




# Creating Visibility: Advocacy for Native Hawaiian People Using Data

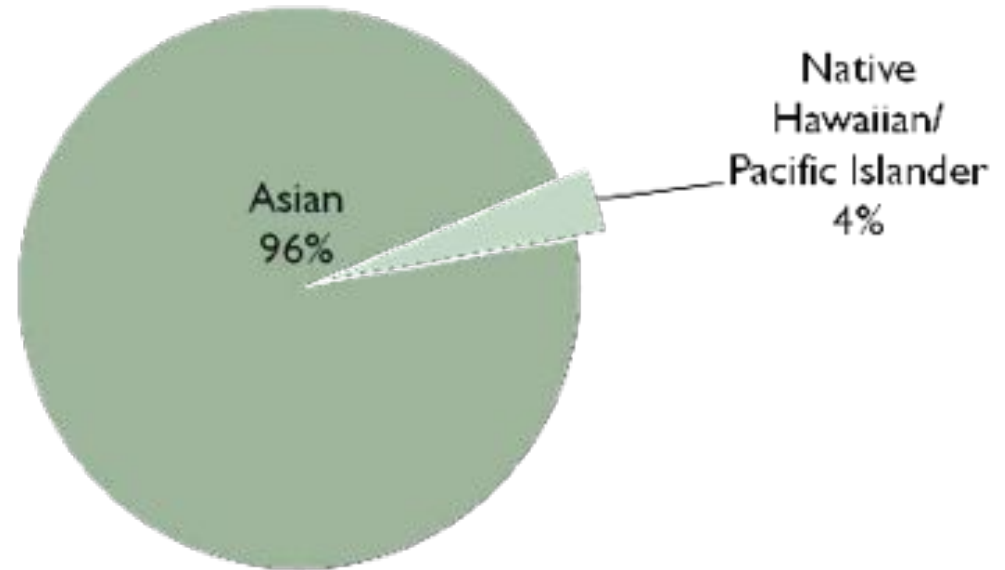
Dr. Maile Tualii  
Native Hawaiian Epidemiology Center

*Excellence in Data Collection, Analysis, and Reporting on the Health  
Status of Native Hawaiians and Other Pacific Islanders*

# Overview...

- ▶ Invisibility as a Determinant of Health
  - ▶ Overview of Native Hawaiian Epidemiology Center
  - ▶ Three Case Examples of Data utilization to Support Native Hawaiian people
    1. Liberating Data on Native Hawaiians and Other Pacific Islanders
    2. Supporting Native Hawaiian Health Clinics
    3. Bio-repository – Community Control Research
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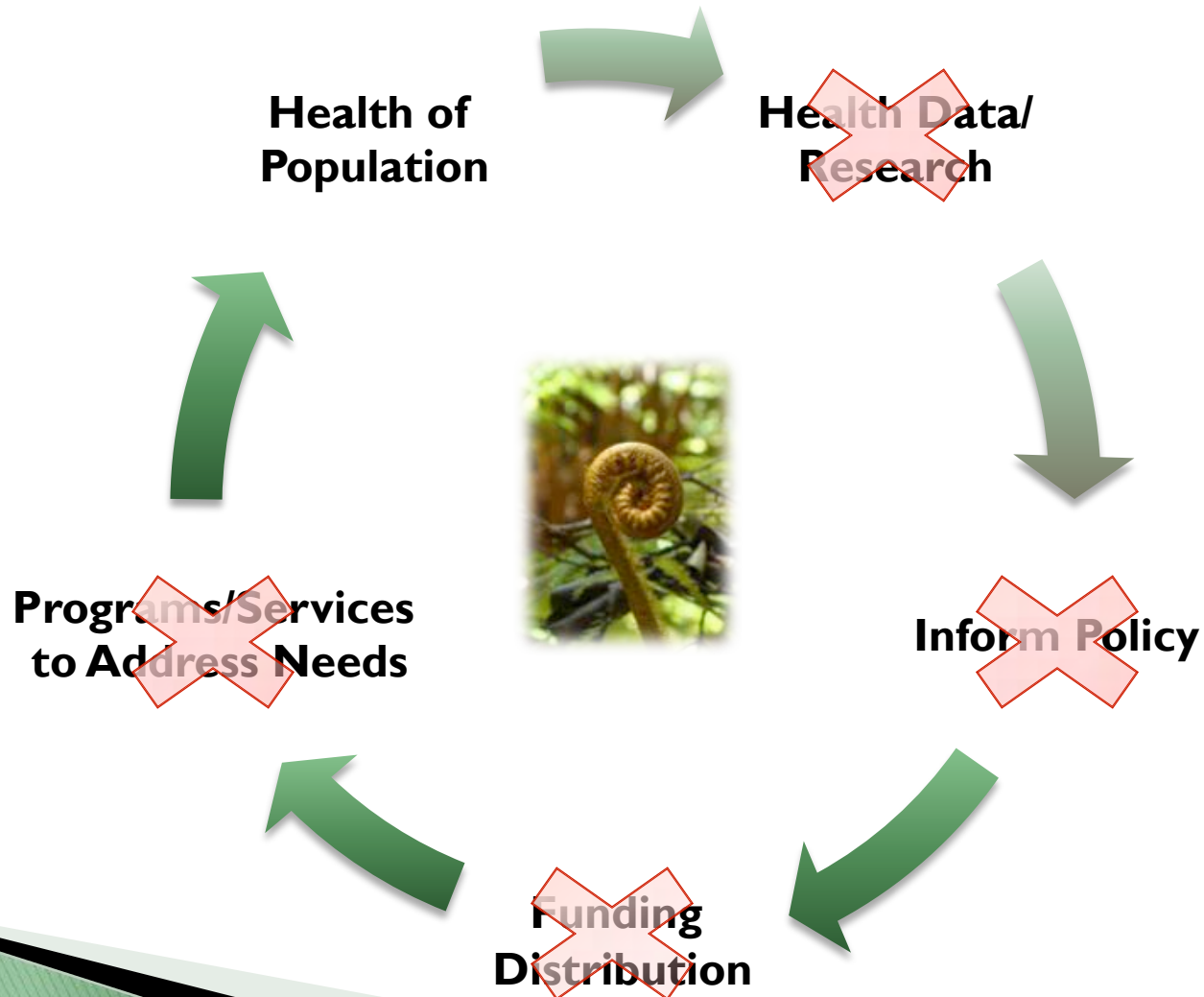
# Invisibility is a Determinant of Health



**Cancer:** Asian/Pacific Islander women are 30% less likely to have breast cancer as non-Hispanic white women.

Native Hawaiian women have the highest incidence and mortality rates for breast cancer in Hawai'i

# Information Cycle





**NATIVE HAWAIIAN**  
**EPIDEMIOLOGY CENTER**  
Accountability, Excellence, Culture and Science

- ▶ Established January 1, 2009
- ▶ Division of Papa Ola Lokahi
  - Authorization from Native Hawaiian Health Care Improvement Act – Health Care Reform Bill
  - Serves Native Hawaiians Nationally

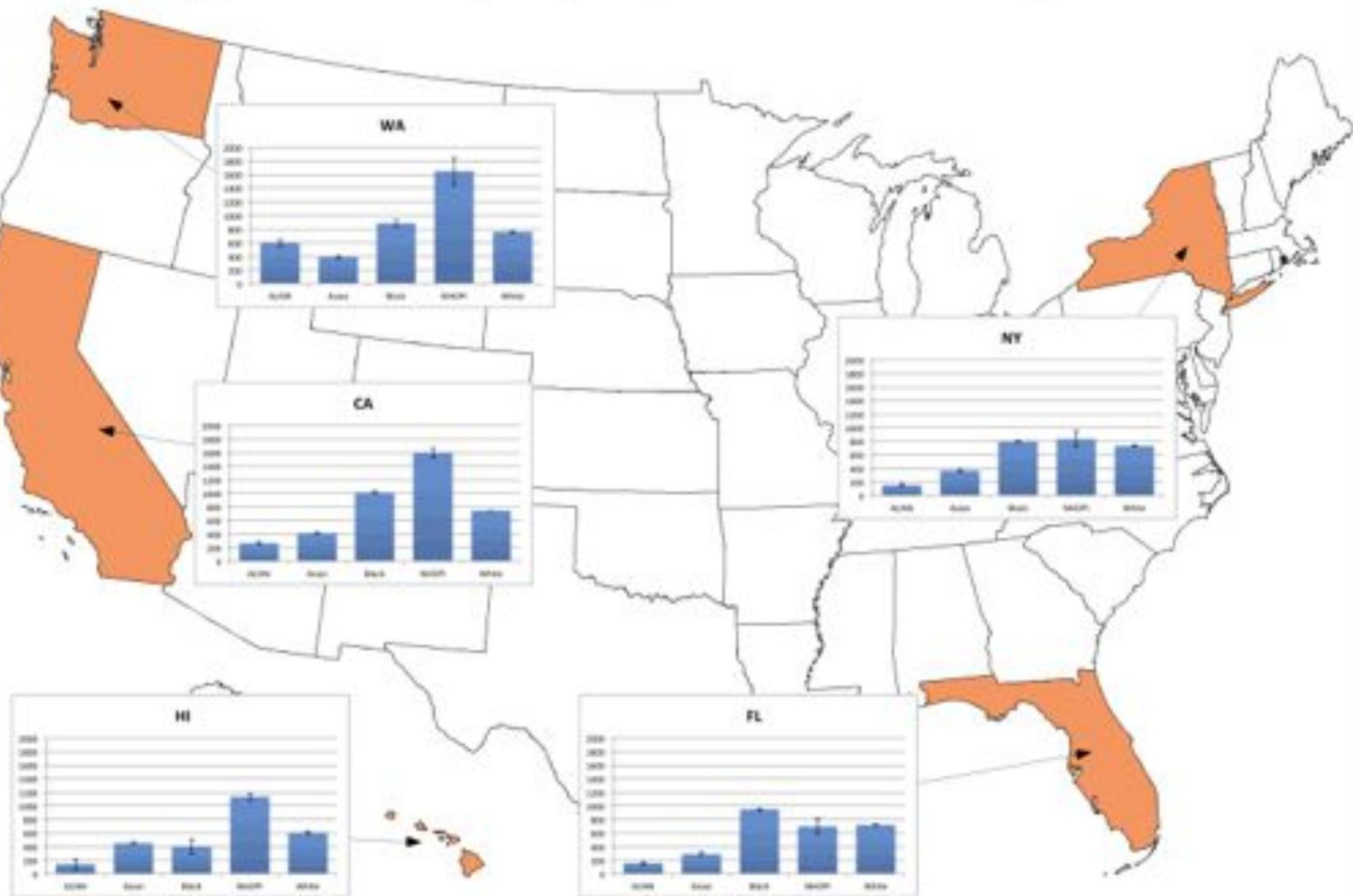


Papa Ola Lokahi  
Nana I Ka Pono Na Ma

# CASE 1: Liberating Data

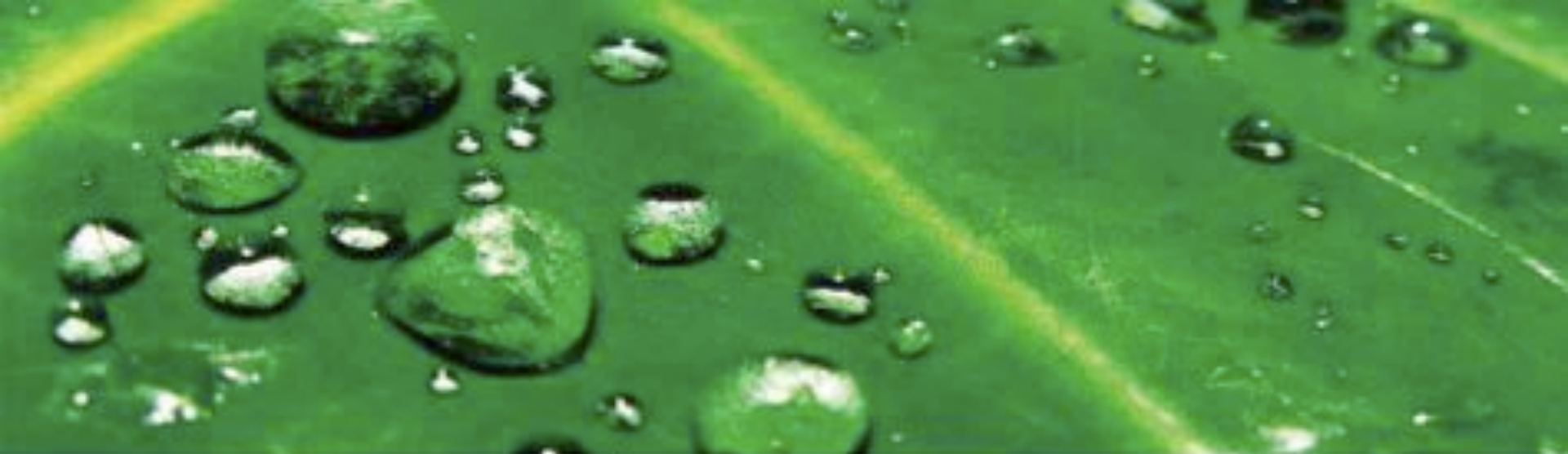


Age-Standardized Mortality Rates per 100,000 and 95% Confidence Limits by Race for 2005



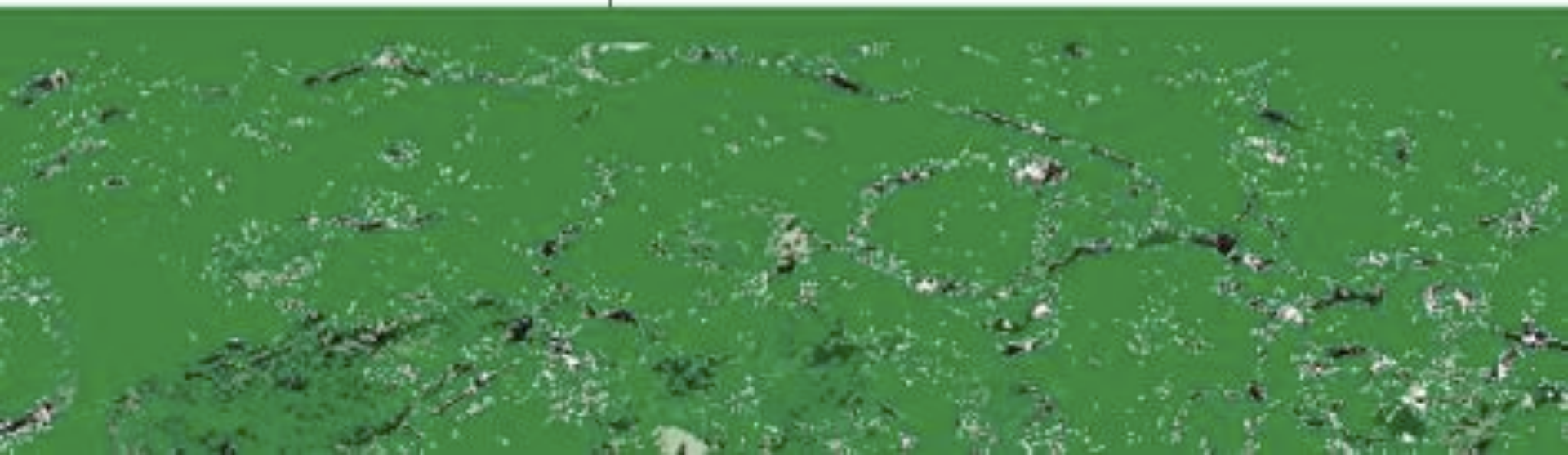
# CASE 2: Clinical Data Utilization for Program Assessment





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2010 Native Hawaiian Diabetes Care and  
Outcomes Audit Report:  
Aggregate Results from  
the Native Hawaiian Health Care Systems



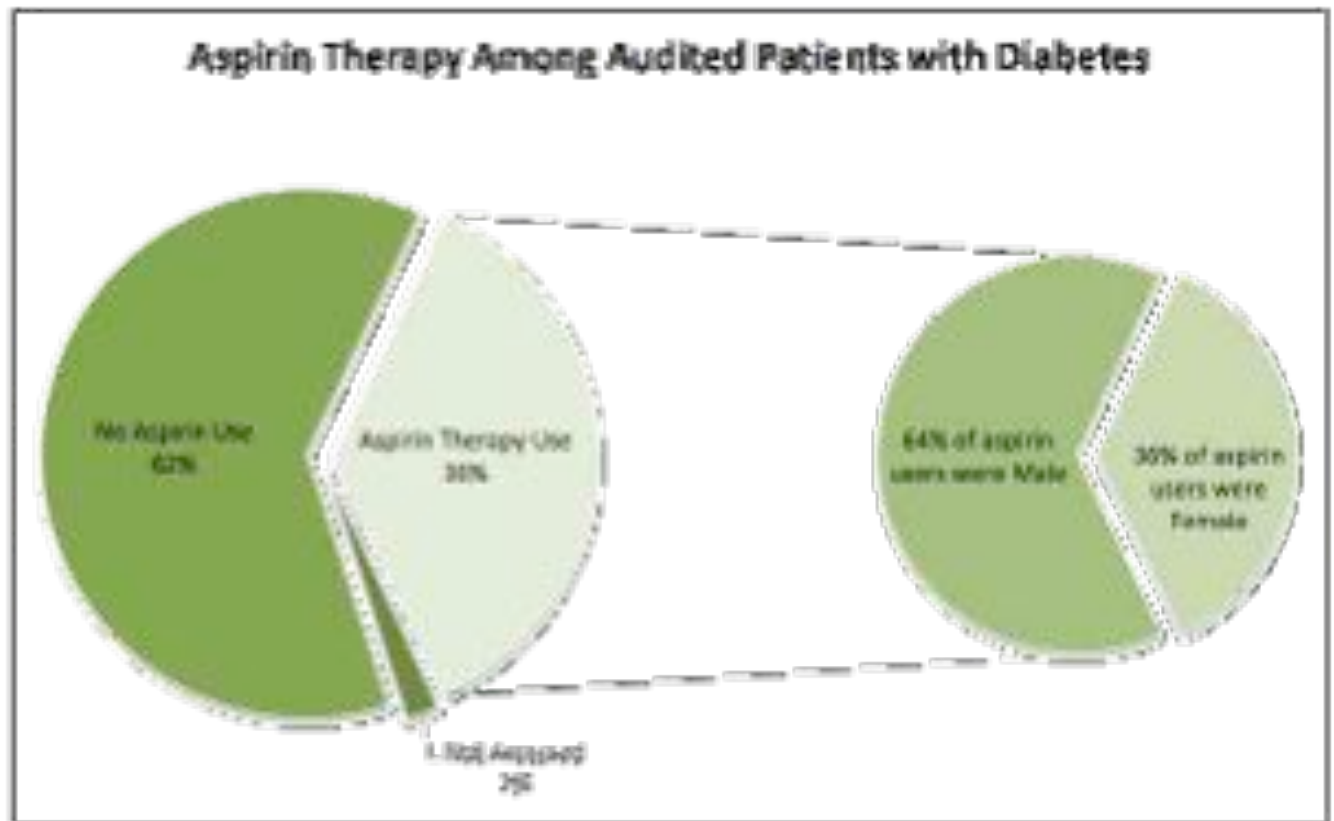
# 1 Standard

## A1c Assessment and Results among Audited Patients with Diabetes



**Description of Graphic:** 96% of audited patients in 2010 have a record of a recent A1c assessment. Among patients with A1c tests, 38% met "at goal" with measures under 7.0%. Over one-third of patients (39%) had median A1c values between 7.0% - 9.5%. 19% of patients were at highest risk with values greater than 9.5%.

# 3 Measure



**Description of Graphic:** In 2010, 98% of audited patients with diabetes were assessed for aspirin therapy use. Over one-third of audited patients (36%) were on aspirin therapy. Males made up about two-thirds of aspirin therapy users (64%) and over one-third (36%) were among females users.

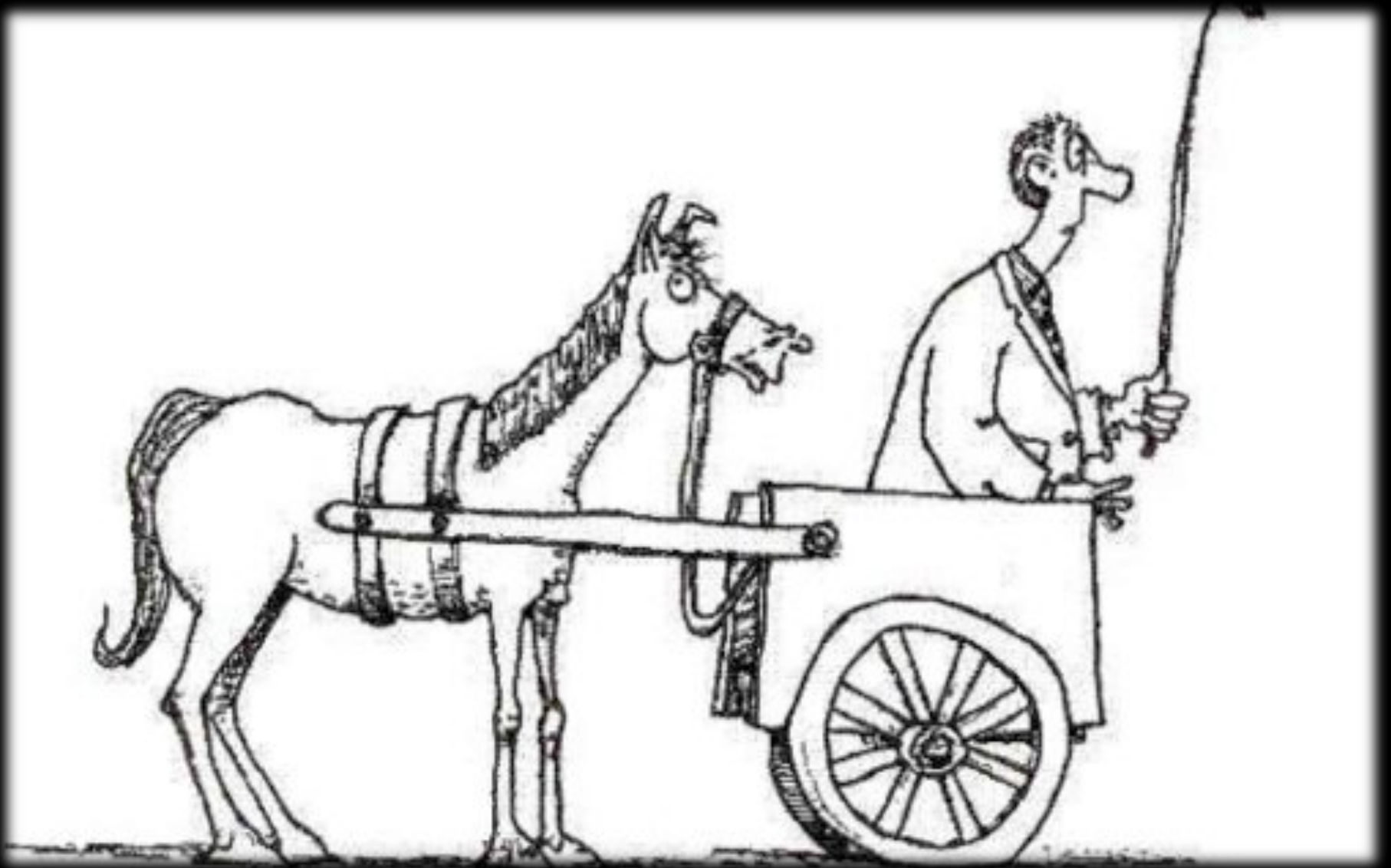


# CASE 3: Bio-repositories

# Social and Ethical Issues in Biospecimen Repository Development:

## Community Engagement, Informed Consent, and Ethical Specimen Use

- ▶ **Vision:** To create a biospecimen repository that is supported by the community, with meaningful, informed consent by participants, and with ethical scientific access policies, that can address health disparities issues
- ▶ **Focused Question:** How do we effectively engage communities and participants in biospecimen repository-based research?





# Lack of Inclusion

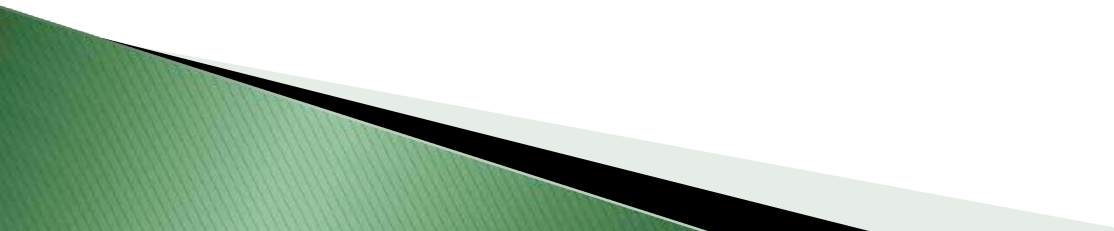
- ▶ Agenda Not Driven by Native Hawaiian People
- ▶ Misunderstanding Causes Distrust – Suspicion



# Knowledge, Attitudes, Perceptions of Native Hawaiians on Bio-Banking



# Themes Identified by Native Hawaiian Community

- ▶ Governance Native Hawaiian community
  - ▶ Transparency All aspects of research
  - ▶ Education Raise awareness & understanding
  - ▶ Re-consent Every time & with aid of technology
  - ▶ Priority Native Hawaiian health concerns
  - ▶ NH Scientists Accountable to community
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# Mahalo



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