



**British Heart Foundation  
Data Science Centre**

Led by Health Data Research UK

# **BHF Data Science Centre: Public Advisory Group (PAG) Meeting**

## **Summary**

Tuesday 4<sup>th</sup> July 2023

**HDRUK**  
Health Data Research UK



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@BHFDDataScience



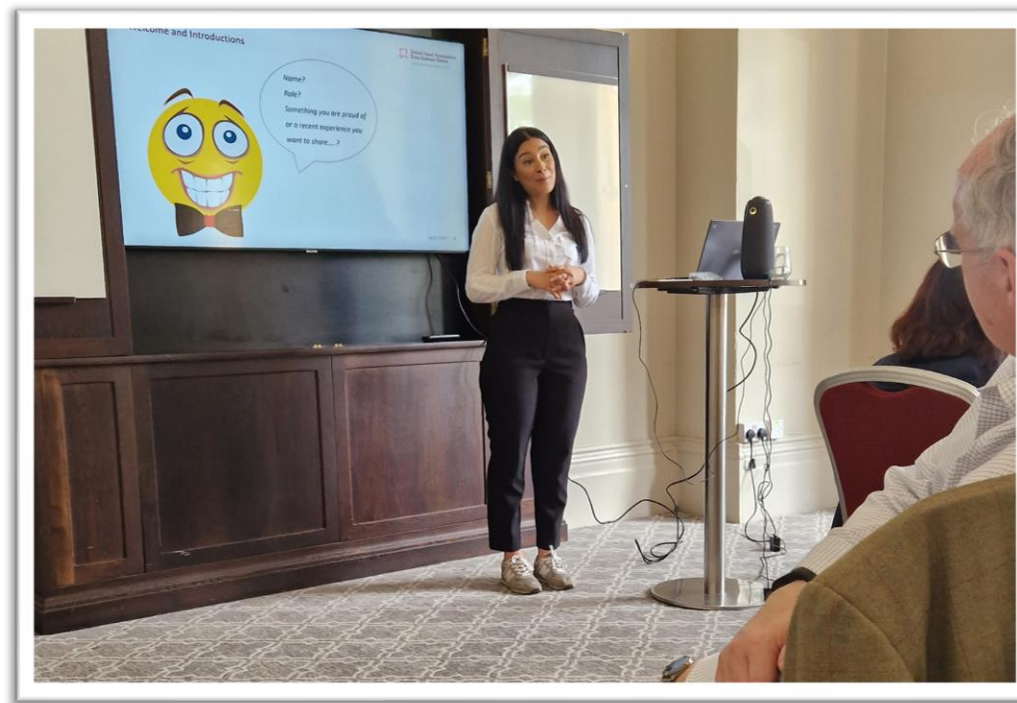
YouTube BHF Data Science Centre

## Welcome and Highlights

At the start of the meeting, Samaira requested attendees to introduce themselves, providing their names, roles/backgrounds, and something they were proud of or a recent experience they might want to share.

Samaira then discussed various PPIE highlights from the year, including contributions to reviewing applications, co-presenting webinars, co-authoring blogs and papers and involvement across thematic areas. She also touched on some exciting plans to look forward to including the launch of the new website, working collaboratively with the Stroke Association and Diabetes UK and capturing our impact.

Samaira also suggested developing case studies to demonstrate the impact of PPIE and improving communication mechanisms to keep PPIE members updated on progress and outcomes.





## BHF Data Science Centre: The Next Steps

Tim and Michelle led a discussion on the 5-year renewal and future steps for the BHF Data Science Centre. They emphasised the importance of creating a strong application to secure more funding, with PPIE playing a crucial role in the process. The BHF is open to the Centre applying for funding for the next five years. The discussion focused on developing an ambitious yet affordable plan, exploring opportunities for self-sustainability and securing additional funding from sources outside the organisation, particularly through partnerships.

Delegates were split into three groups with a facilitator on each table. The groups were asked to focus on four questions:

- What's gone well?
- What could we improve?
- What should be our main focus?
- What would you like to see us accomplish in the next 5 years. After discussion, each group provided feedback.

**Next steps:** The information gathered from the discussions will be used to shape the application.



## Unlocking Clarity: Communication

During the meeting, John Walsh, a public contributor, shared his expertise in public communication, from his time in technical publishing and public and media relations in science research. He highlighted the importance of the "Golden rule" of communication, which involves defining the target audience and tailoring the message to resonate with them. John emphasised the need for the BHF to have greater public ownership and stressed the importance of making the organisation's work more understandable to the general public.

He advised against using technical jargon that could alienate the target audience, urging the use of language that is relatable and easily comprehensible.

He provided all delegates with a handout titled 'Stories from the heart' and has now been assigned as our resident writer.

### Next steps:

- Invite John to present at a future Consortium meeting or Monthly Webinar
- Share 'Stories from the Heart' with the team



**Stories from the heart**

Some fragments from a lifetime of collisions with medicine

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**In praise of cardiologists**

I was doing a task for DH that involved an overnight stay. The Department provided the hotel room and explained that I should buy myself an evening meal, within a cost limit, but that (in bold type) **no alcohol cost would be reimbursed**.

That evening, I found a cosy Italian place for a bowl of excellent orecchiette that cried out for the company of a glass of Primitivo, for which I thought must get a separate bill. But when the coffee came, the bill came with it already printed. I realised I would have to perform a subtraction sum.

When it came to filling in the claim form, though, I felt too old for that sort of pettifogging nonsense, so claimed the lot, and included the following explanatory note:

*"The item of alcohol on the enclosed receipt is the glass of red wine I take daily on the advice of my consultant cardiologist."*

They paid!

**The heart and the matter**

## Defining Disease in Clinical Trials

Jackie and Sarah presented the current progress in defining disease in clinical trials during the meeting. They initiated a discussion to gather feedback, which would be utilised in the future development of the website and communication of this work. The presentation explained the importance of linking patient information from various datasets, using data such as date of birth. The objective was to streamline and enhance trials by focusing on available healthcare systems.

The PPIE group provided feedback on the communication of this work, including preferences for using medical codes instead of technical coding language, clarifying anonymisation processes upfront, emphasising the benefits of changing clinical trial designs, and suggesting the need for more focused presentations.

Other comments included the importance of collecting quality of life data as a standard, including a slide explaining the aim of the presentation and desired outcomes, using clearer language, and highlighting the positive patient impact of research outcomes.



### Next Steps:

- Incorporate PPIE feedback to improve future presentations.
- Reword certain sentences in the slides for improved clarity.
- Consider consolidating instructions for answering research questions.
- Determine the appropriate timing to address the distinction between identifiable and nonidentifiable data
- Revisit at future Writing club to finalise

# Exploring Your Roles within Communities: Influence, Networks, and Alignment with the BHF DSC

During the final session Samaira emphasised the significance of collaboration, engaging diverse audiences, and leveraging personal networks within communities. Everyone was encouraged to explore existing partnerships and learn from each other's experiences. Some metrics were presented around the gaps in our engagement.

Public contributors took a few minutes to reflect on their involvement with local networks, community groups, and organisations. Moving forward, the BHF DSC aims to reach a more diverse audience and actively involve as many individuals as possible.

## Next Steps:

The information shared during the meeting will be utilised to develop an internal spreadsheet which will help with future engagement plans, ensuring inclusive and meaningful interactions with various communities.





## Thank you

Thank you to everyone who attended in person and online and a special thanks to John Walsh for his amazing talk and Phil Blakelock for his brilliant photography.

You can view the slides from the day by [clicking here](#).

Please direct any questions to [samaira.khan@hdruk.ac.uk](mailto:samaira.khan@hdruk.ac.uk)

