



Communities Creating Knowledge

A consensus statement on community-based research

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International Network for Community-Based Research on HIV/AIDS

We the members of the International Network for Community-Based Research on HIV/AIDS (INCBR) recognize 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 document is the product of several years of discussion that began with the Community Forum of the XI International Conference on AIDS in 1996. 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.

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



Case Stories

Auckland

To acquire local information needed to direct its programs, a community organization created its own research department and conducted several rigorous, leading-edge studies despite cultural, financial and institutional barriers.

Cape Town

Using focus groups conducted in several languages, a community agency uncovered vulnerabilities specific to gay men and lesbians of various South African ethnic cultures. By engaging in this groundbreaking research, the agency realized new funding, established reframed programs and increased attention to the health issues of member groups.

Hong Kong

Outreach workers conducting a prevention effort in public lavatories carefully collected data on all contacts to help steer program improvements. They considered their research activities secondary until they eventually recognized that their field data is a key resource for the program's evaluation.

London

In a bid to produce evidence needed to create an effective prevention strategy and get it funded, a well-disciplined, volunteer-driven organization conducted an unprecedented and successful random control trial of one its innovative programs.

Montreal

After hiring a young researcher and supporting several important community studies without funding, a regional network organization expanded its services to include help with the research efforts of its local member agencies and realized new financial opportunities at the same time.

San Francisco Bay Area

A community agency, dissatisfied with its program for in-school youth, collaborated with a university to test an alternative theory of teenage risk. When the innovative theory was validated by their research, the agency offered the model as training for other community organizations across the country.

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Guiding Principles

We believe 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.

Critical Steps for Communities

Recognize that research 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.

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. ▲



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.



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Santiago

To gain insight and bring political attention to the realities of Chilean gay and bisexual men, a group of 16 volunteers and the entire staff of a community agency underwent rigorous training in quantitative data gathering and interviewing. Their analysis of a survey of 400 men not only confirmed their program's effectiveness but also bolstered confidence in their agency's capacities.

Sydney

A community agency hired an academic to uncover why one of its most successful peer education projects works so well, in order to transfer its principles to other programs. Despite early resistance from funders, the research proved so valuable that the agency found support to undertake several more important field studies on local HIV prevention issues.

Toronto

Several concerned advocates for people living with HIV/AIDS organized themselves as a research team and acquired a grant to investigate the undisclosed issues and costs involved in AIDS self-care and care provided by friends and family.

Vancouver

Recognizing the potential for overwhelming demands on its services, a community agency reinvented itself by encouraging research activities in all its programs. By producing its own reports of several important studies, many without funding, the agency succeeded in influencing health policy at several levels of government.

Asia-Pacific Region

Members of a network of people living with HIV/AIDS initiated an eight-city study of AIDS-related discrimination and human rights violations in the region, using a consultative, participatory research strategy to embrace variations in the economic, legal and political context of each country. The study included the training of local researchers to collect survey and case-study data in collaboration with the regional and local team. ▲



A Call for Action

Whereas all research is a collaborative process, we urge international, regional and national interests to join with us in recognizing, encouraging and supporting 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 enables citizens to acquire knowledge.

Commit to funding programs that promote research 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 support 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 organizations that value learning.

Appreciate the research potential that already exists in the people and activities of every organization.

Support the efforts of all personnel to build research skills.

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. ▲

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Get Connected

Visit the **HIV Community-Based Research** web site at: www.hiv-cbr.net or www.cbrc.net

Join the community research list serve. Send an e-mail to: community-research@hivnet.ch and put "join" in the subject line.

