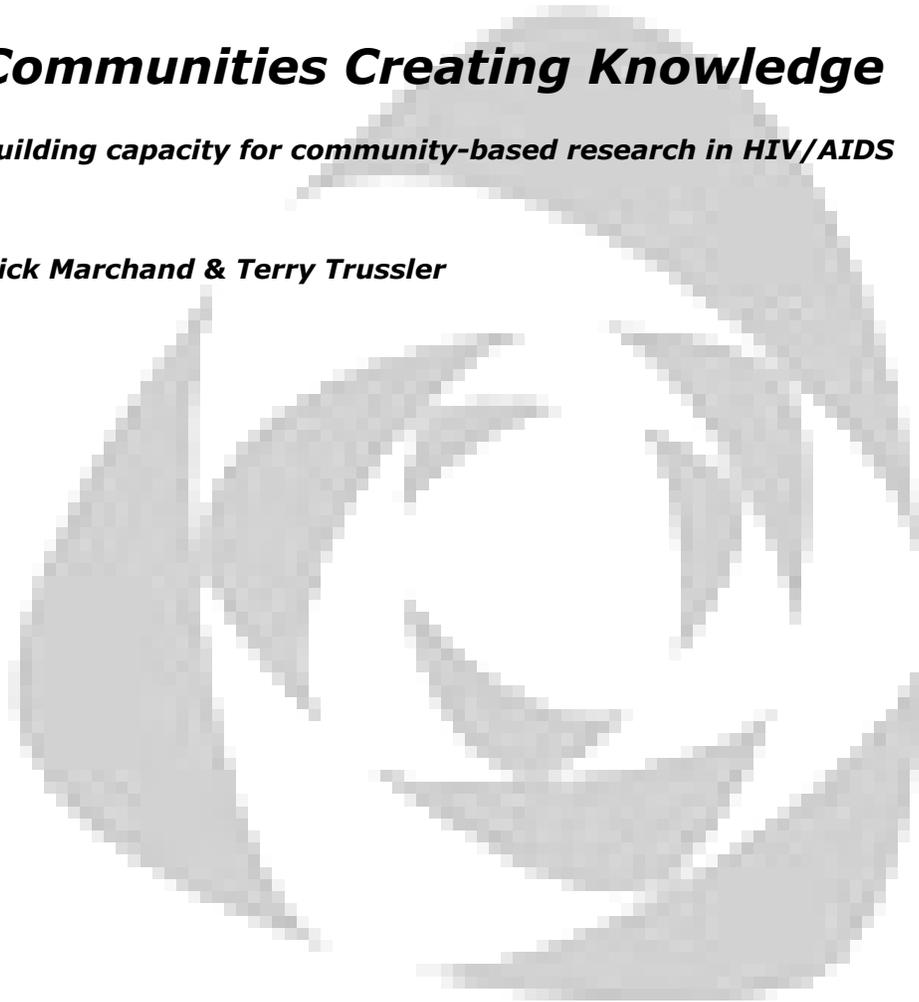# Communities Creating Knowledge

building capacity for community-based research in HIV/AIDS

Rick Marchand & Terry Trussler

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cbrc

The Community-Based
Research Centre

The Community-Based Research Centre (CBRC) organized Communities Creating Knowledge as a satellite symposium prior to AIDS Impact, the 4th International Conference on Biopsychosocial Aspects of HIV Infection in Ottawa, July 1999. The CBRC subsequently coordinated the collaboration on the consensus statement on community-based research from this meeting. Visit the HIV community based research web site at: www.cbrc.net

Acknowledgements

Table of Contents

Introduction

From July 13 to 15, 1999, a satellite symposium entitled, "Communities Creating Knowledge: building capacity for community-based research" was held in Ottawa in conjunction with AIDS Impact, the 4th International Conference on the Biopsychosocial Aspects of HIV Infection.

This gathering drew together nearly 40 individuals from Australia, New Zealand, Norway, South Africa, Sweden, the United Kingdom, the United States and across Canada, with an interest in community-based HIV research. The symposium built on discussions from a number of international meetings on the efforts of communities and community groups in research.

Influencing the research agenda has been an activity of community groups since the beginning of the HIV pandemic. Persons living with HIV and AIDS transformed the field, moving from victim and subject of research to empowered survivors and partners in health research. In Canada, the health promotion policy framework enabled vulnerable communities to get involved in creating supportive environments and strengthening community action as a way of increasing control over and improving our health.

With all the boundary crossing that has occurred in this pandemic, many barriers still exist for vulnerable communities and persons living with HIV and AIDS to fully participate in research. Although community activists have been able to influence areas of the research agenda, basic, clinical, epidemiological and social science research continue to be mainly academically driven and institutionally controlled. Ethical review of research involving humans continues to be mainly controlled by universities and institutions.

Communities Creating Knowledge was organized to gather together community members, persons living with HIV, community researchers, research advocates, policy makers, program managers and their allies in an environment supportive of community research efforts. We met to present community research projects and discuss the possibilities of creating an international network and a charter document for community-based research.

This symposium was held in conjunction with an international AIDS conference to facilitate involvement from individuals from various global regions. Although we were successful in attracting community researchers from many Commonwealth and European countries and from across Canada, we were unable to attain travel funds to assist persons from resource poor countries to participate in the actual meeting. We have ensured that community researchers from every global region have been involved in reviewing follow-up material.

This report reviews the presentations, discussion, recommendations and documents from the satellite meeting and outlines the strategic directions for an international network for community-based research.

Symposium Overview
Workshop Objectives

Our purpose was to discuss issues of theory, method and practice in community-based research and to take the field another step in its evolution. The outcome was to draft a document for national and international dissemination outlining the principles, ethics and practices of community-based research (CBR).

The symposium offered an opportunity to further enhance international, national and regional informal research networks, provided a supportive environment for community members to learn more about community-based research, and enabled us to develop the core principles governing the funding and evaluation of community-based research. It also offered a way for Canada to share resources and provide global leadership for these developments. Several regional and international gatherings have shown that communities are close to developing a consensus on community-based research ethics and principles.

A call to community researchers stated that our purpose was to draft a charter document to establish a vision, strategic direction and operative principles for a community based research network to advocate and support knowledge development capacity building on local, national and international levels.

Workshop Design

The symposium was designed to enable networking, sharing experiences and exchanging views. By the end of the meeting, we wanted a commitment from participants to review and shape their presentations and discussions into a strategic document on community-based research.

The opening plenary was from Canadian HIV researcher, Terry Trussler, who reviewed global highlights in the evolution of community-based research. The next morning was a mini-conference of community based research projects from various global regions: Cape Town, South Africa; Auckland, New Zealand; Montreal, Canada; London, UK; Vancouver, Canada; Sydney, Australia; and Toronto, Canada. Presenters described their projects using a case story frame. This guide suggested a summary, an outline of the conditions that prompted the research, barriers, capacity building aspects, methods, findings, unanticipated lessons learned and the outcomes of the process. Following this, Roger Le Clerc and Rick Marchand presented guiding principles of community-based research.

Participants worked extensively in small groups. They discussed the purpose, role, mission and vision of an international network for community-based research. They considered the principles and core values concerning community-based research. They put forward recommendations on

community-based research to various sectors of the AIDS field. Four discussion groups made recommendations to: 1) international NGO; 2) local, regional, national CBO, NGO, PWA groups; 3) governments, funding agencies and donor agencies; 4) universities, research institutions, professional researchers, health professionals. All small group work was reported to the meeting.

In the end, participants committed to work on a document based on the meeting's proceedings that would put forward a common message on community-based research from this gathering. Feedback on the meeting was collected. The meeting was tape-recorded and tapes transcribed.

Participants

The meeting brought together nearly forty community-based researchers and advocates, university-based researchers, health professionals, government and NGO representatives from many regions. (see appendix for participant list) All were experienced in research and evaluation in HIV/AIDS agencies.

We had hoped to have presentations from Uganda, Chile and Hong Kong, but were unable to obtain funding to support delegates to attend this symposium and AIDS Impact.

Consensus Statement

Following months of work participants have produced a consensus statement on community-based research in HIV/AIDS. Although we had envisioned a "charter document", discussions on community-based research need to continue beyond this meeting. Instead, we have put together a strong statement of values, recommendations and examples of community research efforts. The purpose of this document is to encourage further international discussions and be a tool for communities to create opportunities to engage in research activities.

Feedback

Overwhelmingly, the participants of the symposium scored the format very high. For future gatherings, they recommended using the case story framework and ensuring participation from developing countries. On the content of future international meetings on CBR, participants recommended more case stories, especially from developing countries, ethnocultural and PWA groups. Other areas to cover included, evaluation research, models of good CBR practice, resource exchange, and academic and community skill building.

Participants made a commitment to continue to work together. They suggested several ideas for continuing to evolve community research internationally, including a community research web site and virtual network and advocating for funders to develop community research programs.

Symposium Presentations

Highlights in the Global Evolution of an International Network for Community-Based Research

Terry Trussler from the Community-Based Research Centre (CBRC) in Vancouver opened the symposium with an overview of some of the global highlights in the evolution of community-based research.

He recognized the work of community researchers in the early days of the epidemic, working in isolation with communities, feeling daunted by the slow progress and the many barriers.

A critical event in the evolution of a network came at the Community Forum of the 11th International Conference on AIDS in Vancouver. A group of community researchers from every global region participating in the Social Research and Evaluation section on Strategic Planning compiled a position statement. They engaged in a powerful exchange on fundamental issues of the purpose of social science, the ethical conduct of research and the role of HIV vulnerable communities in knowledge creation.

The session was written up in a document entitled "Toward a Community-Based Research Strategy" with statements that referenced the capacity building effects of community-based research processes,

"Experience in many regions has shown that building the capacity of community organizations to do social research increases their general capacities as community agencies."

They also recognized that strategic community networking was a way to develop capacity in research.

"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."

Now the vision of a handful of community researchers was unfolding in the Communities Creating Knowledge satellite meeting, with case stories of community-based research scheduled to be presented and participants tasked with talking about a vision for a global network for community-based research.

Terry recalled the 3rd AIDS Impact Conference in Melbourne, Australia. Don Baxter, the former Executive Director of AIDS Council of New South Wales (ACON) delivered a plenary address on the policy failures of social science research and its impact on community-based research. This set the stage for papers on bringing research closer to practice, community groups doing their own research, and persons living with HIV/AIDS using research as empowerment.

At the same time, New Zealand had set up a research department within their main community AIDS group, while AIDS Vancouver launched the *Field Guide: HIV Community Health Promotion* highlighting how research can be integrated into community action demonstrated by the study-plan-do model.

In Canada, AIDS activists and community advocates were calling for a renewal of the National AIDS Strategy. Consultations with stakeholders revealed a growing interest in community-based research. Policy shifts began as an ongoing Canadian Strategy on HIV/AIDS was announced with one million dollars per year allocated to community-based research. This shift has had a major impact on research at the community level in Canada.

At Geneva98, the 12th International Conference on AIDS, Terry Trussler and Rick Marchand from Canada and Geoff Woolcock from Australia organized a networking building session for community-based research as part of the Community RendezVous.

Geneva conference organizers offered list serve support to all its networking meetings. An electronic forum on community-based research was set up by the Fondation du Present in Geneva as part of their internet list serve program. Going into the meeting 800 were participating on the list serve. With the commitment to continue it to Durban 2000, there are now over 1250 registered members participating in this e-community.

Over 175 participants attended the three hour networking meeting in Geneva bringing experiences in community-based research from around the world. A quarter of the participants were from African countries. The group heard presentations, engaged in discussion, put forward resolutions to the conference organizers and formed an informal core group to continue with community-based research efforts.

Participants in Geneva committed to finding funds to hold regional meetings on community-based research. One of the first after Geneva was organized by Joe Thomas of the AIDS Advocacy Alliance in Hong Kong. He brought together community workers, researchers and other relevant stakeholders to discuss HIV community-based research in Hong Kong.

Terry encouraged the participants at Communities Creating Knowledge – community- based researchers, university-based researchers, research consultants, project coordinators and advocates – to work together on strategic activities for the further development of community-based research from the perspective of communities and community groups.

In conclusion, Terry reminded us of why we had come together, to build internationally, recognizing ourselves as a community of interest on community-based research and empowering ourselves to strengthen our own practice.

Community-Based Research (CBR) Case Studies

Presenters at the Communities Creating Knowledge Symposium were asked to follow a case story frame as a way of discussing their research project. They were asked to consider the following headings:

- Summary
- Provoking Situation
- Barriers
- Capacity Building
- Methods
- Findings
- Lessons Learned
- Outcomes

This enabled the presenters to talk beyond the methods and findings of the research and to include the process of research within the community or community organization context. This format assisted participants by providing a framework for discussing these community-based research projects.

Seven case stories were presented:

- *"Divided in Ourselves: a community research study at Triangle Project Cape Town, South Africa"*
  Speaker: Nicci Stein

- *"Building CBR at the New Zealand AIDS Foundation"*
  Speaker: Heather Worth

- *"Developing CBR at COCQ-Sida: a regional network for community-based HIV groups in Quebec"*
  Speaker: Yves Jalbert

- *"Developing a Culture of Research at Gay Men Fighting AIDS in London, UK"*
  Speaker: Martin Dockrell

- *"Bringing Research into Programming: integrating research into prevention at AIDS Vancouver"*
  Speaker: Paul Perchal

- *"Doing CBR at the AIDS Council of New South Wales (ACON), Sydney, Australia"*
  Speaker: Brent Allan

- *"Making Care Visible Project: exploring the health work of people living with HIV/AIDS in Ontario"*
  Speakers: Danien Taylor & Craig McClure

"Divided in Ourselves: a community research study at Triangle Project in Cape Town, South Africa"

Nicci Stein, former director of The Triangle Project, began by outlining the context of community based research in South Africa, *"One of the unique things about South Africa and where it is, at the moment is that we don't have a problem with the concept of community-based research and trying to convince people that it's necessary. There's such a focus on community development within the whole country and communities are seen as the roots of knowledge and experience."*

Founded in 1981, the Triangle Project is a health and development non-governmental organization (NGO) serving gay, lesbian, bisexual and transgendered communities located in Cape Town in the Western Cape province. It's one of the only organizations that has a health focus rather than a political focus.

Nicci summarized the focus-group research initiated by Triangle Project as looking at the following issues in the gay, lesbian and bisexual communities of Cape Town:
1. sexual identity (how people define their sexuality and the terms they use) and their attitudes toward their sexual identities;
2. health-seeking behaviour and barriers in the health system for gays, lesbians and transgendered persons;
3. risk behaviours (what people perceive as being risky to their health and what kinds of behaviours are risky).

This research was a follow-up to a quantitative baseline needs assessment survey in 1996, where the Triangle Project identified that more in-depth information was needed about these topics in order to assist the organization in appropriate program development.

But as Nicci pointed out, *"The initial barrier was where to find funding for such an undertaking and how to find the skills we needed but could not afford to hire."* The organization realized that their issues were not necessarily considered a priority for the funders. Gay and lesbian health issues were not seen as significant when compared to children dying of malnutrition.

The Triangle Project also had to consider that from a staff of eight at the time, there was not a lot of expertise in writing proposals for research grants and in running focus groups. Nevertheless the organization persevered and as fate would have it a person who was key in the funding process was pre-disposed to the Triangle Project research. As Nicci put it, *"One of the funding managers was intrigued with our ideas and became a major source of support and advice during the project. They had never funded any gay and lesbian research and at the end of the project she told us how much of a battle it was to convince the funding board how necessary the project was."*

Support came from other sources, *"A researcher from the University of Cape Town, who was a lesbian and a volunteer, offered to come on as a mentor to the project. She didn't come on with any kind of agenda. She said, 'I'm a resource. You can use me in any way at any time'."*

Skill development was a key capacity building feature throughout this complex research project where focus groups had to be organized by gender – male and female, and language – English,

Afrikaan and Xhosa. *"All the people who were involved in the study learned so much because they got advice from all these people, but they actually had to do it themselves. And the best way of learning is doing. We were adamant that the experts were going to remain in an advisory capacity."*

From the research, the Triangle Project learned a lot of new information about the local communities they served – issues for women, issues for African gays and lesbians and the conditions that people are living under. As Nicci stated, *"What the study did was clarify issues for the organization so that we could develop our programs according to what we found out people's needs were rather than what we just thought people's needs were."* The results were integrated into agency and program planning activities.

From the research came other opportunities. *"Further funding was obtained to produce a booklet dealing with the research and that was useful for our anti-homophobia work in the school system and in the health care system."* As well, the organization used the research results to lobby the health department to restore previously cut funds. In the end, the Triangle Project had accomplished a credible research project. Nicci explained it this way, *"We had the feeling that similar funding may not come our way again. However, now that we've done the project, the funders are really keen to fund something else again."*

"Building CBR at the New Zealand AIDS Foundation (NZAF)"

Heather Worth, former community researcher with the NZAF, offered a cautionary tale about the complexity and manageability of issues for a community AIDS group in setting up a research department. The New Zealand AIDS Foundation is the major community AIDS organization in New Zealand with an elected board of trustees and a focus primarily on gay men. It has around 35 staff and five offices around the country.

Some of the research projects undertaken by the New Zealand AIDS Foundation include:

1. Have Your Say
Surveyed the gay community on perceptions of the New Zealand AIDS Foundation's prevention programs. Funded on a shoestring by NZAF.
2. Male Call/Waea Mai, Tane Ma
Large scale quantitative survey research project. Funded by Health Research Council to the value of $450,000. Analysis still ongoing. Seven reports completed. This project is a very similar project to Male Call in Australia.
3. Refugees and HIV/AIDS in the New Zealand context
Literature and interview-based overview of NZ situation. Funded by Auckland Institute of Technology with $22,000.
4. Gay Couples
Qualitative in-depth interviews with 21 gay men in relationships/11 couples. Joint project with Australian National Centre in HIV Social Research, funded NZAF and Macquarie University. Analysis of data is ongoing.

5. Needs of Pacific Islands Men who have Sex with Men
Literature based and quantitative survey of Pacific Islands men who have sex with men for needs analysis. Funded by NZAF.
6. In The Heat Of The Moment
Ethnographic study of 33 HIV positive gay men about their sero-conversion experiences. Funded by Health Research Council for $67,000.

With a dearth of university-based HIV social research in New Zealand, and prevention programs all based on overseas research, mainly Australian, the NZAF board and management acknowledged that there was a real need for local research. At the same time, there was funding for a policy officer position which the organization altered to emphasize research and hired Heather Worth. They started with a survey asking the gay community their perceptions of the NZ AIDS Foundation.

One barrier that the NZAF did not face was access to research funds. As Heather put it, *"The Health Research Council (HRC) at that point in time was very interested in funding community research."* However, they did have to contend with the attitudes of the research sector. Heather continued, *"When we got our first research grant, there was some consternation from other health researchers. We faced a lot of flak because we were a community-based organization who had suddenly come into all this funding."*

The main short term barrier was developing an organizational culture that appreciated research. *"First of all, we had to convince the workers in the organization that research was actually necessary, that it wasn't some university person coming in just to extract information out of gay men for personal gain."*

The difficulties the organization encountered included managing the research while balancing the tensions between competing needs and costs, as well as the tensions between research and other forms of agency work. From Heather's experience, *"While you can do quick and dirty research easily inside community-based organizations, there's a tremendous amount of cost in doing rigorous, academic research in terms of time, infrastructure and resources."*

What it meant for the organization was a range of training opportunities to build research capacity. Heather outlined numerous examples of skill development for staff and volunteers that has occurred over the years. Of critical importance was, *"training so that workers could then translate research findings into practice, including findings into campaign aims."*

Heather reflected how things changed for the organization, *"This experience provided an enormous amount of discussion about the place of research in a community organization. Building capacity in an organization so it will understand the importance of research is a tremendously difficult task."* On the program side, she says she can now conclude that *"the HIV prevention programs are more appropriately evidenced-based."* Using a range of methods in studies over the years, the findings have been used extensively to implement HIV prevention and education programs and to develop campaigns, their latest being on gay couples.

"Developing CBR at COCQ-Sida, a regional network for community-based HIV groups in Quebec"

Yves Jalbert presented a case story on the evolution of community-based research in Quebec since he started working for a community-based AIDS group in 1988. During those years he completed his masters and has just completed his doctorate in community health. In 1994 he started working for COCQ-Sida as the provincial AIDS in the Workplace Coordinator, but they got more than a program coordinator, they also got a researcher. Yves reported, *"When I was hired, we were not talking about research or evaluation at all. There was no research or evaluation. We started doing research and evaluation one year after I was hired."*

Yves continued, *"We did three surveys. We did it without funding. And I did it on my own time. I was working and doing the community-based research."* He brought us up-to-date on their research activities:
1. AIDS in the Workplace research;
2. Research on returning to work when you are on triple drug therapy, side effects of antiretroviral therapies, and adherence to antiretroviral therapies;
3. Projet Epsilon: creating tools to enable community based organization to initiate evaluation research (funded by Health Canada);
4. participation in the Omega Cohort study: an HIV gay men's cohort study run by a university-based research team that includes a place for community based researchers;
5. Projet Outillons-nous (Equipping Ourselves): created to facilitate the dissemination of knowledge from the Omega Cohort (funded by Health Canada), including research on serodiscordant gay couples;
6. Creating a supportive infrastructure for community-based research in Quebec.
They have presented the results of their research at various AIDS conferences.

One barrier community groups have faced in doing community-based research is getting access to funding. As Yves explained, *"If you want some funds to do research in Quebec, you have to have a PhD, and you have to be affiliated with a recognized university. So if you don't have those two criteria, you cannot ask for funding."* Furthermore, *"If you have a good idea for a research area, you can knock at the door of a university researcher and give him or her your idea, and you will lose ownership of your study. You will have to be a co-investigator and not the principle investigator of the research. That's one of the biggest problems when you're doing research and when you're working in a community-based organizations."*

Community groups in Quebec also face a particular issue – translation of studies. Explained Yves, *"The problem we have in Quebec is that the reports are in French and we don't have money to do the translations. People outside of Quebec therefore do not have access to the results of our research and evaluation."*

In spite of many barriers that community groups have faced, community-based research efforts have been developing and Yves has had lots of on-the-job experience. *"The research and evaluation – I did it without funding and I did it on my own time – working and doing research for COCQ-Sida."*

As a networking organization, COCQ-Sida has been able to share their efforts. *"Every time we do research or evaluation, we produce a final report and disseminate it to the 36 members of COCQ-Sida."* A goal of COCQ-Sida has been to build research capacity with their membership. In leading an evaluation project, they explored the kinds of information groups were collecting and how it might fit into an evaluation framework. Yves stated, *" The goal of the Epsilon project was to give empowerment on evaluation from inside a community-based organization and for a community-based organization. We did a report on that and we did training to all the members of COCQ-Sida."*

The next step in Quebec is to develop a supportive and effective infrastructure for doing community-based research. Yves explained, *"This infrastructure development project is coming from what we have done before, and we want the funders to understand that in community-based organizations, there's a lot of good people who can do research and they don't have to have a PhD or be an academic to produce good research."*

"Developing a Culture of Research at Gay Men Fighting AIDS (GMFA) in London, UK"

Martin Dockrell, chair of GMFA, presented a brilliant analogy for community-based research in his re-telling of the movie The Prime of Miss Jean Brodie.

"Apart from wanting to humiliate myself, I tell you this story because it seems to me that there's something really important going on in there about community-based research. It's about passivity and learning. You see, I'm with Maggie Smith on this one. I believe very much that community-based research is about developing people's skills and capacity rather than the more conventional relationship between practitioners and researchers which is an intrusion, and I don't really believe that works all that well."

Gay Men Fighting AIDS is a gay community organization founded in London in 1992. The founders had a vision with several tactical objectives including re-focusing resources on, and improving the effectiveness of, gay men's HIV health promotion. The organization has a number of employees and a strong ethos of volunteer leaders. The culture of the organization had been one of community and developing experience in research and evaluation.

Through the years they have carried out numerous activities both in community-based research and in building organizational research capacity. Martin recalled, *"One of our founding principles was that we would strive for service improvement through the application – the rigorous application of evidence. Both in terms of evidence of need and evidence of effectiveness."* They have a research group within the organization, a journal group that discusses research reports. They have done their own research such as "How Far Will You Go?" that examined the migration patterns of men to gay clubs. They produced a research guide for volunteers called, "What the Fuck Do You Think You're Looking At?" And they had just completed The Hard Times Project, a community-based randomized control trial model of evaluation of a cognitive behavioural therapy program.

GMFA has faced a typical barrier in community-based research – access to funding. As well, even though their posters, press ads, booklets and group work are all designed by volunteers, it's been harder for them to engage in the research. Martin explained, *"Engagement with the evidence comes from getting people committed to and excited by research evidence. And that's not always been easy. We had a range of ways that we tried that. Part of that was to run what we called 'trend seminars'. That would be researchers who would come to speak to a group of volunteers in the evening. Our volunteers would then ask questions about their research."*

Learning from experience has been the best way to engage the volunteers. Martin continued, *"The most effective way of getting people on the cycle of engaging with the evidence is to get them to do evidence gathering and research themselves. There is a value for quick and dirty research. It really does have its place. You're involved in doing the questionnaire and interviewing people, and you're interested in the answers that they're giving you. Which makes you more interested when the report gets done. And so you're interested in hearing about that and you go to the launch or the meeting to discuss the results. Then the next time a researcher comes to town you go to that meeting. And that's how I think our volunteers have been getting into this spiral of engagement with the evidence."*

GMFA took on a randomized controlled trial (RCT) model of evaluation in their Hard Times research project. Although they completed the evaluation project, Martin concluded, *"Research evidence is as important as ever, but randomized control trials are difficult and costly to run. We need to develop a range of research tools that are practical, productive and appropriate."*

"Bringing Research into Programming: integrating research into prevention at AIDS Vancouver"

Paul Perchal outlined some of the history of AIDS Vancouver's involvement in community-based research since its founding in 1983. When he came into the organization, there was already a foundation of experience there. *"The time was right for the research initiatives that I and other members of the staff got involved in."*

Paul introduced us to two projects, *"The Gay Men's Action Plan (G-MAP) is now going into its third year, and the idea is to make this ongoing, because we have identified that there are real advantages to having a research component built right into prevention programs. The Women's Outreach Program research project called 'Listen Up! Women are Talking' has been going for a shorter time. I will talk mostly about G-MAP."*

Paul continued, *"The staff had a pretty strong theoretical understanding of research, but that's still different from putting something into practice. There was awareness that outreach efforts needed to be redirected, that there was some real revitalization that had to happen. Knowledge from local epidemiological research projects was really limited in providing us with any information about socio-cultural factors."*

Funding has always been an issue in their research activities. Paul stated, *"We actually had no funding and have had no funding to date to maintain a research component in the gay men's*

program, but we've managed to do it because the program has had a long history of peer involvement."

Paul outlined aspects of building research capacity within the organization, for example, *"The research consultant basically provided a lot of input in terms of overall research design and was somebody that the team can come to for support around methodology questions."*

Paul reviewed the major findings from the research with gay men, *"That gay men experience challenges to maturity and growth; that gay men experience barriers in negotiating meaningful relationships and that Vancouver has distinct structural weaknesses with respect to gay culture."* There's also been an impact on programming, *"Knowledge development activities ensure sustainability and quality of HIV prevention initiatives. That gets back to the importance of having a good understanding of what your local social and cultural factors are when you're developing programming. What we're doing through research projects is actually blending behavioural and socio-cultural understandings in developing our programs."*

Paul concluded, *"The Gay Men's Program has been completely revitalized – it's pretty outstanding. Planning is now based on local knowledge about HIV vulnerabilities. A renewed sense of direction in HIV prevention programming is possible by integrating HIV research into HIV programs."*

"Doing CBR at the AIDS Council of New South Wales (ACON), Sydney, Australia"

Brent Allan, Director of Education at ACON in Sydney introduced the group to the situation of community-based research in Australia. *"The Australian version of community-based research (often referred to as collaborative research) generally refers to most social science research which has always had a large degree of input from community organizations. However, the research continues to reside primarily within the academy."*

The first research project that ACON undertook was *"an investigation of the good practice principles of peer education in young gay men's health promotion programming in a community AIDS group. The program chosen for examination is the model of many youth-based peer education programs for young gay men in Australia."* ACON saw an opportunity to do some research but the main problem was *"that no funding could be located to set up a community-based research project of this type."*

There was a lot of learning and adjustments as the research project took shape: finding the right researcher, understanding the role of the researcher within the community organization setting and adusting the language of research and education to reflect both perspectives. ACON contracted a researcher from a local university to take on the project. Brent continued, *"I strongly believe that there needs to be an organizational culture that values learning and is patient with the process of discovery. In this community-based research project, there was a distinct development in the organization's valuing of learning through research, as well as an appreciation by the researcher of the unique environment of a community AIDS organization."*

A major lesson learned on this project has been the impact of community-based research itself as a practice. Brent explained, *"The research process provides an opportunity for critical reflection and a better analysis for educators on how they do what they do. Having a community researcher on site provides permission for the educators to think about the work that they do."* This has enabled them to look at some of the fundamental assumptions about program content, participants, outcomes and methodology.

After completing this project there was a wider recognition about how this type of research effects program quality. Brent concluded, *"The success of this project has led to two new community-based action research projects in ACON funded by state-based funders, one on sex-on-premise venues, another on serodiscordant gay male couples."*

"Making Care Visible Project: exploring the health work of people living with HIV/AIDS in Ontario"

Research team members Darien Taylor and Craig McClure presented on the progress of the Making Care Visible Project based in Toronto. Craig first of all explained the model of working on this community-based research project: *"A mixture of six people work in this project – HIV negative and positive, women and men, people who have worked for community AIDS organizations and two academic researchers. That team evolved over the first year and a half with our ideas before we got funding."*

The funds that they eventually received for the project have been administered by a development education group. Darien continued, *"There was some difficulty in locating the research inasmuch as the research team decided it would be freer to approach its research outside of an AIDS service organization where various agendas would not prevail. We ended up not housing the project either in academia or in a community AIDS organization."*

The intention of the project has been to describe the 'health work' done by people living with HIV/AIDS which has largely remained unrecognized and may have increased with Canadian health reforms. In the developed world, the identity of persons living with HIV/AIDS has been informed by concepts of community development and health promotion. Although empowerment and self-care practices shifted health maintenance responsibilities to the individual, research had not accounted for this health work. This project examined the informal and unpaid health work for the active and informed consumer, for example, home infusions, the use of complementary therapies, the acquisition of treatment information, nutritional strategies, and spiritual and emotional care. As the research project evolved, it had to deal with the impact of protease inhibitors on the health work of PWAs.

Collaborative skill building has been part of the research team's capacity building experience. This is a qualitative social research study, in four cities, using focus groups and interviews and including 92 diverse participants. They have completed data collection and preliminary analysis, and have identified eight themes with a final analysis on one theme, treatment information in the work that people with HIV do. Darien suggested that *"while some people living with HIV/AIDS*

use treatment information in their decision-making processes, for others treatment information is not a key factor in decision-making or in health work. In fact, for some it has become a burden and a source of guilt."

Dissemination strategies have been an important consideration for the project. Darien explained, *"Team members who are academics have presented academic papers on the project while those with ties to the AIDS community have presented at community-based events. Presentations of the findings will be made in the communities where research was conducted. Information about the findings will be written in an accessible format for dissemination in brochures and web sites to health care practitioners, AIDS service organizations and people living with HIV/AIDS. It is our hope that these various dissemination strategies will result in a reconsideration of some of the assumptions underlying the ways in which services are provided to people with HIV/AIDS."*

CBR Up Close: a meta-analysis of seven case stories

Because presenters used a common template in their presentations, we were able to focus the analysis of the case stories on several community research issues. In this section we look at five aspects of community-based research: 1) the provoking situation: what prompted the community group to use research?; 2) barriers to doing community research; 3) capacity building aspects of community research; 4) lessons learned; and 5) outcomes.

What Prompted the Research?

Presenters were asked to address the conditions that prompted the research initiative; what provoked them to use research as a way of moving forward on an issue. Community groups initiated research for a range of reasons:

1) To respond to changes in the epidemic or affected community
2) To understand local conditions
3) Internal support and skills for research existed
4) No local university-based research
5) Funding opportunity
6) Prevention efforts needed revitalization
7) Capacity building effects of knowledge development

1) Community AIDS groups looked to research as a way of responding to: a) emerging communities at risk of HIV infection; b) emerging issues in communities or in the epidemic; and c) changes in the epidemic or community.

Following their community empowerment mandate, AIDS groups wanted to continue developing socially and culturally appropriate programs for the communities they serve. The epidemic however has not unfolded at the same rate within all affected populations. What AIDS groups

experience are communities at various stages of being impacted by HIV, have different response patterns to HIV and have different service needs.

In our case stories, community groups were responding to emerging communities at risk such as women and injection drug users. Some were responding to the impact of new treatments. Others were trying to understand the concept of post-AIDS culture in gay communities. As one community group put it, *"The HIV epidemic is no longer dominant in gay men's lives. As men's responses to the epidemic become increasingly diverse, 'one size fits all' safer sex messages lose any utility."* All were examining the responsiveness of their programming. One project clearly stated, *"We didn't have a very good idea of health issues for lesbian and bisexual women and health issues for gay men and women who were not white."*

2) In all cases communities and community groups had recognized the need for relevant local information to create the knowledge they needed on local HIV conditions. As one presenter said, *"We really lacked any local knowledge about the socio-cultural factors influencing people's HIV vulnerability, in order to really make some major changes in the direction of programming."*

3) Research was considered an option for community groups when support or skill for research already existed from within. This ranged from board support to an organizational culture that recognized research and learning, to program staff that had research skills to offer. One community researcher put it this way, *"I was hired to fill a position as a program coordinator. That was my job, but I also had a background in research, so I tried to do some research and evaluation of the programs."*

4) In some locales there was no university interest in the local issues of the community AIDS group. How then were they to create knowledge? As one group put it, *"There was a dearth of university-based interest in social research. Few people at the university were interested in doing HIV research."* To understand local conditions, the community group would have to organize its own inquiry.

5) A few groups recognized a funding opportunity to move ahead with a research project. *"Our main health research funder at that point was very interested in funding community research."*

6) Many of the presenters talked about their organization's frustration with prevention efforts. Programs needed more relevant local information. For example, one group observed, *"Education staff had recognized that behavioural approaches were no longer sufficient in terms of some of the populations we were working with at the time."*

7) Community-based research was valued for its capacity building effects on an organization and its contribution to knowledge development for communities. For one community group, *"Our program provided an example of good practice in peer education and what we saw was an opportunity to do some community-based research examining the organizational and operational aspects of peer education in a stable and successful model."*

Generally, the concern of community AIDS organizations is for ensuring that their programs and services are responsive and appropriate. Their reasons for choosing to use community-based research as a strategy are generally related to program development and delivery. It's the mandate of most community-based organizations to keep their support and education programs responsive to the circumstances and characteristics of the communities they are serving.

Barriers to CBR

Presenters were asked to consider barriers to doing community-based research. What obstacles needed to be addressed to get the research accomplished? How were they overcome? Community AIDS groups experienced a range of barriers doing their research projects:

1) Access to funding
2) Organizational constraints on doing research
3) Access to research skills
4) The confidence factor

1) Most community organizations experienced difficulty gaining access to financial support for research projects. One group received funding after demonstrating capacity, *"We needed to convince the funder that we had the skills to carry out the research."* Another needed to find where funding might be available, *"The initial barrier was where to find funding for such an undertaking."*

For other groups, structural barriers made funding impossible to overcome in the short term. One group reported, *"The biggest problem is that if you want some funds to do research, you have to be a PhD, and you have to be affiliated with a recognized university. If you don't have these two criteria, you cannot ask for funding."*

Community organizations had to be innovative in moving forward with a research project without specific funding. For one group, funding was the major barrier*, "We actually had no funding and have had no funding to date to maintain a research component to the program, but we've managed to do it because of a long history of peer involvement."* For another community group, *"Money to support this research project had to be located from agency operational monies due to a lack of sources that fund community research projects."*

Other experiences were reported regarding poor access to funding. In some cases, issues that community groups wanted to research had not been identified as priority areas for the funder, usually because community groups had not been part of a priority-setting meeting. Also, there were differences in how a funder and community group defined community-based research. As well, the fear of losing control of the project because funding could only be obtained by allowing a university-based researcher to act as principle investigator over the project.

2) For many community groups, there were debates within the agency about how financial and human resources should be allocated. Community organizations are continually facing pressures about the allocation of resources and research may not have wide support within an agency as the

strategy for addressing an issue. One group reported, *"Some staff felt that research was an inappropriate use of resources and that resources should be allocated into direct services."* Another said, *"There's often tension about the amount of time and money research is taking up out of one's day that could be used in the real work of saving lives. Community research is seen as such a luxury compared to the kind of pressing needs of everyday action."*

Research projects can be expensive to run – developing an infrastructure for research, purchasing computers and tape recorders, training volunteers, all need financial and administrative support. Community groups had to justify the costs not only to staff and board members, but also to the community at large.

In some cases fear among staff about research, particularly evaluation research, presented obstacles that had to be addressed. Some staff were concerned about workload levels. In all cases, discussions had to take place on the value of research in program development and planning.

3) Initially most groups had concerns about being able to develop their research capacities and finding the research skills needed to do the project. There was a lot to consider in making a decision to do a research project. One group said, *"At the start, there was not a lot of expertise on the staff in terms of writing proposals for research grants or in running focus groups."*

There was also the consideration of how to interest and train volunteers in research. One group reported, *"All the posters, press ads, booklets and group work we do are all designed by volunteers. It's been much harder to get them to engage in research."*

Community groups had to adapt to creating an environment where research could effectively occur in the organization. As one group presented, *"With this sort of research project, it is imperative that the right type of researcher be found."* A researcher that can adapt to a community culture and is not driven by a mandate to publish findings. Learning the language of research was another challenge that had to be address. One presenter stated, *"There's definitely a research language that exists that can be quite alienating for the community organization educator. Often language used to explain concepts and definitions had to be modified and adjusted to facilitate the ease of access for the educator's and researcher's point of view."*

4) Sometimes moving ahead came down to having confidence in the process. The groups with more research experience reported less anxiety with each project. However, for those entering new territory, lack of confidence came up as an issue to overcome. One group reported, *"There was a lot of planning and planning and planning and not getting down to doing it. So that was a barrier that we had to cross from the planning to the doing."*

Another group acknowledged that community research is an evolving practice within the community culture. *"There is certainly a need to continuously reflect and evaluate the process of research and refine it and feel confident enough about what you think is working, and humble enough to say it's not working, and then change it to make it work better."*

Related to the confidence factor is the environment of skepticism that exists about a community organization's capacity to carry out research. As one group reported, *"Certainly it was expressed in various sectors that this research project, although noble and innovative, was simply nothing more than an elaborate program evaluation and not actual research."*

Research Capacity Building

We asked the presenters to address the area of capacity building in their research projects. What skills and technical resources needed to be developed in the community or agency in order to accomplish the research initiative? And how they developed these capacities?

The following areas were addressed by presenters:

1) Developing skills and experience in research within the organization and community
2) Developing partnerships and relationships with researchers
3) Developing relationships with funders and decision-makers
4) Bringing research findings to programs
5) Making the shift in organizational culture from crisis management to planning for an evolving and shifting HIV epidemic.

1) Clearly the area of greatest capacity building reported by the presenters was in the area of developing skills and experience in research. Projects reported skill enhancement with staff, board members, volunteers and community members in a range of research areas.

There were various reports of experiential learning, on-the-job training and training sessions for staff and volunteers on the research projects. One group described it this way, *"The people who were involved in the study learned so much because they got advice from all these people, but they actually had to do it themselves. And the best way of learning is doing. We were adamant that the experts were going to remain is an advisory capacity."* In some cases the training was on the more long term benefits of collecting information, *"We encouraged support staff, for example, to fill in forms with the clients which we would then use in baseline surveys."* We talked to them about *"how important that was going to be for their own work."* In other cases, projects engaged in collaborative learning, *"Research team members with less experience in focus groups and interviews were paired with a more experienced team members initially."*

Opportunities for volunteers were created in most research projects. One group reported, *"In our organization, we went for a volunteer-led model – a really rigorously volunteer-led model. From the very start, we were trying to get volunteers to use a planning matrix, a form if you like, which required them to specify the measurable, achievable, realistic and time bound goals that they were aiming for. But they also had to specify the evidence of need for what they were doing. We tried to get them to do this with any project."* Volunteer were involved in research discussion groups; they wrote reviews on research projects for newsletters, ran focus groups, and reviewed transcripts. Many volunteers joined the organization after a project was completed. As one group said, *"Although the project took two years from start to finish, the next one could take a year because we have a pool of trained people and we can use that expertise."*

Staff also had opportunities to upgrade their skills. In one project *"the coordinator was invited to go on a training workshop on qualitative methodology at the university summer school. We hadn't known that that was going on and they offered it at some minimal cost to us."* Another group reported, *"The most tangible benefit has been a huge investment in the skills and abilities of staff in relation to research practices and protocols."*

Going through the research process brought some groups to a new level of experience and confidence. Said one group after its first project, *"It was very good for us to know that some of the issues that were coming out of the research reinforced some of the things that we knew."*

2) Developing relationships and partnerships is a major way that community AIDS groups do their work. In the research projects presented, groups formed a variety of productive and lasting relationships with researchers. Mentoring relationships were not unusual. One group reported, *"A researcher at the local university, who was a lesbian and a volunteer, offered to come on as a mentor to the project. She didn't come on with any kind of agenda. She said, 'I'm a resource. You can use me in any way at any time'."* In other organizations, research projects attracted highly skilled volunteers, *"We had people offering quite highly sophisticated methodological input and research input."*

In some projects, relationships were formed with research consultants and with university-based researchers. Reported one group, *"A multi-year large scale research study that was an initiative of university researchers included in the project organization a place for community-based researchers."* Another project reported on the technical support they received from a research consultant, *"The researcher basically provided a lot of the input in terms of overall research design and somebody that the team can come to for support around methodology when we have a question that we're not sure about."*

3) Organizations also developed other strategic relationships through their research projects, especially with governments and other funders. This assisted them in learning about funding sources for research and helped build their credibility and track record with funders. One agency reported, *"We learned of the availability of funds for social research."* Another reported, *"We had the feeling that similar funding may not come our way again. However, now that we've done the project, the funders are really keen to fund something else again."*

4) Organizations acknowledged that being involved in a research project helped them to turn research findings into programs. For example it was reported that, *"workers could translate research findings into practice, including translating findings into campaign aims."* Groups also reported having greater clarity about community needs, *"What the study did was clarify issues for the organization so that we could develop our programs according to what we found out people's needs were rather that what we just thought people's needs were."*

5) Presenters reported that involvement in research helped to develop an organizational culture that was less crisis-driven and more planful in its approach. As one presenter explained, *"In this community-based research project, there has been a distinct development in the organization's*

valuing of learning through research.” Another presenter highlighted shifts in attitudes, *“We've seen major shifts within the organization around attitudes toward research. I think the fact that we're now undertaking a research project in another program is evidence to suggest that the agency's understanding the relevance of knowing about local factors in terms of developing programming.”*

Research prompted organizations to share experience with other community groups and other sectors of the AIDS field. Submitting abstracts to conferences and presenting findings from community research efforts helped groups to make contact with others working on similar issues. Research also prompted groups to disseminate reports to colleagues, *“Every time we do research or evaluation, we produce a final report and disseminate it.”*

Presenters acknowledged that building capacity in an organization is “a tremendously difficult task.” It takes an ongoing commitment, *“Engagement with the evidence comes from getting people committed to and excited by research evidence. And that's not always been easy. We had a range of ways that we tried to do that.”*

Lessons Learned from CBR

We asked presenters to outline the lessons learned from engaging in community-based research. What unanticipated learnings occurred during the process? They reported learnings in four areas:

1) About research
2) About community
3) About building relationships and partnerships
4) About programs

1) Community groups learned a great deal about research from going through the experience of one or many projects. An organization doing it's first qualitative research project talked about the difficult in knowing how much data to collect, *“We're sitting on huge amounts of data. We felt we had to use this opportunity to gather as much information as possible. Perhaps it is better to focus on fewer issues and have more in-depth discussion.”*

Community groups reported learning about the intricacies of research methodology. One group said, *“Research evidence is as important as ever, but randomized control trials are difficult and costly to run. We need to develop a range of research tools that are practical, productive and appropriate.”* For another group this meant learning *“how to adapt research to meet the context of the work.”* It also meant finding an adaptable researcher, *“I think that the researcher on this project learnt much about the need to remain flexible in relation to working in an environment that is highly diverse and changes very rapidly.”*

Because capacity building was a part of every research project, some groups talked about the impact of this on the process of research, *“When capacity building is such an intrinsic part of research, and building from virtually no knowledge to some knowledge, then the project takes much longer than anticipated.”* Groups reported extensively on the capacity building aspects of

meaningful participation. One group reported, *"It became abundantly clear that without the actual educators (both paid and unpaid) being highly involved with the research project, it's not going to work."* Another said, *"We want the funders to understand that in community-based research, there's lots of good people who can do research and they don't have to be a PhD or academic to produce good research."*

They also learned of the positive effects of having a researcher within reach. As one group put it, *"Having a researcher on site who is accessible provides educators an opportunity, for example, to ask why are we even doing this in the first place. They have someone who's able to guide them through that process of critical reflection. Having a researcher is about providing an opportunity for you to think about your own work and what you're doing."*

All groups reported learning through the research findings. Said one presenter, *"Sometimes the results are not what you expect or what you necessarily want and we had to learn to accept that."*

2) Community groups learned much more than expected about the communities they serve. Assumptions were broken, *"We had assumed that divided by language would also mean we had divided by racial groups, but this was an erroneous assumption."*

They reported a greater understanding of their local community. One group learned that, *"it's extremely difficult to create an environment where people feel comfortable to talk openly about sensitive issues such as unsafe sex."* Another group reported that, *"structured discussions on men's thought processes are effective in equipping men to identify risks and empower men to avoid them."* What they all seemed to report was that *"integrating knowledge about local culture and identity and knowledge of sexual behaviours"* into programming was the best practice.

Community groups learned that making research skill building accessible to community members enhanced community relations. One group said, *"By building capacity, there are many advantages for the community, and the whole community is richer for it in the end, even if it is time and energy consuming."*

3) Community organizations reported on learning that the research process provided a context for building relationships. One group made the observation, *"Many academics and researchers will give time and energy to a project in the way that it's wanted. They just need to be asked."*

Experience brought about a greater understanding of the differences between a university and a community environment. One group stated, *"They're very different worlds. Neither is perfect and both have their flaws. I think that there's a healthy respect that comes with community-based research, by both the practitioners and the researchers."* But learning to work with a university can be frustrating. As one group reported, *"The project was not easy. It's very difficult to work with academics because they are not working at the same pace that we are working in the AIDS field."*

Another group recommended, *"that such partnerships continue to be developed in ways which permit communities to retain control over their health and health promotion."* In fact one group

Communities Creating Knowledge

reported that they discovered, *"over the course of the research project that the language used by the researcher and the educator was actually not that different."*

Relationships were also built among community groups, *"Other community groups have actually approached us to see if they can somehow get involved in the research."*

4) Conducting community-based research led to many learnings in the area of programming. One presenter said, *"I think the greatest lesson learned has been that the educators have looked at some of the fundamental assumptions that they have made about the content of the program, the participants, the outcomes and certainly how they do the work."*

Organizations were considering different educational strategies as a result of the research. One group reported that educators, *"must question to what degree print interventions with short snappy messages can continue to be the intervention of first choice. These are useful so far as they encourage gay men to take part in more in-depth projects that listen more than lecture."* Another group reported, *"We are now looking at blending structural interventions with the behavioural interventions currently underway. Looking at how we can have an impact on the larger system through some structural interventions as well."*

Although the groups acknowledged that community-based research ensured greater program sustainability, they also recognized the challenges.

CBR Outcomes

The presenters were asked specifically how things changed because of the research process and findings. They addressed the following in their presentations:

1) Research changed programs
2) Research changed the organization
3) Capacity for research strengthened

1) Community groups reported that the research influenced program development efforts. One presenter stated, *"The research findings helped us pinpoint exactly where we should develop new programs."* Another reported that currently their *"programs are more appropriately evidence-based."* One group reported a significant influence, *"The outcomes included a discernible increased confidence. Our work plan this year has so many ideas, largely based on all the research and data that they gather themselves."*

A few groups talked about research as an intervention in itself. One group put it this way, *"It's possible to achieve educational outcomes through participatory research processes. One of the amazing things that we discovered in this was that in the discussion groups – the focus groups – people were actually learning more about their health issues from talking to each other. In the evaluations that we did of the actual groups, people were learning something from sitting down around the same table with each other. Not only about HIV but about their general health."*

Finally, one group concluded, *"I think that there's a growing acknowledgement that this type of research does have a direct impact on program quality."*

2) Engaging in research changed organizational life in various ways. How groups did planning was a common topic of discussion. One group said, *"Planning is now based on local knowledge about HIV vulnerabilities. A renewed sense of direction in HIV prevention programming is possible by integrating HIV research into HIV programs."* Another simply stated, *"Information was incorporated into the annual strategic planning of the organization."*

New relationships were formed. Many groups reported an increase in volunteers. For example, *"Many people who participated in the groups or were volunteers on the research project became quite attached to the organization and have worked in other projects with the organization."* Others talked about community partnerships, *"As a result of the research, we had community partners who kept away from our agency for years, approach us to get involved."* Relations extended beyond the local scene, *"Some overseas organizations heard about the research and requested copies of it, so it helped in getting more information that we could use and adapt into our organization."*

Two groups reported that engaging in research as a strategy seemed to bring a stability to the organization. For example, *"Some of the findings were really useful for us to use in lobbying efforts and we got our funding back up again last year."* And another group concluded, *"I think if a program has a good direction and everybody feels empowered, you're going to have a stable staff and volunteers."*

3) Capacity building efforts continued and strengthened after organizations had some experience with research. They reported more conference involvement: presenting papers and posters, doing workshops. One had the opportunity of publishing their findings in a journal.

Research was a topic for formal and informal discussions within agencies, *"This experience provided an enormous amount of discussion about the place of research in a community organization."* There seemed to be momentum to continue to build on the experience. One group felt better prepared for the next research project, *"This research project helped to create a ready pool of trained volunteers for any future projects we're going to do."* Another described the next steps for them, *"We are presently trying to create a support infrastructure for the community-based researcher. We want support and training to do a project where someone who is able to do research can help our members to produce a research proposal."*

Finally there is nothing like continued funding to boost the confidence of an organization. As one group reported, *"The success of this project has led to two new action community-based research projects."*

Summary of the CBR Meta-analysis

What Prompted the Research?

- the conditions that prompted the research initiative; what provoked community groups to use research as a way of moving forward on an issue. They reported initiating research for a variety of reasons:

  - To respond to changes in the epidemic or affected community
  - To understand local conditions
  - Internal support and skills for research existed
  - No local university-based research
  - Funding opportunity
  - Prevention efforts needed revitalization
  - Capacity building effects of knowledge development

Barriers to CBR

- barriers to doing community-based research. What obstacles needed to be addressed to get the research accomplished? How were they overcome? Community AIDS groups experienced a range of barriers doing their research projects:

  - Access to funding
  - Organizational constraints on doing research
  - Access to research skills
  - The confidence factor

Research Capacity Building

- capacity building in research projects. What skills and technical resources needed to be developed in the community or agency in order to accomplish the research initiative? And how they developed these capacities? The following areas were addressed by presenters:

  - Developing skills and experience in research within the organization and community
  - Developing partnerships and relationships with researchers
  - Developing relationships with funders and decision-makers
  - Bringing research findings to programs
  - Making the shift in organizational culture from crisis management to planning for an evolving and shifting HIV epidemic

Lessons Learned from CBR

- the lessons learned from engaging in community-based research. What unanticipated learnings occurred during the process? Presenters reported learnings in four areas:

- About research
- About community
- About building relationships and partnerships
- About programs

CBR Outcomes

- how things changed because of the research process and findings. Presenters addressed the following:

  - Research changed programs
  - Research changed the organization
  - Capacity for doing research strengthened

Building a Network to Support Community-Based Research

Participants at Communities Creating Knowledge worked on articulating a purpose, mission and vision for building a network to support community-based research efforts. Participants reviewed existing material on guiding principles for community-based research and generated new material. They also made recommendations to key international AIDS stakeholders on issues of community-based research.

The discussion material generated at the meeting formed the basis of months of follow-up work. Together participants – as a newly formed network – developed a consensus statement on community-based research. This statement will be widely disseminated. It is meant to stimulate discussion on community-based research and be a resource for communities wanting to advocate for funding for community-based research projects. What follows are the critical points of this consensus statement.

International Network for Community-Based Research on HIV/AIDS (INCBR)

The International Network for Community-Based Research on HIV/AIDS (INCBR) recognizes that local research is an essential part of managing HIV/AIDS. We formed the INCBR in 1999 to create a context for discussion, information sharing and capacity building on community involvement in HIV/AIDS research. Our network developed out of the efforts of community researchers to express common experience, articulate guiding principles and advocate best policy and practice.

Purpose
Our purpose is to enhance HIV/AIDS efforts worldwide by advocating community participation in the development of knowledge.

Mission
Our mission is to encourage community participation in the development of HIV/AIDS knowledge worldwide by:
- Advocating community-based research,
- Creating opportunities to build the research capacities of communities,
- Coordinating research skills building events, resources and media,
- Sharing research experiences, models, methods and results,
- Conducting research on community experience,
- Exchanging funding information and strategies,
- Advocating best policy and practice for community-based research.

Vision
Our vision is a dynamic global network of community participants exploring research strategies to effectively influence and manage local conditions affecting HIV infection, treatment and care.

Origins

This consensus statement is the result of several years of discussion that began with the Community Forum of the 10th International Conference on AIDS in 1995. An informal network of researchers, working with community organizations worldwide, took shape over the years following. We met formally in July of 1999, prior to AIDS Impact, the 4th International Conference on Biopsychosocial Aspects of HIV Infection. In that meeting, we collaborated on a statement of principles representing our collective experience on an issue that we believe to be crucial to the future of the HIV epidemic.

We hope that this document will be the beginning of a consensus building process among international partners toward a future charter for community-based research.

Guiding Principles

Participants emphasized that all research must be conducted according to accepted ethical standards. In addition, we are guided by the following principles for research in communities:

community benefit

Community-based research is research conducted by and for communities. Its purpose is to build community capacities that will provide knowledge with which to improve community conditions.

capacity building

In its conduct, community-based research promotes and develops the inquiry skills of all participants. The aim of community-based research is to build sustainable capacities within communities for self-informed, self-inspired transformation.

collaboration

A community's experience is a resource that belongs to the community. As such research initiatives should invite community participation as early as possible in their formation, to shape cooperative agreements about ethical issues, the treatment of data and the dissemination of findings.

equity

Community-based research entails a special relationship between observers and observed, by involving participants in analysis of their own collective condition. In order to ensure respect, dignity and empowerment, relations between those conducting research and those participating must be negotiated in a collaborative spirit of equity.

inclusion

Community-based research is broadly inclusive of community members in all its phases: the review of proposals, construction of protocols, collection of data, interpretation of results and dissemination of findings.

accessibility

Community participation in the development of knowledge is a form of literacy work that builds capacities for collaborative inquiry. In this way, the language and methods used in the conduct of community-based research must be broadly accessible to its diverse range of participants, because their research skills form the basis of community transformation.

empowerment

The conduct of research, the data it generates and the results it produces are tools of the community's empowerment and must be honored as such in all transactions. Community participants should be encouraged to conduct their own inquiries and contribute findings to ongoing efforts to advance new knowledge.

Critical Steps for Communities

- Recognize that knowledge is crucial for guiding community efforts and that local knowledge may be decisive for well-informed action.
- Encourage community members to use their experience as a resource for inquiry.
- Promote the systematic documentation of experiences, events and programs.
- Build a community ethic of collaborative learning through research participation.
- Use research activities as tools for the community's development.

Recommendations

Because all research is a collaborative process, participants urged international, regional and national interests to recognize, encourage and support the inclusion of communities in developing HIV/AIDS knowledge by implementing the following:

International AIDS Society (IAS)

- Affirm community benefit as a criterion for abstract selection in all tracks of future International Conferences on HIV/AIDS.
- Reconfirm the Geneva Principle: integrate community participation in all research tracks.
- Support a research component in all future community forums to encourage skills-building, experience-sharing and network development.

United Nations Program on AIDS (UNAIDS)

- Include, encourage and support research and knowledge development in all community capacity building initiatives worldwide.
- Develop an international program to extend and advance community knowledge development practices, including the dissemination of findings.

International Council of AIDS Service Organizations (ICASO)

- Encourage knowledge development in community organizations worldwide by raising attention to community-based research and supporting capacity building efforts.

Governments and Funding Agencies

- Recognize community-based research as a necessary and unique form of social inquiry that is crucial to the improvement of society.
- Support the development of communities by funding research that includes citizens in the acquisition of knowledge.
- Commit to funding programs for non-institutional research, promoting collaborative inquiry as a tool for community action and social development.

Universities

- Affirm the essential role of communities in health and social research.
- Support the initiatives of academic researchers to build ethical relationships with communities by establishing infrastructure to recognize these efforts and reward achievement.
- Build funding for community dissemination into all related grant proposals in order to include non-academic audiences in reports of findings.

Community Organizations

- Commit to building learning organizations
- Appreciate the research potential already existing in the people and functions of every organization.
- Support the research skills building efforts of all personnel.
- Ensure that the entire organization values documentation.
- Build funding for dissemination methods such as printing, translation and travel into all grant proposals in order to include external audiences in reports of local findings.

Appendices

- **List of Satellite Participants… p. 32**
- **Des collectivités génératrices de connaissances: Énoncé de consensus sur la recherche communautaire… p. 36**

Communities Creating Knowledge
Capacity building for HIV/AIDS community-based research

July 13-15 in Ottawa, Canada

Participants

Brent Allan
ACON (AIDS Council of New South Wales)
PO Box 350
Darlinghurst 2010, Sydney
Australia
Tel: 61-2-9206-2071
Fax: 61-2-9206-2069
Email: ballan@acon.org.au

Sharon Baxter
Canadian AIDS Society
130 Albert St., Suite 900
Ottawa, Ontario, K1P 5G4
Tel: 613-230-3580 ext. 118
Fax: 613-563-4998
Email: sharonb@cdnaids.ca

Torbjorn Bentsen
Pluss-LMA/Norway;
Body Positiv;
Stop AIDS Org.
Gabelsgt. 21A
0272 Oslo
Norway
Tel: 47-22 431501
Fax: 47-22 431501
Email: torbents@eunet.no

Carl Bognar
Bognar and Associates
1710 - 1050 Burrard St.
Vancouver, British Columbia, V6Z 2S3
Tel:604 331 1223
Fax: 604 331 1224
Email: cjbognar@axion.net

Bill Coleman
2705-1050 Burrard St.
Vancouver, British Columbia, V6Z 2S3
Tel: 604-684-7755
Fax: 604-684-7751
Email:bcxca@yahoo.com

Tobin Copley
Centre for Health Services and Policy Research
University of British Columbia
2250 Wesbrook Mall
Vancouver, British Columbia, V6T 1W6
Tel: 604 822-6219 or 604 947-0117 (Bowen Island)
Fax: (604) 822-1370
Email: tobin.copley@ubc.ca

Nick Corrigan
GMFA (Gay Men Fighting AIDS)
Eurolink, Effra Rd.
London, England, SW2 1BZ
Tel: 44-171-738-6872
Fax: 44-171-738-7140
Email: nickc@gmfa.demon.co.uk

Martin Dockrell
GMFA (Gay Men Fighting AIDS)
Eurolink, Effra Rd.
London, England, SW2 1BZ
Tel: 44-181-356-8114
Fax 44-171-738-7140 or 44-181-356-8235 (urgent)
Best E-mail: Mdockrel@gw.hackney.gov.uk

Karen Drysdale
The Ontario HIV Treatment Network (OHTN)
1300 Yonge Street, Suite 308
Toronto, Ontario, M4T 1X3
Tel: (416) 642-6486
Toll-Free: 1-877-743-6486
Fax: (416) 640-4245
Email: kdrysdale@ohtn.on.ca
Website: www.ohtn.on.ca

Richard Elliott
Canadian HIV/AIDS Legal Network
160 John St., 2nd floor
Toronto, Ontario, M5V 2E5
Tel: 416-595-1666
Fax: 416-595-0094
Email: relliott@netrover.com

Ellen Goldstein
Center for AIDS Prevention Studies (CAPS)
University of California
74 New Montgomery, Suite 600
San Francisco, CA 94105
USA
Tel: 415 597-9396
Fax: 415 597-9213
Email: egoldstein@psg.ucsf.edu

Ian Grubb
Health Hounds
249 Shaw Street
Toronto, Ontario, M6J 2W7
Tel: (416) 533-3058
Fax: (416) 537-9469
Email: mcgrubb@interlog.com

Staffan Hallin
Anders Selin
George Sved
RFSL - The Swedish Federation for Lesbian and
Gay Rights - Stockholm
Sveavagen 57-59
Box 350
SE-101 26 Stockholm
Sweden
Tel: 46-8-736-02 11
Fax: 46-8-30 47 30
Email: staffan.hallin@rfsl.se

Richard Harding
Family & Child Psychology Research Centre
City University
London, England, EC1V OHB
Tel: 44-171 477 8555 (direct line)
Fax: 44-171 477 8582
Email: R.Harding@city.ac.uk

Yves Jalbert
COCQ-Sida
(Coalition des organismes communautaires
québécois de lutte contre le sida)
4205, rue Saint-Denis 320
Montréal, Québec, H2J 2K9
Phone : 514-844-2477, ext. 34
Fax: 514-844-2498
Email : cocqsida@videotron.ca

Stephen James
Community Liaison Researcher
Department of Health Care and Epidemiology
University of British Columbia
2250 Wesbrook Mall, Room 105
Vancouver, British Columbia, V6T 1W6
Tel: (604) 822-2908
Fax: (604) 822-1370
Email: stephen.james@ubc.ca

René Lavoie
Séro Zéro
C.P. 246 succursale "C"
Montréal, Québec, H2L 4K1
Tel: 514-521-7778
Fax: 514-521-7665
Email: sero.zero@videotron.ca

Roger Le Clerc
COCQ-Sida,
(Coalition des organismes communautaires
québécois de lutte contre le sida)
4205, rue Saint-Denis 320
Montréal, Québec, H2J 2K9
Phone : 514-844-2477, ext. 26
Fax: 514-844-2498
Email : dg.cocqsida@videotron.ca

Alistair Mac Donald
New Zealand AIDS Foundation
Ettie Rout Centre
PO Box 21285 Edgeware
Christchurch
New Zealand
Tel: 643 379-1953
Fax: 643 365-2477
Email: ettie@ihug.co.nz

David MacInnes
ACON & University of Western Sydney Nepean
Research Centre in Intercommunal Studies
School of Cultural Histories and Futures
University of Western Sydney, Nepean
PO Box 10, Kingswood, NSW, 2747
Australia
Email: d.mcinnes@uws.edu.au

Rick Marchand
The Community Based Research Centre
Suite 2 – 2023 West 4th Ave
Vancouver, British Columbia, V6J 1N3
Tel: 604-736-9150
Fax: 604-736-9120
Email: rfm@attglobal.net

Namaste Marsden
Healing Our Spirit
BC First Nations AIDS Society
415B West Esplanade
North Vancouver, V5T 4N9
British Columbia
Tel: 604 983-8774 x20
Fax: 604-983-2667
Email: hoscdev@pop.intergate.bc.ca

Craig McClure
Health Hounds
249 Shaw Street
Toronto, Ontario, M6J 2W7
Tel: (416) 533-3058
Fax: (416) 537-9469
Email: mcgrubb@interlog.com

Will Nutland
Terrence Higgins Trust
52-54 Grays Inn Road
London, England, WC1X 8JU
Tel: 44 171 816 4642 (direct line)
Fax: 44 171 816 4563
Email: will.nutland@tht.org.uk
will.nutland@virgin.net

Paul Perchal
AIDS Vancouver &
The Community Based Research Centre
1107 Seymour St.
Vancouver, British Columbia, V6B 5S8
Tel: 604-893-2227
Fax: 604-893-2211
Email: paulp@parc.org

Stephen Samis
Samis Research and Consulting
101-814 Nicola St.
Vancouver, British Columbia, V6G 2C3
Tel/fax: 604-688-2997
Email: smsamis@islandnet.com

Nicci Stein
204 Hiawatha Road
Toronto, Ontario, M4l 2Y2
Tel/fax: (416) 463-4938
Email: nstein@519.icomm.ca

Berge-Andreas Steinsvag
Kontekst Kommunikasjon
Theresesgt 44B
1268 Oslo
Norway
Tel: 22-69-55-74
Fax: 22-69-55-64
Email: kontekst@online.no

Darien Taylor
Making Care Visible Project
56 Gladstone Ave.
Toronto, Ontario, M6J 3K8
Tel: 416-516-3147
Fax: 416-973-0009
Email: darient@interlog.com

Terry Trussler
The Community Based Research Centre
Suite 2 – 2023 West 4th Ave
Vancouver, British Columbia, V6J 1N3
Tel: 604-736-9150
Fax: 604-736-9120
Email: ttruss@attglobal.net

Bruce Waring
Interagency Coalition of AIDS & Development
180 Argyle Avenue
Ottawa, Ontario, K2P 1B7Tel:613 788 5107
Fax: 613 788 5095
Email: bwaring@icad-cisd.com

Heather Worth
Institute for Research on Gender
University of Auckland
Private Bag 92019
Auckland, New Zealand
Tel: 649-373-7599 ext. 7042
Fax: 649-309-3149
Email: h.worth@auckland.ac.nz

Tasha Yovetich
Planned Parenthood
430-1 Nicholas St.
Ottawa, Ontario, K1N 7B7
Tel: 613 241-4474
Fax: 613 241-7550
Email: tyovetich@ppfc.ca

Other Contributors

Tim Frasca
Corp. Chilena de Prevención del SIDA
General Jofre No 179 Santiago Chile
Casilla 49, Correo 22
Santiago, Chile
phone/fax (56-2) 222 83 56
Email: chilaids@cchps.mic.cl

Andrew Johnson
AIDS Vancouver
1107 Seymour St.Vancouver, British Columbia,
V6B 5S8
Tel: 604-893-2226
Fax: 604-893-2211
Email: andrewj@parc.org

Joe Thomas
School of Health Sciences
Deakin University, Melbourne
Australia
Tel: 613-9244-6935
Email: joe@deakin.edu.au

Mary Jane Musungu
The AIDS Support Organization – Tororo
C/o Tororo Hospital
PO Box 777
Tororo, Uganda
Tel: 256-45-44109
Fax: 256-45-44295
Email: tasodata@imul.com

Graham Smith
AIDS Concern
Hong Kong
Email: keigo@netvigator.com

Geoff Woolcock
467 Enoggera Road
Alderley, Queensland 4051
Tel: 617-3856-4766
Fax: 617-3856-5833
Email: g.woolcock@spmed.uq.edu.au

Des collectivités génératrices de connaissances

Énoncé de consensus sur la recherche communautaire

Réseau international de recherche communautaire sur le VIH/sida

En tant que membres du Réseau international de recherche communautaire (RIRC) sur le VIH/sida, nous reconnaissons que la gestion du VIH/sida passe inévitablement par la recherche au niveau local. Nous avons donc créé le RIRC en 1999 afin de faciliter les discussions, partager l'information et encourager la participation communautaire à la recherche sur le VIH/sida. Notre réseau est né de la volonté de chercheurs communautaires de partager leurs expériences communes, d'énoncer des principes directeurs et de promouvoir l'adoption de politiques et pratiques exemplaires.

Objectif
Notre objectif est d'intensifier la lutte contre le VIH/sida en encourageant les collectivités à participer activement au développement des connaissances.

Mission
Notre mission est d'encourager les collectivités à participer activement au développement des connaissances sur le VIH/sida dans le monde entier en :

*   appuyant la recherche communautaire;
*   trouvant des moyens d'améliorer les capacités de recherche des collectivités;
*   coordonnant les événements, ressources et moyens favorisant l'acquisition des compétences nécessaires à la recherche;
*   partageant leurs expériences, modèles, méthodes et résultats de recherche;
*   étudiant l'expérience communautaire;
*   échangeant de l'information et des stratégies en matière de financement;
*   recommandant des politiques et pratiques exemplaires en matière de recherche communautaire.

Vision
Nous sommes un réseau mondial et dynamique d'intervenants communautaires en quête de stratégies de recherche nous permettant de gérer adéquatement les conditions locales qui influent sur l'infection à VIH, son traitement et les soins.

Origines
Ce document est le fruit de plusieurs années de discussions lancées lors du Forum communautaire de la XIe Conférence internationale sur le sida en 1996. Au cours des années qui suivirent, s'est créé un réseau informel de chercheurs travaillant avec des organisations communautaires du monde entier. Nous avons fini par nous rencontrer en juillet 1999, avant la IVe conférence d'AIDS Impact. Au cours de cette rencontre, nous avons élaboré un énoncé de consensus expliquant pourquoi notre expérience collective nous incitait à penser que l'acquisition de connaissances par les collectivités aurait un rôle de premier plan dans l'avenir de l'épidémie de VIH. Nous espérons que ce document amorcera un processus de concertation entre les partenaires internationaux et aboutira à la rédaction d'une charte.

Cas concrets

Auckland
Pour obtenir l'information locale nécessaire pour dispenser ses programmes, une organisation communautaire a créé son propre service de recherche et effectué plusieurs études très sérieuses, et résolument d'avant-garde, malgré les obstacles culturels, financiers et institutionnels auxquels elle s'est heurtée.

Cape Town
Grâce à des groupes de discussion multilingues, un organisme communautaire a pu découvrir les points vulnérables des gais et lesbiennes de diverses ethnies sud-africaines. Grâce à ses travaux de recherche innovateurs, cet organisme a pu trouver de nouveaux fonds, restructurer ses programmes et mieux sensibiliser le public au problème de santé qui touche ses membres.

Hong Kong
Dans le cadre d'un programme de prévention dans les toilettes publiques, des travailleurs communautaires ont réuni avec soin des données sur tous les échanges auxquels ils ont assisté; ces données permettront d'améliorer le programme. Ces travailleurs estiment que leurs activités de recherche seront secondaires tant qu'ils n'auront pas établi que les données obtenues sur le terrain sont essentielles à l'évaluation du programme.

London
Afin de mettre en place et de faire financer une stratégie de prévention efficace, une équipe de bénévoles bien organisée s'est livrée à une expérience jamais tentée auparavant. Elle a soumis, avec succès, l'un de ses programmes novateurs choisi au hasard à une analyse approfondie.

Montréal
Après avoir engagé un jeune chercheur et appuyé plusieurs importantes études communautaires alors qu'il n'était pas financé, un organisme membre d'un réseau régional a élargi ses services, réussi à se faire aider dans ses travaux de recherche par d'autres organismes locaux, et trouvé de nouvelles sources de financement.

Région de la baie de San Francisco
Un organisme communautaire, insatisfait de son programme destiné aux élèves, travaille avec une université à la mise en pratique d'une nouvelle théorie sur les risques que courent les adolescents. Lorsque la validité de cette nouvelle théorie aura été établie, l'organisme en fera bénéficier d'autres organisations communautaires du pays.

Santiago
Pour mieux faire connaître la politique menée contre les gais et les bisexuels au Chili, un groupe de seize bénévoles et tout le personnel d'un organisme communautaire ont suivi une formation intensive sur la façon de réunir des données et d'effectuer des entrevues. L'analyse de leurs entrevues avec 400 hommes a confirmé l'efficacité de leur programme et renforcé leur confiance dans les possibilités de leur organisme.

Sydney
Un organisme communautaire a engagé un chercheur pour découvrir pourquoi l'un de ses meilleurs projets d'éducation par les pairs donnait d'aussi bons résultats, et pouvoir appliquer les mêmes principes à d'autres programmes. Malgré la résistance initiale des bailleurs de fonds, les

résultats de la recherche se sont avérés si utiles que l'organisme a pu trouver les fonds nécessaires pour entreprendre plusieurs études encore plus importantes sur la prévention locale du VIH.

Toronto
Poussés par l'inquiétude, plusieurs défenseurs des droits des personnes vivant avec le VIH/sida ont formé une équipe de recherche et obtenu une subvention pour étudier les problèmes et coûts méconnus de l'autogestion du sida et des soins dispensés par les amis et les familles des personnes atteintes.

Vancouver
Craignant d'être submergé par la demande, un organisme communautaire s'adapte en encourageant les activités de recherche dans tous ses programmes. En publiant des rapports sur plusieurs études importantes, dont beaucoup n'avaient pas été financées, l'organisme a réussi à influer sur les politiques de santé de plusieurs paliers de gouvernement.

Région Asie-Pacifique
Les membres d'un réseau de personnes vivant avec le VIH/sida ont lancé une étude sur la discrimination liée au sida et la violation des droits de la personne dans huit villes de la région. Ils ont utilisé une stratégie de recherche concertée et participative qui leur a permis de cerner les différences dues au contexte économique, juridique et politique de chaque pays. L'étude comprend la formation de chercheurs locaux qui réuniront les données de l'enquête et analyseront les résultats avec les membres de l'équipe régionale et locale.

Principes directeurs

Nous pensons que toute recherche doit être menée selon les règles d'éthique reconnues. Nous sommes également guidés par les principes suivants en matière de recherche communautaire :

Avantage pour la collectivité
La recherche communautaire doit être menée par et pour la collectivité. Son objet est d'aider la collectivité à acquérir les connaissances qui lui permettront d'améliorer la situation sur place.

Acquisition de compétences
La recherche communautaire encourage tous les intervenants à développer leurs dons d'investigation. L'objectif de la recherche communautaire est de doter les collectivités de compétences durables leur permettant de se transformer en puisant en elles-mêmes leurs connaissances et leur inspiration.

Collaboration
L'expérience communautaire est une ressource qui appartient à la collectivité. Les initiatives de recherche devraient donc encourager les collectivités à participer dès que possible à la l'élaboration d'ententes de collaboration sur les questions d'éthique, le traitement des données et la diffusion des résultats.

Équité
La recherche communautaire suppose des liens particuliers entre la personne qui observe et celle qui est observée, car elle oblige les intéressés à analyser la situation dans son ensemble. Pour garantir le respect, la dignité et l'habilitation, il faut donc que les rapports entre ceux qui ont les

compétences nécessaires pour faire la recherche et ceux qui se prêtent à l'étude soient fondés sur l'équité et la collaboration.

Inclusion
Chacune des phases de la recherche communautaire doit inclure les membres de la collectivité, que ce soit pour l'étude des propositions, la préparation des protocoles, la collecte des données, ou pour l'interprétation et la diffusion des résultats.

Accessibilité
La participation communautaire au développement des connaissances est une forme d'alphabétisation qui favorise l'acquisition des compétences nécessaires à l'investigation concertée. Il faut donc que le langage et les méthodes employés pour faire de la recherche communautaire soient facilement accessibles au vaste éventail des intervenants, car la transformation de la collectivité dépend de leurs compétences en recherche.

Habilitation
Les travaux de recherche, les données et les résultats qu'elle produit sont des outils essentiels à l'habilitation de la collectivité et doivent être reconnus comme tels dans tous les échanges. Il faut encourager les intervenants communautaires à faire leurs propres recherches et à partager leurs résultats dans le souci constant de faire progresser les connaissances.

Étapes critiques pour les collectivités

- Reconnaître que les connaissances issues de la recherche sont essentielles pour guider les efforts de la collectivité et que les connaissances locales peuvent être déterminantes pour mener une action éclairée.
- Encourager les membres de la collectivité à se servir de leur expérience comme d'un outil d'investigation.
- Encourager les intervenants à documenter systématiquement les expériences, événements et programmes.
- Favoriser une éthique communautaire d'apprentissage coopératif en encourageant la participation à la recherche.
- Utiliser les activités de recherche comme outils de développement communautaire.

Un appel à l'action

Comme toute recherche née de la concertation, nous invitons les responsables internationaux, régionaux et nationaux à se joindre à nous pour reconnaître, encourager et appuyer la participation des collectivités au développement des connaissances sur le VIH/sida en procédant comme suit :

Société internationale sur le SIDA

- Faire valoir que l'avantage pour la collectivité est le critère de sélection par excellence lors des futures conférences internationales sur le VIH/sida.
- Réaffirmer le principe de Genève : intégrer la participation communautaire à toutes les étapes de la recherche.

Communities Creating Knowledge

- Appuyer la recherche dans tous les futurs forums communautaires pour encourager l'acquisition de compétences, le partage des expériences et la création de réseaux.

Programme des Nations Unies sur le VIH/sida

- Inclure, encourager et appuyer la recherche et développement dans tous les programmes d'acquisition de compétences des collectivités du monde entier.
- Élaborer un programme international pour multiplier et faire avancer les pratiques encourageant le développement des connaissances dans les collectivités, et notamment la diffusion des résultats.

Conseil international des ONG de lutte contre le sida (ICASO)

- Encourager l'acquisition des connaissances dans les organisations communautaires du monde entier par la promotion de la recherche communautaire et des compétences nécessaires.

Gouvernements et bailleurs de fonds

- Reconnaître que la recherche communautaire est un outil d'investigation sociale exceptionnel qui est essentiel au mieux-être de la société.
- Appuyer le développement communautaire en finançant des travaux de recherche qui permettent aux citoyens d'acquérir aussi des connaissances.
- S'engager à financer des programmes favorisant la recherche comme outil d'action communautaire et de développement social.

Universités

- Confirmer le rôle essentiel des collectivités dans la recherche médicale et sociale.
- Appuyer les initiatives des chercheurs universitaires qui favorisent l'établissement de rapports éthiques avec les collectivités. Pour ce faire, mettre en place un système qui reconnaisse ces efforts et les récompense lorsqu'ils sont fructueux.
- Prévoir, dans toutes les demandes de subvention, des fonds pour la diffusion de l'information dans les collectivités afin que les rapports sur les résultats soient aussi transmis aux non spécialistes.

Organisations communautaires

- S'engager à créer des organisations encourageant l'acquisition des connaissances.
- Évaluer le potentiel de recherche actuel du personnel et des activités de chaque organisation.
- Encourager les efforts de tous les membres du personnel en vue d'acquérir des compétences en recherche.
- S'assurer que l'utilité de la documentation fournie est comprise à tous les échelons de l'organisation.
- Prévoir, dans toutes les demandes de subvention, des fonds pour la diffusion de l'information, l'impression, la traduction et les déplacements, afin que les rapports sur les résultats locaux soient aussi transmis aux non spécialistes.