

# **Knowledge from Action**

Community-based Research  
in Canada's HIV Strategy

written by

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for Health Canada

under contract with AIDS Vancouver

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# FORWARD

Like so many other people from communities across Canada, I had the privilege of being part of the Canadian AIDS Society's Men's Survey 91, a national survey of gay and bisexual men. As coordinator of the national study, I was motivated by the hundreds of community volunteers who participated. I was also intrigued by the information produced from the gay and bisexual men's community, a community so deeply affected by HIV/AIDS.

What inspired me was the capacity of our community to create knowledge from action. If we are to manage this epidemic in the coming years, we must be able to devise creative ways for vulnerable communities to have greater control and influence over their health. Fundamentally, this is what health promotion is all about.

An example of the success of our community was last year's renewal of Canada's National AIDS Strategy. As a result, we can look ahead with some confidence to a Strategy that will be in place to assist us in meeting the challenges of this epidemic. Our coast-to-coast advocacy efforts were effective because they were backed by community research. If we are to continue to reorient the health care system, communities must have the opportunity to research their own realities. If we are to expand our prevention efforts, then we must have access to funds that will enable us to research and evaluate the success of our programs.

The Canadian Strategy on HIV/AIDS offers \$1 million each year to community-based research efforts. The potential for community-based research to have an effect on the epidemic is enormous. This document represents our contribution to the discussion about that capacity. We also hope to help prepare community AIDS groups for this research opportunity. A responsive research program must be developed to understand the questions communities want addressed. The program must also support community groups and members as they manage research projects and involve research activities in their agencies.

Like many agencies across the country, AIDS Vancouver has a tradition of doing community-based research. That research has often gone unrecognized. We have learned, however, to develop a greater capacity to do research so that our programs and services are more responsive to the communities we serve. We have learned not to make assumptions about who needs our services and what they need. We have learned to listen rather than ordain. The work must continue.

**Andrew Johnson**  
**Executive Director**  
**AIDS Vancouver**

# INTRODUCTION

## Background and purpose

Community involvement in research activities has been evolving along with developments in organized community action on HIV/AIDS since the onset of the epidemic (*Myers & Allman, 1995*). Even so, the capacities of communities to develop valuable local knowledge about HIV and AIDS have remained under-recognized until recently, even amongst organizations themselves. For their part, community organizations have been apt to see direct action on HIV prevention, health promotion, treatment and support as their main priority.

But attitudes about community-based research are shifting. A clear sign came from an event held at the XI International Conference on AIDS in Vancouver that drew more than forty community-based research practitioners from every region of the world. Up until that point, most participants had felt themselves to be working in isolation with possibly idealistic notions about research initiated and controlled by communities. In the two days that followed, that diverse group of community researchers discovered their experience was global. Their meeting produced a powerful and coherent statement (*Trussler, 1996; see appendix for text of statement*) on a world-wide community-based research strategy for HIV/AIDS which is still just beginning to unfold.

In Canada, calls for action on community-based research appeared during the consultation process toward renewal of the National AIDS Strategy for a third phase. Those discussions were widespread and included suggestions and recommendations from a variety of perspectives: research professionals, national stakeholders and community representatives alike. The Strategy renewal consultation process was indeed the first clear indication that both research professionals and community workers valued knowledge development activities at the community level enough to move the idea toward a strategic plan.

The purpose of this document is to organize a conceptual framework for such a strategy: to build the capacities of communities to conduct needed research on HIV/AIDS.

## Scope

This project was undertaken to assemble information on and to provide direction for HIV/AIDS related community-based research experience in Canada. So little previous attention has been afforded this work that the actual extent of research activities in community agencies is difficult to truly know. This document describes only the main themes, issues and experiences and offers concrete suggestions for moving forward on a strategic plan to develop capacities across a broad spectrum of players for meaningful, relevant and worth-while knowledge acquisition from community action.

## Methodology

Concepts, experiences and suggestions for this project were gathered from several sources: a selection of relevant documents; readings from a sample of the current literature on post-modern developments in social science methodology; and a series of key-informant interviews.

# WHY ENHANCE COMMUNITY-BASED RESEARCH?

The prospect of enhancing the research capacities of communities is rich in potential to achieve greater control of HIV/AIDS in Canada. Not only would such a move acknowledge the experience of HIV affected communities, but it would also improve knowledge development and dissemination throughout the health system. All this ultimately to develop new ways of addressing the epidemic with improved policy, programs and services. The following points provide an outline of what would be accomplished by building capacities for community-based research, not only within community agencies themselves, but as well, amongst all partners in Phase III of what is now known as the Canadian Strategy on HIV/AIDS (CSHA).

## **Community experience & information**

Valuable information on local epidemiological dynamics exists in the experience and records of community agencies. For example, information on HIV expansion into injection drug using (IDU) populations was available to the BC Persons with AIDS Society and AIDS Vancouver through outreach and intake programs in 1995. By 1997, the situation had exploded into front page news. Building the research capacities of community AIDS groups would enable them to provide the data on critical trends to health authorities. If heeded, this evidence could ensure a more timely and effective response to early warning signs.

## **Mobilizing HIV health promotion**

Community environments affect the way people live and each has its unique characteristics, issues and problems. Community organizations need good information about the social environment to interest, motivate and mobilize their populations for HIV health promotion. This means communities developing strategies that enable greater control of conditions affecting HIV/AIDS. Enhanced research activities would not only help provide needed evidence for confident decision making, but also important tools and skills for active, meaningful and convincing participation in community health efforts.

## **Community practice**

The rigours of documentation and interpretation of information are a quality-of-practice issue for community personnel. Those who have had research experience recognize immediate gains in their work and obvious improvement in their organizational capacities. Community-based researchers believe that building the capacity for research builds the general capacities of HIV/AIDS agencies (*Trussler & Marchand, 1997*).

## **Research participation**

Developing the research capacities of AIDS agencies would allow better information flow between researchers and communities. Academic researchers will recognize new opportunities to tap into community knowledge available from skilled community-based researchers and frontline workers. A national network of qualified community-based research personnel would create an effective liaison between vulnerable communities and clinical, epidemiological and social scientists.

### **Research knowledge coordination**

Coordination of available knowledge from HIV/AIDS research for best policy and practice development is a recognized need by all partners of the Canadian Strategy on HIV/AIDS (CSHA). Community participants need to be well informed about research findings to be effective with their programs. Better links between social science, epidemiology and community programs would be helped by building the capacity for communities to be involved in developing the “big picture.” This could be achieved by the greater participation of communities in research ventures, in which they control the agenda.

### **Policy development**

Time has shown that the experience of HIV/AIDS affected communities is critical to the development of public policy at all levels of government and the health system. Community AIDS groups deal with the lived experience of AIDS and spend much of their time advocating for social change. Affected communities so often have provided the social and political momentum for improvements in the health system and health policy. Improving system-wide capacities to embrace and enable community-based research would enhance the quality of evidence required for effective decision making on emerging issues.



# WHAT MAKES RESEARCH COMMUNITY-BASED?

Community-based research (CBR) is all about inquiry initiated by and for community interests. CBR is a way of doing research: by developing and employing the inquiry skills of community participants. CBR is also an orientation toward research: affirming the primacy of community interests in developing knowledge. Community-based research is about developing an environment of learning — a literacy of research — where community groups and members are stimulated to learn about how to create knowledge from real-life action.

## **Scope**

CBR may involve a wide range of systematic activities:

- organizational planning
- literature review
- needs assessment
- interview, focus group, survey inquiries
- program and/or services evaluation
- agency impact/outcome evaluation
- community health ethnography
- social science studies
- epidemiological assessments

## **Participation**

Who initiates is the key to understanding the dynamics of participation in community-based research. Who frames the research question and who drives the agenda forward define the difference between community-based and traditional social science. Even so, the degree of professional involvement may vary widely, but the community must manage the research process for a project to be considered community-based.

The mix of community and professional involvements may be diverse:

### **☐ Empowerment research**

Community activists organize programs which enable community members to answer information needs vital to their health issues, using expert advice or guidance only as needed and on their own terms.

### **☐ Research-in-practice**

Community personnel may use research skills and techniques in their everyday work: documenting, reviewing and periodically reporting on the impact and outcomes of initiatives.

#### ❑ **Research consultant**

A community agency may hire an experienced consultant to conduct studies or evaluation research on an occasional basis. Community participation is built-in to the design of the project. Degree of participation in the process may vary according to availability, however, the consultant is directed by community interests who own the project, the data and the product of the work.

#### ❑ **Research staff**

A community agency may also employ qualified personnel (e.g. graduate/post graduate training) to lead action research initiatives, provide evaluation services, analyze data-base trends, conduct studies of the population, educate personnel on research roles and practices.

#### ❑ **Investigator-initiated action research**

A professional researcher linked to a university approaches a community agency or advisory committee on a health question of mutual interest. The researcher's adopted methodology is to lead the community through framing the questions, collecting information, interpreting data and reporting results. Community members perform all the research activities. The professional's role is in facilitating research rather than actually doing research.

#### ❑ **Professional partnership**

In this relationship community leaders approach professional investigators with their information needs to negotiate a project, which may lead to a research proposal or addition to an on-going study. Professionals provide time and technical know-how to get answers. Community participants ask the questions.

### **Stakes in knowledge**

Community-based organizations have a stake in developing knowledge to:

- support community advocacy
- focus programs on specific factors affecting community
- know trends affecting a population or clientele
- develop new thinking and forms of action
- develop organization and personnel capacities
- participate in interagency dialogue
- promote policy reform.

### **Practicalities**

Research costs time and money. Although most organizations could benefit from research and evaluation activities, more immediate priorities often override. Some of the resources needed:

- motivated personnel (staff, volunteers, members)
- expert assistance (volunteer, consultant, professional)
- office space and computer
- time allocated specifically to research activities
- communication/publication links (copying, e-mail, internet)
- funding.

## **Constraints**

Not everyone agrees that research is necessary or that evaluation is the most effective way to interact with communities. Some of the reasons people give for avoiding research may be legitimate or simply a fear of the unknown.

- frontline personnel may think they know the impact of their programs intuitively so resent another challenge
- extra work is required of already over-tasked managers to make research and evaluation easier on frontline personnel
- specific training time and effort may be needed to upgrade skills for research and evaluation in an already packed agenda
- evaluation may be perceived as a job threat or at least a threat to personal assumptions about the quality of one's work
- getting frontline personnel to condense what they do in writing is abstract work which is difficult to find time for amongst other competing demands
- there may be not only a lack of research capacity, but just plain resistance.

# COMMUNITY EXPERIENCE WITH HIV RESEARCH

Significant learning developed in community-based research throughout the work of Phase II of the National AIDS Strategy. Most of the research experience gained by community-based AIDS organizations has been in the form of needs assessments, program evaluation and other informal investigations. The following is not an exhaustive account but a broad review of the research efforts conducted with the involvement of or by HIV affected communities.

## Surveys

*Men's Survey* (Myers, Godin, Calzavara, Lambert & Locker, 1993), a national-scale research project of the early 1990s, is a significant reference point for many working in community AIDS groups. The survey of 4,800 men is an example of a research partnership among community members, professional researchers who considered themselves community members and academic researchers. Procedures involved the cooperation of community organizations across Canada. Many community volunteers had their first experience with research during that study. A similar community level survey using saliva testing was conducted in Winnipeg (Myers, Calzavara, Morrison, Marchand, Major & Allman, 1995).

Numerous surveys have been conducted by agencies themselves. Notably, the BC PWA Society organized a widely heralded study of member migration patterns in partnership with the BC Centre for Excellence in HIV/AIDS (Schilder, de Haan, Hogg, Goldstone, Le & Craib, 1993). Other groups conducted surveys to evaluate services and to measure local shifts in reported HIV related behaviour.

## Ethnocultural studies

The Ethnocultural Communities Facing AIDS project brought together academic researchers with community participants across Canada. The research process provided ethnocultural communities with opportunities to participate in research (Brabazon, Bercovitz, Dospital, Gunter, Mangat, Manson Singer, Tweedlie & West, 1993) that sparked some to conduct their own locally focused studies.

## Needs assessments

Although not a formal study, a national health promotion needs assessment (Pickel, 1993) took place during NAS II. This brought together information from focus groups held in major centres across Canada on the health needs of people living with HIV. Community-based organizations also conducted a plethora of smaller scale needs assessments concerning local issues such as outreach to women, ethnocultural communities and rural MSM.

## Evaluation

Several community organizations have hired research consultants for internal evaluations. Experience has been growing with small scale program evaluation, however, there is much confusion concerning what to look for and how to document it. An attempt to develop a universal model, *The Hands-on Guide to Planning and Evaluation* (Wong-Rieger & David, 1993) achieved some applicability. Community groups are now preoccupied with developing experience with outcome evaluation.

## **Determinants of risk**

Community groups have been involved in various ways in studies investigating qualitative factors influencing HIV risks. Members of the Determinants Research Teams have met to exchange ideas, data and research experience.

## **Policy research**

The Canadian AIDS Society (1997a) and Canadian HIV/AIDS Legal Network (Jurgens, 1995) have conducted legal and policy analysis for use in HIV advocacy. Other approaches have included journalistic research. One such effort, described in *Paradigms Lost* (Wong, 1997), probed Health Canada's policy shift toward a population health model.

## **Treatment research**

Treatment activists have met and put forward priorities for treatment research in Canada (*AIDS Action Now!*, 1993). Communities have now developed networks of treatment activists advising on everything from research and clinical trial protocols to ethics. The Canadian AIDS Treatment Information Exchange (CATIE) and a network of treatment projects across Canada enable research to be disseminated in plain language and community members to carry out consumer research into complimentary therapies, medication interactions and side effects. This is an area where community capacity has excelled.

## **Focus groups**

Community-based organizations have been using focus groups to gain an understanding of their clients and the communities they serve (Maxwell, 1998; Maxwell, 1996; Taylor, 1997). Such efforts have often developed out of program activities and are sometimes not seen as research until an outside expert has pointed it out. In one such case a youth organization used video to document the sexual safety issues of high school students without realizing the value of the data until they showed the tape to an epidemiologist.

## **Health promotion**

While uncovering and developing the health promotion practices of community-based agencies across Canada, the National Health Promotion Project brought forward a realization: the most effective programming and service efforts had research processes underlying them (Trussler, 1995a). Research skills integrated into frontline practice became a theme of the project's education strategy, which included a *Field Guide* (Trussler & Marchand, 1997) and a portable workshop. Several small scale studies are detailed in the publication.

## **CBR at the end of the National AIDS Strategy, Phase II**

Observers in our scan of the field have pointed out that many community-based organizations have been engaged in research processes, some without realizing it. Community workers have also been increasing their participation in conferences by presenting abstracts at the Canadian Association for HIV Research (CAHR), the BC AIDS Conference, the International AIDS Conference, AIDS Impact, and others.

### **❑ Small scale**

Community AIDS groups from every province have been using research consciously. Some organizations may feel unable to conduct research, and yet are actually doing research in various forms connected with everyday organizational life such as tracking program stats, annual planning, keeping board minutes.

### **❑ Qualitative**

One observer pointed out that most of the recent CAHR submissions from community organizations were qualitative research. Community groups have been calling for qualitative studies for years, especially to better understand and unpack the demographic and epidemiological data that are circulated to communities. The use of qualitative research is increasing in the health system because it provides a way to uncover useful information about health experience. Yet, qualitative research paradigms continue to meet with confusion and skepticism. Few people are able to move comfortably between qualitative and quantitative methods.

### **❑ Unguided**

Community organizations venturing into research often receive little expert and experienced support except where funding has allowed hiring research consultants or developing professional partnerships.

### **❑ Uncoordinated**

Certainly most observers agree that community organizations may be gathering important data but that few outside the local scene are aware of it. Except for the annual CAS meeting, the BC AIDS Conference and the annual CAHR Conference, there are few venues to disseminate findings and have discussions with community colleagues about what works or what is emerging. With little monitoring of nation-wide knowledge development at the community level, it is very difficult to coordinate studies or evaluate progress.

# OPPORTUNITIES TO ENHANCE CBR IN CANADA'S AIDS STRATEGY

As Phase II of the National AIDS Strategy (NAS II) began to wind down, individuals, agencies and stakeholders — representing a broad cross-section of the AIDS field — brought forward the subject of community-based research (CBR) from several different perspectives:

- potential for CBR in collaboration between academic/university/institutional researchers and communities
- integrating CBR in prevention and support programs; marrying research with service delivery
- independent CBR managed by community agencies with internal skills, or hiring and managing a researcher or research consultant
- funding for “independent” CBR
- board seat for CBR with the Canadian Association for HIV Research (CAHR)

## Community-based research in Phase III consultations

What follows is a brief review of how the subject of community-based research was handled in discussions during consultations toward the renewal of the Strategy. These suggestions pave the way for a coordinated approach to developing CBR — one that recognizes community-based research as a key way to address the goals of the Canadian Strategy on HIV/AIDS.

### □ National Planning Forum for HIV/AIDS Research

Researchers recognized the following in their position statement (*National Planning Forum for HIV/AIDS Research, 1996b*):

- the high degree of information gathering and knowledge development potential in community agencies across Canada
- the need to facilitate participatory research strategies which include communities in the design, development, and dissemination of findings
- the need to develop systems of communication to disseminate findings to non-scientific audiences
- the desirability of more direct links between research findings and program/policy development

### □ Canadian Association for HIV Research

In proposing recommendations for the third phase of the Strategy, several suggestions anticipating CBR came forward (*Canadian Association for HIV Research, 1997*):

- recognizing four areas of research: basic and clinical; population health and epidemiology; social science; community-based initiatives
- inclusion of community representatives on research grant review committees in basic and clinical research; population health and epidemiology; community-based research initiatives; social science research
- funding for community-based researchers with expertise in targeted interventions or evaluation and ability to promote skills building and information transfer to affected communities

- a National Research Priorities Panel which would include community stakeholders amongst researchers and policy makers

Subsequent points made by CAHR clarify its recommendations:

- CBR is needed research — time needs to be invested to make it work
- peer review for CBR must be truly the peers of community research — not the academic researchers and scientists
- need a panel to monitor CBR to make sure it produces deliverables
- think long term for CBR to evolve and mature
- develop a fair process to deal with competitive aspects of funding
- Health Canada should provide training for communities in CBR funding issues, including sources of funds, how to apply, subjects of interest
- keep in mind that not all community research will be successful — neither is all research in other areas of science successful
- CBR funding may seed research in communities that will expand to other sources of funding if productive

#### □ National Stakeholders NAS III consultation: recommendations

Several recommendations suggest developments which could affect CBR (*National HIV/AIDS Stakeholders Group, 1997*):

- enhance prevention-related research, planning and evaluation
- stimulate organizational development in existing community-based agencies
- develop standards for core community services
- improve partnership between communities and researchers through all research stages from concept design to dissemination of results and evaluation of projects
- facilitate access to and standardization of community controlled data bases for observational research purposes

#### □ Summary Report of consultations for renewal of the strategy

Consultations brought forward a sense of general agreement across sectors that the Strategy should support community-based research. Suggestions included separate funding for community-based research and to establish a centre for excellence in community-based research (*Centre for Health Promotion, University of Toronto, 1997*).

#### **Research issues raised:**

- better coordination between research, policy and practice was an overriding theme
- need to facilitate collaboration between researchers and communities, increasing opportunities for knowledge sharing
- need to somehow balance the goals of researcher and the goals of community without creating another layer of bureaucracy
- community-based research is key to linking research with policy and practice

#### **Priorities for CBR:**

- research that identifies best practices for prevention and education
- research that answers the questions community agencies have regarding effective action



**Principles for CBR:**

- community initiated
- community ownership of process and outcomes
- peer reviewed

**Capacity building:**

- need for community agencies to increase capacity for planning and evaluation
- facilitate mentoring relationships between researchers and communities
- provide scholarship funding to build research skills in communities
- integrate capacity-building into research
- involve community participants as co-researchers rather than “subjects”
- suggestions for establishing a centre for excellence in participatory research and establishing a centre for excellence in community-based research were both put forward

**Coordination:**

- NHRDP funded projects
- proposed National HIV/AIDS Research Committee: to advocate, identify priorities, monitor progress, ensure dissemination, advise on policy — bringing together researchers, communities and policy makers

**Ethics:**

- meaningful and relevant community participation should be an ethical standard of HIV/AIDS research

**CBR assets from National AIDS Strategy, Phase II**

As experience with NAS II has shown there are worthy foundations to build on with regard to planning and implementing activities which would enhance CBR in the third phase of the Strategy. The following is an overview that highlights existing strengths and resources.

**□ CAS Safer Sex Guidelines**

The third iteration of the *Safer Sex Guidelines (Canadian AIDS Society, 1994)* is now in progress, building on years of community-based experience — a unique Canadian contribution to HIV/AIDS prevention recognized world-wide. The procedures used to identify and evaluate the guidelines involve extensive consultation and feedback with participants across Canada — in great measure a product of community-based research.

**□ CATIE**

A growing number of people are accessing the programs and services of the Community AIDS Treatment Information Exchange. CATIE organizers consider the development of treatment information a form of research. The agency empowers consumers to conduct their own treatment investigation and to act as providers of treatment consumer research — treatment research by and for consumers (*Lyons, 1997*). CATIE also has excellent experience with broad dissemination of information.

### ❑ National Health Promotion Project

This project (*Trussler & Marchand, 1997*) produced several promising developments for CBR:

- national case model research discovered that research practices form the core of exemplary community-based health promotion efforts
- publication of the *Field Guide* — addressed the integration of research practices in community-based organizations to build skills and enhance capacities
- a portable workshop *Study-Plan-Do* introduced how to integrate research into agency programming; the workshop proved highly successful with community personnel

### ❑ Concepts, Definitions and Models for CBR: planning guide

The extensive literature review and planning questionnaire contained in this publication (*Allman, Myers & Cockerill, 1997*) will be helpful in orienting communities to the concepts of community-based research. This volume was produced by the research team of the HIV Social, Behavioural and Epidemiological Unit of the University of Toronto Faculty of Medicine, responsible for the *Winnipeg Men's Survey* and other community studies.

### ❑ Community Research Initiative of Toronto (CRIT)

The Community Research Initiative of Toronto is a relatively small agency that has organized around community-based treatment studies. Its work recognizes that people living with HIV and AIDS often identify significant research issues. In cooperation with the Canadian HIV Trials Network and the HIV Ontario Observational Database, CRIT has produced a publication, entitled, *A Workbook for Community-based Research: A guide for the HIV/AIDS community (1996)* and workshop to assist researchers, health care professionals and community members develop research from treatment experience.

### ❑ Epsilon: community self-evaluation

COCQ-Sida has produced a self-evaluation guide (*Jalbert, Pinault, Renaud & Zuniga, 1997*) for community-based HIV/AIDS organizations that acknowledges the research processes which may be involved in everyday practices of agency life such as annual planning. The guide affirms the culture of community AIDS organizations and presents evaluation as a valuable way to enhance ongoing activities.

### ❑ BC AIDS Conference panel discussion on CBR

The 1997 BC AIDS Conference drew together a panel to entertain controversial questions about research in communities. The transcript ("*Community-Based Research: Who Will Listen?*", 1997) is available for use as a think piece on the ethics of community-based research.

### More CBR experience

The following points are worth noting for the way they may figure in planning.

### ❑ International developments

International community linkages have indicated increasing interest in CBR:

- Community Forum of the XI International AIDS Conference 1996, held a strategic planning session on CBR and produced a policy document (*Trussler, 1996; see appendix*)

- several papers at AIDS Impact in Melbourne 1997 featured CBR experience (*Baxter, 1997; Gilbert, 1997; Halkitis, 1997b; Mackie, 1997; Marchand, 1997a; Woolcock, 1997*)
- Community Rendezvous of the XII International AIDS Conference 1998 included a special session on CBR
- experience with in-house research, New Zealand AIDS Foundation (*Marchand, 1997b*)
- health promotion related research in UK (*Terrence Higgins Trust, 1996*)
- popular education methodology in Latin America, for example in Chile (*Corporación Chilena de Prevención de SIDA, 1997*) and Brazil (*Klein-Alonso, 1997*)
- community development research in Africa

### □ Field consultations

The following observations came forward from a diverse panel of experienced participants consulted for this strategy document:

- research is needed on how to accommodate new realities of HIV in injection drug using (IDU) populations, to revive the prevention effort for gay men, to track community support efforts
- community agencies already collect important data (*Graham, O’Brian & van Steenes, 1998*) but may not have capacity to interpret it evaluatively or comparatively
- research capacity building is required for effective evaluation of community programs
- communities need to be able to ask “Why?” on every aspect of research and therefore need education in research practices to be able to participate effectively
- Laboratory Centre for Disease Control (LCDC) surveillance and testing protocols do not always reflect the same priorities and ethical considerations as community groups (*Watershed Writing & 2-Spirited People of the 1<sup>st</sup> Nations, 1996*); community AIDS groups do not want to be competing for research dollars with LCDC and want separate and peer reviewed funding streams developed for community-based research
- community agencies will need research skills to be successful in the health regionalization process, for evaluation and advocacy with local and regional health boards or councils

# TENSIONS AND CHALLENGES

Differences in perspectives between researchers and communities can hinder optimal outcomes from studies (*Myers & Allman, 1995*). On one hand, researchers have access to the skills, the knowledge and the funding to produce knowledge, but may not have developed trusting relationships with the community. On the other hand, HIV/AIDS agencies have access to raw community experience, but their priorities and capacities may get in the way of producing the knowledge they need to fine-focus their actions. A partnership is necessary. But the power differentials make the relationship uneasy. Some tensions may be overcome by community access to research funds and building research capacity in communities. Even so, structural differences between academic reward systems and community service realities may be insurmountable. A study of these tensions is worth considering not only to condition any expectations for easy solutions, but also to clarify the challenges that lie ahead if any improvement is to be brought about.

## **New ethics of community research**

An increase in HIV infection in populations using injection drugs, and the evolving state of HIV prevention have underscored the need for more information about the efficacy of programs within many community AIDS agencies themselves. HIV studies of the past have, however, raised critical consciousness about the finer details of community research ethics. Relationships with communities have become far less certain for researchers, as shown in recent experience with the intense scrutiny of research in aboriginal communities (*Watershed Writing & 2-Spirited People of the 1<sup>st</sup> Nations, 1996*). At the same time, current developments in social research methods favours maximizing participation in every aspect of research done “with” not “on” communities (*Frankish, George, Daniel, Doyle-Waters & Walker, 1997; Stringer, 1996*). This only adds to the jeopardy of professional researchers who receive no particular reward, in academic terms, for community-mindedness — that is, except to publish their completed work.

## **Outcome evaluation**

Community HIV agencies are under increasing pressure from health care reform to show evidence of outcomes resulting from their funded programs. Such evidence requires research knowledge few organizations have at their disposal and fear is growing that evaluation may be used as a tool to decrease or eliminate funding to organizations. Experience with less sophisticated research has only bolstered cynicism amongst community agencies when it is discovered their evaluation reports were not even read.

### **Medical vs. social science**

Even in the face of mounting evidence of the failure of behavioural science to produce expected outcomes (*McKinlay, 1996*), lingering attitudes toward alternative approaches to human studies continue to frustrate developing new knowledge. Some social scientists argue that Canada has funded little social science as it is. Community-based funding will only further fragment limited resources. Skepticism that qualitative research can produce universal knowledge as opposed to mere local relevance creates a further divide even among social scientists. Since most community studies currently submitted to CAHR are qualitative, the results of community research have remained under-valued.

### **Health policy politics**

Even if CBR produces relevant knowledge, who will listen? Many observers believe that medical scientists hold dominant power in health policy decision making which includes specifying the criteria for evidence. The process raises much cynicism but structural change may be difficult to achieve.

### **Academic independence vs. collective action**

Academic culture is competitive where community culture is collective. Academic survival requires publication based on the appraisal of other academics not on the utility of knowledge for community action. One community observer outside of Canada has suggested that these dynamics have produced largely useless knowledge from HIV prevention research, in terms of supporting any renewal of HIV /AIDS prevention efforts (*Baxter, 1997*).

### **Research rigour vs. agency life**

The work culture of community-based AIDS agencies is primarily focused on client needs. While agency personnel may be interested in what may be learned from research, their capacities are sometimes undeveloped. Research, whether conducted in-house or in partnership with academics, needs time, focus and abstract thinking in the face of urgent day-to-day priorities. Disciplined knowledge production is difficult to achieve in community environments.

# A STRATEGY TO DEVELOP CBR

A long term Canadian Strategy on HIV/AIDS provides an excellent opportunity to develop community-based research. It allows for a suitable time period with which to set up a plan, build capacity, manage explorative projects and evaluate the outcomes and impact on programs, organizations and communities. The question is how? What sort of strategy would set CBR in motion as a distinct move beyond the ad hoc activities which have preceded it? What would be reasonable to expect from such a move? How might CBR development impact on HIV/AIDS? What might a good return on the investment look like?

## **Developing CBR**

Good strategy should make one key move, decisive enough to pull an assortment of activities into form — at the right time, the right place, and under the right conditions. The obvious focal piece for CBR development in the Canadian Strategy on HIV/AIDS (CSHA) is discrete funding for CBR. However, close attention to the supporting detail will be necessary to make this work. Research-specific leadership will be needed to invite communities into the process and support their development. The following sketch sets out a scenario for developing system-wide capacities to embrace the role of communities in research on HIV/AIDS in Canada.

### **Basic steps:**

- Funding Announcement — Request for Proposals (RFP)
- Application Guidance for Communities
- Project Selection Activities
- Organizational Development
- Researcher/Frontline Team-building & Network Support
- Publication and education
- Link to policy and practice; advocacy
- Outcome evaluation

### **Key Elements:**

- CBR Funding Program
- Existing Structures
- CBR Centre
- Web Site

Ideally, at the end of the first five year period, communities would be using CBR in mounting the advocacy challenges which will arise as the HIV epidemic evolves and as federal/provincial/territorial health reform continues in Canada. Communities are also looking to community-based research as a critical tool for making prevention efforts more effective and care, treatment and support programs and services responsive to the changing needs of persons living with HIV and AIDS.

## **Priorities prior to announcement**

Consultations on the Strategy's renewal suggested the National Health Research and Development Program (NHRDP), supported by the HIV/AIDS Policy, Coordination and Programs Division, should play the lead role in establishing and managing a CBR funding program.

Communities want to play a role in defining research priorities prior to a first funding announcement. Community informants have suggested regional priority setting, then national. Some groups are now ready to participate while others may want and need skill development opportunities. A steering group of experienced community researchers may be best to develop the process for establishing community research priorities and to govern a peer review process, once applications have been submitted.

## **Application guidance for communities**

Community funding will attract attention, but, given the uneven state of research capacity in AIDS agencies, consideration will need to be given to the preparation of participants to apply. Many community agencies will need to contract the services of a researcher to negotiate the funding proposal. Application guidance may need to take the form of workshop activities, to set out parameters and provide assistance through the new procedures. NHRDP and the HIV/AIDS Division may want to work together on developing this support.

## **Project selection activities**

Peer review will be a new phenomenon for community agencies and, as such, setting up the process will take care. Qualified reviewers will need to come from communities rather than traditional research colleagues. The amount and allocation of funding is still in question but the number of projects should be considered strategically. Keeping the number of projects relatively small would likely facilitate higher quality studies and a manageable network, however, at the expense of broader coverage of topics and regional or cultural interests. A phase-in period should be considered building up from small and manageable projects in the first years.

## **Organizational development**

While research activities are not entirely new for community organizations, dedicated funding is. All agencies involved will need to account for this, working to facilitate community participation in the most empowering way possible. Accommodation will need to be made in existing organizations and new structures will need to be put in place to support the new venture.

## **Existing structures — developing the community research network**

Linking existing structures to accommodate CBR will be important to the success of this strategy. All parties stand to gain from knowledge development, however, the project constitutes extra, albeit important, activity in an already crowded agenda.

□ The **Canadian Association for HIV Research (CAHR)** can play a critical role by implementing its own suggestion of creating a separate category for CBR, a dedicated board seat and by having a community representative in all other tracks.

□ The **National Health Research and Development Program (NHRDP) and the Prevention and Community Action Programs (PCAP)** will find their experience with the Determinants of Behaviour Request for Proposals (RFP) useful in developing a program for CBR but there will need to be strong attention to community capacity building. Support for novice researchers will be as critical as making awards available to experienced community-based researchers. NHRDP needs to be sensitive to the goals, challenges and realities of community AIDS groups and develop appropriate educational and communication resources for community groups about this research program. Financial support for networking and capacity building is as important at this point as dollars for research projects.

□ The **Canadian AIDS Society (CAS)** could play a coordinating role in CBR because already established links with communities across Canada can provide valuable resources. Data from community groups across the country could assist CAS in national advocacy initiatives. CAS may also want to be an active participant in a community-based research program to support and further the development of its policy advocacy.

□ **Community research sites** with experience in various forms of CBR exist across Canada. It is important to note that community agencies in these centres still struggle with core funding issues and would need financial assistance in order to take on new work.

- **Montreal:** COCQ-Sida has experience in evaluation and social science methods and has already moved to extend its capacities by hiring a medical anthropologist. Community groups negotiated a research protocol with the Omega Project (cohort study of gay men) that supports community members and contributes to the development of community services. Links exist with the McGill Centre for AIDS Studies.

- **Toronto:** The Community Research Initiative of Toronto (CRIT) has experience with community-based treatment research as well as the preparation of community members to participate in or manage research. The AIDS Committee of Toronto (ACT) has a history of community-based research to support programming needs and has an environment where research is encouraged. The ACT Library is an excellent resource for community-based research. Support can be found from the HIV Social, Behavioural and Epidemiological Studies Unit, Faculty of Medicine, University of Toronto where models for community-university involvement have been developed.

- **Vancouver:** The organizations at the Pacific AIDS Resource Centre (PARC)— AIDS Vancouver, BC Persons With AIDS Society (BCPWA) and the Positive Women’s Network (PWN)— have experience with action research, qualitative studies and data-base analysis. The National Health Promotion Project established a research accepting culture at AIDS Vancouver. The PARC Library has a wide selection of resources to support community-based research. Support from the Centre for Excellence in HIV/AIDS is another important resource.



Other community agencies such as the AIDS Coalition of Nova Scotia, AIDS New Brunswick, the Village Clinic in Winnipeg, AIDS Calgary and AIDS Vancouver Island have experience with research which needs to be supported and developed. Acknowledging the experience and linking key personnel through the CBR funding competition would assist further developments.

### **Community-Based Research Centre — supporting the research network**

Leadership for the development of CBR with a new funding program will be essential to realizing capacity development gains from this strategy. While existing sites have different experiences, skill bases and approaches, there is little in existence to bring their diverse potentials together. The suggestion of establishing a community-based research centre was put forward from several sectors during the consultations to renew the AIDS Strategy. Such a venue would not have to be a separate agency but an affinity organization with a development mission and a virtual workplace anchored by a web site. The role of the centre would be multifaceted, but the main purpose would be to develop aspects of community-based research both conducted by community agencies themselves and in partnership with institutions. Some of the roles of the centre might be as follows:

- **mentorship:** fostering learning relationships between experienced researchers and community-based research personnel to develop their skills and to guide their inquiry processes
- **education:** providing tools and skill building opportunities for community participants to get involved in research and evaluation
- **consultation:** providing services to community agencies on research and evaluation methodology, technical upgrading; toll free phone service
- **networking:** arranging opportunities to develop the network of funding recipients, professional researchers and community action researchers
- **publication:** specific publications for CBR and program evaluation could be developed for the HIV/AIDS community. Periodic publication of community research in the form of a specific newsletter or journal would bring a higher profile to research findings and applicability to program and organizational development
- **comparative studies:** meta-analysis of community research activities would provide a critical overview of knowledge developed from community research as well as comparisons with CBR progress in other countries

### **CBR network support**

New recipients of CBR funding will need support outside of their own organizations for this project to be successful. Experience has shown that community priorities could isolate researchers within their host agencies. To overcome this potential, the recipients could be brought together to build a sense of mission. In this way, grant recipients could be enlisted in leadership to bring their host agencies into the broader aims of CBR.

## **Publication and education**

The *Field Guide* and workshop developed by the National Health Promotion Project during NAS II anticipated and promoted community-based research conducted within AIDS agencies. The publication and workshop proved only to be a beginning of the resources needed to bring community agencies into optimal conditions. A variety of small and specific publications and workshops have been suggested by participants in previous activities. Developing and testing these resources during the next five years would further enhance experience in the field.

## **Web site**

Establishing an active web site for community-based research would assist developments in a number of ways.

- links to already established parallel web sites, i.e. qualitative research
- links to the developing global network of community researchers
- evaluation support for HIV prevention/ health promotion
- community research ethics
- data base advice, category suggestions
- resource directory
- funding directory
- virtual office/meeting rooms

## **Links to policy and practice**

Research findings themselves will be only part of what will be learned by CBR. Participating agencies such as CAS and CAHR will learn from this focused community research experience and will be in a position to advocate from that basis. Community researchers themselves will be in an excellent position to advocate on policy issues based on their close contact with communities. They should therefore be consulted and included in appropriate meetings.

## **Process, impact & outcome evaluation**

The whole project should be documented and tracked throughout with process evaluation in view of impact and outcome evaluation by the end of a prescribed period, for example, five years. The evaluation should be organized by the community-based research centre with the participation of community groups and community researchers, CAS, CAHR and NHRDP.

## VISION OF CBR AT WORK

While the key element of a strategy to develop CBR would be a research funding program, the prime goal would be to build research capacities in community AIDS organizations beyond funded projects themselves. How would this work? A research application process will raise attention to research as a potentially rewarding activity for some but not all agencies. In addition, it would be reasonable to expect that not all applicants could be accommodated by available funding. How could those agencies not funded directly through the community-based research request for proposals (RFP) participate in developments along with those who have funding for research? What would be the incentives? The following outlines involvement that community AIDS groups could have in research activities:

- research-based program activities: for example, participatory action research
- program outcome evaluation: methodological support
- research partnerships
- CBR Centre: meta-analysis, publication, education, network
- CAHR: profile CBR outcomes
- CAS: advocacy from results of CBR
- CBR leadership: research mentors

### Research-based program activities

Social inquiry methodology has been undergoing a quiet revolution in the last decade. The application of action research, participatory research, ethnography, feminist and social inquiry approaches to community development in health and social services has undergone a virtual explosion in the published literature. Experience with the use of such approaches in HIV prevention work has been developing in countries such as Australia and Brazil. Research-based prevention methods could be encouraged through the AIDS Community Action Program (ACAP) or other programming based funds. Those kind of action research projects could be networked along side developments with CBR funded projects.

### Program outcome evaluation

The mounting pressure to demonstrate provable outcomes from community programs has raised attention to the need for technical support in the development of evaluation methodology for community programs. Debates in the current literature on evaluation indicate that major intellectual change is under way (*McKinlay, 1996*). The most significant for HIV prevention in a population health promotion framework is a shift in focus from behavioural to systemic outcomes. Evaluation of community activities under these terms would not focus on reported sexual change but on systemic change such as the coverage of safer sex messages with intended audiences: how well received they were; how meaningful they were; and how motivating they were. Community agencies that are unaware of such shifts in evaluation science might be at a disadvantage with health funding authorities. By many accounts, local health authorities are

struggling themselves to understand appropriate evaluation frameworks for community health. Technical support could be provided through CBR development efforts like a centre, web page and network of community researchers. Some agencies may be able to pool the evaluation segments of their program budgets to hire assistance. Those evaluation consultants could be linked to an overall CBR development program.

### **Research partnerships**

Current literature is describing major shifts in thinking about the ethics of research with communities. Even in studies that are not directly initiated by communities, there is a strong trend toward rebalancing power in relationships between scientists and communities. The new ethical playing field has already been experienced in Canada. Aboriginal communities have spelled out new terms for monitoring research, and gay communities in Quebec have demanded full participation in the control of a regional cohort study normally conducted by scientists. Given this climate, new terms of community research ethics could be developed to assist both communities and social scientists to prepare for and implement a research project. We need to find ways to make university/community research partnerships successful and sustainable. A community-based research program would organize, encourage and support such partnerships.

### **CBR Centre**

A community-based research centre could be quite significant in the overall scheme of the Canadian Strategy on HIV/AIDS. One vital role that a centre could play is the gathering, synthesizing and distribution of information from community studies, program development research and outcome evaluation from across Canada. Meta-analysis of such studies — a systematic review of the methods, findings and conclusions of the research — would provide a necessary picture of developments in knowledge, methods and techniques with which to inform both policy and practice. Comparative studies between Canada and other countries undergoing similar developments would assist all community AIDS groups by exposing them to prevention and support strategies from compatible countries and cultures, especially to introduce groups to experience beyond the United States. A CBR centre could also play an important role in the education of community practitioners and scientists alike in research, evaluation and community facilitation skills. Such developments could be supported by new learning resources and publications, accessible through internet facilities.

### **Canadian AIDS Society**

Most community AIDS agencies are members of the Canadian AIDS Society where significant resources for networking and advocacy already exist. New developments in CBR should coincide with CAS initiatives, linked directly to community interests. If CBR is to matter at all, community agencies must be able to see the benefit such as access to new funding potential, assistance with evaluation, education of community leaders and so on. The details of such a relationship would be a future agenda item.

## **Canadian Association for HIV Research**

CAHR's recommendations for the third phase of a renewed AIDS Strategy offer a significant opportunity for communities to play a strategic role in knowledge development. The establishment of a specific community-based research stream and community participation in all research tracks should send a message to communities that their intelligence and experience are valued and necessary. CAHR will also provide important opportunities for community researchers to meet on their own terms along with other scientists.

## **CBR leadership**

Funded community researchers could play a significant modelling or mentoring role for other community workers. Experience has shown that agency life can be driven into chronic chaos by the urgent needs of clients, members and other HIV related situations. The systematic and reflective processes involved in social research are a valuable model of work for agency personnel. This experience has already been clearly shown at AIDS Vancouver, the host agency of the National Health Promotion Project, where a community researcher was present and accessible. The experience spawned an ongoing interest in research and evaluation activities, documenting work and reporting outcomes. The effect of a number of such experiences across Canada, with well-informed community research leaders could be a lasting legacy for community capacity. Several mentoring program models exist from which to develop a network and education program for community researchers and community research advocates.

## **Timing issues**

Timing of these developments will need critical and strategic thinking. Mounting a community-based research program that is supportive of community agencies may take a year of work just to set up. Most groups will not be able to participate until the National Health Research and Development Program (NHRDP) and the Prevention and Community Action Programs create accessible structures and mechanisms. Community groups will also need time to set research priorities and to set up supportive resources. Consideration will need to be given to a desirable length for studies and how many new RFPs (Requests for Proposals) will be possible over a set time period. How the administration of this new program unfolds will influence not only the degree of participation by communities but also the perception that the policy environment respects community knowledge.

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## QUESTIONS & DISCUSSION POINTS

- defining community-based research
- what kind of support exists for doing community-based research
- the current climate in communities for research activities
- reviewing examples of community-based research in Canada, other countries
- the current state of HIV research in Canada: social science, clinical, epidemiological research
- program research and evaluation
- areas for community capacity building and skill enhancement, such as, training programs about research and how to make it happen; resource development; program evaluation; partnerships between university researchers and community groups; community-based research centre
- research standards: peer review, capacity building, advisory committee work
- setting research priorities
- structural considerations: NHRDP, CAS, CAHR
- dissemination of research experience and findings: newsletter, journal, web site
- role of provinces, Health Canada
- impact of provincial health reform
- outcome evaluation
- policy development: implications of population health and health promotion frameworks

# READINGS

The following documents were consulted in the writing of this paper. These readings have been organized into several categories for the convenience of the reader:

- community-based research: examples
- community-based research: resources for community capacity building
- community-based research (and evaluation): concepts and methods
- community-based research: policy development
- community AIDS groups
- trends in social science research

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# APPENDIX:TOWARD A COMMUNITY-BASED RESEARCH STRATEGY

*Strategic Planning for Social Research and Evaluation:  
Community Forum — XI International Conference on AIDS  
Vancouver, British Columbia, July 5-6, 1996  
by Terry Trussler EdD*

During the Community Forum event preceding the XI International Conference, participants in the Social Research and Evaluation section on Strategic Planning enjoyed a rich and productive discussion of recent community experience with social research, spanning issues of direction, focus, methodology, and ethics. The recommendations of this group may well mark a turning point in community-based research and response.

The design of the forum involved several rounds of breakout and plenary discussions leading toward a single all-embracing policy resolution. Because the discussion surrounding community perspectives was so fertile, the group of more than forty representatives from five global regions began to fear that much of the significance of their work would be lost. In an effort to document the ground discussion, the following statements were recovered from flip chart sheets used to note points raised as the group moved through their deliberations.

Interestingly, the most significant statements arose when one or two representatives from each global region converged in a small room to process material required to proceed to the next stage. These sessions were vivid, enlightening and powerful exchanges on fundamental issues of the purpose of social science, the ethical conduct of research and the role of HIV vulnerable communities in knowledge creation.

## **Consensus Statements**

- The knowledge of social research is essential for successful HIV programs.
- Research is a learning process where knowledge is created by all actors involved: researchers, community, funding agencies, government.
- The focus of social research is the dynamic relationship between behaviour and social environment and not individual behaviour alone.
- Communities own their data as much as the lived experience of their health vulnerabilities which gives them the inherent right to both guard and understand them.
- Experience in many regions has shown that building the capacity of community organizations to do social research increases their general capacities as community agencies.
- A growing number of NGOs are aware of themselves, appreciate community AIDS work as a practice and are actively engaged in developing this awareness in their organizations using social research practices to facilitate the process.
- Researching community organizations wish to network with each other internationally to develop the field, to consult on design and methodology, to access inside knowledge and to formally publish the results of community based social research experiences.

## General Recommendations

- Community organizations should integrate social research into their program activities.
- Governments should recognize that quality research makes quality health policy.
- Funders should make allowances for research education in their AIDS strategies in order to empower community agencies to build their research capacities, develop appropriate guidelines and training programs. Support should be adequate to ensure mutually agreed standards of quality.
- It should be recognized that building community-based research capacities involves long term processes which require stable, ongoing support and commitment.
- It should also be recognized that social critique is a necessary role of social research in the effort to identify systemic factors which could alter the effects of HIV vulnerability.
- Communities should continue to validate their research by documenting, reporting, and disseminating their findings through their own publications and audio visual materials.
- Special attention should be given to developing knowledge surrounding secondary prevention (midstream health promotion) for those living with HIV/AIDS.
- Social research models should be collaborative between affected communities and researchers throughout the process of design, implementation, evaluation and dissemination.
- The results of social research should be communicated in the most relevant way for communities to use them for their policy and program advocacy purposes.

## Targeted Recommendations

### ☐ Non-government and Community-based Organizations

- Encourage research skill building within community organizations.
- Incorporate ongoing (process) evaluation into community programs.
- Develop a network of organizations doing community-based research: expand existing organizations through internet contact, meetings of community-based social researchers.
- Create a new community research-specific international organization — newsletter and periodicals.

### ☐ Research Establishment

- The forum challenges established researchers to form authentically collaborative partnerships with community organizations to conduct HIV social research.
- Social research should have an applied focus and articulate how it will benefit the HIV affected community.
- Results should be accessible, comprehensible, and actively disseminated to the affected community.

### ☐ Funders

- Recognize the community development potential of social research.
- Funding should support community-based social research network development as well as research projects themselves.
- Active dissemination of findings must be included in project budgets.
- Funds must be made available for ongoing evaluation (action research/ process evaluation) of community based initiatives.

#### **Media**

- Recognize the social responsibility of media to accurately relay research findings.
- Establish a community advisory board to consult on issues related to the ethical publication of research findings.

#### **Communities**

- Recognize the right to refuse research.

### **Guiding principles**

#### **Priorities**

- The common ground between state defined and community defined priorities in research should be a subject of negotiation.
- Expand the focus of social research beyond risk behaviour epidemiology.
- Expand funding in favour of qualitative research and evaluation to establish a balance with quantitative research.

#### **Research subjects**

- Balance research focus between those who could become infected and those already infected.
- Confirm the independence of research funding from pre-existing public health definitions of risk factors, groups at risk, epidemiological research interests.
- Examine the basis of control of the research process to reflect community-directed agenda, inclusions and cultural sensitivity.

#### **Ethics**

- Balance the community and professional research agenda.
- Negotiate ownership of data and knowledge products of research.
- Recognize issues of bias. Present evidence not value judgments.
- Advocate funding parity between community and professional researchers.