

Exploring international variation in consumer involvement methods

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Context

- Numerous models of consumer involvement in the development of clinical policies & guidelines exist
- These vary in the perspective sought (individual patient to generic consumer) and the degree of active engagement
- No consensus exists as to the best methods for patient involvement in guideline development
- The evidence base on this issue is currently poor
- Our previous work (e.g. Pagliari & Grimshaw, 2000) suggests that active participation of lay patients in guideline development panels may be constrained by group dynamics; nevertheless stakeholder involvement during development can facilitate implementation

Map of consumer involvement philosophies

Individual patient

Active involvement

Untrained or 'expert' patients with the condition (or their carers) are fully involved in the process of developing the guideline

Specialist consumer advocates from a disease-specific patient organisation actively participate in the process of guideline development

Patients or patient advocates are invited to comment on the completed draft & suggest revisions

Generic consumer organisations are invited to comment on the draft

The guideline or policy is made accessible to members of the public and comments welcomed

Generic consumer

Passive involvement

Research Questions

- What alternative methods of consumer involvement are employed by guideline development organisations across the world?
- What are the perceived benefits and drawbacks of each method (or combinations)?
- Is there any evidence that certain methods are associated with better outcomes (e.g. stakeholder response to dissemination; implementation)?

Pilot Study

- In 2002 SIGN (JT) sent short survey to all 15 members of the AGREE collaboration, asking about their methods of patient involvement, as a means of informing their own strategy

Country & organisation

Do you involve patients in guideline development?

Do you involve carers in guideline development?

Do you involve patients' representatives in guideline development?

If you answered yes to any, how do you involve them?

If you do not currently involve any, are you planning to do this? If yes, when and how?

Respondents

8 organisations from 5 countries responded. 7 completed the questionnaire

- Holland:
 - Dutch College of General Practitioners
 - Dutch Institute for Healthcare Improvement (CBO), Holland
- Germany
 - Association of the Scientific Medical Societies (AWMF)c/o Institut für Theoretische Chirurgie, Germany
 - Agency for Quality in Medicine (Joint institution of the German Medical Association and the Association of the Statutory Health Insurance Physicians), Germany
- Finland
 - Current Care Guidelines (Käypä hoito) and EBMG
- France
 - Standards, Options & Recommendations FNCLCC - Centre ISTAHC
- Spain
 - Fundacio Biblioteca Josep Laporte
- USA
 - National Guideline Clearinghouse, Agency for Healthcare Research and Quality

Pilot study results

- **5** responding organisations involved patients or consumers to some extent (Germany[2], Holland[1], Finland[1], USA[1]), although **2** others described plans to do qualitative work with patients to inform future guidelines (Spain[1], Holland[1])
- Only **3** organisations actively involved patients, carers or patients' representatives as members of guideline development groups (Germany[2], Holland[1])
- **3** reported inviting patients' groups to comments on draft guidelines (Finland[1], USA[[1], Holland[1])
- Comparison - In **Scotland**, SIGN is involving patients, carers and patient advocates as members of guideline development groups and seeking feedback on draft guidelines from patient organisations. In 2003 it carried out a historical review and appraisal of its patient involvement methods as a means of updating its strategy

Forthcoming GIN Survey

- A survey to be dispatched to all GIN members in January will seek more detailed answers to the research questions by exploring
 - **Descriptive information on**
 - who is involved (e.g. random patient, 'expert patient', specialist patient advocate, generic consumer representative)
 - at what stage of guideline development they are involved (e.g. initial evidence gathering vs. post- guideline drafting)
 - how they are involved in the process (e.g. searching for and synthesising evidence, drafting practice recommendations, reviewing recommendations)
 - how they are recruited
 - **Subjective appraisal of**
 - Perceived benefits and costs of patient involvement/alternative methods
 - Facilitators and barriers to consumer/patient engagement and/or involvement
 - **Any objective indicators of**
 - Outcome
 - **Characteristics of different organisations that may influence their strategies**
 - e.g. national vs. local; specialist vs. general

Procedure

- A draft, mixed-format survey instrument will be piloted on five international guideline development colleagues. Following any amendments, it will be distributed to the GIN Coordinator who will email it directly to the Lead at each of the member organisations
- Results and recommendations will be summarised and published on the GIN and SIGN websites. A workshop for GIN members to explore the implications of the results will be held in 2005 and this may be followed by a further exercise to develop consensus-based guidelines on patient involvement

Hoped-for outcomes

- Objective evidence on the nature of patient involvement activities in clinical guideline development across the world, and views on benefits/costs and barriers/facilitators
- Recommendations to facilitate shared learning between member organisations, reduce duplication of effort, guide best practice and aid the development of an agreed methodology for patient involvement

Associated work

- A systematic review of patient/consumer involvement in guideline development has been initiated

We hope you will complete the
survey

Thank you

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