

In 2022/23 the Institute updated its 5-year strategy and underwent a rigorous international assessment exercise which concluded that the Institute was very well positioned to deliver its mission over the next five years.

To achieve this mission our strategic delivery plan, published in March 2023 sets-out three long-term goals:

1. ACCELERATE	By implementing a national research data strategy and assembling	
TRUSTWORTHY DATA USE	infrastructure and services aligned to research and innovation needs	
2. EMPOWER RESEARCHERS	By valuing people with diverse perspectives and skills, committed to	
	open and team science to advance scientific discoveries and deliver	
	patient and public benefit	
3. PROMOTE PARTNERSHIPS	By building and maintaining critical partnerships, aligning incentives and	
	reducing complexity across a fragmented landscape to streamline health	
	data science	

We continue to deliver 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 formed part of our <u>five-year ('quinquennial') review</u> 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 2022/23 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.

Highlights of HDR UK's research impact during the year are provided below. Further examples can be viewed on <u>our website</u>.

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Applied Analytics - Making text data in health records more useable for research (Bean et al., 2023)

While electronic health records attempt to capture data in a standardised format, clinical letters remain the primary way of recording and sharing medical information. However, this unstructured text is difficult to analyse at scale and can only be converted to standardised clinical codes manually. This means that valuable data are not accessible for many studies, limiting new research insights. The CogStack project, supported by HDR UK, uses natural language processing algorithms to automate the conversion from free text to clinical codes. This was successfully applied to the records of over a million patients at King's College Hospital, revealing patterns in the age of disease onset, sex differences and comorbidities. This approach could allow the large-scale analysis of historical text data, making it research-ready for studies into multi-morbidity.

The Human Phenome - Milestone of 1000 definitions for health conditions

To make large-scale health data useable for research, computer programs need to identify traits, also known as phenotypes, from complex records that are not standardised. Researchers create definitions of each phenotype, which might be a combination of clinical codes, that the programs search for in the health record. The HDR UK National Phenotype Library is the first national platform that allows researchers to store and freely share these definitions. The Library now has over 1,000 phenotypes available to use, which are helping to improve research efficiency and accuracy. For example, this has helped to identify over 10,000 COVID-19 deaths that were previously unattributed, recognise the higher risk of dying from COVID-19 for people with cardiovascular diseases and accelerate recruitment to clinical trials by proactively identifying eligible people.

Understanding the Causes of Disease - How genetics make us chemically unique (Surendran et al., 2022)

Every one of us is unique, right down to the chemicals that circulate in our bloodstream. This variation makes it difficult to understand how these molecules influence the risk of disease and how diseases alter this chemical fingerprint. Compounds produced by the body's metabolism, called metabolites, are particularly interesting as they can reveal changes in key mechanisms. A study supported by HDR UK combined multiple datasets from the HDR UK Multi-omics Consortium and UK Biobank to analyse over 900 metabolites in the blood of almost 20,000 people. The study, the largest of its kind, identified thousands of relationships between genetic variations and metabolites. This reveals how metabolites are controlled, their relevance to health and the connection to rare genetic variants. These results could help to tailor treatments to individual patients based on their risk of adverse effects from certain drugs.

Better Care – Recommendations for implementing learning health systems (Hardie et al., 2022)

The health and care system in the UK faces significant pressures, which will require adapting and reshaping care to meet future health needs. An alternative approach to 'top-down' national policy changes is enabling providers to internally drive improvements through a learning health system (LHS). An LHS takes a systematic approach to iteratively introduce improvements using data and evidence from routine care. The final report produced by HDR UK's Better Care Catalyst Programme's Policy and Insights workstream set out the challenges and opportunities for implementing LHSs in the UK. This extensive work was based on a survey of over 100 expert stakeholders, interviews, a literature review and real-world case studies. The authors identified a gap between the promise and practice of LHSs and made recommendations for policymakers and organisational leaders to advance implementation. These fell into four key areas: learning from data, harnessing technology, nurturing learning communities and implementing service improvements.

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Public Health - Impact of the pandemic on cancer diagnosis (Greene et al., 2022)

The COVID-19 pandemic severely disrupted cancer screening programmes and presentations to primary care. While several studies examined the resulting impact on cancer mortality, most had limited data on incidence, stage and healthcare pathways to diagnosis. To assess the situation at a population level, a collaboration led by the Swansea University HDR UK team used the SAIL Databank to study Welsh cancer clinical records. An analysis of colorectal, non-small-cell lung and female breast cancers revealed that diagnoses decreased by 15 per cent overall in 2020 compared to 2019. Colorectal and female breast cancers detected through annual screening fell by 13 per cent and 48 per cent, respectively, while non-small-cell lung cancer diagnoses at emergency presentation increased by up to 16 per cent. The study's authors suggest that health services must continue optimising cancer screening programmes and transforming cancer services and primary care referrals to mitigate the impact of the pandemic.

Better, Faster and More Efficient Clinical Trials – Establishing the quality of real-world data for clinical trials (Murray et al., 2022)

Existing healthcare data, like GP notes, prescriptions and hospital data, can help to make clinical trials more efficient. However, only about five per cent of UK-based randomised clinical trials obtained routinely collected data. It can be difficult for trial sponsors to incorporate this information as they must show that the data used are reliable, complete and relevant. To help overcome some of these barriers, a report by HDR UK's Healthcare Systems Data for Clinical Trials Collaborative Group set out a process to establish the provenance (the origins and production methods) and integrity (the accuracy and reliability) of real-world data. The report demonstrated this process for two important NHS Digital datasets that are commonly requested by triallists. The authors called on data collators to systematically assess and record the provenance and integrity of each routinely collected dataset to increase their use in clinical trials.

Data and Connectivity National Core Study

HDR UK continued its joint leadership of the Data and Connectivity National Core Study (NCS) with the Office for National Statistics. The programme works with partners to make COVID-19-relevant data more readily available for research. Over the past year, the Data and Connectivity NCS has continued to inform the UK's decision-making on COVID-19 and its ensuing impact on healthcare.

In January 2023, HDR UK announced sixteen rapid research projects to study how to ease winter pressures on the NHS. The projects, designed to run for just three months, aim to publish results later this year so that they can inform policy for future winters. This approach applies lessons from the pandemic, driving research that generates results quickly and directly impacts clinical care.

The EAVE II study continued to yield valuable insights, using patient data to track the COVID-19 pandemic and vaccine effectiveness across Scotland. A study published as a pre-print in March 2023 used electronic health records to estimate that over 90,000 adults in Scotland experienced long COVID. This is likely to be an underestimate, as only some people with long COVID may have visited their doctor and self-reported surveys suggest a higher rate. However, this work is a basis for the next step in the project to predict long COVID from routinely collected data (<u>Jeffrey et al., 2023</u>).

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Another EAVE II analysis showed that the Omicron variant was associated with a lower risk of pregnancy complications than Delta. This finding will help to inform public health measures to prevent infection in pregnant women (Stock et al., 2022).

Research published in September 2022 found that the risk of vascular events, such as stroke, deep vein thrombosis and myocardial infarction, is higher for up to 49 weeks after a COVID-19 diagnosis. The study analysed records from 48 million adults in England and Wales, finding an estimated 10,500 excess vascular events after COVID-19 diagnoses. These results suggest that people at high risk of vascular events should be given preventive therapies after severe COVID-19 (Knight et al., 2022).

As well as yielding new scientific research, the Data and Connectivity NCS has continued to bring together key partners. For example, the <u>'One Wales' initiative</u> united teams across the country to respond to the pandemic led by the Swansea University HDR UK team. Through this partnership, the Data and Connectivity NCS supported the SAIL Databank to gather dozens of new data assets. The results from this collaboration led to informing Welsh policy decisions on support for people shielding, reopening schools, vaccination gaps in ethnic minorities and risks to care workers.

The collaboration with SAIL also helps research beyond COVID-19. For example, a study supported by HDR UK showed that home adaptations helped to reduce the risk of falls. Using SAIL to study over 600,000 older people in Wales, this was the first study to look at fall prevention on a large scale. This provided evidence of the effectiveness of services that identify people at risk of falling and deliver interventions (Hollinghurst et al., 2022).

ICODA – A global health data response to COVID-19

Work undertaken by HDR UK in convening the International COVID-19 Data Alliance (ICODA), which was announced in June 2020 came to conclusion in this period, with all of the driver projects completing successfully by October 2022. 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, had twelve driver projects – specific research questions bringing together a range of datasets for analysis.

Across the twelve ICODA driver projects we had an active cohort of 135 researchers from 19 countries working in our trusted research environment, the ICODA Workbench. This provided them with a wide range of analytical tools, wrapped with rigorous data governance processes and a mechanism to share meta data for further secondary research use through our ICODA Gateway. Our researchers worked 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. Over 40 publications to date have been generated by our project teams and all of our policies and processes genericised and published such that others are able to use them in future. The ICODA researchers remain active as part of a Global health data science community of practice.

Driver Project <u>iPOP</u> which worked on understanding the changes in preterm birth and stillbirth during COVID-19 lockdowns using interrupted time series and meta-analyses with harmonized data from 52 million births in 26 countries. They showed small reductions in PTB in the first, second and third months of lockdown, but not in the fourth month of lockdown, although there were some between-country differences after the first month. (M. Azad et al, Nature Human Behaviour, Feb 23).

Driver Project REHCORD which worked 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

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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).

Following on from ICODA, <u>HDR Global</u> was launched during 2022-23 – part of a five way ecosystem partnership between The Global Health Network and regional partners in Brazil, Africa and Bangladesh. Funded by the Bill & Melinda Gates Foundation, this new programme seeks to enable trustworthy data access, re-use and analysis in regions, communities and areas of global health challenge, where evidence to tackle threats to public health is lacking and builds on HDR UK's mission and expertise.

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BHF Data Science Centre

Launched in January 2020 as a partnership between HDR UK and the British Heart Foundation, the <u>BHF Data Science Centre</u> 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 the leadership team in place and good progress being made across all thematic and disease areas. Following on from the launch in May 2022 of the Diabetes Data Science Catalyst – a strategic partnership with Diabetes UK and the BHF – we have used this successful model to from a partnership with the Stroke Association and the BHF in the development of the Stroke Data Science Catalyst. We also established our Public Advisory Group (PAG) comprises 17 public contributors from diverse backgrounds who serve as public contributors. Throughout the year, their invaluable contributions have had a significant impact on various aspects of our work, including our Patient and Public Involvement and Engagement strategy. The PAG convenes quarterly and has been instrumental in ensuring that our work remains patient-centric and relevant to the public.

Key achievements made this year include:

Working with Swansea University (UKSeRP and SAIL Databank) to <u>establish a cardiovascular and diabetes</u> <u>research cohort trusted research environment (TRE)</u> to link individual disease-based cohorts with other types of health data in a safe and secure environment, to better understand the causes and consequences of disease.

Through the CVD-COVID-UK/COVID-IMPACT consortium supporting three NIHR-funded research projects to rapidly respond to and inform policy by pin-pointing pressures in the health care system, understand their causes and develop ways to overcome or avoid them.

Awarded <u>EHDEN funding for CVD-COVID-UK/COVID-IMPACT consortium</u> to map data onto the Observational Medical Outcome Partnership (OMOP) common data model, to drive standardisation and interoperability of data-driven research internationally.

Awarded funding, following a competitive funding call, to 13 data science research projects focusing on COVID-19 and its links to cardiovascular disease and diabetes.

Key research outputs from the centre during the year included:

A <u>study in Nature Medicine</u> showing a reduction in the number of people starting to take blood pressure lowering and cholesterol lowering medication in the first half of 2021 compared with the same time period in 2019. They estimated that if left untreated this could lead to more than 13,000 additional cardiovascular events.

A <u>study published in Circulation</u> showing COVID-19 infection during the first wave of the pandemic (so prior to vaccines being available) resulted in an increased risk of blood clots for at least 49 weeks post infection in England and Wales

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

UK Health Data Research Alliance

Convened by HDR UK, the Alliance is a non-for-profit association of leading health data providers, custodians and curators. Alliance members are dedicated to improving human health by maximising the potential of multiple forms of data to accelerate progress in biomedicine, health and care through development and adoption of standards, policies, and best practice. During 2022/23 the Alliance has continued to grow with 75 data custodian members as at March 2023. We have welcomed new members as diverse as Cancer Research UK, the Royal Marsden NHS Foundation Trust, UK Longitudinal Linkage Collaboration, Northern Care Alliance, Gloucestershire Hospitals NHS Foundation Trust Grampian Data Safe Haven, and National Pathology Imaging Co-operative.

Three particular areas of focus for the year have been:

- Tackling the challenge of simplifying and streamlining data access governance processes.
- Supporting adoption of the Observational Medical Outcomes Partnership Common Data Model (OMOP CDM) in collaboration with the European Health Data Evidence Network (EHDEN)
- Increasing diversity in data by addressing the challenges and opportunities in the use of data reporting ethnicity.

The Pan-UK Data Governance Steering Group is a working Group of the Alliance representing data custodians and policymakers across the four nations. The Steering Group is focused on simplifying and streamlining data access governance processes. The group is cross-sector, including representatives from the health research and administrative research communities. By bringing together cross-sectoral expertise we can learn from one another and start to facilitate alignment between processes for accessing administrative data, health and care service data and study data, utilising previous work where possible. Members of the pan-UK Data Governance Steering Group are committed to meaningful public, patient and practitioner involvement and engagement (PPIE) to enable us to build governance models on a foundation of deserved public trust. To date, three 'Action Forces' have been set up to take forward priority areas of: mapping data governance processes; developing a Trusted Research Environment (also known as Secure Data Environments) Legal Toolkit; and 'Five Safes' Form adoption and training.

The Alliance is undertaking a number of activities to support the adoption of data standards in the UK health data ecosystem. In particular, we are focusing on OMOP CDM developed by the Observational Health Data Sciences and Informatics (OHDSI) consortium. Supporting data custodians in transforming their data assets to the OMOP CDM, enables the data sets they routinely collect to be leveraged for research, and combined and federated with other data sets. Our work in this area has been accelerated through our collaboration with the EHDEN consortium to support UK data custodians in transforming their data to the OMOP CDM. Five new UK data partners have joined the initiative with our support during 2022/23, positioning the UK in the vanguard of European countries adopting OMOP. We are now working with partners including NHS England to understand the adoption of OMOP and other standards across the UK; what data has and has not been transformed to OMOP; the impact and applications of that work, the barriers to the adoption of standards, and what support is needed to overcome them.

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Diversity in data is a cross-cutting theme which aligns with HDR UK's diversity and inclusion policy. While there are many different aspects to consider within the diversity data field, during 2022/23 an Alliance working group has been focused on challenges and opportunities in the use of data reporting ethnicity. The Alliance has highlighted the need to address concerns around quality of data and missing samples that can hinder the reliability of scientific insights. The leadership of the working group has drafted a set of recommendations to improve the capturing and recording of ethnicity data in the UK, based on community feedback and input received. These recommendations will be published in the coming months.

Looking to the future, Alliance baseline funding has been secured through HDR UK core funding, enabling it to continue to maximise trustworthy use of health data by working across the entire UK 'ecosystem' and connecting with relevant international developments. The Alliance will be strengthened further by bringing together national decision makers and regulatory bodies, industry associations and research funders who have not yet had a direct role in the Alliance, but who are critical to ensuring development of an efficient health data infrastructure ecosystem. These changes are being made after consultation with existing members and other stakeholders and will help shape the legacy of the investment from the Industrial Strategy Challenge Fund (ISCF) Data to Early Diagnosis and Precision Medicine Challenge that led to the creation of the Alliance as part of the Digital Innovation Hub programme which ran from 2018-2023.

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Health Data Research Innovation Gateway

The <u>Health Data Research Innovation Gateway</u> (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. To date, over 800 datasets descriptions from 70+ data custodians have been made available on the Gateway, alongside over 4,000 other health data resources including publications, data uses, tools and educational courses.

The Gateway 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 made more than 11,000 searches in 2022. The Gateway, through its provision of a <u>single data access request process</u> (built around the Five Safes Framework), has also enabled 250+ data access enquiries and over 70 full data access requests.

Throughout 2022, a broad range of health data assets continued to be added to the Gateway. Over 1000 phenotypes are now contained within the <u>Health Data Research UK Phenotype Library</u>, making it the largest national resource for information, tools and phenotyping algorithms to allow researchers to harness data held in Electronic Health Records. The library is also integrated with health dataset information across the Gateway, allowing users to refine their search results further.

In addition, more data sources have been added to the <u>Cohort Discovery tool</u>, including population scale data from Scotland. To date, 19 Gateway datasets covering over 5 million subjects across the UK are now available for researchers to discover using Cohort Discovery. The tool, delivered in partnership with <u>CO-CONNECT</u> and funded by UK Research and Innovation, 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.

Improvements were also made to features and services on the Gateway throughout 2022 to enhance user experience further, including:

- The <u>Gateway Data Use Register</u>, launched in January 2022, aims to improve transparency in the use of health data for research and innovation and provide a best practice example of how information about approved data uses is shared and managed. This new feature describes how Gateway datasets are being used, by who and for what purpose. The register will also support researchers in identifying how datasets listed on the Gateway are already being used to help inform their data request choices, whilst the public and funding bodies might search the register to understand how the data is being used in research. More than 1000 data uses have been uploaded to the Gateway since its release in early 2022. In addition, a data use register widget (developed in September 2022) provides increased accessibility and transparency of data uses published on the Gateway by enabling a clear and direct connection from data custodian websites to relevant Gateway data uses.
- May 2022 saw the launch of a Federated Metadata Automation service. This service allows data
 custodians the option to synchronise their metadata catalogue directly with the Gateway so that data
 descriptions are automatically pulled through (and continuously updated) when onboarding datasets.
- An editable version of the Five Safes Data Access Request form was launched in July 2022 allowing data custodians to select additional questions and tailor guidance to better suit their application requirements.
- Improvements to the design of the search results page now provide users with more information about health datasets up front, including when the metadata was last updated, typical time to access and completeness of the dataset metadata. Search and filter preferences can now be saved and access to the Cohort Discovery tool and Data Utility Wizard can now be performed directly from the search page.

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Nearly three years after its creation, the Gateway is 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. In order to continuously meet the emerging needs of Gateway users, key focus areas for 2023/24 will include convening an open-source technology ecosystem community to co-create and share solutions, develop standards, enhance search capability, and support interoperability, maintainability and scalability.

Health Data Research Hubs

The <u>Health Data Research Hubs</u> 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 is 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.

2022/23 has been a year of transition for the hubs established as part of the Industrial Strategy Challenge Fund as the Digital Innovation Hub programme drew to a close and the NHS England Data for Research and Development programme launched. The Hubs have benefited from having a focus on sustainability from the outset and all Hubs have continued to operate beyond the ISCF funding period, with a variety of models for long-term legacy.

- NHS DigiTrials and Discover-NOW (London Secure Data Environment (SDE)) are directly involved in the NHS England Data for R&D programme,
- PIONEER is collaborating closely with the West Midlands SDE
- DATA-CAN, INSIGHT and Gut Reaction have all changed host organisations and are pursuing mixed sources of funding including grants, research collaborations and service contracts with industry and other users.
- BREATHE, DATA-CAN and PIONEER are also supporting HDR UK's research Driver Programmes from April 2023.

The two newer UKRI Medical Research Council (MRC) funded Hubs - Alleviate (pain) and DATAMIND (mental health) - have developed at pace, benefitting from being part of an established Hub network.

Alleviate is working with HDR UK to create an online, safe, platform as a key resource for the national pain research communities. Creating this hub will enable researchers to tackle the challenges in understanding the complexity and unpredictability of pain. It will also reveal new and improved treatments across diverse chronic and debilitating pain conditions.

DATAMIND makes the most of the UK's rich mental health data to enable coordinated research, with the aim of improving lives by transforming mental health research in the UK by providing a central, integrated data infrastructure with findable, accessible, interoperable, and reusable (FAIR) mental health data sets. Data from diverse sources, underpinned by expertise and innovation, by principles of responsible use, and by public participation, for use across universities, the NHS, the charitable sector, policy makers, and industry. In partnership with charity MQ: Transforming Mental Health, the hub supports the development of the public's involvement in mental health research to ensure that valuable contributions are included from those with lived experience. The hub also works alongside MQ to build capacity and strengthen expertise in this increasingly important area of research through the charity's data science conferences and skills development workshops.

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

<u>DARE UK (Data and Analytics Research Environments UK)</u> is a <u>UK Research and Innovation (UKRI)</u> 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. The DARE UK programme is funded through the <u>UKRI Digital Research Infrastructure</u> portfolio and is one of several investments as part of this portfolio.

Phase 1 of the DARE UK programme, which is planned from July 2021 until March 2024, is jointly led by HDR UK and ADR UK (Administrative Data Research UK). Phase 1 is 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 is needed to enable more efficient, coordinated and trustworthy data research using sensitive data. 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 sensitive data at scale for public benefit.

In 2022, a key achievement of the programme was the publishing of a set of 31 recommendations based on the stakeholder engagement and extensive listening exercise across the UK, with this document capturing and framing the key challenges within the sensitive data research landscape. This was delivered via a programme of engagement including over 60 hours of interviews and over 30 hours of workshops with more than 500 individuals including researchers, technologists, private sector representatives, members of the public and others. The final recommendations can be found here, and were published at the end of August 2022.

Feeding into the recommendations was the work of 9 Sprint Exemplar Projects kicked off in January 2022 through the DARE UK programme, funded by UKRI with a total award of over £2 million, to develop potential use cases, demonstrate the technology and explore best practice for the governance, ethical and public engagement and involvement aspects of developing a more coordinated data research infrastructure. The Sprint Exemplar Projects ran for eight months until August 2022 – further details on the portfolio of projects and their outputs can be found here.

Alongside this work the programme delivered, in collaboration with Kohlrabi Consulting, a UK-wide public dialogue to explore views regarding what a more joined-up, efficient and trustworthy national data research infrastructure should look like. A series of deliberative workshops was held with 44 members of the public from across England, Northern Ireland, Scotland and Wales in January and February 2022. The workshops explored issues related to data security, access and accreditation, trustworthiness and more. The final report, published in May 2022, presents a set of six recommendations for the trustworthy handling and use of sensitive data in research.

In the latter half of the 2022/23 financial year, post-August and the publishing of the initial recommendations, the programme's focus shifted towards refining the roadmap for the second half of Phase 1 (September '22 - March '24) and securing sign off from DARE UK Programme Board for this plan of action. The DARE UK Programme Board officially approved the roadmap in September '22 with minor adjustments, as well as three primary outputs or milestones to be delivered as part of this plan:

- Milestone 1: An architectural blueprint for a federated network of Trusted Research Environments (TRE)
- Milestone 2: A model for delivering the architectural vision defined in Milestone 1
- Milestone 3: A business case and funding model underpinning Milestones 1 and 2

These are key outputs to be delivered by the end of Phase 1 of the DARE UK programme by March '24.

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As part of this effort, a portfolio of Driver Projects was competitively selected to play a leading role in informing the design of different components of what will be a UK-wide network of trusted research environments (TREs). These 5 Driver Projects were funded through UKRI with a total award of over £2.5 million as part of the DARE UK programme, in several thematic areas of focus relevant to the programme and directly linked to the recommendations (as above) that emerged as part of the first half of Phase 1. The Driver Projects kicked off in February 2023 and are funded to run until October 2023 – further details on the portfolio of projects and their work can be found <a href="https://example.com/here-new-components-new-compone

Finally, the DARE UK Delivery Team have begun the initial drafting of an architectural blueprint for a federated network of Trusted Research Environments (TREs) in early 2023 with a target for an initial draft to be published and open for public comment in April 2023.

DARE UK has embedded Public Involvement and Engagement (PIE) in all aspects of programme ideation, strategy and delivery. In the period in review, DARE UK has held a series of public consultations, landscape review surveys, and community-wide interactions across the sensitive data research landscape, which have informed the development of the initial draft of the DARE UK Federated Architecture Blueprint, whose initial public consultation has just been concluded.

By inviting members of the public to join the programme's decision-making boards and provide feedback throughout delivery, DARE UK has sustained its commitment to transparency and accountability while demonstrating trustworthiness and promoting a community-led delivery approach. DARE UK's commitment to meaningful public participation is reflected in its strategic efforts to understand public interests and concerns in sensitive data management. As such, public voice is integral in the delivery of all programme activities.

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In March 2022 a <u>series of six virtual workshops</u> 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

The HDR UK Communications and Policy Team has built upon the successes of the previous year and delivered on increasing HDR UK's reach through working with the media, strategic communications campaigns, events and communicating impact on HDR UK digital channels.

HDR UK's digital channels continue to go from strength to strength. Between 1 April 2022 and 31 March 2023, the HDR UK website received a total of 754,069 views from 283,584 users. 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.

Social media has seen significant growth over the year. At present (June 2023), HDR UK has over 11,900 followers on Twitter, an increase of over 2000 from the previous report, while LinkedIn has seen the largest increase up to 10,600 from 4,500. The monthly institute newsletter, *HIVE*, also continues to provide a concise update on key activities and developments across the organisation to over 6,500 people.

The Black Internship Programme was one of the major projects supported by the communications team this year. HDR UK successfully attracted many talented Black data scientists to apply for the programme and partnered with community TV stations and healthcare podcasts to enable the interns to share their story globally, further promoting the programme.

The team's work generated over 150,000 impressions across HDR UK social media channels and 14,000 views to the programme information. Coverage was secured on NHS England and Genomics podcasts, as well as <a href="https://example.com/Theats-across-new-ac

In recognition of these achievements, HDR UK were awarded first place in the <u>Best diversity and inclusion</u> <u>category 2023 of the CorpComms Magazine annual awards</u>.

The team also launched a highly successful strategic communications campaign ahead of World Mental Health Day on 10 October. Running from 28 September to 14 October, the <u>Data Saves Lives: Mental Health</u> campaign focused on the important role that data has in reducing mental health care inequalities. During the campaign

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the team delivered: a dedicated web hub, written content, co-designed infographics; partnerships with mental health charities to feature HDR UK-funded researchers on their podcasts, social media content, press, and public engagement events. From inception to delivery, the whole campaign was informed by people with lived experience of mental health conditions and their loved ones.

HDR UK's annual scientific conference in December 2022 – <u>Data for Global Health and Society</u> – celebrated the global health data revolution with talks from internationally leading figures across the health data research sector, interactive panel discussions and opportunities for collaboration and networking. The 2022 conference was intended to be a hybrid event in Birmingham, but unfortunate a national train strike was announced which meant that the conference had to be delivered virtually. Despite the significant logistical challenges this presented, the conference was very successful with 878 attendees on the day.

In January 2023, HDR UK announced 16 projects funded through Data and Connectivity in partnership with NIHR that aimed to tackle winter pressures facing the NHS through the use health data research and working alongside policy analysts. As the challenges facing the NHS were of high media prominence, the communications team seized the opportunity to promote HDR UK's work through national coverage. A briefing was held with the Science Media Centre – 'How can data science help alleviate the NHS winter crisis?' – and the story was covered both in print and online across major national news publications including the Telegraph, Daily Mail, and more.

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Patient and Public Involvement and Engagement

HDR UK has shown leadership across the sector in demonstrating transparency and trustworthiness to the public by embedding Patient and Public Involvement and Engagement (PPIE) activities in governance, infrastructure developments, and research.

HDR UK's innovative approaches to bringing public views to the forefront of health data science have shaped our priorities and delivered tools to foster inclusiveness in this field. A prime example of this is the introduction of <u>standards</u> aimed at ensuring clear communication of data access procedures with members of the public. These measures were deemed instrumental in promoting understanding and trust between stakeholders and the wider community.

During the year, we held a campaign to recruit new members to our <u>Public Advisory Board</u> (PAB), which provides strategic guidance to HDR UK. Nine new members were appointed, including a Chair and a Deputy Chair, bringing new voices and expertise to our governance structure. We hugely benefitted from the work of our PAB, along with the significant contribution of numerous public members involved in PPIE activities across the Institute, including <u>HDR UK Voices</u>, British Heart Foundation's (BHF) Public Advisory Group, and DARE UK's Programme Board and Public Advisory Groups. They all made a significant impact and ensured our work was driven by delivering benefits to patients and the public. The range of PPIE activities they have been involved in over the 2022/2023 year include:

- Leading the work behind the <u>Data Saves Lives: Mental Health</u> campaign and promoting patients and public's participation in related engagement activities
- Participating in the planning, delivery, and evaluation of our 2022 Scientific Conference
- Shaping the PAB recruitment by <u>encouraging involvement</u> and participating in the process, from shortlisting to induction sessions
- Supporting the <u>Public Engagement in Data Research Initiative</u> by drafting good <u>practice standards</u> and shaping the New Families 'Your data in action' pilot campaign
- Enhancing the clarity and accessibility of HDR UK PPIE webpage and Voices communications, as well as providing guidance on all public-facing BHF Data Science Centre's outputs
- Advancing the <u>Pan UK Data Governance Steering Group</u>'s mission of streamlining the access and use of health data for research processes by contributing to each of the action forces' mission
- Informing our <u>PPIE Honoraria and Expenses Policy</u> and laying the foundations for the development of our future engagement strategy
- Co-developing <u>surveys</u> for Unstructured Data and Personal Monitoring Data, ensuring their accessibility and inclusivity.
- Co-authoring publications pertaining to Cardiovascular Priorities for Unstructured Data
- Reviewing and providing approval for applications within our CVD COVID IMPACT Consortium
- Co-presenting BHF Data Science Centre monthly webinars, as well as national webinars focused on PPIE in Data Intense Research
- Informing the <u>COVID-19 funding opportunity call</u> launched by the BHF Data Science Centre to encourage data-led research in cardiovascular disease and/or diabetes and the interaction with COVID-19
- Deliberating on core DARE UK's programme decisions and outcomes, as well as collaborating with researchers and industry experts to fulfil the programme's overarching goal
- Informing the development of recommendations for the trustworthy handling and use of sensitive data in research incorporated into the DARE UK programme strategy

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- Impacting the conduct and outcomes of the <u>DARE UK Sprint Exemplar Projects</u> and contributing to the recently started <u>Driver Projects</u>
- Participating in the DARE UK-led stakeholder roundtable to assess the need for an independent, UKwide coordinating function for PIE in the UK sensitive data research landscape.
- 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 <u>COVID-19 response</u>, including through regular reports to SAGE
- Making <u>recommendations to the Goldacre Review</u> on the need for meaningful PPIE in the efficient and safe use of health data for research
- Leading on the development of <u>guidance for public involvement in data access processes</u> 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 <u>#AtoZHealthData twitter campaign</u> 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

The online learning environment Health Data Research Futures now has over 10,000 users and houses 100+ CPD accredited bite-sized videos organised into 13 learning pathways on topics such as Artificial Intelligence for Clinicians, Privacy Enhancing Technologies and Bringing Software as a Medical Device to Market. More learning pathways are currently in development including on PPIE for clinical trials, developed in partnership with Centre for Trials Excellence Cardiff University and HDR UK North, Learning Health Systems, with University of Manchester as part of the Better Care programme, and Research Software Engineering. This year saw the first meeting of the Talent & Training Advisory Group, comprising individuals representing our key sectors and stakeholder groups to help prioritise resource and provide feedback on training activity.

Workshops and webinars

A successful series of workshops and webinars have taken place this year. A series of four webinars on Bringing Software as a Medical Device to Market attracted over 400 attendees, seeing many new interactions with industry and workshops on the same topic are in development for later in 2023. Other workshops include an Introduction to R workshop with Kings College London, Health Information Engineering and Data Wrangling with University of Manchester and a bespoke workshop on Machine Learning delivered for the CPRD team at the MHRA, which is currently being adapted into an online self-directed course. This year we piloted recovering some training costs by charging for attendance, whilst ringfencing free spaces for members of the Alliance, Alumni Network and HDR UK Global. An invitation to tender has been published for freelance trainers and educators to help us develop our training programmes moving forward.

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Outreach

Our career outreach efforts have continued over the past year, including a Researcher Roadshow delivered in partnership with UKRI and then NHS England which attracted over 250 attendees and featured inspiring career talks from speakers working in a range of health data science roles. Our Alumni network continues to grow and currently has 350 members and recently ran successful CV workshops and recruitment event. Our online reach continues to grow with our monthly training newsletter amassing almost 2000 subscribers and our HDR UK Learning Twitter account has over 7000 followers. Our careers pages continue to be among the most visited on the website and we are currently carrying out a redesign of our pages to make them more streamlined. We are working through our Technician Commitment action plan, carrying out various initiatives to empower and support the careers of technologists in the HDR UK central team and wider community.

Partnerships

We continue to work in partnership with organisations spanning the health data science ecosystem. After consultation with AnalystX on skills gaps we provided them with bite-sized videos and recently attended their key partner event. We delivered three workshops to the NHS Digital Leadership Programme on Trust & Transparency, PPIE and ED&I. We sit on NHSX's Developing Data and Analysis as a Profession Board, Turing's Data Skills Taskforce and are partnering with the Medical Schools Council, Health Education England and NHS Education Scotland to carry out a survey of UK medical school staff and students on the teaching of data science in the current UK medical school curriculum. Results of the survey will be analysed by an intern hired as part of the Black Internship Programme 2023.

Masters Scholarships

Applications are currently open for our new master's degree scholarships, jointly funded by HDR UK, Diabetes UK and Alzheimer's Research UK. The scholarships pay £10,000 towards the degree programme and allow students to carry out a research project in one of these disease areas. The scholarships offer the insights, knowledge, experience and qualifications students need to enter a field that provides many great career opportunities.

HDR UK/Turing Wellcome PhD programme

Our PhD programme goes from strength to strength with our newest cohort soon to be defining their PhD proposals to fellow academics and a panel of patients and the public. We have delivered deep-dive immersion weeks for internal and external PhD students on fairness in healthcare modelling and structural causal modelling. Later this summer students have been invited to a residential summer school in collaboration with Roche on single-cell analysis. They will have the opportunity to learn from the scientists as well as an exclusive opportunity to apply for an internship with Roche.

Biomedical Vacation Scholarships

We are now welcoming our second cohort of scholars to host organisations across the UK. Funded by the Wellcome Trust, the scholarships pay for undergraduate students in quantitative disciplines to get a taster of health data research as well as their expenses. Applicants from an underrepresented background were prioritised and supported throughout the application process. These placements have inspired some of our first cohort to change their final year modules and also helped one student secure a placement as a health data analyst.

Building diversity in data science

We hosted our first in-person closing ceremony at the Wellcome Collection for the Health Data Science Black Internship Programme in September last year, welcoming both interns and host organisations to celebrate the interns' achievements. The winning group of the technical challenge presented their work and interns also

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shared their experiences of the programme. Almost half of our 2022 interns attended a non-Russell Group university, with over 60% being women and 25 being first generation university students. Our health programme for this year attracted over 660 applicants, with 95 successful interns joining 54 host organisations this summer. We will be launching the programme this summer with an in-person opening ceremony in Birmingham.

Plans for future periods

The year 2023/24 will mark the start of HDR UK's next five-year strategy, with our core funders – nine of the largest government and charity research funders in the UK – having awarded us £71.3 million for the years 2023 to 2028.

While the institute's long-term mission to unite the UK's data to make discoveries that improve people's lives remains unchanged, we will follow a refreshed plan to increase the speed, scale and quality of health data science and so enable new discoveries.

The next 12 months will see us start work on our three strategic goals:

- 1. Accelerate trustworthy data use by implementing a national research data strategy and assembling infrastructure and services aligned to research and innovation needs.
- 2. **Empower researchers** by valuing people with diverse perspectives and skills, committed to open and team science to advance scientific discoveries and deliver patient and public benefit
- 3. **Promote partnerships** by building and maintaining critical partnerships, aligning incentives and reducing complexity across a fragmented landscape to streamline health data science

For example, we will form UK-wide, collaborative research programmes to drive forward the use of large datasets in different areas: from cancer and heart disease to respiratory disease, from the use of medicines to looking at social and environmental impacts on health.

The current fragmentation and lack of standardisation in the data will be tackled by working with many different organisations, building capabilities and supporting real team science.

Patients and the public will continue to be involved throughout the Institute's work – ensuring that access to data for research is enabled by trustworthy, safe and secure systems and generates public benefit.

Some early developments will include unveiling a new action plan that outlines how HDR UK will support the vital work and careers of technologists within the health data research sector. This is part of our response as signatories of the <u>Technician Commitment</u>, and recognises that technologists play an invaluable role in driving innovation and advancing scientific research.

A £0.5 million pound investment in data-driven approaches to tackle stroke is to be announced. The Stroke Data Science Catalyst will be led from the BHF Data Science Centre at HDR UK. More than 1.3 million people in the UK have had a stroke, which can have devastating consequences for patients and their families. This new initiative aims to speed up the search for better stroke prevention, treatments and care by enabling researchers to securely access, link and analyse existing UK health data.

Professor Cathie Sudlow, Chief Scientist at HDR UK, is to carry out an independent review of the UK's ability to use data to improve health care. The review, which will report in late 2023, has been commissioned by Professor Sir Chris Whitty, the Chief Medical Officer for England, Dr Timothy Ferris, NHS England's National Director of Transformation, and the UK's National Statistician Professor Sir Ian Diamond. The review, entitled

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Uniting Health Data in the UK, will assess the flows of health-relevant data across the four nations of the UK, offering an opportunity for policy makers to evaluate how data can be better managed to improve the public's health, while maintaining privacy and public trust. Patient groups are being consulted and will be actively involved throughout the process.

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 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 (QQ1 only), Cancer Research UK (QQ2 only), and The British Heart Foundation ("Core Funders").

In 2022/23, the Core Funders agreed in principle to provide £71.3m funding to HDR UK in the 5 years to March 2028. In line with the Charities SORP (FRS102) the full amount of Core funding has been recognised in 2023 (2022: £33m). In respect of existing core-funding the Company incurred expenditure on staffing, grants and other costs of £17.7m (2022: £13.3m).

Restricted funding

Restricted funding is received primarily in respect of HDR UK's Infrastructure and Services and Research Driver Programme strategic areas, along with our partnership programmes.

- UK Research and Innovation's Industrial Strategy Challenge Fund in support of the Digital Innovation Hub Programme (2023: £1.9m, 2022: £5.7m)
- 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 (2023: £5.1m, 2022: £10.2m)
- Medical Research Council funding in respect of capital investments (2023: £1.3m, 2022: £0.8m)
- COVID-19 Therapeutics Accelerator funding in support of the International Covid-19 Data Alliance and data analysis Workbench (2023: £1.3m, 2022 £3.5m)
- HDR Global Ecosystem funding (2023: £2.0m, 2022: £0.0m)
- 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 (2023: £8.5m, 2022: £9.4m)
- DARE The UK Trusted and Connected Data and Analytics Research Environments programme aiming to deliver a national federated digital infrastructure (2023: £1.9m, 2022: £1.1m)
- Other charitable expenditure is funded by other funders, or through cost sharing with HDR UK's collaborative partners.

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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 provided £32.4m funding in the 5 years to March 2023 to the eight HDR UK Substantive 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 (University of 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.

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

In 2023 HDR UK funded £10.2m site and national implementation project expenditure (2022: £9.2m). £472k Health Data Research Hub expenditure was funded (2022: £1.5m).

Training Programmes

HDR UK has agreements in principle to provide £6m funding in the period to 2027/28 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 2023 HDR UK funded £1.1m PhD Programme expenditure (2022: £417k) and £719k Masters programmes expenditure (2022: £971k).

National Core Studies: Data & Connectivity Programme

As part of the National Core Studies: Data & Connectivity programme, in 2023 HDR UK provided £2.1m (2022: £5.1m) 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: OpenSAFELY, SAIL Databank,

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Scotland National Data Safe Haven and Northern Ireland Honest Broker Service. £1.3m was spent on Turing cofunded projects (2022: £0.7m) and a further £1.6m was spent on additional activities with partner organisations and cohorts (Outbreak Data Analysis Platform, Intensive Care National Audit and Research Centre, REACT Imperial and scaled up acute admissions activity across 8 partners) (2022: £1.5m).

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 2023 total unrestricted reserves were £60.66m (2022: £20.0m) and total restricted reserves were £25.4m (2022: £12m). Under the terms of HDR UK's existing funding, amounts are not permitted to be set aside for general unrestricted reserves; the value of unrestricted reserves is the balance of core funds not yet spent.

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.

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.

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Structure, Governance and Management

Status

HDR UK is registered as a Company limited by guarantee, incorporated in July 2017, and a registered charity, registered 12 May 2021 (charity number 1194431).

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.

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 is responsible for advising the Board on financial management and reporting, the relationship with external auditors and risk management. Professor Sir Alex Markham stepped down as Chair of the Audit and Risk Committee on 15 December 2022 and William Boa was appointed as Chair.
- The Nominations Committee is responsible for advising the Board on Board recruitment and skills requirement. Professor Sarah Harper CBE stepped down as Chair of the Nominations Committee and Alison Wilcox was appointed as Chair.
- The Remuneration Committee 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. William Boa stepped down as Chair of the Remuneration Committee on 15 December 2022 and Dr Andrew Elder was appointed as Chair.

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Trustees' Duty to promote the success of the Charity – Section 172 Statement

Section 172 ("s.172") of the Companies Act 2006 requires the Trustees of Health Data Research UK (the "Charity" or "HDR UK") to act in a way that they consider promotes, in good faith, the success of HDR UK for the benefit of its members as a whole. In doing this, s.172 requires Trustees to have regard, amongst other matters, to the:

- (a) likely consequences of any decisions in the long term;
- (b) interests of HDR UK's employees;
- (c) need to foster HDR UK's business relationships with suppliers, customers, and others;
- (d) impact of HDR UK's operations on the community and the environment;
- (e) desirability of the Charity in maintaining a reputation for high standards of business conduct; and
- (f) need to act fairly as between members of HDR UK.

The Trustees of HDR UK fully embrace and support these reporting requirements. The Trustees receive regular training on their obligations and have access to advice from the Head of Legal, Trust and Ethics and from the Company Secretary when required. By having a good governance framework and procedures in place, the Trustees ensure that their decision making is open and transparent, decisions are sustainable in the long term and do not disproportionately affect any single stakeholder group.

We set out below how HDR UK has considered the matters found in s.172. First, we explain some of the key decisions taken by the Trustees over the past year and how stakeholder interests were considered over the course of decision-making, in line with HDR UK's values. Then we outline how we engage with our stakeholders generally and the influence that such engagements have on our decision making.

Key decisions of 2022 to 2023

1. Transition to the five-year strategy

The Trustees continually review HDR UK's strategy. As part of this, the Trustees consider HDR UK's business plan for the coming year, its budget and the impact that decisions will have in the long term.

In considering the long-term success of HDR UK, the Trustees engaged with various stakeholders to create an ambitious new strategy for the next five years, starting in 2023. The new strategy sets out an innovative programme to increase the scale, quality, speed and impact of insights derived from health data research in the UK and internationally. By 2028, the Institute will be well positioned to move forward to the next stage of its 20-year vision 'for large-scale data and advanced analytics to benefit every patient interaction, clinical trial, and biomedical discovery and to enhance public health', and to be at the centre of a global, collaborative network of health data science.

In 2022 to 2023, HDR UK has focused on the transition to its future five-year strategy, particularly on three integrated areas of activity to deliver this ambition including: (1) Accelerate Trustworthy Data Use; (2) Empower Researchers; and (3) Promote Partnerships.

HDR UK will continue to work with its partners and funders towards its future vision. The breadth of support for HDR UK's vision and strategy is clearly demonstrated by letters of support received during HDR UK's stakeholder engagement process. By bringing together diverse health data science, HDR UK will advance research discoveries and accelerate insights that benefit patients and the public across the UK and globally.

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

2. Patient and Public Involvement and Engagement

The involvement and engagement of patients and the public in governance, infrastructure developments, and research ensures HDR UK's work is inclusive, trustworthy, and driven by delivering public benefits.

HDR UK is committed to raising awareness of health data research and working with patients and the public to ensure their voices shape the access and use of health data for research that improves people's lives and delivers benefits for all.

By providing opportunities such as joining HDR UK's Public Advisory Board or participating in campaigns like *Data Save Lives: Mental Health,* patients and the public makes a significant impact on HDR UK's work and contribute to the advancement of its mission.

HDR UK involves and engages patients and the public through various means, including:

- Seeking advice from the Public Advisory Board and implementing the feedback received
- · Conducting public consultations to gather diverse perspectives on health data research matters
- Organising accessible and inclusive public events to raise awareness of health data and encourage involvement in related research
- Creating opportunities to shaping health data research, from design to dissemination and evaluation stages
- Sharing relevant information and updates through webpage, social media, and newsletters.

3. Championing Diversity in Data Science

The Board is committed to developing an inclusive culture that promotes diversity. Opportunities have been provided to those from socio-economic backgrounds that are currently underrepresented within health data science.

In response to the significant underrepresentation of Black people in data science, HDR UK launched a Black Internship Programme with interns matched to data roles in Alliance partner organisations. The Black Internship programme is currently in its third year. HDR UK is pleased that many candidates went on to secure roles in the field.

Open discussions about issues faced in the workplace have fed into HDR UK's strategy. To support HDR UK's agenda, HDR UK is looking to continue to attract and retain people from diverse backgrounds. This reinforces HDR UK's open and honest approach to communicating with its people on matters of gender and ethnicity. The businesses goals will be tracked on a frequent basis.

Stakeholder Engagement

We set out below how we engage with our key stakeholders:

• The Public and Patients

Engagement

The public and patients are critical to HDR UK. HDR UK aims to work in partnership with the public and patients to ensure transparency to build trustworthiness in data initiatives.

HDR UK's innovative approach to bring public views in quickly and effectively has shaped research and improved outcomes with thousands of patients and members of the public contributing to HDR UK's work.

How this engagement influenced Board discussions and decision making

HDR UK has widened its public engagement and reach through social media, press campaigns, and events, showcasing the benefits and impact of data. Insights are regularly shared with the Board through quarterly MI packs.

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

Funders

Engagement

HDR UK liaised and interacted with its funders to understand those aspects which are uppermost on their agendas.

How this engagement influenced Board discussions and decision making

Insights are regularly shared with the Board through quarterly Management Information packs. Trustees and members of the executive regularly seek and review feedback from funders, which directly feed into Board discussions and inform strategic decision making.

Employees

Engagement

By engaging with its people, HDR UK will achieve its aim of advancing research discoveries and accelerating insights that benefit patients and the public across the UK and globally.

HDR UK's employees are a strong and talented group of people who work with skill and enthusiasm. We seek regular feedback through staff surveys to assess employee engagement, reduce employee attrition and build stronger teams.

How this engagement influenced Board discussions and decision making

Understanding staff sentiment helps HDR UK to understand how to improve its relationship with employees. HDR UK continues to build a working environment that advances equity, diversity and inclusion.

Partnerships and Suppliers

HDR UK's partnerships have continued to grow and flourish during the year which demonstrates the value of combining expertise to deliver further and faster on joint ambitions. HDR UK partners with various institutes to further advance its health research to improve patient care.

How this engagement influenced Board discussions and decision making

Members of the executive regularly seek feedback from Partners and Suppliers, which feed into Board discussions and inform strategic decision making.

Wider Community

HDR UK's solutions directly and indirectly impact a whole host of stakeholders including patients and public, data custodians and researchers. By operating responsibly and sustainably, HDR UK increases accessibility to its services which is core to its purpose.

How this engagement influenced Board discussions and decision making

The work of HDR UK is centred around medical innovation for the benefit of all:

- Uniting health data by bringing together the UK's datasets and making them safely and securely discoverable and
 accessible for research through the UK Health Data Alliance and Innovation Gateway, in a way that earns the trust
 of patients and the public.
- Improving health data by providing tools, methods, hubs, and national expertise in health data quality improvement for researchers and innovators.
- Enabling research and innovation that has a large-scale impact, demonstrating novel approaches to health data use, and establishing an expert group of national research leaders in health data science.

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

The Trustees are mindful of the impact that the business and solutions have on the wider community. HDR UK's science strategy is centred on prioritising areas that will have the maximum impact for the health of patients and populations across the UK.

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 is a	Dr Graham Spittle is a Council
UK Research and Innovation)	member of the Company. UKRI	Member of the Medical Research
Innovate UK (part of UK Research	brings together the seven research councils, Innovate UK	Council
and Innovation)	and Research England. UKRI provides funding grants to the Company through the Medical Research Council and Innovate UK.	Professor Sir James Smith's spouse was formerly Executive Chair of the Medical Research Council from April 2018 to January 2022
		Alex Markham is Non-Executive Director of Innovate UK, Medicines Discovery Catapult
		Claire Newland is the Medical Research Council Director of Policy, Ethics & Governance
		Emily Jefferson is a Member of the Longitudinal Population Studies Strategic Advisory Panel, MRC and a Member of the MRC Longitudinal Population Studies Task and Finish Group
		Cathie Sudlow is Deputy Chair of the MRC Data Science Advisory Group
Genome Research Limited	Co-ordinating Research	Professor Sir James Smith was a
	Organisation of the HDR UK	Director of Genome Research
	Cambridge Substantive Site and	Limited until July 21.
	lead for HDR UK's Understanding	
	the Causes of Disease national	
	research priority.	

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

TOR THE TEAR ENDED 31 WARCE		
	Genome Research Limited is a	
	wholly owned subsidiary of the	
	Wellcome Trust.	
	Genome Research Limited is the	
	recipient of Core funded grants.	
Wellcome Trust	Wellcome Trust provides funding	James Smith was the Director of
	grants to the company directly for	Science for the Wellcome trust,
	the HDR UK Turing Wellcome PHD	resigned May 21
	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	
The University of Edinburgh	Co-ordinating Research	Andrew Morris is Vice Principal
,	Organisation of the HDR UK	and Professor of Medicine at The
	Scotland Substantive Site and lead	University of Edinburgh
	for HDR UK's Applied Analytics national research priority.	Graham Spittle is Dean of
	Hational research priority.	Innovation
	Lead organisation for BREATHE -	
	Health Data Research Hub for	Cathie Sudlow is Professor of
	Respiratory Health. BREATHE is a	Neurology and Clinical
	member of the UK Health Data	Epidemiology at the University of
	Research Alliance and are	Edinburgh
	represented on the Alliance	, i
	Council	
	The University of Edinburgh is the	
	recipient of grants through Core	
	funds, the Data and Connectivity:	
	National Core Studies programme,	
	and The Alan Turing Institute HDR	
Santial Comment	UK D&C Funding Call.	Andre Marchine Cl. 1 Cit
Scottish Government	Scottish Government members	Andrew Morris is Chair of the
	are represented on the Alliance Council.	Scottish Government Standing
	NHS Scotland and Public Health	Committee on Pandemics and of
	Scotland are Alliance member	the Scottish Government COVID-
	organisations.	19 CMO advisory Group.
	3	
	Scottish Government members	
	are the recipients of grant funding	
	through the Data and	
	Connectivity: National Core	
	Studies Programme.	

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

Imperial College Healthcare NHS	Imperial College Healthcare NHS	Ara Darzi is Consultant Surgeon at
Trust	Trust is an Alliance member and is	Imperial College Healthcare NHS
	represented on the Alliance Council.	Trust.
Department of Health & Social	Department of Health and Social	Ara Darzi is a Member of the
Care	care is a funder for the Winter	Recovery, Resilience and Growth
	Pressures fund.	Oversight Group (RRG),
		Department of Health & Social
		Care
University of Oxford	QResearch is a not-for-profit	Sarah Harper is Professor of
	collaboration between the	Gerontology.
	University of Oxford and EMIS. QResearch is an Alliance member	
	and is represented on the Alliance	Throughout 2022/23, Trudie Lang
	Council.	(HDR UK's Global Research
		Director) has been seconded to
	The University of Oxford is the co-	HDR UK from Oxford university.
	ordinating Research Organisation	This relationship ended 31 May
	of the HDR UK Oxford Substantive Site.	2023.
	The University of Oxford is the	
	recipient of grants through Core	
	funds and the Data and	
	Connectivity: National Core	
	Studies programme.	
	A grant agreement was signed	
	between HDR UK and the	
	University of Oxford (specifically	
	the Centre for Tropical Medicine	
	and Global Health), taking effect 1	
	July 2022 and lasting 5 years. This is a grant from the Bill & Melinda	
	Gates Foundation, with Oxford	
	acting as lead and HDR UK as a	
	partner in this arrangement (i.e.	
	funds flow from BMGF to Oxford	
	to HDR UK)	
NHS Digital	Recently merged with NHS	Alex Markham, Andrew Morris,
	England, sitting within the	David Seymour and Cathie Smith
	Transformation Directorate. NHS	are members of NHS Digital,
	England are represented on the	Research Advisory Group
Imperial College London	Alliance Council Imperial College London is part of	Ara Darzi is Paul Hamlyn Chair &
imperial college Lolldoll	the HDR UK London Substantive	Co-Director of Institute of Global
	Site.	Health Innovation, Imperial
		College London.
		conege London.

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

	Imperial College London is a recipient of grant funding through the Data and Connectivity: National Core Studies Programme and the recipient of Core funding via University College London as part of the HDR UK London Substantive Site	James O'Shaughnessy is Visiting Professor at Institute of Global Health Innovation, Imperial College London. Mark Walport is Honorary Distinguished Professor of Medicine, Imperial College London and Chair, Imperial College Health Partners. Cathie Sudlow is a Member of the External Advisory Board, UKRI CDT in AI for Healthcare, Imperial College London
Imperial College Academic Health Sciences Centre Partnership Board	Imperial College Healthcare NHS Trust is an Alliance member and is represented on the Alliance Council.	Mark Walport is Chair of Imperial College Academic Health Sciences Centre Partnership Board
Research Data Scotland Board	Research Data Scotland are an Alliance member have a representative on the Alliance Council.	Andrew Morris was in attendance at Research Data Scotland Board
NIHR	NIHR Clinical Research Network and NIHR Bioresource are both Alliance members and have representative within the Alliance Council	Cathie Sudlow is a Member of the UK Government Clinical Research Recovery, Resilience and Growth Programme Data and Digital Subgroup, UK Government, NHS Transformation Directorate, NIHR
University of Dundee	Research Organisation within HDR UK Substantive Site and lead for the Alleviate Hub	Emily Jefferson's academic appointment is at University of Dundee

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.

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

Objectives and activity

Objectives

HDR UK's main objectives, 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 information

in 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. A grant award letter from MRC UK to HDR UK for £71.3m was signed 5th April 2023. The Trustees have therefore been able to satisfy themselves that the Company is able to continue as a going concern.

Streamline Energy and Carbon Reporting

The 2018 Streamlined Energy and Carbon Reporting Regulations, imposed by the 2019 SECR regulations, require large unquoted companies to include energy and carbon information within their trustees' report, for any period beginning on or after 1 April 2019.

HDR UK did not consume more than 40,000 kWh of energy in this reporting period, therefore it has qualified as a low energy user and is exempt from reporting under the streamlined Energy and Carbon Reporting (SECR).

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

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.

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2023

Approval

This Trustees' report including the Strategic report was approved by the Board of Trustees on 10 November 2023 and signed on their behalf by:

Dame Julie Moore

Chair of the Board of Trustees

Julie Moore

INDEPENDENT AUDITOR'S REPORT

FOR THE YEAR ENDED 31 MARCH 2023

Opinion

We have audited the financial statements of Heath Data Research UK for the year ended 31 March 2023 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 2023 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

INDEPENDENT AUDITOR'S REPORT

FOR THE YEAR ENDED 31 MARCH 2023

inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

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.

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,

INDEPENDENT AUDITOR'S REPORT

FOR THE YEAR ENDED 31 MARCH 2023

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, regulation and fraud;
- Evaluating management's controls designed to prevent and detect irregularities;
- Identifying and testing journals using data analytics software; 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

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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: 15/11/2023

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Unrestricted Funds £'000	Restricted Funds £'000	Total 2023 £'000	Total 2022 £'000
Income from: Donations		58,327	27,292	85,619	64,637
Investments		-	3	3	-
Other income		1	-	1	15
Total income		58,328	27,295 ———	85,623 =====	64,652
Expenditure on: Charitable activities Research	2	17,651	13,900	31,551	32,900
Total expenditure		17,651	13,900	31,551	32,900
Net income/(expenditure) before transfers		40,677	13,395	54,072	31,752
Transfers between Funds	12	(13)	13	-	-
Net movement in funds		40,664	13,408	54,072	31,752
Reconciliation of funds Total funds brought forward		20,000	11,980	31,980	229
Total funds carried forward		60,664	25,388	86,052	31,981

All of the above results are from continuing activities.

The notes on pages 44 to 63 form part of these financial statements.

BALANCE SHEET AS AT 31 MARCH 2023

Company Registration Number: 10887014 (England and Wales)

Registered Charity Number: 1194431

	Notes	2023 £'000	£′000	2022 £'000	£'000
FIXED ASSETS					
Intangible assets Tangible assets	7 8	50 90		76 123	
CURRENT ASSETS			140		199
Debtors	9	87,221		33,175	
Cash at bank and in hand	15	8,146		14,619	
			95,367		47,794
CREDITORS: amounts falling due within one year	10	(9,455)		(16,012)	
NET CURRENT ASSETS/ (LIABILITIES)			85,912		31,980
NET ASSETS/ (LIABILITIES)			86,052	-	31,980
CHARITY FUNDS Unrestricted funds	12		60,664		20,000
Restricted	12		25,388		11,980
TOTAL FUNDS			86,052 ———	-	31,980

The financial statements were approved by the Board of Trustees and authorised for issue on 10 November 2023 and are signed on its behalf by:

Julie Moore

Dame Julie Moore

Chair of the Board of Trustees

The notes on pages 44 to 63 form part of these financial statements.

STATEMENT OF CASH FLOWS

FOR YEAR ENDED 31 MARCH 2023

	Notes	2023 £	2022 £
Cash flows from operating activities Net cash outflow provided by operating activities	14	(6,425)	(7,991)
Cash flows from investing activities Interest received Purchase of tangible and intangible fixed assets		3 (51)	- (119)
		(48)	(119)
Change in cash and cash equivalents in the year		(6,473)	(8,111)
Cash and cash equivalents brought forward		14,619	22,730
Cash and cash equivalents carried forward	15	8,146	14,619

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

The notes on pages 44 to 63 form part of these financial statements.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

1. Accounting polices

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 Basis of preparation of financial statements

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) - 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 2019), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Health Data Research UK meets the definition of a public benefit entity under FRS 102.

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

1.3 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the 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 (Note 13).

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

1.4 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 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.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

1. Accounting polices (continued)

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.

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.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

1. Accounting policies (continued)

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.

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.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

1. Accounting policies (continued)

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.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

Direct costs £'000	Grant funding of activities	Support costs £'000	Total 2023 £'000	Total 2022 £'000
9,918	19,892	1,742	31,552	32,900
9,918	19,892	1,742	31,552	32,900
Staff costs	Premises and office costs	Other costs	Total 2023	Total 2022
£'000	£′000	£'000	£′000	£'000
1,226	257	259	1,742	2,709
	9,918 9,918 9,918	costs of activities £'000 £'000 9,918 19,892 9,918 19,892 Staff Premises and costs office costs	costs of activities costs £'000 £'000 £'000 9,918 19,892 1,742 9,918 19,892 1,742	costs of activities costs 2023 £'000 £'000 £'000 £'000 9,918 19,892 1,742 31,552 9,918 19,892 1,742 31,552 Staff Premises and costs Other Total costs office costs costs 2023

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 £790k.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

2. ANALYSIS OF EXPENDITURE - Prior year

ANALISIS OF EXPENDITORE - FILO	ANALISIS OF EXPENDITORE - FILOI year					
	Direct costs £'000	Grant funding of activities £'000	Support costs £'000	Total 2022 £'000	Total 2021 £'000	
Charitable activities						
Research	10,354	19,837	2,709	32,900	27,389	
Total 2022	10,354	19,837	2,709	32,900	27,389	
Support Costs						
	Staff	Premises and	Other	Total	Total	
	costs	office costs	costs	2022	2021	
	£'000	£'000	£'000	£'000	£'000	
Charitable activities						
Research	1,814	171	724	2,709	1,374	
Total 2022	1,814	171	724	2,709	1,374	

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 £1,198k.

3. GOVERNANCE COSTS

	Total 2023 £'000	Total 2022 £′000
Chair remuneration	16	16
Reimbursement of Trustee & Director Expenses	1	-
Audit fee including VAT	25	20
Non-audit services including VAT	5	9
Legal fees	-	-
Board costs	125	107
	172 ———	153 ———

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

4. GRANTS PAYABLE

Organisation	Total 2023 £'000	Total 2022 £'000
University College London	3,075	2,478
University Of Edinburgh	2,857	2,657
Genome Research Limited	2,239	1,437
Swansea University	2,038	2,081
University of Oxford	1,920	2,805
University of Birmingham	1,533	1,224
University of Liverpool	1,184	575
University of Bristol	976	606
Scottish Government	646	1,067
Imperial College of Science, Technology and Medicine	459	918
Other	2,966	3,988
	19,893	19,836

The above are the contracting organisations.

Our research locations are: HDR UK Cambridge, HDR UK London, HDR UK Midlands, HDR UK North, HDR UK Oxford, HDR UK Scotland, HDR UK South-West, and HDR UK Wales & Northern Ireland.

Our Health Data Research Hubs are: BREATHE, DATA-CAN, Discover-NOW, Gut Reaction, INSIGHT, PIONEER, NHS DigiTrials, BHF Data Science Centre, DATAMIND, and Alleviate.

Our training locations (Masters and PhD) are: Belfast, Birmingham, Bristol, Cambridge, Edinburgh, Exeter, Leeds, London, Manchester and Oxford.

The full list of fund recipients is listed on our website: https://www.hdruk.ac.uk/about-us/locations/

5.	STAFF COSTS	Total 2023	Total 2022
	Staff costs were as follows:	£′000	£′000
	Staff wages and salaries	5,317	4,738
	Social security costs	659	571
	Other pension costs	522	473
	Apprenticeship Levy		-
		6,517	5,783

Not included in staff costs were recharged seconded salary costs amounting to £1,106k (2022: £765k) and temporary staff costs of £921k (2022: £936k).

Including costs incurred from recharged salary costs charged by third parties, the total compensation of key management personnel was 2023: £866k (2022: £639k).

Termination payments were made to the value of £15k (2022: nil). These were the result of redundancy and settlement payments.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

5. STAFF COSTS (Continued)

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

2023	2022
No.	No.
87	74

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

	2023	2022
	No.	No.
£60,000 - £70,000	14	11
£70,001 - £80,000	10	7
£80,001 - £90,000	3	2
£90,001 - £100,000	4	3
£100,001 - £110,000	1	2
£110,001 - £120,000	-	-
£120,001 - £130,000	-	1
£130,001 - £140,000	1	1
£140,001 - £150,000	1	1
£150,001 - £160,000	-	-
£160,000 - £170,000	-	-
	34	28
	===	

During the year, Dr Graham Spittle, a Trustee, received remuneration for his services as Chair of £16,430 (2022: £16,430) (see note 3). During the period, no other Trustees have been paid any remuneration or received any benefits in kind (2022: nil). Trustees have been reimbursed for expenses incurred to the total value of £668 during the year.

6. TAXATION

The Company applied to the Charity Commission for registration as a UK charity. 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.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

7.	INTANGIBLE FIXED ASSETS	Total Intangibles £'000
	Cost	
	At 1 April 2022 Additions Disposals	358 27 (179)
	At 31 March 2023	<u>206</u>
		Total Intangibles £
	Amortisation	
	At 1 April 2022 Charge for the year Disposals	282 34 (160)
	At 31 March 2023	156 ———
	Carrying amount	
	At 31 March 2023	50
	At 31 March 2022	

At 31 March 2023, the value of capital commitments for intangible fixed assets was £nil (2022: £nil).

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

8. TANGIBLE FIXED ASSETS

	Short-term Leasehold improvements £'000	Office equipment £'000	Computer equipment £'000	Total £'000
Cost				
At 1 April 2022	25	62	146	233
Additions	-	-	24	24
Disposals		(11)	(42)	(53)
At 31 March 2023	 25 	51	128	204
Depreciation				
At 1 April 2022	25	26	60	111
Charge for the year	-	13	22	35
Disposals		(7)	(25)	(32)
At 31 March 2023	25 	32	57 	114
Net book value				
At 31 March 2023	-	19	71	90
At 31 March 2022	-	37	86	123

At 31 March 2023, the value of capital commitments for tangible fixed assets was £nil (2022: £nil).

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

9.	DEBTORS						
		2023	2022				
		£′000	£′000				
	Trade debtors	1	4,819				
	Prepayments and accrued income	83,979	28,339				
	Grants Receivable	3,241	16				
		 87,221	33,174				

The increase in accrued income is largely due to the QQ2 core award of £71.3m, which has been recognised in full but not yet invoiced.

10. CREDITORS: Amounts falling due within one year

	2023 £'000	2022 £′000
Trade creditors	8,591	2,277
Accruals and deferred income (see below)	454	1,493
Accruals for grant payables	165	12,012
Other creditors	245	230
	9,455 ======	16,012
Deferred income		
Deferred income at 1 April 2022	(27)	14,052
Resources deferred during the year	-	(27)
Amounts released from previous years	27	(14,052)
Deferred income at 31 March 2023		(27)

No income has been deferred in 2023. In 2022 £26,727 was deferred as amounts received were not utilised in the period.

11. FINANCIAL INSTRUMENTS

	2023 £′000	2022 £'000
Financial assets measured at amortised cost	95,368 ————	47,793
Financial liabilities measured at amortised cost	9,455	16,012

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.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

12. STATEMENT OF FUNDS

Movement in funds

	funds				
	Balance at 1 April 2022	Income	Expenditure	Transfers Between Funds	Balance at 31 March 2023
	£′000	£′000	£'000	£′000	£′000
Total Unrestricted Funds	20,000	58,328	(17,651)	(13)	60,664
Restricted					
Core funds – restricted	-	13,000	-	-	13,000
Data & Connectivity National Core Study: Phase 1	-	4,904	(4,965)	-	(61)
HDR Global Grant	-	1,982	(7)	-	1,975
DARE Phase 1b	-	1,500	(312)	4	1,192
Digital Research Infrastructure Award	-	1,000	(1,000)	-	-
Turing Data & Connectivity Joint Call projects	-	953	(953)	-	-
Wellcome Trust PhD Programme in Science	-	907	(907)	-	-
Winter pressures programme	-	899	(793)	-	106
BHF DSC Cardiovascular and Diabetes Cohorts TRE	-	783	(783)	-	-
World Class Labs 22/23 Capital Block Grant	-	500	(115)	-	385 300
Diabetes Data Science Catalyst Alleviate Hub	-	300 300	-	-	300
DataMind Hub	-	300	-	-	300
	-	50	(2)	-	48
DARE UK – Driver Project: FX VITT Consortium	-	43	(2) (42)	-	1
Turing Wellcome Trust PhD Programme	-	43 41	(42)	-	1
Biomedical Vacation Scholarship	-	28	(28)	-	-
Health Foundation: Better Care Catalyst Programme	-	26	(26)	-	-
DARE UK – Driver Project: SATRE	-	9	(20)	-	7
International COVID-19 Data Alliance ("ICODA") & Grand	-	9	(2)	-	,
Challenges	1,270	-	(1,174)	-	96
Capital Investment Programme (Phase 2)	19	-	64	-	83
ICODA & Global Health Network: Planning Grant	-	-	-	-	
CO-CONNECT	-	-	-	-	-
DARE UK – Driver Project: SACRO	-	-	(2)	-	(2)
DARE Phase 1	349	-	(379)	-	(30)
Digital Innovation Hub Programme: Phase 3	1,578	(3)	(1,624)	4	(45)
Population Research UK	-	(4)	(3)	-	(7)
Digital Innovation Hub Programme Management	281	(8)	(300)	-	(27)
World Class Labs 20/21	-	(15)	15	-	-
British Heart Foundation Data Science Centre	8,482	(31)	(682)	5	7,774
Data & Connectivity National Core Study: Phase 0	-	(167)	160	-	(7)
Total Restricted	11,979	27,297	(13,901)	13	25,388
Total of Funds	31,979	85,625	(31,552)	-	86,052

Transfers between funds are fixed asset transfers of £13k.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

12. STATEMENT OF FUNDS (continued)

Details of restricted funds are as follows:

Fund	Purpose
Core funds – restricted	Of the total core funds awarded to HDR UK, £13m are restricted to specific programmes.
Data & Connectivity	To continue to respond to emerging COVID-19 research priorities, mapping key data sets
National Core Study:	required by the National Core Studies, NIHR UPH Studies and SAGE sub-groups to allow
Phase 1	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).
HDR Global Grant	To enable the expansion and directional lead of The Global Health Network to shift to
	Global South countries and facilitate the expansion of a network of data analysis
	science led by scientists from low- and middle-income countries.
DARE – Phases 1 and 1b -	To scope out the delivery of a national federated digital research infrastructure to
Data and Analytics	establish the next generation of secure, flexible and interoperable environments for
Research Environments	connecting and analysing complex and sensitive multi- disciplinary data at UK scale.
UK	Control for director and the development of the Health Data December Incorporation
Digital Research Infrastructure Award	Capital funding to support the development of the Health Data Research Innovation Gateway and associated infrastructure services.
Turing Data and	To fund Data and Connectivity joint call projects.
Connectivity Joint Call	To fund Data and Connectivity Joint Can projects.
projects	
Wellcome Trust PhD	To deliver the HDR UK – Turing Wellcome PhD Programme in Health Data Science
Programme in Science	
Winter Pressures	For the funding, delivery and management of the Data Science to inform NHS
programme	compound winter pressure policy
BHF DSC Cardiovascular	To fulfil the secure and efficient data storage, linkage, sharing and analysis requirements
and Diabetes Cohorts TRE	of UK-wide disease-specific cohorts, with an initial focus on cardiovascular and diabetes
World Class Labs 22/23	cohorts To support HDR UK's capital investments programme and assets.
Capital Block Grant	To support fibrox 5 capital investments programme and assets.
Diabetes Data Science	Collaboration between the BHF Data Science Centre and Diabetes UK to enhance our
Catalyst	knowledge of the links between diabetes and cardiovascular disease, facilitate a deeper
,	understanding of the causes and progression of diabetes as a major cardiovascular risk
	factor; and drive improvements in treatment and prevention of diabetes, with associated
	reductions in cardiovascular disease.
Alleviate Hub	Collaboration with the University of Dundee to develop the Alleviate Hub and to integrate
	the Hub as a Health Data Research hub participating in the Hubs Network.
Datamind Hub	Collaboration with the University of Swansea to develop the Datamind Hub and to
BARELIK B: - :	integrate the Hub as a Health Data Research hub participating in the Hubs Network.
DARE UK – Driver Project:	To develop an exemplar framework and reference implementation for federated analytic
FX (Delivering a federated network of TREs to enable	queries.
safe analytics)	
sale allalytics)	I .

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

VITT Consortium	Understanding Mechanisms of Thrombosis and Thrombocytopenia in COVID-19 and with SARS-CoV2 Vaccines
Turing Wellcome Trust	To deliver the HDR UK – Turing Wellcome PhD Programme in Health Data Science
PhD Programme	
Biomedical Vacation Scholarship	To provide 30 Wellcome Biomedical Vacation Scholarships (2020-2024).
Health Foundation: Better	To support the Better Care programme catalyst projects, providing exemplar outputs for
Care Catalyst Programme	use of data-driven analytics in clinical practice.
International COVID-19	To deliver the International Covid-19 Data Alliance and data analysis Workbench to
Data Alliance ("ICODA") &	support the rapid development of insights and treatments to combat the global effects of
Grand Challenges	COVID-19.
DARE UK – Driver Project:	To develop a reference specification for TREs, informed by existing open-source TRE
SATRE (Standardised	implementations, the TRE community, and patients and the public.
Architecture for Trust	
Research Environments)	
Capital Investment	To support HDR UK's capital investment programme in:
Programme Phase 2	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.
ICODA & Global Health	To enable the expansion of the ICODA workbench for COVID data analysis to low- and
Network: Planning Grant	middle-income country partners
CO-CONNECT – COvid	To build the data infrastructure to ensure researchers have the necessary information to
Curated and Open	answer fundamental questions around how immunity may help prevent future spread of
aNalysis aNd rEsearCh	the virus spreads in schools and workplaces, how best to treat it in hospitals, and generally
plaTform	how long immunity lasts.
DARE UK – Driver Project:	To provide a coherent intellectual framework encompassing the latest theoretical
SACRO (Semi-Automated	advances to create resources including practical guidelines for choices about OSDC in a
Checking of Research	range of technical and procedural environments.
Outputs)	
Digital Innovation Hub	To support business development of the Health Data Research Hubs, support the work of
Programme: Phase 3	the UK Health Data Research Alliance and the UK Health Data Research Innovation
riogramme. Thase 5	Gateway.
Population Research UK	To support the development of Population Research UK, a research initiative that that
ropulation Research on	maximises the insights, innovations and research efficiency of the UK's world leading
	social and biomedical data assets, including Longitudinal Population Studies.
Digital Innovation Hub	To support the development of the Digital Innovation Hub Programme under the Life
Programme Management	Sciences Industrial Strategy
World Class Labs 20/21	To support HDR UK's capital investments programme and assets, in particular those
WOITH Class Lans 20/21	relating to the national COVID-19 response.
British Heart Foundation	To deliver the BHF Data Science Centre for cardiovascular health
Data Science Centre	1.5 delite. the bili bata science centre for caralovascular ficaltif
Data Science Centre	

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

Data & Connectivity	To support and accelerate research on COVID-19, supporting the other five National
National Core Study:	Core Studies into key research questions by enabling streamlined, safe and responsible
Phase 0	access to relevant datasets relevant for the pandemic.
Health Foundation: Better	To support the Better Care programme catalyst projects, providing exemplar outputs for
Care Catalyst Programme	use of data-driven analytics in clinical practice.
International COVID-19	To deliver the International Covid-19 Data Alliance and data analysis Workbench to
Data Alliance ("ICODA") &	support the rapid development of insights and treatments to combat the global effects of
Grand Challenges	COVID-19.
ICODA & Global Health	To enable the expansion of the ICODA workbench for COVID data analysis to low and
Network: Planning Grant	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.
Data & Connectivity	To support and accelerate research on COVID-19, supporting the other five National Core
National Core Study:	Studies into key research questions by enabling streamlined, safe and responsible access
Phase 0	to relevant datasets relevant for the pandemic.
Data & Connectivity	To continue to respond to emerging COVID-19 research priorities, mapping key data sets
National Core Study:	required by the National Core Studies, NIHR UPH Studies and SAGE sub-groups to allow
Phase 1	research which can inform policy and operational decision making across the UK. To
- 11000	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	To scope out the delivery of a national federated digital research infrastructure to
Research Environments	establish the next generation of secure, flexible and interoperable environments for
UK	connecting and analysing complex and sensitive multi- disciplinary data at UK scale.
CO-CONNECT – COvid	To build the data infrastructure to ensure researchers have the necessary information to
Curated and Open	answer fundamental questions around how immunity may help prevent future spread of
aNalysis aNd rEsearCh	the virus spreads in schools and workplaces, how best to treat it in hospitals, and generally
•	how long immunity lasts.
plaTform Digital Research	Capital funding to support the development of the Health Data Research Innovation
Infrastructure Award	Gateway and associated infrastructure services.
World Class Labs 22/23	To support HDR UK's capital investments programme and assets.
Capital Block Grant	
Diabetes Data Science	To enhance knowledge of the links between diabetes and cardiovascular disease;
Catalyst	facilitate a deeper understanding of the causes and progression of diabetes as a major
	cardiovascular risk factor; and drive improvements in treatment and prevention of
	diabetes, with associated reductions in cardiovascular disease.
BHF DSC Cardiovascular	To fulfil the secure and efficient data storage, linkage, sharing and analysis requirements
and Diabetes Cohorts	of UK-wide disease-specific cohorts, with an initial focus on cardiovascular and diabetes
Trusted Research	cohorts.
Environment	
VITT Consortium	Understanding Mechanisms of Thrombosis and Thrombocytopenia in COVID-19 and with
	SARS-CoV2 Vaccines

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

DARE UK – Driver Project:	To develop a reference specification for TREs, informed by existing open source TRE
SATRE (Standardised	implementations, the TRE community, and patients and the public.
Architecture for Trust	
Research Environments)	
DARE UK – Driver Project:	To provide a coherent intellectual framework encompassing the latest theoretical
SACRO (Semi-Automated	advances to create resources including practical guidelines for choices about OSDC in a
Checking of Research	range of technical and procedural environments.
Outputs)	
DARE UK – Driver Project:	To develop an exemplar framework and reference implementation for federated analytic
FX (Delivering a federated	queries.
network of TREs to enable	
safe analytics)	
Alleviate Hub	Collaboration with the University of Dundee to develop the Alleviate Hub and to integrate
	the Hub as a Health Data Research hub participating in the Hubs Network.
Datamind Hub	Collaboration with the University of Swansea to develop the Datamind Hub and to
	integrate the Hub as a Health Data Research hub participating in the Hubs Network.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

12. STATEMENT OF FUNDS (continued)

STATEMENT OF FUNDS – prior year

	Balance at	Moveme	Movement in funds		Balance at	
	1 April 2021	Income	Expenditure	Between Funds	31 March 2022	
	£′000	£'000	£'000	£′000	£′000	
Unrestricted	229	33,052	(13,320)	40	20,001	
Restricted		•	, , ,		,	
Digital Innovation Hub Programme Management	-	1,114	(831)	(2)	281	
Digital Innovation Hub Programme: Phase 3	-	4,629	(3,040)	(11)	1,578	
Capital Investment Programme Phase 2	-	783	(764)	-	19	
British Heart Foundation	-	9,357	(873)	(2)	8,482	
Data Science Centre		191	(101)			
Wellcome Trust PhD Programme Health Foundation – Better Care	-	76	(191) (76)	-	-	
ICODA & Grand Challenges	-	2,569	(1,290)	(8)	1,270	
ICODA & Global Health Network Planning	-	971	(971)	-		
World Class Labs 20/21	-	(15)	15	-	_	
Population Research UK	-	461	(460)	-	_	
Data & Connectivity Phase 0	-	1,557	(1,557)	-	-	
Data & Connectivity Phase 1	-	8,694	(8,690)	(4)	-	
DARE Phase 1	-	1,063	(701)	(12)	349	
CO-CONNECT	-	151	(151)	-	-	
Total of funds	229	64,653	(32,900)	1	31,980	

Transfers between funds are fixed asset transfers of £40k.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

13. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted Funds 2023 £'000	Restricted Funds 2023 £'000	Total Funds 2023 £′000
Intangible fixed assets	50	-	50
Tangible fixed assets	90	-	90
Current assets	67,029	28,338	95,367
Creditors due within one year	(6,506)	(2,949)	(9,455)
Total of funds	60,663	25,389	86,052
Analysis of net funds – prior year	Unrestricted	Restricted	Total

, , ,	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	Total Funds 2022 £'000
Intangible fixed assets	76	-	76
Tangible fixed assets	123	-	123
Current assets	27,515	20,279	47,794
Creditors due within one year	(7,714)	(8,298)	(16,012)
Total of funds	20,000	11,981	31,981

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

	£′000	£'000
Net income for the year (as per Statement of Financial Activities)	54,072	31,752
Adjustment for:		
Depreciation and amortisation charges	69	105
Disposals	41	-
Net bank interest	(3)	-
Decrease / (increase) in debtors	(54,047)	(28,237)
(Decrease)/Increase in creditors	(6,557)	(11,611)
Net cash provided by operating activities	(6,425)	(7,991)

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

15.	ANALYSIS OF CASH AND CASH EQUIVALENTS			
		2023	2022	
		£′000	£'000	
	Cash at bank and in hand	8,146	14,619	
		8,146	14,619	

16. OPERATING LEASE COMMITMENTS

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

	2023	2022
	£'000	£′000
Amounts payable:		
In less than 1 year	1	2
In two to five years	3	-
Total	4	2
		

17. RELATED PARTY TRANSACTIONS

In the course of the year 2023, HDRUK received grants of £25,195k (2022: £45,504k) from The Medical Research Council (part of UK Research and Innovation). £345k was owed to HDR UK at 31 March 2023 (2022: £4,502k). UK Research and Innovation (UKRI) is a founding member of the Company.

Over the course of the year the organisation received grants of £795k (2022: £191k) and incurred other expenditure of £153k (2022: £110k) in relation to 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.

During the year the Company received grants of £200k (2022: nil) from Swansea University and incurred expenditure of £3,149k (2022: £1,391k) as grants Payable and £341k as other expenditure. HDR UK owed £928k as at 31 March 2023. Cathie Sudlow, Chief Scientist, Deputy Director of HDR UK and Director of the BHF Data Science Centre, is Chair of the Strategic Advisory Board, DATAMIND at the Swansea University and partners.

Over the financial year the company incurred grant payable expenditure of £1,156k (2022: 390k) towards Imperial College London. Mark Walport, a member of the trustee board, is Honorary Distinguished Professor of Medicine and Chair of the Imperial College Academic Health Sciences Centre Partnership Board.

Throughout the year the company incurred grant payable expenditure of £1,284k (2022: £429k) to Scottish government. £165k was owed at 31 March 2023 (2022: £194k). Andrew Morris is Chair of The Scottish Government COVID-19 CMO advisory Group and Chair of the Scottish Government Standing Committee on Pandemics.

During the year, the institution incurred other expenditure of £780 (2022: nil) to Thrive Worldwide UK Ltd. Alison Hopkinson, Chief Operating Officer and Director of Delivery, is the spouse of the Director and Shareholder Thrive Worldwide UK Ltd.

During the financial year 22/23 the Company incurred expenditure of £3,148k (2022: £393k) as grants Payable and £1,354k as other expenditure to the University of Edinburgh. £105k was owed at 31 March 2023. Professor Andrew Morris, the Director of HDR UK, is Vice Principal and Professor of Medicine at The University of Edinburgh.

NOTES TO THE FINANCIAL STATEMENTS

FOR YEAR ENDED 31 MARCH 2023

17. RELATED PARTY TRANSACTIONS (continued)

During the year, Dr Graham Spittle, a Trustee, was paid £16,430 (2022: £16,430) for his services as chair.

During the year, trustees were reimbursed expenses amounting to £668 (2022: £nil)

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

	Notes	Unrestricted Funds £'000	Restricted Funds £'000	Total 2022 £′000
Income from:				
Donations		33,041	31,596	64,636
Investments Other income		11	4	- 15
Total income		33,052	31,600	64,652 ———
Expenditure on: Charitable activities				
Research	2	13,320	19,580	32,900
Total Expenditure		13,320	19,580	32,900
Net income/(expenditure) before				
transfers		19,732	12,020	31,752
Transfers between Funds	12	40	(40)	
Net movement in funds		19,772	11,980	31,752
Reconciliation of funds		_		
Total funds brought forward		229		229
Total funds carried forward		20,001	11,980	31,981