

PERCEPTIONS OF PREGNANT INUIT WOMEN, ELDERS, COMMUNITY
HEALTHCARE EXPERTS, PROVIDERS AND COMMUNITY HEALTH
REPRESENTATIVES IN NUNAVUT ABOUT MATERNAL PERTUSSIS
IMMUNIZATION

by

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Submitted in partial fulfilment of the requirements
for the degree of Master of Science

at

Dalhousie University
Halifax, Nova Scotia
December 2020

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Dedication Page

I would like to dedicate this thesis to my dear friend Edgar Metcalfe who passed away on June 24, 2020. I am so grateful for the time we shared; I just wish we had more of it.

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Abstract

There are established maternal pertussis and influenza immunization programs in Nunavut. This thesis project provides information about the perceptions of community healthcare experts, providers, and community healthcare representatives about maternal pertussis immunizations and the determinants of maternal pertussis immunization. I used a mixed methods, sequential research design including narrative collection and sharing circles, both of which informed the generation of a panel of survey questions to be validated and tested outside the scope of this thesis.

Participants described working in complex system with various configurations of prenatal and public health. Human resources and retention were identified as either contributing to or detracting from collective knowledge about maternal immunization and trust between patient and provider, both of which are identified as determinants of maternal immunization. These findings suggest that a complexity-informed approach to existing and nascent maternal immunization programs may be both culturally and logistically appropriate in Nunavut.

List of Abbreviations Used

CCfV	Canadian Center for Vaccinology
CHN	Community Health Nurse
CHR	Community Health Representative
CI	Confidence interval
CIHR	Canadian Institutes of Health Research
CIRN	Canadian Immunization Research Network
COVID-19	Coronavirus Disease of 2019
CPNP	Canadian Prenatal Nutrition Program
GBS	Group B streptococcus
HCP	Health care providers
HPV	Human papillomavirus
INC	Individual Narrative Collection
IQ	<i>Inuit Qaujimagatuqangit</i>
LPN	Licensed Practical Nurse
MM	Mixed methods
NACI	National Advisory Committee on Immunization
NGRAC	Nunatsiavut Government Research Advisory Committee
PAR	Participatory Action Research
PHN	Public Health Nurse
QGH	Qikiqtani General Hospital
QHRC	Qaujigiartiit Health Research Centre
RA	Research Assistant
RSV	Respiratory syncytial virus
RTI	Respiratory tract infection
TCPS	Tri-Council Policy Statement
Tdap	Tetanus, diphtheria, acellular pertussis vaccine
VPD	Vaccine-preventable disease
VSC	Virtual Sharing Circle

Acknowledgements

This thesis was a tremendous undertaking that would never have materialized were it not for the support of the most outstanding people. I would like to begin by acknowledging my co-supervisors: Dr. Scott Halperin and Dr. Joanne Langley. I am deeply grateful to Scott for his mentorship, thoughtful insights on my work, unwavering confidence in my ideas and abilities, willingness to make me a priority despite his competing responsibilities, and patience and reassurance as I ruminated over every detail of this project. I also owe my deepest gratitude to Joanne for her careful attention to detail, quantitative and methodological prowess, curiosity about my interpretations and understanding of what I learned throughout this process, thoughtful advice, and insistence that every decision I made as I worked on this project had a defensible rationale behind it. I have become a much stronger, more discerning, and thorough researcher under their supervision.

I would like to acknowledge my committee members: Dr. Donna Halperin and Dr. Bruce Smith. I am very grateful for Donna's qualitative expertise as I undertook this first foray into mixed methods research. She was always able to draw the best quality of work out of me by asking the right questions and allowing me the creative freedom to write my way into the answers. I so appreciate her vision for the project, trust in me to collect, analyze, and interpret these data, and patience as I worked through qualitative growing pains and insecurities. I really appreciate Bruce's willingness to be a member of my committee despite this thesis being far more qualitatively focused than originally proposed. It was very reassuring to have someone with Bruce's quantitative expertise as a sounding board for the survey components of this project. I believe that the quantitative instrument and results collected and analyzed as this project continues will be far stronger due to his involvement, and I look forward to continuing to collaborate with him on this and other projects in the future.

I am deeply grateful for the opportunity to collaborate with Dr. Gwen Healey Akearok, whose work was instrumental in the development of this thesis project. She provided invaluable insights into the context of this project which was instrumental in upholding the principles of Two-Eyed Seeing or *Inummarik* throughout it. It was a

privilege to hear her and her colleague Ceporah Mearns' experiences and interpretations of the data that they collected and analyzed in Nunavut.

I would like to acknowledge Melissa Kervin and Layla Green at the Canadian Center for Vaccinology (CCfV) for their contributions. Between the two of them, they gave extraordinary amounts of their time note-taking, coding, discussing, and meeting about this work. It was very reassuring to have two people whose ideas were so in tune with my own, imbuing me with the confidence to trust my instincts. I would also like to thank Natasha Squires, for her tireless work transcribing the qualitative data on top of all of her other administrative assistance with this project. I want to acknowledge Jessica McCarthy, Michael Best, and Joshua Edwards, who contributed as Project Managers (prior to Melissa Kervin) on this project.

I would like to thank all of the pilot participants who gave of their time to ensure that the qualitative discussion guides were of the very best quality. Of course, I am also very grateful for all of the participants who entrusted my colleagues and I with their stories. It is not a responsibility that we took lightly and hope that I have done them justice here.

I would be remiss were I not to acknowledge the generous financial support of the Canadian Immunization Research Network (CIRN), the Canadian Institutes of Health Research (CIHR), and the Maritime SPOR Support Unit throughout my master's degree.

I would like to thank my friends, especially Michaela Nichols, Rachel Warren, Madison Stevens, Amy Brierly, Sandy Stearns, Gabrielle Mullin, Sahra Skripsky, and Jane Campbell among so many others who make me feel the friend wealthiest. Finally, I am forever grateful and totally humbled by the love and support of Maria, Julian, Zosha, and Theo Di Castri, David, Leonora, and Matéa Adamcyk, Emiliano Cabrera, and my beloved Jason Genée. It is a privilege to love and be loved by you all.

Chapter 1: Introduction

1.1 Pertussis Disease Burden

Pertussis (whooping cough) infection carries a significant disease burden for all age groups; however, its effects can be life threatening in young infants (1). Pertussis can cause serious and sometimes deadly complications in infants and young children affecting their nutritional status and involving the pulmonary and neurologic systems. These complications range in severity from apnea and pneumonia, to seizures and encephalopathy (2,3). The greatest risk for transmission of pertussis in infants comes from a household contact, such as a parent or sibling (1). Infants get vaccines to protect them from pertussis as early as 2 months of age in Canada, but those less than 6 months of age are too young to have their primary pertussis series completed (1,4–6).

1.2 Respiratory Tract Infections in Inuit Infants

Respiratory tract infections (RTIs) are a long-standing public health concern in Canada's northern communities (7). Inuit infants and children have higher rates of RTIs, and RTI-related hospitalizations early in life, compared to non-Indigenous infants and children. Upon diagnosis of severe RTI, Inuit infants are often evacuated to the South for acute care (8–12). The risk factors for RTIs among Canadian Inuit infants and children are multifactorial and include disproportionate levels of poverty, over-crowded and poorly ventilated housing, undernutrition, absence of potable water, exposure to second hand environmental tobacco smoke, and a harsh and changing Arctic climate. Many if not all of these are closely associated with the tremendous cultural shift brought about by colonialism (8,9,13–15). There is a paucity of research on infant pertussis in the Canadian Inuit community; the majority of the literature being on other RTIs such as bronchiolitis.

1.3 Management of Pertussis with Maternal Immunization

While it is imperative that the structural and environmental origins of RTI-related morbidity, hospitalization, and mortality of Inuit infants (less than 6 months of age) in Canada are addressed, vaccination does not require large-scale systemic change and promises immediate and evidence-based prevention of RTIs. One way to protect Inuit infants is by giving their mothers the tetanus, diphtheria, acellular pertussis (Tdap) vaccine while they are pregnant (16).

A maternal Tdap vaccination program was initiated in Nunavut in 2016 in response to an outbreak of 154 confirmed cases of whooping cough across 11 communities (16). At that time, the National Advisory Committee on Immunization (NACI) had a recommendation that pregnant women¹ in Canada be offered Tdap when there was an outbreak in their area. Despite the implementation of the maternal Tdap program, a subsequent outbreak of whooping cough occurred in Nunavut less than six months after the first was declared over (16). In February 2018 the NACI recommendation was revised and now *all* pregnant women in Canada are encouraged to receive a Tdap vaccination during every pregnancy (17). Although there is now an established maternal Tdap vaccination program in Nunavut that predates the revised recommendation by two years, as well as the ongoing maternal influenza immunization program in place since 2007, there have been no empirical studies undertaken to determine the acceptability of maternal immunization among Inuit women and healthcare providers.

1.4 Immunization Coverage and Determinants in Inuit Population

Immunization data for Indigenous populations is unavailable at a national level in Canada (18). Many limitations to accessing current and accurate Indigenous immunization surveillance data exist including variations in the proportion of

¹ It is important to acknowledge from the outset that the literature about immunization during pregnancy involves heteronormative terminology, such as “maternal immunization” and “pregnant women”. In an effort to accurately reflect the work of the original authors cited in this thesis, as well as the language that participants in this project used, I too refer to pregnant people as “women” and immunization during pregnancy as “maternal”. I use “pregnant people” where possible/appropriate to describe future participants in this study to allow for the inclusion of any participants who may not identify as cisgender women.

communities that report coverage data to their region, differences in immunization data collection and reporting practices across First Nations and Inuit Health Branch regions, and receipt of vaccination off-reserve (19). While uptake of pediatric immunizations is reportedly high in some Inuit populations such as Nunatsiavut, vaccine coverage data are not available for Inuit women in particular. Indeed, more data regarding the immunization status of Canada's Arctic residents as a whole are needed (20). Information specific to the determinants of vaccination within the Canadian Inuit community is also unavailable and may not be captured by standard, non-Inuit indicators.

1.5 Project Rationale

Although there have been a few empirical studies of the attitudes, experiences, perceptions, and factors influencing vaccination behaviour of Canadian Indigenous women, this is the first to explore perceptions and experiences of pregnant Inuit women, experts, providers, and Community Health Representatives about maternal immunization. The project of which this thesis is one part, will also generate self-reported maternal immunization coverage data. A mixed method, sequential research design focused on Inuit knowledge provided rigorous qualitative data that laid the foundation for the generation of a panel of quantitative survey questions. In combination, these results as well as those that will follow as this project continues, have the potential to be useful to both clinical healthcare providers and community members. The results will also inform emergent and highly anticipated future maternal immunization programs (e.g. group B streptococcus (GBS), respiratory syncytial virus (RSV)) in the Canadian Inuit community.

Chapter 2: Study Background and Literature Review

2.1 Background

2.1.1 Vaccination

Vaccination is considered by the Centers for Disease Control and Prevention to be among the most important public health achievements of the 20th century because of its contribution to the prevention and control of infectious diseases around the world (21,22). The Public Health Agency of Canada touts low incidence and associated morbidity and mortality of vaccine-preventable diseases (VPD) (23). Evidence suggests however, that vaccine uptake in Canada is still suboptimal. In a 2013 report from the United Nations International Children's Emergency Fund (UNICEF), Canada ranked 28th out of 29 industrialized countries for health and safety because of its low immunization coverage (24). In recognition of this low coverage and without an integrated national vaccine registry to access, the Canadian government committed to improving Canada's ability to identify under- and un-immunized Canadians, and to improve vaccine access and uptake (25). Of particular interest was the identification of under- and un-immunized populations, and the socio-structural barriers associated with lower immunization access and uptake particularly among children and women of reproductive age (26).

2.1.2 Pertussis

Each year, an estimated 20-40 million people worldwide develop pertussis, a vaccine-preventable, bacterial RTI (27). Despite high rates of pertussis vaccination, there has been a notable resurgence of pertussis since the 1980s (4,28–30). Genetic evolution of *Bordetella pertussis*, pockets of under-immunization, and unanticipated rapidly-waning immunity from the acellular pertussis vaccine are cited as potential contributors to this resurgence (1,29,31,32). Pertussis infection carries a significant disease burden for all age groups; however, the effects can be life-threatening in young infants (1). In Canada, infants get vaccinated to protect them from pertussis as early as 2 months of age, but those less than 6 months are too young to have their primary pertussis series completed

(1,4–6). Significant complications of pertussis occur in infants ranging from apnea and pneumonia, to seizures and encephalopathy (2,3,33). The greatest risk for transmission of pertussis in infants comes from a household contact, such as a parent or sibling (1).

2.1.3 Preventive Strategies

There are three potential preventive interventions for preventing pertussis in infants too young to have completed their primary immunization series: neonatal vaccination, cocooning, and maternal immunization (1). The following section describes each in detail.

2.1.3.1 Neonatal Vaccination

Neonatal vaccination refers to adding an infant dose of the pertussis vaccine to the current schedule, meaning it would be given to the infant immediately after birth thus shortening the intervals between doses (29). A prospective, randomized controlled pilot study of immune responses to a birth dose of diphtheria, tetanus and acellular pertussis vaccine revealed it to be safe, but identified significantly lowered antibody response among infants that received the neonatal dose compared to the control group that received routine vaccination. This suggests interference, or the modulation of vaccine responses from concurrent or sequential administration of vaccines (34). Neonatal vaccination also leaves the new born infant vulnerable until they have responded to the first, or successive doses (29,35,36). Results from a recent randomized clinical trial suggest that a neonatal dose of acellular pertussis vaccine is safe, immunogenic, and has potential to reduce the risk of pertussis-related morbidity and mortality in infants whose mothers did not receive the Tdap vaccine during pregnancy (37).

2.1.3.2 Cocooning

Cocooning (the vaccination of family members and other close contacts), is another strategy that has been suggested to protect infants and children from acquiring VPD (1,5,38). While seemingly a reasonable strategy for reducing the transmission of pertussis infection, cocooning is cost ineffective, and logistically challenging to implement widely (1). Cocooning requires that women be vaccinated prior to hospital discharge postpartum, and that family members and other close contacts receive one a couple of weeks prior to infant contact (1). In the case of an infant born prematurely, or one whose mother either refused or was not offered the Tdap immunization in pregnancy, cocooning is one way of protecting infants from pertussis (1). As such, cocooning should be considered a complement to maternal immunization, much like neonatal vaccination (1).

2.1.3.3 Maternal Immunization

Maternal immunization has proven to be the most cost-effective, safe, immunogenic, and scientifically sound of all of the strategies aimed at preventing infant pertussis, and is therefore recommended as the first line of defence (1,4,5,29,35,39). By providing both placental transfer of maternal anti-pertussis antibodies (passive immunity) and indirect protection by vaccinating the mother, maternal immunization programs have a two-fold effect in mitigating infant pertussis (1,4,28,39). Randomized controlled trials support this, demonstrating both the efficacy of maternal antibody transfer and the safety of Tdap vaccination during pregnancy (1,40,41).

Tdap is an inactivated vaccine and therefore poses no theoretical risks to the safety of pregnant women (1). Pertussis does not increase morbidity in pregnant women the way that influenza does, so it can be given at a later stage of pregnancy (up to 37 weeks' gestation) (1,17). Another benefit to maternal pertussis immunization is the maturity of the placental transport system in the late second and third trimester (42). This provides the infant with higher levels of maternally-derived antibodies, which results in more robust protection (1). In Canada the first dose of infant Tdap is administered at two months of age (43). As such, antibodies only need to persist for the first four to six months to protect infants when they are most vulnerable (1).

Maternal Tdap immunization programs have been implemented as a strategy to prevent neonatal pertussis in the United States and United Kingdom because of morbidity and mortality from neonatal pertussis disease outbreaks (44). Approximately 54% of pregnant women respondents to a 2018 internet panel survey in the United States reported receiving a Tdap vaccine during their pregnancy (45). Average annual pertussis vaccine coverage in pregnant women for the 2017-2018 year was nearly 72% in the United Kingdom (46). Greater population coverage noted in the United Kingdom compared to the United States may be related to measurement with the coverage data reported automatically from medical records in the United Kingdom, and self-reported data (with about 14% of respondents with unknown Tdap vaccination status) in the United States (45,46). Despite these differences in coverage, Tdap immunization with every pregnancy remains a standard recommendation in both (47,48).

Beyond the maternal Tdap vaccine, maternal immunization against tetanus has been instrumental in decreasing the incidence of neonatal tetanus, an infection that is almost universally fatal in the developing world (49). Influenza vaccination during pregnancy has also shown to protect pregnant women who are at increased risk of pneumonia and hospitalization, improve fetal outcomes such as birth weight, and to protect the neonate from influenza during the first 6 months of life (50). Maternal immunization is now routinely recommended for women in every pregnancy in Canada, New Zealand, Belgium, Argentina, and Israel (35,51,52). Further, new vaccines against GBS and RSV are being developed specifically for use during pregnancy to protect the new born infant (53).

Recent outbreaks of pertussis have occurred in Saskatchewan (where the First Nations population was disproportionately affected, and a maternal Tdap program was temporarily initiated) (2010), British Columbia (2012), Yukon (2012), New Brunswick (2012) and areas of southern Ontario (2014) (17,32,54). A maternal Tdap vaccination program was initiated in Nunavut in 2016 in response to an outbreak of 154 confirmed cases of whooping cough (16). At that time, NACI had a recommendation that pregnant women be offered a Tdap vaccine when there was an outbreak in the area that they live. Shortly after this sizeable outbreak, another followed resulting in the extension of the maternal pertussis immunization program to the present. In February 2018, NACI revised

their recommendation to advise that *all* pregnant women in Canada receive a Tdap vaccination during *every* pregnancy. This means that even those multiparous women who may have received a vaccination in a previous pregnancy, no matter how recent, are recommended to receive another for their current pregnancy (17). Prior to this project, it was not known how a maternal immunization was perceived by pregnant Inuit women, Elders, community healthcare experts, providers, or Community Health Representatives (CHR).

2.1.4 Determinants of Maternal Immunization

Acceptability of maternal immunization is multifactorial and reflects both societal and individual values and beliefs (4). In non-Indigenous populations, concerns about maternal immunization commonly include lack of knowledge about the disease or vaccine, mistrust of immunizations, fear of needles, apprehension about side effects, and most significantly, safety concerns for both the mother and fetus (4,36). Pregnant women are likely to be reluctant to take any medications and vaccines are no exception (1). There is, moreover, concern that adverse events will be falsely associated with receipt of maternal immunization (1). There have been concerns raised in the vaccinology community about increased local reactions with repeated Tdap immunization (29). From an implementation perspective, maternal immunization also means the widening of some providers' scope of practice which may not have included immunization (1).

In a study of pregnancy-related immunization practices in South Australia, Wong and colleagues found multiparous women to be up to 68% less likely to receive an influenza vaccination while pregnant than their nulliparous counterparts (38). In their study, they also found women whose provider recommended a maternal influenza immunization to be statistically significantly more likely to have received it compared to those who received no such recommendation (38). In a cross-sectional study of the knowledge, attitudes, beliefs, and behaviours of pregnant women in Canada, nearly 90% of participants reported that they would get the maternal Tdap vaccine were it recommended to them by a physician (36).

A study in the United States of attitudes and acceptability of a maternal Tdap vaccine among pregnant women from a demographic population at high risk for infantile pertussis infection revealed generally positive attitudes toward the vaccine. Despite support and acceptance of the vaccine, 63% of the women surveyed were concerned about its safety and 48% that it would be ineffective in protecting their infant from pertussis (5). In a cross-national study of pregnant Australian women published by Wong and colleagues comparing women with English as a second language to those whose first language was English, found the former to be nearly 5 times less likely to have received a pertussis vaccination either postnatally or within 5 years of their pregnancy (38).

2.1.5 Colonial History

While it will not be the focus of this section, it is important to acknowledge that Inuit history in the Arctic environment predates the arrival of Europeans and continues despite the devastating impacts of colonialism (55). Prior to European contact, Inuit ancestors were seasonally nomadic and observed a subsistence-oriented way of life in small communities that relied primarily on natural resources (55–57). Contact between Inuit ancestors and European explorers in the Arctic began as early as the 1500s and continued through the mid-nineteenth century (55,58). The entry of European whalers in the 1850s impacted trade, land use, and particularly Inuit health, which deteriorated upon exposure to infectious diseases such as measles, influenza, syphilis, and tuberculosis (14,55,59,60). When fur traders and missionaries arrived in the Arctic in the early 1900s, the Inuit culture of hunting and fishing quickly changed to one of trapping and trading (14,55,59,60). As Inuit hunters began fur trading, their families started eating less country food, which led to substandard nutrition and health (14). Despite the flourishing trade in the 1920s, fox fur prices declined sharply thereafter, making trapping unsustainable for many families. This resulted in the widespread starvation of Inuit whose livelihoods had become dependent upon European economic forces and goods (14,56). The early 1900s also marked the arrival of the Royal Canadian Mounted Police (RCMP) in the eastern Arctic, and the establishment of the justice system in the 1920s (55,58). This introduction

was on the terms of the police, missionaries, and traders, and not on those of the Inuit that they purported to protect (55).

During the Second World War and at the beginning of the Cold War, both Canadian and American governments worked on defense projects in the North which resulted in an influx of military traffic to the Canadian Arctic. With this influx came an increase in infectious disease (i.e. influenza, polio, pneumonia, meningitis, typhoid fever, scabies, tuberculosis) morbidity and mortality (14,60). The handling of tuberculosis epidemics in Northern communities is an especially egregious example of medical colonialism resulting in social suffering among Inuit families and communities. Upon infection, Inuit were sent to sanatoria in southern Canada for extended periods of time. Some were neither heard from nor seen again and are assumed to have died in the foreign setting of a southern hospital (14,58).

Around the same time (circa the 1950s), the federal government forced resettlement of Northern Canada under the pretense of protecting Canada's sovereignty, opening Hudson's Bay Company trading posts, and protecting Inuit living remotely through policing, educating, and providing healthcare to them (14,56,61). Forced relocation of Inuit into permanent settlements and the killing of Inuit sled dogs are cited as being among the most flagrant government interventions of this time with devastating social costs and disruptions (14,62).

In the 1950s, the government also began removing Inuit children from their homes, families, and communities, and sending them to compulsory residential schools where they were stripped of their language, culture, and identity in favour of the Canadian mainstream (61–64). The impact of federal residential and day schools on Inuit has been multifarious and intergenerational. Some of the schools where Inuit children were sent were located thousands of kilometers from their home communities and resulted in extended periods of time separated from their loved ones (64). In an attempt to lessen that separation, some parents followed their children to communities with hostels where they stayed to be nearer to them while at school but this posed a challenge as they previously subsisted off of the land and water (64).

According to the Truth and Reconciliation Commission of Canada, the individual impact of residential schools in the North exceeds the impact elsewhere because of the

size of the Indigenous population in the northern territories compared to the rest of the country (64). The residential school system in the North is also very recent, so many Survivors and even some of their parents are still alive and therefore the intergenerational impacts and legacy of schools are especially tangible (64). Despite this history of racism, discrimination, and cultural genocide, the courage, determination, and resiliency of First Nations, Metis, and Inuit is a tremendous force towards health and independence in Nunavut and across Canada (64,65).

2.2 Literature Review

2.2.1 Introduction

It is my intention in this section, to review and summarize available evidence of Indigenous women's knowledge, attitudes, beliefs, and behaviours about maternal immunization, as well as those of healthcare providers working in Northern communities. The Inuit knowledge system is transmitted orally between generations using Inuktitut dialects to animate teachings through storytelling (66). It is therefore oxymoronic, according to Mi'kmaw scholar Dr. Marie Battiste, to write a literature review of Indigenous knowledge as it is found in the shared experiences and teachings between people, and not in books or research articles (67). Conducting a literature review about Indigenous knowledge also suggests that Eurocentric research can explain Indigenous ways of knowing. This is problematic according to Dr. Battiste because Indigenous knowledge is its own system that may not be fully understood from a Eurocentric perspective (67). I would like to preface this literature review with the admission that it is limited in both of the ways that Dr. Battiste suggests.

In the absence of any literature about the knowledge, attitudes, beliefs, and behaviours of Inuit women and Northern healthcare providers about maternal immunization specifically, I summarize studies and grey literature that was most relevant to my objectives in this section. The studies reviewed herein are peripheral to the study population and intervention of interest.

2.2.2 Methods

To complete the literature review for this project, I conducted a search of PubMed that was originally developed with the assistance of Darlene Chapman, a health science librarian at the Izaak Walton Killam (IWK) Health Centre, and Robin Parker, a health science librarian at the W.K. Kellogg Health Sciences Library at Dalhousie University. This search was then translated for entry into EBSCO Host (using the Cumulative Index to Nursing and Allied Health (CINAHL) and PsychINFO databases), and Scopus (for the comprehensive search strategy see Appendix 1). All searches were saved as of January 19, 2019, and weekly e-mail alerts were set for any new, relevant literature although this yielded no additions to the review. Reference lists of relevant studies were checked to ensure that all related citations were included in the review. I also searched beyond academic literature for grey literature, defined by Hartling and colleagues as being produced by any organization whose central purpose is not publishing (68). I downloaded all search results to Covidence, (a web-based software platform that streamlines the review process) where I proceeded to screen and review available literature (69).

Inclusion criteria for this review was literature about Indigenous (First Nations, Metis, and Inuit) women's perspectives of maternal immunization as well as those of healthcare providers working in Northern communities. During the screening process as it became clear that no such studies existed, I included articles that made reference to Indigenous women and vaccination more generally. No date restrictions were applied to the searches; however, grey literature (i.e. vaccine recommendation statements, updates to schedules, immunization guidelines) older than 5 years or for which there were newer, more updated recommendations, was considered outdated and was excluded. Much of the literature about immunization involving Indigenous research perspectives originates from First Nations, Native Americans, and Indigenous peoples living in Australia and New Zealand (70). While these provided a global context of the subject matter, they were ultimately deemed ineligible for this review as they were not specific to the Canadian Indigenous population.

2.2.3 Results

Combined search results, and records identified through other sources (i.e. stakeholders, relevant reference lists, Canadian First Nations, Metis, and Inuit research organizations, hand searches, etc.) yielded a total of 1,432 sources. Duplicates (n=459) were removed once all sources were downloaded into Covidence. I completed a title and abstract review of 973 records and excluded 1 published in a language other than English, 558 about an irrelevant population, 365 that reported on an irrelevant subject, 32 due to their outdatedness, and 4 for which there was no abstract or full text available despite extensive searching. This left 13 full-text articles that were assessed for eligibility. Of the 8 excluded after full-text review, 6 were for reasons of subject irrelevance, 1 based on an irrelevant population, 1 on an inappropriate study design (a letter to the editor that made no mention of community perceptions about immunization), and 1 because it was too similar to another that was included in the review (written by the same authors, in the same communities, using the same data, but reported in a different journal and under a different title). In the absence of any studies relating directly to the knowledge, attitudes, beliefs, and behaviours of Inuit women and their healthcare providers about maternal immunization, the 4 sources included in the review were deemed to be most relevant as they detail attitudes, experiences, perceptions, and other factors influencing vaccine behaviour among Indigenous and Inuit women (for the literature review flow chart see Appendix 2). No studies were found that detailed knowledge, attitudes, beliefs, and behaviours of healthcare providers working in the Inuit community about maternal immunization.

2.2.4 Determinants of Immunization Among Indigenous Women

Qualitative data from interviews with First Nations mothers in the Sioux Lookout Zone in North-western Ontario revealed suboptimal childhood immunization uptake to be related to misunderstanding, severe adverse events following immunization, and the influence of vaccine-hesitant parents and Elders (71). Despite believing that immunizations were important, mothers in this study admitted that they had limited

knowledge of how vaccines worked, which infectious diseases they covered, where VPDs came from, and how they are transmitted (71). In addition, participants reported missed opportunities to get their children vaccinated because of misinformation from healthcare providers about whether children were eligible to get vaccinated when sick (71). Stories about adverse events following immunizations circulating through their communities were identified as having a negative impact on vaccine uptake (71). Vaccines were reported to be perceived in the community as causing rather than preventing illness (71). Mothers in this study reported that Elders in their communities were not supportive of immunization. They speculated that the beliefs held by Elders were perhaps related to distrust of the healthcare system and providers more so than of vaccines (71).

A qualitative study of factors influencing H1N1 vaccine behaviour among Manitoba Metis in Canada found geographic variability in self-reported rates ranging from 83% in remote northern communities to 29% in the rural western region of the province (72). Many determinants of vaccination in this population were identified as at once persuasive and dissuasive by participants. Activities of health authorities (i.e. prioritized dissemination of pandemic and vaccine-related information to Aboriginal people) for example were associated with receipt of the vaccine among participants who identified H1N1 as a significant threat to Aboriginal people. Refusal was reported among participants who were sceptical that through prioritization, the government was testing the vaccine on Aboriginal people before making it available to the general population (72). Other factors influencing vaccination behaviours in this study population included “bandwagoning” (positive influence of other community members getting vaccinated), the recommendation of friends and family members, healthcare provider recommendations, knowledge deficits, lack of information about vaccines, and anxiety surrounding the safety of a novel vaccine. Participants often framed their anxieties about the safety of the H1N1 vaccine in the context of colonialism, citing concerns that this was actually an experiment to eliminate Aboriginal people (72). A pregnant Metis woman in this study expressed feeling coerced into getting vaccinated by her healthcare providers, and later came to regret her decision (72).

A high degree of acceptance of the human papillomavirus (HPV) vaccine was found among Inuit women who had heard of the HPV vaccine in Nunavik, Quebec (73).

Cross-sectional survey results revealed that the majority of these women believed the HPV vaccine to be safe and would be interested in having their child(ren) vaccinated for HPV (73). Doctors and nurses were identified as influential sources of vaccine-related information (73). While vaccine uptake may be seen as promising for the potential success of an immunization program in this population, results from this study indicate that uptake may be the result of immunization acceptance due to the historic power differential between Inuit and their health care providers, as well as the active role that community health nurses play in the region (73).

A quantitative survey of Inuit parents and caregivers developed to provide Health Canada with missing data in this population, corroborates many of the findings in the previous qualitative and mixed methods studies (74). Inuit parents in this study identified desire to protect their child from disease and keep them healthy as paramount in vaccine decision-making. Issues of accessibility (including cost), beliefs that vaccines are unnecessary and ineffective, desire to delay immunization until children are older, and forgetting were cited by parents and caregivers whose children were not vaccinated as reasons for this decision (74). The majority of parents and caregivers of Inuit children surveyed were confident in the vaccine advice provided to them by trusted community healthcare providers and believed it to be very important that all children get vaccinated (74). Survey results indicating hesitancy about vaccine safety among Inuit parents, and concerns related to adverse events, are consistent with the previously mentioned qualitative findings (74). A strong majority of Inuit parents in this survey held positive perceptions about childhood vaccination but were concerned that vaccines can cause disease. Nearly half of participants believed that traditional medicines can replace vaccination (74). Inuit parents surveyed identified health professionals as the most trusted sources of vaccine-related information and had no preference for the source to be Aboriginal or non-Aboriginal (74). Younger Inuit caregivers tended to be more apprehensive than older caregivers about childhood vaccination (74). Concerns about adverse events and misperceptions about immunizations, were also more common among younger Inuit caregivers (74).

While substantial data are accumulating about the knowledge, attitudes, beliefs, and behaviours of Canadian, American, and European women regarding immunization

during pregnancy, data are lacking for Indigenous populations. Based on this review, literature specific to the knowledge, attitudes, beliefs, and behaviours of Inuit women and healthcare providers working in Northern communities about maternal immunization does not exist. This kind of literature is critical in guiding practice, policy, and public health initiatives.

2.3 Conclusion

In summary, RTIs like pertussis pose an omnipresent threat to the health of Canadian Inuit infants. Several protective strategies have been proposed to protect infants, however maternal immunization is recommended as the first line of defense against pertussis and has the potential to thwart future outbreaks of pertussis, and other VPDs in this population. Awareness and understanding of Inuit health in its historical, anthropological, and community context are an integral part of undertaking research in the Canadian Inuit community. Inuit knowledge is embedded in the shared experiences and stories of people and not necessarily in biomedical databases like the ones I searched in this section (67). I found no studies detailing the knowledge, attitudes, beliefs, and behaviours of Canadian Inuit women about maternal immunization. Based on a few peripheral studies reviewed for this project, determinants of immunization specific to the Indigenous population may include but are certainly not limited to: stories of adverse events circulating in the community; the opinions of family members, friends, and Elders; healthcare provider recommendation; rurality; perceptions of severity of the VPD; issues related to safety of the vaccination; and historic power differentials between Indigenous women and their healthcare providers. In doing this exploratory project, I sought to engage with the community to learn about how maternal immunization programs have been implemented, are received, and perceived among Inuit women and healthcare providers working in Northern communities specifically.

2.4 Relationship to this Work

Locating myself in relation to this research project, and acknowledging my associated subjectivity is an important step in decolonizing this work (75). My name is Antonia Maria Di Castri and the arrival of my great grandparents in Canada played a direct role in the displacement and marginalization of the Indigenous people to whom it rightfully belongs. Like many other Ukrainian immigrants, my maternal great grandparents settled in Alberta. Two generations later, I was born and raised in the city of St. Albert, immediately North of Edmonton on Treaty 6 Territory. My upbringing afforded me the comfort of a small middle class community, access to the opportunities associated with the big city, and refuge from both at our family cabin just a few kilometers from the homesteads of my beloved Baba and Dido.

My fondness for my Ukrainian and Italian heritage was compounded by my involvement in the Ukrainian community in Edmonton and encouraged by schoolteachers insistent on perpetuating the idea of Canada's multicultural mosaic. We were taught by our teachers to be proud of our ancestry and celebrated as diverse despite our obvious Euro-Canadian homogeneity. History began with the arrival of the explorers who were the protagonists of the Canadian creation story as told to us in school and Indigenous people were only ever cast in secondary and supporting roles. Despite my parents' best efforts to impress upon us otherwise, the reality of my social and geographical location made it easy to categorize Indigenous issues as happening elsewhere and in another time. My relationship to Indigenous people was limited to museums and art gallery exhibits, news stories, and historical fiction.

When it came time to go to University, I moved to Antigonish, Nova Scotia to pursue my undergraduate degree in nursing at St. Francis Xavier University. My favourite part of clinical was (and is still to this day) research day – where we would take an afternoon to get to know everything that we could about a patient. This was done by reviewing their charts, doing in-depth personal interviews, and fulsome physical assessments. Any time that I worked with an Indigenous patient, I felt drawn to their stories and curious about the ways that they understood their health and wellness. In particular, I enjoyed working with them to identify and piece together the complex and

intersecting determinants that coalesced in their clinical presentation. This was when I really started exploring Indigenous health beyond what we touched briefly on in class, and my awareness of the advantages I enjoy simply by the accident of birth sharpened considerably.

At the time when I started working on this project for my master's thesis, it felt like a serendipitous opportunity to merge my experience in vaccine research with my interest in Indigenous health. I now recognize it for the tremendous privilege that it has been. I have spent the past two years learning at an unparalleled velocity about community health, epidemiology, and the dissonance of doing Indigenous health research in an academic setting that historically upholds one way of knowing and doing over the other. I have navigated many tensions as a result of this dissonance: between Indigenous methodologies and research ethics requirements; the flexibility required of a project of this complexity, scale, and nature, and the rigidity of the protocol I naively developed for it; the time and budget required to truly develop the kinds of reciprocal and respectful relationships that ought to be foundational to projects like this one, and the limits of a two year master's program with finite funding; my beliefs about maternal immunization as a burgeoning epidemiologist and Registered Nurse, and those of participants with different professional, personal, and cultural backgrounds; and my assumptions as a non-Indigenous person doing this work, and the experiences of Inuit participants in this project, to name a few.

Beyond contributing to the rigour of this project, in practicing careful reflexivity about my privilege, power, biases, and responsibilities as an ally, I hope to serve and support the Inuit community in good and responsible ways through this work, and beyond it.

Chapter 3: Research Objectives

This thesis project is part of a much broader research study, which seeks to determine the knowledge, attitudes, beliefs, values, and behaviours of pregnant Inuit women, Elders, community healthcare experts, providers, and CHRs about maternal pertussis immunization in Nunavut and Nunatsiavut. The research question for this thesis project was: What are the awareness, attitudes, beliefs, values, behaviours, and experiences of pregnant Inuit women, Elders, community healthcare experts, healthcare providers, and CHRs in Nunavut about maternal pertussis immunization?

The main objectives of this thesis project were:

1. To provide detailed qualitative findings about the awareness, attitudes, beliefs, values, and behaviours of pregnant Inuit women, Elders, community healthcare experts, providers, and CHRs about maternal pertussis and influenza immunizations.
2. To determine which factors influence whether pregnant women in Nunavut are or are not vaccinated.
3. To generate a panel of survey questions based on qualitative data collected, to be validated, tested, and circulated to pregnant Inuit women in subsequent phases of this study, outside the scope of this thesis project.

Specific outcomes of the proposed project were:

1. Qualitative synthesis of the awareness, attitudes, beliefs, values and behaviours of pregnant Inuit women, Elders, community healthcare experts, providers, and CHRs relating to maternal immunization in Nunavut (Objectives 1 & 2).
2. Qualitative synthesis of the barriers and facilitators accessing and delivering maternal immunization programs in Nunavut (Objective 1).
3. Qualitative synthesis of the influence of social, historical, political, and economic determinants of maternal immunization (Objectives 1 & 2).

Chapter 4: Methods

4.1 Study overview

A mixed methods (MM) research design was decidedly appropriate for this project because of the nature of the research question and our desire to embrace the complexity of the research problem instead of attempting to reduce it (76,77). This selection of methodologies based on the research question is typical of the pragmatic approach (78,79). Qualitative data alone would have been insufficient because we were interested in quantifying rates of maternal immunization, determining perceptions about maternal immunization, and establishing confidence and significance at the population-level. Similarly, quantitative data alone would have been insufficient because determinants of maternal immunization are multifactorial and contextually nuanced. Furthermore, we were uncertain about which survey questions should be asked and which variables should be measured or controlled for (79).

MM research combines elements of quantitative and qualitative methodology to increase the breadth and depth of understanding of the research objectives and results, and permit corroboration of results across methods (79). In multi-phase MM designs, the qualitative and quantitative components of the study are sequentially aligned, with each new approach building on what was learned previously to address a central program objective (79). The mixing of methods or integration of qualitative and quantitative aspects in this project was done using the connection model wherein the quantitative approach is built upon the findings of the qualitative approach (76,78). There is a paucity of literature detailing how to link two batteries of qualitative data collection from a single study as most material is focused on mixing qualitative and quantitative results. In this thesis, I chose to analyze the qualitative phases separately, and for the discussion to also be a point of interface where I present my findings along with those of our colleagues in Nunavut, and explain how each component of the project contributes to answering the research question (80). In so doing, I was able to describe the awareness, attitudes, beliefs, behaviours, experiences, and values in a comprehensive way and offer the perceptions of pregnant Inuit women and an Elder, in addition to community healthcare

experts, providers, and CHRs in Nunavut about maternal immunization with depth and dimension (80).

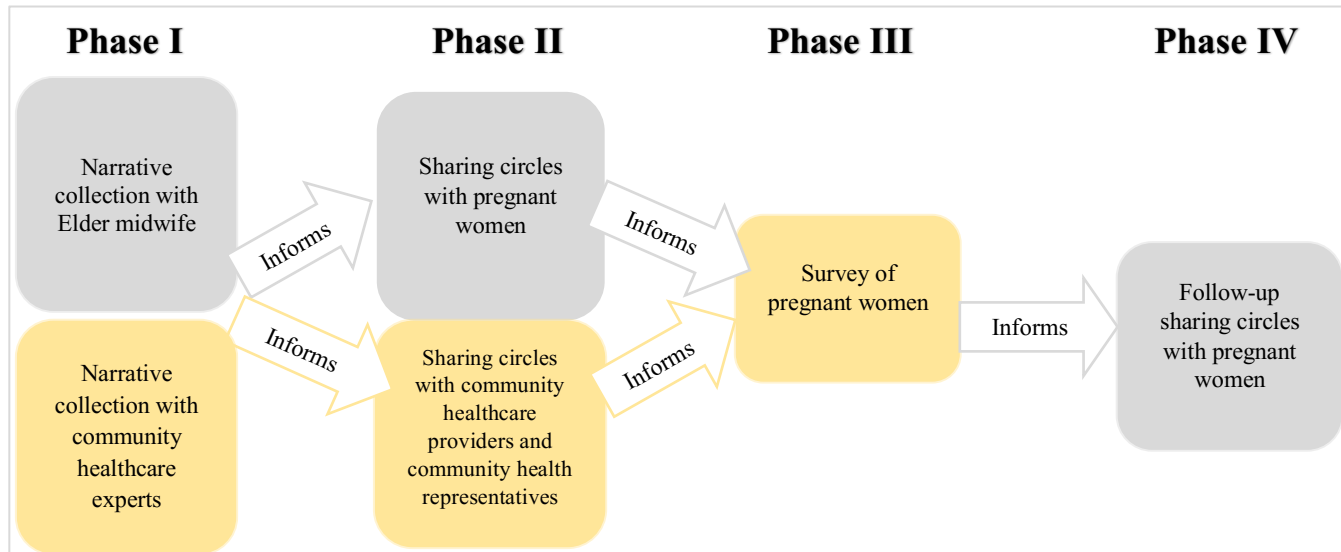
This thesis comprises a portion of a broader multi-phase MM project. The first phase of the broader project involved individual narrative collection from community Elders, healthcare providers (i.e. family physicians, nurses, and midwives), and members of the public health department (collectively, community experts). The conclusions based on the results of the first phase led to the formulation of the design components for the second phase (79). The second phase involved sharing circles with pregnant women, and virtual sharing circles with community healthcare providers. The third phase will involve a quantitative survey delivered to pregnant people, based on, and aimed at evaluating the findings from the previous two phases (79). The fourth phase of the project will consist of follow-up sharing circles with pregnant people in the community to explore more fully the findings from the first three phases. Final inferences will be based on the combined results from all phases of the project.

My thesis involved qualitative data collection and analysis from the individual narrative collection with community healthcare experts (part of phase one) and sharing circles with community healthcare providers and representatives (part of phase two). While the guides that I developed for this thesis project were also the basis for individual narrative collection with an Elder midwife, and for sharing circles with pregnant women, the qualitative data collection and analysis from those parts of this project were done by our colleagues Dr. Gwen Healey and Ceporah Mearns at the Qaujigiartiit Health Research Centre (QHRC) in Iqaluit, Nunavut. Using all of these data, I generated a panel of survey questions (part of phase three) as the third and final component of my thesis project, and I trace the subsequent steps in the validation, testing, and administration of the survey. Using the mixed methods notation system, this project is a $QUAL^2 \rightarrow quant$ design (81). The highlighted portion of Figure 1 is a visual representation of the scope of my thesis in the context of the broader project of which it is a part.

From a practical perspective, data collection and analysis from community healthcare experts, providers, and CHRs, and the generation of a panel of survey questions based on these data was a reasonable undertaking for a master's thesis project. As a non-Indigenous student and healthcare provider, who speaks neither Inuktitut nor

Inuinnaqtun, it also felt more appropriate and ethical to be working with community healthcare experts, providers, and CHRs instead of with Elders, and pregnant women.

Figure 1. Multi-phase mixed methods design²



4.2 Research Principles

Critical to all health research involving Indigenous peoples (including Inuit), is the decolonization of Eurocentric research design and execution, and the refocusing of the research process on Indigenous world views (82). This research is based on the principles of Two-Eyed Seeing/*Inummarik*, Participatory Action Research (PAR), and is informed by *Inuit Qaujimagatunqangit* (IQ). These are **not** methodologies, but rather, the principles that guided how the research was, and continues to be undertaken. We were keenly aware of our non-Indigenusness as we undertook this project and have learned from our Northern co-investigators that these principles are important. We incorporated them to adhere to the new standard of excellence in Inuit research. In this section, each principle is defined and followed by concrete examples of how we incorporated them.

² Boxes in yellow depict the scope of this thesis project

4.2.1 *Inummarik*

The Two-Eyed Seeing (*Etuaptmumk*) approach came from the teachings of Mi'kmaw chief Charles Labrador, was coined by Mi'kmaw Elder Albert Marshall, and refers to learning to see from one eye with the strengths of Indigenous knowledge and ways of knowing, and from the other, with the strengths of Western ways of knowing (83,84). Learning to use both eyes together to explore issues and initiate projects combines strengths from both world views to strengthen any undertaking. The Two-Eyed Seeing approach is being increasingly incorporated in various iterations across provinces and territories. In 2010, it was applied by the Government of Nunavut's Department of Environment to provide educational opportunities for youth in Nunavut (85), and more recently, it was included as a strategic direction in the Canadian Institutes of Health Research (CIHR) Institute of Aboriginal Peoples' Health Strategic plan for 2014-2018 (86). According to our Northern co-researchers, *Inummarik* may be considered the Inuit equivalent to the Two-Eyed Seeing approach. In an essay about self-sovereignty in Classic Inuit Thought, Rachel Qitsualik explains that to be *Inummarik*, is to be a free and sovereign human, aware and respectful of others' self-sovereignty (87). This dual understanding, or ability to walk in two worlds, is critical to sustainable and self-perpetuating health (87).

We initiated this project with Northern co-investigators in response to a call from the CIHR for improved immunization coverage initiatives that explore barriers to vaccination access and uptake, with particular emphasis on vaccination coverage of women of reproductive age, First Nations, Inuit, and Metis, and newcomers to Canada. We asked our colleagues in Nunavut whether they would be interested in forging a partnership for an application on a topic of their interest and need in the community. Maternal immunization, especially with the maternal Tdap vaccine was identified as one such topic. Our research question lays the foundation for a project based on the principle of *Inummarik*. Both Northern and Southern contingents of the research team are able to offer strengths in Inuit knowledge, and in scientific inquiry respectively. An example of how the two ways of knowing have come together to strengthen this project is seen in our choice of mixed methodology. The qualitative component of this research (narrative

collection and sharing circles) deviates from the typical analytical approach used in Western research studies and honours the Inuit tradition of using storytelling as a way of conveying experience. The quantitative survey component is more traditional in Western research studies but is complementary to the qualitative component as it is based on and aimed at evaluating the findings from the previous phases. Neither of these practices are seen as more or less valuable, but in combining them, as is the practice in Two-Eyed Seeing, or *Inummarik*, findings are strengthened and will be useful to both Northern and Southern stakeholders alike.

4.2.2 Inuit *Qaujimajatuqangit*

Inuit Qaujimajatuqangit (IQ) is a term used to convey Inuit epistemology that translates literally as, “that which Inuit have always known to be true” (88). In addition to being foundational to personal and collective health in Inuit communities, the system of beliefs and knowledge comprised within IQ has sustained Inuit throughout history and will continue to do so for generations (88). In order to do this research study in a good way that was and one that continues to be grounded in Inuit ways of knowing, we have adhered to the concepts of *Piliriqatigiinniq* (the concept of working together for the common good), *Iqatautsiartuq* (the concept of cooperation), and *Ikajurniq* (the concept of helping) (70,88).

The concepts of *Piliriqatigiinniq*, *Iqatautsiartuq*, and *Ikajurniq* were emulated early in this research project as we worked together with our Northern co-researchers, specifically Dr. Gwen Healey Akearok (Executive and Scientific Director of the QHRC), and Dr. Kim Barker (the Chief Medical Officer of Health with the Department of Health in Nunavut at the time this study was initiated) to respond to concern about repeated pertussis outbreaks in Nunavut, and inequitable VPD distribution. We continued to ground this study in IQ using these concepts as we collaborated with our Northern co-researchers on the study design, protocol, and associated documents. In October 2018, Dr. Joanne Langley and Jessica McCarthy (a previous Project Manager on this study) presented the project to the Committee of Elders tasked with bringing the IQ perspective to each project and program undertaken by the Government of Nunavut. I also received feedback from Angela Michielsen (a Policy Advisory for Inuit Societal Values with the

Department of Culture and Heritage in Nunavut) and Shuvina Mike (the director of Inuit Qaujimagatuqangit in the Department of Culture and Heritage in Nunavut) about the appropriateness of the virtual sharing circle consent form and guide. As per S.M.'s recommendation, we are continuing to assemble an advisory committee with health as well as cultural expertise to review future study documents, to ensure that our documents are culturally sensitive and topically relevant.

The sequential design of the project is an example of IQ personified. Instead of preparing all of our data collection instruments prior to initiating the study, we proceeded (and continue to proceed) one study phase at a time (see Figure 1). The expertise of the community healthcare experts, and Elder midwife that participated in individual narrative collection was drawn upon to adjust the sharing circle guides for the subsequent phase of the study. Information learned by our colleagues and ourselves in the sharing circles with pregnant women, healthcare providers, and CHRs, as well as in the individual narrative collections with experts, dictated the panel of survey questions proposed in the quantitative section of this thesis, and recommendations made by participants about how to proceed logistically will continue to inform our approach.

4.2.3 Participatory Action Research

Participatory action research (PAR) principles guide research that explores social issues with marginalized populations and is therefore appropriate for conducting research with Inuit women. PAR is very closely related to Indigenous philosophies because of its valuing of community engagement, learning through doing, shared decision-making, and empowerment through working together (89). PAR is also based on principles of equity, social justice, democracy, and reciprocity, and takes a non-hierarchical approach to decision-making by engaging both the researchers and participants in the process (89). Relationships are characterized by open communication, acknowledgement that all participants' contributions are valued, and collaborative decision-making during the research and knowledge dissemination processes. In this project, PAR is **not** thought of as a specific method, nor is it the research design. It is used in concert with other methods to help make this research more relevant and meaningful to the communities involved (90).

As aforementioned, the Northern contingent of the research team, particularly the previous Chief Medical Officer of Health was involved since the study's conceptualization, and the current Chief and Deputy Chief Medical Officers of Health continue to be involved throughout the research processes and will be the primary beneficiaries of the research findings. We are committed to the relationships that we forged in the undertaking of this project and travelled to Iqaluit to meet team members and healthcare providers in person from the outset. Each step of this research process involved transparency and open communication with these, and other decision-makers and stakeholders. Additionally, this project provided local employment as data collection with Elders and pregnant women were all done locally. A community-based bilingual Researcher from the QHRC facilitated individual narrative collection with the Elder midwife and sharing circles with pregnant women in Nunavut. We anticipate hiring a community-based bilingual Research Assistant (RA) when the time comes for the survey to be administered to pregnant women across Nunavut. The process of hiring an RA will be actualized by the research team after my tenure as a student in the Department of Community Health and Epidemiology has concluded.

All participants in the narrative collection and sharing circles were invited to review this document prior to its final submission to the Faculty of Graduate Studies. I also offered to present these results to any participants who preferred to learn about them in this way. Due to their responsibilities related to the Coronavirus Disease of 2019 (COVID-19) pandemic, most participants were unable to provide their feedback by the time of submission. As such, I have sought an embargo for this work to ensure that all those involved have the opportunity to review it in whatever way is most convenient for them.

4.3 Individual narrative collection with community healthcare experts

In this section, I discuss individual narrative collection despite citing some methodological literature for key informant interviews. We learned from our Northern co-researchers that narrative collection methodology would be more appropriate than key informant interviews with community healthcare experts. Narrative collection is a

representation of participants' experiences as conveyed by participants to facilitators one-on-one through storytelling

4.3.1 Individual narrative collection sample

4.3.1.1 Sample size

No formal sample size estimation was calculated for individual narrative collection with community healthcare experts. Purposeful sampling is when researchers engage participants based on their experience with maternal immunization, and willingness to share their insights (91). Purposeful sampling was used for the individual narrative collection to arrive at a reasonable sample of community healthcare experts. Criterion sampling is a type of purposeful sampling that is especially useful for identifying cases that are information rich, and that can provide qualitative insight into quantitative data (92). For this project, we sought maximum variation in a systematic way, using criterion sampling with specific pre-defined criteria detailed in the sampling frame. Our sampling frame identified a diversity of healthcare providers by region (Qikiqtaaluk, Kivalliq, and Kitikmeot), community(ies), and profession (including community health nurses, community health representatives, nurse practitioners, midwives, and physicians). Our intention in using this approach, was to get the breadth of discussion and diversity needed to be able to answer our primary research question and to meet our objectives. Snowball sampling is a subcategory of purposeful sampling where participants are asked to identify others in their social network who meet inclusion criteria (91,93). This type of sampling is especially useful when conducting a study of this nature, where the population of interest may be difficult to reach (93).

Michael Best (M.A. in International and Intercultural Communication; the Project Manager at the time of data collection for the individual narrative collection) used purposeful and snowball sampling to identify community healthcare experts to participate in this study. M.B. sent an email (Appendix 3) to potential participants summarizing the project, inviting them to participate, and asking them to please share the project

information with any colleagues who they thought might be interested and eligible to participate.

4.3.1.2 Inclusion criteria

Inclusion criteria for the individual narrative collection were as follows: community healthcare experts including family physicians, nurses, midwives, and other employees acting in manager, coordinator, director, or administrator positions in the area of public or prenatal health in Nunavut; consent obtained prior to participation; access to telephone or computer; and willingness to be involved and available for up to two hours.

A diverse sample of ten community experts participated in individual narrative collection. Among them were birth centre managers, nursing staff consultants, communicable disease specialists, coordinators of medical travel, maternal newborn services, and community health development, public health and health programming supervisors, and midwifery program administrators. Some of the participants were born and raised in Nunavut, while others moved there in adulthood and had been working in their positions for as few as four months and as many as 17 years. Experts had practiced in a variety of communities across the Kivalliq (Rankin Inlet, Arviat, Coral Harbour, Baker Lake, and Whale Cove), Qikiqtaaluk (Pond Inlet, Iqaluit, Arctic Bay, Grise Fiord, Sanikiluaq, Kinngait, Sanirajak, Kimmirut, Qikiqtarjuaq, Clyde River, Igloolik, Pangnirtung, and Resolute), and Kitikmeot (Gjoa Haven, Taloyoak, Kugaaruk, Kugluktuk, and Cambridge Bay) regions.

4.3.2 Conduct of the individual narrative collection

4.3.2.1 Ethical considerations

This portion of the project was not invasive and had minimal risk associated with it. Any harm associated with participating in narrative collection would have been indirect, and a result of sharing thoughts and stories about, and experiences with maternal

immunization. Participants were informed that should they feel uncomfortable answering a question asked during the narrative collection, they could elect not to.

This study and associated materials were designed and continues to be conducted in accordance with recognized ethical frameworks that include Ownership, Control, Access, and Possession principles of the National Aboriginal Health Association, the Tri-Council Policy Statement (TCPS) 2: Chapter 9 about Research Involving First Nations, Inuit and Metis Peoples of Canada, and the Nunavut Research Institute protocols for conducting research. One example of how this was operationalized in this project was by signing a Research Agreement with our Northern co-researchers, as well as incorporating elements of Chapter 9 of the TCPS 2 into our consent forms appended to this thesis project. We successfully obtained a research licence from the Nunavut Research Institute (NRI), the Nunatsiavut Government Research Advisory Committee (NGRAC), and the Nunatsiavut Health Research Ethics Authority. We also have Research Ethics Board approval from St. Francis Xavier University, and the IWK Health Centre. No changes were made to the protocol or any of the study materials without REB approval.

4.3.2.2 Consent process

Along with his recruitment email to potential participants (Appendix 3), M.B. attached a consent form (Appendix 4) to provide healthcare experts with more information regarding the study, as well as any foreseeable harms and potential benefits associated with participating. He instructed interested participants to read and sign the consent form if they were interested in participating, and scheduled participants for narrative collections at whatever date and time was most convenient for them.

A reaffirmation of consent was obtained immediately prior to beginning each narrative collection with community healthcare experts. Participants were reminded of the project's rewards, risks, and right to quit participating at any time should they so choose (94). Participants were also informed that their privacy would be preserved, except if we learned anything that would require us to disclose information as mandated by a court of law. For those participants who consented to be audio recorded, they were informed that the audio tapes of their narrative collection would be stored securely for the seven-year

retention period as per the ethical protocol for non-interventional research studies and destroyed thereafter. Participants were also told that their transcripts would be transcribed verbatim for analysis by a Research Assistant at the Canadian Center for Vaccinology, but that the transcription would not contain any information that would allow them to be linked to any specific statements.

Upon reaffirming consent with participants prior to starting narrative collection, M.B. also signed the consent form as the “person conducting consent discussion” and provided a copy to the participant for their records. A second copy of the signed consent form was filed at the Canadian Center for Vaccinology.

4.3.3 Individual narrative collection method

4.3.3.1 Discussion guide

I created the narrative collection discussion guide (Appendix 5) to facilitate structuring the narrative collection by highlighting the topics that co-investigators believed ought to be covered. I drew upon qualitative guides previously used by the investigative team, as well as a resource from Alberta Education for some of the preamble language included in the guide (95–98). After the initial protocol was approved by all of the ethics boards, M.B. and Layla Green (an undergraduate student and Research Assistant at the Canadian Center for Vaccinology at the time of the study) worked with Dr. Donna Halperin on refining the guide.

M.B., L.G., and D.H. conducted a pilot narrative collection with a researcher at Dalhousie University who worked as a healthcare provider in Nunavut and was also familiar with the topic of maternal immunization. Through the pilot testing exercise, they found that the questions on the guide elicited the information that we had originally intended to generate and were confident moving forward with the guide as it had been amended and last submitted on January 21, 2019. As M.B. and L.G. collected data, they made edits to the discussion guide probes based how they found the discussions flowed, and where some participants were getting confused. As none of these changes were made to the root questions, they did not need to be resubmitted to the REBs.

4.3.3.2 Conduct

Once M.B. received signed consent forms from community healthcare experts, he scheduled them for individual narrative collections. M.B. facilitated seven of the narrative collections, and L.G. facilitated two of them. Whenever I was able to be present, I took detailed notes in case we experienced any technical difficulties with our recording. L.G. and I co-facilitated the tenth and final narrative collection. We facilitated narrative collection using the online platform Cisco Webex, which allowed participants to call from their computers or toll-free via telephone in the case of poor internet connectivity (99). Using Webex also allowed us to record the sessions. Despite the fact that we had allotted two hours for each narrative collection to ensure that participants had ample time to express themselves, the longest one lasted for one hour and most concluded around 45 minutes.

Saturation is a term used to describe the point in qualitative data collection at which time no new information is discovered (94). Individual narrative collection took place until the data were saturated.

4.3.3.3 Content

The objectives of the individual narrative collections were to generate detailed qualitative findings about the awareness, attitudes, perceptions, and experiences of community healthcare experts related to maternal pertussis immunization, and to determine their perceptions about which factors influence whether pregnant women in Nunavut are or are not vaccinated. Participants were asked to share how pregnancy is perceived in their communities, and what they thought about maternal immunization. We also asked them for any advice about subsequent qualitative and quantitative phases of the study as well as any other recommendations they had about maternal immunization programs in Inuit communities.

4.3.4 Individual narrative collection analysis

Qualitative data was examined using thematic analysis so as to identify common themes that extended throughout the narrative collection (81). While we had initially planned to do thematic analysis after each narrative collection so as to be able to adapt the discussion guide as new issues arose, we were limited in our ability to do so based on availability of a transcriptionist, and L.G. and my respective schedules. Between M.B., L.G., and I, we were diligent about debriefing the narrative collections as we completed them to ensure that we at least spoke about our experiences with the guide and the discussions it elicited.

The phases of thematic analysis as laid out by Braun & Clarke (2006) guided the thematic analysis process. As part of the first phase (familiarizing yourself with the data), M.B., L.G., and I made notes and marked any preliminary ideas about potential codes immediately after each sharing circle (100). In this phase, Natasha Squires (an Administrative Assistant at the Canadian Center for Vaccinology) also transcribed the recorded narrative collections verbatim, and we uploaded them into NVivo (100).

In the second phase of thematic analysis (generating initial codes), we generated codes from the data inductively, meaning that the process was data and not theory-driven. L.G. and I did this independently, while concurrently drafting independent code dictionaries (100). Once we coded three narrative collections separately, we met and compared notes, code names, definitions, and rationales for our process. Once we were satisfied that we were concordant in our approach, we completed our coding independently, taking care to document our process through liberal use of memos and annotations.

Initial codes were collated in the third phase (searching for, or generating themes), by combining related codes into potential themes or categories in NVivo (100). This process also required close collaboration between L.G. and I as we compared notes, proposed categories, and rationales. I then took these categories and used our memos to group them into loose themes that I presented back to D.H. and L.G., who were able to use their qualitative expertise to provide feedback. After several meetings with D.H., L.G., S.H., and J.L., I refined and polished the themes as part of the fourth phase of thematic analysis (reviewing themes) (100).

In the fifth phase (defining and naming themes), I came up with names for the themes and summarized our analyses of the data within them to describe what each theme captures (100).

Finally, I compared the themes with available literature to determine congruency of the findings in the sixth phase (producing report). In the absence of empirical studies reported on this topic identified in our search, I compared themes found in this study to literature about attitudes, experiences, perceptions, and other factors influencing vaccine behaviour among Indigenous women, and other peripherally related bodies of literature. I also explored literature from fields unrelated to the substantive research area to develop themes.

4.3.4.1 Rigour

Qualitative methodological rigor was maintained according to Lincoln and Guba's trustworthiness criteria (101). Trustworthiness has been likened to the conventional quantitative criteria of validity and reliability and involves assessments of credibility, transferability, dependability and confirmability (102).

Credibility is the comparison of the project's findings with other available data (101). The technique of triangulation (the comparison of data across different perspectives to corroborate results) was used to determine the credibility of findings in four different ways (101). The first was by verifying the source of the information which I did by comparing the results between narrative collection with diverse community healthcare experts, and to any available literature on this or adjacent topics (101). The second was by comparing findings from the narrative collections with community healthcare experts to the narrative collection with an Elder midwife and sharing circles with pregnant women done by our colleagues in Nunavut, and to the results from virtual sharing circles with healthcare providers and CHRs when they became available (101,102).

Investigator triangulation was done by debriefing with different investigators on our team to ensure that the findings were credible between us. M.B., L.G., and I met with C.M. after completing individual narrative collection analyses to compare ours and her preliminary findings. G.H.A. also presented her and C.M.'s completed findings to us remotely. Credibility was enhanced further by having both L.G. and I independently

review narrative collection transcripts, and code them separately before collaborating and comparing results (101).

The fourth and final type of triangulation that I have started applying in this project is theory triangulation. I started sharing these results with co-investigators from diverse theoretical backgrounds and any available participants who expressed interest in providing feedback. Due to their responsibilities related to the Coronavirus Disease of 2019 (COVID-19) pandemic, most participants and several co-investigators and stakeholders were unable to provide their feedback by the time of submission of this thesis project. As such, I have sought an embargo for this work to ensure that all those involved have the opportunity to review it.

This study adheres to the Consolidated Criteria for Reporting Qualitative research (CORE-Q) criteria, which contributes to its credibility and overall quality (104). My process of debriefing with G.H.A, C.M., D.H., S.H., J.L., and L.G. about their insights on data collection, analysis, and interpretation is another way in which the credibility of this project was upheld (101,102,105).

Transferability has been likened to generalizability in quantitative research (101,102). I have addressed transferability by providing “thick” qualitative descriptions of my findings to give researchers and/or providers enough information to determine the applicability of these findings to their projects or practice (101). In keeping with IQ, I have tried to preserve as much of the story exchanged between our research team and community healthcare experts as possible through quotations, while still fulfilling the requirements of qualitative thematic analysis (70,105). It is my hope that this will help community members and healthcare providers in and outside of Nunavut to determine whether the findings are relevant to their specific setting (101,102).

Dependability refers to the description of how the context changed throughout the duration of the project (101). This has been addressed by keeping an audit trail which includes raw data, field notes, transcripts, and memos, to ensure that the research process is clearly documented (101,102). Much in the same way that having L.G. and I code and analyze these data independently contributed to the credibility of this project, it also contributes to its dependability.

Confirmability refers to how well the findings of the research reflect the experiences of the participants and not the researcher. There is a lot of overlap between confirmability and the other criteria. The major techniques for establishing confirmability are an audit, triangulation, and the keeping of a reflexive journal (101). As these three techniques have already been addressed, we are confident that this proposed project is confirmable. Furthermore, I have started sharing these findings either electronically and/or in meetings with participants to get their feedback about whether or not they reflect their experiences.

4.4 Virtual sharing circles with community health providers

In this section, I discuss sharing circles despite citing some methodological literature for focus groups. We learned from our Northern co-researchers that sharing circle methodology would be more appropriate than focus groups with pregnant Inuit women and with healthcare providers. As such, we have incorporated characteristics of sharing circles into our approach. These include acknowledging that facilitators and participants are all equals prior to starting the sharing circle, that there is no particular order in which participants must speak, that participants are free to express themselves through storytelling, and that discussion guides are not to be used rigidly, but rather flexibly, as in conversation.

4.4.1 Virtual sharing circle sample

4.4.1.1 Sample size

No formal sample size estimation was calculated for the virtual sharing circles. Purposeful sampling was used for the sharing circles to arrive at a reasonable sample of healthcare providers and CHRs. I sought maximum variation in a systematic way using criterion sampling with specific pre-defined criteria in the sampling frame (Appendix 6). Our intention in using this approach, was to get the breadth of discussion and diversity needed to be able to answer my primary research question and to meet my thesis objectives. M.B. provided me with an excel spreadsheet of potential participants across regions (Qikiqtaaluk, Kivalliq, and Kitikmeot), communities, and profession (including

public health nurses, community health nurses, CHRs, nurse practitioners, midwives, and physicians) which he compiled after scouring the Government of Nunavut Health Staff Directory. Snowball sampling was also used in this phase of the study to optimize participants in this difficult to reach population.

I used purposeful and snowball sampling to invite eligible healthcare providers and CHRs to participate in this study. With the assistance of Allison Young (an Administrative Officer at the Canadian Center for Vaccinology), I circulated an email (Appendix 7-8) to 371 potential participants on June 25, 2019 using an email marketing software called Constant Contact™ (106). This preliminary invitation contained a project summary, but it did not include the consent form as I had discovered some details related to the data sharing agreement that needed to be negotiated with our Northern co-researchers and resubmitted to ethics for approval. I continued to engage with the 11 participants who expressed interest until the ethics approvals were obtained and I was able to share the consent form with them on November 7, 2019. Later on November 7, 2019 I received a cybersecurity advisory from the Senior Director of Information Management and Technology at the Nova Scotia Health Authority informing staff of a cyberattack in Nunavut and advising us to be vigilant and not to open any emails from the Government of Nunavut. I called Information Technology and was advised to try again at the end of the month. On November 27, 2019 I resent the email invitation using Constant Contact™, but on December 3, 2019 I received a report which indicated that my email had an open rate of 0.8% meaning that only 0.8% of addressees opened the email invitation. I connected with a customer service representative from Constant Contact™ and learned that most of the addressees were either flagged as either non-existent or suspended. I followed up with a representative from their delivery team who was able to confirm that the Government of Nunavut had likely firewalled my e-mails. Upon consulting with the Principle Investigator and my co-supervisors, it was decided that I should wait until the New Year to e-mail participants individually in the hopes that my personal email account may not be firewalled the way that Constant Contact™ had been.

In early January 2020 I sent individual email invitations and consent forms to the same 371 potential participants. While some addressees received my email, they were unable to open the consent form. I faxed consent forms (Appendix 9, 10) to any

participants who expressed interest and who had access to fax machines. Only 15 of the 371 participants ended up signing consent forms and two of those ended up not being able to participate due to other responsibilities related to the Coronavirus Disease of 2019 (COVID-19) that demanded their attention. The remaining participant elected to provide their insights and consent via email correspondence as their clinical work was too demanding to be able to participate in a narrative collection or sharing circle.

4.4.1.2 Inclusion criteria

Inclusion criteria for sharing circles were as follows: healthcare providers including public health nurses, community health nurses, nurse practitioners, midwives, physicians, and CHRs currently practicing in Nunavut; involvement in the dissemination of information about vaccines, vaccine programming, or the actual administration of immunizations to pregnant women; consent obtained prior to participating; access to a telephone or computer; and willingness to be involved and available for up to 2 hours.

A diverse sample of fourteen healthcare providers and CHRs participated in sharing circles. Among them were community health nurses, public health nurses, physicians, midwives, and CHRs. Some of these healthcare providers and CHRs were born and raised in Nunavut, while others moved there in adulthood and had been working (or previously worked) in their positions for as few as eight months and as many as 13 years. Some healthcare providers and CHR had identified specific communities within which they practiced across the Kivalliq (Naujaat, Whale Cove, Arviat, Baker Lake, Chesterfield Inlet, Sanikiluaq, Coral Harbour, and Rankin Inlet), Qikiqtaaluk (Pond Inlet, Iqaluit, Sanirajak, Pangnirtung, Igloolik, and Hall Beach), and Kitikmeot (Gjoa Haven, and Cambridge Bay) regions. Others, particularly those in travelling or locum positions, said that they worked in most of the communities in the territory over the course of their career.

4.4.2 Conduct of the virtual sharing circles

4.4.2.1 Ethical considerations

This portion of the project was not invasive and had minimal risk associated with it. Any harm associated with participating in sharing circles would have been indirect, and as a result sharing thoughts and stories about, and experiences with maternal immunization. Participants were informed that should they feel uncomfortable answering a question asked during the virtual sharing circles, they could elect not to.

As aforementioned the study was designed and continues to be conducted in accordance with recognized ethical frameworks and has received REB approval and research licenses. No changes were made to the protocol or any of the study materials without REB approval.

4.4.2.2 Consent process

Along with the invitation to participate in the project, I sent the consent form (Appendix 9, 10) first by e-mail, and then by fax to interested participants who were unable to open the email attachment due to the ransomware attack. I created two separate consent forms, one for community healthcare providers and one for CHRs as we understood the latter to be made up of community members with fewer years of formal education than healthcare providers with professional degrees (107).

Reaffirmation of consent was obtained from each participant immediately prior to beginning each virtual sharing circle and interview with community healthcare providers and CHRs. I reminded participants of the project's rewards, risks, and right to quit participating at any time should they so choose (94). Participants were also informed that their privacy would be preserved, except if we learned anything that would require us to disclose information as mandated by a court of law. In the case of virtual sharing circles (as opposed to interviews), I reminded participants that complete confidentiality (the ethical and obligatory safeguarding of entrusted information by the facilitator (82)) **could not** be guaranteed as data collection was occurring in a group context. I asked all sharing circle participants at the beginning and conclusion of the sharing circles, to respect the

privacy of their peers by keeping information shared in the circle **private** (free from intrusion or interference by others) (82). All participants (save for the participant that provided their insights via email) consented to be audio recorded, so I informed them that the audio tapes of their sharing circles or interviews would be stored securely for the seven-year retention period as per the ethical protocol for non-interventional research studies and destroyed thereafter. I told participants that their transcripts would be transcribed verbatim for analysis by a Research Assistant at the Canadian Center for Vaccinology, but that the transcription would not contain any information that would allow them to be linked to any specific statements.

Upon reaffirming consent with participants prior to starting narrative collection, I signed the consent form as the “person conducting consent discussion” and provided a copy to the participant for their records. A second copy of the signed consent form was filed at the Canadian Center for Vaccinology.

4.4.3 Virtual sharing circle method

4.4.3.1 Discussion guide

I initially created the virtual sharing circle guides (Appendix 11, 12) to facilitate structuring the sharing circles by reviewing qualitative study materials from other studies undertaken by our research team, and by highlighting topics that co-investigators on this project believed ought to be covered (95,96). Once again, I created two separate discussion guides for this phase of the project; one for community healthcare providers, and one for CHRs covering the same questions and topics, but in more plain language.

I used Krueger and Casey’s recommendations that a guide have around 12 questions discussed over the course of two hours (108). Early questions in the guides were factual and asked about participants’ backgrounds and experiences administering or promoting maternal immunization before transitioning into more conversational questions about perceptions of maternal immunization, and which barriers and facilitators patients encounter when accessing and receiving maternal immunizations (108). This order served to establish a connection between participants and the topic of interest before transitioning into key questions guiding the study and aimed at meeting the objectives

specific to the qualitative portion of this thesis project (108). At the end of the guide, I included questions about what they thought about a prospective maternal immunization program, and for their advice to another Department of Health implementing a maternal Tdap vaccination program. This latter question is what Krueger and Casey refer to as an, “all things considered” question, used to capture participants’ final position on the maternal Tdap vaccination program and to assign weight to what all was discussed (108). The very last question in the guide was an insurance question to make sure that any participants who came wanting to say something but did not get the opportunity, can do so (108).

Once I brainstormed, phrased, sequenced, and estimated the time required to answer each question, I circulated the sharing circle guide along with all other study materials to all team members for their feedback (108). The finalized draft of the guide was submitted to ethics with the assurance that we would re-submit should its contents change.

As detailed above, I was present and took notes for several of the individual narrative collections and was able to observe what was and was not working with our discussion guide (Appendix 5). I was also very familiar with the data elicited from the previous phase of the study having coded it a couple of months prior. I collaborated with M.B., L.G., and D.H. on adjustments to the sharing circle guide based on our preliminary findings from the first phase of the study. I also incorporated what we learned from our meeting with Ceporah Mearns (Researcher at QHRC) about their findings into the discussion guide. Adjustments to the discussion guide were significant enough that we resubmitted it to all REBs and licencing bodies as an amendment.

Upon REB reapproval, I facilitated a pilot virtual sharing circle with four healthcare providers who met all of the eligibility criteria for this phase of the study except that they were not *currently* working in Nunavut and therefore not part of the study population. Joshua Edward (the Project Manager at the time of data collection for the virtual sharing circles) was also present for the pilot test and took notes. Much like the pilot test for the individual narrative collection, we found that the questions asked elicited the kind of information that we had anticipated that it would. We noticed that one hour felt too rushed to have a fulsome and inclusive discussion, so we extended our estimated

time commitment to a maximum of two hours to make sure that all participants would have enough time to share their perceptions and experiences. We also observed that four participants was a very comfortable number to be engaging virtually. We figured that if there were any more than four participants in a given sharing circle, they may not all have enough opportunities to share their stories. We refined a few of the probes and changed the order of the closing questions to keep all of the Tdap questions together, and to finish with the prospective maternal immunization question. None of these changes were substantial enough to warrant a REB review, however we did provide all REBs and licensing bodies with an updated guide for their records.

4.4.3.2 Conduct

Once I received signed consent forms from interested community healthcare providers and CHRs, I sent them Doodle polls with timeslots over several weeks to schedule virtual sharing circles at times that were most convenient for as many of them as possible (109). I had initially proposed virtual sharing circles of four to five people based on the pilot test, and on Krueger and Casey's recommendations for telephone focus groups (110). Between competing responsibilities of clinicians and CHRs, drastically different schedules, variable email access, and trying to accommodate four time zones at any one time, it became clear that four or five participants was aspirational at best. I scoured the methodological literature and found examples of focus groups and of a sharing circle with as few as one participant, and as many as twenty (111–115). Some of these and other studies have also combined focus groups and interviews (112,113,116,117). Lambert and Loiselle initially combined interviews and focus groups for pragmatic reasons, but they note that this combination also contributed to a more nuanced understanding and interpretation of their findings than had they chosen one approach exclusively (116). After reviewing this information with the Principal Investigator, we decided that it would be appropriate for us to combine virtual sharing circles of varying sizes with interviews with community healthcare providers so as to accommodate as many participants as were interested in this study.

I facilitated three virtual sharing circles and five interviews with community healthcare experts and CHRs. J.E. took notes for the first sharing circle, and Melissa Kervin (the

current Project Manager for this study) took notes for the rest save for one where I took my own notes. Again, I used Cisco Webex to enable participants to call in using their computers or telephones, and to record the sessions (99). Interviews generally took less than an hour to complete, but all three of the sharing circles took closer to two.

While themes were certainly beginning to recur in these data, I was still collecting data at the beginning of the pandemic at which point the last three potential participants that had previously expressed interest in this project were no longer able to stay in contact or commit to a date or time. Of those potential participants with whom I was able to connect, they explained that their outbreak responsibilities understandably took precedence over participating.

4.4.3.3 Content

The objectives of the sharing circles were to generate detailed qualitative information about the awareness, attitudes, perceptions, and experiences of healthcare providers and CHRs related to maternal pertussis immunization, and to determine their perceptions about which factors influence whether pregnant women in Nunavut are or are not vaccinated. Sharing circle participants were asked to share their experiences and personal beliefs about maternal immunization, their opinions about current recommendations for maternal Tdap and influenza vaccination, their perceptions of which factors influence whether or not pregnant women in Nunavut are vaccinated, for their advice to other jurisdictions implementing maternal immunization programs, and their thoughts on a potential future maternal RSV vaccine.

4.4.4 Qualitative analysis

Qualitative data was examined using thematic analysis to identify common themes that extended throughout the sharing circle data (81). L.G. and I were especially limited in our ability to analyze each sharing circle immediately after it was conducted due to the availability of the transcriptionist in the wake of the pandemic, and our respective schedules once we began working from home.

As with the narrative collections, the phases of thematic analysis as laid out by Braun & Clarke (2006) guided the thematic analysis process. As part of the first phase (familiarizing yourself with the data), M.K., and I debriefed immediately after each sharing circle to discuss preliminary ideas about potential codes, categories, or underlying themes (100). When she was able to do so, N.S. also transcribed the recorded narrative collections verbatim, and we uploaded them into NVivo (100).

In the second phase of thematic analysis (generating initial codes), we generated codes from the data inductively, meaning that the process was data and not theory-driven. L.G. and I did this independently, while concurrently drafting independent code dictionaries (100). Once we coded three sharing circles separately, we met several times by telephone to compare notes, code names, definitions, and rationales for our process. As we were unable to meet in person due to the pandemic, L.G. and I worked line-by-line through the transcripts over the phone to ensure that our coding was comparable. Once we were satisfied that we were concordant in our approach, we completed our coding independently, taking care to document our process through liberal use of memos and annotations and meet periodically to discuss what we were finding. L.G. sent me her complete NVivo file which I converted and carefully compared and combined with my own.

I collated initial codes in the third phase (searching for, or generating themes), by combining related codes into potential themes or categories in NVivo (100). I did so by using L.G.'s and my memos, and the notes from our meetings. Once I had categorized all of our codes into preliminary theme ideas, I had a few meetings with L.G. and M.K. for their input on my interpretation. After meeting with D.H. to review the transcripts and drafted thematic analysis, and with S.H. and J.L. to discuss my process and findings, I refined and polished the themes as part of the fourth phase of thematic analysis (reviewing themes) (100).

In the fifth phase (defining and naming themes), I came up with names for the themes and summarized our analyses of the data within them to describe what each theme captures (100).

Finally, I compared the themes with available literature to determine congruency of the findings in the sixth phase (producing report). In the absence of empirical studies reported on this topic identified in our search, I compared themes found in this study to

literature relating to attitudes, experiences, perceptions, and other factors influencing vaccine behaviour among Indigenous women, and other peripherally related bodies of literature including some of the studies cited in the background section of this proposal. I also explored literature from fields unrelated to the substantive research area to develop themes.

4.4.4.1 Rigour

Qualitative methodological rigor was maintained according to Lincoln and Guba's trustworthiness criteria (101). The first technique of triangulation used in this phase of the project was to verify the credibility of the sharing circle results by comparing them within and between sharing circles and interviews, and to available literature on this topic (101). The second was to compare these findings to those elicited in the narrative collection with community healthcare experts, as well as those collected and analyzed by our colleagues in Nunavut (101,102). Investigator triangulation was done by debriefing with L.G., M.K., and D.H., who were able to determine whether or not my findings and conclusions were credible based on their understanding and interpretation of the qualitative data. Credibility was enhanced further by having both L.G. and I independently review virtual sharing circle transcripts, and code them separately before collaborating and comparing results (101).

The fourth and final type of triangulation that I have started applying in this project is theory triangulation. I started sharing these results with co-investigators from diverse theoretical backgrounds and any available participants who expressed interest in providing feedback. Due to their responsibilities related to the Coronavirus Disease of 2019 (COVID-19) pandemic, most participants and several co-investigators and stakeholders were unable to provide their feedback by the time of submission of this thesis project. As such, I have sought an embargo for this work to ensure that all those involved have the opportunity to review it.

This study adheres to the CORE-Q research criteria, which contributes to its credibility and overall quality (104). My process of debriefing with G.H.A., C.M., D.H., C.H., J.L., and L.G. about their insights on data collection, analysis, and interpretation is another way in which the credibility of this project was upheld (101,102,105).

Transferability will be addressed by providing a “thick” qualitative description of findings to give anyone contemplating the applicability of the findings, enough information so that they can determine similarity (101). In keeping with IQ, I have tried to preserve as much of the story exchanged between myself and community healthcare providers and CHRs through quotations, while still fulfilling the requirements of qualitative thematic analysis (70,105). In so doing, I hope that this will help community members and healthcare providers in and outside of Nunavut determine whether the findings are relevant to their specific setting (101,102).

Dependability has been addressed by keeping an audit trail which will include raw data, field notes, transcripts, and memos, to ensure that the research process is clearly documented (101,102). Much in the same way that having L.G. and I code and analyze these data independently contributed to the credibility of this project, it also contributes to its dependability.

The major techniques for establishing confirmability are an audit, triangulation, and the keeping of a reflexive journal (101). As these three techniques have already been addressed, we are confident that this proposed project will also maintain confirmability. Furthermore, I have started sharing these findings either electronically and/or in meetings with participants to get their feedback about whether or not they reflect their experiences.

4.5 Survey of pregnant women

In this section, I discuss the panel of survey questions that I generated based on the results, analyses, and interpretation of the qualitative phases of this project. I also discuss subsequent steps in the survey development process, which will occur once our co-researchers and community contacts have returned from being out on the land for the summer, and once non-COVID research operations and responsibilities resume in Nova Scotia, Nunavut, and Nunatsiavut. These subsequent steps are outside of the scope of this master's project and will be actualized by the research team after my tenure as a student in the Department of Community Health and Epidemiology has concluded.

4.5.1 Method

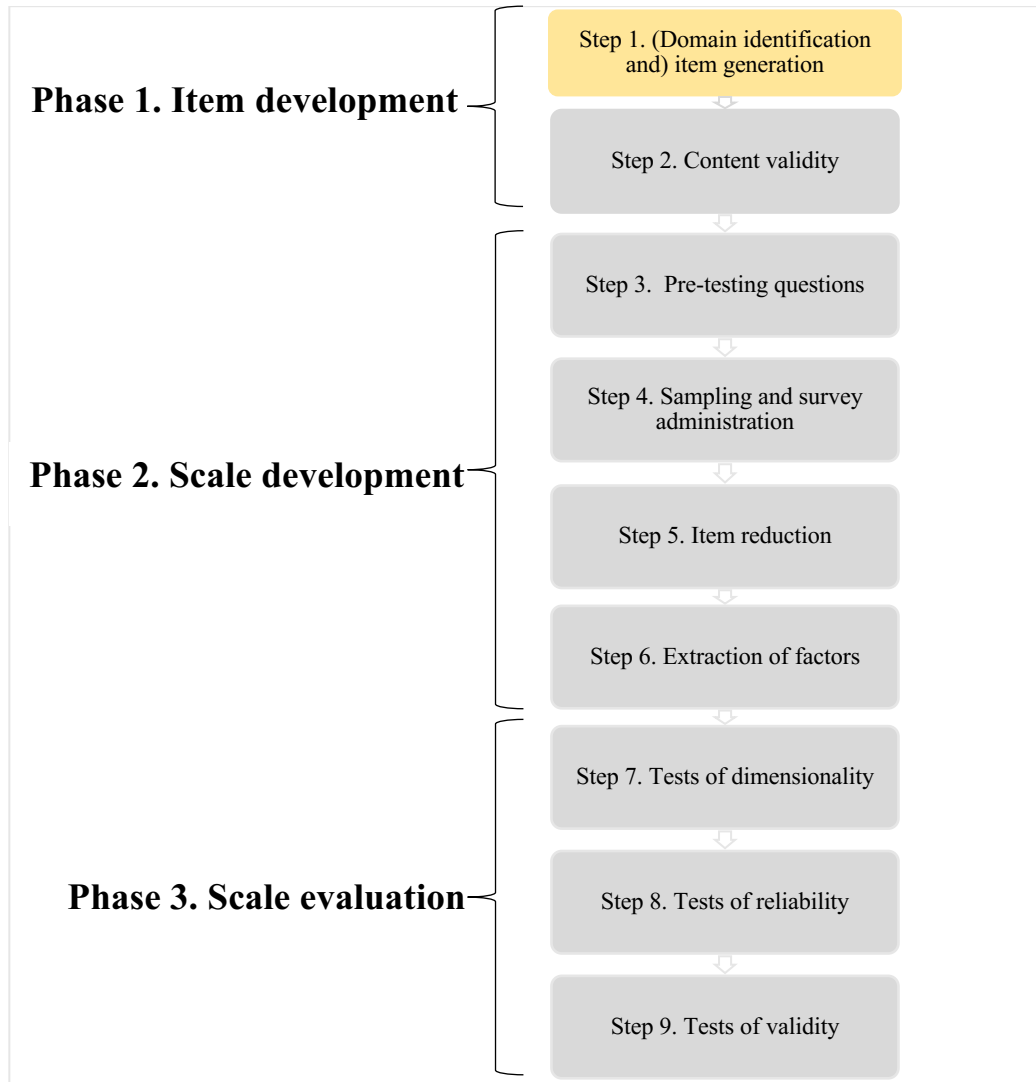
4.5.1.1 Survey instrument

I generated a panel of items for use in a cross-sectional survey of pregnant women in Nunavut to determine their awareness, attitudes, beliefs, and behaviours about maternal immunization, to identify determinants of maternal immunization, and to describe the self-reported uptake of maternal Tdap and influenza immunization in Nunavut. Since the survey questions are aimed at describing vaccine uptake as well as the statistical associations between awareness, attitude, and belief variables and uptake, the survey is at once descriptive and analytic in emphasis (118).

In an amalgamation of methodological literature and lessons learned from extensive experience with scale development and adaptation, Boateng and colleagues have distilled the development and validation of scales into three phases (item development, scale development, and scale evaluation), and nine steps (domain identification and item generation, content validity, pre-testing questions, survey administration and sample size, item reduction analysis, extraction of factors, tests of dimensionality, tests of reliability, and tests of validity) (119). As this project, and particularly this quantitative phase of the project is data- and not theory-driven, domain identification will be determined *a posteriori* (119). For this thesis, I completed item

generation, which represents part of the first step of scale development and adaptation according to Boateng et al. (Figure 2) (119).

Figure 2. Phases and steps of scale development and validation from Boateng and colleagues (119)³



According to Boateng and colleagues, using deductive and inductive methods in combination is the gold standard for item generation (119). I began the process using inductive methods based on the qualitative data that we collected and analyzed, and on the analysis report of our co-researchers in Nunavut, to ensure that the items were

³ The box in yellow depicts the step of survey development and validation that I completed for this thesis.

grounded in and guided by *Inuit Qaujimagatuqangit* (119). In the narrative collection we asked community healthcare experts what they thought we should include in the way of content for subsequent phases of this study (Appendix 5). I used their verbatim responses to lay the foundations for the survey items generated. I also made sure to make note of experts' suggestions for recommendations for the logistics of survey administration. As I completed thematic analysis for the narrative collection and sharing circles, I continued to adjust and add to the healthcare experts' suggested questions with direct quotes from participants in both phases of qualitative data collection.

Once I finished my analyses, I organized all of the quotes collected into categories (e.g. comfort with immunization, Elder and community impacts, trust, sources of information, etc.). I applied deductive methods by using questions from the quantitative studies identified in my background reading and literature review (specifically the questionnaire from a portion of the "*Taima* (stop) Tuberculosis" study which explored the social determinants of health among residential areas within Iqaluit with high tuberculosis incidence (120), and the questionnaire from a Health Canada study of the knowledge, perceptions, awareness, and behaviours of First Nations people and Inuit regarding immunization (74)), and existing questionnaires previously created by our investigator group (about perceptions of universal Tdap vaccination of adults (121), and to measure the knowledge, attitudes, beliefs, and behaviours of older adults about the pneumococcal vaccine (122)) to generate questions. For example: during the past year, did it happen even once that you or any member of your family experienced hunger because you did not have enough food to eat? (120); Have you ever had the flu shot (influenza vaccine) or whooping cough vaccine? (122); If you did (not) receive the flu shot (influenza vaccine) or whooping cough vaccine during your current pregnancy, what are the main reasons for your choice? (74); In order to feel comfortable about your decision to (not) receive a vaccine during pregnancy, what do you need more information about? (121). Each of these are examples that address the categories and quotes collected. Based on my literature review, there are no validated tools in the literature that assess awareness, attitudes, beliefs, and behaviours of pregnant Inuit women about maternal immunization. As such, none of these questionnaires contained context-specific items, so I revised the root of them and in many cases the answer choices. I also used questions from Statistics

Canada questionnaires to measure housing (e.g. including yourself, how many persons regularly live in your household? (9)), Indigenous identity (e.g. are you an Indigenous person, that is, First Nations (North American Indian), Metis, or Inuk (Inuit)? First Nations (North American Indian) includes Status and Non-Status Indians (123)), and location (e.g. are you a beneficiary of an Inuit land claim agreement (123)) (123–125). I included tangential questions that will likely be eliminated in future evaluation, to ensure that the resulting questionnaire is comprehensive and robust (119).

Finally, I provided a careful and comprehensive rationale for each of the questions suggested. Where possible, I offered insight into my hypothesized findings based on my analyses of the narrative collection and sharing circles, as well as potential analytical limitations where appropriate.

4.5.1.2 Content

The panels of questions suggested have been separated into the following four categories: demographics, awareness, behaviours, and attitudes and beliefs. Within the demographics category, questions are focused on social determinants of health including sex and gender, parity, age, Indigenous identity, location, socioeconomic status, nutrition, housing, and access to healthcare. Information-seeking, maternal influenza immunization, and maternal Tdap immunization behaviours are the foci of the behavioural panel of questions. The awareness panel is specific to infectious diseases, the vaccines that prevent them, and recommendations for maternal immunization. The panel aimed at assessing the attitudes and beliefs of participants includes questions about vaccine safety, trust, relationships, and consent.

4.5.1.3 Survey hypotheses

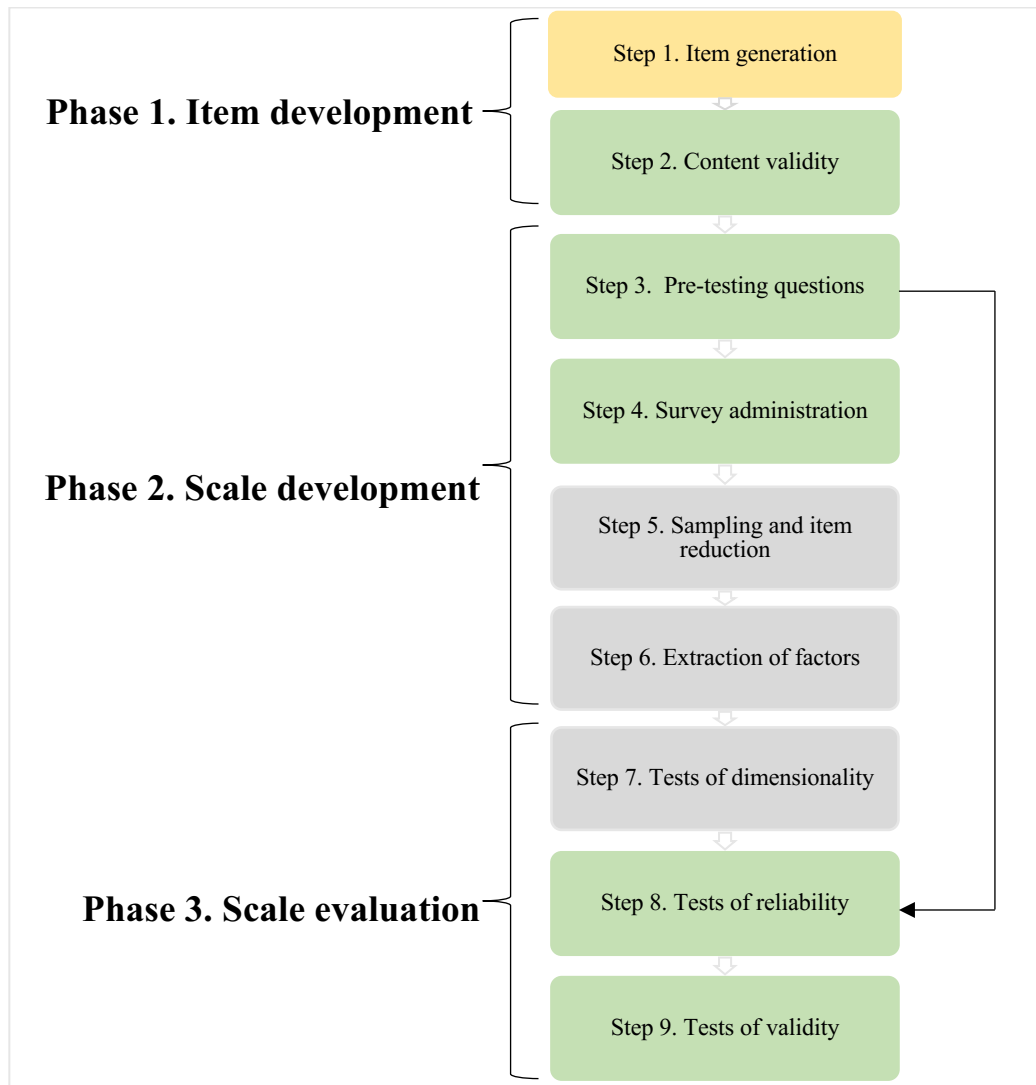
- i. Vaccine coverage for Tdap in pregnancy will be at intermediate levels (30%–60%) in Nunavut and will exceed influenza vaccine coverage during pregnancy by >20% for those eligible for both vaccines.

- ii. Attitudes toward vaccination will be generally positive, but awareness about vaccines and vaccine preventable disease will only be modest (around 33%–50% correct answers)
- iii. While a health care provider recommendation will be an important determinant of vaccine acceptance during pregnancy, vaccine uptake will be more strongly linked to cultural, societal, and moral values than it will to provider recommendation.

4.5.2 Subsequent Methods

According to a comprehensive guide for developing health surveys authored by Aday and Cornelius, it is important that researchers have an understanding of data summary and reduction techniques to be able to define complex concepts to be measured, reduce the number of variables included within the analyses, and appraise whether instruments developed by other researchers are relevant for their own study (118). It is also a valuable exercise to explore the fulsome steps of survey development tempered with the practical and logistic considerations specific to this project. Since we are not constructing a survey completely *de novo*, and there are resource constraints among other limitations to rigorous scale development, I discuss which of the steps put forward by Boateng and colleagues I am purposively choosing for subsequent methods in this project, and which I am omitting in this section (119).

Figure 3. Phases and steps of scale development and validation adapted from Boateng and colleagues (119)⁴⁵



Based on the Boateng et al. framework (Figure 3), the subsequent step in survey development following item generation, should be an evaluation by experts of the validity of the items on the survey, as well as the instrument (119). While there is already preliminary content validity in as much as suggested survey items have been created based on qualitative data, validity should be assessed by a group of five or six content

⁴ The box in yellow depicts the step of survey development and validation that I completed for this thesis.

⁵ Boxes highlighted in green depict the steps of survey development and validation that I have purposively chosen for subsequent methods in this project, outside of the scope of this thesis.

experts (126). For this project, experts may include Inuk health researchers, community members, Elders, and healthcare providers who will be asked to grade the relevance of the questions and the questionnaire using a rating worksheet (please refer to the green highlighted portion of Figure 3). Each item will be rated using a standard content validity index with a four-point ordinal rating scale, where one indicates irrelevance and four, high relevance. Items that receive a score of three or four will be judged to have content validity. Items that do not achieve the required minimum agreement of experts will be eliminated or revised. According to Boateng and colleagues, the next step of survey development would be to have the target population judge its face validity (119). The authors concede that should it be impossible to elicit target population judgement, expert judges will suffice (119). Such is the case in this study, where the population of interest is very small.

Pretesting questions should be the next step of the process for developing and validating scales for health, social, and behavioural research, and is the first step in the scale development phase (Figure 3) (119). Pretesting of the questions ought to be done using cognitive interviews with fellow researchers, potential knowledge-users, and potential participants to understand how questions and responses are interpreted, determine whether the survey questions reflect the identified domains, and meet the objectives of the study (119,127,128). Pretest participants should be asked for their general comments about the questionnaire, as well as comments specific to individual items (127,128). I recognize this step as being very important in developing surveys *de novo*, however I have used several survey questions from the aforementioned existing questionnaires on adjacent topics (e.g. the questionnaire exploring social determinants of health among residential areas in Iqaluit with high TB incidence, the Health Canada questionnaire assessing Inuit knowledge, perceptions, awareness, and behaviours about immunization, the questionnaire previously used by our investigator group to measure perceptions of the universal Tdap vaccine for adults, and a questionnaire for older adults to elicit their knowledge, attitudes, beliefs, and behaviours about the pneumococcal vaccine (74,120–122)) because to my knowledge, there are no validated tools that specifically assess the awareness, attitudes, beliefs, and behaviours of pregnant Inuit women about maternal immunization. I am also keenly aware of the restrictive budget

and timeline for this project. As such, I think the pretesting of questions should be combined with the test-retest exercise, which is a proposal that I expand upon below.

The next step consists of choosing a mechanism of survey administration, and establishing a sample size to test latent constructs (Figure 3) (119). Based on the findings from this individual narrative collection with healthcare experts, the most appropriate approach to the survey would be to have it administered one-on-one with a bilingual Research Assistant (RA) in the way that the Environics group administered their survey on behalf of Health Canada (74). In addition to being more social than self-administered surveys, interviewer-administered surveys have the potential to optimize response rates, motivation, and participant understanding of the questionnaire, and reduce item non-response (127,129). Face-to-face interviews can be disadvantageous in as much as they may introduce social desirability and interviewer biases, and they are both time-consuming and costly (127). An alternative to face-to-face interviews would be to conduct telephone interviews, however in so doing, the interviewer loses the ability to observe non-verbal cues such as facial expressions and gestures of participants. Non-verbal language is especially important in Inuit culture, where communicating through body language is common (66,130). For example, scrunching a nose for “no” or raising eyebrows for “yes” may be misinterpreted as a nonresponse by a telephone interviewer, when an interviewer who is physically present would be able to interpret this physical language appropriately (66,130).

We have not yet decided on a modality for survey administration, but we will either do pen and paper interviewing, or use computer assisted personal interviewing with the assistance of software such as Magpi, which would allow the RA to collect data regardless of internet connectivity (119,131). The latter approach, while susceptible to technical difficulties, is recommended by Boateng and colleagues when feasible (119).

As far as calculating the sample size specifically for latent construct development and item reduction analysis, it is a contentious issue with no universally applicable item-ratio (119,132). Fundamentally, it will depend on how many questions are in the final questionnaire, and on the resources available (119). Bearing the size of the population of interest in mind, and the fact that the qualitative data was not collected exclusively for the purpose of developing the survey instrument, nor was it coded into specific questions and

scales, it would be most appropriate to do latent construct and factor analyses once the survey has been administered to the population rather than as a step in the development of the survey.

Item reduction analysis, the fifth step of developing and validating scales according to Boateng et al., will be undertaken to eliminate or modify any items in the survey that are unrelated to the domain of interest (119). The techniques used (i.e. item difficulty index, item discrimination index, inter-item and item-total correlations, distractor efficiency analysis) will depend on the type of responses to each question (i.e. binary, categorical, multiple choice) (119). Since domains will be identified *a posteriori* due to this survey being data- as opposed to theory-driven, item reduction analysis will also occur once the survey has been administered and the domains identified.

The sixth step of this process is the extraction of factors using factor analysis (Figure 2) (119). *A posteriori* factor analysis would be most appropriate for this project since the finite population complicates our ability to do a pilot factor analysis without asking participants who would otherwise be eligible participants in the study to participate in survey development exercises. *A posteriori* factor analysis will be useful in reducing the survey into something that is culturally appropriate and specific to the population. This has important implications as there are no validated tools in the literature that assess awareness, attitudes, beliefs, and behaviours of pregnant Inuit women about maternal immunization.

The third and final phase of scale development and validation is scale evaluation, the seventh step of which involves testing dimensionality (119). These are tests that look at whether or not items, their factors, and their purpose are consistent within the same sample across time, or across two samples (119). This step will also be postponed until the survey has been administered and may only be undertaken if the survey is administered a second sample in the future.

Tests of reliability are the eighth step in the development and validation of scales (119). Test-retest reliability is an assessment of the (dis)similarity between answers to the survey questions asked to the same participants over a defined period of time (118). For this study, test-retest reliability will be assessed by having five pregnant women complete the pilot questionnaires at two different points in time, approximately 14 days apart. In an

attempt not to draw from the limited population of pregnant women in Nunavut, we will invite pregnant Indigenous women in Nova Scotia to participate in the test-retest assessment instead. Two weeks is suggested for surveys like this one, where participants could conceivably change their behaviour in a short period of time thus altering the correspondence between their responses (118). The type of variable (i.e. nominal, ordinal, ratio) will dictate which correlation coefficient (i.e. Pearson, Spearman, Chi-square) will be calculated to compare the two sets of responses (118). Responses with a coefficient of >0.70 will be interpreted as consistent (118). As part of the test-retest exercise, we will include a free text field after each question as well as at the end of the questionnaire where participants can explain their processes as they answer each item, and any feedback about the instrument. We will use this information in lieu of cognitive interviews to modify, clarify, and reorganize the survey (119).

The ninth and last step in developing the survey for this project, is a test of construct validity that happens after the survey has been administered (119). Criterion validity is tested using predictive measures to see if the scale can predict maternal immunization in the future for example. Concurrent measures are used to compare the survey results to a gold standard however, they require a large sample size and the availability of a gold standard, neither of which are available in this case (119). For these reasons, concurrent measures will likely be omitted in the validation of this survey.

Upon validation, the survey will be translated professionally into Inuktitut and Inuinnaqtun, and backwards translated by a member of our research team to ensure that the translation is accurate.

4.5.2.1 Sample size

The total population for the survey based on birth statistics is 1,763 over the project period. Although the response rate is expected to be higher, surveys returned from 316 individuals will provide a 95% CI of $\pm 5\%$ around the point estimate for any survey question. This sample size was calculated using the finite population correction which was decidedly appropriate given the small population of interest. For the estimate of coverage, 297 survey respondents eligible for both the Tdap and influenza vaccine will

provide 80% power to detect a 20% increase in Tdap vaccine coverage in pregnancy over influenza vaccine coverage in pregnancy; assuming that actual Tdap coverage exceeds influenza coverage by 30%, and that influenza coverage is 10-30%. Northern community co-investigators, and public health practitioners in Nunavut and Nunatsiavut will assist in identifying potential survey participants. Those eligible will be invited by community RAs and community healthcare experts who volunteered during the narrative collection component of this study, to participate in surveys.

4.5.2.2 Inclusion criteria

All pregnant women ≥ 16 years of age who are residents of Nunavut, and from whom informed consent is obtained prior to participation will be eligible to participate in the survey component of this project.

4.5.2.3 Ethical considerations

This study is not invasive and has minimal risk. Any foreseeable harm associated with participation is indirect and might come from answering questions about maternal immunization. If at any point participants feel uncomfortable answering a question, they can choose to end the survey. This study was designed and will continue to be conducted in accordance with recognized ethical frameworks that include Ownership, Control, Access, and Possession principles of the National Aboriginal Health Association, the Tri-Council Policy Statement (TCPS) 2: Chapter 9 about Research Involving First Nations, Inuit and Metis Peoples of Canada, and the Nunavut Research Institute protocols for conducting research. We have successfully obtained a research licence from the Nunavut Research Institute (NRI) and will obtain a licence from the Nunatsiavut Government Research Advisory Committee (NGRAC). We also have Research Ethics Board approval from St. Francis Xavier University, and the IWK Health Centre. We are currently completing the application process for Nunatsiavut's Health Research Ethics Authority. No changes will be made to the protocol or study materials without REB approval. Our original applications included mention of a survey component, but the questionnaire was

not yet available as its contents were dictated by the qualitative components of this project. Once the survey instrument has been finalized as described, it will be resubmitted to the aforementioned ethics bodies prior to testing and validation.

4.5.2.4 Consent process

After being informed about the project by a community-based, bilingual RA, participants will sign a consent form detailing foreseeable harms and potential benefits in private prior to survey. An affirmative consent will be required to proceed with the survey. The participants will be notified that they can withdraw from the study at any time until the survey is submitted. Submission of the survey implies consent.

4.5.2.5 Quantitative analysis

In the first level of analysis descriptive statistics will be used to look at patterns in the data. Descriptive statistics will be used to estimate the proportion of respondents who answered the knowledge-based questions correctly, and who had specific attitudes towards and beliefs about studied vaccines. Continuous variables will be presented as summary statistics (i.e., mean and standard error) and categorical variables by frequency distributions (i.e., frequency counts, percentages and their two-sided 95% exact binomial confidence intervals [95% CI]).

In the second level of analysis tests of association will be performed. Differences in nominal survey responses will be assessed using Fisher's exact tests. We chose the Fisher's exact test over the Chi² test of independence because we anticipate a small sample size ($n < 1,000$) and therefore Fisher's is likely to be more accurate (133). For continuous predictor variables, logistic regression will be used. Associations between attitudinal, behavioral, and demographic responses will either be estimated using ordinal logistic regression or Fisher's exact tests depending on whether or not the order of categories is of importance. Overall knowledge scores will be compared using t-tests to determine whether sample mean knowledge scores differ significantly from our

hypothesized modest knowledge estimates detailed below (134). P-values < 0.05 will be considered statistically significant and will be presented with 95% confidence intervals.

If the data support further analysis, demographic and population community-level characteristics from surveys will be used to develop predictive models for knowledge and attitude responses. Multiple logistic regression will be used to predict binary knowledge responses, in which the model is used to predict the probability of agreeing or disagreeing with the associated statement. Ordinal logistic regression will be used to predict ordered attitude responses, where the model is used to assess the degree to which subjects have knowledge regarding particular issues. Attitudinal outcomes are typically measured on a 5-point Likert scale and have a natural ordering (135). The particular ordinal logistic regression model to be fit therefore, is a cumulative logit model, which will allow us to predict the odds of each response level (135). For each outcome variable, whether binary or ordered, the collection of demographic and population characteristic variables will be used in a backwards elimination stepwise procedure to inform a multiple regression model. Those predictor variables remaining at the end of the stepwise procedure will be summarized and p-values indicated. P-values of < 0.05 will be considered statistically significant. Statistical analyses will be completed using SAS version 9.4 with the support and guidance of the Data Management Group at the Canadian Center for Vaccinology (136).

Chapter 5: Results

5.1 Individual Narrative Collection Results

The objectives of the individual narrative collections were to generate detailed qualitative findings about the awareness, attitudes, perceptions, and experiences of healthcare experts related to maternal pertussis immunization, and to determine their perceptions about which factors influence whether pregnant women in Nunavut are or are not vaccinated. The experiences of ten community experts including managers, consultants, specialists, coordinators, supervisors, and administrators with experience working across all regions of Nunavut constitute the data for this phase of the study. Most of these participants (n=8) are also healthcare providers and thus able to offer insight from intersecting areas of expertise. Interviews were supplemented by detailed field notes, which were coded in the event that participants declined to be recorded (n=4). Memos were used to document the inductive identification of codes and eventually of themes.

Two major themes were generated based on the analysis of these data: complexity of health service delivery, and ways of knowing on both sides of the needle. Within each of these themes, I organized concepts into subthemes to capture the nuances of each central organizing concept. In this chapter I will explore each theme and associated subthemes in detail.

5.1.1 Complexity of health service delivery

There is a systemic complexity to the provision of prenatal health care in Nunavut that influences how and when providers are able to discuss maternal immunization with their patients, if at all. In this theme, I explain the diverse models of prenatal programming and healthcare across the territory which are fundamental to this complexity. That is, if pregnant women are not getting consistent programming and prenatal healthcare, the margin for missed opportunities to discuss maternal immunization is likely going to be wider than in places where prenatal care is delivered through

established programming and with the same provider. Next, I discuss the impacts of transience on trust and relationality between patient and provider. I conclude with an exploration of how providers have come to cope with the complex care needs of presenting patients by prioritizing downstream over upstream care.

Pragmatism in prenatal care and programming

Prenatal programming, as used in this thesis, refers to any educational, social, or health promotional initiatives aimed at supporting women during their pregnancy. In this subtheme, I explore how prenatal health service delivery in Nunavut consists of a pragmatic combination of programs and provider expertise depending on geographic location and community, interest from pregnant women, birthrate, and season.

The Canadian Prenatal Nutrition Program (CPNP) is available to pregnant women in most communities in Nunavut as long as there are local Community Health Representatives (CHRs) willing and able to facilitate it. Funded by the federal government, and hosted weekly in community gathering spaces, CHRs are able to support pregnant women in a way that honours Inuit culture and values through the CPNP.

“...We have community health representatives in each community and they’re local Inuit that are trained to help support different public health programs including...pregnancy immunization [sic], there’s oral months...nutrition months, HIV months. So, for every month ...they help promote as well and...we utilize our community health reps a lot to...talk with our prenatal that’s [Canadian Prenatal Nutrition Program] regarding immunizations, what to expect in their pregnancy. So, yeah we’re, we’re trying to do a lot of health promotion in that department, but it’s fairly new.” (P04)

The CPNP gives pregnant women the opportunity to cook healthy recipes that are taken home to their families, to sew, to socialize, and to learn from CHRs and guest speakers about an array of health promotional topics (i.e. breastfeeding, immunization, healthy infant development, oral hygiene, HIV). This program is promoted via radio, posters

around town, and sometimes through the encouragement of healthcare providers. According to community experts, these programs are generally well-attended; however, attendance decreases in the spring and summer months when women are often out on the land.

There are some geographically remote communities with limited infrastructure and resources that do not have the CPNP. In its absence, healthcare providers may try to organize activities to meet some of the needs of pregnant women. These initiatives are inconsistent and unsustainable, however, as they depend on healthcare providers who are inundated with other responsibilities.

“We have attempted to, for example, fill some positions like CPNP programs – we don’t have that program in the community. We’ve tried to do food clubs and such with the hamlet council to try to get some of these women some food, like a takeout bag from the health centre and funding for that, but many of these projects are not sustainable. They go on for a few weeks and then they fall through because unfortunately, from a nursing perspective, we can’t do it all and we need our partners with us. But the novelty as I call it, sometimes wears off. So, we go back to just coming to the health centre.” (P10)

In several communities, prenatal appointments with healthcare providers are embedded in the prenatal programming, and providers meet the pregnant women wherever they have been convened.

“Women that are pregnant will be called in by that Community Health Rep and they’ll have like a healthy snack and they’ll just talk about pregnancy and do some teaching in there with them, some health promotion which is wonderful. So, then [the nurses] would take each woman one by one for her little appointment in between that. It’s funny it’s kind of like [the nurses are] interrupting them because they are really enjoying it. It’s attended well. It’s like, ah, it’s my turn – great!” (P02)

Prenatal appointments are used to provide critical information about what pregnant women can expect from their health care provider, when during the progress of labour to call their provider, what they can expect during labour, and to answer any questions women may have about pregnancy.

Community experts explain that, in addition to different configurations of prenatal programming depending on geographic location, human resources, and community interest, prenatal healthcare in Nunavut is delivered by three different types of health professionals with different foci which contributes to the complexity of health service delivery. Physicians are typically based out of Iqaluit and act in a predominantly consulting or labour and delivery role. One healthcare expert explained that obstetrical training and preceptorship is mandatory for physicians working in Nunavut, but that it is not usually their specialty. Community Health Nurses (CHNs) are the primary care providers in smaller communities and work at an extended scope of practice, almost that of nurse practitioners. CHNs can be thought of as generalists, caring at once for individuals, families and communities within and beyond pregnancy. Importantly CHNs cannot deliver babies and therefore patients must be sent to referral centers to access obstetrical services. This is in contrast to midwives, who are specialists in women-centered maternity care, and who can offer the option for pregnant women to deliver in their home communities. Midwives provide care in Cambridge Bay and Rankin Inlet and are seen by community experts from nursing and midwifery backgrounds alike as being integral to the health of pregnant women in Nunavut.

“I would say the difference between looking at the midwifery model of care, which is more of a holistic model, it’s based on putting the women at the center of decision-making. So, a lot of informed choice discussion around different options for screening and for care and treatment and so on and place of birth.” (P08)

If pregnant women are not all receiving the same programming and healthcare, the margin for missed opportunities to discuss maternal immunization is likely wider than in other provinces or territories where standard information is shared in established and consistent prenatal programming, and by healthcare providers with maternity expertise.

Until such a time when there is the infrastructure and resources to support the CPNP in every community, and a consistent primary prenatal care provider, pregnant Inuit women may be receiving varying amounts of information about maternal immunization or none at all.

Building trust amid transience

In a culture where relationships are foundational to wellness, sustained continuity of care between patients and providers over time is paramount. In this subtheme, I explain that forging a trusting relationship between patients and providers is difficult given the volume and turnover of short-term locum providers as well as the transience of pregnant women who must be flown elsewhere to deliver. These two iterations of transience may limit patient and provider comfort with having candid conversations about maternal immunizations.

Access to a continuous healthcare provider is especially important in this population as Inuit epistemology is based in relationality. The benefits of a continuous care provider for the health of pregnant Inuit women are noted by participants in communities with long-term nursing staff who develop a trusting rapport with patients. While continuity is certainly not the only determinant of a trusting relationship between a pregnant woman and her healthcare provider, without it there is little opportunity to develop rapport, reciprocity, mutual understanding, and trust.

“We are a nurse-led health centre and it’s part of my role as part of the government mandated programs that these women get their prenatal care. So I think from the, they develop that rapport with the community, they are coming to the community to have their weekly checks, their two weekly checks depending on what’s going on. Also with their rapport with us, they feel comfortable about coming to us and telling us the different aspects of the pregnancy...I think again it’s that rapport with the nurses. I think that’s one of the biggest parts of it.” (P10)

The benefits of a consistent prenatal healthcare provider are especially felt in communities where those providers are midwives. Healthcare experts (both midwives and others) are resoundingly supportive of midwives and the impacts that their care has had on health outcomes ranging from family planning, breastfeeding duration, and formula preparation, to infant vaccination. The following endorsement of midwifery practice comes from a nurse:

*“But the communities that have the midwives I can tell you the women, just from personal experience that pregnant women have better outcomes and are cared for much better. ...If I go to a community that has midwives and I look at a prenatal cart, it’s going to be way more impressive than a community who doesn’t have a midwife and has nurses transiently coming in and out. So that’s a negative factor, nurse turnover, coming in and out, not knowing this pregnant woman, having to do a full chart review on someone every time they come in but not having the time to do that. Whereas **midwifery gives more of a continuity of care.**” (P02)*

Another participant suggested that if a trusting relationship with a healthcare provider is established, they may be able to persuade women to adopt positive health practices such as maternal immunization.

Important for the pregnant woman to have a trusting bond with the healthcare provider. Might be able to change a person’s mind who was unwilling to take the vaccine in the beginning if this relationship is established. (P07)

The reality of practice in Nunavut is that there is a high rate of turnover of healthcare providers. This is a key contributor to the complexity of prenatal care. One participant identified it as its own determinant of maternal health. Staff shortages, and frequent turnover have a negative cascading effect on relationships with patients and the quality of care that providers are able to give. This in turn, exhausts patients and erodes their trust in their providers and the healthcare system.

“Sometimes it’s a challenge for some of the women to come because they develop certain rapport with certain people but also the staff turnover can be a challenge for many of these women as well because you think, you just extended your story to one person and the next time you come you have to do it all again and it’s a different person. But they feel that you’re asking the same questions when they told that person yesterday the same thing, but the questions are generally the same.” (P10)

“...so that continuity of carer, as well as the continuity of care, has a potential to have a negative impact on that woman’s pregnancy. She hasn’t developed any relationships with anyone that she might – by developing a more continuous relationship with a care-giver around pregnancy, it’s my belief that she has more potential to really be able to look at what her concerns are in her pregnancy and know that someone will be there to assist her or listen to her needs, or identify her needs, and help her to fulfill or meet them.” (P06)

Another form of transience contributing to the complexity of prenatal care in Nunavut, is the necessity of having pregnant women leave their community as they approach delivery when adequate resources are unavailable. In some places, healthcare providers do not have access to blood products, and are not trained in labour and delivery. Where this is the case, pregnant women are flown as early as 32 and as late as 37 weeks into their pregnancy, to more equipped communities where they stay until they give birth. If a low risk delivery is anticipated, pregnant women in these communities are sent to Cambridge Bay or Rankin Inlet (which are midwife-managed), or to Iqaluit to be tended to by physicians. If they are deemed higher risk however, women may be sent as far as Montreal, Ottawa, Edmonton, Winnipeg, or Yellowknife depending on their location.

“It is quite a challenge when you look at it like, these women have to leave 4 weeks prior to delivery and that’s for a number of reasons. One is the resources in the community is very limited. Two, many of these women are anemic and sometimes it’s their first baby and there is the possibility and potential of things

going wrong so at least you have them in a safe environment. It also gets them out, gives them a break, but a month is a long time when you're away from home.” (P10)

Not only does this practice fragment whatever trust has been established in the relationship between patient and original caregivers, it may also have impacts on the family unit going into the future.

“My biased opinion, but having families taking part in the prenatal care by attending prenatal visits and you know everybody becomes educated that way on what are the healthiest habits and lifestyle throughout pregnancy. And also being able to take part in the birth you know as a family event, and not being separated from families and having to be sent out for the birth and then coming back with your baby and you know everybody has an adjustment period so you know culturally that's just the way it's been done. For many many years women birthed on the land and had their families involves and may have had a traditional midwife at their birth or may not. It could have just been their partner that helped them, but I think the more of a family unit that is involved the better it is for future family bonding and so on.” (P08)

Stories shared by healthcare experts suggest that recent changes to the medical travel policy allowing partners and children less than two years of age to join the mother should she choose to leave the territory for the birth have resulted in a surge in the number of pregnant women leaving their communities for delivery.

“So now we're actually seeing a drop in birthing in the community, which is interesting. So, I think it's directly related to the fact that this woman and her chosen escort have time together outside of their community, where they can access other fun things that they don't get in their own community.” (P06)

Some participants perceive this to be a positive factor in as much as it is an improvement over the previous practice of sending women out of the community alone. This newer practice mitigates some of the isolation and loneliness associated with delivery and allows partner involvement in prenatal education and support.

“I think the positive part of that, even though they’re not birthing here, the positive part of that is that they have someone with them and so they’re not alone for that month. So, I see that as being positive – the partner’s involved, the partner is now attending prenatal classes in the last month of a woman’s pregnancy.” (P06)

Others suggest that there is still a desire among Elders and politicians, to have women deliver in the communities that they are from.

Politicians, hamlets, and probably even the Elders would rather see the births occur in the territory. Politicians realize that if they set up a successful birthing center, it will keep jobs and economic drive in the community. Births in the territory are also closer to what the Elders would view as the cultural norm. (P05)

When women are flown out for confinement prior to delivery, having a consistent care provider in the territory is instrumental in minimizing the inevitable disruption of her care. One participant explains that their community has made connections with a program in Southern Canada where most of the pregnant women go to deliver. This allows nurses to prepare patients for what to expect, to follow the patients from afar while they are away from the community, and to pick back up with the patients upon their return.

“One of the other parts of it is that we’ve connected recently, well in the last year with [a program] in [Southern Canada]. Women are being sent down, they are being followed through after the baby is born to see if there are any issues. Sometimes they are missing home, there are some issues that happen down there, you know, they don’t want the baby, or they feel overwhelmed. They are a bit of a

support to them as well, and the connect with the community so we can catch up with the women when they get back.” (P10)

In a similar effort to minimize disruption of prenatal care and maximize trust in the relationship between patient and midwife, another participant explains how they adjust staffing to preserve continuity of care through the sharing of midwifery positions.

“If that [sic] is a midwife who wants to come in on a continuous casual contract, then we try to pair her with another midwife who wants to do a continuous, and they share a position. They become one person. When I’m staffing, I look at how to have the least disruption to the women – how the staffing can have the least disruption to the woman in her care.” (P06)

The transience of healthcare providers in Nunavut is antithetical to Inuit relational epistemology, as is the fracturing of care when pregnant women are required to leave their community to receive care from providers with whom they have no relationships. Both contribute to the complexity of healthcare practice in Nunavut. Having long-term nurses or ideally midwives in the community to provide sustained and continuous care for pregnant women within their community will be essential if and when pregnant women across Nunavut are able to deliver in their communities.

Heads above water: Navigating upstream and downstream care

Prioritization of downstream treatment over upstream prevention has become a mechanism by which prenatal providers are able to meet complex care needs in spite of time limits and human resource constraints. In this subtheme, I discuss the implications of this prioritization on maternal immunization practices and present midwives as being well situated to keep their heads above water as they navigate upstream and downstream care simultaneously.

Inuit-specific social determinants of health are understood by participants to be inextricably linked to the health of pregnant women in Nunavut and identified as an omnipresent concern for providers. Determinants of maternal health as perceived by participants include accessibility of health services, education, environment, food security and access to country food, housing, income, and social support. Participants explain that these systemic issues are often beyond their ability to deal with as healthcare providers, coordinators, consultants, supervisors, and administrators because their sphere of influence is comparatively small.

Had a client once that lived in a closet. How do we handle that? Housing is very important. Poverty – not being able to afford good nutrition. Younger people having to take off school for a period of time to have baby and/or take care of child can have a negative impact as well. (P03)

“I’m more concerned about the social diseases than immunization quite frankly.” (P06)

Participants identify the social determinants as impacting the complexity of care required of them because pregnant women often have a constellation of needs that must be addressed in a single prenatal appointment. In addition, with resource constraints in practice, healthcare providers are having to prioritize the care that they are able to offer to their patients. When prioritizing care, emergent and urgent needs are addressed first and immunization tends to fall near or at the end of the list for providers.

*“...when a person comes in for a visit so, **say it’s just a routine prenatal visit it’s never just routine.** It’s never, I’m doing prenatal screening – it’s either they have an upper respiratory tract infection that needs to be looked at, they have a UTI that needs to be treated, they have anemia and I need to now start investigating and treating. There’s always acute things within that routine visit. So that there is an added stress and an added barrier to giving immunizations...I’m thinking of all the times [the vaccine] was either refused and I didn’t even push it because I just*

didn't have time to even give any more information on it, I'm like no I gotta get to the next one. I have six women out there waiting for me.” (P02)

A comprehensive discussion about maternal immunization, if and when providers are able to have one, takes around 10 to 15 minutes and is instrumental in ensuring that pregnant women and their families have enough information to make informed decisions.

“I feel like it takes um...you have to spend a good, a good amount of time, you know 10-15 minutes um...explaining why the, you know, the risks and the benefits of um...receiving your vaccines. Especially when it's flu time season and then at their optimal timing for the Tdap. Um...I do spend quite a bit of time to make sure mum understands, if the father is there as well um...just trying to engage both of them uum...and I think usually it goes well as long as you're spending enough time explaining the risks and emphasizing with their concerns.” (P04)

During an appointment when there *is* time for the topic of maternal vaccinations healthcare providers find that the pregnant women have sometimes reached the point of information saturation and that no further information can be absorbed or discussed productively.

“A lot of them will have misinformation so you try to you know give your view of let me promote this vaccine. Let's make sure let's talk about pertussis but they don't want to hear about it right then because you just gave them ten other messages. Health promotion messages about anemia and nutrition, and what's it going to be like to stay at the boarding home when you're pregnant, you know? It's too many messages so I think that's also a factor because by the end of it they're just not ready to absorb any more information.” (P02)

Some healthcare providers who work in smaller communities can only offer 30 minute prenatal appointments due to staffing constraints. This is insufficient to be able to address

all of the needs and concerns of the patient, and to build any kind of rapport with their patients.

Know that in smaller communities we book patients for 30 minute prenatal visits and a lot of the time we are short staffed, or the workload is overwhelming. So you “check, check, check” and it’s, “go, go, go” and “next!” and you don’t take the time to sit and talk. (P07)

Some healthcare experts express concern that if providers are discussing maternal immunization with their patients, they may be doing so hurriedly and in such a way that supersedes truly informed consent. Participants suggest that even those women who *are* consenting to being vaccinated may not be understanding exactly what is being given to them and why.

People are absolutely consenting to vaccines that they don’t know 100% why they are getting it. Just because someone gives consent to do something doesn’t mean we have the right to go ahead and do it – we need to make sure they are well informed. (P03)

*“I don’t know if it’s a discussion or is there actual consent that’s being obtained like is there enough information being given to clients for them to make an informed choice and to give consent or is it just, I mean, we know this happens not just with vaccines, but we know that in some situations, women come in and say for instance they are going to have some sort of screening test done. **Well, it’s not presented as an option** that you know this is the time in pregnancy where we like to offer this, and here are the reasons why. Or you come into your appointment and the practitioner will say okay, well we’re just sending you to the lab for some tests but some women don’t even know what they are going for.” (P08)*

Informed consent discussions must be open, trustful, intentional, honest, and ongoing, and include information about the safety, risks and benefits of maternal immunization. They

should also be had in whichever language is most comfortable for the expectant mother. This optimizes her understanding of concepts presented and facilitates the best relationship with the health care provider.

*“I mean it’s just basically without having to go into all of that detail of having an informed choice discussion on you know this is why in Nunavut it’s important to have this vaccine and allowing women to make that choice but at the same time giving that information of why it’s important **without talking them into it.** Basically, like informed choice discussion is in my opinion, something **that if we can present the information and allow them to make the decision then they won’t feel coerced into doing something they don’t have enough information on.**” (P08)*

Participants stress the importance of respecting patients’ choices throughout their pregnancy and suggest that pregnant women are the experts when it comes to making the best decision for themselves and for their infants.

“We always celebrate when a woman says no to us, which is great. So we feel that that is the beginning of empowerment to a woman, to be okay being contrary to what someone might be telling her – someone in authority might be telling her. So we like to celebrate those times when a woman says no.” (P06)

One provider suggests that there ought to be an effort to inform patients prior to actually offering them the vaccine. This way, pregnant women are able to digest the information, discuss with those whose opinions and beliefs are important to them, and make an informed decision to be or not to be vaccinated.

“How can that information be disseminated to women prior to that actual appointment where you are offering to give vaccines. Like does there need to be more public access or announcements or posters or I don’t know what that would

look like but I think that it's really important to have that information so they can make that decision.” (P08)

As providers with a singular focus on maternal health, midwives are more likely to provide comprehensive prenatal care, including acute and preventive care, as compared to their nurse counterparts, who are required to attend to a host of other health programs and needs in the community. Midwives also have one-hour long appointments during which time they can have truly informed consent discussions about maternal immunization.

*“We need more focused prenatal care instead of, you know, practitioners that need to deliver everything from emergency care to janitorial services in a day. You need someone that's dedicated to the health and wellbeing of pregnant women in each community. And not just given a Wednesday afternoon to do it. **You know, midwives? Midwives could change everything.** That's my...that's always been my view of that.” (P02)*

Experts raise concerns about whether or not the vaccine decision-making process is truly informed, and about the integrity of the consent process. With resource constraints and the complexity of care sometimes required in a prenatal appointment, many healthcare providers do not have the time to discuss maternal immunization in the depth that they or their patients might like. In light of this midwives, as experts in maternal health with fewer other programs under their jurisdiction, and situated to offer lengthier appointments, are excellent candidates to lead maternal immunization discussions and elicit truly informed consent.

5.1.2 Ways of knowing on both sides of the needle

There are two ways of knowing that feature prominently in healthcare experts' accounts of prenatal health, including maternal immunization in Nunavut. On the recipient side of the needle, healthcare experts suggest that health- (and specifically

vaccine-) related information spreads through social networks made up of family, loved ones, Elders, communities, and increasingly social media contacts. I explain how and why each of these levels contribute to the awareness, attitudes, perceptions, and experiences of pregnant women surrounding maternal immunizations, as perceived by experts. On the provider side of the needle, I summarize experts' interpretation of how information is shared from policy makers and contributes to providers' understanding of maternal immunization. I then focus on intrinsic determinants of whether or not healthcare providers offer maternal immunization to patients, in particular, on the way that their personal perceptions influence their practice.

Relations, reservations, and receiving immunizations

In this subtheme, I describe ways of knowing about maternal health and immunization on the receiving end of the vaccine. I trace expert perceptions about the impacts of relationships between pregnant women and their families, Elders, communities, and social networks on maternal immunization beliefs, reservations, and behaviours. I conclude by addressing residual determinants of maternal immunization at the intrinsic level, including generalized, and antigen-specific vaccine hesitancy.

Healthcare experts report that depending on the community, pregnant women look to diverse sources for advice and guidance about how to have a healthy pregnancy. Historically, immediate female family members were seen as the authority because healthcare providers were uncommon in Nunavut. As a result, some experts perceive that family members, friends, and loved ones are still seen as the primary sources of information, and that healthcare provider advice is sought only when there is concern about medical conditions or complications.

“I would say their immediate family members if it's a sister or mother...and that's usually just based by cultural experiences. So, you know 50 years ago there wasn't many health care professionals and women were still giving birth you know with family members at their side, and no real intervention. So, I think they initially seek advice and guidance from their friends and loved ones, and then

when they are medically ill or they're experiencing something problematic they'll seek the healthcare system.” (P04)

Others suggest that there is more of a blending of information across healthcare providers, family members, and Elders.

“I would say they look to their health practitioner more, I think. Although, as I mentioned earlier, there is quite an influence from Elders on how to have a healthy pregnancy, you know by doing certain things, not doing certain things, eating certain foods, that sort of thing. So it depends on what the topic is I think, and if we're talking in general on how to have a healthy pregnancy, I think that there is a bit of a blend there from family members, Elders, and depending on what it is, your healthcare provider.” (P08)

Relationships with family members and Elders, according to healthcare experts, act as determinants of maternal health in Nunavut. As such, several experts assert that if a family member or Elder is distrustful of maternal immunization, their opinion is highly influential in vaccine decision-making.

“Maybe another influence would be a relative, you know a mother or auntie or somebody that says, you know, ‘You shouldn't be [getting immunized] when you're pregnant.’ ...So there's a lot of influence there as well, so it could come from an Elder or a relative or something like that.” (P08)

In particular, experts speculate that certain family members and Elders may be vaccine hesitant due to Canada's history of colonialism, and “treatment” solutions for infectious diseases.

If there are family members, or especially Elders who do not trust the vaccine, their opinion matters way more than healthcare providers. For the Elders, it has to do with history. Historically, it wasn't pretty, Inuit were being vaccinated, but

really the vaccine made them sick instead of preventing illness. These beliefs have been passed on to the younger generation. (P07)

One expert shares an experience of encountering the impacts of this trauma on offering the human papillomavirus (HPV) vaccine as part of a school-based immunization program.

I ran the HPV vaccine programs in schools, and parents would decline this for their daughters. I had two different parents tell me that they thought it was a sterilization program for their daughters. Common to encounter the powerful thoughts and ideas about what we are trying to do now reflecting the past implementation and how that history affects how people perceive healthcare today. How do you counteract that belief? (P03)

In addition to (un)acceptability of immunization among family members and Elders, the vaccination behaviour of other pregnant women in the community is perceived to influence maternal immunization uptake. One expert who is both an administrator and clinician explains that their patients have come to anticipate being offered maternal immunizations because everybody else has been getting vaccinated.

“No I got no problem, I say my women have taken their shots and I’m here to give you your vaccine now, any questions? And no, their arm is there, just give it to me. So not a big challenge for us here as I said. I think it’s because they see everybody else is getting it so they’re not up, refer to one person who is getting it and the rest aren’t – all people are getting it so it becomes okay.” (P10)

Just as collective acceptability of maternal immunization spreads through the community and family unit, so too do stories of adverse events following immunization. Regardless of the severity of a reaction to an immunization, when one occurs, stories are spread through familial and community social networks and healthcare providers then have to

make a concerted effort to reconvince patients that vaccines are a safe and evidence-based intervention.

“...they wanna know if they’re gonna get any side effects from the vaccine; if they’ll start to feel sick or get a rash. Um...a lot of them are aware of the MMR vaccine in their previous children and you know some of them have developed body rashes and some you know, because they are such small communities, if one person in the community has a bad reaction to a vaccine it causes like a trickle-down effect of hesitancy which requires more health promotion and teaching.”
(P04)

Another mechanism by which vaccine behaviour may be shaped by a pregnant women’s social network is via social media. In particular, healthcare experts explain that negative experiences, perceptions, and misinformation can and do run rampant on social media, which allows them to be spread efficiently, and to a much broader audience.

“Some women want to know more [about maternal immunizations], and even rarer, some women will say, ‘I will not take it.’ And again when we ask them why, they come back with the answer of, ‘I saw on Facebook that if you take any kind, that your baby’s gonna have autism. You’re gonna hurt your baby and yourself.’”
(P01)

Especially around the influenza season, will see people write on Facebook that, “they” are trying to kill us. “They” being the foreigners, white people, healthcare providers, etc. Anti-vaccination sentiment on Facebook gets around and happens every year. (P07)

While family, Elders, communities, and social networks shape pregnant women’s perceptions of maternal immunization, healthcare experts explain that intrinsic motivations for maternal immunization may include, among others, a reciprocal desire to protect their communities from infectious diseases.

“Most people here in Nunavut cherish their communities and everyone is really closely connected. So once you kind of put it on a bigger perspective than just the pregnant woman herself and her baby, I find uptake is good. ...They want to protect everyone in the community and themselves, and make sure baby is born healthy and not experience a lot of the sickness that happens for our babies under two years of age.” (P02)

Most of these women also have other children and care about their families. If they get ill, it is not going to go well at home. They will need to tend to sick kids. Do not want to pass [infectious diseases] along to other family members. (P07)

More immediately, the desire to protect one’s unborn child is also perceived by experts to be among the primary reasons why a majority of pregnant women accept maternal immunization.

“I cannot speak for outside of pregnancy I don’t know, but in pregnancy are obviously on the lookout, wanting to protect their baby from possibly everything that they can. ...If this vaccination, immunization, whatever they’re giving could help prevent their baby from getting something, then most women are on board with it.” (P01)

Acceptability of maternal immunization is not consistent across antigens. According to participants, acceptability of maternal Tdap immunization exceeds that of maternal influenza immunization. The following expert suggests that this trend is attributable to the messaging surrounding the maternal Tdap and influenza vaccines.

*“But I find most women just say, ‘No, no,’ you know, ‘I don’t want [the influenza vaccine] one.’ But I feel that the Tdap is more acceptable. ...**I think because the informed choice discussion [for the maternal Tdap vaccine] focuses on why this will benefit your baby as well,** so I just feel like when it comes to that, women are*

more likely to say, 'Oh yes, I want to do that, because I want to protect my baby.' Whereas the flu vaccine I find I think it's just in the general population, I think that there's less people likely to get the flu vaccine and I don't think it has anything to do with the pregnancy, like dangers of having it during the pregnancy, I don't think it has anything to do with that." (P08)

Other experts speculate that the Tdap vaccine may be more familiar to pregnant women due to the impact of recent pertussis outbreaks on communities in Nunavut. They also suggest that hesitancy surrounding the influenza vaccine is pervasive, irrespective of whether patients are pregnant or not.

"I don't know if it's necessarily because they're pregnant. I think...in Nunavut as a whole we don't have a great amount of flu vaccine in general. So, I don't actually know what the reason for that is if it's just hesitance towards the flu vaccine...opposed to studies and Tdap being safe. They're kind of used to hearing about Tdap being and getting their tetanus and Nunavut did experience our pertussis outbreak back in 2016, so maybe there's more relevancy for them related to pertussis and the babies whereas influenza was always kind of optional and you know wasn't usually offered back when to pregnant women so, it just might be lack of education." (P04)

While P04 does not speculate about why maternal influenza immunization uptake is lower than Tdap, other experts with clinical experience weigh in on some of the (mis)perceptions of the influenza vaccine encountered in practice. For example, several experts cite the belief that the influenza vaccine gives people the virus. The following expert juxtaposes this commonly held misperception with beliefs about the Tdap vaccine.

Influenza and Tdap vaccines are perceived differently for sure. For the influenza vaccine, there is the belief that after you get the vaccine, it will make you sick. If people get sick even a month after [the influenza vaccine], they will attribute it to the vaccine. Have never heard anyone saying that they contracted pertussis from

the Tdap vaccine. Definitely people are more against the influenza than the Tdap vaccine. (P07)

While only present in a small minority of pregnant women, experts weigh in on generalized vaccine hesitancy at the intrinsic level. In a paradoxical logic, pregnant women may be hesitant to accept immunization because they are not experiencing any symptoms of the infectious diseases that the vaccines prevent. This prioritization of downstream over upstream care is reminiscent of providers' process as they deliver prenatal care.

“Um...I think because vaccines are more preventative, so they feel fine in the moment um...where medications are not feeling well at that time. So if it's something as simple as (inaudible) for their nausea, um...it's just something that they can feel the effect right away of feeling better or less pain. Where immunizations work in like a secret magic way where they can't really see it or feel the benefit at that time, so I think it just takes that extra health teaching piece and the need for it at that time.” (P04)

Perhaps, a few experts suggest, hesitancy is rooted in fear of the pain of being vaccinated, but also of the concept of introducing something foreign into their body.

Definitely scary for some people. It's something outside of your body that is going inside. You want to protect your baby; you don't want anything going inside that might harm your baby. Needles are scary in general. (P09)

The invasiveness of immunization is also speculated to impact vaccine decision-making in as much as it is perceived to be a more serious intervention than taking medication orally. The following participant cites an example of another intervention where patients' willingness to receive treatment is dependent on formulation.

“Like even with STI treatment when it went from pills to injectable it was like, ‘Okay I have, I don’t know if I have chlamydia or gonorrhea but I, my partner tested positive, or I got a call that this is positive so I’m here to get treatment,’ and I’ll say, ‘Well do you have symptoms?’ ‘No.’ ‘Do you have um, okay, do you want, let’s just test you for this and then if it comes back positive then we will treat you,’ and people well generally say, ‘No, no, no, can you just treat me?’ And you can by guideline, if you’re a contact, I could just give you the pills. But when it changed to needle form and I said well actually it’s now a pill and a needle. Do you now want to make sure you have it before I give you that? They will wait cause it’s a needle. It’s more serious, does that make sense?” (P02)

According to experts interviewed for this study, immunization, particularly with the Tdap vaccine, is generally accepted among expecting mothers in Nunavut. Ways of knowing about prenatal health and maternal immunization are shaped at the familial, community, and social network level, in addition to the level of the pregnant woman. Determinants of maternal immunization as understood by healthcare experts include historic trauma and personal experiences of families, Elders, and community members, reciprocal desires of pregnant women to protect their families, communities, and especially their unborn child, and the vaccine in question. While generalized vaccine hesitancy is reportedly present in a minority of pregnant women, experts explain that it is common surrounding the influenza vaccine, irrespective of whether a patient is pregnant or not.

Communication, personal persuasion, and providing immunization

In this subtheme, I describe ways of knowing about maternal health and immunization on the provider side of the vaccine. I begin by explaining how information about maternal immunization and associated policies and recommendations are communicated to healthcare providers. I then summarize expert perceptions of determinants of the provision of immunization at the practice-level. Finally, I explore intrinsic provider beliefs about immunization, identified as influencing their approach to maternal immunization discussions with patients.

As discussed in the previous subtheme, there is a reported combination of sources from which pregnant women in Nunavut seek information about how to have a healthy pregnancy, including family members, Elders, and especially healthcare providers for medical advice. Some healthcare experts suggest that pregnant women defer to the judgement of the healthcare provider when it comes to whether or not they should be vaccinated.

“Um, obviously everybody’s got their own views on things if they even have one. Some women are just – if the health care system thinks I should have it, I’ll have it and some women – most women, are in that mindset.” (P01)

If in fact the recommendations made by healthcare providers spurs maternal immunization behaviour, it is important to understand how providers come to learn about maternal immunization, and the associated policies and recommendations.

From a policy perspective, several experts interviewed for this project cite the rollout of the maternal Tdap vaccination program in 2016 as an exemplary and effective method of communicating information about updated immunization guidelines and policies to staff. Experts provide examples of comprehensive staff education, handouts for provider reference, and Communicable Disease Coordinators available by phone to answer provider questions and concerns about the recommendations.

“When things come up like with the whole pertussis thing a couple of years ago, when it came about for women to get it, I think it was good. We got a lot of handouts, we were able to, I don’t remember who we were able to call, but we were able to call people in Iqaluit ... to ask questions if we were not understanding something.” (P01)

There are divergent opinions among participants about whether or not the communication of information about maternal immunization has been effective now that the imminent concern of the outbreak has subsided. Some experts who are also clinicians indicate that they still have access to communicable disease experts, and that they can rely on their

more experienced peers for support in understanding the information being provided to them. Others describe the information sharing as being unreliable as it is communicated electronically to supervisors and may be missed or miscommunicated to healthcare providers.

Updates are currently transmitted electronically (supervisor gets message saying that there are these changes, they update the immunization binder). Due to a lack of time, or maybe human resources, there isn't always someone who gets in touch with healthcare providers in the community to inform them about the changes and how that would affect delivery of care. ...If you happen to miss [the information], or if the regular nurse in charge happens to be away and there's no handover, [new information] can easily be missed. (P07)

One expert adds that communication of any recommendations is inherently complicated by the practice setting, in particular the transience of providers. If providers are coming to Nunavut with incorrect or outdated information, it is possible that updated recommendations may not be communicated to them, or that they may not know where to look, or who to ask, to find it.

"...Prenatal care has many moving parts, and if one is not used to keeping their fingers on all those moving parts, things will have the potential to be lost, forgotten, not attended to, not administered in the right time in the pregnancy. Maybe they have incorrect information that they learned from a health center 10 years ago, and nothing has been updated for them, so they don't know what the newest procedures are or where to find the information." (P06).

As far as communicating recommendations to participants, availability of public health materials about maternal immunization for pregnant women are scarce, according to some healthcare experts, and nonexistent according to others. Where available, materials consist of letters posted in health centres, reminding pregnant women to get their Tdap vaccine.

“I feel like Nunavut could use a little boost on programming and teachings in the communities. You know, like currently, all we have are letters in four languages here in Nunavut, and it’s a reminder for pregnant women to get their Tdap vaccine and it’s posted in every health center as well...I feel we could use a few more resources in the communities regarding this for sure.” (P04)

A couple of experts are uncertain whether these handouts are being read and absorbed and suggest that there ought to be a more effective system for communicating this information to pregnant women.

Other determinants of a providers’ ability to offer maternal immunization from a practice level, include the physical availability of the vaccine. The following expert explains some of the practical determinants associated with acquiring, and safely storing vaccines for provision to pregnant women in Nunavut.

“Some hindrance could be for us here in Nunavut receiving vaccines due to cold chain, delays in flights, bad weather, um...and then ah...different fridge failures and cold chain breaks and things like that, but they don’t happen all that often in the summer months so, winter months we do and avoid ordering vaccines and pre-order them in the spring time so, that’s not too much of a hindrance.” (P04)

Assuming that providers have access to the vaccine, record-keeping is also identified as a determinant of its provision. Clinical experts explain that there have been instances where patients have been unnecessarily repeatedly vaccinated, because their records were not up to date.

“You know I’ve seen over the years that some people have got three or four tetanus’s over the years because they can’t remember if they got it or not but then when you go back and get notes from somewhere else and you realize oh they got it two years ago, they got it a year ago, they got it three years ago. So a better way of being able to track our immunizations going through the communities. Now we

are in an era of people moving, we're not stagnant anymore, we need to improve that as well.” (P10)

The movement of patients mentioned by this participant, is particularly relevant given the transience of pregnant women who often leave their communities to safely give birth elsewhere.

Nearly all of the clinical experts interviewed in this phase of the study report an intrinsic sense of duty to provide immunization; that they vaccinate because it is part of their job.

“I see vaccines the same way I see checking fundal heights or checking fetal heart rates, that it's been deemed a necessary part of maintaining health in a pregnant woman and that of her fetus, and/or newborn, and so I do that as part of her care. I don't have any strong feelings about it one way or the other. I don't spend a lot of time thinking about it.” (P06)

Despite this belief, many of the participants suspect that providers' personal perceptions impact their respective approach to maternal immunization discussions with their patients, and whether or not they offer vaccines to pregnant women. One even suggests that it is the primary and most influential determinant of maternal immunization.

“Oh yeah, there's many many many factors yes...so I would say the number one is the...and I hate to say this is number one, but it is – the caregiver that, the healthcare professionals' view on it. And their attitude towards it, so how much am I going to promote this?...What are my personal beliefs about it? And you know it should really be about that but I often see that. I have seen that it is. 'Oh we can just leave that for later, I don't think that's important. I don't need to give that now,' or 'I don't give the flu vaccination to pregnant women, I don't believe in that.’” (P02)

The optics of physicians refusing the influenza vaccine for themselves are cited by one expert as undermining its importance and may translate into a de-emphasis in their practice.

I think doctors don't push the vaccine enough. Doctors refuse themselves and it is frustrating. (P03)

Another expert identifies vaccine literacy among nurses as being essential in determining whether or not a pregnant woman is offered an immunization during a prenatal visit.

"I think that the main factor would be if the nurse is educated enough to offer the vaccine and of course that the client agrees to the vaccine because it is fairly new in Nunavut." (P04)

Midwives are cited as sometimes having holistic and natural immunity beliefs that may bias their practice.

"We have a lot of midwives across Canada that believe in natural holistic care and natural immunity and those sorts of things too and so I think whether you're a midwife or you're a community health nurse or a public health nurse or physician, we all have our biased opinions about anything we bring that with us to our profession." (P08)

Community experts have several ideas about how to lessen the impacts of intrinsic provider beliefs on the quality and focus of prenatal care. Experts recommend that there be reinvigorated education to staff about maternal immunizations. Several experts also suggest the development of a standardized vaccine conversation template so that no matter providers' personal beliefs and behaviours, pregnant women are getting the same information and are able to make informed choices for themselves.

“The biggest thing for me is that informed discussion. ...I think we need to find some kind of almost like a template or something that all healthcare providers can provide that discussion with clients.” (P08)

Healthcare providers’ recommendations are believed to factor prominently in maternal immunization behaviour, according to experts interviewed for this project. Initial implementation of the maternal Tdap immunization program is provided as an example of effective communication at the policy-level, although ongoing transmission of this information is complicated by provider transience. At the practice-level, physical availability of vaccines, and record-keeping are identified as determinants of maternal immunization. Experts feel that healthcare providers’ personal beliefs are influencing their practice and suggest that there ought to be a standardized curriculum and template for discussion available to providers to ensure that pregnant women are getting a consistent message.

5.2 Virtual Sharing Circle Results

The objectives of the virtual sharing circles and interviews were to generate detailed qualitative findings about the awareness, attitudes, perceptions, and experiences of healthcare providers and community health representatives (CHRs) related to maternal pertussis immunization, and to determine their perceptions about which factors influence whether pregnant women in Nunavut are or are not vaccinated. The experiences of fourteen participants including community health nurses (CHNs), public health nurses (PHNs), CHRs, physicians, and midwives with experience working in communities across Nunavut constitute the data for this phase of the study. Interviews (n=5) were conducted where sharing circles were impossible due to time zones and participant availability. With the consent of one participant, a transcript of an e-mail exchange was used instead of an interview or a sharing circle as they were unable to do either. Memos were used to document the inductive identification of codes, categories, and themes.

Three major themes were generated based on the analyses of these data: opening the door to maternal health and immunization: complexity of access as a determinant of health; communication pathways; and mothers know best: shared experiences, history, and decision-making. Within the communication pathways theme, I organized concepts into two subthemes: connecting maternal immunization policy in practice: bridging the gap between transience and collective knowledge; and speaking the same language: framing maternal immunization discussions. In this chapter I explore each theme and subtheme in detail and provide my interpretation of how they connect to one another.

5.2.1 Opening the Door to Maternal Health and Immunization: Complexity of Access as a Determinant of Health

The ability to access prenatal healthcare, which is not always mutually inclusive with maternal immunization, is cited by healthcare providers and community health representatives as a complex determinant of health that intersects with several others at the individual, intermediate and structural levels. In this theme, I summarize providers' perceptions of the multitude of determinants at the level of the pregnant woman that

dictate her ability to literally and figuratively open the door to maternal healthcare. I also trace the two major configurations of prenatal and public healthcare in Nunavut and explain how they act as both facilitators and barriers to prenatal and public health accessibility.

Participants cite access to prenatal care and the CPNP as opening door to maternal health and immunization. As the following provider suggests, if a pregnant woman has access to a prenatal healthcare provider, there is a reduction in the likelihood of missed opportunities for vaccination. That provider will take responsibility for instructing the patient and keeping on top of the recommended schedule of vaccinations.

“Access to a primary healthcare provider is probably your biggest facilitator [for maternal immunization] because then they are going to be the one who either you know says, ‘Well there’s this option, and they said that you should do it.’” (P13)

“I guess we are facilitators [for maternal Tdap immunization] really, right? Because really, they don’t come to the health centre and they don’t have prenatal visits or regular prenatal follow up, honestly they would never know. ...I would say basically we are the facilitators, and your interaction with the patient, it’s kind of our role and our duty to at least give them that information so they can make an educated decision. Otherwise, reality is, where else would they get that information from, you know what I mean?” (P12)

While participants identify missed prenatal appointments as missed opportunities to provide maternal immunizations, they also acknowledge the complex factors that determine whether or not a pregnant woman is able to get to the metaphorical door of the healthcare system, let alone open it. A few participants cite childcare as being among those factors.

“One of the main barriers is non-compliance with appointments and that’s not always because the patients just don’t want to come like they are usually called in on that day. A lot of them have issues with childcare and aren’t able to come to

the appointment. ...Usually that's what the struggle with compliance come down to is the fact that you know, not only do they have their kids at home, they have their sister's kids and somebody else's kids and there's like eight kids at home and they can't leave to come to their appointment. So I feel like that's one of the main things that causes decreased access it's just like childcare issues and lack of support in the home for them to actually be compliant with their appointments.”
(P11)

Others identify the weather and transportation as determinants of access to prenatal care, and as a result, maternal immunization.

“We do find sometimes that just getting women in for their prenatal appointments can be tough and sometimes you'll have a patient or two that is really really tough to get into the health centre in general. ...If they live a 20-30 minute walk away and it's -50 out then a lot of them are not coming down for their appointment.”
(P02)

One participant working in a setting where pregnant women are required to leave their community to deliver their babies cites this very practice as a deterrent for accessing prenatal care. As this provider mentions in the following quote, the promise of having to leave their community and their family for several weeks may be enough to discourage some pregnant women from seeking any prenatal care until they are in need of immediate obstetrical attention.

“What I find more of an issue is when sometimes in a smaller community, women don't want to be sent out of the community for deliveries. Even you know from say [a smaller community] to [a birthing hub] is quite far and there is no childcare and disrupts [sic] the entire family for several weeks and even worse if they have to be sent to [a Southern city]. ...So some of them will even hide out until they are in labor and then walk into the health centre.” (P05)

Several sharing circle participants suggest that the way that prenatal and public healthcare is delivered in Nunavut may be exacerbating issues related to the accessibility of maternal immunization. In Iqaluit, for example, the Public Health office is the only place where pregnant women can be vaccinated (email correspondence with P01). As the following PHN explains, this means that prenatal patients must be referred by their prenatal care providers (typically physicians or Licensed Practical Nurses (LPNs)) to Public Health to get either the maternal influenza and/or Tdap immunizations.

“We don’t see prenatal - that’s not part of our practice, so we only seek prenats if they come with other kids to their well child appointments or if we see them in a mass immunization flu clinic. They are supposed to be referred down to us from the hospital who sees all of the prenats and they are supposed to be advised when they turn 27-28 weeks to come here to get their Tdap and of course encourage them to get the flu shot at any point in their pregnancy whatsoever.”
(P01)

Participants express their concerns with this practice given that the hospital in Iqaluit is in close proximity to the boarding homes where pregnant women from outside of Iqaluit are housed prior to delivering their babies. This physician suggests that in requiring pregnant women to attend immunization appointments in addition to their prenatal appointments at the hospital, there are now two doors that must be opened and thus unnecessary barriers to accessing public health and maternal immunization.

“I have always felt like there was totally unnecessary restriction placed on women’s ability to get the booster because for some reason the Department of Health feels that we can’t give vaccines at the hospital which makes no sense to me. ...The hospital is where our prenatal clinic is, but the hospital is also placed just beside the boarding home where all the women stay when they are out [of their communities] for delivery. So those women in particular are generally without transportation. ...In order for them to get to the public health building where they are supposedly going to be offered this vaccine, they would have to

arrangements [sic] with the boarding home driver to drive them there or walk. So it's asking them a lot also to make a whole other appointment to get a vaccination.” (P04)

One participant recounts initiatives that have been proposed to try to facilitate accessibility of maternal immunization despite the configuration of healthcare delivery in Iqaluit. At first, they explain, LPNs were explored as potential vaccine providers because they, along with physicians, are responsible for providing prenatal care at the Qikiqtani General Hospital (QGH). Due to the competing responsibilities of LPNs during prenatal visits, the amount of work required to determine whether the vaccines had already been given, and the documentation associated with giving the vaccine, there were too many obstacles and concerns about errors to change their scope of practice to include maternal immunization (e-mail correspondence with P01).

“That LPN that would see that mom in a very rushed - you know you're weighing them, and checking their blood pressure, and getting their pee and blah blah blah. ...[The LPN] is not going to have time or the skill set basically because they are not immunizers, to try to track down to see if that mom actually had her Tdap before they came out for confinement. So we weren't comfortable with that process.” (P01)

Instead of training LPNs to vaccinate, the participant continues, another temporary initiative to facilitate access to maternal immunization was the provision of information sheets from Public Health about maternal immunization, and taxi vouchers, to mitigate barriers associated with transportation. Ultimately this initiative was discontinued, which this provider attributes to staff who were unaware of the program and therefore not championing it.

“They didn't continue with it. They are not doing it. They did it for a little while, but they don't do it anymore so it didn't get continued. It's hit or miss whichever doctor they may see, and we have a lot of doctors that are here for teaching purposes from Ottawa, you know? ...Those may be the ones that see them and they

have no idea about this program so it doesn't get communicated. The ideal person would have been that LPN in the prenatal clinic, but they come and go as well so it doesn't get communicated and isn't consistent.” (P01)

Participants explain that the QGH in Iqaluit is the only hospital in the territory. All other communities are serviced by Health Centres where CHNs, PHNs, midwives, and sometimes physicians, are responsible for providing prenatal care, including maternal immunization. Some participants suggest that this “one-stop-shop” approach as coined by P03, is effective in ensuring maternal immunization uptake.

“It is a bit similar to [a small community] so it is a bit more of one stop shopping here which is fantastic! ...Because we have a midwife and public health here, we have a lot of teaching that happens on site very specifically to the public health component of health promotion and prevention and also the midwifery component of public health. So we're very lucky in that aspect here now with the Tdap we have a full compliance rate with that.” (P03)

“ ...For all the smaller communities that I cover, [maternal immunization is] generally not an issue at all.” (P05)

Others suggest that the “one-stop-shop” approach is not without its own challenges. While the following provider highlights the convenience of pregnant women being able to access prenatal and public healthcare in one place, they suggest that if pregnant women experience difficulties accessing this care, it may result in missed opportunities for prenatal healthcare *and* immunization, instead of just the latter.

“I guess one of the benefits of the small communities is that we see our pre-natal patients that are kind of doing everything so there isn't that gap between their pre-natal visit and then going to public health for the vaccine for the Tdap I mean. ...So there is nowhere else for them to receive their care so it's kind of the only

option which is sometimes simplifies things but then of course if it's far away or difficult to get there can also make things more difficult.” (P02)

When access to prenatal care proves to be an issue in smaller communities serviced by this physician, they explain that they can bring maternal care to the doorstep of patients rather than the other way around. They explain that they literally go door-to-door and provide care directly to patients in the comfort and convenience of their own homes. While admittedly infeasible elsewhere, this provider suggests that this has been a facilitator for the provision of maternal immunization.

“So for my communities - because a lot of them are quite small - generally we know who's pregnant in the community and where they are located. So even if they don't show up to prenatal [appointments], we just end up going door-to-door and we find them. So it's actually not really an issue and often when they don't come...it's because they don't have a ride or they don't have childcare something like that so us going to their home actually really helps.

I think because the environment is so different outside of the arctic, I'm not sure you could really extrapolate exactly what we're doing here to a completely different environment. Like me going door to door well I can't do that in [a large Southern city] like that's just completely not feasible!” (P05)

This provider shares that offering food and encouraging pregnant women to bring their children and families to their appointments, helps to reduce some of the barriers associated with accessing prenatal care, and in this case maternal immunization simultaneously.

“We do find sometimes that just getting women in for their pre-natal appointments can be tough and sometimes you'll have a patient or two who is really really tough to get into the health centre in general. We have found that we started

providing food during our pre-natal days, so that's open to the women and they can bring their kids and family and kind of helps with attendance.” (P02)

Another initiative being explored in this community to facilitate access to prenatal care and maternal immunization, is that of a volunteer transportation service.

“We're hoping to get some more vehicles run by like volunteer groups in the community who can go pick up the women and bring them down for their appointments to help make it easier for them to receive their pre-natal care. That will hopefully be a facilitator in the future.” (P02)

CHNs in smaller communities also emphasize the intensity of the workload required on their side of the metaphorical door to maternal health and immunization. CHNs are responsible for chronic disease, well-child, and prenatal care, in addition to promoting and providing (maternal) immunizations.

“Yeah I would say like in [my community], I tend to be the person who runs all of our programs - whether it's well child, prenatal, or chronic disease programs, I'm kind of the person who helps to kind of make sure that these programs are implemented properly and that we're keeping records and keeping everyone up to date.” (P09)

“Our workload is insane! Sometimes we have normal days but some days it's almost unmanageable and it's extremely stressful and [our supervisors] always want everything to be in regular hours.” (P11)

This participant explains that due to a perfect storm of competing responsibilities, complex prenatal care needs, a lack of full-time nursing staff, and the associated time constraints, maternal Tdap and influenza vaccines may be missed.

“...To be quite honest our prenatal appointments are only 30 minutes ...including documentation, and we have a lot of very high risk prenats who take a lot longer than that. So sometimes the appointments can be overwhelming ...and so sometimes the Tdap vaccine gets missed.” (P11)

“The acuity here is like something you would see in a major emergency department someday so sometimes like flu clinics go to the wayside. ...I was actually the one who ran the full prenatal program while the flu clinic was going on and honestly just staying on top of the basics of all the high risk patients and all the stuff, I was spending hours and hours of overtime every week just trying to stay on top of it. ...We didn’t actually implement flu vaccines like a clinic specifically for prenats and if I’m going to be - unless the prenatal came in by themselves, I don’t think any got vaccinated with that flu vaccine. ...I feel really bad about that and it’s shameful but we have trouble staying afloat for the major stuff sometimes because we’re so short staffed sometimes. ...We all believe in women having the influenza vaccine during pregnancy ...but it’s just implementing it is another thing because there’s a lot of barriers here for the healthcare professionals that work here just because of how busy it is and how short staffed we are on a regular basis.” (P11)

The following participant suggests that underlying these practical barriers, are ongoing concerns about access and compliance to prenatal appointments. As a result, the participant explains that the maternal influenza vaccine specifically may be deprioritized, because providers feel like if they push that vaccine in particular, pregnant women may not return for further care.

“We try to give them education on Tdap as one, and usually I think Tdap goes really well but then to add something else, who knows. You might bring it up and get resistance again, which is something I fear too. ...I don’t want to throw too much at them and then I start losing them. You’re going to get a whole lot of, ‘Well I took this vaccine, why are you giving me another one?’ you know what I

mean? I fear that sometimes if I throw too many things at them, I might start creating a resistance there then maybe they aren't going to look at us as resources anymore. So I kind of tread lightly with that and I feel bad about it too because of course I definitely advocate for the flu vaccine as well, but because we have so many high risk prenatales, the last thing I want is to lose that person or lose them coming to their appointments or them being non-compliant with medication just because they are fearful again. ...Once I start to get that feeling that I'm getting a little bit of resistance, I don't want to lose that patient all together so I'll accept that person not taking the flu vaccination if they are going to take their iron for example you know or if they are going to show up at the next appointment. To me I mean it sucks to say that will try to get the greatest benefit we can get overall and if the flu vaccine has to suffer sometimes then it unfortunately does suffer.” (P12)

A couple of participants explain that they and their colleagues have offered to work overtime to provide a weekend influenza immunization clinic in the hopes that perhaps it would help to get more pregnant women in the door, but that due to the financial constraints associated with paying nurses overtime, this offer was refused.

“And actually, that's a barrier that we didn't touch on, but the reality is that cost is a barrier; it is a barrier to delivering health services and we all know it. It's not a Northern thing, it happens in the South as well. We can have great ideas, but the reality is: can we do this in clinic time? We cannot. Not only do we have the programs, but any moment there could be an emergency that shuts this whole place down. Those are the realities of what we have to work with. So when we try to make ideas that involve you know using extra time, ...there is a barrier from our employer who does not want to be utilizing over time. ...It could work both ways ...it could also be overworking the nurses and that's a reality too right? We've been up 24 hours before dealing with emergencies and that's a fact as well, but there are nurses who are here that are not on call, you know? Nurses who are

here that can be utilized for these extra programs. Yes, cost is a barrier. You have to be realistic about it you know, it is expensive.” (P12)

Due to their experiences dealing with the facilitators and barriers associated with providing prenatal and public healthcare in Nunavut in their respective communities, providers operating within one configuration perceive the other to be more effective. Providers in Iqaluit believe that the unified configuration of prenatal care and maternal immunization in smaller communities is ideal for optimizing uptake because the prenatal care provider is able to give the vaccine during their appointment.

“Also I think health care delivery in Nunavut – not attitudes of women, or vax hesitancy etcetera, is the biggest barrier to good vaccination rates in pregnancy and non-pregnancy. We have advocated repeatedly and for years to have flu and Tdap given at the time and location of our prenatal appointments but resource constraints apparently are why that has not been implemented. The small communities now have better rates of Tdap at least because it is the nurse doing the antenatal care visit that gives the shot... same visit. In Iqaluit they have to go one day per week to another location just to get vaccinated.” (P14)

A CHN practicing in one of those smaller communities however suggests that the separation of Public Health from prenatal care, would be the best remedy for the overwhelming workload associated with providing prenatal care and maternal immunization in a single appointment.

“It sounds awful but honestly we just don’t have time, it should be a separate clinic where they are called in with a public health nurse.” (P11)

Participants insist that it is neither their belief nor intention to suggest that healthcare in Nunavut is “*bad*,” nor that “*the office of public health is not doing its’ job*” (P14). Instead, they acknowledge that prenatal and public healthcare delivery in the territory to be the product of challenging resource constraints.

Healthcare providers and representatives trace two major configurations of prenatal care and maternal immunization in Nunavut: in Iqaluit, maternal immunization is delivered separately from prenatal care otherwise provided at the hospital; in smaller communities, prenatal care and maternal immunization are provided simultaneously. Providers operating in both settings share concerns about the accessibility and feasibility of these configurations, and suggest providing transportation, food, childcare, and where possible, door-to-door prenatal healthcare to mitigate whether or not a pregnant woman is able to get to the literal and figurative door of the healthcare system.

5.2.2 Communication pathways

In this theme, I trace the diverse pathways through which maternal immunization information is communicated from the Government of Nunavut, through healthcare providers, and ultimately to pregnant women in Nunavut. I begin by describing how healthcare providers and CHRs are reportedly informed about maternal immunization, and some of the ways in which their knowledge is either sustained or interrupted over time. I conclude by explaining the awareness, attitudes, perceptions, and experiences that inform how providers frame and provide maternal immunization to meet the perceived needs pregnant women.

Connecting Maternal Immunization Policy in Practice: Bridging the Gap between Transience and Collective Knowledge

In this subtheme, I explain how maternal immunization policies, recommendations, and schedules are communicated to healthcare providers and CHRs. I use the concept of collective knowledge to refer to shared awareness about maternal immunization specific to the practice setting in Nunavut, distributed across policies and providers which interact in a complementary way, and embedded in collective artifacts such as rules, procedures, and documentation so as to be sustained over time (137). I trace some of the particularities of practice cited by providers which contribute to or undermine the ability of providers, permanent and casual, to provide maternal immunizations to patients in Nunavut.

Whether or not providers recommend or offer maternal immunizations to their patients depends on a plethora of factors, one of which is their own awareness of current policies, recommendations, and schedules. As the following participant explains, a successful maternal immunization program is one where providers are fully aware and can confidently recommend vaccines to patients.

“I think in general like just to have your information and to provide as much information as possible like when you do at any immunization clinic, you want to have all the answers ready for any patient that you have, but also you know knowing when to like say, ‘I’m not sure and I’ll find out and getting back to you.’ Those types of things, so just having all of your information, all your ducks in a line, being confident in your ability to ...make that recommendation to having the vaccine. I think those are key things when rolling out a [maternal immunization program].” (P13)

There are an array of methods by which policies, recommendations, and vaccine schedules are communicated from the Government of Nunavut to healthcare providers and representatives. CHRs cite biweekly telehealth conferences and an immunization education month where they are provided with any and all relevant information regarding maternal immunization to share with pregnant women at the CPNP.

“I have enough information to provide to the community. So, if I didn’t have enough templates, that’s where I would recruit more information from headquarters in Iqaluit. If not ...we have our biweekly telehealth conference, so it was pretty much well organized. And if something comes up, nurse in charge would bring that up. We were pretty much up-to-date.” (P08)

“Yes we do, we...let me see here so we have like a calendar of our community health promotion so August is the whole month is all about immunizations and so we have a whack ton of resources like we have a whole CDC file and like it’s all available, it usually comes from territorial but we do telehealth.” (P10)

The following physician explains that they are sent official communications regarding maternal immunization by e-mail, and that they attended a presentation about pertussis and response measures during weekly rounds.

“By email mostly like by official communication, although we have a weekly rounds at the hospital that is [sic] well attended by different disciplines who work in healthcare in [this community] and so I believe we also had a presentation on pertussis like detailing all of the response measures and it would be included in that as well.” (P04)

CHNs and PHNs describe getting information from their managers, nurses in charge, and communicable disease coordinators about maternal immunization.

“So the way that we get our recommendations is through, we have a manager who works in the head office and [they] give us all of our recommendations. ...[They are] like an expert and [they] make sure that our immunization manual is up to date. ...All of our recommendations come from [them] and like [they do] all of the numbers. ...I send [them] my yearly stats and [they do] all of the ordering of the immunizations. Yeah, so [they] are great and each region has their own.” (P13)

A few CHNs explain that they also receive reminders from obstetricians in the territory, which serve to mitigate some of the challenges presented by provider transience.

“So our prenatal guidelines and the Tdap guidelines for prenats come from our obstetricians in Iqaluit in Qikiqtani General Hospital. ...Those guidelines are set for us and we’re kind of sent them once in a while, and just reminded to give the Tdap vaccine. ...They do kind of like just explain to us every time they send it just because there are new staff and a lot of turnover frequently. So every couple of months they will send it and reiterate, ‘Hey don’t forget to give the Tdap vaccine after 26 weeks just for you know acellular pertussis. ...This is the reason, and this

is what evidence shows and this is the reason that we need to give.’ So they kind of like provide the evidence in their communication with us and passing on the guidelines” (P11)

Whether or not vaccine policies, recommendations, and schedules are communicated from the Government of Nunavut to healthcare providers effectively is the subject of varying opinions across participants. Some providers, like this PHN, express their satisfaction with the way that information is shared.

“Well I mean I get sent the immunization schedule like whenever they change and I just go along with it so I haven’t found it difficult at all for the rollout. ...Definitely all the nurses and the physicians that work in the health centres are made aware so I think the onus is on us to convey that information to the pregnant women.” (P05)

Others provide examples to suggest that communication between the Government of Nunavut and healthcare providers could be improved. This physician describes a disconnect between maternal immunization policy and practice in the aftermath of the 2016 pertussis outbreak as it was unclear among them and their colleagues whether the recommendation for maternal Tdap immunization was ongoing.

“The interesting thing is that like in 2016 when they made that decision to recommend immunization in each pregnancy with Tdap. I don’t know that it was ever necessarily communicated to us that that would be a permanent change. We initially felt that it was an outbreak situation response and once the outbreak had stopped there was sort of this lack of knowledge about whether we were actually supposed to be continuing. I think personally I felt like it was still a good idea even if it wasn’t the official recommendation, but I think some of us didn’t know.” (P04)

A CHN shares that the rationale for these policies, recommendations, and schedules were not communicated to them, despite their being responsible for running the immunization program in their community.

“To be honest I’m not even sure, we’ve never really been explained why [the Tdap vaccine] is important to be given in maternal pregnancy so we offer but I’m not even really sure why exactly we do it every year. ...I personally don’t actually understand why we would give it to someone every year if the normal population only gets it every ten. We’re just told that we have to do it. That’s just really what we’re kind of told that this is the new process...do it. Sometimes the Government of Nunavut isn’t very good at disseminating their ideas of the whys of things sometimes, so it’s just like this is the new thing and this is how you have to do it and sometimes there’s not an explanation. So like I said I’m the one who runs the program in [this community] and we’ve never been given information on why.”
(P09)

“...like I said we’ve never really received any education. We’ve just been told, ‘You have to give this.’ So it’s never really been explained to us like how we should approach – how we should talk about it, ...it’s just been told like, ‘At 28 weeks, you give this and that’s the new process.’” (P09)

The following CHN suggests that there are some ambiguous details within the policy. For example, there is no guidance about whether or not to immunize febrile patients.

“I think the government could be more clear because there is always like the ongoing things with vaccines that everyone found is that everybody is always worried about fever. Do you have a fever? No you can’t vaccinate them. ...Nowhere has it been implemented that that is a contraindication for vaccination. It’s kind of just one of those non evidence based practices that so many nurses have, and it’s usually the older nurses and I guess that maybe at one point that was a policy but it’s not anymore. ...That regional coordinator that I

was talking about, like she'll be like, 'Well you can't really...' like I remember talking to her about it once because I wanted to release something saying like, 'This is our policy on fever with immunizations,' and she was like, 'There is no strict policy on it.' So you know it's whatever the nurse is comfortable with because it's ultimately their practice, right? So in order to like mitigate that type of risk you really need to have something from your employer stating you know, 'This is best practice.'" (P13)

In addition to some details surrounding maternal immunization being miscommunicated from the Government of Nunavut to the healthcare providers and representatives, several participants highlight that the prenatal documents (i.e. flow charts, forms, checklists, binders) used in practice are outdated. As a result, neither the maternal Tdap nor the influenza vaccines are included in these documents.

"...One issue I can see is we have a pre-natal flow sheet like a whole charting mechanism like every province and territory does and it was last updated in I think 2015, so Tdap and influenza for that matter is nowhere on there." (P04)

As the following participant suggests, this logistical oversight acts as a barrier to offering maternal immunization, because it relies on providers to remember their immunization responsibilities on top of everything else they need to cover.

*"Just quickly as more of a barrier I guess we also have those pre-printed pre-natal sheets that says like during what week what things are due, but the one things that they're missing is the Tdap, **so we have to remember to add that to the checklist.**"* (P02)

Participants suggest that despite opportunities for the loss of collective knowledge due to ineffective communication of recommendations, and outdated prenatal documents, permanent or returning healthcare staff in Nunavut are generally familiar with maternal immunization.

“I think for the full time staff or people who are up north often [maternal immunizations are] pretty well known and then for the more casual nurses who might not be as familiar we’ve kind of setup a system to make sure we catch that if it’s missed.” (P02)

For others, collective knowledge is more aspirational due to human resource constraints.

“If you are ever in the position where you are able to get five permanent nurses in one community, they are your opportunity to actually set a standard and a culture for that whole community to follow. ...There is going to be consistency in your care, there is going to continuity where they know okay, we know that this is how it functions and this is how it works. But unfortunately we’re not exactly there yet so there are a lot of casual people, so we still have to take over a good amount of the responsibility.” (P12)

“Yeah like if there was to be more one to one care with the midwives or whoever they are seeing throughout their pregnancy. That’s another issue is the resources, the turnover because we have you know contract nurses and you know you’re seeing different people throughout your pregnancy you know. So I feel like if there was a consistency then people would feel a lot better to ask more questions and get information.” (P10)

In particular, several participants suggest that the volume of transient staff coming in and out of communities in Nunavut may contribute to a loss of collective knowledge, as not all providers are aware of the maternal immunization recommendations.

“There are lots of casual staff coming in and out of the health centre and not everybody is aware of the protocols of giving the Tdap in that window after that 26 week period and it might be missed. So most women here I feel like it’s a pretty

positive experience with them being ok with us going ahead and giving the Tdap vaccine.” (P11)

“I feel like that is one of the huge things is sometimes you’ll get casuals coming in and they won’t know that the Tdap vaccine is supposed to be offered at 26 weeks. ...It’s not always their fault, they are thrown into this position where they are seeing prenatal patients and they are just trying to get the basics done and they miss something like the Tdap vaccine because ...they are not made aware.” (P11)

Participants explain that in Southern Canada, unless healthcare providers are working specifically in an immunization capacity, they may not be as familiar or comfortable with providing maternal immunization, as healthcare providers working in Nunavut.

“Especially for casual nurses it’s always a struggle of Northern nursing to get nurses who are going to be adequately prepared and trained for what they are going to be doing when they get to Nunavut. ...It’s quite different from the South and you know, a lot of nurses love it, but a lot don’t. ...So yeah, I think education like just being prepared for what you’re coming in for will really help you know increase the uptake of these prenatal immunization programs. As long as the nurses like know what they are recommending and then as long as they do give a firm recommendation, I think it goes quite smoothly.” (P13)

Providers can be and are taught to vaccinate through a self-directed immunization certification course and exam for nurses. This was the only formal training cited in the sharing circles to orient transient staff to the provision of (maternal) immunizations.

“Yeah, we do have like an immunization exam, so you have to be certified to give immunizations in Nunavut before you can actually give them, and you have to re-certify every two years I think so there is that. ...It comes with like a huge bundle of information - it’s kind of a lot to take in at first but then once you know do enough reading to pass the exam, you kind of have a pretty good basis. ... I think

that that is now mandatory for all nurses coming into Nunavut to have that, or you have to get it before you can give them. I'm not sure if you have to have it before you come or are working on it. It's probably working it because I feel like in my last couple of weeks there was a few nurses who didn't have the exam, so I had to go in and do their immunizations for them. But that exam has now gone online which has greatly improved. It used to be in paper when I first started but it's marked and distributed by the regional coordinator that I was talking about."

(P13)

While formal communications through the aforementioned channels contribute to an underlying collective knowledge of healthcare providers and CHRs, interdisciplinary collaboration is cited by participants as being essential to its sustenance. Collaboration is occurring within and across professions to ensure that the most current information is being shared with participants, and that there are as few missed opportunities to vaccinate pregnant women as possible. A CHR explains that registered nurses are resources for them should they ever have questions about maternal immunization.

"We have a public health nurse in most big communities or in the region and we can call the public health nurse if we have questions about specific information that we're not sure of and or like any of the nurses that are available that can help." (P10)

A CHN provides an example of how they support their midwife peers in providing information, and in some cases maternal immunizations when the midwife may be new to the community and need the extra support.

"...So because I became some sort of expert in the health centre on immunizations, I would help out with the midwives whenever they had questions, concerns or if they were new to the region or didn't know as much. I would come in and do some patient counselling prior to immunizations, I could help them drop off the immunization or actually give it to the patient or if they were

uncomfortable or if the woman was uncomfortable. So I did a lot of that stuff.”
(P13)

A PHN explains that they collaborate with their CHN colleagues to make sure that pregnant women are fully immunized.

“Well before we had midwives you know we certainly had one of the community health nurses oversee the, you know the prenatal program. And certainly, you know, her and I would work together in terms of making sure that the mom was up to date with her immunizations, either she would do it or she would refer the mom over to me.” (P06)

A CHN cites physicians as very supportive and responsive to their questions about anything related to prenatal care. While they have not had any questions regarding maternal immunization, this participant extrapolates that the same support would be available to them if they did.

“I find that the obstetrics program is really well supported like we have access to the obstetrician constantly. We get updates from like the schedule every month. ...Any questions I’ve ever had I can quickly email the obstetrician and get a response in a minute. ...We haven’t really had an exception I think when it comes to immunizations so far but if there ever was a case, ...we could easily just email any other doctors and say ‘Hey, we found so and so. What do you think?’ and get a response really quickly.” (P12)

Another way in which several healthcare providers contribute to the sustenance of collective knowledge about maternal immunization, is by handwriting maternal Tdap into the appropriate prenatal documentation and flagging it so that neither permanent nor casual providers miss the opportunity to offer it to patients. The following participant admits that this is not an infallible solution because there is a high birthrate in their community, and therefore some charts are inevitably missed.

“I’ve noticed that when the pregnant women come from community the Community Health Nurses have to kind of add in sometimes, they’ll add in a little checkmark you know ‘Got Tdap’ check. If you don’t do that then it’s difficult to read the narrative all the narrative notes and pick out that the person got Tdap. So it is a bit of a change and there is sort of a delay in having it be the same as all the other standard recommendations for care in pregnancy.” (P04)

“We’ve never actually got a new sheet that includes Tdap printed on it for after 26 weeks. ...So that’s one of the main reasons it’s missed is because it’s not actually on there; they’re using old forms and they have never made new ones. So people only know when I’ve gone along and put in the checkbox, but we get so many prenatals all the time ...so not all of the binders will necessarily have that checkbox on them unless someone has handwritten it. ...So that’s one of the main reasons it gets missed so I’d say those are the main reasons for decreased access.” (P11)

There are differing opinions among participants about the effectiveness of maternal immunization communication from the Government of Nunavut to the provider level. Inefficiencies in communicating recommendations to providers can contribute to the deterioration of collective knowledge and in so doing, the ability of (especially casual) providers to offer maternal immunizations to patients. Even permanent providers who work in Nunavut full time risk missing opportunities because the infrastructure is not one that is built (nor has it evolved) to connect maternal immunization policy into practice reality.

Speaking the Same Language: Framing Maternal Immunization Discussions

Participants explain the different ways that maternal immunization is communicated to patients from campaigns and educational materials organized at the territorial level, down to individual communication addressing patient priorities and concerns within an appointment. In this theme I discuss providers’ experiences literally

and figuratively speaking the same language as patients move toward understanding and either accepting or refusing maternal immunization.

The majority of the healthcare provider and community health representative participants in this phase of the project identify discrepant uptake across maternal immunizations offered. Almost all of the sharing circle and interview participants report that pregnant women are highly receptive to the maternal Tdap immunization, but that maternal influenza immunization is the subject of ongoing hesitancy among patients.

“...Like I said most moms are very receptive to the Tdap [vaccine]. The flu vaccine however takes a little bit more convincing and many will say, ‘No I’ll have the whooping cough, but I don’t want the flu shot.’ ...I’ve been 13 years trying to work on that!” (P01)

“I rarely get people decline [sic] it so I find that there is some acceptance in contrast to the flu shot where I get a lot of...we don’t have a great uptake for the flu in comparison. So that’s kind of my experience, which I find really, really interesting that there is a discrepancy between those two.” (P07)

“Both [maternal immunizations] are available. But whooping cough was a hit, but the flu was a bit down.” (P08)

Participants with experience working both inside and outside of the territory of Nunavut note that hesitancy surrounding (maternal) influenza immunization is part of a general trend of poor uptake for influenza immunization in Canada.

“There are quite a few people who just don’t get the flu shot ever and it’s sometimes hard even when you are trying to give it because of pregnancy. If they generally haven’t gotten the flu shot in the past then they seem to continue to refuse it even if pregnant. But yeah just kind of just consistently asking them sometimes you wear them down but sometimes it just doesn’t happen.” (P02)

“I mean for the flu vaccine, the flu vaccine has a hard time in the South, and despite all of the education and evidence people are constantly given, I feel every year I often hear the same thing. There’s a huge lack of belief and trust in the flu vaccine and I just can’t figure out why. So in the South we have a hard time getting people to take the flu vaccine. Up here it’s unimaginable how hard it is to get it done.” (P11)

Other factors thought to be affecting the uptake of maternal influenza immunization in Nunavut are the immunization behaviour, language, and attitude of the provider delivering the message, the availability of appropriate teaching materials, and the emphasis laid on protecting the baby.

There is an extensive annual public awareness campaign across Nunavut to promote and provide the influenza vaccine during influenza season. Providers explain that the vaccine is promoted in all health clinics with consent forms available for patients to read and sign in the waiting rooms. Participants also cite public service announcements made on the radio, on social media, and in between community bingo games to generate awareness about the influenza vaccine. In particular, they explain, their campaign strategy is to highlight that pregnant women are part of the high-risk population.

“In the fall of every year we put out a big ...it’s Nunavut wide, that we put out a lot of PSAs which are public service announcements. We put them on Facebook, we put them to all of the [Government of Nunavut] employees, and we put them on all of the local radio stations about the flu vaccine will be coming out we will be having clinics. ...We certainly highlight the high-risk areas which pregnancy is included in the high-risk population for influenza vaccine. So we do do a lot of education campaigning around that. And we have CHRs, which are Community Health Representatives and they work in the health promotion program so that’s their role as well is to go out and deliver all of these packages for teaching about the flu vaccine, setting up clinics outside of the offices and even going to offices where people work to deliver the flu vaccine. ...We do have low uptake and that’s how we do that. ...We branch out and offer it in North Mart, we offer it to the

buildings that house a lot of workers, and of course, you know, the groups. We don't single out pregnancy, but we do always make sure to put that message out there that that is one of the high-risk groups and we strongly recommend it."

(P01)

In addition to promoting the influenza vaccine, providers also set up mobile immunization clinics at flea markets, in private offices, in stores, and at high-volume community events. Participants explain that despite the lengths they go to promote and provide the influenza vaccine, uptake is still below that of the Tdap vaccine.

Other than the preliminary promotion of the Tdap vaccine in the wake of the 2016 pertussis outbreak, there is no ongoing Tdap immunization campaign at a territorial level, according to participants. One provider suggests that they *could* intensify promotion of the maternal Tdap immunization, but that the current uptake suggests this is unnecessary.

"In our community we have even taken great lengths to go to community functions setup booths at the northern store you know announce predetermined dates and times on radio announcements and still our uptake is low for the flu vaccine. ...We purposely you know submerged ourselves into community events where there is a high volume of people and still it's not being taken advantage of but we haven't had that issue with the Tdap." (P03)

"Oh gosh no. This is a campaign that starts every October for the flu season so for Tdap ...I mean ideally we have a movie theatre here that ideally we could be showing a commercial about Tdap and pregnancy and there could be teaching moments on the radio in the communities that certainly could be done if uptake is low for the Tdap for sure." (P01)

Participants explain that while immunization campaigns are organized at a territorial level, it is ultimately the responsibility of nurses, midwives, and physicians to

promote maternal immunizations, share resources, and offer vaccines during their interactions with patients.

*“We are **the teachers and the keepers of all of the vaccines** that are given publicly funded.” (P01)*

“Unless we forcefully kind of put posters or flyers, or talk on the radio and get that information out there, it’s not like how in our major cities we can Google something. ...The health advocacy is very different up here. So would say basically we are the facilitators [of maternal immunization]. ...Your interaction with the prenatal patients it’s kind of our role and our duty to at least give them that information so they can make an educated like decision. Because otherwise, reality is where else would they get that information from? You know what I mean?” (P12)

Due to their ability to speak both Inuktitut or Inuinnaqtun and English, as well as their roles as community members and members of the circle of care, CHRs are identified by participants across professions, as also being essential to the promotion of maternal immunization.

“I’m the one who was implementing [the maternal immunization program]. Knowing that I can speak fluently in both languages. So nurses were the ones who was [sic] doing the planning, I was the one doing the presentation and bring [sic] the awareness.” (P08)

Healthcare providers and CHRs explain the range of topics covered as they discuss maternal immunization with pregnant women in their practice including what each vaccine is for, who is eligible to receive it and when, the risks and especially the safety of the vaccines offered, the mechanism of vaccine action, and the cocooning strategy for both the influenza and pertussis vaccines.

Despite the expectation that healthcare professionals promote and offer maternal immunization, there are no patient teaching materials or literature specific to maternal immunization available to them, nor is the literature specific to Nunavummiut.

“I guess maybe a lack of Nunavut specific education materials around the vaccination. Although I know that at public health they do have information sheets that are in all languages about each vaccine that they give, ...they are not I don't think I could be wrong, but I don't think that they are particularly tailored to pregnancy like giving a vaccination in pregnancy it would just be generic information about Tdap. (P04)

“So the main resources that I have access to in Nunavut are all based on childhood immunization like infant immunization so we don't have any that I know of, the midwives might have access to it and I wasn't aware of anything specifically for women but we do have like an immunization manual that does have handouts on each vaccine.” (P13)

In addition to the paucity of maternal immunization literature, a couple of providers acknowledge that their own perceptions of maternal immunization shape the way that they communicate with patients. This midwife explains that the choice to emphasize the benefits of maternal immunization to both the pregnant woman and the infant reflects their personal beliefs that immunization is a noteworthy and effective intervention.

“For myself, I support vaccination, I support the vaccination program. I see the benefits of it and I think when I'm talking to clients and explaining that you know, pregnant women who get the flu for example will get it worse than someone who is not pregnant because their immunity is slightly depressed when they are pregnant. And when I am talking about the Tdap vaccine and explaining that you know there is immunity crossing the placenta that's protecting their baby. ... I talk about how protecting the adults that are around those vulnerable children is important too so that even though if they are not worried about it themselves

about the flu, that if they get the flu and then their newborn gets the flu their newborn will not do very well. So those are key messages that I'm passing on and I suppose it reflects my own view about which I think mirrors the public health view that vaccination is one of the greatest advances in medicine and they keep us healthier.” (P07)

While the predominant sentiment toward maternal immunization against influenza, pertussis, and RSV is positive in this sample of providers and representatives, participants express concerns that some of their colleagues may be vaccine hesitant. This CHN explains that historically there have been difficulties with midwives' personal views about the influenza vaccine potentially impacting whether or not they recommend it to their patients.

“We've had a bit of difficulty in the past with a few midwives, you know it's their personal opinion that they don't get flu shots ...they don't recommend it to their family, so how can they recommend it to their patients? So I've had a little bit of trouble in the past so that's a bit of a barrier that I see with that program so it's difficult sometimes.” (P13)

This physician also recalls encountering vaccine-hesitant CHNs in practice and speculates that it may impact the messages being communicated to patients.

“Once in a while I encounter a community health nurse who's not as pro-vaccination and so then I wonder what kind of messages might be conveyed from them to some of the patients, but then that's just speculation. I only know that there are some nurses who are less pro-vaccination because they ask me questions about their own kids ...like, 'Well how long should I delay the vaccination?' I say, 'Well you shouldn't delay.'” (P05)

When discussing maternal immunizations, participants describe the importance of sensitivity to *how* the message is framed and provide examples of how they adjust their

messaging based on the concerns and priorities of the patient. For example, participants perceive one of the primary priorities of pregnant women to be to protect their infant. As one provider put it, “[pregnant women] will pretty much do anything for their babies” (P07). It follows that when providers emphasize that maternal Tdap immunization is a method of doing just that, it is generally accepted among pregnant women.

“I find that because it just kind of simplifies it for them just saying you know, ... 'Like what happens is like it helps baby learn how to fight off whooping cough and there's outbreaks of whooping cough in Canada now and it can make them really sick from their breathing and occasionally babies can die from it. ...So it's going to help baby learn how to fight it off and hopefully baby won't get sick with it. And then most of them will say, 'Okay, yes' because they realize it's for baby.”
(P11)

In one of the communities where providers are not framing maternal Tdap immunization as protecting the infant, uptake is reportedly low, and the vaccine perceived similarly to the influenza vaccine by patients.

“We still do offer it when they do come past 28 weeks like if they are 30 weeks or 29 weeks we will still offer it but I would say probably in my experience 80% do decline that would be my kind of experience. ...We do offer [maternal influenza immunization] as well for each pregnancy too. Yeah like I said, it's kind of like the Tdap, they don't always go for those needles to be honest.

...Like I said we've never really received any education [about the maternal Tdap vaccine], we've just been told you have to give this so it's never really been explained to us like how we should approach how we talk about it so it's just been told like at 28 weeks you give this and that's the new process. So - but you're right actually so framing it more as a protection for baby because baby won't get those vaccines until they are quite a bit older might be a better way to sort of to get people to be more on board with getting the vaccine. That's actually a very good question.” (P09)

Participants speculate that a hypothetical maternal RSV vaccine would also elicit high uptake if providers framed it too, as protecting the infant from the virus.

“So maybe when we’re campaigning for [maternal RSV immunization] and we’re putting that education out there, really really important that we emphasize the benefit that this has on the baby. ...Then mothers are realizing, ‘Well this has nothing to do with me, this is about saving the life of my child here!’ So we’re able to make sure to put emphasis on that. Especially in the north were so many children are suffering from respiratory illnesses and the effects of it ...it’s really important to emphasize that this is for the baby.” (P12)

Another way in which providers may positively frame the message, is by acknowledging patient concerns while emphasizing the safety and importance of the vaccine, and that it is routinely administered, not just to pregnant women. One provider explains that the fertility rate in Nunavut is quite high, which means that women are getting several Tdap immunizations in relatively quick succession. This is perceived by this provider to act as a deterrent for maternal Tdap immunization.

“I would say with our maternal vaccination program, we have a lot of moms who get pregnant quite often and quite frequently. ...I would say a lot of them if it’s maybe their first or second pregnancy they’ve been okay to do the Tdap at 28 weeks. But if we have a mom who gets pregnant basically every nine, ten, eleven months, they are usually the moms who decline. ...We tend to have a lot of moms who might be like a gravida seven or a gravida nine sort of pregnancy so yeah they don’t get those Tdap’s every year when they are pregnant. But like I said if it’s new mom then they do they agree to go ahead with it so that’s been my experience so far.” (P09)

A different provider, however, frames the message around the fact that pregnant women have been vaccinated with the Tdap vaccine before, reportedly making them more confident to get it again.

“I like to tell women, ‘This is not new,’ you know, ‘You’ve had the Tdap before.’ I think we get a lot of a lot of restrictions when it’s something that a lot of people don’t know about so I like to emphasize that, ‘Don’t worry, this is not an experiment,’ you know, ‘You’re not a guinea pig, this is totally safe, it’s been tested, children have gotten it,’ etc. Like you know reassure them in giving them facts so they feel like you know they can trust the system and no one is looking to harm them.” (P12)

The logic of this latter participant is congruent with others who have suggested that it is important to emphasize that the maternal immunization recommendations are standard across Canada, and not specific to Inuit women.

“It’s also important to tell them that it’s just not Nunavut and it’s just not Inuit, this is a national standard and actually an international standard of a global recommendation so that they don’t feel like they are singled out, because sometimes they do. In [a smaller community] very well known for that [sic] over the years that they think they’re being singled out for certain vaccines. Like you know that only Inuit children get blah which is ...fortunately not true. Unfortunately it’s a belief that some of them do have and some of the Elders do have as well.” (P01)

Understanding the cultural dynamics of communication and relationships are also important in having discussions with patients about maternal immunizations, according to participants. This physician explains that Inuit patients are quieter and more accepting than their non-Inuit patients.

*“I find that people that come from down South and they’re having their babies in Iqaluit are much more like depending for information and they tend to questions all of the interventions a little bit more. I guess they are just wanting to be more informed and they are a little bit more skeptical about things. **Whereas in my experience, Inuit are a bit more accepting but they are also can be quite quiet so***

sometimes getting out those questions is just more of a challenge and it takes longer.” (P04)

“There’s the whole – more so in my Southern community vaccine hesitancy or wanting to delay vaccines for newborns, you know, fears about side effects and false messages that are out there and can never be taken back somehow or corrected by facts, so all of those kinds things – I hear more of that down South I would say than I do here. ...It may be cultural, that people here have those feelings or thoughts but aren’t chatty maybe in the same way that you know down South people might be.” (P07)

While immunization campaigns are organized at level of the Government of Nunavut, it is the responsibility of nurses, midwives, physicians, and bilingual CHRs to promote maternal immunizations, share resources, and offer vaccines to pregnant women (if this is within their scope of practice). Despite this responsibility, there are no materials specific to maternal immunization, nor to Nunavummiut. Participants in this project suggest that instead of by their own perceptions about maternal immunization, healthcare providers and CHRs ought to be guided by patient priorities and concerns when framing and offering vaccines to pregnant women.

5.2.3 Mothers Know Best: Shared Experiences, History and Decision-making

Healthcare providers describe a shared prenatal decision-making process in which Elders and especially female family members of the pregnant women share their own experiences with infectious diseases, and vaccines used to prevent them. Their collective memory informs the advice they give to the present generation of childbearing women. In this section I explain how providers understand shared experiences, history, and maternal immunization decision-making among pregnant women and the influential women (i.e. aunts, grandmothers, mothers, Elders) in their lives.

According to participants, there is a collaborative approach to prenatal decision-making between pregnant women, and their female family members and Elders, which

includes decisions about maternal immunizations. One community health nurse shares the frequency with which these female knowledge holders are cited by pregnant women in their appointments as influencing their behaviour.

“Yeah just looking through a different lens a little bit, so the Elders here have a large weight in what happens with our pre-natal moms. So often we will hear a lot of saying, ‘My grandmother said I have to do this.’ Like the Elders have a huge influence into what that mother does with that unborn child, and that includes everything from adoption to keeping the child, to vaccines, to what she eats, where she sleeps, how she sleeps; a lot of it is Elder driven.” (P03)

Participants suggest that for pregnant women, the personal experiences of these other mothers are utilized as evidence either for or against maternal immunization. Thus, they contribute to the vaccination behaviour of pregnant women.

The presence, or recent history of vaccine-preventable diseases in the community are cited by providers as motivations for maternal immunization uptake. Participants explain that most pregnant women have seen the impacts of infectious diseases and want to be vaccinated to prevent them.

“I can’t speak for [a larger community], but for all of the smaller communities that I cover, [vaccine hesitancy] is generally not an issue at all. ...Parents actually have very few questions about vaccines. I find that they often do trust the vaccines because there are still so many infectious diseases that are, you know, that usually only happen in third world countries like tuberculosis for example.” (P05)

According to participants, the separation of a pregnant woman or infant from their community to receive treatment for vaccine-preventable diseases has dire consequences for the family and community. The desire to avoid medevacs and consequences associated with them, is perceived by participants to translate into an eagerness among some community members and pregnant women to be vaccinated.

“I think the consequences of having the preventable disease is [sic] dire to the family. So as soon as we know that we have what we call medevac on our hands it means that there are going to be components of this family separated from the greater group. ...I mean that’s a hospital that’s like 800 miles away by flight which means that they don’t get to see their babies and they won’t get to see their pregnant moms or what not because they will be hospitalized. ...I think that in itself is a huge trigger for community members [and] pregnant women to make sure that they are kept as healthy as possible within the community because there is that social isolation component there.” (P03)

In particular, this provider explains that some Elders have experience with being separated from their families due to infectious diseases, or at least with seeing the impacts of these diseases on their communities. This informs their beliefs that pregnant women ought to be vaccinated. The influenza vaccine is an exception to this endorsement.

“So often if you know the Elders have seen these preventable diseases, they’ve seen these things before and they have been through that era and separation from their families due to illness. ...So the vaccines are pushed, with the exception of the flu vaccines, are pushed quite heavily onto the younger generation.” (P03)

For these reasons, participants speculate that if a maternal RSV vaccine were to become available, it would be widely accepted by pregnant women, and other mothers in the pregnant woman’s sphere of influence.

“...So the RSV causes bronchiolitis which is such a big problem in Nunavut and every single family they tend to be so severe and they get so sick and most of them end up getting medevacked out. So every family has experience personally with RSV, so if you tell them that there is a vaccine to prevent all of that, 100% of them would be on board.” (P05)

In addition to vaccine-preventable disease morbidity, providers suggest that word spreads quickly within and between communities about vaccine-preventable disease mortality. Several participants working in different communities referred to the recent death of a newborn infant from pertussis as a motivation for pregnant women to get the Tdap vaccine.

“...I think that when there is something that people can pinpoint, is when the disease really affected a family, affected a baby – that makes a big difference.”
(P02)

“...we actually had a death of a newborn from pertussis and a lot of women do know that, you know not from us, but things spread. So they do know that, which is reinforcing the need for them to get the Tdap [vaccine].” (P01)

Another provider offers an example of a death in the community from the influenza virus that resulted in the opposite course of action from community members. Due to its contentious nature, the influenza vaccine became the suspected cause of the death among community members, instead of its solution according to this provider.

*“...they have had a death from the flu in this community and **there’s people within the community who believe that the individual passed because they received the vaccine.** You know what I mean? So just to say that once again there is fear, there is distrust that we can’t ignore.”* (P12)

Experience (or lack thereof) with the actual immunizations being offered to pregnant women is another way in which providers explain history as evidence for (and against) maternal immunization. If for example a female family member was recently pregnant and received the Tdap vaccine, she may share those experiences with her daughter, creating as this provider coins it, “community confidence” in maternal immunization.

“...It seems to create a positive cycle that, you know if mom has had a couple of babies in the past five ten years, then she remembers getting the Tdap so she can say like, ‘Oh yeah I got this and it was good.’ She can pass that along and then if grandma has had another grandchild whose recently been in and gotten it then they’ve seen it in other circumstances, ...it kind of creates this nice community I guess who is really confident in this vaccine. ...A lot of people are aware of it through their other family members. So that even if it’s somebody’s first time coming in for a pre-natal appointment and their first time being offered this Tdap and they weren’t familiar with it themselves, it’s nice having a family member also reassure them that you know this is the routine this is the norm and this is a really positive thing and it’s not just offering it. That seems to help a lot.” (P02)

According to participants, just as history of the presence of infectious diseases in communities can be used as evidence in favour of (maternal) immunizations, it can also be used to explain why there may be some vaccine hesitancy among Elders and family members. As mentioned earlier, the influenza vaccine in particular is subject to hesitancy in the community. A few providers in this phase of the study speculate that low influenza vaccine uptake may be attributable, in part, to the fact that the influenza virus has not impacted communities the way that pertussis or RSV do.

“...So we haven’t really had the influenza really hit our community. I mean we definitely have upper respiratory illnesses among the children and the adults, but we haven’t like been hit hard for that message to be out there that you need to come in for your flu shot, and usually that’s the way it works in our community.” (P06)

“...For example, okay having that pertussis outbreak is what’s now motivated this right? Having okay we’re going to do Tdap for every prenatal. I feel like a lot of health decisions are made that way. We kind of have to go through a really bad time to come up with a new protocol and new procedure that we’re going to implement. So maybe after we have a really bad flu time or so many that we’ve

had they'll think you know, we need to have a dedicated time [for the influenza vaccine].” (P12)

Another suggests that a community history of adverse events following influenza immunization influences vaccine hesitancy.

“In this very small community years and years ago related to the flu vaccine, we had two people with Guillain-Barré. ...I think that kind of put the idea that we shouldn't, and I say we as collectively for this community received that immunization based on what happened with this community. So our intake for the flu vaccine is generally rejected to the general public. They would rather have the flu than the flu vaccine.” (P03)

A couple of participants also explain that Elders may be skeptical because they did not receive vaccines during their pregnancy.

“Unfortunately it's a belief that some of them do have and some of the elders do have as well, like you know, 'I didn't need that, why are you doing that now? We didn't need that and we didn't have pertussis.' So you need to give them a little bit of history on their terms. You know, 'This is why you didn't need it because you had the vaccine or you actually had the disease as a child and had great immunity to it and didn't need this vaccine in pregnancy.’” (P01)

“I had someone who refused and mostly because their family didn't want them to have it or the family didn't think it was a safe thing for them to have in pregnancy. ...If another member of the family, another woman, a mother who say [sic], 'Well I didn't have a vaccine in my pregnancy, so why do you need one?' So a lot of what I learned especially here is that a lot of women in particular sometimes make health decisions based on what the family have told them or what family says. Like they will discuss with their parents or discuss with family members before they come back and make a decision.” (P12)

When vaccine hesitancy is encountered by providers, a couple of them suggest that it may be due to an Elder or family member who has experienced trauma in the name of medicine and at the hands of non-Inuit people.

“We can’t forget our link here with the community so although it’s great that we’re here, we’re doing as much as we can to get the community healthy and up to date on their health and everything, let’s not forget that there is still a little bit of distrust when it comes to First Nation and Inuit populations and just modern medicine or just non-Inuit people in the community or staff. Although we all agree that we’re here because we want to help and we’re advocates for health, we can’t ignore the history that’s been here and the truth is you know, some people don’t trust us and some people might be worried [about maternal immunization].”

(P12)

Another participant suggests that this trauma is not only transmitted through stories, but viscerally. As such, the discomfort of a vaccination may dredge up emotional trauma.

“And there is a very like pain does matter here like you can give one immunization that might be ok but honestly people don’t respond well to pain here because when they have physical pain it brings up emotional pain and like the same generation as me like trauma passes on through generations. There’s a lot of trauma here and so you, it’s like physical pain and it brings up emotional pain. Like if you watch like if you’re caring for people, you notice how people react quite differently to pain here than maybe some people would in other populations. So with that people don’t want to have procedures that are painful or are uncomfortable because with that sometimes brings emotional pain and it’s like a cascade reaction yeah so people will push to say no to things that are uncomfortable sometimes.” (P11)

While maternal immunization decisions are understood as shared decisions, with input from family, and Elders, there is variability in reports of the physical presence of family during prenatal appointments. In some communities prenatal patients come to appointments with either their partner or a female family member.

“... I think it’s kind of a mixed bag, like women do come [to prenatal appointments] alone sometimes but often you’ll see their partners there and if the partner’s not there you will often see their mother sometimes their sister. I don’t see many dads coming, I don’t see many brothers. Usually if it’s not the partner it’s another female relative.” (P13)

In these cases, where they have the opportunity to engage with family members and Elders, providers emphasize the importance of doing so in a way that acknowledges their collective experiences and knowledge instead of privileging statistics and facts about maternal immunization.

“I will say you know, ‘You had the Tdap before and it’s protecting baby.’ I can say all those nice things but let’s not forget that although we are giving them factual information, educated information with our statistics and all that good stuff, let’s not forget the cultural value the family has on people’s lives up in the North in particular. So we have to keep that in mind and be sensitive and it does play a huge role in your decision-making.” (P12)

The following provider offers an example of how they respectfully engage with Elders about prenatal iron pills.

“I’ve actually had the Elder in on, you know a prenatal visit, and ...[the Elder] said, ‘Oh they don’t need those iron pills, she just needs to eat seal,’ which is true. Seal is great and really high in iron and I just find that ... saying something like you know, ‘You are completely right, like seal is amazing like your country food is so healthy and it is really high in iron and you’re right. I would really like her to

*eat more seal and that's what's best for her. **But at this point her, you know her levels are so low that on top of the seal, I was hoping for her to take this if it's ok with you.*** And so just acknowledging their culture like Elders I feel really respond well to having their belief system and their culture acknowledged and being respectful. Because that's what's been taken away from them the entire time. *...It's just about acknowledging their culture and beliefs and not disregarding them because that's where all of the trauma comes from is we restricted their culture, and we made them feel like nothing they believed in was important.*" (P11)

In other communities, pregnant women attend appointments alone, and providers do not have the opportunity to engage with their immediate or extended family.

"...We really don't have access to immediate or extended family members. Of course, we can't speak to them outside of not being with their partner, or the pregnant person because that's a breach of confidentiality. So we would only have access to them if they came with her." (P01)

In this case, a couple of participants explain that it is valuable to provide pregnant women with tools prior to the appointment when they are offered an immunization. As the following participant suggests, this gives a pregnant woman the opportunity to review the information and make a decision after having consulted with her family.

"Having that window that we have, the 26 to 32 weeks, gives you an opportunity to catch them maybe a little bit earlier and say just heads up, your next couple of visits we're going to discuss the vaccine. ...I've been able to give them to give them teaching tools and then on the next visit when they come, 'Oh did you think about it? Did you read the tools? Do you want to take it?' And that has backfired on me as well whereas like I sent them home with the information thinking, 'I'm doing a good thing here and giving her education,' and she comes back and says, 'Nope! My family said no.'" (P12)

Regardless of whether or not healthcare providers are able to interact with family members and/or Elders during prenatal appointments, they emphasize the importance of involving community members and leadership in maternal immunization programs for Inuit women.

“I think that having the support of the leaders in the community is helpful just given you know the...if the Elders don't support it, then no matter all of facts in the world aren't going to change kind of a recommendations from Elders against something so engaging the existing community leadership would be probably my only thought about that.” (P07)

Pregnant women, their families, and Elders draw on past personal and other mothers' experiences to make decisions about maternal immunization. Participants suggest that the following inform maternal immunization advice provided by families and Elders, and often times the resulting behaviour of pregnant women: morbidity and mortality of infectious diseases; separation of pregnant women or their infants from their communities; past experiences of (maternal) immunization; and historic and intergenerational trauma. Engaging with family members and Elders where possible, and in a way that honours their culture, beliefs, and community memory, is an important piece of providing maternal immunization, and of planning future maternal immunization programs.

5.3 Survey development

The purpose of the survey is three-fold: to provide quantitative data about the awareness, attitudes, beliefs, and behaviours of pregnant Inuit women about maternal pertussis immunization; to determine what factors influence whether pregnant women in Nunavut are or are not vaccinated; and to evaluate the effectiveness of maternal Tdap and influenza programs in Nunavut as measured by self-reported uptake.

I am following the phases (item development and scale evaluation), and steps (item generation, content validity, pre-testing questions, survey administration, tests of reliability, and tests of validity) of survey development synthesized by Boateng and colleagues, and adapted in Figure 3 (119). For this thesis, I completed item generation without domain identification, which represents part of step one in phase one (119). If domain identification will be undertaken as part of this project (outside of the scope of this thesis), it will happen *a posteriori* as the quantitative phase of the project is data- and not theory-driven (119).

In this section, I present qualitative data that has led to the preliminary panel of survey questions organized into the following categories: demographics, awareness, behaviours, attitudes, and beliefs (127). I also provide rationale for why these questions have been included, and my hypotheses about what information I anticipate they will elicit (118,127). I have included several more items in this stage of development than I anticipate being included on the final questionnaire in an attempt to elicit the most precise, appropriate, and robust survey. Further evaluation in future steps of survey development will dictate which of these items will remain in the instrument (119).

5.3.1 Demographics

I included a panel of questions about participant demographics prior to asking participants questions about their awareness, behaviours, attitudes, and beliefs about maternal immunization. Demographic questions cover sex and gender, parity, age, Indigenous identity, physical location, socioeconomic status, food security, housing, and access to healthcare (Table 1).

Questions about sex and gender serve to determine participant eligibility for this phase of the study. Any male respondents will be thanked for their time and the survey will conclude. Questions about sex and gender also serve to ensure that we are not discounting the awareness, attitudes, beliefs, and behaviours of any pregnant people who do not identify as cisgender women. If participants are not currently pregnant, they too will be thanked for their time and the survey will end. I have suggested questions to assess parity of participants because of the observation made by narrative collection and sharing circle participants, that multiparous women are usually more hesitant to be revaccinated with the maternal Tdap vaccine compared to their primiparous counterparts. Age and the associated parental and peer support or pressure was suggested by some healthcare experts as perhaps influencing the experience of a pregnant person. While there are no qualitative data to support questions about Indigenous identity, I have included them so that we can compare and contrast the experiences within and among Inuit women as well as those of any non-Inuit pregnant women who may take this survey. In the narrative collection and sharing circle phases of the study, I learned that availability of the CPNP, type of healthcare provider, location delivery, and configuration of prenatal and public healthcare is dependent upon physical location. For this reason, I have included several questions about participant location.

Measures of socioeconomic status were included in this panel of questions because of healthcare experts' perceptions that income, education, and occupation are determinants of maternal health. I included other social determinants of maternal health as identified by individual narrative collection and virtual sharing circle participants such as food security, housing, and access to healthcare to conclude the panel of questions in this section.

Table 1. Attribute survey question panel, corresponding qualitative data, and rationale

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>Sex and Gender:</p> <p>1. What is your assigned sex? (Couples and Sexual Health Laboratory, email communication, July 6, 2020)</p> <ul style="list-style-type: none"> a. Female b. Male c. Intersex d. Prefer not to answer <p>2. Which of the following best describes you today, that is, for the purpose of doing this survey? (Couples and Sexual Health Laboratory, email communication, July 6, 2020)</p> <ul style="list-style-type: none"> a. Man b. Woman 		<p>While there is no qualitative data to support the inclusion of sex and gender items on this survey, these items will provide important demographic data to characterize the survey sample. This, in turn, will allow us to determine whether or not the survey results are generalizable and to whom. In this particular section, we would like to include all pregnant people to share their awareness, attitudes, perceptions, and experiences surrounding maternal immunization, and not just cisgender women.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. Indigenous or other cultural gender identity (e.g. Two-Spirit)</p> <p>d. Non-binary</p> <p>e. Non-listed, please specify if you wish</p> <p>f. Prefer not to answer</p> <p>3. Do you identify as trans or transgender? (Couples and Sexual Health Laboratory, email communication, July 6, 2020)</p> <p>a. Yes</p> <p>b. No</p> <p>c. Unsure</p> <p>d. Prefer not to answer</p> <p>4. Does your current gender identity match the sex you were assigned at birth?</p>		<p>In order to ask questions sex and gender in the most respectful and appropriate way, I asked a colleague at the Couples and Sexual Health Laboratory for the language that they use in their surveys. They provided me with the questions in this section.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>(Couples and Sexual Health Laboratory, email communication, July 6, 2020)</p> <ul style="list-style-type: none"> a. Yes b. No c. Unsure d. Prefer not to answer 		
<p>Parity:</p> <ul style="list-style-type: none"> 5. Are you currently pregnant? <ul style="list-style-type: none"> a. Yes b. No c. I don't know 6. How many children do you have (127)? <ul style="list-style-type: none"> a. Please specify 7. How many times have you been pregnant? <ul style="list-style-type: none"> a. Enter number of pregnancies 	<p><i>"...They have babies quite frequently, so they're frequently pregnant. And if they're pregnant within a year of their last pregnancy, ...it's kind of like, 'Why? I had [the maternal Tdap vaccine] in my last pregnancy, why would I have it again?'"</i></p> <p>(Individual Narrative Collection (INC) P06)</p> <p><i>"...We have a very high birth rate, so we have women coming back maybe within a</i></p>	<p>The first question in this section will filter any ineligible participants out of the survey. If a participant is not currently pregnant, they will be thanked for their time and the survey will conclude here.</p> <p>Individual narrative collection and sharing circle participants identified the fertility rate in Nunavut as a potential determinant of maternal Tdap vaccine</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>year of also having the Tdap in the last pregnancy. So naturally, the tetanus is going to give them a whopping sore arm because we are just giving it to them so often and sometimes that comes back as a deterrent.” (Virtual Sharing Circle (VSC) P01)</i></p> <p><i>“I would say with our maternal vaccination program, we have a lot of moms who get pregnant quite often and quite frequently. ...I would say a lot of them if it’s maybe their first or second pregnancy, they’ve been okay to do the Tdap at 28 weeks. But if we have a mom who gets pregnant basically every nine, ten, eleven months, they are usually the moms who decline.” (VSC P09)</i></p>	<p>acceptance or refusal. Specifically, healthcare providers explain that patients who have had several children in recent history may be less likely to get the maternal Tdap vaccine due to the perception that it is excessive to receive it repeatedly, or the pain associated with the tetanus component of the vaccine (“Speaking the same language: framing maternal immunization” p.109-119). In an attempt to determine whether or not parity is a determinant of maternal Tdap vaccine uptake, I ask how many times participants have given birth to a live baby. My rationale for asking about live births and not recent pregnancies, is that the maternal Tdap immunization is offered between 27 and 32 weeks’</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
		<p>gestation, and therefore any and all spontaneous and induced abortions before then would be incorrectly assumed to be eligible to receive the vaccine.</p> <p>Assuming an accurate assessment from healthcare provider participants, I hypothesize that multiparous women who received the maternal Tdap vaccine in previous pregnancies, would be less likely to have been immunized with the maternal Tdap vaccine in their current pregnancy than their primiparous counterparts.</p>
<p>Age: 8. How old are you (121,138)?</p>		

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<ul style="list-style-type: none"> a. Less than 16 years of age b. 16-19 years of age c. 20-24 years of age d. 30-34 years of age e. 35-39 years of age f. 40-44 years of age g. 45-49 years of age 	<p><i>The younger the age, the more difficult the pregnancy can be from a psychosocial perspective. Not even with the family, but with the peer group, that is more difficult for a young person to navigate. (INC P03)</i></p>	<p>In addition to being an important demographic to characterize the sample, age was identified by INCP03 as being a determinant of maternal health. I have included the same response categories as Statistics Canada uses for their birth database to assist with determining whether our survey sample is representative of the population in Nunavut. I have adjusted the minimum age to reflect our survey eligibility criteria such that if participants answer “Less than 16 years of age” to this question, they will be thanked for their time and the survey will conclude here.</p>
<p>Indigenous identity:</p> <p>9. Are you an Indigenous person, that is, Inuk (Inuit), First Nations (North</p>		<p>There is no qualitative data to support the addition of questions regarding</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>American Indian), or Metis? First Nations (North American Indian) includes Status and Non-Status Indians (123).</p> <p>a. Yes b. No</p> <p>9a. Are you First Nations (North American Indian), Metis, or Inuk (Inuit) (123)?</p> <p>a. First Nations (North American Indian) b. Metis c. Inuk (Inuit)</p> <p>10. Which of the following best describes you (74)?</p> <p>a. First Nations b. Metis</p>		<p>Indigenous identity, but I have included them because of the paucity of immunization data specific to Inuit women. It may also be informative to compare the reported experiences of non-Inuit with Inuit respondents in Nunavut either descriptively or correlatively depending on the survey response rate and statistical power.</p> <p>Questions about a sense of belonging to the Inuit community came from the Aboriginal Peoples Survey, and are included because of the Inuit definition of poverty which is, “lacking economic wellbeing, lacking human capacities and capabilities, and social exclusion including loss of self-reliance and</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. Inuk d. Non-Indigenous person</p> <p>11. I have spent time trying to figure out more about Inuit history, traditions, and culture (123) (This is a contingency question for participants who answered “Inuk” to question 9a and 10)</p> <p>a. Strongly agree b. Agree c. Neither agree nor disagree d. Disagree e. Strongly disagree</p> <p>12. I am active in Inuit organizations, social events, or cultural activities (123) (This is a contingency question for</p>		<p>connectedness” (123,139). Questions 11 through 14 are aimed at assessing loss of self-reliance and connectedness in particular so that we have more culturally relevant variables to measure the potential association between poverty and maternal immunization uptake.</p> <p>Since vaccination is fundamentally a colonial policy, I hypothesize that there will be a polarization among participants who are deeply connected to their community (i.e. those who answer “strongly agree” to statements 11 through 14). I think there will be a subset who will be vaccine hesitant because of their keen awareness of the</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>participants who answered “Inuk” to question 9a and 10)</p> <ul style="list-style-type: none"> a. Strongly agree b. Agree c. Neither agree nor disagree d. Disagree e. Strongly disagree <p>13. I feel good about my Inuit identity (123) (This is a contingency question for participants who answered “Inuk” to question 9a and 10)</p> <ul style="list-style-type: none"> a. Strongly agree b. Agree c. Neither agree nor disagree d. Disagree e. Strongly disagree 		<p>traumas that continue to be inflicted on Inuit through colonialism that permeates the healthcare system. I also think there will be another subset that will be vaccine-positive as they have experienced these infectious diseases first-hand and want to protect themselves, their babies, and their communities by any means necessary.</p> <p>While I propose several questions about Indigenous identity and belonging here, we will consult with our co-researchers in Nunavut to determine which ones are most appropriate for use in this survey.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>14. I have a deep sense of belonging to my Inuit group (123) (This is a contingency question for participants who answered “Inuk” to question 9a and 10)</p> <ul style="list-style-type: none"> a. Strongly agree b. Agree c. Neither agree nor disagree d. Disagree e. Strongly disagree 		
<p>Location:</p> <p>15. Are you a beneficiary of an Inuit land claim agreement (123)? (This is a contingency question for participants who answered “Inuk” to question 9a and 10)</p> <ul style="list-style-type: none"> a. Yes b. No 	<p><i>“...We have community health representatives in each community and they’re local Inuit that are trained to help support different public health programs including...pregnancy immunization [sic], there’s oral months...nutrition months, HIV months. So, for every month ...they</i></p>	<p>As with other attributes, collecting geographic information from respondents will help us to characterize the generalizability of our survey sample.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. I don't know</p> <p>16. Which Inuit land claim agreement are you a beneficiary of (123)?</p> <p>a. Nunavut Land Claims Agreement</p> <p>b. Labrador Inuit Land Claims Agreement (Nunatsiavut)</p> <p>17. In which province or territory do you live (121)?</p> <p>a. Nunavut</p> <p>b. Newfoundland and Labrador</p> <p>c. Other</p> <p>18. In what region of Nunavut do you live?</p> <p>a. Kitikmeot</p> <p>b. Kivalliq</p> <p>c. Qikiqtaaluk</p>	<p><i>help promote as well and...we utilize our community health reps a lot to...talk with our prenatal that's [Canadian Prenatal Nutrition Program] regarding immunizations, what to expect in their pregnancy. So, yeah we're, we're trying to do a lot of health promotion in that department, but it's fairly new."</i> (INCP04)</p> <p><i>"We have attempted to, for example, fill some positions like CPNP programs – we don't have that program in the community. We've tried to do food clubs and such with the hamlet council to try to get some of these women some food, like a takeout bag from the health centre and funding for that, but many of these projects are not sustainable. They go on for a few weeks</i></p>	<p>Questions 15 through 17 will help to parse Nunatsiavummiut from Nunavummiut once the second arm of this study is initiated in Nunatsiavut.</p> <p>Within Nunavut, narrative collection and sharing circle participants explained the diverse programs, care providers, and configurations of prenatal and public healthcare delivery depending on geographic location ("Pragmatism in prenatal care and programming" p. 60-63; "Opening the door to maternal health and immunization: complexity of access as a determinant of health" p. 88-99). For this reason, I am proposing to ask participants to identify the region and city, municipality, or settlement of</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>19. In which community (city, municipality, or settlement) of Nunavut do you live?</p> <ul style="list-style-type: none"> a. Arctic Bay b. Arviat c. Baker Lake d. Bathurst Inlet e. Cambridge Bay f. Cape Dorset g. Chesterfield Inlet h. Clyde River i. Coral Harbour j. Gjoa Haven k. Grise Fiord l. Hall Beach m. Igloolik n. Iqaluit o. Kimmirut 	<p><i>and then they fall through because unfortunately, from a nursing perspective, we can't do it all and we need our partners with us. But the novelty as I call it, sometimes wears off. So, we go back to just coming to the health centre.”</i> (INCP10)</p> <p><i>“I have always felt like there was totally unnecessary restriction placed on women's ability to get the booster because for some reason the Department of Health feels that we can't give vaccines at the hospital which makes no sense to me. ...The hospital is where our prenatal clinic is, but the hospital is also placed just beside the boarding home where all the women stay when they are out [of their</i></p>	<p>Nunavut within which they live (140). In so doing, we will be able to determine whether for example geographic location and the corresponding configuration of prenatal and public healthcare is as much of a barrier to accessing maternal health and immunization as healthcare providers perceive it to be.</p> <p>Another dimension of location is whether or not there are adequate resources for pregnant women to give birth in their home communities. In addition to interrupting the relationship established between patient and care provider, when pregnant women deliver their babies elsewhere, it is traumatic</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>p. Kugaaruk q. Kugluktuk r. Nanisivik s. Naujaat t. Pangnirtung u. Pond Inlet v. Qikiqtarjuaq w. Rankin Inlet x. Resolute y. Sanikiluaq z. Taloyoak aa. Umigmaktok bb. Whale Cove</p> <p>20. Where do you plan to give birth to your baby?</p> <p>a. In your home community</p>	<p><i>communities] for delivery. So those women in particular are generally without transportation. ...In order for them to get to the public health building where they are supposedly going to be offered this vaccine, they would have to arrangements [sic] with the boarding home driver to drive them there or walk. So it's asking them a lot also to make a whole other appointment to get a vaccination."</i> (VSCP04)</p> <p><i>"It is quite a challenge when you look at it like, these women have to leave four weeks prior to delivery and that's for a number of reasons. One is the resources in the community is very limited. Two, many of these women are anemic and sometimes</i></p>	<p>for the family and community because this practice is rooted in colonialism and divergent from traditional childbirth practices ("Building trust amid transience" p. 63-68). Furthermore, it presents logistical and workload challenges as public health providers in the communities where patients give birth have to determine whether or not patients need their maternal Tdap immunization ("Opening the door to maternal health and immunization: complexity of access as a determinant of health" p. 88-99). While some narrative collection participants suggested that pregnant women may see medical travel as an opportunity ("Building trust amid transience" p. 63-68), sharing circle</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>b. In another, larger community in Nunavut</p> <p>c. In another, larger community in Southern Canada</p>	<p><i>it's their first baby and there is the possibility and potential of things going wrong so at least you have them in a safe environment. It also gets them out, gives them a break, but a month is a long time when you're away from home.</i>" (INCP10)</p> <p><i>"And what does it mean to you to have, does it make a difference, you know you're getting all this prenatal care in your community but what does it mean then when you go somewhere else then to birth with people that never supported you through your pregnancy?"</i> (INCP02)</p> <p><i>"So now we're actually seeing a drop in birthing in the community, which is interesting. So, I think it's directly related</i></p>	<p>participants identified this practice as an additional barrier to accessing prenatal care ("Opening the door to maternal health and immunization: complexity of access as a determinant of health" p. 88-99). I have included a question about where participants plan to give birth to their baby to determine whether there is any association between maternal immunization uptake and anticipated location of delivery.</p> <p>We will consult with our Northern co-researchers about whether it is important for them to know which communities specifically (e.g. Montreal, Ottawa, Winnipeg, Edmonton,</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>to the fact that this woman and her chosen escort have time together outside of their community, where they can access other fun things that they don't get in their own community.” (INCP06)</i></p> <p><i>Politicians, hamlets, and probably even the Elders would rather see the births occur in the territory. Politicians realize that if they set up a successful birthing center, it will keep jobs and economic drive in the community. Births in the territory are also closer to what the Elders would view as the cultural norm.</i> (INCP05)</p> <p><i>“What I find more of an issue is when sometimes in a smaller community, women</i></p>	<p>Yellowknife) pregnant women are giving birth in.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>don't want to be sent out of the community for deliveries. Even you know from say [a smaller community] to [a birthing hub] is quite far and there is no childcare and disrupts [sic] the entire family for several weeks and even worse if they have to be sent to [a Southern city]. ...So some of them will even hide out until they are in labor and then walk into the health centre.” (VSCP05)</i></p>	
<p>Socioeconomic status:</p> <p>21. For statistical purposes only, we'd like to have a general idea of people's annual household income. Which of the following categories best describes the total income of all of the people living in your household in the last year (74,120)?</p> <p>a. Under \$20,000</p>	<p><i>“A lack of income [has a negative impact on the pregnancy]. I mean income we talked about, if they have a good paying government job, it's wonderful!”</i></p> <p>(INCP02)</p>	<p>In the narrative collection component of this study, healthcare experts shared their perception that socioeconomic status, that is, income, education, and occupation, is a determinant of maternal health in Nunavut (“Heads above water: Navigating upstream and downstream</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>b. \$20,000 to just under \$40,000 c. \$40,000 to just under \$60,000 d. \$60,000 to just under \$80,000 e. \$80,000 to just under \$100,000 f. \$100,000 to just under \$150,000 g. \$150,000 and above h. Prefer not to answer</p> <p>22. What is the highest level of education you obtained (120,121)?</p> <p>a. Elementary (7 years or less) b. High school c. High school equivalency program d. Technical training e. Certificate, accreditation, or diploma f. Bachelor’s degree g. Master’s degree</p>	<p><i>Level of education [has a positive impact on pregnancy]. This has to do with the way they care for themselves. (INCP07)</i></p> <p><i>Unemployment [has a negative impact on pregnancy]. (INCP07)</i></p>	<p>care” p. 68-73). Accordingly, I have included measures of socioeconomic status to determine whether this relationship extends to maternal immunization as well as maternal health, and if so, to characterize the shape of this association.</p> <p>Based on what I learned from CHRs and healthcare providers in virtual sharing circles, I suspect that participants with low socioeconomic status might experience disproportionate barriers to accessing maternal immunization and therefore have lower maternal immunization uptake compared to their socioeconomically advantaged counterparts (“Opening the door to</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>h. Doctoral degree i. I prefer not to answer</p> <p>23. In the past year, did you work at a job or business? (123) a. Yes b. No</p> <p>24. Were you an employee or self-employed? (123,125) (This is a contingency question for participants who answered, “Yes” to question 24) a. Employee b. Self-employed c. Working in a family business without pay d. I don’t know</p>		<p>maternal health and immunization: complexity of access as a determinant of health” p. 88-99).</p> <p>By no means is socioeconomic status the only way to measure poverty. It is imperative that the Inuit definition of poverty which includes measures of nutrition, housing, access to healthcare, and a sense of belonging, guide the analysis of this survey (139). As such, I also suspect that participants experiencing food insecurity and overcrowded housing might also experience disproportionate barriers to maternal and public healthcare and therefore maternal immunization. I believe that sense of belonging might</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>25. In the past year, did you work in a government or hamlet job in Nunavut? (123) (This is a contingency question for participants who answered, “Yes” to question 24)</p> <ul style="list-style-type: none"> a. Yes b. No c. I don’t know <p>26. On average, how many paid hours do you usually work per week? (123,125) (This is a contingency question for participants who answered, “Yes” to question 24)</p> <ul style="list-style-type: none"> a. Enter number of hours worked 		<p>defy this pattern, which is something I have detailed in the “Indigenous identity” section of this table.</p> <p>We will consult with our Northern co-researchers about how to handle the concept of material well-being.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>27. Is your job permanent, or is there some way that it is not permanent? (123,125) (e.g. seasonal, temporary, casual, term)</p> <ul style="list-style-type: none"> a. Permanent b. Not permanent c. I don't know <p>28. Overall in the past year, was your household income enough to meet your household's needs for transportation, housing, food, clothing, and other necessary expenses? (123)</p> <ul style="list-style-type: none"> a. More than enough b. Enough c. Not enough d. I prefer not to answer 		
Food security:		

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>29. During the past year, did it happen even once that you or any member of your family experienced hunger because you did not have enough food to eat (120)?</p> <p>a. Yes b. No c. I don't know d. Prefer not to answer</p>	<p><i>Biggest issue is not necessarily the social support which tends to be sufficient, but poverty, housing, nutrition. (INCP03)</i></p> <p><i>“Some negative factors that can affect the pregnancy here in Nunavut ...definitely malnutrition or poverty with not adequate diet during their pregnancy.” (INCP04)</i></p>	<p>Food security was highlighted as a determinant of maternal health by healthcare experts that participated in the narrative collections analyzed for this thesis (“Heads above water: Navigating upstream and downstream care” p. 68-73). The Elder midwife interviewed by our colleagues in Nunavut provided cultural context for</p>
<p>30. During the past year, did it happen even once that you or any member of your family had to reduce your food intake because you could not afford enough food (120)?</p> <p>a. Yes b. No c. I don't know d. Prefer not to answer</p>	<p><i>“As mothers, even before we became pregnant, we were told how to be prepared and what to expect. We were told to eat well, frozen foods, anything from the land, traditional foods, like plants. We have been guided by other mothers of what to expect of how to have a healthy baby with good skin/complexion and a healthy weight. We were always</i></p>	<p>maternal nutrition and access to country food as determinants of maternal and infant health. Bearing this in mind, I included survey questions to measure food security and posit that if a pregnant woman is unable to meet this most basic physiologic need, she too might de-prioritize maternal immunization in the way that healthcare providers</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>31. The food that you and other household members bought just didn't last and there wasn't any money to get more. Was that often true, sometimes true, or never true in the past year? (123)</p> <p>a. Often true b. Sometimes true c. Never true d. I prefer not to answer</p> <p>32. You and other household members couldn't afford to eat balanced meals. In the past year, was that often true, sometimes true, or never true? (123)</p> <p>a. Often true b. Sometimes true c. Never true</p>	<p><i>encouraged to gather plants and keep plants for use for pregnant women. We would make broth with the plants over a quilliq. We would eat the seal liver. Our mothers would always have plants that they gathered for the pregnant women and breastfeeding mother. That's what we knew.</i></p> <p><i>First, for pregnant women who did not listen to what they have been told, they would have a long labour, and their baby would be very skinny. If they didn't listen, if they were young [sic]. However, we would give birth to healthy babies, nice big babies. When they were born and they already knew things. They had beautiful complexions. We were given advice of</i></p>	<p>sometimes do when confronted with competing patient needs ("Heads above water: Navigating upstream and downstream care" p. 68-73).</p> <p>In addition to measuring food security, infant feeding practices also provide information about infant immunity to infectious diseases. Question 33, in combination with maternal immunization behaviour questions, will give some insight about the prevalence of passive immunity conferred to infants through placental and breastmilk transfer of antibodies.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>d. I prefer not to answer</p> <p>33. How do you plan to feed your baby?</p> <p>a. Breastfeeding</p> <p>b. Formula feeding</p> <p>c. A combination of breast and formula feeding</p> <p>d. I don't know</p> <p>e. Other, please specify</p>	<p><i>what to do to make sure they were healthy” (141)</i></p>	
<p>Housing:</p> <p>34. Including yourself, how many persons regularly live in your household? (124)</p> <p>a. 0</p> <p>b. 1</p> <p>c. 2</p> <p>d. 3</p> <p>e. 4</p>	<p><i>Had a client once that lived in a closet. How do we handle that? Housing is very important. Poverty – not being able to afford good nutrition. Younger people having to take off school for a period of time to have baby and/or take care of child</i></p>	<p>One of the most commonly identified determinants of maternal health by healthcare experts, particularly in relation to the spread of infectious diseases, was housing (“Heads above water: Navigating upstream and downstream care” p. 68-73). Questions</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
f. 5 g. 6 h. 7 i. 8 j. 9 k. 10 l. 11 m. 12 n. 13 o. 14 p. 15 q. 16 r. 17 s. 18 t. 19 u. 20	<p><i>can have a negative impact as well.</i> (INCP03)</p> <p><i>“When you have a lot of people in these communities in the same household, we have outbreaks all the time, like bronchiolitis.”</i> (INCP10)</p>	<p>34 and 35 are meant to measure household composition, and questions 36 through 38 to measure household characteristics. I included these questions to assess the characteristics and proximity of occupants and therefore the potential for infectious disease transmission.</p> <p>Another dimension to housing that may contribute to the health of its’ occupants, is the physical state of the home, particularly whether it is in good repair and has adequate ventilation (9). For this reason, I included question 39, which is aimed at assessing whether or not participants’ houses are in need of repair.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>35. The people that live with me include (select all that apply): (121)</p> <ul style="list-style-type: none"> a. Children under 6 months of age b. Children between 6 months and 2 years of age c. Elderly persons (over the age of 65) d. Individuals with a chronic medical problem e. None of these categories apply <p>36. Is this dwelling owned by a member of this household? (124)</p> <ul style="list-style-type: none"> a. Yes b. No <p>37. Is this dwelling part of a condominium or apartment development? (124)</p> <ul style="list-style-type: none"> a. Yes 		

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>b. No</p> <p>38. How many bedrooms are in this dwelling? (124)</p> <p>a. Number of bedrooms</p> <p>39. Is this dwelling in need of any repairs? (124)</p> <p>a. No, only regular maintenance is needed (for example, painting, furnace cleaning, etc.)</p> <p>b. Yes, minor repairs are needed (for example, missing or loose floor tiles, bricks or shingles, defective steps, railing or siding, etc.)</p> <p>c. Yes, major repairs are needed (for example, defective plumbing or</p>		

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
electrical wiring, structural repairs to walls, floors, or ceilings, etc.)		
<p>Access to healthcare:</p> <p>40. Have you had access to a health professional (including a nurse, doctor, traditional midwife, registered midwife) during your pregnancy?</p> <p>a. Yes</p> <p>b. No</p> <p>c. I don't know</p> <p>40a. If yes, which of the following describes your primary prenatal care provider?</p> <p>a. Traditional midwife</p> <p>b. Nurse</p> <p>c. Doctor</p> <p>d. Registered midwife</p>	<p><i>“Access is [the] number one [factor positively impacting the health of pregnant women]. Access to trained professionals in maternal newborn health and also health promotion so that would be early access so not just access, but early access so that any type of risk factors can be identified at an early stage and then those referrals can be made to the appropriate care provider if they are high risk.” (INC P08)</i></p> <p><i>“Access to a primary healthcare provider is probably your biggest facilitator [for maternal immunization] because then they are going to be the one who either you</i></p>	<p>Accessibility of prenatal healthcare was identified by narrative collection and sharing circle participants as influencing the health of pregnant women in Nunavut. I have included a question to determine whether or not participants have access to a prenatal healthcare provider, and which kind (i.e. nurse, physician, midwife, etc.). I have also included a question about accessing prenatal programs, which are typically run by CHRs (“Pragmatism in prenatal care and programming” p. 60-63).</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>e. Other, please specify</p> <p>40b. When you have appointments with your primary prenatal care provider throughout your pregnancy, do you see the same one every time?</p> <p>a. Always b. Often c. Sometimes d. Rarely e. Never</p> <p>41. Are there social, educational, or health promotional programs for pregnant women in your community?</p> <p>a. Yes b. No c. I don't know</p>	<p><i>know says, 'Well there's this option, and they said that you should do it.'"</i> (VSC P13)</p> <p><i>"I guess we are facilitators [for maternal Tdap immunization] really, right? Because really, they don't come to the health centre and they don't have prenatal visits or regular prenatal follow up, honestly they would never know. ...I would say basically we are the facilitators, and your interaction with the patient, it's kind of our role and our duty to at least give them that information so they can make an educated decision. Otherwise, reality is, where else would they get that information from, you know what I mean?"</i> (VSCP12)</p>	<p>Based on stories told to me in sharing circles with healthcare providers and CHRs, if a pregnant woman cannot access prenatal care or programming, it is highly unlikely that they would have access to, or awareness of maternal immunization ("Opening the door to maternal health and immunization: complexity of access as a determinant of health" p. 88-99). For this reason, I hypothesize that vaccine uptake and awareness will be lower among those participants experiencing difficulty accessing prenatal healthcare compared to those for whom it is readily accessible.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>42. Do you attend any programs for pregnant women during your pregnancy?</p> <p>a. Yes</p> <p>b. No</p> <p>42a. If yes, please specify which programs you attend(ed)</p> <p>a. The Canadian Prenatal Nutrition Program (CPNP)</p> <p>b. Other, please specify</p>		<p>Sharing circle participants in particular highlighted the importance of a continuous care provider in the development of trusting relationships with patients (“Building trust amid transience” p. 63-68). Based on this information, I have included question 40b to determine whether or not participants are seeing the same prenatal care provider throughout their pregnancy. I suspect that we might identify lower levels of trust in and awareness of maternal immunization among participants with inconsistent prenatal care providers compared to those with a consistent provider throughout their pregnancy. I also predict that participants with</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
		<p>inconsistent care providers will be less inclined to identify their provider as a trusted source of information about maternal immunization.</p> <p>We will consult with our Northern co-researchers to ensure that the way I have dichotomized “traditional midwife” and “registered midwife” based on data from community healthcare experts is the best way to reflect the two traditions of midwives in Nunavut.</p>

5.3.2 Behaviours

The next section of the survey will contain questions about information-seeking, and vaccination behaviour. The latter is a critical component of the survey as it serves to meet our objective to evaluate the effectiveness of maternal Tdap and influenza programs in Nunavut as measured by self-reported uptake. This question is also important because we found agreement in the vast majority of narrative collections and sharing circles, that uptake of the maternal Tdap vaccine drastically exceeds that of the maternal influenza vaccine.

Infrastructural and human resource challenges associated with communicating maternal immunization policies, recommendations, and schedules to CHRs, community-based healthcare providers, and transient providers with temporary contracts or locum placements were the impetus for asking survey participants whether anybody had told them about maternal immunization. Healthcare experts also wanted to know how pregnant women were informed, and by whom. In an effort to capture participants who may not have thought to identify the internet as a source of vaccine-related information, I have included a couple of questions to gauge internet access, and content and tone of vaccine messaging.

Based on comments made by participants in the first two phases of this study, we ought to ask survey participants about their history of receiving the influenza vaccine outside of pregnancy to provide some context for their behaviour. We also want to know whether they received an influenza vaccine during their current pregnancy. If participants respond that they have, they will be asked about some of the main reasons for their choice. In addition to the prespecified responses provided by Environics Research Group in consultation with Health Canada, I included some others based on participant quotes presented in Table 2. If participants self-report not having received the influenza vaccine during their current pregnancy, they will similarly be asked about some of the main reasons for their choice. Once again, qualitative data, in addition to the prespecified responses from the survey cited constitute the makeup of this question. The creation of maternal Tdap behavioural survey questions followed the exact same process. In addition

to the response categories provided for the influenza vaccine questions, I added the desire to avoid potential future medevac out of the community as a reason for maternal Tdap vaccine uptake, and previous receipt of the Tdap vaccine as a reason for its refusal in pregnancy.

Table 2. Behavioural survey question panel, corresponding qualitative data, and rationale

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>Information-seeking:</p> <p>43. Has anybody ever told you about taking vaccines while you are pregnant?</p> <p>a. Yes</p> <p>b. No</p> <p>43a. If yes, from whom did you hear about this? (select all that apply)</p> <p>a. Elder</p> <p>b. Doctor</p> <p>c. Nurse</p> <p>d. Traditional midwife</p> <p>e. Registered midwife</p> <p>f. Community health representative</p> <p>g. Mother</p> <p>h. Sister</p> <p>i. Aunt</p>	<p><i>Curious to know where they get their information. Curious to know about who influences them the most when making vaccine decisions, taking medications, or about health in general during pregnancy.</i></p> <p>(INCP07)</p> <p><i>“Where do they get the information from I think is really important. You know, if you are reluctant or you’re declining to have a vaccine, like where does that information come from in terms of how did you base your decision?”</i> (INCP08)</p> <p><i>“I guess maybe a lack of Nunavut specific education materials around the</i></p>	<p>As I facilitated sharing circles, I learned of the gaps that exist as maternal immunization policies, recommendations, and schedules are communicated to CHRs, community-based healthcare providers, and transient providers with temporary contracts or locum placements (“Connecting maternal immunization policy in practice: bridging the gap between transience and collective knowledge”, p. 99-109). It is possible that opportunities to discuss maternal immunization are missed, which is why I have included a question about whether anybody has</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>j. Grandmother k. Other family member l. Other pregnant women in the community m. Friends n. Internet o. Television p. Radio q. Other, please specify</p> <p>43b. If yes, how was the information provided to you?</p> <p>a. In print material b. In a conversation c. Through story telling d. Using text messages e. Other, please specify</p>	<p><i>vaccination. Although I know that at public health they do have information sheets that are in all languages about each vaccine that they give, ...they are not I don't think I could be wrong, but I don't think that they are particularly tailored to pregnancy like giving a vaccination in pregnancy it would just be generic information about Tdap.</i>" (VSCP04)</p> <p><i>"So the main resources that I have access to in Nunavut are all based on childhood immunization like infant immunization so we don't have any that I know of, the midwives might have access to it and I wasn't aware of anything specifically for women but we do have like an</i></p>	<p>told participants about maternal immunization.</p> <p>Healthcare experts were interested in learning how pregnant women are told about maternal immunization, and from whom. Narrative collection participants explained that pregnant women seek the advice of several sources about prenatal health, including female family members, healthcare providers, and Elders ("Relations, reservations, and receiving immunizations" p. 74-81). Sharing circle participants emphasized the role of matriarchs specifically in prenatal and vaccine decision-making ("Mothers know best: shared experiences, history and decision-</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>immunization manual that does have handouts on each vaccine.” (VSCP13)</i></p> <p><i>“I would say their immediate family members, if it’s a sister or a mother, ...and that’s usually just based by cultural experiences.” (INCP04)</i></p> <p><i>“I would say they look to their health practitioner more, I think. Although I mentioned earlier, there is quite an influence from Elders on how to have a healthy pregnancy, you know by doing certain things, not doing certain things, eating certain foods, that sort of thing. So it depends on what the topic is I think.” (INCP08)</i></p>	<p>making” p. 119-128), a sentiment shared by the Elder midwife in the summary report provided to us by our colleagues in Nunavut (141). I have accordingly added categories for each of the matriarchs identified in the qualitative data to question 43a, to see whether their influence persists at a population-level.</p> <p>As suggested by INCP08, it will be interesting to see which sources are cited by pregnant women who declined maternal immunization. I hypothesize that we might find an association between participants citing the internet as a source of vaccine-related information and refusal of maternal</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>“Yeah just looking through a different lens a little bit, so the Elders here have a large weight in what happens with our pre-natal moms. So often we will hear a lot of saying, ‘My grandmother said I have to do this.’ Like the Elders have a huge influence into what that mother does with that unborn child, and that includes everything from adoption to keeping the child, to vaccines, to what she eats, where she sleeps, how she sleeps; a lot of it is Elder driven.” (VSCP03)</i></p> <p>“The participants received information from nurses, doctors, mothers, other mothers, friends, sisters. The family and extended family are important roles in support for pregnant women (141).”</p>	<p>influenza and Tdap immunizations because of how quickly misinformation can be spread online.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p>“[The Elder midwife] observes a breakdown in relationships with families, between mothers and daughter that was not like before. This relationship is immensely important for pregnant women for support. This breakdown might lead to young mothers not listening to the elder’s knowledge of how to have a health relationship. Not listening to elder’s advice to a healthy pregnancy. ...[The Elder midwife] was responding saying that, <i>“If the nurses or practitioners help the Inuit, it would be by asking Elders or Grandmothers on their thoughts and values about that particular subject, let’s say vaccination and say if the message is going to be an option, to talk to your</i></p>	

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<i>grandmother first. That might be a way to engage the Inuit more.”” (141)</i>	
<p>44. Do you have access to the internet?</p> <ul style="list-style-type: none"> a. Yes b. No c. I don't know <p>44a. If yes, how often, if at all, do you see vaccine content (i.e. pictures, memes, posts, articles, videos, live streams, etc.) on the internet?</p> <ul style="list-style-type: none"> a. Always b. Often c. Sometimes d. Rarely e. Never 	<p><i>“...some women will say, ‘I will not take [maternal immunizations].’ And again when we ask them why, they come back with the answer of, ‘I saw on Facebook that if you take any kind that your baby’s gonna have autism. You’re gonna hurt your baby and yourself.’” (INCP01)</i></p> <p><i>Especially around the influenza season, will see people write on Facebook that, “they” are trying to kill us. “They” being the foreigners, white people, healthcare providers, etc. Anti-vaccination sentiment on Facebook gets around and happens every year. (INCP07)</i></p>	<p>While not identified by any community healthcare experts or healthcare providers as a <i>source</i> of vaccine-related information, social media came up in the context of vaccine hesitancy and spreading misinformation. Pregnant women that were uncertain about maternal immunization also identified information floating around on social media in their sharing circles with our colleagues in Nunavut (Healey Akearok, oral communication, January 22, 2020). As such, I have included questions about internet exposure. Specifically, I want to gauge how often participants</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>44b. If yes, where do you see vaccine content on the internet? (please select all that apply)</p> <ul style="list-style-type: none"> a. Facebook b. Twitter c. YouTube d. Reddit e. Instagram f. Tumblr g. Health Canada website h. Government of Nunavut website i. Indigenous association/group website j. WebMD k. Other, please specify. <p>44c. How would you describe the general tone of the vaccine content that you see</p>		<p>see vaccine content on the internet, where, and what the general tone of the content is.</p> <p>It is my hope that these questions will generate meaningful data about the most opinion-driving websites among pregnant women with access to the internet so that public health can explore mounting a targeted online maternal immunization promotion strategy.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>online? (This is a contingency question for participants who answered, “Always,” “Often,” “Sometimes,” or “Rarely” to question 44a)</p> <ul style="list-style-type: none"> a. Mostly positive b. Mostly negative c. A combination of positive or negative d. Neutral 		
<p>Influenza vaccine: (if the facilitator is surveying participants outside of the months of the influenza season, they are asked to skip questions pertaining to the influenza vaccine)</p>	<p><i>“Maybe ask them have they ever received a vaccine in pregnancy. Maybe if they received their flu shot that year while they were pregnant and maybe reasons why they feel that they would say no to a vaccine in pregnancy.” (INCP04)</i></p>	<p>Virtual sharing circle participants explained that previous influenza vaccine behaviour generally influences behaviour in pregnancy (“Speaking the same language: framing maternal immunization,” p.109-119). For this</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>45. Have you ever had the flu shot (influenza vaccine) (142)?</p> <p>a. Yes</p> <p>b. No</p> <p>c. I don't know</p> <p>46. Do you get the flu shot every year?</p> <p>a. Yes</p> <p>b. No</p> <p>c. I don't know</p> <p>47. Have you ever had a maternal flu shot? (This will be a contingency question for those participants who indicated multiparity)</p> <p>a. Yes</p> <p>b. No</p> <p>c. I don't know</p>	<p><i>"It seems almost kind of 50/50 here. There are some people that are totally gung ho every year for the influenza vaccine, and that doesn't really change when they are pregnant, and there are some people who are against it regardless."</i> (VSCP02)</p> <p><i>"Most people here in Nunavut cherish their communities and everyone is really closely connected. So once you kind of put it on a bigger perspective than just the pregnant woman herself and her baby, I find uptake is good. ...They want to protect everyone in the community and themselves, and make sure baby is born healthy and not experience a lot of the</i></p>	<p>reason, I have proposed questions 45 through 47 to establish a pattern of behaviour, before asking whether or not the participants received a flu vaccine in their current pregnancy. Based on the aforementioned healthcare providers' understanding, I hypothesize that participants who answer in the affirmative to questions 45 through 47, will be more likely to have also answered "Yes" to question 48.</p> <p>Questions 48a and b will be instrumental in meeting the second objective of this project, which is to determine what factors influence whether pregnant women in Nunavut are or are not vaccinated. I followed the</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>48. Did you get a flu shot during your current pregnancy?</p> <ul style="list-style-type: none"> a. Yes b. No c. I don't know <p>48a. If yes, what are the main reasons you received the flu shot during your current pregnancy? (74) (Do not read - interviewer to code all mentions).</p> <ul style="list-style-type: none"> a. To protect myself against influenza virus b. To protect my baby against influenza virus c. To protect others who are vulnerable (e.g. seniors, children, etc.) 	<p><i>sickness that happens for our babies under two years of age.” (INCP02)</i></p> <p><i>Most of these women also have other children and care about their families. If they get ill, it is not going to go well at home. They will need to tend to sick kids. Do not want to pass [infectious diseases] along to other family members. (INCP07)</i></p> <p><i>“I cannot speak for outside of pregnancy I don't know, but in pregnancy are obviously on the lookout, wanting to protect their baby from possibly everything that they can. ...If this vaccination, immunization, whatever they're giving could help prevent their</i></p>	<p>format of the Health Canada questionnaire for these questions (74). Much in the same way that the RA administering the Survey of First Nations and Inuit Parents Regarding Immunization was instructed not to read all of the response categories, but rather to code all mentions in the appropriate ones, so too will the RA administering this survey. In speaking with narrative collection participants, several expressed concerns about the survey methodology and our ability to elicit any responses out of an over-researched population who already have too many forms to fill out during their encounters with healthcare providers. They also expressed their opinion that open-ended</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>d. To protect other members of the family, household, and/or community</p> <p>e. To avoid potential future medevac out of the community</p> <p>f. My healthcare provider or CHR recommended it</p> <p>g. My friends recommended it</p> <p>h. My family recommended it</p> <p>i. An Elder recommended it to me</p> <p>j. Because it is free/available at the health centre</p> <p>k. Other pregnant women in my community get vaccinated</p> <p>l. I have heard stories about babies dying from the flu (influenza virus)</p> <p>m. Recent flu (influenza) outbreak(s) in the region</p>	<p><i>baby from getting something, then most women are on board with it.” (INCP01)</i></p> <p><i>“So often if you know, the Elders have seen these preventable diseases, they’ve seen these things before and they have been through that era and separation from their families due to illness. ...So the vaccines are pushed, with the exception of the flu vaccines, are pushed quite heavily onto the younger generation.” (VSCP03)</i></p> <p><i>“I think the consequences of having the preventable disease is [sic] dire to the family. So as soon as we know that we have what we call medevac on our hands inaudible, there are going to be components of this family separated from</i></p>	<p>questions would be more appropriate. In adhering to the same format as the Health Canada questionnaire, our survey will be shortened considerably, and will flow more like a conversation facilitated by a bilingual RA.</p> <p>I adjusted the responses to questions 48a and b to reflect the attitudes, perceptions, and experiences of narrative collection and sharing circle participants. In particular, I wanted to capture pregnant women’s desire to protect their communities, families, and unborn babies against infectious diseases that was emphasized by participants (“Relations, reservations, and receiving immunizations” p. 74-81;</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>n. Other, please specify.</p> <p>48b. If no, what are the main reasons you did not get the flu shot during your current pregnancy (74)? (Do not read - interviewer to code all mentions).</p> <p>a. It will make me sick</p> <p>b. I never get sick</p> <p>c. I have heard stories of people dying from the flu shot</p> <p>d. Vaccines are a colonial intervention and Inuit were healthier before vaccines were introduced</p> <p>e. Vaccines are unnecessary</p> <p>f. Influenza does not pose a serious threat to the community</p> <p>g. I am concerned about the side effects of the vaccine</p>	<p><i>the greater group. ...I mean that's a hospital that's like 800 miles away by flight which means that they don't get to see their babies and they won't get to see their pregnant moms or what not because they will be hospitalized. ...I think that in itself is a huge trigger for community members [and] pregnant women to make sure that they are kept as healthy as possible within the community because there is that social isolation component there.</i>" (VSCP03)</p> <p><i>"If they have any experiences or if their loved ones have experienced anything positive or negative."</i> (INCP04)</p>	<p>“Speaking the same language: framing maternal immunization,” p.109-119). Participants also explained the impact of medevac on the relationship between pregnant women and their providers, as well as on the community, and family, which I have added as a potential response to question 38a (“Building trust amid transience” p. 63-68; “Relations, reservations, and receiving immunizations” p. 74-81; “Speaking the same language: framing maternal immunization,” p.109-119). I also accounted for the importance of shared decision-making highlighted in both batteries of qualitative data by adding a responses acknowledging friends, families, and Elders as sources of</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>h. Vaccines are too painful</p> <p>i. I am worried that I am the subject of an experiment</p> <p>j. I don't have access to public healthcare services</p> <p>k. I don't believe in vaccines</p> <p>l. I am concerned about vaccine safety</p> <p>m. I am concerned about vaccine effectiveness</p> <p>n. I didn't have enough information to make a decision</p> <p>o. I am confused by information provided to me about the vaccine</p> <p>p. I am allergic to components of the vaccines</p> <p>q. My healthcare provider or representative did not recommend it</p> <p>r. My friends advised me against it</p>	<p><i>"...It seems to create a positive cycle that, you know if mom has had a couple of babies in the past five ten years, then she remembers getting the Tdap so she can say like, 'Oh yeah I got this and it was good.' ...She can pass that along and then if grandma has had another grandchild whose recently been in and gotten it then they've seen it in other circumstances, ... it kind of creates this nice community I guess who is really confident in this vaccine. ...A lot of people are aware of it through their other family members. So inaudible someone's first time coming in for a pre-natal appointment and their first time being offered this Tdap and they weren't familiar with it themselves, it's nice having a family member also</i></p>	<p>influence ("Relations, reservations, and receiving immunizations" p. 74-81; "Mothers know best: shared experiences, history and decision-making" p. 119-128).</p> <p>Vaccine hesitancy surrounding the influenza vaccine was an underlying theme across narrative collection ("Relations, reservations, and receiving immunizations" p. 74-81) and sharing circles ("Mothers know best: shared experiences, history and decision-making" p. 119-128; Speaking the same language: framing maternal immunization," p.109-119). Pregnant women also expressed their hesitation to get the maternal influenza vaccine in</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>s. My family advised me against it</p> <p>t. An Elder advised me against it</p> <p>u. I don't have enough time</p> <p>v. Other, please specify.</p>	<p><i>reassure them that you know this is the routine this is the norm and this is a really positive thing and it's not just offering it. That seems to help a lot.</i>" (VSCP02)</p> <p>"There was a hesitancy to get the flu immunization, citing that it has made them sick, they have heard that others have been sick after receiving the flu shot, or it hurt too much (141)."</p> <p><i>"I think, you know this sounds trite, but some people have a needle phobia; they are scared of pain. Especially if I've drawn a whole bunch of blood work which I tend to do at 26 weeks or there's second trimester bloodwork and the glucose screening and then I want to give them a</i></p>	<p>sharing circles with our colleagues in Nunavut (141). Among the most salient factors that reportedly influence influenza vaccine refusal are the belief that the vaccine makes patients sick, that the vaccine is too painful, that serious adverse events (e.g. Guillain-Barré, death) are associated with the influenza vaccine, and that the influenza virus does not pose a threat to the community. I also incorporated healthcare providers' concerns about the structure of prenatal and public healthcare services by providing, "I do not have access to public healthcare services" as a response to question 38b.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>flu shot. ...[They] feel like a pin cushion, so you know some people are very needle phobic.” (VSCP07)</i></p> <p><i>“For the influenza vaccine, there is the belief that after you get the vaccine, it will make you sick. If people get sick even a month after [the influenza vaccine], they will attribute it to the vaccine. Have never heard of anyone saying that they contracted pertussis from the Tdap vaccine. Definitely people are more against the influenza than the Tdap vaccine.” (INCP07)</i></p> <p><i>“...in this community they had a death from the flu... and there’s people within the community who believe that the</i></p>	<p>There are potential analytical limitations due to the number of response categories in question 48a and b, and others like it. In particular, it may be difficult to have adequate power for multivariable analyses for any one of the responses.</p> <p>To mitigate this, I suggest presenting detailed descriptive statistical analyses, and then grouping responses into general categories for correlative analyses. For example, we could combine, “My healthcare provider or CHR did not recommend it”, and “My friends, family, or Elder(s) have advised against it” into a, “Social Pressure” category. I have also chosen certain</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>individual who passed [sic] because they received the vaccine which you know inaudible.” (VSCP12)</i></p> <p><i>“...So we haven’t really had the influenza really hit our community. I mean we definitely have upper respiratory illnesses among the children and the adults, but we haven’t like been hit hard for that message to be out there that you need to come in for your flu shot and usually that’s the way it works in our community.” (VSCP06)</i></p> <p><i>“In this very small community years and years ago related to the flu vaccine, we had two people with Guillain-Barré. ...I think that kind of put the idea that we</i></p>	<p>responses that were especially emphasized by community healthcare experts, healthcare providers, and CHRs, and included them as statements in Tables 3 and 4 to ensure that all participants have the opportunity to answer them.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>shouldn't, and I say we collectively for this community received that immunization based on what happened with this community. So, our intake for the flu vaccine is generally rejected to the general public. They would rather have the flu than the flu vaccine.” (VSCP03)</i></p> <p><i>“I have always felt like there was totally unnecessary restriction placed on women's ability to get the booster because for some reason the Department of Health feels that we can't give vaccines at the hospital which makes no sense to me. ...The hospital is where our prenatal clinic is, but the hospital is also placed just beside the boarding home where all the women stay when they are out [of their</i></p>	

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>communities] for delivery. So those women in particular are generally without transportation. ...In order for them to get to the public health building where they are supposedly going to be offered this vaccine, they would have to arrangements [sic] with the boarding home driver to drive them there or walk. So it's asking them a lot also to make a whole other appointment to get a vaccination.”</i> (VSCP04)</p>	
<p>Pertussis vaccine: 49. Have you ever had the whooping cough (Tetanus, diphtheria, acellular pertussis (Tdap)) vaccine in adulthood? a. Yes b. No</p>	<p><i>“...Like I said most moms are very receptive to the Tdap [vaccine]. The flu vaccine however takes a little bit more convincing and many will say, ‘No I’ll have the whooping cough, but I don’t</i></p>	<p>My rationale for asking questions 39 through 41 is comparable to those for the equivalent questions about the maternal influenza vaccine. I want to determine whether or not previous</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. I don't know</p> <p>50. Have you ever had a maternal Tdap vaccine? (This will be a contingency questions for those participants who indicated multiparity)</p> <p>a. Yes</p> <p>b. No</p> <p>c. I don't know</p> <p>51. Did you receive a whooping cough (pertussis or Tdap) vaccine during your current pregnancy?</p> <p>a. Yes</p> <p>b. No</p> <p>c. I don't know</p>	<p><i>want the flu shot.' ...I've been 13 years trying to work on that!" (VSCP01)</i></p> <p><i>"I rarely get people decline [sic] it so I find that there is some acceptance in contrast to the flu shot where I get a lot of...we don't have a great uptake for the flu in comparison. So that's kind of my experience, which I find really, really interesting that there is a discrepancy between those two." (VSCP07)</i></p> <p>"The [pregnant women] received the [maternal Tdap] vaccine, received it at 26 weeks of pregnancy. It was suggested by their Nurse in their home community. Almost all participants did not receive the flu shot" (141).</p>	<p>maternal immunization behaviour is predictive of current behaviour. It is also important to ask the same questions so that we can compare and contrast participants' receipt of the maternal Tdap and influenza vaccines. Uptake of the two vaccines are reportedly discrepant among pregnant women, according to healthcare experts, healthcare providers, and CHRs, with uptake of the maternal Tdap vaccine exceeding that of the influenza vaccine ("Relations, reservations, and receiving immunizations" p. 74-81; Speaking the same language: framing maternal immunization," p.109-119 (141). I hypothesize therefore, that vaccine uptake for maternal Tdap will be high,</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>51a. If yes, what are the main reasons you received the whooping cough vaccine during your current pregnancy? (74) (Do not read - interviewer to code all mentions).</p> <ul style="list-style-type: none"> a. To protect myself against whooping cough b. To protect my baby against whooping cough c. To protect others who are vulnerable (e.g. seniors, children, etc.) d. To protect other members of the family, household, and/or community e. To avoid potential future medevac out of the community f. My healthcare provider or CHR recommended it g. My friends recommended it 	<p><i>“I find that because it just kind of simplifies it for them just saying you know, ... ‘Like what happens is like it helps baby learn how to fight off whooping cough and there’s outbreaks of whooping cough in Canada now and it can make them really sick from their breathing and occasionally babies can die from it. ...So it’s going to help baby learn how to fight it off and hopefully baby won’t get sick with it. And then most of them will say, ‘Okay, yes’ because they realize it’s for baby.”</i></p> <p>(VSCP11)</p> <p><i>“For myself, I support vaccination, I support the vaccination program. I see the benefits of it and I think when I’m talking</i></p>	<p>and will significantly exceed maternal influenza vaccine uptake, for those participants eligible for both vaccines.</p> <p>As aforementioned in the “Parity” section of Table 1 (p. 142-144), healthcare providers suggested that multiparous women may be more likely than primiparous women to get the maternal Tdap vaccine. If this is true, then I would anticipate that multiparous participants who indicated previous receipt of the maternal Tdap vaccine, may have lower odds of reporting receipt of the Tdap vaccine during their current pregnancy compared to primiparous participants.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>h. My family recommended it</p> <p>i. An Elder recommended it to me</p> <p>j. Because it is free/available at the health centre</p> <p>k. Other pregnant women in my community get vaccinated</p> <p>l. I have heard stories about babies dying from whooping cough</p> <p>m. Recent pertussis outbreak(s) in the region</p> <p>n. Other, please specify</p> <p>51b. If no, what are the main reasons you did not get the whooping cough vaccine during your current pregnancy (74)? (Do not read - interviewer to code all mentions).</p> <p>a. It will make me sick</p> <p>b. I never get sick</p>	<p><i>to clients and explaining that you know, pregnant women who get the flu for example will get it worse than someone who is not pregnant because their immunity is slightly depressed when they are pregnant. And when I am talking about the Tdap vaccine and explaining that you know there is immunity crossing the placenta that's protecting their baby. ... I talk about how protecting the adults that are around those vulnerable children is important too so that even though if they are not worried about it themselves about the flu, that if they get the flu and then their newborn gets the flu their newborn will not do very well."</i></p> <p>(VSCP07)</p>	<p>Based on the qualitative data gathered, and the emphasis that healthcare providers put on explaining to their patients that maternal Tdap immunization protects the newborn baby from pertussis ("Speaking the same language: framing maternal immunization," p.109-119), I anticipate that "Protecting my baby against whooping cough" will be among the most commonly identified factors that influence maternal Tdap vaccine acceptance. If community healthcare experts, healthcare providers, and CHRs were able to comment on maternal influenza immunization at all, there was more of an emphasis placed on cocooning and protecting the pregnant</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. I have heard stories of people dying from the whooping cough vaccine</p> <p>d. Vaccines are a colonial intervention and Inuit were healthier before vaccines were introduced</p> <p>e. Vaccines are unnecessary</p> <p>f. Whooping cough does not pose a serious threat to the community</p> <p>g. I am concerned about the side effects of the vaccine</p> <p>h. Vaccines are too painful</p> <p>i. I already got a Tdap vaccine as an adult</p> <p>j. I am worried that I am the subject of an experiment</p> <p>k. I don't have access to public healthcare services</p> <p>l. I don't believe in vaccines</p>	<p><i>"I think that when there is something that people can pinpoint, is when the disease really affected a family, affected a baby – that makes a big difference."</i> (VSCP02)</p> <p><i>"...we actually had a death of a newborn from pertussis and a lot of women do know that, you know not from us but things spread. So they do know that, which is reinforcing the need for them to get the Tdap [vaccine]."</i> (VSCP01)</p> <p><i>"I like to tell women, 'This is not new,' you know, 'You've had the Tdap before.' I think we get a lot of a lot of restrictions when it's something that a lot of people don't know about so I like to emphasize that, 'Don't worry, this is not an</i></p>	<p>woman than on conferring immunity to the infant. For this reason, I expect to see fewer participants identify protecting their baby as one of the factors identified as influencing participants' decision to get the maternal influenza vaccine.</p> <p>The prevalence of pertussis infection, and pertussis-associated deaths in the territory were cited by narrative collection and sharing circle participants as influencing pregnant women's choice to get the maternal Tdap vaccine ("Relations, reservations, and receiving immunizations" p. 74-81; "Mothers know best: shared experiences, history and decision-making" p. 119-128). I</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>m. I am concerned about vaccine safety</p> <p>n. I am concerned about vaccine effectiveness</p> <p>o. I didn't have enough information to make a decision</p> <p>p. I am confused by information provided to me about the vaccine</p> <p>q. I am allergic to components of the vaccines</p> <p>r. My healthcare provider or representative did not recommend it</p> <p>s. My friends advised me against it</p> <p>t. My family advised me against it</p> <p>u. An Elder advised me against it</p> <p>v. I don't have enough time</p> <p>w. Other, please specify.</p>	<p><i>experiment,' you know, 'You're not a guinea pig, this is totally safe, it's been tested, children have gotten it,' etc. Like you know reassure them in giving them facts so they feel like you know they can trust the system and no one is looking to harm them." (VSCP12)</i></p> <p><i>"I would say with our maternal vaccination program, we have a lot of moms who get pregnant quite often and quite frequently. ...I would say a lot of them if it's maybe their first or second pregnancy they've been okayed to do the Tdap at 28 weeks. But if we have a mom who gets pregnant basically every nine, ten, eleven months, they are usually the moms who decline. ...We tend to have a</i></p>	<p>suspect that participants will report personal experiences with pertussis morbidity and stories of pertussis-related mortality more frequently than they will experiences with the influenza virus. Based on my analysis of the qualitative findings, I also think that we will find an independent association between these personal experiences and stories, and receipt of the maternal Tdap vaccine in our multivariable analyses.</p> <p>In the sharing circles, healthcare providers explained that some pregnant Inuit may be wary of practices specific to them and not pregnant women elsewhere (Speaking the same language: framing maternal immunization," p.109-</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>lot of moms who might be like a inaudible seven or a inaudible nine sort of pregnancy so yeah they don't get those Tdap's every year when they are pregnant. But like I said if it's new mom then they do they agree to go ahead with it so that's been my experience so far."</i></p> <p>(VSCP09)</p> <p><i>"It's also important to tell them that it's just not Nunavut and it's just not Inuit, this is a national standard and actually an international standard of a global recommendation so that they don't feel like they are singled out, because sometimes they do. In [a smaller community] very well known for that [sic] over the years that they think they're</i></p>	<p>119). The maternal Tdap immunization program in Nunavut predates the maternal Tdap immunization program in the rest of Canada by two years, a timeline that maybe perceived by pregnant Inuit as an experiment rather than a public health strategy. To try to capture this, I have added a response to question 42b that reads, "I am worried I am the subject of an experiment".</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>being singled out for certain vaccines.</i></p> <p><i>Like you know that only Inuit children get blah which is ...fortunately not true.</i></p> <p><i>Unfortunately, it's a belief that some of them do have and some of the Elders do have as well." (VSCP01)</i></p>	

5.3.3 Awareness

Based on qualitative data collected and analyzed by our colleagues in Nunavut, pregnant women participants in sharing circles were keenly aware of pertussis outbreaks in the territory, but unsure about which vaccines they ought to have received, and why. To determine whether or not this trend persists at a population-level, I have included questions to assess awareness of which vaccines are recommended and by whom, as well as of outbreaks of infectious diseases in the territory. I have also included questions aimed at assessing whether or not pregnant women understand what vaccines are for, and what they feel they may be lacking in the way of information to make decisions. It is my hope that in so doing, we can make more tangible recommendations to public healthcare providers and stakeholders about how to communicate maternal immunization in a way that pregnant women can understand and provide truly informed consent.

Table 3. Awareness survey question panel, corresponding qualitative data, and rationale

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>Infectious disease and vaccine awareness:</p> <p>We are trying to find out what people know about diseases and the vaccines given to pregnant women to prevent them. I am going to read a statement, and then I would like you to tell me if you think it is true, false, or if you don't know. It is important for you to tell me if you don't know the answer instead of guessing an answer. We expect that there will be some things that you don't know about, so please don't feel badly about admitting that (143)!</p> <p>52. The flu (influenza) is a virus that infects our lungs and is easily spread between people.</p> <p>a. True</p>	<p>“[Sharing circle] participants ...knew that some medications should be avoided during pregnancy but were unsure which to avoid. They wanted to know what kind of vaccinations were administered (141).</p> <p>“Observations included that mothers wanted to know the basics on what the vaccines are for, more about outbreaks, and why vaccines were developed to protect from disease and illness” (141)</p> <p><i>Do they understand why [they need immunizations]? Might ask whether they want us to explain vaccination to them.</i> (INCP07)</p>	<p>When healthcare experts were asked what they thought we should include in the way of content for subsequent phases of this study, several wanted to know whether pregnant women were aware of which vaccines were offered in pregnancy, and if not, how they would like to be made aware about maternal immunizations. Our colleagues in Nunavut asked sharing circle participants whether they were aware of the recommendations for maternal influenza and Tdap immunization in Canada and found them to be uncertain about which vaccines were offered and why (141). I am therefore proposing</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>b. False c. I don't know</p> <p>53. The flu (influenza) can lead to being kept in the hospital for treatment or even death.</p> <p>a. True b. False c. I don't know</p> <p>54. All adults, including pregnant women, will have the same problems if they get the flu.</p> <p>a. True b. False c. I don't know</p>	<p><i>"I'd probably look at it again like what is their understanding of the vaccine? Why do they think they need them?" (INCP10)</i></p> <p><i>"Do you fully understand what you're getting when you're given [maternal immunization] at the health centre? Do you feel like enough information is given to you when [maternal immunization] is offered? That would be an interesting one." (INCP02)</i></p> <p><i>"It would be interesting to say, you know, do you know what the pertussis vaccination is for? Do you know what the influenza vaccination is for? Just to see if anybody's actually absorbed the</i></p>	<p>that we ask pregnant women whether they are aware of the public health recommendations for maternal influenza and Tdap vaccination in Nunavut. Based on some of the findings previously presented in Table 2 (p. 169-191), and in the sharing circles (Speaking the same language: framing maternal immunization," p.109-119), I have included a question about participant awareness that these recommendations also apply to pregnant women elsewhere in Canada.</p> <p>Findings from our colleagues in Nunavut also suggest that pregnant women may need more information about the "basics" of vaccines (141).</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>55. The flu is very serious if babies get it, because their lungs are just starting to develop.</p> <p>a. True</p> <p>b. False</p> <p>c. I don't know</p>	<p><i>information we are giving them because I find that's not...even if you give the handouts, you know no one really wants to take handouts home. Or they read it once and you know, even as a healthcare provider, you read about the new medication and then you totally forget about it."</i> (INCP02)</p>	<p>Accordingly, I included questions about the influenza and pertussis viruses, outcomes if left untreated, and populations at risk.</p>
<p>56. There have been a number of flu (influenza) outbreaks in Nunavut in the last five years.</p> <p>a. True</p> <p>b. False</p> <p>c. I don't know</p>	<p>“[Sharing circle] participants had heard of [the pertussis] outbreak and felt nervous, and unsure about the whooping cough outbreak. They wanted to make sure that their baby is protected (141).”</p>	<p>Participants in sharing circles facilitated by our colleagues in Nunavut indicated that they were aware of the pertussis outbreak and that it left them feeling nervous and uncertain about whether or not their children were protected from the virus (141). I have included a question to gauge survey participant awareness of repeated pertussis outbreaks in Nunavut in recent history.</p>
<p>57. Public health recommends that all pregnant women in Nunavut should get a flu shot (influenza vaccine).</p> <p>a. True</p>	<p><i>What do they need us to do? How do they find our approach when it comes to immunization during pregnancy? If we do</i></p>	<p>This will be an important variable to test my hypothesis that awareness of the</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>b. False c. I don't know</p> <p>58. It is recommended that all pregnant women across Canada should get a flu shot (influenza vaccine).</p> <p>a. True b. False c. I don't know</p> <p>59. Whooping cough (pertussis) is a virus that infects our lungs and is easily spread between people.</p> <p>a. True b. False c. I don't know</p>	<p><i>a good job of explaining why it's important to get immunization. (INCP07)</i></p>	<p>pertussis outbreak will be associated with maternal Tdap vaccine acceptance.</p> <p>Rather than providing them with a statement that might make them aware of the recommendation and therefore impact their response (i.e. "Are you aware that public health recommends that all pregnant women should get a vaccine for protection against the influenza virus?"), I included instead that survey respondents be presented with statements which they must identify as true or false (i.e. "Public health recommends that all pregnant women in Nunavut should get a flu shot (influenza vaccine)").</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>60. Whooping cough can last for up to 12 weeks, and can be very serious, even deadly.</p> <p>a. True</p> <p>b. False</p> <p>c. I don't know</p> <p>61. Whooping cough happens most often in pregnant women.</p> <p>a. True</p> <p>b. False</p> <p>c. I don't know</p> <p>62. There have been a number of whooping cough (pertussis) outbreaks in Nunavut in the last five years.</p> <p>a. True</p> <p>b. False</p>		<p>I included questions to evaluate the current maternal immunization programs. Questions 69 and 70 were borne of narrative collection participants' desire to understand what is needed of them to improve the current maternal immunization programs in Nunavut. These questions in particular, will generate important data to be able to inform future maternal immunization programs so that the information provided meets the needs of pregnant women.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. I don't know</p> <p>63. Public health recommends that all pregnant women in Nunavut should get a whooping cough vaccine (Tdap).</p> <p>a. True</p> <p>b. False</p> <p>c. I don't know</p> <p>64. Pregnant women that received a whooping cough (Tdap) vaccine as an adult, or in a previous pregnancy do not have to get one again if they are currently pregnant.</p> <p>a. True</p> <p>b. False</p> <p>c. I don't know</p>		

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>65. It is recommended that all pregnant women across Canada should get a whooping cough vaccine (Tdap).</p> <ul style="list-style-type: none"> a. True b. False c. I don't know <p>66. Do you feel that you have all the information you need about being vaccinated while you are pregnant (74)?</p> <ul style="list-style-type: none"> a. Yes b. No <p>66a. If no, what do you think are the main reasons you do not have all of the information you need?</p> <ul style="list-style-type: none"> a. Did not receive any/enough information from the provider 		

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<ul style="list-style-type: none"> b. Did not know where to get information c. Appointments were rushed d. Did not have enough time to consult with female relatives e. Felt uncomfortable asking questions f. Did not take the time to review the information available to me g. Did not understand the information provided h. Language difficulty i. Not interested j. Have not looked for information k. Other, please specify l. Don't know/not applicable <p>67. In order to feel comfortable about my decision to receive or not receive</p>		

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>immunization during pregnancy, I need more information regarding (check all that apply): (121)</p> <ul style="list-style-type: none"> a. What is in the vaccine b. How effective the vaccine is c. What side effects I might experience if I get the vaccine d. How safe the vaccine is e. Where I can get the vaccine f. My personal risk of getting seriously ill from vaccine-preventable diseases g. I already have all of the information I need h. Other, please specify 		

5.3.4 Attitudes and Beliefs

According to Fishbein and Ajzen, an attitude is an evaluation of the (un)favourableness of a psychological object, concept, or behaviour (144). For example, survey responses reflecting attitudes would be approval or disapproval of maternal immunization policy, or an evaluation of the benefits or harms of maternal immunization (144). Fishbein and Raven define a belief as an evaluation of the (im)probability of an object, concept, or behaviour (145). Survey responses reflecting vaccine-related beliefs would evaluate the perceived likelihood of an adverse event following immunization, or the safety of the vaccine for example. Fishbein has shown attitudes and beliefs to be statistically significantly correlated and thus concludes that attitudes are a function of peoples' beliefs (146). As the two constructs are inextricably related, I have combined them in this section and the corresponding table (Table 4).

Vaccine safety featured prominently as a concern of pregnant women and the Elder midwife interviewed by our colleagues in Nunavut. Community healthcare experts, providers, and CHRs also reported that pregnant women often ask them whether or not vaccines are safe. As such, I have included several questions that gauge general participant beliefs about maternal immunization safety, as well as those specific to each vaccine. Narrative collection participants also wanted to know whether pregnant women trusted their care providers to provide them with accurate information about maternal immunization.

Relationships were cited by pregnant women, experts, and healthcare providers and representatives as being influential in prenatal decision-making, including about maternal immunizations and especially between pregnant women and their female family and community members. I have accordingly incorporated a set of questions asking participants about the perceived attitudes and beliefs of these key informants. Finally in this section, I have included some questions about consent as there was concern voiced by community healthcare experts that pregnant women may be consenting to being vaccinated without fully understanding the information provided to them (if any).

Table 4. Attitudinal and belief survey question panel, corresponding qualitative data, and rationale

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>Infectious diseases</p> <p>Please indicate how much you agree or disagree with the following statements.</p>		
<p>Historic trauma</p> <p>68. Inuit were healthier before vaccines were introduced</p> <ul style="list-style-type: none"> a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree <p>69. I am worried that I am being vaccinated as an experiment</p> <ul style="list-style-type: none"> a. Strongly disagree b. Somewhat disagree 	<p>There are pockets of strong anti-vaccine sentiment in some communities led by a voice along the lines of, ‘Inuit never needed immunizations before,’ and ‘immunizations have high risk of side effects and other challenges and so people shouldn’t be immunized because it’s a perpetuation of colonial policy’ (Dr. Gwen Healey, personal communication, January 22, 2020).</p>	<p>In a meeting where she presented findings from sharing circles with pregnant women and narrative collection with the Elder midwife, our colleague Dr. Healey explained that there are pockets of anti-vaccine sentiment in certain communities in Nunavut. She connected this sentiment as being related to the fact that immunization is sometimes perceived as a perpetuation of colonial policy.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. Neither agree nor disagree d. Somewhat agree e. Strongly agree</p>	<p><i>I ran the HPV vaccine programs in schools, and parents would decline this for their daughters. I had two different parents tell me that they thought it was a sterilization program for their daughters. Common to encounter the powerful thoughts and ideas about what we are trying to do now reflecting the past implementation, and how that history affects how people perceive healthcare today. How do you counteract that belief?</i> (INCP03)</p> <p><i>For the Elders, it has to do with history. Historically, it wasn't pretty. Inuit were being vaccinated but really the vaccine made them sick instead of preventing</i></p>	<p>Community healthcare experts and healthcare provider shared similar perspectives about vaccine hesitancy among Inuit. Among them, that they are being vaccinated as an experiment, and that the recommendations are specific to Inuit and do not apply to other populations.</p> <p>I have created two questions to measure these beliefs and hypothesize that participants who either somewhat or strongly agree with them will have lower odds of having been vaccinated than those who disagree.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
	<p><i>illness. These beliefs have been passed on to the younger generation (INCP07).</i></p> <p><i>“It’s also important to tell them that it’s not just Nunavut and it’s not just Inuit, this is a national standard and actually an international standard of a global recommendation so that they don’t feel like they are singled out, because sometimes they do. In [a smaller community] very well known for that [sic] over the years that they think they’re being singled out for certain vaccines. Like you know that only Inuit are getting blah, which is ...fortunately not true. Unfortunately it’s a belief that some of them do have, and some of the Elders do have as well” (VSCP01)</i></p>	

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>Maternal immunizations</p> <p>Please indicate how much you agree or disagree with the following statements.</p> <p>70. Getting the flu vaccine while I am pregnant will protect me from catching the flu (121)</p> <ul style="list-style-type: none"> a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree <p>71. Getting the flu vaccine while pregnant will protect my baby so they do not catch the flu as a newborn (121)</p> <ul style="list-style-type: none"> a. Strongly disagree b. Somewhat disagree 	<p><i>“[Pregnant women] will pretty much do anything for their babies” (VSCP07).</i></p> <p><i>“So maybe when we’re campaigning for [maternal RSV immunization] and we’re putting that education out there, really really important that we emphasize the benefit that this has on the baby. ...Then mothers are realizing, ‘Well this has nothing to do with me, this is about saving the life of my child here!’ So we’re able to make sure to put emphasis on that. Especially in the north were so many children are suffering from respiratory illnesses and the effects of it ...it’s really important to emphasize that this is for the baby.” (VSCP12)</i></p>	<p>The series of questions about perception of protection conferred by maternal immunizations are important to understand what attitudes and beliefs may be driving maternal immunization behaviour. Narrative collection and sharing circle participants understood protecting babies and communities from harm to be priorities of pregnant women (“Relations, reservations, and receiving immunizations” p. 74-81; “Speaking the same language: framing maternal immunization,” p.109-119). For this reason, I suspect these attitudes and beliefs will be predictive of maternal vaccine uptake.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. Neither agree nor disagree d. Somewhat agree e. Strongly agree</p> <p>72. Getting the flu vaccine while pregnant makes it harder for the flu virus to spread so the community is less likely to get sick from the flu (121)</p> <p>a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree</p> <p>73. I am concerned about getting the flu from the influenza vaccine (121)</p> <p>a. Strongly disagree b. Somewhat disagree</p>	<p><i>“Most people here in Nunavut cherish their communities and everyone is really closely connected. So once you kind of put it on a bigger perspective than just the pregnant woman herself and her baby, I find uptake is good. ...They want to protect everyone in the community and themselves, and make sure baby is born healthy and not experience a lot of the sickness that happens for our babies under two years of age.” (INCP02)</i></p> <p>“There was a hesitancy to get the flu immunization, citing that it has made them sick, they have heard that others have been sick after receiving the flu shot, or it hurt too much (141).”</p>	<p>As identified in Table 2, pregnant women in the qualitative phases of this study identified the belief that the influenza vaccine can make them sick and healthcare experts also reported hearing this misconception from pregnant women. Accordingly, I have included statements to this effect for both the maternal influenza and Tdap vaccines. I suspect that if pregnant women agree that they hold these beliefs, they will have higher odds of being unvaccinated compared to pregnant women who believe these statements to be erroneous.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>c. Neither agree nor disagree d. Somewhat agree e. Strongly agree</p> <p>74. Getting the whooping cough vaccine while I am pregnant will protect me from catching whooping cough (121)</p> <p>a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree</p> <p>75. Getting the whooping cough vaccine while pregnant will protect my baby so they do not catch whooping cough as a newborn (121)</p> <p>a. Strongly disagree</p>	<p><i>“For the influenza vaccine, there is the belief that after you get the vaccine, it will make you sick. If people get sick even a month after [the influenza vaccine], they will attribute it to the vaccine. Have never heard of anyone saying that they contracted pertussis from the Tdap vaccine. Definitely people are more against the influenza than the Tdap vaccine.” (INCP07)</i></p>	

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p> <p>76. Getting the whooping cough vaccine while pregnant makes it harder for whooping cough to spread so the community is less likely to get sick from whooping cough (121)</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p>		

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>77. I am concerned about getting whooping cough from the whooping cough vaccine (121)</p> <ul style="list-style-type: none"> f. Strongly disagree g. Somewhat disagree h. Neither agree nor disagree i. Somewhat agree j. Strongly agree 		
<p>Vaccine safety:</p> <p>You will now be asked a few questions about vaccine safety, that is, whether or not you feel like getting a vaccine when pregnant will cause you any harm, injury, or danger.</p>	<p><i>“Do you think [maternal immunizations] affect your baby in a negative way?”</i> (INCP02)</p> <p><i>“I think you should ask the mom you know, what does that mean to receive a vaccine while pregnant? ...Does it seem</i></p>	<p>When we asked healthcare experts what they would recommend asking pregnant women in sharing circles and surveys, they wanted to know whether pregnant women thought maternal immunizations were safe. It is my intention, in suggesting a question about the perception of maternal immunization</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>78. In general, how safe do you think it is for pregnant women to get vaccinated (74,122)?</p> <ul style="list-style-type: none"> a. Very safe b. Somewhat safe c. Not very safe d. Not at all safe e. It depends on the vaccine f. I don't know/not applicable <p>79. I consider the maternal influenza vaccine to be safe (121,142)</p> <ul style="list-style-type: none"> a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree 	<p><i>like a good idea or something scary?"</i> (INCP04)</p> <p><i>Are vaccines safe? Anything safety-related in pregnancy.</i> (INCP07)</p> <p><i>““I want to know if it's safe or not” – Sharing circle participant”</i> (141)</p> <p><i>“[The Elder midwife] first learned about vaccinations in 1967. A lot of mothers did not agree with all of them. Her observations from then to now is that before 1967, babies were a lot healthier, and their defense systems were stronger. That there are many risks associated with vaccines for infants (141).”</i></p>	<p>safety in general (i.e. not specific to any one vaccine), to get a sense of whether pregnant women believe vaccination itself, to be safe during pregnancy.</p> <p>The other questions in this section are aimed at determining whether there is a difference in the perception of maternal influenza compared to Tdap vaccine safety. Based on the influenza vaccine hesitancy identified by healthcare experts, healthcare providers, CHRs, and pregnant women, and in light of the misinformation reportedly circulating online, I suspect that more participants will identify the maternal influenza vaccine as being unsafe (that is, either strongly or somewhat disagree with the</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>80. I consider the maternal whooping cough vaccine to be safe (121,142)</p> <ul style="list-style-type: none"> a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree 	<p><i>Knowing it is safe is really important.</i></p> <p><i>Having open, honest, and repeated conversations with their healthcare providers is huge. When a woman is pregnant, they are ultra-careful that what they are putting into their bodies is safe.</i></p> <p>(INCP03)</p>	<p>statement provided), compared to the maternal Tdap vaccine (“Relations, reservations, and receiving immunizations” p. 74-81; “Speaking the same language: framing maternal immunization,” p.109-119) (141). I also anticipate, based on our colleagues’ findings, that there will be a pervasive uncertainty about the safety of maternal immunizations among pregnant women.</p> <p>I also think that the perception of vaccine safety will be positively associated with vaccine uptake.</p>
<p>Trust:</p> <p>81. I trust the maternal immunization recommendations made by national</p>	<p><i>“I’d like to know who their most trusted...care giver, practitioner, ...trusted</i></p>	<p>I am suggesting questions about trusting territorial and national recommendations</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>experts who provide recommendations about vaccines (121)</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p> <p>82. I trust the maternal immunization recommendations made by the Department of Health in Nunavut (121)</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p>	<p><i>person is when they are pregnant. I know everyone's gonna have a different person depending on what their social circles are, but you know, who is your first choice to go with your pregnancy-related questions? Is it your mother? Is it your grandmother? Or is it your healthcare provider?"</i></p> <p>(INCP02)</p> <p><i>"Do you trust the nurses that are giving you the immunization and that they are giving you the correct information?"</i></p> <p>(INCP02)</p> <p><i>Important for the pregnant woman to have a trusting bond with the healthcare provider. Might be able to change a person's mind who was unwilling to take</i></p>	<p>to determine whether participant trust is higher in one. If for example, participant trust is high in territorial recommendations, and low or neutral in national recommendations, it would be prudent to recommend that the former be used if and when Nunavut-specific maternal immunization literature is made available for distribution.</p> <p>Healthcare experts recommended that we ask pregnant women about who they trusted most to give prenatal health advice, and whether or not they trusted their immunization provider. This is why I have suggested the remaining two questions in this section.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>83. From whom/where would you most trust to find out about the facts on maternal immunization (74)?</p> <ul style="list-style-type: none"> a. Doctor b. Nurse c. Traditional midwife d. Registered midwife e. Community health representative f. Government of Canada g. Government of Nunavut h. Mother i. Sister j. Aunt k. Grandmother l. Other family member m. Other pregnant women in the community n. Friends 	<p><i>the vaccine in the beginning if this relationship is established. (INCP07)</i></p> <p><i>“We can’t forget our link here with the community so although it’s great that we’re here, we’re doing as much as we can to get the community healthy and like up to date on their health and everything, let’s not forget that there is still a little bit of distrust when it comes to First Nation and Inuit population and just modern medicine or just non Inuit people in the community. Inaudible although we all agree that we’re here because we want to help and we’re advocates for health, we can’t ignore the history that’s been here and the truth is you know some people don’t trust us and some people might be</i></p>	<p>As I explained elsewhere, healthcare experts emphasized the importance of a continuous care provider in forging a trusting relationship with prenatal patients (“Building trust amid transience” p. 63-68). For this reason, I hypothesize that continuity of care provider (see question 40b, p. 164) will be positively associated with participant trust in said care provider.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>o. Elder</p> <p>p. Internet</p> <p>q. Television</p> <p>r. Radio</p> <p>s. Other, please specify</p> <p>84. Who do you trust the most to give you a vaccine while pregnant?</p> <p>a. Doctor</p> <p>b. Nurse</p> <p>c. Midwife</p> <p>d. I don't trust any of these providers to give me a vaccine</p>	<p><i>worried [about maternal immunization].”</i></p> <p>(VSCP12)</p>	
<p>Relationships:</p> <p>85. My primary prenatal healthcare provider thinks that it is important for</p>	<p><i>“We are a nurse-led health centre and it’s part of my role as part of the government mandated programs that these women get</i></p>	<p>As I mention in my analysis of narrative collection with healthcare experts, there is a reported combination of sources of</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>me to receive maternal immunizations (121).</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p> <p>86. My female friends think it is important for me to get the maternal influenza vaccine (121).</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p>	<p><i>their prenatal care. So I think from the – they develop that rapport with the community. They are coming to the community to have their weekly checks, their two weekly checks depending on what’s going on. Also, with their rapport with us, they feel comfortable about coming to us and telling us the different aspects of the pregnancy. I think again it’s that rapport with the nurses. I think that’s one of the biggest parts of it.” (INCP10)</i></p> <p><i>“What do you think Elders’ attitudes are towards vaccinations in pregnancy? That would be an interesting, you know, what have your relatives or the Elders in your community advised?” (INCP02)</i></p>	<p>information from which pregnant women seek advice about having a healthy pregnancy (“Communication, personal persuasion, and providing immunization”, p. 81-87). According to narrative collection and sharing circle participants, each of these sources have their own perceptions, attitudes, and experiences that shape the advice that they give (“Speaking the same language: framing maternal immunization,” p.109-119; “Mothers know best: shared experiences, history and decision-making” p. 119-128). I am therefore suggesting that we ask pregnant women what each of those sources thinks about maternal immunizations, to try to</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>87. My female family members (mother, sisters, aunts, grandmothers) think it is important for me to get the maternal influenza vaccine (121).</p> <p>a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree</p>	<p><i>“If there are family members or especially Elders who do not trust the vaccine, their opinion matters way more than healthcare providers. For the Elders, it has to do with history. Historically it wasn’t pretty; Inuit were being vaccinated, but really the vaccine made them sick instead of preventing illness. These beliefs have been passed on to the younger generation.”</i> (INCP07)</p>	<p>understand who is influencing them and in what ways.</p> <p>My understanding based on phases 1 and 2 of qualitative data collection and analysis, was that Elders who would be consulted about maternal health and immunization would be mothers and grandmothers themselves. I will flag this with discussions with our Northern co-researchers however, to ensure that we are not excluding any Elder fathers and grandfathers who may also inform this decision-making.</p>
<p>88. The Elders in my community think it is important for me to get the maternal influenza vaccine (121).</p> <p>a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree</p>	<p><i>“I will say you know, ‘You had the Tdap before and it’s protecting baby.’ I can say all those nice things but let’s not forget that although we are giving them factual information, educated information with our statistics and all that good stuff, let’s not forget the cultural value the family has</i></p>	<p>I expect that the majority of participants will report that their healthcare providers are pro-vaccine. I think that female</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>89. My female friends think it is important for me to get the maternal whooping cough vaccine (121).</p> <ul style="list-style-type: none"> a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree e. Strongly agree <p>90. My female family members (mother, sisters, aunts, grandmothers) think it is important for me to get the maternal whooping cough vaccine (121).</p> <ul style="list-style-type: none"> a. Strongly disagree b. Somewhat disagree c. Neither agree nor disagree d. Somewhat agree 	<p><i>on people’s lives up in the North in particular. So we have to keep that in mind and be sensitive and it does play a huge role in your decision-making.” (VSCP12)</i></p>	<p>friends and family will be generally supportive of maternal Tdap immunization, and either neutral or unsupportive of maternal influenza immunization. Based on my qualitative analyses, I think we might see the greatest variability in Elder advice because they are of a generation that experienced trauma in the name of medicine and at the hands of non-Inuit people, and yet they also experienced vaccine-preventable diseases (“Mothers know best: shared experiences, history and decision-making” p. 119-128).</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>e. Strongly agree</p> <p>91. The Elders in my community think it is important for me to get the maternal whooping cough vaccine (121).</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p>		
<p>Consent:</p> <p>92. I consented to get the flu vaccine during pregnancy of my own free will</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p>	<p><i>People are absolutely consenting to vaccines that they don't know 100% why they are getting it. Just because someone gives consent to do something doesn't mean we have the right to go ahead and</i></p>	<p>Healthcare experts in particular were concerned about whether or not pregnant women are giving truly informed consent to be immunized. I have therefore suggested that we ask pregnant women about consent to contextualize</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>e. Strongly agree</p> <p>93. I consented to get the whooping cough vaccine during pregnancy of my own free will</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p> <p>94. When I was offered the influenza vaccine during my pregnancy, I felt like I could say “no”</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p>	<p><i>do it – we need to make sure they are well informed (INCP03)</i></p> <p><i>“Basically, like informed choice discussion is in my opinion, something that if we can present the information and allow them to make the decision then they won’t feel coerced into doing something they don’t have enough information on.” (INCP08)</i></p>	<p>maternal immunization uptake. If for example, we find that pregnant women have not consented willingly to being vaccinated, this calls into question a fundamental assumption upon which the eventual multivariable analysis rests: that pregnant women made a conscious choice to be or not to be vaccinated. Depending on the frequency with which non-consensual immunization is reported, this could have implications for the internal validity of the multivariable analyses and results of this survey, and perhaps consent ought to be the outcome variable instead of uptake.</p>

Survey Question	Qualitative Data from Phases 1 and 2 Supporting Survey Items	Rationale
<p>e. Strongly agree</p> <p>95. When I was offered the whooping cough vaccine during my pregnancy, I felt like I could say “no”</p> <p>a. Strongly disagree</p> <p>b. Somewhat disagree</p> <p>c. Neither agree nor disagree</p> <p>d. Somewhat agree</p> <p>e. Strongly agree</p>		

5.3.5 Survey logistics

In addition to suggestions for questions to ask pregnant women about maternal immunizations, community healthcare experts were also quick to offer practical recommendations for recruitment for the surveys. One expert who is also a healthcare provider offered to distribute a write-up to their patients and invite them to participate, although they conceded they did not think many of them would want to participate. Another explained that if we do not go through healthcare providers, the chances of pregnant women looking at our survey are very low. Others suggested that we go through health centres to recruit patients via the prenatal nurse or supervisor of health programs, as they would likely have access to prenatal lists, or through the Hamlet, which is responsible for the coordination of the wellness centres. Regardless of our specific approach, one expert advised us to put an advertisement on social media or on the radio to generate interest.

Healthcare experts also weighed in on survey administration logistics. One expert explained that having paper surveys may contribute to the information overload experienced by a lot of pregnant women during prenatal appointments. They cautioned that the survey may not get filled out as a result, or that it may be filled out but incorrectly thus compromising our ability to generate valid and reliable data. Another expert offered that instead of having a form to fill out, we might consider hiring a bilingual Research Assistant who could make pregnant women feel relaxed and comfortable to open up about their experiences and help them to understand the questions. This is in alignment with our proposed plan, but was an excellent reminder of these dynamics nonetheless. Other identified strategies for the next phase of the study identified by diverse experts included: asking as many open-ended questions as possible, offering food, drinks, and an incentive to pregnant women for their time and insights, and encouraging pregnant women to bring a friend or loved one to put them at ease.

Finally, several participants explained that due to research exhaustion in Nunavut, we may not get the kind of participation we might like. Participants also informed us that Inuit are wary of being tokenized in research studies, which may make them hesitant to participate in this one. Of course, participating in this study will be voluntary for pregnant

women, and they will be allowed to end the survey anytime until it is completed and submitted. We will be transparent about our intentions in the consent forms, and we will ask the minimum number of questions to meet our objectives in an attempt to mitigate these concerns. We will continue to involve our co-researchers as we develop and test this survey instrument and defer to their judgement about any issues having to do with the appropriateness of our approach.

Chapter 6: Discussion

The research question that I sought to answer in undertaking this thesis project was: What are the awareness, attitudes, beliefs, values, behaviours, and experiences of pregnant Inuit women, Elders, community healthcare experts, healthcare providers, and community health representatives in Nunavut about maternal pertussis immunization? In this discussion chapter, I present four lessons learned in response to this question. My decision to do so is based on the rescaling of this project, the flexibility of the discussion guides, the richness and volume of qualitative data collected, and the inductive approach to data analysis. It is also my hope that in sharing lessons learned, these findings will be more useful and appropriate for community readership.

The first lesson focuses on the experiences of participants working in a complex healthcare system with various configurations of prenatal and public health. Participants appreciate the tension between resources and healthcare delivery but believe that these configurations exacerbate inequities for pregnant women accessing healthcare and thus maternal immunization. The second lesson is one of human resources and retention which participants identify as either contributing to or detracting from collective knowledge about maternal immunization. This lesson highlights the value of the patient-provider relationships and explores consistency of provider as a determinant of maternal immunization. The third lesson focuses on relationships with aunts, mothers, grandmothers and Elders, and the sharing of decision-making about maternal health and immunization. As decisions are shared, so too are attitudes, beliefs, and experiences of these influential women, which participants perceive to influence maternal immunization behaviour. The fourth and final lesson is one about the awareness, attitudes, beliefs, and resulting maternal pertussis and influenza immunization behaviour among pregnant women.

I present each of these lessons along with those of our colleagues in this discussion chapter. In so doing, I am able to explore the perceptions of pregnant Inuit women and an Elder midwife in addition to community healthcare experts, providers, and CHRs in Nunavut about maternal immunization with depth and dimension (80). I also contextualize these lessons in peripherally related bodies of literature in the absence of literature on this specific topic.

Complexity is a theme that underlies much of the data collected for this thesis project. Participants describe a foundational complexity at the level of the healthcare delivery structure which they suggest contributes to maternal immunization access inequities among Nunavummiut. The configuration of prenatal and public healthcare in Nunavut was identified by participants in this thesis as being a determinant of maternal immunization, and a product of challenging resource constraints.

Pregnant women in Iqaluit receive prenatal care at the QGH; however, they must be referred to the Public Health Clinic to get vaccinated. Healthcare provider participants in this thesis project were particularly concerned that this fragmented configuration may lead to under immunization of pregnant Inuit women. The configuration of prenatal healthcare in Iqaluit meets the World Health Organization's definition of missed opportunities for vaccination, that is, any contact between an eligible patient and the healthcare system that does not result in that patient getting vaccinated (147).

Childcare, weather, transportation, and the likelihood of being sent away from their communities for specialized care are speculated by participants in this thesis to act as barriers to attending one appointment, let alone a second. Although this did not come up in our colleagues' conversations with pregnant women in Nunavut, First Nations mothers have shared similar stories of vaccine inaccessibility related to competing responsibilities in North-Western Ontario (71,148). The size of Nunavut, cultural and linguistic divide between Inuit patients and non-Inuit providers, potential for medical transfers out of the community, and precarious health human resources also contribute to healthcare access inequities among Inuit according to Inuit Tapiriit Kanatami (149). In a recent qualitative study of their approaches to recommending and providing maternal Tdap immunization to Canadians, perinatal healthcare providers identified convenient access to the vaccine as essential to achieve optimal uptake (150).

Contrary to these findings, issues of accessibility are only identified among the minority of Inuit parents and caregivers whose children were not vaccinated in a Canada-wide survey of their perceptions on the subject (74). This may be explained by the fact that childhood immunizations can be provided from a number of different locations including day cares, nurseries, public health clinics, doctor's offices, hospitals, and nursing stations (74). Other reasons identified in the survey results included the belief that

vaccines are ineffective and unnecessary, the desire to delay the immunization schedule, and forgetting the appointment (74). None of these were found to be prominent barriers to maternal immunization accessibility in this thesis project.

Much like the participants in this thesis project, perinatal care providers in Mijović and colleagues' study identified the *ideal* configuration would be to have maternal immunization physically available at the point of prenatal care (150). If this could be achieved, missed opportunities for maternal immunizations in Nunavut would likely lessen.

Outside of Iqaluit, pregnant women access prenatal and public healthcare in community health centres in what one participant in this project coined the “one-stop-shop” approach. While successful in communities with access to appropriate health human resources (one public health nurse as well as a midwife or community health nurse), this combination of prenatal and public healthcare poses unique challenges for CHNs in under-resourced centres. Prioritization of downstream over upstream treatment is how participants in this thesis project identify navigating the tension between limited resources and the diverse needs of patients presenting for care.

Prioritizing illness over wellness care is reported as an adaptation to meet the needs of patients in Nunavut and in other remote Northern Indigenous communities while working in a complex and under-resourced healthcare system (151,152). In adjacent population health literature, prioritization of basic needs to be met is also identified. For example, Inuit youth interviewed in Healey's study of sexual health identified the need for basic social determinants of health to be addressed and needs met, before they could make decisions about safe sex (153). Rand received similar feedback from Inuit women who highlighted the importance of using a holistic approach to STI prevention and programming (154). By this, Rand means that prevention and programming ought to address the multitude of other determinants of health known to contribute to this health issue (154).

Beyond the fundamental prioritization of treatment over prevention, the results of this thesis project reveal that there is sometimes prioritization happening at the level of the vaccine. Some participants in this thesis project reported prioritizing maternal Tdap over influenza immunization as the former is the subject of less skepticism in Nunavut. In

so doing, participants explain, they hope not to detract pregnant women from coming in for subsequent prenatal appointments in the way that offering them the maternal influenza immunization might. I believe this to be a novel contribution to the literature about maternal immunization as I have not seen it elsewhere.

The complexity of the healthcare system in Nunavut requires healthcare professionals to be creative and pragmatic in their approaches to providing prenatal and public healthcare. Participants in this thesis project offer examples of adaptations to address some of the intersecting social determinants of health that impact issues of accessibility to the healthcare system identified in this thesis project. For example, providers working in small communities sometimes go door-to-door, offering care to patients who might otherwise experience barriers to accessing care. Others offer food and encourage pregnant women to bring their other children to the appointment to alleviate their need to find childcare. A volunteer transportation service was introduced temporarily in one of the communities to help pregnant women access services and professionals. Another was considering something similar. These, among other adaptations highlighted throughout this discussion are examples of the Inuit societal value of *qanuqtuurniq*, or “being innovative and resourceful” (155).

The organizational infrastructure of the healthcare system is itself complex, dynamic, and multifaceted, as are the patients presenting to it (156,157). Despite this, practice has not really adapted to complexity, and continues to be reductionist in its simplistic linear logic (156). McGibbon and McPherson propose that adapting to complexity in healthcare policies, programming, and decision-making, is a way of addressing oppression and associated inequities in health (158). The aim of complexity theory is to explore the complexity of the healthcare system and to providing maternal immunization as a focus rather than treating it as noise to be quieted (159). The aforementioned pragmatic adaptations by participants, as well as those identified throughout this thesis, are essential in coping with the uncertainty and unpredictability of the healthcare system (159). These are evidence of complexity- (or perhaps more appropriately in this context *qanuqtuurniq*-) informed ideas, practices, and approaches that I suggest building upon in the subsequent chapter of this thesis.

Health human resources and retention in Nunavut are perceived by participants in this thesis project to contribute to collective knowledge about maternal immunization among providers. Participants also identify continuity of provider as an important first step towards a trusting patient-provider relationship. Both collective knowledge, and patient-provider relationship are believed by participants to influence maternal immunization behaviour in the territory.

Challenges of recruitment and especially retention of healthcare professionals in Nunavut are commonly identified as a particularity of practice in the literature. The rationale for difficulties with retention, however, is not something that I explored in this project. As such, I will summarize some of the literature here to contextualize the discussion of collective knowledge and the patient-provider relationship that follows. According to the Auditor General's Report, independent healthcare providers from outside of Nunavut are drawn to work in the territory because of their interest in expanding their scope of practice, exploring the territory, and experiencing Inuit culture firsthand (160). Upon their arrival however, the complexity of practice in Nunavut acts as a negative feedback loop for retention of these healthcare providers. Furthermore, challenges such as adapting to the harsh arctic climate, the high cost of living and traveling, lack of adequate staff housing, social isolation, and limited job opportunities for significant others are identified as some of the reasons why providers choose not to stay (151,160,161). As of 2017, 62% of community health nurse positions in Nunavut outside of Iqaluit were vacant (160). The vacancy rate varied regionally, ranging from 60% in Qikqtaaluk and Kivalliq to 71% in Kitikmeot (160). In the absence of human resources, the Department of Health hires casual and agency nurses to fill these positions temporarily (160). Like their contracts in the communities, these casual nurses have a temporary connection to residents for only a few weeks to a maximum of a few months at a time (151).

Participants express sympathy towards their transient nurse colleagues who may be unfamiliar with maternal immunization recommendations due to a different scope of practice than they may be used to. They identify a need for more consistent orientation and documentation to ease this transition. This need for better orientation, training, support, quality assurance, and tracking systems in in Community Health Centres in

Nunavut has been identified by the Auditor General (160). Of particular relevance for this thesis, an audit revealed inconsistent and variable training of nurses in Community Health Centres across the territory, including certification to provide immunization (160).

The benefits of a continuous care provider where available in Nunavut, are identified by participants in this thesis project as positively influencing maternal immunization behaviour. Some participants recount being able to change patients' minds in favour of maternal immunization because of the established rapport between providers and pregnant women. Participants in a study of H1N1 vaccination behaviour among Manitoba Metis identified recommendation from their healthcare providers as influencing their choice to be vaccinated. Like participants in this thesis project, some noted that their doctor was able to change their previously vaccine-hesitant ideas about the H1N1 vaccine (72). Relationships with healthcare providers are identified as being influential for maternal healthcare experiences in a systematic review of Canadian Indigenous women's perceptions of maternal health and healthcare (162). In the adjacent prevention literature, cultural awareness of healthcare workers has been cited as a major positive influence on Inuit women's decision to be screened for cervical cancer (163). Providers who empowered Inuit women to take an active role in decision-making were identified as improving women's trust and attitudes towards the healthcare system (163). A trusting relationship between patient and provider has also been identified by perinatal providers outside of the Indigenous health literature as a determinant of maternal immunization (150).

In contrast, participants in this thesis project explained that it is difficult to forge a trusting relationship between providers and patients in other communities where the volume and turn-over of short-term locum providers is high, and where pregnant women must be sent elsewhere to deliver their babies. In these communities and in keeping with Marchildon and Misfeldt's findings, healthcare services are delivered by transient providers who are unfamiliar with the needs, culture, history, dynamics, and values of the communities (151). None of the articles reviewed for this thesis addressed the impact of provider transience on (maternal) immunization uptake. More than one third of First Nations mothers who participated in a qualitative study of childhood immunization shared negative interactions with healthcare providers where they were left feeling

inadequate about their parenting as a result however (148). These experiences influenced mothers' perceptions of childhood immunizations and their likelihood of returning to the clinic for future care (148). This suggests that perhaps there could be misplaced vaccine hesitancy among patients owing to their discomfort with transient providers, if we assume that transient providers are less comfortable with the needs of the community.

Although only a few healthcare providers identified their and their colleagues' attitudes toward and beliefs about maternal immunization as impacting their practice, it was a salient concern among community healthcare experts tasked with managing, coordinating, and supervising them. Several participants described patterns of attitudes, beliefs, and behaviours specific to each group of healthcare providers. Participants in this thesis project express concern for example that some of midwives' holistic and natural immunity beliefs may be biasing maternal immunization behaviour. CHNs on the other hand, are responsible for a plethora of programs and may not be familiar with maternal immunization as part of their scope of practice outside of the territory. This too might be impacting whether and how maternal immunization is discussed.

In a recent qualitative study of approaches to maternal Tdap immunization, researchers noticed a profession-specific approach consistent with the findings of this thesis (150). Of particular relevance, nurses and physicians were unequivocal in their recommendations that pregnant women get the maternal Tdap vaccine. Midwives on the other hand were irresolute in their recommendation; they felt that a personal recommendation would violate the principle of consent (150). In another study of maternal immunization communication, Kaufman and colleagues found midwives to be undecided as to their role in maternal immunization discussions; some thinking of it as a central responsibility of their practice and others believing it was best to defer to other more "traditional" immunizers (164). In Kaufman et al.'s study, informed consent was identified as a fundamental tenet of midwifery practice, which sometimes resulted in passive recommendations for maternal immunization (164).

In addition to relationships between pregnant women and healthcare providers, participants identify relationships between pregnant women and their aunties, mothers, grandmothers, and Elders as being paramount to maternal health. Advice provided by these influential women is reportedly informed by their own experiences with medical

colonialism, infectious disease, and immunization. According to participants, this leads to a dichotomy of attitudes and beliefs in favour of and opposed to maternal immunization among matriarchs, with implications on the behaviours of pregnant Inuit women.

The attitudes, beliefs, behaviours, and experiences of these influential women were perceived by participants in this thesis project to influence maternal immunization behaviour. This finding is reflective of the societal value of *ajjiiqatigiiniq*, which translates as “decision-making through discussion and consensus” (155). It is also corroborated by the stories of pregnant women shared with our colleagues at the QHRC who identified mothers, other mothers in their communities, friends, and sisters as supporting pregnant women (141). The Elder midwife told our colleagues that Inuit women are taught by their mothers what to expect, how to be prepared, and what to eat to have a healthy pregnancy (141).

Similarly to what I present in this project, relationships are identified in other literature as being particularly influential sources of information and advice about vaccines among Indigenous people. Driedger and colleagues identify friends and family as influencing H1N1 vaccine decision-making among Manitoba Metis for example (72). Healthcare providers, the school system, and the internet were rejected as sources of information about sexual health and relationships in favour of caregivers and parents among Inuit youth in Healey’s qualitative study (153). Inuit women in Rand’s study of HIV and STI prevention and health promotion also identify the influence of lessons learned from parents about safe sex practices, and the importance family-focused, and community-wide programming (154).

Interestingly, few Inuit parents and caregivers surveyed in a study of childhood immunization indicated that they trusted other, non-health-related sources for information about immunization. Family and Elders were trusted sources among only 5% and 2% of participants respectively (74). These findings deviate substantially from mine and are more closely in alignment with what is known about non-Indigenous populations. In a scoping review non-specific to maternal immunization in Indigenous populations, family and friends’ opinions were found to be far less influential on maternal immunization behaviour than they were found to be in this thesis project (4).

Participants in this thesis project identify a dichotomy of attitudes and beliefs about maternal immunization among influential women (including aunts, mothers, grandmothers, and Elders) in the community. Some family members and Elders are perceived by participants to be champions of immunization. Their vaccine positivity is understood by participants to be related to their belief that immunization will prevent the devastating and sweeping impacts of morbidity, mortality, and medevacs associated with infectious diseases. In their qualitative study of the factors influencing H1N1 vaccine behaviour among Manitoba Metis, Driedger and colleagues found that many adults who did not initially want to be vaccinated, ended up getting the vaccine upon the insistence of a relative (72). Other than by Driedger et al., literature detailing the dimension of experience as evidence **for** (maternal) immunization, particularly as championed by Elders, is scarce (71).

On the other hand, participants in this thesis project suggested that family members and Elders may be opposed to immunization due to historic trauma experienced in the name of medicine and at the hands of non-Inuit healthcare providers. The Elder midwife who spoke with our colleagues shared their story of being relocated in the 1960s because of tuberculosis despite not agreeing or wanting to leave their home (141). Shortly after being relocated, this Elder learned about vaccinations, which were contentious among mothers at that time (141). She observed that babies used to be a lot healthier before the introduction of vaccines, and expressed nervousness about the risks associated with them (141). As such, this Elder discouraged her children and grandchildren from getting vaccinated (141).

Our colleagues' findings are corroborated by other articles reviewed for this thesis project (72,148). In particular, Manitoba Metis reported that their friends and families advised them against getting the H1N1 vaccine citing misinformation, concerns about safety, and stories of adverse events circulating in the community as the rationale for their choice not to be vaccinated (72). Mothers in First Nations communities of the Sioux Lookout Zone actually connect vaccine hesitancy to a distrust of the healthcare system and providers working within it (71). Tarrant and Gregory suggest in their interpretation of their study results, that immunizations were historically provided without adequate explanation, which may be contributing to this hesitancy (71). While a reasonable

suggestion, the findings from this thesis suggest that the issue runs deeper than explanation. Immunization is a medical policy originating outside of the territory and administered by predominantly non-Inuit providers. Given the historic trauma that Elders witnessed firsthand, they may be understandably suspicious.

The Elder midwife shared with our colleagues that she observed a breakdown in mother-daughter relationships, which used to be the source of immense support for pregnant women (141) (Healey Akearok, oral communication, January 22, 2020). She suggested that this breakdown may result in pregnant women ignoring Elder knowledge about healthy relationships and pregnancy (141). This generational divide is well documented as one of the many devastating impacts of colonialism (84,154).

If public healthcare providers and CHRs do not want to reinforce this breakdown, it will be important to engage with aunts, mothers, grandmothers, Elders, and others who support pregnant women in their vaccine decision-making. The Elder midwife shared with our colleagues that healthcare providers ought to ask Elders and grandmothers for their thoughts on it. In particular, she explained that providers should give pregnant women the option to talk to their grandmothers before getting vaccinated (141). This same suggestion was echoed by healthcare provider participants in this thesis project who gave examples of how they engage in a respectful and interactive way with Elders.

In the STI and HIV literature, Rand also highlights a gap in knowledge translation between healthcare professionals and Elders that needs to be filled (154). By including Elders in education, planning, and decision-making, relationships between pregnant women and Elders will be nurtured through maternal immunization and not fractured because of it. In fact, authors of an article assessing implementation of a palivizumab program in Nunavik identify a lack of meaningful consultation with the Inuit community as ethically dubious (165).

Participants in this thesis explain that in the case when they cannot interact directly with patient relatives, notifying patients about the immunization ahead of their appointment, and providing them with maternal immunization materials may be advisable. That way, participants explain, pregnant women can go home and consult the

appropriate relatives themselves before making a decision about whether or not to be vaccinated.

In all but one of the communities represented in this thesis project, uptake of the maternal Tdap vaccine reportedly exceeds that of the maternal influenza vaccine several-fold. Participants perceive this to be the product of heightened awareness due in part to recent outbreaks of pertussis in the territory, and the emphasis of maternal Tdap immunization messaging. There is comparatively less awareness of influenza outbreaks in communities according to participants, and pervasive skepticism of the influenza vaccine.

According to healthcare providers and CHRs that participated in this project, there is an exhaustive annual public awareness campaign across Nunavut to promote and provide the influenza vaccine during influenza season. Despite the fact that no such campaign exists for the maternal Tdap vaccine, in nearly all of the communities represented by healthcare providers and CHRs who volunteered to participate in this project, uptake of the maternal Tdap vaccine exceeded that of the maternal influenza vaccine several fold. Much like the healthcare experts, providers, and representatives suggested, our colleagues at the QHRC found that almost all of the pregnant women that participated in the sharing circles received the maternal Tdap vaccine in their previous pregnancy, and almost none of them received the maternal influenza vaccine (141).

Although no published literature exists characterizing maternal immunization among Indigenous women, these findings are much in keeping with data in non-Indigenous populations. According to a scoping review done by MacDougall and Halperin, maternal tetanus immunization is generally accepted, while uptake for maternal pertussis and influenza vaccines is variable (97). A quantitative survey of prenatal patients at a tertiary care center in the United States revealed statistically significantly higher uptake of the maternal Tdap immunization compared to the maternal influenza immunization (166).

Participants in this thesis project speculate that maternal Tdap immunization awareness and uptake among pregnant women in Nunavut may be heightened due to frequent pertussis outbreaks in the territory. This speculation is consistent with our colleagues' finding at the QHRC, that participants in sharing circles had heard and felt anxious about the pertussis outbreak, and wanted to protect their baby from getting sick

(141). This is also corroborated by findings from other studies in First Nations and Metis communities where concerns about infectious disease morbidity and mortality are cited as a primary motivating factors for vaccination behaviour (72,148).

Community healthcare experts understand there to be generally positive attitudes and beliefs among pregnant women in Nunavut about the maternal Tdap immunization because of a shared desire to protect their communities, themselves, and especially their babies from pertussis. This is evidence of the Inuit societal value of *pijittsirniq*, which translates as “serving and providing for family or community, or both” (155). For this reason, healthcare providers and CHRs explain that they specifically frame maternal Tdap immunization as protecting infants from the infection. Interestingly, it was far less common that maternal influenza vaccine was framed as such. A desire to protect their child(ren) was confirmed by pregnant women in the sharing circles led by our colleagues in Nunavut, as a determinant of maternal immunization (141). Pregnant women explained that their healthcare providers had told them that the maternal Tdap immunization would protect their newborn babies from getting sick, and that was important to them (141).

Midwife participants in a study of the barriers and facilitators of maternal immunization in Australia identified a similar pattern of messaging regarding the Tdap and influenza vaccines (164). This resulted in a valuing among pregnant women of those vaccines perceived to protect babies over those perceived to protect themselves (164). This desire to protect children or parents is also cited in Driedger and colleagues’ work as a motivator for Manitoba Metis to get the H1N1 vaccine (72), and identified as paramount in a quantitative study of Inuit parents and caregivers about childhood immunization (74).

A recently published systematic review of determinants of maternal immunization, however, offers evidence against this trend. In their meta-analysis, Kilich and colleagues found the odds of influenza vaccination to be higher among women who believed that the vaccine would protect themselves compared to those who believed the vaccine would protect their baby (167). In theory then, the framing of maternal influenza immunization as protecting pregnant women *should* be effective. The Inuit value of serving and protecting the community and family however, may be a mediating variable that makes the results of Kilich and colleagues less applicable in this instance.

Hesitancy surrounding the influenza vaccine was identified as being common regardless of whether a patient is pregnant or not and is not unique to Nunavut according to participants with experience elsewhere. Participants speculated that the belief among pregnant women (and the community) that the influenza vaccine is less important than the Tdap vaccine may be related to the fact that pertussis outbreaks in the community are more common, whereas influenza outbreaks attract less attention. Furthermore, participants cited the commonly held misperception among patients that the influenza vaccine causes influenza, which does not seem to be the belief about the Tdap vaccine. According to pregnant women that shared their stories with our colleagues, influenza immunization hesitancy is related to experiences where it made themselves or others sick, and the pain associated with the vaccination (141).

In a study of facilitators and barriers to maternal immunization, midwives also noticed influenza vaccine hesitancy among mothers that is absent for the maternal Tdap immunization (164). Concerns about influenza vaccine safety, particularly the misperception that it infects recipients with the virus, have been cited elsewhere as reason for declining it in pregnancy (166,168). While nonspecific to influenza vaccination, Tarrant and Gregory report that First Nations mothers are wary of adverse effects following immunization (i.e. fever, irritability, pain, edema, and injection site pain) which may deter other mothers in the community from getting their children immunized (71). In a later publication, Tarrant and Gregory reach a similar conclusion about stories of serious illness and sometimes death following immunization as reinforcing an anti-vaccination sentiment in some of the mothers' communities (148).

Participants in this thesis project suggest that even those pregnant women who consent to be vaccinated may not understand exactly what is being given to them and why. In sharing circles with our colleagues at the QHRC, pregnant women expressed wanting to know more about maternal immunization; particularly the advent and purpose of vaccines, the mechanism of protection, vaccine schedules, safety, benefits, and infectious disease outbreaks (141). According to Dr. Healey Akearok, even pregnant women that received the maternal Tdap vaccine were not told why it was important as far as the pertussis outbreak was concerned (Healey Akearok, oral communication, January 22, 2020).

Similar communication and ethical concerns arise in a study of providers' perceptions of a palivizumab program in Nunavik (165). Midwives, and some nurses felt like the information provided to Inuit patients about RSV prophylaxis was insufficient, and that consent was not truly being obtained (165). It is suggested that truly informed consent could not be obtained if the Inuit community is not meaningfully informed, consulted, and involved in the program (165). Inuit parents, they conclude, must feel like they can make a free and informed decision about whether or not to accept palivizumab for their child (165).

The majority of participants in a qualitative study by Driedger and colleagues reported feeling like they had insufficient information about the H1N1 vaccine (among vaccines in general) and about the H1N1 pandemic (72). Importantly, this knowledge gap was identified both by participants who had received the H1N1 vaccine, and those who had not (72). A similar trend is shown in a study of Inuit women's experiences with and attitudes about cervical cancer and prevention in Nunavik (73). Despite the fact that most women had a Papanicolaou (Pap) smear in the last year, some did not understand the purpose for this test, and awareness about cervical cancer and the HPV vaccine was generally low (73). This issue also arises in interviews with First Nations mothers in the Sioux Lookout Zone who admit to having limited knowledge about childhood vaccines and the diseases that they prevent (71). Beyond stating that most participants had at least one child with delayed vaccinations, no information is provided or conjectured in the Tarrant and Gregory study about the relationship between knowledge and immunization behaviour (71).

In their systematic review about barriers to maternal immunization in the Canadian context, Poliquin and colleagues explain that pregnant women who need more information about maternal immunization are generally the same ones who opt not to receive it (169). Knowledge, therefore, may be considered a predictor of maternal immunization in the non-Indigenous population in Canada. The results of this thesis project, those of our colleagues in Nunavut, and of other authors whose work was reviewed as I wrote this thesis suggest, however, that knowledge may not be a determinant of (maternal) immunization in Indigenous populations, as people are receiving them without fully understanding what for (72,141,148). In other words, the

information being communicated by healthcare providers and CHRs may not be provided in an accessible format that is meaningful to pregnant women; a reality of which has important implications for *informed* consent and self-determination.

In a reflection on Indigenous access to informed consent, Boivin suggests that informed consent is a sacred ceremony between a patient and provider, built on the latter's respect for the formers' agency in identifying their path to health (170). Boivin asks, "Do health care spaces, laden with colonial baggage, allow enough room for a balanced exchange in the informed consent process?" (170). Findings from this thesis project suggest that so long as pregnant women are getting vaccinated without being provided with adequate information to be able to make an informed decision, the answer is "no".

Chapter 7: Strengths and Limitations

7.1 Strengths

One of the major strengths of this project was the diverse, interdisciplinary research team from both Northern and Southern Canada whose combined ways of knowing resulted in robust and culturally relevant project design, methods, analyses, and results. Another strength in our approach were our engagement trips to Iqaluit where we had the opportunity to discuss our project with members of the Department of Health and Wellness, healthcare providers, and the Tuttarviit (an inter-departmental group of IQ coordinators for each department of the Government of Nunavut who work with Elders to develop IQ initiatives).

The sequential mixing of methods in this study demonstrated in the generation of a panel of survey questions using qualitative data and careful rationale is a strength as it ensured that this thesis was grounded in and sets subsequent steps of this project up to continue to be informed by IQ. The use of two batteries of qualitative data collected from different populations was another strength of this study because it added dimensionality to the analyses of maternal immunization in Nunavut. This in turn will result in more comprehensive results to be considered for future maternal immunization programs in the territory. The mixed methods approach in this thesis also allowed for internal triangulation of the results between and across community healthcare experts, healthcare providers, and CHRs, as well as the results of our colleagues. This meant that it was more robust and rigorous than had I used any one method alone (79).

Another strength of the research design used for this project was that it provided an excellent opportunity for me as a student to become exposed to and comfortable with a variety of methods instead of just one (77). In particular, as I learned and became familiar with qualitative data collection and analysis, I was able to use the flexibility of the discussion guides to make adjustments to my approach so as to maximize the quality and richness of the data elicited.

7.2 Limitations

Physical distance was the source of a couple of notable limitations in this thesis project. Collaborating with co-investigators located several thousand kilometers away proved to be challenging and regrettably contributed to miscommunication regarding project logistics, budget, methods, and developments. Due in part to this distance and the resulting strain on research relationships, the results of this thesis project may be biased in favour of my own way of knowing. It would be ideal to have been able to work in closer physical proximity to co-investigators in Nunavut, and to have been able to nurture those relationships more intentionally.

The distance between Halifax and Nunavut also contributed to my inability to be physically present for data collection, which meant that I could not observe participants' non-verbal cues such as facial expressions and gestures. While this limitation was unavoidable due to travel logistics and budgetary constraints, it is a notable limitation as non-verbal communication is especially important in Inuit culture.

A limitation of the recruitment strategy for the individual narrative collection was our neglecting to specify minimum number of years' experience in our inclusion criteria. Participants were seemingly recruited based on their job titles and not on their experience in the community. As a result, we ended up with some participants with fewer than one year of experience working in Nunavut. While perhaps experts in their fields, they do not meet at the intersection of community and provider that was intended for this phase of the study and therefore these findings may be limited in their validity.

There is a diverse body of literature surrounding saturation in qualitative research. While I felt like I reached saturation in the virtual sharing circles, I would have preferred to have been able to conduct a few more to have at least two to five focus groups per category of participant (in this case profession) to strengthen the dependability of this work (114). This limitation may have had negative impacts on the trustworthiness of these data.

Healthcare staff turnover and transience in Nunavut posed some challenges during the recruitment stages of this thesis project. In particular, providers who were actively employed in Nunavut but not currently working on rotation did not have access to their

Government of Nunavut e-mails which made it difficult to get a hold of several eligible participants and thus impacted the sample sizes of the qualitative components of this project. Once participants had participated, I also found it difficult to re-contact some of them for clarifications. Some of their e-mail addresses had been inactivated either temporarily or permanently depending on whether they were out of the territory or had changed jobs since participating. This may have biased my analyses slightly, as I had to make assumptions about what they meant in certain circumstances when they were unavailable to clarify.

Staff turnover in our own research team posed unforeseen challenges as we transitioned through several Project Managers who needed to be trained, orientated, and to our colleagues in Nunavut. As aforementioned, this likely had consequences on the balance of the two ways of knowing that were initially meant to be captured herein.

Finally, I experienced difficulties collecting data from community and public healthcare providers whose outbreak responsibilities understandably took precedence over participating in virtual sharing circles for this project. This impacted the sample sizes of the narrative collection component of this project and thus potentially the trustworthiness of the results.

Chapter 8: Recommendations and implications

Just as the evidence presented in this thesis provides information beyond the scope of the original research question, so too do the recommendations and implications arising from it. In this chapter, I present recommendations for this project, followed by implications for community health and maternal immunization programs at the system, provider, relative, and personal level. These recommendations and implications are complexity- (or *qanuqtuurniq*-) informed, that is, they are based on the adaptations identified by participants, to navigate the uncertainty and unpredictability of the healthcare system (159).

8.1 Recommendations for this project

As outlined Figure 1 (p.35), and in the subsequent methods section of this thesis (p. 64-70), validation of the panel of survey questions generated is the immediate next step in this project.

Based on the findings of this thesis, the literature reviewed as I wrote it, and discussions with S.M., it will be important to form a community advisory committee with health and cultural expertise. This committee will be an excellent resource for collaborating on future study documents, making study-related decisions, and ensuring that this project progresses in a good way. There were several participants who expressed interest in this project and have extensive experience that would make excellent candidates for one such committee. It would also be invaluable to have community members, especially pregnant women and their mothers, aunts, and grandmothers on this committee to ensure that this project continues to be guided by the very people it purports to protect.

In doing this work, and in learning from our colleagues in Nunavut, I have come to understand that documents created in English and translated into Inuktitut and Inuinnaqtun may lead to ambiguities that could obstruct the message conveyed. As such, it could be beneficial for future documents to be created in Inuktitut and Inuinnaqtun rather than in English so as to ensure the integrity of the message remains intact.

8.2 Implications for maternal immunization programs

There are several implications for community health, and future and existing maternal immunization programs based on the findings from this thesis project.

8.2.1 Systemic implications

It is important that every interaction between a pregnant patient and their healthcare provider be seized as an opportunity to discuss (and provide, if appropriate) immunization (4). In places like Iqaluit where maternal immunization and prenatal care are provided separately, it would be ideal if prenatal healthcare providers were able to offer immunizations during their appointments in the “one-stop-shop” approach. By using a provider at an existing point of care to improve access to maternal immunization, this intervention would be in keeping with the World Health Organization’s Missed Opportunities for Vaccination Strategy (147). As noted by one participant in this project, LPNs may not be ideal candidates due to their competing responsibilities, the amount of work to determine whether vaccines have already been given, and the documentation associated with giving the vaccine. Maternal immunization is however already within the scope of practice of physicians delivering prenatal care and ought to be recommended and provided in all practice settings (4). If there are an insufficient number of physicians providing prenatal care in Iqaluit, one might consider designating a public healthcare provider at the QGH who could provide maternal immunizations to Nunavummiut. This may mitigate some of the challenges associated with accessing healthcare services identified in both configurations of prenatal and public health in this thesis.

Smaller communities are not immune to accessibility issues as community health centres are often understaffed and providers required to attend to a host of patient needs simultaneously. Investment into increasing the number of Indigenous healthcare providers is among the Calls to Action made by the Truth and Reconciliation Commission of Canada (171). Midwives are specialists in women-centered maternity care with lengthier appointments than their CHN counterparts. There have also been updates to their training to reflect the practice of traditional Inuit midwives while upholding the skills and ethical codes established by the regulatory council. As such, midwives could be excellent

candidates to improve maternal immunization uptake in Nunavut. Training, hiring, supporting, and retaining more Inuit midwives in particular also has the potential to allow for births to occur in the communities instead of the current practice of medical relocation reminiscent of the mishandling of tuberculosis epidemics in the 1950s, and other traumatic separations of Inuit from their families and communities.

In recognition of the resource constraints in Nunavut that make these recommendations challenging to implement in the near future, participants in this project share a number of complexity-informed adaptations, any and all of which can be considered in other communities. Participants have found that the provision of food and childcare for pregnant women accessing prenatal and public healthcare services, volunteer transportation for patients for whom the physical location of their appointments acts as a barrier, and door-to-door prenatal and public healthcare services in the communities have been successful initiatives where implemented.

8.2.2 Implications at the provider-level

The results from this thesis suggest that due to a consistently transient healthcare workforce, the maternal immunization program infrastructure could be strengthened such that transient providers feel comfortable working in an expanded scope of practice and providing consistent information and recommendations to patients. Training and hiring more Nunavummiut to work as CHNs, PHNs, physicians, midwives, and CHRs is an ideal remedy to this situation (171). The Truth and Reconciliation Commission also calls upon medical and nursing schools in Canada to teach their students about Indigenous health issues, the legacy of colonialism and residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, and on Indigenous teachings and practices (171). This call to action is strongly supported by the findings from this thesis, which were that non-Inuit healthcare providers sometimes lack an understanding of the cultural and historic context of the system and territory within which they are providing care.

Unless they are working specifically in an immunization capacity in Southern Canada, healthcare providers practicing in Nunavut may not be aware of or comfortable

with providing maternal immunization. In addition to training nursing and medical students in cultural and immunization competencies, it could be beneficial for the self-directed course and exam offered for healthcare providers giving maternal immunizations in Nunavut to be an unequivocal prerequisite for practice. Managers might even consider requiring providers to present proof of completion when beginning their rotation in a community.

Findings from this thesis project also suggest that a reinvigorated effort to communicate maternal immunization recommendations and the rationales behind them to staff may be beneficial. Specifically, documentation needs to be updated to reflect maternal Tdap and influenza immunizations in providers' prenatal checklists so as to cue them to initiate discussions more consistently. This would take some of the responsibility off of seasoned providers to do it themselves. One of the midwives in Kaufman et al.'s study also suggested the adoption of a sticker system on the patient's chart to denote whether or not maternal immunization discussions were had (164). This could safeguard against missed opportunities for immunization by providing an extra layer of insurance that proper discussions are being had.

Furthermore, participants in this project suggested that a factual and culturally appropriate maternal immunization discussion template be available for healthcare providers to ensure that pregnant women get a consistent message, unbiased by providers' personal perceptions. From a factual perspective, Kaufman and colleagues have compiled a list of topics and formats suggested by midwives in Australia for professional training (164).

Based on these results as well as those of our colleagues in Nunavut, the establishment of a trusting relationship between patients and their healthcare providers is critical in providing culturally competent care, and complicated by the transience of healthcare providers (141). Until such a time when continuity of healthcare providers in Nunavut is achieved, it would be beneficial for transient staff to be orientated to the environment and organization of the health system, historical context of the region, and Inuit-specific communication conventions in the same way they are to immunization practices. The Government of Nunavut might consider mandating the exploration of resources such as the Health NU application (66). Critical reflexivity among providers is

also suggested as a way of building trusting relationships between patients and providers in a systematic review of Canadian Indigenous women's perceptions of maternal healthcare (162).

Based on findings from this thesis project, it would be ideal to have fewer transient healthcare providers and an interdisciplinary workforce in rural communities to share responsibilities with CHNs. It would be beneficial for there to be locally trained CHNs and especially midwives who are permanent fixtures of the community and the healthcare system in Nunavut. Midwives with pro-vaccination training in particular would make excellent candidates for providing maternal immunization. They are able to offer lengthier prenatal appointments and thus have time to engage in discussions with patients about maternal immunization and obtain truly informed consent.

8.2.3 Implications for appropriate consultation

Relationships between pregnant women and their family members and Elders were highlighted throughout the phases of this project as being essential to maternal health (141). As such, it may be beneficial to develop information campaigns, messaging, education, and literature specific to aunts, mothers, grandmothers, and Elders and not just for pregnant women. This is supported by the literature reviewed, which suggested holistic, family-centered, and community-wide approaches to disease prevention and health promotion programs are the best practice in Inuit communities (154).

The results of this project also suggest the importance of pregnant women and their relatives being engaged and informed in the maternal immunization decision-making process. This would put mothers and families in a better position to make culturally-informed decisions (141). Whenever they have the opportunity, participants in this study report engaging relatives in a respectful and inclusive way that honours their collective experience and knowledge over statistics and scientific facts. In instances where pregnant women attend prenatal appointments alone, providers and CHRs might consider adopting the midwifery approach of informing patients in advance of the appointment that they will be offered a maternal immunization. Providing pregnant women with information in advance of their immunization appointment could be beneficial as it would allow the time

for them to consult with their relatives. In so doing, she might therefore be in a better position to provide informed consent at her following appointment.

Just as the decision to be or not to be vaccinated is shared by pregnant women with their relatives, so too should the planning of future maternal immunization programs according to participants in this project. A potential maternal Respiratory Syncytial Virus (RSV) vaccine was the source of much enthusiasm among participants in this project. As reported in this thesis, and elsewhere in the literature, future public health plans, programs, and recommendations should be informed by the needs, values, experiences, and beliefs of Inuit, and done by engaging, collaborating, and cooperating with the community (72,172,173).

8.2.4 Implications at the individual level

Negative experiences, perceptions, and misinformation about the influenza vaccine in particular are reportedly spread widely on social media in Nunavut. Based on their scoping review of maternal immunization, MacDougall and Halperin suggest that there ought to be a more intentional and coordinated social media effort than the historic one-size-fits-all message posted on a single platform (4). There should be one such effort from public health professionals in Nunavut to dispel the myths associated with the influenza vaccine, and to reinforce the fact that maternal influenza immunization protects infants too. Public health might also consider who the opinion-drivers, or influencers are (in any sense of the word) in the community and get them to champion immunization on their social media.

A dearth of maternal immunization materials specific to Nunavummiut was identified in this thesis. Community healthcare experts and healthcare providers also emphasized that Nunavummiut are understandably wary of being singled out by recommendations for immunizations due to historic trauma in the name of medicine. Based on these findings, one might consider creating new materials using colloquial language, local examples, and stories as a means of communicating. Findings from a recent study of cervical cancer prevention in Nunavik also suggest that visual language is an important way of communicating public health messages to Inuit women (163).

Dr. Healey Akearok identified the “Tobacco has no place here” campaign as an example of a successful health promotion program that was well-received by the community because of its messaging (Healey Akearok, oral communication, January 22, 2020). This public awareness campaign was initiated by the Government of Nunavut in 2012, and centers its messaging around the fact that tobacco does not come from Nunavut, nor is it a part of Inuit culture, and therefore that it “has no place here” (174,175). Maternal immunization messaging could be framed in a similar way but aimed instead at eradicating infectious disease through immunization. This is merely an example for the purposes of this thesis, but ultimately the community should decide on the messaging that would be most appropriate.

As it is mentioned earlier, our colleague Dr. Healey Akearok explained to us that “immunization” and “medication” are translated with the same wording in Inuktitut (Healey Akearok, oral communication, January 22, 2020). In the same way that I recommended this as the next step for this project, I am inclined to suggest that when maternal immunization literature is developed, that it be developed in Inuktitut so that there is no chance of terminology that cannot be translated.

Finally, the results from this thesis suggest that pregnant Inuit women are receptive to messages about maternal immunization protecting their families, communities, and especially their babies. It could be beneficial therefore to adopt messaging for both the maternal influenza and Tdap immunizations focused on this important Inuit societal value (155). It is of the **utmost** importance however that this messaging is accompanied by appropriate education so as not to usurp informed consent.

Chapter 9: Conclusions

Despite the recommendation that all pregnant women in Canada receive immunizations against the influenza and pertussis infections, outbreaks of pertussis continue to impact Inuit mothers, infants, families, and communities disproportionately. In this thesis project, I explored the perceptions of pregnant Inuit women, Elders, community healthcare experts, healthcare providers, and community health representatives in Nunavut about maternal pertussis immunization.

Stories were shared that contextualize maternal immunization within a complex healthcare system and at the intersection of several determinants of Inuit health. Health human resources contribute to collective knowledge, and the establishment of trusting patient-provider relationships. Both of these are identified as necessary to be able to provide maternal immunization, and as being complicated by provider transience. Also identified as essential to the maternal immunization decision-making process, is the opportunity for pregnant women to consult with their mothers, grandmothers, aunts, and Elders, whose own experiences reportedly shape their advice.

In nearly all of the communities represented in this study, maternal Tdap immunization uptake exceeds that of the maternal influenza vaccine. Protecting their communities, themselves, and especially their infants were identified as the main reasons for accepting the maternal Tdap immunization among participants in this project. The value placed upon protecting Inuit infants is highlighted by providers offering the vaccine, which almost invariably leads to acceptance by pregnant Inuit women. While an effective strategy if uptake is the outcome of interest, it is ethically problematic without proper consultation and raises important questions about whether consent is in fact truly informed.

In a complexity-informed approach, adaptations made by participants and their colleagues are drawn upon to make recommendations and suggest the implications of this project. Perhaps most salient among them is the acknowledgement that for maternal immunization to be *truly* successful in Nunavut, any and all planning, development, and decision- and policy-making, ought to be done in collaboration with Inuit women and any relatives with whom maternal health decision-making is shared.

Appendix 1. Literature Review Search Strategy

PubMed Search History January 19, 2019

Search	Query	Items found
#4	Search (((((((("Vaccination Coverage"[Mesh] OR "Vaccination Refusal"[Mesh] OR "Immunization Programs"[Mesh] OR "Immunization"[Mesh] OR "Immunization Schedule"[Mesh] OR "Vaccines"[Mesh] OR vaccin*[Title/Abstract] OR immuniz*[Title/Abstract]) AND (((((((("Maternal-Child Nursing"[Mesh] OR "Pregnancy"[Mesh] OR "Obstetrics"[Mesh] OR "Maternal Health"[Mesh] OR "Prenatal Education"[Mesh] OR "Prenatal Care"[Mesh] OR matern*[Title/Abstract] OR obstetric*[Title/Abstract] OR pregnan*[Title/Abstract] OR prenatal*[Title/Abstract] OR antenatal*[Title/Abstract] OR perinatal*[Title/Abstract] OR Mothers[Mesh] OR Mother*[Title/Abstract] OR "Pregnant Women"[MH] OR "Midwifery"[Mesh] OR midwif*[Title/Abstract]) AND ((("Inuits"[Mesh] OR "Nunavut"[Mesh] OR "Newfoundland and Labrador"[Mesh] OR "Northwest Territories"[Mesh] OR "Quebec"[Mesh] OR nunatsiavu*[Title/Abstract] OR nunav*[Title/Abstract] OR inu*[Title/Abstract] OR indigen*[Title/Abstract] OR aborigin*[Title/Abstract] OR metis*[Title/Abstract] OR metis[Title/Abstract] OR "Canada"[MeSH Terms] OR "Northern Territory"[MeSH Terms] OR "Arctic Regions"[MeSH Terms] OR "Health Services, Indigenous"[MH] OR "first-nation"[Title/Abstract] OR "first-nations"[Title/Abstract] OR aborigin* [Title/Abstract] OR indigenous[tw] OR northern territory [Title/Abstract] OR northern territory[ad] OR aborigin* [Title/Abstract] OR indigenous [Title/Abstract]))))	426

#3	Search ("Inuits"[Mesh] OR "Nunavut"[Mesh] OR "Newfoundland and Labrador"[Mesh] OR "Northwest Territories"[Mesh] OR "Quebec"[Mesh] OR nunatsiavu*[Title/Abstract] OR nunav*[Title/Abstract] OR inu*[Title/Abstract] OR indigen*[Title/Abstract] OR aborigin*[Title/Abstract] OR metis*[Title/Abstract] OR metis[Title/Abstract] OR "Canada"[MeSH Terms] OR "Northern Territory"[MeSH Terms] OR "Arctic Regions"[MeSH Terms] OR "Health Services, Indigenous"[MH] OR "first-nation"[Title/Abstract] OR "first-nations"[Title/Abstract] OR aborigin* [Title/Abstract] OR indigenous[tw] OR northern territory [Title/Abstract] OR northern territory[ad] OR aborigin* [Title/Abstract] OR indigenous [Title/Abstract])	205,511
#2	Search (((("Maternal-Child Nursing"[Mesh] OR "Pregnancy"[Mesh] OR "Obstetrics"[Mesh] OR "Maternal Health"[Mesh] OR "Prenatal Education"[Mesh] OR "Prenatal Care"[Mesh] OR matern*[Title/Abstract] OR obstetric*[Title/Abstract] OR pregnan*[Title/Abstract] OR prenatal*[Title/Abstract] OR antenatal*[Title/Abstract] OR perinatal*[Title/Abstract] OR Mothers[Mesh] OR Mother*[Title/Abstract] OR "Pregnant Women"[MH] OR "Midwifery"[Mesh] OR midwif*[Title/Abstract])))	1,220,373
#1	Search (((("Vaccination Coverage"[Mesh] OR "Vaccination Refusal"[Mesh] OR "Immunization Programs"[Mesh] OR "Immunization"[Mesh] OR "Immunization Schedule"[Mesh] OR "Vaccines"[Mesh] OR vaccin*[Title/Abstract] OR immuniz*[Title/Abstract])))	454,063

EBSCO Search History

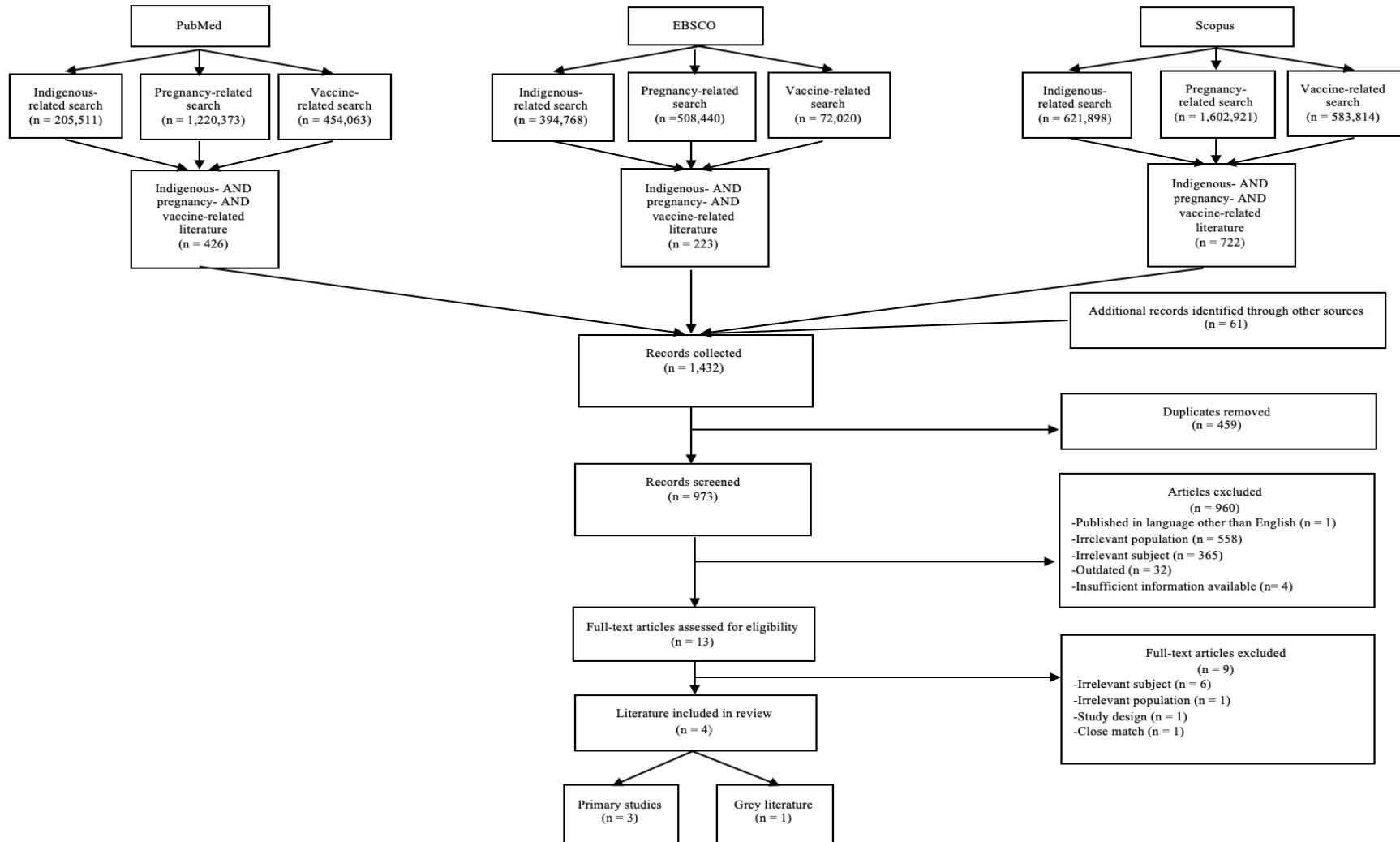
Search	Query	Items found
--------	-------	-------------

S4	S1 AND S2 AND S3	223
S3	"vaccination coverage" OR "vaccination refusal" OR (MH "Immunization Programs") OR "immunization programs" OR (MH "Immunization+") OR (MH "Immunization Schedule") OR (MH "Vaccines+") OR "vaccines" OR "vaccin*" OR "immuniz*" OR "vaccination"	72,020
S2	(MH "Maternal-Child Nursing+") OR "maternal-child nursing" OR (MH "Pregnancy+") OR "pregnancy" OR (MH "Obstetrics") OR "obstetrics" OR (MH "Maternal Health Services+") OR "maternal health" OR "prenatal education" OR (MH "Prenatal Care") OR "prenatal care" OR (MH "Maternal-Child Health") OR "matern*" OR (MH "Obstetric Care+") OR "obstetric*" OR (MH "Obstetric Nursing") OR "pregnan*" OR "prenatal*" OR "antenatal*" OR "perinatal*" OR (MH "Mothers+") OR "mother" OR (MH "Expectant Mothers") OR "pregnant women" OR (MH "Midwifery+") OR "midwif*"	508,440
S1	(MH "Inuits") OR "Inuits" OR (MH "Eskimos") OR (MH "Aborigines+") OR "Aborigines" OR (MH "Indigenous Health") OR (MH "Indigenous Peoples+") OR (MH "Maori") OR (MH "Nunavut") OR (MH "Newfoundland") OR "Newfoundland and Labrador" OR (MH "Northwest Territories") OR "Northwest Territories" OR (MH "Quebec") OR "Nunatsiavu*" OR "nunav*" OR (MH "Northwest Territories Registered Nurses Association") OR "inu*" OR (MH "Health Services, Indigenous") OR (MH "Health Services for the Indigent") OR "indigen*" OR (MH "Aboriginal Nurses Association of Canada") OR "aborigin*" OR "métis*" OR (MH "Canada+") OR "Canada" OR (MH "Northern Territory") OR "northern territory" OR (MH "Arctic Regions") OR "Arctic regions" OR "first nations"	394,768

Scopus Search History

Search	Query	Items found
4	#1 AND #2 AND #3	722
3	(TITLE-ABS-KEY (vaccination AND coverage) OR TITLE-ABS-KEY (vaccination AND refusal) OR TITLE-ABS-KEY (immunization AND programs) OR TITLE-ABS-KEY (immuniz*) OR TITLE-ABS-KEY (immunization AND schedule) OR TITLE-ABS-KEY (vaccin*))	583,814
2	(TITLE-ABS-KEY (maternal-child AND nursing) OR TITLE-ABS-KEY (pregnancy) OR TITLE-ABS-KEY (obstetrics) OR TITLE-ABS-KEY (maternal AND health) OR TITLE-ABS-KEY (prenatal AND education) OR TITLE-ABS-KEY (prenatal AND care) OR TITLE-ABS-KEY (matern*) OR TITLE-ABS-KEY (obstetric*) OR TITLE-ABS-KEY (pregnan*) OR TITLE-ABS-KEY (prenatal*) OR TITLE-ABS-KEY (antenatal*) OR TITLE-ABS-KEY (perinatal*) OR TITLE-ABS-KEY (mother*) OR TITLE-ABS-KEY (pregnant AND women) OR TITLE-ABS-KEY (midwif*))	1,602,921
1	(TITLE-ABS-KEY (inuits) OR TITLE-ABS-KEY (nunavut) OR TITLE-ABS-KEY (newfoundland AND labrador) OR TITLE-ABS-KEY (northwest AND territories) OR TITLE-ABS-KEY (quebec) OR TITLE-ABS-KEY (nunatsiavu*) OR TITLE-ABS-KEY (nunav*) OR TITLE-ABS-KEY (inu*) OR TITLE-ABS-KEY (indigen*) OR TITLE-ABS-KEY (aborigin*) OR TITLE-ABS-KEY (métis*) OR TITLE-ABS-KEY (canada) OR TITLE-ABS-KEY (northern AND territory) OR TITLE-ABS-KEY (arctic AND regions) OR TITLE-ABS-KEY (first-nation) OR TITLE-ABS-KEY (first-nations))	621,898

Appendix 2. Literature Review Flow Chart



Appendix 3. Individual Narrative Collection Invitation Email

Good morning [Participant's first and last name],

My name is Michael Best and I am a Project Manager with the Canadian Center for Vaccinology in Halifax. With the support of support of the Chief and Deputy Chief Medical Officers of Health for Nunavut, Drs. Michael Patterson and Jasmine Pawa, we are conducting a Canadian Institutes of Health Research-funded study in Nunavut pertaining to knowledge, attitudes and beliefs surrounding maternal vaccination in the territory.

This collaborative project includes Inuit community members as participants and co-researchers alike, with the aim of evaluating and enhancing vaccine coverage according to existing recommendations for pertussis and other recommended vaccines such as influenza.

We are looking to recruit several health care administrators, managers or directors in a leadership or decision-making role in Nunavut's Department of Health that touch on any area of maternal health to participate in a one-hour phone interview. In appreciation of participants' time commitment, we will provide them with a \$50.00 VISA gift card.

If you are interested, please read and sign the consent form here, and return it to me to set up a time. If you have any questions, I would be happy to discuss the study with you over the phone.

If you know of any other colleagues who may be interested, please feel free to pass along the information or have them contact me.

Thank you, and I look forward to hearing from you soon.

This study has been approved by ethics committees at Nunavut Research Institute, IWK Health Centre in Halifax, and St. Francis Xavier University in Nova Scotia.

Sincerely,

Michael Best

Project Manager

Canadian Center for Vaccinology

IWK Health Centre

Goldbloom RCC Pavilion, 4th floor

5850/5980 University Avenue

Halifax, NS CANADA B3K 6R8

902-470-3741

Fax: 902-470-7232

www.centerforvaccinology.ca

Appendix 4. Individual Narrative Collection Consent Form

STUDY TITLE: Implementation of a maternal pertussis immunization program: Improving coverage among Inuit women

PRINCIPAL INVESTIGATOR: Donna M. Halperin PhD, RN
Professor, St. Francis Xavier University
Clinical Investigator, Canadian Center for Vaccinology
Scientific Staff, IWK Health Center and NSHA
PO Box 5000 (Courier Address- 1 West Street)
Antigonish, Nova Scotia B2G 2W5
Phone: (902) 867-3392; Fax: (902) 867-2322

CO-INVESTIGATORS:

Cathy MacDonald (St.FX University, CCfV)

Jacqueline van Wijlen (St.FX University, CCfV)

Audrey Steenbeek (Dalhousie University, CCfV)

Françoise Baylis (Dalhousie University, CCfV)

Joanne Langley (Dalhousie University, CCfV)

May ElSherif (Dalhousie University, CCfV)

Scott Halperin (Dalhousie University, CCfV)

Bruce Smith (Dalhousie University, CCfV)

Sarah Wilson (Public Health Ontario)

Sylvia Doody (Government of Nunatsiavut)

Gwen Healey (Qaujigiartiit Health Research Centre)

STUDY SPONSOR:

Canadian Institutes of Health Research (CIHR) through the Improved Immunization Coverage Initiative

FUNDER:

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

1. Introduction

You have been invited to take part in this research project about the vaccination of pregnant women because of your experience as a Community Expert. This form provides information about the project, and what you will be asked to do if you decide to take part. Please read it through before you make your decision. Ask the research assistant if you have questions, if there is anything you do not understand, or if you need any further

information. You can decide today that you want to take part in the project and change your mind later on. You may withdraw from the project at any time without any consequence.

2. Why is this project being done?

Whooping cough (pertussis) is a respiratory infection that is especially common in children. The first stage of the infection is similar to the common cold, but after one or two weeks the infection gets worse and coughing fits end in a “whooping” sound as the child breathes in. Whooping cough can last for up to twelve weeks and can be very serious, even fatal, in babies under one year of age. Babies get vaccines to protect them from infectious diseases as early as two months of age, but they are not fully protected until they get all three doses of the whooping cough (pertussis-containing) vaccine by six months of age. Giving the whooping cough vaccine to pregnant women has the potential to protect both her, and her newborn baby, from getting whooping cough.

Recent whooping cough outbreaks have affected many young children and their families in Nunavut. In response to these outbreaks a whooping cough vaccination program was introduced for pregnant women in 2016. In the Inuit region of Nunatsiavut in Labrador there has not yet been an outbreak yet the Government of Nunatsiavut will also implement a maternal Tdap vaccination program in January, 2019. This varying epidemiology, and staggered implementation of maternal immunization programs in two self-governing Inuit regions provides the unique opportunity to evaluate the effectiveness of the vaccination programs, and to consult with pregnant women, community experts and health care providers about their experiences.

This project has five goals:

1. To describe and understand knowledge, attitudes, beliefs, values, and behaviours about the vaccination of pregnant women in Nunavut and Nunatsiavut.

2. To look at the usefulness of the new whooping cough (Tdap) vaccine program and the flu (inactivated influenza) vaccine program for pregnant women in Nunavut and Nunatsiavut.
3. To describe and understand what factors influence whether women in Nunavut and Nunatsiavut are or are not vaccinated.
4. To identify and describe communities where pregnant women tend not to get vaccinated, and to explore why that might be.
5. To identify actions that could be taken by health care providers to evaluate maternal vaccination programs, and to address gaps in maternal vaccination.

We plan to achieve these goals through individual narrative collection from Community Experts, sharing circles with pregnant women, virtual sharing circles with community health care providers and surveys of pregnant women.

3. What will I be asked to do in the narrative collection?

We will be asking you to tell your story in the narrative collection. Each narrative collection will include a one-on-one conversation where a research assistant will ask you about the factors that influence maternal immunization, your perceptions of pregnancy as a Community Expert, and your perceptions about maternal immunization. A research assistant will also seek your recommendations for the implementation of maternal immunization programs in your community, input on how to access people in your community to participate in this study in the most appropriate and effective way, and which questions we should be asking other participants in future phases of this project.

Individual narrative collection will happen at a mutually agreed upon place of convenience for both you and the research assistant who will be leading the discussion. Individual narrative collection will happen in person, over the phone or via Webex software. Narrative collection will last as long as 2 hours to ensure that you have lots of time to express yourself. There will be childcare, food, and a translator provided for you.

The narrative collection discussion will be audio recorded and later transcribed by a research transcriptionist. You may consent or refuse to participate in the audio recording of this research. Your consent or refusal will also be audio recorded for our records. Please do not feel bad if you do not wish to be recorded. We will understand, and respect your wishes. If you decline to be recorded, you will be thanked for your time asked whether hand-written notes would be more appropriate. If you do not wish to be recorded, or for notes to be taken, you will be thanked for your time and excused from the narrative collection. Findings from this project will be presented in reports and publications in such a way that it does not identify you personally.

4. What are the potential burdens and harms?

You may be indirectly harmed by sharing your stories, thoughts, and experiences about maternal immunization. Some of the questions that are being asked may be difficult to answer. If at any point you feel uncomfortable answering a question or sharing your experiences, you do not need to. If you feel upset as a direct result of participating in narrative collection, you will be referred to a Public Health Nurse who will be able to provide you with more information.

5. What are the potential benefits?

There may be no potential benefits to you from participating in this project. However, by sharing your stories, thoughts, and experiences, you may gain knowledge and awareness about public health activities in your community and territory. You will learn about the role of vaccines in stopping whooping cough and influenza from affecting babies in Nunavut and Nunatsiavut. By taking part in this project, you are adding to knowledge about pregnant women and vaccine programs provided to them.

6. Can I withdraw from the project?

You can withdraw from the project at any point during the narrative collection. After the sharing circle is completed the data will be transcribed and at that time anything that

could identify you will be removed. Once identifying information has been removed and discarded, it will not be possible for you to withdraw your data from the project.

The Canadian Institutes of Health Research (the funder for this project), the Research Ethics Board of the IWK Health Centre, St. Francis Xavier University and Health Research Ethics Authority, and the principal investigator also have the right to stop inviting individuals to participate or cancel the project at any time.

Lastly, the principal investigator may remove you from this project without your consent if you do not follow the narrative collection rules, or if there is new information about unforeseen burdens and harms. If you are withdrawn from this project, the principal investigator will discuss the reasons with you.

7. Will the project cost me anything?

It will cost you nothing to take part in this project.

8. Will I be rewarded/compensated/paid for participation in the project?

In appreciation of your time commitment, you will be given a \$50 gift card.

9. Are there any conflicts of interest?

A conflict of interest is a situation that usually happens in one of the following ways: 1) when a researcher can use their position in the project for financial gain, 2) when outside financial or other interests may influence the way in which a researcher does their job, and 3) when a researcher's interests may cause harm to patients involved in the project. Based on this definition, for this project, there are no known conflicts of interest on the part of researchers or community partners. Funding from CIHR will cover the costs of conducting the project and all research staff will be paid for their time.

10. What happens at the end of the project?

Your contribution to this project will be used to guide the next step of the research process. All data collected will be transcribed and kept in the communities where it is collected. However, the Canadian Center for Vaccinology in Halifax is able to use the data for publication, education, and research purposes. Once analysis of the findings of narrative collection has begun, the themes identified will be reviewed by a selection of Community Experts who have expressed interest, to ensure the findings reflect the discussion.

We expect that the final results of the entire project will be available 3 years from now. At that time, anonymous findings from narrative collection will be presented to leaders and groups in Nunavut and Nunatsiavut. Findings will also be presented to government advisory groups at the territorial and provincial level, and at peer-reviewed national and international meetings. Reports of the project findings will be sent to the National Advisory Committee on Immunization (NACI) and the Canadian Immunization Committee (CIC). The results from this project will also be published in professional medical and bioethics journals. All of the research partners involved in the project (listed as co-investigators above) must agree on the information presented before it is presented, and (as appropriate) they will be listed as co-authors on all publications.

11. How will my privacy be protected?

The confidentiality of your personal information is very important to us. As such, we have put in place careful security measures to respect and protect it. In the case of this study confidentiality is limited by researchers' responsibilities to third parties. The Tri-Council Policy Statement identifies public interests such as the protection of health, life, and safety, as having priority over individual privacy. If in this narrative collection, you identify child abuse, sexually transmitted diseases, or intention to harm to yourself or others, by law the researchers have to disclose this information.

Your identity will be changed in the project record of the discussions. Digital audio files will be destroyed after they are transcribed and checked for accuracy and the results have been published. Transcripts of recordings will be destroyed after seven years (which is the

time that we are required to maintain documents). The audio recordings from the narrative collection will not be released to anyone. Any papers, cassette tapes, transcriptions, computer files or other identifying information will be stored in a secure location. Direct quotes may be used in future publications, however, there will be no way to identify the original speaker.

As a participant of the narrative collection, you have the right to be informed of the results of this project once the entire project is complete. You also have the right to access, review, and request changes to your project data before analysis begins.

Researchers accept responsibility for the return of research results. This will include for example, sending copies of published article(s) to the local Health Unit, and putting information in lay language on a dedicated website.

12. Ethics approval

Research ethics committee reviews for this project have been done by the IWK Health Centre (Nova Scotia), St. Francis Xavier University (Nova Scotia), and Health Research Ethics Authority (Nunavut). This project follows recognized ethical frameworks that include the ownership, control, access, and possession (OCAP) principles of the National Aboriginal Health Association, the Tri-Council Policy Statement (TCPS) 2: Chapter 9 about Research Involving First Nations, Inuit and Metis Peoples of Canada, and the Nunavut Research Institute protocols for conducting research. Researchers have obtained a research license from Nunavut Research Institute, and approval by the Nunatsiavut Government Research Advisory Committee (NGRAC).

13. What if I have questions?

For further information about the project, please contact the principal investigator who will oversee this project, and/or the project manager listed below. Should you experience any problems related to participating in this project, we ask that you please report them to the principal investigator.

Principal Investigator: Donna Halperin

Telephone: (902) 867-3392 or dhalperi@stfx.ca

Project Manager: Michael Best

Telephone: (902)470-3741 or michael.best@iwk.nshealth.ca

14. What are my research rights?

You have the right to all information that could help you make a decision about participating in this project. You have the right to ask questions about this project and your rights as a research participant. You have the right to have your questions answered to your satisfaction before making a decision to continue participating. You also have the right to ask questions and to receive answers throughout this project.

If you have questions about your rights as a research participant in **Nunavut**, you may contact:

Research Services Office, IWK Health Centre
5850/5980 University Ave, 2nd Floor Goldbloom Pavilion
PO Box 9700
Halifax, NS B3K 6R8
(902) 470-7879

If you have questions about your rights as a research participant in **Nunatsiavut**, you may contact:

Ethics Office, Health Research Ethics Authority
Suite 200, 2nd floor, 95 Bonaventure Avenue
St. John's, NL A1B 2X5
(709) 777-6974

In the next part, you will be asked if you agree (consent) to join this project. If the answer is “yes”, please sign the form.

15. Consent Form Signature Page

I have reviewed all of the information in this consent form related to the project called:

Implementation of a Maternal Pertussis Immunization Program: Identifying Barriers, Factors that Predict Success, and Interventions to Improve Coverage among Inuit Women

My signature on this consent form means that I have been fully informed of the objectives of the project being conducted. I understand these objectives and consent to being interviewed for the project. I also give my consent for my words or what I say in my stories to be used as quotes in reports, publications or presentations. I understand that steps will be taken to ensure that this interview will remain confidential. I also understand that, if I wish to withdraw from the project, I may do so without any consequences and that my data will be removed. I have been given the opportunity to discuss this project. All of my questions have been answered to my satisfaction.

By signing this form, I do not give up my legal rights nor do I release the Principal Investigator, the research team, the project sponsor or involved institutions from their legal and professional responsibilities. By signing this form, I acknowledge that I understand that data will be collected by audio recording or by note-taking and later destroyed as described in this form.

Please select your preferred method of recording:

I **agree** to audio recordings as described in this consent form.

I **agree** to note-taking as described in this consent form.

_____/_____/_____
Signature of Participant Name (Printed) Year/Month/Day*

_____/_____/_____
Signature of Person Name (Printed) Year/Month/Day*

Conducting Consent
Discussion

**Note: Please fill in the date personally*

You will be given a signed copy of this consent form.

Appendix 5. Individual Narrative Collection Discussion Guide

Individual Narrative Collection: Discussion Guide

Introduction: *Tungasugit.* Welcome. Thank you very much for agreeing to talk to me today. (Facilitator introduction: name, community of origin). I am speaking to community experts (health care providers and administrators) in the areas of pediatrics, obstetrics, midwifery, and public health in the community to learn about giving vaccines to pregnant women to prevent infection in them and in their babies. In Nunavut, vaccines against tetanus, diphtheria, and acellular pertussis (Tdap) and influenza are currently offered to pregnant women. I will be asking you about your perceptions of pregnancy, vaccine-preventable diseases, and maternal immunization programs.

Confidentiality: The confidentiality of your personal information is very important to us. As such, we have put in place strict security measures to respect and protect it. This discussion will be recorded, and the recording will be password-protected and kept in a locked facility until it is transcribed word for word, after which time the tapes will be destroyed. The transcribed notes of the narrative collection will not contain any information that would allow you to be linked to the stories. At this point I would like to ask again if I may please tape our conversation to facilitate its recollection? Please do not feel bad if you do not wish to be taped. We understand and will respect your wishes. (If yes, switch on the recorder; if no, thank the individual and ask if hand-written notes would be more appropriate).

Reminders: Before we get started, I would like to remind you that there are no right or wrong answers to any of the questions that we are going to talk about. We can skip over topics that you don't want to talk about.

Do you have any questions you would like to ask me before we get started?

1. Can you please tell me a little bit about yourself?

Probes:

- In what region/community do you predominantly work/live? (Baffin region (Qikiqtaaluk), Central arctic region (Kitikmeot), Kivalliq region (Keewatin))
- How many years have you been in clinical practice (if applicable)?
- How many years have you been practicing in your current community (if applicable)?
- What is your area of expertise? (Pediatrics, obstetrics, midwifery, public health, community knowledge)
- Have you received all of the vaccines that are recommended for adults?

2. Can you please explain to me how pregnancy is perceived in your community?

Probes:

- In your opinion, what factors (social, historical, political, economic, etc.) have a positive or negative impact on the health of pregnant women?
- How are the three trimesters of pregnancy perceived in your community?
Are prenatal classes available in your community? Can you talk to me about the attendance in these classes?

3. What do you think about immunization (or vaccination) during pregnancy?

Probes:

- Should any vaccines be given during pregnancy?
- What affects whether a woman will get vaccinated while pregnant in your community?
- What is it about a disease that makes it worth preventing in pregnancy? (Severity, degree of protection, recommendation (and by whom), etc.)
- Do you have any personal experiences with immunization in pregnancy?
- Can you identify some positive aspects of giving vaccines during pregnancy?
Some negative?
- Do you feel women in the community accept or avoid taking medication during pregnancy?

- Would vaccines be perceived differently than medications?
 - Who do women look to most for guidance on medical/health issues during pregnancy? (mothers, Elders, public health, other health providers, etc.)
 - When giving a pregnant woman a vaccination, what is the general process that you follow?
4. In the next phases of this study we are going to be conducting focus groups and surveys with pregnant women. In your opinion, what kinds of questions do you think we should be asking pregnant women about receiving vaccinations during pregnancy?

Probes:

- Would it be important to ask their opinions about recommendations made by public health?
 - Are there other health recommendations that we should ask them about?
 - Should we ask them which key recommendations (e.g. NACI, HCPs, community Elders, etc.) influence their decision?
 - Should we ask them about what kinds of information they need to be able to make a decision about getting a maternal immunization?
 - Should we ask whether they had enough information available when they made vaccine-related information?
 - Do you think that a sharing circle is the most appropriate format for asking pregnant women about maternal vaccination?
 - How would you suggest that we approach pregnant women in a way that is appropriate, and effective?
5. Do you have any recommendations about maternal immunization programs in Inuit communities?
6. Is there anything else that you would like to share about pregnant women, and/or the programs to provide vaccination in pregnancy to protect mothers and babies in Nunavut that you would like to share?

Conclusion: Thank you very much once again for participating, your expertise and insight is very valuable and meaningful to the project.

Appendix 6. Individual Narrative Collection Sampling Frame

Name	Region	Community(ies)	Profession	Contacted	Interested
			Mental Health Nurse		
			Nurse		
			Nurse		
			Community Health Representative		
			Community Health Representative		
			Community Health Representative		
			Physician		
			Physician		

Appendix 7. Healthcare Provider Email Invitation to Participate in Virtual Sharing Circle

Dear [Participant's first and last name],

My name is Antonia Di Castri and I am a Research Associate with the Canadian Center for Vaccinology in Halifax. With the support of the Chief and Deputy Chief Medical Officers of Health for Nunavut, Drs. Michael Patterson and Jasmine Pawa, we are conducting a Canadian Institutes of Health Research (CIHR)-funded study in Nunavut about the knowledge, attitudes, beliefs, values, and behaviours of pregnant Inuit women and Northern healthcare providers about maternal immunization in the territory. We have obtained a research license from the Nunavut Research Institute (NRI), and our project has been reviewed and approved by research ethics boards at the Izaak Walton Killam (IWK) Health Centre (Halifax, Nova Scotia) and St. Francis Xavier University (Antigonish, Nova Scotia).

This project adheres to the concepts of Piliriqatigiinniq (the concept of working together for the common good), Iqatautsiartuq (the concept of cooperation), and Ikajurniq (the concept of helping) as we have been working closely with our Northern co-researchers to respond to concern about repeated outbreaks of whooping cough in Nunavut. Our aim in undertaking this study is to evaluate and enhance vaccine coverage among pregnant women according to existing recommendations for maternal immunization with the pertussis and influenza vaccines.

We are looking to invite any health care providers that are involved in the dissemination of information about vaccines, vaccine programming, or the actual administration of immunizations to pregnant women to participate in a virtual sharing circle. We refer to these sharing circles as “virtual” because they will be conducted in a teleconference format which will allow you to either call in toll-free using your telephone, or participate

online. In appreciation of your time and insights, we are offering each sharing circle participant a \$50.00 VISA gift card.

We are very excited to be able to share our consent form with you, which gives detailed information about our project. If you are interested in participating, please download, sign, and return the attached form to me. We have been informed that some interested participants are having difficulties opening the PDF due to the unfortunate recent ransomware strike in Nunavut. If you also find that you cannot open the PDF but are interested in participating in this study, I can try sending it to you via fax if you are able to provide me with a fax number where I can reach you. As I receive signed consent forms, I will organize you into a small sharing circle group and ask you to fill out a poll with your availability so that we can find a time to meet that is convenient for everybody.

If you have any questions at all about the study, I am happy to discuss them with you over the phone or by e-mail, whichever is most convenient for you! Also, if you know of any other colleagues who may be interested in participating in this study, please feel free to either forward them this e-mail, or have them contact me directly.

Thank you, and I look forward to hearing from you soon.

Best Regards,

Antonia

Antonia Di Castri BScN (Hons), RN

MSc (Candidate)

Research Associate

Canadian Center for Vaccinology

5850/5980 University Avenue

Halifax, Nova Scotia B3K 6R8

Tel: (902)470-8645

Fax: (902)470-7232

Antonia.DiCatri@iwk.nshealth.ca

Appendix 8. Community Health Representative Email Invitation to Participate in Virtual Sharing Circle

Dear [Participant's first and last name],

My name is Antonia Di Castri and I am a Research Associate with the Canadian Center for Vaccinology in Halifax. With the support of the Chief and Deputy Chief Medical Officers of Health for Nunavut, Drs. Michael Patterson and Jasmine Pawa, we are conducting a Canadian Institutes of Health Research (CIHR)-funded study in Nunavut about the knowledge, attitudes, beliefs, values, and behaviours of pregnant Inuit women and Northern healthcare providers about maternal immunization in the territory. We have obtained a research license from the Nunavut Research Institute (NRI), and our project has been reviewed and approved by research ethics boards at the Izaak Walton Killam (IWK) Health Centre (Halifax, Nova Scotia) and St. Francis Xavier University (Antigonish, Nova Scotia).

This project adheres to the concepts of Piliriqatigiinniq (the concept of working together for the common good), Iqatautsiartuq (the concept of cooperation), and Ikajurniq (the concept of helping) as we have been working closely with our Northern co-researchers to respond to concern about repeated outbreaks of whooping cough in Nunavut. Our aim in undertaking this study is to evaluate and enhance vaccine coverage among pregnant women according to existing recommendations for maternal immunization with the pertussis and influenza vaccines.

We are looking to invite any health care representatives that are involved in the sharing of information about vaccines with pregnant women to participate in a virtual sharing circle. We refer to these sharing circles as “virtual” because they will be conducted in a teleconference format which will allow you to either call in toll-free using your telephone, or participate online. In appreciation of your time and insights, we are offering each sharing circle participant a \$50.00 gift card.

We are very excited to be able to share our consent form with you, which gives detailed information about our project. If you are interested in participating, please download, sign, and return the attached form to me. We have been informed that some interested participants are having difficulties opening the PDF due to the unfortunate recent ransomware strike in Nunavut. If you also find that you cannot open the PDF but are interested in participating in this study, I can try sending it to you via fax if you are able to provide me with a fax number where I can reach you. As I receive signed consent forms, I will ask you to fill out a poll with your availability so that we can find a time to meet that is convenient for everybody.

If you have any questions at all about the study, I am happy to discuss them with you over the phone or by e-mail, whichever is most convenient for you! As a student, I am not always in my office so you might find it easiest to get ahold of me by e-mail. Also, if you know of any other colleagues who may be interested in participating in this study, please feel free to either forward them this e-mail, or have them contact me directly.

Thank you, and I look forward to hearing from you soon.

Best Regards,

Antonia

Antonia Di Castri BScN (Hons), RN

MSc (Candidate)

Research Associate

Canadian Center for Vaccinology

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Tel: (902)470-8645

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Antonia.DiCatri@iwk.nshealth.ca

Appendix 9. Virtual Sharing Circle Consent Form for Healthcare Providers

STUDY TITLE:	Implementation of a maternal pertussis immunization program: Improving coverage among Inuit women
PRINCIPAL INVESTIGATOR:	Donna M. Halperin PhD, RN Professor, St. Francis Xavier University Clinical Investigator, Canadian Center for Vaccinology Scientific Staff, IWK Health Center and NSHA PO Box 5000 (Courier Address- 1 West Street) Antigonish, Nova Scotia B2G 2W5 Phone: (902) 867-3392; Fax: (902) 867-2322
CO-INVESTIGATORS:	Cathy MacDonald (St.FX University, CCfV) Jacqueline van Wijlen (St.FX University, CCfV) Audrey Steenbeek (Dalhousie University, CCfV) Françoise Baylis (Dalhousie University, CCfV) Joanne Langley (Dalhousie University, CCfV) May ElSherif (Dalhousie University, CCfV) Scott Halperin (Dalhousie University, CCfV) Bruce Smith (Dalhousie University, CCfV) Sarah Wilson (Public Health Ontario)

Sylvia Doody (Government of Nunatsiavut)
Gwen Healey (Qaujigiartiit Health Research
Centre)

STUDY SPONSOR:

Canadian Institutes of Health Research
(CIHR) through the Improved Immunization
Coverage Initiative

FUNDER:

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

1. Introduction

You have been invited to take part in this research project about the vaccination of pregnant women because of your experience as a community health providers and representatives. This form provides information about the project, and what you will be asked to do if you decide to take part. Please read it through before you make your decision. Ask the research assistant if you have questions, if there is anything you do not understand, or if you need any further information. You can decide today that you want to take part in the project and change your mind later on. You may withdraw from the project at any time without any consequence.

2. Why is this project being done?

Whooping cough (pertussis) is a respiratory infection that is especially common in children. The first stage of the infection is similar to the common cold, but after one or two weeks the infection gets worse and coughing fits end in a “whooping” sound as the child breathes in. Whooping cough can last for up to twelve weeks and can be very serious, even fatal, in babies under one year of age. Babies get vaccines to protect them from infectious diseases as early as two months of age, but they are not fully protected until they get all three doses of the whooping cough (pertussis-containing) vaccine by six

months of age. Giving the whooping cough vaccine to pregnant women has the potential to protect both her, and her newborn baby, from getting whooping cough.

Recent whooping cough outbreaks have affected many young children and their families in Nunavut. In response to these outbreaks a whooping cough vaccination program was introduced for pregnant women in 2016. In the Inuit region of Nunatsiavut in Labrador there has not yet been an outbreak yet the Government of Nunatsiavut will also implement a maternal Tdap vaccination program in January, 2019. This varying epidemiology, and staggered implementation of maternal immunization programs in two self-governing Inuit regions provides the unique opportunity to evaluate the effectiveness of the vaccination programs, and to consult with pregnant women, community experts and health care providers about their experiences.

This project has five goals:

1. To describe and understand knowledge, attitudes, beliefs, values, and behaviours about the vaccination of pregnant women in Nunavut and Nunatsiavut.
2. To look at the usefulness of the new whooping cough (Tdap) vaccine program and the flu (inactivated influenza) vaccine program for pregnant women in Nunavut and Nunatsiavut.
3. To describe and understand what factors influence whether women in Nunavut and Nunatsiavut are or are not vaccinated.
4. To identify and describe communities where pregnant women tend not to get vaccinated, and to explore why that might be.
5. To identify actions that could be taken by health care providers to evaluate maternal vaccination programs, and to address gaps in maternal vaccination

We plan to achieve these goals through individual narrative collection from Community Experts, sharing circles with pregnant women, virtual sharing circles with community health care providers and surveys of pregnant women.

3. What will I be asked to do in the virtual sharing circle?

We will be asking you to tell your story in the virtual sharing circle. Each sharing circle will include five to eight participants. A research assistant will ask you about your perceptions of maternal immunization, perceived facilitators or barriers to accessing maternal immunization encountered by patients, as well as facilitators or barriers encountered in delivering maternal immunization to pregnant Inuit women. You will also be asked about what you learned from the implementation of the maternal Tdap immunization programs in Nunavut and Nunatsiavut or the maternal influenza immunization program in Nunavut and Nunatsiavut. Finally a research assistant will seek your advice for other jurisdictions implementing maternal immunization programs.

This circle will occur in a virtual format, i.e. by web-based teleconference using the online platform Webex. A toll-free number will be made available to call in via phone in case of poor internet connectivity. The circle will last as long as 2 hours to ensure that you have lots of time to express yourself.

The sharing circle discussion will be audio recorded and later transcribed by a research transcriptionist. You may consent or refuse to participate in the audio recording of this research. Your consent or refusal will also be audio recorded for our records. Please do not feel bad if you do not wish to be recorded. We will understand, and respect your wishes. If you decline to be recorded, you will be thanked for your time and excused from the sharing circle. Findings from this project will be presented in reports and publications in such a way that it does not identify you personally.

4. What are the potential burdens and harms?

You may be indirectly harmed by sharing your stories, thoughts, and experiences about maternal immunization, and listening to others do the same. Some of the questions that are being asked may be difficult to answer. If at any point you feel uncomfortable answering a question or sharing your experiences, you do not need to.

5. What are the potential benefits?

There may be no potential benefits to you from participating in this project. However, by sharing your stories, thoughts, and experiences and listening to others do the same, you may gain knowledge and awareness about public health activities in your community and territory. You will learn about the role of vaccines in stopping whooping cough and influenza from affecting babies in Nunavut and Nunatsiavut. By taking part in this project, you are adding to knowledge about pregnant women and vaccine programs provided to them.

6. Can I withdraw from the project?

You can withdraw from the project at any point during the virtual sharing circle. After the virtual sharing circle is completed the data will be transcribed and at that time anything that could identify you will be removed. Once identifying information has been removed and discarded, it will not be possible for you to withdraw your data from the project.

The Canadian Institutes of Health Research (the funder for this project), the Research Ethics Board of the IWK Health Centre, St. Francis Xavier University and Health Research Ethics Authority, and the principal investigator also have the right to stop inviting individuals to participate or cancel the project at any time.

Lastly, the principal investigator may remove you from this project without your consent if you do not follow the sharing circles rules, or if there is new information about unforeseen burdens and harms. If you are withdrawn from this project, the principal investigator will discuss the reasons with you.

7. Will the project cost me anything?

It will cost you nothing to take part in this project.

8. Will I be rewarded/compensated/paid for participation in the project?

In appreciation of your time commitment, you will be given a \$50 gift card.

9. Are there any conflicts of interest?

A conflict of interest is a situation that usually happens in one of the following ways: 1) when a researcher can use their position in the project for financial gain, 2) when outside financial or other interests may influence the way in which a researcher does their job, and 3) when a researchers' interests may cause harm to patients involved in the project. Based on this definition, for this project there are no known conflicts of interest on the part of researchers or community partners. Funding from CIHR will cover the costs of conducting the project and all research staff will be paid for their time.

10. What happens at the end of the project?

Your contribution to this project will be used to guide the next step of the research process. All data collected will be transcribed and kept in the communities where it is collected. However, the Canadian Center for Vaccinology in Halifax is able to use the data for publication, education, and research purposes. Once analysis of the findings of this virtual sharing circle has begun, the themes identified will be reviewed by the research assistant who facilitated the circle to make sure that the findings reflect the discussion.

We expect that the final results of the entire project will be available 3 years from now. At that time, anonymous findings from sharing circle will be presented to leaders and in Nunavut and Nunatsiavut. Findings will also be presented to government advisory groups at the territorial and provincial level, and at peer-reviewed national and international meetings. Reports of the project findings will be sent to the National Advisory Committee on Immunization (NACI) and the Canadian Immunization Committee (CIC). The results from this project will also be published in professional medical and bioethics journals. All of the research partners involved in the project (listed as co-investigators above) must agree on the information presented before it is presented, and (as appropriate) they will be listed as co-authors on all publications.

11. How will my privacy be protected?

Protecting your privacy is an important part of this project, however, complete privacy cannot be guaranteed. As with all sharing circles, there is a chance that your privacy could be compromised because data collection is happening in a group setting. We will try our best to minimize this risk. At the beginning and ending of each sharing circle, the facilitator will ask all participants to respect the privacy of their peers by keeping information shared in the circle private. In the case of this study privacy is also limited by researchers' responsibilities to third parties. The Tri-Council Policy Statement identifies public interests such as the protection of health, life, and safety, as having priority over individual privacy. If in this sharing circle, you identify child abuse, sexually transmitted diseases, or intention to harm to yourself or others, by law the researchers have to disclose this information.

Your identity will be changed in the project record of the discussions. Digital audio files will be destroyed after they are transcribed and checked for accuracy and the results have been published. Transcripts of recordings will be destroyed after the seven years (which is the time that we are required to maintain documents). The audio recordings from the sharing circles will not be released to anyone. Any papers, cassette tapes, transcriptions, computer files or other identifying information will be stored in a secure location. Direct quotes may be used in future publications, however, there will be no way to identify the original speaker.

As a participant of the sharing circle, you have the right to be informed of the results of this project once the entire project is complete. You also have the right to access, review, and request changes to your project data before analysis begins. Researchers accept responsibility for the return of research results. This will include for example, sending copies of published article(s) to the local Health Unit, and putting information in lay language on a dedicated website.

12. Ethics approval

Research ethics committee reviews for this project have been done by the IWK Health Centre (Nova Scotia), St. Francis Xavier University (Nova Scotia), and Health Research Ethics Authority (Nunavut). This project follows recognized ethical frameworks that include the ownership, control, access, and possession (OCAP) principles of the National Aboriginal Health Association, the Tri-Council Policy Statement (TCPS) 2: Chapter 9 about Research Involving First Nations, Inuit and Metis Peoples of Canada, and the Nunavut Research Institute protocols for conducting research. Researchers have obtained a research license from Nunavut Research Institute, and approval by the Nunatsiavut Government Research Advisory Committee (NGRAC).

13. What if I have questions?

For further information about the project, please contact the principal investigator who will oversee this project, and/or the project manager listed below. Should you experience any problems related to participating in this project, we ask that you report them to the principal investigator.

Principal Investigator: Donna Halperin

Telephone: (902) 867-3392 or dhalperi@stfx.ca

Project Manager: Michael Best

Telephone: (902)470-3741 or michael.best@iwk.nshealth.ca

14. What are my research rights?

You have the right to all information that could help you make a decision about participating in this project. You have the right to ask questions about this project and your rights as a research participant. You have the right to have your questions answered to your satisfaction before making a decision to continue participating. You also have the right to ask questions and to receive answers throughout this project.

If you have questions about your rights as a research participant in **Nunavut**, you may contact:

Research Services Office, IWK Health Centre
5850/5980 University Ave, 2nd Floor Goldbloom Pavilion
PO Box 9700
Halifax, NS B3K 6R8
(902) 470-7879

If you have questions about your rights as a research participant in **Nunatsiavut**, you may contact:

Ethics Office, Health Research Ethics Authority
Suite 200, 2nd floor, 95 Bonaventure Avenue
St. John's, NL A1B 2X5
(709) 777-6974

In the next part, you will be asked if you agree (consent) to join this project. If the answer is “yes”, please sign the form.

15. Consent Form Signature Page

I have reviewed all of the information in this consent form related to the project called:

Implementation of a Maternal Pertussis Immunization Program: Identifying Barriers, Factors that Predict Success, and Interventions to Improve Coverage among Inuit Women

My signature on this consent form means that I have been fully informed of the objectives of the project being conducted. I understand these objectives and consent to participate in a sharing circle for the project. I also give my consent for my words or what I say in my stories to be used as quotes in reports, publications or presentations. I understand that steps will be undertaken to ensure that this interview will remain private, unless I consent to being identified. I also understand that, if I wish to withdraw from the project, I may do so right now without any consequences and that my data will be removed. I have been given the opportunity to discuss this project. All of my questions have been answered to my satisfaction.

By signing this form, I do not give up my legal rights nor do I release the Principal Investigator, the research team, the project sponsor or involved institutions from their legal and professional responsibilities. By signing this form, I acknowledge that I understand that data will be audio recorded and that direct transcription will be made and destroyed as laid out in this consent form.

_____/_____/_____
Signature of Participant Name (Printed) Year/Month/Day*

_____/_____/_____
Signature of Person Name (Printed) Year/Month/Day*
Conducting Consent
Discussion

**Note: Please fill in the date personally*

You will be given a signed copy of this consent form.

Appendix 10. Virtual Sharing Circle Consent Form for Community Health Representatives

- STUDY TITLE:** Implementation of a maternal pertussis immunization program: Improving coverage among Inuit women
- PRINCIPAL INVESTIGATOR:** Donna M. Halperin PhD, RN
Professor, St. Francis Xavier University
Clinical Investigator, Canadian Center for Vaccinology
Scientific Staff, IWK Health Center and NSHA
PO Box 5000 (Courier Address- 1 West Street)
Antigonish, Nova Scotia B2G 2W5
Phone: (902) 867-3392; Fax: (902) 867-2322
- CO-INVESTIGATORS:**
- Cathy MacDonald (St.FX University, CCfV)
 - Jacqueline van Wijlen (St.FX University, CCfV)
 - Audrey Steenbeek (Dalhousie University, CCfV)
 - Françoise Baylis (Dalhousie University, CCfV)
 - Joanne Langley (Dalhousie University, CCfV)
 - May ElSherif (Dalhousie University, CCfV)
 - Scott Halperin (Dalhousie University, CCfV)
 - Bruce Smith (Dalhousie University, CCfV)

- Sarah Wilson (Public Health Ontario)
- Sylvia Doody (Government of Nunatsiavut)
- Gwen Healey (Qaujigiartiit Health Research Centre)

STUDY SPONSOR:

Canadian Institutes of Health Research (CIHR) through the Improved Immunization Coverage Initiative

FUNDER:

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

1. Introduction

You have been invited to take part in a research project about the vaccination of pregnant women because of your experience as a community health representative (CHR). This form gives some information about the project and what you will be asked to do if you decide to take part. Please read it before you make your decision and ask the research assistant to explain anything you do not understand. You can change your mind about taking part in the project at any time.

2. Why is this project being done?

Whooping cough is a breathing infection that happens most often in children. The first stage of whooping cough is like a cold, but after one or two weeks a cough begins and it may get worse. Sometimes there are “fits” of coughing which end in a “whooping” sound as the baby breathes in. Whooping cough can last for up to 12 weeks and can be very serious, even deadly, in babies less than one year old. Babies get vaccines to protect them from whooping cough as early as two months of age. They are not fully safe from infection until they get all three doses of the whooping cough vaccine which is at six

months of age. Giving the whooping cough vaccine to pregnant women may protect both her and her newborn baby from whooping cough.

Recent whooping cough outbreaks have impacted young children and their families in Nunavut. As a result, a whooping cough vaccination program was started for pregnant women in 2016. This project will help us to look at how useful the maternal vaccination programs are and to talk to pregnant women, community experts, health care providers and CHRs about their experiences.

This project has five goals:

1. To find out what people know, believe, and think about giving vaccines to pregnant women in Nunavut.
2. To find out if the new whooping cough vaccine program and the flu (influenza) vaccine program for pregnant women in Nunavut is useful.
3. To find out why pregnant women in Nunavut are or are not vaccinated.
4. To see if there are any areas in Nunavut where pregnant women do not get vaccinated, and to find out why that is.
5. To see what health care providers and CHRs in Nunavut could do to improve vaccination for pregnant women.

We plan to meet these goals using individual narrative collection from community experts, sharing circles with pregnant women, virtual sharing circles with community health care providers and CHRs and surveys of pregnant women.

3. What will I be asked to do in the virtual sharing circle?

We will be asking you to tell your story in the virtual sharing circle. The circle will be “virtual” because the participants will not be in the same room. We will conduct the circle over the internet or by phone. Each sharing circle will include as many as five to eight CHRs. A research assistant will ask you about your experience with and thoughts about maternal vaccination, current vaccines offered to pregnant women in Canada, and the

things that might make it easier or harder for pregnant women to be vaccinated. You will also be asked about what you learned from the introduction of maternal vaccination programs in Nunavut, and to give advice to other places introducing similar programs. Finally, you will be asked about future maternal vaccination programs in Nunavut.

This circle will occur in a virtual format using WebEx, which is a website on the internet that you can reach through your computer or phone. You will be given a toll-free phone number that you can call using your phone if you do not have good internet connection. The circle will last two hours to make sure that you have lots of time to tell your story.

The sharing circle will be recorded and later written down and studied by the research team. The recording will be destroyed after it has been written down and checked to make sure everything is right. You can agree to be recorded or choose not to be recorded. Your decision will be written down for our records. Please do not feel bad if you do not want to be recorded. We will understand, and respect your wishes. If you choose not to be recorded, you will be thanked for your time and asked to leave the sharing circle. Results from this project will be presented in reports and publications in a way that does not identify you.

4. Are there risks to taking part in this project?

You may be upset by some of the questions, and some of them might be difficult to answer. You can always skip questions, take a break, or stop answering at any time. If at any time you feel uncomfortable answering a question or sharing your experiences and thoughts, you do not need to.

5. What are the potential benefits of taking part in this project?

You may not get any benefit from taking part in this project. By sharing your stories and thoughts, and listening to others however, you might learn something new about vaccine

programs in your community and territory. You may also make maternal vaccination programs better for pregnant women.

6. If I decide to take part in this project, can I stop later?

You can decide not to take part in the project any time before or during the sharing circle. After the virtual sharing circle is over, a research assistant will write down everything the group said. Information like your name and where you work will be removed from the notes to protect your privacy. Once this information has been taken out, you will not be able to take your information out of the project because we will not be able to find it.

The Canadian Institutes of Health Research (the funder for this project), the Research Ethics Board of the IWK Health Centre, St. Francis Xavier University, Nunavut Research Institute and the principal investigator (Dr. Donna Halperin) also have the right to stop inviting individuals to participate or to cancel the project at any time.

The principal investigator (Dr. Donna Halperin) can remove you from this project without your consent if you do not follow the sharing circles ground rules. She can also remove you if there is new information about unexpected risks and harms. If you are withdrawn from this project, she will explain why.

7. Will the project cost me anything?

There is no cost for you to take part in this project.

8. Will I be rewarded/compensated/paid for participation in the project?

You will be given a \$50 gift card to thank you for your time and for sharing your thoughts and experiences with us.

9. Are there any conflicts of interest?

A conflict of interest is a situation that could happen when a researcher has influences that might change the way that they do their work in this research project (TCPS, 2018).

For example, if a researcher was getting paid to promote a vaccine in Nunavut, that would be a conflict of interest. There are no known conflicts of interest on the part of researchers or community partners in this project. Funding from the CIHR will cover the costs of doing this project and all research staff will be paid for their time.

10. What happens at the end of the project?

What you share with us will be used to guide the next step of the project. Any information that could identify you will be taken out. The recordings and notes will be kept safe. All files will be stored on secure servers in Nunavut and/or the Canadian Center for Vaccinology. If you are interested, we will invite you to look over the themes that we found after the sharing circle is finished. This will help us to make sure that the results are accurate. The Canadian Center for Vaccinology in Halifax and the Government of Nunavut will be able to use the data for publication, education, and research.

We expect that the final results of the entire project will be available two or three years from now. Results from the sharing circles will be presented to leaders and groups in Nunavut. Results will also be presented to government advisory groups and at official meetings. Reports of the project findings will be sent to the National Advisory Committee on Immunization and the Canadian Immunization Committee. The results from this project will also be published in professional medical journals. All of the research partners involved in the project (listed as co-investigators above) must agree on the information before it is presented, and they will be listed as co-authors on all publications if appropriate.

11. How will my privacy be protected?

Protecting your privacy is an important part of this project, however, there is a small chance you're your information might be accidentally shared because some sharing circle members might repeat things discussed in the sharing circle. At the beginning and ending of each sharing circle, the research assistant will ask all people to please respect

everyone's privacy by not repeating anything that was said in the sharing circle outside of the sharing circle. Researchers also have responsibilities that might call for them to share your information if in the sharing circle you identify child abuse, sexually transmitted diseases, or intention to harm yourself or others. By law, the researchers have to share this information.

Your identity will be removed from the notes on the discussions. Recordings will be destroyed after they are written down, checked to make sure that they are right, and the results are published. Notes taken based on the recordings will be destroyed after seven years (which is the time that ethics boards need us to maintain documents). The recordings from the sharing circles will not be shared with anyone. Any other identifying information will be stored in a safe location. Direct quotes may be used in publications, but we will ensure that there will be no way to identify the original speaker.

As someone in the sharing circle, you have the right to learn the results of this project once it is complete. You also have the right to see, study, and ask to change your data before we start to study it. We accept responsibility for the return of research results. This will include for example, sending copies of published article(s) to the local Health Unit, and putting information on website that you can access.

12. Ethics approval

A research license has been given to us from the Nunavut Research Institute. Research ethics committee reviews for this project have been done by the IWK Health Centre (Nova Scotia) and St. Francis Xavier University (Nova Scotia). This project follows the Ownership, Control, Access, and Possession (OCAP) principles of the National Aboriginal Health Association, the Tri-Council Policy Statement (TCPS) 2: Chapter 9 about Research Involving First Nations, Inuit and Métis Peoples of Canada, and the Nunavut Research Institute protocols for conducting research.

13. What if I have questions?

For more information about the project, please contact Dr. Donna Halperin or Michael Best. If you have any problems related to this project, please report them to Dr. Donna Halperin.

Principal Investigator: Donna Halperin

Telephone: (902) 867-3392 or dhalperi@stfx.ca

Project Manager: Melissa Kervin

Telephone: (902)470-7583 or melissa.kervin@iwk.nshealth.ca

14. What are my research rights?

You have the right to all information that could help you make a decision about taking part in this project. You have the right to ask questions about this project and your rights as a valued research participant. You have the right to have your questions answered to your satisfaction before making a decision to continue participating. You also have the right to ask questions and to receive answers throughout this project.

If you have questions about your rights as a research participant in **Nunavut**, you may contact:

Research Services Office, IWK Health Centre
5850/5980 University Ave, 2nd Floor Goldbloom Pavilion
PO Box 9700
Halifax, NS B3K 6R8
research@iwk.nshealth.ca
(902) 470-7879

In the next part, you will be asked if you agree (consent) to join this project. If the answer is “yes”, please sign the form.

15. Consent Form Signature Page

I have reviewed all of the information in this consent form related to the project called:

Implementation of a Maternal Pertussis Immunization Program: Identifying Barriers, Factors that Predict Success, and Interventions to Improve Coverage among Inuit Women

My signature on this consent form means that I know about the objectives of the project. I understand these objectives and consent (agree) to be in a sharing circle. I also agree for my words and what I say in my stories to be used as quotes in reports, publications or presentations. I understand that steps will be taken to make sure that this sharing circle will remain private, unless I want to be identified. I also understand that if I want to leave the project, I can right now and my data will be taken out. I have had the opportunity to ask questions about this project. All of my questions have been answered to my satisfaction.

By signing this form, I do not give up my legal rights and I do not release the investigators, research team, project sponsor or any related institutions from their legal and professional responsibilities. By signing this form, I am saying that I understand that data will be recorded, direct notes will be made, and project files will be destroyed as laid out in this consent form.

_____	_____	___/___/___
Signature of Participant	Name (Printed)	Year/Month/Day*

_____	_____	___/___/___
Signature of Person Conducting Consent Discussion	Name (Printed)	Year/Month/Day*

****Note: Please fill in the date personally***

You will be given a signed copy of this consent form.

Appendix 11. Virtual Sharing Circle Discussion Guide for Healthcare Providers

Introduction: (introduction, consent, responding to questions, and ground rules should take approximately 20 minutes)

Welcome and thank you very much for agreeing to take part in this sharing circle. We recognize that you are all very busy, and appreciate you giving us your time this [morning/afternoon/evening].

You have been invited to participate in this sharing circle because of your experience as community health providers or representatives working in Nunavut. The purpose of this discussion is to explore your overall knowledge, attitudes, beliefs, values, and behaviours, related to maternal immunization in your community, determine any learning you might have from the implementation of the maternal tetanus, diphtheria, acellular pertussis (Tdap) and influenza immunization programs in Nunavut, and your insight and advice for other jurisdictions implementing maternal immunization programs. The sharing circle will take no longer than 2 hours of your time. May I please tape the discussion to facilitate its recollection? (If yes, switch on the recorder; if no, thank the individual who said no, and excuse them).

Privacy: The security and privacy of your personal information is very important to us. We have put in place strict security measures to respect and protect your privacy. This discussion will be taped, and the tapes will be kept safely in a locked facility until they are transcribed word for word, after which time they will be destroyed. The transcribed notes of the sharing circle will contain no information that would allow you to be linked to specific statements. Privacy will be preserved except if something is said within this circle that I must disclose by a court of law. Complete confidentiality **cannot** be guaranteed because we are collecting our data in this group setting. As such, I ask that you respect the privacy of your fellow group members, and please refrain from discussing any comments of group members outside of the sharing circle.

Ground rules: (Aboriginal Services Branch and Learning and Teaching Resources Branch, 2005; Pinnguaq & Qaujigiartiit Health Research Centre, 2017)

- In this sharing circle, everyone is equal, everyone belongs, and everyone deserves respect
- We ask that you help us to foster an environment of kindness by being open, welcoming, inclusive, and by not judging others
- We ask that only one person speaks at a time. Please resist the temptation to jump in when someone is sharing, and wait until they have finished to contribute
- There are no right or wrong answers to any of these questions. All opinions are important
- You do not have to speak in any particular order, however I may intervene if necessary to allow everyone the opportunity to speak
- Please answer questions by stating what you feel or believe starting with “I” statements (e.g. “I feel”, “I think”, etc.)
- If you are asked a question and don’t wish to answer, you can say “I pass”. This is completely acceptable.
- Please feel free to express yourselves in any way that is comfortable (e.g. storytelling, sharing a personal experience, using examples or metaphors, etc.)
- Does anyone have any questions before we begin?

Opening questions: (opening and introductory questions should take approximately 15 minutes)

1. Can you please tell me a little bit about yourself?

Probes:

- Which community/communities/region of Nunavut that are you currently practicing in?
- How many years have you been a community health practitioner or representative in the region?

Introductory question:

2. I am going to give you a couple of minutes to think about your experience with vaccines and pregnant women in your practice. If you feel comfortable to do so, can you please share that experience with the rest of the circle? It is of course a professional standard to keep patient information confidential and private, so please be careful not to disclose a patient identity.

Probes:

- Can you describe *how* you discuss maternal immunizations with your patients (pamphlets, website links, discussions, NACI recommendations, etc.)?
- Can you please describe when in an appointment, you discuss vaccination?
- Could you give me an example of what you mean?

Transition questions: (approximately 10 minutes)

3. What do you think about immunization during pregnancy?

Probes:

- How do you decide to recommend or not to recommend vaccination for your pregnant patients?
- What are some of the influences that have impacted your opinion (colleagues, experts, recommendations, etc.)?
- Have you heard of other points of view on this issue?

Key Questions: (approximately 50 minutes)

We will now move into more vaccine-specific questions. We are curious to hear your opinions about the tetanus, diphtheria, acellular pertussis (Tdap) vaccine. The National Advisory Committee on Immunization (NACI) is a group of experts that makes ongoing and up to date recommendations about vaccines in Canada (Government of Canada, 2019). There is currently a NACI recommendation to administer a Tdap vaccine to all pregnant women, irrespective of their immunization status.

4. Can you tell me your thoughts about this recommendation?

Probes:

- How is new information like this communicated to healthcare providers and community health representatives?
 - Can you please give me an example of what you mean?
5. A maternal Tdap immunization program was initiated in 2016 in response to the pertussis outbreak in Nunavut. In your opinion, are there facilitators that enabled your patients to access and receive the maternal Tdap vaccine? Can you tell me about them?

Probe:

- Can you describe *how* these facilitators improved accessibility and receipt of the Tdap vaccine?
 - What was the effect of these facilitators on pregnant women?
6. In your opinion, are there any barriers that your patients encounter when accessing and receiving the maternal Tdap vaccine? Can you tell me about them?

Probes:

- Are there ways you can tell whether the Tdap vaccine program is being accepted or not accepted by the patients? If yes, how?
 - How do you address barriers to the program?
7. Can you describe how other immediate or extended family members might provide information and support to pregnant women regarding vaccines?

Probe:

- What are some ways to engage these individuals or others who are supports to pregnant women?

8. What have you learned about carrying out a maternal immunization program like the Tdap program in Nunavut?

Probes:

- What have you learned, if anything, specifically from a logistical perspective (i.e. tone of messaging, vaccine supply, etc.)?
 - What ways could immunization information be communicated to pregnant women?
 - What would have made implementation easier?
9. NACI recommends that all pregnant women at any stage of pregnancy should receive an influenza vaccine. Can you tell me your thoughts about this recommendation?

Probe:

- Do you perceive the maternal Tdap and influenza vaccines the same way or differently? Please explain.
10. How is the influenza vaccine program delivered during pregnancy?

Probes:

- Does this differ from how the maternal Tdap vaccine is delivered? If yes, how so?
- Are the Tdap and influenza vaccines perceived the same way or differently by pregnant women? Please explain.
- To what extent are the influenza and Tdap vaccines encouraged or discouraged during pregnancy?

Ending questions: (ending questions through to conclusion should take approximately 20 minutes)

11. Imagine you are asked by another province's Department of Health to help them with implementation of a maternal Tdap vaccination program. What would be your advice to them?

Probes:

- Can you give specific advice for implementation among Inuit or Indigenous women?
- Do you have any thoughts about the consent process with pregnant Inuit women?
- Do you think that the implementation of the maternal Tdap vaccine should be the same or different than that of influenza? Please explain.

12. Respiratory Syncytial Virus (RSV) causes death and serious illness in babies. There is not yet an RSV vaccine available. It is possible that an RSV vaccine for pregnant women to protect their babies, will be available and likely recommended in the next 5 to 10 years.

Can you tell me your thoughts about the use of maternal vaccination to prevent Respiratory Syncytial Virus (RSV) infection in babies?

Probes:

- In the context of Nunavut, what are important to considerations of a potential future maternal RSV vaccine program?

In closing, I would like to invite anyone who came wanting to say something today that they haven't yet had a chance to say, to do so now.

Conclusion: Thank you very much for participating, your expertise and insight is very valuable and meaningful to the project. As I said in my introduction, complete confidentiality **cannot** be guaranteed because we are collecting our data in this group setting. Again, I ask that you respect the privacy of your fellow group members, and please refrain from discussing any comments of group members outside of the sharing circle.

Appendix 12. Virtual Sharing Circle Discussion Guide for Community Health Representatives

Sharing Circle: Discussion Guide

Introduction: (introduction, consent, responding to questions, and ground rules should take approximately 20 minutes)

Welcome and thank you very much for agreeing to take part in this sharing circle. We know that you are all very busy, and we really appreciate you giving us your time today. You were invited to join this sharing circle because of your experience as community health representatives working in Nunavut. The purpose of this sharing circle is to explore your knowledge, attitudes, beliefs, values, and behaviours, related to maternal immunization. We would like to know if you have learned anything from the introduction of the maternal whooping cough and flu (influenza) vaccination programs in Nunavut. We also want to know if you have any advice for other places introducing similar programs. The sharing circle will take 2 hours of your time. Can I please tape the discussion to help me to remember everything that you said? (If yes, switch on the recorder; if no, thank the individual who said no, and excuse them).

Privacy: The privacy of your information is very important to us. This discussion will be recorded, and the tapes will be kept safely in a locked facility until they are written down word for word. After they have been written down, the recordings will be destroyed. The notes from the sharing circle will have no information that would allow you to be identified as saying certain things. Privacy will be protected except if anyone says something in this circle that I have to share by law. Confidentiality **cannot** be guaranteed because this a group setting. I ask that you please respect the privacy of your fellow sharing circle members, and do not discuss anything said here today outside of the sharing circle.

Ground rules: (Aboriginal Services Branch and Learning and Teaching Resources Branch, 2005; Pinnguaq & Qaujigiartiit Health Research Centre, 2017)

- In this sharing circle, everyone is equal, everyone belongs, and everyone deserves respect
- We ask that you help us to foster an environment of kindness by being open, welcoming, inclusive, and by not judging others
- We ask that only one person speaks at a time. Please resist the temptation to jump in when someone is sharing, and wait until they have finished to contribute
- There are no right or wrong answers to any of these questions. All opinions are important
- You do not have to speak in any particular order, however I may intervene if necessary to allow everyone the opportunity to speak
- Please answer questions by stating what you feel or believe starting with “I” statements (e.g. “I feel”, “I think”, etc.)
- If you are asked a question and don’t wish to answer, you can say “I pass”. This is completely acceptable.
- Please feel free to express yourselves in any way that is comfortable (e.g. storytelling, sharing a personal experience, using examples or metaphors, etc.)
- Does anyone have any questions before we begin?

Opening questions: (opening and introductory questions should take approximately 15 minutes)

9. Can you please tell us a little bit about yourself?

Probes:

- Which community/communities/region of Nunavut are you currently practicing in?
- How many years have you been a community health representative in the region?

Introductory question:

10. I am going to give you a couple of minutes to think about your experience with vaccines and pregnant women in your practice. If you feel comfortable to do so, can you please share that experience with the rest of the circle? It is of course a professional standard to keep patient information confidential and private, so please be careful not to share a patient identity.

Probes:

- Can you describe *how* you discuss maternal immunizations with your clients?
 - i.e. pamphlets, website links, discussions, NACI recommendations, etc.
- Could you give me an example of what you mean?

Transition questions: (approximately 10 minutes)

11. What do you think about immunization during pregnancy?

Probes:

- How do you decide to recommend or not to recommend vaccination for your pregnant clients?
- What are some of the influences that have impacted your opinion (colleagues, experts, recommendations, etc.)?
- Have you heard of other points of view on this issue?

Key Questions: (approximately 50 minutes)

I am now going to ask questions about specific vaccines. We are curious to hear your opinions about the whooping cough vaccine. The National Advisory Committee on Immunization is a group of experts that makes ongoing recommendations about vaccines in Canada (Government of Canada, 2019). There is a NACI recommendation that all pregnant women get the whooping cough vaccine at any stage of their pregnancy. Even if pregnant women have had the vaccine before, they are still recommended to get it again.

12. What do you think about this recommendation?

Probes:

- How is new information like this communicated to community health representatives?
- Can you please give me an example of what you mean?

13. A maternal whooping cough vaccination program was started in 2016 in Nunavut because of a big pertussis outbreak. In your opinion, what are some of the things that made getting the whooping cough vaccine easier for pregnant women?

Probe:

- Can you describe *how* these things improved pregnant women's access to the whooping cough vaccine?
- What effect did these things have on pregnant women?

14. In your opinion, what are some of the things that made getting the whooping cough vaccine harder for pregnant women?

Probes:

- How can you tell whether the maternal whooping cough vaccine program is being accepted or not accepted by the patients?
- How do you address these things with pregnant women?

15. In what ways do family members and other people in the community provide information and support to pregnant women about vaccines?

Probe:

- Can you please describe some of the ways that you engage these individuals when you are talking to the pregnant women about vaccines?

16. What, if any, was your involvement in starting a program for pregnant women like the whooping cough vaccination program in Nunavut?

Probes:

- If you were not involved, how should you have been?
- What, if anything, have you learned from your involvement?
- What ways could vaccination information be shared with pregnant women in Nunavut communities?

10. The NACI recommends that all pregnant women get a flu vaccine. What do you think about this recommendation?

Probe:

- Do you think that the maternal whooping cough and flu vaccines are the same or different? Please explain.

13. How is the flu vaccine program delivered during pregnancy?

Probes:

- Is this different from how the maternal whooping cough vaccine is delivered? If yes, how so?
- Are the whooping cough and flu vaccines perceived the same or differently by pregnant women? Please explain.
- To what extent are the influenza and whooping cough vaccines encouraged or discouraged during pregnancy?

Ending questions: (ending questions through to conclusion should take approximately 20 minutes)

14. Imagine you are asked by another province or territory's Department of Health to help them with a maternal whooping cough vaccination program. What would be your advice to them?

Probes:

- Can you give specific advice for communicating with Inuit or Indigenous women?
- What do you think about the consent process with pregnant Inuit women?
- Do you think that the maternal whooping cough vaccine program should be the same or different than the maternal flu vaccine program? Please explain.

Respiratory Syncytial Virus (RSV) causes death and serious illness in babies. There is not yet an RSV vaccine available. It is possible that an RSV vaccine for pregnant women to protect their babies, will be available and likely recommended in the next 5 to 10 years.

15. What do you think about the use of maternal vaccination to prevent Respiratory Syncytial Virus (RSV) infection in babies?

Probes:

- In the context of Nunavut, what is important to think about if a maternal RSV vaccine program were to be started?

In closing, I would like to invite anyone who came wanting to say something today that they haven't yet had a chance to say, to do so now.

Conclusion: Thank you very much for participating, your thoughts and experiences are helpful for the project. Like I said earlier, confidentiality **cannot** be guaranteed because this is a group setting. I ask again that you please respect the privacy of all sharing circle members by not sharing anything said here today outside of this circle.

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