

Case Study: Empowering Public Involvement

The CVD-COVID-IMPACT Approvals and Oversight Board

BACKGROUND

The BHF Data Science Centre coordinates a large programme of research investigating the interaction between heart and/or circulatory disease and COVID-19 (called CVD-COVID-UK). The research programme has >50 projects and analyses NHS data, collected nationally as part of routine care (e.g. hospital visits, medication prescribed). The data has identifiable information removed (e.g. name, address) so individuals cannot be identified. The data is held in a secure data environment (SDE) within the NHS. Before researchers access this data, they must undergo a rigorous approval process including review from our public panel via the CVD-COVID-UK Approvals and Oversight Board.

OUR APPROACH

All public contributors receive training to support their understanding of TREs and health data. The team of public contributors are then able to review each data access request and provide constructive feedback during the project approval process. At an online meeting, researchers present their research idea alongside plans for further patient and public involvement and engagement.

Considerable detail is covered at this meeting, with conversation topics including:

- Choice of outcome sought;
- exclusion criteria and safety aspects for new data providers (anonymised current patients);
- completeness of factors of relevance to people living with the condition in question;
- possible improvements to the “plain English” description of the project;
- and routes for dissemination of any findings.

After the meeting, the public members decide whether they wish to approve or reject the project and provide their reasoning behind this decision.

WHAT DIFFERENCE HAS THIS MADE?

55 applications have undergone review by our dedicated team of six public contributors. Researchers are explicitly informed about the significance of PPIE at this critical planning stage of their projects. Our public members actively engage in the review process, enhancing public understanding of data research, its applications, and its potential impact on the broader community.

The reviews have brought to light several key themes:

- **Diversity** - encouraging researchers to ensure their PPIE plans are representative in the context of their data research project
- **Support and facilitation for PPIE** - ensuring effective integration into the research process
- **Plain English** - advocating for communication in plain language so the public can understand the nature of the research and its goals

"It's been reassuring to see our input and feedback about genuine public involvement not only being taken on board, but extended and made sustainable."

- MARGARET RODGERS,
PUBLIC CONTRIBUTOR

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MARGARET AND OTHER
CONTRIBUTORS.](#)

