



Chapter 6:
DATA COLLECTION
& REPORTING

Promote the Collection and Use of Information: to Increase Professional and Public Understanding and Education about Cancer and its Impact on Wisconsin Residents

Rationale

Wisconsin established a state cancer registry in 1976, and the Wisconsin Cancer Reporting System (WCRS) has been part of the CDC funded National Program of Cancer Registries since 1994. WCRS has been consistently recognized by the North American Association of Central Cancer Registries (NAACCR) for high quality data since 1995 when national certification was first awarded. WCRS maintains data to support several local, state and national functions such as:

- Health care planning by state and local health departments,
- Epidemiological, medical and health services research,
- Citizen education,
- Evaluation of prevention and treatment programs, and
- Comprehensive cancer control strategies.

This information needs to be continually collected and, more importantly, disseminated. Analysis of data can influence the entire continuum of cancer and can offer new insights into how cancer is prevented and treated in the future.

Disparate Burden

Data show that there is a disparate burden of cancer in Wisconsin. The collection, classification, and reporting of cancer-related data can be improved. More can be done within research to increase the understanding of

disparate burden and cancer. Only then will it be clear what variables are causing the disparities. Data will also point to which interventions should be implemented to try and reduce the disparate burden of cancer.

What Can Be Done?

- Continue funding and support for existing cancer-related data collection.
- Improve and enhance the Wisconsin Cancer Reporting System (WCRS).
- Increase awareness of existing cancer-related publications and educate users to the purpose of such publications, how they should be interpreted, and how they can be used for community programs.
- Increase research and professional access to cancer-related data.

Targets for Change

CANCER-RELATED DATA COLLECTION

Examples of data sets in Wisconsin in 2003

- Wisconsin Family Health Survey (WFHS)
- Behavioral Risk Factor Surveillance System (BRFSS)
- Wisconsin Cancer Reporting System (WCRS)
- Tobacco Attitudes and Behavior Survey (TABS)
- Youth Risk Behavioral Survey (YRBS)
- Youth Tobacco Survey (YTS)
- Vital Statistics

2010 Target: Expand cancer-related data collection that is Wisconsin specific.

STRATEGY A: Continue funding and support for existing cancer-related data collection.	
Action Plan	Recommended Implementation Steps
Actively search and apply for grants to provide sustainable funding for cancer-related data collection.	To be determined.
Incorporate the cancer-related data sets into cancer specific reports through the public use data set, Wisconsin Interactive Statistics on Health - WISH.	To be determined.

STRATEGY B: Improve and enhance the Wisconsin Cancer Reporting System (WCRS).	
Action Plan	Recommended Implementation Steps
Obtain additional funding for the Wisconsin Cancer Reporting System.	To be determined.
Partner with the Wisconsin Cancer Registrars Association to promote benefits of Certified Tumor Registrars (CTR) in cancer registry systems in Wisconsin.	Research other states with CTR as models.
	Develop education plan for hospitals on benefits of CTR.
	Develop education plan for employers on use of accredited (ACoS) hospitals.
	Encourage CTR Continuing Education for current CTR staff. Advocate mandating the use of CTR in cancer reporting.



STRATEGY C: Increase awareness of existing cancer-related publications and educate users to the purpose of such publications, how they should be interpreted, and how they can be used for community programs.	
Action Plan	Recommended Implementation Steps
Develop an awareness campaign on cancer-related publications.	Identify a lead organization to spearhead an awareness campaign.
	Disseminate information in a meaningful way to appropriate audiences.

STRATEGY D: Increase research and professional access to cancer-related data.	
Action Plan	Recommended Implementation Steps
Increase awareness of current systems to access individual use data sets.	Disseminate WCRS policy for accessing individual use data sets, both confidential and non-confidential.
	Assess and disseminate non-WCRS cancer data system individual use data set access policies.

Increase Timeliness of Reporting Cancer Cases to the Wisconsin Cancer Reporting System

Rationale

Timely data are needed for a variety of cancer analyses. The state health plan assessment requires timely data to assess “current/emerging threats to the community’s health” (e.g., cancer cluster investigations).¹¹ Timely data are often needed for case/control studies, especially for cancer types with poor survival rates (brain, pancreas, etc.).

There are state and national standards for timely reporting: WCRS requires all cases be reported within six months of diagnosis, CDC requires a 90% complete database 12 months after the close of the reporting cycle.^{22,29} However, most cases are not reported within six months. The majority of cases are reported nine to 12 months after diagnosis. Using the WCRS six-month reporting guideline, 50% of cases diagnosed in 2003 should have been reported by January 1, 2004.

Currently cancer data are published, on average, three years after the diagnosis year.³⁰ In contrast, other health and vital record publications on births, deaths, hospital discharge data, behavioral risk factor data, etc., are often available 18 to 24 months from the close of the event year. While there are standards in place to assess timeliness, there is a lack of enforcement mechanisms to ensure timely reporting.

Disparate Burden

The timeliness of reporting cancer data transcends all racial/ethnic groups. Therefore, it is important that all data be timely and this will only help us see any data-specific emerging disparities more quickly.

What Can Be Done?

- Increase electronic reporting of cancer cases to WCRS by 20%.
- Implement standard procedures for notification of reporting status for non-compliant facilities.
- Develop a work plan to study long-term timeliness improvements for the WCRS.

Targets for Change

ELECTRONIC REPORTING	
Wisconsin Cancer Reporting System Rates	
WI Electronic Reporting Rate 2003	2010 Target
70%	90%

Sources:
Wisconsin Cancer Reporting System (per Laura Stephenson).

STRATEGY A: Increase electronic reporting of cancer cases to WCRS by 20%.	
Action Plan	Recommended Implementation Steps
Promote electronic reporting to those currently using paper reporting.	Identify all reporting facilities in WCRS system that report cases on paper and stratify by annual caseload estimate.
	Send all paper reporting facilities with annual caseloads over 50 a copy of WCRS or CDC data entry software with installation instructions and user's manual.
	Follow up with above selected facilities to make sure WCRS software is installed and operational.
	Send all remaining paper reporting facilities, with more than ten cases per year, data entry software and instructions.
	Assess increase in electronic reporting.

STRATEGY B: Implement standard procedures for notification of reporting status for non-compliant facilities.	
Action Plan	Recommended Implementation Steps
Develop a standard procedure for notification for non-compliant facilities.	Determine the different types of non compliant categories.
	Identify a tiered communication structure that establishes who sends the notification at what time, how often, and to whom the notification is sent. Document procedures.
	Draft and send a letter for non-WCRS notification of non compliance.
Implement notification process.	To be determined.

STRATEGY C: Develop a work plan to study long-term timeliness improvements for the WCRS.	
Action Plan	Recommended Implementation Steps
Develop a plan for exploring the feasibility of electronic data transfer via the Public Health Information Network (PHIN), electronic data editing, and rapid case ascertainment.	Identify key stakeholders to develop the work plan.
	Complete a feasibility study as part of the work plan.

Improve the Quality and Completeness of Treatment Data

Rationale

Data requests for treatment information have been steadily increasing in recent years. CDC and North American Association of Central Cancer Registries (NAACCR) recently testified before Congress on the status of treatment data collection at the state registry level and the need for treatment supplements for the breast and cervical cancer programs around the country.³¹ Based in part on those testimonies, CDC now requires collection of primary site surgeries and a number of state breast and cervical screening programs are providing payment for cancer treatment. However, treatment data are not collected consistently at the state level. WCRS requires reporting of cancer-directed treatment (surgical and nonsurgical), but the quality and completeness of the data are not closely monitored.²² CDC only requires collection on primary site surgeries. The American College of Surgeons Approved Hospitals require collecting all first course treatment data, but only 29 Wisconsin hospitals have this certification, representing about 60-65% of the annual caseload.^{24,32}

Disparate Burden

Data collection for racial and ethnic variables have known limitations, including underreporting, misclassification, and incomplete data items.³³ This also extends into the limited and inconsistent collection of treatment data on different racial and ethnic groups. It is important as more treatment data is collected that racial and ethnic variables within that data are monitored for completeness and proper classification.

What Can Be Done?

- Identify sources that currently collect treatment data.
- Make recommendations on how to collect treatment information for Wisconsin.

Targets for Change

TREATMENT DATA COLLECTION	
In Wisconsin	
2004	2010 Target
Current baseline in WI is not consolidated.	Have a treatment data set that appropriately describes the treatment provided to Wisconsinites regarding their first course cancer treatment plans.



STRATEGY A: Identify sources that currently collect treatment data.	
Action Plan	Recommended Implementation Steps
Identify Wisconsin sources for treatment data.	Determine method to identify treatment data collection sources.
	Complete collection and assessment of treatment data sources in Wisconsin.
Assess federal, state, local and other organizational requirements for treatment data collection.	Complete assessment of treatment data collection requirements.

STRATEGY B: Make recommendations on how to collect treatment information for Wisconsin.	
Action Plan	Recommended Implementation Steps
Assess federal, state, local and other organizational requirements for treatment data collection.	Complete assessment of treatment data collection requirements.
	Determine the major problems areas for treatment data collection in Wisconsin: Are certain treatments not being collected? Are sufficient treatments being collected but cannot be accessed by researchers? Is treatment data collection complete around the state?
Make recommendations on strategies to collect better treatment information for Wisconsin.	To be determined.

Improve Racial and Ethnic Cancer Data Collection

Rationale

Data collection for racial and ethnic variables have known limitations, including underreporting, misclassification, and incomplete data items.²⁴ Because data collection limitations are national in scope, the North American Association of Central Cancer Registries (NAACCR) provides reporting guidelines to help standardize collection of race and ethnicity variables. WCRS and the Wisconsin Cancer Council developed a poster campaign and distributed pamphlets with guidelines for reporting race and ethnicity data. Although collection of racial and ethnic data are becoming increasingly standardized through both national and state level initiatives, there are still many problems to address in meeting state and national objectives of reducing racial disparities.

Disparate Burden

See Above Rationale.

What Can Be Done?

- Publish Hispanic/Latino-specific cancer incidence and mortality rates for Wisconsin.
- Compile data from ancillary sources about cancer risk behaviors, health insurance, and cancer treatment related to cancer disparities across race and ethnic groups.

Targets for Change

HISPANIC/LATINO DATA	
Cancer incidence and mortality rates for Wisconsin	
2004 Baseline	2010 Target
N/A	Publish Hispanic/Latino cancer rates for Wisconsin.

CANCER DISPARITIES DATA	
Summary for Wisconsin	
2004 Baseline	2010 Target
N/A	Summarize available WI data applicable to racial/ethnic groups and gaps/weaknesses in data. Report findings as available.



STRATEGY A: Publish Hispanic/Latino-specific cancer incidence and mortality rates for Wisconsin.	
Action Plan	Recommended Implementation Steps
Evaluate the quality and completeness of Hispanic/Latino data capture in Wisconsin.	Seek national or other state guidance on possible quality measures for ethnicity capture.
	Examine rates for Hispanic/Latino ethnicity in Wisconsin compared to NAACCR Hispanic Monograph before and after running Hispanic surname algorithm.
	Recruit Wisconsin cancer researcher knowledgeable about Hispanic culture and cancer issues.
	Explore possible differences across Hispanic/Latino subgroups based on national origin.
Participate in future NAACCR call for Hispanic data.	To be determined.
Publish guidelines for reporting Hispanic/Latino cancer data in best way possible with caveats and identified limitations.	To be determined.

STRATEGY B: Compile data from ancillary sources about cancer risk behaviors, health insurance, and cancer treatment related to cancer disparities across race and ethnic groups.	
Action Plan	Recommended Implementation Steps
Evaluate existing cancer-related data collection programs for racial and ethnic specific information.	Look specifically at BRFSS, health insurance coverage, and treatment data.
	Summarize available data applicable to racial and ethnic groups and gaps/weaknesses in data. Report findings where race and ethnicity group composites are available.
Make recommendations for improving applicability of databases to tracking and evaluating known disparities in cancer incidence and mortality.	To be determined.

References

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