



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 former 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.

She is co-chair of the PoPPiE Working Group



Maarten de Wit:

Maarten de Wit (1961) 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.



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.



Dr Gary Hickey:

Gary is a Senior Public Involvement Manager at the Wessex Institute, University of Southampton. He is leading on the development of a Digital Centre for patient and public participation, involvement and engagement.

He is also working, on secondment, as a Senior Research Manager for the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre, within their Patient and Public Involvement and Engagement Team driving forward on community involvement and engagement in research.

He is a leading voice on co-production and while working as a Senior Public Involvement Manager at INVOLVE, led on the development of guidance on [Co-producing a research project](#). And while at the Research Design Service South East he hosted a podcast series, '[That Co-production Podcast!](#)', in which guests discuss themes and issues related to co-production.

He is also a founding member of the International Patient and Public Involvement Network and has been involved in a series of [webinars](#) designed to share information and knowledge about effective patient and public involvement in research



Courtney Coleman:

Courtney Coleman coordinates patient involvement and engagement at the European Lung Foundation, working in partnership with respiratory patients, carers and patient organisations to ensure that people affected by a lung condition have the opportunity to influence treatment and care at a European level. Courtney collaborates closely with scientific and clinical members of the European Respiratory Society, making sure that patient perspectives inform clinical practice guidelines, medical education and respiratory research.

Courtney oversaw patient input into the core outcome sets for the management of chronic obstructive pulmonary disease (COPD) exacerbations and for severe asthma. As part of the severe asthma core outcome set, Courtney undertook a systematic review of qualitative literature to better understand patient experiences of living with severe asthma and supported a patient-facing survey to capture preferences on different outcome measures. Courtney has worked in the field of patient and public and service-user involvement for almost 10 years.

**Heather Barrington:**

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.

