CBR: Luxury or Necessity?

An Environmental Scan of the British Columbia Community Based Research Capacity Building Needs, Capacities and Challenges

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Introduction & Acknowledgments

An environmental scan serves to guide community and institutional leaders' attention to potentially significant (as well as unexpected) external developments in their early stages. The earlier the warning, the more lead time there is to foresee the implications of those developments. This document is the report of an environmental scan on community-based research capacity building that was conducted in British Columbia between September 2003 and March 2004. The focus of the scan is to assess the capacity of community-based organizations to engage successfully in community-based research and evaluation initiatives.

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This environmental scan is one of the first steps in setting up a community-based research capacity building program in the province of British Columbia. The general purpose of the program is to provide training education, technical support, partnership facilitation, and promote evidence-based decisions for organizations that work with HIV/AIDS (and by 'natural' extension HCV given the current prevalence of dual diagnosis).

This report begins by offering definitions of 'community-based research' (CBR) and 'capacity building' in the geographical, organizational and human resources context in which they occur; this is followed by a brief description of the methodology, activities, timelines and population of the CBR environmental scan. The subsequent section presents the findings of the environmental scan and their interpretation. The report closes with recommendations for CBR capacity building, implementation of programs, training workshops, communication and coordination.

Much gratitude is extended to those persons from various organizations that contributed their time, energy, experience and expertise to knowledge gathered in this document. A special thanks to Sarah Rohde for her invaluable research work as volunteer of the CBR Program at BCPWA and to Lynette Sigola for her thorough and thoughtful reading and feedback. Lola Brown dedicated many hours of volunteer work to complete this final iteration of the Scan and the support at the second annual meeting of the Advisory Committee.

What is community-based research?

Community-based research is “a philosophy for inquiry and not a discreet research framework” (Allman et al. 1997: 21), it is a “river where the tributaries from feminist, Marxist, queer and environmentalist thought feed into one stream”. Action research, participatory research, and emancipatory research – the ‘decolonizing methodologies’ (Tuhiwai-Smith, 1999) and the ‘methodologies of the oppressed’ (Sandoval, 2000) – are often used within this type of research.

> ***In CBR one does not only learn about method, analysis, and reporting, but one also* unlearns *old ways of conceiving and carrying out research.***

Most CBR includes a commitment to learn, a form of collaborative popular education – sometimes described as ‘transfer of knowledge’ and ‘capacity building’ – in which all the participants systematically learn about their environment, accrue and examine what can constitute evidence, and re-present it by/for themselves and for others. In CBR one does not only learn about method, analysis, and reporting, but one also *unlearns* old ways of conceiving and carrying out research. CBR is also an area where political and personal motivations and spheres of influence intersect to approach the world inductively or deductively and advance, replicate, corroborate, debunk, or simply *indulge* (why not?) new and old knowledges” (Ibáñez-Carrasco, 2004: 36-37).

What is capacity building?

Capacity building entails developing the potential of an organization to engage with research and evaluation activities. This potential can encompass skills as well as motivations and attitudes towards research. Capacity building entails both the critical reflection and the animation of experience and expertise, in short, a *praxis*. The categories of “experience” and “expertise” encompass elements that are often included in the CBR approach to science.[i] In this environmental scan, the category ‘experience’ has been included to report on the assessment of individual and organizational participation in various types of research and in particular in community-based research, be this participation peripheral or direct.

“Experience” is also included to report on how staff and volunteers within community-based organizations may think it is worthwhile or not to participate in research (valuing). The category “expertise” refers to the technical know-how and the practices of individuals in organizations in relation to research

and evaluation (in some cases referred to as ‘best practices’). The category ‘expectations’ was created to gather a series of ideas regarding what research is and ought to do for people expressed by individuals in organizations, and finally, the category ‘needs’ groups technical aspects that must be developed to set the groundwork for CBR beyond the endemic need for funding.

A range of non-profit and private sector classifications of capacity building were consulted to offer a definition that is applicable to the provincial context of B.C. and the CBR capacity building program.[ii] This brief scan of some of the available literature in the area informed the following working definition:

Capacity building is the interrelation of some foundational elements

- Organizational infrastructure
- Human resources
- Communications
- Community ethics

in an active approach to the acquisition of relevant

- Experience (akin to cumulative individual attitudes) and self-reflection
- Expertise (akin to cumulative individual skills and practices)

for developing

- Dialogue
- Leadership
- Values
- Strategy
- Excellence in knowledge and practice
- Sustainability

and meeting

- Community standards
- Needs
- Equity

Context of the environmental scan

Geographic and epidemiological

The province of British Columbia is vast and sparsely inhabited by small pockets of population scattered over the region. This makes the general work of health care difficult to carry out. Over two thirds of B.C.'s population of approximately 4,146,580 inhabitants (as estimated in the 2003 census) live in the Lower Mainland and south Vancouver Island (where Victoria is located). The province is losing population in northern, resource-based rural communities. The BC Centre for Disease Control reports that in 2002, 404 British Columbians tested positive for HIV. 37% were known to be gay or bisexual men, 33.7% were known to be injection drug users, and 19.7% were women. 19.7% of new infections were attributed to heterosexual sex. HIV prevalence and incidence rates are greater in the Lower Mainland where most of the population of B.C. lives (an estimated rate of 10.4 cases per 100,000 population).

Large urban centres, given the visibility of the epidemic, are magnets for researchers, research interests and funds. This steals attention to the issues faced by AIDS Service Organizations (ASOs) in rural and remote areas.

Most of the persons living with HIV/AIDS are aged 25 to 60+ with the highest concentration in the 30 to 59 years old segment of the population. Existing CBR findings tell us that the infection rates for women show a rapid increase in the last five years and that unprotected sex amongst gay men is still a concern.[iii] [iv] The epidemiological impact of these figures is magnified when examined concurrently with sexually transmitted diseases in the province. Of particular relevance to this report is that these estimated figures might play a significant factor in the allocation and deployment of research efforts in the province. The most affected communities have a great need to implement HIV related research and evaluation. Large urban centres, for example, given the visibility of the epidemic are likely to act as magnets for researchers, research interests and funds (particularly academic, clinical and epidemiological research). This may steal attention to the issues faced by small Community-Based Organizations (CBOs) and AIDS Service Organizations (ASOs) in rural and remote areas.

Although there is great personal and professional commitment amongst the workers in this field, low salaries and other conditions may contribute to a professional "brain drain" and a reluctance to engage in what are perceived as onerous and time consuming tasks (such as research and evaluation).

Work conditions

Working in the HIV/AIDS community-based field is to work in an environment of scarcity where ethical principles are greatly valued but the dedicated labour of realizing them in policy and program is grossly underpaid.[v] Although there is great personal and professional commitment amongst the workers in this field, low salaries and other conditions may contribute to a professional "brain drain" and a reluctance to engage in what are perceived as onerous and time consuming tasks (such as research and evaluation). Indeed, various versions of a "research as luxury" theme echo throughout this report.

A 2003 report on job quality in non-profit organizations shows that for a number of professionals in this area, work in an ASO may be a steppingstone to other and more gainful employment.[vi] These became significant considerations when placing community-based research capacity building in context. Professional mobility emerged as a challenge to the sustainability of the research and evaluation capacities acquired in an organization. Those who acquire an understanding of CBR principles and a set of skills are likely to move to higher paid positions in other agencies taking with them their expertise and experience. This poses a challenge (often undetected) of having to stimulate organizational change so capacities stay in an organization even when individuals move between areas of employment or/and interest.[vii]

Role of ASOs as Non Profits

The role of ASOs, and peer-driven AIDS organizations, as part of the voluntary sector in Canada deserves a mention here because it provides further clues for establishing a context in which to explore the issues related to CBR. A clarification of the role that Non-Governmental Organizations (NGOs) play in civil society is a starting point to elucidate the current expectation that CBOs ought to engage in research and evaluation. As stated in Ed Broadbent's landmark "Building On Strength" report, voluntary organizations continue the work of public services and help by "stitching a torn social safety next, educating and caring, responding with compassion and resources to disasters, large and small, environmental and individual, at home and abroad".[viii] There is an implicit expectation that CBOs are set up to perform some kind of 'social triage'.

Indeed, several similarities between the "remedial" quality of CBR and adult education emerged from the environmental scan and, in particular, from the experience of CBR researchers in the HIV/AIDS field. These similarities with adult education are further discussed in the "findings" section of this report. "Building on Strength" adds that the non-profit sector is central to "how our democracy works" because expertise is gathered in it and priorities in specific fields are set. In addition, CBOs "bear public witness" to the government "even if that means being critical of government policy on occasion". This role is magnified in the specific case of peer-driven organizations because it is perceived that governmental actions have a direct impact on participants' lives (e.g. BC Persons With AIDS Society).

It can be reasonably expected then that CBR, by virtue of its attempt to stay closer to the needs of the community, might take on some of these functions and uphold such values: responding to emergencies, educating, engaging citizens with each other and with governments, and bearing witness to the work of governments in a critical manner within a social scientific framework. We know from existing CBR findings that non profit organizations may function as health sentinels, de facto first contact points where epidemiological and clinical trends can be identified.[ix]

Methodology

> "If we are not to be naïve in hoping to bring about dialogue between researchers and communities we should not assume that the community is empowered to participate in a dialogue at the outset of the process" Kelly & van der Riet. Participatory research in community settings. 2000.

Instruments

Survey

To jumpstart the environmental scan, a survey was created and disseminated in provincial gatherings and via e-mail. The uptake of the survey was negligible (n=5 out of a total of 60 distributed to contact persons in regional offices) possibly due to lack of time but most likely due to lack of knowledge of the new provincial CBR program. However, it became a useful expository tool to introduce CBR related concepts. As seen in Appendix A, each survey item introduces one general question designed to tackle a particular area followed by a series of potential responses. The survey was created in October 2003 and sent to several local community-based researchers and frontline workers to obtain feedback on its wording and comprehensiveness.

Research methods elicit learning: Through the Environmental Scan methodology, participants reported finding knowledge they had not reflected upon.

Even though the survey uptake was disappointing, this multiple selection response tool could be used as an educational tool in subsequent interviews. This qualitative strategy encouraged respondents to find their way through a theme (e.g. expectations regarding research) without being put in the awkward position of having to guess an answer. Interviewees' answers tended to be specific as potential responses provided in the survey items covered more global aspects. Participants reported having found angles they had not had the chance to reflect upon or they had not yet conceptualized in such manner. If they disagreed or formulated a different conceptualization, they were still able to pursue that particular line of response.

Interviews

The BC environmental scan consisted of twenty-two in-depth qualitative interviews following the interview schedule set in the CBR survey. Ten of these interviews were conducted in person and the remainder took place over the phone. Some of the interviews required follow up conversations. Following a purposive sampling approach, key informants were chosen amongst the contact names included in existing BCPWA provincial lists of partners in service

and according to their connection with community-based research or with the administration of an organization. In a handful of cases, the interviewees requested the interview transcripts to be returned to them to verify that their remarks had been correctly recorded.

Site visits and case studies

Case studies are designed to "bring out the details from the viewpoint of the participants by using multiple sources of data", what has been known as a "triangulated research strategy".[x] The Research Technical Assistant (RTA) approached three organizations to conduct site visits and in-depth interviews with members, staff and volunteers and members of Board of Directors. These organizations belong to three specific regions within the province: Positive Living North (the Interior region), Positive Living Resource Centre (the Okanagan region) and BCPWA (the Lower Mainland). A "Research Agreement" was drafted and sent to a signing authority of the organization (often the Executive Director and/or the Chair of the Board of Directors).

As individuals within organizations gain knowledge of the CBR RTA program they become enthusiastic about starting research work or getting support with the work they are already doing.

Participant observation

In the course of getting involved in research ventures with provincial organizations a great deal of data was collected. As the individuals within organizations gained knowledge of the CBR RTA program they became enthusiastic about starting some kind of research work or getting support with the work they were already doing. The data collected through interviews was triangulated with the notes taken while embarking on various research phases with local ASOs. Also, attending local and international meetings on community-based research helped to refine the issues that emerged from the field in the course of the environmental scan through discussions with other researchers and RTAs.

In an iterative process of self-reflection, it was possible to present and discuss some of the preliminary findings of this environmental scan to other RTAs, to other researchers in the field and to the participants of various conferences (2003 OHTN, 2004 CAHR, Collaborative Research in Health Research in Portland, June 28-30 2004, and 2004 International AIDS Conference in Bangkok).

Social marketing and popular education

A general explanation of the distinction between conventional research and community-based research was always in order before posing the questions of the scan. This was one of the several clarifications that preceded each interview. There is no clear demarcation of where the necessary social marketing (the 'buy-in') and the popular education begins (the empowerment) to generate trust and interest in CBR amongst the participant organizations (including interest in this environmental scan).

In British Columbia it is not the case that one person can show up at an ASO and ask casually: how do you engage in community-based research? Both parties are likely to be referring to different things (e.g. often research instruments versus a philosophy of engaging in research). An important component of this environmental scan — not uncommon to most research that attempts to involve communities — was that of social marketing to support efforts to give a clear definition of CBR and the "services" that may be available from a capacity building community-based research program. These important explanations needed to be given before asking any members of organizations questions.

The Scan had a social marketing component to promote the "services" of the capacity building community-based research program

The modest social marketing campaign included submitting brief magazine articles to Living Positive magazine, public presentations (e.g. the bi-annual Pacific AIDS Network that gathers a great number of BC ASO representatives), participation in steering committees, and time spent in developing professional liaisons with individual staff, volunteers, and board members. To provide a proper context for the specific questions about CBR, it was necessary to give the potential respondents an introduction to the CBR program in BC, its relationship with Health Canada, a brief chronology of how it came to be, its current mandate and relocation to the Canadian Institutes for Health Research (CIHR), and the role of the RTA. ASOs' staff are often interested in these details and it is likely that such explanations validate the project in their eyes, at least initially.

Participants by regions and sphere of influence

The list of ASOs gathered for this research had sixty-nine entries, most of them non-profit organizations of varied scales and mandates. In addition, there are a number of organizations that work with HIV/AIDS, that is to say, they may have one staff person or program that deals directly with HIV education or indirectly through health or sexual health programs (e.g. Planned Parenthood, Boys & Girls Clubs, etc.). A small number of these organizations have some capacity to sustain any interest in undertaking any kind of research. Many of these organizations have contributed to HIV/AIDS research in various ways that are not integrated fully in the day-to-day or strategic planning of the organization.

University-based researchers may often see community-based research as a distinctive field and not as an approach to do what they already do in their fields of expertise.

A purposive sample was gathered to achieve wide representation of the provincial regions and stakeholders. First, the province was divided into four regions: Vancouver Island, Lower Mainland, the Interior and the Northern regions. ASOs were identified in these areas. Second, the key organizations that with work with AIDS were identified and third, key informants and organizations were approached at the heart of the selected organizations for in-person or phone interviews. Additionally, the environmental scan sampling took into consideration several "spheres of influence": ASOs and peer-driven agencies (this non-profit sphere included the freelance consultants often associated with these organizations), public health, and academic-based researchers sphere. CBR seems to take place at the intersection of these spheres and this gives it its interdisciplinary character.

It was difficult to reach academic-based researchers even when they had work that puts them in relation to various communities. They may often see community-based research as a distinctive territory and not as an approach that may radically alter what they do in their fields of action and/or expertise. However, the BC Environmental Scan acted as catalyst in some instances to galvanize the interest of academic-based researchers. Community-based researchers were reached through AIDS service organizations. Findings/insights regarding the demonstrated interest of researchers, ASO staff and other interviewees are offered throughout this report.

Vancouver Island region

- Group interview with volunteers, board members and staff members from AIDS Vancouver Island (AVI), Victoria Persons With AIDS Society (VPWAS) and Victoria Area Respite Society (VARCS).
- Individual interview with Men's Wellness Coordinator at AIDS Vancouver Island.

Lower Mainland region

- Individual interview with staff person at Positive Women's Network (PWN).
- Individual interviews with four staff persons at Healing Our Spirit.
- Individual interview with staff person at Gayway.
- Individual interview with staff person at AIDS Vancouver.
- Individual interviews with thee members of the Board of Directors of BC Persons With AIDS Society (BCPWA).
- Individual interview with staff person from the Community Based Research Centre (the organization that maintains the HIV CBR network web site).
- Individual interview and follow-up interview with staff persons at the Friends for Life Society.
- Individual interview with Women's Information Safe House (WISH).
- Individual interview with staff person from The Asian Society for the Intervention of AIDS (ASIA).
- Individual interview with Community Health and Safety Evaluation (CHASE) Downtown East Side project coordinator.

Interior region

- Individual phone interview with staff person from AIDS Prince Rupert,
- Teleconference interview with staff persons from Boys & Girls Club and Mental Health Society in Williams Lake involved in research on women in rural settings and violence as risk for HIV infection,
- Individual phone interview with C-Sharp staff person, Salmon Arm.
- Individual interview with staff person from the AIDS Society of Kamloops.
- Site visit to Living Positive Resource Centre (former AIDS Resource Centre). Interviews with two staff members and two volunteers.
- Individual interview with staff person from HIV/AIDS Awareness Program at Dze L K'an Friendship Centre – Smithers.
- Group teleconference interview with volunteers and staff members of ANKORS.

Northern region

- Individual telephone interview with staff person at Positive Living Northwest,
- Site visit to Living Positive North in Prince George (former AIDS Prince George), group and individual interviews with staff.
- Individual interview with staff member of the Cariboo AIDS Information in Williams Lake.

Findings and Interpretation

Opportunities for CBR in challenging times

Following and expanding on the items of the original CBR survey, the findings and interpretations contained in this section have been catalogued. A group analysis session (similar to a focus group) with three frontline workers and volunteers from various Lower Mainland ASOs and peer-driven organizations was held at YouthCo AIDS Society on April 13, 2004. In addition, there was a brief iterative process via e-mail between August 2004 and September 2004. The data collected through interviews, documentation scan and site visits was triangulated with fieldnotes gathered through participant observation. The environmental scan was presented to and feedback gathered as part of the 2004 BCBRAC Advisory Board meeting on October 2004.

Short-term CBR proposals are funded but there is no clear understanding of how to implement activities (and to obtain funding) to translate the knowledge resulting from these projects.

Findings: Three Case Studies

These three case studies intend to be representative of a cross-section of ASOs and their work on HIV and AIDS. Many of the findings in the overall environmental scan are echoed in the case studies.

Research grows in harsh climate: Case study of Living Positive Resource Centre, an ASO in Kelowna, B.C.

The Living Positive Resource Centre (LPRC, former AIDS Resource Centre ARC) is located in the downtown area of the burgeoning city of Kelowna. With a modest core funding, LPRC's mandate is to work to reduce the incidence of new HIV/Hepatitis and other blood borne pathogen infections and improve the quality of life for those infected and affected. LPRC is the largest ASO serving the Okanagan region (population 25,000, mostly English-speaking with a number of Aboriginal nations).

LPRC's client population is 85% homosexual; 54% of the clients identify drug use as a source of HIV/HCV infection. 65% percent of the clients are co-infected. The organization has about 200 registered clients of whom 50 actively receive services. Self-identification in the LPRC Assessment Form and Database are optional according to the new provincial Personal Information Protection Act therefore numbers are not exact. A number of clients are also volunteers who take a one-time training followed by an evaluation survey.

In a regional cultural environment that is conservative in mores and practices, the staff at LPRC are aware of a number of issues related to HIV/HEP C such as men who have sex with men who do not identify as bisexual or gay (MSM non-gay identified) and engage in both homosexual and heterosexual practices that may lead to HIV transmission. As recently as 2003 LPRC was turned down for funding to implement "transfer of knowledge" activities to take the "long but safer" road to accessing local MSM by working with local health providers around prejudice and other barriers to service provision. It is believed that attending to the needs of a population that wants/needs to remain unseen encourages key personal decisions (e.g. HIV disclosure as mandated by recently introduced Canadian HIV related legislation).

Organizations "live from project to project" due to targeted funding. Short-term CBR proposals are funded and completed but there is no clear understanding of how and/or opportunity to translate the knowledge gathered from these projects

One other HIV/HEP C related issue described by ASO workers in the environmental scan is that Kelowna is one stop in a "circuit" of drugs and prostitution (young, female and often Aboriginal). In a province that is losing population in northern, resource-based rural communities, there is a seasonal transient population that originates and ends in Vancouver traveling through several locations in the interior of the province (and maybe as far south as Seattle). In 2004, LPRC has been mandated to expand its services to the drug using population that may be in this circuit and the work of LPRC in the area of harm reduction has acquired a community development character in meetings with local health authorities, civic leaders, and other non-profit groups.

LPRC and other organizations say that they "live from project to project" due to targeted funding. The implications of short term funding for specific projects have not been evaluated. Reportedly, research efforts have encountered similar challenges: Short-term CBR proposals are funded but there is no clear understanding of how to implement activities (and to obtain funding) to translate the knowledge resulting from these projects.

In addition, LPRC's experience reaching out to the local university college for expertise is described as "discouraging". These challenges are confounded by a lack of human resources, funding and time to organize years of project related work into one cohesive picture. Notwithstanding, LPRC has implemented a variety of projects often with the help of external consultants.

In 1998, a needs assessment survey was designed and carried out by a local college student as part of her practicum to determine participants' needs and expectations of services. The subsequent final report was used to implement programming. In 2000, LPRC in

collaboration with a community youth group implemented a project called "Acts of Choices" aimed at preventing the spread of HIV and STDs amongst youth aged 15-25, particularly those *not* involved in the school system. Funded by the B.C. Gaming Policy and Enforcement Branch, the project yielded several 'products' such as workshops, a video, educational materials, and a report in the form of a guideline to creating similar programs.

HIV/AIDS infection rates are higher in marginalized and impoverished populations and the historical processes of colonization have placed the Aboriginal community at the heart of the emerging epidemic in this region.

In 2002, "The Person's Project" placed two outreach workers in the Kelowna streets for 15 evening hours a week in a 17 week period to do needle exchange and referrals. An outcome-based evaluation report was produced. In 2001, the LPRC administered a "Physician Questionnaire" and found out that local physicians were reluctant and/or unprepared to serve HIV-positive patients. In 2002, a small-scale survey of local pharmacists identified their reluctance to selling syringes to Hepatitis C infected clients. In 2002, ARC implemented a Hepatitis C Information Project Program of the Okanagan (HIPPO) as an educational and information program followed by a needs assessment survey.

Reinventing the research wheel: Case Study of Positive Living North. *No Kheyoh T'sih'en T'schena* in Prince George, BC.

The city of Prince George is located at the heart of BC's Northern Interior, a largely undeveloped, sparsely populated region dominated by the Rocky Mountains to the west and south and by the Interior Plain to the north and east. With a population of 72,000 inhabitants, Prince George is the largest urban centre in the region and functions as a service and supply centre for the numerous outlying communities. Prince George has recently emerged as an epicentre in the HIV/AIDS epidemic, particularly within the northern Aboriginal population. Though constituting only about 20% of the city's population Aboriginals accounted for 85% of newly diagnosed cases of HIV last year (2001 census/ Northern Health Authority).

The Fire Pit serves as an important link to street involved patrons and is run in an open and flexible format, maximizing community involvement and accessibility. New forms of evaluation and research are needed for novel enterprises.

Positive Living North (PLN, formerly known as AIDS Prince George) is a vibrant community- based organization operating out of Prince George that seeks to address this crisis within the northern community by providing care and support to those infected and affected and addressing the socio-economic and political roots of the epidemic through community education and cultural empowerment. Started by family members of persons living with HIV "around a kitchen table" in 1991, in 1992 it became incorporated and eventually secured funding from the Ministry of Health 1994 to provide volunteer coordination and some education in the community. HIV/AIDS infection rates are higher in marginalized and impoverished populations and the historical processes of colonization

impoverished populations and the historical processes of colonization and cultural dislocation have placed the Aboriginal community at the heart of the emerging epidemic in this region. In response to this emergency, PLN targets their services and programming to Aboriginal communities even risking criticism from peer organizations that they might be neglecting other members of their constituency. Currently, a full-time staff of 11 provides care, support and advocacy around a whole range of issues to a mainly Aboriginal clientele living with HIV/AIDS, their families and their communities. PLN works with approximately fifty clients, 30 volunteers and, in addition, its focus on Aboriginal and Northern issues attracts a number of University of Northern BC (UNBC) students. For example, the Department of Social Work at UNBC places practicum students with the organization in what has been a largely successful arrangement for all involved.

PLN has a unique approach to evaluation and assessment of its programs that includes journals to record their daily happenings, client stories, and day-to-day experiences of staff.

In an effort to mount a response to the epidemic that goes beyond immediate health care issues, PLN has long recognized that it must address the roots of the problem and has recently initiated an innovative new prevention program. Housed below the Native Health Centre in what was once a local nightclub, the Fire Pit is a "drop-in centre" that deals with health in a cultural context (e.g. health disparities are seen in a context of oppression and colonization of Aboriginal peoples). Part of the Primary Health Care strategy for the region, this project is in partnership with the Central Interior Native Health Society (CINHS) and the Native Health Centre for which it receives funding from Northern Health, Health Canada and HRDC.

PLN staff designs and implements research with the support of a local university-based researcher deeply committed to CBR. A great deal of the staff and client experience and expertise is interpreted through this research.

People with AIDS (PWAs) and at-risk groups take part in numerous cultural and social activities while community outreach workers provide counseling and education. The Fire Pit serves as an important link to street involved patrons and is run in an open and flexible format, constantly evolving towards maximizing community involvement and accessibility. New forms of evaluation and research are being discussed in relation with this novel enterprise.

PLN has long been involved in community education, providing workshops targeting marginalized groups/individuals in such diverse settings as correctional centres, transition houses and local schools (as well as frontline workers involved with at-risk populations). This well-received education program creatively addresses the complex relationships between HIV and the social determinants of health, examining the underlying issues that contribute to people's vulnerability with workshops designed to tackle themes such as racism, homophobia and sexism.

For example, an eighteen-hour program for frontline workers called 'Reducing Barriers/Building Partnerships' composed of six 3-hour modules, was developed in 1996 in response to needs identified by client services. The sixth, and most recent, module addresses Hepatitis C, reflecting the current reality of high co-infection rates in the community. The modules receive constant evaluation with verbal and written feedback and two formal evaluations completed since the program's inception.

Like many community-based agencies, PLN collects a variety of statistics on clients using its services, which enables them to track increasing workloads and trends. While most of these data are kept individually, they are eventually compiled. The statistics serve mainly to further validate what the service providers and frontline workers perceive through client interactions. There is no formalized dissemination of this information within the organization; instead issues are discussed from a basis of need and not from statistics collected.

As the only Aboriginal ASO dedicated to serving the Aboriginal population of Northern Interior BC, PLN draws on the values and ethics that inform its identity as an Aboriginal organization. These values inform CBR at PLN.

PLN has recently embarked upon a unique approach to evaluation and assessment of its programs in which staff members working at the Fire Pit are encouraged to keep journals to record their daily happenings. These journals generate a wealth of information concerning client stories and day-to-day experiences of staff. They create a data pool and narrative where patterns can be observed and organizational memory recorded. While this unique approach to evaluation is currently only a part of the Fire Pit program, there is motivation to integrate other departments to this type of evaluation process. While journals are currently being used for self-reflective purposes, there is significant potential to use this information as a broader evaluative tool that could be filtered and disseminated, for example, in a biannual report. Staff members have identified potential barriers to this project, including the need for significant human resources to do the time consuming work of "blinding data" (e.g. erase individual names or identifying words) and analyzing entries for common themes and insights, as well as the development of an evaluation model and the establishment a set criteria for journaling language to expedite the process through a uniformity in data gathering. Such an undertaking would rely upon increasing the involvement of students and qualified volunteers.

In its brief history, PLN has collaborated on a number of research projects but has seldom initiated its own. It is noteworthy that PLN has staff involved in designing and carrying out/directing research with the support of an academic-based researcher who is committed

to CBR. A great deal of the staff and client experience and expertise is successfully interpreted into research. In the spring of 2002, media coverage of the harassment of a gay youth brought public attention to the discrimination and harassment of youth in Prince George schools. In June of that same year, PLN met with other stakeholders and representatives and set out a list of objectives to explore the issues of harassment in school communities. The *Safer Schools Research Project* was established to identify and explore the extent of the problem and develop recommendations. Qualitative data collection through a series of focus groups was the chosen method of research. In October of 2003, the information gained from the report was presented to the Board of School Trustees (and three recommendations were set out for the School District).

At PLN there is an awareness of barriers to treatment faced by Aboriginals with HIV/AIDS in rural and remote areas. The interest is on research projects that document barriers, build capacity, address health disparities, increase collaboration and networking, and transfer knowledge directly to the communities.

Other collaborative research experiences include an advisory role on a University of Victoria and Northern Health Authority partnered project: *In From the Margins: Assessing the Effectiveness of Primary Health Care Strategies to Improve Access to Appropriate Health Services for Vulnerable Populations.* In 2002, PLN was involved in a joint project with the Northern Health Authority and Needle Exchange to address the need for education around the increasing trend of co-infection with Hepatitis C. The research component of this project involved a needs assessment after which educational tools were developed and piloted. The end product was submitted to Health Canada. PLN further revised the module to fit the needs and format of its own program and it was added to become the sixth module of the “Reducing Barriers by Building Partnerships”.

The Executive Director of PLN is currently involved in a Canadian Alliance of Health Research funded project titled *Primary Health Care Rhetoric to Practice*. Currently in its fourth year, the research project examines the issues around implementing Primary Health Care in rural and urban settings. The partners in this project include UNBC, UVIC, the Native Health Centre and James Bay Health Clinic. This collaboration, although not always successful in its communication with the principal investigators, has fostered a relationship with the Native Health Centre.

The thick of the work in Prince George has revolved around conducting focus groups and interviews. A number of concerns emerged from this research relationship. This experience has fostered an awareness that transparency and accountability need to be set out in writing (i.e. roles, duties, expectations) and still be able to work in an atmosphere of trust, flexibility, compassion and spirituality that is congruent with Aboriginal tradition and values.

As the only Aboriginal ASO dedicated to serving the Aboriginal population of Northern Interior BC, PLN draws on the values and ethics that inform its identity as an Aboriginal organization. Recognizing its unique and successful organizational structure, the organization submitted a proposal to Health Canada to evaluate their 'best practices'. PLN has learned lessons from the proposals that have been turned down and has kept a fine balance between translating their interests into the language of funders and staying true to their mission, principles, and Aboriginal ways-of-knowing. In this regard, it can be said that PLN has learned to reinvent the medicine wheel when it comes to research; it is formulating research ideas in conventional ways, developing without compromising existing local knowledge, experience and expertise. The medicine wheel traditional of Canadian First Nations – sometimes considered not only spiritual architecture but also an astronomic device to orient people – can be overlapped to a process of "triangulation" often pursued in community-based research. In this sense, a research wheel that is constantly reinvented would not only be necessary but desirable.

In 2003-2004, PLN generated several research ideas in conjunction with university-based academics and the CBR RTA program. A couple of these research ideas have been written into proposals aimed to identify and address the barriers to access of anti-retroviral therapy in the Aboriginal community in the region. PLN has long been aware of barriers to treatment faced by Aboriginals with HIV/AIDS in rural and remote areas. These projects will document these barriers, build capacity, address the inequalities regarding research, collaboration and networking, and transfer knowledge directly to the communities affected.

Research without reciprocity

Case study of the British Columbia Persons With AIDS Society

BC Persons With AIDS Society (BCPWA) is one of the largest peer driven organizations in Canada. To the media, health authorities, and research institutions, BCPWA is an agency that represents the interests of a large number of persons in the province living with HIV/AIDS. BCPWA's mandate is to "enable persons living with AIDS and HIV to empower themselves through mutual support and collective action". Since its inception as a peer self-help group under the auspices of AIDS Vancouver in 1983 and its independent establishment in 1986, BCPWA has demonstrated a capacity to respond to the challenges of HIV. BCPWA also addresses Hep C and drug use, and has had a prophetic role in anticipating new challenges (such as the issues regarding the medicinal use of marihuana and HIV) and facing complex questions around HIV and end-of-life decisions. This prophetic role is made evident in the foresight shown when hosting the Provincial community-based Research Capacity Building Program in 2003.

Researchers view a group of persons living with HIV such as BCPWA as a "convenience sample" and not necessarily as partners in research.

Researchers have viewed having a constituency of persons living with HIV such as BCPWA as a 'convenience sample' and not necessarily as a partner in research. BCPWA has participated indirectly in a great deal of social scientific research, particularly with the BC Centre for Excellence in HIV/AIDS in "joint ventures in which the data is owned jointly" (as described by an informant from the BC Centre). These include research surveys such as:

- 'Care Survey' in 1993
- 'Migration Survey' in 1993 that provided clues on how the need for social support, treatment, and care affect where PWAs decide to live.
- 'Taking Care of Ourselves' in 1995 (583 respondents province-wide to questions on quality of life).
- 'Tell Us Your Side of the Story' in 1999 (which examined PWAs access to treatment information, also province wide).
- 'For The Record' in 2002 (supported by the Canadian Working Group on HIV and Rehabilitation – CWGHR, sent to 1058 individuals and completed and returned by 761).

BCPWA membership has rarely been informed about research results in plain language. HIV positive participants of research studies do not see the relevance of completing surveys or how their results may, in a distant future, impact their day-to-day living.

No formal report of the results of these surveys were submitted and members of BCPWA have requested specific information as needed (often statistic cross tabulations). Informants at BCPWA do not necessarily perceive these surveys as 'joint ventures'.

Ordinarily, the BCPWA Collective Representation and Engagement Committee uses the information to lobby for specific policy changes. BCPWA limited participation – often as a member of Advisory

BCPWA limited participation – often as a member of Advisory Committees with input on question development – has translated into unfulfilled expectations for results that could contribute directly to BCPWA programming and policy, and disagreements over the research implementation (e.g. in 1999, sending a survey several times to BCPWA constituency once prompted complaints and may have greatly contributed to 'informant fatigue'). The experience and expertise acquired through this partial participation in research has trickled down to board members, volunteers and staff but until recently they have not been the direct beneficiaries in capacity building around research.

Surveys and other "hard-data" instruments are traditionally seen as legitimate and effective – particularly amongst peer-driven groups trying to acquire legitimacy in the hierarchical environment of health research institutions and health authorities.

BCPWA membership has rarely been informed about survey results in plain language. HIV positive participants of research studies do not see and understand the relevance of completing surveys or how their results may, in a distant future, impact their day-to-day living. Although BCPWA support for many kinds of research has been persistent, the agency has not always (asked for or) received support when carrying out some of its in-house generated research. As early as 1987 BCPWA had to use fundraising events earnings to conduct a pilot study on an AIDS therapy called AL721 which became the first patient-run research project in Canada.

Lately, the orientation of research interests at BCPWA has changed. Community-based organizations are coming to an understanding that they may continue to be valuable contributors — albeit unequal partners – to large scale, academic-based clinical and epidemiological research but they may also become *effective research sentinels* (i.e. critical readers of research that impacts their constituency). They realize they can incrementally become equipped to undertake social scientific research on local issues that directly concern their constituency, stakeholders and sister non-profit agencies. Although surveys and other 'hard-data' instruments have been traditionally seen as legitimate and effective – particularly amongst peer-driven groups trying to gain legitimacy in the hierarchical environment of health research institutions and health authorities – BCPWA is embracing community-based methodologies.

Agency staff, volunteers and HIV positive peers often have difficulty reconciling the time needed to complete a research study with an historical and endemic sense of urgency.

Their participation as partners in the PASS Study, a 2002-2003 community-based reporting system for adverse drug events from anti-HIV drugs spearheaded by the Canadian Treatment Action Council (CTAC) is a promising start. Treatment Information Program (TIP) volunteers and staff participated in formal ways, contracts were signed and fulfilled, and the BCPWA research team presented extensive feedback on the research process. It is expected that CTAC, a national non-profit organization, reciprocates the goodwill and work placed on the research work. However, it is noteworthy in the

work placed on the research work. However, it is noteworthy in the interviews for the CBR environmental scan that agency staff, volunteers and HIV positive peers often have a hard time reconciling the time needed to complete a research study (including its dissemination) with an endemic sense of urgency felt at the heart of these grassroots community agencies.

Presently, BCPWA is pursuing research generated in-house that is collaborative and reciprocal in areas such as the impact of volunteerism in PWAs and the role of HIV in an identified cycle of prison recidivism (a partnership of the BCPWA Prison Outreach Program (POP), the Vancouver Area Network of Drug Users and the Lifeskills Centre).

In community-based research, form often follows function. A number of daily activities pursued by BCPWA contain research and evaluation skills in them even though they are unacknowledged.

Other 2004 CBR steppingstones are BCPWA's presentation of several program posters at the International AIDS Conference in Bangkok 2004, the inclusion of CBR in the BCPWA five year Strategic Plan, and a close collaboration with partner organizations (e.g. YouthCo, VANDU) and the Research Technical Assistant in obtaining training, designing research protocols, and submitting proposals to fund CBR research. In addition, BCPWA has drafted two simple but crucial documents regarding their future participation in research, a 'Partnership Agreement' and a 'Project Partnership Policy', which are steps towards research leadership and ownership of research in general.

Often ASOs and other CBOs are assumed to be working on solving problems and providing services and what is perceived as intellectual work is left to academic-based researchers. This tends to perpetuate a stereotypical division of labour— the doer is separate from the thinker. BCPWA has embarked in conducting theoretical CBR on Positive Prevention (i.e. an approach to prevention that is PWA-centred and entails applied community ethics to controversial issues such as barebacking, unprotected consensual sex, harm reduction and health promotion options in the context of sexuality). The work has been carried out in community roundtables at local relevant university based conferences. Obtaining the support of universities has required a great deal of liaising with academic conference organizers so that they accept the expertise of community members but particularly to defray the costs of attending such events. This community-based theoretical work has programmatic applications in explicit brochures for gay men, workshops and other activities.

In community-based research, form often follows function. A number of daily activities pursued by BCPWA contain research and evaluation skills in them even though they are unacknowledged. For

example, agency departmental activities are recorded in quarterly and yearly Outcome Based Evaluations (OBEs) that are sent to funders and examined by board members to guide governance decisions but there is no formal transfer of this knowledge (by an internal or external evaluator, for example) to guide programs, policy or research.

Also, BCPWA has an extensive database of its membership since it was expanded in 1994. The database contains demographic information and it was characterized as a "great source of un-mined data". As it is the case in other provincial organizations, this database is largely used as a general inventory device.

The long-standing relationship with the B.C. Centre for Excellence in HIV/AIDS, one of the largest and most important AIDS research centres in Canada, deserves a separate mention. The Centre "provides education to health care providers, conducts natural history and observational studies, develops innovative laboratory tests, and carries out clinical trials. Its drug program is at the core of the Centre's activities. HIV-positive persons living in the Province of British Columbia receive their antiretroviral drugs free of charge when in enrolled in this program". The Centre is fully supported by the B.C. Ministry of Health.

Often university-based researchers release results from epidemiological and clinical studies and the media turns to community-based organizations for plain language explanations on their potential impact.

Although liaising with the community or conducting community-based activities such as education or research are not explicit goals of the Centre, this and other large research centres seem to be under mounting pressure to liaise and collaborate with the communities most impacted by their research (that are often the "population" and "sample" of the research projects). The relationship between BCPWA and the Centre has often consisted of individual researchers that temporarily bridge between the Centre and the community and it is characterized as unsatisfactory. For example, it is often the case that results from significant epidemiological studies are released from the Centre to the media and the media turns to BCPWA and other community-based organizations for plain language explanations on their potential impact. By the same token, BCPWA interviewees and others in the province complain that the results of research are often disseminated via professional specialized journals thus losing the potential impact of the research in ASOs where it would be most useful.

In the course of the environmental scan, BCPWA and other ASOs remarked on the seeming lack of interest on the part of the B.C. Centre for Excellence in establishing formal and permanent relationships with them. A member of the Board of Directors reflected on this issue, "How do HIV positive consumers advocate for

reflected on this issue, “How do HIV positive consumers advocate for our right to be at the research table while avoiding the inherent tokenism of Advisory Committees? Can there be a balance between community representation in ‘manageable numbers’ and efficient scientific work?” The experience accumulated by BCPWA has gradually helped them answer these and other questions regarding research in general.

General findings

Research Experience

CBR, the poor (but spirited) cousin to academic research

This section provides a general assessment of peripheral or direct individual and organizational participation in various types of research and, in particular, in community-based research. Participation in research activities in organizations has often been limited to the participation of individuals in advisory committees or data collection procedures for external research. The mechanics of the process are not often explained to the participants and whatever knowledge they acquired does not trickle down to the staff. In very few cases, interviewees reported having taken part in direct training on general and specific principles, techniques and impacts of doing research or the organizational and community implications/impacts of engaging in research activities. In these cases, the staff members who received the training did not always have the chance to act as trainers or even share the progress or outcomes of specific projects. Most importantly, the processes of eliciting research questions or designing most phases of a research project are often preempted by *a priori* interests of clinical and academic-based researchers. A summary of the bulk of the data collected in the environmental scan is listed below in no particular order.

Advisory committees can often be placed in positions of token participation and working for the lead researcher's agenda.

Positive

- Confirmation of what staff and volunteer members knew already.
- Proven ability to *bridge* between communities.
- Communities obtain 'research products' they can use.
- Learning of some practical lessons by trial and error (e.g. never mail the same survey several times, it *fatigues* your population).
- Working with local consultants and college/university students gives the organizations control over the research proposal and other activities.
- Working with local consultants and other associates saves the time and energy that needs to be devoted to educating 'strangers' about the local organizational and health scene.

Overall, ASOs are and continue to place themselves and be placed in a subordinate position to those who are perceived as 'experts' (e.g. scientists) dealing with legitimate knowledge (data).

Negative

- Inconsistent and unexplained demands from investigators and top-down research.
- Advisory committees can often be placed in positions of token participation and working for the lead researcher's agenda.
- Research partnerships are often struck on an honour basis and a number of organizations report broken (verbal) promises of support and follow up from institutions and their researchers.
- In general, ASOs have had a strained relationship with university-based academics.
- The relationship with the BC Centre for Excellence in HIV/AIDS was characterized by mixed opinions.
- In small regional organizations the relationship and potential partnerships with large Lower Mainland ASOs was discussed with great reluctance. Similarly, participants in Lower Mainland organizations underlined such reluctance as a difficulty in working with regional organizations towards partnership in research projects.
- Lack of critical eye to read existing research and acquiescence in relation to research—there is a lack of understanding of how research may impact organizational life and existing programs.

Often, individuals in organizations possess a considerable deal of skills and expertise in various areas of CBR even when they do not recognize them as such.

Overall, ASOs are and continue to perceive and be perceived in a subordinate position to those who are perceived as 'experts' (e.g. scientists) dealing with legitimate knowledge (data). Thus, a number of questions regarding ASOs' experience with CBR that emerged from the environmental scan interviews and analyses of data remain unanswered. Can organizations learn to speak/write in scientific ways without compromising the ethical and political principles contained in their local knowledge? (e.g. Aboriginal organizations might often feel they have to compromise their traditional ways by writing research proposals in predominantly white-Anglo ways).

The first experience with CBR research for a number of organizations proves to be discouraging: they are not prepared to conduct any type of research, funders place high expectations on productivity and organization, and, when left to their own devices, organizations are forced to learn as they go or seek out dependent relationships with local researchers (who might feel they are bailing out organizations). Health research funders and even managers from ASOs do not always place organizations in the best position – this is what has been

place organizations in the best position – this is what has been corrected in part by the introduction of RTAs and also a greater supervision before funds are disbursed at whether organizations are capable of undertaking research.

Nonetheless, organizations need to record systematically their gains, results, failures and what Howard Becker calls the "tricks of the trade";[xi] the tactical moves that allowed us to get through the research experience (e.g. changes in coordination or advisory committee, changes in methods or even re-formulations of research questions).

Volunteers, frontline workers and members of boards of directors favour the kinds of research they are familiar with, even when their experience using them has been negative or unsuccessful in the past.

Research Expertise

Hidden assets and lessons learned

Often, individuals in organizations possess a considerable deal of skills and expertise in various areas of CBR even when they do not recognize them as such. The interviewees reported having skills in

- Designing questions that are culturally relevant and sensitive for the population they serve. Frontline workers often have sensitive and productive questions roll off the tip of their tongue that allow them to get to know a "client" and assess her situation quickly.

- Conducting interviews under normal and catastrophic conditions (e.g. persons who are vulnerable, addicted, homeless, etc.).

- Collecting various forms of qualitative and quantitative data through administrative forms, educational workshops evaluations and other.

Overall, there are great expectations placed on community based research projects on the part of funders, participants, and researchers. CBR might be an eclectic and encompassing strategy to approach the production of knowledge in localized ways, but it may not be able "to be everything to every one".

The existence of informal "assets" does not minimize the importance of making formal research capacity building available to communities. Interviewees often look at what they know how to do as "assets" for community based service and advocacy, but not CBR. The Environmental Scan reveals that the limitations of the existing "assets" mostly lie in their uptake, that is to say, people in institutions often carry out these tasks but

- their value and utility as research techniques and data has not been acknowledged
- what they know (their local ways) has not yet recognized as valuable techniques to conduct research or valuable views (data) on their local reality

Organizational Assets

It is important to keep in mind that "capacity-building" in CBR does not imply that organizations with work in HIV/AIDS lacking *all* capacities.

- A number of evaluations and consultations are carried out in organizations. This is often done piecemeal, sporadically, and in fragmented ways.

- The evaluations and consultations are sometimes designed to provide evidence and support the work of one program at a time.

- ASOs and peer-driven organizations often have a legitimate place in the communities where they exist and an operating professional and social network.

Expectations

Can CBR be everything to everyone?

When asked about the kinds of research an ASO should undertake, organizations and individuals within organizations provided feedback on the kinds of research they had done before and evidenced that they are poised to repeat the successes or difficulties experienced in the past. For example, a frontline worker in an organization that had had a difficult time completing quantitative top-down research on the economic costs of taking care of people living with HIV in a specific ethnocultural community insisted on the need of doing similar large-scale kinds of economic analysis research in this area in the future.

CBR requires organizational change: Informants reflected on the lack of a coherent organizational place for CBR. Research is like a foreign object and, if it was to be placed anywhere, it would be best fitted into the agency strategic plans.

The difficulties had ranged from having lost the original academic collaborators with expertise on economic quantitative analysis to having difficulty keeping coordinators to deal with provincial sites. When pressed on this point, this informant found it difficult reformulating the same questions with a narrower scope and within a qualitative framework. This was the case in other interviews, where volunteers, frontline workers and members of boards of directors tended to favour the kinds of research they are familiar with, even when their experience was negative or unsuccessful in the past.

It is expected that research will produce results or effect changes. Organizations and individuals always expect a product or change at the end of a research project but they do not always see what this *something* is or they do not know how to *translate* their expectations, interests and investments of time, energy and human resources into research — Having expectations, motivations, and intentions expressed explicitly in CBR, does not necessarily mean that CBR meets all expectations, produce change, or provide answers.

Commonly, CBR can inform a situation or elicit critical thinking by describing a reality (informing and critical thinking not often being perceived as action outcomes). In addition, the current "commercialization" of research may have created the expectation that research brings in necessary dollars (much in the same way that

that research brings in necessary dollars (much in the same way that there is an established expectation that all individual participation in research ought to be compensated).

Overall, there are great expectations placed on community based research projects from funders, participants, and researchers alike. CBR might be an eclectic and encompassing strategy to approach the production of knowledge in localized ways, but it may not be able to be everything to every one.

CBR needs to have a place in both the Strategic Planning of ASOs and peer-driven organizations and in the planning of academic institutions such as local universities and the BC Centre for Excellence.

In community-based research—does form always follow function? As in the architectural dictum, it was often the case that interviewed key informants, when prompted to express their views on research needed, they veered off into explanations of the problems they face an how they need to tackle them. They often implied that research would have to take a problem-solving form. It seems that in community-based research it is expected to reasonable accommodate to the needs and interests of the field (e.g. advocacy action research projects) but this may create some tension and anxiety amongst collaborating academic based researchers who expect to adhere to traditional procedures and uphold scientific rigour and other scientific principles, that is to say, they may be reluctant to sacrifice form to function.

Gaps

What is the place of research within organizations?

In general, informants reflected on their lack of a coherent place for CBR or any other kind of research. Research is like a foreign object and, if it was to be placed anywhere, it would be best fitted into the agency strategic plans or action plans. However, there was often a gap in the process of inserting CBR in the overall plans.

- It is the case in some organizations that research is done either spontaneously or as a knee-jerk reaction to Requests For Proposals posted by various funders. Ideas do not always reflect the interest of the community as expressed in a consultation process. Communities feel the pressure to apply and do so hastily.

- Large-scale agencies have human resources to write and submit proposals but they do often have an overall strategy of how to enhance their "winning potential" by submitting proposals in targeted areas.

- Staff does not always have a clear vision of how one piece of research or a series of evaluations relate to the overall strategy of the organization or to their day-to-day activities and impact.

Needs

Money — What else is needed?

- Understanding of the principles and practices of CBR. In addition, the identification of criteria for what constitutes HIV community based research and tools to assess to what degree these criteria must be met to satisfy the needs, interests and standards of all stakeholders.

- Understanding research as an act of interpretation from one language (the everyday of an organization and its community) to another (the social scientific, the epidemiological, the clinical). For example, the distinctions between QUAN and QUAL can be clarified, their perceived mutual exclusion demystified and their complementation emphasized.

One challenge in working with highly committed and skilled individuals in an environment of scarcity is the "brain drain" of experience and expertise.

- Integrate CBR and research in general into the Strategic Planning of organizations in innovative ways
    - Doing research
    - Acting as sentinels/watchdogs for the research done on them as "convenience sample"
    - Reviewing research on regular basis to inform policy and practice (evidence-based programming)
    - Integrating research in ways that do not constitute an added workload to the frontline
    - Integrating research skills to individuals but in ways that are maintained in the organization.

- The acquisition of research related commercial products such as SPSS and NUDIST is sometimes seen as necessary and conducive to research even thought the capacity to use it, and furthermore, the necessary vision for the application of technologies is not always evident to the staff members and volunteers in ASOs.

Challenges and opportunities

The challenges to community based research and evaluation and building capacity in this area that were discovered through the BC Environmental Scan can be mapped out by using the grid of the four elements or areas necessary to build capacity: organizational infrastructure, human resources, communications and partnerships and applied community ethics.

Community-based research is often seen as "solving problems" and "remedial"; it is conceived in a continuum from "magic bullet" solutions to patchwork for endemic problems.

Challenges to organizational infrastructure: including CBR in all the stakeholders' agendas

CBR needs to have a place in both the Strategic Planning of ASOs and peer-drive organizations and in the planning of academic institutions such as local universities and the BC Centre for Excellence.

Health research funders and even managers from ASOs not always place organizations in a optimal position to engage with research, its tests and revenues – this is what has been corrected in part by the introduction of RTAs and also a greater supervision before funds are disbursed at whether organizations are capable of undertaking research. Nonetheless, organizations need to record systematically their gains, results, failures and what Howard Becker calls the "tricks of the trade";[xii] the tactical moves that allowed us to get through the research experience (e.g. changes in coordination or advisory committee, changes in methods or even reformulations of research questions).

Due to limited funding for AIDS work, organizations are placed in untenable situations with respect to research; they see it as a luxury and they often are only able to justify it to their communities if research activities only serve programmatic purposes.

Challenges to Human Resources Development: Why Training the Transient?

As pointed elsewhere in this report, one of the great challenges when working with highly committed individuals albeit in an environment of scarcity is that of a drain of experience and expertise. Individuals in organizations acquire a degree of experience and expertise and, due to combinations of personal and professional motivations, they move onto other jobs within or outside the area (e.g. to other more profitable health related non-profits). The challenge is to train and foster leadership in research (either as critical readers of it or as doers) on a deficit model, that is to say, on the assumption that they will leave.

Is CBR Remedial Research?

A series of similarities between what comprises capacity building in community-based research and the principles of adult education emerged in the course of these interviews. Exploring some of these similarities and their implications is significant to capacity building in community based research by virtue of its strong learning component that is interdisciplinary and often takes place outside conventional schooling institutions.

One of the historical consequences of conventional research is that "subjects" have become fatigued and therefore reluctant to engaging in research without immediate and specific returns in the form of stipends or tangible changes to services and programs

Community-based research is often seen as solving problems and in this sense CBR is conceptualized as "remedial", that is to say, it is conceived in a continuum from magic bullet solutions to patchwork for endemic problems (e.g. that needs assessments will improve the quality of services). In addition, most interviewees are quick to see the potential impact of community-based research in their organizational life to "increase productivity" in the programs and services.[xiii] This is a recognition that may often obscure other potentials of CBR such as those of advancing knowledge and interactive learning. The challenge is not to restrict community based research so a series of stopgap methods to pressing problems but as a sustainable methodology, an approach to organizational change.

Challenges to Communications and Partnership

CBR merges a North American maverick tradition of utilitarianism with a southern tradition of emancipation and struggle against colonization. CBR merges interests of individuals and unprivileged social groups with global processes of social justice and anti-oppression.

There are often confounding communications factors that make the communication between the spheres difficult. It was difficult to reach academic based researchers even when they present work that is community based, they do not see themselves as community-based but in limited and functional relationships to communities (e.g. partnership or temporary employers, or temporary employees). The case studies presented here offer examples of the difficult communication between those who funders envision as unencumbered "partners".

There are some unique academic and community based resources such as the BC Centre for Excellence or the BC Community Based Research Centre but members in ASO may not know hot to seek those services (what is the etiquette, procedure, hierarchy, etc.) or what kind of advocacy they can carry out to obtain some products they feel it is owed to them because their populations and staff contributed indirectly or directly to research projects led by researchers in those institutions —This groundwork needs to be done (e.g. how to approach researchers, etc.)

Challenges to Community Ethics

Even within its comprehensive and compassionate approach to doing science, individuals in organizations engaging in CBR may run the risk of trying to have CBR be "a bit of everything" or do everything for everyone. Although CBR certainly may expand the limits of what is possible in making knowledge and contributing with local forms of community knowledge to a more general scientific body of knowledge. On the other hand, given the dwindling funding for AIDS work in general, organizations are placed in untenable situations with respect to research, they see it as a luxury and they often are only able to justify it to their communities if research activities are/seem to be directly serving a programmatic purpose. "Research for the sake of doing research" (a fairly common misconception) is often used in direct contrast with outcome based research, a catch all phrase used to mean that the research or evaluation done will surely troubleshoot programmatic issues.

This environmental scan identified a need to modify the attitudes with respect to research amongst ASO staff, volunteers, and even researchers.

No More Captive Populations

Community based research, by virtue of its social marketing, health promotion and popular education interdisciplinary approach to engaging with scientific methods and knowledge, also requires a different approach to "research subjects'. Although individuals in ASOs and peer-driven organizations are very attuned to the ethical paradigm shift that strives to transform "subjects" into "agents", participants in research activities who are empowered and empowering, this Environmental Scan identified this as a ongoing challenge. What do we call "research subjects"? What does "research participant" really mean in practice?

The Environmental scan helped individuals in organizations to remember a series of facts that may have seemed unimportant but when put together paint a rich picture of participation in local research and evaluation activities.

One of the historical consequences of conventional research is that "subjects" have become fatigued and therefore reluctant to engaging in research that does not have immediate and specific returns—not matter how small—in the form of stipends or tangible changes to services and programs. One of the challenges is how to continue to promote this change from "captive populations" to "participants" "engaged audiences" and 'agents of change" by transforming the lost faith in research as objective, omniscient, and truthful to a new kind of faith (that is less religious in nature) in the potentials and limitations of research.

A New Attitude: Erin Brockovich Meets Paulo Freire

The demonstrated interest of interviewees and organizations to participate in the CBR Environmental Scan is subjective but indicative of the significance that organizations have begun to place on CBR. Some of the organizations and individuals were quick to respond even when they may have not have a great deal of experience and work in CBR. They expressed willingness to address issues about

and work in CBR. They expressed willingness to address issues about CBR and their experience, they expressed motivation and generated ideas for their own work during the interviews, or they had a political "reading" of the context in which any type of research takes place. It has been suggested that CBR merges a North American maverick tradition of utilitarianism with a southern tradition of emancipation and struggle against various kinds of colonization (e.g. medical colonization of Aboriginal peoples in Canada).[xiv] CBR represents an opportunity to merge the maverick interests of individuals and unprivileged social groups with global processes of social justice and anti-oppression.

Staff, members, participants and clients can benefit from understanding research and assessing the best ways of transferring clinical, epidemiological and social scientific knowledge into policy and programming.

In general, organizations with experience (even if they did not have the in-house) capacity or expertise) in CBR and/or organizations with at least one staff person with experience or expertise in CBR showed a positive attitude towards research. Notwithstanding some harsh experiences when dealing with funding, funders, and investigators (often university-based), they expressed an interest in participating in research again. They said that they would do it again but it was only after critical reflection that a number of the interviewees clearly identified the need to change the terms of engagement in research, any kind of research, and the practical implications of this (e.g. redefine relationships with health authorities, university academics and even funders).

Informants complained about the lack of provincial research agenda and how they could only participate in research when academic-based researchers made them "the 'flavour of the month".

This environmental scan identified a need to modify the attitudes with respect to research amongst ASO staff, volunteers, and even researchers. We have been trained to see research as *something to which we are subjects but that is carried out somewhere else*, always remains in the domain of experts (loosely defined by their credentials and perceived social standing rather than their actual track record—communities do not interview researchers to see if they are a good fit or possess relevant qualifications). Research is intrinsically hierarchical (top-down) and does not necessarily foster democracy and equity at the centre of its endeavours. CBR has signaled a gradual change in the way these values, a new take on applied ethics, is deployed in various communities.[xv] However, this so-called paradigm shift in the social sciences since the 1960s has not necessarily trickled down to the day-to-day of the communities. In general, community based organizations exhibit radical attitudes towards social change but this is not transferred to CBR. There are challenges in valuing CBR not only an approach to problem solving, organization growth, and the advancement of knowledge (not always followed by direct action) but also to social justice.

Dismembered Organizational Memory

The Environmental scan helped individuals in organizations to remember a series of facts that may have seemed unimportant but when put together paint a rich picture of participation in local research and evaluation activities. This was significant in the experience of the organizations involved in the case studies. An Environmental Scan adapted as a community-based intervention CBR show potential for building capacity by contributing to the remembrance of fragmented organizational memory.

In their critical reflection and analysis of their participation in research and evaluation activities, the Environmental Scan participants understood that they can engage in research capacity building activities as peer researchers and as agents of organizational change. Whenever conducting research or contributing directly to external research is not an option, participants began to recognize that they could motivate their peers and volunteers in the organization to become critical readers of research. Staff, members, participants and clients can benefit from understanding research and assessing the best ways of transferring clinical, epidemiological and social scientific knowledge into policy and programming. A great deal of the research and evaluation work done in ASOs in prospective in nature; it is recommended that some retrospective research work and evaluation is undertaken to “dig up” the many boxes of paper data that many organization reported “gather dust while in storage”.

Brief Inventory of CBR Interests in B.C.

In 2003, the BCBRAC, the advisory committee for the CBR capacity building program, directed the RTA to concentrate his attention on agencies outside the Lower Mainland that needed to engage in evaluation, research and capacity building activities.

CBR requires *imagination* (not to be confused with fantasy), CBR may be realistic about the conditions in the field but provides opportunities for great flexibility and creativity in its various phases. When asked about their research interests, interviewees tended to describe their needs for programs and services. In a few occasions they also complained about the non-existent provincial research agenda for CBR and how they could only participate in research when academic-based researchers directed their interest to them and they became the 'flavour of the month'. The following list of research interests is a summary of the topics presented by interviewees. The clinical and epidemiological research interests are not included in this list as they often echoed the current research undertaken by local clinicians and epidemiologists. Prominence was given to research interests that interviewees saw as viable through CBR.

Gay men's health

- Gay men's health issues in general and how they relate to HIV/Hep C.

- Use of party drugs in gay social networks.

- Positive Prevention, its principles and its application to program and policy implementation.

HIV health in remote and rural areas

- Measuring the impact of prevention efforts in small rural locales.

- Assessing the barriers to school based HIV/AIDS education in the regions (e.g. school workers and health care workers admitted to assessing who needs AIDS 101 education based on the type of school: prevention education seems to be targeted to academic schools rather than to vocational schools).

- Assessing the systemic and cultural barriers to undertaking HIV/AIDS education and prevention efforts for on and off research Aboriginal populations.

- Finding ways to overcome existing barriers to access to HIV treatment and services in remote and rural areas (e.g. action research, advocacy research).

- Describing and assessing existing health services policy and procedures for accessing HIV related treatment in rural and remote areas. Further, policy research on how the private sector

can help overcome barriers for accessing HIV treatment for persons living with HIV/AIDS in remote and rural areas (e.g. transportation of blood work impeded by "dangerous goods" airline policy).

- Social mapping of the circuits of sex trade, drug delivery and HIV infection in the interior regions to better understand the ebbs and flows of HIV infection.

- Social mapping of seasonal workers, drug use, sex trade and potential connections with HIV infection.

- Social mapping of sexualities in fish-bowl environments (e.g. men who have sex with men and do not identify their activities or themselves as bisexual or homosexual in rural areas, the phenomenon of "tournament babies" during sports tournaments in small rural towns when sexual mores are relaxed aided by alcohol and drugs).

Research assistance encompasses being a catalyst for new perspectives on education, training, evaluation and research

Organizational evaluation and human resource development

- Measuring the knowledge that academic based researchers in the HIV/AIDS area have of community based research, its principles and applications. Identifying the educational needs of epidemiologists and clinical researchers and how ASOs and peer-driven organizations can be appropriately engaged in their training.

- Measuring the HIV related knowledge of frontline health care workers in public and non-profits (e.g. some degree of misinformation might still persist).

- Evaluation of twenty years of organizational experience of ASOs in British Columbia.

- Post-discharge housing options for IDU HIV positive individuals. Analyze models in other jurisdictions.

- Systematization of data collected through various ASO programs and services (e.g. basic demographic data or service delivery).

Partnership with academic centres

- Establishing community-based dissemination of results of epidemiological research. In the Lower Mainland as well as in the regions, ASOs sometimes find out about epidemiological trends from the newspapers or TV broadcasts. Whose responsibility is it

to stay informed?

Social justice

- Evaluating the impact of the privacy laws on persons living with HIV/AIDS.

- Evaluating the impact of layers of stigma and discrimination on incarcerated and formerly incarcerated persons living with HIV. In general, volunteers and frontline workers identified a need to evaluate organizational environments/cultures (e.g. social services) where many of the people living with HIV may be catalogued as *damaged* and *undeserving*.

When consulted on research interests, most of the interviewees described needed services and programs. One challenge is to harness this urgency for programs and services into systemic research and evaluation work.

Treatment

- Evaluating the impact of holistic treatment options for people living with HIV.
- Describing and evaluating the benefits of volunteerism for people living with HIV. Further, to describe the connections between unpaid volunteer work and the potential of returning to work for PWAs.

Inner city

- Social mapping of Aboriginal people at risk of HIV "getting stuck" in city life.

- The cycle of prison recidivism amongst persons living with HIV.

- Economic impact of death and burial in Aboriginal communities.

Roles of a Research Technical Assistant

Aside from the strictly technical role of providing technical information regarding various types of research, assist individuals and organizations in grasping the essentials and principles of the various phases of research, the RTA position in British Columbia called for various roles.

Consultant

The RTA has a functional glorified consultant role. This activity needs to be carefully assessed as one-person-program is evidently not enough to meet the demands on various groups around the province. The BCBRAC, the advisory committee for the CBR capacity building program, directed the RTA to concentrate his attention on agencies outside the Lower Mainland that wanted to engage in evaluation, research and capacity building activities. Admittedly, this is one of a number of ways of dealing with the CBR capacity building program and the role of RTA as consultant. The ice breaker joke of calling the RTA "a closet organizer" (a person you hire to come deal with your household clutter) became a useful metaphor to mean that the RTA did not have an agenda other than the agenda of the organization, did not own or did any research per se but helped members of an organization figure out the existing parts (skills, attitudes) and the missing parts (funding proposals, specific skills in surveys, statistics, etc.) and how to give them an organization (a methodology).

The RTA can be instrumental in helping people in ASOs identify their research and evaluation needs and, in addition, create an interest in problem solving through action research.

Educator

The "technical" assistance to be delivered by RTAs need not be confused with purely functional activities such as building surveys to account for the progress with programs or volunteers. The assistance often encompasses bringing and being a *catalyst* for a new perspective on education, training, evaluation and research. For example, at BCPWA, the RTA activities were initiated at the same time that the first Prevention Director had been hired. There had been a Prevention Coordinator in 2002-2003, who coincidentally was also both an educator and a researcher, the notion of "Positive Prevention" started to coalesce during that time and the need was identified to create a separate department.

Once the RTA program and the Positive Prevention programs had started, a natural connection was seen between them and the RTA was asked to participate in the Standing Positive Prevention Committee. A series of roundtables that linked community members with academics in doing intellectual work with potential action implementation was created. In three separate sessions, the

roundtables at University of British Columbia, University of Victoria and Simon Fraser University allowed BCPWA to engage in intellectual work that could then be translated into practice.

Liaison

The field of HIV/AIDS work, given its historical inception, its rise to a nonprofit darling in the 1990s and its fall from public interest in the new millennium, is fraught with internal tensions and an endemic sense of emergency and victimhood. An individual placed in a program that intends to have a provincial scope needs to navigate these somewhat troubled waters with dexterity particularly when one of the goals of the CBR RTA program is to foster and help maintain partnership amongst research participants that not always see eye to eye. Liaising between agencies and social groups living with HIV/Hep C that want to engage with research becomes a tacit role of the RTA that should not be taken for granted.

Recommendations

On the basis of the data collected, this report offers a series of recommendations with the purpose of contributing to building and sustaining capacity in community based research and evaluation. The recommendations have been grouped under the areas identified as key to building capacity: organizational infrastructure, human resources, communications and partnership, and applied ethics. When consulted on research interest, most of the interviewees described needed services and programs. The challenge is to transform the urgency for programs and services into systemic research and evaluation work.

In ASOs there is a somewhat romantic view of research that assumes that science discover facts unbeknownst to them. Informants expressed some disappointment with research that shows what they already know. Only after critical reflection they see the value of translating what happens in their everyday experience to the foreign language of research.

Organizational and research infrastructure

Probably the most useful question that arose from the experience and expertise of the Environmental scan participants was the question "if you were to engage in CBR or any research again, what would you do differently?" Therefore, one of the foremost recommendations is to always ask to us as participants, researchers or critical readers of research. Indeed, the question points at one of the elements of the dreaded triumvirate of the social sciences: objectivity, validity and reliability. The question helps elucidate the criteria for a research project to be reliable.

In ASOs: Learning by doing

The informants for this Scan were clear in that often people "learn by doing" and workshops or other training interventions should be designed around well identified research and evaluation needs. The RTA can be instrumental in helping people in ASOs identify their research and evaluation needs and, in addition, create an interest in problem solving through action research. It is recommended that further provincial research and evaluative interventions be implemented in the future as they prove to be effective educational and organizational interventions.

CBR also entails a communications effort to increase the flow of knowledge at the heart of agencies and between agencies.

The CBR Environmental Scan proved to be an efficient intervention. It allowed the RTA and members of staff of various organizations to dialogue about research, sometimes for the first time, either on the phone or in person. A series of practical ideas emerged as an action research approach was easily adopted. For example, the group interview and site visit with all the staff at Positive Living North allowed the group and the RTA to imagine the kinds of research that would be possible and useful. Framing their issues of access to treatment to HAART in rural and remote areas in the interior set the basis for further collaboration with the Community Based research Centre and Dr. Cindy Patton at Simon Fraser University later in 2004.

The RTA functioned as liaison between well-established researchers in the Lower Mainland and the organizations to formulate a proposal for action research in this area.

Reinventing the wheel is to give a scientific structure and language to what we see as commonplace everyday

Similar to the "Research 101" workshops regularly implemented by RTAs, workshops to design, discuss and set feasible steps to implement organizational change around research needs and expectations need to be created. For example, one of the issues that has to do with research itself as well as with the organizational structure is the (much resisted) need to re-invent the wheel, that is to say, to go through similar steps to make systematic the knowledge and practice the we already seem to have (one criterion to make study results replicable). "Reinventing the wheel" does not have to mean lack of imagination or be realized in tedious repetition.

Building capacity in community ethics entails fostering a new "attitude" regarding research

In ASOs there is a somewhat romantic view of research that assumes that science has only new truths and realities to discover. Interviewees in this Environmental Scan expressed sometimes disappointment at research that showed nothing but what they already know and it was only after critical reflection that the saw the value of translating what happens in their everyday experience to the foreign language of research which allowed them to acquire legitimacy and credibility before funders and in their own communities.

Being positive opportunistic as opposed to negative opportunistic, like the HIV virus.

ASOs and peer-driven organizations often have a legitimate place in the communities where they exist and an operating professional and social network. ASOs are fairly adept at using their local leverage and constituency to create change in the social climate towards issues such as sex trade or drug use that have a direct link to HIV.

Being opportunistic in the best sense of the word, the opposite of the opportunism of the HIV virus, can turn local challenges into opportunities. CBR is in the detail. It is a methodology, not a specific method, therefore a great deal of time needs to be spend strengthening partnerships and creating new ones, setting the stage for one or two (often simple) data collection activities to be implemented. Thus, funders, administrators and coordinators must be mindful of what in conventional well-scheduled research would be an inordinate amount of time that needs to be spent in creating (hopefully permanent) inroads and capacity building in a community and its organizations.

Workshops guide organizations in finding their "indie" ways of pooling and analysing their various evaluative and consultant activities—this also entails a communications effort, that is to say, to streamline the movement of relevant information at the heart of agencies. Thus, the findings of small and large format evaluation and research could be quickly and effectively disseminated. Dissemination should begin with an in-house effort.

Urban centres, given the visibility of the epidemic are likely to act as magnets for researchers, research interests and funds (i.e. academic, clinical and epidemiological research) and steal away their attention to the issues faced by small CBOs and ASOs in rural and remote areas.

In the CBR capacity building program

- Include an inventory of CBR proposals in HIV CBR network site for people to browse.
- Sustain the CBR RTA program. The RTA program is an auspicious beginning for a kind of CBR that is often welcomed in the communities. Realistically, it will not be sustainable at the actual rate of staffing and funding. Further funding needs to be granted or RTAs need to be empowered to seek additional funding for their program (which runs the risk of spending a great deal of professional time pursuing funding opportunities).
- Sustain a province-wide Advisory Committee to the CBR RTA program. At present, the program has only been able to meet once a year due to insufficient funds. In the first meeting in October 2003, six representatives from regions outside the Lower Mainland were able to attend but they shared the expenses. The face-to-face was crucial and many creative arrangements to use the RTA time were made at that meeting. The meeting had a number of outcomes, it allowed members to meet and share their expertise, and it allowed regional members to connect directly with academic based researchers to secure specific help with research related tasks.

Human resources

That workshops be implemented in the following areas

a) How to read research reports, what to look for, how to make sure research is legitimate, what makes a research piece legitimate.
b) Workshops of basic health research approaches and techniques.
c) Workshops on how to conduct evaluation, collect data, interpret it and use it in programming.
d) Workshops on how to use Internet search engines to jumpstart research, generate ideas, and narrow research topics.
e) Workshops for university based academic in traditional areas (e.g. epidemiology) who engage in HIV/AIDS research. Although it may seem well outside the range of action of RTAs, a great deal of work needs to be done with academic

based researchers, both in individual appointments or as members of research institutes and foundations. Educating the researchers through the day-to-day research work is one possibility. Creating specific workshops for academic researchers is another option.

Communications, Partnership and Sustainability

A new attitude

The work to build capacity in community ethics envelops the goal of creating a new "attitude" regarding research and needs to be built into each one of the previous three areas. Of paramount importance is that ASO remember the research experience by careful reporting/recording. It is often the case that ASO do not request formalized products or shared ownership over the research process or products the next time. Thus, it is recommended that ASO preserve their candidness in relation to research, and formalize some of the research process when engaging with researchers and research directly (as partners) or peripherally (as data collectors, collection sites, etc.). This formalization does not have to mean, "lack of trust" – as it was hesitatingly pointed out in some interviews – but arrangements that convey that "good fences make for good neighbours".

Another instance of a new attitude towards ethics grounded in community life is demonstrated by the emergence of community based ethics boards such as the Community Based Research Centre Ethics Review Board in British Columbia (See Appendix B which specifies the specifics of this Board). The Environmental Scan detected a general reluctance from ASOs to engage directly with the complex procedures of universities or research institutions. This recommendation is not a call to relax the ethical review for community based research procedure; but aimed at making the process accessible, affordable and most importantly meaningful for community-based organizations.

Can we believe in life after research?

CBR is an approach to engaging individuals and organizations from various fields and communities into doing science together. Unlike the conventional discreet social scientific or clinical research protocol, CBR needs time to mature, to pave the road to implementation (groundwork), to complete the community work after the research phases have been completed. CBR includes the work that continues to be done after the research work is done. In this regard, it is recommended that ASOs make it habitual to request feedback on

all applications for research or ethics review submissions, both successful and unsuccessful ones.

Is tension in health research healthy?

Historically, ASOs have had a strained relationship with university-based academics. Although it may seem counterintuitive, I degree of tension ought to exist between research institutions (particularly when they may insist to behave as brokers for research dollars and assembly lines for grant proposals) and communities and community based organizations. A healthy tension implies checks and balances. In this regard, CBOs and ASOs can maintain their quality as sentinels of research – much in the same manner that Ed Broadbent in "Building on Strength" report hints at NGOs as sentinels o government action in the community – and CBOs can help set and foster community benchmarks of what constitutes relevant, useful and compassionate research.

Further recommendations

- The most affected communities have a great need to implement HIV related research and evaluation; large urban centres, for example, given the visibility of the epidemic are likely to act as magnets for researchers, research interests and funds (particularly academic, clinical and epidemiological research) and steal away their attention to the issues faced by small CBOs and ASOs in rural and remote areas. These often-smaller organizations may benefit from a type of community-based research willing to shift the scientific gaze from the overarching research interests to peripheral, albeit significant, research areas.

- The CBR RTA program should continue its effort to focus on contributing to capacity building in the small organizations in the interior. In the year period of the Environmental scan there was an observable increase in interest, motivation and attempts to get involved in community based research ventures.

- All funders can support ASOs interested in CBR put their best foot forward by granting funds that include capacity building (e.g. technical training, evaluation) or a capacity building item in the future proposals for CBR funds. We must remind mindful that capacity building and "groundwork" for community based research may seem to sue inordinate amounts of time if compared with the efficiency and expediency of top-down hierarchical research.

- There is need to mobilize the private sector, to initiate and sustain

collaborations with local commerce and other institutions to further the work of research, prevention and service delivery. There are some gestures from pharmaceutical companies to participate with communities as they have begun to allocate modest sums of money for community work and community based research is sometimes encouraged. At the time of the writing of this report, Living Positive North (Prince George) in collaboration with Cindy Patton Ph.D. from Simon Fraser University have applied for funding to work towards breaking barriers for HIV treatment in remote and rural areas of B.C. In a more grassroots manner, the BC Persons With AIDS Society has prepared a proposal to work with local bathhouses owners in a sort of personal development and prevention project with gay men living with HIV who frequent these locales. This project presents an interesting mix of evaluation, prevention and community development components.

Appendix A: The Environmental Scan Survey

British Columbia Community Based Research Capacity Building Program Environmental Scan 2003-4

This informal survey asks questions about research in all kinds of community-based organizations with work on HIV/AIDS in B.C. It intends to map out the existing skills and needs in this area. Responses are anonymous. Please, copy and encourage interested people in your organization to fill it out. Thanks for your time.

You can fax it to the Research Technical Assistant—Francisco Ibáñez-Carrasco at (604) 893 2251 – mail it to CBR Program, 1107 Seymour St., 2nd Floor, Vancouver, B.C. V6B 5S8 – an electronic copy can be obtained at francisco@bcpwa.org

A plain language report will be produced and disseminated in 2004.

1. Please, give us the first three digits of your organization postal code_______________

2. Briefly, what is the mandate of this organization? ______________________________
____

3. What do you do in this organization?

□ Volunteer □ Staff □ client/consumer □ Not related

4. Today's date____

5. Has your organization been involved in HIV/AIDS community based research (CBR) ?
□ Yes □ No □ Not sure

a. If yes, when ____

b. Please, describe how has your organization been involved in CBR __________

____

____

Research Experience

6. If your organization was involved in <u>CBR</u>, what were the outcomes of this research for your organization? (Check as many as you need)

- ❑ Advanced new knowledge–found out stuff people didn't know before.
- ❑ Confirmed what we knew already in scientific ways
- ❑ Benefited the HIV/AIDS community/population in our area
- ❑ Created capacity building—our staff/volunteers learned research tips/tools/skills
- ❑ Created collaboration and partnership
- ❑ Promoted equity, ownership/control of 'process' and 'research products' (e.g. final report, abstracts for conferences signed to your name, audiovisual materials, newsletter/website content written by investigators, etc.)
- ❑ Fostered inclusion and accessibility—all kinds of people were invited and opportunities were created so they could participate (e.g. drug users, sex trade workers, nurses in the area)
- ❑ Empowerment—fostered a sense of entitlement and motivation to do more research
- ❑ Funding
- ❑ None of the above.
- ❑ Other?

a. Please, describe other outcomes ____

____

____

7. Has your organization contributed to university-based research? (e.g. worked with a professor, researchers, etc.)

□ Yes □ No □ Not sure

a. If yes, when____

b. Was this experience…

□ Positive □ Negative

c. Please, describe the university-based research experience ____________________

____

____

____

Expectations

8. How do you anticipate your organization to be involved in the CBR in the near future? (Check as many as you need)

- ❑ Finalizing existing research project (e.g. disseminating existing results)
- ❑ Following up on capacity building opportunities (workshops, etc.)
- ❑ Initiating collaboration/partnerships with other organizations interested in same HIV/AIDS related issues
- ❑ Initiating collaboration with local university based researchers
- ❑ Pursuing funding, implementation and dissemination independent from other organizations
- ❑ Other

a. Please describe ____

____

____

____

____

Research Areas

9. What kinds of HIV/AIDS related issues faced by your organization need to be researched with a community based approach? (Check as many as you need)
- ❑ HIV/AIDS and Aboriginal communities (prevention, education, information)
- ❑ HIV/AIDS and youth infections
- ❑ Injection drug use and HIV
- ❑ Children, women and HIV/AIDS
- ❑ Ethnocultural communities and HIV
- ❑ Gay men and HIV
- ❑ HIV positive individuals and prevention
- ❑ Co-infections (e.g. Hep C)
- ❑ Bisexual and non-gay identified women and men and HIV
- ❑ Transgendered/transsexual persons and HIV
- ❑ Poverty, housing and other determinants of health and HIV
- ❑ HIV as disability and return to volunteer/paid workforce (income support issues)
- ❑ Correctional system and HIV
- ❑ Treatment

- ❑ Evaluation of existing HIV related programming
- ❑ Other.

a. Please, describe other HIV/AIDS related issues that need to be researched in your region/area____

____

____

____

Research Skills

10. In your organization, at first glance, do you know of any staff/volunteers/partners who can…(Check as many as you need)

- ❑ Be on the lookout for research and funding opportunities
- ❑ Network and liaise with organizations, funders, educational/research institutions
- ❑ Gather data through interviews, focus groups, etc
- ❑ Do basic data cleaning and data entry
- ❑ Conduct qualitative analysis of any kind
- ❑ Conduct statistical and other quantitative analysis of any kind
- ❑ Do database, library searches on various topics
- ❑ Write basic literature searches in plain English
- ❑ Analyse, interpret, and write qualitative and/or quantitative data
- ❑ Produce research reports
- ❑ Aid in the application of research findings and dissemination
- ❑ Present research in conference, community meetings, other organizations (e.g, City Council, etc.)
- ❑ Carry out other CBR related activities.

a. Please, name other research related activities your volunteers/staff can contribute with ____

____

____

____

Barriers

11. What barriers exist for your organization to conduct CBR? (e.g. staff, technology, capacity, money). Be as specific as you can.

____

____

Appendix B

COMMUNITY BASED RESEARCH CENTRE POLICY:

ETHICS REVIEW for RESEARCH INVOLVING HUMAN SUBJECTS

I Mandate & Purpose:

i.1 Many community-based researchers are not affiliated to institutions that provide a process for ethics review. The purpose of this policy is to encourage researchers to participate in a process of peer review regarding ethical issues and to promote ethical conduct in community-based research (CBR). The primary role of the Research Ethics Committee (REC) is to provide ethical guidance and consultation to community-based researchers and research participants. The CBRC REC does not supervise or monitor research, nor does it prevent research from taking place.

i.2 CBR proposals that appear to promote ethical conduct in research will receive a statement of ethics approval from the CBR REC. Given that many CBR projects are evolutionary in both design and implementation, the CBRC REC provides a forum for ongoing consultation and guidance in matters of research ethics. This process can result in updated statements from the REC about the ethical probity of a project.

II Unique Considerations for CBR:

ii.1 CBR often involves close partnership between the researcher and the community, narrowing the gap between researcher and subject. Community participants may have an active role in research in several ways, including:

- Defining the research questions
- Designing the research method
- Carrying out the research
- Data analysis
- Evaluation of research findings and drawing conclusions

ii.2 The participatory nature of CBR presents challenges to ethical review. For example, where community members are both researchers and research participants, the informed consent process may differ from the traditional administration of an informed consent form. For example, in self-experimentation, participants who are co-researchers may determine a novel informed consent approach. The task of the REC is to assess these on a case-by-case basis. Researchers should be aware of the possibility that prospective community participants could feel coerced to participate by virtue of their community membership and community support for a research project that is anticipated to have direct benefits to the community.

ii.3 Additionally, the qualitative nature of CBR often introduces an ongoing process of research that requires revisions in methodology and measurement techniques. For example, questionnaires and interview protocols may be revised and therefore do not lend themselves to a one-time ethical review. Consequently, researchers and the REC need to be aware of ethical implications that arise from fluid, less regimented types of research. The REC should provide guidance in such situations to assist researchers in maintaining ethical conduct.

III Principles for Ethical Conduct in Community-Based Research:

iii.1 The general principles for ethical conduct in research are outlined in the Tricouncil Policy Statement: *Ethical Conduct for Research Involving Humans* (1998).[1] The Tricouncil policy does not make direct reference to CBR, but it identifies common standards that form a useful guide for the ethical evaluation of research. The role of the CBRC ethics committee is to consider, case-by-case, how the Tricouncil policy applies in community-based research settings. The main principles to consider are:

- Respect for human dignity
- Respect for free and informed consent
- Respect for vulnerable persons
- Respect for privacy and confidentiality
- Respect for justice and inclusiveness
- Balancing harms and benefits
- Minimising harm
- Maximising benefit

iii.2 Additionally, UNAIDS identifies HIV and AIDS related "ethical principles that should guide the international, national, community and individual response to HIV/AIDS."[2] The application of these principles should also be considered for the purposes of ethical conduct in research:

- Compassion
- Solidarity
- Responsibility
- Tolerance
- Information
- Empowerment
- Well-being/Beneficence
- Equity/Distributive justice
- Respect for persons
- Confidentiality

[1] The Tricouncil policy is available at: http://ncehr.medical.org/English/mstr_frm.html

[2] UNAIDS. (1996) HIV and AIDS related ethical principles. Author. http://www.unaids.org/wsite/00_core_frame.html WWW dated October 25, 1999.

- Obligation to treat
- Informed consent

IV Research Requiring Ethical Review

iv.1 The CBRC does not impose ethical review on research. Rather, the CBRC seeks to foster a culture where researchers participate and collaborate in a process of ethical reflection that promotes awareness of ethics and maximises ethical conduct in research. All CBRC researchers involving human subjects are encouraged to participate in REC review. The CBRC REC can also undertake ethics review of non-CBRC research projects where a similar process of ethics review is either unavailable to, or inappropriate for, the researchers.

V Procedure

v.1 A Request for Ethical Review and relevant forms should be submitted to the Chair of the REC. In the event that the proposal is to be submitted to a granting agency, the relevant forms should also be included.

v.2 Initially, the Chair will consult with the applicant and provide assistance in identifying ethical issues. This process is intended to assist the applicant in determining solutions for possible ethical dilemmas arising in the research. The process is also intended to help the Chair to give the REC background information and facilitate the review process.

v.3 When the Chair and applicant have completed the initial process, the application is to be submitted to the REC for consideration. There is no obligation for applicants to make changes to a protocol as a result of issues raised by the Chair, but these must be clarified for the benefit of the Committee by the applicant and Chair.

v.4 Meetings of the REC will consider applications for ethical review and issue, as quickly as possible, a statement regarding the ethical probity of a proposed research project. To promote a culture of ethical conduct in research, researchers are asked to identify new or emerging ethics issues that arise in the course of a research project. These will be documented and relevant advice is to be communicated to the researcher in charge of the project.

v.5 The REC shall keep a record of its meetings and decisions. In keeping with its role in raising awareness of ethical issues in CBR, the REC should prepare periodic reports summarising the nature of ethical issues arising from CBR and the techniques used to address them.

VI Membership of the CBRC REC

vi.1 The CBRC REC shall consist of a Chair and at least four other members. Consistent with the suggestion of the Tricouncil policy, the REC shall be multidisciplinary in nature. It shall also be researcher and community focussed. There shall be male and female members; persons with research expertise in the methodology and ethical considerations salient to CBR; and persons with expertise in ethics and law. Finally, at least one member shall be drawn from the community of persons with HIV/AIDS (or the relevant community in non-HIV research).

End Notes

[i] See "Capacity-Building in Community-Based research: A Review of Initiatives in Selected Countries" (Bognar, 2000).

[ii] "Capacity building is the development of an organization's core skills and capabilities, such as leadership, management, finance and fundraising, programs and evaluation, in order to build the organization's effectiveness and sustainability. It is the process of assisting an individual or group to identify and address issues and gain the insights, knowledge and experience needed to solve problems and implement change. Capacity building is facilitated through the provision of technical support activities, including coaching, training, specific technical assistance and resource networking."
[http://www.tcwf.org/reflections/2001/april/pages/definition_of_capacity_building.htm]

"Specifically, capacity building encompasses the country's human, scientific, technological, organizational, institutional and resource capabilities. A fundamental goal of capacity building is to enhance the ability to evaluate and address the crucial questions related to policy choices and modes of implementation among development options, based on an understanding of environment potentials and limits and of needs perceived by the people of the country concerned". *Capacity Building - Agenda 21's definition (Chapter 37, UNCED, 1992.)* [http://www.gdrc.org/uem/capacity-define.html]

"The concept of capacity building in nonprofits is similar to the concept of organizational development, organizational effectiveness and/or organizational performance management in for-profits. Capacity building efforts can include a broad range of approaches, eg, granting operating funds, granting management development funds, providing training and development sessions, providing coaching, supporting collaboration with other nonprofits, etc. Prominent methods of organizational performance management in for-profits are beginning to be mentioned in discussions about capacity building, as well, for example, the Balanced Scorecard, principles of organizational change, cultural change, organizational learning, etc."
http://www.mapnp.org/library/org_perf/capacity.htm Carter McNamara

" [Capacity building can take many forms and] enables people to participate actively in development processes and usually entails some form of skill enhancement. This can mean many different things ranging from training in skills for proposal writing, workshop facilitation and literacy, through management and administration skills. It would also typically involve developing the capacity to be aware of problems." Kelly, Kevin and Mary van der Riet. (2000). Participatory research in community settings: Processes, methods, challenges. In M. Seedat, S. Lazarus & N. Duncan (Eds.) *Theory, method and practice in community psychology: South African and other perspectives.* Cape Town: Oxford University Press.

[iii] "Listen Up! Women Are Talking About…" Women's Health Research Project. Report on phases 3 and 4. Community Action for Social Change, HIV/AIDS Action Plan for BC Women. October 2003. A project sponsored by Positive Women's Network that is one of the participants of this Environmental Scan. www.pwn-wave.ca

[iv] Trussler et al. (2003) "Sex Now" by the numbers. A Statistical Guide to Health Planning for Gay Men. Community Based Research Centre, British Columbia..

[v] McMullen, Kathryn and Grant Shellenberg. January 2003. "Job Quality in Non-Profit Organizations" Ottawa: Canadian Policy Research Networks Inc.

[vi] ibid.

[vii] This NGO organizational need to "scale-up" and "retool" has been identified within the global scenario as part of a "human capacity crisis" by members of the International Council of AIDS Service organizations (ICASO) in a document titled "Community Research: Questioning the Community Sector. Are We Making a Difference? (Health and Development Networks – Summary July 2004 A satellite meeting at the Bangkok International AIDS Conference preceded by a community research e-Forum). Robin Weir from the Community-Linked Evaluation AIDS Resource has pointed out the "staff turnover" as a challenge to research. See Spring 2004 Newsletter.

[viii] Broadbent, Ed. February 1999. "Building on Strength: Improving governance and accountability in Canada's voluntary sector. Final Report. http://www.vsr-trsb.net/pagvs/Building_on_Strength.htm

[ix] Tyndall, Mark, Calvin Lai, Francisco Ibáñez-Carrasco. 2004. "PASS Study: Community-Based Reporting of Adverse Events From Anti-HIV Drugs" Toronto: Canadian Treatment Action Council. pp. 16 & 43.

[x] Tellis, Winston. 1997. "Application of a case study methodology" in The Qualitative report, Vol. 3, n. 3, September 1997. See http://www.nova.edu/ssss/QR/QR3-3/

[xi] Becker, Howard. 1998. "Tricks of the Trade: How to Think about Your Research While You're Doing It" Chicago: University of Chicago Press.

[xii] Becker, Howard. 1998. "Tricks of the Trade: How to Think about Your Research While You're Doing It" Chicago: University of Chicago Press.

[xiii] In a far more speculative fashion, it has been theorized that adult education is instrumental in "keeping social order"

[xiv] Kaytura Felix Aaron MD. U.S. senior advisor on minority health stated in a keynote speech for the "Improving Our Health Through Collaborative Research" Conference organized by the Northwest Health Foundation, June 28-30 2004.

[xv] For example, The Canadian Aboriginal AIDS Network (CAAN) encompasses principles and criteria for CBR under the acronym OCAP that stands for Ownership, Control, Access, and Possession. See the "Final Report for the Community Based HIV/AIDS Research Environmental Scan" 2004. In March 2000 a consensus statement on community-based research gathered the expertise and experience of a wide range of contributors. It can be found at www.hiv-cbr.net , specifically at http://hiv-cbr.net/files/1032743040/CCK%20eng%20statement.pdf