Engaging with Communities, Engaging with Patients:
Amendment to the NAPCRG 1998 Policy Statement on Ethical Research With Communities

Overview:
In 1998 the North American Primary Care Research Group (NAPCRG) adopted a Policy Statement endorsing responsible participatory research (PR) with communities. Eleven years later, 32 university and 30 community NAPCRG-affiliated research partners, convened a workshop to document lessons learned about implementing processes and principles of participatory research over the previous decade. Here, we reflect on the current relevance of the Policy Statement, lessons learned over time, and future directions and applications for PR in emerging areas of primary care research. We conclude that PR has markedly altered the manner in which research is undertaken in partnership with communities and that the foundational principles articulated in the policy statement remain relevant to the current PR environment. This amendment to the 1998 Policy Statement therefore endorses the ongoing relevance of that statement, presents recommendations for ongoing NAPCRG support for PR, and identifies future directions to move the field of PR in primary care forward.

In 1998, participatory primary care researchers of the North American Primary Care Research Group (NAPCRG) undertook a critical review of participatory research (PR) methods, developed a policy statement for primary health care professionals endorsing responsible PR with communities, and published a synopsis of the recommendations. This articulation of PR from the perspective of primary care emerged as part of a larger trend in public health research which has responded to a recognition that top-down research approaches had failed to generate adequate and appropriate programs addressing key population health problems. At that time, funders promoted the PR approach by establishing expectations that communities provide input regarding public health research strategies. Thus, as an early contributor to this larger trend from a primary care perspective, the NAPCRG Policy Statement (hereafter referred to as the Policy Statement) (1) established the rationale, definition, and validity of the then-emerging participatory research approach; (2) outlined the core processes of partnership development, capacity building, and conflict resolution; and (3) drew attention to the ethical considerations in conducting research with communities. This document represented a groundbreaking synthesis of the PR literature of the era and propelled the emerging science of PR forward from public health into primary health care.

In the ensuing decade, PR -- including community engaged, community partnered, participatory action, and community-based participatory research -- gained importance in clinical and public health research. Attesting to the growth of PR are systematic reviews, internationally sponsored conferences, methodological textbooks, and journals dedicated to participatory health research. These developments speak to the benefits of PR to form research partnerships that increase research relevance, give 'voice' to those affected by the issue under study and those needing to act on the results, and speed implementation of important findings.

As the perceived benefit and uptake of PR has expanded, pressing questions emerged regarding PR best practices, outcomes, and reach within primary care. The authors of the Policy Statement, additional participatory researchers, and community partners, convened a workshop in 2009 to review the key PR principles in the Policy Statement and explore application of PR in primary care. Thirteen PR teams (Table 1) represented partnerships from Canada and the United States were convened in a longhouse in Kahnawake on the outskirts of Montreal Quebec, Canada to reflect on their experience with PR over the prior decade since the development of the original NAPCRG PR policy. Participating projects had an average of 4.8 years of experience (ranging from 1-15 years, with three teams of over 10 years). The projects represented embodied a variety of health topics and a diverse group of communities defined by geography, age, gender, and ethnicity. With approval from the McGill University Faculty of Medicine Institutional Review Board and participant consent, the workshop was video-recorded, transcribed verbatim, and qualitatively analyzed by inductive thematic analysis using constant comparative techniques in the initial stages of coding, followed by inductive and deductive coding. At several subsequent stages in the iterative process, all workshop participants had opportunities to review the findings. This document has emerged with input from 14 of the original participants from that session and extensive, ongoing reflection and discussion in the ensuring years regarding the original Policy Statement, the emerging PR literature, and our own experiences. The purpose of this policy amendment is to reconsider the original 1998 Policy Statement in light of the uptake of PR since its publication and suggest future directions for PR in primary care based on these findings and reflections.
What is Participatory Research?

Key PR principles articulated in the Policy Statement include those common across participatory approaches including: (a) equitable collaboration with individuals, families, and communities affected by a health topic at all stages of the research process, from conception of the study idea through result dissemination; (b) production of knowledge and action for the purpose of improving health and health equity; and (c) promotion of increased capacity by building on existing strengths and resources. These principles continue to set PR apart from other research approaches in that the research process is driven by community-researcher collaborators working in partnerships to address pressing community-defined health problems.

PR generally identifies communities as groups of individuals holding a common identity who self-define as a community. This definition includes geographic, ethnic, and cultural communities but also may describe groups of medical providers or clinics as in practice-based research groups. Participatory approaches may be applied to any collaboration that includes those being studied, and where the collaborators share a common goal of co-defining research questions and developing projects that hold promise for action-oriented application.

Why Participatory Research in 2015?

The rationale for PR articulated over a decade ago continues to be relevant to primary care research today, particularly in translational research. Fundamentally, PR improves the quality of the research enterprise and addresses social injustices inherent in non-participative research. While egregious cases of research ethics violations may be behind us (e.g. the Tuskegee Syphilis Study), tensions between university and community-held ethical priorities and unexamined potential for stigmatization and other community-level ethics violations remain common, and can undermine communities’ willingness to participate in research. While PR will not in and of itself eliminate these ethical problems, its orientation towards social justice and commitment to researcher-community co-decision making is likely to increase researcher awareness of ethical concerns and contribute to rebuilding community trust in research.

An additional imperative for PR is to improve the quality and applicability of research products and to speed their application to community-defined problems. PR has been identified as a means to address vexing methodological and application problems in translational research that have impaired the movement of research knowledge into practice, such as lack of external validity of efficacy trials, and challenges to achieving long-term sustainability in community settings. Methodologists focused on translational research have proposed models such as RE-AIM that use participatory processes early in project inception in order to increase the relevance and usability of efficacy research and improve external validity. Similarly, PR has been proposed as a core component of dissemination research to increase the uptake of evidence-based programming across multiple communities. These and other examples of incorporating PR into more traditional research approaches are important, however additional assessment is necessary to assure that the fundamental intention and practical application of community participation is maintained within these new paradigms. The complexity of community and clinic-based translational trials where community and cultural priorities are emphasized, requires that we look towards new methodological paradigms that move beyond the randomized controlled trial. Thus the Policy Statement presages the call for practice-based evidence to inform evidence-based practice.

The State of Participatory Research in Primary Health Care

The Policy Statement offered justification for PR in primary care by linking the inclusion of community in research to the rationale for moving primary care research from tertiary care centers into practice-based primary care settings. The authors argued that in both cases the result would be a “democratization of knowledge.” Since the Policy Statement was adopted, the growth and scope of PR in primary care settings has expanded greatly. The core approaches of PR have been found to apply to translational research through Practice-Based Research Networks, as well as primary-care-driven, community-based health promotion. Additionally, philosophically similar movements that encourage a partnership and patient-centered approach for care delivery and improvement of health systems through patient-centered care and outcomes have emerged. A recent and innovative approach to development of community-focused, comprehensive care delivery has been proposed through “communities of solution” that incorporate community participation through an ecological approach consistent with PR.

Despite these advances, application of PR principles to outcomes and organizational/medical practice improvement research is still in a developmental phase, with a limited number of experienced PR partnerships working in this area. However recently, a number of funding bodies (the US Patient-Centered Outcomes Research Institute (PCORI) and Agency for Healthcare Research and Quality, the Canadian Institutes of Health Research,) have called for patient engagement in the re-design of primary care practices with the aim of reducing healthcare disparities and improving outcomes. In addition, funding opportunities have arisen that require meaningful patient
engagement in the translation of clinically-relevant science to real-life community applications (e.g., NIH Clinical Translational Science Awards; CIHR's Strategy for Patient-Oriented Research program). These new mechanisms have created the opportunity for increased focus on how to equitably involve patients and communities in research processes.

**Participatory Research Processes Then and Now**

Core processes articulated in the Policy Statement remain fundamental to PR practice. Success in PR hinges on the development of strong collaborative partnerships that are maintained through day-to-day practices that promote shared power relations within the group. Practices and values characteristic of PR include respect for individuals and their opinions, openness in access and decision making, adaptability, and trust. Adherence to these values and practices combined with the development of the interpersonal relationships that are the heart of the participatory process, increase the likelihood that partnerships will strengthen over time. At this point in the history of PR, there are increasing numbers of mature partnerships that provide opportunity to examine stages of partnership development. Partnerships that survive the test of time likely have learned that conflict is not inherently negative, but when addressed in a manner that recognizes and addresses power differentials, may be what pushes the evolution of roles and increased community responsibility within a project. Mature partnerships therefore often include researchers who have learned the skills of being malleable to timelines, power sharing, and decision-making throughout the partnership life-course.

**Partnerships evolve**

Due to the range of years in partnerships represented at the workshop, PR partners were in a unique position to reflect on the maturation of relationships in participatory primary care research. They described distinct stages of initiation, transitioning, and mature relationships characterized by increasing mutual trust and community control of the research process. While partnership stages have been described developmentally and as a function of research tasks, workshop participants emphasized interpersonal relationships as the heart of the participatory process. These interpersonal relationships evolve over time and are classified in three life-course stages:

1. **Young relationships** are not yet formalized and are characterized by participants working and learning the process together and becoming comfortable with one another. Researchers often guide initial research questions and methods, to which communities respond. The processes are inherently unequal, although people may be respectful of each other’s skills and strengths.

2. **Transitioning relationships** develop when research questions, objectives, and methods are established together in the context of initial projects. The partnerships have an identity, and community members exhibit more prominent roles and assume more control in setting research agendas than in young relationships.

3. **Mature relationships** develop over time by working together in trusting relationships on multiple projects. Community members have more control and influence in the process than researchers and successfully direct research toward community-level concerns. Mature relationships often have a formal agreement, and research results have contributed to capacity building and community change. Participants in mature relationships reported experiencing the previous stages and described a need to transcend one stage before achieving the next.

Because young partnerships may “not know what they don’t know,” they may benefit from tools that help to prompt early conversations about issues that are often contentious in PR collaborations. Both community and academic partners may also benefit from training in PR and capacity building. Mature partnerships reported sharing power and control through the development of Memoranda of Understanding (MOUs) or other formal agreements. Formal agreements promote equity and the integration of shared values into the fabric of regular partnership activities and provide a touchstone for partnerships as they move through projects and negotiate potentially contentious topics such as budgets and data ownership. These three stages should be taken as heuristic, as levels of sophistication and community ownership may vary among partnerships of all ages. As more PR examples are published, fledgling partnerships will have the opportunity to learn from others’ experiences.

**Measuring Successes in Participatory Research**

The Policy Statement emphasized that success is defined in PR by the degree to which all partners are satisfied with both the processes and outcomes of their mutual research efforts. In today’s PR environment, increased specificity in the definition of success in these two areas is important. A broad array of measures have been developed and
implemented to evaluate PR processes, but more approaches and validated tools are needed to better delineate the relationship of PR process to research outcomes across projects. In terms of PR outcomes, researchers have made headway in identifying the added value of PR towards improving the quality of interventions and increasing translation of impactful programs to communities. However, success in participatory research extends beyond the completion of projects and the production of research results. In a realist review of participatory intervention studies, Jagosh et al. found that many participants rated the research process as highly satisfactory even when other outcomes did not differ significantly between intervention and control groups, suggesting that projects are impactful even if the intervention is not successful. Success from a community perspective includes joint action towards addressing health concerns, capacity building, social change, and policy advocacy. Needed action is often the initial rationale for community engagement in participatory projects and is the outcome most sought after by communities. Since social change is both a process and an outcome of participatory research, participatory projects have the potential to be transformative on an individual, interpersonal, and community level for all partners. As outlined by workshop participants, social change starts with individuals, including changes in their status in the community, confidence, and career opportunities. Over time participating communities may evolve and changes may occur in their perceptions of health, discourse around health issues, and commitment of resources to improve health. Furthermore, PR has led to policy changes at the local community, regional, and even national levels.

Such transformations are not haphazard. Instead, the participatory research process itself, when guided by the social interactions described in participatory research guidelines like the Policy Statement, creates opportunities for profound transformation among all individuals participating in a project. Though widely acknowledged as important, and often cited anecdotally as transformative, too little attention has been given to documenting success in these participatory research outcomes. Further research is needed to better capture the personal, intrapersonal, organizational, and community level benefits that emerge from short and long-term involvement in participatory research projects.

**Summary and Updates to the 1998 NAPCRG Responsible PR with Communities Policy Statement**

The PR principles outlined in the Policy Statement have proven to be robust over time and still relevant for application across partnerships’ life-stages. Since this early work, much has been learned about the principles of community engagement, the navigation of problems that can arise, and the benefits to the research process of equitable community involvement. Many additional resources exist for researchers, community members, patients, health professionals and policy makers looking to establish PR projects including manuals, training programs, and capacity building approaches. In this reflection, we have identified a number of new best practices that support long term sustainability of research partnerships and areas for future investigation and policy building to strengthen PR in primary care over the coming years. This amendment endorses the ongoing relevance of the NAPCRG 1998 Policy Statement on Responsible Research with Communities: Participatory Research in Primary Care and offers these recommendations that NAPCRG:

**Support Best Practices from the 1998 Policy Statement that Remain Relevant:**

- PR improves the research enterprise by generating research that is relevant to and sustainable within communities;
- PR builds on existing community assets and strengthens existing resources and capacities;
- PR builds community trust in research implemented within partnerships and promotes equity;
- The way we work together matters. Explicit group processes, particularly those contributing to power sharing, communication, and capacity building, contribute to improved participant recruitment and retention, project implementation, research outcomes, and sustainability;

**Adopt Newly Identified Best Practices:**

- PR improves translational science by building in community participation throughout the research and translational processes;
- Partnerships mature over time through distinct stages that are typically characterized by increased community responsibility for all aspects of the research project, as well as the collaborative process and implementation of research outcomes;
- Conflict may have both positive and negative outcomes on research partnerships. On the positive side, conflicts may promote evolution of increasingly equitable roles;
- PR processes may be identified as addressing social determinants of health and so PR is a social justice enterprise with individual and community health benefits. Benefits are generated through the development of
new networks, formal delineation of community research capacities, and community-level change driven by opportunities for community members’ voices to be heard in the policy arena.

**Continue to Promote PR:**
- Re-endorse and prominently post the Policy Statement with this updated amendment on the NAPCRG website;
- Use annual NAPCRG meetings to highlight PR through keynote presentations, workshops, and concurrent session tracts;
- Support publication of ethics reviews and PR outcomes and processes in NAPCRG affiliated journals;
- Advocate for sustained and increased funding opportunities for PR at national levels;
- Support improved understanding of best practices for application of PR processes to clinical settings, patient-provider relationships, and practice change in order to increase utilization of patient engagement in practice improvement research;
- Support the development of methodologies that look beyond traditional randomized controlled trials towards innovative designs that acknowledge and incorporate community complexity in order to address the methodological needs of PR studies.

In conclusion, the next decade promises expanded opportunities to apply the principles and philosophies of PR to a diverse set of health arenas and problems with the goal of addressing persistent health problems across socio-economically and socio-culturally diverse communities in an era of rapid change.

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