

CUH Patient and Public Involvement

Autumn 2021 Newsletter

News and updates on PPI in the East of England

Welcome to the Autumn 2021 edition of our newsletter. 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 to update your preferences.

2021 Researcher Talks Series



Researcher Talks are an exclusive opportunity for members of the CUH PPI Panel to hear directly from researchers about their cutting-edge research.

Each month, we hear from a different BRC researcher on their current research and PPI journey. We have been fortunate to hear from several wonderful speakers, including: Prof Sadaf Farooqi, Professor of Metabolism and Medicine at the University of Cambridge; Prof Gordon Smith, Head of Obstetrics and Gynaecology at CUH; Dr Mark Toshner, joint lead for the national HEAL-COVID trial; Prof Nick Wareham, Director of the MRC Epidemiology Unit; and Prof Roger Barker, Professor of Clinical Neuroscience at the University of Cambridge and BRC Dementia theme lead.

Thank you so much to all our speakers for such interesting talks and to all our panel

members for your continued engagement with the series!

Upcoming talks:

November: Mr Stephen Price, Consultant Neurosurgeon at CUH, will be speaking about a new precision surgery programme for glioblastomas.

December: Mr Dominic Summers, Clinical Lecturer in the Department of Surgery, will be talking about recent work on organ transplants.

Are you a researcher who would be interested in presenting your research to the panel? Please [get in touch with us](#) to ask!

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.

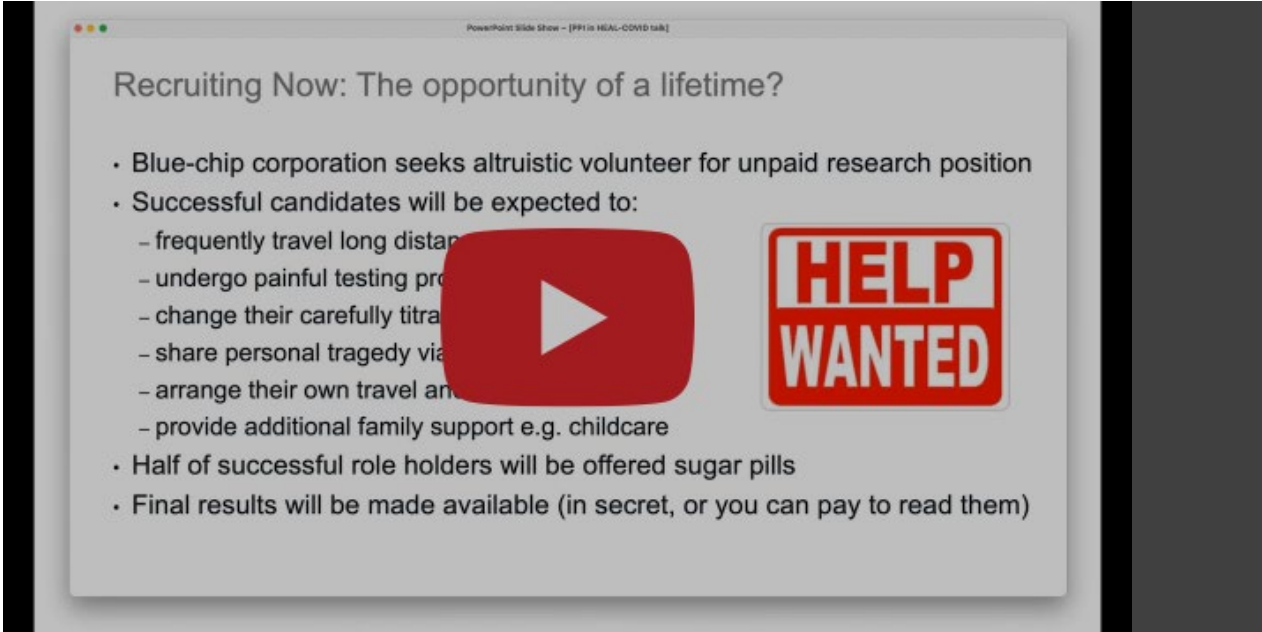
Please [click here](#) to access feedback from academic research projects. Feedback has been shared from projects conducted between April 2021 and September 2021.

Please [click here](#) to access feedback from industry projects. This feedback covers projects undertaken since June 2021.

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

HEAL-COVID PPI talk from Dr Paul Wicks now available online

The [HEAL-COVID study](#) is a national clinical trial that aims to identify treatments that may be beneficial for people discharged from hospital after recovering from COVID-19. The CUH PPI Panel have been involved with this project since the beginning of the year and have worked closely with PPI Lead, Dr Paul Wicks. Paul recently gave a talk on how PPI has impacted the HEAL-COVID study, titled "There's always time to listen to patients". View the talk below!



PowerPoint Slide Show - [PPI in HEAL-COVID talk]

Recruiting Now: The opportunity of a lifetime?

- Blue-chip corporation seeks altruistic volunteer for unpaid research position
- Successful candidates will be expected to:
 - frequently travel long distances
 - undergo painful testing procedures
 - change their carefully titrated diets
 - share personal tragedy via social media
 - arrange their own travel and accommodation
 - provide additional family support e.g. childcare
- Half of successful role holders will be offered sugar pills
- Final results will be made available (in secret, or you can pay to read them)

HELP WANTED

Dr Paul Wicks: There's always time to listen to patients.

The Patient Led Research Hub Newsletter



The Patient Led Research Hub (PLRH) is a service in Cambridge that provides expertise to charities and patient groups to support patient-initiated and patient led research. The PLRH has spent much of the last 18 months supporting covid-related across CUH, but their resources are now shifting back to patient-led research and co-production. You can learn more about the PLRH at [their website](#) and access their previous newsletters on their [Publications page](#).

You can also [subscribe to their quarterly newsletter mailing list](#) to hear about the great work their team are doing!

Virtual PPI Research Related Events This Autumn



An interactive course for new and experienced patient/public reviewers of health and social care research

Location: Free online course. For more details [click here](#).

This course has been produced by a team of public reviewers and PPI professionals with the NIHR. The course covers reviewing in all contexts for NIHR research funding programmes, plus skills and activities required at different levels and stages of research. It is designed for public contributors who are committee members as well as public reviewers.

Researchers may also find this resource useful when writing research funding applications. It can be used as a tool to understand how to get your Patient and Public Involvement right first time!

Further Involvement Opportunities

The [CICADA study](#) is aiming to learn more from the experiences of people with chronic conditions (including long covid) and disabilities who are from ethnic minority groups.

The team are currently inviting people to participate in their study by completing surveys and/or talking about their pandemic experience in an interview. They are planning a range of different co-production and involvement opportunities starting in 2022. If you would like to learn more about involvement, please contact Jenny Camaradou at j.camaradou@ucl.ac.uk.



Do you have an involvement opportunity that you would like to share in our newsletter? [Please get in touch!](#)

News: Medicines and Healthcare products Regulatory Agency (MHRA) publishes proposed PPI Strategy 2020-2025

Following a consultation, the MHRA has proposed a new five-year PPI strategy with five strategic objectives:

1. **Patient and public involvement:** we will develop and introduce clear processes for engagement and involvement, to ensure teams have a systematic means of engaging and involving patients and the public in their work and that we publish how we do that.

2. **Responsiveness:** In designing and delivering our services, we will embed the 'patient and public voice' to ensure that those services meet the needs of the patients and other members of the public who use them. We will implement a process allowing for more agile and regular review of high-risk issues, with a system that flags when more in-depth involvement of patient groups is needed.
3. **Internal culture:** We will introduce new systems, processes and training to support a change in our culture, so that every member of staff considers the patient and public perspective in their decisions, and that all staff are well supported and involved in delivering that change.
4. **Measuring outcomes:** We will develop, build and embed a clear patient outcome evaluation framework that ensures we consider all patients and which enables us to demonstrate our progress in delivering our vision of being a patient focused regulator.
5. **Partnerships:** We will develop a cross sector partnership plan that builds and delivers collaborations with partners across the health sector to improve the effectiveness of engagement and share patient insight.

[You can read the full report here.](#)

[You can read an interesting summary and think-piece from the PHG Foundation here.](#)

Recent PPI Case Studies



LGBTQ+ public involvement panel choose priority themes for research into health of sexual and gender minority populations

Health services delivery, the prevention of health problems, and the intersectionality of sexual orientation and gender identity with other disadvantages are top priorities for LGBTQ+ health research, according to a new research prioritisation exercise carried out with members of the public.

[Click here to read the press release](#) from the Cambridge Research Methods Hub.

[Click here to read the full research article](#) from Dr Catherine Sanders and her team.

Stroke Association Priority Setting Partnership (PSP) identifies top 10 areas in need of investigation in stroke research

The Stroke Association has developed a new report outlining priorities for stroke research, following input into two surveys from 1,400 stroke survivors, carers and professionals. This has been the first UK-wide project to map the priorities for stroke research that span the entire stroke care and treatment journey.

Priorities were split into two areas, the first being stroke prevention, diagnosis, pre-hospital and hospital care. The top 3 research questions were:

1. What are the best interventions to stop stroke happening for the first time?
2. How can the public, paramedics and other health care professionals recognise and respond to stroke or TIA better and more quickly?
3. What are the benefits and risks of acute treatments for intracerebral haemorrhage?

The second priority area was stroke rehabilitation and long-term care. The top 3 research questions here centred around:

1. Mental and emotional (psychological) problems can be caused by stroke/TIA
2. Thinking and memory (cognitive) problems caused by stroke
3. Communication abilities such as reading, speaking, listening, social and related 'thinking' skills

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

CanTest Collaborative Case Study: Involving patients and members of the public to improve the early diagnosis of cancer

The CanTest Collaborative is an international team of primary care cancer researchers working on early detection and diagnosis of cancer. Cambridge's CanTest research, based at the University's Primary Care Unit, focuses on developing strategies to detect symptomatic cancer earlier. The Collaborative worked with a panel of PPI

representatives, chaired by co-investigator and PPI Lead, Margaret Johnson.

The PPI panel are involved in many aspects of the study, including reviewing documentation, co-authoring academic papers, attending conferences and writing blogs about their experiences.

PPI has been instrumental in shaping CanTest research processes and outputs including materials for the studies and research publications. In particular, PPI helped make the research more acceptable and accessible to the target patient group. One such example was the renaming of a diagnostic toolkit on a patient information leaflet, entirely driven by PPI representatives. “They asked that we rename the toolkit from “faecal immunochemical test” to “poo test”, which was much easier for patients to understand, and will, we hope, increase the chances of public engagement with the study”, said Dr Valerie Sills.

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

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!



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Who should I involve in my research and why? Patients, carers or the public?

In this article, the authors (three of whom consider themselves to be patient advocates) debate the pros and cons of involving patients vs members of the public. They argue that "involving people who do not have relevant experiential knowledge may limit impact" because "these people may be as likely as researchers to make wrong assumptions". The authors believe that the purpose of involvement needs to be made clearer, in order to find the most appropriate people to involve in each research project.

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

“The trouble with patient and public involvement (PPI)” – keynote at Cochrane Colloquium 2018

In this transcript of the keynote speech at the 2018 Cochrane Colloquium in Edinburgh, the author, Jennifer Johannesen, discusses issues and challenges with PPI (which is often referred to in the article as "patient engagement" due to Jennifer's Canadian background). As a self-described "critic of patient engagement", Jennifer thinks that "programmatic, institution-sponsored patient engagement needs to end because it allows institutions to monopolize dialogue and constrain the topics that can be discussed" and advocates for "researchers saying no, or protesting loudly, when the requirement for patient engagement risks compromising the integrity of their work". She also encourages patients to "stop, or at least resist, participating in the patient engagement enterprise."

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



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