

# Personal Monitoring Data Lay Members – Role Profile

**The British Heart Foundation Data Science Centre is seeking to appoint 3-4 lay members to work with us as we establish a focus on the use of personal monitoring data, with an initial emphasis on wearable devices.**

The BHF Data Science Centre is a partnership between Health Data Research UK and the British Heart Foundation that works to deliver the data and data science needed to address some of the most important challenges in heart and circulatory disease research.

The Centre aims to enable responsible, ethical research that uses advanced analytic methods on the UK's large and diverse cardiovascular disease (CVD) data. The results can help shape CVD health services, provide patients and health professionals with the tools to make better decisions, and bring the latest medical discoveries to patients across the UK. More background on the work of the centre can be found at: [https://www.hdruc.ac.uk/wp-content/uploads/2021/02/BHF-DSC-Brochure\\_final.pdf](https://www.hdruc.ac.uk/wp-content/uploads/2021/02/BHF-DSC-Brochure_final.pdf)

Personal monitoring data refers to information that is collected by wearable devices, such as health-tracking mobile phone apps and fitness watches. The BHF Data Science Centre wants to see if we can link the data collected by these personal monitoring devices and apps with other existing health information, such as an individual's medical records or scans. We hope to link these types of information together to build a better picture of how cardiovascular diseases develop, and to more effectively be able to monitor and manage an individual's condition.

As we begin our focus on the use of personal monitoring data, we are seeking to recruit 3-4 lay members to ensure the lay/patient voice is considered and embedded appropriately in this work, with the shared aim of improving the quality of research for maximum benefit.

## THE IMPACT YOU'LL HAVE

Becoming a lay member with a focus on personal monitoring data will give you the chance to input into our plans for this important area of our work as they develop. We are keen to ensure we capture a range of lay/patient perspectives on the potential opportunities and challenges for this work, alongside those of researchers, data custodians and industry (eg technology companies). 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 to ensure the research carried out in this area is in the best interests of people affected by heart and circulatory disease.

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

- Attend a virtual workshop over videoconference on the afternoons of **Monday 17<sup>th</sup>** and **Tuesday 18<sup>th</sup> May 2021 (2-5:30pm both days)**, with an induction meeting held w/c 10<sup>th</sup> May. You will hear from a range of speakers working in the field of personal monitoring, and you will participate in breakout sessions and have the opportunity to ask questions.

- Participate in a follow-up discussion meeting held w/c 24<sup>th</sup> May with the other lay members to reflect on the workshop and help to shape our plans to develop appropriate patient/public involvement in this work as it develops.
- Contribute longer-term to our work in personal monitoring as it develops beyond this workshop. This would include informing developing research projects utilising personal monitoring data, as well as joining a new advisory group to contribute more widely to our work. This would involve actively participating in additional meetings and/or correspondence and decision-making by email, to ensure that decisions are made in a timely manner.
- 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
  - Being open, transparent and accountable
- Respect the viewpoints of others
- Where necessary, maintain confidentiality

### EXPERIENCES AND SKILLS WE'RE LOOKING FOR...

Experience of:

- Heart and circulatory disease (including heart disease, stroke, clots in the blood etc) - either as a patient, carer or family member - would be particularly relevant, but not essential.
- Having an awareness of, or being a user of, health-tracking mobile phone apps or wearable devices would be welcome, but this is not essential. We welcome input from individuals who do, and do not, use this technology, and you also don't need to be pro-access when it comes to health data to apply for this role.
- Previous experience of sitting on a committee (either in a professional or voluntary role) or being in a group environment where you actively participate and share your opinions.
- Previous experience of supporting patient/lay member involvement in research is welcomed, but additional support can be provided if applicants are new to involvement work.
- Having the confidence to voice own opinions clearly and participate in group discussions.
- Listening to and respecting differing opinions.
- Demonstrating commitment to openness & transparency.

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 patient and public involvement and engagement.
- Willingness to learn about health data, personal monitoring wearables and the language used.
- Have an awareness of equality & diversity.

<b>Length of Role</b>	Members will initially participate in the workshops being held on Monday 17 <sup>th</sup> and Tuesday 18 <sup>th</sup> May 2021 (2-5:30pm), plus an induction and follow-up discussion. Members need to be available to support our work in personal monitoring beyond this workshop, and would hold their post for an initial period of 12 months, with the potential for extension.
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<b>Location</b>	The workshops and additional meetings will be held online by video conference (Zoom)
<b>Time Commitment</b>	<ul style="list-style-type: none"> <li>• 2-hour induction session to help you prepare for the role (held w/c 10<sup>th</sup> May).</li> <li>• Attendance at workshops on Monday 17<sup>th</sup> May (2-5:30pm) and Tuesday 18<sup>th</sup> May (2-5:30pm).</li> <li>• Participation in a follow-up discussion meeting w/c 24<sup>th</sup> May, likely 2 hours maximum.</li> <li>• There will be meetings throughout the year as required for informing developing research projects and involvement in a new advisory group, likely equivalent to one meeting a month.</li> <li>• You will need to allow a little preparation time in advance of meetings.</li> </ul>
<b>Honoraria and Expenses</b>	Honorarium payments are made to lay members in recognition for their contribution. This will cover the attendance at the two-day workshop and meetings.
<b>Support in your Role</b>	<p>We will support you to carry out the role by providing:</p> <ul style="list-style-type: none"> <li>• A mandatory 2 hour training / induction session</li> <li>• An assigned key contact within the BHF Data Science Centre who will provide you with relevant information and will be available to answer any questions</li> <li>• Ongoing support from the wider patient and public involvement and engagement network within Health Data Research UK</li> <li>• Ad-hoc training as identified by individual Lay Members and/or BHF Data Science Centre</li> </ul>

## HOW TO APPLY

Email [debbie.ringham@hdrug.ac.uk](mailto:debbie.ringham@hdrug.ac.uk) by **12 noon on Monday 19<sup>th</sup> April 2021** with a completed application form.

Shortlisted applicants will be invited to an informal interview, over videoconference, on **w/c 26<sup>th</sup> April 2021**.

## ADDITIONAL BACKGROUND INFORMATION

### About BHF Data Science Centre

The BHF Data Science Centre is a partnership between Health Data Research UK and the British Heart Foundation. The BHF Data Science Centre does not hold data itself. Instead, it works with the data-controllers to provide knowledge and expertise to help researchers from the NHS, academia and industry find, access, understand and connect the UK's unique cardiovascular 'big data' that is distributed across national registries, NHS electronic medical records and other relevant datasets.

### About British Heart Foundation

The British Heart Foundation are working towards a world free from the fear of heart and circulatory diseases to prevent these conditions from developing and those with existing conditions to have better, longer lives. It is the largest independent funder of research into heart and circulatory diseases in the UK, and they focus their efforts on accelerating discovery, turning discoveries into life-saving medical advances and work with patients and the public for better health and care.

### About Health Data Research UK

Health Data Research UK is the national institute for health data science. Its 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, it aims to better understand diseases and discover new ways to prevent, treat and cure them.

### Equal Opportunities Policy Statement

Health Data Research UK is an equal opportunities employer, and as such aims to treat all 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 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.