

# Consumer Involvement in Guideline Development

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# 60 Organisations from 33 Countries

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## AMERICA

Guidelines Advisory Committee (GAC), CA  
Progr. in Evidence-based Care, Cancer Care Ontario (PEBC), CA  
Agency for Health Research and Quality (AHRQ), US  
National Kidney Foundation (NKF), US

## ASIA

Prof. Develo. and Quality Assurance, DoH, (PDQA-DoH) HK-SAR  
Japan Council for Quality Health Care (MISC), JP  
ZDRAV Plus Project (ZPLUS), KZ, KG, TJ, TM, UZ  
HTA Unit, Ministry of Health, Malaysia, MY  
Ministry of Health, School of Public Health, TR

## EUROPE

Austrian Association for Quality in Healthcare (evidence.at), AT  
Belgian Centre for Evidence-Based Medicine (CEBAM), BE  
Flemish College of General Practitioners (WVGH), BE  
Danish Centre for Evaluation and HTA (DACEHTA), DK  
Estonian Health Insurance Fund, EE  
Current Care; Finnish Medical Society DUODECIM FI  
Finnish Office for HTA (FinOHTA), FI  
French National Health Authority (HAS formerly ANAES), FR  
National Federation of Cancer Centres (FNCLCC), FR  
Agency for Quality in Dentistry (ZZQ), DE

Agency for Quality in Medicine (ÄZQ/AQuMed), DE  
Association of Scientific Medical Societies (AWMF), DE  
Berlin Chamber of Physicians (AEKB), DE  
Nat.Inst. for Quality Measurement in Health Care (BQS), DE  
Federal Joint Committee (GBA), DE  
Institute for Quality and Efficiency in Healthcare (IQWiG), DE  
The Mental Health Commission (MHC), IE  
Italian Evidence-Based Medicine Group (GIMBE), IT  
Regional Health Agency Emilia Romagna (ASR), IT  
Moldovan Association of Perinatal Medicine, MD  
Dutch Association of Comprehensive Cancer Centres (ACCC), NL

Dutch College of General Practitioners (NHG), NL  
Dutch Institute for Healthcare Improvement (CBO), NL  
Royal Dutch Society for Physical Therapy (KNGF), NL  
Trimbos-Inst. - NL Institute of Mental Health & Addiction, NL  
Directorate for Health and Social Affairs (SHdir), NO  
Polish Institute for Evidence Based Medicine (PIEBM), PL  
Institute for Quality in Healthcare (IQS), PT  
Center of Health Policies and Services, RO  
Slovene Guidelines Group, SI  
Basque Office for HTA (OSTEBA), ES  
Josep Laporte Library Foundation (FBJL), ES  
Spanish Network for Research on Guidelines (REDEGUIAS), ES  
National Board of Health and Welfare (Socialstyrelsen), SE  
Swiss Federal Office of Public Health (SFOPH), CH  
Clinical Epidemiology Centre (CepiC), University Hospital, CH  
Centre for Reviews & Dissemination, Univ.of York (CRD), GB  
National Institute for Clinical Excellence (NICE), GB  
Royal College of Nursing Institute (RCNI), GB  
Scottish Intercollegiate Guidelines Network (SIGN), GB  
Sowerby Centre f. Health Informatics, Newcastle (SCHIN), GB

## OCEANIA

Joanna Briggs Institute (JBI), AU  
Nat. Health & Medical Research Council (NHMRC), AU  
National Institute of Clinical Studies (NICS), AU  
Therapeutic Guidelines Ltd (TGL) AU  
NZ Accident Compensation Corporation (ACC), NZ  
New Zealand Guidelines Group (NZGG), NZ

## INTERNATIONAL

AGREE Research Trust (ART)  
World Health Organisation (WHO)  
European Union of Medical Specialists (UEMS) - G-I-N Partner  
World Medical Association (WMA) - G-I-N Partner



About us:

**German Agency for Quality in Medicine ÄZQ** - [www.aezq.de](http://www.aezq.de)

NGO established 1995 and co-owned by

- German Medical Association GMA (Bundesärztekammer BÄK)
- Nat. Ass. Statutory Health Insurance Physicians NASHIP (Kassenärztliche Bundesvereinigung KBV)

Activities

[www.aqumed.de](http://www.aqumed.de)

- Center for National Disease Management Guidelines
- Physicians' Patient Information Service
- Programme for Patient Safety and Error Prevention
- Clearinghouse for Quality Management in Healthcare
- Editorship, German Journal for Evidence & Quality in Healthcare (founded 1904 as Zeitschrift für ärztliche Fortbildung by E.v.Bergmann)
- Office & Treasurership, Guidelines International Network
- Office & German Network for Evidence based Medicine - [www.dnebm.de](http://www.dnebm.de)

# Outline

- Describe why consumers and patients should be involved in guidelines
- Describe the experience of working with consumers in New Zealand and Germany
- Suggest resources for further reading



# Setting the Scene

- Too many trials which are addressing utterly trivial issues, issues that are not of prime importance to patients
- A study done in Bristol concerned osteoarthritis of the knee. They asked the question what are the research priorities from the position of patients themselves, rheumatologists, physiotherapists, gps & health service managers?
- They had focus groups of these different people - none of these people wanted any more drug trials. What they wanted was:
  - better evaluation of physiotherapy
  - better evaluation of surgery and
  - better evaluation of interventions to help people cope with this chronic disabling painful condition.
- Yet when they looked at what research was actually being done most of the research being done was on drugs.



# The Starting Point

- The principle benefit of guidelines is to improve the quality of care received by patients/ health consumers
- For patients/ health consumers (and almost everyone else in healthcare), the greatest benefit that could be achieved by guidelines is to improve health outcomes
  - Woolf, Grol, Hutchinson, Eccles, Grimshaw, BMJ Vol 318, 20 Feb 1999



# Guideline Development Processes



- AGREE is the most internationally recognised and scientifically validated guideline appraisal instrument
- Used by majority of G-I-N members to assess the quality of draft guideline or guidelines produced by other agencies
- Stakeholder involvement asks specifically whether patients' views and preferences have been sought



# Involving Consumers

- Stakeholder groups involved in identifying scope and topics for a guideline
- Members of the guideline development team
- Reviewers of draft guidelines
- Participants in focus groups for development of guideline related consumer resources
- Every day users of healthcare services
- Consumers taking part in the evaluation of guideline implementation programmes (eg consumer surveys)





# German Experience

**Patient participation (PP) a policy topic since the late 90s.**

**PP related programmes of German Med. Ass./ AEZQ since 1999:**

**1999: Patient Information Clearinghouse establ.**

**2000: National Patient Forum (Phys. Ass. & Pat. Organ.) establ.**

**2002: Patient Organisations review guideline drafts**

**2005: Pat.& Phys.Org.develop joint methodology on Eb pat. inform.  
Patient Organ. develop CPG based “Patient Guidelines”**

**2006: Pat.& Phys. Org. develop joint guideline methodology  
Patient representatives join national guideline groups**



# Involving Consumers in D - Now and in the Future

- ✓ Stakeholder groups identify CPG scope & topics for a guideline
- ✓ Members of the guideline development team
- ✓ Reviewers of draft guidelines
- ✓ Developers of CPG related consumer resources

Future...

- Every day use of evidence based healthcare services ?
- Consumers taking part in the evaluation of guideline implementation programmes (eg consumer surveys) ?



# Evaluation in Progress (D)

- influence of patient guidelines on:
  - doctor-patient interaction
  - individual decision making process
  - quality of healthcare
  - update and further development of medical guidelines
- best methods to ensure patient involvement
- acceptance of patient panels by medical experts



# NZGG Experience

- 1997/8 - appointed consumers to NZGG Board
- May 1999 - Women's Health Action developed a policy statement for NZGG on consumer participation. NZGG adopted policy of including consumer participants in every guideline project
- 2002 - survey of health consumers on guidelines found that consumers felt isolated and uneasy at guideline meetings. Consumer perspectives included in training programmes
- 2003/04 - developed consumer publications alongside guidelines using DISCERN and focus group testing
- 2004/05 - commissioned an evidence report on consumer participation and invited more than 100 community representatives to a summit meeting



# NZ + D Experience

- Stakeholder Groups
  - Consumer groups have heightened interest in use and applicability of evidence
  - Involved in advocating/ lobbying for new guideline topics
  - Publicise guideline team work and final recommendations



# NZ + D Experience

- Guideline Content
  - GDT keeps the focus on the issues of concern to consumers – often very practical suggestions
  - Topics such as complementary therapies have been highlighted as important
  - Qualitative studies on consumer experiences now routinely included in searches and as part of considered judgement



# NZ + D Experience

- Guideline Team Membership
  - Difficult finding consumer participants on teams
  - Need to take special care to ensure consumers have a voice at the meetings and to feedback to constituents
  - Need to have more than one consumer – “buddy system”
  - Important to have representation from different consumer perspectives (eg birth guidelines had parent reps and children’s reps)
  - Cultural input critical to making recommendations acceptable



# NZ + D Experience

- Development of consumer-oriented guideline publications
  - Assist informed decision making and the health care conversation with practitioners
  - Often used by health providers
  - Need to go through a thorough focus group testing process to ensure that content as well as look and feel will be appropriate
  - Use DISCERN checklist





# Other G-I-N Members

- New NICE advice for patient participation
- **SIGN - Patient Involvement in Guideline Development**
- NZGG
  - appendix on consumer involvement in training handbook
  - evidence report on effective consumer voice and participation
- Go to [www.g-i-n.net](http://www.g-i-n.net) for more consumer resources



# Other Resources

- DISCERN [www.discern.org.uk](http://www.discern.org.uk)
- [www.dipex.org](http://www.dipex.org)
- Eb Patient Info Manual (in German)  
<http://www.aezq.de/english/>



# The Ultimate Situation

- Consumers' use of evidence-based information to choose providers, make treatment decisions, and play a more active role represents the ultimate local application of scientific information
  - Carolyn Clancy and Kelly Cronin, *Health Affairs*, 24 No 1 (2005) 151-162



# Summary

- Involve Consumers
  - You will produce a richer, clearer product
  - Plain language resources make the technical guideline recommendations easier to adopt
  - Your fan club will expand
  - Try it ... You will like it!

