

## Alaska data sources

This website is intended to help users find data that is helpful for their work. Generally, each description includes information about how data are collected and analyzed, which subjects are addressed, an example of how the data might be used, and limitations to consider when using the source.

Community assessment, strategic planning, program development, grant proposal writing, and program evaluation activities all depend on accurate data. Although community-level information would be most useful for community-based programs, local data are often not available due to lack of resources or because of concerns about confidentiality, accuracy or reliability.

Diabetes is featured in many of the examples because work on this website was initiated by the Alaska Diabetes Program and grew from there. Most of these data sources collect information on multiple topics; more detailed information is posted on the data source websites.

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## Community data from Alaska sources

*Alaska Division of Community Advocacy - Alaska Community Database* contains one-page descriptions of all Alaska communities. Each profile has information under the following headings: location and climate; history, culture and demographics; facilities, utilities, schools and health care; economy and transportation; organizations with local offices; and regional organizations.

The URL for this website: [http://www.commerce.state.ak.us/dca/commdb/CF\\_COMDB.htm](http://www.commerce.state.ak.us/dca/commdb/CF_COMDB.htm)

## Community data from Alaska sources

*Fairbanks North Star Borough (FNSB), Community Research Center* produces the quarterly Community Research Quarterly. This document includes economic indicators and FNSB-specific information on employment, housing, the cost of living, and population and social conditions. It brings together data from a variety of sources including the State of Alaska, the FNSB School District, the University of Alaska, and the federal government. The population and social conditions section includes population statistics, vital statistics, university enrollment, K-12 public and private enrollment, alcoholic beverage consumption and traffic crashes.

These reports posted online start with spring 2002:

<http://co.fairbanks.ak.us/CommunityPlanning/CRC/Default.htm>. The Community Research Quarterly example is an excerpt from the winter 2006 issue.

Community Research Quarterly example. Fairbanks North Star Borough Traffic crashes 1988-2006, AK DOT/PF, Traffic and Safety Division, <i>Alaska Traffic Accidents</i>						
	All crashes			Alcohol related crashes		
	Property only	Injury	Fatal	Property only	Injury	Fatal
1988	1340	505	9	96	81	4
1998	1214	495	8	60	56	2
2004	1494	496	10	57	46	1
% change 03-04	12%	1%	43%	4%	24%	-50%

## Community data from Alaska sources

*Municipality of Anchorage, Healthy Anchorage Indicators* is a publication that combines a brief description of each indicator, proven strategies for improvement, the questions asked of Anchorage residents, and graphs. Data are from the Behavioral Risk Factor Surveillance System (BRFSS) Selected Metropolitan/Micropolitan Area Risk Trends (SMART) project; they include responses from residents of the Anchorage Metropolitan/Micropolitan Statistical Area, which includes the Matanuska-Susitna Borough.

The Anchorage Office of Community Planning and Support is responsible for the Anchorage Healthy Indicators project. The website for this office is:

<http://www.muni.org/healthchp/index.cfm>. The publication itself is posted at:

<http://www.muni.org/iceimages/healthchp/HAI%20Final%201-13-05.indd.pdf>. The Healthy Anchorage Indicators example is an excerpt from this publication.

Healthy Anchorage Indicators example. At risk for health problems related to weight classifications based on BMI (body mass index), Healthy Anchorage Indicators			
	Neither obese nor overweight (BMI <25)	Overweight (BMI 25-29.9)	Obese (BMI ≥ 30)
Percent	41.2	37.7	21.1
Confidence interval	(35.5-46.9)	(32.0-43.4)	(16.0-26.2)
n	182	151	74

Limitations: Although a large proportion of Alaska residents live within Municipality of Anchorage boundaries, a limited the number of Anchorage residents surveyed by the BRFSS. Consequently, substantial year to year variability in the results is possible.

## Community data from Alaska sources

*School Districts* issue annual reports to their communities; many districts post these reports on their website. The contents of these reports vary, reflecting the information that is particularly important to the school board and community. The reports may contain more recent enrollment information and they may have other useful statistics that are not included from the State of Alaska Dept. of Education and Early Development.

## Alaska data from Alaska sources

*Alaska Behavioral Risk Factor Surveillance System (AK BRFSS)* has collected information since 1991. It uses a random sample procedure in which all Alaskan households with a phone have a specific likelihood of being selected. Since 1998, the sample has been stratified into five geographic regions, with roughly equal numbers of interviews conducted in each region. From 1991-1997, the sample was stratified into four regions; during that period, the Fairbanks and vicinity and Anchorage and vicinity regions were combined. Regardless of the number of regions used, this stratification means that residents in less populous areas (such as Rural Alaska) are somewhat more likely to be included in the sample than residents of areas with a larger population (such as Anchorage). After being collected, data are weighted to assure a balanced representation of various subgroups and to reflect the total population of the each area.

The 2006 AK BRFSS included questions on these topics:

Alcohol consumption	Emotional support and	Oral health
Anxiety and	life satisfaction	Obesity
depression	Exercise	Prostate cancer screening
Asthma	Falls	Seatbelt use
Cardiovascular disease	Food security	Sexual violence and
Child health insurance	Health care access	intimate partner
Colorectal cancer	Health care provider	violence
screening	Health status	Smokeless tobacco use
Demographics	Healthy days	Tobacco use
Diabetes	HIV/AIDS	Veteran's status
Disability	Immunization	Women's health
Drinking and driving	Injury	

Some questions are included every other year. Questions on cholesterol, fruits and vegetables, hypertension, and physical activity are asked in odd-numbered years while questions on colorectal cancer screening, prostate cancer screening and women's health are asked in even-numbered years.

In some cases, when responses are stratified by categories of interest, the denominator in one or more subgroups drops below 50, producing an unreliable result. For this reason, data from three successive years may be aggregated and reported as a three-year annual average. This strategy reduces the impact of variations in the data between years and improves the precision of the prevalence estimates. When possible, Alaska data are age-adjusted using the US 2000 Standard Population to allow for comparability with national data.

In 2004, Alaska added a survey that is closely modeled on the BRFSS methodology and survey instrument to enrich information on tobacco-related attitudes and behaviors and to address other issues that the regular BRFSS does not incorporate.

The AK BRFSS website is <http://www.hss.state.ak.us/dph/chronic/hsl/brfss/default.htm>. It includes links to annual reports since 1995; these reports contain both data and the

questionnaires that were used. They are available at:  
<http://www.hss.state.ak.us/dph/chronic/hsl/brfss/publications.htm>.

AK BRFSS results are presented as estimated percentages of the total population. The initial BRFSS analysis process involves statistically adjusting (or weighting) results to account for under- or over-representation of subgroups in the sample and to assure that the results reasonably accurately reflect demographic characteristics of the entire state population. The example shows how AK BRFSS data can be used to compare Alaska and national diabetes rates.

AK BRFSS example. Age-adjusted percentages with 95% confidence intervals of adults ( $\geq 18$ ) with diabetes by gender and race and crude percentages by age group, AK BRFSS 2002 – 2004	
Total	5.1% (4.5% - 5.8%)
<i>by Sex</i>	
Male	5.4% (4.6% - 6.4%)
Female	4.7% (3.9% - 5.7%)
<i>by Race</i>	
non-Hispanic White	4.6% (4.0% - 5.4%)
AK Native/American Indian	5.1% (3.7% - 6.9%)
<i>by Age group (crude rates)</i>	
18 – 44	1.4% (1.0% - 2.0%)
45 – 64	6.8% (5.7% - 8.0%)
65 – 74	12.7% (9.6% - 16.6%)
$\geq 75$	15.8% (11.4% - 21.3%)

Limitations: The one main limitation of any telephone survey is that those people without phones cannot be reached and are not represented. In Alaska, about 97% of households have phones; about 98% of all U.S. households have phones (2000 US Census, Summary File 4). The percentage of households with a telephone varies by region in Alaska. In general, persons of low socioeconomic status are less likely than persons of higher socioeconomic status to have phones and are undersampled. However, national BRFSS results correspond well with findings from other surveys conducted in person.

The reliability of a prevalence estimate depends on the actual, unweighted number of respondents in a category or demographic subgroup (not a weighted number). Interpreting and reporting weighted numbers that are based on a small, unweighted number of respondents can be misleading. The degree of precision increases if the sample size is larger and decreases if the sample size is smaller. Prevalence estimates are not usually reported for those categories in which there were less than 50 respondents and are rounded to the nearest whole percent when the denominator is less than 500. Diabetes data are generally reported as three-year annual averages because subdividing single-year AK BRFSS diabetes results would often produce categories with fewer than 50 respondents.

With surveys based on self-reported information, the potential for bias must be kept in mind when interpreting results. Survey response rates may also affect the potential for bias in the

data. The impact of bias associated with self-report varies with the question. About 30% of US adults with diabetes do not know they have this disease, which means that differences between Alaskans with and without diabetes are underestimated in BRFSS results.<sup>1</sup> Although self-reported demographics (age, for example) have been determined to be quite accurate, other responses are less so. Among the measures relevant to diabetes, hemoglobin A1c (HbA1c) tests, high cholesterol, high blood pressure, and height and weight responses seem to be especially prone to under- or over-reporting.

## Alaska data from Alaska sources

*Alaska Birth Certificates* are one set of vital records maintained by AK Bureau of Vital Statistics (AK BVS) under AK Statute Section 18.50.010. In 1994, the AK BVS implemented an Electronic Birth Certificate system, which allows hospital and clinic staff to record all birth certificate information directly into the AK BVS database. Checks during and after data entry assure data accuracy. In 2003, nearly 97% of all births in Alaska were recorded using this system. When an Alaska resident gives birth in another state, that state's registrar sends AK BVS a copy of the birth certificate.

In addition to details on the birth, the infant and his or her parents, birth certificates include information on the mother's prior pregnancy history, conditions affecting the pregnancy, complications affecting the pregnancy, and abnormal conditions or congenital anomalies of the infant. Diabetes and congenital diabetes are included in the list of medical conditions affecting the pregnancy.

The AK BVS website is <http://www.hss.state.ak.us/dph/bvs/default.htm>.

Birth rates are usually reported per 1,000 live births. When the analysis is focused on women with diabetes or gestational diabetes, the rate may be per 1,000 births to women with one or both of those conditions. The birth certificates example shows how birth certificate information can be used to present information on the connection between pre-existing diabetes and increased risk for preterm births.

AK Birth Certificates example: Births per 1,000 live births by diabetes status and gestational age: Alaska 1990-1999 <sup>2</sup>			
Gestational age	Pre-existing diabetes (n=243)	Gestational diabetes (n=2,427)	No diabetes (n=103,497)
<37 weeks	2.14	0.71	0.72
37-41 weeks	7.70	9.04	8.92
≥42 weeks	0.16	0.25	0.35

AK Vital Statistics 1990-1999; data were missing from 1,018 records.  
Note: Differences between Pre-existing diabetes and No diabetes and between Gestational diabetes and No diabetes were statistically significant at p<0.05.

Limitations: The accuracy of birth certificate data varies considerably by item. Mothers' risk factors are among the data that have been found to be particularly problematic.<sup>3</sup> If available, hospital discharge data are more accurate resources for gestational and other types of diabetes.<sup>4</sup>

## Alaska data from Alaska sources

*Alaska Birth Defects Registry (ABDR)* *Alaska Birth Defects Registry (ABDR)* is a population-based surveillance system that collects information on birth defects reportable to the Alaska Division of Public Health. Its purpose is to be a reliable, valid, and timely information source for ascertaining the number of infants and young children with birth defects in Alaska. Guidelines for Birth Defects Reporting can be found in the Alaska "[Conditions Reportable to Public Health](#)." The ABDR website is: <http://www.epi.hss.state.ak.us/mcheper/ABDR/default.stm>.

The *Alaska MCH Data Book 2005: Birth Defects Surveillance Edition* presents detailed information from the Alaska Birth Defects Registry (ABDR). This is the first comprehensive analysis of ABDR data. It provides a detailed descriptive epidemiology of the prevalence and distribution of major congenital anomalies among Alaskan populations. It is available at: <http://www.epi.hss.state.ak.us/mcheper/mchdatabook/2005.htm>.

## Alaska data from Alaska sources

*Alaska Cancer Registry* (ACR) is a population-based cancer surveillance system that collects data on all newly diagnosed cases of cancer (including benign brain) for the State of Alaska. The registry operates under [7 AAC 27.011 - Reporting of cancer and brain tumors](#) and [AS 18.05.042 - Access to health care records](#), which are required for compliance with the National Program of Cancer Registries.

ACR's website includes links to reports on cancer incidence and mortality in Alaska by diagnosis year, sex, race, and borough. The ACR website is: <http://www.hss.state.ak.us/dph/chronic/cancer/registry.htm>.

The AK Cancer Registry example is compiled from *Cancer Incidence and Mortality in Alaska, 1996-2002*<sup>5</sup>, which is posted on the ACR website.

AK Cancer Registry example: Age-adjusted Alaska rates per 100,000 population for the six most frequent and deadly malignant cancers in Alaska, 1996-2002		
Type of cancer	Incidence <sup>a</sup>	Mortality <sup>b</sup>
Prostate	172.7	27.7
Female breast	137.2	24.1
Lung and bronchus	76.0	57.4
Colorectal	59.5	20.6
Bladder	23.6	not in top 6
Non-Hodgkin's lymphoma	20.7	8.2
Pancreas	not in top 6	11.0

<sup>a</sup> In 1996-2002, prostate, female breast, lung and bronchus, colorectal, bladder and non-Hodgkin's lymphoma cancers represented 63.4% of all cancers diagnosed in Alaska.

<sup>b</sup> In 1996-2002, lung and bronchus, female breast, prostate, colorectal, pancreas and non-Hodgkin's lymphoma cancers represented 59.4% of all cancer deaths in Alaska.

Limitations: Because of the low number of cancer cases in Alaska, cancer data are suppressed when there are five or fewer cases for patient confidentiality. Suppression usually occurs when data are presented in small groups, such as by race, by a single diagnosis year, or for a single borough/census area. Aggregating data into larger groupings helps reduce data suppression. Some national web sites suppress cancer data at even higher case-count thresholds.

## Alaska data from Alaska sources

*Alaska Center for Health Data and Statistics* is an index of electronically accessible health information generated, collected and published by programs in the Alaska Division of Public Health, including reports on: alcohol use and substance abuse; arthritis and osteoporosis; asthma and other respiratory diseases; cancer; communicable and infectious diseases; diabetes; food safety; health screenings; heart disease and stroke; HIV/AIDS; high blood pressure; high cholesterol; injuries; maternal and child health; nutrition; obesity and overweight; occupational safety; physical activity; youth and adult risk factors; suicide; tobacco; and violence and abuse prevention.

The URL is: <http://www.hss.state.ak.us/dph/infocenter/default.htm>.

## Alaska data from Alaska sources

*Alaska Death Certificates* are another set of vital records maintained by the AK Bureau of Vital Statistics (AK BVS) under AK Statute Section 18.50.010. Death certificates are filed with the local recording office, then forwarded to AK BVS for registration. If an Alaskan resident dies in another state, that state's registrar sends AK BVS a copy of the death certificate.

In addition to details on the time and manner of death, death certificates include the immediate cause of death and up to three underlying causes of death, contributing causes of death, and demographic information about the decedent. Together, the immediate and underlying causes of death describe the disease or injury sequence leading directly to death. All other significant diseases or conditions that contributed to the death, but were not an underlying cause, are entered separately as contributing causes. Diabetes could be entered on a death certificate as either an underlying cause or a contributing cause of death. The term "any mention" of diabetes refers to any listing of diabetes as either an underlying or contributing cause of death.

Starting in 1991, the AK BVS added contributing causes of death to its reports and analyses, which earlier had only included the underlying cause of death. The AK BVS website is <http://www.hss.state.ak.us/dph/bvs/default.htm>.

Mortality rates are usually reported per 100,000 population. The death certificates example shows how death certificate data can be used to compare Alaska and US mortality rates by cause.

AK Death Certificates example: 2004 Alaska preliminary mortality rates per 100,000 population for the top ten leading causes of death in Alaska, Alaska Bureau of Vital Statistics <sup>6</sup>			
Cause of Death (ICD-10 Codes)	Rank	Deaths	Alaska age-adjusted Rate
Malignant Neoplasms (C00-C97)	1	723	183.9
Diseases of the Heart (I00-I09, I11, I13, I20-I51)	2	582	155.7
Unintentional Injuries (V01-X59, Y85-Y86)	3	318	54.9
Cerebrovascular Diseases (I60-I69)	4	173	52.3
Intentional Self-Harm (Suicide) (X60-X84, Y87.0)*	5	155	23.4
Chronic Lower Respiratory Diseases (J40-J47)	6	138	39.5

Alzheimer's Disease (G30)	8	48	17.5
Chronic Liver Disease and Cirrhosis (K70, K73-K74)	9	46	8.0
Influenza and Pneumonia (J10-J18)	10	42	14.4
TOTAL DEATHS		3,051	748.6
* Included in this category for US deaths, but not Alaska deaths, are those with ICD-10 code U03. This code is not in the ICD-10; CDC uses it to track self-harm deaths due to			

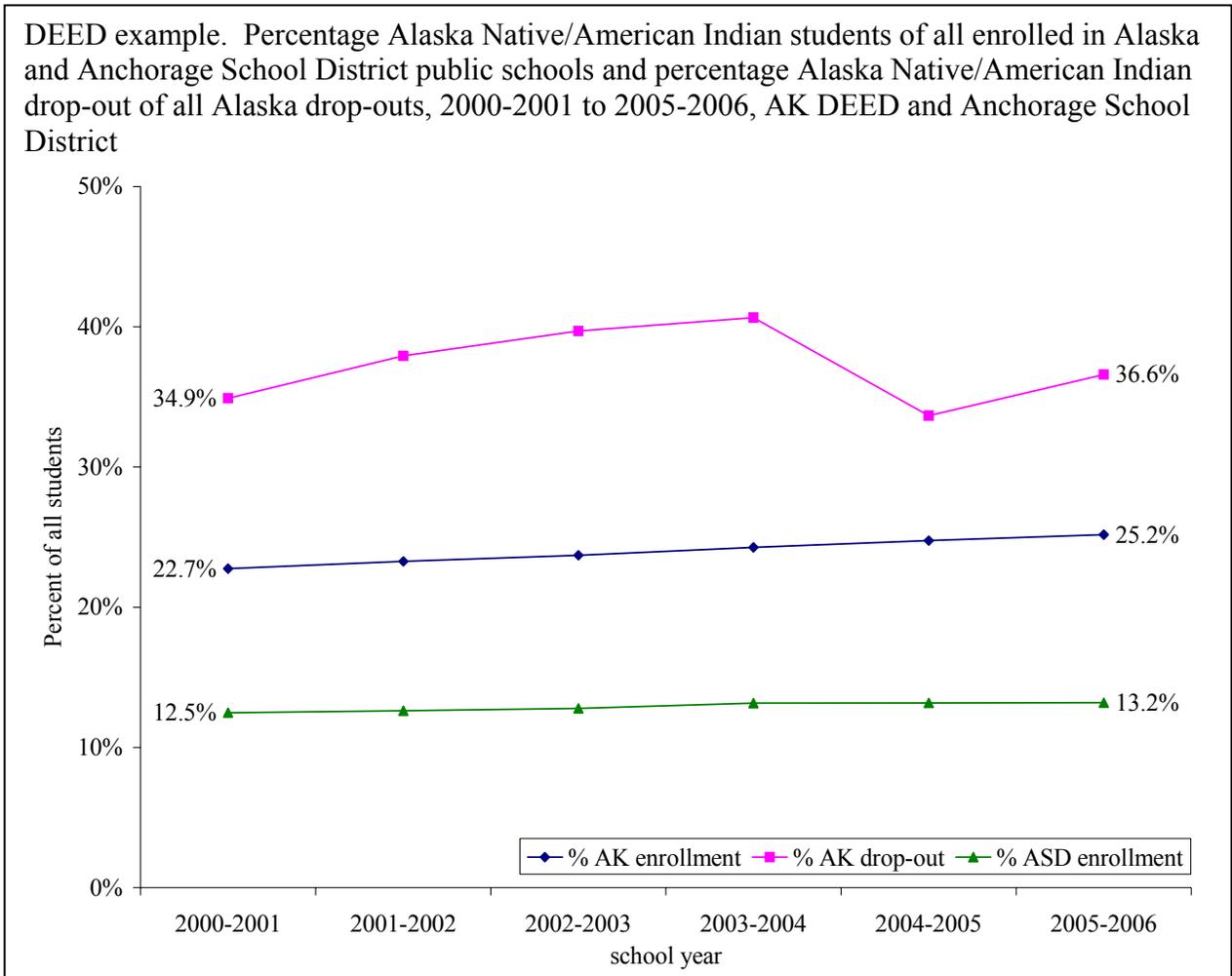
Limitations: Relatively common causes of concern when using vital records as a resource for public health information include (1) incomplete death certificate forms, (2) identified diagnoses may be inaccurate or incomplete, (3) race or ethnicity may be incorrectly entered, and (4) different interpretations of underlying and contributing cause of death by people completing death certificates.<sup>7</sup> In addition, there are specific problems when using death certificate data as a source of information about diabetes. These include:

- Under-reporting of diabetes on death certificates. Among deceased participants in the Translating Research Into Action for Diabetes study, 39% had the disease identified on their death certificates and 10% had it as an underlying cause of death.<sup>8</sup>
- Distinctions between type 1 and type 2 diabetes are often not specified.

## Alaska data from Alaska sources

Alaska Department of Education and Early Development (DEED) posts information on student enrollment in public and all Alaska schools, high school graduates by school, numbers of special education students, and teacher and student counts by school, drop-out rates by school district and race/ethnicity, and other published reports on its website:

<http://www.eed.state.ak.us/stats/>. The DEED example is compiled from the Public School Dropouts report (2/1/2007) and the Anchorage School District Ethnicity Report (October 2006).



## Alaska data from Alaska sources

Alaska Department of Labor and Workforce Development, Research and Analysis Section (AK DOLWD) has population estimates and projections and Alaska census data from the US Census Bureau. AK DOLWD estimates start with the annual total Alaska population estimate from the US Census Bureau; the populations of places, boroughs and census areas are then calculated using a formula based on the 2000 Census, Permanent Fund Dividend applications, an annual AK DOLWD survey of group housing facilities, and the estimated size of the military and military dependant population that did not file for a Permanent Fund Dividend. AK DOLWD population estimates are independent from year to year and are available in age, sex, region, and place-specific tables.

The AK DOLWD website is <http://almis.labor.state.ak.us/>.

	2003	2004	2005	Percentage growth
White	331,010	336,613	340,084	2.7%
AK Native or American Indian	65,963	67,633	69,237	5.0%
Other	38,501	38,567	39,218	1.9%
Total	435,474	442,813	448,539	3.0%

Limitations: (1) AK DOLWD and US Census Bureau population estimates include full-time Alaska residents. Temporary residents, such as seasonal workers, have a substantial impact on some communities but are not included. (2) Population estimates are made once a year; the timing of boundary changes for boroughs or cities may preclude its incorporation in that year's population estimate.

## Alaska data from Alaska sources

*Alaska Hospital Discharge Dataset (AHDD)* involves data provided through an agreement between the Alaska Department of Health and Social Services and the Alaska State Hospital and Nursing Home Association (ASHNHA). The dataset includes hospitalizations from 70% of Alaska hospitals, or about 88% of all hospitalizations in Alaska. It starts with 2001.

Each hospital admission may have several diagnoses, each identified using an ICD-9 code. The immediate reason for the hospitalization is usually listed as the patient's primary diagnosis. Some diseases, such as diabetes, substantially contribute to the need for some hospitalizations but are more frequently listed as a subsequent than a primary diagnosis. An analysis of discharge data that used only primary diagnoses would miss these discharges and would underestimate the impact of diabetes. Consequently, analyses often look for discharges in which diabetes was either the primary diagnosis or any subsequent diagnosis.

Contact Alice Rarig (907) 465-1285 or [alice.rarig@alaska.gov](mailto:alice.rarig@alaska.gov) if you are interested in this data source.

Hospital discharge rates are usually expressed per 10,000 general population, although some diabetes-specific analyses use per 1,000 people with diabetes. One challenge in using a diabetes-specific denominator is that hospital discharge data often includes children, but there is no state-specific means for identifying the prevalence among Alaskans under 18. The AHDD example shows how hospital discharge data can be used to compare demand associated with diabetes between Alaska and the US and demand between diabetes and non-diabetes within Alaska.

AHDD example: Percentage of first-listed diagnoses among hospital discharges for adults age 18 and older, Alaska discharges with and without diabetes as any listed diagnosis and US discharges with diabetes as any listed diagnosis, AK Hospital Discharge Database 2002- 2004			
		Also with diabetes	No diabetes
Circulatory system- includes vascular disease	390 – 459.9	25.9%	11.5%
Respiratory system	460 – 519.9	10.2%	6.5%
Digestive system	520 – 579.9	10.0%	10.6%
Diabetes	250 – 259.9	8.6%	
Injury and poisoning	800 – 999.9	7.5%	10.2%
Musculoskeletal and connective tissue	710 – 739.9	5.3%	6.3%
Genitourinary system	580 – 629.9	5.0%	5.7%
Pregnancy, childbirth, puerperium	630 – 676.94	1.5%	26.0%
Other		26.1%	23.1%

Limitations: (1) As with the National Hospital Discharge Survey (NHDS), the unit of analysis for the AHDD is discharges, not individuals. Multiple admissions of the same

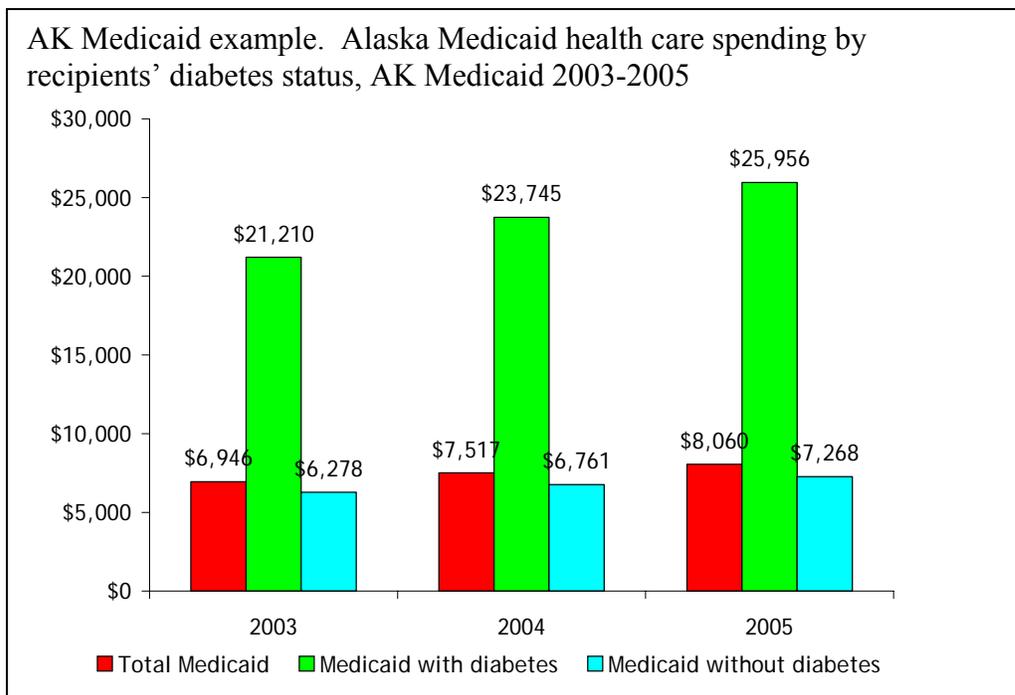
individual for the same or similar reasons may be counted more than once. (2) Excluded from the Alaska hospital discharge database are data from eight of the state's smaller hospitals, which represents about 12% of Alaska's hospitalizations.

## Alaska data from Alaska sources

*Alaska Medicaid (AK Medicaid)* has a huge database containing individual and provider enrollment data and all of the claims submitted for reimbursement by AK Medicaid. Medicaid is a joint state-federal program which is the third-party payer for enrolled Alaskans. Alaskans may be enrolled without using a Medicaid-funded service; to avoid results skewed by this non-user group, the analysis denominator is recipients, or people who have had at least one claim for Medicaid-funded care. Medicaid recipients with diabetes are identified by a) having two or more claims with a diabetes diagnosis within two years, or b) receiving diabetes therapy.<sup>10</sup>

Contact Nancy Cornwell (907) 269-8868 or [nancy.cornwell@alaska.gov](mailto:nancy.cornwell@alaska.gov) if you are interested in this data source.

In addition to total Alaska enrollment and recipient numbers and total expenditures, AK Medicaid results are presented as percentages of the Medicaid population, average per capita cost of care or average per capita reimbursement claims submitted for care. The AK Medicaid example compares per capita Medicaid expenditures by diabetes status.



Limitations: (1) This database only includes care that was reimbursed by Medicaid. If one group of recipients is more or less likely than another to have intermittent Medicaid coverage and have health care that is not reimbursed by Medicaid, differences between the groups will be skewed. (2) The population enrolled in Medicaid reflects the various eligibility categories; it is much easier to gain enrollment for children (< 18) and pregnant women than other Alaskans. It is very difficult for non-disabled adults without dependant children to gain eligibility if they don't have concurrent Medicare enrollment. Consequently, AK Medicaid has less information about the kinds and quality of care provided to reasonably healthy

working-age adult Alaskans. (3) The primary purpose of the information in this database is health care payment. It is organized and monitored for accuracy from that perspective, which means that diagnoses or procedures that have higher reimbursement rates are likely to be favored. Most claims are submitted electronically, with provider clerks doing the data entry. Consequently, there is substantial variation in the completeness, style and accuracy of diagnosis and procedure coding.

## Alaska data from Alaska sources

*Alaska Native Tribal Health Consortium (ANTHC) Alaska Native Epidemiology Center* is one of eleven tribal epidemiology centers established by the Indian Health Service (IHS) to assist the National IHS Epidemiology Program in improving the health of Alaska Natives and American Indians throughout the United States. It supports and serves Alaska tribal health organizations by coordinating, collecting, analyzing, and disseminating timely, accurate, and essential health data. It also supports these organizations by providing technical assistance and advocating for Alaska Native health issues.

The URL for their website is: <http://www.anthc.org/cs/chs/epi/index.cfm>.

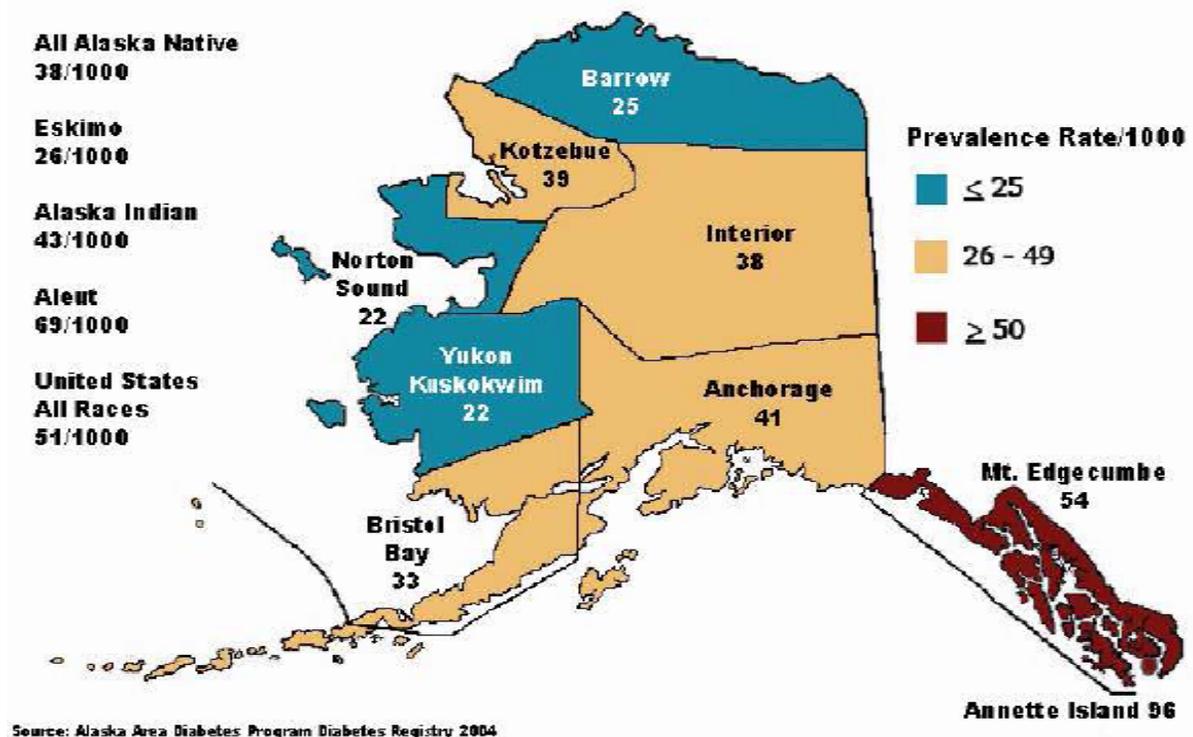
## Alaska data from Alaska sources

*Alaska Native Tribal Health Consortium (ANTHC) Alaska Area Diabetes Registry* is populated by case reports from regional diabetes coordinators, chart and lab reviews from ICD-9 codes, and data entry by the registry team. The latest registry data may not be available immediately. These data are available to tribal health programs, and in certain circumstances, to other programs. Prevalence results are usually presented per 1000 people (age-adjusted). Examples of data available include yearly prevalence, increase in prevalence, ESRD, and amputation rates.

The URL for this website is: <http://www.anmc.org/services/diabetes/>. Contact the epidemiologist at 729-1124 discuss data requests.

ANTHC Diabetes Registry example

### **2004 Diabetes Prevalence Among Alaska Natives Per 1,000 User Population** Age-Adjusted to U.S. 2000 estimated population Regions by Previous IHS Service Units



Limitations: While every effort is made to keep the registry complete, it is possible that people who get care completely outside the tribal/I.H.S. health care system are missed.

## Alaska data from Alaska sources

*Alaska Native Tribal Health Consortium (ANTHC) Office of Alaska Native Health Research* was created in 2001 as one of the programs in the Division of Community Health Services, Alaska Native Tribal Health Consortium. Its purpose is to serve Alaska Natives by working to: identify health research needs and priorities; enhance capacity to conduct research; increase participation of Alaska natives in the conduct of health research; pursue funds for conducting research projects; develop a database of health research involving Alaska natives, and coordinate, whenever possible, all research involving Alaska natives occurring in the state.

The URL is: <http://www.anthc.org/cs/chs/oanhr/>.

## Alaska data from Alaska sources

*Alaska Pregnancy Risk Assessment Monitoring System (PRAMS)* project is an on-going survey of mothers of newborns initiated by the AK Division of Public Health, Section of Maternal, Child and Family Health in 1990. The CDC Division of Reproductive Health developed PRAMS as part of its initiative to reduce infant mortality and low birth weight. PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and after pregnancy. It supplements Vital Records information by providing state-specific data on maternal behaviors and experiences.

PRAMS uses standardized data collection methods, which allows its data to be compared among participating states. Data collection starts with a mailed questionnaire, with attempted telephonic contact if there is no response to the mailed requests. The sample is selected from a list of recent births registered with the AK Bureau of Vital Statistics.

The PRAMS questionnaire includes core questions that are asked by all participating states and state-specific questions that are chosen or developed by individual states. The core portion of the questionnaire includes questions about the following:

Attitudes and feelings about the most recent pregnancy	Awareness of benefits of folic acid
Barriers to and content of prenatal care	Pregnancy-related violence
Use of alcohol and tobacco before and during pregnancy	Infant health care, sleep position, and exposure to tobacco smoke
	Psychosocial support and stress

Alaska-specific topics include: post-partum birth control use, infant safety and co-sleeping habits, marijuana and cocaine use, smokeless tobacco use, and family income.

The PRAMS website is: <http://www.epi.hss.state.ak.us/mchepi/PRAMS/default.stm>. Contact Kathy Perham-Hester (907) 269-3447 or [katherine.hester@alaska.gov](mailto:katherine.hester@alaska.gov) for more information.

PRAMS results are presented as estimated percentages of the total population. The initial CDC PRAMS analysis process involves statistically adjusting (or weighting) results to account for under- or over-representation of subgroups in the sample and to assure that the results reasonably accurately reflect demographic characteristics of the entire state population. The AK PRAMS example shows 2000–2003 trend information for high blood sugar during pregnancy from PRAMS.

AK PRAMS example. Percentages with self-reported high blood sugar during pregnancy, AK PRAMS 2000 – 2003	
year	Percent of respondents
2000	8.0%
2001	8.7%
2002	9.3%
2003	8.9%

Limitations: (1) PRAMS data are not generalizable to the entire United States or to all pregnant women; they only represent those who delivered live-born infants. (2) The prevalence of unintended pregnancies is probably underestimated by PRAMS, because it only reports on unintended pregnancies resulting in a live birth. (3) As PRAMS does not collect data on alcohol or tobacco use during the first or second trimesters of pregnancy, estimates do not capture prevalence of women who used alcohol or tobacco in early pregnancy. (4) Smoking estimates are based on self-reported data, which likely underestimated the true rate of smoking. (5) The indicator for folic acid consumption, multivitamin use, does not capture women's consumption for folic acid precisely, and PRAMS data therefore might not accurately reflect prevalence of women achieving this objective.

## Alaska data from Alaska sources

*Alaska Statewide Diabetes Survey (ASDS)* was conducted in the fall of 1999. Respondents were 501 adults 18 and older with diabetes in Anchorage, Fairbanks, the Kenai Peninsula, the Mat-Su Valley, Juneau and Ketchikan. The 50-question survey asked about demographics, lifestyle, diabetes complications, and disease management.

Adults with diabetes were identified through random digit dialing using all prefixes in the six areas surveyed. A total of 26,700 calls were made, which includes 8,800 disconnected numbers, 324 busy signals, 1,400 voicemails, and 3,100 calls to numbers where there was no answer. Among the households which qualified because of having an adult with diabetes, there was a 70% response rate. Among the qualified households who also spoke English, the response rate was even higher. Contact the AK Diabetes Program ([diabetes@health.state.ak.us](mailto:diabetes@health.state.ak.us)) if you are interested in this data source.

ASDS results are presented as percentages of the respondents. The ASDS example contains information from this survey.

ASDS example. Percentages of Alaskans with diabetes reporting Emergency Room visits or hospitalizations and mean numbers of Emergency Room visits or hospitalizations during the previous year, ASDS 1999			
	Type 1	Type 2	Total
% with ER visit	19%	9%	16%
mean ER visits	0.52 (0.21 – 0.83)	0.41 (0.14 – 0.68)	0.41 (0.25 – 0.57)
% with hospitalization	16%	8%	13%
mean hospitalizations	0.41 (0.16 – 0.66)	0.16 (0.06 – 0.26)	0.25 (0.15 – 0.35)

Limitations: As with other phone surveys, the data are limited because they are self-reported and therefore dependent on the accuracy and memory of the respondent. Because the sample did not include individuals without access to a phone or who were not English-speaking, the results can only be generalized to English-speaking Alaskans with diabetes who had a phone during the survey period. Also, the results are not weighted to accommodate for any differences that may have existed between the group that was surveyed and all Alaskans with diabetes.

## Alaska data from Alaska sources

*Alaska Trauma Registry* is an information system of the most seriously injured patients in Alaska, and the treatment that they have received. Since 1991, the trauma registry has collected data from all 24 of Alaska's acute care hospitals.

The purpose of the registry is to evaluate the quality of trauma patient care and to plan and evaluate injury prevention programs. The criteria for inclusion in the trauma registry are patients with injuries who are admitted to an Alaska hospital, held for observation, transferred to another acute care hospital, or declared dead in the emergency department, and for whom contact occurred within 30 days of the injury. Injuries include trauma, poisoning, suffocation, and the effects of reduced temperature. The Alaska Trauma Registry website is: [http://www.hss.state.ak.us/dph/ipems/injury\\_prevention/trauma.htm](http://www.hss.state.ak.us/dph/ipems/injury_prevention/trauma.htm). Contact the AK Injury Surveillance and Prevention Unit Manager ([deborah.hull-jilly@alaska.gov](mailto:deborah.hull-jilly@alaska.gov)) for more information about this data source. The example is from the AK Trauma Registry website.

AK Trauma Registry example. Ten leading causes of non-fatal hospitalized injuries in Alaska, 1999 – 2003		
Rank	Cause	Number
1	Falls	7632
2	Suicide/Attempt	3045
3	MV Traffic Occupant	2641
4	Assault	1676
5	Snowmachine	767
6	Cut	658
7	ATV	642
8	Sports	580
9	Bicycle	560
10	Pedestrian	430

Limitations: Alaska trauma registry data is limited to patients with injuries who are admitted to an Alaska hospital, held for observation, transferred to another acute care hospital, or declared dead in the emergency department. Ambulatory care information is not included in the ATR.

## Alaska data from Alaska sources

*Alaska Youth Risk Behavior Survey (AK YRBS)* is designed to help monitor the prevalence of behaviors that put Alaskan youth at risk for the most significant health and social problems that can occur during adolescence and adulthood, in order to assist in prevention and intervention planning and evaluation. The AK YRBS is a school-based survey of high school students administered in cooperation with the Department of Education and Early Development. This anonymous survey examines a minimum of six categories of adolescent behavior: behaviors that result in unintentional and intentional injuries; tobacco use; alcohol and other drug use; sexual behaviors that can result in HIV infection, other sexually transmitted diseases (STD's) and unintended pregnancies; dietary behaviors; and physical activity. Alaska has also added questions on connectedness to assess youth well-being. The website is: <http://www.hss.state.ak.us/dph/chronic/school/YRBS.htm>.

The AK YRBS has been administered in Alaska six times, in 1995, 1999, 2001, 2003, 2005 and 2007. Weighted (representative) data were collected in 1995, 1999, 2003 and 2007, resulting in published reports. The example is compiled from the *2003 Youth Risk Behavior Survey (YRBS)*.

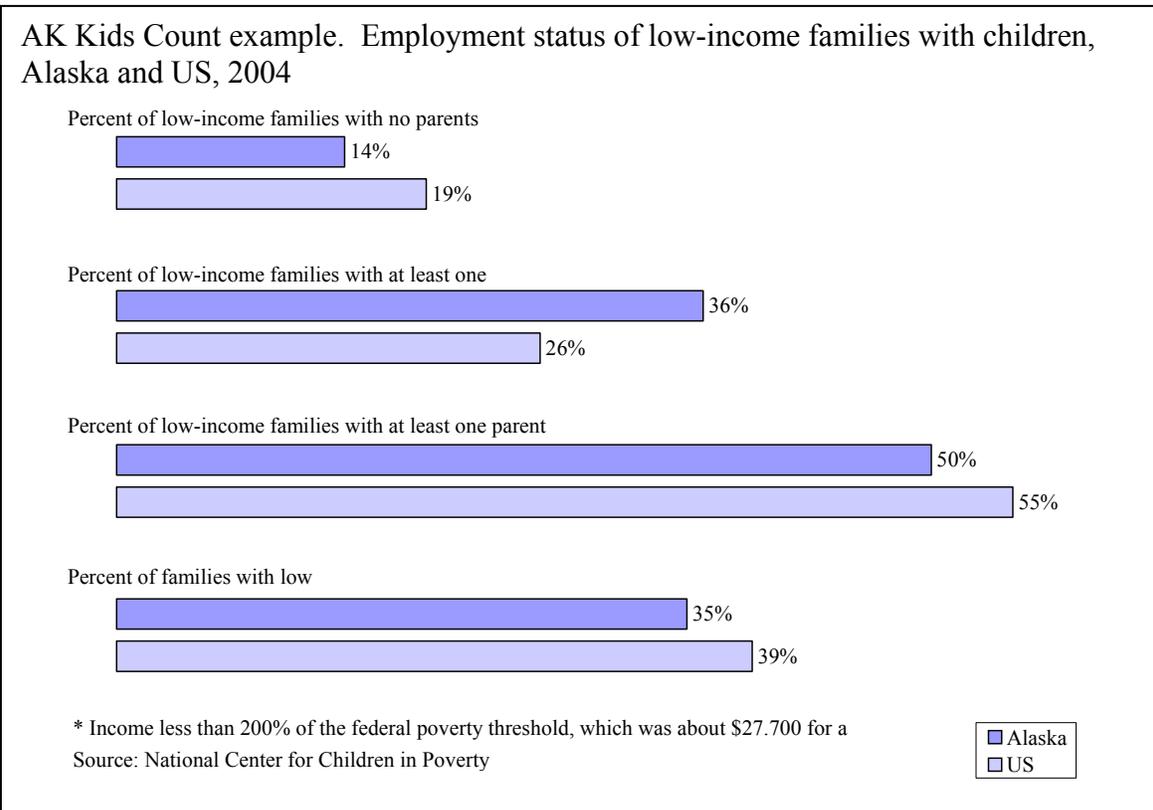
AK YRBS example. Percentage of high school students that participated in vigorous physical activity on three or more of the previous seven days, 2003	
Boys	74.8%
Girls	60.4%

Limitations: High school students respond to the YRBS at school, which means that survey results should not be generalized to adolescents who do not go to school. Also, Alaska state law requires active parental permission for student participation in surveys such as the YRBS since 1999. Consequently, if their parents have not submitted a signed permission form, students are not given the YRBS. Parental reasons for not returning signed permission forms are unknown, as is information about how much their children's' answers might differ from those of the respondents. Another limitation is that depends on self-reported information.

## Alaska data from Alaska sources

*Institute for Social and Economic Research – Kids Count Alaska* is part of a nationwide program, sponsored by the Annie E. Casey Foundation, to collect and publicize information about children's health, safety, and economic status. The purpose of this program is to bring together information from many sources and present it in one place.

This website is: <http://kidscount.alaska.edu/publications.htm>. The AK Kids Count Example 4 is replicated from the 2005 Kids Count Alaska book.



Limitations: This document draws information from many sources. Each source has a unique set of limitations.

## Alaska data from Alaska sources

*Mountain-Pacific Quality Health* is the Medicare Quality Improvement Organization (QIO) for Alaska. In 1992, Medicare started the Health Care Quality Improvement Program to improve the health of Medicare beneficiaries. The Centers for Medicaid and Medicare Services (CMS) contracts with 53 quality improvement organizations that assume responsibility for making sure that Medicare beneficiaries receive health care that meets professionally recognized standards and that all Medicare-funded services are reasonable and necessary. As a QIO, Mountain-Pacific is responsible for collecting data on various CMS initiatives to improve the quality of care for specific beneficiary groups, such as people with diabetes.

The AK Medicare Example contains data that Mountain-Pacific Quality Health shared with the AK Diabetes Program. For more information, contact Terry Keith (561-3201, ext. 107) or [tkeith@akqio.sdps.org](mailto:tkeith@akqio.sdps.org).

AK Medicare Example. Alaska percentages of Medicare beneficiaries (18-75 years of age) with diabetes and certain recommended diabetes health care services, Mountain-Pacific Quality Health, 2003 -2006			
	4/1/03 - 3/31/04	4/1/05 - 3/31/06	7/1/05 - 6/30/06
Annual dilated eye exam	45.9%	46.9%	45.2%
Annual lipid profile	64.7%	64.9%	65.3%
Annual HbA1c	72.4%	73.1%	72.8%

Limitations: (1) Policy changes can have a substantial impact on access to care. For example, the reimbursement levels for Part B services in Alaska dropped \_\_% in 2006, and physicians stopped being able to afford to provide Medicare-funded services. Consequently, Alaskans faced a severe shortage of health care providers, which also affected the quality of the Medicare data for this period. (2) Not all Americans over 65 choose to enroll in Part B.

## Alaska data from regional or national sources

*Cancer Control Plan Link Act Network with Evidence-based Tools (Cancer Control PLANET)*

portal provides access to data and resources that can help planners, program staff, and researchers to design, implement and evaluate evidence-based cancer control programs. It provides access to Web-based resources that can assist in: assessing the cancer and/or risk factor burden within a given state; identifying potential partner organizations that may already be working with high-risk populations; understanding the current research findings and recommendations; accessing and downloading evidence-based programs and products; finding guidelines for planning and evaluation.

The URL is: <http://cancercontrolplanet.cancer.gov/about.html>

## Alaska data from regional or national sources

*CDC Behavioral Risk Factor Surveillance System (BRFSS)* provides state-specific information on behavioral risk factors associated with disease and premature mortality among adults. It is an anonymous, ongoing, yearly, state-based telephone survey of the non-institutionalized adult population in each state. The BRFSS uses a set of core questions to collect demographic and other data of ongoing interest; the core has included a screening question to identify adults with diagnosed diabetes since 1991. States may then choose among several subsets to collect information about topics that they consider particularly important and add them to their survey. One of these subsets is on diabetes; it is asked only of respondents who have diagnosed non-gestational diabetes.

The BRFSS is supported and coordinated by CDC, which also performs the initial data processing. In this step, the CDC statistically adjusts (or weights) results to account for under- or over-representation of subgroups in the sample and to assure that the results reasonably accurately reflect demographic characteristics of the entire state population.

BRFSS results are presented as estimated percentages of the adult population. When using the BRFSS to identify national rates, the CDC uses the median state result to represent all participating states and territories.

The BRFSS website is <http://www.cdc.gov/brfss/>.

<b>BRFSS sample: Percentages with no leisure time physical activity*</b>		
	<b>Nationwide (States, DC, and Territories)</b>	<b>Alaska</b>
<b>Year:</b>	<b>Median % # States</b>	<b>% (95% CI) n</b>
<b>1991</b>	<b>28.0%</b> 48	<b>22.1%</b> (19.0%-25.2%) 320
<b>1992</b>	<b>27.4%</b> 49	<b>22.5%</b> (19.4%-25.6%) 348
<b>1994</b>	<b>28.8%</b> 50	<b>22.8%</b> (19.9%-25.7%) 391
<b>1996</b>	<b>27.8%</b> 52	<b>25.4%</b> (22.1%-28.7%) 400
<b>1998</b>	<b>27.7%</b> 52	<b>23.5%</b> (21.0%-26.0%) 478
<b>2000</b>	<b>26.9%</b> 52	<b>20.0%</b> (17.6%-22.3%) 439
<b>2001</b>	<b>25.7%</b>	<b>21.1%</b> (18.9%-23.2%)

<b>2002</b>	<b>24.4%</b>	<b>22.5%</b> (19.9%-25.0%)
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% = Weighted Percentage, CI = Confidence Interval, n = Cell Size (Numerator)

Use caution in interpreting cell sizes less than 50.

# of States includes District of Columbia, Guam, Puerto Rico, and the U.S. Virgin Islands in years >1995

\*All respondents 18 and older who report no leisure-time physical activity during the past month.

Denominator includes all survey respondents except those with missing, don't know, and refused answers.

The *Selected Metropolitan/Micropolitan Statistical Area Risk Trends (SMART)* project analyzes BRFSS data of selected metropolitan and micropolitan statistical areas (MMSAs) with 500 or more respondents. BRFSS data can be used to identify emerging health problems, establish and track health objectives, and develop and evaluate public health policies and programs. Alaska has two SMART areas: the Anchorage Metropolitan Statistical Area, which includes the Municipality of Anchorage and the Matanuska-Susitna Borough and the Fairbanks Metropolitan Statistical Area, which includes the Fairbanks North Star Borough. This is the URL for the BRFSS SMART project:

<http://apps.nccd.cdc.gov/brfss-smart/index.asp>.

Limitations: (1) The usual limitations associated with phone surveys are compounded for BRFSS questions concerning chronic diseases, because many respondents have a condition that has not yet been diagnosed. For example, about 30% of US adults with diabetes do not know they have this disease.<sup>1</sup> The sample selection process for each state or territory is individually designed in response to the particular needs and interests. Consequently, BRFSS data cannot be lumped together to calculate national rates. Instead, the CDC selects a median state to represent the US when identifying a national rate; if that state's population is very different from Alaska, differences between the rates could correspond to population differences.

## Alaska data from regional or national sources

*CDC Division of Diabetes Translation (DDT)* posts diabetes-related statistics on its website. The data sources for these tables include BRFSS, NHIS, and NHDS. This website has national diabetes-specific rates for many general population measures, such as the hypertension awareness rate.

The DDT website is <http://apps.nccd.cdc.gov/ddtstrs/>. The example is replicated from the DDT website.

DDT example. Crude and Age-Adjusted Incidence of Diagnosed Diabetes per 1000 Population Aged 18-79 Years, United States, 1997-2004				
	Crude		Age-Adjusted	
Year	Incidence	Standard Error	Incidence	Standard Error
1997	4.9	0.3	5.1	0.3
1998	5.1	0.2	5.3	0.2
1999	5.4	0.2	5.6	0.2
2000	6.0	0.2	6.2	0.3
2001	6.5	0.3	6.7	0.3
2002	6.9	0.3	7.1	0.3
2003	7.1	0.3	7.2	0.3
2004	7.0	0.4	7.2	0.4

This table is drawn from the National Health Interview Survey. To calculate incidence, the numerator consisted of adults who were diagnosed with diabetes within the last year and the denominator was the entire adult population, excluding adults who had been diagnosed with diabetes for more than one year and adults who answered "refused," "don't know," or had missing values on the diabetes status question. Incidence was only calculated among adults aged 18–79 years, since age of diagnosis of diabetes was not collected among persons aged 17 years and younger and there were limited data available on age of diabetes diagnosis among adults aged 80 years and older.

Limitations: Comparability between rates on this website and Alaska rates is affected by differences between the data sources. It is important to know which data source was used for which rate to make sure that the same population is in the denominators of the rates being compared.

## Alaska data from regional or national sources

CDC *Health-Related Quality of Life (HRQOL)* includes state and national rates drawn from the BRFSS health-related quality of life questions. These questions are:

1. Would you say that in general your health is excellent, very good, good, fair or poor?  
(*Health status*)
2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? (*Physically unhealthy days*)
3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your physical health not good? (*Mentally unhealthy days*)
4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?  
(*Activity limitation days*)

*Unhealthy days* is a fifth health-related quality of life measure is calculated by adding physically and mentally unhealthy days, with each individual's capped at 30.

Information on physically unhealthy days, mentally unhealthy days and activity limitation days is available as the mean number of days or as the proportion of the population that reported 14 or more days in each category. (People reporting at least 14 days when their mental health was not good are considered to have frequent mental distress.)

The HRQOL website is <http://apps.nccd.cdc.gov/HRQOL/>. The example is replicated from the Health-related quality of life website.

	Mean 95% CI	n
18-24	1.4 (1.2-1.5)	89,799
25-34	1.4 (1.3-1.5)	202,379
35-44	1.9 (1.8-2.0)	260,180
45-54	2.5 (2.4-2.6)	272,831
55-64	2.7 (2.6-2.9)	214,082
65-74	2.4 (2.3-2.6)	162,700
75+	3.0 (2.8-3.1)	131,873
All	2.1 (2.0-2.1)	1,344,302

Limitations: Different BRFSS websites use different health-related quality of life measures. The DDT website uses the proportion of the population that reported at least one unhealthy day, while the BRFSS website uses the proportion of the population with at least seven unhealthy days.

## Alaska data from regional or national sources

CDC and National Cancer Institute State Cancer Profiles provides quick and easy access to descriptive cancer statistics in order to prioritize investments in cancer control. Data sources include published reports and public use files from public health surveillance systems; it is the most recent that has completed the national data synthesis and quality assurance processes.

This website is: <http://statecancerprofiles.cancer.gov/>. The example is copied from the State Cancer Profile for breast cancer in Alaska.

State Cancer Profile example. Female all race breast cancer death rate (1999-2003) and trend comparison, 1990-2003, Alaska boroughs versus Alaska statewide, State Cancer Profile			
	Above State Rate	Similar to State Rate	Below State Rate
Rising Trend	Priority 1: rising ↑ and above ↑ [none]	Priority 2: rising ↑ and similar ■ [none]	Priority 3: rising ↑ and below ↓ [none]
Stable Trend	Priority 4: stable → and above ↑ [none]	Priority 6: stable → and similar ■ Anchorage Municipality <sup>4</sup> Fairbanks North Borough <sup>4</sup> Kenai Peninsula Borough <sup>4</sup> Matanuska-Susitna Borough <sup>4</sup>	Priority 7: stable → and below ↓ [none]
Falling Trend	Priority 5: falling ↓ and above ↑ [none]	Priority 8: falling ↓ and similar ■ United States	Priority 9: falling ↓ and below ↓ [none]

Created by statecancerprofiles.cancer.gov on 04/23/2007 3:31 pm.

### Trend<sup>2</sup>

Rising ↑ - when 95% confidence interval of annual percent change is above 0.

Stable → - when 95% confidence interval of annual percent change includes 0.

Falling ↓ - when 95% confidence interval of annual percent change is below 0.

### Rate Comparison

Above ↑ - when 95% confident the rate is above and Rate Ratio<sup>3</sup> > 1.10

Similar ■ - when unable to conclude above or below with confidence.

Below ↓ - when 95% confident the rate is below and Rate Ratio<sup>3</sup> < 0.90

<sup>1</sup> Priority indices were created by ordering from rates that are rising and above the comparison rate to rates that are falling and below the comparison rate.

<sup>2</sup> Recent trend in death rates were calculated using the Joinpoint Regression Program and are expressed as the annual percent change over the recent trend period. Recent trend period is the period since last change in trend as determined by Joinpoint.

<sup>3</sup> Rate ratio is the county rate divided by the US rate.

<sup>4</sup> Due to data availability issues, the time period used in the calculation of the Joinpoint regression model may differ for selected racial groups or counties.

Source: Death data provided by the National Vital Statistics System public use data file.

Death rates calculated by the National Cancer Institute using SEER\*Stat. Death rates are age-adjusted to the 2000 US standard population (19 age groups: <1, 1–4, 5–9, ... , 80–84, 85+). Population counts for denominators are based on Census populations as modified by NCI.

Note: When the population size for a denominator is small, the rates may be unstable. A rate is unstable when a small change in the numerator (e.g., only one or two additional cases) has a dramatic effect on the calculated rate. Suppression is used to avoid misinterpretation when rates are unstable.

State Cancer Registries may provide more current or more local data. Data presented on the State Cancer Profiles Web Site may differ from statistics reported by the State Cancer Registries (for more information).

Data for the following has been suppressed to ensure confidentiality and stability of rate and trend estimates: Aleutians East Borough<sup>4</sup>, Aleutians West Census Area<sup>4</sup>, Bethel Census Area<sup>4</sup>, Bristol Bay Borough<sup>4</sup>, Denali/Yukon-Koyukuk<sup>4</sup>, Dillingham Census Area<sup>4</sup>, Haines Borough<sup>4</sup>, Juneau City and Borough<sup>4</sup>, Ketchikan Gateway Borough<sup>4</sup>, Kodiak Island Borough<sup>4</sup>, Lake and Peninsula Borough<sup>4</sup>, Nome Census Area<sup>4</sup>, North Slope Borough<sup>4</sup>, Northwest Arctic Borough<sup>4</sup>, Prince of Wales-Outer Ketchikan Census Area<sup>4</sup>, Sitka City and Borough<sup>4</sup>, Skagway-Hoonah-Angoon Census Area<sup>4</sup>, Southeast Fairbanks Census Area<sup>4</sup>, Valdez-Cordova Census Area<sup>4</sup>, Wade Hampton Census Area<sup>4</sup>, Wrangell-Petersburg Census Area<sup>4</sup>, Yakutat City and Borough<sup>4</sup>

Limitations: State cancer registries continue to revise and update their data after they are submitted to the federal funding agency (CDC and/or NCI). Some cancer cases will likely have been reported to state cancer registries after the submission date. In addition, some state health departments customize state population estimates when calculating incidence and death rates. For this reason, incidence (and death) rates and case counts reported directly by the state cancer registry in their reports and/or web site may differ from rates presented on the State Cancer Profiles Web Site.

## Alaska data from regional or national sources

*CDC National Program of Cancer Registries (NPCR)* collects data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment. The NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, the Republic of Palau and the Virgin Islands, representing 96% of the US population. NPCR and the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program collect data for the entire US population.

Annual federal cancer statistics are available from NPCR/SEER in the United States Cancer Statistics: Incidence and Mortality Report, which is available at:

<http://www.cdc.gov/cancer/npcr/uscs/>. The data release activities webpage (<http://www.cdc.gov/cancer/npcr/datarelease.htm>) has state-specific incidence reports by cancer site, race/ethnicity and sex are available under the US County Cancer Incidence Dataset and in greater detail under the USCS Expanded Dataset. The example is compiled from USCS expanded dataset reports.

NPCR example. Six highest invasive cancer incidence rates for Alaska, Washington and the US by site, 1999-2002, USCS Expanded Dataset			
	Alaska	Washington	US
Prostate	82.0 (77.2-87.1)	81.1 (79.9-82.3)	71.8 (71.1-72.0)
Lung and bronchus	70.5 (66.0-75.3)	70.8 (69.7-71.9)	70.0 (69.8-70.1)
Breast	66.4 (62.5-70.6)	79.8 (78.6-81.0)	70.8 (70.7-71.0)
Colon and rectum	59.4 (55.2-63.9)	50.4 (49.5-51.4)	54.4 (54.3-54.6)
Urinary bladder	21.7 (19.1-24.5)	23.9 (23.2-24.5)	21.6 (21.5-21.7)
Non-Hodgkin lymphoma	19.4 (17.2-22.0)	21.2 (20.6-21.8)	18.7 (18.6-18.8)
All	478.3 (466.8-490.1)	592,3 (499.4-505.3)	472.9 (472.4-473.3)

## Alaska data from regional or national sources

*CDC School Health Policies and Programs Study (SHPPS)* is a national survey periodically conducted at the state, district and school levels across the US to assess school health policies and programs. The study provides data to help improve school health policies and programs. SHPPS was conducted in 1994, 2000, and 2006. Eight components of school health programs at the elementary, middle/junior, and senior high school levels are assessed: health education, physical education, health services, mental health and social services, School policy and environment, food service, faculty and staff health promotion, and family and community involvement.

The 2006 study design involved obtaining information through telephone interviews with state- and district-level staff, and through in-person interviews with school staff. Students were not contacted.

The example includes data from the 2000 SHPPS study, which are available from the SHPPS website: <http://www.cdc.gov/healthyouth/shpps/index.htm>.

SHPPS example: States with school policies on tobacco use among students, faculty and visitors, SHPPS 2000

Has a policy that prohibits cigarette smoking and smokeless tobacco use...	Alaska	% of states with a policy
By students		
On campus	yes	72%
Off campus	no	66%
By faculty		
On campus	yes	42%
Off campus	no	38%
By visitors		
On campus	no	48%
Off campus	no	28%
Require a tobacco-free environment	no	24%

Results from SHPPS 2006 were published in the *Journal of School Health*, Volume 77, Number 8, October 2007. A report is also posted on the CDC SHPPS website at: <http://www.cdc.gov/healthyouth/shpps/josh.htm>.

## Alaska data from regional or national sources

*CDC School Health Profiles* were developed to help state and local education and health agencies monitor and assess characteristics of and trends in specific school practices and policies. school health education; physical education; asthma management activities; school health policies related to human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) prevention, tobacco-use prevention, violence prevention, physical activity, and competitive foods (foods and beverages sold outside of the USDA school meal program); food service; and family and community involvement in school health programs. This survey of principals and lead health education teachers in middle/junior and senior high schools has been conducted biennially since 1996.

The website is: <http://www.cdc.gov/healthyyouth/profiles/>.

School Health Profiles example: Percentage of schools that taught about tobacco use in a required health education course during the 2003-2004 school year, selected US sites: School Health Profiles, Lead Health Education Teacher Surveys		
<i>Examples:</i>	Alaska	Range of all states
Addictive effects of nicotine	90.3	90.3-99.4
Health consequences of cigarette smoking	92.8	91.9-100.0
Health consequences of using smokeless tobacco	88.6	88.6-100.0
Influence of families on tobacco use	82.5	82.5-98.1
Influence of media on tobacco use	83.7	83.7-99.3
Social or cultural influences on tobacco use	82.4	79.6-94.4

Limitations: The data presented in this report apply only to public middle/junior high and senior high schools and are limited to these school populations. Because the data were combined across both school levels, program and policy differences between the two levels may be masked. Second, the data are self-reported by school principals and lead health education teachers and may be subject to bias.

## Alaska data from regional or national sources

*CDC Wide-ranging OnLine Data for Epidemiologic Research (WONDER)* is an easy-to-use, menu-driven system that makes the information resources of the Centers for Disease Control and Prevention (CDC) available to public health professionals and the public at large. The CDC Wonder website is: <http://wonder.cdc.gov/>. It is a single point of access to a wide variety of reports and numeric public health data through links to any number of resources, including:

- WISQARS (Web-based Injury Statistics Query and Reporting System) Fatal is an interactive database system that provides injury-related mortality data useful for research and for making informed public health decisions. WISQARS offers three types of reports: mortality reports, leading causes of death reports, and years of potential life lost reports (YPLL). Injury mortality reports provide number of injury deaths and death rates for specific external causes of injuries. Leading causes of death reports provide the number of injury-related deaths relative to the number of other leading causes of death in the United States or in individual states. Years of potential life lost (YPLL) reports compare premature mortality (early death) between different causes of death.

The WISQARS website is: <http://www.cdc.gov/ncipc/wisqars/>. The example is constructed from two WISQARS reports.

WISQARS example: Percentages of total years of potential life lost (YPLL) before age 65 by the six leading causes of death in 2004		
	Alaska	US
Cause of death	% of YPLL	% of YPLL
Unintentional Injury	25.7%	19.1%
Suicide	14.4%	5.9%
Malignant Neoplasms	10.4%	16.2%
Heart Disease	8.5%	12.2%
Homicide	4.5%	4.9%
Perinatal Period	4.4%	7.9%

- Compressed Mortality File, which contains mortality and population counts for all U.S. counties for the years 1979 to 2002. Counts and rates of death can be obtained by underlying cause of death, state, county, age, race, sex, and year.

This is the Compressed Mortality File website: <http://wonder.cdc.gov/mortSql.html>. The example is compiled from compressed mortality file reports.

Compressed Mortality File example. Diabetes as an underlying cause of death in Northwest US by urbanization, rate per 100,000 population, 1999-2003						
	Large Central Metro	Large Fringe Metro	Medium Metro	Small Metro	Micropolitan (non-metro)	NonCore (non-metro)
Alaska	Missing	Missing	14.1	10.0	14.8	12.8
Idaho	Missing	Missing	20.0	29.7	22.9	24
Montana	Missing	Missing	Missing	24.5	22.5	29.8

Oregon	28.1	21.2	29.3	23.6	34.6	36.0
Utah	21.3	15.9	22.9	19.1	26.6	30.3
Washington	19.0	22.1	25.1	26.7	30.8	30.9

Each large metro area must have at least one central county.

Large central metro = Counties in a metropolitan statistical area of 1 million or more population:

- 1) that contain the entire population of the largest principal city of the metropolitan statistical area, or
- 2) whose entire population resides in the largest principal city of the metropolitan statistical area, or
- 3) that contain at least 250,000 of the population of any principal city in the metropolitan statistical area

Large fringe metro = Counties in a metropolitan statistical area of 1 million or more population that do not qualify as large central

Medium metro = Counties in a metropolitan statistical area of 250,000 to 999,999 population

Small Metro = Counties in a metropolitan statistical area of 50,000 to 249,999 population

Micrometropolitan = Counties in a micropolitan statistical area

Noncore = Counties that are neither metropolitan nor micropolitan

## Alaska data from regional or national sources

*CDC Youth Risk Behavior Surveillance System (YRBSS)* is a survey designed to determine the prevalence of health-risk behaviors among high school students, which is used to assess trends in these behaviors and examine the co-occurrence of health-risk behaviors. As with the BRFSS, this survey is conducted by the states and coordinated by the CDC. A complex method is used to select classrooms for the survey; students in the selected classrooms then complete a self-administered paper-and-pencil survey. The standard YRBS survey includes questions on: unintentional injuries and violence; tobacco use; alcohol and other drug use; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; unhealthy dietary behaviors, and physical inactivity.

The YRBSS website is: <http://apps.nccd.cdc.gov/yrbss/>. The example is copied from this website.

YRBS example. Percentages of students who ate less food, fewer calories, or foods low in fat to lose weight or to keep from gaining weight during the past 30 days, US 1999 – 2005			
	Female	Male	Total
1999	56.1% ( $\pm$ 3.4)	25.0% ( $\pm$ 1.5)	40.4% ( $\pm$ 1.7)
2001	58.6% ( $\pm$ 2.0)	28.2% ( $\pm$ 1.5)	43.8% ( $\pm$ 1.8)
2003	56.2% ( $\pm$ 2.4)	28.9% ( $\pm$ 1.7)	42.2% ( $\pm$ 1.5)
2005	54.8% ( $\pm$ 1.6)	26.8% ( $\pm$ 1.4)	40.7% ( $\pm$ 1.2)

Limitations: First, these data apply only to youth who attend school and therefore, do not represent all people in this age group. Second, the extent of under- or over-reporting of behaviors cannot be determined, although the survey questions demonstrate good test-retest reliability. Third, body mass index is calculated on the basis of self-reported height and weight, and tends to underestimate the prevalence of overweight and at risk for becoming overweight.

## Alaska data from regional or national sources

*Census Bureau* is the primary federal source of information about the US people and economy.

The first US census was conducted in 1790; the Census Bureau became a permanent component of the federal government in 1902. The website for databases of Census data is: [http://factfinder.census.gov/home/saff/main.html?\\_lang=en](http://factfinder.census.gov/home/saff/main.html?_lang=en).

- *American Community Survey (ACS)* – collects and publishes data on demographic, social, housing and economic characteristics of the US population. It began in 1996 and has expanded each subsequent year. Data from the 2005 ACS are available for geographic areas with a population of 65,000 or more; in Alaska, this means the state as a whole, the Municipality of Anchorage, and the Matanuska-Susitna and Fairbanks North Star Boroughs. By 2008, data (accumulated over three years) will also be available for all areas of 20,000 or more. Beginning in 2010 when it will replace the Decennial Census long form, ACS will have estimates based on data collected over five years for neighborhoods and rural areas as well as cities and towns.

The ACS sample size is about three million addresses; its website is

[http://factfinder.census.gov/servlet/DatasetMainPageServlet?\\_program=ACS&\\_submenuId=&\\_lang=en&\\_ts=](http://factfinder.census.gov/servlet/DatasetMainPageServlet?_program=ACS&_submenuId=&_lang=en&_ts=). The example is compiled from ACS reports.

ACS example. Percentages of People 21 to 64 Years Old With a Disability: Alaska urban and rural and US, 2005		
Geographic area	Percent	Margin of error
United States	12.7%	+/-0.1
<i>Alaska urban and rural</i>		
Urban	13.7%	+/-1.1
Rural	16.1%	+/-1.4
<i>Alaska in and outside of metropolitan and micropolitan statistical areas</i>		
In metropolitan or micropolitan statistical area	13.8%	+/-0.9
In metropolitan statistical area	14.1%	+/-1.0
In principal city	14.2%	+/-1.4
Not in principal city	13.9%	+/-1.7
Not in metropolitan or micropolitan statistical area	16.8%	+/-1.7

Limitations: As a survey, the ACS is vulnerable to sampling error, unlike the short-form portion of the Decennial Census which attempts to collect information about all US residents. Also unlike the Census, the ACS sample does not include group living quarters.

- *Decennial Census* is the primary source of most general information about US residents, and is commonly used to describe populations of large and small US communities by race, gender, income and age.

It is required by the Constitution of the United States, which calls for an actual enumeration of the people every ten years to be used for apportionment of seats in the House of Representatives among the states. Everyone is asked a few questions, including household relationship, age, race, ethnicity, and if they own or rent their dwelling. About one in six households are asked many more questions, including marital status; school enrollment and educational attainment; language spoken at home and ability to speak English; veteran status; disability; work status in previous year; income in previous year; and a series of questions about their residence.

In the 2000 Census, the race categories changed and for the first time, respondents were allowed to identify more than one race. As a result, the Census 2000 reports a person's race either alone or in combination with one or more races.

The website for the Census is:

[http://factfinder.census.gov/servlet/DatasetMainPageServlet?\\_program=DEC&\\_submenu1d=&\\_lang=en&\\_ts=](http://factfinder.census.gov/servlet/DatasetMainPageServlet?_program=DEC&_submenu1d=&_lang=en&_ts=). The example is compiled from decennial census reports.

2000 Census example. Households by presence of people 65 years and over, household size, and household type: Alaska and US, 2000 Census				
	Alaska		United States	
1-person household	8,985	34.1%	9,722,857	39.4%
Family households	16,421		14,383,826	
Nonfamily households	943		566,025	
2-or-more person household:	17,364	65.9%	14,949,851	60.6%
Households with one or more people 65 years and over:	26,349		24,672,708	
1-person household	43,075	22.1%	17,507,218	21.7%
Family households	135,916		57,403,521	
Nonfamily households	16,260		5,896,654	
2-or-more person household:	152,176	77.9%	63,300,175	78.3%
Households with no people 65 years and over:	195,251		80,807,393	
Total:	221,600		105,480,101	

Limitations: The Census is a huge undertaking. Certain groups have historically been under- or incorrectly counted due to crowding or other data collection challenges.

- *Modified Age, Race, and Sex (MARS)* estimates by the US Census Bureau are based on the most recent decennial census, and are intended to correct shortcomings in census data. The Alaska Department of Labor and Workforce Development (AK DOLWD) starts with the MARS estimate of the total population for Alaska in its annual population estimates for Alaska places, cities and boroughs.

The 1990 MARS file addressed problems associated with the age and race questions. The 2000 MARS file has only modified the race of each age/sex group to adjust for the “Some other race” response. In 1990 and in 2000, most respondents who selected “some other race” when answering the race question were of Hispanic ethnicity. To date, the US Census Bureau has not adjusted age or sex data from the 2000 decennial census.

The AK DOLWD performs and posts annual updates to MARS data (Alaska 1990s Race “Bridged” Smooth Series: 1990-2005) on this website:

<http://146.63.75.50/research/pop/estimates/Alaska1990Race.htm>.

Limitations: AK DOLWD identified significant processing errors for 2000 Census forms from rural Alaska, which meant that the ages of children in large households needed to be estimated. The impact of these errors is that the numbers of children less than ten years of age were under-estimated, while the numbers of children in the 10 – 17 age groups were over-estimated. The US Census has not attempted to correct this problem because of a cascade effect in regional and national age group calculations. AK DOLWD uses age distributions from Permanent Fund Dividend as the model when estimating the number of children by age in rural Alaska. Contact AK DOLWD 465-6029 with questions.

## Alaska data from regional or national sources

*North American Association of Central Cancer Registries (NAACCR)* aggregates and publishes data from central cancer registries in the US and Canada.

Their Cancer in North America (CINA) + Online website (<http://www.cancer-rates.info/naaccr/>) provides reports by geographic area, cancer site, reporting years, sex and race/ethnicity. The example is copied from a Cancer in North America report.

NAACCR example. Invasive Cancer Incidence Rates in Alaska, Prostate, 1999-2003						
	1999	2000	2001	2002	2003	1999-2003
Population at Risk	323,513	324,522	326,902	331,371	334,938	1,641,246
Total Cases	280	301	336	372	281	1,570
Crude Rate	86.6	92.8	102.8	112.3	83.9	95.7
Age-Adjusted Rate	165.9	176.5	180.7	185.5	132.7	167.7
US Age-Adjusted Rate	167.0	168.7	170.7	168.1	148.9	164.6
Source: Data from SEER and NPCR registries as of December 2005 reported by NAACCR as meeting high quality standards for 1999-2003. Table created Mon Apr 23 15:04:40 EDT 2007						

## Alaska data from regional or national sources

*Northwest Renal Network (NWRN)* is a private, not-for-profit corporation dedicated to the promotion of optimal dialysis and transplant care for kidney patients in Alaska, Idaho, Montana, Oregon, and Washington. It collects and analyzes data on patients enrolled in the Medicare End-Stage Renal Disease program and monitors the quality of care given to dialysis and transplant patients in the Pacific Northwest. NWRN also tracks the total number of people in the Northwest who are on dialysis or who have had a kidney transplant.

Summary statistics and annual reports are available through their website <http://www.nwrenalnetwork.org/ARS.htm>. The example presents data averaged from the 2002, 2003 and 2004 NWRN and FESRDN reports.

NWRN example. Three year-average percentages of on-going end stage renal disease cases by primary diagnosis for Alaska, the Pacific Northwest and the US, 2002 – 2004, NWRN and FESRDN			
	Alaska	Pacific Northwest	US
Diabetes	44.5%	43.3%	44.1%
Glomerulonephritis	19.9%	16.2%	12.1%
Hypertension	14.3%	18.8%	29.4%
Cystic kidney disease	5.6%	4.8%	2.9%
other causes (including other urologic)	15.7%	16.9%	11.6%
Annual average number of cases	271.0	8,108.0	310,283.3

Limitations: Because of extensive and multiple data reliability procedures, the NWRN believes their data to be nearly 100% accurate. There may be a small margin of error due to patient transience and re-location. NWRN and US Renal Data System (USRDS) data cannot be compared because the USRDS is limited to dialysis patients receiving outpatient services from Medicare-approved dialysis facilities, and NWRN data are not.

## Alaska data from regional or national sources

*Renal Data Extraction and Referencing System (RenDER)* is an online query application for the US Renal Data System (USRDS), which is a national program that collects, analyzes and disseminates information about end-stage renal disease (ESRD). Medicare data provide the foundation for the USRDS database, which also includes data from the United Network for Organ Sharing and ESRD treatment networks across the country. RenDER is designed to provide easier access to some of the most requested data in the USRDS.

The RenDER website is [http://www.usrds.org/odr/xrender\\_home.asp](http://www.usrds.org/odr/xrender_home.asp). The USRDS website is <http://www.usrds.org/>. The example is compiled from RenDER reports.

RenDER example. Unadjusted point prevalent disease rate per million population, U.S. Renal Data System, USRDS 2006 Annual Data Report: Atlas of End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2006.						
State	Diabetes	Glomerulo-nephritis	Hyperten-sion	Other urologic	Cystic, hereditary, or congenital diseases	Missing, other or unknown
Alaska	305	213.9	122.9	33.4	72.8	144.1*
Idaho	342	211.9	140.1	49.1	75.4	135.8*
Montana	520.8	277	92.3	39.7	78.4	181.4*
Oregon	380.9	246	179.8	50.1	81.7	215.8
Washington	403.4	256.2	163.5	49.8	77.9	210.5

Limitations: Individuals with ESRD are identified when their physician submits their information on a Medicare form or when they are entered into an ESRD network or transplant center database as receiving chronic dialysis or a kidney transplant. Although most ESRD patients are eligible for Medicare coverage as their primary insurance payer, patients covered by employee group health plans must wait 30 to 33 months before they are eligible to apply for Medicare benefits. These patients may not be included in the Medicare database during this waiting period and may not routinely be included in the numerator of rate data. Other events that may reduce data accuracy include: deaths attributed to ESRD prior to receiving treatment, recovery of renal function, emigration to another region of the US or to another country, and having dialysis or a transplant that is not paid for by or reported to Medicare or the United Network of Organ Sharing.

## Alaska data from regional or national sources

*US Department of Veterans Affairs (VA)* manages an integrated health care system for eligible and enrolled Americans who have been honorably discharged from active military service. Access to care depends on proximity to a VA facility, income, and the presence and nature of a service-related disability. In Alaska, VA primary and specialty medical care and outpatient mental health care is available at Alaska Regional Hospital in Anchorage, with inpatient hospital care provided at the Elmendorf Air Force Base Hospital; outpatient clinics are in Fairbanks, Fort Wainwright and Kenai. Data on recipients and quality of care is available can be requested.

Contact Patrick Ozment ([pat.ozment@med.va.gov](mailto:pat.ozment@med.va.gov)) if you are interested in this data source. The example has data given to the Alaska Diabetes Program by the VA.

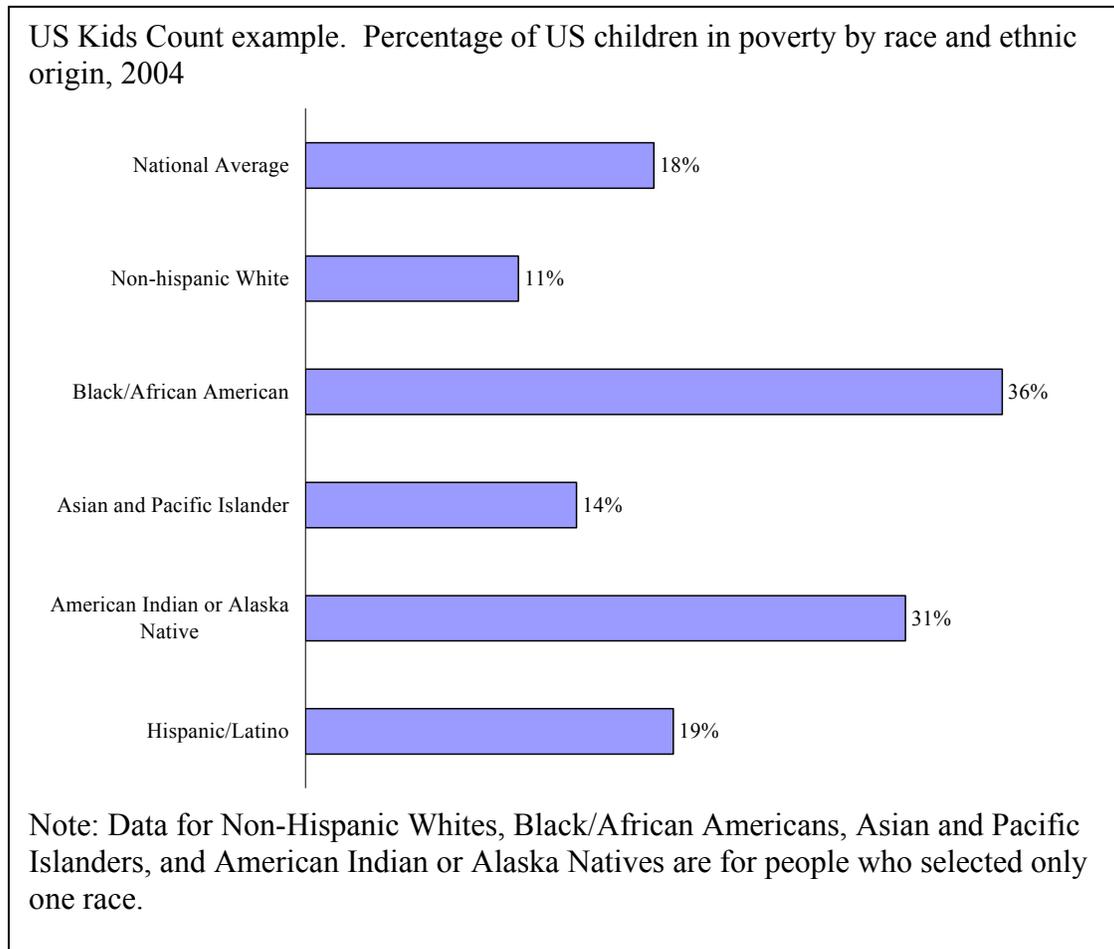
VA example. Per capita cost of health care by the Veterans Administration Anchorage clinic by diabetes status, VA 2005	
Veterans with diabetes	\$9,053
Veterans without diabetes	\$2,166

Limitations: Alaska veterans with diabetes who live some distance away from VA clinics in the state are likely to be receiving at least some of their care from a health care provider that is more conveniently located. Consequently, VA records are likely to be missing patient visits for some individuals.

## Other resources

*Annie E. Casey Foundation - Kids Count* is a national and state-by-state effort to track the status of children in the U.S. By providing policymakers and citizens with benchmarks of child well-being, Kids Count seeks to enrich local, state, and national discussions concerning ways to secure better futures for all children.

The website is: <http://www.aecf.org/MajorInitiatives/KIDSCOUNT.aspx>. The example is copied from the 2006 Kids Count data book online.



## Other resources

*Forum of End Stage Renal Disease Networks* - supports the ESRD Networks in promoting and improving the quality of care to patients with renal disease, thorough education and the collection, analysis, and dissemination of data and information.

The Forum website posts annual reports with nationwide data from the member networks since 1997. It is <http://www.esrdnetworks.org/>. The example contains data from FESRDN.

FESRDN example. 2005 ESRD Dialysis prevalent patients by race, Northwest Renal Network (NWRN) and all networks as of 12/31/2005						
Network	Black	White	Asian/Pacific islander	Native American	Other or unknown	Total
NWRN	817	6934	731	379	13	8874
Total	121275	185718	15113	5195	3592	333064
% Total	36.4%	55.8%	4.5%	4.5%	1.1%	

## Other resources

*Healthcare Cost Utilization Project (HCUP)* is a family of health care databases and related software tools and products developed through a Federal-State-Industry partnership and sponsored by the Agency for Healthcare Research and Quality (AHRQ). HCUP includes the largest collection of longitudinal hospital care data in the United States, with all-payer, encounter-level information beginning in 1988. Five databases enable research on a broad range of health policy issues, including cost and quality of health services, medical practice patterns, access to health care programs, and outcomes of treatments at the national, State, and local market levels. HCUP's objectives are to:

- Obtain data from the statewide information sources.
- Design and develop multi-state health care databases for health services research and health policy analysis.
- Make these data available to a broad set of public and private users.

HCUPnet is an on-line query system that provides access to the largest set of all-payer health care databases that are publicly available. The HCUPnet website is <http://hcup.ahrq.gov/HCUPnet.asp>. The example contains data compiled from queries of the National Inpatient Sample database.

HCUP example. Mean charges and percentage change in mean charges associated with diabetes DRG hospital discharges by type of payer, National Inpatient Survey 1999 and 2004			
	1999	2004	% change 1999 to 2004
Medicare only	8,534	14,135	58.8%
Medicaid only	9,294	13,721	50.7%
Private insurance	7,609	12,737	59.7%
Uninsured	7,564	13,690	73.9%
Other*	8,170	13,483	78.9%
All payers combined	8,382	13,663	59.8%
* "Other" payer includes Worker's Compensation, CHAMPVA, TRICARE/CHAMPUS, Title V, and other government programs			

Limitations: Each of the five HCUP data sources has slightly different characteristics. The Nationwide Inpatient Sample has data from about 20% of all US community hospitals which were selected from a sample frame including about 90% of all US community hospitals. Nonetheless, none of these databases includes data generated in Alaska. Since Alaska's health care system, geography and population are somewhat different from the rest of the US, HCUP results may not accurately represent the situation in Alaska.

## Other resources

*Medical Expenditure Panel Survey (MEPS)* is a set of large-scale surveys of families, individuals, their medical providers and employers across the US. It collects information on the specific services used by Americans; the frequency, cost, and payer for those services; and health insurance cost, scope and breadth. The household survey sample is a subsample of the previous year's National Health Interview Survey (NHIS). The MEPS medical provider component supplements or replaces information obtained during the household survey with data collected from the hospitals, physicians, home health care providers and pharmacies identified by the household survey respondents. The MEPS insurance component is also known as the Health Insurance Cost Study, and involves a sample of private and public sector employers.

Data tables and a database are available from the MEPS website, which is <http://www.meps.ahrq.gov/mepsweb/>. The example contains MEPS results.

MEPS example. Number of private sector employees and percentage of those that are eligible for health insurance that are enrolled in health insurance at private sector establishments that offer health insurance, US 1996-2004		
	Number of private-sector employees (standard error)	Percent of private sector employees with worksite health insurance offered who are eligible and enrolled in health insurance (standard error)
2001	114,488,947 (1,805,071)	79.80% (0.47%)
2002	111,437,203 (1,110,022)	81.00% (.22%)
2003	110,876,535 (1,560,672)	80.30% (0.32%)
2004	112,087,067 (796,961)	79.80% (0.35%)
The percentage of employees with health insurance diminished significantly from 1996 to 2004. ( $z=11.035$ , $p$ value < 0.000)		

Limitations: Since the MEPS household survey depends on the NHIS sample, it has the NHIS limitations. It also requires that respondents contribute a substantial and long-term time commitment to the survey and that they are willing to share access to their health care records from their health care providers.

## Other resources

*Medicare* is the federally-funded health insurance program for all American citizens over the age of 65 who have paid Social Security taxes. It also covers some Americans under the age of 65 who have specific disabilities or permanent kidney failure and need dialysis or transplants. Part A is an entitlement hospital insurance program that is automatically available to nearly everyone and does not usually require a premium. Part B is medical insurance; enrollment in Part B is optional and carries a premium. Individuals over the age of 65 who meet the income requirements of Medicaid (a state-federal health insurance program with eligibility determined by income) are simultaneously enrolled in Medicare and their state's Medicaid program, which then pays the Part B premium. Medicare is the largest health insurance program in the US; its quality improvement and cost control initiatives have a substantial impact on the US health care system.

Medicare data are a potentially rich resource for investigating and monitoring services provided to people on Medicare and the cost and quality of care funded by Medicare. Reports comparing state and national costs and usage do not seem to be regularly available, although many researchers have published results of their specific investigations.

Limited data sets containing Medicare data may be requested from <http://www.resdac.umn.edu/Medicare/Index.asp> and <http://www.cms.hhs.gov/LimitedDataSets/>.

## Other resources

*National Cancer Institute - Surveillance, Epidemiology and End Results (SEER)* program is one of three sources of US cancer registry information. SEER-supported registries operate in Connecticut, New Mexico, Utah, Hawaii, California, New Jersey, Louisiana, Kentucky, and cover specific geographic areas or races in Georgia, Washington, Michigan and Alaska; together, these registries cover about 26% of the US population. SEER registries collect data on patient demographics, primary tumor site, tumor morphology and stage at diagnosis, first course of treatment and follow-up for vital status.

The SEER website is: <http://seer.cancer.gov/>. It is a portal for Cancer Stat Fast Sheets (printable summaries of the most frequently requested statistics for common cancer types) and Faststats (an interactive tool for quick access to key SEER and US cancer statistics for major cancer sites by age, sex, and race). The example is compiled from a SEER Faststats report.

SEER example: SEER age-adjusted rates per 100,000 population and 95% confidence intervals for malignant breast cancer for American Indian/Alaska Native, White and All races: all ages, females, selected SEER registries for 1994-2003 <sup>11</sup>			
	American Indian/AK Native*	White	All Races
Seattle (Puget Sound)	119.86 (103.52-138.90)	153.10 (151.29-154.94)	147.28 (145.60-148.98)
Utah	37.43 (22.49-61.83)	117.62 (115.26-120.01)	115.88 (113.58-118.22)
Alaska Natives	128.76 (115.81-143.05)		130.95 (118.69-144.39)
Total	78.83 (73.79-84.18)	138.07 (137.47-138.66)	132.02 (131.51-132.54)
* Does not include 2003.			

## Other resources

*National Health and Nutrition Examination Survey (NHANES)* is a series of cross-sectional nationally representative health examination surveys that started in 1960. It provides current statistical data on the amount, distribution, and effects of illness and disability in the United States. In each survey, a sample was selected using a complex, stratified, multistage probability cluster design. The survey team interviews participants at home and then conducts a physical and laboratory examination in a mobile examination center. Continuous NHANES data collection started in 1999; the earlier six NHANES surveys collected data over periods of three to five years. Now data are released in two-year groupings although the most stable and reliable estimates are based on more than two years of data. Sample data are adjusted to adjust for oversampling, noncoverage and nonresponses; also, population means and standard errors of the mean are weighted to produce national estimates.

NHANES is a useful resource because it does not depend on self-reported data. For instance, the estimated proportion of US adults with undiagnosed diabetes is based on an NHANES analysis.<sup>14</sup>

The National Center for Health Statistics publishes NHANES papers on a wide variety of topics and posts datasets on the website: <http://www.cdc.gov/nchs/nhanes.htm>. The example contains data from an NHANES report.

NHANES example: US adult mean body mass index by NHANES survey, sex and race/ethnicity <sup>12</sup>				
	NHANES III (1988-1994)		NHANES 1999-2002	
	Mean	Standard error	Mean	Standard error
Non-Hispanic white	26.8	0.1	27.9	0.2
Non-Hispanic black	26.6	1.0	27.5	0.2
Mexican American	27.3	0.2	27.6	0.2

Limitations: NHANES is very expensive, which means that it has relatively small sample sizes (10,291 respondents  $\geq 20$  between 1999 – 2002). Consequently data may be unreliable, especially in situations that combine a small demographic group (such as Alaska Natives) and a relatively rare event (such as having diabetes). In these situations, the subsample size can be increased by expanding the data collection time period, but the consequence is an impaired ability to identify change over time.

## Other resources

*National Health Interview Survey (NHIS)* is an annual household survey of approximately 120,000 US residents conducted by the National Center for Health Statistics. The NHIS provides information on the health of the US population, including the prevalence and incidence of disease and the utilization of health care services. There are two important differences between the NHIS and the BRFSS; 1) the NHIS uses a national sample which means that its results more accurately reflect the entire US population than BRFSS results, and 2) the NHIS collects information throughout the age-span, while BRFSS is usually limited to adults ( $\geq 18$ ). Each year a one-sixth sub-sample of NHIS respondents are asked whether any family member has had diabetes in the past 12 months.

The NHIS website is <http://www.cdc.gov/nchs/nhis.htm>. The example contains data from an NHIS report.

NHIS example. US age-adjusted percentage with diabetes by race among people who selected a single race category and unweighted percentage of all NHIS respondents with a diabetes-related functional limitation, NHIS 2005	
Race	Percent (SE)
White	7.0% (0.17)
Black	11.3% (0.54)
American Indian/AK Native	13.6% (2.8)
Asian	6.5% (1.0)
Native Hawaiian/Pacific Islander	15.4% (4.6)
Unweighted percent of all respondents that mentioned diabetes as a cause of functional limitation <sup>13</sup>	4.5%

Limitations: As with the BRFSS, the usual limitations associated with phone surveys are compounded for questions concerning chronic diseases, because many respondents have a condition that hasn't yet been diagnosed. For example, about 30% of US adults with diabetes do not know they have this disease.<sup>1</sup>

## Other resources

*National Hospital Discharge Survey (NHDS)* is a national survey designed to provide information on characteristics of inpatients discharged from non-Federal short-stay hospitals in the United States. The NHDS collects data from a probability sample of approximately 270,000 inpatient records acquired from a national sample of about 500 hospitals. Data collected include information on the patient's age, race, gender, length of stay, seven diagnoses (one primary and six secondary) and four surgical procedures.

The NHDS website is <http://www.cdc.gov/nchs/about/major/hdasd/nhds.htm>. The example contains data from an NHDS report.

NHDS example. Rate of discharges from short-stay hospitals by age and diabetes as first-listed diagnosis, US 2004 <sup>14</sup>	
Age group	Rate per 10,000 general population
< 15	5.0
15 – 44	11.9
45 – 64	29.5
≥ 65	58.2
All ages	20.5

Limitations: Hospitalizations related to diabetes may be underestimated because the NHDS excludes the analysis of discharges from long-term and federal hospitals. The NHDS counts discharges and not individuals, which means that individuals who are hospitalized more than once for the same condition may be counted more than once.

Appendix 1: Data sources by population addressed							
	Child	Teen	Adults	Women	All ages	AK Native only	All races
<a href="#">AHDD</a>					X		X
<a href="#">ABDR</a>	X						X
<a href="#">AK BRFSS</a>			X				X
<a href="#">AK Cancer Registry</a>					X		X
<a href="#">AK Community Database</a>					X		X
<a href="#">AK DEED</a>	X	X					X
<a href="#">AK DOLWD</a>					X		X
<a href="#">AK Medicaid</a>					X		X
<a href="#">AK PRAMS</a>	X			X			X
<a href="#">AK Trauma Registry</a>					X		X
<a href="#">ANTHC Diabetes</a>					X	X	
<a href="#">ANTHC Epi Center</a>					X	X	
<a href="#">ANTHC OANHR</a>					X	X	
<a href="#">ASDS</a>			X				X
<a href="#">Birth certificates</a>	X						X
<a href="#">Death certificates</a>					X		X
<a href="#">Fairbanks CRQ</a>							X
<a href="#">Kids Count Alaska</a>	X						X
<a href="#">Mountain-Pacific Quality Health (Medicare)</a>			X				X
<a href="#">Municipality of Anchorage</a>			X				X
<a href="#">School districts</a>	X	X					X
<a href="#">YRBS</a>		X					X

Appendix 2: Topics by Alaska data sources									
	Alcohol sales	Alcohol use	Anxiety and depression	Asthma	Birth rates	Cancer	Cardiovascular disease	Chronic disease	Colorectal cancer screening
<a href="#">AHDD</a>									
<a href="#">ABDR</a>					X				
<a href="#">AK BRFS</a>		X	X	X			X	X	X
<a href="#">AK Cancer Registry</a>						X			
<a href="#">AK Community Database</a>									
<a href="#">AK DEED</a>									
<a href="#">AK DOLWD</a>									
<a href="#">AK Medicaid</a>								X	
<a href="#">AK PRAMS</a>		X							
<a href="#">AK Trauma Registry</a>									
<a href="#">ANTHC Diabetes</a>								X	
<a href="#">ANTHC Epi Center</a>						X			
<a href="#">ANTHC OANHR</a>						X			
<a href="#">ASDS</a>								X	
<a href="#">Birth certificates</a>									
<a href="#">Death certificates</a>						X	X	X	
<a href="#">Fairbanks CRQ</a>	X								
<a href="#">Kids Count Alaska</a>									
<a href="#">Mountain-Pacific Quality Health (Medicare)</a>								X	
<a href="#">Municipality of Anchorage</a>		X		X					
<a href="#">School districts</a>									
<a href="#">YRBS</a>		X							

Appendix 2: Topics by Alaska data sources, continued

	Community description	Cost of living	Criminal justice	Demographics	Diabetes	Diet	Dietary behaviors	Disability
<a href="#">AHDD</a>					X			
<a href="#">ABDR</a>								
<a href="#">AK BRFS</a>				X	X		X	X
<a href="#">AK Cancer Registry</a>								
<a href="#">AK Community Database</a>	X							
<a href="#">AK DEED</a>		X						
<a href="#">AK DOLWD</a>				X				X
<a href="#">AK Medicaid</a>					X			
<a href="#">AK PRAMS</a>					X			
<a href="#">AK Trauma Registry</a>								
<a href="#">ANTHC Diabetes</a>					X			
<a href="#">ANTHC Epi Center</a>						X		
<a href="#">ANTHC OANHR</a>								
<a href="#">ASDS</a>					X			
<a href="#">Birth certificates</a>					X			
<a href="#">Death certificates</a>					X			
<a href="#">Fairbanks CRQ</a>		X						
<a href="#">Kids Count Alaska</a>			X					
<a href="#">Mountain-Pacific Quality Health (Medicare)</a>					X			
<a href="#">Municipality of Anchorage</a>					X		X	
<a href="#">School districts</a>								
<a href="#">YRBS</a>					*		X	

\* The 2007 YRBS contained a screening question for diagnosed diabetes, but the CDC indicates that the results nationwide “should be used with caution” because they are higher than the results of other surveys.

Appendix 2: Topics by Alaska data sources, continued								
	Economic indicators	Emotional support and life satisfaction	Employment	Exercise, physical activity	Falls	Food security	Health care access	Health care Cost
<a href="#">AHDD</a>								X
<a href="#">ABDR</a>								
<a href="#">AK BRFSS</a>		X		X	X	X	X	
<a href="#">AK Cancer Registry</a>								
<a href="#">AK Community Database</a>								
<a href="#">AK DEED</a>								
<a href="#">AK DOLWD</a>	X		X					
<a href="#">AK Medicaid</a>								X
<a href="#">AK PRAMS</a>		X						
<a href="#">AK Trauma Registry</a>								
<a href="#">ANTHC Diabetes</a>								
<a href="#">ANTHC Epi Center</a>								
<a href="#">ANTHC OANHR</a>								
<a href="#">ASDS</a>								
<a href="#">Birth certificates</a>								
<a href="#">Death certificates</a>								
<a href="#">Fairbanks CRQ</a>	X		X					
<a href="#">Kids Count Alaska</a>	X							
<a href="#">Mountain-Pacific Quality Health (Medicare)</a>								
<a href="#">Municipality of Anchorage</a>				X				
<a href="#">School districts</a>								
<a href="#">YRBS</a>				X				

Appendix 2: Topics by Alaska data sources, continued

	Health care provider	Health care quality	Health care utilization	Health status	Healthy days	HIV/AIDS	Housing	Immunizations	Industry information
<a href="#">AHDD</a>			X						
<a href="#">ABDR</a>									
<a href="#">AK BRFSS</a>	X			X	X	X		X	
<a href="#">AK Cancer Registry</a>									
<a href="#">AK Community Database</a>									
<a href="#">AK DEED</a>									
<a href="#">AK DOLWD</a>									X
<a href="#">AK Medicaid</a>	X	X	X						
<a href="#">AK PRAMS</a>									
<a href="#">AK Trauma Registry</a>									
<a href="#">ANTHC Diabetes</a>									
<a href="#">ANTHC Epi Center</a>									
<a href="#">ANTHC OANHR</a>									
<a href="#">ASDS</a>									
<a href="#">Birth certificates</a>									
<a href="#">Death certificates</a>									
<a href="#">Fairbanks CRQ</a>							X		
<a href="#">Kids Count Alaska</a>									
<a href="#">Mountain-Pacific Quality Health (Medicare)</a>		X	X						
<a href="#">Municipality of Anchorage</a>				X					
<a href="#">School districts</a>									
<a href="#">YRBS</a>									

Appendix 2: Topics by Alaska data sources, continued									
	Infant health	Infant health care	Infant mortality	Injuries	Low birthweight	Maternal characteristics	Medical services	Mortality	Overweight and obesity
<a href="#">AHDD</a>							X		
<a href="#">ABDR</a>					X				
<a href="#">AK BRFSS</a>				X					X
<a href="#">AK Cancer Registry</a>									
<a href="#">AK Community Database</a>									
<a href="#">AK DEED</a>									
<a href="#">AK DOLWD</a>									
<a href="#">AK Medicaid</a>							X		
<a href="#">AK PRAMS</a>		X				X	X		
<a href="#">AK Trauma Registry</a>				X				X	
<a href="#">ANTHC Diabetes</a>									
<a href="#">ANTHC Epi Center</a>								X	
<a href="#">ANTHC OANHR</a>								X	
<a href="#">ASDS</a>									
<a href="#">Birth certificates</a>	X				X	X	X		
<a href="#">Death certificates</a>			X	X				X	
<a href="#">Fairbanks CRQ</a>									
<a href="#">Kids Count Alaska</a>					X			X	
<a href="#">Mountain-Pacific Quality Health (Medicare)</a>									
<a href="#">Municipality of Anchorage</a>									X
<a href="#">School districts</a>									
<a href="#">YRBS</a>									X

Appendix 2: Topics by Alaska data sources, continued								
	Occupational information	Oral health	Other drug use	Population information	Prenatal care	Prostate cancer screening	Risk factors	School enrollment
<a href="#">AHDD</a>								
<a href="#">ABDR</a>								
<a href="#">AK BRFSS</a>		X						
<a href="#">AK Cancer Registry</a>								
<a href="#">AK Community Database</a>				X				
<a href="#">AK DEED</a>								X
<a href="#">AK DOLWD</a>	X			X				
<a href="#">AK Medicaid</a>								
<a href="#">AK PRAMS</a>								
<a href="#">AK Trauma Registry</a>								
<a href="#">ANTHC Diabetes</a>								
<a href="#">ANTHC Epi Center</a>								
<a href="#">ANTHC OANHR</a>								
<a href="#">ASDS</a>								
<a href="#">Birth certificates</a>								
<a href="#">Death certificates</a>								
<a href="#">Fairbanks CRQ</a>				X				X
<a href="#">Kids Count Alaska</a>								X
<a href="#">Mountain-Pacific Quality Health (Medicare)</a>								
<a href="#">Municipality of Anchorage</a>		X						
<a href="#">School districts</a>								X
<a href="#">YRBS</a>			X					

Appendix 2: Topics by Alaska data sources, continued								
	Seatbelt use	Sexual behaviors	Smokeless tobacco use	Tobacco use	Traffic incidents	Veteran's status	Violence	Women's health
<a href="#">AHDD</a>								
<a href="#">ABDR</a>	X							
<a href="#">AK BRFSS</a>			X	X		X	X	X
<a href="#">AK Cancer Registry</a>				X				
<a href="#">AK Community Database</a>								
<a href="#">AK DEED</a>								
<a href="#">AK DOLWD</a>						X		
<a href="#">AK Medicaid</a>								
<a href="#">AK PRAMS</a>			X	X			X	
<a href="#">AK Trauma Registry</a>								
<a href="#">ANTHC Diabetes</a>								
<a href="#">ANTHC Epi Center</a>				X				
<a href="#">ANTHC OANHR</a>								
<a href="#">ASDS</a>								
<a href="#">Birth certificates</a>								
<a href="#">Death certificates</a>								
<a href="#">Fairbanks CRQ</a>					X			
<a href="#">Kids Count Alaska</a>							X	
<a href="#">Mountain-Pacific Quality Health (Medicare)</a>								
<a href="#">Municipality of Anchorage</a>				X				X
<a href="#">School districts</a>								
<a href="#">YRBS</a>		X		X				

Footnotes:

- <sup>1</sup> Cowie CC, Rust KF, et al. Prevalence of diabetes and impaired fasting glucose in adults in the US population: National Health and Nutrition Survey 1999 – 2002. *Diabetes Care* June 2006; 29(6); 1263-1268.
- <sup>2</sup> Table from: Alaska Section of Epidemiology. Diabetes in Pregnancy Alaska 1990-1999. *Bulletin* Vol. 5 No. 3 December 19, 2001. Available at: [http://www.epi.hss.state.ak.us/bulletins/docs/rr2001\\_3.pdf](http://www.epi.hss.state.ak.us/bulletins/docs/rr2001_3.pdf)
- <sup>3</sup> Northam S and Knapp TR. The reliability and validity of birth certificates. *J Obstet Gynecol Neonatal Nurs* Jan-Feb 2006; 35 (1); 3-12.
- <sup>4</sup> Lydon-Rochelle MT, Holt VL, et al. The reporting of pre-existing maternal medical conditions and complications of pregnancy on birth certificates and in hospital discharge data. *Am J Obstet Gynecol* Jul 2005; 193(1); 125-34.
- <sup>5</sup> O'Brien DK and Bailey AM. *Cancer Incidence and Mortality in Alaska, 1996-2002*. Anchorage (AK): Alaska Department of Health and Social Services, Section of Chronic Disease and Health Promotion, Alaska Cancer Registry, June 2006 (rev. Jan 2007). Available at: <http://www.hss.state.ak.us/dph/chronic/cancer/assets/CancerRegistry1996-2002.pdf> (printed 4/20/07).
- <sup>6</sup> [http://www.hss.state.ak.us/dph/bvs/death\\_statistics/Leading\\_Causes\\_Census/frame.html](http://www.hss.state.ak.us/dph/bvs/death_statistics/Leading_Causes_Census/frame.html) (1/15/07)
- <sup>7</sup> Harris MI, Cowie CC, et al eds. *Diabetes in America 2<sup>nd</sup> Edition* Washington DC; US Dept. of Health and Human Services, National Institutes of Health, National Institute of Diabetes, Digestive and Kidney Diseases (NIH Publication No 95-1468); 1995; 221 – 230 and 233 – 255.
- <sup>8</sup> McEwen LN, Kim C, et al. Diabetes reporting as a cause of death: results from the Translating Research Into Action for Diabetes study. *Diabetes Care* Feb 2006; 29(2); 247-53.
- <sup>9</sup> <http://146.63.75.50/research/pop/estimates/BR01-05.xls> (printed 1/15/06).
- <sup>10</sup> Hebert PL, Geiss LS, Tierney EF, et al. Identifying persons with diabetes using Medicare claims data. *Am J Med Care Qual* Nov-Dec 1999; 14 (6); 270-277.
- <sup>11</sup> Surveillance Epidemiology and End Results Program ([www.seer.cancer.gov](http://www.seer.cancer.gov)) SEER\*Stat Database: Incidence-SEER 13 Regs Public-Use, Nov 2005 Sub (1992-2003), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2006, based on the November 2005 submission. Available at: [http://canques.seer.cancer.gov/cgi-bin/cq\\_submit?dir=seer2003&db=2&rpt=TAB&sel=^0^51^2^2^0&x=SEER%20registry^0,1,2,3,4,5,6,7,8,9,10,11,12,13^Race/ethnicity^0,1,2,3,4,5&y=Statistic%20type^1,2,3&dec=4,4,4&title=SEER+Age-Adjusted+Rates++%26++95%25++Confidence+Intervals~For+Breast+Cancer,+All+Ages,+Females~SEER+13+Registries+for+1994-2003~Age-Adjusted+to+the+2000+US+Std+Population&template=faststats](http://canques.seer.cancer.gov/cgi-bin/cq_submit?dir=seer2003&db=2&rpt=TAB&sel=^0^51^2^2^0&x=SEER%20registry^0,1,2,3,4,5,6,7,8,9,10,11,12,13^Race/ethnicity^0,1,2,3,4,5&y=Statistic%20type^1,2,3&dec=4,4,4&title=SEER+Age-Adjusted+Rates++%26++95%25++Confidence+Intervals~For+Breast+Cancer,+All+Ages,+Females~SEER+13+Registries+for+1994-2003~Age-Adjusted+to+the+2000+US+Std+Population&template=faststats) (printed 4/20/07)
- <sup>12</sup> Ogden CL, Fryar CD, et al. Mean body weight, height, and body mass index, United States 1960-2002. *Advance data from vital and health statistics: no 347*. Hyattsville, MD: National Center for Health Statistics, 2004. (Available at: <http://www.cdc.gov/nchs/data/ad/ad347.pdf>. Printed 4/19/07)
- <sup>13</sup> [ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Dataset\\_Documentation/NHIS/2005/samadult\\_freq.pdf](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2005/samadult_freq.pdf) (1/19/06)
- <sup>14</sup> [http://www.cdc.gov/nchs/data/series/sr\\_13/sr13\\_162.pdf#table12](http://www.cdc.gov/nchs/data/series/sr_13/sr13_162.pdf#table12) (1/19/07)