

All Ireland Institute of Hospice and Palliative Care (AIHPC)

PPI Within the Context of Palliative Care Research

Online Workshop, Thursday 31 March 9:00am – 1:15pm, 2022

On the island of Ireland PPI refers to Personal and Public Involvement or Public and Patient Involvement in research. This workshop aims to build expertise in successfully supporting and facilitating people with life-limiting conditions, their families, and carers, and interested citizens to be involved in all stages of palliative care research.

Delegates attending this event will learn how to:

- Prepare for and manage PPI challenges and sensitivities which are unique to palliative care research
- Widen PPI activities to facilitate meaningful involvement of PPI contributors to improve research outcomes
- Develop PPI recruitment strategies that foster inclusivity and support diversity

Programme

- 9:00-9:05** **Registration**
- 9:10-9:15** **Welcome**
Marie McKeon, Project Manager - Knowledge Transfer, AIHPC (Chair)
- 9:15-9:35** **AIHPC Voices4Care Involvement in Research**
Dr Mary Rabbitte, Research Programme Manager, AIHPC
- 9:35-10:00** **Public involvement in palliative care: principles and practicalities**
Dr Lisa Brighton, Research Associate at Cicely Saunders Institute, King's College London and Margaret Ogden, Patient and Public Contributor at the Cicely Saunders Institute, King's College London
- 10:00-10:40** **Q&A | Facilitated Groupwork | Discussion**
- 10:40-11:00** **Comfort Break**
- 11:00-11:25** **Fostering inclusivity and diversity: Implications of communication impairment for PPI**
Dr Ruth McMenamin, Lecturer in Speech and Language Therapy, School of Health Sciences, co-lead for the PPI Ignite Network, National University of Ireland, Galway and Prof Nicole Müller, Head of Speech and Hearing Sciences in the School of Clinical Therapies, University College Cork
- 11:25-12:00** **Q&A | Facilitated Groupwork | Discussion**
- 12:00-13:00** **Panel Discussion**
Dr Gail Johnston, Public Health Agency, Health & Social Care R&D Division, Northern Ireland, Maureen Gilbert, AIHPC Voices4Care member, Dr Lucia Prihodova, National Office for Research Ethics Committees and Michael Foley, Health Research Board-Irish Research Council PPI Ignite Network
- 13:00-13:15** **Conclusion and AIHPC supports available**
Karen Charnley, Director, AIHPC

Host:



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Speakers, Panel Members and Facilitators



Karen Charnley, Director, All Ireland Institute of Hospice and Palliative Care (AIHPC). As Director, Karen provides strategic leadership for AIHPC including brokering relationships between the Institute's 27 partner organisations funders and key stakeholders. She leads the Institute Team and oversees the delivery of the Institute's Business Plan across education, research, policy and practice, service user and carer engagement and raising awareness. She also represents the Institute on key regional and national fora and contributes to palliative care policy and strategic discussions. Karen has worked both in the UK and Ireland and has significant leadership and management experience in a range of sectors including housing, economic development and offender management.

Prof Nicole Müller, Head of Speech and Hearing Sciences in the School of Clinical Therapies, University College Cork (UCC). Nicole Müller is Professor and Head of the Department of Speech and Hearing Sciences at UCC, and Head of the School of Clinical Therapies, including Audiology, Occupational Therapy, Physiotherapy and Speech and Language Therapy. Her research interests include ageing-related disorders of communication and cognition, such as dementia and acquired brain injury and their impact on interaction in daily life and the ability to speak multiple languages. Before joining UCC in 2017, she held academic appointments in England, Wales, the United States and Sweden. Her current work includes collaboration on research into sensory care for people with dementia in residential care.



Dr Ruth McMenamin, Lecturer in Speech and Language Therapy, School of Health Sciences, co-lead for the PPI Ignite Network, National University of Ireland, Galway (NUIG). Ruth co-leads work package 1 (capacity building focus) for the Irish PPI Ignite Network and she is a guest editor on a "PPI and Aphasia" special issue in the journal *Aphasiology*. Ruth uses participatory approaches to work collaboratively with people with aphasia, healthcare professionals, students and community organisations in research. Ruth is a member of the executive committee of the Collaboration of Aphasia Trialists (CATS) and she co-leads the 'Early-Stage Researcher Training' group. Ruth established and co-ordinates the NUI, Galway Conversation Partner Programme for people with aphasia in the local community.



Dr Lisa Jane Brighton, Research Associate at the Cicely Saunders Institute, King's College London, has a background in psychology and has worked as a health services researcher in palliative care for over seven years. Her research focuses on developing and evaluating complex interventions, particularly for people living with respiratory disease and/or chronic breathlessness. Alongside this, Lisa has supported the development of patient and public involvement infrastructure and activities in palliative care and rehabilitation including co-leading creation of an online forum for public involvement in this field and co-developing the Cicely Saunders Institute's latest public involvement strategy.



Margaret Ogden, Patient and Public Contributor at the Cicely Saunders Institute, King's College London, begun her journey in public involvement in 2006 following the death of her mother from non-Hodgkin's lymphoma. The impact of her mother's death motivated Margaret to begin volunteering as a fundraiser for Cancer Research UK, and then working for 3 years with the National Cancer Research Institute. Since 2014 she has worked with the Cicely Saunders Institute, where she has developed a specialism in evaluation in public involvement, and contributed to a range of activities, including qualitative analysis. Her other interests include diagnostics, community pharmacy, oral health and dentistry, mental health, homelessness, and equality and diversity. Outside of public involvement she enjoys ballet, opera, museums, art galleries and philosophy.



Marie McKeon, Project Manager - Knowledge Transfer and Exchange, AIHPC. Marie is responsible for knowledge transfer and exchange activities and initiatives, associated with the Palliative Care Research Network (PCRN), Early Career Researcher Forum (ECRF), and AIHPC's Palliative Hub websites. She holds a degree in Business Management and a Professional Diploma in Education. Since joining AIHPC in 2017, she has collaborated with PCRN members and other key stakeholders, to design, develop and deliver capacity building workshops on knowledge transfer and exchange, implementation, and digital communication and other events across the island of Ireland. She provides mentorship support to PCRN and ECRF members on local, national, and international projects and related research activities. She also led the development of the free eLearning course '[Developing a Dissemination Strategy for Health Research](#)' available on The Palliative Hub – Learning Platform.





Dr Mary Rabbitte is Research Programme Manager at AIIHPC, where she leads on AIIHPC's research programme and supports the strategic development of the Institute's PCRN and programmes. She has previously managed, developed and delivered research, education, and consultancy programmes in the academic, health care and business sectors. As a clinical psychotherapist she has worked with people with life-limiting conditions within hospice and private practice. Her published research masters on psychotherapeutic approaches for people with MND involved working with a psychotherapist with life limiting neurodegenerative disease in a hospice and home setting to develop qualitative interview questions. This research informed the development of a national training programme to improve psychosocial care of people with MND that she led in collaboration with Irish Motor Neurone Disease Association, Beaumont Hospital, and Our Lady's Hospice and Care Services funded by Irish Hospice Foundation. Mary also holds a PhD in Chemistry from NUIG.

Maureen Gilbert, AIIHPC Voices4Care member. Maureen has been a member of Voices4Care for almost six years, linking her passionate interest in ensuring agency and best quality at end of life with a deep commitment to democratisation and diversity throughout society. In her professional life she is an equality and diversity consultant, working in Ireland and internationally with the UN, statutory bodies, major corporations, NGOs and arts organisations. She designed the UN's approach to both facilitation and disability equality training and has trained facilitators throughout the world. A social anthropologist by education and inclination, she is a keen traveller and arts audient. Maureen also represents the public interest on the steering group of the Irish Health Research Forum.



Michael Foley, Programme Manager, Trinity PPI Ignite Office, Trinity College Dublin. Michael has been facilitating public processes for over twenty years as part of his work in the National Disability Authority, Age & Opportunity and now Trinity College Dublin. He has developed PPI Ignite involvement activities for the autism, dementia, intellectual disability and vision impaired communities. He has worked with NGOs such as: Health Research Charities Ireland to co-produce the Making a Start toolkit; Campus Engage on their How-To Guide on Engaged Research Online Workshops and their upcoming Engaged Research & Innovation for Societal Impact training course; IPPOSI on their Citizens' Jury on Access to Health Information; and the Irish Hospice Foundation on the development of research activity within their organisation. Michael has also been a Research Module coordinator in Maynooth University.

Dr Gail Johnston, Programme Manager, Public Health Agency, Health & Social Care, R&D Division Northern Ireland. Gail undertook a degree in Social Science at Edinburgh University before going on to train as a nurse and district nurse. She subsequently worked as a research sister and fellow in Ninewells Medical School, Dundee, on a variety of health service research projects. She completed her PhD there in 1997 looking at the assessment of psychosocial and spiritual needs of patients with advanced cancer. She moved to Belfast in 1998 and for 9 years worked as a Macmillan Lecturer, initially in the Dept of General Practice at Queens University where she co-developed a special study module in palliative care for undergraduate medical students, and latterly in the Macmillan Education Unit, Belfast where she supported the professional development of Macmillan Postholders. Since 2009, she has worked as a programme manager in HSC R&D Division, Public Health Agency with a special responsibility for Personal and Public Involvement.



Dr Lucia Prihodova, National Office for Research Ethics Committees (NRECs). Dr Prihodova is the Programme Manager for the NRECs in Ireland. As a senior member of the National Office team, Lucia manages the processes and procedures that underpin the national system of research ethics review and works on development of training for the Members of National Committees. Lucia holds a PhD from the Faculty of Medicine at University of Groningen, Netherlands and MSc in Psychology from Trnava University, Slovakia. As an established researcher and research manager, Lucia brings in a wealth of expertise, having led and managed large-scale research projects in health systems research exploring work environment, workforce training and wellbeing, and patient outcomes from design to knowledge translation and dissemination.

Paula Pinto, a Programme Manager for Policy and Practice at AIIHPC. Paula is a Chilean lawyer with a Diploma in Business Administration and a Master's degree in Social Entrepreneurship. She has experience working in the charity sector particularly in relation to grants management, fundraising, policy development, and ensuring overall compliance to policies and procedures. She joined AIIHPC in October 2021 leading in policy and practice including engaging with policymakers, service users, carers and community involvement through AIIHPC Voices4Care across the island of Ireland. As well as working on the plans for Palliative Care Week 2022 to raise the awareness of palliative care.





Clodagh O'Donovan, a Project Manager at AllHPC, joined in 2020 as the Palliative Care Research Network Project Manager and also supports AllHPC's Early Career Researcher Forum. Clodagh previously worked for medical research charities including Health Research Charities Ireland (HRCI), where she managed their Patient and Public Involvement (PPI) Shared Learning Group and helped to develop a series of PPI training workshops. She has a background in communication and community development in the charity sector and has worked extensively in film, television and digital media as an audio engineer, producer, and post-production manager. She has an MSc in Interactive Digital Systems from Trinity College Dublin.