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https://escholarship.org/uc/item/3vp2q6ps

**Journal** American Journal of Public Health, 102(6)

### ISSN

0090-0036

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# **Publication Date**

2012-06-01

### DOI

10.2105/ajph.2011.300304

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# Operationalization of Community-Based Participatory Research Principles: Assessment of the National Cancer Institute's Community Network Programs

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Despite a national commitment to reduce health disparities,<sup>1,2</sup> recent studies show persistent differences in cancer incidence and mortality among racial/ethnic, social, and geographic groups.<sup>3,4</sup> Cancer-related health disparities across groups are caused by numerous interwoven factors, such as differences in environmental stressors, socioeconomic status, health care coverage, providers' racial/ethnic and social biases, access to cancer screening and care, cultural beliefs about cancer, lifestyle behaviors, participation in routine cancer screening, and biological characteristics of the cancer.<sup>5</sup> Attempts to reduce disparities through research are complicated by the fact that many vulnerable groups face a broad array of barriers that reduce their willingness or ability to participate in research.<sup>6-12</sup> For some disadvantaged communities, research has failed to address community concerns, has not benefited the community, has been exploitive, or has caused harm because findings attached unfavorable notoriety to the group.<sup>6,9-11</sup>

Community-based participatory research (CBPR) seeks to improve the capacity of research to decrease cancer rates and reduce other enduring health disparities.<sup>13</sup> CBPR emerges from the social justice and action research traditions, both of which recognize the unique strengths and perspectives of community partners and aim to produce tangible benefits for communities participating in research.<sup>14-16</sup> CBPR principles require that academic and community partners work together to design studies, collect and interpret data, and disseminate results. As a result of this collaboration, community members should gain skills and see tangible benefits of having participated. Such endeavors can improve research methods and enhance the relevance of findings.6,8,15-19

Despite these aims, there is little evidence regarding the extent to which CBPR projects *Objectives.* We examined how National Cancer Institute–funded Community Network Programs (CNPs) operationalized principles of community-based participatory research (CBPR).

*Methods.* We reviewed the literature and extant CBPR measurement tools. On the basis of that review, we developed a 27-item questionnaire for CNPs to self-assess their operationalization of 9 CBPR principles. Our team comprised representatives of 9 of the National Cancer Institute's 25 CNPs.

*Results.* Of the 25 CNPs, 22 (88%) completed the questionnaire. Most scored well on CBPR principles of recognizing community as a unit of identity, building on community strengths, facilitating colearning, embracing iterative processes in developing community capacity, and achieving a balance between data generation and intervention. CNPs varied in the extent to which they employed CBPR principles of addressing determinants of health, sharing power among partners, engaging the community in research dissemination, and striving for sustainability.

*Conclusions.* Although the development of assessment tools in this field is in its infancy, our findings suggest that fidelity to CBPR processes can be assessed in a variety of settings. (*Am J Public Health.* 2012;102:1195–1203. doi:10.2105/AJPH.2011.300304)

have involved communities in research. Processes associated with developing, implementing, analyzing, and disseminating research are poorly documented and have been infrequently evaluated across a range of CBPR projects. In their review of 60 CBPR studies, Viswanathan et al. found varying degrees of community involvement in priority setting, methods selection, proposal development and funding, study design and implementation, translation of research findings, integration and sustainability of programs, and community capacity building, all essential characteristics of CBPR.<sup>18</sup>

Recognizing the potential strengths of CBPR, in 2005 the National Cancer Institute (NCI) Center to Reduce Cancer Health Disparities funded 25 Community Network Programs (CNPs) to employ CBPR methods to reduce the unequal burden of cancer in minority and disadvantaged communities across the United States and American Samoa.<sup>20</sup> Although CNPs

were funded at different levels (by geographic scope), each CNP was charged with developing a research infrastructure that operated on CBPR principles. CNPs were required to convene a community advisory group, sponsor cancer education and outreach, train researchers and community members in CBPR methods, and conduct intervention studies. Community and academic partners were asked to work together to define research priorities in a way that was unconstrained by their biases and that afforded the freedom to address research across the cancer research continuum from discovery to dissemination.<sup>21</sup> Engaging communities in research is consistent with the NCI's commitment to interdisciplinary and team research,<sup>22</sup> intentionally extending team membership to community members who are experts in community culture and resources.

The CNPs provided an opportunity to explore how measures of adherence to CBPR principles—especially the extent to which

community members are engaged in the design and dissemination of research—can be operationalized across a diverse sample of CBPR projects. In 2009, we spearheaded a self-evaluation process among CNPs to help us understand the extent to which each network's research effort reflected CBPR principles. As part of this process, we aimed to design and field-test a quantitative tool to measure adherence to CBPR principles. We also considered how such knowledge might be used to improve participatory processes and outcomes of CBPR endeavors within and beyond the CNPs.

### **METHODS**

The principal investigators (PIs) of the CNPs appointed us (representing 9 of the 25 CNPs) to develop and implement an instrument to measure how the CNPs involved their relevant communities in accordance with CBPR principles. Five of the 9 CNPs we represent were established in 2000, and the others were established in 2005. We reviewed the literature, as well as the available instruments and their previous applications in response to NCI's funding announcement, with the goal of developing an instrument that could be used across a broad spectrum of communities and projects at different stages in their development.

The community involvement measure applied most broadly was used in a 2004 review of CBPR projects by the Agency for Healthcare Research and Quality, but that instrument was used only by the reviewers and consisted only of yes-or-no items.<sup>18</sup> The most concise statement of the domains of community involvement in CBPR projects were the 9 CBPR principles outlined by Israel et al.<sup>14</sup> These principles state that CBPR projects should

- recognize the community as a unit of identity;
- build on the strengths and resources within the community;
- facilitate a collaborative, equitable partnership in all research phases through an empowering and power-sharing process that attends to social inequalities;
- 4. foster colearning and capacity building among all partners;

- integrate and achieve a balance between data generation and intervention for the mutual benefit of all partners;
- focus on the local relevance of public health problems and on ecological perspectives that attend to multiple determinants of health;
- involve systems development in a cyclical and iterative process;
- disseminate results to all partners and involve them in the wider dissemination of results; and
- 9. involve a long-term process and commitment to sustainability.

However, the published literature did not provide guidance on how these principles could be operationalized into measures that could be used across multiple CBPR projects in different communities.

We developed a quantitative rating form incorporating the principles of Israel et al., with 3 items relating to each principle. We based our scoring system on a previously validated guideline developed by Green et al., who published a 26-item tool (each item having 5 response options) for assessing how well participatory research approaches are reflected in grant applications.<sup>23</sup> Green et al. organized their items in 5 domains:

- participants and the nature of their involvement,
- 2. origin of the research question,
- 3. purpose of the research,
- process and methodological implications, and
- 5. nature of the research outcomes.

Although the tool developed by Green et al. was not organized according to the 9 principles delineated by Israel et al., it included items relevant to several of the principles: research partnership, project relevance, colearning, and dissemination of findings. In collaboration with Green, Van Olphen et al. used this tool to evaluate a single CBPR project, but they noted the need to adapt it to better reflect the purpose and circumstances of the particular project.<sup>24</sup>

On the basis of these findings, we developed the tool to more specifically reflect the purposes of the CNPs. We organized it around the 9 principles of Israel et al., which are accepted in the field as key components of CBPR. Our research team, selected from a subset of CNPs because of our extensive experience in CBPR, developed 3 items for each of the 9 principles. For each of the resulting 27 items, we specified 5 response options to reflect low to high levels of operationalization of the principle. The tool evolved through an iterative process of review, discussion, and revision by CNP representatives. We used Excel 2007 (Microsoft Corp, Redmond, WA) in our analysis.

### RESULTS

We sent our 27-item questionnaire to the 25 CNP PIs; 22 questionnaires were returned, completed by either the PI (n=12) or the project manager (n=10) during the summer of 2010. In discussing use of their tool to assess grant proposals, Green et al. cautioned against calculating means and total scores because their response options did not follow a simple hierarchy, and the best response option would likely depend on community context.<sup>23</sup> We followed this same logic in the analysis of data collected with our tool. Thus, we reported findings as frequencies, with no attempt to rank or score responses.

### Operationalization of Community-Based Participatory Research Principles

Recognize community as a unit of identity. In CBPR projects, the community must be clearly defined and must want to engage with academics to research issues of mutual interest.14 As shown in Table 1, almost all CNPs (86%) had detailed or general definitions of their communities. Of the 22 responding CNPs, 18 focused on specific racial/ethnic groups (African Americans, American Indians and Alaska Natives, Asian Americans, Hispanics, Native Hawaiians, or other Pacific Islanders) within or across states, and 4 focused on underserved populations within specific geographic areas (e.g., Appalachia, Arkansas, Tampa, and Boston). All CNPs reported that partnering communities had expressed at least moderate interest in cancer, and all but 2 communities had expressed moderate interest in participating in cancer research. These findings were unsurprising because the CNP request for applications prompted applicants to describe the community, and letters of support were expected to demonstrate community interest in cancer and research.

### TABLE 1—Responses to Questionnaire Assessing Adherence to Community-Based Participatory Research Principles: Community Network Programs, United States (n=22)

Principles and Questions	Response Options	No. (%)
1. Recognize community as a unit of identity.		
Do you have a detailed definition of your community as an underserved	No description or definition	1 (4.5)
ethnic or geographic group? If not, do you have a detailed description of	Inexplicit or general definition	1 (4.5)
the common identity or interests that define the group as a community?	General definition but explicit	1 (4.5)
	General detailed definition	4 (18.2)
	Detailed definition	15 (68.2)
When writing your CNP proposal, did members of the defined community	No concern or experience	0
express interest in cancer health disparities? Was cancer an issue for them?	Little concern or experience	0
	Moderate concern or experience	3 (13.6)
	Much concern or experience	8 (36.4)
	High degree of concern or experience	11 (50.0)
When writing your CNP proposal, did members of the defined community	No interest	1 (4.5)
express interest in participating in cancer research?	Little interest	1 (4.5)
	Moderate interest	8 (36.4)
	Much interest	5 (22.7)
	High degree of interest	7 (31.8)
2. Build on strengths and resources of individual skills, social networks, and organizations.		
Did the community/partner provide significant input into setting CNP	Set by academic researchers and accepted	0
priorities for research projects, programs, and interventions?	by community	
	Set by academic researchers with input	3 (13.6)
	from community	
	Equal input from academic researchers	11 (50.0)
	and community	
	Set by community with input from academic	3 (13.6)
	researchers	
	Set by community and accepted by academic researchers	5 (22.7)
Did your CNP assess and document the strengths and resources of your	No documentation	0
community/partner?	Little documentation	1 (4.5)
	Moderate documentation	7 (31.8)
	Much documentation	6 (27.3)
	High degree of documentation	8 (36.4)
Did the CNP infrastructure apply the strengths and resources of the	Not applied	0
community/partner in its research projects and programs?	Applied in some	0
	Applied in half	1 (4.5)
	Applied in most	15 (68.2)
	Applied in all	6 (27.3)
3. Facilitate a collaborative, equitable partnership in all research		
phases, involving an empowering and power-sharing process that		
attends to social inequalities.		
Was a community advisory group empowered to approve, disapprove,	Not required for any projects	1 (4.5)
and recommend changes to proposals for CNP research projects?	Required for some	3 (13.6)
	Required for half	2 (9.1)
	Required for most	5 (22.7)
	Required for all	11 (50.0)

Continued

### TABLE 1—Continued

Were community members paid to serve as personnel in your CNP?	None	2 (9.1)
Among the CNP's personnel, how many were from the target community?	$\sim$ 25% of the personnel	5 (22.7)
	$\geq$ 50%, but not the PI or coinvestigator	3 (13.6)
	$\geq$ 50%, including a coinvestigator	6 (27.3)
	The PI and most other personnel	6 (27.3)
Did community groups share in research grant funds (e.g., through	Based in university; no funds to community	0
subcontracts, equipment, or incentives)? Where was the grant based?	Based in university; minimal funds to	3 (13.6)
	community	
	Based in university; moderate funds to	11 (50.0)
	community	
	Funding was split equally	5 (22.7)
	Based in a community agency, with	3 (13.6)
	subcontracts to academics	
4. Foster colearning and capacity building among all partners.	Ma anna den ite	0
For community participants in a CNP, were there processes and		0
training activities that allowed them to learn about research methods?		0
	Some opportunity	2 (9.1)
	Several opportunities	0 (27.5)
Can you site examples in which a CND community partner was	Many opportunities	14 (03.0
can you cite examples in which a cive community partner was	1 example	0
succession of an and a constraint in the own (c.g., inipioved capacity to	2 examples	1 (4 5)
provide scholes of engage in researchy:	3 examples	1 (4.3) 4 (18.2)
	>4 examples	17 (77.3)
For academic researchers in the CNP were there processes and	No opportunities	0
training activities that allowed them to learn about the culture and	Few opportunities	0
health issues of the community?	Some opportunities	3 (13.6
······································	Several opportunities	6 (27.3
	Many opportunities	13 (59.1)
5. Integrate and achieve a balance between data generation and		
intervention for the mutual benefit of all partners.		
Has your CNP helped community partners gain other resources	No assistance	0
(e.g., were they able to use research findings to draw attention to the	1 example	0
problem, write program grants, or improve services)?	2 examples	2 (9.1)
	3 examples	7 (31.8)
	$\geq$ 4 examples	13 (59.1)
Did the research enhance the community's cancer care system (e.g.,	Devolved	0
by changing policy, expanding services or funding, or increasing cultural	Unchanged by the CNP	2 (9.1)
sensitivity of services)?	Minimal improvements	4 (18.2)
	Some improvements	7 (31.8)
	Significant improvements	9 (40.9)
Have community members articulated ways their community has	No	0
benefited from the CNP (e.g., in letters of support for CNP applications)?	1 way	0
	2 ways	1 (4.5)
	3 ways	1 (4.5)
	≥4 ways	20 (90.9)
		Continued

### TABLE 1—Continued

6. Focus on local relevance of public health problems and on ecological		
perspectives that attend to the multiple determinants of health.		
Did the CNP sponsor any initiative that addressed a nonproximal	No	1 (4.5)
cause of cancer (e.g., general education, racism/stress, jobs, insurance,	1 example	1 (4.5)
income, housing, or environment)?	2 examples	10 (45.5)
	3 examples	3 (13.6)
	$\geq$ 4 examples	7 (31.8)
Did the CNP sponsor research projects and programs across the 5	Intrapersonal level	0
levels of intervention noted in the social-ecological model-intrapersonal,	Intra- and interpersonal levels	0
interpersonal, organizational, community, and policy?	3 levels	6 (27.3)
	4 levels	4 (18.2)
	5 levels	12 (54.5)
Was a major purpose of the CNP to empower the community to identify	Not at all	1 (4.5)
and address its own issues?	Community partners participated to ability	3 (13.6)
	Community partners received training to better participate	1 (4.5)
	Community partners received training and actively participated	2 (9.1)
	Community partners received training and were supported to lead	15 (68.2)
7. Involve system development through a cyclical and iterative process.		
For this CNP, how many times did academic researchers and community	Never	0
members meet to discuss, propose, review, improve, or interpret findings	Annually	1 (4.5)
related to the CNP?	Twice annually	2 (9.1)
	Quarterly	6 (27.3)
	> quarterly	13 (59.1)
Did community partners feel comfortable initiating meetings about	Extremely uncomfortable	0
the CNP or questioning aspects of CNP research and programs?	Somewhat uncomfortable	0
	Neither comfortable nor uncomfortable	2 (9.1)
	Somewhat comfortable	8 (36.4)
	Extremely comfortable	12 (54.5)
Did the iterative community-university CBPR process include sustainability	No	0
planning after CNP funding ends?	Minimal discussion at university level	1 (4.5)
	Minimal discussion between community and university	7 (31.8)
	Resources are likely to be in place to sustain the partnership	10 (45.5)
	Resources are in place, and the partnership has been sustained	4 (18.2)
<ol> <li>Disseminate results to all partners and involve them in the wider dissemination of results.</li> </ol>		
Was information about CNP programs and research projects shared with	No	0
community partners and research participants (e.g., with a CAG or through	Shared with CAG only	4 (18.2)
a newsletter, e-mail discussion list, annual report, and community meetings)?	Shared with CAG and in annual report	1 (4.5)
	Shared with CAG and through reports and newsletters	1 (4.5)
	Shared with CAG and through reports, newsletters, and community meetings	16 (72.7)
Did community members author or coauthor peer-reviewed or	Never	1 (4.5)
non-peer-reviewed publications about the CNP?	Coauthorship was the exception	4 (18.2)
	Coauthorship was expected	13 (59.1)
	Lack of coauthorship was the exception	4 (18.2)
	Coauthorship was required	0
		Continued

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### TABLE 1—Continued

Did a community member present or copresent CNP or research	Never	0
findings at meetings or conferences?	Copresentation was the exception	4 (18.2)
	Copresentation was expected	12 (54.5)
	Lack of copresentation was the exception	2 (9.1)
	Copresentation was required	4 (18.2)
9. Involve long-term processes and commitment to sustainability.		
If you are not awarded another CNP infrastructure grant, will your	No chance	2 (9.1)
CNP infrastructure continue to exist?	Little chance	3 (13.6)
	Some chance	10 (45.5)
	Good chance	7 (31.8)
	Excellent chance	0
Have community members involved in your CNP gone on to secure	No	0
grants to sustain or expand their own programs related to cancer?	1 grant	2 (9.1)
	2 grants	6 (27.3)
	3 grants	4 (18.2)
	$\geq$ 4 grants	10 (45.5)
Have junior researchers trained through your CNP or involved in your	None	2 (9.1)
research projects gone on to secure their own research funding?	1 junior researcher	3 (13.6)
	2 junior researchers	3 (13.6)
	3 junior researchers	5 (22.7)
	$\geq$ 4 junior researchers	9 (40.9)

Note. CAG = community advisory group; CBPR = community-based participatory research; CNP = Community Network Program; PI = principal investigator. For all items, the 22 respondents considered the life of the CNP. For 14 of the CNPs, the time frame was 2000-2010; for 8 of the CNPs, the time frame was 2005-2010.

Build on community strengths. An assumption of CBPR is that research will be more successful and yield more meaningful findings if it respects community values and capitalizes on the cultural assets and resources of the community.<sup>14</sup> We found that priority setting for CNP research projects and programs was dominated by the community in 8 CNPs (36.4%), grew out of equal input by community and academic partners in 11 CNPs (50.0%), and was dominated by academic researchers in 3 CNPs (13.6%). CNPs reported that, for the most part, their research projects and programs were built on community strengths. All but 1 CNP had at least moderate documentation of the community's strengths and resources.

*Facilitate a collaborative, equitable partnership that attends to social inequalities.* In CBPR, mechanisms should be in place to allow the community to influence research projects and processes<sup>14</sup>; for example, community members could participate as advisers, hired staff, or administrators and leaders of the research. CNPs were required to convene community advisory groups to influence research, but only 11 CNPs (50.0%) reported that this group was

empowered to approve, disapprove, or recommend changes to all CNP research proposals. One CNP did not require community approval for any research projects; the others required approval for some research projects (3 CNPs), half the research projects (2), or most research projects (5). Two CNPs reported having no personnel from the partnering community, and 6 (27.3%) reported that the PI and most other personnel were from the partnering community. Three CNPs were based in community agencies and subcontracted with academic researchers and institutions as needed; the other 19 (86.4%) were based in the university, with different levels of funding going to the community (3 CNPs provided minimal funding to the community, 11 provided moderate funding, and 5 provided half their funding).

Foster colearning and capacity building. CBPR projects should have mechanisms to facilitate the reciprocal transfer of knowledge and skills.<sup>14</sup> We found that all CNPs reported providing opportunities for community partners to learn about research and for academic researchers to learn about the culture and health issues of the community. All CNPs reported 2 or more examples of how community partners were strengthened by participation in the CNP.

Integrate and achieve a balance between data generation and intervention. CBPR projects should do more than produce new knowledge; they should also lead to improvements in the community.<sup>14</sup> All CNPs reported at least 2 examples of helping community partners obtain resources for cancer services. All noted that community members had said they had received benefits from CNP activities (e.g., in letters of support for subsequent CNP applications). Although 2 CNPs reported that the community's cancer care system had been unchanged by their work, 20 (90.9%) reported that the CNP's work had resulted in minimal (4 CNPs), some (7), or significant (9) improvements in the community's cancer services.

Focus on ecological perspectives that attend to multiple determinants of health. Recognizing that health is influenced by social factors as well as community factors, CBPR projects should "strive to achieve broad-scale social changes aimed at eliminating health disparities."<sup>14(p51)</sup> CNPs varied in the number of sponsored initiatives to

address nonproximal causes of cancer (e.g., general education, racism, stress, jobs, insurance, income, housing, or environment) from no sponsored initiatives (1 CNP) to 4 or more (7). No CNP reported that its projects focused primarily on the intra- and interpersonal levels of behavior change, and 12 (54.5%) reported sponsoring projects on all 5 levels of intervention described in the social-ecological model.<sup>25</sup> All but 1 CNP reported that a major purpose was to empower community to identify and address its own issues, and 15 (68.2%) trained and supported community members to serve in leadership roles.

Involve system development through a cyclical and iterative process. CBPR recognizes that it takes time spent in discussion and other aspects of engagement to develop and implement research projects that equally consider community and academic interests.14 Most CNPs (86.4%) reported participating in 4 or more community-academia meetings per year to discuss, propose, review, improve, or interpret findings related to the CNP. Most CNPs (90.9%) noted that community members were somewhat or extremely comfortable initiating meetings about the CNP or questioning CNP research and programs. However, 8 CNPs (36.4%) had initiated no discussions or minimal discussions with the community about long-term sustainability of the program.

Disseminate results, and involve partners in this dissemination. Findings from CBPR projects should be presented respectfully, with presentation and authorship opportunities for community members.<sup>14</sup> Four CNPs (18.2%) reported sharing findings only with community advisers, and 16 CNPs (72.7%) also shared findings through reports, newsletters, and community meetings. No CNPs required community coauthorship of CNP-related publications, but 17 (77.3%) reported that community coauthorship was expected. Four CNPs (18.2%) required community copresentation of CNP findings at meetings or conferences, and 14 (63.6%) expected and supported this.

Involve long-term processes and commitment to sustainability. Funding levels may fluctuate, but CBPR partnerships should continue to function, and communities should be supported in efforts to obtain their own funding.<sup>14</sup> We found that 17 CNPs (77.3%) felt they had some chance or a good chance of continuing their CNP research infrastructures after NCI funding ended. All CNPs reported that community members had secured grants to sustain or expand programs related to cancer, and 10 (45.5%) reported helping the community secure 4 or more such grants. All but 2 CNPs reported that at least 1 junior researcher had secured his or her own research funding.

### DISCUSSION

Like previous researchers who have evaluated CBPR studies, we found variation across research groups in the operationalization of CBPR principles, reflecting the diversity of CBPR partnerships and of the settings where cancer health disparities persist.<sup>18</sup> Some principles seem easier to adhere to than others. For example, we found that most CNPs scored well on recognizing the community as a unit of identity, assessing and building on community strengths, facilitating colearning, embracing iterative processes in developing research and capacity, and achieving a balance between data generation and intervention.

We found wider variation in the extent to which CNPs shared power and resources with their communities. For example, some CNPs did not employ members of the target community or empower their community advisory group to disapprove CNP research projects. Although some CBPR scientists urge that grant funds at least be shared between university and community partners,<sup>12</sup> only 8 of the 22 CNPs shared these funds. Perhaps this finding is not surprising because the CNPs were funded by NCI, with its clear research mission, and 19 of the CNPs were based in universities. Unfortunately, awards through the CNP mechanism were capped at a fixed total cost (i.e., both direct and indirect costs). Hence, university-based CNPs tended to have less money to share with the community than did the 3 community-based CNPs, although a few university-based CNPs were able to negotiate a reduced indirect cost rate.

CNPs also varied in sponsorship of projects addressing multiple determinants of health. CBPR recognizes that underserved groups are likely to live and work in risk-laden environments and may have limited access to health insurance and health care.<sup>14</sup> Some aspects of blue-collar jobs (e.g., shift work, external control of tasks) and the need to work

multiple jobs to meet financial needs can jeopardize health and reduce the amount of time available to access care.<sup>26</sup> Long-term exposure to racism and structural inequalities clearly diminish health.<sup>27</sup> Despite the value of addressing nonproximal causes of cancer and working at the policy level to improve cancer care, many CNP research projects tested interventions aimed at changing individual health behavior (albeit within the context of families, organizations, and communities) rather than at improving socioeconomic status or reducing damage from stress or racism. Efforts to address upstream determinants of health were limited by low funding levels for pilot research projects (\$50000 total cost) and by the usefulness of simple research projects that yielded early victories in training community members and junior researchers in CBPR.<sup>28</sup>

This self-evaluation of CNPs also identified several gaps in CBPR processes. Sustainability remains a profound challenge to the institutionalization of innovation.<sup>29,30</sup> Most CNPs helped community organizations and junior researchers build capacity and secure their own grants. However, it is unclear whether CNPs themselves will be sustained without continued research infrastructure funding. Although community–university partnerships can benefit both entities, maintaining these partnerships requires continued support for meetings, training, and resource sharing as new partners and junior researchers emerge.<sup>31</sup>

Development of a quantitative CBPR measurement tool that is easy to use is important for CBPR projects that lack the resources to collect in-depth qualitative data. Such a tool would allow for some standardization of how CBPR is measured across projects. The high response rate our questionnaire generated from the diverse researchers in the CNPs indicated that it is feasible to implement this tool across a wide variety of CBPR projects. Our adapted tool elicited a wide variety of responses from the CNPs and was highly useful in our self-evaluation process. Such a tool could help programs gauge the extent to which they reflect the essential components of CBPR and engage community partners.

### Limitations

The complexity of interactions between community members and the CBPR

researchers working with them will impose inherent limitations on any quantitative tool to measure adherence to CBPR principles, as will the differences among communities. Comprehensive CBPR evaluation must incorporate other methods, such as focus groups, individual interviews, ethnographic observations, and other documentation from university and community stakeholders.<sup>24</sup>

Although our evaluation tool was informed by the work of Viswanathan et al.<sup>18</sup> and Green et al.<sup>23</sup> to operationalize and quantify the participatory aspects of the CNPs, the tool could be improved. Vetting of the tool was limited to program PIs and their designees. Some items reflected CNP-specific activities (e.g., references to the CNP proposal or cancer research) that could be made more general or contextualized to other CBPR projects by replacing the term CNP with the appropriate proposal title and the topic of cancer with the appropriate topic.

Some response options were vague, such as asking whether CNPs offered no, few, some, several, or many opportunities for training. This was intentional: CNPs were funded at different levels, some focusing on 1 specific geographical community and others on regions or the entire country, precluding the use of absolute numbers in response options for some items. This illustrates a common difficulty that may be anticipated in quantifying some response options. We relied on self-report without justification of answers, and findings were likely biased in favor of the CNPs because the respondents were PIs and project managers. A potential next step is to field-test the tool with community leaders who are an integral part of the CNPs.

To improve this tool, items and associated response options should be further examined for relevance, and response options should be quantified to the extent possible. Future work should include validity testing to ensure that the items measure the 9 principles of Israel et al. and might include broader review by CBPR experts. Attention should be focused on whether criterion validity is feasible and construct validity is practicable. On the assumption that CBPR improves both participatory processes and research outcomes, future studies should examine the association between extent of CBPR operationalization and alleged or anticipated effects (i.e., constructs that would be expected to change with committed application of CBPR principles).<sup>32,33</sup>

#### Conclusions

A validated assessment tool could be used to measure CBPR operationalization in several ways. If used periodically over the course of a program, it could stimulate increased opportunities for participation and empowerment of community members and could facilitate early discussions about sustainability and expected benefits to community programs and health care systems. Asking community partners to complete the tool would allow comparison of community and academic perspectives (although Van Olphen et al. had a low response rate from community partners who were asked to complete a CBPR questionnaire<sup>24</sup>).

Our findings confirm the variability in the extent to which CBPR principles are applied in implementation of CBPR projects. Although tool development in this field is in its infancy, our results also suggest that the CBPR process can be operationalized and measured. In light of the paucity of tools to assess the participatory components of CBPR, we hope our work helps others develop, refine, and test CBPR measures.

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This article was accepted May 19, 2011.

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All authors contributed to conceptualization of the research question, construction of the framework for questionnaire design, data collection, and data interpretation. K.L. Braun, S.P. Tanjasiri, D.S. Blumenthal, and M. Hargreaves led the questionnaire design. J. Campbell led the data analysis. K.L. Braun, T. T. Nguyen, S.P. Tanjasiri, and J.R. Hébert led the writing team.

#### **Acknowledgments**

This research was supported by the 'Imi Hale Native Hawaiian Cancer Network (grant U01CA114630); the Asian American Network for Cancer Awareness, Research and Training (grant U01CA114630); the Weaving an Islander Network for Cancer Awareness, Research and Training (grant U01 CA114591); the University of Oklahoma Community Networks Program (grant U01 CA114626): the National Black Leadership Initiative on Cancer III: Community Networks Program (grant U01CA114652); the Southwest American Indian Collaborative Network (grant U01 CA114696); the Meharry Medical College-Community Health Centers Network (grant U01CA114641); the ATECAR-Asian Community Cancer Network (grant U01 CA114582); and the South Carolina Cancer Disparities Community Network (grant U01 CA114601).

**Note.** The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

#### **Human Participant Protection**

'Imi Hale Native Hawaiian Cancer Network is approved by the Native Hawaiian Health Care Systems institutional review board, which reviewed this study and determined it to be program evaluation and exempt from full review.

#### References

1. *Healthy People 2010: Understanding and Improving Health.* Washington, DC: US Department of Health and Human Services; 2000. Also available at: http://www.healthypeople.gov. Accessed November 10, 2010.

 Centers for Disease Control and Prevention. CDC health disparities and inequalities report—United States, 2011. MMWR Morb Mortal Wkly Rep. 2011;60(suppl): 1–113. Available at: http://www.cdc.gov/mmwr/pdf/ other/su6001.pdf. Accessed March 24, 2011.

 Miller BA, Chu KC, Hankey BF, Reis LAG. Cancer incidence and mortality patterns among specific Asian and Pacific Islander populations in the US. *Cancer Causes Control.* 2008;19(3):227–256.

 US Cancer Statistics Working Group. United States Cancer Statistics: 2004 Incidence and Mortality. Atlanta, GA: Centers for Disease Control and Prevention, National Cancer Institute; 2007.

5. Haynes MA, Smedley BD. *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved.* Washington, DC: National Academies Press; 1999.

 Fong M, Braun KL, Tsark J. Improving Native Hawaiian health through community-based participatory research. *Californian J Health Promot* 2003;1(spec issue):136–148.

 Larson CO, Schlundt D, Patel K, McClellan L, Hargreaves M. Disparities in perceptions of healthcare access in a community sample. *J Ambul Care Manage*. 2007;30(2):142–149.

 Larson C, Schlundt D, Patel K, Goldzweig I, Hargreaves M. Community participation in health initiatives for marginalized populations. *J Ambul Care Manage*. 2009; 32(4):264–270.

 McCallum JM, Arekere DM, Green BL, Katz RV, Rivers BM. Awareness and knowledge of the US Public Health Service syphilis study at Tuskegee: implications for biomedical research. *J Health Care Poor Underserved*. 2006;17(4):716–733.

 Mello MM, Wolf LE. The Havasupai Indian tribe case—lessons for research involving stored biologic samples. N Engl J Med. 2010;363(3):204–207.

11. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved*. 2010;21(3):879–897.

 Burhansstipanov L, Christopher S, Schumacher SA. Lessons learned from community-based participatory research in Indian country. *Cancer Control.* 2005; 12(suppl 2):70–76.

13. Gottlieb B. Community-based approaches to cancer disparities. In: Koh HK, ed. *Toward the Elimination of Cancer Disparities*. New York, NY: Springer; 2009:317–357.

14. Israel BA, Schulz AJ, Parker EA, Becker AB, Allen AJ, Guzman R. Critical issues in developing and following community based participatory research principles. In: Minkler M, Wallerstein N, eds. *Community-Based Participatory Research for Health*. San Francisco, CA: Jossey-Bass; 2003:47–66.

15. 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–S87.

 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–S46.

17. Heiney SP, Adams SA, Wells LM, Johnson H. Evaluation of conceptual framework for recruitment of African American breast cancer patients. *Oncol Nurs Forum*. 2010;37(3):E160–E167.

 Viswanathan M, Ammerman A, Eng E, et al. Community-Based Participatory Research: Assessing the Evidence. Rockville, MD: Agency for Healthcare Research and Quality; 2004. Evidence report/technology assessment no. 99.

19. Israel BA, Eng E, Schulz AJ, Parker EA. Introduction to methods in community-based participatory research for health. In: Israel BA, Eng E, Schultz AJ, Parker EA, eds. *Methods in Community-Based Participatory Research for Health*. San Francisco, CA: Jossey-Bass; 2005:3–26.

20. National Cancer Institute; Centers to Reduce Cancer Health Disparities. *Community Network Programs*. Available at: http://crchd.cancer.gov/cnp/background.html. Accessed Nov 2, 2010.

 Hébert JR, Brandt HM, Armstead CA, Adams SA, Steck SE. Interdisciplinary, translational, and communitybased participatory research: finding a common language to improve cancer research. *Cancer Epidemiol Biomarkers Prev.* 2009;18(4):1213–1217.

22. *NIH Roadmap for Medical Research*. Bethesda, MD: National Institutes of Health; 2008.

23. Green LW, George MA, Daniel M, et al. Guidelines for participatory research in health promotion. In:

Minkler M, Wallerstein N, eds. Community-Based Participatory Research for Health. San Francisco, CA: Jossey-Bass; 2003:419–428.

24. Van Olphen J, Ottoson J, Green L, Barlow J, Koblick K, Hiatt R. Evaluation of a partnership approach to translating research on breast cancer and the environment. *Prog Community Health Partnersh.* 2009;3(3):213–226.

25. McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. *Health Educ Q.* 1988;15(4):351–377.

26. Huisman M, Van Lenthe F, Avendano M, Mackenbach J. The contribution of job characteristics to socioeconomic inequalities in incidence of myocardial infarction. *Soc Sci Med.* 2008;66(11):2240–2252.

 Thomas SB, Quinn SC, Butler J, Fryer CS, Garza MA. Toward a fourth generation of disparities research to achieve health equity. *Annu Rev Public Health*. 2011;32:399–416.

28. Mitchell RE, Florin P, Stevenson JF. Supporting community-based prevention and health promotion initiatives: developing effective technical assistance systems. *Health Educ Behav.* 2002;29(5):620–639.

29. Scheirer MA. Is sustainability possible? A review and commentary on empirical studies of program sustainability. *Am J Eval.* 2005;26(3):320–347.

30. Altman DG. Challenges in sustaining public health interventions. *Health Educ Behav.* 2009;36(1):24–28.

 Silka L, Renault-Caragianes P. Community–university research partnerships: devising a model for ethical engagement. *J High Educ Outreach Engagem*. 2006; 11(2):171–183.

32. Evans WJ. Construct validity of the Attitudes About Reality Scale. *Psychol Rep.* 2000;86(3 pt 1):738–744.

 Smith TW, Frohm KD. What's so unhealthy about hostility? Construct validity and psychosocial correlates of the Cook and Medley Ho Scale. *Health Psychol.* 1985;4(6):503–520.