

# Responsible Research with Communities: Participatory Research in Primary Care

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## Contributors:

**Macaulay AC (Chair), Commanda LE, Freeman WL, Gibson N (Editor), McCabe ML, Robbins CM, Twohig PL.**

**Ann C. Macaulay:** Associate Professor, Department of Family Medicine, McGill University, SMBD Jewish General Hospital, 3755 Cote Ste Catherine, Montreal, Quebec H3T 1E2, Canada. Email: ann.macaulay@mcgill.ca **Laura E. Commanda:** Policy Advisor, HIV/AIDS Policy Coordination and Programs Division, Health Promotion and Programs Branch, Health Canada, Jeanne Mance 1918 B1, Tunney's Pasture, Ottawa, Ontario K1A 1B4, Canada. Email: Laura\_Commanda@hs-sc.gc.ca

**William L. Freeman:** Director, Research Program, Indian Health Service, Public Health Service, 5300 Homestead Road NE, Albuquerque, New Mexico 87110-1293, USA. Email: william.freeman@mail.ihs.gov

**Nancy Gibson:** Chair, Department of Human Ecology, 3-02 Human Ecology Building, University of Alberta, Edmonton, Alberta T6G 2N1, Canada. Email: nancy.gibson@ualberta.ca

**Melvina L. McCabe:** Associate Professor, University of New Mexico, Department of Family and Community Medicine, 2400 Tucker Ave NE, Albuquerque, New Mexico 87131, USA. Email: mlmccabe@unm.edu

**Carolyn M. Robbins:** Community Advocate, 2400 Rio Grande Blvd NW #1-138, Albuquerque, New Mexico 87104-3243, USA. Email: cmrobbins@worldnet.att.net

**Peter L. Twohig:** Research Associate, Dept. of Family Medicine, Dalhousie University, 8th Floor, Abbie J. Lane Bldg, 5909 Jubilee Road, Halifax, Nova Scotia B3H 2E2, Canada. Email: twohig1@is.dal.ca

**North American Primary Care Research Group (NAPCRG):** PO Box 8729, Kansas City, MO 64114, USA, Email: napcrgrg@stfm.org, "<http://views.vcu.edu/napcrgrg/napcrgrg.html>"

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## Executive Summary

The document, "Responsible Research with Communities: Participatory Research in Primary Care," together with the recommendations for NAPCRG, was adopted as organizational policy, by the NAPCRG Board of Directors and membership at the NAPCRG Annual Meeting on November 6, 1998 in Montreal. This document grew out of a successful workshop on Respectful Research With Communities at the 1996 NAPCRG Annual Meeting. The NAPCRG membership and Board of Directors supported and financed development of this document. The Task Force solicited comments from interested parties and incorporated many suggestions into the revisions.

The PR approach, which has its roots in various liberation movements of the last two decades, increases the voice of communities in identifying health issues. PR enhances the relevance and validity of health research by ensuring that the social, cultural and economic conditions of the community are included. PR ensures that

communities share in selecting and designing research projects, gain skills during the research process, share in the reporting, and are in a position to use the results for their future health care planning.

This document describes the process of creating collaborative research projects that include all parties: academics, physicians, community members, government agencies and other relevant players. All partners are considered experts with complementary knowledge and skills.

The first step in participatory research is to develop a strategy that defines the level of collaboration in all stages of a project from design to dissemination of the results. The strategy may be a formal document or code of ethics that guides the research process. Common goals, desired outcomes, potentially sensitive issues such as ownership of research data, and strategies for managing sensitive results to the communities as well as to scientific forums, will be identified by the entire research team.

Participatory research can require a considerable time commitment from all collaborators. The outcome, however, is often health information that is more relevant and accessible to the community. This can lead to community-activated and sustained health programs that address important health problems. A PR project is considered successful if all collaborators are satisfied with the research process and the results.

The recommendations to NAPCRG reflect a commitment to the PR research approach that ensures formal and active recognition of all partners throughout the research process. NAPCRG will play a proactive role in providing guidance regarding PR to both professionals and interested communities. The overall goal is to increase knowledge of a process that can be applied, when appropriate, to achieve successful collaboration with communities.

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## **INTRODUCTION**

The North American Primary Care Research Group (NAPCRG) was founded on the premise of developing and disseminating new knowledge regarding primary care. Its mission is to improve the health of individuals, families and communities in North America, and internationally through the development and dissemination of new knowledge applicable to primary care research, organization and education.

In keeping with the mission of NAPCRG, this policy statement is designed to encourage the development of respectful collaboration with communities in primary care research. It encourages NAPCRG members to seek opportunities to work in partnership with communities to ensure that theoretical and applied benefits are clear and significant to both the researcher and the community. NAPCRG affirms a commitment to respectful development and dissemination of new knowledge by examining the utility of research approaches such as participatory research (PR) in primary care [1,2,3]. This policy statement examines the need for, benefits of, and ethics of, fully collaborative, participatory research with communities. As the President of NAPCRG, Dr William Phillips, observed in 1995, "NAPCRG should help push forward the boundaries to meet these challenges." He emphasized the need for researchers to have a balance of critical analysis and creativity and that "primary care research must focus not only on the costs of care but also on the causes of disease; not just the mechanism of efficiency in systems but the meaning of illness in patients' lives; not just health services to populations but the healing of persons and the health of communities." [4]

The traditional research approach has considered individuals and communities to be "subjects" or "objects" of health research. Current developments in ethics, and research methods, and an expanding recognition of what constitutes expert knowledge, justify the heightened participation of individuals and communities. Primary care providers are uniquely positioned to engage members of the communities in which they work, thus sharing the research process.

The following sections provide a review of the origin and rationale for practicing PR, the rationale and strategies for integrating community collaboration, the attendant challenges and ethical considerations, and, finally, the policy recommendations. A comprehensive list of relevant references is also included as endnotes.

## **KEY TERMS**

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.

Community is any group of individuals sharing a common interest. This definition includes cultural, social, political, health and economic issues that may link together individuals who may or may not share a particular geographic association.

Participatory research (PR) is a process which incorporates "systematic inquiry, with the collaboration of those affected by the issue being studied, for the purpose of education and taking action or effecting social change" [5].

Collaboration is a research partnership among equals with complementary knowledge/expertise.

Partnership is the process of establishing and sustaining a mutually respectful relationship based on the sharing of responsibilities, costs and benefits, with outcomes that are satisfactory to all partners.

Empowerment is the process of enabling groups and individuals (via the removal of barriers, provision of needed resources and sharing of knowledge) to gain understanding and control over personal, economic, social and political conditions and circumstances, in order to improve their life situations (Hulme 1998).

Science includes "all approaches to science that consider scientific knowledge to be obtainable only from sense data that can be directly experienced and verified between independent observers. [It is] value free, logical, empirical.

## **RATIONALE: WHY PR?**

### **Background**

Research is a systematic inquiry. Its aim is to discover and interpret new knowledge that adds to the domain of knowledge. Classical/traditional methods in health and social science research have been slow to address cultural and ethical factors in research which have implications for the interpretation of the findings [6,7]. PR attempts to negotiate a balance between the development of valid generalizable knowledge and meaningful community benefit.

PR strategies that aim to include the cultural context have their roots in the development ideologies, which emerged in the 1960s and 70s. As a movement for social justice, PR has long been practiced in international development settings[8,9,10,11,12]. Such strategies were developed to address the failure of other approaches to ameliorate social and economic conditions or effect change [13], and the consequent alienation of the people being studied [14]. In addition minority communities distrust researchers because:

- traditional knowledge has been used inappropriately, out of context, or for financial or professional profit with no obvious benefit to the community [15];
- destructive notoriety or stigmatization has resulted from the public reporting of research results [16];
- direct harm has occurred without recourse [16 17] and
- traditional research findings lack relevance and fail to inform questions of practice or social use [18].

Other studies affirm these findings [19,20,21]. For example, researchers studying Native Hawaiians have also concluded that many health promotion programs failed because of their cultural inappropriateness [22].

Balancing the distrust are communities that strongly support the need for research on issues that are of direct consequence to their members [23]. These include community groups such as ACTUP for AID/HIV research, promoting drug trials that include women, the Breast Cancer Coalition, and Alzheimer's associations [24]. These groups are using participatory research to both enhance the validity of data, and to increase the capacity of communities to do their own research [9 25,26].

### **What is Participatory Research?**

PR provides a framework from which to respond to health issues within a social and historical context. This is in contrast to approaches wherein health issues are framed only in clinical terms, defining illness in relation to individual behavior [18 27, 28]. There have been several succinct definitions of PR. The definition offered by Green, et al. [5], cited in the box above, bears repeating, where PR is "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change." Maguire defines PR as "a process of collective, community-based investigation, education, and action" [29]. The Commission d'étude sur les universités au Québec has defined PR as research undertaken by scholars who, "joining theory with intervention, work with groups outside of their institution, analyze with them the problems faced by their community, help them to perceive these problems more clearly and to take charge of the sectors that influence their collective life." [30] These definitions encapsulate the key elements of PR: research through collaboration, education and action [2,31,32]. It has been observed that "theory is one of the first casualties of academic-community research collaboration," since researchers may downplay their knowledge of theory so as not to appear elitist or to accommodate community interests, if they are conflicting [33] Strauss and Corbin, among others, counter this view with their grounded theory model, in which theory is generated by the research process [34]. A comprehensive review and critique of the various current theoretical approaches to public health research and education has been compiled by Glanz et al.[35]. What is important is

that each approach, regardless of the name, stresses the commitment to the researcher-community exchange relationship and to social action [36].

In PR, the research process is as important as the outcome [37]. PR is differentiated from other forms of research "in the alignment of power within the research process", and characterized by what McTaggart called "authentic participation" [38]. PR can break down the rigid boundaries between those doing research and being researched and thus affords all participants access to the production of knowledge. Ideally in PR, community partners must be involved in the "way research is conceptualized, practiced, and brought to bear on the life-world." [38] In PR, the research problem is "identified, analyzed and acted upon" [39] jointly by the researchers and the community [40]. Heaney suggests that PR "is credible and legitimate when the action to which it leads brings about better conditions for life. Period." [41].

There are several models of participatory research. Small provides definitions of, and compares four 'action-oriented research models': action research; participatory research; empowerment research; and, feminist research [42]. For those who wish to conceptualize the similarities and differences between these various models, Small's article offers a useful critical comparison. The main point made by the author is that there is more convergence than divergence between the models, even though all evolved from different disciplinary roots and historical doctrines. Other useful references include Susman and Evered,[43] Israel et al,[44] and Hart and Bond [45]. According to Smith et al, "When people form a group with a common purpose, investigate their situation, and make decisions to take actions that re-form power and create justice, their reality is transformed. In so doing, they also are transformed-losing fear, gaining confidence, self-esteem, and direction. This process of participatory action-research produces knowledge based on experience: the wisdom of the people." [9 46,47].

It is important to recognize that there are different 'shades' of participatory research that are equally legitimate. The participatory research approach can be applied to many forms of research<sup>48</sup> and with varying degrees of intensity. The term usually defines research inquiry which involves 1) some form of collaboration between researchers and the researched, 2) a reciprocal process in which both parties educate each other, and 3) a focus on the production of local knowledge to improve interventions or professional practices [5 38]. The ultimate goal is to assist research subjects to assume ownership of the research process and to use the results to improve their quality of life [44]. Some authors argue that participatory research is a health-promoting endeavor in itself [23].

## **PR as an Approach**

PR is a research approach, philosophy or process: at the core is the partnership between researchers and the community (i.e., those being "researched") [31,49]. PR does not follow a restricted and rigid research methodology. Drevdahl has described this as a "world view about the conduct of research, rather than a linear, delineated procedure for collecting evidence." [39]. A successful PR project does not depend on specific methods of data collection or analysis. PR does not replace other forms of research, nor is it characterized by whether it uses qualitative or quantitative methods. Nevertheless, as Cornwall and Jewkes observe, PR is often debated around the "quantitative-qualitative divide" with critics regarding it as "soft" research and its proponents claiming that it is a "panacea for problems besetting conventional practice." [37]. Familiar qualitative and quantitative methods from clinical and social sciences can be readily incorporated into the PR process; seldom do PR projects use only a single method.

PR is most easily conducted with people who have a well-developed consciousness of their community [50]. For this reason, PR in the developed world is usually conducted among people who have shared culture and common ties, including unions, women's organizations, and American Indian/Alaska Native or First Nation communities [51]. Much of the PR literature concerns disempowered communities. PR, because it does not rely solely on traditional power structures and works within communities "vulnerable to colonization" [48], provides an important opportunity for collaboration with disadvantaged social groups. The collaborative process enhances the resilience that exists in every community [2 52]. Participatory research can also include

individuals or groups that would not usually be considered communities (e.g. groups of patients, individuals with a specific problem, family groups, etc) [53]. Green et al noted that "over the last twenty years, participatory research has addressed women's issues, the issues of people with disabilities, and the health and economic issues of the Aboriginal movement in Canada." [5] Researchers in areas as seemingly disparate as National Aviation Space Agency (NASA) [54]. AIDS and breast cancer activism, for example, are now adopting this process. The PR approach has also been adopted by the Environmental Protection Agency (EPA) for health research [55].

The recent philosophical trend towards collaborative research can in part be traced to the increasing autonomy of Aboriginal people around the world [32 52 56,57 58]. This trend has been reinforced by forums on Aboriginal issues, such as the Royal Commission on Aboriginal Peoples (1997) [59], the National Forum on Health (1997) [60], the International Workshop on Ethical Issues in Health Research Among Circumpolar Indigenous Populations (1995) [61], and the Report on the National Workshop on Ethics of Research in Aboriginal Health, Alice Springs, Australia (1986) [62].

All research involves a degree of participation. Much conventional research allows only limited interactions with people, while other models have a great deal of participation, but are not really "participatory" in the sense of sharing power in decision-making [63]. "Participation is a powerful but slippery concept," according to Elden and Levin. They point out that there are different degrees of participation: 'insiders' may be seen by some as source of data only, but yet are still deemed to be 'participating' in the research process. The authors argue, however, that only those who are "...co-creators in each phase of knowledge generation and interpretation..." are full participants in the process [64]. Researchers and practitioners who have been trained to consider themselves to have superior knowledge and who have predominantly used a conventional research approach will need to understand the issue of alignment of power if they are to implement this policy. The major differences between the conventional approach and the PR approach to research lie in the questions of who defines the research problem, and who generates, analyzes, represents, owns and acts on the information resulting from the research project. This entails a shift in personal and professional attitudes of those practicing conventional research regarding these questions. As more researchers and practitioners in primary care come to understand and accept the collaborative element of PR, they will also need to be aware of the issue of trust and relationship building with the collaborating communities. PR is a process of education, a continuous enhancement of knowledge, skills and resources for all partners.

The steps of a participatory research project are outlined succinctly in The Guidelines and Categories for Classifying Participatory Research Projects in Health Promotion, developed for the Royal Society of Canada, and appended to this document with permission. These steps assist all partners to address the major issues in the research process.

## **PR and Primary Care Research**

Research strategies with explicit participatory elements have recently gained respectability and credibility within mainstream health research [37 65]. Participatory primary care research seeks to include the community (ies) in every aspect of the undertaking, from conceptualization to evaluation and dissemination [51 66]. At its inception twenty-five years ago NAPCRG promoted the move to primary care practice-based health research as an alternative to research conducted largely in tertiary care university teaching hospitals. Many researchers recognized that the mystique of research must be dispelled not only for purposes of democratizing knowledge, but also to ensure that research and its outcomes have the desired effect of improving health [67, 68, 69]. Primary care research teams, frequently multidisciplinary, are now expanding to include the community. Contextualization-acknowledging and integrating the relevant patterns of social behavior-is also a strategy to increase the validity of public health research by including socio-cultural factors that influence disease or health service outcomes [56 70]. Collaborative research increases the likelihood of long-term sustainability of health programs, ensures cultural appropriateness, promotes socioeconomic development, and transfers skills and knowledge to the community [71]. Examples of PR within primary care research include the introduction of a patient-centered clinical method at the University of Western Ontario, Reason's study of physicians and holistic

health care [72] and Denz-Penhey and Murdoch's work with chronic fatigue care [73] In Quebec a Mohawk community invited two universities to form a partnership for the primary prevention of diabetes. The resulting program has been taken over by the community [74,75]. Similarly, the current Alberta collaborative project on socio-cultural factors affecting tuberculosis prevention and treatment [76] includes several university departments, several Aboriginal health organizations and a community-level training component wherein community members will become skilled in evaluation techniques and data collection.

## **PROCESS**

### **Establishing Partnerships**

Participatory research ensures that the community is an equal and active partner with the other stakeholders involved in the study, e.g., university, corporations, or governments. The knowledge and expertise of all collaborators are considered complementary. A key element of participatory research involves developing realistic expectations about what each group can and cannot contribute. Just as participatory research enhances validity by including context, so too is the validity of the research relationship enhanced if the context of each partner is understood. The exercise of defining the strengths, limitations and resources that can be brought together contributes to the establishment of trust [77,78], and mutual respect between researchers and community. In participatory research, the research design and the data obtained are iteratively analyzed and discussed by the research partners [40]. Projects are therefore under on-going scrutiny, and subject to evaluation and revision as part of the research process. Primary care researchers will observe the similarity with the argument of Hueston and Mainmou (1996) in favor of family medicine research. Practicing family physicians, they argued, have an important place in research through (1) validating that the issue under investigation is clinically relevant; (2) ensuring that the results of the study will be applicable to a typical family practice; and (3) providing a real life environment for the research that will enhance its external validity [79]. In this way, research becomes a way to more effectively improve health by building bridges between research and application, academician and clinician, academia and community. The goal is to dispel the classical expert/community dichotomy [80].

Mittlemark [81] provides examples of partnerships that can be established between academic researchers and communities. If academic groups are senior partners, authority begins with them and is gradually transferred to community groups [82]. When the community is the senior partner, projects are designed and implemented by community groups and the academic partner is contracted to assist with particular problems. Finally programs with balanced partnerships occur when leadership shifts back and forth depending on which group has expertise for a particular problem. Full partnership takes time to establish and requires: maturation of trust; development of vision, confidence, skills and knowledge; and, a gradual shifting of balance and perspective through genuine, respectful dialogue. It follows then that certain skills and qualities are advantageous in this continuous process of negotiation and compromise. John Collier, one of the originators of action research, stated in 1945:

But let me emphasize that this kind of research makes demands on the research worker that are far more severe than those needed by the specialized and isolated kind. It requires of him [sic] a more advanced and many-sided training, and in addition a type of mind and personality which can sustain, in suspension, complex wholes, and yet which can entertain-yes, and be drawn in and impelled by-human values and policy purposes....[83]

Hagey [84], Hart and Bond [45], Israel et al [85], Fawcett [86], and Sherman[87] all discuss attributes of researchers and participants that contribute to harmony during the research process, and to successful outcomes. These include: a high degree of political awareness, and knowledge of one's own perspective; emotional stability-which underlies a high degree of tolerance for complexity, unpredictability, and conflict; excellent group process skills and commitment to equality of relationships; and versatility.

### **Education and Capacity Building**

By its very nature, PR is an impetus for change, by relating knowledge to action[88]. First, community members become equal partners in all aspects of the research, including any action arising from the project. Second, it is a bi-directional education process, in which researchers and the community learn from one another and share expertise and knowledge. Third, PR is a process that is interactive, and co-learning is a central feature of the process, in contrast to the unidirectional model of outside researchers providing education to the community members [89]. Fourth, PR focuses on concrete problems. Finally, benefits must accrue to the community.[5 88 90].

The PR process is iterative; action and reflection are intertwined in the evolving project [32]. Education occurs throughout the entire PR process, but chiefly through what Freire calls the dialogic method, whereby community members apply their insights and experiences to problem solving [51]. Dialogue is undertaken to prepare for partnership (capacity building), assess the needs and interests of all participants (community, researchers, institutions, funding-agencies), establish a dynamic relation between community needs and research strategies, allow for on-going consideration of broader (or other) contexts, and encourage on-going reflection by all participant [91, 92]. Goulet, in his introduction to Freire's book, states: "If...one is to adopt a method which fosters dialogue and reciprocity, one must first be ideologically committed to equality, to the abolition of privilege, and to non-elitist forms of leadership wherein special qualifications may be exercised, but are not perpetuated." [93].

Encouraging people to think critically about their surroundings puts social problems in a broader political, social and economic context. Disadvantaged people tend to believe that their oppression is their fault [94], a phenomenon that Paolo Freire calls the "doctrine of personal culpability." [95] A central goal of the PR process is the transfer of knowledge, which sets the community on a course for autonomy [32 57]. PR becomes a means of fostering action [32] by involving communities in formulating research questions, collecting and interpreting the data, disseminating and implementing the results.

## **CONSIDERATIONS AND CHALLENGES**

### **Ethical Considerations**

Just as research approaches have changed in the last half of the twentieth century, the post war period has witnessed the further articulation of ethical principles that govern research involving humans. These principles continue to evolve in response to the technical capabilities of science as well as to society's social and moral standards.

The three internationally recognized cornerstones of ethical research are:

- respect for autonomy of the person;
- non-maleficence (to do no harm) and beneficence (to do good to others);
- social justice. [96,97]

These principles emphasize the importance of informed consent, open acknowledgement and assessment of the risks and benefits of the research and the importance of protecting potentially vulnerable people. [98]

### **Codes of Ethics**

The initial development of research ethics concentrated on the researcher's responsibility to individual research subjects. Current approaches address the additional challenge of meeting the ethical needs of researchers, individuals and communities [54 99,100]. The Council of International Organizations of Medical Sciences (CIOMS) states that "the community to be studied should be represented in the review process ... it should not be considered that lack of formal education disqualifies community members from joining in constructive discussion on issues relating to the study and application of its findings." [101]. In recent years institutions, professional organizations, local groups and communities have developed their own ethical codes to incorporate

community needs into their broad research guidelines [74]. The draft of the new Canadian Tri-Council policy statement on Ethical Conduct for Research Involving Humans recommends a participant centered approach to research and recognizes that differences exist in the ethics of research undertaken with defined communities [102].

These developments indicate that researchers must now consider whether it is appropriate for an Institutional Review Board (USA), Ethical Review Board (in Canada), Human Subjects Committee, etc, to judge the suitability of a research project that involves a community, if that project does not involve the community's participation and input. The establishment of ethics review bodies is sound; the question is the current nature of the review process.

Experience has shown that participatory research is strengthened by ethical guidelines and written agreements to ensure the sharing of leadership, power and decision making from design to dissemination of results [103,104]. Every participatory research project is unique and the collaborating parties should jointly negotiate ethical guidelines before research commences. These guidelines, written at the appropriate literacy level [105], will identify the issues, maximize close collaboration between researchers and the community, and reflect local culture, needs and interests.

Experts in participatory research [5], national organizations [106], universities[107], professional groups [108] and Native organizations [22 109,110,111,112] have developed ethical guidelines and checklists. These documents identify principles and obligations for the four phases of a research project: design, implementation, data analysis and interpretation, and dissemination of the results.

The front-line collaborators from each setting—for example academicians and members of a community—together develop a research agenda. These people, however, are not negotiating so much on behalf of, but in consultation with the institutions they represent. The standards and principles of these institutions will guide them. The ethical and procedural issues to be successfully negotiated include: the roles and responsibilities of each collaborator (including researchers and community representatives), the desired outcomes of the research, measures of validity, control of the use of data, control of funding, and the channels/mode of dissemination of the research findings. The outcome of this process is a working relationship based on an articulated set of research questions that is acceptable to all of the research partners; a task that can appear quite daunting at the start of any collaborative research effort. The roles and responsibilities of team members may shift during the research project, a potentially sensitive prospect that can best be managed in an established atmosphere of trust and mutual respect. Another important outcome is capacity building of all partners as collaborators, including training, enhanced infrastructure, control of data collection and storage, a stronger receptivity to collaboration by researchers, and a stronger community voice in policy design[113]. Sustained capacity-building efforts cannot be undertaken in a piecemeal fashion.

Discussion of all the results with the community allows for joint interpretation of the data, and modification if necessary before dissemination. These steps strengthen the cultural and final validity of the results, minimize harm (i.e. both outsider stigmatization of individuals and the community and self-stigmatization) and encourage community education and autonomy. Dissemination of the results includes oral and written presentations in the final report in the both the lay and scientific press as well as the media.

There are many examples where health researchers retained full control or only involved the community at a superficial level. Lack of community involvement has been particularly obvious at the time of scientific publication. In reaction to this some communities have requested veto power for all or part of the publication process, or if necessary, requested that, reports go only to the funding agency [111 114,115]. A alternative solution is that the variant viewpoints be included in reports/publications [74]. Researchers should avoid unilateral decisions, which may inadvertently be ethnocentric [15], and be cognizant of the fact that ethical principles espoused by communities may adopt a different emphasis from those embraced by the traditional research community [116]. For example, the principle of respect for autonomy of the individual may, in some

Aboriginal communities, be of lesser importance than respect for autonomy of the community as a whole. Based on his experience with Aboriginal peoples in Ontario, Brant discusses four principles that he believes are embedded in those groups: non-interference; non-competitiveness; emotional restraint; and, sharing [117]. It is therefore extremely important that researchers familiarize themselves as thoroughly as possible with the cultural norms of the communities with whom they intend to collaborate.

Therefore consensus should be negotiated for:

- the research goals and objectives;
- the methods and duration of the project;
- how community members can be partners on the research team;
- degree of confidentiality;
- strategy for evaluation process;
- interpretation and control of data, knowledge of where data is filed, current and future use of the data and human biological material;
- responsibility for resolving issues arising from the research;
- if and how new researchers can be incorporated into an existing team; and
- joint dissemination of the results in lay and scientific terms to both the communities and the scientists.

### **Empowerment**

The issue of empowerment comes up consistently in the PR literature [118]. Small has stated that empowerment is a primary goal of community research [42]. Rappaport observes that if a research approach has within its framework the empowerment of the community then empowerment by definition should be concerned with those who are excluded by the majority society on the basis of demographic, physical, emotional or cultural differences or difficulties, either in the past or in the present [119]. The use of the term empower is contradictory in the literature, however. Power, by its very nature, is gained or lost, not given. Power that is given is actually a subtle form of control, of the "giver" over the "receiver". Labonte [23] suggests that "continually stating 'we need to empower this or that group' creates and reinforces a world of professional practice in which non-professional groups are incapable of their own 'powerful' actions." No researcher can empower another individual; the empowering process must come from within the disempowered group or individual. Researchers can, however contribute to the creation of an environment wherein empowerment may occur [120].

### **Addressing Complexity**

PR mandates an ongoing relationship. The ethical commitments embedded in the PR process relate to social change, ownership of the research process, and control over research questions and results. As integral and important as the commitment to collaboration may be, there are no guarantees that the participatory research process will not fall prey to the vagaries of human nature. For example, a self-selected individual who purports to represent the community may greet the researcher at the outset of a project, screening access to other community members. So also may the researchers be so deeply embedded within their own academic disciplines that they may be unable to share their traditional power.

This distinction between researcher/other persists in the literature, as in Bartunek and Louis' recent Insider/Outsider Team Research [121]. It is argued that researchers who are insiders to a setting being studied often have a particular view of the setting and their findings may be quite different from those of the outside researchers who are conducting the study. These differences have significant implications for the quality of knowledge that will be gained from the research, its potential to enhance insiders' practice, and the relationship insiders and outsiders have with each other.

This discussion suffers the usual effects of generalizations, by imposing homogeneity on both the insiders and the outsiders. Insiders do not necessarily share a common perspective; people within any culture or community

are differentiated by many variables including gender, age, economic status, religious beliefs, and political affiliations [122]. Although the insider/outsider dichotomy may be useful for academic discussion, it belies the complexity of the characteristics of the range of collaborators. The insider/outsider distinction can become an unnecessary barrier to the establishment of the trust relationship, which Bartunek and Louis correctly identify as an essential component of collaborative partnerships. Research becomes more relevant and data more accurate when the roles and agendas of all collaborating partners are defined. The research community is complex, including institutional and government representatives, ethnically identified health personnel, and geographic community representatives.

Attention to community development does not guarantee successful knowledge development or vice versa. Many projects don the garments of community participation, but fail to realize this goal in any substantial way [123]. It is one thing for a process to be credible and legitimate insofar as it may lead to better conditions for life. It is quite another matter to claim that such a process constitutes research. Participatory research is, or should be, more than community development under the auspices of research [124].

### **Solving Problems and Resolving Conflicts**

The research partners or team players may change as the project develops, when new members with specific theoretical, methodological and experiential skills are recruited [125]. The complexity of the agendas of the various partners in PR and the ambiguous nature of the research environment can raise difficult issues regarding the roles of the participants and the intended outcomes of the research project. Although the ideal process has been described here thus far, the potential for conflict should be acknowledged, and even anticipated by building in mechanisms for addressing changes in personnel, research design, and changes of mind [65]. People conduct PR; this truism is meant to point out the possibility that one or more participants can change their minds during the research process, with an adverse effect on the research.

Some authors [87 126] suggest that potential health issues in community settings are often ignored or overlooked by researchers and participants alike: do the participants who are chosen or self-selected, collectively represent the interests of all levels of the community? Whose interests will prevail when values and expectations of the various participants (including funding agencies, political and academic institutions) come into conflict?

Several authors have identified potential conflicts encountered by participatory researchers in community or organizational settings: conflicts between personal ambition and advancement within the research or academic communities, and the lack of peer recognition for research work that does not meet 'scientific' criteria of rigor, validity, and reliability; loyalty conflicts between the demands and expectations of funding agencies or academic institutions, and those of the community; the requirement for emotional investment and energy in a research process, which by its very nature, is unpredictable, demanding, and long-term; and, pressures to act as political advocate for groups which may be marginalized and/or oppressed [45 85 86 87]

Such situations will sorely try the negotiating skills of the most committed group. Although often unavoidable, the effects of such situations can be mitigated by awareness from the outset of the research process of the possibility of unforeseen shifts in objectives, agendas and political allegiance. Most situations can be dealt with internally; however, including a trained mediator is sometimes useful in limiting the effect of disagreements and shifting agendas on the project itself. Sometimes, however, a participant may choose to withdraw; a community may decide not to continue its participation, and a project may be stopped for many reasons. It is worth noting that a salient ethical commitment is the right to withdraw from a research project at any time in the process. This right should also be extended to the academic partners who also have a considerable involvement in the research process. The process of collaborative research is dynamic [127], and the ethical agreements negotiated at the outset guide the participatory process throughout.

Various groups, including the CDC in Atlanta are currently addressing the issue of individual vs. collective consent [128,129,130]. Additional challenges exist when there is no obvious leadership structure within a

community. Borkan<sup>131</sup> recounts examples with non-union workers, and in Bedouin communities, where there are multiple and competing communal/modern/traditional/family structures. In the first instance he obtained consent from each individual, while in the latter he attempted without success to find recognized leaders and instead had to settle for individual consent.

A final caution: not every academic has the skills to collaborate successfully in community-based research; not every community is interested in academic-linked research; and a collaborative approach is not appropriate for every project.

### **Examples of PR Projects**

There are many examples of participatory research in primary health care in the recent literature, including inner-city populations and marginalized groups [132, 133]; economically depressed communities [126]; consumer groups and organizations [85]; and seniors groups [45 134]. The range of examples is further illustrated by those cited below.

1. The Boston Healthy Start Initiative [135]: This was a federally funded research project that used a community participation model to improve infant mortality rates of African American in the Boston area. Very specific outcomes were achieved from this PR project including a decrease in infant mortality rates in the African American community in Boston, and a demonstration that communities played a major role in redefining services and power relationships in health programs.
2. The Wai'anae Cancer Research Project in Hawaii [22]: The key component of this cancer control research project was community participation in all phases of the project including grant proposal development through to data interpretation. The purpose of the project was to test the effectiveness of a culturally appropriate intervention as a means of increasing breast and cervical cancer screening practices among Native Hawaiian women. The results showed a community-wide impact on cancer-related knowledge, attitudes and behaviors, and economic benefits, increased research capabilities and improvements to health systems and services for the community.
3. Nutrition education for low income, urban women in Halifax [120]: This case study analyzed how PR and community organization surrounding the problem of nutritional inequities was an empowering educational experience for a group of socially disadvantaged women. Participants gained knowledge and initiated collective action for social change toward nutritional inequities.
4. The Motala Injury Prevention Program in Sweden [137]: This was an action research study that used a participatory model to gain a better understanding of community development for injury prevention. This project achieved sustained outcomes. A regular Safety Board for the Motala Municipality was formed and prevention activities in the community continued after the researchers withdrew from the project.
5. Primary care health facilities planning in Soweto, South Africa [138]: A description of the participatory principles and methods used in developing a plan for primary level health facilities in Soweto is provided. Recommendations were developed through the involvement of all stakeholders in the whole research process.

### **Measuring Success**

Participatory research is successful if all parties are satisfied with the utility of the process and the outcomes. This dynamic process involves individuals and institutions from a variety of backgrounds, with varying sets of values. The process of negotiation is not expected to be a smooth articulation of these agendas; rather, the measure of success is the level of satisfaction with the entire process and the outcomes of the research project. Satisfaction may entail acceptance of less than ideal circumstances, and extensive compromise. The highest levels of satisfaction will emerge from a research process that has included all partners to the extent that they want to participate, and which was negotiated with the agendas of each participant fully considered.[139]. The process of program evaluation is yet another opportunity for a participatory approach. Measures of success will vary with the stated objectives of the project and the long-range goals of the research partners. These may

include the establishment of a continuing research partnership on individual and/or institutional levels which addresses further shared research interests and projects. Another measure of success might be community take-over and perpetuation of the research process. Success for participatory research projects will be measured at the individual, the community and the institutional levels, by criteria established jointly and separately by the participants.

### **Validity in PR**

Some researchers, conditioned by the traditional science paradigm [43], are concerned that the PR approach implies a less rigorous methodology which could lead to less valid results. However, participatory research enhances validity by broadening the base for data collection and inclusion of contextual factors. Content validity is achieved in the depth and variety of data collected. Construct validity relates to the degree to which the research is guided by a theoretical framework. Reliability is measured by triangulation of data from more than one source and the rigor with which analysis and interpretation are undertaken [140]. Successful research is not only measured by the production of generalizable knowledge, however. PR is also measured by cultural validity, an assessment of relevance and consistency with the cultural framework in which the research is conducted. This includes the immediate usefulness of the research to the local community, through enhancing resources for community-based problem solving.[141,142].

### **CONCLUSION: PARTICIPATORY RESEARCH AND NAPCRG**

Participatory or collaborative research is aligned with NAPCRG's goals. NAPCRG supports the concept of collaboration and the utilization of participatory research for the benefit of communities and researchers. We acknowledge the PR experience of other disciplines (social science, business, nursing, agriculture, education and anthropology) and the value of a multi-disciplinary approach. As experienced primary care researchers, we recognize that the initial research question may arise from the community or the researchers, and that the research process can be negotiated to address all relevant agendas. We value the equal, trustful, and respectful partnerships between the various communities and researchers, a relationship that begins with the formulation of the research question (s). We also believe that the elements of the research process: 1) the generation of the research question, 2) the conduct of the study, 3) the analysis and conclusions, and 4) the dissemination of the results, can and must be developed in full partnership. Commitment to these principles by NAPCRG will promote responsible collaboration with communities, which in turn will improve the health of individuals, families, and communities.

### **RECOMMENDATIONS**

It is recommended that NAPCRG promote and conduct responsible research with communities by undertaking the following program of action:

1. Endorse the following ethical principles governing participatory research:
  - All participating partners must have a true desire to collaborate;
  - All partners are considered experts;
  - Power differentials among partners (gender, political, cultural) will be acknowledged and sensitively addressed to ensure a democratic research environment;
  - Communities will be fully informed of potential harm as well as potential benefits that may result from the research process; and
  - The research agenda is to be negotiated by all partners at the outset of every participatory, community-based research project.
2. Adopt guidelines for creation of research agreements, together with the resource requirements, roles and obligations of all partners for all phases of a research project, including:
  - the exact nature of the research
  - the research objectives, goals, methods and duration
  - level of confidentiality

- generation of the question(s), design, implementation, data analysis and interpretation, and dissemination of the results
  - principles guiding selection/inclusion of additional team members during the research process
  - interpretation and use of data
  - ownership and storage of data/biological samples and disposition of data and specimens after completion of research
  - dissemination of the results
  - follow-up activities.
3. Promote ethical research by encouraging researchers to:
    - provide communities with an opportunity to react and respond to the findings before the completion of the final report, in the final report and in all relevant publications that arise from the research,
    - ensure appropriate acknowledgement as co-authors, contributors, etc. of community collaborators, and
    - acknowledge and/or including in a mutually acceptable way any diverging or contentious interpretations in results reporting.
  4. Promote participatory research by:
    - soliciting papers that utilize this process for presentation at the annual meetings, e.g. concurrent session tract, workshop, or special interest groups;
    - requiring written documentation of "permission to present/and or publish" from all collaborators known to have policies regarding ownership and dissemination rights, before presentation and/or publication of research with communities;
    - encouraging other primary care organizations to support the use of participatory research and to develop policy statements and guidelines;
    - forming a network to educate and inform members, other researchers and communities regarding the principles and praxis of participatory research;
    - encouraging the inclusion of the principles and applications of participatory research in residency programs and in the curricula of health professionals;
    - advocating for the principles of participatory research at the funding agency level.
  5. Promote capacity development in participatory research by developing the following resources:
    - a framework and list of resources for resolving conflicts arising from the research process;
    - a cadre of mentors with the skills of conducting participatory research, for both researchers and communities, which would serve a mentoring function to communities and researchers for participatory research;
    - a comprehensive, multidisciplinary bibliography on the ethics and praxis of participatory research, including international sources. This database will include examples of codes of research ethics for participatory research, and examples of projects including problem solving and conflict resolution strategies. The database should be available electronically to NAPCRG members and other interested parties at no cost;
    - an electronic clearing house to match interested communities with:
      - researchers, students, advisors and consultants with complementary interests and/or expertise;
      - support services, such as translation, editing assistance, consent forms, summaries/presentations, data collection, community oriented, culturally relevant, meeting coordination and facilitation, planning needs, technical assistance development, outside researchers interest, student projects, guidelines and sample ethical requirements of various institutions and communities; and
      - identifying primary care research groups and organizations.

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## **APPENDIX**

### **Study of Participatory Research in Health Promotion**

The following guidelines can serve to appraise the extent to which research projects align with principles of participatory research.

For each guideline, check only one box. Some of the guidelines may not be applicable to the research project, in which case no boxes should be checked, or boxes labeled "Not Applicable" should be added to all the guidelines for users to check when appropriate. The categories identified by boxes for most guidelines increase in appropriateness to participatory research from left to right, but the most appropriate level for some projects on some guidelines might be more toward the middle or even to the left of the row of boxes.

### **Guidelines**

1. Participants and the nature of their involvement:
  - (a) Is the community of interest clearly described or defined?
    - no description
    - inexplicit/general
    - description
    - general description but explicit
    - general/detailed description
    - detailed description
  
  - (b) Do members of the defined community participating in the research have concern or experience with the issue?
    - no concern or experience with the issue
    - little concern or experience with the issue
    - moderate concern or experience with the issue
    - much concern or experience with the issue
    - high concern or experience with the issue
  
  - (c) Are interested members of the defined community provided opportunities to participate in the research process?

- no opportunity to participate
- little opportunity to participate
- more than one opportunity to participate
- several opportunities to participate
- many opportunities to participate

(d) Is attention given to barriers to participation, with consideration of those who have been under-represented in the past?

- no attention to offsetting barriers
- low degree of attention to offsetting barriers
- moderate degree of attention to offsetting barriers
- moderate/high degree of attention to offsetting barriers
- high degree of attention to offsetting barriers

(e) Has attention been given to establishing within the community an understanding of the researchers' commitment to the issue?

- no attention to the researchers' commitment
- low attention to the researchers' commitment
- moderate attention to the researchers' commitment
- high attention to the researchers' commitment
- explicit agreement on the researchers' commitment

(f) Are community participants enabled to contribute their physical and/or intellectual resources to the research process?

- no enabling of contribution from participants (researchers do it all)
- mostly researcher effort; some support for contribution from participants
- about equal contributions from participants and researcher
- mostly resources and efforts of participants; researchers have some direct input
- full enabling of participants' resources (researchers act only as facilitators)

2. Origin of the research question:

(a) Did the impetus for the research come from the defined community?

- issue posed by researchers or other external bodies
- impetus originated mainly from researchers; some input from community
- impetus shared about equally between researchers and community
- impetus originated mainly from community; some impetus from researchers
- issue posed by the community

(b) Is an effort to research the issue supported by members of the defined community?

- support for research from very few, if any, community members
- less than half of the community supports research on this issue
- community is roughly divided on whether the issue should be researched
- more than half of the community supports research on this issue
- support for research from virtually all community members

3. Purpose of the research:

a) Can the research facilitate learning among community participants about individual and collective resources for self-determination?

- no provision for learning process
- low provision for learning process
- moderate provision for learning process
- moderate/high provision for learning process
- high provision for learning process

(b) Can the research facilitate collaboration between community participants and resources external to the community?

- no potential for collaboration
- low potential for collaboration
- moderate potential for collaboration
- moderate/high potential for collaboration
- high potential for collaboration

(c) Is the purpose of the research to empower the community to address determinants of health?

- purpose devoid of empowerment objective
- low priority empowerment objective
- moderate priority empowerment objective
- moderate/high empowerment objective
- high priority empowerment objective

(d) Does the scope of the research encompass some combination of political, social and economic determinants of health?

- no consideration of political, social or economic determinants
- only one or two determinants are considered
- limited consideration of combined determinants of health
- moderate consideration of combined determinants of health
- comprehensive consideration of combined determinants

4. Process and context-methodological implications:

(a) Does the research process apply the knowledge of community participants in the phases of planning, implementation and evaluation?

- no use of community knowledge in any phase
- use of community knowledge in one or two phases only
- limited use of community knowledge in all three phases
- moderate use of community knowledge in all three phases
- comprehensive use of community knowledge in all three phases

(b) For community participants, does the process allow for learning about research methods?

- no opportunity for learning about research
- low opportunity for learning about research
- moderate opportunity for learning about research

- moderate/high opportunity for learning about research
- high opportunity for learning about research

(c) For researchers, does the process allow for learning about the community health issue?

- no opportunity for learning about the community issue
- low opportunity for learning about the community issue
- moderate opportunity for learning about the community issue
- moderate/high opportunity for learning about the issue
- high opportunity for learning about the community issue

(d) Does the process allow for flexibility or change in research methods and focus, as necessary?

- methods and focus are pre-determined; no potential for flexibility
- mostly pre-determined methods and focus; limited flexibility about equal blend of pre-determined methods and focus with flexibility
- high flexibility; some pre-determined methods and focus
- complete flexibility; methods and focus not predetermined

(e) Are procedures in place for appraising experiences during implementation of the research?

- no procedures for appraising experiences
- few procedures for appraising experiences
- some procedures for appraising experiences
- many procedures for appraising experiences
- comprehensive procedures for appraising experiences

(f) Are community participants involved in analytic issues: interpretation, synthesis and the verification of conclusions?

- no involvement of participants in any analytic issue
- involvement in one or two analytic issues only
- limited involvement of participants in all three analytic issues
- moderate involvement of participants in all three analytic issues
- comprehensive involvement all three analytic issues

5. Opportunities to address the issue of interest:

(a) Is the potential of the defined community for individual and collective learning reflected by the research process?

- research process not aligned with potential for learning
- limited alignment of research process with potential for learning
- moderate alignment of research process with potential for learning
- moderate/high alignment of research process with potential for learning
- comprehensive alignment of research process with potential for learning

(b) Is the potential of the defined community for action reflected by the research process?

- research process not aligned with potential for action

- limited alignment of research process with potential for action
- moderate alignment of research process with potential for action
- moderate/high alignment of research process with potential for action
- comprehensive alignment of research process with potential for action

(c) Does the process reflect a commitment by researchers and community participants to social, individual or cultural actions consequent to the learning acquired through research?

- no commitment to action beyond data collection and analysis and writing report for funding agencies
- low commitment to social actions based on learning through research
- moderate commitment to social actions based on learning through research
- moderate/high commitment to social actions based on learning through research
- comprehensive commitment to social actions based on learning through research

6. Nature of the research outcomes:

(a) Do community participants benefit from the research outcomes?

- research benefits researchers or external bodies only
- research benefits researchers/ external bodies primarily; community benefit is secondary
- about equal benefit of research for both researchers/external bodies, and community
- research benefits community primarily; benefit is secondary for researchers/ external bodies
- explicit agreement on how the research will benefit the community

(b) 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?

- no attention to or any agreement regarding interpretation issues
- low attention to interpretation issues
- moderate consideration of interpretation issues
- high attention to interpretation issues; no explicit agreement
- explicit agreement on interpretation issues

(c) Is there attention to or an explicit agreement between researchers and community participants with respect to ownership of the research data?

- no attention to or any agreement regarding ownership issues
- low attention to ownership issues
- moderate consideration of ownership issues
- high attention to ownership issues; no explicit agreement
- explicit agreement on ownership issues

(d) Is there attention to or an explicit agreement between researchers and community participants with respect to the dissemination of the research results?

- no attention to or any agreement regarding dissemination issues
- low attention to dissemination issues
- moderate consideration of dissemination issues
- high attention to dissemination issues; no explicit agreement
- explicit agreement on dissemination issues

**SOURCE:** L.W. Green, M.A. George, M. Daniel, C.J. Frankish, C.P. Herbert, W.R. Bowie, M. O'Neill, *Study of Participatory Research in Health Promotion*. Royal Society of Canada, Ottawa, Ontario, 1995, pp 43-50. Reproduced with the kind permission of the Royal Society of Canada and the authors.

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  - b. The term community is defined in this context as any group of individuals sharing a given interest; this definition includes cultural, social, political, health and economic issues that may link together individuals who may or may not share a particular geographic association. This definition also includes the traditional concept of community as a geographically distinct entity.
  - c. The term community is defined in this context as any group of individuals sharing a given interest; this definition includes cultural, social, political, health and economic issues that may link together individuals who may or may not share a particular geographic association. This definition also includes the traditional concept of community as a geographically distinct entity.
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