

# Ethnic health data in Hawai'i: describing the databases

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## Where to find ethnic health data

### Introduction

With the intense national and international focus on ethnic and racial health disparities, the need for ethnic-specific data is increasingly more critical. Goals for the health of the United States as articulated in the Healthy People 2010 Objectives, released by the U.S. Department of Health and Human Services in 1998, all rely on data sources that describe and measure over time the health status of the U. S. population. Local and national resources will be allocated based on the interpretation of the data. This poses a dilemma for small populations like Native Hawaiians and other Pacific Islanders that are often hard-pressed to find data that accurately describes their population's demographics, socioeconomic and health status, disease patterns and trends. When data exist, they may lack a statistically representative sample for a small ethnic group and, as is often the case, the data may be aggregated into a collective group such as, "Asian American/Pacific Islanders," resulting in findings that may mask health disparities and are misleading.

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This article is an introduction to the availability of local (State of Hawai'i) and national databases that currently collect and maintain health data related to ethnic minority populations in Hawai'i. Many may find this information relevant including students, program staff, managers, and administrators in private and public agencies and programs.

### Understanding data

Currently, public health systems rely on six types of data sources to meet its needs: vital statistics; health care utilization data; disease and injury registries; disease, injury, and behavioral risk factor surveillance systems; periodic surveys; and individual programmatic data systems. These sources of data individually provide information on the morbidity, mortality, health status, health outcomes, and access to health care for the diverse ethnic groups in the State of Hawai'i. The data are found in several different databases established and maintained by various programs within the Hawai'i Department of Health as well as numerous private sector agencies and organizations. Currently, an inventory or a description of the content of the databases related to measuring the health status of minority populations does not exist. Furthermore, there is limited coordination

among the multiple agencies and programs in the state that are collecting and using the health related data of minority populations. To further compound the problem of the fragmentation of the existing health data for minority populations, there is currently no central agency or program in Hawai'i that has the responsibility for providing the leadership required to create this comprehensive inventory of the various data systems, to describe the characteristics of these databases, and to annually compile and report the pertinent data related to minority health issues.

In response to the 1998 House Concurrent Resolution No. 156, S.D. 1, "Requesting the Legislative Reference Bureau to Identify, Compile, and Summarize Available Demographic Data on Native Hawaiians," the Hawai'i Legislative Bureau produced a document that studied the issues relating to collection and reporting of data on Native Hawaiians<sup>1</sup>. Although the study focused on data related to Native

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Hawaiians, the complex issues and problems of collecting and codifying ethnic data can be related to all the ethnic groups. Currently, there are two major methods of determining ethnicity: (1) by single-source self-identification, or (2) by parent's ethnic heritage (genetic method). The public and private agencies as well as private researchers may use the different methods for determining and codifying ethnic categories. The problems of collecting, codifying, and maintaining data related to ethnicity, race, or ancestry by the various public agencies, private programs, and individual researchers will not be addressed nor solved in this document. However, users of the data must not only be aware of the issues and problems of how these data are collected and codified, but must also be aware of how the databases can be used. The disparity in the numbers of individuals classified in any ethnic group when using either method may be great, therefore, care must be taken in avoiding using data from different databases when attempting comparisons and calculating statistics.

The authors recommend potential users of local and national data related to ethnicity or race refer to the document, *Hawaiian Demographic Data: 'Ehia Kānaka Maoli?*, to better understand the complexities and issues associated with ethnic, racial, and ancestral groupings.

The databases were selected and included in this article based on the following criteria: (1) Data for minority populations including Native Hawaiians were available; (2) data were timely and recent; and (3) data consistency. Because of the limited number of databases identified, not all of the databases have data on the Internet; however, because the data are available upon request, these databases were included along with the contact to obtain the data.

The databases will be described in two categories. The first set includes databases that contain the basic level of data available for baseline population-based and demographic information. These databases include the *Hawai'i State Data Book: A Statistical Abstract*, the Health Department's Vital Statistics, *Hawai'i Health Survey* (formerly *Hawai'i Health Surveillance Program*), and the *Behavioral Risk Factors Surveillance System* (BRFSS). Also included at the basic level is a description of the Hawai'i Public Health Information Virtual Emporium (HiPHIVE), although not a database, it is a website that provides important virtual access to multiple state and national databases and resources.

The second category includes the more specialized databases that are focused specifically on subsets of the population and may reflect the following: (a) minority populations, such as the data presented by the Office of

Hawaiian Affairs (OHA); (b) Department and program specific data such as the data presented by the Hawai'i Department of Human Services, Hawai'i Department of Education, and the U.S. Department of Justice, Bureau of Justice Statistics; (c) and specialized data such as the data from the Center on the Family, the Cancer Research Center of Hawai'i's Surveillance, Epidemiology and End Results (SEER), and selected programs in the Department of Health. Several, but not all, of the databases described can be accessed through the Internet.

Each of the identified databases will contain the following information: an overview of the database, a description of the types of data included in the database, a listing of the major sections of data that are included in the database, and a listing of selected specific data sets and data tables. Information related to data that are stratified based on ethnic categories will be described for each database. For the databases that are locally situated, an interview with managers and key informants of the database were conducted and a data profile of information about the structure, type of data, sampling methodology, and elements of the database is included.

There are numerous limitations to each of the individual databases; however common limitations to all are the following: (1) The most recent data are at least two years prior to the reporting year; (2) data that are reported are for one year only and does not allow for trend analysis; (3) data groupings in the databases are established by the agency and the groupings may not be comparable; (4) data are presented in data tables and are not able to be manipulated; and (5) the definitions for the data are usually not provided.

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## Available resources and databases

### *Hawai'i Public Health Information Virtual Emporium (HiPHIVE)*

*Hawai'i Medical Library & University of Hawai'i, John A. Burns School of Medicine*  
<http://hml.org/hiphive/>

The Hawai'i Public Health Information Virtual Emporium (HiPHIVE) is a website and not a database; however, it is an important website with links to several public health resources, educational materials, and databases. The HiPHIVE project is a collaborative partnership between the Hawai'i Medical Library and the University of Hawai'i, John A. Burns School of Medicine and is funded by a grant from the National Library of Medicine. The primary focus of the project was to provide public health professionals with a website which will provide an access to information re-

**Table 1. Subject directories, Hawai'i Public Health Information Virtual Emporium**

<b>Agencies/Associations</b>	<b>Statistical Sources</b>
Legislation/Code Rules/Regulations	Health Education and Prevention
Public Health Practice	Diseases and Epidemiology
Grant Opportunities	Population Groups
Public Health Metasites	Environmental Health
Public Health News	Mental Health and Substance Abuse
Training and Evaluation	Nutrition

sources in local and web-based health databases as well as training for public health professionals in the use of the internet. The website is being maintained on a voluntary basis by Sharon Berglund, formerly of Hawai'i Medical Library and currently with California State University at San Marcos, and Virginia Tanji, John A. Burns School of Medicine.

The creators of the HiPHIVE website have identified hundreds of the important public health websites, both locally and nationally, and categorized them into the 14 subject directories with links to each of the websites as seen in Table 1.

The following are short descriptions of selected subject directories from the list above that may be directly related to minority health and health data: Statistical Sources, Health Education and Prevention, Diseases and Epidemiology, and Population Groups.

The directory for *Statistical Sources* contains links that are categorized into the topical areas of Hawai'i Data, National Data, International Data, Disease and Population Groups, and Resource Guides and Links. For Hawai'i data, there are direct links to demographic data sources such as the *Hawai'i State Data Book*, the *Maui County Data Book*, and the *County of Hawai'i Data Book*. The direct links to health data sources in Hawai'i include the Hawai'i State Department of Health Vital Statistics, Hawai'i Health Survey, Health Trends in Hawai'i, Child Abuse and Neglect in Hawai'i, Health Department's Communicable Diseases Report, Native Hawaiian Data Book, and Primary Care Needs Assessment Data Book 1998. For National data, there are direct links for the Statistical Abstracts of the United States, Poverty Guidelines, and U.S. Census Data. Links to statistical data sources for specific disease and population groups include Cancer Statistics, HIV/AIDS Surveillance Database, Maternal and Child Health Statistics.

The directory for *Health Education and Prevention* contains links that are categorized into the topics of Consumer Health, Health Promotion, Minority Health, School Health, Smoking Prevention, Associations and Agencies. The direct links in the Minority Health area include *DiversityRX*, which is a resource that promotes language and culture competence to improve the quality of health care for minority, immigrant, and ethnically diverse communities as well as a cross reference to the directory for Population Groups.

The directory for *Population Groups* contains links in the following topical areas: Adolescent Health, Aging, Maternal and Child Health, Men's Health, Minority Health and Cultural Competence, Reproductive Health, and Women's Health. The direct links to websites for the Minority Health and Cultural Competence topical area include: Asian and Pacific Islander American Health Forum, Association of Asian Pacific Community Health Organizations, Cross Cultural Health Care Program, EthnoMed, Healthweb: Minority Health, Minority Health Network, Minority Health Project, National Center for Cultural Competence, Native Hawaiian Center of Excellence, Office of Minority Health, and Refugees and Resources.

The directory for *Diseases and Epidemiology* contains website links in the following topical areas: Databases, Diseases, Governmental Agencies, Public Health Surveillance, Journal and News Resources. Within the category of Diseases, there are multiple links to websites for each of the following diseases and conditions: cancer, chronic disease, communicable disease, disability, and HIV/AIDS.

#### **Descriptions of the selected basic level databases**

##### *The United States Census Bureau*

U.S. Department of Commerce

<http://www.census.gov/>

The United States Census Bureau was created in 1902 and conducts the decennial census to count the population and housing units for the entire United States. The primary purpose of the census is to provide the population count that determines the apportion of seats in the U.S. House of Representatives. The census figures are also used to draw congressional and state legislative district boundaries, to allocate federal and state funds, to formulate public policy, and to assist with planning and decision making in the private sector.

In 1977, the Office of Management and Budget (OMB) issued Statistical Policy Directive Number 15, *Race and Ethnic Standards for Federal Statistics and Administrative Reporting* in which four racial categories were established: American Indian or Alaskan Native, Asian or Pacific Islander, Black, and White. In addition, two ethnicity categories - Hispanic origin and Not of Hispanic origin - were established. Although the Census Bureau traditionally used more categories for decennial censuses, these categories were

collapsed into the four minimum race categories mandated by the OMB. Since 1977, the racial and ethnic makeup of the country has changed which has given rise to the question of whether the standards still reflected the diversity of the current population. In response to these questions, the OMB reviewed the 1977 Directive, organized workshops, appointed an Interagency Committee for the Review of Racial and Ethnic Standards, and conducted public hearings.

In October 1997, the Office of Management and Budget announced the revised standards for federal data on race and ethnicity to include: American Indian or Alaska Native; Black or African American; Native Hawaiian or Other Pacific Islander; Asian; White; and Some other race. The other major revision was the addition of instructions that allows respondents to mark more than one category for race. There are two minimum categories for ethnicity: Hispanic or Latino and Not Hispanic or Latino.

***The State of Hawai'i Data Book: A Statistical Abstract, 1999 Preliminary Data***

*Department of Business, Economic Development, and Tourism*

<http://www.hawaii.gov/dbedt/stats.html>

The *Hawai'i State Data Book: A Statistical Abstract, 1999* is produced by the Hawai'i State Department of Business, Economic Development and Tourism's (DBEDT) Research and Economic Analysis Division. The publication closely follows that organizational structure and format of its counterpart, the *Statistical Abstract of the United States*, to facilitate comparison of state and national data. The *Hawai'i State Data Book* places emphasis on statewide data and less so on counties, islands, urban settings, and small geographic areas. Agencies of the federal, state, and county governments, as well as many private organizations, assisted the DBEDT in preparing the *Hawai'i State Data Book*. Because the data are secondary data provided by other agencies and program, the DBEDT is unable to manipulate the data.

The *Hawai'i State Data Book* contains 24 sections of secondary data that are provided by other agencies and programs that serve as the primary source of the data. Some of the sections include data on the state population, vital statistics and health, education, law enforcement, human services, business and commerce, communications, environment, transportation, agriculture, and housing. The discussion in this document will be limited to the sections on population, vital statistics and health, education, and social insurance and human services.

The section on *population* presents data on the growth, geographic distribution, and composition of the population

of Hawai'i. The principal sources for these data are the decennial population censuses conducted by the U.S. Bureau of the Census, the Health Department's Hawai'i Health Surveillance Program, the Hawai'i Visitor and Convention Bureau, and the U.S. Immigration and Naturalization Service. This section contains 57 data tables and maps of the census tracts and neighborhood statistics program areas. Some of the more important tables of basic population data include: resident population of counties and islands; resident and de facto population (defined as the number of persons physically present in an area, regardless of military status or usual place of residence; it includes visitors present but excludes residents temporarily absent) of counties and islands; resident population by military status; resident population of counties and districts; resident population of islands and census designated places; resident population and households for counties by districts and census tracts and population projections for the years 2010 and 2020. The data related to demographic characteristics of the population include: resident population by age (5-year age groups) and sex; language spoken; marital status; and immigrant status.

Also included in the population section are the statewide and county data on ethnicity, race and Hispanic origin, and ancestry. The ethnicity data are categorized into three major groups: "Unmixed (except Hawaiian)" and include Caucasian, Black, Japanese, Chinese, Filipino, Korean, Samoan/Tongan; "Mixed (except Hawaiian)"; and "Hawaiian/part Hawaiian". The data on race and Hispanic origin is categorized into White, Black, American Indian (includes Eskimo and Aleut), Asian and Pacific Islander, and Hispanic of any race. The data for ancestry is categorized into the English, German, Irish, Portuguese, Puerto Rican, Chinese, Filipino, Japanese, Korean, Okinawan, Vietnamese, Hawaiian, Samoan, Tongan, Afro-American, American Indian, and White.

The section on *vital statistics and health* presents data on the state's births, deaths, marriages, divorces, diseases, accidents, drinking and smoking, hospitals, and health care personnel and expenditures. The major source for data is the annual statistical report of the Hawai'i State Department of Health. This section contains 39 tables of data that include: resident births and deaths, rates of fetal deaths per 1000 live births and rates of infant deaths per 1000 live births; live births, standard fetal deaths, and elective abortions; characteristics of resident births; characteristics of resident deaths; cause of death by sex; prevalence of chronic conditions; specified communicable diseases; number and bed capacity of hospitals and care homes; occupancy characteristics of acute and long-term care hospitals by islands; characteristics of marriages and divorces; personal health care expenditures by type.

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The section on *education* presents data on enrollment in public and private schools, colleges and universities; students graduated and degrees awarded; highest grade of school completed; achievement test results; school facilities, personnel, and expenditures; and libraries. The principal sources of data on education are the U.S. Bureau of the Census, Hawai'i State Department of Education, University of Hawai'i, and private universities and colleges. This section contains 20 tables of data that includes: school enrollment by type of school and age and by geographic areas; educational attainment by geographic area; schools, teachers, enrollment, and high school graduates for public and private school systems by islands; public school enrollment by grades by counties; enrollment by the University of Hawai'i by campus; degrees, diplomas, and certificates awarded by the University of Hawai'i; characteristics of the Hawai'i State Library System.

The section on *social insurance and human services* presents data related to governmental expenditures on social welfare; programs for the elderly, survivors, disability and health insurance; public employee retirement; unemployment insurance; aid to the needy; and child and other welfare services. Also included in this section are selected data on disability, United Way campaigns, foundations, and the quality of life. Major data sources include reports and records of the U.S. Department of Health and Human Services, the Hawai'i State Department of Human Services, the Hawai'i State Department of Labor and Industrial Relations, the Hawai'i State Employees' Retirement System, and the Aloha United Way. This section contains 26 tables of data that includes: selected social welfare expenditures; financial assistance and cases; food stamp program; child adoptions; and United Way's revenues and outlays by islands.

#### **Hawai'i Annual Vital Statistics Report**

Office of Health Status Monitoring, Hawai'i State Department of Health

<http://www.state.hi.us/doh/stats/index.html>

The Hawai'i Department of Health routinely gathers data about births, deaths, marriages, and divorces that take place in the state. Vital statistics data tables are currently available on the website for 1996, 1997, and 1998, as well as preliminary vital data for 1999. The *Annual Vital Statistics Report* contains data on births, marriages, divorces, deaths, fetal deaths, infant deaths, pregnancies, and abortions.

The presentation of the data in the *Annual Vital Statistics Report* is available based on ethnic categories for each of the sections. In determining the ethnicity of the individual for the vital statistics only one ethnicity is coded from the actual certificates. If more than one ethnicity is listed on the

certificate, the following rules apply: (1) If Hawaiian is one of the multiple ethnicities listed, Part-Hawaiian is coded. (2) If a non-Caucasian ethnicity is listed with a Caucasian ethnicity, the non-Caucasian ethnicity is coded. (3) If there is more than one non-Caucasian ethnicity listed, the first one is coded. (4) If there is more than one Caucasian ethnicity listed, the first one is coded. The ethnicity of the child is based on the ethnicity of the father; however, when the ethnicity of the father is unknown, the child's ethnicity is based on the mother's ethnicity.

For all sections in the report, when data are stratified by ethnicity, the following ethnic categories are used: Caucasian, Hawaiian, Chinese, Filipino, Japanese, Puerto Rican, Korean, Samoan, Portuguese, Black, and Vietnamese.

The section on *births* presents data tables for all live births that occurred during the reporting year. Of the 26 data tables in this section, 14 tables are stratified by ethnicity and include: live births by geographical area and ethnicity of child or ethnicity of mother; live births by facility, attendant and ethnicity of child; live births by non-marital status and ethnicity of mother; live births by the ethnicity of father and ethnicity of mother; non-marital births by island of mother and ethnicity of mother; non-marital births by birth weight and ethnicity of mother; live births by birth weight and ethnicity of mother; live births by military status of parents and ethnicity of child; live births by ethnicity of mother and education of mother.

The section on *fetal deaths* presents seven data tables for standard fetal deaths of which three of the tables are stratified by ethnicity and include: standard fetal deaths by residence of mother and ethnicity of mother; standard fetal deaths by age and ethnicity of mother; and standard fetal deaths by ethnicity of mother and education of mother. The section on *elective abortions* presents six data tables for elective abortions of which two of the tables are stratified by ethnicity and include: elective abortions by age and ethnicity of patient; and elective abortions by marital status and ethnicity of patient. The section on *pregnancies* presents data on the characteristics of the pregnancies that is stratified by ethnicity, maternal age and county of residence. The section on *infant deaths* presents seven data tables for infant deaths of which five of the data tables are stratified by ethnicity and include: infant deaths by geographical area and ethnicity of infant; infant deaths by age of mother and ethnicity of mother; infant deaths by ethnicity of mother and trimester of first prenatal care; infant deaths by ethnicity of infant, age and birth weight; infant deaths by ethnicity of mother and education of mother. The section on *resident deaths* presents 18 data tables for deaths of which four of the data tables are stratified by ethnicity and include: resident deaths by geographic area and ethnicity; resident

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deaths by ethnicity, sex, and age; female resident deaths by ethnicity and selected causes of death; male resident deaths by ethnicity and selected cause of death.

### **Behavioral Risk Factor Surveillance System (BRFSS)**

Office of Health Status Monitoring, Hawai'i State Department of Health

<http://www.state.hi.us/doh/stats/surveys/brfss.html> or

<http://www.cdc.gov/> (CDC website)

The Behavioral Risk Factor Surveillance System is a collaborative effort between the state and the Centers for Disease Control and Prevention (CDC). The Department of Health annually conducts a statewide survey using randomly generated telephone numbers. Respondents for the survey are adults 18 years or older and are asked questions about the major behavioral risks associated with premature morbidity and mortality. The sample population includes approximately 4,000 completed interviews. The basic philosophy is to collect data on actual behaviors rather than on attitudes or knowledge that would be useful for planning, initiating, supporting, and evaluating health promotion and disease prevention programs.

The recent prevalence data for the State of Hawai'i and other states is available on the CDC website. The category links for the following behavioral risk factors are listed: Alcohol Consumption, Cholesterol Awareness, Colorectal Cancer Screening, Demographics, Diabetes, Health Care Access, Health Status, HIV/AIDS, Hypertension Awareness, Immunization, Injury Control, Oral Health, Risk Factors and Calculated Variables, Tobacco Use, and Women's Health. Those categories that may be available for other states, but not available for Hawai'i, include: Activity Limitations, Exercise, Firearms, Health Care Utilization, Nutrition, Smokeless Tobacco, and Weight Control.

For each of the category links, there are several questions that elicited behavioral responses related to that behavioral risk factor. The responses for each question are statewide prevalence figures that may be stratified separately based on gender, age, race, income, and educational level. The categories for race include: Black, White, Hispanic, and Others on the CDC website.

The Office of Health Status Monitoring reports the data on ethnicity in the following categories: White, Hawaiian, Filipino, Japanese, and Others; however, it collects more detailed data on an *expanded category of ethnicity* and includes: Caucasian (European, German, Irish, Italian, English, etc.), Hawaiian/Part Hawaiian, Chinese (Taiwanese), Filipino, Japanese (Okinawan), Korean, Samoan/Tongan,

Black, American Indian/Alaska Native, Vietnamese, Asian Indian, Portuguese, Guamanian/Chamorro, Puerto Rican, Mexican, Mixed/Not Hawaiian, Other Asian (Laotian, Thai, Malaysian, etc.), Other Pacific Islander (Tahitian, Fijian, Polynesian, Micronesian, etc.), and Other. Data tables based on this expanded list of ethnicities are available upon special written request through the Office of Health Status Monitoring.

### **Hawai'i Health Survey (formerly Hawai'i Health Surveillance Program)**

Office of Health Status Monitoring,

Hawai'i State Department of Health

<http://www.state.hi.us/doh/stats/surveys/hhs.html>

The Health Surveillance Program was first conducted by the Health Department in 1968 and was modeled after the National Health Interview Survey and collected health and socio-demographic data on a household survey. Since 1996, the name was changed to the Hawai'i Health Survey and became the responsibility of the Health Department's Office of Health Status Monitoring. The other major change was that the methodology of data collection changed from a household survey to a telephone survey. The telephone

survey is a statewide survey of single-family dwelling households and excludes Ni'ihau, Kalawao, and persons in institutions including schools and the military. In 1998, approximately 4,300 households are included in the survey and because the questions relate to all members of the household the sample size is approximately 13,000 individuals.

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The standard output of data tables is presented for the state and by counties and includes stratification by ethnicity as well as by age and by gender. The aggregated ethnic categories for reporting include: Caucasian, Hawaiian, Chinese, Filipino, Japanese, and Other. The age groupings include 0-14 years, 15-17, 18-24, 35-44, 45-54, 55-64, 65-74, and 75+ years. The data tables for 1998 include: uninsured population of Hawai'i by gender, age, and ethnicity by county; prevalence of obesity in the adult population by gender, age, and ethnicity; prevalence of arthritis in Hawai'i's population by age, gender, and ethnicity; prevalence of asthma in Hawai'i's population by age, gender, and ethnicity; Prevalence of diabetes in Hawai'i's population by age, gender, and ethnicity; prevalence of hypertension in Hawai'i's population by age, gender, and ethnicity; prevalence of selected chronic conditions per 1,000 persons by age and gender, and by ethnicity. The Office of Health Status Monitoring collects an *expanded category of ethnicities* to include: White/Caucasian (European, German, Irish, Italian, English), Hawaiian, Part Hawaiian, Chinese (Taiwanese),

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Filipino, Japanese (Okinawan), Korean, Vietnamese, Asian Indian, Other Asian (Laotian, Thai, Malaysian), Samoan/Tongan, Black/African American, Native American/Aleut/Eskimo/Inuit, Puerto Rican, Mexican, Portuguese, Guamanian/Chamorro, Other Pacific Islander (Polynesian, Micronesian, Fijian), Mixed/Non-Hawaiian, and Other. Data tables based on this expanded list of ethnicities are available upon special written request through the Office of Health Status Monitoring.

### **Descriptions of selected specialized databases**

#### *Center on the Family*

*College of Tropical Agriculture and Human Resources*

*University of Hawai'i at Mānoa*

<http://www.uhfamily.hawaii.edu>

The Center on the Family is a unit with the College of Tropical Agriculture and Human Resources at the University of Hawai'i at Mānoa. The Mission of the Center on the Family is to enhance interdisciplinary research, service, and education that supports and strengthens families. Families are critical to the development of children, the well-being of individuals, and the strength of society. For these reasons, the programs and activities of the Center on the Family are preventive in nature and aimed at building strong and resilient families.

Available resources for researchers and health and human service professionals include the *Hawai'i Kids Count Data Books* for 1994 through 1999; the *Hawai'i Family Report* series which includes *Building Resiliency in Children*, *Workers and the Work at Home*, *Family Influences on Emergent Literacy*, and *Job Loss and Families*; Kids Count Issue Papers which include *Understanding Child Abuse and Neglect*, *Violence and Substance Use Increase Risk of Child Abuse*, and *Teen Births Rates Falling: Still Bring Health Costs*; and *Hawai'i Family Touchstones* (1999), which tracks indicators of the well-being of families (available at a nominal cost of \$10 to defray production costs). In addition to these published reports, the Data Center on Children and Families is an on-line database featuring comprehensive data and information about the health, safety, education, family relationships and community engagement of people in Hawai'i. The Data Center provides state, county, and national data as available and includes many maps and charts to further illuminate data. A section with local community data is in development.

The *Hawai'i Kids Count Data Book* is an annual report on 24 indicators of the well-being of Hawai'i's children. The data are compiled as secondary data and uses as its primary source the data from the Health Department's Office of Health Status Monitoring, the U.S. Census data, the Department of Business, Economic Development and Tourism, the

Department of Human Services, the Department of Education, and the Department of the Attorney General.

The data on the demographic profile of Hawai'i's kids are limited to population by county, age and gender, and ethnicity that includes the following categories: Caucasian, Hawaiian, Japanese, Filipino, Chinese, Pacific Islander, African American, and Korean. These ethnic categories are based on the 1990 U.S. Census data. Some of the indicators that are stratified by ethnic categories include: children in poverty, births to single teen moms, early prenatal care, low birth weight infants, infant mortality, child deaths, child abuse and neglect, and juvenile arrests for violent crimes.

Ten core indicators have been identified by the national Kids Count program for tracking and comparison between the states. These indicators include: percent children in poverty, percent of families with children headed by a single parent, percent of low birth weight infants, infant mortality rate, child death rate, rate of births to unmarried teens, juvenile violent crime arrest rate, percent of high school dropouts, teen violent death rate, and percent of teens not attending school and not working.

### **Hawai'i Tumor Registry, NCI/SEER**

*Cancer Research Center of Hawai'i, University of Hawai'i*

<http://www2.hawaii.edu/crch/> or <http://seer.cancer.gov>  
(Data not available on website)

The Cancer Research Center of Hawai'i (CRCH) is one of the 60 National Cancer Institute (NCI) designated cancer centers in the nation. It is the only NCI designated cancer center in Hawaii or the Pacific region. The CRCH unites researchers, modern scientific equipment and technology in improving cancer prevention and treatment. The Center conducts basic and applied research, provides the latest cancer information to public and health care providers and conducts educational programs for professionals and the public. One of the services of the Center is to administer the

Hawai'i Tumor Registry (HTR), which maintains a database of information on all cases of cancer diagnosed in the State of Hawai'i. It provides the reporting on cancer for the state and serves as a resource for epidemiologic cancer research and cancer control activities in the state.

Since 1973, the Hawai'i Tumor Registry has received its primary financial support from the National Cancer Institute through the Surveillance, Epidemiology and End Results (SEER) Program with some additional funding from the Department of Health. As one of the eleven NCI/SEER sites nationwide, the HTR provides detailed information on new cases of cancer in Hawai'i as well as collecting annual follow-up data on all diagnosed patients in Hawai'i until their

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death. Currently the HTR database contains more than 122,000 cases diagnosed between 1960 and 1998. The database contains data on more Native Hawaiians than any other registry nationwide and also contains a large number of patients who are Caucasian, Chinese, Filipino, and Japanese. This racially diverse database has been invaluable in demonstrating ethnic variations in cancer incidence and survival. *The ethnic categories included in the HTR database* is extensive and includes the following: White, Black, American Indian/Aleutian/Eskimo, Chinese, Japanese, Filipino, Hawaiian, Korean, Asian Indian/Pakistani, Vietnamese, Laotian, Hmong, Kampuchean, Thai, Micronesian, Chamorro, Guamanian, Polynesian, Tahitian, Samoan, Tongan, Melanesian, Fiji Islander, New Guinean, Other Asian, and Pacific Islander.

The NCI/SEER website does not contain any data tables, however, a web page for ordering the SEER Public Use CD-ROM is available at no charge. This CD-ROM contains the following: the SEER\*Stat 3.0 which is a statistical system for the analysis of the SEER and other cancer databases; SEER Incidence Data for Cases Diagnosed 1973 to 1997 in nine SEER registries; SEER Incidence Data for Cases Diagnosed 1992 to 1997 in eleven SEER registries; the associated registry and county level populations for the databases; the populations for the 1992 to 1997 database that are available include White, Black, American Indian/Aleutian Islander/Eskimo, and Asian/Pacific Islander.

#### ***Native Hawaiian Data Book 1998***

Office of Hawaiian Affairs  
<http://oha.org/databook/>

The Office of Hawaiian Affairs was initiated as a collective effort on the part of the delegates of the state Constitutional Convention in 1978. At the convention a Native Hawaiian Legislative Package was considered by the delegates. Among the provisions incorporated into the new state constitution was the establishment of the Office of Hawaiian Affairs as a public trust, with a mandate to better the conditions of both Native Hawaiians and the Hawaiian community in general. The Public Information Office, part of the Office of Hawaiian Affairs' administration, plans, coordinates and disseminates information to the Hawaiian community and to the general public. This office is responsible for managing the main website and maintaining the website's *Native Hawaiian Data Book* for 1996 and 1998. The data books are similar in that both the 1996 set of data and the 1998 set of data contain data tables that date back to 1990. The major difference between the two is that some of the data tables are updated in the 1998 data book.

#### **The Native Hawaiian Data Book is the most comprehensive database of secondary data related to Native Hawaiians.**

The *Native Hawaiian Data Book* is the most comprehensive database of secondary data related to Native Hawaiians. The sources of original data for this database includes: U.S. Bureau of the Census; U.S. Department of Commerce; Hawai'i Department of Health; Department of Business, Economic Development and Tourism; Department of Human Services; Department of Education; Department of the Attorney General, Crime Prevention Division; Department of Public Safety; Department of Labor and Industrial Relations; the Department of Hawaiian Home Lands; and the University of Hawai'i. Because the data are secondary data provided by other agencies and program, the Public Information Office is unable to manipulate the data.

The *Native Hawaiian Data Book 1998* contains eight sections of secondary data that are provided by other agencies and programs that serve as the primary source of the data. Some of the sections include data on: the population, housing, land, education, human services, health, crime, and income. The following descriptions are the titles of some of the data tables and figures that are included in each of the sections:

The section on *population* presents data tables and figures of the racial composition of the State of Hawai'i, the distribution of the Native Hawaiian population in the United States, the age and sex distribution of the Native Hawaiian population in Hawai'i and by county, Native Hawaiian population by age and blood quantum, annual family income in Hawai'i, characteristics of Native Hawaiian families in Hawai'i, marital status among Native Hawaiians in Hawai'i and the United States.

The section on *housing* presents data tables and figures on housing units in Hawai'i, racial background of heads of households, household type and relationship characteristics for the Native Hawaiian population, household size by race in Hawai'i, Native Hawaiian households below the poverty level in Hawai'i by county, and the homeless in Hawai'i.

The section on *land* presents data tables and figures on land ownership and tenure in Hawai'i; Hawaiian Homestead Lands - land usage, leases by islands, application waiting list, land use by disposition, revenue producing land; and land tenure development in Hawai'i.

The section on *education* presents data tables and figures on the distribution of Native Hawaiian students in the Hawai'i public schools by school district and by grade distribution, Hawaiian blood quantum among students at Kamehameha Schools, enrollment of Native Hawaiians in the University of Hawai'i system, school enrollment of Native Hawaiians in the United States, educational attain-

ment of Native Hawaiians in Hawai'i by level, enrollment in the Hawaiian Language Immersion Program, and the actual and predicted enrollment of Native Hawaiian students in the Hawai'i public school system and in the University of Hawai'i.

The section on *human services* presents data tables and figures on the Native Hawaiian households in Hawai'i receiving public assistance income by county, individuals receiving assistance from the Department of Human Services by race, Native Hawaiians receiving assistance from the Department of Human Services by geographic distribution, ethnic distribution of JOBS participants, confirmed reports of child abuse and neglect in Hawai'i, and data related to services provided by the Healthy Start Home Visitor Program.

The section on *health* is the largest section and presents data tables and figures on cancer incidence in Hawai'i for Native Hawaiians and by race for males and females; prevalence and rates for chronic conditions among Native Hawaiians in Hawai'i including malignant neoplasms, heart conditions, hypertension, asthma, and diabetes; maternal and child health indicators such as fertility rates, prenatal care rates, pregnancy outcomes, infant mortality rates, low birth weight rates, and births to teen age mothers; Native Hawaiian deaths in Hawai'i by age, sex, selected diseases, and cause; and prevalence of health risk behaviors among Native Hawaiians such as hypertension, sedentary lifestyles, obesity, cigarette smoking, and chronic drinking.

The section on *crime* presents data tables and figures on resident population and crime index in Hawai'i, Native Hawaiian adults and juveniles arrested, racial composition of the sentenced felon population, crime victimization in Hawai'i by race/ethnicity of the victim, and domestic violence-related homicides by race in Hawai'i.

The section on *income* presents data tables and figures on per capita personal income for the United States and the State of Hawai'i, frequency distribution of Native Hawaiian family income in Hawai'i, sources of household income for Native Hawaiians, Native Hawaiian families below poverty level by county, and racial composition of the employed civilian labor force in Hawai'i.

A unique and helpful section is the *Research and Statistics Link* which contains numerous linkages to the websites of other data sources, linkages to the Hawai'i State Government and its various departments and programs and the University of Hawai'i, and to specific departments in the United States Government.

**Hawai'i Primary Care Association (formerly Hawai'i State Primary Care Association)**  
Uniform Data System (UDS)  
<http://www.bphc.hrsa.gov/> (U.S. Bureau of Primary Health Care)

The consolidation of selected data elements from the Uniform Data System was initiated by the Hawai'i Primary Care Association in 1995 in collaboration with the following grantees of the Bureau of Primary Health Care (BPHC): Wai'anae Coast Comprehensive Health Center, Kōkua Kalihi Valley Health Center, Kalihi-Pālāma Health Center, Waimānalo Health Center, the Community Clinic of Maui, Bay Clinic, and the Waikiki Health Center's Homeless Program. In addition to these BPHC grantees, the Hāmākua Health Center, Hāna Community Health Center, and all of the service programs in the Waikiki Health Center also participate in the data system.

Each of the grantee agencies is required to submit a uniform set of data to the BPHC on an annual basis. The Hawai'i Primary Care Association also receives a copy of the completed uniform set of aggregated data from each of the agencies. Some of the data elements related to services that are included in the BPHC's Uniform Data System are: services offered and delivery method, users by race/ethnicity/

language, users by age and gender, socioeconomic characteristics, staffing and utilization, selected diagnosis and services rendered, perinatal profiles, and mental health/substance abuse and enabling services. Out of this array of data, the Hawai'i Primary Care Association extracts selected aggregated data from each of the agency reports and enters data into their database by

health centers/agencies. Some of the data that are extracted include: number of patients by health centers/agencies, number of patients by insurance status, and the patient's ethnicity, income, age and gender. The database has data from 1995 through 1999. The data specific to ethnicity include the following categories: Hawaiian/Part Hawaiian, Caucasian, Filipino, Samoan, Japanese, Other Asian, Other Pacific Islander, and Other.

The type of data that are included in the Hawai'i Primary Care Association's database are secondary data of service utilization in the designated health centers. The primary data is maintained at each of the individual health centers or agencies.

**The Native Hawaiian Data Book 1998 contains eight sections of secondary data that are provided by other agencies and programs that serve as the primary source of the data. Some of the sections include data on: the population, housing, land, education, human services, health, crime, and income.**

**AIDS Surveillance Program**

STD/HIV Prevention Branch, Hawai'i State Department of Health

[http://www.state.hi.us/doh/resource/comm\\_dis/std\\_aids/aids\\_rep](http://www.state.hi.us/doh/resource/comm_dis/std_aids/aids_rep)

The Hawai'i Health Department's STD/HIV Prevention Branch maintains an active AIDS surveillance program that collects and disseminates epidemiological data regarding individuals diagnosed with AIDS in the State of Hawai'i and reported to the Department of Health. The database was originated in 1983 and is current to the most recent quarter of the year. Since 1983 the data collected have been relatively constant, however, it is dependent upon the criteria established by the Centers for Disease Control and Prevention. In 1993, there was a major change in the diagnostic criteria for making the diagnosis of AIDS in individuals and the criteria were changed.

As of September 30, 2000, there were a total of 2,435 individuals in Hawai'i with AIDS since 1983 that were reported to the Department of Health and included in the database. The data are reported by the following categories: county, sex, age, race, and risk status. The data are stratified by the four counties, with the three islands of Maui County aggregated. The data are available by zip codes of residence and a special data run can be performed to stratify the database on residence. The age categories include: <13, 13-19, 20-29, 30-39, 40-49, and >49 years. The race is determined through self-identification by the patients and the case reports are made by the physicians to include: Caucasian, African-American, Hispanic, Hawaiian/Part Hawaiian, Filipino, Chinese, Japanese, other Asian/Pacific Islander, and Others (American Indian/Alaskan). The risk status categories include: male to male sex, injection drug use, male to male sex and injection drug use, female heterosexual, male heterosexual, transfusion, perinatal, hemophiliac, and undetermined.

**Hawai'i Breast and Cervical Cancer Control Program**

Preventive Health Services Branch, Hawai'i Department of Health

The Hawai'i Health Department's Breast and Cervical Cancer Control Program (BCCCP) maintains a database of women who have been identified through an outreach program and have received screening and diagnostic services for breast and cervical cancer. The program reaches women statewide and targets its outreach services for women of Hawaiian and Filipino ethnicity, women between 50-64 years of age, below 250% of the Federal poverty level, and under insured or uninsured. The database was initiated

in 1997 and has a total of 2,200 unduplicated women since that time.

Some of the specific issues related to the data elements are that the dates of birth of the women are collected from which specific ages can be calculated. Addresses with zip codes are also collected as part of the intake form. Although the women targeted for services are Hawaiian and Filipino women, the data for ethnicity includes: Hawaiian/Part Hawaiian, Filipino, White, Portuguese, Samoan, Japanese, Korean, Chinese, Black, American Indian, Hispanic, Other Pacific Islander, Other Asian, and Other.

Because the Hawai'i Breast and Cervical Cancer Control Program is part of a national effort, the data collected at the state level can be compared with similar data being collected in other states as well as at the national level.

**Pregnancy Risk Assessment Monitoring System (PRAMS)**

Maternal and Child Health Branch, Hawai'i State Department of Health

The Pregnancy Risk Assessment Monitoring System (PRAMS) is an initiative of the Center for Disease Control and Prevention (CDC) to reduce infant mortality and infants born with low birth weight. The PRAMS is a population-based survey of women who have recently given birth to a live infant. This survey collects data on women's experiences and behaviors before, during, and after pregnancy based on a standardized data collecting methodology developed by the CDC. Every month, a stratified systematic sample of 100-250 new mothers is selected from a frame of eligible birth certificates. The selected new

mother receives a mailed questionnaire at two to six months after delivery and a follow-up with non-respondents to three mailings by telephone. The questionnaire addresses topics including barriers to prenatal care and content of prenatal care, obstetric history, maternal use of alcohol and cigarettes, nutrition, economic status, maternal stress, and early infant development and health status. Findings from the analysis of the Hawai'i PRAMS data will be used to enhance the understanding of maternal behaviors and experiences and their relationship with adverse pregnancy outcomes.

The sampling framework for selecting participants is based on two stratification variables, maternal ethnicity and geographic area. Because the ethnic group with the highest infant mortality rates among the civilian population in Hawai'i is the Hawaiian/part Hawaiian, this group of mothers constitutes one ethnic stratum (Native Hawaiian) and all other ethnic groups are combined in the second ethnic

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**Table 2. Database summary profiles**

Database	Characteristics	Ethnic Categories	Contact	Comments
Hawai'i Annual Vital Statistics Report	Vital Statistics Registry Data available: 1996-1999 Population: Statewide	African American, Caucasian, Chinese, Filipino, Hawaiian, Japanese, Korean, Portuguese, Puerto Rican, Samoan, Vietnamese	Alvin T. Onaka, Ph.D. Department of Health 808-586-4600 alvino@hawaii.edu	Special data runs available upon request. Completion time depends on request. Charge of \$34/hour for programming.
Behavioral Risk Factor Surveillance System (BRFSS)	Surveillance of primary data based on telephone interviews. Data available: 1996-1999 Population: Persons 18 years and older, statewide	Caucasian, Filipino, Hawaiian, Japanese, others	Alvin T. Onaka, Ph.D. Department of Health 808-586-4600 alvino@hawaii.edu	Special data runs available upon request. Completion time depends on request. Charge of \$34/hour for programming.
Hawai'i Health Survey	Surveillance of primary data based on telephone interviews. Data available: 1998 Reports: 1989-1992 Population: Households, statewide.	Caucasian, Chinese, Filipino, Hawaiian, Japanese, others	Alvin T. Onaka, Ph.D. Department of Health 808-586-4600 alvino@hawaii.edu	Special data runs available upon request. Completion time depends on request. Charge of \$34/hour for programming.
Hawai'i Tumor Registry	Cancer registry Primary data Data available: 1973-1999 upon request only. Population: Hawai'i residents with diagnosed malignancies.	(See text)	Michael Green, C.T.R. 808-586-9750 Michael@crch.hawaii.edu	Special data runs available upon request. No charge. Data not available on website.
AIDS Surveillance Quarterly Report	Population database Primary data Data available: 1983-1999 Population: Persons diagnosed with AIDS	African-American, Asian/Pacific Islander, Caucasian, Chinese, Filipino, Hawaiian/part-Hawaiian, Hispanic, Japanese, others	Pritty B. Borthakur 808-733-9010 pbortha@lava.net	Special data runs available upon request. No charge.
Hawai'i Breast and Cervical Cancer Control Program	Service utilization database. Primary data Data available: July 1997 to 1999 upon request Women 50-64 years old	African-American, American Indian, Caucasian, Chinese, Filipino, Hawaiian/part-Hawaiian, Hispanic, Japanese, Korean, Portuguese, Samoan, other Asian, other Pacific Islander, other.	Tania Kuriki 808-692-7473 tkflee@mail.health.state.hi.us	Special data runs available upon request. Time to complete special data run: One month. No charge. Data not available on website.
Pregnancy Risk Assessment Monitoring System	Surveillance database Primary data Data available: 1999 Population: Mothers with live births	Hawaiian, non-Hawaiian	Momi Kamau 808-733-4044 amkamau@fhds.health.state.hi.us	Special data runs are not available.
Alcohol and Drug Abuse Division	Treatment service utilization database. Primary data Data available: 1996, 1998 Population: Adults, adolescents, pregnant and parenting women	African American, Aleutian/Eskimo, American Indian, Cambodian, Caucasian, Chinese, Filipino, Hawaiian, mixed-part Hawaiian, Japanese, Korean, Okinawan, Portuguese, Samoan, Vietnamese, mixed-not Hawaiian, others	Elaine Wilson 808-692-7506 ejwilson@mail.health.state.hi.us	Special data runs: Available time to complete special data run: Two weeks. No charge.

stratum (non-Native Hawaiian). The three geographic strata include urban Honolulu (City of Honolulu and urban areas around Pearl Harbor which constitute the 'Ewa District), rural O'ahu (the remaining outlying areas in the center and north and west shores of O'ahu), and neighbor islands (the inhabited islands in the remaining four counties). The combinations of these two variables are used to form the six sampling strata: Native Hawaiian in urban Honolulu, Native Hawaiian in rural O'ahu, Native Hawaiian in neighbor island, non-Native Hawaiian in urban Honolulu, non-Native Hawaiian in rural O'ahu, non-Native Hawaiian in neighbor island.

The analysis of the data will be based on the comparison of findings between the following combinations of strata:

Hawaiian vs. non-Hawaiian, urban Honolulu vs. rural O'ahu vs. neighbor island, Hawaiians in urban Honolulu vs. Hawaiians in rural O'ahu, Hawaiians in urban Honolulu vs. Hawaiians in neighbor islands, Hawaiians in urban Honolulu vs. non-Hawaiians in urban Honolulu, Hawaiians in rural O'ahu vs. Hawaiians in neighbor islands, Hawaiians in rural O'ahu vs. non-Hawaiians in rural O'ahu, Hawaiians in neighbor island vs. non-Hawaiians in neighbor island, non-Hawaiian in urban Honolulu vs. non-Hawaiian in rural O'ahu, non-Hawaiians in urban Honolulu vs. non-Hawaiians in neighbor island, and non-Hawaiian in rural O'ahu vs. non-Hawaiian in neighbor island.

The Hawai'i PRAMS started in September 1999 and to date of the 1,248 women who were selected and surveyed, 925 women (72%) responded to the questionnaire.

#### **Client Data System - Treatment Services**

*Alcohol and Drug Abuse Division, Hawai'i State Department of Health*

The ADAD Client Data System was originally developed for the Federal Anti-Drug Abuse Act of 1988 that mandated the collection of data on the incidence and prevalence of various forms of substance abuse and mental illness nationwide. The National Client Data System (CDS) was developed to meet the requirements of the Act by collecting demographic data on individuals admitted to substance abuse treatment programs. Since that time there have been many changes to the data system as evaluation methodologies became more sophisticated. The ADAD implemented the Admission and Discharge Report forms in 1991 to meet the Federal data requirements. In 1994, the Follow-up Report form was implemented to collect data on clients six months after discharge. In July 1997, the ADAD implemented the Purchase of Services information system that integrated client, fiscal, and contract management information and

automated the submission of data from contracted providers.

Currently, the ADAD Client Data System consists of three reports: (1) The Admission Report is completed when a client enters a treatment program or changes levels of service (modality). The Admission Report provides client demographic data and the nature of the substance problem. (2) The Discharge Report is completed for every client discharged from treatment or who changes level of service (modality). The Discharge Report provides data on discharge status, demographic characteristics, and substance use. (3) The Follow-up Report is completed for every client discharged from the program from the treatment episode

to the six-month follow-up period. The Follow-up Report provides data on the client's post-discharge functioning.

The data is submitted by approximately 20 contracted providers in the private sector who provide an entire spectrum of substance abuse treatment services to a variety of

populations including adolescents, adult men, adult women, pregnant women, and mothers and their infants. The array of available treatment services include residential treatment, supportive living, day treatment, intensive outpatient treatment, outpatient treatment, Methadone Maintenance, residential social detoxification, and special treatment residential, day treatment, and supportive living for pregnant and parenting women and children. These services are available through a variety of providers on a statewide basis.

Some of the demographic data that are collected include the date of birth from which age can be calculated; the type of admission (initial admission, transfer from another program, re-admission, change in status); population (adult, adolescent, pregnant woman, woman with child, child, Native Hawaiian, injection drug user, HIV/early intervention); service area; source of referral; educational level; employment status; marital status; living arrangement; health insurance status; and household income.

The ethnic data is self-reported by the client and is collected on the Admission Report. The *ethnic categories* include: Hispanic (Puerto Rican, Mexican, Cuban, Other), Caucasian, Portuguese, Black/African American, American Indian, Aleutian/Eskimo, Japanese, Okinawan, Chinese, Korean, Vietnamese, Cambodian, Filipino, Samoan, Hawaiian, mixed-part Hawaiian, mixed-not Hawaiian, and Other.

## **Conclusion**

With advances in computer and telecommunications technology and the development of medical and health informa-

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tion infrastructures, the availability of health data and information has begun to expand exponentially. This technology is beginning to revolutionize the way people work, learn, and live by providing them with the data and information they need, when they need it and where they need it. Currently, health and medical data relevant to Native Hawaiians and other minority populations are of limited usefulness because of the fragmented nature of how data is collected, maintained, and provided.

This article introduces a limited number of sources of data on the internet from both public and private agencies that offer health data relevant to Native Hawaiian and other

minority populations in the State of Hawai'i. The multitude of resources listed in this article is summarized in Table 2. It is hoped that this article will provide those individuals interested in data of minority populations—researchers, health care providers, public health program managers and administrators, and students—with a first step in accessing these data.

## References

1. Jaworowski S. *Hawaiian Demographic Data: 'Ehia Kanaka Maoli?* Legislative Reference Bureau, Honolulu, Hawai'i, USDA, 1998. Available on <http://www.state.hi.us/lrb/> ■

*Hā'awe i ke kua; hi'i i ke alo*

*A burden on the back; a babe in the arms*

*Said of a hard-working woman who carries a  
load on her back and a baby in her arms*