Partnership for Improving Lifestyle Intervention

PILI ‘Ohana CBPR

Principles and Guidelines for Overall Governance
Partnership for Improving Lifestyle Interventions (PILI) ‘Ohana Program

Principles and Guidelines for Overall Governance

1. Purpose of the PILI ‘Ohana Project

   o Project description:  This research project is a planning grant that aims to develop and implement a pilot intervention to reduce obesity in Native Hawaiians (NHs) and Pacific Peoples (PPs; e.g., Samoans, Filipinos, Chuukese) using community-based participatory research approaches.

   o Program name: The name adopted for this project is PILI ‘Ohana where “PILI” stands for Partnership for Improving Lifestyle Interventions. It is a Native Hawaiian word that means close relationship; relative; be with; adhere to; touch; and join. Therefore, the word PILI exemplifies the spirit of this collaboration, which is to foster and strengthen relationships between and within the communities we serve as well as among the PILI ‘Ohana partners.

   o Program partners: The PILI ‘Ohana Program partnership includes:

       ▪ Hawai‘i Maoli – The Association of Hawaiian Civic Clubs (HM-AHCC)
       ▪ Kalihi-Pālama Health Center (KPHC)
       ▪ Ke Ola Mamo (KOM) – O‘ahu Native Hawaiian Health Care System
       ▪ Kokua Kalihi Comprehensive Family Services (KKV)
       ▪ Kula No Nā Po‘e Hawai‘i (KNNPH)
       ▪ Department of Native Hawaiian Health (DNHH), School of Medicine at the University of Hawai‘i at Mānoa

   o Project goal: The results of this study will be used to reduce health disparities among NHs/PPs 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 NHs/PPs.

   o Project objectives: The project will achieve this goal by:

       ▪ Establishing a community-academic partnership that will promote a co-learning environment within the PILI ‘Ohana Program to implement research activities to overcome health disparities in NH/PP communities.
- Conducting community needs assessments focused on understanding obesity-related health disparities and potential interventions to reduce these disparities across the NH/PP communities in the PILI ‘Ohana partnership.

- 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 NHs/PPs.

- 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/obese NH/PP adults after receiving a standard individual-focused behavioral intervention.

  o **Project ownership:** The research project is based on a collective ownership amongst all research partners, both academic and community, on behalf of the NH/PP communities served by the PILI ‘Ohana Project.

### 2. Guiding Principles for the PILI ‘Ohana Project

  o This project will engage a set of principles that will foster community ownership and empowerment among community partners, including power and resource sharing, capacity building through mentoring and learning exchanges, group participation in all phases of the research project, and community ownership of the project;

  o 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;

  o 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;

  o 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 and work;

  o This project will engage in research strategies and data analysis interpretation processes that are respectful and sensitive to the experiences and knowledge of community members;
This project will employ research strategies leading toward improved health outcomes, health education, health care advocacy, community health benefits, and social change for NHs/PPs;

This project will foster a supportive team environment through critical reflection of our work and group process.

This project will abide by the following values of:

**Traditional Hawaiian**
1. *Aloha* or mutual respect and compassion for others.
2. *Mālama* or reciprocal caring for the physical, spiritual, and emotional aspects of others.
3. *Naʻauao* or seeking knowledge and wisdom for the betterment of humankind.
4. *Pono* or maintaining working harmony between partners and the communities we serve.
5. *Nalu* or flexibility to adapt to unexpected events and circumstances.
6. *Kokua* or lending our expertise to each other to meet the program’s goals.

**Filipino (Ilokano):**
1. *Aloha* or Naindayawan a ka-asi
2. *Malama* or Naimpapusuan nga ayat
3. *Naʻauao* or Panagsursuro a nainsiriban
4. *Pono* or Panagtitimipuyog
5. *Nalu* or Isasaranay
6. *Kokua* or Panagparabon

**Samoan:**
1. *Aloha* or Fefa’aaloaloa’l ma feagalelei ai
2. *Malama* or Fetausiai ile itu ile tino agaga ma lagona
3. *Naʻauao* or Saili ile silafia ma le poto mo le lelei o tagatu uma
4. *Pono* or Faʻatumauina le galulue felagolgoma’l i le va o a tatou paʻaga maalalafaga aloʻo tatou tautuaina
5. *Nalu* or Le mafia ona fetu’unai ona o ni mea e tutupu mai e leʻl fuafuaina
6. *Kokua* or Fefa’asoaa’l a tatou tomai ina ia ausia ai sini a ole polokalama

### 3. Roles and Responsibilities of PILI ‘Ohana Project Partners

This 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.
o **Academic Principal Investigator (API) Responsibilities:** The API will provide leadership in every aspect of the PILI ‘Ohana project with support from research partners (community and Co-Investigators). This includes overseeing the entire project, coordinating research team activities, managing the budget, reporting to funders, supervising staff, and ensuring the dissemination of research findings.

o **Community Principal Investigator (CPI) Responsibilities:** The CPI will provide leadership to the PILI ‘Ohana Project, with support from other research partners (API and other CPIs), as it relates to his or her respective community organization. This includes overseeing activities specific to his or her community organization, such as activities to meet project objectives and goals, coordinating community research team activities, and managing the community organization’s budget. The CPI will also serve as a member of the Intervention Steering Committee (ISC) and provide input for the overall research design and data collection, analysis, and interpretation. The CPI will ensure the dissemination of research findings relevant to his or her community organization and the overall project.

o **Community Co-Director (CC-D) Responsibilities:** The CC-D will provide leadership and guidance in the overall governance of the PILI ‘Ohana Project with support from the Academic Co-Director. This includes facilitating all project meetings between academic and community research partners. The CC-D will also serve as moderator between research partners concerning disputes or issues impacting the project’s objectives and goals.

o **Academic Co-Director (AC-D) Responsibilities:** The AC-D will provide leadership and guidance in the overall governance of the PILI ‘Ohana Project with support from the CC-D. This includes co-facilitating project meetings between academic and community research partners. The AC-D will assist the CC-D in addressing disputes or issues between research partners that impact the project’s objectives and goals.

o **Academic Co-Investigator (ACI) Responsibilities:** ACI will directly assist the API and CPIs and participate in all aspects of the research project, taking into account individual and organizational capacities, (skills and available human and other resources). ACI will participate in partnership meetings, co-learning exchanges, the formulation of research questions, provide suggestions and feedback on the methodology, and provide input on recruitment, data collection, data analysis and interpretation, and dissemination.

o **Program Coordinator’s (PC) Responsibilities:** The PC will assist in the daily operations of the project and project planning. In addition, the PC will provide oversight of project staff, implement policies and procedures, facilitate training
for project partners, and ensure fidelity to research protocols and quality of research methodology.

- **Staff Responsibilities:** Staff responsibilities will include team building (e.g., facilitating meetings and co-learning exchanges, liaising with individual team members), coordinating project administrative activities (e.g., minutes, meeting agendas) coordinating outreach to service providers, and key informants, and setting up and conducting research interviews. Staff will also oversee the collection of data and the delivery of data to the Co-PIs (API and CPI) and the ACI.

- **Community Advisory Board’s (CAB) Responsibilities:** The CAB will ensure cultural integrity, community safety, and fidelity to project’s objectives and goals. This will include a semi-annual meeting to review the activities and progress of the project and to provide feedback and guidance as needed.

### 4. Decision-Making Process for the PILI ‘Ohana Project

Our decision-making process in this project aims to:

- Encourage the participation and empowerment of all project partners;
- Be transparent, open, and clear;
- Provide opportunities for exchanges of learning that draw on the various skills and areas of knowledge of different project partners;
- Recognize the responsibilities of the Co-PIs (API and CPIs), the ACI, and the PC as Project leaders;
- Recognize the responsibilities of the Project Coordinator as the Project’s staff persons.

**Differing Responsibilities:**

- Partnership decisions will include those related to the project’s overall goals and strategies;
- CO-PIs (API and CPIs), ACI, PC, and staff are responsible for decisions related to the management of the research and administration to the Project.

**Process for Team Decisions:**

- Decision-making at PILI ‘Ohana Project meetings will strive first for consensus and then will use simple majority votes.
5. **Data Integrity for the PILI ‘Ohana Project Data**

### Use of Data

Based upon the project’s guiding principles, the Co-PIs (API and CPIs) and the ACI share ownership and have access to relevant research data (e.g., data from CPI’s own community). Usage of the data will be in accordance with the project goals and will adhere to all requirements of the Human Protection Committee of the University of Hawai‘i and the Institutional Review Board of the Native Hawaiian Health Care Systems (for research data from KOM’s partnership).

- Data will be used for:
  - Advancement of knowledge to support the betterment of NHs/PPs;
  - Identification of future research questions to improve the health of NHs/PPs;
  - Making recommendations for policy and service provisions to improve the quality of life for all NHs/PPs.

- The data should not be for:
  - Individual interests that are not related to the goals of this project.

### Dissemination of Data

In accordance with CBPR principles, we are proposing a model of dissemination that encourages the active involvement of all research partners (community and academic) while taking into account their varying responsibilities and capacities. Research findings will be disseminated in various ways including community forums, conference presentations, agency workshops, newsletters, and journal articles. The Co-PIs (API and CPIs), the ACI, and the Project Coordinator are all encouraged to engage in dissemination of the research findings, and are encouraged to share information about potential dissemination activities.

The Co-PIs (API and CPIs) will take the initiative in identifying potential journal articles and discussing them with the project partners. Articles may be written by individuals or by writing groups formed to develop particular manuscripts. All members of a writing group will share authorship on a manuscript. If the paper discusses concerns or issues relating to a particular NHs/PPs community or communities, team members from these communities will be encouraged to participate in the writing group. Order of authorship and mechanisms for feedback on manuscript drafts will be decided up front.
by writing group members. Groups may also be formed for the development of conference presentations, community forums, and other dissemination activities.

Before any dissemination of PILI ʻOhana research findings, the CAB will review the proposed findings and means of dissemination to ensure cultural integrity and validity of information, appropriateness of dissemination, and relevance to project’s goals and stated use of data.

**Security of Data**

For security and identity protection, data will be stored as follows:

- For electronic data:
  - Data will be electronically stored on a computer (e.g., hard drive) and another form of electronic storage (e.g., CD, DVD).
  - Access to data will be protected via password security.
  - Access to electronic data will be limited to relevant research personnel.

- For data in hardcopy form:
  - Hardcopies will be stored in a locked storage cabinet (e.g., file cabinet) at the respective community site and at the DNHH.
  - The locked storage container will be kept in a secure location at the respective community site and at the DNHH.
  - Access to hardcopy data will be limited to relevant research personnel.

- In addition, all identifiable data will be housed only at the community site where the data were collected. Only unidentifiable data will be accessible to PILI ʻOhana Program partners.

**6. Progress Evaluation for the PILI ʻOhana Project**

We will regularly chart our progress against our timeline submitted on a quarterly (every 3 months/year) basis. We will also provide time at the end of each meeting (15 minutes) to review the PILI ʻOhana CBPR approach and philosophy.
Twice a year, we will hold meetings specifically to debrief about our work. At these meetings we will both critically reflect on our progress/outcomes and make recommendations for adjusting our work accordingly.

7. Procedures for Amending Principles and Guidelines for the PILI ‘Ohana Project

In recognizing that CBPR is an evolving research paradigm and that communities we serve are dynamic, the Principles and Guidelines for Overall Governance of the PILI ‘Ohana Project outlined in this document is subject to modification and/or revisions at the discretion of the project partners. This allows for flexibility to accommodate unforeseeable changes and changes that come with the evolution of the PILI ‘Ohana CBPR approach. Any changes to this document will only be made with the mutual agreement between all community and academic partners.