

**Employing Community-based Participatory Research Approaches to Improve Local
Influenza Pandemic Preparedness in Remote and Isolated Canadian First Nations
Communities**

by

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Author's Declaration

I hereby declare that this thesis consists of material all of which I authored or co-authored, please refer to the Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Statement of Contributions

This thesis consists of some material that is a result of joint research. While I am the first author and led each of the five studies that are included in this dissertation (i.e., developed study protocols, collected data, analyzed and interpreted results, and prepared manuscripts and community deliverables), I would like to acknowledge the role and contributions of each co-author. All aspects of this dissertation which are not listed below were solely authored.

Chapter 3: Charania NA, Barbeau CD, McCarthy DDP, Cowan D, Tsuji LJS. Developing a collaborative health informatics system to foster inter-agency collaboration and communication during public health emergencies: remote and isolated First Nation communities of sub-arctic Ontario, Canada. *International Journal of Technology, Knowledge, and Society*. 2012;7(4):75–92.

Christine D. Barbeau assisted with data collection. Dr. Daniel D. McCarthy, Dr. Donald Cowan, and Dr. Leonard JS Tsuji all provided ongoing guidance and supervision of the research design, data collection and analysis. All co-authors reviewed the final manuscript and provided editorial advice and guidance.

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Chapter 5: Charania NA, Tsuji LJS. Assessing the effectiveness and feasibility of implementing mitigation measures for an influenza pandemic in remote and isolated First Nations communities: a qualitative community-based participatory research approach. *Rural and Remote Health*. 2013;13(4):2566.

Chapter 6: Charania NA, Tsuji LJS. Recommended mitigation measures for an influenza pandemic in remote and isolated First Nations communities of Ontario, Canada: a community-based participatory research approach. *The International Indigenous Policy Journal*. 2014; 5(3).

Dr. Leonard JS Tsuji provided ongoing guidance and supervision of the research design, data collection and analysis. He reviewed the final manuscript and provided editorial guidance.

Chapter 7: Charania NA, Martin ID, Liberda EN, Meldrum R, Tsuji LJS. Bird harvesting practices and knowledge, risk perceptions, and attitudes regarding avian influenza among Canadian First Nations subsistence hunters: implications for influenza pandemic plans. *BMC Public Health*, 2014; 14:1113. doi:10.1186/1471-2458-14-1113

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Abstract

Background: Public health emergencies, such as influenza pandemics, continue to disproportionately impact Aboriginal Canadians (First Nations, Inuit, and Métis), especially those populations residing in geographically remote areas. Previous influenza pandemic plans reflected inadequacies with regards to addressing the pre-existing inequalities and special needs of Aboriginal Canadians during an influenza pandemic, and this may be attributed to their limited participation during preparedness efforts. Significant barriers hinder the ability of Aboriginal Canadians to effectively participate in preparedness efforts and there is a limited amount of information of how to operationalize their participation. By addressing the identified barriers to participation, community-based participatory research (CBPR) offers a promising framework and strategy to facilitate the effective participation of Aboriginal Canadians in influenza pandemic preparedness efforts.

Objectives: The overall objective of this dissertation was to explore the use of CBPR approaches to engage community members in directing how to improve local influenza pandemic preparedness in remote and isolated Canadian First Nations communities. This dissertation consisted of five manuscripts grouped into three overarching studies; all of which employed a CBPR approach. The objectives for **Study I** were to qualitatively identify the needs and explore the potential of using a collaborative health informatics system (CHIS) to improve the delivery of health care services during an influenza pandemic response while also identifying any perceived barriers of implementing such a system. **Study II** used a qualitative questionnaire to examine the experiences, perceptions, and recommendations regarding implementing measures to mitigate the effects of an influenza pandemic. **Study III** was a cross-sectional survey conducted to gain an understanding of the bird harvesting practices and knowledge, risk perceptions, and attitudes regarding avian influenza among subsistence hunters and discussed related implications to future influenza pandemic plans.

Methods: The initial needs assessment of **Study I** involved conducting semi-directed interviews with community-based health care professionals (n=9) residing in three remote and isolated Canadian First Nations communities to explore the use of the CHIS. The second needs assessment of **Study I** was conducted with one of the initial three study communities and involved semi-directed interviews and focus groups with community-based health care professionals (n=16). Questions were specifically developed to further explore issues that emerged from the initial needs assessment. Interviews were transcribed verbatim and open, axial, and selective coding were used to create the emerging concepts and categories. **Study II** involved conducting interviewer-administered questionnaires with community-based health care professionals (n=9) residing in three remote and isolated Canadian First Nations communities to explore the experiences, perceptions, and recommendations regarding forty-one mitigation measures. The collected qualitative data were transcribed verbatim and deductively analyzed following a template organizing approach. The cross-sectional survey of **Study III** was conducted with subsistence hunters (n=106) residing in a remote and isolated First Nations community. The survey employed twenty closed-ended questions related to bird harvesting practices, knowledge, risk perceptions, and attitudes about hunting influenza-infected birds. Two open-ended questions allowed for participants to describe their risk perceptions of avian influenza as well as any additional concerns. Simple descriptive statistics, cross-tabulations, and analysis of variance (ANOVA) were used to examine the distributions and relationships between

variables. Written responses were transcribed verbatim and deductively analyzed following a template organizing approach.

Results: For the initial needs assessment of **Study I**, the fifty-five emerging concepts were organized into five categories, including: general issues, potential benefits, potential uses, useful technical functions and suggested technical modifications, and concerns. Participants stated that the CHIS could improve the delivery of health care services by tracking and mapping the occurrence of disease outbreaks, along with facilitating communication and health information sharing between the involved health care organizations. Some concerns of the CHIS were noted, namely the concern of accessibility safeguards considering that confidential health information would be inputted, stored, and presented. For the second needs assessment of **Study I**, one hundred and thirty eight emerging concepts were organized into four overarching categories, including: level of intra- and inter-government agency communication and collaboration, health information sharing within and between government agencies, patient charting and reporting, and solutions. It was noted that having different jurisdictions responsible for providing health care services hindered the ability to share patient's health information and provide quality health care. Participants stated that the CHIS could potentially be utilized to help manage a response by facilitating inter-agency communication, collaboration, and health information sharing. For **Study II**, participants reported that thirty mitigation measures were used during their response to the 2009 H1N1 influenza pandemic (A(H1N1)pdm09). Although participants reported that most measures were modified or altered when being implemented to address the unique characteristics of their communities. All of the mitigation measures implemented during A(H1N1)pdm09 were considered to be effective, along with three measures that were not used and one additional measure suggested by a participant. Measures were considered to be effective particularly if the measure aided in decreasing virus transmission, protecting their high-risk population, and increasing community awareness about influenza pandemics. Participants reported that lack of resources, minimal community awareness, overcrowding in homes, and inadequate health care infrastructure hindered the implementation of some mitigation measures. The list of community-informed recommended mitigation measures created from the collected data revealed many discrepancies when compared to national recommendations and existing literature. For **Study III**, the findings indicated that subsistence hunters partook in some practices while harvesting wild birds that could potentially expose them to avian influenza, although appropriate levels of compliance with some protective measures were reported. More than half of the respondents were generally aware of avian influenza, with fewer being aware of key signs and symptoms, and almost one third perceived a risk of becoming infected with avian influenza while harvesting birds. Participants aware of avian influenza were more likely to perceive a risk of being infected with avian influenza while harvesting birds. The results suggested that knowledge of avian influenza positively influenced the use of a recommended protective measure. Regarding attitudes about hunting influenza-infected birds, the results revealed that the percentage of hunters who would cease harvesting birds increased as avian influenza was detected in birds in more nearby geographic areas.

Conclusions: **Study I** highlighted that the CHIS was viewed as being a useful and valuable tool to improve the delivery of health care, among other potential functions, during an influenza pandemic response. **Study II** highlighted the perceived barriers to implementing nationally recommended mitigation measures and supports the notion of recommending pandemic control strategies in remote and isolated Canadian First Nations communities that may not be supported

in other communities. And **Study III** revealed a need for more education that is culturally-appropriate about avian influenza and precautions First Nations subsistence hunters can take to reduce the possibility of being exposed to avian influenza while harvesting wild birds. Moreover, the inclusion of First Nations subsistence hunters as an avian influenza risk group with associated special considerations in future influenza pandemic plans seems warranted. In general, the three overarching studies of this dissertation display the importance and value of employing CBPR approaches to engage locally impacted populations in improving influenza pandemic preparedness. The CBPR processes used and findings revealed throughout this dissertation can be used to inform future influenza pandemic preparedness efforts to improve the response capacity and health outcomes of Canadian First Nations residing in remote and isolated communities during the next influenza pandemic.

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Dedication

For my parents with much love ... without them I would never be where I am or have the opportunity to go where I will in the future.

Table of Contents

List of Tables	xii
List of Figures	xiii
Chapter 1: Introduction	1
1.0-Problem Context and Rationale	1
1.1-Research Objectives	3
1.2-Dissertation Structure	4
1.3-Dissertation Overview and Past Research	4
Chapter 2: Literature Review	8
2.0-Overview	8
2.1-Aboriginal Health, Health Services, and Health Policy in Canada	8
2.1.1-Terminology	9
2.1.2-Health Status of Aboriginal Canadians	9
2.1.3-Health Services for Aboriginal Canadians	10
2.1.4-Health Policy for Aboriginal Canadians.....	11
2.2-Community Participation.....	13
2.2.1-Terminology	13
2.2.2-Origins and Rationale of Community Participation with Marginalized Populations in Health-Related Activities.....	14
2.2.3-Value of Community Participation with Aboriginal Canadians.....	16
2.2.4-Barriers and Facilitators for Community Participation with Aboriginal Canadians in Health-Related Activities.....	16
2.3-Public Health Emergencies and Public Health Emergency Preparedness.....	19
2.3.1-Terminology	19
2.3.2-History and Concepts of Public Health Emergency Preparedness	20
2.3.3-Importance of Community Preparedness within Public Health Emergency Preparedness	21
2.3.4-Community Participation with Marginalized Populations in Public Health Emergency Preparedness	22
2.4-Community-based Participatory Research	26
2.4.1-Origins and Principles of Community-based Participatory Research for Health	26
2.4.2-Community-based Participatory Research for Public Health Emergency Preparedness with Marginalized Populations	28
2.4.3-Benefits and Challenges of Community-based Participatory Research	29
2.5-Conclusion	30
Chapter 3: Developing a Collaborative Health Informatics System to Foster Inter-agency Collaboration and Communication during Public Health Emergencies: Remote and Isolated First Nation Communities of Sub-arctic Ontario, Canada	32
3.0-Overview	32
3.1-Introduction	32
3.2-Methods and Materials	34
3.2.1-The Collaborative Geomatics System	34
3.2.2-Community-based Participatory Approach	36
3.2.3-Study Area	37
3.2.4-Study Population.....	37
3.2.5-Data Collection	38

3.2.6-Data Analyses	38
3.3-Results	39
3.3.1-General Issues and Potential Benefits	39
3.3.2-Potential Uses	39
3.3.3-Technical Aspects.....	42
3.3.4-Concerns	43
3.4-Discussion.....	44
3.5-Conclusion	45
Chapter 4: Health Care Delivery in Remote and Isolated First Nations Communities in Canada: The Need for a Collaborative Health Informatics System.....	47
4.0-Overview	47
4.1-Introduction	47
4.2-Methods	49
4.2.1-Study Community Profile.....	49
4.2.2-Community-based Participatory Approach	49
4.2.3-Study Population and Data Collection.....	50
4.2.4-Data Analyses	51
4.3-Results	51
4.3.1-Level of Intra- and Inter-government Agency Communication and Collaboration	51
4.3.2-Health Information Sharing within and between Government Agencies.....	52
4.3.3-Patient Charting and Reporting	53
4.3.4-Solutions	54
4.4-Discussion.....	56
4.5-Conclusion.....	57
Chapter 5: Assessing the Effectiveness and Feasibility of Implementing Mitigation Measures for an Influenza Pandemic in Remote and Isolated First Nations Communities: A Qualitative Community-based Participatory Research Approach.....	59
5.0-Overview	59
5.1-Introduction	59
5.2-Methods	61
5.2.1-Study Area and Population	61
5.2.2-Data Collection and Analyses.....	61
5.3-Results	62
5.3.1-Screening the general public and travelers for influenza-like illness at public places	63
5.3.2-Travel restrictions or advisories on arriving and departing passengers.....	64
5.3.3-Closing down all borders and quarantine of a geographic area.....	64
5.3.4-Closing down community schools, childcare centers, and workplaces.....	65
5.3.5-Isolation and quarantine.....	65
5.3.6-Restricting public gatherings, modifying cultural practices, and traditional medicine	66
5.3.7-Rapid influenza diagnostic tests in health care facilities	67
5.3.8-Vaccines and Antivirals.....	67
5.4-Discussion.....	67
5.5-Conclusion	69
Chapter 6: Recommended Mitigation Measures for an Influenza Pandemic in Remote and Isolated First Nations Communities of Ontario, Canada: A Community-based Participatory Approach.....	71

6.0-Overview	71
6.1-Introduction	71
6.2-Methods	72
6.2.1-Community-based Participatory Research Approach.....	72
6.2.2-Study Area and Population	73
6.2.3-Data Collection	73
6.2.4-Data Analyses	74
6.3-Results	74
6.3.1-Travel Measures	82
6.3.2-Community Social Distancing Measures	83
6.3.3-Surveillance Measures	84
6.3.4-Infection Control Measures	85
6.3.5-Pharmaceutical Measures	86
6.4-Discussion.....	86
6.5-Conclusion.....	89
Chapter 7: Bird Harvesting Practices and Knowledge, Risk Perceptions, and Attitudes Regarding Avian Influenza among Canadian First Nations Subsistence Hunters: Implications for Influenza Pandemic Plans	91
7.0-Overview	91
7.1-Introduction	91
7.2-Methods	93
7.2.1-Community-based Participatory Research Approach.....	93
7.2.2-Study Area, Population, and Data Collection.....	94
7.2.3-Data Management and Analyses	95
7.3-Results	96
7.4-Discussion.....	102
7.4.1-Harvesting Activities	102
7.4.2-Awareness, Risk Perception, and Attitudes.....	103
7.4.3-Recommendations for Influenza Pandemic Plans	104
7.4.4-Study Strengths and Limitations.....	105
7.5-Conclusion	106
Chapter 8: Conclusion and Future Research.....	107
8.0-Overview	107
8.1-Overall Findings	107
8.2-Key Contributions to Existing Literature	109
8.3-Recommendations for Future Research.....	113
8.4-Concluding Remarks	114
Letters of Copyright Permission	115
References	118

List of Tables

Table 2.1: Eleven key principles of community-based participatory research	27
Table 2.2: Nine additional principles for community-based participatory research with Aboriginal populations	27
Table 3.1: Health care provision in study communities prior to the formation of the Weeneebayko Area Health Authority	36
Table 3.2: Potential uses of the health informatics computer system proposed by participants...	41
Table 3.3: Useful technical aspects and suggested technical modifications identified by participants	43
Table 4.1: Health care provision in Fort Albany First Nation	49
Table 5.1: Effective and not effective measures to mitigate an influenza pandemic in remote and isolated First Nations communities suggested by participants (n=9)	62
Table 6.1: List of recommended measures to mitigate an influenza pandemic in remote and isolated First Nations communities suggested by participants (n=9)	75
Table 6.2: List of measures not recommended to mitigate an influenza pandemic in remote and isolated First Nations communities suggested by participants (n=9)	82
Table 6.3: List of recommended and not recommended mitigation measures from Annex M of the Canadian Influenza Pandemic Plan for the Health Sector as evaluated by study participants	88
Table 7.1: Demographic and harvesting characteristics of Canadian First Nations subsistence hunters residing in the study community (n=106), November 10-25, 2013	96
Table 7.2: Frequency and percentage of knowledge of avian influenza, risk perception of avian influenza virus infection, and attitudes about hunting influenza-infected birds among Canadian First Nations subsistence hunters residing in the study community (n=106), November 10-25, 2013	98
Table 7.3: Cross-tabulation for awareness of avian influenza by risk perception of avian influenza infection while harvesting birds among Canadian First Nations subsistence hunters residing in the study community (n=106), November 10-25, 2013	100
Table 7.4: Cross-tabulation for sex by cease hunting if influenza detected in regional birds among Canadian First Nations subsistence hunters residing in the study community (n=106), November 10-25, 2013	101
Table 7.5: Cross-tabulation for awareness of avian influenza by sanitizing bird processing equipment in the bush among Canadian First Nations subsistence hunters residing in the study community (n=106), November 10-25, 2013	101
Table 7.6: Recommended precautions for Canadian First Nations subsistence hunters to reduce exposure to avian influenza viruses while harvesting wild birds	105
Table 8.1: Eleven key principles of community-based participatory research	112

List of Figures

Figure 1.1: Outline of initial research project and dissertation endeavors	6
Figure 3.1 The input form of a collaborative geomatics system	37
Figure 3.2: Screenshot of mapping tool	37
Figure 7.1: Compliance with recommended protective health measures among Canadian First Nations subsistence hunters residing in the study community (n=106), November 10-25, 2013	97
Figure 7.2: Analysis of variance for number of birds hunted per year by males and females (a) and number of days hunted per year by perceived risk of avian influenza virus infection while harvesting birds (b) among Canadian First Nations subsistence hunters residing in the study community (n=106), November 10-25, 2013.....	100

Chapter 1: Introduction

1.0-Problem Context and Rationale

A public health emergency (PHE), such as an influenza pandemic, has the potential to cause high rates of morbidity and mortality, along with global social and economic disruption (Osterholm, 2005). PHEs disproportionately impact marginalized populations, such as Aboriginal Canadians (First Nations, Inuit, and Métis), by exacerbating the inequalities these populations face on a daily basis (Uscher-Pines et al., 2007; Kayman & Ablorh-Odjidja, 2006). The inherently complex and multifaceted nature of the health disparities faced by marginalized populations arises from many broader interconnected social, economic, and ecological inequalities that sometimes are beyond their direct control and are influenced by public policies (Milio, 1998; Adler & Newman, 2002; Marmot, 2005; Abrams, 2006). Thus, it is widely recognized that future PHEs will result in marginalized populations bearing more burdens from the impact of the PHE, benefiting less from response measures, and subsequently experiencing higher morbidity and mortality rates (Uscher-Pines et al., 2007; Schoch-Spana et al., 2007).

Public health emergency preparedness (PHEP) is vital to reduce the associated morbidity and mortality rates, along with minimizing the unintended social and economic consequences associated with responding to PHEs (Nelson et al., 2007). The three critical components of PHEP are planning, training, and written plans (Perry & Lindell, 2003). Federal, top-down policies are important to provide guidance for a comprehensive and coordinated PHE response (Pearce, 2003; Klaiman et al., 2009). However, the limitations and inappropriateness of the “one size fits all” approach to planning has been noted (Bennett & Carney, 2010). Having tailored policies in place at levels below the federal level (i.e., provincial, regional, and community) are integral since the actual response will occur at the local level (Pearce, 2003; Klaiman et al., 2009; Nelson et al., 2008). PHEP is especially important at the community-level as these bottom-up policies can cater to regional diversities and outline context-specific yet culturally-appropriate operational details for implementing measures that are required for a successful response (Pearce, 2003).

As marginalized populations are expected to be disproportionately impacted by future PHEs, additional attention to improve PHEP for marginalized populations by anticipating and planning for their special needs seems warranted (Haddow, Bullock & Coppola, 2008; Warren et al., 2011; Jennings & Arras, 2008). The participation of marginalized populations in PHEP activities is needed to create context-specific and culturally-appropriate plans as they possess special knowledge regarding their circumstances and needs during a PHE (Warren et al., 2011; Jennings & Arras, 2008). The participation of marginalized populations can lead to building trust, creating feasible plans, and respecting ethical and local values which are especially important in order to have a successful, coordinated response (Uscher-Pines et al., 2007; Kayman & Ablorh-Odjidja, 2006). Despite the importance and benefits of marginalized populations participating in PHEP efforts for a successful response, these populations have not historically been engaged in PHEP efforts (Klaiman et al., 2010). Engaging marginalized populations in PHEP efforts is challenging and there is a scant amount of information regarding how to operationalize the effective engagement of marginalized populations in planning efforts to draw from (Wingate et al., 2007; Uscher-Pines et al., 2007; Andrulis, Siddiqui, & Gantner, 2007). The need to engage marginalized populations in PHEP efforts, to better understand appropriate and effective methods for doing

so, and for their input to be subsequently reflected in PHEP plans remain significant gaps in PHEP literature (Wingate et al., 2007).

A recent PHE, the 2009 H1N1 influenza pandemic (A(H1N1)pdm09), disproportionately impacted Aboriginal Canadians, especially those populations living in geographically remote communities (Kermode-Scott, 2009; Kumar et al., 2009). The experience of A(H1N1)pdm09 reflected inadequacies in influenza pandemic preparedness with regards to addressing the pre-existing inequalities and special needs of Aboriginal Canadians during a pandemic (Kermode-Scott, 2009; Barker, 2010; Spence & White, 2010). The health inequalities faced by Aboriginal Canadians have been linked to the adverse effects of colonization, assimilation, and socioeconomic marginalization, in addition to the conditions experienced in most Aboriginal communities (e.g., overcrowded impoverished housing, geographical isolation, and food insecurity) (MacMillan et al., 1996; Reading & Wien, 2009; Tsuji et al., 2000; Clark et al., 2002; Skinner et al., 2013). The health disparities experienced by Aboriginal Canadians may also be attributed to a history of inappropriate and inadequate government health policies (National Collaborating Centre for Aboriginal Health (NCCA), 2011). Moreover, during a pandemic, most Aboriginal communities are faced with unique, multifaceted challenges that hinder their response capacity; thus, their special challenges and needs during a pandemic should be addressed in influenza pandemic preparedness plans (Richardson et al., 2012; Spence & White, 2010).

In Canada, the existing national pandemic plan includes a specific section for First Nations and it was reported that 80% of First Nations communities had local pandemic plans in place prior to A(H1N1)pdm09 (Public Health Agency of Canada, 2006; Atkinson et al., 2012). Having local plans in place and specific content for First Nations in the national pandemic plan infers that attention was paid to drafting the documents; however, the plans appear to offer universal recommendations that may be neither effective nor feasible considering the unique conditions experienced in these communities (Atkinson et al., 2012). Moreover, the national plan is silent on if and how First Nations participated during the planning process and if First Nations are actually prepared for future pandemics. Prior to A(H1N1)pdm09, the Assembly of First Nations (AFN) reported being inadequately involved in pandemic planning efforts, plans not appreciating First Nations' unique approach to health, and having serious concerns regarding the level of community influenza pandemic preparedness (AFN, 2007; AFN, 2005). Thus, Aboriginal organizations have called for increased consultation with Aboriginal Canadians during efforts to revise the national pandemic plan after the A(H1N1)pdm09 experience (Eggleton & Ogilvie, 2010). Good pandemic planning should focus on the participation efforts employed during the process of creating the plans rather than simply on the production of a document since having a written plan in place is only one component of preparedness (Patel et al., 2008; Mounier-Jack & Coker, 2006).

Aboriginal Canadians have previously not had a meaningful voice in policy efforts as there are many factors that hinder their effective participation and the actual policy-making process itself is difficult to participate in given the dominance of Western-based values and views (Ten Fingers, 2005; Fridkin, 2012; LaVeaux & Christopher, 2009). By addressing the identified barriers to participation, community-based participatory research (CBPR) offers a promising framework and strategy to facilitate the effective participation of historically excluded marginalized populations in PHEP efforts (Warren et al., 2011; Cordasco et al., 2007). CBPR emerged as an alternative research paradigm to traditional inquiry and draws from principles of action- and participatory- oriented research approaches (Flicker et al., 2007; Wallerstein & Duran, 2008; Minkler & Wallerstein, 2008). The hallmark principles of

CBPR, such as equitably engaging partners, shared control of decision making, and employing various methods can foster the engagement of marginalized populations in influencing public health policy (Macaulay et al., 1999; Israel et al., 2005; Israel et al., 2008; Israel et al., 2010; O'Brien & Whitaker, 2011). Also of importance, in CBPR endeavors, community members are actively and equitably involved throughout the entire process to ensure that locally relevant issues are addressed in an appropriate manner (Minkler & Wallerstein, 2008). CBPR approaches also transcend traditional dissemination avenues with a commitment to combining knowledge generation with action-oriented outcomes that directly benefit the involved community (Israel et al., 2005; Israel et al., 2008). Furthermore, CBPR provides a promising culturally-appropriate approach to engaging Aboriginal Canadians as literature has cited many similarities between the principles of CBPR and those used when working with Aboriginal populations (LaVeaux & Christopher, 2009; Jamieson et al., 2012).

1.1-Research Objectives

The overall objective of this dissertation was to explore the use of CBPR approaches to engage community members in directing how to improve local influenza pandemic preparedness in remote and isolated Canadian First Nations communities. This dissertation was based on the following specific objectives pertaining to three overarching studies that engaged community members residing in remote and isolated Canadian First Nations communities in influenza pandemic preparedness efforts to display the importance, process, and outcomes of CBPR approaches.

Study I: Strategies to improve the delivery of health care services

Objective #1: To explore the needs and potential use of a collaborative geomatics system as a strategy to improve the delivery of health care services during an influenza pandemic response in three remote and isolated Canadian First Nations communities.

Objective #2: To explore additional functions and perceived barriers of implementing a collaborative geomatics system as a strategy to improve the delivery of health care services during an influenza pandemic response in a remote and isolated Canadian First Nations community.

Study II: Experiences, perceptions, and recommendations regarding mitigation measures

Objective #1: To explore the experiences and perceptions of effectiveness and feasibility of implementing measures to mitigate the effects of an influenza pandemic in three remote and isolated Canadian First Nations communities.

Objective #2: To create a list of specific recommendations for measures to mitigate the effects of an influenza pandemic in three remote and isolated Canadian First Nations communities.

Study III: Concern of avian influenza infection while harvesting birds

Objective #1: To gain an understanding of the bird harvesting practices and knowledge, risk perceptions, and attitudes regarding avian influenza among subsistence hunters residing in a remote and isolated Canadian First Nations community.

Objective #2: To discuss the implications for addressing the special considerations of subsistence hunters regarding potential avian influenza transmission while harvesting birds in influenza pandemic plans.

1.2-Dissertation Structure

This dissertation is organized into eight chapters in a manuscript format. The first chapter provides the problem context and rationale, along with the research objectives. Chapter 2 is a review of literature on community participation with Aboriginal Canadians in health-related activities, highlighting participation in PHEP efforts. Of relevance to this dissertation, the focus of the literature review will be on the health disparities experienced by Aboriginal Canadians, community participation, and the value of CBPR approaches in PHEP efforts. In addition, key concepts and terminology used throughout the dissertation will be justified and defined.

Chapters 3-7 present five manuscripts that address the six objectives of the three overarching dissertation studies. As such, each manuscript describes a research endeavor that employed a CBPR approach to improve an aspect of local influenza pandemic preparedness in remote and isolated Canadian First Nations communities. All of the included manuscripts have been published in peer-reviewed journals. Chapter 3 (Study I, Objective #1) was published in the *International Journal of Technology, Knowledge, and Society* in 2012. Chapter 4 (Study I, Objective #2) was published in the *International Journal of Technology, Knowledge, and Society* in 2013. Chapter 5 (Study II, Objective #1) was published in the *Rural and Remote Health* journal in 2013. Chapter 6 (Study II, Objective #2) was published in *The International Indigenous Policy Journal* in 2014. To date, Chapter 7 (Study III, Objectives #1 and #2) was published in author version format in the *BMC Public Health* journal in 2014. Please note that Chapter 7 may appear in forthcoming publications in a manner that reflects revisions suggested by the editorial staff. Also, the versions of the published manuscripts included in this dissertation have been slightly modified from the original versions with regards to formatting in order to fit the style and structure of this dissertation.

As each manuscript is multi-authored with the candidate being first author, a preface statement outlining the role and contribution of each co-author is included at the beginning of the dissertation. Permissions to include the copyright content of the five published manuscripts (i.e., Chapters 3-7) are included at the end of the dissertation. Please note that as this is a manuscript-style thesis, sections of writing, particularly regarding the introductory comments and methods, are repeated throughout this document.

Chapter 8 summarizes the main findings of this dissertation, key contributions to literature, and suggests future research endeavors. Lastly, although this is a manuscript-style dissertation, all of the relevant references are included at the end of the dissertation.

1.3-Dissertation Overview and Past Research

All of the dissertation research endeavors employed a CBPR approach and each manuscript describes the specific details for each study. In general, as CBPR approaches emphasize shared control of decision-making in all research phases, a community-based advisory group (CBAG) was created for each study. The CBAG members played a vital role in the iterative process of designing the studies, developing the interview questions and surveys, informing the data analysis process, and validating and disseminating the results. As producing action-oriented outcomes that directly benefit the involved community is an important aspect of CBPR, the knowledge generated was disseminated to the involved communities via

presentations and used to modify the communities' influenza pandemic plans where appropriate. Also, as capacity building is important, members of the CBAG were included in presentations and associated reports whenever possible and appropriate. Furthermore, in accordance with a CBPR approach, the dissertation research endeavors addressed locally important issues that, in this instance, arose from previous research conducted by this researcher.

To provide some background context, a brief biography about this researcher, along with some details of the initial research project and an overview of how the dissertation research agenda and interconnected projects unfolded are included (Figure 1.1). This researcher has a background in health sciences and practiced as a registered respiratory therapist in various healthcare settings prior to undertaking the initial research project. This researcher is considered to be a pragmatic researcher with an appreciation for both qualitative and quantitative research that results in effective social uses of the knowledge generated. A partnership between this researcher and the study communities had been built since 2009 and arose from a longstanding community-university partnership between this researcher's supervisor and the involved communities. The initial research project addressed the concerns voiced by community-based health care professionals residing in three remote and isolated Canadian First Nations communities regarding the inadequacy of their local health sector influenza pandemic preparedness in light of A(H1N1)pdm09. They were concerned that their existing local influenza pandemic plans did not properly address their communities' unique conditions and they wanted to actively participate in the influenza pandemic planning process in preparation for future influenza pandemics. Hence, the initial research retrospectively examined the barriers faced and opportunities for improvement during the community health sector influenza pandemic response to A(H1N1)pdm09 in the three study communities (Charania & Tsuji, 2011a; Charania & Tsuji, 2011b). The action-oriented outcome of the research involved using the knowledge generated to modify the community influenza pandemic plans of the involved study communities (Charania & Tsuji, 2012). The following paragraphs briefly describe the five manuscripts of the dissertation research in relation to the research objectives, and are presented in a chronological order to display the natural progression of the research activities from the initial research.

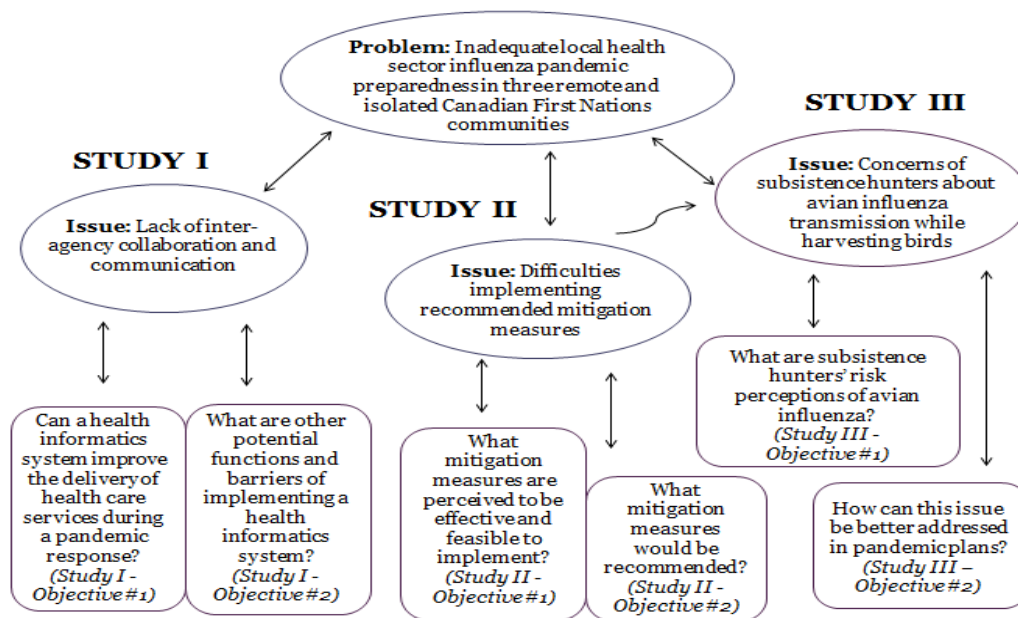


Figure 1.1: Outline of initial research project and dissertation endeavors

The initial research revealed that a lack of communication and collaboration between the multiple government organizations responsible for the health of First Nations (i.e., federal, provincial/territorial, and First Nations) led to a fragmented community health sector response to A(H1N1)pdm09 in the three study communities (Charania & Tsuji, 2011a). Thus, Chapter 3 (Study I, Objective #1) presents a needs assessment conducted with nine community-based health care professionals that explored the use of a collaborative health informatics system (CHIS) as a strategy to improve the delivery of health care services by facilitating inter-agency communication and collaboration during an influenza pandemic response (Charania et al., 2012). The participants indicated many other potential uses of the CHIS which prompted the CBAG to request a second needs assessment. As such, Chapter 4 (Study I, Objective #2) presents the second needs assessment conducted with sixteen community-based health care professionals that explored additional functions and perceived barriers of the CHIS in one of the initial three study communities (Charania et al., 2013).

Study I is the first of its kind to propose the use of a CHIS as a method for improving the delivery of health care in remote and isolated Canadian First Nations communities. The proposed CHIS would be based on a collaborative geomatics system which is a unique interactive, internet-based system capable of capturing, storing, and presenting real-time data. Originally developed for community-based land-use planning, the intent was to modify functions of the collaborative geomatics system in order to implement it in the health care sector if desired by the participants.

The initial research also indicated that some issues arose while implementing mitigation measures during the pandemic response to A(H1N1)pdm09 in the three study communities (Charania & Tsuji, 2011b). Thus, the CBAG requested that additional research be conducted to explore the effectiveness and feasibility of implementing currently recommended mitigation measures and to create more appropriate recommendations for their communities. Chapters 5 and 6 respectively address the two objectives of Study II that involved nine community-based health care professionals residing in three remote and isolated First Nations communities.

Chapter 5 (Study II, Objective #1) presents retrospective opinions regarding the experiences and perceptions of effectiveness and feasibility of implementing mitigation measures during A(H1N1)pdm09 in the three study communities (Charania & Tsuji, 2013). This study presents novel findings regarding the perceptions of a variety of non-pharmaceutical and pharmaceutical interventions of community-based health care professionals. This study aims to contribute to the gaps in literature regarding the effectiveness and feasibility of implementing mitigation measures during an influenza pandemic in various settings.

As the project evolved, the CBAG requested that a separate manuscript present a list of recommendations for mitigation measures that are tailored to their communities' characteristics and explore how these specific recommendations vary from current recommendations. As such, Chapter 6 (Study II, Objective #2) presents a list of community-specific recommended mitigation measures (including the setting, pandemic period, trigger, and duration) and compares these recommendations to national recommendations and literature (Charania & Tsuji, 2014). This study is novel in that it produced a list of community-informed mitigation measures that are context-specific and culturally-appropriate for remote and isolated Canadian First Nations communities. These findings aim to contribute to the very limited amount of knowledge regarding the knowledge, attitudes, and practices of mitigation measures for an influenza pandemic across marginalized populations.

The research endeavor presented in Chapter 7 arose from the data collected and presented in Chapter 6. Concerns were voiced by participants regarding the possibility of avian influenza transmitting to subsistence hunters while harvesting birds as they are in close proximity with potentially influenza-infected birds and the aquatic habitats of birds. As harvesting birds is an especially important part of First Nations' culture, the CBAG requested that these voiced concerns be further explored and recommendations for precautionary measures be included in community influenza pandemic plans. Chapter 7 (Study III, Objectives #1 and #2) presents a cross-sectional survey conducted with one hundred and six First Nations subsistence hunters from a remote and isolated First Nations community. The survey aimed to gain an understanding of the bird harvesting practices and knowledge, risk perceptions, and attitudes regarding avian influenza among subsistence hunters. Chapter 7 also discusses the implications for addressing the special considerations of subsistence hunters regarding potential avian influenza transmission while harvesting birds in future influenza pandemic plans. Since there is a continued concern that an avian influenza virus will cause the next influenza pandemic, past studies have examined the risk perceptions of avian influenza among various high-risk populations. To this researcher's knowledge, this is the first study to explore these perceptions among First Nations subsistence hunters and supports the inclusion of recommended precautionary measures in future influenza pandemic plans.

Chapter 2: Literature Review

2.0-Overview

Public health emergencies (PHEs), such as influenza pandemics, disproportionately impact Aboriginal Canadians by exacerbating the inequalities that these populations face on a daily basis and this trend is expected to continue during future PHEs. It is especially vital that Aboriginal Canadian communities have local public health emergency preparedness (PHEP) plans that cater to regional diversities and outline context-specific yet culturally-appropriate operational details for implementing measures that are required for a successful response. Thus, Aboriginal Canadians require additional attention in PHEP efforts and their participation is particularly important as they possess special knowledge regarding their needs during a PHE. However, significant barriers hinder the ability of Aboriginal Canadians to effectively participate in PHEP efforts and there is a limited amount of information of how to operationalize their participation. By addressing the identified barriers to participation, community-based participatory research (CBPR) offers a promising orientation and method for the effective participation of Aboriginal Canadians in PHEP efforts in the pursuit of better health outcomes for these populations during future PHEs.

This dissertation specifically addressed the research question whether CBPR approaches could be used to effectively engage community members and improve aspects of local influenza pandemic preparedness in remote and isolated Canadian First Nations communities. Due to the limited amount of directly related literature and the importance of contextualizing this dissertation research within the broader field of literature, community participation with Aboriginal Canadians in health-related activities, highlighting participation in PHEP efforts, will be reviewed. As such, the literature review will begin by describing the key factors pertinent to this review that influence the health inequalities faced by Aboriginal Canadians. The origins and related concepts of community participation will be discussed, in addition to exploring the importance, barriers, and facilitators of community participation with Aboriginal Canadians in health-related activities. Next, the history and concepts of PHEP, along with the importance and challenges of Aboriginal Canadians participating in PHEP efforts will be explored. Lastly, the principles of CBPR will be discussed to display how CBPR addresses some challenges of community participation and provides a way forward for the effective participation of Aboriginal Canadians in PHEP efforts. In addition, key concepts and terminology used throughout the dissertation will be justified and defined.

2.1-Aboriginal Health, Health Services, and Health Policy in Canada

The following sections will define relevant key terminology and describe the health status, health services, and health policy for Aboriginal Canadians to provide context regarding the health inequalities they face. Although the focus of the presented dissertation relates to Canadian First Nations, more specifically those populations residing in remote and isolated communities, reference will be made to Aboriginal Canadians. The intent is not to generalize all Canadian Aboriginal populations as it is understood that great diversity of Aboriginal cultures and communities exists. However, Aboriginal Canadians share some historical experiences and are distinct constitutionally recognized populations with Aboriginal and treaty rights that are particularly relevant when discussing aspects of health.

2.1.1-Terminology

Although great variation exists within and between each Aboriginal group in Canada; herein, in accordance with the Constitution and cited preference of terminology, variants of the term “Aboriginal Canadian” will be used to collectively refer to the First Nations, Inuit, and Métis people of Canada (O’Neil, 1995; Waldram et al., 2006). When necessary, explicit reference to the specific Aboriginal group will be made. Furthermore, as it is unavoidable, reference to the term “Indian” will be used in the context of the Canadian legislation but recognizing, with apologies, that this may be offensive to some people (Miljan, 2012).

The terms “health disparities” and “health inequalities” will be used interchangeably to refer to a set of health indicators experienced by a particular population which are considered to be avoidable, unfair, and originate (either directly or indirectly) from social, economic, cultural, and political differences between populations (Adelson, 2005; Braveman, 2006). The term “health equity” will be used to refer to the absence of such health disparities/inequalities between populations and actions to promote health equity will refer to those which aim to reduce and/or eliminate health disparities/inequalities (Braveman & Gruskin, 2003; Braveman, 2006). The term “marginalization” will be used to refer to communities or populations that have been disregarded and excluded based on social and economic factors, such as, race, ethnicity, class, age, and sex, and who experience barriers to accessing necessary resources and have a minimal ability to influence the decision-making processes which impact their lives (Israel et al., 1998).

2.1.2-Health Status of Aboriginal Canadians

Aboriginal Canadians were reported to be in good health prior to the arrival of the Europeans (Reading & Wien, 2009). However, the health and well-being of Aboriginal Canadians declined due to the various effects of colonization (Morin-Labatut & Akhtar, 1992; Health Council of Canada, 2005; Reading & Wien, 2009). Colonization is known to have suppressed the culture of Aboriginal populations and “adversely affected the physical, social, emotional, and mental health, and well-being in traditional societies” (Gracey & King, 2009:65; Robbins & Dewar, 2011). The loss of traditional knowledge and practices, forced attendance of residential schools, and land base restrictions have all negatively contributed to the appallingly low health status of Aboriginal Canadians (Morin-Labatut & Akhtar, 1992; Health Council of Canada, 2005; Reading & Wien, 2009; King et al., 2009). Explorers also introduced various foreign infectious diseases (e.g., syphilis, tuberculosis, and smallpox) to which the Aboriginal population had no immunity; thus, these diseases caused astonishingly high death rates (Weiss & McMichael, 2004).

According to the 2011 National Household Survey, 4.3% of the total Canadian population identified themselves as Aboriginal which has increased from 3.3% in the 2001 Census (Statistics Canada, 2003; Statistics Canada, 2013). In 2011, Canadian First Nations represented 60.8% of the total Aboriginal Canadian population and 2.6% of the total Canadian population (Statistics Canada, 2013). The Aboriginal Canadian population has increased 20.1% between 2006 and 2011, compared with 5.2% for non-Aboriginal Canadians, and is demographically younger than the non-Aboriginal Canadian population (Statistics Canada, 2003; Statistics Canada, 2013). In 2011, the median age of the Aboriginal Canadian population was 28 years, with the median age of First Nations being 26 years, compared to 41 years for the non-Aboriginal Canadian population (Statistics Canada, 2013).

The overall health status of Aboriginal Canadians remains lower than the general Canadian population and has been this way for many years (Tookenay, 1996; MacMillan et al., 1996; MacKinnon, 2005). Aboriginal Canadians are at a higher risk of enduring many health issues, such as malnutrition, obesity, suicide, substance abuse, mental illness, injuries, and various infectious diseases (Tookenay, 1996; MacMillan et al., 1996). Compared to the general Canadian population, the overall mortality rate of Canadian First Nations is 1.4 times higher and the overall life expectancy of Aboriginal Canadians is 6.7 years lower (Health Canada, 2009). The health inequalities Aboriginal Canadians face have been linked to the adverse effects of colonization, assimilation, and socioeconomic marginalization, in addition to the conditions experienced in most Canadian Aboriginal communities (e.g., overcrowded impoverished housing, geographical isolation, environmental contamination, and food insecurity) (MacMillan et al., 1996; Reading & Wien, 2009; Tsuji et al., 2000; Clark et al., 2002; Skinner et al., 2013).

2.1.3-Health Services for Aboriginal Canadians

Prior to the formation of Canada (marked by the passing of the Constitution Act in 1867), health services for Aboriginal Canadians was primarily delivered by the fur traders, whalers, and missionaries (Adelson, 2005; Waldram et al., 2006). Despite their efforts, Aboriginal Canadians were severely impacted by various diseases and, in addition, experienced limited access to medically trained personnel and medical resources (Waldram et al., 2006). When the Constitution Act (1867) was passed, it outlined that health fell exclusively under the jurisdiction of the provincial/territorial governments; and the federal government would be responsible for “Indians and the lands reserved for Indians” (Waldram et al., 2006; Miljan, 2012; Lavoie et al., 2011). This has been inferred to mean that the federal government has the authority to pass laws directly related to Canadian Aboriginal populations (Lavoie et al., 2011). The division of jurisdiction over health services did not immediately result in action to improve the health outcomes of Aboriginal Canadians and has resulted in jurisdictional debates over Aboriginal health that continues to the present day (Waldram et al., 2006; Miljan, 2012; Lavoie et al., 2011).

It is now noted that Aboriginal Canadians are in the best position to determine what their health needs are and how health services should be delivered in their communities (Lavoie et al., 2011). The beginning of the transfer of control over health services to Aboriginal Canadians began in 1979 with the federal government’s Indian Health Policy (Pierre et al., 2007; Lavoie et al., 2011). This policy recognized the need to improve the health status of Aboriginal Canadians via increased Aboriginal community development and a better relationship between the federal government and Aboriginal Canadians (Pierre et al., 2007; Lavoie et al., 2011). The Indian Health Policy (1979) resulted in a policy shift that allowed eligible and willing First Nations and Inuit communities to assume responsibility for decisions regarding any or all of the health services delivered in their respective communities (Pierre et al., 2007; Smith & Lavoie, 2008; Lavoie et al., 2011). To further this goal, the Indian Health Transfer Policy was developed in 1989 which allowed Aboriginal communities south of the 60th parallel to enter into a health services transfer process managed by First Nations and Inuit Health Branch (FNIHB) to assume more control of their community-based health programs (Pierre et al., 2007; Lavoie et al., 2011). Aboriginal communities located north of the 60th parallel could negotiate aspects of transferring control of health programs with other federal departments, namely Indian and Northern Affairs Canada (now Aboriginal Affairs and Northern Development Canada) (Health Canada, 2005). Nowadays, most First Nations communities have control over designing and implementing their community-based

health programs which has led to numerous benefits, such as an increase in health status, empowerment, and culturally-appropriate health care services (Health Canada, 2005; Lavoie et al., 2011).

Currently, in communities where the control of health services has been transferred, the local First Nations authorities determine how community-based health programs will be delivered (Tookenay, 1996; Tsuji, 1998a; Lavoie et al., 2011). Despite transferring the control of some health programs, Aboriginal communities maintain a reliance on the broader health care delivery system that is still under the control of the provincial/territorial and federal governments (Minore et al., 2004). The majority of health services are provided to Aboriginal Canadians living off-reserve via the provincial/territorial governments (Pierre et al., 2007). The federal government, on the other hand, is responsible for providing health services beyond those covered by the provincial/territorial governments directly to (registered) First Nations living on-reserve and Inuit living in their traditional territories via FNIHB (MacKinnon, 2005; Pierre et al., 2007; Thompson, 2010). FNIHB, a branch of Health Canada, provides additional health benefits (e.g., medications, vision care, and dental care), called the Non-Insured Health Benefits Program (NIHB), to all First Nations and Inuit (no matter where they live) due to their fiduciary responsibility (MacMillan et al., 1996; Tsuji, 1998a; Pierre et al., 2007; Thompson, 2010). Furthermore, FNIHB assumes a lead role regarding the delivery and funding of primary health care services, public health, and health promotion to First Nations and Inuit populations (Thompson, 2010). Thus, the provision of health care to Aboriginal Canadians is quite complex given the multiplicity of government authorities involved and this arrangement has become increasingly complex as a result of agreements to transfer the control of health services to Aboriginal communities (Lavoie et al., 2011). This complex arrangement of involved authorities and broadly defined roles and responsibilities in public policies has resulted in a lack of coordination and cooperation amongst the involved authorities and a debate over who is responsible for aspects of Aboriginal health care (Kelly, 2011; NCCAH, 2011). The jurisdictional gaps and debates have resulted in a fragmented health care delivery system for Aboriginal Canadians and contributed to the health disparities experienced by Aboriginal Canadians (MacMillan et al., 1996; Tsuji, 1998a; MacKinnon, 2005).

2.1.4-Health Policy for Aboriginal Canadians

The health disparities experienced by Aboriginal Canadians also stems from a history of public policies aimed at assimilating them into Canadian society and the exclusion of Aboriginal-specific health needs in public policies (Kelly, 2011; Kirmayer et al., 2003; NCCAH, 2011). The Canadian government initially viewed Aboriginal populations as uncivilized and therefore needed to be assimilated into Canadian society (Kirmayer et al., 2003). Based on the premise that formal education was required to assimilate Aboriginal populations, policies were put in place to establish residential schools for Aboriginal children (Kirmayer et al., 2003). Aboriginal children were forcibly removed from their parents to attend faraway residential schools, during which they suffered from constant surveillance and control, cultural suppression, and acts of violence (Kirmayer et al., 2003). Further, Aboriginal parents were perceived to be incapable of raising their children and required government intervention; thus, many Aboriginal children were removed from their families and placed in foster care (Kirmayer et al., 2003).

The management of Aboriginal populations by the Canadian government was institutionalized in 1876 with the passing of the Indian Act that included criteria used to determine who was considered to be Indian (referred to as registered or status Indians) and

thus, considered to be under the federal government's responsibility (Kelly, 2011). The Indian Act (1876) also established geographical lands, called "reserves", that the federal government limits its responsibilities for health services to (Kelly, 2011). In an attempt to further assimilate Aboriginal populations into society, amendments to the Indian Act in 1884 banned traditional ceremonies and healing practices (Robbins & Dewar, 2011).

Between 1871 and 1921, numerous treaties were signed between Aboriginal populations and the Canadian government establishing a relationship with regards to the provision of health services (Health Council of Canada, 2005; Kelly, 2011). However, the ambiguous wording and alleged improper negotiations during the complex treaty signing process created uncertainty regarding the federal government's role in health services for Aboriginals (Health Council of Canada, 2005; Long, 2010). For Aboriginal Canadians, it was understood that health services would be provided by the federal government in exchange for access to their lands and resources (Health Council of Canada, 2005).

In 1969, the federal government published the "White Paper" which proposed to remove the status of Indians in an attempt to further assimilate Aboriginals into society (Kelly, 2011). Although Indian leaders were consulted during the production of the "White Paper", their input was selectively omitted in the final version (Kelly, 2011). As Indian leaders opposed the content of the "White Paper", they wrote an official response referred to as the "Red Paper" in 1970 that confirmed the federal government's responsibility for Aboriginal health and the desire from Indians to obtain more control of community health programs (Kelly, 2011).

In 1991, the Royal Commission on Aboriginal Peoples (RCAP) was created to address issues of Aboriginal Canadians and produced many recommendations, most notably, a call for renewed support for traditional healing practices and for a new relationship between Aboriginal Canadians and the provincial, territorial, and federal governments (O'Neil, 1995; Kelly, 2011; Robbins & Dewar, 2011). Although the majority of the recommendations have yet to be implemented, the RCAP drew attention to the issues faced by Aboriginal Canadians (Kelly, 2011; Robbins & Dewar, 2011).

Currently, there are a limited number of Aboriginal-specific health policies in effect in Canada, and the ones that are in place tend to focus on clarifying jurisdictional responsibilities as more Aboriginal communities gain control over the delivery of health services (NCCAHA, 2011). The Indian Health Policy (1979) and the Indian Health Transfer Policy (1989) are two publicly available policies which refer to Aboriginal health at the federal level; however, the genuine intent of both policies has been disputed (O'Neil, 1995; Jacklin & Warry, 2004; NCCAHA, 2011). Some skeptics claim that the initiative to transfer the control of health services to Aboriginal communities was framed as a step towards self-determination, but instead served to relieve some of the federal government's administrative responsibilities (O'Neil, 1995; Jacklin & Warry, 2004). Current health policies continue to respect the relationship between the federal government and Aboriginal Canadians; however, jurisdictional roles and responsibilities remain broadly defined and open for multiple interpretations (NCCAHA, 2011).

Current policies at the provincial/territorial level generally exhibit minimal mention of Aboriginal-specific health concerns and significant variations exist between each province/territory (NCCAHA, 2011). Ontario has the most comprehensive Aboriginal health policies in place with the Aboriginal Health and Wellness Strategy (AHWS) (in 1990)

followed by the Aboriginal Health Policy (AHP) (in 1994) (NCCAH, 2011). The AHWS outlines a partnership between Aboriginal Canadians and the Government of Ontario in initiating numerous community-based health services and programs aimed at improving the health and healing of Aboriginal Canadians (e.g., healing lodges, and family shelters) (Queen's Printer for Ontario, 2008). Acknowledging the reality that Aboriginal Canadians have been minimally involved in efforts to improve their health status, the AHP provides guidelines for promoting the involvement of Aboriginal Canadians in planning local health services (Ontario Aboriginal Health Advocacy Initiative (OAHA), 2003). Furthermore, the AHP attempts to incorporate Aboriginal views of health by employing a framework based on principles of the Aboriginal life cycle, holistic health, and the continuum of care (OAHA, 2003). Ontario has made other strides by adapting policies to accommodate Aboriginal traditional healing practices, such as exempting Aboriginal traditional healers and Aboriginal midwives from restrictions and guidelines for health professionals (Regulated Health Professions Act, 1991; NCCAH, 2011).

Over the years, efforts have been made to improve the health and quality of health services and programs provided to Aboriginal Canadians; however, significant health disparities remain between Aboriginal Canadians and non-Aboriginal Canadians (Pierre et al., 2007). Furthermore, although Ontario and Canada have noted that health services and programs must be designed by Aboriginal Canadians themselves in order to be culturally-appropriate and progress has been made by including Aboriginal-specific needs in health policies and programs, significant room for improvement regarding community participation remains (OAHA, 2003; NCCAH, 2011; Robbins & Dewar, 2011).

2.2-Community Participation

The following section will define community participation and related concepts, along with its historical origins. The value, barriers, and facilitators of community participation with Aboriginal Canadians in health-related activities will be explored. As literature pertaining specifically to the participation of Aboriginal Canadians in health-related activities is limited, information will also be drawn from the health literature regarding community participation with marginalized populations.

2.2.1-Terminology

Since the literature on community participation is diverse and spans across many disciplines, it has been problematic to define community participation, community, and participation. Community participation itself has been particularly problematic to define as various related terms have been used interchangeably in different contexts. Some of these other terms are community engagement, community organizing, community capacity building, community empowerment, community building, and community development (Butterfoss, 2006; El Ansari, 2005; McCloskey et al., 2011). It is becoming apparent that it is not valuable or possible to come to a universal agreement on the definitions because these terms mean different things to different people and varies according to the context and nature of the endeavor (Rifkin, 2009). Local partnerships are encouraged to create their own definitions that address the context of the health-related activity, and specify the level of participation they want to achieve for which decisions (Rifkin, 1990; Rifkin, 2009; Cornwall, 2008). Thus, the concepts of the key terms will be explored and defined in a manner that resonates most with this dissertation research.

There are two distinct perceptions of participation in the health literature. The first is the utilitarian model in which participation is viewed as an “instrumental” means or intervention to accomplish a specific outcome (Morgan, 2001; Cornwall, 2008). In the utilitarian model, participation is understood as a voluntary contribution of a person’s resources towards a common goal that is often initiated in a top-down manner (Boyce, 2001). The second is the empowerment model in which participation is considered to be “transformational” and viewed as an end by which people are empowered to develop their skills and knowledge to improve their ability to take responsibility for solving their health problems (Morgan, 2001; Cornwall, 2008; Boyce, 2001).

Integral to community participation is the concept of community. If community participation efforts are going to benefit the community, much reflection is needed to define what community the participation is needed from. The concept of community is most often understood in geographical terms as a group of people who live in a certain location and therefore share similar values, interests, and problems (Rifkin, Muller & Bichmann, 1988). However, it is not always appropriate to define community in this manner as the people residing within the same geographical boundaries may not share similar values or health problems (Woelk, 1992). Another definition of community refers to a group of people with similar interests and thus, the community will change over time as peoples’ interests change (Rifkin, Muller & Bichmann, 1988). A more applicable definition when discussing marginalized populations refers to a community as a group of people who ought to be identified so that resources can be accordingly allocated for maximal impact in terms of “equity, effectiveness and efficiency” (Rifkin, Muller & Bichmann, 1988:933). Moreover, in contrast to the individualistic notion of community prevalent in mainstream Western culture, it is important to note that Aboriginal Canadians conceptualize community as relational, ecocentric, and cosmocentric (Kirmayer et al., 2003; Dudgeon et al., 2002). Incorporating the value of family, kinship, ancestral, and environmental connections, community can be thought of as, “a web of relationships that includes not only extended family, kin and clan but, for hunters and other people living off the land, animals, elements of the natural world, spirits and ancestors” (Kirmayer et al., 2003:S18).

When attempting to define community participation, the community development approach is most applicable in this context as this approach understands that factors beyond health services impact human health (Church et al., 2002). Thus, community participation actively involves community members in a bottom-up manner regarding decisions related to the numerous factors that affect human health (Rifkin, 1986). Drawing from the empowerment model, the community development approach, and definitions of community participation in the public health literature (Rifkin, Lewando-Hundt, & Draper, 2000; Morgan, 2001; Butterfoss, 2006), herein community participation will refer to a social process that empowers marginalized populations with shared values to voluntarily take collaborative action in identifying their health problems, barriers, and opportunities and/or strategies to improve health and social well-being.

2.2.2-Origins and Rationale of Community Participation with Marginalized Populations in Health-Related Activities

The rationale for increasing community participation with marginalized populations in health-related activities (i.e., health research, policy, and practice) stemmed from the growing health inequalities faced by marginalized populations, recognizing that many determinants impact population health, and regionalization of health services. In Canada, despite the

introduction of national health care coverage (i.e., Medicare) in the 1950s, the health of Canadians remained poor and demands for health care services continued to rise (Glouberman, 2001). As Medicare only covers acute-care hospital and physician services, because according to the biomedical model of health these services are the most effective for protecting health, the limits of health services to improve population health were starting to be recognized (Glouberman, 2001; Chappell & Penning, 2009). The understanding that many complex social and economic factors impact population health, most of which are outside the direct control of health services, was introduced in Canada in 1974 when the Honourable Marc Lalonde published *The Lalonde Report: A new perspective on the health of Canadians* (Pinder, 1988). In summary, the report offered a different way of viewing health (i.e., the health field concept) and stated that there are four major determinants of health, including: lifestyle, environment, human biology, and health care organization (Glouberman, 2001; Glouberman & Miller, 2003). The report recommended that government health policies should address other determinants of health, instead of traditionally only addressing health care services, and encouraged citizens to take on more responsibility in managing their own health (Glouberman, 2001; Glouberman & Miller, 2003). The ideas of the *Lalonde Report* were reinforced by the *Epp Report, Achieving health for all: a framework for health promotion* and the *Ottawa Charter for Health Promotion* in 1986 (Glouberman, 2001).

The social-ecological model of health builds on the concepts of the *Lalonde Report* and recognizes that the inherently complex and multifaceted nature of health disparities faced by marginalized populations arises from many broader interconnected social, economic, and ecological inequalities that sometimes are beyond their direct control and are influenced by public policies (Milio, 1998; Adler & Newman, 2002; Marmot, 2005; Abrams, 2006). The understanding that many factors impact population health and that no one program or sector is equipped to eliminate health inequalities alone led to issues of how health professionals were going to tackle health inequalities (Baker et al., 2005; Thurston et al., 2005; McCloskey et al., 2011). It was understood that in order to address the health inequalities faced by marginalized populations an approach would be required that includes community members in the very endeavors that are meant to improve their health (McCloskey et al., 2011).

The idea of community participation gained widespread popularity at Alma-Ata in 1978 when the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) presented *Health For All by the Year 2000* (Rifkin, 1986). This Declaration emphasized the need for community participation in primary health care efforts in response to growing health inequalities among marginalized populations, although no specifications were made of how to operationalize community participation and scholars have struggled to achieve effective community participation ever since (Rifkin, 1986). Nevertheless, the field of public health in the 1980s followed this trend of community participation and theoretically shifted from a model of research, policy, and practice *on* the community to one *with* the community (Butterfoss, 2006). It is important to note that in reality any health-related activity that crosses cultures and social classes will face challenges associated with inherent power imbalances (Wallerstein & Duran, 2006; Horowitz et al., 2009). The increased popularity of community participation also followed the trend of regionalization of health services. In Canada, in the 1990s, most provinces/territories restructured the planning and delivery of health services to regional health authorities due to financial constraints and the notion that local decision-makers would be best suited to cater health services to local needs (Naylor, 1999; Lavoie et al., 2011; Chappell & Penning, 2009). By incorporating the views of citizens regarding local health needs, community participation activities were suggested to result in more accountable and appropriate decisions (Church et al., 2002).

2.2.3-Value of Community Participation with Aboriginal Canadians

It is particularly important that more accountable and appropriate decisions are made regarding the health of Aboriginal Canadians given the health inequalities they currently face and the history of culturally-inappropriate policies and practices being forced upon them. Moreover, efforts aimed at making more appropriate decisions regarding Aboriginal health must acknowledge the impact colonization, assimilation, and socioeconomic marginalization continues to have on the culture of Aboriginal Canadians and subsequently their health (DeVerteuil & Wilson, 2010). Community participation can aid in improving the health of Aboriginal Canadians by empowering them to partake in efforts to recognize and solve their health needs in an appropriate manner (Zakus & Lysack, 1998). More community input and responsibility over health-related activities is expected to result in directing resources to locally important issues, addressing issues in a more appropriate manner, and sustaining programs (Zakus & Lysack, 1998; Butterfoss, 2006). Thus, community participation may result in more context-specific and culturally-appropriate health-related activities that may be more effective at improving the health of Aboriginal Canadians. Herein, context-specific refers to content and actions that are applicable for a specific location (e.g., geographically remote communities) (Giles & Rich, 2013). In contrast, culturally-appropriate refers to the content and actions that are relevant and respect the culture of the involved population that could include their beliefs, practices, traditions, language, and knowledge (Kirmayer et al., 2003; Giles & Rich, 2013). Regarding Aboriginal health, culturally-appropriate services may incorporate holistic views of health, traditional healers, and traditional healing practices (DeVerteuil & Wilson, 2010). It is important to note that a population's culture is not necessarily homogeneous or static, rather culture can change and evolve over time (Kirmayer et al., 2003).

2.2.4-Barriers and Facilitators for Community Participation with Aboriginal Canadians in Health-Related Activities

It is important to note that although the use of community participation in health-related activities is widely promoted due to the various associated benefits, "participation is in itself no panacea" (Cornwall, 2008:281; Butterfoss, 2006). Believing that community participation will solve all of the problems faced by marginalized populations is both unrealistic and naïve (Rifkin, 2009; Cornwall, 2008). Although some previous community participation efforts have contributed to improving health at the local level, others have been relatively unsuccessful and faced multiple challenges that impacted the ability for marginalized populations to participate (Rifkin, 2009; Cornwall, 2008). Not surprisingly, relatively low participation rates have been reported in health-related activities with marginalized populations around the world (Boyce, 2001).

Despite the notion that community participation in health-related activities is vital to improve the health inequalities faced by marginalized populations, limited understanding exists regarding the barriers and facilitators to participation (Butterfoss, 2006). As community participation is highly contextual and implementation has been especially problematic where there are cultural differences (Stone, 1992; Morgan, 2001, Rifkin, 2009), in order to effectively engage Aboriginal Canadians, it is important to understand and address the structural factors that impact their desire and ability to participate. The primary factors that hinder the effective participation of Aboriginal Canadians in health-related activities arise from social-cultural, political, and organizational contexts.

Three key factors within the social-cultural context that affect Aboriginal Canadians from participating in health-related activities are local politics, level of interest, and the effects of socio-economic marginalization. First of all, as alluded to in the discussion of defining the term community, it is important to understand that the involved community is not a homogeneous entity comprised of people who share common knowledge and are interested in cooperating with one another solely because they reside in the same geographic location (Stone, 1992). Great heterogeneities exist within each Aboriginal community with some communities having different language and cultural groups (Champion et al., 2008; Taylor et al., 2007). As such, these different groups within an Aboriginal community will have differing knowledge, views, beliefs, and interests regarding health issues and this can result in local power struggles as the different groups compete to exert their views over the others (Stone, 1992; Champion et al., 2008). Furthermore, having different groups with differing values within a community also infers that not all groups will be motivated to participate in initiatives regarding a certain health issue (Woelk, 1992). Thus, participation from the entire community can be unrealistic and problematic as there are inherent challenges with getting people from different groups to participate in health-related activities (Champion et al., 2008).

Another factor that can limit Aboriginal Canadians from participating in health-related activities is peoples' actual level of interest in participating. In general, just because a population is invited to participate in an initiative does not necessarily infer that the population is actually interested in participating. It is important to note that the concept of community participation was introduced by Western organizations under the premise that it will improve the health of marginalized populations (Woelk, 1992). Although this sounds noble, the introduction of community participation can be interpreted as a means for governments to divert their responsibilities and mobilize community resources that would otherwise need to be provided (Stone, 1992; Woelk, 1992). Aboriginal Canadians have a history of culturally-inappropriate Western ideas being forced upon them which has led to general distrust of government activities and research endeavors (LaVeaux & Christopher, 2009). Furthermore, the desire of people to participate may fade over time and "participation fatigue" may set in after being continually asked to participate in initiative after initiative, especially if their voiced concerns are not reflected in the results or outcomes (Cornwall, 2008). For instance, a multi-part study conducted in a remote and isolated Canadian First Nations community reported respondent fatigue as the primary reason for non-participation in follow-up interviews (Skinner et al., 2013). Given the aforementioned factors, it may be difficult for Aboriginal Canadians to participate if they are not actually interested in or motivated to participate in health-related activities.

Lastly, various effects of socio-economic marginalization can negatively influence the desire and ability of some Aboriginal Canadians to participate in health-related activities; thus, sometimes it is simply easier not to participate. Due to a history of marginalization, some people may not participate because they lack confidence and feel like they do not have anything meaningful to contribute and fear that their opinions will not be taken seriously (Boyce, 2001; Cornwall, 2008). As participation is often a voluntary contribution of one's resources, the competing demands of daily life and financial constraints can sometimes make it very difficult to participate in activities (Boyce, 2001; Cornwall, 2008). If the costs of participating do not outweigh the benefits, especially if little consideration has been devoted to choosing a convenient timing and location for the activity, many people may not realistically be able to participate (Cornwall, 2008; Butterfoss, 2006). For instance, certain locations chosen to host participation activities may be unfamiliar or uncomfortable for

participants or may be difficult to travel to which may influence their decision to attend (Cornwall, 2008). Thus, it is important that outsiders to the involved community are aware of these complexities within the community to facilitate community participation.

Two key factors within the political and organizational context that can hinder Aboriginal Canadians from participating in health-related endeavors are the dominance of Western-based approaches and limitations of the organization to effectively engage them. First of all, there are inherent power inequalities between the organizers of participatory activities and Aboriginal Canadians as Western-based approaches and ideologies of colonialism continue to dominate in health research, policy, and practice (Sherwood & Edwards, 2006; Fridkin, 2012). The health of a population is largely influenced by the health policies in place; thus, not surprisingly, who the decision-makers are and how they exercise their power subsequently influences the health of a population (Buse et al., 2005; Fridkin, 2012). Aboriginal Canadians who experience health inequalities are rarely involved in the decision-making process for policies that impact their health as the actual process itself is difficult for Aboriginal Canadians to participate in (Ten Fingers, 2005; Fridkin, 2012). Health policies informed and created by others rather than those affected may perpetuate health inequalities and silence valuable community involvement (Minkler et al., 2003; Horowitz et al., 2009). Historically, culturally-insensitive policies have been imposed upon Aboriginal Canadians as they have not had a meaningful voice in policy efforts; also, in cases where Aboriginal Canadians were included in the decision-making process, their voices were often misrepresented or not included in the final version of documents (LaVeaux & Christopher, 2009; Fridkin, 2012).

Ironically, Aboriginal Canadians are encouraged to participate in the very system that their marginalization is originally attributed to and a process that is dominated by Western-based approaches and knowledge systems that exclude their views (Fridkin, 2012). Current health endeavors are addressed in a linear fashion that believes that knowledge can be divided into separate components and follows the biomedical model of health that focuses on diagnosing and treating individual diseases (Porter et al., 1999; Sherwood & Edwards, 2006). Furthermore, knowledge is thought to be owned by “experts” who have gained scientific knowledge from a formal education that values objectivity and establishing rigor by measurement and explanation (Moreton-Robinson & Walter, 2009). In contrast, Aboriginal Canadians value connectivity and believe in a holistic view of health described as, “the physical, social, emotional, cultural and spiritual well-being of the individual and of the well-being of the whole community” (Anderson, 1997 quoted in Malin & Maidment, 2003:92). Moreover, Aboriginal Canadians view knowledge as shared, contextual, observational, and experiential (Moreton-Robinson & Walter, 2009). Gaining the participation of Aboriginal Canadians will continue to be difficult when the policy system and process that aims to help them is dominated by Western-based approaches and ways of knowing that excludes their views and knowledge systems of health.

The very organization aiming to engage marginalized populations in health-related activities may itself suffer from various limitations that present barriers to effective community participation. Organizations may be restricted in addressing specific health issues voiced by a marginalized population because of the competing priorities of funders and local governments. Due to political commitments or resource constraints, the organization may have to act in accordance with budgetary constraints, preferred groups of participants, and guidelines for their participation that are pre-established by the funders or local government (Boyce, 2001). Conflict can occur when a population is engaged for a predetermined agenda

rather than the population being able to define the agenda (Butterfoss, 2006). Furthermore, guidelines on allowable expenditures sometimes do not allocate funding for supporting community members' participation (e.g., travel expenses, child care) (Boyce, 2001). These factors not only limit an organization's capacity for effective community participation, but can also impact the desire and ability of community members to participate if their identified health issues are not being addressed in a manner that resonates with them.

Despite the aforementioned barriers that can hinder community participation, many facilitators of community participation have been identified and the proponents of these activities remain optimistic that these efforts will help improve the health of marginalized populations. In general, it is imperative that organizers of participation activities begin by acknowledging and understanding factors regarding the target population's social-cultural, political, and organizational contexts that may impact their capacity and desire to participate (Maar et al., 2011; Champion et al., 2008). Prior to starting the endeavor, organizers require a substantial understanding of the community's history, values, and culture and need to build a trusting and respectful relationship with the involved community (El Ansari, 2005; Rae et al., 2013). Early and continuous engagement of community members in developing the agenda will help to ensure that a locally relevant health issue is being addressed in a culturally-appropriate manner (Butterfoss, 2006). Furthermore, some other facilitators of community participation include acquiring sufficient resources, offering incentives, employing methodological pluralism, appointing community representatives, and partaking in knowledge translation activities (Butterfoss, 2006; Maar et al., 2011).

2.3-Public Health Emergencies and Public Health Emergency Preparedness

Community participation with marginalized populations in health-related activities is essential to lessen the health inequalities people face. As marginalized populations are expected to be disproportionately impacted by future PHEs, community participation becomes increasingly vital to enable their particular needs during PHEs to be addressed. The following section will discuss the terminology, importance, origin, and concepts of PHEP, along with highlighting the need for the participation of marginalized populations in PHEP efforts. As literature pertaining specifically to the participation of Aboriginal Canadians in PHEP activities is limited, information will be drawn from the PHEP literature regarding participation with marginalized populations.

2.3.1-Terminology

PHEs are unpredictable, albeit inevitable, events that have the potential to cause high rates of morbidity and mortality, along with large-scale social disruption and economic loss (Osterholm, 2005). PHEs are often characterized as events that disrupt the provision of essential services, potentially damage infrastructure, and require large-scale response measures (Paek et al., 2010). PHEs encompass various events, such as bioterrorism attacks (e.g., distribution of anthrax), natural disasters (e.g., hurricanes, floods, and earthquakes), and large-scale disease outbreaks (e.g., influenza pandemics) (Nelson, Lurie, & Wasserman, 2007). Defining what constitutes a PHE is important as it determines the scope of required preparedness activities; herein, a PHE will be defined as situations "whose scale, timing, or unpredictability threatens to overwhelm routine capabilities" (Nelson et al., 2007:S9).

The devastating PHEs of the 21st century, such as the terrorist attacks in 2001, the SARS epidemic in 2003, the hurricanes in 2005, and the H1N1 influenza pandemic in 2009, have drawn an immense amount of attention and funding to the field of public health, more

specifically, to public health emergency preparedness (PHEP) (Morrow, 2007). As such, the relatively new field of PHEP literature has significantly grown over the past decade and draws from other fields related to protecting population health during a PHE, such as emergency management, emergency preparedness, disaster management, disaster preparedness, and public health preparedness (Yeager et al., 2010; Morrow, 2007; Haddow, Bullock & Coppola, 2008; Coppola, 2007). As PHEs are expected to increase in magnitude and frequency in the future (Arnold, 2002; James, Subbarao, & Lanier, 2008), PHEP is vital to reduce the associated morbidity and mortality rates, along with minimizing the unintended social and economic consequences associated with a response to PHEs (Nelson et al., 2007). Although many definitions of PHEP are available in the literature, PHEP will be defined herein as the, “capability of the public health and health care systems, communities, and individuals, to prevent, protect against, quickly respond to, and recover from health emergencies, particularly those whose scale, timing, or unpredictability threatens to overwhelm routine capabilities. Preparedness involves a coordinated and continuous process of planning and implementation that relies on measuring performance and taking corrective action” (Nelson et al., 2007:S9).

2.3.2-History and Concepts of Public Health Emergency Preparedness

Historically, the field of emergency management was dominated by a “command and control” model rooted in military analogies that viewed PHEs similar to how threatening enemy attack situations were viewed (Dynes, 1994; Waugh Jr. & Streib, 2006). It was thought that PHEs would cause social chaos during which individuals would panic and the existing organizations would be unable to cope (Dynes, 1994). This ensuing social chaos would thereby require command and control actions by strong centralized authority structures to communicate official information top-down (Dynes, 1994). As such, planning efforts were conducted for communities and outlined rules and specific details of how to control the ensuing social chaos (Dynes, 1994; Pearce, 2003). In the context of responding to a PHE, the aforementioned analogies and assumptions of the “command and control” model are thought to be inappropriate as many organizations play a role in the effective management of an emergency thereby requiring shared authority and collaboration (Dynes, 1994; Waugh Jr. & Streib, 2006).

In contrast, the “problem solving” model is a more appropriate model for dealing with PHEs as it encompasses ideas of continuity, coordination, and cooperation (Dynes, 1994). Since PHEP is the responsibility of all levels of the public and private sectors, multiagency collaboration and coordination is required to successfully respond to PHEs (Gensheimer et al., 2003; Waugh Jr. & Streib, 2006). The “problem solving” model assumes that some level of disorganization will arise during a PHE, but that existing organizations will generally be able to cope and PHEP should build upon these existing systems (Dynes, 1994; Nelson et al., 2007). As problems are expected to emerge and continuously change during a PHE, preparedness efforts should focus on improving the capacity of these organizations to solve problems; thus, employing a model that supports preparedness along with flexibility and improvisation is beneficial (Dynes, 1994). Despite the noted drawbacks of the “command and control” model and the notion that drawing from the “problem solving” model has many benefits in the context of PHEP, the creation of hierarchical command and control structures continue to dominate PHEP activities (Abramson et al., 2007). In the context of influenza pandemic preparedness, the WHO continues to recommend the establishment of command and control structures to facilitate management and decision-making processes (WHO, 2009).

It is important that PHEP activities occur prior to an emerging emergency since during a PHE it is too late to accomplish the preparedness activities required to minimize the impact of the PHE and immediate pressures could hinder the decision-making process (Cox et al., 2003). Although each PHE presents different challenges and requires planning for specific issues, some similarities are shared in terms of the topics that plans need to address, such as surveillance, communications, and response efforts (Gensheimer et al., 2003). To optimize preparedness for a broad range of PHEs, PHEP is moving towards an all-hazards approach by building on existing infrastructure for different PHEs and combining lessons learnt from responses to various PHEs (Nelson et al., 2007).

In general, PHEP should include information for activities related to all four phases of the emergency management cycle, including mitigation, preparedness, response, and recovery (Yeager et al., 2010; Moore et al., 2007). The mitigation and preparedness phases occur prior to the onset of an emergency while the response and recovery phases occur during or after the emergency (Moore et al., 2007). Mitigation activities are directed towards reducing the likelihood and/or consequences associated with an emergency, while preparedness activities focus on planning an emergency response and developing required resources (Coppola, 2007; Morrow et al., 2007). Response activities are centered on coordination and refer to the immediate reaction to an emergency with the goal of minimizing lives lost and property damage (Coppola, 2007). Lastly, despite the best mitigation, preparedness, and response efforts to an emergency, short- and long-term recovery activities will be required to restore and rebuild damage caused by an emergency (Coppola, 2007; Morrow et al., 2007). In spite of the importance of each phase of the emergency management cycle, a review of PHEP literature revealed that most PHEP research focuses on planning activities for the preparedness phase (Yeager et al., 2010). Acknowledging the inherent challenges of conducting PHEP research ranging from financial to logistical constraints, there remains a need for more empirical evidence in the PHEP literature and for research that addresses the mitigation, response, and recovery phases (Yeager et al., 2010; Abramson et al., 2007).

2.3.3-Importance of Community Preparedness within Public Health Emergency Preparedness

PHEP activities require the coordination of a broad range of people from all levels of the public sector, private sector, in addition to the general public; however, PHEP is ultimately the responsibility of government public health agencies (Nelson et al., 2007). It is important to note that Canada is federated and health care falls primarily under the jurisdiction of the provincial/territorial governments that in turn have a substantial amount of power during a PHE response (Miljan, 2012; Klaiman et al., 2009). Although the federal government is responsible for national health issues and has vast spending power, during a PHE, the provincial/territorial governments have the ability to decide how to direct financial aid, guidance, and assistance as needed to local levels (Thompson, 2010; Klaiman et al., 2009). Furthermore, due to the regionalization of health care services in Canada, regional health authorities can also play an important role during a PHE response (Chappell & Penning, 2009; Lavoie et al., 2011).

Federal, top-down policies are important to provide guidance for a comprehensive and coordinated PHE response (Pearce, 2003; Klaiman et al., 2009). However, the limitations and inappropriateness of the “one size fits all” approach to planning has been noted (Bennett & Carney, 2010). Thus, having tailored policies in place at levels below the federal level (i.e., provincial, regional, and community) are also integral to a successful PHE response (Pearce,

2003; Klaiman et al., 2009). Notably, the fact that the actual response will occur at the local level highlights the importance of bottom-up preparedness and response activities (Klaiman et al., 2009; Nelson et al., 2008). Moreover, PHEP is especially important at the community-level since these bottom-up policies can cater to regional diversities and outline context-specific operational details for implementing response measures that are required for a successful response (Pearce, 2003). However, since some preparedness issues are similar for all involved levels, it is important that plans at other levels adhere to the general recommendations made by the federal government to ensure that local plans meet the minimum planning recommendations and in turn facilitate a coordinated response for all levels (Klaiman et al., 2009).

The three critical components of PHEP are planning, training, and written plans (Perry & Lindell, 2003). It is important to note that having a written plan in place does not necessarily infer adequate preparedness as it is only one component and captures a snapshot of preparedness at a certain time (Perry & Lindell, 2003). To prepare for a PHE, the community should conduct a vulnerability analysis to assess its susceptibility to various possible PHEs, a capability assessment to identify what resources are available to aid with a response, and develop a plan that outlines the involved organizations and systems required for a coordinated response (Perry & Lindell, 2003). As vulnerability, resources, and infrastructure will change over time, PHEP requires a dynamic, ongoing process of planning, training, and obtaining needed resources for a response that should constantly be improved upon from experiences with drills, simulations, exercises, and real-life events (Perry & Lindell, 2003; Nelson et al., 2007). Thus, good planning should focus on building the capacity for multi-agency collaboration and coordination to ensure that each agency is aware of each other's capabilities and limitations which is essential for a successful emergency response and stems from participation in the planning process (Gensheimer et al., 2003; Waugh Jr. & Streib, 2006; Perry & Lindell, 2003).

2.3.4-Community Participation with Marginalized Populations in Public Health Emergency Preparedness

All of society is impacted by a PHE; thus, public preparedness is a vital component of a successful response (Coppola, 2007). The public must be aware and agree with public health recommendations, in addition to having the ability to implement the recommended mitigation measures (Nelson et al., 2007; Hampton, 2007). Community participation, therefore is essential in all aspects of PHEP in order to gain insight into how local perspectives and values impact the response capacity of people (Hampton, 2007; Blendon et al., 2008; Braunack-Mayer et al., 2010). Furthermore, as value-laden decisions will have to be made during a PHE, it is important that public health recommendations reflect societal values and validate the assumptions made during the planning process (Chatigny, 2006). But the general public is not homogeneous in terms of susceptibility to a PHE. Marginalized populations have historically been disproportionately impacted by PHEs and this trend is expected to continue during future PHEs (Haddow, Bullock & Coppola, 2008). Marginalized populations will require additional attention in PHEP efforts and their participation is particularly important as the people themselves possess special knowledge regarding their needs during a PHE (Warren et al., 2011; Jennings & Arras, 2008). The participation of marginalized populations can lead to building trust, creating feasible plans, and respecting ethical and local values which are especially important in order to have a successful, coordinated response from all of society (Uscher-Pines et al., 2007; Kayman & Ablrh-Odjidja, 2006).

Marginalized populations often lack adequate resources and support systems and are therefore more susceptible to the impacts of PHEs (Hoffman, 2009; Andrulis, Siddiqui & Gantner, 2007). Marginalized populations may include ethnic minorities, individuals with low levels of literacy and/or language barriers, and the impoverished (Hoffman, 2009; Klaiman et al., 2010). Factors such as race, literacy, and cultural values can negatively affect the ability of marginalized populations to cope with a PHE (Haddow, Bullock & Coppola, 2008). PHEs and implementing associated response measures often exacerbate the inequalities marginalized populations face on a daily basis and failures in PHEP are often a reflection of pre-existing inadequacies in the public health infrastructure and other social service systems (Jennings & Arras, 2008; Uscher-Pines et al., 2007; Kayman & Ablorh-Odjdja, 2006). Recent PHEs, such as Hurricane Katrina and A(H1N1)pdm09, reveal the disproportionate impact faced by marginalized populations when PHEP fails to address their pre-existing inequalities and needs during a PHE (Uscher-Pines et al., 2007; Cordasco et al., 2007; Spence & White, 2010). During PHEs, there has been a lack of educational and warning messaging that addresses the communication barriers of different marginalized populations and inadequate training of professionals regarding the special needs of marginalized populations (Klaiman et al., 2010; Wingate et al., 2007; James, Hawkins, & Rowel, 2007). Thus, it is widely recognized that future PHEs will result in marginalized populations bearing more burdens from the impact of the PHE, benefiting less from response measures, and subsequently experiencing higher morbidity and mortality rates (Uscher-Pines et al., 2007; Schoch-Spana et al., 2007).

The disproportionate burden endured by marginalized populations raises many ethical considerations that should be the cornerstone of PHEP efforts (Lee et al., 2008; Berkman, 2009). Herein, ethics will be defined as a set of moral principles, values, and ideals of a particular group (Warren et al., 2011). Science alone is insufficient to inform the difficult decisions that will inherently have to be made during a response; thus, the decision-making process should also be guided by ethics (Kotalik, 2005; Upshur et al., 2005). While it is beyond the scope of this literature review to discuss at length all of the ethical considerations for PHEP, the opposing ethical principles of utility and equity are particularly relevant and worth acknowledging. The principle of utility holds that an equal distribution of benefits and burdens is considered fair and promotes actions that will result in the greatest amount of good for the greatest number of people (Jennings & Arras, 2008; Hoffman, 2009). In the context of a PHE, the utilitarian principle would support the use of resources in a way that maximizes population health and saves as many lives as possible (WHO, 2007). On the other hand, the principle of equity considers the distribution of benefits and burdens according to the needs of individuals or groups as fair and supports the best outcomes for those who are least well off (Hoffman, 2009; WHO, 2007). Utilizing the principle of equity during a PHE would mean employing mitigation measures that do not place unfair burdens on already marginalized populations (WHO, 2007). Moreover, with regards to the benefits of response measures during an influenza pandemic, it may be equitable to prioritize the distribution of scarce pandemic vaccines to marginalized populations (WHO, 2007). As there are no clear answers for the difficult decisions that must be made during a PHE, the ethical considerations that guide the decision-making process should be openly and transparently communicated to the public prior to a PHE to gain their trust and acceptance leading to a more coordinated, successful response (Upshur et al., 2005; Berkman, 2009).

Marginalized populations have particular needs before, during, and after a PHE that are not fully addressed in current PHEP efforts (Wingate et al., 2007). In light of the ethical principle of equity, it is argued that additional efforts should be directed towards anticipating and

planning for the particular needs of marginalized populations (Klaiman et al., 2010; Warren et al., 2011; Wingate et al., 2007). Universally recommended mitigation measures during a PHE may not be feasible or effective for marginalized populations; thus, the creation of tailored response measures that are context-specific and culturally-appropriate is warranted and this requires that marginalized populations participate in the PHEP process (Jennings & Arras, 2008).

Of particular relevance to this literature review is inclusiveness, which is one of the five procedural values recommended to guide ethical decision-making for a PHE (Upshur et al., 2005; Thompson et al., 2006). The value of inclusiveness means that decisions should be made with stakeholders' views in mind and opportunities should be made available to stakeholders to participate in the decision-making process (Upshur et al., 2005; Thompson et al., 2006). Marginalized populations best understand the realities that are experienced and can provide valuable insights regarding their particular needs during a PHE (Uscher-Pines et al., 2007). Also, marginalized populations are best placed to provide advice regarding which response measures would be most effective in order to use scarce resources for maximal impact (Adler & Newman, 2002; Uscher-Pines et al., 2007; Horowitz et al., 2009; Low, 2008). It is important that planners and officials make a concerted effort to specifically include marginalized populations in the decision-making process as these populations may not be as able as others to participate (Schoch-Spana et al., 2007). However, it is important not to generalize the needs of all marginalized populations in PHEP as the values, perspectives, and resources vary within and between each marginalized population (Jennings & Arras, 2008). Thus, it is recommended that marginalized populations are first identified and subsequently engaged in the decision-making process (Jennings & Arras, 2008; Uscher-Pines et al., 2007). The active and direct participation in PHEP efforts of those with special knowledge or lived experience pertinent to the identified marginalized populations is required to address their particular needs during a PHE (Jennings & Arras, 2008; Uscher-Pines et al., 2007). A successful response to a PHE will require a coordinated response effort from all individuals; thus, not including the needs of a marginalized population in PHEP will impede this required coordination (Uscher-Pines et al., 2007; Kayman & Ablorh-Odjidja, 2006).

There are numerous benefits of including the public in PHEP activities, some of which are particularly important for marginalized populations. Notably, the public is more likely to accept and trust decisions made and in turn cooperate during a PHE response if they have been engaged in the decision-making process (Berkman, 2009; Schoch-Spana et al., 2007). Furthermore, participation with the public is encouraged in the PHEP decision-making process to increase the likelihood that the employed ethical and local values reflect the community at hand and to improve the logistical feasibility of response measures recommended in plans (Berkman, 2009; Thompson et al., 2006; Schoch-Spana et al., 2007). Moreover, cultivating the participation of the public could mobilize citizen responders and community resources during a response and pique the continued interest of community members and organizations in PHEP activities that would otherwise only become a priority when an emergency is imminent (Schoch-Spana et al., 2007).

For marginalized populations, building trust, creating feasible plans, and respecting values are particularly important benefits of participation in PHEP activities. Marginalized populations have a history of distrusting their governments for numerous valid reasons, such as having inappropriate policies enforced upon them, and this distrust hinders the success of a PHE response (Uscher-Pines et al., 2007). In light of the fact that hierarchical command and control structures continue to dominate PHEP activities, every effort should be made by

planners and officials to build trust with marginalized populations by engaging them in the decision-making process (Abramson et al., 2007; Cordasco et al., 2007). Also, marginalized populations may be more likely to accept and follow recommendations from locally trusted sources; thus, identifying and engaging these trusted people in the decision-making process can improve cooperation during a response (Jennings & Arras, 2008). Furthermore, given the special needs and circumstances of marginalized populations in the context of a PHE, it is especially important that plans are created that are robust, effective, and feasible for these populations to implement in order to gain their acceptance and cooperation during a response (Wingate et al., 2007; Jennings & Arras, 2008). Lastly, as value-laden and ethically complex decisions will have to be made during a PHE response, participating in PHEP activities is especially important for marginalized populations so that decisions made are perceived as fair and plans resonate with values, perspectives, knowledge, and views (Uscher-Pines et al., 2007; Kayman & Ablrh-Odjidja, 2006; Schoch-Spana et al., 2007).

Despite the aforementioned importance and benefits, previous PHEP efforts have been heavily guided by government agencies, public health agencies, and expert scientists and not the populations that those efforts are trying to protect (Kotalik, 2005; Marshall et al., 2009; Hampton, 2007; Patriarca & Cox, 1995). Although marginalized populations and the organizations that serve them have various strengths, knowledge, and skills that can be leveraged during PHEP activities to benefit the community, these populations and organizations have not historically been engaged in PHEP efforts (Klaiman et al., 2010). Given this, there is a scant amount of information regarding how to operationalize the effective engagement of marginalized populations in planning efforts to draw from and reviews of PHEP plans reflect this limitation (Wingate et al., 2007; Uscher-Pines et al., 2007; Andrulis, Siddiqui, & Gantner, 2007). For instance, a review of 37 national influenza pandemic plans revealed that most countries that identified marginalized populations did not take the next step of involving the identified groups in the planning process (Uscher-Pines et al., 2007). Not surprisingly, an article that reviewed PHEP efforts for marginalized communities revealed a general lack of focus on racially and ethnically diverse communities (Andrulis, Siddiqui, & Gantner, 2007). The need to engage marginalized populations in PHEP efforts, to better understand appropriate and effective methods for doing so, and for their input to be subsequently reflected in PHEP plans remain significant gaps in PHEP literature (Wingate et al., 2007).

Engaging marginalized populations in PHEP efforts has some additional challenges. For instance, defining and identifying marginalized populations in the context of a PHE is difficult as it may vary depending on the nature of the PHE, various definitions of marginalized populations exist, and multiple terms such as vulnerable, at-risk, disadvantaged, and special-needs have been used interchangeably (Nick et al., 2009; Uscher-Pines et al., 2007). Determining who legitimately acts as a representative of marginalized populations can be difficult (Uscher-Pines et al., 2007). There is also a limited amount of guidance and encouragement regarding the participation of marginalized populations in PHEP efforts in international and national documents. In the context of influenza pandemic preparedness, the WHO's guidance for influenza pandemic preparedness planning does not specifically encourage the participation of marginalized populations in planning efforts (WHO, 2007).

Most national plans do not include explicit information regarding how the plan was developed and who was involved; therefore, it is difficult to discern if and how marginalized populations were engaged in the process (Uscher-Pines et al., 2007). With governments struggling for the participation of the general public, it may be particularly difficult to focus

on which methods are effective for engaging marginalized populations in PHEP efforts (Uscher-Pines et al., 2007). Moreover, the participation of marginalized populations in PHEP efforts can be particularly resource intensive and may add extra responsibilities to already overwhelmed and understaffed organizations that address many of the other pressing health issues faced by the marginalized populations that they serve (Klaiman et al., 2010). However, the challenges associated with including marginalized populations in PHEP efforts do not discount the importance of this endeavor (Uscher-Pines et al., 2007).

2.4-Community-based Participatory Research

By addressing the identified barriers to participation, the following section will describe how community-based participatory research (CBPR) offers a promising orientation and method for the effective participation of marginalized populations, more specifically Aboriginal Canadians, in PHEP efforts. First, the origins and principles of CBPR will be discussed. Based on the key principles of CBPR, the role of CBPR approaches in enabling the participation of Aboriginal Canadians in influencing health policy, more specifically PHEP efforts, will be explored. Lastly, the benefits and challenges of CBPR will be discussed, along with strategies to overcome the identified challenges.

2.4.1-Origins and Principles of Community-based Participatory Research for Health

CBPR emerged as an alternative research paradigm to traditional inquiry (Minkler & Wallerstein, 2008). Traditional research, often labeled as “helicopter research”, is associated with researcher driven studies conducted within a community that focuses on producing results to disseminate to academic audiences and ends when funding ceases (Horowitz et al., 2009). Furthermore, traditional research approaches have been reported to consistently stigmatize marginalized populations and have often been a negative experience for the community, leading to distrust of researchers and the research process itself (Flicker et al., 2007; Christopher et al., 2008). Traditional research approaches have been particularly negative for Aboriginal Canadians as culturally-insensitive methods have been used to conduct research *on* versus *with* them (LaVeaux & Christopher, 2009).

In contrast to traditional inquiry, the process of CBPR endeavors usually begins with forming an equitable partnership between researchers and members of the community of interest, followed by identifying an issue to address which is of local relevance (Horowitz et al., 2009; O’Brien & Whitaker, 2011). CBPR emphasizes participation and shared control of decision-making between all involved partners in a process towards creating knowledge and outcomes that benefit the involved community (Israel et al., 2001; Flicker et al., 2007; Minkler & Wallerstein, 2008). Employed in a health context, CBPR is most often defined in literature as, “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities” (Minkler & Wallerstein, 2008:6).

CBPR draws from principles of action- and participatory- oriented research approaches that originated from two traditions (Flicker et al., 2007; Wallerstein & Duran, 2008). The “Northern tradition” of action research involves affected individuals (although not extensively) in a cyclical problem solving process directed at addressing societal problems (Wallerstein & Duran, 2008). The “Southern tradition” of participatory research, which originated from research in the developing world with marginalized populations, embodies

principles of inclusivity and engagement of stakeholders in the research process (Israel et al., 2001; Cargo & Mercer, 2008; Wallerstein & Duran, 2008).

Eight principles of CBPR were originally proposed by Israel and her colleagues and these principles are widely recognized as the guiding principles of CBPR (Israel et al., 1998). Subsequently, Israel and her colleagues added a ninth principle (Israel et al., 2005) and two additional principles were added by Minkler & Wallerstein (Minkler & Wallerstein, 2008). As each CBPR partnership varies in its composition and initiatives, each partnership is encouraged to use the eleven key principles of CBPR as a guide when creating a unique set of principles that align with the partnership and local context (Wallerstein & Duran, 2006) (Table 2.1).

Table 2.1: Eleven key principles of community-based participatory research (Israel et al., 1998; Israel et al., 2005; Minkler & Wallerstein, 2008; Minkler et al., 2012)

- 1) Recognizes community as a unit of identity
- 2) Builds on strengths and resources within the community
- 3) Facilitates collaborative and equitable partnerships in all research phases and involves an empowering and power-sharing process that addresses social inequalities
- 4) Promotes co-learning and capacity building among all involved partners
- 5) Integrates and achieves balance between research and action for the mutual benefit of all involved partners
- 6) Emphasizes public health problems that are of local importance and also ecological perspectives that recognize and address the various determinants of health
- 7) Involves a cyclical and iterative process for systems development
- 8) Involves all partners in the dissemination process and disseminating findings and knowledge gained to all involved partners
- 9) Requires a long-term process and commitment to sustainability
- 10) Addresses issues of race, ethnicity, and social class in a transparent and accepting manner; embodies ‘cultural humility’
- 11) Ensures research conducted is rigorous and valid

In addition to contextualizing the initial eight key principles of CBPR for partnering with Aboriginal populations, nine additional principles specifically pertaining to conducting CBPR with Aboriginal populations were put forth (LaVeaux & Christopher, 2009). These principles are suggested as additional considerations for researchers interested in conducting CBPR research with Aboriginal populations (LaVeaux & Christopher, 2009) (Table 2.2).

Table 2.2: Nine additional principles for community-based participatory research with Aboriginal populations (LaVeaux & Christopher, 2009)

- 1) Acknowledge historical experience with research and with health issues and work to overcome the negative image of research
- 2) Recognize tribal sovereignty
- 3) Differentiate between tribal and community membership
- 4) Understand tribal diversity and its implications
- 5) Plan for extended timelines
- 6) Recognize key gatekeepers
- 7) Prepare for leadership turnover
- 8) Interpret data within the cultural context
- 9) Utilize Indigenous ways of knowing

2.4.2-Community-based Participatory Research for Public Health Emergency Preparedness with Marginalized Populations

Given the importance and benefits of engaging marginalized populations in PHEP efforts, CBPR approaches can facilitate the effective participation of historically excluded marginalized populations in activities meant to aid them by addressing the identified barriers to participation (Warren et al., 2011; Cordasco et al., 2007). Although many different CBPR approaches have been documented, the hallmark principles of CBPR can foster the participation of Aboriginal Canadians in PHEP efforts. Most notably, CBPR approaches encourage participation by building a trusting partnership with community members and engaging them in an equitable, direct, and respectful manner in all aspects of the research process (Israel et al., 2005). Meaningful community participation is central to CBPR and values the expertise and knowledge of community members regarding local issues (Butterfoss, 2006; Macaulay et al., 1999; Israel et al., 2010). Instead of addressing a pre-established agenda that may not resonate with the community at hand, employing CBPR approaches in PHEP ensures that community members play an equitable role in defining the agenda from problem identification to evaluation and leads to activities addressing locally relevant issues (Butterfoss, 2006; Warren et al., 2011). As Aboriginal Canadians are equitably engaged throughout the entire process, they can ensure that their voices have been accurately heard, represented, and utilized (LaVeaux & Christopher, 2009).

Furthermore, the dominance of Western-based approaches and knowledge systems in health research, policy, and practice has been noted to hinder the participation of Aboriginal Canadians (Sherwood & Edwards, 2006; Fridkin, 2012). CBPR provides a promising culturally-appropriate approach to engaging Aboriginal Canadians as literature has cited many similarities between the principles of CBPR and those used when working with Aboriginal populations (LaVeaux & Christopher, 2009; Jamieson et al., 2012). CBPR approaches can also facilitate participation by shifting the power imbalance inherent in the decision-making process by valuing local community-based knowledge and different ways of knowing; thus, emphasis is placed on knowledge exchange and accepting and integrating both scientific knowledge and Aboriginal ways of knowing (Fletcher, 2003; LaVeaux & Christopher, 2009). Embracing Aboriginal cultural underpinnings may encourage the participation of Aboriginal Canadians and result in more appropriate outcomes, such as, the development of “culturally-rooted policy” (Ten Fingers, 2005; Noe et al., 2007). Moreover, as mentioned, a facilitator of community participation in health-related activities is employing methodological pluralism (Butterfoss, 2006; Maar et al., 2011). In accordance, CBPR approaches employ various methods, including qualitative methods that may increasingly resonate with how Aboriginal Canadians share their knowledge via oral stories (Maar et al., 2011; Petrucka et al., 2012; LaVeaux & Christopher, 2009).

Another key principle of CBPR approaches is the commitment to achieving broader action-oriented outcomes and translating the knowledge generated to directly benefit the involved community (Israel et al., 2005; Israel et al., 2008). Compared to traditional research efforts, when employing CBPR, the likelihood of generated knowledge being incorporated and implemented into outcomes in communities is increased as community members are equitably involved in all aspects of the process (Faridi et al., 2007). Moreover, CBPR endeavors aim to transcend traditional dissemination avenues (Israel et al., 2005). By equitably involving community members in the dissemination process, relevant findings are encouraged to be used to influence action-oriented outcomes in a manner that resonates most with the community (Macaulay et al., 1999; St. Denis, 2004; Horowitz et al., 2009). Using

the knowledge generated to create tangible outcomes that benefit the involved community is particularly important for Aboriginal Canadians who have a history of distrusting researchers and the process itself as traditional research efforts often did not directly provide the community with any benefits, feedback, or action (Horowitz et al., 2009). As such, it is hypothesized that employing CBPR approaches may improve the level of interest of Aboriginal Canadians in participating in endeavors based on the principle that the community will directly benefit from the knowledge generated (Noe et al., 2007; LaVeaux & Christopher, 2009).

2.4.3-Benefits and Challenges of Community-based Participatory Research

Overall, employing CBPR approaches in PHEP efforts can facilitate the effective participation of marginalized populations yielding various benefits, such as creating mitigation strategies that are effective by modifying aspects to be context-specific and culturally-appropriate (Warren et al., 2011). Via the authentic participation of marginalized populations in PHEP efforts, organizers will also gain an appreciation of the knowledge and expertise possessed by community members and in return, community members will gain the trust, acceptance, and cooperation required for a successful PHE response (Warren et al., 2011). In general, CBPR endeavors have reportedly been successful in using findings to change policy and practice which supports the effectiveness of CBPR in linking research to action (Horowitz et al., 2009; Minkler et al., 2008). Local capacity building is also integral to CBPR endeavors by supporting the training of community members in research (Wallerstein & Duran, 2006; Horowitz et al., 2009). Massey and his colleagues (2011) revealed how a participatory research endeavor improved the research capacity of involved Aboriginal research assistants that in turn will help future community-based health research initiatives. Moreover, some other reported general community benefits of engaging in CBPR activities have been acquiring new skill sets, improving their sense of empowerment, and improving health outcomes (Macaulay et al., 1999; Horowitz et al., 2009; Israel et al., 2010). For instance, a CBPR partnership with a First Nations community concluded that employing a CBPR approach empowered community members, fostered trust amongst involved partners, and supported community members' skill development (Castleden et al., 2008).

While there are numerous benefits of CBPR endeavors and much interest in supporting these initiatives exist, many challenges have been noted given the nature of CBPR (Horowitz et al., 2009). Most notably, the challenge remains of better understanding how and what type of partnerships and participation are most effective to achieve action-oriented outcomes (Wallerstein & Duran, 2010). Determining what community participation means to the CBPR partnership can be quite challenging (Wallerstein & Duran, 2006). As mentioned earlier when discussing community participation, no consensus or standardization exists with regards to defining who participates, in what aspects, how, and to what extent; thus, these are difficult questions that need to be discussed among members of the CBPR partnership (Wallerstein & Duran, 2006). Given that CBPR partnerships are comprised of various members with diverse cultures, perspectives, and knowledge systems, it is inevitable that conflict will arise from differing opinions regarding priorities, principles, and methods (Israel et al., 1998; Wallerstein & Duran, 2006; Horowitz et al., 2009). Trust, respect, and equitable involvement are hallmark features of CBPR partnerships; thus, partners are advised to schedule regular meeting, facilitate open discussions, prepare to resolve conflicts, and create a set of agreed upon partnership principles that address the local project and context (Israel et al., 1998; Horowitz et al., 2009). CBPR partnerships can also establish a community-based advisory board to aid in addressing some of these identified challenges (Wallerstein & Duran, 2006).

Also, as leadership turnover in Aboriginal communities may frequently occur, CBPR partnerships should proactively maintain trusting relationships with many key leaders in Aboriginal communities (Jamieson et al., 2012).

It is also important to note that CBPR approaches assume that community participation in these initiatives will result in more effective outcomes by reflecting community insights and values (Wallerstein & Duran, 2006; Strickland, 2006). Evaluating CBPR processes and outcomes are difficult as numerous stakeholders and contextual factors beyond the control of the formal CBPR partnership are at play (Minkler et al., 2012). Evaluation of both CBPR processes (formative-oriented) and outcomes (summative-oriented) are vital to recognize positive aspects and areas for improvement, especially since sustaining and evolving CBPR partnerships is important for achieving positive outcomes (Stokols, 2006; Horowitz et al., 2009; Minkler et al., 2012). Thus, recognizing that forms of participation varies and each CBPR endeavor is unique, it is recommended that CBPR partnerships use flexible evaluation criteria that can be altered to reflect what they deem to be most important (Mercer et al., 2008; Draper et al., 2010).

Moreover, CBPR has received criticism regarding its perceived lack of scientific rigor as CBPR involves collecting data from various sources using multiple methods (Israel et al., 1998; Horowitz et al., 2009). Although methodological pluralism and flexibility are required to accommodate the project objectives and concerns of the involved partners, it has contributed to a lack of standardization in CBPR studies making it difficult to yield comparisons and lessons learnt (Israel et al., 1998; Castleden et al., 2008; Faridi et al., 2007). Another common challenge is the substantial length of time and money required to form trusting CBPR partnerships, conduct the studies, and create the deliverables (Israel et al., 1998; Horowitz et al., 2009; Strickland, 2006). Thus, partners are encouraged to adjust timelines as needed and obtain flexible sources of funding that will support these initiatives (Horowitz et al., 2009; Strickland, 2006).

2.5-Conclusion

Health, health care, and health policy are increasingly complex for Aboriginal Canadians given the fact that multiple jurisdictions are involved and the vagueness of historical health legislation. Despite efforts to improve Aboriginal health and quality of health care provided to Aboriginal Canadians, vast health disparities remain which have been attributed to a history of colonization, assimilation, marginalization, and inadequate health policies. Historically, most policies imposed upon Aboriginal Canadians were considered to be culturally-inappropriate since their views and knowledge systems were disrespected and disregarded. Thus, it is being increasingly recognized that Aboriginal Canadians should participate in the very endeavors that are meant to improve their health in order for more accountable and appropriate decisions to be made regarding the health of Aboriginal Canadians. Community participation may result in more context-specific and culturally-appropriate health-related activities that may be more effective at improving the health of Aboriginal Canadians. Having effective and appropriate measures in place becomes especially important during PHEs during which Aboriginal Canadians are expected to be disproportionately impacted. However, as community participation is highly contextual and implementation has been especially problematic where there are cultural differences, it is important to understand and address the structural factors that impact their desire and ability to participate. By addressing the identified barriers to participation, CBPR offers a promising framework and strategy for the effective participation of marginalized populations, more specifically Aboriginal Canadians, in PHEP efforts in the pursuit of better health outcomes

for these populations during future PHEs. As such, the following manuscripts will describe multiple studies that explored the use of CBPR approaches to engage community members and improve aspects of local influenza pandemic preparedness in remote and isolated Canadian First Nations communities.

Chapter 3: Developing a collaborative health informatics system to foster inter-agency collaboration and communication during public health emergencies: remote and isolated First Nation communities of sub-arctic Ontario, Canada

3.0-Overview

Public health emergencies have the potential to cause high morbidity and mortality rates, especially within disadvantaged groups. Remote and isolated First Nation communities face additional challenges when responding to a public health emergency. The lack of collaboration and communication between the multiple government bodies in Canada (i.e., federal, provincial, and First Nations) responsible for the provision of health care may have led to a fragmented response and management of a public health emergency. Disease outbreaks expand over space and time; thus, a web-based geospatial information system capable of capturing, displaying, and sharing real-time knowledge at the community, regional, and national levels regarding disease and its growth would be extremely valuable. The objective is to develop a web-based information system that meets the needs of health care professionals in three remote and isolated First Nation communities of sub-arctic Ontario, Canada, which has the potential to improve public health emergency responses. An initial needs assessment with First Nations-based health care professionals was conducted to guide the development of the collaborative health informatics system. Results indicated that there is the potential to use a web-based information system to improve the level of inter-agency collaboration and communication between involved government bodies during a public health emergency. As well, a secure, web-based information system would provide health care practitioners with easily accessible patient health information visually presented in their desired format. Participants also indicated other potential uses of the system; therefore, future research will be conducted to gain more insight into proposed uses. The developed system will address the participant's identified concerns (i.e., confidentiality of health information, differential access levels, and high-security) and will be presented to each community to gain further feedback before final design and deployment. The study communities will be given their system as it will function as a standalone system with their data securely housed for each community; however, users will retain the ability to request changes and modifications to the system to meet their changing needs.

3.1-Introduction

A public health emergency, such as an influenza pandemic caused by a novel influenza A virus (e.g., H1N1), has the ability to cause high morbidity and mortality rates, along with global economic loss and social disruption (Oshitani, 2006). Data have revealed that established social inequalities (i.e., impoverished housing, lack of access to health care, etc.) experienced by vulnerable populations (i.e., First Nations) will be exacerbated during a public health emergency (World Health Organization, 2009; Lee, Rogers, & Braunack-Mayer, 2008; MacMillan, MacMillan, Offord, & Dingle, 1996; Kermode-Scott, 2009; Barker, 2010). Moreover, First Nation communities that are geographically remote (nearest service center with year-round road access is located over 350 kilometers away) and isolated (only accessible by planes year-round) may endure additional challenges during a public health emergency, such as, limited transportation of required supplies and resources (Public Health Agency of Canada, 2006; Ministry of Health and Long-Term Care, 2008).

A recent public health emergency, the 2009 H1N1 influenza pandemic, disproportionately impacted Canadian First Nation communities, especially those that are in the north and

remote (Kermode-Scott, 2009; Barker, 2010; Spence & White, 2010). Some remote and isolated First Nation communities reported that confusion and multiple disagreements arose owing to discrepancies between various government guidelines (e.g., when to obtain laboratory specimens, how to distribute antiviral treatment, etc.), and further there was a lack of health information sharing between provincial and federal representatives (Charania & Tsuji, 2011a). These issues may be attributable to the dichotomy (or trichotomy) between the multiple government bodies (i.e., federal, provincial, and local) responsible for the provision of health care in Canadian First Nation communities (Charania & Tsuji, 2011a).

In Canada, the provision of health care to First Nations is complex. The provision of public and primary health care is the responsibility of the provincial/territorial governments; and additional non-insured health benefits (e.g., prescription drugs, medical equipment, dental care, etc.) are provided to registered First Nations by the federal government (Tsuji, 1998a). In general, the lack of cooperation and coordination between the provincial and federal governments regarding the provision of health care to First Nations has resulted in the overlap of certain health services and insufficient provision of others (Tsuji, 1998a). In addition, at the community level, the Band Council (elected local government), plays a large role in making decisions regarding health care services (Tsuji, 1998a). Currently, in response to public health emergencies in First Nation communities, the informal collaboration between the federal, provincial, and First Nations governments have inadequately defined the roles and responsibilities of various involved government organizations (Public Health Agency of Canada, 2006; First Nations and Inuit Health Branch, 2009) and the need to share information related to both primary and public health care.

Sharing real-time health information and collaboration is vital for the preparation, response, and recovery stages of managing a disease outbreak (Geo, Mioc, Anton, Yi, & Coleman, 2008). Using geographical information systems (GIS) to share data, information, and knowledge should improve communication and collaboration between decision makers of various jurisdictions (Geo et al., 2008; Kyem & Saku, 2009). Collaborative geomatics infrastructures employing mapping are being developed and deployed to foster inter-agency collaboration with involved government organizations (Cowan, Alencar, McGarry, & McCarthy, manuscript). These collaborative geomatics infrastructures reflect a form of neogeography, in which non-experts create and use custom maps (Haklay, Singleton, & Parker, 2008). The research that forms the foundation of these collaborative geomatics infrastructures (Cowan et al., manuscript) has been ongoing for almost twenty years and incorporates many concepts similar to the more recent Public Participation or Participatory Geographical Information Systems (P(P)GIS) and Collaborative Geographical Information Systems (CGIS), which involve the broader use of geographic data by the public (Sieber, 2006; Balram & Dragicevic, 2006). PPGIS has been originally defined as, “a variety of approaches to make GIS and other spatial decision-making tools available and accessible to all those with a stake in official decisions” (Schroeder, 1996 quoted in Sieber, 2006: 492). CGIS is defined as, “an eclectic integration of theories, tools, and technologies focusing on, but not limiting to structuring human participation in group spatial decision processes” (Balram & Dragicevic, 2006: 3). Therefore, introducing a collaborative information infrastructure with a mapping component in remote and isolated First Nation communities may facilitate collaboration and communication among government bodies (and respective health care practitioners) responsible for the provision of health care during a public health emergency. It is anticipated that this will in turn lead to an increase in the adaptive capacity and resilience of the health care system.

Furthermore, GIS and web-based information mapping tools have other additional properties that may be beneficial in supporting the health sector in remote and isolated First Nation communities. First, these tools improve the accessibility, visualization, and understanding of health information, as one can more easily comprehend patterns and relationships in data when it is presented in a graphic format (Heitgerd et al., 2008). Second, when responding to a disease outbreak or an epidemic, access to real-time data is very important (Public Health Agency of Canada, 2006). A GIS allows for the collection, analysis, and visual presentation of real-time, dynamic information (Geo et al., 2008). As well, since diseases expand over space and time, mapping an outbreak may enable a targeted response during a disease outbreak (Geo et al., 2008). Moreover, a GIS can collect and store various types of data (i.e., demographic, environmental, etc.), thus providing a means to examine if a correlation exists between affected individuals and their surrounding environment (Geo et al., 2008). A GIS could also assist with improving education for the general public, disease surveillance, and health care planning (Geo et al., 2008). Therefore, employing a web-based information system with the aforementioned capabilities in the health sector to aid in the management of public health emergencies in remote and isolated First Nation communities should provide many extra benefits.

While current web-based geomatics systems have various desirable functions and have been shown to be effective in facilitating disease information sharing and collaboration, some barriers have been noted (Geo et al., 2008). For instance, disease information is currently collected by different agencies in various ways, thereby creating a barrier to sharing data (Geo et al., 2008). In addition, there is a lack of interoperability between various disease services making it hard to transfer data, which is important (Geo et al., 2008). As well, some GIS mapping systems are expensive and require a high-level of technical expertise to implement and maintain; thus utilization of the system by the end-user may be difficult.

Thus, the objective of the present research is to identify the requirements of a web-based collaborative health informatics system (CHIS) that meets the needs of First Nations-based health care professionals in remote and isolated communities. The web-based CHIS will address the previously reported barriers (Charania & Tsuji, 2011a); thus, the system has the potential to improve the delivery of health care services during a public health emergency in remote and isolated First Nation communities. Further to this goal, a regional needs assessment with First Nations-based health care workers is required to determine other factors influencing the current and desired way of delivering health care during a public health emergency (MacMillan et al., 1996; Kaufman & English, 1979). The results of the regional needs assessment will guide the design, development, and deployment of the CHIS.

3.2-Methods and Materials

3.2.1-The Collaborative Geomatics System

Members of the University of Waterloo's Computer Systems Group (UWCSG), working through their not-for-profit Center for Community Mapping (COMAP), have developed a Collaborative Geomatics system for community-based land-use planning in the Mushkegowuk Territory. Collaborative Geomatics employs a participatory approach to developing and using web-based, distributed-authority, geomatics applications (McCarthy et al., manuscript). Collaborative Geomatics is an interactive, web-based, informatics system capable of capturing, storing, and presenting geospatial data; thus this system will form one of the basic building blocks of the CHIS.

The Collaborative Geomatics system employs the Web Informatics Development Environment (WIDE) application engine and toolkit, which substantially reduces the need for technical experts as it embodies a declarative methodology (Cowan, Fenton, & Mulholland, 2006). Specifically, the WIDE toolkit employs a forms-based approach that allows for the rapid creation, deployment, and modification (if necessary) of complex web-based systems (Cowan et al., 2006). The WIDE application engine and toolkit also allows for the prompt development and customization of the systems as desired by the end-user since they are involved in the entire process (Cowan et al., 2006; McCarthy et al., manuscript). To meet the evolving needs of the end-users, a stand-alone version of the WIDE application engine is being created which will allow end-users (with some basic training) to create their own applications for their Collaborative Geomatics system (McCarthy et al., manuscript). Furthermore, the Collaborative Geomatics system is relatively inexpensive and user-friendly, thus minimizing the need for technical experts once the system is deployed (McCarthy et al., manuscript).

Currently, the Collaborative Geomatics system has various features, including: a common reference map (based on high-resolution satellite imagery and aerial photography); support for the entry of real-time data (oral, written, and/or visual); and accessibility safeguards (via differential access with a secure login and password) (McCarthy et al., manuscript). The system is internet-based (thereby requiring no installation), and most important, facilitates collaboration within and between communities and involved organizations (McCarthy et al., manuscript).

Users are able to log-in on any Collaborative Geomatics system with their assigned username and password. To enter data into one version of the system, a user follows three simple steps to fill out a form. Step 1 involves entering the title of the data entry, its respective category, and a short description (Figure 3.1). In Step 2, a user is able to enter a longer description along with the geographic location of the entry. The location can be entered using the geographical coordinates or geocode, or by using the mapping tools to map the location (Figure 3.2). In Step 3, the user is able to upload audio files, documents, and photos associated with their entry.

STEP 1
 Title and describe your Area of Interest
 The "Title", "Category" and "Short Description" are required fields, all others are optional

Title * **Category** *

Give your Area of Interest a "Title" (e.g. Edwards' Family Camp) Choose an appropriate category from the "Category" drop-down menu such as "Social"

Short Description
 *

Provide a "Short Description" (e.g. Edwards' Family Camp ♡ Moose Hunting or Edwards' Family Camp ♡ Spring Hunt)

STEP 2
 Scroll down to the map

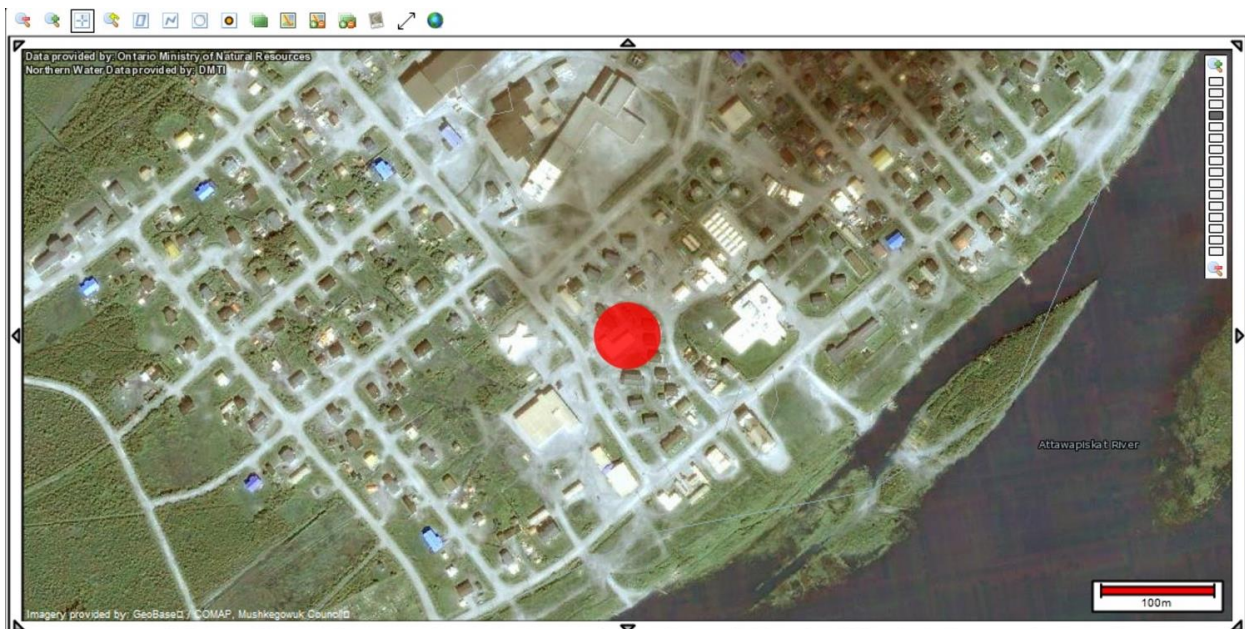
Description

Address **Town** **Postal Code**

UTM Zone 17

Images property of Ministry of Natural Resources, Center for Community Mapping, and University of Waterloo's Computer Systems Group

Figure 3.1: The input form of a collaborative geomatics system (inputted information in text boxes indicates an example)



Images property of Ministry of Natural Resources, Center for Community Mapping, and University of Waterloo's Computer Systems Group

Figure 3.2: Screenshot of mapping tool (filled circle indicates an example of a geographical location entered on a map of a community)

3.2.2-Community-based Participatory Approach

The study was developed in response to the study communities' stated needs and embodies a community-based participatory approach (St. Denis, 2004). This approach fosters collaboration between the researchers and the research participants (Davis & Reid, 1999). In addition, this approach leads to the implementation of applicable benefits that are culturally appropriate for Indigenous communities (Davis & Reid, 1999). A community-based advisory group was formed of representatives from each study community (i.e., health

director/supervisor), in addition to the chair of the regional health board to guide the study's objectives, design, interview style, and questions. Ethics clearance to conduct this research was granted through the Office of Research Ethics at the University of Waterloo.

3.2.3-*Study Area*

The study area includes the western James Bay region known as the Mushkegowuk Territory (Tsuji, 1998a). This area, also known as the Moose Factory Zone, is comprised of six First Nations (i.e., Taykwa Tagamou [formerly New Post], Moose Factory, Fort Albany, Kashechewan, Attawapiskat, and Peawanuck [formerly Winisk]) and the town of Moosonee (Tsuji, 1998a). Fort Albany, Attawapiskat, and Kashechewan are the three First Nations included in this study because community members voiced interest in participating, all are western James Bay coastal communities, and are considered remote and isolated having unique health care service needs. Each First Nation community is governed by an elected Band Council; and the regional First Nation governing body is the Mushkegowuk Tribal Council (Tsuji, 1998a). In 1993, the Mushkegowuk Tribal Council established the regional health authority, the Weeneebayko Health Ahtuskaywin, now re-named Weeneebayko Area Health Authority (WAHA), to reflect a recent integration (Tsuji, 1998a; WAHA, 2009). Providing health care in the Mushkegowuk Territory is challenging, as both provincial and federal medical facilities exist (Tsuji, 1998a). As well, patients requiring care or treatment beyond the capabilities of the nurses and their available medical equipment must be transported to the nearest accommodating health care facility (Tsuji, 1998a) (Table 3.1).

Table 3.1: Health care provision in study communities prior to the formation of the Weeneebayko Area Health Authority (Tsuji, 1998a; WAHA, 2009)

Level of Health Care	Health Care Provider	Health Care Facility
Primary Health Care	Nurses (extended role)	Provincially-funded hospital wing (Fort Albany and Attawapiskat) Federally-funded nursing station (Kashechewan)
Secondary Health Care	Physicians/specialists	Intermittent visits to the communities Nearest accommodating facility
Tertiary Health Care	Physicians/specialists	Nearest accommodating facility
Public Health	Community health nurses	Federally-funded health center (Fort Albany, Attawapiskat, and Kashechewan)

3.2.4-*Study Population*

Purposive sampling was employed to select participants who were particularly informed and had experience relevant to the topic being explored (Daly, 2007; Neuman & Robson, 2009). Selected participants represented the key personnel responsible for the delivery of health care services during a public health emergency in remote and isolated First Nation communities.

Participants who represented the federally-funded health center included: the health director/supervisor, nurse-in-charge, and/or community health nurse. For the provincially-funded hospital wing, the director of patient care and clinical coordinator were included. For the community with a federally-funded nursing station (instead of a hospital wing), the nurse-in-charge was selected to participate. In addition, the chair of the WAHA board was selected to provide an administrative perspective.

3.2.5-Data Collection

This exploratory research employed a modified grounded theory approach to provide a systematic way of gathering and analyzing data using an emergent and flexible design (Daly, 2007). A needs assessment is a tool to guide logical, functional changes that meets the needs of the group in question (Kaufman & English, 1979). A needs assessment is defined as a formal, systematic process that “determines the gaps between current outputs or outcomes and required or desired outcomes or outputs; places these gaps in priority order; and selects the most important for resolution” (Kaufman & English, 1979: 8). Therefore, a needs assessment was conducted to determine if there was a gap between the current and desired mode of health care delivery during a public health emergency in remote and isolated First Nation communities, and this assessment will guide the development of the CHIS. The needs assessment consisted of semi-structured interviews to gather rich, insightful data about the participants’ relevant experiences and perspectives (Charmaz, 2006; Daly, 2007; Minore et al., 2005). All participants were asked broad, open-ended questions, employing frequent probes, to provide the forum for the participant to highlight what they felt was important (Daly, 2007).

The needs assessment was conducted during October 2010, and was developed in a manner culturally appropriate for the Mushkegowuk Territory. Interview questions were vetted through the community-based advisory group and verbal informed consent was obtained (Skinner, Hanning, & Tsuji, 2006; Kirby, Lévesque, Wabano, & Robertson-Wilson, 2007). Individual interviews lasted from approximately 15 minutes to 1 hour. Eight interviews were conducted in English with nine participants at a convenient place and time. Some interviews were conducted face-to-face during which participants were introduced to the Collaborative Geomatics system. This format was chosen so that participants could be exposed to the Collaborative Geomatics system’s various capabilities. Participants were provided with a background explanation of the system, shown how to use the system, and were given time to explore the system themselves. The other interviews were conducted over the telephone and participants were not introduced to the Collaborative Geomatics system. This interview format was chosen to see what information participants revealed when not influenced by the system and its current capabilities. All of the interviews were recorded both in writing and using audio (with the permission of the participant).

3.2.6-Data Analyses

Interviews were transcribed verbatim into electronic format, coded, and analyzed by the lead author (NAC). Collected qualitative data was analyzed both by hand and using QSR NVivo® computer software (version 9.0), as this combined approach has been demonstrated to achieve optimal results (Welsh, 2002). Using a modified grounded theory analytic strategy, data were first coded using open coding in order to create concepts and subsequent categories (Daly, 2007). Axial coding was used to examine emerging categories and how they were

related (Daly, 2007). Last, selective coding was used to integrate and refine the emergent theory (Daly, 2007).

To increase reliability, the thematic analysis was conducted and confirmed by another qualitative analyst belonging to the research team (LJST). Research has shown that the credibility of data interpretation is enhanced if at least two researchers conduct the analysis (Westhues, Lafrance, & Schmidt, 2001). The emergent concepts and categories were presented to each participant to ensure their validity (six changes requested) and confirm that they accurately reflected their perspectives (Neuman, 2006).

3.3-Results

The fifty-five emerging concepts were organized into five categories (i.e., general issues, potential benefits [of using the pilot computer system], potential uses [of the computer system], useful technical functions and suggested technical modifications [of the pilot computer system], and concerns [of using the pilot computer system]).

3.3.1-General Issues and Potential Benefits

Participants identified issues regarding the current way health care is delivered in their respective community, which may be potentially addressed by using a CHIS. Participants reported a relatively low level of collaborative practice with their counterpart health care facility in the community, making it difficult to work in a more synergistic fashion. Therefore, participants believed that a CHIS has the potential to improve coordination and communication if involved health care facilities and practitioners, both local and distant, had access. It was also reported that patient charting is currently fragmented, in that patient charts are scattered amongst various health care facilities, and that a tool to collect health data does not currently exist. A computer system would provide health care practitioners with easily accessible patient health information visually presented in their desired format.

3.3.2-Potential Uses

The pilot computer system was initially proposed as a tool to aid in public health emergencies and was positively received by participants. For instance, participants mentioned that they would like to track and map the occurrence of communicable diseases in their community.

I can see it in my mind, as being able to map out, I'd love to see ... this [disease process] in action and see how you could map out like where disease processes are happening like where a[n] outbreak might be ... imminent or spreading in a certain area ... (Participant #5).

However, the participants also identified many additional potential uses for the computer system (Table 3.2). In particular, participants frequently reported that there were many occurrences in their communities that they wanted to track since the proposed computer system has real-time capabilities. For instance, participants were interested in tracking various diseases and environmental conditions to see if a correlation existed between affected individuals and their surrounding environment.

We know that there's [sic] quite a few cancer cases in different communities ... and there seems to be more in one community than the other ... and there has to be a reason why ... (Participant #7).

... yeah, so you can see the surroundings of the location and basically you find out what, why it's happening ... if you can identify a spot there then you would visually see what's going on [in] that area, maybe it's not well contained ... (Participant #8).

Participants also discussed that using the system to input population statistics and demographic information of their community members would be beneficial. Having a central list of community members and their respective ailments would be especially useful in an emergency situation to know which members needed additional assistance. As one participant mentioned,

... maybe there's an evacuation, we need to know how many community members are there, plus how many Elders need assistance (Participant #9).

It was noted that participants identified using the computer system for triaging purposes would not be desirable. Participants claimed that nurses would not have the time to review the entries submitted by sick community members and nurses would not feel comfortable making health recommendations unless they saw or spoke to the patient in person. Instead, it was suggested that providing links to helpful general health information would be a beneficial use of the computer system.

Table 3.2: Potential uses of the health informatics computer system proposed by participants

Tracking purposes
<ul style="list-style-type: none"> • Chronic diseases
<ul style="list-style-type: none"> • Immunizations
<ul style="list-style-type: none"> • Communicable diseases
<ul style="list-style-type: none"> • School clinics
<ul style="list-style-type: none"> • Teaching sessions
<ul style="list-style-type: none"> • Environmental health concerns
<ul style="list-style-type: none"> • Sexually transmitted infections
<ul style="list-style-type: none"> • General and community historical health events
Mapping purposes
<ul style="list-style-type: none"> • Communicable disease outbreaks
Population statistics
Case and contact management
Demographic information
Links to general health information and websites
Emergency response (e.g., pandemics)
Long term care
Aging at home (home support for people 55-65 years old)
Pre-natals
Post-natals
Well-baby clinics
Health addiction programs

3.3.3-Technical Aspects

Participants who were shown the pilot computer system identified various technical aspects which were useful and some which should be modified when developing the CHIS (Table 3.3). In general, most participants, including ones who regarded themselves as not being particularly computer literate, stated that the pilot computer system was user-friendly. A technical aspect of the system that participants viewed as being especially valuable was the ability to upload audio files, documents, and photos. In particular, a participant mentioned that uploading photos of rare health occurrences could function as a helpful learning tool.

Another technical aspect that participants expressed an interest in was the ability to run real-time collaborative sessions with other invited users. This function allowed users to share their computer screen allowing for them to collaborate over a map, in addition to sharing files and information simultaneously. A participant mentioned that adding a conference call function in which they could verbally communicate with other users would be a useful tool and could possibly replace teleconferences. In addition, many participants reported that adding an instant messaging function would be beneficial, especially to enhance communication between members of the community pandemic committee during a public health emergency.

Moreover, participants stated that having a tool capable of visually presenting selected inputted health information in the form of maps, graphs, and reports, would be especially helpful.

... I think it would be beneficial ... I know that a lot of people are like this, but I'm kind of a visual person, so a tool that would ... spit out graphs and maps and that kind of thing is always, you know, helpful (Participant #5).

... [there are] so many things we are expected to provide reports on each month and this [computer system] would be much handier than another boring report (Participant #6).

Furthermore, participants commented that mapping a disease outbreak occurring in their community and/or in other coastal communities would help to visualize and understand the impact better, thereby, potentially informing planning decisions, such as, whether to implement travel advisories and school closures. Additionally, participants wanted the ability to create graphs and reports to show what diseases were prominent in their community during specific time periods. A participant also suggested creating a database section in which tabular data (e.g., excel files) could be easily uploaded and accessed.

Table 3.3: Useful technical aspects and suggested technical modifications identified by participants

Useful Technical Aspects
• User-friendly
• Upload audio file, document, and/or photo function
• Collaboration session function
• Category search function
• Arrow scroll tool
• Drawing tool option
Suggested Technical Modifications
• Add conference call function
• Add instant messaging function
• Add ability to create maps, graphs, and reports
• Add ability to upload tabular data
• Add ability to verify the addition and deletion of group members
• More colour options for labelling tools
• Make icons bigger
• Add hand scroll tool
• Add ability to move location of inserted point
• Display more current and higher resolution imagery
• Label landmarks on map

3.3.4-Concerns

All participants reported various concerns regarding the use of a computer system, considering that sensitive health information will be inputted, stored, and presented. Almost every participant mentioned that maintaining confidentiality of health information would be a main concern and that precautionary measures need to be in place to protect the individual and their health information. A participant mentioned that,

... I know we have to get patient confidentiality ... form[s] signed, and get everything in place for us to use this [computer system] (Participant #9).

Some participants were also apprehensive about the access levels and security features of the proposed computer system. Many participants suggested that a key person should be designated to restrict access of the computer system solely to health care practitioners. It was also suggested that different levels of access should be granted according to the health profession of the user; for instance, a registered nurse may have more access to information than a community health representative. As for security, participants agreed with the system's accessibility safeguards; it was recommended that each health care facility and user have a password to protect access to the computer system.

Technological concerns were also frequently mentioned by participants, considering a web-based computer system was being proposed. For instance, participants stated that one would need access to a computer and a reliable internet connection (which may be problematic in remote and isolated communities, but not in the communities in the present study who have access to fibre-optic and/or satellite providers), in addition to being computer literate in order to use the computer system.

Despite some concerns, most participants believed that the web-based computer system would be a useful, worthwhile, and valuable tool for the health sector. In addition, some participants commented that they were pleased that the ownership and the rights of access to the deployed computer system belonged to the community and not to outsiders.

... I think there's a lot of potential [referring to computer system] (Participant #7).

... I could already imagine like the possibilities ... I think it's an incredible tool that we could use ... (Participant #6).

3.4-Discussion

It is apparent that the CHIS has the potential to be utilized to manage public health emergencies, and possibly other uses as identified by participants, in remote and isolated First Nation communities. Therefore, it is anticipated that the CHIS will have the following features and functions.

In general, the technical aspects that participants identified as useful will be retained, while the suggested technical modifications will be addressed. Anticipated users of the system will be community-based health care practitioners representing both the federally-funded public health facilities and the provincially-funded or federally-funded primary health care facilities; thus facilitating health information sharing between involved government organizations. People in management positions of the community-based health care facilities (i.e., health director/supervisor, director of patient care, clinical coordinator, and nurse-in-charge) will be the designated people responsible for maintaining the integrity of the CHIS. Ideally, health care practitioners of distant health care facilities will also have access to the CHIS; however, this will be up to the discretion of each community's Band Council.

For security purposes, it is anticipated that users will be able to log-in on computers housed within the health care facilities using their assigned username and password. The CHIS will be pre-programmed according to what information they are allowed to input, access, and view based on their health care profession (i.e., role based access control). Also, as suggested

by participants, patients will sign informed consent forms to allow their health information to be inputted, stored, and presented on the CHIS.

It is anticipated that the CHIS will seamlessly integrate with current processes. For instance, if a registered nurse treats a community member, he/she can input patient data directly into the CHIS. To minimize barriers to data sharing owing to data heterogeneity, users will provide patient's confidential health information in standardized forms. The concept is that users will only have to provide data once, but be able to have selected data presented in multiple formats as desired.

During a public health emergency, users would be able to select entries, which would be organized according to the issue and time period. They could then have the selected information visually presented in their desired format allowing for one to create multiple maps, graphs, and reports for various purposes. For instance, a user could plot on a graph the immunizations performed in relation to the age demographic; thus revealing if a certain age demographic requires an intervention because of low uptake levels. The option to create a graph or report will also be standardized according to provincial or federal guidelines, thereby facilitating the required reporting needs of health care professionals. In addition, users would be able to communicate with other logged on users through the collaboration session function.

Results of the initial needs assessment indicates that introducing a CHIS capable of disease tracking and mapping is a viable and potential option to help improve the coordination of health care delivery during a public health emergency in remote and isolated First Nation communities. However, participants identified many other potential uses of the CHIS. Therefore, the next step of this research is to conduct a more in-depth needs assessment with each study community, in which the design and questions will be created according to the results of the initial needs assessment, as per grounded theory methodology. During the second needs assessment, we hope to gain more insight into the current issues regarding the delivery of health care, other potential and viable uses of the CHIS, and how participants would like the CHIS to appear and operate. Based on the results of both needs assessments, we will collaborate with computer scientists and programmers of UWCSG and COMAP to develop the system. The CHIS will then be presented to each community for further feedback, which will be an iterative and collaborative process until the final system is ready to be deployed. Potential users will be trained to use the CHIS during multiple community-based workshop sessions. The study communities will be given their system as it will function as a stand-alone system with the data securely housed for each community. As this is a flexible system, users will retain the ability to request changes and modifications to the CHIS in order to meet their changing needs.

3.5-Conclusion

The development and use of a community-based, collaborative health informatics system has the ability to improve the delivery of health care during a public health emergency in remote and isolated First Nation communities by fostering inter-agency collaboration and communication. More specifically, using a health informatics system to map disease outbreaks will provide an early detection method; thus, potentially leading to the prevention of further disease spread via a targeted response, an increase in overall health of community members, and less social disruption. It will also provide useful data for community leaders to

make informed decisions and allow remote and isolated communities to network and share information if desired.

As participants identified many possible uses of the proposed collaborative health informatics system, future studies will be conducted to assess the possible modifications that will enable additional functions. In addition, we anticipate that if the proposed collaborative health informatics system is deemed successful in northern, remote First Nation communities, it can also be adapted to meet the needs of other communities. We anticipate that using a common health informatics system by all health care facilities would further improve the adaptive capacity and resilience of the health care sector.

Chapter 4: Health care delivery in remote and isolated First Nations communities in Canada: the need for a collaborative health informatics system

4.0-Overview

Despite recent improvements and supplemental health benefits, the quality of health care delivered to Canadian First Nations continues to be inequitable. Jurisdictional problems (e.g., lack of cooperation and coordination, etc.) have been reported since the federal, provincial, and local First Nations governments share responsibility for the delivery of health care in some remote and isolated First Nations communities. These jurisdictional problems have resulted in a lack of interagency communication and collaboration which may negatively impact the quality of health care delivered. An initial needs assessment was conducted with First Nations-based health care workers of three remote and isolated First Nations communities of northern Ontario, Canada, during October 2010. Results indicated that introducing a collaborative health informatics system could be a viable option to improve the coordination of healthcare services. Thus, a follow-up needs assessment was conducted with one of the study communities to gather additional data. Two focus groups and five semi-directed interviews were conducted with adult key informants representing the federally- and provincially-funded healthcare facilities in Fort Albany First Nation. Collected qualitative data were transcribed verbatim and analyzed using a modified grounded theory analytic approach. The results from this study indicated that there was an improved level of interagency communication and collaboration. Differing legislation, multiple jurisdictions, and the presence of unregulated health care workers were reported to impact the level of interagency health information sharing. Participants also mentioned difficulties (e.g., time-consumption, burdensome) with hand-written patient charting and reporting; thus, they suggested introducing health information technology to improve access and visualization of health information. Participants also suggested two initiatives (e.g., Circle of Care, amalgamating healthcare facilities) to overcome the jurisdictional barriers. The role and organization of government agencies appeared to negatively influence aspects of health care delivery in the remote and isolated First Nations study community. By addressing previously noted barriers and improving access to health information, a collaborative health informatics system has the potential to facilitate interagency communication, collaboration, and health information sharing. Since legislation and the fragmentation of healthcare agencies impacts the ability of agencies to use the same health information technology, re-structuring the organization of health care delivery may be a potential solution to improve the delivery of health care in remote and isolated First Nations communities.

4.1-Introduction

In Canada, the federal, provincial, and First Nations governments share responsibility for healthcare services in some remote and isolated First Nations communities (Tookenay, 1996; Tsuji, 1998a; Thompson, 2010). A remote community is one that is located more than 350 kilometers away from the nearest service center with year-round road access; and an isolated community is only accessible by airplanes year-round (Public Health Agency of Canada (PHAC), 2006). In general, the provision of health care to all Canadian residents is the responsibility of the provincial/territorial governments, which receive funding from the federal government (Thompson, 2010). The federal government provides additional non-insured health benefits (e.g., prescription drugs, dental care) to registered First Nations due to their fiduciary responsibility (MacMillan et al., 1996; Tsuji, 1998a; Health Council of Canada, 2005; Thompson, 2010). Furthermore, at the community level, the Band Council

(elected local First Nations government) can play a large role in making decisions regarding healthcare services (Tsuji, 1998a).

Historically, the lack of cooperation and coordination between the involved federal and provincial/territorial government bodies has negatively impacted some aspects of health care delivery to First Nations; for instance, it has resulted in the overlap or under provision of some healthcare services (Tsuji, 1998a). Jurisdictional problems, such as, the informal collaboration between the multiple government organizations involved in the delivery of health care, has led to poorly defined roles and responsibilities, particularly during public health emergencies (PHAC, 2006; First Nations and Inuit Health Branch (FNIHB), 2008; Charania & Tsuji, 2011a). For instance, some remote and isolated First Nations communities described issues (e.g., confusion, disagreements) that arose during their 2009 H1N1 influenza pandemic response which may be attributed to the reported lack of communication and collaboration, particularly regarding health information sharing, between involved government bodies (Charania & Tsuji, 2011a). Furthermore, this reported lack of health information sharing between government agencies may have negatively impacted health care professionals' ability to conduct case and contact management during the influenza pandemic response (Charania & Tsuji, 2011a).

Herein, health information refers to a patient's medical records, which may include the patient's medical history, list of previous and current medications, and laboratory results (Thompson, 2010). Technically, the healthcare facility that collects the patient's information owns the hard copy of the patient's chart; however, the health information ultimately belongs to the patient (Thompson, 2010). Therefore, in general, the client must sign a written consent form to release their health information to another healthcare facility (Thompson, 2010).

A needs assessment provides a tool to direct logical and functional changes desired by the group in question (Kaufman & English, 1979). Thus, an initial needs assessment was conducted with First Nations-based health care workers in three remote and isolated First Nations communities of northern Ontario, Canada, to identify factors which influenced the current and desired way of delivering health care, particularly during a public health emergency (Charania et al., 2012). Results of the initial needs assessment indicated that introducing a collaborative health informatics system (CHIS) would improve the coordination of healthcare services if employees of all involved healthcare organizations were granted (role-based) access (Charania et al., 2012). The CHIS would be based on a collaborative geomatics system which is a unique interactive, internet-based system capable of capturing, storing, and presenting real-time data (Cowan et al., 2006; McCarthy et al., 2011). Other desirable features of the system are that it is relatively inexpensive, user-friendly, has accessibility safeguards in place, supports a reference map (of high-resolution satellite imagery) and employs the Web Informatics Development Environment (WIDE) toolkit (which minimizes the need for technical experts) (Cowan et al., 2006; McCarthy et al., 2011). Internet-based information systems can improve the accessibility and visualization of health information; thus, these systems may facilitate information sharing and collaboration between jurisdictions, especially regarding disease surveillance (Heitgerd et al., 2008; Geo et al., 2008). To develop and implement the CHIS, a follow-up needs assessment was required to investigate the current issues regarding health care delivery and other potential functions of the CHIS. The results of the follow-up needs assessment are highlighted in the present paper.

4.2-Methods

4.2.1-Study Community Profile

Three remote and isolated First Nations communities were included in the initial part of the needs assessment (Charania et al., 2012). For logistical reasons (e.g., time and financial constraints), the follow-up needs assessment began with Fort Albany First Nation (FAFN). FAFN is occupied by approximately 850 Cree people and is part of the Mushkegowuk Territory, which is located on the western James Bay coast of northern Ontario, Canada (Tsuji, 1998a; Skinner et al., 2006).

FAFN's healthcare system is unique and complex as multiple (both local and distant) government bodies and healthcare facilities are involved (Table 4.1). With regards to the involvement of the First Nations government, at the local level, the FAFN Band Council plays a role in making decisions regarding the healthcare system (Tsuji, 1998a; Charania & Tsuji, 2011a). At the regional level, the Mushkegowuk Tribal Council (regional First Nations government) established the Weeneebayko Area Health Authority (WAHA) (formerly known as Weeneebayko Health Ahtuskaywin before the integration of a regional federal and provincial hospital) to address regional health issues (Mushkegowuk Council, n.d.; WAHA, 2009).

Table 4.1: Health care provision in Fort Albany First Nation*

Level of Health Care	Health Care Provider	Health Care Facility
Primary health care (e.g., acute and/or chronic)	Registered nurses (extended role)	Provincially-funded hospital wing
Secondary health care	Physicians/specialists	Intermittent visits to the community or patient is transported to the nearest accommodating facility
Tertiary health care	Physicians/specialists	Patient is transported to the nearest accommodating facility
Public health (e.g., disease prevention, education)	Registered nurses and front-line workers (e.g., diabetes educator, addictions counsellor)	Federally-funded health center
* Tsuji, 1998a; Mushkegowuk Council, n.d.; WAHA, 2009; Charania & Tsuji, 2011a; Charania et al., 2012; Thompson, 2010; Government of Ontario, 2011; PHAC, 2006		

4.2.2-Community-based Participatory Approach

Participatory methods have been shown to be successful when conducting research with First Nations communities since the research is conducted in a culturally-appropriate manner and directly addresses the needs of the community (Macaulay et al., 1998; Davis & Reid, 1999; Hudson & Taylor-Henley, 2001; St. Denis, 2004; Skinner et al., 2006). Thus, this research

embodied a community-based participatory approach as it involved direct collaboration with First Nations community members (Macaulay et al., 1998; St. Denis, 2004). A community-based advisory group was formed of three community representatives to guide the study's design and objectives, aid in developing the interview questions, and assist with disseminating the study's findings. For instance, prior to commencing the present study, the group was updated on the status of the study and asked to provide feedback regarding the interview questions (three suggested changes were addressed). Ethical clearance to conduct this study was obtained from the University of Waterloo's Office of Research Ethics.

4.2.3-Study Population and Data Collection

To gain a better understanding of the current ways of delivering health care in the study community, participants were purposively selected who had relevant experience and were employed at either the federally-funded health center or the provincially-funded hospital (Daly, 2007; Neuman & Robson, 2009). During the period from February 24 to 28, 2011, two focus groups and five semi-directed interviews were conducted by the lead author (NAC) with 16 adult key informants. Participants held various health related positions in the community and included health directors/supervisors, nurses, nurse practitioners, registered practical nurses, community health nurses, community health representatives, and health counsellors. Informed verbal consent was obtained from participants, as this type of consent is considered to be culturally-appropriate in the Mushkegowuk Territory (Skinner et al., 2006).

Focus groups are deemed to be culturally appropriate and have been successfully used in First Nations communities (Branco & Kaskutas, 2001; Lévesque et al., 2004; Skinner et al., 2006). Focus groups were chosen to provide the opportunity to understand the participants' experiences by providing a forum for participants to discuss issues related to the particular topic, while observing how they collectively interacted (Bryman, 2001; Daly, 2007). The focus groups were conducted according to 'naturally occurring groups' at a convenient place and time for participants (Bryman, 2001; Daly, 2007). Thus, one focus group was conducted for the health center staff (n=4) on-site, and another focus group was conducted at the hospital for their staff (n=7). Semi-directed interviews were conducted at a chosen place and time for participants who were unable to attend the scheduled focus groups. The focus groups and interviews were conducted in English (as requested by participants) and were approximately twenty to fifty minutes in duration (Skinner et al., 2006; Gates et al., 2011).

Consistent with a modified grounded theory approach, the initial portion of the needs assessment directed the subsequent portion of the needs assessment in order to gather more focused data via theoretical sampling (Daly, 2007; Charmaz, 2006). Questions asked during the follow-up needs assessment related to the level of intra- and inter-government agency communication and collaboration, issues with health information sharing, how patient charting and reporting were done, and suggested solutions to identified issues. During the focus groups and semi-directed interviews, open-ended questions and frequent probes were used to allow participants to discuss issues that they deemed to be most important and significant (Bryman, 2001; Minore et al., 2005; Daly, 2007). With permission of the participants, audio recordings and notes were taken.

4.2.4-Data Analyses

The audio recordings from the focus groups and interviews were transcribed verbatim into electronic format. Collected qualitative data were analyzed by hand and using QSR NVivo® (version 9.0) computer software (Welsh, 2002; Daly, 2007). The coding process involved open, axial, and selective coding to create the emerging concepts and categories (Daly, 2007), and has been extensively described elsewhere (Charania et al., 2012). Analyzing the data was an iterative process conducted by the lead author (NAC) and confirmed by another qualitative analyst (LJST) to increase reliability (Westhues et al., 2001).

4.3-Results

One hundred and thirty eight emerging concepts were organized into four overarching categories. The primary findings are highlighted below by participants' quotes to accurately reflect their views (Knafl & Howard, 1984; Minore et al., 2005). As focus groups were chosen to understand how participants collectively interacted; in general, it was noted that their responses were complementary in nature, with participants building on each other's previous comments (Bryman, 2001).

4.3.1-Level of Intra- and Inter-government Agency Communication and Collaboration

Within the health center, participants reported a good level of communication, which was attributed to monthly department meetings and physically working in the same building. Within the hospital, participants reported that it was sometimes difficult to contact people employed at affiliated facilities, which was due to organizational changes associated with the recent integration of a regional federal and provincial hospital.

Participants noted a high level of communication and collaboration between healthcare facilities in their community. Participants stated that the two healthcare facilities worked closely together, especially regarding issues that affected the whole community. Some participants stated,

"...I think we've been through a little bit of problems, but there's a will from all the parties to really talk about the problems we have and improve it and it's working, you know, it's already getting better" (Participant #12).

"...I think all around it's been really positive and we've recently been complemented on the amount of communication" (Participant #2).

They commented that regularly scheduled multi-disciplinary meetings and presentations were helping to resolve issues as it provided a forum for people to communicate and be more cognizant of each other's roles. A provincial participant mentioned,

"...we collaborate on a lot of stuff ... couple of times a year we'll have them [federal health care workers] come over and present on what programs they got, especially if we got new staff, right, we got to make them aware of the programs that are over there ..." (Participant #13).

4.3.2-Health Information Sharing within and between Government Agencies

Federal participants revealed that there were no mentionable problems with sharing health information within the health center. However, the provincial representatives reported that they experienced some difficulties with health information sharing with distant provincial agencies. The difficulties often arose when patients' discharge summaries and specialists' reports were not received in a timely manner after a patient received care at a distant healthcare facility. A provincial participant mentioned,

"...one of the bigger issues from hospital to hospital...there is a gap when we transfer someone out, we have that gap, that time period, where we don't know what happened...we don't have the information in paper form back yet, and we don't ever really get a phone call report or anything like that, so we're lost in the loop very often" (Participant #8).

The participant went on to state that,

"...we don't have it right now...EMR [electronic medical records] but we don't have it, that access, so it makes it a little difficult for us especially if they've [patients] gone to see a specialist and we don't have the report ..." (Participant #8).

When appropriate, health information was shared between agencies via telephone, email, and/or fax. The provincial representatives did not report any issues with sharing patient health information between government agencies; however, some difficulties were noted by the federal representatives. In general, both provincial and federal participants stated that there are many rules, guidelines, and policies (e.g., the *Privacy Act*, oaths of confidentiality) that all health care workers need to be aware of which affect their ability to share health information. Furthermore, participants stated that the presence of unregulated health care workers employed at the health center sometimes impacted the ability to share health information since they do not have a regulating body to which they are held accountable. Federal participants noted,

"There's...hardly any information sharing...it's kind of fragmented...I feel that it would be beneficial for all the health services to be well coordinated, but it's an issue about jurisdiction ..." (Participant #15).

"...the problem with sharing information are not the community's, are not the organization's, it's the higher levels...it's the rules...we must follow" (Participant #14).

The provincial representatives stated that they adhere to the *Privacy Act* and cannot share a patient's health information unless the patient gives signed consent. Participants noted that there were some exceptions to the aforementioned procedure, for instance, when the patient is receiving the same medical care but at a different healthcare facility or the patient is under sixteen years old. However, participants stated that resources exist (e.g., privacy officers) to guide them and ensure that the proper protocol is followed before a patient's health information is released.

The federal representatives reported that the two different jurisdictions responsible for providing healthcare services impacted the ability to share health information between government agencies. As some federal participants stated,

“...the biggest issue that I regard [with] health information sharing is confidentiality and the different levels of government and different organizations, so there’s things to work out between those levels of government ...” (Participant #14).

“...the way we were set up...the federal system being under their own, under Health Canada, and the provincial hospitals being under the province, so that kind of limited the way we work with our clients ...” (Participant #15).

Some federal participants reported that this lack of health information sharing between government agencies impacted their ability to deliver quality health care. Federal participants described the following scenarios,

“...we need the front-line [federal] workers in the community to get involved...because there’s been a crisis...and they [front-line worker] say, well where’s the information...we [provincial workers] can’t give it to you...that’s a big problem right there” (Participant #15).

“...we had no access [to patients’ charts] and I couldn’t do no research, no follow-ups” (Participant #16).

Also, federal participants stated that not having access to health information regarding what was happening at the community level impeded their ability to request and receive improvements to healthcare services delivered in their community. A federal representative stated,

“So the federal government has that information on hand and can target things there [in a nearby community]...we don’t have that information...I have no way to find out that knowledge...so, it kind of impedes our ability to deliver kind of timely interventions...and it’s because of this disparity...the physical separation of the entities as well as the inability to really share that stuff [health information]...” (Participant #14).

4.3.3-Patient Charting and Reporting

All participants stated that they currently have written patient charts that are securely stored on-site at each respective healthcare facility. Some participants stated that it was sometimes hard to find needed patient information due to inconsistent charting methods and the disordered state of some patient’s charts.

With regards to reporting, the provincial and federal representatives used different tools. Provincial participants stated that they inputted health information (e.g., how many admissions, how many patients received treatment) into a system daily, which they called the Census. Participants mentioned that it was generally complicated and time-consuming to do; thus, the reporting task became particularly problematic when they were short-staffed. Also, participants were not able to search the inputted information for trends and statistics, nor did they often receive feedback. As mentioned by the provincial participants,

“...we put a lot of information in there [Census] and it could be set up better so that we could pull information out...at present, you have to sit and look, there’s no way you can search this information” (Participant #7).

“...once we put it in, we very rarely get feedback ... I’d like it compiled to see how we are doing compared to the rest of the region ...” (Participant #13).

The federal representatives stated that nurses enter information about services (e.g., immunizations, Mantoux tests) provided at the health center into the Health Information System (HIS). Although HIS was described as not always being user-friendly, participants thought it worked well. Federal participants explained,

“...it’s just in First Nations, because of the way that...the programming that they have under non-insured health benefits, and the provision of services to the First Nations from Health Canada, that’s why that was set up that way, and that’s how our health center was set up, that we got funding from them, so it more or less they wanted accountability back to them, you know how we operate and all that, so they provided their own system [Health Information System] of reporting” (Participant #15).

“...that [Health Information System] is a great example of information sharing that works so well...all the immunizations that I give are entered onto one system and it’s shared between the [nearby] communities...the clients move around between the communities and we have all [of the] records ...” (Participant #14).

Other employees at the health center complete hand-written monthly reports regarding the services they provided during the month (e.g., how many meetings held, how many people seen). Participants stated that producing month- and year-end reports manually were time-consuming and burdensome, and in some cases did not accurately reflect the diversity of services provided.

4.3.4-Solutions

Participants alluded to some solutions to help improve the aforementioned issues with health information sharing, patient charting, and reporting.

4.3.4.1-Health Information Technology

Since producing statistics and reports manually was conveyed to be quite time-consuming and difficult for participants, most wanted health information technology for charting and reporting purposes. Many benefits of introducing an electronic system were noted, such as, increased security and being able to chart a high volume of information faster. Some participants mentioned,

“...electronically, there’s a lot more security in place, it can be accessed if permissible from an outside location, the information is stored off-site, so that it’s duplicated, backed-up, and you’re not going to lose it, and of course, as you know where trends are going, have already gone provincially, and where they are going to be going federally” (Participant #2).

“...more accessible (patient health information) and show us trends, right, and I think it would help us prepare or maybe change the way we deliver care if we see that something is not working ...” (Participant #13).

With regards to reporting, participants wanted the inputted information presented as numbers and graphs as needed. Also, participants mentioned that having the report templates standardized to their reporting requirements for their respective bosses would be desirable. A federal participant suggested,

“...possibly take a look at...what is the reporting requirement...and then deduce down what actually the front-line workers need to be reporting...and that [report template] could be standardized in a way that, you know, if the field doesn't relate to me, I don't have to put anything in...or it can be shaded out or something like that ...” (Participant #2).

Furthermore, participants wanted the electronic system to be user-friendly since some consider themselves to be computer illiterate. Most importantly, the system would need to interface between both provincial and federal healthcare facilities in order to improve health information sharing.

“...cause it only makes sense...if we get some kind of system or...a different system than the hospital...then we'd just be clashing all the time right and we won't be able to, things won't be able to be sent back and forth” (Participant #16).

“...we have to be able to interface with both because we deal with both...it would be just interesting to keep in the mind that they'd have to be able to bridge both provincial and federal standards ...” (Participant #2).

4.3.4.2-Circle of Care

Another solution suggested by participants to improve health information sharing between government agencies was what was referred to as the Circle of Care. The Circle of Care initiative aimed to allow health care workers directly involved with a patient's care to access a patient's health information to do case management. A federal participant explained,

“...the Circle of Care model was only worked out so that the First Nation would be the ultimate authority giving direction to both [the] province and feds [sic] to work more closely...with case management...because it's important, it's [a] life-saving issue that we're talking about” (Participant #15).

The Circle of Care initiative was positively seen as a forum for health care workers to discuss concerns in a more holistic manner and about general issues affecting the whole community.

“...I think it [Circle of Care] is helping us a lot, you know, to have a better holistic approach toward the patient...and it helps us to identify problems even in the communities...so it opens our eyes” (Participant #12).

However, participants noted that legislation would still prevent sharing health information regarding individual cases.

“...I think it [Circle of Care] is a really good community initiative...but, where I see the impediment is how much information you can release...without the patient’s consent” (Participant #13).

4.3.4.3-Amalgamating under Weeneebayko Area Health Authority (WAHA)

Finally, participants discussed the possibility of the federally-funded health centers amalgamating under WAHA, the provincial entity. Thus, all community healthcare facilities would be provincial, potentially allowing them to share health information and use the same health information technology.

“...once we build on that relationship...we’re in the process of, from the...hospital board at Weeneebayko, which is now the amalgamated board, working on us taking over the health center...under our wing, so that we can work together with them, like being under the provincial system more or less” (Participant #15).

Participants stated that they were still exploring other options to improve health information sharing which would provide the opportunity for the healthcare facilities to work together in a more coordinated fashion. Furthermore, a participant noted that issues with health information sharing may only get more complex in the future, which may create additional difficulties.

“...it’s too many ownership issues, meaning the sharing of information in this day and age is just, it can only get more complex...newer and unforeseen complexities that [may] arise” (Participant #14).

4.4-Discussion

In general, the role and organization of government agencies influenced aspects of health care delivery in the remote and isolated First Nations study community. With regards to interagency communication and collaboration, it was noted to be improving due to regularly scheduled multi-disciplinary meetings and presentations. However, some participants reported that interagency health information sharing was limited due to the fact that multiple different jurisdictions are responsible for health care delivery, which in turn negatively impacted the quality of health care delivered. Studies have shown that, in addition to the organizational structure of healthcare facilities, varying individual and agency interpretations of applicable legislation may influence interagency health information sharing (Richardson & Asthana, 2006). For instance, health care professionals tend to place more emphasis on protecting a patient’s confidential health information versus sharing information (Richardson & Asthana, 2006). Thus, it is important that members of multi-agency health teams are aware when it is or is not appropriate to share a patient’s health information across agency boundaries (Richardson & Asthana, 2006). Providing guidance documents that clarify the pertinent legislation regarding interagency health information sharing may prove to be helpful for health care workers (Richardson & Asthana, 2006). Furthermore, participants indicated that the presence of unregulated health care workers impacted the ability to share health information.

As suggested by participants, to facilitate appropriate interagency health information sharing, patient charting and reporting, we recommend that a form of health information technology

be introduced. Health information technology, such as electronic medical records (EMR), has many benefits, in addition to the ones stated by the participants. Studies have shown that EMR can lead to better access to information, a decrease in medical errors, and improved patient safety and quality of patient care (Wang et al., 2003; Miller & Sim, 2004; Hillestad et al., 2005). Furthermore, implementing EMR in a healthcare facility can positively change how members of the health team communicate with one another and provide healthcare services (Wager et al., 2000). However, some concerns with implementing EMR have been noted, which include: high cost, substantial time investment, lack of incentives, and concerns about security and patient confidentiality (Loomis et al., 2002; Wang et al., 2003; Miller & Sim, 2004; Hillestad et al., 2005). Other health information technology, such as telehealth, which uses information and communications technology to delivery health related services, has been a promising mechanism for improving health care delivery to rural and remote areas (Muttitt et al., 2004). Some reported challenges of using telehealth in these areas are related to difficulties with obtaining the required technical infrastructure and human resources (Muttitt et al., 2004).

Given this, a collaborative health informatics system (CHIS) is a potential and viable option as it would address previously noted barriers and would be capable of patient charting and reporting, and facilitate interagency health information sharing (Charania et al., 2012). This in turn should lead to improved communication and collaboration between health team members of different jurisdictions (Geo et al., 2008; Kyem & Saku, 2009; Charania et al., 2012). Most importantly, the CHIS can be customized to meet the needs of the community at hand, and studies have shown that it is vital that health information technology is designed to appropriately meet the needs and organizational structure of the health team (Wager et al., 2000; Reddy & Bradner, 2005). However, as noted by the participants, the introduction of health information technology will only improve interagency health information sharing if both government healthcare facilities are involved; however, this is limited by legislation and fragmentation of involved healthcare agencies. Thus, a potential solution, as suggested by participants, is to restructure how health care is delivered in remote and isolated First Nations communities of the Mushkegowuk Territory. Amalgamating under one government jurisdiction would allow health care workers to effectively and efficiently share patients' health information as needed, which would in turn improve the quality of health care delivered to residents.

The presented research has various strengths in that it provided insight into issues and solutions regarding health care delivery, particularly health information sharing, in the setting of a remote and isolated First Nations community. A limitation of this study is that some findings may not be widely generalizable due to the unique characteristics of health care delivery present in the study community. The next step of this research will explore how to overcome the jurisdictional barriers that influence interagency health information sharing in remote and isolated First Nations communities.

4.5-Conclusion

The role and organization of government agencies negatively influenced aspects of health care delivery in the remote and isolated First Nations study community. The organizational structure of healthcare facilities, differing individual and agency interpretations of applicable legislation, and the presence of unregulated health care workers may all affect interagency health information sharing, which in turn impacts the quality of health care provided. Furthermore, participants stated that written patient charting and reporting was time-

consuming and burdensome; in addition, they were unable to search information for needed trends and statistics.

By addressing previously noted barriers and improving access to health information, health information technology, such as, a collaborative health informatics system, has the potential to facilitate interagency communication, collaboration, and health information sharing. However, as legislation and fragmentation of healthcare agencies impacts the ability of agencies to use the same health information technology, re-structuring the organization of health care delivery may be a potential solution. Thus, future studies will be conducted to assess how to overcome jurisdictional barriers to facilitate interagency communication, collaboration, and health information sharing to improve the delivery of health care in remote and isolated First Nations communities.

Chapter 5: Assessing the effectiveness and feasibility of implementing mitigation measures for an influenza pandemic in remote and isolated First Nations communities: a qualitative community-based participatory research approach

5.0-Overview

The next influenza pandemic is predicted to disproportionately impact marginalized populations, such as those living in geographically remote Aboriginal communities, and there remains a paucity of scientific literature regarding effective and feasible community mitigation strategies. In Canada, current pandemic plans have not been developed with adequate First Nations consultation and recommended measures may not be effective in remote and isolated First Nations communities.

This study employed a community-based participatory research approach. Retrospective opinions were elicited via interview questionnaires with adult-key health-care informants (n=9) regarding the effectiveness and feasibility of implementing forty-one interventions to mitigate an influenza pandemic in remote and isolated First Nations communities of subarctic Ontario, Canada. Qualitative data were manually transcribed and deductively coded following a template organizing approach.

The results indicated that most mitigation measures could potentially be effective if modified to address the unique characteristics of these communities. Participants also offered innovative alternatives to mitigation measures that were community-specific and culturally-sensitive. Mitigation measures were generally considered to be effective if the measure could aid in decreasing virus transmission, protecting their immunocompromised population, and increasing community awareness about influenza pandemics. Participants reported that lack of resources (e.g., supplies, monies, trained personnel), poor community awareness, overcrowding in homes, and inadequate health care infrastructure presented barriers to implementing mitigation measures.

This study highlights the importance of engaging local key informants in pandemic planning in order to gain valuable community-specific insight regarding the design and implementation of more effective and feasible mitigation strategies. As it is ethically important to address the needs of marginalized populations, it is recommended that these findings be incorporated in future pandemic plans in order to improve the response capacity and health outcomes of remote and isolated First Nations communities during the next public health emergency.

5.1-Introduction

It is inevitable that a novel influenza virus will cause another global influenza pandemic in the future (Oshitani, 2006). Influenza pandemics can cause high rates of morbidity and mortality in humans, along with wide-scale social and economic disruption (WHO, 2009). Marginalized populations, such as, Canadian Aboriginal (First Nations, Inuit, and Métis) populations living in geographically remote areas, continue to be disproportionately impacted by influenza pandemics (O'Neil, 1995; Kermodé-Scott, 2009; Kumar et al., 2009; Barker, 2010; Spence & White, 2010). In fact, Aboriginal Canadians reportedly overrepresented the number of patients admitted to an intensive care unit during the 2009 H1N1 influenza pandemic (pH1N1) outbreak and the severity of disease experienced was higher among Canadian First Nations (Kumar et al., 2009; Zarychanski et al., 2010). Most Canadian Aboriginal communities are faced with unique, multifaceted challenges that impact their pandemic response capacity; for instance, being geographically remote limits their access to

required healthcare services and medical supplies (Ministry of Health and Long-Term Care (MOHLTC), 2008; Groom et al., 2009; Richardson et al., 2012). Access and provision of healthcare services for First Nations Canadians is further complicated since various government organizations (e.g., federal, provincial, and First Nations) are responsible for the health of First Nations in Canada and these organizations have yet to clearly define their roles and responsibilities during an influenza pandemic (Public Health Agency of Canada (PHAC), 2006). Furthermore, overcrowded housing conditions and impoverished lifestyles appear to promote virus transmission during an infectious disease outbreak in these already marginalized communities (Groom et al., 2009).

Given the aforementioned, it is vital for Canadian First Nations to have pandemic plans in place that include context-specific, community-informed measures in order to improve their pandemic response capacity and mitigate the injustice that may occur during the next public health emergency (Richardson et al., 2012; Uscher-Pines et al., 2007; Lee et al., 2008). However, in Canada, existing national and provincial pandemic plans appear to recommend universal mitigation measures that may not be effective in remote and isolated First Nations communities due to the underlying social, economic, environmental, and cultural differences that impede feasible implementation (Kermode-Scott, 2009; MOHLTC, 2008; PHAC, 2006; Webster, 2009). Commonly recommended mitigation measures can be categorized as either pharmaceutical interventions (e.g., vaccines, antivirals) or non-pharmaceutical interventions (e.g., isolation, quarantine, etc.) (Oshitani, 2006). Although pharmaceutical interventions are considered to be the best mitigation measures, limitations of supply and cost restrict their usage, especially in remote and isolated First Nations communities (Oshitani, 2006; MOHLTC, 2008; Low, 2008). Non-pharmaceutical interventions may help reduce the number of attack and death rates, along with lessening the pressure on the health care infrastructure, associated with influenza pandemics and are therefore recommended to supplement the use of pharmaceutical interventions (Low, 2008; Bell et al., 2006a; Markel et al., 2007). Unfortunately, there are significant gaps in the scientific literature regarding the effectiveness and feasibility of implementing non-pharmaceutical interventions, especially for remote and isolated First Nations communities (Oshitani, 2006; PHAC, 2006; Aledort et al., 2007). It is vital to understand which mitigation measures are most effective in order to use the limited amount of resources available for maximal impact and reduce the associated unintended social and economic consequences (PHAC, 2006; Low, 2008).

Previous pandemic planning efforts world-wide have been typically guided by government agencies, public health agencies, expert scientists, and mathematical modeling studies (Kotalik, 2005; Marshall et al., 2009; Hampton, 2007; Patriarca & Cox, 1995). While these various sources provide important information during the pandemic planning process, the limited use of public consultation has been noted (Kotalik, 2005; Marshall et al., 2009; Hampton, 2007). In fact, in Canada, the Assembly of First Nations noted that First Nations were not appropriately included in the creation of the national and provincial influenza pandemic plans (Assembly of First Nations (AFN), 2005). Public participation is increasingly being encouraged in the health policy-making process (Maxwell et al., 2003; Thurston et al., 2005) since locally impacted populations best understand the barriers faced when implementing public health recommendations and can propose innovative modifications or solutions (Uscher-Pines et al., 2007). Engaging Aboriginal populations in the pandemic planning process can provide valuable insight into how local community perspectives and cultural values impact the effectiveness and feasibility of executing recommended mitigation measures (Groom et al., 2009; Hampton, 2007; Blendon et al., 2008; Braunack-Mayer et al., 2010).

Thus, the purpose of the presented study was to elicit retrospective opinions regarding the effectiveness and feasibility of implementing mitigation measures during pH1N1 from adult-key health-care informants residing in remote and isolated First Nations communities, using a community-based participatory research approach. These insights will aid in creating much needed recommendations for mitigation measures in remote and isolated First Nations communities that are context-specific and include First Nations perspectives. It is important for remote and isolated First Nations communities to have specific recommendations in place to increase compliance and reduce virus transmission (Massey et al., 2009). In turn, as these recommendations address the unique challenges faced by Canadian First Nations, they should be incorporated into future pandemic plans to improve the response capacity and health outcomes of Canadian First Nations during the next public health emergency.

5.2-Methods

5.2.1-Study Area and Population

The present study employed a community-based participatory research (CBPR) approach as participatory research methods have been shown to be successful when partnering with Aboriginal communities (St. Denis, 2004; Macaulay et al., 1998; Davis & Reid, 1999). CBPR approaches can encourage Aboriginal participation and including their input may result in more appropriate outcomes from research and policy efforts (Ten Fingers, 2005; Noe et al., 2007). As CBPR approaches value equitably engaging partners, collaboration occurred between the researchers and community members throughout the research process (St. Denis, 2004; Macaulay et al., 1998; Davis & Reid, 1999; Israel et al., 2005). As such, a community-based advisory group was formed of three representatives (one from each study community) to aid in designing the study, informing and piloting the questions, and disseminating the results (Charania & Tsuji, 2011a; Kirby et al., 2007). Approval to conduct this research was granted by the Office of Research Ethics at the University of Waterloo, and the involved communities (e.g., Band Councils, the locally-elected First Nations government).

The three study communities (names omitted for anonymity purposes) are characterized as remote (i.e., nearest service center with year-round road access is located over 350 kilometers away) and isolated (i.e., only accessible by airplanes year-round) First Nations communities and are located in northern Ontario, Canada (PHAC, 2006; Tsuji, 1998a). Adult key informants were purposively selected based on their experience as health care professionals (e.g., health directors, clinical coordinators, registered nurses) working in a health care facility (e.g., hospital, nursing clinic, health center) in a remote and isolated First Nations community. Selected participants were also directly involved in their respective communities' response to pH1N1; thus, they had the required experience and authority to comment. Based on the high rate of health care personnel turnover in the study communities and availability of participants, a total of nine participants (three from each community) met the inclusion criteria and were invited to participate in the presented study.

5.2.2-Data Collection and Analyses

Based on a literature review of current national, provincial, regional, and community level pandemic plans and relevant literature, forty-one mitigation measures (two pharmaceutical and thirty-nine non-pharmaceutical) were included in the interview questionnaire. The key informants were asked open-ended questions regarding whether each measure was used during their response to pH1N1 and the effectiveness of each measure in the setting of a remote and isolated First Nations community. Effectiveness was defined as, "effects under

real-world constraints” that could include “feasibility, cost, logistics, operational and infrastructure constraints, and acceptability in terms of concerns surrounding legality and ethics, equity, public confidence, and potential unintended consequences” (Aledort et al., 2007:2). Neutral probes were used to promote elaboration, and participants were encouraged to suggest and discuss alternative and/or additional mitigation measures based on their previous experiences (Bryman, 2001).

The interview questionnaires were conducted by the lead author (NAC) from July 2010 to October 2011, at a place and time most convenient for the participant after verbal informed consent was obtained (being culturally appropriate for the region) (Kirby et al., 2007; Skinner et al., 2006). Interviews ranged from two hours to four hours in duration, were conducted in English (as requested by the participant), and audio recorded (with the participant’s permission).

The qualitative data were manually transcribed into electronic format and deductively analyzed following a template organizing approach utilizing the interview questionnaire as a coding template (Bryman, 2001; Crabtree & Miller, 1999). For subsequent analysis and interpretation, the data were further categorized according to whether or not the measure was used and considered to be effective by the participants. The aforementioned data analysis was an iterative process completed multiple times by the lead author (NAC) and confirmed by the co-author (LJST) to increase accuracy (Westhues et al., 2001).

5.3-Results

Participants reported that thirty of the forty-one questioned mitigation measures were used in some form or the other during their response to pH1N1. All of the measures used were considered to be effective and an additional mitigation measure was also suggested. Participants agreed that three measures which were not used during their pH1N1 response would be considered to be effective in mitigating an influenza pandemic in a remote and isolated First Nations community (Table 5.1). The most relevant findings are presented below and highlighted by participants’ representative quotes (Knafl & Howard, 1984).

Table 5.1: Effective and not effective measures to mitigate an influenza pandemic in remote and isolated First Nations communities suggested by participants (n=9)

Effective mitigation measures	Not effective mitigation measures
<ul style="list-style-type: none"> • Entry screening of travelers • Screening for influenza-like illness at public places • Travel restrictions or advisories on all arriving passengers • Travel restrictions or advisories on all departing passengers • School closures • Childcare center closures • Workplace closures • Isolation (of ill individuals) • Quarantine (of non-symptomatic contacts of ill individuals) • Restricting attendance or cancelling public gatherings 	<ul style="list-style-type: none"> • Exit screening of travelers • Closing down all borders • Quarantine of a geographic area (cordon sanitaire) • Disinfection of clothing, shoes, or other objects of persons exiting affected areas • Sanitary measures at frontiers or on conveyances • Self-health monitoring and reporting if ill, but no restrictions on movement • Urge entire population in an affected area to check for fever at least once daily

<ul style="list-style-type: none"> • Modifying cultural practices (at church and funerals) • Traditional medicine • Rapid influenza diagnostic tests • Vaccines • Antivirals • Public education • Hand hygiene • Respiratory etiquette • Social distancing measures • Avoid visiting • Avoid crowding • Voluntary sheltering • Home support program • Monitoring trends of influenza-like illness • Contact tracing • Human surveillance and case reporting • Wearing surgical masks and N95 respirators • Wearing other personal protective equipment • Air disinfection • Surface disinfection (beyond usual practice) • Ventilation (i.e., open windows) • Visitor restrictions (in health facilities) • Minimize aerosol-generating procedures (in health facilities) • Isolation precautions (in health facilities) 	<ul style="list-style-type: none"> • Animal/human interchange (measure was not applicable)
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5.3.1-Screening the general public and travelers for influenza-like illness at public places

Participants reported that screening the general public for influenza-like illness (ILI) using health questionnaires and declarations at public places (e.g., airport, school, church, local stores, health facilities) was successful during pH1N1. Although the lack of required supplies and trained personnel were reported issues, participants stated that screening was a particularly effective measure because it provided an opportunity to diagnose and treat people with ILI early on. However, one participant raised an important ethical concern with implementing screening measures,

It's like a moral decision, do you send your workers over there, [they] have a chance of getting infected ... morally, ethically can we put our people at the front line for people to die for other people? (Participant #2).

Thus, the participants suggested some alternatives to reduce the risk associated with implementing screening measures. One alternative was to provide personal protective

equipment for screeners and a 'sick bay' for them to take short-term residence in so as not to risk transmitting the virus to their family. Another suggested alternative was to only provide relevant health information instead of having personnel to screen at public places if the virus was highly pathogenic.

Participants said that screening incoming travelers at the airport was an effective measure because it was feasible to implement and would increase awareness in community members regarding the severity of the influenza pandemic situation. However, participants reported that it was difficult to have enough manpower available to screen passengers on each arriving plane. A suggested alternative was to request the airline companies to screen and provide health information to their passengers prior to boarding flights. Participants did not screen departing travelers during pH1N1 as the measure was perceived to not be feasible nor a priority due to the additional manpower and resources required to screen all departing passengers in addition to all arriving passengers. However, as some participants still stated that this was an ethical measure and aided in containing an outbreak, a suggested alternative was to direct efforts towards community educational health campaigns in an effort to inform community members about when it was safe to travel.

5.3.2-Travel restrictions or advisories on arriving and departing passengers

The participants reportedly employed both travel restrictions and advisories on all arriving and departing passengers, no matter if they were visitors or community members, during their pH1N1 response. The travel recommendations generally began as voluntary advisories and escalated to mandatory restrictions as the outbreak progressed and more cases were confirmed in the nearby region. Anecdotal commentary indicated that these measures had low rates of compliance as some community members doubted the worthiness of these measures and were difficult to enforce, especially if other travel methods besides flights were available (e.g., winter road, boat). However, most participants reported that these travel measures helped contain the outbreak and were effective owing to the feasibility and cost-benefits associated with their implementation. In addition, participants described that these measures helped increase awareness amongst community members about the pandemic. Furthermore, other participants stated the importance of executing these measures to aid in decreasing virus transmission, especially in a remote and isolated community with a high prevalence of immunocompromised individuals,

The community did ... the restrictions and the advisories because we are isolated, so I think it was necessary ... considering the grave consequences that H1N1 had on terms of health and ... considering all the chronic diseases prevalent in this community, I think it was very prudent and wise. (Participant #3).

5.3.3-Closing down all borders and quarantine of a geographic area

Closing down all borders and quarantine of a geographic area (cordon sanitaire) were not implemented during the study communities' response to pH1N1, although the possibility of implementing these measures was discussed during the community pandemic committee meetings. The majority of participants said that these measures were not effective; however, some participants believed that these measures could potentially protect their immunocompromised population under certain conditions. For instance, participants said that these measures could be effective if the virus was highly pathogenic, if an outbreak was not yet present in the nearby region, and if all of the coastal communities quarantined simultaneously. Participants reported that these measures would be difficult to implement,

but still feasible since the communities are primarily accessed by airplanes and the Band Councils would have the political power to declare these measures.

[Be]cause we can probably quarantine the whole community ... to keep the community safe, we're [in] ... a better position to do that because we only get flights in. (Participant #2).

That's what they were discussing during our meetings, that they [First Nations governing body] could override all the other political levels out there and just say nope, nobody is coming in or out. (Participant #3).

On the other hand, some participants raised concerns about being able to maintain and enforce these measures, especially with regards to acquiring needed supplies and resources.

It would have to be [a] pretty severe virus ... it's hard to make an isolated community more isolated. It's the manner of how you get supplies, and how do you actually maintain life, especially [because it is] so remote up here. So, it would need to be done with caution and planning, careful planning. (Participant #9).

To reduce disturbances associated with implementing these measures, participants suggested that community members could practice a subsistence lifestyle to sustain themselves during this period. Also, another beneficial modification suggested was to partially close the community's borders, in that a mode of receiving needed supplies and human resources could still function.

5.3.4-Closing down community schools, childcare centers, and workplaces

The majority of participants said that closing down schools and childcare centers in the community were effective mitigation measures that were employed during their pH1N1 response. Generally, participants stated that these measures limited virus transmission in the community since they reported that it was difficult to implement other infection control measures (e.g., hand hygiene, respiratory etiquette) in the younger age groups. Participants noted that school closures done in tandem with restricting children's access into local community stores limited the ability of children to congregate elsewhere. Furthermore, participants stated that school and childcare center closures were feasible because there was often a guardian at home to care for the children, especially if workplaces were closed simultaneously. Although not used during their pH1N1 response, most participants thought closing workplaces would be an effective measure. Some participants raised concerns about the expense of employees' wages due to lost hours; thus, only closing non-essential community workplaces was suggested to minimize the associated economic losses. However, this modification was contested as some participants did not consider any workplaces in a northern remote and isolated community to be non-essential.

I can't think of any non-essential work places here ... all the ones I'm thinking of are essential, like we only have two stores, so no ... it wouldn't be practical. (Participant #3).

5.3.5-Isolation and quarantine

Both mandatory and voluntary isolation of ill individuals and quarantine of non-symptomatic contacts of ill individuals were used to mitigate the effects of pH1N1 in the study communities. These measures were perceived to be effective in minimizing virus

transmission, especially if implemented at the beginning of a community outbreak. However, some participants mentioned that these measures were not feasible to implement since it was challenging to ensure that community members followed the recommendations. Also, finding locations to isolate and quarantine individuals was problematic due to the overcrowding present in most homes and the lack of space to accommodate ill people in community health care facilities.

Not effective, not in our community because it's like, there's overcrowding in their homes already [and] in the nursing station [local health care facility] there's no place to isolate them, it's just not physically possible to isolate them in our center. (Participant #8).

Thus, participants noted that some buildings in the community (e.g., school, church) could be potential places to isolate or quarantine people as needed. Furthermore, participants suggested that only the home contacts of an index case should be requested to quarantine, as it would be challenging to maintain daily community functions if all of the casual contacts were also required to quarantine since extensive social networking occurs in their communities.

5.3.6-Restricting public gatherings, modifying cultural practices, and traditional medicine

Participants stated that all non-essential community events (e.g., dances, pow wows), whether indoors or outdoors, were either cancelled or postponed during pH1N1. Participants generally reported that cancelling or postponing events was more effective than simply restricting attendance since no manpower or resources were required to screen people attending the event. Furthermore, as people generally travel often between the coastal communities, participants reported that cancelling or postponing events limited virus transmission as people would not have the opportunity to congregate. Participants stated that most community members seemed disappointed by the enforcement of these measures but generally complied.

Church services and funerals were still held during pH1N1 as these events were considered to be essential and culturally important. Thus, participants stated that cultural practices (e.g., kissing, handshaking) were modified and various infection control measures (e.g., limiting attendance, health teachings, using hand sanitizers and masks) were employed to decrease virus transmission. The vast majority of participants believed these measures to be effective, feasible to implement, and accepted by community members especially if advocated by the Band Council and the Elders in the community.

They teach people right at the entrance door of the church and they provided gloves and masks if they ... [had] mild signs and symptoms, they had the cleaning soap ... they were told not to do it, not even the communion, and also you know limit church gathering as much as you can. (Participant #1).

Moreover, traditional medicine was suggested as an additional effective measure to mitigate an influenza pandemic in a remote and isolated First Nations community as some community members reportedly sought treatment from traditionalist during pH1N1. Thus, participants reported that traditional medicine should be included as a helpful mitigation measure for the next influenza pandemic.

5.3.7-Rapid influenza diagnostic tests in health care facilities

Although commercially available influenza diagnostic tests were not available for use during their pH1N1 response, the majority of participants said that these diagnostic tests would be effective to determine if influenza was the causative agent of a community outbreak. Participants stated that these point-of-care diagnostic tests would be helpful to reinforce a diagnosis and ensure proper treatments are prescribed. Although some participants raised concerns about the accuracy and cost-effectiveness of these diagnostic tests, others said it would be especially valuable in a remote and isolated setting because of the long time period typically required to receive laboratory results.

Point-of-care is critical up here because it can be days before we get specimens out and then days before we get results back. So any kind of point-of-care, anything is most effective here, more so than it would be in a hospital where there's a lab that can do it. (Participant #9).

5.3.8-Vaccines and Antivirals

All of the participants reported that pandemic vaccines and antivirals were used during their pH1N1 response and were effective since community infection rates appeared to reduce after commencing these measures. It was also noted that antivirals were not given prophylactically to providers or contacts of an index case during pH1N1. Although some participants reported that prophylactic antiviral treatment would be ideal, others said it would not be the best use of resources and may contribute to the creation of antiviral resistant virus strains.

Although the communities received enough vaccines and antivirals, some difficulties related to distribution to and within the communities were reported. For instance, it was noted that one community was only distributed half of their allotted vaccines in a timely manner. Also, shortages of qualified personnel to immunize and lack of adequate education hindered the distribution of vaccines in the communities. Confusion regarding what symptoms were required to receive antivirals led to inadequate patient treatment in some cases and some participants reported that antivirals with short expiration dates were delivered to their community. Thus, participants suggested that providing more education regarding these measures would increase community vaccine uptake rates and help ensure that individuals seek and receive antiviral treatment when appropriate.

5.4-Discussion

In general, participants reported that most of the questioned measures could potentially be effective in mitigating an influenza pandemic in a remote and isolated First Nations community. Participants reported that mitigation measures were considered to be effective particularly if the measures aided in decreasing virus transmission, protecting their high-risk population, and increasing community awareness about influenza pandemics. However, participants reported that some of the measures that they considered to be effective were not necessarily feasible to implement given the unique conditions experienced in their communities. A number of barriers limited the feasibility of implementing community mitigation strategies, such as, lack of supplies, monies, trained personnel, and community awareness, along with overcrowding in homes and insufficient health care facilities. Furthermore, participants noted that compliance with some recommendations was low and therefore the measures were hard to enforce. As previously alluded to, many characteristics of remote and isolated First Nations communities (e.g., geographic isolation, inadequate

access to health care, culture) (Tsuji, 1998a) affect their pandemic response capacity (Richardson et al., 2012). Thus, in order to address their unique conditions and reduce the unintended consequences associated with implementing mitigation measures, the study participants suggested numerous alternatives and modifications to most of the proposed measures.

The retrospective insights collected from this study reveal some important issues that are necessary to address when planning for a future influenza pandemic in a remote and isolated First Nations community. Considering the challenges of timely distributing pharmaceutical interventions to remote locations, these findings suggest that the implementation of non-pharmaceutical interventions are especially vital in order to mitigate the effects of an influenza pandemic in these communities. Accordingly, the participants desired that many options for mitigation measures be recommended and that the measures are modified to address their specific community needs. It is also important that mitigation measures incorporate traditional medicine and practices as this aligns with First Nations holistic approach to health and the importance First Nations place on these practices to aid in health emergencies (AFN, 2007).

Moreover, these findings suggest that community acceptance of mitigation measures is conducive to people actually adhering to the measure. In many cases, participants mentioned the need for educational health campaigns to increase community awareness and in turn adherence to public health recommendations. These findings highlight the importance of providing community- and culturally- appropriate education to these communities to raise awareness so members understand the situation and how to appropriately respond (Massey et al., 2009; Charania & Tsuji, 2011a; Charania & Tsuji, 2011b). Also, these results revealed that participants often stated that the decision to implement mitigation measures would be dependent on the virulence of the virus. This notion of considering different community mitigation strategies depending on the severity and magnitude of the influenza pandemic situation aligns with the direction given from reputable authorities (Bell et al., 2006b; Nuzzo & Toner, 2007).

Furthermore, previous research has noted that living in a remote and isolated community may initially provide a barrier to the introduction of an infectious disease (Groom et al., 2009). However, due to the living conditions (e.g., impoverished overcrowded housing), small population sizes, high proportion of immunocompromised individuals, and tight social networking apparent in most remote and isolated communities, disease transmission is typically intensified and difficult to contain once community exposure has occurred (Kermode-Scott, 2009; Groom et al., 2009; Massey et al., 2009; Massey et al., 2011; Finnie et al., 2012). Thus, participants emphasized the value of rapidly commencing measures that helped to delay or contain a community disease outbreak. For instance, rapid diagnostic interventions ideally implemented at the initial stages of a community outbreak are particularly important in enclosed settings (Finnie et al., 2012; Balicer et al., 2005).

Likewise, border control measures (e.g., travel restrictions and advisories, screening measures) were generally considered to be effective by the participants and may be more feasible in isolated communities because identifying exposure sites and monitoring the movement of individuals may be more easily achieved (PHAC, 2006). Also, participants highlighted the importance of limiting or preventing the ability of community members to congregate (e.g., closing down schools, cancelling public gatherings) in order to reduce virus transmission. Although church services and funerals were still held for cultural reasons, these findings support the results of previous studies in that participants were open to modifying

cultural practices to decrease virus transmission, especially if advocated by community Elders (Massey et al., 2009).

Given the aforementioned, these findings have some implications for pandemic planners. Previous studies have highlighted the importance of addressing local characteristics in pandemic plans so that recommended measures will be feasible, culturally-appropriate, and accepted by the community (Blendon et al., 2008; Braunack-Mayer et al., 2010; Massey et al., 2011; Charania & Tsuji, 2012). These findings reinforce the importance of engaging and partnering with community members in the pandemic planning process as they possess a vast amount of knowledge regarding community mitigation measures and the potential unintended consequences of implementing such interventions (Blendon et al., 2008; Massey et al., 2011). Thus, CBPR approaches are recommended to update current pandemic plans with more recommendations specific for remote and isolated First Nations communities as these plans are important guides for communities. These participatory approaches foster engagement as partners are equitably engaged, knowledge generation is combined with action-oriented outcomes, and various methods can be employed (Israel et al., 2005; Macaulay et al., 1999; Israel et al., 2008; Israel et al., 2010; O'Brien & Whitaker, 2011). Also, it is imperative that action is directed at addressing the barriers these communities faced when implementing recommended mitigation measures. For instance, supply and resource distribution plans and the strategies that guide these plans should be revamped to better address the needs of remote and isolated First Nations communities during a public health emergency (Charania & Tsuji, 2011b).

The presented research has various strengths in that it provided policy makers and health professionals with insight from local key informants regarding the effectiveness and feasibility of implementing mitigation measures in remote and isolated First Nations communities in hopes of designing more appropriate mitigation strategies for the future. However, some limitations were noted. In this study, we assumed that the key informants would share reliable and trustworthy information regarding their experiences and the topic at hand (Braunack-Mayer et al., 2010). Also, the results may not be widely generalizable due to the unique characteristics of the study communities and the non-random sample of participants; however, the presented suggestions and insights may be of use to other similar enclosed settings.

Future studies evaluating the use of community mitigation measures in geographically remote Aboriginal communities during various influenza pandemic scenarios are required as great variation exists within and between each Aboriginal group in Canada (O'Neil, 1995; Waldram et al., 2006; Robbins & Dewar, 2011). Furthermore, research suggests that community level epidemiological and modeling studies are required to quantitatively confirm the effectiveness and potential cost-benefits of recommended mitigation measures (Ferguson et al., 2006; Lee et al., 2009). Given this, future research should be directed towards conducting community mitigation models to quantitatively evaluate which of the suggested community-specific mitigation measures would be most optimal in geographically remote Aboriginal communities.

5.5-Conclusion

As another global influenza pandemic is inevitable, it is important that pandemic plans contain effective community mitigation measures. Geographically remote Aboriginal communities are predicted to be disproportionately impacted by a future influenza pandemic; thus, it is vital that recommended mitigation strategies are feasible, accepted, and culturally-

appropriate. However, current Canadian pandemic plans have been developed without adequate First Nations consultation and universally recommended mitigation measures may not be effective in remote and isolated First Nations communities.

The results indicated that most mitigation measures would only be effective and feasibly implemented in a remote and isolated First Nations community if modifications were made to account for the unique characteristics of these communities. Local key informants should be engaged using participatory approaches in the pandemic planning process as they possess a wealth of knowledge concerning the effectiveness of mitigation strategies and the direction of mitigation efforts in health policies. These findings should be used by pandemic planners to update current pandemic plans and include more recommendations specific for remote and isolated First Nations communities as it is ethically important to address the concerns of marginalized populations to improve their pandemic response capacity and health outcomes during the next public health emergency.

Chapter 6: Recommended mitigation measures for an influenza pandemic in remote and isolated First Nations communities of Ontario, Canada: a community-based participatory approach

6.0-Overview

Influenza pandemics disproportionately impact remote and/or isolated Indigenous communities worldwide. The differential risk experienced by such communities warrants the recommendation of specific mitigation measures. Interviewer-administered questionnaires were conducted with adult key health care informants from three remote and isolated Canadian First Nations communities of sub-Arctic Ontario. Forty-eight mitigation measures (including the setting, pandemic period, trigger, and duration) were questioned. Participants' responses were summarized and collected data were deductively and inductively coded. The participants recommended 41 of the questioned mitigation measures, and often differed from previous literature and national recommendations. Results revealed that barriers, such as overcrowded housing, limited supplies, and health care infrastructure, impacted the feasibility of implementing mitigation measures. These findings suggest that pandemic plans should recommend control strategies for remote and isolated Canadian First Nations communities that may not be supported in other communities. These findings highlight the importance of engaging locally impacted populations using participatory approaches in policy decision-making processes. Other countries with remote and/or isolated Indigenous communities are encouraged to include recommendations for mitigation measures that specifically address the unique needs of such communities in an effort to improve their health outcomes during the next influenza pandemic.

6.1-Introduction

Since another global influenza pandemic is inevitable (Osterholm, 2005), the World Health Organization (WHO) recommends that nations have effective pandemic plans in place to minimize the associated social and economic consequences (World Health Organization, 2009). In Canada, the Canadian Pandemic Influenza Plan for the Health Sector (CPIP) provides guidance for a consistent and comprehensive pandemic response and recommends various mitigation measures, both pharmaceutical and non-pharmaceutical, to reduce the impact of an influenza pandemic (Public Health Agency of Canada, 2006). As the CPIP is national in scope and regional diversities regarding healthcare delivery exist, it recommends that jurisdictional plans address specific operational details associated with implementing an influenza pandemic response (Public Health Agency of Canada, 2006).

Having specific details regarding the implementation of effective mitigation measures is particularly important for marginalized populations, such as Aboriginal (First Nations, Inuit, and Métis) populations in Canada living in geographically remote and isolated areas. Although the 2009 H1N1 pandemic (A(H1N1)pdm09) was mild compared to previous pandemics (Gatherer, 2009; Reed et al., 2009; Shen, Ma, & Wang, 2009), Indigenous populations residing in remote and/or isolated areas suffered disproportionately, particularly in Canada, the United States, and Australia (Barker, 2010; Flint et al., 2010; Kermode-Scott, 2009; Kumar et al., 2009; La Ruche et al., 2009; Spence & White, 2010; Trauer, Laurie, McDonnell, Kelso, & Markey, 2011; Zarychanski et al., 2010). The differential health outcomes experienced in such communities during a pandemic may be attributed to a variety of complex challenges that arise from social, economic, environmental, and cultural inequalities (Groom et al., 2009; Richardson, Driedger, Pizzi, Wu, & Moghadas, 2012; Tsuji, 1998a). Previous research suggests that differences in the presence of pre-existing co-

morbidities, population profiles, access to healthcare services, transmission dynamics, and malnutrition in remote and/or isolated Indigenous communities may result in more severe influenza-related outcomes (La Ruche et al., 2009; Morrison, Buckeridge, Xiao, & Moghadas, 2014; Mostaço-Guidolin, Towers, Buckeridge, & Moghadas, 2013; Spence & White, 2010). Thus, the differential risk experienced by remote and/or isolated Indigenous communities warrants the recommendation of mitigation measures that are context-specific and community-informed to better prepare them for the next public health emergency (Lee, Rogers, & Braunack-Mayer, 2008; Richardson et al., 2012; Uscher-Pines, Duggan, Garoon, Karron, & Faden, 2007).

Scientific evidence regarding effective community measures to mitigate the ensuing effects of an influenza pandemic is limited (Aledort, Lurie, Wasserman, & Bozzette, 2007; Oshitani, 2006). Although important evidence and lessons learnt pertaining to the use of various mitigation measures emerged after the A(H1N1)pmd09 experience, gaps in knowledge remain (Cowling et al., 2010; Aburto et al., 2010; Halder, Kelso, & Milne, 2010). For instance, there remains a lack of data regarding the knowledge, attitudes, and practices of mitigation measures for pandemic influenza across diverse populations, especially those that are marginalized (Aiello et al., 2010). Recommendations for implementing mitigation measures are inherently complex as it varies according to the pandemic period, setting, availability of resources, severity of the pandemic, and requires reflection on societal values (Aledort et al., 2007; Thompson, Faith, Gibson, & Upshur, 2006). Since marginalized populations best understand how their community perspectives and values impact their ability to comply and implement public health recommendations, directly engaging locally impacted populations can provide valuable insights to guide recommendations for specific mitigation measures (Braunack-Mayer et al., 2010; Groom et al., 2009; Uscher-Pines et al., 2007). Prior to the next pandemic, governments and relevant institutions are recommended to identify populations that have been historically marginalized and engage these populations in the planning process to facilitate the inclusion of ways to address their specific needs during a pandemic outbreak (Uscher-Pines et al., 2007).

Given this, the purpose of the presented study is to elicit a list of recommended mitigation measures (including the setting, pandemic period, trigger, and duration) specific for remote and isolated First Nations communities in Canada, using a community-based participatory research approach. These specific recommendations will subsequently be compared and contrasted to current national recommendations and relevant literature. This study also aims to highlight the importance and value of using participatory methods to engage locally impacted populations in health policy decision-making processes.

6.2-Methods

6.2.1-Community-based Participatory Research Approach

The present study employed a community-based participatory research (CBPR) approach, as participatory research approaches have been successful in influencing policy and practice (Horowitz, Robinson, & Seifer, 2009; O'Brien & Whitaker, 2011; Themba-Nixon, Minkler, & Freudenberg, 2008). The hallmark principles of CBPR, such as equitable partnerships, valuing different ways of knowing, and addressing issues of local importance, can foster the engagement of Indigenous populations in influencing health policy (Fletcher, 2003; LaVeaux & Christopher, 2009). As such, this project arose from a longstanding partnership between the co-author's (LJST) research team and the involved communities, and addressed a locally

relevant issue (Horowitz et al., 2009; O'Brien & Whitaker, 2011). The study stemmed from previous research that involved modifying the community-level pandemic plans of the study communities by engaging various community stakeholders (e.g., Band Councils [locally-elected First Nations government], health care staff, clergy, education boards, etc.) (Charania & Tsuji, 2012). Since CBPR endeavours also emphasize shared control of decision-making, a community-based advisory group was formed of three community representatives (one from each study community) to aid in various aspects of this study including designing the study, piloting the questions, informing the data analysis process, and disseminating the results (Charania & Tsuji, 2011a; Kirby, Lévesque, Wabano, & Robertson-Wilson, 2007). Achieving action-oriented outcomes that benefit the involved communities is an important aspect of CBPR (Israel, Eng, Schulz, & Parker, 2005; Israel et al., 2008) so the communities requested that the results of this study be used to further update the community infection control measures section in each of the community's influenza pandemic plan (Charania & Tsuji, 2012). Ethics approval to conduct this study was granted by the Office of Research Ethics at the University of Waterloo, and was supported by the Band Councils of the involved communities.

6.2.2-Study Area and Population

Three communities (names omitted for anonymity purposes) were included in the present study and are located in northern Ontario, Canada. All are characterized as being remote (i.e., the nearest service center with year-round road access is located over 350 kilometers away) and isolated (i.e., the communities are only accessible by airplanes year-round) First Nations communities (Public Health Agency of Canada, 2006). Nine adult-key health-care informants were purposively selected (three from each community) based on the inclusion criteria of having experience as a practicing health care professional (e.g., health director, nurse-in-charge, clinical coordinator, etc.) in a remote and isolated First Nations community and being directly involved in their respective community's health sector response to A(H1N1)pdm09; thus, they had the required experience and authority to comment. Furthermore, as multiple government organizations are responsible for Aboriginal health in Canada (e.g., federal, provincial, and First Nations) (Public Health Agency of Canada, 2006), participants were chosen within each of the three communities to ensure that each applicable government body was represented. All of the participants invited subsequently agreed and consented to participate in the study.

6.2.3-Data Collection

An extensive review was conducted of relevant literature and existing (international, national, provincial, regional, and community level) pandemic plans to create a comprehensive list of currently discussed mitigation measures. Forty-eight mitigation measures (accounting for variations of 41 mitigation measures) were included in the interview questionnaire. The questionnaires were administered by the lead author (NAC) from July 2010 to October 2011 at a place and time chosen by the participants after obtaining informed verbal consent, which is culturally appropriate for the region (Kirby et al., 2007; Skinner, Hanning, & Tsuji, 2006). To gain additional insights regarding the data analysis and dissemination process, the community-based advisory group was consulted in person by the lead author (NAC) in June 2013.

The interview questionnaire employed a combination of closed- and open-ended questions; thereby allowing for comparability amongst participants' answers in addition to providing the

opportunity for participants to expand on their opinions (Bryman, 2001). For each mitigation measure, the key informants were asked if they would recommend the measure in their community during a future influenza pandemic. If a mitigation measure was recommended, the participant was subsequently asked to elaborate on the setting, pandemic period, trigger (to begin implementation), and duration (of implementation) of the mitigation measure. Definitions of the mitigation measures and aforementioned terms were provided to the participant. The interviews ranged in duration from 2 to 4 hours long, were conducted in English (as requested by the participant) and audio recorded (with the participant's permission).

6.2.4-Data Analyses

The collected data were manually transcribed verbatim into electronic format to allow for deductive coding and inductive coding (to reveal any additional insights) using QSR NVivo® computer software (version 9.0). The data were deductively analyzed using a template organizing approach in which the interview questionnaire was used as a coding template (Bryman, 2001; Crabtree & Miller, 1999).

The closed-ended questions regarding setting and pandemic period were coded according to pre-established options, based on previous literature. The participants chose any option that applied for the setting (i.e., hospital, ambulatory/community-based healthcare facility, community, and home) (Aledort et al., 2007) and pandemic period (i.e., interpandemic, pandemic alert, and pandemic) (Public Health Agency of Canada, 2006). The CPIP outlines the WHO pandemic alert system, which consisted of six pandemic phases categorized into three pandemic periods. The interpandemic period (phases 1 and 2) was characterized by outbreaks in animals caused by a novel influenza subtype that has not yet been detected in humans. The pandemic alert period (phases 3, 4, and 5) was characterized by a novel influenza subtype causing outbreaks in humans. And the pandemic period (phase 6) was characterized by increased and sustained human-to-human transmission of the novel influenza subtype in the general population.

The open-ended questions regarding the trigger and duration of the mitigation measure were categorized and coded to allow for comparability amongst participants' responses. The categories for the implementation trigger were outbreak in the zone, outbreak in the community, all the time, and other. Herein, zone will refer to the geographic zones in Ontario within which health services are provided by the First Nations and Inuit Health Branch of Health Canada (Health Canada, 2011a). Implementation duration categories were post-outbreak in the zone, post-outbreak in the community, two weeks post-vaccination of community members (the time required to induce protective antibody titres) (Cox, Brokstad, & Ogra, 2004), post-pandemic, all the time, and other.

Participants' responses were summarized and the answer most commonly chosen is reported. When there was disagreement amongst participants' responses, the community-based advisory group was consulted to decide whether the measure would or would not be recommended.

6.3-Results

The participants stated that they would recommend 41 of the questioned mitigation measures to be implemented in their communities during the next influenza pandemic. The collected

data are summarized as a list of mitigation measures recommended for use (including the most commonly answered setting, pandemic period, trigger, and duration of implementation) (Table 6.1) and not recommended for use (including participants' rationale for not supporting the measure) (Table 6.2). As the level of agreement regarding the recommendation of measures sometimes varied, the most pertinent results (as suggested by the community-based advisory group) are highlighted below and supplemented by participants' quotes (Knafl & Howard, 1984).

The majority of participants deemed one measure, animal-human interchange as not applicable in their communities because domestic animal farming does not occur. However, a participant was concerned that avian influenza could be transmitted to humans while hunting and harvesting potentially infected wild geese. One participant suggested traditional medicine as an additional mitigation measure that would be beneficial and culturally-appropriate. The participant recommended that traditional medicine practices should be implemented in the community and community members' homes all of the time, but particularly during the alert period.

Table 6.1: List of recommended measures to mitigate an influenza pandemic in remote and isolated First Nations communities suggested by participants ($n=9$)

	Mitigation Measure	Setting	Period	Trigger	Duration
Travel Measures	Entry screening of travelers (8 ^a ,1 ^b)	Community (8 ^a ,0 ^b)	Alert (7 ^a ,1 ^b)	Other (5 ^a ,3 ^b)	Post-zone outbreak (4 ^a ,4 ^b); Post vaccine (4 ^a ,4 ^b)
	Exit screening of travelers (5 ^a ,4 ^b)	Community (5 ^a ,0 ^b)	Alert (5 ^a ,0 ^b)	Zone outbreak (2 ^a ,3 ^b); Other (2 ^a ,3 ^b)	Post vaccine (4 ^a ,1 ^b)
	Travel restrictions on all arriving passengers (6 ^a ,3 ^b)	Community (5 ^a ,0 ^b ,1 ^c)	Alert (5 ^a ,0 ^b ,1 ^c)	Other (5 ^a ,1 ^b)	Post vaccine (3 ^a ,2 ^b ,1 ^c)
	Travel advisories on all arriving passengers (8 ^a ,1 ^b)	Community (8 ^a ,0 ^b)	Alert (7 ^a ,1 ^b)	Other (5 ^a ,3 ^b)	Post-community outbreak (3 ^a ,5 ^b)
	Travel advisories on all departing passengers (9 ^a ,0 ^b)	Community (8 ^a ,0 ^b ,1 ^c)	Alert (6 ^a ,1 ^b ,2 ^c)	Zone outbreak (4 ^a ,4 ^b ,1 ^c)	Other (3 ^a ,5 ^b ,1 ^c)
	Closing down all borders (7 ^a ,2 ^b)	Community (7 ^a ,0 ^b)	Alert (6 ^a ,1 ^b)	Zone outbreak (4 ^a ,3 ^b)	Post vaccine (4 ^a ,2 ^b ,1 ^c)
	Quarantine of a geographic area (<i>cordon</i>)	Community (7 ^a ,0 ^b)	Alert (5 ^a ,2 ^b)	Other (4 ^a ,3 ^b)	Post-zone outbreak (3 ^a ,3 ^b ,1 ^c)

	<i>sanitaire</i>) (7 ^a ,2 ^b)				
Community Social Distancing Measures	Avoid visiting (9 ^a ,0 ^b)	Community (9 ^a ,0 ^b); Home (9 ^a ,0 ^b)	Alert (7 ^a ,2 ^b)	Zone outbreak (7 ^a ,2 ^b)	Post-community outbreak (4 ^a ,5 ^b); Post vaccine (4 ^a ,5 ^b)
	Avoid crowding (8 ^a ,1 ^b)	Hospital (8 ^a ,0 ^b); Ambulatory (8 ^a ,0 ^b); Community(8 ^a ,0 ^b); Home (8 ^a ,0 ^b)	Alert (8 ^a ,0 ^b)	Zone outbreak (7 ^a ,1 ^b)	Post vaccine (5 ^a ,3 ^b)
	Social distancing measures (9 ^a ,0 ^b)	Community(9 ^a ,0 ^b)	Alert (7 ^a ,2 ^b)	Zone outbreak (5 ^a ,4 ^b)	Post-community outbreak (4 ^a ,5 ^b); Post vaccine (4 ^a ,5 ^b)
	Voluntary sheltering (9 ^a ,0 ^b)	Home (7 ^a ,2 ^b)	Alert (6 ^a ,3 ^b)	Zone outbreak (4 ^a ,5 ^b)	Post vaccine (5 ^a ,4 ^b)
	School closures (9 ^a ,0 ^b)	Community (9 ^a ,0 ^b)	Alert (5 ^a ,4 ^b)	Community outbreak(8 ^a ,1 ^b)	Post vaccine (8 ^a ,1 ^b)

(continued)

	Mitigation Measure	Setting	Period	Trigger	Duration
Community Social Distancing Measures (continued)	Childcare center closures (6 ^a ,0 ^b ,3 ^d)	Community (6 ^a ,0 ^b)	Alert (4 ^a ,2 ^b)	Community outbreak (5 ^a ,1 ^b)	Post vaccine (6 ^a ,0 ^b)
	Workplace closures (4 ^a ,4 ^b ,1 ^c)	Community (4 ^a ,0 ^b)	Pandemic (3 ^a ,1 ^b)	Community outbreak (4 ^a ,0 ^b)	Post-community outbreak (3 ^a ,1 ^b)
	Mandatory isolation of ill individuals (7 ^a ,2 ^b)	Home (6 ^a ,1 ^b)	Alert (5 ^a ,2 ^b)	Community outbreak (3 ^a ,4 ^b)	Post-zone outbreak (2 ^a ,5 ^b); Other (2 ^a ,5 ^b)
	Voluntary isolation of ill individuals (6 ^a ,3 ^b)	Home (6 ^a ,0 ^b)	Alert (4 ^a ,2 ^b)	Zone outbreak (3 ^a ,3 ^b)	Post-zone outbreak (2 ^a ,4 ^b); Post-community outbreak (2 ^a ,4 ^b)
	Mandatory quarantine of case contacts (5 ^a ,4 ^b)	Home (5 ^a ,0 ^b)	Alert (4 ^a ,1 ^b)	Community outbreak (3 ^a ,2 ^b)	Other (3 ^a ,2 ^b)
	Voluntary quarantine of case contacts (6 ^a ,3 ^b)	Home (6 ^a ,0 ^b)	Alert (5 ^a ,1 ^b)	Community outbreak (5 ^a ,1 ^b)	Other (5 ^a ,1 ^b)
	Restricting attendance at public gatherings (6 ^a ,2 ^b ,1 ^c)	Community (6 ^a ,0 ^b)	Alert (3 ^a ,3 ^b); Pandemic (3 ^a ,3 ^b)	Zone outbreak (3 ^a ,3 ^b); Community outbreak (3 ^a ,3 ^b)	Post-community outbreak (3 ^a ,3 ^b)
	Cancelling public gatherings (9 ^a ,0 ^b)	Community (9 ^a ,0 ^b)	Alert (5 ^a ,4 ^b)	Zone outbreak (5 ^a ,4 ^b)	Post vaccine (4 ^a ,5 ^b)
Surveillance Measures	Monitoring trends of influenza-like illness (9 ^a ,0 ^b)	Ambulatory (9 ^a ,0 ^b)	Alert (7 ^a ,2 ^b)	All the time (3 ^a ,6 ^b); Other (3 ^a ,6 ^b)	All the time (3 ^a ,5 ^b ,1 ^c); Post pandemic (3 ^a ,5 ^b ,1 ^c)
	Human surveillance and case reporting (9 ^a ,0 ^b)	Hospital (8 ^a ,1 ^b)	Alert (8 ^a ,1 ^b)	All the time (4 ^a ,5 ^b); Other(4 ^a ,5 ^b)	Post-community outbreak (3 ^a ,6 ^b); All the time(3 ^a ,6 ^b)
	Contact tracing (6 ^a ,3 ^b)	Ambulatory (5 ^a ,1 ^b)	Pandemic (4 ^a ,2 ^b)	Community outbreak	Other (4 ^a ,2 ^b)

			(6 ^a ,0 ^b)	
Home support program (7 ^a ,1 ^b ,1 ^c)	Ambulatory (7 ^a ,0 ^b)	Alert (5 ^a ,2 ^b)	Community outbreak (6 ^a ,1 ^b)	Post-community outbreak (3 ^a ,4 ^b)
Urge entire population in an affected area to check for fever at least once daily (5 ^a ,3 ^b ,1 ^c)	Home (5 ^a ,0 ^b)	Alert (3 ^a ,2 ^b); Pandemic (3 ^a ,2 ^b)	Community outbreak (3 ^a ,2 ^b)	Post pandemic (2 ^a ,3 ^b)

(continued)

	Mitigation Measure	Setting	Period	Trigger	Duration
Surveillance (cont.)	Rapid influenza diagnostic tests (8 ^a ,1 ^b)	Hospital (8 ^a ,0 ^b)	Alert (7 ^a ,1 ^b)	All the time (5 ^a ,3 ^b)	All the time (4 ^a ,4 ^b)
	Screening for influenza-like illness at public places (8 ^a ,1 ^b)	Hospital (8 ^a ,0 ^b); Ambulatory (8 ^a ,0 ^b); Community (8 ^a ,0 ^b)	Alert (7 ^a ,1 ^b)	Zone outbreak (4 ^a ,4 ^b)	Post vaccine (4 ^a ,4 ^b)
Infection Control Measures	Modifying cultural practices at church and funerals (9 ^a ,0 ^b)	Community(9 ^a ,0 ^b)	Alert (8 ^a ,1 ^b)	Zone outbreak (4 ^a ,5 ^b); Community outbreak (4 ^a ,5 ^b)	Post-zone outbreak (4 ^a ,5 ^b); Post-community outbreak (4 ^a ,5 ^b)
	Hand hygiene (9 ^a ,0 ^b)	Hospital (9 ^a ,0 ^b); Ambulatory (9 ^a ,0 ^b); Community(9 ^a ,0 ^b); Home (9 ^a ,0 ^b)	Interpandemic (9 ^a ,0 ^b); Alert (9 ^a ,0 ^b); Pandemic (9 ^a ,0 ^b)	All the time (9 ^a ,0 ^b)	All the time (9 ^a ,0 ^b)
	Respiratory etiquette (9 ^a ,0 ^b)	Hospital (9 ^a ,0 ^b); Ambulatory (9 ^a ,0 ^b); Community(9 ^a ,0 ^b); Home (9 ^a ,0 ^b)	Interpandemic (9 ^a ,0 ^b); Alert (9 ^a ,0 ^b); Pandemic (9 ^a ,0 ^b)	All the time (9 ^a ,0 ^b)	All the time (9 ^a ,0 ^b)
	Surface disinfection (beyond usual practice) (9 ^a ,0 ^b)	Hospital (9 ^a ,0 ^b); Ambulatory (9 ^a ,0 ^b); Community(9 ^a ,0 ^b); Home (9 ^a ,0 ^b)	Alert (8 ^a ,1 ^b)	Zone outbreak (4 ^a ,5 ^b); Community outbreak(4 ^a ,5 ^b)	Post-zone outbreak (4 ^a ,5 ^b)
	Ventilation (i.e., open windows) (8 ^a ,1 ^b)	Home (8 ^a ,0 ^b)	Alert (7 ^a ,1 ^b)	Zone outbreak (5 ^a ,3 ^b)	Post vaccine (3 ^a ,5 ^b)
	Air disinfection (7 ^a ,2 ^b)	Hospital (6 ^a ,1 ^b)	Alert (7 ^a ,0 ^b)	All the time (4 ^a ,3 ^b)	All the time (4 ^a ,3 ^b)
	Visitor restrictions (in health	Hospital (7 ^a ,0 ^b)	Alert (6 ^a ,1 ^b)	Zone outbreak (6 ^a ,1 ^b)	Post vaccine (5 ^a ,2 ^b)

facilities) (7 ^a ,1 ^b ,1 ^d)				
Isolation precautions (in health facilities) (8 ^a ,1 ^b)	Hospital (8 ^a ,0 ^b)	Alert (8 ^a ,0 ^b)	Zone outbreak (4 ^a ,4 ^b)	Post vaccine (5 ^a ,3 ^b)
Minimize aerosol-generating procedures (in health facilities) (8 ^a ,0 ^b ,1 ^d)	Hospital (7 ^a ,1 ^b)	Alert (7 ^a ,1 ^b)	Zone outbreak (4 ^a ,4 ^b)	Post-community outbreak (4 ^a ,4 ^b)

(continued)

	Mitigation Measure	Setting	Period	Trigger	Duration
Infection Control Measures (cont.)	Wearing surgical masks and N95 respirators – provider and patient use (9 ^a ,0 ^b)	Hospital (9 ^a ,0 ^b); Ambulatory (9 ^a ,0 ^b); Community(9 ^a ,0 ^b)	Alert (5 ^a ,4 ^b); Pandemic (5 ^a ,4 ^b)	Community outbreak (3 ^a ,6 ^b); Other (3 ^a ,6 ^b)	Post-community outbreak (5 ^a ,4 ^b)
	Wearing personal protective equipment – provider and patient use (9 ^a ,0 ^b)	Ambulatory (9 ^a ,0 ^b)	Alert (7 ^a ,2 ^b)	Community outbreak (5 ^a ,4 ^b)	Post-community outbreak (4 ^a ,5 ^b)
	Public education (9 ^a ,0 ^b)	Community(9 ^a ,0 ^b); Home (9 ^a ,0 ^b)	Interpandemic (9 ^a ,0 ^b); Alert (9 ^a ,0 ^b); Pandemic (9 ^a ,0 ^b)	All the time (9 ^a ,0 ^b)	All the time (9 ^a ,0 ^b)
Pharmaceutical Measures	Vaccines (9 ^a ,0 ^b)	Ambulatory (8 ^a ,1 ^b)	Alert (8 ^a ,1 ^b)	Other (8 ^a ,1 ^b)	Other (9 ^a ,0 ^b)
	Antivirals (9 ^a ,0 ^b)	Hospital (8 ^a ,1 ^b)	Alert (8 ^a ,1 ^b)	Community outbreak (8 ^a ,1 ^b)	Post-community outbreak (6 ^a ,3 ^b)

^a Participant recommended measure ^b Participant did not recommend measure ^c Participant suggested a modification to the measure ^d Participant deemed measure not applicable ^e Missing data

Table 6.2: List of measures not recommended to mitigate an influenza pandemic in remote and isolated First Nations communities suggested by participants ($n=9$)

Mitigation Measure	Rationale for Not Recommending
Disinfection of clothing, shoes, or other objects of persons exiting affected areas (4 ^a ,5 ^b)	Measure would not be feasible to implement in a remote and isolated community due to required monies, supplies, and human resources.
Sanitary measures at frontiers or on conveyances (2 ^a ,7 ^b)	Measure would not be feasible, practical, or cost-effective to implement.
Travel restrictions on all departing passengers (2 ^a ,7 ^b)	Community members would not adhere to the measure and measure would be difficult to enforce.
Self-health monitoring and reporting if ill but no restrictions on movement (0 ^a ,9 ^b)	Self-health monitoring and reporting would be beneficial, but difficult for community members to conduct. Measure would also contradict the purpose of other mitigation measures directed at limiting virus transmission.
Wearing surgical masks and N95 respirators – public use (4 ^a ,5 ^b)	Limited resource availability, proficiency regarding proper use and adherence to the measure would render the measure ineffective for the general public.
Wearing personal protective equipment – public use (1 ^a ,8 ^b)	Limited resource availability, proficiency regarding proper use and adherence to the measure would render the measure ineffective for the general public.

^a Participant recommended measure ^b Participant did not recommend measure

6.3.1-Travel Measures

The majority of travel mitigation measures were recommended for a future influenza pandemic. All of the recommended measures were to be implemented in the community, primarily at the airport, during the alert period. Most participants agreed that these measures should be implemented when positive cases are detected in Canada or at the latest when positive cases are detected in the zone. These measures were recommended to be implemented until the outbreak has ceased in the zone or two weeks post-vaccination of community members.

Participants almost unanimously agreed that entry screening of travelers would be a beneficial measure if executed properly because the airport is typically the only entry point into their remote and isolated communities during the ice-free season. Screening measures could include health questionnaires and declarations, temperature screening, thermal scanning, medical examinations, and stop lists (Bell, Nicoll, Fukuda, Horby, & Monto, 2006a; Bell, Nicoll, Fukuda, Horby, & Monto, 2006b; Gostin, 2006). Although participants felt that exit screening of travelers is an important measure and would help contain an outbreak, participants were more mixed about recommending the measure as it was expected that the receiving community would conduct screening.

Participants generally agreed with implementing voluntary travel advisories instead of mandatory travel restrictions, although the recommendation would depend on the severity of

the community outbreak. Participants reported that voluntary measures encourage people to be more self-conscious and responsible for their health, while mandatory measures were not perceived to be as practical or feasible.

Also, participants reported that voluntary travel advisories would effectively deter the majority of people from traveling:

With voluntary advisories, you would weed out a lot of people...there would probably only be a select few that would probably still want to travel anyways and if you could implement the precautions and if they would follow them, then I think that would be enough. (Participant #7)

The majority of participants recommended travel measures that would block the main entry point into their communities. Participants reported that closing down all borders and quarantine of a geographic area (cordon sanitaire) would help protect their at-risk population if a community outbreak has not yet occurred. However, the decision to implement these measures would depend on the severity of the pandemic because participants considered these measures to be difficult to implement, enforce, and maintain.

6.3.2-Community Social Distancing Measures

Participants recommended that all of the proposed community social distancing measures be implemented in their communities. Measures that decrease the frequency and duration of social contact, such as avoid visiting, avoid crowding, and general social distancing measures (e.g., spacing people, staggering work schedules, allowing employees to work from home, etc.) were highly recommended by participants during the alert period. Although participants noted the difficulties associated with avoiding crowding in overcrowded homes in the communities:

Overcrowding in the home, it's hard to try to stay your distance from someone that is sick because you're close to each other walking by and stuff. (Participant #3)

Participants reported that voluntary sheltering of healthy persons to avoid exposure would be a beneficial mitigation measure during the alert period, although it would be the community members' prerogative to implement. Most participants recommended this measure to be implemented in the community members' homes; however, some mentioned that members could camp in the bush as long as they had sufficient resources. Participants recommended that these measures should be implemented when an outbreak occurs in the zone until the community outbreak has ceased or two weeks post-vaccination of community members.

In the community, participants unanimously recommended that schools and childcare centers close during the alert period to aid in controlling influenza transmission in the younger age groups, especially given the prior experience of infections among First Nations populations.

It stops the spread of the flu because there are so many children and they are close together and it's a lot more difficult telling a child to close their mouth, wash their hands. (Participant #8)

It helps a lot to control the spreading...I think the community here took it [A(H1N1)pdm09] very seriously...there's fear because of the history, so the fear is so

high here, it's not like anything else down South ... they've been decimated by infection [in the past]... (Participant #1)

Conversely, participants' responses were divided regarding the closure of workplaces during the pandemic period. Some participants reported that closing workplaces would be impractical as the limited amount of workplaces is essential for the daily functioning of the community; however, others were willing to recommend this measure if the severity of the pandemic warranted it. All of these measures were recommended to be implemented when a community outbreak occurred and workplaces should re-open as soon as the community outbreak ceases, but schools and childcare centers should stay closed until two weeks post-vaccination of community members.

Although all of the participants recommended these measures during the alert period to reduce virus transmission, participants were also divided regarding whether recommendations for isolation of patients and quarantine of contacts should be mandatory or voluntary. In general, participants recommended voluntary isolation when there is an outbreak in the zone, escalating to mandatory isolation when a community outbreak occurs. Participants agreed that mandatory or voluntary quarantine should only be implemented when there is a community outbreak. Some participants stated that community members should isolate until the outbreak has ceased in the community and the zone; however, others recommended only isolating until the symptomatic period is over. Participants recommended that community members should quarantine for the incubation period post-exposure, and then isolate for the symptomatic period if the person falls ill.

6.3.3-Surveillance Measures

Participants recommended the implementation of all of the surveillance measures, except for one. Participants did not recommend the mitigation measure of self-health monitoring and reporting if ill without restrictions on movement. Participants unanimously agreed that monitoring and reporting about one's health would be a beneficial surveillance measure, but not limiting the movement of ill individuals would provide opportunities for virus transmission within the community.

Of the recommended measures, participants reported that monitoring trends of influenza-like illness and human surveillance and case reporting during the alert period would produce helpful statistics to indicate how effective the response was and how they could better target future response efforts. Participants generally suggested that these measures should be implemented on an ongoing basis; however, in the context of a pandemic, these measures would be implemented when treating a symptomatic person and continue until the outbreak has ceased in the community or post-pandemic.

The majority of participants also recommended that contact tracing be implemented in the ambulatory setting during the pandemic period in order to identify contacts of an index case that may be at risk of becoming infected and, in turn, help contain a community outbreak. Participants reported that contact tracing should ideally occur until all of the contacts have been reached, but would realistically occur until available resources and manpower became overwhelmed. Support for conducting contact tracing was qualified by concerns regarding human resources, as a significant number of household and casual contacts would have to be contacted due to the overcrowding in homes and extensive social networking.

Overcrowding is a problem, so even if you call them but you have a family [and] they have 15 people around them, or 20, if they've made contact ... and those contact[s] have to be contact[ed], so at the end you have to call the whole community for contact tracing ... because everybody's related with someone. (Participant #6)

If enough resources and manpower were available, participants recommended the implementation of a home support program, which involves the provision of infection control supplies and education to families in need, during a community outbreak. Moreover, participants considered recommending that community members check for fever on a daily basis in their homes during a community outbreak, as this measure is a valuable diagnostic tool that would raise awareness about self-health. However, participants noted that many families do not own thermometers because they are not available for purchase in community stores.

6.3.4-Infection Control Measures

Participants recommended most of the proposed infection control measures. Participants recommended modifying the cultural practices of kissing and handshaking at church and funeral services during the alert period. Hand hygiene and respiratory etiquette were unanimously recommended to be implemented all of the time in all of the settings to decrease virus transmission. Participants also recommended other general infection control measures during the alert period, including disinfecting surfaces (beyond usual practice) and ventilation (i.e., opening windows); although, some drawbacks were noted.

Moneywise...because of the cost of the things we have in here, I don't think every... [person] can buy that [cleaning supplies] to clean the house ... [and] most of the houses in here have a mold problem... (Participant #6)

All depends on how well their windows are in the community, but some have broken windows, some are boarded up... (Participant #2)

In the hospital setting, participants recommended that visitor restrictions, isolation precautions, and minimizing aerosol-generating procedures be implemented when an outbreak in the zone occurs; these measures would be in effect until after the community outbreak ceases or two weeks after community members have been vaccinated. Participants unanimously recommended that health care providers and patients wear surgical masks to reduce virus transmission during a community outbreak, although it was suggested that providers wear N95 respirators if the situation warrants it. Furthermore, participants recommended that providers wear personal protective equipment (PPE) during a community outbreak. Symptomatic patients were not recommended to wear PPE as the person will ultimately contaminate any items that he or she wears, thereby rendering the measure ineffective. Moreover, participants did not recommend that the general public wear masks and PPE due to concerns of supply, proficiency regarding proper use, and adherence to the measures.

Lastly, all of the participants reported that pertinent health teachings about influenza and the importance of infection control measures should be occurring in Cree and English on an ongoing basis to raise awareness. Participants reported that community members received lots of misinformation during A(H1N1)pdm09 from various media sources. Thus, participants suggested using multiple community-based measures, such as announcements on

the local radio station and door-to-door visits with Cree translators, to rectify the received misinformation. Also, participants suggested that educational materials should be visual, simple, and targeted to their community members in order to be most effective.

Be more specific and simple, too much information is not better than not enough, and I think we have too much information on that case [A(H1N1)pdm09] coming from...too [many sources] at the same time, confusing the people, confusing the health care provider, confusing almost everyone. (Participant #6)

6.3.5-Pharmaceutical Measures

The participants unanimously recommended implementing pandemic-sensitive vaccines and antivirals during a community outbreak. The mass vaccination campaigns should commence as soon as the vaccines are delivered to the community and ideally continue until herd immunity is achieved. The community-based healthcare facility would be responsible for distributing the vaccines to community members in a variety of settings, including the hospital, school, and homes of people who are not mobile. The antivirals would be dispensed by the hospital to symptomatic people meeting the required criteria.

6.4-Discussion

Given the unique challenges experienced in remote and isolated Canadian First Nations communities during an influenza pandemic that in turn impact their pandemic response capacity and may result in more severe health outcomes, the participants recommended that the majority of questioned mitigation measures be implemented in their communities. Not surprisingly, similar to national recommendations, the participants unanimously recommended the use of vaccines and antivirals, since pharmaceutical measures are the best measures to mitigate the impact of a pandemic outbreak (Oshitani, 2006; Public Health Agency of Canada, 2006). Although much uncertainty still remains regarding optimal vaccine allocation (Tuite, Fisman, Kwong, & Greer, 2010), previous modelling studies have reported that rapidly immunizing the population, even with a poorly matched vaccine, could significantly reduce the outbreak and number of ill people (Ferguson et al., 2006; Germann, Kadau, Longini Jr., & Macken, 2006; Wu & Cowling, 2011). Furthermore, the implementation of antiviral drugs for treatment and/or prophylaxis purposes during a pandemic could reduce influenza-related attack, hospitalization, and death rates (Gani et al., 2005; Longini Jr., Halloran, Nizam, & Yang, 2004; Wu & Cowling, 2011). Previous modelling research has suggested that aggressive antiviral therapy significantly reduced the impact of A(H1N1)pdm09 in an isolated Canadian First Nations community (Xiao et al., 2013).

As limitations of supply and cost restrict the use of vaccines and antivirals, especially in remote and isolated settings (Finnie, Hall, & Leach, 2012; Low, 2008; Oshitani, 2006), the participants noted the importance of recommending a wide variety of non-pharmaceutical mitigation measures to supplement the use of pharmaceutical measures. Non-pharmaceutical mitigation measures may aid in delaying, reducing, and containing a pandemic outbreak (Bell et al., 2006a; Low, 2008; Markel et al., 2007). Pandemic response strategies that appropriately combine pharmaceutical and non-pharmaceutical interventions have been shown to be more effective than individual strategies in terms of delaying the outbreak, reducing the number of ill cases, and delaying and reducing the peak attack rate (Lee, Lye, & Wilder-Smith, 2009).

At the national level, of relevance to the presented paper, Annex B of the CPIP discusses planning considerations for on-reserve First Nations communities, while Annex M outlines public health recommendations including public education, case and contact management, travel and border related measures, and community-based interventions (Public Health Agency of Canada, 2006). Three community-based interventions are recommended to control a community outbreak, including self-isolating if symptomatic, closing schools and daycare centres, and restricting “high-risk” indoor public gatherings (other than schools) (Table 6.3) (Public Health Agency of Canada, 2006). All of the aforementioned recommendations were also supported by the participants. The participants recommended that isolation and quarantine measures begin as voluntary and escalate to mandatory as needed. Previous research states that isolation and quarantine are generally effective and acceptable measures (Crabtree & Henry, 2011); however, mandatory isolation and quarantine are considered ineffective and impractical since viral shedding occurs prior to the onset of symptoms and healthcare facilities would rapidly become overwhelmed (Aledort et al., 2007; Bell et al., 2006b). Furthermore, although participants recommended the closure of schools and daycare centres, along with cancelling and/or restricting public gatherings, due to increased influenza transmission in these settings, there are limited data to support the effectiveness of these measures (Roth & Henry, 2011).

Interestingly, the participants recommended 8 of the 10 community-based interventions that are not nationally recommended (Table 6.3) (Public Health Agency of Canada, 2006). Contrary to national recommendations, the majority of participants placed much value in recommending various travel measures to protect their communities. Previous research has reported that screening travelers, travel restrictions, and closing down airports are generally ineffective and result in substantial economic and societal costs (Bell et al., 2006b; Inglesby et al., 2006). However, the CPIP does note that travel measures may be more feasible to implement in geographically remote and isolated communities due to small population sizes and limited ports of entry (Public Health Agency of Canada, 2006). As disease transmission is typically amplified due to the characteristics of the study communities (Finnie, et al., 2012; Groom et al., 2009; Kermode-Scott, 2009; Massey et al., 2009; Massey et al., 2011), travel measures directed at preventing the importation of the pandemic virus, especially during a severe pandemic, may be particularly important.

The CPIP notes that recommendations will vary according to local conditions, especially with regards to the timing of their implementation (Public Health Agency of Canada, 2006). The participants also highlighted the importance of specifying the timing of implemented mitigation measures, especially since these specifications may vary for geographically remote and isolated communities. Three mitigation measures – hand hygiene, respiratory etiquette, and public education – were recommended by participants to be implemented all of the time. Similar to the CPIP recommendations, the participants recommended that the trigger to implement mitigation measures would be dependent on the location of confirmed cases (Public Health Agency of Canada, 2006). Participants generally recommended that measures should be employed until the outbreak ceases in their community and/or the zone, or until herd immunity is achieved two weeks post-vaccination of their community members.

Table 6.3: List of recommended and not recommended mitigation measures from Annex M of the Canadian Influenza Pandemic Plan for the Health Sector as evaluated by study participants

Recommended Community-Based Interventions	Not Recommended Community-Based Interventions
<ul style="list-style-type: none"> ● Close schools and daycares* <ul style="list-style-type: none"> ○ Trigger: declaration of one or more confirmed cases in the local community, depending on the epidemiological context. ● Self-isolate if symptomatic* <ul style="list-style-type: none"> ○ Trigger: arrival of one or more confirmed cases in the province/territory. Reinforce recommendation when cases occur in the local jurisdiction. ● Restrict indoor public gatherings in ‘high-risk’ settings (other than schools)* <ul style="list-style-type: none"> ○ Trigger: when transmission occurs within the community. 	<ul style="list-style-type: none"> ● Thermal scanning in public places* ● Restricting travel to and from affected areas* ● Cordon sanitaire* ● Broadly restricting indoor public gatherings (other than schools) * ● Urge entire population in an affected area to check for fever at least once daily* ● Hand-sanitizing stations in public settings* ● Surface disinfection beyond usual practice in public settings* ● Air disinfection* ● Disinfection of clothing, shoes, or other objects of persons existing affected areas** ● Use of masks by the general public (well individuals)**

Note. Source: Public Health Agency of Canada, 2006

*Participants in the study recommended the measure

**Participants in the study did not recommend the measure

Interestingly, although typical responses for the implementation trigger were outbreak in the zone or community, the participants recommended that most of the mitigation measures be implemented in the alert period (before the official declaration of a pandemic). In contrast, during the alert period, the CPIP recommends measures to aggressively contain an outbreak and prevent a pandemic, such as isolation and quarantine, contact tracing, exit screening, and antiviral therapy; while population-based measures are recommended during the pandemic period to reduce and delay the pandemic outbreak (Public Health Agency of Canada, 2006). This finding may infer the desire of participants residing in remote and isolated First Nations communities to be prepared to rapidly implement mitigation measures to prevent the introduction and subsequent spread of a pandemic virus in their communities.

Since community-level measures will likely be more effective at mitigating a pandemic than international- and national-level measures (Bell et al., 2006b), it is vital that remote and isolated First Nations communities have appropriate recommendations included in pandemic plans. In light of these findings, pandemic planners, especially those that are dedicated to community-based pandemic planning, should consider the following policy implications. Given the different challenges and health outcomes experienced in remote and isolated First Nations communities, it may be appropriate that future pandemic plans recommend pandemic control strategies in such communities that may not be supported in other Canadian communities. These findings highlight the importance of developing mitigation measures that address the population’s values, beliefs, perceptions, and cultural differences in order to be

appropriate and effective (Massey et al., 2011). For instance, culture influenced some of the recommended mitigation measures since participants were open to modifying the cultural practices of kissing and handshaking at church and funeral services, and traditional medicine was suggested as an additional beneficial mitigation measure.

It is also important that future policies address community differences. Participants raised concerns that overcrowded impoverished housing and limited supplies impacted the ability of community members to comply with the recommended mitigation measures. Participants also noted that the implementation of some mitigation measures might overwhelm their limited health care infrastructure. As these communities have a high proportion of people with pre-existing co-morbidities who are at risk of more severe influenza-related outcomes, the capacity of their health care infrastructure may be further strained by patients visiting with influenza symptoms and by the effects of non-pharmaceutical mitigation measures. To help overcome these barriers, policies and action aimed at improving living conditions, providing money for stockpiling supplies, and improving health care infrastructure in these communities is imperative prior to the next influenza pandemic.

Furthermore, the implementation of certain measures, such as the distribution of scarce resources (e.g., antivirals), may raise many legal, political, and ethical issues, especially when there is limited scientific evidence to support the measure (Aledort et al., 2007; Thompson et al., 2006). For instance, although mandatory isolation and quarantine may infringe upon the ethical value of individual liberty and are not commonly recommended (Thompson et al., 2006), the majority of participants reported that they would recommend these measures to help minimize virus transmission if a community outbreak occurred. Engaging and partnering with community members using participatory approaches are vital to create pandemic plans that are community- and culturally- appropriate (Massey et al., 2011).

The optimal community-level approach to mitigate the effects of an influenza pandemic in remote and/or isolated Indigenous communities is still unknown. There remains a paucity of scientific evidence regarding the assumptions that currently guide pandemic planning and the effectiveness of mitigation measures; thus, most planners resort to historical accounts, mathematical modelling studies, and expert opinion (Aledort et al., 2007; Bell et al., 2006b; Markel et al., 2007). To aid planners in making more informed recommendations, future research regarding influenza transmission characteristics should be encouraged in remote and/or isolated Indigenous communities because vast heterogeneities exist. Future studies should also explore what mitigation measures are most cost-effective and what combination of mitigation measures would be most effective in these communities.

6.5-Conclusion

Influenza pandemics continue to disproportionately impact Indigenous populations worldwide, especially those residing in geographically remote and/or isolated areas. The differential risk experienced by such communities warrants the need for recommendations for mitigation measures that are context-specific and community-informed. The present study elicited a list of recommended pharmaceutical and non-pharmaceutical measures to mitigate the effects of an influenza pandemic in three remote and isolated Canadian First Nations communities. The results indicated that participants recommended a wide variety of mitigation measures that often differed from national recommendations and existing literature. Participants also revealed that a number of barriers impacted their ability to feasibly implement recommended measures.

These findings suggest that it may be appropriate to recommend pandemic control strategies in remote and isolated Canadian First Nations communities that may not be supported in other communities. These findings also highlight the importance of engaging locally impacted populations using participatory approaches in policy decision-making processes. Other countries with remote and/or isolated Indigenous communities are encouraged to include recommendations for mitigation measures that specifically address the unique needs of such communities in an effort to improve their health outcomes during the next influenza pandemic. Future research should be directed towards better understanding the current assumptions that guide pandemic planning and the effectiveness of mitigation measures in remote and/or isolated Indigenous communities, as vast heterogeneities exist.

Chapter 7: Bird harvesting practices and knowledge, risk perceptions, and attitudes regarding avian influenza among Canadian First Nations subsistence hunters: implications for influenza pandemic plans

7.0-Overview

There is concern of avian influenza virus (AIV) infections in humans. Subsistence hunters may be a potential risk group for AIV infections as they frequently come into close contact with wild birds and the aquatic habitats of birds while harvesting. This study aimed to examine if knowledge and risk perception of avian influenza influenced the use of protective measures and attitudes about hunting influenza-infected birds among subsistence hunters.

Using a community-based participatory research approach, a cross-sectional survey was conducted with current subsistence hunters ($n = 106$) residing in a remote and isolated First Nations community in northern Ontario, Canada from November 10–25, 2013. Simple descriptive statistics, cross-tabulations, and analysis of variance (ANOVA) were used to examine the distributions and relationships between variables. Written responses were deductively analyzed.

ANOVA showed that males hunted significantly more birds per year than did females ($F_{1,96} = 12.1$; $p = 0.001$) and that those who hunted significantly more days per year did not perceive a risk of AIV infection ($F_{1,94} = 4.4$; $p = 0.040$). Hunters engaged in bird harvesting practices that could expose them to AIVs, namely by cleaning, plucking, and gutting birds and having direct contact with water. It was reported that 18 (17.0%) hunters wore gloves and 2 (1.9%) hunters wore goggles while processing birds. The majority of hunters washed their hands ($n = 105$; 99.1%) and sanitized their equipment ($n = 69$; 65.1%) after processing birds. More than half of the participants reported being aware of avian influenza, while almost one third perceived a risk of AIV infection while harvesting birds. Participants aware of avian influenza were more likely to perceive a risk of AIV infection while harvesting birds. Our results suggest that knowledge positively influenced the use of a recommended protective measure. Regarding attitudes, the frequency of participants who would cease harvesting birds was highest if avian influenza was detected in regional birds ($n = 55$; 51.9%).

Our study indicated a need for more education about avian influenza and precautionary behaviours that are culturally-appropriate. First Nations subsistence hunters should be considered an avian influenza risk group and have associated special considerations included in future influenza pandemic plans.

7.1-Introduction

Influenza A viruses may cause pandemics at unpredictable, irregular intervals resulting in devastating social and economic effects worldwide (World Health Organization, 2009). Wild aquatic birds in the orders Anseriformes and Charadriiformes are the natural hosts for influenza A viruses; these viruses have generally remained in evolutionary stasis and are usually non-pathogenic in wild birds (Riedel, 2006; Olsen et al., 2006). Most avian influenza viruses (AIVs) primarily replicate in the intestinal tract of wild birds and are spread amongst birds via an indirect fecal-oral route involving contaminated aquatic habitats (Webster, 2002). Humans who are directly exposed to the tissues, secretions, and excretions of infected birds or water contaminated with bird feces can become infected themselves (Riedel, 2006; Webster, 2002; Dórea et al., 2013). The transmission of an AIV from a bird to a human has

significant pandemic potential as it may result in the direct introduction of a novel virus strain or allow for the creation of a novel virus strain via reassortment (Olsen et al., 2006; Dórea et al., 2013).

The transmission of AIVs from birds to humans depends on many factors, such as the susceptibility of humans to the virus and the frequency and type of contact (Riedel, 2006; Dórea et al., 2013). Most AIVs are generally inefficient in infecting humans; however, there have been documented cases of AIVs transmitting directly from infected birds to humans (Beigel et al., 2005; Peiris et al., 2007). During the 1997 Hong Kong “bird flu” incident, there was demonstrated transmission of highly pathogenic avian influenza (HPAI) A virus (H5N1) from infected domesticated chickens to humans (Olsen et al., 2006). More recently, some Asian countries have reported human infections of avian influenza A virus (H7N9) with most patients having a history of exposure to live poultry in wet markets (World Health Organization, 2014). As such, most pandemic plans include special considerations (e.g., enhanced surveillance, prioritization for vaccination, and antiviral prophylaxis) for avian influenza risk groups that include humans who come in close, frequent contact with domestic birds, such as farmers, poultry farm workers, veterinarians, and livestock workers (World Health Organization, 2011; Public Health Agency of Canada, 2011).

Longitudinally migrating wild birds appear to play a primary role in influenza transmission and there is increased concern about the introduction of HPAI virus strains in North America from Eurasia, as migratory flyways around the world intersect (Olsen et al., 2006; Webster, 2002). Thus, bird hunters may also be at risk as hunting and processing practices directly expose them to the bodily fluids of wild birds and water potentially contaminated with bird feces (Dórea et al., 2013; Dishman et al., 2010). Although the risk of AIV infection while hunting and processing wild birds is assumed to be very low (Dórea et al., 2013), transmission has been previously reported. One study reported serologic evidence of past AIV infection in a recreational duck hunter and two wildlife professionals, inferring direct transmission of AIVs from wild birds to humans (Gill et al., 2006). Another study reported that recreational waterfowl hunters were eight times more likely to be exposed to avian influenza-infected wildlife compared to occupationally-exposed people and the general public (Siembieda et al., 2008). A study conducted in rural Iowa, USA, reported that participants who hunted wild birds had increased antibody titers against avian H7 influenza virus (Gray et al., 2008). Further, in the Republic of Azerbaijan, HPAI H5N1 infection in humans is suspected to be linked to defeathering infected wild swans (*Cygnus*) (Gilsdorf et al., 2006).

Since handling wild birds and having contact with the aquatic habitats of wild birds are potential transmission pathways for AIV infections in hunters, it is important to better understand hunters’ risk perceptions of avian influenza and include special considerations in pandemic plans. This is particularly important for some Canadian Aboriginal (First Nations, Inuit, and Métis) populations whose hunting of wild birds represents subsistence harvesting as opposed to a recreational activity (Tsuji, 1998b). Herein, subsistence harvesting will refer collectively to activities associated with hunting, fishing, trapping, and gathering of animals and other food for personal, family, and community consumption (Berkes et al., 1994; Tam et al., 2013). The practice of subsistence harvesting for some Canadian Aboriginal populations, such as the Cree First Nations of the Mushkegowuk region, is culturally and economically important with the majority of hunters harvesting wild birds (Berkes et al., 1994; Tsuji & Nieboer, 1999). Traditional land-based harvesting activities are economically valuable for the region and can reduce external economic dependence (Berkes et al., 1994). Moreover, as there are many physical, nutritional, and social benefits of this practice, it is a vital, well-

established component of health and well-being in Canadian Aboriginal communities (Van Oostdam et al., 2005). For instance, as Canadian Aboriginal populations, particularly those residing in geographically remote and isolated communities, experience a high prevalence of household food insecurity (Hlimi et al., 2012; Skinner et al., 2014), subsistence harvesting can provide an important source of healthy traditional foods and lessen the reliance on costly market foods.

The potential of AIV infection while hunting and harvesting wild birds varies with geographical areas, seasons, and specific activities (Dórea et al., 2013; Dishman et al., 2010; Gill et al., 2006). Moreover, previous studies have shown that knowledge and risk perception of avian influenza can positively influence compliance with recommended protective health behaviours (Abbate et al., 2006; Di Giuseppe et al., 2008). We conducted a cross-sectional survey of the bird harvesting practices and knowledge, risk perceptions, and attitudes regarding avian influenza among Canadian First Nations subsistence hunters. The purpose of this study was to examine if knowledge and risk perception of avian influenza influenced the use of personal protection measures and attitudes about hunting influenza-infected birds. The implications for addressing the special considerations of Canadian First Nations subsistence hunters in pandemic plans will be discussed.

7.2-Methods

7.2.1-Community-based participatory research approach

The present study employed a community-based participatory research (CBPR) approach since the hallmark principles of CBPR can foster the engagement of Aboriginal populations and participatory methods have previously been a successful approach to partnering with Aboriginal communities (St. Denis, 2004; Macaulay et al., 1998; Davis & Reid, 1999). As such, the research topic was locally relevant as it stemmed from previous research conducted in the region that explored culturally-appropriate measures to mitigate the effects of an influenza pandemic in the setting of a remote and isolated First Nations community (Charania & Tsuji, 2014). Residents of the study community expressed questions and concerns about the transmission potential of AIVs from influenza-infected wild birds to subsistence hunters. Thus, the present study was specifically developed and conducted to address the identified questions and concerns.

Following a CBPR approach, collaboration occurred throughout the research process between the researchers and a community-based advisory group (CBAG) comprised of two community representatives from the study community (Israel et al., 2005; Charania & Tsuji, 2011a; Kirby et al., 2007). The two members of the CBAG were of First Nations heritage and were particularly interested in the topic at hand and desired to be involved. The CBAG helped design the study and was part of the iterative process of developing the survey questions and layout. The CBAG also provided input during the data analysis process, on the interpretation of results, and aided with disseminating the results to the community. CBPR endeavors aim to use the knowledge generated to achieve action-oriented outcomes for the involved community (Israel et al., 2005; Israel et al., 2008). At the request of the CBAG, the results of this study were disseminated via an oral presentation to community members during a lunch-and-learn activity in June 2014. An information sheet explaining avian influenza and recommended precautionary behaviours created by Health Canada was distributed to attendees (Health Canada, 2011b). Information about emerging avian influenzas that currently are of pandemic concern and the information sheet were also

incorporated into the community's influenza pandemic plan as a newly created appendix section.

Approval to conduct this research was granted by the Office of Research Ethics at the University of Waterloo (ORE #16534), and was supported by the Band Council (locally elected First Nations government body) of the involved community.

7.2.2-Study area, population, and data collection

The study community (name omitted for anonymity purposes) is considered remote (i.e., nearest service center with year-round road access is located over 350 kilometers away) and isolated (i.e., accessible only by airplanes year-round) (Public Health Agency of Canada, 2011). The Cree First Nations community belongs to the Mushkegowuk region which is located in northern Ontario, Canada along the western shores of James Bay and the southern portion of Hudson Bay (Berkes et al., 1994; Tsuji & Nieboer, 1999). The region is a productive wildlife area and the majority of hunters partake in the spring and fall bird harvests (Berkes et al., 1995).

The cross-sectional survey was conducted in English (as suggested by the CBAG) from November 10-25, 2013. The time period was chosen to maximize participation, as most hunters would have returned from fall hunting activities. The survey was based on previous literature (Dishman et al., 2010) and was developed in collaboration with the CBAG to ensure that it adequately addressed the objectives of the study and was culturally-appropriate. The survey employed closed-ended questions to gain a better understanding of First Nations hunters' general harvesting practices, knowledge and risk perception of avian influenza, and attitudes about hunting influenza-infected birds. Open-ended questions were also included to allow for participants to describe their risk perceptions of AIV infection while harvesting birds as well as any additional concerns. Basic demographic questions to record the age and sex of participants were also included.

Community First Nations subsistence hunters were invited to participate by the lead author (NAC) and a local community research assistant during individual meetings. The research assistant was of First Nations descent and a prominent Elder in the community. Being fluent in the Cree language, the assistant acted as a Cree translator upon request by the survey respondents. A current community housing list (updated in November 2013) which recorded all known community members living in First Nations (Band) households was used by the research assistant to identify eligible participants. Contemporary harvesting practices in the region typically involve multiple short trips versus traditional long trips (Berkes et al., 1995). To include as many hunters as possible from the study community, eligible participants were defined as current hunters, a group which included "intensive", "active", and "occasional" hunters (for definitions, see Berkes et al., 1994). In addition to being a current hunter, participants were required to be First Nations (Band member), an adult (18 years old and over), and available to complete the survey in person during the study period to be eligible. Both male and female hunters were approached as it is widely recognized in Cree First Nations that both sexes play an important role while subsistence harvesting (Ohmagari & Berkes, 1997).

When approached, the participants were provided with an information/recruitment letter and the study was explained in English or Cree as required. Informed verbal consent was obtained, being culturally appropriate for the region (Kirby et al., 2007; Skinner et al., 2006). Incentives were not offered for participation. As participants preferred to complete the survey

alone on their own time, a convenient time and location was arranged to collect the completed survey. Up to five follow-up visits and new survey copies were provided if the survey was not completed at the specified time and if the person was still interested in participating.

7.2.3-Data management and analyses

Collected surveys were coded by an identification number to maintain confidentiality of the participants. The CBAG was consulted to determine how to code inexact responses. Of note, it was decided that if a participant responded with a range of numbers, the median value was recorded. If a participant selected all of the possible response options or only provided a written response, the result was recorded as missing data. In instances where a pattern was observed amongst participants' written responses, the responses were coded according to newly created response options approved by the CBAG to maintain the integrity of the data.

Sample size for individual statistical analyses varied from 88 to 106, as not all participants answered each survey question; thus, presented percentages may not always equal 100% owing to missing data. Simple descriptive statistics were used to examine the distributions of variables pertaining to general harvesting practices, knowledge and risk perception of avian influenza, and attitudes about hunting influenza-infected birds. Cross-tabulations, as 2 X 2 contingency analyses, were used to examine the relationships between each of the main effects of sex, awareness of avian influenza, and risk perception of AIV infection by precautionary behaviours and attitudes about hunting influenza-infected birds. In instances where the expected cell count was less than five, the Fisher's Exact Test was used in preference to the Pearson chi-square test. Absolute values greater than 1.96 of the adjusted standard residual (ASR) indicated a significant departure from the expected count and therefore considered to be a major contributor to the observed chi square result.

The influence of outlier values for continuous dependent variables (age, years of hunting, days of hunting per year, birds hunted per year) was examined using boxplots of raw and log transformed data. Owing to the presence of outlier values, we log-transformed values for days of hunting and number of birds hunted per year to satisfy the homogeneity of variance assumption of analysis of variance (ANOVA). It was decided that one individual's improbable response for number of birds hunted per year should be removed as it continued to distort the results. Also, one individual's response for years of hunting was recorded as missing data since the response did not reflect the age of the participant. Differences in mean values of these dependent variables between groups for sex, awareness of avian influenza, and risk perception of AIV infection were examined using ANOVA. Statistical results were considered to be significant at $p < 0.05$. Data analyses were carried out using SPSS version 22 (SPSS Inc., Chicago, Illinois, U.S.A.).

Written responses to the two open-ended questions and any additional comments were manually transcribed verbatim into electronic format to facilitate organization and coding. Qualitative coding of the transcribed data was conducted using QSR NVivo® version 9.2 (QSR International Pty Ltd., Doncaster, Victoria, Australia). Responses were deductively analyzed following a template organizing approach using the survey questions as a coding template (Bryman, 2001; Crabtree & Miller, 1999). Analyzing the data was an iterative process conducted multiple times by the lead author (NAC) and findings were presented to the CBAG as a way of member checking to verify the results (Bryman, 2001).

7.3-Results

A total of 173 participants in the censused community were deemed eligible to participate given the inclusion criteria and of these, 126 received surveys, for a 73% contact rate. Of the 126 distributed surveys, 106 completed surveys were returned, representing an 84% cooperation rate. Overall, a response rate of 61% was achieved. Of the 106 community members that participated in the survey, 80 (75.5%) were male and 26 (24.5%) were female. The untransformed demographic and harvesting characteristics of the participants are presented in Table 7.1.

Table 7.1: Demographic and harvesting characteristics of Canadian First Nations subsistence hunters residing in the study communities (n = 106), November 10-25, 2013

	n	Minimum	Maximum	Mean	Std. deviation
Demographic Information					
Age	92	18	76	43.3	12.9
Harvesting Characteristics					
Years of hunting	99	1	65	27.2	14.0
Days of hunting per year	105	1	200	26.2	30.5
Number of birds hunted per year	100	0	200	42.6	40.6

All who responded participated in the spring/summer hunting activities (n = 105; 99.1%) with fewer hunters participating during the fall (n = 57; 53.8%) and winter (n = 16; 15.1%) seasons. During these hunts, 98.1% of participants hunted Canada geese (*Branta canadensis*), 88.7% hunted various species of ducks (*Anatinae*), 69.8% hunted lesser snow geese (*Anser c. caerulescens*, also referred to as wavies), and 43.4% hunted species of shorebirds (*Charadriiformes*).

While hunting, the majority of participants reported having direct contact with water (n = 89; 84.0%). Bird harvesting practices were generally similar whether camping in the bush or at home; thus, only results pertaining to camping in the bush are presented. In the bush, most hunters processed the birds themselves (n = 72; 67.9%) or a family member was involved (n = 67; 63.2%). Most hunters partook in all of the bird processing activities in the bush; the percentage of participants who reported cleaning, plucking, and gutting the birds were 74.5%, 94.3%, and 77.4% respectively. Regarding the use of precautionary measures while processing birds in the bush, it was reported that 18 (17.0%) hunters wore gloves and 2 (1.9%) hunters wore goggles. In the bush, the majority of hunters washed their hands (n = 105; 99.1%) and sanitized their equipment (n = 69; 65.1%) after processing birds. Moreover, about half of the participants (n = 50; 47.2%) reported receiving the annual vaccination against seasonal human influenza viruses (Figure 7.1).

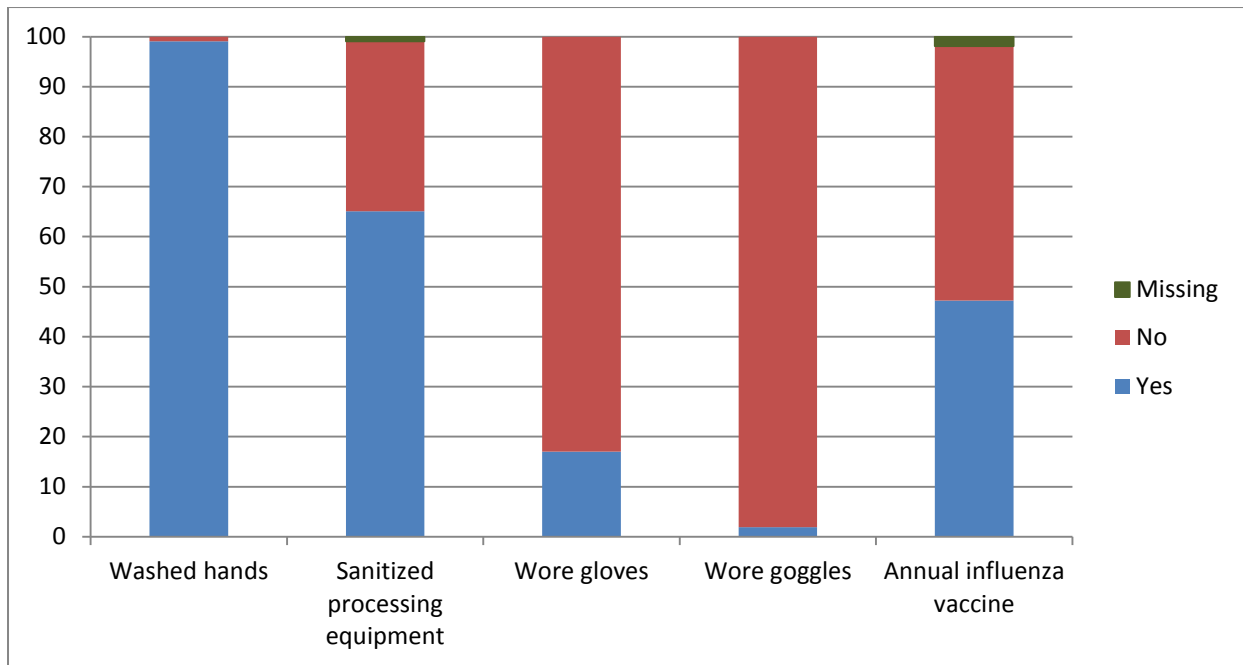


Figure 7.1: Compliance with recommended protective health measures among Canadian First Nations subsistence hunters residing in the study community (n=106), November 10-25, 2013

The total frequency and percentage of participants' knowledge of avian influenza, risk perception of AIV infection, and attitudes about hunting influenza-infected birds are presented in Table 7.2. Approximately half of the participants (n = 56; 52.8%) reported being generally aware of avian influenza, but few were aware of the signs and symptoms of avian influenza in birds (n = 16; 15.1%) or humans (n = 9; 8.5%).

Table 7.2: Frequency and percentage^a of knowledge of avian influenza, risk perception of avian influenza virus infection, and attitudes about hunting influenza-infected birds among Canadian First Nations subsistence hunters residing in the study community (n = 106), November 10–25, 2013

	All Hunters		Males		Females	
	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)
Knowledge						
Aware of avian influenza	49 (46.2)	56 (52.8)	37 (46.3)	42 (52.5)	12 (46.2)	14 (53.8)
Aware of signs and symptoms of avian influenza in birds	89 (84.0)	16 (15.1)	67 (83.8)	12 (15.0)	22 (84.6)	4 (15.4)
Aware of signs and symptoms of avian influenza in humans	95 (89.6)	9 (8.5)	74 (92.5)	4 (5.0)	21 (80.8)	5 (19.2)
Risk Perception						
Perceived risk of avian influenza virus infection	68 (64.2)	29 (27.4)	52 (65.0)	23 (28.8)	16 (61.5)	6 (23.1)
Attitudes						
Cease hunting if avian influenza detected in North American birds	60 (56.6)	43 (40.6)	49 (61.3)	29 (36.3)	11 (42.3)	14 (53.8)
Cease hunting if avian influenza detected in Province of Ontario birds	54 (50.9)	45 (42.5)	45 (56.3)	30 (37.5)	9 (34.6)	15 (57.7)
Cease hunting if avian influenza detected in Regional birds	46 (43.4)	55 (51.9)	39 (48.8)	37 (46.3)	7 (26.9)	18 (69.2)

^aPercentages may not always equal 100% owing to missing data.

Some participants (n = 29; 27.4%) perceived a risk of contracting avian influenza while harvesting birds.

“Just wondering every time we go out hunting geese in the spring, if any of the geese that come in [the] spring are carrying the flu” (Participant #41).

“Yes there is a risk [be]cause the birds [are] from the South ... who knows what they’ll catch out there” (Participant #103).

“It will concern me if the bird flu is here on our Land and I wouldn’t be sure about hunting birds” (Participant #42).

On the other hand, many participants did not perceive a risk of AIV infection while harvesting birds, since local regional birds were not perceived to be infected with avian influenza.

“I thought there was only bird flu in Asia ...” (Participant #24).

“If birds were sick, I don’t think they would make it this far [North]” (Participant #70).

“No reports that bird flu has arrived in this area and people are not getting sick” (Participant #36).

Detection of avian influenza in wild birds in nearby geographic areas would reportedly influence the participants’ harvesting behaviour. The frequency of participants who would cease harvesting birds was highest if avian influenza was detected in local regional birds (n = 55; 51.9%). It was reported that 45 (42.5%) respondents would stop hunting if avian influenza was found in birds from within the Province of Ontario, and 43 (40.6%) respondents would stop hunting if the virus was found in North American birds. For all of the aforementioned scenarios, some participants added written responses indicating that they were not sure if they would stop hunting and requested relevant information. The majority of respondents also were interested in receiving information about avian influenza transmission (n = 83; 78.3%), flyways of migrating birds (n = 79; 74.5%), and precautions to minimize exposure (n = 82; 77.4%).

ANOVA showed that males hunted significantly more birds per year than did females ($F_{1,96} = 12.1$; $p = 0.001$; Figure 7.2). No significant difference in mean values of age, years of hunting, and days of hunting per year was observed between males and females. ANOVA did not identify any significant differences in mean values of age, years of hunting, days of hunting per year, and number of birds hunted per year between those who were or were not aware of avian influenza. However, ANOVA did show that those who hunted significantly more days per year did not perceive a risk of AIV infection while harvesting birds ($F_{1,94} = 4.4$; $p = 0.040$; Figure 7.2). No significant difference in mean values of age, years of hunting, and number of birds hunted per year was observed between those who did or did not perceive a risk of AIV infection.

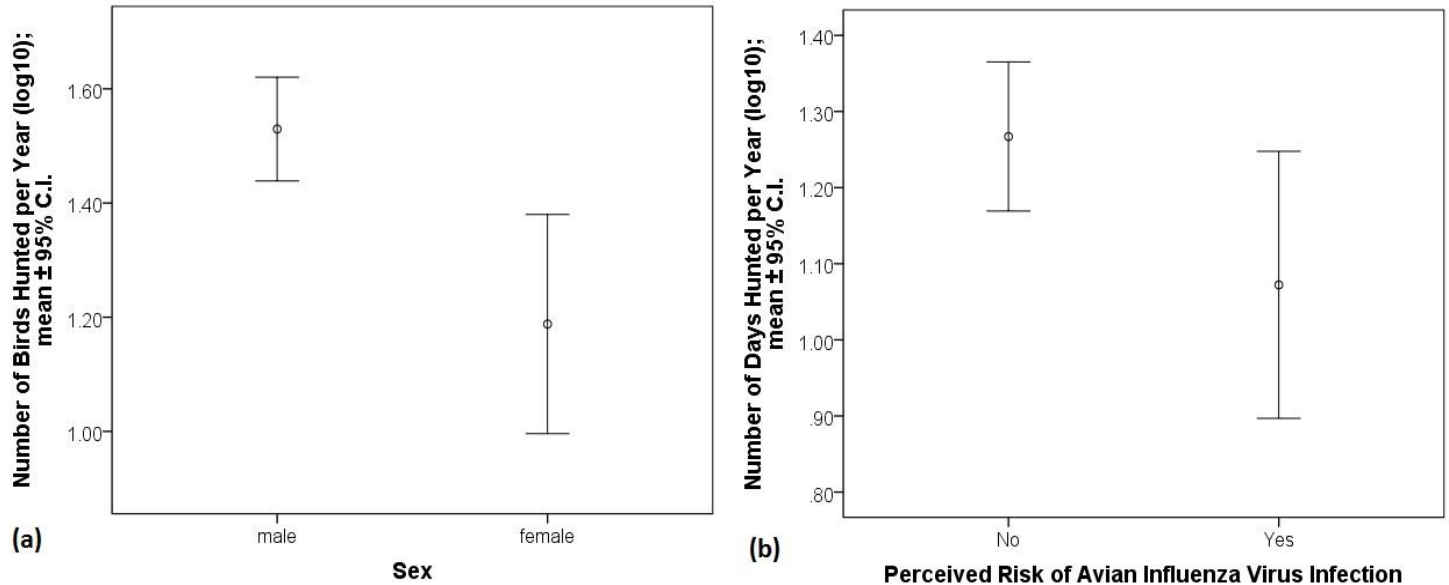


Figure 7.2: Analysis of variance for number of birds hunted per year by males and females (a) and number of days hunted per year by perceived risk of avian influenza virus infection while harvesting birds (b) among Canadian First Nations subsistence hunters residing in the study community (n = 106), November 10-25, 2013

For all participants, in 2×2 contingency analysis, a significant dependence was observed between awareness of avian influenza and risk perception of AIV infection (Pearson $\chi^2 = 4.456$; $p = 0.035$) (Table 7.3). An ASR of +2.1 indicated that participants aware of avian influenza were significantly more likely to perceive a risk of AIV infection while harvesting birds. No significant dependence was seen between sex and awareness of avian influenza or sex and perceived risk of AIV infection.

Table 7.3: Cross-tabulation for awareness of avian influenza by risk perception of avian influenza infection while harvesting birds among Canadian First Nations subsistence hunters residing in the study community (n = 106), November 10–25, 2013

		Perceived risk of avian influenza infection while harvesting birds		Total	
		No	Yes		
Aware of avian influenza	No	Count	37	9	46
		Adjusted Residual	+2.1	-2.1	
	Yes	Count	31	20	51
		Adjusted Residual	-2.1	+2.1	

A significant dependence was observed between sex and the attitude of ceasing hunting if influenza was detected in regional birds (Pearson $\chi^2 = 4.123$; $p = 0.042$) (Table 7.4). An ASR of -2.0 indicated that males were significantly less likely to stop hunting if influenza was detected in

the local regional birds. No significant dependence was observed between the two main effects of awareness of avian influenza and perceived risk of AIV infection by attitudes about hunting influenza-infected birds.

Table 7.4: Cross-tabulation for sex by cease hunting if influenza detected in Regional birds among Canadian First Nations subsistence hunters residing in the study community (n = 106), November 10–25, 2013

			Cease hunting if influenza detected in Regional birds		Total
			No	Yes	
Sex	Male	Count	39	37	76
		Adjusted Residual	+2.0	-2.0	
	Female	Count	7	18	25
		Adjusted Residual	-2.0	+2.0	

A significant dependence also was observed between awareness of avian influenza and the precautionary behaviour of sanitizing equipment after processing birds while camping in the bush (Pearson $\chi^2 = 4.070$; $p = 0.044$) (Table 7.5). An ASR of +2.0 indicated that a significantly greater frequency of aware participants were among those who cleaned their bird processing equipment. No significant dependence was observed between awareness of avian influenza by any of the other recommended precautions to be used while harvesting birds. Moreover, no significant dependence was observed between the two main effects of sex and perceived risk of AIV infection by any of the precautionary behaviours.

Table 7.5: Cross-tabulation for awareness of avian influenza by sanitizing bird processing equipment in the bush among Canadian First Nations subsistence hunters residing in the study community (n = 106), November 10–25, 2013

			Sanitize bird processing equipment in the bush		Total
			No	Yes	
Aware of avian influenza	No	Count	21	27	48
		Adjusted Residual	+2.0	-2.0	
	Yes	Count	14	42	56
		Adjusted Residual	-2.0	+2.0	

7.4-Discussion

7.4.1-Harvesting activities

As mentioned, the potential of AIV infection while hunting and processing wild birds varies with specific practices, seasons, and geographical areas (Dórea et al., 2013; Dishman et al., 2010; Gill et al., 2006). The hunters reported being in frequent contact with wild birds, as some participants hunted for more than 100 days per year and harvested up to 200 birds per year. Our findings indicated that First Nations subsistence hunters were involved in bird harvesting practices, such as processing the birds and having direct contact with water in the bush, that pose an increased hazard to AIV infections among this subpopulation. The main proposed pathway of transmission of AIV to humans is close contact between the tissues, secretions, and excretions of an infected bird and the respiratory tract, gastrointestinal tract, or conjunctiva of a human (Riedel, 2006; Peiris et al., 2007; Weber & Stilianakis, 2008). Infected birds shed copious amounts of virus particles in their feces which can also contaminate the environment and bodies of water (Nazir et al., 2010; Zarkov & Urumova, 2013). Our findings revealed that the majority of hunters had direct contact with water and cleaned, plucked, and gutted the wild birds themselves. If processing an influenza-infected wild bird in this manner, hunters may be exposed to virus-laden tissues, secretions, and excretions (Riedel, 2006; Dórea et al., 2013). The use of personal protective equipment was not routine practice as most hunters did not wear gloves and goggles to protect themselves while processing birds. However, most hunters reported using other measure of personal protection, such as washing their hands and cleaning their equipment, which can limit post-harvest AIV exposure.

The timing of the hunters' bird harvesting activities in relation to when the prevalence peaks for AIVs and human influenza viruses is of particular interest. Similar to previous reports, our study revealed that the majority of hunters were involved in the spring and fall bird harvests (Tsuji, 1998b; Tsuji & Nieboer, 1999; Berkes et al., 1995). The timing of these harvests is in relation to freeze-up and break-up events in the region which varies every year, but generally runs from April to October (McDonald et al., 1997). During these harvests, participants reported hunting migratory wild birds that are potential carriers of AIVs as all known influenza A virus subtypes have been identified in these birds (Olsen et al., 2006; Krauss et al., 2007). For instance, in North American wild ducks, AIV prevalence peaks around late summer/early fall prior to south bound migration, with highest virus isolation rates reported in juvenile ducks (Stallknecht & Shane, 1988; Hinshaw et al., 1985). On the other hand, previous studies have reported relatively low prevalence of AIVs in Canada geese regardless of the season (Hinshaw et al., 1985; Harris et al., 2010). Moreover, in Canada, the peak season of influenza A infection in humans typically runs from November to April (Health Canada, 2011b). Similar to another study, our results suggest that the possibility of co-infection with AIVs and human influenza viruses resulting in a reassortment event is unlikely as the timing of the hunters' potential exposure to AIVs is different from that of seasonal human influenza viruses (Dórea et al., 2013).

Based on previous studies, the surveyed participants generally hunt for wild birds around the southwestern coast of Hudson Bay and the western coast of James Bay which is along the Mississippi migratory flyway (Olsen et al., 2006; Berkes et al., 1995; Hanson & Currie, 1957; Krauss et al., 2004). Migratory flyways around the world intersect, particularly between eastern Eurasia and Alaska and between Europe and eastern North America, raising concerns about the

exchange of AIVs between the Eurasian and American virus superfamilies (Olsen et al., 2006; Krauss et al., 2007). Intercontinental exchange of entire AIV genomes has not yet been reported and Eurasian HPAI virus subtypes have not been previously detected in North American migratory birds (Krauss et al., 2007; Koehler et al., 2008). However, reassortment events between the two lineages has been reported, notably in Alaska and along the northeastern coast of Canada (Krauss et al., 2007; Koehler et al., 2008; Ip et al., 2008; Hall et al., 2013). These observations suggest that the introduction of a novel AIV is more likely to occur along the Pacific and Atlantic coasts of North America, but once introduced, it has been suggested that migration to major congregation sites may disperse the novel AIV across flyways (Koehler et al., 2008; Hall et al., 2013; Bahl et al., 2013).

7.4.2-Awareness, risk perception, and attitudes

Approximately half of our study participants were generally aware of avian influenza (52.8%), which is lower than previous studies conducted with bird hunters in the USA (86%) and poultry workers in Nigeria (67.1%) and Italy (63.8%) (Dishman et al., 2010; Abbate et al., 2006; Fasina et al., 2009). Similar to a previous study, our findings indicated that a general awareness of avian influenza was more common among the surveyed bird hunters compared to knowledge of the signs and symptoms (Dishman et al., 2010). Previous studies conducted with high-risk populations in Thailand and Laos also reported limited knowledge of the key signs and symptoms of avian influenza (Maton et al., 2007; Barennes et al., 2007). Almost one third of surveyed participants perceived a risk of contracting avian influenza while hunting and processing birds which is similar to the values found in other studies (Di Giuseppe et al., 2008; Fielding et al., 2005).

Our results revealed that the frequency of First Nations hunters who would cease harvesting birds increased as AIV was detected in more nearby geographic areas. This observation aligns with findings from a previous study; however, the percentage of hunters who would stop was relatively higher in our study as only 3% and 19% of active duck hunters in Georgia, USA reported that they would stop hunting if HPAI were found in duck populations in USA and the state of Georgia, respectively (Dishman et al., 2010). This result is interesting as harvesting activities are integral to First Nations' culture and an important source of healthy food, especially in communities experiencing food insecurity (Berkes et al., 1994; Van Oostdam et al., 2005; Skinner et al., 2014).

Our findings suggested that being aware of avian influenza or perceiving a risk of AIV infection did not influence the hunters' decision to cease harvesting influenza-infected birds. However, those who were knowledgeable were more likely to clean their equipment after processing birds in the bush. This finding suggests that First Nations hunters are not only willing to use precautionary measures while harvesting birds, but that improving their knowledge level may lead to an increased use of recommended precautionary measures. Previous studies also found that knowledge and perception of risk was a significant determinant of greater compliance with recommended protective measures (Abbate et al., 2006; Di Giuseppe et al., 2008). However, in our study, being knowledgeable or perceiving risk did not always result in greater use of protective measures. Moreover, in general, the limited use of gloves and goggles while processing harvested birds was noted. These observations may be explained by the protection motivation theory which states that complying with a recommended protective health behavior is

influenced by risk perception as well as efficacy variables, including response efficacy (i.e., whether the recommended measure is effective) and self-efficacy (i.e., whether the person is capable of performing the recommended measure) (Roger, 1975; Floyd et al., 2000; de Zwart et al., 2007). According to this theory, risk perception will generate a willingness to act, but efficacy variables will determine whether the resulting action is adaptive or maladaptive (Roger, 1975; Floyd et al., 2000). In our study, those who perceived a risk may have doubted the effectiveness of recommended measures and/or had low self-efficacy owing to limited access to resources and ability to afford supplies required to implement the measures (Charania & Tsuji, 2013).

7.4.3-Recommendations for influenza pandemic plans

These data support previous findings which suggest that bird hunting and processing activities may potentially expose individuals to avian influenza (Dórea et al., 2013; Dishman et al., 2010; Gill et al., 2006; Siembieda et al., 2008; Gray et al., 2008). Acknowledging the various benefits and cultural importance of subsistence harvesting (Berkes et al., 1994; Van Oostdam et al., 2005), while taking into account the increased hazard of potential AIV exposure in First Nations hunters, their inclusion as an avian influenza risk group with associated special considerations in pandemic plans seems warranted. The potential for a novel AIV to be introduced into an Aboriginal Canadian population is of great concern as they face many health disparities and are particularly susceptible to influenza and related complications (MacMillan et al., 1996). Moreover, previous influenza pandemics have disproportionately impacted Aboriginal Canadians, especially those populations living in geographically remote communities, and reflected inadequacies in preparedness with regards to addressing their pre-existing inequalities and special needs during a pandemic (Kermode-Scott, 2009; Kumar et al., 2009; Barker, 2010; Spence & White, 2010).

Efforts should be directed towards improving education for First Nations hunters regarding avian influenza and the hazard posed by AIVs while harvesting wild birds. More specifically, our results indicated that educational endeavours should include information regarding the signs and symptoms of avian influenza, transmission dynamics, flyways of migrating birds, and recommended precautionary measures (Table 7.6). Accordingly, access to supplies required to comply with recommended protective measures, such as cleaning solutions and gloves, should be improved for First Nations subsistence hunters. Moreover, our findings suggested that detection of avian influenza in wild birds in nearby geographic areas would influence the participants' harvesting behaviour. Given this, we recommend that a culturally-appropriate communication system be implemented to promptly inform subsistence hunters and other community members of the findings and any associated recommendations.

Table 7.6: Recommended precautions for Canadian First Nations subsistence hunters to reduce exposure to avian influenza viruses while harvesting wild birds (adapted from Health Canada, 2011b)

- Do not touch or eat sick birds or birds that have died for unknown reasons
 - Avoid touching the blood, secretions, or dropping of wild game birds
 - Do not rub your eyes, touch your face, eat, drink or smoke when processing wild game birds
 - Keep young children away when processing wild game birds and discourage them from playing in areas that could be contaminated with wild bird droppings
 - When preparing game, wash knives, tools, work surfaces, and other equipment with soap and warm water followed by a household bleach solution (0.5% sodium hypochlorite)
 - Wear water-proof household gloves or disposable latex/plastic gloves when processing wild game birds
 - Wash gloves and hands (for at least 20 seconds) with soap and warm water immediately after you have finished processing game or cleaning equipment. If there is no water available, remove any dirt using a moist towlette, apply an alcohol based hand gel (between 60-90% alcohol) and wash your hands with soap and water as soon as it is possible
 - Change clothes after handling wild game birds and keep soiled clothing and shoes in a sealed plastic bag until they can be washed
 - When cooking birds, the inside temperature should reach 85°C for whole birds or 74°C for bird parts (no visible pink meat and juice runs clear)
 - Never keep wild birds in your home or as pets
 - Receive the annual influenza vaccine
 - If you become sick while handling birds or shortly afterwards, see your doctor and inform your doctor that you have been in close contact with wild birds.
-

7.4.4-Study strengths and limitations

To our knowledge, this is the first study to examine the risk perceptions of avian influenza among Canadian First Nations subsistence hunters. The censused approach taken to select participants and the high contact and cooperation rates strengthen the assertion that our findings are representative of the study community. Also, in accordance with a CBPR approach, the CBAG was involved throughout the entire research process, thereby ensuring that the study was conducted in a culturally-appropriate manner and that the knowledge generated was used to directly benefit the involved community.

Despite the novelty and significance of our findings, some limitations of our study must be highlighted when interpreting our results. First, the analysis was based on a cross-sectional survey of self-reported data which may limit drawing definitive conclusions about the observed relationships. The biases in recalling and reporting cannot be entirely ruled out; however, to help alleviate the potential for biased responses, participants were assured that their responses would remain anonymous. Also, it is not possible to discern whether those who did not return the survey or refused to participate were different in any way from those who did participate. However, there is no obvious reason to suspect that non-respondents and people who chose not to participate were any different from the respondents.

Future research should examine the prevalence of AIVs, particularly those strains that are currently of concern to humans (e.g., H5, H7), in birds from within the Mushkegowuk Territory that are typically harvested. Also, analyzing the sera for antibodies against AIV subtypes would be helpful to evaluate if previous AIV infections occurred in First Nation subsistence hunters. Moreover, conducting a quantitative exposure assessment would provide information to help characterize the study population's exposure potential to AIVs. Lastly, previous research has noted that various barriers impede the effectiveness of implementing recommended pandemic mitigation measures (Charania & Tsuji, 2013). Thus, future research should aim to understand if any barriers exist with regards to complying with recommended precautions to reduce exposure to AIVs while harvesting birds and if measures need to be adapted to be more context-specific and culturally-appropriate, while still maintaining the effectiveness of the measure.

7.5-Conclusion

Our study aimed to gain an understanding of the bird harvesting practices and knowledge, risk perceptions, and attitudes regarding avian influenza among Canadian First Nations subsistence hunters and provide recommendations for pandemic plans. The findings herein indicated that First Nations subsistence hunters partook in some practices while harvesting wild birds that could potentially expose them to avian influenza, although appropriate levels of compliance with some protective measures were reported. More than half of the respondents were generally aware of avian influenza and almost one third perceived a risk of AIV infection while harvesting birds. Participants aware of avian influenza were more likely to perceive a risk of AIV infection while harvesting birds. Our results suggest that knowledge positively influenced the use of a recommended protective measure. Regarding attitudes about hunting influenza-infected birds, our results revealed that the frequency of First Nations hunters who would cease harvesting birds increased as AIV was detected in more nearby geographic areas.

Given that the potential exposure to AIVs while hunting is assumed to be low but the cultural importance of subsistence hunting high, our study indicated a need for more education about avian influenza and precautions First Nations hunters can take to reduce the possibility of AIV exposure while harvesting wild birds that are culturally-appropriate. We posit that First Nations hunters should be considered an avian influenza risk group and have associated special considerations included in pandemic plans.

Chapter 8: Conclusion and Future Research

8.0-Overview

The overall objective of this dissertation was to explore the use of CBPR approaches to engage community members in directing how to improve local influenza pandemic preparedness in remote and isolated Canadian First Nations communities. The purpose of this chapter is to summarize the main findings of this dissertation, highlight the key contributions to existing literature, and make recommendations for future research endeavors.

8.1-Overall Findings

Chapter 3 (Study I, Objective #1) presented an initial needs assessment conducted with nine community-based health care professionals that explored the needs and potential use of a collaborative health informatics system (CHIS) as a strategy to improve the delivery of health care services during a PHE by facilitating inter-agency communication and collaboration. The fifty-five emerging concepts were organized into five categories, including: general issues, potential benefits, potential uses, useful technical functions and suggested technical modifications, and concerns. Participants reported that fragmented patient charting and a low level of collaborative practice with affiliated health care organizations were general issues that hampered the delivery health care in their communities. Participants stated that the CHIS could aid during PHEs by tracking and mapping the occurrence of disease outbreaks, along with facilitating communication and health information sharing between the involved health care organizations. The CHIS was deemed to be user-friendly and participants desired additional technical modifications that would be appropriate and helpful for their communities. Some concerns of the CHIS were noted, namely the concern of accessibility safeguards considering that confidential health information will be inputted, stored, and presented.

Given that the evidence from the study presented in Chapter 3 supported the development and implementation of the CHIS, a follow-up study was conducted with one of the initial three study communities. Chapter 4 (Study I, Objective #2) presented a second needs assessment conducted with sixteen community-based health care professionals that explored issues regarding health care delivery, potential additional uses and functions of the CHIS, and perceived barriers of implementing the CHIS. One hundred and thirty eight emerging concepts were organized into four overarching categories, including level of intra- and inter-government agency communication and collaboration, health information sharing within and between government agencies, patient charting and reporting, and solutions. Although an improved level of inter-agency collaboration was reported, it was noted that having different jurisdictions responsible for providing health care services ultimately hindered the ability to share patient's health information and provide quality health care. Among the suggested solutions, health technology was recommended to be introduced to facilitate appropriate inter-agency health information sharing and patient charting and reporting. The involved participants stated that the CHIS has the potential to be utilized to help manage a PHE by facilitating inter-agency communication, collaboration, and health information sharing, but the CHIS was also viewed as being a useful, valuable tool for the health sector in general.

Chapter 5 (Study II, Objective #1) presented retrospective opinions regarding the experiences and perceptions of effectiveness and feasibility of implementing mitigation measures during

A(H1N1)pdm09 from nine community-based health care workers in three remote and isolated First Nations communities. Participants reported that thirty of the forty-one questioned mitigation measures were used in some form or the other during their response to A(H1N1)pdm09. All of the mitigation measures implemented during A(H1N1)pdm09 were considered to be effective, along with three measures that were not used and one additional measure suggested by a participant. Measures were considered to be effective particularly if the measure aided in decreasing virus transmission, protecting their high-risk population, and increasing community awareness about influenza pandemics. Participants reported that lack of resources, community awareness, overcrowding in homes, and inadequate health care infrastructure hindered the implementation of some mitigation measures. Therefore, participants reported that most measures were modified or altered when being implemented to address the unique characteristics of their communities.

Chapter 6 (Study II, Objective #2) presented a list of community-informed specific recommended mitigation measures (including the setting, pandemic period, trigger, and duration) based on the input of nine community-based health care workers in three remote and isolated First Nations communities. Participants recommended that the majority of questioned mitigation measures be implemented in their communities during a future influenza pandemic. These community-specific recommendations were compared to mitigation measures that are recommended in the national pandemic plan and existing literature. The community-informed specific recommendations agreed with the three main community-based interventions recommended in the national pandemic plan, but interestingly participants supported the use of eight measures which are not nationally recommended. Overall, the results revealed that participants wanted many options of mitigation measures available and these often differed from national recommendations and existing literature.

Chapter 7 (Study III, Objectives #1 and #2) presented a cross-sectional survey conducted with one hundred and six subsistence hunters from a remote and isolated Canadian First Nations community. The findings indicated that First Nations subsistence hunters partook in some practices while harvesting wild birds that could potentially expose them to avian influenza viruses (AIVs), although appropriate levels of compliance with some protective measures were reported. More than half of the respondents were generally aware of avian influenza, with fewer being aware of key signs and symptoms, and almost one third perceived a risk of AIV infection while harvesting birds. Participants aware of avian influenza were more likely to perceive a risk of AIV infection while harvesting birds. The results suggested that knowledge of avian influenza positively influenced the use of a recommended protective measure. Regarding attitudes about hunting influenza-infected birds, the results revealed that the frequency of First Nations hunters who would cease harvesting birds increased as AIV was detected in more nearby geographic areas. The study indicated a need and desire by participants for more education that is culturally-appropriate about avian influenza and precautions First Nations hunters can take to reduce the possibility of AIV exposure while harvesting wild birds. Given the aforementioned, the inclusion of First Nations subsistence hunters as an avian influenza risk group with associated special considerations in future influenza pandemic plans seems warranted.

8.2-Key Contributions to Existing Literature

The overall findings from the studies included in this dissertation make some key significant and original contributions to the existing body of literature.

1. Collaborative health informatics system as a strategy to improve the delivery of health care services

The lack of coordination and collaboration between the multiple authorities responsible for Aboriginal health has been reported to contribute to a fragmented delivery of health care services for Aboriginal Canadians (Tsuji, 1998a). Jurisdictional gaps and debates have resulted in the overlap or under provision of health care services for Aboriginal Canadians and sometimes has resulted in tragic outcomes (e.g., the case of Jordan River Anderson) (Tsuji, 1998a; Lavoie et al., 2011). Furthermore, these jurisdictional problems have led to poorly defined roles and responsibilities during PHEs (PHAC, 2006; FNIHB, 2008; Charania & Tsuji, 2011a).

Data from Study I presented evidence of some current issues that hamper the delivery of health care in remote and isolated First Nations communities from the perspective of community-based health care workers. Fragmented patient charting and lack of coordination and collaboration between involved health care organizations were commonly reported issues. Despite the knowledge that jurisdictional problems continue to contribute to the health disparities experienced by Aboriginal Canadians, not much progress has been made to rectify the situation. Study I is the first of its kind to propose the use of a collaborative geomatics system as a strategy for improving the delivery of health care in remote and isolated Canadian First Nations communities. Originally designed for community-based land-use planning, the collaborative geomatics system is novel in terms of its technology and reflects a form of neogeography. Given the vast capabilities of the collaborative geomatics system, Study I displayed the potential of repurposing and modifying the system for use in the health care sector. Most importantly, Study I revealed that local health care workers desired that the system be implemented as it could be customized to meet their specific issues and needs, and would address the noted drawbacks of other available health information technologies (e.g., electronic medical records, telehealth). Participants reported that the proposed health informatics system would be a helpful strategy to bridge the jurisdictional gap and improve inter-agency coordination, collaboration, and health information sharing which would in turn improve the quality of health care services delivered to Aboriginal Canadians, especially during a PHE.

2. Evidence of inadequate nationally recommended mitigation measures for an influenza pandemic and creation of community-specific recommendations

Federal, top-down policies are important to provide guidance for a comprehensive and coordinated PHE response (Pearce, 2003; Klaiman et al., 2009). However, it has been noted that Aboriginal Canadians were not adequately involved in the creation of the current national pandemic plans and that the recommendations for mitigation measures may not be effective in remote and isolated First Nations communities due to their unique community characteristics (PHAC, 2006; Kermodé-Scott, 2009; Webster, 2009; AFN, 2005). Study II revealed the difficulties experienced in remote and isolated Canadian First Nations communities with regards to implementing mitigation measures during an influenza pandemic outbreak. Also, Study II provided evidence that current national recommendations are not well-suited or appropriate to

mitigate the effects of an influenza pandemic in remote and isolated First Nations communities. Since the actual response to a pandemic occurs at the local level, community-level measures will likely be most effective at mitigating a pandemic (Klaiman et al., 2009; Nelson et al., 2008; Bell et al., 2006b). Therefore, Study II highlights that the unique conditions and differential risk experienced by remote and isolated Canadian First Nations communities during an influenza pandemic warrants the recommendation of mitigation measures that may not be supported in other communities. Study II is novel in that it produced a list of community-informed mitigation measures that are context-specific and culturally-appropriate for remote and isolated Canadian First Nations communities. These findings contribute to the very limited amount of knowledge regarding the knowledge, attitudes, and practices of mitigation measures for an influenza pandemic across marginalized populations (Aiello et al., 2010). To my knowledge, studies conducted by Massey and his colleagues in rural and remote Australian Aboriginal and Torres Strait Islander communities are some of the only studies aimed at gaining a better understanding and developing a list of culturally-appropriate and effective mitigate measures for an influenza pandemic (Massey et al., 2009; Massey et al., 2011).

3. Addressed a gap in knowledge regarding the risk perceptions regarding avian influenza of a high-risk population and advocated for the inclusion of information specific for subsistence hunters in future influenza pandemic plans

Most pandemic plans include special considerations (e.g., enhanced surveillance, prioritization for vaccination, and antiviral prophylaxis) for avian influenza risk groups that include humans who come into close contact with domestic birds, such as, farmers, poultry farm workers, veterinarians, and livestock workers (WHO, 2011; PHAC, 2011). However, other subpopulations, such as bird hunters, may also be at risk as hunting and processing practices directly expose them to the bodily fluids of wild birds and water potentially contaminated with bird feces (Dishman et al., 2010; Dódrea et al., 2013). Thus, it is important to better understand bird hunters' risk perceptions of avian influenza and include special considerations in pandemic plans to better protect this at-risk population from AIV infections. Previous studies have assessed the exposure and risk perception of avian influenza among various high-risk populations, including bird hunters, in many countries (Dódrea et al., 2013; Fielding et al., 2005; Fasina et al., 2009; de Zwart et al., 2007; Barennes et al., 2007; Dishman et al., 2010; Di Giuseppe et al., 2008; Maton et al., 2007; Xiang et al., 2010; Abbate et al., 2006; Leslie et al., 2008; Fatiregun & Saani, 2008).

To my knowledge, Study III is the first study to gain this understanding among Canadian First Nations hunters which is particularly important as their hunting of wild birds represents subsistence harvesting (Tsuji, 1998b) and their practices, knowledge, and attitudes regarding avian influenza may vary from other identified high-risk populations. Moreover, Study III is the first study to suggest that subsistence hunters should be included in future influenza pandemic plans as an avian influenza risk group with associated special considerations, particularly regarding education on recommended precautionary measures to reduce exposure to AIVs while harvesting wild birds.

4. Examples of using CBPR to improve local influenza pandemic preparedness in remote and isolated Canadian First Nations communities

The need to engage marginalized populations in PHEP efforts, to better understand appropriate and effective methods for doing so, and for their input to be subsequently reflected in PHEP plans remain significant gaps in PHEP literature (Wingate et al., 2007). All of the studies included in this dissertation add to this body of literature by documenting examples of engaging a marginalized population in PHEP efforts, more specifically Aboriginal Canadians in influenza pandemic preparedness efforts using CBPR approaches. Furthermore, in general, there are very few documented examples in the existing literature of using CBPR to influence policy and practice (Minkler et al., 2008). Moreover, existing literature is lacking from examples of using CBPR approaches in the context of improving PHEP for marginalized populations. All of the studies included in this dissertation add to this body of literature by documenting examples and broadening our understanding of how CBPR can be used in the context of improving local influenza pandemic preparedness in remote and isolated Canadian First Nations communities. These studies highlight the process of using CBPR to improve local influenza pandemic preparedness and the action-oriented outcomes that resulted from the endeavors, where appropriate. For example, Study II highlights how the generated knowledge was used to update local influenza pandemic preparedness plans with lists of effective and recommended mitigation measures specific for the involved communities. Moreover, Study III highlights how the findings were used for an informative community presentation and to modify local influenza pandemic preparedness plans. Overall, the studies included in this dissertation draw attention to the value of community members participating in planning efforts as they possess special knowledge and how incorporating community-based insights resulted in improved local influenza pandemic preparedness.

5. Lessons learnt and recommendations for CBPR principles

There is a continued need to better understand how to improve the participation of marginalized populations in health-related activities and produce directly beneficial action-oriented outcomes. Others have started this discussion by sharing their lessons learned from using CBPR to engage marginalized populations in various activities (Burhansstipanov et al., 2005; Petrucka et al., 2012; Strickland, 2006). Given this, I believe it is important to add to this discussion by sharing some of my lessons learnt and making recommendations to guide future endeavors based upon my experiences of using CBPR to improve local influenza pandemic preparedness in remote and isolated First Nations communities.

Based on my experiences, some of the main lessons I learnt relate to sustaining CBPR partnerships and disseminating the knowledge generated. First off, I learnt how important it is to have an understanding of the community's history, values, and culture prior to starting a CBPR endeavor. As a clinically trained health care professional, gaining this understanding really deepened my awareness of the many complex social and economic factors that impact a population's health, most of which are outside the direct control of health services. With regards to creating and sustaining CBPR partnerships, it was very apparent from my experiences that additional time and effort was required to build a trusting working relationship between the involved members. Also, with multiple stakeholders being involved, it was important to create opportunities where the involved stakeholders could openly communicate and be transparent regarding their opinions throughout the process in person. Looking back, I think it is critical to

spend more time upfront during the study design phase to better understand how the project will unfold and how each person wants to be involved in the various research phases.

Most notably, I found it challenging at times to juggle the demands of disseminating the knowledge generated via traditional academic avenues and community avenues as each had varying content and formatting requirements. However, from my experiences, I learnt that disseminating the knowledge generated in a manner that resonated best with the involved community is of utmost importance. As research results need to be more promptly and optimally used to change current practice (Graham et al., 2006), I think that it is incredibly important to make an impact beyond the academic community and link research to action in a way that directly benefits the involved community (Graham et al., 2006; Majdzadeh et al., 2010). Despite the importance of achieving action-oriented outcomes that benefit the involved community, I learnt that those desired outcomes sometimes evolved from the original deliverable or did not materialize at all. Many external factors beyond the direct control of the members of the CBPR partnership are at play which can sometimes hinder the ability to produce the desired community outcomes and I believe that this is acceptable as long as all of the members are aware and agree.

Based on the principles of CBPR employed in the presented studies, I would like to make some recommendations regarding the currently accepted list of CBPR principles. In general, I question the necessity of including all of the principles as it appears that the list continues to grow as researchers critique it and add to it based on their experiences. While I understand that each partnership is encouraged to create their own set of principles using the existing CBPR principles as a guide, I believe that having too many guiding principles detracts from the core values of CBPR. Moreover, I believe that having too many guiding principles makes the CBPR process very rigid as partnerships attempt to address each pre-established principle and expectation instead of allowing the partnership to naturally evolve. Also, I believe that some principles are interrelated and some principles refer more to general research considerations. Therefore, based on my experiences, I would like to highlight what I believe are the key principles of CBPR upon which each partnership can develop their own addition principles that resonate most with the people involved and the local context. I believe that this reframed set of core CBPR principles will have increased utility and applicability, in addition to allowing for more flexibility to address the needs of each partnership.

Table 8.1: Eleven key principles of community-based participatory research (Israel et al., 1998; Israel et al., 2005; Minkler & Wallerstein, 2008; Minkler et al., 2012)

- | |
|--|
| <ol style="list-style-type: none">1) Recognizes community as a unit of identity2) Builds on strengths and resources within the community3) Facilitates collaborative and equitable partnerships in all research phases and involves an empowering and power-sharing process that addresses social inequalities4) Promotes co-learning and capacity building among all involved partners5) Integrates and achieves balance between research and action for the mutual benefit of all involved partners6) Emphasizes public health problems that are of local importance and also ecological perspectives that recognize and address the various determinants of health7) Involves a cyclical and iterative process for systems development8) Involves all partners in the dissemination process and disseminating findings and |
|--|

- knowledge gained to all involved partners
- 9) Requires a long-term process and commitment to sustainability
 - 10) Addresses issues of race, ethnicity, and social class in a transparent and accepting manner; embodies ‘cultural humility’
 - 11) Ensures research conducted is rigorous and valid

Out of the eleven guiding principles of CBPR (Table 8.1), I would highlight three of them as being particularly important when conducting CBPR research as I believe that the other principles stem from these main ones. First of all, and most importantly, I agree that CBPR endeavors should facilitate a trusting, collaborative, and equitable partnership in all research phases. I would add the qualification that partnerships should be open to the fact that even if given the opportunity, not every member will want to be a part of every research phase depending on the individual’s interests. While I believe that addressing an issue that is locally relevant and disseminating findings to all involved partners are incredibly important features of CBPR; from my experiences, this occurred naturally if members were equitably involved in the problem identification and dissemination stages. Secondly, I believe that generating knowledge and using the knowledge for action-oriented outcomes that are beneficial to the partnership is a key, defining feature of CBPR. However, rather than stressing the importance of the outcomes being mutually beneficial to all involved partners, I would stress the importance of achieving outcomes that are directly beneficial to the involved community. Lastly, I believe it is important to highlight that CBPR endeavors are long-term processes and are committed to sustainability. Once again, I would add the qualification that partnerships should be open to allowing the initial partnership to evolve as needed to fit the changing circumstances.

8.3-Recommendations for Future Research

While the studies included in this dissertation made some contributions to the existing body of literature, gaps in knowledge remain that need to be addressed in the future. There is a need to further improve PHEP for marginalized populations as these populations are expected to be disproportionately impacted by future PHEs and this requires their participation in the process (Jennings & Arras, 2008). Given that marginalized populations have not historically been engaged in PHEP efforts, there is a scant amount of information regarding how to operationalize the effective engagement of marginalized populations in PHEP planning efforts (Klaiman et al., 2010; Wingate et al., 2007; Uscher-Pines et al., 2007; Andrulis, Siddiqui, & Gantner, 2007). Thus, some general directions for future research include better understanding effective ways for Aboriginal Canadians to participate in PHEP efforts and what types of partnerships are most effective for producing beneficial outcomes.

More specifically, as the lack of coordination and collaboration between authorities responsible for Aboriginal health continues to hinder the quality of health care services delivered to Aboriginal Canadians, it is important that future research is directed towards understanding strategies that will improve inter-agency collaborative practice. Study I revealed how introducing a health informatics system could facilitate inter-agency collaborative practice; thus, future studies should better understand this potential and pilot health information technologies in remote and isolated Canadian Aboriginal communities. Moreover, future research should explore the potential of re-structuring the organization and delivery of Aboriginal health care, such as

amalgamating health care facilities under one jurisdiction, to improve the quality of health care delivered to Aboriginal Canadians.

Furthermore, there remains a paucity of scientific evidence regarding the effectiveness of measures to mitigate the effects of an influenza pandemic in general (Aledort et al., 2007). Related literature is almost non-existent for remote and isolated Canadian Aboriginal communities. Thus, the optimal community-level approach to mitigate the effects of an influenza pandemic in remote and isolated Canadian Aboriginal communities remains unknown. Study II provided insights regarding the perceptions of currently recommended mitigation measures and created a list of community-informed, context-specific, culturally-appropriate mitigation measures. To aid planners in making more informed recommendations, future research should be encouraged to evaluate the effectiveness of these specific community-informed recommendations in remote and isolated Canadian Aboriginal communities using quantitative methods and mathematical modelling. It is important to better understand which of these specific community-informed recommendations (and the respective timing of implementation and duration) are most cost-effective to drive maximal impact using the least amount of resources and causing the least amount of associated consequences.

Given that subsistence hunters may be potentially exposed to AIVs while harvesting birds, future research should examine the prevalence of AIVs in the regional birds of the Mushkegowuk Territory. Analyzing the sera for antibodies against AIV subtypes would also be helpful to evaluate if previous AIV infections occurred among First Nation subsistence hunters. Moreover, conducting a quantitative exposure assessment would provide information to help characterize the study population's exposure potential to AIVs. Lastly, given that efficacy variables may have impacted the compliance rates of subsistence hunters with recommended protective measures while harvesting birds, future research should aim to understand if any barriers exist and if measures need to be adapted to be more context-specific and culturally-appropriate, while still maintaining the effectiveness of the measure.

8.4-Concluding Remarks

Aboriginal Canadians are expected to be disproportionately impacted by future PHEs; thus, these populations require additional attention in PHEP efforts and their participation is particularly important as they possess special knowledge regarding their needs during a PHE. Significant barriers hinder the ability of Aboriginal Canadians to effectively participate in PHEP efforts and there is a limited amount of information of how to operationalize their participation. CBPR offers a promising orientation and method for the effective participation of Aboriginal Canadians in PHEP efforts. This dissertation presented three overarching studies exemplifying the use of CBPR approaches to engage community members and improve local influenza pandemic preparedness in remote and isolated Canadian First Nations communities.

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