

Job description and person specification

Post:	Research Governance Manager
Location:	Flexible. 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:	£50,000 - £58,000, this post would be suitable as a secondment.
Duration:	Full-time, 18 month fixed-term contract (with possibility of extension), or a secondment.
Reporting to:	Interim Head of Information and Research Governance

About Health Data Research UK

Health Data Research UK (HDR UK) is accelerating trustworthy use of health data to enable discoveries that improve people's lives.

We are the national institute for health data science. Our 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.

Safe and secure use of this data could improve treatments, deliver better health care and save lives. It could help tackle some of the biggest health challenges worldwide, including cancer, diabetes and cardiovascular disease.

However, access to this data for researchers is often a lengthy, fragmented process, meaning the potential for improving healthcare is far from being realised in full.

We work in partnership with the NHS, industry, charities and universities to realise the potential of the UK's health data in life-changing research. Patients and the public are actively involved in shaping HDR UK's work and ensuring it delivers public benefit.

The Institute played a major role in the COVID-19 pandemic, working with the NHS and collaborators internationally to link and coordinate the use of large-scale data. With these resources, scientists and doctors could understand more about this new disease, identify which drugs were effective and provide evidence to allow the NHS and policymakers to respond to the challenge.

Our successes include:

- A Trusted Research Environments (TRE) for England was created early in the pandemic with health data covering >54 million people, thanks to a collaboration between NHS Digital and HDR UK through its British Heart Foundation (BHF) Data Science Centre. TREs are highly secure computing environments that provide remote access to health data.

- During the roll out of the Pfizer-BioNTech and Oxford-AstraZeneca vaccines against Covid-19, it was vital to understand how they performed in the population. A team supported by HDR UK through the BREATHE Health Data Research Hub were able to rapidly show the high protection offered by the vaccines after a single dose, thanks to assembling linked health data for 99% of the Scottish population.
- Nearly half a million people missed out on starting medication to lower their blood pressure during the Covid-19 pandemic, according to research enabled by the BHF Data Science Centre at HDR UK. The research included 1.32 billion records of medications dispensed to 15.8 million people in England, Scotland and Wales between 1 April 2018 and 31 July 2021.
- The Green Algorithms initiative promotes more environmentally sustainable computational science and is run by Loïc Lannelongue and Michael Inouye at HDR UK Cambridge. They have built tools for carbon footprint estimation, raised awareness about the environmental impacts of algorithms and driven change in the computational science community.
- A significant landmark early in 2024 saw the first research study of health records for 67 million people in all four UK nations. It looked at gaps in Covid-19 vaccine coverage and found that between a third and a half of the populations of the four UK nations had not had the recommended number of vaccinations and boosters by summer 2022. The approach could be extended to many other areas of medicine with great potential for new discoveries in the understanding and treatment of disease.

HDR UK is a virtual institute, with staff and partners in all four nations of the UK and an office in central London. We are an independent, registered charity with five years of core funding from nine of the UK's leading medical research funders, including 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 Institute's vision and benefit the whole team. 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 five-year objectives are to:

1. Accelerate trustworthy data use by sorting the data

- Make it easier and quicker for researchers to find, access and use high-quality, large-scale data
- Fix the technical challenges needed for swift, safe and secure data use, by assembling innovative infrastructure solutions
- Increase health research efficiency and productivity by accelerating adoption of the FAIR (Findable, Accessible, Interoperable and Reuseable) data principles

2. Improve people's lives by unlocking the power of data

- Deliver cutting-edge research that harnesses large-scale data to change health policy and practice
- Exemplify trustworthy data use to deliver research that was previously impossible
- Test and improve the infrastructure so it serves all researchers

3. Shape the future of health data research

- Connect data, people and organisations to bring about cultural change and realise the UK's potential to be at the forefront of health data innovation
- Develop people and teams with diverse perspectives and skills needed to deliver health data research
- Embed good practice in patient and public engagement and involvement to build confidence in health data research for public benefit by increasing transparency and trustworthiness.

Purpose of the post

Joining the growing Information and Research Governance team, as part of the wider Legal, Trust and Ethics team, this exciting new role provides an excellent opportunity for someone who is looking to use and enhance their information and research governance skills to improve trustworthy access to data for research and innovation that has the potential to transform lives. The successful candidate will work across the entire organisation to provide information and research governance support to a range of high-profile public health initiatives including cutting edge efforts to coordinate UK health data infrastructure and to facilitate life-changing research in the UK and abroad. This includes regular work with universities, funders, and governmental entities regarding complex data infrastructure and research projects. This fast-paced role will involve regular contact with senior internal and external stakeholders. The successful candidate will share our values, have strong collaboration skills, be comfortable with working at pace and have a passion for professional, high-quality approaches to engagement.

Main responsibilities

- Developing and implementing innovative data governance processes and policies to ensure the safe, secure, compliant and trustworthy use of health data for research.
- Working with partner organisations, including the NHS, universities, research bodies, charities, funders, industry representatives, data processors and Trusted Research Environment (TRE) Host Organisations, developing strong working relationships and driving initiatives to simplify and streamline data governance processes.
- Demonstrating the impact of HDR UK's innovative work on health data governance through peer-reviewed articles, blogs, bulletins, presentations, and through providing updates to relevant groups.
- Project managing funding calls to accelerate adoption of tools and resources across partner organisations.
- Implementing legal agreements for the provisions of and access to data for research and advising on compliance with UK GDPR and other applicable data protection requirements.
- Advising on compliance with ethical and governance approval processes for data access.
- Providing advice on international data transfers of data, seeking expert legal input where necessary.
- Conducting Data Protection Impact Assessments (DPIAs), preparing fair processing notices, updating and maintaining HDR UK's Records of Processing Activities (ROPA).

- Working closely with HDR UK's Patient and Public Involvement and Engagement (PPIE) team to involve and engage members of the public, including HDR UK's Public Advisory Board (PAB), in the use of health data for research and data governance.
- Developing a strong network of working relationships with stakeholders within and outside HDR UK.
- Providing training to HDR UK staff and members of the broader research community on information and research governance.

Planning and Organising

The successful candidate will plan and manage a diverse workload of complex, overlapping tasks and will require high levels of organisational skill. The post-holder will need to effectively plan and deliver their work but also be able to respond to changing needs in a fast-paced organisation.

Decision Making

The post-holder will be required to make day-to-day operational decisions for their own workload where required.

Problem Solving

The successful applicant will be expected to use problem solving skills to respond to diverse demands. The post holder will operate with significant independence and will require confidence and resilience in dealing with enquiries, problem solving and decision making. The post holder will be expected to make effective judgements on when to escalate issues to senior colleagues' attention and with what urgency.

Continuous improvement

HDR UK is dedicated to continuous improvement through our quality management system and has achieved ISO 9001 accreditation. The post-holder will review, analyse, identify and implement opportunities for quality improvement within their role and as part of the wider team through our strategy development and internal audit processes.

Experience

Essential:

- Experience of working in research governance,
- A track record of implementing successful information governance processes.
- A deep and up to date understanding of data protection and privacy laws, particularly UK GDPR.

Beneficial (but not essential) for the role:

- Experience of advising on compliance with research ethics (REC), NHS R&D, and confidentiality advisory group (CAG) approvals processes in any of England and Wales, Scotland or Northern Ireland.
- Experience drafting and implementing relevant legal agreements including data sharing and data access agreements.
- Experience of advising on consent requirements for data sharing under the common law duty of confidentiality.
- Experience of navigating the NHS England DARS process for accessing routinely collected data.
- Awareness of the growing network of TREs/SDEs across the UK.

Skills

- Ability to develop relationships with diverse stakeholders within and outside immediate role.
- Excellent communication skills, written and verbal, including the ability to explain concepts without technical jargon and communicate confidently with people at all levels.
- Ability to analyse complex scenarios, distil key points, identify innovative approaches and take pragmatic actions.
- Proactive and supportive approach to engagement with colleagues to support problem solving with the ability to determine when issues need to be escalated.
- Excellent planning, organisation and time-management skills, with the ability to manage competing priorities in a fast-paced environment.
- Ability to work autonomously and make decisions without supervision.

Knowledge

- Appreciation of the public sensitivities of using health data for research

Education

- Minimum educated to degree level

Dimensions

- This is a full-time role. Travel in the UK may be required to partner organisations.
- HDR UK is a national institute, and our activities take place across the UK.

Application Process

How to apply: Unless specified, please apply using our online portal. We use a recruitment process that is based on finding out more about the relevant skills and knowledge an applicant has and to help us with this we ask you 3 or 4 skills-based questions as part of the application process.

We will ask you to upload your CV and covering letter, these will be anonymised and will be used if you are shortlisted. If applying for this role as a secondment, please add a letter from your institution supporting your secondment to perform this role if appointed to the cover letter document.

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

Summary of Benefits

- 27 days annual leave plus 8 days for Bank Holidays
- Annual leave purchase scheme
- Medical Cash-Plan and Doctorline
- Wellbeing support, including access to the TogetherAll app
- Generous pension scheme, with 10% employer contributions

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.

Safeguarding

HDR UK is committed to robust safeguarding policies, we expect everyone who works with us to share our commitment to safeguarding.