

Native American Cancer Data 101: Cancer Incidence and Mortality

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Northern Plains Comprehensive Cancer Control Program
(NPCCCP) Northern Plains Tribal Cancer Data Improvement
Initiative (NPTCDI)

Aberdeen Area Tribal Chairmen's Health Board
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Acknowledgement

- This material was prepared for AATCHB by College of Public Health, University of Nebraska Medical Center
 - Cate Malone
 - Shinobu Watanabe-Galloway
- Slides on counts/rates were developed by Chuck Wiggins of New Mexico Tumor Registry

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Pre-Training Knowledge

5 Items

3

1. Which region has the highest cancer incident rate (rate of newly diagnosed cancer) among Native American men?

1. Alaska
2. Southwest
3. Northeast
4. Northern Plains
5. Southern Plains
6. Don't know / Not sure

4

2. Which state(s) in the Northern Plains region has a cancer registry?

1. Iowa and Nebraska
2. Nebraska and North Dakota
3. South Dakota and North Dakota
4. Iowa, Nebraska, and North Dakota
5. Iowa, Nebraska, North Dakota and South Dakota
6. Not sure/Don't know

5

3. What is the reason for linking State cancer registries data with Indian Health Service (IHS)?

1. To collect detailed clinical information
2. To identify tribal affiliation
3. To address racial misclassification
4. To report cancer cases to IHS clinics
5. Not Sure/Don't know

6

4. Cancer registry data is used to:

1. Monitor cancer trends over time
2. Determine cancer patterns
3. Guide planning and evaluation of cancer control programs
4. Help set priorities for allocating health resources.
5. All of the above
6. Don't know/Not Sure

7

5. Usually it takes about ____ for the cancer data to be collected, cleaned, analyzed, and reported.

1. 6 months
2. 9 months
3. 1 year
4. 2 years
5. Don't know/Not sure

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Workshop Objectives: By the end of the session, the participant will be able to:

1. Describe cancer disparities among Northern Plains Native Americans
2. Describe how new cases of cancers are identified.
3. Identify cancer-related information collected by state cancer registrants.

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.... (a person) who controls the data is very influential on policy

Rashi Fein, PhD

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Data is power.

Make the best use of it.

11

Terminology and definitions

12

What are prevalence and incidence?

(1)

The National Cancer Institute estimates that about 10.8 million Americans with a history of cancer were alive in January 2004. Some of these people were cancer-free, while others still had evidence of cancer and may have been undergoing treatment (ACS Report 2008).

Number of people living with cancer

= number of cancer survivors

= cancer prevalence

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What are prevalence and incidence?

(2)

About 1,437,180 new cancer cases are expected to be diagnosed in 2008 in the United States (ACS report).

New cancer cases = incident cases (incidence)

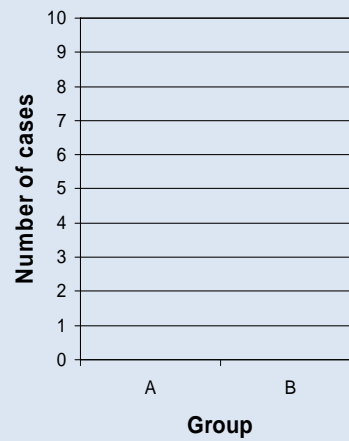
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Counts vs. Rates

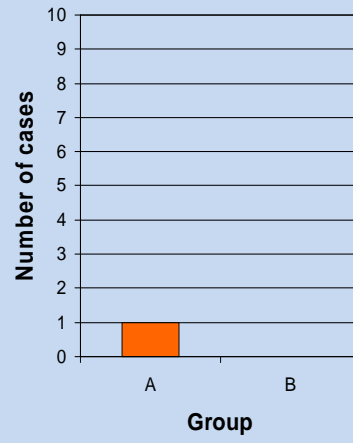
The following 9 slides are credited to: Charles Wiggins, Ph.D. Director and Principal Investigator New Mexico Tumor Registry, as presented at the Comprehensive Cancer Control Leadership Institute for American Indian and Alaska Native Tribes on September 21, 2005 in Tucson, AZ.

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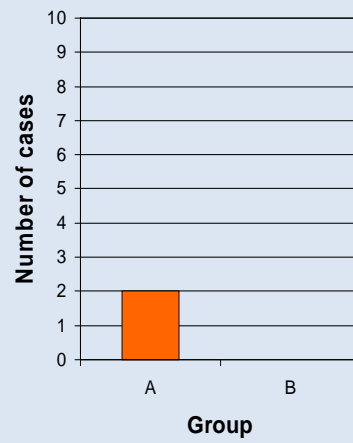
Plotting data



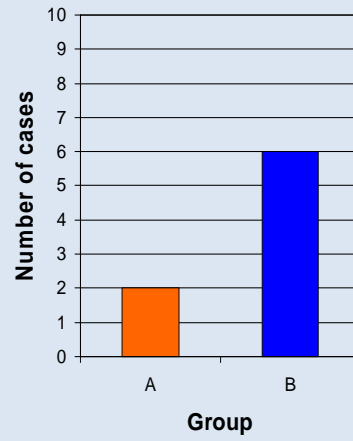
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Plotting data

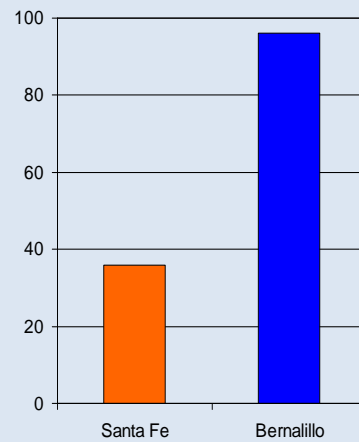


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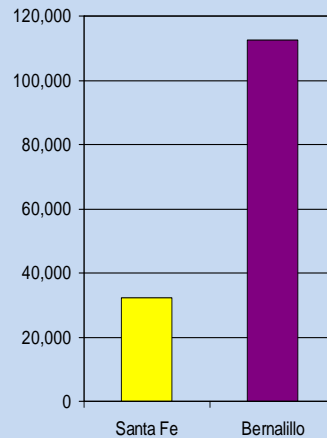
Tools for measuring the occurrence of cancer: "Counts"

- Santa Fe County
36 new cases of prostate cancer were diagnosed in Hispanic men in 2002
- Bernalillo County
96 new cases of prostate cancer were diagnosed in Hispanic men in 2002
- Which county has "more" prostate cancer?



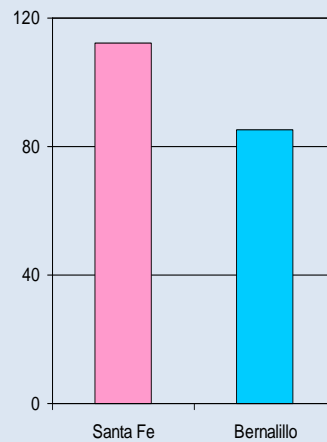
Simple “counts” do not account for population size

- Santa Fe County
32,104 resident Hispanic men
- Bernalillo County
112,477 resident Hispanic men
- Must consider population size when comparing number of cancer cases from two areas

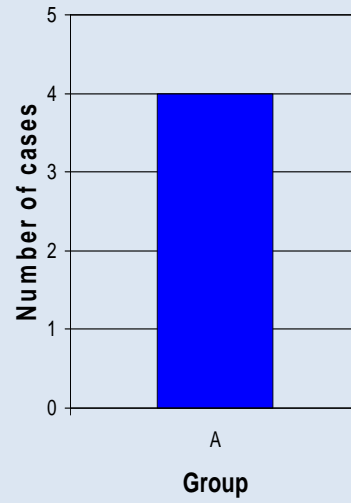


These “rates” express number of cases per 100,000 people

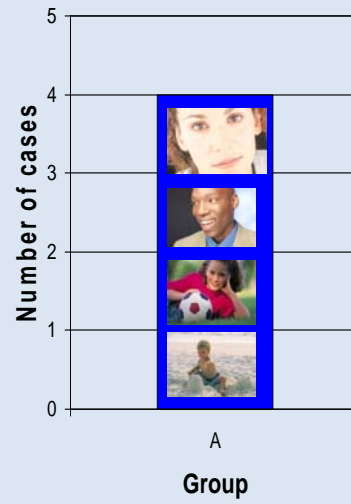
- Santa Fe County
(36 cases / 32,104 people) Rate = 112.1
- Bernalillo County
(96 cases / 112,477 people) Rate = 85.4



These are not numbers...



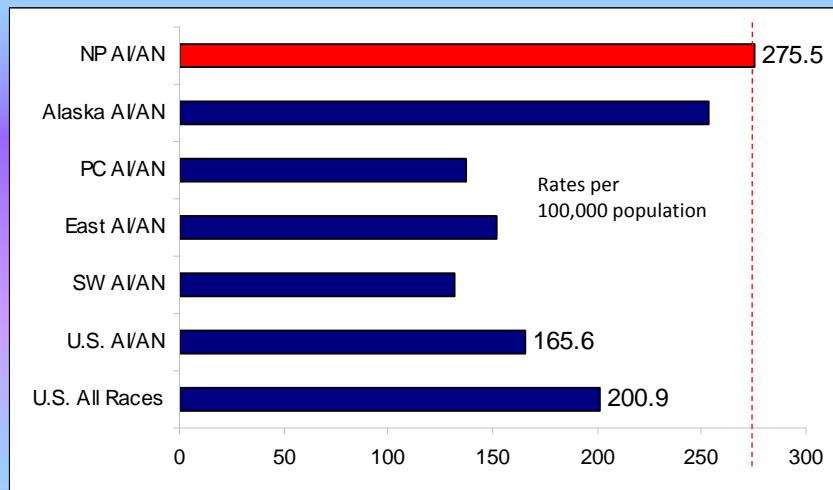
These are not numbers...they are people



Cancer Burden in the Northern Plains

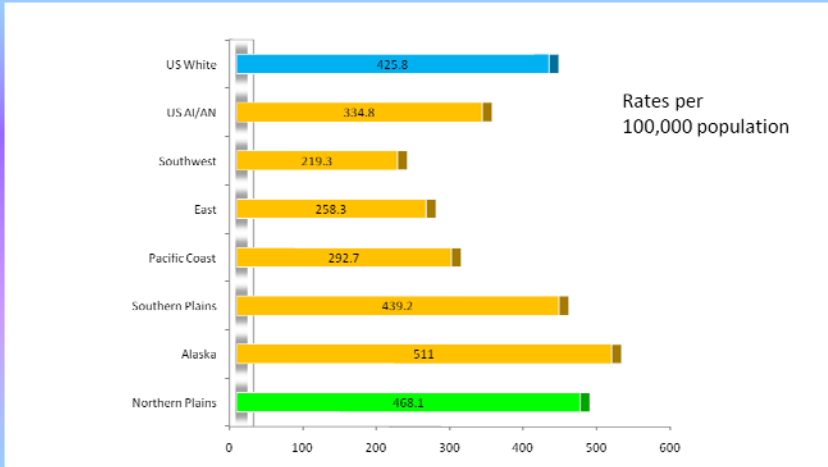
What does data tell us about cancer in our communities?

AI/AN All Cancer Mortality Rates: 1996-2001



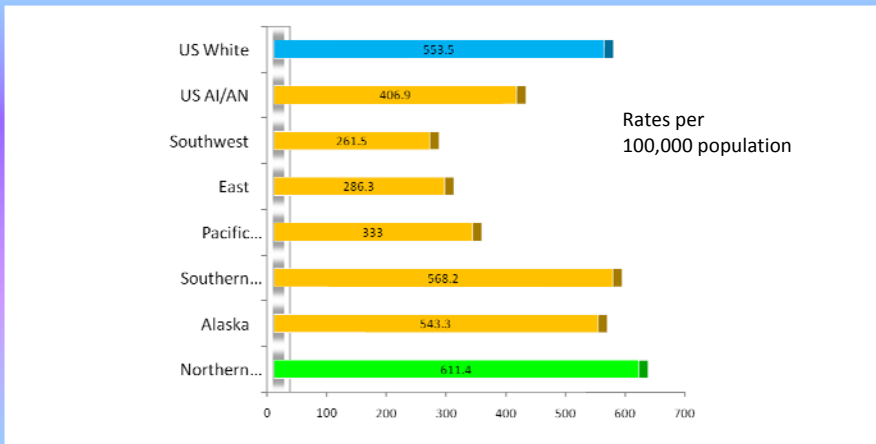
Source: Espey, et al. "Regional Trends and Patterns in Cancer Mortality" Cancer 2005;103:1045-53.)

Cancer Incidence Rates among Native American Women 1999-2004



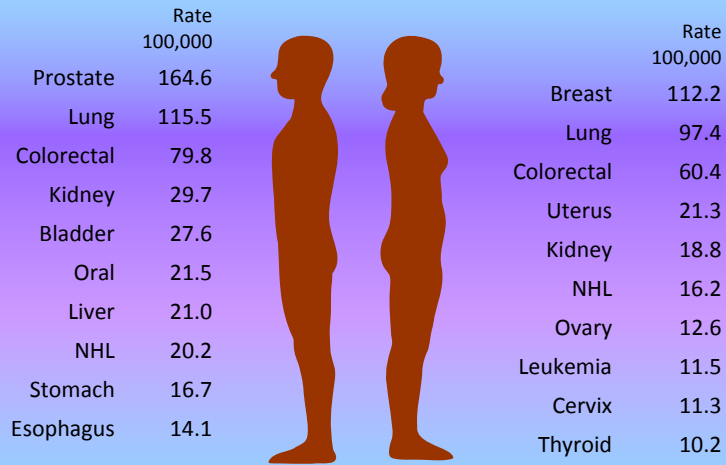
Source: Espey, et al. Annual report to the Nation on the status of Cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. Cancer 2007;110:2119-52.

Cancer Incidence Rates among Native American Men 1999-2004



Source: Espey, et al. Annual report to the Nation on the status of Cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. Cancer 2007;110:2119-52.

Top 10 Cancers (incidence) among Northern Plains Native Americans



Source: Espey, et al. Annual report to the Nation on the status of Cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. Cancer 2007;110:2119-52.

Cancer in Native American young adults

Cancer in Native American young adults (age 20-44): 1999-2004

- 3775 new cancer cases diagnosed among Native American young adults
- Women are more likely to be diagnosed with cancer than men (both AI/AN and whites)
- In most of regions, cancer incidence rates are lower among Native Americans compared to whites
- Disparities: stomach, liver, kidney
- Colorectal cancer in Native Americans seems to be increasing

Source: Weier, et al. Cancer in American Indian and Alaska Native Young Adults (ages 20-44 years): US 1999-2004. Cancer 2008; 113 (5 suppl):1153-67.

Cancer **in Northern Plains** Native Americans young adults

- Higher risk of developing stomach cancer
 - Risk factors for stomach cancer include: H. pylori infection, diet low in fruits/vegetables, high in red meat consumption
- Higher risk of developing colorectal cancer
 - Risk factors for colorectal cancer include: family history of polyps, inflammatory bowel syndrome, smoking, alcohol, lack of physical activity, diet low in fruits/vegetables, high in red meat consumption

Source: Weier, et al. Cancer in American Indian and Alaska Native Young Adults (ages 20-44 years): US 1999-2004. Cancer 2008; 113 (5 suppl):1153-67.

Specific cancers among Native American adults (all ages) in Northern Plains

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Lung Cancer Incidence Rates: 1999-2004



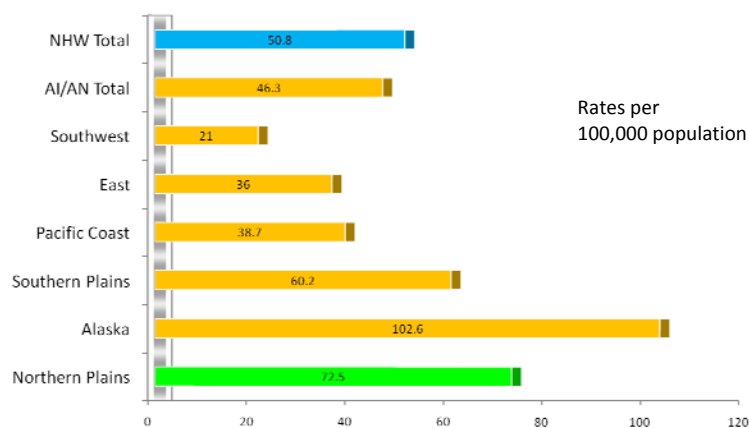
Source: Bliss, et al. Lung cancer incidence among American Indians and Alaska Natives In the United States, 1999-2004. *Cancer* 2008;113(5 suppl):1168-78.

Lung Cancer in Northern Plains Native Americans

- Highest incidence and mortality rates compared to Native Americans in other regions
- In the Northern Plains, compared to whites Native Americans are:
 - 1.6 times more likely to be diagnosed with lung cancer
 - 1.7 times more likely to die from lung cancer

Sources: Bliss, et al. Lung cancer incidence among American Indians and Alaska Natives in the United States, 1999-2004. *Cancer* 2008;113(5 suppl):1168-78.
Espey, et al. Regional Trends and Patterns in Cancer Mortality. *Cancer* 2005;103:1045-53.

Colorectal Cancer Incidence Rates: 1999-2004



Source: Perdue, et al. Regional differences in colorectal cancer incidence, stage, and subsite Among American Indians and Alaska Natives, 1999-2004. *Cancer* 2008;113(5 suppl):1179-90.

Colorectal Cancer in Northern Plains Native Americans

- Second highest incidence and mortality rates compared to Native Americans in other regions (Alaska is Top)
- In the Northern Plains, compared to whites Native Americans are:
 - 1.4 times more likely to be diagnosed with colorectal cancer
 - More likely to diagnosed at later stage
 - 1.6 times more likely to die from colorectal cancer

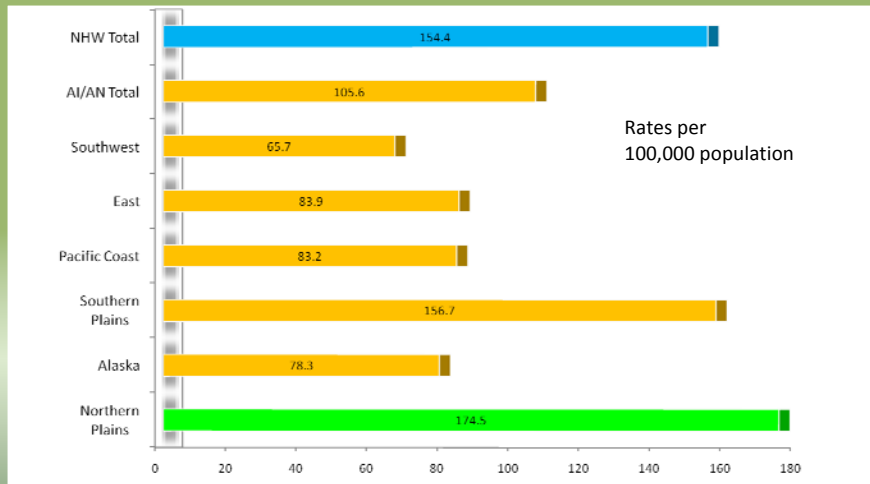
Sources: Perdue, et al. Regional differences in colorectal cancer incidence, stage, and subsite Among American Indians and Alaska Natives, 1999-2004. *Cancer* 2008;113(5 suppl):1179-90. Espey, et al. Regional Trends and Patterns in Cancer Mortality" *Cancer* 2005;103:1045-53.

Breast Cancer in Northern Plains Native Americans

- Second highest incidence and mortality rates compared to Native Americans in other regions
- In the Northern Plains:
 - Native Americans are less likely to develop or die from breast cancer compared to whites
 - A higher percentage of Native American women are diagnosed at later stage than whites

Sources: Wingo, et al. Breast cancer incidence among American Indian and Alaska Native women: US, 1999-2004. *Cancer* 2008;113(5 suppl):1191-202. Espey, et al. Regional Trends and Patterns in Cancer Mortality" *Cancer* 2005;103:1045-53.

Prostate Cancer Incidence Rates: 1999-2004



Source: Henderson, et al. Prostate cancer incidence among American Indians and Alaska Natives, 1999-2004." Cancer 2008;113(5 suppl):1203-12.

Prostate Cancer in Northern Plains Native Americans

- Highest incidence and mortality rates compared to Native Americans in other regions (Alaska is Top)
- In the Northern Plains, compared to whites Native Americans are:
 - At the same risk of developing prostate cancer as whites.
 - 1.3 times more likely to die from colorectal cancer

Sources: Henderson, et al. Prostate cancer incidence among American Indians and Alaska Natives, 1999-2004." Cancer 2008;113(5 Suppl):1203-12. Espey, et al. Regional Trends and Patterns in Cancer Mortality" Cancer 2005;103:1045-53.

Other Cancers in Northern Plains Native Americans (1)

- Urinary tract cancer
 - Highest incidence rate compared to Native Americans in other regions
 - Within the NP region, Native Americans 2 times more likely to develop urinary tract cancer than whites
- Gastric cancer
 - Second highest incidence rate compared to Native Americans in other regions
 - Within the NP region, Native Americans 2.4 times more likely to develop and 2 times more likely to die from gastric cancer than whites

Sources: Wilson, et al. Cancers of urinary tract among American Indians and Alaska Natives in the United States, 1999-2004. *Cancer* 2008; 113 (Suppl 5): 1213-24. Wiggins, et al. Gastric cancer among American Indians and Alaska Natives in the United States, 1999-2004. *Cancer* 2008; 113 (Suppl 5): 1225-33. Espey, et al. Regional Trends and Patterns in Cancer Mortality" *Cancer* 2005;103:1045-53.

Other Cancers in Northern Plains Native Americans (2)

- Cervical cancer
 - Second highest incidence rate compared to Native Americans in other regions
 - Within the NP region, Native Americans 1.7 times more likely to develop cervical cancer than whites

Sources: Becker, et al. Regional differences in cervical cancer incidence among American Indians and Alaska Natives, 1999-2004. *Cancer* 2008; 113 (Suppl 5): 1234-43.

Other Cancers in Northern Plains Native Americans (4)

- Oral cancer
 - Second highest incidence and rate compared to Native Americans in other regions
 - Within the NP region, Native Americans 1.3 times more likely to develop oral cancer than whites

Sources: Richman, et al. Incidence of cancers of the oral cavity and pharynx among American Indians and Alaska Natives, 1999-2004. *Cancer* 1008;113(5 Suppl): 1256-65.

Other Cancers in Northern Plains Native Americans (3)

- Liver cancer
 - Second highest incidence and mortality rate compared to Native Americans in other regions
 - Within the NP region, Native Americans 3.7 times more likely to develop and 2 times more likely to die from liver cancer than whites

Sources: Jim, et al. Primary liver cancer incidence among American Indians and Alaska Natives, US, 1999-2004. Espey, et al. "Regional Trends and Patterns in Cancer Mortality" *Cancer* 2005;103:1045-53.

Roles of State Cancer Registries

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New cases of cancers among Native Americans Northern Plains Region - examples

- Nebraska: 1996-2005 (10 yrs): 335
- North Dakota 2001-2005 (5 yrs): 457

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Where these data come from?

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Cancer Surveillance

The systematic collection
of information on cancer

- *and* -

Timely and effective use of such information
for the purposes of cancer prevention and control

***Who collects and disseminates
cancer data?***

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Cancer is a reportable disease

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www.ndhealth.gov/Cancerregistry/aboutus.htm

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About Us

of Health
tion & Control

General Information about the North Dakota Cancer Registry

Cancer is a reportable disease as stated in the North Dakota Administrative Rules. On July 1, 1996, administrative rules were added in situ carcinomas (except basal and squamous cell skin carcinomas or in situ carcinoma of the cervix uteri) and tumors of the central laboratories, physicians, and other health care providers who administer screening, diagnostic or therapeutic services are required facilities that provide inpatient and/or outpatient services and mobile units that provide screening, diagnostic or therapeutic services Century Code Chapters 23-07-01 and 33-06-01)

The primary purpose of the cancer registry is to support cancer control by targeting, monitoring and evaluating programs that promote cancer. The cancer registry supports efforts by community hospitals and health systems with respect to the evaluation of their cancer local health care agencies and providers by:

- Providing summary statistics on the distribution of cancer cases by type.
- Following cancer incidence and treatment trends throughout the state.
- Facilitating rapid reporting of cancer, thereby allowing state or local health officials to assess suspected cancer clusters or special communities.
- Providing accurate cancer data for cancer-related reports to legislative bodies and agencies.

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South Dakota Department of Health

Doneen Hollingsworth
Secretary of Health
600 East Capitol Avenue
Pierre, SD 57501-2536
605-773-3361
1-800-738-2301 (in state)

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SDCR South Dakota Cancer Registry

The South Dakota Cancer Registry (SDCR) is a statewide population-based cancer registry. It collects data on cancer incidence and reports on cancer incidence and mortality. It began in 1992 as a limited cancer data collection system that monitored cancer incidence through pathology reports and reports from hospital tumor registries approved by the American College of Surgeons. In 2005 a law passed requiring reporting by all entities detecting, diagnosing and treating cancer cases in South Dakota.

In 2001, SDCR became part of the National Program of Cancer Registries (NPCR) which supports central registries in 45 states, the District of Columbia, and the territories of Puerto Rico, the Republic of Palau, and the Virgin Islands. NPCR registries collect information on cancer cases accounting for 96% of the U.S. population.

NPCR is administered by the Centers for Disease Control and Prevention, which provides funding for states to implement statewide population-based registries and to enhance existing registries to meet national standards for completeness, timeliness and data quality. The North American Association of Central Registries sets standards for central registries.

News

- South Dakota Cancer Registry Achieves NAAACCR Gold Standard
- Sister Study - long-term study of women aged 35 to 74 with sisters who had breast cancer. It is a national study to learn how environment and genes affect the chances of getting breast cancer. Effective April 1, 2008, the Sister Study is limiting enrollment to groups of women who are underrepresented in the study. It is still seeking Native Americans, African Americans, Latinas, Asians and Pacific Islanders between the ages of 35 and 74 to enroll. It is also seeking Caucasian women who have a high school degree or less or are between the ages of 65 and 74. Find out about enrolling at the [Sister Study website](#).

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South Dakota Connect

SERVSD
STATEWIDE EMERGENCY
REGISTRY OF VOLUNTEERS

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Official Nebraska Government Website

NEBRASKA DEPARTMENT OF HEALTH & HUMAN SERVICES

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Search

Nebraska Cancer Registry

The Nebraska Cancer Registry (NCR) was created by the Legislature in 1986 ([relevant sections in the statutes](#): 81-638, 81-642 through 81-650 and 81-665 through 81-675) and began collecting information in 1987.

- [Data](#)
- [NCR Brochure](#)
- [Helpful Links](#)
- [Contact Us](#)

The purpose of the registry is to document the cases of cancer, analyze patterns/trends and to use the information to help control the burden of cancer over time. The registry also provides statistical and background information about cancer incidence in Nebraska.

Financial support for the NCR comes both from state revenues (a portion of tobacco taxes) and the Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR), which began funding the NCR in 1994.

The Nebraska Department of Health and Human Services administers and directs the operation of the Nebraska Cancer Registry. The NCR is part of a national and international surveillance system that collects information about cancer to document trends in cancer prevalence, cancer cases by site and stage, and other information that may be useful in cancer prevention and control.

Every cancer diagnosed in Nebraska is reportable to the NCR. Generally, this information comes from hospital reports submitted by cancer registrars. In addition, physicians, osteopaths, pathology labs or free-standing radiation centers also report any information they have about persons with cancer. No reporting is required for pre-cancerous cell types, benign polyps, basal and non-invasive or local squamous-cell cancers of the skin, and most benign tumors. However, since January 1, 2004, benign brain and other central nervous system cancers are now reportable to the NCR.

The NCR's latest [annual report](#) provides comprehensive data on specific sites and cancer rates by race or county.

Given the wealth of valuable information about cancer, links are provided to a number of useful sites. Persons needing or seeking to know more about a specific cancer type, the probabilities for developing cancer, prevention, treatment options, the burden of the disease, national statistics, resources available and survivorship issues can visit [these sites](#).

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SHRI State Health Registry of Iowa Iowa Cancer Registry

Welcome to the Iowa Cancer Registry

The Iowa Cancer Registry (ICR) is a population-based cancer registry that has served the State of Iowa since 1973.

The ICR has been a member of the [National Cancer Institute's Surveillance, Epidemiology, and End Results \(SEER\) Program](#) since its inception in 1973.*

The goals of the State Health Registry of Iowa are to:

- Assemble and report measurements of cancer incidence, survival and mortality among Iowans;
- Provide information on changes over time in the extent of disease at diagnosis, therapy, and patient survival;
- Promote and conduct studies designed to identify factors relating to cancer etiology, prevention and control;
- Respond to requests from individuals and organizations in the state of Iowa for cancer data and analyses;
- Provide data and expertise for cancer research activities and educational opportunities.

*This project has been funded in whole or in part with Federal funds from the National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Contract No. N01-PC-35143

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Roles of Cancer Registries

- Identify report sources & keep them informed of reportable tumors
- Process reportable tumors as submitted by hospitals
- Follow back to physicians offices on cases not reported by a hospital identified through pathology reports

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- Consolidate submitted information so incidence counts are accurate and treatment information is complete
- Train registrars to keep them abreast of changing coding rules & manuals
- Conduct case-finding & re-abstracting audits
- Conduct death clearance follow back

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How is the cancer registry data used?

- Monitor cancer trends over time
- Determine cancer patterns
- Guide planning and evaluation of cancer control programs (eg, determine whether prevention, screening, and treatment efforts are making a difference).
- Help set priorities for allocating health resources.

<http://www.medterms.com/script/main/art.asp?articlekey=33287>

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How is the cancer registry data used? (cont'd)

- Advance clinical, epidemiologic, and health services research.
- The state cancer registries in the US, taken all together, provide key cancer data of national importance (National Program of Cancer Registries/SEER Registries)

<http://www.medterms.com/script/main/art.asp?articlekey=33287>

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How does State Cancer Registry identify possible cancer cases?

- State cancer registrants visit health care facilities on a regular basis
- At each facility, potential cases are identified using ICD-9 codes
- Registrants review pathology records to confirm the cases

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Why don't state cancer registrants visit all health care facilities?

- Limited resources and manpower do not allow registrants to collect data from all the facilities
- Registrants visit facilities where cancer diagnosis and treatment are more likely to be done

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How about patients diagnosed or treated in other states?

- Neighboring states generally have agreements to exchange cancer data.
 - NE:
 - ND:
 - SD:
- There are some exceptions.

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What kind of information is collected by cancer registries?

- Patient demographic characteristics
- Cancer diagnosis
- Cancer treatment
- Death (through linkage with death certificate database)

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How does the state cancer registry identify people who died from cancer?

- Linkage with national death certificates are done on a regular basis to identify people who died from cancer

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How can I access cancer statistics?

- “Report to the Nation” by Espey, et al. (2007)
- Articles in the special issue of “Cancer” (2008)
- State cancer registry reports/websites

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Issues with under-reporting

- Due to misclassification of race/ethnicity information, under-reporting of Native Americans has been recognized.
- One way to improve the data is to link with IHS data
- Because IHS data only captures the registered patient population, there are still lots of cases where Native Americans are recorded under other race/ethnicity

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Discussion about Cancer Surveillance

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Questions/Issues Raised

1. Can the state cancer registry give information about the patients treated at our tribal health clinic?

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Questions/Issues Raised cont.

2. Is it feasible for our community to develop our own cancer registry?

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Questions/Issues Raised cont.

3. Once patients are referred out for diagnosis and treatment, we lose track of them. Is there any way to address this?

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Interactive Activity:

Bingo Time!

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Post-Training Knowledge

5 Items

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1. Which region has the highest cancer incident rate (rate of newly diagnosed cancer) among Native American men?

1. Alaska
2. Southwest
3. Northeast
4. Northern Plains
5. Southern Plains
6. Don't know / Not sure

72

2. Which state(s) in the Northern Plains region has a cancer registry?

1. Iowa and Nebraska
2. Nebraska and North Dakota
3. South Dakota and North Dakota
4. Iowa, Nebraska, and North Dakota
5. Iowa, Nebraska, North Dakota and South Dakota
6. Not sure/Don't know

73

3. What is the reason for linking State cancer registries data with Indian Health Service (IHS)?

1. To collect detailed clinical information
2. To identify tribal affiliation
3. To address racial misclassification
4. To report cancer cases to IHS clinics
5. Not Sure/Don't know

74

4. Cancer registry data is used to:

1. Monitor cancer trends over time
2. Determine cancer patterns
3. Guide planning and evaluation of cancer control programs
4. Help set priorities for allocating health resources.
5. All of the above
6. Don't know/Not Sure

75

5. Usually it takes about ____ for the cancer data to be collected, cleaned, analyzed, and reported.

1. 6 months
2. 9 months
3. 1 year
4. 2 years
5. Don't know/Not sure

76

Great Job!

