



## People and Patient Participation, Involvement and Engagement (PoPPIE) Working Group

### Members' biographies

#### **Rosemary Humphreys:**

Formerly, I was a teacher and then a manager in higher education and professional organisations.

While volunteering with the National Eczema Society I joined the Cochrane Skin Group and began to represent patients in dermatology research. I have since worked with many organisations to encourage and develop Patient and Public Involvement (PPI) in both research and patient care.

I became involved with COMET through membership of HOME (Harmonising Outcome Measures for Eczema) and spoke at 'COMET – Involving the Public' and at COMET IV. I believe COS to which patients have contributed are essential to make research more useful and accessible.

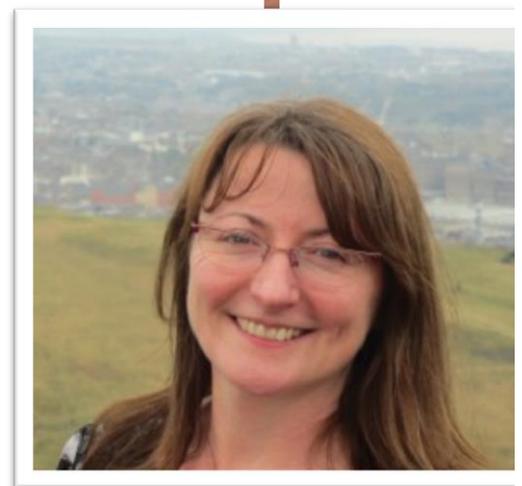
I am co-chair of the PoPPIE Working Group.



#### **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.

I am 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.



### **Simon Denegri:**

Simon Denegri is National Director for Patients and the Public at the National Institute for Health Research (NIHR), and Chair of INVOLVE – the national advisory group for the promotion and support of public involvement in research funded by NIHR. He was Chief Executive of the Association of Medical Research Charities (AMRC) from 2006 until 2011 and, prior to this, Director of Corporate Communications at the Royal College of Physicians from 2003. He also worked in corporate communications for Procter & Gamble in the United States from 1997 to 2000. He has a long-standing personal and professional interest in the needs and priorities of people with dementia and their carers and currently chairs the Lay Champions Group for the national portal on dementia research that is to be launched this year. He is a member of the NIHR Advisory and Strategy Boards, and a Board member of the UK Clinical Research Collaboration (UKCRC), Farr Institute and care. data programme respectively. He blogs about the public and health research at: <http://simon.denegri.com/> and publishes his poetry at <http://otherwiseknownasdotcom.wordpress.com/>



### **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, Slutsky 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. Slutsky is particularly interested in pragmatic user-driven research and its implementation into healthcare decision making.

Slutsky 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.



### **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.

