

PATIENT AND PUBLIC INVOLVEMENT FOCUS

Cicely Saunders Institute (CSI)

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GREETINGS FROM THE CICELY SAUNDERS INSTITUTE

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Greetings!

We hope that everyone is keeping well.

Check out some updates from around the Cicely Saunders Institute (CSI) about patient and public involvement (PPI) and some upcoming events to keep an eye on.

PATIENT AND PUBLIC INVOLVEMENT PROJECT UPDATES

THE CHILDREN'S PALLIATIVE CARE OUTCOME SCALE (C-POS) STUDY AND THE GREAT ORMOND STREET HOSPITAL YOUNG PEOPLE'S ADVISORY GROUP

On Saturday 28th July 2023, the C-POS study team joined the Great Ormond Street Hospital Young People's Advisory Group (GOSH YPAG) virtually for the fifth time. The group enjoyed hearing more about the project, learning about the development of C-POS and how their suggestions and expertise have been incorporated in short animations to explain the ongoing study to children and young people taking part. The study team asked the young people about how to make sure that C-POS gets used in practice. We told them what parents and health care professionals think is important to consider and then asked them their thoughts to make sure that children's voices are considered in the development of an implementation plan for C-POS.

We look forward to the next time we can join the GOSH YPAG and feed back to them the impact they have had on the implementation plan development, how their suggestions have been integrated, and to show them our new logo!

You can find out more about the Children's Palliative care Outcome Scale study here: <https://www.kcl.ac.uk/research/c-pos>. To sign-up to our C-POS study newsletter mailing list, please email hannah.m.scott@kcl.ac.uk

The GOSH YPAG also helped select a new study logo. They voted on their favourite logo and told us what they liked and disliked about each option. We are very excited to reveal our new logo:



BUILDING CAPACITY – PPI SEED CORN FUNDING

First of all, what is seed corn funding?

In the context of research, seed corn funding is usually a small pot of money that provided to a researcher to give them a chance to conduct exploratory research that might lead to bigger research projects.



What will we do with this funding?

In December, several CSI researchers received seed corn funding with the aim of building capacity for patient and public involvement on their projects. We have heard from a few of them on their projects and how they intend to use their funding for PPI activities.

Hannah Scott received funding to co-produce some short videos with PPI members to explain what the Children's Palliative Care Outcome Scale (C-POS) is and its' benefits to parents and professionals.

Lisa Brighton received funding to co-design and run a feasibility trial for a novel psychological intervention for depression symptoms in people with severe COPD in collaboration with people with lived experience.

Catherine Evans, Katherine Sleeman, Annabel Farnood and Emel Yorganci received funding to put on an exhibition centred around living with dementia at the Science Gallery London.

Eleanor Rochester received funding to host two workshops this spring with caregivers of people with breathlessness.

EAPC - 13TH WORLD RESEARCH CONGRESS



This year the European Association for Palliative Care 13th World Research Congress will be held on 16th-18th May in Barcelona.

There will be around 30 presentations given by CSI staff, and around 25 staff members are attending, including public members who have been with us. This conference is a great opportunity to share our research with colleagues internationally and discuss the implications for clinical care.

PATIENT AND PUBLIC INVOLVEMENT RECENT EVENTS

ENGAGEMENT OPPORTUNITIES – OCTOBER DRAGONS' DEN

On 3rd October 2023 we hosted an online Dragons' Den event. This is a regular event for researchers to present their research ideas to public members and explore with them opportunities to strengthen the work to align with priorities for patients and families. Four researchers presented and discussed topics including:

- "Palliative care interventions for older people living in care homes: an evidence synthesis", **Dr Anna Bone**
- "Optimising Mobility in Life Limiting Illness", **Dr Joanne Bayly**
- "Better identification of palliative care needs in hospital for better patient outcomes", **Dr Peter May**
- "Understanding and meeting the out-of-hours needs of South Asian patients and their families living with life-limiting illness." **Dr Sabrina Bajwah**

KING'S ENGAGED RESEARCH NETWORK AWARDS



On Tuesday 16th January, the King's Engaged Research Network hosted in the Grand Hall on the Strand Campus, an inaugural award ceremony to recognise the innovative public engagement work undertaken by researchers with public and community partners. We were delighted that the CSI had three submissions [shortlisted](#). Two projects won awards in the categories, 'Communicating Research (Local)' and 'Transforming Research Culture'. These projects were:

The D-Words

This project is from the research programme 'Empowering Better End of Life Dementia Care' (EMBED-Care). This is a joint programme between King's College London and University College London. The six-year programme encompasses a novel public engagement work stream that is guided by public members affected by dementia.

The EMBED-Care team were nominated for their work engaging young people about palliative dementia care research at a Science Museum late event. For this event, celebrating the 75th birthday of the NHS last July, the team developed a suite of activities, collectively named 'the D-words.' Visitors were invited to take part in activities including a card game about priorities at the end of life, a wishing tree for people to write what mattered at the end of life, and a myth buster quiz about importance of palliative and end of life care for people with dementia and their families. Visitors also had opportunity to chat with the research team and public members about living and dying with dementia.



Dr Sarah Crabtree, Prof Catherine Evans and Emel Yorganci, all members of the EMBED-Care research team, accept the KERN award for Communicating Research.



Prof Catherine Evans, Marion Sumerifield and Dr Sarah Crabtree accept the KERN Award for 'Implementing a co-developed public involvement strategy for palliative care research'.

Implementing a co-developed public involvement strategy for palliative care research

This entry reflected our long-standing partnership working between public members (Margaret Ogden, Rashmi Kumar, Pam Smith, Marion Sumerfield, Alan Quarterman) and researchers (Lisa Brighton, Sarah Crabtree, Beka Torlay, Cat Harvey, Halle Johnson, India Tunnard, Tofunmi Aworinde, Jo Bayly, Joanna Goodrich, Juliet Gillam, Monica Oancea, Steve Marshall, Catherine Evans)

This entry was about how we have worked together to co-develop, implement, and evaluate our Public Involvement Strategy to strengthen meaningful

collaboration with lived experts and community partners, and enrich research at the Cicely Saunders Institute. The Strategy has ensured that public involvement is at the core of the Institute's research culture, enabling us to work to increase the diversity of members involved, the influence of public members at a strategic level, and work in partnership with other organisations to build local, national, and international capacity in public involvement in palliative care research.

Read more about the [nominated projects from the CSI](#) and [other award winners](#)


Contributed by Dr Sarah Crabtree and Prof Catherine Evans

Photo credits: Jack Latimer

STRATEGY DEVELOPMENT

Over the last year we have conducted an evaluation of the Public Involvement Strategy (2021-2023). The findings informed the co-developed our new Public Involvement Strategy (2024-2026).

Highlights form the last three years of collaboration include PPI:

 <p>RESOURCES</p>	<ul style="list-style-type: none">12 PPI Strategy Meetings AttendedPPI Buddy Scheme CreatedPPI Research Training Video Series CreatedPPI Handbook Developed
 <p>FORUM</p>	<ul style="list-style-type: none">62 new members343 items posted2893 views
 <p>TRAINING</p>	<ul style="list-style-type: none">3 MSc Palliative Care PPI Lectures3 PPI Methodological Skills Sessions
 <p>EVENTS</p>	<ul style="list-style-type: none">6 Dragon Den Events15 New Projects SupportedKnowledge Exchange Event Held
 <p>AWARDS</p>	<ul style="list-style-type: none">KERN Award for Transforming Research CultureKnow Your ARC Award

We would like to extend a **huge** thank you to the four key public members in the Strategy Development team who have been supportive of this work over the past year. Also, a big thank you to public members who were able to complete surveys and participate in focus groups which contributed to the content of the strategy.

Contributed by Dr Sarah Crabtree

CICELY SAUNDERS INSTITUTE

Bessemer Road
Denmark Hill
SE59PJ

PPI Strategy Group:

Tofunmi Aworinde
Joanne Bayly
Lisa Brighton
Sarah Crabtree
Catherine Evans
Annabel Farnood
Miki Fujimoto
Juliet Gillam
Rashmi Kumar
Alan Quarterman
Pam Smith
Marion Sumerfield
Beka Torlay
India Tunnard

E-mail: csi.ppi@kcl.ac.uk
Twitter: [CSI_KCL](#)



Visit our website:
www.kcl.ac.uk/palliative

UPCOMING EVENTS

Launch of Public Involvement Strategy, Buddy Scheme, Research Training

Video: Feb/Mar 2024

Dragon's Den: April (Keep an eye out for more information soon!)

Dementia Journeys Exhibition at the Science Gallery London: Opens 3 April

Dementia Community Research Network (DCRN) event: 9 May
(venue TBD)

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.