



Interested but challenged by patient and public involvement? Practical ways to develop high quality patient-oriented guidelines.

August 25, 2010, Chicago, USA

Background

There is growing recognition and evidence that patients can play important roles in improving the quality of healthcare. Efforts are increasingly under way to involve them in systematic reviews, clinical practice guidelines, performance measurement, and other quality improvement activities. However, patient and public involvement pose a number of practical and methodological challenges for guideline organizations:

- How to ensure that patients contribute competently and confidently to guideline development and implementation?
- How can guidelines be communicated in a meaningful way to patients and the public?
- How to develop a structured patient and public involvement program that is in line with the mission, resources, and context in which guideline organizations operate?

Course aim and target audience

This course will support mentoring and exchange between guideline organizations that have different levels of experience with patient and public involvement. It will offer opportunities for guideline organizations to discuss challenges and explore practical solutions to foster the development of high quality patient-oriented guidelines.

Preliminary program

Workshop co-chairs:

- *Kay Dickerson. Professor of Epidemiology, Johns Hopkins University. USA.*
- *Gill Gyte. Cochrane Pregnancy and Childbirth Group, United Kingdom.*

9h-9h30: Welcome and introduction

Antoine Boivin. Guideline International Network Patient and Public Involvement Working Group

9h45-12h15. Recruitment and training to support patient participation in guidelines

Jane Cowl and Sarah Chalmers. National Institute for Health and Clinical Excellence
Carol Sakala, Childbirth Connection, USA

Lunch

13h30-14h45: Communicating guidelines and evidence to patients to support informed and shared decision-making

Trudy van der Weijden. Maastricht University

15h-16h: Concluding remarks and plenary discussion

Speakers' biography

Kay Dickersin, PhD, is professor of Epidemiology, at Johns Hopkins University, and Director of the U.S. Cochrane Center. Dr. Dickersin's major research interests are related to randomized clinical trials, trials registers, systematic reviews and evidence-based health care. She has developed Project LEAD (leadership, education, and advocacy development), a science course for breast cancer activists. (...)

Gill Gyte has worked with the Cochrane Pregnancy and Childbirth Group since 1997 bringing women's views to the Cochrane reviews in that group. She is very interested in guideline development and dissemination, and has been a consumer representative on two NICE guidelines and one WHO guideline, and commented as a consumer on a number of others guidelines. Gill received the 2003 Chris Silagy Prize in recognition of her contribution to the Cochrane Collaboration.

Antoine Boivin, MD, PhD(c), is chair of the Guideline International Network Patient and Public Involvement Working Group, and a doctoral candidate at the Scientific Institute for Quality of Healthcare. His research interests focus on patient and public involvement in quality improvement. Dr Boivin is currently leading a cluster randomized trial of public involvement in quality indicator prioritization in Canada, and is co-principal investigator with Dr France Légaré on a knowledge synthesis of patient involvement in guideline development and implementation.

Trudy van der Weijden, MD, PhD is appointed as professor in Implementation of Clinical Practice Guidelines at the department of General Practice of Maastricht University. Her studies are about knowledge transfer; defining and describing quality of care, and improving quality of care through implementation of guidelines and innovations. Her research has a specific focus on the patient perspective and patient participation in medical decision making where the tension is felt between rationalizing work (the application of guidelines) and patient-centered work (the practice of the consultation). She is currently leading an international qualitative study on the integration of patient decision aids and clinical practice guidelines.

Jane Cowl is a programme manager at NICE (National Institute for Health and Clinical Excellence), providing advice and support on patient and public involvement, including running training programmes. She leads on work involving lay people in developing public health guidance, building on NICE's experience in clinical guidelines. Jane has a background in consumer health advocacy and social science teaching. She has run health advocacy services, research projects and campaigns, and was the lead for consumer issues in the national team that promoted the development of woman-centred maternity services. Jane is currently completing a master's degree in conflict resolution.

Sarah Chalmers, MA, MSc, is a project manager working in public involvement in the development of guidelines at NICE. Her work includes recruiting and supporting patient and carer members for guideline development groups working in areas including mental health and women's health, and on the short guidelines programme. She has a background working as a commissioning manager in the English National Health Service, with responsibility for patient engagement, and has also worked in health service improvement research as part of her MSc in healthcare leadership and management.

Carol Sakala, PhD, MSPH, is Director of Programs at Childbirth Connection, a National U.S. not-for-profit Organization that Works to Improve the Quality of maternity care Through research, education, advocacy and policy. She is involved with Clinical effectiveness activities, including systematic reviews, performance measurement, practice guidelines, and informed decision-making. She is a member of the Guidelines International Network Patient and Public Involvement Working Group Steering Committee.

Registration

This full day pre-conference course will be held on August 25, 2010, before the 7th G-I-N conference in Chicago. Registration fees are 200\$US (G-I-N members), 300\$ (non G-I-N members), and 100\$ (consumers and students). **Registration deadline is June 25 and the maximum number is set at 50 participants.**

You can register here: http://www.gin2010.org/?page_id=253

Organizers

This course is organised by the Guideline International Network Patient and Public Involvement Working Group (G-I-N PUBLIC) and sponsored by the National Institute for Health and Clinical Excellence (NICE). G-I-N PUBLIC (www.ginpublic.net) is an official working group of the Guideline International Network, an international not-for-profit association of organizations and individuals involved in the development and use of clinical practice guidelines. NICE (www.nice.org.uk) is an independent organization in the United Kingdom responsible for providing national guidance on promoting good health and preventing and treating ill health.

Scientific committee members:

- Antoine Boivin, MD, PhD (c). Chair, Guideline International Network Patient and Public Involvement Working Group. Doctoral Candidate, Scientific Institute for Quality of Healthcare. Canada.
- Carol Sakala, PhD. Director of Programs, Childbirth Connection. USA.
- Victoria Thomas, MSc. Associate director. Patient and Public Involvement Program. National Institute for Health and Clinical Excellence (NICE). The United Kingdom.
- Mary Nix. Project officer, Center for Outcomes and Evidence, Agency for Healthcare Research and Quality. USA.
- Kay Dickersin, PhD, Director, U.S. Cochrane Center, and Professor of Epidemiology, Johns Hopkins University. USA
- Linda Pinsonneault, MD, FRCPC. Medical advisor, Agence d'évaluation des technologies et des interventions en santé. Canada.
- George Browman, MD, MSc, FRCP(C), Chair, Canadian Partnership against Cancer Guidelines Action Group, and clinical professor, University of British Columbia, Canada.
- Jako Burgers, MD, PhD. Senior researcher. Scientific Institute for Quality of Healthcare. The Netherlands.