Cette présentation a été effectuée le 12 mars 2010, au cours de la journée « Délibérer pour guider la prise de décision » dans le cadre des Journées annuelles de santé publique (JASP) 2010. L'ensemble des présentations est disponible sur le site Web des JASP, à l'adresse http://www.inspq.qc.ca/archives/.







- Public consultation
 - One-way, top-down, one-way information flow
 - Past experiences have produced cynicism and distrust
- Citizen/public engagement (the 'new' public participation)
 - Two-way obligations, information sharing, trusting relationships
 - Linked to deliberation and reason-based decisions
 - Effort to correct past failures, re-establish trust between citizens and government officials







Five Conditions of Deliberation (from Jacobs et al. 2009)

- **Universalism** inclusion of everyone affected by a decision and equal opportunities to participate in deliberation
- **Inclusivity** include a range and diversity of citizen voices; who actually participates not just who shows up
- **Rationality** important role for evidence; claims are grounded in logic and facts; listening and responding to counterarguments

Five Conditions (2)

- **Agreement** work through conflicts to reach common shared perspective and practical solutions
- **Political efficacy** citizen confidence, learning and interest in politics and government affairs contributes to increased political participation and impacts on policy

The Critiques of Deliberation

- Elitist "gated democracy"
- **Exclusionary** disadvantaged groups will continue to be disadvantaged through the deliberative process
- **Manipulative** requirements for reason-based arguments fosters dependence on on experts for information
- **Divisive** deliberation will intensify disagreements, sharpen conflict, and polarize citizens
- **Oppressive** encourages suppression of conflict to produce agreement
- **Politically insignificant** impact on decisions is only slight if present at all



Deliberation: What does it look like?

- **Discourse among citizens** public exchange of ideas and arguments about public issues (reflects on and contributes to political process)
- Multiple settings
 - Informal, unplanned exchanges
 - Formally convened exchanges
 - By citizens
 - By public officials
- Multiple formats
 - Face-to-face exchanges
 - Phone conversations
 - Electronic communication (e-mail; internet)



- citizens jury (Crosby, US; Dienel, Germany)
- citizens panel (roots in public opinion research)
- consensus conference (European roots)
- deliberative polling (Fishkin)
- citizens dialogue (Yankelovich)

d how often)? (Source: Jacobs et al. 2009)		
Table 2.1 Reported levels of discursive particip United States	oation in the	
TYPE OF DISCURSIVE PARTICIPATION	percentage (%)	N
Public deliberation		
"Face-to-face deliberation" about a public issue	25	379
"Internet deliberation" (communication via Internet chat rooms, message boards, or other online discussion groups about a public issue)	4	61
Informal public talk		
"Traditional talking" (phone or in-person conversation about a public issue)	68	101
"Internet talking" (e-mail or instant messaging about issues of public concern)	24	360
Political persuasion		
Persuade someone about your view on a public issue	47	698
Persuade someone about whom to vote for Source: Discursive Participation Survey. Total sample: N = 1,501 (31 weighted general popula	45 ation







Recent History (1990-2005)

• Ad-hoc experimentation

- Following the UK (who followed the US)
 - Citizens juries, deliberative polling for regional health planning and resource allocation (mid-1990s)
- Researcher-initiated
 - Deliberative polling, citizens juries (regional health authorities)
 - Citizens Forum on genomics in society, pandemic planning
- Policy maker initiated
 - Citizens dialogues for Romanow Commission;
 - Public consultation on xenotransplantation, influenza pandemic planning

New Experiments

• Creation of new deliberative consultation bodies modeled on NICE Citizens Council (UK) in Ontario (2006, 2008) and Québec (2005)

• Policy arenas:

- health system performance monitoring (Québec)
- provincial drug policy program decisions and priorities (Ontario, 2006)
- Health technology assessment and health technology coverage policy (Ontario, 2008)

Example 1: Loi sur le Commissaire à la santé et au bien-être

"... the Commissioner is responsible for assessing the results achieved by the health and social services system ..., and for **providing the public with the necessary background for a general understanding** of the actions undertaken by the Government to address the major issues in the health and social services arena."

- le Commissaire doit constituer un Forum de consultation

Forum de consultation

"The mandate of the forum is to provide the Commissioner with **its point of view** on the matters or issues the Commissioner submits to it as part of a consultation." (2005, c. 18, s. 28)

- 27-member citizen-expert panel (18 citizens, 9 experts)
- meets 3-4 times per year for 1.5 days

- deliberates on topics provided by the Commissioner's office

Sample Deliberation Topics

• Prenatal testing for Down's Syndrome As a society, what do we want to preserve? What do we

want to avoid? What do we want to promote? By what means?

• **Rights and responsibilities for health care** What are the positive and negative impacts of transferring responsibilities for health care from the State to citizens?

Chronic diseases

What does equity mean in the context of chronic diseases and the health system?

Example 2: Public Deliberation to inform Pharmaceutical Policy and the Evidence-based Analysis of Health Technologies

• <u>Policy problem</u>: How do we (meaningfully) incorporate public values and social judgements into expert-driven, highly technical processes? With what effects?

Two Ontario Experiments

- Implementation of 2 new "citizen representative" models to inform pharmaceutical and health technology assessment processes
 - Citizens' Council (legislatively mandated)
 - Citizens Reference Panel on Health Technologies (MOHfunded research project)

Citizens' Council Role and Mandate

1.5 The Minister shall establish a Citizens' Council whose duty shall be to ensure the involvement of <u>patients</u> in the development of pharmaceutical and health policy.

(Bill 102, Chapter 14 Statutes of Ontario, 2006:13)

"The Citizens' Council will **discuss and provide opinions** about questions or topics posed to its members, and make a report to the Executive Officer (EO) of the Ontario Public Drug Programs and the Minister of Health and Long-Term Care."

- 25-member panel (selection criteria unknown); meets twice per year





Questions for Consideration

- What have we learned from the Canadian experience to date with public deliberation?
- Do the examples provided meet the conditions of public deliberation (e.g., universalism, inclusivity, rationality, agreement, political efficacy)?
- What are the experiences of citizen participants
- Why are decision makers choosing to engage directly with citizens through these mechanisms?
- What impacts have these experiments had on learning, trust, competency and policy?



Researching Public Deliberation

- Research on public deliberation has been limited to a series of isolated studies
 - Group meetings
 - Informal neighbourhood and city conversations
 - Deliberative polling (public opinion surveys before and after deliberation)
 - On-line communication
 - Experimental studies
 - Media roles in "mediated deliberation"

The State of the Research Evidence

"... there is a striking imbalance between the amount of time, money and energy that governments in OECD countries invest in engaging citizens and civil society in public decision making and the amount of attention they pay to evaluating the effectiveness and impact of such efforts."

(OECD, 2005)

- similar results from recent scoping review of public participation in health care priority setting

(Mitton et al. 2009)





Approach

- Critical interpretive synthesis of theoretical work, empirical studies and grey literature:
 - health field only
 - focus on evaluation studies, methods and frameworks
 - 2000-2009 (updating prior work)
- Searches of 11 databases yielded 34 core documents
 - systematic, scoping and narrative reviews (N=5)
 - empirical studies (N=12),
 - non-empirical papers (N=8)
 - Canadian grey literature (N=9)



- Heightened interest in scoping and systematic reviews of public engagement in the health field
- Some improvements in the rigor of empirical evaluation studies
- Need for greater conceptual clarity about the meaning of effective public involvement, common evaluative criteria and outcomes of interest

Messages related to effects

- High levels of satisfaction with aspects of deliberative processes (e.g., communication of objectives, provision of adequate information material to inform discussions, and logistics and management of the deliberation)
- Increased levels of:
 - topic-specific learning
 - interest in and knowledge of public issues
 - trust of fellow citizens and social bond formation
- Improved capacity for future involvement







Building a Platform for Public Deliberation (Health) Research

• Key elements:

- strong theoretical foundation
- rigorous methods
- innovative research-practice partnerships
- research capacity (e.g., trainees, investigators)



Is Public Deliberation a Means for <u>Informing</u> Health Policy?

- YES and we have evidence that this is starting to happen but the realities of 'politics-constrained' public engagement must still be acknowledged
 - PP (and therefore PD) still a politically contested concept
 - policy makers are risk averse and reluctant to share power but are also pragmatists
 - dominance of and deference to experts in health care will continue

Is Public Deliberation a Means for Improving Health Policy?

- **DON'T KNOW** an empirically testable question that hasn't been addressed
- **POSSIBLY** provided the following can be addressed:
 - Publics see this as important and useful
 - Contributions of deliberative bodies are seen as credible by other groups
 - Informational requirements are carefully managed
- **BUT** Improving policy is one goal among several need to assess against <u>all</u> goals

Is it a means for <u>strengthening</u> democratic governance?

- A QUALIFIED YES to the extent that participation in public deliberation processes changes the way people perceive decision-making and to the extent that informal deliberation continues to grow and put pressure on the governments to open themselves up to contributions from citizens who are keen to contribute to public-spirited decision making
- This will be an incremental process

Those who practice public deliberation design, facilitate processes to have citizens talking to each other, working through difficult issues and making tough choices. They are trying to move people from having an individual opinion to having more of a public judgment. When citizens do this, we become problem solvers, rather than mere consumers or political spectators. And, part of the work of deliberative democracy is moving away from these images of citizens as mere "consumers" or "spectators" as these models on their own offer less productivity to our community.

(Centre for Public Deliberation, University of Houston)