



## CUH Patient and Public Involvement

### Spring 2022 Newsletter

News and updates on PPI in the East of England

You are receiving this as you have previously asked to be added to our newsletter subscriber list. We use this regular newsletter to keep you up to date with local and national PPI news, training events and other opportunities. If you would rather not remain on our subscription list, please email [ppi@addenbrookes.nhs.uk](mailto:ppi@addenbrookes.nhs.uk) to update your preferences.

## Online Researcher PPI Training: Autumn 2022 Dates Announced

These online sessions are held on Zoom. They are open and free-of-charge for UK-based students and staff employed or funded by the NIHR, NHS, academic institutions and charities. They are designed to provide training for health researchers on a range of important PPI skills and activities. We also host public information sessions on PPI aimed at members of the public.

These sessions predominantly cover involving adults in research, as we have substantially less experience working with children and young people. Although content in these topics can relate to all audiences, please be aware that we do not specifically cover PPI with children or young people.

You can register to attend all sessions by visiting the [Online PPI Events page on the NIHR Cambridge BRC website](#). Please note that a work associated email (e.g. .nhs.net, .ac.uk etc.) is required to confirm registration.



### [Introduction to PPI for researchers](#)

**Tuesday 5 July 2022, 10.00-12.00**

This interactive session covers what PPI is, how it can help research and tips for doing it well. The session also includes one of our CUH PPI Panel members sharing their experiences of getting involved, and a PPI case study presented by a local researcher.

### [PPI toolkit: Ways to involve the public in research](#)

**Wednesday 20 July 2022, 10.00-12.30**

This session looks at some of the methods that can be used for PPI to help researchers find ways that might be suitable for their project. The session covers activities that can be used throughout the research cycle, with examples from research taking place on campus.

### [How to build and maintain PPI groups](#)

**Thursday 11 August 2022, 9.30-11.30**

Forming a PPI group can be an effective way of involving people in your research. This session looks at the different ways a PPI group can work, how to recruit group members and how to keep them involved throughout the lifecycle of your project. Includes one of our CUH PPI panel members and a researcher who will share their experiences.

### [Running successful PPI groups](#)

**Tuesday 13 September 2022, 14.00-16.00**

Focus groups can be a great way to support discussion about your research with a group

of interested people. In this session we will look at how focus/discussion groups can be useful for PPI, when they might not be appropriate and how to plan, organise and follow up a successful session.

### [Planning inclusive PPI](#)

**Thursday 6 October 2022, 10.00-12.30**

To maximise the impact of PPI and improve research for everyone, we need to involve a diverse range of people and communities. This session encourages participants to think about ways to design inclusive PPI opportunities that work for the communities they wish to involve. We will look at best practice and examples for relationship building, recruitment, planning and follow up.

### [Evaluating PPI](#)

**Monday 24 October 2022, 14.00-16.00**

PPI is seen as essential to improving the value and relevance of research - but how can we evaluate the impact that our PPI has had, to know whether it has worked well and how it can be improved in the future? In this session we will look at why traditional evaluation is difficult for PPI, how best to plan for success, and monitoring and recording your impact.

### [Writing lay summaries for health research](#)

**Wednesday 30 November 2022, 9.30-11.30**

An interactive session for health care researchers on communicating your research to a wide audience. Looking at what makes a successful lay summary and things to avoid based on feedback from our public contributors.

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## **PPI Information Sessions for Members of the Public: 2022 Dates Announced**

The CUH PPI Team are running three online information sessions for members of the public who may be new to PPI or interested to learn more about everyone can contribute to health research to make it the best that it can be.



### **Understanding clinical research and how you can help to shape it!**

**Wednesday 4 May 2022, 1200-13.00**

[Register here.](#)

From new ways to diagnose, treat and prevent health care conditions, the aim of all clinical research is to improve patient care. Join this information session to find out about the different types of clinical research and the 'rules' and processes researchers follow to turn an idea into a scientific discovery.

Patients and members of the public have an important role to play in the research that we do, and this session will also look at how patient and public involvement helps to make our research even better.

So, if you are interested in science and learning more about clinical research this information session is for you.

### **Getting involved in health research at the NIHR Cambridge BRC**

**Monday 31 October 2022, 12.00-13.00**

[Register here.](#)

Join this information session to learn more about our research and how we work with our partners across the Cambridge Biomedical Campus to turn our scientific discoveries into

new ways to diagnose, treat and prevent health care conditions.

Patients and members of the public have an important role to play in the research that we do, and this session will also look at how you can help make our research even better by getting involved.

### **What can PPI contributors in research actually do?**

**Thursday 16 June 2022, 13.00-14.00**

[Register here.](#)

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 information session to find out about some of the different roles that patients and members of the public can hold in research.

We will cover:

- Acting as a lay reviewer for Patient and Public Involvement (PPI) panels - a flexible “offline” opportunity covering multiple projects.
- Attending discussion groups and workshops - sharing your opinions with researchers and other members of the public in virtual or in-person meetings.
- Sitting on a steering, oversight or data access committee - helping to guide high level strategic decisions over the course of a project.
- Being a co-applicant - joining a research team to help design and deliver a research project
- We will hear from public contributors on their experiences in these different roles and there will be an opportunity for Q&A.

If you are passionate about health and social care research and think you would be interested in acting as a patient/public contributor, this session will let you know what to expect.

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## **Update on Research Information Sessions for people involved in health research**

These online sessions have been organised by the CUH PPI Team from a list of topics suggested by the CUH PPI Panel. These talks will be open to members of the public currently involved in research through a PPI group or panel in the East of England, or acting as a public contributor on a research project that is linked to a local institution. If

you have not already received details about these talks and would like to register your interest, please email [ppi@addenbrookes.nhs.uk](mailto:ppi@addenbrookes.nhs.uk) for the joining details.



**The development and regulation of medical devices, with Dr Anita Marguerie de Rotrou.**

**Thursday 5 May 2022, 13.00-14.00**

There is an established process for developing and testing new drugs. Lab experiments eventually lead to clinical trials, where experimental drugs are tested against existing medicines or a placebo under controlled conditions to see if they are safe and effective.

But what happens when new medical devices are developed?

Join Dr Anita Marguerie de Rotrou, Head of the Office for Translational Research at the University of Cambridge, for this talk covering how new medical devices are developed, tested, and regulated to reach the market.

**Ethics, science and the public, with Dr Richard Milne.**

**Monday 18 July 2022, 12.00-13.00**

Scientific research can result in progress that transforms the lives of patients, but it can also raise concerns and questions for society.

There are big questions around who bears responsibility for the ethical implications of new scientific discoveries and how the views of the public can shape the direction and requirements of scientific research. The new Kavli Centre for Ethics, Science, and the Public at the University of Cambridge will tackle these critical questions.

Join Dr Richard Milne, Deputy Director and Lead for Research at the Kavli Centre for Ethics, Science and the Public, to learn more on this fascinating topic.

**Why do we need different phases in a clinical trial? With Ms Jo Piper.**

**Tuesday 9 August 2022, 12.00-13.00**

Before they can be used to treat patients as part of usual clinical care, drugs must be tested in clinical trials.

There are multiple types of clinical trials and the entire process consists of multiple phases. If you've ever wondered what it means when people refer to a Phase 1a or a Phase 2b trial, this talk is for you!

Join Ms Jo Piper, Manager at the NIHR Cambridge Clinical Research Facility (CRF), to hear about why we need different phases in a clinical trial and how clinical trials fit into the wider research context. Jo will provide some illustrative examples from work undertaken here in Cambridge during the talk.

**What are the NIHR looking for in funding applications? With Mr Andy Sharpe.**

**Tuesday 22 November 2022, 12.00-13.00**

The National Institute for Health Research (NIHR) is a government agency which funds research into health and social care. The NIHR funds the Cambridge BRC and much of the research that takes place on campus. As the largest clinical research funder in the UK, it is commonly referred to as the "research arm of the NHS".

As public contributors, many of you have assisted researchers by commenting on their early research ideas before they apply to the NIHR for funding. You may have read lay summaries, project protocols, PPI plans and draft materials for patients or participants.

So, what are the NIHR really looking for in the funding applications that researchers submit after your review?

If you'd like to learn more about the answer to this question, join this talk from Mr Andy Sharpe, Manager at the Cambridgeshire & Peterborough NIHR Research Design Service! Andy will talk about different funding streams that researchers can apply for, what the full applications include, and what the NIHR asks to see in these applications.

Did you miss one of our earlier talks on artificial intelligence or translational research? [You can watch a recording here!](#)

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## Researchers Feedback to CUH PPI Panel Members



Researchers ask PPI contributors for comments on their research, PPI contributors provide comments and then researchers provide their feedback and updates. We have had a very busy start to the year, so thank you to all our panel members for your continued enthusiasm and excellent comments! Researchers are really grateful all your hard work and send their thanks.

Please [click here](#) to access feedback from academic research projects. Feedback has been shared from projects conducted between January 2022 and March 2022.

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

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## Recent PPI/E Case Studies





## **Cambridge Creative Encounters - Behind the Curtains project uses theatre to communicate genetics research**

[Cambridge Creative Encounters \(CCE\)](#) is a public engagement project that brings together University of Cambridge researchers looking for creative ways to communicate their research, with creative professionals.

Through this programme, Sarah Fahle (PPIE Lead at the the NIHR Blood and Transplant Research Unit (BTRU) in Donor Health and Genomics), Amy Mason, Sam Lambert and Mike Inouye (researchers at the University of Cambridge Department of Public Health and Primary Care) chose to communicate Polygenic Risk Scores (PRS) through the medium of theatre.

PRS are a way of using the information in your DNA to predict future health outcomes and can be a challenging concept to communicate. As part of the project, Amy and Sam developed handouts which were used to explain PRS to a group of young performers and two people with sickle cell disease collaborating with the wider team. They also held a workshop with 25 patients/members of the public, where they discussed what PRS are and how they could be communicated to the public.

Their play, [Genetic Destinies](#) was written and performed by local young performers and was well received!

All the plays are available to watch [here](#). Genetic Destinies starts at 57.28.

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**British Society for Immunology and UK Coronavirus Immunology**

## Consortium (UK-CIC) publish report on the impact of PPI in immunology research

The UK-CIC was a 12 month collaboration between scientists, clinicians, and patient and public contributors. Their research focussed on important questions surrounding SARS-CoV-2, the virus that causes COVID-19. This report celebrates the positive impact of PPI, including how key questions about the implications of research could be addressed, and provides suggestions on how to better bridge the gap between basic research and the lived experience of patients.

By the end of their project, the UK-CIC reported the following statistics:

- **83%** of the Management board agreed that the impact PPI had on UK-CIC was valuable or extremely valuable
- **67%** felt that the input from the PPI panel provided a novel perspective on UK-CIC research which may not otherwise be considered
- **83%** said that spending funding on PPI was value for money
- **83%** said that as a result of their experience with PPI in UK-CIC they would consider including PPI in future research projects

[Read the press release from the British Society for Immunology here.](#)

[Read the full report here.](#)

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## PPI Articles

The PPI Team often comes across articles on the topic of PPI that challenge our assumptions and encourage us to think more deeply about the PPI we do, although we don't always agree with their conclusions. Let us know what you think!



## **How to make study documents clear and relevant: the impact of patient involvement**

In this paper, a team based at the Institute of Psychiatry, Psychology and Neuroscience at Kings College London discuss the effectiveness of the FAST-R document review service at the NIHR Maudsley Biomedical Research Centre (BRC). The [FAST-R team](#) links researchers with people who have lived experience of mental health conditions and have been trained to advise on participant-facing documents like information sheets, consent forms and lay summaries.

The authors found that although FAST-R reviewers suggested many alternatives for jargon words and phrases, documents remained long. This presents issues as over-long documents can still be challenging to read and present their own barriers to informed consent.

[Click here to read the full article.](#)

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## **Data is the new oil: is that true for research data?**

For many years now, data has been heralded as "the new oil". It isn't too difficult to see the similarities between refining crude oil into useful products like petrol and mining huge sets of unstructured raw data to find useful patterns that can be useful to solve problems across many industries.

In this article, the author investigates whether the analogy applies for the analysis of routinely collected health data and asks some big questions about the venture. How can IT systems cope with the wealth of data collected by NHS Trusts? How is data suitably contextualised? What can be done about data that is inconsistently input into record systems, or out of date, or incomplete? And how do the needs, expectations and rights of patients come into play?

[Click here to read the full article.](#)



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