

Papa Ola Lōkahi

E OLA MAU A MAU

THE NEXT GENERATION OF NATIVE HAWAIIAN HEALTH

DATA GOVERNANCE REPORT

E OLA MAU A MAU – THE NEXT GENERATION OF NATIVE HAWAIIAN HEALTH

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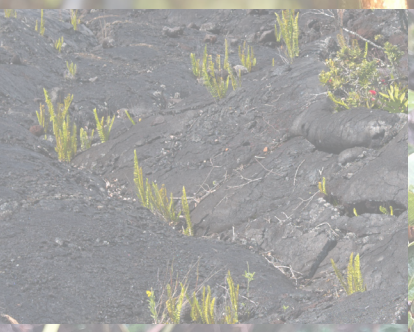
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Chapter Six:
Data Governance

Data Governance

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Executive Summary

Increased Understanding

- Data sovereignty is the right of the nation to govern the collection, ownership, and application of its own data.
- Data governance is a critically important component to improving Native Hawaiian health.
- Adverse societal-level factors complicate the issues regarding quality data and data sovereignty for Native Hawaiians.
- Qualitative data can be an integral part of Native Hawaiian health data.
- Availability and disaggregated use of quantitative data have increased for Native Hawaiian health data.

Effective and Promising Approaches

- Large existing health data sets allow for a relatively efficient way to gain information regarding Native Hawaiian health.
- Enhancing quantitative methodologies with more wholistic, qualitative, and mixed-method approaches increases the cultural meaningfulness and utility of Native Hawaiian health data.
- Collaborations and partnerships among Native Hawaiian-serving organizations and researchers increase the yield from Native Hawaiian health data.
- Advocacy on the part of organizations is beginning to change policies, practices, and laws regarding Native Hawaiian data practices.

Gaps

- The Office of Management and Budget Directive 15 (OMB 15), adopted in 1997, provides guidance on maintaining, collecting and presenting data on race and ethnicity across federal agencies. Specifically, OMB 15 distinguishes Asian American from Native Hawaiian or Other Pacific Islander, yet non-compliance is high among federal agencies. Many large data sets aggregate the two groups or present the data as one “API” rubric. Aggregated data misrepresents the needs of all groups.
- The Data Governance Task Force lacks resources, capacity, and continuity to sustain meaningful positive impact.
- There remains a lack of culturally meaningful, disaggregated data, both qualitative and quantitative, on Native Hawaiian health.
- There is insufficient organization and coordination of resources to optimize culturally meaningful data conceptualization, collection, storage, security, access, analysis, interpretation, dissemination, and use.
- There is insufficient workforce capacity to optimize the utility of Native Hawaiian health data.

Recommendations for Impact

- **Enforce use of OMB Statistical Directive 15 (1997) across all Federal agencies.**
- **Require State of Hawai‘i agencies to similarly separate Asian American and Pacific Islander data. Furthermore, require the State to collect data as to whether client or beneficiary is Native Hawaiian, i.e. “Are you Native Hawaiian? YES or NO.”**
- **Support, sustain, and expand the Native Hawaiian Data Governance Task Force.**
- **Strategically support and foster culturally meaningful, disaggregated data on Native Hawaiian health.**

- **Increase the coordination and governance of, and resources/funding related to, Native Hawaiian health data.**
- **Establish a sufficient workforce to optimize the utility of Native Hawaiian data.**

Introduction

The Kumulipo:
A Hawaiian Creation Chant
(Queen Liliuokalani, 1978), Ka Wa Umi[1]

O mai la, o Laʻilaʻi ka paia
O Kane a Kapokinikini ka pou,
o Kiʻi ka mahu
Hanau Laʻiʻoloʻolo i noho ia Kapapa
Hanau Kamahaʻina he kane
Hanau Kamamule he kane
O Kamakalua he wahine
O Poʻele-i e-holo, kama
O Poʻele-a a-holo, kama
O Wehi-wela-wehi-loa
Hoʻi hou Laʻilaʻi noho ia Kane
Hanau o Haʻi he wahine
Hanau o Haliʻa he wahine
Hanau Hakea he kane
Hanau ka muki, muka, mukekeke

Mulea, kukuku, kunenewa
Moku, monu, mumule ana
Mumule wale ana Kane i ka mule
I mule, i keʻeo, i ka maua
I ka wahine weweli wale
Peʻe e kane ia e hoʻohanau kama
E hoʻohanau kama i kana keiki
Hoʻole ka lani iaia muli wale

Haʻawi i ka ʻape kapu ia Kiʻi
E Kiʻi no ke moe iaia
Haʻili Kane i ka mua, heleu wale
Haʻili o Kiʻi o Laʻilaʻi i ka muli lae
punia
Pehi i ka pohaku hailuku ia Kane
O kani ka pahu ke wawa nei ka leo
O kaʻu hoʻailona ia, kaka muli
Huhu lili Kane moe muli ia mai la
O ka ewe o kana muli i muli ai
Haku ai kama hanau mua
Imua ia Laʻiiaʻi, imua ia Kiʻi
Ka laua kama hanau lani la
Puka--

Maila, with Lailai for protection,
And Kane of Kapokinikini was support,
Kii was helpless.
Laioloolo was born and lived at Kapapa.
Kamahaina was born a man,
Kamamale was born a man,
Kamakalua a woman,
Poeleieholo a child,
Poeleaaholo a child,
Then Wehiwelawehi loa.
Lailai went back to Kane,
Hai was a born a woman,
Halia was born a woman,
Hakea was born a man,
The Muki, Muka, and Mukekeke were born
(kisses, smacks, chirruping),
Smacks, boils, and other weaknesses,
Moku, Monu, mumuleana (strife, broils, and huffiness),
The men became speechless from sulkiness,
Became cross from envy of ours,
Of the woman who is brave and fearless,
Then hid and dared not claim kin,
To claim kin with her child.
The heavens deny the right of kin
(being of younger branch),
Yield the sacred right to Kii;
For to be with Kii, ʻtis his claim.
Kane then taunts her eldest for this,
Kii retaliates through Lailai for his being the younger branch;
He flings a stone and hits Kane;
Then is heard the sound of the drum,
The sign of life for the younger.
Kane, furious with jealous anger, struck her for faithlessness
For the younger child of the younger branch.
That is why first-born are always hakus (superiors, lords),
First through Lailai, next by Kii,
Their first-born with sacred birthright
Is born.

[1] Chant Ten

❖ Kumulipo

The opening oli,[2] the Kumulipo, our beloved account of the beginning of life for our pae ʻāina[3], life sources, creatures, and kāne[4] and wahine,[5] illustrates that our data sovereignty journey is rooted in the traditions of our ʻike kūpuna[6] through moʻolelo[7] and oli. The retelling of the story of origin for Native Hawaiians is important in moving forward because it insists that any Western thoughts and methodologies around the idea of data governance must be set aside in order to breathe life into the stories that recall the customary Hawaiian ways of knowing and doing.

❖ Background

To contextualize the concept of Native Hawaiian data and data collection, one must look to the past to inform the present. Native Hawaiians are the indigenous people who settled the Hawaiian Islands and founded their sovereign nation. Authenticated documentation, archaeological inquiry, oral histories, chants, and genealogies validate this fact (Kamakau, 1961, 1992a, 1992b; Malo, 1951). Further confirmation is provided in more recent history by the Hawaiʻi Legislature, Act 195, which stated that the Native Hawaiian people are the "only indigenous, aboriginal, maoli[8] people of Hawaiʻi" (Native Hawaiian Roll Commission, 2011).

Hawaiian intellectual history is rich. Historical accounts show that through the Hawaiian traditional way of life, Native Hawaiians were scientists and innovators. For example, the ahupuaʻa[9] illustrated the sophisticated social system in which they carried out their everyday lives. Ruling chiefs had the kuleana[10] of creating an infrastructure that employed their makaʻāinana[11] efficiently—streamlining their talents and abilities to develop complex ʻauwai,[12] loko iʻa,[13] and loʻi kalo[14]—ensuring livelihood and food security for their increasing population. The way Native Hawaiians planted their crops and fished their seas was according to natural occurrences such as the phases of the moon and the changing of the tides.

To accommodate for sustainable daily living while trying to plan for rapid expansion, some forms of data collection and processing were utilized. During traditional times, there was no official written language; therefore, information and knowledge were typically passed down through genealogies, oli, or moʻolelo. Native Hawaiians consider their moʻokuauhau[15] as the connective tissue between them as a people, and as the moʻolelo of their people that provide guidance and knowledge.

It was not until the reign of Kamehameha III, also known as Kauikeaouli, that the Kingdom of Hawaiʻi began its careful balancing act of Western modernization through establishing a governance structure in written form, while keeping the nation intact. Hawaiian wisdom was preserved in the Hawaiian language newspapers, which became a pathway to understanding Hawaiian epistemology and ontology. Many other sources, such as geographical surveys, biographies, historical narratives, translations, political and economic analyses, and poetry were catalogued over the years by various scholars. These efforts demonstrated that Native Hawaiians had the forethought to record these pieces of data so that they could transmit their ancestral knowledge to future generations.

❖ Data Sovereignty

As a collective from various health professions, the Data Governance Task Force (DGTF) desires to achieve data sovereignty, by which we, as health professionals, providers, and patients, might regain control over the data methodologies for Native Hawaiian health practices and regain sovereignty over the stages of data collection to dissemination of the data and the results. How do we honor our traditions of past data practices to understand the richness of our ʻike kūpuna?[16] Moreover, how do we use these guiding principles of our moʻolelo,[17] like the Kumulipo, to inform our practice and transform data sovereignty into a functional practice we use today? The DGTF states that data sovereignty is an openly defined process to regain control of our indigenous story and acknowledge the significance of indigenous perspectives on research and data governance.

[2] oral communication
[3] archipelago
[4] men
[5] women
[6] traditional, elder knowledge
[7] story
[8] native, indigenous, aborigine
[9] land division(s)
[10] responsibility
[11] commoners
[12] irrigation
[13] fishponds
[14] taro terraces
[15] genealogy
[16] traditional, elder knowledge
[17] stories

Pūpūkahi i holomua

Unite in order to progress

ʻŌlelo Noʻeau #2758
(Pukui, 1983, p. 302)

"[Community outreach] starts the conversation, but you need to have facts in order to get the information and plan your programs appropriately. We want to get the data so that we know that anything that we recommend is based in truth and reality, but that's not the only benefit; that's not the only goal of the project. When we go out into the community, what we're actually trying to do is stimulate conversation and activity and investment and teamwork among the people that are in each local community. What this does is not only helps facilitate future projects that are designed on a state-wide level, but it also facilitates projects that are designed and implemented locally by the people who have come together as part of this small team. So it's about building relationships, and the relationships are as important a goal and are going to be as important in any effort to improve health as [are] the hard data. One does not come at the expense of the other. They actually go hand in hand. The data and the relationships together are going to lead to a solution that improves public health."

Gavin Uchida, DDS, MBA
Dental Director, Family Health Services Division
State of Hawai'i Department of Health

Increased Understanding

- **Data governance is a critically important component to improving Native Hawaiian health.**

The 1985 *E Ola Mau: The Native Hawaiian Health Needs Study* (Native Hawaiian Health Research Consortium, 1985) reported on the quantitative results that existed at that time. Despite the importance of the findings reported in 1985, there remained a lack of data in many key areas. Without meaningful, valid, and timely information regarding Native Hawaiian health, we will not know how Native Hawaiians are progressing, and subsequently what needs to be done to improve Native Hawaiian health. Therefore, we have added the Data Governance Task Force (DGTF) to this *E Ola Mau a Mau* update not only to address Hawaiian data quality and scope, but also to speak to the issue of data sovereignty. In addition, the inclusion of the DGTF will begin to address the needs of the other *E Ola Mau a Mau* task forces around the disparity of Native Hawaiian data, and the analytic results that will be used to inform practice, research, and priorities for funding.

- **Adverse societal-level factors complicate the issues regarding quality data and data sovereignty for Native Hawaiians.**

Macro-level influences upon indigenous health have been identified. These include social determinants of health, colonialism, and historical trauma.

- Social determinants of health are the complex and interconnected structures, circumstances, environments, institutions, and systems that contribute to or harm the health of individuals and communities. Social determinants of health are shaped by cultural, political, environmental, social, and economic conditions. (Office of Hawaiian Affairs, 2015, p. 3).
- The structural and systemic contexts render colonialism a distal determinant of health. Distal determinants are generally beyond the individual or community's control and are the *causes of causes* of unjust life situations for certain groups or people over others. Exploring colonialism as a distal determinant of health is linked to examining how current ideologies and historic events influence the health of contemporary Indigenous peoples (Czyzewski, 2011, p. 4).

Historical trauma, a concept introduced by Maria Yellow Horse Braveheart, PhD, is the cumulative emotional and psychological wounding across generations, including the lifespan, which emanates from massive group trauma (Brave Heart, 2003).

Within the context of data sovereignty, these societal-level factors not only adversely impact the health of Native Hawaiians, but also influence data quality and governance. Native Hawaiians' rich epistemological history of knowledge has been largely suppressed and marginalized over the years. The result has been that Native Hawaiians, for generations and generations, have believed that their ways of knowing and living were not an adequate basis for reasoning and understanding by Western standards. Native Hawaiians currently ask, "Can our Native Hawaiian data be truly trusted?" There are historic barriers to Native Hawaiian use of Western mainstream health care services due to socioeconomic disadvantage, discrimination, cultural misunderstanding, and mistrust, making it challenging to capture accurate, timely, and longitudinal data. Further, has a lack of data resulted in lack of services,

and/or have inaccurate data resulted in inappropriate interventions offered to Native Hawaiian communities?

- **Qualitative data can be an integral part of Native Hawaiian health data.**

In addition to the previously identified sources of qualitative data (e.g., ancestry, genealogy, chants, Hawaiian newspapers, geographic surveys, biographies, historical narratives, poetry), Hawaiian values, beliefs, and healing practices have been increasingly incorporated throughout the development of practitioners and staff, in direct service provision, and in the evaluation and research process. This more integrative approach has increased confidence and reliance on cultural ways of data gathering to tell the story of our communities and has been a better reflection of the Native Hawaiian families and individuals whom we serve. Qualitative data from Native Hawaiian communities complement quantitative data and serve as a foundation for potential solutions to barriers to equitable health care.

- **Availability and disaggregated use of quantitative data have increased for Native Hawaiian health data.**

Along with the increased emphasis on quantitative data to inform health practices, there has been an increase in the collection, availability, use, and disaggregation of Native Hawaiian health data. Historically, even when available, data from Native Hawaiians and Pacific Peoples were aggregated together with data from Asian Americans in most health surveys and demographic data. The results from the analyses of these data obscured significant health disparities, with potential adverse impact on access to health care and other resources for Native Hawaiians.

Hoʻomoe wai kahi ke kaoʻo.

Let's all travel together like
water flowing in one direction.

ʻŌlelo Noʻeau #1102
(Pukui, 1983 p. 118)

Effective and Promising Approaches

- **Large existing health data sets allow for a relatively efficient way to gain information regarding Native Hawaiian health.**

There are numerous examples of large existing data sets being utilized to gain knowledge regarding Native Hawaiian health. Although in some cases there may be a fee involved in the use of the data, the overall cost is low when considering that it bypasses the need to conceptualize the survey, gain access to the sample, collect the data, and clean up the data. These data sets include the following (see http://hhdw.org/health-reports-data/data-source/):

- Vital Statistics
- Behavioral Risk Factor Surveillance System (BRFSS)
- Hawaiʻi Health Survey (HHS)
- Pregnancy Risk Assessment Monitoring System (PRAMS)
- Youth Risk Behavior Survey (YRBS)
- Hawaiʻi Youth Tobacco Survey (YTS)
- Hawaiʻi Health Information Corporation (HHIC) (emergency room & inpatient; https://hhic.org/)

- **Enhancing quantitative methodologies with more wholistic, qualitative, and mixed-method approaches increases the cultural meaningfulness and utility of Native Hawaiian health data.**

Native Hawaiian-serving organizations that utilize non-quantitative approaches to enhance quantitative methodologies obtain more culturally meaningful results and information on Native Hawaiian health, and thereby advance cultural wellness and wholistic health.

As just one example, the mission of the Center for Culturally Responsive Evaluation and Assessment – Hawaiʻi (CREA-Hawaiʻi) is to use a Native Hawaiian lens to offer empowering, values-based evaluation approaches that support insights and conclusions which promote equity and justice in the diversity that is Hawaiʻi. To do this, we will weave together and share cultural knowledge, tools, and practices that are grounded in and affirm a Native Hawaiian worldview. Our first work product will be a Native Hawaiian evaluation framework that can be used by evaluators, program managers, communities, and funders to guide evaluation practice from their various positions. The framework will lay the foundation for the next steps of training and advocacy. (http://creablog.weebly.com/blog/introducing-crea-hawaii)

- **Collaborations and partnerships among Native Hawaiian-serving organizations and researchers increase the yield from Native Hawaiian health data.**

Native Hawaiian health-serving organizations have created a network of strong partnerships with one another and with researchers, thus tearing down walls and silos. These partnerships improve the quality of data collected, analyzed, and reported.

- **Advocacy on the part of organizations is beginning to change policies, practices, and laws regarding Native Hawaiian data practices.**

Service providers, community leaders, community members, and researchers are taking action to submit testimony and advocate for efficient ways to report qualitative and wholistic indicators of health.

Kau i Kāpua ka poʻe polohuku ʻole.

Those without resources will land at Kāpua.

Without resources one gets nowhere.

ʻŌlelo Noʻeau #1608
(Pukui, 1983 p. 173)

Gaps

- **The Data Governance Task Force (DGTF) lacks resources, capacity, and continuity to sustain meaningful positive impact.**

Despite greater recognition of the importance of quality data and data governance to improve Native Hawaiian health, the DGTF was only recently formed as a key component of *E Ola Mau a Mau*.

- **There remains a lack of culturally meaningful, disaggregated data, both qualitative and quantitative, on Native Hawaiian health.**

Despite the progress that has been made in conceptualizing, collecting, accessing, disaggregating, analyzing, and disseminating Native Hawaiian health data and results, there remains a substantial gap in culturally meaningful Native Hawaiian health data for epidemiology purposes and evaluation of services. In particular, colonized data methods are neither current nor comprehensive in telling an indigenous story of Native Hawaiian well-being and health status. For example, quantitative methods tend to emphasize more easily measurable constructs.

- **There is insufficient organization and coordination of resources to optimize culturally meaningful data conceptualization, collection, storage, security, access, analysis, interpretation, dissemination, and use.**

There remain gaps in the organization and coordination of data-related tools, community engagement, partnerships, and a common repository of culturally meaningful data. Within the context of data sovereignty, there does not exist an entity or partnership that fosters and leads the processes of data-linking, repository, and sharing across disciplines. Technology is being under-utilized to streamline data collection, storage, and sharing. There may be an undercurrent of concern that resources devoted to data and research will detract from direct services and other opportunities for Native Hawaiian communities.

- **There is insufficient workforce capacity to optimize the utility of Native Hawaiian health data.**

There are not enough experts working in the area of Native Hawaiian health data and research to optimize Native Hawaiian health (e.g., mixed-method researchers, technology specialists).

E ala! E alu! E kuilima!

Up! Together! Join hands!

A call to come together and tackle a given task.

ʻŌlelo Noʻeau #258
(Pukui, 1983 p. 32)

Recommendations for Impact

The methodological and conceptual indigenous framework that will increase data availability, accountability, and governance will take a wholistic-health and cultural-wellness approach, providing reports for the Native Hawaiian population. As exemplified by the Kumulipo, order and methods to account for the creation and well-being of our communities have been a traditional part of our history. Therefore, data governance and research methodologies should be developed to ensure that research with indigenous peoples can be more respectful, ethical, and useful.

The approaches to extend this governance and address each gap will include the following recommendations:

- **Support, sustain, and expand the Native Hawaiian Data Governance Task Force (DGTF).**

- The DGTF should be continued beyond *E Ola Mau a Mau*. The mission of the DGTF would be to help fulfill the Native Hawaiian health data needs, including the culturally meaningful conceptualization, collection, storage, security, analysis, dissemination, sharing, and use of Native Hawaiian health data. The mission may include addressing the remaining recommendations of this *E Ola Mau a Mau.*
- The DGTF could be the lead entity to coalesce a network of dedicated individuals and groups to foster a wholistic health and cultural wellness approach within an indigenous methodological framework. Members would include individuals from Hawaiian communities and Hawaiian community organizations, and other experts in Native Hawaiian health data.

- **Strategically support and foster culturally meaningful, disaggregated data on Native Hawaiian health.**

  - A comprehensive community needs assessment should be carried out to examine current and future needs of Native Hawaiian health data (e.g., community-defined meaningful health outcomes). The results would drive the culturally meaningful use of available data and the pursuit of future data.
  - Depending on the purpose of particular Native Hawaiian health data, mixed-method approaches that consider both qualitative and quantitative data should be utilized to ensure cultural meaningfulness. The latter would include health data coded in such a way as to allow for analysis of health disparities among different ethnic groups in Hawai‘i.

- **Increase the coordination, governance, and resources/funding related to Native Hawaiian health data.**

  - Coalesce a group of dedicated individuals who will provide coordination and governance of Native Hawaiian health data.
    - If deemed appropriate, this group could be the Native Hawaiian Data Governance Task Force (DGTF). Define each position and its specific responsibilities.

- Determine the model of indigenous data governance that will be utilized.

  - Bruhn (2014) identified three data governance models used for indigenous research: “In concluding this review, we might place the three major models—along with the steps between them—on a spectrum. At the one end is the single hierarchical organization, governing its data with a close focus on its own institutional needs. At the other is the theoretically limitless data commons, which promotes accessibility of data in a given community, subject to limited constraints. In the middle is the data partnership, where governance by a single organization gives way to genuine co-governance—shared decision-making—of the data asset” (p. 7).
    - As with our traditional ownership of data, it may be possible to begin with indigenous peoples’ stories to understand which model would fit the needs of Native Hawaiians. The Hawaiian concept of the piko[18] connecting Native Hawaiians to past and future generations could serve as a model for an inter-agency data system that links health data across communities, practitioners, and researchers.

- Develop and implement guidelines regarding data governance and sovereignty.

  - Allow for flexibility and modifications given the unique circumstances of each community or project, and the continually changing methodology and environment of data governance and sovereignty.
  - Given the principles of data governance and sovereignty, a variety of issues must be treated with sensitivity: (1) culturally meaningful data; (2) community-based participatory research (CBPR); (3) methods of consent and data collection; (4) linked data sets; (5) storage, security, accessibility, and sharing; (6) individual and community confidentiality; (7) autonomy and ownership; (8) responsible analysis, interpretation, and dissemination; and (9) regulations (e.g.,

[18] navel

review boards weighing risks and benefits, Health Insurance Portability and Accountability Act [HIPAA]).

- ❖ Where beneficial, offer tools and training opportunities to data users on topics ranging from culturally meaningful data to the interpretation and dissemination of results.
- ❖ Given the important role of technology with respect to health data, ensure the efficient use of technology throughout the process (e.g., data collection, storage, security, access).
- ❖ Foster and engage in trusting interdisciplinary collaborations and partnerships that will support Native Hawaiian data governance, sovereignty, and resources/funding.

    - ❖ One essential benefit of data governance and sovereignty is to encourage the rebuilding of Indigenous nations and communities and recovery of our own stories of the past and present. A unified understanding of the barriers to data governance generates a comprehensive gathering of researchers to engage in partnerships. These partnerships may work on a community level to identify empirical ways to collect data, to understand data and research needs of the community members, and to serve as a caveat in utilizing and changing larger systems. Partnerships should be of mutual benefit to the producer and user of the data. A major factor that has been absent in colonized research of Native Hawaiian communities is hilina‘i.[19] In the various roles and positions within the partnership, there should be confidence in the method and ability of each partner to act in a way that fits with Hawaiian values and with the community, first and foremost.

- ❖ Advocate for policies and legislation that foster Native Hawaiian data governance, sovereignty, and resources/funding.

- ❖ **Establish a sufficient workforce to optimize the utility of Native Hawaiian data.**

    - ❖ Through outreach, training, and sustainable efforts, increase the diverse workforce capacity that will be needed to optimize the use of Native Hawaiian data. Experts will be needed in the pursuit of culturally meaningful health outcomes, indigenous methodologies of assessment and evaluation (e.g., qualitative and mixed methods), indigenous research ethics (e.g., regarding community harm, human biological specimens, etc.), culturally sound dissemination guidelines (e.g., regarding authorship, community autonomy, etc.), and so on.

‘A‘ohe hana nui i ke alu ‘ia.

No task is too big when done together by all.

‘Ōlelo No‘eau #142
(Pukui, 1983 p. 18)

Conclusion

Culturally meaningful, high-quality data are at the heart of improving Native Hawaiian health. If we do not meaningfully define, collect, analyze, interpret, and use the results of these data, we cannot evaluate the status or trajectory of Native Hawaiian health. Despite the rich Hawaiian history of qualitative data, there remains a fundamental need for Native Hawaiian health data governance and sovereignty. Since the 1985 *E Ola Mau*, there has been increased understanding of the importance of Native Hawaiian data governance, adverse societal factors, the integral role of qualitative data, and the importance of disaggregating Native Hawaiian data. Effective and promising approaches to date have included the use of existing large data sets, the use of mixed-methods approaches, collaborations among Native Hawaiian-serving organizations, and advocacy that has begun to change data practices and policies. However, remaining gaps include (1) inadequate support for the Data Governance Task Force (DGTF); (2) a lack of culturally meaningful, disaggregated data; (3) a lack of organized, coordinated efforts; and (4) an insufficient data-related workforce. To address these gaps and attain meaningful impact, we recommend the following: (1) support and expand the DGTF; (2) foster more culturally meaningful, disaggregated Native Hawaiian health data; (3) organize a group that will enhance governance and sovereignty of Native Hawaiian health data; and (4) establish a sufficient workforce.

[19] trust, confidence

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