

Public Advisory Board

ROLE PROFILE

TIME COMMITMENT	LOCATION	HONORARIA AND EXPENSES
		
2-hour meetings 3-4 meetings over 6 months	National Video conference available	Travel expenses covered Optional £75 honoraria per meeting

SUMMARY

The UK has some of the richest health data of anywhere in the world. However, these datasets across health, care, genomics and biomedicine are fragmented making it difficult, sometimes impossible, to access and use for research purposes. This causes delays and, in some cases, prevents accredited researchers and industry innovators from analysing data to help deliver better care and improve health for patients, society and for future generations. It is important, however, that we strike an appropriate and safe balance between recognising the benefits and the risks.

Health Data Research UK (HDR UK) is the new national Institute for data science in health. Our UK team of experts develop and apply cutting-edge data science approaches to clinical, biological, genomic and other multi-dimensional health data to address the most pressing health research challenges facing the public. HDR UK believes engaging with patients, carers and communities to be an ethical imperative that will improve the quality of our work.

A Public Advisory Board is being established to provide advice on the delivery of the HDR UK vision, principles and future strategy, with particular emphasis on ensuring that health data is used responsibly for research and innovation.

In this stage HDR UK is looking to appoint three to seven members to form the initial Public Advisory Board. Appointed members will bring diverse experience, understanding and skills to HDR UK and will be expected to reflect on further growth of the Public Advisory Board to diversify voice, experience or skills.

The Public Advisory Board is one strand of the emerging HDR UK public engagement strategy.

LENGTH OF ROLE

Six months initially as processes are established, with the potential for extension or renewal through mutual agreement with the Chair. Two-hour meetings every six to eight weeks.

LOCATION

Those who are unable to join meetings in person may join by video conference. While the initial meetings of the HDR UK Patient Advisory Board will be in London, there is interest in exploring meeting in other locations. Travel to HDR UK sites and partner organisations may be requested on occasion.

HONORARIA AND EXPENSES

Public Advisory Board members will be offered an honorarium (payment) for their time at a rate of £75 per meeting / half day. HDR UK will cover reasonable travel, and accommodation where appropriate, expenses where agreed in advance. Reimbursement for other expenses, including care responsibilities, may be agreed at the discretion of HDR UK.

YOUR SKILLS AND EXPERIENCES

We are looking for people who...

- Have experience as:
 - A person who uses health and social care services, occasionally or more regularly; OR
 - An unpaid carer or relative of a person who uses health and social care services; OR
 - An advocate or person working with relevant voluntary or support organisation in health; OR
 - A professional supporting engagement or involvement of patients, carers and the public in healthcare or health research
- Have an interest in:
 - How health data is collected, processed, used and safeguarded
 - The role of research in improving health and healthcare for patients and population
 - The use of innovative approaches to public engagement
- Have confidence to voice their own opinions clearly and participate in group discussion
- Are able to listen and respect differing opinions
- Are committed to openness & transparency
- Have an awareness of equality & diversity

YOUR ROLE

You will be required to...

- Attend and take an active part in HDR UK Public Advisory Board meetings
- Prepare for each meeting by reading any paperwork required
- Give your opinion and advice on topics like:
 - The interests and values of patients and the public in health data use
 - Engaging with patients and the public in ongoing dialogue
 - Demonstrating impact, outcomes and success to population
 - Being open, transparent and accountable
 - Being accessible and inclusive of diverse communities and groups
- Provide an independent perspective on operational and strategic issues
- Support HDR UK in embedding public involvement and engagement in work
- Provide advice on approaches to earn public trust and confidence in how health data is collected, processed, used and safeguarded
- Respect the viewpoints of others in the group

WE WILL SUPPORT YOU BY PROVIDING...

- An induction
- Ongoing support from the Public Advisory Board Chair and relevant HDR UK member of staff
- Adhoc training as identified by the member and HDR UK

HOW TO APPLY

To apply please email the following to fiona@hetangata.co.uk:

- Name, email address and preferred phone number
- A covering statement of no more than 500 words outlining your experience and interest in this role
- Your CV
- Your availability for exploratory workshop and first formal meeting dates and times (below)

The closing date for this role is **Friday 14 December 2018 at midday**.

In the place of an interview, all applicants will be invited to participate in an exploratory workshop on **Tuesday 8 January 2019, 1-2:30pm**, in London. Please let us know on applying if you are unable to attend this date and time and we will organise a separate discussion.

Applicants are also asked to hold **Wednesday 16 January 2019, 2-4pm**, in their diary for the first formal meeting of the Public Advisory Board.

ADDITIONAL BACKGROUND INFORMATION

About Health Data Research UK

Health Data Research UK (HDR UK) is the new national Institute for data science in health. Our UK team of experts develop and apply cutting-edge data science approaches to clinical, biological, genomic and other multi-dimensional health data to address the most pressing health research challenges facing the public.

Our mission is to harness the power of data to help people live healthier and longer lives.

For the first time, we are bringing together our unique nationwide data assets and specialists across academia, research and healthcare to unlock knowledge and deliver new insights. By undertaking research at scale, across a population of up to 65 million people, we have an unrivalled opportunity to use data to the highest ethical standards to drive breakthroughs in medical research. This unleashes the potential to improve the way we are able to prevent, detect and diagnose diseases such as cancer, heart disease and asthma.

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.

This structure of this role profile is based on [a template developed by Cancer Research UK](#).