

# TOWARD AUTHENTIC PARTICIPATORY RESEARCH IN HEALTH; A CRITICAL REVIEW

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## EDITORIAL COMMENT

Faced with a research question, the first step the academic or health professional researcher takes is a literature review. The purpose of the review is to find out what, if anything, other researchers have written about the research question. The researcher reads as many relevant articles and books as possible, making careful notes along the way. The next step is to analyze, from the notes taken, common themes and differences of opinion. This analysis may show the researcher that more than one model can be followed to answer the research question. It may lead to the discovery of new perspectives on the research question. In the academic and professional worlds, a literature review is similar in intent to asking Elders for their guidance before embarking on any new exploration.

*Artwork by Henry Letendre, courtesy of Native Counselling Services of Alberta*

## ABSTRACT

Current literature indicates that participatory research has emerged as one of the major research approaches in health. This paper examines the practice of participatory research in primary care, health promotion and public health. It focuses on strategies and interventions employed by practitioners that demonstrate the core elements and principles of participatory research. The key themes generated from issues and problems experienced by practitioners are: achieving authentic participation, sharing power between professional researchers and community members, building trust and relationships among research participants, resolving ethical dilemmas, and ensuring sustainability of research outcomes in the community. Areas for further research on the key themes are also suggested.

## INTRODUCTION

The appeal of participatory research in health practice comes from a growing awareness of the inequities of health status among populations. These inequities may be associated with age, gender, race, status, or class. Hagedorn (1995: 2) defines health as the “power to critically understand, resist and transform social, political, environmental and ideological contradictions that affect individual and collective well-being.” Health care practitioners and health researchers find that participatory research is an approach that increases their understanding of health inequities. For example, participatory research has been widely used in public health studies of minority groups (Green and Mercer 2001). Participatory research (PR) embodies important ethical principles of equity, social justice, and autonomy. It stresses the importance of ownership and control of the research by those involved in and affected by the research. Participatory research provides the concepts and methods to enable patients to be active agents of their own health rather than passive receivers of services. The participatory dimension of PR is often referred to as the critical base for primary community health care (Rains and Wiles, 1995). The patient and the health service provider must share ownership of health knowledge. When healthcare belongs to the people as well as to the health professionals, it fosters self-reliance in patients and lessens their dependency on health service providers.

Participatory research is also known in the literature as *participatory action research*, *collaborative research*, *emancipatory research* and *action research*. Many researchers who have been involved in evaluating participatory research projects have been less concerned with labels than with how the project dem-

onstrates the principles and elements of PR. For consistency, in this paper, we will use the Green et al. (1995) definition of PR: “systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education, taking action or effecting social change.” The articles included in this review approximate this definition although their authors and proponents may label them differently. The term *primary care*<sup>1</sup> is also used in the broadest sense as articulated in the North American Primary Care Program Research Group (NAPCRG) policy statement (Macaulay et al. 1998).<sup>2</sup>

## PURPOSE

This paper examines the practice of participatory research in several self-reported PR studies in clinical and community settings in the area of primary care, primary health care, health promotion and public health practice. The review focuses on strategies and interventions used by PR practitioners in demonstrating the core elements or principles of PR, the difficulties they have encountered and the lessons, insights and caveats the authors wished to share with others in the field. From these experiences, emerging themes and lessons were drawn to inform the practice of participatory research. The literature review was initially conducted for the North American Primary Care Research Group (NAPCRG) in 2000 to describe current PR practice in health care and generate ideas for strengthening the practice in primary care.

## A REVIEW OF THEORETICAL ASSUMPTIONS

Deshler and Ewert (2000) capture the different traditions of PR and provide a succinct overview of the field of participatory inquiry and knowledge creation. Their papers emphasize that regardless of the traditions of theory and practice, any research effort that seeks to be participatory and action-directed must articulate and demonstrate the following core elements:

### DEMOCRATIZING THE DEVELOPMENT AND UTILIZATION OF KNOWLEDGE

“Democratizing research” means enabling access to people and groups the tools and the resources to generate knowledge on their own. Participatory action research is sometimes described as “democracy” in action where par-

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1. Primary care is the provision of integrated, accessible health care services by professionals who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community. (Macaulay et al,1998 p. 2)
  2. The NAPCRG Policy Statement can be found at <http://napcrg.org/exec.html>

ticipants are seen as equals in the conduct of the research (Meyer 2000). The term “participation” opens the research process to a wider circle of participants that include community members, practitioners and citizens, in addition to academic researchers. It can also be said that PR is the appropriate approach to engage people who are powerless – the exploited, the poor, the oppressed and those who are isolated or marginal. Hall (1992) and Cancian (1993) strongly emphasize that those who have been disadvantaged deserve the opportunity to question and challenge the structures that oppress them. With PR, the research could be directed and controlled by those who are affected by the research problem or the outcomes. The participants can assume a continuum of roles and responsibilities ranging from full control of the research to mutually agreed academic researcher-participant collaborative relationship. This collaboration is the “democratic space” in the research where power sharing is negotiated, challenged and established. Within healthcare practice, PR lessens the monopoly of health knowledge of professional health providers. It also demystifies expert knowledge by grounding it in the experiences of lay people and community members.

### **OWNERSHIP AND CONTROL OF THE RESEARCH PROCESS**

Ownership and control of the research process is almost inseparable with the democratization principle and a test of the authenticity of the PR process (Found 1997, Mason and Boutilier 1996, Wallerstein 1999). Deshler and Ewert (2000) believe that genuineness of PR is demonstrated when people are able to articulate issues and problems they find most important so that the research can build its investigation on these issues and problems. The origins of the issues and how they are carried through the research determine the claim to ownership and control by the research participants (Boston et al. 1997, Clarke and Mass 1998, Found 1997, Hecker 1997, Plough and Olafson 1994, Robinson and Miller 1996). Hall (2000) writes about the “organic” character of PR where research problems and questions come from the day-to-day lives and struggles of people and communities.

The emergence of patients’ rights in advocating a shared responsibility for decision-making between patient and health provider demonstrates the relevance of participatory research to health care practice. Similarly, people and communities will learn and appreciate health knowledge when they are part of creating and producing that knowledge.

### **MULTIPLE CONSTRUCTION AND INTERPRETATIONS OF REALITY**

Participatory research is a systematic process of generating knowledge that is open to various ways of constructing and interpreting reality. It

starts from where people are and how they make sense of their experiences. This is how PR remains faithful to the context of problems and issues being studied. Grounded in people's reality is what makes knowledge-seeking meaningful and relevant, particularly to those who must use this knowledge to their benefit (Boston et al. 1997, Heslop, Elsom, and Parker 2000, Jacobson et al. 1998, O'Neil et al. 1993, Plaut and Landis 1992). For example, we know that every culture defines health differently. Thus, the health experience of people can best be understood within the contextual reality of their values and beliefs, historical experience and socio-political circumstances and so on. While PR does not limit itself to a single paradigm of arriving at truths, it is committed to methodological rigor and consistency in the search for new knowledge (Hall 1992, Henderson 1995, Koch and Harrington 1998, Lindsey and McGuiness 1998, Willms et al. 1996). Participatory research draws on a variety of research methods that are currently used in the field of qualitative research to gather data, analyze findings and interpret results. Over the years, the body of knowledge on PR practice has grown and evolving including a repertoire of tools and processes for collecting and analyzing data.

### COMMITMENT TO ACTION

Commitment to action exemplifies the direction and goal of the PR process (Deshler and Ewert 2000). Action-taking is the concrete expression of change and learning: the objects of participatory research. The essential question in PR is — did the research result in change and action. Where to take the results of PR can vary depending on what researcher's and the participants' believe to be the ultimate goal of the research. Drevdahl (1995) presents three approaches to change and action-taking in PR: pragmatic, historical materialist and critical. The pragmatic approach basically asks whether the research had answered the research question. The historical materialist asks whether the research contributed to advancing the status of the oppressed class in society. The critical approach addresses the issue of whether the research has revealed underlying social structures that result in unequal relations and opportunities for change (Henderson 1995).

### BELIEF IN PEOPLE'S CAPACITIES

The PR process is founded on the notion that people have the inherent ability to reflect, learn and change (Smith 1997). Participatory research provides the tools and processes where people can exercise their capacities and direct the benefit and outcomes of the research to address their needs and concerns. PR is about people and their experience, particularly those who are disenfranchised, and "the pursuit of answers to the questions of their daily

struggle and survival” (Lee Sohng 1995: 3). Their view of the world is as important as the researcher’s. Thus every PR effort strives to reveal the capacities and potentials of people and communities in their quest for learning and change.

## SCANNING THE LITERATURE ON PARTICIPATORY RESEARCH

The literature on participatory research has grown extensively in the last two decades (Israel, Schulz, Parker, and Becker 1998). Nursing research suggests participatory research in promoting individual and community health (Hagedorn 1995, Henderson 1995). Despite the steady growth, however, participatory research studies have not exhaustively explored power and power sharing, community-researcher relationships, and ethical issues. Participatory research practice that does not examine these issues will find its in the sidelines of critical social thought (Hall 2000, Cooke and Kothari 2001).

In my review, I scanned participatory research articles from 1990 to 2000. The articles discussed the theory and the practice of PR in health and health care. Of these, I selected 27 articles on PR that reflected a diversity of health issues, research participants and research settings. After reading these articles, I searched for articles that assessed PR projects and I studied their methods of analysis. I found three articles that presented yardsticks for evaluating PR projects and studies. I discuss these in greater detail in the next section. I used Found’s (1997) evaluation model as my organizing framework for reviewing the 27 articles. His evaluation components include measuring outcomes of the research process that can be used and sustained by the community. These can be applied to PR projects using a community development approach. I prepared a matrix of Found’s evaluation components and used it to assess each of the 27 PR projects. The matrix distilled consistent themes in the practice of PR covering patient-focused care, primary healthcare, health promotion and community health in aboriginal communities, culturally diverse populations, urban and rural areas. Once that was done, I did another literature search to find publications that further strengthened the themes.

## EVALUATING PARTICIPATORY RESEARCH

Participatory research is one of the important research approaches in the social and health sciences. It became a formal approach to research in the early 1980s (Green et al. 1995). Academic institutions and funding organizations in research and international development have funded and supported an increasing number of PR studies and projects over the last two decades.

Several of these studies assessed the integrity of PR projects, their faithfulness to the principles of PR, and their dedication to improving PR practices.

Green et al. (1995) did a study for the Royal Society of Canada on participatory research in health promotion. Its comprehensive review of 29 health-related projects across Canada produced classifications of PR projects based on their core elements and principles. The core concerns of the guidelines are: participants and the nature of their involvement; origin of the research question; purpose of the research; process and context; opportunities to address the issue of interest. The guidelines are a useful appraisal tool for funding organizations and a valuable planning tool in the development of PR proposals. Although comprehensive, the guidelines avoid the ideological issues inherent in participatory research. For example, there are no criteria to assess the contribution of the project or study to an understanding of inequalities and power relations. There are those who strongly argue that PR was created to transform and improve the lives of people who have been oppressed and disempowered (Hall 2000, Lee Sohng 1995).

The International Development Research Centre (IDRC) did a comprehensive evaluation of 145 PR projects it had funded since 1975 (Found 1997). Found (1997) describes these projects using the range of participation by community members from little to full involvement. These projects focused on development issues such as resource management, food security, workers' rights, and health. The analysis of these projects yielded eight groups of factors bearing a strong relation to the success of PR projects. These factors became the components of an evaluation framework that the IDRC adopted to assess PR projects (Found, 1997):

1. Nature and origin of the research problem.
2. Clarity and meaning of PR among participants.
3. Selection, motivation and training of research participants.
4. Capacity of the managing research organization for PR.
5. Degree of fit of PR project with local culture.
6. Sustainability of PR in local community.
7. Communication within the diversity of research participants.

This evaluation framework is similar to the Royal Society of Canada Guidelines, but it adds the dimension of sustainability from a perspective of promoting community empowerment. Found (1997) argues that any community PR project should make provisions for community development, the transferability of results to others, and building the skills for such communities to do PR on their own.

Petras and Porpora (1993) provide three models of mutual engagement between academics and community from their own review of PR studies. They contend that collaborative work rests on “equalizing the exchange relationship” between the researchers and the community. This relationship can be achieved when the roles and responsibilities of the academic researchers clearly define their mutual obligations to the community. This role/responsibility definition also determines how and in what capacity the community will participate in the research. Petras and Porpora (1993) offer the following models of researcher-community collaboration:

1. Parallel Process Model — the academic researcher and community have similar goals and pursue the research by mutual beneficial exchange.
2. Mutual Engagement Model — the academic researcher and the community actively interact to set the goals and directions of the research.
3. UCA (University of Central America) Model — the University offers its institutional resources, including its influence with funding agencies, to support PR. It actively engages the community participants in a research partnership.

The UCA model represents a radical stream of participatory research, which the authors admit will be met with resistance in the North American academic community. Petras and Porpora (1993) contend that most North American universities do not recognize PR as a legitimate research methodology. The “untidiness” of PR as a philosophy, approach, or methodological orientation for research is the usual criticism. This criticism comes from the following features of PR (Lee Sohng 1995):

- ✱ It values a collaborative relationship between academic researchers and community participants that may compromise the objectivity of the data.
- ✱ People are involved in the investigation and this excludes methods that separate researchers and participants.
- ✱ It adopts democratic processes that could make the research vulnerable to uncertainty and conflict created by community dynamics or tension between the academic researcher and the community participants.

Frideres (1992) likens PR to a “moving target” because of its constantly changing definitions and criteria depending on the practitioner’s political orientation. We must recognize that the nature of PR makes it more relevant in the arena of social problems which Petras and Porpora (1993) appropriately named “the struggles of the excluded.” The realm of social problems is so unavoidably



vast and complex that no one methodological orientation can address its many facets, nor can the social scientists claim its exclusive possession.

## EMERGING THEMES FROM PR PRACTICE

The 27 articles on participatory research were in four main categories.

<i>Category</i>	<i>Article Authors</i>
Research in developed and developing countries conducted with a minority population	Diaz and Simmons 1999 Douglas 1998 Kelly and Van Maeren 1996 Plaut and Landis 1992 Willms et al. 1996
Aboriginal communities	Boston et al. 1997 Davis and Reid 1999 Dickson 2000 Hecker 1997 Jacobson et al. 1998 Kavanagh, Absalom, Beil, and Schliessman 1999 Macaulay et al. 1997 O'Neil et al. 1993
Lay health workers	Hecker 1997 Nichter 1984 Parker, Schulz, Israel, and Hollis 1998
Health professionals	Dowswell et al. 1999 Graver 1997 Heslop et al. 2000 Robinson and Miller 1996

These PR projects, most of which were based in geographic communities, had three main areas of focus:

- generating technical knowledge (i.e., community diagnosis),
- fostering dialogue and human relationships (i.e., collaboration in a multidisciplinary team)
- advocating social action (i.e., community-based primary care).

Over all, there is evidence that most of the projects were faithful to the core elements of participatory research. Whether the projects were researcher-initiated or community-initiated, the academic researchers make a deliberate effort to facilitate and guide the participants in taking ownership of the research process. The most common participatory structure or mechanism is a steering committee or advisory board that oversees the research in

the community. Training community members in the research process is a consistent strategy to equip them with research skills that enable their full participation in the research.

### ON ACHIEVING AUTHENTIC PARTICIPATION

Participatory research practice aims to achieve *authentic participation*. The beliefs and values of this term define the dimensions of participation:

- Who should the research participants be?
- What is the extent and quality of individual participation?
- To what extent will the outcome of participation be increased community research capacity?

Participation encompasses all phases of research: the identification of issues and problems to be researched, conception and planning of the research, collection and analysis of data, dissemination of results, and the sharing of the benefits of the research. In these PR studies, the design of the research was built around appropriate participation faithfully implemented in practice.

#### Degrees of Participation in the Research Process

Involved participants in most steps of the research process to achieve the defined goal and outcome.	Dickson 2000 Dowswell et al. 1999 Graver 1997 Heslop et al. 2000 Kavanagh et al. 1999 Lindsey and McGuinness 1998 Patronis Jones 1997 Robinson and Miller 1996
Short-term outcomes paved the way for setting up participatory structures and processes for community problem-solving and decision-making.	Boston et al. 1997 Diaz and Simmons, 1999 Douglas 1998 Jacobson et al. 1998 Nichter 1984 Parker et al. 1998 Plaut and Landis 1992

The PR projects that advanced the research to community development processes were those that had a strong community-researcher relationship (Jacobson et al. 1998); addressed problems and issues that were important to the community (Found, 1997); and adapted the research to the dynamics of community processes (Kelly and Van Vlaeren 1996). Lindsey *et al* (1999) recommend the understanding of community development processes and the use of community tools to enrich and strengthen PR. Ideally, a PR project

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should have a community organizer who would bring people together, possess a history of community involvement and have the respect of the community (Israel et al. 1998: 11).

Rahnema (1990) raises concerns about pursuing *any* agenda other than that of the community. The corruption of participation is not restricted to traditional and conservative researchers: even participatory research practitioners make assumptions about participants in the research. Some see community members as human resources to be developed, putting the PR focus on intensive skills training and knowledge acquisition. Participatory activists may regard the community as the “unconscious” mass who must be engaged in a dialogue to raise their consciousness. This is an example of an outsider’s agenda that diminishes the empowering process of change within people (Mosse 2001). Such assumptions, according to Rahnema (1990), hinder the growth of authentic participation because people are categorized before they can speak about their own experiences.

Rahnema (1990: 209) introduces the intransitive or non-directive concept of participation where the intent of participation is to “discover and enjoy the joys of sharing that make us human and fulfilled.” This means that participation is enjoyed and shared as a process separate from the research outcomes. Often, research becomes too focused on achieving goals and outcomes to allow enjoyment of the process. In her work with Aboriginal grandmothers, Dickson (2000) brought a sense of joy and sharing to the research process. Using an interpretive case study, the research was integrated into the grandmothers’ group activities including healing circles, sweetgrass burning, prayers, and learning sessions. Recognizing the age and pace of change of the group, Dickson felt that it was more relevant and meaningful to concentrate on the process of personal empowerment than to raise political consciousness.

Another aspect of participation involves the equality of relationships between the trained researcher and the community participants. In PR projects involving health professionals as participants, there was a high rate of participation in almost all stages of the research. There were strong indications that the actions resulting from the research would be sustained. Furthermore, the education of the participants was highly appreciated (Dowswell et al. 1999, Forchuk et al. 1998, Graver 1997, Heslop et al. 2000, Patronis Jones 1997, Robinson and Miller, 1996). Graver (1997) and Robinson (1996) attribute the success and positive outcomes of their research to equal relationships among the research participants in terms of their education, social status, and position. In these particular projects, both the academic researcher and participants were health professionals. In community-based participatory research,

particularly involving minority and marginalized populations, the projects with a high degree of participation were those that put in place structures and processes that levelled the unequal status between researcher and participants (Jacobson et al. 1998, Plaut and Landis 1992). Drevdahl (1995) cites the tremendous commitment of time and energy from both indigenous and professional researchers in creating “equal partnerships” since each has different limitations in resources, skills, support, and training. Strauss et al. (2001) stress the importance of putting resources within the research budget for the development, training, and management of community advisory boards (CABs) in research. CABs have an important role in facilitating the discussion of the purpose, risks, benefits, and implications of the research projects within the cultural context of the community. Furthermore, in a CAB, the community can assert its autonomy as equal partners.

Capacity building, most often of community or lay people, is another facet of participation. In Kelly and Van Vlaeren’s (1996) opinion, capacity building allows the community to gain skills in scientific and participatory inquiry while the professional researchers develop their participatory capacity. Participatory capacity is the ability to build egalitarian relationships with ease and comfort and to understand the difficulties of encouraging participation (Kelly and Van Vlaeren 1996). Participatory researchers, particularly in the health and medical profession, often naively assume they have the skill to engender participation until they are confronted with the tensions and changing dynamics of the community. Hagey (1997) emphasizes the following skills for a competent participatory researcher: good emotional intelligence, a high tolerance for conflict, and excellent group process skills.

## ON SHARING AND RELINQUISHING POWER

The concept of power is integral to the discussion of participatory research. PR is about unmasking, negotiating and sharing power where inequalities, domination and oppression exist. Because power is a central question in PR, Hall (1992) strongly advocates shifts in power to the less powerful as the ultimate outcome of knowledge seeking and creation. However, power is rarely documented explicitly in the literature of PR practice (Mason and Boutilier 1996). Most PR researchers assume that simply making their position known at the outset of the research unmasks their power bases. Wallerstein (1999) and Mason and Boutilier (1996) found instead that their assumptions continued to be challenged and power dynamics continually changed throughout the research process. All the authors in the PR projects reviewed believe that power and inequality must be stated assumptions in

the research so that professionals can recognize and deal with the difficulty of engaging community partners on an equal basis. Wallerstein (1999) challenges professionals who are truly committed to empowerment in research to undertake the three tasks laid out by Tierney (1994):

- Initiate self-reflection so that one can understand one's personal identity related to race, education and social status, gender and institutional position;
- Make visible and name the inequities within the research among research partners and reveal their influence on the power dynamics in the research;
- Work for caring and change as the ultimate commitment by PR practitioners.

Lee Sohng (1995) and Orb et al. (2001) suggest that participatory researchers should practise analytical reflection of their roles, intentions, and actions in the research. Participatory researchers will always encounter the difficulty of giving up the expert's role, particularly when the community as lived through a long experience of oppression and subordination (Lindsey et al. 1999). Including analytical reflection as part of their research practice allows participatory researchers to "examine privately and publicly the sources of power in their lives and how these sources appear in the research" (Lee Sohng 1995: 9). Addressing the agendas of each partner can be a useful exercise (Gibson et al. 2001)

Jacobson and his colleagues (1998) speak of "running the gauntlet" as a way of expressing their willingness to be exposed to harsh treatment and criticism in their research with the Mvskoke Indians. Throughout the research, they were prepared to be challenged, knowing that power and control over the research process would continuously be negotiated and renegotiated with the community.

### **"GROUNDING IN": AN INVESTMENT IN TIME**

Participatory research is also described as a relationship-based research practice. Much of the success of PR projects can be attributed to the relationship between trained researchers and research participants. This is particularly true when the research is done with communities as partners – whether the communities are geographic or cultural (Parker et al. 1998). In Aboriginal communities, the credibility of external researchers rests on the friendships they have built with the community people (Hecker 1997, Jacobson et al. 1998). Those with previous relationships and an on-going collaboration with

Native communities are more likely to have the trust and confidence needed to undertake research. Obviously, these relationships are not built overnight, but require time and patience. This process, called *grounding in* by Boston et al. (1997) and Plough (1994), is the immersion of the academic researchers in the daily lives of prospective research participants in the community. In this manner, researchers become acquainted with community cultural beliefs and etiquette; they become sensitive to daily struggles and build friendships. In their study with the Mvskoke Indians, Jacobson and his colleagues (1998) spent two years on the Indian reservation before they wrote the grant proposal for a PR study on diabetes. The relationship they established with the community helped them weather some critical moments in the actual study. Their experience was so rewarding, from research and personal perspectives, that they have become skeptical of research proposals submitted by people who have spent less time with the research participants.

Similarly, Douglas (1998) planned for a long-term participatory research health promotion project of four years to allow more time for groundwork and community immersion as part of the project activities. For those who do not have such luxury of time, a number of authors strongly recommend that resources for pre-grant activities be secured for sufficient grounding in. This is important for planning and logistical requirements as well as the process of building the trust and relationships critical to the success of the participatory research project (Davis and Reid 1999, Douglas 1998, Israel et al. 1998, Jacobson et al. 1998, Plaut and Landis 1992, Plough and Olafson 1994). It is naïve of researchers to think that communities are homogeneous, or that they automatically share the researcher's goals for the research (Lindsey et al. 1999). A community also may not see itself as the problematic entity a researcher perceives. A community is as dynamic as the people who live in it — a place where conflict and friendships can happen at the same time; of people shifting alliances; where there is a hierarchy of power relations and social structures that create unequal relationships (Clever 2001).

Grounding in builds trust and relationships that enrich the participatory research experience and bring life to the untapped creative energies of the community. To begin the process of grounding in, Wallerstein (1999: 49) reminds PR practitioners that relationships do not take place in a vacuum: they are “based on institutional history and links with academic and community; the history of previous research and on negotiations among community and academic stakeholders.” Lindsey et al. (1999) offer the practical suggestion that PR practitioners build time into the research proposal timeline for creating these relationships with the community .

## ADDRESSING ETHICAL CONSIDERATIONS

The core of authentic participatory research is the creation of a shared set of values and norms, between academic researchers and community participants, to guide the research process (Israel et al. 1998). It is a code of ethics, including ethical principles and research principles, reflecting the values and beliefs of all who will be involved in the research. PR prescribes a code of conduct which makes the research participants conscious of fundamental principles of justice, democracy, and mutual respect. There is a growing body of literature supporting the joint formulation of ethical principles as a starting point in any participatory and community-based research (Israel et al. 1998, Macaulay et al. 1999, Weijer 1999).

The idea of protecting communities from research is a consequence of the negative impact and harmful outcomes of past research (Weijer, Goldsand, and Emanuel 1999). Communities, in this sense, refer not only to geographic communities but to “a group of people sharing a common interest — cultural, social, political, health and economic” (Macaulay et al. 1999: 775). Engaging the community early in the research lays the groundwork for a partnership between community and researchers (Weijer 1999). This mutual engagement establishes the democratic research process and ensures that the ethical ground rules address the “concerns that arise from the traditions and values unique to and constitutive of the community” (Weijer 1999: 277). Weijer, Goldsand and Emanuel (1999) refer to this “respect for communities” (previously termed by Levine as “respect for culture”) as the fourth ethical principle in addition to respect for persons, beneficence, and justice. Respect for communities acknowledges that the individuals and their community are not separate units in which the community has a superior moral status as a collective participant in the research (Weijer, 1999). Finally, the researcher is obliged to respect the values of the community and, wherever possible, protect the community from harm.

Of the 27 studies, only four clearly included a discussion of ethical considerations. The ethical considerations of PR include discussion and reaching a shared understanding of ethical ground rules. In Davis and Reid’s (1999) article, a core ethical principle is the right of research participants to determine the kind of research and the questions to be asked. This principle targets academic researchers who assume that community members have neither the theoretical knowledge nor the skills to distinguish between different levels of research (Frideres 1992). Most PR projects undertake training of community members in all aspects of the research from conception and data collection to data analysis and report writing. Various PR studies demonstrate a cre-

ative mix of learning experiences upon which community members can build their participatory research skills. These include group workshops (Boston et al. 1997, Nichter 1984) and hands-on training (Dowswell et al. 1999, Heslop et al. 2000, Kavanagh et al. 1999, Lindsey and McGuinness 1998, Zakus 1998). These studies provide evidence that community members can and do learn research skills. However, whether these skills are sustained and used by the community to develop and conduct their own research was not explored in these PR studies.

Another ethical area relates to the ownership of data and approval of publication. The Tribal Council in Hecker's (1997) article insisted that data be returned to them and that the council should approve all publication about the research. The researcher implemented this policy. In addition, Hecker assisted the research participants (Aboriginal health workers) to write their own article for publication in a journal of Native issues. In Jacobson's (1998) research project, a publications advisory committee was created to ensure the report was accurate and sensitive to the cultural context of the research participants. The committee members were also remunerated for their work.

Publication approval is a thorny issue if there are negative findings that the community refuses to publish. The academic researcher may be declared guilty of scientific misconduct if he/she fails to publish because of a negative finding (Malone 1998). If the research is funded from public sources, failure to publish can be construed as misuse of public funds. This creates an ethical dilemma between proper respect for communities and the exercise of scientific integrity. The concern for publication approval of research by indigenous communities is not so much about what is written in the technical report. The larger concern is media reports that create a negative, and often erroneous impression, such as the inaccurate or unbalanced portrayal of communities as having certain diseases or general ill-health. Publication approval in relation to negative findings is an issue that Weijer et al. (1999) have suggested as a topic for discussion and negotiation at the beginning of a project so that strategies can be drawn up to ensure that communities are protected from harmful consequences of publication required by funding sources or scientific ethics.

Kothari (1997), in his work with the *Fundacion Sabiduria Indigena* (FSI), introduces another ethical concern related to benefits accruing from the publication of research. He argues that indigenous peoples have a right to benefit from the product and process of research corresponding to the intellectual property rights (IPR) of professional researchers. The right to the benefit of research (RBR) includes the following (FSI and Kothari 1997: 128):



- Receive a fair share of the non-monetary and monetary benefits of research in their communities, or benefit in other meaningful ways;
- Have access and control over the use of findings;
- Be acknowledged as the rightful owners of their knowledge;
- Have the option to participate in the entire process.

FSI and Kothari suggest that research grants should allow a certain percentage in the budget to benefit the community similar to the overhead cost charged by universities when they host the research site.

### RECIPROCITY AND SUSTAINABILITY

The right of communities to benefit from the research is an expression of the concept of reciprocity inherent in participatory research which should be seriously considered in other types of research. The PR process is, in essence, a relationship in which trained researchers with scientific and technical knowledge pursue their academic agenda while the communities use their expertise. The concept of reciprocity is emphasized by Davis and Reid (1999) in their research with minority populations which operate in an “ecologic give and take approach.” Participation is necessary to ensure accountability of researchers, the relevance of the research, and positive outcomes for the participants. If researchers take something valuable, then they must return something of equal value such as skills, employment, training, mentoring or increased access to funding.

Reciprocity is not limited to short-term benefits. It also includes sustainability of the benefits and outcomes of the research partnership. The IDRC evaluation framework includes sustainability as one of its main criteria in assessing PR projects (Found 1997). After all, PR is built on the premise that participants are empowered with a means to assert their autonomy and self-determination. Most of the researchers whose PR projects are reviewed here were conscious of their reciprocal responsibilities to their research participants. The commitment to action demonstrated by the concrete outcomes resulting from the research is an example of the mutual exchange relationship. For example, PR in clinical settings produced clinical guidelines to improve emergency and psychiatric services (Heslop et al. 2000), culturally appropriate discharge instructions for patients (Robinson and Miller 1996), and a collaborative stroke training program for the continuing education of nurses (Dowswell et al. 1999). These products of participatory knowledge development are useful tools for current health providers and will have long-term benefits in improving the quality of care in their health institutions.

In community-based PR projects, there is a consistent theme of developing research skills among community members as a way of sharing the researcher's expertise to the community. The intent is for the community to use these skills in their own research. Hagey (1997) raises the issue articulated by First Nations communities who claim that participatory research has not gone far enough to bring communities into the research and development arena. The skills that PR researchers transfer are not adequate for communities to conceptualize and develop their own research. In addition to equipping communities with basic research skills, PR researchers should also develop the capability to manage research when the community chooses its own external researcher. Instead of researcher-community partnerships, Hagey (1997) calls this "management of research under self-determination."

Perhaps the closest illustration of Hagey's claim is the experience of Madison County in North Carolina with the Community Oriented Primary Care (COPC) Project (Plaut and Landis 1992). The COPC project began as a partnership between county agencies, the Hot Springs Health Program and several community organizations. A Community Advisory Board (CAB) was created to oversee the implementation of the project which emphasized mobilizing the community towards the research. It also ensured that whatever gains the community made from the project, the community would participate in sustaining those gains. The CAB represented some of the key players in the community and was responsible for policy and planning decisions of the project. The community groups, organized by 350 community helpers trained and hired under the project, generated the data through a series of group interviews. This strategy integrated the research into the daily lives of the people in the community and stimulated community discussions about health issues outside of the formal research process. It mobilized the residents to press actively for a resolution of their health issues. The final outcome of the mobilizing strategy was the evolution of the CAB into a Madison Community Health Consortium with even wider community representation. With this accomplishment, the community eventually achieved a level of research capability that won them a national award on health services improvement. There was no turning back for Madison County. They had reached a level of collective consciousness which Plaut and Landis (1992) called an "organic community praxis" that created the energy required to change and improve their lives.

## CONCLUSIONS AND IDEAS FOR FURTHER STUDY

It is important to note that the themes identified and explained in this paper as theory do not exist in isolation from each other. In practice, the

themes are interrelated and exert a synergistic action on the outcomes of the research. In other words, aiming for authentic participatory research means striving to find the most powerful combination of enabling factors and/or conditions. In conclusion, this review offers a few insights on what authentic PR might be:

- Participation is determined by those who are involved in the research process according to their motivations, capacities, and relationships.
- Professional, academic, or external researchers are willing to reflect on their power and how it influences the research process; by this reflection, they share and relinquish this power to those who have less power.
- There is willingness to invest time and effort to build collaborative relationships, including material resources to support such an investment.
- There is a readiness to discuss, negotiate and resolve ethical issues, especially those issues that create the most discomfort among us.
- Reciprocity or mutual exchange between academic researchers and community participants is most appreciated and productive when the benefits and outcomes of the research become an essential part of community life.

The list of emerging themes culled from the various PR projects and studies is by no means exhaustive. It is certain that there are still important lessons and insights in these projects that are waiting to be extracted. The next step is the development of research ideas that make the themes visible and clear in the practice of participatory research. For example, a study to expand the work of Wallerstein (1999) on power and relationships would be valuable. Such a study will allow health professionals to examine their own experience in confronting and resolving power issues and dynamics in participatory research projects. This would advance the knowledge about perceptions of power and power sharing among health professionals.

Another study might follow up PR projects in health promotion and public health to determine how the projects have sustained the outcomes and benefits of PR. Other exciting areas of study are how ethical issues are resolved and how ethical principles are jointly developed. These studies would have profound significance in the field of relational ethics and the subsequent application to primary care practice in culturally diverse communities and indigenous populations. The notion that participatory research contributes to healthy outcomes because of the empowering process it creates, is a pow-

erful research idea that could further enrich the literature on the determinants of health.

Hagey (1997) describes the realm of participatory research as the new “frontier of fruitful research.” PR has indeed unleashed the creative energies of people and communities to participate, share, and nurture a collective knowledge-seeking and knowledge-creating process. In the arena of health research, participatory research represents the primacy of people in the development of health knowledge.

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# APPENDIX ONE: PARTICIPATORY RESEARCH GUIDELINES, ROYAL SOCIETY OF CANADA

## PARTICIPANTS AND THE NATURE OF THEIR INVOLVEMENT

1. Is the community of interest clearly described or defined?
2. Do members of the defined community participating in the research have concerns or experience with the issue?
3. Are interested members of the defined community provided opportunities to participate in the research process?
4. Is attention given to barriers to participation, with consideration of those who have been under-represented in the past?
5. Has attention been given to establishing within the community an understanding of the researchers' commitment to the issue?
6. Are community participants enabled to contribute their physical and/or intellectual resources to the research process?

## ORIGIN OF THE RESEARCH QUESTION

1. Did the impetus for the research come from the defined community?
2. Is an effort to research the issue supported by members of the defined community?

## PURPOSE OF THE RESEARCH

1. Can the research facilitate learning among community participants about individual and collective resources for self-determination?
2. Can the research facilitate collaboration between community participants and resources external to the community?
3. Is the purpose of the research to empower the community to address determinants of health?
4. Does the scope of the research encompass some combination of political, social and economic determinants of health?

## PROCESS AND CONTEXT-METHODOLOGICAL CONSIDERATIONS

1. Does the research process apply the knowledge of community participants in the phases of planning, implementation

and evaluation?

2. For community participants, does the process allow for learning about research methods?
3. For researchers, does the process allow for learning about the community health issue?
4. Does the process allow for flexibility or change in research methods and focus, as necessary?
5. Are procedures in place for appraising experiences during implementation of the research?
6. Are community participants involved in analytic issues: interpretation, synthesis and the verification of conclusions?

## OPPORTUNITIES TO ADDRESS THE ISSUE OF INTEREST

1. Is the potential of the defined community for individual and collective learning reflected by the research process?
2. Is the potential of the defined community for action reflected by the research process?
3. Does the process reflect a commitment by researchers and community participants to social, individual or cultural actions consequent to the learning acquired through research?

## NATURE OF THE RESEARCH OUTCOMES

1. Do community participants benefit from the research outcomes?
2. Is there attention to, or an explicit agreement for acknowledging and resolving in a fair and open way any differences between researchers and community participants in the interpretation of the results?
3. Is there attention to, or an explicit agreement between researchers and community participants with respect to ownership of the research data?
4. Is there attention to, or an explicit agreement between researchers and community participants with respect to the dissemination of the research results?