

Public Advisory Board – Role Profile

Health Data Research UK is seeking to appoint three new members to its Public Advisory Board to represent the patient and public voice in Northern Ireland, Scotland and Wales.

Health Data Research UK is the national institute for health data science. Our mission is to unite the UK's health data to enable discoveries that improve people's lives. By working in partnership with the NHS, industry, academia and patients, and providing safe and secure access to rich health data, we aim to better understand diseases and discover new ways to prevent, treat and cure them.

Our Public Advisory Board has been in place since January 2019 to guide Health Data Research UK in ensuring that our work is driven to deliver benefits to patients and the public. They provide strategic advice to help us achieve our aim of:

- Encouraging effective health data science by involving patients and the public
- Earning public trust and building confidence in Health Data Research UK's work and the use of health data in research
- Building public understanding in the use of health data in research
- Ensuring people have confidence in contributing their data for research

The Public Advisory Board currently has 8 members – all from England – and we are seeking to grow this with a specific requirement for new members to represent Northern Ireland, Scotland and Wales.

THE IMPACT YOU'LL HAVE

Becoming a part of the Public Advisory Board will give you the chance to provide strategic input. Our mission can only be achieved if the public has trust and confidence in the use of health data for research and innovation and it is important that we strike an appropriate and safe balance between recognising the benefits and the risks of this activity. We can only do this with your help.

IN THIS ROLE, YOU'LL BE REQUIRED TO...

- Attend and actively participate in Health Data Research UK Public Advisory Board meetings (6-8 meetings a year)
- Prepare for each meeting by reading any paperwork required
- Contribute in a constructive and thoughtful manner to give your opinion and advice as a patient, carer or member of the public 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 the population
 - Being open, transparent and accountable
 - Being accessible and inclusive of diverse communities and groups
- Provide an independent perspective on strategic areas of work
- Support Health Data Research UK in embedding public involvement and engagement in our work
- Provide advice on approaches to earn public trust and confidence in how health data is collected, processed, used and safeguarded
- Actively participate in training and other meetings and events as agreed in advance

- Respond to communications and request for input in a timely manner
- Respect the viewpoints of others
- Where necessary, maintain confidentiality
- Offer regular feedback to help develop the Public Advisory Board and wider Patient and Public Involvement and Engagement activities

EXPERIENCES AND SKILLS WE'RE LOOKING FOR...

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

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
- Willingness to learn about health data and the language used
- Able to read and absorb complex information (seeking clarity through key contact at Health Data Research UK and/or through own research)
- Have confidence to voice their own opinions clearly and participate in group discussion
- Able to listen and respect differing opinions
- Committed to openness & transparency
- Have an awareness of equality & diversity
- Based in Northern Ireland, Scotland or Wales

Remember, you don't need to be pro-access when it comes to health data to join the Public Advisory Board. We want the Board to be as representative as it can be so need to ensure there are a mix of thoughts and opinions – all we ask is that you are respectful of the views of others and are interested in this area of work.

Length of Role	Members hold their post for an initial period of 12 months, with the potential for extension or renewal for a further one year. This allows membership to change to bring in new or additional perspectives.
Location	Currently, meetings are held in Central London but this is reviewed on a regular basis and will be adjusted so that members are able to attend in person if they wish to do so. Members who are unable to join meetings in person may join each meeting by video conference (<i>this happens on a regular basis and works quite well</i>).

	Travel to Health Data Research UK Sites, Hubs and partner organisations may be requested on occasion.
Time Commitment	<p>2-hour induction session to help you prepare for the role.</p> <p>Meetings will run for 2 - 2.5 hours and will be held every 8 weeks (usually 6 - 8 meetings a year).</p> <p>You may need a couple of hours before meetings to read through any relevant papers as well as in between meetings as and when needed.</p> <p>You will be offered the chance to attend other meetings and events as relevant to the role but this will be completely optional.</p>
Honoraria and Expenses	<p>Honorarium payments are made to Public Advisory Board members in recognition for their contribution made to HDR UK and the standard fee rate is £75. This covers attendance at meetings and when invited to review documents.</p> <p>We also cover reasonable travel and accommodation where appropriate expenses are agreed in advance.</p>
Support in your Role	<p>We will support you to carry out the role by providing:</p> <ul style="list-style-type: none"> • A mandatory 2 hour training / induction session • Ongoing support from the Public Advisory Board Chair • An assigned key contact within Health Data Research UK who will provide you with relevant information and will be available to answer any questions • Ad-hoc training as identified by individual Public Advisory Board members and/or Health Data Research UK

HOW TO APPLY

Email hdruk@gravitatehr.co.uk by **Sunday 22 March 2020** with

- Your 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

Shortlisted applicants will be invited to an interview, either face-to-face or videoconference, on **w/c 30th March 2020**.

ADDITIONAL BACKGROUND INFORMATION

About Health Data Research UK

Health Data Research UK is the national institute for health data science. It is funded by UK Research and Innovation, the Medical Research Council, the British Heart Foundation, the National Institute for Health Research, the Economic and Social Research Council, the Engineering and Physical Sciences Research Council, Health and Care Research Wales, Health and Social Care Research and Development Division (Public Health Agency, Northern Ireland), Chief Scientist Office of the Scottish Government Health and Social Care Directorates, and Wellcome.

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, volunteers 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.