

Lay Member for ‘Improving and Uniting Data Delivery Group’ (IDG) - Role Profile

Health Data Research UK is seeking to appoint two lay members to its Governance structure to represent the patient and public voice.

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.

The Improving and Uniting Data Delivery Group (IDG) will be coming together for the first time in April 2020 to provide strategic advice and report into our Executive Committee. The IDG will be focusing on areas of work which support our aims to unite (i.e. bring together) and improve the data (through various tools and methods) to enable researchers and innovators to make advances in healthcare. This includes:

- [UK Health Data Research Alliance](#)
- [Digital Innovation Hubs](#)
- [Health Data Research Innovation Gateway](#)

You will also have close links with our Public Advisory Board who have been running since January 2019 and have been our main source of patient and public input thus far. They’ve been vital in helping us develop our work that incorporate the interests and values of patients and the public in health data use.

THE IMPACT YOU’LL HAVE

Becoming a part of the Improving and Uniting Data Delivery Group 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. To help us achieve this we want to work in partnership with all of the different types of stakeholders such as researchers and innovators, data custodians, health data research hubs, regulators and public and patients to name a few. This will help ensure 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...

- Work with the second IDG Lay Member to represent the patient and public voice
- Attend and actively participate in IDG meetings once a month
- Provide an independent perspective on strategic areas of work
- Participate in group discussions, listening to, understanding and synthesising differing opinions to help drive and monitor progress on areas of work as detailed above
- Connect with wider patient and public groups to ensure you’re able to provide a representative views in discussions
- 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 such as:

- The priorities, interests and values of patients and the public
- Being open, transparent and accountable
- Being accessible and inclusive of diverse communities and groups
- Engaging with patients and the public in ongoing dialogue
- Demonstrating impact, outcomes and success to the population
- Support Health Data Research UK in embedding public involvement and engagement in our work and act as advisors in our approach
- Provide advice on approaches to earn public trust and confidence in how health data is collected, processed, accessed 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 IDG, wider Patient and Public Involvement and Engagement activities and the Health Data Research UK Institute as a whole

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

Experience:

- Working with senior leaders and/or at a strategic level e.g. through universities or NHS
- Able to read and absorb complex information (seeking clarity through key contact at Health Data Research UK and/or through own research)
- Confidence to voice own opinions clearly and constructively and participate 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 and the language used OR a willingness to learn

Interest in:

- How health data is collected, processed, accessed and safeguarded
- The role of research in improving health and healthcare for patients and the population
- How patients and the public have a role to play in health data in research and innovation
- Connecting with the wider patient and public population to inform own views
- Committed to openness & transparency
- Have an awareness of equality & diversity
- Proficient in written and spoken English
- IT literate

Remember, you don't need to be pro-access when it comes to health data to become a Lay Member. There is a great value to having 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 at which point we will work with you to review the role and ensure it is the right fit for everyone involved. The roles will then be extended.
Location	Meetings will alternate locations and move across the UK – locations will be shared in advance. Members who are unable to join meetings in person may join by video conference (<i>this happens on a regular basis and works quite well</i>).
Time Commitment	2-hour induction session to help you prepare for the role (on Thursday 23 rd April). Meetings will run once a month for 2.5 hours and dates for the year will be put in your diary if you are selected for the role. 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.
Honoraria and Expenses	Honorarium payments are made to Lay Members who sit in our Governance structure 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. We also cover reasonable travel and accommodation as outlined in our expenses policy.
Support in your Role	We will support you to carry out the role by providing: <ul style="list-style-type: none"> • A mandatory 2 hour training / induction session on Thursday 23rd April 2020 • Support from the IDG Chair and Secretariat when needed • Peer support from the second IDG lay member and two lay members from the 'Using the Data Delivery Group' (UDG) • 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 Lay Members and/or Health Data Research UK

HOW TO APPLY

Email hdruk@gravitatehr.co.uk by **Wednesday 15th April 2020** with

1. Your name, email address and preferred phone number
2. A covering statement of no more than 500 words outlining how your experiences and interests make you a good fit for the role (referring to the role profile as appropriate)
3. Your CV (particularly outlining any relevant patient and public involvement / volunteer roles)
4. Where you heard about this role – this is purely used to help us with our recruitment processes in the future

Shortlisted applicants will be invited to an interview, over videoconference, on **Monday 20th and Tuesday 21st April 2020** (by videoconference) so please do keep this time free.

An induction session will be held on **Thursday 23rd April 2020 from 10.00 – 12.30** (by videoconference) so please do keep this time free.

The **first IDG meeting will be held on Tuesday 28th April from 3.00 – 5.00pm** so please do keep this time free (this will be over videoconference).

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.