

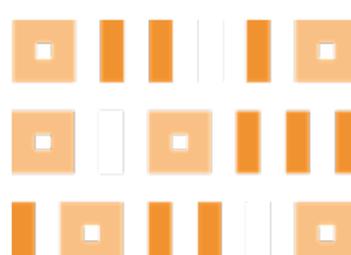
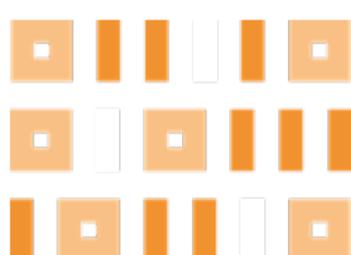
CUH Patient and Public Involvement Summer 2023 Newsletter

News and updates on PPI in the East of England



Welcome to the Summer 2023 edition.

This newsletter is being delivered to you since you have previously asked to be added to our subscriber list. We use this quarterly newsletter to keep you informed about PPI news, training opportunities, and other events on the local and national levels. Please email cuh.ppi@nhs.net to update your choices if you would prefer to be removed from our subscriber list.



Remaining Research Information talks for the public in 2023

We have two research information talks left from Cambridge researchers for 2023 which will cover the following topics:

- **How AI is impacting healthcare research? Joshua Kaggie**
6th October 2023 from 12:00-13:00
- **What are Biomarkers and how are they used in research? Francesca Gaccioli**
21st November 2023 from 11:00-12:00

We have included links to earlier talks that are now on YouTube:

How Immunotherapy Works https://youtu.be/kqAlu4C_sE

Dr. James Jones and Professor Mark Evans, our keynote speakers for this session are both experts in the field of immunotherapy. They will be sharing their research and insights in this exciting area of medical research and you will have the opportunity to hear about the latest findings related to immunotherapy.

From Idea to Practice: The Research Journey Towards

Commercialisation <https://youtu.be/CWJNW6Ru7Ys>

Dafne Chirivino, our keynote speaker, works with Cambridge Enterprise, which is run by the University of Cambridge to help researchers make sure their research has an impact in the real world. You will have the opportunity to learn more about what it takes for research to make a difference, and the various steps that research takes from idea through to product or treatment.

These talks are open to anyone involved in research across Cambridge, and the links will be shared with both CUH PPI panel members and public involvement/engagement staff in our network. If you are a researcher who would like to contribute to this series, or if you have public contributors who may wish to attend, please get in touch at cuh.ppi@nhs.net

What does regional 'success' in PPI look like to you?

The Cambridge University Health Partners (CUHP) PPI forum brings together people working in public involvement at health and research organisations based on the Cambridge Biomedical Campus. Together, we discuss how we can best work together to involve people living in the East of England in our collective research. The directors of CUHP and Cambridge University Hospitals recently posed us the question of what 'successful' PPI would look like on a regional level, and how we might be able to gauge our progress.

We'd love to hear your thoughts through the following survey link - there are 3 free text boxes to help collect ideas, and you don't have to fill them all in. These are quite hand-wavy questions, so there are no right or wrong answers and you can write as much or as little as you like!

Survey link [here](#)

Would you be interested in networking with other local public contributors?

Over the past few months, several public contributors have commented that it would be nice to know more about, and perhaps meet other public contributors. Working

with the CUHP PPI forum, we would be happy to organise a networking event if there is interest, and if you can give us a bit more information about what you would like it to look like!

We'd love to hear your thoughts through (yet another) survey link - this survey has both a free textbox and some multiple choice options.

Survey link [here](#)

Would you be interested in helping us pilot a new health-data research engagement activity?

Amanda has been working on a new tool to help support discussions between members of the public and researchers about the use of health data. We need some public contributors to help test it out! No experience of working with health data is necessary - it would be great to have a mix of contributors who have and have not previously worked with health data.

Date: 12th Oct, 10 am- 1 pm, with lunch included (final timings TBC)

Location: Hexagon room, Frank Lee Building, Cambridge Biomedical Campus

Honoraria: £25 + reimbursement of parking+ public transport/mileage up to 30 miles outside Cambridge

Expressions of interest: a.stranks@nhs.net

Curious to know more about becoming a PPI panel member?

Watch testimonials from a few of our members explaining their reasons for joining:

Abi - <https://youtu.be/3bYLMz5BsNc>
Phil - <https://youtu.be/xwb6BdJ8A4o>
Serrita - https://youtu.be/ytwO_UF1OCo
Andy - <https://youtu.be/SZ8BfA5wGC0>
Amy - <https://youtu.be/Tblj5C-gFyg>
Allen - <https://youtu.be/-Zt1Kyv9VFg>

Researchers' feedback to CUH PPI panel members



It's been a busy time with researchers needing your help. What did they think of your involvement? Check out the feedback they gave on the academic research projects [Click here](#)

Feedback has been shared from projects conducted between April 2023 to July 2023

These files are password protected and only available to CUH PPI panel members.



Events



Help shape health data research in Cambridge

Tues 29 Aug 2023 from 6.30 pm to 8.00 pm - Online

Medical records contain a wealth of health data including tests, diagnoses, treatments, and outcomes. These data can be used in cutting edge health data research including modelling more efficient planning of services, identifying new treatments that work for specific patient groups or training AI models to help clinicians diagnosis illness faster. These innovations can ultimately help to improve services and transform the care that patients receive.

It is vital that researchers work with patients and the public to ensure that health data are used in ways that protect privacy and that patients are comfortable with.

CUH have established the Electronic Patient Record Research and innovation (ERIN) database and will be setting up a patient panel to review applications from researchers for data; information on how you can get involved in and start shaping health data research will be provided at the event.

Our speakers will share their unique perspectives, knowledge and experience of health data research before joining a panel discussion and Q&A session. Audience members are encouraged to submit their questions about health data research to the panel in advance as well as asking live questions on the day.

Join speakers including Dr Ari Ercole and Dr Raj Jena for an event exploring health data research, AI and how you can get involved.

To book bit.ly/ShapeHDr

What can PPI contributors in research actually do?

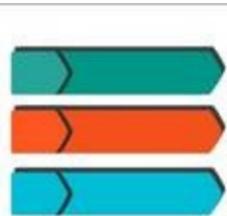
Date: Tuesday 12th September 2023 Time: 13:00 - 14:00

Would you like to learn more about the different roles that patients and members of the public involved in health research can hold?

Patients and members of the public can play an important role supporting quality health research by providing their voice throughout a research project. Hearing from people outside of the research community makes sure that the needs of patients are kept front and centre.

There are many opportunities for both people with lived experience of health conditions and people providing a "general public" perspective to get involved.

Join this [Online](#) information session to find out about some of the different roles that patients and members of the public can hold in research.



Interested in data science?

Monday 2nd October from 5:30 to 7pm.

The British Heart Foundation (BHF) Data Science Centre would like to invite you to an informal evening drinks reception at the **Clayton Hotel, Station Road, Cambridge**.

The event will be a chance to learn about plans to improve the UK's data infrastructure, hear about our work in areas such as wearables and imaging, and find out about key outputs from our CVD/COVID-UK/COVID-IMPACT Consortium. You will also meet others working in cardiology, data science and related fields, and find out how we support research and involve patients and the public.

Please register for the event on this [link](#).

We are looking forward to a lively Q&A and discussion after short talks from:

Professor Cathie Sudlow, Director

Professor Steffen Petersen, Deputy Director

Margaret Rogers, public contributor

The BHF Data Science Centre is part of Health Data Research UK (HDR UK), the UK's national institute for health data science, and was set up in 2020 as a partnership between HDR UK and the BHF. Our aim is to enable data-led research to improve heart and circulatory health. We work with a wide range of partners including patients, clinicians, researchers, and NHS organisations to enable data-led research into the causes, prevention, and treatment of all diseases of the heart and circulation, including heart attacks, stroke and vascular dementia.

You can find out more about our work [here](#).

Kate McAllister, on behalf of the BHF Data Science Centre

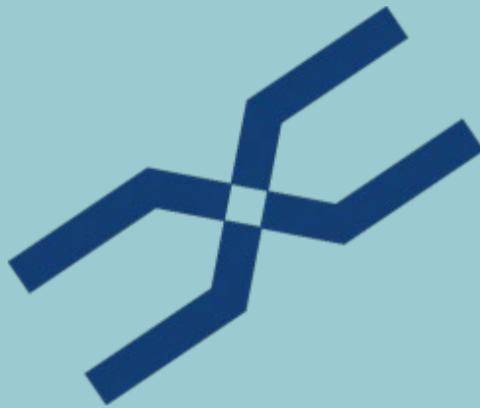
PPI Articles





Medical Writing in Plain English

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Largest genetic study of brain structure identifies how the brain is organised

The largest ever study of the genetics of the brain – encompassing some 36,000 brain scans – has identified more than 4,000 genetic variants linked to brain structure. [Read more](#)



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