Public Communication about Pandemic Influenza: A Critical Public Health Ethics Analysis

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Abstract

The purpose of this research was two-fold: two-fold: firstly, to critically analyze, using a critical public health ethics perspective, public communication directed toward the population of Ontario regarding a future influenza pandemic and compare this communication with information needs and interests of a sample of this population, and secondly, to examine public preferences for engagement in pandemic planning. First, public communication/education materials developed by Public Health Agency of Canada, Ministry of Health and Long-Term Care (Ontario) and Health Canada concerning pandemic influenza were analysed using a four step coding process. Next, survey data was collected regarding general pandemic knowledge, informational needs, desires and expectations, including opinions regarding public engagement from a First Nations and a university sample. Results from the document analysis and survey were compared and analysed using a critical public health ethics lens.

Results indicated that: (a) Considerable overlap exists between the most important topics as identified by respondents and the topics most covered in documents, although several areas in which information desired by respondents was not included in documents, (b) Respondents underestimated the projected scale and impact of influenza pandemic, (c) Respondents were largely unaware of government pandemic plans including Canadian Pandemic Influenza Plan, although expressed great interest in pandemic plans, (d) Respondents were in favour of having involvement in pandemic decision making at some level, and indicated their preferred methods of participation, (e) Communication documents largely portrayed pandemic influenza as a biomedical issue, and pandemic planning as within the jurisdiction of experts. Prevention, particularly self-protection behaviours on the part of the individual, was also a dominant theme. The author posits practical suggestions for improving future public communications.

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1.0 Introduction

Anticipation of another pandemic of influenza has prompted governments and public health authorities to develop elaborate sets of plans for this contingency. Timely and effective public communication is a vital aspect of this planning. The purpose of this research is two-fold: firstly, to critically analyze, using a critical public health ethics perspective, public communication directed toward the population of Ontario regarding a future influenza pandemic and compare this communication with information needs and interests of a sample of this population. Secondly, it will examine public preferences for engagement in pandemic planning. This study takes a step toward answering the questions: Are Ontarians, at least those sufficiently aware of the nature of threat of the next influenza pandemic, receiving communication that corresponds to their needs and desires concerning this contingency? What are their preferences for engagement in pandemic decision-making?

1.1 Glossary of Terms and Acronyms

Below are stipulative definitions used for the purposes of this study:

(General)Public/Citizens: Those citizens having no particular affiliation, professional or otherwise that would include them as "key stakeholders" in the pandemic influenza planning process, who "meanwhile have a broader and longer-term interest in the health service, as voters, taxpayers and members of the community: they are interested in what happens not only to themselves, but also to their families, neighbours and fellow citizens, both now and in the future" (Lenaghan, 1999 p.48).

Public communication: Under the umbrella of "public involvement" (see below):

1. Communication messages, materials and channels developed or commissioned by public health authorities (Public Health Agency of Canada, Ministry of Health and Long-Term

Care, Health Canada) for the public. These might include: telephone hotlines, pamphlets, handbills, posters, public education media campaigns. This does not include communication messages or channels between government and non-government or professional organisations.

2. Communication channels for feedback, questions, and comments addressed to public health officials coming from the public. These include channels initiated, implemented and monitored by public health or other government officials (i.e. does not include personal web-pages, chat room dialogue). The relationship between public communication and public engagement will be discussed in Section 3.2.

Pandemic planners: Public health agents and government officials working in the field of public health, and specifically pandemic influenza planning, and developing and distributing public communication regarding pandemic influenza (i.e. Pandemic Influenza Committee).

Public Involvement: Health Canada's "public involvement" framework defines public involvement as, "interactions between the public and the decision-making body (e.g., Health Canada), which include surveys, focus groups, feedback on discussion documents, public consultation, dialogue, workshops, advisory boards and partnerships" (Health Canada, 2004), and includes public awareness methods such as education campaigns.

Public Engagement/Community Engagement: (community participation, public participation, participation in decision making). A process for involving the public/citizens in pandemic influenza decision-making processes. Although it is acknowledged that the term "public engagement" is often used in reference to the larger framework of public involvement, including communication with the public, for the purposes of this study, public participation will refer to members of the public providing feedback, posing questions, making policy recommendations or

commenting on decision making at some or all levels, facilitated through official channels (i.e. Public Health Agency of Canada). The relationship between public communication and public engagement will be discussed in Section 3.2.

Acronyms

Canadian Pandemic Influenza Plan/The Plan: CPIP

Health care worker(s): HCW

Lac des Mille Lacs First Nation: LDML

Lakehead University: LU

Ontario Ministry of Health and Long-Term Care: MOHLTC

Non-government organisation: NGO

Ontario Health Plan for an Influenza Pandemic: OHPIP

Public Engagement Pilot Project for Pandemic Influenza: PEPPPI

Pandemic Influenza Committee: PIC

Public Health Agency of Canada: PHAC

World Health Organisation: WHO

2.0 Background

2.1 Pandemic Influenza and Pandemic Planning

The influenza 'A' virus, responsible for seasonal flu outbreaks, is subject to antigenic shifts and drifts allowing new strains of the virus to develop. Cyclically, a strain develops to which the population has little or no immunity, and a global epidemic or "pandemic" occurs. In the past century, three pandemics occurred within a period of 11 to 39 years. Based on this history, most experts in the health fields expect that another pandemic will be forthcoming, but they are unable to predict when it will happen.

It is extremely difficult to predict the pathogenicity and severity of a novel influenza strain to which the population has little resistance (WHO, 2005a, p. 15). However, the devastation and great loss of life recorded during a key pandemic of the last century, in 1918, offers some insight as to the immense potential damage that the next pandemic might bring. It is estimated that 50% of the population will become infected, and between 15-35% will become clinically ill if not given an effective vaccines or antiviral drugs as a prophylaxis (PHAC, 2006a, (Background) p.8). Therefore, the threat of the next influenza pandemic necessitates formulation of a comprehensive, cohesive strategy of pandemic preparedness, response and recovery (Wilson, 2006).

The current Canadian Pandemic Plan was published by a former branch of Health Canada now known as The Public Health Agency of Canada (PHAC). It is a collaborative effort of federal, provincial and territorial advisory committees and government agencies, including The Centre for Infectious Disease Prevention and Control, PHAC and the Centre for Emergency Preparedness and Response. The Plan's directive is to delineate recommended strategies and

procedures, and to serve as a guide for planning at the federal, provincial, territorial, municipal and organizational levels (PHAC, 2006a, (Introduction) p. 1-2).

The Canadian Pandemic Influenza Plan (CPIP, or The Plan) and the subsequent provincial and territorial programs (including the Ontario Health Plan for an Influenza Pandemic) that the federal plan mandates are modern and progressive instruments of public policy. The Plan's most recent incarnation is the 2007 version, but it too is a work in progress. It continues to be modified and updated as more information about the potential virulence and trajectory of the virus are made available (Kort, Stuart & Bontovics, 2005).

The intended audiences of The Plan are provincial and territorial (P/T) Ministries of Health and the vast networks of organizations and individuals concerned with pandemic preparation and response. These include health care workers, public health planners, emergency responders, public health laboratories and organizations involved in the manufacture and regulation of pharmaceuticals. An official Pandemic Influenza Committee (PIC), reporting through the Advisory Committee on Population Health and Health Security, will serve to advise the federal, provincial and territorial Ministers of Health in the areas of health economics, immunology and microbiology, medicine, public health and ethics throughout the pre-pandemic, pandemic and post-pandemic periods. While developed for these audiences, both the federal and provincial pandemic plans outline steps effecting the population as a whole.

2.2 Vaccines and antiviral drugs

Vaccines and antivirals will be two of principal instruments that Canada's health officials expect to use during the influenza pandemic (Kort, Stuart & Bontovics, 2005). "Flu" vaccines stimulate the body to produce antibodies, thus providing immunity. Unlike vaccines, antiviral

drugs cannot provide immunity, but they do play an important role to reduce symptoms and serious complications by interfering with the life cycle of the virus.

According to CPIP, the Canadian government is dedicated to producing and distributing enough vaccines for all citizens. Canada has secured a domestic supplier for the vaccine and is taking steps to ensure adequate supplies of antivirals will be available (PHAC, 2006a, (Preparedness) p.8). However, production of a vaccine against a pandemic virus cannot begin until the novel virus is first isolated and cultured. Based on latest estimates this process will take approximately 6 months (Osterholm, 2005). This is due to the time needed to develop a vaccine once the specific virus is identified, as well as problems with logistics of delivery and dispersal (Langley and Faughnam, 2004). The vaccine will be in short supply during initial pandemic stages, and will become available as produced. Thus, some form of rationing will be necessary, at least during initial stages.

In response to this need, a national recommendation on priority setting was developed (See Table 1) after significant deliberation, and in collaboration with provinces and territories (PHAC, 2006a, (Annex D) p.1). Dispersal of antiviral drugs for early treatment, and outside of Ontario for prophylaxis, is similarly being developed. It should be noted that as of October 2006, reference to priority groups in regards to antivirals had ceased. This is due to on-going revisions regarding the use of the National Antiviral Stockpile (PHAC, 2006a).

Table 1
Recommended Priority Groups for Vaccination in Canada

Priority	Description of group	Rationale
1	Health Care Workers, Public Health Responders and Key Health Decision Makers	Maintain health services, reduce morbidity & mortality
2	Pandemic Societal Responders and Key Societal Decision Makers	Mount effective pandemic response & community services
3	Persons at High Risk of Severe or Fatal Outcomes Following Influenza Infection	Reduce morbidity and mortality
4	Healthy adults	Reduce morbidity, mortality, and societal disruption
5	Children 24 months – 18 years	

Source: Kotalik, 2006, p.36

It is because of the anticipated scarcity of antivirals and vaccines that an important issue exists: the equitable and ethical distribution of antivirals and vaccines. The CPIP mentions that distribution of vaccines and antivirals is an outstanding problem that has yet to be fully resolved (PHAC, 2006a, (Preparedness) p.7). Priority groups will be reassessed and changed as necessary once the virus has been identified. Although the afore mentioned national and provincial plan recommends priority setting, Kotalik (2005) noted that previously there had been little or no discussion regarding practical aspects of how this will be done or the rationale behind expanding some resources (e.g. antiviral drugs) and rationing others (e.g. intensive units beds). He argues that the disconnection between scarcity policies and the knowledge of the impact of these policies on larger society ought to be remedied, and that before accepting the terms of pandemic plans, careful consideration should be given toward the number of people who will be affected by such policies, and the degree to which they will be affected. Very recently, there has been

increasing discussion about access to ICU resources, as this topic is coming to the forefront of public health issues.

In a correspondence piece in The Journal of Clinical Oncology, Abratt (2005) critiques the use of the term 'rationing' regarding a particular clinical procedure. His opinion is "rationing" is an emotional and value laden word which may cause "patients" to feel deprived, and suggests two more neutral phrasings: "priority setting" and "resource allocation". These terms will be used for the duration of this study.

2.3 Communication

Communication is an integral aspect of pandemic preparedness (Fukuda, 2000). Effective communications was hailed as thwarting greater damage during the recent SARS outbreak, (Di Giovanni et al., 2004, Tseng et al., 2005) as cited by Kotalik, (2006).

Annex K of CPIP provides a breakdown of roles, responsibilities and objectives of Canada's health partners concerning communications before during and after influenza pandemic. Detailed communication tactics have been designed at global, national and local levels. In like manner, Chapter 12 of OHPIP (MOHLTC, 2007a) lays these points out at the provincial level. Both pandemic plans share a common communications objective: "accurate, timely and consistent information" for all affected groups (p. 12-1).

Different communication strategies and methods are slated for the various pandemic stages, for example, the Interpandemic phase and Pandemic alert phase. Specific communications strategies are also planned for different audiences: citizen/public, stakeholder/partner, healthcare worker (HCW), and organizational levels. Topics covered in present and planned communiqué for the public are: awareness of the threat of pandemic influenza (and other types of influenza), self-protective measures, organizational level plans and

encouragement to seek and follow direction from authorities (PHAC, 2006a, (Annex K) p.2-16; MOHLTC, 2007a, (12) p. 1, 2, 3).

Some of the public communication channels presently available include the PHAC web-based pandemic influenza portal, the weekly Flu Watch online bulletin, brochures and fact sheets developed by PHAC and MOHLTC, 5 million of which were distributed in 25 languages across Canada in 2006 alone. As well, telephone hotlines have been or will be put in place and future media briefs and advertising campaigns are being developed. Local public health units are entrusted with implementing local public education campaigns. As stated in the OHPIP, "This education is designed to reinforce the importance of good hand and respiratory hygiene and to encourage public cooperation and compliance with FRI (febrile respiratory illness) screening and other precautions health care settings are now taking to reduce the spread of respiratory illnesses (MOHLTC, 2007a, (12) p.3)." The key messages in future public communication will differ according to pandemic stage (MOHLTC, 2007a, (12) p. 2, 3, 4).

It is noted that Canadian audiences will likely seek out a variety of sources for information (PHAC, 2005, (Annex K) p. 421). These sources might include both professional and medical groups and Non-Governmental Organizations (NGO). Additionally, communication is intended to be carried out in an "international context". That is, audiences will likely access information from the diverse sources around the world (WHO, USHHS CDC) via news media, the internet, and television.

An article by Kort, Stuart & Bontovics, (2005) outlines Ontario's experience developing the OHPIP. The authors mention that learning from the SARS experience, planners identified multiple "communications modalities to facilitate two-way communications between government and stakeholders" (p.410). Further, efforts were made to include an extensive range

of health stakeholders in the planning process, and the current plan deals mainly with acute care, critical care and public health issues rather than on primary care in the community. However, citizens and members of the general public are not mentioned as participating in this process, although according to Tam et al., (2005) public consultations will provide further input into Canadian pandemic planning strategies and activities. A national study making use of citizen and stakeholder dialogue in determining the use of the National Antiviral Stockpile for prophylaxis was completed during the writing of this thesis and is now available on the PHAC website (PHAC, 2007).

2.4 Ethics and Pandemic Planning

Given that an influenza pandemic might be forthcoming, it is an ethical responsibility of public health agents to establish contingency plans to protect the public and reduce harm. Numerous authors agree that threat of an influenza pandemic presents unique and significant ethical issues (Bayer & Fairchild, 2004; Kotalik, 2005).

During the initial draft stage of the CPIP in 2002, external advice on ethics and legal issues of the document was commissioned by Health Canada. (Kotalik, 2006, p.27) This report was disseminated among PIC members and decision-makers and made available on request to a number of interested parties in Canada and abroad but was not made publicly available. The 2004 version of CPIP contained a short "Ethical Consideration" segment. This pointed out that ethical and legal aspects were reviewed and that future CPIP versions would further examine these issues (PHAC, 2004, p. 23).

Certain ethical principles pertaining to pandemic planning were identified both in this report and at a 2003 international meeting (Tamblyn and Kotalik, 2003). These principles include: beneficence & nonmaleficence, respect for autonomy, justice, subsidiarity principle,

precautionary principle, principle of proportionate response, transparency and principle of minimal necessary interferences. Among the issues identified as most urgent were: scarcity of resources; use of vaccine and antiviral drugs; engagement of health care workers; and communications with all sectors of society (Kotalik, 2006, p. 27-8).

The 2005 version of Ontario Health Plan for Influenza Pandemic introduced a section entitled "Ethics Framework for Decision Making" (MOHLTC, 2007a, (2) p.8). This was developed by the University of Toronto Joint Centre for Bioethics and adopted by OHPIP. This section presents the ethical values identified as central to the plan's development. Those particularly relevant to this study include: Individual liberty (least restrictive means, proportional to risk of harm etc.); Protection of the Public from Harm, (make stakeholders aware of reasons, benefits & consequences of not complying, and establishing process for reviews of decision and complaints); Privacy (preventing stigma); Equity (establish fair decision making process/criteria for providing individuals with vaccination, antivirals); Trust (building trust with stakeholders before the pandemic occurs and ensure that decision making processes are ethical and transparent); Solidarity (between communities, institutions and government with straightforward communication, and open collaboration); Stewardship (public health authorities entrusted to protect and be accountable for public well-being and equity (MOHLTC, 2007a, (2) p. 8-11). Two influenza pandemic issues identified as presenting significant ethical concerns are priority setting and public communication.

3.0 Literature Review

3.1 Priority setting

The major report entitled "Stand on Guard for Thee" (University of Toronto Joint Centre for Bioethics and Pandemic Influenza Working Group, 2005) examined ethical concerns of a

pandemic in detail and identified "Four Key Ethical Issues". Two of these most relevant to this study are priority setting and communications with all sectors of society. These will be discussed further below.

The authors draw a connection between ethical priority setting and communication. They note a condition of an effective communications strategy is transparency in the priority setting process. Specifically, they recommend that the government and the health care sector: (a) publicize rationale for priority access to health care service, (b) engage stakeholders (public is among groups listed) to determine priority setting criteria, guaranteeing that rationales for decisions are publicly available, and (c) establish mechanisms for appeals and concerns from stakeholders concerning those decisions. "The decision makers should initiate and facilitate constructive public discussion about these choices" (p. 17).

The first of these recommendations is announcing the rationale for priority access. This is also a key feature of the "accountability for reasonableness" formula for ethical resource allocation developed by Daniels (2000). He states:

> A fair process requires publicity about the reasons and rationales that play a part in decisions. There must be no secrets where justice is involved, for people should not be expected to accept decisions that affect their well being unless they are aware of the grounds for those decisions (p.1301).

Elsewhere this is termed the "Publicity Condition," where Daniels and Sabin (1997, 1998) argue that decisions regarding allocation of health technology, and the reasons for those decisions ought to be made publicly available (1998, p. 57, 59).

Childress et al. (2002) and Upshur (2002) agree that transparency and publicity regarding reasons for decisions are important parts of fair process. Gostin (2004, g. 571) argues that public

health and government officials must inform the public of what is known and not known, including the evidence informing decisions and policies. This transparency is also mandated by the United States Department of Health and Human Services Pandemic Plan (2005, Part 1, Appendix D). The need for transparency is also mentioned in the CPIP. The 2006 version calls for open communication of "pandemic risks and control options, and transparent, accessible communication regarding the assumptions, values, methods and plans" of the CPIP (PHAC, 2006a, (Annex K) p.1).

Further to this, the Joint Centre for Bioethics report suggests that "decision makers should initiate and facilitate constructive public discussion about these choices" (p. 17). A study by Kenny, et al. (2006) confirms that processes for improving health ought to be developed in a collaborative fashion, including citizen engagement. Specifically, pandemic decision-making ought to be "reasonable, open and transparent, inclusive, responsive and accountable" (University of Toronto Joint Centre for Bioethics and Pandemic Influenza Working Group, 2005, p.4, 11). Giocommini et al., (2000) and Childress et al., (2002) claim that the ethical consideration of procedural justice requires public participation, particularly the participation of affected parties.

Kotalik agrees that the monumental decisions of drug stockpiling and resource allocation should not be made without incorporating public input (2005 p. 428). According to Kotalik, this would result in greater public knowledge of decisions and increased likelihood of approval by the affected population. In his seven step process for dealing ethically with vaccine and antiviral drug scarcity, he recommends incorporating input from the general public. This is also the second recommendation of the Joint Centre for Bioethics report: stakeholder engagement in determining priority setting criteria.

Upshur (2002) argues that, as much as is possible, "political interference and coercion" should not bias the decision-making process. According to Bennett and Chanfreau (2005), public engagement will ensure that decisions reflect societal values, and not political agenda. They agree that decisions about stakeholder allocation should include public consultation and debate, and warn that without deliberate measures to obtain a societal-value based system for rationing, individual decision makers will default to personal value systems and judgments, resulting in conflict.

The last suggestion from the Joint Centre for Bioethics report is for the government and health authorities to create systems for hearing and responding to appeals and stakeholder concerns. Allowing the population to make queries is also a key step in Kotalik's resource allocation decision making process (2005). This also resonates with the argument in Childress et al., (2002) regarding transparency and public justification. In this paper, the authors contend that when a policy infringes (in reality, potentially or in perception) with one or more relevant moral considerations, (as with our example of protecting the public from fear, and providing transparent information) public health authorities are accountable to clarify and justify this to relevant parties. Specifically, he stated, "This is especially...important when one of the other prima facie general moral considerations is infringed, as with coercive protective measures to prevent epidemics" (Childress et al., 2002, p.174).

Notably, Childress et al. argue the public justification process is not a one-way path, but a dialogue between those in authority and the public. They state that it is a responsibility of public health agents to "work with the public and scientific experts to identify, define, and understand at a fundamental level the threats to public health, and the risks and benefits of ways to address

them" (p. 175). It should be noted that the authors also concede limiting disclosure of some information for a period of time during sensitive situations (Childress et al.).

A procedure for revising decisions is a part of the "accountability for reasonableness" Daniels proposes (2000). Daniels claims that fair process "requires opportunities to challenge and revise decisions in light of the kinds of considerations all stakeholders may raise". He also states that this process will be conducive to social learning: "Since we may not be able to construct principles that yield fair decisions ahead of time, we need a process that allows us to develop those reasons over time as we face real cases" (p. 1301).

3.2 Public Communication and Engagement

Given that connections between ethical priority setting, public communications and public involvement, it is necessary to consider the relationship between public communication and public engagement. The Health Canada Policy Toolkit for Public Involvement in Decision Making (2000, p.8) features a detailed 5 step continuum of public involvement. The continuum ranges from Step 1: "Inform/Educate" (what in this study we refer to as "public communication" on which the citizen is the audience/target of communication) through to Step 5: "Partner" (in which there is an agreement to implement the solutions citizens/groups identify). In this example, public communication is viewed as an initial aspect or at least a subset of the greater process of public involvement (see Figure 1).

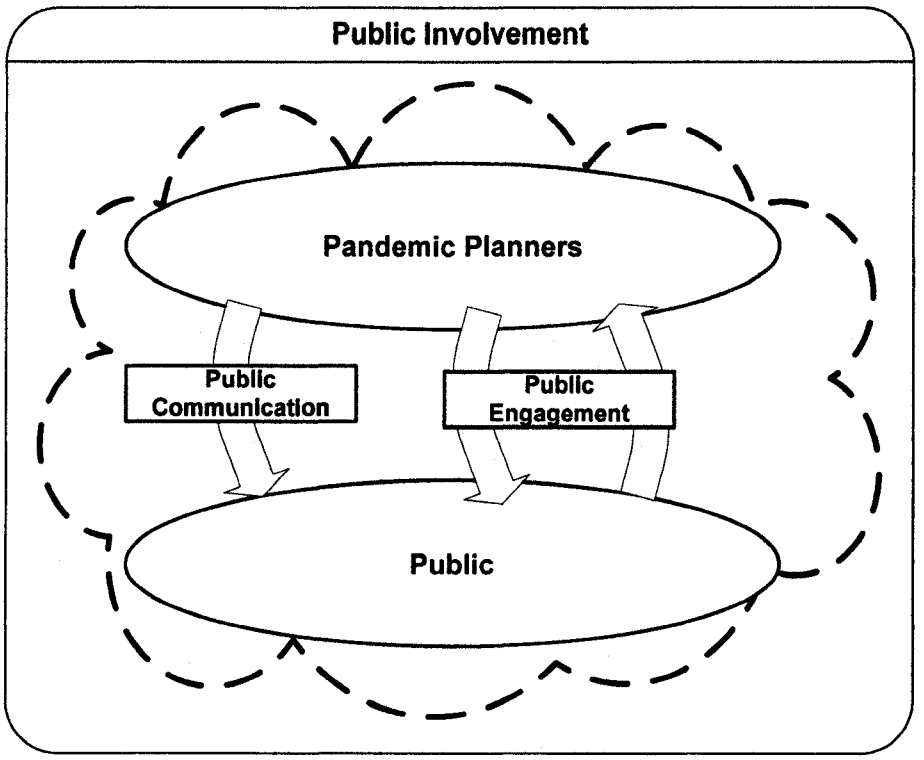

Figure 1. Interrelationship between Public Involvement, Public Communication and Public Engagement

Considering this interconnected and overlapping relationship, it is prudent to ask what "good" public communication is comprised of. This will be briefly discussed here. The WHO Outbreak Communication Guidelines (2005b) is the result of an extensive review of risk communication literature and collaboration with outbreak control experts from a variety of cultural, political and economic systems (p.1). They recommended five overarching guidelines to steer communication with the public:

1. Trust: this entails bidirectional between the public and communicators and outbreak managers, trust and between communicators, technical outbreak response staff and policy makers (p. 2).

2. Announcing Early: refers to "timing, candour and comprehensiveness" (p. 3), and is particularly significant in light of modern global communication.

3. Transparency: that is allowing "the public to "view" the information-gathering, risk-assessing and decision-making processes associated with outbreak control." (p. 4).

4. The Public: this point refers to understanding both the public's perspectives during an outbreak, and their part in the communication dialogue (p. 6).

5. Planning: having a communication strategy and plan in advance of an outbreak (p.7).

For pandemic influenza communication, the CPIP states several goals: "to raise awareness of the threat of pandemic influenza (and other types of influenza) by building on annual influenza campaigns, leading to better self-protective measures" so "...that they can develop a personal/family plan" (PHAC, 2006a, (Annex K) p.7). As mentioned previously, several key communication messages are planned in order to achieve these goals: awareness of the threat of pandemic influenza (and other types of influenza), self-protective measures, organizational level plans and encouragement to seek and follow direction from authorities (PHAC, 2006a, (Annex K) p.2-16; MOHLTC, 2007a, (12) p. 1, 2, 3).

The WHO Field Guide for Effective Media Communication during Public Health Emergencies (2005c, p. 40), offers suggestions for delivering specifically targeted messages such as these. Particularly relevant to pandemic influenza, in light of the WHO Outbreak Communication guidelines, the messages of "Fairness" and "Trust" are prominent. To communicate fairness, they advise that communicators should develop and deliver messages that: acknowledge possible inequities; address inequities; and discuss options and trade-offs. To communicate trust, messages that: cite credible third parties; cite credible sources for further information; acknowledge that there are other points of view; indicate a willingness to be held accountable; describe achievements; indicate conformance with the highest professional, scientific and ethical standards; cite scientific research (specific published studies); describe the

review, approval and advisory processes; identify the partnerships; and indicate willingness to share the risk (p. 40).

3.3 Public Engagement-The Debate

Debates regarding public engagement in health care and priority setting decision making is certainly not new. An article by Smith (1996), a decade old, illustrates the relatively slow progress that has been made. Smith declares that rationing in health care is an inevitable reality, and to best deal with this reality, governments must "come clean" and lead public debate on the subject (p. 312). He mentions that Sweden, New Zealand, Norway and the Netherlands have active, continuing (at the time of publication) public engagement projects.

Recently Thompson et al. (2006) developed an ethical framework for use in pandemic influenza decision making, based upon the Toronto SARS experience. They developed their framework with input from clinical, organisational and public health ethics, and incorporating a stakeholder engagement process. They argue the need for ethics in this issue because, "Good pandemic planning requires reflection on values because science alone cannot tell us how to prepare for a public health crisis" (p. 12).

Communications and the way in which decisions would be reviewed were among what Thompson et al., termed "hot button" issues. As an example, they referred to priority setting for vaccine and antivirals. They maintain that the values of trust and the principle of transparency mandate a well-informed public, conversant with those values in the ethical framework. Further, that the public be aware of the expertise that informed priority setting decisions. While they concede that broad public engagement may not be easy or pragmatic, solidarity and equity imply that public dialogue regarding ethical issues is needed. They suggested public debate concerning ethical issues to "increase the robustness of pandemic planning in general" (p. 12).

This was confirmed in a study on hospital priority setting during the SARS outbreak by Bell et al., (2004). Using the accountability for reasonableness framework mentioned briefly above, they found: "In the midst of a crisis such as SARS where guidance is incomplete, consequences uncertain, and information constantly changing, where hour-by-hour decisions involve life and death, fairness is more important rather than less (p. 36)." Further, Coote (1997) maintains that obtaining public opinion on the matters of communication and priority setting is vital to ethical public health practice. He argues that the public's views on priority setting are relevant for two reasons: a national health service must be truly answerable to the public, and priority setting decisions are ultimately political issues—the fair distribution of finite resources.

Most articles reviewed strongly promote public involvement and engagement in priority setting decisions in the interests of fairness, democracy and moral and ethical reasons. However this standpoint is certainly not unanimous. Although maintaining that transparency and open communication are ethical responsibilities, Newdick, (2005) suggests that public engagement can introduce nearly as many problems as it addresses (p. 668).

An article by Doyal (1998) offers an argument opposing public engagement, suggesting that it should be limited to protect democracy. He begins by acceding both that citizens should be able to participate in decision making about issues which affect their imperative welfare, and that policy decisions have long been dominated by "experts with specialized knowledge", a situation which in turn "engenders political passivity as well as stifling the bottom up feedback required for monitoring the effectiveness, efficiency, and fairness of policy decisions" (p. 98).

However his main argument is the danger in allowing the majority to dictate the health care received by minorities. He states that "public consultation can irrationally be influenced by the way in which policy questions are selected and worded for consideration, who presents the

options to be considered, and of course, the socioeconomic background of participants themselves (p. 99)." This is certainly a valid point. To the best of my knowledge, other studies in public engagement overwhelming indicate that the public makes decisions reflecting the views and values of the general public. In essence, Doyal claims that this is a power imbalance—the interests of minority groups lose to majority rule. Doyal seems to fear that the populace would make choices that might conflict with the principles or beliefs held by health care professionals, such as the importance of equity, preventative health care strategies or cost effectiveness.

However, my opinion is that Doyal's argument is flawed. It is based on privileging the moral judgments and abilities of public health agents and health practitioners over those of the general public. If indeed the public is subject to irrationality, bias, value judgments, personal, class-based, ethnicity-based, gender-based agendas, or "collective arbitrariness", aren't public health agents and HCW equally subject? If value-neutrality cannot be expected in the general population then how can it be expected in HCW and public health agents? Public engagement at the very least can provide those minority voices an opportunity to be heard.

Taking a Structuralism view, another possible argument is that the general populace is itself the minority—or at least a minority presence in policy making. Biomedical tradition, the prominence or medical discourse and a privileging of scientific and bio-medical knowledge is a dominant ideology in Canada. In a pandemic planning situation, the opinions and knowledge of the "average" or typical individual are not valued to the same degree as those of a person with significant scientific, biomedical training or credentials. Public engagement then would offer the minority voices of the public a venue for larger consideration.

Another prominent argument opposing public engagement and transparency concerns reducing fear and preventing unwarranted panic. Should pandemic plans anticipate a severe or

less severe pandemic (Kotalik, 2006, p.27), and what degree of severity should public communication express?

One notable viewpoint is that public communication ought to encourage trust in authorities and stymie unnecessary fear and panic. This seems to be the stance expressed in CPIP and MOHLTC communication plans. The OHPIP communications chapter (MOHLTC, 2007a, (12) p. 2) lists "reassurance" as one of three key communications objectives (the other two being education and accountability). Specifically, messages are intended to allay fears and reduce panic by demonstrating government and authority competence and preparation and modeling a calm approach (p.2).

Some researchers argue that public health communication has oftentimes contributed to public fear through use of "shock tactics" (Guttman and Salmon, 2004). The issue of panic was brought up during the recent SARS outbreak, where poor communication is thought by some to have "fueled public fears" (Schabas, 2003) but no evidence was presented that a fear affected adversely people's behaviour at that time. Media coverage of health issues is also blamed for inciting fear. May (2005) argues that during the 2004-5 influenza vaccine shortage in USA, media coverage provoked public fear leading to irrational and panic-induced behaviours. Jackson (2003), as well suggests mass news media distorts and biases public opinion on health priorities.

This might seem to conflict with the ethics based arguments reviewed above that maintain citizens should be made aware of health threats, such as through traditional health promotion and communication messages, have access to open, transparent communication, and be involved in the process of developing that communication as an equal stakeholder. This is a flawed argument because they are not mutually exclusive scenarios. To claim that we must

disregard transparent communication to preserve order and prevent panic is a logical fallacy. In the discipline of public health we have traditionally sought a balance for the populace between complete ignorance of health threats and excessive concerns and fears. This is achieved through education and health promotion.

Additionally, this argument seems to conflate sensational media coverage with official public communication. In the above articles, evidence of public panic is associated with media campaigns—that is, the authors are commenting on the belief, or suggesting that sensational media can incite panic, but they do not offer evidence to suggest that public communication does the same.

In Outbreak Communication Guidelines, the World Health Organization (2005b) maintains that if openly informed, public panic is very rare (p.2). They state the technological and communications advancements of the modern world provide multiple points of access for individuals to be informed of outbreaks. Thus, information will eventually come to light. The authors contend that announcing information as early as possible will prevent the spread panic, rumour and misinformation (p.3), noting that if information is withheld, the more frightening it will appear. Further, they warn that the consequences of losing public trust are severe.

This was confirmed in a study by Melnick, et al., (2005) examining priority setting and seasonal influenza vaccine and antiviral drug availability in Virginia, USA. The authors concluded that transparent decision making, clearly communicated to the public, helped to build community trust.

In addition to building and maintaining trust, infection control can be improved through transparent and inclusive communications and decision making processes. The OHPIP (MOHLTC, 2007a, (2) p. 2-7) and Joint Centre for Bioethics report (University of Toronto Joint

Centre for Bioethics and Pandemic Influenza Working Group, 2005) agree that stakeholders are more likely to accept difficult decisions if decision-making processes are: open and transparent (explained, open to scrutiny), reasonable (based on evidence, principles, values; made by people who are credible and accountable), inclusive (stakeholders could engage in the process), responsive (revised and updated as required, with mechanism to deal with complaints and disputes), and accountable (decision-making sustained throughout the pandemic).

Gostin (2004) acknowledges the predicament intrinsic to finding a balance in open communication and preventing panic. He notes that in a situation in which scientific knowledge is limited (such as the scope and severity of an influenza pandemic) dilemmas are unavoidable. He points out that if actions are taken that are later revealed to have been needless, it will be viewed as excessive and "draconian," while too passive a stance will lead to disaster. He concludes that "the only safeguard is the adoption of ethical values in formulating and implementing public health decisions" (p. 572).

3.4 Measuring Public Opinions and Public Engagement Examples

Public engagement is found increasingly in Canada. The cities of Edmonton (Capital Health, 2007) and Vancouver (Vancouver Coastal Health, 2007) operate Community Health Councils and Community Health Advisory Committees respectively, comprised of appointed community representatives. Though they wield no decision making power, they act in an advisory role regarding health needs and priorities. Calgary Health Region runs a Public Participation Framework (Calgary Health Region, 2002) featuring five participation levels with increasing public control of decision making. Very recently in Ontario, Local Health Integration

Networks (LHINs) were developed and will utilize community engagement to determine health needs and priorities (MOHLTC, 2007b).

Some prominent methods of engagement will be briefly described here:

Deliberative Polling: This is a method of polling to determine respondent's views before and after they are given time and opportunity to deliberate on an issue. Starting with a probability sample of the national citizen voting age population, participants are questioned on an issue. Next, they review briefing materials for background information and to stimulate thought on the subject. Finally, participants are brought to a single site for intensive debate and discussion, followed by a final poll (Luskin, et al., 2002). This method was used in a recent Ontario study regarding health and social services (Abelson, et al., 1995).

Public Opinion Surveys: This method is often used to measure public attitudes, perceptions and behaviours. It usually entails asking a representative population sample predefined questions and using trained interviewers. It is considered to be a relatively inexpensive, fast and efficient way to garner public opinions (Health Canada, 2000, p.45).

Citizen's Juries and Planning Cells: Popular in the UK, and having roots in US and Germany (Smith and Wales, 2000), a citizen's jury is comprised of 12 and 16 jurors who are recruited through a combination of random and stratified sampling, to be broadly representative of their community. At baseline they are fully briefed about the background of the issue, through written information and oral evidence from witnesses. Then, for four days, with a team of two moderators they address an important question about policy or planning, cross examining the witnesses and deliberating on different aspects of the question. Verdicts are not definitive nor must they be unanimous. (Lenaghan, 1999).

Consensus Conferences/Citizen's Panels: Citizen's panels are similar to citizen's juries, in that they are largely comprised of the general public in dialogue with subject matter experts. They are however, often larger, comprised of more individuals and more permanent. A recent example is a study involving an Ontario community and health goal setting (Abelson, et al., 2003). Methods included mail and telephone surveys as well as face-to-face meetings.

Focus Groups: A focus group is a small assemblage of people for the purpose of generating detailed information regarding a specific concern or issue. Under the facilitation of a skilled moderator, focus group participants discuss an issue, often sharing personal experiences or stories, usually over the course of several hours (Health Canada, 2000, p.25).

Citizen's Dialogues: This public engagement tool uses a sample of individuals to identify values and make policy suggestions. In the Citizens' Dialogue on the Future of Health Care in Canada (Forest et al., 2002), twelve day-long sessions were held, engaging 481 participants. Participants were presented with scenarios and a pre and post test questionnaire. Important Canadian social and cultural values intrinsic to health care decision making were uncovered during the course of this study.

Public Education and Communication: Both the Health Canada Policy Toolkit for Public Involvement in Decision Making (2000, p.24, 28) and the Public Involvement Framework (Health Canada, 2007, Appendix C) include educational campaigns and public communications strategies as an important aspect of public engagement. This entails the step of providing the public with accessible information on the issue at hand, such as through advisories or educational campaigns. The Public Involvement Framework lists the "Inform or Educate" step as the first level in their larger public involvement structure.

Giacomini et al., (2000) calls for "rigor" in the process of public participation and critique of decisions, similar to evidential and scientific rigor informing other aspects of pandemic planning. There are a variety of public engagement techniques in use. Jordan et al., (1998) note that there are roughly two styles of garnering public input: the first is a system that encourages in depth deliberation and debate. This attempts to measure public views as they might be, providing all citizens were given adequate information and a forum for debate. The second system tries to measure public opinion as it is presently. In this situation, educational components are not included and the measure of interest is present opinion and knowledge.

Mullen (1999) also provides an overview of methods for eliciting public values and opinions. She argues that the validity of methods is contingent upon the purpose of the specific projects. For example, if the results obtained will be used to inform priorities and resource allocation, methodological validity is essential, but if the purpose is an exercise in public engagement, methodology is less important. This indicates that choosing methods for garnering public opinions is not an "exact science". She does state however, that measurements ought to be modified according to the application to which they will be put.

Martin, Pater & Singer (2001) examined the public engagement in the priority setting of cancer drugs. They felt that survey tools framed the issue in overly simplistic and rigid terms and thus were not adequate to capture its depth and complexity. Jordan et al., (1998) point to research suggesting that respondents to opinion surveys are reluctant to accept a public role in determining priorities for health care. To combat this bias, they propose that mechanisms with informed and deliberated components may enhance participation when the aim is to produce substantive recommendations. Shaw agrees that the survey can be fraught with methodological difficulties (Shah, 2003, p.87). Engaging disenfranchised and oppressed populations poses

particular challenges, and O' Keefe and Hogg (1999) suggest that community development approaches are a way to increase participation and build confidence of these groups.

Several prominent studies do advocate the survey as an appropriate tool for gauging public opinion on priority setting, including an economics-based project in the UK (Roberts et al., 1999) and another study in the US (Wittenberg et al., 2003). The Public Engagement Pilot Project for Pandemic Influenza (PEPPPI) is another such example. PEPPI was a large-scale study of public engagement and pandemic influenza spanning major U.S. centres, with participating organizations including Georgia Department of Human Resources: Division of Public Health, Massachusetts Health and Human Services, National Immunization Program at the Centers for Disease Control and Prevention, National Vaccine Program Office in the Department of Health and Human Services, Nebraska Health and Human Services, Oregon Department of Human Services, University of Georgia, and University of Nebraska Public Policy Center. PEPPPI used a 24 question survey as pretest and post test to evaluate the public engagement and education process.

The PEPPPI final report (Bernier and Marcuse, 2005) provides evidence that issues of pandemic influenza priority setting can be fruitfully examined using survey tools, and perhaps more importantly, that a diverse assemblage of stakeholders, experts and citizens could courteously collaborate and make recommendations on the issue of pandemic influenza priority setting.

Unfortunately, not much is known about the benefits or drawbacks of public and client involvement in health care decision making or the public's preferences as to the types and degrees of involvement. Guadagnoli and Ward (1998) reviewed literature regarding engagement in the decision making process at the patient-physician level. They determined that previous

studies addressing the benefits of patient involvement were sorely lacking due to small sample size and methodological issues. Recently, more work has been done in this area. A study in the UK by Litva et al., (2002) looked at data from 58 focus groups composed of randomly selected citizens, and in-depth interviews with informants from health care and non-health related organisations. They too suggested that further research be done in this area, and in determining the preferences and extent to which the public wishes to be involved.

This leads to numerous questions of how best to inform, communicate with and engage the public: What is the degree to which the public wishes to be engaged regarding priority setting, what are their preferences for being involved in different types of decisions, and what is the best way to gauge this?

Litvia et al., (2002) look at this issue in some depth concerning health care in the UK. Using a variety of qualitative methods, the researchers found a strong desire among participants for the public to be involved both at the system and program levels of decision making, and posit the need for further exploration of the subject.

These findings are not exceptional in recent studies on public engagement. Current literature indicates a move, at least in Western democratic states, toward a more actively engaged public electing to "taking charge" of their health. Many individuals are becoming less willing to passively follow the instruction of medical authorities and prefer a more collaborative approach to health communication at all levels (Stevenson and Scambler, 2005). In European countries, (Saltman and Figueras, 1997) there is a growing demand from citizens for "explicitness, transparency and greater public involvement in the decisions that must be made." In discussing the effects of postmodernism on health care, Gray (1999) asserts that public involvement in health and health-care policy making is now a central tenet. He notes that "empowerment"

versus "paternalism" (p. 1552) improves patient or client satisfaction and suggests it could positively affect clinical outcome.

For example, in Guadagnoli and Ward (1998) the researchers found that at the patient-care provider level, individuals wanted an active role: to be informed of treatment alternatives, and to be involved in treatment decisions when more than one treatment alternative exists. A sense of public "ownership" regarding health policies and an entitlement to be involved in decision making at the policy level was also documented (Lenaghan, 1999, p. 53). However this is not an undisputed cultural norm. Fay (2001) states that the modern "neo-conservative" phenomenon, contained in the maxim—"there is no such thing as community, only individuals" (p.85) —is a factor behind a distinct drop in community participation in recent decades.

These examples seem to indicate that socio-cultural forces, including cultural norms, values and history, play a role in not only *what* community engagement tools are effective, but in understanding *why* individuals may prefer one method over another and the extent to which they wish to be involved in these matters.

Further, some researchers argue that public health communication itself is influenced by these social factors—that both communication messages and audience interpretations are shaped by often implicit socio-cultural, linguistic norms and political history. May (2005) refers to these as "background schemas" (p.419) and challenges that they are integral in how an audience interprets a message. Mah and Myers (2006) argue that "in a postmodern era of social fragmentation and intellectual ambiguity," infection control authorities require a "socioethical approach to behavior change" (p. 73).

3.5 Critical Public Health Ethics

Callahan and Jennings (2002) identified four overlapping branches of health ethics: professional ethics, bioethics, applied ethics and critical public health ethics. They state that these are not exclusive branches, but share overlapping elements. For example, professional ethics, while also practically oriented, deals more with the central duties and tasks of practitioners. While applied ethics takes into account social and cultural context, and advocacy ethics is focused on equality and social justice, critical public health ethics combines these. They assert that "critical" public health ethics combines the strengths of the other branches mentioned (p. 172) in that it is: (a) historically informed, (b) practically oriented, (c) takes larger social values and historical trends into account, (d) has much in common with advocacy ethics, specifically, an egalitarian and human rights-oriented discourse (Callahan and Jennings, 2002, p.169).

It seems entirely appropriate to apply a critical public health ethics perspective to such a seemingly practice oriented topic as pandemic influenza planning. Namely, as suggested in the above literature, social and historical trends play a large role in both public engagement and decision making, which this framework emphasizes. Other researchers have found this conceptual framework valuable in examining public health and power relations. Notably, Nixon, (2006) who states that this viewpoint is an excellent way to examine a public health issue in light of social values, historical trends and institutional and power dynamics.

The author was impressed by this perspective and much of the study design was shaped by these concepts. The author felt that the critical public health ethics approach was more suitable than theoretical frameworks that were traditionally more anthropologically and sociologically centered for two reasons:

1. Practical Results: Due to the many unknowns and sense of urgency surrounding the prospect of a future pandemic situation, it is important to have data leading to practical suggestions for improvement. Examining pandemic influenza communication requires both looking at the socio-cultural "climate" influencing the participants and planners, and generating data that can help to formulate practical recommendations for future communications strategies. While anthological and sociological frameworks (I.E. Interpretive Theory, Illness Narratives), would be useful in generating data concerning societal communications preferences, social trends in media usage or perspectives regarding public engagement, the data would not directly lend itself toward making concrete suggestions. A critical public health ethics approach, however, seeks a practical application for results.

2. Capacity Building Process: Callahan and Jennings (2002) asset that the "critical ethics approach" calls for:

> "discussions of ethics and public health policy to be genuinely public or civic endeavors: not the advocacy of a well-intentioned elite on behalf of needy clients, but a search for forums and programs of meaningful participation, open deliberation, and civic problem solving and capacity building" (p. 169).

This emphasis on meaningful participation in problem solving ensures that participant voices and views are at the forefront of both data analysis and research outcomes. Other theoretical orientations (for example, Community-based research/Participatory Action) are also focused on participation from and cooperation with participants. The critical public health ethics perspective, however, is not only concerned with involving research participants, but in searching for those forums that will bring the most meaningful participation. As the secondary

objective of this study was to determine preferences for public engagement in the sample populations, the author felt this perspective was well suited.

In other words, while other theoretical frameworks have been proven to successfully ask these types of questions, critical public health ethics is equally interested in identifying practical responses, using participant capacity building and open participation. For these reasons the principles of a critical public health ethics perspective strongly contributed to the development of the survey design and analysis.

3.6 Rationale for Proposed Study

This study will contribute to knowledge in: public health communication, public engagement and public health ethics.

3.6.1 Communication:

Public health communication/promotion endeavours to promote healthful behaviours and attitudes in individuals (Maibach and Holtgrave; 1995, Sindall, 2002). Thus, although public health uses "societally-oriented strategies" (Kass, 2004), communication tends to centre on empowering the individual to take charge of their own health and wellbeing through knowledge of healthy behaviours and actions.

From a conventional public health perspective this makes perfect sense. In typical public communication campaigns, the emphasis is on empowering the individual to take charge of their own health through knowledge, increased self-protection and disease management skills. It is not considered imperative for the public to be advised of the specific details of the larger plan for combating and controlling disease. However, there are some unique circumstances regarding

pandemic influenza that distinguish it from the health issues that public health is already actively dealing with. Among those, scarcity of vaccine and antiviral drugs and their priority setting so far received most attention. A pandemic influenza outbreak would also likely result in an extraordinary scarcity of many resources including hospital beds and medical staff, equipment and drugs (Gostin, 2004; Johnson, Bone & Predy, 2005; Kotalik, 2005; Melnick, et al., 2005). In this situation, even if individuals were to practice model personal health behaviours, (the benefits of which in a pandemic situation are not established) the extenuating circumstances, including the scarcity of resources, would supersede individual level control and health capacity.

This situation mandates scrutiny of the techniques used and messages contained in pandemic communication. Guttman and Salmon (2004) suggest that since ethically sound communications are more likely to be trusted and implemented, inquiry should be made into communications strategies and message design (p.535). This study will critically investigate the strategies and key messages latent in communication developed for the general public. Information will be useful for future public communications regarding infectious disease, and in better understanding of health literacy in the sample populations.

3.6.2 Public Engagement:

Although numerous scholars have produced valuable research regarding citizen preferences for involvement, there remains much work to be done concerning specific methods and modalities of public involvement. As community engagement continues to expand in Ontario and other areas of Canada, this information will be valuable in the development and implementation of future community engagement methods for pandemic influenza and other infectious diseases.

3.6.3 Public Health Ethics:

There is much work to be done in the relatively new field of public health ethics. There is a clear need for development in public health ethics to develop foundational knowledge and address the unique concerns of the discipline (Callahan and Jennings, 2002; Childress et al., 2002; Schabas, 2002; Wolder-Levin and Fleischman, 2002; Bayer and Fairchild, 2004; Kass, 2001, 2004). Further, some scholars contend that infectious diseases, such as influenza, raise unique ethical concerns (Smith et al. 2004) that have not been adequately addressed in bioethics previously (Francis et al., 2005; Selgelid, 2005). Using this approach will further knowledge in this discipline, by assisting ethicists to develop empirically grounded practices in public communication for pandemic influenza.

3.6.4 Proposed Study

The purpose of this research was to critically analyze public communication directed toward the population of Ontario regarding a future influenza pandemic using a critical public health ethics perspective, as well as examine public preferences for engagement in pandemic planning. This study takes a step toward answering the questions: Are Ontarians, at least those sufficiently aware of the nature of threat of the next influenza pandemic, receiving communication that corresponds to their needs and desires concerning this contingency? What are their preferences for engagement in pandemic decision-making?

For the first part of this study I will report on a document analysis on a sample of official public health communication emanating from both provincial (Ontario) and federal levels regarding pandemic influenza and particularly vaccine and antiviral drug allocation. Next part of the thesis will report on the collection and analysis of data regarding the public's knowledge, information needs and expectations of official communication. Results from the document

analysis and survey will be compared. Lastly, findings will be used to develop practical suggestions for public communication concerning potential public health emergencies, especially concerning pandemic influenza. The objective is to assist public health professionals to reflect on the social and ethical implications of communicating with the public in the current pre-pandemic period.

4.0 Methods

4.1 Methodology/Epistemology and Ontology

As a further step in the development of ethics in this field, the tenants of critical public health ethics influenced the development and data analysis of this study. The major features of the public health ethics perspective, as described by Callahan and Jennings (2002) (see below) were incorporated into the document analysis and survey in the following:

4.1.1 Practical Orientation

Information was sought on communication preferences and health literacy behaviours, with the purpose to gather data for practical application. Factual coding of the reviewed documents thus sought messages and phrases relating to prevention and treatment of pandemic influenza, options for medical care and ways in which pandemic will affect daily life. The survey asked respondents to rate the importance of these messages.

4.1.2 A Search for Meaningful Forums of Participation

This influenced both the choice of subjects/topics explored in the document analysis (see Section 4.2) and the interpretation of survey responses. For instance, in a critical public health ethics framework, community engagement is regarded as an important part of the

communication and larger decision-making process. In this study, factual coding was used to seek information on antiviral drug and vaccine priority setting decision making, and survey respondents were questioned regarding community engagement in general pandemic planning and priority setting decision making. Respondents were also asked to rate their preference for various community engagement methods.

As well, this framework recognizes the need for transparency in communication from and with pandemic planners. Through factual coding messages were sought regarding the persons to be included in priority setting groups and by whom this is determined. Survey respondents were asked to rate the importance of this information.

4.1.3 Social Trends:

It is assumed that social factors and cultural values bear upon participant responses, beliefs and preferences. Similarly it is expected these values influence scientific, ethical and financial practices or principles either implicitly or explicitly. Factual coding was used to identify key messages on the influence of science, ethics, and finance on priority setting decisions, and survey participants rated the importance of this information. This information provides a sense of the social climate of the communication documents (for example, which health and social behaviours are valorized and which are discouraged). Further, preferences for timing of messages and communication channels (e.g. television, website) were examined. As well, open ended questions allowed for insight into cultural and social values within the sample shaping survey responses, (i.e. valorization of biomedical knowledge, (dis)trust for decision-making authority).

4.2 Document Analysis

There exists a prodigious and unwieldy amount of official communication currently available at both the provincial and federal levels. Therefore, all extant documents could not be reviewed given the scope of this thesis. This document analysis is not exhaustive, but included all documents the author was able to locate, which fit the inclusion criteria. They are intended to comprise a "snapshot" of available information.

Official communication at both the federal and provincial (Ontario) levels was included. These included media releases, a news report, and educational communication developed for the Canadian public. The sample was limited to documents written in English and available online (audio, video and PowerPoint presentations were excluded). Paper documents (pamphlets, fact sheets, handbills) were originally included in the review. However after comparing the documents available online, most of which were also available in PDF format (thus printable as pamphlets, fact sheets and handbills), it was apparent that the text was identical in both online and paper versions of the same documents. As well, in Ontario, local public health departments and units play a large role in pandemic preparation and are responsible for developing and distributing public information. Thus, local messaging may differ from region to region. I thus continued the document analysis using the online sources in the interest of a more systematic and repeatable search.

Included were all documents the author was able to locate, which were:

1. Available on MOHLTC, PHAC, and Health Canada websites,
2. Available during data collection January and early February 2007,
3. Purposely designated as information intended for the public, families and/or media distribution.

Specifically, these included all documents located on the PHAC website listed under "Pandemic Influenza, Information for the Media" and "Information for Individuals and Families" headings, and all documents on the MOHLTC website listed under "Pandemic Influenza: Public Information" heading. Six additional documents, containing information on avian influenza, First Nations and Inuit Health, a Health Canada new release, were taken from Health Canada websites. Though not pertaining specifically to pandemic influenza, these documents were included because they "linked" to the PHAC pandemic portal website. 31 documents were reviewed in total (see Appendix A for a complete listing).

After making several telephone and email inquiries at both PHAC and MOHLTC, I was invited to submit my query through General Inquiries email form on the PHAC website. I submitted a list of the documents chosen for review, and the resulting email reply suggested additional items. These documents were then included in the analysis.

Only one document included in the review was not aimed at explicitly informing or educating the general public. This was the Highlights of the Canadian Pandemic Influenza Plan for the Health Sector (PHAC, 2006b), which was constructed primarily for health professionals and based on a larger document (CPIP). The Highlights from the CPIP was included at the recommendation of informal email contact at PHAC. Both the CPIP itself and the OHPIP were not included in this review because the general public is not their specifically intended audience. To illustrate, although the OHPIP can be easily found on the MOHLTC site, it is listed under Information for Health Professionals. As well, the CPIP states in its Introduction that its primary audiences are emergency responders, P/T Ministries of Health and other health professionals and pandemic planners.

The documents were analyzed in a four step coding process. Firstly, the researcher "opened" the data by giving a first read through and, using open coding, identified passages of text that related to an idea or theme. Words and phrases, viewpoints and ideas that were prominently displayed in the text, repeated, given emphasis or were positively or negatively positioned were identified. During this stage, using factual coding, the researcher tallied the occurrence (a "count" of the presence or absence) of words or phrases corresponding to the following 11 topics: 1) prevention of pandemic influenza; 2) treatment of pandemic influenza; 3) options for medical care; 4) effects on daily life; 5) vaccine and antiviral resource allocation plans; 6) priority groups composition; 7) scientific rationale for priority grouping; 8) ethical/moral rationale for priority grouping; 9) financial rationale for priority grouping; 10) by whom priority grouping is determined; 11) how priority grouping/resource allocation will affect those not in a priority group. These topics were identified prior to factual coding data collection and were chosen based on the WHO Effective Media Communications during Public Health Emergencies Field guide and the PEPPPI study concerning pandemic influenza and public engagement.

The WHO communication field guide provides detailed information on the various concerns the public might have and how to address them in public communication messages and strategies (2005c, p. 37). The first 5 topics in the document review, as well as topics 8 and 9 were chosen as representing the possible public concerns listed.

The PEPPPI study included providing background information handouts and presentations to participants regarding various aspects of pandemic influenza and pandemic planning, such as historical information on past pandemics, and presentations by ethicists and epidemiologists. PEPPPI participants were then presented with various hypothetical scenarios

and participated in facilitated small group discussions to deliberate on the values and goals therein (Bernier and Marcuse, 2005, p.12, 13). Among the many subjects contained in the handout and discussed during the deliberation process concerned decision-making rationales, ethical principles, financial trade-offs, and the effect of a pandemic on society (Bernier p.42, 43). Given the scope of this thesis, it was not possible to include a deliberative process such as used by PEPPPI. However, the author felt it was important to look for information pertaining to these topics in the public communication documents. Topics 6 through 11 were included for this reason.

Considerable caution was exercised at this stage of the coding to include any information that could pertain to one of the topics regardless of length or complexity. For instance, in counting the incidence of words or phrases addressing Topic 1 (how to prevent catching pandemic influenza), the researcher included documents with information as brief as "it (vaccine) helps prevent people from getting the disease" along with the documents providing much more detailed information on self-protection measures. See Appendix B for a list of key terms and phrases.

Next, using axial coding similar concepts were grouped into conceptual categories (e.g. Risk, Self-protection, and Transmission) and were further developed to enhance understanding of the concepts and their meanings in relationship with other communication documents. Finally, conceptual categories were further developed through selective coding. This entailed overlaying the findings from the open, factual, and axial coding with the four major components of the critical public health lens. As a result, four central themes of the sample were identified. All coding was done by hand and conducted concurrent to survey data collection. It must be noted that due to the nature of document collection and qualitative research methods, results

from the document analysis are not repeatable or generalizable to all pandemic influenza communication.

Coding is an oft used and a highly recommended method for analyzing qualitative data (Neutens and Rubinson, 2002, p.187-189; Sterk and Elifson, 2004, p.145-147). This approach has been previously used to examine issues concerning priority setting decision making. Singer et al., (2000) analysed documents using open, axial and selective coding to identify qualitative "domains" in the process of making priority setting decisions for new medical technologies. Bell et al. (2004) used open and axial coding to analyse documents regarding SARS and hospital priority setting.

4.3 Survey Instrument

A 36 question survey (Appendix C) was developed to broadly assess these key factors:

1. Knowledge of pandemic influenza.
2. Knowledge of vaccines and antiviral drugs, including priority setting.
3. Public communication needs, preferences and level of satisfaction.
4. Preference/opinion on community engagement in the decision making process.

The choice of questions was deliberate to address the concerns of public health ethics, and specifically to identify informational and communication preferences within the sample and practical applications for public communication and community engagement. Questions included multiple choices and Likert scaled questions to produce nominal and ordinal data respectively.

As mentioned in Section 4.2, the WHO communication field guide provides detailed information on the various concerns the public might have and how to address them in public communication messages and strategies (2005c, p. 37), and the PEPPPI study participants were presented with hypothetical situations and presentations to stimulate thought on various social

and ethical values relevant to communication and public engagement. These points formed the basis of the factual coding topics. Questions 21 and 25 of the survey correspond to these topics to determine the level of importance respondents rate each topic.

Several steps were taken to increase reliability and validity. The PEPPPI final report (Bernier and Marcuse, 2005) includes a 24 question survey used as a pretest and post test to evaluate the public engagement and education process. The survey included four sections: Opinions about "flu" vaccine policy, general pandemic influenza knowledge, PEPPPI processes, and personal information. Questions were designed to collect both nominal and ordinal data. To increase reliability and validity, much of the survey for this study was modeled after PEPPPI tools. Specifically, Questions 1 through 10 of the survey, regarding general pandemic influenza knowledge, are adapted from the PEPPPI pre/post test questionnaires with only slight modifications made as necessary for the Canadian context.

A "Context and Clarity" analysis (The Health Communication Unit at the University of Toronto, 2006) was conducted on early versions of the survey. This was comprised of a 2 step pilot test: firstly with 17 volunteers similar to the target sample, and secondly by 4 individuals currently working in the fields of public health, health promotion and infection control. These 21 individuals provided feedback on the design, wording and content of the survey questionnaire to improve comprehension of questions and answers. Additionally, survey development tools and worksheets from the Evaluating Health Promotion Programs InfoPak Version 3.5 (The Health Communication Unit at the University of Toronto, 2006) resource strongly informed the development of the survey.

The data from the completed surveys was tabulated for subsequent statistical analysis and findings were analyzed using SPSS 13.0 (2004) statistical analysis software.

Data analysis was conducted similarly to the PEPPPI study. Descriptive statistics, including frequency distribution, were conducted on the nominal data. Mean score and standard deviation were determined for each question producing ordinal data.

Questions relating to pandemic influenza knowledge (having a correct answer) were weighted. Respondents were assigned a score according to number of correct answers from a scale of 1, high knowledge through 4, low knowledge. These measures were correlated to examine relationships between level of knowledge and preferences and opinions. Results of the factual coding and respondent preferences for communications topics were compared.

Correlation was calculated to measure the association between participant pandemic knowledge score with their self rated ability to make health decisions based on: present pandemic influenza knowledge; present knowledge of government plans for influenza pandemic; present knowledge of vaccines and present knowledge of antiviral drugs. Correlation was also calculated to measure association between age, gender and pandemic knowledge and belief that general government pandemic plans and priority setting plans should be shared with the public.

The PEPPPI project also included focus groups as a method of qualitative data collection. To compensate, this survey contained 16 open-ended questions to allow for further elaboration or context from respondents. Responses to these were analyzed along the same processes as the communications documents in the document analysis, minus factual coding. Key themes from these responses are identified and included in the study results.

Lastly, survey results were compared with the results the document analysis of public communication. These were developed in a conceptual analysis which was strongly influenced by a critical public health ethics perspective.

Sampling and Recruitment

Sampling was comprised of a convenience sample from two populations from North-Western Ontario: students, faculty and staff at Lakehead University and the Lac des Milles Lacs First Nations band. Sample size was determined by opportunity and budget.

Lakehead University, in Thunder Bay, Ontario, currently has 7,400 full-time and part-time students and 1,600 staff and faculty members. Potential participants were students, staff or faculty, aged 18 and over, residing in Ontario for the past five months.

During a 2 day span, a recruitment table and a survey table were set up in high traffic areas of the University. Recruitment posters were distributed throughout the campus. Potential participants requesting more information about the study or interested in participating were supplied with a cover letter and consent form advising the purpose and expectations of the study, instructions on how to complete the survey, length of time estimated, and return procedure. A small incentive gift was offered to all potential participants.

The surveys were self-administered, and all participants were given the option of either completing the survey at designated tables, separate from the researcher and passers by, or at nearby locations on campus or at the health fair, to their discretion. This provided respondents with greater comfort, privacy and control to reduce anxiety. The majority of surveys were completed on the spot, with several participants taking the survey to complete in other areas on campus and returning them the following day. The survey took approximately fifteen to twenty minutes to complete. 150 participants were recruited with 121 returned surveys.

The Lac des Mille Lacs First Nation of Northwestern Ontario is a largely urbanized First Nations population, with most members residing off-reserve in the city of Thunder Bay. There are currently 500 listed on the membership list. Potential participants included LDML band members, aged 18 and over, residing in Ontario for past 5 months.

Participants were addressed at an informal health fair hosted by the LDML health and wellness programs. After attendees were informed of the purpose and expectations of the study, a cover letter, consent form and incentive gift were distributed to potential participants aged 18 and over. Participants were encouraged to complete the survey at tables provided while at the fair. 50 participants were recruited with 40 surveys returned.

Data from the two populations were inputted and analysed separately.

Research ethics

This study was approved by the Research Ethics Committee of Lakehead University, and by the Lac Des Milles Lacs First Nations band office. Each participant provided consent. Refer to Appendix D for cover letter and consent forms.

5.0 Results

5.1 Document Analysis

A sample of pandemic influenza communication was analysed through a three-step coding process. 31 documents from PHAC, MOHLTC, and Health Canada websites were analysed. Results are based on the author's interpretations of the text, and due to the nature of qualitative research methods, it is not suggested that results are repeatable or generalizable to all pandemic influenza communication.

5.1.1 Factual Coding

During factual coding of the reviewed documents the presence or absence of the following eleven themes were tallied. Please refer to Appendix B for a table of documents and factual coding themes.

5.1.2 Prevention:

Prevention of pandemic (and also avian and seasonal) influenza was the strongest theme in these documents. 20 of the 31 communication documents featured information on prevention. Most commonly this included in-depth instructions on hand hygiene, respiratory etiquette, the benefits on seasonal flu vaccine and lesser information on social distancing, safe handling of poultry and wild birds and so on. However, some of the prevention information was as limited as brief encouragement to the reader to stay home during a flu pandemic or get a flu vaccine. Less detailed self-protection information examples were included if these behaviours were positioned as a self-protection measure, (for instance, coupled with "prevent" or "protect" : "It is therefore important that you prepare yourself in case you have to remain in your home for several days to protect yourself and others from being infected with the virus (Document 21)."

5.1.3 Treatment:

A total of 16 of 31 the reviewed documents exhibit information on how to treat pandemic influenza. Of these, four offer more detailed recommendations for symptom control, hygiene and general practices. The remaining 11 documents suggested one or more of the following: stay home when ill, rest, call their health care provider or mentioned that antivirals were available for treatment.

5.1.4 Options for medical care:

A total of 10 of the 31 documents mentioned that access to health care services may be in greater demand delayed, reduced, restricted, or unavailable. Several commented that special flu clinics may be set up to deal with this, but most did not explain how this will affect availability of care.

5.1.5 Vaccine and Antiviral Allocation:

This topic relates to the explicit mention of priority setting with regard to vaccines and antivirals. Only one document (Document 16) specifically refers to vaccine priority setting, although Document 12 briefly mentions that the vaccine may be in short supply at first. 3 of 31 documents distinctly disclose the possibility/planning of priority setting of antivirals (Documents 9, 14 and 20). Three further documents indirectly indicate the prospect there may not be enough antivirals for everyone (Document 22), that there are "distribution systems for supplies" (Document 23), and the Ontario government is stockpiling for 25% of the population (Document 30) but these do not explicitly address the possibility of priority setting.

This contrasts with the message in 5 other articles alluding that shortages (thus priority setting) may not be an issue. For example, 5 documents assert that Canada's contract with a domestic vaccine supplier will afford Canada the ability to provide "all Canadians" (Document 5) with vaccines "when they need them" (Document 15) or "as quickly as possible (Document 9)."

5.1.6 Who is included in Priority Groups:

5 of 31 make some mention of who will be included in priority groups. (There was some discrepancy in actual responses as vaccine and antiviral allocation strategies vary by province.) Notably, no documents specifically defined how high risk persons will be identified. For instance, several documents noted that those "most likely to benefit" (Document 31) or "high risk" individuals will have priority access, but it is not explained how this will be determined. Nor do those documents mentioning 'high risk" populations specify the possibility of priority setting.

5.1.7 Daily Life:

11 of 31 documents point out that pandemic influenza will possibly bring some form of social disruption, including store and bank closures, disruptions in transit, healthcare, work hours and travel restrictions. No documents indicate what measures are being anticipated to reduce the social disruption or reduce its impact on vulnerable persons.

5.1.8 Scientific Rationale for Priority Setting:

There was no explanation provided in any reviewed documents as to the scientific information or principles for determining priority groupings, for instance, which individuals will be at high risk and why.

There was some limited scientific rationale providing explanation as to why shortage might occur. 9 of 31 documents noted that vaccine or antiviral shortage will occur due to a 4-6 month time period needed to develop a vaccine. One text noted that "The number of people we'll be able to treat will depend on our supply of drugs at that time" (Document 22).

5.1.9 Ethical/Moral Rationale for Priority Setting:

None of the reviewed documents made reference to ethical or moral principles used to develop vaccine and antiviral drug allocation plans. To clarify, these might have included the disclosure of principles used (i.e. utilitarian, first come first served, accountability for reasonableness) to determine potential priority groups. Several documents do mention the motivation behind pandemic planning "to minimize serious illness and deaths resulting from an influenza pandemic, and to minimize societal disruption (Document 16, p.7)".

Motivation for priority setting is alluded to in a few documents as well, for instance, "because it will be important to maintain health care services, the Plan recommends that planners

consider how they might identify and give the pandemic vaccine to health care workers first (Document 16 p.11)." One document did, however, note the PIC group included an ethicist.

5.1.10 Financial Rationale for Priority Setting:

None of the documents made explicit note of how financial circumstances influence vaccine and antiviral allocation. One document did, however, note that the federal government invested $34 million in vaccine research and development and $24 million toward creating a national antiviral stockpile (Document 9)), but did not indicate what this expenditure is expected to achieve or why this particular level of funds were decided upon as appropriate to spend for this purpose.

5.1.11 Who determines Priority Groups:

10 of 31 documents make some indication as to who is responsible for making priority setting decisions. In most cases, however, it was not explicitly stated as such, for example: "The Chief Medical Officer of Health and the Ministry of Health and Long-Term Care are... setting up distribution systems so we can get drugs and protective equipment to where they are needed quickly (Document 22)". It was noted that "PHAC officials," "government," "provincial and territorial public health experts and/or emergency response experts," "expert committees," and PIC were responsible for these decisions. MOHLTC, First Nations and Inuit Health and Health Canada were also mentioned as being involved with priority group decision making in some respect.

5.1.12 Affect on those not in Priority Groups:

None of the documents specify how priority setting will affect individuals not in a priority group.

5.2 Open, Axial and Selective Coding:

Open, axial and selective coding was used to identify themes in the communication reviewed. Four central themes were identified during this process.

5.2.1 Strong emphasis on prevention

Overwhelmingly infection prevention is a key message in reviewed documents. This would be consistent with the public health approach, which champions infection control, primary and secondary prevention. This theme is evident in the generous information in most documents regarding one or more of the following: hand hygiene, respiratory etiquette, seasonal and pandemic flu vaccines, self-isolation, social distancing and the safe handling of poultry, wild game and poultry products. This information is well coordinated between documents and agencies (PHAC, Health Canada, and MOHLTC): prevention methods are described similarly, often identically, from document to document.

Not only the amount of prevention information, but the framing of it reveals its significance. Prevention methods are described as being "important," "beneficial," "effective" or "good" as in "good respiratory etiquette." Use of bullet points or coloured boxes draws attention to and increases visibility of prevention methods within the text.

5.2.2 Pandemic positioned as a biomedical issue

The language of the majority of the reviewed documents is largely accessible, using familiar words and phrases and not laden with heavy jargon. There is also extensive usage of 'biomedical' phrasing. This includes referring to pandemic influenza as a "virus" or "strain" talk of reducing "infection," "contamination," or "bacteria" and managing the situation through

biomedical processes such as immunization and hygiene. This is in keeping with the mandate of those health agencies issuing the documents, and the public health approach.

There are several mentions of societal disruption included in a few reviewed documents, and mention of socially oriented strategies for disease control, such as options for social distancing, and becoming informed regarding the pandemic situation. However, biomedical processes are given prominence in both quantity of information and framing. For example, pandemic influenza risk is largely depicted in terms of incidence and clinical illness.

Closely related to the use of biomedical wording, prominence is given to biomedical, scientific and technical knowledge. This is demonstrated through the generous use of information and facts based on knowledge gained through scientific or biomedical fields such as epidemiology, medicine, biology, and statistics. Data is presented numerically and statistically. Health facilities and workers are mentioned often, for example, hospitals, clinics and doctors.

5.2.3 Principle of Personal responsibility

The third theme identified in reviewed documents was personal responsibility. Documents encourage the reader to practice preventative self-protection behaviours, for instance "minimize your risk" (Document 3). Personal responsibility is also highlighted by reminding the reader that they could infect others. The reader is urged to "encourage others," including family, to follow similar behaviours, for example, "Make sure family members get a flu shot too!"(Document 1) and "Take care of yourself and your family" (Document 28). Reader responsibility for contingency planning is emphasized by asking: How would your community respond? How can you keep track of pandemic developments? Several documents encourage the reader to ensure pandemic plans are in place at their places of employment.

As well, the documents exhort the reader to assume responsibility for acquiring knowledge, through phrases and titles such as "What you need to know" (Document 19) and "Stay informed" (Document 8). Several of the documents prompt the reader to seek out municipal, provincial/territorial and federal plans or call their local public health authority for more information.

Preferred behaviours (self-protection, preventative, individual-level action) are valorized by framing them with positive connotations. This is mainly done through associating these behaviours with positive qualities such as goodness, as in "good respiratory etiquette" (Document 3) or conscientiousness as in "be a good role model [to parents]" (Document 1).

5.2.4 Ownership of pandemic planning and knowledge

The last theme identified during the document analysis is that the documents highlight the knowledge and authority of experts in pandemic planning. Documents present experts and pandemic planners as capable and responsible for development and facilitation of pandemic plans. Terms connoting specialized knowledge or experience in pandemic planning fields are recurring in most documents, mainly: "experts," "professionals," "government planners" and "key stakeholders." Many if the documents feature federal and provincial government logos and letterhead-style font for the titles, the Canadian flag, or Canadian government copyright. These act as symbols of government jurisdiction and involvement in pandemic planning.

5.3 Survey

5.3.1 Overview

To recapitulate, a survey was designed to explore communication regarding pandemic influenza in these four major areas: participant knowledge of pandemic influenza, participant

knowledge of government pandemic planning including vaccines and antiviral drugs and priority setting, public communication needs, preferences and level of satisfaction, and preferences and opinions on community engagement. Descriptive statistics and frequency distributions were calculated on participant responses.

Further comment from respondents was encouraged and space was provided within the survey for this. 383 additional comments were made in total. All comments were included in the thematic analysis. However, due to the length and abundance of comments, they could not all be displayed in results. However, participant comments tended to focus on certain issues, express similar sentiments, and use similar phrasing. Selections of quotations are presented below and are intended to provide a representative précis of all participant responses. (The majority of quotations come from female LU students aged 18-24, as comments from this group were more numerous and intelligible.) Please refer to Appendix C for the complete survey.

5.3.2 Description of participants

Table 2
Gender and Age of participants from Lakehead University (LU) and Lac des Mille Lacs (LDML) samples

		Ages					
Sample		18-24 y	25-34 y	35-44 y	45-54 y	55-64	65y+
LU female	53.7%	72.7%	19%	2.5%	2.5%	2.5%	0.8%
LU male	45.5%						
LU other	0.8%						
LDML female	65%	15.4%	25.6%	7.7%	30.8%	15.4%	5.1%
LDML male	35%						

The Lakehead University sample (LU) consisted of 121 individuals, mainly students and some faculty and staff. Participant ages reflected this. Of the 40 individuals in the Lac des Mille

Lacs sample (LDML), respondents were on average older than LU respondents with nearly half between the ages of 45 and 64. Sampling was not stratified by age and gender, but was categorized as such for the supplemental analysis (see Section 5.3.6) and is displayed here to give the reader a clearer picture of the sample composition.

5.3.2.1 General pandemic knowledge

To determine knowledge of pandemic influenza, participants were questioned on general influenza pandemic facts and history specific to the Canadian population. They were assigned a score according to number of correct responses out of ten. Lakehead participants scored an average of 3.05/10 and LDML participants 2.43/10.

The majority of respondents (LU 76.9%, LDML 61.5%) correctly defined influenza pandemic, while others (LU 14.9%, LDML 17.9%) confused it with seasonal outbreak. 73% of Lakehead and 65% of LDML respondents correctly identified virus mutation as the cause of influenza pandemic. However nearly half (LU 47%, LDML 40%) indicated poor hand washing and a full 25% from both groups reported lack of annual of flu vaccine as causing a pandemic. Historical information appeared to be less well known (63% of LU respondents indicated they did not know when the last flu pandemic occurred in Canada and 57.5% of LDML indicated they did not know).

Although experts estimate between 2 and 5 million could become ill in Canada, most respondents (45% LU; 50% LDML) believed it to be less. Only 10% from each group answered correctly. Over a third of respondents (33.9% LU; 35% LDML) did not know.

Expectations for hospitalization were greatly varied between the two groups. A total of 20.7% of LU respondents correctly considered it probable to have greater than 34,000 hospitalizations. On the other hand, 30% of LDML respondents believed there would be between

1000-3000 hospitalizations nationwide. Still, the majority of participants from both were unsure as to the numbers to expect. (LU 37%, LDML 42.5%).

Experts predict between 11,000 and 58,000 fatalities across Canada, but 33 % of Lakehead and 43.5% of LDML respondents believed 5,000 or less would die. Again the largest portion indicated they didn't know. Seasonal influenza was also underestimated: While the average country-wide death toll from flu and flu-related complications is between 4,000 and 8,000, nearly 40% of Lakehead 25.6% of LDML respondents believed that 1000 or fewer persons die annually.

Knowledge and beliefs regarding vaccines and antiviral drugs varied widely. However, there were several noticeable trends: respondents tended toward optimism regarding the abilities of antivirals: 43% of Lakehead and 37.5% of LDML respondents incorrectly answered that antiviral drugs can prevent flu. In both samples, roughly half of respondents were aware of pandemic priority setting: 55.4% of LU and 55.3% of LDML. Responses varied considerably on time expected to develop a vaccine, with the largest portion indicating they didn't know how long it would take (28.9% LU, 40% LDML).

5.3.3 Knowledge of Pandemic Planning and Priority Setting

Respondents largely indicated a lack of knowledge regarding government pandemic planning and the availability of such information. Only 8.4% (N=9) of Lakehead respondents sought information regarding government planning for pandemic influenza. LDML respondents scored higher, with 20.6% (N=7) reporting they looked for information. 76.3% of Lakehead and 66.7% of LDML respondents said that they were unaware of the existence of the CPIP, with only a single Lakehead and three LDML respondents reporting that they read or researched the CPIP.

As seen in Figure 2, respondents from both groups reported lack of knowledge of the CPIP, time constraints, and not thinking about it as the major deterrents to researching government planning. Respondents were asked to indicate all answers that apply.

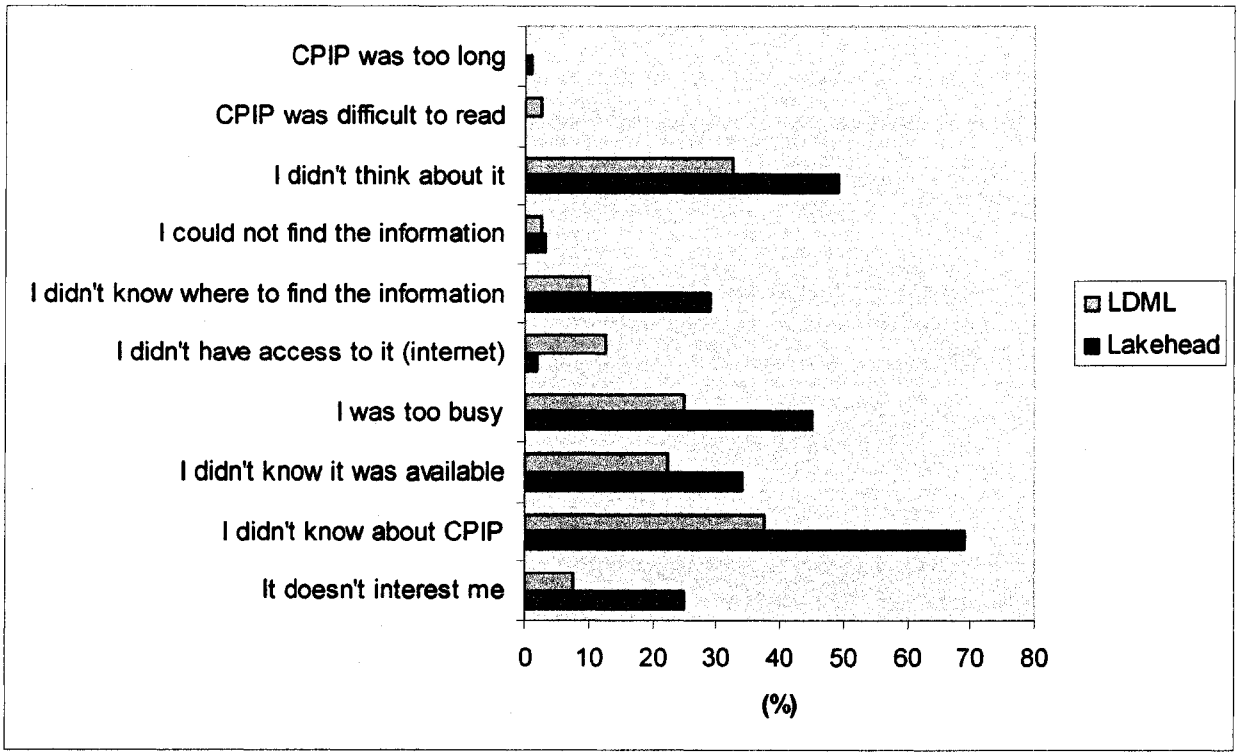

Figure 2. *Responses to Q18: Factors contributing to lack of readership of the Canadian Pandemic Influenza Plan*

Comments indicated a low sense of urgency concerning pandemic influenza: "I don't feel like a pandemic is upon us" *(from) LU(sample) female, (age group) 18-24*". "...not necessary at this time *LU female, 45-54.*"

Figure 3 illustrates the style in which respondents prefer to read of government planning, with the majority indicating a preference for a briefer document written specifically for the public. Several comments indicated a preference for fact sheets. A number of respondents commented that they would not prefer to read plans at all, but would be interested in watching a

video or hearing a presentation: "I'd rather hear about it in a presentation than read a document *LU female, 18-24.*" "If print were the way most people learned about such things, then print media would be used. But we get most of our info from TV...so most money should be spent there. It only makes sense to do it this way *LU male, 55-64.*"

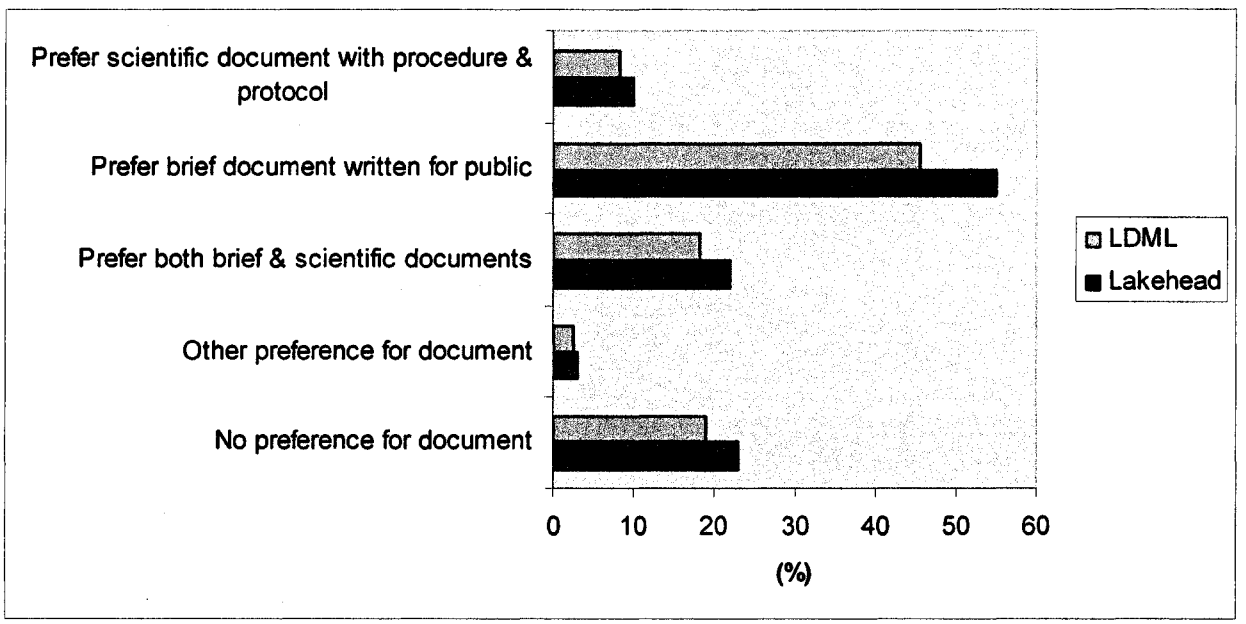

Figure 3. *Responses to Q 19: A comparison between preference for reading national pandemic plans in Lakehead University and Lac des Mille Lacs samples*

Participants were asked to rate their level of agreement with statements on a 5 point scale (1=strongly disagree through 5=strongly agree) regarding their ability to make health decisions based on current pandemic knowledge. Table 3 contains the mean ratings of self-rated ability. Responses varied regarding ability to make health decisions based on present knowledge. LDML respondents were more confident of their knowledge of government pandemic planning and reported slightly higher scores in all categories. (See Appendix C for full survey.)

Table 3
Mean Ratings of Self-Rated Ability to make informed health-related decisions based on present pandemic knowledge from Lakehead and Lac des Mille Lacs respondents

Question 20 (a, b e and f)	Lakehead		LDML	
I am able to make informed decisions about my health...	M	SD	M	SD
Q 20-a. Based on my present knowledge of flu pandemic	3.21	1.09	3.41	0.85
Q 20-b. Based on my present knowledge of government plans regarding a flu pandemic	2.88	1.06	3.46	0.87
Q 20-e. I know all I need to regarding vaccines to make informed decisions	2.68	1.22	3.08	1.16
Q 20-f. I know all I need to regarding antiviral drugs to make informed decisions	2.66	1.15	3.00	1.13

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

As seen in Table 4, respondents were slightly less than satisfied with communication and educational materials they have seen thus far, both in terms of quality and quantity. Both groups felt least satisfied with the amount of information on antiviral drugs.

Table 4
Mean Ratings of Self-Rated Satisfaction with Public Communication from Lakehead and Lac des Mille Lacs respondents

Question 20 (c, d, g and h)	Lakehead		LDML	
I am satisfied with...	M	SD	M	SD
Q 20-c. The quality information I have seen regarding pandemic influenza	2.66	1.10	2.89	1.06
Q 20-d. The amount information I have seen regarding pandemic influenza	2.55	1.09	2.84	1.07
Q 20-g. The quality of quality information I have seen regarding vaccines	2.55	1.15	2.95	1.05
Q 20-h. The amount of information I have seen regarding antiviral drugs	2.47	1.05	2.76	1.12

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

This question prompted additional comments from thirty participants. From these comments several dominant themes emerged: a feeling of entitlement to transparent

communication, concern about fairness in communication, and feelings of ignorance or being unqualified to critique communication messages. A selection of these comments is presented below.

Respondents affirmed the importance for transparency in pandemic communication with the public and many framed this as a right of citizenship: "It's the government's responsibility to make the general public aware of flu pandemic and their plan of action. Public input could benefit there (sic) planning *LU female, 18-24.*" "It should be made public if it is not already as we have a right to know *LU female, 18-24*". "When it comes to well being of public health all advances, fallbacks and other info should be shared with the public whose health could be at risk *LU female, 18-24.*" "Open information rule of thumb...Open government rule of thumb *LU male, 18-24*".

Concern over fairness was also evident in these comments: "I feel that if the government wants to avoid a flu pandemic they have to educate the public. And by that I mean that they must gear their education towards all aspects of the population. Presenting info that is easy for academics to understand and well as non-academics *LU female, 18-24*". "There should be door to door campaigns to better inform the public, especially the people who are living in poverty who don't have internet, may be illiterate *LDML female, 45-54*". "Nothing is said until there is something wrong and there is a mass panic. The average person who doesn't have time to go to clinics and find information...doesn't know until [information is] released by media *LDML male, 35-44"*

A number of respondents indicated they felt uninformed regarding pandemic communication, for example: "I really haven't seen any advertisements at all for the flu

pandemic *LU female, 18-24.*" "I'm surprised I have not heard about the pandemic influenza- or maybe I did hear, but just figured it was somewhere else and reasoned that most likely would not affect Canadians—which is an admittedly ignorant stance to take *LU male 25-34.*" "I don't know what's going on and I'm a nursing student. I think that is a poor reflection on public health education from the government *LU female 18-24.*" "All these things affect the public but aren't public knowledge right now *LU female, 18-24.*"

Closely related to this, several of these were respondents were reticent to comment on their level of satisfaction due to their perceived lack of knowledge or qualification: "I don't feel that I have obtained enough information to make thorough judgments for health issues *LU female, 18-24.*"

5.3.4 Public Communication

To determine what pandemic information is most important, participants were asked to rate topics on a 5 point scale (1=strongly disagree through 5=strongly agree). Lakehead and LDML respondents agreed that all information was important and mean rating ranged from 4= agree to 5= strongly agree (see Table 5). Both groups were slightly more intent on learning how to treat of pandemic influenza, and Lakehead respondents were somewhat less interested in being informed of vaccine and antiviral allocation.

Table 5
Mean Ratings of Preferences for Various Pandemic Messages from Lakehead and Lac des Mille Lacs respondents

Question 21 (a through e)	Lakehead		LDML	
I would like to be informed of...	M	SD	M	SD
Q 21-a. How to prevent catching pandemic influenza	4.46	0.81	4.61	0.60
Q 21-b. How to treat pandemic influenza	4.49	0.85	4.72	0.57
Q 21-c. My options for medical care	4.45	0.87	4.69	0.62
Q 21-d. Dispersal plans for antivirals and vaccines	4.18	1.01	4.57	0.65
Q 21-e. How a pandemic will affect daily life	4.35	0.95	4.53	0.77

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

Next, the importance of more detailed vaccine and antiviral priority setting information was rated. As seen in Table 6, respondents were slightly less intent on these matters although all topics are still rated highly. Along the same 5 point scale, mean rating for topics is between 3= neutral to 5= strongly agree. Both groups indicated least interest in knowing the financial rationale behind priority setting. LDML respondents were most concerned with which persons are included in priority groups and Lakehead respondents on how those not included will be affected by pandemic. It is noteworthy as well that LDML respondents rated financial and ethical/moral rationales a fair bit lower, but indicated much greater interest in priority groupings and scientific rationale than the LU group.

Table 6
Mean Ratings of Preferences for Vaccine and Antiviral Drug Messages from Lakehead and Lac des Mille Lacs respondents

Question 25 (a through f)	Lakehead		LDML	
I would like to be informed of...	M	SD	M	SD
Q 25-a. Who is included in priority groups	3.98	1.03	4.51	0.61
Q 25-b. Scientific reasons for priority groups	3.90	0.97	4.30	0.78
Q 25-c. Ethical/moral reasons for priority groups	3.83	1.08	3.97	0.93
Q 25-d. Financial reasons for priority groups	3.80	1.16	3.86	1.22
Q 25-e. Who determines priority groups	4.01	1.06	4.31	0.79
Q 25-f. How priority setting will affect those not in a priority group	4.17	0.90	4.14	0.83

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

Table 7 shows a comparison of the factual coding results (see Section 5.1) of with these communication preferences. Comparison of the rated importance of public communication topics with the occurrence of those topics reveals: (a) considerable overlap between the most important topics as identified by respondents and the topics most covered in documents, and (b) several areas in which information desired by respondents was not included in documents. Both groups rated information on treatment of pandemic influenza as the most important. Both samples included prevention of influenza and medical care options in the top three topics and all three are rated closely. This roughly corresponds with the content of the document analysis. The top three topics as rated by respondents have among the highest factual coding counts.

Scientific, ethical, and financial rationale (topics 7, 8, and 9 respectively) were rated among the least important by both groups, and no documents explicitly addressed these topics. It should be noted that although rated lower, mean ratings still ranged close to 4 (agree information is important). Ten documents made some mention as to by whom priority groups were determined (topic 10). Although rated in 7th place by both groups, indicated interest in this topic ranged between 4 (agree it is important) to 5 (strongly agree it is important). Although rated

lower in importance, ratings for topics 4 through 11 still range between 3 and 4, with 3.80 as the lowest rating of all topics. This means that the topic rated as least important by participants still ranged between 3 (neutral) and 4 (agree) and were considered at least moderately important. Areas in which the content of documents did not completely align with respondent preferences were topics 5, 6, 7, 8, 9 and 11 (see Table 7).

Table 7

Comparison of Factual Coding within Public Communication Documents with Mean Ratings for Preferences from Various Pandemic, Vaccine and Antiviral Drug Messages from Lakehead and Lac des Mille Lacs respondents

Communication topic preference Questions 21 (a through 3) and Questions 25 (a through f)	Survey Responses				Document Analysis
	Lakehead		LDML		No. Docs Addressing Topic Area
Topic Area I would like to be informed of...	M	SD	M	SD	
1) Prevention of pandemic influenza	4.46	0.81	4.61	0.60	20/31
2) Treatment of pandemic influenza	4.49	0.85	4.72	0.57	16/31
3) Options for medical care	4.45	0.87	4.69	0.62	10/31
4) Effects on daily life	4.35	0.95	4.53	0.77	11/31
5) Vaccine and antiviral resource allocation plans	4.18	1.01	4.57	0.65	4/31
6) Priority groups composition	3.98	1.03	4.51	0.61	5/31
7) Scientific rationale for priority grouping	3.90	0.97	4.30	0.78	0/31
8) Ethical/moral rationale for priority grouping	3.83	1.08	3.97	0.93	0/31
9) Financial rationale for priority grouping	3.80	1.16	3.86	1.22	0/31
10) By whom priority grouping is determined	4.01	1.06	4.31	0.79	10/31
11) How priority grouping/ resource allocation will affect those not in a priority group	4.17	0.90	4.14	0.83	0/31

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

Additional comments from these two sets of questions were plentiful (from 90 respondents) and indicate strong interest in influenza pandemic issues, chiefly on treatment: how

to deal with flu once it has been contracted, how to safely care for others who have been infected, and signs/symptoms of flu. A selection of these comments is presented here.

Numerous respondents voiced their concern regarding vaccine safety: "I think it's important for the public to know what chemicals are in the flu shot and the harmful effects *LU female, 18-24.*" "I never have made it a point to take drugs or even vaccines; I think they are a ploy. I have an immune system and I guess it has to work full time at all times *LU male, 18-24*". "I believe vaccines wear down your immune system. Your body tries to fight what it's vaccinated for (most of what you don't ever encounter) and can't fight common colds *LU female, 18-24*". "...if we get vaccines, anything that survives will create new strains after mutating *LU female, 18-24".* "Do people get informed of all the risks to receiving the drugs/vaccines? Many other vaccines have been linked to such things as autism yet most people are unaware of this fact *LU female, 18-24."*

Comments also suggested distrust of government planning, agenda or communications: "I don't fully trust in what the government say(s) about such things. Sometimes they tend to provide part-information. Share unfairly, discriminate in how they share *LDML female, 65+".* "I think... well, what I think does not really matter. We will here what the government wants us to hear when they want us to hear... and it will be hyped up by the media *LU female45-54".* *"It* is laughable to think that First Nations are even considered priority...What medicine do they really send to First nations? Probably not the same used by Harper! *LDML male, 25-34.*" Additionally, several expressed concern over availability of vaccines in rural areas.

Further, many comments indicated strong concern for fairness and transparency of priority setting: "I would like to be informed on all priority groups...so I can understand the reasoning behind the allocation *LU female, 25-34.*" "Would certain people who have ties

to..."ruling class" gain advanced vaccine and viral (sic) treatments? *LU male, 25-34"* : "Governments are biased in their decisions as it doesn't really matter what happens for them since they will receive top notch quality care if a pandemic struck *LU female, 18-24.*" "I would like to know who exactly decides priority groups and their reasons for doing so. People should have equal right to be cured *LU female, 18-24*". "If the government's going to be prioritizing who lives and who dies, I want to know why *LU male, 18-24.*"

Overwhelmingly, respondents agreed that plans for both pandemic influenza and vaccine and antiviral priority setting ought to be shared with the public. On the same 5 point scale, Lakehead participants provided mean ratings of 4.58 (SD.89) in favour of general government plans, and 4.6 (SD .83) for vaccine and antiviral drug allocation plans being shared with the public. LDML participants responded to those questions similarly, with mean ratings of 4.51 (SD .77) and 4.59 (SD .60) respectively.

Participants were asked how they would like to be informed of government plans for pandemic influenza. As seen in Table 8, both groups were least in favour of government websites as information sources. Both groups rated news, television public service announcements and pamphlets slightly above online and radio public service announcements. LDML respondents rated all options slightly higher and showed less standard deviation in responses. Schools and workplaces were also suggested by both groups as venues to learn about pandemic planning.

Table 8
Mean Ratings for Preference of Information Channels regarding general Pandemic Information from Lakehead and LDML respondents

Q 23 (a through g)	Lakehead		LDML	
I would like to be informed of general gov't plans for flu pandemic from...	M	SD	M	SD
Q 23-a. Government Websites	3.92	1.00	4.12	0.81
Q 23-b. News	4.36	0.89	4.43	0.92
Q 23-c. Online Public Service Announcement	3.98	1.02	4.36	0.93
Q 23-d. Radio Public Service Announcement	3.98	0.99	4.31	0.82
Q 23-e. Television Public Service Announcement	4.22	0.92	4.58	0.55
Q 23-f. Pamphlets in doctor's office	4.18	0.92	4.53	0.65
Q 23-g. Pamphlets in public places	4.11	0.96	4.61	0.65

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

Similarly, both groups indicated government websites as last preference when asked about information channels regarding government plans for vaccine and antiviral drug allocation. This sentiment was explained in additional comments: "I...feel that government sites are not as effective because they are fairly unheard of *LU female, 18-24.*" Further responses signified no strong preference for information channels, but again news scored slightly higher with both groups, and television and pamphlets with LDML respondents. As with the above question, LDML respondents rated all options slightly higher and showed less standard deviation in responses (See Table 9). Findings potentially suggest a preference for a mixed-methods communications strategy.

Table 9
Mean Ratings for Preference of Information Channels regarding information on vaccine and antiviral drug allocation from Lakehead and LDML respondents

Question 27 (a through g)	Lakehead		LDML	
I would like to be informed of government flu vaccine and antiviral drug allocation plans from....	M	SD	M	SD
Q 27-a. Government Websites	3.89	1.11	4.29	0.75
Q 27-b.News	4.29	0.99	4.50	0.81
Q 27-c. Online PSA	4.00	1.09	4.40	0.81
Q 27-d. Radio PSA	4.03	1.04	4.53	0.74
Q 27-e. Television PSA	4.16	1.07	4.72	0.51
Q 27-f. Pamphlets in doctor's office	4.18	1.02	4.56	0.65
Q 27-g. Pamphlets in public places	4.17	1.04	4.61	0.60

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

Respondents overwhelmingly preferred to be informed of pandemic plans and vaccine and antiviral allocation plans before a pandemic begins. Both questions were presented on scale of 1= "before the pandemic begins worldwide" to 5= "while the flu pandemic is underway." Lakehead participants responded with a mean of 1.42 (SD.90) for general pandemic plans and 1.4 (SD.86) for vaccine and antiviral plans (meaning, timing ranged between "before the flu pandemic beings worldwide" and "once the flu pandemic begins worldwide"). LDML respondents indicated a slightly later time frame, with a mean of 1.75 (SD 1.189) and 1.84 (SD 1.214) for both questions respectively.

5.3.5 Public Engagement

Respondents from both samples indicated a strong preference for some level of community engagement. As seen in Table 10, a majority of the Lakehead and LDML samples agreed that there was benefit to having the Canadian public involved in pandemic planning, the public should be more involved in pandemic influenza decision making in general, and more

involved in decision making as it pertains to priority setting. The Lakehead sample was more divided on these issues (close to a third answered "no" in each case), while the LDML responses indicated more uncertainty.

Table 10
Percentage of Responses Regarding Involvement of the Canadian Public in the Decision Making Process in planning for Pandemic Influenza

Questions 29, 30 and 31	Lakehead %				LDML %			
Regarding the Canadian public in pandemic influenza decision making...	N	Yes	No	Unsure	N	Yes	No	Unsure
Q 29. There is some benefit to involvement	119	61.3	26.1	12.6	38	55.3	7.6	36.8
Q 30. There should be more involvement in general pandemic decision making	119	57.1	28.6	14.3	38	73.7	7.9	18.4
Q 31. There should be more involvement in priority setting decision making	119	58	25.2	16.8	36	68.4	10.5	21.1

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

Respondent comments (141 comments from 2 open-ended questions) represented views both for and against greater public involvement in pandemic planning. For those in favour, responses seemed to stem from awareness of rights as citizens, ownership of health, fairness, and more pragmatically, to prevent panic and increase public knowledge of pandemic.

Many responses reflected that respondents felt a right to voice their opinion: "Such a complex situation, but when talking vaccines and pharmaceuticals, a democratic action should be utilized by a "free" nation *LDML male, 25-34.*" "...everyone should have the right to voice their opinions *LU male 25-34.*" "The Canadian public has the right to make informed decisions about their health and should be involved in decisions because in the end we are the ones who are affected *LU female, 18-24.*" "Canadian government should be for the people *LU male, 18-24.*" "Aren't we a democracy? *LDML male, 25-3.4"*

Closely tied to this, many responses revealed a sense of communal and personal ownership of health: "...it will affect everyone and we have a right as a collective to say what would be done *LU female, 18-24.*" "Everyone can be affected; therefore everyone should be involved *LU female, 18-24.*" "It affects us all! *LU female 18-24.*" "It's our health *LDML male, 55-64.*"

Further, responses indicated these respondents associated community engagement with fairness in priority setting: "To ensure plan meets the needs of majority and is ethical/moral *LU female 35-44.*" "Smaller isolated towns will have different needs from larger cities...Various groups may be missed/overlooked by government planning groups. With public access these groups can make themselves known *LU female 18-24.*" "It has to deal with us, so why don't we get a say? *LDML female, 18-24*". "Well I think the public would have different views about the grouping process and have the right to add input *LU male 18-24.*"

Several respondents indicated that community engagement will generate greater interest in the pandemic and result in a more informed, prepared and less panicked community: "The government will have more support from the public *LU female, 18-24.*" "The public will be more likely to comply with decisions they feel they've been a part of *LU female, 18-24.*" "When the public is involved there is interest. Take more responsibility/take it more seriously *LDML female, 65+".* "Prevent panic and people know the procedures that are taken when people get infected LU male, 25-34." "To decrease panic states *LU female, 18-24.*" "Spread awareness, it then becomes an issue to Canadian public once they have a say in decision making *LU male, 18-24."*

Among options presented there was a close distribution of responses when participants were asked how they would like to be involved in the decision making process. Both samples

indicated a slight preference for open forums and "phone in" television or radio programs. Townhouse meetings were rated last by both samples. Table 11 lists mean ratings of responses.

Table 11
Mean Ratings of Preference for Community Engagement methods from Lakehead and LDML respondents

Question 33 (a through e)	Lakehead		LDML	
I would prefer to be involved in pandemic decision making....	M	SD	M	SD
Q 33-a. Not Involved	2.68	1.30	2.83	1.30
Q 33-b. Through opinion polls of a sample of the public	3.66	1.07	3.97	0.81
Q 33-c. Through open discussion/forums across districts	3.48	1.14	4.00	0.70
Q 33-d. Through townhouse meetings	3.13	1.07	3.75	0.77
Q 33-e. Through phone-in Radio/TV programs	3.43	1.20	4.06	0.84

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)

Several respondents suggested the internet be used as a tool in community engagement, and LDML respondents mentioned that appropriate languages should be used here.

As well, some respondents indicated that although in favour of community engagement, it might not be effective: "...they probably wouldn't listen *LU female, 18-24.*" "Our voice carries no power *LU female, 45-54.*" Further comments indicate genuine interest in community engagement and reflect a variety of opinions: "Limitations on decision making should be set and the public can participate through set channels, yet not when assets...are allocated *LDML female, 25-34*". "There's a balance however between democratic input and authoritative decision-making *LU male, 25-34.*"

On the other hand many (close to a third of LU) respondents were opposed to community engagement (see Table 11 above). Additional comments centered on concerns regarding the qualifications and ability of the general public to make health decisions. "They may be too emotionally involved to make a fair, unbiased judgment *LDML female*, 45-54". "People only

want what's good for themselves (sic)... People need to be in charge, you can't have 30 million people make a decision *LU male, 18-24.*" "People only think for themselves *LU male, 18-24.*" "The process would be too slow, too political and in many cases too uninformed. It would require a lot of knowledge that many people don't have and would become far too political. A referendum would also slow the works too much, possibly costing lives during the pandemic *LU male, 18-24.*"

Many of these comments indicated a preference for either government or health care professionals to act in this capacity: "Doctors should make such decisions *LU male, 18-24.*" "Let the experts make the decisions. They know best *LU male, 45-54.*" "Civilians tend to complicate instead of solve. Let the government do what they are supposed to: we elected them for that reason *LU male, 18-24.*" "...the ordinary person...may/may not have the knowledge or ability to understand/act critically...We have to let those with the training/knowledge do their job *LU female*, 45-54." "The public's opinion may not be the best when dealing with a scientific topic. Those people responsible for making these decisions are informed, most of the public is not *LU male 25-34.*" "Why should we have high-school graduates telling PhDs what to do? *LU male 18-24.*"

5.3.6 Supplementary Analysis

Correlation was calculated to measure the association between participant pandemic knowledge score with their self rated ability to make health decisions based on: present pandemic influenza knowledge; present knowledge of government plans for influenza pandemic; present knowledge of vaccines and present knowledge of antiviral drugs. Correlation was also calculated to measure relationship between pandemic knowledge and belief that general government pandemic plans and priority setting plans should be shared with the public. As seen

in Table 12, individuals in the LDML sample reported significantly greater ability to make health decisions based on knowledge of pandemic influenza and government plans, indicating those with more knowledge of pandemic influenza and government pandemic plans felt better able to make health decisions. In the LU sample, there was a significant positive association between knowledge score and the belief that government pandemic plans should be shared with the public. There was no significant relationship found between other variables, including age and gender. (See Appendix E for a list of non significant correlations.)

Table 12
Correlation between Pandemic Knowledge Score and other variables from Lakehead and Lac des Mille Lacs respondents

Pandemic knowledge score correlated with Questions 20 (a through j)	Lakehead Score			LDML Score		
	r	p	N	r	p	N
Q 20-a. Ability to make health decisions based on present knowledge of flu pandemic	0.16	0.08	121	0.41**	0.01	39
Q 20-b. Ability to make health decisions based on present knowledge of government plans regarding a flu pandemic	0.11	0.22	120	0.50**	0.002	37
Q 20-c. Satisfied with the quality information I have seen regarding pandemic influenza	0.03	0.71	120	0.12	0.47	36
Q 20-d. Satisfied with the amount information I have seen regarding pandemic influenza	0.09	0.34	121	0.02	0.90	37
Q 20-e. I know all I need to regarding vaccines to make informed decisions	0.04	0.68	121	0.09	0.58	37
Q 20-f. I know all I need to regarding antiviral drugs to make informed decisions	-0.03	0.78	119	0.04	0.83	37
Q 20-g. Satisfied with the quality information I have seen regarding vaccines	-0.06	0.53	121	0.10	0.56	37
Q 20-h. Satisfied with the amount information I have seen regarding antivirals	-0.06	0.54	120	0.08	0.65	37
Q 20-i. Gov't pandemic plans should be shared with the public	0.18*	0.05	120	0.11	0.52	37
Q 20-j. Gov't plans for vaccine and antiviral drug allocation should be shared with the public	0.14	0.14	121	0.16	0.35	37

Note. Values are the mean of reported scores on a 5-point scale (1=strongly disagree, 5=strongly agree)
** Correlation is significant at the 0.01 level (2-tailed)
* Correlation is significant at the 0.05 level (2-tailed)

7.0 Discussion

7.1 Overview

The purpose of this research was to critically analyze public communication directed toward Ontarians regarding a future influenza pandemic, and compare them with the communication needs and preferences of two population samples.

Results indicated that respondents largely understand what a pandemic is, however misunderstand the causes and underestimate expected impact. Participants underestimated the impact of seasonal influenza in terms of the number of ill, hospitalizations, annual flu deaths, and deaths. As well respondents underestimated the expected impact of pandemic influenza (during a moderately severe pandemic without aid of vaccines or antivirals as predicted by PHAC), particularly projected number of hospitalizations and deaths.

The results showed the pandemic influenza communications (both documents reviewed and as identified by respondents) aligned considerably with respondents preferences, but did not fully corresponded all preferences indicated. Survey respondents rated preventing pandemic influenza, treatment options, effect of pandemic on daily life and medical care options very highly in terms of importance. The public communication documents reviewed addressed prevention with straight-forward, detailed and abundant information. Information on treatment, medical options and pandemic affect on daily life was less robust, but was covered to various degrees across documents reviewed. Nearly a third of documents made some mention as to who makes priority setting decisions.

Other topics were rated relatively highly by respondents, but were not addressed in the reviewed documents. Very few documents explicitly disclose priority setting plans or rationale,

and several appear to make contradicting statements about the need for priority setting. This does not seem to correspond with respondent's desire and sense of entitlement to transparent information regarding vaccines, resource allocation and rationales behind decisions.

Generally respondents were somewhat unsatisfied with both amount and quality of information they had seen regarding pandemic influenza. It should be noted, however, that only 16 out of 141 participants reported seeking out such information. Most were unaware of national level plans, but expressed interest in the contents thereof.

There was a significant positive correlation between pandemic knowledge and confidence in making health decisions regarding an influenza pandemic in the LDML sample. Greater pandemic knowledge in the LU sample was correlated with belief that pandemic plans should be shared with the public.

Documents tended to portray the public in a passive role regarding pandemic planning and priority setting processes. This is in conflict with the majority of respondents who saw benefit in, and expressed a desire for some involvement in pandemic planning or decision making. Respondents' desire to voice opinions regarding pandemic planning strongly surpass community engagement opportunities available at the time of data collection.

However, documents portray the public as having an active role and personal responsibility for prevention of pandemic influenza spread, but a passive role in pandemic planning. Little mention is made as to accountability to the public in terms of planning or decision making.

Influenza pandemic is depicted as a predominately biomedical issue, with emphasis on biomedical processes for infection control. This seems to be in alignment with the strong desire for scientific information expressed by both samples. Related to that, the key messages suggest

government, biomedical and scientific figures possess ownership of both pandemic knowledge and planning authority. This possibly conflicts with the respondents' sense of ownership for health seen in survey responses.

In sum, two major concerns were identified by both participant groups and represent the most valuable findings of this study: an expectation for information on all aspects of pandemic influenza planning, and desire for some form of community engagement.

7.2 Study Limitations

It is anticipated that the methodology represents a valid test of the research question. The strengths of the study lie in the high level of construct validity yielded by use of the survey, in that all participants in both samples were presented with identical information and survey questions in a similar environment and timeframe.

There are four social threats to validity that were specifically pertinent to this study: hypothesis guessing, evaluator apprehension, social desirability bias and researcher expectancies. These were anticipated from baseline and adjustments were made to the study design to mitigate their effect. The social threats to validity are described as follows:

1. Hypothesis guessing (survey respondents guess the purpose of the study and alter responses accordingly).

2. Social desirability bias (respondents answer what they deem to be the "right" response to appear informed, responsible, etc): A content and clarity analysis was conducted on the entire survey tool before distribution. This step incorporated the feedback, input and suggestions of 17 volunteers similar to the survey respondents. The content and clarity analysis was helpful in identifying potentially "leading" phrases and fostering a value-neutral tone throughout the survey (see Appendix C for survey).

3. Steps were taken to reduce evaluator apprehension (respondents test poorly on general knowledge section due to anxiety).

4. Researcher expectancies (the researcher consciously or unconsciously biases the results). The majority of respondents from both samples completed their surveys at designated tables separate from the researcher and passers by. The remaining respondents opted to complete surveys at nearby locations on campus or at the health fair, at their discretion. This provided respondents with greater comfort, privacy and control to reduce anxiety. As well, the consent form, cover letter (Appendix D) assured the participant of their privacy and used neutral, non confrontational language to increase participant comfort and encourage honesty. This data collection design also reduced the chance that the researcher might inadvertently encourage certain responses through body language, smiling, etc while respondents completed the survey. To further reduce the researcher expectancies threat, a three-step coding process was employed throughout qualitative analysis. Validity of the document review was enhanced by incorporating informal input from the PHAC, via email correspondence, regarding the documents chosen. Reliability of the survey was enhanced by utilizing a large portion of the PEPPPI survey tool, which was successfully used in a large US study on a comparable topic.

The findings presented here should be treated as exploratory as they represent a first look at the communications preferences and needs in the sample communities. It is important to bear in mind several sample characteristics when interpreting results. The Lakehead sample was mainly comprised of university students as well as some staff and faculty. People in this sample have ample access to computers and the internet. As most pandemic communication presently available is featured on government websites, this puts the Lakehead sample at a distinct advantage over the general population. Students by necessity must possess a level of

technological savvy that allow easier navigation of the internet and perhaps greater access to pandemic communication. Also, students are exposed to important current events, health and social issues through their studies, classes, and campus advertisements and events.

Lac des Mille Lacs participants were recruited at an Aboriginal health fair, indicating that participants have had some prior interest in health issues. The LDML sample, though small, indicated a great interest in government planning activities and the distribution of health care. It should be noted the differing authority structures of health care for this population: the federal authority of health for First Nations on-reserve, as opposed to provincial authority for most other residents. Perhaps this difference might account for some of the increased interest in government plans, but further investigation with a larger sample size is required before any such associations could be asserted.

7.3 Theoretical Implications

This represents the first study (to my knowledge) to investigate the desires, needs and opinions of the Ontario population concerning communication on pandemic influenza using a survey technique. Thus, it is not possible to compare these results with those of similar studies. Further research is required in this area.

7.3.1 A surprising lack of knowledge

In the PEPPPI study pretests (prior to PEPPPI discussion of pandemic influenza situation or plans), citizen respondents tended to correctly answer questions on pandemic knowledge more often than did either LU or LDML respondents. The percentage of correct answers on the PEPPPI pre-survey was 52.1% for Atlanta, 42.7% for Boston, 59.5% for Omaha, and 59.3 for Portland (Bernier and Marcuse, 2005, p.75). The percentage of correct answers on this survey

was 30.5% for Lakehead and 24.3% for LDML samples respectively. However, it must be noted while both groups were asked the same or very similar questions, recruitment and survey procedure differed between the two studies and might account for some of this difference in knowledge scores. The LU and LDML samples were recruited and surveyed "on the spot" so that answers would be based on present knowledge. PEPPPI respondents were recruited in advance through public appeals and advertisements, and then participants were pre and post tested at the research location (Bernier and Marcuse, 2005, p.44). The US participants had an opportunity to inform themselves about pandemic issues in advance of the survey, while Canadian participants did not.

Participant knowledge scores do not reflect the effectiveness of communications documents, because it is not known if participants actually saw any of these documents (thought it is noteworthy that many participants were unaware of such documents, and this perhaps speaks to the effectiveness of a web-based communications strategy). Knowledge scores do reveal valuable information about the sample populations. Both groups tend to dramatically underestimate the scope and impact of an influenza pandemic. This might be because most respondents have no frame of reference for an influenza pandemic as the last pandemic was in 1968 (not in living memory for most respondents) and comparatively mild.

In the LDML sample, greater knowledge of pandemic influenza was, not surprisingly, associated with greater confidence in making health decisions based on present pandemic knowledge and present knowledge of government pandemic planning. Although significant correlation between these variables was not found in the LU sample, the low p value for the former variable is noteworthy and possibly merits further study (see Table 12).

7.3.2 Comparison of factual coding and respondent preferences

Comparison of the rated importance of public communication topics with the occurrence of those topics reveals: (a) considerable overlap between the most important topics as identified by respondents and the topics most covered in documents, and (b) several areas in which information desired by respondents was not included in documents. The three highest rated topics (treatment, prevention and options for medical treatment) were among those most often addressed. Two other topics (effects on daily life and by whom priority grouping is determined) were addressed in close to a third of reviewed documents. Other topics were not rated quite as highly, but still ranged a mean rating of between 3 (neutral) and 4 (agree) that the topic was important to respondents.

This emphasis on prevention, treatment, medical care options seems to be in keeping with the mandate of the health organizations issuing these documents. That close to a third of documents contain information (albeit vague) on the effects of a pandemic on daily life and by whom priority groups are determined is noteworthy. It is also in alignment with indicated preferences of the population.

Interestingly, no documents explicitly addressed scientific, ethical, and financial rationale (topics 7, 8, and 9 respectively), and these were rated as among the least important by both groups. It should be noted that although rated lower, mean ratings still ranged close to 4 (agree information is important). However, emphasis on biomedical processes for infection control was apparent, and this would be in keeping with respondent preferences for scientific information, if not scientific rationale for priority setting. Areas in which the content of documents did not completely align with respondent preferences were topics 5, 6, 7, 8, 9 and 11 (see Table 7).

7.3.3 A desire for involvement

The majority of respondents were in favour of some form of community engagement and saw benefit to including the public in some capacity concerning both pandemic decision making and priority setting. Notably, a higher pandemic knowledge score in the LU sample was positively correlated with belief that pandemic plans should be shared with the public. Numerous additional comments suggest that respondents felt a sense of ownership for their own health and a right to voice opinions regarding health care. These results correspond to those found in previous studies by both Litva (2002) and Lenaghan (1999) in that:

a) Respondents desire to be involved in some form of community engagement, and

b) This desire seems to stem from a sense of ownership for health, and/or as a democratic right.

Litva et. al (2002) examined the issue of public participation in health-care decision making in the UK and determined that the public was very interested to be involved, "with the guarantee that their contribution would be heard and that decisions made following consultation would be explained (p.1834)." Lenaghan examined the use of citizen's juries in priority setting decisions in the UK (Lenaghan, 1999). Those results indicated that participants felt a sense of "ownership" regarding National Health Service (NHS) policies and felt entitled to their say in decision making (p. 53). The present study suggests similar values or opinions regarding community engagement in the sample populations of Canadians.

These same concepts of ownership of health and citizen rights were carried over when respondents were asked to rate the importance of various topics to be potentially included in pandemic communication. Respondent comments from both samples called on these concepts to justify their desire for open, transparent communication in all areas of pandemic planning.

7.4 Prevention and Personal Responsibility:

7.4.1 A personal responsibility for prevention

The emphases on prevention and personal responsibility found in reviewed documents echoes public communication goals stated in the CPIP: "to raise awareness of the threat of pandemic influenza (and other types of influenza) by building on annual influenza campaigns, leading to better self-protective measures" so "...that they can develop a personal/family plan" (p.7 PHAC, 2006a, (Annex K)). In this respect, it appears that communications documents are meeting their intended mark.

The analysis indicates that in this respect communication documents align with the needs and desires of the sample populations. Survey results and comments indicate that respondents are strongly in favour of information on prevention and self-protection and recognize the need to develop personal and family plans. The emphasis on prevention (in framing, amount and depth of information), ensures that the reader is told how to protect their health in the event of a pandemic. The information presented is clear and concise. An emphasis on prevention is in agreement with sample populations indicated desire and need for this information.

One potential draw back to this approach is that a focus on self-protective behaviours and personal and family plans can inadvertently focus reader attention on what they can do to prevent infection, not what public health officials are planning and prepared to do for the public in order to reduce morbidity and mortality and minimize social disruption. This is undoubtedly a very effective way to get the attention of the reader and inform them of behaviours to control the spread of influenza. Taken in isolation, however, this might construct an ideology or worldview of individual/citizen responsibility in preventing infection, (particularly if the reader does not delve deeper into government planning documents such as OHPIP or CPIP). Embedded in this is

communication is the illusion that even at the time of influenza pandemic, control is still in the hands of the individual (do your part, get a flu shot, wash your hands and you health can be protected). This can puts the onus on the reader (in his/her understanding of the pandemic situation) and perpetuate the power imbalance between the public and pandemic planners. Ethically, this might be seen as a scientifically dubious and socially perilous notion.

7.4.2 A relinquishing of government liability

There is very little, if any, mention of public health and government accountability to the public for their success or failure in preparing for a pandemic and protecting the public. Close to 70% in both survey samples were not even aware of the existence of a government pandemic plan. This can contribute to the ideology of the reader's responsibility. Responsibility on the part of the reader might effectively relinquish responsibility of the government and public health planners in the eyes of the reader. That is the creation of a worldview or implicit understanding that the individual is not only solely responsible for their own health, but can guarantee their own survival and protection during an influenza pandemic regardless of larger plans and circumstances.

Health planners are well aware that self-protection measures cannot themselves be sufficient to prevent spread of influenza pandemic to this province and country, due to the nature and scope of an influenza pandemic (including scarcity and priority setting of vaccines and antiviral drugs). In addition, if all people would be motivated solely by desire for self-protection, there would be no one to care for the sick, implement preventive measures and provide essential services.

Therefore, along with information on individual level self-protection behaviours, the plans that are being developed to minimize morbidity and mortality by social distancing, the

judicious use of vaccines and antivirals (including priority setting) are very salient issues that ought to be communicated to the public. A strong emphasis on reader responsibility must be balanced with corresponding emphasis on government plans and actions to prevent pandemic influenza spread (such as vaccinations).

7.4.3 A social desirability bias

Although the language in these documents is not overtly confrontational, neither is it value-neutral (e.g. "good" hand hygiene). In Lupton's (1993) review of literature on risk perception in public health, she determined "risk" was far from an unbiased or objective concept. Lupton concluded that risk discourse is often used in public health to blame the victim for socially unacceptable behaviour and place responsibility for illness on the individual based on lifestyle choices (p 425, 427). Guttman and Salmon (2006) more recently identified personal onus and blame in public health communication as an ethical concern (p. 531).

It is evident that the health promotion content of the reviewed documents was written with honest intentions. However, this emphasis on personal responsibility might unwittingly encourage social stigma. Presenting self-protection behaviours with a social desirability bias (readers desire to appear responsible, be a good role model, a good parent, a good citizen, etc.) serves the purpose of encouraging the reader to practice vital self-protection and infection control behaviours. However, taken a step further, those who choose not to follow the valorized behaviours might be seen as guilty or responsible for their own illnesses (both by self and others) should they contract the flu.

This type of stigma or social sanction is not unheard of in health and priority setting. For instance, Wittenburg et al., (2003) found that a cross section of US residents was strongly

influenced by notions of personal responsibility for health status when asked about priority setting plans. Medical experts have also been swayed by these ideologies. In a poll of transplant physicians regarding priority setting, (Randall, 1993) 88% felt that the individual was responsible for his or her own risk factors and "unrepentant noncompliance" was an acceptable contraindication in priority setting decisions. Randall argues that this can lead to discrimination against marginalized populations.

This resonates with several notions in sociological literature regarding the dangers of focusing responsibility on the individual in health promotion, for instance the idea of "worthy and unworthy ill" (Lippmann, 1998) and "being ill" as "being guilty" (Gillick, 1984). For instance, if an individual chooses not to take an annual "flu shot" as advocated in these documents, either for religious reasons, unawareness or concerns on the safety of vaccines, access or availability problems, misunderstanding, or autonomous choice, will they be seen as somehow to blame for their illness or the illness of others? Would this potentially affect whether the individual will feel free to seek treatment when ill, for fear of social sanction, stigma or retribution? Will they be assured that whatever their choices, they will have equal access to treatment?

The reader's autonomy is limited by the social desirability bias inherent in these messages. That is, reviewed documents position certain behaviours as good or responsible and even valorize such behaviour. Thus, to deviate from these socially-accepted behaviours might leave the individual vulnerable to social retribution, stigma or other sanctions.

Considering the concern over vaccine safety in survey results, this is important to ponder. It is also important to note that even if individuals practice model self protection behaviours they

could easily become ill and then be subject to the same stigma. At the same time, it might be necessary to hold individuals morally responsible for actions within their control.

7.5 Privileging specialized knowledge

7.5.1 A biomedical problem best dealt with by the biomedical elite

There are notable benefits to highlighting the biomedical aspects of pandemic influenza. Most importantly, readers are made aware of vital infection control information. This information can certainly save lives and reduce the number of sick in the event of a pandemic. This would not be the case if documents centered on the bank and school closures a pandemic might bring. This emphasis appears to align with the greatest communications needs identified by sample populations: information on treatment, prevention and options for medical care. As well, given respondents desire for scientifically based information, this appears to be in keeping with expectations.

While influenza pandemic certainly is a medical issue, it is also a social, cultural, political and ethical issue. Some of the societal and cultural effects might include widespread death, grief and social disruption, changes in proxemics (acceptable distance during various social interactions, personal space and body language) and public conduct, and in societal trust in and opinion of government and medical authorities. As well, a pandemic is a political issue (dealing with resource allocation and the provincial/federal jurisdiction on health care) and an ethical issue (dealing with protecting the public from harm, transparency, building trust). The reviewed documents do not address most of these factors, but largely present the pandemic situation and pandemic planning as a scientific or biomedical problem. Consequently, scientific methods of inquiry, expertise and knowledge are given priority. This specialized knowledge is

largely inaccessible to the average citizen, effectively shrouding the pandemic planning process in a mystique of scientific knowledge and government expertise.

It is understood that the reviewed documents were developed by health-focused organisations (PHAC, Health Canada, and MOHLTC) and logically view the issue with a scientific and biomedical lens. It is not suggested that these organisations be responsible to provide detailed analysis of the social, political and ethical ramifications of pandemics in public communication. However, it is useful to consider these themes as they possibly contribute to incorrect public perceptions of the pandemic situation and potentially contribute to ethical dilemmas.

An example is the issue of providing priority access to vaccines for high risk groups. Until the novel virus emerges and is identified, it is difficult to gauge how people will be affected medically, however, as mentioned previously, individuals determined to be at "high risk" are slated for potential priority access. However, determining who is at "high-risk" cannot be determined entirely by scientific objectivity, because even the concept of risk is shaped by the influence of society, politics, ethics and culture. For example, it could easily be argued that the large population of homeless individuals, many of them immunocompromised, staying in crowded shelters across Canada could be among those most at risk. In this example, failing to identify the social and cultural aspect of pandemic planning can lead to the unintentional of privileging of life, or the appearance thereof in the eyes of the general public. It is societal and cultural values that play a large part in how we determine risk, therefore a biomedical or scientific viewpoint, although necessary, is not alone sufficient to determine "risk."

7.5.2 An imperfect picture?

Documents reviewed in this study highlight and privilege the knowledge and experience of the medical and scientific elite, for example, referring to "experts" and "professionals." Most of these labels represent a high level of abstraction: by definition "expert" denotes a person with specialized knowledge or experience, but in its usage here, it connotes someone other than the reader. Documents reviewed feature symbols of this authority and professionalism in pandemic planning, for example logos of health agencies.

There are obvious benefits to this strategy. Firstly, the reader knows that the information being read is from a reputable and trusted source. This can help them differentiate between official communication and other information available on the internet. Given the desire for information on government planning indicated by the sample populations, this is likely an important and necessary feature.

Secondly, it assures the reader that plans are being made by those possessing qualifications and experience in public health emergencies and infection control. According to the WHO Effective Media Communications during Public Health Emergencies Field Guide, (2005c, p. 72) indicating conformance with highest professional and scientific standards is a central tenet to building trust.

One possible negative result of an emphasis on scientific and biomedical experts, however, is that it might paint an imperfect picture of the pandemic situation: that pandemic influenza is largely a biomedical and highly technical issue, and pandemic planning and information beyond the surface level is best handled and interpreted by members of those intellectual disciplines and within the bounds of biomedicine and government. For example, even within those documents encouraging exploration into of CPIP and other pandemic plans,

the level of involvement is limited to passive activities (reading/research) and not encouraging reader agency (voicing opinions or concerns, or engagement in planning process). No documents frame the reader or general public as an equal partner or participant in pandemic influenza planning. It should be noted here that public communication is the most "passive" public engagement technique, in that it does not require active feedback from the public. In focusing the document analysis on public communication alone, results likely reflect this theme more so than a study examining the stakeholder dialogue on the National Antiviral Stockpile, for example.

This phenomenon has previously been identified in biomedicine by Ettore (1999). She contends that experts (in her study, geneticists) practice knowledge ownership and maintaining a distinction between the social and the scientific in producing ideologies (p. 549, 550-55).

Many of those survey respondents opposed to public engagement commented that the public either lacks sufficient scientific and medical knowledge or the expertise and logical impartiality required to make a valuable contribution in the planning or decision making process. This argument is based on the perception of the pandemic as chiefly a biomedical or scientific issue.

A perception of the public as unqualified to participate in resource allocation decision making was also identified by Lenaghan (1999). She found that there was a dominant assumption that the general populace is unable to correctly make difficult health care decisions (p. 50). As well, the idea that the public is irrational or too emotional for health care decision making has been recognized by Litva et al., (2002). Participants in that study shared a "common perception" (p. 1384) that the public's emotional reactions might hinder rational decision making. This also relates to Cronje and Fullan's idea of "rationality" in medicine, in that

"people find it useful to distinguish actions based on reason from actions based on emotions, impulses or random choice–"'rationality', then, is what protects our actions from arbitrariness, subjectivity, bias or error (2003, p. 354)."

However, the arguments that the public should not participate or provide input based on the limits of their scientific expertise or lack of scientific impartiality are flawed. They are based on the incorrect premise that pandemic influenza is only a biomedical issue to be best handled by the biomedical elite. Certainly, in dealing with a purely scientific and technical issue public opinion might not be needed. However as the social and ethical implications of pandemic influenza cannot be denied, this excuse is invalid. Secondly, the idea that public is too irrational to deal with the responsibility of pandemic is similarly flawed. If pandemic influenza is indeed a social, political and ethical issue, it ought to be handled similarly to other social, political and ethical issues. Reviewed documents do not challenge but rather contribute to this imperfect picture of the influenza pandemic situation through the emphasis on biomedicine, and scientific/government expertise. An imperfect picture of the influenza pandemic scenario hinders ability to take appropriate actions, effectively disempowering the reader.

7.5.3 A disempowered public

Based on the themes discussed above, there seems to be a contradictory message in these communications documents: both empowerment and disempowerment. The reader is told that he or she has the ability (and often responsibility) to protect their own health and the health of their families through self protection behaviours. This can be seen as empowerment. However, s/he is excluded from participating in the planning process, both implicitly (through privileging of specialized knowledge and expertise) and explicitly (lack of community engagement opportunities). Unfortunately, this may inadvertently condition the reader to disqualify

him/herself from further inquiry into or critique of pandemic planning. This can be seen as disempowerment.

The ownership of knowledge by experts in present communication documents and the lack of immediate provisions for receiving and addressing public input and concerns tacitly assume a passive public—one that will accept and respond to emergency health direction without question. This corresponds with the expected "role of the public" in pandemic planning as outlined in the OHPIP (MOHLTC, 2007, (2) p. 5): "The public is expected to actively participate in efforts to reduce the spread of the influenza, to comply with any public health measures (emphasis mine) and to participate in their own care in a pandemic."

Based on survey results it may not be reasonable to suppose that the public will calmly accept and follow the pandemic protocol (including priority groupings) while under great stress, particularly if the basis of the protocol has not been outlined before hand.

As suggested by survey findings, and considering the emphasis on open communication and cooperation that will be demanded by Canadian health authorities (i.e. self-reporting, self isolation), the public might feel entitled to similar levels of transparency and cooperation from the individuals and organizations responsible for protecting their health during an influenza pandemic. These needs are not currently addressed in pandemic public communication, maintaining an imbalance of power and knowledge between pandemic planners and the individual.

7.6 Suggestions

The following two suggestions for future pandemic influenza public communication are tentatively made based on the findings of this study. Future research, as discussed below, is needed to validate them.

7.6.1 Inquire: Ask citizens of their communications needs and develop communication practices accordingly.

Recognizing the active role of the public before, during and after an influenza pandemic, it is necessary to consider what information is most important to them and how will they interpret information provided. This entails detailed investigation into social and cultural "climate" of the intended audience. For instance, will citizens trust and accept public communication information? To know this, current opinions of public health policies and government's roles must be determined. As well, it is important to evaluate how the public interpret the messages and language of the documents, and if any structural or societal circumstances exist that would affect this interpretation. Developing public communication without considering the larger social and cultural "climate" might hamper effectiveness.

For example, based on survey results, a portion of respondents expressed their reticence regarding vaccines due to concerns about their safety and a preference for "natural healing methods". These persons identified these reasons for their indifference toward a future influenza pandemic, and seasonal flu vaccinations. Perhaps messages addressing the socio-cultural, political and ethical sides of pandemic influenza (for instance disclosure of priority setting plans and criteria; the possibility of social distancing) might catch the interest of these individuals.

Ascribing agency to public is supported by Mah and Myers (2006) argument regarding infection control workers and behaviour change. Those authors argue that as the postmodern mindset pervades modern healthcare, pluralism and a lack of shared "truth" necessitates a "socio-ethical approach." The major trends of this approach can be expressed as moving from: individualism to community, rationality to rhetoric, productivity to praxis and monologue to dialogue.

May (2005) similarly suggests that embedded themes, of "background schemas" or "packaging" in messages are foundational to the way an audience receives and interprets information. He states that if the information is not formatted and shaped in accordance with public perceptions they may be misunderstood or misconstrued by the audience (p.419).

To develop public communication in this vein, several secondary suggestions are made based on responses to this survey:

1. Utilize communication channels preferred by public.
2. Ensure timing and content of messages is in keeping with the public's expectations.
3. Address confusion and concerns regarding vaccines.
4. Fully disclose priority setting plans and rationale.

7.6.2 Engage: Actively engage the public in pandemic decision making

To empower the public we must acknowledge their role in an influenza pandemic—not as simply responding to predetermined pandemic plans, but, as survey results indicate, active players who will assess and appraise the pandemic scenario and respond in possibly an unknown or unpredictable manner. The WHO outbreak communication guidelines state that crisis communication is a "dialogue" (WHO, 2005b, p. 6). We must be aware of the relationship "dialogue" that will occur between pandemic planners and those who will be affected by the pandemic plans. Francis et al., (2005) refers to this phenomenon in bioethics of infectious disease as the "victim and vector" (p. 309) and posits the need to rethink the agency of the individual as concerns these issues.

To acknowledge the agency of the public is to involve them as key stakeholders, not as an afterthought. Thompson agrees that the public be considered stakeholders in the interests of solidarity in a public health crisis and (hospital) pandemic planning (Thompson et al., 2006).

Consultation with the public is strongly recommended by the WHO and other researchers concerning priority setting decisions and mentioned is key "next steps" in the CPIP. Kotalik (2005, p. 427) and the PEPPPI project (Bernier and Marcuse, 2005) have both suggested community engagement steps regarding pandemic influenza and priority setting. Given that survey respondents agreed that they would prefer communication before the start of pandemic influenza, and the many unknowns of the pandemic situation, a sense of urgency should accompany the practice of gathering public input and initiation of communication channels.

A number of survey respondents made additional comments indicating they felt that community engagement will contribute positively to ensure priority setting decisions are ethical and in accordance with community values. Giacomini et al., (2000) agree that in allocating medical technology, those affected by allocation policies and members of the general public should be included to scrutinize value bias and conflicting interests inherent in resource allocation (p. 998).

Strong emphasis on reader responsibility must be balanced with corresponding emphasis on government plans and actions to prevent pandemic influenza spread (such as vaccinations). As well, the accountability structure of pandemic planning should be disclosed to the public both in the interest of transparency and building and maintaining public trust.

These can be abbreviated into four secondary suggestions to increase public agency:

1. Show greater transparency regarding decision-making processes, accountability and ways in which the public can be involved.

2. Make provisions for public feedback, such as through inviting comment on draft policies.

3. Provide avenues for public engagement and deliberation, for example through sponsoring open forums or deliberative polls.

4. Incorporate public values into pandemic planning and policymaking.

7.7 Implications for Future Research

Results posit the need for further research on the following areas:

1. Health literacy of public concerning pandemic influenza, particularly public reading level, accessibility of language, public perceptions of procedures and concepts, particularly vaccination, access to information, preferences for media channels.

2. Public perceptions and opinions on influenza vaccination and prophylaxis with antiviral drugs.

3. Public interest in community engagement methods, what methods and tools the population would be more inclined to make use of, utilizing a larger sample population.

4. Further qualitative research into the themes and biases inherent in public health communication, particularly as concerns infectious disease.

5. Further research into bioethical concerns in public health communication about infectious disease.

8.0 Conclusions

The purpose of this research was to analyze, using a critical public health ethics perspective, public communication directed toward the population of Ontario regarding a future influenza pandemic and compare this communication with informational needs and interests identified by a sample of this population. This study represents a preliminary investigation of public communication regarding pandemic influenza in Ontario, and of the desires, needs and wishes of the Ontario public concerning pandemic influenza communication.

The first part of the study examined public communication/education materials, including pamphlets, fact sheets and web page text, available in electronic form, developed by the Public Health Agency of Canada, Ministry of Health and Long-Term Care (Ontario) and Health Canada concerning pandemic influenza using a four-step coding process. Next, survey data was collected regarding general pandemic knowledge, informational needs, desires and expectations, including opinions regarding public engagement. Data was collected from a First Nations and a university sample. Results from the document analysis and survey were compared and analysed in light of using a critical public health ethics perspective.

Results indicated that:

1. Considerable overlap exists between the most important topics as identified by respondents and the topics most covered in documents, although several areas in which information desired by respondents was not included in documents.

2. Respondents underestimated the projected scale and impact of influenza pandemic.

3. Respondents were largely unaware of government pandemic plans including CPIP, although expressed strong interest in pandemic plans.

4. Respondents were in favour of having involvement in pandemic decision making at some level, and indicated their preferred methods of participation.

5. Communication documents largely portrayed pandemic influenza as a biomedical issue, and pandemic planning as within the jurisdiction of experts. Prevention, particularly self-protection behaviours on the part of the individual, was also a dominant theme.

The author posits practical suggestions for improving future public communications based on survey responses: Ask citizens of their communications needs and develop communication practices accordingly; and actively engage the public in pandemic decision making, with several secondary suggestions within these headings. Results of this study can assist public health professionals to reflect on the social and ethical implications of communicating with the public in the current pre-pandemic period, gain insight into public opinions concerning public engagement, and develop future public communication concerning pandemic influenza.

9.0 Appendices

9.1 Appendix A

9.1.1 Document Analysis

31 documents were reviewed in total. Documents are not presented in numerical order, but are grouped according to their location at the time of data collection. The number assigned to the documents here corresponds to number cited in the text.

Five documents were found on the PHAC website, Home: Infectious Disease: Influenza: Pandemic Influenza : Information for Individuals & Families. All documents found under this heading available at the time of data collection were included.

1) PHAC. (2006). *Flu Prevention Checklist.* Retrieved January 4, 2007, from http://www.phac-aspc.gc.ca/influenza/flupc_e.html

4) PHAC. (2006). *Understanding Pandemic Influenza-Fact Sheet.* Retrieved January 10, 2007, from: http://www.phac-aspc.gc.ca/influenza/faf_e.html

8) PHAC. (2006). *Pandemic Flu and You: Get Informed, Stay Informed.* Retrieved January 15, 2007, from http://www.phac-aspc.gc.ca/influenza/fam-fluinform_e.html

11) PHAC. (2006). *Pandemic Influenza.* Retrieved January 18, 2007, from http://www.phac-aspc.gc.ca/influenza/pandemic_e.html

13) PHAC. (2006). *Pandemic Flu Planning Checklist.* Retrieved January 18, 2007, from http://www.phac-aspc.gc.ca/influenza/fam-pl-ckl_e.html (2006-04-19)

Eight documents were found on the PHAC website: Home : Infectious Diseases : Influenza : Pandemic Influenza : Information for the Media. All documents found under this heading available at the time of data collection were included.

2) PHAC. (2007). *Key Facts on Pandemic Influenza.* Retrieved January 4, 2007, from http://www.phac-aspc.gc.ca/influenza/pikf_e.html

7) PHAC. (2006). *Pandemic Periods and Phases.* Retrieved January 4, 2006, from http://www.phac-aspc.gc.ca/influenza/pi-pp_e.html

9) PHAC. (2005). *Frequently Asked Questions.* Retrieved January 15, 2007, from http://www.phac-aspc.gc.ca/influenza/pandemic_qa_e.html

12) PHAC. (2006). *The Role of Vaccines and Antivirals Controlling and Preventing Influenza.* Retrieved January 18, 2007, from http://www.phac-aspc.gc.ca/influenza/influenza-vacantiv_e.html (2006-01-30)

17) PHAC. (2006). *You can play a role in preventing the spread of Pandemic Influenza.* Retrieved February 4, 2007, from http://www.phac-aspc.gc.ca/influenza/pdf_ms/05-Role-in-Preventind-the-Spread.pdf

18) PHAC. (2006). *Preventing the Spread of Influenza During a Pandemic.* Retrieved February 4, 2007, from http://www.phac-aspc.gc.ca/influenza/pdf_ms/04-Preventing-the-spread.pdf

19) PHAC. (2006). *What You need to know about pandemic influenza.* Retrieved Feb 2006, from http://www.phac-aspc.gc.ca/influenza/pdf_ms/01-About-Pandemic-Influenza.pdf

20) PHAC. (2006). *The Public Health Agency of Canada's Pandemic Preparedness Activities.* Retrieved February 4, 2007, from http://www.phac-aspc.gc.ca/influenza/pdf_ms/03-Pandemic-Preparedness-Activities.pdf

Six additional documents were included because the PHAC Pandemic Portal website provided a website link to them.

3) Health Canada (in collaboration with PHAC). (2006) *It's Your Health: Preparing for an Influenza Pandemic*. Retrieved January 4, 2006, from http://www.hc-sc.gc.ca/iyh-vsv/diseases-maladies/pandem_e.html

5) Health Canada. (2006). *First Nations and Inuit Health: Influenza (the Flu).* Retrieved January 5, 2007, from http://www.hc-sc.gc.ca/fnih-spni/diseases-maladies/influenza/influenza_e.html

6) Health Canada. (2005). *First Nations and Inuit Health: Fact Sheet on Avian Influenza.* Retrieved January 12, 2007, from http://www.hc-sc.gc.ca/fnih-spni/pubs/influenza/2006_fs-fi/index_e.html
* document appears to be designed for First Nations audience

10) Health Canada. (2005). *About Health Canada--Global Pandemic Influenza Readiness.* Retrieved January 16, 2007, from http://www.hc-sc.gc.ca/ahc-asc/intactiv/pandem-flu/index_e.html
*a news bulletin

14) Health Canada (in collaboration with PHAC). (2006) *It's Your Health: Avian Influenza (Bird Flu).* Retrieved January 18, 2007, from http://www.hc-sc.gc.ca/iyh-vsv/diseases-maladies/avian-aviare_e.html

15) Health Canada: (2005) *It's Your Health: The Flu.* Retrieved January 18, 2007, from: http://www.hc-sc.gc.ca/iyh-vsv/diseases-maladies/flu-grippe_e.html

The PHAC was contacted regarding the choice of documents included in this review. As per suggestion, a further document was included.

16) PHAC. (2006). Highlights from the Canadian Pandemic Influenza Plan for the Health Sector. Retrieved January 21, 2007, from http://www.phac-aspc.gc.ca/cpip-pclcpi/hl-ps/index.html

Ten documents were listed as "fact sheets. They were found on the MOHLTC website, Home: Public Information: Pandemic Information. All fact sheets available at the time of data collection were included.

21) MOHLTC. (2007). *In case of a flu pandemic: Additions to your emergency supply kit for home.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_home_kit_fs_02_20070205.pdf

22)MOHLTC. (2006). *What you should know about a flu pandemic.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/languages/english.pdf

23) MOHLTC. (2007).*Preparing for a flu pandemic: How will Ontario Be Affected?* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_ontario_fs_02_20070205.pdf

24) MOHLTEC. (2007). *Preparing for a Flu Pandemic: Making Individual and Family Plans.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_prepare_fs_02_20070205.pdf

25) MOHLTC. (2007). *Staying Healthy During a Flu Pandemic.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_stay_healthy_fs_02_20070205.pdf

26) MOHLTC. (2007). *Limiting the Spread: Travel, Social Contact and Pandemic Flu.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_travel_fs_02_20070205.pdf

27) MOHLTC. (2007). *Pandemic Flu and Personal Protection: Hand Hygiene.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_hand_fs_02_20070205.pdf

* document appears to be designed for HCW audience

28) MOHLTC. (2007). *Taking Care of Yourself and Your Family: What to do if you get Pandemic Flu.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_self_fs_02_20070205.pdf

29) MOHLTC. (2007). *Treating Pandemic Flu: What Your Health Care Provider Will Need to Know and May Ask You to Do.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_provider_fs_02_20070205.pdf

30) MOHLTC. (2007). *Treating Pandemic Flu: Vaccines and Antiviral Drugs.* Retrieved February 7, 2007, from http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_antiviral_fs_02_20070205.pdf

31) MOHLTC. (2007). *Protecting the Circle of Life: What You Should Know About Pandemic Flu.* Retrieved February 7, 2007, from

http://www.health.gov.on.ca/english/public/program/emu/pub/pan_flu/fact_sheet/panflu_first_nations_fs_02_20070205.pdf

* document appears to be designed for First Nations audience

9.2 Appendix B

9.2.1 Factual Coding

Breakdown of Document Analysis and 11 Factual Coding Themes

Doc. #	Prevention	Treatment	Options Med. Care	Priority Setting	Daily life	Who is in priority groups	Scientific rationale	Ethical rationale	Financial rationale	Who determines. priority groups	Affects on others
1		☑									
2	☑	☑				☑				☑	
3	☑		☑		☑					☑	
4											
5	☑										
6	☑										
7											
8		☑	☑		☑						
9	☑	☑		☑	☑	☑				☑	
10											
11	☑										
12	☑	☑									
13			☑		☑						
14	☑	☑		☑						☑	
15	☑	☑								☑	
16	☑	☑	☑	☑	☑	☑				☑	
17	☑	☑									
18	☑	☑			☑						
19	☑	☑									
20				☑	☑					☑	
21	☑		☑		☑						
22	☑	☑	☑		☑					☑	
23			☑							☑	
24			☑		☑						
25	☑	☑									
26	☑				☑						
27	☑										
28	☑	☑	☑								
29		☑	☑								
30						☑					
31	☑	☑	☑			☑				☑	
Total	20	16	10	4	11	5	0	0	0	10	0

Topic 1) Prevention: close contact with infected, cover cough/sneeze, following general emergency preparedness guidelines, hand hygiene, hand washing, handling poultry, eggs or wild game, pandemic flu vaccine (as preventative, not regarding priority setting), respiratory etiquette, self-isolation (stay home as pertains to preventing), seasonal flu vaccines (flu shot), shared surfaces, social distancing (relating to prevention). Behaviours associated with phrases connoting protection, including: how you can prevent, how you can stop the spread, what you can do (to help), protect yourself, protect your health, stop the spread, reduce infection

Topic 2) Treatment: antivirals drugs, contact their health care provider, drink water/fluids, painkillers, rest, seek medical treatment, self-isolation(relating to treatment), stay home (work from home) as pertains to treatment, symptom control

Topic 3) Options for medical care: (This pertains to any extraordinary medical care conditions the might occur during influenza pandemic.) flu clinics/centres, health care facilities, implementation of alternate assessment, health care workers, home treatment, keep individuals who are ill with flu away from hospitals, limitations on medical staff, prepare Emergency Health information sheet and contingency plans with family, Telehealth, treatment and referral centres antibiotics. Pertaining to health care services: access, cancellation, delayed, difficult to get med attention, interrupted, pressure, reduced, restricted or unavailable

Topic 4) Priority Setting: (This relates to the explicit mention of priority setting with regard to vaccines and antivirals.) first access/ priority access/setting/groups/grouping, large enough supply, scarcity, shortages of vaccines "initial stages, shortness, supply

Topic 5) Daily Life: closure, contingency plans, disruptions, emergency plan, including emergency kit with supplies, restrictions: bank, school, store, travel, work hours, transit quarantine/self-isolation/social distancing (pertaining to daily life disruption)

Topic 6) Who is included in Priority Groups: essential service workers, key individuals, (persons at) high risk, high risk groups as required, those most likely to benefit, those hospitalized for influenza, those at high risk of influenza related complications, health care workers.

Possibly conflicting: anyone who has the flu and would benefit from them, those most likely to benefit, Canada's contract with a domestic vaccine supplier will afford Canada the ability to provide all Canadians with vaccines/build the infrastructure and systems to produce enough pandemic vaccine for all Canadians as quickly as possible, in the event of a pandemic, when they need them, the goal of Canada's pandemic vaccine contract is to produce enough vaccine to protect all Canadians as quickly as possible, ensure that supplies of safe and effective vaccines are available when Canadians need them, "Pandemic Vaccine Program, which aims to provide a safe and effective vaccine to all Canadians, as soon as possible, in the event of a pandemic outbreak

Topic 7) Scientific Rationale for Priority Setting: (This pertains to an explanation based on scientific information or principles as to priority setting decisions). No terms found. *Note: 9 documents noted that vaccine or antiviral shortage will occur due to a 4-6 month time period needed to develop a vaccine.*

Topic 8) Ethical/Moral Rationale for Priority Setting: (This pertains to ethical or moral principles used to develop vaccine and antiviral drug allocation plans.) No terms found. *Note: One document did mention the PIC group included an ethicist.*

Topic 9) Financial Rationale for Priority Setting: (This pertains to how and why financial constraints might demands vaccine and antiviral priority setting.) No terms found. *Note: One document mentioned that the federal government invested $34 million in vaccine research and development and $24 million toward creating a national antiviral stockpile.*

Topic 10) Who determines Priority Groups: Chief Medical Officer of Health, emergency response experts, experts, expert committees, First Nations and Inuit Health, government, Health Canada, health care professionals, key stakeholder(s), Ministry of Health and Long-Term Care, PHAC officials, PIC, provincial and territorial public health experts,
Associated with: get drugs and protective equipment to where they are needed quickly, setting up distribution systems

Topic 11) Affect on those not in Priority Groups: (This pertains to special instruction, guidance or information for those individuals not included in priority groups, for instance how to attain alternative protection.) No terms found.

9.3 Appendix C

Survey Questionnaire

Dear Participant:
Thank you for taking a few minutes to thoughtfully fill out this survey. It should take between 15 and 30 minutes to complete. You may chose not to answer a question at any time. The answers you do provide will be kept confidential and anonymous.

Please answer the following questions based on your knowledge and opinions **at this time. Provide one answer per question unless instructed otherwise.**

Question 1) **What is a flu pandemic?**
☐The annual outbreak of influenza usually running from about November to April
☐ No one really knows what a flu pandemic is
☐ A worldwide outbreak of influenza which affects a large proportion of the population
☐ Don't know

Question 2) **What causes a flu pandemic? Check all that apply.**
☐ Poor hand washing
☐ No one really knows what causes flu pandemics
☐ Flu virus changes so much that nobody has any immunity to it
☐ People don't get annual flu shots
☐ Don't know

Question 3) **When was the last flu pandemic in Canada?**
☐ 1900
☐ 1918-19
☐ 1968-69
☐ 1985-86
☐ Don't know

Question 4) **About how many people could be ill in a moderately severe flu pandemic in Canada?**
☐ <100,000
☐ 100,000-500,000
☐ 500,000-2,000,000
☐ 2,000,000-5,000,000
☐ >5,000,000
☐ Don't know

Question 5) **About how many people could be hospitalized from the flu and flu complications in a moderately severe pandemic in Canada?**
☐ <1,000
☐ 1,000-10,000
☐ 10,000-33,000

☐ 34,000-138,000
☐ >138,000
☐ Don't know

6) **About how many people do you think die in a typical year from flu and flu related complications in Canada?**
☐ <1,000
☐ 1,000-3,000
☐ 4,000-8,000
☐ 8,000-12,000
☐ >12,000
☐ Don't know

Question 7) **About how many people could die from the flu and flu related complications in a moderately severe flu pandemic in Canada?**
☐ < 1,000
☐ 1,000-5,000
☐ 5,000-10,000
☐ 11,000-58,000
☐ >58,000
☐ Don't know

Question 8) **Antiviral drugs are used to treat the flu. Check each of the item(s) below that describe why antiviral drugs are important:**
Code:
☐ They can reduce the symptoms of the flu
☐ They can shorten the time you are sick from the flu by 1 or 2 days
☐ They can keep you from getting the flu
☐ They can make you less contagious to others
☐ Don't know

Question 9) **The ability of flu vaccine to combat the flu (its effectiveness) depends on: Check all that apply.**
Code:
☐ The health status of the person getting the vaccine
☐ The age of the person getting the vaccine
☐ The similarity or "match" between the vaccine and the virus
☐ All of the above
☐ None of the above
☐ Don't know

Question 10) **Each flu "strain" is somewhat different. In order to make a vaccine for pandemic flu, the specific virus causing the pandemic must first be identified and studied. About how long would it take to produce a flu vaccine after the virus causing a pandemic is identified?**
☐ <1 month

☐ 1-5 months
☐ 6-12 months
☐ >12 months
☐ Don't know

Question 11) **The circumstances surrounding pandemic influenza will likely make it necessary for the Canadian government to offer vaccines and antiviral drugs to population groups (for example, essential service workers, front line health care workers) on a priority basis. Were you previously aware of this?**
Code:
☐ Yes
☐ No
☐ Don't know

Question 12) **Have you sought out information regarding government planning for the pandemic influenza, for example, research on the internet or books? If no, skip to Question 14.**
☐ Yes
☐ No
☐ Don't know

Question 13) **Where did you look for information on the government's plans for flu pandemic? Check all that apply.**
☐ Internet
☐ Newspaper
☐ Books or Magazines
☐ Medical Professional (i.e. nurse, family doctor)
☐ Other (please indicate) _____

Question 14) **There is a federal plan for pandemic influenza (The Canadian Pandemic Influenza Plan). Were you previously aware of this? If no, please skip TO Question 18.**
☐ Yes
☐ No
☐ Don't know

Question 15) **Have you researched or read any of the Canadian Pandemic Influenza Plan? If no, please answer this question and skip to Question 18.**
☐ Yes
☐ No
☐ Don't know

Question 16) **How would you describe your experience reading the Plan?**

_____

Question 17) **Did you find the answers and information you were looking for in the Plan? Please answer and skip to Question 19.**

☐ Yes
☐ No
☐ Don't know
Please elaborate:

Question 18) **If you did not read the Canadian Pandemic Influenza Plan can you please tell me why? Check all that apply.**
☐ Doesn't interest me
☐ Didn't know about such information/plan
☐ Didn't know such information/plan was available to public
☐ Too busy
☐ Didn't have access to it (internet)
☐ Didn't know where to find information
☐ Could not find information
☐ Didn't think about it
☐ It was difficult to read due to language used (wording, technical jargon)
☐ It was difficult to read because it was too long
☐ Other (please specify)

Question 19) **How would you prefer to read about the Canadian Pandemic Influenza Plan?**
☐ In a briefer document written specifically for the public
☐ In a "scientific" document outlining official procedure and protocol
☐ No preference
☐ Both
☐ Other (please specify)

Question 20) **Please indicate how strongly you agree or disagree with the following statements:**

a) Given my present knowledge of flu pandemic I am able to make informed decisions about my health.
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

b) Given my present knowledge of government plans for flu pandemic I am able to make informed decisions about my health.
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

c) I am satisfied with the quality communication/educational information I have seen about pandemic influenza (i.e. government websites, media campaigns, advertisements, pamphlets)
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

d) I am satisfied with the amount of communication/educational information I have seen about pandemic influenza (i.e. government websites, media campaigns, advertisements, pamphlets)
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

e) I know all that I need to about vaccines to make informed decisions about my health regarding flu pandemic.
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

f) I know all that I need to about antiviral drugs to make informed decisions about my health regarding flu pandemic.
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

g) I am satisfied with the quality of communication/educational information I have seen about pandemic influenza vaccines (i.e. government websites, media campaigns, advertisements, pamphlets).
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

h) I am satisfied with the amount of communication/educational information I have seen about pandemic influenza antiviral drugs (i.e. government websites, media campaigns, advertisements, pamphlets).
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

i) Government plans for flu pandemic should be shared with the Canadian public.
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

j) Government plans for flu vaccine and antiviral drug allocation should be shared with the Canadian public.
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

Would you care to elaborate? Please feel free to offer additional comments. ☐

Question 21) **What information is most important for you to be informed of concerning pandemic influenza? Please indicate how strongly you agree or disagree with the following statements.**

I would like to be informed of:

a) How I can prevent catching pandemic influenza
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

b) How I can treat pandemic influenza if I catch it
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

c) What options I have for medical care
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

d) Antiviral drug and vaccine dispersal plans and priority groups
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

e) How the pandemic will affect my daily life (ie. Quarantine)
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

f) Other (please specify) ☐

Question 22) **Please elaborate or provide a brief explanation for your answers in Question 21 (i.e., why or why these things aren't important to you, did any points stand out as particularly significant or irrelevant?)**

☐

Question 23) **I would like to be informed about *general* Government plans for flu pandemic from:**

a) Official government websites
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

b) In the news
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

c) Online Public Service Announcement
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

d) Radio Public Service Announcement
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

e) Television Public Service Announcement
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

f) Pamphlets in doctors office
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

g) Pamphlets in public places
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

h) Other (please specify) ☐

Question 24) **When would you like to be informed of *general* Government plans for flu pandemic:**

☐ Before the flu pandemic begins worldwide

☐ Once the flu pandemic begins worldwide
☐ Before the flu pandemic begins in Canada
☐ Once the flu pandemic begins in Canada
☐ While the flu pandemic is underway

Question 25) **What information is most important to you specifically concerning vaccine and antiviral drug priority setting and resource allocation? Please indicate how strongly you agree or disagree with the following statements.**

I would like to be informed of:

a) Who is in the priority groups to receive preferred access to antiviral drugs and vaccines?
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

b) Priority groups/resource allocation on the basis of scientific reasons
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

c) Priority groups/resource allocation on the basis of ethical/moral reasons
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

d) Priority groups/resource allocation on the basis of financial reasons
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

e) By whom priority groups/resource allocation is determined (ie, medical officers, ethicists etc)
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

f) How priority grouping/resource allocation will affect those not in a priority group, that those people can make informed decisions regarding their health)
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

g) Other (please specify) ☐

Question 26) **Would you care to elaborate? Please feel free to provide a brief explanation for your answers in Question 25 (i.e., why or why these things aren't important, did any points stand out as particularly significant or irrelevant?)**

☐

Question 27) **I would like to be informed about Government *flu vaccine and antiviral drug allocation* plans for flu pandemic from:**

a) Official government websites
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

b) In the news
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

c) Online Public Service Announcement
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

d) Radio Public Service Announcement
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

e) Television Public Service Announcement
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

f) Pamphlets in doctors office
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

g) Pamphlets in public places
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

h) Other (please specify) ☐

Question 28) **When would you like to be informed of Government plans for flu *vaccine and antiviral drug dispersal:***
☐ Before the flu pandemic begins worldwide
☐ Once the flu pandemic begins worldwide
☐ Before the flu pandemic begins in Canada
☐ Once the flu pandemic begins in Canada
☐ While the flu pandemic is underway

Question 29) **Do you see any benefit to having the Canadian public involved in the decision-making process when planning for pandemic influenza? Please provide a brief explanation (i.e. Examples) for your response.**
☐ Yes
☐ No
☐ Don't know

☐

Question 30) **Do you think that the Canadian public should be more involved in the decision- making process when planning for pandemic influenza in general?**
☐ Yes
☐ No
☐ Don't know

Question 31) **Do you think that the Canadian public should be more involved in the decision making process specifically as concerning planning for antiviral and vaccine dispersal and priority grouping?**
☐ Yes
☐ No
☐ Don't know

Question 32) **Why or why not? Please elaborate or provide a brief explanation for your responses to Questions 30 and 31.**

☐

Question 33) **How would you prefer to be involved in this process? Please indicate how strongly you agree or disagree with the following statements.**

a) Not at all
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

b) Opinion poll of a sample of Canadian public
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

c) Open discussions/forums across cities/districts
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

d) Townhouse meetings
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

e) Phone in radio and TV programs
☐ Strongly disagree ☐ Disagree somewhat ☐ Neutral ☐ Agree somewhat ☐ Strongly agree

f) Other (please specify) ☐

Question 34) **Did we miss something? Please list any concerns you have about pandemic flu information. Additionally, feel free to add any other suggestions on how these things would be communicated more effectively (for example, important topic you would like to see mentioned in media, ways to get this information across more effectively, how to get this information across in a way that people will take notice of)**

☐

Questions about You: A bit of information about yourself would help us to understand whose voices are being heard in this study! Please remember that the information you provide in this survey is anonymous, but you may leave blank any and all questions.

Question 35) **What is your gender?**
☐ Female
☐ Male
☐ Other

Question 36) **In which of the following categories is your age?**
☐ 18-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65 or older

END OF SURVEY- THANK YOU!

9.4 Appendix D

Cover Letter for LU participants

Dear Potential Participant,

Thank you for considering participating in a study concerning **Public communication about pandemic influenza.**

As you are well aware, the threat of pandemic influenza is an urgent and pressing issue. Clear and effective **communication** is vital to ensure that we are all armed with current and thorough information to protect their health during the influenza pandemic. This information generated by this study will be used for just that—to improve public communication in future and make a difference by improving public communication strategies.

Should you choose to participate in this study, you will be asked to complete a **short survey** concerning your present knowledge about pandemic influenza and your expectations and wants for communication about it. This will require approximately **15-30 minutes** of your time. You may at any time choose not to answer one or more of the questions asked in the questionnaire. All answers you do provide are acceptable and valuable. You may withdraw from the study at any time. Withdrawal will not disqualify you from the **incentive gift**.

Information from all the questionnaires will be coded, analyzed and securely stored at Lakehead University for seven years. Your **privacy and anonymity** are important and I will not ask you to provide any information to identify yourself, so that the survey will be anonymous. A consent form (below) must be signed before you can participate in the study. This form will be kept in a file separate from the study results in order to maintain your anonymity. The results will be prepared as a graduate thesis and may be used in an article for publication.

In appreciation for your help with this study you will receive a gift certificate Tim Horton's or The Study campus coffee shop (up to $3).

If you have any questions or concerns, or would like to see the results of this study, please do not hesitate to contact me via the telephone number or email address below.

Laena Maunula 647-439-9645
lkmaunul@lakeheadu.ca

Cover Letter for LDML participants
Dear LDML Member,

My name is Laena Maunula and I am in my second year of the Master of Public Health program at Lakehead University. I am deeply committed to public health and the principle that all people should have access to the resources and conditions necessary for health and well being. I am writing to you to about an important opportunity to participate in a study concerning **public communication of pandemic influenza.** As you are well aware, the threat of pandemic influenza is an urgent and pressing issue.

Historically First Nations people have been mainly excluded from academic research. The effect of this is exclusion is that the views, opinions, preferences and needs of First Nations people are not documented in academic literature and thus not reflected in the policies which are formed upon the findings of such research. Urbanized First Nations populations such as Lac des Mille Lacs represent a unique facet of the larger Canadian populace with unique and distinct needs and views that that merit further study. **Members of the Lac de Mille Lacs band will have a unique opportunity to make their voices heard to a greater degree regarding public communication.**

Should you choose to participate in this study, you will be asked to complete a **short survey** concerning your present knowledge about pandemic influenza and your expectations and wants for communication about it. This will require approximately **15-30 minutes** of your time. You may at any time choose not to answer one or more of the questions asked in the questionnaire. All answers you do provide are acceptable and valuable. You may withdraw from the study at any time.

Information from all the questionnaires will be coded, analyzed and securely stored at Lakehead University for seven years. Your **privacy and anonymity** are important and you will not be asked to give me any information that would identify you, so that the survey will be anonymous. A consent form (below) must be signed before you can participate in the study. The survey will be mailed to you after you return the signed consent form. This form will be kept in a file separate from the study results in order to maintain your anonymity. The results will be prepared as a graduate thesis and may be used in an article for publication.

In appreciation for your help with this study you will receive a gift certificate **Tim Horton's or The Study campus coffee shop (up to $3).**

If you have any questions or concerns, or would like to see the results of this study, please do not hesitate to contact me via the telephone number or email address below.

Laena Maunula 647-439-9645

lkmaunul@lakeheadu.ca

Consent Form:

I _____ have read the cover letter regarding the study: Public communication about influenza pandemic: A critical public health ethics analysis. I am aware of the purpose of this study, I understand that I am a volunteer—I have the right to decide how much I want to participate and I can withdraw at any time. I understand that there is no apparent risk to me associated with my participation. I realize that information I provide will be confidential and that it will be stored securely at Lakehead University for 7 years upon completion of this study. I can access the results of this study by contacting the researcher at lkmaunul@lakeheadu.ca. or phoning 647-439-9645
In signing below, I agree to the above statements and to participate in this study.

Name:
Date:

9.5 Appendix E

Non-significant correlations

The following correlations were not statistically significant:

Pandemic knowledge and:

Satisfactions with the quality information seen regarding pandemic influenza;

Satisfaction with the amount information seen regarding pandemic influenza;

Satisfaction with the quality information seen regarding vaccines;

Satisfaction with the amount information seen regarding antiviral drugs;

Belief that respondent has sufficient knowledge of vaccines to make informed decisions;

Belief that respondent has sufficient knowledge of antiviral drugs to make informed decisions;

Belief that government plans for vaccine and antiviral drug allocation should be shared with the public

Due to limited sample size and characteristics it was not possible to analyze the following:

Relationship between having sought out pandemic communication and:

Satisfaction with public communication,

Self-rated ability to make health decisions

Belief that government pandemic plans ought to be shared with the public;

Benefit or no benefit to having general public involved in decision making

Desire to be involved in decision making process

Preferred communication channel (i.e. television, internet)

Relationship between having read or researched CPIP and:

Satisfaction with public communication,

Self-rated ability to make health decisions

Belief that government pandemic plans ought to be shared with the public;

Benefit or no benefit to having general public involved in decision making

Desire to be involved in decision making process

Relationships between age and:

Belief that government pandemic plans ought to be shared with the public;

Benefit or no benefit to having general public involved in decision making

Desire to be involved in decision making process

Community Engagement preferences

10.0 References

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