

## CUH Patient and Public Involvement

### Summer 2021 Newsletter

News and updates on PPI in the East of England

Welcome to the Summer 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](mailto:ppi@addenbrookes.nhs.uk) to update your preferences.

## CUH PPI Panel Diversity Drive

Firstly a big thank you to our current panel members for filling out our recent Diversity and Monitoring Survey. We are using the results of this survey to better understand the characteristics of the CUH PPI Panel, so that we can try to build a panel that is as diverse as the people in Cambridgeshire and the surrounding areas, and all the people that we see at CUH.

Everyone is welcome to join the CUH PPI Panel, regardless of identity, background or lived experience and we want to ensure the widest possible range of experiences are represented within the panel. This is very important to us because different groups have different lived experiences, and bring different perspectives to the table. By listening to lots of different people, we are seeking to build an understanding that encompasses all these different perspectives, so we can usefully support new research projects to be designed with everybody in mind.

Based on the findings from our survey, it is clear that several groups are currently under-represented. We would particularly like to hear from people who belong to the below groups. Please [get in touch](#) if you are personally interested in joining the panel or if you know of any local community groups that you feel we may be able to initiate partnerships with.

## Men

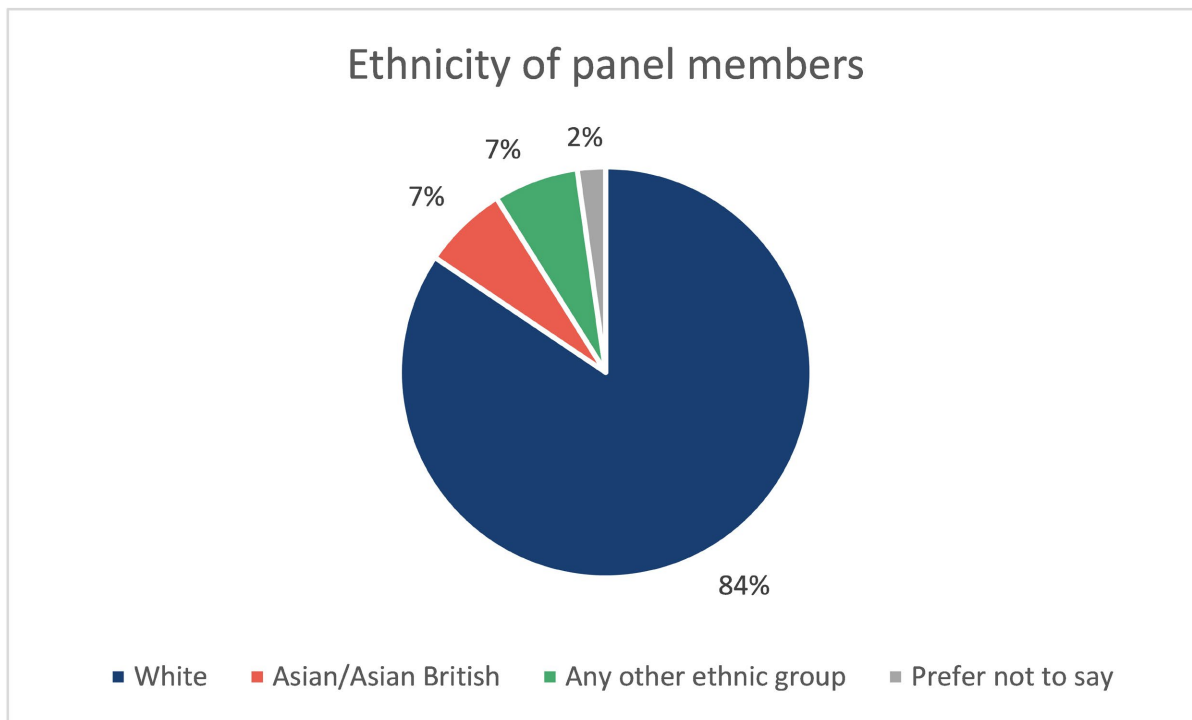
Men currently make up 36% of panel members. Men's voices are important for all research projects, but especially those relating to men's health issues such as prostate cancer.

## Black people

There are currently no Black members of the CUH PPI Panel and we would like to rectify this. Positive or negative, we want to hear how people from Black communities feel about our research, so that we can ensure it is accessible and relevant to people from all walks of life. Together, we can identify, and start to break down, barriers to research and healthcare.

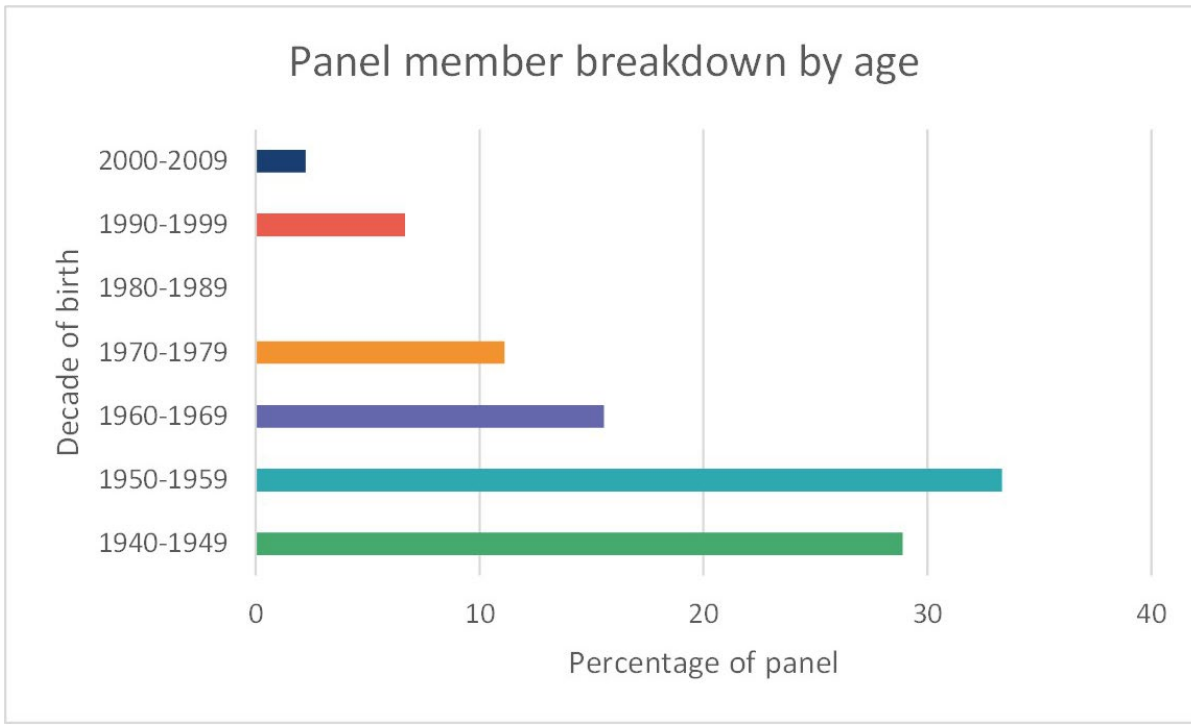
## People from Asian communities, especially East Asian people

According to the 2011 Census, 11% of people in Cambridge identify as British Asian and Chinese [1], compared to 8% of people in England and Wales more broadly [2]. Despite this, only 7% of the CUH PPI Panel identify as Asian or Asian British and none as Chinese, meaning people of this background are under-represented on the panel. We would like to rectify this and invite Asian and British Asian people to join the panel to share their views on research proposals, so that different cultures and perspectives are considered and accommodated for in the work that we do.



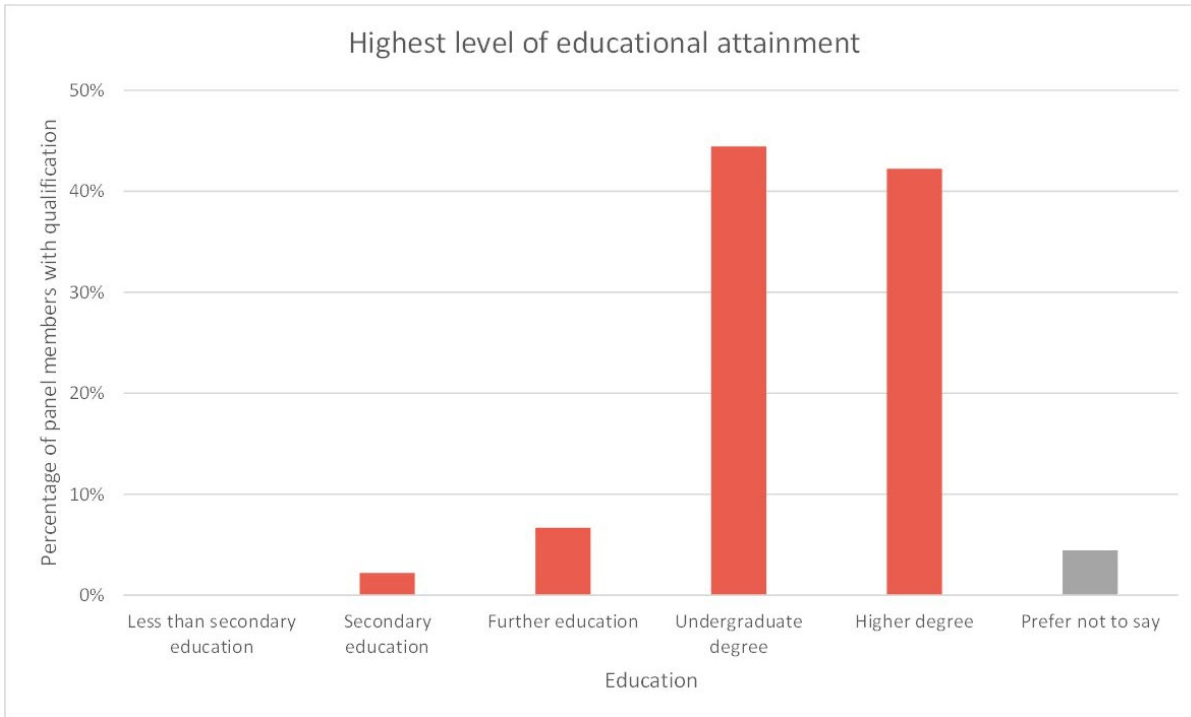
## People born since 1970

Over 60% of the CUH PPI Panel were born before 1960 (i.e are aged 60+). No panel members were born in the 1980s and only 9% panel members are aged under 30. Younger people provide a crucial perspective on topics spanning both mental and physical health, including things like digital health, paediatric topics (for those under 18) and parental experiences (for those with children still living at home).



**People without a degree**

The majority of panel members (86%) are educated to degree level and almost half of the panel possess a higher degree, such as a PhD. We greatly value these perspectives, but we also need to hear from people without these qualifications.



**Members of the LGBTQ+ community**

There are currently no people identifying as LGBTQ+ on the CUH PPI Panel. We recognise that LGBTQ+ people may have different experiences of healthcare compared to straight/heterosexual and cisgendered people. We would like to learn more about the lived experience of LGBTQ+ people from Cambridge and the surrounding areas to continue ensuring that research taking place is inclusive.

[1] [2011 Census - Local Area Report](#)

[2] [2011 Census analysis: Ethnicity and religion of the non-UK born population in England and Wales: 2011](#)

If you are a researcher and you have any questions about our Diversity and Monitoring Survey, such as what questions were asked or how the survey was run, please feel free to [get in touch with us](#).

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## New Weekly Roundup of PPI Opportunities



The CUH PPI Team are now sharing a weekly roundup of PPI opportunities. The weekly roundup contains a list of various opportunities for researchers, patients and members of the public living in and around Cambridge including PPI training, events, involvement opportunities and participation opportunities.

CUH PPI Panel members interested in learning more about further involvement opportunities are given a first look at the list, which will be circulated on Thursday afternoons. For other interested parties, this information can be accessed on our new [PPI Opportunities](#) web page, which will be updated each Friday.

If you have an opportunity you would like us to share in our weekly roundup, please email [ppi@addenbrookes.nhs.uk](mailto:ppi@addenbrookes.nhs.uk) with full details. Items must be shared before Thursday noon in order to be published on Friday.

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## 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. In the past couple of months we have organised talks on cardiology and gastroenterology. In April we heard from Prof Ziad Mallat and Dr Tian Zhao from the University of Cambridge on drug repurposing in cardiovascular medicine. In May, Mark Avery (Director of Health Informatics at the Eastern Academic Health Science Network) and Prof Miles Parkes (CUH consultant gastroenterologist and Director of the Cambridge BRC) spoke to the panel about how the GutReaction Health Data Hub has been used for research into Inflammatory Bowel Disease.

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:**

**June:** Prof Sadaf Farooqi (Professor of Metabolism and Medicine at the University of Cambridge) will be speaking about her research into the genetic causes of obesity.

**July:** Prof Gordon Smith (Head of Obstetrics and Gynaecology at CUH) will be giving a talk on screening for pregnancy complications.

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.

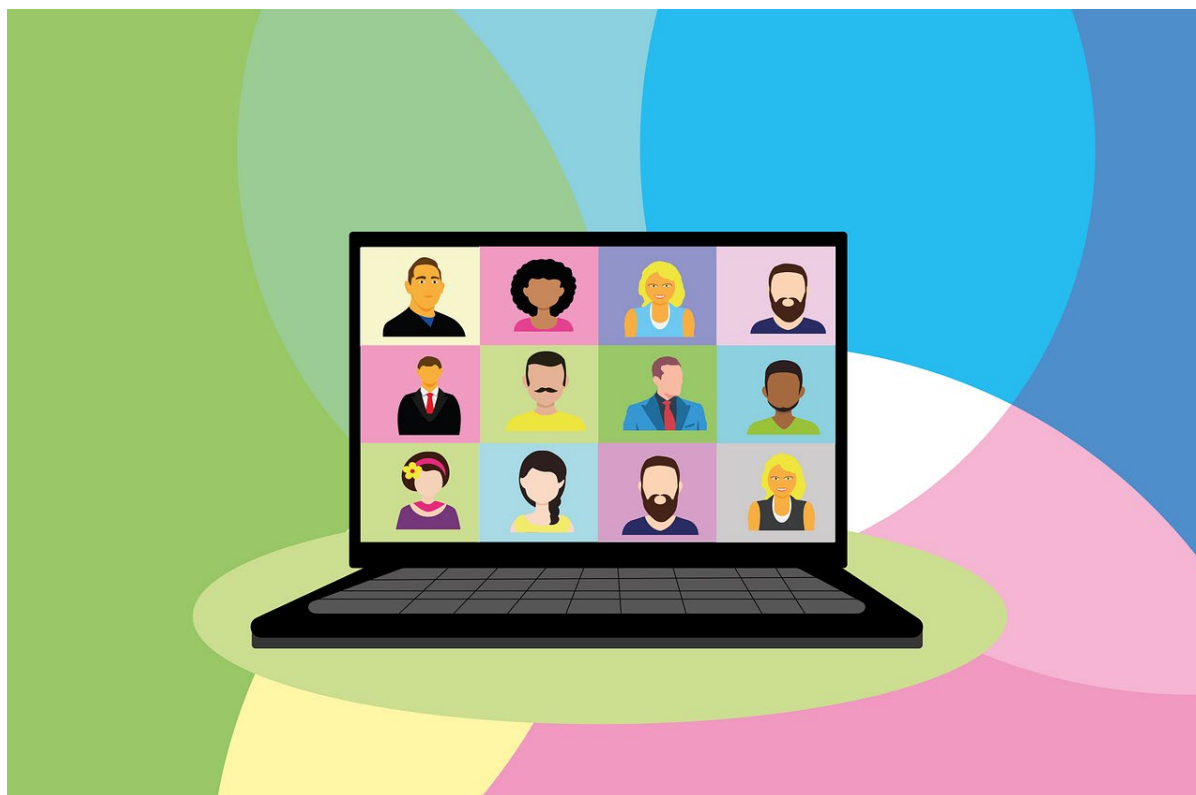
Please [click here](#) to access feedback from academic research projects. Feedback has been shared from projects conducted between December 2020 and May 2021.

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

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

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## Virtual PPI Research Related Events This Summer



**Brain Injury Technologies Think (BITT) Tank 2021 Series: Series 1 - 'Covid-19 Brain Injury Challenges and Solutions'**

**Date:** Friday 18 June 2021, 10.30-12.30

**Location:** Zoom. Register [here](#).

An opportunity to hear from clinicians and professionals on the front line. The session will be chaired by Professor Peter Hutchinson, NIHR Brain Injury MedTech Co-operative Honorary Clinical Director. Talks will be delivered by:

- Professor Mark Wilson OBE, NIHR Brain Injury MedTech Co-operative Prevention & Pre-hospital Care Theme Lead

Dr Alexis Joannides, NIHR Brain Injury MedTech Co-operative Deputy Director & Clinical informatics and Registries Theme Lead

- Professor Topun Austin, NIHR Brain Injury MedTech Co-operative Paediatrics and Neuro-development Theme Deputy
- Ms Abigail Bush, NIHR Brain Injury MedTech Co-operative Technology Lead

Session 2 of this series will cover solutions in a post pandemic world and will be held on Friday 25th June 2021, from 10.30-12.30. Further details can be found on the [website](#).

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### **PPI Research Training Courses at The Royal Papworth Hospital: 'Study designs in clinical research'**

**Date:** Tuesday 22 June 2021, 11.00-12.00

**Location:** Teams. Register [here](#).

This session explains some of the key study designs used in clinical research projects, describes the advantages and disadvantages of each design and considers how the results from different study designs are used to inform clinical and public health practice.

This session is run by Royal Papworth Hospital Research and Development team and will be hosted on Microsoft Teams.

For any queries please contact: [papworth.ppi@nhs.net](mailto:papworth.ppi@nhs.net)

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### **COVID-19: Understanding the Research Behind the Pandemic**

**Date:** This is a free online course. Participants can start when ready.

This free course, developed by the University of Leeds, covers the following topics:

- Introducing the challenge that the pandemic posed to the health research community.
- How was the process of developing vaccinations sped up?
- How do we ensure the rights, safety and wellbeing of participants in research and those who take future vaccines and treatment?
- Research and development of treatments for COVID-19.
- The critical role of the public as partners to the research team and participants.
- The next challenges for health research and COVID-19 eg new vaccinations and long COVID.

It is open to everyone interested in finding out about the research on COVID-19. This course is also useful for people that work in healthcare to help answer the questions members of the public may ask about COVID-19 research.

Find out more information [here](#).

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## **Further Involvement Opportunities**

The Department for Health and Social Care (DHSC) is seeking your

views to help inform the development of the government's Women's Health Strategy.

The easiest way to participate in the call for evidence is by participating in the [public survey](#) by **13 June 2021**. Those with expertise in women's health may wish to complete a [written submission](#).



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

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## PPI Reports, Opinions and Blogs for Discussion



**Co-producing knowledge in health and social care research: reflections on the challenges and ways to enable more equal relationships.**

This paper by Farr et al. was published in Humanities & Social Sciences Communications in May 2021. The paper discusses the challenges with power sharing (a key principle of co-produced research) within



embedded hierarchies in universities and public service institutions. The article also puts forward potential ideas and resources that may help put co-production into practice.

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

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## **'A limpet on a ship', spatio-temporal dynamics of patient and public involvement in research.**

Stan Papoulias from Kings College London has written this paper on where and when PPI happens. The paper concludes that often, PPI ends up being "everywhere and nowhere" due to difficulty in defining PPI and clarity on what can arise from PPI activities. This thought-provoking paper further adds to the debate on the ideal values of PPI versus the practicalities of involvement in practice.

You can download the full report from [The Patient Experience Library](#).

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