



Lessons Learned in the Recruitment and Retention of Native Hawaiians & Pacific Islanders

A NIA Workshop on Innovation Issues in Minority Aging Research
November 13, 2019

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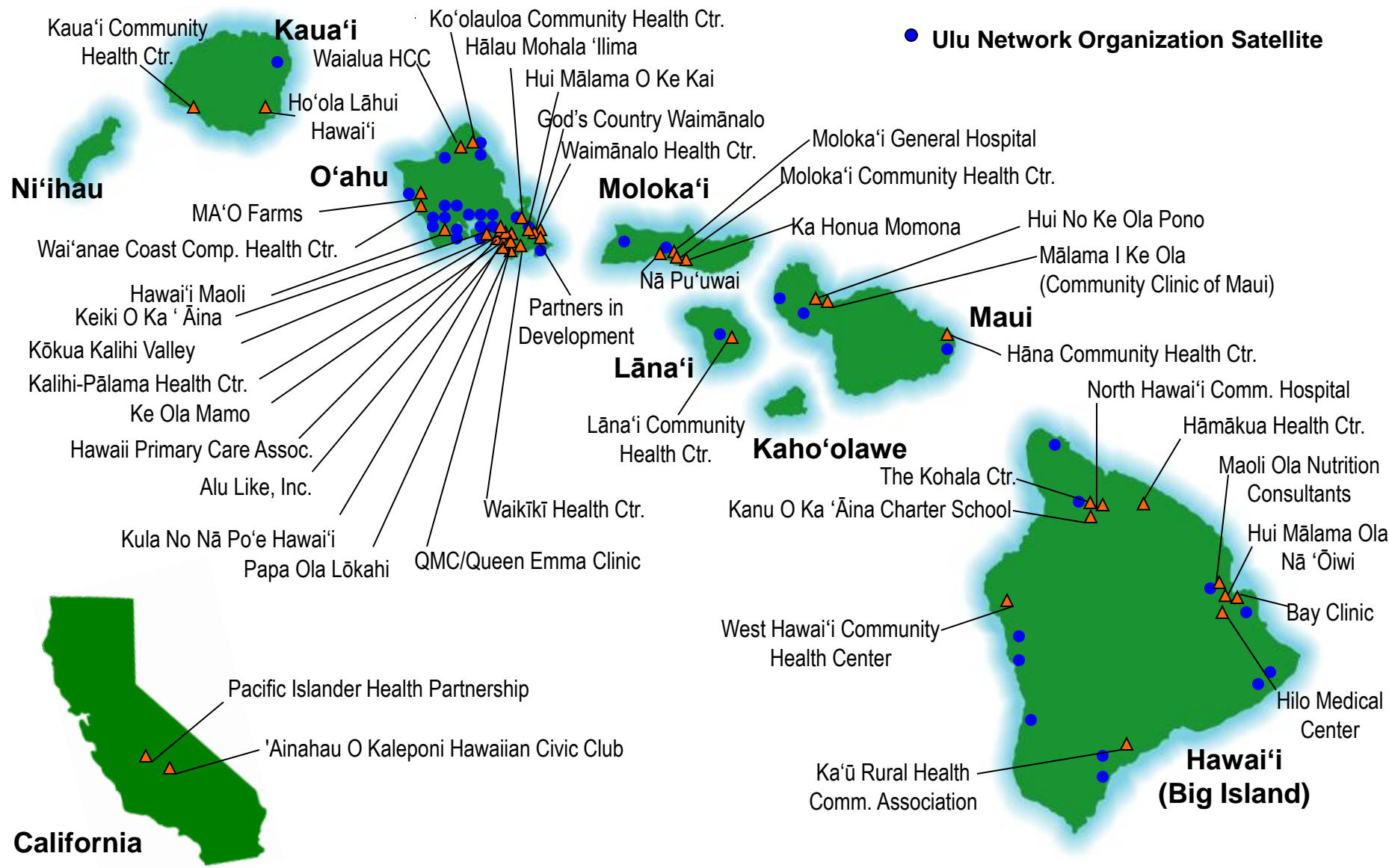
Department of Native Hawaiian Health



Ulu Network: Community coalition

LEGEND:

- ▲ Ulu Network Organization Main Site
- Ulu Network Organization Satellite





Welcome

"COMMUNITY 101 FOR RESEARCHERS"

An Educational Program for Researchers Working in Grassroots Communities

A Joint Project of RMATRIX & The Center for Native and Pacific Health Disparities (CNPHDR)*

Welcome and Aloha to the "Community 101 for Researchers" Program. We are pleased to share this inaugural educational program that brings our mana'o (thoughts) to YOU ... about how to work WITH many of the diverse communities that live in Hawai'i ... in a good way!



The 5 modules of the program provide an introductory learning opportunity for RESEARCHERS to understand our communities, especially Native Hawaiian and Pacific Islanders populations. The modules are concise and offer practical information for researchers to use when pursuing or considering the idea of conducting biomedical and behavioral research that involves grassroots communities or the lay public.

However, this program is not intended to be an exhaustive review of the field of community-based participatory research (CBPR), nor community partnerships or health disparities research. References and suggested reading are provided at the end of each module to offer options for self-directed



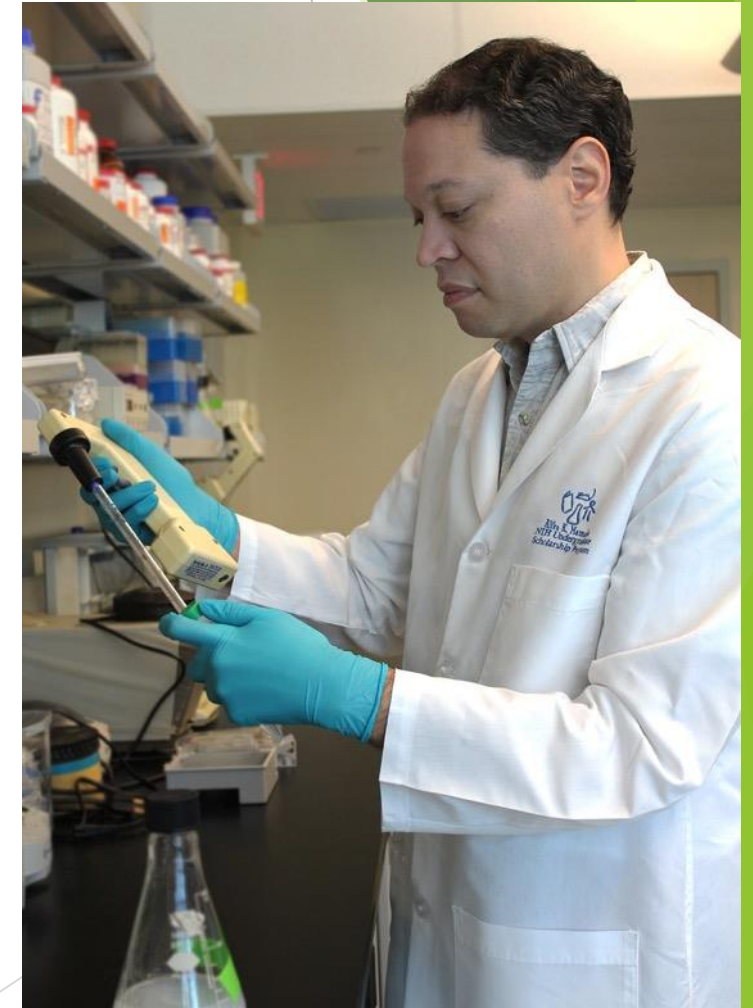
Chung-Do JJ, Look MA, Mabellos T, Trask-Batti M, Burke K, Mau MK. Engaging Pacific Islanders in Research: Community Recommendations. *Prog Community Health Partnersh*. 2016;10(1):63-71.

Community-based participatory research framework

CBPR often begins with a health issue or research topic of **importance to the community** with the aim of **combining knowledge and action** for social change to improve the community's health and wellness and ultimately to **eliminate health disparities**.

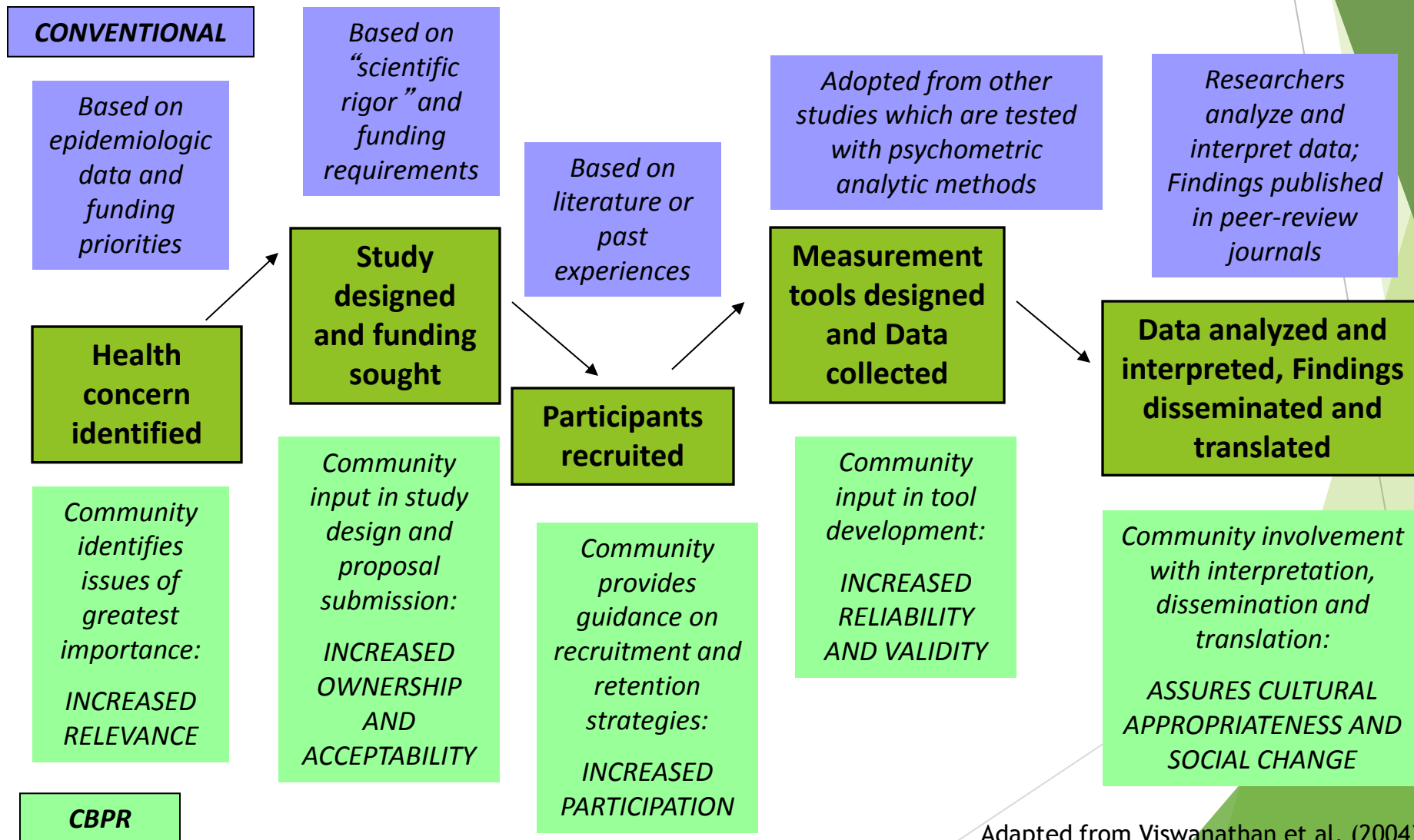
Definition modified from WK Kellogg Foundations' Community Health Scholars Program (2001)

Townsend CK, Dillard A, Hosoda KK, et al. Community-Based Participatory Research Integrates Behavioral and Biological Research to Achieve Health Equity for Native Hawaiians. *Int J Environ Res Public Health*. 2015;13(1)



Dr. Alike Maunakea Epigenetic Researcher

CBPR vs. conventional research approaches



Adapted from Viswanathan et al. (2004)

“I am not YOU”

Researcher says	Community thinks
“We have federal funding to do a cognitive decline study (APoE) with Hawaiian and Pacific Islander elders”	<i>“We are worried that too many of our kupuna have diabetes”</i>
“This is an important health issue”	<i>“Will this project help my ‘ohana NOW?”</i>
“We will be publishing the results in an important peer-reviewed scientific journal”	<i>“What does this mean to my everyday life?”</i>

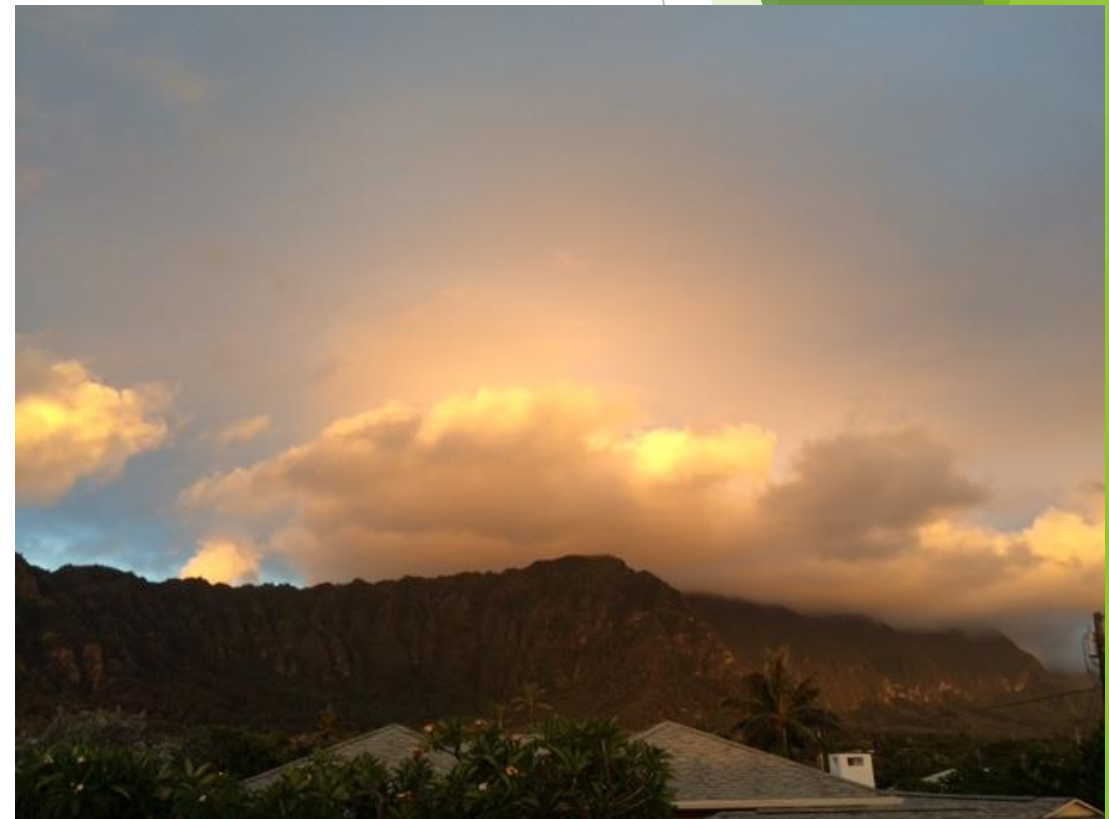
Overview

1. Do your homework
2. Relationships are key
3. Cultural humility facilitates communication
4. Direct community benefit is essential
5. Equitable partnership is expected

Chung-Do JJ, Look MA, Mabellos T, Trask-Batti M, Burke K, Mau MK. Engaging Pacific Islanders in Research: Community Recommendations. *Prog Community Health Partnersh*. 2016;10(1):63-71.

Community 101 for Researchers

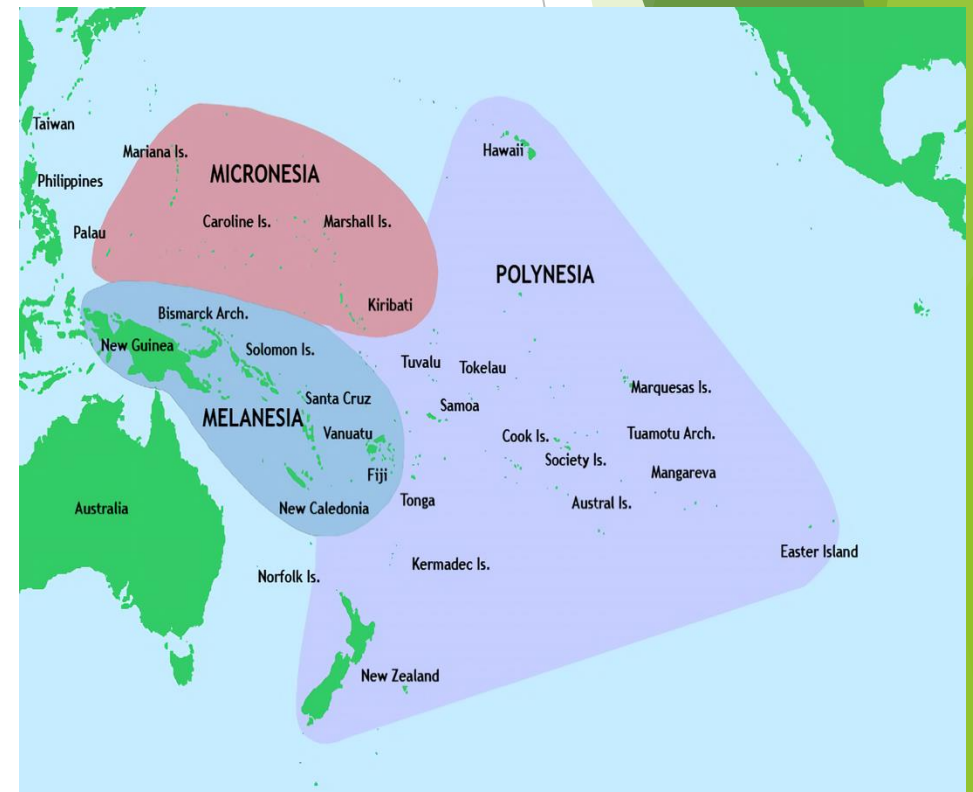
<http://rmatrix2.jabsom.hawaii.edu/community-101/>



Do your homework

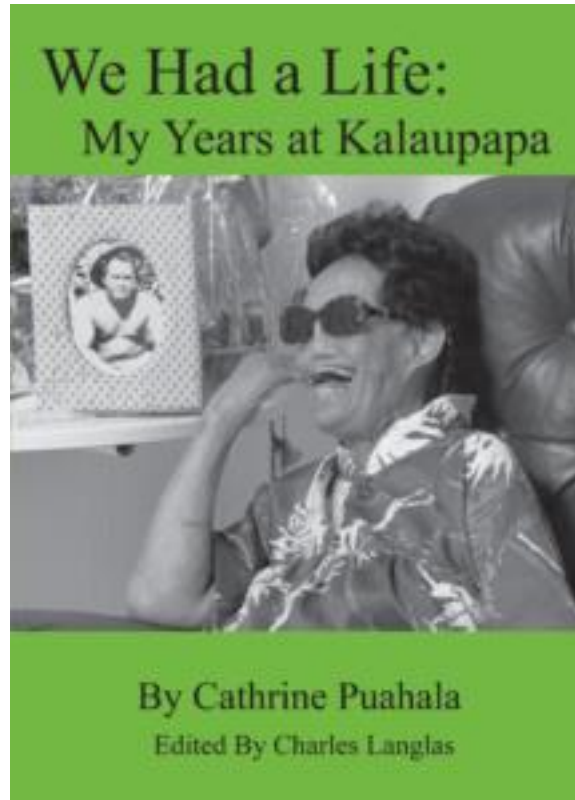
- ▶ “We are not all alike”
- ▶ Understand the specific community you are working with
 - ▶ Different languages
 - ▶ Different political colonization
 - ▶ Different religion colonization
 - ▶ Different migration paths
- ▶ Be mindful of the communities experience with researchers

Practical tip:
Attend community events, and also take time
to “talk story” with community members



Do your homework

- Understand the historical context of research in your community



Hansen's Disease (Leprosy) patients



Marshall Islands nuclear bomb testing in 1950's & long term radiation exposure

Example: Hawaiian core values

Central to how they view and order their world

- ▶ Aloha
 - ▶ *Greeting*
 - ▶ *love, affection, grace, kindness, compassion, empathy, greeting, sweetheart*
- ▶ 'Ohana
 - ▶ *Family*
 - ▶ *relatives, kin group - [including ancestors - sometimes deified, and future generations]*
- ▶ 'Āina
 - ▶ *Land*
 - ▶ *that which feeds physically, emotionally, spiritually*
- ▶ Lōkahi
 - ▶ *Unity*
 - ▶ *agreement, accord, unison, harmony*

Pukui MK, Elbert SH, 1986. Rezendes WC, 1996



Relationships are the key *strong and enduring*

- ▶ Trust begins with mutual values & goals
 - ▶ Take the time to develop
 - ▶ Demonstrate you are trustworthy through actions, be clear about intentions
- ▶ Small success builds to big success
 - ▶ moving from informant interviews to biospecimen collection
- ▶ Give aloha - receive aloha

Practical tip:
Observe and understand the etiquette of language and behavior appropriate to the place and community



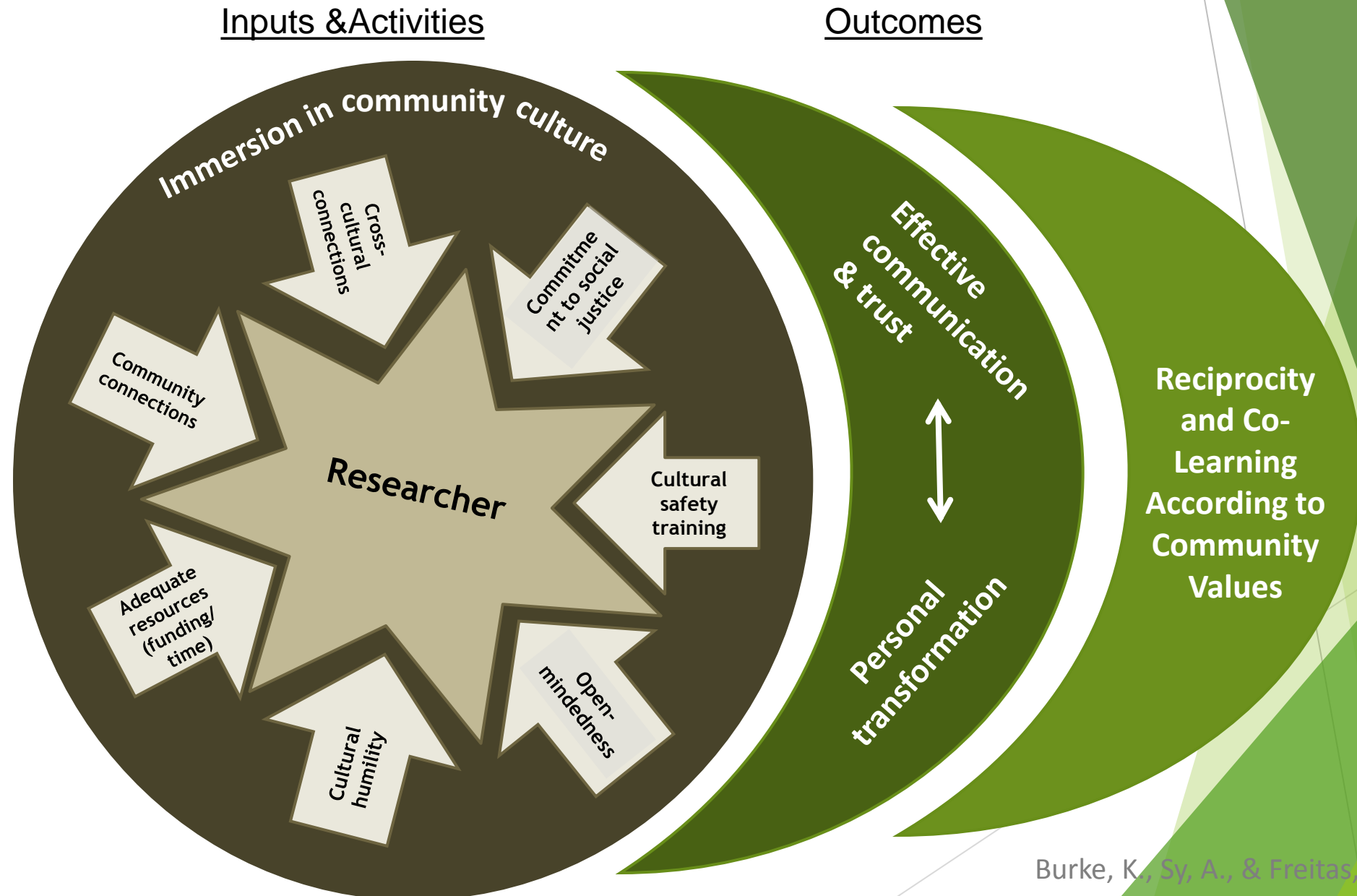
Cultural humility facilitates communication

- ▶ Acknowledge and incorporate Pacific Peoples knowledge systems
 - ▶ Identify and develop cultural translators
 - ▶ If Pacific elders are a focus they need to be involved throughout
- ▶ It is important to know who the gatekeepers and work together

Practical tip:
Be aware of cultural practices related to appropriate dress, personal space, touching, and greetings.



Ripple Model: Growing Community-Engaged Performative Researchers



Example:

KaHOLLO Project [R01 NHLBI]

- ▶ Cultural dance training to improve hypertension management in Native Hawaiians (n=263)
- ▶ Randomized Control Trial - largest with exclusively Hawaiians
- ▶ Mixed methods in program development
 - ▶ Transcreation framework
- ▶ Guided by elders and cultural experts
- ▶ Cultural integrity prioritized
- ▶ Retention: 83% at 6 months, 77% at 12 months



Kaholokula JK, Look M, Mabellos T, et al. Cultural Dance Program Improves Hypertension Management for Native Hawaiians and Pacific Islanders: a Pilot Randomized Trial. *J Racial Ethn Health Disparities*. 2017;4(1):35-46.

Direct community benefit is essential

- ▶ The question you're committed to answer must be important to the community
- ▶ Be clear with the potential benefits and negative impacts
- ▶ Identify resources and capacity-development opportunities

Practical tip:
Ensure immediate and direct benefits for the community such as jobs, funding, or educational training.



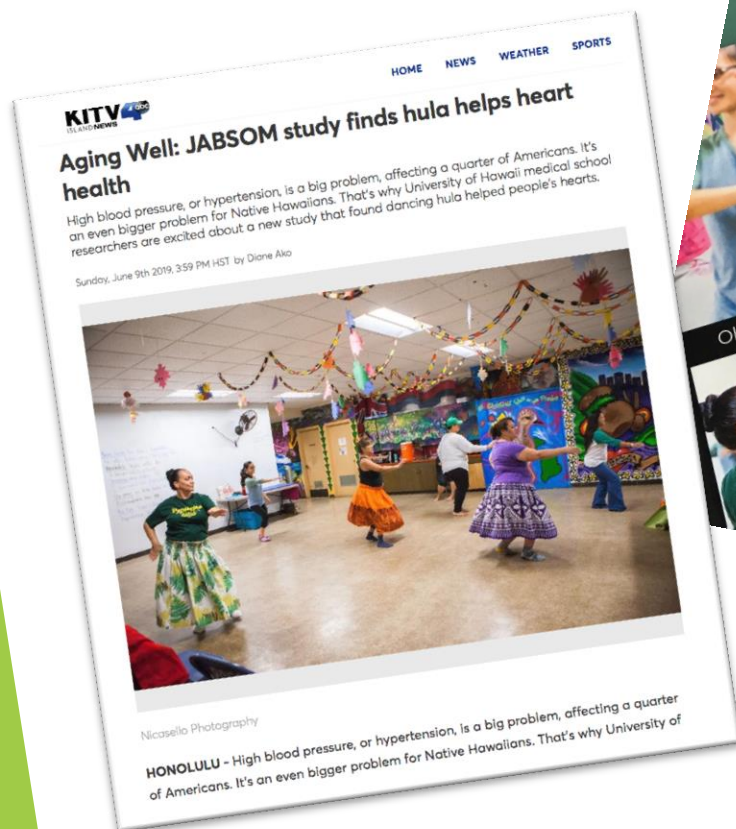
Equitable partnership is expected

- ▶ Consider the limitations and flexibility of the grant
- ▶ Establish agreement on what is collected, and how data and materials are used, stored, and what will be done with it at the end of the project
- ▶ Collaborative understanding on protocol for data ownership, and any dissemination
- ▶ Share back results in relevant forms to the community

Practical tip:
Ensure discussions are conducted early in the partnership, and revisited at key milestones



Community-driven dissemination activities



Ku'i ka lono

(Spread the news)

Let's celebrate the success of the KaHOLO Project's Ola Hou i ka Hula Program

Kamehameha Schools Hawai'i campus sponsored event in partnership with John A. Burns School of Medicine Hilo site invites you to a remarkable occasion celebrating hula & health

We will be sharing exciting new findings from the KaHOLO research study which you have helped make a great success

Thursday, October 10th, 10:00 a.m.
Kamehameha Schools Hawai'i - High School campus
Kamaka'eha building Rm 2817
16-716 Volcano Rd, Kea'au

Must RSVP to Stacy Haumea at text/cell 430-6735 or email: stacy.haumea@gmail.com by Friday, October 4th.



Summary

- ▶ Community-based participatory research framework is a successful approach
- ▶ Meaningful Native Hawaiian and Pacific Islander engagement can be created:
 1. Do your homework
 2. Relationships are key
 3. Cultural humility facilitates communication
 4. Direct community benefit is essential
 5. Equitable partnership is expected



Resources

- ▶ Mele Look, Director of Community Engagement
University of Hawai'i, School of Medicine, Dept Native
Hawaiian Health mele@hawaii.edu
- ▶ Community 101 for Researchers working with NHPI
<http://rmatrix2.jabsom.hawaii.edu/community-101/>
- ▶ Chung-Do JJ, Look MA, Mabellos T, Trask-Batti M, Burke K,
Mau MK. Engaging Pacific Islanders in Research: Community
Recommendations. *Prog Community Health Partnersh.*
2016;10(1):63-71



Beverly Noa, E Ola Mau awardee, 2018