Consumer & Public Involvement in Guideline Development

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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.¹ Additionally, the Guidelines International Network (G-I-N) called for patients and healthcare consumers to be included in guideline development groups.²

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.³ The manual was referencing frequently in the IOM’s consensus report.

Best Practice:
• Consumers 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.

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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.