

**HIV/AIDS
Community-Based Research
Needs, Interests,
Capacities and Challenges:**

*An Environmental Scan of
Manitoba and Saskatchewan*



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Introduction

The prairie provinces of Manitoba and Saskatchewan are the last region to join the HIV community-based research (CBR) capacity-building program funded by the Canadian Institutes of Health Research (CIHR). Manitoba and Saskatchewan join Alberta, Ontario, Quebec and British Columbia in the task to support communities and community organizations in their research activities dealing with HIV/AIDS related issues¹.

The goals of the HIV community-based research capacity-building program in Manitoba and Saskatchewan are to:

- develop research capacity of community-based AIDS service organizations (CBASOs) agencies and
- improve the information flow between researchers and communities.

In the first phase of the program a number of objectives were identified to contribute to accomplish the main goal of the project.

One of the objectives is to learn about current interest, capacity and shortcomings in HIV/AIDS community-based research faced by AIDS Service Organizations (ASOs) and community-based organizations that manage HIV related programs or projects, and research institutions in the region through the implementation of an environmental scanning.

The scan also inquires on other external factors that can affect the performance of CBR and the role of the HIV CBR capacity building program such as the shape of the epidemics and other socio-cultural factors as well as the larger research environment, including the academic and other institutional realms and government and funding opportunities.

This study is meant to shed light on the strategies required to increase capacity in conducting community-based research leading to appropriate courses of action.

Environmental Scanning

The objectives of this study are:

- To describe current and future HIV Community Based Research perceptions, interest, needs, barriers or challenges among community-based AIDS serving organizations

¹ These regions are funded through the general stream of the HIV CBR Program, while the Aboriginal Community-Based Research Capacity-Building program aimed at serving Aboriginal AIDS serving organizations. Two positions are funded for the Aboriginal stream.

- To describe community-based research resources available through local Universities and other research centres, in particular those focusing on health and social aspects related to HIV
- To describe/assess the current capacity and enabling factors to meet those needs and challenges; and
- To identify gaps between needs and challenges, and capacities and enabling factors
- To identify HIV CBR issues

The results will assist the Prairie HIV CBR program to

- Assess the degree to which organizational needs for conducting HIV Community-Based research, are being met through the current system
- Determine future strategies to promote CBR and meet the challenges it may present.

The results will provide the HIV Community-Based Research capacity-building program in Manitoba and Saskatchewan with foundational information that will shape the future of the program in the Prairie Region.

Community-Based Research

Community-Based Research is an approach to conducting systematic investigation that involves the people affected by the particular issue under study. This collaborative approach engages community members and researchers in all aspects of the research process in an equitable manner.

Community-Based Research

“...a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings.” (Kellogg Foundation, 2001)

Through participation all parties are committed to learning from each other, empowering participants in the process, and transforming the knowledge into practical actions oriented to address health and social disparities. Community-based research can be basically characterized by three main aspects:

- **Collaboration** refers to the development of research involving trained researchers and community members.
- **Validation of multiple sources of knowledge** refers to the promotion of multiple methods of knowing that are expected to develop as result of the collaboration.
- **Social action and social change** refers to the final purpose of the research as contributing to social justice (Stoecker, 2003).

Methodological Approach

The need to conduct the environmental scan was identified an initial step for program development in the area of community-based research involving community-based organizations and communities around HIV/AIDS in Manitoba and Saskatchewan. The local Research Technical Assistant (RTA) conducted the scan. Still, we incorporated some principles of community-based research by incorporating another people and processes into the study. A Peer Research Assistant was hired to take notes during interviews and search relevant documentation, as well as to provide feedback on the findings.

Interviews

Eighteen community-based organizations in Manitoba and Saskatchewan were identified as potential participants in the environmental scan. Some of these organizations have an exclusive focus on HIV/AIDS work, including a peer driven organization. Others hold broader mandates such as sexuality education or programs or services geared to populations vulnerable for contracting HIV/AIDS that incorporate HIV/AIDS programs or activities to their work. All these organizations were invited to participate with thirteen agreeing to participate (with 2 in Regina, 1 in Saskatoon, 4 in rural and Northern Manitoba – including an inter-provincial Network, 6 in Winnipeg – including a peer driven organization). Some of those declining an invitation to participate indicated that they have provided feedback to the issues raised in the environmental scan during a community-based research capacity-building workshop delivered in September 2005.²

In person and telephone interviews were conducted following a semi-structured interview guide that included a few close-ended questions. Face to face interviews were tape-recorded and notes were taken when interviews were conducted by phone.

A number of research centres and university related institutions or departments from Manitoba and Saskatchewan were identified as well as other research centres working independently from university to inform this report. A few informal interviews were conducted with staff related to these research institutions.

Informal interviews were also conducted with representatives from the Manitoba provincial and federal government.

² 31 representatives from most community organizations working in HIV in Manitoba and Saskatchewan participated of the Community-University Participatory Inquiry Design (CUPID) CBR capacity-building workshop. 23 participants returned a questionnaire that included questions on the potential outcomes of CBR, involvement in CBR, areas of research, organizational capacity to conduct CBR and barriers to do so. See report at <http://www.ninecircles.ca/CBR/CUPID%20Final%20Report.pdf>

Documentation Review

We also reviewed secondary data. In order to develop an understanding of the context of HIV/AIDS in Manitoba and Saskatchewan we reviewed epidemiological data on HIV and sexually transmitted infections. This information is believed to enlighten relevant areas for future research. In addition, we searched and examined written material from organizations (community and research institutes), reports on community-based research in the provinces (e.g., evaluations of CBR workshops). Some of this information was obtained from personal contact and through publications found in the Internet.

Participant Observation

We collected notes of meetings and presentations, and individual informal encounters with community members, staff from community organizations, research institutions, and government representatives. Preliminary findings of the study were presented and discussed in Manitoba and Saskatchewan with participants to update meetings, members of the HIV CBR Network, and conference participants.

The capacity-building workshop conducted at the onset of the program (September 2005) helped immensely in the introduction of community-based research, together with the role of the Research Technical Assistant and set the initial stage for this environmental scan. In the framework of this interactive two-day workshop the concepts and processes involved in CBR were explored. Without this initial discussion across agencies the response to the invitation to participate in this study may have been yet more limited.

Throughout the establishment of the HIV CBR program information stemming from all sorts of activities and informal conversations and interactions about this work also became part of the dataset. Much learning of issues and perspectives organizations and individuals hold about research was realized through participant observations and conversations in numerous settings, such as workshops, conferences, colloquia and meetings. Preliminary findings were presented in three opportunities. Two presentations were made in Winnipeg, one was done to update on the progress of the overall work of the RTA – including the scan (November 2005) and another presentation on the preliminary findings of this study was conducted in January 2006 for the HIV CBR Network³. A presentation

³ The HIV Community-Based Research Network brings together frontline workers, community and academic researchers and community members. The aim of the Network is act as a catalyst of communication between the different sectors. The Network meets in Winnipeg and members from Saskatchewan join in through teleconference.

was made to participants to the *Epidemics in Our Communities* annual conference in Regina.⁴

Data Analysis Plan

The first stage of data analysis was to examine interview transcripts and notes for issues and ideas emerging to ensure that these are raised in later interviews. Second stage analysis to discover categorical aggregations and patterns in the interviews were carried out when the data is all collected (Stake, 1995). Concurrently with this analysis, documents were be searched and analyzed for in-depth description of the context of CBR. Triangulation of data sources will add to the credibility of the findings. The findings will be reported with rich description, using participant's words to illustrate the experiences and insights of the stakeholders.

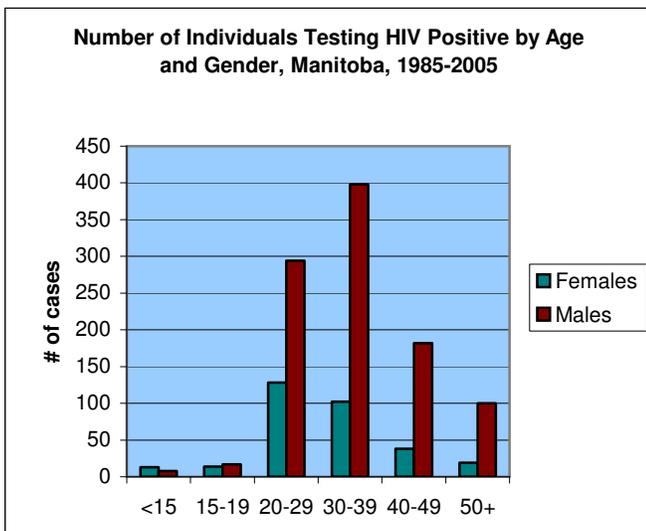
⁴ *HIV Community-Based Research in Manitoba and Saskatchewan: Shaping the Future of Research*, Regina, Saskatchewan, February 2nd, 2006.

Manitoba and Saskatchewan: The Context of the Environmental Scan

The Epidemics: A Snapshot

In Manitoba and Saskatchewan the population is mostly concentrated in the largest urban centres; that is Winnipeg, and Saskatoon and Regina respectively. These are two vast provinces with population dispersed across their territory.

Manitoba Health's statistical update for January 1985 – December 2005 (Manitoba Communicable Disease Control Unit, 2006) reports a total number of 1313 reported cases of HIV. It shows that in the last decade there has been a significant increase in reporting of *female* having contracted HIV from 8% in the previous decade to about 34% between

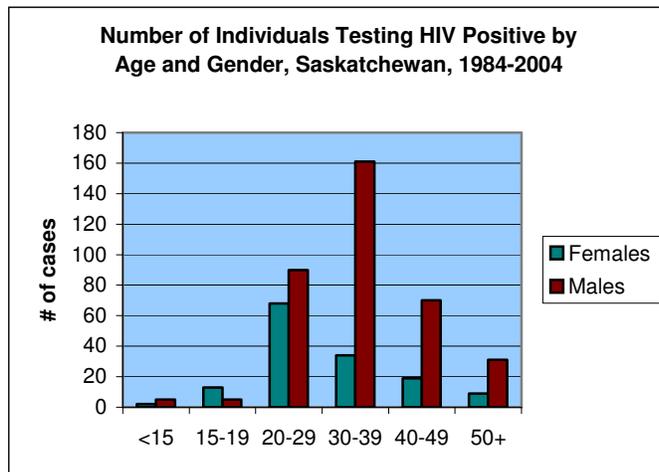


1995 and 2005. The majority of all new cases, for both genders, were between the ages of 20 and 39 years. 83% of all HIV cases reported in the last two decades were residents of Winnipeg. With about one quarter of missing information for self-reported ethnicity, between 1999 and 2004, the majority of new HIV cases were *Aboriginal*, representing 36% of all cases. In the last year, from January to December 2005 (total of 116 cases, with 73 being males and 43 being females) the distribution of was more even: 28% were Caucasian, 25% were Aboriginal and another 28% self-reported as African/African-Canadian. For that last

same period, 37% of new infections among females were attributed to having lived or traveled in an HIV endemic country, while another 35% was attributed to having sex with men who are at an increased risk of HIV. Among males, 27% of new HIV cases were attributed to having sex with females who are at an increased risk of HIV and 23% by having sex with men at an increased risk of HIV. While in the first decade the more likely mode of transmission was men having sex with men (65%), for the last decade it was heterosexual transmission (30%), followed by drug injection (24%) and then, men having sex with men (18%).

According to Saskatchewan Health (2004), in Saskatchewan the number of positive HIV test reports doubled from 2002 to 2004 (26 to 54). Between 1984 and 2004 there were 515 individuals who tested positive for the antibody (Saskatchewan Communicable Disease Control Unit, 2005) 71% of total HIV cases were evenly distributed between Saskatoon and Regina. Individuals between 20 and 49 years comprise 85% of cases reported.

There was a significant increase of *female* HIV cases in 2004. With regards to ethnicity, in 2004 about 60% of HIV cases were *Aboriginal*. In the same year, 68% of females were *Aboriginal*. There has been a decrease of male



cases whose primary risk exposure for HIV was engaging in sex with other men – from 84% in 1991 to 4% in 2002. However, 2003 registered an increase to 38%. Injection drug use (IDU) is one of the major risks exposures. In 2004 the cases reporting IDU as the main risk exposure grew three times from the previous year (9 to 27 cases). This was mostly found among Aboriginal people. An increase in cases is also noticed for those reporting heterosexual exposure in countries where HIV/AIDS is endemic or

through heterosexual relations with someone from an endemic country.

Other epidemiological studies in Manitoba and Saskatchewan provide valuable information for specific sectors of the population. A survey of 435 people who inject drugs conducted in Winnipeg in 2003-2004 indicated a prevalence of HIV of 7% and hepatitis C of 54% (Wylie 2005). In Regina, the 2002-3 survey by the HIV and hepatitis C – associated risk behaviour enhanced surveillance system (I-Track) found the HIV prevalence of 1.2%, slightly lower than the 2.0% reported by the Regina Seroprevalence Study involving a similar sample size of IDU in 2000 (Regina Health District, Saskatchewan Health and Health Canada, 2000; HIV/AIDS Epi Updates May 2004). It is estimated that among Saskatchewan 3,500 to 4,000 injection drug users, the risk of contracting HIV, Hepatitis B and C through needle sharing and unsafe sexual activity is significant, with a prevalence of hepatitis C approaching 50% in this population (Provincial Strategy Team on HIV, Blood-borne Pathogens and Injection Drug Use, 2002).

In understanding the vulnerability to contracting HIV, we also need to consider the picture for sexually transmitted infections (STI) in Manitoba and Saskatchewan. These infections have been proven to increase the risk of HIV transmission. Manitoba Communicable Disease Control Unit (2005b) reports that Manitoba and Saskatchewan are two provinces that tend to have the highest rate of chlamydia compared to other provinces, with Manitoba second only to Saskatchewan. Manitoba Health reports that chlamydia infections have increased from 1999 to 2002. From 1999 to 2003 there was a rate increase of roughly 21%. In Manitoba, the highest rates of chlamydia are found among 15-24 year old females with seven times the overall provincial rate. The highest increase has been among

female 15-19 year olds. However, it is the group of 20-24 year old males that has seen the greatest increase of chlamydia (18%) from 2002 to 2003. Highest rate of chlamydia can be found in Northern Manitoba. More than one-third of cases in 2003 were among Aboriginal people. Yet, it was found that from 1999 to 2003 there was a decrease of 23% of chlamydia within this population.

Manitoba and Saskatchewan tend to have the highest rates of gonorrhoea, where there was an increase of 69% from 1999 to 2003. Again, in Manitoba the highest vulnerable group is youth. Similar to chlamydia the increase is apparent among 15-19 year old females with a 66% increase from 2002 to 2003. The highest gonorrhoea rate in males is among 20-24 years old, with a highest increase among younger male youth. Again, the rate is higher in Northern Manitoba. In 2003, 30% of people diagnosed with gonorrhoea were of Aboriginal descent. However, similar to gonorrhoea there was a decrease of 17% among Aboriginal people from 1999-2003.

Syphilis is another infection to consider. While by 1999 Manitoba had achieved its goal of eliminating locally acquired infectious syphilis, and adopted a near elimination rate of imported endemic cases, in 2003 Manitoba detected an outbreak of locally-acquired syphilis (Manitoba Communicable Disease Control Unit, 2005b).

This information would in part determine or influence the direction programs take, including research.

Managing the Epidemics in Manitoba and Saskatchewan

Community-based responses to HIV/AIDS

Community-based organizations and AIDS service organizations in Manitoba and Saskatchewan provide a gamut of services to people living with HIV/AIDS and communities affected by the disease and other vulnerable populations. These organizations are in the front-line and regular contact with the community and program participants' lives. With exception of few, most of these organizations or programs are very small with short-term and tenuous financial support.

Manitoba

In Manitoba, Nine Circles Community Health Centre (NCCHC) is a community-based, multi-faceted, primary health care centre that provides advocacy, care, treatment and support for people living with HIV/AIDS, those at-risk for HIV/AIDS, as well as gay, lesbian, bi-sexual, transgender and two-spirited persons. NCCHC was established through a joint strategic planning process undertaken among five Manitoba AIDS Service Organizations: AIDS Manitoba, AIDS Shelter Coalition of Manitoba, Kali Shiva AIDS Services, the Manitoba Aboriginal AIDS Task Force and

Village Clinic with the goal of creating an integrated model of HIV/AIDS Service Delivery. Today, NCCHC is the only agency offering community based HIV/AIDS clinical care along with support services in Manitoba and Saskatchewan.

Other AIDS-focused organizations in Winnipeg are Kali Shiva AIDS Services, and an up and coming peer-driven group, the Manitoba People Living with HIV/AIDS Caucus – commonly known as the Manitoba PHA Caucus AIDS, which stemmed from the Manitoba AIDS Cooperative (MAC).⁵ The Caucus aims at empowering the membership through skills-building, information sharing, and informal support activities. All these organizations and programs play a role in HIV/AIDS prevention, education, support and care in Manitoba.

In northern and rural Manitoba, a number of small and geographically dispersed organizations provide HIV related services. These organizations are the Northern AIDS Initiative (NAI) in Thompson (Northern Manitoba) and Red Prairie AIDS Project in Brandon (Southwest Manitoba), the Play It Safer Network, an inter-provincial coalition in Northwest Manitoba and Northeast Saskatchewan and the Sexuality Education Resource Centre (SERC) in Brandon. .

There is also an organized coalition of on-reserve First Nations programs and services, the Manitoba First Nations AIDS Working Group (MFNAWG). The Manitoba First Nations AIDS Working Group brings together frontline workers from First Nation communities, elders, federal government representatives and Aboriginal people living with HIV. The group is meant to provide otherwise disconnected people working on HIV with a space of dialogue and a way to harness resources on the matter.

Other community-based organizations and programs play a role in prevention, education, support and care in Manitoba. Among these organizations are the Sage House Program of Mount Carmel Clinic, the Sexuality Education Resource Centre in Winnipeg and Brandon, and the Rainbow Resource Centre.

Saskatchewan

In Saskatchewan, CBASOs are located in the major urban centres of Regina and Saskatoon. Three organizations, one in Saskatoon – AIDS Saskatoon – and two in Regina – AIDS Program South Saskatchewan and All Nations Hope – are the main CBASOs in the province. All these

⁵ The Manitoba AIDS Cooperative (MAC) is a network of community based organizations. Its mission is to ensure the design, development, and implementation of appropriate HIV/AIDS programs, services and policies for people living in Manitoba. Presently, with lack of resources and small number of agencies in Manitoba, MAC meets to attend to advocacy related issues as they arise.

organizations are community-based, dedicated to providing support, prevention and education for people living with and affected by HIV/AIDS, including those at risk of contracting the virus. They also provide education resources for service providers and the community in general. All Nations Hope is the only Aboriginal ASO in Saskatchewan.

As in Manitoba, other series of community-based organizations and programs play a role in dealing with issues regarding HIV/AIDS such as the Avenue Community Centre for Gender and Sexual Diversity (formerly known as the Gay and Lesbian Health Services in Saskatoon), or Planned Parenthood Regina and Planned Parenthood Saskatoon.

Manitoba and Saskatchewan health and social non-profit sector play a role in establishing the context in which to explore the potential for community-based research. Community-based organizations are the ones conducting education and capacity-building, engaging the community and working in partnerships with other organizations and sectors. Their work is geared toward social change through direct services and advocacy. These organizations are crucial in the development of any research strategy intended to sustain the main principles of CBR (i.e., collaboration, capacity-building or education, and action or social change). By virtue of their closeness to the community, these organizations are also key in becoming aware of the social, clinical and epidemiological issues.

Research Infrastructure for HIV/AIDS and Related Fields

Manitoba and Saskatchewan have an institutional research infrastructure that could become an asset when engaging in HIV/AIDS community-based research. Most research infrastructure in these two provinces is university-based or affiliated. In this section we only include those institutions, programs or services that have an explicit mandate to collaborate with communities. Community-based research is also supported by individual academic researchers and fostered by some university departments. These individuals and departments are also an asset for the future development of HIV CBR in the prairies.

Manitoba

Research that follows principles of community-based research in Manitoba is embodied in many institutions. Among the institutions there is the Institute of Urban Studies of the University of Winnipeg, an applied research centre. Among its objectives are to conduct research that is of public interest, and engage in contractual research for governments, community groups and the private sector. The main focus of the Institute is on finding practical solutions to urban problems through research.

In the prairies, a tradition of collaboration between university and Aboriginal communities has developed for many years. In Manitoba, one of the most salient examples is the development of a formal relationship between the

University of Manitoba and Manitoba First Nations leading to the establishment of the Manitoba First Nations Centre for Aboriginal Health Research (CAHR), a unit of the Department of Community Health Sciences in the Faculty of Medicine, in 1999. The mandate of the Centre is to initiate, coordinate and support research to assist First Nations and Aboriginal communities to promote wellness and improved health services. The Centre aims at supporting community-based, collaborative, culturally appropriate studies; and research capacity-building in First Nations and Aboriginal communities. These objectives have developed as result of working through the legacy of research among First Nations communities and the need to gain control over knowledge development by the community (O'Neil, Elias and Wastesicoot, 2005).

The objectives of the Manitoba First Nations Centre for Aboriginal Health Research (CAHR) are compatible with the principles of community-based research. Their interest in addressing health disparities and improving health services makes the Centre an appropriate partner in HIV/AIDS research in Aboriginal communities in Manitoba.

With preference in rural and Northern Manitoba, the Brandon University Community Outreach Service assists in matching the needs of community organizations with the learning and research interests of faculty and students. The Outreach Service provides assistance through their annual call for proposals (for projects that draw together the interests of community groups with the skills and interests of BU faculty and students), their open call for proposal for unexpected project opportunities that fall outside the Annual Call for Proposal. Outreach Services are exploring the expansion of their role in the community through "service learning"⁶ involving students, community organizations, and government agencies. Service learning is one approach to community-based research (Savan and Sider 2003). Small grants are available to support proposed research or projects that connect university and community.

Another research resource in the region is the Prairie Women's Health Centre of Excellence (PWHCE) with offices in Manitoba and Saskatchewan. The PWHCE is one of the Centres of Excellence for Women's Health supported by the Bureau of Women's Health and Gender Analysis of Health Canada. The Centres are dedicated to improving the health status of Canadian women by supporting policy-oriented, and community-based research and analysis on the social determinants of women's health. The Centre conducts or commissions research and advocate for policy recommendations and does so in collaboration with

⁶ Service Learning is an approach by which students' needs to transfer the classroom knowledge into real situations. It also promotes civic engagement and community participation (Walsh, D. and Annis, R. 2003).

community and university partners. The approach of the work is bringing together community-based and academic research and policy expertise. The current research and policy priorities of the Centre are Aboriginal women's health issues; women, poverty and health; health of women living in rural, remote and northern communities; and gender-based analysis in health policy. Currently, the Centre is collaborating with its counterpart in the Atlantic region, the Atlantic Centre of Excellence for Women's Health, on gender and HIV related matters.

The Canadian Centre on Disability Studies (CCDS), in Winnipeg, is an independent Centre that conducts applied research towards the participation of people with disabilities in all aspects of society. CCSD also collaborate with organizations, academicians, and researchers in research projects promoting this mandate. The Centre supports research capacity-building among community-based disability groups, including grassroots groups, and researchers through research grants, ethics reviews, and research skills training. The CCDS offers annual small grants to support collaborative research.

In addition to these specific research services available to community groups and organizations, individual academic researchers embedded in different faculties and departments are invested in the principles of community-based research. Some of these researchers – mostly already involved in the HIV/AIDS field – are currently involved in the HIV Community-Based Research Network coordinated through the Prairie HIV CBR program hosted by Nine Circles Community Health Centre. However, other researchers who may not be directly working on the HIV/AIDS field may be mobilized to participate in HIV research because of their interest in the methodology, in connecting with the community and advancing the non-profit sector research agenda.

Saskatchewan

Saskatchewan's universities have a number of research units and centres with expertise in areas that could make a contribution to the understanding and development of solutions to HIV related problems posed by the community and community organizations.

Based in Saskatoon, the Community University Institute for Social Sciences Research (CUISR) provides an infrastructure for community-university partnerships for the development of policy and evaluation research and research capacity building. The main areas of research interest are community health determinant and health policy, community economic development, and quality of life indicators. A report of the awarded projects conducted by CUISR demonstrates the wide range of research topics and questions, and partnerships the institute has developed over the years (2006). The CUISR provides funding

opportunities for students and academic researchers to conduct research on behalf of community-based organizations. The Institute funds internships for graduate students to learn and practice applied research skills within a community organization. Students, faculty supervisors or community-based organizations are eligible to apply for an internship. CUISR also offered an innovative approach to supporting community-based organizations. Until recently, staff from community organizations interested in pursuing research capacity-building activities such as attending capacity-building activities (e.g., training, courses), time release to write a research proposal or conduct an applied research project were able to apply for funding to support these activities. Due to lack of funding the Centre is not longer able to support this activity.

The Saskatchewan Population Health and Evaluation Research Unit (SPHERU) supports research on determinants of health. The research focuses on health determinants and their policy and programmatic implications, and evaluation studies of policy and program implementation, to promote equitable health outcomes. Partnership with community-based organizations and policy makers is included in the research process. HIV and hepatitis C had been one the themes of research supported by the Unit.

Indigenous Peoples' Health Research Centre (IPHRC) is a partnership between First Nations University of Canada, the University of Saskatchewan and the University of Regina) with support from Aboriginal health organizations and other health boards. The main focus of the IPHRC is on capacity-building in health research among Aboriginal people, communities and institutions on chronic diseases, nutrition and life style, indigenous healing (addiction, mental health and the judicial system) and the appropriate delivery of health services and prevention measures. All the areas of interest identified by the Centre are relevant to HIV/AIDS research. The Centre provides opportunities to Aboriginal students and extends development grants to support the development of community-university networks and collaborations for Aboriginal health research in Saskatchewan.

With an interest on health promotion research, evaluation and practice, the Prairie Region Health Promotion Research Centre offers capacity-building activities and pursues research on health promotion related areas. One of the goals of the Centre is to “link communities, practitioners, researchers and policy makers through creating spaces and opportunities for shared dialogue”.⁷ The centre supports a participatory action research approach to research. Their current focus is on mental health promotion and, health and literacy, and interested in knowledge translation, indigenous and evidence-based health promotion.

⁷ See, <http://www.usask.ca/healthsci/che/prhprc/programs/about1.html>

Another source of information or potential partner in HIV research is the Health Quality Council. The Council measures and report on quality of care in Saskatchewan. Among its activities, the Council develops evidence-based standards, promotes effective practices to professionals, conducts research into the effectiveness of care and disseminates findings about the quality of health services in Saskatchewan to the general public. Community organizations interested in the quality of health care for people living with HIV are in a position to advocate for the inclusion of this topic in the Council's agenda.

While some of the research centres and institutions provide some direct funding for CBR activities, sources of research funds are limited in Manitoba and Saskatchewan. Researchers and communities have to look elsewhere (i.e., federally) for research funds. Established researchers would know and have experience in working with large funding research institutions. However, as it is found in other sections in this report, this is not the reality of community-based AIDS service agencies.

The alignment to the principles of community-based research in the goals or activities of research institutions and centres included in this report provides an understanding of current and potential actors for enhancing HIV community-based research capacity-building and activities in Manitoba and Saskatchewan.

Government Support of Community-Based Research

Federal and provincial government produce and support research in the HIV/AIDS area. Community-based research is a component of the Federal Initiative to address HIV/AIDS in Canada (Health Canada, 2004). This commitment to CBR came about as result of many years of advocacy in support of the involvement of community members in research (Trussler & Marchand, 1998). A focus on research is supported by the expressed need for research, program evaluation and data collection by government in Saskatchewan and Manitoba.

In this study, we directed our search towards data that would suggest an understanding and support on community-based research as an approach to inquiry on HIV matters. Statements of this nature are found in documents such as the *Healthy Choices in a Healthy Community – A report on substance abuse, prevention and treatment services in Saskatchewan*, and the report on Saskatchewan's strategy on HIV, blood-borne pathogens and injection drug use (2002). This later report explicitly supports the use of community-based research (Provincial Strategy Team on HIV, Blood-borne Pathogens and Injection Drug use, 2002: 3, 45).

In 2005, the Aboriginal Strategy on HIV/AIDS, a component of the Manitoba Provincial AIDS Strategy, adopted four strategic goals: prevention and education; care, treatment and support; co-ordination of services; and research and evaluation. The Strategy promotes the adoption of Community-Based Research and Aboriginal Community-Based Research to respond more effectively to the epidemic. Research, based on the principles of ownership, control, access and possession, is encouraged to inform programming and policy decision-making (Manitoba Health, 2004). At the time of this scan, the government was in the process of conducting an environmental scan of existing HIV-related services for the Aboriginal population as a next step to assist in operationalizing the Strategy. The results from the scan should dictate the Provincial commitment, resources and path towards Aboriginal community-based research in Manitoba.

Federal government support for CBR is provided through funding directly or indirectly allocated for research purposes. The Canadian Institutes of Health Research (CIHR) offers research funding through the CBR HIV program. When research is directly aimed at program development and planning – e.g., needs assessment, environmental scan, evaluation, funding can be obtained through other government funded programs such as the AIDS Community Action Program (ACAP). We found no evidence of specific financial support - in the form of grants - towards HIV CBR through the provincial governments.

General Findings from Community-Based Organizations

Understanding of Community-Based Research

Most participants in the scan had been recently exposed to training in Community-Based Research or have previously participated of similar training in Manitoba or Saskatchewan.⁸ They demonstrated an understanding of some of the principles of CBR and employed varying definitions of this approach.

Participants had a broad understanding of community-based research. That was translated into the definition of some of what they believed to be the most important tenets of community-based research. They emphasized different elements of CBR.

The main elements of CBR endorsed by the participants were the need for the definition of the research question being led by members of the community affected by the problem, and the orientation towards the development of solutions to a particular social problem.

Community participation in research was seen as paramount for research outcomes to be relevant. In most cases, community was defined as people affected by a particular health or social issues, not necessarily by service providers or researchers. As members of community-based organizations, community meant the clients or consumers of services. A good number of participants agreed on the fact that the issues, the topics of research and the research questions have to be defined by the community.

Characteristics of Community-Based Research

Definition of the topic of research and research questions by community affected by the issue

Collaboration with the community and other stakeholders

Orientation towards the development of solutions to a particular social or health issue

Some interviewees indicated the participation of community members in other aspects of the research process such as data collection. The participants spoke about this type of research as “community-driven”, “community owned” or “grassroots research”. Those organizations working with members of Aboriginal communities mentioned that CBR honors the principles of Ownership, Control, Access and Possession (OCAP); which have been born in the context of Aboriginal research and represent self-determination in knowledge creation.

⁸ Most participants have attended the Community-University Participatory Inquiry Designs workshop held in partnership between the Prairie and B.C HIV CBR programs, Nine Circles Community Health Centre, HeRMET facility at Simon Fraser University and the Sexuality Education Resource Centre in Winnipeg.

The second and intertwined characteristic of CBR mentioned was its collaborative nature. In this case, most of the emphasis was in the collaboration between community organizations and community members. In some cases the academic community would come into the picture. Academic researchers were believed to be able to contribute with specific research skills and access to funding, and credibility of the results within the academic circles, and helping educate the academia on matters of community-based research.

Lastly, there was some emphasis on the fact that CBR is meant to provide information for action to help develop solutions to a particular health issue. This belief was reiterated by most participants.

However, when analyzing some of the examples of research that people believed to belong under the category of community-based research, it appears that there is a discrepancy between their understanding of CBR and the practice of what believed to be a CBR project. There were even some cases in which programs were confused with CBR projects, as there was one case in which the participant would indicate not having participated in a CBR project when in fact the description of one of their research projects would adhere to some of the principles of CBR.

Some of the understandings about CBR was the belief that CBR was a qualitative approach. This understanding may be based on the fact that most research examples of research utilizing a CBR approach are qualitative methodology.

In a few situations participants would describe community-based programs as if there were community-based research projects. The distinction between programs and research was not clear. While community participation in program development is also supported when carrying out CBR, research is a different activity. Research is based on some research methodological tenets such as the production of reliable information based on systematic processes, a strict methodology for the purpose of learning something new or confirming something people know through a scientific approach.

The fact that most people have a good grasp of CBR is very encouraging. Yet, when we talked about their experiences with CBR the way these principles were applied was very diverse raising questions about the extent people have being able to maintain a full collaboration with the community in research, the success in the application of the findings, the lessons learned from their research experiences, and the supports still required to fully embrace CBR as part of the organizations' operations.

Experiences with CBR

Research has taken different shape in community-based organizations in the area. Most organizations have engaged in research, following different principles of CBR. Participants provided examples of different models of community-based research (CBR), as it relates to the principle of collaboration between researchers, community organizations and community members.

A range of models of collaboration is found in the history of research conducted by organizations. In some cases, organizations have conceptualized, designed, implemented and disseminated their own research projects, in other cases they have invited independent or academic researchers to collaborate in specific projects as in some cases organizations have been approached by academic researchers, including students and professors, to partner in research initiatives identified by the researchers.

In one case an independent researcher and the research team successfully approached and partnered with a CBO to receive support for housing the research project. Both the research team and the organization benefited from the project. While working independently from the organizations, both groups would benefit from their work. The research team would have a house, which would allow to access funding and, at the same time, have autonomy to make decisions without interference. At the same time, the organization would fulfill its mandate by supporting this work and gaining information that could be used for programming and dissemination.

Models of Research Collaboration in Manitoba and Saskatchewan

Organization initiated and/or led

University initiated and/or led

With community or organization participation at certain stages of the research process

Community-led

In terms of the collaboration with community members, the experiences were about involving community members as research assistants to collaborate in specific stages of the project such as providing feedback in data collection tools development, performing data entry, engaging in data interpretation by providing feedback to the findings. In a few cases community members affected by a particular issue were involved as equal partners in the complete process of research, from the formulation of the research questions, design of the methodology and implementation of the project, to the dissemination or knowledge translation.

There were a few cases in which the organization counted with internal researchers and evaluators who could dedicate time to CBR initiatives.

All these models or examples can be organized along a continuum of how closely they meet the principles of community-based research.

Participants have engaged in different capacities in community-based research. They have conducted research as part of team of researchers, collaborating throughout the research process by providing feedback at specific stages of the project (e.g., providing feedback on questionnaires or validating results), providing access to research participants, or by becoming members of advisory groups.

In few cases, organizations counting with some research infrastructure were able to conduct skills-building activities, by engaging on one-on-one or small group discussions and consultation around a specific research project within their own organizations or with outside organizations requesting support.

Some of the participants were also involved in a network of researchers, the HIV Community-Based Research Network. The Network was created as part of the HIV Community-Based Research Capacity-Building program in Manitoba and Saskatchewan with a membership of academic researchers, federal and provincial government and community organizations. The purpose of the Network is to provide a forum to address research issues and promote collaboration in CBR projects.

Benefits of Engaging in Community-Based Research

Some participants reflected on their experiences in engaging in research, others were able to articulate its potential benefits. They offered a number of benefits and difficulties in partnering with community members, other community-based organizations and independent or academic researchers in HIV/AIDS research.

The benefits stemming from participation in research have been varied. Participants indicated that the process of engaging in research, and mainly evaluation, has provided organizations with the opportunity to see the value of research as a means to enhance programming. “It has the potential of creating practical products out of the research”. The information has assisted organizations in the development of “plans of action”, “to translate research into actual programs”, and to “help meet the needs” of program participants. The most sought after product of research findings is its use for the justification of projects ideas in funding applications. There was value in fulfilling the recommendations from the studies through specific actions.

There are also many organizations struggling to build their evaluation infrastructure. One of the interviewees was sold on the benefits of research and evaluation; however, indicated the opposite among other staff in her organization. Yet, she thought that CBR would be a way to engage through a participatory process staff that resist or who may not see the outcomes of incorporating evaluation into their work. CBR would help to develop an evaluation and research culture.

CBR was seen as “helpful to segments of the demographics we serve”, through the process as because of the outcomes. A participant reflected on the empowering effect of the participatory nature of the process by saying,

CBR might prove useful in assessing what is working and what is not. Community-based research puts the means of production into the hands of people affected by an issue, especially in the community that our organization works in, the Aboriginal community, where people feel that they have been researched to death by the mainstream. To be able to empower the Aboriginal community to do research by themselves for themselves I think it is profoundly important.

The CUPID survey also indicated that enhancing the inclusion of community members as peer researchers was one of the most important outcomes of CBR (Migliardi et al., 2005).

For few other organizations, the increased number of requests from university to partner in research and being able to develop those relationships was seen as positive. They understood that the organizations were becoming to be accepted for their knowledge and experiences in the field. This would render the benefit to shape the research agenda.

Another real positive it's the partnership building, meeting people and developing that relationship, what we can share, dissemination of results and inform their practices.

In sum, the process may lead to increased understanding and communication across sectors, the organizations, community members and academic researchers.

The development of indigenous knowledge was believed to be another important benefit of CBR. The process invites many points of views and ways of knowing. One participant

It is rewarding when you see what happened, it is information that is locally derived, a lot of research happen, but we haven't had a lot of research done in our area. In fact, I cannot think of any research that

happened in our area. Anything, new knowledge, that it is locally derived is great.

The development of local knowledge through community participation guide organizations full circle to the development of sound practices and improved quality of life for people living with HIV or affected by the infection.

Community-Based Research Skills

Capacities and Strengths

The individual engaged in the scan demonstrated a great deal of skills in different aspects of community-based research. In some cases more than in others, individuals were more readily able to recognize these skills – in part due to their closeness to a specific research project or their own research experiences with the school system. We asked the participants to rate their skills using a 4-point scale from Novice to Advanced. An analysis of the results shows that most participants have skills and expertise in:

- Conducting literature searches. Individuals tend to search for materials and information to strengthen their own programs and practices searching the Internet. Some interviewees were specific about doing literature searches for research papers because they are in school or have been in school. A majority of participants (85%) rated themselves as intermediate-advanced.
- Conducting interviews. In particular performing focus groups interviews, was another important strength. Community organizations count on many individuals, staff and volunteers, who are trained group facilitators. The transfer of group facilitation skills to the performance of focus groups interviews was easy to observe. Many participants (63%) rated themselves as intermediate-advanced.

Research Strengths

Conducting literature searches

Conducting interviews

Networking

Dissemination

These skills were believed to be transferable from program design and implementation, and advocacy to research.

Networking. Community organizations are increasingly working in collaboration for the purposes of providing better services, program development and advocacy. Interviewees felt very confident when it came to be able to utilize this skill for research purposes. However, later on we explore the barriers to certain types of collaboration in research. About 70% of participants rated themselves as intermediate-advanced. Those responding to the CUPID survey also agreed on this point (Migliardi et al., 2005).

ion. Although most of the interviewees have not made formal presentations of research results, they reported being

comfortable making presentations. They have experience in disseminating information on their programs or advocating for HIV issues, in some cases utilizing research findings. About 70% indicated being at between intermediate and advance level in this area.

In all, interviewees transferred their skills in program design and implementation, and advocacy to research. However, this transfer does not necessarily mean that formal approaches to enhance these skills in relation to community-based research are not necessary.

The environmental scan has revealed that although there are strengths in the organizations, the interviewees would not guarantee that people would put forward those skills towards a research project in the sense of fully taking on some the research tasks – yet, these findings at least indicate that the organizations have the capacity to critically engage in research, and be able to speak the language, be aware of what researchers would talk about or be themselves able to provide ideas based in those strengths.

Challenges

With regards to challenges faced by individuals and organizations in their research skills participants also coincided on a few areas that require some improvement for their future research initiatives. Among these research skills and capacities the areas that presented some limitations were:

- conducting participant observation. Although participants' regular assessment of their work and the conditions and situations of their clients is in part based in their observations; the use of systematic observation techniques and tools was believed to fall under the skills challenge category.
- conducting statistical and other quantitative data analysis. A large number of participants identified this as a major area for improvement. Organizations are required to produce numbers about their services to demonstrate the results of the work; however, this practice does not usually go beyond the basics such as the development of simple databases, simple reporting (e.g., number of clients).
- developing ethical protocols

We know a lot about ethical issues in our practice; however, writing an ethical protocol for research purposes is a different story. We have not been exposed to that process.

- conducting qualitative data analysis

- developing surveys
- applying evidence-based information into the practice or knowledge mobilization.

These limitations only represent a specific area to address for the development of a research infrastructure in HIV CBR in the prairies. Other challenges are addressed in the upcoming section that examines in-depth the barriers to embracing CBR.

Priorities for Research Capacity-Building

In terms of the identification of priority areas for research capacity-building most of the focus was on research methods and data analysis. Members of community-based organizations were interested in:

- Conducting data analysis with an emphasis on quantitative data analysis. A few mentioned qualitative data analysis as an area of interest, including the application of current software for data management.
- Development of databases for purpose of improving data entry and management.
- Development and utilization of alternative data collection methods other than conventional surveys, interviews or focus groups that would best suit organizational “values and approaches to work with the community”
- Development of research tools.

Beyond data collection and management, participants were interested in other aspects of research. In these cases they turned to some specific dimensions of community-based research and their implications in practice:

- Ethics applied to research is an area of interest in community-based research. Participants understood the most common tenets of ethical conduct to protect research participants; however, community-based research raises other ethical issues based on the principles of participation and democratization that require discussion.
- Exploring possibilities to create community ethics review boards to assure community-based research projects are reviewed utilizing appropriate processes. Except for research conducted in partnership with or by university, most community organizations do not access any formal mechanism for ethical review when designing and implementing research
- Developing research partnerships is another area that puzzled a few participants. Partnership building is a standard practice for most

organizations; however, little is in place about how to develop and maintain “healthy” partnerships, including for making partners fully accountable of each other, in particular when it comes to dealing with power differentials. The negotiation of agreements, roles and responsibilities are seen as important; however, hardly looked at.

- Applying research recommendations was seen as another area of interest. Participants believed that much research has been done; however, some of them were not sure of how to make use of that research to inform their own practices and programs. The best

approaches to engage in CBR learning was face-to-face encounters that take a hands-on approach accompanied by materials for future reference and to share with the organization. Participants have benefited from general CBR training. Now, the demand for capacity-building initiatives is more related to specific research activities than to grasp the tenets and methodologies of CBR. This was believed to be more effective since time allocation for lengthy workshops may be a problem for small organizations. Capacity would be best construed through the development of a specific research project than by imparting general concepts related to research.

Hands-on experience through specific research development and workshops and are the most valuable method for research capacity building.

Development of resource materials specific to different research area would be valuable complement to face-to-face workshop style training

Barriers to Embracing Community-Based Research

Barriers to conduct research through a community-based research process were explored. These barriers were related to two main areas: organizational infrastructure and partnership development.

Organizational Infrastructure

While the participants would see value in having a strong research and evaluation agenda, many organizations in Saskatchewan and Manitoba do not count on sufficient or qualified staff to conduct research. Overall, there is limited allocation of time to the incorporation systematic research and evaluation activities within the daily provision of programs and services. Except on a few cases where evaluation and research have become funded areas of the organizations and qualified staff has been hired to carry out the work, the rest of the organizations count on sporadic support – mainly in evaluation of specific short-term projects – and unsystematic documented activities that provide some insights on how programs are doing in their implementation (i.e., process evaluation), with little information on the effects of program or project interventions on participants well being (i.e., outcome evaluation). For some, only “extra money” and “extra time” allows them to explore research and evaluation opportunities.

We tend to be so focused on service delivery that research falls under the radar very fast, it is not the main priority for our organization... So we think that if we have extra money and extra time we can do those things [CBR], educate people at the university, explore opportunities for research with us, those things don't happen on a very proactive way.

While access to research funding is a foundational issue, funding for service provision becomes the priority when it comes to assigning resources to fundraising (i.e., proposal writing). When organizations are in need for supplies, materials, improvement of facilities and program staffing, a focus on research may be considered irrelevant. Research funding is not believed to be a priority.

We apply for funding on all kinds of things, but how important is for us in the whole scheme of things to apply for research funds? If we are going to go after that money and we have other priorities, where does [research] fit in our list of priorities?

Also, it was believed that when organizations are surviving year- to-year, project- to- project, their priorities for seeking funding would not necessarily be on fulfilling their research interests. This was also true for some larger, more established organizations where competing interests and priorities would not make research an easy sell. It was observed that talks about submitting research proposals resulted in the need to carefully weight the funding organizations may receive for a project against the overall budget of the organization quickly cooling off the excitement to embark in such enterprise or at best slowing the process. The optics of potentially receiving as much funds for research as for the operations of the whole organization may put into question on the eyes of outsiders their commitment to providing services.

The mandate of community-based organizations is to provide a gamut of services from prevention, support to treatment. However, organizations strive to provide sound programs and services, participants considered that their mandate did not include research. Community-based research was not a priority for many organizations. As a participant indicated "we tend to be so focused on service delivery that research falls under the radar very fast. It is not the main priority of our organization." Research tends to fall out of organizational strategic planning. Data collection and reporting tend to be done reactively to funders' demands. Sometimes organizations take advantage of some funding opportunity to include research as part of proposals, mainly taking the form of needs assessments, environmental scans and evaluation.

Lack of staff time to engage the community in a participatory process of research as well as funds to carry out meetings and even pay participants for their time for participating, as research partners were the actual or perceived main detriments to conducting CBR.In a case, the participant explained that time required to CBR includes opportunities to learn techniques and methods to conduct CBR.

Apart from the inability to allocate time to research and evaluation, and related to this, is the lack of access to funding exclusively for research and evaluation purposes. Some participants were well aware of the existence of funding sources for research purposes that could be of great help in furthering their research interest; however they did not have the academic credentials to access such funding. Further, some participants knew about the CBR HIV community-based research program of the Canadian Institutes of Health Research; then again, they found the process cumbersome enough to having to invest the time and energy necessary with uncertainty in the potential return. It was believed that funding for research is more accessible to academic researchers than to community-based organizations aspiring to incorporate research and develop evidence-based programs and services.

Partnerships with Researchers and the Community

A number of participants had engaged with university. This relationship has taken different formats from working with academic researchers to providing placement opportunities for students in research or direct service provision. In some cases, participants reflected on the concerns stemming from such relationships.

One of the contentious issues between community-university is the incompatibility of the partners' agenda. While organizations see their role of research to translate into direct and timely improvement of people's health status; they observed that for academic researchers the most immediate motivation may be the focus on the publication of research results, academic requirements and career advancement as for students the motivation may be to pass a course or obtain a diploma. Intellectual interests may clash or not seen compatible with political or service interests.

A clear indicator of the incompatibility of goals between community organizations and researchers is the lack of access to the results of the research. When results were not discussed or at least received by the community organizations, it was believed that the message was that the organizations were again helping others, this time those in actual or potential privileged positions. The end product was the publication itself with no need to extend beyond the academic realm.

Another matter was the perception that community-based research may not be a valued approach of inquiry that is fostered within the academic realm. This barrier would make people difficult to find academic researchers interested or capable to partner in community-based research projects with community organizations and community members.

[It would be important] having people at the university that specialized in CBR (...) I think that what would be a priority for us would be looking for supports on research that would be community-based, instead of feeling pressure that you have to do research this way, and I think that there is some need for capacity building with the university.

Some participants felt that there were also few opportunities available for partnering with academic researchers in HIV/AIDS research. One participant indicated that her organization has been exploring the possibility to partner with a local university for years to no avail.

With respect to the involvement of students, while students' work has been valuable as at least some have been able to obtain copies of research done involving the organizations, in some cases the situation was not different that we other researchers when it came to balancing the agendas. One of the participants indicated that not having the "language" to fully engage in the discussion about the research prevented the organization from providing input into the student's research agenda.

For those who have not engaged in partnerships with university researchers the obstacle has plainly been having "a lot of work to do in terms of identifying academic partners interested in working in this type of research that we would like to do." The barriers were about finding and consulting with researchers to collaborate in the research process, and the lack of experience in negotiating roles and expectations concerning research projects.

In spite of the help from technology, geographic isolation can also be a problem when partnering or accessing resources to conduct research. Distance from research centres and resources, including the Research Technical Assistant, are a barrier to further the research interests of isolated communities.

While much of the focus on partnerships is being directed toward relationship development between community organizations and university, engagement with community members living with or affected by HIV/AIDS is another piece of the equation. With respect to partnering with the community, the main shortcomings are attributed to available resources. However, there were also concerns about "how to involve the community".

A participant from a rural community noticed that “true” community-based research would be a major challenge as communities think that “there are absolutely no people at risk, no gay people, no injection drug user”, and because of this lack of acknowledgment believed to be rooted in stigmatization, people living with HIV/AIDS, those vulnerable for contraction HIV and hepatitis C, and those affected by the epidemics would not come forward to participate in a CBR project for further fear of discrimination. This raises ethical issues in conducting CBR in small communities where people involved are likely to be identified, since “anonymity is not possible”. It also raises an important research problem.

These findings were consistent with findings from our survey conducted as part of the community-based research workshop delivered in September 2005 with community-based organizations, volunteers and students (CUPID Team 2005)⁹.

Research Interest and Priorities

Based on the organizational and personal experience in working in the HIV field, participants were asked to identify the HIV/AIDS related issues that require to be explored using a community-based approach.

Except for those living in Northern, rural and isolated areas, some participants had the view that much research has been or is been conducted. Although some of them were still interested in gaining new insights on research issues, the major problem concerned the lack of translation into action or how research findings get to be translated into benefits to people living with HIV/AIDS.

Access to health and social services

- Access to services by sectors of the population in situations of vulnerability, in particular those least able to access services due to barriers in the health care, justice and social service system. Those working in different environment were interested in exploring the problems around access to services or programs by immigrant and refugees, Aboriginal people, sectors of youth population, people who inject drugs, pregnant women who inject drugs or people in rural and remote areas, among others.

- Barriers to HIV treatment for different sectors of the population living with HIV/AIDS.

⁹ CUPID Team (2005) Community-University Participatory Inquiry Designs: A Community-Based Research Workshop Capacity-Building Workshop Final Report, Winnipeg: Nine Circles Community Health Centre. See: www.ninecircles.ca

- Ethical and human rights issues in accessing services for people who use drugs.
- Assessment of experiences of people living with HIV engaged in the employment and income assistance system.
- Access to traditional healing practices.
- Assessing experiences of access to services by status and non-status Aboriginal people.

Best Practices and Program Evaluation

- Exploring best practices models when working with specific sectors of the population such as youth, adults re-entering the dating scene, or immigrant and refugee communities.
- Program evaluation, i.e., learning about the outcome of services and programs in participants' lives.
- Measuring the impact of services in people's quality of life.

HIV health support and prevention

- Experiences of sero-discordant couples with a focus on communication, sexuality and intimacy.
- HIV positive youth.
- Youth knowledge, attitudes and practices/behaviours.
- Experiences of family and caregivers of people living with HIV/AIDS.
- The experiences of HIV positive staff providing services in AIDS services organizations.
- HIV positive heterosexual men.

HIV health in Aboriginal communities

- Aboriginal people living with HIV/AIDS returning to their rural home communities, reasons for leaving and returning and specific issues faced as result of reintegrating into their communities.

Most issues of research interest were directly related to access to social and health care services. Participants are keen in addressing questions that provide key learnings for their own practice. This in turn would benefit people living with HIV/AIDS by accessing improved services. In some

cases where the research questions were oriented towards systemic issues, they had a social justice undertone.

The Role of the Research Technical Assistant

Participants were asked how the Research Technical Assistant (RTA) of the HIV CBR program would be able to assist with their research needs. This section explores these answers. Participants' vision of the RTA have been categorized under

Access to Resources

Access to resources when working on research initiatives or evaluation of programs was believed to be crucial for community-based organizations. For some participants it was important to access a person who would assist in some of the research activities such as data gathering tool development or data analysis. It was also important to also be able to learn about different methodological options beyond the approaches more commonly used such as focus groups. Participants interested in alternative research options require access to these alternatives. A resource person would be able to conduct such research on their behalf and present the different options to address the research questions organizations wish to explore.

Brokerage

However, in addition to the “technical” support, participants are looking for a person who knows about the realities organizations and the community faces to facilitate appropriate and relevant research, and even assist in the communication between researchers and community.

When an organization has limited knowledge and experience in that to find out that maybe there are other data collection methods that maybe you don't have to use that one, maybe there are resources out there that would help us to see what questions are appropriate to ask ... and maybe realize that we can do data collection and analysis that are valid; but don't have to be invasive and having someone with experience in our side to be able to fully engage in that conversation I think that would have been able to influence the decision.

Technical Support

The RTA was also believed to be helpful in proposal development. Lack of funding for research was a main barrier for organizations to focus on research (see next section). In order to dedicate time and resources to research proposal writing, participants would benefit from specialized support to assure some success in the application.

So I think that the RTA could also provide some assistance in developing proposals, someone we can say does this look like is good, we are having trouble writing this part how can we do this, I think that that could be invaluable.

Technical support could also take the form of “troubleshooting” when organizations are developing their own research projects, tools, translation of findings into programming or helping in gaining contacts to conduct research. Participants believed that having access to a person who could quickly respond to their short-term or immediate research concerns would contribute towards the growth of their research infrastructure. As a “hub of research information”, the RTA would be able to quickly tap into resources needed for any particular research need.

Skills-Building

Participants supported the role of the RTA in conducting capacity-building activities. Based on their experiences as participants of research workshops, interviewees proposed skills-building activities that address the specific needs of any given project or organizational research need.

Participants were also interested in the assistance of the RTA in evaluation aspects of their services and programs.

Conclusions and Ideas for Action

Research Infrastructure

There is a broad understanding and experiences in community-based research in HIV/AIDS in Manitoba and Saskatchewan. However, many obstacles to an established use of research among community organizations present challenges to the flourishing of CBR. The limitations are mostly based on the perceived role of research in relation to other areas of priority and, therefore the resources that are made available towards this matter. Most organizations count on limited resources to dedicate to research and evaluation initiatives. Organizations do not have sufficient or qualified personnel to pursue a strong research agenda.

Yet, there is support to engage in CBR. The development of a research infrastructure that foster and facilitate organizational readiness to conduct research in HIV/AIDS related issues is the goal of the HIV CBR capacity-building program in the prairies.

Manitoba and Saskatchewan have a research infrastructure that could contribute to increasing research capacity of community-based organizations. While in some cases the infrastructure takes the shape of researchers (“human resources”), in some cases this comes with the value added to access to funding. This study exposed some of these elements; however, to capitalize on these resources in HIV CBR research the further development of collaboration to promote the agenda in the Prairie Provinces is required.

Findings from evaluation reports of CBR capacity-building workshops in Winnipeg have repeatedly pointed out to the development of a strategy to sustain CBR work, including the development of a working group, continued support for capacity-building, and support throughout specific research proposals (Bond, 2002; Schellenberg & Hakim, 2001)

Through the findings of this scan the program is urged to explore approaches that incorporate support to organizations in research and evaluation. The following sections address some of the areas for research development and support stemming from this study.

CBR Skills-Building

Design skills-building activities to maximize the time and resources already available in organizations.

The scan demonstrated that organizations count on much strength as much as they face challenges to engage in CBR. To take advantage of the organizational strengths and capacities and, at the same time, provide

opportunities for further skills development, it is suggested that capacity-building activities be tailored to the specific needs and requirements of the organization or organizations involved in the process.

Hands-on approaches to skills-building that are embedded throughout the development of research and evaluation projects – from proposal or framework development to deployment and knowledge translation – are recommended.

Paying close attention to what each organization needs at any given time would maximize the resources already available in the organization and at the same time prevent from using time and resources that would be best used in organization. These activities must be designed to attend to the needs, time and resources available at any given time in each organization requesting guidance, resources and training.

Develop flexible education delivery models to accommodate the research needs of organizations and communities.

The design and delivery of research skills-building activities will require to paying close attention to the specific requirements of the organizations at any given stage of research processes, including at the proposal development stage.

Among this task are: collection and sharing of resource materials, development of topic specific workshops such as ethics in CBR, partnership development, basic research approaches, and translation of data into programming or policy direction. Stand-alone workshops should also become part of the battery of services available to organizations and community groups. However, the emphasis should be on the delivery of workshops as related to specific identified needs that could be easily translated into practice by the organizations.

Written materials supporting education activities need to accompany these activities. That way, the material would be available for sharing among staff not able to participate in the sessions. The material could also be utilized independently of training sessions.

Development of training modules that could be easily adapted for application with any specific request for capacity building activities or consultation with any given organization would assist in meeting the diverse needs of individual organizations.

Partnership Building

Explore the development of collaboration between academic and research centres, and community organizations towards the advancement of a CBR culture.

Manitoba and Saskatchewan have research resources that could contribute to increasing research capacity of community-based organizations. Trained researchers housed in university or research centres could be valuable resources for community organizations seeking access to research resources, including funding opportunities. Collaboration between researchers and community organizations, and community members can be enhanced by:

- Promoting the exchange of research experiences.
- Exploring possible partnerships with other researchers, including academic and non-academic, in the development and assessment of training modules and research resource materials. These researchers could play different roles in the process of capacity-building resource development from providing feedback to becoming full partners in the development of the material.
- Enhancing and maintaining the communication exchange between ASOs/CBOs and researchers through face-to-face meetings.
- Exploring the role of students in the partnerships.

Building a Culture of Research

Promote all aspects in which the program can support community organizations in their research interests

The program should support organizations on a variety of approaches. All these approaches would result on a strengthened culture of research on HIV and related matters. Some of the suggestions are to:

- Support the development of relevant and needed research (e.g., the most affected communities should become a priority).
- Share research findings in plain language.
- Explore the existence, and also develop a directory of, funding sources for HIV CBR research that could, in part, stimulate the inclusion of research as part of organizational planning.

- Promote the HIV CBR Capacity-Building program on a regular basis to create ownership of the resources available to all organizations with interest in HIV research.
- Enhance and maintain the communication exchange between ASOs/CBOs and researchers through face-to-face meetings.

It is also imperative to find creative ways to support organizations away from larger centres. Small organizations in resource limited areas, in particular without contact with research centres or access to resources, require increased attention.

The HIV CBR program should assist organizations in their pursuit for funding for research. However, an alternative would be to assist organizations to incorporate research and evaluation capacity-building activities within their regular program or project proposals.

The development of the environmental scan assisted in the promotion of the work of the RTA and development of relationships. However, the geographic distance between the site of residence of the program, Winnipeg, rural and Northern Manitoba and Saskatchewan continue to be a barrier to the realization of the full potential of the program for organizations in those areas. Realistically, the work across provinces requires extra resources as the reality of the provinces in terms of resources available and research priorities differ. To maximize the work, regional meetings with attendance from different organizations involved in HIV related research projects may be step to harness energy for the development of partnerships for the development of relevant research projects and develop a creative plan to better access the services of the RTA.

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Resources

Manitoba AIDS Service Organizations and Programs¹⁰

- **Kali Shiva AIDS Services**
- **Manitoba First Nations AIDS Working Group (MFNAWG)**
- **Manitoba People Living with HIV/AIDS (PHA) Caucus**
- **Nine Circles Community Health Centre**
www.ninecircles.ca
- **Northern AIDS Initiative**
www.northernaids.ca
- **Play It Safer Network** (Manitoba and Saskatchewan inter-provincial network)
- **Rainbow Resource Centre**
- **Resource Assistance for Youth**
www.rayinc.ca
- **Sage House**
www.mountcarmel.ca/programs.community.htm
- **Sexuality Education Resource Centre**
www.serc.mb.ca
- **Teen Talk**
www.klinic.mb.ca/teentalk.htm

Saskatchewan AIDS Service Organizations and Programs

- **AIDS Programs South Saskatchewan.**
www.aidsresourcesask.ca
- **All Nations Hope AIDS Network**
www.allnationshope.ca
- **The Avenue Community Centre for Gender and Sexual Diversity** (former Gay and Lesbian Health Services)
www.avenucommunitycentre.ca
- **Planned Parenthood Regina**
www.regina.pafc.info
- **Sexual Health Centre Saskatoon**
www.saskatoon.pafc.info

¹⁰ This list is not exhaustive as other small organizations may at any point in time access funding for HIV related projects.

Research Institutions and Centres

- **Canadian Centre on Disability Studies**
www.disabilitystudies.ca
- **Community University Institute of Social Research**
www.usask.ca/cuisr
- **Health Quality Council**
www.hqc.sk.ca
- **Indigenous Peoples' Health Research Centre**
www.iphrc.ca
- **Institute of Urban Studies**
<http://ius.uwinnipeg.ca>
- **Manitoba First Nations Centre for Aboriginal Health Research**
<http://www.umanitoba.ca/centres/cahr/resources/resources-links.html>
- **Prairie Region Health Promotion Research Centre**
www.usask.ca/healthsci/che/prhprc
- **Prairie Women's Health Centre of Excellence**
www.pwhce.ca
- **Saskatchewan Population Health and Evaluation Research Unit**
www.spheru.ca