Case Study: Patients and the public at the heart of cardiovascular research

A model for patient & public involvement and engagement

BACKGROUND

The BHF Data Science Centre works with partners including patients, researchers, clinicians, and the NHS to enable data-led research into the causes, prevention, and treatment of cardiovascular disease, diabetes, stroke, and dementia. To ensure our research is relevant and trustworthy to patients and the public the Centre has designed and embedded a model for patient and public involvement and engagement (PPIE).

OUR APPROACH

Our PPIE model integrates the public voice across all areas of our work, including governance, planning and priority setting, funding calls, communication, and evaluation, spanning all the areas in which our own staff work. Our diverse group of public contributors work with us across multiple areas to co-produce studies, materials and dissemination plans, placing patients and public at the heart of the research journey. Our model is aligned with the UK Standards for Public Involvement and PEDRI Draft Standards of Public Involvement.

"Our views are not only listened to but acted on. In addition, we are privileged to witness some amazing research done by amazing people."

MUSTAPHA KORIBA, PUBLIC CONTRIBUTOR

LEARN MORE ABOUT OUR MODEL FOR PPIE HERE

WHAT DIFFERENCE HAS THIS MADE?

This model improves the quality of our work in two ways, by increasing diversity, and ensuring our members provide meaningful input on areas most relevant to their expertise or experience. This flexibility has increased our own capacity, as well as ensuring that the patient voice is incorporated at each stage of the research journey. Thereby increasing the impact and visibility of our PPIE, building trust, transparency, and relevance within health data research.

This model has influenced change across the following themes:

- **Relevance** – improved the quality of research across the Centre and the research community, ensuring that it is relevant to patients and benefits the public.
- **Diversity** - has helped us consider diverse audiences across the UK, both in the co-development of communications and dissemination plans, leading to equitable research.
- **Culture** - set expectations of and providing a framework for mutually beneficial and respectful relationships between the public and researchers. We've created an environment where the public feel empowered and confident to share their differing ideas freely.
- **Trust** - co-developed trustworthy and meaningful research that matters to patients and have ensured we are transparent by communicating this work with the public using relevant formats.