

## **TAKING ACTION: USING ARTS-BASED APPROACHES TO DEVELOP ABORIGINAL YOUTH LEADERSHIP IN HIV PREVENTION**

### **SPECIFIC AIMS**

Our concern with HIV prevention among Aboriginal youth is situated in the current HIV epidemiological context that suggests Aboriginal youth are overrepresented in the Canadian HIV epidemic. The Public Health Agency of Canada states that “Aboriginal peoples appear to be infected at a younger age than non-Aboriginals.”<sup>1</sup> A national review of HIV prevention programming targeted to Aboriginal youth reveals significant gaps in services, capacity and prevention resources.<sup>2</sup> “Incorporating history into awareness programs may help disrupt the racist stereotypes associated with AIDS. Such efforts may diminish the stigma, fatalism and self-blame that negatively impact on Aboriginal youth while allowing for youth populations to distance themselves from the disease.”<sup>3</sup> Arts-based approaches to engaging youth in health promotion activism have been effective with youth populations in Canada<sup>4</sup> and beyond.<sup>5,6</sup> The **goals** of this study are:

- To build Aboriginal youth capacity in the areas of HIV prevention knowledge and resources development to address HIV issues in their local communities;
- To examine the efficacy of engaging Aboriginal youth in HIV prevention leadership using art-based approaches.

The assembled multi-stakeholder team of community leaders and academic researchers has expertise in community-based research, community-based Aboriginal health programming, adolescent HIV prevention, health promotion and arts-based approaches to research. Our specific **objectives** are:

- (1) To further explore how Aboriginal youth link structural inequalities with individual risk, HIV and Aboriginal culture(s) using art-based methodologies;
- (2) To investigate the efficacy of art-based models of engagement (e.g., hip-hop, video/photographic documentary, popular theatre, music and/or dance, etc.);
- (3) To develop and disseminate community-specific “by youth for youth” HIV prevention and support materials; and
- (4) To create a national digital repository of “by youth for youth” HIV prevention materials.

### **LITERATURE REVIEW**

**HIV/AIDS in Aboriginal Communities** – HIV infection is a serious and ongoing health concern in Aboriginal\* communities. In fact, Aboriginal persons living with HIV/AIDS continue to be over-represented in the HIV epidemic in Canada. There are roughly one million Aboriginal peoples living in Canada today, accounting for approximately 3.3% of the total population. However, the Public Health Agency of Canada estimates that “[Aboriginal peoples] are estimated to account for 7.5% of persons living with HIV in Canada at the end of 2005 and 9% of all new HIV infections in 2005. This shows an estimated overall infection rate in Aboriginal persons that is nearly 3 times higher than among non-Aboriginals.”<sup>1</sup> The profile of Aboriginal AIDS diagnoses differ from non-Aboriginal diagnoses in three important ways: gender, age and exposure category: women, youth and injection drug users are over-represented in the Aboriginal epidemic as compared to the general Canadian population.

**Aboriginal Youth and HIV** – Young people are at the center of the global HIV pandemic with an estimated 11.8 million youth living with HIV/AIDS (UNAIDS, 2004). Each day nearly 6 000 young people between the ages of fifteen and twenty-four acquire HIV, accounting for half of all new infections (UNICEF, UNAIDS, & WHO, 2002). Globally, Indigenous youth are disproportionately affected by HIV/AIDS and available epidemiological evidence suggests that Canada’s Aboriginal First Nations, Inuit

and Métis youth are among them. The increasing rates in Aboriginal youth infection rates coupled with a recent surge in sexually transmitted infections<sup>7</sup> and a decline in youth knowledge about HIV<sup>8</sup> are signs of the potential for the spread of HIV amongst youth in Canada.

**Accounting for HIV rates of Infection in Aboriginal Communities** - Local, as well as global research, indicates that HIV follows patterns of inequity,<sup>9,10</sup> with marginalized groups most at risk. Globally, Indigenous peoples are more likely to be economically disadvantaged, displaced from their lands or live in rural locations, have lower educational attainment and have poorer health outcomes than their non-Indigenous counterparts.<sup>11</sup> Locally, these outcomes can be linked directly to historical and ongoing systemic oppression. Factors facing Aboriginal peoples in Canada including racism, assimilation, the legacies of the residential schools, persistent economic inequality and cultural and social isolation.<sup>12-19</sup> As a result, Aboriginal peoples are disproportionately affected by many social and behavioural factors that increase their vulnerability to HIV infection including higher rates of substance abuse, (sexual and physical) violence, sexually transmitted infections, and limited access to, or use of, health care services.<sup>20</sup> While most HIV prevention approaches tend to focus on individual behaviors, an active engagement with the social, political and historical determinants of health (eg colonialism) that shape these behaviors may be crucial to reaching Aboriginal youth.<sup>21</sup> In order to address HIV, prevention and education strategies need to consider the socioeconomic and systematic factors that put youth at risk in the first place.<sup>21-25</sup> Learning to cope with hardships such as poverty, violence and racism as a result of colonialism may put youth at risk.<sup>22</sup> Common coping mechanisms are associated with high risk behaviours such as trading sex for food, shelter or drugs; alcohol and substance abuse; inconsistent condom use; sex with multiple partners; and sharing needles or other drug equipment.<sup>22</sup>

**HIV Prevention for Young Aboriginal/Indigenous Peoples** - In preparation for this grant submission, we conducted a global scoping review of the published literature relating to HIV prevention with Indigenous youth and collected community based reports from North American agencies engaged in this work.<sup>26</sup> In total, we found 38 relevant scholarly peer-reviewed articles, and 14 community reports. Key findings from the scoping review indicate:

#### *Colonial Impacts*

- In order to address HIV with Indigenous youth, prevention and education strategies need to consider the socioeconomic and systematic factors that put youth at risk in the first place.<sup>21-25</sup>
- Historical and current systemic factors facing Aboriginal youth include racism, assimilation, residential school system legacies and isolation.<sup>12-18</sup>
- Young people may adopt a fatalistic outlook and may be less able to negotiate with partners about safe behaviours, or they may be seeking consolation or affirmation through risky behaviour after dealing with stressful situations.<sup>27</sup>

#### *Attending to Diversity*

- Culturally sensitive HIV prevention services and education are needed.<sup>12,14-16,18,20,28-34</sup>
- Taking a pan-Aboriginal approach to HIV prevention will not be successful; youth are not a homogenous group and they come from diverse, distinct cultures and each needs to be addressed and respected.<sup>21,22</sup>
- Messages need to address the environment youth live in: urban messages for urban youth and relevant messages for on-reserve youth, Inuit youth and those who live in rural areas.<sup>21,22</sup>

#### *Reaching youth at a younger age*

- Prevention messages need to reach youth before the age of 15; develop and implement programs to address the service gap for children ages 7-12.<sup>21-23</sup>

- Education that addresses risks, consequences and prevention needs to begin in sixth grade; continued education or information on “safe” sex practices i.e. condom use.<sup>35-37</sup>

#### *Peer Education*

- Peer education is an effective choice for HIV prevention with Indigenous youth.<sup>12,15,16,22,23,36,38</sup>
- Using peer educators as part of an intervention strategy can have both positive impacts on the peer educators and the youth they are targeting.<sup>12,24,25,36,38,39</sup>

#### *Traditional Knowledge, Community Involvement, Strengthening and Building Partnerships*

- All members of the community need to be a part of the solution – collaborations with various members the community including, youth, Elders, front-line workers, community members, nurses and community organization are necessary.<sup>13,16,17,22,23,28,33,34,36-38,40,41</sup>
- Involving leaders in the community will build awareness in the community.<sup>22</sup>
- The importance of adult role models (both familial and otherwise).<sup>42,43</sup>
- The use of traditional knowledge in sex education and curriculum works better in some communities than others.<sup>22,23</sup>

#### *HIV testing, Harm Reduction, Condoms & Other ‘Risky’ Behaviors*

- HIV prevention, testing and counseling and new treatment options need to be made more relevant for Aboriginal youth.<sup>21,22,29,40,44</sup>
- Harm reduction programs are needed to address existing or exacerbated vulnerabilities.<sup>14,27,45</sup>
- It is important to situate condom use in the context of youth lives, and address issues of access.<sup>20-23,27,46</sup>
- It is important to address the links between physical and sexual violence and HIV risk.<sup>13,14,23-25,27,37,47-49</sup>
- It is important to address the links between substance use and HIV risk factors.<sup>14,22-25,30,35,45,50-52</sup>

#### *Stigma*

- Stigma and negative attitudes towards people living with HIV is present; stereotypes about who can become infected are prevalent<sup>12,31,53</sup>. Addressing the ways in which stigma intersects with HIV risk is key.<sup>21,22,31</sup>

#### *Decolonizing Methodologies*

- Extensively collaborating with the local community and designing culturally appropriate methods for collecting data improved research outcomes.<sup>13,20,29,45,54</sup>
- The importance of adhering to Indigenous ethical guidelines and protocols.<sup>40,45,55,56</sup>

### **PRELIMINARY RESEARCH**

The Canadian Aboriginal AIDS Network’s (CAAN) mission is to provide leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS regardless of where they reside. Founded in 1997, CAAN is a national umbrella organization representing over 200 member organizations and individuals, and provides a forum for ongoing dialogue around pressing HIV prevention and support issues facing the Aboriginal community. CAAN believes strongly in the adoption of community-based research approaches that subscribe to the principles of OCAP (Ownership, Control, Access and Possession).<sup>57,58</sup> Careful attention to these principles means including Aboriginal community and academic scholars as full partners in the research process. CAAN has been a leader in addressing issues related to Aboriginal HIV youth issues and has spearheaded a number of studies that have lead to the development of this proposal. This included a national review of HIV prevention resources targeting Aboriginal youth that found significant gaps in services, capacity and prevention resources.<sup>2,59</sup> In addition, a recent CAAN/University of Alberta examination of 413 purposively sampled Aboriginal youth testing attitudes and practices<sup>60</sup> revealed that nearly half (49.2%) had never been tested for HIV, however, 2/3 of the

sample reported unprotected oral sex in the past six months and about 1 in 4 reported unprotected anal or vaginal sex.

The Gendering Adolescent AIDS Prevention (GAAP) Project is a community/academic partnership across two countries (i.e., Canada and South Africa). GAAP uses a variety of innovative approaches (e.g., Photovoice,<sup>5</sup> performed ethnography,<sup>61,62</sup> peer developed surveys,<sup>63</sup> youth-lead focus groups<sup>64-66</sup> and participatory video making<sup>67</sup>) to engage youth in transnational HIV activism, awareness and curriculum development. Most recently, in partnership with CAAN, we have completed a small qualitative study focusing on how Aboriginal youth understand HIV risk. We held six focus groups and spoke with 61 Aboriginal youth in Ontario and Quebec.<sup>68</sup> Several themes emerged from the data including how youth understood the role of colonialism and traditional knowledge in relation to HIV risk and how youth want these issues to be addressed and incorporated into HIV prevention strategies. In terms of addressing HIV in their communities, youth identified the need for adopting peer approaches, leveraging youth media, incorporating GIPA (Greater Involvement of People with HIV) principles to address issues of stigma, increasing condom accessibility, intergenerational programming, and making HIV prevention fun while integrating the issues of risk with other issues going on in their lives. The present proposal seeks to take their advice and build on this work. We will build on this knowledge, network and infrastructure to create a space for Aboriginal youth and communities to see and learn from each other's experience.

#### **METHODS, RESEARCH APPROACH & DESIGN**

***Arts-based Approaches to Participatory Action Research (PAR).*** This study adopts PAR as a methodology emerging from work with oppressed peoples in developing countries.<sup>69,70</sup> Heavily influenced by the work of Paulo Friere among others,<sup>71</sup> PAR takes an empowerment approach to social change.<sup>72</sup> PAR is premised on the notion that local communities ought to be full partners in the processes of knowledge creation and social change,<sup>70,73,74</sup> and breaks down the distinctions between the researcher and the researched.<sup>75</sup> PAR approaches have been used effectively to partner with youth on health promotion interventions in a variety of contexts.<sup>76-81</sup>

Our interest in investigating arts-based approaches to engaging youth in HIV leadership is situated in our understanding of the importance of framing youth as 'Knowledge Producers.' This is supported by a growing body of literature<sup>82-85</sup> that is interested in the links between "youth media" or a framework incorporating a wide range of communication tools (e.g. the Internet, photography, video, and music production software) that promote community development, critical literacy, artistic expression, civic engagement and social activism.

At the crux of this approach is an understanding that our world is indeed transformable, and youth can play active roles as change agents.<sup>4</sup> By using arts-based approaches, youth are encouraged to critically research their worlds using familiar youth media methodologies and then supported in developing active strategies for change. By taking successful concrete actions towards improving their communities, youth can build their self-respect and confidence to cope with other life situations<sup>86</sup> while becoming better connected with their communities and cohort.<sup>87</sup> Furthermore, engaging in community action projects, can foster positive relationships with caring adults<sup>88,89</sup> and allow marginalized youth who have few positive outlets to feel like they can make a positive difference.<sup>77,90</sup>

Furthermore, our scoping review highlighted the appropriateness of this approach with Aboriginal youth.<sup>24,25,39</sup> Teaching through storytelling was an effective method of educating women, youth, 2-Spirit people, and Elders. Performances also proved to be powerful in educational settings, health conferences

and community events. Project activities that focused on different creative arts workshops were also very successful. Disseminating HIV information in creative ways has been shown to engage and mobilize Aboriginal communities in strategies for prevention in other contexts.<sup>38</sup>

**Indigenous Approach to Research** – Despite centuries of colonization in Aboriginal communities, Aboriginal people continue to value their cultural traditions.<sup>91-93</sup> The history of research and its colonizing effects have failed to distort underlying cultural values, beliefs, and perspectives. As Lavalee and Clearsky’s research call to arms states: “[our] tacit resilience is found within our Aboriginality. We need not rely on Eurocentric ways of knowing to know ourselves” (p. 5).<sup>94</sup> By contrast, we need to provide Aboriginal people with opportunities to tell their own stories through their own frameworks and adopt Aboriginal centered approaches. To do otherwise is to invalidate Aboriginal encounters with research within mainstream academic settings and to perpetuate discriminatory research practices. As Tuhiwai Smith states<sup>95</sup>:

It appalls us that the West can desire, extract, and claim ownership of our ways of knowing, our imagery, the things we create and produce, and then simultaneously reject the people who create and produce, and deny them further opportunity to be creators of their own culture and own nations. It angers us when practices linked to the last century, and the centuries before that, are still employed to deny the validity of Indigenous peoples’ claim to existence, to land and territory, to the right to self-determination, to the survival of our languages and forms of cultural knowledge, to our natural resources and systems of living within our environments. (p. 1)

Smith proposes the need for reflexivity in research to uncover discriminatory practices that perpetuate colonizing research practices before infusing the process with an Aboriginal centered “Indigenization” of research methods that seek to promote the inclusion of uniquely Aboriginal thematic constructs. Our approach to this synthesis, therefore, is to interact with the literature and to question ‘Western’ research assumptions that frame Aboriginal HIV prevention research, and to “Indigenize” our interpretation through meaningful Aboriginal youth leadership and participation in this study. In so doing, it is hoped that this contribution can make HIV prevention research more culturally appropriate and supportive of Aboriginal youth. Embedding principles of OCAP and CAAN’s *Principles of Research Collaboration* (see Appendix A) support this approach. Furthermore, by encouraging and facilitating youth to dictate the media with which they will create their own data (eg music, video, photography), we hope to challenge dominate constructions of knowledge and who has the power to produce and shape it.

**Data Collection** – In year one, we will hire a research manager to manage and oversee all aspects of the project under the supervision of the co-principal investigators (Jackson & Flicker). We will also begin the process of intensive partnership with two local communities. In each community, we will hire an Aboriginal youth coordinator. We will work closely with the coordinators and provide training on research methods, event planning, interviewing techniques, etc.

In year one, both coordinators and the investigators will participate in a 3 day retreat to refine protocol, build the research team and conduct capacity building workshops to support our coordinators and manager in project implementation. The research team is cognizant of embedding cultural content in the implementation of this proposed project. As such, team training session will be held at Aboriginal run conference centres (e.g. Dr. Jessie Saulteaux Resource Centre, etc.) where cultural programs will be offered (e.g., sharing circles, sweats lodges, traditional fire, etc.). Each year, the team will visit a different centre so that we can learn from a variety of First Nation traditions to inform our work and practice. These retreats

will be a combination of skill-building workshops, team building exercise, planning activities and data analysis, etc.

Coordinators will then return to their home communities and begin the process of more extensive community consultations. Each coordinator will be responsible for liaising and recruiting youth in their community to participate in 2.5 day *Taking Action* cultural production workshops. Depending on the number of youth in each site (we anticipate larger groups in urban settings and fewer youth in remote northern communities), between 8 and 40 youth (ages 12-18) will participate. As part of the recruitment strategy, youth will be asked to identify 1-3 arts-based media that they would like support with over the course of the workshop. Coordinators will then identify local artists willing to attend and support the workshops with the skills in the media youth have provided (e.g professional photographers, print-makers, documentary film makers or musicians). Where possible, we will strive to work with local Aboriginal artists. Artists will receive a \$1,000 stipend for their participation. While each workshop will be catered to meet the needs of the local communities – they will all roughly follow a similar format.

### **Day 1 (evening):**

- Introduction and overview of goals
- Elder participation in a welcome ceremony
- HIV 101 – a fun and interactive session where we lay out the facts about HIV and prevention opportunities
- Dinner
- HIV and Me – a session where we map out structural links and how they may relate and create individual risk based on our preliminary work<sup>64</sup>

### **Day 2 (whole day):**

Youth break up into groups and work on their chosen media projects. They spend the next day and a half exploring the issues through their chosen media and developing productions, resources, material and curricula. Workshops will be a mix of technical skill building around the chosen media, an opportunity to explore, document, edit, and refine created media on the issue and group reflections/critique. A note taker will be assigned to each group to document issues and group reflections will be audio-recorded. Media foci may include: Photography/photo-voice, Hip hop, music and dance, Video documentary, mural making, print making, popular theatre, creative writing, storytelling, etc

### **Day 3 (whole day)**

- AM: Finish productions working in small groups
- Lunch
- Display of work – invite community
- Plan next steps around HIV action in the community
- Conduct evaluation survey and check-in with all those in attendance

Coordinators will then work with local communities to find a ‘gallery home’ to display youth projects. With permission of the youth artists, copies of all work produced will be collected for further data analysis and national dissemination. Post-workshop, participating youth will be interviewed individually and asked to reflect on key knowledge gained and how their artistic productions address HIV prevention and are embedded in structural realities. Coordinators will also follow-up with participants 3 months following the workshops to ask youth to reflect on the process, their work, the potential to use it to create prevention media

and the ways in which attending the workshop has influenced how they think about HIV in the Aboriginal community. All interviews will be audio-recorded and transcribed verbatim by a trained transcriptionist (with help from graduate assistants).

In year two, we will hire another 3 coordinators in 3 different communities and host similar retreats and workshops. During these sessions, year 1 coordinators will assist in the training of year 2 coordinators. Collectively we will analyze the data and media collected in year one, what we have learned from the process and what changes need to be made in the following year. Coordinators in year one will be retained on a consultant basis to assist us in developing a guide to how to do this work which will become one of our outputs for the grant, for a similar example, see: [http://globalyouthvoices.org/pdfs/youthvoices/Youth%20Voices%20Guide%20\(Pages%2041-42\).pdf](http://globalyouthvoices.org/pdfs/youthvoices/Youth%20Voices%20Guide%20(Pages%2041-42).pdf).

In year 3 we will host 1 final cultural production workshop (for a total of 6 communities over 3 years). In this final year, we will host a 5 day retreat for all youth coordinators (year 1, 2 and 3), the manager and the entire investigator team to collaboratively analyze the data and develop a detailed and focused dissemination strategy. Our goal will be to produce a variety of academic and community friendly out-puts to share the work produced and the analyses developed.

**Methods/Analysis** - Data sources for study will include the oral, written, visual, audio and digital images created by youth themselves, as well as video and audio recordings of their group work, focus groups and individual interviews, and evaluation data from the community itself (through key informant interviews and surveys at the production performances). All media will be inputted into N6 qualitative data management software. Adopting an Indigenous approach to research and with assistance from youth participants and research assistants, interviews and media will be qualitatively analyzed for thematic content. The framework for the analysis will be developed collaboratively by the team at annual retreats and monthly team meetings. Various members of the team may take the lead in coding for themes of interest.

Coding and analysis of data will commence using the constant comparative method outlined by Strauss and Corbin.<sup>96</sup> This type of coding will involve the development of codes that describe respondent's accounts of participation in their own words. As codes are developed, they will be applied and compared to newly collected data and will be modified as necessary. Descriptive codes will then be combined to develop theoretical or analytical themes. In addition, we will take a phenomenological approach to reading the data by drawing on the stories that youth tell. We will encourage them to provide concrete examples of experiences that highlight both their challenges and successes in creating prevention resources. While we intend to allow for themes to emerge from the data, our preliminary work in the area suggests that we will approach the analysis in the following ways:

- 1) **How do youth understand and represent the links between colonialism (and other systemic factors) and individual HIV risk?** (a) Is there diversity across Nation, location and geography – what are the similarities and differences in the ways that Aboriginal youth from different spaces, places and cultural identity think about HIV and the links to systemic factors? (b) Is there diversity across by media – what are the similarities and differences across media in terms of the ways that HIV risk gets represented and activism is mobilized?
- 2) **What is the impact of engaging in these art-based workshops on youth participants?** (a) Is there diversity across Nation, location and geography – what are the similarities and differences in the ways that Aboriginal youth from different spaces, places and cultural identity relate to this

approach? What inspires activism? What constrains limit this approach? For whom? (b) Is there diversity across by media – what are the similarities and differences across media in terms of the ways that HIV risk gets represented and activism is mobilized? What constrains limit this approach? For whom?

**3) How do other community stakeholders (eg elders, parents, teachers, etc) relate to the work produced and how do they see/understand their role in Aboriginal youth HIV prevention?**

**Quality control.** Lincoln & Guba<sup>97</sup> suggest criteria for assessing the “trustworthiness” of qualitative data. They propose that research be assessed for ‘credibility,’ ‘transferability,’ ‘dependability,’ and ‘confirmability’ A number of different methods will be employed to ensure research quality and trustworthiness of qualitative results:

- 1) *Thick description*<sup>97-101</sup>: Careful background case notes of the research settings (eg each hosting community and medias adopted) will be incorporated into the analysis.
- 2) *Clear audit trail*<sup>97-100,102</sup>: Clear records and field notes will be kept of all data collection and analytic decision-making points.
- 3) *Triangulation*<sup>97-99,101,102</sup>: Triangulation is the process of using a variety of data sources and approaches to understand a problem. In this study, we will be able to triangulate data from a number of communities and a number of sources within the same community (eg media produced, interviews, audience surveys, etc).
- 4) *Member checks*,<sup>97,99-103</sup>: We will include youth coordinators in all analysis meetings; additionally by returning to youth artists for 3 month post-reflections we will allow youth to shape preliminary analyses.

**Recruitment** – Investigators will work with local ASOs, Friendship Centres, Universities, listservs and other community-identified resources to post for the local youth coordinator positions. Youth coordinator applicants will be assessed based on their knowledge about (1) working with local Aboriginal youth communities; (2) interest in HIV and/or health promotion; (3) knowledge or understanding of arts. After training, coordinators will return to their home communities (and with support from the project manager centrally and the investigator team), build a customized recruitment strategy that makes sense in their local context. For instance, in an urban environment, this may mean contacting local service-providers ASOs, Friendship Centres, special high schools, universities, listservs and other community-identified resources to post information about the project. In more remote/reserve communities, this may mean talking to chiefs or school principals or peers directly. In all case, information about the project will be posted online and in person and those interested in participating in the workshops will be asked to fill out a registration form indicating their interest in participating. Youth interested will be contacted for an interview. During the interview, the study and workshop will be explained in detail and youth who are willing, able and interested in participating will be enrolled in the study. In all cases, informed consent will be sought and parental/guardian consent will be sought for those under the age of 18. Some may be invited to sit on a local youth planning committee. Efforts will be made to have diversity in terms of age, gender (and where applicable) ethnicity in each group.

**Ethics** – This project will undergo community ethics review by members of CAAN’s national research advisory committee and by any of our participating communities that have structures/policies in place to review projects. Efforts will be made to accommodate local concerns and issues around honoraria and consent. It will also be submitted to the Research Ethics Board of York University, University of Toronto and McGill University for approval. Before beginning each workshop and interview, we will review the purpose of the study and obtain informed consent. Participation is entirely voluntary. Participants will have

the opportunity to ask questions before the workshop/interview commences, and they will be reminded of their right to refuse to answer any question or to withdraw from the study at any time without penalty. If they choose to withdraw, they will keep the \$25 participant gift.

The research team has paid particular attention to concerns that are specific to arts-based approaches to research in designing the protocol. Drawing from our work engaged in similar workshops with youth, several ethical dimensions need to be considered in this work. In particular, the following considerations have been taken into account<sup>5,104-106</sup>: **1. Confidentiality/Anonymity.** Some youth who participate may choose to remain anonymous. Others may decide that they want to be credited with their productions. The decision about how they want themselves and their work to be shared/credited is one that will be made mutually with the research coordinator, the youth and parents/guardians. Where youth choose confidentiality, any identifying information will be changed to protect participants' identities. This will be particularly important in smaller settings where youth may be more easily identifiable. No personal information about youth participants will be shared publicly or with our collaborators without explicit permission. **2. Privacy.** Discuss with participants the need to get permission before taking someone's picture. One option is to use photo release forms in which youth obtain written permission from a subject before taking their picture/video/recording. Privacy can also be respected by taking pictures in such a way that the identity of the people in the photograph is not clear, for example by taking pictures from far away, or by blurring out faces after the picture is developed. **3. Safety.** It is important to orient group members towards safety measures when taking pictures. As a general rule youth should not take a photograph/video if they feel the situation is uncertain or potentially dangerous. **4. Misrepresentation.** Discuss with the youth the use of photography/video as a tool for documenting the reality of their communities, and the importance of not misrepresenting individuals or issues. **5. Consent.** All media produced should be considered the property of the artist. Youth will retain original copies of all their work. Written consent will be obtained from youth for the use of any media that will be displayed to others outside of the project or used in the development of prevention materials. **6. Direction/suggestion.** Facilitators will take care not to direct youth towards photography/representation of a particular subject area or issue. **7. Disempowerment.** Asking youth to document the realities of their communities has the potential to be disempowering if it is not done with a focus on giving youth a voice to speak out about issues in their lives. Even if tangible social change is a long-term project, ensure that the project ends on a note of empowerment and celebration.

Where youth choose confidentiality, any identifying information will be changed to protect participants' identities. This will be particularly important in smaller settings and where as a result, participants may be more easily identifiable. No personal information concerning participants will be shared with our collaborators. We do not anticipate involvement in the study will lead to psychological distress. However, in the event that such occurs, we will ask each community collaborator to provide a list of local counselors and elders who would be available to participants who wish to seek support after their involvement in the study. The collaborators will not be informed if any such referrals are made.

Members of the research team take seriously issues of community ownership, control, access, and possession. Once the study begins, we will sign the appended draft agreement, Principles of Research Collaboration, that outlines the process by which decisions about community involvement in the study, data collection, data sharing and analysis, and community and academic dissemination will be decided (refer to Appendix A). This approach is consistent with CIHR's guidelines for health research involving Aboriginal peoples.<sup>107</sup>

## **RESEARCH TEAM**

All members of the research team have been actively involved in identifying the research focus and in developing the research plan. All members will take responsibility for supporting the research manager, local youth coordinators, attending workshops in their area, reviewing data and will contribute to coding, analysis, and interpretation. Team members will also all contribute to the drafting of community and academic reports that result from the project. Most of the work of gathering and managing the data will be conducted by the research manager, local youth coordinators and student trainees. The research team will hold regular (monthly) teleconferences to discuss the project to ensure the meaningful involvement of all members. Research team members will also be involved in activities related analysis of interview data, interpretation and in presenting findings to various audiences as described below (*see section related to knowledge transfer/exchange and dissemination*). Investigators will also all participate in annual project retreats.

**Sarah Flicker** – *nominated principal applicant* – is an assistant professor at the Faculty of Environmental Studies at York University and an Ontario HIV Treatment Network Scholar. She has a track record of success engaging and working with marginalized youth on community-based research around HIV prevention and support issues. Her research interests are in the areas of urban health, youth health, HIV, health promotion, ethics, the social determinants of health, and community-based participatory research. She is an active member of the TeenNet Research Group and the Gendering Adolescent AIDS Prevention Research Group, and the Positive Youth Project. Previously, Sarah was the Director of Research at the Wellesley Institute where she worked with community based organizations across Toronto on developing research agendas to answer pressing urban health questions. She has expertise in quantitative, qualitative and arts-based methods.

**Randy Jackson** – *co-principal applicant* – is the Director of Research and Programs with the Canadian Aboriginal AIDS Network and an OTHN Community Scholar. Originally from and a member of the Chippewas of Kettle and Stoney Point First Nation, Randy has been involved in a number of pivotal research projects that involve community engagement and incorporate Aboriginal values and perspectives. Topics of research areas include, cultural competence in service provision, homophobia, mental health and depression, the influence of stigma on access to health services, Aboriginal participation in clinical trials, knowledge translation and exchange, cultural resiliency, and capacity-building and mentorship. Randy is a champion for Aboriginal peoples' health issues nationally, Indigenous peoples internationally, and is highly skilled in disseminating knowledge to people who will use it. Randy is a qualitative researcher and brings with him a background in sociology.

**Melanie Rivers** – *co-applicant* – has been an Educator for Chee Mamuk, Aboriginal Program, British Columbia Centre for Disease Control for the past nine years. Melanie received her Bachelors of Arts in anthropology and honors psychology from the University of Victoria in 1995. Melanie travels to Aboriginal communities and organizations within BC to provide HIV/AIDS, Sexually Transmitted Infection education in a culturally appropriate way. She works with a holistic and community based approach sharing information and ideas in hopes of inspiring people to reduce harm to themselves, gain compassion for people living with HIV, and work towards preventative programming. Melanie has coordinated innovative projects such as the production of “The Gathering Tree” which is a culturally relevant book for children to learn about HIV. Melanie also recently coordinated a positive sexual health campaign created by Haisla youth called “Stand True”. Under Melanie’s leadership, the youth created a DVD and campaign which includes positive messages about sex and condom use.

**Tracey Prentice** – *co-applicant* – has been involved in Aboriginal and non-Aboriginal community-based HIV/AIDS research for the past five years. Tracey has completed national projects related to Aboriginal and non-Aboriginal women living with HIV/AIDS, HIV prevention for Aboriginal youth, HIV testing and care among Aboriginal youth and HIV/AIDS-related discrimination. Tracey holds a CIHR Doctoral Training Award in Aboriginal Community-Based HIV/AIDS Research and is currently working towards a doctorate in Population Health at the University of Ottawa where she plans to build on her work with Aboriginal women living with HIV/AIDS. Current research interests include the social determinants of health with particular emphasis on gender and culture, mental health, wellness studies, and issues affecting women and youth. Tracey is a qualitative researcher and brings with her a background in anthropology.

**Claudia Mitchell** – *co-applicant* – **Claudia Mitchell** is a professor in the Faculty of Education, McGill University where she also holds the title of James McGill Professor; she is also an Honorary Professor in the Faculty of Education, University of KwaZulu-Natal, South Africa where she is also the Co-director of the Centre for Visual Methodologies for Social Change. Her research areas include participatory and visual research methodologies in the context of youth, gender and HIV and AIDS, gender-based violence and schooling, girlhood studies, and teachers' self-study. Her work in international development includes studies in South Africa, Swaziland, Ethiopia, Malawi, Mozambique, Rwanda, Russia, Trinidad and Tobago. She has conducted policy work on gender based violence and HIV and AIDS in Rwanda and South Africa. She is currently heading up a SSHRC study on arts based methodologies in addressing HIV and AIDS in South Africa as well as a study on the use of the internet in linking up youth-focused arts-based participatory studies with youth on HIV and AIDS. She is the author of 8 books with two books in press, *Putting People In the Picture: Visual Methodologies for Social Change* and a two volume encyclopedia on *Girl Culture*.

**Jean-Paul Restoule** – *co-applicant* – is Anishinaabe and a member of the Dokis First Nation. He is Assistant Professor of Aboriginal Education at the Ontario Institute for Studies in Education of the University of Toronto. His research has included Aboriginal identity development in urban areas and the application of Indigenous knowledge in academic and urban settings. He is currently researching traditional Anishinaabek teachings for ethical research and access to post-secondary education for Aboriginal people. Jean-Paul is actively involved in creating a network and support program for Aboriginal graduate students in Ontario (Supporting Aboriginal Graduate Enhancement).

**June Larkin** – *co-applicant* – June Larkin is the Vice-Principal of New College and a lecturer in the Women and Gender Studies Institute, University of Toronto. Her research interests include sexual harassment, violence against women, gender equity and schooling, body image and eating disorders, and gender and HIV/AIDS. She is the author of "Sexual Harassment: High School Girls Speak Out" (1994/1997, Toronto: Second Story Press) and author/co-author of several articles and book chapters.

**Jeanette Doucet** – *co-applicant* – Jeanette Doucet is an advocate for reproductive rights and sexual health with a background in communications and education. She lived and worked in the Western Arctic for two-and-a-half years and currently works at Pauktuutit Inuit Women of Canada as Manager of Sexual Health and HIV/AIDS Policy and Programming. Jeanette is co-chair of the Inuit Caucus of the National Aboriginal Committee on HIV/AIDS and is a member of the Canadian Inuit HIV/AIDS Network. She also sits on the Board of Directors of Canadians for Choice and Planned Parenthood Ottawa, where she worked for two years as Peer Education Coordinator. Most recently, Jeanette lead a team through the seed phase of an Inuit-specific community-based CIHR project to strengthen approaches to education and screening among youth.

## **DISSEMINATION: KNOWLEDGE TRANSLATION & EXCHANGE PLAN**

Knowledge translation and exchange (KTE) strategies are an important component of any community-based research approach, and are particularly meaningful given the urgent context within which this research program is situated. The need for timely and appropriate youth-driven Aboriginal prevention messages is crucial. The articulation of effective KTE strategies in Aboriginal communities in Canada is an emerging area of learning. The Indigenous People's Health Research Centre (IPHRC) based in Saskatchewan ([www.iphrc.ca](http://www.iphrc.ca)) has taken a lead in promoting the development of Aboriginal KTE policies grounded in discussions during the Sharing What We Know About Living a Good Life: Indigenous Knowledge and Knowledge Translation Summit.<sup>108</sup> In addition, The Canadian Journal of Aboriginal Community-Based HIV/AIDS Research also included an article regarding KTE in an Aboriginal context.<sup>109</sup> These materials and others from international literature contribute to a foundation for the dissemination activities for this project.

The research team will build on and work with community stakeholders towards principles of KTE that will most directly inform action to enhance prevention efforts and related policy, and further contribute to the evidence base that informs ongoing and newly developed HIV prevention initiatives. With many years of collective experience in the HIV/AIDS movement, the research team has extensive experience responding to the HIV prevention evidence needs of stakeholders across Canada and with Aboriginal peoples and youth specifically.

### ***KTE Audiences :***

- **Local communities:** At the end of each workshop, we will host an open gathering for youth to showcase their work and encourage them to invite their friends/other youth, parents, teachers, siblings, elders and other important community stakeholders to see their works in progress. In addition, we will work in consultation with host sites to secure community space to showcase local productions for a longer period.
- **Reaching other youth:** With permission of youth artists, we will use the CAAN youth portal ([http://www.caan.ca/youth/html/index\\_e.html](http://www.caan.ca/youth/html/index_e.html)) and the Positive Youth Project ([www.livepositive.ca](http://www.livepositive.ca)) to create a digital repository of all art-works (sounds, images and video) created as part of the project. A communications plan will also be developed to attract the attention of local print-based media, including newspapers, websites, teen magazines; and radio. Targeted press releases will be sent out to attract local and national media. In particular, we will try and highlight the youth's work as well as overall project themes.
- **Other community stakeholders** (e.g non-participating communities, Aboriginal community members, youth and Aboriginal/non-Aboriginal service organizations, etc.): findings from the research project will be presented as workshops to assist in data analysis and as opportunities for dissemination at key conferences and meetings (e.g., community health fairs, CAS and/or CAAN's Annual General Meeting, Healing our Spirits Conference, OHTN's annual conference, etc.). Community publications such as fact sheets will also be made available, for example, postings of fact sheets, community reports, and other tools on relevant websites (e.g., [www.caan.ca](http://www.caan.ca), [www.cdnaids.ca](http://www.cdnaids.ca), [www.hiv-chr.net](http://www.hiv-chr.net), etc.).
- **Academic audiences:** findings will be presented at key scientific conferences (e.g., Canadian Association of HIV Research and International AIDS Conferences, etc.) coupled with the submission of papers to leading peer reviewed journals for publication in journals such as the Canadian Journal of Public Health, Journal of Adolescent Health, Health Promotion International, Health Education and Behavior, Social Science and Medicine, the Journal of Aboriginal Health,

PIMATISIWIN, the Journal of Aboriginal Community-Based **HIV/AIDS** Research (CJACBR), etc.

- **Policy makers** (e.g., Minister of Health at a federal level and/or Aboriginal and non-Aboriginal political leadership): findings will be used in public consultations, meetings with elected officials, and presentation to civil servants.
- We will also apply under separate cover for PHAC and/or CANFAR funding in year 2 to develop a national 'by youth – for youth' Aboriginal campaign based on the materials created.

A final report from this study will be provided to these audiences to support a comprehensive approach to KTE. As a national research team, it will be imperative to develop resources that are meaningful to a number of different levels – local, regional, provincial, territorial, national and increasingly on an international stage. The assembled team draws together expertise and, as a collective, decades of experience integrating the role of context in influencing the use of knowledge generated through research.

### **SIGNIFICANCE**

While Aboriginal youth are diverse in terms of culture, languages spoken, social and geographical location, they share the legacies of colonialism, the residential school system and their ongoing harmful impacts. Learning to cope with resulting hardships such as poverty, racism, and personal and structural violence contribute to shaping youth risk.<sup>2</sup> As such, Aboriginal youth shoulder a disproportionate burden of HIV<sup>1</sup> and culturally appropriate resources are lacking.<sup>2</sup> Arts-based methods may be an effective strategy for engaging youth in imagining new prevention possibilities that link individual and structural determinants of risk.<sup>3,5,65,68,110</sup>

The study is innovative as by necessity, it involves collaborations with community organizations that work with young Aboriginal people and will seek to partner and build the capacities of Aboriginal youth to address HIV in their own communities. Intervention content and methods developed as a result of data collected in the present study can be used in Aboriginal organizations, schools, support settings and AIDS Service Organizations which currently lack information on how to best serve these youth. With the increased capacity built from the collaborations and training from the present study, this study is likely to have significant community buy-in in and will therefore have increased feasibility and potential efficacy.

## **Endnotes**

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\* Consistent with CAAN's Aboriginal Strategy on HIV/AIDS in Canada (2003), the term 'Aboriginal' is used to include Inuit, Métis, and First Nations (Status and Non-Status) peoples. There are eleven (11) major language groups with more than fifty-eight dialects and Aboriginal peoples possess far greater diversity beyond linguistic assignment when considering differences across groups that account for intra-group social, cultural and environmental differences. As Kirmayer et al. (2000) report, "there is an enormous diversity of values, lifestyles and perspectives [within] any community or urban Aboriginal population. While this diversity makes lumping people together under generic terms like 'Aboriginal' or 'Indigenous' profoundly misleading, most groups nevertheless share a common social, economic, and political predicament that is the legacy of colonization (pg. 607)."

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