



**British Heart Foundation
Data Science Centre**

Led by Health Data Research UK

BHF DATA SCIENCE CENTRE

PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT STRATEGY

2024 - 2025



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.

Health data is often used without individuals' explicit consent; involving the public is critical to ensure that research carried out using their data is ethical, trustworthy, acceptable and meaningful from a public perspective.

This strategy has been co-produced by our PPIE Group and Operations team.

Our work follows the [Health Data Research UK \(HDR UK\) Involvement and Engagement Guiding Principles](#).

Visit [our website](#) for more information.



Our Vision for PPIE

Recognising that health data is often used without individual consent, our vision is to work collaboratively with patients and the public to co-produce quality research that aligns with the British Heart Foundation Data Science Centre's (BHF DSC) vision of faster, efficient, effective and data-driven research that benefits the public's health.

Our Audience

Our aim is to actively involve and engage patients with lived experience of heart disease, as well as various other conditions, in our work. We also include members of the public, such as carers and family members, who are directly impacted by these diseases.

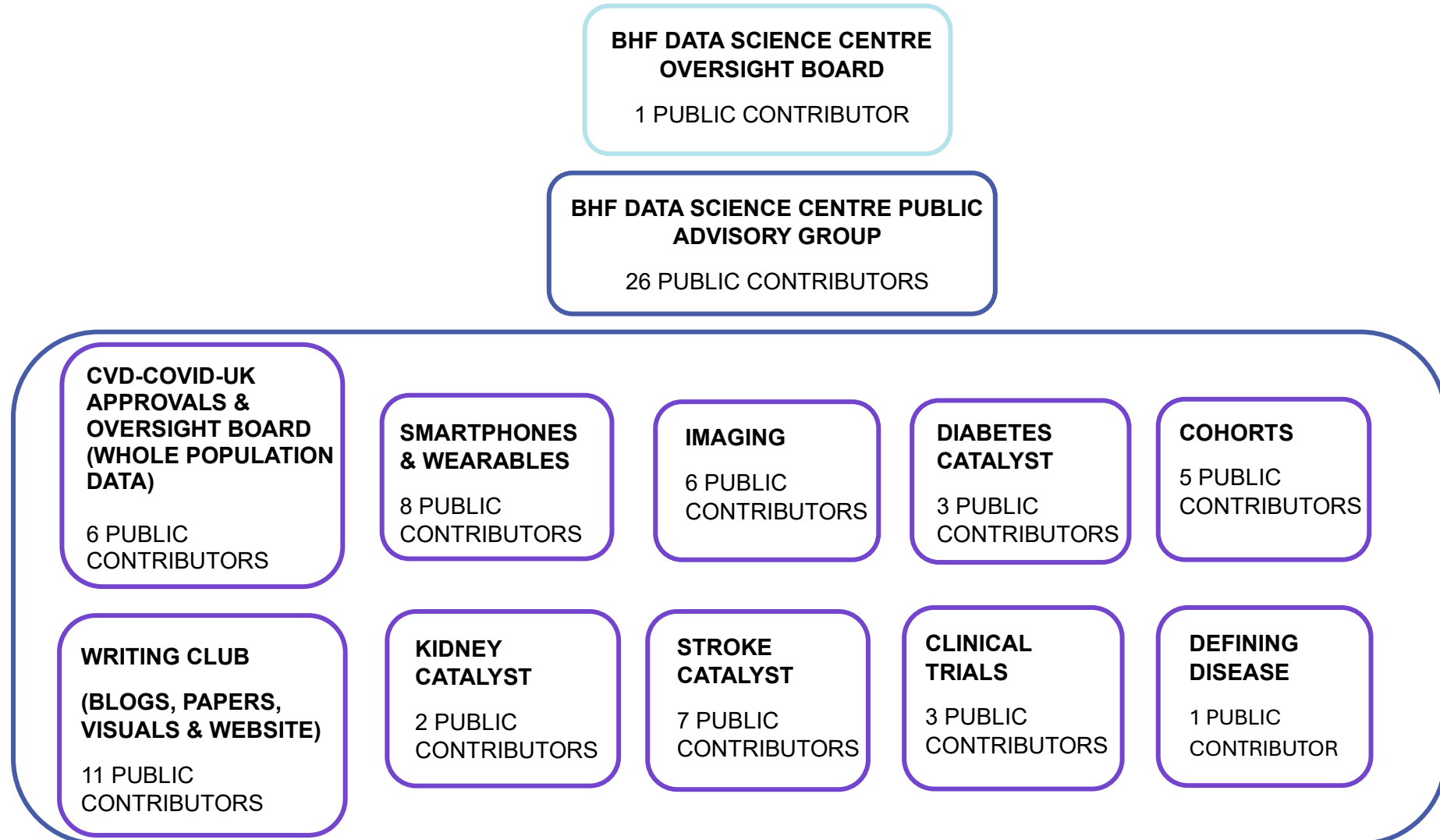
Additionally, we seek to engage the wider public, including those who may be sceptical about data use or unaware of how health data can drive positive change.

Our goal is to ensure everyone has the opportunity to be involved in health data research, improving the diversity of voices contributing to this field.

By bringing together researchers, health data scientists, healthcare professionals, patients, and the public, we strive to build a collaborative community dedicated to making positive changes within the health data research sector.

Governance

We currently work with 26 public contributors who are aligned to different areas of research and governance:



Summary of objectives:

- 1. Ensuring collaborative patient and public involvement is embedded at all levels of the BHF Data Science Centre.**
 - Integrate the public voice in all aspects of our work by regularly engaging with the public, adhering to relevant policies and standards, and collaborating with colleagues to enhance trust, transparency, and relevance.
- 2. Involving and engaging with a diverse group of people, including less represented groups.**
 - Set equality, diversity, and inclusion objectives, recruit diverse members, engage under-represented groups, reduce barriers to involvement, and foster partnerships to enhance accessibility and representation.
- 3. Utilising existing networks and working in partnership with organisations to improve our learning, strengthen our approach and reduce duplication within the field.**
 - Strengthen existing partnerships, seek new collaborations, share resources for effective PPIE, contribute to national networks and standards, and co-develop a partnership framework.
- 4. Developing a strong culture around PPIE so that all BHF DSC stakeholders are confident in involvement and engagement approaches and our public contributors feel supported and empowered to contribute effectively.**
 - Provide tailored support and training for public contributors, enhance researchers' PPIE skills, share resources and training opportunities and keep public contributors informed through regular updates.
- 5. Monitoring and evaluating our PPIE activity, highlighting impact and changes as a result of public input with our public contributors and wider audiences.**
 - Monitor and report on PPIE activities, review impact annually, develop case studies and blogs, facilitate good practice exchange, celebrate best practices, and continually evaluate and improve our approach.
- 6. Working with our Communications Manager to ensure PPIE is transparent and embedded into all relevant external communications.**
 - Host Writing Club sessions, run website review workshops, involve public contributors in webinars, increase PPIE visibility internally, engage wider audiences, use accessible communication formats, collaborate with community organisations, and co-develop human interest stories.

Our Objectives

1. Ensuring collaborative patient and public involvement is 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 it is patient centred and the work we are doing is relevant and appropriate from a public perspective. To achieve this objective, we will:

- Integrate the public voice across all areas of our work, including governance, planning and priority setting, funding calls, communication, and evaluation.
- Recruit and meet regularly with public contributors to support and advise on the work of the BHF Data Science Centre with an aim to increase trust, transparency and relevance.
- Public contributors can be:
 - those with lived experience of heart and circulatory disease
 - those with lived experience of other linked diseases
 - parents, partners or others with experience of supporting those living with heart, circulatory or other linked disease
- Promote and apply appropriate policies, procedures, and guidelines (including the Health Data Research UK guidance for remuneration of public contributors).
- Work towards [UK Public Involvement Standards](#) and [Public Engagement in Data Research Initiative \(PEDRI\) good practice standards](#) when involving members of the public.
- Work with our BHF DSC colleagues to identify PPIE opportunities within centre projects and support and capture PPIE activity within these areas of work.
- Promote and support public engagement activities across the BHF Data Science Centre and Health Data Research UK where relevant.
- Celebrate success of PPIE in our research and work through regular webinars and showcasing events.

Our Objectives

2. Involving and engaging with a diverse group of people, including less represented groups.

We believe that involvement in research 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:

- Set clear equality, diversity and inclusion objectives aligned with HDR UK and map current practices against objectives to highlight areas for development.
- Recruit diverse members to our Public Advisory Group (PAG), aiming to have broad representation across age, gender, ethnicity, location, health data literacy, etc.
- Work collaboratively with HDR UK to attend science festivals across the UK, including rural, remote and underserved locations.
- Promote and facilitate the inclusion of under-represented and seldom-heard groups through active engagement with local partners, organisations, and communities.
- Reduce barriers and increase accessibility to involvement and engagement by being flexible and accessible, using innovative approaches and utilise alternative formats for sharing information and engaging with the wider public.
- Actively seek and develop partnerships with trusted organisations, including diverse community groups, to help us reach diverse audiences at local, regional, and national levels.
- Work with HDR UK and PEDRI to enhance diversity in our involvement activities.
- Model a culture where different viewpoints are encouraged and valued across all our work.

Our Objectives

3. Utilising existing networks and working in partnership with organisations to improve our learning, strengthen our approach and reduce duplication within the field.

To achieve this objective, we will:

- Build upon existing relationships such as with British Heart Foundation, PEDRI and HDR UK and identify new opportunities for collaborative working with other organisations.
- Work collaboratively with partners to share learning and resources to support effective PPIE, making best use of resources and reducing duplication.
- Contribute to national PPIE networks, guideline and standards development and impact evaluation when we locate suitable opportunities and in response to invitations.
- Co-develop a framework with our public contributors that outlines principles and procedure for partnership working, aiming to embed PPIE within the process.

Our Objectives

4. Developing a strong culture around PPIE so that all BHF DSC stakeholders are confident in involvement and engagement approaches and our public contributors feel supported and empowered to contribute effectively.

To achieve this objective, we will:

- Offer a tailored and person-centred approach to induction, training and ongoing support for public contributors.
- Supporting BHF Data Science Centre staff and partners to include PPIE as a standard process in the set up and delivery of new and ongoing projects, including induction, one to one support and resources available.
- Supporting researchers to develop their knowledge and skills in PPIE through formal and informal learning opportunities, this includes training, workshops and webinars.
- Share resources and case studies to promote the importance of PPIE.
- Sharing training opportunities for public contributors to be involved in across HDR UK and BHF DSC.
- Work collaboratively with public contributors and researchers within the CVD-COVID-UK consortium (research focused on COVID-19 and heart and circulatory disease e.g., cardiovascular disease) to ensure robust PPIE within all proposed projects and conduct yearly training sessions for public contributors involved.
- Provide public contributors with the knowledge they need to effectively engage and get involved with an activity by providing updates on projects and sharing additional information via regular meetings and an internal newsletter.

Our Objectives

5. Monitoring and evaluating our PPIE activity, highlighting impact and changes as a result of public input with our public contributors and wider audiences.

We believe in the importance of continually developing our PPIE approaches and showcasing the positive impact public involvement and engagement has across our work. To achieve this objective, we will:

- Monitor public involvement and engagement via our reporting log to capture all PPIE activity and impact.
- Share updates and changes with the public group via a monthly newsletter, highlighting changes made as a direct result of their involvement and where changes can't be made, clearly explaining the reasons why.
- Annually review the impact of our PPIE work with our Public Advisory Group, Operations team and Senior management.
- Develop at least two case studies a year to capture impact of our PPIE activities and share these internally via our online platforms and externally with partners via newsletters and at events.
- Develop blogs and other opportunities alongside our public contributors to showcase how public involvement is making a difference across our work.
- Establish a mechanism that facilitates the exchange of good practices and mutual learning through quarterly PAG gatherings, as well as spontaneous ad-hoc meetings as the need arises.
- Sharing and celebrating examples of best practice and innovation across our work with partners and the wider community.
- Evaluate PPIE activities to identify areas for improvement and work to continually develop and strengthen our approach.

Our Objectives

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

To achieve this objective, we will:

- Host our Writing Club as need arises, allowing opportunity for our PAG to contribute to all external facing messages where relevant.
- Run workshops for website reviews and updates as needed.
- Invite our public contributors to co-present for our monthly webinars and networking events where appropriate.
- Increase the internal visibility of PPIE, e.g., new staff inductions, PPIE resources for internal communication, monthly PPIE update for staff and PAG including a member's corner written by public contributors.
- Develop new ways to engage wider audiences new to health data research.
- Utilise plain language, visuals and alternative information formats to be more accessible across all our communications at the Centre.
- Work with community-led organisations and healthcare partners to share external communications reaching wider audiences.
- Co-develop human interest stories alongside our public contributors bringing relevance and meaning to our work for patients and the public where possible.

CONTACT US

If you would like to find out more about our strategy, how we can help you or how you can get involved, please contact our friendly PPIE team.



Jemma Austin, PPIE Officer:
jemma.austin@hdruk.ac.uk



Amy Hodgkinson, PPIE Manager:
amy.hodgkinson@hdruk.ac.uk



Samaira Khan, Senior PPIE Manager:
samaira.khan@hdruk.ac.uk



<https://bhfdatasciencecentre.org>

