

# **Protocol for a qualitative study exploring perspectives of Native Hawaiian Elders to improve health outcomes**

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*Submitted 15 May 2024, revised 6 February 2025, accepted 4 April 2025.*

This project was supported by grants from the US Administration on Aging (90OIRC0001) and the National Institutes of Health, including the Ola HAWAII Research Center in Minority Institution (2U54MD007601-36) and the PIKO IDeA Center for Translational Research (U54GM138062). Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Support also was received from the Barbara Cox Anthony Endowment at the University of Hawai'i at Mānoa.

## **ABSTRACT**

This paper introduces a 48-page guide for conducting qualitative interviews with Native Hawaiian elders. The guide was developed based on work with and for Native Hawaiian elders through a partnership between ALU LIKE, Inc., a community-based service provider, and Hā Kūpuna National Resource Center for Native Hawaiian Elders at the University of Hawai'i at Mānoa. Components of the guide include a brief history of research harms experienced by Native Hawaiians, a summary of advancements in Hawaiian-led research, tips for researcher self-reflection as required by community-based research, and recommendations for successfully engaging community, developing research questions, gathering and analyzing data, and reporting findings in ways meaningful to community members. Although experiences of colonization and discrimination are unique to each group, this protocol has application for qualitative research with other Indigenous and minority communities.

**KEYWORDS:** Native Hawaiian, Elder, Qualitative Research, Protocol, Health Services, Indigenous

## Introduction

This paper introduces the *Qualitative Research with Kūpuna (Native Hawaiian elders): A Guide to Respectful, Collaborative Interviewing*.<sup>1</sup> We discuss the need for this protocol and provide summaries and examples of some of the guide's sections.

## Need for the Guide

Historically, research in Indigenous communities was based on Eurocentric frameworks and methods that ignored Indigenous worldviews, cultural norms, and environments.<sup>2</sup> Because Indigenous Peoples did not measure up to European standards, they were considered less human and therefore subject to unequal and unethical treatment.<sup>3</sup> These attitudes were used to justify dominion over Indigenous lands<sup>2</sup> and establish policies that continue to disadvantage Indigenous Peoples.<sup>4</sup> For these reasons, Māori scholar Linda Tuhiwai Smith<sup>5</sup> wrote: “The word itself, ‘research,’ is probably one of the dirtiest words in the Indigenous world’s vocabulary.”

An early example of unethical research in Hawai‘i centered around Hansen’s disease, which afflicted many Native Hawaiians. These individuals and accompanying family members were exiled to Kalaupapa, an isolated, inaccessible peninsula on the island of Moloka‘i. Researchers ran human experiments by transplanting leprous skin onto healthy individuals to determine mode of transmission and sterilizing patients without consent.<sup>6</sup>

Even when not blatantly unethical, research in Indigenous communities is often extractive, with researchers entering a community to collect data, but failing to return to share back findings and provide benefits. Researchers sometimes disseminate racist findings that cause community harm.<sup>7,8</sup> Common complaints heard in Hawaiian communities in the last century included “we’re good enough to study, but not good enough to cure” and “we make you famous, but we don’t benefit.”<sup>9</sup> As more Native Hawaiians have gained Western-research skills, they are

demanding that Western research integrate community-engagement principles and operationalize culturally based frameworks.<sup>10,11,12,13</sup>

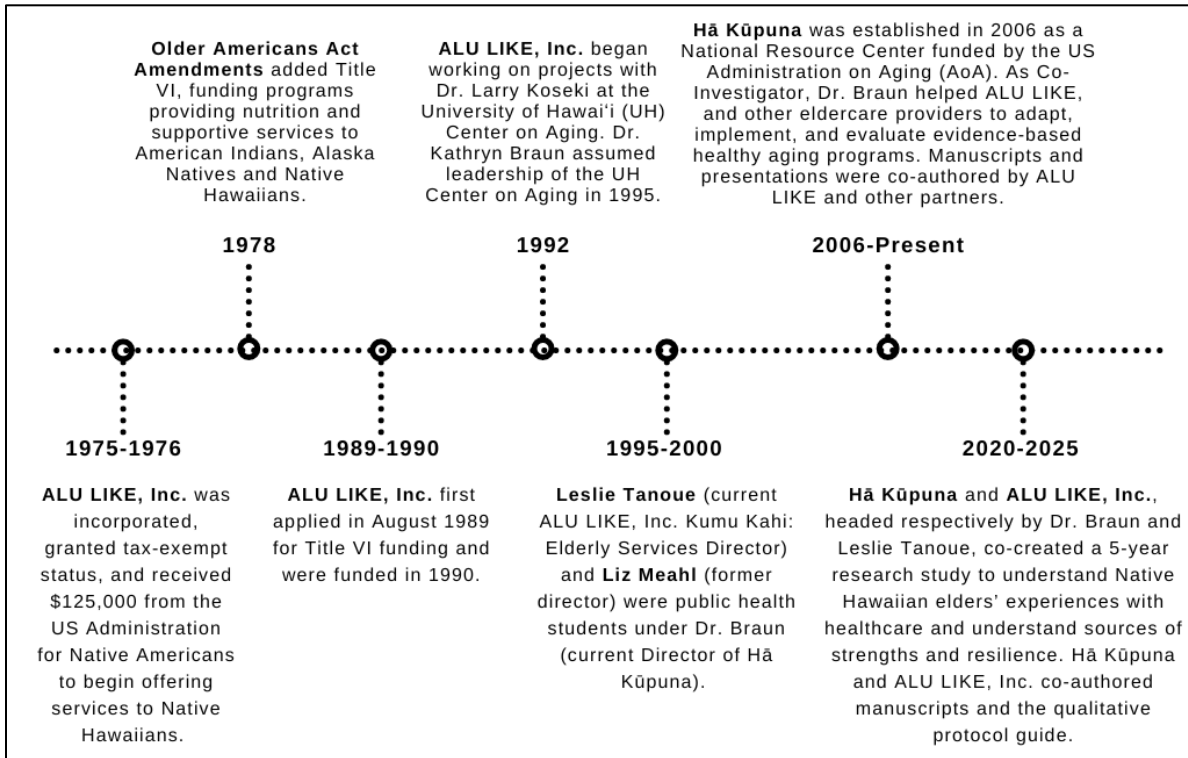
Interviewing protocols exist, but they either discuss qualitative research generally or focus on other populations, including caregivers,<sup>14</sup> providers,<sup>15</sup> and people with mental health disorders.<sup>16</sup> Although Native Hawaiian frameworks, methodologies, and tips have been documented, a “how-to” guide useful to both students and faculty did not exist. This 48-page guide was developed to promote respectful and collaborative interviewing with Native Hawaiian elders.

### **Tool Development**

This guide was developed by Hā Kūpuna National Resource Center for Native Hawaiian Elders at the University of Hawai‘i and the elder-focused Kumu Kahi program at ALU LIKE, Inc. A Hawaiian-serving non-profit, ALU LIKE coordinates 14 sites across five islands to provide meals, education, social engagement, and caregiver support. Organizational missions are aligned, as Hā Kūpuna’s aims to create knowledge to improve Native Hawaiian elder health, and Kumu Kahi aims to enrich the lives of Native Hawaiian elders by preserving and restoring health and promoting lifelong learning, self-respect, and cultural identity.

Although gerontologists at the University of Hawai‘i and ALU LIKE have worked together since the 1990s (Figure 1), the two organizations established their formal research partnership in 2006. This partnership was structured to advance both organizational missions and to conduct research that was non-extractive and beneficial to research participants. Appropriately, as community-engaged research, ALU LIKE staff are co-authors of dissemination products.<sup>17</sup>

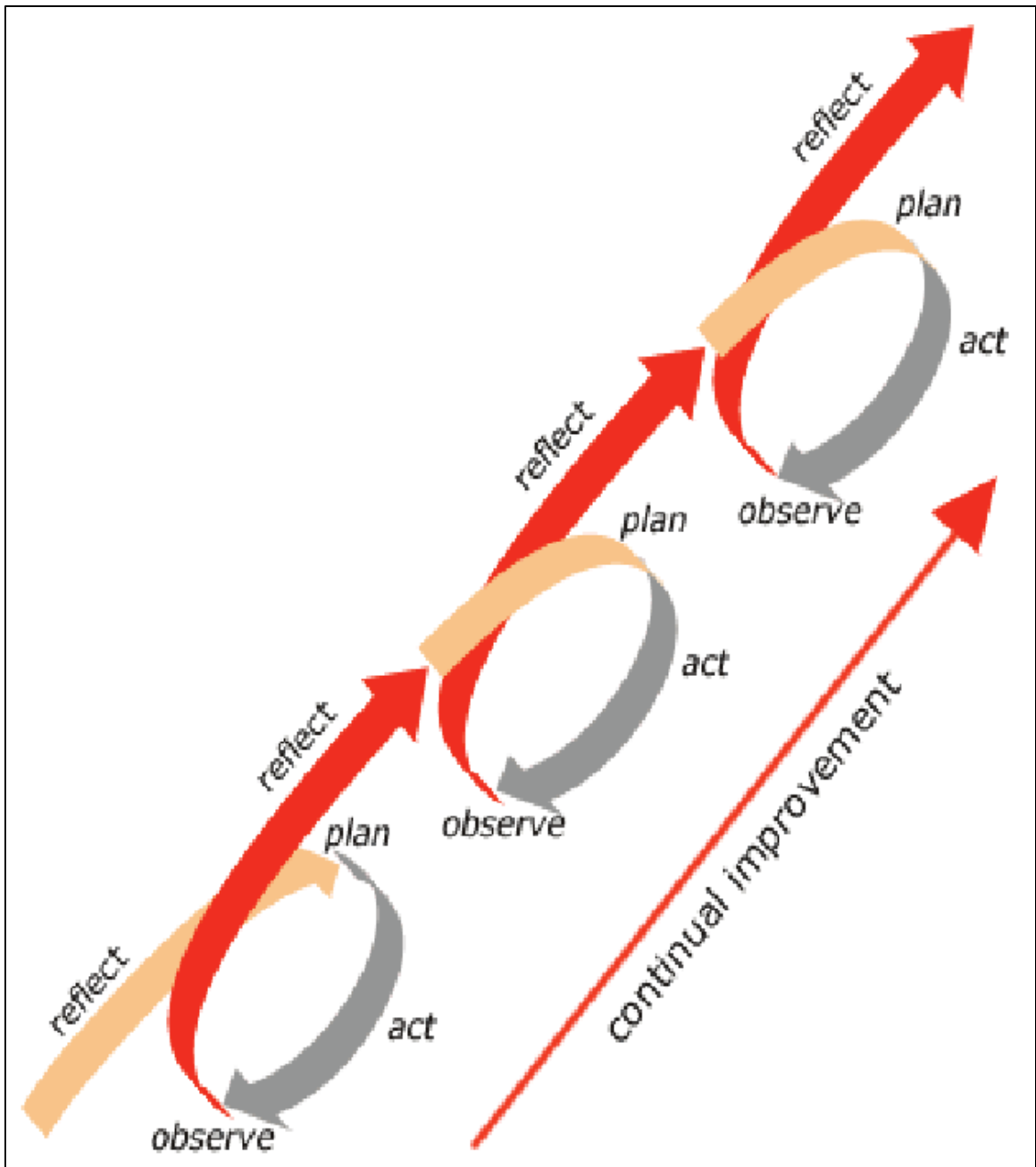
**Figure 1: Descriptive Timeline of Hā Kūpuna and ALU LIKE, Inc.’s Collaborative Partnership**



The impetus for developing the guide came in 2020 when we co-created a 5-year interviewing project to understand the values kūpuna wanted to pass to future generations, their healthcare experiences, and their advice to healthcare providers. Planning required negotiation of design issues and paying close attention to ALU LIKE's experience with program participants.

Following the Participatory Action Research (PAR) model<sup>18,19</sup> (Figure 2), this protocol was created through a cyclical and reformative process in collaboration with the community partner. Thus, development of the protocol began prior to the start of the study, as we strengthened our community partnership and co-designed the study, and it continued as we recruited and interviewed participants, and analyzed and disseminated findings. As interviews progressed, researchers noted which methods were successful and which needed improvements. Refinements were discussed and approved by the full team before incorporation. At the end of the third year of the project (2023), researchers and the community partner were able to reflect on the entirety of the project, discuss important components and recommendations, and finalize the protocol guide.

**Figure 2: Participatory Action Research Spiral**<sup>18-19</sup>





## **The Protocol**

Section I of the protocol presents its purpose and a brief history of Native Hawaiian people and their experiences with unethical research. This is followed by positive examples of Native Hawaiian-led research and research frameworks.

Section II presents tips for developing a strong foundation for research projects, such as articulating researchers' positionalities and building relationships with the community prior to conducting research. Other subsections explore potential research roles for community members and provide tips on working together to develop research questions and proposals, create consent forms and data-sharing agreements, conduct respectful interviews, disseminate findings, and thank participants.

## **Selected Tips**

Researcher Self-Knowledge and Reflection. When conducting community-based research, each partner should reflect on their individual and group motives and discuss how privilege and positionality may affect biases, intentions, interpretations, and power within a research project.<sup>20</sup> Without practicing reflexivity, researchers may unintentionally harm communities by reifying inaccurate stereotypes, stigmas, and power imbalances.

Our research team, which included four Native Hawaiians, one Asian, and two Caucasians, participated in reflection activities throughout the project. All members were challenged to reflect on their social indicators, job titles, privileges, motives, insider-outsider traits, and how their positionalities and power may affect their interactions. Examples of the questions researchers asked themselves and each other included: “Who is my “community?,” “What privileges do I hold?,” “How does my positionality and power affect how I interact with community members?,” and “What steps do I need to take to ensure that the space I hold in this

community does not lead to harm?” Through these discussions, we decided that Native Hawaiian team members should conduct the interviews, as they could identify and build upon genealogical and cultural connections with participants.

Building Relationships and Entering the Community. The guide summarizes tips on building and maintaining community relationships. This includes asking about and following established cultural or research protocols and offering to provide training on research and other requested topics. Established friendships between partners and a shared desire to answer specific research questions help facilitate trust and prioritize benefits. For this project, the two entities worked together to conceptualize the study, refining the project design to benefit kūpuna and avoid overtaxing ALU LIKE staff. Staff buy-in was essential, as researchers relied on them to vouch for the researchers and the project, identify elders willing and able to participate, explain the project, obtain consent, and schedule and facilitate interviews.

Designing the Research. Hā Kūpuna and ALU LIKE believed that individual interviewing, as opposed to focus groups, would be the best approach to data collection. Initially, Hā Kūpuna staff envisioned a 1-hour interview focused on healthcare experiences. However, ALU LIKE staff advocated for three 1-hour interviews with each elder to build trust and increase opportunities for elders to socialize during COVID-19. The first interview centered around sharing personal history and establishing rapport. The second interview focused on the elders’ strengths, resiliencies, and values they would like to pass to future generations. The third interview explored elders’ experiences with allopathic healthcare and Hawaiian health practices. Due to COVID-19, interviews were conducted via Zoom, which also provided elders with opportunity to increase their online communication technology skills. With the extra time afforded by multiple interactions, interviewers were often able to establish familial and social

connections with participants, and elders seemed more at ease and willing to share more deeply as the interviews progressed. However, adjusting the project to include three interviews required additional time and hiring a third graduate assistant to support transcript cleaning and coding.

Consent Forms and Institutional Review Boards. University researchers must apply for approval for human studies research through their Institutional Review Board. Community partners that help with interviewing and interpretation should be added as key personnel and assisted in securing required ethics certifications. Many universities provide sample consent forms that prompt for an explanation of the research purpose, data collection methods, benefits and foreseeable risks, compensation, confidentiality statement, and statements on voluntary participation and withdrawal. However, community partners should review consent forms to ensure they are written in language that will be accepted and understood by participants. Researchers should ask about and comply with any formal or informal processes of the community partner for approving research projects. Although ALU LIKE did not have its own review board, the university-based consent form was discussed in several meetings and tested with several elders before it was finalized.

Conducting Interviews. Interviews should be conducted in a private location where the participant feels comfortable to share but also have access to assistance if needed. Interviewers should practice interviewing beforehand, so they know the interview questions well. They should be respectful and tactful in asking questions, listening to responses, prompting, or clarifying as needed. Providing participants with the interview questions ahead of the interview increases transparency and is particularly useful if interviewees are hard of hearing. Finally, researchers should close the interview on a positive note, expressing gratitude for the participant's

willingness to share, thanking them for their time and stories, answering any questions they may have, and reviewing how and when findings will be shared.

Hā Kūpuna researchers found it worked well to introduce themselves and take time to review the consent form, reminding interviewees that there are no right or wrong answers and that they could decline to answer, take a break, or withdraw. The elder was in turn invited to introduce themselves, and researchers would gently look for shared connections to people and places significant to the elder. Actively fostering mutuality helped to build trust and put elders at ease. ALU LIKE staff commented that elders felt heard when interviewers expressed understanding, asked follow-up questions, and thanked them for sharing. They also noted how elders' comfort with sharing and with technology increased over the three interviews.

Reciprocity and Incentives. To honor the value of reciprocity, members should receive benefits for their participation. Gifts need to be negotiated within budgetary and bureaucratic limits, but should be meaningful and reflect sincere gratitude for the participant's time and contribution.

In our project, each interview participant received audio and video interview recordings on a thumb drive, as well as transcripts in a book format. Additionally, for each elder, Hā Kūpuna staff drafted a 2-page personal story of achievements and values they wanted to pass down. This story was edited and approved by the participant. Elders appreciated having these documents to share with family. Participants also received small packets of 'ai pono (healthy foods) such as pa'akai (Hawaiian salt) and māmaki tea. ALU LIKE staff also received gifts, including books on Hawaiian cultural practices.

Analysis and Dissemination of Findings. Findings must not be used to harm the research population. Ways to avoid this include continuously checking data and findings with participants

and discussing with community partners how findings can improve health for individuals and communities.

Prior to data coding, two Hā Kūpuna researchers reviewed and edited each transcript. The transcripts were then shared with the interviewee, who was asked for corrections and clarifications. The team developed a codebook to intentionally capture elder and cultural strengths, rather than strictly capturing deficits.<sup>21</sup> Personal strengths were reflected in the 2-page kūpuna stories and in reports from the project as a whole. Deficits were reframed as structural and used to outline directions for improving community health. After we coded early transcripts, we improved the codebook by using a semantic approach to analyze participants' words at face value rather than positing underlying themes beyond their words.<sup>22</sup> Hā Kūpuna recommends this methodology when working with Indigenous communities, as it is a realist approach to epistemology and allows for the interpretation of the participant's words as direct reflections of their lived experience, rather than interpreting their responses as socially constructed reflections. Findings were shared after data from ten kūpuna were coded, again after 20, and then at the end of all coding. Partners also jointly decided how to disseminate findings through infographics (Figure 3, Figure 4), ALU LIKE site visits (Figure 5), local and national presentations, and academic publications.

**Figure 3: Infographic Example**

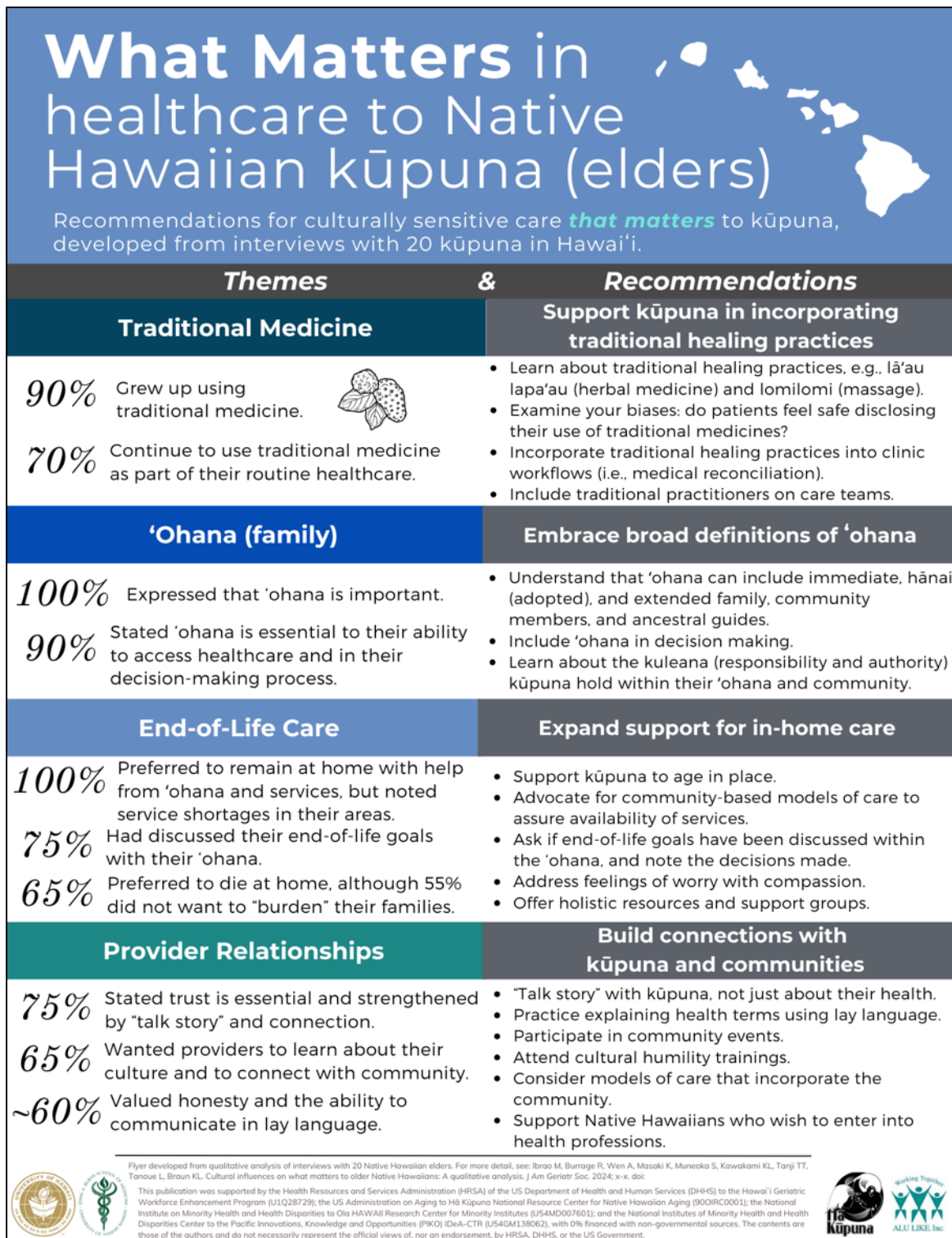
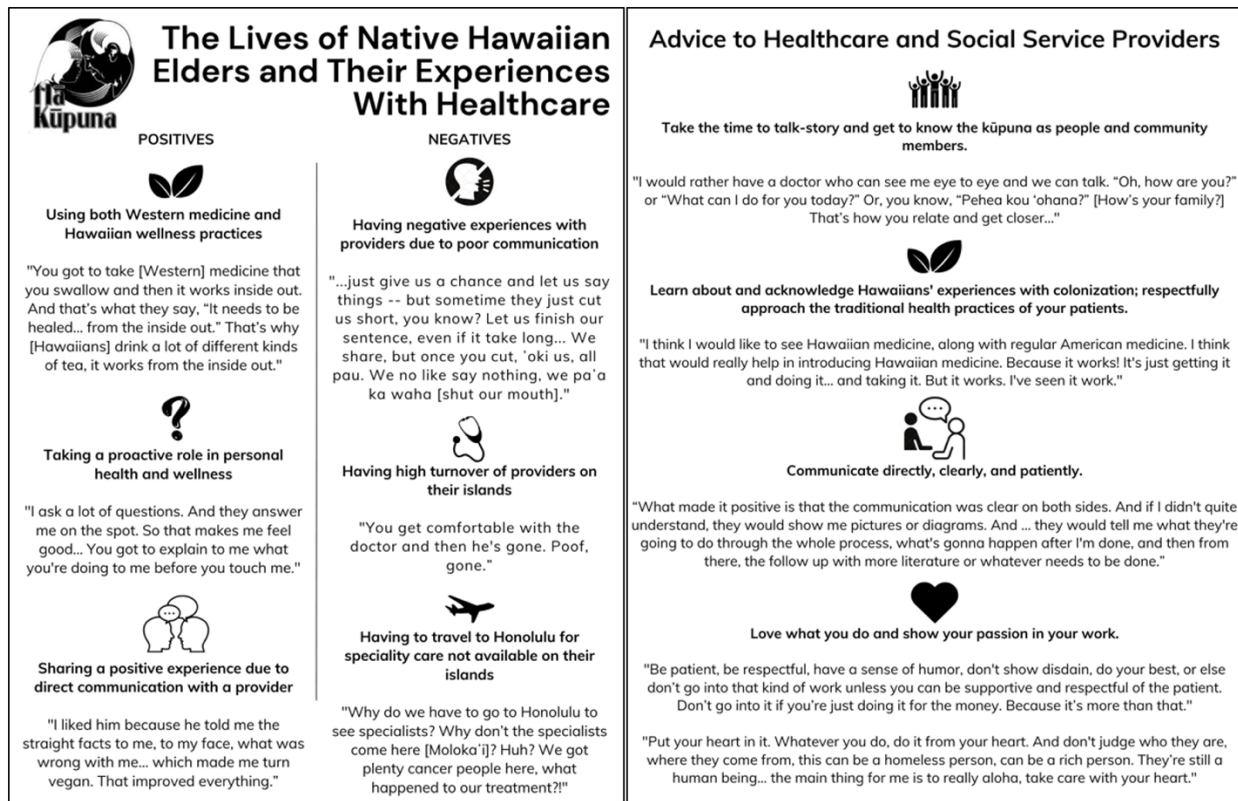


Figure 4: Infographic Example 2 (Disseminated at ALU LIKE Site Visit)





**Figure 5: Photo from ALU LIKE, Inc. Site Visit**





## **Conclusion**

The qualitative guide was created and tested through the partnership between ALU LIKE and the University of Hawai'i. The team hopes that researchers working with Indigenous and minoritized communities can use this guide to help decolonize Western research processes in their own communities. Download the guide at <https://manoa.hawaii.edu/hakupuna/qualitative-interviewing-guide/>

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**Figure Legend**

<b>Figure</b>	<b>Description</b>
1	A descriptive timeline showcasing the longstanding partnership between Hā Kūpuna and ALU LIKE, Inc.
2	A model titled the “Participatory Action Research Spiral” which exemplifies the collaborative communication process that occurred between Hā Kūpuna and ALU LIKE while developing and testing the qualitative protocol (tool).
3	An infographic co-created by Hā Kūpuna and ALU LIKE regarding “‘What Matters’ in healthcare to Native Hawaiian kūpuna (elders).”
4	An infographic sharing results from a qualitative study titled, “The Lives of Native Hawaiian Elders and Their Experiences with Healthcare,” which was disseminated back to study participants and other ALU LIKE members during a site visit.
5	ALU LIKE kūpuna share an impromptu hula during a visit with Hā Kūpuna staff sharing music and research findings.

\* Figures 2 and 5 are used with permission from Daniel G. Krutka, PhD.