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,[1] and published a synopsis of the recommendations.[2] This articulation of PR from the perspective of primary care emerged as part of a larger trend in public health in response to a recognition that top-down research approaches had failed to generate adequate and appropriate programs addressing key population health problems.[3] At that time, funders promoted the PR approach by establishing expectations that communities provide input regarding public health research strategies.[4-6] 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.[1] 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,[7-10] internationally sponsored conferences,[11,12] methodological textbooks,[13-15] and journals dedicated to participatory health research.[16,17] 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.[18] Thirteen PR teams (Table 1) represented partnerships from Canada and the United States were convened in a longhouse in Kahnewake 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:[10, 19,20] (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.[2,21-23] 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.[24-26] This definition includes geographic, ethnic, and cultural communities but also may describe groups of medical providers or clinics as in practice-based research groups.[27] 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[28] and unexamined potential for stigmatization and other community-level ethics violations remain common,[29] and can undermine communities' willingness to participate in research.[30] 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.[18]

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.[18,31-36] 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.[37] Similarly, PR has been proposed as a core component of dissemination research to increase the uptake of evidence-based programming across multiple communities.[38] 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.[39] 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.[40] Thus the Policy Statement presages the call for practice-based evidence to inform evidence-based practice.[41]

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,[27,42] as well as primary-care-driven, community-based health promotion.[43-47] 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.[48,49] 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.[50,51]

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.[52-54] However recently, a number of funding bodies (the US Patient-Centered Outcomes Research Institute (PCORI)[55] and Agency for Healthcare Research and Quality,[56] the Canadian Institutes of Health Research,[57]) 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).[58] 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.[26,59] 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.[10,60,61] 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.[9,60] 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[60] and as a function of research tasks,[10,61] 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.[62] Both community and academic partners may also benefit from training in PR and capacity building.[12,63,64] Mature partnerships reported sharing power and control through the development of Memoranda of Understanding (MOUs) or other formal agreements.[65] 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.[66-68]

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.[10,18] 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.[9] 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.[69]

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.[70] 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.[18] 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,[2] much has been learned about the principles of community engagement,[71] the navigation of problems that can arise, and the benefits to the research process of equitable community involvement.[9] Many additional resources exist for researchers, community members, patients, health professionals and policy makers looking to establish PR projects including manuals,[71] training programs,[12,63,64,72,73] and capacity building approaches.[72,74] 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.

Acknowledgements

This document was produced by the 2009 NAPCRG PR policy writing group: Michele L. Allen, MD, MS; Jonathan Salsberg, MA; Michaela Knot, MA; Joseph W. LeMaster, MD; Maret Felzien, MA; John M. Westfall, MD, MPH; Carol Herbert, MD; Gilbert Gonzales, MHA; Katherine Vickery, MD; Kathleen A. Culhane-Pera, MD, MA; Vivian R. Ramsden, RN, PhD; Linda Zittleman, MSPH; Ruth Elwood Martin, MD, MPH; Ann C. Macaulay, CM, MD

We would also like to acknowledge the community and academic participants in the 2009 pre-conference workshop from the following partnerships: Kahnawake Schools Diabetes Prevention Project, High Plains Research Network, Menominee: Healthy Children, Strong Families, and Supportive Communities, Walpole Island First Nations & University of Western Ontario, Healthy Youth Peer Education, Women in2 Healing, Sleep for Success, Taking Neighborhood Health to Heart, YMCA-McGill University, Go Ward One, Herzl Today, Tomorrow, and the Future, Métis Nation – Saskatchewan, Partners in Research: Maximizing Immigrant and Refugee Health.

In addition, the following individuals from the NAPCRG Participatory Research Special Interest Group have reviewed the document and offered suggestions: Jean Légaré

The entire day was videoed and can be viewed at http://pram.mcgill.ca/napcrg2009.php.

The NAPCRG Preconference workshop funded by Canadian Institutes for Health Research Meetings, Planning, and Dissemination grant FRN #40870.

References:

1. Macaulay AC CL, Freeman WL, Gibson N, McCabe ML, Robbins CM, Twohig PL,. Responsible Research with Communities: Participatory Reserach in Primary Care. http://www.napcrg.org/responsibleresearch.pdf. Accessed September, 2013.

2. Macaulay AC, Commanda LE, Freeman WL, et al. Participatory research maximizes community and lay involvement. North American Primary Care Research Group. *BMJ.* 1999;319(7212):774-778.

3. Green LW, Mercer SL. Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *Am. J. Public Health.* Dec 2001;91(12):1926-1929.

4. Bell JI, Barrett-Connor E, Berkman L, et al. *Year 5 International Review Panel Report 2000-2005.* Ottowa: Canadian Institutes of Health Research;June 2006.

5. Aungst J, Hass A, Ommaya A, Green LW, Editors. *Engaging the Public in the Clinical Research Enterprise: Clinical Research Roundtable Workshop Summary.* Washington, DC: The National Academies Press; 2003.

6. Green LW. The prevention research centers as models of practice-based evidence. *Am. J. Prev. Med.* Jul 2007;33(1):S6-S8.

7. Viswanathan M, Ammerman A, Eng E, et al. *Community-based Participatory Research: Assessing the evidence.* Rockville MD: AHRQ Publication 04-E022-2;2004.

8. Cook WK. Integrating research and action: a systematic review of community-based participatory research to address health disparities in environmental and occupational health in the USA. *J. Epidemiol. Community Health.* 2008;62(8):668-676.

9. Jagosh J, Macaulay AC, Pluye P, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q.* Jun 2012;90(2):311-346.

10. Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. *Annu. Rev. Public Health.* 2008;29:325-350.

11. Wright MT, Roche B, von Unger H, Block M, Gardner B. A call for an international collaboration on participatory research for health. *Health Promot Int.* 2010;25(1):115-122.

12. Community-Campus Partnerships for Health. Community-Campus Partnerships for Health: Transforming Communities and Higher Education. 2011; http://www.ccph.info/. Accessed October 28, 2011.

13. Israel BA, Eng E, Schulz AJ, Parker EA, eds. *Methods in Community-Based Participatory Research for Health.* 2nd ed. San Francisco, CA: Jossey-Bass; 2012.

14. Minkler M, ed *Community Organizing and Community Building for Health.* New Brunswick: Rutgers University Press; 2006.

15. Minkler M, Wallerstein N, eds. *Community-Based Participatory Research for Health.* 2nd ed. San Francisco: Jossey-Bass; 2008.

16. Fox CE. Every effect has its cause. *Prog. Community Health Partnersh.* 2007;1(1):1-2.

17. Mary Brydon-Miller, Davydd Greenwood, Maguire P. Why Action Research? *Action Research.* 2003;1:9-28.

18. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Publ Health.* 2010;100 Supplement 1:S40-46.

19. Jones L, Wells K. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA.* 2007;297(4):407-410.

20. Salsberg J, Parry D, Pluye P, Macridis S, Herbert S, Macaulay AC. Successful Strategies to Engage Research Partners for Translating Evidence into Action in Community Health: A Critical Review. *J. Environ. Public Health.* 2015.

21. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu. Rev. Public Health.* 1998;19:173-202.

22. Whyte WF, Greenwood DJ, Lazes P. Participatory action research: Through practice to science in social research. In: Whyte W, ed. *Participatory Action Research*. Newbury Park, CA: Sage; 1991.

23. Minkler M, Wallerstein, N. Introduction to Community Based Participatory Research. In: Minkler M, Wallerstein, N., ed. *Community Based Participatory Research for Health*. First ed. San Francisco, CA: John Wiley & Sons, Inc.; 2003:1-27.

24. MacQueen KM, McLellan E, Metzger DS, et al. What is community? An evidence-based definition for participatory public health. *Am. J. Public Health.* Dec 2001;91(12):1929-1938.

25. Green LW, George, M.A., Daniel, M., Frankish, C.J., Herbert, C.P., Bowie, W.R., O'Neill, M. Guidelines for Participatory Research in Health Promotion. In: Wallerstein N, Duran, B., ed. *Community Based Participatory Research for Health*. First ed. San Fransisco, CA: John Wiley & Sons, Inc.; 2003:419-428.

26. Israel B, Schulz A, Parker E, Becker AB, Allen A, Guzman JR. Critical issues in developing and following CBPR principles. In: Minkler M, Wallerstein N, eds. *Community-Based Participatory Research for Health: From Process to Outcomes*. Second ed. San Francisco: Jossey-Bass; 2008:47-66.

27. Westfall JM, Fagnan LJ, Handley M, et al. Practice-based research is community engagement. *J. Am. Board Fam. Med.* Jul-Aug 2009;22(4):423-427.

28. Harmon A. Indian Tribe Wins Fight to Limit Research of Its DNA. *New York Times*2010.

29. Ross LF, Loup A, Nelson RM, et al. Human Subjects Protections in Community-Engaged Research: A Research Ethics Framework. *Journal of Empirical Research on Human Research Ethics.* Mar 2010;5(1):5-17.

30. Physician Patient and Environmental Barriers to Clinical Trial Access in Education Network to Advance Cancer Clinical Trials (ENACCT) and Community-Campus Partnerships for Health (CCPH). Communities as partners in cancer clinical trials: Changing research, practice and policy. Silver Springs (MD): Available from: communitiesaspartners.org; 2008:82-83.

31. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *American journal of public health.* Apr 1;100 Suppl 1:S40-46.

32. Minkler M, Corage Baden A. Impacts of CBPR on academic researchers, research quality and methodology, and power relations. In: Minkler M, Wallerstein N, eds. *Community-Based Participatory Research for Health.* 2nd ed. San Francisco: Jossey-Bass; 2008.

33. Leung MW, Yen IH, Minkler M. Community based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *Int. J. Epidemiol.* 2004;33(3):499-506.

34. Wali A. Collaborative Research: A Practical Introduction to Participatory Action Research for Communities and Scholars. *Field Museum Center for Cultural Understanding and Change*. Chicago IL: The Field Museum; 2006.

35. Horowitz CR, Robinson M, Seifer S. Community-based participatory research from the margin to the mainstream: are researchers prepared? *Circulation.* 2009;119(19):2633-2642.

36. Green LW, Glasgow RE. Evaluating the relevance, generalization, and applicability of research: issues in external validation and translation methodology. *Eval. Health Prof.* Mar 2006;29(1):126-153.

37. Glasgow RE, Lichtenstein E, Marcus AC. Why don't we see more translation of health promotion research to practice? Rethinking the efficacy-to-effectiveness transition. *Am. J. Public Health.* Aug 2003;93(8):1261-1267.

38. Katz DL, Murimi M, Gonzalez A, Njike V, Green LW. From controlled trial to community adoption: the multisite translational community trial. *Am. J. Public Health.* Aug 2011;101(8):e17-27.

39. Trickett EJ. Community-based participatory research as worldview or instrumental strategy: is it lost in translation(al) research? *Am. J. Public Health.* Aug 2011;101(8):1353-1355.

40. Trickett EJ, Beehler S, Deutsch C, et al. Advancing the science of community-level interventions. *Am. J. Public Health.* Aug 2011;101(8):1410-1419.

41. Green LW. Making research relevant: if it is an evidence-based practice, where's the practice-based evidence? *Fam. Pract.* Dec 2008;25 Suppl 1:i20-24.

42. Williams RL, Shelley BM, Sussman AL, clinicians RN. The marriage of community-based participatory research and practice-based research networks: can it work? -A Research Involving Outpatient Settings Network (RIOS Net) study. *J. Am. Board Fam. Med.* Jul-Aug 2009;22(4):428-435.

43. Adams AK, LaRowe TL, Cronin KA, et al. The Healthy Children, Strong Families intervention: design and community participation. *J. Prim. Prev.* Aug 2012;33(4):175-185.

44. Allen M, Garcia-Huidobro D, Hurtado GA, et al. Immigrant family skills-building to prevent tobacco use in Latino youth: study protocol for a community-based participatory randomized controlled trial. *Trials.* Dec 19 2012;13(1):242.

45. Paradis G, Levesque L, Macaulay AC, et al. Impact of a diabetes prevention program on body size, physical activity, and diet among Kanien'keha:ka (Mohawk) children 6 to 11 years old: 8-year results from the Kahnawake Schools Diabetes Prevention Project. *Pediatrics.* Feb 2005;115(2):333-339.

46. Macaulay AC, Ing A, Salsberg J, et al. Community-based participatory research: lessons from sharing results with the community: Kahnawake Schools Diabetes Prevention Project. *Prog. Community Health Partnersh.* Summer 2007;1(2):143-152.

47. Ramsden VR, McKay S, Bighead S, et al. Participatory health research: Celebrating smoke-free homes. *Can. Fam. Physician.* Sep 2013;59(9):1014-1015.

48. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff. (Millwood).* Feb 2013;32(2):223-231.

49. Roseman D, Osborne-Stafsnes J, Amy CH, Boslaugh S, Slate-Miller K. Early lessons from four 'aligning forces for quality' communities bolster the case for patient-centered care. *Health Aff. (Millwood).* Feb 2013;32(2):232-241.

50. Griswold KS, Lesko SE, Westfall JM, Folsom G. Communities of solution: partnerships for population health. *J. Am. Board Fam. Med.* May-Jun 2013;26(3):232-238.

51. Norman N, Bennett C, Cowart S, et al. Boot cAMP translation: a method for building a community of solution. *J. Am. Board Fam. Med.* May-Jun 2013;26(3):254-263.

52. Miller WL, Crabtree BF, Nutting PA, Stange KC, Jaen CR. Primary care practice development: a relationship-centered approach. *Ann. Fam. Med.* 2010;8 Suppl 1:S68-79; S92.

53. Schmittdiel JA, Grumbach K, Selby JV. System-based participatory research in health care: an approach for sustainable translational research and quality improvement. *Ann. Fam. Med.* May-Jun 2010;8(3):256-259.

54. Glasgow RE, Green LW, Taylor MV, Stange KC. An evidence integration triangle for aligning science with policy and practice. *Am. J. Prev. Med.* Jun 2012;42(6):646-654.

55. Patient-Centered Outcomes Research Institute. 2103; http://pcori.org/. Accessed September, 20, 2013.

56. Agency for Healthcare Research and Quality. AHRQ Activities Using Community-Based Participatory Research. http://www.ahrq.gov/research/findings/factsheets/primary/cbprbrief/index.html. Accessed September 20, 2013.

57. Canadian Institutes of Health Research (CIHR). Canada's Strategy for Patient-Oriented Research: Improving health outcomes through evidence-informed care. 2013; http://www.cihr-irsc.gc.ca/e/44000.html. Accessed September 23, 2013.

58. National Center for Advancing Translational Sciences. Clinical and Translational Science Awards. http://www.ncats.nih.gov/research/cts/ctsa/ctsa.html. Accessed September 20, 2013.

59. Allen ML, Culhane-Pera KA, Pergament SL, Call KT. Facilitating Research Faculty Participation in CBPR: Development of a Model Based on Key Informant Interviews. *Clin. Transl. Sci.* 2010;3(5):233-238.

60. Allen ML, Svetaz MV, Hurtado GA, Linares R, Garcia-Huidobro D, Hurtado M. The Developmental Stages of a Community-University Partnership: The Experience of Padres Informados/Jovenes Preparados. *Prog. Community Health Partnersh.* 2013;7(3):271-279.

61. Wallerstein N, Duran, B., Minkler, M., and Foley, K. Developing and Maintaining Partnerships with Communities. In: Israel BA, Eng, E., Schulz, A., and Parker, E., ed. *Methods in Community-Based Participatory Research for Health*. First ed. San Francisco, CA: John Wiley & Sons; 2005:31-51.

62. Allen ML, Culhane-Pera KA, Call KT, Pergament SL. Partnership Checklist. 2011; http://www.ctsi.umn.edu/prod/groups/ahc/@pub/@ahc/@ctsi/documents/article/ahc_article_370767.pdf.

63. Allen ML, Culhane-Pera KA, Call KT, Pergament SL. Partners in Research: Curricula to Prepare Community and Faculty for CBPR Partnerships. 2011; http://ces4health.info/find-products/view-product.aspx?code=T63W5WBC.

64. National Institutes of Health. Community-Based Participatory Research Targeting the Medically Underserved. 2009; http://conferences.thehillgroup.com/si2009/index.html. Accessed May 7, 2013.

65. Macaulay AC, Delormier T, McComber AM, et al. Participatory research with native community of Kahnawake creates innovative code of research ethics. *Canadian Journal of Public Health-Revue Canadienne De Sante Publique.* 1998;89(2):105-108.

66. Sandoval JA, Lucero J, Oetzel J, et al. Process and outcome constructs for evaluating community-based participatory research projects: a matrix of existing measures. *Health Educ. Res.* Sep 21 2011.

67. Glasgow RE SK. How engaged are we? Measuring community engagement and partnership. *Research to Reality* 2013; https://researchtoreality.cancer.gov/node/1203. Accessed September 12, 2013.

68. S. L. Mercer, L. W. Green, Cargo M. Appendix C: Reliability-tested guidelines for assessing participatory research projects. In: M. Minkler, N. Wallerstein, eds. *Community-Based Participatory Research for Health: From Process to Outcomes.* San Francisco, CA, USA: Jossey-Bass; 2008:407–433.

69. Ramsden VR, McKay S, Crowe J. The pursuit of excellence: engaging the community in participatory health research. *Global health promotion.* Dec 2010;17(4):32-42.

70. Martin RE, Chan R, Torikka L, Granger-Brown A, Ramsden VR. Healing fostered by research. *Can. Fam. Physician.* Feb 2008;54(2):244-245.

71. Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. *Principles of Community Engagement.* NIH Publication;2011.

72. Guide to Researcher and Knowledge-User Collaboration in Health Research http://www.irsc-cihr.gc.ca/e/documents/Guide_to_Researcher_and_KU_Collaboration.pdf

73. Clinical and Translational Science Awards Consorium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. *Principles of Community Engagement.* NIH Publication;2011.

74. Allen ML, Culhane-Pera KA, Pergament S, Call KT. A capacity building program to promote CBPR partnerships between academic researchers and community members. *Clin. Transl. Sci.* Dec 2011;4(6):428-433.