CBPR in Native Communities:
Fostering Partnerships for Intervention Research

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State of Hawai‘i: The 1st Minority Majority State (N=1,211,537)

- Ethnic specific data
- Stable Asian (multiple), Pacific Island & Native Hawaiian populations
- Multi-generational families
- 90-95% health insurance coverage

Pie chart showing ethnic population distribution:
- White: 24.3%
- Japanese: 16.7%
- Filipino: 14.1%
- Chinese: 4.7%
- N Hwn: 19.8%
- Other: 20.4%
<table>
<thead>
<tr>
<th><strong>Academia</strong></th>
<th><strong>Community</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Negative Perceptions</strong></td>
<td><strong>Negative Perceptions</strong></td>
</tr>
<tr>
<td>-University researchers not seen as individuals but as the institution (long history of injustices to overcome)</td>
<td>-Researchers take information from community and leave nothing behind (data, capacity)</td>
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<tr>
<td>-Research planned w/out community input because not sure who to ask permission (CBO, Kupuna Indiv.)</td>
<td>-Researchers are paid to do research, but they don’t pay for community involvement or training (staff time, resources, etc.)</td>
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<td><strong>Positive Attributes</strong></td>
<td><strong>Positive Attributes</strong></td>
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<tr>
<td>-Researchers “know the science” (technical aspects)</td>
<td>-Community wisdom (know what will work)</td>
</tr>
<tr>
<td>-Eligible for research funds</td>
<td>-Established relationships through programs &amp; services</td>
</tr>
<tr>
<td>-In the business of training and educating</td>
<td>-Identify gaps &amp; challenges (priority of research question)</td>
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Analytical Framework

Figure 1. Community-based Participatory Research Framework

**Community-Based Participatory Component**
- Full participation of community in identifying issues of greatest importance
- Increased motivation to participate in research process

**Traditional Research Component**
- Issues identified based on epidemiologic data and funding priorities
- Design based entirely on scientific rigor and feasibility; funding requested primarily for research expenses

**Community Representation**
- Community representatives involves with study design and proposal submission
- Increased acceptability of study approach, include funds for community

**Community Understanding**
- Community representatives provide guidance regarding recruitment and retention strategies
- Enhanced recruitment and retention

**Measurement Instruments**
- Measurement instruments developed with community input and tested in similar population
- Potentially sensitive issues handled better and increased reliability and validity of measures

**Community Involvement**
- Community members help guide intervention development
- Assures greater cultural and social relevance to the population served, increasing the likelihood of producing positive change

**Data Collection**
- Data analyzed and interpreted; findings disseminated and translated

**Researchers**
- Researchers design intervention based on literature and theory
- Researchers report findings from statistical analysis and publish in peer reviewed journals
Definition

- Community Based Participatory Research (CBPR) is a research approach that allows for community-researcher partnerships to investigate locally identified problems to develop locally relevant solutions.
Key Principles of CBPR*

1. CBPR recognizes **community** as a unit of identity
2. CBPR builds on strengths and **resources** within the community
3. CBPR facilitates **collaborative, equitable partnership** in all phases of the research
4. CBPR promotes co-learning and capacity building among all partners.
5. CBPR integrates and achieves a balance between research and action for the mutual

Key Principles of CBPR (con’t.)

6. CBPR emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease.

7. CBPR involves systems development through a cyclical and iterative process.

8. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.

9. CBPR involves a long-term process and commitment.
Starting Point for CBPR

- Ulu Network
  - 19 health care organizations Hawaii
  - Strategic Planning via EXPORT (Diabetes 101, DM Pt. Ed. Brochures, Other PE materials, Participation in Research)

- RFA on Intervention Research using CBPR (NIH)
  - Planning, Intervention, Dissemination

- Identified areas of greatest concern in communities
  - Previous strategic planning & focus groups

- Organizational Structure
Papakolea Hawaiian Homestead Community

Kula No na Poʻe
PILI ‘Ohana Project
Kokua Kalihi Valley – ‘100 Acres’
PILI ‘Ohana Project – Organizational Structure

PILI ‘Ohana Program

Administrative Core
Co-Directors: C. Rose & M. Mau

Community Advisory Board
(All partners)

Intervention Steering Committee
(Community-Academic Investigators)

CBPR Development Aims

- Admin. Structure & Policies
- Community Assessments
  - Design Intervention Protocol
  - Implement Pilot Intervention

Pilot Intervention Research Aims

- Admin. Structure & Policies
- Community Assessments
  - Design Intervention Protocol
  - Implement Pilot Intervention
PILI ‘Ohana Principles & Guidelines

1. Purpose of the PILI ‘Ohana Project
   - Project description: This research project is a planning grant that aims to develop and implement a pilot intervention to reduce obesity among Native Hawaiians (NH) and Pacific Peoples (PP), e.g., Samoans, Filipinos, Chinese, using community-based participatory research approaches.
   - Program partners: The PILI ‘Ohana Program partnership includes:
     - Hawai‘i Mauli – The Association of Hawaiian Civic Clubs (MAHC)
     - Kupuna Hawai‘i Health Care (KHHC)
     - Ke Ola Mamo (KOM) – O‘ahu Native Hawaiian Health Care System
     - KoholaKohola Comprehensive Family Services (KSV)
     - Kealakekua Bay Hawai‘i (KBHH)
     - Department of Native Hawaiian Health (DNHH), School of Medicine at the University of Hawai‘i at Mānoa
   - Project goals: The goals of this study will be to reduce health disparities among NH/PP by developing effective and culturally-informed weight-control programs, building community and university capacity for CBPR, and impacting social policy in the area of health care among NH/PP.
   - Project objectives: The project will achieve the following goals:
     1. Establishing a community-academic partnership that will promote a collaborative environment wherein the PILI ‘Ohana Program to implement research activities to overcome health disparities among NHPP communities.
     2. Conducting community needs assessments focused on understanding obesity-related health disparities and potential interventions to reduce these disparities across the NHPP communities in the PILI ‘Ohana partnership.
     3. Developing an intervention protocol that will integrate the best combination of community expertise and scientific research methods into a pilot intervention to address maintenance of weight loss in NH/PP.
     4. Implementing a pilot study to determine whether a Family Plus Community focused intervention will improve weight loss maintenance compared to Standard follow-up in overweight to obese NH/PP adults following standard individual-focused behavioral intervention.

2. Guiding Principles for the PILI ‘Ohana Project
   - Project ownership: The research project is based on a collective ownership among all research partners, both academic and community, on behalf of the NHPP communities served by the PILI ‘Ohana Project.
   - This project will engage in an open and transparent process where a collective vision of community and research goals and objectives is shared, and where the roles and expectations of community partners and academic partners are clearly understood.
   - This project will be a collaborative and equitable research partnership where members draw upon individual knowledge and skills to meaningfully and mutually work toward this project’s vision.
   - This project will provide opportunities for capacity building through a “co-learning” environment where community partners can learn about research skills and academic partners can learn about community development work.
   - This project will engage in research strategies and data analysis interpretation processes that are responsive and reflective of the experiences and knowledge of community members.
   - This project will employ research strategies that lead toward improved health outcomes, health education, health care advocacy, community health benefits, and social change for NH/PP.
   - This project will foster a supportive team environment through critical reflection of our work and group process.
   - This project will adhere to the following Traditional Pacific Islander values of:
     1. Aloha or mutual respect and compassion for others
     2. Malama or reciprocal caring for the physical, spiritual, and emotional aspects of others
     3. Ka‘ana or seeking knowledge and wisdom for the betterment of humanity
     4. Pono or maintaining harmony between partners and the communities we serve
     5. Nani or flexibility to adapt to unexpected events and circumstances
     6. Kama‘o or learning from our experiences to each other to meet the program’s goals.

3. Roles and Responsibilities of PILI ‘Ohana Project Partners
   The project recognizes that roles and responsibilities differ among Co-Principal Investigators (both academic and community), Co-Investigators, and staff, based on principles of equity, empowerment, capacity building, and collective ownership of the project.

Full document 6 pages
Approved 11/14/05
Training Opportunities

- **Community Prep. for Research**
  - Program Evaluation vs. Research (Huliau)
- **Human Subjects Training**
  - On-line Training (HIPPA & general HS)
  - Federal wide assurance (FWA)
- **Research Administration**
  - Federal allowable expenses (subcontracts)
  - Budget creation & tracking
  - Establishing Indirect Rate
Training (Con’t.)

- Community Assessment Tools
  - Focus Groups
  - Expert Interviews
  - Community Resources
    - Windshield Tours
    - GIS mappings

- Behavioral Intervention
  - Clinical Measures & Questionnaires
  - Individual Lifestyle Program
Community Needs Assessment – Year 1

- Informant Interviews
  - 15 total (5 from each of the three types of communities – CHC, NHHCS, grassroots)

- Focus Groups
  - 9 groups with 10-15 participants each (N=112)
    - 6 w/ community members
    - 3 w/ health professions serving communities
    - Conducted in language for Samoan, Chuukese, and some Filipino groups.

- Windshield Tours
  - 5 distinct areas surveyed
  - 1 mile radius

- Community Survey
  - 206 households responded
GIS Mapping
Community Awareness

- **Windshield tour**
  - “It was eye opening in regards to the # of weight loss scams in our community”
  - Our community has a lot of physical activity resources, but many are not in working order”
PILI ‘Ohana Project: Individual Lifestyle Intervention

**BEHAVIORAL STRATEGIES:**
- Self-monitoring
- Slowing the rate of eating
- Reducing eating cues
- Responding to social pressure
- Pre-planning and relapse prevention
- Problem-solving
- Stress management

**DIET**
- Low fat
- Low calorie

**EXERCISE**
- Walking
- Jogging
- Cycling
- Swimming
- Goal = 60-80% of max. heart rate

Focus of Intervention

Primary and Secondary Outcomes

- Quality of Life
- Weight Loss/Short-Term Maintenance
- Blood Pressure
- Physical Functioning

Based on PILI ‘Ohana Community Needs Assessment
Community-initiated healthy lifestyle programs

Family leadership / role models

Cultural/Social attitude toward obesity

Social/Family Issues

Diet

Parental/kūpuna influence

Community-resource Strategies:
- Eating meal same time and together
- Focus on the cook in the home
- Focus on the senior women in the household as agents of change
- Family eat same kinds of foods
- Role models’ (e.g., influential/respected person, church) influence on family/community
- Group activities
- Family eat same kinds of foods
- Assistance in house chores
- Childcare

Accessibility of existing community/public facilities

Outdoor exercise equipment at parks

Weight Management

Physical Activity

Community-resource Strategies:
- Walking clubs/groups
- Use of Churches
- Walk ways, bike paths
- Use of schools
- Farmer’s markets
- Community-tailored activities

Social/Family Strategies:
- Eating meal same time and together
- Focus on the cook in the home
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Based on PILI ‘Ohana Community Needs Assessment
## Intervention Study Design

<table>
<thead>
<tr>
<th>Type of Community Group</th>
<th>Community Organization Name</th>
<th>Individual-focused Lifestyle Intervention</th>
<th>Family (F) + Community (C) focused Intervention</th>
<th>Program goals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Phase 1 (12 weeks)</td>
<td>Phase 2 (6 months)</td>
<td></td>
</tr>
<tr>
<td>CHC</td>
<td>Kokua Kalihi Valley</td>
<td>X</td>
<td>X</td>
<td>Goal at 9 mon: Improve: ○ Performance (6 min walk) ○ Functional status</td>
</tr>
<tr>
<td></td>
<td>Kalihi Palama</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>NHHCS</td>
<td>Ke Ola Mamo</td>
<td>X</td>
<td>X</td>
<td></td>
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<tr>
<td>&quot;Grassroots&quot;</td>
<td>Papakolea</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>AHCC</td>
<td></td>
<td>X</td>
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</tbody>
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Goal at 9 mon: Improve:
○ Performance (6 min walk)
○ Functional status

Secondary goal: 5-10% weight loss
Added Value of CBPR

Community Perspective

- Better able to understand communities research needs
- Baseline for evaluating other research opportunities
- Community owned-data
- Data summaries used for further preliminary studies
- Communities more similar than different, just have different perspectives
- Facilitator training (focus groups & intervention) very useful for
Added Value of CBPR

University Perspective

- More opportunities for teaching and training
- Co-learning environment ("science meets the community")
- Serve in a coordinating role for several communities (able to reach greater numbers)
- Opportunity for exploration of what will work (i.e., design and test assessment tools) in different populations
PILI ‘Ohana Project CBPR: Lessons Learned (so far...)

- Different Communities have different strengths
- Recruitment – exceeded
- Retention – staff & ppts
- Building (trust) relationships – within & between each partner
- Extra Time – Research training – technical
- Concept of Standardization – across community sites
- Added Administrative Tasks – i.e., FWA, indirect rate proposals, IRBs
PILI ‘Ohana Project
Community & Academic PIs

Donna Palakiko (Ke Ola Mamo)  Keawe Kaholokula (UH)
Henry Gomes (Hawai‘i Maoli)  Margaret West (UH)
Puni Kekauoha (Kula No na Po’e)  Jana Silva (UH)
Sheryl Raneses (KKVHC)  Charlie Rose (Community)
Anne Leake (KPHC)  Marjorie Mau (UH)