



**British Heart Foundation
Data Science Centre**

Led by Health Data Research UK

BHF Data Science Centre

Patient and Public Involvement and Engagement Strategy

December 2022

HDRUK
Health Data Research UK

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Who we are?

The BHF Data Science Centre (DSC) is a partnership between Health Data Research UK (HDR UK) and the British Heart Foundation (BHF), and sits within HDR UK.

What we do?

We work with a wide range of partners including patients, public, clinicians, researchers and NHS organisations to help them carry out research using health data into the causes, prevention and treatment of all diseases of the heart and circulation (such heart attacks, stroke and vascular dementia). We do this to ensure new advances in treatment and care to reach the patient as quickly as possible. The centre started in January 2020 and has initial investment from the BHF of £10 million over the first five years.

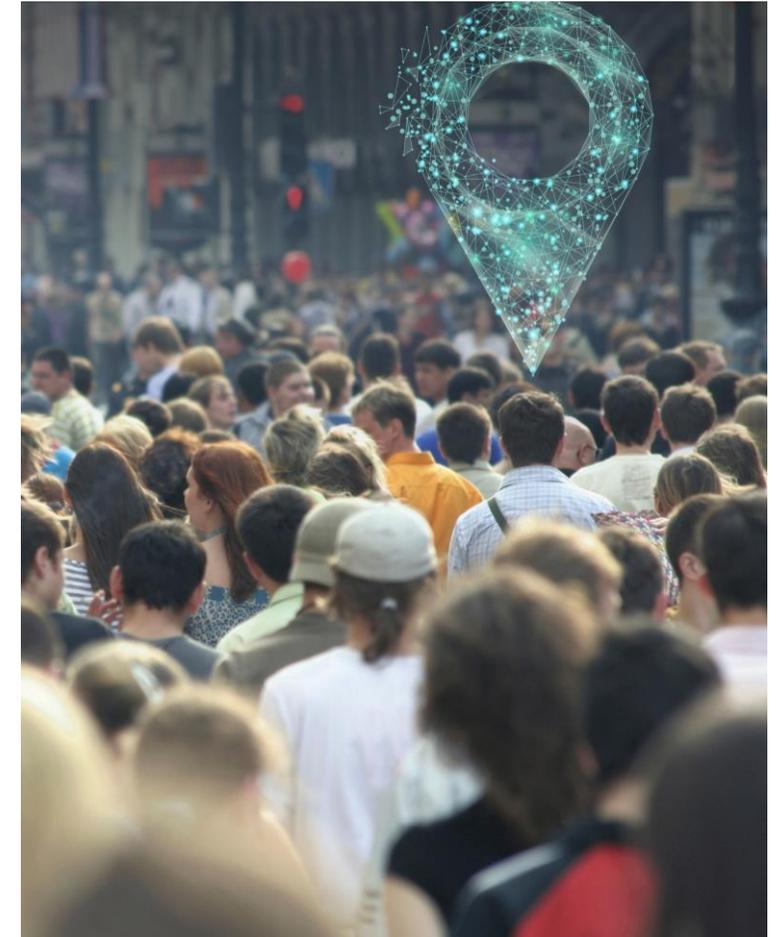
Our Vision for PPIE

To work with patients and the public to co-produce quality research that is relevant to patients affected by heart and circulatory disease, and the public as a whole.

To work collaboratively with heart and circulatory disease patients and the public to build mechanisms which support transparency and trust to achieve the [BHF Data Science Centre's](#) vision of faster, efficient, effective and data-driven research that benefits the public's health.

To engage and involve people affected by heart and circulatory conditions and members of the public in agreed priority areas of our work will be at the heart of our approach. Health data is often used without individuals' explicit consent, therefore, involving the public is critical to ensure that research carried out using their data is transparent, trustworthy and acceptable from a public perspective.

The PPIE work of the BHF DSC will be delivered in alignment with the [HDR UK Involvement and Engagement Guiding Principles](#)



Our PPIE Objectives

To ensure that there is collaborative patient and public involvement embedded at all levels of the BHF DSC. This will include representation at a governance level; working in partnership with the BHF DSC management team; and working with researchers/data custodians involved in specific areas of research.

To meaningfully involve a diverse group of people, including less represented groups affected by heart and circulatory conditions, and members of the public in agreed priority areas of the work of the BHF DSC, enabling public insight to be incorporated and acted upon in a meaningful way.

To work in partnership with existing groups and organisations with PPIE expertise across the health data and cardiovascular landscape. We will share expertise and resources, obtain input from existing PPIE panel members (when appropriate), avoid unnecessary duplication.

Our PPIE Objectives

Providing an induction session, any required training and facilitating peer support to patients, researchers and the public as required.

- we will signpost researchers to existing PPIE resources and provide PPIE guidance ourselves
- connect researchers with existing PPIE networks in host institutions for additional support

Having a flexible approach, being prepared to change, review and adapt as work progresses. We will review activity with public contributors, staff and researchers involved to ensure our PPIE activity is fit for purpose to help us meet our desired outcomes.

Consideration of a variety of ways of suitably involving patients and the public (e.g., panels, social media polls, surveys, workshops) for both short and longer-term time commitments, seeking to capture a breadth of opinions.

Our PPIE Objectives

We will record and feedback to our public contributors with tangible examples of what has happened, changed and/or improved as a result of their involvement, to evidence what value has been added (*e.g., make research better, clarify patient benefit*). This information will be shared in external communications and used to inform future activities.

We will work nationally with our partners and stakeholders including the BHF, NIHR, the NHS and other national organisations to avoid duplication of effort, share best practice and increase efficacy in PPIE for data science overall.

Work with our Communications Manager to ensure PPIE is embedded into all relevant external communications aiming to amplify the patient experience and ensure all public facing outcomes have had PPIE input where possible.

How we developed our Strategy?

The PPIE strategy has been co-produced by our [PPIE Group and Operations team](#).

Workshop with BHF DSC
PPIE Group to develop
draft objectives

Draft updated by PPIE
Manager and reviewed
by BHF DSC PPIE Group

Input from Operations
Team

Final review and input
from PPIE Group



Putting the PPIE strategy into practice

All members of the BHF Data Science Centre are responsible for putting the strategy into practice, supported by Samaira Khan, our PPIE Manager.

We currently work with **16 public contributors** who are aligned to different thematic areas of our research and governance as follows:

- One public contributor recruited to the **BHF DSC Oversight Committee**, attending meetings, and providing input;
- Six public contributors recruited to the **CVD-COVID-UK Approvals and Oversight Board** within the ‘**Structured Data**’ thematic area;
- Five public contributors recruited to align with the ‘**Personal Monitoring**’ thematic area;
- Five public contributors recruited to align with the ‘**Unstructured Data**’ thematic area;
- Four public contributors recruited to align with the ‘**Enhancing Cohorts**’ thematic area;
- We are in the process of recruiting for our Data Enabled Clinical Trials, Computable Phenotypes thematic areas and for the Diabetes Data Science Catalyst.
- All public contributors meet quarterly as a group to share best practice, discuss challenges, and provide overall guidance in shaping PPIE activities for the BHF DSC.



Further information

*For any further details or questions please contact our PPIE Manager, Samaira Khan
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*For more information about the BHF Data Science Centre please visit our website
<https://www.hdruk.ac.uk/helping-with-health-data/bhf-data-science-centre/>*