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Resource Paper

# Creating Community Criteria for Research Participation at Community Health Centers

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## Abstract

Research conducted to benefit communities is often done without community involvement, threatening its relevance for the groups the studies purport to serve. A great need exists for education of both researchers and community members on how research can be more appropriately conducted in partnership with community members. This paper presents Community Criteria for Research Participation developed by community health centers (CHCs) with input from academic partners to support CHCs' capacity to conduct research of community significance.

## Introduction

Research efforts to improve health and decrease health disparities, particularly for Asians, Native Hawaiians, and Pacific Islanders have traditionally been conducted through academic institutions. Despite rigorous scientific efforts and incremental improvements, health inequities have not been eliminated (Horowitz, Robinson, and Seifer, 2009) and continue to persist in indigenous and immigrant populations (Hune and Kagawa-Singer, 2011; Look et al., 2013). Increasing attention and recognition have been focused on identifying and assessing the nonclinical circumstances that impact the prevention and control of complex health conditions. These social determinants of health (SDOH) are the social, economic, educational, spiritual, environmental,

and political circumstances that impact places where we live, work, play, and pray.

Health care providers and researchers are recognizing the need to address and improve these SDOH to affect significant change in complex health conditions and thereby reduce health disparities (Hartwig, Calleson, and Williams, 2006; Horowitz et al., 2009; Hune and Kagawa-Singer, 2011; Look et al., 2013; Ro and Yee, 2010). However, equitable community participation in research is critical in identifying SDOH barriers and strategies to address these barriers. Hence, education on how research can be appropriately conducted in partnership with community members is essential.

## Background

Community health centers (CHCs) provide primary health care to over 21 million underserved patients who are disproportionately low-income, uninsured or publicly insured, have limited English proficiency, are racial/ethnic minorities, and/or tend to suffer from poorer health than the general population (Health Resources and Services Administration, 2012). Hence, CHCs have become the mainstay of the nation's safety net for medically underserved populations. CHCs frequently engage in research efforts and have the potential to improve health services, address health inequities, translate research findings to their patient populations, and disseminate information to their communities. Significant CHC and community involvement can generate scientifically sound research and make the research products user friendly, relevant, applicable, and culturally appropriate.

Conducting research in the CHC setting is particularly critical for the medically underserved populations the CHCs serve, given the limited information available about this population's health conditions and effective interventions. However, most CHCs lack the resources and infrastructure necessary to adequately develop, implement, and sustain research. A unique network of CHCs and universities was established in 2010 through the Community Health Applied Research Network (CHARN) (<http://www.kpchr.org/charn>), which is funded by the Health Resources and Services Administration (HRSA), to build capacity to conduct patient-centered outcome research in order to improve patient care at federally supported CHCs. Four research node centers and one data coordinating center comprised CHARN. The authors of this resource paper rep-

represent the Association of Asian Pacific Islander Community Health Organizations (AAPCHO) node, which includes CHCs serving primarily an Asian, Native Hawaiian, and Pacific Islander population.

To inform CHARN research training programs and other capacity building efforts, all four nodes (across the nation) and the data coordinating center collaboratively developed and implemented the CHARN needs assessment staff survey, which investigated CHCs' current involvement in research activities (Song et al., in press). This survey also investigated CHCs' research training, technical assistance, and resource needs, including preferred information type and content, strategies for translating research findings to the clinical setting, and current level of infrastructure for general and clinical research activities.

Results from the survey showed that the network participants were particularly interested in learning about training needs and gaps at the CHARN CHCs. Responses from AAPCHO-member CHC staff (N=40) highlighted their interest in receiving research-related trainings. Over half of AAPCHO survey respondents reported that they had not received any research-related training in the past three years. When asked about effective training methods, responses were highly in favor of workshop/seminar format (97%) as compared to webinar (59%) and toolkit/resource manual (56%). In addition, staff indicated that relevance to work (82%) and real world examples (53%) were the most important factors to make the trainings effective. Further response highlights are shown in Table 1. In response to these results, the AAPCHO node, including participating CHCs, organized and conducted a research training workshop in August 2012 tailored to CHCs, including some of their community leaders.

## Methods

A CHC network, spearheaded by AAPCHO, came together to identify the structure and topics that would be of benefit to the communities served by CHCs through a two-day research training. Four CHCs, including Asian Health Services (CA), Charles B. Wang Community Health Center (NY), Waianae Coast Comprehensive Health Center (HI) and Waimānalo Health Center (HI), and their collaborating academic partner, University of California, Los Angeles (UCLA) developed and facilitated this research training.

The four CHCs have a long history of working collaboratively on multiple research projects. These CHCs have well to fairly estab-

Table 1. AAPCHO Node Needs Assessment Survey Results (N=40)

Question	Total Count	Percent
1. In general, what made the partnership with external researchers challenging (top 4 responses) (N=30)		
a. The resources were not equitably shared	14	46.7
b. The researchers did not understand our community	13	43.3
c. The researchers did not understand our priorities	13	43.3
d. The partnership took up more staff time than it was worth	13	43.3
2. What role do you or your staff take when conducting research? (N=38)		
a. Carry out the research work and data collection	27	71.1
b. Serve as a site for recruiting research participants	26	68.4
c. Serve as a site for conducting research	25	65.8
3. Have you received any research-related training in the past three years? (N=38)		
a. No	21	55.3
b. Yes	17	44.7
4. How were the trainings (you received) effective? (N=17)		
a. The curriculum was relevant to my work	14	82.4
b. The curriculum included real world examples	9	52.9
5. What training, technical assistance, or resources of interest (would you like to receive) for CHCs to support participation in research? (N=34)		
a. Finding and capitalizing on funding opportunities	31	91.2
b. Sustaining programs and initiatives	30	88.2
c. Grant writing for research and evaluation	30	88.2

lished research infrastructures to identify, review, and implement research projects on their own and gain community input through community advisory groups or patient councils. They have served their communities of predominantly Asians, Native Hawaiians, and Pacific Islanders for more than twenty to forty-two years. A high percent of patients are served in a language other than English and have incomes at or less than 100 percent of the federal poverty level. Table 2 describes additional patient characteristics of these CHCs.

### **Selection and Description of Participants**

The four AAPCHO nodal CHCs wanted to ensure that CHC staff and community members had an opportunity to share their thoughts, ideas, lessons, and challenges about designing, implementing, and participating in research within their CHCs and respective communities. CHC staffs from various job classifications (i.e., research and nonresearch staff) and respective community members interested in research and/or involved in the implementation of research were invited to participate in person. Staff from three additional CHCs in Hawai`i attended the training. Research consultants from UCLA, Asian Health Services, other CHARN nodes (Alliance of Chicago Community Health Services), and the CHARN data coordinating center were also invited to participate. A total of thirty-six participants were involved in this two-day training.

### **Training Setting**

It was important to the participating CHCs that this training occurred in the community to ensure that the flow of information and knowledge moved from the community to the researchers. Hosted by their respective CHCs in the State of Hawai`i, the training occurred in two communities. Located on the west side of the island of O`ahu, Waianae Coast Comprehensive Health Center (WCCHC) hosted the first day of training. Established in 1972 and serving primarily an indigenous Native Hawaiian population, the WCCHC has been involved in community-based participatory research (CBPR) since 1985, when it collaborated with the University of Hawai`i to investigate cancer incidence among Native Hawaiians. In 1990, it received a five-year grant from the National Cancer Institute to conduct a CBPR project on breast and cervical cancer screening. Staff and community advisory committee members involved in this project developed a set of guidelines for commu-

**Table 2. Patient Characteristics of the AAPCHO CHARN Community Health Centers (Health Resources and Services Administration, 2012)**

CHC	AHS	CBWCHC	WCCHC	WHC
Total # of patients	24,387	44,787	31,152	4,312
% Asians	94%	96%	15%	9%
% Native Hawaiians	0.07%	0.03%	53%	52%
% Pacific Islanders	0.06%	0.00%	12%	14%
% Patients at or below 100% FPL	54%	74%	70%	77%
% Uninsured	40%	25%	11%	30%
% Medicaid	33%	59%	58%	50%
% Patients best served in language other than English	67%	89%	0.40%	2%

AHS=Asian Health Services, California; CBWCHC=Charles B. Wang Community Health Center, New York; WCCHC=Waianae Comprehensive Coast Health Center, Hawai'i; WHC=Waimanalo Health Center, Hawai'i

nity research that formed the foundation for research conducted at the WCCHC. Since that time, the WCCHC has collaborated on research grants addressing health disparities and has developed a Research Committee and a community Institutional Review Board (Oneha, Proser, and Chang-Weir, 2012) to review all research projects involving WCCHC staff and patients. A Community Advisory Group also provides consultation or expertise to researchers on how best to engage the community or community members as it pertains to particular research topics.

Located on the southeast side of the island of O`ahu, Waimānalo Health Center (WHC) hosted the second day of the training. Incorporated in 1989, WHC saw its first patient in 1992 and also serves primarily an indigenous Native Hawaiian population. WHC has also collaborated on research projects addressing health disparities and joined the AAPCHO node in the last year (2012) of the CHARN project. Within that year, research policies and forms were developed and a committee to review research proposals was established. Though located on opposite sides of the island, both communities and health centers have a long-lasting relationship, a relationship held together

by friendship and trust that creates a safe space to invite community participation. In an effort to respect diversity, understand differences, and continue working for the benefit of communities, a community participant (and a coauthor on this paper) from Wai`anae opened the training with this poem:

He Alo a He Alo (Face to Face)  
That's how you learn about what makes us weep

He Alo a He Alo (Face to Face)  
That's how you learn about what makes us bleed

He Alo a He Alo (Face to Face)  
That's how you learn about what makes us feel

What makes us work  
What makes us sing  
What makes us bitter  
What makes us fight  
What makes us laugh  
What makes us stand against the wind  
What makes us sit in the flow of power  
What makes us, us

Not from a distance,  
Not from miles away  
Not from a book  
Not from an article you read  
Not from the newspaper  
Not from what somebody told you  
Not from a "reliable source"  
Not from a cliff  
Not from a cave  
Not from your reality  
Not from your darkness

But, He Alo a He Alo (Face to Face) (Burgess, 1991)

### **Goal of the Training**

The goal of the training was to increase CHC and academic partner research capacity by developing a set of research criteria that CHCs, academic partners, and communities could use to evaluate their participation in research studies. The training was also motivated by lessons learned from past research projects, which underscored the need for more value-based, community-centered research as well as balanced partnerships. The training also pro-



vided an opportunity to test the criteria with four research concept proposals submitted by the four nodal CHCs.

A concept proposal template was distributed to each CHC team prior to the training. Each CHC team was asked to come up with a mutually agreed upon, one-page concept related to patient-centered outcomes research.

AAPCHO and the four nodal CHCs developed the agenda, which included panel sessions by CHC staff and community members. The panel sessions included topics on CHC staff experiences with research projects, building the research infrastructure at CHCs, and engaging community members in research. The panel of research consultants then summarized and presented comments on what was shared in the prior “Research Capacity Building at CHCs,” “CHC Staff’s Experience with Research,” and “Engaging Community Members in Research” panels. This summary initiated the development of the Community Criteria for Research Participation. On the second day, pilot research projects identified by the four nodal CHCs were presented to the large group and then discussed within each CHC team with a research consultant. The draft Community Criteria for Research Participation was reviewed during these discussions to refine the pilot research projects.

## Results

This two-day training successfully demonstrated that community members, CHC staff, and researchers can come together comfortably in an interactive, colearning environment, where the community is the lead and the researcher is the listener. This process also helped to set the tone of giving community members and CHC staff voice to compile principles for research participation. Two primary outcomes resulted from this training: (1) the empowerment of community members and CHC staff and (2) the development of the Community Criteria for Research Participation.

### **Empowerment of Community Members and CHC Staff**

Responses from community members and CHC staff indicated that the training process was empowering. Critical to this sense of empowerment were the training being situated in communities where community members come from, where they live, go to school, where the perspective of the problem is understood and articulated through their eyes; the creation of an intimate setting

versus a large conference, with time to listen and develop solutions and the intention to focus and begin with the community. As one community member shared,

A lot doesn't begin at the community, unless you're intentional, thinking, feeling, and weeping together. Bringing all these people together was critical, in one place, within communities. Funding is not enough, money is not enough, stand with us face to face. Get to the eye level of the community, what are they seeing, feeling, and saying. Where are we today in empowering community to lead, participate, and be involved in research?

A CHC staff member shared,

We're often focused on the outcome of the research and rarely feel the importance to have such an open forum where all partners of the research team share, listen, and reflect in order to bring change. We felt like what we shared could possibly impact/change future implementation of similar projects. In my mind, I truly believe that change can only take place when someone is willing to share, others are willing to listen (even if it's not what they want to hear), and in the end, both groups come back together to generate new ideas for improvement based on the discussion.

Another aspect critical to community empowerment was participant representation and diversity. This training reflected the diversity of race/ethnicity, which is critical to addressing health inequities in our communities.

The training process served as an opportunity to empower communities and CHC staff from different job roles (ranging from physicians and high-level administrators to front-line staff) to lead, participate, and be involved in research. After the training, a CHC staff reflected,

What I felt most strongly about in coming to Hawai'i was that I needed to represent my project team and the need to convey to the group the importance of each team member that was involved and the role(s) that they played, regardless of where they stand in the academic or organizational hierarchy. Having started as a frontline staff, I've felt and experienced the everyday challenges we face in our work setting, and that is something that should not be overlooked. In fact, staff experience and workflow issues should have direct impact on

research design and implementation because the success of the project not only depends on the researchers but the well-being of each and every team member that's involved.

This was definitely an eye-opening experience and certainly changed my attitude towards research from wanting to stay away from it at all cost because of the challenges involved versus wanting to participate and expecting that people are willing to work on finding solutions to those challenges.

Importantly, while the participating CHCs differ from one another in terms of geography, culture, patient population, development of internal research infrastructure, and history of collaboration with universities, they had strikingly similar experiences in working with academic researchers on prior CBPR-type research grants. This could also contribute to the empowerment aspect of training participants, as participants recognized the trend in their experiences, which further reinforced the need for developing community criteria, as one community member stated: "If the problem is in the community, the solution is in the community. Understanding the community is essential. We need to recognize the role of the community in research, and we need to change the metrics of research to capture the value of research in the community."

### **Community Criteria for Research Participation**

The research training, as the venue for developing the community research participation criteria, was the natural next step toward establishing these principles. The AAPCHO CHCs have a long history of engaging in research that examined challenges related to community equity, engagement, and accountability. The needs assessment survey (Table 1) identifies challenges offered by AAPCHO CHC respondents to partnering with external (non-CHC) researchers, including the following, as asked on the survey: "inequitable sharing of resources," "researchers did not understand our community," "researchers did not understand our priorities," and "the partnership took up more staff time than it was worth."

Many challenges have been identified in the execution of CBPR within the research partnership, such as trust; decision making; satisfaction; stability of the research team; methodological issues; the limited applicability of findings to other populations when the research is tailored to meet the needs, resources, and priorities of the partnership; differing assumptions, values, and beliefs; inflex-

ible institutional rules that make it difficult to promote equity and redirect power to all partners; priorities not aligned with funding agency; and balancing responsibilities between the primary agency and the partnership (Lazarus et al., 2012; Oneha and Beckham, 2004; Oneha and Dodgson, 2014; Shoultz et al., 2006; VanDevanter et al., 2011). This research training presented an opportunity to address these challenges and initiate systemic change through the development of Community Criteria for Research Participation.

The criteria (Figure 1) are rooted in the CBPR model of research in which communities actively and equitably engage in the research process (Horowitz et al., 2009; Israel et al., 1998, 2008; Macaulay et al., 1999; Matsunaga et al., 1996; Shoultz et al., 2006). The criteria were designed to ensure that research on communities of focus was relevant and directly beneficial to the community being studied. The community criteria were further refined after the training when five categories emerged: 1) community involvement in designing the community project, 2) alignment with the mission of the CHC and its consumers, 3) equitable and balanced budget allocation between partners, 4) accountability to the community and not just the funding agency, and 5) mutually agreeable standards for research collaborations between partners. Criteria under each category were collaboratively identified and described from training participants. These criteria could assist institutions or organizations interested in partnering with CHCs or community-based organizations, or those organizations interested in making funding available to focus on specific community groups, evaluate the community relevance, equity, and accountability of their proposal to determine whether the invitation to participate in research meets these criteria. The Community Criteria for Research Participation has been disseminated at national conferences and shared with community organizations. The community criteria can also be accessed at the AAPCHO website ([http://www.aapcho.org/resources\\_db/community-criteria-for-research-participation/](http://www.aapcho.org/resources_db/community-criteria-for-research-participation/)).

## Discussion

Developing the community criteria for research participation is a critical step for these CHCs as they continue to devote efforts to increase research capacity at their respective sites. This training served to illustrate the importance and relevance of community input when developing criteria for a community-based activity to address health

## Figure 1. Community Criteria for Research Participation

### Community Involvement in Designing the Community Project

1. Recognizes community expertise, gives voice and value to the community
2. Community is engaged throughout entire research process such that equal value is placed on community vs. academic expertise
3. Has clearly specified community relevance and impact
4. Includes processes that are collaboratively developed with the community and includes protections for the researcher, community partners, and the researched
5. Includes investigators who have previous experience working within the community and who have a true desire to learn from the community
6. Includes plan for community training and monitoring of “knowledge gained” and capacity building
7. Includes appropriate language when referring to the community (e.g., “participants” instead of “subjects”)
8. Includes CHC staff, such as front-line staff and/or community members in planning and all phases of research
9. Includes CHC or community principal investigator (as co-PI) in research

### Alignment with the Mission of the CHC and Its Consumers

1. Includes research plan that is part of CHC executive priorities or organizational roadmap
2. Views CHC/consumer as an equal partner in the proposed research
3. Designed in a way that will be sustainable (staff research skills or intervention, if proved effective and efficacious) to the CHC
4. Includes goals of value to CHC and community to the extent that CHC is committed to investing in it in the future, even after project ends
5. Includes training to raise capacity of staff and community

### Equitable and Balanced Budget Allocation Between Partners

1. Includes allocation in budget reflecting the cost of CHC staff for research implementation, including recruitment, data collection, data management/analysis, interpretation, and dissemination to the community
2. Includes a balanced budget that reflects the strengths and expertise of CHCs and consumers
3. Includes allocation in budget for community advisory group or community member FTE support
4. Includes allocation in budget for indirect costs like space for research implementation at the CHC

#### Accountability to the Community and Not Just the Funding Agency

1. Provides research that will make a contribution and prove value to community, not just to the research world
2. Provides research that is pertinent to and reflective of lived community experiences
3. Includes clear plan for how knowledge or research findings is to be shared with the community
4. Includes plan for how to mobilize the community for social change (e.g., training for “change agent” skills)
5. Incorporates community events and initiatives as well as popular and ethnic media and literature, not just peer-reviewed publications and conferences, in its dissemination strategy
6. Includes plan for research funder to visit and better understand the community
7. Includes a mechanism for community to reach out to funders in case of unresolved issues, if the main study contact is not the community
8. Includes plan for how research findings will be used for social change to inform practice and policy as well as improve health equity

#### Mutually Agreeable Standards for Research Collaborations Between Partners

1. Includes a Memorandum of Agreement (MOA) between all partners in the project (e.g., the CHC, academic institution), not just a letter of support
2. Includes roles and responsibilities that are clearly laid out in a manual of operations that is available in case of staff turnover
3. Includes plan for orientation for all staff involved that includes sharing of history and values
4. Minimizes disruption of clinic workflow and thus patient direct care
5. Includes a mutually acceptable plan for monitoring/evaluating partnership development and project advancement as well as publication participation from the inception of the paper(s)
6. Includes plan for project risk management (e.g., how to resolve specified potentially challenging issues that arise)
7. Includes plan for workforce development, including training on project management, contract negotiation, and conflict resolution.

The Community Criteria for Research Participation, developed August 2012 in Hawai'i, by CHC, community, and academic partners associated with AAPCHO and CHARN. Access document at: [http://www.aapcho.org/resources\\_db/community-criteria-for-research-participation/](http://www.aapcho.org/resources_db/community-criteria-for-research-participation/).

inequities. The training provided a valuable opportunity for CHC staff and their research allies to share research experiences and the lessons learned, to identify values that would ground the CHCs in their decision-making around research participation, and most notably, to collectively develop such criteria. For some CHC staff, the colearning, less didactic approach of this training provided them with a safe space to discuss “negative experiences” with research that they previously had not been able to express. As a result, these staff members felt empowered to share their stories and insights and had renewed hope about the prospects that research can bring if done through a truly collaborative and community-based approach. Furthermore, the diversity of training participants with respect to race/ethnicity as well as the positions they held at their respective organizations reinforced that equal value should be placed on not just the different partners (research and community), but also on the different players within these entities. Of importance, the training also provided a space for CHC staff to network with others from the local community, other CHCs, and potential research partners, as well as to step outside of their specific experiences and even their own CHCs to evaluate the critical role that community plays in health disparities research. This experience underscored the importance of empowering community members and CHC staff and reminding them that they contribute to the science in a significant way. This realization might be the first step in addressing social change and developing community responsive health programs. Creating a colearning environment for researchers, community, and CHC staff helps to address challenges when conducting Community Based Participatory Research.

This experience was structured within a western framework of panels, presentations, and discussions about community criteria in response to the western mainstream funding sources and research standards. If we are to successfully respond to health inequities, particularly for indigenous peoples and immigrant populations, future efforts need to engage communities through their language, place, values, and practices (Chino and DeBruyn, 2006). Understanding and responding to the proximal (i.e., conditions that have a direct impact on physical, emotional, mental, or spiritual health, such as health behaviors, employment, income, etc.), intermediate (i.e., the origin of those proximal determinants, such as the health care system, environmental stewardship, cultural continuity, etc.), and distal

(i.e., political, economic, and social contexts that construct both intermediate and proximal determinants, such as colonialism, self-determination, etc.) determinants of health (Reading and Wien, 2009) can only be accomplished if we are immersed in the social-political-environmental structures communities live in to survive. Communities have their own borders, priorities, ways of negotiating entry, language or codes, and analysis of self-determination (Smith, 1999). Immersion into this community-specific participatory context over time enhances the skills of the researcher and nurtures his or her relationship with the community. This relationship requires more than “token” participation from letters of support (without resources), data, and/or publication sharing; it requires a conscious redistribution of power allowing for full and equitable community participation (Arnstein, 1969). Knowledge creation, particularly with distinct and nonwestern racial or cultural groups, requires understanding of their worldview, like “walking in another’s shoes” (Umemoto, 2001). Community-led processes shift the locus of power to the community members, mobilize their collective voice, and have the potential to be far more transformative than an imposed process (Umemoto, 2001). The community and relational processes cultivated during a research project are just as important as the outcomes of the research. Community members and researchers learn from each other and can communicate and accommodate other worldviews as a consequence of participating within this framework.

A critical next step in building the research capacity of CHCs and raising the impact of health disparities research efforts is to identify community criteria for research focused on indigenous or immigrant models of reality, as lived within specific communities.

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