



Published in final edited form as:

Prog Community Health Partnersh. 2015 ; 9(0): 1–4. doi:10.1353/cpr.2015.0022.

Community-Based Participatory Research Adds Value to the National Cancer Institute's Research Portfolio

James R. Hébert, ScD¹, Kathryn L. Braun, DrPH², Cathy D. Meade, PhD, RN³, Joan Bloom, PhD⁴, and Erin Kobetz, PhD, MPH⁵

¹South Carolina Cancer Disparities Community Network, Cancer Prevention and Control Program, Arnold School of Public Health, University of South Carolina

²Imi Hale—Native Hawaiian Cancer Network, Papa Ola L kahi, Hawai'i, and Office of Public Health Studies, University of Hawai'i at Mano

³Tampa Bay Community Cancer Network (TBCCN), Moffitt Cancer Center, Division of Population Sciences, Health Outcomes & Behavior

⁴Alameda County Network Center to Reduce Cancer Disparities, School of Public Health, University of California at Berkeley

⁵South Florida Center for the Reduction of Cancer Disparities (SUCCESS), Department of Public Health Sciences, University of Miami

Community-based participatory research (CBPR) is the core research approach used by all 23 Community Network Program Centers (CNPCs), funded from 2010 to 2015 and charged by the National Cancer Institute to reduce cancer health disparities in racial/ethnic minority and medically underserved communities across the United States. Sixteen of these CNPCs were funded under a similar initiative, called the Community Networks Program (CNP), from 2005 to 2010. All of the centers provided data, and 22 collaborated on the writing of the nine papers presented in this special issue.

Communities engaged through the CNP and CNPC initiatives often experience limited access to cancer knowledge, screening, and treatment owing to a myriad of factors, including geographic isolation, low socioeconomic status, lack of insurance, immigration status, limited English language skills, low literacy, and discrimination.^{1–8} For example, the Miami CNPC works in Haitian and Cuban immigrant communities where less than 45% of women have health insurance,⁹ and upwards of 30% of residents of the communities engaged with the Deep South CNPC live in poverty.¹⁰ These conditions contribute to stress, which further jeopardizes health through direct and indirect pathways, as illustrated in examples from CNPCs in South Carolina, Washington State, and Hawai'i.¹¹ CBPR-based approaches foster trustworthiness between high-risk communities and academic partners, especially when the population has experienced a history of discrimination and negative interactions with health care providers and researchers.^{12–14} Most important, CBPR approaches bring to light community strengths and insights that can help to accelerate improvements in health.

CBPR, which emerged from social justice and action research traditions,^{15–19} entails extensive sustained processes of community engagement. As such it is more likely than

other research approaches to benefit communities directly, largely because CBPR seeks engagement to identify relevant research questions, design feasible studies, and interpret and disseminate data, while building leadership capacity and research resources in the community.

It is acknowledged widely that CBPR provides an ethical and moral alternative to the “top-down” research approach typically seen in biomedicine. However, as noted by Hébert et al in this issue,²⁰ it also has the potential to reduce the risk of type III errors.^{15,19} These include drawing incorrect inferences from a faulty conception of how things work or selecting and/or implementing a study design that produces an answer (even if correct) to the wrong question.²¹ In other words, CBPR strategies offer great promise for addressing cancer-related health disparities in communities because they increase the 1) relevance of research questions, 2) fit of interventions for the community of interest, and 3) recruitment and retention of diverse participants, leading to materially superior scientific outcomes.^{15,18,22–24}

CBPR approaches can lead to formulating high-value research questions by engaging the community in defining and explaining the research problem or health concern. In short, research questions begin to take on new meaning and new excitement because unique and varied perspectives inform the ways that studies take shape. As the reports presented in this special issue indicate, community involvement across the research continuum facilitates greater specificity of research questions asked, and improved strategies to collect, analyze, and disseminate study data. Papers by Arevalo, Seay, Shirazi, and Hébert and their colleagues in this issue^{9,11,13,14} describe the benefit of community collaboration for identifying risk conditions associated with health disparities, as well as improving saliency of intervention design and delivery. Moreover, when community members take part in the research process and participate in studies on topics that they find interesting and important, recruitment and retention rates are higher than the norm for racial/ethnic minority involvement in research.²⁵ Still, the long-term sustainability of CBPR initiatives is not without difficulties. Partridge and co-authors¹⁰ provide an example of challenges encountered in Deep South CNPC communities when the CNPC demanded greater emphasis on controlled intervention trials, a position that departed from the expectation of the communities, which had become comfortable with CNP approaches that emphasized outreach, education, and pilot studies to reduce disparities.

CNPCs also were charged with identifying, training, and mentoring CBPR researchers. Felder and colleagues²⁶ describe the cohort of CBPR researchers and mentors associated with the CNPCs. Perhaps not unexpectedly, almost 80% of mentors were non-Hispanic White, and almost one-half were male.²⁶ However, less than 40% of early-stage/mid-career investigators and student trainees were non-Hispanic Whites, and 80% were female. Thus, the CNPCs are responsive to the federal call for increasing diversity of the scientific workforce.²⁷ This group of younger scientists is the future generation of researchers we need to equip to use CBPR approaches to confront and eventually triumph over the cancer-related health disparities seen in the United States. Yet, only 37% of trainees felt they were thriving in the academic environment. Although more research needs to be done to elucidate reasons

for this finding among CNPC trainees, other studies suggests that academia needs to more fully recognize and reward researchers engaged in CBPR.

Two articles in this special issue focus on evaluating the effectiveness of CBPR for conducting cancer disparities research.^{28,29} A qualitative analysis of the CNP final reports provides evidence of the potential of CBPR in knowledge and intervention development, improving research methods and, of even more importance to researchers, the buy-in of communities resulting in increased participation and retention.²⁹ Controlled studies of interventions often use delayed control groups so that no one is denied the opportunity to participate. Methods developed by Arroyo-Johnson and associates²⁸ focuses on individual projects within these programs.²⁸ Their experience suggests some of the challenges of operationalizing specific concepts. For example, sharing of “power, influence, and resources” can be viewed from the interpersonal level or from the locus of budgetary control.

Our work is conducted against the backdrop of two concerns expressed by the National Institutes of Health in general, and the National Cancer Institute in particular. First, there is well-placed apprehension regarding the general inability or reluctance to translate existing knowledge to places of real public health relevance and clinical need. This generalized angst about translation is warranted and is especially acute in high-risk populations such as those represented in the CNPCs.^{30,31} Second, there has been a general failure to reduce disparities in cancer-related behaviors.³² Cancer incidence and mortality rates^{33,34} have been refractory to efforts that have been used successfully in European-American populations around the country (i.e., disparities in some of our populations have actually gotten worse relative to Whites over the past several decades^{33,34}).

Clearly, both of these concerns are well-substantiated by the data and, indeed, they are related. Biomedical research has often favored working with groups that are more accessible and familiar to researchers, and these populations are predominantly White and affluent. Working solely with these groups may lead to erroneous conclusions because of exposure differences between these easier-to-get-at populations and their high-risk counterparts.³⁵ These problems also are reflected in available statistics, such as lagging accrual of minorities into clinical trials.²⁵ Because research is often designed with this intrinsic bias that results in high rates of type III error, internal validity is severely compromised. Clearly, we cannot expect to have good external validity (on which translation depends) without “getting it right” in the first place.

All competent research, including CBPR, is designed and conducted to answer important questions about disease causation, establish the magnitude of the effect of one or more risk factors on health-related outcomes, or test an intervention, or some combination of these. As the articles that comprise this special issue of *Progress in Community Health Partnerships* show, the activities of the CNPCs reflect and demand a commitment to work in partnership with communities and to collaborate in a spirit that honors meaningful engagement and capacity building for impacting health disparities.^{36,37}

Acknowledgments

Financial Support: The study was supported by National Cancer Institute grants U54 CA153461 (for the South Carolina Cancer Disparities Community Network to the University of South Carolina), U54 CA153459 (for 'Imi Hale—Native Hawaiian Cancer Network to Papa Ola L kahi), U54 CA153509 (for the Tampa Bay Community Cancer Network (TBCCN) to the Moffitt Cancer Center); U54 CA153506 (for the Alameda County Network Center to Reduce Cancer Disparities to the University of California at Berkeley); U54 CA153705 (for the South Florida Center for the Reduction of Cancer Disparities (SUCCESS) to the University of Miami).

The authors thank the members of the Community Advisory Groups of each of the projects described in this paper for their ongoing insights and generous feedback to ensure the relevance of each of the research projects for their communities.

References

1. Freedman DA, Pena-Purcell N, Friedman DB, Ory M, Flocke S, Barni MT, et al. Extending cancer prevention to improve fruit and vegetable consumption. *J Cancer Educ.* 2014; 29:790–5. [PubMed: 24748060]
2. McCracken JL, Friedman DB, Brandt HM, Adams SA, Xirasagar S, Ureda JR, et al. Findings from the Community Health Intervention Program in South Carolina: Implications for reducing cancer-related health disparities. *J Cancer Educ.* 2013; 28:412–9. [PubMed: 23645547]
3. Gwede CK, Castro E, Brandon TH, McIntyre J, Meade CD, Munoz-Antonia T, Simmons VN, et al. Developing strategies for reducing cancer disparities via cross-institutional collaboration: outreach efforts for the partnership between the Ponce School of Medicine and the Moffitt Cancer Center. *Health Promot Pract.* 2012; 13:807–15. [PubMed: 22167362]
4. Casey MM, Thiede Call K, Klingner JM. Are rural residents less likely to obtain recommended preventive healthcare services? *Am J Prev Med.* 2001; 21:182–8. [PubMed: 11567838]
5. Moscovice I, Rosenblatt R. Quality-of-care challenges for rural health. *J Rural Health.* 2000; 16:168–76. [PubMed: 10981369]
6. Nemet GF, Bailey AJ. Distance and health care utilization among the rural elderly. *Soc Sci Med.* 2000; 50:1197–208. [PubMed: 10728841]
7. Bronstein JM, Morrissey MA. Determinants of rural travel distance for obstetrics care. *Med Care.* 1990; 28:853–65. [PubMed: 2205769]
8. Coughlin SS, Thompson TD, Seeff L, Richards T, Stallings F. Breast, cervical, and colorectal carcinoma screening in a demographically defined region of the Southern U.S. *Cancer.* 2002; 95:2211–22. [PubMed: 12412176]
9. Seay JS, Carrasquillo O, Gastineau Campos N, McCann S, Amofah A, Pierre L, Kobetz E. Cancer screening utilization among immigrant women in Miami, Florida. *Prog Community Health Partnersh.* 2015; 9(Special Issue):11–20. [PubMed: 26213400]
10. Partridge EE, Hardy CM, Baskin ML, Fouad M, Willis L, James G, et al. Shifting community-based participatory infrastructure from education/outreach to research: Challenges and solutions. *Prog Community Health Partnersh.* 2015; 9(Special Issue):33–39. [PubMed: 26213402]
11. Hébert JR, Braun KL, Kaholokula JK, Armstead CA, Burch JB, Thompson B. Considering the role of stress in populations of high-risk, underserved Community Networks Program Centers. *Prog Community Health Partnersh.* 2015; 9(Special Issue):71–82. [PubMed: 26213406]
12. Braun KL, Browne CV, Ka'opua LS, Kim BJ, Mokuau N. Research on indigenous elders: from positivistic to decoloniz-ing methodologies. *Gerontologist.* 2014; 54:117–26. [PubMed: 23841952]
13. Meade CD, Rodriguez EM, Arevalo M, Luque JS, Harris N, San Miguel G, et al. Introducing biospecimen science to communities: Tools from two cities. *Prog Community Health Partnersh.* 2015; 9(Special Issue):51–59. [PubMed: 26213404]
14. Shirazi M, Engelman KK, Mbah O, Shirazi A, Robbins I, Bowie J, et al. Targeting and tailoring health communications in breast screening interventions. *Prog Community Health Partnersh.* 2015; 9(Special Issue):83–89. [PubMed: 26213407]

15. Braun KL, Nguyen TT, Tanjasiri SP, Campbell J, Heiney SP, Brandt HM, et al. Operationalization of community-based participatory research principles: Assessment of the National Cancer Institute's Community Network Programs. *Am J Public Health*. 2012; 102:1195–203. [PubMed: 22095340]
16. 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; 33:499–506. [PubMed: 15155709]
17. National Institute of Environmental Health Sciences, National Institutes of Health. Environmental justice & community-based participatory research. [cited 2008 Sep 1]. Available from: <http://www.niehs.nih.gov/research/supported/programs/justice/>
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 Public Health*. 2010; 100(Suppl 1):S40–6. [PubMed: 20147663]
19. Hébert JR, Brandt HM, Armstead CA, Adams SA, Steck SE. Interdisciplinary, translational, and community-based participatory research: Finding a common language to improve cancer research. *Cancer Epidemiol Biomark Prev*. 2009; 18:1213–7.
20. Hébert JR, Satariano WA, Friedman DB, Armstead CA, Greiner A, Felder TM, et al. Fulfilling ethical responsibility: Moving beyond the minimal standards of protecting human subjects from research harm. *Prog Community Health Partnersh*. 2015; 9(Special Issue):41–50. [PubMed: 26213403]
21. Schwartz S, Carpenter KM. The right answer for the wrong question: Consequences of type III error for public health research. *Am J Public Health*. 1999; 89:1175–80. [PubMed: 10432902]
22. Freeman HP, Reuben S. Poverty, culture, and social injustice: Determinants of cancer disparities. *CA Cancer J Clin*. 2004; 54:72–7. [PubMed: 15061597]
23. Minkler M. Linking science and policy through community-based participatory research to study and address health disparities. *Am J Public Health*. 2010; 100(Suppl 1):S81–7. [PubMed: 20147694]
24. Viswanathan, M.; Ammerman, A.; Eng, E.; Gartlehner, G.; Lohr, KN.; Griffith, D., et al. Community-based participatory research: assessing the evidence. Rockville (MD): Agency for Healthcare Research and Quality; 2004. [Report No.: AHRQ Publication 04-E022-1]
25. Greiner KA, Friedman DB, Adams SA, Gwede CK, Cupertino P, Engleman KK, et al. Effective recruitment strategies and community-based participatory research: Community Networks Program Centers' recruitment in cancer prevention studies. *Cancer Epidemiol Biomark Prev*. 2014; 23:416–23.
26. Felder TM, Braun KL, Brandt HM, Khan S, Tanjasiri S, Friedman DB, et al. Mentoring and training of cancer-related health disparities researchers committed to community-based participatory research. *Prog Community Health Partnersh*. 2015; 9(Special Issue):97–108. [PubMed: 26213409]
27. Notice of NIH's Interest in Diversity National Institute of Health. 2015. [cited 2015 Feb 5]. Available from: <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-15-053.html>
28. Arroyo-Johnson C, Allen ML, Colditz GA, Hurtado A, Davey CS, Sanders Thompson VL, et al. A tale of two Community Networks Program Centers: Operationalizing and assessing CBPR principles and evaluating partnership outcomes. *Prog Community Health Partnersh*. 2015; 9(Special Issue):61–69. [PubMed: 26213405]
29. Braun KL, Stewart S, Baquet C, Berry-Bobovski L, Blumenthal D, Brandt HM, et al. The National Cancer Institute's Community Networks Program Initiative to reduce cancer health disparities: Outcomes and lessons learned. *Prog Community Health Partnersh*. 2015; 9(Special Issue):21–32. [PubMed: 26213401]
30. Ramirez A, Perez-Stable E, Penedo F, Talavera G, Carrillo JE, Fernandez M, et al. Reducing time-to-treatment in under-served Latinas with breast cancer: the Six Cities Study. *Cancer*. 2014; 120:752–60. [PubMed: 24222098]
31. Rebbeck TR, Weber AL, Walker AH, Stefflova K, Tran TV, Spangler E, et al. Context-dependent effects of genome-wide association study genotypes and macroenvironment on time to

- biochemical (prostate specific antigen) failure after prosta-tectomy. *Cancer Epidemiol Biomarkers Prev.* 2010; 19:2115–23. [PubMed: 20826827]
32. Wells KJ, Roetzheim RG. Health disparities in receipt of screening mammography in Latinas: a critical review of recent literature. *Cancer Control.* 2007; 14:369–79. [PubMed: 17914337]
 33. Howlader, N.; Noone, AM.; Krapcho, M.; Neyman, N.; Aminou, R.; Waldron, W., et al., editors. *SEER Cancer Statistics Review, 1975–2008.* Bethesda (MD): National Cancer Institute; 2011.
 34. U.S. Department of Health and Human Services Centers for Disease Control and Prevention and National Cancer Institute. *United States cancer statistics: 1999–2010 incidence and mortality web-based report.* [updated 2014; cited 2014]. Available from: <http://www.cdc.gov/cancer/npcr/uscs>
 35. Hébert JR. Invited commentary: Menthol cigarettes and risk of lung cancer. *Am J Epidemiol.* 2003; 158:617–20.
 36. Israel, BA.; Eng, E.; Schulz, AJ.; Parker, EA. *Methods in community-based participatory research for health.* San Francisco: Josey-Bass; 2005.
 37. Israel BA, Coombe CM, Cheezum RR, Schulz AJ, McGranaghan RJ, Lichtenstein R, et al. Community-based participatory research: a capacity-building approach for policy advocacy aimed at eliminating health disparities. *Am J Public Health.* 2010; 100:2094–102. [PubMed: 20864728]