LINKING THE PUBLIC IN PRIORITY-SETTING FOR HTA:
FINDINGS FROM A CITIZENS JURY

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Presentation Overview

• Why involve the public in health care decision-making?

• Why involve the public in health technology assessment?

• What role could the public play in HTA?

• A recent experiment in public involvement
Why involve the public in health care decision-making?

Recent health care reform papers:

- 2000: *Emerging Solutions (Clair Commission Report)* Quebec


- 2001: *Caring for Medicare: Sustaining a Quality System (Fyke Report)* Saskatchewan

- 2002: *The Health of Canadians – the Federal Role: Report of the Standing Senate Committee on Social Affairs, Science and Technology (Kirby Report)* Canada

Why involve the public in health care decision-making?

Common findings:

• Eroding public confidence in Canadian health policy
• Greater scrutiny by the public over health care rationing decisions
• Increased use of process oriented decision-making frameworks
• Growing consumerist orientation towards health care policy

Call for greater:

• Accountability
• Transparency
• Legitimacy

in health care decision-making
Why involve the public in HTA?

• New technologies represent a significant cost driver in health care systems

• HTA is a tool used to inform health technology policy
  - Which technologies should be included in the basket of services covered by the public care system?
  - Does a specific technology offer good “value” for money?

• HTA increasingly involves the need to make value-laden judgments
  - Whose values?
Patients and the Public

• **Patient/User** – in frequent and direct contact with health care providers
  
  *easy to identify*

• **Citizens/Non-users** – not currently using health care services but may need to in the future
  
  *not easy to identify*

Can be both!!!
What role should the public play in HTA?

Basic HTA process

- Identify potential technologies
  - Should the public help to identify technologies for assessment?
- Select technologies to assess
  - Should the public be involved in deciding which technologies to assess?
- Conduct HTA
  - Should the public have a say in deciding what aspects of a technology are important to assess?
- Disseminate findings to policy-makers
What methods can be used to involve the public?

• Opinion polls/surveys
• Focus groups
• Referenda
• Public meetings
• Citizens’ panels or fora
• Deliberative polls
• Citizens’ juries
What is a Citizens’ Jury?
Where and when have Citizens’ Juries been used?

- Germany (since 1969), United States (since 1974), and United Kingdom (since 1996)

To address issues including:

- Seniors’ rights
- The future of secondary schools
- Housing shortages
- Genetic testing
- Genetically modified foods
- Community responses to drug-related crime
- Rationing health care
- Services for the dying
- Mental health services
- Agriculture Water Quality
- Metro Solid Waste
- Traffic congestion
- Property tax reform
Why a Citizens’ Jury to assess priorities for HTA?

- Priority-setting is a complex issue
- The jury process is a familiar one
- Jurors are exposed to a wide range of points of view, much wider than if their opinion is sought using survey techniques
- Members of the public are given both time and information to deliberate fully
- Evidence from previous juries appear positive
Our experiment with Citizens’ Juries

Purpose:
To pilot the citizens’ jury as a mechanism for identifying criteria that the public feels ought to be used to set priorities for HTA in Canada

Objectives:
1. To assess the public’s willingness to participate in citizens’ juries that address priority-setting issues in HTA
2. To establish the feasibility of conducting a citizens’ jury within a regional health authority
3. To develop a list of criteria to guide priority-setting decisions for HTA
Methods - Overview

1. Selection of jurors
2. Organization and conduct of jury session
3. Analysis of jurors’ findings
4. Evaluation of jury process
Selection of jurors

Stage 1

Capital Health Region

Random sampling of individuals with registered telephone numbers

1600 residents

Mail-out of information letters and consent forms for participation in telephone screening survey

1124 Non-respondents
- 11 Deceased
- 982 “Returned to sender” (undeliverable)
- 131 No reply

476 Respondents
- 420 willing and available to participate
- 56 willing but not available to participate on selected dates
Selection of jurors

Stage 2

420 Respondents

1. Telephone screening interviews conducted
2. Demographically representative jury of 16 potential participants assembled using purposive sampling techniques

16 potential jurors

Potential jurors contacted by telephone and invited to participate in jury session

16 jurors
Selection of jurors

Profile of Jury

- **Gender distribution:** 8 men; 8 women
- **Age range:** 18 years to 70 years
- **Employment status:** 12 employed; 2 unemployed; 2 retired
- **Education:** < high school to post-graduate degree
- **Income range:** <$20,000/year to >$80,000/year
- **Dependents:** 12 yes; 4 no
- **Ethnicity:** 12 Caucasian; 1 African; 1 First Nations; 1 Asian; 1 Spanish
Jury Session

• 2 ½ days long

• Presentations by “witnesses” on current health technology decision making processes

• Technology scenario-based exercises

• Deliberative sessions (to draft list of criteria)

• Involved moderators with expertise in Citizens’ Juries
Jury session

Session Overview

**Day 1**
- Welcome and introductions
- “Getting to know each other” exercise
- Introduction to HTA and Citizens’ Jury process

**Day 2**
- Presentations by expert witnesses on current priority-setting processes + Q&A period
- Scenario-based Exercise 1: 13 mini technology scenarios
- Jury deliberations: What criteria should be used to set priorities for HTA?
Overview of scenario-based exercise 1

13 technologies examined in mini scenarios

- Laparoscopic adjustable gastric banding
- Metal-on-metal hip prosthesis
- Fetal fibronectin testing
- Uracyst\(^R\) for interstitial cystitis
- Newborn hearing screening
- Acomplia\(^R\) for weight control and smoking
- Combrestatin\(^R\) for thyroid and colon cancer
- MammoSite\(^R\) radiation system for breast cancer
- Vagus nerve stimulation
- Implantable cardiac defibrillator
- Positron emission tomography
- Ceredase\(^R\) for Gaucher’s disease
- Titanium rib vertical expandable prosthesis
Day 3

- Technology Scenario-based Exercise 2: In-depth technology case studies

- Presentations by expert witnesses:
  - Clinician’s perspective
  - Patient’s perspective
  - Funder’s perspective
  - Manufacturer’s perspective
- Q&A period

- Jury deliberations: What criteria should be used to set priorities for HTA?
Analysis of jury’s findings

- Transcription of audiotapes
- Content analysis of transcripts
  - independently reviewed by 2 researchers
  - criteria sets “coded” through iterative process
- Development of ranked list of criteria
  - each criterion “weighted” based upon frequency and magnitude of “importance” score
Final set of HTA priority-setting criteria:

1. Potential to benefit a number of people
2. Extends life with quality
3. Offers ability to detect a condition which, if treated early, averts future costs
4. Availability of existing treatment(s)
5. Offers clinical benefits over existing treatments
6. Offers improved quality of life
7. Potential for additional applications
8. Offers value for money
9. Extends life
10. Completeness of available data on adverse events
Evaluation of the jury session

- Administration of juror feedback questionnaires
- Analysis of jurors’ responses
Results – What did jurors think?

Question: What did you think about the scope of the question presented to the jury, “What criteria ought to be used to set priorities for HTA?”

Response: “About right” = 15 jurors
“Too broad” = 1 juror

Question: What did you think about the balance of information presented?

Response: “Good” = 15 jurors
“Overlap” = 1 juror

Question: What did you think about the time allowed for jury deliberations?

Response: “About right” = 16 jurors
Results – What did jurors think?

Additional comments:

• “This was an extra-ordinary opportunity to participate in an important, ground breaking, innovative approach to allow the Canadian taxpayer/general public to become better informed of and to be actively involved in decision making processes around the commitment of health care funds”.

• “A great way to get involved and have some input as a member of the general public. It is so important that our elected representatives hear and follow what the public has to say. Thank you for this effort!”

• “I could hardly sleep from all the info I got and continually thinking about it. Thanks for such a great opportunity!”

• “The exercises were excellent in part because they were presented in a real way.”

• “Having the two patients, who explained their own experiences, was a plus”.

What can we conclude?

1. The public appears willing to participate in citizens’ juries

2. Stakeholders from all sectors appear willing to participate in citizens’ juries

3. Based upon the jury’s findings, priority for HTA should be given to technologies that have the potential to help many individuals and/or extend life with quality.
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