

## Sixth National Public and Patient Involvement (PPI) in Research conference PPI - Creating the new normal in research

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### **Robert Joyce** – Embedded Patient Researcher

Robert has, over the last 4 years, moved from being involved in the commercial world to becoming a Patient Advocate. In 2019 he started as a part time research assistant on the COBMS trial (a new therapy for people living with multiple sclerosis and cognitive symptoms), which led him to start training with EUPATI to be a Patient Expert. Since then he has shared his patient experience with the governmental agencies and pharmaceutical companies. Over this time he has used his voice to share his experience on national radio and press, and developed online training programmes for managing anxiety, stress & depression for PwMS, and is working on a new programme for people with Progressive MS with the intent of increasing resilience.



**Professor Martin O'Halloran** is a European Research Council (ERC) and Science Foundation Ireland (SFI) Investigator at the National University of Ireland Galway. Professor O'Halloran is also co-lead of the PPI Ignite Network @ NUI Galway. Reflecting the interdisciplinary nature of his research, he holds a joint affiliation with the College of Engineering and Informatics; and the College of Medicine, Nursing & Health Sciences, and leads the Translational Medical Device Laboratory in the Lambe Institute. Professor O'Halloran has received over 30 national and international research awards and was recently awarded SFI's Early-Stage Researcher of the Year, Engineers Ireland Chartered Engineer of the Year, and the European Research Council's Starting Investigator Grant. He was a co-proposer of a European COST Action (entitled "MiMED") and is now leading a network of over 180 medical device researchers from 24 countries, focused on the clinical evaluation and commercialisation of novel medical devices in Europe.



**Professor Aoife Lowery** is a Consultant Breast and Endocrine Surgeon in Galway University Hospital, and Associate Professor of Translational Research and Regenerative Surgery in NUI Galway. She has trained in Ireland and France. Her PhD focusing on biomarkers in the detection of breast cancer, was undertaken as part of the Molecular Medicine Ireland Clinician Scientist Fellowship Programme (CSFP). She also holds a Masters of Medical Science, and a Diploma in Clinical Education.



**Emily Atkinson** holds an undergraduate degree in Psychological Studies, Sociology and Politics from NUI Galway and is currently pursuing a H. Dip in Psychology. She has been on the Youlead YAP for the past year. Emily was the President of NUI Galway Psychological Society, as well as a NUI Galway Welfare Crew member, Ceim Student Leader, and an Active Consent workshop facilitator.



**Jack Gaffey** is a third-year undergraduate student in NUI Galway. He has been an active member of the PPI Advisory Committee since its inception in 2018 giving thoughts and suggestions on PPI matters from a unique youth perspective.



**Johanna O'Shea** is currently a lecturer in Social Work at Maynooth University, having previously worked at Ulster University for seven years. Her broad area of research is probation work. Her current PhD studies are critiquing the area of risk assessment and notions of public protection in the justice system against a backdrop of protecting human rights. She has a keen interest in individuals' experiences of the justice system, in particular their experience of social work services within it. Prior to her academic career, Johanna gained extensive practice experience working as a probation officer, in both Germany and Northern Ireland.



**Dr Ciara Shiggins** is a speech and language therapist and post-doctoral research fellow within the Centre of Research Excellence in Aphasia Recovery and Rehabilitation (CRE Aphasia) ([www.latrobe.edu.au/aphasiacre](http://www.latrobe.edu.au/aphasiacre)), based at La Trobe University, Australia. She holds an Honorary Fellowship with the University of East Anglia, (UEA), UK. Her overarching research aim is to address and optimise the inclusion of people with aphasia across stroke rehabilitation and research to enhance their wellbeing. She is an advisor on the ASSENT Project ([sites.uea.ac.uk/assent](http://sites.uea.ac.uk/assent)), which aims to develop an assent-based process for the inclusion of adults with capacity and/or communication difficulties in ethically sound research. She also helped to organise an international conference, specifically for and accessible to people with aphasia and their family members, and has facilitated peer-support groups for people with aphasia. Ciara is a member of the Collaboration of Aphasia Trialists Societal Impact and Re-integration research working group.



**Ian Duffy** was born in Hull, England in 1958 and his father came from Ballina. Ian left Hull in 1976 to study Law at Newcastle University, graduated in 1980 and started a career as a retailer. He joined IKEA in 1987 - working in England, Sweden, Denmark, China, Japan and Australia. Lived in Beijing, China from 2002 to 2011. Ian experienced two major brain haemorrhages in 2012 and have been unable to work although still employed by IKEA. Learning to live with Aphasia has brought Ian in contact with peers, therapists, creative arts and the University of East Anglia, UK. Life is still a challenge but Ian can rely, more and more, on a structure and activities that provide him with meaning and satisfaction.



**Dr Nana Folmann Hempler** is a senior researcher and team leader at Steno Diabetes Center Copenhagen, Denmark. She has expertise in developing, testing and disseminating research-based interventions focusing on providing sustainable care and health promotion for people with or at high risk of type 2 diabetes. Her research focuses on hardly reached groups and include complex interventions, implementation research, digital public health and design-based research where solutions are developed and implemented in collaboration with end-users and a variety of stakeholders. She leads an active consumer programme in the Danish Island Bornholm aiming to increase access to care for people with multimorbidity.



**Carl Erik le Sage de Fontenay** is a senior citizen living on Bornholm, Denmark. He is treasurer and board member of the local branch of the Danish Diabetes Association. He is the user and social network representative on somatic diseases in the Bornholm co-ordination committee from Hospital, Municipality and GPs. He is involved in local networks for patient associations and other NGOs. He is a user representative and an external advisor on the research project "Together with Diabetes and Multimorbidity on Bornholm". He holds a PhD, MSc (struct.eng.) specialized in concrete production and durability and has been living in The Persian Gulf for 12 years.



**Dr Olinda Santin** is a senior lecturer in supportive cancer care in the School of Nursing and Midwifery at Queen's University Belfast. Her background is in health psychology and public health. Her research particularly focuses on understanding the psychosocial impact that cancer has on families and the development of supportive feasible digital solutions. She specialises in co-design and the involvement of stakeholders in the design of supportive services, recent examples of this are the development of the online resource [www.cancercaringcoping.com](http://www.cancercaringcoping.com). She is currently leading a programme of work in partnership with families affected by cancer across Vietnam to understand the impact of cancer and the development remote supports.



**Nikolett Warner** holds a Bachelors in Denominated Psychology (Hons) and Masters of Science in Health Psychology (Hons) from NUI Galway. She is currently a PhD candidate in the School of Psychology in NUI Galway, and her research explores the experiences of people with a BRCA1/2 alteration within the Irish health care system. She recently won the inaugural Public and Patient Involvement (PPI) Ignite @ NUI Galway award for the use of PPI in her PhD. She has a keen interest in genetics and the psychological impacts of hereditary cancer conditions. She is based in Galway City and has worked with the Marie Keating Foundation as a Peer Supporter for individuals with a BRCA1/2 alteration for the past 3 years.



**Professor Sean Dinneen** is Consultant Endocrinologist and National Lead of the PPI Ignite Network, having previously been lead of PPI Ignite Programme at NUI Galway. Funded by the HRB, the PPI Ignite programme aims to change the culture across health research in the University so that meaningful involvement of public and patients across the full research cycle becomes the norm. Sean pioneers a patient-centred approach in both clinical and health research domains and is the Principal Investigator of the D1 Now study, which has been informed by a strong PPI ethos. Young adults living with type 1 diabetes frequently struggle with self-management (and clinic attendance) - working in partnership with Jigsaw Galway, the D1 Now study has seen the establishment of a Young Adult Panel (YAP) of young people with diabetes who have acted as co-researchers in the study.

