

Job description and person specification

Post:	Research and Governance Project Officer
Location: Salary:	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 £42,000 -£50,000 depending on experience
Duration:	Full-time, 18 month fixed-term contract (with possibility of extension or permanent role)
Reporting to:	Information and Research Governance Manager

About Health Data Research UK

The UK is in a unique position to realise the potential of health data, thanks to the NHS and its cradle-tograve 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.

Health Data Research UK (HDR UK) is working to unite the UK's health data to enable discoveries that improve people's lives. Our vision is for large-scale data and advanced analytics to benefit every patient interaction, clinical trial and biomedical discovery, and to enhance public health.

We are a dynamic organisation, committed to accelerating trustworthy access to health data. By working in partnership with the NHS, industry and universities, we aim to facilitate research to better understand diseases and discover new ways to prevent, treat and cure them. Patients and the public are involved throughout, shaping the Institute's work and ensuring that access to data for research is enabled by safe and secure systems and generates 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.



- In autumn 2020, HDR UK was asked to lead a Data & Connectivity programme in partnership with the Office for National Statistics. The collaboration between many partners mapped Covid-19 datasets and delivered data infrastructure and services to allow high-priority research questions to be answered.
- 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.
- 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 goals are to:

- Accelerate trustworthy data use by implementing a national research data strategy and assembling infrastructure and services aligned to research and innovation needs.
- 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.
- Promote partnerships by building and maintaining critical partnerships, aligning incentives and reducing complexity across a fragmented landscape to streamline health data science.



Purpose of the post

This is an exciting new role providing an excellent opportunity for someone who is looking to use and enhance their research governance and project management skills to improve trustworthy access to health data for research and innovation that has the potential to transform lives. The successful candidate will work across the entire organisation to provide information governance support to a range of high-profile public health initiatives including cutting edge efforts to coordinate UK health data infrastructure and facilitate lifechanging 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. The successful candidate will be part of HDR UK's growing Legal, Trust & Ethics team and will report to the Information and Research Governance Manager.

Main responsibilities

- Developing and implementing innovative data governance processes and policies to ensure the safe, secure and trustworthy use of sensitive data for research.
- Disseminating HDR UK's innovative work on health data governance, including drafting and contributing to blogs, bulletins, peer reviewed articles and other publications.
- Engaging partners across the health data landscape and wider communities to develop and define best practice including resources and materials that can be adapted and re-used.
- Supporting partners to adopt best practice in data governance including supporting with overcoming challenges that have the potential to block or slow down research.
- Successfully planning and delivering stakeholder workshops, meetings, and events across multiple organisations.
- Working closely with our Public and Patient Involvement and Engagement (PPIE) team to involve and engage members of the public, including HDR UK's Public Advisory Board, in the use of health data for research and data governance.
- Developing a strong network of working relationships with stakeholders within HDR UK.
- Providing training to HDR UK staff and members of the broader research community on information and research governance.
- Develop communication materials such as standard presentation and comms decks.
- Working with internal teams and external partners to horizon scan for opportunities to share successes that help raise the profile of our work.
- Work flexibly to support colleagues as needed, adapting to an evolving environment and emerging priorities.

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 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

The successful candidate will have the following experience:

- Experience of information governance within research, ideally including experience of implementing or operating successful information governance and/or data access processes.
- Demonstrable experience of planning, running and evaluating activities.
- Success in running several projects at once to similar timeframes with conflicting priorities.
- Experience of facilitating meetings and delivering presentations.
- Excellent experience in collaborating across teams and/or organisations to help create and codeliver shared goals.
- Experience of working on diverse projects with stakeholders from different disciplines and appreciation for differences between working practices and regulatory regimes.

Some or all of the following experience would also be beneficial for this role:

- Experience working in the health data sector.
- Experience of advising on:
 - compliance with research ethics (REC), NHS R&D, and confidentiality advisory group approvals processes in any of England and Wales, Scotland or Northern Ireland;
 - legal agreements including data sharing and data use agreements; and
 - consent requirements under common law for data sharing.
 - Working knowledge of GDPR



- Experience in project management with an ability to apply management principles and processes and proactively manage risk.
- Experience of involving in research and/or communicating with patients and members of the public.
- Experience of organising and managing successful events, including managing external suppliers.
- Experience of defining and documenting project requirements from multiple stakeholders.

Skills and Knowledge

The successful candidate will demonstrate the following skills and knowledge:

- Ability to develop relationships with 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, show initiative and take pragmatic actions.
- Proactive and supportive approach to engagement with colleagues to support problem solving with ability to determine when issues need to be escalated.
- Excellent people skills including working with diverse groups of people.
- Excellent planning, organisation and time-management skills, with the ability to manage competing priorities in a fast-paced environment and deliver projects to a deadline.
- Appreciation of the public sensitivities of using health data for research
- Excellent attention to detail with the ability to produce high quality materials.

The following would also be beneficial for this role:

• Awareness of UK and international health data research landscape, research data management and data policies and standards.

Education

Minimum educated to degree level or equivalent level of experience

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: 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, this will be anonymised and will be used if you are shortlisted.



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

The closing date for this position is 20/03/24

Interviews will be held virtually. Dates will be confirmed with shortlisted candidates.

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.