

**Appendix 8. Community Consultation to Design an Intervention to Reduce AIDS Stigma
Final Report.**



**Community Consultation to Design an Intervention
To Reduce AIDS Stigma
Final Report**

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This report presents findings from a Canadian Institutes for Health Research (CIHR) funded project to support a capacity building workshop entitled “Community Consultation to Design an Intervention to Reduce AIDS Stigma”. This project was funded by CIHR’s HIV/AIDS Community Based Research program. This workshop was a collaborative initiative by researchers at the Universities of Alberta and Ottawa and the Canadian Aboriginal AIDS Network (CAAN). CAAN participated on the project as the community based research partner. In addition, the workshops were conducted in partnership with the Ontario HIV Treatment Network (OHTN) and the Alberta Community Council on HIV (ACCH) who actively supported the workshops and assisted with the advertisement and recruitment of workshop participants.

Three 1 day workshops were conducted as an enhancement to the CIHR-funded research project entitled “The Influence of Stigma on Access to Health Services by Persons with HIV Illness”. Research capacity-building workshops were used with our Aboriginal and non-Aboriginal community partners to design an intervention to reduce AIDS stigma and to develop dissemination plans for the findings from the “Stigma project”. This is congruent with the principles of Ownership, Control, Access and Possession [OCAP]¹ that are fundamental to working with Aboriginal communities and with the Principles of Research Collaboration that the research team adopted. Community consultation workshops to design an intervention to mitigate AIDS stigma were an appropriate and meaningful way to bring the community-based “Stigma project” to a successful conclusion.

Some of the key findings from the “Stigma project” included:

- Stigma and discrimination influences the decision to disclose HIV status and the decision to access health services
- Stigma related to being HIV positive is layered with stigma related to other illnesses (e.g. mental health problems), lifestyles (e.g. being gay, working as a prostitute), behaviours (alcohol and drug use), gender (female), culture (e.g. being Aboriginal) and social class (e.g. being poor).
- Protecting the confidentiality of persons living with HIV (PHAs) and Aboriginal persons living with HIV (APHAs) was a concern among both persons living with HIV and health care providers (HCPs)
- Policies and practices in organizations could contribute to stigma and discrimination.

Design features to eliminate/minimize stigma in health care services

Organizational

- Policies and practices to minimize or eliminate stigma in organizations were identified based on the study findings. Organizational features included: ensuring respect for privacy and confidentiality; adopting a harm reduction philosophy; maximizing access to care and support service (eg minimal screening processes); adopting a flexible approach to care; adopting a shared care approach; providing safe working environments; providing education and training for staff; and ensuring supportive work environments.

Individual

- In addition to organizational features, several individual attributes of HCPs emerged as essential to non-stigmatizing care. These attributes include; respectful, non-judgmental relationships; the provision of culturally appropriate care; recognition of the complexities of clients lives; and building and maintaining connections.

Dissemination is arguably a key component of community-based research, yet dissemination planning has been identified by CAANs environmental scan² as a research skill that is not particularly strong in community-based organizations. Therefore, the **goals** of our community consultation workshop were two-fold:

- 1) to build research capacity among our community-based partners as it relates to designing an intervention to reduce AIDS stigma; and
- 2) to engage community partners in designing culturally and community-appropriate dissemination strategies for the CIHR-funded ‘The Influence of Stigma on Access to Health Services by Persons with HIV Illness’ project.

The purpose of each one-day community consultation workshop was to meaningfully engage PHAs, APHAs, HCPs and decision-makers in the design of an intervention to reduce AIDS stigma. Following an overview of the key findings from the research project, the workshop participants were asked to assist with the design of the intervention. The development of best practice guidelines for the provision of health services to PHAs and APHAs was an outcome of this process. Engaging the community in the design of the intervention helped to ensure that the resulting intervention was culturally, socially, educationally, and linguistically appropriate for the community for which it was designed³. Furthermore by engaging HCPs and people living with HIV in the design of interventions the likelihood that the interventions will be implemented is enhanced. This increased community support for the intervention and increased the likelihood that the intervention would have a direct policy impact⁴. This approach assisted in building research capacity in workshop participants to translate research findings into actionable policy interventions and to participate in future CBR projects⁵.

Description of the Outcome Objectives for Workshops

The initial objective for each 1 day workshop was to increase the participants’ knowledge of the research results of the “Stigma” project. The intermediate objective was to increase the knowledge and skills of participants in the design of an effective intervention to reduce AIDS stigma for persons living with HIV, including the process required to reorient health services to incorporate the optimal design. The long-term objective was to build research capacity in community-based organizations related to designing and implementing dissemination strategies. As well there was the potential to build upon the outcomes of the workshop by developing further research projects with the participants and their organizations.

Workshop Activities and Methods

The workshops were advertised and promoted via email using CAAN’s membership network. The Ontario HIV Treatment Network (OHTN) also assisted in advertising the

Toronto workshop by sending out an email to all of their annual conference delegates. Alberta Community Council on HIV/AIDS (ACCH) assisted in the advertising and promoting the Alberta workshop. Similarly, CAAN ensured that all of their members attending their HIV/AIDS CBR Capacity Building Conference in Vancouver were informed about the workshop.

Each workshop employed a combination of instructional and participatory learning strategies that recognized the capacities and learning needs of the researchers and the workshop participants (see Table 1 for workshop agenda). The underlying principle in this mixed-method approach was ‘learn by doing’. Following in-depth discussion of the research results and the factors involved in designing and implementing interventions to reduce AIDS stigma, workshop participants were asked to brainstorm ideas for culturally and community-appropriate strategies that would reduce AIDS stigma and facilitate access to health services. Key questions were asked to guide these small group discussions:

- Are you aware of additional best practices to reduce AIDS stigma?
- How do you integrate best practices into health services?
- How can best practices be maintained across settings?
- What is the role of HIV ‘specialists’ in the education of ‘generalist’ health care providers?

Strategies to reduce AIDS stigma that were generated from the discussions were evaluated by the participants for merit, efficacy and feasibility for health care organizations to implement. The workshop participants were then asked to evaluate the processes that are required for organizations to implement these strategies. The active participation and full engagement of the workshop participants in designing the intervention ensured that participants gained a better understanding of the processes involved in developing HIV interventions. The primary responsibility of the research team and staff were to facilitate this process. Handouts, work books and summaries of the key findings of the “Stigma” project were distributed to workshop participants.

Table 1. Workshop Agenda, Toronto November 29, 2006

Time	Activity	Presenter
8:00 am	BREAKFAST	
8:30-9:30 am	Opening Prayer and Introduction	Elder (prayer), Randy Jackson
9:30-10:00 am	BREAK	
10:00-12:00 am	Overview of Research Findings	Judy Mill
12:00-1:00 pm	LUNCH	
1:00-2:45pm	Designing AIDS Stigma Interventions – Small group sessions	Tracey Prentice as facilitator and members of research team
2:45-3:00 pm	Wrap-up and Closing Prayer	Elder (prayer), Judy Mill

Summary:

Workshop #1, Toronto, Ontario November 29th, 2006- Hilton Hotel - Designing Interventions to Reduce AIDS Stigma

Judy Mill, Randy Jackson, Wendy Austin, Nancy Edwards, Lynne Leonard, Lynne MacLean, Claudette Dumont Smith & Stan Houston

After discussions with Ontario HIV/AIDS Treatment Network (OHTN), the research team decided to hold the “Ontario” workshop in Toronto in conjunction with the OHTN Annual Research Conference. The OHTN were supportive of the objectives for our workshop and felt that this workshop would complement the OHTN conference, and be of interest to their membership. The OHTN provided financial support for the workshop which enabled participants from outside of the metropolitan Toronto area to attend. The costs associated with out of town participants were not part of the original workshop budget. Forty participants attended the workshop, including PHAs, APHAs, and representatives from Aboriginal communities and agencies providing services to PHAs and APHAs. Registered nurses and students from health disciplines, advisory committee members and researchers also attended the workshop.

Workshop #2 Calgary, Alberta February 6th, 2007 – Four Points Sheraton Hotel - Designing Interventions to Reduce AIDS Stigma

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The “Alberta” workshop was held in Calgary in partnership with the Alberta Community Council on HIV/AIDS (ACCH). 47 participants attended the workshop which was conducted prior to the bi-annual ACCH Conference. ACCH, a consortium of AIDS service organizations from across Alberta, assisted in advertising the workshop to their member organizations. Participants included APHAs, PHAs, registered nurses, registered social workers, nursing students, and representatives from AIDS service organizations.

Workshop #3. Vancouver, British Columbia February 14th 2007 – Empire Landmark Hotel - Walking a Path to Wise Practices: 1st CAAN HIV/AIDS CBR Capacity Building Conference.

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The research team was invited by the Canadian Aboriginal AIDS Network (CAAN) to conduct a third workshop in Vancouver in conjunction with a HIV/AIDS CBR Capacity Building Conference. During the Vancouver workshop, the research findings were highlighted in a 1 hour plenary session attended by 201 individuals, approximately two-thirds

of whom were First Nation, Métis, or Inuit. Following the plenary session, 10 individuals participated in a workshop to provide feedback and assist with the design of interventions to reduce AIDS stigma. CAAN provided technical support by advertising the sessions to their members, and financial support related to the costs of the plenary and workshop sessions. The Vancouver workshop was in addition to the two workshops proposed in our application under this funding call. The support provided by CAAN enabled the research team to engage more Aboriginal peoples in the research process. This approach is consistent with principles of active engagement and OCAP.

Workshop participants:

- ✓ received up to date knowledge of the research results from the project titled “Influence of Stigma on Access to Health Services by Persons Living with HIV Illness”.
- ✓ were involved in the design of an effective intervention to reduce AIDS stigma for persons living with HIV including the process required to reorient health services to incorporate the optimal design.
- ✓ were engaged in building/increasing research capacity between researchers and community based organizations related to the designing and implementation of dissemination strategies.

Key intervention strategies developed by the small group discussions to reduce AIDS stigma: (Findings from 3 workshops)

- Best practices to reduce AIDS stigma
 - Ensure that clients feel a sense of belonging and cultural safety
 - Start [anti]-stigma education at an early age
 - Consider work that has been done in other settings
 - Ongoing training of health workers (eg anti-oppression)
 - Adopt universal precautions
- Integrating best practices into health services
 - Build on existing frameworks/best practices from other fields (eg. mental health, addictions)
 - Include PHAs and men in intervention design and implementation
 - Influence portrayal of HIV in media
 - Consider innovative interventions (drama, narrative)
 - Increase HIV/AIDS curriculum in university curriculums for health professionals
- Maintaining best practices across settings
 - Implement interventions at places people go
 - Acknowledge diversity - best practices cannot be generalized
- Role of HIV ‘specialists’ in the education of ‘generalists’ health care providers
 - Be a role model

- Intervene and challenge bad practice
- Sites of specialized knowledge must be catalysts for change
- Keep stigma on the agenda

Sample of Feedback from Participants

Most informative. We need to make sure that this research project gets to the grassroots organizations to implement. So many good research project end up in shelves gathering dust. Thank you for doing the work.

I thought the breakout groups were a great idea. There were a lot of feedback and networks! I like the handouts I can take them and read for later. This was a wonderful learning experience especially from a community level all the way to health care institutions. There were a lot of interesting ideas.

PAR design is highly congruent with topic. Although I've studied about some this was my first experience with being involved with PAR. Thanks. Opening/closing speaker (Casey Eaglespeaker (Elder) is inspiring.

Thank you for the opportunity to participate in the workshop. I believe that the education and knowledge I obtained can be utilized within my practice and allow me to increase the knowledge within my community.

The discussion in small groups, demonstrated the difficulty of identifying and focusing on feasible and specific interventions. (This is not intended as a criticism; it is meant as an observation on the difficulty of the task).

References

1. Patterson, M., Jackson, R., & Edwards, N. (2006). Ethics in Aboriginal research: Comments on paradigms, process and two worlds. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*, 1(Summer), 47-57.
2. CAAN (2004). *Final Report: The Community-Based HIV/AIDS Research Environmental Scan*, pp9. Ottawa: ON: CAAN.
3. Majumdar, B., Chambers, T., & Roberts, J. (2004) "Community-based, Culturally Sensitive HIV/AIDS Education for Aboriginal Adolescents: Implications for Nursing Practice." *Journal of Transcultural Nursing*, 15(1):69-73.
4. Smylie, J., Kaplan-Myrth, N., Tait, C., Martin, M., Chartrand, L., Hog, W., Tugwell, P., Valaskis, G., & Macauley, A. (2004) "Health Sciences Research and Aboriginal Communities: Pathway or Pitfall?" *Journal of Obstetrics and Gynecology Canada* 26 (3):211-216;
5. Fisher, Andrew & Foreit, James (2002) *Designing HIV/AIDS Intervention Studies: An Operations Research Handbook*, pp. 109-114. New York, NY.