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building the community voice into planning

**Summary Report**  
**SR-CA-acra-07**

**Canada**

***First Nations youth resilience to HIV/AIDS***

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## **SUMMARY**

Given the current ‘transfer’ of former Federal government responsibilities to Aboriginal communities, it is important for First Nations’ community governments to be able to quantify problems and to build solutions from evidence gathered at the community level. This ability is a cornerstone of good governance, in that communities should have the capacity to tailor decisions to their needs rather than have decisions made based on what there is to be given. HIV/AIDS is one intractable problem that has to be faced by First Nations communities, and the ability to approach it successfully within a First Nations paradigm both speaks of good governance and helps build the skills and processes needed for good governance.

The main result to report from this pilot exercise is that the survey was carried out successfully; it was possible to include, in the design, key opinion makers in the aboriginal communities, their service workers and the youth themselves. Participation of the youth was good and the quality of data received seems reliable, indicating that this pilot experience can be followed by a much bigger initiative, as proposed by the AFN. The overall strategy of design and consultation was successful in several dimensions:

- it obtained buy-in from the community authorities
- it generated participation from the youth, said to be the most resilient to surveys
- it produced comparable data from very different communities, each with their own design and capacity building process, although sample size is small in some of the sites.

The survey was developed in four locations, two rural (Mistissini and Waswanipi) and two urban (Montreal and Winnipeg). A total of 289 youth were interviewed, slightly more than one half of them female, with an average age of slightly over 16 years. Three out of four of the youth were school goers. One in five young women interviewed said she had been pregnant in the years prior to the survey.

The youth were very clear about what they feel are the biggest problems in their home communities. Top of their list came alcohol and drugs, each mentioned by one third of the youth. Violence followed in third place. In the main, the youth interviewed had positive self images and felt good about themselves, though an identifiable core (one in four) felt they were failures and were not positive about themselves. Two in three said they considered themselves healthy.

Most received information on HIV/AIDS “at school”, but would prefer to hear it from a doctor. Three out of four youth (72%) said they would prefer to have information on HIV/AIDS presented in their own language. Asked whether and how this health education had helped them, three out of four (77%) said yes. Most of these mentioned safer sex as the main change they had made as a result.

**...out of 10?**

- 2/10 youth do not want to know if their sexual partner is HIV-positive
- 2/10 do not know about the risk of injecting drugs
- 3/10 cannot distinguish between HIV and AIDS
- 3/10 fear they might be infected by taking care of an HIV/AIDS infected person
- 4/10 think novelty (edible) condoms are safe
- 5/10 do not know tattooing or body piercing carry a risk
- 5/10 do not know an infected woman can pass the virus on to her baby
- 5/10 think the pill or spermicide jelly can protect them from HIV infection

**...how are we doing?**

Asked if they think birth control methods like a diaphragm, the pill, spermicidal jelly or pulling out are safe enough to protect one from getting HIV/AIDS, less than one half could say “no”. Knowledge levels were lower in the remoter sites (22% and 36% in Mistissini and Waswanipi respectively) than in the more urban sites (67% and 60% for Montreal and Winnipeg). Even in the better informed urban sites, this is an important level of misinformation.

Asked what they thought were their chances of getting HIV/AIDS, over one-half felt they had some chance of getting HIV/AIDS. No less than 18% felt they probably would get it and one claimed already to be affected.

The results, particularly the gradients between rural and urban areas, are interesting enough. Perhaps a more important finding, however, was that it was possible to mount these very local processes – with considerable community buy-in to local design – and still turn out highly comparable data across the four quite different communities.

The key to this success was the modular questionnaire developed and tested in this pilot project, and it offers a partial model for future AFN surveys. Each module in the questionnaire covers a specific concern which, in the design process, was offered for discussion as an entity. For example, if the design group chose to look at self-declared risk, this module offers some standard questions that work. Relatively little tinkering was done within the modules and, since each of the design groups was concerned with roughly the same aspects of the problem, the questionnaire stayed virtually identical despite going through four independent and lively design processes. In some sites, the design group elected not to include certain questions; for example, in Montreal and Winnipeg, they opted not to ask directly about the use of other drugs or pregnancy. In the final analysis, this left a large amount of directly comparable data that has hitherto not been available from these communities.

Another modest success was the local capacities built and research networks strengthened, if unevenly, in the four communities. Because of the time lag in receipt of funding – the first

payment was received into account in late January, for a one year research process due to end in March – implementation was considerably more rushed than desirable for optimal capacity building. Nonetheless, one Aboriginal intern received some training and considerable field exposure, and small teams of Aboriginal researchers were trained in each of the sites. These add to the existing skill base for implementation of a national survey.

“We need the leadership of the AFN and in Federal Government to take a role in spreading this HIV/AIDS message to the people. We need people at all levels to care beyond what will be politically correct.”  
*Health Service Worker, Montreal FG*

Several very direct conclusions can be drawn for HIV/AIDS education in these (and possibly other) First Nations communities. Three out of four youth said they would be willing to take part in information sessions on HIV/AIDS. This was a more common response in the remoter communities. Even in the urban communities, however, two out of three said they would take part. The pilot also generated considerable clarity about some of the content of the HIV/AIDS education. For example, the nature of the infection and syndrome, the focus on condoms and on different risk groups all need to be held up. The youth were also quite clear about who they wanted involved in the education.

Through this project, these four First Nations communities, with some relatively unobtrusive external technical assistance, have demonstrated that they are quite capable of designing and carrying out their own research on this high priority and methodologically difficult area. With the leadership and mandate of the Assembly of First Nations, this process can be initiated in other First Nations communities to build resilience to the threat of HIV/AIDS.

“Everyone in the Aboriginal community needs to recognise HIV/AIDS is as big as bingo and as important as hockey. We shouldn’t have to have a chief’s child become HIV positive before we do something about this disease. We should be much more proactive, taking prevention and education messages to our people before it gets too much of a hold on our population.”

*First Nations Health Worker, Montreal*