

PUBLIC INVOLVEMENT GROUP NEWSLETTER

New Year 2024

Introductions

Welcome to the **2024 New Year edition of the Public Involvement Group newsletter**. We would like to start by saying a big thank you to Rachael Frost, who was 'Patient and Public Involvement and Engagement' (PPIE) lead for our department at UCL. The department is grateful for all her hard work, and we all wish her well for the future.

Sarah Griffiths and Tom Witney have taken on the role as co-leads since September 2023. They work closely with a Public Involvement Group team: Sadie Lawes-Wickwar, Richard Cable and Sarah McMullen.



Sarah is a dementia researcher. She works on projects aiming to improve care and support for people with dementia and their carers following a diagnosis. She has experience of working alongside people with lived experience to develop research processes and share research findings.

Tom is a medical sociologist, with an interest in sexual health and relationships. Whilst co-lead he has been instrumental in planning new department systems for PPIE. He is moving on from the department to work on a project exploring the impact of remote consultations in sexual and reproductive health services (SRHS) on health inequalities.



We will miss Tom but wish him all the best!

Message from Sarah

In the UCL Research Department of Primary Care and Population Health (PCPH) we have a small group of researchers, dedicated to developing and strengthening public involvement in research. We have called ourselves the Public Involvement Group.

How does public involvement work in the department?

We receive funding for public involvement work from the National Institute for Health Research (NIHR), via the School for Primary Care Research. We use this funding to support researchers to work with patients and members of the public on their projects. Researchers apply to us for this funding, and we work with them to develop advertisements, which are then sent out to our 'Experts by Experience' network.

Our plans

In the coming months we will be contacting our 'Experts by Experience' network to get to know everyone better and to explore ways to work together more closely, including producing and featuring in this newsletter. We have some exciting ideas coming up, such as running a 'Research Café' where public contributors have the chance to meet a range of researchers. It's an opportunity to actively feed back on ideas.



NIHR | School for Primary
Care Research

We are really looking forward to getting stuck in and would love to hear from you! If you have any ideas, feedback, or questions you can contact us at public.advisors@ucl.ac.uk.



Dementia Research News

In October 2023, Sarah Griffiths presented her work, ‘Co-producing a research funding application with a diverse lived experience group’ at the Alzheimer Europe Conference in Helsinki.

One of her co-leads on this work, Martin Robertson, is a public contributor who has dementia.



He contributed to the presentation via a pre-recorded video. Sarah and Martin shared the benefits and challenges of co-producing a funding application from the very beginning of a research idea.

Alzheimer's Society



A video of Martin talking about his experiences was shown at the conference (see picture).

One of the carers involved in the project said:

‘It’s been exciting to help create something. Normally we are just quotes in a [research] paper.’

Sarah has been awarded funding by the Alzheimer’s Society and has started the project ‘CAPPD: Communication Aspects of Personalised care Planning in Dementia’ in January 2024.

PPI Spotlight on...Madiha Sajid



My journey as a Public Contributor led me to some wonderful opportunities, from the bustling streets of London to the noble academic halls at Cambridge. I was invited by the research team, led by the brilliant Dr Abigail Woodward, and the most wonderful Sarah McMullen, to co-present the findings of our project **"Improving culturally appropriate support services for Pakistani family carers through social prescribing"** at the **Society for Academic Primary Care (SAPC) South East conference 2024** at the lush green Madingley Hall, University of Cambridge .

I found this to be a fantastic opportunity to share our findings about the importance of social prescribing for Pakistani carers, my role as a PPI, and what I brought to the table. I had several planning meetings with the research team to finalise our presentation. During the presentation, our research findings generated a lot of engagement and audience members asked several questions about my role as a carer, and about culturally appropriate support that might be made available to the wider Pakistani group.

The conference provided an opportunity for me to hear fantastic keynote speeches, and to network with colleagues from across the South East region. I also attended a workshop on “Stigma, blame and exclusion in medical terminology and language” by Dr Julia Bailey (UCL). I believe that co-designing, and co-presenting with Public Contributors is an incredible way to bring life to any research study, and is a very rewarding experience for the PPIs in several ways. After spending a day and a half in Cambridge, I left the city with a refreshed mind, and a newly found appreciation for my experiences as a carer.



Creative Public Engagement: A Photovoice and Art Workshop

In June 2023, Joanna Dobbin, Eleanor Turner-Moss and Fiona Hamilton, ran a public engagement 'Photovoice and Art' workshop to explore the concept of community and health for female Afghan asylum seekers living in contingency accommodation in Camden.

The workshop investigated the barriers and facilitators of uptake of social prescribing and community activities in the area. This workshop highlighted the negative impact of using some types of contingency accommodation for asylum seekers, particularly hotels for women.

It also highlighted the positive potential of community projects and the benefits of integrating support from local services. It is important to mention that the women participating were all part of a specified immigration scheme, in most part the Arap scheme, and as such had additional resources made available for them on arrival.



These so called 'safe routes' account for the minority of asylum applications, with those arriving by so called 'irregular' routes often subjected routinely harsher treatment under both the Nationality & Borders Act and the Illegal Migration Act.

PPI in Medical Education

The Primary Care Education Expert by Experience (PCE EbE) Group continues to drive patient and public involvement (PPI) in medical education forward. Dr Sadie Lawes-Wickwar, the Group Lead, is also a member of the national Doubleday Medical Schools Patient Partnership Collaboration.



This year the Doubleday Collaboration held two roundtable discussions with the General Medical Council (GMC). The GMC published their guidance for patient and public involvement and engagement (PPIE) in medical education in 2011 and since then there have been significant developments in education, technology, and PPIE working practices generally. We continue to offer information on how the guidance can be developed and updated as a group.

The PCE EbE Group has collaborated with the School of Pharmacy EbE Group and academics, medical students, and pharmacy students. Workshops have explored the contributions patients and carers can make to clinical student assessments and provided feedback in relation to person-centred communication skills.



The Chris Sandford Award



This year the PCE EbE group announced the 'Chris Sandford Primary Care Medical Education Award,' which will be awarded to one EbE representative who has demonstrated excellence in, and a commitment to, medical students' learning.

The award is in memory of Chris Sandford, who sadly passed away in November 2022. Chris was a passionate member of the EbE Group and taught UCL medical students for many years. He dedicated his life to HIV advocacy, teaching medical students, and HIV research.

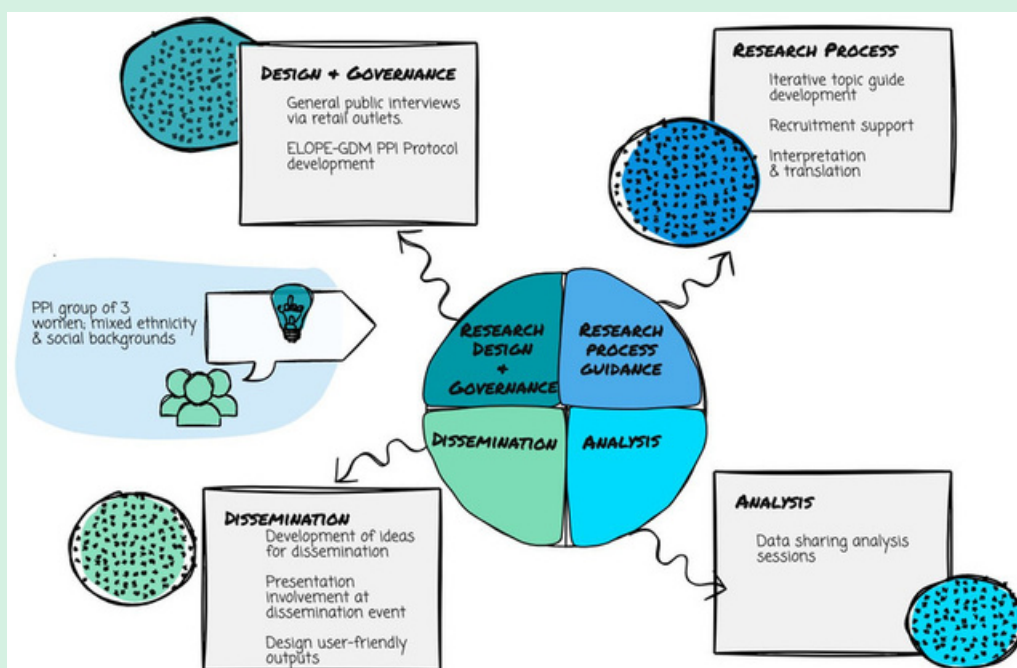
The winner of this year's Chris Sandford Primary Care Medical Education Award will be announced at the annual Primary Care Clinical Education Conference on Friday 9th February 2024.

Developing Inclusivity in Research

Dr Shoba Poduval, Dr Jamie Ross and Dr Amanda Moore conducted a study Exploring Longterm Outcomes following a Pregnancy with Gestational Diabetes Mellitus (ELOPE-GDM).

Women from minority ethnic groups and those facing socioeconomic diversity are most at risk of type 2 diabetes after pregnancy but are under-represented in research. The PPI strategy was fundamental to developing a programme of research that was relevant and engaged these communities.

The PPI group supported the research in four key areas (see figure). They helped shape the protocol, develop topic guides, supported with recruitment, conducting interviews in Bengali and data analysis.



The PPI group helped develop a web event to share findings and user-friendly infographics. They also took part in the event, by providing feedback about their own involvement. One participant summarised their views about the study:

“Having been diagnosed with GDM in my second pregnancy, the opportunity to contribute to research into the condition was something that really mattered to me....”

Read more about the study here: <https://www.ucl.ac.uk/epidemiology-health-care/research/primary-care-and-population-health/research/elope-gdm-study>

Attention all Researchers!

Would you like more information regarding PPI?

- Please visit our [PCPH Public Involvement Group teams](#) to access guidance on PPI and funding opportunities.
- Need some pre-grant funding for PPI or further information?



Public involvement resources for PCPH

Email us at public.advisors@ucl.ac.uk

Calling out our PPI Contributors!

We want to get to know you!

Getting to know our Public Involvement group network will enable us to effectively connect researchers with PPI contributors and organise events and activities in line with your interests.

We will be sending round a survey by email in the next few weeks for you to complete.

For questions or queries, email us at

public.advisors@ucl.ac.uk



Share your feedback

The newsletter

We have developed this newsletter with public contributors; it will be circulated twice a year. We welcome your feedback. We want to make this work for you!

- Do you find the articles engaging? Do you like the way the newsletter looks?
- Want articles that give guidance on doing PPI?
- Want to know more about the impact of PPI?
- Anything else you want to share?

Please let us know!

Submit newsletter articles

Want to share your experiences of PPI? Are you working with a local community? Got an interesting story to tell?

Whether you are a patient, member of the public, student or staff, please contact us about submitting an article for future editions.

Would you like the next PPI spotlight to be on you or would like to nominate a PPI contributor for our next newsletter?

For any of the above, email us at public.advisors@ucl.ac.uk.