



People and Patient Participation, Involvement and Engagement (PoPPiE) Working Group

Members' biographies

John Turner, MBE

John was a patient participant in the SCORE-IT study, a COS study for future trials of glucose-lowering interventions for type 2 diabetes. Since participating in the study, John has also been involved in developing an animation to disseminate the results of the SCORE-IT study and has presented in a COMET webinar explaining COS studies to UK patient organisations from a patient perspective.

John has undertaken patient and public involvement in research for several years, as a public contributor on the Diabetes UK Grants Advisory Panel. He also volunteers as a Mental Health Act Manager for both Devon and Cornwall NHS mental health trusts. John runs a charity fundraising company alongside administering a national carers charity.

John was awarded an MBE (a British award for outstanding achievement or service to the community) in 2019 for his volunteering roles in mental health and for services to the young people of Portsmouth, UK, where he lived for many years, through his role as a trustee of The Bentley Young Persons Trust.

John is co-chair of the PoPPiE Working Group



Bridget Young:

Bridget Young is Professor of Psychology at University of Liverpool and co-lead for the Patient Perspectives Theme of the Northwest Hub for Trials Methodology Research. Her work focuses on psychosocial processes in healthcare and clinical research, with the overall goal of improving patient care. She specialises in the use of qualitative methods to investigate patient-practitioner communication in illness, recruitment to clinical trials, stakeholder perspectives on clinical research, and most recently on ways to ensure the distinctive perspectives of patients, carers and members of the public are taken into account in the development of core outcome sets.

Bridget is co-chair of the PoPPiE Working Group



Maarten de Wit:

Maarten de Wit PhD, has been active in organisations of patients with rheumatic diseases at local, national and international level for almost 15 years. Maarten has psoriatic arthritis since 1984 and is member of the Outcome Measures in Rheumatology (OMERACT) Executive Committee. In January 2014 Maarten defended his doctoral thesis “Patient participation in rheumatology research. A four level responsive evaluation” at the VU University, Amsterdam. The evaluation of 10-year patient participation in OMERACT was an important part of this thesis. Maarten participated in the second COMET meeting (Bristol) and is interested in ways to incorporate the patient perspective in outcome research.



Maureen Smith, M.Ed:

Maureen has a long history of collaboration with the healthcare system subsequent to a rare disease diagnosis in childhood. She is the co-chair of Cochrane’s Consumer Executive and is involved in several Cochrane projects. For the past 11 years, Maureen has been a member of the Board of Directors of the Canadian Organization for Rare Disorders (CORD) and is involved with Rare Disease International and the International Rare Disease Research Consortium’s Task Force on Clinical Research Networks. She is an enthusiastic patient partner in a number of research studies, including a co-investigator on two pan-Canadian studies in paediatric rare diseases and a principal investigator in a systematic review of coaching for shared decision making. Maureen co-led the patient engagement strategy for the development of core outcome sets in two rare inherited metabolic diseases and is now working on the implementation phase. For the past six years, Maureen has been involved in health technology assessment for both drugs and devices as a patient member on two provincial bodies.



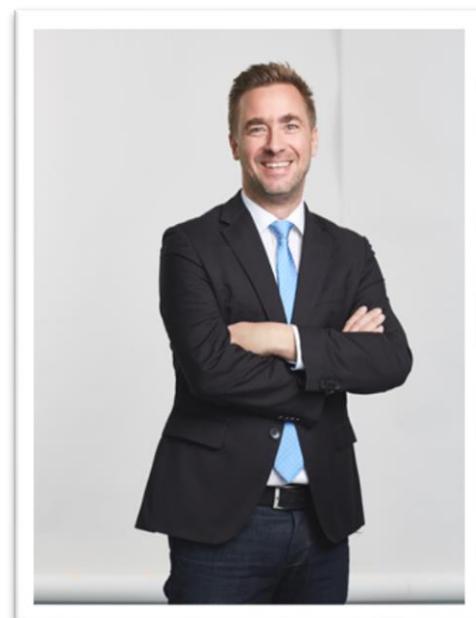
Doreen Tembo:

Doreen is the Senior Research Manager for Patient and Public Involvement and External Review at the National Institute for Health Research (NIHR) Evaluations Trials and Studies Coordinating Centre in the UK and the NIHR Co-Chair for the NIHR Global Health Research Community Engagement and Involvement Working Group. Doreen sits on various advisory groups for NIHR INVOLVE, the national advisory group for the promotion and support of public involvement in research funded by NIHR.

Doreen's early career was spent working with NGO's and international development agencies in Zambia. After studying and working in the area of international social policy in Oxford, Doreen joined the University of Essex, School of Health and Human Sciences and the NIHR Research Design Service (RDS) in 2010 where she worked as a consultant in mixed-methods research design and patient and public involvement. Doreen carries out research and publishes on community and public involvement and engagement as well as health research.

**Jan Geissler:**

Jan Geissler is the founder and CEO of Patvocates, a think tank on patient advocacy, health policy and medical research. He was the Director of the European Patients Academy (EUPATI) from 2012-2017 and still leads the EUPATI FUTURES Team and the German EUPATI platform. Jan is a work package leader of the new IMI2-funded EU Project HARMONY on big data for better outcomes in hematology. A leukemia survivor since 2001, Jan co-founded the patient organisations LeukaNET/Leukaemie-Online.de in 2002, the European Cancer Patient Coalition in 2003, the CML Advocates Network in 2007, and the Leukemia Patient Advocates Foundation in 2011. Jan represents patients on a number of advisory boards and committees, e.g. ECCO, ESMO, ISPOR, Berlin Institute of Health and the International CML Foundation. He is a member of the EHA's European Affairs Committee and the European Reference Network EuroBloodNet.



Jean Slutsky:

Jean R. Slutsky is the Chief Engagement and Dissemination Officer at the Patient-Centered Outcomes Research Institute (PCORI). She leads PCORI's Engagement Program and growing dissemination and implementation planning efforts. She also serves as Director of PCORI's Communication and Dissemination Research Program.

Before joining PCORI, Jean directed the Center for Outcomes and Evidence at the Agency for Healthcare Research and Quality, where she conceived and implemented the Effective Health Care program. The Effective Health Care program is an integrated program of research, stakeholder engagement, research training, and dissemination and implementation of comparative effectiveness research. Jean is particularly interested in pragmatic user-driven research and its implementation into healthcare decision making.

Jean received her baccalaureate degree from the University of Iowa, trained as a Physician Assistant at the University of Southern California, and received a MSPH in health policy from the University of North Carolina at Chapel Hill.

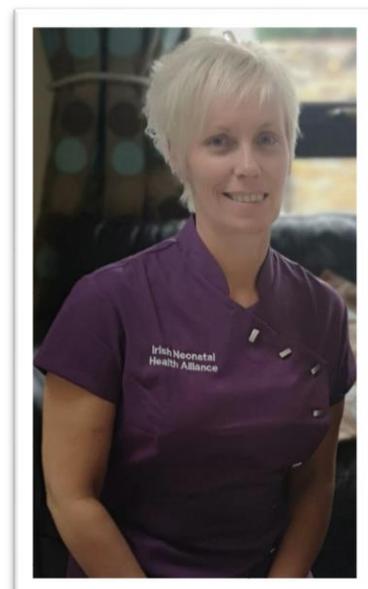


Mandy Daly

Mandy Daly is one of the founding members and the Director of Advocacy and Policy Making at the Irish Neonatal Health Alliance. She also sits on the board of EFCNI and the NIDCAP Federation International. The INHA platform partners with healthcare professionals, educators, industry partners, government officials and researchers and is patient collaborator on several research studies with the Health Research Board Mother and Baby Clinical Trials Network, the Neonatal Brain Consortium of Ireland and the Infant Centre in Cork as well as partnering with international researchers.

Mandy was a member of the international consortium who developed the European Standards of Care for Newborn Health which were launched in 2018.

Mandy has worked with 10 neonatal core outcome set studies, providing a patient organisation perspective. She has also participated in COMET's work around Standards for Reporting a Core Outcome Set and Minimum Standards for Core Outcome Sets.



Heather Bagley:

Heather is a part time Patient and Public Involvement (PPI) co-ordinator with the COMET Initiative at the University of Liverpool, UK. Heather originally trained as a nurse but has worked in research and National Health Service (NHS) service improvement for the majority of her career.

Heather is also a public contributor in research and attended the first COMET meeting in that role. Heather is keen to develop resources to support researchers involving patients in core outcome sets (COS) either as public research partners or as participants in COS studies. She also wants to raise awareness about COS, the COMET Initiative and the importance of patient involvement / participation.

Heather is undertaking a PhD in Optimising Patient Participation in Core Outcome Set development.

