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Australia's approach to consumer involvement in the development of breast and ovarian cancer guidelines.

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Background: Consumers should be active partners in decisions about evidence-based practice. This ensures relevance and acceptability of guidelines and provides an additional perspective in the guideline development process. In Australia, meaningful involvement of consumers in the development of breast and ovarian cancer guidelines has been achieved by National Breast and Ovarian Cancer Centre (NBOCC).

Purpose: To describe the methods used to facilitate meaningful consumer input into all levels and stages of the guideline development process. This includes topic identification, development of research questions, guideline writing, external review, endorsement and implementation of guidelines.

Methods: Consumer representatives are members of all advisory and guideline working groups established by NBOCC. In all aspects of these groups, consumers, who are often trained in advocacy skills, have the same role and responsibilities as other professional groups represented. During external review and endorsement, the consumer perspective is sought both through individuals, and organisations which represent women with breast or ovarian cancer. Targeted dissemination strategies encourage consumers to promote implementation of the guidelines.

Results: In 2009, NBOCC conducted a review of its guideline development methodologies. The current high level of consumer involvement was highlighted and recommended to continue. A significant factor in the success of consumer involvement was attributed to the training provided through the Breast Cancer Network Australia 'Seat at the Table' Program.

Two additional recommendations were made to improve consumer involvement:

1. Establishing an online forum that will encourage a wider group of consumers to identify and prioritise topics for future guidelines.
2. Increase transparency of consumer involvement by developing and providing information to the general public about how they can be involved in guideline development.

Discussion: Building on existing consumer involvement by implementing these recommendations, will ensure consumers continue to play an active and significant role in the development of evidence-based clinical practice guidelines.