

## CUH Patient and Public Involvement Panel

### Winter 2020 Newsletter

News and updates on virtual PPI in the East of England

Welcome to the Winter 2020 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.

## Welcome Beth!

We are delighted to welcome Beth Vincent to the PPI Team. Beth joined as a PPI Research Coordinator on 2 November and is looking forward to getting stuck into the role!



Beth has a BSc (Hons) Biology from the University of Bath and an MSc in Health Research from Warwick Medical School. As part of her first degree, she spent one year working as a Technical Assistant at the Medical Research Council - Protein Phosphorylation and Ubiquitylation Unit (MRC-PPU) in Dundee. More recently, Beth worked in management consulting, supporting pharmaceutical, biotechnology and medical device companies to develop solutions to policy and strategic challenges within the Life Sciences industry.

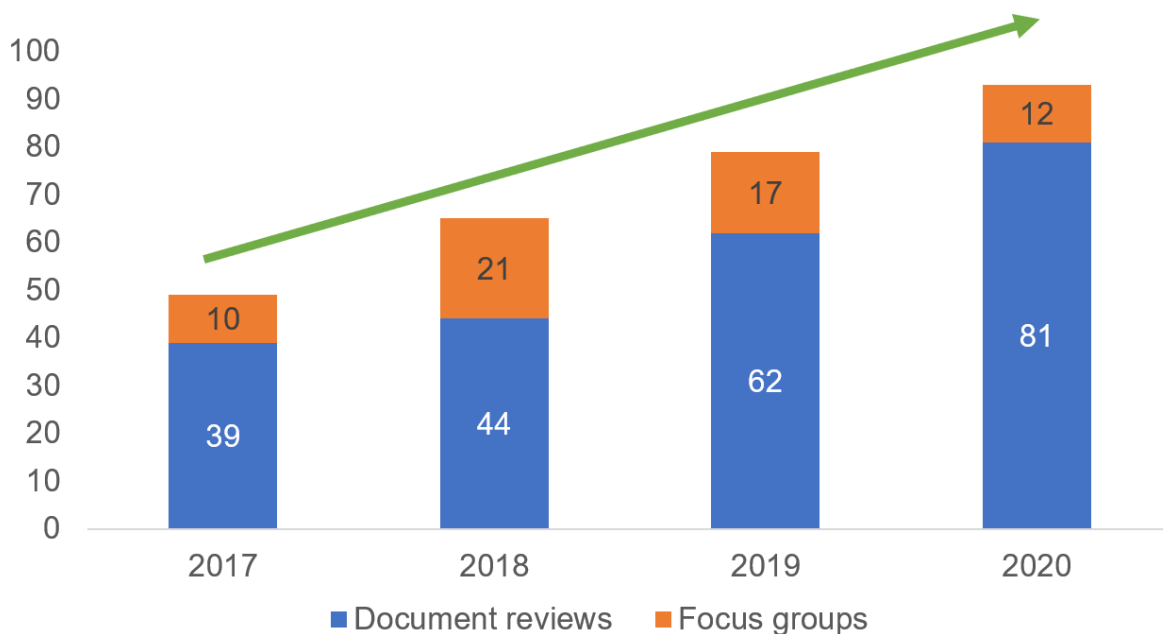
Beth has also volunteered extensively with Anthony Nolan, a charity aiming to recruit young people to the bone marrow and stem cell donor register.

## 2020: A Year in Summary

Thanks to all of our panel members that attended the end-of-year wrap-up meeting earlier in December. We enjoyed an excellent presentation from Dr Serena Nik-Zainal, Advanced Clinician Scientist at Cancer Research UK and Clinical Geneticist at CUH. Serena spoke to us all about her work on whole genome sequencing and how recent advances are allowing clinicians to personalise cancer treatment, improving quality of life and extending life-span for patients! Thank you Serena!

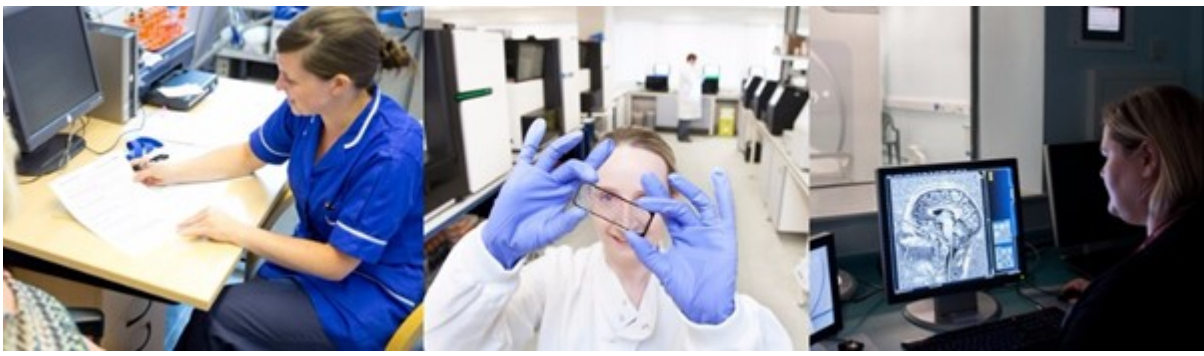
We also got to say a big thank you to all our panel members for all their hard work this year. We had more document reviews than ever before and no shortage of these related to exciting and important research on COVID-19, conducted at the Biomedical Research Campus and with partner organisations.

### Number of document reviews and focus groups conducted in 2020



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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. Recently, there have been several grant application deadlines and panel members have responded with excellent comments in a short period of time. Researchers are really grateful for this turnaround and send their thanks. Please [click here](#) to see all the researcher responses to PPI panel member comments that we have received since November 2020. This file is password protected and **only available to CUH PPI panel members**.

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## Virtual PPI Research Related Events This Winter



**#LivefromLucy: 'Practical ethics in the Covid-19 pandemic' with Dr Elizabeth Fistein.**

**Date:** Wednesday 20 January 2021, 18.00-19.00

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

Dr Fistein, from the Department of Public Health and Primary Care at the University of Cambridge, will be discussing what decisions she has been asked to advise on and what she has learned from her experience. She will tell the story of how she set up clinical ethics advisory groups at a district general hospital (West Suffolk) and a highly specialized tertiary centre (Royal Papworth), using a model for practical ethical deliberation (Helen Manson's Core-Values Framework).

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## The New Cambridge BRC PPI Network



We are currently in the process of reforming the PPI Network. This 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!

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## Further Involvement Opportunities

If you have been participating in remote Patient and Public Involvement and Engagement (PPI/E), you can complete [this survey!](#)

Researchers from the University of Liverpool are looking for people aged 18 years or older to help explore how they can facilitate and improve doing PPI/E in health and social care research, without direct face-to-face contact and remote working.

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## **Are you a parent/guardian, nurse, or health or community practitioner supporting migrant families and young people person with a long-term health condition?**

Researchers from Anglia Ruskin University and the University of Sheffield would like to hear from you! They are hosting an online (via Zoom) research workshop on **Friday 29th January, 10.00-12.30** to share experiences and identify key priorities for supporting young migrants with long-term conditions and their families.

They would like to hear from from young people, families, nurses, community groups and researchers with an interest in migration, long-term conditions and families.

For more information click [here](#) or contact the study team:

- Dr Grace Spencer, Anglia Ruskin University: [grace.spencer@aru.ac.uk](mailto:grace.spencer@aru.ac.uk)  
Dr Jill Thompson, University of Sheffield: [jill.thompson@Sheffield.ac.uk](mailto:jill.thompson@Sheffield.ac.uk)

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## **Can you help design research at the University of Cambridge on how healthcare data is used in breast cancer screening?**

If you are:

- Eligible for breast cancer screening
- Have previously attended breast cancer screening
- Have previously been diagnosed with breast cancer through screening or another route

Complete [this survey](#) on using artificial intelligence to detect breast cancer by 31 January 2021.

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## **East of England Ambulance Service are establishing a Research Involvement Group (RIG) - are you interested?**

EEAST are looking for people who are interested in research and the ambulance service to join this group. Anyone 16 years and above and living in the East of England region (excluding Trust employees) are eligible and welcome.

Varying activities will exist to offer people with differing levels of time, interest and ability to travel to be involved in research. No special knowledge or experience is required.

If you would like to involved, represent your community and feel you can be an ambassador for EEAST research then they would love to hear from you.

For further information and to complete the RIG Expression of Interest Form please click [here](#).

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**Versus arthritis are looking for volunteers who have arthritis and experience of research involvement to help shape a new PPI offer for a larger and more diverse group of volunteers by filling out [this survey](#).**

The Research Involvement team at Versus Arthritis would like to hear from people who are interested in research involvement to influence their thinking and inform our plans. Through their “Involvement to Impact” review they want to create exciting and accessible ways for more people with arthritis to work with the charity and its researchers to share their experiences in order to shape research projects and funding priorities.

### What do they need from you?

Before they design their research, Versus Arthritis would like to understand more about what you think. They want to gather opinions on this topic firstly using [this survey](#). There will also be an opportunity for some respondents to attend a focus group where you can explore the survey findings in greater detail. We expect these groups to be held towards the beginning of 2021.

If you're interested in taking part in a group as well as the survey, please make sure you include your contact details and “opt in” to hear more about this project.

If you have any questions about research involvement or the new offer please contact [patientinsight@versusarthritis.org](mailto:patientinsight@versusarthritis.org)

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## PPI Reports, Opinions and Blogs for Discussion



### **The debate on measuring PPI continues:**

In 2017, researchers from the University of Oxford published '[Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study](#)'. This paper examines calls for more robust evaluation of the impact of PPI in health research and questions whether it should be done at all.



More recently, a team from the University of Oxford and Queen Mary University of London published '[The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it?](#)'. In this paper, published in October 2020, the authors call for a new research agenda for public involvement that considers PPI a practice of dialogue and learning between researchers and the public, explores power dynamics, and asks questions about the possible harms of PPI, in addition to the benefits.

What are your thoughts on this discussion? Let us know by emailing [ppi@addenbrookes.nhs.uk](mailto:ppi@addenbrookes.nhs.uk).

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### Other articles of interest:

[Family perspectives of COVID-19 research](#): A look at how speaking to parents about their perspective of family disruption can help guide research on the effects of the pandemic on children.

[Enabling participation of Black and Minority Ethnic \(BME\) and seldom-heard communities in health research: A case study from the SCAMP adolescent cohort study](#): As part of research into the impact of using mobile phones and wireless devices on teenagers' cognition, behaviour and mental health, researchers explore the facilitators of, and barriers to the involvement of under-represented groups.

[From anonymous subject to engaged stakeholder: Enriching participant experience in autistic-language-use research](#): This study brought together pairs of autistic and non-autistic strangers to talk about their experiences of loneliness and potential responses to the problem and is a really interesting look into autistic-led participatory research.

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