

Public Advisory Board – Role Profile

Health Data Research UK (HDR UK) is looking for up to nine new members to join its Public Advisory Board to provide strategic advice to the organisation. Members will be asked to use their unique patient, carer and public perspectives on the safe and secure access and use of health data in research for public benefit to shape and influence our work.

Health Data Research UK (HDR 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 providing safe and secure access to rich health data and other types of data (e.g., administrative data which is information created when people interact with public services), we aim to better understand diseases and discover new ways to prevent, treat and cure them. Central to this is working in partnership with the NHS, industry, academia, patients, carers and the public.

Our [Public Advisory Board](#) has been in place since January 2019 to guide HDR UK in ensuring that our work is driven to deliver benefits to patients and the public and that the organisation is recognised as a leading international institute for health data research.

We can only achieve our vision and strategy if everyone, including patients, carers and the public, have trust and confidence in the safe access and use of health data for research and innovation. To support this, the Public Advisory Board sit within HDR UK's governance structure to provide strategic advice to HDR UK, with a particular focus on how we can work together to:

- Encourage and enable effective health data science by involving patients and the public
- Build public understanding of the safe and secure access and use of health data in research
- Demonstrate trustworthiness and build public confidence in both HDR UK's work and the safe and secure access and use of health data in research
- Ensure people feel confident in contributing their data for research and data linkage purposes.

The Public Advisory Board currently has nine members, including seven members from England, one member from Scotland and one member from Northern Ireland. They come from a range of backgrounds and bring a range of perspectives. We are aware of the differences in health systems across the four nations and are keen to involve people with different experiences to help inform and complement the current Board.

We are looking to grow this Board and are particularly keen to include public contributors who have experiences and viewpoints that are currently under-represented on the Public Advisory Board. We hope to ensure that the Board is reflective of the richness of diversity of experience across the UK.

THE IMPACT YOU'LL HAVE

Becoming a member of the Public Advisory Board will give you the chance to provide strategic input and shape the direction of our work. Our mission can only be achieved if the **public has trust and confidence in the access and use of health data for research and innovation**, so it is important that we get the balance right between recognising the benefits and the risks of this activity. We can only do this with your help.

AS A PUBLIC ADVISORY BOARD MEMBER, YOU'LL BE REQUIRED TO...

- Attend and **actively participate** in monthly Public Advisory Board meetings.
- Provide an **independent perspective on strategic areas** of work.
- Work with the other members of the Board to identify and advise on approaches to handle areas of work that have potential risk and/or impact on public trust in data access and use for research.
- Provide advice on approaches to demonstrate trustworthiness and build public confidence in how health data is collected, processed, used and safeguarded.
- Support and share ideas in ways to embed and align public involvement and engagement across the HDR UK Institute.

- Contribute in a **constructive and thoughtful manner** to give your opinion and advice as a patient, carer or member of the public on topics such as:
 - HDR UK's strategy and individual programmes of work
 - Priority areas of focus that relate to the access and use of data for research and innovation e.g., processes for granting access to health data
 - Engaging with patients and the public in an ongoing dialogue to support the building of public confidence
 - Communicating research impact and outcomes to the general public
 - Ways to improve transparency and accountability
 - Supporting researchers and partner organisations in their approach to working with patients and the public
 - Being accessible and inclusive of diverse communities and groups
 - Ensuring representativeness, equality and diversity

- Prepare for each meeting by reading any paperwork provided and preparing your contributions for the meetings in advance.
- Respond to emails between meetings to support the Board and HDR UK in driving activities forward in a timely manner.
- Keep up to date with activities going on across the HDR UK institute, for example, by reading the fortnightly update.
- Where necessary, maintain confidentiality.

EXPERIENCES, SKILLS AND INTERESTS WE'RE LOOKING FOR...

Knowledge, experience and skills:

- A person who uses health and social care services, occasionally or more regularly; OR
- A (paid/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
- Member of the public with an interest in the access and use of data for research and innovation
- Able to **read and absorb complex information** (seeking clarity through key contact and/or through own research), challenging jargon and offering plain English alternatives
- Confidence **to voice own opinions clearly and constructively** when participating in group discussion
- Good **communication skills** and able to listen and **respect differing opinions**
- Understanding of how health data can be used for research and innovation, the language used in this field OR a willingness to learn it

- Committed to **openness and transparency**
- Have an **awareness of equality and diversity**

Interest in:

- The **role of data and research** in improving health and healthcare for patients and the wider population
- Using **patient, carer and public perspectives to provide strategic advice** to the organisation’s work
- How health data and social care **data is collected, processed, linked, accessed and safeguarded**
- How the **public have a role to play in the access and use of data in research and innovation**
- **Connecting with the wider public population** to inform own views
- The **use of innovative approaches to public involvement**
- Willingness to learn about health data science and the language and terminology used

Remember, we want the Board to be as representative as it can be so need to ensure there are a mix of thoughts and opinions so encourage those who are supportive of data being used for research as well those who have reservations to get involved and share your views – 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 two years. This allows membership to change to bring in new or additional perspectives.
Location	<p>We will be taking a hybrid approach to meetings, and as new members join the Board we will take the lead from the Board on how often they prefer to meet online only or through a hybrid approach.</p> <p>Travel to Health Data Research UK Sites, Hubs and partner organisations may be requested on occasion.</p>
Time Commitment	<p>Meetings will be monthly for 1 hour and 30 minutes.</p> <p>You will need a couple of hours before meetings to read through any relevant papers as well as in between meetings as and when needed. We also ask that you stay up to date on work across the institute where possible. A fortnightly update to the Board is provided to support you with this.</p> <p>Between meetings there may also be other pieces of work, meetings and events that are of relevance to your role with PAB. These are optional but encouraged as it may support you to be fully involved with the wider work of the Public Advisory Board and HDR UK. However, we will put in support systems in place to ensure you are up to date if you are unable to get involved in additional activities.</p>

<p>Honoraria and Expenses</p>	<p>Honoraria are paid to Public Advisory Board members in recognition of their contribution made to HDR UK, and the standard fee rate is £75. This covers attendance at meetings and when invited to create and/or review documents.</p> <p>Additional involvement from PAB members will be reimbursed in line with HDR UK policy. We also cover reasonable travel and accommodation where appropriate expenses are agreed in advance.</p>
<p>Support in your Role</p>	<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 HDR UK Staff, Public Advisory Board Chair and Deputy Chair • An assigned key contact within HDR 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 HDR UK • We endeavour to continue supporting remote access to meetings

HOW TO EXPRESS YOUR INTEREST

Email involvement@hdruk.ac.uk by **1.00pm on 21 November 2022** with a completed [expression of interest form](#) outlining your experience and interest in this role.

Shortlisted applicants will be invited to a discussion session via videoconference on Zoom, on **Wednesday 7, Thursday 8 or Friday 9 December 2022**

Successful applicants will be invited to attend:

- an induction session **on 11 January 2023**
- the first meeting of the Public Advisory Board you will attend is on **25 January 2023**.

We will get the specific dates to you as soon as they are confirmed. **Please endeavour to hold these dates in your diary if you can, however availability will not impact our shortlisting process.**

If you have any questions or would like to find out more about the role email involvement@hdruk.ac.uk. We look forward to hearing from you!

ADDITIONAL BACKGROUND INFORMATION

Equal Opportunities Policy Statement

Health Data Research UK is an equal opportunities employer, and as such aims to treat all volunteers, employees, consultants and applicants fairly. It is our policy to provide 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 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.

Please have a look at the Privacy Policy of Health Data Research UK to find out more information about how the organisation collects and uses the personal information you provide to us (<https://www.hdruk.ac.uk/privacy-policy/>).