

**ENGAGING MI'KMAQ COMMUNITIES IN ASTHMA RESEARCH: A
COMMUNITY-DRIVEN ASSESSMENT OF THE NEEDS, CHALLENGES, AND
OPPORTUNITIES SURROUNDING ASTHMA SUPPORT IN UNAMA'KI (CAPE
BRETON), NOVA SCOTIA**

by

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Submitted in partial fulfilment of the requirements
for the degree of Master of Environmental Studies

at

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SCHOOL FOR RESOURCE AND ENVIRONMENTAL STUDIES

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ABSTRACT

Asthma is the second most common chronic condition among Aboriginal youth (age 12 and under) affecting approximately 13% of this population. Research to date is primarily limited to the examination of physiologic aspects of the condition leaving the psycho-social difficulties facing them and their parents/caregivers largely understudied. This three-phase study aims to understand the psycho-social barriers facing asthmatic Mi'kmaq youth and their parents/caregivers living on-reserve in Unama'ki (Cape Breton), Nova Scotia and facilitate health promoting behaviours at the community level. A community-based participatory research approach was undertaken to: 1) identify the support needs and intervention preferences of asthmatic Mi'kmaq youth and their parents/caregivers; 2) design and pilot test a culturally appropriate support-education intervention that meets these preferences; and 3) identify the implications of the findings for asthma programs, policies, and practices specific to Mi'kmaq peoples and determine appropriate community-level dissemination strategies. The findings suggest that there is a lack of community-level asthma support available to Mi'kmaq families managing the condition despite a strong desire for these services. This study offers three community-driven recommendations to increase available support: improve school-based asthma policy, develop asthma expertise within each community health center, and implement an annual, culturally appropriate asthma camp.

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CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

This chapter provides an introduction to the thesis. I begin with a positionality statement acknowledging how I came to be involved in this research. From there, I provide a problem statement describing the overarching issue addressed by this thesis and its importance. Next, I give an extensive literature review to contextualize this study as a whole. I then provide a detailed account of the research design and methodologies undertaken. Lastly, I present the format of this thesis to prepare readers for the chapters that follow.

1.2 POSITIONALITY

I am a third generation settler of European ancestry. Raised in a middle class home in London, Ontario, I grew up surrounded by others just like me in terms of race and socio-economic status. For the first 20 years of my life I enjoyed the privileges of being a white male without ever stopping to consider what that meant. It is fair to say that I held an uncritical view of my physical and social environment. After high school, I began an undergraduate degree at the University of Western Ontario majoring in business. It was not until the third year of my program, through a Geography course elective I enrolled in by chance, that I discovered my passion for exploring environment and health issues. I began to reevaluate my academic program and decided that I would be in a better position to make a positive contribution to society with less emphasis on business and more on my newfound interest. By the start of my fourth year, I had adjusted my program of study to include a major in geography where I had the opportunity to explore the impacts of various social and environmental factors on the health of (especially marginalized) populations. Through a number of courses, I was challenged to think of health as a socially and economically constructed phenomenon, a position I had previously not considered.

As part of my geography major, I had the opportunity to complete an undergraduate honours thesis under the supervision of an Aboriginal scholar whose expertise was in environment and health and where, for the first time in my life, I was exposed to the health challenges and inequities facing Canada's Aboriginal peoples. As part of a larger community-based participatory research (CBPR) project, my honours thesis research focused on food security for a local First Nation. While I felt my contributions were meaningful to the overall project, I did not have any direct community engagement, which I recognized as a major void in my work. It was through this experience that I realized if I wanted to engage with Aboriginal communities in a meaningful way, I needed to spend significant time in a community, developing relationships of my own.

When Dr. Heather Castleden, an assistant professor in the School for Resource and Environmental Studies at Dalhousie University, presented me with the opportunity to continue my education at the graduate level through a CBPR project about social support for asthmatic youth with five Mi'kmaq communities in Nova Scotia, I felt that the study was an ideal fit with my background and academic goals. As a lifelong asthma sufferer, not only was I able to engage with a topic that I could relate to, but I was also able to work directly with five Aboriginal communities where I could strive for culturally relevant research on a community-identified health priority; this set the stage for my research journey.

1.3 PROBLEM STATEMENT

Asthma affects approximately 13% of Aboriginal youth in Canada making it the second most common chronic illness suffered by this population (First Nations Regional Health Survey, 2011). Equally concerning is that just 40% of those youth receive treatment for their condition despite the disproportionate increase in asthma-related hospitalizations when compared to non-Aboriginal youth (First Nations Regional Health Survey, 2011; Liu et al., 2000). Existing literature associates a lack of asthma support with harmful health consequences yet research efforts to date have primarily been limited to the examination of physiological aspects of the condition leaving the psychosocial difficulties facing asthmatic youth and their parents/caregivers largely understudied, especially in

Aboriginal contexts (Nocon, 1991; Padur, et al., 1995). Given the high rates of asthma affecting Aboriginal youth, the physical, mental, and social ailments attributed to this condition, and the lack of research undertaken in this area of study, there is a clear need to address this issue. As such, this thesis seeks to identify the psychosocial barriers facing the Aboriginal population - Mi'kmaw - living in Unama'ki (Cape Breton Island), Nova Scotia. Specifically I sought to understand the experiences of Mi'kmaq families affected by asthma in an effort to facilitate health promoting behaviours at the community level.

1.4 LITERATURE REVIEW

1.4.1 Aboriginal Health in Canada

Comprised of First Nations, Inuit, and Métis, Aboriginal peoples represent nearly four percent (numbering 1.2 million) of the Canadian population (Statistics Canada, 2010). Increasing 45% since 1996, the Aboriginal population is the fastest growing demographic in Canada (Statistics Canada, 2010). With a median age of 27, compared to 40 for non-Aboriginal Canadians, they are also the youngest population. Recent trends indicate that Aboriginal peoples are becoming increasingly urbanized (Place, 2012). In 2002, the proportion of the Aboriginal population living in cities surpassed the 50% mark for the first time in history (Statistics Canada, 2010).

It is well established that Aboriginal peoples suffer worse health than their non-Aboriginal counterparts as reported by virtually all population-based measures of health (Adelson, 2005; MacMillan et al., 1996). The pervasive state of existing Aboriginal health disparities can be linked to political, social, and economic inequalities stemming from the colonization of Canada (Reading & Wien, 2009). Although well intentioned, government initiatives to redress this situation have been largely unsuccessful, often exacerbating Aboriginal health issues (Royal Commission on Aboriginal Peoples, 1996). As a result, Aboriginal groups and allies nationwide (even globally) have called for new

ways of creating and implementing policy that more accurately reflects and addresses Aboriginal realities¹.

Some examples of the health realities faced by the Aboriginal population include alarming rates of Type 2 diabetes, obesity, cardiovascular disease, tuberculosis, HIV/AIDS, and suicide, all of which have received considerable attention from both academics and policy makers alike (Frohlich et al., 2006; MacMillan et al., 1996). While the gap is closing, life expectancies at birth for Aboriginal men and women are reported to be 8.1 and 5.5 years lower respectively than Canadian men and women in general (Statistics Canada, 2010). Nearly two-thirds of the off-reserve Aboriginal population suffers at least one chronic condition compared to just half the non-Aboriginal population. Obesity, diabetes, and suicide affect Aboriginal peoples at a rate twice that of Canadians generally (Frohlich et al., 2006). Similarly, the incidence of cardiovascular disease among Aboriginal peoples is 1.5 times the rate of the general Canadian population (Frohlich et al., 2006). While the disproportionate incidence of disease and mortality endured by Canada's Aboriginal population is well established, more recently, literature aimed at conceptualizing the health of Aboriginal peoples from a social determinants perspective has emerged (Richmond & Ross, 2008; Reading & Wien, 2009).

1.4.2 The Social Determinants of Health

The social determinants of health are the underlying economic and social conditions that impact individual and communal health (Raphael, 2004). Recognized on an international scale, they include the social gradient, stress, childhood health, social exclusion, work, unemployment, social support, addiction, food, and transport (Wilkinson & Marmot, 2003). More recently and in a Canadian Aboriginal context, Reading and Wien (2009) summarize the state of Canada's Aboriginal peoples attributing existing health inequalities to social determinants linked to proximal, intermediate, and distal scales.

¹ Research in Atlantic Canada has identified the benefits that can be obtained from combining the strengths of mainstream western knowledge with Mi'kmaq (First Nations) knowledge. Known as Two-Eyed Seeing, this concept, generated by Mi'kmaq elder Albert Marshall, aims to engage with a mindset that consistently, respectfully, and passionately allows for the overlap of these two knowledge systems in the way one thinks and talks about a topic (Iwama et al., 2009; Hatcher et al., 2009).

Proximal determinants of health are those that directly influence physical, emotional, mental, and spiritual aspects of health. They are traits specific to an individual that lead to individual-level health outcomes (Reading & Wien, 2009). Aboriginal peoples are more likely to engage in and be exposed to harmful health behaviors such as alcohol abuse (Millar, 1992), smoking (Ritchie & Reading, 2004), sedentary lifestyles, poor diet (Campbell, 2002; Hanley & Harris, 2000), and poor prenatal care (Health Canada, 2005). The physical environments where Aboriginal peoples reside also contribute to health inequalities at the proximal level. Housing shortages (Bryant, 2004), low quality homes (Berghout et al., 2005; Lawrence & Martin, 2001), food insecurity (stemming from geographic isolation) (Chan et al., 2006; Lambden et al., 2006), and a lack of community resources such as clean water, adequate waste management, and sufficient sanitation (Anand et al., 2001) all pervade Aboriginal communities throughout Canada. Furthermore, a lack of educational attainment among Aboriginal peoples often results in illiteracy, unemployment, and poverty, all of which have a direct impact on one's ability to obtain the resources necessary to achieve good health (Task Force on Aboriginal Languages and Cultures, 2005; Cardinal, 2004).

The intermediate determinants of health represent the source of the proximal determinants. Aboriginal peoples often lack access to political, social, and physical services, which are prerequisite for satisfying health needs at the proximal level (Reading & Wien, 2009). Inequitable health care systems are common in Aboriginal communities as trained medical staff, culturally appropriate care, timely care, and comprehensive services (as a result of the federal Non-Insured Health Benefit plan) are often unavailable resulting in barriers to health promoting behaviours (Health Canada, 2007; Brown & Fiske, 2001; Assembly of First Nations, 2005). Existing education systems do not incorporate Aboriginal specific material or Indigenous² ways of learning into school curriculum contributing to low educational attainment (Dunn et al., 2006). Additionally, a

² Since being formally defined by the Canadian government in the creation of the Constitution Act of 1982, the term "Aboriginal" has been used as an all-inclusive reference to unique First Nations, Inuit, and Métis populations. The term "Indigenous" refers to a population that holds a longstanding occupation or historical claim over a geographic region but also recognizes their

lack of community resources and capacity inhibit Aboriginal communities from developing the infrastructure needed for economic prosperity (Tolbert Kimbro et al., 2008).

Distal determinants have been identified as having the most significant impact on health; they encompass social, political, and economic conditions in which the proximal and intermediate determinants are composed (Reading & Wien, 2009). For Aboriginal peoples, colonialism, racism, social exclusion, and a lack of self-determination are clearly linked to health determinants at the proximal and intermediate levels (Kelm, 1998; Warry, 1998).

Throughout the 20th century, the Canadian government enacted a number of colonial driven policies and legislations in an effort to assimilate Aboriginal peoples into mainstream Canadian society. Individuals who resisted this movement for the purpose of attempting to retain their cultural identity, were punished through the provision of inadequate resources, incarceration, and in some cases death (Galabuzi, 2004). Arguably the most detrimental assimilation effort to the health of Aboriginal peoples made by the Canadian government was the implementation of the residential school system (CBC News, 2013). This attempted genocide resulted in the loss of language, culture, family ties, and community networks for generations of Aboriginal children (Reading & Wien, 2009). The lingering effects of the residential school system are prevalent today in the form of inequitable health determinants at multiple scales (First Nations Regional Longitudinal Health Survey, 2005; Truth and Reconciliation Commission of Canada, 2012).

Aboriginal peoples have experienced racism and social exclusion since shortly after the time of first contact by European settlers (Reading & Wien, 2009). This has resulted in their marginalization and inability to access socio-economic resources such as income and education (Adelson, 2005). Without adequate access to these, among other

struggle as a marginalized population bound to an industrializing or industrialized nation state (Kesler, 2009).

recognized determinants of health (e.g. self-determination), Aboriginal peoples face virtually insurmountable barriers to attaining a level of health comparable to that of Canadians in general (Reading & Wien, 2009).

1.4.3 Aboriginal Perspectives of Health

In order to understand the complex processes influencing Aboriginal health, it is necessary to have an understanding of what it means to be healthy from an Aboriginal perspective. Where western perspectives of health stress the legitimacy of biomedical knowledge stemming from science, academics, and literature (Adelson, 2005), Aboriginal perspectives of health encompass Indigenous knowledge³ that lacks (western) scientific confirmation and can be described as ecologic, holistic, relational, pluralistic, experimental, timeless, infinite, communal, oral, and narrative-based (Smylie et al., 2003). Culture is integral to meanings of Aboriginal health as it is embedded into Indigenous knowledge systems (Waldram et al., 2006). It is through a holistic perspective encompassing the balance of physical, emotional, spiritual, and mental components in harmony with the natural environment that many Aboriginal societies conceptualize health (Reading & Wien, 2009); among many Indigenous peoples in North America, these four elements are often represented as the medicine wheel with each quadrant encompassing one entity and their interrelation reflecting relationships to family, community, and the world (Abele, 1985). Achieving balance in this system is recognized as essential for optimal growth and development (Saskatoon Aboriginal Women's Health Research Committee, 2004); even a minor imbalance can result in harmful health outcomes (Isaak & Marchessault, 2008).

It is important to note that while some similarities exist, differences between Aboriginal and western perspectives of health are significant and that emphasis on the latter has resulted in health services that do not represent Aboriginal needs. These differences have

³ Indigenous knowledge is not easily defined, but for the purpose of this thesis it is understood as a holistic system of knowing specific to a particular culture, locale, or society. Emphasizing experiential reality, Indigenous knowledge is developed through daily experiences and spiritual connections to the environment. It mirrors the values, practices, and traditions of those societies in which it is created and is often passed down through generations using oral discourse (Battiste, 2007; Kovach, 2009).

created a health care system that is underutilized by Aboriginal peoples (Wilson & Rosenberg, 2002; MacMillan et al., 1996). In response, there has been pressure from Aboriginal health organizations such as the Ontario Aboriginal Healing and Wellness Strategy (AHWS) and the Tui'kn Partnership (an organization representing the five First Nations communities in Cape Breton, Nova Scotia) to incorporate Aboriginal specific healing strategies into the Canadian health care system. The applicability of traditional Aboriginal healing methods (e.g. sweat lodges, traditional medicines, smudging ceremonies) are being increasingly recognized among both scholars and policy makers dedicated to addressing the multi-faceted dimensions of Aboriginal health (Walker et al., 2010; AHWS, 2002; Health Canada, n.d.).

1.4.4 Connections between Environment and Health

The connection that many Aboriginal peoples have with their environment surpasses that of most other Canadians (Doyle-Bedwell and Cohen 2001). Operating under the traditional philosophy that everything is connected, Aboriginal societies tend to conceptualize humanity as part of the natural world. As such, Aboriginal health is inextricably linked to the environment (Reading & Wien, 2009) where the health of the land is an accurate reflection of the health of the people living on it and vice versa (Castleden, 2007). Traditional activities such as hunting, fishing, trapping, and gathering have not only sustained Aboriginal peoples for generations but also provide individuals and communities alike with spiritual and cultural connections to their lands (Waldram et al., 2006). For Aboriginal peoples, the strength of these connections is cited as an accurate indicator of individual and community health (Richmond & Ross, 2008).

As a result of colonial agendas, however, Aboriginal peoples have been dispossessed of much of their traditional territory (Battiste, 1997). This has severely limited the available opportunities to lead traditional lifestyles and engage in cultural practices that are prerequisite to good health (Richmond & Ross, 2008). Where opportunities for traditional activities do remain intact, oftentimes these landscapes have been contaminated by industrial pollutants, leaving fish, plants, animals, and water unfit for traditional uses (Shkilnyk, 1985; Mascarenhas, 2007). This has led many Aboriginal groups to stop

harvesting their natural resources, eliminating their intake of traditional foods and creating a reliance on less nutritious, more expensive market foods which lack ceremonial significance (Willows, 2005); rather than eating whatever is available through traditional food harvest, the market food system creates an environment where educated food choices are necessary for a healthy diet, a skill that is not yet widespread among Aboriginal groups (Martin, 2011). In communities where traditional foods are necessary for a significant portion of dietary intake, these groups are left to suffer the health consequences of ingesting harmful environmental contaminants (Richmond & Ross, 2008).

As numerous Aboriginal peoples continue to rely on the environment for their social, cultural, physical, and economic needs, the state of Aboriginal health is embedded in that environment. Given the drastic alterations to the Canadian landscape over the past 100 years and the subsequent lifestyle changes forced upon many Aboriginal groups, new chronic conditions have started to show up in Aboriginal populations at an alarming rate (Waldram et al., 2006). While conditions such as diabetes and obesity among others have received extensive attention from researchers, asthma presently remains underrepresented in Aboriginal health literature.

1.4.5 Asthma

Asthma is a chronic condition resulting in inflammation of the airway. Symptoms can range from mild to severe and include shortness of breath, tightness in the chest, coughing, and wheezing; although rare, the rapid onset of a severe asthma attack (the sudden worsening of asthma symptoms) can cause death (Asthma Society of Canada, 2013). The exact cause of asthma remains unknown and there is currently no cure for this disease; it is often diagnosed at a young age, however, adult onset asthma is not uncommon. Asthmatic individuals experience asthma symptoms or asthma attacks when exposed to asthma triggers. Triggers vary from one person to another and include anything that causes inflammation of the airway such as smoke, pollen, mold, exercise, pets, etc. While asthma is a lifelong condition, with proper asthma management that includes prescription medication and regular visits to a family physician, the frequency

and severity of asthma symptoms can be controlled to a point where asthmatic individuals can lead virtually symptom-free lives (Asthma Society of Canada, 2013).

1.4.5.1 Asthma among Aboriginal Peoples

Indigenous peoples worldwide endure a disproportionate incidence of asthma compared to their non-Indigenous counterparts (Chang et al., 2007). In Canada, asthma is becoming increasingly prevalent within the general population yet even higher rates of this condition exist among Aboriginal groups (Asthma Society of Canada, 2009). Asthma is reported to affect 12% of Aboriginal peoples compared to 8.5% of Canadians generally (Asthma Society of Canada, 2009). As discussed in the introduction, this condition is even more prevalent among Aboriginal youth, with approximately 13% affected by asthma. Moreover, just 40% of those asthmatic Aboriginal youth are being treated for it (First Nations Regional Health Survey, 2011).

For Aboriginal peoples, asthma is inextricably linked to the social determinants of health at multiple scales. Recent research associates the high rates of asthma pervading Aboriginal communities with exposure to tobacco smoke, dust and mould, overcrowded housing, poor indoor air quality, low socioeconomic status, and life stress (Asthma Society of Canada, 2009). Smoking rates among First Nations peoples are roughly 2.5 times that of the general Canadian population (First Nations Regional Health Survey, 2011). Many Aboriginal families live in overcrowded or substandard housing where there is an increased risk of being exposed to dust, mould, and mildew (Statistics Canada, 2005), all common causes of respiratory infections (Asthma Society of Canada, 2009). Contributing to degraded indoor air quality in many Aboriginal households is the use of wood burning stoves and the practice of certain cultural activities such as curing and tanning (Guggisberg et al., 2003). What is more, with a median income of less than \$40,000 annually (Statistics Canada, 2003), most Aboriginal families are on the disadvantaged end of the socioeconomic spectrum resulting in a financial barrier to accessing asthma treatment and medication (Kozyrskyj et al., 2001). Moreover, the likelihood of an Aboriginal child living with a single parent/caregiver is far greater than non-Aboriginal youth, which places them at an increased risk of living in a stressful home

environment (First Nations Regional Health Survey, 2011). Distressing but certainly important to note here, related literature identifies youth who are exposed to maternal stress during their first seven years of life to be at an increased risk of an asthma diagnosis (Kozyrskyj et al., 2008).

1.4.5.2 Gaps in Aboriginal Asthma Research

While the vast majority of asthma-related research focuses on physiological aspects of the condition, the psychosocial difficulties facing asthmatic youth remain largely unexplored. Existing literature identifies these youth to be at a greater risk of anxiety, depression, acting-out behaviours, and low self-esteem (Padur et al., 1995; Nocon, 1991).

Exacerbated through inadequate support, education, and treatment strategies, these issues are particularly problematic for Aboriginal youth as recent research finds this group to be 55% less likely to see an asthma specialist and 66% less likely to undergo spirometry than non-Aboriginal youth (Sin et al., 2002). Moreover, while access to sufficient support resources and adherence to a detailed asthma management plan is correlated with effective asthma management and a higher quality of life for youth in general (McGhan et al., 2010; McGhan et al., 2006), to date no peer-reviewed published literature has identified the asthma support needs unique to Aboriginal youth living with asthma or the needs of their parents/caregivers.

A recent report by the Asthma Society of Canada (2009) identifies an existing lack of asthma research specific to Aboriginal peoples and stresses the need for work in this area of study. The report goes on to make the following recommendations for dealing with asthma-related issues in Aboriginal communities: increased culturally relevant education and community asthma awareness, the development of asthma guidelines specific to Aboriginal communities, improved access to health care, and improved family and community resources for asthma management. With such asthma-related support gaps cited as problematic to the health of Aboriginal peoples, the importance of asthma research in an Aboriginal context appears to be evident.

1.4.6 Support Strategies for Chronic Illness in Aboriginal Communities

Although there is minimal research identifying effective Aboriginal-specific community health support strategies, social support has recently emerged as a recognized determinant of Aboriginal health (Richmond, 2007). Generally speaking, communities fostering socially supportive environments are shown to be healthier than their socially unsupportive counterparts; in certain instances however, social support has been shown to have the opposite effect, leading to harmful health consequences where unhealthy behaviours are common practice (e.g. if an individual's social group frequently engages in substance abuse such as smoking, then they are more likely to engage in that behavior as well) (Richmond & Ross, 2008). This finding raises concern for the many Aboriginal communities that are embracing the philosophy of "a community raised child" where entire communities provide support for youth with chronic illnesses (Bennett et al., 2005). While research stresses the importance of community participation and buy in for health intervention strategies to be effective in an Aboriginal context (Health Canada, 2011; Rowley et al., 2000; Green et al., 1995), it would appear that education for community members is essential to ensure that they are aware of how to assist with the progression of chronic disease management rather than inadvertently hindering it.

While not specific to asthma, research investigating the effectiveness of health intervention strategies for other chronic diseases stresses the need for programs that are culturally appropriate, community relevant, and driven by members of the community (Rowley et al., 2000; Green et al., 1995; Potvin et al., 2003; Health Canada, 2011). Findings from such studies offer the following suggestions to accomplish this; utilize community Aboriginal service care providers, emphasize relationship building, consider the physical, mental, spiritual, and emotional health of the individual, ensure that services are convenient and accessible to everyone, encourage community and family member involvement, incorporate traditional teachings, ceremony, and spirituality, and integrate elders into the healing process. As asthma support strategies specific to Aboriginal peoples have only begun to be identified (see Asthma Society of Canada, 2012), it is likely that for future interventions to be effective, they will need to make use of the strategies outlined in this report (i.e. community engagement, educational outreach, and

culturally relevant toolkit development) as their starting point and supplement these with the established support guidelines for other chronic illnesses highlighted in the literature.

In order to engage Aboriginal communities in the identification of their asthma support needs and promote the implementation of asthma support initiatives through research, it is first necessary to develop meaningful community partnerships that are based on relationships of trust. The importance of this initial step cannot be overstated and requires a thorough understanding of the historical relationship between university researchers and Aboriginal communities as well as the ongoing legacy that affects all research with Aboriginal peoples.

1.4.7 Canada's Research Legacy with Aboriginal Peoples

Aboriginal peoples in Canada have been subject to decades of research by non-Aboriginal researchers 'parachuting' into their communities, collecting data and leaving without ever returning to communicate the findings of their research. Such research was unethical and often served little more than as a means of career advancement for researchers themselves (Ball & Janyst, 2008; Brant Castellano, 2004; Korsmo & Graham, 2002). As a result of this colonial research legacy, many Aboriginal communities remain hesitant to engage in research projects to this day. Exacerbating feelings of resentment and skepticism towards the academic community, Indigenous peoples have been cited as the most researched group of peoples in the world; they have articulated this experience as "being researched to death" (Schnarch, 2004, p.82; Ball & Janyst, 2008, p.38). Some have even gone so far as to describe the term research itself as a "dirty word" for Indigenous peoples worldwide making reference to the perpetuated marginalization that has resulted from research conducted *on* rather than *with* Indigenous communities (Smith, 1999, p.1).

With increased awareness of the shortcomings of colonial research and its implications for Aboriginal research participants, research protocols specific to Aboriginal communities have emerged. One of the most significant advances made in this area has been the switch from doing research *on* to doing research *with* Aboriginal peoples (Warry, 1990), stressing the need to acknowledge Aboriginal communities as equal

partners in the research relationship (Ball & Janyst, 2008; Louis, 2007; Louis & Grossman, 2009). Related literature identifies the importance of adhering to the following principles if future research is to be ethical and promote self-determination among Aboriginal peoples: ownership, control, access and possession (termed the OCAP Principles) (First Nations Information Governance Centre, 2010). Ensuring Aboriginal communities' collective ownership of cultural knowledge/data/information, control of research/information, management of the accessibility of the data and possession of the data itself is thought to translate into the rebuilding of trust, improved research quality, decreased bias, capacity building and community empowerment (Schnarch, 2004). Supplementary to the OCAP principles, research with Aboriginal peoples must exhibit *respect* for their culture, *relevance* to participating communities, *reciprocity* between the researcher and community and *responsibility* to both individual and community relationships (known as the 4 Rs of research) to be truly ethical (Kirkness & Barnhardt, 1991).

The Canadian Institutes of Health Research (CIHR) has published their own set of Guidelines for Health Research Involving Aboriginal Peoples (2007), a precursor to the 2010 2nd edition of the Tri-Council Policy Statement (TCPS 2), outlining specific research procedures to ensure appropriate ethical conduct with Aboriginal partners. Both the OCAP principles (Schnarch, 2004) and 4 Rs (Kirkness & Barnhardt, 1991) of research are embedded in these guidelines, and stress the need for research that is ethically and culturally sensitive, upholds Aboriginal values and traditions and respects the need for partnerships between researchers and participating communities (Castleden et al., 2012). Researchers working with Aboriginal communities are expected to adhere to the protocol outlined in these documents for their research to be approved by university ethics boards. Several Aboriginal groups have also implemented their own ethical approval process to ensure they have an active role in deciding what research is conducted within their communities (e.g. Mi'kmaq Ethics Watch, Aurora Research Institute, Royal Commission on Aboriginal Peoples). In addition to empowering communities through self-determination, community-level ethical approval facilitates strong research relationships, ultimately improving both the quality and relevance of

Aboriginal health research (Castleden et al., 2012; Ball & Janyst, 2008; Louis, 2007; Louis & Grossman, 2009).

While progress has been made with respect to salvaging the relationship between university-based researchers (who are still primarily non-Aboriginal) and Aboriginal peoples, researchers must be mindful of the lingering effects that colonial-driven, ‘parachute’ research can have on potential Aboriginal research partners. Academics should exercise care when designing their research to ensure they are working with Aboriginal peoples to address meaningful research questions in a culturally sensitive way that will provide community-level benefits (Ball & Janyst, 2008; Brant Castellano, 2004; Louis, 2007; Louis & Grossman, 2009). Adherence to such standards may ultimately end decades of unethical research on Aboriginal peoples and progress to a state of decolonization where research agendas are self-determined by those they affect most (Smith, 1999).

1.4.8 The Importance of Community-Based Participatory Research

Research agendas that effectively address the needs and wants of participating Aboriginal communities in their application are cited as paramount to doing effective, ethical research (Louis, 2007; Louis & Grossman, 2009; Ball & Janyst, 2008; Castleden et al., 2008). As such, community-based participatory research (CBPR) has become increasingly popular with researchers committed to engaging in culturally meaningful health research with Aboriginal communities. CBPR is a research design and philosophy that equitably involves both the researcher and their community partners throughout all stages of the research process including problem definition, data collection, data analysis, results interpretation, and dissemination strategies (Minkler & Wallerstein, 2003). The adoption of CBPR has increased to the point where it is recommended in the CIHR’s Guidelines for Health Research Involving Aboriginal Peoples (2007) and more recently in the TCPS 2 (which has replaced CIHR’s Guidelines for Health Research Involving Aboriginal Peoples (2007)) as an effective way to engage in research with Aboriginal communities. Much of its effectiveness stems from its ability to facilitate ethical research with Aboriginal peoples that is consistent with community agendas.

The applicability of CBPR to Aboriginal communities can be seen through an examination of emergent Indigenous research paradigms. An Indigenous research paradigm is a guiding set of beliefs, values and principles that parallel Indigenous ways of being, knowing, and learning (Wilson, 2008; Smith, 1999). Indigenous research paradigms are a response to western claims of superiority over Indigenous ways of doing research that stress the need for acceptance of research generated as a result of Indigenous methodology (Smith, 1999). Wilson (2008) articulates an Indigenous research paradigm through which the importance of relational accountability, holding oneself accountable to the relationships he/she has established, is stressed as a guiding principle for researchers operating under this mindset. Interestingly, much of the effectiveness of CBPR stems from the relational accountability between researchers and community partners. With recognition of Indigenous research paradigms becoming widely adopted, the strength and applicability of CBPR principles are evident.

1.5 RESEARCH DESIGN AND METHODOLOGY

This thesis represents a portion of a larger, three-phase, multi-site study that has taken place in Alberta, Manitoba, and Nova Scotia. Conducted in collaboration with participating Aboriginal communities and employing a CBPR design, the overarching goal of this research is to identify the psychosocial barriers facing Aboriginal families affected by asthma in an effort to facilitate health promoting initiatives at the community level. At the onset of this project, the research team⁴ conceived that each site would carry out identical research activities aimed at achieving a set of common objectives. As the project progressed, each site modified the methodology set out in the initial proposal to accommodate input from their respective local community advisory committees (CAC). This has resulted in three distinct strategies for addressing the overall project goal; in Alberta, semi-structured interviews, asthma camps, and support sessions (provided face-to-face and via Telehealth) were utilized; in Manitoba, support sessions and focus groups

⁴ Nominated Principal Investigator, Dr. Miriam Stewart (University of Alberta) together with Co-Principal Investigators, Dr. Malcolm King (University of Alberta), Dr. Jeff Masuda (University of Manitoba), and Dr. Heather Castleden (Dalhousie University) - also my thesis supervisor - led this multi-site study with a host of other Co-Investigators and Collaborators.

were utilized; and in Nova Scotia, semi-structured interviews, focus groups, a sharing circle, participant employed art, and an asthma camp were utilized.

1.5.1 Research Goal and Objectives

The research reported on in this thesis is specific to the Nova Scotia site of the larger project; in Nova Scotia, Mi'kmaq are the original inhabitants of the landscape and five Mi'kmaq communities were partners in this arm of the study. With the goal of the larger study in mind, this thesis seeks to achieve the following objectives:

Objective One: To identify the support needs and intervention preferences of Mi'kmaq youth with asthma and their parents/caregivers living on-reserve in the five Mi'kmaq communities of Unama'ki (Cape Breton Island) in Nova Scotia.

Objective Two: To design and pilot test a cultural support-education intervention that meets these needs, in collaboration with Mi'kmaq participants.

Objective Three: To identify the implications of the findings for asthma programs, policies, and practices specific to Mi'kmaq in addition to determining appropriate audiences and vehicles for dissemination.

To address these objectives, three phases of data collection were conducted. In Phase 1, 17 Mi'kmaq families participated in individual semi-structured interviews aimed at identifying their support needs and intervention preferences (Objective 1). In Phase 2, participating families attended a two-day educational awareness asthma camp (Objective 2). In addition to taking part in cultural and educational activities related to asthma, culturally appropriate methodologies (i.e. a focus group, a sharing circle, participant employed art, participant observation, and field notes) further explored participants' asthma support needs and intervention preferences (Objective 1). In Phase 3, 22 community health centre employees and school personnel participated in focus groups to identify the implications of Phase 1 and 2 findings for asthma programs, policies, and practices in a Mi'kmaq context and determine dissemination strategies (Objective 3). Each of these phases are discussed in detail below.

1.5.2 Community-University Relationship Development

Prior to initializing the first phase of this study, an extensive effort was made by the lead researcher of the Nova Scotia site, Dr. Heather Castleden, to develop relationships with five Mi'kmaq communities in Unama'ki (Cape Breton). This began first through her involvement in the Mi'kmaq Health Research Group, a representative body of the Confederacy of Mainland Mi'kmaq, the Union of Nova Scotia Indians, the Atlantic Policy Congress of First Nation Chiefs, and Dalhousie University faculty members aiming to augment educational opportunities and research initiatives that have a Mi'kmaq community health focus; here, she presented the research proposal and sought guidance and advice from the other members. From there, she was encouraged to contact the Tui'kn Partnership, an Unama'ki (Cape Breton)-based health group comprised of the Health Directors representing the five Mi'kmaq communities in the region (i.e. Membertou, Potlotek, Eskasoni, Waycobah, and Wagmatcook First Nations (see Figure 1.1: Map of Participating Communities), whose goal is to develop innovative, culturally relevant solutions for primary care planning and delivery. After following up on her contacts within the group, the Tui'kn Partnership expressed interest in partnering with Dr. Castleden on the proposed research project, commencing the relationship building phase of this work (see Appendix A: Community Partnership Letters). Spanning over a year (2010-2011), this process involved numerous meetings, teleconferences, and community visits. Once this relationship was established, a local CAC consisting of community health nurses and community health representatives from each of the five communities was appointed by the Health Directors. Members of the CAC informed participant recruitment strategies, refined the research design, piloted-tested the data collection process, commented on preliminary findings, and communicated community protocols.

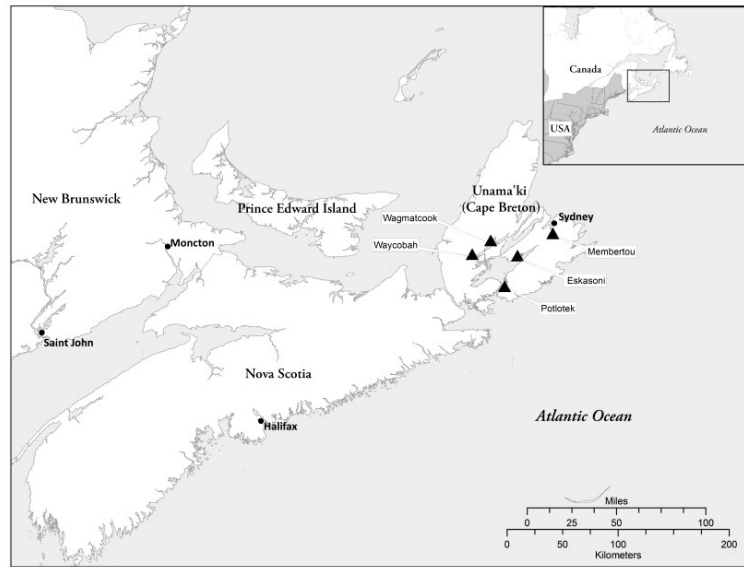


Figure 1.1: Map of Participating Communities

As the project design evolved, additional personnel were required for its implementation. April 2011 marked the commencement of my own involvement in the study as I was brought on as the research coordinator for the Nova Scotia site. Not having established a community relationship prior to being recruited for this project, it was important for me to spend a significant amount of time working in each of the five communities to develop relationships of my own. On the day I arrived in Nova Scotia from Ontario, I attended a meeting of the CAC in Unama'ki with Dr. Castleden, where I was introduced to the community representatives, briefed on the project, and provided with points of contact in each community. In order to further develop meaningful relationships with our community partners while simultaneously facilitating Phase 1 and 2 of this project, I lived in Unama'ki between April and July 2011, visiting each community weekly (at minimum). One of the tenants of doing 'good' CBPR, these initial efforts by Dr. Castleden and I to establish positive community relationships translated into a research partnership that enabled the study to proceed in an ethical and community-relevant manner (Louis, 2007; Louis & Grossman, 2009; Ball & Janyst, 2008; Castleden et al., 2008).

1.5.3 Working with a Team of Community Researchers

During my time living in Unama'ki, I coordinated a team of six Mi'kmaq community researchers who were hired and trained to recruit participants for Phase 1 and 2, conduct and transcribe interviews, engage in preliminary data analysis, and assist with an asthma support intervention. Our funding allowed the team to hire one community researcher per community with the exception of one community where two community researchers shared these responsibilities. This team was comprised entirely of local Mi'kmaq women, five of whom had university training in health, and were recruited based on the recommendation of the CAC. Growing up in their respective communities, each researcher was able to expediently identify families that would meet the project's criteria for potential participation in Phase 1 and 2. Oftentimes they had a personal relationship with these families resulting not only in improvements to recruitment efficiency but also improvements to the level of comfort among participants hesitant to be a part of university sponsored research (Schnarch, 2004). Three of the community researchers were also available to assist with participant recruitment in Phase 3 of this project; the strength of their community ties was useful throughout this process as well.

1.5.4 Community Profiles⁵

1.5.4.1 Eskasoni

Eskasoni is a rural Mi'kmaq community located on the eastern shore of the Bras d'Or Lake 40 kilometers south west of Sydney, the nearest urban center. Its population of over 4,000 (Aboriginal Affairs and Northern Development Canada, 2013) makes it the largest Mi'kmaq community in Nova Scotia and it is home to over 2,600 fluent Mi'kmaq speakers (Statistics Canada, 2007a). Eskasoni reserve lands are 36 square kilometres and house substantial community infrastructure including a health centre, school, supermarket, community rink, gas station, cultural centre, the Unama'ki Institute of Natural Resources, and Crane Cove Fishing Company (Eskasoni Mi'kmaq Nation, 2013).

⁵ The population data used in this section refers to registered band membership, not on-reserve population. As such, it is only used here to approximate actual on-reserve populations.

1.5.4.2 Membertou

Membertou is an urban Mi'kmaq community located 3km from the downtown core of Sydney, Nova Scotia. With a population of over 1,300, it is the second largest concentration of Mi'kmaw in Nova Scotia (Aboriginal Affairs and Northern Development Canada, 2013). Although their reserve lands are relatively small geographically at 1.1 square kilometers (Statistics Canada, 2012), Membertou is recognized as an economically thriving community as residents have access to a variety of community services (e.g. health centre, school, convention centre, gas station, and a variety of local businesses) in addition to the amenities offered by neighboring Sydney (Membertou, 2013). While English is the primary language spoken, over 200 residents are fluent in Mi'kmaq according to a Statistics Canada survey (2012).

1.5.4.3 Waycobah

Waycobah is a rurally located Mi'kmaq community on the north shore of the Bras d'Or Lake approximately 100 kilometers west of Sydney and 55 kilometers north east of Port Hawkesbury, the nearest urban centers. The community has reserve lands of 7.4 square kilometers and a population of nearly 1000, which makes it the third largest Mi'kmaq community in Unama'ki (Cape Breton) (Aboriginal Affairs and Northern Development Canada, 2013); over 500 community members speak Mi'kmaq (Statistics Canada, 2007c). Waycobah offers residents amenities such as a health centre, gas station, local school, and supermarket (Waycobah First Nation, n.d.).

1.5.4.4 Wagmatcook

Also rurally located, Wagmatcook is a Mi'kmaq community on the north shore of the Bras d'Or Lake, 90 kilometers west of Sydney and 85 kilometers north east of Port Hawkesbury, the closest urban centers. With a population of over 700, it is the second smallest Mi'kmaq community in Unama'ki (Cape Breton); approximately 315 of its residents are fluent in Mi'kmaq (Aboriginal Affairs and Northern Development Canada, 2013). Wagmatcook has reserve lands of roughly 4 square kilometers (Aboriginal Affairs and Northern Development Canada, 2013) and houses a community health centre, cultural centre, gas station, and local school (Wagmatcook First Nation, n.d.).

1.5.4.5 Potlotek

The rural Mi'kmaq community of Potlotek is located on the southern shore of the Bras d'Or lake approximately 100 kilometers south west of Sydney and 55 kilometers east of Port Hawkesbury, the two closest urban centers. Its population of nearly 700 (Aboriginal Affairs and Northern Development Canada, 2013), approximately 200 of which are fluent in Mi'kmaq (Statistics Canada, 2007), makes it the smallest Mi'kmaq community in Unama'ki (Cape Breton). Potlotek reserve lands are 5.6 square kilometers (Statistics Canada, 2007b) and offer residents access to a local school, community health centre, and restaurant/gas station (Potlotek First Nation, 2012).

1.5.5 Phase 1 and 2: Support Needs and Intervention Preferences

1.5.5.1 Phase 1 and 2: Recruitment and Participant Characteristics

Seventeen Mi'kmaq families (17 parents/caregivers and 21 asthmatic youths) were recruited from the five communities⁶ for Phase 1 and 2 using a combination of purposive and snowball sampling techniques; six additional families were contacted but declined to participate due to busy schedules. In most cases, a participating family consisted of one parent/caregiver and one youth. Where a parent/caregiver was responsible for more than one asthmatic youth, a family was defined as one parent/caregiver and two (or more) youths. Purposive sampling is a technique researchers use to sample a specific population of interest when they are interested in discovering, understanding, or gaining insight into particular phenomena of which these individuals have knowledge (Mirriam, 2009). In snowball sampling, researchers begin by collecting data on participants with specific characteristics they can identify and then seek guidance from those same individuals on how to access others who share the same traits; this is a particularly useful approach for identifying members of a population that are difficult to locate (Babbie, 2011). The combination of these two sampling approaches proved ideal as the research team was

⁶ Originally the research team had planned to recruit five families from each community. In the event that this number could not be achieved in any given community, we would look to Eskasoni, having the largest population, to fill the remaining spots. While it was our intention to recruit 25 families, due to withdrawals, the breakdown of participating families by community is as follows: five from Eskasoni, four from Membertou, three from Waycobah, three from Potlotek, and two from Wagmatcook.

interested in recruiting participants with a shared set of specific characteristics who were not always easily identifiable; participant inclusion criteria included: 1) self-reported Mi'kmaq heritage, 2) parent/caregiver-reported asthma or spirometry (lung function test) diagnosis of asthma and the use of any asthma medication in the last year, 3) age 8 to 12 years for asthmatic youth, and 4) the ability to understand, speak and read English.

Our team of community researchers, who were responsible for participant recruitment, utilized a variety of recruitment tools. To assist with identifying prospective participants, the CAC provided each community researcher with a list of asthmatic youth living in their respective community who frequented the health centre along with their parent/caregiver's contact information. Supplementing these lists, the team also relied on their own knowledge and experience as community members to identify additional families affected by asthma. To ensure our project gained community-wide exposure and did not overlook those families that rarely visit the community health centre or remain unknown to the community researchers, recruitment posters were placed in high visibility areas throughout the communities (i.e. community health centres, community news bulletins) and run as a full page advertisement in an issue of each community's newsletter at the request of the CAC (see Appendix B: Recruitment Poster).

Once identified, community researchers contacted prospective participants (parents/caregivers) in person or over the phone using a recruitment script (see Appendix C: Phase 1 and 2 Recruitment Script). At that point, if a prospective participant expressed interested in taking part in the project, an in-person meeting was set up with the parent/caregiver and youth to go over the study information sheet, which gave an in-depth explanation of the project with emphasis on Phase 1 and 2, and provide an opportunity for questions to be answered (see Appendix D: Parent/Caregiver Information Sheet); a separate information sheet that used age appropriate language was given to each youth (see Appendix E: Youth Information Sheet). After the meeting, if *both* the parent/caregiver and youth(s) wished to participate in the study, a date was set to conduct the individual interviews and participants were informed of the logistics pertaining to the

two-day asthma camp; oftentimes, at the request of participants, the interviews occurred immediately after this meeting rather than at a later date.

1.5.5.2 Phase 1: Semi-Structured Interviews (May-June, 2011)

Both the parent/caregiver and youth interview guides were developed using a template designed by the national research team and tailored to the Nova Scotia site through the inclusion of input from a pilot test with the local CAC. Once feedback from the CAC was included, the interview guides were again pilot tested, this time with a non-Indigenous parent/caregiver and youth to gauge the appropriateness of the language; final revisions were then made based on this exercise (see Appendix F: Parent/Caregiver Interview Guide; and Appendix G: Youth Interview Guide).

Each youth and their parent/caregiver took part in individual semi-structured interviews aimed at exposing their asthma support needs and intervention preferences. Youth interviews were often conducted with a parent/caregiver present depending on participant preferences. Semi-structured interviews utilize a set of pre-determined open-ended questions to explore phenomena of interest but also to permit the flexibility to probe interviewee responses, resulting in a more in-depth data set (Schensul & LeCompte, 1999). After participants were provided with an information sheet and had the opportunity to ask questions about the study to the community researchers, and prior to each interview, participants were provided with a consent form through which written consent (or assent for youth) was obtained for Phase 1 and 2 data collection procedures (see Appendix H: Parent/Caregiver Informed Consent Package; and Appendix I: Youth Informed Assent Package). Participants were also reminded that their involvement in the study was completely voluntary and that they had the right to withdraw and have their data removed from the project at any time up until the start of the Phase 2 asthma camp. While none of the participants withdrew from the study, if they had wished to withdraw during or after the camp, their Phase 1 individual interview data would have been removed, however due to the use of data collection activities at the camp that did not allow for individual contributions to be identified (as a result of their reliance on group

dialogue and participant observation), their participation in Phase 2 would remain part of the project.

Community researchers conducted all interviews in the homes of participants; their questions explored issues surrounding existing community asthma support, asthma education, and asthma intervention preferences. Parent/caregiver interviews lasted approximately one hour while youth interviews were significantly shorter in duration (15-20 minutes); all interviews were digitally recorded using an audio recorder and transcribed using a word processor to ensure their accuracy.

1.5.5.3 Phase 2: Asthma Camp Intervention (July, 2011)

In Phase 2, the 17 participating families attended a two-day asthma camp held in July 2011 at the Gaelic College in St Ann's, Cape Breton, which provided both the space to facilitate daily activities, as well as food and accommodation for all participants, members of the research team, and those assisting with the camp⁷. To ensure widespread uptake, participants did not bear a financial cost to attend the camp, rather the research grant assumed all associated costs, including transportation to and from each community (either by providing vehicle mileage or pick-up/drop-off services). As a token of our appreciation for participating in this research, all parents/caregivers were given a \$50 honorarium and all youth were provided with a gift bag consisting of age-appropriate toys and healthy snacks (\$50 value) at the conclusion of the camp.

At the camp, participants took part in Aboriginal ceremonies (smudging, prayer); cultural activities (drum-making, drumming, singing, dancing); entertainment (games, art about living with asthma, asthma relay races, movie night); social support (informal networking opportunities); and education (asthma awareness training, guest speakers⁸ with asthma support expertise in asthma education, and outreach)⁹ (see Appendix J: Asthma Camp Agenda). In addition, one focus group and one sharing circle were held with the

⁷ The CAC determined that this would be an ideal, central location to hold the camp.

⁸ Invited guest speakers included a representative from the Nova Scotia Lung Association, a chest nurse, a pediatric allergist/immunologist, and an asthma/allergy nurse.

⁹ The camp agenda was largely informed by the asthma support and intervention preferences identified by participants during Phase 1.

parents/caregivers to further explore their asthma support needs and intervention preferences. The focus group solely explored parent/caregivers' intervention preferences while the sharing circle focused both on parent/caregivers' asthma support needs and their intervention preferences. Sharing circles are distinct from focus groups in that equality among everyone involved in the circle is emphasized; they involve formal turn-taking, sacred meaning, sharing of the whole individual rather than just knowledge-sharing, non-judgmental, helpful, and supportive discourse, respectful listening, and ceremony (e.g. smudge, talking stick) (Lavalley, 2009).

The focus group and sharing circle, held on the first and second day of the asthma camp respectively, were approximately one hour each in length and facilitated by community researchers who used an interview guide containing open-ended questions (see Appendix K: Parent/Caregiver Focus Group Guide; and Appendix L: Parent/Caregiver Sharing Circle Guide). Both interview guides were developed by the Nova Scotia research team and incorporated feedback from a pilot testing exercise with the CAC. Although informed consent had already been obtained for this round of data collection prior to the Phase 1 interviews, participants were once again reminded of the voluntary nature of this project and their right to withdraw at any time. The sharing circle and focus group were digitally recorded and transcribed to ensure their accuracy. The research team consisting of Dr. Castleden, myself, and the six community researchers also engaged in participant observation, recorded field notes, and held two debriefing sessions during the gathering (one at the end of the first day and one at the end of the second day); debriefing allowed the preliminary findings to be triangulated across the research team, improving our confidence in the findings (Farmer, Robinson, Elliott, & Eyles, 2006; Baxter & Eyles, 1997).

A sharing circle and focus group exercise were also attempted with participating youth, however these methods were unsuccessful as a result of the youths' discomfort sharing personal experiences in a large group setting. In response to this and consistent with the flexible nature of CBPR, the research team invited the youth to instead create drawings of their experiences with asthma and then in individual and small group conversations,

explain their drawings without the use of a recorder, which was also a source of discomfort for the youth. As a result, participant observation and field notes comprise much of the youth specific data set for Phase 2.

1.5.6 Phase 3: Implications of Earlier Findings and Dissemination

In Phase 3, I sought to understand the implications of Phase 1 and 2 findings for asthma programs, policies, and practices specific to Mi'kmaq communities and determine appropriate dissemination strategies. Outlined below are the research activities for this phase.

1.5.6.1 Phase 3: Recruitment and Participant Characteristics

Twenty-two participants consisting of 18 community health care professionals (i.e. nurses, doctors, and community health representatives) and four school staff members (i.e. teachers, coaches, and principals) were recruited from the five communities to participate in focus groups. Participants were recruited using a combination of purposive and snowball sampling techniques based on their involvement with the design or implementation of Mi'kmaq health programs, policies, or practices. In addition to the 22 individuals comprising the participant pool for this phase, three additional health professionals, four school staff members, and four members of Chiefs and Councils were recruited, however these individuals either declined to participate or were absent on the day of data collection. Three community researchers and two members of the CAC led the recruitment for this phase with the aid of a recruitment script (see Appendix M: Phase 3 Recruitment Script). The recruitment team first approached community health centre staff to recruit participants given their role in community health. From there, local school personnel were also contacted as our findings showed that these individuals play an important role in school-based health programs, policies, and practices. Lastly, as recognized leaders in Mi'kmaq communities, members of Chiefs and Councils were invited to participate (although none were present at the focus groups). After receiving a verbal explanation of the research and their potential role in the study, if an individual agreed to participate, they were provided with a date, time, and place to meet for the focus group; all participants were reminded of this information the day before the focus

group took place. The recruitment team largely relied on their pre-established rapport with community members when contacting prospective participants.

1.5.6.2 Phase 3: Focus Groups (July- September, 2012)

Five focus groups (see Table 1.1: Phase 3 Participant Characteristics) were held with community health care professionals (i.e. nurses, doctors, and community health representatives) and school personnel (i.e. teachers, coaches, and principals) between July and September 2012 to explore the implications of Phase 1 and 2 findings for programs, policies and practices specific to asthma in Mi'kmaq communities in addition to identifying appropriate audiences and vehicles for dissemination. Each focus group was held in one of the five community health centres during a lunch hour to accommodate the work schedules of participants; as a token of appreciation for taking part in the study, lunch was provided; I facilitated each focus group. Before the focus group began, I greeted each participant at the door and provided them with a study information sheet and consent form through which informed consent was obtained (see Appendix N: Phase 3 Information Sheet; and Appendix O: Phase 3 Consent Form). I then asked them to read a 15 page, 1000 word booklet¹⁰ created for the general public in Mi'kmaq communities, with which they were provided; the booklet contained a summary of the study purpose and Phase 1 and 2 findings, all of which were interspersed with photographs taken at the Phase 2 asthma camp (see Appendix P: Asthma Booklet). Afterwards, I gave a brief (5 minute) oral presentation of the booklet's contents to ensure that there was a common understanding of the main findings across the group. I then facilitated each focus group using an interview guide containing open-ended questions that addressed issues surrounding new information offered by the study to date, the utility of the findings for the planning and design of Mi'kmaq specific asthma-programs, recommendations for improved community asthma support, and appropriate dissemination strategies (see Appendix Q: Focus Group Interview Guide). The focus groups lasted approximately one hour each and were digitally recorded and transcribed verbatim to ensure accuracy. In addition, I recorded field notes and utilized participant observation to capture

¹⁰ During a meeting between Dr. Castleden and the Health Directors, a diabetes booklet (Patterson et al., n.d.) was circulated. Everyone thought it was a great resource and that it had transferability to our asthma study. From there we began developing the contents for an asthma booklet.

conversations I engaged in while the digital recorder was turned off (with participants' permission).

Table 1.1: Phase 3 Participant Characteristics

Membertou Focus Group (July 25, 2012)			
<i>Occupation</i>	<i>Mi'kmaq/Non-Mi'kmaq</i>	<i>Gender</i>	<i>Number</i>
Health Professional	Non-Mi'kmaq	Female	1
Health Professional	Mi'kmaq	Female	2
Health Para Professional	Mi'kmaq	Female	1
Health Professional in Training	Mi'kmaq	Female	1
Total Number of Participants			5
Waycobah Focus Group (August 16, 2012)			
<i>Occupation</i>	<i>Mi'kmaq/Non-Mi'kmaq</i>	<i>Gender</i>	<i>Number</i>
Health Professional	Non-Mi'kmaq	Female	1
Health Professional	Mi'kmaq	Female	3
School Professional	Non-Mi'kmaq	Female	1
Total Number of Participants			5
Potlotek Focus Group (August 22, 2012)			
<i>Occupation</i>	<i>Mi'kmaq/Non-Mi'kmaq</i>	<i>Gender</i>	<i>Number</i>
Health Professional	Non-Mi'kmaq	Male	1
Health Professional	Non-Mi'kmaq	Female	1
Health Professional	Mi'kmaq	Female	1
Total Number of Participants			3
Eskasoni Focus Group (September 7, 2012)			
<i>Occupation</i>	<i>Mi'kmaq/Non-Mi'kmaq</i>	<i>Gender</i>	<i>Number</i>
Health Professional	Non-Mi'kmaq	Male	1
Health Professional	Mi'kmaq	Female	2
School Professional	Non-Mi'kmaq	Male	1
School Professional	Mi'kmaq	Female	2
Total Number of Participants			6
Wagmatcook Focus Group (September 26, 2012)			
<i>Occupation</i>	<i>Mi'kmaq/Non-Mi'kmaq</i>	<i>Gender</i>	<i>Number</i>
Community Health Professional	Non-Mi'kmaq	Female	2
Community Health Professional	Non-Mi'kmaq	Male	1
Total Number of Participants			3

1.5.7 Confidentiality and Anonymity of Data

All interview, focus group, and sharing circle data were audio-recorded, transferred onto a password-protected computer, and transcribed verbatim. The transcripts and tapes were only accessible by the research team members and are now stored in a research office in the School for Resource and Environmental Studies at Dalhousie University in steel cabinets under lock and key. All data stored on computers is password-protected. Data

will be kept on site in the secure location described above for 5 years and then destroyed according to Dalhousie policy.

Participant anonymity was not a goal in this study; participants were known to the research team and to each other in Phase 1 and 2 (for parents/caregivers and youth) and Phase 3 (for professionals in the communities). However, to ensure confidentiality, all identifying data were stored separate from the tapes and demographic data. Identities of participants have been kept confidential by allocating codes to each person's data. This allowed the research team to remove the names of participants as soon as the demographic information of each participant was linked to their transcript. Members of the research team conducted all transcriptions. When using quotations in publications and reports, names were not used, rather a broad description of the participant was provided instead (e.g. community health nurse, Mi'kmaq parent/caregiver) as per our informed consent protocol.

1.5.8 Analytical Procedures

All data obtained from Phase 1 (semi-structured interviews) and Phase 2 (intervention - participant observation, field notes, sharing circle, and focus group) underwent an inductive thematic analysis to identify the support needs and intervention preferences of Mi'kmaq families affected by asthma. A thematic analysis was also conducted on all Phase 3 data (focus groups) to identify the implications of Phase 1 and 2 findings for asthma programs, policies, and practices in a Mi'kmaq context. In this section, a detailed audit trail of the analytical procedures utilized is provided to increase the transferability and reliability of the study findings (Baxter & Eyles, 1997). Broadly speaking, I followed Braun and Clarke's (2006) six step guide to conducting a thematic analysis which includes data familiarization, generating initial codes, searching for themes, reviewing themes, defining themes, and thematic analysis.

Thematic analysis is a process designed for categorizing coded qualitative data; specifically, it facilitates the identification and organization of emergent themes from an existing qualitative data set (Boyatzis, 1998; Strauss & Corbin, 1990). The categories

must be inclusive (i.e. reflecting a range of content in data); useful (i.e. meaningfully connected to data); mutually exclusive (i.e. separate and independent); and clear and specific (Marshall et al., 1995). Thematic analysis can be used in isolation or in conjunction with other qualitative methodologies (Boyatzis, 1998; Strauss & Corbin, 1990). Applicable to a wide variety of information types, thematic analysis allows researchers to systematically interpret and understand phenomena of interest while respecting diverse epistemological views. For the purposes of this study, it is also important that the use of thematic analysis in recent decolonizing literature has demonstrated its effectiveness in honoring Aboriginal ways of knowing (Bartlett et al., 2004).

I began to familiarize myself with the data as soon as the community researchers started sending me transcriptions and audio recordings of the Phase 1 semi-structured interviews. Given that I did not personally conduct or transcribe those interviews, it was essential that I listen to the audio recording of each interview twice and read each transcript multiple times to fully immerse myself in the data, which is the basis for effective analysis (Braun & Clarke, 2006). During this phase, I made notes, highlighting my initial observations and possible codes and themes which served as a preliminary analysis that I included in biweekly reports to the Nova Scotia lead researcher, Dr. Castleden, while I was living in Unama'ki (Cape Breton), Nova Scotia; we also held regular debriefing sessions via Skype which served as an additional layer of analysis and data immersion. While I had not yet received all interview data, these preliminary finding reports also informed the agenda of the Phase 2 asthma camp and ensured that it was community-driven and relevant to the participants who had generously volunteered their time for Phase 1 (and 2).

It was not until after the asthma camp that I received the remainder of Phase 1 data along with the entire Phase 2 data set. Again, since I did not collect or transcribe this data myself, I needed to familiarize myself with it before I could engage in in-depth analysis. I proceeded with this process using the methods described above, but instead of submitting biweekly reports and participating in online debriefing sessions with Dr. Castleden, I

prepared a preliminary summary of Phase 1 and 2 data and debriefed in-person with Dr. Castleden on four separate occasions.

In Phase 3, having personally conducted all five focus groups, and having transcribed the digital recordings, I was already familiar with and immersed in this data set. Similar to Phase 1 and 2, I recorded my initial impressions regarding potential themes and codes; however, in this case, I did so immediately after facilitating each focus group while the information was fresh in my mind. After completing all five focus groups, I prepared a summary report of the preliminary findings and discussed these in detail with Dr. Castleden. Prior to conducting a more thorough analysis, I re-read all transcripts and listened to the audio recordings of each focus group to ensure I had a good grasp of the subject matter.

After familiarizing myself with the data, I began the process of coding pieces of text that were pertinent to the research objectives. During this phase I was primarily looking for latent codes however in several instances, manifest codes were also included. Latent codes, which are subject to interpretation, represent the underlying meaning of a data selection and lend themselves to being examined within the larger body of research and study objectives, whereas manifest codes are generally defined based on their descriptive qualities (Richards, 2005). All coding was done by hand using a highlighter colouring system and transcript printouts. Once an extensive list of codes was generated, I sorted each into a potential theme. These possible themes underwent two distinct stages of refinement; first at the code level and second at the theme level. At the coding level, I reviewed each theme to ensure that its contained codes formed a coherent pattern. In cases where this did not hold true, I reworked those codes into other themes or simply deleted them. Once each code fit well into its overarching theme, I then moved on to the theme level of refinement where I examined the validity of each individual theme within the data set along with the how well the entire set of themes represented the data set; in several instances it was necessary to combine themes to achieve an accurate representation of the data. To achieve theme validity, I ensured that each theme was substantiated by the data set. To ensure I had an exhaustive set of themes, I searched the

data set to confirm that new ones did not continue to emerge. After finalizing a set of themes, I then compared them to existing literature and the study objectives; the most compelling quotations were chosen for inclusion in each manuscript.

1.5.9 Data Triangulation

To increase the transferability and reliability of the findings, a concerted effort was made to triangulate all data (Farmer, Robinson, Elliott, & Eyles, 2006; Baxter & Eyles, 1997). In Phase 1 and 2, this process involved three steps. First, two debriefing sessions were held during the two-day asthma gathering with myself, all six community researchers, and Dr. Castleden to discuss individual interpretations of the data collected. Second, Dr. Castleden and I met regularly to discuss the findings at each stage of their development. Lastly, a copy of the preliminary findings was given to the CAC for review and comment. In Phase 3, the triangulation process was less extensive but still involved Dr. Castleden and I engaging in a lengthy discussion about the findings, which spawned several iterations of theme definition. Before any findings were publically disseminated, they were confirmed with the Health Directors for accuracy.

1.5.10 Ethical Considerations

There were a number of ethical considerations that arose throughout this study related to the cross-cultural and personal nature of the research activities. Given the lasting colonial research legacy with Aboriginal peoples, it was imperative that the project proceed in a culturally appropriate fashion and fully engaged the participating Mi'kmaq communities as equal partners in this process. To achieve this, guidance was regularly sought from the five Health Directors and appointed CAC who were able to guarantee that Dr. Castleden and I respected and followed community codes of conduct throughout all stages of the research. In addition to receiving ethical approval by the Dalhousie Health Sciences Research Ethics Board (see Appendix R: Dalhousie Ethical Approval Forms), approval was also granted by Mi'kmaq Ethics Watch (see Appendix S: Mi'kmaq Ethics Watch Approval Forms).

The personal nature of the data collected presented an additional ethical consideration. To ensure that participants were comfortable sharing their asthma experiences with the

research team, local community researchers with community rapport facilitated the individual interviews, sharing circle, and focus group. Individual interviews were conducted in the homes of all participants, which provided a safe space to share potentially emotional experiences; this was especially important for participating youth. At the two-day asthma camp, a number of outlets were available to participants should they have needed medical or emotional support; these included community elders, community researchers, asthma specialists, and university researchers. While all participant data is kept confidential, as discussed above, participants were permitted to withdraw their comments at any point during the study up until the start of the Phase 2 asthma camp, after which only Phase 1 data could be removed. Given that the Phase 3 focus groups relied on group dialogue which does not allow for individual contributions to be identified, participants in this phase were unable to have their comments removed from the study. No participant withdrew from the study in any phase.

1.6 FORMAT OF THIS THESIS

This thesis is presented in a manuscript-based format. As such, Chapters Two and Three are comprised of stand-alone papers that have been published (Chapter Two) or will be submitted for peer-review publication (Chapter Three). Both chapters include a problem introduction, background of relevant literature, detailed account of the findings, and discussion/conclusions. While Chapter Two focuses on the asthma support needs and intervention preferences identified by participating Mi'kmaq families and Chapter Three centres on the implications of these needs for programs, policies, practices, and dissemination strategies, both chapters make an important contribution to the thesis objectives despite their unique focus. Given that Chapters Two and Three are stand-alone papers presented after a comprehensive literature review and methodology included in Chapter One, there will be some repetition throughout these sections. Chapter Four ties this thesis together as a focused program of research through an overview of the research activities as they relate to the objectives, key findings and contributions, study strengths and limitations, and directions for future research.

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CHAPTER TWO

IDENTIFYING GAPS IN ASTHMA EDUCATION, HEALTH PROMOTION, AND SOCIAL SUPPORT FOR MI'KMAQ FAMILIES IN UNAMA'KI (CAPE BRETON), NOVA SCOTIA, CANADA

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2.1 STATEMENT OF STUDENT CONTRIBUTION

R. Watson coordinated the primary data collection, conducted analysis, and wrote all sections of this manuscript. H. Castleden provided supervisory oversight of the data collection, assisted with the analysis, and actively contributed to the writing process. The Tui'kn Partnership represented the CAC and reviewed this manuscript for accuracy. J. Masuda, M. King, and M. Stewart are members of the national research team and made an intellectual contribution through editorial feedback and suggested revisions.

2.2 ABSTRACT

Asthma is the second most common chronic condition affecting Aboriginal youth in Canada; approximately 13% of this population ages 12 and under are asthmatic. Yet,

research investigating the psychosocial challenges is limited. This study examines support resources, support-seeking strategies, support and education needs, and intervention preferences of asthmatic Aboriginal youth and their parents/caregivers in an effort to enact community-level health promoting behaviours. A community-based participatory research design was employed to conduct interviews with 21 youths (ages 8-12) and 17 parents/caregivers from five Mi'kmaq communities in Unama'ki (Cape Breton) Nova Scotia, Canada. Participants were recruited using a combination of purposive and snowball sampling techniques. Following interviews that explored existing and desired social, educational, and health support in their communities, a two-day Asthma Camp was held to engage participants in asthma education, social support networking, and cultural activities. At the camp, data were collected through participant observation, sharing circles, focus groups, and youth drawings of their experiences living with asthma. A thematic analysis revealed four key findings: asthma triggers included household mould, indoor smoking, pets, seasonal change, strenuous exercise, extreme cold, and humidity; social and educational support is lacking despite a strong desire for these services; cultural, linguistic and geographic barriers to accessing support exist; and family members are primary support resources. Improved support and educational resources are needed to foster effective Mi'kmaq asthma support networks. Regardless of the support strategies identified, future asthma interventions for marginalized populations must be culturally-meaningful and linguistically-accessible to those utilizing and providing asthma support.

2.3 INTRODUCTION

The health of Aboriginal peoples (First Nations, Inuit, and Métis), who comprise approximately 4% of the Canadian population, is poorer than that of non-Aboriginal Canadians by virtually all population-based measures of health and disease (Adelson, 2005). Existing health inequalities facing Aboriginal peoples can be linked to social determinants of health at multiple scales: proximal (e.g. poverty, overcrowded housing, smoking, household mold); intermediate (e.g. health care systems, education systems, economic development, language), and distal (e.g. colonization, racism, social exclusion, confinement to “Indian reserves,” mandatory attendance at Indian residential schools run

by missionaries and colonial government agents) (Reading & Wien, 2009). New chronic conditions that have begun affecting Aboriginal peoples, especially type 2 diabetes, obesity, and cardiovascular disease, have received considerable attention from health researchers and policy makers (Frohlich et al., 2006). Although disparities in rates of these conditions and others (e.g. suicide, HIV/AIDS, substance abuse) are well documented in the literature, albeit largely limited to the on-reserve population (Wilson & Cardwell, 2012), little research addresses asthma despite its prevalence (Asthma Society of Canada, 2009). Approximately 13% of Aboriginal youth in Canada aged 12 years and under have asthma (First Nations Regional Health Survey, 2011). Just 60% of those asthma-affected youth receive treatment (FNRLHS, 2005); however, hospitalization rates for asthma among Aboriginal children have increased by 200% since the 1980s compared with a 50% increase among non-Aboriginal children (Assembly of First Nations, 2007; Liu et al., 2000).

The lasting effects of colonization that are known to affect asthma are easily evident in observations of the underlying conditions on Aboriginal reserves (Warry, 2009). Aboriginal peoples are more likely to live in overcrowded or substandard housing where respiratory infections resulting from exposure to dust, mold, and mildew can easily pass between family members (Statistics Canada, 2005). Smoking rates among Aboriginal peoples are nearly 3 times that of the general Canadian population (FNRLHS, 2005; Tait et al., 2007). The use of wood burning stoves (often a financial necessity) and the practice of curing and tanning in living areas are common in Aboriginal communities, further contributing to degraded indoor air quality (Guggisberg et al., 2003). Many Aboriginal peoples live in poverty (Reading & Wien, 2009), creating a financial barrier to asthma treatment and medication (Kozyrskyj et al., 2001). Moreover, Aboriginal children are more likely to live with a single parent/caregiver than Canadian youth in general, putting them at a greater risk of being exposed to a stressful home environment (FNRLHS, 2005; Tait et al., 2007). Maternal stress during the first 7 years of a child's life has been positively associated with an increased risk of asthma diagnosis (Kozyrskyj et al., 2008). An understanding of the social determinants of health among Aboriginal peoples is

necessary to an understanding of the social etiology of asthma in Aboriginal communities (Reading & Wien, 2009).

Although most asthma research is centered on physiologic aspects of the disease, less commonly examined are the psychosocial difficulties persistent among youth who have asthma. In addition to having the physiologic symptoms of asthma, youth with asthma are reported to experience low self-esteem, social isolation, family problems, poor relationships with peers, and worry (Nocon, 1991; Padur et al., 1995). With satisfactory asthma-support programs in place, however, the quality of life for these young people can be greatly improved (McGhan et al., 2006; McGhan et al., 2010; Goffin et al., 2003).

The research reported here is part of the first two phases of a larger 3-phase, multisite national study that seeks to examine the support resources, support-seeking strategies, support and education needs, and intervention preferences of Aboriginal youth with asthma and their parents/caregivers (referring to either biological parent or appointed guardian) to facilitate community-wide health-promoting behaviors. We employed a community-based participatory research (CBPR) design with guidance from regional community advisory committees (CACs) across 3 study sites in Canada (Alberta, Manitoba, and Nova Scotia) (Shiu-Thorton, 2003; Delemos, 2006; Castleden et al., 2008). To ensure that local considerations were prioritized from the inception of the research, each study site employed independent methods for project design, data collection, intervention design, and data analysis to tailor their studies to the common objectives. The focus of methods, results, and discussion in this article are limited to the data arising from the Nova Scotia site involving Mi'kmaq peoples, Aboriginal descendants of the original inhabitants of this region of Canada.

2.4 METHODS

The lead researcher for the Nova Scotia site (H.C.) spent a year (2010) establishing relationships with 5 Mi'kmaq communities in Unama'ki (Cape Breton), Nova Scotia (see Figure 2.1: Map of Unama'ki (Cape Breton), Nova Scotia, showing location of the 5 participating Mi'kmaq communities) via each community's health director. Once the

research partnership was established, a local CAC was created with representation from each community's cadre of health care professionals to offer guidance to the research team throughout the study. The CAC informed recruitment strategies, refined the research design, pilot-tested the data collection process, commented on preliminary findings, and communicated protocols to the communities. In spring 2011, 6 Mi'kmaq community researchers were hired and trained in participant recruitment and qualitative data collection.

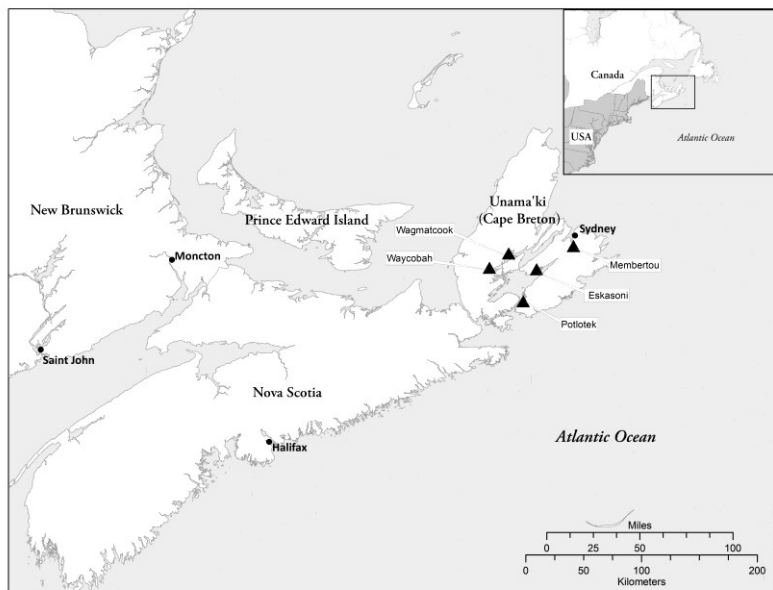


Figure 2.1: Map of Unama'ki (Cape Breton), Nova Scotia, showing location of the 5 participating Mi'kmaq communities

During May and June 2011, we recruited 17 Mi'kmaq families (17 parents/caregivers and 21 youths) from the 5 communities by using a combination of purposive and snowball sampling techniques. Generally, a participating family consisted of 1 youth and 1 parent/caregiver. In instances in which a parent/caregiver was responsible for more than 1 youth with asthma, the family was defined as 1 parent/caregiver and 2 (or more) youths. Inclusion criteria for families were 1) self-reported Mi'kmaq heritage, 2) parent/caregiver-reported asthma or spirometry (lung function test) diagnosis of asthma and the use of any asthma medication in the last year, 3) age 8 to 12 years for youths with asthma, and 4) ability to understand and read English. Although all participants spoke English, we learned that many used Mi'kmaq in the home and in daily activities. Half of

the community researchers were fluent or functionally conversant in both languages and, often spontaneously, conducted portions of their data collection activities in Mi'kmaq. All data were translated and transcribed in English.

In Phase 1, the youth and their parents/caregivers individually participated in semi structured interviews with the intent of identifying their asthma-related support needs and intervention preferences. The interviews with parents/caregivers lasted approximately 1 hour each and were conducted by community researchers using an interview guide. Interviews with youth were much briefer because they did not elaborate on their responses. Open-ended questions addressed issues specific to existing community asthma support, asthma education, and asthma intervention preferences.

In Phase 2, all participants were invited to a 2-day asthma camp held in July 2011. The camp agenda included Aboriginal ceremonies (smudging, prayer); cultural activities (drum-making, drumming, singing, dancing); entertainment (games, art, relay races, movie night); social support (informal networking opportunities); and education (asthma awareness training, guest speakers with expertise in asthma support, education, and outreach). We also held 1 sharing circle and 1 focus group (Lavallee, 2009) during the camp with the 17 parents/caregivers to help identify their asthma support intervention preferences. Distinct from focus groups, sharing circles emphasize equality among everyone involved in the circle. Sharing circles involve formal turn-taking versus spontaneous dialogue of a focus group; sacred meaning for many Aboriginal peoples in terms of spiritual and emotional growth; more sharing of the whole individual rather than just knowledge-sharing; nonjudgmental, helpful, and supportive discourse; respectful listening among participants; and, often, ceremony (e.g. smudge, talking stick) (Lavallee, 2009). Both the focus group and sharing circle lasted approximately 1 hour each and were facilitated by community researchers who used an interview guide. Open-ended questions were used throughout these sessions. The sharing circle focused on both existing asthma support needs and intervention preferences of participants, while the focus group centered solely on intervention preferences. The interviews, sharing circle, and focus group were digitally recorded and transcribed to ensure accuracy. In addition to the participant data

collected, the research team engaged in participant observation, recorded field notes, and held 2 debriefing sessions during the gathering, all of which were taken into consideration and applied to our analysis.

The research team tried out a sharing circle and focus group activity with participating youth, similar to those used with parents/caregivers; however, these methods proved ineffective because the youth were uncomfortable with sharing personal experiences in a group. The flexible nature of CBPR use in the field enabled the research team to replace large group interactions with opportunities for the youth to make drawings of what it was like to have asthma. Then, in informal, individual, and small-group conversations, the youth talked about what they had drawn without interviewers using recording devices, which were also a source of discomfort for youth. As a result, the research team relied heavily on participant observation and field notes to document youth experiences with asthma.

All data obtained from the Phase 1 pre-camp interviews and Phase 2 participant observations, sharing circle, and focus group underwent a thematic analysis (Aronson, 1994) to identify diverse factors influencing challenges facing Aboriginal youth with asthma and their families. This analysis offered suggestions for how youth with asthma and their parents/caregivers can cope with the challenges.

Ethical approval for this study was obtained from the Dalhousie University Health Sciences Research Ethics Board and the Mi'kmaq Ethics Watch, an Aboriginal community-based ethics review board. Participating parents/caregivers gave informed consent for their own and their child's involvement in the study. In addition, youth participants assented to taking part in the research activities.

2.5 RESULTS

Four themes related to existing asthma support and future intervention preferences for Mi'kmaq families affected by asthma emerged from the data: 1) triggers and prevention strategies, 2) current asthma supports and services, 3) types of support-seeking strategies,

and 4) desires for future support and education interventions and programs. The presence of these themes throughout the data was triangulated across the research team and CAC, increasing our confidence in the findings (Farmer et al., 2006).

2.5.1 Triggers and Prevention Strategies

Virtually all parents/caregivers were aware of asthma triggers specific to their children and had developed strategies for avoiding them. Triggers were household mold, smoking, pets, season change, strenuous exercise, and extreme cold or humidity. Most parents/caregivers indicated that they had had mold in their homes. Parents/caregivers made extensive efforts to provide mold-free environments for their family. For example, one parent/caregiver said: “We got this house . . . because [my son has] asthma . . . our last house we lived in had mold in the basement and it was causing him to get really sick.” Several parents/caregivers also reported that smoking occurred throughout their communities either inside the home or in the car. Although smoking tended to be limited to certain rooms or floors of the residence, second-hand smoke still triggered attacks. Contact with household pets was also identified as an asthma trigger for some youth. In these cases, parents/caregivers usually made an effort to remove the pet from the home in an attempt to more effectively manage their child’s asthma.

Virtually all parents/caregivers developed strategies for avoiding triggers that they knew would influence the severity of their child’s asthma.

You have to do things differently in the house. You have to use certain products. Some products you find after a while are triggers, and one of the big things was floor wax. . . . You have to keep fresh air circulating in the house. But it is the opposite in the summer; when the [gravel] road is graded and the road is dusty, you have to keep the doors and windows closed. So you just always have to be aware of the triggers and of the air quality. [parent/caregiver]

Although some parents/caregivers used strategies that were developed on the basis of trial and error representing years of asthma management, others worked closely with their doctors to minimize the occurrence of asthma attacks.

[My daughter's] asthma is induced by exercise. During her games she takes her inhalers when she gets sick. But we have learned this year to take the inhaler half an hour before the game and then play. This reduced her chance of getting an attack. That's what the doctor told us to do. [parent/caregiver]

Parents/caregivers rely on lived experience and medical advice in formulating prevention strategies against asthma attacks. Although Mi'kmaq youth were often able to identify asthma triggers specific to their own condition, their awareness did not necessarily lead to avoidance. Despite recognizing strenuous exercise as a likely asthma trigger, 1 youth recalls, "I was at school and did the Terry Fox run and took an asthma attack. I forgot that I didn't have my inhaler and was in the office for a half hour, waiting." None of the youth were able to identify specific prevention strategies aside from acknowledging their reliance on inhalers. They also relied on their parent/caregiver(s) to both supply and administer inhalers appropriately during an asthma attack.

2.5.2 Current Asthma Supports and Services

Participating parents/caregivers reported a lack of community-level asthma support resources. When asked if they were aware of any asthma support resources or services in or outside their community, none were identified. As one parent/caregiver explained, "Right now there is nothing. I never even heard of anything outside the community." Geographic distance from services available in urban centers was cited as a major barrier to accessing support. Many parents/caregivers shared their frustration with having to travel well outside of their reserve community to connect with specialized asthma support personnel.

Although Mi'kmaq youth did not specifically comment on the accessibility of asthma support resources and services in their community, several parents/caregivers indicated

that language barriers were contributing to existing asthma support gaps: “My kids are fluent in [our Aboriginal language] . . . and my youngest one, he is more comfortable speaking [our language] than English, so a lot of the times there’s that barrier of understanding” [parent/caregiver]. Parents/caregivers indicated that although health promotion materials were available for other chronic illnesses, very few of these were available in the Mi’kmaq language.

Due to the absence of a regular family physician in the participating Mi’kmaq communities, many parents/caregivers reported challenges associated with seeing multiple doctors to assist them in the management of their child’s condition. Participant observation at the two-day asthma camp revealed that while all doctors are capable of effectively treating asthma, each does so using a slightly different strategy. This can create confusion for parents/caregivers who are offered advice from multiple physicians resulting in a barrier to effective asthma management.

2.5.3 Types of Support-seeking Strategies

Generally, parents/caregivers rely on family members to provide them with the support they need to manage the demands of raising a child with asthma. Often these family members have direct experience raising their own child with asthma.

When [my children] are having an attack, it is really hard watching them suffering. Talking helps me cope. I have a really good support network with my sisters and my mother, family, and friends . . . you just don’t feel so alone and my sisters, 2 of them have kids with asthma, so it helps talking to them because they know what you’re going through. [parent/caregiver]

Parents/caregivers rely to a lesser extent on health professionals than family for asthma support resources. However, parents/caregivers said such support usually involved writing prescriptions and giving basic instructions on administering medication rather than psychosocial support.

Participating youth also relied heavily on family, particularly mothers, as their primary asthma support. Teachers and peers also represent a support resource when children are absent from parental care. One youth explained, “. . . my parents and sometimes my teachers. If my teachers aren’t around then my friends.” However, not all youth indicated support beyond their immediate family, suggesting that many felt the same sense of social isolation reported in the literature (Nocon, 1991; Padur et al., 1995).

2.5.4 Desire for Future Support and Education Interventions

Many parents/caregivers identified the need for increased information and educational resources. Parents/caregivers felt they did not have enough information to manage their child’s asthma effectively.

My biggest wish is . . . if every health centre in [our region] would take 1 person and really seriously train them on this topic. So then they could pass on the information to the parents. Because a lot of the parents don’t have the proper information or they are not sure how to give the medication. That’s all I wish for.
[parent/caregiver]

Although doctors are acknowledged as asthma support providers, many parents/caregivers feel they would benefit from additional education. One parent/caregiver describes this scenario: “The doctor, like all she ever did was give him inhalers. That’s it. No information. I really don’t know anything about asthma right now.” Not only did parents/caregivers want asthma education for themselves and their children; they also wanted the community to be better informed. Parents/caregivers considered community education and provision of resources that promote community-wide understanding of asthma a priority. One parent/caregiver described a situation where her daughter was involved in an after-school activity with another family: “When she came back, she was coughing, and her clothes smelled like smoke because the person who drove them was smoking in the car with them.”

In addition to increased education, parents/caregivers also expressed a strong desire for support groups in their community. One parents/caregiver explained, “We need support groups . . . I really don’t have anybody else to go [to] other than my doctor.”

Virtually all parents/caregivers commented on the value of the asthma camp as a way of connecting with peers, specifically other Mi’kmaq parents/caregivers dealing with asthma-related issues. They also suggested that future community-based health interventions and health-promoting resources be provided in the Mi’kmaq language.

Although participating youth were reluctant to identify any support or education needs, in several cases parents/caregivers voiced concerns about a lack of asthma-friendly school policies: “[My daughter’s old school] didn’t want her to take [her inhaler]. They thought that she would get addicted to it. [Teachers don’t] like your child to take it when they need it, only when they [italics added] feel that the child should take it.”

Parents/caregivers suggested that culturally relevant, school-based, asthma support is needed for youth with asthma to effectively manage their condition; school teachers, counselors, administrators, and teaching assistants needed asthma-awareness training.

2.6 DISCUSSION AND CONCLUSIONS

The lack of culturally relevant and linguistically accessible asthma support resources is problematic for the Mi’kmaq youth and parents/caregivers involved in this study.

Adequate support resources can improve the quality of life for asthma-affected youth; conversely, the absence of these supports can lead to ineffective asthma management, resulting in harmful health consequences (Nocon, 1991; Padur et al., 1995; McGhan et al., 2006). Our study results suggest there is a need and desire among Mi’kmaq families in this region for a community-level asthma-support intervention. For future intervention strategies to be effective, however, the issue of accessibility must be addressed. Because these Mi’kmaq communities are geographically removed from each other (ranging from 15 to 80 miles apart), it is imperative that future interventions be implemented within each community. Providing culturally relevant and linguistically accessible resources will

also honor Mi'kmaq traditions, values, and language (Smylie, 2001; McKeough et al., 2008).

Given that many Aboriginal communities embrace a philosophy of a community-raised child (Bennett et al., 2005) in which family members, teachers, and peers are all looked upon to provide support for youth with asthma and their parents/caregivers, it is paramount that entire communities and government agencies support asthma management strategies (e.g., reducing traffic-related dust on gravel roads, eliminating mold from housing, relieving overcrowding in housing). Improving asthma education at both the family and community level would result in more effective asthma management for Mi'kmaq youth with asthma. Knowledge holders such as health professionals must be made aware of the lack of asthma-related information available to community members and must be willing to provide it through a medium that is culturally relevant, accessible, and designed for a broad audience. The results of this study indicate the need for expanded awareness of asthma: what triggers asthma attacks, strategies for avoiding attacks, methods of administering asthma medicine, and an overall improved understanding of the condition. In addition, greater consistency between school policy and asthma management needs is required.

Parents/caregivers expressed strong interest in establishing support groups. Communities fostering socially supportive environments are healthier than their socially unsupportive counterparts (Berkman et al., 2000). Asthma support groups or support networks are a viable, culturally appropriate way to supplement asthma education strategies. Regular in-community gatherings of asthma-affected families would provide parents/caregivers and youth with a safe space to talk about asthma, share information, voice concerns, and ask questions in an effort to aid each other in their own asthma management. In our case, the multigenerational asthma camp was an effective strategy for connecting Mi'kmaq families with their peers in the region.

Although our study provides insight into the asthma support needs and preferences of on-reserve Mi'kmaq youth with asthma and their parents/caregivers in 5 Mi'kmaq

communities in Unama'ki (Cape Breton) Nova Scotia, its geographic and cultural applicability beyond these communities is limited. Nevertheless, the study reveals a lack of asthma support resources in these communities. Improved support and educational resources are needed to foster effective asthma support networks that include both people closely involved with youth with asthma and members of the larger community. Although the general public faces many of the same challenges reported here in terms of asthma support and education (Nocon, 1991; Padur et al., 1995; McGhan et al., 2006), the social determinants of Aboriginal peoples' health exacerbate existing health inequalities for this group. Asthma support and education specific to Aboriginal peoples are required for effective management of this disease (Reading & Wien, 2009). Future asthma support interventions involving Aboriginal peoples or other marginalized populations must overcome geographic barriers, be culturally relevant, and be linguistically accessible both to those using asthma support and to those providing it.

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CHAPTER THREE

IDENTIFYING OPPORTUNITIES AND CHALLENGES FOR IMPLEMENTING ASTHMA PREVENTION AND MANAGEMENT INITIATIVES IN MI'KMAQ COMMUNITIES IN UNAMA'KI (CAPE BRETON), NOVA SCOTIA, CANADA

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3.1 STATEMENT OF STUDENT CONTRIBUTION

R. Watson conducted the primary data collection, led the analysis, and wrote all sections of this manuscript. H. Castleden provided supervisory oversight of the data collection, assisted with the analysis, and actively contributed to the writing process. The Tui'kn Partnership represented the CAC and reviewed this manuscript for accuracy. J. Masuda, M. King, and M. Stewart are members of the national research team and made an intellectual contribution through editorial feedback and suggested revisions.

3.2 ABSTRACT

Asthma affects approximately 13% of Aboriginal youth (aged 12 and under) in Canada making it the second most common (only to allergies) chronic disease suffered by this demographic; asthma support strategies specific to Aboriginal peoples have only begun to

be identified. This research builds upon our earlier assessment phase of a recent study focused on identifying the support needs and support intervention preferences of asthmatic Aboriginal youth and parents/caregivers. Here, we seek to identify the implications of our initial findings for asthma programs, policies, and practices in an Aboriginal context and determine appropriate dissemination strategies. We employed a community-based participatory research design to conduct five focus groups with 22 community health professionals and school personnel in five Mi'kmaq communities in Unama'ki (Cape Breton) Nova Scotia, Canada. Participants were recruited using a combination of purposive and snowball sampling techniques. Each focus group explored issues surrounding new information offered by the study to date, the utility of the findings for the planning and design of Mi'kmaq specific asthma-programs, recommendations for improved community asthma support, and appropriate dissemination strategies. Thematic analysis revealed three key areas of opportunity and challenges for implementing asthma prevention and management initiatives in Mi'kmaq communities: 1) a lack of professional awareness about the extent of asthma and asthma-related issues and needs, 2) school-based opportunities and challenges, and 3) health centre-based opportunities and challenges. Asthma support initiatives within local schools, across the community health centres, and through culturally appropriate asthma camps are feasible and effective community-driven ways of improving asthma support in Mi'kmaq communities; ongoing support is needed from those responsible for allocating community funds and through partnership with other health service organizations.

3.3 INTRODUCTION

It is widely recognized that there are gross disparities in the health status of Canada's Aboriginal¹¹ population in comparison to that of Canadians generally (Adelson, 2005). Social determinants of health at the proximal (e.g. poverty, smoking), intermediate (e.g. health care systems, education systems, language) and distal (e.g. colonization, racism) levels have both obvious and subtle links to existing Aboriginal health inequities (Reading & Wien, 2009). Since the time of first contact with European settlers,

¹¹ The term "Aboriginal" is used in the Canadian Constitution to refer to First Nations (formerly Indians), Inuit (formerly Eskimo), and Métis (formerly half-breeds) (Waldram et al., 2006).

Aboriginal peoples have endured colonial agendas and the subsequent attempts to destroy cultural ways of being and knowing (Kubik et al., 2009). Efforts to assimilate Aboriginal peoples into mainstream society (e.g. dispossession of traditional Aboriginal lands, the relocation of Aboriginal communities to ‘Indian reserves’, and the implementation of mandatory residential schooling for Aboriginal children) contributed to cultural loss and had deleterious effects on individual and communal health (Royal Commission on Aboriginal Peoples, 1996; Waldram et al., 2006; Czyzewski, 2011). Moreover, racism towards Aboriginal peoples, evident through their marginalization within the colonial social, political, and economic system, has created barriers to accessing recognized determinants of health such as adequate housing, income, education, and health care (Reading & Wien, 2009; Tang & Browne, 2008; Awofeso, 2011).

While the state of Aboriginal health is extensively documented in the literature (Wilson & Cardwell, 2012), there is little research addressing asthma among Aboriginal populations (notable exceptions include Watson et al., 2012; Goa et al., 2008; Sin et al., 2004; Stewart et al., in press). Yet asthma affects approximately 13% of Aboriginal youth (aged 12 and under) in Canada (First Nations Regional Health Survey, 2011), making it the second, only to allergies, most common chronic disease suffered by this demographic, (First Nations Regional Longitudinal Health Survey, 2011). These statistics indicate asthma is slightly less prevalent (by 1%) and management has, to a small extent, improved over the course of a five-year time span (First Nations Regional Longitudinal Health Survey, 2005); at the same time, however, nearly 20% of affected Aboriginal youth report having an asthma attack in the past year and 40% remain untreated, highlighting the ongoing seriousness of this condition (First Nations Regional Health Survey, 2011). The incidence and severity of asthma and asthma symptoms can be linked to the inadequate living conditions (e.g. overcrowded housing, exposure to mold) (Warry, 2009), degraded indoor air quality (from tobacco smoke (Statistics Canada, 2005), cultural practices, and the use of wood burning stoves (Guggisberg et al, 2003), lack of financial resources (Reading & Wien, 2009), and stressful home environments (Kozyrskyj et al., 2008) that pervade many Aboriginal communities.

Research involving Aboriginal peoples has a history of being undertaken without sufficient regard to the health and well-being of community members (Ball & Janyst, 2008; Brant Castellano, 2004). Community-based participatory research (CBPR) has been proposed as a way of including Aboriginal peoples' perspectives in research (Delemos, 2006; Castleden et al., 2008). As a result, we undertook a CBPR design in partnership with local community advisory committees (CAC) at each of three Canadian sites: Alberta, Manitoba, and Nova Scotia (see Figure 3.1: Study Site Locations). Each site then tailored methodological approaches that aligned with meeting the study's common objectives but also ensured that local community needs were given priority throughout the entire research process. The research reported on in the methods, results, and discussion sections of this article is specific to the Nova Scotia site involving five partnering Mi'kmaq (Aboriginal) communities. During the first two phases of this project, we identified the support resources, support-seeking strategies, support and education needs, and intervention preferences of asthmatic Mi'kmaq youth and their parents/caregivers (Watson et al., 2012). Specifically, we found that there was a lack of community level asthma support available to Mi'kmaq families affected by asthma despite a strong desire for these services. From there, we were interested in identifying the implications of those findings for programs, policies, and practices specific to Mi'kmaq peoples in

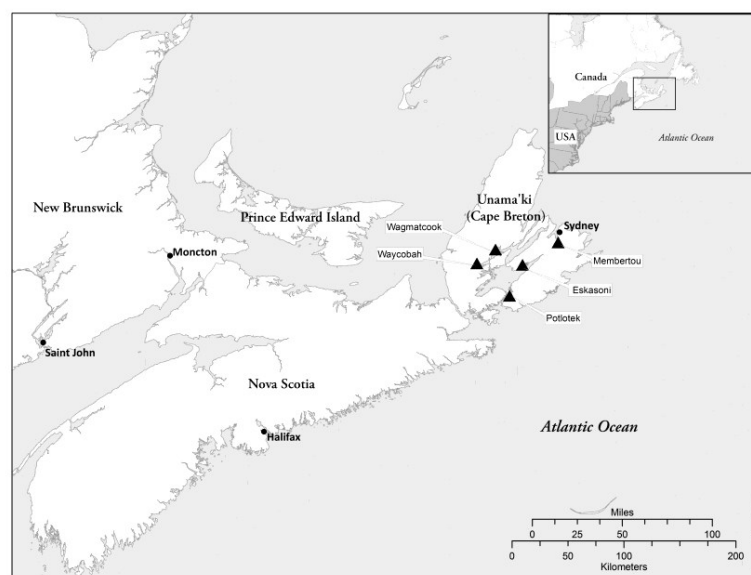


Figure 3.1: Study Site Locations

addition to determining appropriate audiences and vehicles for dissemination. Thus, the purpose of this paper is to share final phase (Phase 3) findings from the Nova Scotia site of a three-site study that elicited perspectives of Aboriginal families affected by asthma and community professionals who influence policies and programs.

3.4 STUDY BACKGROUND

This study involved three phases. While the research reported on in this paper is specific to Phase 3, Phase 1 and 2 are summarized in this section for contextual purposes. Since 2010, we have held a research partnership with five Mi'kmaq communities in Unama'ki (Cape Breton), Nova Scotia. The local CAC representing each of the five communities was comprised of Health Directors and/or their delegates (e.g. Community Health Nurses or Community Health Representatives); they offered guidance on recruitment strategies, research design, data collection, analysis, and community protocols. In spring 2011, 21 Mi'kmaq youth with asthma and 17 family caregivers were recruited and interviewed by Mi'kmaq community researchers to identify their asthma support resources, support-seeking strategies, support and education needs, and intervention preferences (Phase 1). Afterwards, each youth and their parent/caregiver participated in a two-day asthma camp where, in addition to being provided with opportunities to engage in cultural and educational activities related to asthma, we further explore their asthma support needs and intervention preferences through culturally appropriate methodologies (i.e. sharing circle, focus group, participant employed art) (Phase 2).

Data from the interviews and asthma camp were thematically analyzed (Aronson, 1994) with four key themes emerging; 1) Mi'kmaq families exhibited an awareness of asthma triggers and had developed avoidance strategies derived from personal experience and guidance from their doctor; 2) there is virtually no professional asthma support available in the participating Mi'kmaq communities; 3) other family members were most commonly looked upon for asthma support by both asthmatic youth and their parents/caregivers followed less frequently by teachers and peers (for youth) and health professional service providers (for parents/caregivers); and 4) there is strong desire

among Mi'kmaq families for accessible, culturally appropriate asthma support services at the community-level.

The absence of accessible asthma support implies that participating families are at an increased risk of ineffective asthma management and susceptible to the negative health outcomes that often follow (i.e. preventable asthma attacks) (McGhan et al., 2006). Our results show that Mi'kmaq youth consider teachers and peers to be asthma support providers, yet a number report relying exclusively on immediate family, suggesting that many of these youth face the psychosocial difficulties (e.g. low self-esteem, social isolation, poor relationships with peers, and worry) that can be associated with asthma (Nocon, 1991; Padur et al., 1995). While it is clear that improved asthma support is needed for Mi'kmaq families to effectively manage this condition, guidelines for implementing asthma-support programs in an Aboriginal context are virtually non-existent (for an exception, see Asthma Society of Canada, 2012¹²). This is particularly concerning given the fact that many Aboriginal peoples have health support needs that are unique to their diverse cultural and epistemological perspectives (Brown & Varcoe, 2006). Health intervention guidelines for other chronic conditions specific to Aboriginal peoples stress the need for programs that are culturally appropriate, community relevant, and driven by members of the community (Rowley et al., 2000; Health Canada, 2011). While the first two phases of our study identify a need for a community-driven asthma intervention, it was paramount that we turn to community members involved with the design and implementation of health policy and education to ensure that our results contribute to culturally meaningful and community relevant asthma initiatives; our methodological approach proceeded with this in mind.

3.5 METHODS

Between July and September 2012, 22 health care professionals (i.e. nurses, doctors, and community health representatives) and school board personnel (i.e. teachers, coaches, and

¹² The Asthma Society of Canada (2012) successfully piloted an asthma support module in seven Aboriginal communities that included community engagement, educational outreach, and culturally relevant toolkit development; the module was shown to improve respiratory health awareness and support in most communities.

principals) from the five Mi'kmaq communities were recruited by three Mi'kmaq community researchers and two members of the CAC using a combination of purposive and snowball sampling techniques. Participants were recruited based on their involvement in the design or implementation of Mi'kmaq community health programs, policy, or practices. Each of the health care professionals and school board personnel participated in one of five focus groups (3-6 participants per focus group) held in their respective community health centers. Participants were provided with a one-page information sheet and gave their free and informed consent to participate in the activities described below. Both the Dalhousie University Health Sciences Research Ethics Board and Mi'kmaq Ethics Watch, an Aboriginal ethical review board, granted approval for this study to proceed.

Immediately prior to each focus group, participants were greeted and given approximately 15 minutes to read a 15 page, 1000-word booklet created for Mi'kmaq residents in the five communities; the booklet contained a summary of the study purpose and Phase 1 and 2 findings, all of which were interspersed with photographs taken at the Phase 2 asthma camp. Afterwards, a team member delivered a brief oral account (5 minutes) of the booklet's contents to ensure widespread understanding among the group. All focus groups were facilitated using an interview guide containing open-ended questions that addressed issues surrounding new information offered by the study to date, the utility of the findings for the planning and design of Mi'kmaq specific asthma-programs, recommendations for improved community asthma support, and appropriate dissemination strategies. Each focus group lasted approximately one hour and was digitally recorded and transcribed. Supplementary field notes and participant observation were also included in the data set to capture conversations that occurred while the audio recorder was turned off (with participants' permission).

A thematic analysis was performed on qualitative data emerging from focus group transcripts, field notes, and participant observation to identify the implications of Phase 1 and 2 findings for asthma programs, policies, and practices in a Mi'kmaq context, in addition to determining appropriate dissemination strategies.

3.6 RESULTS

Data analysis revealed three key areas of opportunity and challenges for implementing asthma prevention and management initiatives in Mi'kmaq communities: 1) a lack of professional awareness about the extent of asthma and asthma-related issues and needs, 2) school-based opportunities and challenges, and 3) health centre-based opportunities and challenges. Each of these themes are elaborated on below.

3.6.1 Lack of Professional Awareness about Extent of Asthma and Asthma-related Issues and Needs

Participants indicated that the Phase 1 and 2 findings offer a range of new information for health programs and policy related to asthma. For example, as policy influencers and program planners working in Mi'kmaq communities, many participants did not think it was appropriate to treat asthma as a community health priority. Despite it being identified as one of two top chronic illnesses amongst Aboriginal youth, “Asthma is not one of the more prevalent problems that I have found. There are other problems and situations that seem to be more at the forefront with the population in this community” [nurse practitioner]. Although participants had regular interaction with community youth, rarely did they encounter individuals openly acknowledging their asthma diagnosis, giving the false impression about the severity of the situation.

In the 23 years I have been working at the school, I have seen very few kids with asthma that I am aware of. If [the students] don't tell us [about their condition], we don't really know ... [this study] brings awareness that there may be some significant cases of asthma in our schools that we currently don't know about.
[physical education teacher]

Many participants reported that while they were aware of the challenges associated with being asthmatic, they had not considered that local Mi'kmaq families managing the condition would require additional support and education beyond the basic health services offered by the health center. That there is a strong demand for health initiatives specific to

asthma came as a surprising finding not well known among health center or school board staff.

The part of the study I find most useful is that [Mi'kmaq families] say they have no supports... This is interesting since we could... talk about [asthma] with the schools, I mean we just don't think of that. I usually think of a support group as Alcoholics Anonymous or something like that. [community health director]

The presence of policies in several schools that are incompatible for asthma-sufferers (i.e. no prescription drugs allowed in schools or in the possession of students) was also identified as valuable, new information.

I see the study providing baseline information for moving forward with developing policy [within the school board], especially when people see that teachers are not letting the children have puffers [at school or in their possession] ... the school system needs an eye opener into the disease itself and how it affects the children ... I see the study being influential in supporting this process. [nurse practitioner]

Participants indicated that raising awareness to the fact that the school policy banning prescription drugs (either in student possession or on school premises) is having negative implications for the health of asthmatic youth, will provide policy makers with relevant information capable of initiating positive change in local schools.

In order to apply the Phase 1 and 2 study findings, participants identified several key audiences for dissemination. Specifically, those with power to initiate change at the policy level and access to financial resources were reported to be ideal recipients of future knowledge translation strategies; chief and council, school administrators, funding agencies, and health directors were recognized in this capacity. Distributing lay summaries of the findings to select individuals, engaging with social media (i.e. Facebook), and establishing a community newsletter presence were reported to be

potential vehicles for reaching pertinent audiences. Several participants also suggested conducting additional research to determine asthma statistics specific to each community to augment the findings of our study (and the First Nations Regional Health Survey) and give them more clout at the policy and funding levels.

3.6.2 School-Based Opportunities and Challenges

Community health professionals and school staff identified a number of opportunities for improving asthma support through local schools. Implementing school-based educational initiatives that utilize, for example, “lunch and learn” events, guest speakers, and regular asthma seminars were reported to be ideal ways to provide improved asthma support amongst Mi’kmaq youth.

What would be most beneficial is to have [some kind of intervention] set up in the schools. [The school staff] is the front line with the kids who are spending the majority of their time with these people. If we can educate [school personnel] on what they can do to create a safer environment [for asthmatic youth], that would be most beneficial. [licensed practical nurse]

Participating health care professionals, in particular, recognized the importance of school-based asthma education for improving not only the management of physiologic aspects of the condition, but the psychosocial barriers some asthmatic youth encounter as well.

A lot of times these [asthmatic children] are being limited in the types of school activities they are allowed to participate in ... [With improved teacher education], activities can be modified to accommodate the child’s specific needs so they can still participate. When they don’t get to participate, it’s social isolation. They become introverted. We want to encourage [asthmatic children] to grow and be successful members of the community but it is probably really difficult because they are socially isolated from their friends and limited in the activities they can take part in. [licensed practical nurse]

Given that our Phase 1 and 2 findings indicate that Mi'kmaq youth living with asthma rely on peer support in addition to parental support, which is consistent with asthma support strategies for youth in general (see, for example, Stewart et al., 2011a; Stewart et al., 2011b), participants in this phase noted that in addition to educating school staff, the entire student body population was identified as an important audience for asthma education. Classroom asthma education was also thought to promote asthma awareness among the wider community: "Once the teachers are educated, they can pass that information along to the kids who can take it home [and share it with their family members]" [physical education teacher].

At the same time, participating physical education teachers reported challenges with identifying asthmatic students due to the high volume of student medical files they have to review each semester. Although one physical education teacher explained that it was difficult to keep up with every student's medical profile, "between myself and [the other gym teacher] we teach 400 kids and by the time we get around to reading everyone's file, it's too late"¹³. Reluctance of youth to disclose their asthma exacerbates this challenge.

Now that you are speaking about your son, I had him [in my class] this morning and I always get the kids to write down any medical issues they have. Your son did not say he had asthma. You surprised me when you said he [was asthmatic]. [physical education teacher in response to a comment from a community health nurse]

Participants, on the whole, agreed that youth with mild to moderate symptoms are often hesitant to openly identify as asthmatic presenting a barrier for those in positions to offer asthma support.

¹³ The physical education teachers indicated that much of the information in students' files pertained to mental health disorders and learning disabilities rather than chronic physical diseases; this suggests a potential area for improving and streamlining reporting mechanisms.

3.6.3 Health Centre-Based Opportunities and Challenges

Participants identified three health centre-based opportunities and challenges for improving community asthma support. First, health professionals and school personnel agreed that the health interventions (i.e. support groups, asthma seminars, monthly asthma education nights) recommended by Mi'kmaq families in phase 1 and 2 offer potential solutions to existing community asthma support deficiencies. While feasible, one barrier to such initiatives is linked to Aboriginal people's limited participation in face-to-face support group sessions specific to other chronic conditions. A community health nurse explains, "It's just difficult to get people to come to [support] groups. [Community members] say they want [support] groups but when you put them on they don't attend". In all five focus groups, ensuring that health initiatives are advertised well in advance and provide transportation, childcare, food, door prizes, personalized invitations, culturally relevant education, and enjoyable activities were identified as key to achieving moderate to strong uptake, however participants cautioned that adhering to these guidelines is no guarantee of success.

Both health professionals and school personnel reported that while various efforts to support chronic disease through the health centre and school have been ineffective in reaching target audiences (e.g. Patterson et al., n.d.), health initiatives spearheaded by local community members have been met with widespread community uptake. For example, in one focus group, participants referred to the success of a local cancer initiative that was brought on by a community member. "[A local community member's] cancer [support session] had more participation than [the health centre] has ever had ... [community members] wanted to support [the work] of a community member rather than [health centre staff]" [community health nurse]. While community health professionals remain willing to operationalize asthma support initiatives on their own, they recognized that an asthma champion emerging from within the community might result in stronger uptake, and they suggested that they could funnel support and resources through that individual where necessary.

Second, before reading about the findings from Phase 1 and 2 in the booklet provided prior to each focus group, participants were largely aware of and commented on the success of the two-day asthma camp in achieving wide community uptake and improving asthma support for those Mi'kmaq families who participated. The implementation of an annual asthma camp was recognized as a viable asthma support opportunity if continued on an ongoing basis. Since this took place, health professionals in all five communities have fielded numerous inquiries from community members regarding the prospect of another camp.

There is interest [in another camp]. All those families who participated last summer asked me if there would be another asthma camp because they want [support]. I told them we'll have to wait and see but there wasn't. It's too bad. [community health nurse]

While participants supported annual asthma camps given the comparatively greater community commitment than traditional chronic disease interventions initiated by the health centre, limited and competing financial priorities within health centre budgets were a preventive factor in terms of operating an annual camp.

Third, within the health centres themselves, opportunities for improved professional asthma support were identified. Health professionals recognized that currently there is very little asthma expertise amongst the staff in the five community health centres. They suggested investing in asthma training for employees to ensure that sufficient resources exist on a community-level thereby reducing the need for families managing the condition to seek asthma expertise outside the community.

We have limited amounts of knowledge on everything and not a lot of knowledge on anything. It would help if we had someone in-house that was your chest expert so they could be your "go to" person for asthma ... [Asthma] education for staff persons would be very relevant. It is something that is doable and we could do it

[in the health centre]. That would be a really good resource for the community and [asthmatic] children. [nurse practitioner]

While the provision of asthma education is an underlying theme throughout this study, several participants indicated that more work needs to be done in order to understand how to effectively communicate with Mi'kmaq peoples around the management of their health. As one (non-Mi'kmaq) doctor explains, "There is a lot in [this study] about education. I can educate, but if I don't know how the other side learns then I will not get my point across". Participants indicated that cultural awareness among non-Mi'kmaq knowledge providers is essential to effectively address existing community-level asthma education gaps.

3.7 DISCUSSION AND CONCLUSIONS

The findings from this study provide new and relevant information for moving forward with the development of asthma programs, policy, and practices in Mi'kmaq communities. Our earlier findings, shared directly with community-based health and education professionals, have brought awareness about asthma as a pressing community issue, one that is in need of attention from community health policy makers and program planners. Participants identified specific opportunities and challenges for addressing the absence of community-level asthma support; increasing the availability of asthma resources through local schools and community health centres will improve the ability of Mi'kmaq families affected by asthma to manage the condition, ultimately minimizing the negative health implications associated with a lack of asthma support (McGhan et al., 2006). Building upon findings that reflect the support needs and intervention preferences of asthmatic Mi'kmaq youth and their parents/caregivers, the study results are ideally positioned to reconcile existing misconceptions regarding the perceived lack of community asthma incidence and promote the implementation of relevant, community-wide asthma initiatives. The remainder of the discussion will address the lack of professional awareness surrounding Mi'kmaq asthma issues in addition to community-based opportunities for asthma support within local schools, among health centre staff, and through a novel, culturally appropriate health intervention.

Due to limited encounters with self-reporting asthmatic children in their professions, many participants were under the impression that there are very few cases of asthma in Mi'kmaq communities and that it is not a pressing community health concern. While statistics show that asthma rates are high among Aboriginal youth, these figures are based solely on physician diagnosis (either symptom based or spirometry based or both); research suggests that the prevalence of asthma is likely greater than reported due to the exclusion of many remote populations from the data set and potential underrepresentation of asthma within many Aboriginal communities lacking access to appropriate health care (i.e. absence of a family physician) (Asthma Society of Canada, 2009). The existing lack of professional asthma awareness identified through this study is consistent with the nature of this chronic condition in Aboriginal communities as it is often under-diagnosed, untreated, and hidden from those outside of immediate support networks (i.e. family) (Asthma Society of Canada, 2009). While determining community-level asthma statistics may promote improved awareness of this condition, given the difficulties associated with identifying asthmatic individuals in Aboriginal communities that are shared in a Mi'kmaq context (i.e. absence of family physician, lack of spirometry testing), doing so may not provide an accurate indicator of community asthma prevalence.

The pressing need for improved asthma policy and practices within local schools is reinforced in these findings. It is essential that school staff create asthma friendly environments where Aboriginal students have immediate access to their medication thereby encouraging youth to take control of their condition, which is an integral part of effective chronic disease management (Holman & Lorig, 2000). Moreover, tailoring certain classroom activities to enhance inclusiveness for Aboriginal children with asthma will limit social isolation experienced by these youth (e.g. modifying the degree of physical exertion necessary to take part in gym class to suit individual thresholds). Providing asthma education for students and school staff will bring improved awareness to the condition and a better understanding of the implications that school policy can have on the health of asthmatic children. In order for school staff to fully engage with asthmatic Mi'kmaq youth in the management of their condition however, asthmatic

students must be easily identifiable; the general reluctance of asthmatic students to disclose their condition poses a significant barrier to achieving this awareness. Research shows that youth often choose not to communicate information pertaining to their chronic disease to avoid stigmatization and being labelled as different from their peers, yet such behaviour may lead to an emergency situation such as a severe asthma attack (Suris et al., 2004). Regardless, improved communication between teachers and students and streamlining the process through which teachers review student medical files would appear to be a necessary component of any school's management plan.

Our findings also reveal a gap in asthma expertise within the five community health centres. Providing professional development in asthma support, education, and intervention for health centre staff will mean that community members seeking advice from an asthma specialist have an accessible community resource at their disposal, reducing existing geographic barriers to obtaining support (see Watson et al., 2012). Similar to other acute and chronic disease scenarios, asthma support should be provided in a way that is culturally meaningful to enhance effectiveness (Aboriginal Health Research Networks Secretariat, 2006; Tui'kn Partnership, n.d.; National Collaborating Centre for Aboriginal Health, 2012).

Given the historical lack of community uptake in traditional chronic disease initiatives (e.g. support groups, seminars, guest speakers etc.) organized by these local community health centres, there is a call for novel, community-relevant support interventions to engage with Mi'kmaq families affected by asthma. Our study demonstrated that an annual asthma camp is an effective way to generate enthusiastic participation from asthmatic Mi'kmaq youth and their parents/caregivers in a health intervention. Participating health professionals and school staff were equally enthusiastic about implementing such a camp to reduce existing barriers to asthma support facing Mi'kmaq families. The challenges to doing so are two-fold: financial drain on health resources in Aboriginal communities

already overwhelmed with significant health burdens¹⁴ and identifying a community champion to improve the likelihood of successful uptake.

While limited in geographic and cultural scope, our study provides new insights into opportunities and challenges for Aboriginal asthma programs, policies, and practices – from Mi’kmaq perspectives. This study revealed that asthma support initiatives within local schools, across the community health centres, and through culturally appropriate asthma camps are feasible and effective community-driven ways of reducing the existing barriers facing Mi’kmaq families affected by asthma. Given the financial commitment required to operationalize the proposed health interventions however, ongoing support is needed from those responsible for allocating community funds and suggests the need to partner with other health service organizations (e.g. the Lung Association of Nova Scotia and the Asthma Society of Canada). Multiple competing health priorities stemming from gross disparities that pervade Aboriginal communities may present a barrier to accessing financial resources; engaging in future knowledge translation strategies (i.e. distributing lay summaries to select individuals, utilizing social media, and establishing a community newsletter presence) that are culturally meaningful, position asthma as a pressing community concern, and reach Chiefs and Councils, school administration, funding agencies, and community health directors is paramount.

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¹⁴ Our two-day asthma camp operated with a budget of approximately \$20,000; \$7,500 for camp organization personnel; \$7,000 for facilities rental, accommodation, and catering; \$500 for transportation (i.e. vehicle rental and mileage); and \$5,000 in in-kind contributions from the Nova Scotia Lung Association and a Nova Scotia-based pediatrician specializing in asthma/allergies (i.e. asthma awareness training, guest speakers, asthma education/outreach).

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CHAPTER FOUR

CONCLUSION

4.1 INTRODUCTION

This chapter synthesizes the many stages of this thesis as a unified program of research. First, an overview of how the research objectives were addressed provides a summary of the study. Second, key recommendations emerging from this work are highlighted. Third, the contributions to theory, methods, and policy are examined. Fourth, an account of the research strengths and limitations assists with a critical interpretation of the results. Fifth, directions are given for future research. Concluding comments round out the end of this chapter.

4.2 ADDRESSING THE RESEARCH OBJECTIVES

4.2.1 Overview of the Research Objectives and Methodology

As stated in the introductory chapter and subsequent manuscripts, asthma is currently the second most common chronic condition among Aboriginal youth in Canada; while recent statistics suggest that the prevalence of asthma may be on a slight decline, 20% of affected Aboriginal youth report having had an asthma attack in the past year and 40% do not receive treatment for their condition (First Nations Regional Health Survey, 2011). To date, research investigating asthma has primarily focused on physiologic aspects of the disease with the psychosocial difficulties facing asthmatic youth (i.e. low self-esteem, social isolation, family problems, poor relationships with peers, worry) (Nocon, 1991; Padur et al., 1995) and their families receiving less attention, especially in Aboriginal contexts. Moreover, while asthma-support programs have the potential to improve the quality of life for young people affected by asthma (McGhan et al., 2006; McGhan et al., 2010; Goffin et al., 2003), support guidelines specific to Aboriginal peoples and created with input from Aboriginal peoples have only begun to emerge in the literature (see, for example, Asthma Society of Canada, 2012).

This study utilized multiple qualitative methods to identify the psychosocial barriers facing Mi'kmaq families affected by asthma and pursue health promoting behaviours at the community-level. Specifically, three objectives related to the overarching research goal were pursued over the course of a three-year period and involving three distinct phases. These objectives are as follows:

Objective One: To identify the support needs and intervention preferences of asthmatic Mi'kmaq youth and their parents/caregivers living on-reserve in Unama'ki (Cape Breton), Nova Scotia.

Objective Two: To design and pilot test a culturally appropriate support-education intervention that meet these needs, in collaboration with Mi'kmaq participants.

Objective Three: To identify the implications of the findings for asthma programs, policies, and practices specific to Mi'kmaq peoples in addition to determining appropriate audiences and vehicles for dissemination.

In Phase 1, community researchers conducted individual, semi-structured interviews with asthmatic Mi'kmaq youth and their parents/caregivers to identify their support needs and intervention preferences (Objective 1). In Phase 2, all participants were invited to a two-day asthma camp to pilot test a culturally appropriate support-education intervention that met their expressed needs (Objective 2). At the camp, parents/caregivers took part in a one sharing circle and one focus group exercise which further explored their asthma support needs and intervention preferences (Objective 1). While participating youth were uncomfortable engaging in the open group dialogue of a sharing circle or focus group, some felt comfortable with drawing pictures to depict what it is like to have asthma and discussed these drawings in individual or small group conversations with a member of the research team. Unfortunately, these drawings by themselves did not provide a source of rich data suitable for in-depth analysis as we had hoped, limiting the research team to the use of participant observation and field notes taken during the individual and small group conversations; these data also contributed to the identification of asthma support needs and intervention preferences (Objective 1). In Phase 3, focus groups were held with Mi'kmaq and non-Indigenous community health care professionals and school staff to

identify the implications of Phase 1 and 2 findings for asthma programs, policy, and practices in Mi'kmaq communities in addition to determining appropriate audiences and vehicles for dissemination (Objective 3).

4.2.2 Main Findings

4.2.2.1 Phase 1 and 2

Four main findings emerged from analysis of Phase 1 and 2 data; 1) Mi'kmaq families are aware of asthma triggers and have developed avoidance strategies based on personal experience and guidance from their doctor; 2) there is a lack of community-level asthma support available to Mi'kmaq families managing the condition; 3) asthmatic youth and their parents/caregivers rely most often on family, and occasionally teachers and peers (for youth), for social networks and receiving assistance with asthma attacks, while doctors and pharmacists represent a resource occasionally utilized (by parents/caregivers) for asthma medication and treatment advice; and 4) a strong demand exists among participating Mi'kmaq families for accessible, culturally appropriate asthma support services at the community-level.

The absence of professional and educational asthma services available to the Mi'kmaq families participating in this study is problematic for their overall health and wellbeing as relevant literature asserts that inadequate asthma support can result in harmful health consequences (Nocon, 1991; Padur et al., 1995; McGhan et al., 2006). Although the philosophy of a community-raised child is commonplace in many Aboriginal communities (Bennett et al., 2005) where family members, teachers, and peers are all recognized as support providers for families affected by chronic disease, in actuality many Mi'kmaq families reported practical challenges stemming from community policies and practices inconsistent with effective asthma management. School policy banning possession of or restricting access to asthma medication, exposure to second hand smoke, traffic-related dust from gravel roads, and household mold were all brought forward as examples of particular concern by participants. Despite the fact that many Mi'kmaq youth and parents/caregivers participating in this study were aware of asthma triggers, knew how to avoid them, and often (but not always) had family support systems in place, our

findings suggest that there is a need and desire for the implementation of community-based asthma support resources. For example, pursuing opportunities for asthma education and awareness training that are accessible to Mi'kmaq families affected by the condition but also and perhaps especially available to the wider community (i.e. Chief and Council, school staff, coaches, community health professionals, and community residents) were identified as key to rectifying existing asthma support deficiencies. Regardless of the support strategies pursued, participants stressed that they must be provided in a way that is culturally relevant in order to maximize community uptake.

4.2.2.2 Phase 3

Three key findings emerged from the Phase 3 data; 1) a lack of professional awareness about the extent of asthma and asthma-related issues and needs; 2) school-based opportunities and challenges for improved asthma support; and 3) health centre-based opportunities and challenges for improved asthma support.

Our findings point to a wealth of new information for considering asthma policies in Mi'kmaq communities. Given that many of the professionals participating in Phase 3 rarely encountered community youth who openly identify themselves as asthmatic, they were largely unaware of the need to treat asthma as a community health priority. This lack of awareness is consistent with the nature of asthma in general, as it is a condition that often remains undiagnosed, untreated, and unnoticed by those outside of the immediate family. While challenges identifying asthmatic youth are not uncommon, the inequitable health care systems pervading Aboriginal communities that result in a lack of accessible asthma services (e.g. spirometry testing) present additional difficulties to asthma identification in an Aboriginal community context (Asthma Society of Canada, 2009). To make use of the new information offered by this study, health professionals and school staff helped to identify potential community driven initiatives for improving asthma support within local schools, among health centre staff, and through an annual asthma camp. While each of these initiatives represent important findings independently, together they comprise valuable recommendations for improving asthma support in Mi'kmaq communities; as such, each will be discussed in detail in the following section.

4.3 RECOMMENDATIONS

To address the existing lack of support available to Mi'kmaq families managing asthma, this study offers three community driven recommendations: improve school-based asthma policy, develop asthma expertise within each community health center, and implement an annual, culturally appropriate asthma camp. For these strategies to be effective however, a financial commitment is necessary from individuals in a position to distribute community funds; obtaining such a commitment may present challenges due to multiple competing community health priorities that stem from existing widespread Aboriginal health disparities in many Mi'kmaq communities. Effective dissemination of the study results to Chief and Council, school administration, funding agencies, and community health directors is required to make these recommendations a community priority; distributing lay summaries of the findings to pertinent individuals, engaging with social media (i.e. Facebook), and establishing a community newsletter presence were reported as potential vehicles for reaching desired audiences.

As a result of school policy that restricts asthmatic youths' access to their medication (either through banning possession of or restricting access to asthma medication) and the harmful health outcomes associated with ineffective asthma management (Nocon, 1991; Padur et al., 1995; McGhan et al., 2006), there is a clear need for local schools to adopt asthma friendly policies. In order for asthmatic youth to take ownership of their condition, an essential component of effective chronic disease management (Holman & Lorig, 2000), they must be permitted to maintain possession of their medication at all times and granted full autonomy to administer it as needed. To create asthma friendly environments within local schools, asthma education for all students and staff is necessary to promote a widespread understanding of the condition and the negative implications that existing policy can have for these youth. Proceeding with basic asthma awareness training for all staff and integrating asthma education into school curriculum will make a significant contribution to community asthma resources. Furthermore, given their role as support providers when asthmatic youth are absent from parental care, teachers must be easily able to identify asthmatic students in order to fully assist them in

the management of their condition. With current identification strategies proving to be largely ineffective as a result of poor communication and an inefficient student medical file review system, strategies to facilitate open communication between teachers and asthmatic youth are necessary.

To improve upon the general lack of asthma expertise within the community health centres and reduce existing geographic barriers to obtaining support for Mi'kmaq families affected by asthma, it is recommended that health centre staff receive basic asthma education and training to ensure that community members seeking advice from an asthma expert have an accessible community resource at their disposal. Moreover, integrating cultural sensitivity training into an asthma education program will ensure that non-Aboriginal health care providers (and other relevant professionals) are aware of the importance of culturally meaningful support for effective community uptake (Health Canada, 2011).

This research provides strong support for implementing an annual asthma camp to reduce existing geographical, cultural, and educational barriers facing Mi'kmaq families affected by this chronic condition. Pilot testing the two-day asthma camp generated widespread uptake from asthmatic Mi'kmaq youth and their parents/caregivers in a health intervention that overcame the historical lack of community participation in traditional chronic disease initiatives spearheaded by community health centre staff (e.g. support groups, seminars, guest speakers etc.). Operationalizing an annual camp has the potential to provide asthmatic Mi'kmaq youth and their parents/caregivers with opportunities for peer networking in addition to an improved and holistic understanding of asthma and associated treatment strategies, both of which are essential components to effective asthma management (McGhan et al., 2006).

4.4 RESEARCH CONTRIBUTIONS

4.4.1 Theoretical Contributions

This thesis contributes to the scholarly literature that approaches health from a social determinants perspective. Augmenting existing asthma research, this study is among only a few to examine asthma as a social construct and one of the first to do so in an Aboriginal context. Our findings show that the social determinants of health at multiple scales have a direct impact on Mi'kmaq families dealing with asthma in terms of their ability to effectively manage the condition. At the proximal scale, frequent exposure to road dust, household mold, and second hand smoke were widely reported environmental factors known to exacerbate asthma symptoms. At the intermediate scale, the lack of comprehensive services offered by local health centres (i.e. the absence of asthma expertise, spirometry testing, and health promoting initiatives) culminates in a health care system where effective asthma support is unavailable to asthmatic Mi'kmaq youth and their parents/caregivers. While participants did not explicitly identify distal determinants related to asthma, given the political, social, and economic conditions of Aboriginal reservations in Canada, these issues were raised during CAC meetings and it is clear that the ongoing effects of colonization underlie existing proximal and intermediate determinants of health in terms of individual and collective abilities to manage asthma in Mi'kmaq communities.

4.4.2 Methodological Contributions

The research design undertaken in this study contributes to the growing body of academic literature recognizing CBPR as an effective and relevant way to engage Aboriginal communities in university-based research. Throughout this project, the application of CBPR principles has been instrumental to the successful completion of this study. Specifically, the inclusion of relationship building, a CAC, and a team of community researchers ensured that the research proceeded in a relevant, culturally appropriate fashion whereby community members played an active role throughout. Moreover, the creative and flexible nature of CBPR allowed the research team to adapt various research activities as the project rolled out to maximize participant engagement while upholding

community protocols; the effectiveness of such an approach was particularly evident throughout the planning and operationalization of the asthma camp, which proved to be a novel, community driven way of examining asthma support in Mi'kmaq communities through a health intervention. Future chronic disease research with Aboriginal families should consider incorporating a health camp into a CBPR agenda.

4.4.3 Policy Contributions

This thesis offers new information for moving forward with health policy specific to asthma in Mi'kmaq communities. Given the absence of asthma resources available to Mi'kmaq families managing this chronic condition, our findings reveal a need for community-level asthma supports and offer recommendations for the design and implementation of relevant, culturally meaningful asthma policy. Specifically this study identified recommendations for improving asthma policy at the school and health centre level; these have been discussed at length in the recommendations section. The contributions of this work are particularly relevant to Mi'kmaq communities as they are driven by Mi'kmaq families affected by asthma and experienced community health professionals and school staff.

4.5 STUDY STRENGTHS

This study exhibits a number of strengths that stem from the utilization of a CBPR design. At the outset of the project, specific methodologies were identified through collaboration with the five community Health Directors and CAC. Consistent with the benefits of CBPR outlined in the literature, collective decision making allowed the participating communities to remain equal partners in the research relationship ensuring the relevancy of this project to the community as a whole (Minkler & Wallerstein, 2003; Ball & Janyst, 2008). Assistance from the CAC also contributed to the avoidance of potential pitfalls caused by cultural differences and lack of my familiarity with the communities themselves; the CAC represented a community voice and ensured that local concerns related to the study were heard and respected, resulting in successful project outcomes and ensuring that historical research errors were not perpetuated.

The data collection processes and analytical procedures undertaken in this study also contribute to the project strengths. Utilizing multiple qualitative data collection methods (i.e. individual interviews, sharing circles, focus groups, participant employed art, and participant observation) in a variety of settings ultimately increased the quality of the data set. Moreover, triangulation across the research team of all themes emerging from a thematic analysis and oversight from the CAC improved the credibility of our results (Farmer et al., 2006; Baxter & Eyles, 1997).

4.6 LIMITATIONS

Although this thesis makes a number of important theoretical and substantive contributions, there are three important limitations that must be considered when interpreting this research. This section addresses the transferability of this study, the difficulty eliciting youth responses, and researcher bias. Efforts to alleviate the effect of these limitations are also discussed.

Given that the geographic and cultural scope of this research is constrained to five Mi'kmaq communities in Unama'ki (Cape Breton) Nova Scotia, the transferability of the findings is somewhat limited. In addition, the participant pool is relatively small, reducing the applicability of the conclusions on a broader scale. To address the issue of scope as it relates to transferability, this research has been positioned in relevant Aboriginal health literature, which has helped to contextualize the findings of this research as being relevant outside the specific geographic and cultural context of Unama'ki (Cape Breton), Nova Scotia. Our conclusions and recommendations may be particularly pertinent to Mi'kmaq communities across the Mi'kmaq Nation (i.e. Nova Scotia, Prince Edward Island, New Brunswick, and Newfoundland) looking to improve available support for asthmatic youth and their parents/caregivers. Given the fact that many Aboriginal communities in Canada share similar characteristics with respect to the physical and social conditions that are known to affect asthma and asthma symptoms, this study also has national relevance. It is important, however not to make sweeping generalizations when interpreting the results as one must recognize that individual communities have unique needs meaning that these conclusions and recommendations will not be applicable everywhere. With respect to a

relatively small participant pool, research undertaking a qualitative approach is primarily interested in the examination of rich, in-depth data as opposed to obtaining a high volume of quantitative responses suitable for statistical analysis. Moreover, during my analysis, new themes did not continue to emerge from the qualitative data set; data saturation in qualitative research is indicative of a sufficient data set (Baxter & Eyles, 1997).

Throughout the first two phases of this study, many of the methods (i.e. interviews, focus group, sharing circle) used to gather youth specific data did not produce the desired result of eliciting detailed responses. While not true in all cases, participating youth were generally reluctant to elaborate during individual interviews and uncomfortable partaking in group exercises such as sharing circles and focus groups even though they were being facilitated by community members. In an attempt to minimize the effect this limitation would have on the analysis, the research team experimented with an arts-based approach where the youth drew their perceptions of asthma and discussed them in individual and small group conversations without a digital recorder, which was an additional source of discomfort for the youth. While the use of art more effectively engaged these youth in the data collection process, the drawings did not lend themselves to an in-depth analysis. As such, this research relies heavily on participant observation, field notes, and some of the more detailed individual interviews for addressing the support needs and intervention preferences of asthmatic Mi'kmaq youth.

A further limitation of this study is the possibility of researcher bias during the data interpretation. As a non-Indigenous researcher with preconceived hypotheses surrounding this research, it is unlikely that I remained completely removed and objective throughout the data analysis process, nor is that the goal in qualitative research. While the effect on the outputs of this study is believed to be minimal, it is important to recognize this potential bias when moving forward with knowledge translation strategies. To minimize the potential for bias to compromise the findings, triangulation between multiple members of the research team and CAC was undertaken to achieve credible results (Baxter & Eyles, 1997).

4.7 DIRECTIONS FOR FUTURE RESEARCH

This study is the first academic exercise to explore the psychosocial challenges facing Mi'kmaq families affected by asthma. Given that the scope of this research was limited to Mi'kmaq communities in Unama'ki (Cape Breton), Nova Scotia, additional research is needed to provide a basis for comparing these findings to the asthma support needs and intervention preferences of Mi'kmaq communities in mainland Nova Scotia and other parts of Atlantic Canada. Identifying the asthma support related consistencies and differences between communities will result in a better understanding of how this chronic condition affects Mi'kmaq peoples in Nova Scotia and will assist in the development of asthma policies and practices at the provincial and community levels. Future research should also seek to move beyond a regional scope to include Aboriginal communities across Canada to augment existing conceptions of asthma in a national Aboriginal context. This thesis solely examined an on-reserve Aboriginal population, however greater attention to asthma among off-reserve or urban Aboriginal groups will also provide a further basis for comparison and direction for aligning policies and protocols.

Given the lack of community uptake in chronic disease initiatives sponsored by the community health centres reported in this study, more research is needed to understand how to engage Mi'kmaq peoples in health interventions. Few studies have explored this issue in Atlantic Canada and those that do are context specific (see, for example, Patterson et al, n.d.). A comprehensive examination of the barriers to attending chronic disease initiatives (for multiple conditions) in Mi'kmaq communities would be an invaluable resource for the development of future support resources.

4.8 CONCLUSION

Asthma is a significant chronic condition facing Aboriginal youth in Canada today, second only to allergies (First Nations Regional Health Survey, 2011). Although inadequate asthma support is associated with a number of harmful health outcomes (Nocon, 1991; Padur et al., 1995; McGhan et al., 2006), many Aboriginal youth do not receive treatment for their condition, which poses a significant health risk to their overall

wellbeing (Asthma Society of Canada, 2009). Despite possessing health support needs unique from the non-Aboriginal population (Brown & Varcoe, 2006), relevant asthma support strategies specific to Aboriginal peoples have only begun to emerge (Asthma Society of Canada, 2012). This thesis has identified the psychosocial barriers facing asthmatic Mi'kmaq youth and their parents/caregivers and it has offered a number of community driven recommendations for proceeding with culturally relevant asthma policy in a Mi'kmaq community context.

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APPENDIX A: COMMUNITY PARTNERSHIP LETTERS



Eskasoni Community Health Centre
PO Box 7745
Eskasoni, NS

December 16, 2010

Dr. Heather Castleden
School for Resource and Environmental Studies
Dalhousie University
6100 University Avenue, Suite 5010
Halifax, Nova Scotia B3H 3J5

Dear Dr. Castleden;

Please be advised that the Eskasoni Health Centre has reviewed the Research project:
"Engaging Aboriginal Families Affected by Asthma in Support-Education Program Development"

The Eskasoni Health Centre has granted support of the following Research project.
Upon completion of the research, Eskasoni requires a presentation and copy of the research report and findings.

Sincerely;

Sharon Rudderham
Health Administrator

Membertou
111 Membertou Street
Membertou, Nova Scotia

August 17, 2010

Dr. Heather Castleden
School for Resource and Environmental Studies
Kenneth C. Rowe Management Building
6100 University Avenue, 5th Floor
Dalhousie University, Halifax, NS B3H 3J5

www.membertou.ca



Membertou

Dear Dr. Castleden,

I am writing to follow up from our previous correspondence and meetings concerning the Youth Asthma Project titled "*Engaging Aboriginal Families Affected by Asthma in Support-Education Program Development*" to confirm that Membertou Wellness Home would like to partner with you on this AllerGen funded project. The research goals of this project are central to Membertou Wellness Home's vision, which is to bring about quality health care services, prevention programs and encourage healthy behaviours. We continue to strive to promote and serve the health care needs of our community members.

In recognition of this important and timely study and in my official capacity as Director of Health, I along with Tanya Poulette, Community Health Nurse and Angela Paul, Health Support Worker/Health Information and Evaluation Co-ordinator will sit on the local Advisory Committee to assist you in undertaking this research. The Advisory Committee will assist with recruiting youth participants and guide the research process and analysis. I am also able to support this research by providing you with meeting space, photocopying and faxing while you are in our territory.

My signature below confirms that Membertou Wellness Home supports the content of the proposed research. As such, I am looking forward to continuing to work with you on research that engages Mi'kmaq people in respectful and relevant ways.

Yours in the Spirit of Healing, I remain,

Sincerely yours,

Director of Health
Membertou Wellness

welcoming the world!



12004 Highway 4, Box 538, Chapel Island, Nova Scotia

November 3, 2010

Dr. Heather Castleden
School for Resource and Environmental Studies
Kenneth C. Rowe Management Building
6100 University Avenue, 5th Floor
Dalhousie University, Halifax, NS B3H 3J5

Dear Dr. Castleden:

I am writing to follow up from our previous correspondence and meetings concerning the Youth Asthma Project titled "***Engaging Aboriginal Families Affected by Asthma in Support-Education Program Development***" to confirm that Potlotek First Nation would like to partner with you on this AllerGen-funded project. The research goals of this project are central to Potlotek's vision for a health community.

In recognition of this important and timely study and in my official capacity as Health Director, I will help you in undertaking this research by assisting with recruiting youth participants (advertising the study at the Health Centre) and receiving regularly updates on the research process and analysis. I am also able to support this research by providing you with meeting space while you are in our territory.

My signature below confirms that Potlotek First Nation supports the content of the proposed research. As such, I am looking forward to continuing to work with you on research that engages Mi'kmaq people in respectful and relevant ways.

Laurie Touesnard
Potlotek Health Director



WAGMATCOOK HEALTH CENTRE

PO BOX 30004
WAGMATCOOK
NOVA SCOTIA
B0E 3N0

July 15, 2010

Dr. Heather Castleden
School for Resource and Environmental Studies
Kenneth C. Rowe Management Building
6100 University Avenue, 5th Floor
Dalhousie University, Halifax, NS B3H 3J5

Dear Dr. Castleden:

I am writing to follow up from our previous correspondence and meetings concerning the Youth Asthma Project titled "*Engaging Aboriginal Families Affected by Asthma in Support-Education Program Development*" to confirm that Wagmatcook First Nation would like to partner with you on this AllerGen-funded project. The research goals of this project are central to Wagmatcook vision.

In recognition of this important and timely study and in my official capacity as Health Manager, I will sit on a local/regional Advisory Committee to help you in undertaking this research (or appoint an appropriate community-based representative in my place). The Advisory Committee will assist with recruiting youth participants and guide the research process and analysis. I am also able to support this research by providing you with meeting space, access to the internet, photocopying, faxing, and phone communications while you are in our territory.

My signature below confirms that Wagmatcook Health Center supports the content of the proposed research. As such, I am looking forward to continuing to work with you on research that engages Mi'kmaq people in respectful and relevant ways.

Wagmatcook Health Manager



WAYCOBAH
FIRST NATION
Theresa Cremo Memorial Health Centre

07,12, 2010

Dr. Heather Castleden

School for Resource and Environmental Studies
Kenneth C. Rowe Management Building
6100 University Avenue, 5th Floor

Dalhousie University, Halifax, NS B3H 3J5

Dear Dr. Castleden:

I am writing to follow up from our previous correspondence and meetings concerning the Youth Asthma Project titled "*Engaging Aboriginal Families Affected by Asthma in Support-Education Program Development*" to confirm that Waycobah First Nation would like to partner with you on this AllerGen-funded project. The research goals of this project are central to Waycobah's vision, which is to provide health, healthy lifestyle opportunities and a holistic approach to wellness for all.

In recognition of this important and timely study and in my official capacity as Health Director, I will sit on a local/regional Advisory Committee to help you in undertaking this research (or appoint an appropriate community-based representative in my place). The Advisory Committee will assist with recruiting youth participants and guide the research process and analysis. I am also able to support this research by providing you with meeting space, access to the internet, photocopying, faxing, and phone communications while you are in our territory.

My signature below confirms that Waycobah First Nation supports the content of the proposed research. As such, I am looking forward to continuing to work with you on research that engages Mi'kmaq people in respectful and relevant ways.

Jennifer MacDonald,

Director of Health and Wellness



APPENDIX B: RECRUITMENT POSTER



Aboriginal Youth with Asthma Research Project

Are you between the ages of 8 and 12?

Do you have asthma?

Do you want to meet other kids in Unama'ki with asthma?

If you said 'yes' to these three questions, come join our research project about helping Aboriginal kids with asthma help each other!

What's it all about?

1. First, a community researcher will talk to you about what it's like to have asthma.
2. Second, a community researcher will talk to one of your parents (or guardian) about your asthma.
3. Then, you and your parent (or guardian) are invited to join 25 other families from the five Unama'ki (Cape Breton Mi'kmaq) communities at a two-day asthma camp at the Gaelic College!

At the asthma camp, you will get to..

- hang out with other kids who have asthma
- make new friends - see old friends
- do some arts and crafts
- play games
- learn more about asthma
- your parent/caregiver will also learn more about your asthma



If you want to join this project or have any questions, just e-mail "insert name of community researcher" at "insert e-mail address"

Or, you can e-mail Rob Watson (research coordinator) at rob.watson@dal.ca



Dr. Heather Castleden at Dalhousie University is leading this study. She can be reached at heather.castleden@dal.ca or [redacted] is study has been approved by the Dalhousie Research Ethics Board and Mi'kmaq Ethics Watch; it is funded by Allergan NCE.



APPENDIX C: PHASE 1 AND 2 RECRUITMENT SCRIPT

Hello,

I am a Research Assistant for an Aboriginal health researcher at Dalhousie University. Her name is Heather Castleden. She is working with (names of Community Advisory Committee members) on a study about Aboriginal families affected by asthma and allergies. (Name of Community Advisory Committee member) suggested that I see if you (and parent/guardian) would be interested in participating in a research study on asthma.

Heather is interested in learning about the kinds of support you and other Aboriginal youth with asthma and allergies would like to have and the things you need. We are also interested in what kind of support your parents/guardians need.

Heather's study is funded by AllerGen and it has received ethical approval from the Dalhousie Health Sciences Research Ethics Board and [appropriate community-based Ethical Review Board].

Would you be interested in receiving more information?

[If yes, provide hard copy of information letter; set up a time to arrange a meeting where consent information can be presented]

[If no: ask if he/she might be able to suggest someone else as a potential participant who fits the participant recruitment criteria]

Thank you.

APPENDIX D: PARENT/CAREGIVER INFORMATION SHEET



Research Project: Engaging Aboriginal Families Affected by Asthma in a Support-Education Program

Project Lead: Dr. Heather Castleden, Dalhousie University

Project Partners: Eskasoni, Membertou, Wagmatcook, Waycobah, Potlotek First Nations

Funding: AllerGen

Purpose of the Research

As a parent/caregiver of a youth with asthma, we invite you to participate in a study about the kinds of supports that are available to Mi'kmaq youth (ages 8 to 12) with asthma and their families. Your participation in this study is completely voluntary. We want to learn about the kinds of support you and other families with asthma-affected Mi'kmaq youth would like to have and the things you need.

This study has three phases. **Phase 1:** we would like to learn about your needs and your family's needs through a short interview. **Phase 2:** we invite you to attend a two-day asthma gathering that we have organized at the Gaelic College in Cape Breton on July 9-10th. **Phase 3:** From what you tell us at the gathering and in the interviews, we will talk with policy makers and program planners in your community to come up with recommendations for helping to support and educate Aboriginal families affected by asthma in your community.

At this point, we are only seeking your consent to participate in Phase 1 and 2: the short interview in your community and the two-day Asthma Gathering on July 9-10 at the Gaelic College.

What will happen?

1. Consent to participate: Both you and your child need to agree that you want to be part of the study. If you choose to be in the study, a community researcher will meet with you and your child to obtain your written consent for participation in the study. The community researcher will explain that taking part in the study involves participating in an interview and two-day Asthma Gathering.

Included in this package is a one-page Asthma Gathering agenda.

2. Interview: Prior to the two-day asthma gathering we will ask you and your child, separately, about who provides you with support and your support needs so that you can deal better with your child's asthma/allergies. We will ask your child similar questions about how s/he gets help to deal with his/her asthma. Each interview will take no more than 45 minutes. A community researcher will ask you these questions and record your answers on paper and/or with a digital recorder.

3. Asthma Gathering: The Asthma Gathering will include various activities (e.g., sharing circles, knowledge-holders' teachings about asthma, relationship-building, arts and crafts, dancing and drumming). We hope that 20-25 youth will attend along with one of their parents/guardians. During the gathering, we will look at how things are going, and will chat with you once in a while, and make notes. There are two goals of the camp: first, to create a fun, learning and relationship-building opportunity for young Aboriginal people who have asthma and their parents/guardians; second, to talk about challenges you and your family face that require support and resources.

4. Sharing Circles: At the Asthma Gathering we will ask adults and youths to participate in sharing circles, separately, to hear more about your experiences of living with asthma (or having a child with asthma) and to find out what we could do together to create meaningful and useful social and educational programs. You will also be asked about what kinds of support you would want in the future to help you deal with your child's asthma/allergies. We also want to know what you and your child thought about the Gathering, how helpful it was in terms of building relationships and getting to know the research team as well as your advice to us on how a cultural gathering like this one could be improved in the future. We will record this sharing circle using a digital audio-visual recorder.

5. Thank you: We want to thank you for participating in the first phase of this study (the interview and the Asthma Gathering). On the final day of the gathering, we will give you with a small gift of appreciation: an Atlantic Superstore gift certificate of \$50.

Who Will Know?

Privacy: The questions that you answer for us in the interview, as well as the brief chats researchers might have with you during the two-day gathering, will be kept private. We will not put your name or your child's name on any files; instead we will use numbers to keep track of your information. The information will be stored in a locked cabinet inside the researcher's office at Dalhousie University for 5 years. Only members of the research team will see the information we collect at the gathering. However, if you or any other participants tell us about abuse or a risk of self-harm then we will need to tell the appropriate agency.

Sharing Results: We will be sharing the things we learn from this study with the research team, the five Health Directors of the Unama'ki First Nations and in academic papers or conference presentations. No names or information that you give us that could identify you or your child will be shared. It is possible that you will be audio/video taped during the gathering and/or you may be quoted in the final paper or presentations, however these activities will only happen with your written permission and no personal information will be attached to quoted material.

Recording interview: We would like to record your interview and the sharing circle, the questions we ask you and your child both prior to and on the final day of the gathering. By recording, it means that the person asking the questions can listen to you and talk to you without having to write everything that you say down. It also means that the person asking the questions can hear the interview again and make sure your words are right. There are no wrong or right answers and if anything comes up that you would not want written down then we can just take it out. You can review your answers, which will be written on paper after the gathering, if you want to. If you decide that you do not want what you said in the interview to be used in the final results the research team will not use the information. A member of the research team will listen to your interview tape and write what was said on paper. All research team members have signed confidentiality agreements. The research team will review information collected in an effort to develop a program to better support your asthma-related needs.

Anonymity: Because this research is being done with youth who are affected by asthma and their families, it may not be possible to keep your participation completely anonymous. However, your name will not be used and a fake name will be used in any quotes from your interviews when we talk about the results of this research in presentations and reports. All information shared during the interviews will be kept confidential and your identity will not be revealed unless you ask this in writing.

It's Your Choice:

It is your choice to be part of this project. You may choose not to answer a question. You may stop being in the study at any time. You may ask questions at any time. If there are issues that are upsetting for you, we will help find a professional for you to talk to.

Risks:

There are minimal risks to being in this study, including a possibility of accidents or asthma attacks due to being away from home at the Gaelic College. These risks are no greater than in your everyday life.

Questions:

If you have more questions please call Heather Castleden, at [REDACTED] or email heather.castleden@dal.ca. If you have any concerns about this project, you may also call the Director of the Dalhousie Office of Research Ethics Administration at [REDACTED]. The Director is not linked to this project.

Thank you for your interest!



APPENDIX E: YOUTH INFORMATION SHEET



Engaging Aboriginal Families Affected by Asthma in a Support-Education Program

Project Lead: Dr. Heather Castleden, Dalhousie University

Project Partners: Eskasoni, Memberton, Wagmatcook, Waycobah, Potlotek First Nations

Funding: AllerGen

This is a research project about asthma.

What is research anyway?

Research is about asking good questions and working together to find answers to those questions.

What's this asthma research all about?

You are invited to a two-day Asthma Camp along with 25 other Mi'kmaq kids (ages 8-12) who have asthma. We want to do this Camp because we think it is a good way to figure out what you want and how to better help Mi'kmaq kids with asthma. We are also interested in what kinds of help your parents/guardians need.

You don't have to do this, unless you want to.

This research has three parts.

Part 1 and 2: we want to learn about what kinds of things you need to help your asthma through a short interview here with your community researcher and then a two-day Asthma Camp at the Gaelic College in Unama'ki (Cape Breton) on July 9-10th.

Part 3: we will talk with adults in your community to see what we can do to help you with your asthma.

What will happen?

1. Agree to participate? In order to do the interview and Asthma Camp, you and your parent/guardian both have to agree to get involved. If both of you do, a team member will meet with you and your parent and ask you to sign your name saying that you both want to do this project. We will see if you want us to contact you later about Part 2 and 3.
2. Interview. Before the two-day Asthma Camp we will ask you and your parent some questions. This is called an interview. The questions will be about who helps you and what help you need for your asthma. Your parent will be asked the same kind of questions about how s/he gets help for you so that you are ok with your asthma. This will take less than an hour. A community researcher will ask you these questions and record your answers on paper and/or with a tape recorder.
3. Asthma Camp. At the Asthma Camp you will get to do lots of different things (sharing circles, learning more about asthma, making friends, playing games, doing arts and crafts, watching movies, and eating good food). We hope that about 25 Mi'kmaq kids from Unama'ki (Cape Breton) will be there along with one of their parents (or guardian). At the camp, we will look at how things are going, and will chat with you once in a while, and make notes. There are two goals of the camp: first, to have

fun, learn, make friends with other kids who have asthma; second, to talk about what you and your family find hard about your asthma, and figure out how we can help.

4. Sharing Circles. At the Asthma Camp we will ask you and the other youth to participate in two sharing circles, separate from your parents, to hear more about your experiences of living with asthma and to find out what we could do to help. We also want to know if you liked the Camp what you think we could do to make a better camp next time. We will record this sharing circle using a digital audio-visual recorder.

5. We want to thank you for being in the first part of this study (the Asthma Camp). On the last day of the camp, we are going to give you a goody bag with books, games, and some healthy snacks.

Who Will Know?

When your talk to us during the interview and at the two-day Asthma Camp, we will keep everything you say private. But, if you tell us about someone hurting you or if you tell us you want to hurt yourself, then we will get you the help you need right away.

We will be sharing what we learn with others – like your community Health Director, your Chief, and also at the university. You might be audio/video taped during the Asthma Camp and/or we might repeat what you said in our reports, but only if you write down that we are allowed to. We will not tell anyone your name or other stuff about you if you do not want us to.

We would like to make a recording of what we talk about. This means that the researcher asking the questions can listen to you and talk to you without having to write everything that you say down. It also means that the person asking the questions can hear the talk again and make sure we understand what you said. There are no wrong or right answers and if you don't want something written down just tell us and we'll fix it. If you want to read what we write after the camp, you can. If you think that you do not want what you said in the interview or sharing circles to be used by the research team then we will not use it. All research team members have signed agreements saying that they cannot tell anyone who is not on the research team anything that you said.

Because this research is being done with Mi'kmaq kids who have asthma in Unama'ki (Cape Breton), other people might know who you are at the Asthma Camp. But all the things you tell us during the talks will be kept private and will not be told to anyone unless you want us to. We will ask everyone at the Camp to respect each other and their privacy.

It's Your Choice:

It is your choice to be part of this. You can choose not to answer questions. You can stop being in the project at any time. You can ask questions at any time. If something upsets you, we will help find a professional for you to talk to.

Risks:

There are very small risks to being in this project (you might scrape a knee at Camp or have an asthma attack) but no more than the normal dangers of everyday life.

Questions:

If you have more questions just ask your community researcher!

Thank you for your interest!

Nova Scotia Lead Researcher:
Dr. Heather Castleden

heather.castleden@dal.ca Phone: ([REDACTED])



APPENDIX F: PARENT/CAREGIVER INTERVIEW GUIDE

Phase 1 – Parent/Guardian Interview (pre-gathering)

Thank you for agreeing to talk to me today. My name is **[name]**, and I want to ask you some questions about your child’s asthma. I will ask what it is like for you to have a child with asthma. I will ask you what kinds of things might help you to cope with having a child with asthma. After, I’ll ask you some general questions about your age, where you live, and who you live with. The whole interview will take about an hour. If at any point you don’t want to answer a question or you want the interview to stop, just say so. Do you have any questions before we start?

Questions regarding your child/children with asthma

1.) How old was [child’s name] when you suspected he/she had asthma? What led you to believe this? Was there specific incident? What was the reaction? Did you do anything at the time of incident e.g. go to the hospital, see a doctor?

Child 1 _____

Child 2 _____

Child 3 _____

2.) How old was [child’s name] when he/she was diagnosed with asthma? Who diagnosed him/her?

Child 1 _____

Child 2 _____

Child 3 _____

3.) Is [child’s name] being treated for asthma? (If yes, ask how? If not, ask why?)

4.) Besides asthma, what other medical conditions does [child’s name] have?

Child 1 _____

Child 2 _____

Child 3 _____

Caregiving demands

1.) Tell me about what it’s like to have a child growing up with asthma.

2.) What challenges or demands do you experience as a parent of a child with asthma?

3.) What’s the most important thing for parents like you in your situation?

4.) Has your life changed in any way since your child was diagnosed asthma?

5.) Does asthma in any way influence/constrict your family’s lifestyle?

Coping strategies

1.) Do you feel there are additional stresses due to your child having asthma? If so, what helps you cope with these stresses?

Support needs and resources

1.) What kind of support do you receive to care for a child with asthma?
Probe: practical help, do you talk to anybody about your child's asthma? If yes, how do you feel this helps? If no, do you think it would help?

2.) Who helps you to manage the demands of being a parent of a child with asthma?
Probe: Spouse, friend, parent, Dr, other professional. How do they support you?

3.) What do you feel you need to help manage the stresses/demands of being a parent of a child with asthma?
Probe for types of support: emotional, information, practical, affirmation

Support programs and services

1.) Do you know of any community/non-community services that are available to help you deal with being a parent of a child with asthma?

Do use them? If so, why?

If the respondent does use them, ask if are they helpful? If so why? If not why? Is there anything you feel needs to be added to these services?

If the respondent doesn't use them ask why? (e.g. resources are unknown, barriers to support).

If services/programs are not in place, ask if they were available, would you access these supports? Why or why not?

Gaps in supports and services

1.) In your opinion, what are the gaps in support for parents of children with asthma?

2.) What advice would you give to other parents who just found out their kid had asthma?

Great! We're almost done. I just want to ask you some general demographic questions...

Demographic Questions

1.) Sex: Male _____ Female _____ (No need to ask participant this but write it down in the space provided)

2.) Age: _____

3.) What is your marital status?

1. Single (never married) 3. Widowed 5. Separated
 2. Married 4. Divorced 6. Common law

4.) How many children do you have?

1. One 2. Two 3. Three 4. Four 5. More than four

5.) a) How many bedrooms are in your home? _____

b) How many people live in your household, including yourself? _____

6.) Please tell me who they are and whether they have asthma:

Relationship	Age	Gender	Do they have asthma?	Initials/identifiers

7.) Can you tell me the age of your house and describe its condition? _____

8.) Do you have an air exchanger? If the respondent answers yes, ask if they use it? If they have an air exchanger but do not use it, ask why? _____

9.) Are you aware of mould in your home? _____

10.) Do you or does anyone else in your household smoke? (If the respondent answers yes, ask if smoking occurs in or outside the home)(Does it occur in any particular room or every room?)

11.) What is your highest level of education?

1. Incomplete elementary
 2. Complete elementary
 3. Incomplete Junior High
 4. Complete Junior High

- 5. Incomplete High School
- 6. High School Diploma
- 7. Trade or technical certificate/diploma
- 8. Some University or College
- 9. University undergraduate degree
- 10. University graduate degree

12.) What is your occupation? _____

13.) What is your current employment status? (mark all that apply)

- 1. Working full-time
- 2. Working part-time
- 3. Student
- 4. Homemaker
- 5. On sick leave
- 6. On workers' compensation
- 7. On unemployment insurance
- 8. On disability plan
- 9. Retired from work
- 10. Unemployed

Thank you for taking the time to speak with me today. At this point, I am finished with all of my questions but I wonder if there might be something that you wanted to say that I haven't asked you?

Ok, great! We'll meet again for a second interview during the gathering.

APPENDIX G: YOUTH INTERVIEW GUIDE

Phase 1 – Adolescent Interview (pre-gathering)

Hi [name of child], my name is [name], and I want to ask you some questions about your asthma. I will ask what it is like for you to have asthma and what kinds of things might help you if you find it hard to have asthma. After these questions, I will ask you some general questions about your age, where you live, and who you live with. This will take less than an hour. If at any time you don't want to answer a question or you want the interview to stop, just say so. Do you have any questions before we start?

General Questions about Asthma

- 1.) What are your first memories of having asthma? _____
- 2.) How old were you when you found out that you had asthma? _____
- 3.) Do you have to go to the doctor a lot for your asthma? How often? _____
- 4.) Have you ever been to the hospital or emergency room for your asthma? _____
- 5.) Do you take anything to help your asthma? E.g. Puffers (If they do not, ask why?) _____
- 6.) Do you have to keep your medicine with you at all times? _____
(If yes, ask: Do you have it with you now? Do you ever forget it?)

Note to encourage...

- 7.) Is your medicine something that you have to worry about or does someone else look after it for you? _____
- 8.) Do your parents ever give you a hard time about remembering your medicine? _____

Support resources, needs, gaps in support

- 1.) Tell me what it is like to have asthma.
Probe: Do you have any challenges at home, school, among friends, going out, field trips, sports?
- 2.) Do you know any other kids with asthma? Younger/older grades? Would you like to know more kids with asthma?

3.) What are the hardest things about having asthma? If they are unsure ask, what is one thing that comes to your mind that's hard about having asthma? And what's that like?

Probe: Do you ever get left out of activities (Sports days/gym class), teased/bullied, feel different (If yes, what's that like?), think your asthma is a problem for anybody else?

Note to encourage...

4.) What kinds of help do you get for your asthma?

Probe: Do you ever talk/listen to Dr's, teachers, nurses, coaches, parents, grandparents? Do they encourage you or give you information?

5.) Who do you turn to for help with your asthma? Who helps you?

Probe: Family, friends, teachers, doctors, nurses

6.) What kinds of help do you need that you aren't getting? If you could think of one thing to help you with your asthma, what would it be?

7.) Is there anything else that you would like to tell us about your asthma? Any stories?

Almost done! More encouragement...

Demographic Information

1.) Sex: Male _____ Female _____ (No need to ask the participant this but write it down in the space provided)

2.) Age: _____

3.) What grade are you in? _____

4.) a.) How many bedrooms are in your home? _____

b.) How many people live in your house, including yourself? _____

5.) Tell me who they are and whether they have asthma:

Relationship	Age	Gender	Do they have asthma?	Initials/identifiers

6.) Does anyone in your house smoke? (If the respondent answers yes, ask if that person does so in or outside? If inside, in what rooms of the house do they smoke?)_____

Thanks for talking with me [Name of child]. You did a great job! We're all done for now.

APPENDIX H: PARENT/CAREGIVER INFORMED CONSENT PACKAGE

Research Project: Engaging Aboriginal Families Affected by Asthma in Support-Education Program Development

Purpose of the Research

We invite you to participate in a study about the kinds of supports that are available to Aboriginal youth (ages 8 to 12) with asthma and their families. Your participation in this study is completely voluntary. We want to learn about the kinds of support you and other families with asthma-affected Aboriginal youth would like to have and the things you need.

This study has three phases. **Phase 1:** we would like to learn about your needs and your family's needs through a short interview. **Phase 2:** we invite you to attend a two-day asthma gathering that we have organized at the Gaelic College in Cape Breton on July 9-10th. **Phase 3:** From what you tell us at the gathering and in the interviews, we will talk with policy makers and program planners in your community to come up with recommendations for helping to support and educate Aboriginal families affected by asthma in your community.

What will happen?

1. Consent to participate: Both you and your child need to agree that you want to be part of the study. If you choose to be in the study, a community research assistant will meet with you and your child to obtain your written consent for participation in the study. The research assistant will explain that taking part in the study involves participating in a two-day asthma gathering. We will ask your permission to contact you later about the second and third phases of the study.

Included in this package is a one-page agenda and list of items needed for the asthma gathering.

2. Interview 1: Prior to the two-day asthma gathering we will ask you and your child, separately, about who provides you with support and your support needs so that you can deal better with your child's asthma/allergies. We will ask your child similar questions about how s/he gets help to deal with his/her asthma. Each interview will take about 45-60 minutes. A community Aboriginal research assistant will ask you these questions and record your answers with a digital recorder.

3. Asthma Gathering: The asthma gathering will include various activities (e.g., sharing circles, Elders' teachings about health, relationship-building, arts and crafts, dancing and drumming ceremony). We hope that 20-25 youth will attend. Each youth must be accompanied by one of their parents/guardians. During the gathering, Aboriginal research assistants will watch how things are going, and will chat with you once in a while, and make notes. There are two goals of the camp: first, to create a fun, learning and relationship-building opportunity for young Aboriginal people who

have asthma and their parents/guardians; second, to talk about challenges you and your family face that require support and resources.

4. Interview 2: On day two of the asthma gathering we will ask you and your child, separately, about what you and your child thought about the camp, how helpful it was in terms of building relationships and getting to know the research team as well as your advice to us on how a cultural gathering like this one could be improved in the future. You will also be asked about what kinds of support you would want in the future to help you deal with your child's asthma/allergies. An Aboriginal research assistant will ask the interview questions. Interviews will last about 20-30 minutes and will be recorded using a digital recorder.

5. Thank you: We want to thank you for participating in the first phase of this study (the gathering). On the final day of the gathering, we will give you with a small gift of appreciation: an Atlantic Superstore gift certificate of \$50.

Who Will Know?

Privacy: The questions that you answer for us in both interviews, as well as the brief chats research assistants might have with you during the two-day gathering, will be kept private. We will not put your name or your child's name on any files; instead we will use numbers to keep track of your information. The information will be stored in a locked cabinet inside the researcher's office at Dalhousie University for 5 years. Only members of the research team will see the information we collect at the gathering. However, if you or any other participants tell us about abuse or a risk of self-harm then we will need to tell the appropriate agency.

Sharing Results: We will be sharing the things we learn from this study with members of the research team and in papers or presentations. No names or information that you give us that could identify you or your child will be shared. It is possible that you will be audio/video taped during the gathering and/or you may be quoted in the final paper or presentations, however these activities will only happen with your written permission and no personal information will be attached to quoted material.

Recording interview: We would like to record your interviews, the questions we ask you and your child both prior to and on the final day of the gathering. By recording the interview, it means that the person asking the questions can listen to you and talk to you without having to write everything that you say down. It also means that the person asking the questions can hear the interview again and make sure your words are right. There are no wrong or right answers and if anything comes up that you would not want written down then we can just take it out. You can review your answers, which will be written on paper after the gathering, if you want to. If you decide that you do not want what you said in the interview to be used in the final results the research team will not use the information. A member of the research team will listen to your interview tape and write what was said on paper. All research team members have signed confidentiality agreements. The research team

will review information collected at the two-day asthma gathering in an effort to develop a program to better support your asthma-related needs.

Anonymity: Because this research is being done with youth who are affected by asthma and their families, it may not be possible to keep your participation completely anonymous. However, your name will not be used and a fake name will be used in any quotes from your interviews when we talk about the results of this research in presentations and reports. All information shared during the interviews will be kept confidential and your identity will not be revealed unless you ask this in writing.

It's Your Choice:

It is your choice to be part of this project. You may choose not to answer a question. You may stop being in the study at any time. You may ask questions at any time. If there are issues that are upsetting for you, we will help find a professional for you to talk to.

Risks:

There are minimal risks to being in this study, including a possibility of accidents or asthma attacks due to being away from home at the Gaelic College. These risks are no greater than in your everyday life.

Questions:

If you have more questions please call Heather Castleden, at [REDACTED] or email heather.castleden@dal.ca. If you have any concerns about this project, you may also call the Director of the Dalhousie Office of Research Ethics Administration at [REDACTED]. The Director is not linked to this project.

Thank you for your interest!

Nova Scotia Lead Researcher: Dr. Heather Castleden
Dalhousie University
heather.castleden@dal.ca Phone: ([REDACTED]) - [REDACTED]

Alberta Co-Lead Researchers: Dr. Miriam Stewart and Dr. Malcolm King
University of Alberta
miriam.stewart@ualberta.ca Phone: ([REDACTED]) - [REDACTED]
Dr. Malcolm King
king@ualberta.ca Phone: [REDACTED]

Manitoba Lead Researcher: Dr. Jeffrey Masuda,
University of Manitoba
jeff_masuda@umanitoba.ca Phone: ([REDACTED]) - [REDACTED]

Parental Consent Form

Title of Study: Engaging Aboriginal families affected by allergies and asthma in support-education program development

Nova Scotia Researcher: Dr. Castleden (heather.castleden@dal.ca or [REDACTED])

To be completed by the research participant:

Circle Yes or No

1. Do you understand that you have been asked to be in a research study? Yes/No
2. Have you received and read a copy of the attached Information Sheet? Yes/ No
3. Do you understand the benefits and risks involved in taking part in this research study? Yes/ No
4. Have you had a chance to ask questions and discuss this study with a member of the research team? Yes/No
5. Do you understand that you do not have to participate and you can withdraw from the study at any time? You do not have to give a reason and it will not affect you. Yes/No
6. Has the issue of confidentiality been explained to you? Do you Understand who will be able to see the information you provide? Yes/No
7. Would you like to see and confirm the accuracy of your interview answers once they have been written down? Yes/No
8. Would you like to receive a copy of what we learn from the gathering (preliminary findings) to comment on them? Yes/No
9. We will take pictures and record video during the asthma gathering for Future presentations and papers to show gathering activities. Do you want to be photographed and/or video-recorded? Yes/No

If you circled "yes" for #7 or #8, please provide your e-mail or postal address.

I agree to take part in this study.

Signature of Research Participant: _____

Printed Name: _____

Signature of Witness: _____

Printed Name: _____

Date: _____

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

Signature of Researcher or Designee: _____

Date: _____

**THE INFORMATION SHEET IS ATTACHED TO THIS CONSENT FORM AND A
COPY IS GIVEN TO THE RESEARCH PARTICIPANT**

APPENDIX I: YOUTH INFORMED ASSENT PACKAGE

Research Project: Engaging Aboriginal Families Affected by Allergies and Asthma in Support-Education Program Development

This is a research project about asthma.

What is research anyway?

Research is asking questions to understand what is going on better.

What's this research all about?

We would like you to come to a two-day Asthma Camp along with 25 other Mi'kmaq kids (ages 8-12) who have asthma. We want to do this because we think and want to know what you think about how to help Mi'kmaq kids with asthma. You only have to do this study if you want to. We are also interested in what kind of help your parents/guardians need.

This study has three parts. In Part 1 and 2, we want to learn about what kinds of things you need to help your asthma through a two-day Asthma Camp at the Gaelic College in Unama'ki (Cape Breton). Part 3: we will talk with adults in your community to try and come up with ways to help you with your asthma.

What will happen?

1. You and your parent have to agree that you want to do this. If both of you do, a team member will meet with you and your parent to get you to write down that you want to be in the study. We will also tell you that being in the study means going to the two-day Asthma Camp. We also want to know if you will let us ask you later about being in Part 2 and 3.
2. Before the two-day Asthma Camp we will ask you and your parent some questions. This is called an interview. The questions will be about who helps you and what help you need for your asthma. Your parent will be asked the same kind of questions about how s/he gets help so they can help you so that you can deal better with your asthma. Each interview will take less than an hour. An Aboriginal team member will ask you these questions and record your answers with a digital recorder.
3. At the Asthma Camp you will get to do lots of different things;(e.g., sharing circles, Elders' teachings about health, making friends, playing games, doing arts and crafts). We hope that 20-25 kids will be there. Each child must come with one of their parents. At the camp, Aboriginal team members will watch how things are going, and will chat with you once in a while, and write things down. There are two goals of the camp: first, to make a fun, learning and friend-making opportunity for Aboriginal kids who have asthma; second, to talk about what you and your family find hard about your asthma.

4. On the second day of the Asthma Camp we will ask you and your parent separately some more questions (another interview) about what you and your parent thought about the camp, how it helped you to make friends, and getting to know the research team as well as what you think we could do to make a better camp next time. You will also be asked about what kind of a help program you would like us to make for you that will help you with your asthma. Someone from the Aboriginal research team will ask you these questions. This will take about half an hour and will be recorded using a recorder.

5. We want to thank you for being in the first part of this study (the Asthma Camp). On the last day of the camp, we will give you a \$50 gift bag.

Who Will Know?

Your talks with us, as well as the brief chats the research team might have with you during the two-day Asthma Camp, will be private. Only members of the research team will be able to look at what you told us. But, if you tell us about someone hurting you or if you tell us you want to hurt yourself, then we will get you the help you need.

We will be sharing what we learn from this the research team and in papers or presentations. We will not tell anyone your name or other stuff about you. You might be audio/video taped during the Asthma Camp and/or we might say what you said in the final paper or presentations, but only if you write down that we are allowed to.

We would like to record our chats. This means that the research team member asking the questions can listen to you and talk to you without having to write everything that you say down. It also means that the person asking the questions can hear the talk again and make sure your words are right. There are no wrong or right answers and if you don't want something written down just tell us and we'll fix it. If you want to read about our chat after the camp, you can. If you think that you do not want what you said in the chat to be used by the research team then we will not use it. All research team members have signed confidentiality agreements which means that they cannot tell anyone who is not on the research team anything that you said.

Because this research is being done with kids who are affected by asthma, other people might now know who you are at the Asthma Camp. All the things you tell us during the talks will be kept private and will not be told to anyone unless you want us to.

It's Your Choice:

It is your choice to be part of this. You may choose not to answer a question. You may stop being in the project at any time. You may ask questions at any time. If something upsets you, we will help find a professional for you to talk to.

Risks:

There are very small risks to being in this project. This is not any more dangerous than your everyday life.

Questions:

If you have more questions just ask me. I'll be around in your community.

Thank you for your interest!

Nova Scotia Lead Researcher:

Dr. Heather Castleden

Dalhousie University

heather.castleden@dal.ca Phone:

██████████

Alberta Co-Lead Researchers:

Dr. Miriam Stewart and Dr. Malcolm King

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██████████

Dr. Malcolm King

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██████████

Manitoba Lead Researcher:

Dr. Jeffrey Masuda

University of Manitoba

jeff_masuda@umanitoba.ca Phone: (

██████████

Combined Assent/Parental Consent Form for Adolescents

Title of Study: Engaging Aboriginal families affected by allergies and asthma in support-education program development

Nova Scotia Researcher: Dr. Castleden (heather.castleden@dal.ca or [REDACTED])

To be completed by the research participant: **Circle Yes or No**

1. Do you understand that you have been asked to be in a research study? Yes/No
2. Did you get and read a copy of the Information Sheet? Yes/No
3. Do you understand the benefits and risks of being in this research study? Yes/No
4. Have you had a chance to ask questions and talk about this study with a member of the research team? Yes/No
5. Do you understand that you do not have to do this and you can stop being in this project at any time? You do not have to give a reason and nothing will happen to you. Yes/No
6. Do you understand that no one except the research team will be able to see anything that you say and it will not be told to anyone else unless you say it is okay. Yes/No
7. Would you like to read your interview to make sure what you said was right? Yes/No
8. Would you like to get a copy of what we learned at the gathering (preliminary findings) to tell us what you think about them? Yes/No
9. We will take pictures and record video during the Asthma Camp to show people. Do you want in the future. Do you want to be photographed and/or video-recorded? Yes/No

If you circled "yes" for #7 or #8 , please tell us your e-mail or postal address.

I agree to take part in this study.

Signature of Research Participant: _____

Printed Name: _____

Signature of Parent/Guardian: _____

Printed Name: _____

Signature of Witness: _____

Printed Name: _____

Date: _____

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

Signature of Researcher or Designee: _____

Date: _____

**THE INFORMATION SHEET IS ATTACHED TO THIS CONSENT FORM AND A
COPY IS GIVEN TO THE RESEARCH PARTICIPANT**

APPENDIX J: ASTHMA CAMP AGENDA

Activity	Description	Time
DAY 1 / Saturday July 9 2011		
Saturday Arrival	Families to arrive by vehicle/carpool/van rental	10:30 am
Welcome Prayer/Smokeless smudge	Elder Lawrence Wells (Membertou) Elder Sylvia Denny (Eskasoni)	11:15 am
Welcoming Remarks	Thank people for coming; introduce research team; agenda	11:30 am
Ice Breaker	Meet and Greet BINGO for kids and adults *Door Prize	12:00 pm
Lunch and Learn	Jonathan Dyer, Nova Scotia Lung Association and Camp Treasure Chest Director	12:30 pm
Kids Circle	Opportunity for kids to talk about asthma experiences	1:30 pm
Adults Circle	Opportunity for adults to talk about their kids' asthma experiences	1:30 pm
Refreshment Break	Networking	3:00
Kids Activity	Asthma Relay and Drum Painting	3:30 pm
Adults Activity	Asthma Aware Training	3:30 pm
Drum/Dancing	Eskasoni dancers performing with drummers from Wagmatcook and Waycobah	4:30 pm
Supper and Learn	Dr. Wade Watson, MD and Pediatric Allergist, IWK	6:00 pm
Movie Night	Comedy/Action films (2 rooms) and Snacks	7:30 pm
DAY 2 / Sunday July 10 2011		
Mi'kmaq Sunrise Ceremony	Smokeless Smudge and Prayer (optional)	7:00 am
Group Activity	Pack out bags	8:00 am
Breakfast and Learn	Anne Marie Woodrow, Allergy Clinic Nurse, IWK	8:30 am
Kids Circle	What are you taking away from this experience? What can we do to create social support for you?	9:00 am
Adults Circle	What are you taking away from this experience? What can we do to create social support for your kids and you?	9:00 am
Refreshment Break	Networking	10:30 am
Group Activity	Sharing Circle Would you like to be involved in the next phase of the study?	10:30 am
Lunch and Learn	Pat Steele, Chest Clinic Nurse, Cape Breton	12:30 pm
Closing Prayer/Smudge	Elder Lawrence Wells (Membertou) Elder Sylvia Denny (Eskasoni)	1:30 pm
Thank You	Honoraria to Participants (small 'thank you' gifts)	1:45 pm
Sunday Departure	Families depart by vehicle/carpool/van rental	2:00 pm

APPENDIX K: PARENT/CAREGIVER FOCUS GROUP GUIDE

Gathering experience

In the first interview, we talked about what it's like for you to look after a child with asthma and what kinds of support you get in order to look after your child. I will now ask you some questions about what kind of support program you would like to have in the future to better deal with your child's health challenges.

- 1.) What do you think about the asthma gathering so far?
- 2.) What have you learned about asthma that you didn't know before?
- 3.) What benefits have you received from spending time at the gathering with other parents with children with asthma?
- 4.) What do you think your child benefited from this gathering?
- 5.) If we were to do this again, what do you think we could improve?

Support preferences

I will now ask you some questions about what you would prefer for a support program.

1.) Intervention level – Would you prefer to talk to other parents of children with asthma in a group format (e.g. chat room, message board, teleconference, face-to-face), a one-on-one format (e.g. on the phone, by email, text message, instant message), or a combination? Please explain why.

2.) Intervention agents – Who would you like to receive support from:

- Another parent of a child/adolescent with asthma?
- An expert (professional)?
- Someone else?

Please explain why.

3.) Timing, frequency, duration –

- When should the sessions be held? [Probe: evening, weekend, during day]
- How long should each session be? [Probe: One hour, longer, shorter]
- How often would you like to meet with other parents? [Probe: Once a week, more than once a week, less than once a week]
- For how long should the program last? [Probe: 24 weeks/6 months, longer, shorter] Please explain why.

4.) Content –What would you like to talk about with other parents of children with asthma?

5.) What factors would prevent you from attending the support session?

6.) Do you have any other advice or ideas about support for parents of children with asthma?

Thank you for taking the time to speak with me today. At this point, I am finished with all of my questions but I wonder if there might be something that you wanted to say that I haven't asked you?

As was stated in the information sheet, you have the option of receiving a copy of your answers and/or the study summary. I want to confirm if this is something you would like? (re-record address/e-mail)

I would like to re-emphasize that everything that has been shared during your interviews and any comments on the interviews once they have been written down will remain confidential. In the future, should this information be used in any papers or presentations, a pseudonym, or fake name, will be assigned.

If you have any questions regarding this study, or questions regarding some of the issues we discussed, please do not hesitate to talk to me or talk to Dr. Castleden who is leading the project or to any member of the Community Advisory Committee.

Thank you

APPENDIX L: PARENT/CAREGIVER SHARING CIRCLE GUIDE

In the focus group yesterday, we talked about what kinds of asthma intervention preferences you would like to have. Now, going around the circle clockwise, we would like to know further talk about the kind's intervention preferences you would like and the types of support that you feel you need. If you don't have anything to say about a particular question that's fine, just pass the talking stick along.

- 1.) Tell me about what it's like to have a child growing up with asthma.
- 2.) What challenges or demands do you experience as a parent of a child with asthma?
- 3.) What's the most important thing for parents like you in your situation?
- 4.) Has your life changed in any way since your child was diagnosed asthma?
- 5.) Does asthma in any way influence/constrict your family's lifestyle?
- 6.) What kind of support do you receive to care for a child with asthma?
- 7.) Who helps you to manage the demands of being a parent of a child with asthma?
Probe: Spouse, friend, parent, Dr, other professional. How do they support you?
- 8.) What do you feel you need to help manage the stresses/demands of being a parent of a child with asthma? If you could name one thing, what would it be?

Support programs and services

Do you know of any community/non-community services that are available to help you deal with being a parent of a child with asthma?

Do use them? If so, why?

If the respondent does use them, ask if are they helpful? If so why? If not why? Is there anything you feel needs to be added to these services?

If the respondent doesn't use them ask why? (e.g. resources are unknown, barriers to support).

If services/programs are not in place, ask if they were available, would you access these supports? Why or why not?

I would like to re-emphasize that everything that has been shared during this sharing circle and any comments on the interviews once they have been written down will remain confidential. In the future, should this information be used in any papers or presentations, a pseudonym, or fake name, will be assigned.

If you have any questions regarding this study, or questions regarding some of the issues we discussed, please do not hesitate to talk to me or talk to Dr. Castleden who is leading the project or to any member of the Community Advisory Committee.

I will be in touch regarding the next phase of the study in a few months to see if you are still interested in participating.

Thank you.

APPENDIX M: PHASE 3 RECRUITMENT SCRIPT

Hello,

I am a Research Assistant for an Aboriginal health researcher at Dalhousie University. Her name is Heather Castleden. She is working with (names of Community Advisory Committee members) on a study about asthma and asthma support in Mi'kmaq communities. (Name of Community Advisory Committee member) suggested that I see if you would be interested in participating in a research study on asthma.

As a (Mi'kmaq community representative/program planner, practitioner, service provider, service manager, or policy influencer working with Mi'kmaq communities), Heather wants to invite you to attend a group interview at (name of Community Health Centre). She is interested in learning about how the results from this study to date can be used for programs, policies, and practices specific to Mi'kmaq peoples affected by asthma as well as determine who to communicate these findings to and how to do this.

Heather's study is funded by AllerGen and it has received ethical approval from the Dalhousie Health Sciences Research Ethics Board and [appropriate community-based Ethical Review Board].

Would you be interested in receiving more information?

[If yes, provide hard copy of information letter; set up a time to arrange a meeting where consent information can be presented]

[If no: ask if he/she might be able to suggest someone else as a potential participant who fits the participant recruitment criteria]

Thank you.

APPENDIX N: PHASE 3 INFORMATION SHEET

Research Project: Engaging Aboriginal Families Affected by Allergies and Asthma in a Support-Education Program

Project Lead: Dr. Heather Castleden, Dalhousie University

Project Partners: Eskasoni, Membertou, Wagmatcook, Waycobah, Potlotek First Nations

Funding: AllerGen

Purpose of the Research

As a Mi'kmaq community representative or program planner, practitioner, service provider, service manager, or policy influencer working with Mi'kmaq communities, we invite you to participate in a study about the kinds of asthma support and education available to asthma affected families in Mi'kmaq communities and the impact this has on their health and well-being. Your participation in this study is completely voluntary. We want to learn what implications the findings from a study identifying the support resources, support-seeking strategies, support and education needs, and intervention preferences of asthmatic Mi'kmaq youth and parents/caregivers have for programs, policies, and practices specific to Mi'kmaq peoples, as well as determine appropriate audiences and vehicles for sharing these findings.

This study has three phases. **Phase 1:** we learned about the needs of Mi'kmaq families dealing with asthma through short interviews. **Phase 2:** we held a two-day asthma gathering at the Gaelic College in Cape Breton on July 9-10th, 2011. At the gathering, in addition to participating in cultural and educational activities, participating families told us more about the kinds of asthma support and education they need but are not getting in their communities. **Phase 3:** we will talk with Mi'kmaq community representatives and program planners, practitioners, service providers, service managers, and policy influencers working with Mi'kmaq communities to identify the implications of Phase 1 and 2 findings for programs, policies, and practices specific to Mi'kmaq peoples, as well as determine appropriate audiences and vehicles for disseminating these findings.

At this point, we are seeking your consent to participate in Phase 3: one short group interview taking place over part of an afternoon. Prior to the group interview, you will be asked to read a summary of Phase 1 and 2 findings so that you are prepared to answer related questions during the interview.

What will happen?

1. Consent to participate: If you choose to be in the study, a member of the research team will meet with you to obtain your written consent for participation in the study. The research team member will explain that taking part in the study involves reading a short summary of Phase 1 and 2 findings and participating in a group interview.

Included in this package is a copy of the interview script.

2. Summary of Phase 1 and 2 findings: One week prior to the group interview, you will be provided with a short summary of Phase 1 and 2 findings to read at your convenience before the group interview.

3. Brief presentation: Immediately before the group interview begins, a member of the research team will present a short review of the findings from Phases 1 and 2. This will take approximately 10 minutes.

4. Group interview: After the presentation, you will be asked about how these findings can be used in future programs, policies, and practices specific to Mi'kmaq peoples as well as what are the appropriate audiences and vehicles for sharing these findings. This will take approximately 2.5 hours.

Who Will Know?

Privacy: The questions that you answer for us in the group interview will be kept private. We will not put your name on any files; instead we will use numbers to keep track of your information. The information will be stored in a locked cabinet inside the researcher's office at Dalhousie University for 5 years. Only members of the research team will see the information we collect during the group interview. However, if you or any other participants tell us about abuse or a risk of self-harm then we will need to tell the appropriate agency.

Sharing Results: We will be sharing the things we learn from this study with the research team, the five Health Directors of the Unama'ki First Nations and in academic papers or conference presentations. No names or information that you give us that could identify you will be shared. It is possible that you will be quoted in the final paper or presentations, however this will only happen with your written permission and no personal information will be attached to quoted material.

Recording the Group Interview: We would like to record the group interview. By recording, it means that the person asking the questions can listen to you and talk to you without having to write everything that you say down. It also means that the person asking the questions can hear the interview again and make sure your words are right. There are no wrong or right answers and if anything comes up that you would not want written down then we can just take it out. You can review your answers, which will be written on paper after the group interview session, if you want to. If you decide that you do not want what you said to be used in the final results the research team will not use the information. A member of the research team will listen to the interview tape and write what was said on paper. All research team members have signed confidentiality agreements. The research team will review information collected in an effort to identify ways of improving asthma support and education for Mi'kmaq families.

Anonymity: Because this research is being done in a group setting, it may not be possible to keep your participation completely anonymous. However, your name will not be used and a fake name will be used in any quotes from your interview session when we talk about the results of this research in presentations and reports. All information shared during the group interview will be kept confidential and your identity will not be revealed unless you ask this in writing.

It's Your Choice:

It is your choice to be part of this project. You may choose not to answer a question. You may stop being in the study at any time. You may ask questions at any time. If there are issues that are upsetting for you, we will help find a professional for you to talk to.

Risks:

There are minimal risks to being in this study, including a possibility of emotional discomfort due to the sensitive nature of the topic. These risks are no greater than in your everyday life.

Questions:

If you have more questions please call Heather Castleden, at [REDACTED] or email heather.castleden@dal.ca. If you have any concerns about this project, you may also call the Director of the Dalhousie Office of Research Ethics Administration at [REDACTED]. The Director is not linked to this project.

Thank you for your interest!

APPENDIX O: PHASE 3 CONSENT FORM

Consent Form

Title of Study: Engaging Aboriginal families affected by asthma in a support-education program

Nova Scotia Researcher: Dr. Castleden (heather.castleden@dal.ca or [REDACTED])

To be completed by the research participant:	Please Circle	Yes	or	No
1. Do you understand that you have been asked to be in a research study?		Yes		No
2. Have you received and read a copy of the attached Information Sheet?		Yes		No
3. Do you understand the benefits and risks involved in taking part in this research study?		Yes		No
4. Have you had a chance to ask questions and discuss this study with a member of the research team?		Yes		No
5. Do you understand that you do not have to participate and you can withdraw from the study at any time? You do not have to give a reason and it will not affect you.		Yes		No
6. Has the issue of confidentiality been explained to you? Do you understand who will be able to see the information you provide?		Yes		No
7. Would you like to see and confirm the accuracy of the group interview once it has been written down?		Yes		No
8. Would you like to receive a copy of what we learn from the group interview (initial findings) to comment on it?		Yes		No
9. Do you understand that this is Phase 3 of a 3 phase study? We are only asking for your consent to participate in Phase 3.		Yes		No

I agree to take part in this study.

Signature of Research Participant: _____ Signature of Witness: _____

Printed Name: _____ Printed Name: _____

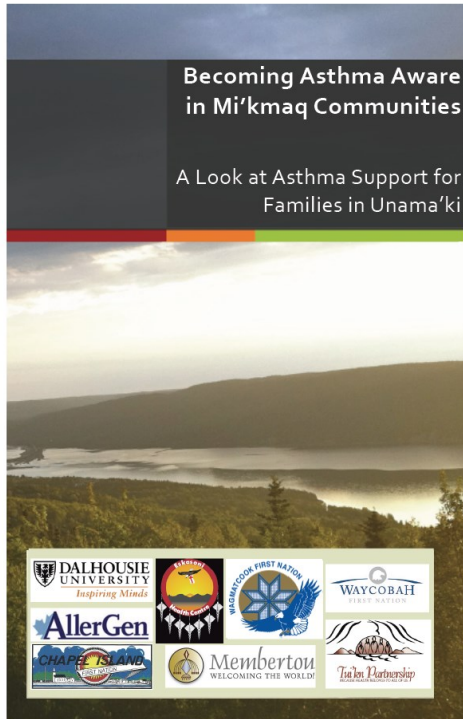
Date: _____ Date: _____

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

Signature of Researcher or Designee: _____ Date: _____

THE INFORMATION SHEET IS ATTACHED TO THIS CONSENT FORM AND A COPY IS GIVEN TO THE RESEARCH PARTICIPANT

APPENDIX P: ASTHMA BOOKLET



Principal Investigators of the National Research Team

Dr. Heather Castleden, Dalhousie University, Nova Scotia

Dr. Malcolm King, University of Alberta, Alberta

Dr. Jeffrey Masuda, University of Manitoba, Manitoba

Dr. Miriam Stewart (Lead), University of Alberta, Alberta

How to cite this booklet:

Castleden, H., Watson, R. & The Tui'kn Partnership. (2012). *Becoming Asthma Aware in Mi'kmaq Communities: A Look at Asthma Support for Families in Unama'ki* (Project Report). Halifax, Nova Scotia: Dalhousie University.

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Nova Scotia Research Team

Tui'kn Partnership Health Directors:

Darlene Anganis, Membertou
Elaine Allison, Wagmatcook
Sharon Rudderham, Eskasoni
Jennifer MacDonald, Waycobah
Laurie Touesnard, Potlotek

Principal Investigator:

Dr. Heather Castleden, Dalhousie University

Research Coordinator:

Rob Watson, Dalhousie University

Community Researchers:

Sam Carter, Potlotek
Julie Francis, Eskasoni
Dawn Googoo, Waycobah
Athena Paul, Membertou
Lorissa Sylvester, Membertou
Dawn Marshall, Wagmatcook

Special thanks to Alana Vineberg for designing the layout of this booklet.

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About this Booklet

This booklet is for Mi'kmaq families who have a child with asthma, as well as anyone who provides support or assistance to asthmatic Mi'kmaq youth (e.g. doctors, nurses, teachers etc.).

In this booklet you will learn about existing asthma support in Unama'ki communities, how Mi'kmaq families currently get asthma help, the kinds of help and information they need, and how they would prefer to get asthma help and information.

About the Research

The information in this booklet is an overview of the Nova Scotia findings of a national research project funded by AllerGen NCE. The Health Directors of the Tui'kn Partnership and a Community Advisory Committee provided assistance and guidance to university and community based researchers for this research project.



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Why this research was conducted:

- The World Health Organization recognizes that asthma is a serious chronic disease and it is often under-diagnosed, untreated, and creates a serious burden on individuals and families that last a lifetime.
- Asthma is the most common chronic condition affecting Aboriginal youth in Canada.
- Many Aboriginal children with asthma do not receive proper treatment.
- Studies have shown if asthma support is not available it can be harmful to health.
- Very little is known about what Aboriginal families need to cope with asthma.
- It is important to understand how to provide support and services for Aboriginal families affected by asthma to improve their health and wellbeing.



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What We Learned:

Mi'kmaq families talked about four main themes related to asthma support in their communities:

1. Awareness of asthma triggers and ways of avoiding them;
2. Current asthma supports and services;
3. Ways of getting help with asthma; and
4. A desire for more asthma support and services.

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How this research was conducted:

Six community researchers talked with 21 asthmatic children (ages 8-12) and 17 parents or caregivers, from the five Mi'kmaq communities in Unama'ki about asthma support and services available in and outside their communities.

After these conversations, children and their caregivers were invited to a two-day asthma camp where they participated in ceremonies (smudging; prayer); cultural activities (drum-making; drumming; singing; dancing); entertainment (games; art; relay races; movie night); social support (informal networking opportunities); and education (asthma awareness training; guest speakers with asthma expertise). During the camp, participants also talked about the kinds of help they needed to improve their ability to deal with asthma.

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1. Awareness of Asthma Triggers and Ways of Avoiding Them

- Most Mi'kmaq parents or caregivers said they were aware of what triggers their child's asthma and tried to avoid them.
- Examples of asthma triggers given in this study are mould, indoor tobacco smoke, road dust, pets, and seasonal change.

Parents learned how to avoid triggers on their own:

"You have to do things differently in the house. You have to use certain products. Some products you find after awhile are triggers and one of the big things was floor wax... You have to keep fresh air circulating in the house. But it is the opposite in the summer, when the gravel road is graded and the road is dusty you have to keep the doors and windows closed. So you just always have to be aware of the triggers and of the air quality."

And they learned from their doctor:

"My daughter's asthma is induced by exercise. During her games she takes her inhalers when she gets sick. But we have learned this year to take the inhaler half an hour before the game and then play. This reduced her chance of getting an attack. That's what the doctor told us to do."

8

Almost all Mi'kmaq children knew what could lead to an asthma attack, but **they didn't always avoid those triggers:**

- Physical exercise was the most common asthma trigger identified by Mi'kmaq children.
- Most children said they rely on their inhalers to avoid an asthma attack, but require an adult's help.

One child explained that even though she knew that running without taking her inhalers could cause her to have an asthma attack, sometimes she forgot:

"I was at school and did the Terry Fox run and had an asthma attack. I forgot that I didn't have my inhaler and was in the office for a half hour, waiting."



3. Ways of Getting Help with Asthma

When dealing with asthma, Mi'kmaq families rely on:

- Family members, often with shared experiences.
- Doctors, pharmacists and nurses, mostly for prescription medication and how to properly use inhalers.
- Children in particular rely on teachers and friends.

"When my children are having an attack it is really hard watching them suffer. Talking helps me cope. I have a really good support network with my sisters and my mother, family and friends... you just don't feel so alone and my sisters, two of them have kids with asthma so it helps talking to them because they know what you're going through."



2. Current Asthma Supports and Services

Parents or caregivers participating in this research said:

- There is a lack of asthma support in Mi'kmaq communities.
- Connecting with asthma specialists outside the community is difficult because of the long distances they have to travel.
- There is no information available in Mi'kmaq.

"My kids are fluent in Mi'kmaq... and my youngest one, he is more comfortable speaking our language than English, so a lot of the times there's that barrier of understanding."



4. Desire for More Asthma Support Services

Most Mi'kmaq parents or caregivers felt that they needed more education to manage their child's asthma. They felt that doctors did not give them or their children enough information about asthma to properly understand it.

Parents or caregivers also wished everyone in the community knew about asthma. This is especially important when their children are in the care of others.

"When she came back she was coughing and her clothes smelled like smoke because the person who drove them was smoking in the car with them."

Some parents said they would benefit from talking to other parents in the same situation as themselves.

“My biggest wish is... if every health centre in Unama’ki would take one person and really seriously train them on this topic. Then they could pass on the information to the parents because a lot of the parents don’t have the proper information, or they are not sure how to give the medication” (Mi’kmaq Parent).

“We need support groups... I really don’t have anybody else to go to other than my doctor.”

Almost all caregivers commented on the value of the asthma camp as a way of connecting with other Mi’kmaq families about asthma-related issues. They felt future asthma support in the community needed to be in Mi’kmaq.

In several cases parents were also concerned about the lack of asthma-friendly school policies.

“My daughter’s old school didn’t want her to take her inhaler. They thought that she would get addicted to it. Teachers don’t like your child to take it when they need it, only when they feel that the child should take it.”

Caregivers feel in order for their child to be able to control their asthma, both an asthma-friendly school environment and asthma education for school-teachers, counsellors, administrators, and educational assistants is needed.

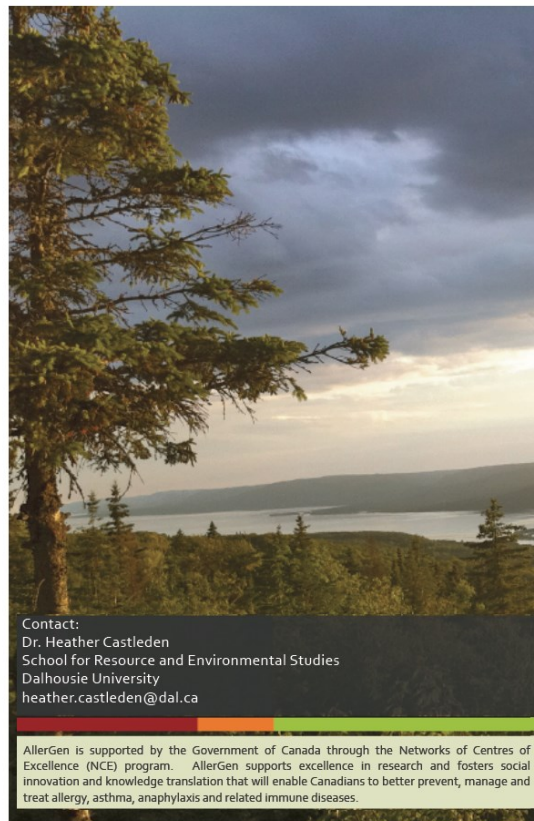


Summary of Research Findings

Improved support and educational resources are needed to develop effective Mi’kmaq asthma support networks. No matter what type of support and educational approaches are identified, future strategies for improved asthma management in Mi’kmaq communities must be culturally meaningful and accessible to asthma-affected families and those providing them with support.

Mi’kmaq Families Affected by Asthma Offered 5 Community-Based Solutions

1. Develop a community asthma management action plan that includes indoor and outdoor realtime air quality monitoring that is accessible to all community members.
2. Establish a monthly Asthma Clinic that brings asthma specialists to the community for onsite asthma (spirometry) testing and asthma educators for onsite asthma awareness training using culturally appropriate teaching strategies and resources.
3. Provide age-appropriate asthma awareness education in school for all children.
4. Develop asthma-friendly school policies that allow children immediate access to their asthma medications.
5. Develop asthma-friendly community policies that reduce asthma triggers (e.g. avoid field grass burning in the spring; limiting dirt road grading during dry spells; avoiding the use of chemical cleaners with strong odours; reducing commercial tobacco use; and removing household mould).



Contact:
 Dr. Heather Castleden
 School for Resource and Environmental Studies
 Dalhousie University
 heather.castleden@dal.ca

AllerGen is supported by the Government of Canada through the Networks of Centres of Excellence (NCE) program. AllerGen supports excellence in research and fosters social innovation and knowledge translation that will enable Canadians to better prevent, manage and treat allergy, asthma, anaphylaxis and related immune diseases.

APPENDIX Q: FOCUS GROUP INTERVIEW GUIDE

Interview Guide

Thank you for agreeing to participate in this study on Mi'kmaq asthma research. Before I start recording the interview, I want to tell you a little bit about how our conversation will go. First, I'm going to take 10 minutes to present the findings from Phases 1 and 2 to you so that they are fresh in everyone's mind. After, we'll begin the interview which should take no more than 2.5 hours.

I just wanted to remind you that during this interview I will record our conversation. There are no right or wrong answers; I am just interested in what you think. If there are things you don't want to talk about that's ok. We'll just move on. If you say something that you don't want recorded, just say so, and it can be removed, even after you have completed the interview. The only people who will hear and see the interview material will be members of the research team and a transcriptionist, who has signed a confidentiality agreement. All original notes, digital recordings and back-up files will be stored at Dalhousie University in a secure location and will be kept until 2017.

Are there any questions before we begin?

Present Phase 1 and 2 findings

Interview Questions

1. What new information does this study offer to policy makers, policy influencers and program planners?
Probe: What information is most useful to your department/organization?
2. How can the information from this study be used to influence the planning and designing of programs that benefit Mi'kmaq children/adolescents with asthma and their families?
3. What are your recommendations for improved programs and policies relevant to asthma in Mi'kmaq communities?
4. How can we communicate the findings of this study?
 - Who are appropriate audiences?
 - What are appropriate strategies?
 - How can your organization/department assist in dissemination of findings?

APPENDIX R: DALHOUSIE ETHICAL APPROVAL FORMS



Health Sciences Human Research Ethics Board Letter of Approval

Date: May 12, 2011.

To: Dr. Heather Castleden, School for Resource and Environmental Studies

The Health Sciences Research Ethics Board has examined the following application for research involving human subjects:

Project # 2010-2134

Title: Engaging Aboriginal Families Affected by Asthma in a Support-Education Program

and found the proposed research involving human subjects to be in accordance with Dalhousie Guidelines and the Tricouncil Policy Statement on *Ethical Conduct in Research Using Human Subjects*. This approval will be in effect for 12 months from the date indicated below and is subject to the following conditions:

1. Prior to the expiry date of this approval an annual report must be submitted and approved.
2. Any significant changes to either the research methodology, or the consent form used, must be submitted for ethics review and approval *prior to their implementation*
3. You must also notify Research Ethics when the project is completed or terminated, at which time a final report should be completed.
4. Any adverse events involving study participants are reported immediately to the REB

Effective Date: May 12, 2011.

signed:

Expiry Date: May 12, 2012.

Heather Castleden (Chair, REB)

IMPORTANT FUNDING INFORMATION - Do not ignore

To ensure that funding for this project is available for use, you **must** provide the following information and **FAX** this page to **RESEARCH SERVICES** at

Name of grant /contract holder _____

Signature of grant / contract holder _____

Funding agency AllerGen _____

Award Number _____

**Health Sciences Human Research Ethics Board
Letter of Approval**

Date: June 6,2012.

To: Heather Castleden , School for Resource and Environmental Studies

The Health Sciences Research Ethics Board has examined the following application for research involving humans:

Project # 2012-2708 (v2) (R# 1011208)

Title: Engaging Aboriginal Families Affected by Allergies and Asthma in Support-Education Program Development

and found the proposed research involving human participants to be in accordance with Dalhousie Guidelines and the Tricouncil Policy Statement on *Ethical Conduct in Research Using Humans* . This approval will be in effect for 12 months from the date indicated below and is subject to the following conditions:

1. Prior to the expiry date of this approval an annual report must be submitted and approved.
2. Any significant changes to either the research methodology, or the consent form used, must be submitted for ethics review and approval *prior to their implementation*
3. You must also notify Research Ethics when the project is completed or terminated, at which time a final report should be completed.
4. Any adverse events involving study participants are reported immediately to the REB

Effective Date: June 5,2012.

signed:

Expiry Date: June 5,2013.

Dr. _____

IMPORTANT FUNDING INFORMATION - Do not ignore

To ensure that funding for this project is available for use, you must provide the following information and **FAX** this page

Name of grant /contract holder _____
Signature of grant / contract hold _____
Funding agency Alderben
Award Number _____

APPENDIX S: MI'KMAQ ETHICS WATCH APPROVAL FORMS

CAPE BRETON UNIVERSITY

May 19, 2011

Dr. Heather Castleden
Assistant Professor
School for Resource & Environmental Studies
Dalhousie University
6100 University Avenue, Suite 5010
Halifax, Nova Scotia
B3H 3J5

Dear Dr. Castleden:

I wish to inform you that the Mi'kmaq Ethics Watch committee has reviewed and approved your ethics application: "Engaging Aboriginal Families Affected by Allergies and Asthma in a Support-Education Program".

This enables you to move forward with your project.

While we are overseeing Mi'kmaq districts ethics, each person/organization/agency seeking to do research in Mi'kmaq communities must determine what other ethics processes they must go through. It is your responsibility to do this as we have not been given information from all the communities as to their various ethics processes. We do not oversee university, government, health/medicine, law, or community ethics processes. They have their own.

We would be pleased or appreciative if and when the study is completed that it be provided so as to allow our students to build further academic foundations and a better understanding of Indigenous knowledge.

If you have any questions concerning same, please do not hesitate to contact us.

Sincerely,

Lor/Lindsay Marshall
Principal
Unama'ki College
of Cape Breton University

LM/vl

UNAMA'KI COLLEGE OF CAPE BRETON UNIVERSITY



October 5, 2012

Heather Castleden, PhD
School for Resource and Environmental Studies
Dalhousie University
6100 University Avenue
PO BOX 15000
Halifax, NS B3H 4R2

Dear Dr. Castleden,

I wish to inform you that the Mi'kmaw Ethics Watch committee has reviewed and approved "*Engaging Aboriginal families affected by asthma in support-education program development*".

As your project moves forward with the approval of the Mi'kmaw Ethics Watch, I must note that individual communities have their own perspective on research projects and it is your responsibility to consult them to ensure that you meet any further ethical requirements. Governments, universities, granting agencies, and the like also have ethical processes to which you might have to conform.

When your project is completed, the Mi'kmaq Resource Centre at Unama'ki College would be pleased to accept the results in a form that could be made available to students and other researchers (if it is appropriate to disseminate them). Our common goal is to foster a better understanding of the Indigenous knowledges.

If you have any questions concerning the Mi'kmaw Ethics Watch review of your project please do not hesitate to contact me and I will forward them to the committee members.

Dean of Arts & Social Sciences
Acting Principal, Unama'ki College
Cape Breton University