

# Consumer & Public Involvement in Guideline Development



AMERICAN ACADEMY OF  
OTOLARYNGOLOGY–  
HEAD AND NECK SURGERY

F O U N D A T I O N

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## Background:

There have been growing calls for increased participation of consumers and members of the public in the development of clinical practice guidelines. The Institute of Medicine's (IOM) 2011 consensus report on trustworthy guidelines called for patient and public involvement in guideline development.<sup>1</sup> Additionally, the Guidelines International Network (G-I-N) called for patients and healthcare consumers to be included in guideline development groups.<sup>2</sup>

## Context:

The American Academy of Otolaryngology-Head and Neck Surgery Foundation (AAO-HNSF) is the world's largest organization representing specialists who treat the ear, nose, throat, and related structures of the head and neck. The AAO-HNSF represents more than 12,000 otolaryngologist—head and neck surgeons who diagnose and treat disorders of those areas. Since 2007, the AAO-HNSF has developed and published 8 clinical practice guidelines. In addition, the AAO-HNSF guideline development manual, which outlines our methodology, has been updated twice.<sup>3</sup> The manual was referenced frequently in the IOM's consensus report.

## Best Practice:

- Consumer s as members of the guideline development group  
Each AAO-HNSF clinical practice guideline development group includes two consumer. Consumers are identified through our collaborative relationships with consumer advocacy organizations, such as Consumers United for Evidence-Based Healthcare (CUE).
- Consumer and public engagement during peer review  
Consumer advocacy organizations are invited to participate during the external review process. In addition, CPGs are made available for review during a period of public comment. The input of consumer advocacy organizations is solicited during this public comment phase.

Guideline development phase	Consumer and Public Involvement
Formulation of guideline development group	Two consumers invited to participate
Development of quality improvement topics (the basis of guideline key action statements)	Quality improvement topics made available for public comment
External peer review of guideline draft	Consumer groups invited to review the guideline draft
Public comment	Consumer groups solicited for input and review of guideline draft

## Lessons:

- Ensures CPGs include the perspective of health care consumers.
- Consumer participation in guideline development has increased the number of guideline key action statements that focus on patient education.
- Consumer input has helped the AAO-HNSF improve our definition of patient preferences and how they are included in each key action statements profile.

1. Institute of Medicine (U.S.). Committee on Standards for Developing Trustworthy Clinical Practice Guidelines., Graham R. *Clinical practice guidelines we can trust*. Washington, DC: National Academies Press; 2011.  
2. Qaseem A, Forland F, Macbeth F, Ollenschlager G, Phillips S, van der Wees P. Guidelines International Network: toward international standards for clinical practice guidelines. *Ann Intern Med*. Apr 3 2012;156(7):525-531.  
3. Rosenfeld RM, Shiffman RN. Clinical practice guideline development manual: a quality-driven approach for translating evidence into action. *Otolaryngol Head Neck Surg*. Jun 2009;140(6 Suppl 1):S1-43.