



Wisconsin Cancer Reporting System

Data Quality Task Force

Final Report

June 2015



DATA QUALITY TASK FORCE ACKNOWLEDGEMENTS

Chairs

Frank Wilson, MD, FACR, FASTRO, Director Emeritus, Medical College of Wisconsin Cancer Center

Amy Williamson, MPP, Director of Research, Cancer Health Disparities Initiative, University of Wisconsin Carbone Cancer Center

Authors

Amy Williamson, MPP, University of Wisconsin Carbone Cancer Center

Mary Foote, MS, Epidemiologist, Wisconsin Cancer Reporting System

Frank Wilson, MD, FACR, FASTRO, Medical College of Wisconsin Cancer Center

Content Contributors and Reviewers

Milda Aksamitauskas, MPP, Section Chief, Health Analytics Section, Office of Health Informatics (OHI)

Nancy Freeman, CHES, Executive Director, Wisconsin Cancer Council

Robin Malicki, Population Registries Unit Supervisor, OHI

Laura Stephenson, CTR, Quality Assurance, Wisconsin Cancer Reporting System

Mark Wegner, MD, Chief Medical Officer, OHI

Cancer Information Management Program Development

Sarah Biese, RHIT, CTR, St. Vincent Hospital, Vice-Chair, National Cancer Registrars Association

Katie Garrity, MSN, Dean of Health Education and Public Safety, Southwest Wisconsin Technical College

Kathy Loppnow, RN, MSN, Health Occupation Education Director, Wisconsin Technical College System

Funding

This publication was supported by Cooperative Agreement Award Number 5U58DP003897-03, as part of the National Program of Cancer Registries, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

Task Force Members and Guests – see Appendix 1

Many thanks to the dedicated Task Force members and external partners who gave freely of their time and resources, provided invaluable counsel and guidance, and were dedicated to improving the quality of cancer data in Wisconsin.

Contact

For questions regarding this report, contact

Mary Foote, Task Force Coordinator, at mary.foote@dhs.wi.gov



TABLE OF CONTENTS

Executive Summary.....	4
INTRODUCTION.....	5
BACKGROUND.....	7
THE WISCONSIN CANCER REPORTING SYSTEM	9
TASK FORCE PRIORITIES	13
TASK FORCE PRIORITY 1: MEET NPCR DATA QUALITY STANDARDS	13
TASK FORCE PRIORITY 2: INCREASE CTR RESOURCES/CTR UTILIZATION IN WISCONSIN	14
TASK FORCE PRIORITY 3: INCREASE CASE REPORTING RATES FOR NONHOSPITAL FACILITIES	17
TASK FORCE PRIORITY 4: INCREASE CROSS-BORDER CASE REPORTING WITH NEIGHBORING STATES....	19
CONCLUSIONS AND RECOMMENDATIONS.....	20
REFERENCES AND END NOTES	23
APPENDIX 1 Task Force Members and Guests.....	24
APPENDIX 2 Briefing Paper - Workforce Need for CTRs	27
APPENDIX 3 Wisconsin Cancer Council Merit Awards - Timeliness and Completeness.....	32



EXECUTIVE SUMMARY

The Wisconsin Cancer Reporting System (WCRS) is a population-based registry guided by statutory mandate to collect, manage and analyze data on all cancer cases for Wisconsin residents. This report summarizes the goals and outcomes of the WCRS Data Quality Task Force convened in November 2012 and ended in December 2014. The Task Force consisted of a diverse group of highly experienced and dedicated people who represented institutions of higher education, hospitals, cancer treatment centers, and other nonprofit cancer-related organizations. Task Force members typically met four times per year, at one in-person and three teleconference meetings. Their collaboration greatly benefited the WCRS on important data quality initiatives, new workforce opportunities for cancer registrars, and resource enhancement.

The Task Force was structured as a two-year, finite project with clear objectives and action steps to be completed or attempted within that timeframe. The mission of the Task Force was to improve the timeliness and accuracy of reported cancer data and ultimately better utilize cancer data. The Task Force had four priorities:

- 1) Meet National Program of Cancer Registries data quality standards in terms of timeliness, data quality and completeness.
- 2) Enhance Certified Tumor Registrar resources in Wisconsin.
- 3) Increase nonhospital reporting among target groups (dermatologists, urologists and oncologists).
- 4) Increase data exchanges with bordering states, especially certain facilities in Minnesota.

The major accomplishments of the Task Force include implementing an award system to encourage reporting systems to provide high-quality, timely data to WCRS; and increasing awareness of the value of cancer reporting data and WCRS through media and publications. The Task Force also helped to develop and launch a Cancer Information Management training program through the Wisconsin Technical College System. The Task Force supported development of comprehensive databases of targeted physician specialties in Wisconsin, which will be used to increase nonhospital reporting.

An overriding outcome of the Task Force was increased awareness and advocacy from the many stakeholders to enhance WCRS resources and public and targeted education about the purpose and value of cancer registries and the role of registrars. Former Task Force members will also continue as stakeholders in advocating for a change in policy that will increase reporting from Minnesota hospitals and thus improve cancer data available for Wisconsin border counties.



INTRODUCTION

Purpose

The Wisconsin Cancer Reporting System (WCRS) is a population-based registry guided by statutory mandate (Wisconsin Statute § 255.04, Cancer Reporting) to collect, manage and analyze data on all cancer cases for Wisconsin residents. This report summarizes the goals and outcomes of the two-year WCRS Data Quality Task Force (DQTF) convened from November 2012 to December 2014. The Task Force fulfilled a grant requirement for WCRS to convene an advisory committee. The purpose of the Task Force was to improve the timeliness and accuracy of reported cancer data and ultimately to better utilize cancer data. The Data Quality Task Force consisted of a diverse group of highly experienced and dedicated people who represent Wisconsin's institutions of higher education, hospitals, cancer treatment centers, cancer clinics and outpatient centers, and other nonprofit cancer-related organizations. Task Force members convened four times per year; their collaboration greatly benefited WCRS on important data quality initiatives ranging from recognition of facility-level achievements in reporting to legislative recommendations. Please refer to the complete member roster with a listing of participating affiliations in Appendix 1.

The Data Quality Task Force's specific mission was to advise and support the Wisconsin Cancer Reporting System in achieving its mission to collect cancer data to meet national standards in terms of timeliness, quality and completeness. Its primary goals were to:

- 1) Meet National Program of Cancer Registries (NPCR) data quality standards in terms of timeliness, data quality and completeness.
- 2) Enhance Certified Tumor Registrar (CTR) resources in Wisconsin.
- 3) Increase nonhospital reporting among target groups (dermatologists, urologists and oncologists).
- 4) Increase data exchanges with bordering states, especially certain facilities in Minnesota.

Assessment of Need

In the fall of 2012, the Data Quality Task Force identified the following deficits in meeting data quality standards.

WCRS Data Do Not Meet All National Standards for Completion

WCRS falls short of NPCR standards for data completion. WCRS 2009 data were 86 percent complete at 24 months, compared to the NPCR standard of 95 percent. WCRS 2010 data were 76 percent complete at 12 months, compared to the NPCR standard of 90 percent.



Wisconsin Has a Deficit of Certified Tumor Registrars

Approximately 130 Wisconsin hospitals report cancer data to WCRS, but only one-third are approved by the American College of Surgeons and are thus required to employ Certified Tumor Registrars (CTRs). Other hospitals and facilities rely on untrained or less qualified staff, such as medical coders, nursing staff or health care assistants, to report data to WCRS. Additionally, an estimated 300 independent physician offices and clinics do not employ CTRs and state that reporting cancer cases is beyond current staff resources. In 2006-2008, Wisconsin had an average caseload of 413 total cancer cases per CTR compared to the national average caseload of 295 per CTR. Based on a review of National Association of Cancer Registrars CTR registration lists, the Task Force found that the statewide CTR annual caseload in Wisconsin was the fifth highest in the U.S and higher than all surrounding states in the Midwest.

Most Wisconsin Physician Offices/Clinics Do Not Report Cancer Cases to WCRS

With the proliferation of clinics and physician offices, cancer is increasingly treated in outpatient settings. NPCR therefore has an objective of increasing the reporting of cancer cases from nonhospital facilities to reach the goal of 75 percent compliance by the end of the current five-year contract (2017). WCRS did not have adequate lists of independent clinics and offices to assess how close it is to meeting the NPCR goal of 75 percent nonhospital reporting among cancer-oriented specialties of dermatologists, urologists and oncologists. WCRS is aware that only 134 of approximately 380 physician offices/clinics in the targeted specialties (urology, dermatology, oncology, hematology, gastroenterology, and obstetrics/gynecology) in Wisconsin reported to WCRS in 2012 (see Table 2 on page 18).

There Is Significant Underreporting of Wisconsin Cancer Cases from Minnesota

Wisconsin currently receives cancer case reports from 19 other state central cancer registries, but not from the Minnesota cancer registry. Some Minnesota facilities report Wisconsin resident cases directly to WCRS, but others do not. For example, the Mayo Clinic in Rochester – the Minnesota facility with the largest Wisconsin resident caseload – does not have an agreement with the WCRS. WCRS has not received case data from Mayo since 2001. This results in artificially low incidence rates for many Wisconsin counties that border Minnesota.



BACKGROUND

Cancer in Wisconsin

In Wisconsin, from 2007 to 2011, an average of 30,200 residents were diagnosed with invasive cancers each year and more than 11,000 residents died of these diseases annually. For all cancer sites combined, the Wisconsin age-adjusted incidence rate was 469.5 per 100,000, compared with the national rate of 460.4 per 100,000 (SEER 18 registry national estimate). As found nationally, males in Wisconsin have higher cancer incidence rates than females; the age-adjusted incidence rate among males was 524.5 per 100,000 population, compared with the rate of 430.7 per 100,000 among females for the five-year period.

Breast cancer is the most frequently diagnosed cancer in Wisconsin females, representing 29 percent of all female cancer diagnoses. Prostate cancer is the most common cancer among males and represents 26 percent of all new cancers in males. For both sexes combined, lung cancer is the most common cancer, representing 19 percent of all cancers. Lung cancer is diagnosed in almost 4,000 Wisconsin residents each year.

Based on mortality rates, cancer surpassed heart disease as the leading cause of death in Wisconsin starting in 2007. In 2011, the cancer mortality rate was 174.9 per 100,000, compared to the heart disease mortality rate of 162.6 per 100,000. The recent five-year trend shows heart disease mortality is declining more rapidly than cancer mortality.

The 2007-2011 cancer mortality rate in Wisconsin for all sites was similar to the national rate, 174.6 per 100,000 compared with 173.8 per 100,000, respectively. Lung cancer is by far the leading cause of cancer deaths among both males and females in Wisconsin, with more than 1,600 males and more than 1,300 females dying from the disease each year.

Colorectal cancer is the second leading cause of cancer deaths in Wisconsin, with males having a higher rate of mortality than females. During 2007-2011, the male rate was 17.9 per 100,000 (491 deaths) and the female rate was 12.4 per 100,000 (468 deaths).

For the five-year period 2007-2011, the cancer mortality rate in Wisconsin was 236.1 per 100,000 for African Americans and 252.2 per 100,000 for American Indians/Alaska Natives, compared to 173.3 per 100,000 for whites. Continued WCRS surveillance is critical in monitoring disparities, trends and progress in cancer control programs.

Role and Purpose of Cancer Reporting

The purpose of the cancer registry is to consistently and accurately collect high-quality cancer information that is used for cancer control and prevention efforts and to develop new treatments and methods to improve patient care and outcomes. These data are used by health care providers, planners and researchers and are reported to state and national entities for use in determining cancer incidence and treatment trends.



Function and Importance of State Cancer Registries

Established by Congress through the Cancer Registries Amendment Act in 1992 and administered by the Centers for Disease Control and Prevention (CDC), the National Program of Cancer Registries (NPCR) collects data on cancer occurrence (including the type, extent and location of the cancer) and the type of initial treatment.

Before NPCR was established, 10 states had no registry and most states with registries lacked the resources and legislative support they needed to gather complete data. Prior to joining the NPCR, WCRS had only 3 FTE staff; WCRS was not collecting all of the NPCR required data items or following national coding standards; only 43 percent of hospitals in Wisconsin were reporting electronically, and WCRS had data exchange agreements with only 7 states. At the onset of the NPCR cooperative agreement, funding was provided to WCRS for additional staff: epidemiologist, CTR, and data quality specialist. WCRS currently follows established national standards for consistency in data collection and preparation. WCRS has data exchange agreements with 19 states.

Today, NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico and the U.S. Pacific Island Jurisdictions. These data represent 96 percent of the U.S. population.

Together, CDC's NPCR and the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program collect data for the entire U.S. population. This national coverage enables researchers, clinicians, policy makers, public health professionals, and members of the public to monitor the burden of cancer, evaluate the success of programs, and identify additional needs for cancer prevention and control efforts at national, state and local levels.



THE WISCONSIN CANCER REPORTING SYSTEM

Mandated Responsibilities

The Wisconsin Cancer Reporting System was established in 1976 to collect cancer incidence data on Wisconsin residents as mandated by Wisconsin Statute § 255.04, Cancer Reporting. The statute specifies that all cancer cases must be reported to the state cancer registry in the manner prescribed by the Wisconsin Department of Health Services. Under the statute, the Department prescribes to all reporting facilities (a) the form on which the cancer report shall be submitted, (b) the time schedule under which the report shall be submitted and (c) the types of cancer and precancerous conditions to be reported. The statute also requires that data shall remain confidential. The statute can be viewed at www.legis.state.wi.us/rsb/Statutes.html.

In 1994, WCRS was enhanced by the Cancer Registries Amendment Act (Public Law 102-515), which established the National Program of Cancer Registries. This national legislation authorized the CDC to provide funds to states and territories to improve existing cancer registries; to plan and implement registries where they do not exist; to develop model legislation and regulation for states to enhance viability of registry operations; to set standards for completeness, timeliness and quality; and to provide training.

In October 2002, Public Law 107-260, the Benign Brain Tumor Cancer Registries Amendment Act, was passed. This federal mandate requires cancer registries participating in NPCR to collect data on all benign, borderline and malignant tumors of the central nervous system in addition to the previously required data on malignant tumors. Data collection for the additional non-malignant primary and intracranial central nervous system tumors started with cases diagnosed on January 1, 2004.

Description of Current Operations

Data Collection

The Wisconsin Cancer Reporting System collects cancer incidence data on Wisconsin residents newly diagnosed with pre-invasive and invasive cancers. In compliance with state law, hospitals, physicians and clinics report cancer cases to the WCRS, in the Office of Health Informatics, Division of Public Health, Wisconsin Department of Health Services. In fulfilling the state mandate, WCRS specifies that cancer case submission be based on the "Neoplasm Record/Report" in electronic format. Hospitals are asked to report cases within six months of initial diagnosis or first admission following a diagnosis elsewhere. Clinics and physicians are expected to report cases within three months of initial diagnosis or contact. All tumors with malignant cell types are reportable except basal cell and squamous cell carcinomas of the skin and in situ cervical cancer. (For more information about reporting requirements, visit the WCRS cancer reporter's website at <http://www.dhs.wisconsin.gov/wcrs/reporterinfo/index.htm>.)

Other state cancer registries provide reports on Wisconsin residents diagnosed in their states to the Wisconsin registry under data exchange agreements with WCRS. Registry records are also matched to



the Wisconsin resident death file on a yearly basis to identify cases not reported by the regular reporting process.

For each reported cancer case, WCRS collects timely and important data such as:

- Demographic information - age, sex, race/ethnicity, county of residence at the time of diagnosis
- Tumor characteristics - date of diagnosis, primary site, cell type, stage of disease, type of diagnostic confirmation
- Treatment - cancer-directed treatment including surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy

Data Maintenance

Quality control is essential for the approximately 30,000 newly diagnosed cancer cases reported to WCRS each year. WCRS checks the accuracy of incoming data using nationally approved edits from CDC and additional edits designed by WCRS. Edit-checking is done on a case-by-case basis. Any inconsistencies or errors are resolved with the reporting facility. After the data have been edited, they are matched with the WCRS registry database. Those records that do not match are added to the system as newly diagnosed cases. Additional quality control tasks include ongoing monitoring of reporting completeness and timeliness.

Training

WCRS offers data reporting training to Wisconsin-based reporting sources through on-site visits, phone, mail, webcasts and regional training sessions. The training is ongoing and covers timeliness and completeness of reporting as well as data accuracy.

Data Use

WCRS is the sole provider of statewide population-based cancer data for Wisconsin. Data are publicly available from three online data query systems:

- Cancer-rates.info: Generate customized maps, graphs and tables of Wisconsin cancer incidence or mortality rates. <http://www.cancer-rates.info/wi/index.php>
- Wisconsin Interactive Statistics on Health (WISH) Cancer Module: Generate data tables of Wisconsin cancer incidence, mortality and stage at diagnosis. <https://www.dhs.wisconsin.gov/wish/cancer/index.htm>
- SEER*Stat Software: The National Cancer Institute SEER Program provides free software that can be used to analyze public-use datasets with national cancer incidence and mortality data and Wisconsin cancer mortality data. <http://seer.cancer.gov/seerstat/>



Data users include cancer researchers, hospital cancer registry personnel and governmental agencies (local, state and federal). In 2014, a total of 2,718 Wisconsin-specific queries were documented in Cancer-rates.info.

WCRS also fulfills special data requests for research related to cancer prevention or control. WCRS is able to provide this service to researchers under strict guidelines. Protecting patient confidentiality is required by state law under Wisconsin statute § 255.04. WCRS data containing personal identifiers or information on very small geographic areas can only be released for research approved by an institutional review board, with additional approval from the Wisconsin Department of Health Services Data Governance Board.

Reports and Publications

WCRS prepares publications in several formats, including Department of Health Services publications, WCRS Data Bulletin, and collaborative reports with the American Cancer Society, the Wisconsin Comprehensive Cancer Control Program, and other state-level cancer organizations and university systems. Examples include *Wisconsin Cancer Facts & Figures 2013-2014*. For a complete listing, see <https://www.dhs.wisconsin.gov/wcrs/publications.htm>.

WCRS also contributes data to the major national publications *Cancer in North America* (North American Association of Central Cancer Registries) and *U.S. Cancer Statistics* (CDC).

WCRS Reporting Relationships/Partnerships

Since 1994, WCRS has received federal funding from CDC's National Program of Cancer Registries with a three-to-one federal-to-state dollars match. Federal funding constitutes 80 percent of all WCRS funds. WCRS must meet the standards and requirements established by this organization to ensure future funding.

Specifically, CDC funds the Wisconsin Department of Health Services to conduct the Wisconsin Cancer Prevention and Control Program (WCPCP). This grant includes three programs--the Wisconsin Comprehensive Cancer Control Program (WCCCP), the Wisconsin Well Woman Program (WWWP) and WCRS--which have worked collectively on cancer prevention and control efforts for more than nine years. Dr. Mark Wegner, Principal Investigator for the WCPCP, was a member of the Task Force, and the Task Force was staffed by both WCRS and WCCCP senior staff. The Wisconsin Cancer Council is integrated closely with the three grant programs, and helps implement the WCCCP objectives.

Publications from the three programs have been coordinated to cover crosscutting objectives and provide results of projects that address WCPCP primary objectives. The publication *Wisconsin Cancer Facts & Figures 2013-2014* was a collaborative project of the three programs and the American Cancer Society. The WCRS and WCCCP epidemiologists jointly prepare reports for a variety of publications, including the WCCCP Issue Briefs, chronic disease reports and journal articles. WCCCP routinely uses data from the WCRS to monitor cancer burden and make adjustments to program activities in the Wisconsin Comprehensive Cancer Control Plan.



WCRS staff are members of the Wisconsin Cancer Registrars Association and the National Cancer Registrars Association to maintain professional alliances and regularly network about local and facility-level reporting experiences. WCRS is also an active member in the Wisconsin Cancer Council (WCC) and participates in statewide coordinated programs and activities, interacting with other professional members including staff from reporting facilities involved in statewide cancer control programs. A WCRS staff person serves as an ex-officio member of the WCC Steering Committee, which consists of 19 members that meet quarterly. The Steering Committee provides overall leadership and oversight for the WCC.

Comparative Staffing Data

In 2013, the Journal of Registry Management published results from a survey conducted by NPCR and the National Cancer Registrars Association.¹ The survey found that the number of FTEs performing core state registry activities (abstracting, editing, case consolidation, resolving edits) averaged 12 FTEs. This estimate did not include data analysis, data requests or other non-essential but common registry activities. WCRS has had 6 FTE staff since 1997 and 7 since 2013. Neighboring states of Minnesota and Illinois have 28 and 25 FTE staff, respectively.

Unmet Registry Requirements

The rapidly growing demands for timely, accurate and detailed registry data have created challenges to addressing one of the greatest burdens in health care for Wisconsin citizens. At current staffing levels, WCRS is unable to meet several labor-intensive requirements:

- 1) NPCR's timeliness requirement stipulates that facilities report cases within six months of diagnosis. Currently, Wisconsin has very few facilities that report in this timeframe. For example, in the spring of 2014, WCRS received 450 new reports for 2010 diagnoses, 422 for 2011 diagnoses, and 1,244 for 2012 diagnoses. This is a problem for surveillance reports and research of aggressive cancers.
- 2) Auditing at reporting hospitals is required by NPCR once every five years; this requires Certified Tumor Registrars (CTRs) from state cancer registries to visit reporting facilities, audit medical records, re-abstract cases and work with cancer reporters. Auditing confirms that all cases are being reported and that cases are being abstracted correctly.
- 3) WCRS does not collect pathology lab reports for cancer cases, even though pathology lab reporting is required in Wisconsin statute in addition to being supported by NPCR guidelines. This is important because state registries find cases not reported by facilities from pathology lab reports; almost all cancers are microscopically confirmed.
- 4) Cancer diagnosis and treatments are increasingly occurring outside of hospitals in clinics and physician offices. NPCR requires a 10 percent annual increase in nonhospital reporting, and 75 percent compliance by the end of the NPCR grant period. Many independent, freestanding clinics and physician offices do not routinely report cancer cases; and WCRS must identify and contact them, train office staff, offer reporting software from CDC, and monitor data quality.



TASK FORCE PRIORITIES

The mission of the Data Quality Task Force was to address four priorities. Following is a summary of need, strategies and outcomes for each priority.

TASK FORCE PRIORITY 1: MEET NPCR DATA QUALITY STANDARDS

National Program of Cancer Registries Standards

NPCR has established data quality standards² for state cancer registries requiring that reported cases be 90 percent complete at 12 months after the date of diagnosis and 95 percent complete at 24 months after the date of diagnosis. To meet this standard, Wisconsin specifies that cases should be reported to the central cancer registry within six months of diagnosis by reporting facilities.

Current Status

The Task Force determined that WCRS was not meeting NPCR standards for data quality:

- **Timeliness** - For 2010 through 2012, the average number of WCRS cases received within 6 months was only 48 percent; 32 percent were received within 7-15 months, and 20 percent were received after 15 months. (For the years 2006-2008, only 56 percent of cases were received at the six-month juncture.)
- **Completeness** – WCRS 2010 data were only 76 percent complete at 12 months. WCRS 2009 data were only 86 percent complete at 24 months. Completeness estimates are based on prior annual data submissions to CDC and case volume estimates from reporting facilities. This does not address nonhospital/physician offices and clinics that have not reported cancer cases to WCRS.

The Task Force also measured missing stage at diagnosis. For 2010 data, 1,698 cancer cases (5.6 percent of total) were reported with “unknown” stage at the time of diagnosis in the final dataset. For some Wisconsin counties, over 20 percent of the cases were reported with unknown stage at diagnosis.

Strategies for Increasing Data Quality

The Task Force implemented two strategies to increase compliance with reporting requirements: develop an award system to provide an incentive for reporting facilities; and increase awareness of the need for high-quality data through more media coverage.

Task Force Outcomes

The Task Force developed an annual award system for outstanding facilities in terms of timeliness, completeness and data accuracy. The goal of the award system is to provide incentive for facilities to improve their reporting. The award program is administered by the Wisconsin Cancer Council (WCC).

Under the standards outlined in Table 1, WCC recognized 24 facilities in 2014 for timeliness of case reporting through new merit awards. Of the 24 facilities receiving timeliness awards, 1 received



Platinum, 11 received Silver, and 12 received Honorable Mention. The WCC also recognized 70 facilities for completeness of reporting 2012 cases, under the Merit Award program. Of the 70 facilities that received completeness awards, 46 received Platinum, 14 received Gold, and 10 received Silver.

Table 1. Cancer Data Quality Merit Award Program Standards for Timeliness and Completeness

Timeliness of Case Reporting	
Platinum	95 percent of cases received September 2013–August 2014 were within 6 months of diagnosis (or first seen, if diagnosed at a different facility)
Gold	95 percent of cases received within 9 months
Silver	95 percent of cases received within 12 months
Honorable Mention	90 percent of cases received within 12 months
Completeness of Case Reporting	
Platinum	100 percent of 2012 cases were received by August 2014 (percent = number of cases submitted compared to annual estimated caseload)
Gold	95 percent of cases received
Silver	90 percent of cases received

In October 2014, the Cancer Data Quality Merit Awards were presented at the Wisconsin Cancer Council Annual Meeting; reported in the Wisconsin Cancer Council newsletter and on its website; and announced at the annual Wisconsin Cancer Registrars Association Meeting (see Appendix 3).

The Task Force also collaborated to promote awareness of reporting requirements through several publications. In 2014, the Wisconsin Medical Society Medigram featured an article highlighting the collaborative publication *Wisconsin Cancer Facts & Figures 2013* and explaining the physician reporting requirement.³ In addition, the Task Force targeted rural facilities by publishing two articles in the Rural Wisconsin Health Cooperative newsletter in 2014. Rural facilities generally treat a smaller volume of cancer patients and have fewer resources for reporting cancer data to WCRS. One article focused on the importance of cancer reporting⁴ and the other featured the impact of WCRS data on an Adams County cancer collaboration.⁵

TASK FORCE PRIORITY 2: INCREASE CTR RESOURCES and CTR UTILIZATION IN WISCONSIN

Current Status of CTR Workforce

Role of Certified Tumor Registrars

Certified Tumor Registrars (CTRs) are professionals who are credentialed to collect and submit cancer data to state and national cancer registries to enable cancer programs to accurately determine cancer



patient populations and measure outcomes of treatment and survival, among other uses. Cancer registrars are vital contributors to cancer treatment teams, researchers and health care planners. They collect, manage and disseminate data on the location of the cancer in the body, the type of cancer, the extent or spread of the disease, and the treatments provided to the patient. The CTR's primary task is abstraction – a detailed review of the patient's medical record in which the registrar identifies specific data elements needed to accurately describe the patient's cancer and course of care. The registrar applies a comprehensive set of coding rules and enters the data into a specialized database. Other tasks the cancer registrar performs include casefinding, follow-up, quality control and data analysis.

CTR certification is the required registry credential for American College of Surgeons approved cancer programs and is increasingly in demand for all cancer registries.

Educational Eligibility Requirements for CTR Exam

Nationally, industry leaders and standard setters increased educational requirements for cancer registrars in 2010. In 2008-2009, there was a phase-in of the new educational requirement requiring courses in anatomy and physiology, medical science/biology, and medical terminology. This culminated in 2010 with the minimum requirement of an Associate's Degree (four semesters). The additional requirements resulted in fewer candidates in 2011: 316 candidates nationally compared to over 600 candidates in 2007. The CTR credential is awarded to cancer registry professionals who pass the National Cancer Registrars Association's (NCRA) certification examination.⁶ The NCRA Council on Certification sets eligibility requirements for the exam. In 2012, only 373 candidates in the U.S. took the CTR final exam, with 262 first-time candidates. There were only 4 CTR candidates in Wisconsin in 2012.

According to NCRA, of all new CTRs, 73 percent were employed by hospital registries. The second-largest employer in 2012 was central state registries, employing 13 percent of newly certified CTRs.⁷

Only a dozen education programs designed to meet the NCRA requirements are offered in the United States. Many of these offer online coursework in Cancer Information Management (CIM) via the Internet, making it convenient for CIM candidates who have already completed some of the required coursework in a Health Information Technology (HIT) program and who are presently working in the field. The CIM program and the HIT program share many of the same required courses in IT. Unfortunately, there are a limited number of online programs and many have waiting lists. In Wisconsin, no academic program of preparation for the cancer registrar profession existed at the start of the Task Force in 2012.

CTRs in High Demand, but Short Supply

According to the National Cancer Registrars Association,⁸ the average age of current cancer registrars is 50 years; more than 60 percent are 50 years of age or older, so many registrars are expected to retire in the near future. Given the aging of the population, with the resulting increase in cancer diagnoses, and the level of detail required in data for cancer prevention, diagnosis and treatment, the CTR shortage and demand for CTRs will only increase over time.



In response to this workforce shortage, NCRA formed a recruitment and retention task force and national advisory committee, and in 2011 conducted two workforce studies. One of the studies found an average staffing level of 12.4 FTEs among central state cancer registries. The second study of hospital cancer registries found an average of 1.6 CTRs for registries with 100-500 cases annually and an additional CTR for each additional 500 cases.⁹

Approximately 130 hospitals report cancer data to WCRS, but just under half employ CTRs (40 American College of Surgeons Commission on Cancer (ACoS) approved hospitals and another 20 non-ACoS approved hospitals). Additionally, most of the estimated 300 independent physician offices and clinics do not currently employ CTRs, with a large percentage of them stating that reporting cancer cases is beyond current staff resources. Wisconsin has only 70 CTRs (June 2013) and an annual average caseload of 413 total cancers per CTR, compared to the national average caseload of 295 per CTR. This caseload was fifth highest in the U.S and higher than all surrounding states in the Midwest.

New Professional Opportunities

According to a NCRA workforce study,¹⁰ employment of medical records and health information technicians is expected to increase by 21 percent through 2020, much faster than the average for all occupations. The mean annual wage of cancer registrars and abstractors is \$50,599. CTRs make a mean salary of \$63,000 annually, compared to \$48,920 for registrars who are not certified – a difference of 29 percent.

The current workforce deficit calls for the development of a new specialization in Certified Tumor Registrar/Cancer Information Management at universities and technical colleges. This specialization would include required courses in anatomy and physiology, medical terminology, and information science and would result in an Associate's Degree. Students with a two-year technical degree, such as the Health Information Technology degree, may have already fulfilled some of the required prerequisites and could transfer qualifying credits from the two-year degree to the CTR degree. Educational institutions could provide online degree plans, including courses specific to cancer registrars.

These new programs would provide an excellent opportunity to attain an Associate's Degree (60 credits) and complete experience in the field (12 months). Students completing the CTR certification will qualify for employment in hospital cancer programs, cancer treatment centers, oncology physician group practices, state and federal cancer registries, military and VA hospitals, companies providing cancer registry software, contract registrar companies, and pharmaceutical companies.

Strategies for Promoting the Cancer Registrar Workforce

Based on review of these workforce data, the Task Force concluded that in Wisconsin, the lack of a formal education track for the cancer registry profession and the shortage of trained and certified staff affects the ability of Wisconsin facilities to report their data with the required accuracy and timeliness.



To meet these needs, the Task Force implemented several strategies to promote the development of an academic Cancer Information Management program and the CTR profession more generally.

As a first step, Task Force members developed a CTR workforce briefing paper (Appendix 2), which they disseminated to Task Force members and potential collaborators. Subsequently, beginning in September 2013, Task Force members collaborated with representatives of the Wisconsin Department of Health Services Workforce Program and the Wisconsin Technical College System to explore options for developing CTR training. This led to a connection to the Health Education Department at Southwest Technical College in Fennimore, Wisconsin, and the identification of that college's interest in exploring a CTR program. The group of partners collaborated to explore curriculum requirements, paths to certification, salary levels and CTR job descriptions. The partners then presented a proposal to create a Cancer Information Management program to the Southwest Technical College Education Board and the Wisconsin Technical College System Education Board, including letters of support provided by the Task Force and organizations represented on the Task Force. The program was approved in the summer of 2014 for launch in the fall 2014 semester.

Outcomes

The Cancer Information Management Program was launched in September 2014 as an online education program offered through Southwest Wisconsin Technical College. It can be completed at any location in the state. The new CTR education program offers an Associate's Degree and is the only one of its kind in Wisconsin and one of only a few in the United States. In 2014 there were only four NRCA-accredited associate education programs in the United States; the new Cancer Information Management program in Wisconsin expects to obtain NCRA accreditation. Information about the program can be found at <https://www.swtc.edu/academics/programs/health-occupations/cancer-information-management>.

In recognition of the new Cancer Information Management Program, the Wisconsin Cancer Council awarded the Outstanding Leadership and Partner Collaboration Achievement Award to the Southwest Technical College of Wisconsin, the Wisconsin Technical College System, and the Wisconsin Cancer Reporting System.

TASK FORCE PRIORITY 3: INCREASE CASE REPORTING RATES FOR NON-HOSPITAL FACILITIES

New NPCR Standards for Clinics/Physician Offices

NPCR standards require funded states to have "A means to assure the complete reporting of cancer cases to the statewide cancer registry by physicians, surgeons and all other health care practitioners diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that state and reported by those facilities."¹¹ Individual state laws vary in how the physician reporting



requirements are implemented. While all physicians may be required to report according to state law, NPCR Program Standards (effective 2012-2017)¹² target the following goals:

- Annually increase the percent of urologists, dermatologists and gastroenterologists that report to the central cancer registry, as required by state law, in order to meet the goal of having at least 75 percent of these physicians reporting by the end of each five-year project period.
- Annually increase the percent of medical oncologists, radiation oncologists and hematologists that report to the central cancer registry, as required by state law, in order to meet the goal of having at least 90 percent of these physicians reporting by the end of each five-year project period.

Current Status of Reporting Compliance

Table 2 presents WCRS’s estimate of existing and potential sources of cancer cases in 2012. It shows that only 134 physician offices/clinics in the targeted specialties are currently reporting to WCRS. At least 246 do not report their cases to WCRS. Note that the total number of eligible facilities is unknown.

Table 2. Existing and potential sources of cancer cases – Wisconsin, 2012

Type of Reporting Source	Total Number of Facilities	Number Currently Reporting to WCRS	Number Not Reporting to WCRS (potential source)
Wisconsin ACoS Hospitals (non-federal)	40	40	0
Wisconsin Non-ACoS Hospitals (non-federal)	93	93	0
Wisconsin Stand-Alone Pathology Laboratories	128	0	128
Wisconsin Radiation Centers	3	3	0
Wisconsin Physician Offices/Clinics*	~380	134	246
Wisconsin VA Hospitals	3	3	0
Wisconsin Tribally Owned Health Centers	12	2	10
Wisconsin Ambulatory Surgery Centers**	40	30	10
Wisconsin Nursing Homes	~400	5	~395
Out-of-State Laboratories	~12	5	~7
Out-of-State Central Cancer Registries	49	19	30
Minnesota Hospital w/Data Agreements	30	4	26

* Includes urology, dermatology, oncology, hematology, gastroenterology, OB/GYN.

** Most of Wisconsin’s ambulatory surgery centers are reported through hospitals.

Physician offices, clinics and ambulatory surgery centers are not monitored by any central statewide regulatory agency; therefore, the number of these facilities is undercounted.



Strategies for Increasing Compliance

NPCR provides recommendations to state cancer registries for increasing physician reporting, ranging from assembling an advisory group (such as the Task Force) to communicating with other central registries to exchange best practices. The Task Force advised WCRS to focus on identifying physicians/practices in two target specialties—dermatologists and urologists—essentially, compiling a comprehensive list of physicians in the state.

Outcomes

With Task Force oversight, in 2014 WCRS first compiled and consolidated a list of 350 dermatology physicians in Wisconsin, assumed to treat cancer patients outside the hospital setting, based on 4 major independent dermatologist data sources:

- The Wisconsin Department of Safety and Professional Services' database of licensed physicians (MDs and DOs)
- The National Provider Inventory (NPI) of the Centers for Medicaid and Medicare Services
- The 2014 roster of members of the Wisconsin Dermatological Society
- Web pages for physician group practices for which links were provided by the Wisconsin Department of Health Services (<http://www.dhs.wisconsin.gov/guide/find/doctor.htm>)

In 2015, WCRS will send introductory letters to nonreporting clinics from this list, including a questionnaire to ascertain the number of cancer cases diagnosed or treated and available resources at the facility for reporting. The mailing will also include a copy of *Wisconsin Cancer Facts & Figures*, highlighting the melanoma chapter, which relies heavily on nonhospital reporting, as an example of the value of reporting cancer cases to WCRS.

TASK FORCE PRIORITY 4: INCREASE CROSS-BORDER CASE REPORTING WITH NEIGHBORING STATES

Current Status

Wisconsin currently receives cancer case reports from 19 other state central cancer registries, but not from the Minnesota cancer registry, the Minnesota Cancer Surveillance System (MCSS). State statutes governing MCSS, as currently interpreted, do not allow it to share data with other state cancer registries. WCRS currently has contractual agreements with 30 Minnesota facilities to report Wisconsin resident cases directly to the Wisconsin central registry. However, facilities vary in their level of compliance with these agreements and WCRS has no statutory authority over Minnesota facilities. Of particular importance, the Mayo Clinic in Rochester – the Minnesota facility with the largest Wisconsin



resident caseload – does not have an agreement with WCRS. Mayo Clinic does not report Wisconsin cancer cases to MCSS.

MCSS has a restriction that data can only be used for purposes listed in Minnesota statute. The Minnesota Attorney General has indicated that without an interstate compact enacted by both state legislatures, assuring privacy protections required by Minnesota, identifiable data cannot be shared. Discussion with Mayo clinic staff indicate that the clinic is concerned about the Minnesota privacy rule stating that medical records cannot be shared without specific legal mandate. Mayo Clinic estimates that from 2008 to 2010, it collected a total of 2,982 Wisconsin resident cancer cases, of which 1,909 were analytic¹³ (diagnosed and/or treated at the Mayo Clinic) and 1,073 were non-analytic.¹⁴ This means that at least two-thirds of the Wisconsin cases at Mayo (the analytic cases) would probably not be reported to WCRS by any other facilities.

The WCRS Data Bulletin *Wisconsin Northwestern Counties with Apparent Low Cancer Incidence Rates Due to Underreporting of Cancer Cases Treated at Minnesota Facilities*¹⁵ illustrates the result of incomplete reporting from Minnesota. In 11 northwestern Wisconsin counties, cancer incidence rates are lower than the overall Wisconsin incidence rate, but mortality rates are consistent with the statewide mortality rate – indicating that not all cancer cases in these counties were reported to WCRS.

Outcomes

Task Force members initiated discussions with Mayo Clinic staff to address this problem but no progress in receiving Wisconsin resident case reports from Mayo was achieved by the end of the Task Force in December 2014.

CONCLUSIONS AND RECOMMENDATIONS

The Data Quality Task Force succeeded in laying the foundation for future improvements in Wisconsin cancer data available for health care providers, health planners, advocates, researchers, policy makers, and the general public. It has implemented steps to make cancer reporting more timely and complete, enhance Certified Tumor Registrar resources, and increase nonhospital reporting to the registry.

Task Force members are committed to continuing to support WCRS. Improved cancer data will encourage dissemination of cancer information for public health education and increase public knowledge of available diagnostic, screening and treatment opportunities. The strengthened cancer registry will provide researchers with more timely and accurate cancer data. A stronger WCRS will be better able to support the efforts of other statewide programs (e.g., Wisconsin Comprehensive Cancer Control Program, Healthiest Wisconsin 2020) to more effectively set and accomplish program objectives. Finally, a strong WCRS will enable the registry to meet NPCR standards and requirements for central cancer registries, thus ensuring its ability to secure federal funding for years to come. Recommendations for future activities include communications and education.



Communications

The Task Force identified a continuing need for education about the purpose, function and value of cancer registries and the role of registrars. Audiences with greatest potential interest are cancer reporters and reporting facilities; end users of data for cancer prevention, control and research; state agency officials; and state and national cancer organizations. In addition, the Task Force identified the value of education on the importance of the cancer reporting system to health care providers and systems seeking to develop new treatments and methods to improve patient care and outcomes. Below is a list of specific strategies for advocates who seek to increase WCRS data quality and enhance WCRS resources.

- Development of a toolkit to support education efforts. This will include compelling arguments and personal stories of the value of cancer reporting data.
- Continued collaboration between WCRS, American Cancer Society and Wisconsin Cancer Council to enhance public perception of WCRS.
- Distribution of announcements to reporters and cancer registrars about the Cancer Information Management Program at Southwest Wisconsin Technical College.
- Media messages about the cancer registrar profession as a promising career.
- Periodic revision of the WCRS website to promote program reports and special publications.
- Use of traditional and social media to reach the target audience and general public about cancer prevention and control opportunities.
- Newsletters and bulletins to reporting facilities with announcements and updates.
- Dissemination of special publications that report on the impact of cancer control programs.
- Letters to health care and facility administrators to educate about the impact of timely cancer data on program-related objectives.
- Information about available WCRS data and publications for public health education and cancer control programs.

Policy Recommendations

Task Force members will continue to leverage their networks and organizational resources to increase the capacity of WCRS to consistently and accurately collect high-quality cancer information and to share that information with health care providers, planners, researchers, and other decision makers to support cancer control and prevention and to develop new treatments and methods to improve patient care and outcomes.



Improve Availability of WCRS Data

WCRS and the WCCCP will collaborate to develop a comprehensive list of cancer data resources for data users and requestors: data query systems, state and national publications, data request tracks for specific subjects, and journal publications. Wisconsin data submitted to NAACCR and CDC are available in national data query systems and publications not currently featured on the WCRS website. The data portal would offer comprehensive guidance for accessing and using an increasing number of cancer data sources.

Advocate for Minnesota Reporting of Wisconsin Cancer Cases

The Mayo Clinic reporting deficit rests upon the current interpretation of the Minnesota statute as prohibiting release of Wisconsin cancer cases to WCRS. The Task Force concluded that the Minnesota statute should be revised accordingly to allow release of data for Wisconsin residents receiving cancer care in Minnesota. The Task Force recommends that the Wisconsin Department of Health Services and partner organizations continue to work together on Mayo Clinic reporting, as follows.

- Promote discussion between the Wisconsin and Minnesota Attorneys General.
- Promote change through the Wisconsin Cancer Council and the Minnesota Cancer Alliance.
- Request that the Administrator of the Wisconsin Division of Public Health discuss the problem with the Minnesota public health administrator.
- Promote change through the Wisconsin chapter of the Wisconsin American Cancer Society's contacts with the Minnesota chapter of the American Cancer Society, Mayo Clinic and Minnesota Cancer Surveillance System.



REFERENCES AND END NOTES

- ¹ NCRA/NPCR Workload and Time Management Study: Guidelines for Central Cancer Registry Programs, May 2013. http://www.ncra-usa.org/files/public/Central_Summary2013_Final.pdf
- ² http://www.cdc.gov/cancer/npcr/pdf/npcr_standards.pdf
- ³ <https://www.wisconsinmedicalsociety.org/resources/medigram/current-issue/medigram-january-16-2014/report-shows-decline-in-wisconsin-cancer-incidence-and-mortality-rates/>
- ⁴ <http://www.rwhc.com/Portals/0/EOH14/May.pdf>
- ⁵ <http://www.rwhc.com/Portals/0/EOH14/February.pdf>
- ⁶ <http://www.ncra-usa.org/i4a/pages/index.cfm?pageid=3864>
- ⁷ NCRA Workload and Staffing Study Guidelines for Hospital Cancer Registry Programs, January 2011 http://www.ncra-usa.org/files/public/NCRAWorkloadStaffing_Summary.pdf
- ⁸ http://www.ncra-usa.org/files/public/NCRASalaryConsiderations_May2013.pdf
- ⁹ NCRA Workload and Staffing Study Guidelines for Hospital Cancer Registry Programs, January 2011 http://www.ncra-usa.org/files/public/NCRAWorkloadStaffing_Summary.pdf
- ¹⁰ *ibid*
- ¹¹ The statute can be viewed at <http://www.cdc.gov/cancer/npcr/amendmentact.htm>
- ¹² The standards can be viewed at http://www.cdc.gov/cancer/npcr/pdf/npcr_standards.pdf
- ¹³ Analytical Case: Case diagnosed and/or receiving all or part of the first course of therapy at the facility.
- ¹⁴ Non-analytical Case: Case diagnosed and receiving the first course of therapy elsewhere prior to the date of referral to the facility; case diagnosed at autopsy.
- ¹⁵ WCRS Data Bulletin Wisconsin Northwestern Counties with Apparent Low Cancer Incidence Rates Due to Underreporting of Cancer Cases Treated at Minnesota Facilities: <https://www.dhs.wisconsin.gov/publications/p0/p00243.pdf>



Appendix 1

WCRS Data Quality Task Force (DQTF) Members and Guests

DQTF Officers

J. Frank Wilson, MD, FACR, FASTRO

DQTF Chair

Chairman and Bernard & Miriam Peck Family Professor of Radiation Oncology
Director Emeritus, Medical College of Wisconsin Cancer Center

Amy Williamson, MPP

DQTF Chair

Assistant Director of Population Sciences
Director for Research Program Development, Cancer Health Disparities Initiative
University of Wisconsin Carbone Cancer Center

DQTF Members

Sara Biese, RHIT, CTR

Cancer Registry Coordinator
St. Vincent Hospital
Vice-Chair, National Cancer Registrars Association
National Education Foundation Board of Directors

Beth Brunner

Wisconsin Director of Healthcare Partnerships
Wisconsin Midwest Division, American Cancer Society

Kelly Court

Chief Quality Officer
Wisconsin Hospital Association

Richard Ellis, MD

Director of Breast Imaging Section
Gundersen Lutheran Medical Center

Kathy Farnsworth

Public Policy Coordinator
Wisconsin Comprehensive Cancer Control Program

Nancy Freeman, CHES

Executive Director
Wisconsin Cancer Council



Amy Godecker, PhD

Director, Survey Research Shared Resource
UW Carbone Cancer Center

Robert Greenlee, MPH, PhD

Research Scientist
Marshfield Clinic Research Foundation

Cara Jones, RHIT

Utilization Review/Clinical Information
The Richland Hospital Inc
Rural Wisconsin Health Cooperative

Robert Millholland, CTR

Cancer Registry Manager
University of Wisconsin Hospital and Clinics

Keith Novenski

Project Leader, Cancer Services
ThedaCare

Adedayo Onitilo, MD, MSCR, FACP

Marshfield Clinic

Lisa Robinson, RHIA, CTR

Director, Clinical Data Registries
Aurora Health Care CIS Dept

Amy Trentham-Dietz, PhD

Associate Professor, Principal Investigator
UW Carbone Cancer Center

Mark Wegner, MD, MPH

Chronic Disease Medical Director
Division of Public Health
Wisconsin Department of Health Services

WCRS/Office of Health Informatics Staff:

Mary Foote, MS

DQTF Coordinator and Epidemiologist
Wisconsin Cancer Reporting System
Division of Public Health
Wisconsin Department of Health Services



Laura Stephenson, CTR

Quality Assurance
Wisconsin Cancer Reporting System
Division of Public Health
Wisconsin Department of Health Services

Milda Aksamitauskas, MPP

Section Chief, Health Analytics Section
Office of Health Informatics
Division of Public Health
Wisconsin Department of Health Services

DQTF Partners/Guests:

Katie Garrity, MSN

Dean of Health Education and Public Safety
Southwest Wisconsin Technical College

Kathy Loppnow, RN MSN

Health Occupation Education Director
Wisconsin Technical College System



Appendix 2

Briefing Paper – Workforce Need for Certified Tumor Registrars (CTRs)

I believe that the quality of data collected by a CTR is equally as important as patient care. If we want to understand our care, to analyze it and improve outcomes, then we must have good data. And the quality of the registrar professional is vitally important to having this quality data.

Manager of accreditation and standards, American College of Surgeons, Asa Carter, CTR

Role of Certified Tumor Registrars (CTRs)

Cancer registrars, or Certified Tumor Registrars (CTRs), are vital contributors to cancer treatment teams, researchers, and health care planners. They collect, manage and disseminate data on the location of the cancer in the body, the type of cancer, the extent or spread of the disease and the treatments provided to the patient. The primary task that a Cancer Registrar performs is a process called *abstracting* which requires a detailed review of the patient's medical record where they identify specific data elements needed to accurately describe the patient's course of care. A comprehensive set of coding rules are applied and the data is entered into a specialized database. Other tasks the cancer registrar performs include: *casefinding, follow-up, quality control and data analysis.*

Ultimately, the purpose of the cancer registry is to consistently and accurately collect high-quality cancer information that is used for cancer control and prevention, and to develop new treatments and methods to improve patient care and outcomes. These data are used by health care providers, planners and researchers, and are reported to state and national entities for use in determining cancer incidence and treatment trends. CTR certification is the required registry credential for American College of Surgeons (ACoS) approved cancer programs, and increasingly in demand for all cancer registries.

Wisconsin Cancer Data Quality Task Force

In the fall of 2012, the Data Quality Task Force addressed the well documented shortage of CTRs in Wisconsin and the delays in reporting cancer data to the central state cancer registry, Wisconsin Cancer Reporting System (WCRS). The Data Quality Task Force, included representatives from the Wisconsin Registrars Association, American Cancer Society, Wisconsin Cancer Council, UW Carbone Cancer Center, Marshfield Clinic, and the Wisconsin Hospital Association.

In Wisconsin, the task force addressed serious problems with both timeliness and accuracy of reported cancer data. The task force concluded that the lack of a formal education track for the cancer registry profession and the shortage of trained and certified staff impacted the ability of the Wisconsin institutions to report their data with the required accuracy and timeliness.



Educational and Eligibility Requirements for CTR Exam

Today's cancer registrar is challenged to perform a high-level, analytical function within the comprehensive cancer programs and become skilled in electronic records transmission. As a relatively new profession, cancer registrars have a challenging road ahead. To address these challenges, industry leaders and standard setters increased education requirements for the field. There was a phase-in of the new educational requirement during 2008-2009, requiring courses in anatomy and physiology, medical science/biology and medical terminology. This culminated with the minimum requirement of an associate's degree (4 semesters) in 2010. The additional requirements resulted in fewer candidates in 2011, only 316 candidates, compared to over 600 candidates in 2007. The CTR credential is awarded to cancer registry professionals who pass National Cancer Registrars Association's (NCRA) certification examination. The NCRA Council on Certification sets eligibility requirements for the exam. Table 1 shows the current paths for CTR certification, or eligibility requirements for taking the CTR exam. In 2012, only 373 candidates in U.S. took the CTR final exam, with 262 first time candidates (Map 1) and there were only 4 CTR candidates in Wisconsin.

Designed to meet the NCRA requirements for students interested in entering the cancer registry profession, there are only a dozen education programs offered throughout the United States. Many offer online coursework in Cancer Information Management (CIM) via the internet, making it convenient for individuals who have already completed a CIM or HIT program and are presently working in the field. Unfortunately, the limited number of online programs have waiting lists, and do not begin to address the current shortage.

Table 1 NCRA Eligibility Requirements for CTR Exam

Route A – Path A1:

- Education minimum (Associate Degree or equivalent – 60 college-level credits)
- Completion of an NCRA-Accredited Formal Education DEGREE Program
- 160-hour practicum in a CTR-staffed cancer registry

Route A – Path A2:

- Education minimum (Associate Degree or equivalent – 60 college-level credits)
- Completion of an NCRA-Accredited Formal Education CERTIFICATE Program
- 160-hour practicum in a CTR-staffed cancer registry

Route B

- Education minimum (Associate Degree or equivalent – 60 college-level credits)
- Coursework of two semesters of 'Human Anatomy & Physiology' or equivalent
- 1950 hours (equivalent to one year full-time) experience in the Cancer Registry field

In 2012, 26 percent of candidates selected eligibility Route A; Route B was selected by 74 percent of candidates in 2012. The primary place of employment for 71 percent of new CTRs in 2012 was hospital registries. The second-largest employer in 2012 was central state registries, employing 13 percent of newly certified CTRs.



CTRs in High Demand, but Short Supply

The average age of the current cancer registrar is 50 years, and over 60 percent are 50 years of age or older, so many of these individuals are expected to retire in the near future. Given the aging of the population, with the resulting increase in cancer diagnoses, the level of detail required in data for cancer prevention, diagnosis, and treatment will accelerate the current shortage.

In response to this workforce shortage, the National Cancer Registrars Association (NCRA) formed a recruitment and retention task force and national advisory committee. NCRA conducted two workforce studies. The results of one study summarized among central state cancer registries, an average staffing level of 12.4 FTEs. WCRS has 6 FTEs with one CTR. The second NCRA study of hospital cancer registries, reported 1.6 CTRs for registries with 100-500 cases, and an additional CTR for each additional 500 cases

Approximately 120 hospitals report cancer data to WCRS, but only one-third or 40 hospitals (College of Surgeons approved) employ CTRs. Additionally, an estimated 300 independent physician offices and clinics do not currently employ CTRs and state that reporting cancer cases is beyond current staff resources. The state of Wisconsin has only 70 CTRs (June 2013) and an annual average cancer case count (2006-2010) of 28,923, resulting in a high caseload of 413 total cancers per CTR, compared to the national average caseload of 295 per CTR. Cancer cases are reported by more than one source so the approximately 50,000 reports are completed each year for consolidation to the final 28,923 cancer cases. The statewide CTR annual caseload in Wisconsin, based on new cancer cases, was fifth highest in the U.S. and higher than all surrounding states in the Midwest.

New Professional Opportunities

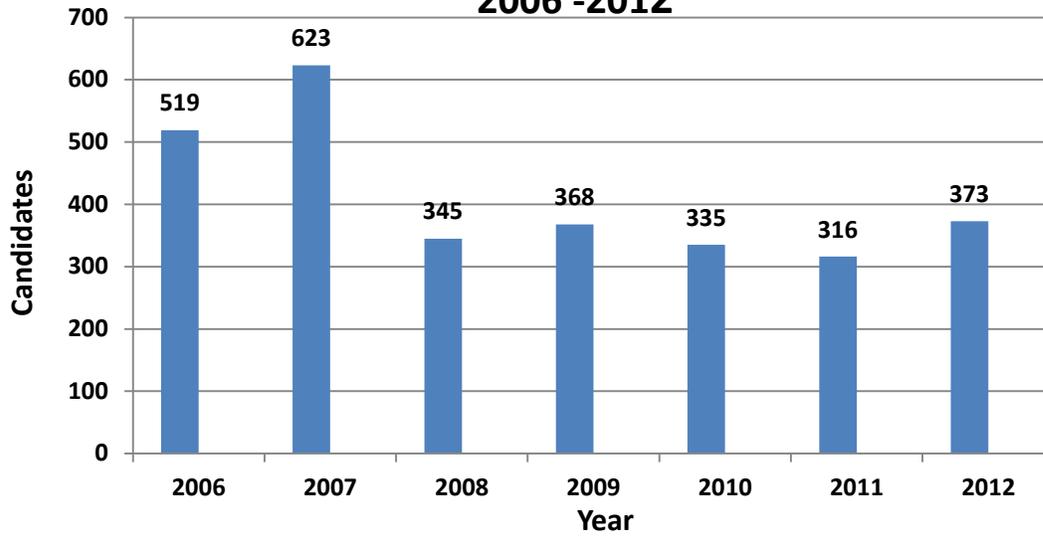
Employment of medical records and health information technicians is expected to increase by 21 percent, much faster than the average for all occupations through 2020. The mean annual wage of cancer registrars/abstractors is \$50,599. CTRs make a mean of \$63,000 annually, compared to \$48,920 for non-CTRs – a difference of 29 percent. For details, please visit this link http://www.ncra-usa.org/files/public/NCRASalaryConsiderations_May2013.pdf

The current workforce deficit calls for the development of a new specialization in CTR/CIM at universities and technical colleges including: 1) A clear educational track with required courses in anatomy and physiology, medical terminology, and information science resulting in an Associate's degree; and 2) Students with a two-year technical degree, such as the HIT degree (other degrees may also fulfill the required prerequisites) could apply to an associate degree program. This would allow the transfer of qualifying credits from the two-year degree to the CTR degree. The educational institutions could provide online degree plans including courses specific to cancer registrars.

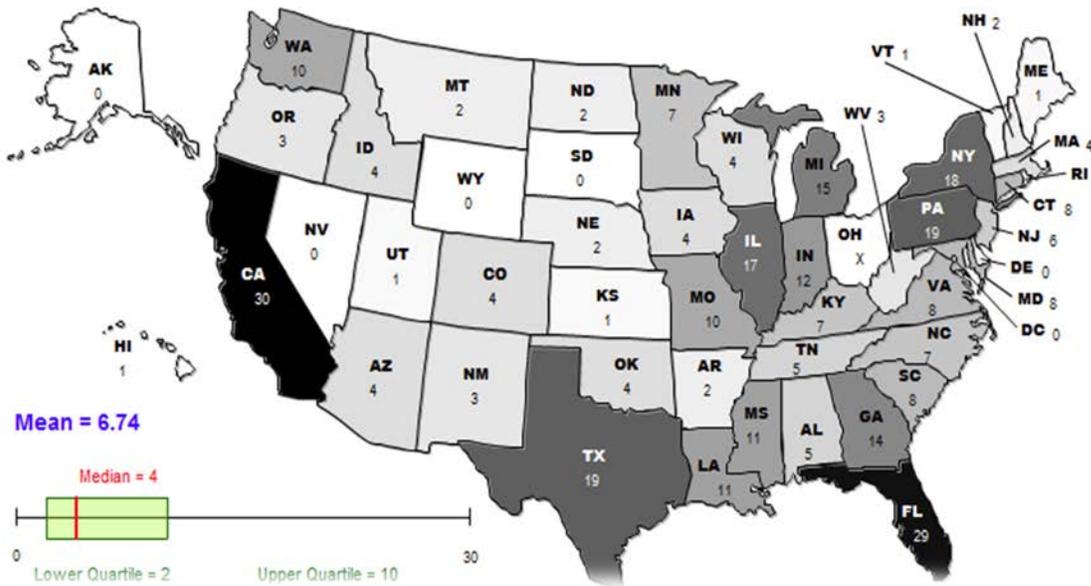
These new programs would provide an excellent opportunity for individuals to attain an Associate's Degree (60 credits), and complete experience in the field (12 months). This CTR education will open many doors, such as starting a new career in the cancer registry field. Students completing the CTR certification will qualify for employment in hospital cancer programs, cancer treatment centers, oncology physician group practices, state and federal cancer registries, military and VA hospitals, companies providing cancer registry software, contract registrar companies and pharmaceutical companies.



Figure 1. Number of CTR Exam Candidates, U.S., 2006 -2012



2012 Candidate Demo: U.S. Residence



References

1. Mulvihill L, Chapman S, Lindler V. Journal of Registry Management. 2006. Vol. 33, No. 3
2. The National Cancer Registrars Association, Updated 1012 Survey Data: Salary Considerations for Cancer Registrars.
3. NCRA Workload and Staffing Study Guidelines for Hospital Cancer Registry Programs, January 2011
4. Chapman et al. NCRA/NPCR Workload and Time Management Study: Guidelines for Central Cancer Registry Programs, May 2013.
5. Source for data about medical registrars: <http://www.bls.gov/oco/>
6. NCRA, Cancer Registrar FAQ: <http://www.ncra-usa.org/i4a/pages/index.cfm?pageid=3301>
7. NCRA, Council on Certification, 2012 CTR Results: <http://www.ctrexam.org/pdfs/CTRExam2012FULLreport.pdf>



Appendix 3

Wisconsin Cancer Council 2014 Merit Awards - Timeliness

Facility Name	Award Level
Upland Hills Health, Inc.	Platinum
Appleton Medical Center	Silver
Aspirus Wausau Hospital	Silver
Bay Area Medical Center	Silver
Columbus Community Hospital	Silver
Community Memorial Hospital - Menomonee Falls	Silver
Meriter Hospital	Silver
Saint Clare's Hospital - Weston	Silver
Saint Elizabeth Hospital	Silver
St. Nicholas Hospital	Silver
University of Wisconsin Hospital & Clinics	Silver
Waukesha Memorial Hospital	Silver
Mayo Clinic Health System-Eau Claire Hospital	Honorable Mention
Sacred Heart Hospital	Honorable Mention
Oakleaf Surgical Hospital	Honorable Mention
Gundersen Lutheran Medical Center	Honorable Mention
Columbia Saint Mary's Hospital – Milwaukee	Honorable Mention
Froedtert Memorial Lutheran Hospital	Honorable Mention
Ministry Sacred Heart Saint Mary's Hospitals	Honorable Mention
Columbia Saint Mary's Hospital - Ozaukee, Inc.	Honorable Mention
Marshfield Clinic - St Joseph's Hospital	Honorable Mention
Affiliated Dermatologists – Brookfield	Honorable Mention
Marshfield Clinic - Wisconsin Rapids Center	Honorable Mention
Turville Bay	Honorable Mention



Wisconsin Cancer Council 2014 Merit Awards - Completeness

Facility Name	Award Level
Affiliated Dermatologists - Brookfield	Platinum
Appleton Medical Center	Platinum
Aspirus Medford Hospital	Platinum
Aspirus Wausau Hospital	Platinum
Aurora Baycare Medical Center – Marinette	Platinum
Aurora Lakeland Medical Center	Platinum
Aurora Medical Center - Grafton	Platinum
Aurora Medical Center - Kenosha	Platinum
Aurora Medical Center - Summit	Platinum
Aurora Memorial Hospital of Burlington	Platinum
Bellin Memorial Hospital	Platinum
Calumet Medical Center	Platinum
Childrens Hospital of Wisconsin	Platinum
CJ Zablocki VA Medical Center	Platinum
Columbia Saint Mary's Hospital - Milwaukee	Platinum
Dermatology Associates of Wisconsin, SC	Platinum
Divine Savior Healthcare	Platinum
Family Practice Associates	Platinum
Fort Memorial Hospital	Platinum
Langlade Hospital	Platinum
Marshfield Clinic - Wisconsin Rapids Center	Platinum
Marshfield Clinic-Minocqua Center	Platinum
Mayo Clinic Health System-Eau Claire Hospital	Platinum
Mercy Medical Center - Oshkosh	Platinum
Meriter Hospital	Platinum
New London Family Medical Center	Platinum
Oakleaf Surgical Hospital	Platinum
Osceola Medical Center	Platinum
River Falls Area Hospital	Platinum
Sacred Heart Hospital	Platinum
Saint Joseph's Community Hospital	Platinum
Saint Mary's Hospital - Madison	Platinum
Saint Mary's Hospital Medical Center	Platinum
Saint Mary's Janesville Hospital	Platinum



Saint Vincent Hospital	Platinum
St. Nicholas Hospital	Platinum
United Hospital System - St. Catherine's Medical Center	Platinum
University of Wisconsin Hospital & Clinics	Platinum
Upland Hills Health, Inc.	Platinum
UW Medical Foundation - Surgery Center	Platinum
Vince Lombardi Cancer Clinic - Aurora Medical Center - Marinette	Platinum
Wheaton Franciscan Healthcare - Elmbrook	Platinum
Wheaton Franciscan Healthcare - Franklin	Platinum
Wheaton Franciscan Healthcare - St. Francis	Platinum
Wm. S. Middleton Memorial VA Hospital	Platinum
Aurora Saint Luke's Medical Center	Gold
Aurora Sinai Medical Center	Gold
Aurora West Allis Medical Center	Gold
Community Memorial Hospital - Menomonee Falls	Gold
Gundersen Lutheran Medical Center	Gold
Marshfield Clinic - Eau Claire	Gold
Mayo Clinic Health System-Northland, Inc.	Gold
Memorial Medical Center - Ashland	Gold
Mercy Health System	Gold
Ministry Sacred Heart Saint Mary's Hospitals	Gold
Saint Clare's Hospital - Weston	Gold
Saint Elizabeth Hospital	Gold
Saint Joseph's Hospital - Chippewa Falls	Gold
Wheaton Franciscan Healthcare - All Saints	Gold
Aurora Medical Center – Oshkosh	Silver
Froedtert Memorial Lutheran Hospital	Silver
Holy Family Memorial Inc.	Silver
Hudson Hospital	Silver
Marshfield Clinic - St Joseph's Hospital	Silver
Marshfield Clinic - Weston Center	Silver
Ministry St Michael's Hospital - Stevens Point	Silver
Riverview Hospital Association	Silver
St. Agnes Hospital	Silver
West Allis Dermatology	Silver

