Consumer Involvement in decision making for health care policy and planning

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Levels of consumer participation

• Individual – patient working with physician to make health care decisions, self-management

• Community – patient involved in patient groups, local hospital committees

• Population – involvement in decisions that will affect a population of people
  – health care policy and planning (e.g. HTA)
  – Clinical practice (e.g. guidelines)
  – Clinical research (e.g. ethics)
  – Patient information (e.g. for personal health care decisions)
Why do it? Does it work?

FOR:

– voice of the people directly affected by the decisions and services
– Voice of those living with the disease on day to day basis
– may lead to more accessible and acceptable health services
– improve health and quality of life
– lead to health research of greater quality and clinical relevance
Why do it? Does it work?

AGAINST:

– makes research projects costlier
– makes research projects longer
– consumers may have biased views on certain health issues
– consumers may represent themselves not a group

Cochrane systematic review pending:

Interventions for promoting consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material
ES Nilsen, HT Myrhaug, M Johansen, S Oliver, AD Oxman
Anyone doing it?

- **UK: NICE...** NICE technology appraisal recommendations are prepared by an independent committee called the Technology Appraisal Committee. Committee members include:
  - the NHS
  - patient and carer organisations
  - academia
  - pharmaceutical and medical devices industries

- **UK: NCCHTA...** help to identify and prioritise research topics. Comment on research proposals, help inform the research question and the extent of the health problem, comment on reports

- **Australia: Medical Services Advisory Committee (MSAC)** consists largely of doctors and health economists, exceptions are people nominated to represent consumers’ interests

- **US: AHRQ** - National Advisory Council for Healthcare Research and Quality – include individuals representing the interests of patients and consumers of health care
# Key Opportunities in HTA process and Drug Review

## Canadian Expert Drug Advisory Committee (CEDAC)
- “an independent advisory body comprised of individuals with expertise in drug therapy and drug evaluation.”
- “makes recommendations to each of the participating federal, provincial and territorial publicly-funded drug plans regarding the listing of drugs on their formularies.”

## HTA PROCESS
- **Step 1:** Selecting topics
- **Step 2:** Defining the research question
- **Step 3:** Forming a project team - Scientific Advisory Panel.
- **Step 4:** Assembling the evidence
- **Step 5:** Synthesizing and interpreting the evidence – clinical relevance?
- **Step 6:** Reviewing the report
- **Step 7:** Knowledge Transfer

## Decision Making Committees
What do they want to do?

- In Canada, interviews with approx 50 health consumer organisations about how would like to participate in the HTA process showed that…
- 100% wanted information
- 70% want to participate in other ways
  - 70 to 80% participate as part of the research (complete surveys, interviews, focus groups, etc.)
  - 71% would be willing to send representatives to take part in a decision-making committee

How to do it?

• Avoid doing it to simply placate
• Avoid tokenism — work to consultation with a goal of collaboration
• Actively recruit — consumers should be linked to service user/carer networks and be able to draw on a wide body of public opinion
• Enable participation — money, transportation
• Ask how they would like to participate
• Provide training - technical knowledge and skills about research and HTA process, health issues and policies VIA workshops, manuals, guidelines on the internet
Does it work? Who's doing it?
The Canadian Experience

*The Canadian arthritis patient community knows it works. We're doing it!*

- **Canadian Arthritis Network (CAN) requires patient involvement in all CAN funded research**
  - CIHR Institute of Musculoskeletal Health and Arthritis and other groups encourage involvement

- **Canadian Arthritis Network-Consumer Advisory Council**
  - Provides patient input into research
  - Members on internal CAN committees to manage multi-million $$ Network Centre of Excellence.

- **Consumer members of grant Peer Review Panels**
The Canadian Experience

- CMSG – consumers:
  - peer reviewers, consumer reviewers and members of CCNet
- Participation in COMPUS Workshops across Canada – 2004
- CAN Annual Scientific Conferences; Participation in CRA Annual Meetings; CAN Informatics and Ethics Workshop
- Participation in Towards a National Pharmaceutical Strategy-2006
- Consumer involvement in HC Expert COX-2 Panel
COX-2 Panel

- Health Canada Expert Advisory Panel (EAP) on selective COX-2 NSAIDs
  - First time Health Canada invites public to present before an EAP
  - First inclusion of patients as members of EAP
  - Panel examined issues regarding risks of COX-2's versus benefits associated with their risks.
  - Received:
    65 written submissions from individuals
    7 submissions from organizations
COX-2 Panel

- Patient Panel Member contributions:
  - Living with chronic disease – the patient perspective
  - Treatment availability/choices – the patient perspective
  - Risks vs benefits – the patient perspective
  - NSAIDs – the patient perspective

  . The case of ibuprophen
What do we want?

• We want to contribute to CCOHTA-Health Technology Assessment
  • Step 6 – Reviewing the Report
    ... involves internal and external assessments that may include methodologists, clinicians and industry.”

• Suggestion:
  – Include patients who are part of the disease group most affected by the information.
What do we want?

- We want to contribute:
  - to health care planning
  - to design and planning of National Pharmaceutical Strategy
    - Through consultations by NPS task force with all stakeholders groups including patients

*Patients do not accept that universal health care can be affirmed in theory, but denied in practice. Theory and practice meet in collaboration.*
Does collaboration work?

- Yes it can!
- If you:
  - Don't placate – it doesn't work
  - Forget tokenism – it's counter productive
  - Recruit organizations and coalitions – we have the members, networks, knowledge and interest
  - Enable our participation – funding is important
  - Provide training – goals; technical knowledge and skills
“... CCOHTA is considering methods of greater public involvement in CDR; this cannot occur soon enough.”

Andrea Laupacis, CMAJ, January 31, 2006