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**Head of Participant and  
Public Involvement and  
Engagement  
UK Biobank  
Candidate Brief  
January 2023**

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## Introduction from UK Biobank's Principal Investigator/Chief Executive Professor Sir Rory Collins



UK Biobank is scientifically unparalleled and arguably the UK's most significant scientific asset. With its unique combination of scale, depth, maturity and accessibility, more than 1,700 peer reviewed publications based on UK Biobank in 2021 alone, and an exponential increase in citations and patents, UK Biobank has become the world's most important health resource.

Its great success is testament to a visionary collaboration between successive UK Governments and scientific research funders – most notably the MRC and Wellcome – who understood the significance of advances in genomics and that information from such a database could ultimately lead to improved diagnosis, treatment and prevention strategies for the most devastating diseases, benefiting millions of people in the UK and around the world.

Since inception, UK Biobank has also leveraged £227m of industry funding with increasing levels of interest in, and use of, UK Biobank by industry. UK Biobank is a major contributor to the advancement of modern medicine and treatment and has enabled many scientific discoveries that improve human health.

UK Biobank has a unique role to play in the Government's UK Life Sciences Vision, in both its Preconditions for Success and its Healthcare Missions, set out in June 2021. UK Biobank's role can be best understood both in terms of its ability to attract vital industry investment in UK Life Sciences and in enabling major scientific discoveries that improve public health.

The key focus of UK Biobank over the last five years has been on generating increasingly detailed genetic information on all 500,000 participants and making those data available to the international research community. The unprecedented scale, detail and quality of these data has enabled researchers to make unique discoveries about the relevance of genetics for disease.

For the next five years, our focus will shift to measuring the products of the genes. In particular, the levels of different proteins and metabolites in the blood, urine and saliva collected from participants more than ten years earlier. Completion of the initial whole body imaging of 100,000 participants, followed by repeat imaging of 60,000 of them, will add to the richness of the data available for studying biological changes that lead to the development of disease, or provide protection against it.

None of this would be possible without the altruism of the 500,000 British citizens who agreed to join the study some decades ago and the many tens of thousands of scientists around the world ensuring that their contributions deliver on the long-term vision of the funders to make improvements in human health and wellbeing that are of global significance.

## Company Overview

UK Biobank is a uniquely detailed large-scale prospective study, containing genomic, lifestyle, imaging and health information from 500,000 UK participants. The resource is globally accessible to approved researchers to enable novel and important scientific discoveries that improve human health.

UK Biobank's database is unique, combining several powerful differentiators, including:

- scale (500,000 people);
- depth (detailed lifestyle information, genetic and other assay data, imaging data);
- maturity (large numbers of different health outcomes available for study, 15 years ahead of any comparable cohort study); and
- accessibility (with over 30,000 researchers worldwide already using the data).

Increasing awareness of UK Biobank is more important than ever as the database grows in value.

With over 75% of all new researcher registrations coming from outside the UK, it truly is a global resource accessible to approved researchers undertaking health-related research.

UK Biobank is a distributed organisation, currently headquartered in Stockport, Greater Manchester, with four imaging centres delivering the world's largest multi-modal imaging study located in Stockport, Reading, Bristol and Newcastle. UK Biobank's epidemiological, health data teams and many of our systems are hosted at the Oxford Population Health (the Nuffield Department of Population Health, University of Oxford).

UK Research and Innovation have announced that subject to final approval, UK Biobank will receive an additional £128m of funding to support the next phase of our development. This transformative award will replace and enhance UK Biobank's infrastructure, creating a state-of-the-art facility in Manchester that will become the UK Biobank's headquarters from 2026.

## UK Biobank's impact on research

With the addition of genetic sequencing data on a scale never seen before in health research, UK Biobank is one of the most significant resources for identifying target genes for drug discovery.

Large scale genetic sequencing on the whole exome and whole genome of 500,000 participants is accelerating scientific discovery for human health. For example, scientists have identified rare protein-coding variants that have a large impact on complex traits, such as obesity. Individuals with a variant that suppresses protein production by the GPR75 gene expressed in the brain were observed to have significantly lower rates of BMI. The finding may lead to development of a drug that can inhibit GPR75 to offer a therapeutic strategy for treating obesity.

UK Biobank is also becoming increasingly important for the NHS and the public purse. Implementation of outputs derived from UK Biobank will result in significant savings of public expenditure, by improving prevention, early diagnosis and treatment, thereby improving population health and lowering NHS costs. For instance, the UK Biobank-derived polygenic risk score concept, allows a low-cost genotyping test to identify a substantial proportion of the population at high risk of one or more common conditions, such as heart disease, who could benefit from more effectively targeted prevention and screening strategies.

The unprecedented scale, detail and quality of UK Biobank's imaging project has enabled researchers to make unique discoveries about the development of many diseases in older age. These images are allowing scientists to study the impact of dementia risk factors on the brain and define early brain "signatures" of dementia that are providing clues to how cognitive decline and dementia start. When combined with the wealth of health data in UK Biobank, such as cognitive function tests, and genetics, this is allowing researchers the opportunity to spot dementia before symptoms appear.

A high degree of participant engagement within the cohort has enabled UK Biobank to play a vital role in helping to manage the global coronavirus pandemic. Surveillance studies during the COVID19 pandemic have increased researchers' understanding of the longer-term health impacts of coronavirus infection with over 237 COVID- related publications produced based on the UK Biobank resource.

Given the current pace of UK Biobank's development, coupled with the large increase in the number of researchers accessing the resource, there is likely to be an exponential growth in the impact of the discoveries that emerge that will be of global significance.

## Overview of the Role

- Location: Nuffield Department of Population Health, University of Oxford
- Salary: £50,000-£65,000 per annum depending upon experience
- Working hours: 35 hours per week Monday-Friday, although part-time work would be considered for the right candidate
- Contract type: Permanent

The UK Biobank Communications Team aims to enhance and nurture the reputation of this world-leading scientific project. An important part of this work includes engaging with and listening to the 500,000 participants who donate their time and medical data to this vital work. In this new role, we are seeking an experienced and passionate individual to co-ordinate UK Biobank's participant and public involvement and engagement activities (PPIE).

The Head of PPIE will be responsible for developing and delivering an ambitious strategy to consult, involve and engage study participants via a range of activities that will inform the future direction of UK Biobank's work. This includes assessing participant involvement, fostering participant engagement, helping UK Biobank hear the feedback and ensuring that UK Biobank continues to meet the needs of the growing global research community.

UK Biobank is the world's most informative clinical study and has helped to drive innovation and best practice across a range of areas related to cohort studies and biobanks. We want PPIE to be no exception, and the post-holder will be encouraged to undertake relevant collaborative research and to co-author publications to help inform other large-scale research initiatives.

This role will also involve working with the Director of Communications to implement a strategy to involve and engage a range of other stakeholders, including the general public, partner organisations, researchers, funders and policy-makers in the work of UK Biobank.

## Principal Duties & Responsibilities

- Devise and undertake consultation activities with UK Biobank participants to inform our future engagement strategy.
- Write a UK Biobank participant and public engagement strategy that will involve and engage study participants and inform the future scientific direction of UK Biobank.
- Lead the planning, organisation and delivery of participant involvement activities, both online and in person. This may include developing quantitative surveys, discussion schedules, briefing/explanatory materials, short films and animations.
- Plan and coordinate involvement and engagement activities of relevance to other stakeholders, including the public, UK Biobank staff, partner organisations, researchers, funders and policy-makers.
- Evaluate and report on the performance of PPIE activities.



- Collaborate with UK Biobank's Ethics Advisory Committee regarding findings that arise from this work.
- Assist in preparing funding applications to support PPIE projects, and provide input and expertise into other funding proposals.
- Encourage and support researchers using the UK Biobank resource to engage with the public about the findings of their research, including providing advice on engagement activities.
- Identify, develop and maintain partnerships with relevant external organisations, including participating in local and national networks to learn and share best practice.
- The role is based in Oxford (with some travel involved to UK Biobank's facilities in Greater Manchester and other sites in the UK) and will report to the Director of Communications.

## Person Specification

### Essentials:

- Educated to degree level or equivalent.
- Extensive experience overseeing and delivering patient/participant and public consultation, involvement and engagement activities in the research, community or healthcare sector, including focus groups, panel discussions and/or workshops.
- Experience of using a variety of tools to create, deliver, monitor and evaluate public and patient/participant involvement and engagement activities.
- Experience in deliberative methodologies for analysing and interpreting data from involvement and engagement activities.
- Excellent interpersonal skills, necessary for building and managing the varied internal and external relationships critical to the role.
- Excellent organisation, planning and project management skills, including an ability to work to tight timelines, solve unforeseen problems, and manage multiple projects.
- Excellent oral and written communication skills and attention to detail, including an ability to translate often complex scientific information for non-expert audiences.

### Desirables:

- Further degree or professional qualification in communications, journalism, public affairs, marketing or a related field and evidence of continuing professional development.
- Relevant PPIE research experience (as demonstrated via a publication record).
- Experience leading and developing others effectively, e.g. volunteers.
- Understanding of issues relating to the use of patient data for research purposes.
- Experience of working in the medical research sector.

## Benefits

- 26 days annual leave (which increases with length of service) + bank holidays (including Christmas closure)
- Holiday buy scheme (buy up to 1 week of additional leave per year)
- A paid day off for your birthday (in addition to annual leave)
- Flexible (hybrid) working
- Free lunch
- USS Pension Scheme which is a 'hybrid' defined benefit/defined contribution scheme (9.8% Employee Contribution, 21.6% Employer Contribution)
- Enhanced family leave (available from day 1 of employment)
- Employee discounts portal
- Life Assurance cover
- 20% discount at EE

## How to Apply

Apply by completing our application here: <https://careers.ukbiobank.ac.uk/en/jobs/82763>

If you require assistance in applying for the role, or attending interviews, please contact our HR department via [hr@ukbiobank.ac.uk](mailto:hr@ukbiobank.ac.uk) so that we can make suitable arrangements.

Our passion for diversity and equality means creating a work environment for all employees that is welcoming, respectful, engaging, and enriched with opportunities for personal and professional development.

For detailed information on how we process your personal data, please review our [privacy policy](#).

In line with GDPR, we ask that you do NOT send us any information that can identify children or any of your Sensitive Personal Data (racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, data concerning health or sex life and sexual orientation, genetic and/or biometric data) in your CV and application documentation. Following this notice, any inclusion of your Sensitive Personal Data in your CV/application documentation will be understood by us as your express consent to process this information going forward. Please also remember to not mention anyone's information or details (e.g. referees) who have not previously agreed to their inclusion.