

Cancer Information Gaps for American Indian and Alaska Native Populations

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(Native Network) Meeting

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Introduction



Purpose

Provide an overview of existing data information specific to cancer among AI/AN and present a critical review of the cancer data gaps



Intended Audiences

1. American Indian/Alaska Native (AI/AN) community leaders
2. Individuals and entities that work to improve the cancer health status of the AI/AN communities
3. Federal and state agencies that sponsor and/or administer health data collection activities.



Goals

- Develop an inventory of existing population-based data sources for cancer
- Identify and classify gaps within the existing population-based cancer data for AI/AN populations
- Recommend strategies for increasing and improving availability, access and use of AI/AN cancer data



Methods



Inclusion Criteria

1. Contain **cancer-related information** (e.g., risk or protective factors , cancer incidence and death, and cancer screening and treatment use)
2. **Population-based.** Designed with intent to produce a representative sample of the source population. (If the data collection were based on a convenient sample of patients seen at one health clinic, it would not meet this inclusion criterion)
3. **National coverage** or based on a **national initiative** to collect multi-state data.



Data Extraction

1. data title and sponsoring organization,
2. purpose and description of the data,
3. type of cancer information collected,
4. race and tribal affiliation reported and sample size,
5. data collection methods and data period
6. data availability



Results



24 sources met inclusion criteria (Table 1)

Types

- Survey data: 16
- Administrative data: 5
- Registry data: 2
- Vital statistics: 1

Major sponsors of data collection

- CDC: 16
- NCI: 4
- AHRQ: 2



Source Populations & Sampling Methods (Table 2)

Surveys:

- American Indian Adult Tobacco Survey (AI-ATS) and South Dakota Tribal Pregnancy Risk Assessment Monitoring System (SD-Tribal PRAMS) exclusively sampled from the American Indian communities.
- All other health surveys were designed to produce a sample that is representative of the U.S. population.
- Without oversampling, this approach often leads to a small sample size of AI/AN population and other racial minority groups.



Administrative databases, disease registries & vital statistics

By definition these data sources are supposed to capture demographic and clinical information about all individuals who meet certain criteria or eligibility (e.g., Medicare = all individuals 65 years and older; cancer registry = all individuals diagnosed with cancer)



Race and Tribal Affiliation Information (Table 3)

- The majority of the existing data sources reviewed for this project collect information from the general population such as data that contain information on individuals of different racial/ethnic groups. The exceptions are AI-ATS, SD-Tribal PRAMS and RPMS, which primarily focus on American Indians.



Sample Size (Table 4)

Survey (Of the 16 surveys, sample size info was available for 15 surveys)

- BRFSS had the largest sample size with 6,470 followed by NHIS (3,192), TUS CPS (1,851), PRAMS (~1,000), CAHPS (642), HBSC (526), and NIS (396)
- But the remaining seven survey data sources had size smaller than 300 including 61 AI/AN respondents for HINTS and 86 AI/AN respondents for NHANES.



Administrative & Registry Data

- Relatively large number of individuals.
- Medicare: 185,666 individuals (Year 2008)
- IHS-wide RPMS: 1,483,423 patients (Year 2008)
- Registry data (1999-2008) contain information on 28,874 AI/AN cancer cases.



Cancer Information Collected (Table 5)



Prevention	Early Detection		Treatment	Survivorship	Other
	Screening	Diagnosis			
Commercial tobacco use (10)	Breast cancer screening receipt (7)	Self-report of diagnosis (5)	Treatment receipt (7)	Type of provider who gives majority of care (2)	Family history of cancer (2)
Secondary smoke exposure (5)	Cervical cancer screening receipt (7)	Diagnosis based on provider records (7)	Type of primary care provider (1)	Insurance coverage of cancer treatment (1)	Knowledge and perception of cancer risk (1)
Smoking cessation (9)	Prostate cancer screening receipt (7)	Availability of diagnostic tests at the facility (1)	Routine cancer check-up (1)	Limitations caused by cancer (2)	Cancer care giving experience (1)
Tobacco policies (3)	Colorectal cancer screening receipt (7)		Participation in clinical trial (1)	Pain and pain control (1)	Death caused by cancer (4)
Youths access and exposure to tobacco (1)			Cost of treatment (3)		
Alcohol use (7)			Availability of treatment at the facility (1)		
Physical activity (6)					
Nutrition (6)					
Obesity (6)					
Sexual behavior (2)					
HPV infection (2)					
HPV vaccine receipt (4)					
Hep B vaccine receipt (4)					
UV exposure (4)					
Occupational exposure (2)					
Pesticide use (2)					

Recommendations



Recommendations

- 1. Population-based data that allows trend analysis for monitoring of progress**
 - One of the priorities is to ensure the appropriate sample size of the AI/AN in the major national surveys (e.g., NHANES and HINTS) so that reliable estimates will be available to establish the baseline and track the progress in coming years.



2. Resources and technical assistance for local data collection

- Because cancer prevention and control activities are planned and implemented by individual tribes, local data are needed, which is one of the most persistent messages our program has received from tribes in the Northern Plains.
- Resources should be invested in the communities



3. Balancing information across the cancer continuum

- Treatment information is relatively scarce and/or difficult to access.
- Palliative care and end-of-life care information is largely missing.
- As for survivorship, with the exception of a few surveys (e.g., BRFSS), little data exist to understand the experience of survivors, families and care givers.
- An increased collaboration and coordination across agencies should happen to eliminate duplicating efforts and to fill in cancer data gaps



4. Increasing data access and sharing

- While protecting the confidentiality of data, make the data more accessible for program evaluation and research.
- National efforts to establish clinical and public health data standards to make data systems more inter-operational.
- Promotion of formal data exchanges and use agreements would lead to increased access to data.
- Increase in sharing of clinical data, perhaps through RPMS and similar system, may be helpful in improving communication and coordination of care across providers.



Thank you for this opportunity... for a question about the project or this presentation, please contact:

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