

Public Engagement to Inform Ethically Challenging Public Health Policies

Approaches, Evidence and Insights

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Centre de collaboration nationale
sur les politiques publiques et la santé

National Collaborating Centre
for Healthy Public Policy

*Institut national
de santé publique*

Québec 

Poll: who gets it when not all can?

Scenario: 25 children and 25 adults present to your remote clinic, all exposed to a lethal toxin; you have 50 antitoxin doses; children need 1 dose, adults 2.



Image: © iStockphoto.com/ Pedro Antonio Salaverría Calahorra

Poll: who gets it when not all can?

1. 1 dose to all children, 2 to 12 adults?
2. 1 dose to everyone?
3. Pull names from a hat?
4. Your patients/family first?
5. Most educated?
6. Most disadvantaged?

Poll: who gets it when not all can?

1. 1 dose to all children, 2 to 12 adults? (Utilitarianism)
2. 1 dose to everyone? (Strict Egalitarianism)
3. Pull names from a hat? (Equality=Fair Opportunity)
4. Your patients/family first? (Professional/Communitarian ethics)
5. Most educated?
(Social Utility)
6. Most disadvantaged?
(Social Justice)

What's it all about, Alfie?

The combination of

Public health ethics (which promises a re-broadening of bioethics, fulfilling original mandate to population and environmental health, and overcoming “damaging preoccupation” with autonomy and justice within states) with

Public engagement (which promises to establish a partnership with government, in which the public actively engages in the policy-making process) in order to

better inform public health **practice & policy**

Today's workshop

1. Introduction [15 min.]
2. Define public health ethics [30 min.]
3. Small & large group discussions: “The HPV Vaccine Trial” [15 + 15 min.]
4. Define public engagement [20 min.] [break]
5. Small & large group discussions: “The Proposed Refinery” [15+ 15 min.]
6. Success factors for effective engagement [10 min.]
7. Group discussion - How can public health ethics engagement be tailored to your professional activities? [20 min.]
8. Conclusion: Sin taxes, Safe injections & Public Health Rationales

Who are we?



NCC Public Health

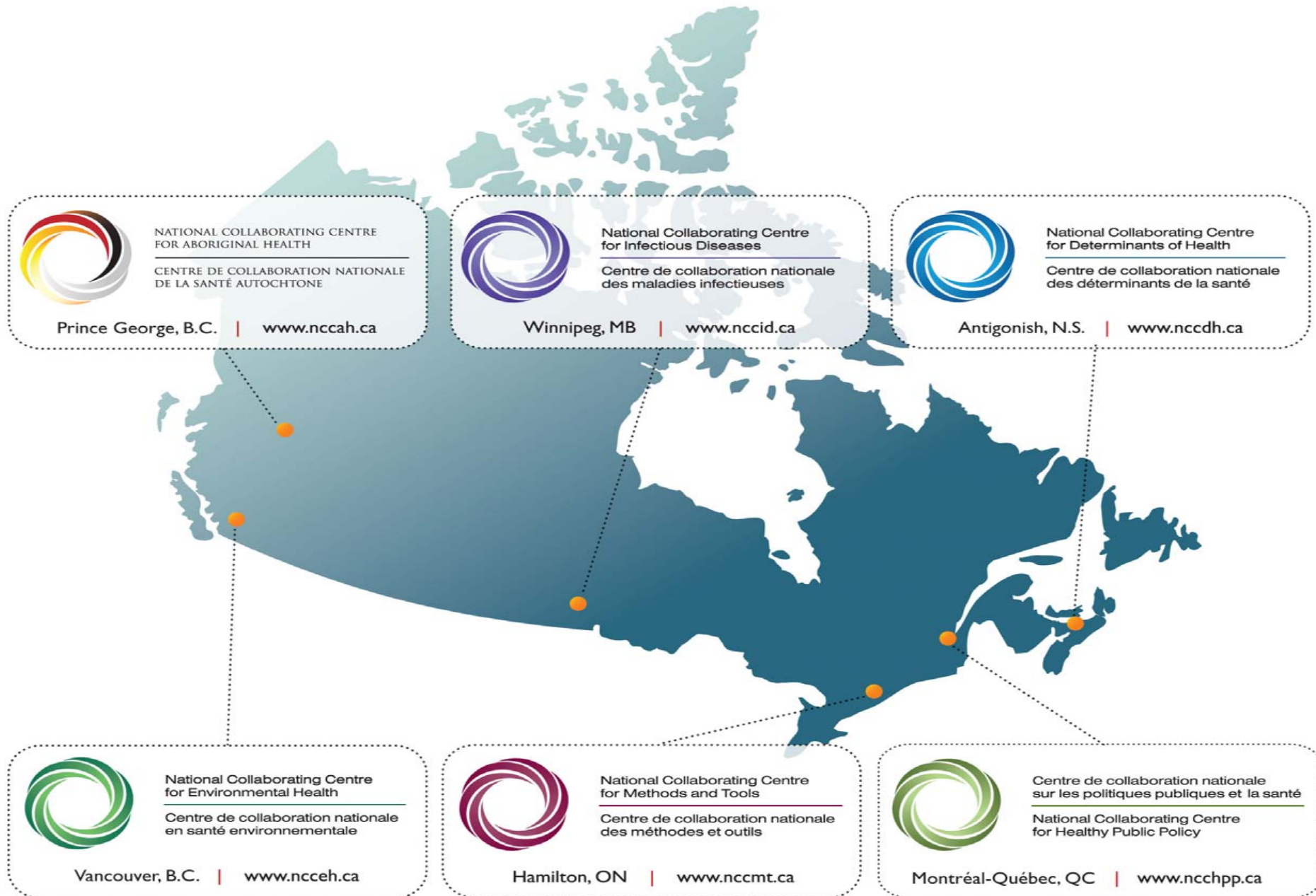
Mission

- To “bridge” the communities of researchers, practitioners & decision-makers

Activities

- Knowledge Synthesis, Translation & Exchange
- Identification of Knowledge Gaps
- Research Promotion
- Network Development

The 6 National Collaborating Centres for Public Health



Different topics - Different institutions - Collective projects

NCC Healthy Public Policy

Objective

- To increase expertise in public policy

Focus

- Public policy processes, impacts on health, & methods to study these and apply findings

Synthesis, exchange, translation

- Co-construction with users
 - Elicit and capture practices
- Usable
 - Adaptable/adapted to context
 - Multiple diffusion strategies/formats

Who are you?

Public Health Ethics

Primer: Public Health Ethics

- Why public health ethics?
 - Background: ethics, SARS & other Crises and challenges
 - Emerging Policy Standards
 - Emerging Professional Standards
- What is public health ethics?
 - Ethics & ph decision-making
 - Some (but not much) moral theory
 - Public health ethics vs. Bioethics
- Several frameworks & a reflection tool
- Group Discussions

Why Ethics?

- Need for a **moral compass** to guide difficult decisions that have to be made in public health policy & practice
- Moral analysis is **part of coherent, accountable decision-making and public policy formation**
- Ethical issues are **one set of considerations** (among many – risk analysis, economics, law, etc...)

Lessons from SARS

- SARS underscored the need for a clearly understood and widely accepted ethics approach to dealing with public health decision and policy making
- Health care systems are generally not prepared to deal with hard ethical choices that arise rapidly, or that involve complex systems
- Lesson learned is to establish the ethical framework in advance and to do so in an open and transparent manner

2 ways for ethics to contribute

Decision and policy making in public health ought to be

- Informed by (substantive) ethical values/principles
- Guided by (procedural) ethical decision-making processes

Poll: who to evacuate first?

- Most ill or disabled?
- Most ambulatory?
- As if it were the titanic?



Katrina: varying priorities, none clearly “right”

- Hospitals: **most critically ill** patients first
- Firefighters: **least ill patients** first and most ill later
- Helicopter Pilots: **pregnant women and babies**



Renewed interest in public health

Public health “crises”

- Tainted blood
- BSE
- *e coli* outbreaks
- Living conditions of indigenous communities
- H5N1, XDR-TB, SARS, H1N1

Growing challenges

- Value of universal health care
- Persistent health inequities according to class, race, gender
- Genetic screening, bio-banks, commercialization (e.g., HPV vaccine)

Renewed Interest in PH Ethics

- Proliferation of **publishing** in last 10 years
- Increased **teaching** in schools of PH
- International **symposia, journals, books**
- APHA **Code of Ethics**, 2002
- **Pandemic Ethics**
- **Global Health Ethics**
- Nuffield Council (UK): **Ethical Issues**, 2007

= emerging policy and professional standards

Poll: who to vaccinate first?

- the most vulnerable?
- those most likely to transmit the most illness?
- those “essential” to ongoing efforts against the outbreak?
- it’s another titanic situation... (pregnant women and babies)



Public health

... frequently involves ethical dilemmas for which practitioners may **not feel well trained, skilled or prepared** to confront, and **on which they may profoundly, but reasonably, disagree...**

Public health ethics

... provides a common language (and thus perhaps more clarity) about the **goals, means, and limits of public health**, which may reduce conflicts arising from **the heterogeneous (and often conflicting) values** on which health protection, promotion and prevention rest

EG: New PH Policy Standards

“Ethical Governance”

- Requires that policy-making process be:
 - Fair, Equitable, Transparent & Accountable
- Encourages that policies be explicitly values-based, and that policy-makers account for the impact of their decisions, especially on:
 - Equity, Solidarity & Social Justice

eg: WHO EURO Health For All agreement (2005); Qc Loi sur la santé publique (2001) (common good & equity) + CESP + volet éthique du CSBE (2005)

EG: Emerging Professional Standards

"Public Health Ethics"

- PHAC Core Competencies for Public Health in Canada (2007) requires practitioners to:
 - “Utilize public health ethics to manage self, others, information and resources” (Leadership section 7.3)
- Quebec Public Health Program (2003-2013) requires practitioners to:
 - Develop their “ethical expertise” so as to integrate “values and ethical principles into the exercise of each of the public health functions” (Section 3)

5 broad categories of ethical issues common across occupations and locations

- determining **appropriate use** of public health **authority**
- making decisions related to **resource allocation**
- **ensuring** standards of **quality**
- questioning the role or **scope of public health**
- negotiating **political interference**

+ low use of core PH values & frameworks for d-m'ing

(Baum, Gollust, Goold & Jacobson, 2009)

The value of practical ethics

- Of 1200 nurses & social workers surveyed, half with Masters, only approx **50% of have some ethics education** (& 25% of nurses had none)
- Those with were **more confident in their judgments** and **more likely to explicitly use ethical arguments in their decision-making**
- “Ethics education has a significant positive influence on moral confidence, moral action, and use of ethics resources”

(Grady et al, Am J Bioethics 2008)

But which ethics?

- Whose goals, which principles, what processes, which outcomes?
- Who decides?
- Where does moral authority reside?

Surely not principlism... (even though most health ethics training teaches it exclusively...)

- Autonomy
- Beneficence
- Non-maleficence
- Justice

eg: Cdn PanFlu Plan (2006)

Goals

- “To minimize morbidity and mortality and to minimize societal disruption”

Principles

1. Protect and promote the public's health
2. Ensure equity and distributive justice
3. Respect the inherent dignity of all persons
4. Use the least restrictive means
5. Optimize the risk/benefit ratio
6. Work with transparency and accountability

Bioethics

... has become “**stale & tedious**” and has no future in its present form...

Public health ethics

... is a “means to an **invigorated, richer and socially-engaged** bioethics”

(Dawson, 2010)

Historical Roots of Clinical Ethics

- Post-WW2 then 1950/60's
 - concern for ethics of **health research**
 - critiques of **medicalization**
 - attention to **power relations** between researcher/subject, doctor/patient
- 1970/80's
 - drama of **high technology** medicine, beginning and end of life decisions

Historical Roots of Public Health

- State intervention and health paternalism
 - Authoritarian, even coercive, enforcement
 - Goals: protect common good, promote utility
- Progressive Social Reform Movements
 - Mitigate worst consequences of industrial revolution
 - Goals: protect inherent value/dignity of all, promote equity

How is PH ethics distinct from clinical ethics?

Clinical ethics

- **Context:** fiduciary responsibility of clinician in therapeutic contract with patient, legitimized by informed consent of patient
- **Pattern of practice:** patient seeks out clinician, may accept or reject advice

Public Health ethics

- **Context:** contract is with society as a whole, legitimized by policies and law of government
- **Pattern of practice:** patient sought by PH practitioner, may not be able to refuse advice

Recap: Why is public health ethics distinctive?

- Public health is a **collective good**
- Public health has a particular focus on **prevention**
- Public health generally requires **government action**
- Public health, is intrinsically **utilitarian/consequentialist**, but draws from a wide range of values/principles to guide practice and policy

Examples of Frameworks for PHE

- **Kass (2001)**

- What goals can be achieved?
- Will the intervention be effective in achieving those goals?
- What are the known and potential burdens?
- Can the burdens be minimized? Are there alternative approaches?
- Can the intervention be implemented fairly?
- How can the benefits and burdens of the intervention be fairly balanced?

- **Barbera et al (2001)**

- Reasonable (risk)
- Favourable (cost benefit analysis)
- Feasible (effectiveness)

- **Childress et al (2002)**

- Effectiveness
- Proportionality
- Necessity
- Least infringement
- Public justification
- Trust

Examples of Frameworks for PHE

- **Upshur (2002)**

- Harm Principle
- Least restrictive means
- Reciprocity
- Transparency

- **Buse (2003)**

- Representative
- Transparent
- Accountable
- Equitable

- **JCB (2003)**

- Individual Liberty
- Public Protection from harm
- Proportionality
- Reciprocity
- Trust
- Privacy
- Duty to provide care
- Equity
- Solidarity
- Stewardship
- + Fair Procedure = Reasonable, Transparent, Inclusive, Responsive, Accountable

Examples of Frameworks for PHE

- **Stone & Parnham (2005)**

- Equal & substantial respect
- Justice
- Care
- Beneficence
- Community
- Cultural humility & openness
- Critical trustworthiness
- Competency
- Critical reflection

- **Tannahill (2008)**

- Do good
- Do not harm
- Equity
- Respect
- Empowerment
- Sustainability
- Social responsibility
- Participation
- Openness
- Accountability
- + “Ethical logic modeling”
(explicitly drawing on principles to make decisions, informed by available evidence and theory)

Public health ethics is value pluralistic

Selected ethical principles, values & norms potentially relevant to public health decision-making

Ethical Considerations from the Nova Scotia Pandemic Flu Plan¹ (adapted)				
Social Values	Policy Values		Individual Values	
<i>Justice/Fairness</i>	<i>Issues</i>	<i>Outcomes</i>	<i>Individual</i>	<i>Institutional</i>
Universality	Utility/Necessity	Efficiency	Liberty	Interdependence
Equity/Equality	Need	Quality	Freedom	Trust
Protection from harm and of life	Accountability	Feasibility	Dignity	Loyalty
Protection of the vulnerable or marginalized	Relevance	Acceptability	Autonomy	Stewardship
Protection from stigma	Reasonableness	Effectiveness	Privacy	Solidarity
Fair access	Transparency	Sustainability	Beneficence	Evidence
Fair outcomes	Proportionality	Value for cost	Non-Malfeasance	Subsidiarity
Precautionary principle	Inclusivity	Least restrictive means	Conflict of interest	Duty to care
Social cohesion	Legality	Neighbourliness	Informed consent	Advocacy
Collaboration	Revisibility	Unity	Integrity	Flexibility

A core challenge from public health ethics

Recognize and make relevant the interdependence of autonomy, relationality, and community trust

From autonomy...



*a form of personal liberty of action
where the individual determines his or her
course of action in accordance with a plan
chosen by him or herself*

Contemporary liberal theory has yet to take account of the fact that men are not mushrooms." *Susan Moller Okin*

...To relationality

Agency is not isolated,
but inherently relational



Victims and vectors



“Infectious disease reminds us that we are related in our vulnerability.” *Leslie Francis*

Group discussion

Small group Workbook

Ethical Decision-Making *Worksheet*

- I** Identify the facts
- D** Determine the ethical principles in conflict
- E** Explore the options
- A** Act on your decision and evaluate

Adapted from the Toronto Community Care Access Centre Community Ethics Toolkit, developed by the Community Ethics Network (CEN) 2008.

http://www.jointcentreforbioethics.ca/partners/documents/cen_toolkit.pdf#search=%22CEN%20toolkit%22

Case: HPV Trial Proposal

- Pharma offers \$5M to provide *Gardasil* to an entire isolated remote community (all children 9-12), with 10 year observation + boosters if necessary
- Fed + Prov govt's match funding in order to assure long-term surveillance, comprehensive paediatric immunization coverage, family planning, and cancer screening, as well as investment in clinical and PH capacity
- Prevalence of HPV is slightly higher than national average in this (adult) population, but cervical and testicular cancer rates no higher than elsewhere in Canada

Case: HPV Trial Proposal

1. What are the most pertinent facts?
2. What are the most relevant principles or values, and how do they combine or conflict?
3. What trade offs (between values, between objectives, between outcomes) are implied?
4. What role could or should the community play in decision making?

15 min Break



Public Engagement

Engaging the public in decisions affecting their lives is a fundamental value of our democratic societies that is entrenched in health promotion charters...

“Health promotion works through concrete and effective **community action in setting priorities, making decisions, planning strategies and implementing** them to achieve better health. At the heart of this process is **the empowerment of communities** - their ownership and control of their own endeavours and destinies.”

- Ottawa Charter for Health Promotion, 1986

Who's the "public"?

Public Engagement

What does "engagement" mean?

And why should we be doing this?!

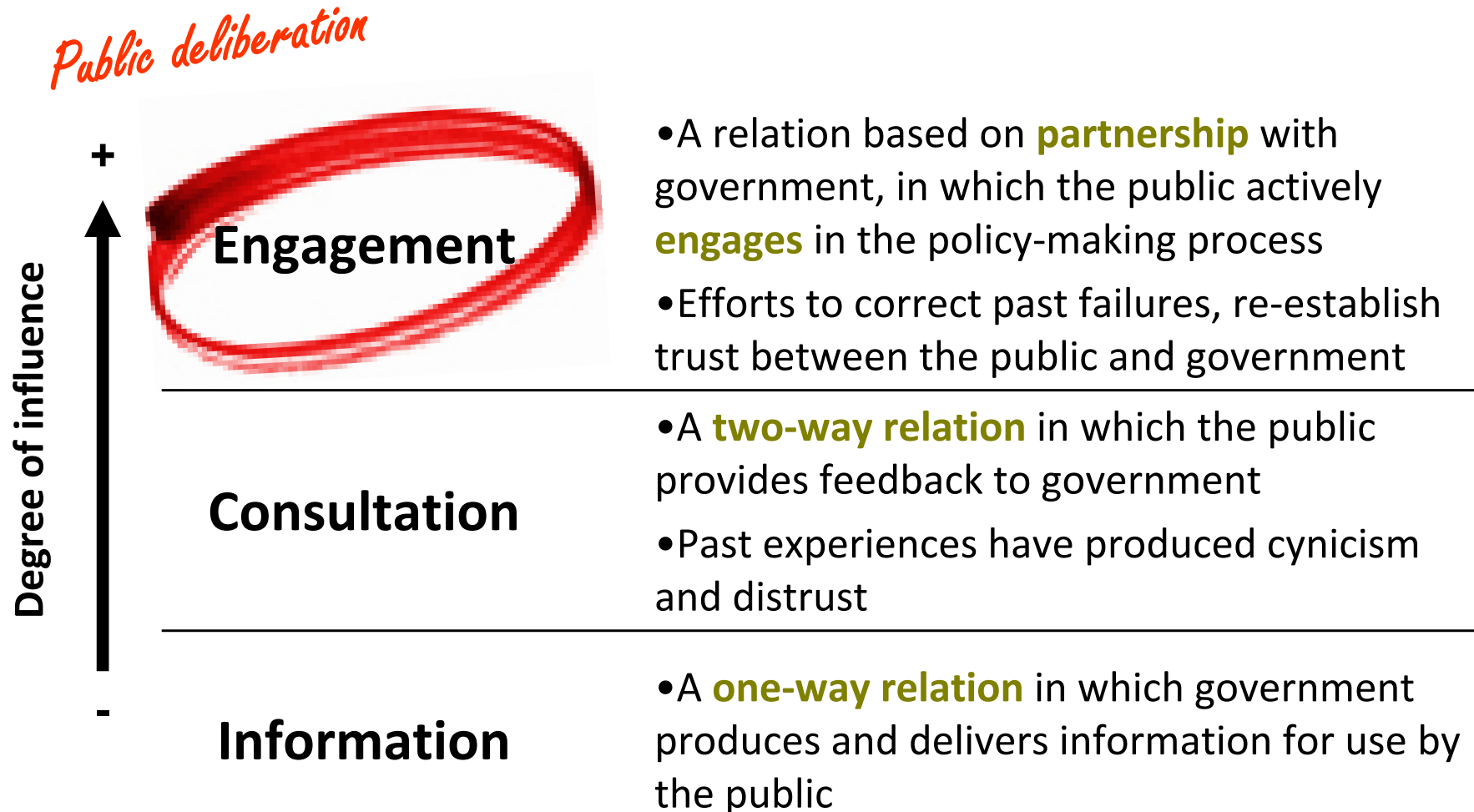
Why engage the public?

- A means to **democratize** policy-making
- A means to **ensure transparency**
- A means to **raise awareness, inform and/or educate** the public
- A means to **empower** the public
- A means to **inform policy-making in context of social and ethical dilemmas**
- A means to **find innovative and durable solutions** to solve collective problems

Who is the “public”?

- Not a monolithic entity; context dependent (class, culture, geo)
- Narrow vs all inclusive definitions
 - **Citizens, elected officials, patients, services users, NGOs, and other stakeholders**
- Variations in power, legitimacy, and urgency (i.e., desire to participate)

What does 'engagement mean?



*Inspired by OECD (2001). *Engaging citizens in policy-making: Information, consultation, and public participation*. PUMA Policy Brief no.10, Online [http://www.oecd.org/dataoecd/24/34/2384040.pdf]

Deliberative mappings

Charettes

Planning cells

Consensus
conferences

Community Health
Impact Assessment

21st Century Town
Hall Meetings

Public
engagement
mechanisms

Citizen juries

Scenario workshops

Deliberative polls

Citizen panels

McMaster Health
Forum

Open space
technologies



What do they have in common?

Composition

- Members of the public with different backgrounds, interests, and values

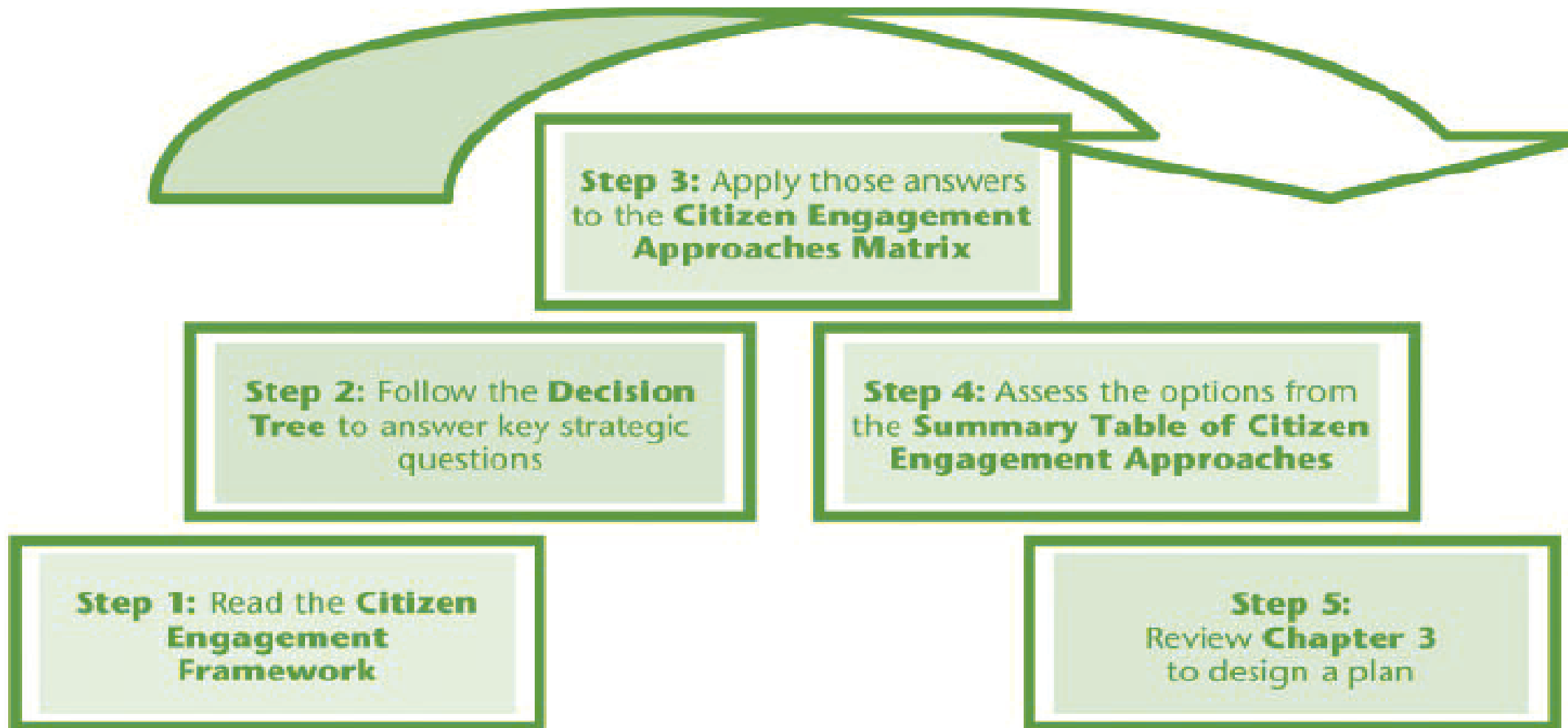
Process

- Participants receive and exchange information (e.g., background material distributed to participants and expert testimonies)
- Participants listen, learn, and potentially persuade each other

Expected outcome

- Participants come to more reasoned, informed, and public-spirited judgments

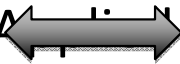
CIHR's decision tree model



Examples of Public Engagement (1):

**The Canadian Program of Research on
Ethics in a Pandemic**

CanPREP Methodology

- Stakeholder engagement
- Research partnerships
- Ethical Theory  Ethics
- 4 types of Public engagement (mixed methods)
 - Town hall forum (x3)
 - National public telephone survey (x2)
 - Online health care worker survey
 - Focus groups

CanPREP Public Engagement Objectives

Examine legitimacy of ethical frameworks for pandemic influenza planning by soliciting public perspectives on four key ethical challenges

- Restrictive Measures
- Duty to Care
- Priority Setting
- Global Governance & Obligations

CanPREP Town Halls

Events

- One day in each of Vancouver (Sept 08), Winnipeg (Feb 09), Saint John (May 09)
- Total N=69
- 4 issues, 4 unfolding scenarios

Select findings

- vulnerable populations
- public vs private goods
- role of public engagement and deliberation deeply felt to be significant

Aims of public engagement

To observe & capture the process of group deliberation around ethical issues in pandemic influenza planning, in a safe and open space

- Capture range of opinions
- Probe reasoning behind specific beliefs/positions
- Create a respectful environment
- Engaging people as “citizens”, not as policy-makers, health professionals
- Only seek a decision (not necessarily collectively) at the very end of process

Examples of Public Engagement (2):

The Consultation forum of Quebec's Health and Welfare Commissioner

Quebec's Health and Welfare Commissioner

Created in 2005 with the mandate to:

- Assess
- Consult
- Inform
- Recommend

The Consultation Forum

Created in 2008 with the mandate to formulate opinions on:

- Health system performance
- Social and ethical dilemmas
- Citizens' rights and responsibilities

The Consultation Forum (cont'd)

Composed of **18 citizens** and **9 experts** appointed for a **3-year mandate**, and meeting **4 times/year, each meeting lasting 2 days**

- One citizen is selected from each of the 18 regions in Quebec
- Each expert has a specific expertise related to health and social services (e.g., physician, nurse, social worker, ethicist, law professor, expert in health technologies, manager, etc.)

Consultation on the ethical challenges of prenatal screening for Down Syndrome

- Literature review (Jan-2008)
- Call for position papers (February-March 2008)
- Hearings (April-May 2008)
- Online consultation (June 2008)
- Consultation Forum (June & September 2008)
 - **As a society, what do we want to avoid, preserve, and promote?**

Group discussion

Environmental board OK's Rabaska liquid gas plant

« .. despite concern expressed by two public health departments ... »

- Robert Dutriscac, Le Devoir, 25 octobre 2007



Publié le 17 septembre 2010 à 05h00 | Mis à jour le 17 septembre 2010 à 10h57

La Santé publique enquête sur les impacts sanitaires



L'opposition à l'exploration et à l'exploitation des gaz de schiste reste très forte au Québec. Même si certaines firmes tentent de jouer la transparence en dévoilant les listes des produits chimiques utilisés, les données sont loin de rassurer la population.

Photo: François Roy, La Presse



Charles Côté

La Presse

Dans un geste qui semble précipité, le ministère de la Santé a demandé à ses experts de préparer un rapport sur «les impacts sanitaires liés à l'exploration et à l'exploitation des gaz de schiste au Québec», a appris *La Presse*.

Ce mandat, donné le 13 septembre, doit aboutir sur un «document de travail» vers la mi-octobre, selon Nathalie Lévesque, porte-parole du ministère de la Santé et des Services sociaux (MSSS).

Le travail a été confié à un comité composé de membres de l'Institut national de santé publique et de représentants des agences régionales de santé publique de la Montérégie, du Centre-du-Québec et de Chaudière-Appalaches.

Le comité doit revoir la littérature scientifique sur le sujet, évaluer les impacts des activités normales, des accidents potentiels et des nuisances et formuler des recommandations.

Pendant ce temps, l'industrie tente d'endiguer la vague d'opposition qui s'est levée dans les dernières semaines en jouant la carte de la transparence.

La firme Questerre a dévoilé la liste des produits qu'elle utilise dans ses forages. Elle énumère 12 produits mélangés à l'eau de fracturation, à des concentrations variant de 0,048% à 0,00002%.

Case: The Refinery Proposal

- A small poor remote community is the proposed site for a multinational, highly polluting processing plant (petro, uranium, creosote, waste incinerator, take your pick)
- Fed + Prov govt's promise tax incentives scaled to locally unprecedented targets for employment, and expansion of social, education, and health services & resources
- Much of the final product is to be shipped from or to other countries

Case: The Refinery Proposal

1. Who should have a greater say in this decision, the community, or outside experts (environmental activists, for example)? Can a community give “informed consent”? Who represents the community?
2. What data are needed, how much certainty and/or consensus is needed about that data? Who should bear the burden of proof?
3. What if the community is First Nations, Inuit or Métis? Can a balance be found between “economic development” and “environmental injustice” (that disproportionate enviro health impacts affect marginalized groups disproportionately often and severely)?
4. Even if rejected, is this an opportunity to promote positive indirect community values/practices (solidarity, sustainable development, mobilization, social justice, etc.)? How?

Success factors for effective participation



Create and support an 'expertise space' fit for the public (i.e., a space that makes the best use of their time and knowledge) see Davies et al. 2005

Don't create false expectations...
Clarify the roles and mandates.



Make sure that the group is representative and diversified...
and that everyone has the opportunity to participate meaningfully!

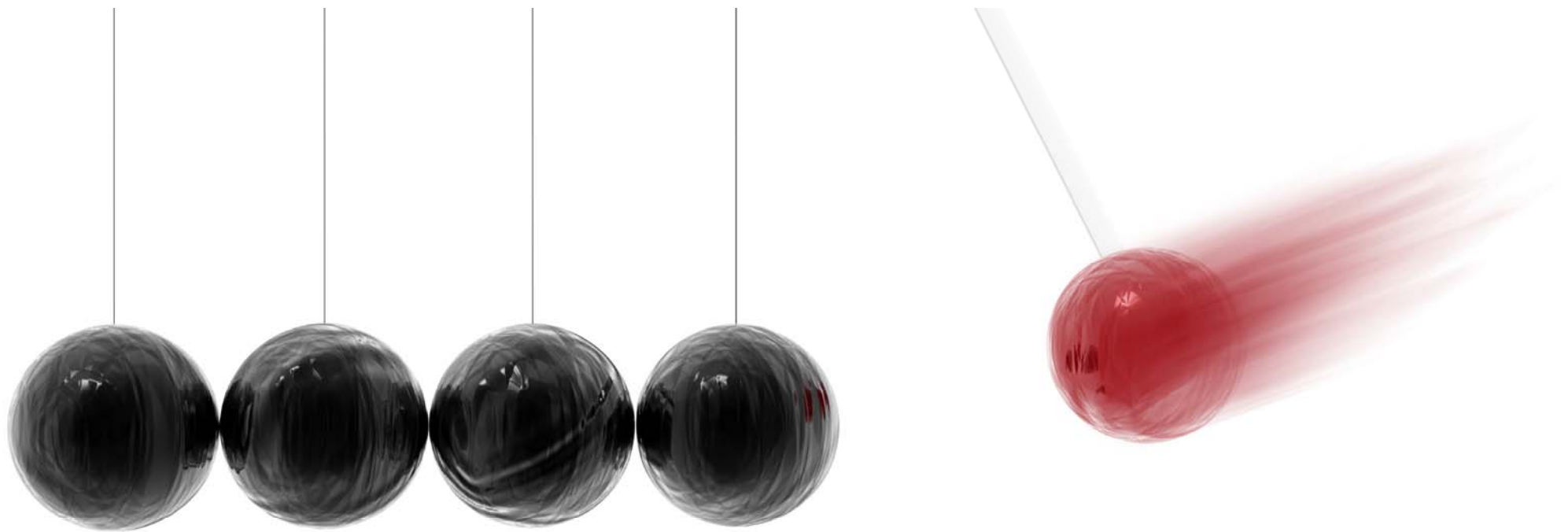




Make sure that participants have access to all the resources they need to participate meaningfully (e.g., information, time, \$, logistics).



Hope for the best, plan for the worst... Think about a conflict resolution strategy or a strategy to reach consensus (if necessary).



Clearly explain early on how their input will be used, and have a strategy to provide feedbacks to participants.



Evaluate your public engagement practices!

Tailoring public engagement to your professional activities

What are the **challenges to engage the public** in your professional activities?

What **support, resources, and access to expertise**
do you need to engage the public in your
professional activities?

What should we do when **science is not consistent with prevailing public views** regarding a public health issue?

Are there circumstances in which public views or prevailing public attitudes **should be given greater consideration** than what the science of the day has to offer?

Are there circumstances in which public views or prevailing public attitudes **should not be given greater consideration** than what the science of the day has to offer?

Conclusions

1. Public health ethics is integral to population level health protection and policy
2. The assumption of shared core values and virtues may be misguided
3. Public engagement strategies, diverse and increasingly required, can be powerful if they are carefully tailored

You're interested in this topic?

Visit us at www.ncchpp.ca for more resources on ethics and public engagement.



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