

Workshop title: Developing a local coalition of consumer advocacy groups

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The Cochrane Collaboration is committed to involving consumers in every phase of its work, and the Cochrane Consumer Network (CCNet) enables this process by supporting communication, training and guidance. As with the rest of the Collaboration, much of the work of CCNet occurs via electronic communication. While health professionals have opportunities for forging links at conferences and other venues, consumers and consumer advocates have fewer opportunities for establishing partnerships and forwarding their agendas collaboratively. Furthermore, advocates who are committed to evidence-based healthcare (EBHC) and who understand the importance of consumer participation in the informed healthcare decision-making processes, have had no standing forum for meeting outside Cochrane. Consumer interests span health conditions and topic areas and thus they are currently unlikely to cross paths with consumers from different disease areas.

Consumers United for Evidence-based Healthcare (CUE) is a US-based coalition of health and consumer advocacy organizations committed to empowering consumers to make the best use of EBHC. The mission of CUE is to promote the health of populations and the quality of individual health care by empowering consumers, public health policy makers, and health care providers to make informed decisions based on the best current evidence through research, education, and advocacy. CUE was started in 2003 by the United States Cochrane Center (USCC), as a partnership between consumer advocacy groups and scientists involved in EBHC. Membership is now at 27 organizations and growing.

Initial funding from the Agency for Healthcare Research and Quality (AHRQ), has enabled the USCC to nurture CUE's development and to provide a secretariat and staff. CUE is guided by an elected Steering Committee providing overall direction, policy development, and program management. CUE has hosted an annual meeting, an online course on evidence-based healthcare, and other projects. Members have engaged in CCNet and other EBHC activities, and have brought EBHC back to their constituencies.

This workshop will present a history of the development of CUE, with lessons learned for others wishing to form consumer coalitions in their own regions. We will provide an outline of an approach that has worked for us, resources required, and ongoing challenges. Discussion will center on regional variations and possible approaches.