Ensuring Communities are Visible

The Importance of Accurate Race and Ethnicity Data Collection in Healthcare

HCSRN Scientific Data Resources Forum Webinar

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Learning Objectives

- Understand the role of race and ethnicity data in healthcare.
- Examine the consequences of data invisibility.
- Explore Native Hawaiian and Pacific Islander examples.
- Identify strategies for improving data collection and use.

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Why This Matters

- Healthcare systems cannot address disparities they cannot see.
- Accurate race and ethnicity data are foundational to equitable care.

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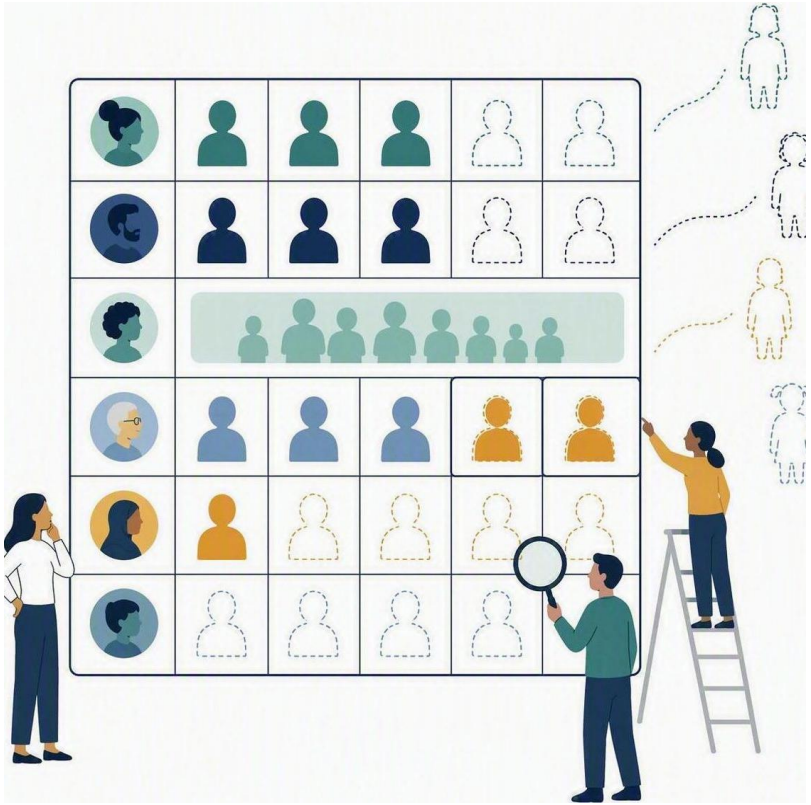
What is Data Invisibility?

- Communities may be omitted, misclassified, aggregated, or excluded.
- Invisibility affects policy, funding, research, and services.



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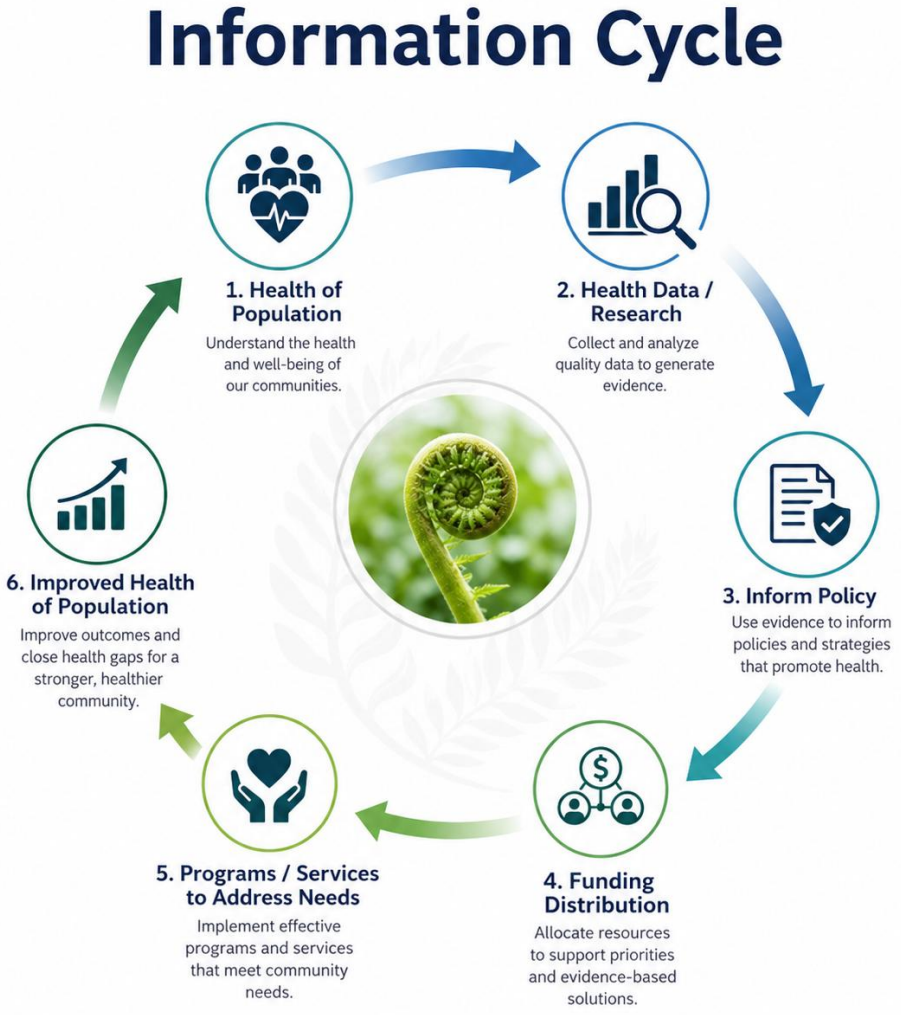
Health Equity Framework

Each step depends on accurate collection



The Cost of Health Disparities

- The economic burden of health disparities is **$451 billion** annually in the U.S.
- There is an unmeasurable cost to all aspects of society, in terms of years of life lost, quality of life, and injustices experienced by minorities.

Source: LaVeist TA, Pérez-Stable EJ, Richard P, et al. The Economic Burden of Racial, Ethnic, and Educational Health Inequities in the US. JAMA. 2023;329(19). doi:10.1001/jama.2023.5965

Historical Context

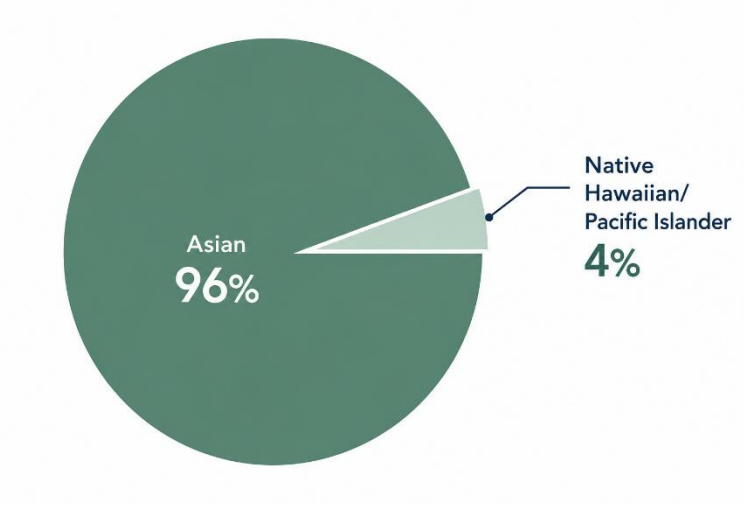
- Many Indigenous populations have been statistically marginalized.
- Data systems often reflect historical power structures.

"Kill the Indian, and save the man" a defining 19th-century philosophy and slogan stated by Richard Henry Pratt, founder of the Carlisle Indian Industrial School. It guided the forced assimilation of Native American children in federally funded boarding schools.

It is a human right to be counted in population statistics and Indigenous Peoples should not be invisible in national health statistics.

Case Study: Aggregation Problem

- Asian and NHPI populations are frequently combined.
- Important differences in disease burden become hidden.



Source: Taualii, MM. Self-Rated Health Status Comparing Pacific Islanders to Asians. J Health Disparities Research and Practice. 2007 Vol 1 (2): 107-116

Invisibility – Data Aggregation API *VS* Asian & NHPI

- Cancer: “Asian/Pacific Islander women are 30% less likely to have breast cancer as non-Hispanic white women.”
- Diabetes: “Asian/Pacific Islanders are 29% less likely than the overall U.S. population to die from diabetes.”
- Heart Disease: “Asian/Pacific Islander adults are 28% less likely than the overall U.S. population to have coronary heart disease.”

- Cancer: “NHPI females have the highest mortality rate from lung, liver, pancreatic, breast, cervical, uterine, stomach, and rectal cancer.”
- Diabetes: “NHPI have a rate of diabetes that is over twice that of other populations (79 vs. 34 per 1,000).”
- Stroke: “NHPI have higher rate of death and disability due to stroke and cerebrovascular conditions than other populations (mortality rate of 52.7 per 100,000).”

Sources: U.S. Dept. of Health and Human Services, Office of Minority Health — Asian American and Native Hawaiian/Pacific Islander population profiles (Cancer, Diabetes, Heart Disease, Stroke), minorityhealth.hhs.gov, drawing on CDC/NCHS data.

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SUMMARY: By this Notice, OMB is announcing its decision concerning the revision of Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting. OMB is accepting the recommendations of the Interagency Committee for the Review of the Racial and Ethnic Standards with the following two modifications: (1) the Asian or Pacific Islander category will be separated into two categories -- "Asian" and "Native Hawaiian or Other Pacific Islander," and (2) the term "Hispanic" will be changed to "Hispanic or Latino."

The revised standards will have five minimum categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. There will be two categories for data on ethnicity: "Hispanic or Latino" and "Not Hispanic or Latino."

EFFECTIVE DATE: The new standards will be used by the Bureau of the Census in the 2000 decennial census. Other Federal programs should adopt the standards as soon as possible, but not later than January 1, 2003, for use in household surveys, administrative forms and records, and other data collections. In addition, OMB has approved the use of the new standards by the Bureau of the Census in the "Dress Rehearsal" for Census 2000 scheduled to be conducted in March 1998.

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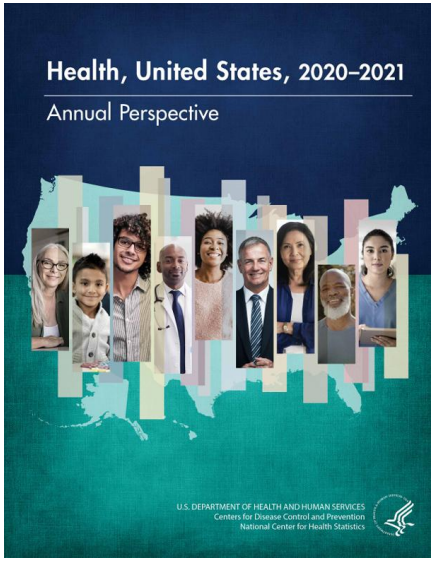
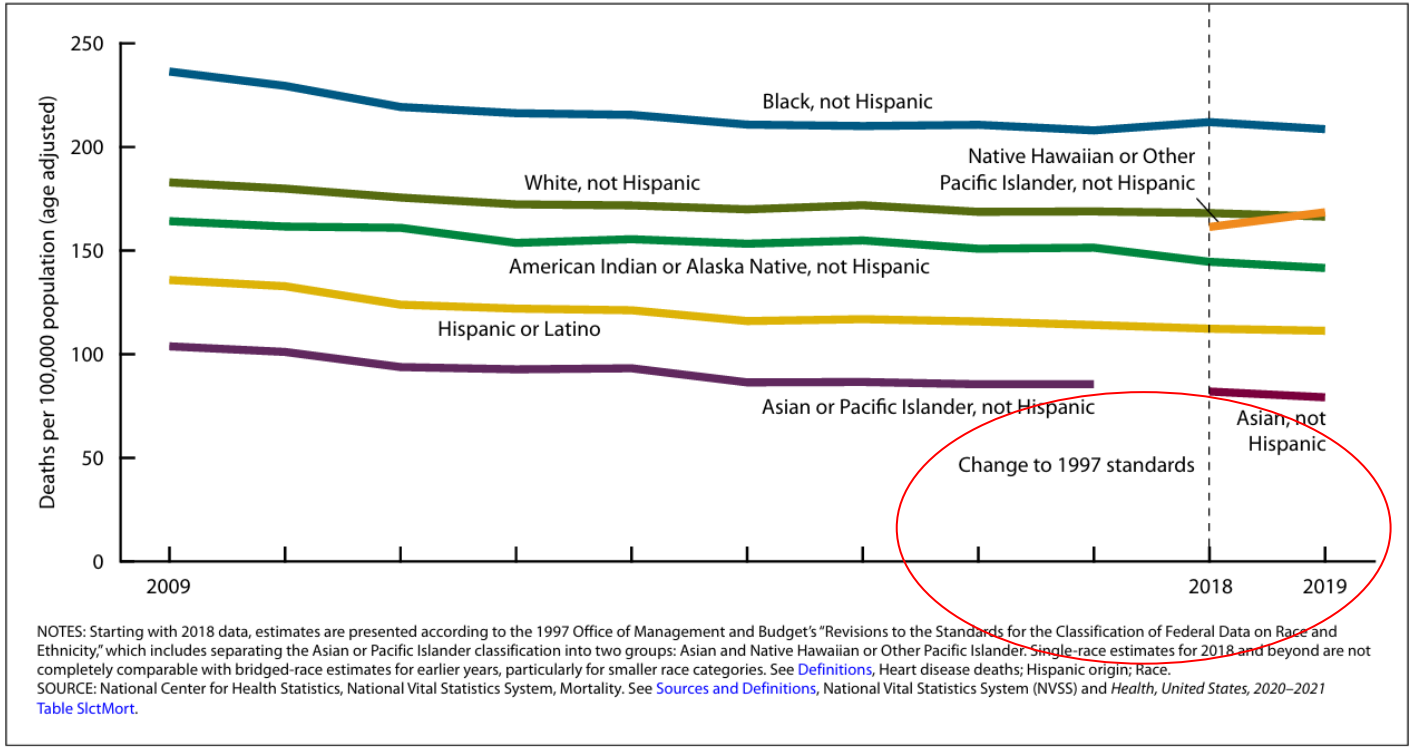
Timely?



National Center for Health Statistics. Health, United States, 2020–2021: Annual Perspective. Hyattsville, MD. 2023.

https://dx.doi.org/10.15620/cdc:122044

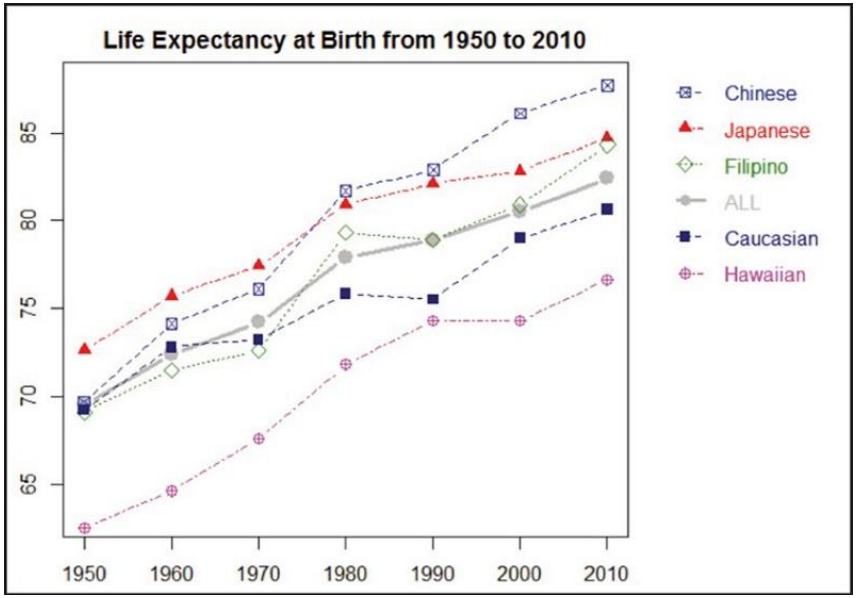
Figure 1. Heart disease death rates, by race and Hispanic origin: United States, 2009–2019



NOTES: Starting with 2018 data, estimates are presented according to the 1997 Office of Management and Budget's "Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity," which includes separating the Asian or Pacific Islander classification into two groups: Asian and Native Hawaiian or Other Pacific Islander. Single-race estimates for 2018 and beyond are not completely comparable with bridged-race estimates for earlier years, particularly for smaller race categories. See Definitions, Heart disease deaths; Hispanic origin; Race.
SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality. See Sources and Definitions, National Vital Statistics System (NVSS) and *Health, United States, 2020–2021* Table SlctMort.

Life Expectancy for the US Population

"According to the U.S. Centers for Disease Control and Prevention, in 2023 the average life expectancy at birth for Native Hawaiian/Pacific Islander people was not produced due to limited race and ethnicity data (the life expectancy for all races was 78.4 years)."



Source: National Vital Statistics Reports Volume 74, Number 6 July 15, 2025 United States Life Tables, 2023

Source: Healthy Life Expectancy in 2010 for Native Hawaiian, White, Filipino, Japanese, and Chinese Americans Living in Hawai'i. *Asia-Pacific Journal of Public Health*, 31(7), 578–588.

Impact on Healthcare Services

- Data determine funding prioritization
- Invisible populations don't influence funding

According to DHHS, funding allocation is determined by:

- Grants prioritize high-risk geographic areas and **racial/ethnic minority groups** experiencing extreme disparities.

The HRSA Maternal and Child Health Services Block Grant,[11] approximately $730 million in FY-2004

Program Objective: The program "focuses solely on improving the health of all mothers and children," including "gap filling" clinical services, "population-based functions" that enable MCH services and strengthen the public health infrastructure, and programs for "children with special healthcare needs."

Target populations: (1) All pregnant women, mothers, infants, and children; (2) those pregnant women, mothers, infants, and children in need of "gap filling" health services; and (3) children with "special healthcare needs"

Funding allocation for primary program: $594 million, state block grant program. Allocation based on "the amount awarded to the states in 1981 for the preblock programs later consolidated into the state grant" (nearly three fourths of formula-awarded funds) and "the remaining amount is distributed based on the proportion of low income children that a state bears to the total number of such children for all the states"

Funding allocation for set-aside program: Remaining funds ($135 million in FY-2004) "are awarded on a competitive basis to a variety of applicant organizations" for special projects

Impact on Funding

- Federal, state, and philanthropic investments are data-driven.
- Communities not represented receive fewer resources.

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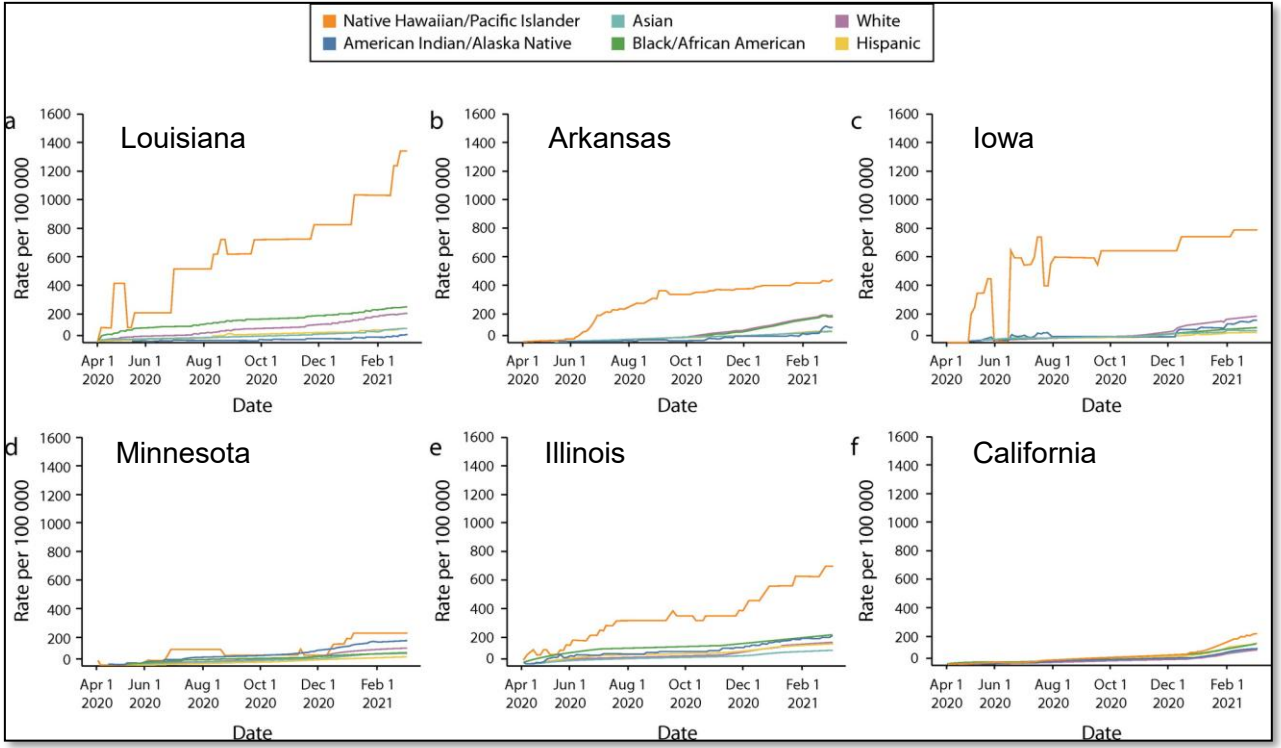
COVID-19 Lessons

Native Hawaiians and Pacific Islanders experienced some of the highest COVID-19 death rates of all racial and ethnic groups in the United States.

Select State Racial and Ethnic COVID-19 Death Rates/100 000



Source: Corina S. Penaia, Brittany N. Morey, Karla B. Thomas, Richard C. Chang, Vananh D. Tran, Nicholas Pierson, John Greer, and Ninez A. Ponce: Disparities in Native Hawaiian and Pacific Islander COVID-19 Mortality: A Community-Driven Data Response American Journal of Public Health 111, S49_S52.

“May 3, 2023 – The National Cancer Institute (NCI) has revealed for the first time the full cancer burden carried by Native Hawaiian and Pacific Islander communities.”

- NHPI between the ages of 20 and 49 had the highest death rate from any cancer, compared to 20 to 49 year-olds from other racial and ethnic groups (American Indian/Alaska Native, Asian, Black, Latino, or White).
- NHPI women have the highest and NHPI men have the second highest cancer incidence per 100,000 compared with all ethnicities.
- Breast cancer incidence and mortality highest among NHPI women compared to any other racial or ethnic group.
- Lung cancer incidence highest among NHPI men and women with lung cancer mortality highest in NHPI women.

NEWSROOM

Young Native Hawaiians and Pacific Islanders face highest cancer death rates

May 3, 2023

The National Cancer Institute (NCI) has revealed for the first time ever that young Native Hawaiians and Pacific Islanders (NHPI) experience the highest rates of cancer death among people their age in any other race group in the United States.

Source: Haque AT, Berrington de González A, Chen Y, et al. Cancer mortality rates by racial and ethnic groups in the United States, 2018-2020. JNCI. 2023;115(7):822-830. https://doi.org/10.1093/jnci/djad069

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“Disaggregation Effect”

Separating NHPI populations from Asian categories proved critical, correcting past data masking that hid high mortality risks in Pacific Islander communities.

Age-Adjusted Malignant Cancer Death Rate among NHPI and Asian populations separately and combined in the US, Aged 20 or Older From 2018 to 2020

Cancer Site	NHPI Populations	Asian Populations	NHPI and Asian Populations Aggregated
All Cancers	197.3	126.8	128.7
Oral Cavity and Pharynx	3.7	2.8	2.8
Esophagus	2.8	2.1	2.1
Stomach	8.7	6	6.1
Colorectum	14.6	12.5	12.6
Liver	15.1	11.4	11.5
Pancreas	12.2	10.4	10.5
Lung	38.5	26.1	26.4
Soft Tissue including Heart	2.7	1.2	1.2
Breast	33.2	15.9	16.3
Cervix	6.9	2.1	2.2
Uterus	19.5	4.6	5
Ovary	7.8	6	6
Prostate	23	11.6	11.8
Bladder	3.9	2.3	2.4
Kidney	3.7	2.1	2.2
CNS	3.8	3	3.1
Non-Hodgkin Lymphoma	6.8	4.9	4.9
Myeloma	3.8	2	2.1
Leukemia	7.9	4.4	4.5

Abbreviations: NHPI=Native Hawaiian and Pacific Islander; CNS= Central Nervous System

Source: Haque AT, Berrington de González A, Chen Y, et al. Cancer mortality rates by racial and ethnic groups in the United States, 2018-2020. JNCI. 2023;115(7):822-830. https://doi.org/10.1093/jnci/djad069

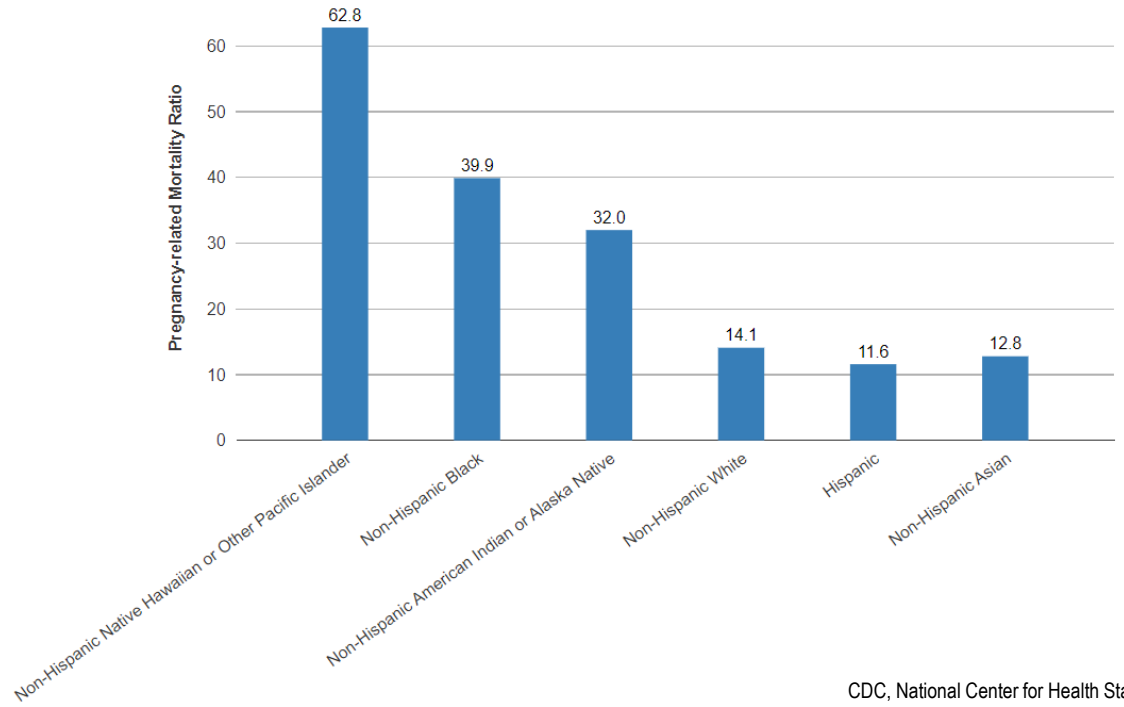
Maternal and Infant Health

Native Hawaiian infant mortality was more than twice that of whites (7.9 vs 3.5/1000 live births)

35% of extreme preterm (<26 weeks gestation) births are Native Hawaiian

51% of teen pregnancies are Native Hawaiian

Pregnancy-related mortality ratio by race-ethnicity: 2017–2019



CDC, National Center for Health Statistics

REPORT JUN 1, 2026

How Federal Attacks on Diversity and Inclusion Policies Have Dismantled Public Health Infrastructure and Threaten National Health Security

Federal executive orders targeting initiatives that seek to ensure diversity and equity for all are systematically dismantling America's public health infrastructure—cutting research, surveillance systems, and workforce programs while raising costs and putting national health security at risk.

Source: Mariam Rashid, Associate Director, Racial Equity and Justice & Perry N. Halkitis, Dean, Rutgers School of Public Health
https://www.americanprogress.org/article/how-federal-attacks-on-diversity-and-inclusion-policies-have-dismantled-public-health-infrastructure-and-threaten-national-health-security/

Federal health equity cuts shift the burden downstream—to hospitals

"Hospitals across the country have been absorbing the consequences of housing instability, untreated behavioral health conditions, transportation barriers, and caregiver shortages while facing coverage losses and fewer public health resources.

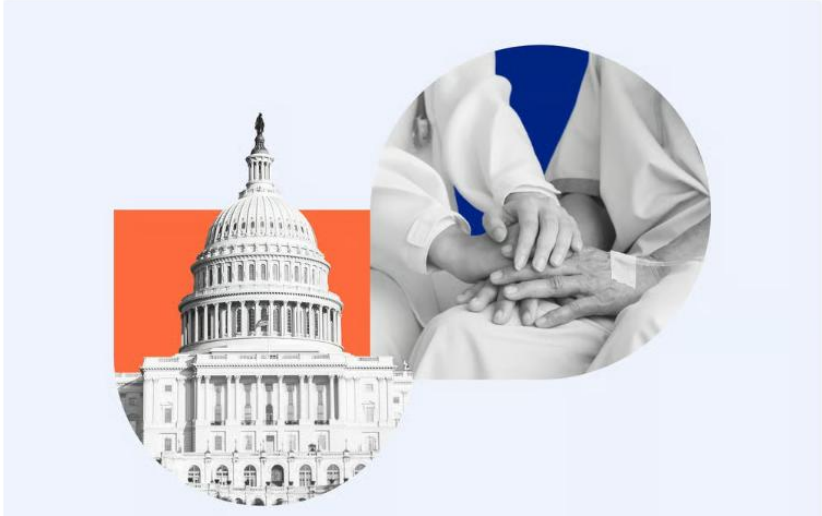
Recent hospital earnings already point to rising uncompensated care as coverage losses grow.

For hospitals, the question is no longer whether states will take different paths—it's how wide those differences will become, and how much geography will determine the care patients receive."

HOSPITALS & FACILITIES

Op-ed: Federal health equity cuts shift the burden downstream—to hospitals

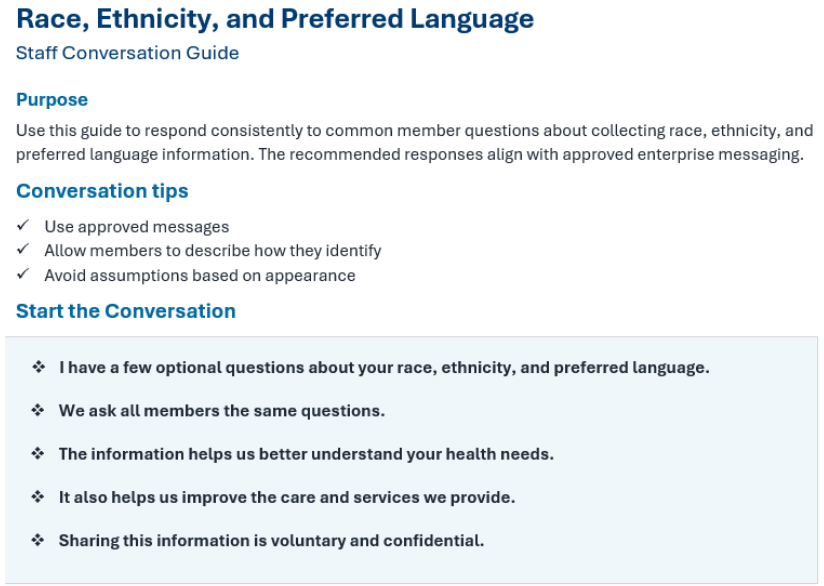
Congress is still funding some health equity initiatives, but the government has put states and hospitals in a bind.



Source: Author, Christian Laurence-Diaz July 30, 2026 www.healthcare-brew.com/resources/federal-health-equity-cuts-shift-the-burden-downstream-to-hospitals

Collection of Race, Ethnicity, Language Data at KP

KP has had extensive efforts to improve the collection of race, ethnicity, and language (REL) data, including completing the definition of national KP standards for collecting this data through the Member Demographics Data Collection (MDDC) initiative.



Race, Ethnicity, and Preferred Language

Staff Conversation Guide

Purpose

Use this guide to respond consistently to common member questions about collecting race, ethnicity, and preferred language information. The recommended responses align with approved enterprise messaging.

Conversation tips

- ✓ Use approved messages
- ✓ Allow members to describe how they identify
- ✓ Avoid assumptions based on appearance

Start the Conversation

- ❖ **I have a few optional questions about your race, ethnicity, and preferred language.**
- ❖ **We ask all members the same questions.**
- ❖ **The information helps us better understand your health needs.**
- ❖ **It also helps us improve the care and services we provide.**
- ❖ **Sharing this information is voluntary and confidential.**

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Call to Action

- As researchers and data consumers, it’s on us…
- Assess, disaggregate, engage, invest
- Visibility is a health intervention
- Advocate for those who are invisible

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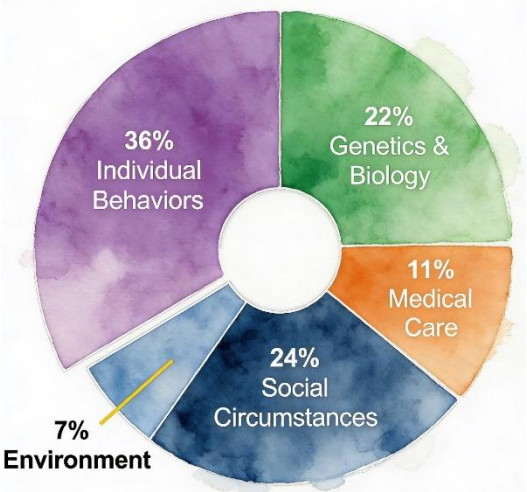
What is KPHI doing to create visibility and ensure health equity?

HOW ARE WE DOING?

QUALITY
Measure
Statin
Statin Adherence
BP control for adults
BP control for HTN/DM
BP control for HTN/DM, calendar year
BP measurement for HTN/DM, calendar year
HbA1c<8 for DM
HbA1c<8 for DM, CE=1yr
HbA1c<8 for DM, Hawaiian
HbA1c<8 for DM, Hawaiian, CE=1yr
HbA1c<8 for DM, Filipino
HbA1c<8 for DM, Filipino, CE=1yr
HbA1c within the past 12 months for DM
HbA1c within the past 12 months for DM, Hawaiian
HbA1c within the past 12 months for DM, Filipino
Eye Screen for DM

- Awareness is key to understanding disparities
- Allows for action and intervention



Hawaii Market Interventions to Address Health Inequities Among NH/PI

Audience	Intervention	Description
Patients	Shared Medical Appointment – Ke Kahua ʻAiola	A Culturally Grounded Cooking Intervention for Native Hawaiian Patients with Pre-Diabetes in Group Visits
Clinicians	Serving the People of Hawaii	5-part orientation series to help clinicians learn more about the communities of Hawaii – Includes Hawaiian history, cultural safety, communication tips and Hawaiian language training.
Clinicians	Traditional Food Education	Food Is Medicine Education – Health Statistics, Pre-Contact Food Systems, Growing, Harvesting, Cultural significance and Preparation and Recipes
Health Care System & Community Partnership	Hoʻokele (to navigate): A Pilot Study to Improve Diabetes Management through Family-Based Health Care Navigation	Gold Standard, Randomized Controlled Trial, R01, Funded by National Institute of Diabetes and Digestive and Kidney Diseases
Clinicians & Staff	Hauola: Hawaiian Cultural Safety to Improve Birth Outcomes - Exploring Birthing Traditions – Native Hawaiian Lens	3-Part series offered to clinicians and staff in Labor and Delivery, NICU, & Pediatrics. Focus is support those who are working with expecting families to integrate discussions about local and traditional foods into patient counseling to improve engagement, cultural responsiveness, and health outcomes. The program aims to increase awareness of traditional practices and beliefs to support a healthy, safe birth for both mom and baby.

Ke Kahua ‘Aiola

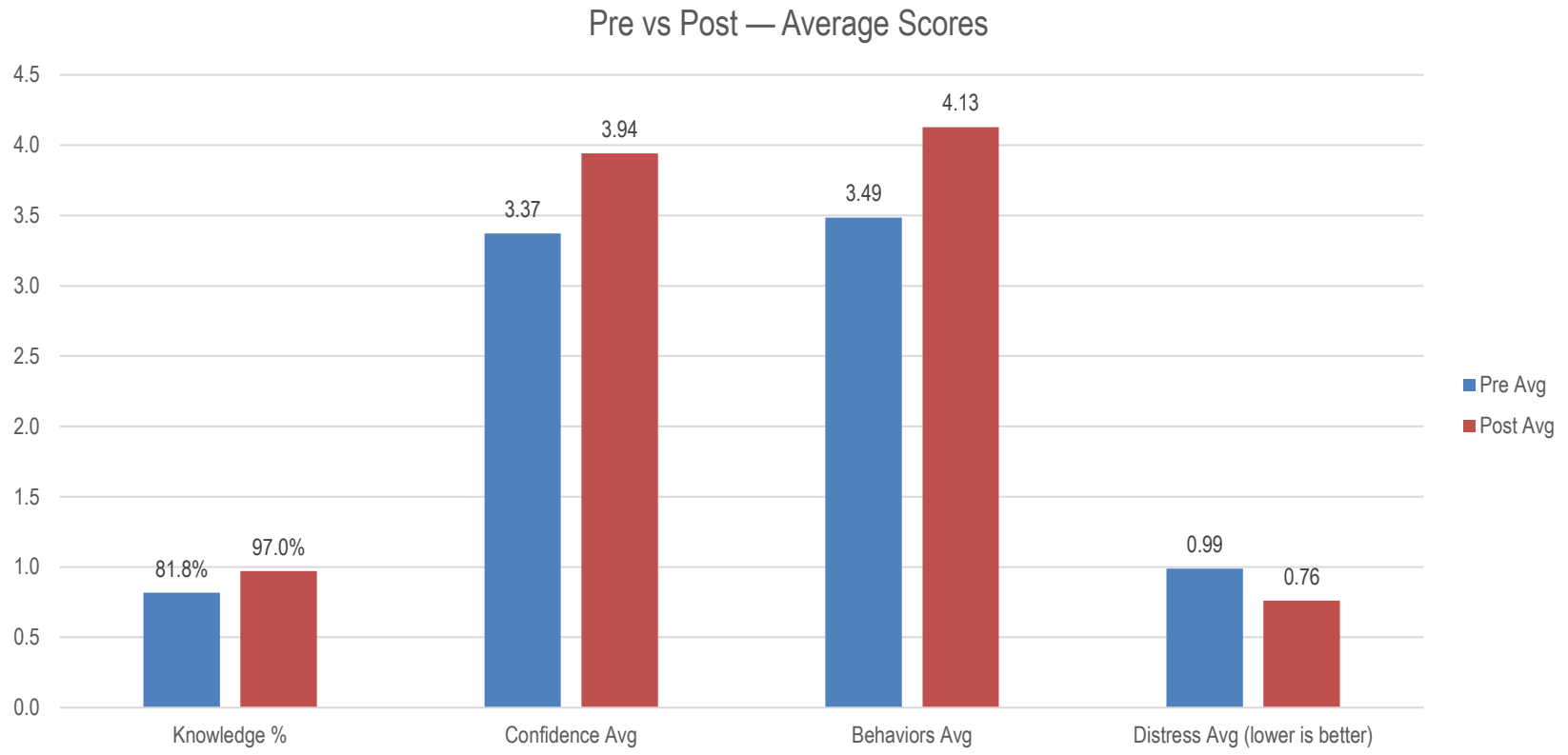
The foundation for healthy eating

Shared Medical Appointment PDSA

3 Week – Lesson Structure

Wk	Theme	Instant Pot Recipe	Cultural Messaging	Education
1	**Kalo** *Taro*	kalo pa‘a, kalo poke, lu’au stew	**Myth-busting and brief history** Diabetes (DM) is not part of our collective identity. **Introduce Kupuna Crops** What they are, the meaning they carry, and their nutritional value. **Connect past and present** Highlight traditional wisdom and how modern science is catching up. **Focus on culturally engaged, positive action** Encourage reintroducing Kupuna Crops, with practical ways to prepare and enjoy them.	Program overview, what is prediabetes/diabetes, intro to healthy eating (general rules, carb servings, portions) Introduce SMART goals Homework: Create first smart goal
2	**‘Ulu** *Breadfruit*	‘ulu pa‘a, poke, ‘ulu hummus, ulu corn chowder, ulu salad, ulu bread, ulu cake		Review goals, common barriers and how to handle them. Label reading, more in-depth diet education. SMART goal optimization. Homework: Count the carbs for your favorite healthy recipe or meal.
3	**Uala** *Sweet Potato*	uala pa‘a, koelepalau, uala salad		Review homework recipes. Address exercise, sleep, access, and community resources; introduce Lifestyle Medicine resources. **Receiving and cooking with Instant Pot** Final optimization of SMART goals

Pre-Post Average Score



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Ke Kahua ‘Aiola - Testimony

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Discussion Questions

- Who is invisible in your data?
- How can your organization improve collection and reporting?

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NHPI – Not just a Hawai‘i based population

- There are more NHPI outside of Hawai‘i than there are in Hawai‘i.
- As the scientists who work with and share health information it is our responsibility to ensure accurate and timely access and sharing of population health data.
- On ALL populations