

Enhancing the Legitimacy of Pandemic Response Through the Lens of Public Health Ethics

Cécile Bensimon, PhD

on behalf of

University of Toronto Joint Centre for Bioethics



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Canadian Program of Research on Ethics in a Pandemic



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From William Stewart



“The time has come to close the book on infectious diseases. We have basically wiped out infection in the United States.”

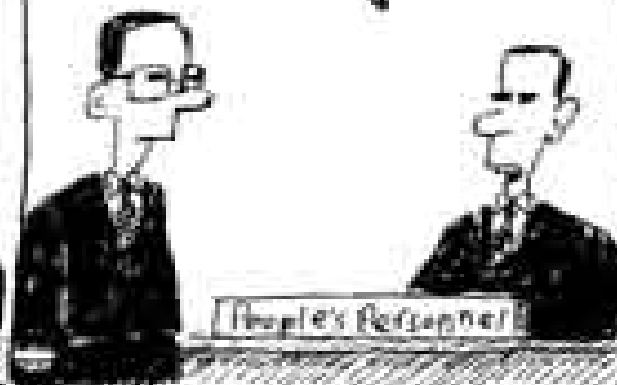
William Stewart, Surgeon General 1967

Meanwhile, back in Beijing...

I was
fired
for
downplaying
the SARS
outbreak.



What
was
your
job?



Minister
of
downplaying
the SARS
outbreak.





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Addressing ethical issues in pandemic influenza planning

Examining the wide range of issues raised by a potential influenza pandemic



The Ethics team of the Department of Ethics, Trade, Human Rights and Health Law (ETH) has been working on a project to study the wide range of challenging ethical issues raised by a potential influenza pandemic. A technical meeting was held on 18-19 May 2006 in Geneva to examine the major issues and an international consultation was held on 24-25 October 2006. The conclusions and recommendations of these meetings were used to develop a WHO guidance document entitled: Ethical considerations in developing a public health response to pandemic influenza.

Ethical considerations in developing a public health response to pandemic influenza:
[Contents](#)

Importance of infectious diseases to ethics

- ❧ Neglect of dilemmas inherent to infectious disease
- ❧ Yet of immense historic and future significance
- ❧ Crossing border from personal to global ethics
- ❧ Reinforcing our universal vulnerability
- ❧ Challenging traditional concepts

Importance of ethics to infectious diseases

- 1. The tension between the public good and individual rights in the application of restrictive or social distancing measures**
- 2. The duty to care of health care workers and the obligations of institutions to support them**
- 3. The setting of priorities in the allocation of scarce resources in critical care and community settings**
- 4. The scope of practice of community health centres within the broader community**
- 5. Risk communication and risk planning of practices and policies**

Myriad other issues

- ✓ **Shared decision-making** among key actors
- ✓ **Public/community engagement** in policy decisions
- ✓ **Transparency and accountability** in complex situations
- ✓ **Collaborative capacity surge**
- ✓ **Data Sharing**

Social distancing: what is at stake?

- Should we be concerned about burdening liberties and rights in a pandemic?
- Can we negotiate a balance between the benefits to public health and the rights of individuals?
- On what grounds does public health justify – or ought to – justify decisions about restrictive interventions?
- How do those most affected, the community of citizens, view the use of restrictive measures?

Duty to care: what is at stake?

- Is there a delineation of what constitutes a health care worker?
- Which health care worker has a duty to care?
 - Do unregulated health care workers have a duty to care?
- Do health care workers have an obligation to treat patients despite risk of infection?
 - Are there and what are the limits to the duty to care?
- Do institutions have an obligation to provide support to enable health care providers to carry out their duties?
 - Are there and what are the reciprocal obligations?

Priority-setting: what is at stake?

- What constitutes an essential service?
- How ought allocation decisions be made?
- By whom should allocation decisions be made?
- Who ought to have priority for access to resources?
 - Those that are sickest or those most likely to survive?
 - To save the most lives or give everyone an equal chance?
 - Give special consideration to vulnerable populations?
- What considerations should be taken into account in making these decisions?

Scope of practice: what is at stake?

- Does the duty to care extend beyond the borders of a clinician's own institution?
- Are community health care workers stepping out of scope if they are required to work in a higher risk environment?
- To whom does the responsibility fall to provide what is deemed to be an essential service?
- Does a community health centre have an obligation to extend services that may not be within the realm of its mandate?
- Ought governments have the right to mandate community health care centres to extend services to the broader community?

Risk management: what is at stake?

- How do we define, and who defines, what is an acceptable level of risk?
- How do we make decisions within a context of a lack of evidence of the effectiveness of interventions?
- How, and by whom, should decisions and processes be designed and implemented?
- In what ways can we promote a dialogue with those most affected, the community of citizens?
- How do we establish a common sense of purpose?

Importance of ethics to infectious diseases

1. The use of **restrictive or social distancing measures**
2. The **duty to care**
3. The **setting of priorities**
4. The **scope of practice**
5. **Risk management**



UNCERTAINTY

Access to treatment: Katrina



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

Access to vaccines: H1N1

Target group	SAGE (WHO)	U.S. (CDC)	ECDC	UK
Health care workers	✓	✓+ emergency medical services personnel	(✓)	✓= frontline health + social care workers
Pregnant women	✓	✓	✓	✓
High risk conditions: < age 65 > Age 65	✓	✓	✓	✓ ✓
Household contacts of: Children < 6 months immunosuppressed		✓	(✓) ✓	✓
Healthy children	✓	✓	☐ < age 2 ✓ all children	
Healthy adults : < age 65 > Age 65	✓ ✓	☐ to age 24 (✓)		
Critical infrastructure			✓	

Uncertainty

Can we make decisions based on **evidence-based assessments of risk?** (Coker et al.)

+

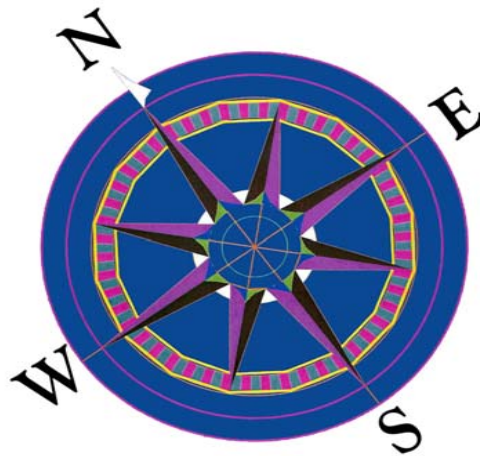
Or must we rely on decisions carrying **varying levels of empirical certainty?** (Callahan)

=

**Basis for decision
scientific analyses *and* value systems**

Ethics as anchor

Need a **moral compass** to navigate through crisis



Framework can guide the
how, why, when and by whom?

Ethical framework as guide

Decision-making for and during a pandemic influenza outbreak ought to be:

1. *guided* by ethical decision-making **processes**
2. *informed* by ethical **values**





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STAND ON GUARD FOR THEE

**Ethical considerations in
preparedness planning for pandemic influenza**

November 2005

A report of the
University of Toronto Joint Centre for Bioethics
Pandemic Influenza Working Group

Ontario Health

Pandemic Influenza Plan



June 2005

 Ontario

Accountable

There should be mechanisms in place to ensure that decision-makers are answerable for their actions and inactions. Defence of actions and inactions should be grounded in the 14 other ethical values proposed below.

Inclusive

Decisions should be made explicitly with stakeholder views in mind, and there should be opportunities to engage stakeholders in the decision-making process.

Open and transparent

The process by which decisions are made must be open to scrutiny and the basis upon which decisions are made should be publicly accessible.

Reasonable

Decisions should be based on reasons (i.e. evidence, principles, and values) that stakeholders can agree are relevant to meeting health needs in a pandemic influenza crisis. The decisions should be made by people who are credible and accountable.

Responsive

There should be opportunities to revisit and revise decisions as new information emerges throughout the crisis. There should be mechanisms to address disputes and complaints.

Equity	<p>All patients have an equal claim to receive the health care they need under normal conditions. During a pandemic, difficult decisions will need to be made about which health services to maintain and which to defer. Depending on the severity of the health crisis, this could curtail not only elective surgeries, but could also limit the provision of emergency or necessary services.</p>
Duty to provide care	<p>Inherent to all codes of ethics for health care professionals is the duty to provide care and to respond to suffering. Health care providers will have to weigh demands of their professional roles against other competing obligations to their own health, and to family and friends. Moreover, health care workers will face significant challenges related to resource allocation, scope of practice, professional liability, and workplace conditions.</p>
Individual liberty	<p>In a public health crisis, restrictions to individual liberty may be necessary to protect the public from serious harm. Restrictions to individual liberty should: be proportional, necessary, and relevant; employ the least restrictive means; and be applied equitably.</p>
Protection of the public from harm	<p>To protect the public from harm, health care organizations and public health authorities may be required to take actions that impinge on individual liberty. Decisions makers should: weigh the imperative for compliance; provide reasons for public health measures to encourage compliance; and establish mechanisms to review decisions.</p>
Proportionality	<p>Proportionality requires that restrictions to individual liberty and measures taken to protect the public from harm should not exceed what is necessary to address the actual level of risk or critical needs of the community.</p>

Privacy	Individuals have a right to privacy in health care. In a public health crisis, it may be necessary to override this right to protect the public from serious harm.
Reciprocity	Reciprocity requires that society support those who face a disproportionate burden in protecting the public good, and take steps to minimize burdens as much as possible. Measures to protect the public good are likely to impose a disproportionate burden on health care workers, patients, and their families.
Solidarity	As the world learned from SARS, a pandemic influenza outbreak, will require a new vision of global solidarity and a vision of solidarity among nations. A pandemic can challenge conventional ideas of national sovereignty, security or territoriality. It also requires solidarity within and among health care institutions. It calls for collaborative approaches that set aside traditional values of self-interest or territoriality among health care professionals, services, or institutions.
Stewardship	Those entrusted with governance roles should be guided by the notion of stewardship. Inherent in stewardship are the notions of trust, ethical behaviour, and good decision-making. This implies that decisions regarding resources are intended to achieve the best patient health and public health outcomes given the unique circumstances of the influenza crisis.
Trust	Trust is an essential component of the relationships among clinicians and patients, staff and their organizations, the public and health care providers or organizations, and among organizations within a health system. Decision makers will be confronted with the challenge of maintaining stakeholder trust while simultaneously implementing various control measures during an evolving health crisis. Trust is enhanced by upholding such process values as transparency.



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Guidance on H1N1 Flu Vaccine Sequencing

For readers interested in the PDF version, the document is available for downloading or viewing: [PDF Version \(79 KB - 2 pages\)](#) >> [Help with PDF documents](#)

Preamble

It is recognized that some individuals or groups not identified below may be at higher risk of severe illness or hospitalization due to socio-economic and lifestyle conditions, access to health care, and elevated risk of exposure to the H1N1 flu virus. Consideration will be given to targeting these individuals for immunization as our understanding of the virus evolves. Further consideration could be given to immunizing additional groups or individuals if needed to minimize societal disruption.

Recognizing that many Aboriginal populations are younger; may be more socio-economically disadvantaged compared to Canadians as a whole; have higher numbers of pregnant women; have higher rates of diagnosed and possibly un-diagnosed chronic disease; and may live in remote and isolated communities, all efforts will be made to enable those Aboriginal people who would benefit most from immunization, wherever they reside, to have access to H1N1 flu vaccine as soon as possible.

1. Those Who Will Benefit Most From Immunization and Those Who Care For Them

Persons with chronic conditions (NACI list) under the age of 65

Rationale: at higher risk of complications; 65+ less affected to date, Canadian modeling

Guidance on H1N1 Vaccine Sequencing

Persons residing in remote and isolated settings or communities

Rationale: limited access to medical care, potential for development of mass immunity and prevention of infection, logistically easier to target whole community; **equity**, high concentration of persons with chronic conditions, observed morbidity/mortality in some remote Aboriginal communities

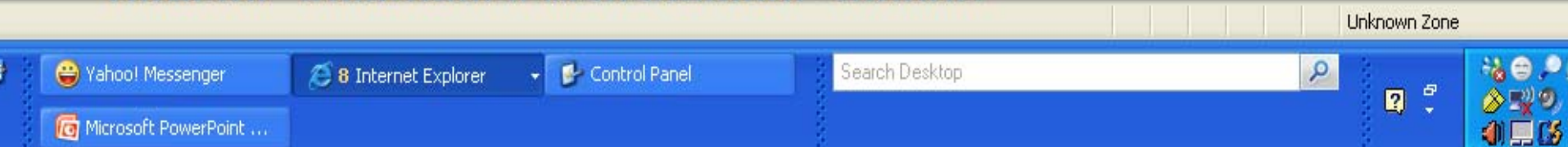
Health care workers (all health care system workers involved with the pandemic response or delivery of essential health services*)

Rationale: prevent health care worker (HCW) spread to vulnerable patients, prevent outbreaks, protect HCW (**reciprocity**) and protect essential health infrastructure

Pandemic H1N1 2009: Roles and Responsibilities

OHA February 25, 2010

Brian Schwartz MD, CCFP(EM), FCFP
Director, Emergency Management Support



The Public Health Measures Task Group

Interim Pandemic Planning Guidance Document: Options for Public Health Measures

September 29, 2009

“Ethics and Planning for PHMs: *The Task Group has explicitly sought to ensure that ethical principles, especially those articulated in the Joint Centre for Bioethics document Stand on Guard for Thee (2005) have been considered in a deliberative manner in the assessment of and development of recommendations on the implementation of PH measures.”*

Measures: case/contact management

“Although we are trying to make this as **least restrictive** as possible], there will be **restrictions on liberty to safeguard the health of the public.**

Proportionality needs to be anchored: The potential severity of the infection vs. the somewhat restrictive means to reduce transmission; The overall risks of transmission and the health consequences vs. pulling out people from the economic and social means of production...

Reciprocity addresses the measures that families, communities and governments will take to address the costs and consequences of cases complying with self-isolation recommendations. This was a powerful learning from SARS, and is recommended that it be addressed not just in the theoretical recognition but in the practical manner in which support for those in self-isolation is provided. And given that the capacity to endure this recommendation may not be equally distributed, this PH measure has important **equity** issues that must be understood and addressed, e.g. the more limited support capacity certain disadvantaged groups may have when they try to comply with [measures].”

Conclusion

“In the midst of a crisis where guidance is incomplete, consequences uncertain, and information constantly changing, where hour by hour decisions involve life and death, **fairness is more important rather than less.**”

Bell et. al. 2004

“Perhaps all of us should be considering **the kinds of persons, roles, and society** we want to work to create in advance of crisis.”

Dwyer and Tsai, 2008



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CanPREP Collaboratory



Collaboratory in Pandemic Ethics Knowledge Generation and Dissemination

A collaboratory is "an organizational entity that spans distance, supports rich and recurring human interaction oriented to a common research area, and provides access to data sources, artifacts, and tools required to accomplish research tasks."¹ Derrick L. Cogburn has further defined a collaboratory as "a new networked organizational form that includes social processes; collaboration techniques; formal and informal communication; and agreement on norms, principles, values, and rules."² The concept of a collaboratory originated in information sciences and has been successfully adopted by bench sciences. A collaboratory model is adaptable for conducting research with

Polls

If you had to choose a purpose for the (Pandemic Plan, what would it be?

- Saving as many lives as possible, IN CANADA
- Saving as many lives as possible, GLOBALLY
- Maintaining the economy
- Protecting human rights
- Preventing ecological damage