



**British Heart Foundation  
Data Science Centre**

Led by Health Data Research UK

# BHF Data Science Centre Patient and Public Involvement Strategy

July 2023 -24

**HDRUK**  
Health Data Research UK



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# Introduction

- This strategy sets out our vision, commitment and approach to patient and public involvement and engagement (PPIE). It underpins our commitment to actively involve patients and the public as partners across all our areas of work.
- This strategy has been co-produced by our [PPIE Group and Operations team.](#)
- Our work follows the [HDR UK Involvement and Engagement Guiding Principles.](#)
- Visit our [website](#) for more information



## Our Vision for PPIE

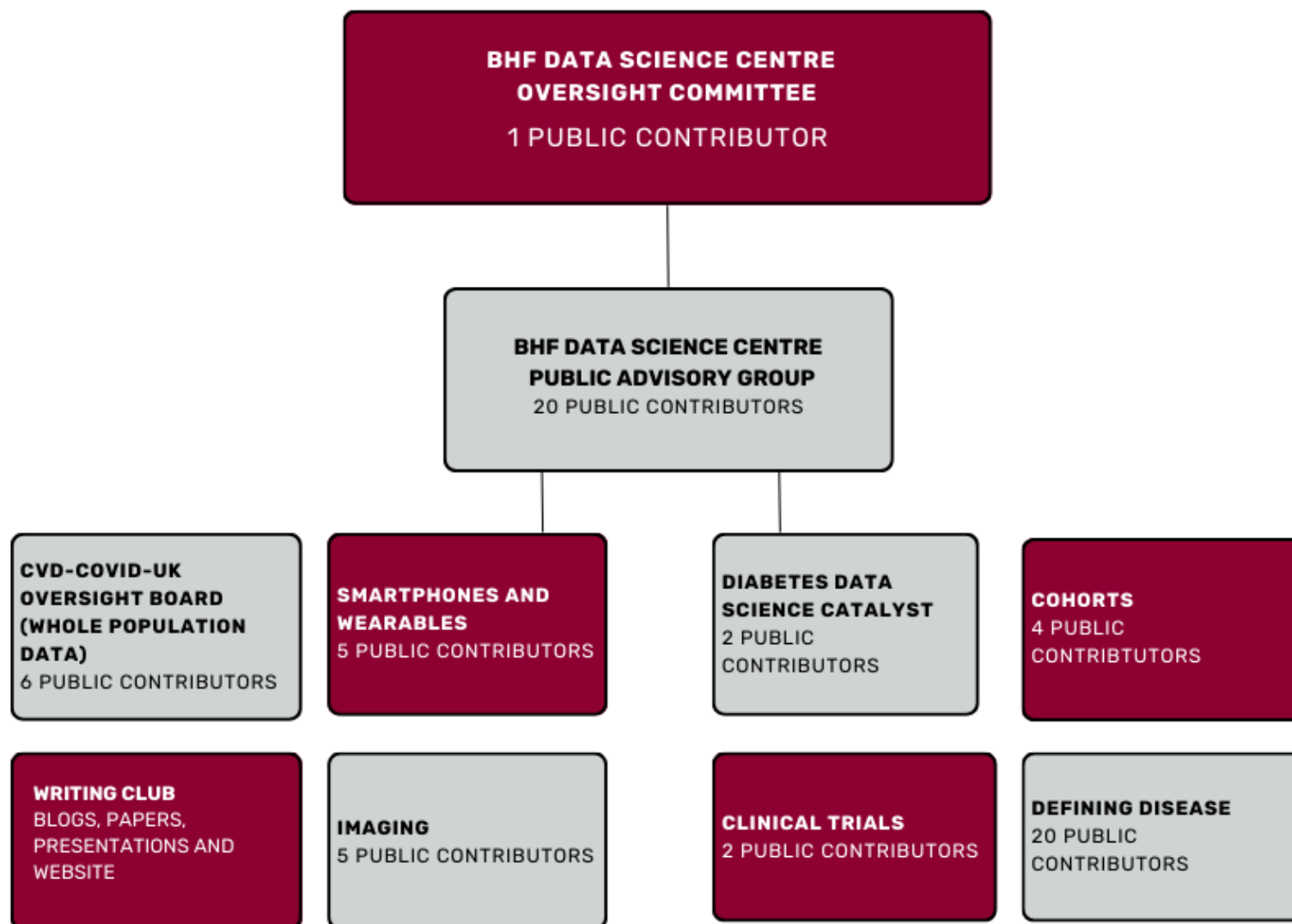
Our vision is to work with patients and the public to co-produce quality research that is relevant to patients affected by heart and circulatory disease, and the public as a whole.

To work collaboratively with patients who have heart and circulatory conditions and/or linked diseases 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 ethical, trustworthy, acceptable and meaningful from a public perspective.

# Governance

We currently work with 20 public contributors who are aligned to different areas of research and governance. 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 Data Science Centre.



# We will achieve our vision by:

1. Ensuring that there is collaborative patient and public involvement embedded at all levels of the BHF Data Science Centre.
2. Meaningfully involve and engage with a diverse group of people, including less represented groups affected by heart and circulatory conditions.
3. Considering a variety of ways of suitably involving patients and the public to capture breadth of opinions and working in partnership with existing groups and organisations with PPIE expertise across the health data and cardiovascular landscape.
4. Using a flexible approach to induction and ongoing training for our public contributors and facilitating peer support, being prepared to change, review, and adapt as work progresses.
5. Providing feedback to our public contributors with tangible examples of what has happened, changed and/or improved as a result of their involvement.
6. Working with our Communications Manager to ensure PPIE is embedded into all relevant external communications.

# OUR OBJECTIVES

## 1. Collaborative patient and public involvement embedded at all levels of the BHF Data Science Centre.

We believe that PPIE should be co-produced and embedded into all our areas of work to ensure they are patient centred and the work we are doing is relevant and appropriate from a public perspective. To achieve this objective, we will:

- Promote appropriate policies, procedures, and guidelines (including the Health Data Research UK guidance for remuneration of public contributors).
- Work towards UK Public Involvement Standards when involving members of the public.
- Work with our Project Managers and maintain a record and support PPIE activity within the areas of work.
- Promote and support public engagement activities across the BHF Data Science Centre and Health Data Research UK where relevant.
- Meet quarterly with our Public Advisory Group (PAG) who support and advise on the work of BHF Data Science Centre with an aim to increase trust and transparency.
- Celebrate success of PPIE in our research through regular webinars and showcasing events.
- Ensure patient and public representation in the governance and oversight of the Centre.

# OUR OBJECTIVES

## 2. To involve and engage with a diverse group of people, including less represented groups.

We believe that involvement in research as lay partners should be accessible to everyone and we aim to broaden the diversity of those involved in our PPIE activities and make a conscious effort to reach out to diverse groups for engagement and dissemination activities. To achieve this objective, we will:

- Develop a broad Public Advisory Group as a resource to collaborate on research, quality improvement, engagement, and dissemination across all areas of our work.
- Promote and facilitate the inclusion of under-represented and seldom-heard groups through active engagement with local partners, organisations, and communities.
- Actively seek and train new partners to ensure sustainability, diversity, and new perspective in the group.
- Work with Health Data Research UK (HDR UK) and PEDRI (Public Engagement Data Research Initiative) to enhance diversity in our involvement activities.

# OUR OBJECTIVES

## **3. Consideration of a variety of ways of suitably involving patients and the public to capture breadth of opinions and working in partnership with existing groups and organisations.**

To achieve this objective, we will:

- Share learning and resources to support effective PPIE, making best use of resources and reducing duplication.
- Work in partnership with our Public Advisory Group (PAG) to find suitable mechanisms for involvement adapting our approach accordingly.
- Maintain and strengthen relationships with BHF, HDR UK and other partner organisations.
- Contribute to national PPIE networks, guideline and standards development and impact evaluation when we locate suitable opportunities and in response to invitation.



## OUR OBJECTIVES

### 4. Using a flexible approach to induction and ongoing training for our public contributors and facilitating peer support.

To achieve this objective, we will:

- Conduct yearly training sessions for our CVD COVID IMPACT public contributors who actively contribute to the PPIE reviews conducted by the Approvals and Oversight Board.
- Provide internal updates on what is happening across our areas of work for all our public contributors.
- Needs based approach to training across all activity e.g. ad hoc training across online systems including Mural and Continia.
- Meet quarterly with our Public Advisory Group (PAG) to provide peer support for public contributors.

## **5. Recording feedback to our public contributors with tangible examples of what has happened, changed and/or improved because of their involvement.**

We believe in the importance of adhering to appropriate standards in PPIE and embedding a culture of evaluation to demonstrate and evidence the impact of PPIE.

To achieve this objective, we will:

- Update our reporting log to capture impact of all PPIE activity and continuously capture the impact over a period of time as a result of the activity.
- Share updates and changes with the public group as required e.g. Monthly internal email update, involvement in website development.
- Develop at least two case studies a year to capture impact of our PPIE activities and share on our webpages.
- Evaluate all PPIE activity across the Centre.
- Establish a platform that facilitates the exchange of best practices and mutual learning through quarterly Public Advisory Group (PAG) gatherings, as well as spontaneous ad-hoc meetings as the need arises.

# OUR OBJECTIVES

## 6. Working with our Communications Manager to ensure PPIE is embedded into all relevant external communications

To achieve this objective, we will:

- Host our Writing Club on a needs-based approach, allowing opportunity for our PAG to contribute to all external facing messages where relevant.
- Run workshops for website reviews and updates as needed.
- Circulate one off and/or unplanned opportunities for involvement in communications including infographics, posters and banners etc.
- Invite our public contributors to co-present for our monthly webinars and networking events where appropriate.



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