

Finding What Works in Health Care: Updating Standards for Systematic Reviews

Engagement Methods for Systematic Reviews

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Helen Bulbeck has experienced cancer from both a caregiver and patient perspective. This 360 degree view means that she is well placed to understand the perspectives of patients, caregivers and health care professionals and is skilled in PPI advocacy. Her roles in brainstrust, a national brain cancer charity which she founded, and as a consumer representative are as a disseminator of information and the provision of a network and community, so that she can provide advice on achieving effective consumer involvement and creating a voice. Helen's key drivers are the patients, their caregivers and healthcare professionals, with whom she interacts daily. Her ethos of 'none of us is as smart as all of us' is a core value for her. Elemental to Helen's work is high performance coaching and shared decision making. When we are no longer able to change a situation we are challenged to change ourselves. The coaching relationship enables us to face these challenges, so that we learn how to develop resilience and utilise resources, becoming true co-pilots in our care.

Trish Greenhalgh is Professor of Primary Care Health Sciences and Fellow of Green Templeton College at the University of Oxford. She studied Medical, Social and Political Sciences at Cambridge and Clinical Medicine at Oxford before training first as a diabetologist and later as an academic general practitioner. She has a doctorate in diabetes care and an MBA in Higher Education Management. Her research sits at the interface between the social sciences and medicine. Her work seeks to celebrate and retain the traditional and the humanistic aspects of medicine and healthcare while also embracing the exceptional opportunities of contemporary science and technology to improve health outcomes and relieve suffering. Three key interests are the health needs and illness narratives of minority and disadvantaged groups; the introduction of technology-based innovations in healthcare; and the complex links (philosophical and empirical) between research, policy and practice. She is currently developing novel synthesis methods for complex evidence, based on hermeneutic principles and supported by AI. Trish is the author of over 500 peer-reviewed publications and 16 textbooks. She was awarded the OBE for Services to Medicine by Her Majesty the Queen in 2001 and made a Fellow of the UK Academy of Medical Sciences in 2014. She has also been elected to Fellowship of the UK Royal College of Physicians, Royal College of General Practitioners, Faculty of Clinical Informatics, Faculty of Public Health and Faculty of Medical Leadership and Management. In 2014 she was awarded International Fellowship of the United States National Academy of Medicine for "major contributions to the study of innovation and knowledge translation and work to raise the profile of qualitative social sciences".

Dr. Deborah Marshall is a health economist and health services researcher leading a programme of applied research using patient preferences, patient engagement and simulation modelling methods. Dr. Marshall is also the Svare Chair in Health Economics, Value and Impact, University of Calgary. Dr Marshall leads the health economics, socioeconomic benefits, patient

preferences and patient engagement activities for several national and international research programmes (funded by CIHR and/or Genome Canada) in precision health and patient-oriented research to develop health economic tools and approaches to evaluate outcomes. She is the former chair of both the Arthur J.E. Child Chair of Rheumatology Outcomes Research; and Canada Research Chair, Health Services and Systems Research (2008 - 2018). Deborah also holds various memberships in University of Calgary and Alberta Health Services. Deborah is a founding co-investigator of the innovative Patient and Community Engagement Research (PaCER) programme at the University of Calgary which trains patients to design and conduct health research, using specific adapted methods of qualitative inquiry. She is an active member of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) as the current chair of the Health Science Policy Council (HSPC), the Past President of the Board of Directors, the Chair of the Dynamic Simulation Modeling Applications in Health Care Delivery Research Task Force and as a member of the Patient Preferences Special Interest Group, the Optimization Methods Task Force and co-author of related ISPOR Task Force Reports. She has also served as a member of the Board of Directors for Health Technology Assessment International (HTAi) and is a member of the HTAi Patient Preferences Working Group. She was co-chair of the Scientific Research Committee and Board of Directors of the Arthritis Alliance of Canada (AAC), and the Scientific Advisory Committee of the Alberta PROMs & EQ-5D Research & Support Unit (APERSU). She is a founding member of the Global Economics and Evaluation of Clinical Genomics Sequencing Working Group (GEECS).

Jennifer Petkovic is the Coordinator of the Campbell and Cochrane Health Equity Thematic Group and the MuSE Consortium. She is an Affiliate Investigator at the Bruyère Research Institute. Jennifer earned her PhD in Public Health at the University of Split in Croatia in 2017 and her MSc in Population and Public Health (Global Health) from Simon Fraser University in 2007. Her research interests include systematic review methods for disadvantaged populations, engagement in research and guidelines, and knowledge translation.

Jaime Sanders is the author of the award-winning blog *The Migraine Diva* and the book *More Than Migraine: A Journey Through Pain, Advocacy, and Hope*. She is a participant with the Coalition for Headache and Migraine Patients, with whom she worked to create an Issue Brief on Disparities in Headache and served as part of the leadership of the Disparities in Headache Advisory Council (DiHAC). Jaime is a stakeholder with the Headache and Migraine Policy Forum, worked with the Society for Women's Health Research Interdisciplinary Migraine Network, sits on the Patient Leadership Council with the National Headache Foundation, and served on HealthyWomen's Chronic Pain Advisory Council. She has lived with migraine since the age of two and has been chronic and intractable for the last eighteen years. Through her advocacy work and blog, Jaime's mission is to make a very invisible disease visible to the rest of the world and validate the real pain of millions.