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## Daily CBR Update from AIDS 2006

August 14, 2006

CBR related topics of the day

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## 1. Community-based social research: Using evidence to build reflective practice

Presented at: *MSM & HIV: Advancing a Global Agenda for Gay Men and Other Men Who Have Sex with Men*, pre-conference satellite, Friday, August 11, 2006

Authors: **Gary W Dowsett, PhD**

Professor, Deputy Director & VicHealth Senior Research Fellow  
Australian Research Centre in Sex, Health & Society  
La Trobe University, Melbourne, Australia

### **Background**

- Emphasis placed on the fact that *social research* as a tool is continuing to have a major contribution to HIV/AIDS, and that it is **multi-disciplinary** (e.g. sociology, psychology, anthropology, history, political science, social epidemiology etc.) and employs multiple research methods (e.g., surveys and in-depth interviews).
- Highlighted the fact that researchers have particular skills such as:
  - o Experience in running research programs and funding processes
  - o Expertise in a specialty field as well as in using & developing research techniques
  - o Skills in analysis, interpretation and drawing conclusions
  - o A range of dissemination practices (not always the best way to do this)
- Major themes of the sessions included discussions about what an **evidence-base** is, **types of research** that can be used, what **community-based research** can do, the different **levels of research relationships** and the **limitations of community-based research (CBR)**.

### **CBR Highlights**

- An evidence-base is the **accumulation of knowledge** from research and it can help get as accurate a picture as possible of **what happened or is happening** and can subsequently be used to **convince funders** that we are doing our job and achieving **expected outcomes**, or to note that a new task/issue needs to be tackled.
- **Community-based research** involves both researchers and community-based practitioner/providers working in collaboration and ensures that research is done **WITH** and not just **ON** communities. CBR is a useful approach for many activities including pre-program implementation analyses (e.g. needs analysis and formative evaluation), concurrent program evaluation and post-program evaluation. However, CBR is often ignored for more conventional ways of research.
- The **levels of research relationships** include **consultation** (e.g. advisory committees), **cooperation** (e.g. recruitment of respondents) and **collaboration** (e.g., helping design the research)
- **Limitations of CBR** identified were; issues of whether communities are actually involved or just the agencies and workers; communities and researchers often work under different conditions, pressures, required outcomes and responsibilities to funders; some research

methods don't work well in community settings; some researchers do not possess the skills necessary to work with communities; and many funding agencies won't fund CBR.

## 2. Ensuring knowledge-transfer and exchange through a multi-stakeholder community-based research project

Authors: **Murray J, Adam B, Husbands W & Maxwell J**

### **Background**

- The importance of knowledge transfer and exchange between researchers, the HIV service community and HIV policy makers has been long recognized. Yet, it remains a challenge to ensure that research informs practice and policy and vice versa. A meaningful multi-stakeholder collaborative research project provides a model for which knowledge-transfer and exchange becomes inherent.
- The AIDS Committee of Toronto, a social researcher at the University of Windsor and the AIDS Bureau, Ontario Ministry of Health and Long-Term Care, are collaborating on a community-based research project examining the risk-taking discourses of gay and bisexual men in Toronto.
- Prevention educators, university-based researchers and government policy makers were engaged in the decision-making process throughout all stages of the project.
- The nature of the collaboration in this project fosters the identification of the unique needs and vulnerabilities of local populations and thereby the development of innovative and responsive HIV prevention programming.

### **CBR Highlights**

- **Lessons learned:** A multi-stakeholder collaboration in research provides a model by which knowledge-transfer and exchange between program planners, policy makers and researchers is inherent. The particular needs of researchers, community organizations and policy makers can be satisfied through a collaborative process where decision-making is shared throughout.
- **Recommendations:** Researchers consider the value of establishing partnerships with key stakeholders in the response to HIV in their communities and that these partnerships be meaningful, with all stakeholders engaged in the decision-making process from the outset of the project.

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### 3. Making Research Work for Community-Based Organizations in Ontario: Strategies for Linking Research to Action

Authors: Sean B. Rourke, Robb Travers, Michael G. Wilson, John N. Lavis, Jean Bacon, Tarik Bereket, Shelley Cleverly, Evan Collins, Rick Kennedy, Ed McDonnell, Peggy Millson, Ron Rosenes & Ruthann Tucker

#### **Background**

- Community-based AIDS organizations (CBAOs) face increasing pressure to use **research evidence** in their **decision-making, service delivery and program planning**.
- Consequently, there is a need to establish an **evidence-informed knowledge transfer (KT) strategy** for Ontario CBAOs that supports their service delivery and programming.
- 25 CBAOs in Ontario participated in 3 focus groups and filled out the *Is Research Working for You?* survey that was developed by the Canadian Health Services Research Foundation ([www.chsrf.ca](http://www.chsrf.ca)) and adapted for use in the HIV sector.

#### **CBR Highlights**

- The **major outcome** of the project will be a **comprehensive knowledge transfer strategy** for community-based organizations in Ontario that is **based on the recommendations and information that the community organizations provided** in the focus groups and the survey.
- The survey indicated that the capacity of CBAOs in Ontario to acquire, assess, adapt and apply research in their organizations was low.
- The information from the focus groups indicated that CBAOs would like to use research in their decision-making, service delivery and program planning but suggestions for how to best form a knowledge transfer strategy were diverse.
- Based on the suggestions from the focus groups, the Ontario HIV Treatment Network is planning on pursuing a multifaceted knowledge transfer strategy that focuses on 4 initiatives; 1. knowledge transfer and exchange (i.e. facilitating partnerships between community organizations and academic researchers); 2. capacity-building (e.g., creating toolkits and running workshops); 3. identifying actionable messages from research (e.g., newsletters and rapid response services for research questions); and 4. knowledge mobilization (e.g., think tanks or funding targeted systematic reviews).

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#### **4. Assessing community involvement in HIV prevention research: Process, results, and application of findings**

Authors: S. Morfit, J. Stanton, W. Wilson, S. Kirkendale, J. Frohilich & S. Morin  
University of California, San Francisco; Family Health International

##### **Background**

- Community involvement in HIV prevention research is becoming increasingly common, however, evaluation of such partnerships has been limited.
- Monitoring and evaluation are essential for strengthening community involvement in research and identifying challenges to collaboration.
- The aim of the project was to design and implement a survey assessing community participation in the HIV Prevention Trials Network (HPTN) (a collaborative network of 26 international research sites that evaluate the safety and efficacy of non-vaccine HIV prevention interventions.
- HPTN has a policy to promote community involvement in HIV prevention research with community typically being represented by Community Advisory Boards (CAB) and other consultative structures.

##### **CBR Highlights**

- A Community Indicators Committee was formed and they collaborated to produce a 31-item questionnaire that assessed community participation in six domains; CAB function, CAB process, research team involvement, research design and process, ethical issues and outcomes.
- The survey was completed by research staff and CAB members through one of two means: individual responses or consensus method (CAB/research staff collectively read, discussed the questions, and responded to the questions with answers agreed upon by the group.
- Overall, the results are supportive of community participation, with all mean scores above 75% in the direction of greater community partnership.

**5. Action research to improve mental health service access for immigrants and refugees living with HIV/AIDS: A progressive example of applying the GIPA principles in community based research**

Authors: Y.Y. Chen, Alan Li, Josephine Wong, Kenneth Fung, Fanta Ongoiba, Lena Soje, Noulmook Sutdhibhasilp, Seema Opal, Consuelo Llanos  
Committee for Accessible AIDS Treatment, Toronto, Canada

**Background**

- GIPA principles embody the ideal of engaging people with HIV/AIDS (PHAs) in all aspects of the responses to the HIV epidemic. However, the principle does not set out how the vision of greater PHA involvement might be achieved. (more on GIPA here....  
[http://www.unaids.org/bangkok2004/GAR2004\\_html/GAR2004\\_13\\_en.htm](http://www.unaids.org/bangkok2004/GAR2004_html/GAR2004_13_en.htm) )
- The GIPA principles have been integrated into this community-based research project that aims to improve mental health service access for immigrants, refugees and non-status people living with HIV/AIDS (I&R-PHAs) in the Greater Toronto Area.
- The presentation demonstrates how the application of the GIPA principle not only strengthens HIV research but also can open an opportunity for PHAs involvement in higher-level program planning and policy development.

**CBR Highlights**

- The emergence of community-based research (CBR) in recent years offers PHAs an opportunity to move from the margin to the centre of the research discourse. CBR seeks to engage community members and their representatives in every aspect of the research process. With a common vision, the CBR paradigm represents a logical starting point for the integration of GIPA into the realm of HIV research.
- However, the application of GIPA in community-based HIV research is not without its barriers. Some significant barriers to applying GIPA in community-based HIV research are:
  - There are currently no accountability measures in place to make sure that CBR researchers engage community members in their studies in a meaningful way, which could result in CBR projects being developed and funded with PHAs and the affected communities being treated merely as tokens. The actual control of the research in these instances still remains in the hands of academic researchers.
  - The existing funding structure often does not take into account the time and resources needed in CBR projects to develop equitable research partnerships and to train and continually support community members on the research team.
- Through the channel of community-based action research, PHAs may find a rare opportunity to influence or even set the agenda for the mainstream discourse on HIV/AIDS. To further facilitate the merge between GIPA and CBR, the authors strongly urge these recommendations be promptly adopted by decision makers:

- Research funders need to restructure the review criteria for CBR projects so that the researchers' experiences and relationship with the target community are given due consideration while less emphasis is placed on researchers' credentials and publication records in peer-reviewed journals.
- PHAs need to be meaningfully involved in all aspects of a research study that has potential impact on their lives.
- Funding agencies need to support CBR projects with multi-year resources to allow meaningful and equitable engagement of the affected communities in the research process.

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**6. The Innovative Women's Health Engagement Tour**

**Background**

- The Engagement tours were organized as part of the International AIDS Conference's Community Outreach Initiative. They are designed to showcase model community-based HIV/AIDS initiatives in Toronto to conference participants.
- The Innovative Women's Health Engagement Tour included three different community based initiatives that are working to meet the needs of different groups of women who are marginalized within the health care system; including immigrant and refugee women, homeless women, and women living in poverty.

**CBR Highlights**

- Two of the organizations- Women's Health in Women's Hands (WHIWH) and Voices of Positive Women (VOPW) provide services, engage in research and advocate for women's health and rights within a feminist, anti-oppression and anti-racist framework.
- WHIWH is Toronto's only community health centre that specifically works with Black women and women of colour from Africa, Asia and Latin America providing culturally and linguistically appropriate services to women regardless of their citizenship status and geographic location in Ontario.
- Recognizing a gap in research specifically focused on the realities of women of colour living in Ontario, WHIWH has engaged in community-based research as a core area of its programming for over a decade. Historically, much of the research on women of colour - particularly Black women's health issues - in Canada has been drawn from research conducted in the United States which does not adequately represent the social, political and cultural realities of Black women living in Canada.
- Most communities of colour living in Toronto are young communities, having immigrated to Canada within the past 40 years. One of the recent research publications conducted by

WHIWH's is "Silent Voices of the HIV/AIDS Epidemic: African and Caribbean Women in Toronto: 2002-2004" which can be accessed online at the link below.

**Contact Information**

Voices of Positive Women [www.vopw.org](http://www.vopw.org)

Women's Health in Women's Hands [www.whiwh.com](http://www.whiwh.com)