

## CUH Patient and Public Involvement

### Spring 2021 Newsletter

News and updates on PPI in the East of England

Welcome to the Spring 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.

## 2021 Researcher Talks Series



The new CUH PPI Panel Researcher Talks Series has kicked off to a great start! 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 will hear from a different BRC researcher on their current research and PPI journey. We plan to hear from researchers involved across many of our 12 research themes, to ensure that a wide-range of topics are covered.

In January, we were fortunate to hear from Dr Sarah Hickman, a medical doctor and PhD student in Professor Fiona Gilbert's group, on using artificial intelligence (AI) for breast cancer screening. February's talk on research in the CUH Neonatal Intensive Care Unit (NICU) was delivered by Dr Kathryn Beardsall. Both talks were really informative and

engaging so thank you to Sarah, Kathy and all panel members who came along to ask such wonderful questions!

This month, we are excited to hear from Dr Rudolf Cardinal, a consultant liaison psychiatrist at CUH and Cambridgeshire and Peterborough Foundation Trust (CPFT) on the use of routinely collected clinical data for research and recruitment in health care. This will be followed by talks on cardiology and gastroenterology in April and May, respectively.

**Are you a researcher who would be interested in presenting your research to the panel? Please get in touch with us to ask!**

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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 December 2020 and February 2021.

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

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

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# New Gut Reaction Health Data Video

Gut Reaction is the Health Data Research Hub for Inflammatory Bowel Disease (IBD). IBD includes the conditions Crohn's disease and ulcerative colitis, which together affect around 500,000 people in the UK. Crohn's and Colitis cause recurring abdominal symptoms and bowel symptoms, and can cause problems outside the gut, affecting the joints, eyes or skin. IBD needs long-term treatment and often major surgery, and can significantly affect the lives of those who live with it.

PPI is a critical part of Gut Reaction and now you can watch a 3 minute video to see how researchers across the UK have already been helped by thousands of people with IBD!

In this new animation, the Cambridge-based [Gut Reaction](#) Health Data Hub show the huge potential in using health data for research and what this could mean for people living with long-term conditions such as IBD.

The most powerful way to use data is through multiple data sources – picture it like bricks. The more bricks joined together, the stronger the structure and the bigger the opportunity. This is what makes Gut Reaction so unique.

Despite the huge potential to improve lives through data research, patients may have concerns about how their data is secured, stored and used. Keeping our data safe - and only using it for the good of health care - is critical.

Victoria King who sits on the Gut Reaction Patient Advisory Committee says, *“I was so overwhelmed by the final video it’s amazing. It helped me explain the project to my dad in a simple way. You might have some concerns about your data being used in research, but data can really change things for us.”*

Find out more about Gut Reaction [here](#). And visit the Health Data Gateway to discover the IBD collection data [here](#).

We hope that you will watch and share the animation, and get as excited about the future of research as we are!





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## Virtual PPI Research Related Events This Spring



### **Cambridge Festival: 'Tackling COVID TACTICally'.**

**Date:** Thursday 1st April 2021, 20.00-20.45

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

Join the NIHR Cambridge BRC on the 1 April where researchers will be hosting a live talk called 'Tackling COVID TACTICally', which will focus on the Cambridge-led study Tactic-R.

Dr Frances Hall, Prof Ian Wilkinson and Prof John Bradley will discuss how two drugs currently prescribed for rheumatoid arthritis could also help COVID patients.

The Cambridge Festival will take place from 26th March to 4th April 2021. Detail on all events can be found at the [Cambridge Festival website](#).

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## The New Cambridge BRC PPI Network



The PPI Network is intended to be a platform for professionals working in PPI at the Cambridge Biomedical Research Campus so we can meet on a semi-regular basis to discuss PPI experiences. This is likely to be over Zoom for the foreseeable future, but we hope that they will be in person eventually!

We hope this will be a way to make new connections, share our learnings from PPI activities and work out the best way to help each other develop the best PPI for researchers, patients and the general public.

If you would like to join the network, please email [ppi@addenbrookes.nhs.uk](mailto:ppi@addenbrookes.nhs.uk) with the following:

- Your name
- Role
- Organisation
- Email address

Please also feel free to invite any colleagues you think may be interested to the network! Our first meeting will be held via Zoom on 15th April.

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**Further Involvement Opportunities**

**Plans are well underway for the new Cambridge Cancer Research Hospital and you can get involved in planning and decision making for this exciting new project!**

The team are creating a new kind of hospital to improve clinical pathways and transform outcomes. If you, or someone you know, would like to be involved in planning and decision-making, we will be recruiting patients, families and interested members of the public for our Cambridge Cancer Patient Network.

Please register your interest by emailing: [hello@cambridgecancer.org.uk](mailto:hello@cambridgecancer.org.uk).

You can read more about the Cambridge Cancer Research Hospital in their [first newsletter](#).

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### **Participants needed for NHS Innovation Service development!**

The NHS Innovation Service will help people with innovative ideas in healthcare to understand how to develop and spread their idea in the NHS. These ideas can be anything from medicines, medical devices, apps, surgical procedures, new models of care, and non-clinical services like training, recruitment etc.

The Innovation Service will bring information and support that already exists into one central place, making it easier to find relevant, practical advice.

It will:

- explain the route to widespread adoption of new innovations in the NHS
- signpost to appropriate resources
- connect people with organisations that provide support or assess products

### **We are looking to recruit two types of roles:**

- **5 content reviewers** –to ensure information on the website is understandable to newcomers to the health innovation sector, and meets expectations of NHS content. **For this role, you don't need any background knowledge of healthcare, technology or innovation.**
- **10 accessibility testers** – to ensure this service is accessible for everyone who might use it, we would like to test our service with people who have the following accessibility needs:
  - Sight impaired screen magnifier users
  - Severely sight impaired screen reader users
  - Users with multiple conditions

- Profoundly deaf users
- Motor impaired users
- Cognitive impaired users
- Dyslexic users

**For this role, you do not need to have a product or service that you are developing, but it would be helpful if you work in healthcare, tech, or a small business.**

### **Time commitments**

We will be running a **series of activities between April and June 2021** and would value your insights. Until restrictions are lifted, we are conducting all our research activities remotely.

### **For content reviewers:**

We will **send you some text to review**, either on a webpage or a document, and ask you to **provide feedback either in written format or over a video call** (or both), whichever you prefer. We expect this to take **half a day**.

### **For accessibility testers:**

Each activity will involve a **90-minute remote one-to-one video call on Microsoft Teams**. We will ask you some questions, send you links to our prototype and ask you to share your screen so we can see how you're using it. We may ask you to take part in more than one activity so you can review any changes we make, but you can take part in as many or as few as you like.

If a Teams video call will not work for you, please get in touch so we can design an accessible session together.

### **Contact details:**

Please get in touch with Sophie Parslow at: [england.aacppi@nhs.net](mailto:england.aacppi@nhs.net) for more information or to register your interest. Please let us know which type of role you would like, or you could participate as both roles. If you'd like to be an accessibility tester, please let us know your needs and any assistive technology you use.

**Please register your interest by:** Sunday 4 April 2021

**Do you have an involvement opportunity that you would like to share in our newsletter? Please get in touch!**

## PPI Reports, Opinions and Blogs for Discussion



### **MHRA pilots patient involvement in new applications**

The Medicines and Healthcare products Regulatory Agency (MHRA) has announced a pilot project putting PPI at the centre of evaluations for new medicines. As of the 23rd March, new applications for selected medicines will require evidence on the patient involvement activities undertaken throughout the development of the product.

During the pilot, the information provided will not alter the outcome of applications, but the MHRA are hopeful that this pilot will be the first step towards a much greater role for patient involvement in the final assessment process for clinical trials.

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

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### **The strength of the wolf is the pack: how a lupus research study involved patients**

Our colleagues at the Primary Care Unit, University of Cambridge have teamed up with lupus patients to hear about their experiences of lupus and related diseases. Lupus is a chronic auto-immune condition which can damage many parts of the body, affecting people's lives deeply, yet can take years to diagnose.

The research, called the LISTEN study, is focused on the impact of patient-physician interactions on patient well-being, behaviour and disease acceptance during and after diagnosis. [Click here](#) to read more about the research and read testimonials from patient



representatives.

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## Other articles of interest:

[Creativity in public involvement: supporting authentic collaboration and inclusive research with seldom heard voices:](#) A research team used videos, pictures and objects to support people with communication difficulties to be more involved in meetings. They found that using activities rather than words alone helped establish a successful PPI group.

[Patient and public involvement prior to trial initiation: lessons learnt for rapid partnership in the COVID-19 era:](#) Clinical trials have been vital during the pandemic, but Research Ethics Committees have seen far less PPI, in part because researchers may feel that they do not have time to properly involve patients and the public. In this paper, the research team share their experiences of rapidly involving patients and the public in the RAPID COVID-19 trial.

[Ethical considerations for engaging frail and seriously ill patients as partners in research: sub-analysis of a systematic review:](#) Good PPI can be more challenging when patients are very unwell, as there may be challenges with elements such as obtaining informed consent. This paper discusses ethical considerations that research teams consider when partnering with frail and seriously ill patients. These include how to ensure autonomy (e.g. by helping patients choose their level of involvement) and that no harm is caused (e.g. by preventing emotional suffering).

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