



Concepts, Definitions and Models for Community-Based HIV Prevention Research in Canada

and

A Planning Guide for the Development of Community-Based Prevention Research

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1.1 Objectives of the Project

The specific objectives of this project have been to conduct a literature review of concepts, definitions and models related to community-based research, to identify in the published literature documented accounts of community-based HIV prevention models and processes, to examine and analyze issues and diversity found in the concepts, definitions and models, and to develop an analytic framework that may be applied to the planning and evaluation of community-based research projects.

1.2 Overview of the Report

This report provides a brief history of community-based HIV prevention research in Canada, defines the term *community* and describes the role of community in HIV prevention research. It examines different types and forms of research, and explores some traditions of community involvement in research, particularly action research, participatory research and participatory action research. Additionally, this report investigates a community-based approach to research methodology and community participation including advocacy, partnerships, research roles, knowledge creation, dissemination, barriers, limitations, benefits and advantages. Finally, the report presents a model for decision-making and a planning guide for community-based HIV prevention research.

1.3 Focus and Scope

The focus and scope of this report are limited to published sources accessed through the library systems of the University of Toronto, the Ontario Institute for Studies in Education (OISE), the AIDS Committee of Toronto and the City of Toronto Department of Public Health. Although extensive, the literature search is not exhaustive, although every possible effort was made to identify and access documents with potential application. Initially, databases covering HIV/AIDS, basic science, education, health administration, medicine, psychology and sociology, as well as the university library's general catalogue, were searched with the keywords action research, participatory research, and community-based research. This search disclosed books, book chapters, journal articles and published reports in dozens of diverse fields (Table 1). Identified sources were subsequently scanned for additional bibliographic references. Ultimately, more than 425 books, manuscripts, journal articles, briefs and abstracts were incorporated into this investigation.

Background

to the Project

This report gathers information on a plethora of research models and subsumes them under the frameworks of action, participatory,

participatory

community-based

action, and

research.

Table 1: Some academic fields in which a tradition of action and/or participatory research frameworks were identified.

Anthropology	Behavioural Science
Community Health	Community Development

Demography Dentistry
Ecology Economics

Education Environmental Studies

Epidemiology Ethics

Epidemiology Ethics
Ethnography Evaluation

Health Promotion Health Administration

Industrial Relations Management
Medicine Midwifery
Nursing Nutrition

Occupational Health Organizational Development

Philosophy Political Science Program Planning Psychiatry

Psychology Rehabilitation Medicine

Social Work Sociology

1.4 Approaches to Research

This report gathers information on a plethora of research models (Table 2), and subsumes them under the frameworks of action research, participatory research, participatory action research or community-based research, depending on how our sources typify or identify their work.

Table 2: Some research frameworks incorporating elements of action and/or participatory research.

Appreciative Inquiry	Collaborative Research
Communicative Inquiry	Cooperative Research
Cooperative Experiential Inquiry	Critical Research
Demonstration Research	Ecological Research
Experiential Inquiry	Fourth-generation Research
Goal-free Evaluation	Holistic Research
Implementation Research	Insider/Outsider Research
Interactive Research	Learned Hopefulness Research
Maximum Feasible Participation	Mutation Research
New Paradigm Research	Participatory Evaluation
People-centred Research	Programmatic Action Research
Pseudo Relevant Social Psychology	Self-full Research

ogy Self-full Research
Stakeholder-based 1

Stakeholder-based Evaluation Visionary Action Research

Socially Relevant Research

Utilization-focused Evaluation

Start where the people are is a principle that has led many current health promotion, illness prevention and health education programs. This statement holds that successful prevention and education must involve individuals in defining their own needs, setting their own priorities, controlling their own solutions and evaluating their own progress (Green, 1986c:p. 212; also see Health and Welfare Canada, 1986). Inherent in this view are three beliefs regarding human behaviour: 1) that individuals make decisions and take actions in the interest of their own health; 2) that the actions individuals take empower other individuals, thus creating healthy and empowered communities and environments; and 3) that healthy environments and communities are conducive to health for all:

encouraging public participation means helping people to assert control over the factors which affect their health...[to] equip and enable people to act in ways that preserve or improve their health. By creating a climate in favour of public participation, [one] can channel the energy, skills and creativity of community members into the national effort to achieve health (Health and Welfare Canada, 1986:p. 9).

Whereas traditional definitions of health education and promotion were once thought to be the exclusive concern of health professionals, more current definitions recognize the creation of an empowered and active citizenry able to face health concerns and problems in partnership (Harris, 1992). This is a conception of population-level health behaviour that suggests that lifestyle and behaviour changes should reach beyond the level of the individual to entire communities (Labonte, 1995; Nutbeam et al, 1993). Canadian community-based HIV prevention research has traditionally encompassed the ideologies of health promotion, education and prevention. The role this conception plays in Canadian HIV prevention efforts suggests its strength and utility, but in addition, this particular conceptualization of health promotion helps explain why in Canada, the goals, aims and requirements of community-based research have proven to be so important for so many stakeholders (Trussler and Marchand, 1993, 1994).

HIV/AIDS and

Health Promotion

in Canada

2.2 Community-based HIV Research in Canada

Foremost among the elements precipitating the growth of community-based research in Canada are the influences of current concepts of health promotion and community health, the growth of HIV prevention research amongst affected communities in Canada, the need for community-researcher partnerships, and the impact of unique work by specific committees, consultations and research initiatives.

Historically, in Canada, alliances between community groups and researchers were established relatively early in the AIDS epidemic (Rayside and Lindquist, 1992). In 1988, a National Conference on AIDS brought together governmental officials, public health professionals, AIDS service organization representatives and AIDS activists. Spurred on by activists' discontent, members from diverse groups with varied interests began to lobby against political inaction, placing the need for research funds on the national agenda.

Canada has a history of community involvement in HIV prevention research.

2.2.1 HIV/AIDS Prevention Research

Generally, research activities evolved slowly at the beginning of the HIV/AIDS epidemic in Canada, and those individuals who chose to study it were really only a handful of researchers. Whether this was the result of homophobia or a lack of awareness that the disease was a major health threat is difficult to discern, but it is important to recall that initially AIDS was regarded as "a gay plague". Not only were many initiatives not attracting established researchers—due in part to this early stigma—but many political and funding infrastructures were initially unprepared to study the behaviours and populations beginning to appear at risk.

2.2.2 Researcher-Community Partnerships

Nationally, community involvement in HIV research has evolved at both the federal and a number of provincial government levels through the appointment of community representatives to major policy advisory bodies (such as the National Advisory Committee on AIDS), where, indirectly, such bodies have a role in establishing research funding priorities. Further, policy-makers have actively consulted with organizations such as the Canadian AIDS Society, a coalition of community-based AIDS organizations formed in 1986, the Canadian Network of Organizations of Persons Living with HIV and AIDS established in 1990, and activist groups such as AIDS Action Now!. The Canadian Association for HIV Research (CAHR) has also demonstrated its commitment to community through consultation with community activists to establish the association's research recommendations (Hankins and Handley, 1993).

Workshops in HIV/AIDS research priorities, sponsored by federal government departments and provincial HIV/AIDS programs, have provided an additional mechanism for community involvement. In the area of AIDS prevention and education, two National Agenda Building workshops on research priorities have been sponsored by the HIV/AIDS Prevention and Community Action Programs, Health Canada. The first was held in 1990, the second in 1993. At these workshops, researchers, educators and community representatives together discuss and advise on research priorities. Similarly, since 1992, Annual HIV/AIDS Epidemiologic Research and Surveillance meetings have been organized by the Division of HIV/AIDS Epidemiology, Laboratory Centre for Disease Control, Health Canada.

While organized workshops comparable to those held in HIV education, prevention, epidemiology and surveillance research have not occurred at a national level within the clinical and basic science field, and only in a limited number of provinces, community groups have contributed their voices to the establishment of priorities in these areas (Treatment Access and Research Committee, 1993). In 1993, thirty-three community-based treatment activists from twenty organizations in communities from Halifax to Victoria gathered in Toronto to review the state of clinical and basic science research in Canada. Most of those who attended were people living with HIV or AIDS. The objective of this encounter was to develop an HIV/AIDS research agenda for Canada and to produce a document to be of use to Canadian researchers and policy-makers for improving the clinical and basic science research agendas. More recently, Health Canada initiated a National Planning Forum on HIV/AIDS Research where representatives from across the spectrum of AIDS research have met to discuss future directions.

2.2.3 Research Initiatives

Though a number of HIV/AIDS education and prevention research projects reflecting a wide variation in community-researcher partnerships have been undertaken in Canada, it is beyond the scope of this paper to provide an inventory or description of these projects. However, we believe that most have been researcher-led, though not necessarily researcher-initiated, whereas very few have been conducted and controlled strictly by community.

Community-based research initiatives have not been restricted to population science and health promotion (behavioural, social science and epidemiology), but may be found in projects such as the Community Research Initiative of Toronto (CRIT), which has established a community database that tracks the spectrum of HIV disease for treatment and clinical research, and ultimately for policy purposes (Farlinger and Calvano, 1996). Similar partnerships to those seen in Canada have been developed in other countries (Sieber, 1992). The importance of such initiatives was highlighted in a plenary session titled "Community-based Research at the Crossroads" at the 1993 International Conference on HIV/AIDS in Berlin (Delaney, 1993).

Yet, few Canadian HIV prevention research initiatives have been conducted and controlled strictly by community.

2.3 Definition of Community

In the realm of Canadian HIV prevention research, the rise of community power has been an evolving process. Traditionally, the term community has been used to refer to a psychological sense of a community, a political entity, a functional or spatial unit that meets sustenance needs, a unit of patterned social interaction or an aggregate of individuals in a geographic location (McLeroy et al, 1988). In contrast, in the context of health, the term community often refers to a group of individuals who share social, cultural or economic ties and who may share a physical location (Cheadle et al, 1992). As travel and communication technologies develop, as populations increasingly become citizens in a global village, a community can no longer be defined by geographic boundaries, but rather is more appropriately and holistically defined as:

a specific group of people usually living in a geographical area who share a common culture, are arranged in a social structure and exhibit some awareness of their identity as a group. In modern societies individuals maintain membership in a range of communities based on geography, occupation, social contacts or leisure interests (Nutbeam, 1986:p. 116).

An interest in the role of community may be traced to various authors and methodologies, for example the action research of Lewin (1946), the applied methodologies of Glasser and Strauss (1967) and the empowerment education of Freire (1973). In addition, a number of other factors come into play.

First, there has been an increasing recognition of the importance of community in many diverse academic disciplines (for example, evaluation and program planning, anthropology, engineering and forestry), which has been subsequently propelled by a concept of community that is increasingly influenced by social network theory rather than geographic or situational factors (Wellman and Leighton, 1979; Tilly, 1973).

2.4 Community Development and Community-based Research

A second factor that explains this current community-research focus is the rise of community-development models. In its purest form, the community-development approach holds that, in order to gain control over their lives and the circumstances that affect their health, communities must identify their own problems and develop and implement their own solutions (Planning Committee on AIDSIDA Consensus, 1992). The ultimate agenda of community development and health promotion is not only to understand the world, but to change it (Harris, 1992).

Community organization as utilized by community development models has been defined as the process by which community groups may identify common problems or goals, mobilize resources and develop and implement strategies for reaching set goals. Strict definitions also suggest that the needs or problems around which community groups are organized must be identified by the community itself, and not by an outside

Community development and health promotion seek not only to understand the world, but to change it.

organization or change agent (Minkler, 1990). Community organization is viewed as an integral component in achieving health promotion objectives, in disseminating health information, and in motivating healthy choices while providing opportunities to change behaviour and maintain such changes (Wakefield and Wilson, 1986).

2.5 Contributing Structural Forces in Canada

The movement towards community-based frameworks for research in Canada also has been fostered by changes in social institutions. For example, within universities, over the past two decades, there has been greater emphasis on graduate education. Graduate programs, both academic and professional, now emphasize research training, producing more graduates with research skills who find employment outside universities. With more highly trained individuals working in the community, there has been a shift in the location of research expertise away from academic institutions. At the same time, public and community-service agencies have established research departments for program planning and evaluation. In addition, some teaching hospitals have expanded beyond clinical research to encompass health promotion and social science, and in some provinces, system-linked research units have established partnerships between one or more community agencies and universities (Myers and Allman, 1995).

Another related factor is the growth of research and evaluation specialization in professional disciplines such as social work, nursing and education. Reinforcing these educational changes is the decentralization of governmental administration, requiring a shift in demand for local knowledge with which to guide action.

2.6 Community as Partner in the Research Process

A community for whom programs of any sort are being considered may constitute a highly valued resource, because a community is a fertile and powerful environment in which to attempt to alter normative beliefs and behaviour (Griffin, 1986). Proponents of community-based HIV prevention research justify the inclusion of community members as partners in the research process by recognizing the key contributions that communities may make to the development of educational initiatives (Planning Committee on AIDSIDA Consensus, 1992). Increasingly, social scientists, funding agents and community groups recognize that community ownership of a social problem is essential for successful community-based research (Jackson et al, 1982).

Although we are able to trace the evolution of community involvement in HIV/AIDS research in Canada across the history of the epidemic, very little has been written about it. While there are many references to *community-based research* in the Canadian and the international literature, the applied practicalities of a community-based approach—and how these might vary from other forms of research—are seldom discussed.

Although we are able to trace the evolution of community involvement in Canadian HIV prevention research, very little has been written about it.

Concepts of Research

Increasingly, Canadian HIV prevention research has required the development of strategic alliances between communities, the traditional research hierarchy and funding sources. These alliances, together with a series of methodological issues to be detailed later, have necessitated the adaptation of the conventional research cycle.

This section explores the differences between "conventional" or traditional forms and alternative approaches to research. It briefly outlines the continuum of positivist, interpretivist and critical research approaches, and examines many of the presumptions that underlie how traditional research envisions the role of research subject in the research process.

3.1 Forms of Research

Succinctly explained by McCutcheon and Jung (1990) are the variety of perspectives by which research may be defined. Essentially, these authors discuss the differences between positivism, interpretivism (or constructivism) and critical science. Though their monograph describes social science from the viewpoint of action research, these ideas are just as reflective of processes of participation found in other research approaches.

3.1.1 Positivism

Within a *positivist* conception of social science, the nature of reality is singular and measurable (that is, there is only one reality, and it is entire, tangible and able to be described). Individuals are considered removed or separate from their knowledge, and events are explained in terms of cause-and-effect relationships. Positivist research is value-free, unbiased and rooted in quantitative methodologies. By its strict scientific nature, positivism is viewed as capable of leading to the discovery of the laws that underlie reality. For the most part this is the conceptualization that has come to characterize most conventional scientific research.

Few of the research frameworks discussed in this document reflect a positivist conception of social science. This is because the melding of community with participation and the goals of action-oriented sciences are incongruent with the notion that individuals are removed from their own knowledge. For these research strategies, individuals are their knowledge, and any interpretation of reality is both value-based and biased.

3.1.2 Interpretivism

In contrast to positivism, an *interpretivist* (or constructivist) social science conceptualizes the nature of reality as constructed. Realities are not fixed, but multiple, fluid and open to interpretation. The relationship between the perceiver and what is perceived is interrelated, and the individual is not considered separate from his or her knowledge. Events are understood through the interaction between an individual's

mental sphere and the external context or environment. An interpretive conception cannot envision a value-free research, because individuals are thought to be unable to separate themselves from either their knowledge or their biases. Thus an interpretive view of social science conceives of research as value-bound.

3.1.3 Critical Science

At the extreme opposite of positivism is the *critical* view of social science. In a critical approach, reality is seen as social and economic. Reality exists and is experienced in tandem with the varying degrees of equality and dominance. The individual and society are interrelated, and their relationship is embedded within a particular society's (economic) reality. In critical science, research is neither value-free, as with positivist science, nor value-bound, as with interpretivist science. For the critical scientist, the goal of research is to uncover inequality, to understand why and how such inequality exists and to explore ways in which true equality may be achieved.

3.2 Conventional Research

Conventional social research is built upon the belief that the primary function of science is the enhancement of understanding, prediction and control. This enhancement is accomplished by discovering the laws or principles that govern relationships between observable phenomena. In conventional research social phenomena are stable and measurable (Cooperrider and Srivastva, 1987).

Most conventional science is based on the assumption that there is a single reality that is able to be deconstructed and measured. Thus, a social problem is understood in terms of cause and effect. This view envisions the relationship between the researcher and the research subject or community as separate (Susman and Evered, 1978; McCutcheon and Jung, 1990).

The aim of conventional research is to advance academic knowledge. The choice of the research problem, question or hypothesis often derives from the primary interests of the researcher, the literature and previous research, or from the request of the research funders. External consultation is often limited to interactions between other researchers and experts (Alary, 1990b). To develop and conduct such research, one needs a thorough knowledge of analytic techniques and research methods. The methods used are often linear, and follow a conventional research cycle, which evolves from theory to results. In conventional research, measures are standardized, replicable and deductive (Chesler, 1991). Hypotheses are defined at the outset, are highly specific and are verified through controlled experimentation. Research is planned in detail before its initiation, and includes many control procedures to prevent error and bias (Alary, 1990b).

In conventional science a social problem is understood in terms of cause and effect.

3.2.1 Control in Conventional Research

One element of the researcher's role in conventional research is to maintain control over the process and all participants. Often the researcher is removed from the field of study in order to maintain a desired objectivity. The products of this type of research rarely involve action. Instead, end points require the researcher to file research reports, to contribute to the scientific literature and to test and advance theory (Chesler, 1991; see also Maquire, 1987b; Clark, 1972a; Emery, 1976). The aims of this dominant form of social inquiry are universality and generalizability, and the researcher's relationship to the subject is one of detachment and neutrality (Evered and Louis, 1981).

Advocates for alternative paradigms of social inquiry feel that researcher control is inadequate to describe complex realities. These critics favour forms of social inquiry that promote social justice and self-reliance and that envision individuals as active agents in their environments.

3.3 Research and its Subjects/Community

The placement of the person into the role of *research subject*, with the allowance of only a limited range of behaviour, removes the person's actions from the actor. Conventional research may envision its subjects in this way, and treat them as fragments whose human elements are secondary to the needs of the research cycle (Rowan, 1981a).

By treating people as objects to be counted, surveyed, predicted and controlled, traditional research mirrors ... social conditions which cause ordinary people to relinquish their capacity to make real choices and to be cut out of meaningful decision making (Maquire, 1987a:p. 37).

The generation of new knowledge is a participative enterprise (Raush, 1986). Community-based research allows a community the opportunity to self-reflect and generalize findings to a community or individual level. It is these elements that may make a community-based research project more than just an abstract academic exercise (Morris, 1992). When a research activity is organic—that is, when it originates and is embedded within a community—there is an increased likelihood that the results may be of direct benefit to the community (Kelly et al, 1988).

Research can be done in the community. It requires a systematic curiosity, a willingness to ask questions and sufficient organization and initiative to work towards an answer (Morris, 1992:p. 128).

One element of the researcher's role in conventional research is to maintain control over the process and all participants.

Although community involvement in Canadian HIV prevention research is singular in certain respects, it is not unique. As stated earlier, community involvement in social science research predates many non-positivist contemporary research frameworks. One of the earliest examples of a research framework that contemplates the role of community is action research, which this section examines. This is followed by a brief examination of participatory research and participatory action research and their contributions to today's community-based research.

4.1 Action Research

The process of action research as a system for the development and application of social study was first articulated by Kurt Lewin in the 1940s and, historically, was a direct affront to the dominant research ideology of the day. In contrast to conventional research, action research was envisioned as problem-driven, client-centred and challenging to the status quo or the university and its setting (Lewin, 1946). Though it was unable to produce the same kinds of accepted or rejected hypotheses as more conventional forms of research and analysis, the research findings of an action research project could be used in everyday life and integrated into general social theory (Argyris, 1983).

4.1.1 Definitions of Action Research

Since Lewin, action research has been defined as:

- 1) the systematic collection and analysis of information for the purposes of informing political action and social change (Barnsley and Ellis, 1987d).
- 2) a systematic process of collaborative review and improvement of educational or social policies, programs and practices (Kemmis, 1983).
- 3) a kind of social science that deals primarily with primary data encountered 'on line' in the midst of perception and action and only secondarily with secondary data (Torbert, 1991c).
- 4) a cyclical inquiry process that involves diagnosing a problem situation, planning action steps and implementing and evaluating outcomes. Evaluation leads to diagnosing the situation anew based on learnings from the previous activities' cycle (Elden and Chisholm, 1993).
- 5) a dialectical experiential process that treats the four territories of experience as distinct (Torbert, 1991c).
- 6) a field developed to satisfy the needs of the sociopolitical individual—who recognizes that, in science, he or she can find the most reliable guide to effective action—and the needs of the scientist who wants his or her labours to be of maximal social utility as well as of theoretical significance (Chein et al, 1948).

Traditions

of Community

Involvement

in Research

Action research
has been defined
as a system,
a process,
a cycle,
an approach,
an innovation,
a theory,
a strategy and
a competence.

- 7) an approach where researchers work with and train people from the study population to carry out research on matters of direct concern to them (Borrero et al, 1982).
- 8) a process during which both general and social-science inquiry are carried out, and practical help towards resolving a group's day-to-day problems is given (Rubinstein, 1986).
- 9) a complex innovation that embodies the process of innovation itself. It is the vehicle, the procedural framework for initiating and implementing other innovations (Holly, 1991).
- 10) an empowerment methodology (Schoepf, 1993).
- 11) a joint process aimed at meeting both research and intervention objectives (Israel et al, 1989).
- 12) research aimed at producing new knowledge that contributes both to general knowledge and to the practical solutions to immediate problems (Elden and Chisholm, 1993).
- 13) the creation and refinement of theory based on the application of theoretical principles of organizational science in an effort to alter a social system (Tichy and Friedman, 1983).
- 14) a strategy for distributing knowledge (Clark, 1972a).
- 15) a cooperative, cyclical process of diagnosing and analyzing problems and planning, implementing and evaluating interventions aimed at meeting identified needs (Hugentobler et al, 1992).
- 16) a combination of participatory fact-finding with implementation (Sommer, 1990).

Rapoport's (1970) definition of action research incorporates two main tenets, and is currently the most frequently cited within a modern context. This definition holds

- A) that action research aims to contribute to the practical concerns of people in an immediate problematic situation,
- B) and that action research aims to contribute to the goals of social science by joint collaboration within a mutually acceptable ethical framework.

To this, Piette (1990) has added a third aim of action research:

C) to develop the self-help competencies of people facing problems.

4.1.2 Variations in Action Research

The definitions that describe action research are incredibly varied. In some, the desire or need for action, learning and empowerment may be more important than

the actual research findings. Variations may be conceptualized in terms of the approach or the goals of a research project (Heller, 1976), or in terms of the strength or role of the action component within a given project:

there are two versions of action research, weak and strong, and among them they share three characteristics: involvement in change, organic processes and collaboration. The weak version—which entails these three as a minimum—is not incompatible with other forms of social research whereas the strong or stronger version of action research entails a commitment to an entire philosophy of science (Peters and Robinson, 1984:p. 121).

4.1.3 Process and Action Research

Action research views the research cycle as a process where applied knowledge is produced in order to fuel subsequent action (Oquist, 1978). Action research embodies many broad process factors that distinguish it from other forms of research. These include the motivations and roles of the researchers, the role of community, the definition of the problem, the goals and the scope of the research, the research design and approach and the analysis of the data (Cunningham, 1976). By beginning with the principle or belief that people experience their own situations, action research is able to build upon these experiences through processes of social interaction (Schoepf, 1993). One of the fundamental principles or beliefs of action research is that the study population should be active participants in the organization, design and implementation of a research project (Holmila, 1989; Pederson et al, 1990).

For many, the primary value of an action research model is its interactive nature. Projects are designed not only to monitor the research questions that exist within a specific environment, but also to assist in the development and empowerment of the community within that environment (Power et al, 1991). As Sims (1981) states:

If we wish to do research with persons without denying their everyday human qualities, the methodological choice we have is not whether or not the research we conduct should be action research, but rather, whether we should acknowledge to ourselves that it is so, and be explicitly aware of...the complexity of what we are doing (p. 380).

In its simplest form, an action research model has three main features – planning, fact-finding and analysis (Sanford, 1976). The process accompanying this model is not unlike the process found within a conventional research cycle. This includes the definition or identification of the problem, the creation or appropriation of the research question, the choice of a theoretical framework, preliminary or investigatory data collection, further clarification of theory and method, final data collection and analysis, preliminary feedback of results, reporting results, follow-up and finally, evaluation (Thorsrud, 1976).

For many, the primary value of an action research model is its interactive nature. Action research projects or models do not require a single set of research techniques or procedures (van Manen, 1990). Often, however, research subjects and researchers are brought together from the very inception of a project to define the problem(s) to be investigated (Mattingly and Gillette, 1991). In terms of methodology, most action research holds that a project should not explore areas that move beyond the boundaries of human reason; that is, there should be no exploration of research questions that cannot be answered during a project (Cooperrider and Srivastva, 1987). Action research envisions a reciprocal relationship between the spheres of action and research, where action may lead to or require research, or research may lead to or require action, or the two may occur simultaneously (Angus and Tregunna, 1989). Due to this interrelation, and the necessary flexibility inherent in the action research process, the effective linkage of research and action requires that projects address the right questions. Thus, esoteric or abstract academic questions have little value for an action research framework (Siassi and Fozouni, 1980).

4.1.4 Research Subjects in Action Research

Action research may require the development of systems of social interaction, which, together with the research process, empower both researchers and community populations. Even though conventional forms of research must adhere to strict ethical guidelines for the use of human subjects, scientifically they have often viewed or treated the communities under investigation as little more than research subjects. For action research the opposite is true. Study populations are considered self-reflective subjects with whom researchers collaborate. The underlying philosophy need not necessarily follow a conventional research model, which often requires large groups of respondents and large data sets to guarantee statistical significance. For action research, individual cases may provide sufficient information.

4.1.5 Goals of Action Research

One goal of action research is to develop guidelines that lead the researchers and the community to take the required actions to produce the desired outcomes often education and empowerment. One strategy for the growth and dissemination of this type of knowledge is the creation of an applicable research setting and environment suitable for learning. Conventional social science generally evaluates the success of a project by whether the researchers are able to accept or reject a preformulated hypothesis. With action research, the criteria for success are not based on prediction of this kind, but on the evaluation of the intended consequences of the research process. The overall implication is that a project's findings need not be universally generalizable. Rather, the interpretation of findings and how they best may be generalized or applied to other individuals or communities may be narrow, situational and bound by the context of a project (Susman and Evered, 1978).

Action research is open to involvement by all parties or subjects in the community being studied, and the basis for involvement is concrete experience.

4.1.6 Characteristics of Action Research

The elements that differ between the action research framework and more conventional frameworks are the underlying intentions of the work and the extent to which these contribute to the research cycle. Elements or dimensions that allow for comparison and contrast between various action research projects may include the organization of the research setting, the openness of the process, the goals and purposes of the research effort and the researcher's role (Chisholm and Elden, 1993).

Action research is open to involvement by all parties or subjects in the community being studied, and the basis for involvement is concrete experience. The choice of the research problem is usually based on socially recognizable needs rather than on the personal interests of a researcher, academic institution or funding agency, and the research is often multidisciplinary, aimed at the development of new knowledge for all participants (Lamoureux, 1989).

One of the most effective ways to combine action and research is through the establishment of a set of measurable and attainable objectives. If individuals and community groups are to participate in action at every stage of the research cycle, the necessary tools must be developed in the community (Angus and Tregunna, 1989). Ultimately, the success of action research begins with the willingness of the researched community to be deeply reflective and open (Mattingly and Gillette, 1991).

According to Stebbins and Snow (1982), successful action research projects involve collaboration between individuals both inside and outside the research system. Attention must be paid to the hierarchy of academic and community bureaucracies. Some of the key characteristics of action research may include participation, collaboration, learning, system development and empowerment (Israel et al, 1989), as well as cooperation. The goal is to strive for a balance between action and research (Israel et al, 1992).

4.1.7 Action Research as an Alternative Methodology

Though some aspects of it are now becoming mainstream, action research has never been envisioned as a mainstream research approach, but as one that simultaneously embodies a type of inquiry, a type of action, a type of science and a type of politics (Torbert, 1991c). Action research provides an alternative to conventional forms of research, in which conditions such as the research environment are held constant (Harris, 1992). The philosophy behind an action research framework cannot be removed from its political and ideological roots of liberty, equality and fraternity (Torbert, 1991c), and in this sense it is the opposite of externally generated inquiry and forced change (Holly 1991). As a framework, action research "has the potential to be for the postindustrial era what scientific management was to the industrial era" (Cooperrider and Srivastva 1987:p. 130). Yet, in the fifty years since Lewin's initial conception, pure action research has become increasingly rationalized and encultured, and at present the method risks becoming little more than a cruder form of

The action research cycle is a process of involvement, empowerment and social change.

more conventional methods (Cooperrider and Srivastva 1987). The inclusion of action in the research environment is bound in part to a certain political philosophy or orientation that seeks varying degrees of social change. It is not surprising that such a philosophy has not found unanimous appeal in academic or funding circles.

4.2 Participatory Research

Unlike action research, participatory research is a form of inquiry that proposes new ways of perceiving knowledge and research: "it is where the social division of knowledge and power between various partners is put into question" (Alary 1990b:p. 208). Participatory research brings individuals and groups with different interests together in joint inquiry, education and action. In participatory research,

ideally all parties become learners. They share control over the research process, they commit themselves to constructive action instead of detachment, and their participation promotes empowerment as well as understanding (Brown, 1985:p. 70).

Participatory research has been described as:

- 1) The process by which the people investigating their problems with the researcher analyse the results of their investigation and develop action plans to solve these problems (Kirkpatrick, 1990).
- 2) A methodology of alternative systems of knowledge production for ordinary people who are deprived, oppressed and underprivileged (Tandon, 1988).
- 3) A research process in which the community participates in the analysis of its own reality to promote a social transformation for the benefit of the participants (Vio Grossi, 1981).
- 4) The process where local people are involved in investigating their own development process and formulating solutions to their own problems. This approach is based on the belief that researchers should not impose their frames of reference on those being researched (Corcega, 1992).
- 5) An approach that brings people together to study the issues that determine health in their community (Abbott et al, 1993).
- 6) An integrated activity that combines social investigation, educational work and action (Hall, 1981).

The relationship between participatory research and action research is a natural development in the evolution of an action science methodology. The two frameworks differ in their conceptualizations or beliefs of how the values of research may be attained and in the use to which these values might be put (Brown, 1985). In addition, the two traditions focus on different levels of analysis, methods and beliefs about the nature of society (Brown and Tandon, 1983).

In participatory research, ideally all parties become learners.

Like action research, participatory research is a collective undertaking, a cooperative, hands-on approach that integrates both a research strategy and an action strategy. Where action and participatory research begin to diverge is in the recognition of the utility of knowledge. Unlike action research, participatory research requires the intellectual and emotional commitment of all participants as the process moves towards its goal of increasing knowledge (Alary, 1990b). With participatory research, the research agenda is internal to the community. This internalization ensures that participants will have the capacity to engage in issues that are of interest and concern to them (Robottom and Colquhoun, 1992). One guiding principle of participatory research is an inherent commitment to the resources of the study community upon which the research is based (Corcega, 1992). It is very much a grassroots approach to research.

The aim of participatory research is to find a means of integrating research, education and action in such a way as to stimulate individuals, groups and communities to take control of the circumstances within which they live their lives. In doing so, participatory research attempts to break down the barriers between researchers and participants and academic and popular knowledge, and to dissassemble the traditional hierarchy of these relationships (Mellor, 1988).

4.2.1 Models and Processes for Participatory Research

A typical participatory research model may not be radically different from an action research model. Such a model may include community preparation, the training of local leaders and organizers, the design of the research and the training of the local research team, data-gathering by the local research team, data tabulation, analysis and validation by the community, community planning based on research data, project implementation by local action teams and community monitoring and evaluation (Chin et al, 1992).

Corcega (1992) suggests that a participatory research initiative includes discussion by the community of the problem situation, consensus about the problems or issues, the selection of a small group responsible for the research cycle, the design of a research program and the preparation, implementation and operation of a plan, including the development of contingency plans, the discussion of operational problems, joint data analysis, joint data collection, the implementation of recommendations and the consolidation of learning.

4.2.2 Planning Participatory Research

While the course of a participatory research project may follow a conventional research cycle, the goals for its development may be quite distinct. For many participatory research projects, work experience in the field is considered as valuable as expert knowledge. The roles of the academic researcher and the community member evolve throughout the project with the collaboration of other participants. Though many facets of participatory research may mirror more conventional

Where action and participatory research begin to diverge is in the recognition of the utility of knowledge.

approaches to research, there are some marked differences in the planning stages, specifically in terms of flexibility. While frequently there is a general plan, many decisions are made by the research collective, which may consider the goals of community development to be more important than the goals of the research. In participatory research the treatment and analysis of results are not necessarily 'results oriented'. Instead, interpretations and conclusions are aimed at direct application to practical solutions and to social improvements and general community development (Alary, 1990b).

If one is able to define the problem and the project's objectives, then one should have sufficient information to orient the research. It is important to note that unlike conventional research, which sets out to sample a representation of the population, the participatory research collective often represents the research sample itself.

4.3 Participatory Action Research

Evolving from Action and Participatory Research frameworks is a third approach: Participatory Action Research. It has been defined as:

- 1) A strategy in which professional social researchers go beyond treating those studied as gatekeepers and passive informants, and involve some of them as active participants in the research process (Whyte, 1991a).
- 2) A form of action research that involves practitioners as both subjects and coresearchers (Argyris and Schon, 1989).
- 3) A form of action research in which professional social researchers operate as full collaborators with members of organizations in studying and transforming these organizations (Greenwood et al, 1993).
- 4) A group activity where people of different power, status, influence and facility of language come together to work on a thematic concern (McTaggart, 1991).
- 5) A method where some of the people in an organization or community under study participate actively with the professional researcher throughout the research process, from the initial design to the final presentation of results and discussions of the action implications (Whyte et al, 1989).

Participatory action research combines action and participatory research and includes many of the methodological and ideological stances that have already been discussed. Critics of participatory action research view the distinctions between action and participatory frameworks as unnecessary, because by its very nature and grounding, action research would be impossible to conduct without an element of participation from both the study and research communities. However, proponents of participatory action research feel that sufficient evidence exists to show that some forms of action research are devoid of participation. They believe the distinction is useful and necessary (Greenwood et al, 1993).

For many participatory research projects, work experience in the field is considered as valuable as expert knowledge.

Participatory action research aims to solve problems, legitimate group claims, serve group goals, strengthen service capacity, empower members and generate and advance new knowledge. Like action research and participatory research, participatory action research requires the use of a number of community development techniques, with the belief that any resulting action should be congruent with both community need and theoretical advancement. Overall, a participatory action research approach is considered interpretive and inductive. Research issues evolve from experience in the field, and they focus on problem-solving (Reason, 1994; Whyte, 1991a; 1991b).

Participatory action research should be congruent with both community need and theoretical advancement.

Community-based

Research

5.1 A Continuum of Research Frameworks

The research frameworks discussed in this document exist on a continuum. At one extreme, these frameworks are concerned with radical social change. Often the goal is to transform entire social systems, networks or communities and to analyze structural conflicts and contradictions. Some versions of these frameworks view current social systems as incapable of equitably meeting basic human needs. In some versions, research has the potential to provide a reinterpreted vision of what could be (Maquire, 1987b). Yet, all entail an element of collaboration. In these research frameworks we expect to find genuine engagement, commitment, mutual respect, reciprocity and recognition of participants and of the product that will emerge at the end of the process (Raush, 1986).

The research frameworks subsumed under community-based research differ in the degree of researcher-participant mutual learning, the degree of participant influence over the research process and in the emphasis on action relative to research and theory-building (Israel et al, 1992). These research frameworks provide the investigator with a greater understanding of the research subject and provoke the community to ask questions so they may understand their own conditions (Pagaduan and Ferrer, 1983). More conventional approaches to research, with their dependence on academic or textbook expertise, are inherently unable to produce results that may be directly translated into actions for the community (Forrester and Ward, 1992). Community-based research begins where the people and the problems are. Such research entails innovative and practical problem-solving methodologies that build on cultural, social and spiritual values derived from the community itself (Hudson, 1980).

If we compare these research frameworks to conventional research approaches, the basic differences are easily identified. With action and participatory oriented frameworks, researchers immerse themselves in the study setting and take on the role of actor as opposed to onlooker. Researchers do not apply predetermined measures, rather measures are interactive and emerge throughout the research process. Criteria are based on what is deemed most relevant for a particular situation. For these approaches, results have to make sense and be directed towards the public, not the scientist. Validation is based not on measurement and logic but on experience, with the understanding that the acquired knowledge will be pragmatic, useful and empowering (Evered and Louis, 1981).

5.2 Paradigms

A paradigm is an entire constellation of beliefs, values and techniques shared by members of a given scientific community (Evered and Louis, 1981, discussing Kuhn, 1970). In social science, a paradigm is an accepted means of problem-solving (Barnes, 1982), or a basic set of beliefs that guides action (Guba, 1990a). A paradigm can be said to exist when a group of individuals concurs about general ways of seeing the world, the kind of theory that is acceptable and the kind of science that

should be done. Kuhn found that early versions of most new paradigms were crude, and that when paradigms changed there were significant shifts in the criteria determining research questions, research approaches and proposed solutions. This active evolution or process of change was termed a paradigm shift:

At the start a new candidate for paradigm may have few supporters, and on occasions the supporter's motives may be suspect. Nevertheless, if they are competent, they will improve it, explore its possibilities, and show what it would be like to belong to the communities guided by it. And as that goes on, if the paradigm is one destined to win its fight, the number and strength of the persuasive arguments in its favour will increase (Kuhn, 1970:p. 159).

Changes or shifts in paradigms, as patterns of assumptions and world views, start creeping into one's thinking and discussion in the normal course of trying to solve particular substantive problems (Smith, 1990:p. 146).

5.3 A Community-based Research Approach

The fundamental assertion of this document is that community-based research is a philosophy for inquiry and not a discrete research framework to be set alongside action, participatory or participatory action approaches:

if by virtue of nothing else than an accident of birth, all of us are participants in a postpositivistic culture of inquiry...we are thinking about and conducting our inquiries in a Zeitgeist that is characterized by a general rejection of the logical positivist or logical empiricist program of inquiry (Schwandt, 1990:p. 259).

By definition, action research requires action, and participatory research requires participation. Community-based research may incorporate either full action, varying degrees of empowerment, or, at the other extreme, nothing more than the permission of an involved community regarding any one particular research initiative.

Conceived as a philosophy for inquiry as opposed to a method, a framework or a strategy, community-based research becomes an ideology for research that is able to adapt from non-action through to full participation, or, as earlier elaborated, from the extremes of positivism through to critical methodology. Community-based research is a philosophy for inquiry that allows for variation in the nature of action and participation and in the conceptualizations of what constitutes social-science research.

In view of the influence of this approach on so many recent and current Canadian HIV prevention research initiatives, the authors propose that in this context, community-based research represents the evolution of an alternative paradigm for social-science investigation.

Community-based research is not a discrete research framework but rather a philosophy for inquiry.

5.4 Summary

The previous sections have outlined the historical and methodological evolution of action, participatory action and participatory action frameworks. Factors leading to the growing importance of communities as verifiable partners in the research process have been discussed, as have the research frameworks that have fostered the evolution of community-based approaches. Finally, it has been postulated that community-based research may be considered a paradigm for HIV/AIDS research in Canada.

The sections that follow examine a number of key issues for those that wish to incorporate or increase the role of community in the research process. The focus is on the research methodologies and skills most appropriate for effective community participation. These includes the varying degrees of participation that communities and community representatives may have, the role and form of mechanisms for decision-making, the relationships and partnerships that may develop between a community and a traditional research hierarchy, the importance of results and result dissemination, and the ways by which these findings may be turned into knowledge, education and empowerment. Physical and ideological barriers to a community-based research process are discussed, as are the benefits and advantages that such an approach can have.

We consider community-based research to be a paradigm for Canadian HIV prevention research.

6.1 Research Design

The primary objectives of a community-based research project often are not limited to obtaining new data or even to the production of new knowledge. As a result, issues of research methodology and design may become quite important (Forrester and Ward, 1992). Conventional research processes cannot always simply be transferred to a community-based research project (Bengtson et al, 1977). This is because there are important considerations for the incorporation of community elements into academic research. These include the degree of isolation or assimilation of a community, the complexity of the economic activity within a community, the community's quality of leadership, the vitality of culture, the community's cohesiveness, the existence of community-specific resources, the nature and extent of the community's social problems and the intensity of inter- and intra-community divisions (Hudson, 1980). The credibility of a project, the key players involved and a plan detailing the type of knowledge or expertise required at each stage need to be established early in the research process (Giesbrecht and Ferris, 1993).

The external environment may significantly influence how individual partners think about research (Argyris, 1983). This environment may consist of local or community-level conditions, or it may be affected by provincial or national issues. The political climate or context "is likely to be as important to the process and outcomes of a project as the selection of the intervention" (Giesbrecht et al, 1990:p. 187). For these reasons, community-based research projects should be undertaken in as culturally appropriate a manner as possible.

6.1.1 The Importance of Language

The complexity of social science research terminology and methods raises concern. A community that is unable to understand the language of a project will never be able to exert any real control over the research process or outcomes (Mergler, 1987). A community-based research project should employ words that all parties involved can understand. This may present a double-edged sword: it is critical for a community-based research project to give the community a real understanding of research method and practice, but at the same time the method should be rigorous enough to maintain credibility through design (Abbott et al, 1993). Agreement on terminology and methodology is as important as agreement on the values that will guide the research. Both must take into account the point of view and the expertise of the researcher and the community (Emery, 1976). For these reasons, the adaptability of the research process is a critical component. Flexibility in language and design enables a community-based research project to accommodate surprise developments or events while the original purpose is maintained and addressed (Giesbrecht and Ferris, 1993). By adopting a flexible stance, a community-based research project will maintain the continuity and integrity of the research effort (Bengtson et al, 1977).

Elements of

Community-based

Research

6.1.2 Qualitative and Quantitative Methodologies

Many community-based research frameworks favour qualitative over quantitative methods. Researchers in public health have traditionally preferred quantitative methodologies, whereas community leaders are often more comfortable with qualitative methods (Powell and Cameron, 1991). For community-based research, the use of qualitative methods, or even the combined use of qualitative and quantitative data collection techniques, may yield a more in-depth understanding on a number of issues (Israel et al, 1989).

Powell and Cameron (1991) suggest that neither academic researchers nor funding agents should prematurely rush into either qualitative or quantitative studies without a basic understanding of the phenomenology of the community they will be studying:

In many instances the research questions identified are wide ranging and complex. As such, they are not easily adaptable to narrowly-focused, short term investigations that use only quantitative methods. Health promotion research needs to place increased emphasis on qualitative methods, longitudinal studies, action research, program evaluation and target group involvement. Moreover, a multidisciplinary approach is needed and—for the time being at least—applied research should predominate over theoretical inquiry (Health and Welfare Canada, Winter 1989/1990:p. 9).

The communitybased researcher often adopts a role that gives rather than takes.

6.1.3 Goals and Objectives

The goals of any research approach should be explicit. Important for the success of a community-based research project is the development of flexible, feasible and justifiable goals (Cunningham, 1976). This is because

the development of project structures which are goal driven rather than ad-hoc may reduce the potential for conflict between research and community agenda (Giesbrecht and Ferris, 1993:p. 898).

In many community-based research projects, problem formulation must be stimulated by the community's needs and theory must serve as a means rather than an end. There should exist an inherent belief in research as a tool for social action, and there should be an explicit formulation of a project's values. Ultimately, the researcher in this type of project should adopt a role that gives rather than takes (Heller and Monahan, 1977).

6.1.4 Skills for Community-based Research

Kurt Lewin equates the development of skills with empowerment (Lewin, 1946). The training and skill enhancement of individuals are both essential elements and byproducts of community-based research. The types of analytical, critical and organizational skills that evolve throughout a community-based research project are trans-

ferable to those who have direct access to the project, and also to others through the dissemination and use of results (Forrester and Ward, 1992). The training of participants and the working conditions under which a research project unfolds should be flexible enough to allow for experimentation with various methods and means of training (Cunningham, 1976).

Some methods of research training conveyed through community-based research initiatives have included the development of trained community researchers, both knowledgeable and concerned with community issues; the combination of training in research methods through experience-based learning; the development of a team or network of individuals who work together around commonly perceived community problems over an extended period; and the collaboration of university and community-trained researchers who combine resources and knowledge to effect planned change (Borrero et al, 1982).

Often, the training of community members is essential if they are to attempt any meaningful participation. Such training should involve an understanding of how the identified problem or problems may be approached, the development of individual self-reliance and the conceptualization and introduction of tools for leadership, teamwork and negotiation. Above all, collaboration and shared trust are essential to community-based interventions (Sieber, 1992):

It is seldom possible to improve the action pattern without training personnel. In fact, today the lack of competent trained personnel is one of the greatest hindrances to progress in setting up more experimentation. The training of large numbers of social scientists who can handle scientific problems but are also equipped for the delicate task of building productive, hard-hitting teams...is a prerequisite for progress in social science (Lewin, 1946:p. 42).

6.1.5 Validity and Bias in Community-based Research

A discussion of methodologies for community-based research is incomplete without consideration of the concepts of validity and bias. Validation in these types of projects may be found not in descriptive numbers or significant statistics, but rather in the corrective feedback and review by researchers and community participants (Heron, 1981a). Though Chern (1969) suggests that action research leads to findings that have a low generalizability and a limited range of application (cited in Heller, 1976), applicability is only one means of estimating validity. Another is consensus. Thus, any element of a project may be considered valid if a number of people make the same observations and draw the same conclusions as the researcher or the community (Holmila, 1989).

By virtue of its deviation from conventional research design, a community-based research project may be construed as more open to contamination and bias (Blumberg and Pringle, 1983). However, when participation and community involvement are incorporated into the arena of research, theory and method become derived and validated through the immersion of the researcher as partici-

Applicability is only one means of estimating validity. Another is consensus.

pant in the community under study (Stokols, 1986). A community approach

assumes that the magnitude and the nature of the problem precludes a simple externally initiated solution. Instead, [a] program has to be integrated with the existing social and health service structure of the community...the population itself has to make the decision to organize itself to solve the problem with the help of the project experts. A community program assumes that existing scientific knowledge can be applied to serve the population or that the community can be helped by having better access to the use of existing knowledge (Puska et al, 1985:p. 151-52).

6.2 Participants

Community-based research accommodates participation from a wide array of interests, with participants involved in the design, administration, data-gathering, analysis and interpretation as well as dissemination of the results and final report (Ayers, 1987). The more the community is allowed to direct or influence the course of the research, the more participants will be able to interact with academic researchers and funding agents (Dorfman et al, 1992). In community-based research, a participant may act as a human catalyst, assisting communities to identify and select present needs, initiate action and ultimately carry it through to its conclusion (Hudson, 1980).

6.3 Resources and Access in Community-based Research

In community-based research, at least two participants share power and control. These are often the scientist (the academic researcher) and the community member (Sandow, 1979). One of the unique characteristics of this type of research is that the community member is able to limit the researcher's access to the data source.

While communities may not always control research dollars, they may control access to other resources. In community-based research, individuals acting as gatekeepers may limit the conditions of entry, define the problem area of study, limit access to data and to respondents, restrict the scope of the analysis and retain certain publication prerogatives and conditions. Often the gatekeeper's most important concern in the negotiation of access is reciprocity, that is, what may the research offer to the community as a whole? Or, at another level, how may the research enhance the particular careers of the gatekeeper or other players (Broadhead and Rist, 1976)?

Participants in community-based research are often individuals whose lives are affected by the research and who, at the same time, may make decisions that affect further research efforts (Greene, 1988b). It may be important to consider the factors that differentiate individuals who choose to participate from those who do not (Florin and Wandersman, 1984). Questions that may be posed are the same questions that have been frequently raised in the areas of citizen and voluntary participation in

Collaboration and shared trust are essential to community-based interventions.

general—who participates, who does not participate and why (Florin and Wandersman, 1990).

6.3.1 The Funding of Community-based Research

In community-based research there is almost always a third party or sponsoring agency, often a government funding arm. The exact nature of the participation of this organization may fluctuate. This agency may not be as removed from the research process by purely administrative or evaluative functions as they are in more conventional research frameworks. Instead, in community-based research, the third party may interact in a number of ways: as a co-investigator, evaluator or mediator.

Traditionally, funding for social-science research that incorporates action or participation from community members has been a difficult to secure. Most funding protocols are inherently opposed to a collaborative, pragmatic and flexible flow of information, education and empowerment. "Until this situation changes there is little likelihood of success in applying to traditional sources of funding" (Sommer, 1990:p. 211). Funding agencies still need to learn the value of participation-based research as a process of good science that leads to practical action. "Traditional funding criteria need to be expanded to include the relevance of the research question and agenda to society" (Abbott et al, 1993:p. 27). Conchelos and Kassam (1981) caution that because of the funding agency's power, and thus their potential control over the research process, the results generated by a community-based research project may run the risk of being appropriated.

6.4 Participation

Participation is defined as a process by which individuals become involved in the decision-making of the institutions, organizations and environments that affect them (Florin and Wandersman, 1990). Genuine participation occurs when people are involved throughout the decision-making process (Kirkpatrick, 1990):

Participation is based on the premise that improving the quality of life in the community is the product of the partnership formed by the community (Chin et al, 1992:p. 104).

In a community-based research project, involvement becomes participatory because the project gathers the community in social or educational settings and involves them in many stages of the research process (Kemmis, 1983). However, it is necessary to make the distinction between participation and involvement. To participate means to share or to take part in some activity, whereas to involve means to entangle, implicate or include (McTaggart, 1991).

Participation may be effectively visualized as a continuum or a ladder, with manipulation at one extreme and citizen control at the other (Arnstein, 1970). High levels of participation may ensure that the results of the research process are met and that findings are disseminated and utilized. Involvement by citizens may help to ensure that research objectives are in accordance with citizen concerns. Such involvement

Traditionally, it has been difficult to secure funding for social science research that incorporates community action or participation.

can also ensure that data-collection techniques and the interpretation of results are valid and culturally sensitive.

Participation may also be visualized in somewhat more discrete categories. Seeley et al (1992) have developed a schema for community-based HIV/AIDS research based on Ashby et al's (1987) typology of participation. The schema includes:

- 1) Contract participation, where the researchers contract the community for participation.
- 2) Consultative participation, where researchers consult the community about their problems and then develop solutions.
- 3) Collaborative participation, where researchers and the community collaborate as partners in the research process.
- 4) Collegiate participation, where researchers strengthen the independent research and development systems that already exist within the community.

At times, the concept of participation is ambiguous and may be equated with an agent's desire to secure cooperation from a specific community. In some cases community participation may be a mechanism by which an agency demonstrates it has secured the consent of the participants. The idea of participation may also be problematic when people with different power status, influence and facility with language are brought together. In some instances pure participation may be polluted by issues of power, culture and gender (McTaggart, 1991):

A crucial criterion is not the degree of participation, but whether the planning and action accompanying the research emancipates the people involved (Swantz and Vainio-Mattila, 1988:p. 130).

In some ways projects that foster participation offer a more scientific method of research, as participation of the community facilitates a more accurate and authentic analysis of social reality (Pagaduan and Ferrer, 1983).

6.4.1 Participative Ownership

The concept of participative ownership refers to the process whereby community members take an active role in the decision-making processes that shape programs (Kelly et al, 1988). This usually involves having the academic research staff create the opportunities for community input, feedback and often control. Such participation gives members of the community the opportunity to discover their options and to make choices while furthering their abilities to develop research issues (Seeley et al, 1992).

The concept of self organization is supported by a wide literature that indicates that collective action for group interests is most effectively based on organization among and by the persons sharing the interest rather than on organizations run by outsiders (Friedman et al, 1987:p. 202).

Funding agencies still need to learn the value of participation-based research as a process of good science that leads to practical action.

Some very narrow definitions of citizen involvement and participation exist, which include only the activities of those involved in direct decision-making. Such definitions suggest that measures of interpersonal interaction, increased responsibility and organizational problem-solving also may be used when one attempts to define participation and empowerment (Zimmerman and Rappaport, 1988). MacCall (1981) proposes that participation may be used by a local community in a number of ways: as a means to facilitate and lubricate outside interventions; as a means of mediation to modify, guide or redirect interventions; as a means to empower weak or weakened groups. Authentic participation permits ownership and control and a stake in the way research is conceptualized and practised (McTaggart, 1991).

There is a general assumption throughout the literature that community participation in the research process is beneficial for all parties and that there exists an inherent need, though not necessarily desire, to participate if given the opportunity. Community involvement or participation in the planning may benefit the research process in a number of ways. Such participation permits a test of the feasibility and acceptability of new programs or ideas, the possibility of gaining wide citizen and volunteer support, the incorporation of local values, attitudes and symbols into implementation plans, the ability to gain access to local leaders, resources and technical skills not otherwise available, the ability to build the layperson's point of view into program delivery; the creation of local skills and competencies for future community development between loosely structured public and private agencies and organizations, the negotiation of conflicts between political factions and special interest groups, and the assurance of local ownership (Bracht and Tsouros, 1990).

6.4.2 Facilitating Participation

Training community members in research skills requires special attention (Piette, 1990), yet allowing individuals from the community to have a role in setting the agenda of the research inquiry, to participate in the collection and analysis of data and to enable the community to take control over the use and outcomes of the research process, are avenues that will guard against mere involvement and encourage genuine participation (McTaggart, 1991). Early participation by a wide range of players will also encourage dissemination of information and provide support for research findings (Angus and Tregunna, 1989).

The enhancement of public participation is one of the guiding principles of healthy public policy (Pederson et al, 1988). Integration of the policy-development process into the design of a community-based research project means that results may be more widely disseminated. In addition, incorporating policy-makers as partners or participants may ensure that results are more likely to be implemented. However, community-based projects do involve the uncertain mixture of researchers and community members, and there is always the danger that policy efforts may need to be modified or even eliminated in the negotiation process in order to secure a common research agenda (Giesbrecht and Ferris, 1993).

There is a general assumption throughout the literature that community participation in the research process is beneficial for all parties.

6.5 Researchers

Researchers and the roles they assume throughout the course of a community-based research project also require special attention. Often those researchers who approach a community-based inquiry are themselves community stakeholders. Frequently the same individuals who devise, manage and undergo the experience of the research also perform the actions that are being researched (Heron, 1988), and hence, are able to provide corrective feedback for themselves and their colleagues (Heron, 1981b).

Through collaboration with members of the community, researchers combine theoretical with practical knowledge and practical experience in order to understand and solve problems (Blumberg and Pringle, 1983). In this type of inquiry, researchers, like community individuals, can also

act as catalysts to stimulate awareness of common interests, to introduce communication techniques that facilitate analysis and to provide information on organizational strategies employed in similar circumstances elsewhere. While there is always the danger that the participatory researcher will fall into the role of expert director, the principle adhered to is that the knowledge and authority of the people is paramount (Castellano, 1986:p. 25).

6.5.1 The Role of the Community Researcher

The participatory nature of community-based research forces a change in the traditional role of the researcher. It is a change that is not always easy to accommodate. The researcher may become more of an advisor or a facilitator than a supervisor of a research project (Pederson et al, 1989). Yet this revised role may be instrumental in establishing the conditions for the development of community participation and ownership (Susman and Evered, 1978). By permitting the development of a genuine relationship between researcher and subject, community-based research leaves open

the possibility that both will change in the process. The researcher becomes the subject's partner or student, and describes the events using the language of the subjects rather than the language brought from outside the context of study (Reinharz, 1981:p. 417).

The primary tasks of the community-based researcher are to generate valid information, to help the community make informed and responsible choices and to develop an internal commitment to those choices (Heller, 1976). These are not always simple processes. Traditionally, researchers and scientists have had restrictive, narrowly defined agendas, often at odds with community perceptions of the problem studied (Giesbrecht and Ferris, 1993). Researchers who choose to work in collaboration with the community ultimately have to be flexible, because the exact nature of such collaboration may vary widely across projects or even within a single project (Giesbrecht et al, 1990).

Many researchers
who approach a
community-based
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themselves
community
stakeholders.

6.5.2 When the Researcher is Part of the Community

Conventional social science requires a separation between the researcher and the subject of the research. The aim of such a separation is to retain objectivity and to avoid bias by restricting the interactions between experimenter and subject (Chavis et al, 1983). Combining action or participation with research often eliminates the separation of researcher and subject.

One unique component of community-based research is that the process does not recognize the researcher as the sole possessor of knowledge. In community-based research no single individual may lay claim to all information. The roles a researcher might assume throughout the community-based research cycle include that of a chronicler of social activity, an agent of social change, a broker or an educator (Uzzell, 1979). Such roles may manifest themselves in the setting of the agenda of inquiry, the collection and analysis of data and the use of results (Abbott et al, 1993).

Tasks associated with the researcher's role may include the development of the preliminary study design, such as goals and objectives of research, facilitation of group interaction to generate ideas, specification of possible areas of inquiry, the creation of research instruments, preparation for data collection, synthesis of findings into pragmatic and usable information, assistance with the presentation of reports and assistance with overseeing and polishing the basic process. In contrast, tasks associated with the role of the community member may include review of the evaluator's preliminary documents, selection of questions, review and revision of research instruments, distribution and collection of instruments, data collection, development of recommendations and formal writing of summary findings and the presentation of reports to media (Ayers, 1987).

Importantly, community-based research does not recognize the researcher as the sole possessor of knowledge.

Issues In

Community-based

Research

7.1 Advocacy in Community-based Research

Research that involves elements of advocacy has a different orientation than research that evolves from a purely academic base. Community-based approaches may benefit from the presence of an advocate or an individual or group of individuals capable and willing to interpret scientific data and to develop findings into action and policy (Sommer, 1987). Seashore (1976) finds that advocacy is an inevitable part of the role of community-based researcher. As a result, participants in community-based research should pay special attention to the roles the researcher/advocate will play and the flexibility for advocacy that the research process will allow (Peterson, 1974):

Investigators must not be naive about the concerns and about the power of community advocates. Researchers must build community involvement into the process of the research and be prepared for both conflict and unanticipated benefits from the resultant collaboration. They must be aware of the new rules of accountability emerging in social research—that legitimacy will not be judged solely on the grounds of research design or scholarly contributions, but also on benefits to the communities involved (Bengtson et al, 1977:p. 90).

The role of the researcher/advocate perhaps is unique to community-based research approaches. The skills necessary for assuming this role include the abilities for cross-cultural communication, facilitation of group maintenance skills, an understanding of methods and techniques of a variety of subject disciplines, the ability to analyze situations and problem-solve, nonreactive translation of ideas and organizational ability, including the ability to direct and coordinate the activities of many individuals (Peterson, 1974).

Each role an individual brings to the research process may have characteristics that predispose participants to a certain point of view. For example, the role of the scientist may be construed as being at odds with the community change agent (Giesbrecht and Ferris, 1993). Frequently such concerns will reveal themselves in an attitude to community participation that leans towards transforming desires and wishes into an "administrative strategy of co-optation" (Metsch and Veney, 1976).

7.2 Collaboration between Researcher and Community

Collaboration between community and researcher requires negotiation and planning. Some elements that may be explored at the beginning stages of these research relationships include the availability of time, characteristics of the participants, compatibility of the participants in terms of the topic under investigation, the personalities of the participants and potential benefits of the project to the individuals and institutions involved (Singleton et al, 1982).

The collaborative relationships that develop within community-based research are open to suspicion and misunderstanding. As a result, academic researchers—who

have traditionally maintained control of the research process because of scientific and funding criteria—must be careful not to dominate interactions:

It is important that this participative process does not become merely a symbolic requirement to be met. Rather, genuine citizen participation will promote the authenticity of the research and enhance the potential for its findings to be integrated within the community (Kelly et al, 1988:p. 127).

Researchers and communities considering a community-based research approach need to recognize that there may be inherent conflicts in the roles of the researcher, and that they may need to reconcile a community orientation with the constraints of an academic researcher's environment (Mergler, 1987).

7.3 Conflict in Community-based Research

Partnerships are based on the recognition of power dynamics, and genuine collaboration necessarily involves a redistribution of power (Drake and Griffiths, 1976). Often lacking in conventional research relationships, but needed for community-based projects, are arrangements that ensure a balance between the interests of the research, the researchers, the funding agents and community members (Giesbrecht and Ferris, 1993).

One of the most fundamental sources of conflict between researchers and community members is often found in the definition of the overall goals of the research enterprise (Goodstadt, 1989). In community-based research, the communities involved in the research should have some control over the process of knowledge and action. "The process of the research has to shift power and control" (Tandon, 1981). Without some community control over the research process, power may easily be retained and even increased by those already in control (Hall, 1981). Yet the desired shift of power may be difficult because in many instances the community lacks the experience, expertise and ability to delegate in a research environment. This is in part because

researchers do not try to explain the simple and logical basis of experimental research designs, and because [they] fail to report [their] results in terms that can be understood by others (Goodstadt, 1989:p. 228).

7.3.1 Power Imbalances

At the outset of any community-based research process there may be a power imbalance. Researchers may be driven towards the expansion of a body of knowledge, whereas the community may be more concerned with the development or implementation of services or programs (Goodstadt, 1989). The greatest potential for conflict of ideology and values exists where arrangements have to be negotiated with the community (Giesbrecht and Ferris, 1993), and where community power struc-

At the outset of a community-based research process there may be a power imbalance.

tures attempt to control which issues are placed on the public agenda (McLeroy et al, 1988).

7.3.2 Mediation in Community-based Research

Community-based research should incorporate techniques to bridge the gaps that separate scientist from citizen (Chavis et al, 1983). Essentially this requires the creation of a means of mediation between the community and the research establishment. Such mediation may possibly create a link between the research system and the community system, arrange the entry of the researchers into the community or reinforce community expectations, sanction the presence and activity or action plan of the research and be alert and flexible enough to accommodate shifts necessary to maintain the equilibrium of relationships. Mediation also should create the conditions to help both parties engage in shared tasks (Goodman and Clark, 1976).

7.3.3 Conflict Resolution

Mechanisms for conflict resolution are essential for the community-based research process.

The nature of the conflict between the lay community and the professional researchers demands that strategies for conflict resolution be given consideration equal to that directed toward design criteria and methodological procedures (Bengtson et al, 1977:p. 89).

One of the ways to reduce conflict or power imbalances is through accountability (Mellor, 1988). Encouraging accountability among researchers and community can facilitate clarification of the roles for all participants and provide a context in which different partners and contributors may develop working relationships with each other.

7.3.4 The Roles of Communication and Dialogue

The facilitation and maintenance of open communication and dialogue also ensures that conflict can be negotiated or reduced. Communication throughout all stages of the research process may help to create continuity across the research experience, and may also help to resolve issues of conflict and power (Webster and Nabigon, 1993). Communication is a process based on equality of understanding and mutual respect.

Debate and dialogue among key interest groups increase awareness about varying perspectives, goals, models of change, working hypotheses and interventions...project personnel and other community members should be encouraged to discuss their perspectives in order to establish a common ground for developing and refining a project, interpreting one anothers' orientations as the project evolves, and assessing action steps based on the model from which the intervention was developed (Giesbrecht et al, 1990:p. 287).

Genuine collaboration necessarily involves a redistribution of power.

Dialogue is not necessarily a constant. Certain values and approaches may facilitate or prevent dialogue and communication. And the dialogue possible at one stage of a project may not necessarily be possible at all stages (Southgate, 1981).

7.4 Partnerships in Community-based Research

A partnership is an active process: an "informed, flexible and negotiated distribution and redistribution of power among all participants in the processes of change for improved community health" (Goeppinger, 1993). Through partnerships, people can extend the limitations of knowledge and resources, thus strengthening the research enterprise.

The partnerships and relationships that are likely to develop across a community-based research process will be based on a combination of power, knowledge and negotiation, and may best be described as symbiotic, where both parties gain from the exchange. Such partnerships have the advantage of enriching the opportunities for innovation within the research process because, ultimately, "it is more effective to share resources, facilities, knowledge, ideas and experience, than to work in isolation" (Mergler, 1987).

The development of the relationship or partnership between the researcher and the community is in itself a process. Successful interaction requires the establishment and development of a shared model of reality. One of the challenges posed by community-based research is

how...the values behind the philosophy of forging partnerships become a way of life...[how] communities, the government and non-government organizations become members of these partnerships (Chin et al, 1992:p. 110).

The literature suggests that

the values, predispositions and agendas that define the strategies that provider organizations and their representatives bring to the participatory setting may be a key factor in determining the outcome of that participation (Metsch and Veney, 1976:p. 285).

7.4.1 Community Research Bases

While an identifiable community base such as an AIDS service organization or an advisory working group is not necessarily essential for the development of a community-based HIV prevention research project, many projects do institute these types of community bases to facilitate such research. Community research bases that have formed in response to the AIDS epidemic have found that action and participatory research frameworks are able to "enhance the capacity of existing community groups and networks to undertake risk assessment and social support for behaviour change" (Schoepf, 1993:p. 1402). A community research base increases the odds that

For community and researchers to work together there has to be communication and dialogue.

research will be meaningful as it elaborates the experience and commitment of knowledge within the community. One offshoot of the process is that it may build "ties for future collaboration around community health issues" (Norr et al, 1992:p. 255). Many communities affected by HIV contribute self-reflective knowledge to prevention research. Such knowledge "brings a richness of interpretation" to data collection, dissemination and implementation that would not be present otherwise (Altman, 1993:p. 3).

Research aimed at the design, implementation and evaluation of AIDS interventions depends in many ways on the organizations that can represent and reach the communities that are the targets for those interventions. Beyond providing entry into these communities, collaboration with organizations and individuals in the community can enrich the research process and improve the chances that the interventions will be effective (Turner et al, 1989b:p. 364).

A factor influencing the success of partnerships in HIV research is the ownership felt by members of affected communities. This ownership has been followed by community sanction of programs and their evaluation. As a result,

much of the best behavioural and statistical research on AIDS has occurred through collaborations among scientists from universities, the staffs of government agencies, [and] the organizations rooted in the communities that have borne the brunt of the AIDS epidemic (ibid).

Successful interaction requires the establishment and development of a shared model of reality.

7.4.2 The Danger of Tokenism in Community-based Research

In the document Towards an HIV/AIDS Research Agenda for the 1990s, Hankins and Handley (1993) indicate that one area in particular was of concern to community groups: the degree of tokenism or exploitation of community groups and community members by researchers.

Some research projects were perceived to be targeted at communities rather than developed from within communities. As a consequence, the research results which were subsequently produced were often not translated into either meaningful programmes or policy changes (Hankins and Handley, 1993:p. 9).

Increasingly, community leaders make clear the real need for active participation by affected communities in the planning phases of research projects, rather than just in the data collection. In part this recognizes that regardless of the rhetoric behind much of the current discussion of communities and involvement in research, the potential does remain for researchers to continue to dominate the decision-making process. Community representatives have expressed the desire to be consulted on the establishment of an overall research agenda and on the design and conduct of behavioural research studies (Planning Committee on AIDSIDA Consensus, 1992) in

order to reduce duplication and ensure the relevance of questions and findings of the research to an agency's AIDS education and prevention programs.

7.5 Dissemination and Use of Results

The use of non-conventional avenues to disseminate results is considered important for community-based research (Pederson et al, 1989). Ayers (1987) believes that the process of involving community members and respondents in all aspects of research dissemination will lead to an increased acceptance and use of results. One way to involve the community is to guarantee a clear method for making decisions about the use and dissemination of research findings (Kaye, 1990). Researchers who participate in community-based research projects and succeed in convincing the community to support their visions have a strong obligation to report the outcomes of the research to the community (Heller and Monahan, 1977).

7.5.1 Strategies for Dissemination

Unlike conventional research projects, community-based research projects often build dissemination strategies into their overall design (Sommer, 1987). Such projects are easily translated into programs of action because they are able to provide insight into the methods of promoting empowerment through knowledge and control (Florin and Wandersman, 1990). The dissemination and use of results may be improved if members of the study population are closely involved in the development and execution of the project (Sommer, 1987). Another means to facilitate dissemination and utilization of results is to synthesize and publicize research findings in an accessible language (Health and Welfare Canada, Winter 1989/1990). This may entail exploring new and somewhat non-conventional forms of dissemination. Strategies derived from concepts of stakeholder evaluation and models of community development may enhance the utilization of findings by the community. One means to guarantee that research is accessible, disseminated, utilized and diffused is to include a guide to how findings could or should be implemented (Rothman, 1974).

Community involvement may enhance the use of research and ensure that research objectives are congruent with citizen concerns. Such involvement may help ensure ecological validity and cultural sensitivity in data-gathering and measurement techniques and, in the measurement and interpretation of results. In addition, community involvement may also facilitate dissemination by fostering a sense of ownership and by increasing the credibility of the results. It may provide training in the acquisition and use of results and link people with common concerns (Wandersman et al, 1983).

Community involvement can facilitate dissemination by fostering a sense of ownership and by increasing the credibility of the results.

7.6 Knowledge, Education and Empowerment

Knowledge and the acquisition of knowledge are at the core of the community-based research process, where they are considered to be the single most important basis of power and control (Tandon, 1981). Action, participatory and participatory action research approaches contribute to our knowledge base because they strengthen and legitimize the knowledge of ordinary people and communities. Community-based research may refine peoples' capacity to conduct research. It may allow people to appropriate knowledge produced by conventional or academic systems of knowledge development. It may develop relevant knowledge and liberate and empower the minds of people and communities (Tandon, 1988).

7.6.1 Knowledge Production

Numerous types of knowledge may be generated through community-based research, and all have potential value for partners and stakeholders. These types of knowledge may include concepts that serve as the building blocks for substantive classification schemes, descriptive information related to various aspects of the program under consideration and factors that affect the development and delivery of services (Ketterer et al, 1980).

Criteria for what is considered significant knowledge vary. For community-based research, the roles and goals of science may be flexible and interactive with the acquisition and trade-off of knowledge. A community-based research project may attempt to counter the researcher's monopoly over the process of knowledge generation and replace it with cultural forms, language and policies that are derived from research (Chesler, 1991). In part, changes in the system of acquiring knowledge entail a demystification of the research process. This may be accomplished through the demystification of the interpretive process, the dissemination of information and training and the assurance that community feedback is not an end in itself but rather a link in the goal of empowering entire communities (Swantz and Vainio-Mattila, 1988).

7.6.2 Education and Community-based Research

Projects that involve participants from the study community often include a special educational commitment. Ideally a community-based research project provides the proper conditions under which subjects may acquire knowledge (Heron, 1981b). In conventional forms of research, education takes place at the beginning of a project, when one investigates the literature, and later at the end of the project, when one attempts to discuss and interpret the findings. In contrast, community-based research views the research cycle as a learning process in itself, with education not only a component at opposite ends of the cycle, but also continuous across the project itself (Whyte et al, 1989). Thus the research process may be construed as

a total educational experience which serves to determine community needs and to increase awareness of problems and commitment to solutions within the community (Hall, 1982 p. 22).

Community-based research views the research cycle as a learning process in itself.

7.6.3 Empowerment and Community Involvement

Empowerment may be defined as a connection between a sense of personal competence and a desire and willingness to take action in a community setting (Zimmerman and Rappaport, 1988). Alternatively it has been described as a process by which people, organizations and communities gain control over their own destinies (Rappaport, 1987). Empowerment is not a state or a commodity, but rather, as Kieffer (1984) has suggested, the ordered and progressive development of participatory skills and understandings (as discussed in Pederson et al, 1989). An emancipatory social research—the type of research that characterizes a community-based research project—is one that goes beyond the traditional:

it calls for empowering approaches to research whereby both researcher and researched become the changer and the changed (Lather, 1986:p. 263).

In a community-based research framework the study community is the direct beneficiary of the research. Only if the community is involved in all stages of a research process will members be able to inform and direct the work, monitor the progression of the research, empower themselves and their communities and ultimately utilize results for social change (Chesler, 1991).

7.7 Barriers and Limitations

Community-based research is not an approach that may be applied to every population, nor is it appropriate for every research problem. A common criticism of action approaches to research is that the action element may compromise the scientific merit of the research. This can become a particularly relevant issue within academic environments. A second criticism is that the constraints this type of research entail may hamper the implementation of further initiatives, especially in the prevention field (Giesbrecht and Ferris, 1993). This is because

information on large scale, community-based health promotion programmes can disseminate quickly and interfere with classic intervention/evaluation control designs through contamination (Nutbeam et al, 1993:p. 127).

Ultimately, the issue, according to Argyris (1968), is not one of contamination versus non-contamination, but under what conditions the researcher may have the greatest awareness of and control over any contamination that might unfold (cited in Blumberg and Pringle, 1983).

Other hazards may arise in community-based projects that do not arise in a strict, researcher-controlled environment. The community-based research environment may demand accountability. It may be naturally unstable, may keep the researcher as an outsider regardless of the steps taken, may require an extraordinary amount of time and energy and may, ultimately, be comprised of priorities that differ from those

Community-based research is not an approach that may be applied to every population, nor is it appropriate for every research problem.

of the researcher (Snowden et al, 1979). It has also been suggested that community-based projects may be hampered by irreconcilable perceptions and expectations of the major partners or inherent difficulties in conducting the research, and there may be few genuine and valid opportunities for real community involvement. In practice, the ideas and ideals of many community-based research projects are difficult to achieve, though whether that is due to inherent deficiencies in the method or only the planning stages of these projects is unknown (Hyndman and Giesbrecht, 1993).

7.7.1 Manipulation in Community-based Research

Lay bureaucracies—be they government funding agents who are pressured to deliver results, academics who are pressured to publish or community groups who seek additional power—are often concerned with two things: how to use research results to perform their functions better, and how to maintain control of any further initiatives as a result of their findings (Bengtson et al, 1977). Special attention should be directed at the role of cooptation in the processes through which a community-based research project evolves. Some researchers may look at the inclusion of community as the ultimate way to improve their project, and not as a tool for developing a process of social transformation. Here, the rubric of community-based research risks becoming little more than an unethical means of community manipulation (Vio Grossi, 1981).

the ideas and ideals of many community-based research projects can present special challenges.

In practice,

7.7.2 Barriers to Community Involvement

Barriers to true community involvement are not always as tangible as contamination or manipulation. Instead, they "may be in our heads, in our organizations, our...funding criteria and in our academic reward system" (Health and Welfare Canada, 1989/1990:p. 11). Other barriers may be related to the ideology that research partners bring to their endeavour and may emanate from conflicting views regarding what research questions and what research method may most appropriately provide answers (Powell and Cameron, 1991). Often proponents of community-based research fail to distinguish between information that requires methodological rigour, validation and a theoretical perspective, and information that is simply the opinion or conviction of a specific individual (Frideres, 1992). When a research framework incorporates elements of community participation, barriers may include lack of official or political support or difficulty in determining representatives from the community. The goals of the research project may take longer to achieve than the community can accommodate, or there may be the potential for increased conflict, or for more conflict than might initially exist. Some people may think the inclusion of community is simply a front for professional manipulation, or that the call for community representatives only brings out 'professional volunteers' (Bracht and Tsouros, 1990). On the other hand, participants may believe that hierarchies in the research process are normal and should therefore be in place in any research initiative, and that mutually held stereotypes and discriminatory procedures and elements of role status and power differentials are societally defined, and normal, as well (Everett and Steven, 1989).

Other barriers may be community members who are not truly representative or who may not commit or who drop out. There may be time constraints and difficulty organizing community or researchers, or community members may burn out. Group roles may not be clearly defined or clearly understood by community members. Finally, the political or funding agency may interfere, so the researcher may have less autonomy and objectivity. Ultimately the study will be less rigorous. In the course of a research project limitations may lead to greater logistical problems and to decreased generalizable long-term knowledge (Ayers, 1987).

All partners who choose to work together within the system of community-based research should be aware of the side effects of community-oriented research:

These effects have organizational and research implications...decision makers may choose to build community-organization alliances and promote public education to create supportive and informed consumers and a responsive healthcare system (Milio, 1992:p. 24).

7.8 Advantages and Benefits of Community-based Research

Singer (1993) proposes that community-centred applied research has a number of direct benefits to the communities who participate. Such research is locally grounded, and provides empirically sound information for community-education projects. The research may provide current information for community agency staff training. It may be a tool for refuting oppressive stereotypes. It may be used to advocate for the creation of culturally appropriate health and social services from institutional providers. The research also may be used as data for demonstrating need to funding agents, a weapon for supporting community struggles with information about community needs, an aid for influencing the direction of policy development, a means to monitor and evaluate the efficacy of programs, a tool for tracking changes in the community over time, a resource for sustaining the institutional structure of the organization and a form of therapeutic intervention for respondents.

Finally, for the social study of HIV and AIDS in Canada, community-based research has many advantages over other research paradigms. A community-based approach often brings together people of diverse skills and knowledge, resulting in a demystification of the research process. Community-based research builds analytical capacity within communities and increases the likelihood that research results will be used by non-researchers (Curtis, 1989). If the community-based researcher

can develop a research style where the research activity is specifically and genuinely participative, several positive outcomes will follow. One is that both researcher and participant will have a consensual definition of the task. Second, informal occasions can be created where meaningful discussions about the findings of the research can take place; the participant's context will be appreciated. The practical benefits of the research will be increased as the participants see the tangible positive consequences of the collaboration (Kelly, 1986:p. 583-84).

Yet, for the social study of HIV and AIDS in Canada, community-based research has many advantages over other research paradigms.

8 Project Summary

Initially, this project was driven by two overlying goals. The first was the identified need to understand community-based HIV prevention research as a framework and a method of increasing popularity within Canada and abroad. The second was to create a model to conduct this type of research in a variety of communities affected by HIV.

As this project draws to conclusion, we find no one single model for community-based HIV prevention research is possible, or even desirable. The research needs of communities affected by HIV and AIDS are just too varied. So, rather than dictate a definitive set of actions suitable for a community-based research project, we have chosen instead to provide a series of tools to facilitate a community-based research process; tools, which though tailored specifically for HIV prevention research, have potential application for the investigation of a number of other health and non-health related issues. At times it has been difficult to incorporate the theories and concepts contained in this report in such a way as to remain faithful to academic sources as well as maintain a true dialogue with all of our potential audiences. It has been the striking of a balance between these two which has proven to be particularly challenging, and may be this document's greatest limitation.

Much of the literature reviewed has been political in nature. The action principles of Lewin, the empowerment education of Freire, the participatory research of Hall and the participatory action research of Whyte—all spring from the same general dissatisfaction with conventional frameworks for social science. At one extreme is work that denotes social-science research as a dialectic between the powerful and the powerless, between the haves and the have-nots. At the other extreme is work that views research as a tool able to incorporate community development into the gathering, interpretation and dissemination of information. Defining and describing the concepts, models and definitions of community-based research has required a broad and politically neutral sweep of the literature. In this report we have attempted to put aside our own politics for those of our sources.

We have provided an overview of the concepts, models and definitions for community-based HIV prevention research. The development of any research approach is a process, influenced as much by social, political and philosophical environments as by scientific necessity. If we envision the development of community-based research as a shift in the beliefs and assumptions that serve as touchstones for guiding our research activities (Guba and Lincoln, 1989), then this document lies somewhere in the middle of such a shift. We know from our own involvement, anecdotal accounts and some published cases that many community-based HIV prevention initiatives have been completed or are currently in existence. We also know that in this burgeoning field, community-based initiatives continue to develop. (A more elaborate discussion of the specific manifestations of these projects is difficult without a fuller inventory.) From our overview of action and participatory approaches, we know what community-based HIV prevention research initiatives might look like, yet without further study, it remains difficult to define prototypes.

Summary .

9 Planning Community-based HIV Prevention Research

The discussion to this point has been largely academic, derived as it has been from mostly academic sources. While this may be of value to the university-based researcher, its applicability from the point of view of a community base is likely variable, depending on the particular use. Recognizing this, we have developed a **planning guide** for community based HIV prevention research and a decision-making model to assist in the planning process. We view the decision-making model and the **planning guide** as a means of translating the discussion from the theoretical into the practical, and as way of constructing a bridge from the realm of discourse to the firm ground of application.

The uniqueness of the **planning guide** lies in its attempt to translate this document's theoretical discussion into an applied framework. We have chosen to develop this guide as a means of allowing all parties engaged in community-based HIV prevention research to apply the theoretical concepts outlined in this document, and to raise some of the issues reflected in the literature. The **planning guide** is organized into five conceptual categories reflecting twenty-nine facets of a community-based research process. It is unlikely that in their entirety they will ever be applicable to any one initiative. Thus the element of choice or selection. The questions are derived directly from our literary sources. These are the questions our readings identified as important to ask.

The model for decision-making is indebted to the reflections on moral reasoning of Smith (1990) and Brody (1981). We have borrowed what we feel are their most applicable ideas, and have added our own. The model asks involved parties to choose, evaluate and resolve select issues summarized from the literature and contained within the planning guide. It is hoped that, by linking the realities of the social, political and economic environments with the goals and objectives of all stakeholders, this model will provide a means to further facilitate the development of community-based prevention research.

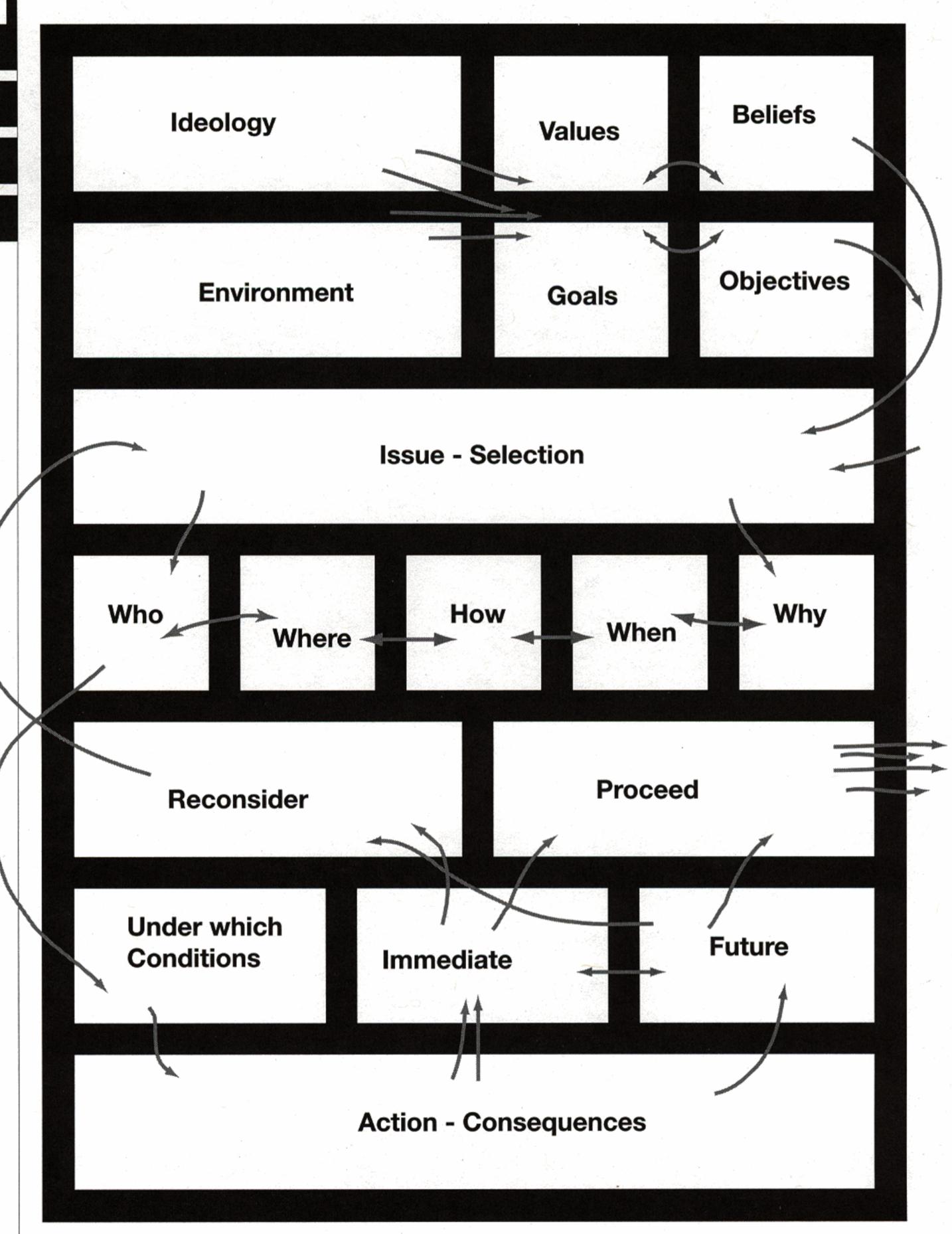
In our experience, many difficult to reconcile questions need to be asked through the course of any community-based research project in order to meet the needs and requirements of all stakeholders. It is our hope that the information contained in this document will continue to facilitate Canada's evolving tradition of community involvement in HIV prevention research. **Planning**

Community-based

HIV Prevention

Research

A Model
for Decision-making
in Community-based
Research



A Planning Guide for Community-based Prevention Reseach

I. Organization and Structure of The Research

- 1 Research Partnerships and Strategic Alliances
- 2 Type of Decision Making
- 3 Control and Power Differentials

II. Extent of Participation

A summary

Guide for

Prevention

Research

of the Planning

Community-based

- 4 Researcher Participation
- 5 Community Participation
- 6 Sponsor and Funding Agency Participation
- 7 University and Academic Participation

III. Research Environment

8 - Community Setting

IV. Research Roles

- 9 Role of Knowledge
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V. Research Methods and Approach

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- 22 Flexibility
- 23 Results and Findings
- 24 Dissemination
- 25 Evaluation
- 26 Resources
- 27 Conflict and Accountability
- 28 Mediation and Communication
- 29 Limitations and Barriers

1. Research Partnerships and Strategic Alliances

What consultation is there with other researchers and experts?

Is the research multidisciplinary?

What is the relation between the researcher and the practitioner?

Does the research collective represent the research sample itself?

Do professional social researchers operate as full collaborators?

Are people of different power, status and influence being brought together?

Are all parties committed?

Is there mutual respect between all players?

How will trust be developed between the community and the research establishment?

Are the values of researchers and communities compatible?

Will participants be able to interact with academic researchers and funding agents?

How will relationships between researcher and community be developed?

What are the personalities of the participants?

How will the project benefit the individuals and institutions involved?

In what way is the researcher separated from the community?

Is there a collaborative community-academic steering committee or leadership body?

What are the intended consequences of the research process?

Who will oversee and polish the process?

How does the research define *community*?

How will partners collaborate to identify the problems and needs of the community?

2. Type of Decision-making

Are subjects removed from meaningful decision-making?

Is there a systematic process of collaborative review?

Does the project aim to achieve a working consensus on goals and priorities?

Does the community itself make the decision to undertake the research?

Can the community make decisions that affect the future of further research efforts?

Do community members take an active role in the decision-making processes?

Will the community influence the selection of research questions?

Organization

and Structure

of the Research

3. Control and Power Differentials

Does the research employ a mutually acceptable ethical framework?

Does the research involve a democratic process?

Do all parties share control over the research process?

What is the ultimate agenda of the research?

What is the degree of community influence over the research process?

How will the community be able to exert control over the research process?

How will prescribed procedures be regulated?

Does the community control resources?

Can the community control access?

Do specific individuals act as gatekeepers?

May gatekeepers limit the conditions of entry?

What role will the community have in setting the agenda of the research inquiry?

How will consensus be established?

Does the community have the proper understanding and knowledge to control the project?

What are the power imbalances at the inception of the project?

Will researcher influences over the process be truly diminished?

How will the community monitor the progression of the research?

To what extent will community be allowed to influence the course of the research?

What are the opportunities for community input, feedback and control?

4. Researcher Participation

Do researchers work with and train people from the community to carry out research?

What is the researcher's personal interest?

Does the researcher maintain objectivity through detachment?

What is the researcher's relationship to the community?

What are the motivations of the researchers?

Is the choice of the research problem based on the personal interests of a researcher?

Is the researcher immersed in the study setting?

How will the research respond to the need of social support for the investigator?

Will members of the research team comprise the study or target population?

Are researchers concerned with community issues?

How will this approach change the traditional role of the researcher?

How will changes in the role of the researcher be accommodated?

Will the revised role of the researcher aid the development of others?

Is the inclusion of community viewed only as a means of improving the final product?

Have the previous efforts of researchers provided valid and meaningful results?

What characteristics are desirable and adaptive for community work?

Does the role of the researcher evolve with the action of the project itself?

Does the role of the researcher evolve with the collaboration of the community?

Will the research provide the investigator with a greater understanding of the subject?

Are researchers committed to an action philosophy of science?

Are researchers prepared to share responsibility with community members?

Have the previous experiences of researchers been appreciated by the community?

Extent

of Participation

5. Community Participation

Does the research bring people together to study the issues in their community?

Is the research client-centred?

What is the role of the community?

Will the community be active participants in the research?

How will the research involve the perspectives of the community?

Who in the community will be involved?

What is the basis for involvement?

Is the community involved in the research process from its inception?

Does participation promote empowerment as well as understanding?

Does the research provide for community preparation?

Will the community gather data?

Is there community discussion of research questions?

Is the community involved as both subjects and co-researchers?

How will the research facilitate meaningful community participation?

Will the research be an experience the community can relate to?

Does the project involve the entire community?

Who participates, who does not participate and why?

What areas demand special attention to facilitate community participation?

What tasks are associated with the role of the community member?

Will the research refine the community's capacity to conduct research?

Is the initiative guided by criteria that ensure community ownership of solutions?

Are roles clearly defined and clearly understood by community members?

Will the community be present in the planning phases of the research?

What past research experiences has the community had?

Have previous research experiences been satisfactory for the community?

Will the research provoke the community to ask questions?

Is the community able to understand the language or design of the project?

Will participation enable the assurance of local ownership and long-term maintenance?

Will the research employ language that is familiar to the community members?

Will community participation help ensure that results of the research process are met?

What can the research offer for the particular careers of the gatekeeper or other players?

How will community participation be achieved?

How will community involvement be maintained?

How will community morale be maintained?

Is there a demonstrated recognition and realization of the importance of community?

How have interested people been recruited to become co-researchers?

What avenues will guard against tokenism on the part of the community?

Are members from the community truly representative?

6. Sponsor and Funding Agency Participation

Is there a third party or sponsoring agency?

What is the sponsor's interest?

What is the role of the sponsor/funder?

Is the choice of the research problem based solely on the interests of a funding agency?

How might third-party participation fluctuate?

Does the funding agency recognize the value of community-based research?

Will incorporating policy makers as partners help ensure that results will be implemented?

Will policy efforts have to be modified to secure a common research agenda?

Is there a lack of official or political support?

Does the possibility of political or funding-agency interference exist?

What effect could the lack of government support have on the research?

Is the central funding agency responsive to the needs of the community?

Will the third-party agency concentrate on administrative or evaluative functions?

What are the values and agendas that third parties bring to the participatory setting?

7. University and Academic Participation

What is the role of the university?

Is the choice of the research problem based on the interests of an academic institution?

Does the project's action need to be reconciled with academic constraints?

What constraints and limitations are involved in operating from an academic setting?

How will the project deal with academic rewards?

How does the academic reward system view community participation?

Have the responsibilities of academic staff been allocated?

8. Community Setting

Research

Environment

How is the research setting organized?

Is community planning based on research data?

Does the research build on cultural, social and spiritual values?

What is the degree of isolation or assimilation of the community?

What is the complexity of the economic activity within the community?

What is the quality of leadership within the community?

What is the extent of the community's cohesiveness?

What are the nature and extent of the community's social problems?

What is the intensity of inter- and intra- community divisions?

How might the research affect the social environment?

How will the effects on the social environment be monitored?

What are the characteristics of the community?

Does the research setting demand accountability?

Will stigmatization and prejudice affect the research?

9. Role of Knowledge

Who has knowledge of analytic techniques and research methods?

How does the research define knowledge?

Will the research empower community members?

Is there a plan detailing the type of knowledge or expertise required at each stage?

Does the research process recognize the researcher as the sole possessor of knowledge?

Will the research partnership extend the limitations of knowledge and resources?

Where does the research envision knowledge and knowledge acquisition?

Does the research strengthen and legitimize the knowledge of the community?

Will the research develop relevant knowledge?

Is the research flexible and interactive in the acquisition and trade-off of knowledge?

Are there strategies for the growth and dissemination of knowledge?

Is an understanding of the field considered more valuable than expert knowledge?

Will the research generate and advance new knowledge?

10. Role of Education

Is the need for learning more important than the actual research findings?

Is the need for empowerment more important than the actual research findings?

Is the research process viewed as a learning process in itself?

Is education continuous across the cycle?

Is there training of local leaders and organizers?

What is the degree of researcher-participant mutual learning?

Is skill-enhancement an element and a by-product of the research?

Will participation enable the training of the population representatives?

Have the necessary tools been developed in the community?

Does the project demystify the research process?

Research

Roles

11. Role of Science

Is research oriented towards the advancement of academic knowledge?

Is the aim of the inquiry universality?

Can findings be integrated into general social theory?

Does the research meet both research and intervention objectives?

Is research a combination of participatory fact-finding and implementation?

Does research aim to contribute to the goals of social science?

Are there payoffs to the scientific research community?

Is the primary objective limited to obtaining new data?

Is the primary objective limited to the production of new knowledge?

Is the community capable of maintaining scientific rigour?

Is the community willing to maintain scientific rigour?

What is the role of theory testing?

What is the role of theory advancement?

Are research methods rigorous enough to maintain standards of validity?

Can the action element compromise the quality of the research?

Can the research build ties for future collaboration?

12. Role of Community Development

Are the goals of the research more important than the goals of community development?

What can the research offer to the community as a whole?

Will the research process create positive role models within the community?

How may the project alleviate community problems?

Can a sense of community be built up?

Does the research aim to solve community problems?

Will the research serve community goals?

Is research a vehicle for initiating and implementing other innovations?

Will the project empower individuals within their environment?

Is the community more concerned with community development than with research?

Are researchers prepared to relinquish ownership of materials the project develops?

13. Role of Politics

Does research aim to improve educational or social policies?

Can the research lead to changes in policy?

Will anyone want to modify results in order to look good in the eyes of funding agents?

Is the project committed to the political empowerment of the community?

How might the results be translated into programs or policy?

What effect can the political climate or context have on outcomes?

Is the larger social, economic and political context considered?

Is there a lack of official or political support?

14. Role of Social Change

Is the need for action more important than the actual research findings?

What is the strength of the action component within the project?

To what extent is the research concerned with social change?

Will there be an attempt to alter normative beliefs and behaviour?

Is research viewed as a tool for social action?

How will community life be affected by the research?

Are the goals ethically justifiable?

Is research designed to lead to action?

What is the role of advocacy?

What roles will the advocate play?

Are investigators naïve about the concerns of community advocates?

Is there an overdependence on individual change agents?

What is the role of the researcher/advocate?

What skills are necessary for the individuals who assume the role of researcher/advocate?

Research Methods

and Approach

15. Research Cycle and Processes

How is research defined?

Is research planned in detail before it begins?

Is the research sufficiently organized?

Does the research include a cooperative hands-on approach?

Does the research process incorporate the elements of a traditional research cycle?

Does the research utilize community development techniques?

Does each step or stage of the research project feed into the next?

Is the research approach interpretive and inductive?

Will the research be undertaken in a culturally appropriate manner? How will this happen?

What information is necessary to orient the project?

Who is responsible for the research cycle?

Who is responsible for the planning stages?

To what extent will the research incorporate action or empowerment?

How might the roles of community and researcher affect the direction of the research?

16. Research Goals and Objectives

Is the sampling designed to be representative?

What are the goals of the research?

Have specific and measurable objectives been set?

Have aims and goals been defined?

Are mutual interests and goals clarified?

Are research objectives in accordance with citizen concerns?

Who will be responsible for the goals and the objectives of the research?

Are the issues and foci of the research symbolized in some single concept?

Will focus groups be employed to discern the agenda of the community?

Do all participants agree on goals and actions?

How explicit and up-front are the goals of the research?

How will the research enterprise achieve a working consensus on goals and priorities?

How will the project agree on ways and means to implement the agreedupon goals?

17. Theory and Literature

Is there clarification of theory?

Is the literature analyzed and read in terms of practical issues?

Have the basic and applied literatures been reviewed?

Who chooses the theoretical framework?

How is the theoretical framework chosen?

18. Research Methodology

Is the chosen methodology linear?

Are measurements standardized, replicable and deductive?

Are concepts clarified?

Is there clarification of method?

How can measures be taken at the community level?

Is quantification possible?

Is quantification desirable?

Do researchers have a preference for quantitative over qualitative methods?

Does applied research predominate over theoretical inquiry?

Are research methods understandable to the participants?

Does the project train community researchers in research methods?

Who will be responsible for the development of the preliminary study design?

Has there been pilot testing of the instruments?

Will the community review and revise research instruments?

Who will be responsible for the creation of research instruments?

Will measures emerge through the course of the research?

19. Research Questions and Hypotheses

How has the research problem been identified?

Are there research questions that cannot be answered during the course of a project?

Does the project address the right questions?

Are research questions as specific as possible?

Are research questions and issues rational and empirically defensible?

Is there consensus on what constitutes the research problems?

When are hypotheses defined?

Will research accept or reject pre-stated hypotheses?

20. Data Collection and Analysis

Who will assume responsibility for the preparation for data collection?

Who will assume responsibility for data collection?

Will outreach be designed to reach diverse segments of the population?

Will research be conducted where the subjects feel comfortable?

Does the research require a large sample size to guarantee statistical significance?

Is there preliminary feedback of results?

Are data evaluated and assessed towards the goals of dissemination and utilization?

How will data be processed, organized and analyzed?

Who will analyze the results of the investigation?

How might the roles of the various stakeholders affect the collection and analysis of data?

21. Validity and Bias

To what extent is validation based on experience?

Are there control procedures in place to prevent error and bias?

What is the process for overcoming individual biases?

Is there an explicit formulation of a project's value issues?

Can the research retain objectivity and avoid bias?

Can the complexity of the research be accentuated by the sensitive nature of the topic?

Is there agreement on the values that will guide the research?

22. Flexibility

How much flexibility is there in the planning process for the research?

How will the research respond to the unpredictability of social events?

Are research questions adaptable?

Is the training of participants flexible?

What kind of flexibility is there for advocacy?

How much flexibility can the research process allow?

23. Results and Findings

Can findings be utilized in everyday life?

What will be the overall implications of the project's findings?

Will results be directed towards the community or towards the scientist?

How will the results be translated into action?

How might results be interpreted?

Who will interpret and synthesize results?

How might the roles of community and researcher affect the use of results?

Will community involvement lead to increased acceptance and use of results?

Will findings be converted into specific applied forms?

Will findings provide examples that show how results could be implemented?

Will findings present possible pitfalls to implementing recommendations?

Who will findings apply to?

How will the findings be generalized to other groups and populations?

Will informal occasions be created to discuss the findings?

How will results be followed up?

24. Dissemination

How will results be reported and diffused?

What is the finished product that will emerge at the end of the process?

What will be the mechanisms for community feedback and result dissemination?

How might community feedback be received?

Will participation encourage the dissemination of research findings?

Will findings be disseminated using the language of the subjects?

Who will present reports to administration and media?

Will the research report results in easily understood terms?

Will non-traditional avenues of dissemination be used?

Will the research project build dissemination strategies into the overall design?

Are there suggestions for how findings could or should be implemented?

Will the research increase the likelihood that results will be used by non-researchers?

Who are the potential consumers of the results?

Are interpretations and conclusions aimed at direct application in the community?

Is there a clear method for decision-making in terms of the use and dissemination of research findings?

25. Evaluation

How will research evaluate the success of a project?

How will research be evaluated?

Is there collaborative research and evaluation design?

Are mechanisms established that provide feedback?

Can the research hamper the implementation of further initiatives?

Who will evaluate the research?

Have appropriate and measurable end points been set?

26. Funding Sources

Is the research limited by the resources of the study community?

Can the community mobilize resources?

Are there community-specific resources?

What resources does the community control?

Will participation enable researchers to gain access to resources not otherwise available?

What effect could the lack of community resources have on the research?

Is the community itself willing to search for funding sources?

27. Conflict and Accountability

What is the potential for conflict between research and community agendas?

Does participation entail manipulation?

Can participation be polluted by issues of power, culture or gender?

Can the relationships that develop be open to suspicion and misunderstanding?

How will researchers avoid dominating interactions?

What are the inherent conflicts in the role of the researcher?

How will the research guard against co-optation?

Are researchers prepared for unanticipated conflict?

Are participants aware of the rules of accountability?

What are the rules of accountability?

Is there conflict about the overall goals of the research enterprise?

To what extent is the research based on equality of understanding and mutual respect?

Is the inclusion of community simply a front for professional manipulation?

To what degree may there be tokenism or exploitation of the community?

Is there the potential for increased conflict or for more conflict than might initially exist?

What elements might prove to be especially delicate?

Is research a way of gaining privileged access?

28. Mediation, Communication and Dialogue

Are there mechanisms for resolving value conflicts?

How will unexpected disruptions be dealt with?

Will an individual be assigned the role of community liaison?

Will participation enable roles of facilitation?

Are there mechanisms for mediation?

Who will be the mediator?

How will the mediator create links between the research system and the community?

How will the mediator arrange the entry of the researchers into the community?

How will mutual trust be established between the researcher and the community?

Will strategies for conflict resolution be given consideration?

What kind of mechanisms for accountability will the research provide?

Is the relation between the researcher and the practitioner democratic?

Do researchers and participants continually review channels of communication?

What communication techniques will be employed?

Will the project set in place mechanisms that can facilitate communication and dialogue?

How will communication be facilitated throughout the research process?

What values and approaches can either facilitate or prevent dialogue?

29. Limitations and Barriers

Are there organizational limitations?

What constraints are there in terms of time, skills and commitment?

What might the side effects of this type of research be?

What are the inherent difficulties in conducting such research?

Can certain roles predispose participants to a certain point of view?

Will the research break down potential barriers between researchers and community?

Might some people drop out?

What types of burnout might develop?

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