



www.ohtn.on.ca

XVI International AIDS Conference, Toronto, Ontario, Canada

Daily update from the Ontario HIV Treatment Network:

August 15, 2006

CBR related topics of the day

1. [*Community matters: Engaging, mobilizing & sustaining community involvement in HIV vaccine & prevention research*](#)
2. [*Involving people with HIV/AIDS in the decisions which affect our lives*](#)
3. [*Innovation in support of community-based research as a tool in the fight against HIV/AIDS*](#)
4. [*Embodied knowledge: the unique contribution of people living with HIV/AIDS in HIV treatment knowledge building and decision-making*](#)
5. [*AIDS Education Programme \(AEP\)*](#)
6. [*"Beyond Tired of Driving That Far": Living with HIV/AIDS in Rural Canada*](#)
7. [*The results from the three-year evaluation of Vancouver's supervised injection facility*](#)
8. [*HIV Testing and Access to Care: The Experience of Canadian Aboriginal Youth*](#)
9. [*Assessing the vulnerability and impacts of HIV/AIDS on children - from the perspectives of children*](#)

1. Community matters: Engaging, mobilizing & sustaining community involvement in HIV vaccine & prevention research

Background

- In this small group satellite session, the AIDS Vaccine Advocacy Coalition (AVAC) presented information about how they seek to promote debate, dialogue and scenario planning that will help anticipate the issues that the next few years will bring for AIDS vaccine research. Their goal is to ensure that a wide range of stakeholders are informed and empowered to make decisions.
- In order to ensure a comprehensive approach to AIDS vaccine research, AVAC recognizes that community involvement is necessary for important information to reach beyond the boundaries of the scientific world.
- If AIDS vaccine research reaches community organizations then advocacy networks can be fostered between communities and researchers.
- As treatments and vaccine research knowledge become available, researchers often don't know how to get the information to communities; thus, there is a need to create knowledge about the ways in which researchers can effectively engage communities in their research processes.
- For effective networks and knowledge sharing to happen, there is a need to teach the community about science and to teach science about the community

CBR Highlights

- In order to help get AIDS vaccine research knowledge into the hands of community organizations it has created an AIDS Vaccine Clearinghouse (see link below) that provides an index of existing knowledge about vaccine research and email updates about new findings as they become available.
- The satellite session primarily discussed options for how AVAC can enhance their clearinghouse in a way that will more effectively foster advocacy by getting AIDS vaccine research into the hands of communities. Notable topics discussed were:
 - Providing information about what research is currently happening and not just what is completed.
 - Provide ideas for how to become an AIDS vaccine advocate.
 - How to get communities involved from beginning to end in AIDS vaccine research.

- Provide summaries of research (e.g., executive summaries of the larger ideas presented in the larger report).
 - Create a method of evaluating the amount of community involvement in research.
 - Researchers need models for how to translate research into a format that will be useful for community organizations.
- It was identified that there is a need to get publications into high impact journals such as the British Medical Journal and the Lancet that discuss the value of involving communities in the research process.
 - AVAC welcomes (see contact information below) input from communities and/or advocates for how to improve their clearinghouse and how to more effectively engage community organizations in AIDS vaccine research.

Contact Information

Email: avac@avac.org

www.avac.org

www.aidsvaccineclearinghouse.org

2. Involving people with HIV/AIDS in the decisions which affect our lives

Authors:

Stephen Alexander, Canadian AIDS Society, Ottawa, Ontario

Murray Jose, Toronto People with AIDS Foundation, Toronto, Ontario

Background

- The Greater Involvement of People Living with HIV/AIDS (GIPA) principle affects all aspects of HIV work including event coordination. The GIPA Principles emerged out of the 1994 Paris AIDS Summit and has been supported by UNGASS 2001 and 2006 policy documents. GIPA is about self-empowerment and self-help and has a policy-related foci.
- However, despite widespread attempts to operationalize and implement GIPA, there is a lack of evidence about the impact of the GIPA principles.
- Despite the lack of evidence about the impact of the GIPA principles, there are numerous barriers that have been identified for the implementation of GIPA including
 - stigma
 - discrimination, and
 - issues related to disclosure and confidentiality.

- In addition, there has been a lack of concerted effort to build new leadership among PHAs so that they are better equipped to interact with caregivers and policymakers.
- Finally, some speak about tensions between social movements and institutional structures where PHAs who are recruited into organizations risk being tokenized or co-opted.

CBR Highlights

- Three organizations – the Public Health Agency of Canada, the Toronto People with AIDS Foundation, and the Canadian AIDS Society presented strategies for including people living with HIV/AIDS in event planning. The events were diverse and included skills building initiatives, fundraisers, and workshops and symposia.
- They spoke of the need to provide tools and infrastructure (such as scholarships and training) to ensure that PHAs are ‘at the table’ in the planning of various initiatives.
- Other outcomes included a reduction in isolation for people living with HIV/AIDS and a tendency to build local networks and capacities that encourage PHA involvement in local organizations.
- Other challenges were noted as a means of sharing lessons learned with those present. These included:
 - o Having PHAs at the table as early as possible;
 - o Recruiting for the right reasons – i.e., moving beyond tokenism and seeking out necessary skill sets;
 - o The need to strive for consensus while moving decisions forward;
 - o Issues associated with having drug users and government representatives at the table at the same time.

Pearl of Wisdom – “The more we build skills in PHAs, the more they will enhance the relevance and strength and value of all initiatives... including this conference for both PHAs.”

3. Innovation in support of community-based research as a tool in the fight against HIV/AIDS

Cleverly, S., Bailey, M., Bayzand, L., Diallo, D., Ibanez-Carrasco, F., Kinasevysch, B., Masching, R., Migliardi, P., Ticknor, J.

Background

- The Canadian HIV/AIDS CBR Program: An innovative strategy in support of community-based research for community-based AIDS service organizations.
- As CBR gains popularity as a tool to support community and policy development, the Canadian Institutes of Health Research created a program to facilitate CBR

in community-based AIDS organizations (CBAOs). The program provides assistance and advice to support research and capacity-building initiatives.

- The program situates facilitators for CBR in community organizations across regions of the country (two work specifically with Aboriginal communities).

CBR Highlights

- This program advances the CBR agenda in Canada by building the capacities of CBAOs to participate in equitable collaborations with academic researchers.
- To advance the CBR agenda, more work is required in academic and granting institutions. Policy work in support of CBR is particularly needed in these sectors.

Contact Information

Email: s.cleverly@sympatico.ca
www.ontarioaidsnetwork.ca

4. Embodied knowledge: the unique contribution of people living with HIV/AIDS in HIV treatment knowledge building and decision-making

Authors: Darien Taylor, Director, Treatment Information, Canadian AIDS Treatment Information Exchange & Tim Rogers, Director, Publication and Research, Canadian AIDS Treatment Information Exchange

Background

- Experience-based treatment knowledge is traditionally considered less important than evidence-based knowledge.
- Previous research has shown, however, that the creation of embodied knowledge, by translating biomedical information into experimental terms, is central to the learning strategies used by people living with HIV/AIDS (PHAs) for building treatment knowledge.
- The Canadian AIDS Treatment Information Exchange (CATIE) is a National organization mandated to provide accessible, accurate and up-to-date HIV treatment information. Important concepts and practices in CATIE's delivery of HIV treatment information that is both accessible and credible include:
 - the meaningful involvement of PHAs in guiding and delivering all of our programs and services
 - the use of multiple learning formats and media
 - the support of staff and volunteers development in adult learning methodologies

- the translation of our treatment information resources into a variety of languages

CBR Highlights

- CATIE offers approximately 20 Different HIV treatment information topics free of charge to PHAs, AIDS service providers and healthcare providers working in the HIV sector across Canada.
- CATIE produces The Positive Side Magazine, which is a Canadian national bilingual treatment information magazine for PHAs, involving extensive participation by PHAs as readers, writers and interview subjects.
- The Positive Youth Project www.livepositive.ca is a multi-phase research project conducted in collaboration among CATIE, The Hospital for Sick Children, Positive Youth Outreach and other youth serving agencies across Canada.
- www.livepositive.ca was created from informal research by Positive Youth Outreach (an organization run by and for HIV positive youth in Toronto) as it showed that youth prefer accessing information through web sites.

Contact Information

Email: info@catie.ca

www.catie.ca

5. AIDS Education Programme (AEP)

Poster presentation by: **Dr. Dusit Duangsa and Dr. Usa Duongsaa**, Faculty of Education, Chiangmai University, Thailand

Background

- AEP has been conducting AIDS related programming for the last 15 years within various Thai provinces.
- During 2001-2005 AEP coordinated the Project for Promoting Participatory Learning from Local Responses to HIV/AIDS (PPLLR). This project was a multi-sectoral, multi-disciplinary, multi-level and multi-site initiative designed to promote participatory learning, capacity building, community transfer of knowledge and lessons learned from action and experiences, and linkages between local community responses and policy work, advocacy and development.

CBR Highlights

- Over the past few years AEP has shifted project focus specifically to promoting learning, sharing, human capacity development and knowledge management in

response to HIV/AIDS issues affecting various Thai communities, which include women, children and migrant workers.

Contact Information

Dr. Dusit Duangsa, Programme Director; Dr. Usa Duongsaa, Programme Coordinator
AEP, Faculty of Education, Chiangmai University, Chiangmai 50202, Thailand
usaduongsaa@gmail.com

6. “Beyond Tired of Driving That Far”: Living with HIV/AIDS in Rural Canada

Poster presentation by **Tiffany Veinot, Roma Harris, Leslie Bella, Irving Rootman and Judith Krajnak**

Background

- Many challenges face rural Canadian communities including geographic isolation, lack of services, physician shortages and a necessity to travel for health care
- In Canada, lack of local access to specialist health care has been linked to relocation of PHAs from rural to urban areas.
- However, little else is known about the experiences of rural dwelling PHAs and their caregivers who live in rural regions of Canada.
- This community based research project aimed to increase collective knowledge of these experiences.
- The study took place in three rural regions of Canada (Ontario, British Columbia and Newfoundland). The poster presentation reported on the results of qualitative interviews with 16 PHAs and 14 friends/family members of PHAs from two rural counties in Ontario.

CBR Highlights

- The results of this study found that many rural-dwelling PHAs and their friends/family members face challenges regarding disclosure, and frequently are selective in sharing information about their experiences with others.
- The presence of *out* PHAs and family members in a rural community appears to facilitate local response to the issue.
- Rural-dwelling PHAs and their friends/family have unique experiences due to geographic isolation, densely knit local communities, values-based stigma and limited local services.

Contact Information

Tiffany Veinot, PhD Candidate and Rural HIV/AIDS Information Networks Study Coordinator, Faculty and Information and Media Studies, University of Western Ontario
tveinot@uwo.ca

7. The results from the three-year evaluation of Vancouver's supervised injection facility

Authors: **T. Kerr, M. Tyndall, W. Small, C. Lai, K. Li, J. Montaner, E. Wood.**
BC Centre for Excellence in HIV/AIDS, Vancouver Canada

Background

- In September 2003, North America's first safer injection facility (SIF) opened in Vancouver, Canada
- A three-year scientific evaluation was conducted to assess evidence of positive health and community benefits and evidence of adverse health and community impacts. All findings were subjected to scientific peer review.
- The evaluation methodology consisted of: a comprehensive database located at the SIF, a randomly selected prospective cohort of 1046 SIF users, a pre-existing external community-recruited control cohort of injection drug users, and extensive data linkages.
- SIF supports approximately 600 injections per day, serves 6500 individuals, and conducts over 1,000 service referrals daily.
- The SIF staffs injection drug users as peer counsellors and views the involvement of community members as crucial to the success of the facility.

CBR Highlights

- Community benefit (1): the impact of the SIF was found to be only beneficial to the community by: reaching high-risk injection drug users, reducing HIV risk behaviour, increasing use of detox & community services, decreasing public injections, reducing needle sharing, reducing bacterial infections, decreasing crime, public disorder, drug dealing and relapse rates.
- Community benefit (2): At the presentation, The Honourable Libby Davis (Canadian Member of Parliament representing the downtown east side in Vancouver where the SIF is located) commented that when the SIF was proposed for development there was a lot of controversy and division in the community, but that since it has opened the broader community has witnessed tangible benefits (including stabilization of users and the neighbourhood) and now fully supports the SIF.

- Community and policy relevance: activists and supporters of the SIF have used the results of the evaluation to advocate to the federal government to extend an exemption in federal drug laws that have allowed for the existence of the facility (the exemption expires on Sept. 12, 2006 and the facility will be shut down if the newly elected Conservative government does not extend the exemption).

Contact: Thomas Kerr, PhD

BC Centre for Excellence in HIV/AIDS: <http://www.cfenet.ubc.ca/> site SIF: www.communityinsite.ca/

8. HIV Testing and Access to Care: The Experience of Canadian Aboriginal Youth

Authors: **C.P. Archibald, T. Prentice, J. Mill, R. Jackson, C. Worthington, T. Wong, S. Sommerfeldt, T. Myers**

Background:

- The Canadian Aboriginal population is over-represented in Canada's HIV epidemic (the infection rate of among Aboriginal persons in 2005 was about 2.8 times higher than among non-Aboriginal persons and the proportion of new HIV infections due to injection drug use was 53% among Aboriginal persons and 14% among all Canadians).
- Approximately 2/3 of the Aboriginal population is under the age of 30.
- Many Aboriginal people face significant barriers to accessing HIV testing and care due to the remoteness of communities, confidentiality concerns and feelings of discomfort accessing mainstream health services.
- An exploratory, community-based research design was used to conduct a study that: describes testing behaviour, explores self-reported stage of disease at the time of HIV diagnosis; evaluates access to care.
- Methods included: a self-administered questionnaire with a purposive sample of 413 youth (aged 15 - 30 years old) and an in-depth, open-ended interview with 28 youth (a few youth participated in both).
- Participants were recruited through agencies from across Canada that provide services for Aboriginal persons living off reserve, including Aboriginal and non-Aboriginal AIDS service organizations, health centres, community organizations and friendship centres.

CBR Highlights:

- Community involvement: the study had significant community involvement and support and was guided by the principles of Ownership, Control, Access and

Possession (OCAP – see here for more.... <http://www.cihr-irsc.gc.ca/e/9188.html>) of research information by Aboriginal communities themselves.

- Community and policy relevance: youth made specific recommendations on how to improve access to and use of HIV testing and care services including street outreach and non-judgmental post-test counseling.

Contact

Public Health Agency of Canada: http://www.phac-aspc.gc.ca/new_e.html

Centre for Infectious Disease Prevention and Control:

<http://www.phac-aspc.gc.ca/cidpc-cpcm/>

9. Assessing the vulnerability and impacts of HIV/AIDS on children - from the perspectives of children

Author: Elaine Ireland

Save the Children, South-East and East Asia Regional Office,
Bangkok, Thailand

Background

- HIV/AIDS interventions in South-East and East Asia are well established in many countries. However children continue to be inadequately considered in HIV/AIDS responses across the region. As a result, Save the Children decided in 2005 to conduct a multi-country participatory action research study to gain a better understanding of the scale of risks and problems faced by children affected by HIV/AIDS.
- The primary aim of this research study was to understand the situation of children in relation to HIV/AIDS from their own perspectives. 2256 people participated in the research, over 70% of whom were children under the age of 18. In selected sites children were the researchers and research assistants. Participatory methodologies including interviews, focus group discussions and children's workshops were used to both gather relevant data and share information on HIV/AIDS.

CBR Highlights

- One of the unique aspects of this research project was the emphasis given to obtaining information on HIV/AIDS risks, impacts and responses from children themselves.
- The countries under investigation were chosen to highlight how responses for children need to adapt to the relevant HIV context.
- Two principle approaches were used to conduct this research and ensure the greatest availability of information from children as possible. In Cambodia and

China fully child-led research was conducted. In the remaining countries also studied, children remained the primary respondent group but the research was conducted by adults using child-friendly data collection techniques.

- In the case of Cambodia, the child-researchers also produced their own report entitled: "This is my Real Story"
- The most important foundation of both approaches used, however, is the participation of children. A range of methods were used to engage the children in the manner both age and culturally appropriate, also considered literacy levels. These methods included visual techniques such as mapping and drawing, verbal techniques (storytelling and role-plays), writing (especially for literate children who may be shy), and semi-structured and unstructured interviews.

Contact:

Author: Elaine Ireland

Save the Children, South-East and East Asia Regional Office,
Bangkok, Thailand