

# Journal of Risk Research



ISSN: 1366-9877 (Print) 1466-4461 (Online) Journal homepage: https://www.tandfonline.com/loi/rjrr20

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To cite this article: S. Michelle Driedger, Ryan Maier & Cindy Jardine (2018): 'Damned if you do, and damned if you don't': communicating about uncertainty and evolving science during the H1N1 influenza pandemic, Journal of Risk Research, DOI: 10.1080/13669877.2018.1459793

To link to this article: <a href="https://doi.org/10.1080/13669877.2018.1459793">https://doi.org/10.1080/13669877.2018.1459793</a>

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# 'Damned if you do, and damned if you don't': communicating about uncertainty and evolving science during the H1N1 influenza pandemic

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#### **ABSTRACT**

During the 2003 SARS outbreak in Toronto, Canada, communication with the public was poorly executed by health authorities. Key problems included mixed and unclear messages, widespread public confusion, and attributions of incompetence toward health officials. Subsequently, Canadian health officials developed pandemic plans that included specific sections dedicated to communication. Plans counseled a strategy of transparent risk messaging to give people the information they need and build public trust. When the H1N1 influenza pandemic arrived in Canada in 2009, these plans were put to their first test in a major public health event. However, many of the same problems that existed during SARS arose again during pH1N1. This study investigates the dissonances between the ideals and reality of communication during pH1N1 based on analyses of two data sources: (1) key informant interviews with senior health officials (n = 28) from federal and three provincial (Alberta, Manitoba, Ontario) health jurisdictions in Canada; and (2) focus groups (n = 15) with general population Canadians (n = 140) in Alberta, Manitoba, and Ontario. Discussions with participants showed that even with a transparent communication approach, aspects of the pandemic, such as its 'risk' and the complexities of the immunization campaign, proved difficult to convey without causing public confusion. Members of the public often resorted to their own inventories of knowledge – usually those related to seasonal influenza - to interpret and make sense of pandemic messaging, but these did not guarantee accurate understandings. The inherent uncertainty of a real-time pandemic was also a difficult concept to communicate to a public with little prior experience of such an event. While transparent communication was intended to build trust, resulting confusion fueled a loss of confidence in health officials. A more 'reasoned' approach to transparency needs to inform future pandemic communication and further research is required to determine how to refine such an approach.

#### **ARTICLE HISTORY**

Received 7 November 2016 Accepted 10 February 2018

#### **KEYWORDS**

Risk communication; transparency; Canada; infectious disease outbreak; immunization

#### Introduction

During the H1N1 pandemic in Canada, health authorities across the country implemented pandemic plans which emphasized the importance of communicating with the public in an open,



clear, and transparent fashion. However, Canadian media coverage during pandemic (Alphonso 2009; Babbage 2009; Picard 2009) and follow-up evaluations conducted by health authorities themselves (Public Health Agency of Canada 2010) generally agreed there was considerable public confusion concerning the nature of both the pandemic itself and the organized response activities (i.e. the immunization campaign). To our knowledge, there has yet to be a systematic attempt to investigate how a transparent communications approach could not prevent significant public confusion and the unintended consequences that can arise if efforts fall short of their goals.

# **Background**

### Pandemic preparedness in Canada: communication, transparency, and trust

During the SARS outbreak in Toronto in 2003, communication with the public was poorly executed by health authorities, leaving many people mired in confusion and having to wade through a variety of mixed messages and perceived disagreement among experts and officials (Health Canada 2003; Campbell 2004: MOHLTC 2006: Tvshenko and Paterson 2010), With these lessons still fresh and the specter of potential threats looming large on the horizon (i.e. H5N1 influenza), federal and provincial/territorial health authorities began developing pandemic preparedness plans, including sections dedicated specifically to 'communication' (Government of Manitoba 2006: Public Health Agency of Canada 2006; Government of Alberta 2008; Government of Ontario 2008).

Pandemic outbreaks are characterized by many areas of uncertainty and evolving science: the unpredictable and changing details related to potential scale, risk, and severity of the outbreak; the differing categories of vulnerable people and patterns of mortality; and the development of response efforts (Morens and Taubenberger 2011). Such ambiguities create challenges for clear, consistent, and understandable messaging. To meet these challenges, Canadian pandemic plans incorporated best practice guidelines of the World Health Organization and principles of Health Canada's Strategic Risk Communication Framework (World Health Organization 2005; Health Canada 2006).

A cornerstone of strategic risk communication is transparency. Transparency commits health officials to communicate pandemic information that is 'candid, easily understood, complete and factually accurate [... and which ...] allows the public to 'view' the information-gathering, riskassessing and decision-making processes' of response efforts (World Health Organization 2005, 4). Along with providing clear information about 'risks, benefits, and risk mitigation options,' transparent communication also aims to put the health system's underlying 'assumptions and values' on full display (Health Canada 2006, 7). During a pandemic, transparency means being open about its inherent uncertainty, and that people should be told what is known, unknown, and evolving, and that response efforts may likewise change as new evidence emerges. While these principles are still endorsed by leading expertise (Council of Canadian Academies 2015), the H1N1 pandemic was the first time that the newly developed plans and their transparent communication approach was put to a real-world test.

Transparency is also a means to foster and maintain trust in public health authorities (Public Health Agency of Canada 2006). During a pandemic, the public is generally expected to assist in mitigation efforts by preventing infection and transmission by adopting personal protective behaviors (i.e. hygienic practices and/or being immunized). Since many laypeople will lack the specific scientific expertise that underpins pandemic epidemiology and response efforts, they will have to trust that experts and health system officials are giving them pertinent and timely information on how to best protect themselves (World Health Organization 2005; Prati, Pietrantoni, and Zani 2011a; Dupras and Williams-Jones 2012). Trust in risk managers provides a means to cope with the complexities and uncertainties inherent to a pandemic situation (Siegrist and Zingg 2014).

# Challenges for trust

Trust focuses attention on the relationships between the lay public and risk experts and how the latter can influence the risk perceptions and intentions of the former. However, it is not simply a unidirectional flow of information. Wynne (1993, 1996a, 1996b) and others (Bostrom 1997; Sjöberg 1999; Joffe 2003) have shown that experts and the lay public are invested in situated, epistemic, social, and personal commitments and both dialogically (co-) interpret and (co-) negotiate knowledge in ways that reflect their specific local contexts, knowledge, and identities. Wynne (1996a) further argues that there is no guarantee that trust in experts will automatically result because it is also influenced by the degree of dependency, ambivalence, or powerlessness people can feel about the information they receive from experts. These dynamics suggest an unavoidable challenge for pandemic risk communication – especially when the threat seems relatively ambiguous: while trust is generally accepted as a crucial element in pandemic risk mitigation, the public negotiates the information they receive from health authorities according to their own personally and socially derived experiences, interests, and concerns (Dupras and Williams-Jones 2012).

While many people may receive and trust information from experts as intended, many others may reframe, misinterpret, disagree with, lose confidence in, or distrust expert risk information for many different reasons. For instance, Joffe (2011) and Holland and Blood (2013) have argued that the lay public can respond to pandemic risk information through particular strategies – i.e. blaming institutions or social groups, or metaphorically distancing themselves from the risk. Or, when people reflect on repeated warnings of impending pandemics that have not materialized (i.e. SARS, H5N1 influenza), they may begin to lose interest and experience emerging infectious disease fatigue. The media also plays a pivotal role as a mediating channel between experts, however it will only figure peripherally in this article (while being the subject of another forthcoming paper that is part of the same research study). Our focus here will be more exclusively on words and actions of health officials and the associated perceptions of the public during the H1N1 pandemic. Taken together, we may envisage both sides as being partners in (an attempt at) a conversation.

# Pandemic research and the Trust, Confidence, and Cooperation Model

The H1N1 pandemic provided an opportunity to research public perceptions on various aspects of the outbreak (Prati, Pietrantoni, and Zani 2011b; Agarwal 2014; Yang 2015). Notably, surveying the public's trust in government/health authorities also garnered increased research interest (Freimuth et al. 2013; Quinn et al. 2013). Using a theoretical framework called the Trust, Confidence, and Cooperation (TCC) Model, Siegrist and Zingg (2014) reviewed much of the trustbased research and assessed that trust between the public and their respective health authorities was a common factor in increasing the likelihood that people would adopt recommended protective behaviors - like being vaccinated.

The TCC Model (Siegrist, Earle, and Gutscher 2003; Siegrist, Gutscher, and Earle 2005; Earle, Siegrist, and Gutscher 2007; Earle and Siegrist 2008) is a dual-pathway framework that functions much like similarly structured models that are also organized into binaries of feelings/emotions and cognitive/rational routes to processing risk information (Zajonc 1980; McAllister 1995; Finucane et al. 2000; Slovic et al. 2004). In all cases, pathways can be interactive and dynamic as people can employ one or both while they make judgments about either any risk information received and/or its communicators (Figure 1).

The TCC Model holds that trust is a measurement of similar values or moral appraisals. Applied to a pandemic scenario, one may judge openness and transparency in communication as signaling a shared (and expected) value of honesty and accountability, with which they may more positively assess the veracity of the messaging. The pathway of confidence involves evaluations of the past experience and knowledge one has of an event or issue, or of the past performance of the people/organizations involved. Confidence evaluations can provide assurance that

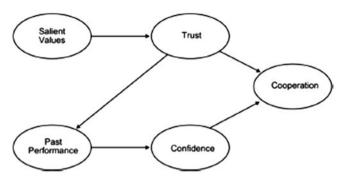


Figure 1. The Trust, Confidence, and Cooperation (TCC) Model. Reproduced with permission from *European Psychologist* 2014; Vol. 19(1):23–32. doi: 10.1027/1016-9040/a000169. © 2013 Hogrefe Publishing www.hogrefe.com.

events will proceed as expected. However, if one's past experience suggests an alternative interpretation of events, or if one believes that health authorities' actions have shown them to be incompetent or to lack accountability, people may lose confidence in associated messaging about risk and protective behaviors. Aside from one study (Jardine et al. 2013), all other research using the TCC Model has been quantitative in method or based on hypothetical risk scenarios – not on people's narrated perspectives of an unfolding major public health event.

### The prospect of confidence in risk communication

Like Siegrist and Zingg, this study also employs the TCC Model as a guide for analysis, but with a fundamental shift of focus. If we retain the framework of the TCC Model at its full binary scope, the pathway of confidence still stands largely and curiously unexamined in the pandemic context. Siegrist and Zingg (2014) only provide a cursory mention of people's existing vaccine knowledge in this regard. We now pivot from the domain of trust, and turn to the potential modalities of the confidence pathway that may fall within its purview in a pandemic context.

First, if the terrain of confidence incorporates assessments of knowledge and past experience, we propose that the domain can also integrate the insights of Wynne, Joffe, and Holland and Blood noted above. Although individuals may not have experience with a pandemic situation, most people do have knowledge and experience of seasonal influenza and its attendant vaccination campaigns. This knowledge is locally, personally, and socially situated in reflexive ways that can influence how people interpret and negotiate pandemic messaging. Secondly, if transparency requires that a pandemic's inherent uncertainty needs to be clearly communicated, prior to the H1N1 pandemic most people would have had little to no past experience with pandemic uncertainty. Lastly, in terms of performance evaluations, the public's day to day experience of health officials' response activities offered a cumulatively growing pool of information upon which the public could reflexively make judgments over time. We propose that it is on these confidence-based accounts that a better understanding can be had on why a transparent communication approach was still met with significant public confusion.

#### Pandemic H1N1 in Canada

A timeline of significant developments and events during the pandemic and the response efforts provides the necessary context for this study's results (see Table 1). From that chronology, two key areas emerge with which to explore how certain aspects of the pandemic invited confusion and challenged transparent communication: perceptions of pandemic risk and the immunization campaign.



meline of the H1N1 pandemic in Canada – key events.

2003-2009

Table 1. Timeline of the
Pre-pandemic period SARS and pandemic plan development
Pandemic period Wave 1 (12 April–29 August 2009)
Wave 2 (30 August 2009–27 January 2010)

Following SARS, Canada establishes the Public Health Agency of Canada (PHAC) as the lead federal actor to prepare for and respond to threats of an emerging infectious disease

PHAC develops national pandemic plans which form the template for similar plans created by provincial/territorial health authorities (who are ultimately responsible for the delivery of health care programs and services and for implementation of policy in their respective jurisdictions)

Pandemic plans are based at minimum on a moderately severe pandemic scenario (predicting up to 138,000 hospitalizations and up to 58,000 deaths)

April-May

First cases of H1N1 infection confirmed in Canada. From the earliest infections and throughout the pandemic, most cases are characterized by relatively mild symptoms. However, one of the unique aspects of the H1N1 virus was that it was younger people who were more vulnerable than people who were older than 65 years of age (the opposite of the risk profile for seasonal influenza)

Multiple jurisdictions (federal, provincial/territorial, regional/ municipal) across Canada launch simultaneous respective risk communication campaigns to provide Canadians with current information about the emerging virus. Information includes rates of hospitalization and deaths and preventive messaging (personal hygienic practices that are also advised for seasonal influenza) and mitigation efforts. This means that the public was receiving risk communication from multiple jurisdictions

World Health Organization declares the H1N1 outbreak as a global pandemic

Peak H1N1 activity reached in Wave 1

Especially in Manitoba, a number of First Nations communities experience high rates of severe infection which leads to surge of cases almost overwhelming intensive care and ventilator capacities

Health Canada procures contract with a single vaccine manufacturer to produce 50.4 million doses of H1N1 vaccine, with assurances that when it is ready it will be freely available to everyone who wants to be vaccinated

Canadian Health Minister Leona Aglukkaq remarks to the media: 'What may come this fall [with the second pandemic wave and immunization campaign] is something that could test all of us, possibly to a limit we've never experienced' (Public Health Agency of Canada 2010, 47)

Vaccine production delays for numerous reasons: sole-source procurement meant finite production capacity; manufacturer instructed by Health Canada to first complete production of seasonal influenza flu vaccine; H1N1 production switched midstream to produce an unadjuvanted version for pregnant women. Such delays reduced projected supply for the first weeks of the planned immunization campaign

In response to anticipated early limited supply and batched distribution across Canada, through PHAC the federal Chief Public Health Officer releases guidance document on recommended priority sequencing for vaccine distribution. Those considered most vulnerable to H1N1 were prioritized to be among the first to receive the vaccine once made available

Results of a study (that had not yet been peer-reviewed or published) were leaked that showed that seasonal influenza vaccination may actually increase risk of H1N1 infection. This prompts most provinces to suspend seasonal influenza immunization for people under 65 years of age when the H1N1 vaccine is finally ready for distribution (though some provinces maintain standard seasonal influenza vaccine availability)

lune

July-August

August-September



#### October-November

- 26 October: the first batches of H1N1 vaccine arrive at distribution centers across Canada. Although PHAC issued sequencing quidelines, each provincial health authority often adapted and altered the recommended priority groups respectively to reflect their own capacity and patterns of disease activity
- 26 October: A 13-year-old Ontario teenager dies from H1N1, prompting widespread media coverage across Canada. The child's death sparks renewed fears about the virus' potential severity and massive lineups at vaccine clinics
- Peak H1N1 activity for Wave 2 is reached in early November
- Wave 2 showed significantly more H1N1 activity than Wave 1, with four to five times more hospitalizations and deaths

#### December-January 2010 •

- Rates of infection decline and response efforts begin demobilization. Overall, the H1N1 virus proved to cause mild symptoms for most people, but was severe for a small portion of those infected
- In Canada, about 40% of the population was immunized for H1N1, which is slightly higher than the usual rates for seasonal influenza vaccination
- During the pandemic, there were over 40,000 laboratory-confirmed cases of H1N1 infection in Canada (however, this number is considered a substantial underestimation of actual cases. because many people were not tested, and many tests did not distinguish between types of influenza - which also prohibits a clean comparison between rates of H1N1 and seasonal influenza infection)

Source: CBC News (2009c, 2009d, 2009e, 2009f, 2009g), Fitzpatrick (2009), Kendal and MacDonald (2010), Moghadas et al. (2011), and Public Health Agency of Canada (2010).

While pH1N1 came to be seen as relatively mild for most who were infected (CBC News 2009b), high profile events in each wave (i.e. hard hit First Nations communities in Wave 1 and the high-profile death of an otherwise healthy teenager in Wave 2) also made clear the lethal potential of the virus and significantly amplified public fear. The death of the teenage child also confirmed a key difference in the mortality profiles of risk groups between seasonal influenza and pH1N1: most people who die from seasonal flu are over 65 years of age, whereas younger people were more at risk for severe H1N1 (Public Health Agency of Canada 2010). Thus, the risk posed by the pandemic existed along a spectrum from mild (akin to seasonal influenza) to severe (portending a much worse scenario).

The nationwide immunization campaign was the first of its kind and scale in Canada. Above all, the decision to prioritize certain at-risk groups to receive the vaccine first became the defining feature of the campaign and also introduced a cascading series of complex and potentially confusing elements. While access to the vaccine was universally guaranteed, the timing was delayed (at least initially) and implementation of priority groups was not uniform across the country (see Table 2). Further, Wave 2 coincided more closely with arrival of seasonal influenza and the priority groups for H1N1 were different than those traditionally recommended to receive the seasonal vaccine (e.g. the seasonal flu vaccine is traditionally recommended for those over 65 years of age, but the H1N1 vaccine was not). When vaccine distribution finally began, it occurred in the same week that the teenager in Ontario died. Clinics were soon overwhelmed with long lineups of people wanting a vaccine but who faced being turned away if supplies ran out or if they were not on priority lists (and young people were not).

During the pandemic, media commentators remarked that information about pandemic risk and the vaccination campaign was indeed marred by health officials giving 'mixed' and confusing messages (Alphonso 2009; Babbage 2009; Picard 2009). Thus, it would seem that pandemic plans were not as effective as had been hoped in preventing a recurrence of some of the same communication problems that arose during the SARS outbreak. In this article, we aim to document how public confusion about risk messaging may have arisen even though newly developed



Table 2. H1N1 vaccine priority lists for Manitoba, Ontario, and Alberta.

### Province/Agency

## Prioritized groups - Vaccine availability

Public Health Agency of Canada - issued a guidance document on H1N1 vaccine sequencing (16 September 2009)

- People with chronic medical conditions under 65 years old
- Pregnant women
- Children six months to under five years old
- People living in remote and isolated settings or communities
- Health care workers involved in pandemic response or who deliver essential health services
- Household contacts and caregivers of individuals who are at high risk, and who cannot be immunized (such as infants under six months old or people with weakened immune systems)
- Populations otherwise identified as high risk

Week of 26 October 2009 – H1N1 vaccine becomes available to:

- Children aged six months to under five years old
- Anyone of Aboriginal ancestry (First Nations, Métis, or Inuit)
- Disadvantaged individuals (for example, the homeless)
- People living in remote or isolated areas
- People under 65 with a chronic medical condition or other risks including severe obesity, substance abuse, or alcoholism
- Anyone with a weakened immune system or those who live with or care for them
- Those who live with or care for infants under six months old
- Single parents or anyone response for a dependent
- Health care workers and medical first responders
- Pregnant women

11 November 2009 - H1N1 vaccine available to:

Children six months to under 18 years old

18 November 2009 - H1N1 available to all Manitobans

Week of 26 October 2009 - H1N1 vaccine becomes available to:

- People with chronic medical conditions under the age of 65
- Children between the ages of six months and five years
- Pregnant women
- People living in remote and isolated communities
- Health care workers
- Household contacts and care providers of infants less than six months of age and persons who are immunocompromised

10 November 2009 - H1N1 vaccine available to:

- Front line first responders (police and firefighters)
- Institutional correctional workers
- People aged 65 and older who live in institutions like long-term care homes 16 November 2009 - H1N1 vaccine available to:
- Children under 13 vears old
- Adults 65 years and older with underlying health conditions

19 November 2009 - H1N1 vaccine available to all Ontarians

Week of 26 October 2009 – H1N1 vaccine becomes available. Vaccination clinics are open to all Albertans.

- 31 October 2009 Vaccination clinics are suspended due to supply shortages
- 4 November 2009 H1N1 vaccine available to:
- Health care workers
- 5 November 2009 H1N1 vaccine available to:
- People living in remote and isolated communities
- Pregnant women
- Children six months to four years old

10 November 2009 - H1N1 vaccine available to:

- Children under 10 years old with chronic conditions and parents of infants under six months old
- 12 November 2009 H1N1 vaccine available to:
- People with chronic conditions aged 55 to 64 years old and people with chronic health conditions aged 10 to 17 years old
- 13 November 2009 H1N1 vaccine available to:
- People with chronic conditions aged 45 to 54 years old
- 14 November 2009 H1N1 vaccine available to:
- People 18 to 44 years old with chronic conditions as well as a household contact of people who cannot be vaccinated.
- 17 November 2009 H1N1 vaccine available to:

Manitoba

Ontario

Alberta

(continued)



Province/Agency	Prioritized groups – Vaccine availability			
	Seniors over 75 years old plus their spouses/partners of any age			
	<ul> <li>19 November 2009 – H1N1 vaccine available to:</li> <li>Seniors 65 years and older plus their spouses/partners of any age</li> <li>20 November 2009 – H1N1 vaccine available to:</li> </ul>			
	<ul> <li>Children under 18 years old plus their families members and caregivers in the same household</li> </ul>			
	23 November 2009 – H1N1 vaccine available to all Albertans			

ty Council of Alberta (2010), and MOHLTC (2010).

and laudable communications principles were put into practice specifically to avoid such issues. There is currently little research investigating the intersection of risk communication implementation dilemmas and public reactions, specifically with respect to uncertainty and changing information (Gesser-Edelsburg et al. 2014), and what does exist is primarily experimental in design and hypothetical in nature (Jensen et al. 2016).

#### Methods

We have used a qualitative approach to connect the perspectives of health officials and members of the public. Two data sources are used in this research: (1) key informant interviews held with senior level officials; (2) and focus group discussions with members of the general public. The University of Manitoba's Health Research Ethics Board approved this study (H2010:182).

We conducted 28 key informant interviews following the H1N1 pandemic with senior health officials working at federal, provincial (Alberta, Manitoba, Ontario), and local jurisdictions. Officials' roles included Chief Medical Officers of Health, Chief Public Health Officers, communications directors and managers for federal, provincial, and local health organizations, Chief Executive Officers of Regional Health Authorities, as well as managers of public health and emergency planning offices. Interviews were semi-structured and participants were asked to share their experiences during the pandemic and what their role entailed, plus any defining moments, challenges, and successes. Interviews were transcribed verbatim and audio-verified before being imported into NVivo9 for analysis. A coding guide was generated through an iterative reading and analysis of the data's surface content. Issues identified for inclusion into this article are a subset of themes that were coded as communications challenges that health officials faced during the pandemic. Representative quotes are used to illustrate common themes related to the topics under investigation. Given the senior posts held by many public health key informants, we do not attribute any direct quotation to any specific jurisdiction as this could provide potentially identifying information thereby compromising confidentiality.

We also conducted 15 focus groups conducted with general population Canadians (n = 140) in three provinces (Alberta, Manitoba, Ontario). Discussions with participants focused on public perspectives of the health system's response efforts. Transcripts were analyzed and coded in the same fashion used for key informant data. Representative quotes are included that relate to the public's views of health systems communication activities and the challenges they saw. As such, these results contextualize as well as corroborate key informant data. Table 3 provides demographic information about the focus group participants.

#### Results

#### **Key informant interviews**

Public health officials - whether public or Medical Officers of Health, public health scientists, or communications officials - were generally knowledgeable and well-versed about the



Table 3. Characteristics of H1N1 focus group participants.

	Overall % (n = 140)	Edmonton, Alberta (%) $(n = 28)^a$	Winnipeg, Manitoba (%) $(n = 54)$	Toronto, Ontario (%) $(n = 58)^{b}$
Gender				
Men	48.5	50.0	46.3	50.0
Women	51.5	50.0	53.7	50.0
Age (years)				
18–34	26.9	32.1	31.5	18.8
35-54	36.9	32.1	35.2	41.7
55+	36.2	35.7	33.3	39.6
Education				
Less than High School	3.8	3.6	3.7	4.2
High School Degree	21.5	14.3	27.8	18.8
Some	23.1	21.4	24.1	22.9
College/University				
College/	51.5	60.7	44.4	54.2
University Degree				
Income (Can \$)				
Less than 50,000	33.6	29.6	41.5	27.1
50,000-75,000	29.7	40.7	26.4	27.1
75,000-100,000	18.8	22.2	11.3	25.0
100,000+	18.0	7.4	20.8	20.8
H1N1 Vaccine (yes)	37.0	33.3	40.7	34.8
Seasonal Influenza Vaccine (yes)	36.7	32.1	37.0	39.1

<sup>&</sup>lt;sup>a</sup>Only 3 focus groups (18–34, 35–55, 55+) were conducted in Edmonton.

transparency elements that were part of strategic risk communication plans. However, most then outlined the difficulties they faced in putting those principles into practice. The following quote captures a persistent theme that was heard in most interviews:

The theory and research tells us that citizens are more responsive to your messages if they're treated like mature adults, that they're shown respect, that if you don't know something, you tell them you don't know something, and you signal that things will change as new information becomes available. We played it that way, right? I mean, the [Medical Officer of Health] every day would say 'what we know today is this, and that could change,' right? And a week later, they'd come back and say 'I said that something could change and it has. So here's how we're adapting now. This is why we're making the following recommendation.' The theory is you're open, you're transparent, you say what you don't know and people will track along with you. And yet the criticism came that we were changing our minds and that we didn't know what our policy was. We understand the [risk communication] theory, we understand the approach ... it was in the implementation that it then became very, very challenging.

Theory set the ideal, but practice identified the obstacles, of which the participants offered some similar examples. First, there were the challenges stemming from the nature of the pandemic itself. Communicating the uncertainty of pandemic risk was a common problem alluded to by all key informants. The risk posed by the virus was an abstract concept that did not translate well into simple and clear messaging.

Risk for a pandemic - that's sort of the mother of all risk communications in some ways because it's a disease, it's unknown, it's vague, you don't know when it's coming, but you certainly need to be prepared for it. It's a bit of a nightmare to try and communicate.

Another participant further argued that people do not all interpret terms like 'high risk' and 'low risk' in the same way – whether they are expert or lay populations. For them, the key dilemma was to be able to communicate 'risk' in a way that tried to make it more tangible and that most people could apply some value of comparability.

Nevertheless, some public health officials maintained that in the midst of a mild to moderate pandemic the need to avoid downplaying risks as well as not 'crying wolf' meant that their

<sup>&</sup>lt;sup>b</sup>Only demographic data from 5 (of 6) focus groups is available. No data were collected for one focus group (10 participants) held in Toronto, age category: 55+. Thus, only demographic data for 48 of the 58 Toronto participants can be included in Table 3.



preferred approach was just to try to communicate the known evidence. However, the threat posed by the pandemic was open to contradictory interpretations which could feed perceptions of 'mixed' messaging about pandemic risk. Even admitting that H1N1 was not exceedingly threatening for many people clashed with needing to advise the public that getting vaccinated would still be their best protection.

A lot of people said we're giving mixed messages. On the one hand I'm reassuring people this [pandemic] isn't so bad. On the other hand I'm saying but you should get vaccinated. So how do you get that through without confusing people?

One participant pointed to an example where another contemporary prominent health official publically claimed that many health authorities were indeed 'crying wolf' and had overstated the risk of H1N1 (CBC News 2009a), giving further impressions of mixed messages and expert disagreement. Additionally, most key informants acknowledged little control over media framings and hype that unnecessarily amplified the risk of the pandemic.

Second, all participants recalled experiences where scientific knowledge was emerging in 'real time' and constantly evolving – i.e. new risk profiles were emerging, severity was unpredictable, and disease management was necessarily ad hoc. Communicating this fluid and changing information each day was challenging, and it was a new experience for many officials who were involved.

The first wave, with how sick they became and the fact that it was a different [younger] population group getting sick. So I think that was surprising. And how much ICU time they needed, that these lungs virtually turned into cement, and nobody had seen anything like that ever. There were no previous experiences that said well if we just do this or just do that. So we were figuring out how to manage the illness on the fly.

Moreover, participants acknowledged that adapting to new evidence and adjusting response measures accordingly left the impression that health officials were inconsistent and potentially unable to responsibly handle a major public health crisis:

Our communications were shifted to address whatever the new evidence was coming out [...] People saw it, going, 'I don't think they know what they're doing,' and it's just a part of how we do our business [...] We're adapting.

Confusion over seemingly 'mixed messages' were also attributed to the fact that multiple levels of government were conducting their own communication campaigns and were speaking toward evidence contextualized to their respective jurisdictions.

So those risk communications messages were not the same everywhere at every moment at the same time, because we weren't mitigating the risk quite in the same way. So you're damned if you do and you're damned if you don't. We felt they were always complementary messages [...] but some interpreted that as mixed and confusing.

More generally, some participants opined that some of the public's confusion over mixed messages could be attributed to the public having little experience with an evolving situation like the pandemic and its inherent uncertainty. During the pandemic, many individuals may not be as familiar as health experts with the process of cumulatively adding bits of new (and potentially unanticipated or contradictory) knowledge on a daily basis.

Third, almost every aspect of the vaccine campaign seemed liable to invite accusations of inconsistent or 'mixed' messaging. Managing the public's expectations proved difficult, as vaccine shortages in the beginning meant having to say that only limited amounts would be available, and prioritization of certain groups clashed with assurances that everyone wanting the vaccine could receive it. H1N1 prioritization did not match up with seasonal influenza priority groups, and distribution sequences were inconsistent between provinces. With the public receiving communications from multiple layers of government, they would have seen different decisions being made. Along with surges in demand and large lineups at many vaccine clinics, it was a risk communication 'perfect storm' (as one participant put it).

Between the priority groups and vaccine shortage, to me, are some of the defining moments of this particular pandemic because they were challenging public messages. We did them in daily briefings, we had them on the web, we put them in ads, we put them in all kinds of places, but it was just very complex for people. They [the public] were stressed and uncertain and particularly about their health and the health of their family, and they want things to be simpler. [People said] 'This is too hard; this is too complex.'

Ultimately, many participants acknowledged that public perception of mixed messages was often an unavoidable consequence given the uncertain nature of the pandemic, with some referring to the situation as being caught in a 'catch 22.' In such circumstances, some degrees of confusion were perhaps inevitable despite officials' best efforts to communicate uncertain and evolving information with the public. Unfortunately, it also carried the potential for a loss of confidence in health officials as well, leading some people to turn to other sources of information that offered greater certainty.

And all through H1N1 you had that uncertainty that you had to build into our message, and as our message was changing to accept the current evidence, what ends up happening is we lose the credibility as we move. Instead of gaining credibility by saying, 'hey, we're adapting to what we know and what we don't know,' that worked against us. And in a world where people were looking for the certainty they were gravitating towards people who were saying, 'You know, that vaccine is bad for you,' or media who are saying, 'You know what? Don't get the vaccine because they're dropping the ball. It's three and four hour long waits.'

### Focus group discussions with members of the public

Overall, a consistent theme heard from most focus groups was that many people had been frustrated with confusing, contradictory, and mixed messages that they were receiving from public health officials (to be sure, many participants stated that they had been keen to try to keep the messaging from media and health officials distinct, and generally preferred receiving health information directly from health authorities). In terms of their perceptions of pandemic risk, such confusion hampered many participants' ability to assemble a clearer picture of the threat the pandemic posed. They often noted how overwhelmed they felt by the sheer amount of information they were receiving from health officials, yet more disconcerting was that information always seemed to be changing.

The numbers were changing on how many deaths there were - just constantly going up or down. You didn't know what was going on. There was too much information and it was too scattered. It kept changing and almost built up a panic more from that [than the pandemic itself].

One point that was relatively common was that participants felt some confusion over who was the ultimate authority in leading the pandemic response. Many participants noted that they would have wanted to have a more consistent 'voice' of the health system, but instead were met with competing messages coming from multiple experts or levels of government. This left some wondering about who possessed the final word on what the facts of the pandemic actually were.

The only problem is it seemed like it was always conflicting. Like they would be saying one thing and then the Minister of Health would come out and then the head doctor or whatever would come out and say another thing and then provincially [someone] would say something different, and it seemed like it was always changing - it was a moving target type of thing - it didn't give you a reassuring feeling.

However, a bewildering array of risk messaging about the virus did not generally prevent participants from reaching their own conclusions about pandemic risk. In fact, many focus group participants reported that they had not been very concerned with the risk posed by the pandemic (only 37% reported being vaccinated) and many arrived at that determination through personal risk calculations and observations. Many participants acknowledged that H1N1 could be quite severe for some people, but viewed seasonal influenza in much the same way, and the comparison often produced more benign judgments about the pandemic's risk - especially as the rates of H1N1 mortality were not very alarming to them and the recommended personal protective hygiene practices were identical to seasonal influenza. Most also agreed that fear about the severity of the virus had been unreasonably hyped by media outlets.

I treated it just like another virus so it wasn't something that was exceptionally concerning. I mean it was, they said it was quite a nasty bug, to be prepared for it, but it seemed like they were planning for the worst and I wasn't seeing, you know, like mass proportions; like people weren't going in droves into the hospital or anything.

I felt if I could stay on top of things and cough in my shoulder, wash my hands, try and eat a little bit more healthy, then I should be fine.

At the same time, many other participants had felt more at risk from H1N1, especially when they heard that it could severely affect younger people. Some (but not many) also indicated that they were included in a priority group (i.e. they had been pregnant during the pandemic or had an immunocompromising condition) and that status elevated their sense of risk. Most commonly, it was the story of the death of the young teenage boy in Ontario and his grieving parents that substantiated the potential threat of the virus.

What was so shocking about about H1N1 is that it was people our age [18-34] who were actually getting incredibly sick, hospitalized, and dying.

When the 12-year-old died there was suddenly a freak out. Wait a minute, older kids are getting it, so the ones who are supposed to be the healthiest are suddenly prone to it as well.

Therefore, across all focus groups there was a spectrum of perceived risk ranging from those who were completely indifferent to those who felt that the pandemic posed a more significant threat.

Confusion over changing information implicitly acknowledged the pandemic's inherent uncertainty, but it also brought to the surface a tension between the kinds of information that participants desired (and likely felt that they had not received). Some participants were not particularly comfortable with uncertainty messaging, and stated that they had just wanted health officials to offer them some facts with a degree of certainty – a certainty that (as one participant noted) could promote greater confidence in health officials.

It would be good if they were sure [about information]. Because that gets everyone's confidence and trust and you can rely on them. But if they come out saying that they're not sure, then how is everyone else going to be sure.

On the other hand, many other participants agreed that they wanted health officials to be more open and upfront about uncertainties (which may indicate that health officials were not clear about uncertainty – or, that such messages was not received as intended). They too wanted 'facts' but were comfortable acknowledging the tentative nature of those 'facts.'

We would prefer uncertainty to some sort of false certainty - which we've come not to trust.

With my experience with doctors, what any person is looking for is just that this is what could potentially happen. Just give you the straight facts, 'This is what we have, we're not really too sure, but these are the facts of what we have now."

By and large, what most participants believed they had received the most 'mixed' information about was the vaccine campaign, and this often generated confusion more generally about who was most at risk from the pandemic.

I think it was mixed messages for me because I read about the young people being affected but then the people that were supposed to go first were the seniors and it just didn't make sense to me why, if they were concerned about the, you know, say 15 to 30 age range that were getting sick and being harmed by this, why they would put the seniors - I'm sure it was the seniors that were first. I found it very confusing the way they explained the prioritizing.

As the above quote shows, some participants could not accurately recall who was prioritized, and tended to confuse H1N1 vaccine prioritization with those groups usually recommended to receive the seasonal influenza vaccine (i.e. seniors). Other participants shared similar recollections that confused H1N1 priority groups with the seasonal influenza vaccine.

Any time there's any kind of the flu vaccine or whatever it is they always recommend people who are asthmatic, young, like really young children, seniors, should all go first kind of thing. And so that was in my own head. It was those people can go first.

The confusion over who was first eligible to receive the H1N1 vaccine fed into some indignation among some participants who wished to be immunized but learned that prioritization initially meant restricted access. Some people knew that some groups had been prioritized but assumed that it would play out similarly to seasonal influenza vaccination campaigns, where some groups are recommended to receive the vaccine, but it is expected that anybody who wants one, and shows up, can get it.

But there was a lot of panic and fear in the people, and then you turn around and say, 'Oh, but only you can get it this week.' You know, this is a free country, okay?

Some people - particularly seniors in the focus groups - lined up early to be vaccinated for H1N1 (because they are usually the group that is targeted for seasonal influenza) only to be turned away because they were not yet eligible. With low confidence in the information they had received, and facing the prospect of waiting in long lines where they could be turned away due to priority lists or lack of supply, some participants concluded that the clinics were poorly managed, inefficient, and perhaps not worth the effort.

Availability messages were a bit confusing or conflicting probably because of supply and it was not necessarily the most accurate information in terms of how it was becoming available and to whom it was available; so I didn't know when to jump and when not to jump and whether to even bother jumping.

In the end, it is likely that all of the confusion and uncertainty about the pandemic and vaccine information played a role in making many people generally indifferent to the pandemic's risk. With so much information seen as mixed or contradictory, unfortunately many participants simply started to tune a lot of the messaging out.

We were getting a lot of information and a lot of it was conflicting. The health officials were not on the same page [...] I turned it into white noise.

It was just a lot of different information that you tried to figure out what was right and what wasn't. There was mixed messages and the messages were not clear. [The health officials] instilled absolutely no confidence.

Again, there was a spectrum of public perspectives about seemingly inconsistent messaging, and not all public participants felt that they were confused on the issues. Some participants did claim that information they were receiving seemed consistent enough, or that they were comfortable with evolving information.

I was pretty confident with what I was getting. It seemed consistent [...] I actually think that swine flu or H1N1 was handled much better than the SARS crisis was in terms of getting information out to the public and engaging people in protective behaviour. I definitely felt more informed.

Some even expressed some sympathy for the situation in which health officials found themselves. One participant quite accurately captured the challenges of communicating uncertainty and evolving science, as well as the problem of making it understandable enough for the lay public to follow along.

I think that they [health officials] were trying to shoot at a moving target because it was totally unknown and every day they were trying to adjust so that they were on top of it. So it WAS confusing. I think they were doing the best they could under the circumstances. They were handed the latest research and were



putting it together and then saying, 'Okay, we've got to change what we're doing,' and they tried. But to the average person it was really difficult to understand what was happening.

Some participants provided further rationale for public confusion. They saw it as symptomatic of public inexperience with facing a pandemic event (and, by extension, all the kinds of acute uncertainties and shifting knowledge that are manifest in such contexts).

I think because it was the first time that this kind of thing happened, it was hard for people.

If this has never happened before and all of a sudden it's thrown at you, why should anybody know what to do?

#### Discussion

Our results confirm the federal and provincial official reviews of response efforts (of the respective jurisdictions covered here) which also admitted that communication created public confusion especially for the vaccination processes and that the pandemic exposed a need to better communicate about risk, uncertainty, and evolving science (Government of Manitoba 2010a; Health Quality Council of Alberta 2010; MOHLTC 2010; Public Health Agency of Canada 2010). However, what our findings add to our understanding of public confusion during H1N1 is that some of it may have actually been due to health officials' commitment to transparently communicating about uncertainty and evolving knowledge during a pandemic. Although laudable, we found that the adoption of this principled approach to risk communication seemed to inadvertently create degrees of public confusion and provoke negative opinions about the performance of the health authorities who were responsible for managing the pandemic. Of course, it should be acknowledged that the inherent uncertainty of the pandemic and the complexity of response efforts did not lend themselves easily to clear and simple decision-making and communication. Transparent pandemic communication was wholly untested when H1N1 arrived. Moreover, the H1N1 pandemic turned out to be a relatively mild outbreak, and not the 'moderately severe' scenario that existing plans had been based on (Public Health Agency of Canada 2010, 88). Accordingly, it is possible that health authorities had underestimated just how central communicating uncertainty would be when faced with a more ambiguous threat. On the other hand, official evaluations also found that communication efforts during the H1N1 pandemic showed significant improvement compared to the SARS outbreak (Standing Senate Committee on Social Affairs, Science and Technology 2010). Our results support this assessment as well, as some members of the public appreciated and welcomed the evolving information.

#### Trust, confidence, and confusion

Our results highlight the interactive dynamics of the TCC Model's domains, particularly in the dissonances between intentions and outcomes. Indeed health officials were keen to engage in best practice efforts of strategic risk communication – through transparency about uncertainty, evolving science, and decision-making. Although the objectives were to provide the public with the information they need and to build trust, messaging often became seen as confusing and 'mixed.' This led many participants of focus groups to question not only the integrity of the messaging they received but also the competency and ability of health officials to handle the situation. Therefore, actions intended to increase trust had an unintended consequence of negatively influencing the domain of public confidence in health officials' performance. Interestingly, there was no general theme emerging from the focus groups that trust suffered a similar loss (distrust was mainly reserved for media). In this case, they may have judged the actions of health officials as sincere (i.e. of having the appropriate values – such as honesty), but it was their communication and execution (i.e. their performance) that invited confusion and criticism. This manner of performance evaluation also fits well within Joffe's (2011) typology of common public responses to a pandemic. In our case, a large part of the confusing communication environment was 'blamed' upward at government health authorities (as well as at media hype) tasked with managing the pandemic. Similar directions of blame have also been found in another Canadian study (Henrich and Holmes 2011) and in Britain (Joffe 2011), but not in Australia (Holland and Blood 2013).

An 'upward' loss of confidence may have been more marked because the many members of the public relied on health officials to give them information that they need, and thus a sense of situated dependency is also a factor in these relationships (Wynne 1996a). However, with many people seeing only confusing information and inconsistencies between experts, this dependency - which may attain an even higher degree in the midst of a pandemic - was liable to be thrown into turmoil or pushed into a sharper reflexive focus (or, just the same, people may remain relatively ambivalent if they did not see a cause for concern). At any rate, the health system's own assessment of their pandemic response conceded that many Canadians became exhausted with confusing H1N1 messages (Public Health Agency of Canada 2010). We also found that some members of the public responded to confusing and 'mixed' messaging by eventually ignoring or 'tuning out' what officials were saying – invariably circumscribing any dependency on health officials who were seen as unreliable. In this sense, we may be able to slightly modify Joffe's (2011) concept of emerging infectious disease fatigue. It can also be aroused over the long course of a single pandemic event that was relatively mild yet characterized by continuously changing and seemingly contradictory information. Confusion cost confidence and it was psychologically draining (MacPhail 2014).

While many members of the public may not have had past experience with response efforts from a previous pandemic, in accordance with our use of the TCC Model, the H1N1 outbreak lasted long enough that many people were able to accumulate enough relevant information upon which to make assessments of health officials' performance. Consistent with our research, several other studies have similarly shown that seemingly mixed messaging that is actually adaptation to newly emerging evidence can be interpreted by the public as signs of the health system's incompetence, inability to handle the situation, or conflict among experts (Frewer et al. 2003; Holmes et al. 2009; Rosella et al. 2013; Taha, Matheson, and Anisman 2013). Other postpandemic research has also shown that among members of the Canadian public, attributions of incompetency toward the health system became more common as the pandemic progressed over its entirety (Henrich and Holmes 2011).

Confusing information also forced many focus group participants to turn to their own localized, situated, and extant frameworks of influenza knowledge when grappling with how to interpret risk messaging and the complex vaccination campaign. For some, recommended preventive hygienic behaviors for H1N1 seemed too consistent with that of the generally mild annual seasonal influenza to warrant any extra concern. Comparisons to seasonal influenza mortality rates also produced more benign perceptions of H1N1 risk, and together these inventories of knowledge increased the metaphorical 'distance' some participants felt between themselves and the risk of H1N1 – similar to findings from Australia (Holland and Blood 2013). On the other hand, the (largely media-driven) story about the death of the young teenager resonated among parents across the country and also underscored messaging that the virus could be severe for younger age groups traditionally considered low risk for seasonal influenza. This knowledge tended to make the risk more proximate. During the immunization campaign, if people looked toward their routine knowledge of the seasonal vaccine recommendations as a guide, this could obscure the substantial differences that existed with H1N1 priority sequencing.

Unfortunately, mix-ups such as these led not only to a loss of confidence in messaging, but also to people being turned away at vaccination clinics or questioning whether to vaccinate at all. Ultimately, transparent communication did not enter a vacuum but a field of existing knowledge and expectations that, under the circumstances, many people tried their best to reconcile.



# Uncertainty and transparent pandemic communication

Evidence still points to the need for health authorities to continue to function under trust-based principles of transparent communication (Visschers et al. 2011; Siegrist and Zingg 2014). However, a 'catch-22' exists where a degree of uncertain and changing messages will likely be unavoidable in an evolving environment (Sandman 2009). Sandman and Lanard (2005, 2011) argue that the element of uncertainty itself should remain a core and consistent element of messaging and its relevant challenges for communication should be confidently 'proclaimed' and reiterated to the public throughout a pandemic.

Yet coping with pandemic uncertainty was a novel experience for many people during the pH1N1 outbreak. Simply being more open and transparent about pervasive uncertainty and evolving science did not always help the public understand, contextualize, or give meaning to that uncertainty (although some had no problems following along). To be sure, now with having had the experience of transparent communication during pH1N1, the next time a pandemic occurs it is possible that public reactions will be better primed for constantly evolving information. Nonetheless, it is still necessary to acknowledge recent critiques of the principle of transparency. Löfsted and Bouder (2014) problematize the concept as being socially mediated and valueladen as much as any other communicative practice. This study lends support to such a view, finding no straight line connecting transparency and trust – rather, that line can take unanticipated turns as people grapple with how to interpret risk messages. Löfstedt and Bouder contend that risk communicators need to be critically aware of how messaging can be perceived, and that transparency is not simply communicating the science without restraint, but about understanding communication science. While they, among others (Coglianese 2009), call this approach 'reasoned transparency' (as opposed to 'fishbowl transparency'), we similarly argue that during the pandemic there needed to be a better integration of the science that needs to be communicated and the science of communication.

#### Conclusion

The province of Alberta's official pandemic response evaluation noted that the inter-pandemic phase needs to continue the difficult task of engaging the public in discussions to strengthen cultural understandings of uncertainty and how knowledge emerges and evolves during a pandemic (Health Quality Council of Alberta 2010). This is a laudable goal, however it cannot simply be a 'knowledge deficit' approach to educate the public in a top-down fashion. Health system officials too must also learn how to more effectively communicate uncertainty and evolving information in a transparent yet 'reasoned' fashion. At this point, more research is needed to better map the coordinates of what 'reasoned transparency' would actually look like for communicating uncertainty during a pandemic. Nevertheless, a fundamental goal should be building and maintaining the public's trust as well as confidence – while being mindful that attempts to improve prospects in one domain can have incidental consequences in the other.

## Acknowledgments

The authors would like to thank all of the members of the public who participated in focus group discussion and sharing their experiences and opinions. We also thank public health officials who gave their time to be interviewed by study researchers.

#### Disclosure statement

The authors have no competing financial interests to disclose.

# **Funding**

This research was supported by a grant from the Canadian Institutes of Health Research [grant number MOP 210293].

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