

Health Data Research UK

in partnership with

UK Dementia Research Institute & Dementia Platform UK

Applicant information

Job description and person specification

- Post:** Research Director, Brain Health
- Location:** Primary base could be anywhere in the UK, but must be willing and able to travel to London and elsewhere (mainly UK) in connection with the role
- Salary:** This post would be suitable as a secondment
- Duration:** Approx. 2-3 days per week for 2 years
- Reporting to:** Director, HDR UK (Professor Andrew Morris)

About Health Data Research UK

[Health Data Research UK \(HDR UK\)](#) is the national Institute for data science in health.

Our mission is to accelerate trustworthy data use to enable discoveries that improve people's lives. Our 20-year vision is for large-scale data to benefit every interaction with patients, every clinical trial and every biomedical discovery, and to transform public health.

The UK is in a unique position to realise the potential of health data, thanks to the NHS and its cradle-to-grave records for a population of over 65 million people. However, safe and secure access to this data for researchers is often a lengthy, fragmented process, meaning the potential for improving healthcare is not being realised in full.

We are a dynamic, growing organisation. By working in partnership with the NHS, industry, universities and patients, we aim to better understand diseases and discover new ways to prevent, treat and cure them.

Patients and the public are 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.

As a national charity, we are funded by UK Research and Innovation, the Department of Health and Social Care in England and equivalents in Northern Ireland, Wales and Scotland, and leading medical research charities.

At Health Data Research UK, we employ talented individuals who bring their own unique skills and experience to support the vision and benefit the whole team. As a UK-wide and increasingly global Institute, we act as a flagship for team science, drawing on skills, resources, and expertise from academic, NHS, industry and government partners.

Our values of transparency, optimism, respect, courage and humility guide how we work together within HDR UK, with our partners and other stakeholders.

HDR UK's strategy

Our strategy focuses on three core areas:

1. **Research Data Infrastructure and Services** - providing the UK-wide and global co-ordination and leadership of health data infrastructure and services required to make health-relevant data FAIR (Findable, Accessible, Interoperable and Reusable). This builds on the convening, collaborative and co-ordinating role of the [UK Health Data Research Alliance](#) and includes the [Health Data Research Innovation Gateway](#) and the [Health Data Research Hubs](#).
2. **Research Driver Programmes** - advancing research discoveries through high impact UK-wide programmes that address major health and societal challenges, guide the development of the infrastructure and services for the benefit of other researchers and are outward-looking with global reach.
3. **One Institute Partnerships** - through national leadership with a clear vision and ambition to assemble a health data research ecosystem with enduring benefits for all researchers. As an innovative distributed UK-wide and increasingly global Institute, we act as a flagship for team science, drawing on skills, resources, and expertise from academic, NHS, industry and government partners.

A National Leadership Opportunity

Throughout the COVID-19 pandemic HDR UK has had particular success unlocking population-wide routine data resources such as primary care and medicines data, including [the first whole UK study using data from 67M individuals to reveal the impact of COVID-19 under-vaccination](#).

Realising the potential of integration and interrogation of multi-dimensional data on brain health, neurological and neurodegenerative diseases at population level will be key to improving health in an ageing society. **There is now an opportunity, working with the UK Dementia Research Institute (UK DRI) and Dementia Platform UK (DPUK) to develop a critical mass of diverse skills and partnerships, with coherent leadership to push forward a UK-wide data and infrastructure strategy dedicated to brain health research.**

To fully understand the determinants of neurodegenerative disorders and wider neurological conditions and develop innovations that can improve people's lives, it is critical that the full range of health-relevant data can be accessed through a trustworthy health data research ecosystem. As well as NHS-generated, whole population, 'real world' data, other diverse data sources include research-generated cohorts and registries,

clinical trials, multi-omics, imaging and pathology data, as well as environmental, social, administrative and citizen-generated digital data. Connecting existing data capabilities across the UK, including DPUK, Alzheimer's Disease Data Initiative (AD Data Initiative) and wider partnership programmes including the NHS England Secure Data Environment Network has significant potential to accelerate trustworthy data use. By working in partnership **our aim is to bring the power of large-scale data and infrastructure to accelerate research that benefits patients and carers living with devastating neurodegeneration and neurological conditions – from Alzheimer's disease to motor neuron disease to the consequences of traumatic brain injury.**

In partnership with the UK DRI and DPUK, we have ambitious plans to build upon existing strengths and capabilities **to accelerate trustworthy research data use for neurodegeneration, neurological conditions and to support long-term brain health.**

We are seeking an accomplished data science leader who will lead the strategy and cultivate the partnerships to enable the collection, management, curation, linkage and access to large UK-wide datasets relevant to brain health research. The Research Director will work with research teams across the UK to deliver driver projects that will exemplify use of large-scale data for the diagnosis, prevention, intervention, and care of neurological conditions, reducing existing health inequalities in outcomes. The Research Director will work closely with HDR UK's Infrastructure and Services teams alongside the BHF Data Science Centre, as well as colleagues at the UK DRI and DPUK, to share health data science knowledge and expertise from across the Institute supporting synergies across all disease areas.

Purpose of the Post

We are looking for an established leader who is well connected and highly respected across the neuroscience clinical and research communities in the UK and internationally. They will have an excellent track record in the use of large scale, multimodal data types in brain health research, and a strong commitment to developing linked health data-enabled approaches to enhance understanding of the causes and progression of neurodegenerative and neurological diseases to improve strategies for treatment.

The Research Director for Brain Health will work closely with the Directors of HDR UK, alongside UK DRI and DPUK, to identify and prioritise key areas of work in brain health data science research, demonstrating impact at national and international level in clinical practice, the health system and for people affected by neurological disease. The successful candidate will also draw support from the leads/partners of HDR UK's Research Driver Programmes and the Associate Directors in the BHF Data Science Centre (including the [Stroke Data Science Catalyst](#)) in developing priorities and areas of collaboration.

Current funded programmes that will contribute to the portfolio include:

- **Dementia Trials Accelerator** – a new collaboration between UK DRI, HDR UK and Medicines Discovery Catapult (MDC), and funded by the MRC, NIHR and the Office for Life Sciences designed to

enabled the UK Government Dementia Mission, with a vision to rapidly position the UK as the destination of choice for investment and innovation in the delivery of clinical trials of new therapies for dementia, rapidly delivering significant patient and NHS benefits.

- **MND Research Data Catalyst** - a new partnership programme, led by HDR UK, DPUK and UK DRI, working in close partnership with the MND patient and research community to convene and deliver data infrastructure and services, specifically designed to accelerate MND research. When launched, the MND Research Catalyst will first focus on enhancing discoverability of MND relevant datasets, building on the technology used by DPUK's Data Portal.
- [AD Data Initiative-HDR UK Brain Health Data Pilots](#) – a collaboration between HDR UK, the AD Data Initiative, the University of Edinburgh, Public Health Scotland (PHS) and Moorfields Eye Hospital NHS Foundation Trust to support a two-year pilot to make some of the UK's most comprehensive routine health imaging data more findable and accessible for dementia research projects both within the UK and internationally.
- [NEURii](#) - a collaboration between HDR UK, the University of Edinburgh, LifeArc, Eisai and Gates Ventures with the ambition to translate healthcare data and digital sciences into projects that can enhance the quality of life of people living with dementia and contribute to a national data infrastructure in the UK.
- [TBI-REPORTER](#) - A UK-wide research platform – UK-TBI REpository and data PORTal Enabling discoverY (TBI-REPORTER), led by the University of Cambridge in collaboration with HDR UK to boost the use of data to advance treatment and care for people with traumatic brain injury.

Supported by HDR UK, the postholder will work with stakeholders, including people affected by neurological disease, across the UK to:

- identify research priorities for large-scale, data-enabled brain health research;
- forge relevant collaborations to progress brain health research priorities;
- draw upon existing infrastructure innovations across HDR UK, identify and address the data infrastructure and analytics challenges that need to be overcome to enable linkage across health data and their analyses at UK-wide scale, to improve people's health and care.

This part-time role will provide leadership and strategic planning for health data research related to brain health, using large-scale data and innovative analytical methods, working strategically with a wide range of partners.

Main responsibilities

- **Provide strategic leadership** to bring together, interdisciplinary research, clinical, data science, professional societies and networks, NHS organisations, patients, public, industry and wider stakeholders to shape, influence and build consensus on the use of multi-modal health and health-related data for brain health research. An ability to see the bigger picture and focus on national priorities above local incentives, to ensure benefit to the wider neuroscience and data science communities.
- Create and maintain new **partnerships**, building on existing networks across the data science, neurological disease communities, NHS organisations, industry, patients and public, regulatory and information governance partners to identify and address the key challenges of using, linking and

analysing multi-modal health data at national scale. Manage competing demands and perspectives of partners to ensure priorities can be addressed and delivered effectively.

- Work with health data science communities, patients and public, NHS organisations and industry, to identify and build on existing **exemplar driver projects** that will highlight and address key requirements for brain health data science. In collaboration with the wider health data science and brain health research communities, provide strategic leadership in the development of novel and/or reproducible methodological and analytical approaches.
- Provide strategic direction and champion a **team science** approach to deliver projects, providing negotiation and brokering skills where necessary to drive improvement in the reproducible use, linkage and analysis of multimodal health data for brain health research.
- Work with the Directors of HDR UK, UK DRI and DPUK and partners to lead the development of:
 - **strategic plans** for brain health data science at a national level
 - **strong stakeholder and investor relationships**, building on a track record of data-led innovation and delivery.
- Contribute to and lead on relevant funding applications and other initiatives to **leverage additional resources** to enhance the research-enabling activities across the brain health data science portfolio.
- Working with wider HDR UK colleagues, partners and patient/public groups to identify opportunities and provide content to **communicate to diverse audiences** the impact of data enabled activities for brain health data science.

Day-to-day project management support will be provided by the HDR UK team.

Planning and organising

The postholder will lead on the development of a strategy and delivery plan to progress the use, linkage and analysis of large-scale multi-modal data in brain health research. This will require co-working with a wide selection of stakeholders to plan and organise projects as well as providing oversight across a number of complex partnerships to ensure delivery of objectives within deadlines.

Problem solving

This role involves significant application of prior knowledge accumulated from professional and research experience. An enhanced level of initiative and problem-solving ability is needed to develop new ideas and novel approaches in response to issues and research problems, as well as tenacity to resolve infrastructure, organisational or information governance bottlenecks. This approach will involve sharing knowledge and development with leading experts in the field, requiring collaboration, excellent negotiating skills and creative thinking. Considerable strategic awareness will need to be used.

The postholder will operate with significant independence and will make effective judgements on when to escalate issues to the Director or other senior HDR UK colleagues.

Decision making

Responsibility for developing and delivering on the strategy for brain health data science, working in partnership with UK DRI and DPUK.

Initiate, develop and build on opportunities for collaborative working with the broader members of the neurological and health data science communities, NHS organisations, patients and public, industry, wider HDR UK community, relevant national and international partners and organisations.

Key contacts/relationships

The post holder will build and maintain effective working relationships with colleagues within and across HDR UK, UK DRI and DPUK partner Institutions. Within HDR UK partners span the HDR UK Driver Programmes, HDR UK Regions, HDR UK Infrastructure and Services Programmes, the BHF Data Science Centre and its hosted Data Science Catalysts, NHS organisations and health data science communities, related Health Data Research Hubs and Data Pilots, and other key stakeholders.

A key relationship will be with patients and the public to build trust and acceptability in the use of health data at scale for brain health research.

Research programme management and delivery capability to support delivery of all joint programmes will be provided by HDR UK in partnership with UK DRI and DPUK where appropriate.

Eligibility

Candidates must:

- hold a substantive post at a UK organisation
- have a contract of employment at their organisation that extends up to 2029 or beyond,
- have the written support of their organisation (an institutional supporting letter will be required at the application stage)

Knowledge, skills and experience

Experience

- Extensive experience in brain health research as well as an interest and understanding of relevant aspects in health data science, in particular, access, linkage and analysis of electronic data from a variety of systems including hospital, primary care, registers, laboratory, multi-omic, imaging, voice, wearable and other digital data and specialist registries and audits. Understanding of national scale capability and patient/public trust to link health-relevant data from a wide-range of research cohorts and longitudinal studies to healthcare systems data, providing opportunities for the integration of increasingly granular, meaningful and/or person-centred information.
- Proven leadership skills to provide direction and deliver change across the UK.
- Ability to lead and inspire trust in a wide range of stakeholders and to build consensus across multiple stakeholders.
- Advanced understanding of the complexities, challenges and limitations of using research and routinely collected data from different health settings (e.g., secondary care, primary care, dispensed medications, specialist registry data etc.) as well as from different devolved nations of the UK in health research.

- Knowledge of innovative methodological and analytic approaches (e.g., AI and/or machine learning) and their application to analysis across routinely collected and other health data sources in health research.
- Well connected with neurological and health data science research networks, NHS organisations, professional societies, industry and wider stakeholders of relevance to the ambitions of brain health data science portfolio.
- Experience of working with patients, the public, and patient and public involvement networks/organisations in planning, delivering and communicating research.
- Commitment and ability to bring together people with diverse skills and understanding of the importance of data and infrastructure to drive forward improvements and change systems through collaborative team working and exemplar projects.

Skills

- Personal drive and ambition to provide leadership in the area of health data science in brain health research.
- Excellent influencing and negotiating skills.
- Creative and innovative thinker.
- Ability to work flexibly with a team of highly skilled individuals, with expertise across disciplines and sectors in alignment to HDR UK's values of Transparency, Optimism, Respect, Courage and Humility.
- A commitment and enthusiasm to engaging with patients, the public, and patient and public involvement networks/organisations is essential.
- Excellent communication skills with the ability to listen to and bring on board a wide range of stakeholders with competing priorities and views.
- Excellent networking and influencing skills with a desire to work collaboratively to achieve goals.
- Excellent organisational and time management skills, with the ability to manage competing priorities and issues under time pressures.

Dimensions

- This role is a secondment for approx. two to three days/week to provide leadership and strategic direction brain health within HDR UK, working with HDR UK's partners.
- There will be project management support from HDR UK to the post-holder in their role.
- The post-holder will be expected to work flexibly to fit the requirements of the role.
- HDR UK is a national institute, and our activities take place across the UK. Therefore, the post-holder should be willing to undertake travel within the UK and occasionally internationally when required.

Application Process

Interested applicants are encouraged to contact any of: Professor Andrew Morris:

Andrew.Morris@hdruk.ac.uk, Dr Rhoswyn Walker: Rhoswyn.Walker@hdruk.ac.uk, Professor Siddharthan Chandran Siddharthan.chandran@ed.ac.uk and Professor John Gallacher john.gallacher@psych.ox.ac.uk

Prior to application, candidates should discuss with their line manager / other relevant senior colleagues how this part-time secondment position would fit with their existing post.

How to apply:

Please apply via recruitment@hdruk.ac.uk with the following:

- Your CV (listing no more than **20** of your most relevant publications or other research outputs and no more than **10** of your most relevant funding awards)
- A covering letter of no more than 500 words explaining what you can bring to this role.
- A letter from your institution supporting your secondment to perform this role if appointed.

Please contact recruitment@hdruk.ac.uk if you have any queries regarding your application.

The closing date for this vacancy is 30th June 2024.

Interviews will take place in mid-July.

Equal Opportunities Policy Statement

Health Data Research UK is an equal opportunities employer, and as such aims to treat all employees, consultants and applicants fairly. It is our policy to provide employment equality to all, irrespective of:

- Gender, including gender reassignment
- Marital or civil partnership status
- Having or not having dependants
- Religion or belief
- Race (including colour, nationality, ethnic or national origins)
- Disability
- Sexual orientation
- Age

We are opposed to all forms of unlawful and unfair discrimination. All job applicants and employees who work for us will be treated fairly and will not be unfairly discriminated against on any of the above grounds. Decisions about recruitment and selection, promotion, training or any other benefit will be made objectively and without unlawful discrimination.