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What is This?
Patient-centered Guideline Development: Best Practices Can Improve the Quality and Impact of Guidelines

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

Abstract
Guideline development is improved when diverse stakeholders, including patients, specialists, and experts, share power in the process, from defining the scope of the question to the final stages of review. The Institute of Medicine (IOM) and Guidelines International Network (G-I-N) have each released best-practice standards for clinical guidelines that place health care consumers at the forefront of guideline development. The AAO-HNSF has placed a growing emphasis on consumer engagement in its latest guideline development manual and has developed clear, multifaceted infrastructural approaches to identify and utilize consumers in guideline development and guideline review. This article reviews those recommendations and emphasizes that patient-centered guideline development can improve the quality and impact of medical guidelines.

Keywords
patient-centered guidelines, guideline development

Introduction
Patient-centered care is more than a buzzword. Patients are increasingly regarding themselves as consumers of health care and are interested in ensuring the product they are purchasing is in fact improving their health.1 This interest extends from the bedside to the level of policymaking,2 where patient engagement in health care decisions can both lead to better health outcomes and help control health care costs.3 This profound shift toward patients and consumers in health care is perhaps most notable in the establishment by the Affordable Care Act (ACA) in 2010 of the Patient-Centered Outcomes Research Institute (PCORI). The institute’s mission is to ensure that consumers and the public have information to make decisions in order to reflect desired health outcomes. PCORI engages in comparative clinical effectiveness research to examine the relative health outcomes, efficacy, and appropriateness of medical treatments from a patient perspective.4

The movement toward patient and consumer engagement has led to significant changes in the methodology of guideline development. Recently, both the Institute of Medicine (IOM) and the Guidelines International Network (G-I-N) have published standards for guideline development that reflect the importance of patient involvement.5,6 Yet in a recent review, only 7.4% of guidelines published over the past 2 decades in the United States included patient/consumer involvement.7 Here we review the evidence and recommendations for patient involvement in guideline development from the IOM and G-I-N and discuss how the American Academy of Otolaryngology—Head and Neck Surgery Foundation (AAO-HNSF) has adopted these practices throughout the process of guideline development.8

Institute of Medicine Recommendations
In 2011, the IOM published “Clinical Practice Guidelines We Can Trust,” a report intended to provide standards for developing rigorous, trustworthy guidelines. The report discusses consistent evidence suggesting that group composition influences recommendations in guideline development. Heterogeneity in a decision-making group can lead to additional clarity and creativity, more strategic decisions, and fewer assumptions about shared values than homogeneity. The report argues that including consumers in the process of guideline development fosters a heterogeneous group dynamic and makes for more universally applicable, multidisciplinary guidelines.

The IOM report describes 3 specific levels of impact that consumer engagement can have on the process of guideline development. First, when patients are involved, there is increased transparency, which is essential to attaining buy-in...
from all stakeholders. Consumers need to know that guidelines are not developed “behind closed doors” in accordance with any special interests of the drafters. Patients help to safeguard against conflicts of interest that may skew the guideline recommendations. Second, patient involvement helps define the scope of the problem being addressed and focuses the recommendations on achieving patient-centered outcomes. Third, consumers play an important role in making the guideline recommendations comprehensible, which can increase adherence to the recommendations.

Methodologically, the IOM recommends that current or former patients or consumer organization representatives should facilitate patient and public involvement throughout the guideline development process. Simple selection criteria can be used to choose consumers who will consider evidence objectively, act in the interest of all patients, and not be unduly influenced by personal experience. Guideline development groups should employ strategies such as training consumers in appraisal of evidence to increase effective participation in writing the guidelines. Once a draft is complete, patients and representatives of the public should be on the board of external reviewers along with scientific and clinical experts, organizations, and agencies. In addition, guideline drafts at the external review stage should be made available for general public comment.

Guidelines International Network Recommendations

The G-I-N is an organization composed of a network of people devoted to the science of guideline development, adaptation, and implementation.9 In a position piece on key components of the guideline development process, G-I-N emphasizes that best practices in guideline development dictate that patients and health care consumers should be intimately involved.6 While G-I-N acknowledges that there is not necessarily consensus on the most effective form of patient participation in guideline development, their position is that patients should be involved from the very beginning phase of formulating key questions, the most important phase in the process. To this end, G-I-N has a Patient and Public Involvement Working Group (G-I-N PUBLIC), which consists of consumers, developers, and researchers that supports effective patient and public involvement in guideline development.

AAO-HNSF Guideline Development

The AAO-HNSF is a leader in guideline development among specialty societies. Through the work of the Guidelines Task Force, the AAO-HNSF has authored more than 10 clinical practice guidelines. In addition, the AAO-HNSF recently published the third edition of its guideline development manual.8

The AAO-HNSF has incorporated patients into nearly every phase of guideline development. Patients and consumer groups are an integral part of the guideline development groups (GDGs), which help formulate the questions, define and rank quality improvement topics, review the clinical evidence, and formulate the action statements. Often, consumers participate as either primary or secondary authors of key action statements supporting guideline text, which dictate what clinicians should and should not do according to the compiled research. Consumers are also involved in reviewing and editing guideline manuscripts. Additionally, consumer advocacy organizations are invited, along with other guideline stakeholders, to participate as a board of 30 to 40 reviewers for external peer review. Finally, consumer organizations are solicited for input and review during a 2-week public comment period after the guideline manuscript is publicly available.

AAO-HNSF GDGs include consumers and representatives to consumer advocacy organizations who serve as experts in advocating for the public, patients, and their proxies. Consumers are often identified through collaborative relationships with consumer advocacy organizations or specific health associations for particular diseases. For instance, the AAO-HNSF partnered with the American Tinnitus Association (ATA) in order to find patients for the development of the tinnitus guideline.

An increasingly important source for patient and consumer involvement in guideline development is Consumers United for Evidence-based health care (CUE), a project of the US Cochrane Center.10 CUE empowers consumers through training, meetings, projects, and outreach in order to disseminate evidence-based findings to improve consumers’ ability to engage in and demand high-quality health care. The coalition encourages its members to collaborate in systematic reviews of health care interventions.

The Future of Guideline Development

Guidelines are most trusted and therefore best disseminated and implemented when they are sensitive to the needs and experiences of health care consumers. A robust methodology for engaging patients throughout the process can help mediate possible misunderstanding and disagreement from stakeholders. Ultimately, engaging patients’ perspectives will lead to better adherence to more accessible, unbiased guidelines and will improve the quality of care with greater cost efficiency.

The partnerships between institutions that write guidelines such as the AAO-HNSF and organizations like CUE are crucial for ensuring that consumers are informed and help inform guideline development. These partnerships will become increasingly important as guideline development becomes more standardized through the work of institutions like the IOM and G-I-N.

Author Contributions

Benjamin R. Roman, conception and design; acquisition, analysis, and interpretation of data; drafting, revising, and final approval of the manuscript; Jordyn Feingold, analysis and interpretation of data; drafting, revising, and final approval of the manuscript.
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References