

Community Research Participation Criteria for Community Health Centers

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WAIMĀNALO
HEALTH CENTER

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AAPCHO

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About AAPCHO

- Association of Asian Pacific Community Health Organizations
- Non-profit national association established in 1987 with a mission to improve health status and access of Asian Americans, Native Hawaiians and other Pacific Islanders.
- Represents 33 community health organizations, mostly FQHCs serving primarily medically underserved Asian Americans, Native Hawaiians and Other Pacific Islanders.



A lot doesn't begin at the community, unless you're intentional, thinking, feeling, and weeping together.

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?

Community member, Wai`anae, HI



AAPCHO

Presentation Overview

- Purpose of Training
- Participants Involved
- Methods we used to solicit input
- Community Criteria for Research Participation
- Questions



Background: Traditional Research vs. CBPR

Traditional	CBPR
Researcher defines problem	Community identifies problem or works with researcher to identify problem
Research IN or ON the community	Research WITH community as full partner
People as subjects	People as working together
Community organizations may assist	Community organizations are partners with researchers
Researchers gain skills & knowledge	Researchers & community work together to help build skills in the community
Researchers control process, resources & data interpretation	Researcher & community share control equally
Researchers own data, control use & dissemination	Data is shared, researchers and community decide its use and dissemination



Background

Community Health Applied Research Network (CHARN)

- A unique nationwide network of 18 community health centers (CHCs) within 4 health center networks and their academic partners, and 1 data coordinating center.
- The mission of CHARN is to build capacity to carry out Patient-Centered Outcomes Research (PCOR) that will lead to better patient care at federally supported community health clinics.
- Website: <http://www.kpchr.org/CHARN>

AAPCHO Node within CHARN

- Partnerships in Asian American, Native Hawaiian, and other Pacific Islander Comparative Effectiveness (PACE)
 - Asian Health Services, Oakland, CA
 - Charles B. Wang Community Health Center, New York, NY
 - Waianae Coast Comprehensive Health Center, Waianae, HI
 - Waimanalo Health Center, Waimanalo, HI
 - University of California, Los Angeles Fielding School of Public Health
 - Association of Asian Pacific Community Health Organizations

AAPCHO PACE Research Training

- Identified as a **top priority** in the CHARN CHC Research Capacity Needs Assessment.
- Conducted in August 2012 on the island of Oahu, HI, where two of the partner CHCs are located.
- Participating organizations included:
 - all PACE members
 - Bay Clinic
 - Ko'olauloa Community Health and Wellness Center
 - Waikiki Health Center
 - Alliance of Chicago Community Health Services
 - Kaiser Permanente Center for Health Research (CHARN Data Coordinating Center)

Training Participants

- Community researchers
- Academic researchers
- Community members
- CHC staff
 - Front line Staff
 - Providers
 - Executives
 - Administrators



Training Goals

1. Understand the significance and uniqueness of conducting research in a CHC setting.
2. Develop innovative strategies to expand usual quality improvement efforts and effectively address community health issues.
3. Apply the knowledge gained from the research training to real-world examples.



Training Agenda

- Panel Discussion – Research Capacity Building at CHCs
- Plenary Session – CHC Staff Experience with Research
- Plenary Session – Engaging Community Members in Research
- Panel Discussion – Conducting Research in a CHC Setting
- Group Exercise – Developing a CHC Research Program
- CHC Site Visits



I Community Criteria for Research Participation – Five Domains

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
5. Mutually Agreeable Standards for Research Collaborations Between Partners



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 in community vs. academic expertise
3. Has clear, specified community relevance and impact
4. Includes processes collaboratively developed with the community that includes protections for both researcher and the researched



Community Involvement in Designing the Community Project (2)

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 gain,” capacity building
7. Includes appropriate language of the community (e.g. “participants” instead of “subjects”)
8. Includes CHC staff, including front-line staff, and/or community members in planning and all phases of research
9. Includes CHC or community principal investigator in research



Alignment with the Mission of the CHC and its Consumers

1. Research plan is included in CHC executive priorities or organizational roadmap
2. CHC / consumer is an equal partner in the proposed research
3. Designed in a way that will be sustainable to the CHC
4. Includes goals of value to CHC and community to 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





Asian Health Services

Charles B. Wang Community Health Center



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 for space for research implementation



Accountability to the Community and Not Just the Funding Agency

1. Research will make a contribution and prove value to community, not just value to research world
2. Research is pertinent to and reflective of lived community experiences
3. Includes clear plan for how knowledge is shared with the community
4. Includes plan for how to mobilize the community for social change (training for “change agent” skills)
5. Incorporates community events and initiatives and popular and ethnic media and literature, not just peer-reviewed publications and conferences, in its dissemination strategy



Accountability to the Community and Not Just the Funding Agency (2)

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 will be used for social change to inform practice and policy and improve health equity





**Waianae Coast
Comprehensive
Health Center**



**Waimānalo Health
Center**

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. Roles and responsibilities 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



Mutually Agreeable Standards for Research Collaborations Between Partners (2)

5. Includes a mutually acceptable plan for monitoring/evaluating partnership development and project advancement
6. Includes plan for project risk management (e.g. how to resolve specified potential challenging issues that arise)
7. Includes plan for workforce development including training on project management, contract negotiation, and conflict resolution.



A community member emphasized community engagement in research:

“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.”

Resources

- The Community Criteria for Research Participation, developed August 2012 in Hawai`i, by CHC, community, and academic partners associated with AAPCHO and CHARN can be accessed at:
http://www.aapcho.org/resources_db/community-criteria-for-research-participation/.
- Creating Community Research Participation Criteria for Community Health Centers by Mary Oneha et al. (peer review publication in progress)
- Community Health Centers: Why engage in research and how to get started, by Mary Oneha
http://www.aapcho.org/resources_db/community-health-centers-why-engage-in-research-and-how-to-get-started/



Thank you to our training participants and contributors!

Partners

- Asian Health Services, Oakland, CA
- Charles B. Wang Community Health Center, New York, NY
- Waianae Coast Comprehensive Health Center, Waianae, HI
- Waimanalo Health Center, Waimanalo, HI
- University of California, Los Angeles
- Association of Asian Pacific Community Health Organizations
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Community Leaders from Across the U.S. Call for Health Research Equity & Impact

Highlights from the 2nd National Community Partner Forum • December 5-7, 2012 • Washington DC



**Join us for the
3rd National Community Partner Forum on Community-Engaged Research
April 29-30, 2014 in Chicago!**

Details: <http://ccph.info>



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THANK YOU.



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Questions?



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