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INTRODUCTION

The current H1N1 influenza pandemic raises a number of ethical and practical challenges for Canadians as individuals and as citizens. How we tackle these challenges as a society will have significant implications for the building and maintaining of public trust, for sustaining the process of public engagement, and for the protection of vulnerable populations. From government and medical leaders to health care providers and the general public, all will be affected at some level and to some degree – thus the prevailing ethical issues cannot be disregarded. The *CanPREP Policy Briefs* report on research findings related to ethical issues in a pandemic. Our hope is that these papers will provide a basis for deliberation and discussion of the issues *right now*, when there is still time to respond.

A. WHAT IS CANPREP?

The Canadian Program on Research of Ethics in a Pandemic (CanPREP) is a CIHR-funded research program focused on identifying, studying, and contributing in response to ethical challenges in an influenza pandemic. The CanPREP team is an interdisciplinary group of researchers and practitioners, who are working closely with health sector collaborators to link research to practice in response to an influenza pandemic. Located at the University of Toronto Joint Centre for Bioethics (JCB), the CanPREP team is investigating key ethical questions, such as:

- what are the obligations of health care workers in a pandemic and what are the reciprocal obligations of the health care system to health care workers?
- how should resources, such as ventilators, antiviral medication, or community health services, be allocated in a pandemic?
- how should information be communicated to the public during a pandemic, and who should lead this dialogue?

Central to the CanPREP project is a commitment to citizen and broader stakeholder engagement in addressing these issues. We are exploring novel communication modalities in these efforts, including social networking. CanPREP is also committed to understanding community needs in a pandemic, recognizing that an influenza pandemic will affect some groups more than others.

B. CANPREP RESEARCH

1. “Stand on Guard for Thee” – Ethical Framework for Pandemic

In 2005, we prepared a report called “Stand on Guard for Thee: ethical considerations in preparedness planning for pandemic influenza.”¹ The report outlined an ethical framework to guide planning efforts in the health sector (See Appendix 1). Based on local experience with SARS, the report explored four key ethical issues, including: duty to care of health professionals, priority setting of limited health resources, restrictive measures (e.g., quarantine), and global governance. In the wake of SARS, members of the CanPREP team were actively involved in research to understand the ethical issues raised by SARS and to draw lessons from this work to inform planning for other communicable disease outbreaks, such as an influenza pandemic. The

need for an ethical framework to guide pandemic planning has been reinforced by colleagues at Dalhousie University, who have called for new thinking on how ethical frameworks might meaningfully guide policy discourse in Canada and elsewhere.²⁻³

2. Engaging the Voices of the Public – Citizen Perspectives on Ethical Issues in a Pandemic

Pandemic preparedness planning is typically based on expert input on behalf of the public, but without active engagement of the public. Public engagement in pandemic planning is important because it enhances accountability, especially in government decision-making⁴⁻⁶ and contributes to improving the legitimacy of decisions taken.⁷⁻¹⁴ In 2006, we launched a CIHR-funded study called “Ethics and pandemic planning: engaging the voices of the public” to explore Canadians’ perspectives on ethical issues in a pandemic. We were interested to understand how the values we proposed in the “Stand on Guard for Thee” report resonated with and would be endorsed by Canadian citizens. We have focused our research activities on three interrelated projects, which were designed to elicit Canadians’ and other stakeholders’ perspectives on ethical issues in a pandemic:

- National Public Opinion Survey of Canadians
- Town Hall Meetings in Vancouver, Winnipeg, and Saint John
- National Stakeholder Forum with policymakers, regulators, and community groups in Toronto.

A brief summary of each research project is provided in the Appendix 2. Preliminary results from these projects are highlighted in these CanPREP Policy Briefs.

C. CANPREP POLICY BRIEFS

The *CanPREP Policy Briefs* provide a preliminary analysis of CanPREP research findings. Each paper discusses ethical issues related to a particular research theme (e.g., priority setting, duty to care) and addresses the following questions:

- A. Why is this research theme an ethical issue in a pandemic?*
- B. What are some of the key ethical considerations?*
- C. What did Canadians tell us about this research theme in a pandemic?*
- D. What does this mean for H1N1 response?*

The *CanPREP Policy Briefs* are intended to stimulate reflection on and discussion of these issues. In the coming months, we will continue to report on our research findings.

For more information about our work, please visit: www.canprep.ca.

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+ = Ethics and Pandemic Planning: Engaging Voices of the Public

± = Stand on Guard for Thee: Ethical considerations in preparedness planning for pandemic influenza

DUTY TO CARE - ETHICAL CONSIDERATIONS

CanPREP Policy Briefs

Maria, a 35-yr old family physician and mother of three children aged 4-8, works in a primary care clinic in Toronto and is one of 12 doctors practicing in the clinic. After hearing media reports regarding the H1N1 pandemic, her husband is worried that Maria may become ill or bring home illness to her family and encourages her not to go to work. Maria is torn because she doesn't want to abandon her patients and increase the workload of her colleagues, many of whom like her have young families. Maria and her husband are also concerned about their children, who attend daycare and might be exposed to the virus. What should Maria do?

A. WHY IS DUTY TO CARE AN ETHICAL ISSUE IN A PANDEMIC?

Infectious disease is an occupational risk for health care workers and others who care for infected patients. In the developed and developing worlds, front line health care workers (HCWs) face disproportionate risks of serious morbidity and mortality from infection.¹ Response to a pandemic will call upon a wide range of care givers. These will come from both the formal and informal health care system, and involve clinical and non-clinical HCWs, professional and non-professional staff. In an influenza pandemic, HCWs may face competing personal and professional obligations – to their patients, colleagues, employers, family members, and to their own health. Indeed, competing obligations may explain why 25 - 85% of HCWs report being unwilling to show up for work in a pandemic.² Do HCWs have an obligation to treat patients despite risk of infection? What limits, if any, are there to health care workers' duty to care? What institutional supports are owed to health care workers in a pandemic?

B. WHAT ARE SOME OF THE KEY ETHICAL CONSIDERATIONS?

Health care workers' duty to care is rooted not only in the professional virtues, self sacrifice and altruism of individual workers. Rather, it arises from a social response to what values our society hold as important, how we are all vulnerable to infection and illness, and that this shared vulnerability underscores the importance of solidarity and reciprocity.³ However, we also found that important documents such as codes of ethics and professional directives were not clear in stating the precise level of acceptable risk for HCWs to assume.¹ Our research results have indicated that the duty to care must be understood as transcending individual provider considerations as such considerations are embedded within institutional and social contexts.⁴ Other relevant ethical issues include reciprocity, trust, and solidarity.⁵

C. WHAT DID CANADIANS TELL US ABOUT DUTY TO CARE IN A PANDEMIC?

Reciprocity - Our national survey results reflect the ethical complexity of this issue, however there is some strong consensus. The public believes that HCWs should report to work and face all risks (90% agreed) provided safety precautions are provided. 85% believed that governments should provide disability insurance and death benefits at no charge for HCWs at risk during an influenza crisis. 84% of respondents thought that if HCWs do not feel safe at work, they have a right to file a grievance. Participants felt that governments have an obligation to ensure the safety and health of populations living on their territory, regardless of ethnicity, nationality, religion, registration to a social service system or income. They also felt that governments have an obligation to ensure the ability of HCWs to provide care in a manner that protects the HCW as much as possible. The recognition of mutual vulnerability and of reciprocal obligations of HCWs is integral to understanding the ethical challenges posed by pandemic influenza. The public, though, was somewhat conflicted on what to do with HCWs who do not come to work without a legitimate reason. 48% agreed that they should face loss of employment or professional license, whereas 38% disagreed. The sharpest division appeared with respect to the government using conscription of HCWs during a pandemic. 47% agreed with conscription of HCWs while 43% disagreed.

Social Contract - Participants of the Town Hall forums were in strong agreement that health care professionals are under an implicit social contract based on their profession and training to provide care under adverse conditions such as a pandemic influenza outbreak. This group focused on the idea that the education required to become a health professional was a valuable

“If people that work in labs don’t want to come to work, then do you have a job or do you not have a job, right? I mean, that is your job and you’re always exposed to something and you have precautions anyway.”

-Study Participant

societal resource provided to the individual; those who did not wish to accept such service demands should not have used the society’s educational resource. Some participants voiced that not reporting for work in general was inexcusable (e.g. discussion surrounding the Hippocratic Oath). It was felt that like soldiers, HCWs should be expected to uphold their duties no matter how challenging and frightening the situation. On the other hand, the group also felt that the government and health care organizations had

reciprocal obligations to protect health care professionals from elevated risks in all ways possible, including policies to ensure a safe working environment.

Vulnerability of HCWs - The obligation to work is not without qualification, as 89% of survey participants agreed that having a serious health problem that could increase vulnerability to influenza was a legitimate reason not to be expected to work. The public was somewhat less supportive of other competing care obligations such as having young children or elderly relatives. 57% agreed that caring for a family member is a legitimate reason to not work. The Town Hall participants felt strongly that while most HCWs would uphold their duty to care, it is the right of the individual HCW to refuse to come to work, whether out of concern for personal safety, or other

“She’s not going to be any good at work if she’s dealing with a crisis at home.”

-Study Participant

obligations such as family. Furthermore, the group stressed that individuals should not be penalized for not reporting for work. Rather, emphasis should be placed on positive action, such as education, and addressing fearfulness, building a collegial environment, and building the sense of being a valued member of the team.

Solidarity – Town Hall participants felt that as a health care provider, not going into work could potentially place colleagues and the general public at an increased risk during a pandemic. Ultimately, the refusal of an HCW to work during a pandemic may likely diminish the quality of health care that can be provided during a pandemic. Therefore it seems that during a pandemic solidarity is a very significant moral impetus that should inform HCWs decisions about whether or not to work.

D. WHAT DOES THIS MEAN FOR H1N1 RESPONSE?

1. Pandemic planners should ensure the right of HCWs to safe working conditions is maximized to ensure the discharge of duties and that HCWs receive sufficient support throughout a period of extraordinary demands, which will include training on hygienic measures to reduce infection risk.
2. Consideration should be given to needs of health care providers to ensure care to their families.
3. Professional associations should provide, by way of their codes of ethics, clear guidance to members in advance of an influenza pandemic. This may include information regarding existing mechanisms to inform members as to expectations and obligations regarding the duty to provide care during a communicable disease outbreak.
4. Pandemic planners should ensure that processes be in place to accommodate legitimate exceptions to the provision of clinical care (e.g. pregnancy, immunodeficiency).
5. Pandemic planners should assess local circumstances and ensure the participation of the community sector in planning of formal and informal care networks and engage clinical and non-clinical, professional and non-professional HCWs.

DUTY TO CARE - LEGAL CONSIDERATIONS

CanPREP Policy Briefs

A. LEGAL DUTY TO CARE

Legal duty to existing patients

Physicians, nurses, and other health care providers (HCPs) who provide hands-on care to patients have a legal duty to provide a certain standard of skill and care to their patients.¹ In determining what HCPs' 'duty to care' requires of them, one must consider whether the care they are providing is the standard of care that a 'reasonable' HCP in that discipline would provide under the circumstances. Specialists will be required to exercise a higher degree of care and skill in their area of expertise.² If a HCP breaches his or her 'duty to care' and a patient suffers an injury or loss as a result, the HCP may be found guilty of negligence and forced to pay the injured patient monetary damages to compensate for the injuries caused.³ Professional insurance may cover these costs for some professions.⁴

During a pandemic, HCPs may wonder what is required of them considering their competing responsibilities to their uninfected patients, their infected patients, their families and themselves.⁵ Notwithstanding that there has been limited case law, literature, and legislation on what a HCP's legal duty of care is during a pandemic, HCPs can gain insight into their obligations by informing themselves about the general legal doctrines developed in non-pandemic cases and legislation.⁵

Legal duty to non-patients

During a pandemic, HCPs may have a legal obligation to treat individuals who are not already their patients. If a pandemic is declared a 'state of emergency', the government has the power to authorize, or in some provinces, require HCPs to provide services that they are reasonably qualified to provide. The liability of HCPs who are acting under these 'emergency management' statutes varies, but is usually limited to that of gross negligence ("very great negligence")⁶ or acts that are committed in bad faith.

Absent a declared state of emergency, the traditional view has been that HCPs only owe a duty to provide care to their existing patients.⁷ There is an exception in Quebec, where the Quebec *Charter* states that every person must come to the aid of anyone whose life is in peril.⁸ There has been some indication, however, that Courts may be willing to shift away from the traditional view. Some Courts have used HCPs' ethical obligation to treat in emergencies to inform a legal duty to treat in emergencies.⁹ In addition, HCPs working in emergency rooms or providing emergency services may be found to owe a duty to care because of the reliance the public places on them to provide emergency care.¹⁰

HCPs serving rural or isolated communities might also be precluded from turning away non-patients. Members of these rural or remote communities often come to rely upon these HCPs to provide care, which might mean HCPs have a legal duty to treat non-patients, at least while

the condition of the individual is serious and travel to receive alternative medical assistance is unrealistic.¹¹

Irrespective of a legal duty to aid a non-patient, if HCPs choose to come to an individual's aid, they may have created a HCP/patient relationship and thus assumed any resulting liability.¹² This liability may be limited by 'Good Samaritan' legislation that exists in all the provinces (except New Brunswick).¹³ This legislation states that HCPs providing aid at the scene of an emergency and without expectation of compensation will only be found liable if they commit *gross negligence* (i.e. "very great negligence").⁶

Legal duty to protect the public

There are times when HCPs may owe a legal duty to members of the public at large. For example, some HCPs in the United States have been found to owe a duty to care for relatives of patients who presented with infectious disease symptoms. The American Courts found these HCPs negligent because they failed to warn relatives, or other persons foreseeably at risk, of the risks of associating with the patient or of the precautions they should take to prevent infection.¹⁴ Courts in Canada could make similar decisions with respect to HCPs who provide hands-on care to patients during a pandemic.

B. LEGAL RIGHT TO REFUSE TO WORK

Any individuals working in a health care facility or hospital during a pandemic may have a legal right to refuse work in unsafe working conditions. This right applies to all health care workers ("HCWs"), which includes both HCPs and workers who do not provide hands-on care to patients. HCWs may or may not have a right to refuse to work while the unsafe conditions exist, depending on the circumstances surrounding the unsafe work and the province in which they work. If they have a legal right to refuse to work, they may stop working until the unsafe situation has been addressed.¹⁵ The legal right to refuse work because of unsafe working conditions is described in provincial occupational health and safety statutes.

Pandemic as a 'workplace hazard'

A preliminary issue to be addressed is whether a pandemic virus can constitute a 'workplace hazard'. One labour board indicated that an infectious disease might be understood as a 'workplace hazard' if the risk of contracting the virus in the workplace is *significantly* elevated compared to the risk of contracting the virus in the community at large.¹⁶ This will depend on the nature of the pandemic virus.

Justifying refusing work: satisfying the four criteria

Labour boards across Canada have affirmed that a worker must satisfy four criteria to justify refusing to work because of unsafe working conditions:¹⁷

- 1) The worker must *honestly* believe that his or her health or well-being is endangered. A worker cannot refuse to work for a non-safety reason; the safety concern must be 'firmly and sincerely felt'.¹⁸
- 2) The worker must *reasonably* believe that his or her health or well-being is endangered. A reasonable belief is one where an average worker at the work place with the same training and experience would believe that the circumstances represent an 'unacceptable' degree of hazard.¹⁹

- 3) The worker must communicate this belief to his or her supervisor in a reasonable manner.
- 4) The danger must be sufficiently serious to justify the particular action taken. The danger must be of an immediate and serious nature.²⁰

HCWs with increased susceptibility to infection: right to refuse work

As the research on a pandemic virus progresses, certain populations will emerge for whom the virus will pose a particularly grave risk. When HCWs with particular susceptibilities are justifying a work refusal order, they may consider what an average *susceptible* HCW would believe to satisfy the second criteria above.²¹

An employer has a duty under provincial anti-discrimination laws to try and accommodate a HCW with a particular susceptibility.²² If an employer refuses to accommodate the HCW, that employer may be found to be discriminating on the basis of sex (when pregnancy is the source of susceptibility) or disability (when an underlying medical condition is the source of susceptibility). What will be sufficient ‘accommodation’ will depend on the facts of each HCW’s case. Human rights law requires accommodation to the point of ‘undue hardship’, which means employers should be willing to endure some degree of hardship in their accommodation.²³ This may include requiring the employer to create a new position or displace another worker.²⁴

Limit to the right to refuse work: acceptable degree of hazard

A HCW will only be able to refuse work if they reasonably believe that the work creates an ‘unacceptable’ hazard. It has been suggested that there are two types of ‘acceptable’ hazards. First, hazards that are *inherent to the occupation* of the worker are usually ‘acceptable’ hazards.¹⁵ In joining their occupation, HCWs implicitly accept a certain level of risk. When determining if something is inherent to their occupation, HCWs might ask themselves, “if you remove the thing claimed to be inherent, does my job continue to exist?”²⁵ Second, hazards created by work that are part of the *normal working conditions* are usually ‘acceptable’ hazards.¹⁵ Normal working conditions have been suggested to include the existing and established practices of an institution that are part of a workers’ established routine.²⁶ Normal working conditions can usually be called into question under two circumstances: 1. Situations where standard safety equipment is malfunctioning;²⁶ and 2. Situations where the practice, in the new circumstances, creates the risk of imminent danger.²⁷

With respect to a pandemic, some risk of exposure to a virus might be considered a normal working condition in workplaces where the HCWs are in contact with the public on a daily basis.²⁸ An employer will likely be expected to do everything reasonably possible to minimize workers’ exposure to the virus. The remaining minimal possibility of exposure to the virus might be viewed as a normal condition of work.²⁸

Many workplaces may rely on provincial occupational health and safety standards to protect their workers. HCWs would likely have to show a *significant* change in circumstances to illustrate that the once acceptable safety standards are now likely to endanger.²⁹ It is possible however, that the characteristics of the pandemic virus might change so quickly and drastically that a HCW could argue that the occupational health and safety boards have not had to time to react.

Currently, it is unlikely that workplaces can depend on general government Directives as acceptable standards for protecting HCWs’ safety.³⁰ A recent Ontario Court of Appeal case

found that safety Directives issued during the SARS crisis were issued for the benefit of the public at large, not for the safety of HCWs alone.³⁰ Thus, it is likely that only health and safety standards with a primary aim of protecting the health and safety of HCWs specifically can be relied upon as minimum standards.

Limit to the right to refuse work: refusal that endangers another person

The occupational health and safety statutes of Ontario, Quebec, Nova Scotia, Yukon Territory, and the Federal government state that workers may not refuse to work if the work refusal will put the life, health or safety of any other person directly in danger. There has been limited interpretation of what this limit means. The cases where this limit will apply will likely be highly context specific. For example, if a HCW works in a large health care facility where someone else can take up his or her responsibilities, a work refusal might not be viewed as endangering a patient or another HCW.³¹ However, HCWs in remote communities who are the only individuals capable of performing certain essential tasks may be seen as endangering others if they refuse to work.

If no legal right to refuse work exists

The limits to the right to refuse work might result in a HCW not having the legal right to refuse work, even though they have a reasonable belief that their health or well-being is endangered. The limits discussed above, however, only preclude a HCW's right to refuse work; they do not preclude a HCW from filing a complaint with a workplace safety inspector.²⁶

C. PROFESSIONAL RESPONSIBILITIES AND THEIR LEGAL IMPLICATIONS

Some HCWs (nurses, physicians, physiotherapists, etc.) are members of self-governing professions. These regulated HCWs have certain professional responsibilities to their patients, society, the profession, and themselves. These responsibilities are generally articulated in codes of ethics, codes of professional conduct, or in legislation. For example, physicians are governed by the *CMA Code of Ethics*³² and registered nurses are governed by the *Code of Ethics for Registered Nurses*,³³ and the *Nursing Act, 1991* regulations.³⁴ If any member of the public has a concern about a HCW breaching their responsibilities, he or she may lodge a complaint with the College of that regulated profession in the province the HCW is registered or licensed.³⁵ If HCWs are found to have violated their professional responsibilities, they may be found guilty of professional misconduct and can face a range of penalties, the most severe being a revocation of membership to that profession.³⁶

During a pandemic, regulated HCWs may experience tension between their professional responsibilities and their legal rights and duties. For example, HCWs may have a professional responsibility to continue providing care to their patient,³⁷ but have a legal right to refuse work in unsafe working conditions. HCWs should remain aware of their professional responsibilities and the potential discipline they may face for breaching these responsibilities. However, HCWs should also remain aware that the existence of this separate regulatory regime does not negate HCWs right to refuse work in unsafe working conditions, nor does it shield HCWs from negligence liability for breaching a legal duty of care.

PRIORITY-SETTING

CanPREP Policy Briefs

Mr. M requires admission to the intensive care unit (ICU) after suffering a severe but potentially reversible brain injury caused by a bicycling accident. Just as his transfer is about to be made, an ICU nurse named Ms. A is admitted. She has been infected with the influenza virus, which she may have contracted while caring for patients in the hospital's ICU. She needs immediate ventilation support, which is only available in the ICU bed designated for, but not yet occupied by, Mr. M. Who should be given the ICU bed and why?

A. WHY IS PRIORITY-SETTING AN ETHICAL ISSUE IN A PANDEMIC?

In a pandemic influenza outbreak, demand for health care services can be expected to exceed available resources. Difficult decisions will need to be made about who ought to have access to ventilators, vaccines, antivirals, and other necessary resources in hospitals and in the community. Clinical criteria will provide some guidance on which patients are most likely to benefit from a particular therapeutic intervention. However, when resources are scarce, tough choices will need to be made about which patients can be treated and what services can be offered. These are value-based decisions that cannot be made with reference to clinical criteria alone. For example, should priority be given to the sickest patients or those most likely to survive? Should resources be allocated to save the most lives or to give everyone a fair chance at survival? Should special consideration be given to vulnerable populations in determining access to resources? Who should make these allocation decisions?

B. WHAT ARE SOME OF THE KEY ETHICAL CONSIDERATIONS?

The ethical goals of priority-setting are legitimacy, fairness, and equity.¹ This is especially important in the process of determining which medical services to maintain and which services to place on hold during a pandemic.² A clear message emerging from the SARS experience was that, in a public health crisis, when resources are scarce and decisions must be made with limited information, a fair process is critical to establish the legitimacy of allocation decisions and to preserve trust among affected stakeholders. Following SARS, some clinicians reflected on the “collateral damage” to some patients, whose surgeries were cancelled in response to the infectious risk, and to clinicians themselves, who were faced with tough choices about who should have access to care.³ Other relevant ethical issues for priority-setting are: trust, solidarity, and stewardship.⁴ To fully characterize these issues, it is important to include public perceptions facilitated through ethical deliberation.

C. WHAT DID CANADIANS TELL US ABOUT PRIORITY-SETTING IN A PANDEMIC?

“We only need to rethink how we use our resources and use them in more creative ways.”

- Study Participant

The notion of scarcity – A strong majority (72%) believed that priorities should be set for access to hospital treatment services, but were more likely to argue for giving every Canadian an equal chance of receiving access to antivirals (59%). However, many participants were not convinced that resource scarcity was the primary challenge of priority-setting in health organizations, nor that rationing was the

solution to scarcity. They were not willing, for example, to accept that there were no other alternatives for Mr. M or Ms. A in the scenario above. Instead, they contended that we ought to rethink how we use our resources and to use them in more creative ways, including involvement of informal caregivers.

Balancing Need and Utility – Participants identified three relevant considerations in making priority-setting decisions: need, survivability, and social value. Need was described as giving resources to those persons who are were the sickest or required being healthy because they were directly responsible for the care of others (e.g. elderly parents). The notion of need most often occurred with regard to need for medical resources. Participants suggested that need should be balanced by two “utility” considerations. First, participants felt that scarce medical resources ought to be given to individuals who are most likely to survive with the use of medical resources, and hence, benefit from allocated resources. Second, it was recognized that there might be social utility in treating some patients rather than others. Specifically, participants reflected on the social value of health care workers, police officers, or others who might be integral to the ongoing functioning of society in a pandemic crisis.

How to decide and who should decide – Participants stated that in a fair priority-setting process, criteria for priority-setting decisions should be made in advance of a crisis situation by groups of people that include members of the public and other disciplines outside of medicine. Participants suggested that predetermined guidelines or criteria could help decision-makers formulate concrete allocation decisions in the context of an actual influenza pandemic. Moreover, there should also be an appeals process open to those persons denied resources. All decisions taken should be transparent in order to engender a sense of public trust during a difficult time. If time should not allow for such preliminary deliberation on allocation criteria, then participants felt that one person should be appointed to make decisions since efficiency would become vital; however, this was felt as inappropriate if proper planning had occurred prior to the influenza pandemic.

“It’s all got to be taken care of and be right out there, right from the beginning, so everyone knows that that’s the only way it can be fair.”

- Study Participant

- Study Participant

Priority for health care workers – Town Hall participants and stakeholders felt that health care workers should be prioritized for access to some health care resources given their critical role in protecting the health of the public in general and in recognition of their willingness to assume the risks of infection. 94% of survey participants claimed that health care providers should receive priority for antivirals during an influenza pandemic, confirming what Town Hall participants and stakeholders expressed, and 89% believed that children were a second priority. However, the priority of health care workers was not seen to be absolute. It was felt that, depending on the circumstances, there may be other groups with a stronger claim for these resources.

Concerns about the current health care system – Finally, participants expressed skepticism about the Canadian health care system's capacity to respond effectively to an influenza pandemic. They noted that priority-setting is already a challenge in Canadian health care and that an outbreak of H1N1 would simply highlight and exacerbate the weaknesses of the current health system. The perceived existing deficiencies in the health care system would make setting priorities and the fair allocation of resources that much more difficult. In spite of this, approximately 91% of survey participants identified the goal of saving lives as the most important goal of pandemic influenza preparations, with 41% endorsing saving lives solely in Canada as the highest priority and 50% endorsing saving lives globally as the highest priority.

D. WHAT ARE THE IMPLICATIONS FOR H1N1 RESPONSE?

1. Governments and health sector officials should engage the public actively in transparent, inclusive, and accountable deliberations about priority-setting issues related to the use of limited resources for treatment and prevention.
2. Governments and health care sector officials should engage stakeholders (including health care workers and administrators, and the public) in determining what criteria should be used to make resource allocation decisions (e.g., access to ventilators, vaccines, antivirals).
3. Governments and health care sector officials should provide an explicit rationale for resource allocation decisions, including priority groups for access to limited health care resources and services. The rationale should be publicly accessible, justified in relation to the defined criteria, and include a reasonable explanation for any deviation from the pre-determined criteria.
4. Governments and health care sector officials should ensure that there are formal mechanisms in place for stakeholders to bring forward new information, to appeal or raise concerns about particular allocation decisions, and to resolve disputes.

RESTRICTIVE MEASURES

CanPREP Policy Briefs

Imagine that public health officials are strongly recommending the immediate use of restrictive measures to help slow the spread of infection. This includes the closing of community centres and the cancelling of all large public gatherings. One family, whose two daughters were killed in a car accident, plans to hold a large memorial service with family and friends the following day. Over 500 people are expected to attend the funeral. Should public health officials impose a restriction on the funeral - a sacred rite to honour the passing of loved ones - and prevent it from happening?

A. WHY IS RESTRICTIVE MEASURES AN ETHICAL ISSUE IN A PANDEMIC?

Restrictive measures may be an important public health tool to limit spread of the H1N1 virus in the community.¹ Public officials may close schools or daycares, cancel public gatherings and sporting events, or impose quarantine or isolation, where needed. Restrictive measures raise questions about the legitimate limits of individual liberties to achieve public health goals. How should individual liberties and the public good be balanced? What constitutes an appropriately proportional response to the risks of infectious spread recognizing the impact of such measures on individual citizen's lives? What obligations, if any, does society have to those whose liberties have been restricted? On what basis should decisions about the use of restrictive measures be made?

B. WHAT ARE SOME OF THE KEY ETHICAL CONSIDERATIONS?

Governments may need to limit three basic personal freedoms – mobility, freedom of assembly, and privacy – in order to protect the public good.⁴ In the aftermath of SARS, JCB research showed that citizens understood and accepted the need for restrictive measures to control the spread of infection.² Most saw it as a form of civic duty and were willing to accept limits to their individual liberties for the public good.¹ Our data also highlighted the importance of reciprocity. Reciprocity requires society in turn to ensure that those affected receive adequate care, and do not suffer unfair economic penalties.^{3,5} If decision makers expect full compliance with restrictive measures, the decisions need to be made in a fair manner and people affected by such measures need support.¹ The SARS epidemic also highlighted how scientific uncertainty can permeate public health decision-making in pandemics, leading us to think about how to justify public health action when there is insufficient evidence of the effectiveness of a restrictive intervention.³ Other relevant ethical issues to consider are privacy and individual liberty.¹

C. WHAT DID CANADIANS TELL US ABOUT RESTRICTIVE MEASURES IN A PANDEMIC?

“For me, this raises the question of interactive societal responsibility. If society deems it necessary for [someone] to stay at home to protect society from the spread of infection...then society must, in turn, be responsible to him to ensure he is well provided for and will not suffer the results of his patriotic duty.”

- Study Participant

Reciprocity – Overall, citizens reported support for the use of restrictive measures. A large majority (85%) of survey respondents agreed that governments should have the power to suspend some individual rights (e.g. traveling, right to assemble) during an influenza pandemic. However, they also contended that there is a reciprocal obligation of governments to provide for the basic needs of restricted individuals (e.g., food, shelter, social support) (95%) and support services after the restrictive measures ended (79%). These views were echoed by Town Hall participants, who raised specific concerns about the implications of restrictive measures for the job security and economic stability of

individual citizens. In particular, they argued that restricted individuals should not be penalized by an employer for following a quarantine order (e.g., losing a job) and that society as a whole has the obligation to provide social and material support to persons subjected to restrictive measures (e.g., ensuring access to essential goods and services).

Protecting the public from harm – Appropriate use of restrictive measures were linked to the public’s right to health protection. Indeed, 50% of survey respondents reported that violation of an appropriate quarantine order was equivalent to manslaughter. While citizens were broadly supportive of using more coercive measures, such as isolation and quarantine, their expectation was that these measures should only be ordered if necessary to protect the public good, be applied equitably, and be accompanied by appropriate supports. It was also mentioned that instead of employing a punitive model centred on non-compliance, compliance to restrictive measures should be encouraged and addressed proactively.

Communication as information – The theme of transparent, timely, and accurate communication emerged as many participants stressed the fact that clear communication of vital information is critical for compliance and public trust. Open and transparent communication was thought to foster voluntary participation by engaging people in understanding what and why measures were needed. Along with that, participants felt that it was preferable, indeed more appropriate, to communicate uncertainty rather than to give inconsistent estimates or assessments of the

“Our morals certainly influence how we are going to make decisions, and you and I may not share the same philosophies or values and therefore this creates what seems like irresolvable conflict. But I think what helps resolve that is deliberation and hopefully, as a result of that, we’ll be able to come to some common ground on how and which and why decisions are made.”

- Study Participant

situation. That being said, communicating uncertainty was not thought to preclude communicating with clarity and decisiveness. One of the most common themes identified as an element of pandemic response was the need for consistency and coherence in the messages that public health authorities and community leaders communicate to the public.

Communication as deliberation – Overall, participants believed that dialogue and deliberation can move us towards greater clarity and, ultimately, toward better and more informed decision-making. Participants frequently expressed the view that the management of a pandemic influenza outbreak, including the use of restrictive measures, requires a citizenry that is informed, engaged, and responsive. This means involving citizens *prior to* the outbreak as policy and plans are set as well as *during* the outbreak when these will be implemented. There was strong support for public input in pandemic planning and response, emphasizing the need for an open and collective process of public deliberation well before a crisis emerges. Many participants thought that deliberative processes were a means to inform the public, make decisions, resolve uncertainty, and formulate norms for public health emergencies such as H1N1. Public deliberation was viewed as a source of democratic authority and legitimacy that ought to guide practice and policy.

D. WHAT ARE THE IMPLICATIONS FOR H1N1 RESPONSE?

1. Public health officials should ensure that pandemic influenza response plans include a comprehensive and transparent protocol for the implementation of restrictive measures. The protocol should be founded upon the principles of proportionality and least restrictive means, should balance individual liberties with protection of public from harm, and should build in safeguards such as the right to appeal.
2. Governments and the health care sector should ensure that the public is aware of the rationale for restrictive measures, the benefits of compliance, and the consequences of non-compliance.
3. All pandemic influenza plans should include measures to protect against stigmatization and to safeguard the privacy of individuals and/or communities affected by quarantine or other restrictive measures.
4. Measures and processes ought to be implemented in order to guarantee provisions and support services to individuals and/or communities affected by restrictive measures during a pandemic influenza emergency. Plans should state in advance what backup support will be available to help those affected by restrictive measures (e.g., food, bills, loss of income). Government should have public discussions of appropriate levels of compensation, including who is responsible for compensation.
5. In order to get the public “on board” with decisions regarding restrictive measures, policy-makers need to include the public in deliberations about public policy with respect to pandemic influenza.

GLOBAL ETHICS

CanPREP Policy Briefs

Billions of dollars are being spent in wealthy countries to combat H1N1 as Canadians debate how to allocate ventilators, antivirals and vaccines. Meanwhile, more than 10,000 people in the developing world die every day of treatable infections, and those in the poorest countries can expect to live on average half as long as those in the most affluent. The vastness of current global health inequities means that while resources necessary for responding to a pandemic are in short supply in Canada, they are vanishingly scarce in poor countries. As a result, much of the world's population will face the influenza pandemic empty-handed without the tools needed to identify,

A. WHY IS GLOBAL GOVERNANCE AN ETHICAL ISSUE IN A PANDEMIC?

Public health is inherently global in the 21st century, particularly with respect to outbreaks of infectious disease. Preventing the spread of pandemics is a fundamental obligation of national governments, but one that they cannot accomplish on their own. Porous borders, mutual vulnerability, and economic and scientific interconnectedness mean that communication, cooperation, and mutual support are needed between countries in concert with international organizations.¹ New global norms, networks, and regulations provide us with an unprecedented ability to detect emerging outbreaks and intervene to limit their impact. These are accompanied by new commitments to expand international assistance to build public health capacities such that all countries are able to prepare for, respond to, and recover from pandemics.² At the outset of the SARS crisis, the WHO emphasized border management for containment purposes, which included an issuance of travel advisories to reduce global transmission. By contrast, the H1N1 virus is already widespread in many communities globally. As a result, containment measures are not likely to reduce the spread of disease but are likely to exacerbate social and economic damages, particularly in poor countries. Should countries have the right to close their borders to travelers coming from affected areas? How might a collaborative focus on minimizing harms, avoiding stigmatization, and preventing unnecessary constraints on international travel and trade be fostered and maintained? Should Canada assist developing nations by sharing its vaccines?

B. WHAT ARE SOME OF THE KEY ETHICAL CONSIDERATIONS?

International law and pandemic plans have created a common structure and set of procedures for global cooperation in response to outbreaks. However, global health solidarity remains low. Massive inequities remain in health investment patterns, and there is little proportionality between disease burden and health spending at the global level.³ Progress has also been slow in improving public health practices and facilitating access to needed resources (e.g., antivirals and

vaccines) in the countries most vulnerable and least resistant to a pandemic.⁴ Moreover, compliance with new global regulations remains spotty. While some countries are providing public health advice and emergency response support, others are simultaneously imposing protectionist measures to isolate affected countries. As a result, poorer countries may see no alternative but to impose disproportionate measures of their own, which may include applying domestic containment strategies that breach human rights⁵ or withholding biological information and viral samples needed to track and combat infectious diseases.⁶ The international community, and in particular Canada and other wealthy developed countries of the G8 and OECD, has a shared responsibility to make good on their legal obligations to enhance global health collaboration and their moral commitments to equal human worth and dignity.⁷ In the face of an H1N1 pandemic influenza and other threats to global public health, anything less than the mobilization of substantial enduring financial and other support will amount to an abdication of the shared responsibility for global health and of the fundamental values of equality, reciprocity, and justice.⁸

C. WHAT DID CANADIANS TELL US ABOUT GLOBAL OBLIGATIONS DURING A PANDEMIC?

Balancing National and Global Responsibilities – Our research found that Canadians not only recognize the lack of equality, reciprocity and justice at the global level, but regard them as ethical imperatives and support policies that take aim at changing current realities. For example, a majority of survey respondents (50%) gave priority to saving lives *globally* over saving lives of Canadians (41%) in response to an influenza pandemic.

“We’ve made a commitment [to providing aid to other countries during a pandemic]...if we renege, and then we get into hot water and ask other countries [for help], they’ll say well, you didn’t help them, we don’t help you.”

- Study Participant

Canada’s International Obligations – Canadians believe that pandemic planning should reflect a commitment to collective well-being, global consciousness, and shared humanity. Town Hall participants reported that the pandemic response should include immediate targeted international assistance to develop public health capacities, information-sharing networks, and better overall global public health collaboration. A strong majority (70%) of those surveyed agreed that Canada should provide international assistance to poorer countries facing a pandemic, even if this means fewer resources for Canadians as a result. When asked how much assistance should be provided, most Canadians (92%) responded that aid should amount to at least 7% of total resources committed to pandemic preparedness, and many (43%) felt that that amount should be 10% or more.

Increasing Cooperation and Collaboration – Overall, Town Hall participants expressed optimism that enhanced global health solidarity would result from efforts to increase and extend international cooperation and collaboration in the pandemic response. Participants thought that Canada ought to assume a more prominent leadership role internationally and that the traditional distinction between public and private sector responsibilities needed to change in order to mount an effective global response to the pandemic. For example, governments and the pharmaceutical industry were seen to have a shared responsibility to ensure access to essential medicines in poorer countries. Support ran high for increasing regulatory control over drug manufacturing

capacity and profit-seeking, and for prioritizing equity in global distribution of drugs. Town Hall participants were less united on the extent to which domestic obligations and the recent global economic downturn should modulate Canada's duty to reach out globally. Nevertheless, there was a strong recognition among participants that Canada's health care and food distribution systems are critically dependent on global supply chains. This interdependency was seen as a rationale for global cooperation from the perspective of collective self-interest.

D. WHAT DOES THIS MEAN FOR H1N1 RESPONSE?

Canada has recently taken some important steps in the direction of improved global solidarity for health. While new requirements have been made in domestic legislation on development assistance and in international agreements on aid harmonization, investment, and resource sharing to strengthen pandemic preparedness, some critical gaps remain.

1. Canada can demonstrate global leadership by agreeing to share at least a 10% portion of its national stockpile of antiviral medications, H1N1 vaccine allocations, and outbreak management kits with poor countries, and by encouraging other wealthy countries to follow suit. It should also seek global reassurances that vaccine priority will be given to health care workers, as well as the most vulnerable (children under five years of age, pregnant women, the immunocompromised, and members of indigenous communities). Prioritizing the *most* vulnerable in other countries prior to the *least* vulnerable in this country would contribute immensely to allaying fears that the rich will live and the poor will die during a worsening global influenza pandemic.⁹
2. Canada can demonstrate a tangible commitment to an ethical domestic and international response to the H1N1 pandemic by contracting with domestic vaccine producers to maintain full production capacity for as long as there is need in other countries and even after all Canadians have been offered vaccines. Consideration of the use of adjuvants in order to extend the overall vaccine supply should also be a priority, as should exploration of policy initiatives to create a global network of regionalized vaccine production sites insulated from market forces.
3. Canada can attend concretely to the needs of the most vulnerable by targeting assistance to those countries in need of increased pulmonary treatment capacity.
4. Finally, Canada can boost global public health capacities and collective health security by adopting policy and financing innovations that match the scale of current global health priorities, of which H1N1 is just one. Innovative revenue generation approaches like airline travel solidarity levies would provide funding to improve access to essential medicines, health systems development, and human resources for health.

VACCINES

CanPREP Policy Briefs

A. CONTEXT

As Canada prepares for a potential second wave of the H1N1 pandemic, it is becoming increasingly apparent that the central element to mitigating the effects of the virus will be the creation and distribution of an effective and safe pandemic influenza vaccine. Canada is fortunate that its public health officials were sufficiently prescient to secure a contract guaranteeing production of enough vaccine for virtually every Canadian. While our public health officials should be congratulated for taking this important step, several challenges face the execution of a successful vaccine program. These challenges incorporate key ethical and policy elements that public health officials need to consider.

B. KEY ETHICAL PRINCIPLES

Despite its documented benefits, vaccination remains a contentious issue amongst some and raises many ethical concerns. Vaccinations are distributed to a large segment of the population and are often provided to healthy people. In these instances the burden of safety is increased. Perhaps most significantly vaccines are often not only provided for the benefit of the individual receiving the vaccine but also for the benefit of the public. The process of creating herd immunity allows for individuals who do not get vaccinated, cannot get vaccinated, or do not develop sufficient immunity from vaccination to derive some measure of protection from others in the population being successfully immunized.

To determine the ethical principles that govern an H1N1 vaccination programme it is first essential to determine the purpose of the program. Are public health officials primarily making the vaccine available to Canadians for their own protection? In this instance autonomy of decision-making and individual liberty would predominate as the guiding principles. Under these circumstances there can be little justification of any coercion on the part of public health officials, in particular the use of mandatory vaccination legislation, and the government's reciprocal responsibilities to vaccine recipients are limited. On the other hand, is the objective of the program to reduce the population health effects of the virus? In this case principles of solidarity and the protection of the public from harm could predominate over individual liberty. Public health officials can be justified in introducing more coercive policies. However, accompanying this infringement of individual liberty is an increase in the government's reciprocal responsibilities to vaccine recipients.

C. JUSTIFICATION OF COERCION

Coercion in the development of vaccination policy can range from aggressive marketing campaigns to introducing policies that exclude individuals who are not vaccinated, to introducing mandatory vaccination. In order for public health officials to justify the use of more coercive measures, they need to have scientific evidence that supports the population health benefits of the vaccination programme. Arguably, the greater the evidence for population health benefit, the more coercion is permitted. For example, many public health officials argue that there is adequate evidence supporting the fact that immunization of health care workers with the seasonal influenza vaccine can result in reduction of mortality and morbidity in their patients. This scientific basis has permitted some work places to introduce laws that require health care workers to go home without pay when an influenza outbreak occurs. It has also led to the call by some for mandatory immunization policies for health care workers. The population health benefits of immunization of school children could also be supported by scientific evidence. A previous study demonstrated that mass immunization of school children was accompanied by a decrease in respiratory illness related death in the elderly. Simulations of a H1N1 second wave have consistently demonstrated that school children are a key population to be vaccinated to prevent the spread of the virus. Based on this evidence coercive policies could be justified, such as not permitting school attendance during an outbreak if the child is not vaccinated.

While there may be a reluctance to use and justify coercion, public health officials also have a responsibility to justify the lack of use of coercive policies for vaccination, particularly if there is evidence for the population health benefits of such policies. The failure to do so would violate the principle of solidarity and protecting the public from harm, resulting in avoidable illness and death. In making this decision, officials will have to balance the potential risks and benefits of the vaccination programme taking into account the strength of evidence for both of these. Officials will also have to be guided by the precautionary principle, which advocates a lower evidentiary standard for taking action to protect against a large scale risk than what is traditionally used in evaluating the benefit of health technologies at the individual level.

D. RECIPROCAL RESPONSIBILITIES

With the decision to use coercion comes an increase in reciprocal responsibilities of the state to vaccine recipients. As the degree of coercion used in advocating for vaccination increases, so to increases these reciprocal responsibilities. There are two areas in which these responsibilities are particularly salient: ensuring the safety and effectiveness of the vaccine, and providing just compensation to those who suffer an adverse event following vaccination.

Safety and effectiveness

If autonomy is infringed for the sake of protecting the public from harm then it must be done in the least intrusive way possible. This requires that the vaccine be provided as safely as possible.

Therefore, the primary reciprocal responsibility accompanying the use of any coercive strategy to deliver a pandemic vaccine program is to ensure that mechanisms are in place to evaluate the safety of the vaccine. Historically, the regular seasonal influenza vaccine has a highly favourable safety profile. However, concerns about adverse events, specifically the rare paralytic disorder Guillain Barre syndrome, combined with the expedited development of the new H1N1 vaccine and the use of an adjuvant, have heightened the public's concern about the new vaccine. To fulfill their responsibilities to vaccine recipients, public health officials need to have the capacity to detect expected adverse events that occur at a higher than expected frequency as well as unexpected adverse events. This also needs to be done in a timely manner to identify problems as soon as possible.

While monitoring the safety of the vaccine is likely foremost in the public's mind, determining the effectiveness of the vaccine is equally critical. A newly developed vaccine has increased uncertainty about its effectiveness and the immune response it will generate in recipients. It would be important to determine early on whether the vaccine is not working effectively to reduce needless exposures to any of the risks associated with the vaccine.

Therefore to ensure both the safety and effectiveness of the vaccine, public health officials need to institute rigorous active and passive surveillance systems that exceed the requirements of standard pharmaceuticals.

No-fault compensation

If in the process of providing a public good, through agreeing to be vaccinated, a person should develop an injury from the vaccine, they should receive compensation for this injury by the state. This compensation should not require recipients of vaccines to rely on the traditional tort system, which has not been demonstrated to be an effective mechanism to provide just compensation. Furthermore, the standard of evidence to support the link between the vaccination and the injury should not be prohibitive. A no-fault compensation system for vaccination injuries would allow recipients who perceive that they have developed an adverse event to receive such compensation if such an adverse event is recognized and has occurred within a specified time period after vaccination. Such systems often have mechanisms for evaluating unrecognized adverse events. These systems are in place in all G8 nations except for Canada and Russia, although such a system does exist in the province of Quebec. In order to meet their reciprocal responsibility to vaccine recipients, public health officials should develop a no-fault compensation program for all of Canada to accompany the H1N1 vaccine programme.

E. SUMMARY

Mass vaccination policies create ethical dilemmas primarily because an important component of the benefit of such programmes is through the creation of herd immunity. Therefore, some rare individuals may be harmed in the process of providing benefit to others. Guiding ethical principles for an H1N1 vaccination programme would suggest that Canadian public health

officials clearly specify whether the goal of the programme is primarily to protect individuals or primarily to provide a population health benefit. The more strongly the decision is to provide a population health benefit, the more justified, and perhaps required, are the use of coercive strategies to ensure vaccination. However, the more coercive the strategy, the greater are the reciprocal responsibilities of the state to the vaccine recipients. Two key elements of reciprocity would include the creation of enhanced safety and effectiveness of post market surveillance and the introduction of a no-fault compensation programme for post vaccination adverse events.

RISK COMMUNICATION

CanPREP Policy Briefs

A. CONTEXT

Responding to the H1N1 pandemic has become a top priority for public officials in Canada. Doing so involves consideration of the lessons from the 2003 SARS crisis. Two major Canadian public health reports on the SARS crisis identify risk communication as a significant factor in outbreak response that needs improvement. Poor communication between public health officials, health care workers and the public was cited as a major factor contributing to the confusion and even spread of the virus during the time of SARS.^{1,2} The Campbell report called poor communication the “steel thread throughout the story of SARS”.¹

The final report of the WHO Global Conference on Severe Acute Respiratory Syndrome concluded that “information should be communicated in a transparent, accurate, and timely manner.”³ SARS has demonstrated the need for better risk communication as a component of outbreak control”.^{3,4} These principles of outbreak communication have been fully articulated in the recent release of the WHO’s Outbreak Communications Planning Guide.⁵

B. ETHICS AND INFECTIOUS DISEASE OUTBREAK COMMUNICATIONS

i) The Importance of Trust

Incorporating ethical principles into the planning and implementation of outbreak communications provides both public health and strategic advantages. Furthermore, there is an additional rationale that is central not only to the management of a specific public health threat like H1N1, but also to the capacity of the public health authority to fulfill its ongoing mandate – that of preserving and building trust.

Outbreak communications that build and preserve public trust can ultimately be an extremely effective public health tool that has a direct impact on mortality and morbidity at the local and the international levels.⁵ For people to accept public health measures that may limit their individual liberty and potentially cause them to be stigmatized, they must trust the information they receive as well as the authorities who provide the information.^{4,6-8} In addition, trust is important at the global level, as countries need to be able to trust each other to be transparent and honest about infectious disease outbreaks. Reciprocally, countries that do not trust the international community to be fair and to provide assistance may fear things such as economic loss as a consequence of having open and honest communications about outbreaks. The result may be that they chose not to be transparent with the global community.

ii) Ethical Principles

The ethical principles outlined below should guide infectious disease outbreak communication planning and response and will ultimately help to build and maintain public trust.

Transparency

In order to build trust, communication must be open and honest.^{4,9} Information must be complete, accurate, and communicated proactively to the public.^{4,6,8-9} The data from the Town Hall meetings conducted by the CanPREP team supports the premise that transparent communications build and enhance public trust, which will subsequently lead to greater co-operation and compliance with public health measures. Being transparent means being open about what is known *and* what is not known about the situation. Transparency in risk communications is necessary, if not sufficient, to ensure fairness and accountability in the management of a public health crisis.⁴

The CanPREP Stakeholder Forum participants also felt that information must be available through a variety of sources for both professionals and the public, and that recipients should know where information is coming from and from whom. This speaks to the need for outbreak communicators to deliver information in an accessible and understandable way. An “information dump”, so to speak, may seem to meet the requirement of transparency but is often the best way to hide important information. Participants in the Town Hall meetings felt it is important to have information available in different languages and for people with communication difficulties (e.g. hearing or visual impairment) so that the entire public can become empowered to make good decisions about what actions to take during a pandemic. Part of transparency then, is ensuring *equitable access* to information, especially for populations who are vulnerable. Vulnerability may take many forms and it requires careful consideration to devise a communication strategy that can reach vulnerable people like the homeless, for example.

The CanPREP Stakeholder Forum also emphasized the need for transparent communications *between* and *within* organizations. This applies to countries as well. The reporting requirements during infectious disease outbreaks for signatory states are now codified in the latest iteration of the International Health Regulations.¹⁰

Reciprocity

The principle of reciprocity is a correlate principle to that of transparency. In order to encourage the public to be transparent about their own health status, there needs to be an acknowledgement

on the part of the state that there are reciprocal moral obligations to ensure that transparency will not have negative consequences. For example, for someone who is voluntarily quarantined, there needs to be assurance that they will not lose their job.

The same applies at the international level. Global public health measures and international trade and travel bans can have significant economic impacts on countries that declare public health emergencies. If countries have a moral duty to be transparent, then the global community has reciprocal moral obligations to compensate and support those countries that may suffer economic or health consequences as a result of transparent communication. This is especially true for those countries that benefit directly from information about public health emergencies to which they may be vulnerable. Exactly to whom in the global community these reciprocal duties apply however, and how to discharge such duties remains a question for the international community to debate; reciprocity can take many forms such as financial compensation and human resource support. There is little dissent however, about whether or not reciprocal moral obligations for compensation or assistance exist in situations where collateral damage results from a country's compliance with the moral and regulatory imperatives for transparency.¹¹

Respect for the Views of Others

This principle has two important facets. The first involves inclusiveness in decision-making. In a recent article, O'Malley, Rainford, and Thompson state that "trust requires honest, open and two way communication...[and] efforts to build and maintain trust are best made in collaboration with stakeholders before a public health emergency occurs".⁴ This acknowledgement of stakeholders as legitimate partners is seen as an essential component of effective risk communication.⁹ It is also an essential component of fair and accountable decision-making processes which ultimately can aid in the building of trust (or the lessening of public suspicion).⁷

The second facet of this principle involves dialogue with the public. It is essential to good outbreak communications to engage the public. Outbreak communications must be bi-directional for strategic reasons, in order to avoid the potentially fatal consequences of public misinterpretations of public health information and public health officials' actions. The Town Hall participants felt that bi-directional communication is important and allows communicators to have a "more co-operative, empowering kind of relationship with the public." Communication must also be bi-directional so that legitimate concerns may be brought to the attention of those in a position to hear and respond to them. The importance of listening to the concerns and perspectives of the public is reflected in both the WHO and the Canadian Public Health Agency's risk communication guides.^{5,6,8} It is particularly important to ensure that efforts to listen to the public include difficult to engage, vulnerable, populations.

Responsiveness

Responsiveness is the correlate principle to have Respect for the Views of Others. Public health communicators need to be responsive to public concerns and perspectives and may need to revise its messaging in light of public feedback. In addition, communication channels need to be

established in order for persons with legitimate claims to scarce resources such as antiretrovirals or vaccines to be heard from and responded to.⁷ Again, the same applies at the international level - there needs to be communication channels within the international community to deal with concerns over such things as travel bans or trade restrictions.

Solidarity

Outbreak communications takes place at many different levels - from the physician's office, to the municipal level, all the way to the international level. One crosscutting issue that emerges at the national level from the combined experiences with SARS and the early phase of the H1N1 pandemic is inter-governmental coordination of communications. Lack of jurisdictional coordination in communications, be it municipal, FTP or international, has created problems with inconsistent messaging and this raises anxiety, undermines trust in public officials, and redoubles the need for engagement with the public. The need to coordinate messaging across all these levels is compelling, yet daunting. Building relationships across these sectors is important for developing a sense of common purpose that can help to overcome the territoriality that often exists between communications jurisdictions. While there may be a need for some jurisdictions to deviate from the messaging of other jurisdictions in order to tailor communications to their publics, there needs to be transparency about why they are doing so, both to their fellow outbreak communicators and to the public.

At the international level, developing a sense of solidarity within and between countries can encourage transparent outbreak communications between countries. Essential to the development of a sense of solidarity among nations who face acute outbreaks of international significance is the acknowledgement of countries' reciprocal obligations to countries that communicate in a transparent manner.

VULNERABILITY

CanPREP Policy Briefs

A. CONTEXT

When a new and virulent pathogen emerges, such as H1N1, we are all rendered vulnerable to its effects. If one important goal of pandemic planning and response is to minimize loss of life, then it behooves us to identify those who are most vulnerable so that appropriate preparations can be made. From its conception, CanPREP has aimed to address the inter-related questions of how best to engage the public in a public health emergency and how best to protect so-called “vulnerable groups” or “at-risk populations.” The manner in which these questions are framed and the mode in which these issues are addressed will have significant implications for the building and maintenance of public trust, which is a critical element of effective emergency response and management. This was a difficult lesson learned from the SARS crisis, as has been reported in a number of public inquiries.¹⁻²

After a preliminary analysis of the data, three broad themes emerged from the vulnerable population group: resistance to the name ‘vulnerable’, identification of different conditions that make individuals vulnerable, and ways to mitigate the effects of vulnerability and being vulnerable during an influenza pandemic. Each of these three themes will be addressed in turn.

B. RESISTANCE TO THE LABEL ‘VULNERABLE’

Some stakeholders found the very use of the word ‘vulnerable’ as a descriptor troubling and misrepresentative of their personal experiences: “*I somewhat resent using the term ‘vulnerable’ for people in categories like [name] or myself at [age]. Am I vulnerable? Well, some of my colleagues are much younger than I am, and are very vulnerable*” and “*I know some of them don’t like the ‘vulnerable population’ you know, sort of label*”. Stakeholders felt that whether a person is vulnerable or not is often contingent upon external factors and moreover, masks the interdependence that exists between people of different capacities: “*I don’t think that the*

population knows the amount of, the amount of dependence and independence and interdependence and contribution that our population makes. I think it's undervalued and therefore would be even more underserved in consideration of a limited ration, limited resources."

In order to further goals of social justice, inclusivity, and advocacy, 'vulnerable people' must be conceptualized as conditional or situational. The concept of vulnerability during an influenza pandemic will often be contextual, and is very much interconnected.

C. CONDITIONS OF VULNERABILITY

Stakeholders identified a variety of different conditions that might make a person vulnerable during an influenza pandemic. First, participants stated that physical conditions might make a person vulnerable, such as having "*multiple degenerative diseases*". However, although the prevalence of chronic and acute diseases is higher within certain groups of people, such as the 'elderly', stakeholders felt that it was important to distinguish between age and disease and noted that age should not be a proxy for disease or provide the basis for allocation decisions: "*I think we can't put the elderly together as one group. I think when we're talking about allocation of resources, I think we must run with age alone as a poor criteria*".

Second, geography, including a person's physical environment or remoteness relative to others, was seen by many as a condition that might make people vulnerable during an influenza pandemic. With regard to challenges of geography: "*In Northeastern Ontario alone, the land mass is equivalent of Spain and Portugal combined, so 100,000 square miles, so logistical distribution of emergency supply and stockpile is a huge issue*". The physical environment itself might also make fighting a pandemic influenza difficult: "*Many aspects are beyond our control, such as weather, flooding, all these natural disasters create, present a huge challenge to our people*". One stakeholder noted, though, that the remoteness of First Nations communities in northern Canada might actually work to the advantage of those communities: "*What could be deemed a possible saviour is sometimes our remoteness in the event of a pandemic. When you speak to some of our isolated members, they say well, it's quite simple – we'll just go back to the land*". A particular challenge noted by many stakeholders was that pandemic influenza planning occurred primarily at urban centres and for urban centres, thus not being sensitive to the difficulties that might arise in rural areas: "*We've been referring to both urban and rural settings, so those up in the north do face extra special challenges and hurdles when these types of incidents strike*".

Third, many stakeholders argued that the disproportionate amount of planning occurring for hospitals during a pandemic influenza was diverting time away from community planning and the allocation of resources, thus making vulnerable those who rely upon community supports: "*It's all focused on acute care, curative medicine rather than prevention and supports*" and "*This idea that everything should be hospital based is a short sighted*". In particular, one participant identified that the small size of community health organizations adds to vulnerability during a pandemic influenza: "*Hospitals are vulnerable, but I think that there*

are added vulnerabilities to smaller organizations that don't have infection control expertise, that aren't stockpiling medications the way that hospitals [are]".

Implicit within discussions of age, geography, and a bias toward planning for hospitals, stakeholders identified a fourth condition that makes persons vulnerable, namely that of social power structures that lead to vulnerability and discrimination against certain groups of people. Some stakeholders talked about how certain groups of persons, due to social or physical conditions, are prejudiced and discriminated against by the general population even in non-pandemic moments, and how this might further disadvantage persons during an influenza pandemic: *"Society tends to decide who should live and who should die and it's usually based on prejudice, bias used against disability, against age, against difference"* and *"I'm just thinking about these structures of power – how do we get at them?"* Persons in conditions of poverty or underprivileged may be further disadvantaged during a pandemic influenza: *"The one that keeps me up at night is that intersection of poverty in this whole issue and crowded housing conditions and people using shelters and prisoners, and those groups where the whole concept of social distancing is absurd"*. As implied in the preceding quote, public health measures designed to keep people safe during a pandemic influenza might endanger persons who are already vulnerable, thereby demonstrating a lack of insight and planning toward individuals often forgotten by the public: *"How does social distancing, how does cancelling community events, how does that interfere with people getting the information they need, in particular people that can't read or don't have access to radios to have the information they need to survive. What are the costs of what is generally thought to be effective and of course public health?"* Stakeholders felt that persons who are vulnerable were not being heard, whether in general or with regard to pandemic influenza planning: *"I have come from people who are sick to death of somebody exploring me, talking to me, figuring me out, trying to figure out what I need, what I don't need. They don't ask me. All they do is ask me about my medical illness. They don't ask about me as a person"*.

D. MITIGATING VULNERABILITY

Despite the frustration that many stakeholders felt about not being heard and the social conditions that unjustly lead to vulnerability, many stakeholders also expressed optimism that changes were occurring and that there is a role for 'vulnerable' persons in responding to an influenza pandemic. One participant mentioned that emergencies might be seen as an opportunity for empowerment: *"So once the realization that the money wasn't going to do anything [i.e. help solve the public emergency] it was very interesting to see what was created was for themselves"*. Another participant felt that the issues facing vulnerable populations were not a lack of resources but a lack of imaginative thinking and solutions: *"It's not an issue of rationing... [rather] 'how could I think differently?'"*

Two possible solutions were brought forth by the stakeholders to make persons less vulnerable during an influenza pandemic. First, stakeholders felt that it is important that decision-makers listen to those who are normally considered vulnerable: *"Now I think that if we can get all the voices so that we're not the vulnerable, we're people who demand to be part of*

the process, we have to be engaged and we can't write off people in the north and we can't write off people who are poor, we can't do that, people that have a disability, you know. Come on!" However, it is insufficient to merely listen to people; rather, all individuals (vulnerable or not) need to collaborate when planning for, and responding to, a pandemic influenza: *"To engage the populations in planning how they can contribute with what they will need in order to maintain their independence, their capacity to function in society... let them be part of the planning and they can be part of the delivery"* and *"We've got to engage with a full population and its diversity"*.

Second, stakeholders felt that individuals and communities need to be given the resources and space to take care of themselves during a pandemic: *"To get people back to where they feel that interdependence, when you talk about your co-op and people helping each other, that may be the model to survive any of these things"* and *"Put some of the resources that are in health into community alternatives and expand a number of hours available to the people and care for them in ways they want to be cared for, that allow them to live their lives the way they want to live, and be productive and reduce the burden on the overstretched hospital system"*.

PUBLIC TRUST

CanPREP Policy Briefs

A. INTRODUCTION

Trust is fundamental to our social fabric. Without trust society cannot function. We trust that the buildings we enter will not crumble; we trust that our mail will arrive untampered; we trust that our food is not contaminated; we trust that our tap water is properly treated; we trust that 'experts' know what they are talking about.¹⁻³ In her 2002 BBC Reith Lecture series entitled, "A Question of Trust", O'Neill (2002) describes the current climate in society more precisely as a "culture of suspicion".² In this era of information technology, the public is inundated by "a flood of unsorted information and misinformation that provides little but confusion unless it can be sorted and assessed"⁴ with the result that the public often does not know what sources are reliable. The public seems willing to trust but increasingly does not know who to trust.

B. WHAT IS TRUST?

Trust is generally considered to be relational⁵ involving two or more parties. It has been characterized in many ways: as an interpersonal feature, as contractual, as rational/irrational, as an emotion, a capacity, or a psychological state. This variability reflects to some extent the contextuality and "dimensionality" of trust.⁶ Trust can exist at many levels – interpersonal, institutional, societal – and some scholars have noted the interconnectedness of trust at these different levels.^{5,7} Expressions often used interchangeably or in association with trust include "confidence", "faith", and "reliance".⁸

C. SYSTEMIC TRUST

Trust appears to be something that is shaped by experience.⁹ With each trust encounter, trust "imperceptibly" evolves into something that can be more voluntary or voluntarily given under specific circumstances.^{1,9} Simultaneously, however, one's "confidence" in the "good will" of the trusted alerts one to a realization of one's vulnerability to the potential risk of harm or "ill will".¹

Risk and vulnerability are inherent in all trust relations - from the intimate and personal to the social – because all relationships involve expectations and uncertainties.^{1,2,5,6,9,10} Trust rests on the calculation – however inherent – of the probability that the entrusted will behave in the manner expected. Hence, trust can be seen as a way of managing risk.^{6,9} In interpersonal relationships where "the parties know one another well", most of us are able to determine "whom I can trust for what".⁹

When we move beyond the individual level of trust to consider public trust, the stakes are raised with respect to relative "powerlessness" and vulnerability. Given the "simple Socratic truth that no person is self-sufficient",¹ social life requires that we place our trust in others in order to make advancements and sometimes simply to survive. This "generalised trust in others" is based in a belief that "other citizens of a society will act in our collective interest".⁵ But, often, at the social level of trust the possibilities for "reciprocal cooperation" are either absent altogether or extremely difficult to construct. Thus, in the public domain, how do we know who, what or when to trust?

D. TRUST, COMMUNICATION AND TRUTHFULNESS

Ableson et al examined themes around trust in an analysis of the values and attitudes of Canadians to the health care system.⁸ They found, in part, that there is a public expectation by those within the health care system of a *duty to care*. The public's expression of *vulnerability* reflects an awareness of the necessity of trust but an apprehension in knowing where to place it. While *transparency* is named as one of the elements that might help to build trustworthiness and to reduce the public's suspicion, a greater underlying issue seems to be inadequate or deficient systems of communication.

In the name of “transparency”, the public is experiencing an overload of unfiltered information. This may, in fact, “add to uncertainty rather than to trust” because appeals for “transparency” can foster deception, evasiveness, and increase suspicion of how things are “spun”. With so much information available, it is no longer a matter of *what* information to trust rather *who* is reporting that information – e.g., the source.²

But, with so much focus on measures of trust, we have, in effect, eroded the social networks of trust. With the increasing use of information technology, something is lost in our human interactions.¹¹ Indeed, “the new information technologies are ideal for spreading reliable information, but they dislocate our ordinary ways of judging one another's claims and judging where to place our trust.”²

E. CREATING TRUSTWORTHY SYSTEMS: FOSTERING A “CULTURE OF TRUST”

The necessity of trust binds us all in a sort of “commons”. We exist in a “network” of trust relationships¹ in which we accept a degree of risk, leaving ourselves vulnerable to the actions of those in whom we place our trust. However, this dependence on the entrusted comes loaded with a set of expectations that serves a normative function for those who are entrusted.^{1,5} The expectations “that the other will have concern for your interests”⁵ and for a particular kind of behaviour by the entrusted present a kind of regulatory and moral mechanism inherent in the trust exchange. This, of course, invokes the notion of fiduciary obligation. Furthermore, the entrusted also stands to potentially lose something in a failed trust exchange, in part, because “distrusts lead to forgone opportunities”.⁹ In other words, trust requires reciprocity in some form, and by extension, a kind of solidarity. This will be of particular significance in the context of a pandemic influenza outbreak in which high levels of public trust are essential for effective intervention.

F. CONCLUSION

From the preceding discussion, it is clear that the task ahead, in relation to public trust, is to determine how “climates of trust” can be fostered within societies.¹ Despite the conceptual multidimensionality of trust, on an operational level it seems there are certain concrete and consistent factors for building a system or a culture of trust, including: face-to-face interaction, two-way communication, encouraging participation and being responsive in the creation of trust. While it may not be practical to interact directly with every individual, it seems that even just “engaging voices” can provide a basis for trustworthiness. There also seems to be a role for greater stewardship on the part of public officials, for the problem does not seem to be with public trust itself but rather with the more concrete question of “*who* can we trust?”

In consideration of CanPREP, there are several relevant themes that emerge from this short review:

1. Trust is multidimensional – interpersonal, institutional, social, societal.
2. Trust is linked to vulnerability and power.
3. There is a relationship between trust and risk, risk perception and risk communication.
4. Trust has a normative function which raises possibilities for creating “systems of trust” or fostering “systemic trust.”
5. Truth and transparency don’t necessarily go hand in hand. Indeed, overemphasizing transparency and accountability may actually erode the inherent social mechanisms needed to foster trust.
6. The media play a powerful role in garnering, as well as eroding, public trust.
7. The public is seeking an authority in which to place their trust.
8. Trust both generates and is generated by interdependence, reliance and reciprocity. Thus, trust can lead to social solidarity.

APPENDIX 1: ETHICAL FRAMEWORK FOR PANDEMIC PREPAREDNESS

(Source: “Stand on Guard for Thee: ethical considerations in preparedness planning for pandemic”)

SUBSTANTIVE VALUES	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:</p> <ul style="list-style-type: none"> • be proportional, necessary, and relevant; • employ the least restrictive means; and • be applied equitably.
	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. Decision makers should:</p> <ul style="list-style-type: none"> • weigh the imperative for compliance; • provide reasons for public health measures to encourage compliance; and • establish mechanisms to review decisions.
	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 to or critical needs of the community.</p>
	Privacy	<p>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.</p>
	Duty to provide	<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</p>

	conditions.
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.
Equity	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.
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.
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.

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

APPENDIX 2: RESEARCH PROJECTS

1. National Public Opinion Survey - A national telephone survey was conducted with a random sample of 500 Canadians to better ensure an accurate characterization of national attitudes. The sample was stratified by gender (50% male and 50% female); age (18-35/ 35-65 / 65+); residence (rural vs. urban); and province – to best reflect the national population. Within these constraints, Random Digit Dialing (RDD) was used to obtain a random population within each target strata. Survey data was analyzed by logistic regression and factor analysis to identify areas of agreement and disagreement among survey participants, noting any significant variation related to age, sex, or geography.
2. Deliberative Town Hall Meetings: The goal of these Town Halls in major Canadian cities was to bring together members of the public to share, reflect on, and discuss their perspectives on pandemic preparedness and response. At each forum, roughly thirty

participants divided into breakout groups and explored, through case scenarios, ethical issues surrounding healthcare workers' duty to care, priority setting, restrictive measures, and global governance. Town Hall Meetings were held in Vancouver, British Columbia, Winnipeg, Manitoba, and Saint John, New Brunswick.

3. Stakeholder Forum: In January 2009, CanPREP hosted a Stakeholders Forum in Toronto, Canada, where different collaborators from across disciplines and experiences came together to brainstorm and participate in focus groups where they shared important considerations regarding pandemic influenza planning. Participants at the Stakeholder Forum were divided into one of three groups: decision-makers, healthcare professionals, and vulnerable populations.

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