



**British Heart Foundation
Data Science Centre**

Led by Health Data Research UK

SUMMARY REPORT

Public Advisory Group Meeting : 16th May 2024

PRESENTED BY :
BHF Data Science Centre



Contents

Introduction	3
British Society of Heart Failure	4
Highlights and achievements.....	5
BHF Data Science Centre: Hot Topics	6
PPIE Strategy 24/24: Defining our objectives	7
Thank you	8

Introduction

The British Heart Foundation (BHF) Data Science Centre is proud to have a dedicated [Public Advisory Group \(PAG\)](#).

Our public contributors are members of the public with lived experience of heart disease, diabetes and/or stroke and they meet quarterly to share ideas, discuss challenges, and provide guidance and support to the Centre.

Once a year we hold a hybrid meeting, and we invite our public contributors to meet face to face at a venue situated in a preferred location of their choice.

This year the venue was based in York. Public contributors from all parts of England travelled to join us in person for an interactive meeting. We provided an option for anyone who couldn't attend in person to join us online. This is important as some of our public contributors can't join us in person for various reasons, so we want to ensure we are inclusive with our approach.

This year we asked our public contributors if they would like to hear from an external speaker.

They voted to hear from a speaker that could share more about their work with patients and the public with an aim to include underserved communities within cardiovascular research and to address health inequalities.

The rest of the meeting was dedicated to celebrating their involvement, sharing outputs and metrics as a result of their involvement within our work, important updates across our work and a session dedicated to gathering their input in relation to our PPIE strategy for 24/25.

These meetings are a fantastic way for us to build connections, facilitate engaging discussions and to hear from our public contributors who always have insightful perspectives and advice to share with the Centre.

British Society of Heart Failure

We were pleased to introduce Chief Executive Officer (CEO), Lynn MacKay Thomas from the British Society of Heart Failure (BSH) as our guest speaker. Lynn presented the [25in25 campaign](#) to our group and started the talk with a powerful film called '[Detect the Undetected: Find Me](#)' which was recently launched during Heart Failure Awareness Week 2024.

The 25in25 campaign is a national quality improvement initiative aimed to reduce heart failure deaths by 25% over the next 25 years using a community-based approach to early detection of heart failure. The BSH has encouraged commitment from fifty-eight organisations to work collaboratively to reduce unnecessary deaths due to heart failure.

Lynn explained why it's important for them to act now to reduce deaths, shared data insight predications into the rise of heart failure cases over the next 15 years, highlighted factors which have an impact on heart failure rates within the UK and addressed the wider implications of heart failure rates rising. Lynn introduced the initiative, highlighting their community-based approach to reaching local communities who may be dis-engaged with healthcare provision, the patient data process collected via primary care services and shared more information about their pilot sites across the country.

Lynn was joined by Laurence Humphrey-Davies the chair of the BSH Patient Advisory Panel (PAP) who also happens to be a public contributor for the Centre. Laurence kindly shared his knowledge from working with other existing groups and offered to introduce us to Lynn. Our public contributors are keen to help the Centre by sharing networks and ideas.

Our public contributors were invited to share their thoughts and they had lots of questions about the initiative. Some of their questions included:

- How are they tackling a rise in demand on healthcare services as a result of healthcare screening in the community?
- Is there a role for smart data and wearables in this work?
- How is the project sustainable if there is spike in patients needing care as a result of screening?

Next steps: We thoroughly enjoyed hearing from Lynn. The BHF Data Science Centre will reach out to BSH to work collaboratively on heart failure projects in the future.



Highlights and achievements

Samaira Khan, Senior PPIE Partnership Manager and Jemma Austin, PPIE Officer provided an overview of key highlights, outputs, and metrics as a result of our public contributor's involvement across the Centres work over the last nine months.

This included the success of our newly launched website and the co-designed patient and public involvement website page. The impact of public involvement across our areas of work such as Imaging, Smartphones and Wearables and Cohorts. A reflective look at some of our new outputs such as case studies, a short film, and co-authored papers. A reflection on successes when working with external members of the public, and finally our public audience reach through national media outlets as a result of their ideas and real-life patient stories.

We've compiled a list of publications to showcase some of the key highlights here:

- [Diabetes Data Science Catalyst Case Study](#)
 - [CVD-COVID-UK/IMPACT Approvals and Oversight Board Case Study](#)
 - [Kelvins Journey: Short Film](#)
 - [Patient and Public Website Page](#)
 - [Cardiovascular Priorities Research Findings](#)
 - [COALESCE Study](#)
 - Smartphones and Wearables: Patients help shape the use of smartphone and wearable data in cardiovascular research study
- [Web Story](#)
 - [Maidenhead Advertiser](#)
 - [BBC Online](#)

'It's all thanks to his smartwatch that Chris was diagnosed. It would've been so easy to dismiss if we hadn't had that data.'

- Nicola Monk, 'Smartphones and Wearables Patient Advisory Group'



BHF Data Science Centre: Hot Topics

Jackie MacArthur, Senior Programme Manager, Lynn Morrice, Operations Director and Ross Forsyth, Research Project Manager provided updates on key areas of work and future plans with the group.

This section of the meeting ensures that our public contributors feel informed about developments and hear about new opportunities for public involvement.

Jackie shared more information about our plans for Smart.Health -a proposal to deliver a data service to acquire, steward and enable safe access to smart data.

Jackie shared information about an area of work called 'Defining Disease' and recent work whereby we carried out an analysis to provide information on completeness, accuracy and estimates of key disease statistics and patient characteristics indifferent datasets. We will be inviting some of our public contributors to a workshop to help us plan how best to communicate this work with the public.

Lynn shared information about the Centre's renewal plans and timelines, ensuring that our public contributors knew that their input earlier last year and further input will incorporate into these plans.

Finally, Ross briefly introduced the group to a new name for our Cohorts Trusted Research Environment (TRE) platform and asked for their thoughts.

Next steps:

- Keep the group updated on Smart.Health proposal outcome
- Invite some of our public contributors to a Defining Disease workshop
- Gather further input from our public contributors where needed for our renewal plans
- Provide an update on the name for the Cohorts TRE platform



"I very much valued the short project and grant application updates: that was an essential part of the meeting" – Public contributor.

PPIE Strategy 24/24: Defining our objectives

Amy Hodgkinson, PPIE Manager conducted an interactive session exploring our current strategy and objectives with our public contributors.

This forms the first phase in a series of steps to update our strategy ensuring its current and in line with good practice for public involvement. The strategy acts a tool to drive forward our approach to achieve our vision.

We want to co-design our strategy with our public contributors so we can ensure that the patient and public perspective is central throughout our work.

The group were split into small groups and each group focused on one or two objectives. The groups had a facilitator and flipchart paper to capture ideas. Online participants were invited to share ideas using an online jam board or via the chat.

We used the 'Six Thinking Hat' framework to help shape our questions and discussions. The questions for each objective were as follows:

1. What are your initial thoughts about these objectives, any strengths, or concerns?
2. How does the objective help improve and add value to PPIE across our areas of work at the BHF DSC?
3. What obstacles might we face in achieving these objectives?
4. Beyond these objectives, are there any new ideas or approaches we could consider?
5. Are there case studies or success stories we could learn from?
6. Considering these objectives, highlight two areas you think are of importance – one to improve and one to uphold?



Next steps:

- Input shared on the day will be collated to help inform changes where relevant to the objectives
- Further input will be gathered from anyone who couldn't attend the meeting via a survey
- We will consider further stakeholders we need to engage
- An update will be shared in due course

Thank you

We would like to thank everyone for their involvement on the day. We would particularly like to thank all our speakers, background support and our public contributors. Without all your contributions this day wouldn't have been a success.

You can view the slides from the presentations on the day [HERE](#) and [HERE](#).

If you have any questions or would like further information, please contact our PPIE team using the following contact details:

- PPIE Officer, Jemma Austin: jemma.austin@hdruk.ac.uk
- PPIE Manager, Amy Hodgkinson: amy.hodgkinson@hdruk.ac.uk
- Senior Partnerships PPIE Manager, Samaira Khan: samaira.khan@hdruk.ac.uk



*"A huge thanks to you and the whole team for all the behind-the-scenes organisation for today. It really was a great round up of everything that's been achieved, vibrant, fun, and full of great ideas. You all do such a great job and I'm very proud to be part of such a brilliant team." – **Public contributor.***