Role of Consumers in Guideline Development Process

Samantha Anne, MD, MS¹ and Richard Rosenfeld, MD, MPH²

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

Abstract
Clinical practice guidelines (CPGs) inform patient care by providing recommendations based on a thorough examination of risks and benefits of medical care or intervention. With the ever-increasing importance placed on shared decision making, and because of the valuable perspective on patient-related topics and patient-centered outcomes, consumers of health care have been incorporated in the American Academy of Otolaryngology—Head and Neck Surgery Foundation CPG development process. Consumers bring a unique perspective and add transparency to the guideline development process. In addition, they are instrumental in formulating patient-friendly recommendations that are easier to understand. Studies that have been done to evaluate the role of consumers in the CPG development process found that consumers had a positive impact. In addition, studies report that consumers felt adequately prepared after appropriate training and education on the process. Further studies are needed to understand how to best engage, train, and educate consumers in future guidelines development.

Keywords
guideline development, consumer involvement

Received February 1, 2018; accepted March 8, 2018.

Do Consumers Enhance Guidelines?
Consumers have now been involved in the American Academy of Otolaryngology—Head and Neck Surgery Foundation (AAO-HNSF) clinical practice guideline (CPG) process for nearly a decade. The main question that arises from health care providers regarding involvement of the consumers in the process is whether the consumers (defined as recipients of health care) added anything meaningful to the process, considering that many of them lacked a medical background and/or formal training in the guideline process. This question prompted us to evaluate the existing evidence on consumer involvement in guideline development process.

Guidelines and Consumer Engagement
The Institute of Medicine defines CPGs as “statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.”¹ Acceptance by consumers of recommendations made in these guidelines depends on their ability to participate in the shared decision-making process. The need for greater transparency in guideline development, while managing conflicts of interests and presenting more consumer-friendly recommendations, prompted the Guideline Development Task Force to incorporate consumers as full members of the guideline development group.²

Two international societies that advocate for consumer engagement in guidelines and systematic reviews are the Guideline International Network (GIN) and the Cochrane Collaboration. GIN is a global network of organizations and individuals interested in guidelines that serves to facilitate collaboration and networking to create high-quality CPGs. GIN Public is a working group of GIN composed of researchers, health professionals, and public representatives that was created solely to support consumer engagement in CPG development. In their “Toolkit on Patient and Public Involvement in Guidelines,” first published in 2012 and revised since in 2015, the authors compiled advice on how best to recruit, train, and involve consumers in guideline development and implementation. The toolkit includes information on how the chair can best facilitate consumer involvement and how to best involve consumers in creating patient versions and dissemination of guidelines. Similarly, Consumers United for Evidence-Based Healthcare, a branch of the US Cochrane Center, is a partnership among consumers and scientists that works to strengthen the consumers’ voice in health science research and evidence-based medicine.

¹Cleveland Clinic, Cleveland, Ohio, USA
²SUNY Downstate Department of Otolaryngology, Brooklyn, New York, USA

Corresponding Author:
Samantha Anne, MD, MS, Assistant Professor of Surgery, Medical Director, Pediatric Ear & Hearing Disorders Pediatric, Otolaryngology, Head & Neck Institute Cleveland Clinic, 9500 Euclid Ave A71, Cleveland, OH 44195, USA.
Email: annes@ccf.org
Hanley et al describe levels of participation in terms of consumer involvement in health care. They describe consumer involvement as consultation, collaboration, and user controlled. Consultation is when the consumers are asked for their views, and this information is used in the decision-making process. However, this does not always mean that the views are incorporated into the final product. Collaboration is when there is an active participation and partnership with consumers. The use of consumers in the AAO-HNSF CPGs largely follows this model of participation. Lastly, user controlled is when the consumers are largely the primary leaders in the project with professionals invited at the consumers’ discretion. A Cochrane review has been completed to study the effects of consumer involvement and to compare the different ways the consumers are involved. The review found 6 randomized controlled trials; most trials compared consults with consumers with no consults with consumers. The authors found moderate-quality evidence that shows that consumer involvement resulted in material that is more relatable to patients. In addition, this material created with consumer involvement was shown to improve patients’ knowledge.

In terms of addressing the concern about the lack of medical backgrounds in many of the consumers involved in the guideline development process, there have been studies that report successful incorporation of consumers with provision of adequate training and support. Williamson defined 3 ways to incorporate patients into working groups: patients themselves, members of organized groups of patients, or patients who advocate for patients. The study by van Wersch and Eccles shared experiences with these 3 ways of patient involvement in guideline development in addition to the fourth way in which guidelines were discussed with group of patients after completion. The authors conclude that consumers need support and training, but it is feasible to understand the elements of CPG development. Similarly, Robertson et al reported their experience with use of consumers. This group identified consumers through a consumer advocacy alliance and employed 2 consumers for each guideline panel. To help the consumers acclimate and understand the process, the group provided education about the process and outlined expectations. These authors also report that they feel consumers can bring valuable insight and perspective to the guideline process and have improved the ultimate product.

Based on the few studies that exist, it seems consumer involvement does bring value to the guideline development process. In addition, education and training opportunities can prepare consumers to be active participants even if they do not have the medical background for the specific topic under discussion. There is room to understand this further, and future studies are needed to study how best to engage the consumers and how best to train them to be prepared for the process.

Conclusions

There is mounting evidence that using consumers in the CPG development process is helpful in incorporating patient perspective, making the process more transparent, and developing related literature that is more patient friendly. As we increasingly move toward the practice of medicine based on shared decision making and patient-centered care, continued incorporation of consumers into the guideline development process seems logical and appropriate.

Author Contributions

Samantha Anne, design, acquisition, interpretation of data, drafting of manuscript, final approval, and agreement to be accountable; Richard Rosenfeld, guidance on design, research material, data contribution, manuscript revision and writing, final approval and agreement to be accountable.

Disclosures

Competing interests: None.

Sponsorships: None.

Funding source: AAO-HNS Foundation G-I-N Scholar Grant; no influence on design, conduct, collection, analysis, interpretation of data, or writing/approval of manuscript.

References