

**University of Alberta**

Information vulnerability in seniors and its  
influence on H1N1 influenza vaccine uptake

by

Leah Ann Lechelt

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## **Dedication**

This thesis is dedicated to my family, always unwavering in their support of my mid-career return to school. To my husband, Ron, for believing in me and for unselfishly setting aside so many of your own aspirations while I pursued mine. I hope one day to return this incredible act of love. To my son, Keaton, for inspiring me to set my standards high, as you always do. To my daughter, Helena, for reminding me that obstacles are there for a reason: to strengthen our resolve to find a way through. And finally, to mom and dad, who taught me long ago that schooling doesn't give you an education; it teaches you how to learn.

## Abstract

Communicating risk information to promote adoption of protective behaviours was challenging during the 2009 H1N1 influenza pandemic. Focus group research in Alberta, Canada involving 65 seniors aged 65 and older suggests this population had difficulty comprehending risk information due to inconsistent and sensationalized coverage in traditional media (television, newspapers) and low self-efficacy with online sources. I propose a new phenomenon, *information vulnerability*, as a consequence of seniors' poor adaptation to this changing media environment. This vulnerability reduced seniors' capacity to use *analytic* (scientific) information to assess H1N1 risk and led to preferential weighting of certain types or sources of positively *affective* (emotional) information, particularly personal experience, physicians and family members. These findings suggest that in the absence of clear, consistent risk information, prior attitudes and habituation related to seasonal influenza were determinants of H1N1 vaccine acceptance among seniors, whereas fear-based media messaging had little impact on vaccination decisions.

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I would like to acknowledge the many seniors in this study who spoke so candidly about their experiences during the H1N1 pandemic. Even when faced with a public health threat and an unfamiliar mass media environment, you demonstrated wisdom and a sense of humour in your approach to life's challenges.

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I would like to recognize the Canadian Institutes of Health Research (CIHR) for funding the large research initiative from which my seniors' study evolved, and for the Master's award that supported my scholarly pursuits while I took leave from work.

## Table of Contents

<b>Chapter 1: Introduction.....</b>	<b>1</b>
Introduction.....	1
Context in Alberta.....	2
Purpose of study.....	4
Relevant literature and context for this study .....	7
Health information seeking behaviour.....	7
Risk communication .....	9
Role of mass media in risk communication and HISB.....	10
Seniors' risk assessment capacity.....	11
Seniors' HISB preferences and habits.....	12
Summary.....	13
Bibliography.....	15
<b>Chapter 2: Methods.....</b>	<b>23</b>
Methods.....	23
Sample .....	25
Maintaining rigour during design, recruitment, data collection and analysis.....	29
Ethics statement.....	32
Limitations .....	33
Personal reflection.....	36
Bibliography.....	38
<b>Chapter 3: Has the changing media environment created information vulnerability in seniors? Findings from the H1N1 influenza pandemic.....</b>	<b>40</b>
Introduction.....	40
Background literature and conceptual framework .....	42
The Internet's influence on mass media .....	42
Computer and Internet usage among seniors.....	43
Media preferences for health information seeking .....	44
The literacy and digital divides .....	45
Age-related cognitive decline .....	47
H1N1 influenza pandemic as the context.....	48

Pandemic situation in Alberta, Canada .....	48
Methods.....	50
Results .....	52
Sensationalism in media coverage .....	52
Use of computers and the Internet for HISB.....	53
Media preferences.....	53
Computer confidence and competence .....	54
Cognition and the ability to process complex or changing information .....	57
Discussion .....	58
Conclusions and implications .....	62
Limitations .....	64
Bibliography.....	65

**Chapter 4: H1N1 risk assessment, decision processes and vaccine uptake:**

**How seniors responded to a changing media environment ..... 75**

Introduction.....	75
Background.....	78
Theories of risk perception and health behaviours.....	78
Role of analysis and affect in risk assessment.....	79
Importance of experience and familiarity on affect.....	81
Summary and study aims .....	82
Study setting.....	83
Methods.....	85
Analysis .....	86
Results .....	87
Sources and assessment of influenza information.....	87
Vaccination decisions .....	90
Positive influences on seasonal vaccination uptake.....	91
Negative influences on seasonal vaccination uptake.....	92
Affective media messaging and participant responses.....	93
Decision factors related to H1N1 vaccination .....	94
Factors influencing a change in habitual vaccination pattern.....	96
Discussion .....	97

Role of media in risk assessment and decision-making .....	97
Role of affect in risk assessment and decision-making .....	100
Familiarity and experience with respect to influenza and vaccines .....	101
Personal, interpersonal and social determinants of vaccination behaviour .....	102
Physicians and family: analytic or affective influence? .....	103
Conclusions and implications .....	105
Limitations .....	107
Bibliography .....	108
<b>Chapter 5: General discussion and conclusions .....</b>	<b>116</b>
Study implications .....	119
Recommendations.....	122
Bibliography .....	125
<b>Appendices.....</b>	<b>126</b>
Appendix 1: <i>Vulnerable Populations</i> study overview .....	126
References .....	128
Appendix 2: Newspaper recruitment advertisement.....	129
Appendix 3: Recruitment poster .....	130
Appendix 4: Recruitment pre-screening script.....	131
Appendix 5: Participant demographic survey .....	136
Appendix 6: Focus group script .....	137
Appendix 7: Participant information and consent form.....	140
Appendix 8: Ethics approval .....	145

## List of Tables

Table 2-1: Participant residency by population.....	26
Table 2-2: Demographic characteristics of focus group participants.....	28
Table 4-1: Vaccination behaviour of focus group participants .....	90



## List of Figures

Figure 2-1: Alberta focus group locations .....	26
Figure 4-1: Alberta vaccine clinic timelines, 2009 .....	84

## Chapter 1: Introduction

### Introduction

In 2009 the H1N1 influenza virus spread rapidly from its index case in Mexico in April, 2009 to more than 100 countries within 10 weeks (World Health Organization [WHO] 2009a). In June 2009 the World Health Organization (WHO) upgraded the pandemic from phase 5 to 6 (WHO 2009b) when it deemed the spread of the virus “unstoppable” (Chan 2009); within the year more than 18,000 lives had been lost across 214 affected countries (WHO 2010).

Due to their urgency, unpredictability and alarming nature, pandemics pose difficult challenges for public health officials (WHO 2005), not the least of which is “immediate, intense and sustained demand for information from the public, healthcare providers, policy makers, and news media” (Reynolds 2007, p. 5). The H1N1 pandemic was no different, with the WHO Director General concluding, “One of our greatest challenges ... is helping people to understand when they do not need to worry, and when they do need to seek urgent care . . . . Between the extremes of panic and complacency lies the solid ground of vigilance” (Chan 2009, para. 33).

Officials were required to strike a balance between informing the public early to promote adoption of preventive behaviours versus delaying the release of information pending certainty about the threat. With no vaccine available for the first six months of the H1N1 outbreak, there was considerable public fear as the virus caused significant morbidity and mortality in populations not normally considered at high risk for influenza complications, including healthy children and younger adults (WHO 2009b).

As had been predicted years earlier, relying on mass media in the new online era to deliver and interpret scientific and health information would pose new challenges for officials: “An influenza pandemic of a highly pathogenic strain,

occurring now in an information age -- where instant horizontal communication takes place around the clock -- will severely tax the ability of response officials to provide accurate, timely, consistent and credible information” (Reynolds and Quinn 2008, p. 14S).

### ***Context in Alberta***

In Alberta, one of 13 provinces and territories in Canada, health officials tracked the arrival of H1N1 and interpreted information from global and national expert sources, such as the WHO, the United States Centers for Disease Control and Protection (CDC), and the Public Health Agency of Canada (PHAC). From the time the virus arrived in Alberta in April 2009, both traditional media (television, newspapers, radio) and online sources (websites, Internet-based news sources, social media) played a central role in all aspects of H1N1 risk communication including outbreak tracking, risk assessment and protective measures such as social distancing, hand hygiene and vaccination strategies (Spears 2009).

When a vaccine became publicly available in October 2009, all 3.58 million Albertan citizens aged six months and up were offered seasonal and H1N1 vaccination free of charge (Alberta Health Services [AHS] 2010). Mass media coverage was intense throughout the province during this time, due in part to the highly publicized H1N1-related death of a healthy Canadian teenager in Ontario (Health Quality Council of Alberta [HQCA] 2010, Reinhart 2009). Furthermore, Alberta’s provincial health care system was undergoing a major organizational restructuring at that time, leading to significant public and media criticism about the confused and disorganized rollout of public vaccine clinics (Alberta Health and Wellness [AHW] 2009, Alphonso *et al.* 2009, HQCA 2010).

Alberta citizens relied on mass media to report information about the evolving pandemic, the changing risk environment, available protective behaviours, and vaccination priorities and protocols. Therefore, the media likely played an important role in supporting the health information seeking activities

and protective behaviours of citizens. However, the intensity and continually changing nature of mass media information during this time also raised questions about the effectiveness of scientific and health communication between the public, health officials and scientific experts.

This thesis focuses on understanding the pandemic risk communication environment from the perspective of Alberta seniors (adults aged 65 and older). This population had personal experience with influenza (including pandemics) and was accustomed to being encouraged to accept influenza vaccines. However, while seniors were considered *sensitive* to seasonal influenza (i.e., an increased likelihood of becoming seriously ill or dying if infected) (Lemyre *et al.* 2009), they were considered *not susceptible* to H1N1 influenza due to probable prior exposure to strains circulating before 1957 (WHO 2009c).

Seniors were therefore expected to learn about this novel influenza risk and assess their individual (and seemingly contradictory) risk within a very complex and confusing mass media environment, characterized by rapidly changing information and the proliferation of online information through search engines (e.g., Google), websites, Internet radio and television, and interactive social media platforms such as Facebook and Twitter. These unique circumstances provided an opportunity to assess how Alberta seniors acquired risk information and made decisions about protective measures, including vaccine uptake, and whether the changing media environment influenced their health information seeking behaviours and actions.

It was especially important to understand how this population arrived at their vaccination decisions given that seniors were not considered a priority group for H1N1 vaccination (HQCA 2010) yet at 60%, the H1N1 immunization uptake rate among Alberta seniors was higher than the 41% rate for citizens overall aged 12 and up (Gilmour and Hofmann 2010). Alberta seniors also recorded the lowest five-year *seasonal* influenza immunization rate in 2009 at 56%, down from 68% in

2005 (AHS 2011), suggesting that even intense media coverage regarding influenza vaccination in 2009 did not halt the progressive, five-year decline in seasonal vaccine uptake among seniors in Alberta. This raises questions about whether this population may have had difficulty understanding their risks related to seasonal and H1N1 influenza and which protective measures to pursue. Developing a better understanding of seniors' vaccination decisions and practices during this atypical influenza season will assist public health agencies to improve risk communications for this population during future outbreaks.

### ***Purpose of study***

The purpose of this study is twofold:

1. To explore the information-seeking behaviours and experiences of seniors during the H1N1 pandemic, with a particular focus on the sources of information that influenced their decisions regarding H1N1 vaccination.
2. To examine seniors' assessment and use of traditional media and online sources of information, as well as the role of these sources in this population's understanding and uptake of H1N1 protective behaviours.

The opportunity to pursue this study evolved from a larger research project, *H1N1 Knowledge Translation<sup>1</sup> for Pregnant Women and Seniors: Sources, Content, Understanding and Uptake* (also referred to as *Vulnerable Populations Study*) (Appendix 1), which was funded by the Canadian Institutes of Health Research

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<sup>1</sup> Although the larger research project included 'knowledge translation' in its title and intent, it is worth noting that this term commonly refers to the dissemination of scientific or medical knowledge from research/experts so as to improve uptake as well as health care delivery, outcomes and systems (Graham 2007). 'Risk communication', on the other hand, can refer to "an interactive process of exchange of information among individuals, groups, and institutions (that) raises the level of understanding of relevant issues or actions for those involved and satisfies them that they are adequately informed within the limits of available knowledge" (US National Research Council 1989). While there is overlap between knowledge translation and risk communication, there are also important conceptual differences. This thesis and its study of seniors focuses primarily on risk communication and not on knowledge translation.

(CIHR) through the Institute for Population and Public Health, and was led by principal investigators Cynthia (Cindy) Jardine, Tania Bubela and Lisa Given. The multi-method *Vulnerable Populations* study involved several distinct research initiatives; I assumed responsibility for one component, the seniors' focus group study, from which this thesis evolved. My responsibilities included:

- Conducting all literature searches related to seniors
- Developing participant recruitment criteria and publicity materials
- Developing the initial seniors' focus group script
- Recruitment of focus group participants
- Facilitating eight focus groups sessions with seniors
- Collaborating with three co-researchers to develop the initial common (pregnant women/seniors) codebook
- Coding all seniors' transcript data
- Adapting the seniors' coding frame during coding and thematic analysis
- Analyzing and interpreting all seniors' data including administrative (recruitment) records
- Developing concepts and theories
- Authoring all chapters in this thesis.

This paper-based thesis includes two distinct manuscripts that will form the basis of articles to be submitted to peer-reviewed journals in health risk communication. Readers will note some minor areas of duplication between the two manuscripts (chapters) in this thesis, which is necessary to ensure each paper has sufficient context to stand alone as a published manuscript.

The first manuscript, which develops the novel concept of *information vulnerability*, is presented in Chapter 3, *Has the Changing Media Environment Created Information Vulnerability in Seniors? Findings from the H1N1 Influenza*

*Pandemic*. This concept draws upon the literature across the social sciences, library and information studies, information communications technology, media studies and geriatric psychology domains. Specifically, information vulnerability posits that seniors are less able than other adults to find, access, retrieve, interpret, verify, trust or use mass media health information that is appropriately targeted to their level of comprehension.

Chapter 3 discusses *information vulnerability* as a multifactorial phenomenon emanating from: sensationalism and reduced information quality in traditional media such as newspapers, television and radio (Krimsky 2007; Leask *et al.* 2010); seniors' low confidence and self-efficacy with Internet-based new media technologies (Veenhof and Timusk 2009); the double digital divide (Neter and Brainin 2012); and a reduced ability to use information-based strategies to make decisions due to age-related cognitive decline (Echt and Burrridge 2011, Labouvie-Vief 2003).

Chapter 4, *H1N1 Risk Assessment and Vaccine Uptake: How Seniors Responded to a Changing Media Environment*, presents findings on seniors' decision-making processes regarding both seasonal and H1N1 vaccination in 2009. Using a context of health behaviour theories and risk communication (Brewer *et al.* 2007), this paper argues that the mass media environment during the pandemic further eroded seniors' already reduced capacity for analytic or cognitive processing, leading this population to defer instead to affective processing to guide vaccination decisions (Loewenstein *et al.* 2001, Slovic *et al.* 2004). Certain affective messages (e.g., experiential knowledge about influenza) were highly influential on decision-making whereas other affective messages (e.g., fear-based media coverage) produced a negative response, leading to the conclusion that while seniors generally gave preferential weight to affective over analytic information, not all affective information or sources were positively influential on decision-making.

## **Relevant literature and context for this study**

This thesis on pandemic risk communication with seniors is rooted in five distinct intellectual domains: (1) general health-information-seeking behaviours (HISB); (2) risk communication; (3) role of mass media in risk communication and HISB; (4) seniors' risk assessment capacity; and (5) seniors' HISB patterns and preferences.

### ***Health information seeking behaviour***

Information acquisition refers to *active* behaviours (intentional or purposeful seeking of information) as well as *passive* behaviours (unintentional or incidental encountering of information) (Case 2002, Savolainen 2008). Both active and passive information seeking tend to be habitual through the regular use of mass media sources (e.g., newspapers, television), networked sources (e.g., Internet) and human sources (e.g., family and friends) for daily or orienting information needs as well as problem-specific information (Savolainen 2008).

Health information seeking behaviour (HISB) is the acquisition of information related to health, health promotion activities, risks to health, or illness, although there is inconsistent use of the terms *intentions*, *strategies*, *actions* and *behaviours* to describe and define HISB (Case 2002; Savolainen 2008). Most HISB definitions and constructs reference the type and amount of information individuals seek within a health- or medical-related context, the method of seeking information, and the specific behaviours or actions associated with information-seeking (Lambert and Loiselle 2007).

While sources such as health professionals, friends, family, newspapers and television have been a mainstay of HISB, the Internet has dramatically changed individual patterns of HISB in recent years (Weaver *et al.* 2009), generating much interest in whether there has been a repositioning of preferred sources or habits among certain groups. As well, the interplay between individual-level HISB and societal-level risk communication (see next section) is important



during public health risk events such as the H1N1 pandemic, particularly as officials strive to disseminate timely, accurate information to the public. Vaccination, for example, was one of the protective measures available during the H1N1 pandemic, and information about the vaccine (availability, effectiveness, safety, priority groups, protocols) was relayed to the public through mass media within a risk communication context. However, vaccine uptake is well-documented in the literature as having a strong HISB underpinning (Marton and Choo 2012) within the context of health behaviour and risk perception (Brewer *et al.* 2007), and it is unclear how the respective tenets of risk communication and HISB may have interacted to influence public uptake of vaccine during the pandemic.

Historically, physicians and family members have been particularly influential on the health behaviours of older adults, including vaccine uptake (Crawford *et al.* 2011, Holm *et al.* 2007, Kwong *et al.* 2010). However, given the high-risk environment of the H1N1 pandemic, less is known about other potential influences on seniors' uptake of H1N1 vaccine. Of particular interest is whether online information sources may have altered the historical HISB preferences and vaccination decision-making processes of seniors aged 65 and older, as may have been the case for younger adults who increasingly prefer online sources over physicians and family members for HISB (Taha, Sharit, and Czaja 2009, Tian and Robinson 2008).

This thesis discusses whether the principles or activities associated with HISB have changed due to the emergence of online media/information sources, and whether seniors experienced any particular information needs or challenges during the H1N1 pandemic that may have influenced their information acquisition and health protective behaviours. The study places online HISB in the context of general vaccination decision-making processes for seniors related to both seasonal and pandemic influenza.

### ***Risk communication***

Risk communication is distinct from health information seeking behaviour (HISB) in that the former may be precipitated by a crisis or risk event, necessitating rapid access to information (Reynolds 2007), whereas the latter may span everything from passive acquisition of information and general orienting information through to crisis-related information seeking (Savolainen 2008). Furthermore, risk communication in public health outbreak situations often involves crafting and disseminating messages to promote public understanding of the risk and the adoption of certain behaviours, which necessitates regular dialogue between experts and the public to discuss their respective interpretation of the hazard and recommended actions (Reynolds and Seeger 2005).

Because risk communication is often triggered by a human health risk event, scientific and expert sources are often called upon to explain technical information so it can be interpreted and understood by the public (Leiss and Krewski 1989). The media is an important conduit for risk information due to its ability to quickly and effectively disseminate highly specialized or technical information to large audiences (Reynolds and Seeger 2005). However, if scientific or expert sources provide conflicting or contradictory information, it can be difficult for both the media and the public to determine the accuracy, reliability and credibility of information sources (WHO 2005), thereby affecting individuals' ability to take precautions or adopt protective behaviours. Ideally, credible sources should collaborate (Covello *et al.* 1988) to ensure consistent messages are developed at the federal, provincial and local level (Reynolds 2007). Otherwise, differing messages from expert sources may erode public trust (Sandman 2003), increase panic, and reduce compliance with public health measures such as vaccine prioritization (WHO 2007, Vaughan and Tinker 2009).

During the H1N1 pandemic, the Internet provided public access to diverse sources of information including official and unofficial, local and distant, expert

and lay, and mainstream and fringe sources (Bo karlsson 2010, Chew and Eysenbach 2010). My research assesses seniors' perspectives on H1N1 information in terms of clarity, accuracy, reliability and utility. It evaluates whether seniors interpreted messaging to be conflicting, contradictory or confusing, and how this may have affected their ability to assess personal risk and make appropriate decisions about protective measures, including vaccination. Finally, I discuss whether participants viewed H1N1 vaccination within an *immunization* frame (e.g., as a routine health behaviour) and/or within a *crisis/risk event* frame (e.g., as a novel risk necessitating a personal risk assessment).

### ***Role of mass media in risk communication and HISB***

The social amplification of risk framework suggests that the response to potential risks is socially constructed and is influenced by the type, volume and connotations of information (Hill 2001, Kasperson *et al.* 1988, McComas 2006). Furthermore, the mere existence of media coverage on an issue can amplify risk signals, even in the absence of media bias or misinformation (Hooker 2010). Once an issue has been amplified, it can be difficult to attenuate the perceived risk even when new knowledge is reassuring (WHO 2005, Hooker 2010).

The gatekeeper theory (Lewin 1947) suggests that media organizations choose which topics they consider to be newsworthy. Media framing theory (Nisbet 2010, Tversky and Kahneman 1981) posits that news organizations "frame" or portray issues in certain ways to promote public understanding, response or action. The initial framing of an issue is likely to influence the tone and messaging of most subsequent information (WHO 2005), and the first 10 days of the event are particularly critical in shaping future coverage (Driedger *et al.* 2009). This phenomenon can make it exceptionally difficult to change media messaging in situations where the initial framing is not entirely accurate or complete in its representation of the risk.

Electronic media have led to a new era of participatory journalism, resulting in “the news media losing control to some extent over what becomes published as news and the contexts in which the news is presented” (Bo Karlsson 2010, p. 212). This new paradigm complicates risk communication because the absence of gatekeeping and verification in online media, and the frequent crossover between traditional and online media, can perpetuate inaccuracies and sensationalism (Tsfati 2010, Leask *et al.* 2010). Furthermore, second-level agenda setting, which refers to the substantive and affective characteristics of the story that are communicated and reinforced through tone and accompanying visuals (Coleman *et al.* 2009), can have an important influence on audience interpretation and understanding.

Public health officials argue that while reaching multiple audience segments during a risk event is a laudable goal, in fact “the (single) most pivotal public is the media” (WHO 2005, p. 43) because media can positively or negatively influence the public’s ability to learn about emerging risks. In a positive light, media provides scientific experts with access to a public that is both entitled to and hungry for information about health risks; in a negative light, media can fuel public anxiety in a manner far out of proportion to the reality of the actual threat to health (WHO 2005). Mass media is often criticised for bias and omissions (Bubela *et al.* 2006, Leask *et al.* 2010) as well as inaccuracy and sensationalism (Leask *et al.* 2010) in the dissemination of scientific information.

This study provided an opportunity to evaluate how a group of Alberta seniors interpreted the framing of H1N1 information, and how their interpretation of media coverage influenced the decisions of a population that required a high level of information clarity and accuracy.

### ***Seniors’ risk assessment capacity***

According to WHO, outbreaks are inherently alarming to the public, especially to vulnerable populations who may “have a remote risk but think their

risk is high” (WHO 2005, p. 41). While HISB can help individuals cope with the uncertainty of risks such as H1N1, seniors have particular difficulties with conflicting expert and scientific messages due to declining cognitive skills, which cause seniors to process less information, make decisions more slowly, and demonstrate worse judgements than younger adults when complex or changing rules must be learned (Peters *et al.* 2007). Seniors also tend to use simpler strategies to construct judgments (Mutter and Williams 2004); use fewer pieces of information to make decisions (Johnson 1990); are more likely to be influenced by false information and make judgment errors based on irrelevant information (Chen 2002); and are less capable than younger adults of using an information-focused strategy to make decisions (Labouvie-Vief 2003).

In short, seniors may be disadvantaged in this information-abundant era and even more so during a crisis situation that is characterized by complex and rapidly changing information. My research, therefore, assessed whether the perceived volume, complexity or variability of scientific information during the H1N1 pandemic posed any challenges for seniors who relied upon this information for risk assessment and vaccination decisions.

### ***Seniors’ HISB preferences and habits***

While approximately 94% of Canadians under age 45 used the Internet in 2010, the percentage is nearly halved for seniors aged 65-74 at 51%, and nearly halved again (27%) for those aged 75 and up (Statistics Canada 2011). The digital revolution seems to have largely bypassed seniors, who continue to rely on traditional media (television, newspapers, radio) for a significant proportion of their news and information (Kaiser Family Foundation 2005, Veenhof and Timusk 2009, Wicks 2004).

Generally, seniors have limited access to or interest in online sources of information (Selwyn *et al.* 2003, Statistics Canada 2011, Veenhof and Timusk 2009) for a number of reasons. Many have not learned how to use computers or

believe they are too complicated to use (Kaiser Family Foundation 2005, Statistics Canada 2011, Taha *et al.* 2009). Others believe online information is too difficult to understand (Ybarra and Suman 2008) or too voluminous to be useful (Bawden and Robinson 2009, Eppler and Mengis 2004, Taha *et al.* 2009). Whereas younger information seekers generally prefer online sources for health information (Taha *et al.* 2009, Tian and Robinson 2008, Pew Research Center 2009), the elderly prefer medical and personal sources (Hesse *et al.* 2005, Ybarra and Suman 2008) particularly when it comes to vaccination information (Crawford *et al.* 2011, Holm *et al.* 2007, Kwong *et al.* 2010, Lu *et al.* 2009, Nichol *et al.* 1996).

My research identified dominant, underlying information-seeking preferences and habits among a group of seniors, and determined whether these patterns affected their ability to acquire and use information to guide H1N1 decision-making. It offers insights into seniors' use of online media for HISB and assesses whether their adoption of new technologies affected their access to health risk information.

## **Summary**

In summary, my research project, as a distinct study within the broader H1N1 *Vulnerable Populations* study, assessed how a group of seniors in Alberta, Canada used mass media, online and personal information sources to inform decision-making during the H1N1 pandemic; how the new media environment influenced their health information-seeking behaviours; and to what extent media may have influenced uptake of protective behaviours, including vaccination, in a population with a confusing risk profile during the H1N1 pandemic.

Chapter 2 describes the methods used for this study, followed by Chapter 3 which presents a novel concept conceived during my research, *information vulnerability among seniors*, as a consequence of the changing media environment. Chapter 4 explains how information vulnerability influenced vaccine

decision-making and uptake among seniors. The thesis concludes with a general discussion and recommendations in Chapter 5.

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## Chapter 2: Methods

### Methods

This study was designed to provide insights into the information-seeking experiences of adults aged 65 and older during the H1N1 pandemic and the extent to which those experiences influenced their decisions about protective behaviours, including vaccination. I therefore adopted a qualitative approach to comprehensively probe the beliefs, perceptions, experiences and expectations of seniors as they sought information about H1N1; this approach also allowed me to gain insights through data analysis and interpretation (Richards and Morse 2007).

I used an *interpretive description* approach, a relatively new hybrid approach that advances beyond merely studying a phenomenon by subsequently “putting it back into the context of the practice field” (Thorne 2008, p. 50), allowing researchers to deconstruct the vantage point of prior knowledge, generate new insights, shape new inquiries, and apply evidence to practice.

Interpretive description draws upon the respective strengths of ethnography (deriving meaning from human observation) (Creswell 1998, Thorne 2008); phenomenology (understanding truth through the human subjective experience) (Cohen 1987, Thorne 2008); and grounded theory (building theory through sociological inquiry) (Creswell *et al.* 2007, Strauss and Corbin 1998, Thorne 2008). This approach offered numerous advantages for this particular study:

- Given their historical familiarity with influenza and pandemics as well as their low adoption of online technologies compared to other population groups (Statistics Canada 2011), seniors could be considered a unique and distinct ethnographic group during the H1N1 pandemic. Drawing upon ethnographical approaches allowed for deeper study and probing of this population as participants



described, in an interactive group setting, how they came to make sense of the pandemic based on their historical roots and perspectives.

- The 'truth' that emerged for seniors during the H1N1 pandemic could only be understood by probing into their subjective experiences; therefore, a phenomenological approach was important to coalesce the experiences of individual participants into a 'universal truth' about how this group arrived at their HISB and vaccination decisions based on their interpretation of the risk.
- Grounded theory typically delves into the socially constructed and potentially sub-conscious forces that influence individual interpretation and actions, leading to the discovery of theory based on the analysis of data. Using elements of this approach allowed me to construct a theoretical explanation for seniors' HISB practices and outcomes by immersing myself in the data and integrating and synthesizing the findings.

Focus groups were the chosen data collection method because of their numerous advantages for this type of research problem. First, due to widespread public concern, discussion and publicity during the H1N1 pandemic, the issue became as much a *social* issue as a *personal* health threat. Individual risk assessment and uptake of protective behaviours was rooted in several domains, ranging from personal (health status) to interpersonal (protecting loved ones) to social (group norms and expectations). For this reason it was imperative to allow the discussion about H1N1 information-seeking and decision-making to occur within a setting where the group dynamic could add depth and richness, which can be readily achieved through focus groups (Thorne 2008).

Second, as mass media and online coverage of the pandemic traced the growing threat of H1N1 through to the end of the pandemic, over time Albertans were exposed to continually changing information about threat and efficacy. Focus groups enabled careful probing across the various time and threat periods of the pandemic: as the moderator I was able to encourage participants to recall and reconstruct the relevant pandemic time periods through shared memories and experiences.

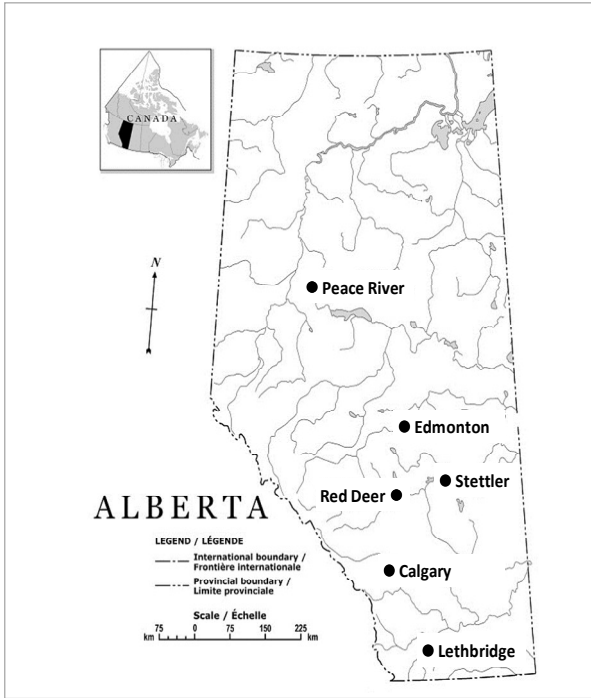
Finally, because this research was conducted one influenza season (2010-11) after the H1N1 pandemic (2009-10), it was important to use a method that allowed for continual prompting and reminders about the prior influenza season under study (2009-10). Due to the risk of participant difficulties in separating the two influenza seasons, focus groups were a preferred method because they allowed for continual probing in ways that would not have been possible through other methods such as surveys.

### **Sample**

I scheduled eight focus groups in six Alberta locations (Figure 2-1). A mix of urban and rural locations were selected to reflect the geographic distribution of seniors (higher density in central and southern parts of the province; more than 80% in urban locations) (Government of Alberta 2010) and to reflect the geographically distinct economic sectors within Alberta (e.g., energy, agricultural, technology, tourism).

In Alberta, to be designated a city or urban area, the population of the geographic area must be at least 10,000 residents (Alberta Municipal Affairs 2012). I opted to include Alberta's two largest urban centres (Edmonton and Calgary), each with a population greater than 750,000; two mid-sized urban centres (Red Deer and Lethbridge), each with a population greater than 75,000; and two rural centres (Peace River in the North and Stettler in Central Alberta), each with a population of less than 7,500 (Table 2-1).

**Figure 2-1: Alberta focus group locations**



Adapted from (Natural Resources Canada 2002).

**Table 2-1: Participant residency by population**

	Population (2009)	No. of participants
Peace River	6,315	10
Edmonton	782,439	9
Stettler	5,843	9
Red Deer	89,891	10
Calgary	1,065,455	19
Lethbridge	85,492	8

Source: Alberta Municipal Affairs 2009

While I initially recruited participants using snowball and volunteer sampling methods (Appendices 2 and 3), these methods proved difficult to manage across multiple locations, leading to persistently small samples. To ensure adequate sample sizes, I contracted with a professional market research firm with a large and diverse database of subjects to recruit study participants through telephone and email. The recruiter used pre-screening questions (Appendix 4) to ensure an appropriate mix of participants including a range of ages, male/female, income, education, marital status and H1N1 vaccination status (accepted/declined). As shown in Table 2-2, the sample is a reasonable reflection of Alberta seniors except for the higher educational attainment of the study sample. The oldest segment of seniors (85+) is slightly under-represented in this study, potentially due to the barriers this segment must overcome if they wish to attend a focus group session (mobility, transportation, energy). As well, rural residents are slightly over-sampled in our study to ensure saturation (see discussion later in this chapter). Finally, family income could not be directly compared between this study and provincial data due to differences in data capture and reporting.

It is important to note that ethnically diverse seniors may not be adequately reflected in this study because potential subjects who demonstrated reduced language or comprehension skills during telephone pre-screening may have been denied an opportunity to participate based on their presumed inability to contribute meaningfully to an English-language focus group discussion. This study did not have access to translation services and therefore I was only able to accommodate participants with proficiency in English.

**Table 2-2: Demographic characteristics of focus group participants**

		Female	Male	Total	% of seniors in study	% of seniors in Alberta <sup>1</sup>
Place of residence	Urban (pop. ≥ 10,000)	23	23	46	71%	82%
	Rural (pop. < 10,000)	10	9	19	29%	18%
Age	65-74	21	18	39	60%	53%
	75-84	10	13	23	35%	33%
	85+	2	1	3	5%	13%
Education	High school or less	15	14	29	45%	61%
	Diploma/college/trade	10	9	19	29%	29%
	University	8	9	17	26%	10%
Family income	< \$25,000	7	5	12	Median <sup>2</sup> : \$25,000 - \$49,999	Mean: \$68,500
	\$25,000 - \$49,999	17	9	26		
	\$50,000 - \$74,999	3	9	12		
	\$75,000 - \$99,999	3	4	7		
	\$100,000 +	1	2	3		
	Not stated	2	3	5		
Marital Status	Married/Common law	15	25	40	62%	57%
	Divorced/Separated	6	2	8	12%	10%
	Widowed	10	3	13	20%	28%
	Single	1	2	3	5%	5%
	Not stated	1	0	1	2%	N/A
H1N1 vaccine status	Accepted	24	17	41		
	Declined	9	15	24		
<b>Total</b>		<b>33</b>	<b>32</b>	<b>65</b>		

<sup>1</sup> Source: Government of Alberta 2010

<sup>2</sup> Participant recruitment data captured broad incomes ranges only; therefore a mean value could not be calculated.

The recruiter recorded responses to pre-screening questions and provided these to the researchers to ensure recruitment criteria were met. In addition, participants completed a written questionnaire at the start of each session (Appendix 5) to validate demographic information obtained during pre-screening and to provide additional information on individual and household vaccination behaviours in 2009.

I developed an initial script for the focus group sessions (Appendix 6) based on the research questions and prior literature review. Questions were structured to: allow full discussion and disclosure by participants; probe into specific pandemic time periods to elicit information about emotional and behavioural responses over time; and allow for common questioning across all sessions while permitting the discussion to expand or deepen according to the unique interests and experiences of each focus group. I offered participants a \$50 honorarium to cover transportation, parking, family caregiving fees and other costs of participation. Participants provided written, informed consent to participate in the research project and to permit audio-recording of the sessions (Appendix 7).

### **Maintaining rigour during design, recruitment, data collection and analysis**

This study maintained reliability by: using the same experienced facilitator (Lechelt) for all focus group sessions; ensuring the research manager and/or a principal investigator were present at all sessions; using both trained note-takers (observers) and mechanical (audio) recording at all sessions; using dual tape recorders to protect against mechanical failure; using a professional transcriber to transcribe all focus group sessions; and verifying data across multiple sources (e.g., participant demographic data and vaccination decisions) (Kidd and Parshall 2000). The transcriber, note taker and facilitator all signed a confidentiality agreement to commit to upholding the study's ethics requirements.

This study shared a common focus group script with the parallel *Vulnerable Populations* study involving pregnant women. Therefore, the two sets of transcripts were initially treated as a single data set, imported into NVivo™ qualitative analysis software, and coded using analytic and thematic coding (Richards and Morse 2007). To ensure consistency in interpretation between coders working on the parallel data sets (Thompson *et al.* 2002), the three coders working on the two data sets collaborated to develop a common codebook for both the seniors' and pregnant women data. The coders continued to meet throughout data analysis to review common and divergent codes, frames and themes across the two sets of data (Richards and Morse 2007), allowing for in-depth, iterative discussions about the coding frames of the respective studies and to ensure consistency of approach and interpretation.

During this iterative process it became apparent that pregnant women and seniors had markedly different experiences and interpretative frames during the H1N1 pandemic, and therefore the data from these two groups reflected important differences in what were initially believed to be common concepts and definitions such as “fear”, “preferred sources” and “experiential knowledge”.

Once several transcripts in each study had been coded, I and two coders from the pregnant women study jointly coded one complete seniors' transcript, representing 6% of the data set. To assess inter-rater reliability, which is the degree of consistency and agreement between two or more coders on a single data set or project (Thompson *et al.* 2004), I conducted a coding comparison query in NVivo™ to measure the percentage of agreement and the Kappa coefficient between each of the three pairs of coders. I imported these results into an Excel spreadsheet and calculated a weighted average for all nodes and sources for each coding pair, and then calculated the average across the coding pairs to produce a Cohen's Kappa coefficient score of 97.64, which is considered excellent agreement (Journal of the American Medical Association 2002).

These nuances gave rise to critical conversations and negotiation between coders, and later ensured my own open, axial and selective coding of the seniors' data set was iterative and rigorous.

Because I coded the entire set of transcripts within the seniors' data set, this ensured all transcripts were subject to the same interpretation. I updated the seniors' codebook throughout the coding process, and upon final completion of all coding, I reviewed and recoded all earlier transcripts to capture nodes, concepts and themes that had emerged only later in the coding process. This ensured there was consistency of coding and interpretation over the duration of the six-month coding process.

As an additional measure to ensure reliability, once all the seniors' transcripts were coded, additional data sources (i.e., recruitment records and participant demographic questionnaires) were analyzed and compared to focus group data to ensure data consistency with respect to participant attribute values such as age, sex, education, marital status and H1N1 vaccination decision.

Validity was maintained in this study because participant recruitment reflected a range of demographic indicators (age, income, education, sex, occupation, rural/urban location) as well as vaccination decisions (accepted/declined H1N1 vaccine), producing a sample that is reasonably reflective of seniors in Alberta. The use of a marketing research firm enabled purposive sampling: I selected individuals who belonged to desired demographic subgroups, were comfortable in a focus group setting, and were interested in the topic under discussion (Richards and Morse 2007).

The protracted scheduling of focus groups allowed for preliminary analysis of focus group notes as well as concurrent review of the literature. Both processes ensured full exploration of concepts as they emerged during data collection plus ongoing refinement of the focus group script. Once all focus groups were completed, official transcripts were analyzed in NVivo™ using a



constant comparative approach (Charmaz 2006) in which I compared the transcripts of earlier focus group sessions (these were moderated using a preliminary script) with those from subsequent sessions (moderated using a more refined script) to analyze for divergence and convergence of themes (Richards and Morse 2007). Saturation was deemed to have been reached when redundancy of information became apparent (Lincoln and Guba 1985 ), which is often achievable with 3 to 5 focus groups of 6 – 10 participants each (Morgan 1997) for a total of 18 to 50 participants. Although this study initially had 56 participants, questions about saturation led me to schedule an additional focus group session of 9 participants to ensure saturation of information from rural residents had been achieved.

Member checking is considered a hallmark of qualitative research quality (Cohen and Crabtree 2008). The ethics approval for this study (next section) precluded me from contacting participants following the study unless express consent had been obtained. However, during focus group sessions, participants were invited to voluntarily provide their contact information if they wished to receive a summary of study results; 45 of 65 participants (69%) provided this information. These subjects will receive summary results and, at the same time, be invited to offer additional comments or feedback as a means of informal member checking. This participant information can then be incorporated into the peer-reviewed manuscripts produced from this research.

### **Ethics statement**

Ethics approval for the focus groups was received from the Education, Extension, Augustana and Campus Saint-Jean Research Ethics Board (EEASJ REB) at the University of Alberta (Appendix 8). Conditions required to satisfy the ethics board included:

- Use of intermediaries (professional market research firm, seniors' community associations, etc.) to communicate with potential subjects during recruitment (Appendix 4)
- Thorough briefing of all subjects (written and oral) regarding the study goals, outcomes and risks (Appendix 7)
- Obtaining signed, written consent from all participants for both participation and audio-recording of the sessions (Appendix 7)
- Discussion among focus group participants regarding the expectation of confidentiality between participants
- Offer of an honorarium to cover the costs associated with participation, such as transportation, parking and caregiving fees.
- Commitment by researchers to protect confidentiality and anonymity of participants by removing all identifying information from published documents; ensuring all individuals involved in the research (transcribers, facilitator, etc.) were familiar with the University of Alberta ethics requirements and had signed a written confidentiality agreement; and maintaining all study records in a secure, locked filing cabinet or on a password-protected computer.
- A provision for study subjects to withdraw from the study at or prior to the conclusion of the focus group session.

### **Limitations**

This study has several limitations that should be considered.

1. While the results of this qualitative study accurately reflect the views of participants, and may be transferable to seniors under similar circumstances and/or other vulnerable groups, the findings are not generalizable to other populations or geographic areas.

2. Using a marketing research firm for recruitment may have introduced self-selection bias into the study due to the characteristics of individuals who consented to remain on the database of the firm.
3. Ethnic origin and immigrant status were not used as criteria for sample selection and therefore it is unlikely that this study adequately reflects the ethnic composition of Alberta seniors. This bias may have been perpetrated by the need for participants who were comfortable conversing in English.
4. These focus groups were conducted during the *second* season (2010-11) of Alberta's H1N1 vaccination program, meaning that the accuracy or completeness of participant recall on some details from the vaccination season under study (the prior season in 2009-10) may be compromised.
5. The diminishing threat of H1N1 over time, whether due to the natural course of the pandemic or the impact of mass immunization programs, may have increased participants' perception that media publicity was excessive, sensationalized or unbalanced.
6. The province of Alberta was undergoing a major restructuring of its health care system at the time of the pandemic, resulting in confusing and ever-changing vaccination clinic protocols. This particularly information-poor information environment may have been atypical and might have had a particularly negative impact on seniors' experiences and memory.
7. The sequencing and locations of vaccine delivery may have influenced uptake among seniors: H1N1 vaccine was offered exclusively for the first two months of the public immunization program, and only in large, unfamiliar and mobility-unfriendly location; seasonal vaccine was offered much later.

8. This study relied exclusively on self-reported measures of Internet usage, confidence and success, which may differ from more objective measures of efficacy such as the Computer Self-Efficacy Scale (Barbeite & Weiss, 2004). It would be useful to validate and expand upon this study's findings through the use of standardized computer literacy measures.

### **Personal reflection**

I have a number of personal opinions and experiences that may have influenced my perceptions and interpretations during this study. As a communications professional, I have a strong understanding of the way mass media works and the challenges facing scientific experts and health officials in attempting to channel important public information through media sources. My experience may lead me to be particularly empathetic toward information sources (experts) who struggle to 'get it right' and also toward journalists who may be pressured by news outlets to hasten story delivery. I made every effort to approach this study with sensitivity, and perhaps heightened compassion, toward both sides of the information-exchange process.

While I believe vaccination is a personal choice, I am a habitual vaccinator who does not routinely question the safety or efficacy of vaccines or the intent of vaccine manufacturers. This likely led me to initiate this thesis on the assumption that vaccination is 'good for public health' and that the goal of promoting vaccine uptake is a worthwhile public health pursuit. To reduce the possibility of this belief introducing bias into the study, I took the following measures:

- Throughout literature searching I actively sought articles that reflected a range of findings related to prior vaccination beliefs and behaviours; this ensured I was cognizant of the many legitimate reasons that may lead individuals to not support vaccination.
- While facilitating focus groups I took extra care to ensure that my verbal and non-verbal (body) language did not appear to favour any particular beliefs toward vaccination. I

started each focus group session by saying that “No matter what your personal opinion, all of you are right.” During discussions I acknowledged the personal nature of decision-making, ensured participants with diverse viewpoints were given equal opportunity to speak during the sessions, and assured participants that they did not need to defend their positions to other group members.

- During data analysis I considered all attribute data (age, sex, education, etc.) as potential contributors to vaccination decisions, considering vaccination behaviour as just one such attribute. This ensured I was not actively seeking thematic differences related to pro- versus anti-vaccine beliefs.

Finally, my personal experiences with aging parents have shown, without doubt, the reality of cognitive decline and this population’s aversion to new technologies. It was not uncommon for me throughout this research to quietly question participants’ Internet capabilities, believing that this population has a propensity to over-report their skills and be unaware of their own limitations. While this phenomenon has been well documented in the literature, it is likely not the case for all seniors; therefore it could be interpreted as a source of bias while probing regarding Internet skills and self-efficacy. To prevent the possibility of bias, during focus group discussions I probed repeatedly to ensure I had not missed an opportunity to hear about any participants’ experiences with computer technology, and for those who offered their perspectives, I probed fully to ensure I had a complete description and understanding of their self-reported computer/Internet experiences.

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### **Chapter 3: Has the changing media environment created information vulnerability in seniors? Findings from the H1N1 influenza pandemic**

#### **Introduction**

A substantial body of literature on health information seeking behaviour (HISB) and information literacy suggests that numerous factors contribute to an individual's ability to access, interpret and use information to inform health decision-making and actions. The Internet has radically changed the face of HISB, leading to both positive and negative consequences for consumers seeking health information (Gonzalez-Herrero and Smith 2008).

In this paper I introduce a new HISB concept, *information vulnerability*, which arose through qualitative research conducted with a group of seniors from Alberta, Canada following the 2009 H1N1 pandemic. Information vulnerability, which emanates from today's rapidly changing mass media and online environment, is defined as the inability to find, access, retrieve, interpret, verify, trust or use health information that is appropriately targeted to an individual's level of comprehension. It may present in the form of *too little* relevant, reliable or appropriate information through preferred or habitual information channels, or *too much* information, overloading individuals' ability to interpret or navigate through the maze.

This paper begins with the context for information vulnerability, drawing upon the social sciences, library and information studies (LIS), information communications technology (ICT), media studies and geriatric psychology domains. It summarizes the literature from which information vulnerability has emerged, including: the Internet's influence on mass media; computer and Internet usage among seniors; media preferences for health information seeking; the literacy and digital divides; and age-related cognitive decline. This overview is followed by the results of a qualitative study of seniors (adults aged 65 and older)

which analyzes the experiences of this population in navigating the changing media environment during the H1N1 pandemic as it unfolded in Alberta, Canada.

It is through the lens of the pandemic, and the acquisition and use of various information sources by seniors, that the concept of information vulnerability was conceived. This study illustrates that while many audience segments have benefitted from the changing media environment, seniors are unlikely to embrace new information and technology sources due to media habituation and a lack of interest (Selwyn *et al.* 2003, Taha *et al.* 2009), low competency with online technologies (van Deursen *et al.* 2011), and barriers such as low literacy and cognitive decline (Echt and Burridge 2011). The discussion concludes with the implications of information vulnerability, particularly as seniors are at risk of being left behind in a high-technology, information-overload world due to their inability to fully understand or navigate today's changing media environment.

This analysis will be useful to health professionals and policymakers in understanding the extent to which the continually changing environment for both mass media and online technologies may be creating information vulnerability among seniors. It will also identify how to best meet the health information needs of seniors given the trend of diverting health information resources away from senior-friendly traditional media in favour of new media.

Throughout this paper, the term 'traditional media' refers to print newspapers, television and traditional analog/digital radio. 'New' or 'online' media refer to interactive or searchable forms of Internet-based media (websites, social media, email, Internet radio and television, podcasts) that are accessible through computers, mobile phones and other technology-based devices.

## **Background literature and conceptual framework**

### ***The Internet's influence on mass media***

The Internet has radically changed the broadcast news and media environment, placing mass publishing within the grasp of lay producers (Bokarsson 2010, Gonzalez-Herrero and Smith 2008). Exponential growth in online media has resulted in a significant diminishing of traditional media's role in gatekeeping (selecting which news stories are selected for broadcast or print) (Berkowitz 1990) and framing (the context in which stories are presented) (Bokarsson 2010, Gonzalez-Herrero and Smith 2008, Nisbet 2010, Tversky and Kahneman 1981). The digital age has been heralded as good news for consumers with the desire and the capacity to search online for relevant and timely information (Glik 2007, Hayes *et al.* 2007, Malone *et al.* 2005). To meet the growing thirst for information, government and health organizations routinely direct the public to online media for health consumer information (Marton and Choo 2012).

Meanwhile, traditional media have experienced an erosion of market share and profitability as audiences increasingly migrate to online information sources. Advertisers, in response, are diverting their expenditures to other advertising channels (Curran 2010, Downie and Schudson 2009, Pew Research Center's Project for Excellence in Journalism 2010). In this competitive and economically challenging traditional media environment, there has been a reduction in the investment of staff, time and resources for story research (Downie and Schudson 2009, Leask *et al.* 2010) and an increase in sensationalized, inaccurate, outdated, biased, non-credible, and erroneous information (Chou *et al.* 2009, Hayes *et al.* 2007, Krinsky 2007, Leask *et al.* 2010).

Not surprisingly, during the 2009 H1N1 pandemic, Canadians were attuned to these media changes, feeling the level of concern about H1N1 had been exaggerated in the media (EKOS 2009). In the US, a content analysis study of 200

newspaper articles concluded that most stories made reference to the threat of the H1N1 virus, sometimes overemphasizing and sensationalizing virus-related death (Goodall *et al.* 2012). Without doubt, as witnessed during the H1N1 pandemic, the media environment around the world has radically changed due to the influence of the Internet and online technologies.

### ***Computer and Internet usage among seniors***

Whereas computer adoption rates have reached 80 - 94% in most age categories (Statistics Canada 2011, Veenhof and Timusk 2009), usage patterns among seniors continue to deviate from those of other segments (Kaiser Family Foundation [Kaiser] 2005, Selwyn *et al.* 2003, Statistics Canada 2011, Veenhof and Timusk 2009). While 51% of Canadian seniors reported being online in 2010, which is up significantly from 29% in 2007, only 27% of the oldest seniors (aged 75 and older) were online in 2010 (21% in 2007) (Statistics Canada 2008, Statistics Canada 2011). Despite being the *fastest growing segment* of the computer user market, seniors continue to lag beyond all other age groups in the rate of Internet adoption (Veenhof and Timusk 2009), particularly those over age 75.

The reasons seniors have offered for seniors' low adoption of computer technology remained largely unchanged between 2005 and 2010, with more than 40% indicating they simply had not learned how to use computers and an additional one-third believing computers were too complicated (Kaiser 2005, Taha *et al.* 2009, US Department of Commerce 2011). Not unexpectedly, seniors were more likely to report using the Internet if they had learned how to use computers while still working (Eastman and Iyer 2005, Loges and Jung 2001, Taha *et al.* 2009).

Offline seniors do not believe they are missing anything by not being online and they are no less satisfied than online seniors (Kaiser 2005). This suggests that non-users may have little motivation to change or to start using computers if their information needs are being met (Kaiser 2005, Taha *et al.* 2009). Indeed, of the

73% of Canadians aged 75 and over who consider themselves non-computer-users, 95% expressed no intention of starting to use computers in the future (Veenhof and Timusk 2009).

### ***Media preferences for health information seeking***

Health-information-seeking behaviour (HISB) refers to the acquisition of information related to health, health promotion activities, risks to health, or illness (Lambert and Loiselle 2007). Information behaviours are largely habitual, and while new media may offer information channels previously unavailable to health consumers, the theory of media complementarity posits that new media channels augment rather than replace the established media habits of users (DiMaggio *et al.* 2001, Dutta-Bergman 2004, Malone *et al.* 2005, Tian and Robinson 2008). Thus it is not surprising that North American studies conclude that the elderly continue to rely on traditional media for news and information. In terms of media preferences, television and newspapers remain far ahead of the Internet, which typically occupies last or second-last place among this population (Kaiser 2005, Pew Research Center 2008, Veenhof and Timusk 2009, Wicks 2004). One study suggests that nostalgia proneness and risk aversion are important factors in low adoption of the Internet among seniors (Reisenwitz *et al.* 2007).

Socioeconomic factors are an historical and well-documented determinant of computer usage (Echt and Burridge 2011, Kalichman *et al.* 2006, Lambert and Loiselle 2007, Ramanadhan and Viswanath 2006, Weaver *et al.* 2009, Wei and Hindman 2011). 'No-Nets' (non-computer users) tend to be older, more economically disadvantaged, less educated, and have poorer health overall than 'Pro-Nets' (computer users) (Cresci *et al.* 2010). While No-Nets have the most to gain from using the Internet for health management purposes, this segment is the least likely to adopt computers (Cresci *et al.* 2010), suggesting that even if a decline in health prompts a need for new health management information, older

individuals who are not currently online are unlikely to start using the Internet to acquire such information.

### ***The literacy and digital divides***

Adults aged 65 and older have the lowest general literacy scores of all age groups (Statistics Canada *et al.* 1996), and there is an even larger literacy gap between the lowest and highest educated adults as they progress beyond age 65 (Brown *et al.* 2004, Rootman and Gordon-El-Bihbety 2008, Statistics Canada *et al.* 1996). Low-literacy is linked to poorer health status, higher mortality risk, and reduced ability to take medications appropriately and interpret labels and health messages (Baker *et al.* 2007, Bennett *et al.* 2009, Berkman *et al.* 2011, Sudore *et al.* 2006).

Literacy also exerts considerable influence on individual preferences and self-efficacy with certain media sources (Eriksson-Backa *et al.* 2012, Rootman and Gordon-El-Bihbety 2008, Sloat and Willms 2000). Compared to low-literacy adults, high-literacy consumers are more likely to read newspapers or magazines daily (Roberts and Fawcett 2007), have more detailed and sensitive recall of television news story facts (Grabe *et al.* 2000), and are up to 10 times more likely to use the Internet for health information (Echt and Burrige 2011).

The link between general and online literacy is so strong that the term *digital divide*, which was initially described as differential access to computer infrastructure (Asla *et al.* 2006, DiMaggio *et al.* 2001), has since grown to incorporate concepts such as the reading level of online information, the interpersonal and psychodynamic factors that contribute to low literacy and cognition, and the literacy skills required to function in a knowledge society (Berland *et al.* 2001, Benotsch *et al.* 2004, Birru *et al.* 2004, Fogel 2003, International ICT Literacy Panel 2002, Malone *et al.* 2005, Mossberger *et al.* 2003). It is now widely accepted that the digital divide has created a chasm between the information-rich and information-poor, leading to the “double” or

“second” digital divide (Chou *et al.* 2009, Kalichman *et al.* 2006, Neter and Brainin 2012, Vehovar *et al.* 2006, Wei and Hindman 2011).

Attention is now shifting away from the disparities between online versus offline consumers to the significant variation among online users in their ability to navigate and search effectively. The concepts of *information overload* (being overwhelmed with the volume of information) and *information anxiety* (a stress response related to access and comprehension) are well documented in the literature (Bawden and Robinson 2009, Eppler and Mengis 2004, Wurman 2001). Older Internet users in particular report that there is too much information and it is difficult to find the desired information or discern its trustworthiness (Kaiser 2005, Taha *et al.* 2009).

A number of studies over the past decade suggest that compared to higher-literacy adults, low-literacy online users do not use optimal search terms, are unable to interpret the information they find, and may be unaware of the magnitude of their difficulties (Aqili and Nasiri 2010, Benotsch *et al.* 2004, Birru *et al.* 2004, Echt and Burrige 2011, Kirsch *et al.* 2002, Neter and Brainin 2012, Robertson-Lang *et al.* 2011, Weaver *et al.* 2009). Even moderate- to high-literacy seniors may lack the requisite technical skills and self-efficacy in this new media environment (van Deursen *et al.* 2011).

In short, the digital divide is a more complex continuum than once thought, with socially disadvantaged No-Nets at one end (typically older seniors with lower education, income and health status). At the other end are seniors who do have access to computers but vary considerably in their level of technical or information literacy, rendering a majority unable to use the technology optimally.

### ***Age-related cognitive decline***

Cognitive decline affects seniors' ability to decipher conflicting expert and scientific messages due to difficulties processing complex information. Older adults process less information (Johnson 1990, Peters *et al.* 2007), use simpler strategies to construct judgments (Johnson 1990, Mata *et al.* 2011), and use fewer pieces of information to make decisions (Mata *et al.* 2011). They also make decisions more slowly (Johnson 1990, Mata *et al.* 2011, Peters *et al.* 2007), use simpler, less cognitively demanding strategies (Mata *et al.* 2011), are more likely to be influenced by inaccurate or irrelevant information (Chen 2002), and demonstrate worse judgements than younger adults when complex or changing rules must be learned (Peters *et al.* 2007). Finally, older adults are less capable than younger adults in using an information-focused strategy to make decisions (Mikels *et al.* 2010, Labouvie-Vief 2003), which may be a manifestation of poorer working memory, technological reasoning and cognition (Echt and Burridge 2011).

Seniors who are unable to process voluminous, conflicting or changing information may abandon their information search, end the search prematurely, or resort to information avoidance (Lambert and Loiselle 2007). Like many information seekers, seniors are also prone to 'satisfice': to conclude that they are *satisfied* that their information search effort will *suffice* (Simon 1955, Connaway *et al.* 2008). In other words, search success may be evaluated according to 'effort' rather than 'efficacy' based on a subjective determination of the point at which the individual has searched long enough or wide enough to make a better decision. Lengthy but fruitless searches for information may well be terminated based on a 'satisfice' determination.

Decisions about media choices may be based in part on a calculation of the required investment of mental and emotional energy, explaining why seniors often have a preference for less cognitively demanding emotional information (Peters *et al.* 2007). Seniors lacking the interest or energy to adopt new media



technologies due to perceived low relevance or minimal advantage (Selwyn *et al.* 2003) may continue to seek information from traditional and habitual sources even if the utility, accuracy or news value of those sources have declined in recent years.

Hence, there are a number of reasons to believe that seniors may be affected by *information vulnerability* in the changing media milieu. This new environment may be unfamiliar and confusing to the elderly due to: fewer controls on media reporting, verification and accuracy; an increase in sensationalized and inaccurate coverage; low uptake of and self-efficacy with computer and Internet technologies among seniors; comparatively lower general and information literacy among seniors; and a reduced ability to navigate a complex information environment due to age-related cognitive decline.

### **H1N1 influenza pandemic as the context**

The 2009 H1N1 influenza pandemic was a high profile public risk event characterized by intense media coverage, rapidly changing information, and concern and confusion as citizens around the globe attempted to learn more about the emerging threat and consider protective behaviours. The pandemic presented an ideal opportunity to assess the health information-seeking behaviours and challenges of citizens as they were exposed to more than six months of publicly disseminated information about risks and protective behaviours.

### ***Pandemic situation in Alberta, Canada***

The H1N1 pandemic claimed more than 18,000 lives across 214 countries worldwide (World Health Organization [WHO] 2010). Canada was one of the earlier nations affected as the virus spread rapidly to more than 100 countries in its first 10 weeks (WHO 2009a); by year-end H1N1 had claimed 428 lives in Canada (Gilmour and Hofmann 2010).

In Alberta, one of Canada's 13 provinces and territories, media coverage was intense during the six-month period (April – September) preceding vaccine availability (Health Quality Council of Alberta [HQCA] 2010, Reinhart 2009). The virus infected individuals not normally considered at-risk for seasonal influenza (Alberta Health and Wellness and Alberta Health Services 2010), including healthy children and younger adults (WHO 2009b). Even after the vaccine became available in October, public fear continued to escalate amidst media and public accusations that the province's health authority, Alberta Health Services, failed to adequately manage vaccination clinic rollout given unanticipated shortages of vaccine and unprecedented public demand (HQCA 2010).

Seniors heard complicated messages during this time about their seemingly 'dual-risk' status. On one hand, due to underlying health conditions and frailty, they were considered *sensitive* to seasonal influenza (i.e., an increased likelihood of becoming seriously ill or dying if infected) (Lemyre *et al.* 2009) and encouraged to accept the *seasonal* influenza vaccine. On the other hand, they were considered not susceptible to *H1N1* influenza due to probable prior exposure to strains circulating before 1957 (WHO 2009c).

This seemingly contradictory and confusing risk status presented considerable challenges for health officials as they communicated with seniors through various channels, including mass media, about their risk and priority status for influenza vaccine in 2009. With media coverage across Alberta focused on the threat of H1N1, the risk factors for various populations, and the disorganized vaccination clinic rollout, I recognized that the unique circumstances in this province presented an opportunity to study seniors' perspectives on H1N1. Specifically, I sought to better understand how seniors used available information to assess their risk and consider protective behaviours, focusing on the role and effectiveness of media in guiding this population's risk assessment and decision-

making during the pandemic. It was through this study that the new concept of *information vulnerability* was conceived.

## **Methods**

Following the H1N1 influenza pandemic in 2009, I undertook a qualitative study to explore the transmission of information from public health agencies to seniors (adults aged 65 and older) in one Canadian province, Alberta. I examined the influence of various information sources (health officials, mass media, personal sources, online information) on the knowledge, attitudes and adoption of protective behaviours, especially vaccination, among a group of 65 adults aged 65 to 88. All subjects participated in one of eight, 90- to 120-minute focus group sessions held in six Alberta towns and cities between October 2010 and April 2011 (Figure 2-1).

The sample was purposively selected to be equally split between males (n=32) and females (n=33) and included a range of ages (mean age = 73.4), education levels, family income, employment history and rural/urban locations, as well as a mix of self-reported seasonal and H1N1 influenza vaccination behaviours during the H1N1 pandemic period (Table 2-2). Recruitment methods included snowball sampling (producing 5% of the sample), print newspaper advertising (Appendix 2) and posters (Appendix 3) in public locations frequented by seniors (10% of sample), and recruitment by telephone and email from the large database of a professional marketing research firm (85% of sample). Ethics approval was received from the Education, Extension, Augustana and Campus Saint-Jean Research Ethics Board (EEASJ REB) at the University of Alberta (Appendix 8) and all subjects provided written consent to participate (Appendix 7).

An initial focus group script (Appendix 6) guided the moderated discussion. It explored participants' sources of mass media and personal information about the emerging H1N1 pandemic; their perceptions about personal risk; their

assessment of the available information in terms of accuracy, comprehensiveness and utility; their decision-making processes regarding vaccination behaviour; and their recommendations regarding future public health risk communication. All sessions were facilitated by the same experienced researcher and focus-group leader, tape-recorded, and transcribed by a professional transcriber. A research assistant also attended all sessions to record field notes and observations, which were included in the overall data set for analysis.

The protracted scheduling of focus group sessions (eight sessions over six months) allowed for concurrent analysis of detailed focus group notes using a constant comparative approach (Charmaz 2006). The emerging concepts related to information vulnerability were simultaneously explored through ongoing literature reviews. This process, analogous to convergent interviewing (Driedger *et al.* 2006) but applied to focus groups instead of individual interviews, allowed for expansion of the focus group script as well as validation and more intensive probing into the concept of information vulnerability in subsequent focus group sessions.

Once all sessions were completed, I imported the transcripts into the qualitative software analysis program, NVivo™, and analyzed the transcripts using analytic and thematic coding (Richards and Morse 2007), inductive reasoning (Thorne 2000) and a general inductive approach (Thomas 2006). I re-assessed and adjusted the emerging codebook midway through coding, and upon final completion of transcript coding, I reviewed and recoded all earlier transcripts to capture nodes, concepts and themes that had emerged only later in the coding process. Finally, I analyzed recruitment records and participant demographic questionnaires for further validation of emerging themes. Saturation was reached when informational redundancy was consistently achieved (Lincoln and Guba 1985).

## Results

Focus group results provided a rich set of data regarding seniors' use of media during the H1N1 pandemic, their mass media preferences for H1N1, their use of computer technology to augment mass media sources of information, and their self-efficacy and confidence with online sources. Major descriptive themes related to sensationalism, low online usage and confidence, a preference for traditional mass media, and difficulties processing complex and changing information are presented below, using representative verbatim comments to illustrate key findings. 'Urban' subjects are those residing in an Alberta city with a population greater than 10,000, whereas rural subjects are those residing in a community of less than 10,000 residents (Alberta Municipal Affairs 2012).

### ***Sensationalism in media coverage***

Focus group participants made numerous references to sensationalism or hype in traditional media reporting, often expressing a sense of disgust or disappointment in journalism.

*I find newspapers to be probably the worst mode of information of anything in the world because they have to sensationalize everything that happens no matter what it is. – Urban male, age 73*

*The newspapers have gone more from reporting to speculation. It's ... pushing a panic button ... it makes me just want to throw the paper away. – Urban male, age 71*

*I think they overdid it on ... talking about (H1N1) on TV and radio. It got disgusting after a while. – Urban male, age 67*

Many participants expressed a sense of loss or disappointment regarding changes in the mass media environment, with several believing profit motives and/or a lack of integrity were driving the changes.

*When it's all hyped to one side, then we get ...somewhat cynical ... So I hold the news, the media, responsible in a way that I don't know yet how to describe, but it seems to me they have a responsibility. – Urban male, age 66*

*This is what they're paid for – to come forward with something really dramatic and drastic and get the listeners. If they lose the listeners, they lose their jobs. – Urban female, age 75*

*If it makes a good story the media is going to be on it because they want to sell newspapers, of course, as well as provide a little factual information from time to time. - Urban male, age 80*

### **Use of computers and the Internet for HISB**

While some participants said that they do not use computers at all, a majority indicated they had used computers at some time in some capacity (e.g., “I keep in touch with my daughter by email”). When prompted specifically about online health information seeking, about one-quarter of participants indicated they had used or attempted to use the Internet to seek information about H1N1. Some indicated that although computers are available to them, they take considerable energy or motivation to use:

*(The Internet) is available but I didn't use it for this particular thing (for information seeking). I'm getting lots of information elsewhere. So it would be another time consuming thing to do this. So I didn't. – Urban female, age 77*

*I'm not a computer fan. I've got a computer but I just - I'm not one of those people. I like talking on the phone and stuff like that. – Rural female, age 68*

Non-computer users laughed when asked whether they looked for H1N1 information online.

*You're talking to some old guys here. – Rural male*

*How do you turn it on? [laughter] – Rural male, age 77*

### **Media preferences**

Participants reported a strong preference for traditional media sources, often due to established relationships with specific media.

*There are some credible people and I tend to look at some regular people who report regularly for CBC and I believe they have established their credibility. – Urban female, age 74*

Many indicated they had not, and likely would not, migrate to online media sources.

*You have to realize that not all of the population are going to be using computers day and night . . . people watch the night news or the morning news or whatever, and I think a lot of seniors do that. – Rural female, age 68*

*Well, mostly (I use) radio and TV because I am computer illiterate so I don't go there. – Urban female, age 75*

Even self-reported computer users cited a preference for traditional mass media for H1N1 information, suggesting that habituation was an important driver of HISB. Many computer-using seniors were comfortable ignoring online media, feeling they were not missing anything important.

*I never even thought of going into the Internet. – Urban female, age 72*

*I just don't use (the computer) for that (information seeking). It's more fun just to play a game on it. – Urban male, age 73*

*They run courses here but ... you can't be going on a course all the time to learn about the computer and I don't want to do it anymore. I just decided art was more important. – Urban female, age 67*

### **Computer confidence and competence**

Several focus group participants reported frustration with using computers and the Internet as a medium.

*I got started with (the computer), then I gave it up. I think a bug got into it or something. It didn't work. – Urban male, age 82*

*Well, we had a computer down in the basement, but ... anytime I tried to use it I kept getting into a box, I couldn't make it do what I wanted to, and waiting for someone to come and fix it, I just ... lost my patience with it. – Urban female, age 80*

Focus group participants who attempted to seek information online overwhelmingly reported difficulties interpreting and assessing the volume and credibility of the information.

*You're bombarded with all this information but you've got to pick and choose for yourself and come up with a plan and ... follow your plan. - Urban female, age 67*

*So ... you go out to the Net and you can find anybody ...you can find somebody who will say almost anything ... like each day it gets worse and worse and worse, okay? So you know they're lying ... - Urban male, age 67*

*... Everybody can put information on (the Internet); not only professional but everybody can ... and if you Google, for instance, swine flu, there'll be a hundred articles and you don't know which one you trust and how they are reliable; who put them on the website. You just don't. – Urban male, age 70*

When asked to describe their search techniques, search terms or websites visited, several participants appeared to be employing unsophisticated search strategies.

*You just go on and go to Google H1N1, yeah. And see what happens. – Urban female, age 70*

*Oh, I don't know. Just punch it (H1N1) in. Google will find it for you. – Rural male, age 72*

*I typed in (H1N1) and you click on it and then it comes and then you can go from here and there and there and there. – Rural male, age 73*

Some less-sophisticated Internet users identified tools and tips they used to help navigate through information more effectively.

*If you go on the website when these things happen ... on the website page you've got a big banner in there, "This is where you access," and you've got your information well-arranged so that even a person who's not an aficionado of a webpage thing and used to finding that little fine print where you click on ... you have it easily arranged so people can get it and you get text or you have your little YouTube*



*video or whatever they got, and you can listen to the actual source. – Rural male, age 65*

Some participants reported that their experiences navigating the Internet and retrieving information about H1N1 had been useful, worthwhile or successful in some way.

*Mostly I went on the Internet and I normally only view the ... websites from medical schools in the universities that I have the most respect for. – Urban, female, age 65*

*Of course you get a mixed bag. However ... you could tell which ones, like WebMD is reasonable stuff ... but there were other ones where the sky is falling ... the wilder ones were saying you shouldn't (get vaccinated) because you'll grow an extra foot or something. – Urban male, age 73*

Despite thorough probing at each focus group session regarding Internet usage and efficacy, only six of 65 participants volunteered information to suggest that their online searches were successful. While not a reliable measure of online success or self-efficacy, the limited number of participants contributing to this discussion suggests that online information-seeking was not productive for many participants. Three of the six participants who found the Internet useful for H1N1 information indicated they had used computers at work, while a fourth reported a lengthy history of computer and Internet experience:

*I was working for government services when the outbreak occurred and we started getting ... emails through work, and I bookmarked (various websites). – Urban male, age 65*

*I use the Internet for news and things like that ... and for a lot of research ... or related to engineering work. – Urban male, age 67*

*I'm on the Internet all the time. I've believed in computers since before they were invented. I have a smart phone so I can, you know. - Urban male, age 73*

Of the six participants who articulated confidence and success in their online experiences, five had either a bachelor or master's level university degree. Two of the four who reported marginal success with their information searches had attained university or college level education and the other two had completed high school. None of the other participants with high school education or less volunteered that their Internet searches were productive or satisfying, leading us to believe that higher education likely contributes to search proficiency.

In addition, participants focused on *self*-efficacy when speaking of their online experiences (i.e., the ability or inability to locate and interpret information). This was in contrast to their focus on the integrity or ethics of the *medium* when referencing traditional broadcast/print media. Participants seemed to feel that the burden of interpretation rested with the *individual* for online information but on the *news producer* for traditional media sources.

### ***Cognition and the ability to process complex or changing information***

Focus group participants reported difficulty in processing and interpreting the rapidly changing and conflicting information across all media sources during the H1N1 pandemic. Some lamented the lack of trusted gatekeepers to investigate and interpret information.

*Well, I think there was a lot of misinformation at first, or you couldn't understand what they were talking about it. The information has to be very direct so you can really understand what's happening. – Rural female, age 76*

*It's like ... this man interprets that this way and somebody else on the radio says, "Oh, this is what I thought they said," and you're left trying to sort it out so it's very confusing. – Urban female, age 71*

*Oh, you get too much conflicting information. And so who do you trust, and how do you make your decisions to what you're going to do. – Urban female, age 75*

Several participants resorted to 'blocking out' the information when it became too difficult to decipher confusing or conflicting information:

*I think sometimes when all this information gets to be maybe too much and you kind of just turn it off, you know. – Urban male, age 76*

*I said (to my daughter), "Go, go online. You've got to find out some information." She said, "Well, how much do you want? There's lots here." So she started reading a little bit that she thought I should know. I said, "Oh, forget it. That's okay, that's okay." – Rural female, age 68*

*I think sometimes when all this information gets to be too much and you kind of just turn it off. I know enough about it, so because sometimes they get on a bandwagon and it ... becomes too much and then you start blocking it instead of paying attention. – Urban male, age 76*

## **Discussion**

This qualitative study on seniors' information-seeking experiences during the 2009 H1N1 pandemic describes the challenges this population faced as they learned about the emerging threat through various information sources including mass media; sought information about their personal risk and available protective behaviours; assessed the value and utility of available information; and considered both traditional and new sources of information about H1N1. This has led me to develop a new concept, *information vulnerability*, as a consequence of major changes in the mass media environment over the past two decades, including: the Internet's influence on mass media; low computer and Internet usage among seniors; a preference for traditional media for health information seeking; the effects of the literacy and digital divides on seniors; and age-related cognitive decline.

Seniors in this study reported a strong preference for traditional mass media for both daily and problem-specific information-seeking, which is consistent with numerous studies suggesting that seniors are highly habitual in

preferring the media sources they have become accustomed to (Savolainen 2008, Selwyn *et al.* 2003). As also reported in the literature, newspapers and television were consistently identified as preferred sources of information among seniors (Veenhof and Timusk 2009) with radio also mentioned as an important source, particularly in rural areas where local television and newspaper are often unavailable or published too infrequently to be useful.

Despite their preference for traditional media, participants found most of these sources to be 'hyped' or 'sensationalized' and therefore of limited utility during the pandemic. Citing concerns about the lack of balance, trustworthiness and usefulness of traditional media, participants validated several findings from the literature, including a reduction in the level of accuracy, credibility and comprehensiveness of news produced by traditional media (Chou *et al.* 2009, Krinsky 2007, Leask *et al.* 2010); and a loss of gatekeeping safeguards to ensure consumers benefit from journalistic ethics and integrity (Bo Karlsson 2010, Aqili and Nasiri 2010). Many participants felt a sense of betrayal by their once-trusted media sources, laying blame on the journalism sector for the deterioration in quality.

Seniors who reported being non-computer users were unable to personally access online information sources to augment or verify information acquired through traditional media. Surprisingly, however, only a small minority of computer-literate participants attempted to access information online. Even some individuals who were highly dissatisfied with traditional media indicated they 'never even thought of going online' for information while others felt online searching would require too much time or effort. Although the literature suggests that non-computer users may have little motivation to use computers if their information needs are being met elsewhere (Kaiser 2005, Taha *et al.* 2009), this study suggests that even computer-using seniors whose information needs were

*not* being met through traditional media still had little interest in migrating to online sources.

It is apparent from this study that being a self-reported 'computer user' does not imply competence, comfort or habituation in using online technologies. Of note is the wide range of participant opinions regarding what it means to be a 'computer user', suggesting that more objective measures of efficacy such as the Computer Self-Efficacy Scale (Barbeite and Weiss 2004) might increase the understanding of seniors' actual computer competence. Contributing to this gap is the inconsistency in the literature regarding definitions of computer usage, with some studies considering a single episode of computer usage over a 12-month period to be sufficient to declare the subject a 'computer user' while other studies differentiate between daily, weekly or monthly usage (Kaiser 2005, Statistics Canada 2008). These discrepancies make it difficult to determine the proportion of seniors who are comfortable with the technology and have truly integrated online technologies into their health-information seeking practices.

Among the minority of study participants who did seek information online, most were discouraged by the large volume of material, a lack of consistency across information sources, their inability to assess the trustworthiness or credibility of sources, and low confidence in weighing and interpreting conflicting information. These findings are consistent with previous studies suggestive of low competency among seniors in using the Internet as a *medium* (technical and navigation skills) as well as optimally using Internet-based *content* (interpreting and using information for decision-making) (van Deursen *et al.* 2011).

While some seniors did report limited success in retrieving information online, their verbal search descriptions suggested that many participants may have used suboptimal search strategies and some might have lacked insight into their Internet-searching shortcomings. This validates findings from the literature which suggest that even seniors who report being 'online' may have limited

awareness of the information literacy skills required to navigate effectively (Echt and Burrige 2011, van Deursen *et al.* 2011).

This study also affirms the impact of the digital divide in rendering online information inaccessible or unusable for many seniors, although this research did not attempt to discern the root cause of seniors' online challenges such as inadequate technology skills, poor general or information literacy, cognitive decline, or other barriers. Regardless, the results are still suggestive of generally low online self-efficacy in this study cohort and a general tendency to avoid online technologies or to abandon Internet usage in favour of more familiar information sources.

A very small number of participants felt they succeeded in retrieving useful information online, were able to recall their information-seeking activities with reasonable accuracy, and articulated the health decisions they made through the information-seeking process. This small subgroup, however, included primarily university educated seniors which is not reflective of the typical Canadian senior with high school education or less (Industry Canada 2011). Given that the majority of our highly educated participants reported difficulties with Internet searches, it is very likely that a more typical sample of Canadian seniors might report even greater challenges with online technologies.

This study was not able to assess the role of age-related cognitive decline on seniors' information-seeking pursuits as it was impossible to determine which of many factors, such as habituation, education, information literacy, etc., may have contributed to this group's difficulties in managing and interpreting the complex, voluminous and rapidly changing information that was communicated via traditional media and online sources. Regardless of the cause, however, it was evident that most seniors in our study felt unable to cope with the confusing and contradictory nature of H1N1 pandemic information, with many admitting defeat by 'tuning off' and 'tuning out' media information.

## Conclusions and implications

In summary, seniors in our study generally shunned traditional media due to low trust and confidence in the level of accuracy and neutrality, and most opted to also forego online sources of information. The minority of participants who ventured online for clarification or validation of H1N1 risk information experienced information overload or anxiety due to the volume and complexity of online sources; felt that they failed in their attempts to find, interpret or trust health information that was appropriate to their level of comprehension; had difficulties assessing the accuracy or reliability of available information; and commonly abandoned their information-search efforts out of frustration or lack of success. As a result, participants were left with few viable information options; therefore it can be argued that these seniors indeed experienced *information vulnerability* as they rejected or dismissed traditional media sources while either shunning or experiencing low success with new, online sources of information.

Our study participants overall reflected a group that is more educated and literate than the typical Canadian over age 65. Yet in spite of their education, these seniors expressed a high level of discomfort with new media technologies and a high level of frustration with previously trusted traditional media, suggesting that even higher-literacy seniors are increasingly disadvantaged in the wired world as they reach a level of information inequality that was previously associated primarily with disadvantaged populations. The resulting media and information exclusion -- once limited to individuals in lower socioeconomic strata -- threatens to affect a majority of seniors regardless of education, income or health status.

This study has a number of public health implications. First, while this changing media environment may be beneficial to many consumers, it is unfamiliar and confusing to the elderly, many of whom learned and honed their information-seeking skills, behaviours and preferences during an era characterized by fewer media sources; a higher degree of gatekeeping and

control over what was published or broadcast; higher standards related to journalistic accuracy, verification and ethics; and a relatively high degree of consumer trust in mass media.

Contrary to earlier definitions of the digital divide, it is now clear that mere access to computers and the Internet are unlikely to narrow the existing knowledge gaps between online and offline seniors. Navigating today's media environment requires advanced literacy and cognition, and seniors who are already 'information-poor' in a traditional media environment are likely to become even 'poorer' in this new media environment because they lack the skills, cognition or motivation to adopt new technologies. Even the highly educated seniors in our study found themselves among the 'information poor', suggesting that *information vulnerability* among seniors may cross all educational and socioeconomic boundaries.

The phenomenon of age-related cognitive decline implies that adults with low computer or information literacy as they approach age 65 are unlikely to adopt or expand their use of online technologies as they continue to age. Even seniors with moderate to high computer and information literacy at age 65 may experience deterioration in their ability to navigate voluminous or conflicting online information as they age, which could reduce the utility of online information over time. As this study has demonstrated, even well educated, 'information-rich' seniors with advanced health-information-seeking behaviours are finding it difficult to navigate the new online environment.

In the new online world, information literacy has become the new currency of health knowledge and self-efficacy. Public health officials and the media may therefore have an important role to play in preventing the effects of information vulnerability among all audience segments, particularly seniors and other vulnerable populations. Officials should not rely exclusively on online media for dissemination of public health risk information because seniors, who are already



vulnerable due to declining health, reduced cognition, and habitual media preferences, will be further disadvantaged in this information-savvy world if they are expected to rely on new technologies or navigate traditional mass media without the benefits of gatekeepers, framers and trusted advocates.

### **Limitations**

While the results of this qualitative study accurately reflect the views of participants, and may be transferable to other seniors under similar circumstances, the findings are not necessarily generalizable to other populations or geographic areas. However, there is concordance in findings between this and other studies.

The risk of participant recall error exists given the 12- to 18-month gap between the pandemic period and the focus group sessions. The passage of time and the diminishing threat of H1N1 may also have had a moderating effect on the views of participants with respect to perceived risk, protective behaviours and responses to media information.

Finally, given the association between literacy, education and online efficacy, the relatively high education level of these study participants may not reflect the true extent of information vulnerability in a more typical group of Canadian seniors.

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## **Chapter 4: H1N1 risk assessment, decision processes and vaccine uptake: How seniors responded to a changing media environment**

### **Introduction**

Influenza is a significant cause of morbidity and mortality worldwide, particularly among seniors (adults aged 65 and older) and other high risk groups (World Health Organization [WHO] 2009a). Influenza vaccine reduces severe illness and complications in the elderly by up to 60% and deaths by 80% (WHO 2009a), prompting the World Health Organization (WHO) to set an international target of annually vaccinating 75% of all seniors against influenza by 2010 (WHO 2003). Few countries achieved this target, including Canada with only 59% coverage in 2010 despite free, universal vaccination programs (Statistics Canada 2012), raising the question of how to increase uptake of seasonal influenza vaccine among seniors.

The rapid spread of H1N1 influenza in 2009, and its declaration in June 2009 as a phase 6 pandemic (WHO 2009b), intensified concerns about public acceptance of influenza vaccine. Health agencies internationally anticipated that acceptance of a novel influenza vaccine amidst the uncertainty and confusion of pandemic conditions could pose considerable public health and communication challenges (Reynolds 2007, WHO 2005). Numerous studies and publications attempted to predict public uptake of the novel H1N1 vaccine based on prior attitudes or behaviours with respect to influenza vaccination, perceived threat (susceptibility, severity), perceived vaccine efficacy or threat, and persuasiveness of information source (Henrich and Holmes 2009, Jones and Salathe 2009, Kaboli *et al.* 2010, Myers and Goodwin 2011).

Anticipating H1N1 vaccine uptake among seniors was particularly challenging because this population was in an unusual situation during the pandemic: while generally considered *at risk* or sensitive for serious complications

from seasonal influenza and therefore routinely advised to accept seasonal vaccination, seniors were considered *not susceptible* to H1N1 due to probable prior exposure to strains circulating before 1957 (WHO 2010). Seniors were therefore deemed *not* to be a priority group for H1N1 vaccination (HQCA 2010). Under what could be considered an especially confusing and contradictory risk status, public health agencies and researchers had difficulty predicting how seniors would approach H1N1 vaccination decision-making during the pandemic. Given the infrequency of pandemic influenza, would seniors consider H1N1 a novel risk, thereby worthy of a personal risk assessment? Or would they deem it a familiar risk (akin to seasonal influenza), meriting a decision based more on experience and past behaviour? Would seniors use the same or different information sources, information-seeking methods and decision-making processes for H1N1 as for seasonal influenza vaccines?

Based on prior risk communication research, if seniors perceived H1N1 to be a new or unfamiliar risk, or the vaccine to be novel, they could be expected to use a range of strategies to weigh the perceived risk or threat of disease (H1N1 influenza) against the perceived risks and benefits of vaccination, using various information-gathering approaches to guide decision-making (Roberto and Goodall 2009; Prati *et al.* 2012). As an important source of public health risk information, mass media would likely play a central role in their information-seeking processes (Henrich and Holmes 2009; Nougairède *et al.* 2010). By helping seniors to assess whether H1N1 was a known or unfamiliar risk, mass media would guide their personal risk assessment and ultimate vaccination decision.

However, media coverage of the H1N1 pandemic was described as being sensationalized (EKOS 2009; Goodall *et al.* 2012) and disproportionately high compared to local disease prevalence (McDonnell *et al.* 2012), contributing to heightened public fear, uncertainty and confusion (Goodall *et al.* 2012, McDonnell *et al.* 2012). Furthermore, seniors reported discomfort and low self-efficacy with

what they considered to be a new and unfamiliar media environment during the pandemic, and also with the volume and complexity of information (Lechelt *et al*, in preparation), potentially leading to a compromised ability to conduct a personal risk assessment about H1N1 and make informed decisions on vaccination and protective behaviours. Seniors were therefore confronted with dual challenges – a novel influenza strain under pandemic conditions and a novel online and interactive media environment.

Nonetheless, estimates of H1N1 vaccine uptake in Canada indicate that vaccination coverage for those aged 65 and older was the highest of all age groups at 60% compared to 41% for Canadians overall aged 12 and older (Gilmour and Hofmann 2010), even though seniors were not considered a high priority group for the vaccine. Somewhat counter-intuitively, these statistics point to confusion generated by public health agency communications during the H1N1 pandemic. While seniors indeed opted to present for H1N1 vaccination despite what they described as a difficult media and information environment, little is known about how individuals in this population arrived at their H1N1 vaccination decision and which factors or information sources were most influential in their decision-making.

To fill this knowledge gap, my qualitative study into the health-information-seeking behaviours (HISB) and pandemic vaccine uptake among seniors aged 65 and older in Alberta, Canada provides important insights into the decision-making processes of this population during the H1N1 pandemic. Seniors in Alberta were offered both H1N1 and seasonal influenza vaccines free of charge in 2009, but the vaccines were delivered in separate doses (only H1N1 early in the season; both H1N1 and seasonal later in the season, but as separate vaccines), predominantly in different physical venues, and initially during distinct time periods. Therefore, many Alberta seniors in 2009 were required to make decisions and take action on H1N1 influenza vaccination (a new risk necessitating

new actions) independently of their seasonal influenza behaviour (a familiar risk associated with historical behaviour). This provides the ideal backdrop against which to analyse the unique decision factors associated with pandemic influenza vaccination uptake by seniors.

Study findings will assist public health officials, governments, and health professionals to understand, first, how seniors reached decisions about both seasonal and H1N1 influenza vaccination in 2009 and, second, whether the new media environment affected the ability of seniors to conduct an adequate health risk assessment and reach a personal decision about H1N1 vaccination. The study illuminates which factors had a positive impact on pandemic vaccine uptake in this population, and perhaps more importantly, which elements caused seniors to change, either positively or negatively, established influenza vaccination patterns. These findings may guide strategies to increase uptake of, or reduce dropout rates for, seasonal influenza vaccine among seniors and assist in planning for future pandemics in which seniors may be considered a distinct population in terms of risk.

## **Background**

### ***Theories of risk perception and health behaviours***

Over the past three to four decades, a number of theories have been proposed to explain or predict general human behaviour and, more specifically, to understand health behaviours within the context of risk perception. In a meta-analysis of the associations between risk perceptions (i.e., beliefs about potential harm) and vaccination behavior, Brewer *et al.* (2007) cite, among other theories, the health belief model (Nexoe 1999, Rosenstock, 1974), the protection motivation theory (Rogers, 1975), the extended parallel process model (Witte, 1992), the theory of planned behaviour (Ajzen, 1985), and the subjective expected utility theory (Ronis 1992). The authors propose these health behaviour

theories as possible explanations for how individuals perceive risk as well as the factors that influence health intentions and behaviours.

Brewer *et al.* (2007) report that in spite of slightly different constructs and definitions, most of the risk perception theories centre around three core dimensions of risk: perceived likelihood (probability of being harmed by the hazard); perceived susceptibility (individual resistance or vulnerability to a hazard); and perceived severity (the extent of harm caused by a hazard). The meta-analysis provided strong evidence that all three dimensions are reliably associated with vaccination (Brewer *et al.* 2007).

These health behaviour theories are therefore an appropriate context for an analysis of seniors' vaccination decision processes during the H1N1 pandemic. Indeed, early in the pandemic, several studies referenced behavioural theories to anticipate H1N1 vaccination uptake among various populations (Henrich and Holmes 2009, Jones and Salathe 2009, Kaboli *et al.* 2010, LaVela *et al.* 2012, Seale *et al.* 2010, SteelFisher *et al.* 2010), with one Canadian systematic review concluding that infection risk perceptions (severity of health issue, risk of infection and risk of severe illness) and individual risk assessment of the vaccine (risk of harm) would be consistent predictors of intention to vaccinate (Ngyuen *et al.* 2011).

### ***Role of analysis and affect in risk assessment***

The health behaviour theories that emerged between 1975 and 1995 have benefitted tremendously from subsequent risk communication research, much of it based on the foundational work of dual-process theories of information processing (Cameron and Leventhal 2003, Sloman 1996). Dual-processing constructs assert that individuals rely on two distinct yet interdependent processes to guide risk assessment and decision-making: *analytic* (Slovic *et al.* 2004) or *cognitive* (Loewenstein *et al.* 2001) processes (herein termed *analysis*),



and *affective* processes (Slovic *et al.* 2004, Loewenstein *et al.* 2001) (herein termed *affect*).

*Analysis* uses information based on logic, reason and scientific expertise. During the H1N1 pandemic, information of this type would have included, in part, probabilities of infection or illness, the advice of medical professionals, and expert/official information conveyed through mass media and online sources. However, seniors reported distinct challenges related to analytical information processing during the pandemic, including: low trust in traditional media (newspaper, television, radio) which was an expected deliverer of analytic information; poor confidence and self-efficacy with online media; information overload; limited information from medical professionals; and an inability to navigate or comprehend the confusing, voluminous and rapidly changing information environment. These contributed to *information vulnerability*: the inability to find, access, retrieve, interpret, verify, trust or use mass media health information that was targeted to their level of comprehension (Lechelt *et al.* in preparation). This phenomenon raises a central question about information dissemination during the H1N1 pandemic: did information vulnerability undermine seniors' information-seeking and analytical processing capacity? Did this compromise their ability to conduct a personal risk assessment and, if so, did it affect vaccination decision-making?

The second process guiding personal risk assessment is *affect*. The affect heuristic (Finucane *et al.* 2000, Slovic *et al.* 2005) is a gut instinct, intuition or a "mental shortcut ... (of) the feelings that become salient in a judgment or decision-making process" (Slovic *et al.* 2005, p. S36). Although affect has inherent biases that can preclude individuals from fully benefitting from analytic information (Slovic *et al.* 2004), it remains a quick, easy and efficient way to orient and navigate in a complex and uncertain world, allowing individuals to make rapid, intuitive and instinctive decisions in dangerous situations (Slovic *et al.*

2005). Slovic asserts that both analytical and affective reasoning are instrumental and necessary to making informed risk decisions.

### ***Importance of experience and familiarity on affect***

Affect is largely rooted in the experiential system of everyday life (Slovic *et al.* 2005) and, during high risk events, may produce immediate feelings of dread or outrage (Peters and Slovic 1996). In less threatening situations, intuitive or experiential knowledge plays an important role in decision-making (Slovic *et al.* 2005, Slovic and Peters 2006, Weinstein 1989), particularly when individuals are faced with routine or predictable situations (Finucane 2008). Vivid or long-standing experience (Loewenstein 2001) can significantly increase individuals' reliance on experiential knowledge; as well, the positive feelings of familiarity can increase the appeal of affective information (Finucane 2008).

It should come as no surprise, then, that seniors have been shown to give preferential weight to emotional information (Finucane 2008, Mikels *et al.* 2010, Peters *et al.* 2007) for reasons that include years of lived experience, age-related cognitive decline, and a tendency toward conservation of mental and physical energy. As a result, seniors are more heavily influenced than other populations by the affect heuristic (Lockenhoff and Carstensen 2004) and may weight affective information favourably over analytic information.

Given their familiarity with influenza and vaccination, it is possible that seniors perceived H1N1 to be more aligned with the 'known' risk of seasonal influenza, leading to preferential weighting of experiential knowledge over analytic information about H1N1. Indeed, throughout the pandemic a number of studies predicted that uptake of H1N1 vaccine would be influenced by factors that also influence seasonal influenza vaccination uptake, including: positive beliefs toward and/or previous positive experience with influenza vaccination (Godin *et al.* 2010, Prati *et al.* 2012, Telford and Rogers 2003); perceived vaccine efficacy or benefits (Kwong *et al.* 2010, Nexoe *et al.* 1999, Wray *et al.* 2009);

perceived likelihood, susceptibility and/or severity of influenza (Brewer *et al.* 2007, Kwong *et al.* 2010, Prati *et al.* 2012, Telford and Rogers 2003, Zimmerman *et al.* 2003); and advice from physicians and other health professionals (Nexoe *et al.* 1999, Nougairede *et al.* 2010, Nowalk *et al.* 2004, Tabbarah *et al.* 2005, Zimmerman *et al.* 2003). Concerns about vaccine safety or negative attitudes toward vaccination (Tabbarah *et al.* 2005, Zimmerman *et al.* 2003) as well as perceived barriers to vaccination (Nexoe *et al.* 1999) were cited as deterrents to influenza vaccination.

Many of these influences on vaccine uptake are affective in nature. Past positive or negative experience with either influenza or vaccines relates to emotions, memory and familiarity. Perceived likelihood, susceptibility and severity of influenza, as well as vaccine efficacy, are conclusions drawn through lived experience. Advice from others may be emotionally salient due to trust-related factors. The weighting of these affective influences on seniors' decisions regarding H1N1 vaccination decision may be linked, at least in part, to whether seniors deemed H1N1 influenza to be either similar or dissimilar in risk profile to seasonal influenza.

### ***Summary and study aims***

In summary, a number of factors likely influenced the information-seeking, risk assessment and vaccine uptake decisions of seniors during the H1N1 pandemic. Some of these factors are predicted by established health behaviour theories and include perceived likelihood, susceptibility and severity of the health risk; seniors' experience and familiarity with seasonal influenza and vaccination; the dual yet complementary processes of analytic versus affective processing; the propensity of seniors to preferentially weight affective information; and the many affective responses seniors might have experienced during the pandemic, such as fear, dread, outrage and familiarity. The novel theory of information vulnerability

and the difficulties faced by seniors in accessing and interpreting information about H1N1 in a changing media environment add to this complex set of factors.

My study, conducted in 2010-11, addresses the knowledge, attitudes and behaviours of a group of seniors in Alberta, Canada during the H1N1 pandemic. It examines how seniors perceived, interpreted and used available information to inform their risk assessment and vaccination decisions, answering questions such as: Did the mass media environment affect seniors' ability to conduct a personal risk assessment regarding H1N1? Did seniors perceive H1N1 influenza to be similar to or different from seasonal influenza, and how did this influence vaccination decision-making? Did seniors perceive media information to be affective in nature or tone? Did seniors assess information using analytic or affective cognitive processes?

### **Study setting**

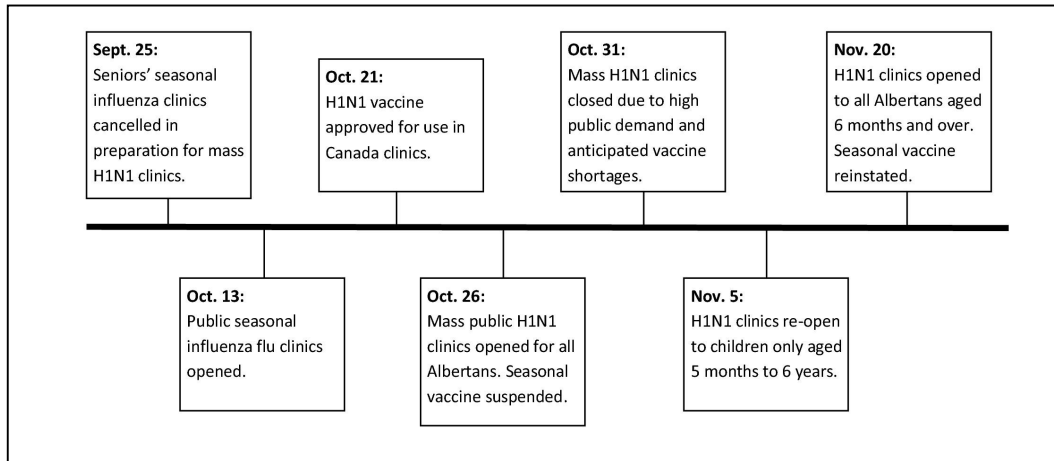
The Province of Alberta is situated in western Canada and had a population of 3.58 million in 2009 (Alberta Municipal Affairs 2009), comprising approximately 82% urban and 18% rural residents (Government of Alberta 2010). The first wave of the H1N1 influenza pandemic in Alberta occurred between April and July 2009 (HQCA 2010), which is the spring/summer off-season for influenza outbreaks throughout North America.

In October 2009, six months after the initial start of the outbreak, a vaccine for H1N1 was approved for use in Canada, and planned mass immunization clinics opened immediately across Alberta. During this time, prominent media coverage about the sudden H1N1-related death of a young, healthy Canadian teenager (Reinhart 2009) amplified public fear as well as demand for vaccination. Vaccination clinics in Alberta were immediately overwhelmed with a surge of Albertans presenting for vaccination, far exceeding projections as well as the available supply of vaccine (which was initially less than originally promised to the

province). The ensuing lineups were widely reported in both provincial and national media (Alphonso *et al.* 2009).

Exacerbating the situation was the simultaneous, ill-timed reorganization of Alberta’s nine regional health authorities into a single health system. The new health authority was responsible for amalgamating delivery of all publicly funded health services in the province but lacked a centralized emergency operations centre to manage pandemic logistics, leading to confusion regarding roles and decision-making authority during the crisis event (Alberta Health and Wellness 2009, HQCA 2010). Furthermore, to cope with the unanticipated public demand for a limited supply of vaccine, the processes governing Alberta’s H1N1 immunization clinics changed frequently (Figure 4-1).

**Figure 4-1: Alberta vaccine clinic timelines, 2009**



At 37% coverage, Alberta joined three other Canadian provinces (Ontario, British Columbia and Manitoba) in achieving overall H1N1 immunization rates below 40%, compared to the 69% coverage of the country’s best performer, Newfoundland and Labrador (Gilmour and Hofmann 2010). However, the age group with the highest rate of H1N1 immunization in Alberta was those aged 65 and older, even though this age group was not considered a priority group (HQCA 2010). Furthermore, the overall *seasonal* influenza immunization rate for seniors

continued its five-year downward trend, dropping to 56% in 2009-10 from 68% in 2005, well below the target rate of 75%, and returning to just 59% in 2010-11 (Alberta Health Services 2011).

This atypical and confusing influenza season in Alberta provided an opportunity to examine how and where seniors obtained information about H1N1 influenza; the effectiveness of risk communication to this population; their use of various media channels for health-information-seeking purposes; and the factors influencing their decision-making processes that year for both seasonal and H1N1 influenza.

## **Methods**

Following the H1N1 influenza pandemic in 2009, I undertook a qualitative study of seniors aged 65 and older, examining individual information-seeking behaviours and vaccination decisions as well as the influence of various information sources, including mass media and online information. Study subjects were 65 adults aged 65 to 88, all of whom participated in one of eight, 90- to 120-minute focus group sessions held in six Alberta towns and cities between October 2010 and April 2011 (Table 2-1; Figure 2-1). All sessions were facilitated by the same experienced researcher and focus-group leader (Lechelt), tape-recorded, and transcribed by a professional transcriber. A research assistant also attended all sessions to record field notes and observations, which were included in the overall data set for analysis.

The sample was purposively targeted to be equally split between males (n=32) and females (n=33) and included a range of ages (mean age = 73.4), education levels, family income, employment history and rural/urban locations, as well as a mix of self-reported H1N1 influenza vaccination behaviour during the pandemic period. Recruitment methods included snowball sampling (producing 5% of the sample), posters in public locations frequented by seniors (10% of the sample), and recruitment by telephone and email from the large database of a

professional market research firm (85% of the sample). Ethics approval (Appendix 8) was received from the Education, Extension, Augustana and Campus Saint-Jean Research Ethics Board (EEASJ REB) at the University of Alberta and all subjects provided written consent to participate.

The moderated discussion was guided by a focus group script. I designed it to explore participants' sources of mass media and personal information about the emerging H1N1 pandemic; their perceptions about personal risk; their assessment of the available information in terms of accuracy, comprehensiveness and utility; their decision-making processes regarding vaccination behaviour; and their recommendations regarding future public health risk communication. In moderating the focus groups, I probed for perceptions and actions during specific pandemic time periods: initial awareness of the emerging pandemic threat; local risk conditions and transmission of the virus during the pre-vaccine period; the mass vaccination clinic timeframe and peak of the pandemic; and the post-pandemic period.

The protracted scheduling of focus group sessions (eight sessions over six months) allowed for concurrent analysis of detailed focus group notes using a constant comparative approach (Charmaz 2006), which allowed for refinement of the focus group script throughout data collection as well as validation and more intensive probing into decision-making factors during subsequent focus group sessions. Saturation was deemed to have been reached when informational redundancy was consistently achieved (Lincoln and Guba 1985).

### **Analysis**

The focus group recordings were transcribed verbatim, and the information was organized for analysis using the qualitative software analysis program, NVivo™. Using inductive reasoning (Thorne 2000) and a general inductive approach (Thomas 2006), I coded the transcripts for thematic and theoretical

concepts. The emerging codebook was re-assessed and adjusted midway through coding, and upon final completion of transcript coding, all earlier transcripts were reviewed and recoded to capture nodes, concepts and themes that had emerged only later in the coding process.

Two data sources for the project (recruitment records and participant demographic questionnaires) were analyzed and combined with focus group transcript data to develop a discrete record for each participant regarding seasonal and H1N1 influenza vaccination behaviour in 2009 (received/declined). This data was used to determine patterns of habitual (historical) influenza vaccination behaviour by assigning descriptors of 'normally receive', 'normally decline', 'inconsistent' or 'unknown'.

Through the analysis of these data sets, the H1N1 vaccination behaviour in 2009 was discernible for all 65 participants and the seasonal vaccination behaviour for 64 of 65 participants (all single-year [2009] vaccination decisions). Habitual vaccination behaviour (e.g., typical actions over time) was established for 54 of 65 participants. This participant attribute data was used to augment other demographic information such as age, sex, education and income.

## **Results**

Major results are presented below, using representative verbatim comments to illustrate key findings. 'Urban' subjects are those residing in an Alberta city with a population greater than 10,000, whereas rural subjects are those residing in a community with less than 10,000 residents (Alberta Municipal Affairs 2012).

### ***Sources and assessment of influenza information***

Participants reported receiving a large proportion of their information through traditional mass media, relying most heavily on television, newspapers and radio.



*I listened to the TV and the radio and the newspaper. - Urban male, age 65*

Online media, such as websites, social media and Internet television/radio, were not a preferred or accessible source of information for most participants.

*Well, mostly (I use) radio and TV because I am computer illiterate so I don't go there. – Urban female, age 75*

Participants perceived a large gap between the H1N1 health risk information they needed and what was actually delivered through expert and mass media sources. Seniors highlighted the intensity of media coverage during the pandemic and the difficulties they faced coping with the volume, complexity and inconsistency of information.

*Well, I think there was a lot of misinformation at first, or you couldn't understand what they were talking about it. – Rural female, age 76*

*You get too much conflicting information. And so who do you trust, and how do you make your decisions as to what you're going to do? Where does it lead to? – Urban female, age 80.*

*There's so many opinions, so many different research, and sometimes you don't know what is the truth, what is the real information, what is not. – Urban male, age 70*

Participants for the most part described mass media coverage as being hyped, sensationalized and contributing to public fear.

*It was all over the radio and TV and to me it was a scare tactic. Like you've got to get this flu (vaccine) or you're going to surely die. – Urban female, age 75*

*Fear, fear, nothing but fear during this. – Urban male, age 76*

*I think they overdid it on the - talking about it on TV and radio. It got disgusting after a while. – Rural male, age 77*

Several participants laid blame on mass media for inaccurate, irresponsible or sensationalized reporting.

*I'm not very happy about the way the news media handled H1N1 because I figured they deliberately panicked the people. – Urban female, age 76*

*And (if you're a reporter) you don't have to be an expert. You don't have to go out and do any reportage. You don't have to be going out interviewing people, nothing. You can just sit back (and) come out with anything – Rural male, age 65*

Many turned to health professionals or family members for clarification and direction, with or without success.

*I trust people like doctors, nurses, people who've had experiences. – Rural female, age 77*

*Some reports were scary, and I thought well, what should I be doing? So we talked to some health people, but it's really hard to understand because some doctors said yes and some said no. – Rural female, age 68*

Others resorted to tuning out or ignoring the media.

*I found it was changing constantly. So I actually dismissed most of that and said let's see what's going to happen. – Urban male, age 69*

*It got overbearing after a while ... and you block it out. – Urban female, age 70*

Many seniors felt information about risk groups was initially confusing or conflicting.

*It was confusing that these people could get it but these people couldn't, and so people went and lined up and then some were told to go away. It was very upsetting seeing it on the news or reading it. – Urban female, age 71*

Rural participants faced a particular challenge in obtaining locally relevant information.

*It has to be local information so that we know HERE what's going to happen. The media thing is the local radio ... or the local coffee shop. – Rural male, age 78*

### ***Vaccination decisions***

Anecdotally, many seniors in this study reported congruence between their seasonal and H1N1 vaccination decisions in 2009, with most indicating they received *both* vaccines or *neither* vaccine in 2009. For several participants, the congruence was attributable to a perception that seasonal and H1N1 influenza were similar.

*Well, I guess I thought they were more or less the same. I didn't feel there was any difference – Urban female, age 80.*

A subsequent analysis of transcript and survey data provided information on the self-reported seasonal and H1N1 vaccination behaviour of focus group participants (Table 4-1). Further analysis revealed that there was indeed congruence between their H1N1 and seasonal vaccination decisions for most participants in 2009, with 38 electing to receive *both* H1N1 and seasonal influenza vaccines that year and 20 electing to receive *neither* vaccine that year. Six participants had incongruence between the two vaccines, and the record for one participant could not be determined with accuracy.

**Table 4-1: Vaccination behaviour of focus group participants (N=65)**

Seasonal influenza			H1N1 influenza		
Received	Declined	Unknown	Received	Declined	Unknown
43	21	1	40	25	0

When asked to describe the rationale for their H1N1 and seasonal influenza vaccine decisions in 2009, a number of participants spoke initially about their underlying beliefs or practices about influenza vaccination.

*I immunized all my life, so that's part of who I am and what I am.*  
- Urban female, age 69

*I don't have the flu shots. I don't believe in flu shots or vaccines. –*  
Rural female, age 82

When discussing the factors that influenced their vaccination decisions, many participants described a link between their H1N1 vaccination decision and their historical seasonal vaccination pattern.

*I've always had the flu shot for the last ten years so I thought well, I might as well do (H1N1) too.* – Urban male, age 81

This link with habitual seasonal influenza vaccination was also reflected in the review of transcripts and recruitment data: of the 32 seniors who reported that they normally (historically) receive the seasonal influenza vaccine, 30 received the seasonal vaccine and 28 opted to receive the H1N1 vaccine in 2009. Of the 22 who indicated they normally (historically) abstain from the seasonal influenza vaccine, 17 declined the seasonal vaccine in 2009 and 18 declined the H1N1 vaccine in 2009.

### ***Positive influences on seasonal vaccination uptake***

Habituation was such a strong influencer of vaccination decision-making that most study participants, when asked to articulate their H1N1 decision process, first referenced factors influencing their habitual *seasonal* influenza pattern. Personal risk assessment regarding the potential severity of seasonal influenza was an important factor raised by individuals with underlying health conditions, with several habitual vaccinators believing that their influenza risk is higher due to health problems.

*Yeah, I thought I was at risk. I had followed health rules very carefully. I'm diabetic. I have compromised lungs. I have had chronic leukemia for 25 years so I don't have a lot of resistance.* – Urban female, age 75

Several participants indicated they had become habitual vaccinators to protect family members with health conditions:

*I think my risk to (my wife) was the more important thing. It was a risk to her if I was a carrier of the virus -- not necessarily (at risk of) getting it myself.* – Urban male, age 65

Several participants indicated that a physician or nurse had been an important influence at some point in the past, convincing healthy individuals as well as those with newly diagnosed health problems to be vaccinated for the first time. This often led to habitual vaccination behaviour.

*I feel that it's silly to have a doctor and not pay attention to what he says. So when he said, "Yes, you're diabetic - you must have (the vaccine)," as far as I was concerned that settled it. – Urban male, age 73*

*Well, years ago the doc asked me to start taking flu shots because I get pneumonia at the drop of a hat. So I got shots every year. – Urban male, age 76*

For some non-vaccinators, an acute health issue or declining health in 2009 was the impetus to begin accepting seasonal influenza vaccine, often on the advice of a medical professional:

*(Throughout my life) I have never been at a stage of being sick or nothing, but in 2009 I had some cancer so that was a big surprise. So down we went and I got the regular and the H1N1 (vaccine). – Rural male, age 65*

### **Negative influences on seasonal vaccination uptake**

A number of non-vaccinators reported becoming ill after receiving influenza vaccine in the past, sparking their anti-vaccine beliefs.

*I've had one flu shot in my life and that winter I was talked into it by a doctor, and I had the flu I bet you five times that year and then I haven't had a shot since. – Rural male, age 77*

Many participants in this study – all non-vaccinators -- felt they possessed a natural immunity to influenza, either due to previous exposure or to 'good genes'. Others believed in healthy lifestyle practices to build their immunity.

*I just (have) no susceptibility for these things. When I was working the whole office would be sick and I'd be the only one that wasn't. – Urban female, age 77*

*I decided I was going to go health-wise, and I don't like to put certain things in my body that I feel that are not good for it, so I tried to keep healthy by exercise, walking and taking vitamins – Rural female, age 82*

Some non-vaccinators were skeptical about the science, safety or efficacy of the vaccine:

*Every time I heard of somebody having the flu, well, it wasn't the flu that was covered with the vaccine they were being given, so I thought well, what is the point of getting the vaccine? – Rural female, age 82*

*I made my decision to avoid them. I just don't like them (because of) what you hear is in them and some of the side effects. – Urban female, age 82*

### ***Affective media messaging and participant responses***

Participants perceived H1N1 media messaging to be affective and some seniors expressed fear or concern, particularly those with chronic health problems, reinforcing their decision to get vaccinated.

*No, I don't think it's hyped. It's real and you have to believe it. To me it was true and I went and I got in line and did what I had to do. – Urban female, age 67*

*They said so many people died and seniors were vulnerable, and I was a little scared because I have chest problems and chronic bronchitis and I was worried about that. It was the consequences of the flu that decided me to get the (H1N1) shot. – Urban female, age 67*

More participants, including habitual vaccinators, found the amplification of risk in the media to be unnecessary, unhelpful and even annoying.

*It was real hyped up ... it was blown up too much. I have a way of minimizing some of the stuff. – Urban female, age 72*

*The tone of course in the mass media was hysteria ... pretty much what I expected from what I'd learned about previous flu outbreaks in the past century or so. – Urban female, age 65*

Several non-vaccinators said they were not moved by the fear-based media messaging and in fact were turned off by the hype and the lack of clarity, deciding

to dismiss media altogether.

*I think was being put off by the hysteria that was going on. – Urban female, age 77*

*There seemed to be a lot of paranoia and panic almost at the onset. It didn't scare me. I wasn't scared about anything. I just thought it was too much paranoia there, trying to frighten and panic people. – Urban female, age 73*

### **Decision factors related to H1N1 vaccination**

The majority of participants made a decision about H1N1 vaccination that was consistent with their usual seasonal influenza vaccination behaviour, with several indicating the decision was relatively straightforward and made without much additional investigation or thought.

*My wife and I have gotten the flu shot every year, pretty well. We got the H1N1 too. Yeah, we never thought twice about it. – Rural male, age 80*

Several struggled with their decision and proactively researched pandemic information. Habitual vaccinators in particular spoke about the impact of ambiguous and inconsistent information on their decision-making process.

*When we first started hearing about it, the news media made it sound very, very frightening. And we've always got our flu shots so I thought well we should get (the H1N1 vaccine) but I sure wanted to know more about it. – Urban female, age 74*

Others consulted with family or health professionals before finalizing their decision.

*So I hesitate to take this (H1N1) flu vaccine ... because I'm afraid for side effect. But I met a doctor acquaintance and I ask his opinion and he said, "You should go and make this vaccine." – Urban male, age 70*

Several habitual vaccinators who intended to vaccinate against H1N1 felt even more committed to their decision in order to protect loved ones.

*When it came to the H1N1, I really felt that if this was the bad one, I wanted to have it, and that way I wouldn't be the one passing it on to children and grandchildren. – Rural female, age 77*

Habitual vaccinators and non-vaccinators alike expressed concerns about the safety of the H1N1 vaccine and the risk of side-effects, although most habitual vaccinators concluded that the risk of vaccination was outweighed by the benefits.

*My husband had just had open heart surgery, so I was very worried that I (might) bring it home to him. So my feeling was yeah, let's risk whatever to get (the H1N1 vaccine) rather than the fright risk of not having it. Maybe we'll have a reaction but at least it would be better to have it than not have it. – Urban female, age 74*

For several habitual non-vaccinators, concerns about vaccine quality or potential side-effects reinforced their decision not to receive the vaccine.

*There was a problem with the vaccine itself. Now that made me fear it too. How do we know what the vaccine is? How safe is it? – Urban male, age 76*

Several participants, all non-vaccinators, spoke of profits or hidden motives behind the push for H1N1 vaccination.

*Is it an ulterior motive, we wonder? Is there money involved? – Urban female, age 73*

*It just seemed to me that it was a put up job. And I'm not sure the drug companies weren't behind it all. – Rural female, age 82*

Long lineups, either experienced locally or reported through the media, and confusion regarding priority groups were dominant topics of discussion throughout the focus group sessions. Many participants were turned off by the disorganized vaccine delivery.

*I couldn't believe that they made such a monumental mess of it, actually, because it seemed like something that could be done rather simply. I had expected a great deal more of our great minds but obviously I was mistaken. – Urban male, age 80*



*For a city over a million people, can't they do the math? – Urban female, age 67*

For non-vaccinators, the disorganization was just another reason to avoid vaccination clinics altogether. Habitual vaccinators, however, were either accepting of the barriers or resigned to tolerate the inconvenience if they wanted the vaccine.

*It was a terrible thing. We went three times ... I have a walker and it was so cold I couldn't wheel the walker. There were people in wheelchairs ahead of us at one point that were turned away. But we waited. – Urban female, age 75*

*I do believe in vaccinations. When it came to the H1N1, I was quite happy to stand in line and take it because I really felt that if this was the bad one, I wanted to have (the vaccine). – Rural female, age 77*

### **Factors influencing a change in habitual vaccination pattern**

Some participants deviated from their usual vaccination behaviour during the H1N1 pandemic, and these findings are of particular interest to this study as they reflect either a positive change in vaccination behaviour (uptake by a habitual non-vaccinator) or a negative change (decline of vaccine(s) by a habitual vaccinator). Habitual (historical) vaccination behaviour could be discerned for 54 of 65 participants; the remaining 11 did not offer this information during focus group discussions.

Four habitual non-vaccinators made a change in their usual vaccination pattern during the H1N1 pandemic. Two felt compelled to receive both seasonal and H1N1 vaccines for the first time in 2009, one on the advice of her physician due to declining health and the other, to protect a vulnerable family member.

*I have a daughter who has an immune suppressed health. She has a chronic health condition, (and) when the H1N1 flu was becoming more prevalent the message came down that to protect her we should be protected just so we wouldn't expose her. – Urban female, age 80*

Two others accepted one or both vaccines in 2009 due to the influence of their wives:

*I wasn't worried because I didn't get the flu shot the year before that or the year before that, so I never bothered. Well, my wife had more of a sense of risk and said, "You've got to get that." So she drug me down there. - Urban male, age 69 (received seasonal but not H1N1)*

At least five habitual vaccinators declined one or both vaccines in 2009. One received the H1N1 vaccine but not the seasonal influenza vaccine due to apparent ambivalence. Four others received the seasonal vaccine but decided not to receive the H1N1 vaccine due to concerns about vaccine safety/quality, clinic disorder and ambivalence.

*For years I was always in the line-up on the first day for the normal influenza injections, so I went ahead with that and I said, well, qué sera sera. I'll just stick with the normal injection or inoculation and forget about the swine flu, the H1N1. And nothing happened. – Urban male, age 73*

*I do (get vaccinated) every year, but (in 2009) I didn't get (the H1N1 vaccine) and it was mainly because of the mix up in the batches, the bad batch being returned. And I certainly didn't want to stand in a line. So I made the decision not to. The more I looked into it the more positive I was not going to get it. – Urban male, age 65*

## **Discussion**

### ***Role of media in risk assessment and decision-making***

Participants in this study recognized the important role of media in delivering information about the pandemic. Most reported a strong reliance on traditional mass media (television, newspaper, radio) to guide decision-making, with the majority reporting low use of or efficacy with online media. Seniors seemed strong in their conviction that the role of the media should be to provide them with the information needed to conduct a cognitive- or reason-based assessment of their H1N1 risk and the risks/benefits of vaccination.

Those most keenly interested in understanding their personal risk for H1N1 infection were habitual vaccinators, particularly those with underlying health concerns. These individuals perceived the threat of H1N1 to be potentially high and were motivated to assess their risk and determine whether vaccination would be protective. This finding is consistent with health behaviour theories which suggest that individuals assess their risk based on perceived likelihood, susceptibility and severity of the hazard (H1N1 influenza) (Brewer *et al.* 2007). Emerging studies on actual H1N1 vaccine uptake corroborate these theories in finding that having a chronic disease (Podlesek 2011) and positive beliefs about vaccine efficacy (Bish *et al.* 2011, Brien *et al.* 2012) were determinants of H1N1 vaccination intention or acceptance.

In this study, however, although many participants intended or attempted to conduct a personal risk assessment, most found information on H1N1 to be confusing, conflicting, contradictory and unclear. Many seniors reported feeling ill-equipped to 'make sense of it' or cope with the volume of information, suggesting they struggled with making an analytic or cognitive assessment of their risk.

A number of factors may have contributed to the difficulties seniors faced navigating the available scientific or risk information environment, including a lack of consistency in expert information and actual confusion or contradiction in reported scientific details. These have been cited in recent studies as an explanation for reduced uptake of H1N1 vaccine (LaVela 2012, Maltezou *et al.* 2012). Information vulnerability (Lechelt *et al.* in preparation) likely played a central role due to seniors' low trust in sensationalized traditional media and their inability to readily verify information through other sources. Cognitive decline may have also played a role, causing many seniors to be less capable than younger adults to process the complex and rapidly changing information in traditional media.

Study participants were, for the most part, unable to navigate online technologies or sources; ascertain the reliability of information found online; or cope with the volume, complexity and inconsistency of online information. Their generally low confidence and competency in using online media was a significant barrier given that, paradoxically, public health agencies such as the Public Health Agency of Canada and the World Health Organization routinely promoted online information as a source of scientifically accurate and reliable information. Seniors' inability to access these sources of expert information, while simultaneously not trusting sensationalized coverage in traditional media, rendered this population highly vulnerable to the resulting information void.

Regardless of their preferred sources of information, habitual vaccinators in this study seemed more committed than non-vaccinators to try to make sense of the confusing and conflicting H1N1 information by searching or consulting more widely for clarification, perhaps on the expectation of eventually finding information that would support their usual vaccine uptake behaviour. This is consistent with a recent Slovenian study in which people who received the H1N1 vaccine reportedly tried harder than non-vaccinators to interpret available information and put more effort overall into their decision-making process (Podlesek 2011).

While habitual non-vaccinators also noted the high volume and inconsistency of H1N1 information in the mass media, this group seemed to make their no-vaccination decision early, considering the conflicting information as reinforcement of their decision to decline the vaccine. For these participants, the low quality and reliability of information was of little consequence from a decision-making perspective, as most seemed content to 'tune out' media and abide by their usual non-vaccination pattern.

### ***Role of affect in risk assessment and decision-making***

Affect was a dominant theme throughout several focus group discussion threads, including: the affective nature of media reports; individuals' positive and negative responses to affective messaging; the role of fear or worry in promoting vaccine uptake; the sense of familiarity and personal experience with respect to influenza and vaccines; trusting physicians and family members for guidance; and a low level of trust in vaccines or manufacturers as a reason to downplay the pandemic and reject the vaccine.

Most participants in this study found traditional and online media coverage to be affective (fear-based) and sensationalized, leading many to discredit media for the ensuing 'hype', 'panic' and 'paranoia'. While the messaging convinced some individuals to receive the H1N1 vaccine, particularly those who believed they had increased sensitivity due to ill health, most participants in this study were offended by the hype and indicated it did not influence or change their vaccination decision. Even habitual vaccinators who felt at-risk for H1N1 were 'turned off' by fear-based affective messaging, considering it to be nothing more than irresponsible fear-mongering on the part of mass media.

Many participants reported feeling 'disgusted' by and 'dismissive' of the hype, and among habitual non-vaccinators, this strengthened their resolve to decline the vaccine. One health behaviour theory in particular, the Extended Parallel Process Model (EPPM), offers an explanation for these participant feelings in suggesting that sensationalized or risk-focused coverage (high in threat) with low efficacy messaging may lead to message rejection and therefore failure to act (Goodall *et al.* 2012, Prati *et al.* 2012, Witte 1992, Witte and Allen 2000). Two habitual seasonal vaccinators who expressed concerns about vaccine safety and testing protocols could be considered examples of participants who 'failed to act' on H1N1 vaccine uptake but it appears their decisions were not

based solely on a negative response to sensationalized messaging (affect) but also due to uncertainty regarding vaccine quality and safety (analysis).

### ***Familiarity and experience with respect to influenza and vaccines***

The majority of participants demonstrated congruence between their seasonal and H1N1 vaccination behaviour in 2009, which is consistent with a recent study by Myers (2011) showing a strong correlation between seasonal and H1N1 vaccination behaviour in 2009. In addition to corroborating this same-year congruence in vaccination behaviour, my study also suggests that participants' H1N1 vaccination decisions were closely linked to their historical seasonal vaccination behaviour. This finding is consistent with a Slovenian study (Podlesek 2011), a Canadian study of health care workers (Kaboli *et al.* 2010) and a systematic review of vaccination (Brien *et al.* 2012), all of which concluded that a history of seasonal vaccination was positively associated with pandemic vaccination. Also in line with these findings, Podlesek (2011) further concluded that a lack of reliable information led people to make an H1N1 vaccination decision that was consistent with their behaviour in previous (seasonal) influenza situations.

Our findings suggest that familiarity – an affective response based on experiential knowledge – was an important determinant of H1N1 vaccination behaviour because participants perceived the pandemic virus to be very similar to seasonal influenza. Since seniors were not able to fully interpret or effectively draw conclusions from analytic information available through media sources, they likely weighed the confusing analytic information as less relevant or useful than their experiential, affective knowledge. This led most participants to receive or decline *both* the H1N1 and seasonal vaccine in 2009 in accordance with their habitual seasonal vaccination pattern from prior years, irrespective of public health messaging about priority groups necessary for an orderly vaccination rollout.

A large number of habitual non-vaccinators described an unpleasant experience with influenza vaccination in the past, with many indicating they had succumbed to influenza shortly after receiving the vaccine – an experience that has been reported in other studies as well (Jones *et al.* 2004, Zimmerman *et al.* 2003). Several study participants also spoke about their perceived low risk of infection or their ambivalence toward influenza in general as reasons for low seasonal and H1N1 vaccine uptake. This is consistent with other studies suggesting that perceptions of low personal risk and/or low pandemic severity would be important predictors or determinants of H1N1 non-vaccination (Bish *et al.* 2011, Kaboli *et al.* 2010, Kraut *et al.* 2011, SteelFisher *et al.* 2010).

In this study of actual H1N1 uptake, as well as in other studies predicting H1N1 uptake, seniors appear to have relied heavily on experiential and/or selected affective information to guide H1N1 vaccination uptake. While some participants in our study believed there was a difference between H1N1 versus seasonal influenza, most still viewed H1N1 as similar to seasonal influenza in terms of susceptibility and potential for adverse reactions to the vaccine.

Several non-vaccinators expressed concerns about H1N1 or seasonal vaccine safety, quality or side effects as deterrents, which are well documented in the literature as deterrents to vaccine uptake (Kraut *et al.* 2011, LaVela 2012, Schwarzingler 2010, SteelFisher *et al.* 2010). These concerns may relate to analytic information (scientific/expert information about vaccine composition, testing, etc.) as well as affective interpretations based on trust in official sources. The latter was evident among participants who spoke of a profit motive and/or collusion between pharmaceutical companies and governments as the driver for public vaccination campaigns.

### ***Personal, interpersonal and social determinants of vaccination behaviour***

Several habitual vaccinators expressed a desire to protect loved ones from the threat of H1N1, and these feelings were communicated with strong emotional

conviction during the focus group sessions. These perspectives are consistent with a recent study of health care professionals (Kaboli *et al.* 2010) which found similar concerns about protecting loved ones, as well as a Canadian study which found that habitual vaccinators and non-vaccinators alike identified concerns about passing H1N1 to family members as their top reason for considering vaccination (Kraut *et al.* 2011).

Overall, participants in all focus group sessions demonstrated a high level of respect and tolerance for each others' vaccination decisions and seemed cognizant of the many important influences on decision-making, such as personal (health risk), interpersonal (protection or reassurance of loved ones; advice from trusted friends and physicians), and social (community norms and media messaging).

***Physicians and family: analytic or affective influence?***

To counter the perceived shortcomings of both traditional and online media, seniors reported relying on physicians and family members to guide their risk assessment of H1N1 infection likelihood, susceptibility and severity as well as the risks/benefits of H1N1 vaccination. Some participants indicated that medical advice to accept H1N1 vaccine was precipitated by an acute health event or the diagnosis of a chronic health condition. Some males also noted the influence of their wives in promoting regular vaccination. These findings are consistent with recent studies suggesting that physician and family influence (Bish *et al.* 2011, Brien *et al.* 2012, Lau *et al.* 2010, Myers and Goodwin 2011) were determinants of H1N1 vaccination intention or acceptance.

In their descriptions about why physicians and family members were influential in their vaccination decisions, participants made reference to both analytic processing (i.e., scientific or logical information) as well as affective processing (i.e., trusting the person's judgment). This suggests that physicians and family members played a dual role by offering guidance in both analytic and



affective realms, potentially placing these sources in a particularly influential and powerful position to promote vaccine uptake (physicians and family members) or vaccine decline (predominantly family members). However, more importantly, physicians and family members may precipitate *change* to established vaccination behaviours due to the extent of their influence. Physicians in particular carried far more weight than mass media in communicating and clarifying analytic or scientific information about H1N1 and, given their unique status as both analytically and affectively trusted sources of information, could perhaps have played a central role in helping seniors make better sense of confusing and conflicting mass media and online information.

In this study, all four habitual non-vaccinators who deviated from their usual pattern by receiving one or both vaccines for the first time during the pandemic did so either on the advice of physicians and family members, or specifically to protect family members. In other words, physicians and family members played a pivotal role in convincing these individuals to change their usual vaccination behaviour, once again suggesting that these influences have a particularly powerful and influential role in changing uptake patterns.

Finally, vaccination clinic organization was a factor for some seniors in this study. For many habitual vaccinators, changes in clinic venues, processes, and timing were confusing and disruptive; however, those with strong pro-vaccine beliefs or a high level of concern about their risk remained committed to getting vaccinated. More ambivalent vaccinators and non-vaccinators viewed the inconveniences as reasons not to get vaccinated, suggesting that poor clinic organization can be a deterrent for all but the most committed or fearful habitual vaccinators. The continually changing immunization venues and processes likely contributed to a negative impact on overall seasonal influenza immunization rates for this population (HQCA 2010).

## Conclusions and implications

This study provides important information about the information-seeking behaviors and vaccination decisions of seniors during the 2009 H1N1 influenza pandemic. As suggested by a number of health behaviour theories, members of this population did attempt to base their H1N1 vaccination decision on perceived likelihood, susceptibility and severity of infection, affirming the important role of these factors in predicting the protective health behaviour of influenza vaccine uptake. Seniors in this study expected media to play a key role in relaying analytic (scientific, logical) information about the pandemic, thereby informing their personal risk assessments and protective behaviour decisions.

To the contrary, however, participants found media unhelpful and confusing, which undermined their ability to use analytic information to guide risk assessment and decision-making. The result was a high level of *information vulnerability* in today's changing and confusing media environment. This phenomenon, potentially combined with the onset of age-related cognitive decline and its impact on cognitive processing, led seniors to (1) be more attuned to selected affective information, (2) assign greater weight to affective interpretations, and (3) rely more heavily on experiential (affective) knowledge about seasonal influenza and vaccination to guide H1N1 vaccine uptake.

Rather than emerging as a reliable source of analytic or cognitive information, mass media was instead perceived by study participants to be highly fear-based (affective). While this could have figured into seniors' vaccination decisions by causing them to preferentially weigh this affective information and accept the vaccine out of fear, media information was instead deemed offensive and was routinely dismissed by participants as fear-mongering, regardless of seniors' previous beliefs about influenza risk or vaccine efficacy. In short, media's attempt (whether intentional or not) to communicate with audiences in a fear-inducing affective manner to promote vaccine uptake during the H1N1 pandemic

instead resulted in audience rejection of the messaging and an overall loss of trust of media. This led seniors to discredit media as unreliable and to defer instead to other trusted affective sources.

Experiential knowledge was deemed the most trusted and influential source of information among seniors in this study, and most participants opted to either accept or decline H1N1 vaccine in accordance with their usual seasonal influenza vaccination behaviour. In other words, in spite of efforts by public health officials and media to encourage seniors to present for H1N1 vaccination based on their personal risk factors, in fact seniors in this study were unable to ascertain their risk using official and media information and instead used their historical seasonal vaccination behaviour as their guidepost.

Physicians and, to a lesser extent, family members were cited as important sources for influencing and reinforcing established vaccination patterns, as well as in causing a small number of participants to change their vaccination behaviour during the H1N1 pandemic. Our findings suggest that physicians and family members played a unique role by offering both analytic (scientific, reason-based) and affective (trust-based) information, placing them in a coveted position as highly influential on vaccination decisions, but only for a small minority of participants who specifically sought information from these sources or whose physicians initiated a discussion about H1N1 vaccination.

The implications of this study are important to health officials and government in suggesting that during high-risk situations, seniors may selectively give preferential weight to certain affective messaging, such as protecting loved ones, while dismissing other affective messaging such as fear-based appeals. Seniors also afforded less weight in general to analytic (scientific) information, likely due a reduced ability to cognitively process complex or changing information, and further exacerbated by their discomfort with the confusing and voluminous media environment.

During the H1N1 pandemic, seniors did not consider mass media to be a credible source of messaging. This reduced the opportunity for seniors to receive analytical H1N1 information and instead forced this population to rely on personal experience, physicians and family members as sources of decision guidance. Given the inability of public health officials to change personal experience and its important influence on decision-making processes, the most effective medium through which to influence vaccine uptake among seniors is likely physicians and family members. In other words, public health campaigns in the future need to consider communication strategies that effectively utilize these influential intermediaries rather than attempting to reach seniors primarily through traditional mass media or online sources.

### **Limitations**

While the results of this qualitative study accurately reflect the views of participants and may be transferable to other seniors under similar circumstances, the findings are not necessarily generalizable to other populations or geographic areas. However, there is concordance in findings between this and other studies. The risk of participant recall error exists given the 12 to 18 month gap between the pandemic period and the focus group sessions. The passage of time and the diminishing threat of H1N1 may also have had a moderating effect on the views of participants with respect to perceived risk, protective behaviours, and responses to media information.

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## Chapter 5: General discussion and conclusions

This qualitative study of seniors aged 65 and up from Alberta, Canada had two aims:

1. To explore the information-seeking behaviours and experiences of seniors during the H1N1 pandemic, with a particular focus on the sources of information that influenced their decisions regarding H1N1 vaccination.
2. To examine seniors' assessment and use of traditional media and online sources of information, as well as the role of these sources in this population's understanding and uptake of H1N1 protective behaviours.

As suggested in the literature, seniors in this qualitative study indicated that they preferred habitual sources of information during the H1N1 pandemic, including trusted personal sources (i.e., physicians, family members) and traditional media (i.e., television, newspapers, radio). While youth and much of the adult world has gravitated to online media to either supplement or replace historical information sources, seniors in the study either had little search/navigation success with online media or they did not use online media at all.

Trust was an important theme as seniors indicated they did not trust traditional media during the pandemic due to a perception of sensationalism in television and newspaper reporting, leaving many participants feeling betrayed by traditional media. Seniors also reported low trust and self-confidence with online sources, primarily due to an inability to assess the credibility or accuracy of online information or to cope with the volume of information. This rendered online sources unusable for all but the most highly educated study participants. With trust levels low for both traditional and online media, most seniors in this study felt they had few viable media options for information.

This study adds weight to the argument that the digital divide is not a phenomenon affecting primarily those of lower socio-economic status (the historical No-Nets) but now includes a majority of seniors, many of whom may own computers but lack the technical or information literacy skills to use these new technologies more optimally. For all but the most educated seniors in our study, the barriers and low motivation to use online technologies were perceived as insurmountable. Therefore, it can be concluded that these seniors indeed experienced *information vulnerability* as they rejected or dismissed traditional media sources while either failing to divert their health information-seeking behaviour (HISB) efforts to new, online sources of information or attempting to use online sources but experiencing low levels of success.

Consistent with the theories of a number of health behaviour models (Brewer *et al.* 2007), this group of seniors did attempt to base their H1N1 vaccination decisions on perceived likelihood, susceptibility and severity of infection. Media was highly anticipated to be a critical source for this type of analytic (scientific, logical) information about the pandemic risk (Lowenstein *et al.* 2001, Slovic *et al.* 2004); however, most participants felt they were ill-served or let down by both mass media and online sources. To exacerbate the situation, seniors experienced significant discomfort with the new media environment and a reduced ability to cognitively process complex or changing scientific information. This resulted in a high level of information vulnerability in today's changing and confusing media environment, seriously undermining seniors' ability to use analytic information to guide personal risk assessment and decision-making.

Contrary to seniors' expectations of it being a reliable source of analytic information, mass media was instead perceived by study participants to have highly affective properties. While affective information is important to individual risk assessment (Lowenstein *et al.* 2001, Slovic *et al.* 2004), seniors made a clear

distinction between information or sources they considered to be *positively* versus *negatively* affective. Fear-based media messaging, in particular, was deemed to be *negatively* affective and therefore offensive; as a consequence, it was discredited or rejected by most participants in this study. This led seniors to effectively limit their inventory of *positively* affective sources of information to just three trusted, credible sources: (1) experiential knowledge about seasonal influenza and vaccination; (2) advice from physicians; and (3) influence from family members.

Most participants used the positively affective response of *familiarity* or experiential knowledge to guide their H1N1 vaccination decision: they considered H1N1 to be a familiar risk and therefore used similar information sources and made similar vaccination decisions as in past influenza seasons rather than employing a *crisis* or *risk event* frame (i.e., conducting a personal risk assessment based on a perception that H1N1 was a novel risk meriting an interpretation of new information). This led seniors to generally defer to habitual vaccination behaviours, with most habitual vaccinators accepting both the seasonal and H1N1 influenza vaccine in 2009; a comparable pattern of declining both seasonal and H1N1 vaccine was observed among habitual non-vaccinators.

Physicians were uniquely positioned to offer both analytic (scientific, reason-based) and affective (trust-based) information (Lowenstein *et al.* 2001, Slovic *et al.* 2004) to participants and were therefore able to convince a small number of participants to change their historical vaccination behaviour during the pandemic. Family members also exerted both analytic and affective influence but appeared to carry more affective weight.

## **Study implications**

The implications of this study are important for public health officials, extending well beyond pandemic situations and into the realms of general communication of health information, immunization campaign organization and rollout, risk communication to seniors, and uptake of health protective behaviours.

This study illustrates that the intersection of health promotion and risk communication presents unique challenges for public health officials: while certain risks may be immediate and absolute (e.g., a sour gas leak) with a clear and unambiguous urgency around protecting the health of citizens, other public health risks such as pandemic influenza are far more ambiguous and uncertain. For this reason, the goal of influencing or attempting to change established health behaviours using risk communication principles can, in and of itself, be somewhat controversial. Health officials need to be clear and transparent from the outset regarding their desired or intended outcomes of such public health campaigns because the strategies and ethical considerations associated with “compelling more seniors to accept H1N1 vaccine” will be markedly different from those associated with “providing seniors with appropriate information to guide vaccination decision-making”.

This study has led me to conclude that seniors’ general preference for certain types and sources of affective information, which is rooted in their experiential knowledge and the value they place on trust, should compel health officials toward three important considerations when communicating with seniors. First, it is far more difficult to alter established health behaviour patterns among seniors than among younger adults because seniors trust and value the experiential wisdom that has guided their decisions in the past. Even compelling scientific or analytic information may be insufficient to penetrate the ‘shield’ of



familiarity, experience and positive affect that governs decision-making for many seniors, often trumping scientific evidence.

Second, due to the importance of trust and affect, the 'messenger' may be far more important than the 'message' when attempting to influence health behaviour patterns among seniors. Trusted sources, even if they lack scientific or analytic expertise, may exert more influence on seniors' decision-making than 'expert' sources. Participants in this study clearly identified their most coveted, trusted sources of information: physicians, family members, friends, experiential knowledge, and even certain media sources, outlets or personalities. If any particular source failed to fulfill its trust role, seniors rejected the source and turned to alternate trusted sources. Due to a lack of consistent messaging and information across many of their trusted sources, most seniors ultimately based their vaccination decision on their only remaining trusted source: personal experience.

Third, it is important to recognize that complex or changing scientific information (the message) delivered in the absence of a positively affective context (the messenger) is likely to be lost on seniors for a number of reasons including their reduced capacity to process conflicting or ambiguous information. In other words, while today's media environment is rapidly moving toward a gatekeeper-less model, characterized by broad public access to a diverse and often conflicting range of expert, institutional and consumer-generated sources of information, seniors clearly need and prefer a positively affectively and salient source to serve as gatekeeper and interpreter of that information. Any other model of information delivery will likely result in *information vulnerability* for this population.

Physicians and, to a lesser extent, nurses were identified in this study as a highly influential source of information due to their dual analytic-affective qualities. This would suggest that for any public health risk event involving

seniors, it makes sense for health officials to make physicians and other health professionals a *primary and direct target audience*. This would see public health officials directing some of their communication efforts toward health providers, allowing these professionals to maintain and utilize their highly influential role in communicating with seniors. It would also avoid the challenges associated with routing public health messaging solely through less effective and less trusted channels such as mass media. Seniors indicated that even second-hand information from health professionals (e.g., “My daughter’s friend is a doctor and told her that ...”) was highly influential, suggesting that this old-fashioned ‘social media’ is the *de facto* Facebook and Twitter of seniors’ world.

It may have been discouraging for public health officials in Alberta to discover that the H1N1 pandemic failed to halt the five-year trend that had culminated, by 2009, in a 12% drop overall in seasonal influenza vaccine uptake among seniors. While the final 2% drop in uptake in 2009 may have been attributed to multiple challenges (changes in immunization clinic venues, the cancellation of ‘senior friendly’ local clinics, the poor availability of seasonal vaccine for the first two months of the vaccination season, and the continually changing information about H1N1 vaccine priority status), it is not clear why seasonal uptake failed to return to previous levels the following year (2010) when conventional vaccine clinic processes and venues in Alberta were restored. It could be speculated that habitual seasonal vaccine uptake is a somewhat fragile phenomenon, particularly among ambivalent vaccinators, and that anything that breaches the comfort, familiarity, routine, localness or convenience of habitual or rote vaccination behaviour may have a precipitous impact on uptake patterns in the future.

## Recommendations

Based on the findings of this research study, the following recommendations are offered:

- **Public health officials should agree on and be transparent about the goals, scientific rationale and ethical considerations associated with any proposed risk communication campaign or intervention.** The strategies, messages, delivery channels and ethical considerations of a ‘change vaccination behaviour’ campaign may be markedly different than those of a ‘reinforce vaccination behaviour’ or ‘inform vaccination decision-making’ campaign.
- **When communicating with seniors, standardize and simplify complex information.** To the extent possible, scientific information intended for audiences aged 65 and older should be consolidated, streamlined and reduced to critical, salient information. Communicating scientific uncertainty (e.g., “We don’t know the impact yet, but we will let you know when we are more certain”) may be more comprehensible to senior audiences than continually changing or contradictory information.
- **When communicating with seniors, anchor appropriate scientific information in positively affective (non-fear-based) messaging and sources.** Due to their unique HISB patterns, preferences and capabilities, seniors are more likely to understand and accept information that is delivered by and through trusted sources and channels, and also appeals to their preference for positive affect. Perhaps even more so than other populations, seniors are likely to assess source trust and familiarity first and, if it meets their needs, then consider the content of the message.

- **Frame information in alignment with the positively affective sources that are most salient to seniors.** For example:
  - Relating new information to seniors' **experiential knowledge** will help this population makes sense of it.
  - Explaining risks and benefits in terms of **personal and interpersonal factors**, such as the impact on family members, can help seniors interpret the information within the context of their own family situation.
  - Making efforts to channel important information through **trusted personal sources** such as family members and physicians will allow these important influencers to act as trusted intermediaries and interpreters in the delivery of information to seniors.
  
- **Structure and frame information so it can be reported verbatim by news media.** Confusing, complex and contradictory information from expert sources leaves media in the difficult position of having to investigate, verify, interpret and translate information for delivery to public audiences, often without adequate resources to fulfill this obligation. Information that is targeted and packaged for immediate public consumption is less likely to undergo substantial translation by mass media, thereby reducing the risk of inaccuracies, bias or omissions in reporting.
  
- **Offer a 'single source of truth' for scientific information.** The importance of designating a single agency as the Canadian or Alberta 'expert' on a risk event cannot be overstated. This alone would allow media and the public to access expert information directly, and those with limited capacity or interest in conducting their own online research (e.g., seniors) would be spared the need to locate,

interpret and validate complex scientific information from multiple online sources.

- **Do not change historical service delivery processes, patterns or venues unless absolutely necessary.** Disrupting or discontinuing familiar immunization clinic locations, timing and processes was confusing for seniors in Alberta, particularly given this population's comfort with experience and habituation, and it may take years to return to former seasonal influenza uptake levels. Vaccination habituation may be a fragile phenomenon and it should not be breached indiscriminately.
- **Findings from this study should be considered within the context of other vulnerable populations.** Although this study focused on seniors, it is possible that *information vulnerability*, vaccination habituation, HISB preferences, and a preference for positively affective information and sources may also apply to other populations such as immigrant populations and those with lower socioeconomic status. Future studies should explore whether this research is transferable or generalizable to similar populations.

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## Appendices

### **Appendix 1: *Vulnerable Populations* study overview**

The research conducted for this thesis was a distinct study within a larger, multi-method study, *H1N1 Knowledge Translation for Pregnant Women and Seniors: Sources, Content, Understanding and Uptake* (“Vulnerable Populations Study”). This study was funded by the Canadian Institutes of Health Research (CIHR) and included three principal investigators (Drs. Cynthia Jardine, Tania Bubela and Lisa Given), one research manager, and more than 10 research assistants. Following are excerpts from the multi-method research proposal.

The Vulnerable Populations study addressed the following research question: Were communications and knowledge translation (KT) activities by public health agencies effective in providing information and promoting informed decision-making in two vulnerable or “at-risk” populations in Alberta: (1) women who were pregnant and/or lactating during the nine month period between May 1, 2009 to January 31, 2010 (“pregnant women”); and (2) seniors aged 65 or older (Jardine *et al.* 2009).

The overall research objectives were (Jardine *et al.* 2009):

1. To examine public health agency messages (news releases, websites and media ads) targeted at pregnant women and seniors, and how these messages were proactive in setting out real-time evidence-based information and/or reactive in responding to public concerns.
2. To assess knowledge translation (KT) effectiveness by comparing these public health agency messages with information available in both conventional media sources and internet sources.
3. To analyse public commentary identifiable as being from or about pregnant women and seniors in letters to the editor and commentary on media internet sites, blogs and social networking sites.

4. To determine the sources of information accessed by pregnant women and seniors, their trust in these sources, the effectiveness of this information, their uptake and understanding of the information, and how this information was used in making individual decisions on preventative behaviours (including being vaccinated or not).
5. To determine the sources of information, decision-making and experiences of health reporters in preparing and delivering messages for pregnant women and seniors.
6. To examine the role of Web 2.0 (i.e., interactive internet) technologies in shaping the ways that pregnant women and seniors located information and engaged in dialogue with other Canadians about issues related to H1N1 transmission, vaccination, etc.

Of particular interest was the acquisition and use of information by vulnerable populations: individuals who, for reasons as diverse as having low socioeconomic status to having underlying health conditions (Cutter *et al.* 2003, Galastri 2009), could be more at risk from H1N1. We narrowed our focus to two populations, seniors and pregnant or breastfeeding women, who were considered more sensitive to H1N1, defined as being more likely to become seriously ill or die if infected (Lemyre *et al.* 2009).

These two populations faced unique information challenges during the pandemic: pregnant/breastfeeding women were at high risk of complications from H1N1 (WHO 2009a) and needed to consider the impact of both the virus and the vaccine on their unborn child or neonate; and seniors had seemingly 'dual-risk' status due to their vulnerability to seasonal influenza (related to underlying health conditions and aging/frailty) while being 'not vulnerable' to H1N1 influenza due to probable prior exposure to strains circulating before 1957 (WHO 2009b).



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## Appendix 2: Newspaper recruitment advertisement

# Seniors' input wanted!

University of Alberta researchers are looking for seniors (65+) to be part of a focus group on communication about **H1N1/Swine Flu**.

You do not need to have received the vaccine to participate.

Please contact Dr. Lisa Given at  
[lgiven@ualberta.ca](mailto:lgiven@ualberta.ca) or  
(780) 492-2033



UNIVERSITY OF  
ALBERTA

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education, Extension, Augustana and Campus Saint Jean Research Ethics Board (EEASJ REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EEASJ REB c/o (780) 492-2614.

### Appendix 3: Recruitment poster



# Seniors: Input wanted on H1N1!

University of Alberta researchers are looking for people to be part of a focus group on communication about H1N1/Swine Flu.

The purpose of the discussion is for university researchers to learn about:

- The sources of information you used during the 2009 H1N1 outbreak
- How and why you decided to receive, or not receive, the H1N1 vaccine.

#### We welcome SENIORS:

- Who DID and DID NOT receive the H1N1 vaccine
- Are healthy OR have health problems
- Of all ages (65+) and type of residence (own home, supportive living, etc.)



Photo from Flickr user Damon Duncan

#### Session details

Friday, Oct. 29

9:30 - 11:30 a.m.

Central Lions Club Senior Centre

11113-113 St., Activity Room #4

**Lunch included**

OR

Tuesday, November 2

9:30 - 11:30 a.m.

Seniors Association of Greater Edmonton

(SAGE) 15 Sir Winston Churchill Square

**Lunch included**

**Pre-registration is required.** To register, or for more information, please contact Dr. Franziska Borner: phone toll-free at 1-888-681-2626 or email [borner@ualberta.ca](mailto:borner@ualberta.ca)

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education, Extension, Augustana and Campus Saint Jean Research Ethics Board (EEASJ REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EEASJ REB c/o 780.492.2614.

## Appendix 4: Recruitment pre-screening script

### H1N1 Vulnerable Populations Recruitment Guide – University of Alberta For Alberta Focus Groups – November 2010 - March 2011

Recruit for 10 participants per focus group session.

- For all Senior's focus group sessions

Eligibility criteria:

- Seniors (male or female) need to have been 65 years of age or older before May 1, 2009 [in other words they were born on or before April 30, 1944].
- A mix of 50:50 males:females in each focus group session.
- Get a mix of younger seniors (65-74); and older seniors (75+), if possible.
- Need a mix of H1N1-vaccinated and not vaccinated seniors (NOT FOR THE 2010-11 INFLUENZA SEASON). Need a minimum of 3 people per focus group to have been vaccinated with the H1N1 vaccine. On the flip side, if a greater majority of seniors contacted have been vaccinated, then need a minimum of 3 people per focus group to have not been vaccinated with the H1N1 vaccine.
- Highest level of education attained. Focus group participants should mirror Stats Canada:
  - Less than high school (seniors with no certificate or diploma): 42.6%
  - High school completion (or equivalent): 21.3%
  - Non-University diploma, certificate or trade: 21.8%
  - University degree – Bachelor's level: 5.1%
  - University degree – Master's level or higher: 2.8%

- For all Pregnant / breastfeeding women focus group sessions:

Eligibility criteria:

- There is no age restriction for women.
- Women need to have been pregnant and/or breastfeeding between May, 2009 and January, 2010 [in other words, their children from that time would now range in age from ~14 months to ~34 months of age].
- Need a mix of H1N1-vaccinated and not vaccinated women (NOT FOR 2010-11 INFLUENZA SEASON). Need a minimum of 3 women per focus group to have been vaccinated with the H1N1 vaccine. On the flip side, if a greater majority of women contacted have been vaccinated, then need a minimum of 3 women per focus group to have not been vaccinated with the H1N1 vaccine.

**Telephone Script:**

Good afternoon/evening, this is \_\_\_\_\_, and I'm calling on behalf of the University of Alberta. The University is conducting some focus groups with seniors and women who were pregnant and/or breastfeeding to discuss communication about H1N1/"Swine Flu". The purpose of the discussion is for researchers to learn about the sources of information you or your family might have used to learn about H1N1, or swine flu, during the 2009 outbreak. Specifically, we will be asking questions about the people and places you got information from, such as television, newspapers, friends, doctors, etc. We will also ask questions about your decision to receive, or not receive, the H1N1 vaccine.

These small group discussions will involve about 8 to 10 individuals and will take about 1½ hours to complete. You will receive \$50 for your time. The researchers are interested in speaking with people from a variety of backgrounds in Red Deer [**OR SPECIFIC CITY/TOWN RECRUITING FOR**]. We are recruiting for two groups of people: (1) Seniors who were aged 65 and over as of May 2009 (in other words seniors who were born on or before April 30, 1944); and (2) Women who are between the ages of 18 to 48 who were pregnant and/or breastfeeding between May 2009 and January 2010 (in other words, women whose children are now between the ages of ~14 months to ~34 months of age.

I just have a few questions to ensure you are in the right group. Just to let you know, any information collected from this phone call will be destroyed in accordance with the Marketing Research and Intelligence Association guidelines.

1. Are you or any members of your household involved in any of the following businesses?

Market research.....1 [END WITH THANKS]

Media.....2 [END WITH THANKS]

Advertising.....3 [END WITH THANKS]

2. [FOR SENIORS], were you born before April 30, 1944?

If NO .....1 [END WITH THANKS]

If YES, What age group are you in (GET A MIX OF YOUNGER SENIORS (65-74) AND OLDER SENIORS (75+).

- 65 to 70.....1=>SENIORS GROUP
- 71 to 75..... 2=>SENIORS GROUP
- 76 to 80.....3=>SENIORS GROUP
- 81 to 90.....4=>SENIORS GROUP
- 91+.....5 [END WITH THANKS]

3. [FOR WOMEN], how old were you in May, 2009?

- 18 to 22.....1=>PREGNANT/BREASTFEEDING GROUP
- 23 to 30.....2=>PREGNANT/BREASTFEEDING GROUP
- 31 to 34.....3=>PREGNANT/BREASTFEEDING GROUP
- 35 to 40.....4=>PREGNANT/BREASTFEEDING GROUP
- 41 to 48.....5=>PREGNANT/BREASTFEEDING GROUP
- 49 to 54..... 6 [END WITH THANKS]
- 55 to 60..... 7 [END WITH THANKS]
- 61 to 64..... 8 [END WITH THANKS]
- 65 to 70..... 9 [END WITH THANKS]
- 71 to 75.....10 [END WITH THANKS]
- 76 to 80.....11 [END WITH THANKS]
- 81 to 90.....12 [END WITH THANKS]
- 91+.....13 [END WITH THANKS]

4. [FOR WOMEN BETWEEN THE AGES OF 18 to 48] Were you either pregnant or breastfeeding between May, 2009 and January, 2010. In other words, your child would now be between the ages of ~14 months to ~34 months.

- Yes.....0
- No.....1 [END WITH THANKS]

5. [FOR WOMEN BETWEEN THE AGES OF 18 TO 48] How many children aged 18 or under do you have in your household?

\_\_\_\_\_ children

6. Which child were you pregnant with or breastfeeding between May, 2009 and January, 2010? [GET A MIX IF POSSIBLE]

- I. First child.....1
- II. Second child.....2
- III. Third + child.....3

7. Would you be interested in participating in a focus group?

- Yes.....1
- No.....0 [END WITH THANKS]

8. During the focus groups, people will need to feel comfortable speaking in a group environment, brainstorming ideas, as well as sharing thoughts and experiences about H1N1 communication and you and your families' decision to either receive, or not receive the H1N1 vaccine. How comfortable do you think you would be with these kinds of discussions?

- Extremely comfortable.....5
- Very comfortable.....4
- Somewhat comfortable.....3
- Not very comfortable.....2 [END WITH THANKS]
- Extremely uncomfortable.....1 [END WITH THANKS]

9. Did you receive the H1N1 vaccine between September/October of 2009 and January, 2010? To be clear, this was during the fall of 2009 and the winter of 2010, when the H1N1 vaccine FIRST became available and was a vaccine that was administered by itself. We are NOT referring to the current flu season, which is the fall of 2010 [Need a mix of H1N1-vaccinated and not vaccinated seniors and women (NOT FOR 2010-11 INFLUENZA SEASON). NEED A MINIMUM OF 3 FOCUS GROUP PARTICIPANTS PER FOCUS GROUP in the non-dominant group, so there is never a ratio of greater than 7:3 (vaccinated:unvaccinated OR unvaccinated:vaccinated) in any one session.

- Yes.....1
- No.....2

10. What is the highest level of education you have completed? [FOR SENIORS, GET A MIX THAT REFLECTS STATS CANADA STATISTICS: ~43% less than high school; ~21% completed high school; ~22% received a non-University diploma, certificate or trade; ~5% with a Bachelor's degree; ~3% with a Masters or higher degree.

Not completed high school.....	1
High school grad.....	2
Diploma, certificate or trade.....	3
University Bachelors.....	4
University Masters or higher.....	5



## Appendix 5: Participant demographic survey



### Demographic Information

H1N1 Focus Group Participants – Seniors

Please provide the following information about you and your family. All responses will be kept confidential, and no individual information will be included in the final report. Only summary information about participants in general (e.g., total number of participants; range of ages and income; etc.) will be included in the project report.

1. What is your sex?
  - Male
  - Female
2. What is your current age? \_\_\_\_\_ years
3. What is your current marital status?
  - Legally married (and not separated)
  - Common law
  - Single (not married or common law)
  - Separated
  - Divorced
  - Widowed
4. What is the highest level of education you have achieved?
  - Less than high school
  - High school completion
  - Non-university diploma, certificate or trade
  - University degree – bachelor level
  - University degree – master's level or higher
  - Other: \_\_\_\_\_
5. What is your current employment status?
  - Homemaker who was not actively employed outside the home prior to retirement age.
  - Former workforce participant who is now fully retired from active employment.
  - On leave of absence (illness, disability) from paid employment
  - Employed part-time up to 15 hours per week, on average
  - Employed part-time, between 16 – 30 hours per week, on average
  - Employed 31 hours per week or more (full-time)
6. Please indicate your approximate household income (current). Include the income of all adults within the residence who are supporting the household. Do not include the incomes of tenants or children who are not contributing to household expenses.
  - Under \$25,000 per year
  - \$25,000 - \$49,999
  - \$50,000 - \$74,999
  - \$75,000 - \$99,999
  - \$100,000 - \$124,999
  - \$125,000 - \$149,999
  - \$150,000 or higher
8. Please indicate which household family members had received which vaccines **as of Jan. 31, 2010** (check all that apply). Only respond for family members or caregivers who were **living in your residence** on or before Jan. 31, 2010.
  - SELF – Received H1N1 (swine flu) vaccine
  - SELF – Received seasonal flu vaccine
  - SPOUSE/PARTNER: Received H1N1 (swine flu) vaccine
  - SPOUSE/PARTNER: Received seasonal flu vaccine
  - ADULT RELATIVES or CAREGIVERS RESIDING IN THE HOUSEHOLD: Received H1N1 (swine flu) vaccine
  - ADULT RELATIVES or CAREGIVERS RESIDING IN THE HOUSEHOLD: Received season flu vaccine
  - CHILDREN LIVING IN THE HOUSEHOLD: Received H1N1 (swine flu) vaccine
  - CHILDREN LIVING IN THE HOUSEHOLD: Received seasonal flu vaccine

***Thank you for your participation!***

## **Appendix 6: Focus group script**

### **General**

#### **1. Think back to when you first began hearing about “swine flu” or H1N1.**

##### PROBING QUESTIONS:

- a. What do you recall hearing about it at that time?
- b. From which sources did you hear about it? (i.e. Local/National/US television, radio, newspaper; nurse/physician/medical practitioner; word-of-mouth; Internet websites/forums/social media)
- c. Do you recall hearing different messages or types of information from different sources? What did the various sources of information tell you about "swine flu"?
- d. Describe your initial reaction to news of "swine flu".

#### **2. Tell me about your experiences re: getting more information about H1N1 as the issue unfolded and as you became more interested in staying informed. I am interested in finding out where you looked for information, and how useful or valuable various sources of information were to you.**

##### PROBING QUESTIONS:

- a. What would you say were the top sources for your information about H1N1? By this I mean the people, places, organizations or media that you relied on the most for information.
- b. Can you name specific sources of information (actual websites, newspapers, TV or radio programs, etc) that you consulted that affected your understanding of the "swine flu"?
- c. Considering the information you located on your own, as you started paying more attention to the issue, would you say this newer information was the SAME, or DIFFERENT, from the information you heard at very beginning, when H1N1 was first hitting the news.
- d. What specific sources of information did you find the most helpful or informative? How about the least helpful or informative? Why?
- e. Did you feel that you had access to enough information about H1N1?

- f. Overall, how would you say Alberta, or Canada, handled coverage of the H1N1 issue? Was it communicated to the public well or not so well, and why?

**3. What role did the Internet [defined broadly – including e-mail] play for H1N1/"swine flu"-related information?**

PROBING QUESTIONS:

- a. Do you use the Internet generally?
- b. Did you use the Internet for information about H1N1? If yes, what sites?
- c. Where you chatting with other people?

**4. Now think back to the time between April and October, which is the period where there was a lot of information coming out about H1N1, but there was not a vaccine available yet. I want you to think specifically about RISK.**

PROBING QUESTIONS:

- a. First, in your opinion, did you personally feel at risk, or not at risk, during this period when vaccines were still being developed?
- b. Did you believe that certain people or groups were at higher or lower risk than others?
- c. How did you define risk? What exactly does it mean to be "at risk" or "not at risk"?
- d. (SENIORS ONLY) Did you think the risk of H1N1 was the same or different than the risk of seasonal flu?

**Vaccination**

**5. Regardless of whether you ended up getting or not getting the H1N1 flu shot, tell me about your decision process, as well as your experiences carrying out whatever decision you made.**

PROBING QUESTIONS - ALL PARTICIPANTS

- a. Did you get the H1N1 flu shot? Why/Why not?
- b. When and where did you get vaccinated? How/where did you get information about where and when to get the vaccine?
- c. Did you have any positive, negative, confusing or other issues regarding eligibility?

- d. Did you encourage your family or friends to get the vaccine? Why/why not?
- e. Do you believe the vaccination campaign prevented H1N1 from becoming a serious pandemic?

PROBING QUESTIONS – SENIORS ONLY

- f. How did you find the process of H1N1 vaccine different from normal flu shots?
- g. How did you find the accessibility of vaccination centers? Tell me about your experience with eligibility for shots?

**Infection**

**6. In the end, do you think you ever had swine flu?**

PROBING QUESTIONS:

- a. Were you formally diagnosed with H1N1 influenza A virus or "swine flu"? Presumed by a medical professional to have it? Self-diagnosed as having it?
- b. In your opinion, how does H1N1 compare in severity to the seasonal flu?

## Appendix 7: Participant information and consent form



INFORMATION SHEET for the University of Alberta Research Project:

### ***H1N1 Knowledge Translation for Pregnant Women and Seniors: Sources, Content, Understanding, and Uptake***

**Purpose:** This research project seeks to better understand the communication challenges faced by public health agencies related to the 2009 H1N1/ “swine flu” outbreak and subsequent rollout of vaccination programs.

**Background:** Information availability, knowledge translation and communication are known to be critical strategies for potentially allaying public fears and promoting informed decisions on appropriate health protection behaviours. The goal of this research project is to assess whether these factors achieved their intended results, especially with vulnerable populations. This proposal focuses on two distinct vulnerable populations: (1) women who were pregnant or lactating between May 1, 2009 to January 31, 2010; and (2) seniors aged 65 or older. This study will examine the information available to these two populations, and how individuals accessed, understood, processed and acted on the information provided by public health agencies and other sources.

As a member of one of these groups, you are invited to participate in a focus group related to your experience of information availability during the H1N1 outbreak.

This research is being funded by the Canadian Institutes of Health Research (CIHR).

**Methods:** Focus groups are the first stage of collecting information for this study. In this phase, we would like to talk to you, as an informed member of the public. As part of our focus group, we will ask you some general questions on how you found out about H1N1/ “swine

flu,” and how you got information about the virus. We will also ask some questions about your decision to get vaccinated or not. You do not need to have received an H1N1/ “swine flu” vaccination to participate. We are interested only in your opinion. We anticipate that the focus groups will take approximately one and a half hours to complete.

The second stage of this research involves surveying up to 1000 Canadians on their experiences. The information from focus groups will serve as the basis for the survey questions. The third stage of this research involves interviewing members of the media who covered the H1N1/“swine flu” story.

**Incentive:** As a participant in this study, you will be offered an honorarium in recognition of your contribution to the study and to cover any costs associated with attending the session.

**Benefits:** Results from the study will be useful to various federal, provincial and regional health agencies to determine the importance and effectiveness of different types of communication, and to plan for future events. Specific benefits will include: (1) providing a comprehensive and critical assessment of the knowledge translation and communication strategies used for pregnant women and seniors; and (2) providing recommendations on how to enhance the development of effective communication strategies and actions (including use of Web 2.0) to improve knowledge translation for a similar event.

**Risks:** There is no identifiable risk from participating in this project.

**Withdrawal from the Study:**

Even after you have agreed to participate in the focus group you can decide at any point you do not wish to continue. Up to the end of the focus group, you may decide that you do not want what you said to be used. The researchers then cannot use this information.

**Confidentiality:** We ask all focus group participants to maintain other group members' confidentiality and not disclose information that would identify anyone in the group. You will be given a pseudonym in all research documents to protect your identity and confidentiality.

**Use of the Information:**

From the results of this research, the researchers will make recommendations to policy makers about how to better communicate health concerns with the public. The results may also be used in academic presentations and be published in academic journals.

**Contacts:** This study is co-run by Drs. Lisa Given (School of Library and Information Studies), Cindy Jardine (School of Public Health) and Tania Bubela (School of Public Health). You can reach Dr. Given at the following addresses:

School of Library & Information Studies  
3-20 Rutherford South, University of Alberta  
Edmonton AB, Canada T6G 2J4  
Ph: 780-492-2033 Fax: 780-492-2430  
Email: [lisa.given@ualberta.ca](mailto:lisa.given@ualberta.ca)  
Web: <http://www.ualberta.ca/~lgiven>

**Additional Contacts:**

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education, Extension, Augustana and Campus Saint Jean Research Ethics Board (EEASJ REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EEASJ REB c/o (780) 492-2614.



## CONSENT FORM

### To Participate in the University of Alberta Research Project:

*H1N1 Knowledge Translation for Pregnant Women and Seniors:  
Sources, Content, Understanding, and Uptake*

Investigator:

**Dr. Lisa Given**

**School of Library and Information Studies**

**University of Alberta**

**(780) 492-2033**

Do you consent to being audio-taped?	Yes	No
Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you can quit taking part in this study at any time? You do not have to say why.	Yes	No
Has the issue of confidentiality been explained to you?	Yes	No



Do you agree to maintain other group members' confidentiality and not disclose information that would identify anyone in the group?      Yes      No

Do you understand who will have access to the records from these discussions?      Yes      No

Do you understand that the information you provide will be used to make recommendations for communicating health issues with the public?      Yes      No

Can we use this information in the future for presentations and publications?      Yes      No

This study was explained to me by: \_\_\_\_\_

I agree to take part in this study.

\_\_\_\_\_  
Signature of Research Participant                      Date                      Printed Name

I would like to receive a copy of research results (check one):       No       Yes

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

\_\_\_\_\_  
Signature of Investigator    \_\_\_\_\_  
Date

## Appendix 8: Ethics approval

### Notification of Approval - Delegated Review

Study ID: Pro00015108

Study Title: H1N1 Knowledge Translation for Pregnant Women and Seniors: Sources, Content, Understanding, and Uptake

Study Investigator: Lisa Given

	Approval Date	Approved Document
Date of Informed Consent:	6/29/2010	<u>Focus Groups Info/Consent Letter</u>
	6/29/2010	<u>Media Info/Consent Letter</u>

Funding/Sponsor: Canadian Institutes of Health Research

Thank you for submitting the above ethics application to the Education, Extension, Augustana and Campus Saint-Jean Research Ethics Board (EEASJ REB). Ali Shiri has reviewed your application and, on behalf of the EEASJ REB, approved it as of June 29, 2010. The approval will expire on June 28, 2011.

A renewal report must be submitted prior to the expiry of this approval if your study still requires ethics approval at that time. If you do not renew before the renewal expiry date, you will have to re-submit an ethics application.

Sincerely,

Dr. Stanley Varnhagen  
Chair, Education, Extension, Augustana and Campus Saint-Jean Board (EEASJ REB)

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*