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"When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention

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"When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention

#### **Abstract**

Cultivating and supporting Indigenous peer youth leaders should be an important part of Canada's response to HIV. This paper examines how a group of Indigenous youth leaders took up the notion of leadership in the context of HIV prevention. Taking Action II was a community-based participatory action research project. Eighteen Indigenous youth leaders from across Canada were invited to share narratives about their passion for HIV prevention through digital storytelling. One-on-one semi-structured interviews were conducted with participants after they developed their digital stories, and then again several months later. A thematic analysis of the interviews was conducted to identify major themes. Youth identified qualities of an Indigenous youth leader as being confident, trustworthy, willing to listen, humble, patient, dedicated, resilient, and healthy. A number of key examples and challenges of youth leadership were also discussed. In contrast to individualized mainstream ideals, Indigenous youth in our study viewed leadership as deeply connected to relationships with family, community, history, legacies, and communal health.

#### **Keywords**

Indigenous, HIV, youth, leadership, community-based participatory research, digital storytelling, Canada

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#### Introduction

In the time of the Seventh Fire a Osh-ki-bi-ma-di-zeeg' (New People) will emerge. They will retrace their steps to find what was left by the trail. (Benton-Banai, 1988, p. 91)

As described by the Seven Fires prophecy of the Anishinabe<sup>1</sup> oral tradition, the seventh generation is currently upon us (Benton-Banai, 1988; Bergstrom, Miller Cleary, & Peacock, 2003; Monchalin, 2016). It represents a time of Indigenous youth leadership, in which youth will retrace their steps to restore balance among our Nations (Bergstrom et al., 2003). While each individual plays a vital role within Indigenous communities, youth are responsible for "doing the work of the people" (Anderson, 2011, p. 10). The beginning of this paper is influenced by Anishinabe teachings from the ancestry of the first author; it sets the stage for what it means to do Indigenous health research in a decolonizing context. For us, it means situating our work within Indigenous frameworks, teachings, and ways of knowing.<sup>2</sup>

According to the UN, "youth is best understood as a period of transition from the dependence of childhood to adulthood's independence. ...The United Nations, for statistical purposes, defines 'youth' as those persons between the ages of 15 and 24 years" (UNDESA, 2013, p. 1). A recent UNAIDS report (2010) states that, globally, "young people are leading the

personal communication, February 7, 2016).

The lead author is an Indigenous youth participant of the project, as well as a community-based researcher currently pursuing her PhD. Being an Anishinabe woman, her teachings on the Seven Fires prophecy have guided and informed this paper.

<sup>&</sup>lt;sup>1</sup> For the purposes of this paper, the spelling of *Anishinabe* will follow Benton-Banai (1988). It is important to note, however, that individuals and communities may spell this word differently, depending on their personal and/or communal preference and/or geography. These alternate spellings may include *Anishinaabe*, *Anishinaabe*, *Anishinaabe*, *Anishinaabe*, and *Nishinaabe* (A. Judge, personal communication, February 7, 2016).

prevention revolution by taking action to protect themselves from HIV ... [as a result], HIV prevalence among young people is falling in 16 of the 21 countries most affected by HIV" (p. 3). The UN attributes these changes to a heavy investment in youth leadership and capacity building.

In Canada, HIV is on the rise among Indigenous youth, with rates of new infections currently at 7 times that of non-Indigenous youth (Ning & Wilson, 2012). Between 1998 and 2012, just under one third (31.6%) of HIV diagnoses among Indigenous people in Canada were among youth ages 15 to 29 (Public Health Agency of Canada, 2014). Yet models of promoting Indigenous youth leadership are noticeably absent in the literature (Crooks, Chiodo, Thomas, & Hughes, 2009).

Behaviours such as intravenous drug use play a large role in the HIV epidemic, yet determinants of health unique to Indigenous youth must be considered (Flicker, Larkin, et al., 2008; Loppie Reading & Wien, 2009; Public Health Agency of Canada, 2014). For instance, although Indigenous youth are diverse in terms of culture, language, social and geographical locations, they share the legacies of colonialism and its ongoing harmful impacts (Flicker et al., 2013, 2014; Flicker, Larkin, et al., 2008; Oliver et al., 2015). Many Indigenous youth link colonialism, including ongoing effects of residential schools, such as substance abuse and sexual abuse, to HIV in their communities (Flicker & Danforth, 2012). The Royal Commission on Aboriginal Peoples (RCAP) reported that Indigenous youth are paying the price for cultural genocide, racism, poverty, and colonial policy (RCAP, 1996). According to the Seven Fires prophecy, "The task of the New People will not be easy ... If the New People will remain strong in their quest, the Waterdrum of the Midewiwin Lodge will again sound its voice" (Benton-Banai, 1988, p. 93).

Supporting Indigenous youth models of HIV leadership may be an important part of reversing high rates of HIV (National Aboriginal Youth Council on HIV & AIDS, 2010). RCAP (1996) recommended that all branches of government pursue goals of developing and implementing a Canada-wide policy for Indigenous youth "participation at all levels, leadership development, economic development and cultural rebirth, youth involvement in nation building, and cultural and spiritual development" (para. 4.4.9). Similarly, the report of the Standing Senate Committee on Aboriginal Peoples called for Indigenous youth leadership and involvement (Chalifoux & Johnson, 2003). Although policy continues to theoretically affirm the importance of Indigenous youth participation in decision making, little has been written (or done) about its implementation, or towards understanding the nuances and meanings of leadership in an Indigenous youth context.

This paper explores how a group of Indigenous youth leaders, who participated in a community-based participatory action research project, Taking Action II (Danforth & Flicker, 2014), took up the notion of leadership in the context of HIV prevention. Here, we are purposefully inserting the language of action into the common nomenclature of community-

based participatory research (Minkler and Wallerstein, 2003), as a gesture towards reminding others and ourselves that the end goal of our project was to have meaningful action and social change.

## **Indigenous Youth Leadership in the Literature**

Investing in youth engagement and supporting youth leadership represent "a strong protective factor against a host of negative outcomes" and has been associated with positive "widespread ripple effects" (Crooks et al., 2009, p. 13). In the context of HIV, youth leaders can inspire other youth through HIV prevention, peer-to-peer modelling, and setting positive examples in their communities (Kahn, Hewes, & Ali, 2009; Pearlman, Camberg, Wallace, Symons, & Finison, 2002). Moreover, as youth are often more open to change and new ideas than adults, supporting youth leadership may be critical to communal innovation and social change (Kahn et al., 2009). Through discussions with Indigenous youth, Matthew (2009) found that supporting youth leadership can promote resilience, build on current personal strengths, enhance physical and emotional health, improve youth programming, and promote youth commitment to programs by enhancing youth involvement in decision-making processes affecting them.

There is a dearth of literature that interrogates Indigenous models of youth leadership, especially written by Indigenous youth. Existing literature predominantly focuses on the challenges of engaging youth in leadership, emphasizing barriers such as lack of support, tokenism, being silenced in decisions affecting them, stereotypes, intergenerational trauma, and a lack of financial support (Matthew, 2009). Public discourses (i.e., academia, social services, and public health) regularly paint youth as rebellious, unmanageable risk takers (Macneil, 2006). Indigenous youth in particular are often portrayed as "dangerous" and "reckless" (Riecken et al., 2006). Consequently, adults often engage in "adultism," in which they assume power over youth (Tate & Copas, 2003, p. 41) thereby denying young people's agency to create change. This discrimination has led to the suppression and underestimation of Indigenous youth's capacities, skills, and talents by the mainstream public and the academic research community (Checkoway & Richards-Schuster, 2004).

Literature that examines Indigenous adult leadership models often focuses narrowly on those in positions of mainstream conventional power, such as chiefs or tribal councils (Buchanan & Blue Quills First Nations College, 2010). This focus is largely due to colonial interventions such as the Indian Act, which enforced Western notions of leadership and governance (Cote-Meek, Dokis-Ranney, Lavallee, & Wemigwans, 2012). These legal arrangements were designed to undermine, divide, and assimilate Indigenous people and their traditional models (often non-hierarchical/non-patriarchal) of leadership (Alfred, 1999; Monchalin, 2016). Moreover, within a traditional Indigenous paradigm that honours the interconnections of all elements of the community, focusing on a single element (e.g., adults) without understanding its role in maintaining the well-being of all is considered unwise. According to Alfred (1999):

Communities cannot do what is right for the next generation without involving [youth] ... where the link between the young people and leaders is broken, a future negotiated only by politicians and elders will last only as long as those people stay in control. Then who will lead the communities? (p. 130)

## **Methods**

The Taking Action project involved a group of community activists and university-based researchers and students who came together to think about and develop decolonizing approaches and new methods to respond to the elevated rates of HIV in Indigenous communities (Danforth & Flicker, 2014; Flicker & Danforth, 2012). Decolonizing approaches are about changing focus, "centering our [Indigenous] concerns and worldviews and coming to know and understand theory and research from our own perspectives and for our own purposes" (Smith, 1999, p. 39). This community-based participatory action research project was guided by the National Aboriginal Youth Council on HIV and AIDS and adhered to their guidelines for research related to HIV, sexually transmitted and blood borne infections (STBBIs), sexual health, and harm reduction (National Aboriginal Youth Council on HIV and AIDS, 2010). The Native Youth Sexual Health Network, an organization of and for Indigenous youth that works across issues of sexual and reproductive health, rights and justice throughout the United States and Canada, led the project. Community based participatory research (CBPR) continues to be recognized as an effective strategy for working on health related issues with Indigenous Peoples and other marginalized populations (Darroch & Giles, 2014), According to Minkler and Wallerstein (2003):

Community-based participatory research (CBPR) is 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. (p. 31)

In the first 3 years of the project (2007-2010), we collaborated with over 100 youth in six different communities on developing art that examined the relationship between structural inequalities and HIV (Flicker & Danforth, 2012). In their evaluations, youth asked for more opportunities to come together with their peers from different communities to learn from each other. As a result, Taking Action II invited 18 Indigenous youth leaders from across Canada to a week-long retreat in Toronto in the summer of 2012 to create digital stories about their interest and involvement in HIV prevention. The goal was to allow youth leaders to share their own digital stories about HIV leadership, activism, and engagement (Danforth & Flicker, 2014; Wilson et al., in press.).

"Digital stories are 3-5 minute visual narratives that synthesize images, video, audio recordings of voice and music, and text to create compelling accounts of experience" (Gubrium, 2009, p. 186). Digital storytelling projects are increasingly being used in public health practice and as part of community-based participatory research (Gubrium, Hall & Flicker, 2014). They fit particularly well within a decolonization framework, which seeks to challenge "the power relations that govern who can speak, what they can say, and how they can say it" (Adelson & Olding, 2013, para. 7). As such, digital storytelling has the potential to respond to Smith's call for decolonizing research by (re)claiming, remembering, representing, reframing, creating, and sharing (Smith, 1999). In this project, we engaged Indigenous youth leaders in digital storytelling as both a decolonizing approach to research and a public health intervention, which created space for imagining new possibilities for Indigenizing HIV prevention with youth.

Twenty Indigenous youth leaders were selected from across Canada. Eighteen youth were able to participate in all aspects of the project, while two left the project early for personal reasons. Youth were from a mix of First Nations, Métis, and Inuit communities, rural areas, and urban contexts. They hailed from eight different provinces and one of the territories. At recruitment, youth ranged from 16 to 26 years old. There were seven male and 11 female youth leaders.

Youth leaders were recruited to a week-long retreat in Toronto through a call-out via social media and online outlets (i.e., listservs, Youtube, Facebook, Twitter). Personal networks were also tapped to encourage leaders to apply. Recruitment materials purposefully defined leadership broadly and provided the following examples:

Have you ever been part of an event about: HIV, drugs, poverty, human rights, justice, Aboriginal rights, sexual health, or violence? A volunteer or peer outreach worker? ... A helper or organizer of a workshop, event, or fundraiser about HIV? ... Part of any effort to spread the word about HIV? We are seeking motivated, passionate and energetic Aboriginal youth to share their stories about HIV leadership or activism ...

Leaders were selected based on their interest or involvement in HIV prevention, engagement, and activism. Two of the selected youth identified as being HIV positive; others were affected in multiple ways. Youth were selected to reflect the diversity within Indigenous communities (e.g., Nation, gender, HIV experience), capture multiple experiences, and understand various ways that youth have engaged in the HIV movement. Once youth had accepted our invitation, they were supported in preparing their digital story in which they shared their personal journey. Four months prior to their arrival in Toronto, youth were provided with the appropriate tools for collecting images, sound clips, and videos to use in their story; they also participated in regular teleconference calls in preparation for the retreat. The digital storytelling retreat was conducted on York University's campus and made use of the Faculty of

Environmental Studies' computer lab and other facilities. Youth were provided guidance and support by project facilitators and their peers in putting together their digital stories (Danforth & Flicker, 2014). In order to create their own digital stories, youth worked in groups and individually to develop and refine their narratives, record them, and then enhance the audio with pictures and video. Youth learned how to use video-editing software to compile and edit their audiovisual material and complete a final product. In some cases, youth staged and filmed new material. Often these processes were iterative rather than linear. Youth were both learning about and applying their new knowledge in a number of different areas at the same time. At the end of the week, we held a private screening where each youth got to share their final story with the group. For many youth participants, this process involved difficult intellectual and emotional work. However, nearly all found it rewarding.

Youth leader participants were provided with training, support, and resources during all stages of the project. This support included creating a sense of community and safe environment to explore what are sometimes difficult issues. Part of decolonizing the research process meant embedding Indigenous practices and ceremony into the project programming. For example, access to art and beadwork supplies, smudging (a purification ceremony involving the burning of one or more of the four sacred medicines so that the smoke can do its cleansing work; Monchalin, 2016)), and cultural support were all regular features. In addition, different youth took turns leading/sharing their own traditional songs and ceremonies. In recognizing that these Indigenous youth leaders were being called upon to do "heavy work," it was important to break up the retreat with activities that were fun and supported relationship building. These activities included shopping and movie excursions into the city, as well as visiting a nearby First Nations community to learn about their sexual health initiatives.

#### **Data Collection**

Once youth leaders developed their digital stories, one-on-one semi-structured interviews were conducted with them. Youth were asked to introduce themselves and their community, tell us about their digital stories, discuss their feelings about being Indigenous, share what being a "youth leader" means to them and provide examples, and reflect on the retreat itself.

Subsequently, the youth were supported in screening their digital stories within their respective communities. Shortly after their community screenings, another semi-structured interview was completed either via telephone or in person. The second interview provided youth with an opportunity to reflect on a concrete example of their leadership (organizing and presenting their screening) and how it felt to share their stories more publicly.

Interviews were transcribed verbatim. A small subset of investigators, graduate students, and Indigenous youth reviewed the transcripts and developed a coding framework that represented both inductive and deductive themes emerging from the transcripts; data were coded by at least two research assistants and managed in QSR NVIVO 10. Data for this paper were drawn from all the leadership codes (e.g., What Leadership Means, Support for Leaders, Who

Am I, Educating Others, Changing My Path, Living in a Good Way, Connections to Land, Family, Community, Self, etc.). All of the leadership codes were reread, re-analyzed, and reorganized, and an inductive thematic analysis (Vaismoradi, Turunen, & Bondas, 2013) was conducted to find patterns and trends (within themes analyzed). Three overarching themes emerged: qualities of a leader, challenges of being a leader, and examples of demonstrating leadership. Using MS Word, summary quote tables were created with named subheadings to help organize the findings; these tables became the framework for this paper.

We engaged in a form of participatory "member checking" 1 year later at a follow-up retreat with the youth leaders in July 2013. We invited participating youth to come together again in Montreal for a weekend to engage in participatory analysis. Youth came together to review and reach consensus about themes, quotes, and key ideas as well as provide feedback on preliminary analyses. In general, the youth were very proud of one another's accomplishments, definitions, and leadership initiatives.

Each youth received a \$1,000 honorarium (spread over 3 years) for their substantial contribution to the project. In addition, they received a \$20 honorarium per conference call, and all travel and accommodation costs were covered for both retreats. Each youth leader managed a \$500 budget to defray costs associated with the "movie nights" in their communities. Project facilitators were present for each of the movie nights and provided ongoing support and assistance with logistics and implementation.

#### **Results**

Although the youth were diverse in terms of culture and geographical locations, they shared many similar ideas surrounding leadership in the context of HIV prevention. Drawing on the interviews, three main themes emerged regarding HIV leadership: qualities of a leader, challenges of being a leader, and examples of demonstrating leadership. Grounded in a critical social science perspective (Eakin, Robertson, Poland, Coburn, & Edwards, 1996), these themes are explored below, with quotes from the youth leaders provided in tabular format.

# **Qualities of a Leader**

Leadership qualities identified by youth participants included being confident, trustworthy, willing to listen, humble, patient, dedicated, resilient, and healthy (see Table 1).

Table 1
Qualities of a Leader, as Defined by Indigenous Youth Leaders

Confident	"Being a leader generally means you know that you are not afraid to take the steps accomplishing your goals." (Female)	
	"A leader is someone who is not afraid to lead the way, to be the first one. To do something. To explore something." (Male)	

Qualities of a	Qualities of a Leader, as Defined by Indigenous Youth Leaders		
Trustworthy	"Doing the work with the people that trust in you and believe in you or even would put their life in your hands. You would have to work with them and show them that you are actually caring." (Male)		
	"Leadership means that there is a person that stands out for the people. They help people that need help. They do stuff for people when someone needs something done." (Male)		
Willing to listen	"It is also someone who steps back and listens to the needs of everybody else it's someone who can take initiative, who can listen and with their heart, their mind, with everything to, I guess, start the movement."  (Female)		
	"A lot of people have this image that leaders are the ones that are talking, but I feel a lot of leaders, youth leaders, are the ones listening being able to support people even though they may not be necessarily supported in their decisions." (Female)		
Humble	"It's not about having that title of leadership you are out there to make a difference, you are out there to work with one person at a time, to work with another person, and to build a community that is solid." (Female)		
Patient	"Being a leader also means being patient you know that it means it's not going to happen overnight." (Female)		
Dedicated	"Being a leader, you have to have a plan, you have to have a destination or a goal that you are after." (Male)		
	"You got to be dedicated to the change that you want to see in your communities and it's not going to be easy. But if you really believe in something then you are going to continue to get back up and keep working towards different approaches." (Male)		
Resilient	"He realized he was in a bad environment and he wanted to change it for himself." (Male)		
	"Our youth are so resilient and so inspirational that we have found our strengths within each other and created our own community within ourselves to support each other." (Female)		
Healthy	"Know and understand that it's okay to take a step back sometimes to just take care of yourself. Because if you can't take care of yourself then you can't help anyone else." (Female)		

Confidence was understood to be a key attribute of a leader. The youth defined confidence as "not being afraid to lead the way," to take action in their communities, and to accomplish their goals.

Youth believed trustworthiness is also an important quality of a leader in the HIV movement. Given the high degree of HIV stigma in their communities, youth felt that a leader needs to be someone that individuals can rely on and trust in the face of adversity.

Youth asserted that leaders are individuals who listen to the needs of their communities. Rather than making decisions unilaterally, a leader is someone who listens, and who serves the community's needs. The youth described how a good leader is not necessarily someone who is looking for a leadership title. Rather, the focus of a leader should be on things that benefit the community, rather than themselves. As a result, they felt humility is also an important characteristic of a strong Indigenous leader.

Many of the youth noted the struggles and barriers associated with substance use in their communities. They described a leader as someone who is able to make the decision of living a good life without substance abuse (or who actively tries to recover from an addiction). They further stated that a leader is someone who strives to be physically, mentally, and spiritually healthy. Youth leaders emphasized that leaders must remember to take care of themselves if they are going to be able to take care of their communities.

### Challenges of Being a Leader

The youth described many barriers they regularly face within their communities when they, themselves, or their peers try to take on a leadership role. These challenges to leadership were as follows: being a young population, a lack of role models in their communities, tokenism, intergenerational trauma, HIV stigma, and pressure to succeed (see Table 2).

Table 2
Challenges of Being a Leader, According to Indigenous Youth Leaders

Young population	"We have a younger, a very young, up and coming population. If
	these youth are not being brought up with good mentors, whether
	it's their parents, or whether it's somebody else teaching them in
	the community, then where do they go and what do they do? It
	really, really hurts because I know so many young people who are
	trying the best that they can and people look at them and it's just so
	easy to look down on them when they don't know the struggles"
	(Female)
Lack of role	"We don't got too many leaders on the reserve in our community."
models	(Male)
	"In my community you don't see a lot of Aboriginal people
	graduating." (Female)
Tokenism	"I feel a little bit upset sometimes when our leaders utilize our
	youth as the reason why they are doing things yet they don't really
	include us we feel that we are not being supported by the people
	who claim to be our leaders." (Female)

Challenges of Being a Leader, According to Indigenous Youth Leaders	
Intergenerational	"We still face the legacy of the residential schools to this day, and
trauma	the things that happened to our grandparents, great-grandparents, even sometimes our parents residential school has kind of trickled down by generations." (Female)
	"There is a lot of healing that needs to still take place and unfortunately there are still a lot of people who are healing in our communities." (Female)
Stigma	"It can be tough because some people don't want to believe it or
~ · · · · · · · · · · · · · · · · · ·	they just don't want to listen, and, or maybe some parents might
	think, 'I am teaching my children the way I want them to be taught'
	kind of thing, 'I don't want anyone else to teach them about
	HIV/AIDS because that leads to sex or drugs or whatnot.' They
	take it the wrong way." (Female)
Pressure	"It is the pressure of always having, the feeling of always having to
	be strong, to look strong for others you will have that weight
	pushing down on you while you lead." (Male)

Almost half of the Indigenous population in Canada is under the age of 24 (Statistics Canada, 2011a). This skewed demographic was reflected in the youth's responses to the question of challenges to leadership. Youth believed that they lacked positive mentors, role models, and young leaders within their communities. Specifically, they described widespread apathy and a lack of motivation and ambition to finish school among their peers. Youth believed that leaders within their communities were individuals who graduated from either high school or postsecondary school.

Many youth felt they experienced tokenism. This meant that although they were often asked to participate on committees or represent youth issues, they were rarely treated equally, and (diverse) youth voices continued to be underrepresented. Youth reported that they seldom had support to fully participate as decision makers, and they were often excluded from important conversations.

A major challenge to the development of leadership discussed among these youth was intergenerational trauma, which is defined as cumulative emotional and psychological wounding across generations (Blanchet-Cohen, McMillan, & Greenwood, 2011; Lavallee & Poole, 2009). Youth stated that they continued to face intergenerational trauma due to the legacy of residential schools in their communities. They believed that this was a major challenge to becoming a leader because there was a lot of healing that needed to take place both internally as individuals, and within their communities.

Another challenge to being a leader was stigma and discrimination associated with HIV. When youth tried to educate others in their communities about HIV, they often received a

negative response. Some parents believed that education would lead to increased sexual activity and substance use. Other youth discussed how, because of the stigma, members of their communities denied the existence of HIV.

Lastly, due to the history of Indigenous communities in Canada marginalizing their own people with HIV and a general lack of discussion about HIV in communities (Vizina, 2005), the youth leaders of this project felt a lot of pressure to succeed in their efforts to challenge stigma. The high rates of stigma around HIV within many Indigenous communities in Canada have resulted in some HIV-positive Indigenous community members being shunned or treated poorly because of their health status (Lesperance, Allan, Monchalin, & Williams, 2015; National Aboriginal Youth Council on HIV & AIDS, 2015; Restoule, Campbell McGee, Flicker, Larkin, & Smillie-Adjarkwa, 2010; Worthington et al., 2010). This situation has created a sense of urgency for youth leaders to educate their community to overcome stigma.

# **Demonstrating Leadership**

Despite multiple challenges, the Indigenous youth in this project continued to take action and demonstrate leadership in a variety of ways. Common themes regarding how they enact Indigenous models of leadership included starting small, getting an education, mobilizing community, teaching others, and preserving culture (see Table 3).

Table 3
Demonstrating Leadership, as Described by Indigenous Youth Leaders

	1, 0
Starting small	"Being a leader starts in the most smallest and intimate places I try to be a good role model for my brothers and my sisters and my cousins. And that's initially where I guess being a leader starts, is in your family." (Female)
	"We need to start in our community and where we live we are having issues, too many to deal with. So we need to work on ourselves before we can work outside." (Female)
Getting an education	"I was graduating for all Aboriginal people and I guess all of my community, and all of my family. You know, it was just like this big stepping stone. A bigger place." (Female)
Mobilizing community	"I really try to spend most of my time trying to like mobilize community, my poor community has had to deal with so many events. But it's like a really big part of me, teaching educating people, just because that's just something that I always loved to do." (Female)

Demonstrating Leadership, as Described by Indigenous Youth Leaders		
Teaching others	"By educating myself more in HIV and AIDS, I can discreetly educate other people and that may spark something inside of them, some inspiration where they might want to do difference and change things." (Female)	
	"When I go back home, that's what I am going to be trying to do educating people more towards how to support other people and to how we can work together to break down the barriers." (Male)	
Preserving culture	"If I can help somebody grow or help them find an opportunity or to even be there just to have a conversation with them, then I know that I am doing what my ancestors would like me to do. And that's just following my heart. 'Cause when you follow your heart you provide that path for others to follow your lead, and I think that that's what a lot of our young people and a lot of our people are doing 'cause we are following our heart back to that remembering of who we are as Indigenous people." (Female)	

Youth highlighted the importance of a leader's "starting small." For them, this meant being a role model for their friends, family members, and community. Youth stated that a leader is someone who works to establish strong ties in their family unit and communities before venturing outside their personal networks. Many provided examples of slowly expanding their influence by being active on youth councils and committees in their schools and communities. One explanation for this understanding might come from the teaching that everyone in a community carries responsibility for the whole; this interdependency is crucial to an Indigenous understanding of communal health (Anderson, 2011).

Youth noted the importance of educational achievement as an example of how they demonstrate leadership. When they spoke about education, the youth talked about finishing high school and pursuing postsecondary education, such as college or university. Youth participants believed that when they graduate, they are doing it for their entire community. Completing high school is a particularly important accomplishment in the context of current low graduation rates within many Indigenous communities across Canada. For example, only 9.8% of Indigenous people aged 25 to 64 have a university degree, compared to 26.5% of non-Indigenous people in Canada of the same age group (Statistics Canada, 2011b). Thus, education was not understood as merely an individual achievement, but a community achievement.

The youth talked about their experiences of participating in this project as an opportunity to teach others within their communities. Prior to and during the Toronto retreat for the Taking Action II project, youth did research on HIV and AIDS to assist with developing their digital stories. Youth stated that by educating themselves further about HIV, they were better able to educate their communities. Many youth shared plans for being HIV peer-educators "back home."

This role involved educating others about how to better support one another. Several youth talked with excitement about how showing their digital stories sparked important dialogue around the topic of HIV prevention.

Most notably, during conversations around leadership, youth returned to the importance of their ancestors and culture. Many youth believed that demonstrating leadership in their communities means preserving culture, and remembering who they are as Indigenous people. This meant different things for each youth; for instance, for one youth this meant "following your heart." Wilson et al. (n.d.) support this notion and state that culture, community, history, and tradition are essential for effective HIV prevention and health-promotion initiatives for Indigenous youth.

#### **Discussion**

Although the Indigenous youth participants in this study were diverse in regards to Nation, location, and culture, common themes emerged in defining models of leadership in the context of HIV prevention. Notably, participants privileged qualities of Indigenous leadership (e.g., humility, patience, trustworthiness, resilience, and health), which contrast mainstream hierarchical notions of power, status, and individualism (Buchanan & Blue Quills First Nations College, 2010; Monchalin, 2016; Ottmann, 2002, 2005; Stonefish, 2013).

Participants' views about leadership echoed much of the literature on Indigenous perceptions of leadership. These perceptions included focusing on and responding to community (Ottmann, 2005), being resilient (Crooks et al., 2009; Julien, Wright, & Zinni, 2010), preserving culture (Ottmann, 2002), mobilizing others (Buchanan & Blue Quills First Nations College, 2010), being honest, and showing confidence (Muskego, 1995). Nonetheless, much of the literature examining Indigenous leadership models continues to perpetuate mainstream hegemonic concepts of leadership and focuses narrowly on those in positions of conventional power imposed by colonial interventions, such as the Indian Act (Buchanan & Blue Quills First Nations College, 2010; Ottmann, 2002, 2005). The Indigenous youth leaders in our study did not openly strive for the titles associated with leadership; instead, many felt it was important to lead by listening. Alfred (1999) describes this as the ability to lead by being led.

Indigenous youth strategies for reversing the negative trends of HIV in their communities involved educating themselves, teaching others, mobilizing community, and starting within their families and intimate social networks. Their ideas demonstrate a holistic understanding of leadership. Holism can be viewed as sustaining a balance, and recognizing "our interconnectedness to everything in the world, and to living in harmony with all of creation" (Monchalin, 2016, p. 34). Moreover, Anderson (2011) argues that the ways in which Indigenous communities are holistically interconnected across generations are "critical to the health and well-being of the present-day and future community" (p. 168). This concept of holism speaks to youth notions of leadership as the connection of family, community, and culture.

Many youth noted the importance of education as an example of how they demonstrate leadership. For youth, education meant finishing high school and pursuing postsecondary education such as college or university. Despite a long history of educational assimilation in Canada, which has led to ambivalent attitudes toward formal education among many Indigenous people, young Indigenous people (and their parents) aspire to attain ever higher levels of education (Hudson, 2009; Restoule, 2005; Restoule et al., 2013). According to Stonechild (2006), "education is truly the new buffalo" (p. 1). In the past, the buffalo met virtually every need with regards to food and shelter, and it was considered a gift from the Creator (Stonechild, 2006). According to Stonechild (2006), some Elders now claim that education, like the buffalo, is necessary for survival (Restoule, 2005) and should be supported alongside cultural and environmental teachings.

In their responses, many of the youth in this project focused on the challenges and barriers that young Indigenous people experience. The most prominent of these is the impact of intergenerational trauma caused by residential schools, which operated in Canada from 1831 to 1996 (Kelly, 2008). Anderson (2011) provides a circular model entitled "Social Organization of 'Traditional' Communities," demonstrating the roles undertaken within an Anishinabe community that was promoting community health and well-being. In the diagram, youth are the heart of the circle, surrounded by Elders, women, and men, in that order. Anderson explains that "the circle was blown apart when residential schools ripped the children—the heart—out of the community" (p. 169). Many Indigenous children suffered sexual, mental, and emotional abuse committed by figures of authority and caretakers in the schools (Chavoshi et al., 2012). Generations of former students brought home devastating burdens of unresolved trauma into their communities, perpetuating the cycle of abuse (Chavoshi et al., 2013). As Anderson further articulates, "Alcoholism, depression, and suicide were not long to follow" (p. 170). Youth indicated that there was still a lot of healing that needed to take place in their communities, and that this was a direct barrier to becoming a leader.

Despite the challenges, youth provided many examples of how they were demonstrating leadership, and how our project motivated them to continue to agitate for change. For example, after returning home from the retreat, each participant hosted digital story screening events to promote discussions around HIV in their communities. Many facilitated peer-led, community arts-based programs and sexual health outreach initiatives. They have also spoken at conferences, developed new interventions for their peers, become involved in Idle No More and other social justice causes, and been more engaged in traditional ceremonies. Some have pursued postsecondary education in health studies; others have entered the film and music industry.

Peer educators can "address misconceptions, prejudices, attitudes and stigmas surrounding sexual health" (Sriranganathan et al., 2010, p. 63). The peer-led initiatives youth brought back to their communities illustrate that investing in youth leadership can play an important role in reversing the negative trends of HIV, and improving the overall health of

Indigenous communities. However, to reverse those trends, youth must be met "where they are at" (Native Youth Sexual Health Network, 2013). This means that it is not about "saving" Indigenous youth and imposing conventional disease-control approaches onto them. Rather it is "about creating space for youth to tell us what makes them feel empowered, supporting the self determination they have over their bodies, lives and spaces" (Native Youth Sexual Health Network, 2013). This empowerment can be accomplished through peer education, a health-promotion approach that provides youth the opportunity and safe space to learn about sexual health and ask questions from their peers who will likely understand (Sriranganathan et al., 2010).

Ultimately, supporting youth voices in decision making is a fundamental part of tackling HIV and making positive change within our communities (UNAIDS, 2010). The research team who led this project did just that. The goal of this project was to support and empower Indigenous youth leaders to effect positive change. The examples below demonstrate the support provided by this team, which may function as recommendations for future Indigenous youth leadership support work. The Taking Action II team supported youth leadership in this project through the following:

- 1. *Training:* During the retreat, youth were provided with training on how to create a digital story through computer video software, including tips on how to record (visually and orally) stories surrounding HIV and Indigenous youth leadership.
- 2. *Resources:* Youth were given information packages and video cameras 4 months before the Toronto retreat to record footage. Doing so provided youth with the freedom to collect video footage prior to the retreat, and to start conversations within their communities around what they were doing.
- 3. A support network: The Taking Action II team consisted of facilitators and organizers whose primary goal was to support the youth. This support included having a traditional knowledge holder and cultural support person on the team, peer-to-peer support, multiple conference calls, and a safe space for sharing. The research team also supported youth with screening their films within their respective communities, and youth were given an opportunity to share their experiences and reflections in the follow-up Montreal retreat.
- 4. *Connections:* Youth leaders were provided with the opportunity to connect with various individuals through this project to support their leadership endeavours. These connections included other youth leaders from across the country, community-based organizations affiliated with the project, and researchers within their respective fields of interest. Team members also worked hard to bring youth into their networks and wherever possible, link youth into other projects and events.

- 5. *Financial support:* Youth were provided an honorarium for each teleconference in which they participated, along with sponsored travel, accommodation, and meals during the Toronto retreat and the follow-up Montreal retreat. In addition to this support, youth were provided financial support to host a movie night within their communities to show their digital stories.
- 6. *Capacity building:* By providing training, resources, a support network, and connections, the youth have developed their capacity to catalyze leadership within their communities. As reported in the results, youth are motivated to mobilize and teach others in their communities about HIV and AIDS.

#### Limitations

This study was a first step in unpacking how a select group of self-identified Indigenous youth leaders conceptualized leadership. Although youth were selected from different communities, Nations, and contexts, the sample was not representative of all Indigenous youth in Canada. For example, the voices of two-spirit youth were absent in our sample. Moreover, those who participated did so because they were particularly interested in HIV and/or digital storytelling. Nevertheless, this purposive sample elicited surprisingly consistent views on leadership across individuals from disparate regions and cultures.

This project raises important themes around Indigenous youth leadership that warrant further investigation. Because our sample was small and diverse, we were unable to disaggregate models of leadership by Nation. Further exploration within specific community settings around how Indigenous youth define leadership may raise important distinctions about how to support the diversity of Indigenous youth leaders.

## Conclusion

The National Aboriginal Youth Strategy on HIV/AIDS recommends "meaningful Aboriginal youth participation and engagement that provides supportive spaces for Aboriginal youth to share, create strong partnerships, build capacity and skills, and be empowered to influence policy, programming and education about HIV and AIDS" (National Aboriginal Youth Council on HIV & AIDS, 2010, p. 5). Indigenous youth must be treated as equals and be fully immersed in decision-making processes (Matthew, 2009). With the right support, Indigenous youth can be important producers of knowledge (Flicker, Larkin, et al., 2008) and can play active roles as change agents (Flicker, Maley, et al., 2008).

Additionally, according to the Canadian Aboriginal AIDS Network (CAAN), "diversity within the Aboriginal population demands creativity to respectfully engage all of our Peoples in the response to HIV/AIDS," and adopting a pan-Aboriginal approach may obscure important cultural differences (Masching, 2009, p. 5). An effective response to sexual health education must take into consideration local contexts and diversity. Smylie et al. (2004) further this and state that "successful health research in Aboriginal communities requires community relevance"

(p. 139). Although each youth leader created and showcased a digital story reflecting their own unique community context, this paper clustered the youth's thoughts around leadership. Further investigation must be undertaken to explore Nation-specific Indigenous youth models of leadership and to learn about the diverse goals, strengths, and aspirations of Indigenous youth across Canada.

Moreover, we suggest further analysis of the intersection of gender and Indigenous youth leadership in the context of HIV, particularly in light of the colonial impact on Indigenous gender roles (Clark, 2012; Cote-Meek et al., 2012). For example, while Indigenous women are taking up more key leadership positions within their communities, they remain underrepresented in decisions that affect them (Lawrence & Anderson, 2005; Voyageur, 2008). Clark (2012) explains that "matriarchal and co-operative societies did not fit within the individualistic and patriarchal ways of the colonizer" (p. 145). Despite this, young females within this project are challenging colonial norms of leadership through demonstration. Brant-Castellano (2009) provides a quote by an Iroquoian chief which emphasizes the importance of equality: "When you go out to gather medicine ... you must be careful to gather both the male and the female, otherwise your medicine will have no power" (p. 206). Further exploration around leadership must support Indigenous youth in fulfilling the Seven Fires prophecy by enabling them to revive equality within their communities. Restoring this balance may be important in eliminating high rates of HIV and in healing communities.

This project demonstrated that youth are producers of knowledge and play active roles as change agents who can influence policy, programming, and education. By investing in youth leadership through appropriate supports and resources, and by supporting Indigenous models of youth leadership, researchers, policymakers, educators, and communities can gain key allies in the fight against HIV.

#### References

- Adelson, N., & Olding, M. (2013). Narrating Aboriginality on-line: Digital storytelling, identity and healing. *The Journal of Community Informatics*, 9(2). Retrieved from http://cijournal.net/index.php/ciej/article/view/740/1004
- Alfred, T. (1999). *Peace, power, righteousness: An Indigenous manifesto*. Don Mills, ON: Oxford University Press.
- Anderson, K. (2011). *Life stages and Native women: Memory, teachings, and story medicine.* Winnipeg, MB: University of Manitoba Press.
- Benton-Banai, E. (1988). *The Mishomis book: The voice of the Ojibway*. Minneapolis, MN: University of Minnesota Press.
- Bergstrom, A., Miller Cleary, L., & Peacock, T. (2003). *The Seventh Generation: Native students speak about finding the good path.* Charleston, WV: ERIC Clearinghouse on Rural Education and Small Schools.

- "When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention Renee Monchalin, Sarah Flicker, Ciann Wilson, Tracey Prentice, Vanessa Oliver, Randy Jackson, June Larkin, Claudia Mitchell, Jean-Paul Restoule, Native Youth Sexual Health Network• DOI: 10.18357/ijih111201616012
- Blanchet-Cohen, N., McMillan, Z., & Greenwood, M. (2011). Indigenous youth engagement in Canada's health care. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 9(1), 87–111.
- Brant-Castellano, M. (2009). Heart of the Nations: Women's contribution to community healing. In G. Valaskakis, M. Dion Stout, & E. Guimond (Eds.), *Restoring the balance: First Nations women, community, and culture* (pp. 203–235). Winnipeg, MB: University of Manitoba Press.
- Buchanan, J. L. & Blue Quills First Nations College. (2010). *Indigenous leadership: A talking-circle dialogue with Cree leaders*. (Unpublished doctoral dissertation). University of San Diego, San Diego, CA.
- Chalifoux, T., & Johnson, J. (2003). *Urban Aboriginal youth: An action plan for change*. Standing Senate Committee on Aboriginal Peoples. Retrieved from Parliament of Canada website: http://www.parl.gc.ca/content/sen/committee/372/abor/rep/repfinoct03-e.pdf
- Chavoshi, N., Christian, W., Moniruzzaman, A., Richardson, C., Schechter, M., & Spittal, P. (2013). The Cedar Project: Understanding barriers to consistent condom use over time in a cohort of young Indigenous people who use drugs. *International Journal of Sexual Health*, 25(4), 249–259. doi:10.1080/19317611.2013.794184
- Chavoshi, N., Waters, S., Moniruzzaman, A., Richardson, C. G., Schechter, M. T., & Spittal, P. M. (2012). The Cedar Project: Sexual vulnerabilities among Aboriginal young people involved in illegal drug use in two Canadian cities. *Canadian Journal of Public Health*, 103(6), e413–e416. doi:10.17269/cjph.103.3460
- Checkoway, B., & Richards-Schuster, K. (2004). Youth participation in evaluation and research as a way of lifting new voices. *Children, Youth & Environments, 14*(2), 84–98.
- Clark, N. (2012). Perseverance, determination and resistance: An Indigenous intersectional-based policy analysis of violence in the lives of Indigenous girls. In O. Hankivsky (Ed.), *An intersectionality-based policy analysis framework* (pp. 133–159). Retrieved from Institute for Intersectionality Research and Policy website: http://www.sfu.ca/iirp/ibpa.html
- Cote-Meek, S., Dokis-Ranney, K., Lavallee, L., & Wemigwans, D. (2012). Building leadership capacity amongst young Anishinaabe-Kwe through culturally-based activities and creative arts. *Native Social Work Journal*, *8*, 75–89.
- Crooks, C. V., Chiodo, D., Thomas, D., & Hughes, R. (2009). Strengths-based programming for First Nations youth in schools: Building engagement through healthy relationships and leadership skills. *International Journal of Mental Health and Addiction*, 8(2), 160–173. doi:10.1007/s11469-009-9242-0
- Danforth, J., & Flicker, S. (2014). *Taking Action II: Art and Aboriginal Youth Leadership for HIV Prevention*. Retrieved from Taking Action Website: http://www.takingaction4youth.org/wp-content/uploads/2009/11/1455\_TakingAction2\_Booklet\_LowRes.pdf

- "When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention Renee Monchalin, Sarah Flicker, Ciann Wilson, Tracey Prentice, Vanessa Oliver, Randy Jackson, June Larkin, Claudia Mitchell, Jean-Paul Restoule, Native Youth Sexual Health Network• DOI: 10.18357/ijih111201616012
- Darroch, F., & Giles, A. (2014). Decolonizing health research: Community-based participatory research and postcolonial feminist theory. *The Canadian Journal of Action Research*, 15(3), 22–36.
- Eakin, J., Robertson, A., Poland, B., Coburn, D., & Edwards, R. (1996). Towards a critical social science perspective on health promotion research. *Health Promotion International*, 11(2), 157–165. doi:10.1093/heapro/11.2.157
- Flicker, S., & Danforth, J. (2012). *Taking Action! Art and Aboriginal Youth Leadership for HIV Prevention*. Retrieved from Taking Action Website: http://www.takingaction4youth.org/pdfs/Taking\_Action\_Government\_Report.pdf
- Flicker, S., Danforth, J., Konsmo, E., Wilson, C., Oliver, V., Prentice, T., ... Lachowsky, N. (2013). "Because we are Natives and we stand strong to our pride": Decolonizing HIV prevention with Aboriginal youth in Canada using the arts. *Canadian Journal of Aboriginal Community-based HIV/AIDS Research*, *5*, 3–24.
- Flicker, S., Danforth, J., Wilson, C., Oliver, V., Larkin, J., Restoule, J.P., ... Prentice, T. (2014). "Because we have really unique art": Decolonizing research with Indigenous youth using the arts. *International Journal of Indigenous Health*, 10(1), 16–34.
- Flicker, S., Larkin, J., Smilie-Adjarkwa, C., Restoule, J. P., Barlow, K., Dagnino, M., ... Mitchell, C. (2008). "It's hard to change something when you don't know where to start": Unpacking HIV vulnerability with Aboriginal youth in Canada. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 5(2), 175–200.
- Flicker, S., Maley, O., Ridgley, A., Biscope, S., Lombardo, C., & Skinner, H. A. (2008). E-PAR: Using technology and participatory action research to engage youth in health promotion. *Action Research*, 6(3), 285–303. doi:10.1177/1476750307083711
- Gubrium, A. (2009). Digital storytelling: An emergent method for health promotion research and practice. *Health Promotion Practice*, 10(2), 186–191. doi:10.1177/1524839909332600
- Gubrium, A. C., Hall, A. L., & Flicker, S. (2014). A situated practice of ethics for participatory visual and digital methods in public health research and practice: A focus on digital storytelling. *American Journal of Public Health*, 104(9). doi: 10.2105/AJPH.2013.301310
- Hudson, N. (2009). Contextualizing outcomes of public schooling: Disparate post-secondary aspirations among Aboriginal and non-Aboriginal secondary students. Unpublished master's thesis. University of Toronto, Toronto, ON. Retrieved from https://tspace.library.utoronto.ca/handle/1807/18119
- Julien, M., Wright, B., & Zinni, D. M. (2010). Stories from the circle: Leadership lessons learned from Aboriginal leaders. *The Leadership Quarterly*, 21(1), 114–126. doi:10.1016/j.leaqua.2009.10.009

- "When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention Renee Monchalin, Sarah Flicker, Ciann Wilson, Tracey Prentice, Vanessa Oliver, Randy Jackson, June Larkin, Claudia Mitchell, Jean-Paul Restoule, Native Youth Sexual Health Network• DOI: 10.18357/ijih111201616012
- Kahn, L., Hewes, S., & Ali, R. (2009). *Taking the lead: Youth leadership in theory and practice*. Retrieved from The Young Foundation website: http://youngfoundation.org/publications/taking-the-lead-youth-leadership-in-theory-and-practice/
- Kelly, F. (2008). Confession of a born again pagan. In *From truth to reconciliation: Transforming the legacy of residential schools* (pp. 11–42). Retrieved from Aboriginal Healing Foundation website: http://www.ahf.ca/downloads/from-truth-to-reconciliation-transforming-the-legacy-of-residential-schools.pdf
- Lavallee, L. F., & Poole, J. M. (2009). Beyond recovery: Colonization, health and healing for Indigenous people in Canada. *International Journal of Mental Health and Addiction*, 8(2), 271–281. doi:10.1007/s11469-009-9239-8
- Lawrence, B., & Anderson, K. (2005). Introduction to "Indigenous women: The state of our Nations." *Atlantis*, 29(2), 1–8.
- Lesperance, A., Allan, E., Monchalin, R., & Williams, K. (2015, April). *Sexy Health Carnival: Empowerment, resistance, and reclamation*. Paper presented at the meeting of Critical Ethnic Studies Association, Toronto, ON.
- Loppie Reading, C., & Wien, F. (2009). *Health inequalities and social determinants of Aboriginal Peoples' health*. Retrieved from National Collaborating Centre for Aboriginal Health website: http://www.nccah-ccnsa.ca/docs/social determinates/NCCAH-loppie-Wien\_report.pdf
- Macneil, C. A. (2006). Bridging generations: Applying "adult" leadership theories to youth leadership development. *New Directions for Youth Development*, 2006(109), 27–43. doi:10.1002/yd.153
- Masching, R. (2009). Aboriginal Strategy on HIV/AIDS in Canada II for First Nations, Inuit and Métis Peoples from 2009 to 2014. Retrieved from Canadian Aboriginal AIDS Network website: http://caan.ca/wp-content/uploads/2012/05/ASHAC.pdf
- Matthew, C. (2009). Nurturing our garden: The voices of urban Aboriginal youth on engagement and participation in decision making. In D. Beavon & D. Jetté (Eds.), *Journeys of a generation: Broadening the Aboriginal well-being policy research agenda* (pp. 53–58). Retrieved from Association for Canadian Studies website: https://acs-aec.ca/en/publications/canadian-issues/#?limit=10&start=20
- Minkler, M & Wallerstein, N. (2003) Introduction to community-based participatory research: New issues and emphases. In Minkler, M., & Wallerstein, N. (Eds.), *Community-based participatory research for health* (5-24). San Francisco, CA: Jossey-Bass.
- Monchalin, L. (2016). *The colonial problem: An Indigenous perspective on crime and injustice in Canada*. Toronto, ON: University of Toronto Press.

- "When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention Renee Monchalin, Sarah Flicker, Ciann Wilson, Tracey Prentice, Vanessa Oliver, Randy Jackson, June Larkin, Claudia Mitchell, Jean-Paul Restoule, Native Youth Sexual Health Network• DOI: 10.18357/ijih111201616012
- Muskego, P. (1995). *Leadership in First Nations schools: Perceptions of Aboriginal educational administrators* (Unpublished master's thesis). University of Saskatchewan, SK. Retrieved from http://ecommons.usask.ca/bitstream/handle/10388/etd-12202006-092651/Muskego\_Pauline\_1995.pdf
- National Aboriginal Youth Council on HIV & AIDS. (2010). *National Aboriginal youth strategy on HIV & AIDS in Canada: For First Nations, Inuit and Métis youth in Canada from 2010 to 2015*. Retrieved from CATIE website: http://librarypdf.catie.ca/pdf/ATI-20000s/26358.pdf
- Native Youth Sexual Health Network. (2013). *Our bodies are a ceremony of Indigenous Nationhood*. Voices Rising. Currently unavailable online.
- Ning, A., & Wilson, K. (2012). A research review: Exploring the health of Canada's Aboriginal youth. *International Journal of Circumpolar Heath*, 71. doi:10.3402/ijch.v71i0.18497
- Oliver, V., Flicker, S., Danforth, J., Konsmo, E., Wilson, C., Jackson, R., ... Mitchell, C. (2015). "Women are supposed to be the leaders": Intersections of gender, race and colonisation in HIV prevention with Indigenous young people. *Culture, Health & Sexuality: An International Journal for Research, Intervention and Care, 17*(7). doi:10.1080/13691058.2015.1009170
- Ottmann, J. (2002). First Nations leadership and spirituality within the Royal Commission on Aboriginal Peoples: A Saskatchewan perspective (Unpublished master's thesis). University of Saskatchewan, SK. Retrieved from http://ecommons.usask.ca/handle/10388/etd-05142010-081425
- Ottmann, J. (2005). First Nations leadership development within a Saskatchewan context (Unpublished doctoral dissertation). University of Saskatchewan, SK. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.395.4492&rep=rep1&type=pdf
- Pearlman, D. N., Camberg, L., Wallace, L. J., Symons, P., & Finison, L. (2002). Tapping youth as agents for change: Evaluation of a peer leadership HIV/AIDS intervention. *Journal of Adolescent Health*, 31(1), 31–39. doi:10.1016/s1054-139x(02)00379-8
- Public Health Agency of Canada. (2014). Chapter 8: HIV/AIDS among Aboriginal people in Canada. In *HIV/AIDS Epi Updates*. Retrieved from http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/8-eng.php
- Restoule, J.-P. (2005). Education as healing: How urban Aboriginal men described post-secondary schooling as decolonising. *Australian Journal of Indigenous Education*, *34*, 123–131.
- Restoule, J.-P., Mashford-Pringle, A., Chacaby, M., Smillie, C., Brunette, C., & Russel, G. (2013). Supporting successful transitions to post-secondary education for Indigenous students: Lessons from an institutional ethnography in Ontario, Canada. *The International Indigenous Policy Journal*, 4(4). doi:10.18584/iipj.2013.4.4.4

- "When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention Renee Monchalin, Sarah Flicker, Ciann Wilson, Tracey Prentice, Vanessa Oliver, Randy Jackson, June Larkin, Claudia Mitchell, Jean-Paul Restoule, Native Youth Sexual Health Network• DOI: 10.18357/ijih111201616012
- Restoule, J.-P., Campbell McGee, A., Flicker, S., Larkin, J., & Smillie-Adjarkwa, C. (2010). Suit the situation: Comparing urban and on-reserve Aboriginal youth preferences for effective HIV prevention messaging. *Canadian Journal of Aboriginal Community-based HIV/AIDS Research*, *3*, 5–16.
- Riecken, T., Conibear, F., Michel, C., Lyall, J., Scott, T., Tanaka, M., ... Strong-Wilson, T. (2006). Resistance through re-presenting culture: Aboriginal student filmmakers and a participatory action research project on health and wellness. *Canadian Journal of Education*, 29(1). doi:10.2307/20054156
- Royal Commission on Aboriginal Peoples [RCAP]. (1996). *Report of the Royal Commission on Aboriginal Peoples*. Retrieved from Indigenous and Northern Affairs Canada website: http://www.aadnc-aandc.gc.ca/eng/1307458586498/1307458751962
- Smith, L. T. (1999). *Decolonizing methodologies: Research and Indigenous Peoples*. London, UK: Zed Books.
- Smylie, J., Martin, C. M., Kaplan-Myrth, N., Steele, L., Tait, C., & Hogg, W. (2004). Knowledge translation and Indigenous knowledge. *International Journal of Circumpolar Health*, 63(Suppl. 2), 139–143. doi:10.3402/ijch.v63i0.17877
- Sriranganathan, G., Jaworsky, D., Larkin, J., Flicker, S., Campbell, L., Flynne, S., ... Erlich, L. (2010). Peer sexual health education: Interventions for effective programme evaluation. *Health Education Journal*, 71(1), 62–71. doi:10.1177/0017896910386266
- Statistics Canada. (2011a). *Aboriginal Peoples in Canada: First Nations people, Métis and Inuit* (Analytical document 99-011-X). Retrieved from http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.cfm
- Statistics Canada. (2011b). *NHS in brief: The educational attainment of Aboriginal Peoples in Canada*. National Household Survey (NHS), 2011 (Catalogue no. 99-012-X2011003). Retrieved from http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-012-x/99-012-x2011003 3-eng.pdf
- Stonechild, B. (2006). *The new buffalo: The struggle for Aboriginal post-secondary education in Canada*. Winnipeg, MB: University of Manitoba Press.
- Stonefish, T. (2013). Discovering the meaning of leadership: A First Nations exploration (Unpublished master's thesis). University of Windsor, Windsor, ON. Retrieved from http://scholar.uwindsor.ca/cgi/viewcontent.cgi?article=5998&context=etd
- Tate, T. F., & Copas, R. L. (2003). Insist or enlist? adultism versus climates of excellence. *Reclaiming Children and Youth, 12*(1), 40-45.
- UNAIDS. (2010). *Young people are leading the HIV prevention revolution*. Retrieved from http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/unaids publication/2010/20100713\_outlook\_youngpeople\_en.pdf
- UNDESA (United Nations Department of Economic and Social Affairs). (2013). *United Nations youth: Definition of youth.* Retrieved from http://www.un.org/esa/socdev/documents/youth/fact-sheets/youth-definition.pdf

- "When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention Renee Monchalin, Sarah Flicker, Ciann Wilson, Tracey Prentice, Vanessa Oliver, Randy Jackson, June Larkin, Claudia Mitchell, Jean-Paul Restoule, Native Youth Sexual Health Network• DOI: 10.18357/ijih111201616012
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3), 398–405. doi:10.1111/nhs.12048
- Vizina, Y. (2005). Supporting Métis needs: Creating healthy individuals and communities in the context of HIV/AIDS. Ottawa, ON: Canadian Aboriginal AIDS Network.
- Voyageur, C. (2008). Firekeepers of the 21st century: First Nations women chiefs. Kingston, ON: McGill-Queen's University Press.
- Wilson, C., Flicker, S., Danforth, J., Konsmo, E., Oliver, V., Jackson, R., ... Mitchell, C. (in press.). "Culture" as HIV prevention: Indigenous youth speak up! *Gateways: International Journal of Community Research and Engagement.*
- Worthington, C., Jackson, R., Mill, J., Prentice, T., Myers, T., & Sommerfeldt, S. (2010). HIV testing experiences of Aboriginal youth in Canada: service implications. *AIDS Care*, 22(10), 1269-1276.