



## ENHANCING THE COMPLETENESS OF THE WISCONSIN CANCER REPORTING SYSTEM – THE BORDER COUNTY PILOT PROJECT

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### INTRODUCTION

In 2005, a Steering Committee of 37 individuals representing over 100 public, private, local and statewide organizations jointly published a Comprehensive Cancer Control Plan for Wisconsin.<sup>1</sup> The plan integrates six key areas including prevention, screening and detection, treatment, quality of life, palliative care, and data collection. In order to quantify progress in implementing the plan, quality data must be available to track trends in cancer incidence, morbidity and mortality. Twenty percent of the Wisconsin Comprehensive Cancer Control Plan's priorities deal specifically with data collection and reporting improvements. Those priorities include: increasing the timeliness of reporting cancer cases; improving the quality and completeness of treatment data; improving racial and ethnic cancer data collection; and promoting the collection and use of information. The logical partner for working towards improvements in data collection and reporting is the Wisconsin Cancer Reporting System (WCRS). The WCRS was established in 1976 by the Wisconsin state legislature to collect cancer incidence data on Wisconsin residents and to maintain a population based database for public health surveillance purposes and research to assess Wisconsin's cancer burden. As mandated by Chapter 255.04, Wisconsin Statutes, the WCRS began collecting data statewide in 1978 on all invasive and noninvasive malignant primary tumors with the exception of squamous and basal cell carcinomas of the skin (and beginning in 1996 in situ cancer of the cervix uteri).<sup>2</sup> The surveillance data collected by the WCRS is routinely used to identify cancer trends, direct cancer control planning, conduct epidemiological and health services research, educate Wisconsin residents, and evaluate prevention and treatment programs.

The WCRS data meet national high quality standards of completeness, timeliness and quality. The registry has been awarded Gold (1995,1996, 1998-2002 data) or Silver (1997 data) certification by the North American Association of Central Cancer Registries every year since certification rules were adopted.<sup>3</sup> Those standards measure completeness and quality for selected variables on statewide data. However, many Wisconsin residents are diagnosed and/or treated in out-of-state facilities that are not required to comply with Wisconsin state statute. The majority of these out-of-state cases are in Wisconsin's four bordering states: Illinois, Iowa, Michigan, and Minnesota. WCRS established data exchange agreements with the Michigan, Illinois and Iowa central cancer registries in the late 1970s to capture those cases. Minnesota is the

only border state for which WCRS does not have such an agreement with its central cancer registry. Minnesota's central cancer registry is prohibited by Minnesota law to exchange data with other states. Therefore, in 1992 WCRS established agreements with 29 individual Minnesota hospitals to obtain cases for Wisconsin residents diagnosed and/or treated in that state. All out-of-state agreements are voluntary.

Statewide, 1-2% of reports submitted to WCRS are a result of out-of-state voluntary reporting. However, this percentage is substantially higher—as high as 94%—for counties along or close to the Minnesota border.<sup>4,6</sup> This

geographic variance in reporting completeness could potentially undermine research, education, and program evaluations derived from the information collected by the WCRS. This pilot project was developed to address two reporting problems: 1) the declining number of reports submitted by Minnesota hospitals since agreements

### Summary

**Objective** – To collect information regarding unreported cancer cases among Wisconsin residents that were diagnosed and/or treated in Minnesota, and to estimate the changes in Wisconsin cancer incidence rates that occur after accounting for these missing cases.

**Methods** – After including newly ascertained cases, we calculated the change in age-adjusted cancer incidence rates by county and overall for the state of Wisconsin.

**Findings** – 2,835 previously unreported cases were submitted from participating Minnesota facilities. For counties that had newly ascertained cases, the overall age-adjusted cancer incidence rates increased between 0.8% and 19%. The statewide increase was 0.8%.

**Implications** – Although the Wisconsin statewide cancer incidence rate is unlikely to be largely affected by complete Minnesota reporting, county-level rates may be greatly affected.

were established in 1992, and 2) the incomplete information on cases reported by a Wisconsin facility for which complete staging and treatment information are not available because the patient was referred to a Minnesota hospital. The purpose of this report is to present data regarding the changes in cancer incidence rates that occurred after the WCRS collected new submissions from participating Minnesota facilities.

## METHODS

The reporting status of the 29 Minnesota facilities with which the WCRS had data agreements was assessed. Of those, 17 that had substantial average number of cases were identified with either declining reporting rates or no reported cases to the WCRS since 1999. These facilities were approached by mail and by telephone. Continual follow up methods were employed to increase participation levels. Participating facilities were given two options for case submission: electronically or via paper through in-house medical records abstraction. This project hired a Certified Tumor Registrar to defray the cost of abstracting cases for facilities that could not report electronically.

The second phase of the project focused on contacting Minnesota facilities that did not have data exchange agreements with the WCRS. Medical facilities in the 3-digit zip code regions bordering Wisconsin were identified. Facilities with the highest number of potential cases, as determined by size of the hospital/clinic and proximity to the Wisconsin border, were selected. After identifying a contact person at those facilities, a letter was sent inviting them to participate in the project and to sign a data sharing agreement.

The most recent WCRS publication, Wisconsin Cancer Incidence and Mortality, reported cancer incidence and mortality data for cases diagnosed in 1998-2002. Therefore our analysis focused on age-adjusted rates observed before and after processing the newly reported cases for both Wisconsin statewide and for border counties during that five-year period.

## RESULTS

A total of 145 clinics and hospitals in Minnesota are located within the 3-digit zip code regions that border Wisconsin. The 29 (20%) facilities that have negotiated data sharing agreements with the WCRS have reported 8,269 cancers diagnosed since 1990 (2,411 of these cases diagnosed during 1998-2002), and 27 (93%) of these facilities reported at least once to the registry since 1992. We focused on 17 of the 29 facilities that had not consistently reported cases since 1999, when reporting rates began to decline. These 17 facilities reported 5,419 cases of cancer to the WCRS since they had first signed data sharing agreements in 1992 and 1,364 (25.2%) were diagnosed in the five-year period of 1998-2002. We successfully obtained new case reports from 10 (58%) of the 17 facilities through electronic data transfer or with the assistance of a certified tumor registrar. The seven other medical facilities elected not to participate in this study. One new facility provided data, for a total of 11 participating facilities.

The 11 facilities that participated in this special data collection effort submitted 2,835 case reports; of those, 977 were diagnosed in 1998-2002. Renewed data sharing agreements were obtained from 6 (35%) of the 17 facilities initially contacted in the first phase. Case counts and incidence rates, before and after the inclusion of the new case reports, are shown in Table 1. The overall age-adjusted cancer rates increased between 0.8% and 19% by county after the addition of the new case reports (Figure 1). The total rate increase for the state of Wisconsin was 0.8%.

Although we successfully obtained new cases from the two Minnesota facilities that had previously reported the greatest number of diagnosed and/or treated Wisconsin residents, we were unable to obtain information from other large facilities. Their internal policies did not allow them to share data with outside sources. Continual contact was made with these facilities to encourage participation, but at the project's conclusion, no data had been submitted from these facilities to the WCRS.

Of the 116 remaining facilities located in 3-digit zip code regions that border Wisconsin, 19 facilities were contacted to initiate new data sharing agreements. Of these, 3 (16%) have begun to draft data sharing agreements with the WCRS.

## COMMENTS

Medical facilities in the state of Minnesota are required to report incident cancer cases to the Minnesota Cancer Surveillance System (MCSS). Most of these facilities report their information to the MCSS via electronic data transfer in a standardized layout created for central cancer registries by the North American Association of Central Cancer Registries (NAACCR). The certified tumor registrar who was hired for this project abstracted cases for two facilities. The remaining nine facilities submitted data electronically to the WCRS using the NAACCR layout. The MCSS is unable to exchange data with the WCRS due to Minnesota state statute limitations. However, Minnesota state law does not prohibit medical facilities from sharing data across state borders. MCSS staff reviewed all project correspondence written for the Minnesota medical facilities prior to its release. The MCSS included an article in their statewide newsletter that encouraged Minnesota facilities to enter into data sharing agreements with border states. The Minnesota Cancer Registrars Association updated contact information and facilitated contact with the various hospitals and clinics, and assisted with identifying a Minnesota certified tumor registrar for the project.

We were able to collect an additional 2,835 case reports during the project's 6-month timeframe. Increased data collection will likely continue in the future because the WCRS will maintain contact with the facilities. Still, the complete and timely reporting of cases from Minnesota will require increased time from already limited WCRS staff availability. Without routine monitoring, the WCRS risks reverting to the incomplete case ascertainment rates for the Wisconsin counties that border Minnesota. Each new medical facility that begins reporting to the WCRS will require more time

**TABLE 1. Case Increase\* and Averaged Age-Adjusted Cancer Incidence Rates for Selected Counties Along or Near the Wisconsin – Minnesota Border for Cases Diagnosed 1998-2002**

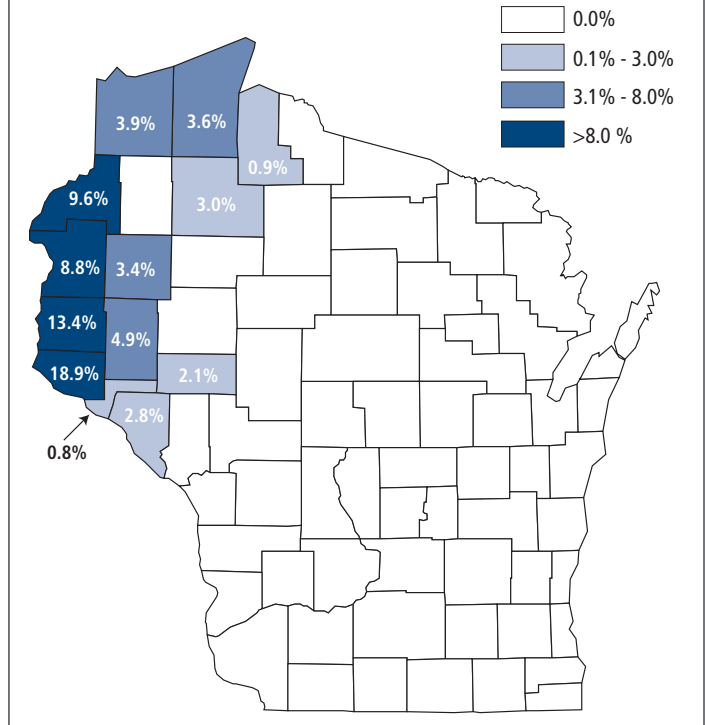
County	Case Increase N=506	Pre-Project Rate per 100,000 per year	Post-Project Rate per 100,000 per year	Percent Increase
Ashland County	2	486.0	490.4	0.89%
Barron County	35	385.2	398.3	3.41%
Bayfield County	14	421.5	436.5	3.57%
Buffalo County	11	441.7	454.2	2.83%
Burnett County	37	367.6	402.9	9.61%
Douglas County	37	388.4	403.6	3.92%
Dunn County	31	367.5	385.5	4.90%
Eau Claire County	34	390.8	398.9	2.08%
Pepin County	2	448.4	451.9	0.78%
Pierce County	93	322.0	383.0	18.94%
Polk County	73	354.2	385.4	8.82%
St Croix County	121	321.0	364.0	13.38%
Sawyer County	16	466.3	480.0	2.95%
State Rate Increase**		482.6	486.5	0.81%

Source: Wisconsin Cancer Reporting System. Rates adjusted to the U.S. Census Bureau 2000 standard population and calculated using NCI SEERStat.

\*Reflects number of new primary tumors submitted to the WCRS for diagnosis years 1998-2002 (post registry person and tumor consolidation processing). This does not reflect the number of actual reports received during the project.

\*\*The state age-adjusted rate increase shown in this table reflects the increase strictly from the 506 new cases added through this Minnesota Border Project. Additional cases from Wisconsin reporting facilities not involved in this project for the 1998-2002 period were also received during the project period. Therefore, the actual state increase for 1998-2002 is higher than what is shown in this Table (1.3% increase from all reporting sources).

**Figure 1. Cancer Incidence Rate Increase for Selected Wisconsin Counties after Including Additional Cases, Minnesota Border Pilot Project, 2005**



and effort to implement a successful submission protocol than what was needed for this project because the facilities most willing to participate were already contacted through this pilot. In addition, the WCRS does not have sufficient funds to hire a certified tumor registrar to report for any new facility that cannot submit electronically. Although the Wisconsin statewide cancer incidence rate is unlikely to be largely affected with increased Minnesota reporting, several regional differences greater than 8% were found after working with only a subset of those medical facilities that are assumed to be serving Wisconsin residents.

## PROGRAM / POLICY IMPLICATIONS

Accurate, timely and complete data on cancer incidence and mortality is a requirement for non-biased analysis of cancer trends, epidemiological and health services research, and prevention and treatment programs. With twenty percent of the Wisconsin Comprehensive Cancer Control Plan's priorities dealing specifically with data

collection and reporting issues, the importance of obtaining complete information from Minnesota needs to be emphasized. In addition, the increased need for community-level data, such as county data, through the state's new Comprehensive Cancer Control plan stresses the importance of having complete and accurate data at these smaller geographic definitions to accurately assess Wisconsin's cancer burden. A renewed effort to obtain Wisconsin resident cases from the MCSS should be pursued through discussions with the MCSS, the Minnesota and Wisconsin Comprehensive Cancer Control staff, Minnesota Legislature, WCRS and other affected parties instead of collecting information from the 145 individual medical facilities in Minnesota that may serve the citizens of Wisconsin. In lieu of centralized reporting, efforts need to continue at the WCRS and with other partners to secure funds for maintaining routine communication, providing abstracting support and increasing facility participation in reporting Wisconsin resident cases to the WCRS.

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