

Workshop Summary

Close Encounters of a Third Kind? Involving Patients and Consumers in Guideline Development: A Joint Workshop of G-I-N PUBLIC and CUE (Consumers United for Evidence-based Healthcare)

Philadelphia, Pennsylvania
Tuesday, September 27, 2016

Workshop organizers and speakers:

Members of G-I-N Public:

Corinna Schafer
Melissa Armstrong
Jane Cowl

Members of CUE:

Kay Dickersin
Reva Datar
Brenda Shelton-Dunston
Ann Fonfa

Aims and objectives: Involving patients and/or consumers is considered a quality criterion for guideline development: the IOM or G-I-N standards as well as AGREE II ask for patient involvement. But for many guideline developers, successful involvement still remains a challenge: Where to find patients and/or consumers? How to train them? How to deal with conflicts of interest? This workshop aims at providing practical support and sharing international experience to facilitate successful patient or consumer involvement for guideline developers.

Target audience: Guideline developers, health care professionals or lay people involved in guideline development; with specific interest to learn and share experience how to find and support patients and consumers in guideline groups.

Program:

Time	Title of session
9:00 - 9:30 am	Introduction to the course
9:30 - 10:00 am	Advantages and benefits of involving patients and/or consumers in guideline development
10:00 – 10:45 am	Interactive small group breakout: Sharing of individual goals and resource challenges
10:45 – 11:15 am	Refreshments
11:15 – 11:45 am	Finding and recruiting patients: Designing and implementing an effective recruitment plan
11:45 am – 12:30 pm	Individual patients or patient advocates: What’s right for your organization?
1:30 – 2:00 pm	Empowering and training lay group members: Sharing international experience for successful engagement
2:00 – 2:45 pm	Voices of experience: Patients and consumers share their first-hand account of participating in a guideline development group
2:45 – 3:15 pm	Refreshments
3:15 – 3:45 pm	Alternate methods of engagement: Consultation and communication strategies

Time	Title of session
3:45 – 4:30 pm	Interactive small group breakout: Sharing barriers and methods to overcome them
4:30 – 5:00 pm	Wrap up and evaluation

CUE’s contributions: The workshop participants were internationally diverse, with varying levels of experience and understanding of consumer engagement in research implementation. The program (1 day in length) was relatively informal, with time in each session for presentation by one or more of the organizers and discussion. G-I-N Public members presented their own work as those who organize guidelines panels, and work with G-I-N members to engage consumers as part of the process. CUE staff and members presented work CUE has done to prepare consumers for participation of guidelines and research implementation advisory panels. Two CUE members, Brenda Shelton-Dunston, of the Black Women's Health Alliance, and Ann Fonfa, of the Annie Appleseed Project, shared their experiences serving on guideline development groups in a 45-minute session (2:00 – 2:45 pm, *Voices of experience: Patients and consumers share their first-hand account of participating in a guideline development group*). They also answered questions from health professionals looking to engage consumers on panels. A video featuring their perspectives is available on the CUE YouTube channel: (<https://www.youtube.com/watch?v=Tujm39Z7gmw>) and the CUE website (<http://consumersunited.org/node/55>). Thus, the workshop incorporated consumers as both organizers/speakers/leaders and as participants.

Evaluations:

Seventeen participants signed in during the workshop and another 10 were registered but did not sign in. We emailed evaluations to the 17 who provided email addresses via sign in, and received nine evaluations in response. The evaluations asked that participants rate the overall quality of the workshop and the quality of the small group breakout session on a 5 point scale with a “1” indicating the lowest score of “poor” and a “5” indicating the highest score of “excellent.” The overall quality of the workshop was evaluated using three categories: informative content; adequate time allotted; and questions answered to satisfaction. All three items were rated as above average: The mean score for each category was 4, 3.7, and 4.1, respectively. The small group breakout session was evaluated using two categories: whether participants learned from what others talked about and whether participants had enough time to present their own perspective. As before, the items were rated as above average: the mean score for each category was 4.1 and 3.8, respectively. According to evaluations, all participants believed that the program was presented without evident commercial bias or influence and that it met their expectations. Evaluations included one qualitative comment: “I enjoyed the session. It was helpful to hear what the other groups are doing.”