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Building on the Resilience of Aboriginal People in Risk Reduction Initiatives Targeting Sexually Transmitted Infections and Blood-borne Viruses

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BUILDING ON THE RESILIENCE OF ABORIGINAL PEOPLE IN RISK REDUCTION INITIATIVES TARGETING SEXUALLY TRANSMITTED INFECTIONS AND BLOOD- BORNE VIRUSES: THE ABORIGINAL COMMUNITY RESILIENCE TO AIDS (ACRA)¹

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1. This paper provides an example of a successful research project proposal that was funded in 2006 by the Canadian Institutes of Health Research, a division of Health Canada. The proposal includes a sample data sharing agreement as an Appendix.

ABSTRACT

There is evidence that Aboriginal people may be at increased risk of HIV infection; they also experience higher rates of other blood-borne viral (BBV) and sexually transmitted infections (STI). This project will provide insights into the role of resilience and its impact on the health and well-being of Aboriginal youth, especially as it relates to sexual and injecting behaviour. The primary recipients of this information will be agencies that provide risk education related to BBVs and STIs.

The project involves several phases. First, the framework for the research will be established, with Aboriginal leadership and involvement at every level. Next, both qualitative and quantitative methodologies will be used to identify factors that protect Aboriginal youth against blood-borne viral and sexually transmitted infections and their transmission within local communities. Finally, results from this project will be used to develop interventions and appropriate frameworks for their evaluation in Aboriginal communities.

An important component of this project will involve the building of capacity within participating communities, with the goal of identifying strategies related to resilience that can be incorporated into public health and clinical practice. The project will run for five years.

BACKGROUND AND PURPOSE

Communities cut off from mainstream information sources and care can be at disproportionate risk of sexually transmitted infections (STI) and blood-borne viruses (BBV) including HIV infection (Parker, Easton, and Klein, 2000; Parker, 2002). Worldwide, youth aged 15–24 years old account for nearly 50% of all new HIV infections. In Canada, the proportion of Aboriginal people among AIDS cases has increased steadily over the past decade (Health Canada, 2004a). Aboriginal peoples make up 3.8% of the Canadian population, according to 2006 Census data, yet represent an estimated 6–12% of new HIV infections; 40% of newly diagnosed HIV infections among Aboriginal people are under 30 years of age (FNIHB, 2000; Health Canada 2004b). It is estimated that one in five of the 56,000 annual reported *chlamydia* cases in Canada are among Aboriginal peoples, with two-thirds in youth under 25 years of age (Sevigny et al., 2003).

Injecting drug use is an important risk factor for HIV and hepatitis C among Canada's Aboriginal people (Health Canada, 2004b; Archibald et al.,

2003b; Miller et al., 2003; Miller, et al., 2004). The incidence of acute hepatitis C is five to six times higher in Aboriginal peoples than in non-Aboriginal Canadians, mostly from injection drug use (Zou, Forrester, and Giulivi, 2003; Wu, H.X. et al., 2006).

The specific objectives of this proposal are therefore:

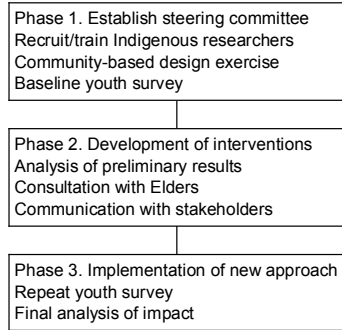
- i. Identify resilience factors and behaviours among Aboriginal people that protect against STI and BBV infections, including HIV;
- ii. Develop community based interventions to increase resilience of Aboriginal populations in regard to STI/BBV infections;
- iii. Implement the community-led interventions and develop a framework to assess their impact at the individual, family, and community levels.

RESEARCH DESIGN

Our central research question is: How can STI/BBV risk reduction initiatives build on the resilience of Aboriginal peoples to improve health outcomes in Aboriginal communities?

Our interest is primary prevention (building resilience to prevent the development of risk). The research design over the five years of this study will be three phases, corresponding to the three main objectives.

Three phases



PHASE 1 (YEARS 1–2): BUILDING PARTNERSHIPS WITH COMMUNITIES TO ASSESS RESILIENCE

1. **Community involvement:** Steps are in place to guarantee community ownership of the research process, including nomination of Aboriginal researchers for training, participation in the Aboriginal steering committee, and establishment of community working groups.
2. **Training:** The Band Council or the health board will identify a trainee researcher in each design community. The trainee will be part of the community design group convened to discuss the research objectives, contents, and process.
3. **Instrument development:** The research team will develop survey instruments in partnership with the urban and rural communities. This

will begin with standards-based approaches to risk and resilience factors associated with STI/BBV, including sexual violence, unsafe sexual practices, injection drug use (IDU), substance abuse and personal coping mechanisms. We will examine factors including relationship with family, integration within the community and schools, sexual violence, unsafe sexual practices, IDU, substance abuse, and inadequate personal coping mechanisms.

4. **Deepening the enquiry:** An important aspect of this phase of the project will be the identification of gaps in the knowledge of the burden and impact of STI/BBV in Aboriginal communities. Added value is the identification of at least seven “layers” of youth engagement with information about youth risk. Developed in an eight-country study of youth reactions to mass media education on HIV in southern Africa, the CASCADA approach documents **c**onscious knowledge, **a**ttitudes, **s**ubjective norms, intention to **c**hange a risk factor, sense of **a**gency to implement change, ability to **d**iscuss the issue and **a**ction. Interviews with Elders and a community environment assessment (availability of externally motivated health messages) will provide a community context.
5. **Sampling:** Two types of Aboriginal communities (urban and rural) will participate in the design. Based on this design, a school-based survey will be conducted in schools serving the participating communities (400 youth in the rural setting). There will be no sampling within schools: all youth aged 12 and 19 years attending school on the day of the survey will be invited to complete a facilitated self-administered questionnaire. For the urban settings where schools are not an adequate way to contact Aboriginal youth, snowball sampling will attempt to include in-school and out-of-school youth through community youth organizations, drop-in centres, needle-exchange sites, and street outreach.
6. **Data collection:** We will use individual, confidential, anonymous, self-administered questionnaires. Previous experience in Canadian Aboriginal communities using this approach has yielded very high response rates. Completed questionnaires will be sealed in front of the respondents and removed from the community for anonymous digitizing.
7. **Minimizing bias:** Dropouts and absentees may be at greater risk than those in school on the day of the survey, and community-based researchers will make a special effort to reach them. Those who opt not to

respond may be most at risk. Additional methods and special attention may be needed to address the issue of out-of-school youth (Shields et al., 2004; Health Canada, 2004c; Archibald, et al., 2003a).

PHASE 2 (YEARS 2–3): DEVELOPMENT OF INTERVENTIONS

The main activity to achieve this objective is in-depth analysis and socialization of evidence generated by Phase 1. The epidemiological analysis will include:

1. **Basic frequencies for outcomes of interest**, including knowledge about STI/BBV risk, access to information, gender violence, sexual practices, alcohol and drug abuse. We will stratify these factors by sex and age group to identify resilient groups.
2. **Quantifying associations** between STI/BBV protective factors, including congruency with peer opinions and behaviours; confidants; parental control and guidance; community integration; group membership and school attendance; recognition of risk behaviour; desire to change; ability to change; and the ability to express opinions about risk taking not in accordance with those of peers (deviation from subjective norms). With the limited size of the youth survey, we may not obtain decisive results about the *absence* of effect from mainstream educational messages. We do expect, however, to identify the strongest resilience factors and positive associations between resilience and source of information. We will look for the confounding effects of age, sex, community size, remoteness, and other variables on promising associations between resilience factors and protective attitudes and practices.

Risk analysis will use *CIETmap* (Andersson and Mitchell, 2002) freeware, including the Mantel-Haenszel procedure (Mantel and Haenszel, 1959), adjusted for clustering. We will also link risk analysis to local services, community contexts, and discussion group outcomes. This approach (known as mesoanalysis) links factors operating in the community or institution with the behaviour and attitudes of the individuals, situating individual data in a local context (Andersson, 1996). It may also be appropriate to develop a random effects logistic regression model (Hosmer and Lemeshow, 2000).

3. **Developing evidence-based interventions to increase resilience:** Results will be submitted to the community working groups in the design communities, to relevant health/educational personnel, and to

Elders in the communities served by the sample schools. In addition, focus groups and talking circles will be held with youth in both urban and rural settings to discuss the interventions most suitable to their own youth population. The interest of the Canadian team is primary prevention (building resilience to prevent the development of risk).

The interventions could include development of health promotion materials to inform protective behaviours against STI/BBV infection (for example, via schools and community organizations). They may improve service offers (STI/BBV testing, counselling, and treatment) or enhanced access to harm reduction programs (needle exchange or drug substitution programs for injecting drug users and condom distribution for youth), or programs to deal with gender violence.

PHASE 3 (YEARS 3–5): IMPLEMENTATION AND ASSESSMENT OF INTERVENTIONS

The central activity of Phase 3 is to promote implementation of the intervention(s) to increase resilience of Aboriginal people to STI/BBV infection. The follow-up survey will be appropriately comparable to the baseline. It will assess uptake and acceptability of the intervention. Outcomes will depend on actual interventions, but could include resilience, knowledge, attitudes/perceptions, behavioural intention, reported behaviour, availability and utilization of services, and prevalence/incidence of STI/BBV.

1. *Project governance*

Based on the OCAP (ownership/control/access/possession) principles (Canadian Aboriginal AIDS Network, 2004), an Aboriginal steering committee will be involved in all aspects of the project (design, data collection, analyses, interpretation, dissemination, etc.), to ensure genuine and meaningful involvement of the communities. This committee will be composed of representatives from: 1) Elders from the participating communities; 2) the health department serving the communities; and 3) Chief and Council. In each design community, a working group will be convened to guarantee the interests of the community are translated into the design.

2. *How the proposed research will address “resilience”*

Over the past two decades, resilience has become a central theme in social analyses of strategies people use in responding to adversity. Across all three countries involved in this application, we define resilience as *the means by*

which people choose to use individual and community strengths to protect themselves against adverse outcomes, and to build their future.

In this project, resilience is more than just behaviour that protects against infections; it is a complex interplay of social, cultural, and behavioural factors that operate at individual, family, and community levels (Health Canada, 2004d; Dion-Stout and Kipling, 2003). We understand resilience to combine spirituality, family strength, Elders, ceremonial rituals, oral traditions, tribal identity, and support networks (HeavyRunner and Marshall, 2003) – beyond the negative tone implicit in “the capability of individuals and systems to cope and flourish successfully in the face of significant adversity or risk” (Reid et al., 1996/97).

Hostility to authorities can discourage Aboriginal people from accessing community controlled health services and western health institutions. Language and culture are also important determinants of access to sexual health education in some communities. A resilience focus helps to counter a dominant research trend into “what is wrong” in Aboriginal communities, helping to ensure research is framed in a positive manner and results in practical benefit for Aboriginal peoples. This shift away from risk behaviour to the way STI/BBV interventions reinforce resilience has several effects: it increases relevance and acceptability of the research to Aboriginal peoples, and it also increases immediacy of solutions. Resilience offers a pathway by which disadvantaged populations can become informed about sexual and drug injection risk, take responsibility to reduce risks, engage with Aboriginal and European health care systems, and share experience.

Risk and resilience factors are poorly researched among Aboriginal communities. In the Ontario First Nations AIDS and Healthy Lifestyle Survey, only 9% of participants always used condoms in vaginal intercourse and 11% in anal intercourse (Calzavara et al., 1999). The Regional First Nations and Inuit Health Surveys (RFNIHS) included some data relevant to HIV/STI risk and the perceived importance of the epidemic (National Aboriginal Health Organization [NAHO], 2004; Myers et al., 1993). In Nova Scotia, 31% of respondents said they did not always practice safe sex. A third of these were youth under the age of 19 years (Mi'kmaq Health Research Group, 1999). In Manitoba, 72% believed they were not personally at risk of HIV and 61% did not practice safe sex. Although 84% said more education was required, nearly one-half felt HIV was not likely to become a problem in First Nations communities (NAHO, 2004). One region in the RFNIHS that

looked at sexual abuse (Ontario) showed a significant proportion of youth had experienced physical (25%) or sexual (14%–28%) abuse (NAHO, 2004; Centre for Studies of Children at Risk, 1998). There is a well-recognized link between sexual violence and HIV infection (NAHO, 2004; Myers et al., 1993; Mi'kmaq Health Research Group, 1999; Centre for Studies of Children at Risk, 1998; Buzi et al., 2003; Blumenthal, Gudjonsson, and Burns, 1999; Garcia-Moreno and Watts, 2000). A recent study of school-goers concluded that views on HIV infection risk were compatible with “adaptive” attitudes about sexual violence (Andersson et al., 2004). There are no similar published studies for Canadian youth. Research into social dimensions of STI/BBV risk in Aboriginal peoples is seriously underdeveloped (O'Neil, 1998; Spittal et al., 2002).

3. Contribution to existing research, fostering new research in Aboriginal health

This project fosters ethical and community contributions to Aboriginal health research, identifying community and home factors that protect youth from STI/BBV. At the individual level, questions about sexual experience could be injurious to the youthful respondents. Harm to the community could result from research findings stated negatively, or if individual responses became inappropriately public. Several precautions will be taken to ensure that the community and its members are protected.

1. *Informed consent of the community.* The researchers will discuss and evolve objectives with participating communities to ensure goals are clear and that the research flows from community beliefs and traditions. In the event that language prevents interested community members from participating, we will employ a translator.
2. *Ethical appropriateness of the community working groups.* The community discussions will involve social services personnel, youth councillors, teachers, and Elders. These individuals are well positioned to identify shortfalls of support mechanisms, and they will be the ultimate beneficiaries of the research results.
3. *Protecting the privacy of the community/ownership of research data.* Data resulting from this project remains the property of the communities. We will invite the urban and rural community working groups to discuss the ethical safeguards that protect the individual participants, to be clarified with a formal Aboriginal ethics board prior to starting:

- i. *Parental consent*: Parental consent can lead to the exclusion of those youth most at risk. This is especially likely when parental contact is initiated through the child, as is often the case in classroom surveys. The steering committee will ultimately decide the method by which consent is to be obtained.
- ii. *Voluntary consent and participation by youth*: At the time they are approached to participate, facilitators will explain the instrument, that participation is strictly voluntary, that any question which proves uncomfortable can be skipped and that they may stop at any time. Parental consent will not override the decision of youth *not* to participate.
- iii. *Confidentiality*: The research will be administered in a way that guarantees confidentiality and anonymity. Participating youth will be informed that their responses are confidential. Completed instruments will have a unique identifying number for data entry purposes, but no identifying marks or names will appear on the completed form.
- iv. *Protection of those at risk*: To protect youth at risk while honouring their confidentiality, participants will receive contacts to appropriate services, should questions prove injurious or provoke unpleasant memories. Again, the opinion of the steering committee will influence the methods to protect both participants and confidentiality.
- v. *Ownership, control, access and possession*: A data-sharing agreement with each participating community will specify community ownership of data with data stewardship. This will allow for access to the data by the communities, while protecting the individual rights of young people who participate.

Training of community-based researchers is integral to this research process. However, capacity building involves more than just the researchers, as several stakeholders get involved in discussions about the research problem and in the development and implementation of intervention strategies. The resulting interaction among local groups and organizations will help to empower communities to develop and implement evidence-based solutions. This may be of much wider relevance than just HIV risk.

The widespread dissemination of findings from our work in academic literature and community reports will help stimulate a larger response, with credit accruing to the originating communities. CIET already works

on Aboriginal youth suicide resilience and the Public Health Agency of Canada has multiple study sites across Canada in high-risk, marginalized populations such as street youth and injecting drug users that include many Aboriginal people (Shields et al., 2004; Health Canada, 2004c). CAAN is involved in ensuring the OCAP principles are an integral part of the research process in Aboriginal communities in Canada. The results offer a solid basis for additional grant applications to extend this work in Canada.

4. How the research will improve health outcomes for Aboriginal peoples

Most health research is not geared to Aboriginal paradigms and Aboriginal groups are increasingly critical of research that views them as objects (Smylie, 2000; Reading and Nowgesic, 2000; Dixon, 2003). The trend has been to focus on what is wrong in Aboriginal communities. This project focuses on the way externally motivated STI/BBV risk education initiatives build upon the resilience (positive adaptation to serious adversity) among young people of Aboriginal cultures in both rural and urban settings. A youth survey with in-school and out-of-school components will apply these instruments designed with the communities (Table 1). The results will be shared with the main STI/BBV risk education role players, and the impact of this measured. It will enable Aboriginal communities *as a whole* to build on their resilience, not just targeting high-risk subgroups like youth, homosexual men, sex workers, and injecting drug users. We will develop recommendations to government and community services.

For many Aboriginal people, improving resilience at the individual, family, or community level is an important outcome. Our work narrows the knowledge gaps between urban and rural communities (Swaminathan et al., 1998) and strengthens the information base to improve health outcomes through more effective STI/BBV prevention and care. Implementation will involve three sets of stakeholders. The first deals with in-school education (the Board of Education and, for health related components of education, the Board of Health), represented in this project through the Aboriginal steering committee. The second set includes the nongovernmental, community-based, and advocacy organizations involved in HIV risk education, represented in this project by CAAN. The third set is the public health initiative recommended to the Canadian government, represented in this project by the Public Health Agency of Canada, in collaboration with Health Canada's First Nations and Inuit Health Branch.

Table 1: Proposed Community Involvement with the Research Design Process

<i>Action</i>	<i>Implementation</i>
1. Identify and involve relevant community stakeholders to guide the development of the research process.	1. The two design communities will designate Aboriginal research trainees, community working groups, and members of the steering committee. Research will be guided by the concerns and input of working group members.
2. Identify relevant resilience factors for Aboriginal youth.	2. Resilience factors identified from existing literature will help initiate discussions. Stakeholders will make their input in their multiple contexts of individual, families, and communities.
3. Develop an Aboriginal stakeholder process to increase depth and breadth of understanding of resilience.	3. Working groups will review the survey instruments. Ongoing discussions will provide continued fine-tuning. Piloting of the instruments in the design communities will further ensure that questions are suitable and clear.
4. Maximize data quality while protecting youth privacy and safety.	4. Researchers and communities will jointly establish a procedure for data collection in school settings. Communities will participate in discussions of the ethical consideration of the project.

5. How the project identifies and implements international collaboration

An International Steering Committee will oversee the collaboration between the three countries. This has three representatives from each country, of whom at least two are Aboriginal. This Committee will be chaired by one of the Aboriginal members, on an annually renewable basis. It is anticipated that the Committee would meet once a year face to face, and by teleconference as required. Canada may learn specific lessons from Australia and New Zealand where, unlike Canada, HIV infection rates in Aboriginal populations are not higher than those in the general population. Comparisons will identify best-practice solutions and learning about resilience of Aboriginal people. The budget allows an international meeting each year, coinciding with national STI or BBV conferences. Annual meetings will allow team learning and transfer of successful models between countries. Exchanges of trainees and community-based researchers will promote an international network of emerging Aboriginal researchers.

6. Training and career development for Aboriginal researchers

The team will employ Aboriginal people at all levels of research. CIET at the University of Ottawa promotes the use of epidemiology in Aboriginal health planning and governance. The Ottawa ACADRE supports training of Aboriginal researchers through Master's and Doctorate levels. There are also linkages to relate this research training directly to population health policy (Majumdar et al., 2004) through the Public Health Agency and CAAN.

The training and involvement of two Aboriginal trainee researchers is integral to this research process. The project will hire one Aboriginal postdoc-

toral fellow and accept two Aboriginal Masters students from the ACADRE program. Capacity building also entails community involvement in discussions about the research problem and, importantly, in the development and implementation of intervention strategies. The evidence-based interaction among community service organizations will increase awareness of the social resources that can protect youth. Opportunities for Aboriginal undergraduate students exist at various stages of the project.

7. Translation of research findings to improve Aboriginal health outcomes

On equal footing, the team includes the Canadian Aboriginal AIDS Network (CAAN), Community Information and Epidemiological Technologies Canada (CIETcanada) at the University of Ottawa, and the Public Health Agency of Canada. CAAN has links with Aboriginal AIDS organizations across Canada and advocates for community-based participatory research involving Aboriginal communities in the OCAP framework (ownership, control, access and possession of research products by and for the Aboriginal community, CAAN, 2004). CIET has experience of community-based research in Aboriginal populations in Canada and runs the Aboriginal Capacity and Developmental Research Environment Centre (ACADRE) at the University of Ottawa. The Public Health Agency of Canada has extensive experience in national surveillance, epidemiologic studies, training, and policy development related to STI/BBV infections.

The team will explore ways to transfer the findings to government and nongovernment organizations, promoting culturally appropriate interventions and policies. Guided by the communities in the appropriate format (Talking Circle, Band Council, Elders, or community meetings), a dissemination strategy throughout the research process will be directed to a range of knowledge users (Table 2), evolving as community requirements are articulated more clearly.

This project will make *existing* knowledge translation (KT) efforts about HIV/STI/BBV risk more appropriate to Canada's Aboriginal population. The project KT strategy is thus to inform and possibly to reorient the main agencies involved in risk education with Aboriginal peoples, not to take over their KT competence. Although HIV/STI/BBV are not traditional problems, traditional knowledge and resilience systems can help to protect Indigenous youth, and should be taken into account by KT agencies. In a research approach attuned to Indigenous cultures, we will measure youth knowledge in

Table 2. Dissemination

<i>What will be communicated</i>	<i>To whom</i>	<i>Timing (When)</i>	<i>Communication method (How)</i>	<i>Communication outcome (Why)</i>
Concepts behind the research. How it applies in this community	Community stakeholders (including service providers, Elders and community members)*	1. During initial contact. 2. Revisited as required throughout process	1. Initial presentation to band council and /or initial meeting with stakeholders. 2. Discussions with working group	Identify appropriateness of goals and methodology for each community
Ethical considerations pertaining to this project	Steering committee Community (including band service providers, Elders)* Working groups	1. During initial contact 2. Revisited as required throughout research process.	1. Initial presentation to band council and /or initial meeting with stakeholders. 2. Discussion with working group	1. Address concerns about protecting individual participants and community 2. Encourage discussion of ethics and community rights
Detailed presentation of the research instruments and data collection methodologies	Community stakeholders Designated community working group	1. During initial presentations 2. During working group discussions throughout project.	Via ongoing discussions 1. Reasons information is important to community 2. Lessons learned (feedback about youth risk work done in other Aboriginal communities)	Customized community process to increase understanding of and involvement in methods
Research results and intervention plans	Community stakeholders Working group Steering comm.	During analysis	Involvement in the planned analysis.	Identify concerns of steering committee and ensure relevance of research at community level
Outcome of income assessment	Board of education; NGOs; government agencies	Post analysis Throughout project for modification of interventions	Inter community meetings or workshops.	Stronger capacity to change community institutions through lessons learned.

the context of existing risk education. We will workshop this evidence with KT agencies, both Aboriginal-run (CAAN, the local boards of health and education) and non-Aboriginal run (PHAC, FNIHB). This sharing of results with KT agencies will combine conventional formats (tables, graphics) with community representation and Elders, who can explain the scientific evidence in their own words. We will then measure the uptake of community-based evidence by these education agencies and, as these implement KT initiatives modified by Indigenous culture and knowledge, their reception, coverage, and impact at community level. Locally, the project steering committee includes the local Board of Health, Friendship Centres, and the participating

communities. We also propose to publish the process and findings in peer-reviewed journals, to make these accessible to others.

The team includes senior CAAN and PHAC staff who access the reach of CAAN's partner organizations countrywide and the PHAC's national Hepatitis C and STI prevention and control initiatives under the Federal Initiative to Address HIV/AIDS in Canada. Plans and results will be shared with the National Aboriginal Council on HIV/AIDS, which advises PHAC on Aboriginal HIV/AIDS. The team has agreements to share findings with FNIHB. Both PHAC and CAAN will be key role players in the large-scale intervention trial that will result from this project. The composition of the research team and its multiple linkages with organizations and projects on Indigenous resilience and HIV/STI/BBV will thus ensure the study findings benefit Indigenous peoples across Canada.

EVALUATION FRAMEWORK

The process and outcome evaluation framework is inclusive of all phases of the research.

Strategic focus: Evaluation focuses on processes and outcomes of community-driven resilience enhancement in reducing risk of hepatitis C, HIV, and other STIs.

Stakeholders: The local steering committee, participating communities, and international 3 country Aboriginal steering committee will monitor progress through face-to-face meetings and bi-monthly teleconferences. Qualitative and quantitative assessment, including views of Elders and Aboriginal youth, will address:

Process concerns: To what extent was the intervention acceptable and feasible? How did each community participate? Did the intervention lead to the nurturing of new community leadership? To what extent was the international collaboration beneficial?

Short term changes: To what extent did the intervention reach targeted individuals? Change in knowledge, attitude, and practice from baseline; change in youth's perception of how youth-supportive their communities are; change in youth involvement in traditional practices; change in social cohesion indicators.

Design issues: We will use findings to design an Aboriginal-led randomized community intervention trial to detect longer-term changes in HIV/STI/BBV risk.

Generalizability. We opted to work with rural communities that have self-determination in education, to develop an Aboriginal-run best practice relevant to other Indigenous groups, rather than “representing” them. Segments of urban youth in Edmonton and Ottawa share a cultural background with rural communities, permitting analysis of the urban/rural differences affecting many Aboriginal groups in Canada. Other segments of our urban subpopulation represent a broad mix of First Nations, Inuit, and Métis. This intentional focus of limited resources, combined with decisive Aboriginal community participation, will identify and increase *local* resilience factors against HIV/STI/BBV infection. In addition, we anticipate, it will illustrate methods and value of achieving this on a larger scale. Generalizability of methods and findings will be enhanced by links with several other youth resilience initiatives run by the same research team.

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Data Sharing Agreement

BETWEEN:

CIET, as represented by its Executive Director

(“CIET”)

AND

_____, as represented by the

(the “Community”)

1. Preamble

It is acknowledged and respected that the right to self determination of the First Nations, Métis and Inuit includes the jurisdiction to make decisions about research in their communities. The benefits to the communities, to each region and to the national effort should be strengthened by the research. Research should facilitate the First Nations, Métis and Inuit communities taking control and management of their health information and assist in the promotion of health lifestyles, practices and effective program planning.

The agreement describes data sharing of the data collected from the project [_____ insert project name]

2. Background (example from ACRA)

Sexually transmitted infections (STIs) and blood born viruses (BBV) — including HIV/AIDS — are of rising concern in all communities, and Aboriginal communities are not exempt from this risk. Communities cut off from mainstream information sources and care can be at higher risks of STDs and BBV including HIV infection. AIDS cases in Aboriginal communities have increased steadily over the past decade to roughly twice the average rate among the Canadian population at large. Injecting drug use is an important cause of BBVs among Aboriginal people, with two-thirds of new infections attributed to this cause compared with less than one-third among non-Indigenous Canadians.

Aboriginal youth obtain information about HIV from television and from newspapers, magazines or newsletters. A 1998 CIET pilot study on risk edu-

cation found one in five Aboriginal youth believed they would probably suffer from AIDS. The study also found a dramatic difference in knowledge between urban and rural communities. The conclusion was that risk education is not geared to the needs of Aboriginal youth.

3. Purpose of agreement

The purpose of this agreement is to formalize an arrangement between the Community and CIET regarding the sharing of data collected as part of the project.

4. Goal of project

Determine how STI and BBV (including HIV/AIDS) risk reduction initiatives can build on the resilience of Aboriginal peoples to improve health outcomes in their communities.

5. Objectives

1. Identify resilience factors and behaviours that protect against STIs and BBV;
2. With Aboriginal youth, develop community-based resources and intervention program designs that build on resilience of First Nations communities in regard to STIs and BBV;
3. Encourage risk educators to change their approaches, based on input from the communities, and then to assess the impact of this by repeating the baseline study;
4. Build on existing skills of key community members by providing training in the area of research, both quantitative and qualitative, data entry and analysis as well as program design and proposal development

6. Guiding Principles

1. The Project will enhance the capacity and skills of community members in community based research;
2. The communities will be involved as full partners in all aspects of the research, from design through to implementation;
3. Respondents will remain anonymous at all stages, and their identities protected when data are entered and when results presented;
4. The Community retains ownership of the data and will be the first to receive the results;

5. To protect the identities of respondents, CIET will store data on behalf of the Community in a secure setting;
6. All data will be collected and maintained according to the roles established in this agreement; and
7. The data from this Project will only be used to meet the stated goal and objectives.

7. Roles

Therefore the parties hereby agree that the Youth voices on risk project will take place as follows.

1. CIET will contract an individual identified by the Community to coordinate communication between the participating Community and CIET;
2. CIET will train Community Based Researchers (CBRs) selected by the Community to conduct research, enter their data and interpret their results for sharing with their communities;
3. CIET will provide funding to bring together Elders from the four tribal councils to act as advisors for the duration of the Project;
4. CIET will provide funding to bring youth together from the four tribal councils to provide feedback and direction for the Project;
5. The Community will conduct surveys and collect all of the data via the community-based researchers;
6. The completed survey instruments will be transmitted securely to CIET for training CBRs in data entry, and their subsequent analysis;
7. CIET will present the findings to the Community in a way that is appropriate and useful, and respond to additional requests for analysis.
8. Participating communities will be presented with the findings and invited to provide feedback/interpretation of the results. CIET will also assist in the presentation of the findings at the community level as requested.

8. Use of information and confidentiality

The data from this project will only be used to meet the goal and objectives of the Youth voices on risk project. As custodians, the Community and CIET agree to safeguard the privacy and security of all information containing personal and/or community identifiers. Permission from survey respond-

ents will be obtained prior to collecting personal information. Survey questions of a personal nature will remain completely anonymous.

9. Further Disclosure

The Community and CIET should not release the information collected for any purpose unless agreed to by the parties and authorized by statute.

10. Changes to this Agreement

Amendments to this agreement may only be made in writing by both parties.

IN WITNESS WHEREOF THE PARTIES HAVE SIGNED THEIR NAMES effective

the _____ day of _____, 200__.

_____))
_____))
Witness) CIET

_____))
_____))
Witness) Community