# "It was a once in a lifetime opportunity": The Power of Participating in a Video Research Project for Aboriginal Youth

by

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#### Abstract

Community-based participatory research (CBPR) and arts-based research methods such as participatory video have proven to be effective in engaging youth in research projects. However, limited evidence exists on how participation in these research projects specifically impacts individuals' health. Assessment of research impact tends to focus on the intended intervention outcomes, and overlooking the experience of participating in the research process. Moreover, youths' perspectives of being included in participatory research are rarely explored. Guided by community-based participatory research principles and Indigenous research methodologies, I examined from the perspectives of the research participants, the perceived impact on their health and wellbeing.

Situated within a larger participatory video project, I worked with high school aged Aboriginal youth in grades 9-12 and their schools (K'alemi Dene School, Northwest Territories and Queen Elizabeth High School, Alberta) to explore how engaging in a participatory video project on tobacco misuse impacted the youth participants. Using focused ethnography to guide the data generation strategies, I conducted 11 focus groups at three time points throughout the research project (March/April 2013, May/June 2013, and October/November 2013) with 28 youth and 15 one-on-one interviews pre and post project (April/May 2013 and June/July 2013), with eight adult partners.

The research highlighted how engaging in participatory video can contribute to youths' journey of becoming empowered. The youth participants described how participating in the video project was an opportunity for them to act as health promoters within their school and wider communities. Through the participatory research process, youth increased their sense of belonging, purpose, and agency. These are all assets required for positive youth development. By

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comparing and contrasting two different locations, the results show how the context and mechanisms of the project influenced outcomes differently. Overall, the youth were positively impacted from participating in a research project focused on tobacco misuse. The findings provide evidence of how participation in participatory video projects has the potential to be a transformative experience for the participants.

This study contributes to our limited knowledge on how participatory methods and engaging in participatory research impacts participants during the research process, and extends beyond the intended outcomes. This work provides a starting point to begin understanding the potential impacts of participatory research on youths' development and empowerment. I conclude this thesis by providing recommendations for future practice and policy changes in CBPR, and participatory health research.

## Preface

This thesis is an original work by Megan Lukasewich. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, for the project "Engaging Aboriginal Youth in Tobacco Prevention Using Social Media" No. Pro00021643. In addition, this research project obtained a Scientific Research License from the Aurora Research Institute for projects taking place in the Northwest Territory, Project Name "Engaging Aboriginal Youth in Tobacco Prevention Using Social Media" No. 15546.

The research conducted for this thesis is situated within the larger research project "Engaging Aboriginal Youth in Tobacco Prevention Using Social Media," led by Dr. Cindy Jardine at the University of Alberta. The research team included Dr. Candace Nykiforuk (University of Alberta), Dr. Tracy Friedel (University of British Columbia), Dr. Lisa Given (Charles Stuart University, Australia) and Dr. Christine (Cassie) Kenney (Massey University, New Zealand). The knowledge users included Dr. Parminder Thiara (First Nations and Inuit Health Branch, Health Canada), Angeline Webb, (Canadian Cancer Society, AB/NT Division), and Miriam Wideman (Health Promotion Specialist, Government of the Northwest Territories). The community collaborators included Yellowknives Dene First Nation, K'alemi Dene School (Northwest Territories) and Queen Elizabeth School (Edmonton, Alberta).

Chapter 3 will be submitted to the International Journal of Qualitative Methods as Lukasewich, M., & Jardine, C., "Not all of us Aboriginals smoke": Exploring empowerment as a process through participatory video research with Aboriginal youth.' I was responsible for facilitating data collection and analysis, assisted by the partnering schools, and composing the manuscript.

Chapter 4 will be submitted to the Education Action Research as Lukasewich, M., & Jardine, C., "We came out of our shells through this whole process": Fostering space for positive youth development through community-based participatory research.' I was responsible for facilitating data collection and analysis, assisted by the partnering schools, and composing the manuscript.

# Dedication

To the youth with whom I worked, learned from, and laughed together. Thank you for sharing your wisdom and insights with me. Working with you has transformed and inspired me. Remember that you are capable, strong, and will achieve amazing things!

To all youth. You are our future. Stand up and speak out, as you can make a difference!

# Acknowledgements

They say it takes a village to raise a child. I believe it also takes a village to raise a master student as well! Numerous people have been instrumental in the success of this research and my accomplishments. I will be forever grateful for all of the support. Mahsi-cho! Thank you!

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To the teachers and principals of my partner schools – Queen Elizabeth High School and K'alemi Dene School - thank you for opening your school to me and wanting to engage in this research project. It was a wonderful experience to collaborate with you and be in your schools. This research would not have been possible without your support. I am grateful to have had the opportunity to work with you on a project that met your school's needs.

To my thesis committee – your work inspired and guided me. Thank you to my supervisor Dr. Cindy Jardine. I truly appreciate having the opportunity to situate myself within your larger research project. It has been a tremendous learning opportunity that I will never forget. Most of all thank you for your guidance and flexibility as I made my way through this journey. I am very thankful for my thesis committee members, Dr. Jane Springett and Dr. Yoshitaka Iwasaki who were patient fielding my endless questions and encouraging me that I was heading in the right direction. I am also grateful for your feedback and critical questions of my work. I am extremely appreciative for my external examiner Dr. Heather Castleden. I connected immediately with you and your work. I feel so fortunate to have had the opportunity to have you be a part of mine. Thank you very much for your insightful comments and critical review.

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To the Law and Risk Communication Health (LARCH) research group, I will be forever indebted for you unconditional support, encouragement, and guidance. You were always there for me and I can truly say my journey would have turned out much differently if I did not have your empathy and love. In particular, Janis Geary, Westerly Luth, Jennifer Ann McGetrick, Shelagh Genuis, and Stephanie Kowal, you ladies are true gems. A million thanks would never make up for what you have done for me over the years. I am truly grateful to have had you all along for my journey. Specifically, a huge thank you to Janis, Westerly, and Steph for their critical and supportive reviews of my thesis chapters. I would like to thank Keren Tang for being my companion while we navigated our journey in the North. Thank you for our many thoughtprovoking conversations about researching with Northern communities and working through my analysis with me. Erica Roberts, my critical health promotion buddy! Our endless tea dates and yoga sessions were critical to maintaining my health and wellness during my masters. Thank you for always being there for me. It has been wonderful to grow and learn with you throughout this process.

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# List of Abbreviations

CPBR	Community-based participatory research
EBHSR	Evidence based health science research
IRM	Indigenous research methodologies
NT	Northwest Territories
PYD	Positive youth development
SJYD	Social justice youth development
YEF	Youth empowerment framework

#### **Prologue: Situating the Researcher**

I contemplated for a long time about how to approach the beginning of my thesis. For me it did not seem appropriate to jump into a detailed explanation of my research without first providing background on who I am and where I come from. I have chosen to begin my thesis through a story with the intention of building a connection with you, the reader (Wilson, 2008). It is essential for me, as a non-Indigenous researcher working with Indigenous peoples, to build relationships first. Indigenous scholar Tuhiwai-Smith (1999) describes relationships as being the glue to life. This is the most important teaching I gained while on this journey of my master's degree.

I also struggled with the idea of writing in a linear structure when this approach is unable to capture the cyclical nature of the research process. This piece reflects my attempt to overcome the challenge of linearity, which is typically expected by academic audiences (Riecken et al., 2006; Wilson 2008). Arranged in one dimensional-sequential order, written words are unable to capture the dynamic and emergent nature of my lived experience during this research process. I hope that I am able to bring life and breath to the words on the page (Riecken et al., 2006). By exploring my personal tensions through telling a story, I aim to bring the reader along for my transformative journey. This also challenges the traditional expectations of academic writing, which tends to exclude the author's personal voice. After sharing a personal story, I will move on to locating myself where I will provide further detailed aspects of my life including who I am, and from where I come.

Writing a thesis is a very individual activity that is based on a collective process (Herr & Anderson, 2005). The words of my thesis have been constructed through a collaborative process, ongoing relationships, and collective discussions. I have struggled to distil the collaborative experiences into words on a paper, which never seem to capture fully the essence of the experience. Herr and Anderson (2005) describe the experience as a strange disconnect between the actual work that has been done and the solitary process of writing a dissertation. I therefore provide this story to show how collaborative research was a transformative experience for me, requiring me to explore beyond my initial ideas and expectations of the research process.

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## Sharing a Story: The Start of My Research Saga

I am grateful that the plane ride was quick. My nerves were getting the best of me as I was approaching a place I had never been before. Stepping out on to the tarmac of the airport to a breezy minus 30, I do not know where to go. I follow fellow passengers and manage to find my way into the noisy airport terminal where I can see the excitement of travellers being greeted by their loved ones. Standing in front of a giant mounted polar bear, I am so excited for the adventure I am about to embark on. But as I wait for my luggage the sense of nervousness washes over me again. I begin to question why I am here? I know that I have an amazing opportunity to experience a community based-participatory research project first hand, but I feel a sense of unease. The discomfort I am feeling makes me wonder what has brought me to this unfamiliar place; I am a Caucasian, heterosexual, middle class, university educated woman, and I was born into privilege and opportunity as a Canadian citizen. I am fearful of what has brought me here; do I have the right intentions? Whose interests does this work serve? Who is going to benefit? Am I creating or taking space? Leaving the airport, I am unable to honestly answer the questions that I have.

Fast-forwarding to the next day, my colleagues and I walk into the school; no one seems to be surprised or concerned that we are there. They all have seen many people come in and out of their school before. As I look around my new surroundings, the sun shines brightly through the school's large windows. I see students busy preparing food for their catering business, youth reading with younger children in the hallways, and a few students trying to catch up on their sleep by napping on a bench by the school's front doors. Then I hear the warmest "Hello, welcome, it is such a pleasure to meet you". As I am introduced to the school's principal, the unease and nervousness I feel briefly washes away. She proceeds to give us a tour of the beautiful school. I am amazed that it was built specifically to meet the needs of the children from the community. After the tour, we meet the youth who were to be participating in the project. I could see their excitement as they get to start working with the filmmaker to develop storyboards for the films they will be creating. I am excited too as I walk around to each youth group to introduce myself and have our first conversations. However, this short interaction is the extent of our relationship building before we jump into generating data, prior to having the youth immerse themselves in their film. As a new graduate student, I have only been in my master's program for six months as I sit down with the first group of youth. In the back of my mind, I feel unprepared. I wonder how I have gotten myself into a situation where I am uncomfortable with the direction and speed at which data generation was going. We sit around a circular table in the school's culture room. My pencils are freshly sharpened and as I turn the voice recorders on to start and what is the first thing that happens? One of the youth's says, "Why do we even need to do this?" I respond:

"Because your opinions matter and I want to hear what you have to say, it is important for me to listen to you as we create this project together. I also need to report to the people that gave us money, tell them what worked, and did not work and what you thought about the project. This is also a part of my school."

Instantly I thought: Whoa, what just happened, what did I just say? I just tried to convince him to do an interview that he didn't see value in. I was doing the one thing that I originally set out not to: perpetuate colonizing practices of research. I was not serving the interests of the youth. I jumped straight into data generation, serving the needs of the research project rather than being respectful and honouring the importance of building relationships and collaborative inquiry. We continued to complete the focus group despite the unease I felt with proceeding. I was completely unprepared to navigate the situation and emotions that arose from both the youth participants and myself.

The youth and I were packing up all the video gear and saying goodbye as the school bell rang. I leave the school feeling discouraged. Walking to my car, the frigid northern wind whips at my face, and I wonder how appropriate is it for me to be generating data when I do not even have a relationship with the youth. We did not even discuss what they want to get out of the research project and how they want to be involved. Caught up in generating data before the youth started making their videos, I was unable to take the time necessary to start building relationships and a collaborative partnership. I knew this was the opposite of what I originally aimed to do, enjoy the process of participatory research by building relationships. This facilitates the development of meaningful connections and supports the school and youth in carrying out a research project, that meets their needs. I know this is what is important and where the transformative learning occurs. The teachings that I receive while in the community and the knowledge we co-create is more important than the data I collect and the results that I write in my thesis. At this point, I felt an awakening of my own critical consciousness. I decided

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to commit to my research partners and myself to self-critique my work with the intension of being accountable to my participatory worldview.

Initially I was uneasy with sharing this specific story with you. I have subsequently come to realize that participatory research frequently involves balancing ideals and realities, and that the research process itself facilitates relationship building. However, I chose this story to build a relationship with you, by showing my vulnerability and emotional involvement with my research partners and the learning that took place for me on the importance of building relationships within research projects prior to data generation. I felt that it was important to show where the self-reflexive journey of my own positionality truly started and where my "lifelong commitment to self-evaluation and critique, to readdressing power imbalances" began (Tervalon & Garcia, 1998, p. 123). I acknowledge that I must continue to analyze critically, commonly accepted research practices in academia before applying these dominant methods to my research. Rather than focusing on scientific validity and reliability, I must first fulfill my relationship not only with myself and the world around me, but also the relationships I have with my community partners.

Thank you for allowing me to share openly and honestly with you, as this research journey has been a humbling experience for me. I hope that by reading this story you have started to get to know me better. I have done my best to be transparent about my intentions and to show my vulnerability in this process. I continue to move forward with an open mind and a good heart. I know that the opportunity to collaborate with the youth and their schools is a gift and an honour for which I will be forever grateful.

## **Self-Location**

Now that you have read one of my stories, I would like to locate myself. Location is fundamental to Indigenous research methodology (IRM), where from the outset the researchers put themselves forward. The researcher considers elements of who they are by exploring spiritual, political, economic, relational, geographic, environmental, and social aspects of their life (Absolon &Willett, 2005). When people locate themselves, it is more than merely their name and where they are from. Location situates and positions the researcher allowing, "the readers to make their own judgements about the research, knowing that there is no such thing as neutrality" (Absolon, 2011, p. 72). Indigenous scholars advocate that neutrality and objectivity in research

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does not exist and therefore location can begin the process of "establishing legitimacy and credibility" for the researcher (Absolon 2011, p. 72; Absolon & Willett, 2005). Particularly when researching in Indigenous contexts, location matters because "people want to know who you are, what you are doing and why" (Absolon, 2011, p. 71). When researchers locate themselves, the readers begin to understand their identity, who they are, where they are coming from, and where they are going (Absolon & Willett, 2005; Absolon, 2011).

Describing first who I am also allows the readers to "form their own judgements about [my] credibility and authority to search and write" (Sinclair 2003 in Absolon 2011, p. 73; Absolon & Willett, 2005) about the impact of participatory research approaches for Aboriginal youth's health and wellbeing. The only thing that I can represent with authority is myself (Absolon & Willett, 2005) and I begin here to gain your trust as I locate myself and describe my investment and my intention.

I am a daughter, a granddaughter, a sister, an aunt, a partner, and a friend. I am a graduate student, a researcher, and a human rights activist. I am a third generation Canadian with Ukrainian, Polish, and Irish heritage. I grew up in Edmonton, Alberta, Canada, a place that I am happy to call my home no matter where I am in the world. I love to travel to new places, and to step out of my comfort zone to learn about other cultures, experience different ways of living, and build relationships with people around the world. I feel connected to places I have never been, natural wonders I have never seen, and people I have never met because I believe we are all united by the breath that we share with each other and the trees that provide this breath. My spirit and soul are happiest in nature. This is where I feel the most connected to all beings, when I am listening to the whispers of the trees and learning from the wisdom of the earth. I go to my yoga mat to find inner peace. This is where I can go within to heal and grow, to balance my mind, body, and soul. Here too my practice emphasizes self-inquiry of who I am and why I am here. These questions facilitate my connection with the environment around me and understanding myself.

However, I know that when locating oneself it is more than just stating who I am and where I am from. Who I am and what brings me to this place, is the result of my lived experiences and the political, cultural, and social contexts I have been socialised in. Exploring critical life experiences to understand myself has required me to search into my own past to learn about how my journey has brought me here today. This has been a hard and painful, but

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rewarding and healing process, to truly reflect and acknowledge what brought me to work with Aboriginal youth. I believe there are two main pieces to my journey.

First, as a young adolescent I struggled to figure out who I was as many adolescents do. I felt underappreciated, that my opinions were not important, and I had no voice to express myself in meaningful ways. The coping mechanisms I used to deal with my struggles were not positive. It was not until I started to mature into adulthood that I began to find myself and be confident and happy with who I was becoming. I believe the painful journey of feeling alone as an adolescent and trying to find the strength within to know that I was valued has led me to work with youth. I think together, we can uncover their strength and belief in themselves, showing them that they really are assets and resources.

Secondly, I did not learn about the impacts of colonization until the last year of my undergraduate degree. I was horrified to learn about the disparities experienced by Aboriginal peoples because of residential schools, assimilation, and oppressive institutional policies. I was particularly disturbed because I had been educated in the Canadian school system my whole life and knew very little about the histories and lived realities of the first people of this land. I could not accept my ignorance because of being socialized in a Western<sup>1</sup> dominant culture and receiving my 'Western' education. I felt it was important for me to learn the true stories and histories from Aboriginal peoples and stand beside, supporting them in advocating for their rights.

I continue to struggle with the role my ancestors would have played in colonization, which I know continues to impact Aboriginal peoples to this day. Unfortunately, I cannot change the past, but I can change the future for our children. I am motivated to work for the first peoples of this land who generously shared their knowledge and resources with my ancestors so that they could survive. As the Aboriginal activist and educator, Lilla Watson says, "If you have come here to help me, you are wasting your time. But if you've come because your liberation is bound up with mine, then let us work together."

I think that my journey thus far has led me to this place, a place where I am committed to ensuring trust, accuracy, and truth. A place where, on the deepest level I believe we are all the same and through our interconnectedness, we can create positive change. I know youth are our

<sup>&</sup>lt;sup>1</sup> The term "Western" is referring to a worldview that developed from European culture and the Western hemisphere. Western ways of knowing tends to be dualistic, individualistic, bracketing concepts of time to focus on one generation, and knowledge is valid through objective observations, rejecting intuitive knowledge.

future generation of parents, leaders, and advocates. We must support them to achieve their true potentials.

I would like to thank you for allowing me to take the time to share a bit about myself and to have the space to locate. This is important because locating oneself as a researcher is "related to one's paradigm, or worldview" (Absolon 2011, p. 74), which I will discuss in Chapter 2. Through the process of locating myself, I have begun to know my own history and how my personal journey is integral to the research process. I realize that this is only the beginning and it is truly a continual process of learning and transformation. I know my location will change as the context of my life changes, as I grow, learn, and share experiences with others and myself. Yet, this is where I speak from now and is my current reality.

## **Thesis Outline**

This is a five chapter paper-based thesis, where Chapters 3 and 4 are standalone manuscripts prepared for potential submission to peer reviewed journals. In Chapter 1, I provide a general research introduction, review the literature, and situate the need for this research. In Chapter 2, I discuss the theoretical underpinnings of my work and the qualitative inquiry employed. I detail 'how' I conducted the research, first beginning with a description of my worldview, research paradigm, and methodological orientation to research. I provide descriptions of how I utilized IRM and the principles of community-based participatory research (CBPR) to inform my work. I then explain the theoretical frameworks that influenced my work, and the strategies of inquiry and data analysis employed. I also provide comprehensive details about the various aspects of the research project in the aim of facilitating transferability to other populations and/or situations.

Chapter 3 is prepared for potential submission to the journal *Education Action Research*. This manuscript explores how CBPR projects, specifically participatory video, have the potential to empower research participants. I concentrate on what the impact of the CBPR process was for the youth, and which aspects of the process lead to positive changes. Youth participating in this interactive, skill-building research project experienced positive personal transformation by increasing their capacity to act as change agents. The process of video making was more influential on youths' wellbeing than the actual final product developed. This was because they were active participants in exploring a health issue rather than passive recipients of a health

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message. The youth participating in this research project showed that, when provided an opportunity to effect positive changes, they not only have the desire and determination but also the ability. This paper highlights the common empowerment journey experienced by the youth from both locations, and how participatory video projects can contribute to this journey.

Chapter 4 is prepared for potential submission to the *International Journal of Qualitative Methods.* This paper explores the effect of involvement in participatory research processes for Aboriginal youth. The focus is on how participatory approaches to research truly impact the participants. This comparison paper explores similarities and differences between the two different research locations. The results show that a foundation of meaningful relationships, a culture of support and encouragement, and utilizing a strength-based approach can create a safe space for Aboriginal youth to participate. Youth from Edmonton, Alberta increased their sense of belonging while youth from Ndilo, Northwest Territories increased their sense of purpose. Both groups of youth also further developed their identities in ways that were meaningful to them. This manuscript also explores how the research context, specifically the school and community environment, had the potential to impact the positive assets youth can develop during a participatory research project.

In the final chapter, I provide a summary of key messages from this research, recommendations for researchers, policy-makers and youth, and ideas for future research and practice with Aboriginal youth. I conclude this thesis with a personal reflection on how the research process was a transformative learning experience for me.

## **Chapter 1: Introduction and Literature Review**

#### **General Research Introduction**

The research outlined in this thesis forms part of a larger, on-going, community-based participatory research (CPBR) program, led by Dr. Jardine in collaboration with various Canadian Aboriginal communities. Her research initiatives focus on producing visual health promotion messages together with Aboriginal youth, who act as agents of change in their communities. My research is situated within Dr. Jardine's CBPR project, *Engaging Aboriginal Youth in Tobacco Prevention Using Social Media*. In the CBPR video project, Aboriginal youth developed tobacco misuse prevention and cessation videos. The research project was designed to encourage Aboriginal youth to act as health promoters during and after the completion of the project by influencing their peers and school community to practice healthy behaviours.

I collaborated with high school age Aboriginal youth from the K'alemi Dene School, Ndilo, Northwest Territories, Canada and Queen Elizabeth High School, Edmonton, Alberta, Canada, as well as the schools' principals and teachers. As partners in this research project, the school personnel were interested in addressing tobacco misuse amongst their youth. In particular, the school personnel were interested in exploring the impact of the research process on the youth's health and wellbeing. I intended to have the research project extend beyond the traditional, narrow focus of final 'outcomes', to explore the process of participation, capturing how involvement in research provides the building blocks for youth to further positive health and wellbeing changes. Furthermore, the intention of this thesis is not to compare the health status of Aboriginal youth to non-Aboriginal youth, rather to discuss the opportunities for engaging youth in CBPR for positive health outcomes.

The overall aim of my thesis research was to explore from the perspectives of the participants the impact of participating in a CBPR video project that was focused on tobacco misuse. Specifically, I assessed how participation can affect participants' health and wellbeing, beyond the deliverables associated with tobacco misuse such as reduction or cessation of tobacco products and changes in knowledge, attitudes, and behaviours towards smoking. I determined the value added from engaging in a participatory video research process and the impact of participation for the youth participants' health and wellbeing. By working with Aboriginal youth

and their schools, the goal of this thesis was to contribute to the limited evidence on the impact of the process of participating in a CBPR video project for youths' health and wellbeing.

#### **Choice of Terminology**

Terminology has the potential to misrepresent people, is powerful enough to divide people, but also has the potential to empower populations through self-identification (Kesler, 2009). My intention is to use language that is inclusive, allowing space for different ways of knowing and understanding. In this thesis, I have deliberately and thoughtfully chosen to follow the terminologies outlined by the International Journal of Indigenous Health (International Journal of Indigenous Health, n.d.), as well as Indigenous scholars.

The term 'Indigenous' is inclusive of all First Peoples around the world whose ancestry is the original inhabitants of the land (Wilson, 2008). The term encompasses international, transnational, and global Aboriginal groups (Kesler, 2009). Indigenous is an inclusive term and "is a way of including many diverse communities, language groups, and nations, each with their own identification" (Tuhiwai-Smith, 1999, p. 6). However, it is important to recognize the political nature of this universal term and acknowledge that it represents the collective of many distinct populations who have different experiences with colonization and imperialism (Tuhiwai-Smith, 1999; Wilson, 2008) and that there is not solely one Indigenous paradigm.

I use the term 'Aboriginal' when I am referring specifically to the first inhabitants of Canada. The Canadian Constitution Act of 1982 recognizes three distinct groups of Aboriginal peoples (First Nations, Métis, and Inuit) who all have unique histories, languages, cultural practices, and spiritual beliefs (Government of Canada, 2009). When possible I refer to Aboriginal peoples' specific identity, when they have identified themselves in that way, as this more accurately represents their unique aspects (International Journal of Indigenous Health, n.d.; Wilson, 2008).

The term research is "one of the dirtiest words in the indigenous world's vocabulary" and many Indigenous communities believe they are the most researched group in the world (Tuhiwai-Smith, 1999, p. 1). Stemming from a history of research associated with colonization and Western ideals of research being imposed on communities that they did not ask for or want, has created a history of mistrust (Tuhiwai-Smith, 1999; Wilson, 2008). I therefore approached this research *with* my community partners and utilized the principles of participatory research

and Indigenous research methodologies (IRM) to guide my actions. I was also critically reflective throughout my thesis work and aimed to continually question "taken-for-grantedness" (Ledwith & Springett, 2010, p. 151), critiquing research dialogue that is inherently colonised.

Research terminology is traditionally situated within positivistic language. I choose to use the term "strategies of inquiry" suggested by Wilson (2008, p. 40). The terminology implies that there is more than one research method that can be used to explore the topic. Using this terms allows for change and adaptation throughout the research process (Wilson, 2008), essential to CBPR and the emergent research design utilized in my research.

I choose to use the term 'tobacco misuse' to capture inappropriate tobacco use for all form of tobacco except for traditional uses (e.g. smoking, chewing tobacco, cigars, and dipping tobacco). When referring to tobacco used for traditional or ceremonial purposes I use 'tobacco use'.

When referring to the larger CBPR project "*Engaging Aboriginal Youth in Tobacco Prevention Using Social Media*", which my thesis research is situated within, I refer to it as the 'CBPR video project'.

When discussing health and wellbeing within this thesis, I am referring to the pre-requisites for healthy being. This includes but is not limited to; social inclusion (e.g. supportive relationships and involvement in community and group activities), freedom from discrimination and violence (e.g. valuing diversity, self-determination, and control of one's life) (Victorian Health Promotion Foundation, 2005), increased capabilities to be active agents in addressing health inequalities (e.g. increasing ones agency) (Abel & Frohlich, 2012), and community empowerment (e.g. process in which people gain control, increase the attributes, and build capacities to address factors that shape their lives) (World Health Organization, 2009).

#### **Literature Review**

On the whole, Indigenous peoples are resilient (Stout & Kipling, 2003), culturally diverse (Voyageur & Calliou, 2000), and prioritize community over self (Adelson, 2005; Denzin & Lincoln, 2008) despite experiencing significant systemic health inequalities (Ning & Wilson, 2012). Reflecting these characteristics, Indigenous communities are mobilizing to address health inequalities experienced, and the related coping mechanisms such as tobacco misuse (Daley et al., 2010; Ross, 2011; Valentine, Dewar, & Wardman, 2003). CBPR is a particularly effective

approach for addressing Aboriginal youth tobacco misuse (Ford, Rasmus, & Allen, 2012; Horn, McCracken, Dino, & Brayboy, 2008; Jardine & James, 2012). In CBPR, the research question originates from the community, the research process equitably involves community members, and the research culminates in actions to enable change (Israel, Schulz, Parker, & Becker, 1998; Cargo & Mercer, 2008). CBPR is based on a view of youth as resources for community change as opposed to the commonly portrayed image of youth as problems (Checkoway & Gutierrez, 2006; Lombardo, Zakus, & Skinner, 2002). This perspective is particularly important for marginalized groups, including Indigenous peoples and youth, who traditionally have not had a voice in the research process (Blodgett, Schinke, Peltier, & Pheasant 2011; Flicker, 2008; Wallerstien & Duran, 2008).

Limited evidence exists on how participation in CBPR affects individuals' health. In particular, youths' perspectives of being included in CBPR projects are rarely explored. Therefore, this misses the context of their unique experiences (Jacquez, Vaughn, & Wagner, 2012) and we do not know how the process of participation in research activities affects their health and wellbeing.

This literature review explores CBPR with Aboriginal youth. I then describe Aboriginal youth and tobacco misuse. Next, I review evidence-based health science research (EBHSR) and health research with Indigenous peoples. I subsequently focus on participatory research and a strength-based approach to working with youth as an alternative to the biomedical deficit-based research approach. I specifically focus on CBPR and arts-based participatory research with youth. Lastly, I conclude by presenting how participation in CBPR can have health impacts for participants and situate the present study within the larger body of research.

However, before moving onto discussing the impact of participation in research, it is necessary to first review colonization and the effect on health inequalities experienced by Aboriginal peoples in Canada. I choose to discuss this topic to respect Indigenous peoples and scholars who clearly document that health and wellness of Indigenous peoples must be considered within the broader context of colonialism and its impacts (Greenwood, 2005; Kovach, 2009; Lawrence, 2003; Tuhiwai-Smith, 2012; Wilson, 2008).

## Health Inequality Experienced by Aboriginal Peoples

Aboriginal peoples are the original peoples of North America. The Canadian Constitution Act of 1982 recognizes three groups of Aboriginal peoples with unique histories, languages, cultural practices, and spiritual beliefs: First Nations, Métis, and Inuit (Government of Canada, 2009). European colonization of Canada was accompanied by an attempt to exterminate Aboriginal cultures (Kelm, 1996; Sinclair, 2007), social distinctiveness (Bourassa, McKay-McNadd & Hampton, 2004; Lawrence, 2003), and remove Aboriginal peoples from their lands and traditional territories (Coates, 2008; First Nations Study Program, 2005). This systematic destruction of Aboriginal cultures has not improved the quality of life for Aboriginal peoples (Adelson, 2005). Unfortunately, the legacies of the policies are contemporary realities of Aboriginal peoples in Canada today (First Nations Study Program, 2005; Simpson, 2004).

Because of the Canadian government's colonial policies and practices, Aboriginal peoples continue to struggle due to generations of historical trauma; cultural, identity, and language loss; and a disconnection to their land (Adelson, 2005; Mikkonen & Raphael, 2010). Aboriginal people remain essentially excluded from the political, economic, and social arenas in Canada, resulting in increased health disparities and social and economic disadvantage (Adelson, 2005; First Nations Study Program, 2005; Kiepal, Carrington, & Dawson, 2012; Reading, 2009).

The undermining of Aboriginal cultures and societies has had serious ramifications for the health of Aboriginal people. Social exclusion reduces communities' and individuals' ability to cope with adverse life events (Wallerstein, 2006). People misuse tobacco as a coping mechanism to deal with the social, political, economic, cultural, and historical injustices they face (Brady, 2002; Dawson, Cargo, Stewart, Chong, & Daniel, 2012; Siahpush, Brown, & Scollo, 2002). For Aboriginal people injustices include, as illustrative examples, the enduring effects of colonialism (Adelson, 2005), residential school attendance (Kelm, 1996), low socioeconomic status (Kiepal et al., 2012), poor housing (Mikkonen & Raphael, 2010), and limited health care (Macaulay, 2009; Reading & Wien, 2009). Adults and youth tend to misuse tobacco to cope with family disruptions, stressful situations, and to manage and self-regulate their moods and emotions (Braverman, 1999; Turner, Memelstein, & Flat, 2006; Valentine et al., 2003). In the context of the significant personal and societal stress Aboriginal peoples in Canada experience, it is unsurprising that Aboriginal peoples, particularly Aboriginal youth in Canada

have higher rates of tobacco misuse than non-Aboriginal peoples, resulting in further health disparities.

#### Aboriginal Youth and Tobacco Use and Misuse

'Youth' is a fluid age category, encompassing the period of transition from childhood dependence into adulthood independence (UNESCO, 2014). The focus of this thesis is high school aged youth ranging from ages 14-18 years old and in grades 9-12. These youth are at a critical stage of biological, cognitive, emotional, and social transition (Eccels & Gootman, 2002; World Health Organization, 2015). They are learning social norms and values, forming relationships and the skills to grow into healthy adults (Eccles & Gootman, 2002; World Health Organization, 2015). This transition period into adulthood is when behaviours, such as substance abuse, smoking, violence, and unsafe sexual practices that cause 70% of premature deaths among adults, begin (World Health Organization, 2001). Therefore, it is essential to develop specific tobacco misuse interventions that address the particular needs of youth.

Aboriginal peoples are the fastest growing demographic in Canada, comprising 4% of the Canadian population (Ning & Wilson, 2012). Forty-six percent of the Aboriginal population are under 24-years old, whereas 30% of non-Aboriginal people are under 24-years old (Government of Canada, 2014). This means Aboriginal youth have the potential to dramatically shape Canadian society. However, Aboriginal youth continue to experience health disparities and social inequities in Canada (Ning & Wilson, 2012), creating a challenge for youth to reach their full potential.

The high rates of tobacco misuse amongst Aboriginal youth are concerning (First Nations Centre, 2005; Retnakaran, Hanley, Connelly, Harris, & Zinman, 2005). In northern Canadian communities, Aboriginal youth are 2-3 times more likely to misuse tobacco than other urban youth (GNT Health and Social Services, 2009). In the Northwest Territories, Aboriginal youth are five times more likely to misuse tobacco (GNT Health and Social Services, 2009). Although tobacco misuse rates for Aboriginal youth are declining, they are still higher than the Canadian average (Ritchie & Reading, 2004). The high rates of Aboriginal youth misusing tobacco may be related to the social and cultural acceptability of tobacco misuse (Valentine et al., 2003), particularly among their peers (Ritchie & Reading, 2004).

Considered a sacred plant within Aboriginal populations across Canada, traditional tobacco is used for ceremonial purposes to communicate with the spirits; thank the Creator; purify the mind; heal the body with prayer; in rites of passage; and for medical purposes (Boomer, 2003). The traditional uses of tobacco are associated with many positive social, spiritual, and mental health outcomes (Stanton Elders' Council, n.d.), whereas the commercial uses of tobacco are associated with negative physical health outcomes (Centre for Disease Control and Prevention 1994; Mackay & Eriksen, 2002). To be successful, tobacco misuse programs must acknowledge the positive cultural uses for tobacco in different communities and differentiate these from commercial tobacco misuse (McKennitt, 2007).

A culmination of centuries of injustice, and resulting social inequalities has highlighted the need to address the health disadvantages experienced by Aboriginal peoples, including Aboriginal youth. Health research has attempted to address the disparity of tobacco misuse amongst Aboriginal youth. However, public health interventions that address tobacco misuse have failed to consider different knowledge systems and life contexts that impact behaviours (Springett, Owens, & Callaghan, 2007). Particularly in relation to tobacco misuse prevention and cessation, interventions developed have actually "increased the levels of health inequalities" for disadvantaged groups (Springett et al., 2007, p. 244). The current dominant biomedical perspective, within which these interventions are developed, EBHSR, is fundamentally flawed when used in Indigenous contexts.

#### Health Research with Indigenous Communities

Despite good intentions, public health research in Indigenous communities is strongly linked to imperialism and colonialism (Tuhiwai-Smith, 2012). The dominant evidence based research movement in public health research, EBHSR, is rooted in a Euro-Western postpositivist paradigm, and is shaped by centuries of colonial policies (Holmes, Murray, Perron, & Rail, 2006). EBHSR is grounded in a disease-based and deficit-based biomedical medicine model (Fletcher 2003; Stewart, Reicken, Scott, Tanaka, & Riecken, 2008; Springett, 2010; Wright, Roche, von Unger, Block, & Gardner, 2009), where the improvement of health is directed by curing illnesses rather than preventing disease (Springett, 2010). The goal of EBHSR is to find objective knowledge and systematically address health problems and their causes (Glasgow, Vogt, & Boles 1999; Wright et al., 2009). In EBHSR, an intervention will create

evidence of the effectiveness of the intervention by producing the desired health outcome (Holmes et al., 2006).

EBHSR currently dominates the planning of health interventions (Glasgow et al., 1999; Wright et al., 2009). Focusing on isolated behavior changes, EBHSR ignores the interactions between people's lives, behaviors, and environmental, social, political, and economic contexts (Cross et al., 2010; Springett et al., 2007). This reductionist and dualistic perspective separates the person into individual parts that are addressed independently without consideration of the whole person. Furthermore, the one size fits all prevention approach fails to acknowledge other ways of knowing and alternative research practices (Blodgett et al., 2011; Cross et al., 2010; Springett et al., 2007). Not considering different knowledge systems and cultures has actually resulted in an increased in health inequalities for marginalized populations (Springett, 2010).

EBHSR defines what constitutes 'good science' - what knowledge can be used for public health practice. Unfortunately, many policy makers and health professionals venerate EBHSR, thereby constructing a hierarchy of knowledge excluding all other forms of knowledge (Fletcher, 2003; Springett et al., 2007) as scientifically imperfect and lacking practical value (Holmes, et al., 2006). This hierarchical process uncritically accepts EBHSR as the superior knowledge system, promoting and reproducing one objective way of knowing while excluding other forms of knowledge (Fletcher, 2003; Springett et al., 2007). On the rare occasion that Indigenous ways of knowing are acknowledged in research, it is still often forced to fit within a Western framework (Hart, 2010). This deficit approach silences Indigenous ways of knowing within the academic, policy, and practice domains while also failing to address the health needs of Indigenous communities (Kendal et al., 2011; Tuhiwai-Smith, 1999). Consequently, Indigenous peoples are frequently further colonized within research and healthcare settings and health inequalities persist.

While there is much diversity among Indigenous peoples, the perception of health is generally broader than the definition endorsed by EBHSR. Indigenous people describe health as holistic wellness, not just the absence of disease. For many Indigenous peoples, the holistic wellness model encompasses four areas of health: physical, mental, emotional, and spiritual (Lavallée, 2007; McKennitt, 2007). The dismissal of this wellness model in the biomedical-based health care system in Canada further marginalizes Aboriginal peoples (Adelson, 2005; Macaulay, 2009) and reduces the effectiveness of health programs developed through EBSHR.

The unwillingness of public health researchers to integrate the Indigenous wellness model of health into interventions for Indigenous populations perpetuates implicitly colonial attitudes when conducting health research on Indigenous peoples.

Within this EBHSR approach, research has been conducted *about* and *on* Indigenous peoples rather than *with, for,* or *by* Indigenous peoples (Blodgett et al., 2011; Brant Castellano, 2004; Wilson, 2008). Researchers parachute into the communities to conduct their research and leave just as quickly, never to be heard from again (Brant Castellano, 2004; Castleden, Sloan Morgan, & Lamb, 2012). This kind of research has led Indigenous communities to mistrust the research process (Kendal et al., 2011). Because of this legacy, researchers need to critically assess their relationships with communities and the impact of research approaches and methods on the community not only during the research process but also once the research is completed.

The EBHSR paradigm implicitly endorses a deficit-model that focuses exclusively on the problems Indigenous populations face without recognizing any other aspects of the Indigenous experience of wellness (Brough, Bond, & Hunt, 2004). Researchers aim to "fix up the problems for Indigenous peoples rather than supporting their existing and potential strengths" (Tsey et al., 2007, p. S35). Focusing on problems, negative aspects of life, and illness instead of Indigenous conceptions of health and wellness (Reynolds-turton, 1997 in Wilson, 2008) has resulted in a "proliferation of negative stereotypes about Indigenous communities" (Wilson, 2008, p. 17) in public health. Public health researchers have recognized the need to move towards holistic approaches in health research (Reading & Nowgesic, 2002). However, holistic approaches are not generally being used as a central approach to public health research, planning, and treatment with Indigenous peoples (Stewart et al., 2008).

Currently, the EBHSR approach of 'fixing' Indigenous problems and health disparities through Western research methods is not working, and in some cases is causing further harm. Research programs and practices need to build from the knowledge base of Indigenous peoples' beliefs and values to contribute to greater community well-being. When developing interventions with Indigenous communities, public health researchers "need to not only involve, but also collaborate with, communities through all stages of the research process " (Castleden et al., 2012, p. 162). According to Kendal, Sunderland, Barnett, Nalder & Matthews (2011), researchers need "new ways of seeing that respect local Indigenous ways of knowing and adopt participatory approaches" (p. 1719). Participatory research is a methodological orientation to research that can

work towards decolonizing the research process (Castleden et al, 2012; Fletcher, 2003; Simons & Christopher, 2013) and addresses the unsuitability of EBHSR in Indigenous contexts.

#### **Participatory Research**

Participatory research addresses the weaknesses of EBHSR by rejecting the positivist paradigm and allowing, respecting, and endorsing multiple ways of knowing (Israel et al., 1998). Participatory research includes communities in the decision-making processes (Wallerstein & Duran, 2008), increases research relevance to participants (Macaulay et al., 2011), and is effective at reducing health disparities (Cargo & Mercer, 2008). 'Participatory research' is an umbrella term used for research approaches that engage community partners in collaborative relationships throughout the whole research process (Macaulay et al., 2011; Minkler & Wallerstein, 2008). Participatory research is also known as action research, participatory action research, cooperative action research, participatory evaluation, and CBPR (Cargo & Mercer, 2008; Israel et al., 1998). This thesis focuses specifically on CBPR, which I describe briefly in the following section and in greater detail in Chapter 2 - Theoretical Underpinnings and Strategies of Inquiry.

#### **Complementary Approaches to Research with Aboriginal Youth**

Aboriginal youth, a disenfranchised population, can benefit from participatory approaches to research. Utilizing a strength-based approach to research where youth are viewed as resources and community assets (Checkoway & Gutierrez, 2006), and following CBPR principles (Israel et al., 1998), creates an opportunity to address the marginalization that Aboriginal youths often experience.

**Strength-based approach.** As a society, it is necessary for us to work with and support youth who are transitioning through the challenging period of adolescence to build positive attributes that support healthy development and behaviours. Unlike the deficit-based EBHSR approach, which uses disease statistics and epidemiological risk factors that ultimately stereotype Indigenous populations (Brough et al., 2004), strength-based approaches enable communities to work towards empowerment (Brough et al., 2004), a central tenet in positive youth development (Wong et al., 2010). In a strength-based approach, youth are considered resources for their

communities rather than problems (Checkoway & Gutierrez, 2006; Lombardo, Zakus, & Skinner, 2002).

Underpinning a strength-based approach is the belief that all youth have the capacity and potential for success (Kim, Crutchfield, Williams, & Hepler, 1998; Lerner, Dowling, & Anderson, 2003). The approach acknowledges youths' intrinsic assets, and emphasizes their capacity to address issues they have identified as important (Lerner et al., 2003; Wong, Zimmerman, & Parker, 2010). Predicated on the idea that youth have the ability and potential for success, a strength-based focus promotes positive youth development and empowerment (Kim et al., 1998; Lerner et al., 2003). Using this approach with Aboriginal youth in Canada is important as it takes into consideration the historical context of colonization and assimilation policies that youth experience (Crooks, Chiodo, Thomas, & Hughes, 2009). For this reason, I focus on positive attributes of Aboriginal youth in my attempt to move away from a deficit-based description of their lived experiences.

Crooks and colleagues (2009) further explain, "for youth to benefit from these strengthsenhancing opportunities, they need to be engaged by them" (p. 161). Youth engagement is defined as the "meaningful participation and sustained involvement of a young person in an activity, with a focus outside of him or herself" (Centres of Excellence for Children's Wellbeing, n.d., p. 2). Youth engagement will look different for different youth, where youth can show interest by attending meetings without contributing verbally, while other youth may engage by advocating for program activities (Centres of Excellence for Children's Wellbeing, n.d.). Furthermore, engagement can be difficult to measure because youth can express a variety of "thoughts, feelings, and actions" for the same activity (Crooks et al., 2009, p. 167). Nonetheless, combining a strength-based approaches with CBPR can create a research process that facilitates youth engagement as youth increase their critical thinking skills (Wong et al., 2010), acquire knowledge (Mitra, 2004), develop awareness of problems, and engage in teamwork that provides solutions to pressing community problems (Caraveo, Perez, & Hernandex, 2010).

**Community-based participatory research.** Aside from the goals of the research itself, CBPR aims to develop mutual trust and respect, facilitate empowerment, and create ownership of the research, leading to sustainability of research outcomes and projects in communities (Cargo & Mercer, 2008). In CBPR, the research processes tend to be described as more important than the intended research outcomes (Castleden et al., 2012; Tuhiwai-Smith, 1999).

CBPR facilitates the development of context-specific solutions by working with communities to address their specific needs and improve social and economic conditions (Cargo & Mercer, 2008; Castleden et al., 2012; Horn et al., 2008). Through responsive and responsible research, CBPR projects have positively impacted Aboriginal communities in Canada (Blodget et al., 2011; Riecken, Scott, & Tanaka, 2006; Mackinnon & Stephens, 2010). Furthermore, involving youth in CBPR initiatives is also a promising way to promote positive health behaviour development (Flicker, 2008; Ford et al., 2012; Jardine & James, 2012; MacDonald et al., 2011).

## **Participatory Research with Youth**

Youth draw on their own experiences to help develop innovative solutions to problems faced in their communities (Bradley, Deighton, & Selby, 2004; Genius, Willows, Alexander First Nation, & Jardine, 2014). Rather than being passive recipients of a pre-determined research program, engaging youth in CBPR "has potential to promote individual and community health by satisfying developmental needs in a positive manner while enhancing the relevance of research...to [the] lived experiences of children and adolescents" (Wong et al., 2010, p. 101). Engagement in research refers to meaningful and sustained participation with a focus beyond the individual (Centres of Excellence for Children's Wellbeing, n.d.). However, there is a difference between youth engagement and youth participation. In other words, youth can participate in research to varying degrees, which will be expressed differently for each youth and may not necessarily result in meaningfully engaged. Hart's ladder of youth participation delineates eight stepwise levels of participation for youth and adult interactions (Hart, 1992). The progression of participation ranges from non-participation (manipulation, decoration, and tokenism) to degrees of participation (informed, consulted and informed, adult-initiated and shared decisions with children, child-initiated and directed, and child-initiated sharing decisions with adults) (Hart, 1992). Within the context of this thesis, youth participation can be described as adult-initiated with shared decision-making with youth. The adults had the initial idea but the youth were involved in all phases and steps of the research process, including decision-making and consideration of their views throughout the research project.

Participatory research is fundamentally about creating opportunities for community members to have a voice and right to speak. Youth also need a voice in the research process if programs are going to positively affect their health (Blodgett et al., 2011; MacDonald et al.,

2011). As youth are experts in their own lives, they can contribute to developing solutions to problems faced in their own communities (Genius et al., 2014). More importantly, the solutions to the problems that youth face are not found in expert knowledge but rather from the lived experiences of the youth themselves (Bradley et al., 2004). Therefore, to develop effective health interventions in their communities, youth need to have a voice that is acknowledged and incorporated throughout the research process.

Gaining a voice and being heard also facilitates youth empowerment as they develop the skills and confidence to be agents of change in their communities (Charmaraman, 2010; Foster-Fishman, Nowell, Deacon, Nievar, & McCann 2005; Kohfeldt, Chhun, Grace, & Langhout 2011). It is also through the process of participation in social action, formation of sustainable groups, engagement in community and increases in self and collective efficacy that empowerment occurs (Holden , Crankshaw, Nimsch, Hinnant, & Hund, 2004; Wallerstein, 2006). The process of empowerment itself leads to improved health outcomes (Holden et al., 2004; Wallerstein, 2006). Marginalized youth have described the importance of having their abilities and potential recognized, increasing their confidence, and empowering them to feel that they can succeed (Iwasaki et al., 2014).

After participating in tobacco misuse control efforts, youth have described feeling empowered to create positive changes (Holden et al., 2004; LeRoy, Benet, Manson, Astin, & Mills, 2004; Ribisl et al., 2004). Specifically, participatory youth empowerment programs have been effective in addressing risk factors associated with youth tobacco misuse (LeRoy et al., 2004). Furthermore, Indigenous youth have positively benefited from participating in tobacco misuse initiatives (Ford et al., 2012; Horn et al., 2008; Jardine & James, 2012; Ross, 2011). However, Aboriginal youths' perspectives of being included in CBPR are rarely assessed, missing the "contextual input necessary to represent the unique youth experience" (Jacquez et al., 2012, p. 177). Exploration into Aboriginal youths' experiences is timely to contribute to existing knowledge on youth led programs that facilitate youth as leaders within their community, transforming their voices into community resources for change.

However, there is limited evidence on what the health impacts are of including Aboriginal youth in participatory video projects, particularly when they develop health promotion videos for their peers and communities. Chinman and Linney (1998) propose that, for youth to benefit from an empowerment approach, they must participate in positive and

meaningful activities, learning useful and relevant skills for behaviour change. Furthermore, marginalized youth have discussed how meaningful engagement is key for their own positive development (Iwasaki et al., 2014). Meaningful engagement with youth in the research process can be achieved through arts-based participatory research.

Arts-based participatory research with Aboriginal youth. Youth are increasingly involved in health research through arts-based participatory research (Conrad & Kendal, 2009) including methods such as photovoice, (Wang, 2006), popular theatre (Conrad, 2008), and media technology research (Flicker et al., 2008). Through these forms of research, youth create personal responses to the issues affecting their lives (MacDonald, 2011). Participatory video is one arts-based method that is gaining traction among researchers working with Aboriginal youth (Genuis, Chekoa Program, & Jardine 2013; Ford et al., 2012; Riecken et al., 2006;).

Participatory video is a technique used to involve youth in shaping and creating their own videos (Lunch & Lunch, 2006). The aim is to increase accessibility for participants to voice their concerns by using creative methods (Lunch & Lunch, 2006). "Video is a medium for connecting ideas with messages" (Riecken et al., 2006, p. 277), and the process of creating that video can be empowering for individuals taking part (Lunch & Lunch, 2006). Participatory video has the potential to engage marginalized populations, enabling them to communicate their needs, find creative solutions to their problems, and facilitate empowerment (Lunch & Lunch, 2006).

Through participatory video, youth can develop health promotion messages for their peers and communities. Participatory video research projects facilitate health promotion activities that address the community's specific needs (Chávez et al., 2004). Working with communities to address their concerns enhances the empowerment process of participation, "key to enabling people to make healthy choices within the limits set by their social, political, cultural, and economic environment" (Springett, 2010, p. 283). Participatory video is a method for creating health promotion interventions that benefit the whole community.

Youth also benefit from participatory video. Youth become active participants in their community, and are seen as assets and resources to be included in community programming (Holden et al., 2005). Youth feel that they have ideas that benefit their communities and want to be involved in creating changes (Valaitis, 2002). By creating their own videos, youth can recreate social norms and resist negative forces that may influence their health behaviours (Riecken et al., 2006). Through engaging in participatory video, youth build resilience, which

can reduce negative coping behaviours, such as tobacco misuse, when facing adversity (Kim, et al., 1998; Maton, 2008). They can articulate and share their own stories in the way that they choose (Riecken et al., 2006). Youth can also show their world, perspectives, and convey their culture and traditions, through videos (Sharma, Reimer-Kirkham, & Meyerhoff, 2011). Participatory video is an excellent way for youth to participate in their community and develop programs that meet their needs, ultimately empowering youth, and impacting healthy development.

Participatory video has already been effectively employed in youth tobacco misuse interventions (Genuis et al., 2013). Previous research has shown that through the creation of videos Aboriginal youth developed critical consciousness about their environment and sociopolitical settings as well as increased their confidence (Stewart et al., 2008). Furthermore, participatory video is a viable strategy in health promotion practice, providing opportunity for inclusion and diverse images and voices (Chávez et al., 2004)

# The Social and Health Benefits of Youth Participating in Research

Not only does including youth in research projects lead to context-specific solutions, involvement also encourages healthy cognitive and social development (Wong et al., 2010). The process of meaningful participation in research activities has transformative potential for marginalized groups, who traditionally have had limited power in the research process (Blodgett et al., 2011; Flicker, 2008; Wallerstein & Duran, 2008). Youth not only develop research and leadership skills, and an increase sense of ownership over the final research project (Jardine & James, 2012), but through participation and contribution, youth increase their confidence, self-efficacy, empathy, and self-esteem (Wong et al., 2010). Subsequently, youth develop self-confidence that extends beyond the life of any project. Engaging youth in constructive dialogue can facilitate social inclusion (Wallerstein, 2006), creating a healthy environment for active decision-making (Checkoway & Gutierrez, 2006) leading to positive social relations and societal change (Hamilton, Hamilton, & Pittman, 2004).

The methods chosen to use in research projects have been demonstrated to have an impact on those who are a part of the research process (Lunch & Lunch, 2006; White, 2003). Regardless of the intended benefit of the research project, the research approach can significantly affect participants. Therefore, it is vital that researchers are critical of the methods employed and

take into consideration the potential unintended outcomes of those methods. Scholars are calling for research that explores the ways in which participation itself affects individuals and communities health (Foster-Fishman et al., 2005; Wallerstein, 2006; Wright et al., 2009). By understanding the added benefit of the participatory process in health research, improvements in health outcomes of the populations involved can be enhanced (Wallerstein, 2006; Wright et al., 2009).

#### How Does Participation in Research Impact Health?

CBPR is a significant improvement over EBSHR, however, there is a lack of evidence on certain outcomes of CBPR. Most of the literature on CBPR projects focuses on describing the processes to create and maintain research partnerships (Edwards, Lund, Mitchell, & Andersson, 2008; McHugh & Kowalski, 2009); key principles for CBPR implementation (Fletcher, 2003; Israel et al., 1998); CBPR research design and methodological challenges (McHugh & Kowalski, 2009); and outcomes attributed to CBPR partnerships (Cargo & Mercer, 2008; Viswanathan et al., 2004). Moreover, there is a tendency to report on group and partnership dynamics when exploring participation in CBPR (Israel et al., 1998). While these areas are important to capture for researchers approaching CBPR projects, they miss the impact of participation for those involved, particularly youth who tend not to be included in discussions of impact.

There is a paucity of evidence on the effectiveness of participatory research approaches to achieve positive health outcomes over traditional non-participatory approaches in the literature on participatory research (Cargo & Mercer, 2008; Israel et al., 1998; Viswanathan et al., 2004). This is partially due to the complexity of documenting CBPR projects and resultant health outcomes among participants, which can result in weak assessments of CBPR outcomes (Macaulay et al., 2011; Wallerstein et al., 2008). Furthermore, there is a little evidence to suggest that participation in CBPR promotes positive health outcomes in youth.

A realist review on the benefits of participatory research found that unintended outcomes, such as capacity building and increased self-empowerment, tended to have a greater impact on the participants' wellbeing than the primary intervention outcomes (Jagosh et al., 2012). Aboriginal youth have also identified positive personal impacts from being meaningfully engaged through CBPR (Ford et al., 2012). Previous research has used the voices of program participants to explore their meaning of successful outcomes and the impact of participation in

various community-based organizations on individuals, families, neighborhoods, and communities in the inner city of Winnipeg (Mackinnon & Stephens, 2010). As CBPR is an interactive process rooted in communities and built on their local knowledge, it is important to capture the impact or changes that occur through the research process rather than focusing solely on the intended outcomes at the end of the research.

Since "contemporary public health is as much about facilitating a process whereby communities use their voice to define and make their health concerns known as it is about providing prevention and treatment" (Wallack, Dorfman, Jernigan & Themba, 1993 cited in Bradley et al., 2004, p. 198), consideration should be made on the impact of these research processes. Authors have argued that "the process is the impact" in participatory research projects (Bowers, 2013, p. 68) and that "more needs to be done to critically and explicitly consider who benefits (and how)" in CBPR (Flicker, 2008, p. 71).

### **Research Gap**

There is a gap in knowledge of what happens for participants in a research projects. With a focus on final products, intended outcomes as a result of the research, and deliverables of tobacco control initiatives, the lived experience of participation is missed. Therefore, this thesis addresses the significant gap in our knowledge of the impact of CBPR processes for Aboriginal youth who are participating in a tobacco misuse video project.

It is known that EBHSR propagates disenfranchising attitudes and practices in public health interventions. CBPR is a much better alternative, particularly when combined with strength-based approaches that envision youth as community assets. The majority of research on CBPR outcomes focuses on the primary research goal of the project, but very little work has been done to determine if the underlying goals of participatory approaches, such as capacity building, increased self-esteem, and empowerment are being met. Even less research has been conducted on the experiences of Aboriginal youth engaging in participatory video research. These knowledge gaps limit our ability to ensure our community partners are being positively affected by their involvement in CBPR. To address the gaps in our understanding, I will identify the impact of participating in CBPR focused on tobacco misuse by exploring the participant perspectives throughout the research process.

This research has the potential to benefit future participatory research projects engaging with Aboriginal youth. Within the context of tobacco misuse prevention and cessation, this research provides evidence on how participating in research processes builds a foundation for youth to incur positive health and wellness outcomes. Findings lend support to the value of youth participation throughout the research process, and how acting as community change agents builds youths' capacity, necessary for true community development. These areas need to be addressed in future programs if Aboriginal youth are to experience positive health and wellness changes.

### **Chapter 2: Theoretical Underpinnings and Strategies of Inquiry**

This chapter provides a detailed description of my research paradigm and the strategies of inquiry employed. Grounded in a participatory paradigm, Indigenous research methodology (IRM) and community based participatory research (CBPR) principles informed this research. The theoretical underpinnings of the research include the youth empowerment framework (YEF) and the positive youth development (PYD) framework. Focused ethnography informed the qualitative inquiry that generated data through focus groups, one-on-one interviews, field notes, and my personal journal. Lastly, content analysis guided the process of coding and interpreting the results. Within this chapter, I also describe the research context and conclude by explaining how I attended to rigor throughout the research process.

I have chosen to represent my philosophical orientation (paradigm), methodology, and data generation strategies within embedded circles to illustrate the interrelatedness and blending of the concepts. Figure 2.1 illustrates how "ideas flow from one to the next in a cyclical fashion" (Wilson, 2008, p. 70). It is important to recognize how "all parts of the circle are equal; no part can claim superiority over, or even exist without the rest of the circle" (Wilson, 2008, p. 70).

# **Participatory Paradigm**

A paradigm represents our worldviews and forms the framework of our beliefs about what we can know and how we can know it (Heron & Reason, 1997; Mayan 2009). Paradigms are the "net" that holds the researcher's overarching beliefs, assumptions, epistemological, and ontological orientations together (Mayan, 2009, p. 42; Wilson, 2008). Wilson (2008) describes how a researcher's orientation is the foundation on which the framework of their research actions is guided.

Grounded in a participatory paradigm, I value different forms of knowing, and I collaboratively work with others to inform our inquiry (Heron & Reason, 1997; Springett, 2010). Collaborative inquiry acknowledges participants' experiential knowing through participation in the world (Heron & Reason, 1997, p. 277). Heron and Reason (1997) clearly articulate that "to experience anything is to participate in it, and to participate is both to mold and to encounter" (p. 278). I value the collective nature of experiences and participation. Therefore, utilizing a participatory paradigm in my thesis was appropriate for the research because it relied on the participants to explore their personal experiences as they participated within the research project.

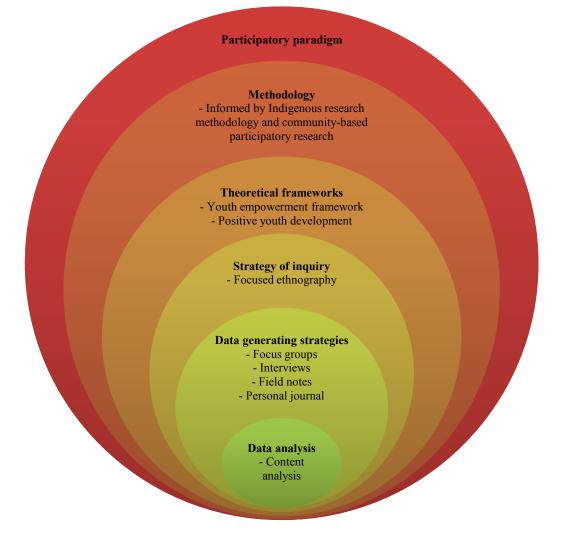


Figure 2.1 Interconnectedness of researcher paradigm and research methods

Working with Aboriginal communities, I recognized the importance of grounding the research in a participatory paradigm where relationships and experiences are co-created. I aimed to move away from an empirical-positivist worldview, which has traditionally formed the foundation of Western scientific inquiry *of* and *on* Aboriginal peoples rather than *with* them (Reason & Bradbury, 2006; Wilson, 2008). As a non-Indigenous person, approaching my work from a participatory paradigm, facilitated ethical research where collaborative inquiry guided the research process and we made meaning of our realities together. I will now describe my understanding of how we perceive the nature of our reality and truth (i.e., ontology), how we feel this reality and truth can be known (i.e., epistemology), and how we come to know about this reality and truth (i.e., methodology).

# **Epistemology and Ontology**

Within the participatory paradigm, the nature of our reality is subjective-objective, resulting from our interactions in the world. Due to the interactive and participatory nature of reality, there is no single truth but rather multiple realities (Heron & Reason, 1997). This subjective-objective ontological view was suitable for my thesis as I aimed to capture diverse perspectives and experiences of Aboriginal youth and my research partners. It was important to have the space for multiple interpretations of realities to exist.

Epistemology is about how we feel we can come to know about the world around us, and the value we have in ways of coming to know. Within a participatory paradigm, epistemology is rooted in experiences. Specifically in a research context, epistemology requires researchers to ask themselves, "What is the relationship between the researcher and the participant?" (Mayan, 2009, p. 24). In participatory research, researchers develop relationships through active participation in the research process, co-constructing knowledge that accurately reflects the participants' realities. Therefore, we cannot claim to be objective (Lincoln, Lynham & Guba, 2011). This constructivist-subjectivist epistemology (Lincoln et al., 2011) forms the basis of research inquiry within a participatory paradigm. Social interactions between the researcher and participants, combined with personal experiences, shape the meaning generated from our research and knowledge is co-created through dialogue and relationships.

Adopting a participatory paradigm in my thesis came easily to me, as it is important for me to build meaningful relationships as I engaged with people. I value relationships that work to improve the livelihood of marginalized populations. Therefore, the CBPR methodology was a natural fit. However, working with Aboriginal youth and their schools it was important for me to come from a place that respects and honours Indigenous worldviews and knowledges. For this reason, IRM also informed aspects of this research.

# Methodologies

Methodology is how we approach knowing about our reality. Based on our ontological and epistemological assumptions within our paradigm, methodology is the actions we take to find out about our reality (Wilson, 2008). I approached my methodologies by utilizing the concept of Two-Eyed Seeing, and used aspects of CBPR and IRM together. I describe in detail below, Two-Eyed Seeing and how I aimed to bring two worldviews together, to be recognized

alongside each other while acknowledging how the different knowledge systems overlap. I also made an ongoing effort to understand and deepen my knowledge of the common ground shared between the two approaches.

#### **Two-Eyed Seeing**

Elder Albert Marshall, Mi'kmaw Nation, conceptualized the principle of Two-Eyed Seeing as weaving Indigenous knowledge systems into mainstream Western science practices (Bartlett, Marshall, & Marshall, 2012). Two-Eyed Seeing is about "learning to see from one eye the strengths of Indigenous ways of knowing and from the other eye the strengths of Western ways of knowing and using both eyes together" (Hatcher, Bartlett, Marshall, & Marshall, 2009, p. 146). It is important to learn how to use the gift of multiple perspectives to benefit all beings (Institute for Integrative Health and Science, n.d). To utilize the principle of Two-Eyed Seeing throughout my research, I kept personal journals, and talked with community members, the research team, peers working in similar fields, and Indigenous scholars. In this way I critically assessed my research approach, activities, and relationship building from an IRM perspective, being mindful of the historical relationship between Indigenous peoples and Euro-Western colonizing forces. I aimed to intentionally incorporate and blend both Western and Indigenous ways of knowing, respecting Indigenous knowledge systems and methodologies.

The intention of Two-Eyed Seeing is to have the two eyes work together. The perspective recognizes how two different knowledge systems overlap (Martin, 2012). However, there may be instances where we choose the strengths of Indigenous science and others where we choose Western science (Institute for Integrative Health and Science, n.d). Elder Albert Marshall describes this as a "weaving back and forth between knowledges" (Institute for Integrative Health and Science, n.d). In practice, this required an on-going effort to understand and deepen my knowledge on the common ground we share and develop respect for the differences. The concept of weaving within Two-Eyed Seeing allowed me to learn how to be mindful of each and every one of my actions. I was able to choose appropriate times to look at the world with both eyes at the same time or formulate separate pictures and then merge them together. For example, I utilized an Indigenous lens to be cognisant of the responsibilities I had as a researcher working with Aboriginal communities, building relationships , following cultural and community protocol, and understanding that knowledge is relational. I utilized a Western lens by integrating

CBPR principles such as maintaining equitable partnerships and meaningful collaborations, colearning, capacity building, and viewing youth as resources throughout the research process.

Within Two-Eyed Seeing it is also important to understand the common ground that is shared between the different ways of knowing. There are parallels and a shared common language between participatory and Indigenous paradigms. Because of the "critical, collective, and participatory principles" (Kovach, 2005, p. 23), Kovach describes participatory research as an ally in decolonization of the research process, which aims to understand and integrate Indigenous worldviews into the research process. However, research can perpetuate Western colonizing forces that have dominated the approach to health research, which traditionally tends to suppress Indigenous worldviews and practices (Holmes, Murray, Perron, & Rail, 2006; Vukic, Gregory & Martin-Misener, 2012). This research approach leads to ignoring or trying to fit Indigenous knowledge within a Western framework, further colonizing Indigenous peoples (Hart, 2010). Therefore, it is necessary to have Indigenous paradigm inform the research process to resist dominant approaches.

Participatory and Indigenous paradigms emphasize collaboration with communities to generate outcomes that are of benefit to everyone (Kovach, 2005). Both paradigms value relationships that socially construct knowledge and highlight that there are multiple realities shaped by our surroundings and connections to the cosmos. I will now explain in detail the specifics of each methodology that I used throughout the research process.

**Community-based participatory research methodology.** CBPR is a methodological orientation to research, rather than a set of methods (Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Springett, Wright & Roche, 2011; Wallerstein & Duran, 2006), for which it is commonly mistaken. The semantics of participatory research terminology, corresponding goals, and theories vary depending on the research discipline and geographical orientation (Wallerstein & Duran, 2008). However, the disciplines share the methodological philosophy of engaging community partners throughout the research process, rather than only having them participate as research subjects (Cargo & Mercer, 2008) and the research process is viewed as cyclical and iterative (Springett, 2010). CBPR projects that are locally based are now receiving credibility as an approach to improve health outcomes and eliminate health disparities in marginalized populations (Andrews, Newman, Health, Williams, & Tingen, 2012; Cargo & Mercer, 2008). Israel and colleagues (1998) seminal work on CBPR principles, which they later expanded on to

include nine principles/characteristics of CBPR (Israel et al., 2008) (Table 2.1), is one of the most cited works on guidelines for effective CBPR.

Table 2.1 Key CBPR Principles<sup>\*</sup>

- 1. Recognize the community as a unit of identity
- 2. Build on the strengths and resources within the community
- 3. Facilitate collaborative, equitable partnership in all research phases, involving power-sharing processes that attend to social inequalities
- 4. Promote co-learning and capacity building
- 5. Integrate and achieve a balance between research and action for the mutual benefit of all partners
- 6. Emphasize public health problems of local relevance and recognize ecological perspectives and attend to social determinants of health
- 7. Involve systems development through a cyclical and iterative process
- 8. Involve all partners in dissemination of findings and knowledge gained
- 9. Long term process and commitment to sustainability
- \* Adapted from Israel et al., 2008

For this thesis, I followed the Kellogg Foundation's Community Health Scholars Program definition of CBPR, as cited in Minkler & Wallerstein:

"...a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities" (Minkler & Wallerstein, 2008, p. 6).

Utilizing a participatory approach means that the research is being conducted with individuals and communities (Reason & Bradbury, 2006; Wallerstein, 1999). The aim is to have equitable participation between the researchers and participants "with researchers acting as facilitators ... [while] recognizing how power relations within a particular context may constrain this" (Springett et al., 2011, p. 5). Within an anti-oppressive and emancipatory framework, participatory approaches are a preferred means to collaborative research involving communities (Wallerstein & Duran, 2008). This creates a space where researchers and community members can conduct respectful and ethical research together.

There is significant research indicating that CBPR methodology can be used to decolonize research methods with Indigenous people and their communities (Castleden, Sloan Morgan, & Lamb, 2012; Fletcher, 2003; Simonds & Christopher, 2013). However, careful consideration must be taken before initiating CBPR with Indigenous communities as this methodology has been developed within Western research frameworks (Castleden et al., 2008).

This requires thoughtful and conscious discussions and decisions throughout the research process and openly engaging in the tensions that may arise from different paradigms and ways of knowing. It is through CBPR's fundamental characteristics of relationship building, shared decision-making, equal power and ownership between communities and researchers that ethical research is conducted, improving health and wellbeing. Cargo and Mercer (2008), further explain that a "key strength of participatory research is the integration of researchers' theoretical and methodological expertise with non-academic participants' real-world knowledge and experiences into a mutually reinforcing partnership" (p. 327), akin to Two-Eyed Seeing. Furthermore, utilizing a CBPR approach makes it possible "to be respectful of Aboriginal customs without losing the strengths of the scientific method" (Fletcher, 2003, p. 36).

CBPR methodology is used with many Indigenous communities around the world. In addition to Israel and colleagues' (1998) nine CBPR principles, LaVeaux and Christopher (2009) added nine further recommendations for research with Indigenous communities, specifically in North America (Table 2.2). The 18 principles put forward by both LaVeaux and Christopher (2009) and Israel and colleagues (2008) were attended to throughout the research project when applicable. I will now expound upon how I specifically aimed to address recommendation # 9 from LaVeaux and Christopher (2009) additional principles by explaining IRM and how I incorporated aspects of the methodology into my work.

### Table 2.2 CBPR principles to follow when working with Indigenous communities<sup>\*</sup>

1. Acknowledge historical experience with research and with health issues and work to overcome the negative image of research

- 2. Recognize Indigenous sovereignty
- 3. Differentiate between Indigenous and community membership
- 4. Understand Indigenous diversity and its implications
- 5. Plan for extended timelines
- 6. Recognize key gatekeepers
- 7. Prepare for leadership turnover
- 8. Interpret data within the cultural context
- 9. Utilize Indigenous ways of knowing

\* Adapted from LaVeaux and Christopher (2009)

**Indigenous research methodology.** Despite my deepest respect and desire to continue learning all that the Indigenous paradigm entails, as a non-Indigenous person I recognize that I cannot claim the Indigenous paradigm to be my source of knowledge. I acknowledge that I do not have the lifelong learnings and relationships necessary to solely work from an Indigenous paradigm (Wilson, 2001). However, working within the context of Indigenous communities it

was necessary for me to try and understand Indigenous worldviews and utilize aspects of IRM to the best of my ability throughout the research process.

For this section, I first describe my understanding of the Indigenous paradigm using Indigenous scholars' work. I do not mean to be restrictive or definitive as I explain the Indigenous paradigm. I do not assume that all Indigenous peoples have the same worldview, rather shared similar aspects (Wilson, 2008). I focus on IRM, highlighting key principles and teachings that I received from Indigenous scholars, Aboriginal Elders, and Aboriginal peoples that influenced the way I approached my research inquiry. I explain how I aimed to honour and apply IRM principles and teachings within my work. I approach this piece with utmost respect and willingness to continue learning from Aboriginal youth, Elders, and their communities.

Wilson (2001), explains that the "Indigenous paradigm comes from the foundational belief that knowledge is relational, knowledge is shared with all of creation" (p. 176). Wilson (2008) clearly summarises the Indigenous paradigm: "Indigenous epistemology and ontology are based upon relationality... axiology and methodology are based upon maintaining relational accountability" (p.11). He also describes how the ontology, epistemology, and methodology of the Indigenous paradigm are within a circle where the entities "blend from one into the next" (Wilson, 2008, p. 70). The uniqueness of the Indigenous paradigm is that it views the sum as greater than the parts. This is a distinct difference to the post-positivist paradigm. Post-positivist paradigm compartmentalizes and studies entities in isolation of each other, resulting in knowledge that is only valid through objective observation (Tonmyr & Blackstock, 2010; Wilson, 2008). Contrary to objective knowledge, the fluidity and holistic nature of knowledge in the Indigenous paradigm requires recognition of the subjectivity of knowledge and reality.

Similar to the ontological belief of multiple realities within a participatory paradigm, there are also multiple realities in Indigenous ontology (Wilson, 2008). However, Indigenous ontology expands "to say that reality *is* relationships or a set of relationships" (Wilson, 2008, p. 73), meaning reality exists through the set of relationships one has developed, and therefore knowledge exists through a process of relationships.

Indigenous epistemology is "where the relationship with something ... is more important than the thing itself" (Wilson, 2008, p. 73). These relationships, build systems of knowledge that extend to understand the relationships between things. The relationships between things include "interpersonal, intrapersonal, environmental, and spiritual relationships, and relationships with

idea... [encompassing Indigenous] cultures, worldviews, times, language, histories, spirituality and [their] places in the cosmos" (Wilson, 2008 p. 74). Therefore, knowledge is based on a holistic understanding of our relationships to the things around us.

Relational accountability is the axiological orientation where the researcher is inseparable from the research participants due to the nature of the relationships built (Wilson, 2008). The process of fulfilling the research relationships (relational accountability) is Indigenous methodology (Wilson, 2008). Weber-Pillwax describes the process of relational accountability as adhering to the "three R's of - Respect, Reciprocity, and Relationality" (Cited in Steinhauer, 2002, p. 73). Entering into research with Indigenous peoples and their communities requires the researcher to utilize the three R's to guide the research.

Respect comes from valuing other ways of knowing and being in the world (Vukic et al., 2012). Researchers demonstrate respect by showing the importance of integrating diverse knowledge into the research process and how Indigenous communities can contribute to this knowledge (Vukic et al., 2012).

Reciprocity is about being accountable to not only yourself but also to your participants and to the earth. Reciprocity also requires researchers to be engaged in learning from Indigenous communities and ensuring the research process benefits both parties (Riecken, Tanaka, & Scott, 2006; Vukic et al., 2012).

Through the research process, we become responsible for the relationships that we build, which is relationality. Relationality is also about having "sincere, authentic investment in the community ... [taking] time to visit with people from the community, whether or not they are research participants" (Kovach, 2005, p. 30). Not only are the three R's a way of knowing for Indigenous people, they are also action words of IRM that result in the building of more relationships. The building of relationships fosters collective wellbeing through the notion of interconnectedness of all things. Thus, rather than focusing only on the individual, research becomes about collaboration as a community or group.

The connection and responsibility of our relationships extends beyond the collective to include the natural laws. Steinhauer (2002) describes the importance of the natural laws of love/kindness, honesty, sharing, and determination/ strength guiding the research. These laws "help the researcher to understand the importance, validity, and sacredness of the information being shared" (Steinhauer, 2002, p. 79).

Because of my participatory worldview, I was able to come from a place of respect, reciprocity, and relationality, maintaining authenticity of who I am while learning about another's worldview. Kovach (2005) explains that, "the greatest ally of indigenous research will be those non-indigenous 'methodologies from the margins' that do not hide from but embrace the political nature of research" (p. 33). I critically approached my research and worked to understand alternative ways of knowing. I aimed to prioritize IRM within my participatory research approach. Utilizing the concept of Two-Eyed Seeing, I followed the tenets of IRM that emphasize relationships and the holistic nature of Indigenous knowledge.

*Applying Indigenous research methodology to the research process.* This section describes how I specifically integrated IRM into my research practices. I will first discuss the responsibility I accepted when I decided to conduct this research. As Steinhauer (2008) explained, there is personal responsibility a researcher needs to consider seriously that accompanies the decision to conduct research with Aboriginal communities. I needed to assess the decisions I made throughout the research, ensuring that I was doing the 'right' thing for my partners, and not harming anyone in the process (Steinhauer, 2008). I needed to be aware of the impact my motives and intentions would have on the research participants and community partners. I was a part of the research and had obligations to maintain the research relationships.

When accepting responsibility as a researcher, ethics extends beyond traditional academic ethical standards. The three R's of respect, reciprocity, and relationality should be incorporated into the research process. I respected the worldviews of my partners and continually worked to learn from them and understand their worldviews. Throughout the research project, I reminded myself to be cognizant of the privilege and honour involved in being able to conduct research with my partners. Rather than talk only about what I do as an academic when I was in the community, I also talked about who I was and things that were close to my heart such as my family, hobbies, and future dreams. While I was in the communities, I consciously adopted the role of "co-learner, rather than outside expert" (Minkler & Wallerstein, 2008, p. 18).

Reciprocity is about engaged learning between the researchers and partners (Riecken et al., 2006). I participated in school and community activities that I was invited to by youth and Elders from both settings. I also spent the time with the youth to talk to them about my history, education, the research project, and answered questions they had about my life experiences. I

ensured reciprocal relationships were built and that the research activities were of benefit to all those involved.

I learned that IRM is grounded in relationships. Fulfilling my role in relationships was contrary to learning about reliability, validity, and objectivity from a Western research perspective (Wilson, 2001). I have learned that you cannot or should not compartmentalize the relationships you are building in your research apart from other relationships; the relationships that I built through my thesis are a part of who I am.

I was extremely fortunate that I entered into existing relationships my supervisor already built with the communities. Staff and students not only welcomed me into their schools but also were keen on building relationships with me. To establish my own relationships and build trust throughout the project, I participated in various local activities and volunteered to give back. In Edmonton, I volunteered at 'family fun night' and at the 7<sup>th</sup> Truth and Reconciliation Commission where I participated in the Education Day with the Queen Elizabeth students. My openness to participate in local activities resulted in me being involved in a variety of events at K'alemi Dene School, which ranged from building schoolbook shelves, to participating in fish camp, and being the photographer during the last day of school events. The relationships that developed seemed to create a space that from my perspective resulted in the youth and me feeling comfortable around each other. I was an active participant throughout the research process, showing commitment and support to the youth.

# **Addressing Power Dynamics**

Within research relationships, there can be unequal power dynamics, particularly when there are differing knowledge contexts, available resources, and opportunities (Cargo & Mercer, 2008; Ermine, Sinclair, Jettery, & Indigenous Peoples' Health Research Centre, 2004). Wallerstein (1999) explained how she found it difficult to do participatory research when she did not recognize the position of power she represented in relation to the communities. She explained the importance of self-analysis to address these tensions.

To address power dynamics within the relationships that I was building, I too practiced self-reflection to understand how my status and privilege affected the partnerships in which I engaged. I then actively worked to change any unequal power dynamics (Cargo & Mercer, 2008; Wallerstein, 1999). Through locating myself, exposing my own stance, and deconstructing my

ideology I aimed to be honest about my own history and culture that shaped my reality. I intentionally tried to use my power to act as an advocate for the communities. As I played only one of the many roles in interpreting and telling of the participants' stories, I needed to address power imbalances through power sharing with school personnel and youth participating in the project and by taking a flexible and open approach throughout the research process (Castleden et al., 2008). I recognized and acknowledged the power differentials and aimed to foster trust by involving myself in community activities, listening, and addressing community and youth needs throughout the research process (Castleden et al., 2008).

**Researcher responsiveness.** Another piece required to address power imbalances is the need for researcher responsiveness (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Researcher responsiveness occurs when a researcher practices reflexivity and works to become aware of the dynamic research environment in which they are working (Morse et al., 2002). The researcher is open to conversations that include diverse experiences and cultural practices that facilitate learning from others to improve the research process and further relationship building. A responsive researcher adjusts the research processes to meet the needs of their research partners. An emergent research design can achieve the fluid and flexible nature required.

An emergent research design in participatory research can lead to a complete change of research focus (Mohajer & Ernest, 2009). This change is acceptable because it maintains relevance of the research process to the community. An emergent research design is ethical practice during CBPR projects, particularly because CBPR projects rarely follow a linear progression and require the flexibility of all partners to adapt to the dynamic environments in which they are working (Morgan, 2008). In their work, Castleden and colleagues (2012) cited Kirkness and Barnhardt, who described that CBPR principles include four R's: "respect, relevance, reciprocity, and responsibility" (p. 1). I previously explained how I attended to the three R's defined by Weber-Pillwax cited in Steinhauer (2002). However, I still needed to address the fourth R of relevance. I describe below how I operationalized the fourth R in my work, which led to the development of my thesis research question.

Due to the nature of academic institutions, students are required to have a fully developed proposal to acquire research funding and ethical approval. My supervisor (Principle Investigator for the CBPR video project) and I thought it would be appropriate to conduct an impact evaluation of the CBPR video project for my thesis. We thought the results of an impact

evaluation would be most relevant to our community partners. Because of our decision, I developed a thesis proposal outlining an impact evaluation and the necessary data generation tools to receive ethical approval. It was necessary for me to obtain ethical approval for my proposed thesis research prior to entering into the communities and carrying out data generation.

Upon meeting our school partners and after the initial relationship building stages, I discussed with them the impact evaluation. Both school partners explained how the results of an impact evaluation would not be relevant for them. Rather they were interested in what occurred through the process of participating in the research project, youth's experience, and how their experience affected them. By concentrating only on the intended outcomes (change in tobacco misuse behaviours) of the CBPR video project, we would miss the value youth gained from being a part of the research project. The following quote describes this sentiment:

I think sometimes we base things on success too rigidly, we don't look at the big picture, and I think it's really important to look at the big picture. I have to say sometimes what we set out to do isn't necessarily what we're getting the great results in, but maybe it's impacting in another area... Maybe there were students that were super shy yet they stepped up and said something on film and that was really a BIG step for them. That was a big risk for them to take, and I guess acknowledging that the end product isn't necessarily the only way to judge success; that we have to look at the whole process and the effects of the whole process. (Adult school partner #18)

Based on our discussions it was necessary for me to change the proposed research to address the concerns of my community partners. In following IRM principles, it is important that that research partners have a voice in framing the research question (Wilson, 2008). We collaborated to re-work the focus of the research question to produce results that would to be useful for the community partners.

Furthermore, we also discussed the amount of participation the partners wanted to have throughout the research project. Cargo and Mercer (2008), explain that, when following the principles of mutual respect and equitable participation, community partners should not be expected to participate when they choose not to do so. However, this is not "an excuse for less participation; instead, non-academic partners must at least be given the opportunity to participate in all phases" (Cargo & Mercer, 2008 p. 333). This means that community partners determine their level of involvement in the research processes. I provided opportunities for the partners to

participate in all phases of the research and they decided on their degree of involvement. The partners were most interested in developing the research question and data generating strategies.

#### **Research Question**

Now that I have described how I came to the question with my community partners, I feel it is necessary to recall the research question and expand on the research objectives. The collaboratively developed research question is; "From the perspectives of the project participants, what is the perceived impact of participating in a CBPR video project on the health and wellness of youth?" Guided by this question, I addressed the following objectives:

- 1. Assessed the impact of the larger CBPR process as a health promoting activity by exploring the experiences of the project participants.
  - a. Explored how participating in a CBPR video project affects youth's attitude towards tobacco misuse.
  - Explored if participation in the CBPR video project led to any changes in factors central to personal health and wellbeing, which extended beyond the projects focus on tobacco misuse.
  - c. Identified from the perspective of the adult partners (school personnel & film makers), the perceived impact of the CBPR process on the youth's health and wellness.
- Determined if there were context specific similarities and difference between the project locations (Ndilo, Northwest Territories and Edmonton, Alberta) that may have played a role in influencing youth health outcomes.

# **Research Context**

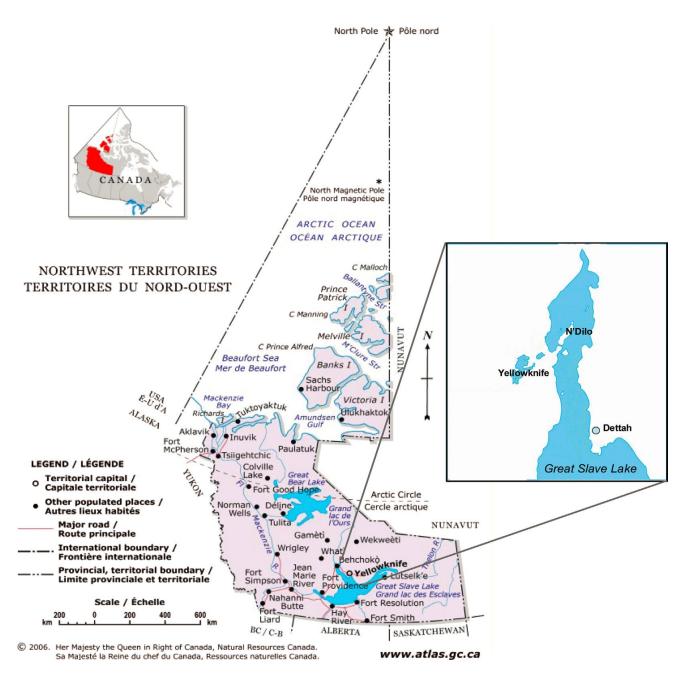
In this section, I detail the research context, the larger CBPR video project my thesis was situated in, and the role I played in the CBPR video project. Providing details of the research context facilitates transferability of the research findings to similar projects (Blichfeldt & Andersen, 2006). I will describe the geographical, demographic, and cultural characteristics of the partner communities and schools.

The Northwest Territories (NT) includes 33 communities that are sparsely distributed across an area of 1,346,106 km<sup>2</sup>, for a total of 0.4 persons/km<sup>2</sup> (Government of Canada, 2005;

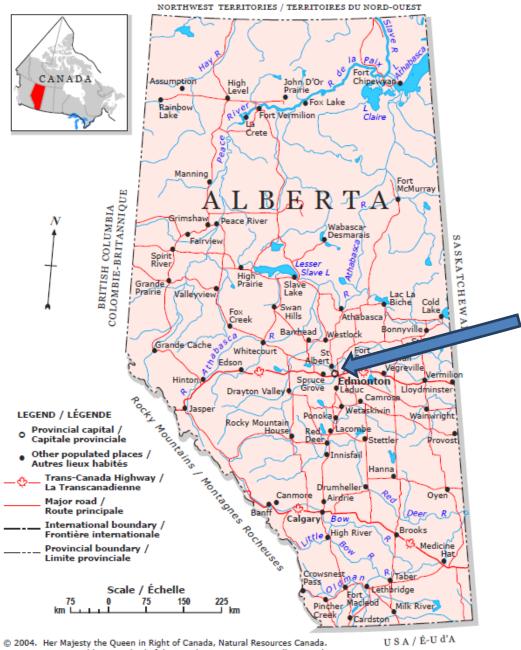
Young, 2012). There are two major highways in NT, but these highways reach less than half of the communities. Therefore, many communities are only accessible by plane or winter ice roads (Auditor General of Canada, 2011). There are approximately 43,600 people residing in the territory, of which 50 % self-identify as Aboriginal peoples (Northwest Territories Bureau of Statistics, 2014). The Yellowknives Dene First Nation community, Ndilo, is located just outside of the city limits of the NT capital, Yellowknife (Figure 2.2). The total population of the community is approximately 200 people (Northwest Territories Teachers Association, 2014). The community school, K'alemi Dene School has approximately 100 students, the majority of whom identify as Dene First Nation. Students from both Yellowknife and Ndilo attend the school. The school offers education for Kindergarten to Grade 12. The school curriculum honours and celebrates the culture, traditions, and language of the Dene people.

Alberta is the fourth largest province in Canada, covering 642,317 km<sup>2</sup> (Government of Canada, 2005). In 2014, Alberta's population was approximately 4 million people, of which the capital city of Edmonton had a total population of approximately 1,328,300 people (Statistics Canada, 2015). Edmonton is an ethnically diverse city and home to over 50 international cultures and 70 ethnic groups; 27% of the population identify as non-European decent (City of Edmonton, 2009; Neilson, Dowdell, & Kolkman, 2013). The most recent statistics for the City of Edmonton indicate that it has the second highest urban Aboriginal population (City of Edmonton, 2009). An estimated 62,000 Aboriginal peoples (14% of the Edmonton population) are living in the Edmonton Census Metropolitan Area (Neilson et al., 2013), of which 2%, 38%, and 60% identify as Inuit, Metis, and First Nation, respectively (Statistics Canada, 2013).

Queen Elizabeth High School is located in northeast Edmonton. The multi-cultural school offers grades 10 to 12 and has a student population of approximately 1,200, of which there are about 150 Aboriginal students (Edmonton Public School Board, 2013). The majority of the Aboriginal students identify as Cree First Nation or Métis. While Queen Elizabeth High School was the partner school for the research project, three grade 9 students from a neighbouring junior high school came to Queen Elizabeth to participate in the research project. Figure 2.3 depicts the geographical location of Edmonton, Alberta and Figure 2.4 depicts the geographical of both Edmonton, Alberta and Ndilo, NT.



**Figure 2.2** Map of the Northwest Territories (The Atlas of Canada, 2012)



© 2004. Her Majesty the Queen in Right of Canada, Natural Resources Canada. Sa Majesté la Reine du chef du Canada, Ressources naturelles Canada.

Figure 2.3 Map of Alberta (The Atlas of Canada, 2012)



**Figure 2.4** Geographical location of both Edmonton, Alberta and Ndilo, NT Retrieved from: http://www.freeusandworldmaps.com/html/USAandCanada/CanadaPrintable.html

### **Engaging Aboriginal Youth in Tobacco Prevention Using Social Media**

Dr. Cindy Jardine initiated the CBPR video project; *Engaging Aboriginal Youth in Tobacco Prevention Using Social Media* in response to school concerns about the early initiation and high rates of Aboriginal youth tobacco misuse. This project aimed to work with Aboriginal youth in a participatory manner to develop videos that encouraged prevention and/or cessation of tobacco misuse. A subsequent goal of this initiative was to empower youth to act as health promoters, becoming agents of change by influencing their peers, schools, and Aboriginal communities to practice healthy behaviours. Figure 2.5 shows pictures of the youth as they participated in various aspects of the CBPR video project, from filming, to knowledge dissemination, and attending the film festivals.



Figure 2.5 Youth participating in various aspects of the CBPR video project

The research project was conducted in partnership with the schools principals, teachers, and Aboriginal students in grades 9-12 from March 2013 to January 2014. The video project was integrated into classroom time at K'alemi Dene School as students were meeting learning objectives in social studies, language arts, and technology studies. In comparison, the majority of the research project was conducted during lunchtime for the Queen Elizabeth students, outside of the school curriculum. On occasion, the project ran into classroom time after the lunch period, which required the principal to call the student's teachers and excuse them from missing class time. The students were still required to make up any missed assignments but did receive one credit for their high school diploma for participating in the project.

While my thesis research was situated within the CBPR video project, I was intimately involved in running all aspects of the larger project. This further facilitated relationship building within my research.

The project started in March 2013. The first step involved youth working together to determine who they were going to work with for their video making team. The youth stayed within these teams for the duration of the research project. The teams ranged from 2-7 youth. From March 2013 to June 2013, the youth worked with local filmmakers and created participatory videos that portrayed their own personal messages about tobacco misuse. Within their video teams, youth created storyboards, learned film making skills, carried out video filming and editing, and participated as actors in their videos. During this time, I personally supported the Edmonton youth through twice-weekly visits at Queen Elizabeth School where we worked on their films. The work included learning how to use the video cameras, story boarding, filming, and editing their footage to create the final video product. During this time, I also travelled to K'alemi Dene School five times to work with the youth there and provide the same support. The length of trip depended on the amount of support required by the school partners. The trips ranged from two to five days.

From May 2013 to January 2014 youth participated in video dissemination which included inviting the wider community and screening the videos at the school, posting the videos on YouTube, and creating DVDs to hand out to peers, family and community members. They also participated in two school exchanges and local film festivals. In May 2013, I arranged for the youth participants from K'alemi Dene School to come to Queen Elizabeth High School where they screened each other's videos. In Edmonton, I attended the Aboriginal film festival, Dreamspeakers, with both schools.

In October 2013, I arranged to have Queen Elizabeth High School youth travel to K'alemi Dene School. I accompanied the Queen Elizabeth students to Yellowknife, NT to participate in the Yellowknife International Film Festival with the K'alemi Dene students. There we participated in a three day video skill-building workshop, attended film screenings, and visited the K'alemi Dene School, the community of Ndilo, and the city of Yellowknife.

I also facilitated video dissemination activities with the K'alemi Dene School post project. In January 2014, we presented the videos at the school's family fun night. We coupled the screening with an informative and interactive survey on the impacts of tobacco misuse. In

May 2014, I also co-presented the research findings with two youth participants from K'alemi Dene School to the Government of the Northwest Territories. At the time of writing, in collaboration with the Queen Elizabeth students we had presented at one international conference (October, 2014) held in Winnipeg, two local conferences (November, 2014 and February, 2015) held in Edmonton, and an invited a seminar at the School of Public Health, University of Alberta (March, 2015). Attached, with the youths' permission, please see Appendix A and B for the reflections that they have shared at the conferences, documenting what participating in the CBPR video project meant to them. The youth felt it was important to include their reflections as a part of my thesis. They wanted to have their experiences presented as written and published text, as the conference presentations limited the reach of their voices to those attending the conferences.

#### **Research Ethics**

The research study followed the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) (Canadian Institutes of Health Research, Natural Sciences & Engineering Research Council of Canada, Social Sciences & Humanities Research Council of Canada , 2010). I also utilized Chapter 9 within the TCPS2, which is specific to research involving the First Nations, Inuit, and Métis peoples of Canada and is premised on respectful relationships (Canadian Institutes of Health Research, Natural Sciences & Engineering Research Council of Canada, Social Sciences & Humanities Research Council of Canada, 2010).

To meet the ethical standards set out by the TCPS2 for research involving human participants I received ethical approval for my thesis work within the CBPR video project. Ethical approval was obtained from the University of Alberta, Health Research Ethics Board #1, No. Pro00021643 (Appendix C). I also obtained a research license from the Aurora Research Institute for the research conducted in the NT, license No. 15546 (Appendix D).

To ensure participants understood informed consent, prior to the start of the research and before each data generating strategy commenced, participants were provided information on the research project and purpose. The conversation included potential benefits and negative effects of the program, data generating techniques, what the data would be used for, and an explanation of confidentiality and anonymity. Time was provided for participants to ask any questions. No undue pressure was placed on the participants to sign the consent form. For participants under the age of 18 years old parental consent was obtained as well as participant assent. I also

emphasized that they had the right to withdraw at any point and could choose not to answer particular questions during the data generating times. Prior to the start of data generating strategies we talked about the topics that were going to be discussed to ensure the participants were comfortable and understood the process. Please see Appendix E1 and E2 for the information and consent/assent forms provided to and discussed with the youth, school personnel and filmmakers. The school principals gave permission for their schools to be identified for this research project. They felt that the youth had pride and were proud of their work in the project and by naming the school increased ownership.

The research team, including the school administrative partners thought the students would be proud of the videos they produced and were given the option of including their first names in the videos. The youth also had the choice to not have their names attached to their videos. The identification of individuals in the videos were limited to first names to allow for collective ownership, but to also maintain some aspect of anonymity. The youth were happy to share photos of themselves participating in various activities. Multiple consents were obtained for the photos throughout the CBPR video project, also required for each film festival they attended (Dreamspeakers in Edmonton, and the Yellowknife International Film Festival). The data generated and specific quotes used were de-identified to not single out any particular student.

Working with Indigenous partners requires ethical considerations beyond what is provided by standard academic institutional review. In keeping with the principles of IRM and CBPR, I applied relational ethics where I practiced self-reflection and worked to build authentic relationships (Wallerstein, 1999; Wilson, 2008). It was important for me to take the time to get to know my partners and youth participants. We spent many hours talking about our lives and interests that extended beyond discussion of the research project.

#### **Theoretical Frameworks**

Multiple theoretical frameworks informed this research. Egmose's (2011) stance is that no single theory can provide a full explanation for the phenomenon of interest. Therefore, by using a number of frameworks in my thesis work I richly explored my research question. My aim was to utilize theories that focused on wellness instead of illness and strengths instead of deficits. To form the theoretical basis for analysis and interpretation of the research results, I used Holden and colleagues (2004a) youth empowerment framework (YEF) that was drawn from the Zimmerman empowerment theory (Zimmerman, 1995; Zimmerman, Israel, Schulz, & Checkoway, 1992) and its application to positive youth development (PYD) (Chinman & Linney, 1998; Damon, 2004). This model has been used to explore youth empowerment within the context of tobacco control initiatives (Holden et al., 2004a; Holden, Crankshaw, Nimsch, Hinnant, & Hund, 2004b; Holden, Evans, Hinnant, & Messeri, 2005). I also used PYD in greater detail (Damon 2004; Eccles & Gootman, 2002; Lerner et al., 2002).

The YEF builds on empowerment theory (Holden et al., 2004a), which focuses on psychological empowerment outcomes (Zimmerman, 1995). Empowerment theory has three individual characteristics: *intrapersonal* (domain-specific perceived control, domain-specific self-efficacy, motivation to control, perceived competence, and mastery), *interactional* (critical awareness, understanding causal agents, skill development, skill transfer across life domains, and resource mobilization), and *behavioral* (community involvement, organization participation, and coping behaviors) (Zimmerman, 1995). Zimmerman (1995) explained that the process of psychological empowerment can occur through a change in these individual characteristics. While a few models link empowerment theory to PYD (Chinman & Linney, 1998; Kim, Crutchfield, Williams, & Helper, 1998), Holden and colleagues felt that there was limited application of youth empowerment in tobacco control initiatives (Holden et al., 2004a). Holden and colleagues conceptualized YEF to define key components of youth empowerment and youth developmental assets specific to tobacco control (Holden et al., 2004a).

Major domains of the YEF include: *predisposing characteristics* (reason for joining/motivation, demographics, and history of involvement similar groups), *collective participation* (level and intensity of participation, roles played, and opportunities for involvement), *group structure* (decision-making process, existing relationships, incentives, support, and resources), *adult and institutional involvement* (adult coordinator characteristics and parental and agency support), and *group climate* (group resiliency and cohesion, collective and outcome efficacy) (Holden et al., 2004a). Corresponding operational measures were also developed that reflected the major domains of the YEF in relation to psychological empowerment to be 'participation', and the action of participation to impact intrapersonal and interactional components. This notion of 'participation' as a

component of empowerment is relevant to exploring the impact for Aboriginal youth who participate in a video research project. Rather than use the operational measures developed by Holden and colleagues (2004b), which quantitatively assessed empowerment, I was mindful of the emerging results while analyzing the data and how the emerging themes aligned with YEF.

The YEF focuses on opportunities for youth participation and active engagement, consistent with PYD (Holden et al., 2004a). YEF in the context of PYD is appropriate because it "replaces the view of youth as community problems, which dominates prevailing intervention theories, with a view of youth as community assets and resources" (Holden et al., 2005 p. 264). Rather than focusing on youths' deficits, research programs work to explore their developmental potential (Damon, 2004). Utilizing youth potential in research programs can have positive effects on their health and wellbeing (see, for examples, Genius, Willows, Alexander First Nation, & Jardine, 2014; Holden et al., 2004a).

I found the focus of empowerment and PYD within the YEF useful to theoretically contextualize the promotion of the emancipatory nature of CBPR (Holden et al., 2004a), which is particularly relevant when working with Aboriginal youth. However, the YEF does not take into consideration all aspects of PYD. I therefore explored PYD in greater detail, utilizing aspects from both YEF and PYD.

PYD has received recognition as an alternative approach to deficit-based work with youth by emphasizing "the manifest potentialities rather than the supposed incapacities of young people" (Damon 2004, p.15). PYD emphasizes the development of skills, attitude, and competencies that result in successful transition into adulthood while avoiding risky behaviours (Eccles & Gootman, 2002; Lerner et al., 2002). Programs that utilize PYD focus on the following areas: youth bonding, competencies of social, emotional, cognitive, and behavioural, self-efficacy, self-determination, positive identity, and fostering of spirituality, belief in the future, and prosocial norms (Catalano, Berglund, Ryan, Lonczak, Hawkings, 2004). PYD is consciously holistic (Damon, 2004), I aimed to explore the data from a holistic lens, viewing youth as assets and resources, capturing the positive attributes of youth.

However, PYD has been critiqued based on the Eurocentric nature in which many of the constructs such as assets for health development have been explored (Tuck and Yang 2011). Critics assert that PYD is situated within a Euro-Western perspective, limiting the consideration and assessment of structural conditions, social, economic, and political forces that impact

community settings and the lives of youth (Ginwright & Cammarota, 2002). When applying PYD to work with Aboriginal youth it is thus essential to ensure that differences in Aboriginal knowledge and concepts of youth are not over looked (Howard, 2010). Furthermore, particularly when working within tobacco control initiatives, it is important for youth to develop awareness of how race, class, and power affect their lives, enabling youth to address oppressive practices of tobacco companies (Ross, 2011). Researchers have utilized PYD together with social justice youth development (SJYD) to work with marginalized youth to address power imbalances (Iwasaki et al., 2014; Ross, 2011).

Nonetheless, despite the critiques, the PYD framework was useful for contextualizing the approach I took towards my research and framing the way I engaged with Aboriginal youth. Particularly for my research, I was exploring youths' experience within the larger CBPR video project, and used PYD to conceptually guide the exploration of their experience rather than to develop a research program. I also utilized PYD as a lens to explore the research findings, looking at the data generated from the perspective that youth are experts in their own lives (Foster-Fishman et al., 2005) and have the potential for positive development in a way that meets their needs. Furthermore, being guided by IRM and CBPR principles, I was able to build respectful relationships that ensured the research was truly informed from the youth's perspective.

# **Strategy of Inquiry**

This qualitative inquiry presents a research study guided by focused ethnography on youth's experience of how participating in a CBPR project influenced their health and wellbeing. Qualitative inquiry is useful when aiming to generate a rich description of youth experiences by hearing their voices, facilitating authentic representation (Valaitis, 2002). I describe how focused ethnography guided the data generation and analysis strategies. I conclude this chapter with a description of trustworthiness.

## **Focused Ethnography**

Operating within the CBPR video project and a participatory paradigm, this research project used focused ethnography to guide the data generation strategies. Focused ethnography was an appropriate method to guide the inquiry because it aimed to explore a specific research

question from the "cultural perspectives held by a sub-group of people within a context-specific framework" (Higginbottom et al., 2013, p. 1). The research was centred on a discrete phenomenon (the experience of participating in a CBPR project), within a specific context (the CBPR video project operating within each school setting), and the project participants had rich knowledge and understanding of the context and experience of the topic (participating in a video research project on tobacco misuse).

This strategy of inquiry acknowledges the existence of multiple realities, resulting in findings that are meaningful and useful in the community, essential to CBPR (Higginbottom et al., 2013; Springett et al., 2011). Ethnographic data generation strategies "offer interactive, flexible, and readily accessible ways in which academically trained researchers and community members can conduct research together" (Schensul, Berg, & Nair, 2012, p.162). Conducting research together increases the likelihood that the anticipated results are applicable to the community.

Due to the nature of the study being conducted in two geographically distant locations, focused ethnography supported short-term field visits that occurred in intervals and were data intensive at times (Higginbottom et al., 2013). These times aligned with the schedules of the two schools.

# Sampling

**Recruitment of participants.** I worked directly with the administrative staff at the K'alemi Dene School and Queen Elizabeth High School, who were the community partners for this research. They were also the personnel who provided the space and allocated the time spent in the school and with the youth participants.

At their respective schools, youth and school personnel were invited to collaborate on the CBPR video project. The CBPR video project was open to all of the high school youth from K'alemi Dene School. For Queen Elizabeth High School the research team worked with the school's First Nation, Inuit, and Métis liaison. The liaison invited youth to participate who had been self-identified by their parents as Aboriginal when registering for school. All the youth who were recruited to participate in the CBPR video project and the adult partners were invited to participate in focus groups and one-on-one interviews for the smaller research project (my thesis

work). This occurred in March 2013, during the initial meetings and start-up phase of the CBPR video project.

To reach saturation in ethnography a sample size of 25-30 participants is typically required (Mayan, 2009). However, sampling in focused ethnography is determined by the total number of participants in the sub-culture under investigation and tends not to be predetermined because it is dictated by the researcher's ability to reach saturation (Higginbottom et al., 2013). The CBPR video project had 28 youth participants, six school personnel and two film makers. Therefore, the sample size for this project was 36 participants. Please see Table 2.3 for the specific location distribution of participants.

Table 2.3 Location distribution of participants

	Queen Elizabeth	K'alemi Dene	
School personnel	3	3	
Film maker	1	1	
Youth participants	15	13	

**Inclusion criteria.** The participants were the school personnel, filmmakers and youth who were directly involved in the CBPR video project. It is important to note that this was not a homogenous group of Aboriginal youth and consisted of a variety of Aboriginal identities. Youth were not specifically asked to self-identify or categorize their background, as it was not necessary for this project.

#### **Data Generation Strategies**

Guided by focused ethnography, qualitative inquiry was used. The naturalistic, interpretive, and inductive approach to qualitative inquiry is fitting because it focuses on cocreating knowledge and illuminates the complexities of individuals' interactions and experience in their sociocultural world (Mayan, 2009). Moreover, in line with IRM and CBPR, qualitative inquiry is relational, increasing the participation and voice of those less powerful and often not heard in a community (Mayan, 2009; Wilson, 2008). The specific data generating strategies used were semi-structured open-ended focus groups, semi-structured open-ended one-on-one interviews, field notes, and personal journaling. **Focus groups.** Focus groups align with the practices of conversation and storytelling found in many Aboriginal cultures (National Collaborating Centre for Aboriginal Health, 2009; Tagalik, 2010). I conducted the focus groups based on the youth video teams in which the youth were working. Conducting a group discussion shifted the power to the participants, generating data based on their different perspectives as they operated as a social group (Alcock, Camic, Barker, Haridi, & Raven 2011; Mayan, 2009). This is particularly important for studies promoting social inclusion, allowing the youth to discuss their shared and collective experience of participating in the project (Alcock et al., 2011). The group format can also serve as a collective memory of the youths' perspectives, experiences, and lessons learned.

Focus groups traditionally have 6-10 participants (Mayan, 2009). However, due to the nature of the CBPR video project, youth created their video teams, which ranged from 2-7 youth. Therefore, focus groups included the same teams ranging from 2-7 participants. The flexible, fluid nature of semi-structured guides resulted in collaborative data generation and an in-depth understanding of the participants' unique experiences. This format also provided a space for participants to convey their personal perspective on the topic.

I conducted a total of eleven focus groups with the youth (Table 2.4). I conducted focus groups at the start of the CBPR video project. Following the completion of the videos, I conducted a second round of focus groups to facilitate reflection on the content of the videos as well as the experience and process of developing the videos (Nolas, 2014). Lastly, I conducted short-term follow up focus groups with the youth after the school exchanges and attendance at both of the film festivals. The second and third focus groups built on the initial preliminary themes identified from the previous interviews (Nolas, 2014), providing insight throughout the various stages of the research project.

It was important to generate data over multiple points throughout the research project to check for consistency in what participants were saying over time (Patton, 1999) and to have the opportunity to see changes that take time to occur. With consent, the focus groups were audio recorded and ranged from 12 to 44 minutes, averaging 20 minutes. Two youth who participated in the CBPR video project chose not to participate in any of the focus groups.

Table 2.4 Woltans in which focus groups with youth participants were field						
	March – April	May – June	October 2013	November		
	2013	2013		2013		
Queen Elizabeth School	Video team # 1 (n=7)	Video team #1 plus Youth #14 from Video	Video team #1 (n=6)	-		
	Video team #2 (n=6)	team #2 (n=6)	-			
K'alemi Dene School	Video team #3 (n=6)	Video team #3 (n=4)		All three video		
	Video team #4 (n=2)	Video team #4 (n=1)	-	teams combined (n=5)		
	Video team #5 (n=4)	Video team #5 (n=3)				

Table 2.4 Months in which focus groups with youth participants were held<sup>\*</sup>

\* n = number of participants participating in each focus group

The questions that I put forward to the youth facilitated discussion on their involvement in the CBPR video project, and aimed to capture a holistic description of the youth's experiences. Through the common questioning across all of the focus groups, I was able to explore or expand on areas of interest to the participants.

I conducted the first focus groups at the start of the CBPR video project (March-April 2013). Questions included: youths' knowledge, attitude, and behaviour on tobacco misuse, tobacco misuse in their communities, youth inclusion in decision making processes, why the youth wanted to participate in the project, and how the youth thought we could determine the success and challenges of the project (Appendix F: First-CBPR video project youth focus group guide).

Once the youth had completed making and disseminating their videos and had attended one film festival, I conducted the second focus group May-June 2013. The aim was to explore what occurred for the youth throughout the process of making their videos and health promotion messages. The question topics included conversations around: youth participation and leadership roles, youths' video messages, the impact the process had on the youth, and youth behaviour changes (Appendix G: Second- CBPR video project youth focus group guide).

To explore short-term changes that occurred after the completion of the project and how the experience of participating in the CBPR video project may affect youth in the long term, I conducted follow-up focus groups. During the second film festival in Yellowknife, I met with the Queen Elizabeth youth (October 2013); after the film festival, I met with the K'alemi Dene youth (November 2013). The interviews aimed to explore short-term changes. The questions included topics on: the youth's experience while participating in the project, changes in their personal wellness, and member checking of themes that had occurred for each group from the previous interviews (Appendix H: Follow-up youth focus group guide). A Cree Elder from Edmonton recommended and provided me with the personal wellness wheel and 'honoring my path' work sheets to facilitate discussion with the youth (Appendix I). I also received approval from a Dene Elder from Yellowknife who said this was an appropriate way to explore holistic health with Dene First Nation youth.

Adult interviews. To cover all aspects of the topic being explored, I included multiple perspectives (i.e. adult partners, youth participants, and filmmakers) to achieve a complete picture (Fenech, Adami, & Kiger, 2005). Adding rigour and breadth to the study, adults involved in the CBPR video project were interviewed to augment in-depth perspectives and observations to the topic of interest (Denzin & Lincoln, 1994), and further capture the impact of participatory research on youth's health and wellbeing. I conducted semi-structured, one-on-one interviews with the adult partners. This included the school personnel involved in the project and a filmmaker from each location. If I only used one viewpoint during data generation, insights may have been missed, resulting in an incomplete picture. Being able to compare multiple perspectives from people who have different points of view enhanced the quality and credibility of the results (Patton, 1999). Darbyshire (2005) has also reported that when exploring children's experiences, multiple perspectives and data sources offer complementary insights.

The interviews with the adults explored similar topics as the youth focus groups, but from an outsider's perspective. This provided additional observations and insights into youth changes from the adults who worked with them on a consistent basis. Gaining the adults' perspectives contributes to validity in confirming conclusions by having data from multiple sources. The adults provided insight into the way they perceived impacts on the youth because of their participation in the CBPR video project. The first interviews explored partner expectations, youth smoking behaviours, the role youth play in their communities/schools, youth participation,

and project evaluation. The second interviews followed up on the first interviews, determining if the project met partner expectations, successes, and challenges of the project, the perceived impact of the CBPR video project, as well as perspectives on observed changes in youth empowerment and participation. Please see Appendix J and Appendix K for both of the adult partner interview guides. The adult interviews, which were also audio-recorded with permission, ranged from 15 to 45 minutes and averaged 27 minutes.

In Edmonton, four adult partners participated in interviews at the start of the CBPR video project (April and May 2013). Upon completion of the project, the same four adults participated in a concluding interview between June and July 2013. In total, I conducted eight interviews with Edmonton adult partners. Three adult partners in Ndilo participated in interviews during April 2013. Four adult partners participated in concluding interviews in June 2013, for a total of seven interviews with Ndilo adult partners. In total, seven interviews were conducted at the start of the CBPR video project and eight were conducted upon completion of the project.

**Field notes.** To supplement the one-on-one interviews and focus group transcripts, I wrote a field note after each interview with the youth participants and adult partners. I documented the interview setting and atmosphere, participants' non-verbal cues not captured in the audio recordings, and any analytical thoughts. This process was important because a transcript is unlikely to represent the experience of the participants without a fuller description of the emotional context and other aspects that can be contained in a field note (Poland, 1995). This is particularly imperative for this research as it explored the experiences of the youth and aimed to express their voices in authentic manner as possible (Poland, 1995).

I also wrote a field note after each encounter throughout the project to detail interactions of interest not captured during the interviews. These field notes included informal conversations with the youth and adult participants, my involvement in the field/project, and thoughts and feelings that arose while working with the youth. For example, I wrote field notes after; each session with the youth and filmmakers, each day we attended the film festivals, and after any knowledge translation activities where the youth disseminated their videos. Please see Appendix L for an example field note that includes both a focus group field note and observations during a project wrap up lunch at Queen Elizabeth School, which occurred simultaneously.

**Reflexive journaling.** Through my journals, I reflected on my interactions with the youth and community partners. I recorded notes on my thoughts around my position within the

communities and how my intentions were manifested through my behaviours. It was important for me to be critical about my behaviours and how they affected my relationships. I also reflected on my overall assumptions, perspective on the process, frustrations, and highlights to ensure rigor and aid in data analysis (Mayan, 2009). It was important for me to explore what I felt was occurring through the research process and ideas for improvement. By keeping a personal journal, I was able to go back and assess how my positionality and perspective changed through my experiences (Castleden, Daley, Sloan Morgan, & Sylvestre, 2013). This is also in line with Freire's (1970) work on critical consciousness. I used my personal journals to reflect critically on my social, economic, and political place in the world and how this influenced the way I approached the research process and relationship building. Using reflexive journals to provide contextual observations is also used as a data generating strategy in focused ethnography (Higginbottom et al., 2013).

#### Data Management

To ensure confidentially and anonymity of participants, interview and focus group data generated were de-identified upon transcription by replacing names with codes, as well as the videos and photographs taken. Personal identifiers are kept separate from the data. All data was stored in locked cabinets in a locked room. I will keep the data for five years, and after which it will be destroyed.

### **Data Analysis**

Using content analysis (Krippendorff, 2004; Mayan, 2009), data generation and data analysis occurred concurrently through an iterative process. Data analysis in focused ethnography requires a "cyclic, self-reflective process, as preliminary interpretations are challenged and data are continually revisited to plan for further data collection" (Higginbottom et al., 2013, p. 6). The simultaneous process was important, as examining earlier data provided insights that were useful to pursue in detail during and following focus groups, interviews, and informal discussions during community visits.

The interview schedules did not allow for immediate transcription and analysis during each of the data generating phases. However, I documented preliminary codes in an analytic memo where I pulled key concepts out of the transcripts from previous interviews that influenced

the following interview guides and facilitated informal member checking conversations throughout the project. I compared the concepts that emerged from previous interviews and adjusted the focus of the questions for the following interviews. To ensure data quality, interviews were transcribed verbatim by a professional transcriptionist between data generating points. The transcriptionist signed a confidentiality agreement. I cleaned the transcripts for accuracy by reviewing each against the original audio file prior to analysis of the textual data.

I coded, organized, and managed the data using the qualitative data management software, NVivo 10<sup>TM</sup>. First, I became familiar with all the data and organized persistent words, phrases, and themes into codes. I generated categories by cutting out coded sections of text and grouping them together. I reviewed all excerpts to ensure fit within each category and I identified subcategories that developed. I wrote a summary for each category and then judged each category for internal and external homogeneity. This means I checked to ensure that all the data within a category fit together and that there was a relationship among the categories chosen. I confirmed that the differences among the categories were clear. By returning to the "big-picture" to see how the categories together (Mayan, 2009, p. 97). I wrote reflexive memos throughout the data collection and analysis to document questions, hunches, and connections. Analytic memos during analysis documented the theme development process. Through the content analysis process, member checking with the research partners and youth participants strengthened rigor.

**Member checking.** Member checking on the developing themes and interpretations ensured that the results represented participant's experiences, maintained cultural context, and ensured concepts resonated with the participants (Lincoln & Guba, 1985; Mayan, 2009). Member checks were done within the interviews, where I discussed themes emerging from the analysis to ensure the interpretation of the data reflected participants' views while maintaining meaning and cultural context. To confirm my understanding of the themes emerging from the data set, I also conducted member checks with the community partners and available youth. For the school partners, I prepared a brief summary of the preliminary results with corresponding quotes for discussion. I followed up with youth through informal conversations and lunch meetings. I prepared summaries of the preliminary results to serve as discussion points with the youth during the lunch meetings. Feedback and questions from the participants were encouraged throughout the member checking process and incorporated into the final analysis.

## Trustworthiness

When using a qualitative inquiry approach to research, trustworthiness features of credibility, confirmability, dependability, and transferability are used to address and evaluate rigor (Lincoln & Guba, 1985; Mayan, 2009). Higginbottom et al. (2013) further explain how establishing rigor can occur through self-conscious and reflective approaches, such as the reflexive journaling I utilized throughout the research process. Through my introductory chapter, I presented my personal characteristics to allow others to determine for themselves to what extent I have represented my work with integrity (Lincoln & Guba, 1985). Rigor also requires an explicit methodological framework (Higginbottom et al., 2013), such as the IRM and CBPR frameworks which I previously described.

Credibility is a measure of how accurately and completely the researcher has described the phenomenon of interest, accurately representing the participants (Given & Saumure, 2008; Mayan, 2009). I maintained credibility through prolonged engagement in the communities. I conducted multiple member checks to ensure that the findings represented the participants' experiences correctly (Lincoln & Guba, 1985). I also engaged in inter-coder exercises before and after I had developed a preliminary coding framework.

The second coder was a qualitative health promotion researcher who had experience working with Aboriginal youth and participatory video. First, the student independently coded four of the most complex transcripts from the dataset (15%) without restrictions or a predetermined codebook, to allow ideas to emerge freely. We then discussed the rationale behind our codes as well as inconsistencies and similarities of concepts. I then used the information from our discussions to update the codebook and re-coded previous transcripts. In the second stage of this exercise, my colleague coded another two transcripts using the revised codebook. At this stage, we aimed to solidify appropriate language for the emerging categories, discuss any missing concepts, and ensure all the codes accurately captured the meaning of the texts.

To ensure confirmability (Given & Saumure, 2008), all quotes were reviewed in their original context prior to integration into the study results. To minimize bias from a single perspective, during analysis I engaged in peer debriefing to discuss the emerging findings with

professors from interdisciplinary backgrounds and a critical friend (Mayan, 2009; Spall, 1998). Peer debriefing contributes to confirmability by facilitating exploration of possible areas of bias that may not be apparent and ensuring interpretation of the results is credible, plausible, and accurate (Spall, 1998). The meetings provided insight from diverse perspectives, increasing confirmability, as I was able to modify the analysis based on their feedback. I met with a critical friend (a public health master's student working in the field of comprehensive school health) on a weekly basis to discuss the direction of my results. She held me accountable to the decisions that I made throughout my analysis and required me to reflect further on the findings by providing objective critique and support (MacKenna, 2000), while we talked through the changes in the results that I made as themes emerged.

Lincoln and Guba (1985) describe dependability as accounting for factors of instability and research design changes. To increase dependability of the research results, I continually updated my codebook and went through a series of iterations. After each member check and inter-coder/critical friend meeting, it was necessary for me to revisit and update the codebook. This iterative process required me to review and recode previous transcripts. I used NVivo 10<sup>TM</sup> data management software throughout the process of data coding and organization to create a detailed audit trail of analysis procedures, increasing the dependability of the analysis (Mayan, 2009).

Generalizability was not the intended goal of the study. However, I addressed transferability by providing a thick description of the scope of the study, setting and participants, and data generation and analysis (Given & Saumure, 2008). I also detailed the similarities and differences between the study contexts. This allows for aspects of the research to be transferred and replicated to other settings in some broader or narrower contexts (Given & Saumure, 2008; Lincoln & Guba, 1985). Readers can determine the extent to which the results detailing what health and wellness impacts occur from participation in research projects may be application in other contexts.

## Chapter 3: "Not all of us Aboriginals smoke"- Exploring empowerment as a process through participatory video research with Aboriginal youth

## Introduction

Community-based participatory research (CBPR) is a methodological orientation to research (Wallerstein & Duran, 2006). The goal of CBPR is collaborative research that establishes meaningful relationships and structures for community participation, aiming to create societal transformation (Viswanathan, et al., 2004; Wallerstein & Duran, 2006). Within an anti-oppressive and emancipatory framework, participatory approaches are a preferred means to collaborative research involving communities (Wallerstein & Duran, 2008). This is particularly important when working with Aboriginal communities who have traditionally had research conducted *about* and *on* them, rather than *by*, *for*, or *with* them (Wilson, 2008). It is through CBPR's fundamental characteristics of relationship building, shared decision-making, empowerment, and ownership between communities and researchers that ethical research is conducted, with the goal to improve participants' health and wellbeing.

Adopting a CBPR approach has the potential to improve individual and community health outcomes and reduce disparities (Wallerstein & Duran, 2006). Reducing health disparities amongst Aboriginal youth in Canada is a pressing issue as Aboriginal youth continue to experience greater health burdens than other youth in Canada (Greenwood & de Leeuw, 2012). As one of the fastest growing populations in Canada (Ning & Wilson, 2012), it is important that Aboriginal youth are provided opportunities to reach their full potential (Greenwood & de Leeuw, 2012). CBPR projects focused on particular health issues and including Aboriginal youth throughout the research process have resulted in positive health impacts (Cross et al., 2011; Riecken, Scott, & Tanaka, 2006).

Youth tend to be involved in pre-set research agendas constructed through an adult lens (Bradley, Deighton, & Selby, 2004; Wong, Zimmerman, & Parker, 2010), limiting their ability to have a voice in creating solutions to improve their wellbeing. Typically viewed as problems (Checkoway & Gutierrez, 2006), youth tend to be excluded from decision-making processes (Charmaraman, 2010), and their voices are seldom present in research activities (Garakani, 2014). However, youth have the right to be involved and their voices included while making decisions in areas relevant to their wellbeing (Committee on the Rights of the Child, 2009).

Utilizing a strength-based approach to research enables youth to gain a voice as they are viewed as resources and communities assets (Checkoway & Gutierrez, 2006; Lombardo, Zakus, & Skinner, 2002). Combining a strength-based approach and CBPR principles is particularly well suited to develop health promotion activities that address the disenfranchisement often experienced by youth. Health promotion strategies for socially excluded populations, such as Aboriginal youth, provide an opportunity for them to recreate social norms and generate changes by addressing inequitable conditions (Wallerstein, 2006). Furthermore, scholars have advocated that a corner stone of health promotion projects and CBPR should be individual and community empowerment (Robertson & Minkler, 2010; Zimmerman, 1995).

Empowerment is a benefit for youth participating in health promotion activities (Chinman & Linney, 1998; Holden, Messeri, Evans, Crankshaw, & Ben-Davies, 2004). Through active participation, multiple empowerment and health outcomes can occur such as increased self-esteem and self-efficacy, participation in social action (Holden et al., 2004), development of a healthy identity, and involvement in positive activities (Chinman & Linney, 1998). Empowerment is a dynamic process of change that can fluctuate over a period of time and is context specific (Maton, 2008; Wallerstein, 2006; Zimmernman, 1995). Building on previous definitions, empowerment here is defined as: "a group based, participatory, developmental process through which marginalized or oppressed individuals and groups gain greater control over their lives and environment" (Maton, 2008 p. 5) by gaining a "greater voice in matters that affect their lives" (Tirreton, 2008, p. 55), enabling them to increase mastery over issues of concern to them and their communities (Rappaport, 1987).

Participatory video is one method that has the potential to empower youth by increasing their skills, capacity, and agency to "take control of their own health and wellness through the processes of knowledge translation" (Fox, 2013; Riecken et al., 2006, p. 13). This technique provides youth the opportunity to shape and create their own videos (Lunch & Lunch, 2006). Lunch and Lunch (2006) explain that the aim of creative video making is to increase accessibility to arenas where people can voice their concerns on topics of importance, a potentially empowering experience for individuals partaking in the activity.

Participatory video provides youth the opportunity to use film to explore their stories in unique and innovative ways (White, 2003). Generating creative solutions to problems faced, youth explore using their voice and having their messages heard (White, 2003). This method is

gaining traction as a viable and effective participatory research approach to engage Aboriginal youth to be health promoters and agents of change in their communities (Genuis, Chekoa Program, & Jardine, 2013; Riecken et al., 2006). However, there is limited knowledge on the health impacts of participation in research projects (Wallerstein & Duran, 2006). Specifically, a paucity of evidence exists on how the process of participatory video contributes to youth engaging in an empowering journey that can ultimately lead to improved health and wellness.

Literature on participation impacts tends to focus on how participation can improve the research program (Jardine & James, 2012), increase partnership sustainability (Horn, McCracken, Dino, & Brayboy, 2008), and result in equitable distribution of services (Wallerstein, 2006). Furthermore, health impact is traditionally empirically and quantitatively assessed, the impact of health research interventions is isolated to only the topic of interest (Rod, Ingholt, Bang Sørensen, & Tjørnhøj-Thomsen, 2013). Quantitatively measuring an individual's experience limits the depth of knowledge that can be co-created and misses the opportunity of the participant to have an empowering experience through the discussion of their involvement (Mackinnon & Stephens, 2010). However, there has been limited reporting on how participation is a transformational process that actually leads to empowerment (Larson, Kang, Perry, & Walker, 2011; Ozer & Douglas, 2013). Therefore, we aim to explore in what ways the process of participatory video, influenced by CBPR principles, impacts participants' wellbeing and if there is an effect on their empowerment.

The method of participatory video is considered to be empowering (Lunch & Lunch, 2006), however there is limited discussion on the context of the empowerment process and what features of participation are empowering (Mohajer & Earnest, 2009). Therefore, it is important to explore if this method of participatory video is truly affecting participants in the intended ways (Foster-Fishman, Nowell, Deacon, Nievar, & McCann, 2005). We do not argue for the legitimacy of utilizing participatory approaches to research with Aboriginal youth, as this literature is well-established and supported (Ford, Rasmus, & Allen, 2012; Horn et al., 2008; Jardine & James, 2012). Rather, the primary focus of the study is to explore the impact of the process of participating in a CBPR video project on youths' wellbeing. Specifically, the context and mechanisms that lead to development of empowerment are assessed.

In this article, we explore to what extent participation in a school-based health promotion CBPR video project conducted with Aboriginal youth led to positive youth perspectives of their

health and wellbeing. The focus is on how the process of participation in research can contribute to building the necessary foundation for youth to embark on an empowering journey.

## Methods

K'alemi Dene School, Ndilo, Northwest Territories, Canada and Queen Elizabeth High School, Edmonton, Alberta, Canada collaborated on the CBPR project, "*Engaging Aboriginal Youth in Tobacco Prevention Using Social Media*", to address tobacco misuse amongst their high school youth. The aim of the project was to work with Aboriginal youth to encourage prevention and/or cessation of tobacco misuse using participatory video methods. A subsequent goal of this video project was to empower youth to act as health promoters, becoming agents of change by influencing their peers, schools, and Aboriginal communities to practice healthy behaviours.

Ethical approval was received from the University of Alberta, Health Research Ethics Board #1. A Northwest Territories Scientific Research License was also obtained from the Aurora Research Institute, Northwest Territories. For participants under the age of 18 years old parental consent was obtained as well as participant assent. No undue pressure was placed on the participants to sign the consent form.

#### Setting

K'alemi Dene is a community school with approximately 100 students from kindergarten to grade 12. The majority of students identify as Dene First Nation. The school curriculum honours and celebrates Dene culture, traditions, and language. Queen Elizabeth is an urban, multi-cultural school with grades 10-12. There is a student population of approximately 1,200, with about 150 Aboriginal students. The majority of the Aboriginal students identify as Cree First Nation or Métis.

#### **Participatory Video Project**

The video project was carried out from March 2013 to January 2014. The youth worked with local filmmakers and created videos that portrayed their own personal health promotion messages about tobacco misuse. The videos the youth produced were showcased at their schools, during two exchanges between the schools, at film festivals the youth attended (Dreamspeakers Film Festival, Edmonton, Alberta and Yellowknife International Film Festival), on DVDs that

were developed and handed out to youths' peers, wider community, family members, and community centres, and at academic conferences. The youth also co-presented the research findings to the Government of the Northwest Territories, and at international and local academic conferences. The videos were also posted to YouTube:

(https://www.youtube.com/channel/UCbu7HOxP-5s2sxe2WVu3SPQ).

## Participants

The participatory video project was conducted in partnership with the school principals, teachers, and Aboriginal students in grades 9-12. Working with the school personnel collaborating on the project, all Aboriginal youth in the school were invited to participate in the video project. The participants included in this research were anyone involved in the CBPR video project who were interested in talking about their experience of participating in the research project and how they felt it influenced their health and wellbeing.

There were a total of 28 youth participants: five females and eight males from the K'alemi Dene School, and ten females and five males from the Queen Elizabeth High School. Three adult personnel from each school participated as well as a local filmmaker from each location.

## **Data Generating Strategies and Analysis**

Focused ethnography was utilized to guide the data generation strategies (Higginbottom, Pillay, & Boadu, 2013). A semi-structured interview guide was developed to examine the research question: from the perspectives of the project participants, what was the perceived impact of participating in a CBPR project on the health and wellness of youth? The qualitative data generation strategies involved focus groups with the youth and one-on-one interviews with the adult partners. Prior to the start of the research and before each data generating strategy commenced, participants were provided with information on the research project and purpose. The conversation included potential benefits and negative effects of the program, data generating techniques, what the data would be used for, and an explanation of confidentiality and anonymity. Time was provided for participants to ask any questions.

Eleven focus groups were conducted with the youth participants at three points throughout 2013/2014 (prior to the start of the project, after they completed their video, and after

project wrap up and attendance at two film festivals). The focus groups were conducted with each video team the youth were working within; teams ranged from two to seven youth. With consent, the focus groups were audio recorded and ranged from 12 to 44 minutes, averaging 20 minutes. Youth were asked about their participation in the project and their experience, how they felt the process impacted them, and any personal changes that they experienced as a result of participation.

The adult collaborators included school teachers, principals, and filmmakers. Eight oneone-one interviews were conducted with the adults. The adult interviews ranged from 15 to 45 minutes and averaged 27 minutes. The adult interviews explored similar topics as the youth focus groups, but from an outsider's perspective. The aim was to have the adults provide insight into the way they perceived impacts on youth because of their participation. Gaining the adults' perspectives demonstrates validity in confirming conclusion by having data from multiple sources (Fenech, Adami & Kiger, 2005; Patton, 1999). Field notes also captured informal discussions with the youth and adult partners, the participatory research processes, and researcher involvement in the project.

All focus groups and interviews were audiotaped with permission, professionally transcribed verbatim, and imported into NVivo 10<sup>TM</sup> software to assist with data management and coding. The field notes were also imported into NVivo 10<sup>TM</sup> for analysis. Using content analysis (Krippendorff, 2004; Mayan, 2009), data generation and data analysis occurred concurrently through an iterative process. Through preliminary coding, key concepts were identified that influenced the development of the subsequent interview guides, the interview questions were adjusted as necessary during the data generation. This approach also facilitated member checking within the focus groups and interviews.

Transcripts were coded and organized into persistent words and phrases. The codes generated categories, which integrated and anchored themes that weaved throughout and tied the categories together. Member checking exercises on developing themes and interpretations were formally conducted with the adult partners and informally with youth participants. The member checking ensured that the results represented the participants' experiences, maintained cultural context, and ensured concepts resonated with the participants (Mayan, 2009).

## Results

Across participants, three main areas of impact were identified: capacity building, the opportunity to 'shine in a positive light', and increased sense of agency.

## **Capacity Building**

Youth developed technical skills and increased their critical thinking skills.

**Technical skill development.** Youth learned and practiced a variety of different skills. They increased their technological capacity by learning the necessary skills for video making. These included developing storyboards and creating effective video messages, techniques used to film scenes (e.g. how to frame their shots), filming material for their videos, sound, and computer editing.

Many youth expressed that the project had been fun, particularly because they were able to learn about video making processes. When asked what they learned, youth responded by saying the following: "I learned how to do sound" (Youth #6), "Work[ing] together. I learned how to make videos" (Youth #20), "I learned how to use the editing system on the Mac computers" (Youth #28), and "I've never even really knew how to work a camera before" (Youth #9).

**Cognitive skill development.** Youth practiced their critical thinking skills through the creation of their video messages. They created their messages in a way that they thought would have the most impact on people's decisions to smoke. For example, one group discussed how they made their video on the effects of smoking while pregnant for the baby.

She shouldn't be smoking when she's pregnant. She should have a healthy baby and a health life (Youth #23).

How come you chose to make a video on that? (Interviewer)

Because there [are] some mothers that smoke when they're pregnant (Youth #20).

The child can [be] affected in the future; they're [mothers] not making the right choices (Youth #23).

Many of the youth expressed that they thought the videos would have a greater impact on people who did not smoke rather than those who already smoke because "people aren't going to quit smoking after they've seen a video" (Youth #26) and "if they're hooked on it, then they wouldn't change" (Youth #22).

In one conversation youth also described starting to think critically about their own behaviours and the impacts of smoking on their health by saying, "I'm not going to smoke" (Youth #14), "yeah, me too" (Youth #5), "that's a no-no" (Youth #6), "and I'm going to convince my family members to quit" (Youth #5).

## Shine in a Positive Light

Participating in the video project was an opportunity for the youth to shine in a positive light. As many of the Queen Elizabeth School youth expressed, by participating in the project youth felt that they were being positively targeted to participate, showing them "that we're important" (Youth #7). Youth #9 expressed this sentiment during a member check meeting by stating "…natives, we're people too." Youth #8, followed up by explaining that being identified to participate in a project where their skills were valued increased her self-esteem. The youth were able "to show we exist…when other people listen to use, to show what I learned, that we were really there in purpose" (Youth #23) and "that we tried [to do our best]… by finishing the video and having a good video" (Youth #13).

The adult partners in the project also commented on how participating in the video project was a chance for youth to have a positive experience at school. Adult #3 expressed this sentiment: "I think it was a neat experience for kids that often don't choose to do school activities. I think that it was beneficial and let those kids shine in a positive light when sometimes they don't make those [positive] choices."

**Increase pride in capabilities.** The youth valued celebration of their achievements in forums with their schools and peers, and through receipt of a certificate of project completion. A field note from May 14, 2013 recorded, "the older youth enjoyed having an afternoon that was dedicated to celebrating their work." Youth #26 expressed how she felt successful because "you guys [researchers] gave me an award today... in front of everybody."

The adult partners also conveyed how "it's a great project as it unfolds just in terms of the opportunity to be showcased for their expertise and understanding" (Adult #2) and the importance of having "their work [being] recognized by their peers... [where] their ideas were not belittled" (Adult #4). Furthermore, adult partners linked celebration of youths' success to fostering youth empowerment as explained by Adult #37: "I think making the videos definitely

empowers them, and I think ... anywhere where they took those finished videos and celebrated them, I think that's what's empowering."

Showcasing the youths' work and celebrating their successes throughout the project increased youths' pride in their own capabilities to be health promoters in their school and communities. Youth #13 was proud of her group's progress; she said that they felt that the group was working hard and that they would have a really good video (field note May 6, 2013). Not only was the youths' "favourite part that we published the videos and we showed them to the other Aboriginal kids" (Youth #23), it was also increasing their skills through "the film festival [because] it's a great opportunity. At first I first thought the film [was] going to be boring...actually I find it quite a lot of fun here [Yellowknife International Film Festival] and I quite enjoy doing film more than I thought I would" (Youth #7).

The adults also commented on the sense of pride displayed by the youth. Adult #18 explained how she "certainly saw pride in what they were doing... they were ALL able to participate and do their best and be a part of a team." Adult #19 also described how he saw that, "they're proud about it [video]. They feel a little bit empowered to give that message."

Adults felt that the youth "can always refer back to this [video project]" (Adult #19), and that is "reinforcing that they CAN do it, they've had this one success now and hopefully...keep building upon it" (Adult #37). Adult #18 articulated how she felt participating in the video project would affect the youth in the long term: "Every experience you have scaffolds and builds on the next one, once you have that experience, not only do you feel more capable and know your own skills and ability level, but then that's what you're going to strive for in the future."

#### **Increased Sense of Agency**

Through engaging in the process of creating the videos, youth took on responsibility and decision-making. They also cultivated their voice, enabling them to act as health promoters, increasing their sense of agency.

**Responsibility and decision-making.** Throughout the process, youth were supported and encouraged by other youth participants and adults. However, they were responsible for their work and decisions. During the course of the project, youth made a variety of decisions ranging from choosing the groups to work in, the messages to portray in their videos, and how to disseminate their videos.

The Queen Elizabeth School youth stated they normally felt in the shadows around decisions that affect them. They are "...told what happens and what to do. It's not like we're really asked about it" (Youth #7). Many thought their opinions were not listened to because they are "too young" (Youth #11), and "don't have much experience in life" (Youth #9). Consequently, "because we're kids, we apparently don't know anything" (Youth #8), adults "don't trust us" (Youth #6). In one conversation, when asked about being involved in decision making within the video project the youth responded by saying:

We understand more than they think... [being involved] shows us that we're important, because smoking, [starts] between junior high and high school, rather than after that because then it's too late (Youth #7).

Through member checking, these youth clarified that they appreciated being able to make decisions throughout the project. They valued having the adults listen to what they wanted to do, rather than being told.

In contrast, many K'alemi Dene School youth felt that they were included in decisions and adults would listen to their opinions. From a field note the first author noticed that this was an "…important finding, because the community seems to be trying to include youth, as well as the school. Youth talked about being included in the decision making processes when creating programs." In one conversation youth discussed wanting to be included in decisions related to tobacco prevention and cessation to "tell other people" (Youth #22), "how bad smoking is" (Youth #25), "in your own words" (Youth #22).

Being involved in the participatory video project where youth were able to make their own decisions was an empowering process "because it shows people that we know more than they [adults] think we know" (Youth #9). The adults also spoke about how youth empowerment occurred through decision-making: "Where they're taking initiative, they're taking responsibility, it's theirs, they own it, they're making their choices, so empowerment is not about other people doing for them; it's about doing for yourself "(Adult #3).

**Gaining a voice.** Youth described that by participating in the video project, they started to feel comfortable expressing themselves. During member checking exercises, youth articulated the importance of having a place to use their voice. They felt that their concerns were listened to throughout the project and having adults ask their opinions was extremely meaningful. The youth also stated that participating in the project facilitated them voicing their opinions on topics that

they felt strongly about, such as tobacco misuse. In particular, youth #26 wanted to use the platform of the research project to "say not all of us Aboriginals smoke."

The adult partners described that they saw the youth gain confidence to use their voice and speak up for themselves.

That was their first experience...learning how I can have a voice... Now they have a voice and they have an audience that is captive... they can't be interrupted, they can't be shut down... I think that will be powerful, that they're actually listened to, they're having a say, and we're not brushing them off...providing that voice may empower some of them.

(Adult 3)

One of the filmmakers described from personal experience the importance of participatory projects providing an opportunity for youth to gain confidence in using their voice.

When teenagers find that they have a voice that is actually listened to, it becomes a game changing experience...When you have a project where people do listen to you, it's a point of pride. It creates leaders...when you can get your idea across, you become a force of change ... I run into these kids down the road and I'll hear, "You know, you gave me a voice. I never had it before" (Adult #4).

Acting as health promoters. Youth described wanting to influence their friends and family through the video messages they created. They wanted to change the harmful tobacco misuse that they saw around them. Youth recalled the value of having the opportunity to explain to people in their own words the impacts of tobacco misuse on their health. Youth #11 explains this sentiment, "a lot of my friends and family smoke. This will be good." Some of the youth from K'alemi Dene School felt they could have the greatest impact on younger children because "there's a lot of kids in smaller communities, [we could] tell them don't start smoking" (Youth #22).

Over all, the majority of the youth described how they wanted to learn how to act as health leaders. Youth #7 expressed this clearly:

I want to learn how to like seriously impact someone, rather than them just thinking, 'Oh, it's just a kid teaching me something. I already know it's bad for me ...' I want to teach them something new so it can affect them so they know how bad it [tobacco misuse] can affect other people around them.

The youth described how they gained confidence by knowing their potential to positively affect change in other people. Youth #5 explained how the project "helped me see that I could help people try to quit smoking and that smoking is not really good for you." When asked if they will continue working towards promoting a healthy school and community environment, the youth responded by saying:

Most definitely...We all can learn to take that extra step and start creating a difference in someone's life (Youth #8).

To show how much we're doing better than smoking ... and saying that it could be better than smoking (Youth #23).

One youth in particular emphasized how she was going to continue working towards "encouraging others to quit smoking, or don't start smoking" (Youth #26). The adults saw the youth using the opportunity to participate in the video project to "use their skills of writing and creative scripting ... [to] make a difference" (Adult #2).

It is important to note that upon completion of the research project a few of the Queen Elizabeth School youth who participated in the video project borrowed film equipment to create another video on binge drinking because they saw it as an issue in their community. Youth #22 and #20 from K'alemi Dene School, co-presented with the research team, the project findings to the Government of the Northwest Territories. The youth wanted to tell their own story and describe the impact participation in the research had on them. They felt it was important to advocate for further programs that include youth throughout the process, from inception to completion. Youth #7, #8, and #9 from Queen Elizabeth School have also co-presented at international and local conferences as well as at an invited seminar at the School of Public Health, University of Alberta.

#### Discussion

According to the majority of the participants, the participatory video project was an opportunity for them to act as health promoters within their school and wider communities. Our results show that the essential elements required to contribute to these Aboriginal youths' empowering journey included capacity building, having an opportunity to shine in a positive light, and the chance to increase their sense of agency.

The word journey is used to emphasize that we are not aiming to imply that the positive changes youth experienced are the final results and empowerment is the end outcome. Rather the changes that occurred throughout the project have the potential to continue affecting the youth once the project is completed. The process of empowerment is a participatory developmental process similar to a journey, where one develops as they grow and learn (Maton, 2008; White, 2003). In many circumstances, the process of making the video is more meaningful than the final video created (White, 2003). Therefore, participation is a stepping-stone, building blocks for youth empowerment to continue growing and influencing them in other areas of their lives.

#### **Capacity Building**

Participatory video not only has an impact on those who view the film but also has the power to transform the individuals who produced them (White, 2003). The participatory environment created conditions that facilitated youth building on and enhancing their existing knowledge and skills. By participating in the research project youth were active participants as opposed to passive recipients receiving a message.

Through the process of participatory video, youth increased their capacity to be agents of change by gaining technical and cognitive skills. Overall, the film making skills youth learned are applicable to future work and the cognitive skills gained can transfer to other areas of youths' lives (Larson et al., 2011). This is particularly important because one of the principles of CBPR is to promote learning and capacity building (Israel et al., 2008).

Participating in meaningful activities that lead youth to learn new and useful skills, including critical awareness of how to contribute to community development, and being recognized through positive reinforcement are aspects required for adolescent empowerment (Chinman & Linney, 1998). Youth critically thought through the health messages they wanted to portray in their videos. Larson and colleagues (2011), describe how critical thinking develops when youth creatively engage in challenges that arise through their work. Developing critical awareness is a key aspect of empowerment in youth (Chinman & Linney, 1998). Furthermore, actively participating in their skill development is also important for the development of empowerment in youth (Chinman & Linney, 1998).

## Shine in a Positive Light

Exclusion of Aboriginal youth in creating their own stories has repeated a "single story of despair, poverty, loss, abuse, and addiction" (Garakani, 2014, p. 236). However, through participating in this research, youth created counter-narratives by showing how they are resources for positive changes. Youth were able to shine, being viewed positively instead of perpetuating negative stereotypes. Shifting the perspective of youth as problems to youth as resources and community assets (Checkoway & Gutierrez, 2006), is necessary to positively recognize the value youth have in community change. Viewing youth as resources can facilitate youth empowerment where they are motivated to better their own lives and the lives of their community members (Holden et al., 2004). This research demonstrates how youth want to be valued for their strengths and abilities, and to have their wisdom and self-determination recognized.

Celebrating youths' success further facilitated youth shining in a positive light, and reinforced their positive behaviours. Recognizing youths' involvement in positive roles is not only important for positive youth development but is also a key element in development of youth empowerment (Chinman & Linney, 1998). Youth started to view themselves as resources for change, and saw the value in the skills they had developed and their potential to foster positive community changes. Celebrating the end video product is only one essential part of the process (White, 2003). Other aspects of this research included acknowledging their participation with certificates and lunch celebrations, attending film festivals to showcase and build on the skills and creativity they were developing, and celebrating the diversity of the youths' culture and traditions during the school exchanges. Moreover, the opportunity to display their abilities and receive positive reinforcement increased their personal pride.

The results provide evidence that when youth are able to shine in a positive light and their achievements and successes are recognized, it can lead to increased pride, building the scaffolding for youth empowerment. Youth in other research programs have also described being positively impacted and achieving an increased sense of pride when their talents and accomplishments were recognized (Charmaraman, 2010). Acknowledging youths' achievements results in meaningful self-affirmation for youth, and furthers their confidence to be engaged in activities that address health disparities (Dawes & Larson, 2011). Our findings of youth increasing their confidence in their skills through celebration is in line with participatory video

literature that explains how participants can increase their internal confidence and sense of pride in their capabilities by being positively viewed in the community (White, 2003).

Research shows that increased pride improves participants' belief in their ability to accomplish their goals (Foster-Fishman et al., 2005). Youth are also able to learn the association between action and outcome, and the necessary work required to achieve their goals (Larson et al., 2011). Learning and gaining their own skills results in sustainability and empowerment for youth because they are able to advocate for positive changes they desire (Wallerstein, 2006).

#### **Increased Sense of Agency**

Arts-based programs have the potential to provide youth the opportunity to develop their agency (Larson et al., 2011). Youth participating in the process of creating videos indicated they cultivated their voice and increased their decision-making skills, enabling them to act as health promoters, increasing their sense of agency.

Within CBPR, importance is placed on shared decision-making and power throughout the research project (Wallerstein & Duran, 2006). Decision-making and negotiating control is an important aspect of the empowerment process (Mohajer & Earnest, 2009), because it results in inclusion and contribution from participants (Wallerstein, 2006). This is important for populations traditionally excluded from decision-making processes (Charmaraman, 2010). Our results show that the youth participants felt included and involved in decision-making throughout the research project, which was a powerful experience for many of the youth. It is important that youth are involved in environments such as CBPR projects where they have the opportunity to be included in decision making, as this is an interactional component of empowerment (Zimmerman, 1995). Developing their decision-making skills enables youth to use this skill in other areas of their lives, creating youth independence to be their own advocates in creating positive circumstances in their lives (Zimmerman, 1995).

Gaining a voice is a challenge for those who are traditionally excluded, disenfranchised, or marginalized from systems of power in society (White, 2003). Exercising their voice may be a new experience for many (White, 2003). This research project was not about 'giving' youth a voice per se but rather providing a platform for youth to be supported in gaining strength and confidence in their ability to use their voice. Having the space to speak up and express their opinions was empowering for many of the youth. They were able to contribute their own ideas

and actively participate in solving problems throughout the project. The youth voiced their concerns and started speaking up for what they wanted, needed, and expected. Rather than being talked at, youth learned and practiced speaking for themselves.

Participatory video is a mechanism where youth can use their voice and generate messages that are interpreted by viewers (White, 2003). Through planning, strategizing, and completing tasks throughout the video project, youth were building critical components of voice and agency (Dugan & Reger, 2006). Charamaraman (2010) explains that "exercising one's voice is integral to developing agency" (p. 1). Furthermore, agency is an attribute of empowerment because it enables individuals to exercise choice, transforming their lives (Wallerstein, 2006). The youth who participated in this video project gained a voice and became "empowered with media literacy skills, technical production, and social management skills", which in turn, may lead them to use these tools to reconceptualise and address oppressive societal structures they experience as Aboriginal peoples (Charamaraman, 2010, p. 16).

The youth participants had the opportunity to use their agency and creatively work together to be health leaders in their schools, addressing tobacco misuse in a way that suited their needs. Other youth have described how participation in media programs showed them that they have agency to make positive changes, rather than passively watching others make decisions for them (Charmaraman, 2010). Knowing that they can facilitate transformation and have the power to be agents of change, youth have the potential to grow into advocates (White, 2003), addressing health concerns for themselves, schools, and communities. Our research is consistent with other tobacco control efforts with youth where participation in the project led to changes in their self-conception and their ability to act as social agents of change for tobacco misuse (Holden et al., 2004).

#### **Limitations and Challenges**

This study involved a small number of Aboriginal youth from Edmonton, Alberta and Ndilo, Northwest Territories, Canada and therefore should not be considered representative of Aboriginal populations across Canada. However, the results can be used to understand similar situations that focus on youth participation using arts-based methods.

Participation in the video project was voluntary, which may have resulted in selection bias of the participant sample. The project was open to all the youth and they made their own decision to participate or not. Regardless of bias, the youth participating in the study were interested in being health leaders and there needs to be consideration of the importance of engaging and supporting Aboriginal youth who want to enhance their skills to become community leaders.

CBPR needs to be responsive and respectful of community needs and time. This can limit the opportunities for suitable times and location for data generation to take place. The data generation for this study did not always occur at opportune times (e.g. during breakfast at a film festival or in a condensed time period because the youth had another activity to attend to), which may have limited the potential to gain richer or different types of knowledge. However, within CBPR, it is difficult to achieve opportune conditions. Through member checking exercises and prolonged engagement in the communities with the youth, we are confident that the results adequately capture the participant's experiences and perceptions.

#### **Concluding Remarks**

Aboriginal youth have previously described that being involved in CBPR projects was important because the participation contributed to their positive health and wellbeing (Ford et al., 2012). Our research highlighted how participatory video can contribute to positive health and wellbeing by being an empowering method for Aboriginal youth who participate in a CBPR project on tobacco misuse. These findings are consistent with White (2003), who describes participatory video as empowering because it creates a space to identify problems and create changes to improve the lives of those impacted.

Aboriginal youth need to have the opportunity to both act and be seen as agents of social change because they tend to be marginalized and excluded from decision-making processes in wider society. Through this research, they rose to the challenge of addressing health issues in their schools and communities. Not only is there potential impact on the people receiving the messages, our findings suggest that creating health-promoting messages actually empowers the youth creating the messages. Through this participatory process, youth are building their capacity, shining in a positive light, and increasing their sense of agency. Overall, the participatory video process has the potential to affect participants beyond the intended outcomes. Therefore, it is critical when developing health promotion programs with youth that

consideration is taken to not only focus on the final product that is to be developed, but to explore the potential of the whole participatory process and how it can positively impact youth.

Scholars call for research processes that are beneficial to participants, contributing to their empowerment (Foster-Fishman et al., 2005; Garakani, 2014). Participatory research projects need to build the capacity of participants to foster empowerment, enabling them to address power imbalances and health disparities (Wallerstein, 2006). Since the methods used in research projects can affect the participants (Foster-Fishman et al., 2005), it is important that the perspectives of the participants - how they changed through the research process - is captured and communicated (Rasmus, 2014). From our analysis, it was clear that the youth in this study who shared their perspectives, were positively impacted by engaging in a participatory video project.

Future research projects need to ensure that the method or approach to engaging youth is creating the opportunity for the process to positively impact youths' development of empowerment. This participatory video project contributed to these youths' journey of becoming empowered, and overtime will hopefully impact not only their own health and wellbeing but future community development.

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# Chapter 4: "We came out of our shells through this whole process" – Fostering space for positive youth development through community-based participatory research

#### Introduction

Research is evolving to better meet the needs of Indigenous communities. Traditionally, research has been conducted *on* Indigenous peoples (Brant Castellano, 2004; Wilson, 2008). Community-based participatory research (CBPR) is gaining traction as an acceptable way to conduct research *with* Indigenous communities (Castleden, Sloan Morgan, & Lamb, 2012; Fletcher, 2003; Simons & Christopher, 2013). Through responsive research, CBPR projects have demonstrated positive impacts with Indigenous communities (Cross et al., 2011; Daley et al., 2010; Riecken, Scott, & Tanaka, 2006; Mackinnon & Stephens, 2010). Furthermore, CBPR is an appropriate approach when working with Indigenous communities as it democratizes the research process, enhances research results by incorporating community knowledge and expertise, and builds on existing individual and community strengths.

CBPR equitably involves all partners throughout the research process, emphasizing the importance of co-creation of knowledge (Cargo & Mercer, 2008). CBPR aims to develop mutual trust and respect, facilitate empowerment strategies, and create ownership, leading to sustainability of research outcomes and projects in communities (Cargo & Mercer, 2008). It facilitates the development of context-specific solutions by working with communities to address their needs and improve their social and economic conditions (Cargo & Mercer, 2008; Castleden et al., 2012). Locally based CBPR projects are acknowledged as approaches that have the potential to improve health outcomes and reduce health disparities for marginalized populations (Cargo & Mercer, 2008; Wallerstein & Duran 2010). One health disparity of particular concern is the high rates of tobacco misuse amongst Aboriginal youth in Canada (First Nations Centre, 2005; Retnakaran, Hanley, Connelly, Harris, & Zinman, 2005).

CBPR projects are gaining wide spread recognition in tobacco misuse prevention and cessation initiatives with youth (Andrews, Newman, Health, Williams, & Tingen, 2012; Horn, McCracken, Dino, & Brayboy 2008; Jardine & James, 2012; Ross, 2011). Youth are best positioned to develop tobacco prevention resources, as they are able to take into consideration their unique perspectives, enhancing the products developed (MacDonald et al., 2011; Wong, Zimmerman, & Parker, 2010). Involving youth in CBPR initiatives is emerging in the literature

as a promising approach for promoting positive health behaviour development in adolescents (Flicker et al., 2008; Ford, Rasmus, & Allen, 2012; MacDonald et al., 2011; Ozer, Ritterman, & Wanis, 2010). However, there is limited evidence if the utilization of participatory research approaches with youth is truly achieving the intended impacts. A better understanding is needed of how participation in research may actually provide youth the opportunity to develop building blocks (Charmaraman, 2010) for healthy development, particularly when research projects are situated within the school context.

Traditionally in a school environment, adults control and drive the inquiry. This results in youth having limited control and autonomy in decision-making processes (Ozer et al., 2010). CBPR is one approach to facilitate youth-driven inquiry within the school setting, opening up opportunities for youth to meaningfully participate in decision making (Kohfeldt, Chhun, Grace, & Langhout, 2011), gain a voice, and develop a sense of efficacy (Ozer et al., 2010). Moreover, collaborative research can improve the relationships between students and school personnel as they "engage together in inquiry about issues relevant to the school and to students" (Ozer et al., 2010, p. 155). The school environment has the potential to create a safe space for youth to develop these positive relationships (Garkani, 2014). Furthermore, Ozer and colleagues (2010), describe how participatory research in a school setting can promote positive identity development for youth.

Utilizing participatory video with youth is a method that not only has the potential to create effective and relevant health promotion resources but also to promote positive developmental outcomes for youth. Participatory video is a process for individual and community development (White, 2003). It is a technique used to involve youth in shaping and creating their own videos (Lunch & Lunch, 2006). The primary purpose is to promote "a sense of belonging, a feeling of importance, [and] a claim to an identity" (White, 2003, p. 65). All participants' voices are heard, their views are validated, and they are able to develop skills and construct health promotion messages on topics of personal interest (White, 2003).

Involving Indigenous youth in the research process enhances the overall study (Ford et al., 2012). However, there is little knowledge about the actual impact for the youth who participated in the research. It is important to know under what conditions and contexts positive development for youth occurs (Benson, Scales, Hamilton, & Sesma, 2006). There has been significantly less attention paid to whether participatory approaches actually achieve the desired

outcomes (Foster-Fishman, Nowell, Deacon, Nievar, & McCann, 2005). This research aims to explore the necessary environment required for quality youth participation and subsequent positive developmental outcomes that result from their participation in a school-based video project. Specifically, this article explores the process and subsequent impact of youth participating in a project where they used the interactive process of video making on tobacco misuse to influence their peers, family, and communities. The research is timely to determine if this participatory method is benefiting Aboriginal youth in the intended ways, such as increasing their sense belonging, importance, and identity development (White, 2003). The results of this work will contribute to our knowledge on the benefits of participatory research with youth.

## Methods

Two research questions guided the qualitative inquiry: 1) Does participation in a CBPR project lead to changes in assets central to youth development (such as bonding, sense of purpose, positive identity growth), extending beyond the projects focus of tobacco misuse? 2) Are there context specific similarities and differences between the project locations (Ndilo, Northwest Territories and Edmonton, Alberta) that may have played a role in influencing youth health outcomes? Ethical approval was received from the Health Research Ethics Board #1, University of Alberta and the Aurora Research Institute, Northwest Territories.

## **Study Context**

Our study on the effects of participation in research is embedded in a two site schoolbased CBPR video project with the K'alemi Dene School, Ndilo, Northwest Territories (NT), Canada, and the Queen Elizabeth High School, Edmonton, Alberta, Canada. The school principals identified tobacco misuse prevention and cessation as a topic for school level change that the youth could collectively address. The project utilized participatory video with Aboriginal youth on tobacco misuse, particularly encouraging smoking prevention and/or cessation. A secondary goal of this initiative was to empower youth to act as health promoters in their schools and community.

K'alemi Dene School is the community school of Ndilo, NT. Ndilo is a Yellowknives Dene First Nation community located just outside of the city limits of Yellowknife, the capital of the NT. The school has a student population of approximately 100 students, of which the

majority identify as Aboriginal, Dene First Nation. The school curriculum honours and celebrates the culture, traditions, and language of the Dene people, offering education from Kindergarten to Grade 12.

Queen Elizabeth High School is an urban school located in Edmonton, the capital of Alberta. The multi-cultural school offers grades 10-12 and has a student population of approximately 1,200, with about 150 Aboriginal students. The majority of the Aboriginal students identify as Cree First Nation or Métis. Figure 4.1 depicting the geographical location of both Edmonton, Alberta and Ndilo, Northwest Territories.



**Figure 4.1** Geographical location of both Edmonton, Alberta and Ndilo, NT Retrieved from: http://www.freeusandworldmaps.com/html/USAandCanada/CanadaPrintable.html

## **Participatory Video Implementation**

From March 2013 to May 2013, youth learned filmmaking skills from local Aboriginal filmmakers and worked together in teams to develop films that portrayed their own personal messages about tobacco misuse.

The K'alemi Dene School invited all of the high school students to participate in the CBPR video project, and youth were able to choose to participate or not. For the students who participated, the school incorporated the CBPR video project into their teaching curriculum, which enabled students to meet the schools' learning objectives through the project. The project occurred during a one week intensive period and then the youth were able to use class time to continue working on completing the editing and finalizations of their videos.

At Queen Elizabeth High School, the research team worked with the school's First Nation/Inuit/Métis liaison to identify Aboriginal students who would be interested in participating in the project. The CBPR video project was developed as an extracurricular activity for the youth at Queen Elizabeth High School. The project was carried out during lunch time and occasionally carried over into class time, which the students were excused from but were required to make up any missed assignments.

From May 2013 to January 2014, the youth's videos were screened at their schools, posted on YouTube (https://www.youtube.com/channel/UCbu7HOxP-5s2sxe2WVu3SPQ), and DVDs were created to hand out to peers, family, and community members. Youth also participated in one local and one international film festival, and two school exchanges. Post– project, Ndilo youth co-presented the research findings to the Government of Northwest Territories and the Edmonton youth co-presented at local and international academic conferences as well as an invited seminar at the School of Public Health, University of Alberta.

## **Participants**

The participants for this study were the Aboriginal youth involved in the CBPR video project (n=28), the school principals and teachers who collaborated on the CBPR video project (n=6), and the local filmmakers (n=2).

## **Data Generating Strategies**

Operating within the CBPR video project and a participatory framework, this research project used focused ethnography to guide the data generation strategies (Higginbottom, Pillay, & Boadu, 2013). Data sources included focus groups with the youth, one-on-one interviews with the adult partners, and the first author's research field notes and personal journal.

Eleven focus groups were conducted at three stages during the project. Each focus group was comprised of the members of each of the youth video-making teams. The focus groups included questions on youths' involvement in the CBPR video project, the process of making their videos, what it was like for them to participate in the research project, and reflection on health and wellness changes they experienced because of participation. Each focus group built on the previous focus groups interview guide and emerging themes. This process facilitated member checking and confirmation of emerging themes within the following focus groups, and documentation of youth growth and changes over the course of the research project.

Semi-structured, one-on-one interviews were conducted with the adult partners. The interviews with the adults explored similar topics as the youth focus groups. This provided observation and insights into youth changes from the adults who worked with them on a consistent basis. Seven interviews were conducted at the start of the CBPR video project and eight were conducted upon completion of the project. Field notes captured informal discussions with the youth and adult partners, the participatory research processes, and researcher involvement in the project.

#### **Data Analysis**

Data generation and data analysis occurred concurrently through an iterative process. Interviews and focus groups were recorded with participant permission using digital voice recorders. A professional transcription service was used to transcribe interview recordings verbatim. Transcripts were verified prior to analysis. Using NVivo10<sup>TM</sup> qualitative analysis software, a content analysis of the interview and focus group transcripts was employed. A final codebook was inductively developed and themes were formed. After analysis was completed the first author conducted member checking exercises with available youth and adult partners. She discussed emerging themes and participants were invited to add, subtract, and clarify the content

to ensure that their thoughts and comments were accurately represented. Any new insights provided were added to the dataset and analysed accordingly.

The results from each location are compared and contrasted. Analysis of the participatory video project in two distinctly different locations highlighted factors that facilitate youth participation in CBPR and the different outcomes of participation on their well-being.

## Results

The main themes that arose included fostering a safe space for youth participation, youth participation, and building assets for youth development. To differentiate responses, youth and adults from K'alemi Dene School, Ndilo, NT are identified as ND Youth/Adult # and Queen Elizabeth, Edmonton, Alberta participants are identified as ED Youth/Adult #.

#### **Fostering a Safe Space**

**Collaborative, strength-based research approach.** The research project required a collective approach and effort from all partners and participants to build a meaningful place for youth to participate safely. ED Adult #3 described, "there's a part of this whole project that is just building community", meaning that there was a focus on fostering a space for youth "to have the supports between and amongst themselves to make some [positive] decisions" (ED Adult #2). ND Adult #18 felt the success of building a safe space within the project was from "committed people [seeing] it through."

Many Edmonton youth described feeling excluded from making decisions that affected them because adults did not listen to their opinions. As explained by ED Youth #8, "it's our parents that are asked about it more than we are. Then our parents [give] them their opinion when it's not exactly OUR opinion." In Ndilo, many youth believed that adults would listen to them but they did not have actual experiences of community members doing so to share. ND Youth #27 expressed this by saying, "they wouldn't just ignore what you have to say...I'm pretty sure they would listen to you."

Utilizing a strength-based approach to working with youth in the CBPR video project resulted in youth feeling valued by being heard. Through member checking exercises, Edmonton youth described the importance of being identified for their positive work and feeling important because their voices were listened to throughout the process rather than being told what to do.

ND youth #23 felt that gaining a voice was important "just to show that we exist... when other people listen to us... we can show what we learned, and that we were really there in purpose."

**Support and encouragement.** Support and encouragement of the youth participating in the CBPR video project was received from all project participants (youth, school personnel, filmmakers, and researchers).

Working together as a team, youth supported each other throughout the research project by taking on different leadership roles when they were more comfortable completing a task than their peers. During the school exchanges, youth supported each other when they showcased their videos through congratulatory remarks, clapping, and sharing personal stories of their experience creating their videos (field note, May 28, 2013).

Youth commented on the support they received throughout the project. ED Youth #14 was very appreciative saying, "whoever provided everything did a good job because otherwise we wouldn't be able to did it...Thanks for an awesome experience, you guys... thanks for the food, transportation, thanks for all the equipment and time commitments, and the film festival." This shows that the adult partners (school personnel, filmmakers, and researchers) played an important role in building a foundation of support and encouragement. One Ndilo youth conversation also described support and encouragement from the school personnel involved in the project:

Well, it was pretty much all the teachers. (ND Youth #23)

Helped us. (ND Youth #20)

They helped you? How did they help you? (Interviewer)

They were supporting us to do our videos, so we did. (ND Youth #23)

Even though we fall apart we still get back up. They helped us. (ND Youth #20) The adults talked about support in the sense of creating structure, while providing guidance and flexibility to facilitate youth's success. Youth did not explicitly describe the adults' support in this way. However, as illustrated by the following quote, the adults involved in the project clearly described their role as supporting and encouraging youth through the research process:

Youth #7 is directing with me. Smart chick, but she's not too sure of her place in the world, and then as soon as I gave her the responsibility, she became a new person because someone is listening to her. Someone actually gives a shit about what she has to say and what she is thinking about. (ED Adult #4)

**Relationality.** Relationships grew and fostered within and between the following groups: youth and youth, youth and their school, and youth and researchers. Through the formation of their groups, peer to peer support nurtured relationships between the youth, as the youth indicated by explaining:

We came out of our shells a lot through this whole process, before it was a challenge. (ED Youth #9)

...meeting new people, getting out of your bubble and just instantly having a bond with them. (ED Youth #8)

Youth also built friendships while they participated in the film festivals and school exchanges. The youth were excited to meet youth from the other school, and many mentioned during the follow-up focus groups how they enjoyed seeing each other's school and learning about the different lives of the youth. Two youth explained in one focus group, "[ I want to] meet other kids and see what we can learn from them (ND Youth #23), from each other (ND Youth #22), yeah, what they can learn from us too (ND Youth #23)."

The school personnel also saw the relationship building within each of the groups. This is important because the school personnel from both schools commented on the challenges of group work. ND Adult #19 explains, "it's really difficult to do group work within our group of high school students. Often it's a lot more individual, it was good to get them to be part of groups... they tried to work hard."

The project was a catalyst for building relationships between the youth and school personnel, particularly in Edmonton. The Edmonton youth viewed the CBPR video project as one of the first times they had been positively targeted as Aboriginal youth to be a part of an activity in their school. When asked during a focus group "in what ways has your school taken steps to include you in activities that are meaningful to you", youth responded by saying:

This is the first time that someone actually came and got me, to want me to be in a group like this...it's kind of a bummer. (ED Youth #13)

They should have other Native stuff for us. (ED Youth #14)

Overall, being meaningfully engaged and supported through the project resulted in positive interaction between the youth and their school. As ED Adult #3 described, "I think the benefit was getting to hang out with those kids in a way outside my office, where I'm dealing with discipline ... it [CBPR project] created relationships, DIFFERENTLY (adult's emphasis)."

Developing relationships between the youth and researchers took time and required the researchers to be active participants throughout the research process, showing commitment to the youth. By sharing personal stories and being herself in the field, the first author developed relationships with the youth where they felt comfortable around each other. ND Youth #26 told her during an interview that she wanted to participate in the project to hang out with the research team. ND Youth #26 also said that she wanted her to keep doing interviews because "it is the first time [she had] been to something like this [research project] and they gave us an interview."

## **Youth Participation**

Captured through the first author's field notes, youths' participation varied throughout the stages of the research project.

**Motivation to participate.** The focus on tobacco misuse was meaningful to approximately half of the youth, while the other half were interested in participating regardless of the topic. For example, ND Youth #25 talked about how his group was "trying to show the world not to smoke... not smoking, at such a young age." ND Youth #22, was more interested in "meeting people from out of town and having the experience of doing movies."

The filmmakers both described that they felt "the hook wasn't the message [tobacco misuse]; it was how the message was made. They [youth] were interested in the filmmaking more than the message, although they seemed to take the message to heart" (ND Adult #33). ED Youth #5 explained that the project "was a new experience because I never thought I would be working with video cameras and making a video...it opened my eyes to see how the videos are made, and it was really fun." Many of the youth in the project also felt this way. Some of the youth also described this by explaining how they were interested in participating in further video making projects. In particular one Ndilo youth wanted to explore the topics of "bullying and cancer" (ND Youth #26) while one Edmonton youth wanted to participate in "more video competitions" (ED Youth #6) and another Edmonton youth subsequently created a film on binge drinking post project.

Edmonton youth were further motivated to participate in the project "because it's the first Native thing available to participate in the school!" (ED Youth #14) and "to learn whatever you can teach us, whatever you can jam into our heads [laughter] (ED Youth #16)." Youth from

Ndilo wanted to participate to learn leadership skills, and to "be able to go on a trip to Edmonton [to show their films]" (ND Youth #28).

**Meaningful activities and opportunities.** ND Adult #18 emphasized how important it was that the research project was youth-led to have meaningful activities for youth to participate in: "One of the things I probably loved the most was how our students were taken through the whole process … They were given guidance and support right through… they were learning how to do it right."

Having flexibility throughout the research project allowed youth to choose their own group and create their own videos in a way that was meaningful for them. ND Adult #18 indicated that the flexibility of the project gave youth the space to have "creative license, they were able to pretty well do whatever they wanted; they didn't have a whole bunch of guidelines and restrictions and criteria." Flexibility of the CBPR video process to meet youths' needs was easier at K'alemi Dene School because the teachers were able to meet their teaching curriculum criteria through the project. This enabled youth to use class time to work on the project. ND Adult #19 indicated that "we gave a lot of flexibility to the times when they could edit or shoot the video…other teachers were ... aware of it [CBPR project]. Being a small school, we have that advantage." At Queen Elizabeth School, the project occurred during lunch and classroom time and the youth had to make up any missed assignments. The teachers in the school were also not partners on the project. A challenge from ED Adult #2 perspective "was the amount of time the kids were away from class to complete this project and … it [CBPR project] isn't particularly aligned with Alberta education curriculum."

The multiple opportunities for participation throughout the project provided a range of activities in which the youth could choose to engage. Youth who lost interest during the filming process became interested in presenting the final videos to their school and participating in knowledge dissemination activities of the research results (field note, May 4, 2014). ND Adult #18 expressed how it is important to have "as many opportunities to succeed in a wide variety of areas as possible [because] you never know what that magic key is for any one person."

# **Building Assets Central to Youth Development**

Through the video development process, youth started to build the scaffolding necessary for positive health and wellness outcomes. ED Adult #3 described the impact of participating in the research project as "planting seeds to germinate."

Sense of belonging. As previously described many of the Edmonton youth wanted to participate because it was the first activity offered specifically for Aboriginal students. The Edmonton youth talked about feeling socially excluded at school, and the project was a way to be included, as emphasized by ED Youth #14: "I thought it [CBPR project] was pretty cool because my school doesn't offer stuff like this...not a lot of Aboriginal things going on here." The Edmonton youth in particular described that the CBPR video project facilitated relationship building that resulted in a connection to others and created a place to belong. Through the project youth expressed how "after a while it was all [of us] talking, being able to communicate with each other and get along. We all felt supported and felt like a sense of belonging with each other" (ED Youth #7). ED Youth #8 expanded on this to say that throughout the project she started to connect and have bonds with her team members, "if it's a project, normally I'm usually quiet at the start of it, but when we got here [Yellowknife] I was more outspoken the entire time, because I was with people I was comfortable around." ED Adult #3 also witnessed the youth connecting in ways they never had before:

We've got such a different group of kids and they're such a mix... you have kids that are athletes and kids that ARE the smokers and kids that ARE into party lifestyle, kids that are NOT into party lifestyle. It's a really nice mix of okay, here is somebody, I can identify with them. It's peers on peers and that whole belonging piece. Now you can belong with somebody you didn't think you could before, and now you're belonging to a non-smoker that's a good student and you didn't maybe know that before.

Edmonton youth became interested in exploring and learning more about their cultural identity through the formation of their groups, meeting the Ndilo youth, and travelling to Yellowknife. When asked if anything changed for him over the course of the project, ED Youth #5 replied by saying, "It [CBPR project] made me want to learn more about the Native culture and the whole traditions that they used to do." ED Youth #9 also reflected on this comment to say: "I don't think that any of us are really traditional and spiritual. And like that maybe it's [participating in

the project] is bringing us together, like learning about it [Aboriginal traditions] together and stuff."

Edmonton youth saw how integrated cultural practices can be in the school environment and people's everyday lives when they met with the Ndilo youth, saw their school, and learned about the lives of the Ndilo youth. This resulted in the Edmonton youth wanting to learn more about their own identities, histories, and traditions because "we're the next generation, and if we're not going to learn it then our future generations won't know it either so the tradition will just get lost down in time" (ED Youth #8). By travelling to Yellowknife and Ndilo, the Edmonton youth learned and gained hands-on experience of how other Aboriginal youth in Canada live. "I really do enjoy Yellowknife because there's a lot of cultural experience. You can learn a lot about Aboriginal culture here and I think that's really cool" (ED Youth #7).

**Sense of purpose.** The Ndilo youth felt that adults in their school and community listened to and supported them. The school was already taking measures to engage the youth by collaborating with them to create programs that meet their needs. Therefore, the Ndilo youth did not describe a need to belong as Aboriginal youth like the Edmonton youth. Rather through participation the safe space created within the CBPR video project, resulted in the Ndilo youth developing a sense of purpose.

Through the project, many of the youth identified a need to learn leadership skills, enabling them to "be role models to our own home communities" (ND Youth #20). The youth identified that "younger kids are smoking so they can learn from us" (ND Youth #21). The youth felt it was important to be youth leaders to "the younger kids and show them that they can be the same as us [smoke free]" (ND Youth #23). There are also expectations within K'alemi Dene School that the older youth need to be good role models to the younger students in the school. Participating in the CBPR project was another way for the youth to be positive leaders. ND Adult #18 expressed this sentiment: "the school is hoping to get positive role models coming out there and being advocates for non-smoking, being advocates for smoke-free, because that's that we need."

It was important to the Ndilo youth to promote and preserve their culture enabling them "to show who we are, and where we came from" (ND Youth #20), because our "culture is slowly fading... Elders and all the way to a child, are doing drugs at such a young age. I don't think they

deserved it. Not enough people are going to treatments. I thought I'd try to tell them that [you don't] deserve to be like that [addicted to smoking]" (ND Youth 25).

As Dene First Nation peoples, the youth also wanted to "learn about Cree stuff" (ND Youth #20) from the Edmonton youth. A few Ndilo youth mentioned how they enjoyed receiving teachings from a Cree First Nation Elder while they were in Edmonton participating in a local film festival.

#### Discussion

The primary purpose of this study was to explore the impact of participation in a schoolbased, CBPR video project for the youth participants. The aim was to determine if participation leads to changes in assets central to positive youth development, extending beyond the project's focus of changing knowledge, attitudes, and behaviours around tobacco misuse. Overall, the findings support that participation in a participatory video project has the potential to be a transformative experience for the participants. The results illustrate how local context such as the school environment and the different life circumstances of the project participants, influences the project implementation and outcomes. Each school received the same project but the interaction between the context and the way the project was implemented resulted in different outcomes for the youth at each school.

# Fostering a Safe Space For Youth Participation

Fostering a safe space for youth participation formed the foundation of the resulting impacts. The space created a mechanism for youth participation. Marginalized youth have described the importance of creating safe, open, and judgement free spaces where they can learn with their peers and meaningfully participate (Iwasaki et al., 2014). Ultimately, through their participation in the space, youth developed assets such as sense of purpose, belonging, and identity, central to positive development.

Some may assume that working together on a research project would result in the creation of a collective space where participants feel safe to participate. However, it cannot be expected that this will automatically happen, particularly when working in schools where traditionally there is a teacher-student role; the teacher is a gatekeeper, authority, and disciplinary, leaving youth with limited power and control (Kohfeldt et al., 2011; Mitra, 2004). It is important to create a space where youth can meaningfully participate, lead, and play a role in decision-making

processes (Kohfeldt et al., 2011; Mitra, 2004). Other youth studies utilizing media tools such as digital video and radio have shown that having a safe space for youth participation leads to greater ownership and commitment to the topic (Camino & Zeldin, 2002; Charmaraman, 2008). This research highlights the essential elements for creating a safe space for youth participation are utilizing a strength-based approach, supporting and encouraging youth, and building meaningful relationships.

Through applying a strength-based approach, youth in the CBPR video project felt valued and that their voices were sincerely listened to, rather than feeling excluded from decisions that affect them. According to the Edmonton youth, they felt their opinions were not normally considered. This finding is consistent with other research that describes how youth traditionally feel a low degree of control, as their opinions are excluded because they are thought to lack credibility (Valaitis, 2002). Consequently, their parents are included in the decision-making rather than the youth (Valaitis, 2002). The collaborative, strength-based approach of this research resulted in youth being viewed as resources as opposed to the commonly portrayed image as youth as problems (Checkoway & Gutierrez, 2006). Incorporating youth's opinions in decisionmaking processes involved in the research project, affected youth who felt valued and important.

The youth participants explained that the support and encouragement they received from the adults was necessary for their success. Other authors have noted adult involvement influences youth participation and therefore adults should share the responsibility of creating a sense of security for youth by providing guidance and support throughout the research process (Eccels & Gootman, 2002; Holden, Messeri, Evans, Crankshaw, & Ben-Davies, 2004; Wong, et al., 2010). For the youth involved in this CBPR video project, the guidance and support led to the creation of positive relationships.

In CBPR, it is critical that time and care is taken to build relationships (Fletcher, 2003; Garakani, 2014). As Tuhiwai-Smith (2005) explains, "establishing, maintaining, and nurturing reciprocal and respectful relationships" (p. 97) is key to successful CBPR projects. Riecken and colleagues (2006), describe how a video project with First Nation youth fostered the development of positive relationships, not only between students and their teachers but also with community members. The need to build new relationships was stronger for Edmonton youth, as they were from various grades and schools, had never worked together before, nor had they been involved in research. Many of Ndilo youth have had the same teachers and peers throughout their

entire education and have been involved in previous research projects. They had already built strong relationships.

This research highlighted youths' voluntary relationship building with youth from their own school as well as youth from diverse backgrounds. Tupuola (2006) explains that participatory research has the potential "to connect young people across local and global spaces" (p. 293). Thus, it is critical that future projects aim to connect and foster relationship building between youth of diverse backgrounds. Particularly in this CBPR video project, youth were able to learn from one another and strengthen group bonds across large geographical distances.

The project also promoted relationship building between youth and the school personnel involved in the project, which can aid youth in finding meaning in their school experiences (Mitra, 2004). The youth found meaning in their work with adult support, as they worked towards promoting healthy behaviours. The research of Dawes & Larson (2011) provides evidence that building relationships "may be a central mechanism in the change process through which youth become motivated and engaged" (p. 265). Furthermore, marginalized youth have described the importance of having peers and adults encourage them to achieve their full potentials, relationship building was an important aspect of this (Iwasaki et al., 2014).

Despite the geographical distance between K'alemi Dene School and the researchers' location, relationships still developed. This is significant, as other authors have noted building relationships in Northern communities during the school year is virtually impossible for 'southern' researchers (Garakani, 2014).

#### **Youth Participation**

Wong and colleagues (2010) describe that "the concept of youth participation can be observed on a continuum" (p. 104). Youths' participation in this project was also observed to be on a continuum. Youth were motivated to participate for various reasons ranging from being advocates for smoking cessation and prevention, to wanting to meet other youth and travel to new communities. These findings are consistent with previous research, which shows youths' drive to participate fluctuates from wanting to learn new skills, alleviate boredom (Perkins et al. 2007), and to be included in meaningful activities (Dawes & Larson, 2011). While youth join a project for various reasons, it is important to explore opportunities within the project for youth to

foster authentic connections to the activities to obtain the development benefits of participation (Dawes & Larson, 2011).

Our research shows that for youth to develop authentic connections to the research activities, the project needed to be youth-led, flexible, and have multiple opportunities for participation. This is consistent with research with Inuit youth whose participation also varied due to their comfort level, personal circumstances, and availability (Garakani, 2014). These factors required the project to be flexible to meet their needs (Garakani, 2014). Research also shows that "meaningful participation and sustained involvement" in activities varies depending on the type of activity and can by expressed differently by youth participating in the same activity (Crooks, Chiodo, Thomas, & Hughes, 2009, p. 2).

There is research to support that youth participation in structured and organized activities at school can be a protective factor connected to decreased substance use and involvement in criminal behaviours (Li et al., 2011), lower rates of school dropout (Crooks et al., 2009), improved academic success and increased life satisfaction (Upadyaya & Salmela-Aro 2013). Given the link between meaningful and sustained youth participation in school activities and positive behaviours, CBPR projects can create the necessary safe space for youth participation and development of positive outcomes. Research further supports the need to provide youth with multiple opportunities for learning within the school environment (Damon, 2004; Riecken et al., 2006). While teachers already have demanding schedules, youth-led CBPR projects may provide an opportunity for youth to engage in further activities in their schools that support their needs.

Understanding the factors that influence youth's participation in a CBPR project can result in the creation of programs that better suit their needs, leading to increased growth of positive development assets. Research has described that positive development assets can increase for youth who show greater involvement in the project compared to youth who participate infrequently and demonstrate lower levels of agency (Mitra, 2004). However, the way youth participate in activities and the resulting expression of engagement levels varies depending on the youth (Crooks et al., 2009). Specifically within this CBPR video project, each youth came to the video project with a different level of desire to participate, which affected the benefits the youth gained from participating in the project. Depending on the reasons youth in this research project specifically choose to participate, youth who frequently partook and were interested in

discussing their experiences with the research team showed an increased sense of belonging and purpose and started to develop their identity further.

#### **Youth Development**

Eccles & Gootman (2002) describe the importance of working beyond a focus of eliminating problems to developing "skills, knowledge, and a variety of other personal and social assets to function well during adolescence and adulthood" (p. 3). Participation in this research encouraged healthy development where youth developed a sense of purpose and belonging. The growth occurred through the development of a safe space that facilitated youths' participation. Fostering these assets and competencies is critical for the development of positive health and well-being of youth (Mitra, 2004; Scales, 1999).

Edmonton youth described feeling excluded in their school environment, as there were no activities offered specifically for Aboriginal youth. Research shows that many adolescents feel alienated at school, particularly when there is a large student population and class sizes (Mitra, 2004). Social isolation and disconnect to a sense of membership in a large school setting appears to lead to higher likelihood of school dropout (Osterman, 2000) and drug use (Fletcher, Bonell, & Hargreaves, 2008). Having a sense of belonging in school tends to lead to increased resiliency against drug and cigarette use (Kulis, Napoli, & Marsiglia, 2002), increased academic achievement, particularly for ethnic minority students (Napoli, Marsiglia, & Kulis, 2003), and an increased sense of ethnic pride (Neel & Fuligni, 2013). The results of this study are important as participation in this project led the Edmonton youth to gain an increase in their sense of belonging and inclusion in the school environment. These changes could lead to a decrease in coping behaviours related to alienations and stress, such as drug and tobacco misuse, in the long term.

In addition, the results suggest that the reasons the youth chose to participate in the project influenced the developmental outcomes. The Edmonton students gained a sense of belonging within a large school environment; however, this already existed for the Ndilo youth who are situated within a small community school. Rather the Ndilo youth wanted to learn leadership skills and be role models to the younger students.

Participating in the CBPR video project provided the opportunity for the Ndilo youth to grow their sense of purpose, working towards positive health changes in their communities. The

conversations with the Ndilo youth demonstrate how the youth valued having the opportunity to act as role models for the younger children and peers in their schools. In other tobacco misuse prevention and cessation projects, youth have reported wanting to be positive role models to their younger peers (Valentine, Dewar, & Wardman, 2002). Authors have noted that youth value "being role models for younger children in their neighborhoods" (Perkins et al., 2007, p. 437) and leadership roles increase their motivation to make a difference on topics that affect their schools (Ozer & Douglas, 2013). The consistency of our findings with the literature further substantiates that CBPR projects have the potential for youth to develop a sense of purpose and contribute to community development when they are working on topics of importance to them. Furthermore, participatory research approaches can facilitate youth taking on roles where they are change agents, necessary for community development.

Enhancing youths' sense of purpose through participation can affect others and transcends self-needs, expanding beyond individual influence (Dawes & Larson, 2011) to create positive changes. Damon and colleagues (2003) describe that, from a developmental perspective, youth gaining motivation and skills to influence their schools can positively impact their sense of purpose and identity formation. Identity formation occurs through youth making meaning out of their lives.

The development of a sense of belonging (Mitra, 2004) and purpose are critical assets towards identify formation (Damon et al., 2003; Ozer et al., 2010). Wong and colleagues (2010) explain that through the process of engaging with others, adolescents are able to explore who they are and where they want to go, which encourages positive identity development. Participating in this CBPR project provided opportunities for the youth to explore their identity in a variety of roles. Edmonton youth described belonging with each other within the larger school context. This sense of belonging as urban Aboriginal youth also facilitated them wanting to learn more about their cultural identity. Learning about their Aboriginal identity was not a missing link for the northern youth; instead they described wanting to promote and preserve their cultural traditions. By exploring their culture, youth experimented and started to build their identity (Chinman & Linney, 1998). Our findings are consistent with identity development as youth from both locations started to develop their identity in ways that met their specific needs.

Building youths' abilities and competencies can positively influence their participation in health-comprising behaviours such as tobacco misuse. This research provides evidence on how

youth meaningfully participating in a participatory video project can lead to other positive outcomes that will affect their health and wellbeing in the long term. The results provide evidence on how participating in CBPR builds the foundation for different areas of positive youth development to occur. The process of participating in a CBPR project can be described as a mechanism for youth development. Furthermore, research outcomes are influenced through the interaction between the research context (school and community environment) and the mechanism (CBPR video project). Therefore, consideration needs to be taken of the different contextual factors to ensure the best outcomes for youth.

# **Limitations and Challenges**

CBPR in a school setting has particular challenges including competing interests for youth time, hard deadlines, and designated time to work with the youth (Ozer et al., 2010). However, despite these challenges, the project was still able to create the conditions necessary to open up a mechanism for meaningful youth participation, meeting youths' needs.

The research findings argue for the potential benefits of participating in CBPR based on the youth who participated frequently, showed active engagement throughout the CBPR video project, and voiced their experience of participating in the research project during the focus groups and informal conversations with the researchers. Because youth express authentic participation and commitment to project activities differently, this limits our ability to capture their experience of participation if they do not express it verbally. This is also a limitation of the data collection activities, as focus groups require youth to be vocal about their experiences. This results in discussion of the research outcomes for the youth who were comfortable exploring their experience verbally. There may have been youth who were more engaged throughout the process but not as vocal throughout. Therefore, their experience may not be included in the results because we are only able to report on the information youth provided verbally, which may miss other realities.

A challenge of any research with youth is low engagement and meeting the diverse learning and expression needs of all the youth participants. However, the researchers and school personnel did their best to meet the needs of all of the youth participating in the CBPR video project and it was the youths' choice to participate in as much or as little of the activities as they

liked. Through prolonged engagement in the school, with the youth and member checking, we were able to verify the themes and are confident that the results represent the youths' experience.

The results of this research are not intended to be generalizable to other Aboriginal youth contexts across Canada. The aim of the research was not to make generalizable statements but rather provide a rich description of the context and results to create transferability of findings. Comparing and contrasting the research results from two different settings increases the transferability of the results.

## Conclusion

When planning CBPR, there needs to be consideration on investing time to develop a safe space for youth participation. This requires using a strength-based approach, providing support and encouragement to youth, and building relationships. Through this space, youth feel safe to participate, which subsequently results in an increase of positive assets for youth development. This research provides evidence on the importance of creating a space for youth to participate, and highlights the potential of participatory research processes to positively impact youth.

Our work provides a starting point to begin understanding the potential impacts of participatory research on youths' development that extends beyond the intended research outcomes. In particular, understanding the impacts from the youths' perspective allows us to understand their lived experience. Furthermore, the research method did achieve the aims of participatory video to increase youths' sense of belonging and purpose, as well as identity development (White, 2003).

By comparing and contrasting two different research locations, we can see how the different life circumstances of the youth influenced the outcomes. When conducting research in multiple settings, the context, such as the school environment and life circumstances of each location, must be considered to achieve the greatest benefit. Providing opportunities to participate in CBPR research projects has the potential to contribute to positive youth development outcomes in Aboriginal youth in urban and remote schools.

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#### **Chapter 5: Conclusion**

Situated within the larger CBPR tobacco misuse video project, this research was conducted in collaboration with Aboriginal youth and school personnel from K'alemi Dene School and Queen Elizabeth High School. The overall aim was to explore from the perspectives of the project participants, the perceived impact of participating in the CBPR video project on youths' health and wellness. Utilizing IRM and CBPR principles to guide my work, I explored with Aboriginal youth and our school partners, their experience participating in the research project "*Engaging Aboriginal Youth in Tobacco Prevention Using Social Media*." Focused ethnography guided the data generation, involving focus groups with the youth and one-on-one interviews with the adult partners.

For this concluding chapter I summarize the research findings. I then review how this research contributes to the existing literature. I provide recommendations for practice, policy, and directions for future research. I conclude by providing a final reflection about my personal transformation as not only as a researcher, but also as a person.

#### **Summary of Research Findings**

In participatory research, much attention has been given to developing key principles for engaging in CBPR (Cargo & Mercer, 2008; Israel et al., 2008), increasing partnership sustainability (Horn, McCracken, Dino, & Brayboy, 2008), and how the research can lead to reducing health disparities (Wallerstein, 2006). However, there has been less focus on the actual impact of participation in these research projects for participants' health and wellbeing. It is important to understand if participatory health promotion research is truly having the intended impacts. Overall, these research findings provide evidence that participation in CBPR promotes positive health and wellbeing changes for the youth involved beyond the intended intervention outcomes.

## "Not all of us Aboriginals smoke": Exploring Empowerment as a Process

Common across both locations, youth came together around a topic and method of interest, to be school and community health promoters using video messages. Youth participated in this interactive skill-building project, and increased their capacity to act as change agents. Rather than being passive recipients of a message, youth were able to engage creatively and

critically in the production of their own messages. Consist with previous research, the process of video making for youth in this project was more influential on youths' health and wellbeing than the actual video product developed (White, 2003). The positive health outcomes youth experienced were a result of how the messages were made, rather than the actual message.

During the video making process, all of the youth were able to shine in a positive light. For disenfranchised Aboriginal youth, this is particularly important because they are able to challenge negative narratives about their capacity (Garakani, 2014). The youth in this project created a different story about the abilities of Aboriginal youth to be leaders in their schools and communities. They showed that, when given the opportunity to effect positive changes, Aboriginal youth not only have the desire and determination but the ability. Furthermore, the results show how celebrating youths' success further reinforces their positive behaviours and leads to an increased sense of pride in their abilities.

Participating in a project that provided an avenue for youth to gain a voice and be involved in decision-making processes was a powerful experience for the youth. This is important because exercising one's voice is integral to independence and developing agency to advocate for positive changes (Charmaraman, 2010). Moreover, participating in meaningful activities, increasing critical awareness of how to contribute to community development, and being recognized through positive reinforcement are three aspects of adolescent empowerment (Chinman & Linney, 1998). Overall, this research highlights that across both locations, participatory video was an empowering method for the youth involved. Participation in CBPR using participatory video methods can contribute to building the foundation to contribute to youths' empowerment journey.

# "We came out of our shells through this whole process": Fostering Space for Positive Youth Development

The findings show that a foundation of meaningful relationships, a culture of support and encouragement, and utilizing a strength-based approach created a safe space for Aboriginal youth to participate in the CBPR video project. Participating in the project was voluntary and subsequently youth determined their level of involvement. Each youth came to the video project with a different level of motivation to participate, which affected the benefits youth gained from participating in the project. Depending on the reasons youth chose to participate in the project,

youth that frequently partook and verbally expressed their authentic investment showed higher levels of engagement, increased their sense of belonging and purpose, and started to develop their identity further. The research context, specifically the school and community environment and the youths' different life circumstances and experiences also impacted these changes.

The Edmonton youth increased their sense of belonging. This is important, as they felt isolated and excluded within their school environment. Since Ndilo youth felt included in their school and wider community, they already had a sense of belonging and instead fostered a sense of purpose. The Ndilo youth wanted to be role models to the younger children in their schools and communities. The Ndilo youth further expressed their desire to learn skills that would enable them to be leaders in their communities. Furthermore, both of these developmental assets - sense of belonging (Mitra, 2004) and sense of purpose - are important in identity formation (Damon, Menon, & Cotton Bronk, 2003; Ozer, Ritterman, & Wanis, 2010).

The Edmonton youth found it challenging to develop their Aboriginal identity in a large urban city. Through participation in the CBPR video project, the Edmonton youth increased their desire to learn more about their Aboriginal history and culture. In comparison, the Ndilo youth already had a strong Aboriginal identity. Instead they described wanting to promote and preserve their cultural traditions which became part of their identity as Dene First Nation peoples. These results show how youth can develop and foster their identity through participatory video methods.

## **Tying It All Together**

Extending beyond the project's focus of changing knowledge, attitudes, and behaviours around tobacco misuse, and youth acting as health promoters in their schools, the findings support the potential of participatory video projects to be a transformative experience for the participants. The results provide evidence on how meaningful participation in a video research project can lead to positive outcomes that will affect their health and wellbeing in the long-term. This research thus supports the premise that participating in CBPR contributes to the necessary foundation for positive youth development and empowerment to foster and grow. The process of participating in a CBPR video project can be described as a mechanism to encourage positive changes for youth. Furthermore, as illustrated through the results, research outcomes are influenced through the interaction between the research context (school and community environment and the youths' different life circumstances) and the mechanism (CBPR video project). Therefore, local context matters and the research outcomes vary depending on the location. Personal life circumstances of the youth also modify the research outcomes, where youth personally benefit it ways that meet their own needs.

#### **Overall Significance of Research Contribution**

This research contributes to the gap in knowledge about the health impacts for Aboriginal youth participating in research. Specifically, this research adds to the literature on the benefits of participation in a participatory video project built on the principles of CBPR. I explored the potential of the process of participating in CBPR to positively affect youth participants' health and wellbeing.

The knowledge that was co-created can be used to improve future participatory research programs with Aboriginal youth. By fostering a safe space for youth participation in future research programs, Aboriginal youth have the potential to gain the greatest benefit. Future programs need to consider the importance of utilizing strength-based approaches to working with youth where there is opportunity for relationship building and support and encouragement from those involved in the project, facilitating youth participation. Future research programs should also incorporate opportunities for youth to shine and have their work celebrated. In this research project, celebrating youth led to an increase in their pride of their capabilities and sense of agency. Research involving Aboriginal youth should provide opportunities for youth to use their voice and act as health promoters in their schools and communities. This approach also has the potential for youth to embark on an empowering journey. Additionally, this research provides evidence of the importance of not only utilizing participatory research to impact health and wellbeing, but also how the process of participation further affects research participants, an area seldom explored.

There is a call for greater understanding of how participation in research projects affects the health and wellbeing of the individuals and communities participating (Foster-Fishman, Nowell, Deacon, Nievar, & McCann, 2005; Wallerstein, 2006; Wright et al., 2009). This is because evidence shows that the methods used in participatory research do have an impact on

those engaging in the process (Foster-Fishman et al., 2005), but that this is rarely explicitly described. The research conducted for this thesis provides evidence that participatory video does indeed meet many of the underlying goals of participatory research. Youth increased their capacity and decision-making skills (Israel et al., 2008) and fostered empowerment (Lunch & Lunch, 2006). By recognizing their unique strengths (Minkler & Wallerstein, 2008), youth increased pride in their capabilities and gained a voice. Furthermore, participatory research aims to work with communities to address their specific needs and improve health outcomes (Cargo & Mercer, 2008). Youth addressed tobacco misuse in their schools and communities by working as agents of change. Based on personal need, youth also increased specific assets central to positive youth development. This shows how participatory research creates a space where participants can meet their specific developmental needs.

This study provides a starting place for understanding how participatory research processes impact youth participants. Traditionally, research impact is assessed through evidence based health science research (EBHSR) deliverables and intended research outcomes. The experience of the participants is not included, missing important contextual knowledge (Jacquez, Vaughn, & Wagner, 2012). Understanding the impact of participatory research processes from the youth participants' perspective increases our knowledge of their lived experience. The knowledge co-created in this research project adds to the limited understanding of Aboriginal youths' experience throughout the research process. As youths' voices tend to be excluded from the research process (Garakani, 2014), the results show the importance of meaningfully involving youth throughout the process and engaging them in critical dialogue about how participation influences them.

By explicitly considering who benefited from participation in research and why (Flicker, 2008), collectively the participants and I generated new knowledge of how the process of participation can and should be viewed as part of the outcomes. I was able to identify the impact of participatory research process for the research participants. The findings are consistent with Tuhiwai-Smith (1999), who argues that the research process can be more important than the intended outcomes in Indigenous research. Furthermore, by understanding the added benefit of the participatory process in health research, improvements in health outcomes of the populations involved can be enhanced (Wallerstein, 2006; Wright et al., 2009). The results provided in this

study legitimize the need to move away from solely focusing on final products or intended intervention impact, to expanding our definition of impact to include the participatory process.

Research participants have differing experiences while engaging with participatory research methods (Foster-Fishman et al., 2005). The results of this research show how the process of working with participatory video methods can influence youths' health and wellbeing depending on their level of participation and the context in which the research is taking place. More importantly, research projects that include youth from different backgrounds and geographical locations have the potential to connect them across global spaces (Tupuola, 2006). Learning from individuals and communities with different backgrounds increases participants' knowledge of different lifestyles and enhances their understanding of contextual factors that influence their own and other communities' health and wellbeing.

Within the broader context of tobacco misuse prevention and cessation, this research cocreated knowledge on how participating in research processes builds a foundation for youth to have positive health and wellness outcomes. The findings support how the process of participating in CBPR can impact youth who gain assets for positive development and increase their empowerment. Youth were able to become community change agents, necessary for true community development.

## Recommendations

In this section, I outline suggestions for youth, schools, and CBPR practitioners engaging in participatory research with Aboriginal youth, implications for policy makers, and recommendations for future participatory health research.

#### **Recommendations for Future Practice**

First, I would like to address the youth. For any youth who are going to be engaging in participatory research I suggest that you work with adults on projects that are meaningful to you. Ensure that through the research process you are able to build the necessary skills you need to achieve the positive changes you are aiming for in your schools and communities. The skills you gain will influence you in all areas of your life, achieving positive changes you wish to see. Through this research, I have seen how the youth participants inspired their peers through their work. Remember that you are able to motivate not only your peers, but also your family

members and wider community. Take risks and advocate for what you believe in, you are our future.

For schools collaborating with academic institutions on research projects I would suggest creating a timeline where the research can run in parallel with the partner schools' teaching calendar. This creates opportunities to have the project follow with the school year and reduces challenges associated with navigating a research project with differing timelines that are not coordinated with the school schedule. Additionally, based on the research findings, there is evidence to suggest that youth are learning and gaining skills that align with schools' educational goals and curriculum. For future research projects situated in a school setting, it would be important to ensure such experiences can also be a part of the curriculum rather than only being available as extracurricular activities. This would require school administration to work with school boards to incorporate these types of projects into the curriculum. Doing this would provide further benefit to the youth who will gain school credits towards their high school completion, if done within class time as an assignment.

The school environment is an ideal place for youth to gain the necessary assets for positive youth development. While teachers already have demanding schedules, youth-led CBPR projects may provide an opportunity for youth to engage in further activities in their schools that support their needs. I recommend that schools explore their options to collaborate with academic institutions, which would result in opportunities for youth engagement over and above the dayto-day activities taking place in the school.

I recommend that CBPR practitioners collaborating with Aboriginal youth work towards creating a safe space for youth participation. The research results show that it is important to provide multiple opportunities for youth to choose how and when they would like to participate. It is important that the opportunities provided enhance active as opposed to passive engagement. Instead of running pre-determined adult-led programs that focus on behaviour change, youth need to be involved in a supportive environment where they are supported to independently or co-determine with adults how they want to address topics of personal importance. This will create higher levels of ownership and engagement, which is important because the youth who are the most engaged throughout the research gain the greatest health benefits. Furthermore, based on the research findings, researchers need to create programs that provide opportunities for youth to build their identity, and increase their sense of belonging and purpose. Programs should support leadership development and self-determination, and work towards creating a positive outlook of the abilities and achievements of Aboriginal youth.

When planning participatory programs it is important to remember that Aboriginal youth are not a homogeneous group and what works for one group may not meet the needs of the other. Consideration should to be taken particularly when working in geographically distinct locations as to how the contextual factors, such as the school environment may influence the youths' decision to participate. This research showed how the same participatory video project resulted in different outcomes based on the youths' needs and experiences. Future participatory research programs should recognize the cultural diversity of language, practices, and beliefs when developing programs with the Aboriginal communities.

Lastly, one of the frameworks this research utilized was the positive youth development framework, a strength-based approach to working with youth. Our findings are consistent with research that has shown how positive youth development does result in positive individual changes during short-term research projects (Ross, 2010). However, when working with marginalized and oppressed communities it is essential that future research critically analyze the dynamics of race, gender, social, political, and economic factors at play in communities (Ross, 2010). Addressing the broader socioeconomic and political determinants of health requires specific attention to the structural conditions in which Aboriginal youth experience higher levels of health disparities (Greenwood & de Leeuw, 2012). To address the loss of cultural continuity and identity that has arisen largely because of colonization and colonialism, future research needs to account for the social determinants of health in which Aboriginal youth are situated (Greenwood & de Leeuw, 2012). I suggest practitioners incorporate aspects of the social justice youth development (SJYD) theoretical framework. The framework emphasizes "building youth's self-awareness of how race, class, and other dimensions of power affect their lives on a daily basis" (Ross, 2010, p. 618). Using this framework has the potential to foster conditions and skills for Aboriginal youth to challenge and address the determinants of health that continue to perpetuate health inequalities, resulting in sustainable improvements of Aboriginal youths' health and wellbeing.

## **Policy Change Recommendations**

Participatory research programs are expected to fit within funding agencies' guidelines and predetermined measurable research goals that have proven to be effective (Mohajer & Earnest, 2009) and adhere to EBHSR. The guidelines and funding agency goals are created without input from the vulnerable populations the intended research activities are supposed to be affecting (Mohajer & Earnest, 2009). This approach implies that funding agencies have little interest in how participation in research may influence participants beyond quantifiable indicators (Mackinnon & Stephens, 2010). It is time for funding agencies to move beyond the 'gold standard' of randomized control trials and EBHSR to include lived experiences of participants that are captured through qualitative inquiry.

I recommend that funding agencies move beyond the narrowly defined concept of 'research impact' and their preoccupation with measuring concrete outcomes (Mackinnon & Stephens, 2010), and instead explore the lived experiences of research participants. This will facilitate research programs that are founded on culturally based definitions of impact and success, creating not only relevant research for communities, but also further improving the health and wellness of research participants by working towards their perception of success.

I also recommend that school administrators assess how they engage with marginalized youth in their schools. This research shows how urban Aboriginal youth in particular felt excluded within their school environment. They appreciated being singled out to participate in a positive activity that celebrated their cultural identity. The school administration at Queen Elizabeth School explained that, because it is a multicultural school, they try not to single students out based on their ethnicity. However, the Aboriginal youth from this school had a different perception. The youth wanted targeted programs that that celebrated their differences and were tailored for them to learn about their culture and practice their traditions. Therefore, it is vital for school administrators to understand why certain youth in their schools are choosing to participate or not in extracurricular activities. The results show how participation in the school environment is vital for creating a safe space for positive youth development. Therefore, school policy makers should consider how they are supporting the needs of marginalized youth within the school setting.

## **Recommendations for Future Participatory Health Research**

The results of this research have significant implications for future participatory health research. I provide three recommendations.

First, it is important to explore long-term health and wellness changes that result from participation in research. This research was a short-term project and due to the nature of being limited to the time afforded in a masters' degree, captured only immediate changes in youth. It is necessary to explore changes over longer periods to see how the immediate changes continue to impact youth. The results provided in this thesis built a foundation of knowledge on how participation in video research projects immediately affects participants. Researchers can utilize this work to assess longer-term and sustainable outcomes in future participatory programs.

Second, more work needs to be done to define what impact means to communities. The results of this research provide an example of how impact can be explored differently than the conventional focus on end outcomes and narrowly defined concept of impact. However, this is just a starting point for health researchers and more research exploring different conceptualization of impact is necessary. Ideally, each time a research project is initiated, researchers should work with youth and communities to define their conceptualization of impact and success, ensuring the indicators measured reflect the participants' perspectives (Mackinnon & Stephens, 2010), and guide the development of the research program. Having researchers advocate for alternate ways to conceptualize impact would ideally lead to a paradigm shift away from solely focusing on end outcomes to consideration of how the process of participation affects individuals.

The final recommendation for participatory health researchers is to explore how the process of engaging with different types of participatory research methods affects participants. The results of this study are based on participatory video methods, however there are many other forms of arts-based and other types of participatory methods used with youth that have the potential to affect their wellbeing in different ways.

#### **Overall Challenges and Limitations**

While I aimed to follow the principles of CBPR and incorporate aspects of IRM into the research process, there was limited partner and youth participation in the data analysis. I had conversations with the school principals, the partners on the research project, and they were most

interested in developing the research question. Due to the limited time they had in their daily schedules they were comfortable having me move forward on the data generation and analysis. As categories and themes emerged, I was able to conduct member checks and informal conversations to ensure that the results accurately reflected the participants' experiences. However, the process I took to develop the research question, and subsequent data generation and analysis is in line with CBPR and IRM. It is important that the research partners have a voice in framing the research question, while also having the opportunity to be able to determine their level of involvement in the research process (Cargo & Mercer, 2008; Wilson, 2008). In future research, I will aim to work directly with the youth participants throughout the entire research process, enabling us to generate data and carry out analysis collaboratively, together.

This study aimed to generate knowledge on the impact of participation from the perspective of the research participants. The participatory nature of the research, where youth and school personnel were able to choose their level of participation resulted in a fixed sample size (n=28 youth and n=8 adults), potentially limiting the depth and richness of the knowledge co-created. Researchers from a positivist perspective may narrowly consider this research not to be scientifically rigorous due to the 'small' sample size. However, the flexibility and goals of participatory research actually enables co-creation of specific knowledge relevant to communities, regardless of sample size (Wright et al., 2009). The sample size was specific to the CBPR video project and produced a thick description of the participants' perspective of the impact of participation. Furthermore, generalizability was not the intended goal of the study, and therefore a large sample size was not required. Rather providing a rich description of the context and results creates the potential for transferability of findings.

The results presented in the study are based on the participants' verbal expression of their experience while participating in the CBPR video project. This may have resulted in a biased description of the perceived impact. Participants who were able to express themselves verbally may have over emphasized the positive aspects of participation and limited their discussion of the negative features. The limitation for data generating strategies that emphasize verbal expressions can result in missing the realities of participants who are not as vocal. There is a bias in assuming vocal participation reflects higher engagement. This may not be true; however, I was unable to determine the level of engagement and the experience of the youth who were not vocal in reporting their experience. It is important to recognize that I aimed to capture all of the youths'

realities but was restricted to the youths' desire and ability to verbally express to me their experience. Nonetheless, through prolonged engagement in the school and communities with the research participants, member checking exercises, and informal conversations I have confidence in the credibility of the findings that emerged. I acknowledge that not all participants engaged in the project to the same degree and future work I carry out with youth needs to take into consideration youths' different learning styles and ways of expression that do not only require verbal expression.

Furthermore, the responses reported within this thesis are overwhelmingly positive and there was limited discussion about negative aspects of the research. I did ask the youth openended questions about their experience and probed to see if they had any negative experiences. However, there was limited discussion about negative associations from participating in the project other than frustrations with group work (e.g. taking too long to get a shot and challenges editing their film). This may have occurred because questions about negative aspects were not explicitly asked, or because the students who may have had a negative experience choose not to verbally express their feelings in the focus groups, resulting in missing their realities in the overall results.

Within the focus groups, we did not discuss overshadowing systemic factors such as oppression and colonization that may affect youths' health and wellbeing. These topics did not spontaneously arise through the conversation. I recognize the importance of addressing the systemic conditions that result in Aboriginal youth experiencing higher levels of health disparities (Greenwood & de Leeuw, 2012). However, for the purpose of this thesis I focused on exploring the youths' experience of participating in a CBPR video project, and chose not to explore issues of colonial impacts and systemic oppression if these were not raised by the youth themselves. In essence, I was researching the research process.

As I noted in the recommendations, in future research with marginalized populations I will ensure that I utilize the SJYD framework to critically analyze the dynamics of race, gender, social, political, and economic factors at play in communities (Ross, 2010). I will use each opportunity within the research project to have those critical conversations. I have learned that it is possible to build these important conversations into the data generating strategies, such as focus groups. By utilizing the SJYD framework, together we can explore youth as agents of change to address the oppression and marginalization that they may experience.

I used content analysis to analyze the transcripts. This approach is situated within a Euro-Western research perspective of how knowledge can be generated, breaking down knowledge and ideas into small pieces (Wilson, 2008). From an IRM perspective, this process destroys "all of the relationships around it" (Wilson, 2008, p. 119). Furthermore, I primarily analyzed the data on my own, using member checking exercises and informal discussions to confirm emerging themes with the youth participants and school personnel. This may have influenced the analysis and resulting themes that emerged. However, qualitative research is rooted in a constructivist perspective where subjectivity and multiple realities are accepted (Mayan, 2009). In future research, I will aim to utilize Two-Eyed Seeing and work with my community partners to determine how to approach the analysis phase of the research from an Indigenous perspective, while recognizing the increased time that is required to do this appropriately.

# Conclusion

Through participatory research processes, such as participatory video, youth can build their capacity, and increase their sense of belonging, purpose, and agency. This participatory video project contributed to the youths' journey of becoming empowered. The positive changes youth experienced will continue to influence their health and wellbeing. Overall, the process of participatory video has the potential to affect participants throughout the research process and the impacts extend beyond the intended research outcomes. Therefore, it is critical that when developing health promotion programs with youth there is consideration of more than the final product. Rather the research should equally explore the potential impact of the whole participatory process and how it can positively affect youth.

#### **Concluding Reflection: The End is My Beginning**

I began my thesis by providing a personal story, situating myself, and stating my research intentions. I would like to end this chapter and my thesis by reflecting on the transformative potential of engaging in community-based research for the researcher. Stan Wilson in Shawn Wilson (2008) explains, "something that should go in the writing is how you have changed and what the whole process has done to you" (pg 123). Lavellee (2009) further describes how personal growth in research is an important end product. Not only did the youth who participated in the research project experience personal growth, but also for myself as the 'researcher', I too personally benefited and was affected from my participation. For me, the research process and relationship building became a tremendous learning journey that included mental, spiritual, physical, and emotional growth, changing me as a person and a researcher.

Life happened as I wrote this thesis and I am a different person now than when I started. I have come to know that half of what we learn is in the process. Tuhiwai Smith (1999) explains that for many Indigenous research projects, "the process is far more important than the outcome" (p. 128). My master's research journey in CBPR has taught me everything that happens in between is where the most important learning occurs. The relationships built, the teachings gained, the memories created, and the skills developed are what is meaningful and carried with you once the project is completed. It is sometimes messy, but the flexible and fluid process of community-based research results in meaningful experiences for everyone involved. In the future, I may not remember the specifics of the strategies of inquiry employed or the themes and categories that emerged from the data, but I will never forget the youth participants and the memories and laughter that we shared.

Reflecting back to when I first started this research process, I was very new to qualitative inquiry and even newer to IRM. I had no experience conducting focus groups, knew little about working with Aboriginal youth, and knew even less about participatory video methods. Despite my limited experience and the anxiety that surfaced during the start of my journey (see prologue), I learned the principles of CPBR, gained an appreciation for the application of IRM as a non-Indigenous person, and was able to move beyond the linear biomedical way of thinking to viewing health holistically and valuing relational ethics. Engaging in community-based research was a transformative experience for me as I was able to move "from behind books and lecture halls" to interacting with the youth and school partners in their communities (Castleden, Daley, Sloan Morgan, & Sylvestre, 2013, p. 488). Being in the communities is where I felt the greatest amount of learning took place.

To be in the communities with the right intentions, I needed to critique my own assumptions and expectations of the research project if I was to be able to engage in concepts and ways of knowing that were unfamiliar to me (Castleden et al., 2013). As I discussed in the prologue, I had to take the time to explore my position in relation to the research topic and truly understand what had brought me to work with Aboriginal youth. Actively assessing the beliefs and ideas I brought to the communities resulted in me starting to not only understand myself

better but also the role I played in either maintaining or challenging socially constructed norms and research processes.

I learned the importance of equitably including Indigenous voices throughout the research process and that the 'researcher' should play a facilitator role rather than an expert role. This is something that I will take with me forever as I move into future health promotion work with Indigenous communities. I have experienced firsthand the strength and power of Aboriginal youths' voices when they are provided a platform to speak up. It is not me that needs to tell Indigenous stories, but rather I need to stand beside and support Indigenous peoples in telling their own stories.

I also learned that youth centred and driven projects are extremely powerful for the youth involved. Youth are true agents of community change, necessary for positive development. Adults need to work with youth to create space for meaningful and positive engagement. Communities will become stronger if we build on the strength of the youth. I feel that the following quote eloquently reflects this: "When 'I' is replaced by 'we' even 'illness' becomes 'wellness'" (author unknown).

My understanding of IRM also evolved throughout my masters' journey. I still do not claim to know all that is entailed of IRM but I have gained a greater appreciation for the process of conducting IRM and the importance of relationship building. I have learned research is a lived experience that should focus on co-creating answers and solutions that positively affect communities. Attending to this should always be the first concern of the researcher. Furthermore, it is about being accountable to the communities and their protocols. As an outsider, I must take the time to learn from the people that I am working with, to understand their worldviews, and to ensure that the research is beneficial. I will continue to learn from my community partners and listen closely to the teachings Elders provide me.

IRM acknowledges, considers, and respects all beings, as all things are interrelated. I connected with and understood all my relations when I read Graveline (1998), who explained the closeness and interconnectedness of all things as "that which the trees exhale, I inhale. That which I exhale, the tree inhale. We live in a world of many circles; these circles go out into the universe and constitute our identity, our kinship, our relations" (p. 57). This truly shows me how everything is interconnected. Leroy Little Bear (2009) describes that all things are animate and have spirit. This is what is meant when we say all my relations, referring to the "relationships

with everything in creation" (p.7). IRM moves past the idea of it is not measureable it does not exist, to include all things that have spirit. Because of the acknowledgement of all beings have spirit, knowledge becomes relational and is to be shared with all creation. It is not an individual entity which any one person has ownership over. Knowledge is seen as belonging to the cosmos of which we are a part and where researchers are only the interpreters of this knowledge (Wilson, 2008). I do not have the right to claim to own any knowledge. Furthermore, knowledge is also never complete because it is always evolving and we are always continuing to learn. Moving forward I understand that addressing social and health inequities is not about Western solutions it is about Indigenous solutions. Ermine and colleagues (2004) discuss Roger Poole's concept of ethical space as an appropriate framework for Indigenous and non-Indigenous people to work together, which can support the attainment and sustainability of these solutions. Ethical space aims to, "identify an abstract space that frames an area of encounter and interaction of two entities with different intentions" (Ermine, Sinclair, Jettery, & Indigenous Peoples' Health Research Centre, 2004, p. 19). Specifically, ethical space is where partners with differing worldviews move beyond talking to one another, to talking together (Ermine, 2007). This means that there is an in-between space where different histories', knowledge, and interests come together, requiring a neutral zone of opportunity to have critical conversations about the nebulous space that is to be engaged in through the research process (Ermine et al., 2004).

More than a concept, ethical space is a process of bringing different ways of knowledge together and applying it to the practice of research (Ermine et al., 2004). Through ethical space, partners can come to an understanding of how to create research projects that meet everyone's needs. Using ethical space, Aboriginal people are directly included in the conversation resulting in responsible and decolonizing research. Ermine and colleagues explicitly state that one of the fundamental requirements of ethical space is an affirmation of its existence (Ermine et al., 2004). While I had conversations with my school partners where we acknowledged cultural differences, the dialogue was not explicit in addressing ethical space. I was not familiar with this process until I had completed the research. I now recognize the importance of affirming the existence of ethical space to create meaningful dialogue based on different ways of knowing, enhancing the research process and outcomes.

*I have come to realize that I am on a journey of lifelong learning that could not be contained within a masters' degree. My knowledge will never be complete and I will continue to* 

evolve as I build more relationships and continue to take the longest journey of all, moving from working from my head to working from my heart. I must continue to come from a place of compassion and cultural humility, where I am able to further understand Indigenous perspectives, knowledges, voice, and ways of being. Through the process of engaging in the research, I have become aware of the need to be critical of not only my research practices but everyday life choices, in the aim to not perpetuate colonizing practices.

Although this is the end of my thesis, this is where I believe my journey starts. The more I hear, read, and feel, the more I am driven to keep increasing my knowledge. The research process has been truly humbling and a transformative experience. It was a first step in beginning to understand the "historical, present, and future relationships" between Indigenous and non-Indigenous peoples (Castleden et al., 2013, p. 495). I will be forever grateful to the youth and school personnel who worked with me on this project.

In conclusion, research is a journey, an emotional journey where learning occurs through lived experiences, personal stories, and compassion. It is through meaningful relationships true learning occurs and utilizing participatory research approaches allows love to foster and stories to be told. As Indigenous scholar Shawn Wilson (2008) states, "if research doesn't change you as a person, then you haven't done it right" (p.135).

 $\sim$  All my relations  $\sim$ 

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# Appendix A. Reflection: Through the voices of the youth - Courtney Reimer

# Hi!

In high school, it was mostly the teachers telling their students what to do, how to do it, had what might benefit them in their future. The school I attended never offered anything specific for aboriginal youth, until my senior year.

My senior year I was invited to do this project. Considering my interests and my culture, I was extremely happy to take part. During the duration of the project I felt like I was able to be myself, and it felt like I belonged.

Through the project, I got to open my circle and find new friends. It was nice because I already had a bunch of stuff in common with the other students in the group.

Unfortunately, in my high school aboriginal students were not singled out for positive things. So when my communication technology and video production teachers came to me, it meant a lot when they identified my nationality, and for them to tell me that they wanted me and that my voice was important for this project. In a way, it boosted my self esteem going into it.

The youth tobacco project was close to my heart, because my love for video production and that I had a lot to say about tobacco use and how it is connected to my family. For the duration of the project, I felt like my opinions were valued by making decisions that were meaningful to me.

In conclusion, this entire program has benefited me in ways that I never thought were possible, and has kept me on track for setting me up for my future and my goals. Thanks.

# Appendix B. Reflection: Through the voices of the youth - Chasidy Gray

Good afternoon everyone, I hope you're enjoying the conference!

I would like to share my perspective on my experience as a participant in a project where we were concerned about aboriginal youth health. Although I gained knowledge about the negative health impacts of tobacco misuse, I also learned that tobacco misuse does not only impact the individual, but also the surrounding people. I felt that there was a much stronger push for me to participate because it was a safe place for me to belong with other Aboriginal students.

As Courtney previously mentioned, we were not exactly in an environment that promoted Aboriginal culture and tradition. Although our high school was multicultural, it did not offer any sort of aboriginal events or classes. I felt that I experienced more culture on our trips than I did in my own city.

As a young aboriginal woman, I know nothing of my heritage. Having a history where there was attempted assimilation of my peoples resulted in me learning nothing about my own culture and traditions. Then experiencing such an explosion of culture in Yellowknife was unbelievable, I really felt there was finally a place I could connect and meet new Aboriginal people. I definitely think that my experiences brought me out of my shell, because ultimately I felt included rather than excluded, I think this is something everyone can relate to.

Through the school exchanges and activities I really gained a sense of belonging, and because of that, I was able to be part of a group. This was previously a missing link for me. The whole experience of participating in the research project ultimately made me want to be involved with my community, and if it were not for the school exchanges, I would not have acquired so much knowledge and inspiration from other First Nation cultures and traditions.

# Appendix C. Ethics Approval from the University of Alberta

## Notification of Approval - Amendment

Date:	April 29, 2014				
Amendment ID:	Pro00021643_AME9				
Principal Investigator:	Cynthia Jardine				
Study ID:	MS10_Pro00021643				
Study Title:	Engaging Aboriginal Youth in Tobacco Prevention Using Social Media				
Sponsor/Funding Agency:	CIHR - Canadian Institutes for Health Research	CIHR			
RSO-Managed Funding:	Project ID Project Title	Speed Other Code Information			
	View RES0011408 Engaging Aboriginal Youth in Tobacco Prevention Using Social Media				
	View RES0015888 Engaging Aboriginal Youth in Tobacco Prevention Using Social Media				
	View RES0020393 Engaging Aboriginal Youth in Tobacco Prevention Using Social Media				
	View RES0011408 Engaging Youth in Tobacco Prevention Using Social Media 21D2	21			
	View G118160634 Community based research on the socio-cultural factors underlying multiple addictions in northern urban aboriginal comm	21C87 nunity			

Approval Expiry Date: December 19, 2014

Thank you for submitting an amendment request to the Health Research Ethics Board - Health Panel. The following has been reviewed and approved on behalf of the committee:

- Change in research focus to explore the youth participants' experiences throughout the research project. Specifically, to assess the impact of community-based participatory research processes on factors that are known to lead to improved health and wellness in Aborigi nal youth.
- Information Letter and Consent/Assent for Student Participants (14/04/2014)
- Interview Guide Teachers, Principals and Filmmakers Project Conclusion (19/03/2014)
- Interview Guide Student Participants Project Conclusion (19/03/2014)
- Interview Guide Student Participants Project Outset (19/03/2014)
- Interview Guide Student Participants Project Long Term Follow Up (21/03/2014)
- Interview Guide Teachers, Principals and Filmmakers Project Outset (19/3/2014)
- Personal Wellness Wheel Honouring My Path Worksheet (21/03/2014) Note:

Approval for an amendment does not change the original approval date.

#### Sincerely,

Anthony S. Joyce, Ph.D. Chair, Health Research Ethics Board - Health Panel *Note: This correspondence includes an electronic signature (validation and approval via an online system).* 

# Appendix D. Northwest Territories Scientific Research License Approval



Aurora Research Institute - Aurora College PO Box 1450 Inuvik NT X0E 0T0 Phone: 867-777-3298 Fax: 867-777-4264 E-mail: licence@nwtresearch.com

> Licence No. 15546 File No. 12 410 882 September 16, 2014

2014	
	Northwest Territories Scientific Research Licence
Issued by:	Aurora Research Institute – Aurora College Inuvik, Northwest Territories
Issued to:	Dr. Cindy Jardine University of Alberta Centre for Health Promotion Studies 3-295 Edmonton Clinic Health Academy 11405 – 87 Avenue Edmonton, AB T6G 1C9 Canada Phone: (780) 492-2626 Fax: (780) 492-0364 Email: cindy.jardine@ualberta.ca
Affiliation:	University of Alberta
Funding: Team Members:	Canadian Institutes for Health Research Alice Abel; Miriam Wideman; Eileen Erasmus; Shelagh Genuis; Justin Wong; Megan Lukasewich
	Engaging Aboriginal Youth in Tobacco Prevention Using Social Media To explore if a social media intervention developed by Aboriginal youth os to be available through YouTube) using a participatory approach can be an oking prevention and/or cessation amongst youth and others in Aboriginal
Dates of data collection:	September 17, 2014 to December 31, 2014.
Location:	Ndilo
Licence No.15546 expire 31, 2014 Issued in the To	

on September 16, 2014

\* original signed \*

Pippa Seccombe-Hett Director, Aurora Research Institute

## Appendix E1. CBPR video project: Information sheet, parental consent, and youth consent





**School of Public Health** Centre for Health Promotion Studies

5-10 University Terrace www.chps.ualberta.ca 8303 – 112 Street health.promotion@ualberta.ca Edmonton, AB T6G 2T4 Tel: 780.492.4039 Fax: 780.492.9579

Dear Parent/Guardian:

Your child has been asked to participate in a research project on called **Engaging Aboriginal Youth in Tobacco Prevention Using Social Media**. The purpose of this project is to see if working together with youth to develop videos on tobacco use is a good way to convince youth and others not to smoke or to quit smoking. The principal of the school supports this research project.

Smoking is one of the biggest health problems in many communities today. Of particular concern is the high rate of smoking in youth. Programs to prevent smoking in Aboriginal youth have had limited success. In part, this has been because the approaches are often not based on how youth seek information. Social media information communication technologies (such as YouTube videos) have been shown to engage youth with health information on smoking in new and interesting ways.

#### Who is doing the research?

This research project is being done as a partnership between university researchers, schools, agencies working to stop smoking and local filmmakers. The lead researcher team is Cindy Jardine from the School of Public Health at the University of Alberta.

#### How will we be doing the research?

Students from the K'álemi Dene School in the Northwest Territories and Queen Elizabeth High School in Edmonton will develop and produce videos on smoking. Local filmmakers with an interest in telling Aboriginal stories on film will provide both instruction and mentorship. The process will be documented by the students, researchers, and filmmakers. The videos will be uploaded to YouTube. The best video from each school determined through YouTube voting and through a contest in their schools and other Aboriginal schools. We will conduct a group discussion with your child and their team members at the beginning of the project to better understand what they know and believe about smoking. We will conduct a second group discussion at the end of the project to see if their knowledge and attitudes have changed. The group discussions will each take about one hour. Making the videos will occur over three to four months.

#### How will we respect people's privacy?

We will do our best to make sure any information obtained through the group discussion is kept confidential –Because this is a group discussion, your child will know the names of the other people in the group and what they say. To protect everyone's privacy, we will ask that the children do not talk about what other people say outside the group. Your child's name will not be used when talking about this information. Only the other researchers will see any information with names attached. This information will be locked up when we are not using it. We will store the information in a locked filing cabinet in a locked office that can only be accessed by the researchers. The data will be stored for at least five years.

When we talk about the results, we will use a number or false name so your child's identity will be protected. However, other students will know that that your child was part of this project and gave us information. Your child may also choose to discuss what they said with other students and community members.

We will also do our best to protect the privacy of the people who are in the videos. Your child will be instructed to ask permission before taking anyone's picture. We will then ask the person for written permission to use their picture in the video before it is shown in public.

We think the students may be proud of the videos they produce and wish to have their names included with the videos when they are uploaded to YouTube and presented in other places. However, your child will also have the choice to not have their name attached to their video.

#### What are the risks and benefits to my child?

There is a small chance that your child might feel bad about their decision or experiences with smoking. There is also a small chance that your child might be upset if their video does not win the competition. The benefits to your child are being able to learn about making videos. They will also have an opportunity to meet with other students from the Northwest Territories and share their learning experiences.

#### What will we do with this information?

The videos produced by the students will be shown to people in several ways:

- They will be uploaded to YouTube. Viewers will be invited to vote for the best video.
- They will be shown to other students in their school and the partner school. All students in the school will be asked to vote on the best video.
- They will be made available to other Canadian schools with Aboriginal students, who will be asked to vote on the best video
- The best videos will be presented at various Aboriginal conferences and festivals, including the National Aboriginal Health Organization conference and the Dreamspeaker Festival
- The best videos will entered in the ReelYouth Film Festival
- The best videos will be uploaded onto CES4Health.info (a website for health-related communityengaged research)

We will also talk about how well this process worked in various presentations and papers we prepare after the research is completed.

#### What we need from you...

We need your permission for your child to be involved in this project, and to show people the videos they produce. If you agree, please check the "yes" box on the attached form. If you do not agree, please check the "no" box. If you would like more information before making a decision please contact one of the following people.

Cindy Jardine, University of Alberta	(780) 492-2626
Eileen Erasmus, Program Coordinator, K'álemì Dene School	(867) 920-7260
Allison Barber, Vice-Principal, Queen Elizabeth High School	(780) 476-8671

If you check the "no" box, your child will not be allowed to participate in the research project.

We need you to write your name, your child's name and the date on the form whether you check "yes" or "no".

#### Concerns?

The plan for this study has been reviewed to make sure it follows ethical guidelines and approved by the Health Research Ethics Board (HREB) at the University of Alberta. If you have any concerns about this study that you feel you cannot talk about with the people listed above, you may contact the Chair of the HREB at (780) 492-0302.

#### Please read the following carefully:

- I have read or had explained to me the information provided on the research project.
- I understand that my child will be making videos about smoking.
- I understand that my child will not be specifically identified in any presentations or reports talking about the information they provided in the interviews.
- I understand that the data will be safely stored for five years or more
- I understand the possible risks and benefits of my child participating in this research
- I understand that my child will decide if or if not they wish to be identified in association with their videos.
- I understand that the videos produced will available to people through YouTube and through other ways.
- I understand that information about this process may be used in community and other presentations and in reports.

#### I agree with these statements and agree that my child can participate in the project

	Yes		
	No		
Print Name	 	Signature	
Child's Name:			
Date:			

If you agree that your child can participate in this project, but would rather not sign the form, please tell the person who read this information to you and they will sign to witness your agreement.

\_\_\_\_\_ (name) has said that their child can participate in this

research project.

Witness Name

Witness Signature

Child assent to participate:

(Child/Witness Name)

(Child/Witness Signature)

## Appendix E2. CBPR video project: Information sheet school personnel/filmmaker consent





**School of Public Health** Centre for Health Promotion Studies

5-10 University Terrace www.chps.ualberta.ca 8303 – 112 Street health.promotion@ualberta.ca Edmonton, AB T6G 2T4 Tel: 780.492.4039 Fax: 780.492.9579

# **Engaging Aboriginal Youth in Tobacco Prevention Using Social Media**

You are currently involved in the research project **Engaging Aboriginal Youth in Tobacco Prevention Using Social Media** as a (research collaborator/teacher/filmmaker). The purpose of this project is to see if working together with youth to develop videos on tobacco use is a good way to convince youth and others not to smoke or to quit smoking. We are also interested in exploring if the participatory research process itself is important in influencing knowledge and perspectives on smoking for everyone involved in the process. Finally, we would like to know if this approach is effective as a means of informing future programs and policies.

To help us make these assessments, we would like to talk to you at the beginning of the project about your interests and knowledge on Aboriginal tobacco use, and your expectations of this project. We would then like to talk to you again at the end of the project to see what has changed and if your expectations were met. Each of these interviews will take 30 to 60 minutes, depending on how much you have to say.

You do not need to answer any of the questions if you do not wish to do so and can stop the interview at any time without any penalty. You may also contact the researchers for up to 30 days after each interview to change any of the information you provide (either by withdrawing a comment, changing a comment or adding further comments).

We do not see any direct personal risks to you in participating in this interview. Your participation in this project may benefit you personally in prompting you to think about your expectations of the project. The information you provide will directly benefit the research by allowing us to assess if we have been successful in meeting everyone's expectations and in making a positive change in tobacco prevention with Aboriginal youth.

We will do our best to make sure any information obtained through the interviews is kept confidential. Only the other researchers will see any information with names attached. This information will be locked up when we are not using it. The study data will be securely stored in a locked filing cabinet in a locked office accessible only by the study researchers for a minimum of five years.

We will let you see how we have used the information you provide before it is reported in the research results. When we talk about the results, we will do so using general terms. However, it is possible that other people will know about your participation in the research study and may try

to identify the source of the results we report. The results from this project will be used in any reports, papers, and presentations on the results of this study and the effectiveness of the process.

The plan for this study has been reviewed to make sure it follows ethical guidelines and approved by the Health Research Ethics Board (HREB) at the University of Alberta. If you have any concerns about this study that you feel you cannot talk about with the interviewer, you may contact the Chair of the HREB at (780) 492-0302.

# Please read the following carefully:

- I have read or had explained to me the information provided on being interviewed as part of this research project.
- I understand that I do not need to answer a question if I do not wish to do so, and may withdraw from the interview at any time without penalty.
- I understand that I may withdraw, change or add to any information up to 30 days after the interview.
- I understand that the data will be securely stored for five years.
- I understand the risks and potential benefits of participating in this research.
- I understand that I will be able to see how my information will be used prior to the results being shared with anyone outside the project.
- I understand that I will not be specifically identified in any presentations or reports talking about the information I provided in the interviews, although people may try to identify the source of comments based on their knowledge of the people involved in this project.
- I understand that information from these interviews may be used in reports, papers and presentations.

# I agree with these statements and am willing to participate in an interview at the outset and conclusion of this project

	Yes		
	No		
Print Name		Signature	
Date:	_		

# Appendix F. Pre-CBPR video project youth focus group

# Preamble:

I would like to thank you for taking the time to talk to me about why you want to participate in the social media tobacco project that will be taking place over the next year. I am going to ask you questions about why you would like to participate and what you would like to learn.

I would like to remind you that you do not have to participate in this interview. If you do not feel like answering a question, you do not have to. You may tell me as little or as much as you want. You may choose to end this interview at any time without giving me any reasons. Stopping the interview is completely okay. I would like to confirm with you that it is alright if this interview is recorded.

## Opening question:

1) Can we go around the circle and introduce ourselves? How about we start by saying one interesting fact about ourselves and if you could be any animal what would you be?

## Introductory questions:

## Smoking Knowledge:

- Do you think smoking can harm you? [How? When? Impact your relationships, health, financial? Does it take a while for it to impact you]
- 2) Do you think knowing about the health effects of smoking can change peoples' decisions about smoking?
- 3) Over all, do you feel that you have access to enough information to make informed health decisions about smoking?

# Key questions:

# Smoking in the community:

1) Can you tell me about smoking in your community?

[Why do you think people in your community chose to smoke? Or not? What would change people's decisions to smoke? What would change people's decisions to not smoke? Are there programs in your community about smoking? Or to help those who want to quit smoking? Do these programs work? Why or why not?]

2) What are the rules and regulations in your school about smoking in your school? [In your community?]

#### Youth inclusion:

 Can you tell me about your involvement in decision making in your community? [Do you feel that community members look to the youth in the community to help in making decisions? What about when the decisions will affect youth?]

- Do you think your opinion is listened to or not? Why or why not? [Would you like to be involved in the decision-making? How would you like to be involved with the development of community programs?]
- 3) Has your school taken steps to include students in activities that are meaningful for you? [What about your community? Are there activities that you would have liked to be included in but were not?]

## Project participation:

- 1) Can you tell me why do you want to participate in this project? [What skills would you like to learn throughout the project?]
- 2) What would you like to see happen as a result of your video?

## **Closing questions:**

- 1) Can you tell me what would be indicators of a successful project for you?
- 2) Is there anything else about project that we haven't talked about that you would like to discuss?

This is a semi-structured interview guide and may require further follow-up and probing questions not identified. The flexibility of the semi-structured guide may result in some variance in question wording or probing.

<sup>[</sup>further probes to consider]

# Appendix G: Second-CBPR video project youth focus group

# Preamble:

I would like to thank you for taking the time to talk to me about your experience participating in the social media tobacco project. I am going to ask you questions about your experience participating as a team in the social media project and the results you felt you achieved.

I would like to remind you that you do not have to participate in this interview. If you don't feel like answering a question, you do not have to. You may tell me as little or as much as you want. You may choose to end this interview at any time without giving me any reasons. Stopping the interview is completely okay. I would like to confirm with you that it is alright if this interview is recorded.

# Introductory Questions:

1) Can you think back to when you were first asked to participate in the project, can you tell me about why you decided to participate?

[How did you choose your partners? What skills did you want to learn throughout the project?]

# Key Questions:

Youth video messages

- 1) Can you describe for me how you decided on the message you portrayed in your video?
- 2) Can you tell me why you chose that message?
  - [What does the video message me to you?]
- 3) Can you tell me about the impact you think your messages may have had on your peers? [ Do you feel your messages were listened to? Did the messages encourage you or your peers to quit or to not start smoking? How do you think the messages you created impacted members of your community? What do you think made you messages effective?]

# Youth participation

1) Can you tell me what it was like for you to participate in the project?

[What were your favorite things, why? What did you not like about participating, why? What were the more important things you learned, why?]

# Youth leadership

- Can you tell me how you felt about being included in the social media project? [Do you feel as a group you will continue working towards creating a healthier community? How would you like to be involved in future community projects?]
- 2) Did working on the video influence you to change any health behaviours including smoking?

[Why or why not?]

Youth behaviour changes

- 1) Did working on the video project change your tobacco use?
- 2) Do you feel that you are better equipped with skills to make positive changes for yourself after completing the project?
  - [Do you feel that you can make changes for yourself?]

## Ending Question:

- 1) Overall, did you feel that your concerns and opinions were listed to throughout the project?
- 2) Is there anything about your experience in the social media project that we haven't talked about that you would like to discuss?

This is a semi-structured interview guide and may require further follow-up and probing questions not identified. The flexibility of the semi-structured guide may result in some variance in question wording or probing.

<sup>[</sup>further probes to consider]

# Appendix H: Follow-up youth focus group guide

# Preamble:

I would like to thank you for taking the time to talk to me about your experience participating in the social media tobacco project. I am going to ask you questions about your experience participating as a team in the social media project and what personal changes you think have happened since the completion of the project.

I would like to remind you that you do not have to participate in this interview. If you don't feel like answering a question, you do not have to. You may tell me as little or as much as you want. You may choose to end this interview at any time without giving me any reasons. Stopping the interview is completely okay. I would like to confirm with you that it is alright if this interview is recorded.

## Introductory question:

1) Thinking back almost 4 months ago when you completed the project, can you tell me from your own experience what it was like for you to participate in the tobacco project?

[NOTE: take the time to describe what I learned from the project and the youth before moving onto the following questions. This will build two-way dialogue and open conversation as I learned from the project as well]

2) Can you talk about some of the things you learned?

Key questions:

- 1) Can you talk about the process of participating and what that meant for you?
  - a. [what did you take away from the project? Why is that important to you?]
- 2) Based on your personal experience, do you feel that by participating in the project things in your life changed anything for you?
  - a. [changed smoking behaviour, increased "critical thinking" skills, felt like a community leader, started making other "healthier lifestyle" choices]
  - b. [relationship building, creating support and belonging]
- 3) Can you talk about your personal wellness and how the experience of participating in this project may have changed it? [use the Personal Wellness Wheel and the worksheet 'Honouring my path' as talking points to discuss the fours holistic areas of health]
  - a. Emotional: love, recognition, acceptance, understanding
  - b. Spiritual: sense of connectedness with others, culture
  - c. Mental: concepts, ideas, thoughts, habits, discipline
  - d. Physical: health, safety
- 4) How did you like your experience leading the project? Was is positive or negative? Why or why or why not?
  - a. [can you please expand on why or why not]

5) Member checking of themes that came up from the pre and post intervention group interviews will be added here. This ensures any ideas and themes that are emerging during the analysis are checked with the youth for relevance and accuracy.

## Ending questions:

- 1) Can you describe how you may take what you learned through this project and apply it to situations in your life once the project is done?
- 2) Was there anything else you would like to add about your experience and the process of being a health promoter that I did not ask you?

This is a semi-structured interview guide and may require further follow-up and probing questions not identified. The flexibility of the semi-structured guide may result in some variance in question wording or probing.

<sup>[</sup>further probes to consider]

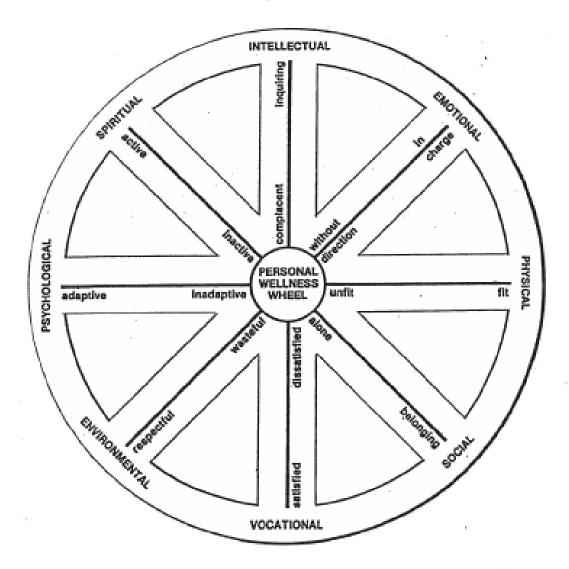
**Appendix I: Personal Wellness Wheel and Honoring My Path Worksheet** 

## PERSONAL WELLNESS WHEEL

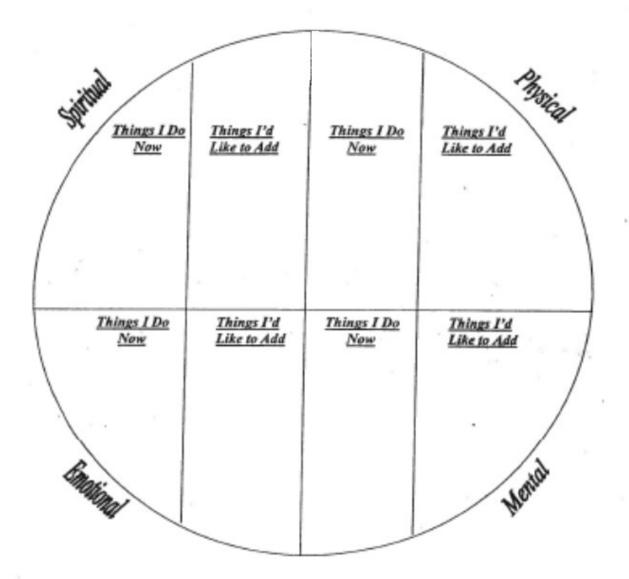
# a dot to dot activity

# Directions:

 Place a dot on each spoke (line) on the Personal Wellness Wheel Indicating where you feel you are now.
 Connect the dots. The distance between your spoke and the rim — the wellness "ideal" — indicates opportunities for personal growth and development.



Honouring My Path



All My Relations.

# Appendix J: First-CBPR video project interview guide with school personnel/filmmakers

# Preamble:

I would like to thank you for taking the time to talk to me about your expectations of participating in the social media tobacco project. I am going to ask you questions about what you would like to get out of participating in the project and what you are hoping the youth experience.

I would like to remind you that you do not have to participate in this interview. If you do not feel like answering a question, you do not have to. You may tell me as little or as much as you want. You may choose to end this interview at any time without giving me any reasons. Stopping the interview is completely okay. I would like to confirm with you that it is alright if this interview is recorded.

**Opening question:** 

1) Can you please tell me about your role within your school (or community)?

# Introductory Questions:

# **Teachers:**

- 1) What are the rules and regulations in your school about smoking?
  - [How successful do you think these are? Why are they/aren't they successful?]
- 2) What are your expectations of our partnership throughout the project?
  - [What are your hoping your school gets from being a part of this research project?]
- 3) What are you hoping your students will get from being part of this research project?

# Film makers:

- 1) How come you wanted to be a part of a project that was working with Aboriginal youth and smoking behaviours?
- 2) What are you hoping to achieve by participating in this research project? What are your expectations of our partnership throughout the project?

# Key questions (for everyone):

Youth smoking behaviours:

- 1) Can you tell me why do you think youth take up smoking?
- 2) What do think would change youths' decisions to smoke or not?
- 3) What do you think would be effective mechanisms for smoking prevention/cessation for Aboriginal youth?

[What resources do you know of that are provided to Aboriginal youth about smoking prevention and/or cessation?]

4) Can you please describe how you view and/or experience youth smoking within your school (or community)?

[Do you feel that there are social norms that influence youth to smoke? Can you please elaborate on the conditions which you think influence youth to smoke.]

Role of youth in community:

- 1) Can you please describe the relationship youth in the school (or community) have with adults?
- 2) How do you view the role of youth in your school (or community)?
  - [Are they engaged in any decision-making processes within your school (or community)? Do you think that your school (or community) has effective programs in place that prevent youth from smoking or encourage them to quit? Are there specific attributes of your school (or community) that you think contribute to influencing youth smoking behaviours?]

# Youth engagement:

- 1) How do you think participation in the project might impact youth?
- 2) What specific activities do you feel would empower participants? [What specific activities do you feel would increase their agency and self-efficacy to be in control of their decisions? What specific activities do you feel would allow youth to act as positive role models for others in youth school (or community)?]

Social media project evaluation:

- 1) What do you feel would make the Engaging Aboriginal Youth in Tobacco Prevention Using Social Media successful?
- How would you like the project to measure the indicators of success? [Do you have any suggestions of ways you would like to report on the outcomes of the project?]

Ending Question:

1) Is there anything else about the social media project that we haven't talked about that you would like to discuss?

This is a semi-structured interview guide and may require further follow-up and probing questions not identified. The flexibility of the semi-structured guide may result in some variance in question wording or probing.

<sup>[</sup>further probes to consider]

# Appendix K: Concluding-CBPR video project interview guide school personnel/filmmakers

# Preamble:

I would like to thank you for taking the time to talk to me about your experience participating in the social media tobacco project that you have been involved with over the past year. I am going to ask you questions about your experience participating in the social media project and how you saw the project impacting the youth at your school.

I would like to remind you that you do not have to participate in this interview. If you do not feel like answering a question, you do not have to. You may tell me as little or as much as you want. You may choose to end this interview at any time without giving me any reasons. Stopping the interview is completely okay. I would like to confirm with you that it is alright if this interview is recorded.

# Introductory Questions:

# **Teachers:**

- 1. Can you please tell me about how your viewed the research project and the ability to meet your students expectation of participation?
- 2. Can you talk about the expectations of your school and their participation in the research project?
  - [Did the research project and partnership meet your expectations?]
- 3. What were some of the most important things you learnt from having your youth participate in the project?
- 4. How can we continue working together to ensure meaningful and appropriate use of the research result in your school programming?

# Film makers:

- 1. Can you please tell me about how your viewed the research project and the ability to meet the youths expectation of participation?
- 2. Do you think this research project met the objectives of participatory film making?

# Key questions (for everyone):

# Social media project impact:

- 1) Can you tell me about your experience of the social media project?
  - [From your perspective, what were the good things about this research project? What were some of the limitations of this research project? What were some of the challenges of this research project?]
- 2) Can you talk about your perspective of the intervention to encourage smoking prevention and/or cessation in your school (or community)?

[What did you think of the youth's messages in the videos? Do you feel that the messages the youth decided to portray in their videos had an impact on peer smoking behaviours?

3) From your perspective have smoking behaviours within your school (or community) changed?

[Please elaborate on what you have seen change]

# Youth empowerment:

3) Can you talk about any changes you may have seen in youth's empowerment? [Were there specific activities do you feel increased youth's empowerment? Do you think youth in your school increased their agency to be in control of their decisions? Do you think youth in your school increased their self-efficacy to be positive role models for others in their school?]

Youth engagement in community:

- Can you tell me how see youth's reaction to being included in the social media project? [Do you feel that as a group they will to continue working towards promoting a healthy community? Do you feel that they can make changes within their community by being a youth leader? Would you like youth to be involved in future community projects?]
- 2) How do you think the school (or community) reacted to the new role of youth as the facilitators of the project?[Has the role of youth within your school (or community) changed?]
- 3) Can you talk about any impacts this project has had on school (or community) smoking programs?

[Do you think the programs are likely to change due to this project? Have there been other health changes within your community because of the project that does not have to do with tobacco use?]

4) Do you feel that the youth are better equipped with skills to make positive changes for themselves after completing the project?

# Ending question:

1) Is there anything about your experience in the social media project that we haven't talked about that you would like to discuss?

This is a semi-structured interview guide and may require further follow-up and probing questions not identified. The flexibility of the semi-structured guide may result in some variance in question wording or probing.

<sup>[</sup>further probes to consider]

# Appendix L. Example field note

Date: Friday June 7<sup>th</sup> 2013 Time: 11:30-1:00 pm Location: Queen Elizabeth

Purpose:

- Final wrap up lunch before summer holidays
- Second interview with group #1 and participant #14 from group #2
- We were meeting with the youth for a final lunch to discuss the film festival, what they wanted to do with their videos (where they wanted them to go)

Description of the participants:

- Researcher # 39, Researcher # 38, Participant # 3 and I attended and Participant # 1 showed up and skipped his class even though he said that he wasn't going to be there and that I originally was going to need to drive the Rosslyn youth back afterwards
- The Monday group (group #1) showed up except for Participant # 11 who was not at school that day, Participant # 8, Participant # 7, Participant # 9, Participant # 5, Participant # 6 and then Participant # 14 was the only one that showed up from the Tuesday group (group #2).
  - NOTE: This may be due to the fact that the majority of the Tuesday group got in trouble during the Dreamspeaker film festival and they aren't interested in participating anymore, don't know for certain
  - This is unfortunate because we didn't get a chance to talk to them about their videos. I am not even sure if we should be submitting or putting them anywhere as Participant # 14 was the only one there who could speak about it. This is difficult as the group was really starting to come around and enjoy the process. I think if the negative things didn't happen at the festival they would have been more likely to show up and keep engaging as the whole group did come to the meet and great with the Yellowknife youth [where we show cased each locations videos and had lunch delivered so that the youth could get to know each other]

Description of the setting:

- We met in a conference room on the second level of Queen Elizabeth at a very large table, so large in fact it was difficult to hear each other and I feel that you weren't able to have a conversation with the person across from you
- Researcher # 39, Researcher # 38, Participant # 3 and Participant # 1, stood to the side, against the walls while I was conducting the focus group

Thoughts from the interview:

- The interview was quick and it was difficult as Researcher # 39, Researcher # 38, Participant # 3 and Participant # 1 were all watching. I am not sure if this would have changed the youth's response or not. They all were very positive about their experience talking about all the things the learned and said thank many times to us and everyone else who assisted in the project
- I would have liked to have more time with them to really get more detail on their experience and thoughts, however due to a school wide talent show the lunch period was

condensed and we only had 35 minutes with the youth so everything that we did was extremely quick. Hopefully there is an opportunity for me to still do follow-up interviews and generate more detailed knowledge of their experience

• Difficulty in doing the interview as everyone was excited about the CDs their certificates, having a mini party with subs and cake to celebrate their successes. There was also a lot of adults in the room standing around watching the interview (Researcher # 39, Researcher # 38, Participant # 3, Participant # 1) compared to the pre interviews where it was just me and the youth and the adults weren't watching over us. This may have changed their responses or resulted in the youth not being as open and honest.

Overall thoughts and comments from the session:

- Researcher # 38 gave a nice talk about how proud we all were of them for working so hard, what great messages they had and handed out the certificates of project completion and a CD of all the Edmonton videos on it which I think they were surprised but super happy to receive as they didn't seem to know that they would get a copy of them
  - The youth were all really appreciative of the certificates and excited to receive recognition for their work even though I spelt 4 of their names wrong on the certificate and need to get the certificates reprinted. I turned into a joke, when their names were called to pick up their certificate if their name was going to be spelled right or not
  - They would be interested in editing/creating some bloopers from the video that they took. As we ran out of time for the youth to edit this may be a good way for them to learn some editing skills. Even though it would not be the actual video they would still learn a lot from the process.
- Participant # 6 was just so excited to be in a 'video' and I even heard Participant #14 say that she was going to stop smoking that would be such a great outcome. I look forward to seeing her next year to see if things changed, although it will be hard as she won't be coming on the YK festival based on her behaviour during the previous film festival
- Participant # 8 and Participant # 11 graduate this year and we have their contact information, hopefully we are able to get in contact with them in the Fall to come to YK
- The youth wanted to see their videos disseminated to global TV, APTN, CBC
   Were all ok with the videos going on youtube
- I need to work with Participant # 3 to coordinate the YK trip which seems to be a lot of work to take youth out of province. I am hopeful that we will get it all done in time
- Participant # 5 wanted to know if we were going to do animation and we told him that if he wanted to create one on his own time we would be more than happy to help him disseminate it but that we wouldn't be working on that through the project
- Conversation with Participant # 3 she talked about the project being both very positive as well as a few negative things
  - Participant #36 used the project as an excess to skip. Participant # 3 said she would skip all her classes but then show up to the project. I am not sure though if this means that she was using the project to skip because she may have missed her classes anyways
  - She said Participant #35 wasn't the most positive because he keep getting suspended and Participant #13 who was continually getting in trouble shaped up in the last semester when the project was happening