



Wednesday 27 April 2022
virtually from NUI Galway
#PPIGalway2022



Seventh National Public and Patient Involvement (PPI) in Research conference PPI: Partners in today's research culture

Some presenters on the day include:

Dr Avril Kennan
CEO
Health Research Charities Ireland

Dr. Avril Kennan is CEO of Health Research Charities Ireland (HRCI), an organisation that supports a community of 40 charities to engage in all aspects of health research. Under her leadership, HRCI runs the Irish Health Research Forum (IHRF), manages a funding scheme for patient-focused research projects in partnership with the Health Research Board and hosts a patient and public involvement (PPI) 'Shared Learning Group' for over 30 charities. HRCI is also a national partner on the National PPI Ignite Network.

Avril's PhD and subsequent lab experience are in the field of molecular genetics. In previous roles in DEBRA Ireland and DEBRA International, she drove a range of patient-focused international initiatives. She's passionate about improving lives through research.

Dr Nikki Dunne
Research Officer
Family Carers Ireland

Dr Nikki Dunne is the Research Officer with Family Carers Ireland, the national charity supporting the 500,000 family carers across the country who care for children and/or adults with physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental ill-health or addiction.

As the organisation's Research Officer, Nikki leads Family Carers Ireland's programme of research and manages a diverse range of qualitative and quantitative projects relating to family carers. She is particularly focusing on building and coordinating research involvement and engagement among family carers, researchers and other stakeholders

Cíara O'Reilly
Research Project Officer
The Alzheimer Society of Ireland

Cíara O'Reilly is the Research Project Officer at The Alzheimer Society of Ireland. Cíara supports the members of the Dementia Research Advisory Team (a group of people living with dementia and family caregivers / supporters) to engage in dementia research in a PPI capacity

Dr Jenny Preston
Senior Patient and Public
Involvement and Engagement
Manager, University of Liverpool

Jenny Preston is the Senior Patient and Public Involvement and Engagement (PPIE) Manager at the University of Liverpool. Her main role is to deliver a strategy for the involvement and engagement of children and young people and families in paediatric health research both in the UK, Europe and internationally. She leads the GenerationR Alliance of young people's advisory groups and is a founding member of the European Young Person's Advisory Group Network (eYPAGnet). Jenny is currently studying part-time for a PhD to develop an evidence based best-practice framework with children and young people involved in the design and conduct of clinical studies.

Parallel Session: PhD and PPI In this session, a panel of PhD candidates and PPI contributors will present their work and discuss the role of PPI in student research.

Presenters:

Pádraig Carroll, "Advancing PPI in Pre-clinical Research: A Participatory Action Research Study" PhD candidate in the School of Pharmacy and Biomolecular Sciences, RCSI and Tissue Engineering Research Group, RCSI

Nerilee Ceatha, "A mixed-methods exploration of protective factors that promote LGBTI+ youth wellbeing" SPHeRE Scholar at the School of Public Health, Physiotherapy and Sports Science, UCD, joined by PPI contributors **Ayrton Kelly**, **Jayson Pope**, and **Niamh Scully James Larkin**, "The Burden of Financial Costs for People with Multimorbidity" PhD candidate in the Department of General Practice, RCSI joined by PPI contributor **Tony Hickey**

Chair:

Nikolett Warner, PhD Candidate, Galway Doctoral Scholar and IRC Scholar, School of Psychology, NUI Galway

Parallel Session: HRB Clinical Trial Networks and PPI

This session brings together a selection of both established and newer Clinical Trial Networks for a discussion of the role of PPI in their individual groups.

Chair Dr Fionnuala Keane will be joined by representatives of the following networks:

Irish Network for Children's Clinical Trials (In4Kids)
Irish Critical Care Clinical Trials Network
Dementia Trials Ireland
Diabetes Collaborative Clinical Trial Network
Primary Care Clinical Trials Network

Parallel Session: PPI Contributor panel: my voice shaping research

In this session attendees will have the opportunity to hear from PPI contributors on their first hand experience of getting involved in research.

Mandy Daly, Anne Lawlor, Denis Mockler, Marian O'Mahony and Caoimhe O'Neil

Mandy Daly

Mandy is a medical and disability underwriter and a parent of a preterm infant born in 2006. Since that time she has been advocating in the neonatal space and in 2013 she founded the collaborative multi-stakeholder platform, The Irish Neonatal Health Alliance (www.inha.ie).

She has extensive experiential and deep sectoral knowledge and specialises in the areas of Advocacy, Education and Research. Her achievements include effecting several neonatal and paediatric health system reviews, developing and delivering curricula and continued education to medical, nursing and allied health professional students, mentoring PhD students, serving on the parent advisory board of the European Foundation For The Care Of Newborn Infants and the NIDCAP Federation International Board since 2012 and working as patient collaborator and embedded patient researcher on several national and international research studies. Mandy was a chair committee member of group that developed the European Standards of Care For Newborn health, is a public reviewer for the Health Research Board and the British Medical Journal Open Pediatrics, is a member of the National Office of Research Ethics Clinical Trials Committee and has published papers in several journals including the British Medical Journal, The Lancet, The Journal of Obstetrics and Gynaecology and Trials.

Anne Lawlor

Anne is a founding member and chairperson of the 22q11 Ireland Support Group. The organisation, set up in 2007, supports families affected by 22q deletion syndrome and together with 22qCARA (Clinicians and Research Advocates) works to develop integrated health and social care across the lifespan.

Dedicated to raising awareness of 22qDS as a poorly understood and under-recognised condition Anne completed a Masters in Management of Community and Voluntary Groups and works in a voluntary capacity with 22q11 Ireland. She lives in Dublin with her daughter Áine aged 39 who was diagnosed with 22qDS aged 15

Denis Mockler

Denis Mockler is an active member of the PPI group of the HRB Primary Care CTNI, since the group was set up in 2016. Denis had previously brought a patient perspective to the development of content for undergraduate and postgraduate modules in the School of Nursing and Midwifery at NUI Galway. He has also contributed in an advisory capacity to the development of research applications prepared in the School. Denis is a well-known singer songwriter on the local scene in Galway.

Marian O'Mahony

Marian O'Mahony's interest in PPI began when she became a palliative carer for her 18-year-old son who developed leukaemia and died just months later. Finding the experience isolating and frightening she wrote their family story in her book 'Goodbye, My Son' and has a website <https://www.marianomahony.com>. She is a UCC and IPPOSI graduate and her mission is to contribute experience and information to promote the best outcome for patients, carers, researchers, and professionals in the field.

Caoimhe O'Neill

Caoimhe O'Neill has just finished an undergraduate degree in Irish and geography in St Patrick's College DCU. She has been an active member of IPPOSI since doing a year long course in 2020 giving thoughts and suggestions on patient involvement from a unique youth perspective. She is also a member of the iCAN youth panel.

Edel Tierney
National Research Officer,
Tusla Child and Family Agency

My name is **Edel Tierney** and I am a National Research Officer with Tusla Child and Family Agency. The National Research Office is part of Tusla's Quality and Regulation Directorate.

Tusla is also a National Partner on PPI Ignite National Network.

In the National Research Office, we endeavour to keep child and youth voices at the core of our work programme and today we wish to speak to the conference delegates about how Tusla have embedded a PPI approach in Tusla research ethics structures and processes. We are going to draw on the example of having PPI contributors on Tusla's independent Research Ethics Committee.

My other key research interests lie in finding ways to embed the voice of children and young people in the research activities of Tusla and how this can inform practice and policy. I am interested in the questions of how can research inform and improve our responses to children? How can research make a difference in the day-to-day lives of children and families? And how can the voice of children and families be embedded in this process? PPI is central to this and involves the voices of all stakeholders in the research conducted across the Agency.

I also a Chartered Member of the Psychological Society of Ireland (C.Psychol.Ps.S.I.)

Joe Murphy
PPI representative on Tusla REC

I have worked as a Quality Manager in the pharmaceutical industry for over 30 years . I am married with two grown up daughters.

In 2017 I volunteered to act as a Public representative supporting the HRB in their drive to improve the Patient/ Public Involvement in research. Over the past 5 years I have been involved in various health research programs acting as a PPI representative either directly with the HRB or in other publically funded health research programs. Currently involved in a review of research proposals for projects being sponsored by charities and HRB.

In 2021 I was given the opportunity to join the REC board of Tusla which I was very happy to accept and have enjoyed being a member of the committee over the past year.

Anne Papyan
PPI Ignite Network @ UL
Shannon Family Resource Centre

Anna is a graduate of sociology from Yerevan State University, Armenia. With extensive experience in both quantitative and qualitative research methods, she has worked on a variety of research projects in health, education, migration, human rights, civic activism, public policy. Anna has also collaborated with several community development initiatives on awareness raising, capacity building, civic participation, activism and the promotion of human rights. She has organised and facilitated trainings, seminars and discussions using participatory approaches and techniques. Anna is currently involved in a number of initiatives with the Shannon Family Resource Centre (FRC) and served as Community Liaison Officer in the Ethnic Minority Health research project conducted by UL Graduate Medical School in collaboration with Shannon FRC. Within the project she organised and supported facilitation of participatory group discussion with community members of different ethnic backgrounds. Anna was involved in the Research Prioritisation for Migrant Health project, coordinated by the HRI funded PART-IM (Participatory and Arts-Based Methods Involving Migrant in Health Research) as research assistant. She supported to organisation and facilitation of series of online cafés aimed to generation of migrant health research agenda, as well as contributed to elaboration of final report and action plan.

Anna recently appointed as Research Assistant to PPI Ignite Network within PPI Unit at University of Limerick. She also took a position of Community Development Worker at Shannon Family Resource Centre.