NIHR | Applied Research Collaboration South London

Cicely Saunders International
Better care at the end of life

King's College London

PATIENT AND PUBLIC INVOLVEMENT FOCUS

Cicely Saunders Institute (CSI)
Issue No. 15; Winter 2025-26

GREETINGS FROM THE CICELY SAUNDERS INSTITUTE

In this Issue:

Greetings!

Don't forget your earmuffs and enjoy these updates from across the CSI PPI group and different projects.

A PERSONAL PERSPECTIVE

THE NEED FOR ADDRESSING DISPARITIES IN DEMENTIA CARE AND ACCESS FOR ETHNIC MINORITY COMMUNITIES IN THE UK

We put out a call for content for the newsletter from our public member community and Dr Smarajit Roy has posed some potential research questions regarding dementia care for Ethnic Minority communities in the UK.

Approximately 50 million people worldwide were living with dementia in 2017, and this number is projected to triple by 2050. Dementia poses a significant and growing public health challenge in the UK, with prevalence rates projected to increase substantially in the coming decades. While dementia affects individuals across all ethnic groups, there is increasing evidence of disparities in prevalence, diagnosis, access to care, and outcomes for ethnic minority communities in the UK.
I proposed to carry out some research which will address the following key research questions:

1. **WHAT** are the prevalence rates of dementia among different ethnic minority groups in the UK, and how do they compare to the White British population?

2. **WHAT** are the barriers and facilitators to dementia diagnosis and access to care for ethnic minority individuals and their families?

3. **HOW** do cultural beliefs, attitudes, and practices influence the experience of dementia and caregiving among ethnic minority communities?

4. **WHAT** are the culturally appropriate interventions and strategies that can improve dementia care and support for ethnic minority populations in the UK?

Contributed by Smarajit Roy

PATIENT AND PUBLIC INVOLVEMENT PROJECT UPDATES

NIHR POLICY RESEARCH UNIT ON PALLIATIVE AND END-OF-LIFE CARE

The NIHR Policy Research Unit in Palliative and End-of-life Care works closely with the Department of Health and Social Care and NHS England. We provide policy makers with timely, relevant evidence to help shape policies that improve access to care for children and adults living with life-limiting conditions, as well as support for their families and carers.

The Policy Research Unit has a Rapid Response facility, which delivers short, focused research studies responding to policy needs. These projects explore a wide range of important issues affecting people at the end of life. Below are some key findings from recently completed rapid response projects:

1. **What is the evidence on the cost-effectiveness of interventions to improve palliative and end-of-life care?**
    a. The project found that the mean cost for each adult who died in England and Wales was £24,222 in 2024, and 78% of this was spent on acute hospital costs.
    b. To read more of the findings, click the link here.

2. **Are there differences in awareness, knowledge, and trust about palliative care services among adults from ethnically diverse backgrounds in the UK?**
    a. The project found that regardless of age, gender, or income levels, people from Asian, Caribbean, and African backgrounds had less awareness, understanding and trust of palliative care services.
    b. To read more of the findings, click the link here.

3. **What is the link between socioeconomic status and pain at the end of life?**
    a. The research found that people struggling financially were more likely to be in more pain in the last week of life than those who were financially comfortable, regardless of age, sex, or diagnosis.
    b. To read more of the findings, click the link here.

The Policy Research Unit is co-led by Professor Katherine Sleeman at King's, and Professor Fliss Murtagh at Hull York Medical School. Rashmi Kumar is the PPI lead, supported by Professor Catherine Evans as Academic PPI Lead and Georgina Macdonald as PPI coordinator.

Contributed by Georgina MacDonald and Katherine Sleeman

DRAGONS' DENS FOR PHD STUDENTS

INDIA TUNNARD, RACHEL CHAMBERS AND MEGAN BOWERS HAVE BEEN SUCCESSFUL IN GAINING FUNDING TO HOLD WORKSHOPS THAT WILL ENABLE COLLABORATION BETWEEN PHD AND PPI MEMBERS.

We have now held two of three workshops in our 'Developing future leaders in palliative care' series. These workshops aim to support collaboration between PhD students and PPI members.

In the first workshop, three PhD students presented their PhD projects to PPI members, this grew to four in the second workshop. The PhD projects were on dementia, breathlessness, specialist palliative care in hospitals and measuring palliative care needs in different cultures. Each student presented their work for feedback from PPI members and discussion around key aspects of the project. All PhD students were in their first year, enabling the PPI members to be involved early on and have an impact on the design of the research.

All workshops have been rated as ‘good’ and PPI members were keen to attend another event. PPI members felt they were able to contribute, and their contributions were respected. One PPI member commented:

“I love everything about it. I also loved the fact that I was able meet people who have had a similar experience as mine.”

The only negative comment was around the length of the workshop: PPI members wished for more time. PhD students have also really valued the opportunity to present their work to PPI members, and for many it was their first time working with PPI members. Following the first workshop, a PhD student shared their reflections:

“I found the PPI workshops to be invaluable to my PhD research. They have provided me with the opportunity to involve PPI at a very early stage of my research. It was very affirming to hear that the people who I hope my research will benefit are appreciative and excited about the work I am doing. It is these experiences of meeting with people with lived experience that drive on my development towards becoming a future leader in palliative care.” – Ana Maksimovic, PhD student

Our final workshop is scheduled for late September. We hope to apply for the funding again in November to run another year of workshops to support the PhD students within the department. If you have any questions or thoughts on the workshops, please feel free to contact me at india.tunnard@kcl.ac.uk

Contributed by India Tunnard, Rachel Chambers, and Megan Bowers

A SYMPTOM-BASED APPROACH TO PPI

While many patient and public involvement groups coalesce around the treatment and research of certain conditions such as cancer and dementia, some groups at the CSI are zooming in even further on a particular symptom that can occur across different conditions: breathlessness.

Our Breathlessness Public Involvement Group, established in early 2019, now includes thirteen people (patients and carers) affected by breathlessness. This novel symptom-led approach to our public involvement work enables breathlessness researchers at the institute and people with relevant lived experience to collaborate and progress research of this complex symptom. Research Assistant and PhD fellow Subashini Rajagopalan coordinates the group and recently recruited PPI members for her PhD project from this group and other respiratory PPI groups within KCL. Subashini is looking forward to the first workshop planned for January 2026.

On the SELF-Breathe trial, Research Assistant Eleanor Rochester noted that she appreciates the contributions of their PPI members. She noted how they help to guide the priorities of the study and really keep the researchers focused on what matters. Eleanor says that she looks forward to seeing how the study progresses as they move into the trial steering group meetings.

On the PhotoBreathe study, Research Assistant Laura Cottrell said that PPI members have contributed valuable expertise by shaping the study documents and helping to problem-solve accessibility and other issues, particularly around camera use, such as sending digital photos securely. Their work transformed our Participant Toolkit, which is currently helping study participants navigate the study. As the study moves to its next phase, we look forward to including our PPI group members in data analysis.

Contributed by Laura Cottrell, Subashini Rajagopalan, Eleanor Rochester, and Beka Torlay

EVENTS

PUBLIC INVOLVEMENT CONTRIBUTES TO EAPC PRESENTATIONS

At Messukeskus Convention Centre in Helsinki, Finland, over 1700 people joined together to discuss the cutting edge of palliative care and end-of-life research. This group was made up of nurses, doctors, social workers, occupational therapists, rehabilitation specialists and more. Among the 280 speakers at the conference were many of our own researchers who presented on their own cutting-edge research. Here are some updates from a couple of researchers who presented work at the conference that could not have happened without the contributions of lived experts.

'Patient and caregiver experiences and motivations in an international trial of mirtazapine for severe breathlessness in respiratory diseases (BETTER-B)' - Professor Irene Higginson.

The Better-B grant included two PPI members on the trial steering committee and a specific PPI board that advised on the activities throughout the trial period. There was also partnership with key patient, stakeholder, clinician and research organisations, in particular the European Lung Foundation, and the European Respiratory Society, engagement with the CSI virtual forum and PPI Engagement at all stages of the project including dissemination.

My presentation (Meaningfulness and quality of end of life for people with dementia: a systematic review and framework synthesis) covered work from a systematic review as part of my PhD. My PPI group provided invaluable support throughout the review; directing the research question, developing the framework used in analysis, and sense-checking results. The presentation went well with some great feedback from clinicians attending the conference and I think this is in large part due to the PPI voice keeping it all focussed on what really matters to people living with dementia.

- Liam Gabb

Contributed by Beka Torlay, Research Administrator

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www.kcl.ac.uk/palliative

UPCOMING EVENTS

Keep an eye on your email and the PPI forum for upcoming events!

CSI PPI ONLINE FORUM

The PPI online forum continues to be a great way to engage with researchers on topics of interest, and to hear about updates within the CSI. Anyone can become a member, but we specifically invite those with experience of palliative care (as a patient, family member, friend, or carer), and members of the public with an interest in palliative care and rehabilitation research.

If you haven't signed up yet but would like to please visit:
http://www.csipublicinvolvement.co.uk/

The Cicely Saunders Institute is the first purpose-built institute for research into palliative care and rehabilitation. Palliative care is the active total care of patients whose disease is not responsive to curative treatment. The goal is the best possible quality of life for patients and their families, and includes control of pain and other symptoms, as well as attention to psychological, social and spiritual problems. The Institute brings together academics, healthcare professionals, community organisations, patients, and carers in one centre and acts as the hub for a network of international research. It offers high quality palliative care solutions to patients, as well as providing education, patient information and support.