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    - Lung: 14% of total cancer patient volume | 10% increase from prior year
    - Prostate: 12% of total cancer patient volume | 29% increase from prior year

- **How many patients came to your facility for treatment that were diagnosed elsewhere?**
  - 207 patients or 40% of total cancer patient volume

- **Have you thought about your downstream revenue?**
  - IN-MIGRATION
    - Prior Services: 166
    - Home Surgery Services: 284
    - Post Services: 194

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The Journal of Registry Management is indexed in the National Library of Medicine’s MEDLINE database. Citations from the articles indexed, the indexing terms (key words), and the English abstract printed in JRM are included and searchable using PubMed.

For your convenience, the Journal of Registry Management is indexed in the 4th issue of each year and on the Web (under “Resources” at http://www.ncra-usa.org/jrm). The 4th issue indexes all articles for that particular year. The Web index is a cumulative index of all JRM articles ever published.
Dear Colleagues,

Hope your 2017 is off to a great start and you had an opportunity to read my letter from the fall 2016 issue, where I discussed continuously educating yourself—one important habit of successful people. Another habit of successful people I would like to share with you is that successful people minimize distractions. In order to minimize distractions, you first have to identify your goals (short- and long-term), vision, and dreams. Secondly, write your goals, vision, and dreams down on paper or on your electronic device. Lastly, you have to be willing to say “no” to anything that does not fall into the scope of your goals, vision, and dreams. We are not being selfish by doing this, we are being self-full. This is a tough one for me and it may be tough for you as well. If saying “no” is easy for you, then you are far ahead on the pathway of success. “No” is a complete sentence and we must be intentional about how we spend our time so that we can focus and eventually minimize distractions. I challenge each of you to stay committed to your goals, vision, and dreams because no one is going to be as committed as you. Starting today, focus on you (your goals, vision, and dreams) and minimize distractions.

In this issue of JRM, we have 4 original manuscripts. First, we have Abdulrahman M. Jabour, MHSM, PhD, and colleagues evaluating timeliness of breast, colorectal, and lung-cancer cases submitted to the Indiana State Department of Health Cancer Registry. Secondly, Laura P. Ruppert, MHA, and team discuss the value-added and match rate for linking Indiana State Cancer Registry data and electronic health records from the Indiana Network for Patient Care. Thirdly, Christie R. Eheman, MS, PhD, and colleagues evaluate the treatment pattern of stage II colon cancer patients using population-based data. Lastly, Xiang-Rong Li, MD, MSPH, and team determine if benign and borderline brain tumors are underreported using data from the North American Association of Central Cancer Registries. Additionally, we have a How We Do It article by Lindsey M. Hutchison, MS, CTR, and Francis P. Boscoe, PhD, on how to identify missed deaths using the SEER*DMS SQL data search function.

Our National Cancer Registrars Association 43rd Annual Education Conference is being held April 5 through April 8, 2017 in Washington, DC at the Gaylord National Resort and Convention Center. Hope you are planning to attend. We are planning to have a JRM roundtable discussion and I look forward to meeting you!

Respectfully,

Vonetta L. Williams, PhD, MPH, CTR
Editor-in-Chief, Journal of Registry Management
National Cancer Registrars Association
Original Article

Data Quality at the Indiana State Cancer Registry: An Evaluation of Timeliness by Cancer Type and Year

Abdulrahman M. Jabour, MHSM, PhD; Brian E. Dixon MPA, PhD, FHIMSS; Josette F. Jones, RN, PhD; David. A. Haggstrom, MD, MAS

Abstract: Background: Central cancer registries collect tumor-related data to monitor incidence rates and support population-based research. One concern with using registry data for research is timeliness of reporting. Timeliness has been recognized as an important data characteristic by both the Centers for Disease Control and Prevention and the National Academy of Medicine. Yet, few studies in the United States have systematically measured timeliness. The purpose of this study is to evaluate timeliness in cancer-case reporting to a state population-based cancer registry. Method: Using the Indiana State Department of Health Cancer Registry, 66,395 breast, colorectal, and lung cancer diagnoses recorded during the years 2001–2009 were examined for timeliness. Timeliness was measured from the date the cancer was diagnosed to when the data were available at the state registry. Differences over time and among the 3 cancer types were examined. Result: Timeliness of reporting improved since 2003. Mean reporting time ranged from 426 days in 2003 to 253 days in 2009. We found significant difference in reporting time between the 3 cancer types. Conclusion: Timeliness of reporting has improved over time. Advances in health information technologies may have contributed to this improvement. However, achieving even more timely reporting for research purposes and care intervention may require moving away from traditional reporting methods.

Key words: cancer data, cancer registry, cancer reporting, cancer surveillance, data quality, timeliness

Introduction

In cancer research, the quality of data is paramount. High-quality data enable reliable surveillance of cancer cases as well as improved decisions regarding cancer prevention and treatment. Registries are important sources of data on cancer cases as they provide statistics about populations and monitor the trends in cancer incidence.1

While the concept of data quality is multifaceted, timeliness is an important dimension to population-based cancer surveillance and research. In several reports, the National Academy of Medicine has discussed the importance of timeliness of cancer data.2-4 Access to recent data is also critical for quality-improvement programs and comparative effectiveness research.5,6 Timely reporting supports cancer-related studies by providing data relevant to current care. Reporting delays undermine data quality by underestimating incident rates, which can lead to an inaccurate decline signal.7

Currently, timeliness requirements vary among registry standards. For instance, whereas the Surveillance, Epidemiology, and End Results (SEER) Program requires 98% of cases to be reported within 22 months from the date of diagnosis, the Centers for Disease Control and Prevention’s National Program of Cancer Registries (CDC/NPCR) require 90% to be reported within 12 months or 95% within 24 months.8 Other registries, like the North American Association of Central Cancer Registries (NAACCR) require 95% of cases to be reported within 23 months for gold certification and 90% for silver certification.9

Timeliness in reporting has improved in recent decades following the introduction of electronic information systems. Health information technologies, such as the electronic health record (EHR), support timeliness by facilitating data sharing, data quality, and data retrieval.10 Larsen and Småstuen (2009) reported a 50% improvement in Norway’s reporting timeliness from 2001 to 2005.11 Similar findings were reported by Tomic and Sandin in Sweden (2015), who found that the percentage of cases reported within 12 months of diagnosis improved from 77% in 2008 to 95% in 2012 after using Web-based reporting.12 Both studies suggest the improvement in timeliness might be attributed to the introduction of electronic reporting or the use of EHR systems.

Another factor that may affect reporting timeliness is the type of cancer. State registries require hospitals to collect a defined set of information to consider the abstract complete and ready for reporting. The information required and the test performed may differ based on the cancer site13;

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The data used in this study was retrieved from the Indiana State Department of Health (ISDH) Cancer Registry. The authors would like to thank the staff at the ISDH for their work in collecting the data used in this study. The primary author, Abdulrahman M. Jabour, would like to thank the Ministry of Higher Education (MOHE) of Saudi Arabia for their sponsorship. MOHE had no role in study design, data collection, analysis, or interpretation.
thus, cancer types that require fewer procedures to diagnose, or those associated with a shorter waiting time, may take less time to be reported. To release cancer incidence reports for recent years, statistical models are sometimes applied to adjust for the reporting delay. Studies reported that a delay adjustment factor needs to consider the variation in reporting time among the different cancer sites. The goal of this study is to measure the timeliness of cancer reporting to a state population cancer registry and examine the improvements in timeliness longitudinally. This study also examines timeliness variation by type of cancer.

Method

The study was approved by the Institutional Review Board at Indiana University. We obtained data from the Indiana State Department of Health (ISDH) Cancer Registry, which collects all cancer cases required for reporting by federal regulation or the National Program of Cancer Registries. This repository contains cancer cases and relevant information for performing epidemiological, preventive, and cancer control studies. The registry also contains demographic data, tumor-related data, and some treatment information from the state’s hospitals, physicians’ clinics, and radiology centers. A total of 68,118 records were retrieved for patients diagnosed with breast, colorectal, or lung cancer from 2001 to 2009. Variables included cancer type, date of first patient contact with the reporting facility for the diagnosis and/or treatment of the tumor, and the date when the data were made available by the state registry to be counted as an incident tumor.

Timeliness was defined as “the rapidity at which a registry can collect, process and report sufficiently reliable and complete cancer data.” To measure cancer registry data timeliness, we focused on calculating the interval between date of diagnosis and date the case was available in the registry for research, as in prior studies. This interval includes the time taken by the facility to abstract and send the report to the state registry and the time taken by the state registry to compile and process the information received from the reporting sources.

Timeliness was measured by analyzing the timestamps of reported cases. We measured the number of days from the date of first contact to the date when data compiled from the reporting sources were available in the central cancer registry database to be counted as an incident tumor.

All analyses used the Statistical Package for Social Sciences (SPSS) software, version 21. Descriptive analysis of timeliness focused on mean reporting times for each cancer type. To compare means between the 3 cancer types, we performed the nonparametric Kruskal–Wallis followed by Wilcoxon–Mann–Whitney test for pairs of cancer types (breast—lung, colorectal—lung, breast—colorectal). Nonparametric tests were necessary because the data were skewed and the sample sizes differed. A 2-tailed test of statistical significance was used ($P < .05$).

Out of the 68,118 cases retrieved from the registry, 1,327 were excluded for missing either the date of diagnosis or the date when the record was made available. An additional 395 cases were excluded for 1 of the following reasons:

- cases where any of the individual components of a date (day, month, year) were missing; invalid cases where the date when data was made available at the state registry was earlier than the date of diagnosis; or outlier cases beyond the 0.99% end of the distribution.

After these steps, 66,395 cases remained. The numbers of breast, colorectal, and lung cancer cases were 25,013 (37.6%), 17,074 (25.7%), and 24,308 (36.6%), respectively. The annual number of cases ranged from 7,083 to 7,726 except for the 2009, when only 6,693 were reported. The reporting timeliness was then stratified by cancer type and the year of diagnosis. Lastly, we calculated the percentage of records reported within different timeframes after diagnosis such as 6, 12, 22, 23, and 24 months. The timeframes were drawn from the timeliness requirements of national registry standards such as SEER, NAACCR, and CDC/NPCR.

<table>
<thead>
<tr>
<th>Year</th>
<th>Median (Days)</th>
<th>Mean (Days)</th>
<th>$P$</th>
<th>$n$</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>292</td>
<td>322</td>
<td>.001</td>
<td>7,566</td>
</tr>
<tr>
<td>2002</td>
<td>280</td>
<td>292</td>
<td>.000</td>
<td>7,702</td>
</tr>
<tr>
<td>2003</td>
<td>425</td>
<td>426</td>
<td>.335</td>
<td>7,571</td>
</tr>
<tr>
<td>2004</td>
<td>336</td>
<td>368</td>
<td>.354</td>
<td>7,208</td>
</tr>
<tr>
<td>2005</td>
<td>277</td>
<td>334</td>
<td>.003</td>
<td>7,083</td>
</tr>
<tr>
<td>2006</td>
<td>237</td>
<td>303</td>
<td>.282</td>
<td>7,553</td>
</tr>
<tr>
<td>2007</td>
<td>220</td>
<td>300</td>
<td>.000</td>
<td>7,293</td>
</tr>
<tr>
<td>2008</td>
<td>219</td>
<td>313</td>
<td>.000</td>
<td>7,726</td>
</tr>
<tr>
<td>2009</td>
<td>203</td>
<td>253</td>
<td>.000</td>
<td>6,693</td>
</tr>
</tbody>
</table>

Results

There was large variation in reporting time means across years, ranging from 253 to 426 days (Table 1). The lowest reporting time was 253 days in 2009 and the highest 426 in 2003. The reporting times for the remaining years show less variation, ranging from 292 to 368 days. The variation between cancer types was statistically significant for several years ($2001, P = .001; 2002, P = .000; 2005, P = .003; 2007, P = .000; 2008, P = .000; and 2009, P = .000$). Furthermore, the results show a large difference between the mean and median, indicating skewed data distribution. The difference between the mean and median was highest during 2007 (300 for the mean and 220 for the median) and 2008 (313 for the mean and 219 for the median).

The results also show inconsistency in the timeliness trend across the years. The average timeliness declined from 2001 to 2002 and then increased by about 46% (from 292 days in 2002 to 426 days in 2003; Figure 1). This was followed by a gradual, near continuous decline until 2009.

Comparisons of mean reporting times between breast—colorectal, lung—colorectal, and breast—lung are presented in Table 2. Differences in reporting time between breast and colorectal were statistically significant in 2002 and 2005 ($P < .001$ and .001, respectively). In addition, differences in

The highest percentage of cases reported within the first 6 months was 37.2% (2009) and the lowest was 3.9% (2003). For the remaining years, the percentage of cases reported within the first 6 months ranged from 10.8% to 23% (Table 3).

The percentage of cases reported within the first 12 months was also highest in 2009, with 82.6% and lowest in 2003, with 34.4%. For the remaining years, this percentage ranged from approximately 60% to 75%. Cases reported within the first 18 months were also lower during 2003, with 82.6%, but the highest was during 2002, with 95.7% (Table 3).

Cases reported within the first 22, 23, and 24 months were highest in 2002, with 98.3%, 98.5%, and 98.8%, respectively. As for the percentage of cases reported within the first 22 and 23 months, both were lowest in 2010, with 92.2% and 93.6% respectively. However, cases reported within 24 months were lowest in 2004, with 94.8% (Table 3). In most years, over 95% completion rate was achieved after 23 month of diagnosis (Figure 2). Figure 3 visualizes the variation in timeliness across time. Median reporting times were quite variable, ranging from 277 to 425, between 2001 and 2005, then stabilized below 250 days after 2006.

### Discussion

Using data from a state cancer registry, we examined timeliness of case reporting, which is a critical aspect of assessing the quality of data. The result showed a sharp increase in reporting time during 2003. This was concurrent with changes in the policy and procedure requirements for reporting facilities. Starting in 2003, the ISDH cancer registry implemented the Facility Oncology Registry Data Standards (FORDS) coding standard. The FORDS coding standard was developed by the Commission on Cancer (CoC) and was required by all CoC-approved cancer programs. Additional, major changes also occurred in 2004. By the beginning of 2004, reporting facilities were required to report all benign and borderline brain and central nervous system tumors. In the same year, the state also began requiring all reporting facilities to start coding using the Collaborative Staging System.17

With the exception of 2003 and 2004, the results show a decreasing trend in reporting time. For 2005, the results demonstrate that researchers are able to access an average of 15% of the cases within the first 6 months of diagnosis, 68.8% after the first year, and 95.7% after 2 years. The percentage of cases available within these time periods were improving as of 2009, reaching 37.2%, 82.6%, and 97.5% for 6 months, 1 year, and 2 years, respectively. Other studies show similar results wherein timeliness decreased over time.11,12 These studies suggest that the improvement in timeliness could be attributed to the increasing adoption of health information technologies.11,12
Table 3. The Percentage of Cases Reported within Each Time Period by Year

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 months</td>
<td>11.9</td>
<td>16.5</td>
<td>3.9</td>
<td>10.8</td>
<td>15.1</td>
<td>19.6</td>
<td>21.1</td>
<td>23.0</td>
<td>37.2</td>
</tr>
<tr>
<td>12 months</td>
<td>71.4</td>
<td>82.1</td>
<td>34.4</td>
<td>59.2</td>
<td>68.8</td>
<td>76.6</td>
<td>74.7</td>
<td>70.6</td>
<td>82.6</td>
</tr>
<tr>
<td>22 months</td>
<td>97.1</td>
<td>98.3</td>
<td>93.7</td>
<td>93.3</td>
<td>94.3</td>
<td>94.2</td>
<td>95.3</td>
<td>92.9</td>
<td>97.5</td>
</tr>
<tr>
<td>23 months</td>
<td>97.6</td>
<td>98.5</td>
<td>95.0</td>
<td>94.1</td>
<td>95.3</td>
<td>94.7</td>
<td>96.0</td>
<td>94.5</td>
<td>97.8</td>
</tr>
<tr>
<td>24 months</td>
<td>98.1</td>
<td>98.8</td>
<td>95.8</td>
<td>94.8</td>
<td>95.7</td>
<td>95.3</td>
<td>96.6</td>
<td>95.9</td>
<td>98.2</td>
</tr>
</tbody>
</table>

Figure 2. The Proportion of Cases Reported within 6 Months, 12 Months, 23 Months, and 24 Months

The National Academy of Medicine highlighted the importance of secondary use of data and the importance of data timeliness for understanding and improving cancer treatments and care. Access to recent data is key for timely intervention and quality improvement. The last 5 years of the studied period show an average reporting time of 253 to 334 days and about 22 months to report 92.9% to 97.8% of cases. This finding suggests that data users typically have to wait a year on average after diagnosis before they can access this data via the ISDH cancer registry. By observing the percentage of the reported cases at each time period, we also highlight the tradeoff between completeness and timeliness (Figure 2).

At present, these time periods are considered acceptable by national registry standards given the resource restraints upon both individual facilities and state departments of health. Reporting times approaching a year, however, are too long for investigators who wish to enroll newly diagnosed patients in a clinical trial, or health care organizations who may wish to measure the type and

Figure 3. Box Plot Representations of Data Timeliness from 2001 to 2009
quality of care received on a real-time basis. Shortening of the reporting period could perhaps be accomplished with the application of innovative information technologies, such as Rapid Quality Reporting System (RQRS).

Rapid reporting, facilitated by additional investment of focused resources, can reduce these reporting times to less than a month.\(^\text{18}\) The RQRS is a voluntary program introduced by the CoC at the end of 2011 and tested at 65 accredited programs.\(^\text{19}\) The CoC reported that utilizing RQRS improved the quality of cancer care by providing real time updates on pending adjuvant treatment.\(^\text{19,20}\) Individual facilities, such as Moffitt Cancer Center, use RQRS to shorten the time wherein diagnostic, surgical, and staging information is collected.\(^\text{21}\)

Another question of interest in this study was the variation in timeliness among the different cancer types. A study by Gagen et al reported that timeliness varied by the type of cancer and that such variation may be due to the fact that different types of cancer are often diagnosed and reported by different sources, such as hospitals, laboratories, or physician’s clinics. Cancers diagnosed and reported by hospitals are expected to have shorter timeliness than non-hospital settings, such as independent laboratories or physician’s clinics. Cancer types such as breast and colorectal are more likely to be treated and reported by hospitals compared with melanoma or prostate cancer\(^\text{15}\); therefore, these may have shorter reporting times than otherwise.

In contrast to prior studies attributing variation in reporting time to the types of reporting sources,\(^\text{22}\) we found significant variation among cancer types when 98% of the cases examined were reported by hospitals. One possible cause of this variation is differential waiting times from diagnosis to treatment for each cancer type. Studies showed that treatment waiting time tends to be longer for patients with lung cancer with an average of 37 days (20 minimum, 63 maximum) compared to breast (average of 24 days, 14 minimum, 40 maximum) and colorectal (average of 25 days, 13 minimum, 46 maximum).\(^\text{22}\) The same study also found significant association between hospital types (eg, academic, community, federal) and waiting times for treatments.\(^\text{22}\)

The underlying case of the variation among cases presented in a box plot (Figure 3) cannot be determined in this study. This variation can be attributed to many causes such as the variation in the treatment waiting time between patients within the same cancer type or the variation in reporting speed among the reporting hospitals. As seen in previous studies, treatment waiting time for patients with lung cancer for example could range from 20 to 63 days.\(^\text{22}\) This study highlights the need to understand both variation in reporting timeliness among hospitals, as well as the impact of treatment waiting time,\(^\text{23}\) on data timeliness.

**Limitations**

An important factor to consider is that our study only included 3 cancer sites, whereas national registries consider all cancer types. Although our study included some of the most common types of cancer, many cancer sites were not included.\(^\text{9}\) Another important factor to consider is the calculation method used. Timeliness can be calculated using different techniques. Where some studies use the date stamp to calculate the difference between the start and end date, others use the observed and expected numbers of cases. In this study, we calculated the difference between the date of diagnosis and the date when data was made available on the state registry using data items that conform to NAACCR standards. However, the CDC/NPCR uses the observed-to-expected ratio to determine the rate of completeness within the specified period.\(^\text{24}\) This method uses the registry’s previous reporting experience to determine an expected number of cases. As this method may have the advantage of estimating timeliness in recent years, historical data can leverage the date stamp for a more accurate measurement. This is especially important if the number of annual incidents is inconsistent.

**Conclusion**

In this study, we examined the timeliness of cancer cases reported by multiple facilities to a single state cancer registry. In general, timeliness appears to have improved over time. Improvement in timeliness may be attributed to the increasing adoption of health information technologies. The study also showed variation in reporting timeliness from year-to-year, some of which may be attributed to changes in reporting requirements. There were further significant differences in timeliness between the 3 cancer types examined. For future studies, we recommend examination of the variation in timeliness between the different reporting sources. To improve timeliness, process and workflow evaluation approaches could be applied to better understand what reporting processes and steps are key to rapid case ascertainment.

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Linkage of Indiana State Cancer Registry and Indiana Network for Patient Care Data
Laura P. Ruppert, MHA; Jinghua He, PhD, MPH; Joel Martin; George Eckert; Fangqian Ouyang; Abby Church, MPH; Paul Dexter, MD; Siu Hui, PhD; David Haggstrom, MD

Abstract: Background: Large automated electronic health records (EHRs), if brought together in a federated data model, have the potential to serve as valuable population-based tools in studying the patterns and effectiveness of treatment. The Indiana Network for Patient Care (INPC) is a unique federated EHR data repository that contains data collected from a large population across various health care settings throughout the state of Indiana. The INPC clinical data environment allows quick access and extraction of information from medical charts. The purpose of this project was to evaluate 2 different methods of record linkage between the Indiana State Cancer Registry (ISCR) and INPC, determine the match rate for linkage between the ISCR and INPC data for patients diagnosed with cancer, and to assess the completeness of the ISCR based on additional validated cancer cases identified in the INPC EHRs. Methods: Deterministic and probabilistic algorithms were applied to link ISCR cases to the INPC. The linkage results were validated by manual review and the accuracy assessed with positive predictive value (PPV). Medical charts of melanoma and lung cancer cases identified in INPC but not linked to ISCR were manually reviewed to identify true incidence cancers missed by the ISCR, from which the completeness of the ISCR was estimated for each cancer. Results: Both deterministic and probabilistic approaches to linking ISCR and INPC had extremely high PPV (>99%) for identifying true matches for the overall cohort and each subcohort. The combined match rate for melanoma and lung cancer cases identified in the ISCR that matched to any patient occurrence in INPC (not by disease) was 85.5% for the complete cohort, 94.4% for melanoma, and 84.4% for lung cancer. The estimated completeness of capture by the ISCR was 84% for melanoma and 98% for lung cancer. Conclusion: Cancer registries can be successfully linked to patients’ EHR data from institutions participating in a regional health information organization (RHIO) with a high match rate. A pragmatic approach to data linkage may apply both deterministic and probabilistic approaches together for the diverse purposes of cancer control research. The RHIO has the potential to add value to the state cancer registry through the identification of additional true incident cases, but more advanced approaches, such as natural language processing, are needed.

Key words: electronic health records, record linkage

Introduction
With the passage of the Indiana General Assembly’s Public Law 174-1985 in 1985, the Indiana State Cancer Registry (ISCR) was established “for the purpose of recording all cases of malignant disease and other tumors and precancerous diseases required to be reported by federal law or federal regulation or the National Program of Cancer Registries that are diagnosed or treated in Indiana, and compiling necessary and appropriate information concerning those cases, as determined by the state department, in order to conduct epidemiologic surveys of cancer and to apply appropriate preventive and control measures.” Reporting for both providers and hospitals began on January 1, 1987.

Population-based cancer registries have been widely used to study the epidemiology of various cancers, including incidence across geographical locations and time. Cancers captured in registries are well characterized around the time of diagnosis, including type, stage, and initial treatment. These case characteristics are seldom captured elsewhere, but they are invaluable for researchers in conducting in-depth epidemiological studies such as geographical variations of surveillance2 and time trends of treatment patterns for specific cancer types and stages, eg, stage IV oral cavity and pharyngeal cancers.3 The availability of mortality data associated with cancer registries also enables studies of factors on survival.4 However, cancer registries are usually limited in other follow-up information such as subsequent adjuvant or chronic treatments, clinical course and patient outcomes or adverse events. Linking cancer registry patients’ records to an individual’s electronic health records (EHR) can create a resource for asking
more complex questions in longitudinal, population-based studies, especially regarding patterns of follow-up care.

In a working example of such a resource, the ISCR data were linked to the Indiana Network for Patient Care (INPC). The INPC is a unique federated EHR data repository that contains data collected from a large population across various health care settings throughout the state of Indiana. The INPC includes clinical data from 103 Indiana hospitals, 41 core hospital systems, and 60 community clinics, as well as state and local public health departments. Each participating institution provides common data elements, which can include inpatient admission/discharge information; outpatient visit information; laboratory values; microbiology, pathology, radiology, and cardiology reports; and clinical notes that can be analyzed via natural language processing. The INPC was originally developed by the Regenstrief Institute, which developed an accompanying clinical data environment to allow quick access and extraction of information from medical charts. The purpose of this project was to develop and validate linkage algorithms to match the cancer cases in ISCR to medical records in the INPC. The linked records were used to assess the completeness of the ISCR in capturing specific cancers in Indiana. The findings have implications for the value and design of future longitudinal studies that make use of linked cancer registry and EHR data.

**Methods**

**Cohort Selection**

Three cohorts were selected from the ISCR for this study: 1 overall cohort encompassing all cancer patients and 2 subcohorts consisting of melanoma and lung cancer cases.

**Complete Cohort.** The complete cohort of cancer patients was selected from all entries with a primary date of diagnosis from January 1, 2005 to December 31, 2013 in the ISCR. To allow for the most complete diagnosis and first round treatment information, cancer cases are reported to the ISCR within 6 months of diagnosis or first round treatment. This expanded range of dates ensured that the cancer registry capture was complete for cases in the 2005–2012 time frame. Population-based data collection approaches have undergone progressive changes in the 3 decades since the ISCR was first established. Starting in 2003, the ISDH Cancer Registry implemented the Facility Oncology Registry Data Standards (FORDS) coding standard, developed by the Commission on Cancer (CoC). Consequently, we assembled our cohort over a 10-year time frame from 2005–2013 to both encompass data collected after the FORDS standard was fully implemented, as well as to allow for a sufficient cohort of cancer cases for analysis.

To maximize the likelihood that ISCR cancer cases would be identified in the INPC, these cases were further restricted to those submitted to the ISCR by 61 health care institutions that send EHRs to INPC. Of these 61 institutions, 42.6% were accredited by the CoC. For this estimate, institutions include both hospitals, as well as integrated delivery care systems that may encompass more than a single hospital.

**Selection of Melanoma and Lung Cancer Cases from the ISCR.** These specific cancers were chosen from the complete cohort because experience at the ISCR suggested that the capture rate was relatively higher for lung cancer, but lower for melanoma compared to other cancers. Specific cancer cases were selected from the ISCR cohort by histology code. The Surveillance, Epidemiology, and End Results (SEER) Program and International Classification of Diseases for Oncology, 3rd edition (ICD-O-3) list categorizes melanoma as 8700–8799 (http://seer.cancer.gov/icd-o-3/). Lung cancer cases were selected from the complete cohort by including all SEER ICD-O-3 codes C340–C349.

The mean ages (and standard deviations) of the melanoma and lung cancer cases were 58.5 (16.6) and 66.0 (11.4) years, respectively. Of the melanoma cases, 45% were female and 98% were white (1% or less other races); of the lung cancer cases, 48% were female, 88% were white, and 11% were African American.

**Linkage Algorithms Applied between ISCR and INPC**

An attempt to match all eligible cancer cases from the complete ISCR cohort to the INPC was made using 2 different linkage approaches.

**Deterministic Linkage.** The Regenstrief Global Linkage Algorithm, which is run daily on the INPC production database to link newly generated clinical data to existing patient records in the INPC master file. The Global Linkage Algorithm is considered a conservative deterministic algorithm. Deterministic algorithms assess whether record pairs agree or disagree on a given set of identifiers, where agreement is assessed as a binary (“all-or-nothing”) outcome. For this study’s purposes, Global Linkage made use of name, date of birth, gender, ZIP code, telephone number, and Social Security number, whenever these data elements were available.

**Probabilistic Linkage.** A majority of patients in the ISCR had a value representing the medical record number (MRN) of the submitting institution, which should have very high specificity if matched to the MRN in the INPC. Therefore, separate probabilistic linkage processes were run, based upon whether the institution and MRN matched between ISCR and INPC among all possible pairs from the 2 data sources. Probabilistic algorithms assign different weights for each record field based upon the probability that agreement on this field increases or decreases the probability that the 2 records refer to the same person. Probabilistic linkages allow imperfect matches due to partially inaccurate or missing data. The specific probabilistic linkage algorithm used for each linkage process is named RecMatch, a Regenstrief-developed probabilistic matching program based on the Felligi-Sunter model. To limit the number of pairs being considered, RecMatch functions by first selecting blocking variables. Each eligible match pair within a block must exactly match on the blocking variables. Other data fields are then evaluated for similarity and a score is generated based on their likelihood of being a true match. All eligible matches scoring above that cut-off score are considered true matches. Multiple blocks based on different blocking variables were used, and pairs identified
as matches from any block were considered to be matches. For the complete cohort, the institution ID was required to be one of the blocking variables within each block in order to keep the number of potential pairs of matches within feasible computational parameters. For the 2 subcohorts, no such requirement was necessary.

Validation of Matches for Testing Optimal Linkage Method and Match Rate between ISCR and INPC

Pairs of identifiers from the ISCR and INPC that were declared as matches by both the Global and MRN/probabilistic algorithms were considered true matches. Pairs declared as matches by 1 algorithm, but not another, were manually reviewed by 2 reviewers to determine the “true” match status. Medical record review was used as the reference standard for evaluating the performance of the linkage algorithms.

Evaluation of Linkage Algorithms for Linkage Method and Match Rate between ISCR and INPC

Within each “zone” where pairs of identifiers are declared matches by only 1 algorithm, the proportion of true matches was estimated based on the validation results. To arrive at an estimate of the positive predictive value (PPV) of each linkage algorithm, the estimate of each “zone” was combined with the presumed 100% accuracy in the zone in which all pairs were declared matches by both algorithms.8

Estimating completeness of ISCR’s capture of melanoma and lung cancer cases

A subset of patients identified as having cancer in INPC, but who were not identified as having cancer through linkage to the ISCR, were sampled to estimate the completeness of the ISCR. Patients were selected from the INPC if they had a first occurrence of an ICD-9 diagnostic code of lung cancer (162.2-162.9) or melanoma (172.X) between the dates January 1, 2005 to December 31, 2012. A subset of 200 charts of each cancer type was randomly selected for manual review by 2 reviewers to determine if each case was a true incident case of the specific cancer within the time period. The estimated number of true incident cases in the INPC that were not found in the ISCR was used to estimate the completeness of the ISCR.

Results

Evaluation of the Performance of Linkage Algorithms

Complete Cohort. From 2005–2013, a total of 202,153 cases were submitted to the ISCR from institutions also reporting data to the INPC. Application of the deterministic algorithm to these 202,153 cases in the ISCR resulted in 132,893 cases being validated as matches to patients in the INPC.

For 126,779 cases, ISCR MRN matched to a corresponding MRN in the INPC; in this instance, the probabilistic algorithm did not converge because manual validation of a random sample of pairs of identifiers in this group showed a 99% accuracy by MRN alone. For 75,374 cases, the ISCR MRN did not match to any MRN in the INPC; in this scenario, the probabilistic algorithm declared 22,804 as matched to patients in INPC. The stratified MRN/probabilistic algorithm approach declared a total of 149,583 ISCR cases as matched to patients in the INPC.

Overall, a total of 172,895 ISCR cases could be matched to the INPC using either of the 2 algorithms, resulting in an overall match rate of 85.5%. These results are summarized in Table 1. From each cell, a random sample of pairs of patient identifiers was manually reviewed (2 independent reviewers) to determine whether each pair came from the same patient. The sample sizes of the manual reviews are shown in parentheses in Table 1. The 2 independent reviewers had high agreement on whether a pair was truly the same patient (intrarater \( \kappa = 0.988 \)). The estimated PPV was 99.96% (s.e. = 0.04%) for the deterministic algorithm and 99.39% (0.19%) for the stratified MRN/probabilistic algorithm.

Melanoma and Lung Cancer Cohorts. After all eligibility criteria were met, the total number of cases in the melanoma (n = 6,853) and lung cancer (n = 31,565) cohorts were determined over the study period. For melanoma, 6,471 of the original 6,853 ISCR cases could be linked to INPC using any of the algorithms, a match rate of 94.4%. For lung cancer, 26,662 of the 31,565 ISCR patients were linked to INPC, a match rate of 84.4%. For each of these 2 cohorts, the cases linked by each algorithm, and in combination, are shown in Table 2. For melanoma, the estimated PPV was 99.9% for the probabilistic algorithm and 100% for the deterministic algorithm if cases identified by both algorithms were assumed true matches. For lung cancer, the respective PPV estimates were 99.8% and 100%.

The probabilistic algorithm has a lower PPV than the deterministic algorithm for both cohorts. Although the sensitivity of each of the 2 algorithms cannot be estimated without reviewing some cases missed by both, their sensitivity can be compared using McNemar’s test, which is based on only the counts in the discrepant cells (ie, matched by 1 algorithm but not the other). The McNemar’s test was highly significant for both cancer cohorts because there were many more cases found in 1 cell (identified by deterministic, but not probabilistic algorithm) than found in

| Table 1. Numbers of Indiana State Cancer Registry Cases Declared Matched to Indiana Network for Patient Care (Numbers Sampled for Manual Review) for the Complete Cohort |
|--------------------|----------------|
|                     | Probabilistic Algorithm | Deterministic Algorithm |
| Match               | No Match               |
| MRN Match           | 94,134                 | 32,645 (400) |
| MRN No Match        | 15,447                 | 7,357 (400)  |
| Probabilistic Match | 23,312 (400)           | 29,258 (200) |

MRN, medical record number.
this project represents an uncommon linkage of state cancer and 1 was a lung metastasis all on the INPC side). Presented disagreements (2 were coded as the incorrect cancer to be independent patients in the ISCR, and 3 cases represented disagreements (2 were coded as the incorrect cancer and 1 was a lung metastasis all on the INPC side).

Completeness of the ISCR

A search for melanoma administrative codes in INPC with a first diagnosis date between January 1, 2005 and December 31, 2012 yielded 9,043 cases, 3,083 (34.1%) of which were found in the ISCR. Among the 5,960 cases that did not link to the ISCR, a chart review of INPC data from a random sample of 199 patients with any text report data was undertaken; this chart review was intended to determine whether the INPC was identifying patients who should have been found in the cancer registry, or if the patients were incorrectly identified as having cancer by the INPC. Of the 199 patients, 44 (22%) were confirmed as true incidence cases in the time period. Therefore, the estimated capture rate of melanoma by the ISCR was 84%.

A search for lung cancer administrative codes in INPC over the same time period yielded 21,259 lung cancer cases, 13,593 (63.1%) of which were found in the cancer registry. Of 200 charts reviewed from the patients not identified in the ISCR, only 15 (7.5%) were confirmed as true incident cases, leading to an estimate of 98% completeness of the ISCR.

To further investigate true cancer cases not captured by the ISCR, 78 unique melanoma cases were delivered to the ISCR for manual review, 39 of which were truly not captured in the ISCR, rather than a failure of the linkage algorithm. When 74 validated INPC lung cancer cases not linked to ISCR were investigated by the ISCR, only 14 were not found to be independent patients in the ISCR, and 3 cases represented disagreements (2 were coded as the incorrect cancer and 1 was a lung metastasis all on the INPC side).

Table 2. Numbers of Melanoma and Lung Cancer Cases in Indiana State Cancer Registry Declared Matched to Indiana Network for Patient Care (Numbers Sampled for Manual Review

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<tr>
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<tr>
<td><strong>Melanoma</strong></td>
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<td></td>
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<tr>
<td>MRN/Probabilistic Match</td>
<td>5,894 (0)</td>
<td>94 (72)</td>
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<td>MRN/No Probabilistic Match</td>
<td>3,944 (200)</td>
<td>4,903 (0)</td>
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<tr>
<td><strong>Lung Cancer</strong></td>
<td></td>
<td></td>
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<tr>
<td>MRN/Probabilistic Match</td>
<td>22,198 (0)</td>
<td>292(165)</td>
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MRN, medical record number.

the other (identified by probabilistic, but not deterministic algorithm).

Cancer control covers the continuum of care from prevention to end-of-life care. Given the complementary nature of cancer registry and EHR data, merging these 2 data repositories has the potential to create a unique resource for many types of epidemiologic studies and clinical research topics. The EHR data, again, offers a longitudinal perspective that enables the ascertainment of services before, during, and after cancer diagnosis. Clinical data before diagnosis can be used to measure functional status and comorbidities14 that might influence treatment decisions, while after initial treatment, the EHR data can be used to evaluate adjuvant or chronic treatment, surveillance procedures, and long-term outcomes, such as anticipated and unanticipated late effects of cancer treatment15.

Trade-offs existed in the choice between the deterministic and probabilistic algorithms. While the probabilistic algorithm identified more matches than the deterministic algorithm across the complete cancer cohort, the deterministic algorithm had a higher PPV than the probabilistic algorithm. One contributing factor to the difference may be a higher duplicate rate associated with probabilistic approaches. Ultimately, the pragmatic decision was made to implement both deterministic and probabilistic

Discussion

The state population-based data linkage described in this project represents an uncommon linkage of state cancer registry (ISCR) cases with federated EHR data from the INPC, an regional health information organization (RHIO). Prior population-based cancer registry linkages have commonly involved the use of insurance claims data, either public9 or private.10 Compared to linkages with Medicare claims focused upon older populations, the linkage of a state cancer registry with EHR data leverages longitudinal, electronic data which documents care delivered to all of the general population served by several community-based health care institutions. Therefore, EHR data linkages hold the promise of generating knowledge about cancers more common in younger populations, eg, testicular cancer, thyroid cancer, lymphoma, and leukemia. Compared to administrative claims, EHR data also has the potential to provide more clinically detailed information, such as the results of lab or imaging tests, than the event-based billing information available in insurance claims. For this reason, it has been proposed that quality measures should preferably be based upon clinical data from EHRs, rather than administrative claims.11

The overall match rate of 88.5% discovered here is encouraging, suggesting that information about longitudinal, follow-up care may be ascertained among a significant proportion of cancer patients shared between the ISCR and INPC. Based upon these findings, this Indiana state-based partnership will continue moving forward to explore how this data resource can best be implemented to meet the cancer control, policy, and health services research needs of the state’s population. A growing number of RHIOs exist throughout the United States,12 and we recommend that other state departments of health and cancer registry programs explore the possibilities for collaboration with local partners. While both the population reach, and clinical functionality, of Health Information Exchanges (HIEs) will vary geographically13; currently, the opportunities made possible by cancer registry-EHR/HIE linkages in the field of cancer control are numerous.

Cancer control covers the continuum of care from prevention to end-of-life care. Given the complementary nature of cancer registry and EHR data, merging these 2 data repositories has the potential to create a unique resource for many types of epidemiologic studies and clinical research topics. The EHR data, again, offers a longitudinal perspective that enables the ascertainment of services before, during, and after cancer diagnosis. Clinical data before diagnosis can be used to measure functional status and comorbidities14 that might influence treatment decisions, while after initial treatment, the EHR data can be used to evaluate adjuvant or chronic treatment, surveillance procedures, and long-term outcomes, such as anticipated and unanticipated late effects of cancer treatment.15

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algorithms together, as the PPV associated with both was quite high. Even this small degree of error may be unacceptable for clinical uses; but for the purpose of longitudinal, epidemiologic cancer control studies, this threshold is still determined to be reasonable.

Reporting to the ISCR had a higher completion rate for lung cancer compared to melanoma, based upon the additional cases identified in the INPC. Prior study has reported that timeliness of reporting varies by cancer type. Such variation may be explained by the fact that different types of cancers are more likely to be diagnosed in different health care settings. Similar to timeliness, completeness may also be influenced by the reporting institution. Cancers diagnosed in hospitals may more often be reported to the state cancer registry than those diagnosed in non-hospital settings. Specifically, lung cancer is more likely to be not only diagnosed, but treated, in hospitals than melanoma, and thus, may have more complete reporting than melanoma which is more likely to be diagnosed in independent laboratories or physicians’ clinics.

These findings confirm that administrative data alone (in this case, from the RHIO) has a limited ability for cancer case identification due to high false positive rates, reinforcing that ICD-9 data should not be used as a stand-alone approach. In fact, the INPC does not have access to comprehensive administrative data from any single insurance source, further limiting its potential for case identification. Among the INPC cases that could not be linked to the ISCR, only a small proportion (22% for melanoma and 7.5% for lung cancer) could be validated as true cancer incident cases during the study period. The state cancer registry data still serves a vital function in the identification of incident cases (which is not possible from claims data) with detailed site and staging information. Data from EHRs are unlikely to further enrich the state cancer registry with information about previously unrecognized incident cancer cases without the addition of natural language processing abilities across an adequate supply of clinical documents.

**Conclusion**

In summary, it is concluded that by linking the ISCR with the INPC, the ISCR is able to identify missing cancer cases. Although the accuracy of the ISCR is high, identification of any missing cases adds value to the overall accuracy of the ISCR, and it ensures proper incidence and mortality can be assessed and targeted approaches for cancer control can be implemented across the state. One can also ascertain that for epidemiological studies based on large databases such as a HIEs and EHRs, case identification using cancer registries that can be linked to EHRs will provide definitively diagnosed cancer cases with the added advantage of rich data on treatment, disease progression, and outcomes.

Most, but not all, patients with specific cancers identified by ICD-9 codes in the INPC could be linked to the ISCR. Among those who could not be linked, about half were found to be false negatives from the registry perspective, ie, a cancer was present based on manual review of their EHRs in INPC. The public health importance of this approach is significant. The potential of a HIE to capture cancer cases in real time, especially cases that are not otherwise identified by the state cancer registry, suggests future models for disease surveillance using EHR data.

**References**

Abstract: Background: Some guidelines advise adjuvant chemotherapy be considered after surgical resection for high-risk stage II colon cancer patients; however, high-risk criteria are poorly defined and the long-term benefits are still debated. This study documents patterns of care by selected patient and tumor characteristics using a US population-based cohort of stage II colon cancer patients diagnosed in 2011. Methods: Data were collected from 10 specialized cancer registries participating in the Centers for Disease Control and Prevention’s National Program of Cancer Registries’ Enhancing Cancer Registry Data for Comparative Effectiveness Research project. The data were used to describe characteristics of stage II colon cancer patients treated by surgery to evaluate factors associated with receiving adjuvant chemotherapy. Results: Of the 3,891 stage II colon cancer patients, 14.3% were treated with surgery and adjuvant chemotherapy compared to 82.9% by surgery alone. The patients treated with adjuvant chemotherapy were predominately non-Hispanic white (66.1%), of younger age, and had private insurance (39.9%). Compared to surgery alone, the 5 characteristics associated with adjuvant therapy were younger age (adjusted odds ratio [AOR] for 5-year decrease below 75 years, 1.25; \( P < .001 \)); more advanced stage (IIIB/IIC vs IIA) (AOR, 4.79; \( P < .001 \)); lymphovascular invasion (AOR, 1.76, \( P < .001 \)); higher grade (III/IV vs I/II) (AOR, 1.84; \( P < .001 \)); and registry area. Conclusions: In this population-based cohort, younger patients with more advanced stage II colon tumors, with lymphovascular invasion, and poor differentiation were more likely to receive adjuvant chemotherapy in addition to surgery. These characteristics align with high-risk profiles defined in guidelines. Ongoing data collection on outcomes, including recurrence and survival, will help clarify the benefits of adjuvant treatments for stage II colon patients.

Key words: adjuvant, cancer registries, chemotherapy, colonic neoplasms, National Program of Cancer Registries, stage II

Background

In 2012, colon cancer was the fourth leading cause of cancer incidence and mortality in the United States, representing 71% of the cancers of large intestine (colon and rectum), with an age adjusted incidence rate of 27.8 per 100,000 persons. While surgery has been the primary curative treatment mode for colon cancer, adjuvant chemotherapy has been shown to decrease the risk of recurrence in some patients. However, early assessments of the survival benefits of adjuvant therapy did not support its use for all resected stage II colon cancer patients. The American Society of Clinical Oncology’s (ASCO) guidelines indicated in 2004 that clinical trial evidence was insufficient to recommend adjuvant chemotherapy but the benefits in stage III patients could be considered in making treatment decisions in high-risk stage II patients. Following these recommendations, the benefit of adjuvant chemotherapy for stage II cancer cases was assessed in multiple studies with varied conclusions. Based on evidence from randomized clinical trials, Jonker et al argued high-risk stage II patients had survival more similar to stage III disease with a 5-year overall survival of 40% to 50%. However, their resulting conclusions mirrored ASCO’s guidelines since the risks of adjuvant chemotherapy are significant and must be weighed against the possible benefits.

Similar to previous recommendations, the National Comprehensive Cancer Network 2016 treatment guidelines for surgically resected, stage II colon cancer patients include adjuvant treatment options ranging from clinical trial recruitment and initiation of standard follow-up testing, to considering specific chemotherapies. However, the risks related to chemotherapy contrasted with the potential for reduced recurrence makes this decision a complex one. Therefore, while the identification of high-risk stage II patients is critical when determining adjuvant treatment approaches, the definition of what constitutes high risk is unclear. A number of factors that could place a patient into a high-risk category have been suggested; however, a single
list of proven prognostic characteristics has not been identified. Tumor characteristics studied which may be prognostic include vascular invasion, T4 lesion, bowel perforation, inadequately sampled lymph nodes, poor differentiation, bowel obstruction, and microsatellite instability. 8 Those with less evidence include KRAS (mutation indicative of poorer survival and no benefit from adjuvant therapy) 11 and carcinoembryonic antigen (CEA). 12 Clinical trials have not been able to clearly identify specific prognostic factors, in part due to insufficient numbers of patients with these characteristics who can be prospectively followed. 13

Prior population-based studies have been limited with respect to geographic and population characteristics, including age. 14-16 Given the variation in clinical recommendations and the lack of precision in defining high-risk stage II colon cancer patients, receipt of adjuvant chemotherapy may vary significantly by characteristics of the tumor as well as patient characteristics. 13 Focusing on stage II colon cancer cases diagnosed in 2011, we evaluated the use of adjuvant treatment by tumor and patient characteristics in a population-based study that spanned 10 US states and included people of all ages, genders, and races/ethnicities in these areas.

Methods

Detailed methods of the National Program of Cancer Registries (NPCR) Enhancing Cancer Registry Data for Comparative Effectiveness Research (CER) project have previously been described. 17 In brief, in addition to the North American Association of Central Cancer Registries (NAACCR) standard data variables 18 that population-based cancer registries routinely collect (eg, patient demographics, tumor characteristics, and cancer stage), the 10 NPCR CER specialized registry areas (including the entire states of Alaska, Colorado, Idaho, Louisiana, New Hampshire, North Carolina, Rhode Island and Texas, as well as 13 counties of the California Sacramento region, and 5 Miami, Florida metro counties) also collected expanded patient information. This includes census tract-level socioeconomic status, tumor biomarkers, and detailed first course of cancer-directed treatment. 17, 19

First course of cancer treatment was defined as the therapy regimen that was given or planned at the time of initial diagnosis, prior to disease recurrence or progression. 19 In addition to the routinely collected detailed information on surgery and radiation, the CER project also collected complete adjuvant treatment occurring within 12 months of diagnosis. The chemotherapy data included each chemotherapy agent’s name and Chemotherapy National Service Center (NSC) number, plus start and end dates of chemotherapy by agent.

Data were abstracted from hospital and nonhospital (for example, outpatient and independent hematology/oncology practice groups) sources. Cases were followed back to treating physician and/or facility to obtain missing information. First course of treatment received within 12 months of diagnosis was edited and consolidated so that the data could be provided for comparative effectiveness of treatments. All CER areas ran their data through the NAACCR Hispanic Identification Algorithm 20 and the NAACCR Asian/Pacific Islander Identification Algorithm. 21 They also participated in linkages with the Indian Health Service to improve the quality of their data on race and ethnicity. 22

In this study, cases were male and female patients diagnosed in 2011 with colon cancer (American Joint Commission on Cancer, 7th edition [AJCC-7] criteria; primary site C18.0-18.9 and all histologies except 9050-9055, 9140, and 9590-9992) at stage II, categorized using the Collaborative Stage AJCC-7 derived stage group variable. 24 Data from the November 2014 submission to the Centers for Disease Control and Prevention were used in this analysis. We excluded patients who died 30 days or less after resection (n = 152), were identified only through a death certificate or autopsy report (n = 3), were missing race (n = 8), were missing sex or were coded as “other” sex (n = 1), or whose adjuvant chemotherapy was initiated 365 days or more after resection (n = 2), resulting in 3,891 stage II colon cancer patients in the analysis.

Frequencies and percentages were calculated for patients’ demographics, tumor, and treatment characteristics using SAS 9.3 (SAS Institute). Demographic characteristics included: sex, race/ethnicity, age, chronic disease status (using Charlson comorbidity index comorbidities), 25 which were grouped into 3 categories: non-Charlson comorbidity, 1 Charlson comorbidity or 2 or more Charlson comorbidities; those who were coded as having no comorbidity were set to unknown, as this category could have included both individuals having no comorbid conditions and situations where there was no mention of comorbidity in the medical record, insurance payer, and US census tract level measures of family poverty status and urbanization. Census tracts were created by geocoding patient’s residence at the time of diagnosis and linking case data with Census Bureau census tract level socioeconomic indicators, including family poverty level (percent of families below Federal poverty level) and urbanization (100% urban setting, 100% rural setting, and mixed urban and rural settings). 17 Tumor characteristics were stage category (IIA, IIB, or IIC based on whether the primary tumor is classified as T3, T4a, or T4b, respectively), grade, number of nodes examined (total number of regional lymph nodes that were removed and examined by a pathologist), and lymphatic and/or vascular invasion (as reported in the pathology report). Treatment was categorized as surgery-only or surgery plus adjuvant chemotherapy, based on dates of surgery and start date of chemotherapy and a valid NSC chemotherapy agent for treating colon cancer.

Statistically significant (P < .05) characteristics associated with patients receiving adjuvant chemotherapy in addition to surgical resection were assessed using logistic regression. Due to a high percentage of missing comorbidity data, a multivariate analysis was conducted using multiple imputations for missing data. The imputation was conducted using R (3.14-5) 26 software, Hmisc 27 package’s aregImpute function. This method consists of multiple imputations using predictive mean matching. Ultimately, the imputed data were not used because characteristics
associated with patients receiving adjuvant chemotherapy did not differ and also the significance level of association in the models using imputed and non-imputed data did not differ greatly. Furthermore, comorbidity was not significant after adjusting for other covariates and was excluded from the final model.

The final model was developed using backward elimination variable selection. The linearity assumption for the continuous age variable was tested using restricted cubic spline functions and it was found to be nonlinear. The age variable was transformed in the final model using a linear spline. Age was split into 2 linear segments at age 75 and the odds ratios for this continuous variable are presented for 5-year increments. Additional information on restricted cubic spline regression and transforming independent variables is available at [http://support.sas.com/resources/papers/proceedings16/5621-2016.pdf](http://support.sas.com/resources/papers/proceedings16/5621-2016.pdf) (Croxford R. Restricted cubic spline regression: a brief introduction. SAS Paper 5621-2016). Cases missing adjuvant chemotherapy information (n = 110) were excluded from the final model. Patient’s sex and race/ethnicity were controlled for in the final model, although they were not significant. Modeling was conducted in R (version 3.1.1).27

Results

Of the 3,891 stage II colon cancer patients diagnosed in the 10 specialized registry areas, 14.3% (n = 557) were treated with adjuvant chemotherapy following surgery and 82.9% (n = 3,224) were treated with surgery alone (Table 1). The percent distributions of sex between the treatment groups were similar; 52.0% of the surgery alone and 51.2% of the surgery plus adjuvant patients were women. The distribution of race/ethnicity for surgery-only patients and surgery plus adjuvant patients was 70.1% vs 66.1% non-Hispanic white, 12.2% vs 14.4% non-Hispanic black, and 14.6% vs 16.3% Hispanic (Table 1). The patients who were treated with adjuvant chemotherapy were younger (median age: 60.9 years) compared to surgery-only patients (median age: 70.7 years). Correspondingly, there was a higher percent of patients with 2 or more Charlson comorbidity conditions among the surgery-only patients compared to those receiving adjuvant therapy (10.6% vs 5.9%, respectively). A larger proportion of surgery-only patients were covered by Medicare alone (44.6%) than those treated with surgery and adjuvant chemotherapy (28.0%) (Table 1).

The 2 treatment groups were similar in sociodemographic characteristics. The census level assessment of poverty (ie, patients who lived in a census tract where ≥20% of families had incomes below the Federal poverty line in the last 12 months) for surgery-only patients and surgery plus adjuvant patients was 17.4% and 14.2%, respectively. Also, the percent of surgery-only patients living in a 100% urban census tract, as defined by the US Census, was 58.9% and 52.4% for patients also receiving adjuvant chemotherapy (Table 1).

There were differences in the tumor characteristics of the 2 treatment groups. These included stage: the surgery-only patients had a higher frequency of stage IIA (89.5%) than the patients treated with surgery and adjuvant chemotherapy (65.7%). Surgery-only patients also had a lower frequency of grade III cancer (14.0%) compared to patients treated with adjuvant chemotherapy (21.5%); and lymphovascular invasion was present less frequently among surgery-only patients (11.3%) than patients treated with surgery and adjuvant chemotherapy (20.8%). However, the 2 groups were similar in regards to the number of nodes examined: 85.2% and 85.1% of the surgery-only patients and surgery plus adjuvant therapy patients, respectively, had 12 or more nodes examined (Table 1).

Table 2 shows the 5 characteristics associated with a patient being treated by surgery and adjuvant chemotherapy: younger age (in age segment below 75 years, every 5-year decrease was associated with an adjusted odds ratio [AOR] of 1.25; 95% CI, 1.18–1.31; and for age segment above 75 years, every 5-year decrease was associated with AOR of 2.80; 95% CI, 2.12–3.68); higher stage (AOR comparing IIB/IIC to IIA, 4.79; 95% CI, 3.71–6.17); higher tumor grade (AOR comparing Grade High III/IV vs Low I/II, 1.84; 95% CI, 1.41–2.40); the presence of lymphovascular invasion (AOR comparing invasion to no invasion, 1.76; 95% CI, 1.34–2.31); and registry area (for example, AOR comparing North Carolina to Texas, 1.54; 95% CI, 1.12–2.11 and AOR comparing Rhode Island to Texas, 2.61; 95% CI, 1.37–4.98).

Discussion

For patients with surgically resected stage II colon cancer, adjuvant chemotherapy is not always beneficial or routinely recommended. Identification of characteristics that indicate a higher risk of recurrence or progression is important in avoiding the risks associated with chemotherapy in patients who are not likely to benefit.3,8 We examined the use of adjuvant therapy in a population-based study utilizing data from 10 population-based cancer registries which collected expanded data for colorectal cancer patients diagnosed in 2011. The inclusion of all stage II colon cancer patients allows an unbiased examination to the use of adjuvant chemotherapy in this study population.

Only 14.3% of stage II colon cancer patients in our study were treated with adjuvant chemotherapy after surgery. Those treated with adjuvant chemotherapy tended to be younger (median age, 60.9 years) than those treated with surgery alone (median age, 70.7 years). There was a nonlinear relationship between chemotherapy and age. When age was modeled as 2 linear segments, we found that, among patients younger than 75 years, those 5 years younger had 1.25 times the odds of receiving surgery and adjuvant chemotherapy compared to someone 5 years older. Among patients older than 75 years, the effect was larger: someone 5 years younger had 2.80 times the odds of receiving surgery and adjuvant chemotherapy than an individual 5 years their senior.

Adjuvant chemotherapy was more frequently used in patients whose cancer was a stage IIB or IIC and somewhat more common for those with a high grade tumor or lymphovascular invasion. Having 2 or more Charlson comorbidities and Medicare-only insurance was more common among those with surgery alone. We did find geographic differences in treatment patterns (specifically,
Table 1. Selected Demographic, Tumor, and Treatment Characteristics of Individuals with Stage II Colon Cancer Diagnosed in 2011 within 10 NPCR Cancer Registry Areas

<table>
<thead>
<tr>
<th></th>
<th>Stage II Colon Cancer</th>
<th>Stage II, Surgery Alone</th>
<th>Stage II, Surgery and Adjuvant Chemotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 3,891</td>
<td>n = 3,224</td>
<td>n = 557</td>
</tr>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
<td>Frequency</td>
</tr>
<tr>
<td>Treatments classification</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery alone</td>
<td>3,224</td>
<td>82.9</td>
<td>3,224</td>
</tr>
<tr>
<td>Chemotherapy alone</td>
<td>—</td>
<td>—</td>
<td>N/A</td>
</tr>
<tr>
<td>Surgery and adjuvant chemotherapy</td>
<td>557</td>
<td>14.3</td>
<td>N/A</td>
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<tr>
<td>Neo-adjuvant chemotherapy</td>
<td>—</td>
<td>—</td>
<td>N/A</td>
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<tr>
<td>No surgery or chemotherapy</td>
<td>41</td>
<td>1.1</td>
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<tr>
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<td>45</td>
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<tr>
<td>Sex</td>
<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>1,879</td>
<td>48.3</td>
<td>1,547</td>
</tr>
<tr>
<td>Female</td>
<td>2,012</td>
<td>51.7</td>
<td>1,677</td>
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<tr>
<td>Race-ethnicity</td>
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<tr>
<td>Non-Hispanic white</td>
<td>2,699</td>
<td>69.4</td>
<td>2,261</td>
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<tr>
<td>Non-Hispanic black</td>
<td>485</td>
<td>12.5</td>
<td>392</td>
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<tr>
<td>Hispanic</td>
<td>589</td>
<td>15.1</td>
<td>472</td>
</tr>
<tr>
<td>Non-Hispanic other</td>
<td>118</td>
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<td>99</td>
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<tr>
<td>Age (years)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>0-49</td>
<td>299</td>
<td>7.7</td>
<td>183</td>
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<tr>
<td>50-59</td>
<td>609</td>
<td>15.7</td>
<td>456</td>
</tr>
<tr>
<td>60-69</td>
<td>951</td>
<td>24.4</td>
<td>749</td>
</tr>
<tr>
<td>70-79</td>
<td>1,071</td>
<td>27.5</td>
<td>926</td>
</tr>
<tr>
<td>≥ 80</td>
<td>961</td>
<td>24.7</td>
<td>910</td>
</tr>
<tr>
<td>Age (years) – Median</td>
<td>69.2</td>
<td>70.7</td>
<td>60.9</td>
</tr>
<tr>
<td>Chronic disease status</td>
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<tr>
<td>Non-Charlson comorbidity</td>
<td>1,411</td>
<td>36.3</td>
<td>1,130</td>
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<td>1 Charlson comorbidity</td>
<td>828</td>
<td>21.3</td>
<td>697</td>
</tr>
<tr>
<td>≥ 2 Charlson comorbidity</td>
<td>382</td>
<td>9.8</td>
<td>341</td>
</tr>
<tr>
<td>No comorbidity or missing data</td>
<td>1,270</td>
<td>32.6</td>
<td>1,056</td>
</tr>
<tr>
<td>Payer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No insurance</td>
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<td>5.9</td>
<td>163</td>
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<tr>
<td>Private</td>
<td>1,057</td>
<td>27.2</td>
<td>807</td>
</tr>
<tr>
<td>Public: Medicaid</td>
<td>375</td>
<td>9.6</td>
<td>312</td>
</tr>
<tr>
<td>Public: Medicare (only)</td>
<td>1,638</td>
<td>42.1</td>
<td>1,438</td>
</tr>
<tr>
<td>Public: Medicare and private</td>
<td>365</td>
<td>9.4</td>
<td>322</td>
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<tr>
<td>Other</td>
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<tr>
<td>Unknown/missing</td>
<td>101</td>
<td>2.6</td>
<td>84</td>
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<tr>
<td>Poverty group (census level)</td>
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<tr>
<td>Not in poverty</td>
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<td>2,644</td>
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<td>Poverty</td>
<td>674</td>
<td>17.3</td>
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<td>Unknown/missing</td>
<td>25</td>
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</table>
Table 1, cont. Selected Demographic, Tumor, and Treatment Characteristics of Individuals with Stage II Colon Cancer Diagnosed in 2011 within 10 NPCR Cancer Registry Areas

<table>
<thead>
<tr>
<th></th>
<th>Stage II Colon Cancer</th>
<th>Stage II, Surgery Alone</th>
<th>Stage II, Surgery and Adjuvant Chemotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 3,891</td>
<td>n = 3,224</td>
<td>n = 557</td>
</tr>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
<td>Frequency</td>
</tr>
<tr>
<td>Urban / Rural (census level)\textsuperscript{h}</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>100% urban</td>
<td>2,240</td>
<td>57.6</td>
<td>1,899</td>
</tr>
<tr>
<td>100% rural</td>
<td>369</td>
<td>9.5</td>
<td>297</td>
</tr>
<tr>
<td>Mixed urban and rural</td>
<td>1,260</td>
<td>32.4</td>
<td>1,010</td>
</tr>
<tr>
<td>Unknown/missing</td>
<td>22</td>
<td>0.6</td>
<td>18</td>
</tr>
<tr>
<td>Derived stage\textsuperscript{i}</td>
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<td></td>
<td></td>
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<tr>
<td>Stage IIA</td>
<td>3,305</td>
<td>84.9</td>
<td>2,884</td>
</tr>
<tr>
<td>Stage IIIB</td>
<td>294</td>
<td>7.6</td>
<td>193</td>
</tr>
<tr>
<td>Stage IIC</td>
<td>285</td>
<td>7.3</td>
<td>143</td>
</tr>
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<td>Stage II NOS</td>
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<td>—</td>
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<tr>
<td>Grade</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well differentiated (I)</td>
<td>317</td>
<td>8.2</td>
<td>270</td>
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<tr>
<td>Moderately differentiated (II)</td>
<td>2,811</td>
<td>72.2</td>
<td>2,386</td>
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<tr>
<td>Poorly differentiated (III)</td>
<td>591</td>
<td>15.2</td>
<td>452</td>
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<tr>
<td>Undifferentiated (IV)</td>
<td>65</td>
<td>1.7</td>
<td>49</td>
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<tr>
<td>Unknown / missing</td>
<td>107</td>
<td>2.8</td>
<td>67</td>
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<tr>
<td>Lymphovascular invasion</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Not present</td>
<td>2,668</td>
<td>68.6</td>
<td>2,269</td>
</tr>
<tr>
<td>Present</td>
<td>484</td>
<td>12.4</td>
<td>363</td>
</tr>
<tr>
<td>Not applicable</td>
<td>125</td>
<td>3.2</td>
<td>101</td>
</tr>
<tr>
<td>No information in pathology report</td>
<td>299</td>
<td>7.7</td>
<td>230</td>
</tr>
<tr>
<td>Missing</td>
<td>315</td>
<td>8.1</td>
<td>261</td>
</tr>
<tr>
<td>Number of nodes examined</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>78</td>
<td>2.0</td>
<td>22</td>
</tr>
<tr>
<td>1-11</td>
<td>521</td>
<td>13.4</td>
<td>435</td>
</tr>
<tr>
<td>≥12</td>
<td>3,266</td>
<td>83.9</td>
<td>2,748</td>
</tr>
<tr>
<td>Unknown / missing</td>
<td>26</td>
<td>0.7</td>
<td>19</td>
</tr>
</tbody>
</table>

N/A, not applicable; NOS, not otherwise specified; NPCR, National Program of Cancer Registries.
\textsuperscript{a}American Joint Commission on Cancer 7th Edition definition of colon cancer. Excludes those with death certificate diagnosis only/autopsy diagnosis only, sex unknown or other, or race unknown.
\textsuperscript{b}Demographics of patients with multiple sequence numbers are only reported once; this excludes 31 observations.
\textsuperscript{c}Frequencies and percentages suppressed if fewer than 16 cases were reported in a specific category.
\textsuperscript{d}Treatment classification was not possible as information on the patient’s surgery data, chemotherapy and/or chemotherapeutic agent information were missing.
\textsuperscript{e}Non-Hispanic other includes American Indian or Alaskan Native and Asian or Pacific Islander.
\textsuperscript{f}Other insurance includes Tricare, Veterans Affairs, and Indian/Public Health Service.
\textsuperscript{g}Not in poverty defined as <20% of census tract families had income below Federal poverty line in last 12 months; Poverty defined as: ≥20% of census tract families had income below poverty line in last 12 months.
\textsuperscript{h}A census tract residence was considered urban if all households in that census tract were considered to be in an urban setting as defined by the Census Bureau, rural if all households in that census tract were considered to be in a rural setting, and mixed if some of the households in the census tract were considered to be in an urban setting and some in a rural setting.
\textsuperscript{i}American Joint Commission on Cancer 7th Edition Stage Group from coded fields using Collaborative Stage algorithm.
Table 2. Characteristics Associated with Being Treated by Surgery and Adjuvant Chemotherapy vs Surgery Alone for Individuals with Stage II Colon Cancer Diagnosed in 2011 within 10 NPCR Cancer Registries

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Unadjusted Odds Ratio</th>
<th>95% CI</th>
<th>P</th>
<th>Adjusted Odds Ratio</th>
<th>95% CI</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, 5-year decrease in the below 75 years segment</td>
<td>1.21</td>
<td>1.16–1.27</td>
<td>&lt;.001</td>
<td>1.25</td>
<td>1.18–1.31</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Age, 5-year decrease in the above 75 years segment</td>
<td>2.42</td>
<td>1.91–3.07</td>
<td>&lt;.001</td>
<td>2.80</td>
<td>2.12–3.68</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Stage (IIB/IIC vs IIA)</td>
<td>4.43</td>
<td>3.60–5.46</td>
<td>&lt;.001</td>
<td>4.79</td>
<td>3.71–6.17</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Grade (High III/IV vs Low I/II)</td>
<td>1.77</td>
<td>1.42–2.19</td>
<td>&lt;.001</td>
<td>1.84</td>
<td>1.41–2.40</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Lymphovascular invasion (invasion vs no invasion)</td>
<td>1.96</td>
<td>1.55–2.48</td>
<td>&lt;.001</td>
<td>1.76</td>
<td>1.34–2.31</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Sex (male vs female)</td>
<td>1.04</td>
<td>0.86–1.24</td>
<td>.71</td>
<td>0.95</td>
<td>0.77–1.18</td>
<td>.66</td>
</tr>
</tbody>
</table>

Race/ethnicity

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>Unadjusted Odds Ratio</th>
<th>95% CI</th>
<th>P</th>
<th>Adjusted Odds Ratio</th>
<th>95% CI</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic black vs Non-Hispanic white</td>
<td>1.25</td>
<td>0.96–1.63</td>
<td>.39</td>
<td>0.95</td>
<td>0.69–1.31</td>
<td>.75</td>
</tr>
<tr>
<td>Hispanic vs Non-Hispanic white</td>
<td>1.19</td>
<td>0.92–1.52</td>
<td>.70</td>
<td>1.15</td>
<td>0.82–1.60</td>
<td>.41</td>
</tr>
<tr>
<td>Non-Hispanic other vs Non-Hispanic white</td>
<td>1.12</td>
<td>0.67–1.87</td>
<td>.94</td>
<td>0.97</td>
<td>0.50–1.87</td>
<td>.92</td>
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</table>

NPCR CER area or registry

<table>
<thead>
<tr>
<th>NPCR CER area or registry</th>
<th>Unadjusted Odds Ratio</th>
<th>95% CI</th>
<th>P</th>
<th>Adjusted Odds Ratio</th>
<th>95% CI</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska vs Texas</td>
<td>0.94</td>
<td>0.37–2.43</td>
<td>.61</td>
<td>0.75</td>
<td>0.24–2.36</td>
<td>.62</td>
</tr>
<tr>
<td>California-Sacramento b vs Texas</td>
<td>0.71</td>
<td>0.45–1.14</td>
<td>.02</td>
<td>0.91</td>
<td>0.51–1.59</td>
<td>.73</td>
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<tr>
<td>Colorado vs Texas</td>
<td>1.14</td>
<td>0.80–1.65</td>
<td>.88</td>
<td>1.20</td>
<td>0.77–1.86</td>
<td>.42</td>
</tr>
<tr>
<td>Florida-Metro Miami c vs Texas</td>
<td>1.22</td>
<td>0.92–1.61</td>
<td>.79</td>
<td>1.28</td>
<td>0.91–1.81</td>
<td>.16</td>
</tr>
<tr>
<td>Idaho vs Texas</td>
<td>1.57</td>
<td>0.94–2.62</td>
<td>.22</td>
<td>2.16</td>
<td>1.18–3.95</td>
<td>.01</td>
</tr>
<tr>
<td>Louisiana vs Texas</td>
<td>1.88</td>
<td>1.40–2.53</td>
<td>&lt;.001</td>
<td>2.05</td>
<td>1.42–2.97</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>North Carolina vs Texas</td>
<td>1.46</td>
<td>1.12–1.90</td>
<td>.08</td>
<td>1.54</td>
<td>1.12–2.11</td>
<td>.01</td>
</tr>
<tr>
<td>New Hampshire vs Texas</td>
<td>0.60</td>
<td>0.29–1.26</td>
<td>.05</td>
<td>0.70</td>
<td>0.31–1.58</td>
<td>.39</td>
</tr>
<tr>
<td>Rhode Island vs Texas</td>
<td>2.06</td>
<td>1.19–3.57</td>
<td>.03</td>
<td>2.61</td>
<td>1.37–4.98</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

NPCR, National Program of Cancer Registries.

a American Joint Commission on Cancer 7th Edition Stage Group from coded fields using Collaborative Stage algorithm

b California-Sacramento includes Alpine, Amador, Calaveras, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Solano, Sutter, Yolo, and Yuba counties.

c Florida-Miami includes Broward, Hillsborough, Miami-Dade, Orange, and Palm Beach counties.

more adjuvant chemotherapy in Idaho, Louisiana, North Carolina and Rhode Island); however, we did not detect an obvious regional effect. Our statistical modeling included race and ethnicity in addition to demographics: insurance status, urban/rural residence, Charlson comorbidities, and poverty status based on census tracts. In the final model, the factors significantly associated with receiving adjuvant therapy following surgery were: younger age, stage (IIB/IIC vs IIA), grade (high vs low); lymphovascular invasion (presence vs absence) and registry area. More advanced stage of disease (stage IIB/C) was the strongest indicator for adjuvant therapy with an adjusted odds ratio of 4.79 (3.71–6.17) when compared to stage IIA patients.

While our study provides population-based data, there were limitations with respect to the analysis. Because cancer registry data are based on clinically-relevant data available in the medical chart and some factors known to influence patterns of care are not routinely and consistently captured in clinical documentation, we were unable to examine some variables of interest such as patient’s preference. We were not able to examine individual level measures of poverty or “urbanicity” and instead used area-based measures. We also did not have needed detail to explore the differences identified among the registry areas. With respect to high-risk tumor characteristics, we were not able to examine colon obstruction or microsatellite instability, which may have influenced treatment decisions (the project did not collect data on colon obstruction and, while microsatellite instability was collected, the number of missing values was too high to allow for inclusion in the analyses). Though information on comorbidities was collected from medical charts and data linkages for this study, we could not discern between those instances where no comorbidities existed and when data were missing. Consequently, a large proportion of the comorbidity information was treated as missing. There were indications in the modeling that those with 2 or more Charlson comorbidities were less likely to receive adjuvant chemotherapy; however, multiple imputation was used to impute missing comorbidity data and comorbidities overall were not significant in the final model. The presence of comorbid conditions has been shown to be associated with less aggressive treatment in other population-based studies.
Increasing age is often associated with the presence of comorbid conditions and both are related to cancer survival. The relationship between age, comorbidity, and cancer is a complex, influencing the risk of cancer occurrence, treatment, and outcomes. In our study, increasing age was significantly associated with less aggressive treatment, but we were not able to fully explore the possible confounding relationship between age and comorbidities. However, a meta-analysis of treatment in colorectal cancer patients of all stages indicated that older patients in good health otherwise had survival benefits from the use of chemotherapy. Health insurance status has been found to influence many aspects of cancer care; however, it is also strongly correlated with age because of the eligibility criteria for Medicare coverage. Because of this collinearity, insurance was removed from the final model for our study.

Conclusions

Within the 10 geographic areas included in this study, surgery is often used alone for stage II colon cancer patients, particularly for stage IIA. In addition, in most, though certainly not all cases, adjuvant therapy was focused on patients with the higher risk characteristics that had been identified in practice-based guidelines at the time that treatment decisions were made. These findings correspond with guideline recommendations that adjuvant chemotherapy should not be routinely administered and physicians consider discussing the option with patients who are at risk of recurrence. Given the variation in the characteristics of the states and regions included in this study, the surgical and chemotherapy practices are likely similar to those that would be found throughout the United States. Our study included all ages, genders, races, and income levels which can only be accomplished through a large population-based cohort. This population is being followed and data collected on recurrence, progression, and mortality. Subsequent comparative effectiveness analyses based on these data will provide population-based assessments of survival outcomes among these patients.

Acknowledgments

The authors wish to acknowledge the contributions of the NPCR CER cancer registry personnel.

References


Are Benign and Borderline Brain Tumors Underreported?

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Abstract: Background: Primary benign and borderline (BB) brain tumors have been reportable since 2004 by population-based cancer registries in the United States. Because these tumors often are diagnosed clinically at nonhospital settings, underreporting is a big concern. Despite this, the magnitude and geographic variations in underreporting are unknown. The objectives of this study are to assess variations in BB brain tumor incidence rate by registry and trend in comparison to malignant brain tumors, as well as to identify the factors associated with the completeness of BB brain tumor reporting. Methods: North American Association of Central Cancer Registries (NAACCR) Cancer in North America (CINA) Deluxe 1995–2012 Analytic File, which included data from 47 US population-based cancer registries, was used. Age-adjusted incidence rate and average annual percent change (APC) were calculated. Correlation coefficients were used to assess the relationships between incidence rates and clinical factors. Results: The overall age-adjusted incidence rate was 14.2 per 100,000 for BB brain tumors and 6.6 per 100,000 for malignant brain tumors. The age-adjusted incidence rates of BB brain tumors varied by registry from 9.8 per 100,000 to 19.9 per 100,000, whereas the variations in malignant brain tumors were much smaller from 4.1 per 100,000 to 7.7 per 100,000. BB brain tumor cases were more likely than malignant brain tumors to be diagnosed through radiography without microscopic confirmation or surgery. Overall, the BB brain tumor incidence rate significantly increased by 2.3% per year from 2004 to 2012. In contrast, incidence rates of malignant brain tumors significantly decreased by 0.9% per year in the same period. Higher BB brain tumor incidence rates were significantly associated with higher proportions of cases without microscopic confirmation or surgery. These associations were not observed for malignant brain tumors. Conclusions: Incidence rates of BB brain tumors varied substantially across 47 US registries and were higher than those of malignant brain tumors in the United States. The variations in incidence rate of BB brain tumors may be largely attributable to difference in identifying clinically diagnosed cases. The increasing incidence rate of BB brain tumors may reflect improved case ascertainment rather than a biological trend.

Key words: benign and borderline brain tumors, cancer registry, incidence rate, underreporting

Introduction

Although benign and borderline (BB) brain tumors rarely invade adjacent tissues and do not spread to other parts of the body, they can press on sensitive areas of the brain and central nervous system (CNS), producing severe clinical effects and causing serious health problems, which may even be life threatening. The collection of BB brain tumors is mandated by Public Law 107-260, the Benign Brain Tumors Cancer Registries Amendment Act (signed by President George W. Bush in October 2002). BB brain tumors with International Classification of Diseases for Oncology, 3rd edition (ICD-O-3) behavior codes /0 for benign and /1 for borderline diagnosed in January 1, 2004 and after are reportable by all state cancer registries in the United States receiving funding from the Centers for Disease Control and Prevention (CDC)’s National Program of Cancer Registries (NPCR) or the National Cancer Institute (NCI)’s Surveillance, Epidemiology, and End Results (SEER) Program.

Compared with malignant brain tumors, BB brain tumors are more likely to be clinically diagnosed, and patients usually do not receive any surgery until the tumors become life threatening, which may occur years after the initial diagnosis. Due to limited resources, many cancer registries do not routinely conduct casefinding at radiography centers, clinics, and physician offices. Although underreporting of BB brain tumors is a big concern, relatively little is known about the magnitude of the issue and the underlying causes. The purposes of this study are to assess variations of BB brain tumor incidence rate by registry and incidence rate trends of BB brain tumor in comparison to malignant brain tumors, to identify the factors that are associated with BB brain tumors reporting, and to discuss and explore target approaches to improve in case ascertainment and reporting of the BB brain tumors.

Data and Methods

Data Source

Data from 47 US population-based cancer registries including the District of Columbia were obtained from the North American Association of Central Cancer Registries (NAACCR) Cancer in North America (CINA) Deluxe Analytic File. We included BB and malignant brain and
Primary brain and CNS tumors sites were defined based on ICD-O-3 topography codes of C70.0–C70.9, C71.0–C71.9, C72.0–C72.9, and C75.1–C75.3, which were obtained from the SEER nonmalignant brain tumors reportable cases website.2 BB tumors were defined using ICD-O-3 behavior codes of “0” (benign) or “1” (borderline), and malignant tumors were defined using codes of “3” (malignant). Minnesota and Puerto Rico were not included in the NAACCR CINA Deluxe analytic file; Kansas, Arkansas, and Nevada were excluded because data were incomplete for 2004–2012 diagnosis years. Death-certificate only and autopsy cases were excluded.

The outcomes of interest were age-adjusted incidence rates of BB and malignant brain tumors, as well as the rate ratios of BB versus malignant brain tumors at both individual registry level and all data combined. Demographics and clinical variables, such as age, race, gender, type of diagnostic confirmation, surgery status, and type of reporting source, were also included in the analysis.

We categorized diagnostic confirmation as microscopically confirmed, nonmicroscopically confirmed, and unknown. Microscopically confirmed included positive histology, positive cytology, and positive microscopic confirmation, method not specified. Surgery status was defined as no surgery, surgery (codes 10 to 90), and unknown. The type of reporting source was grouped into 2 categories: hospital and nonhospital. Hospital included hospital inpatient/outpatient or clinic, radiation or medical oncology center, and other hospital outpatient units/surgery centers. The nonhospital group included laboratory only, physician’s office, and nursing home/hospice.

### Statistical Analysis

SEER*STAT version 8.2.1 was used to generate age-adjusted incidence rates based on the standard US 2000 population and average annual percent changes (APCs) for BB brain tumors and malignant brain tumors.3,4 To examine the correlation between age-adjusted incidence rates for BB brain tumors and malignant brain tumors, the rate ratios were calculated and statistical significances were examined. Pearson correlation coefficients were used to assess the relationships between age-adjusted incidence rates (BB brain tumors and malignant brain tumors, respectively) and clinical factors, including the proportion of cases without microscopic confirmation, the proportion of cases with no surgery, and the proportion of cases reported from hospitals at the individual cancer registry level. Data analyses were conducted with SAS version 9.4. All statistical tests were 2-sided with a 0.05 significance level.

### Results

A total of 385,469 BB brain tumors and 178,729 malignant brain tumors diagnosed in 2004–2012 were reported by 47 US cancer registries. The overall age-adjusted incidence rate was 14.2 per 100,000 for BB brain tumors and 6.6 per 100,000 for malignant brain tumors. Incidence rates of BB brain tumors varied significantly by registry ranging from 9.8 per 100,000 to 19.9 per 100,000, whereas the variations in incidence rates of malignant brain tumors were much smaller from 4.1 per 100,000 to 7.7 per 100,000. Rate ratios for BB brain tumor versus malignant brain tumors varied from 1.3 to 3.2 by registry (Table 1 and Figure 1).

Compared with malignant brain tumors (13.2%), BB brain tumors (3.9%) were less likely to occur in children (age

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### Table 1. Measures of Central Tendency and Dispersion on Primary Brain Tumor Incidence Rates* from 47 US Population-Based Cancer Registries, NAACCR 2004–2012

<table>
<thead>
<tr>
<th></th>
<th>Incidence Rates</th>
<th>Benign/Malignant Rate Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Benign Malignant</td>
<td></td>
</tr>
<tr>
<td>Overall incidence rate</td>
<td>14.2 6.6</td>
<td>2.1</td>
</tr>
<tr>
<td>Interquartile range (IQR, 25th–75th percentile)b</td>
<td>11.8–14.9 6.4–7.1</td>
<td>1.7–2.3</td>
</tr>
<tr>
<td>Minimum</td>
<td>9.8 4.1</td>
<td>1.3</td>
</tr>
<tr>
<td>Mean</td>
<td>13.6 6.7</td>
<td>2</td>
</tr>
<tr>
<td>Median</td>
<td>13.2 6.7</td>
<td>2</td>
</tr>
<tr>
<td>Maximum</td>
<td>19.9 7.7</td>
<td>3.2</td>
</tr>
<tr>
<td>Upper whiskerc</td>
<td>19.6 8.2</td>
<td>3.2</td>
</tr>
<tr>
<td>Lower whiskerd</td>
<td>7.2 5.4</td>
<td>0.8</td>
</tr>
<tr>
<td>Number of registry outside upper whisker</td>
<td>1 0</td>
<td>1</td>
</tr>
<tr>
<td>Number of registry outside lower whisker</td>
<td>0 1</td>
<td>0</td>
</tr>
</tbody>
</table>

NAACCR, North American Association of Central Cancer Registries.

* Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups—Census P25-1130) standard.

b Interquartile range is the middle 50% of a data set.

c Upper whisker: extends to the largest data point within the boundary of Q3 + 1.5*(Q3–Q1).

d Lower whisker: extends to the smallest data point within the boundary of Q1 - 1.5*(Q3–Q1).
Figure 1. Incidence Rates\(^a\) for Primary Brain Tumor and Rate Ratio\(^b\) of Benign and Borderline vs Malignant Brain Tumors, 47 US Population-Based Cancer Registries, NAACCR 2004–2012

\(\text{Incidence Rate Per 100,000} \quad \text{Rate Ratio of Benign \& Borderline vs Malignant} \)

\[\text{Benign \& borderline brain tumor incidence rates} \]
\[\text{Malignant brain tumor incidence rates} \]
\[\text{Rate ratios of benign \& borderline vs malignant brain tumors} \]

\(\text{47 Population-based US Central Cancer Registries} \)

\(\text{NAACCR, North American Association of Central Cancer Registries.} \)
\(^a\) Incidence rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups—Census P25-1130) standard.
\(^b\) Rate ratio is incidence rate of benign and borderline brain tumor vs incidence rate of malignant brain tumor at individual registry level.

< 20 years). Females were more likely to be diagnosed with BB brain tumors than males (17.2 per 100,000 vs 10.9 per 100,000). BB brain tumors were more likely to occur in black patients (16.2 per 100,000) than in white patients (13.9 per 100,000). The most common site for BB brain tumors was the meninges (53.2%), followed by CNS endocrine (24.3%), whereas the vast majority of malignant brain tumors occurred in the brain (92.3%) (Table 2).

BB brain tumors were more likely than malignant brain tumors to be diagnosed clinically (48.1% versus 11.4%) with a rate ratio of 8.9. BB brain tumors were less likely than malignant tumors to receive surgery as the first course of treatment (52.9% vs 30.6% no surgery); the rate ratio of no surgery for BB brain tumors vs malignant brain tumors was 3.7. Over 96% of both BB brain tumors and malignant brain tumors were reported from the hospital (Table 2). The vast majority of nonmicroscopically confirmed cases were diagnosed through radiography (97.2 % for BB brain tumors vs 93.9 % for malignant brain tumors) (Table 3).

The incidence rate of BB brain tumors increased significantly over time, from 11.8 per 100,000 in 2004 to 14.7 per 100,000 in 2012, and the APC was 2.3 (Table 4). The rapid increase took place from 2004 to 2009, and changes in the incidence rates were not significant from 2009 to 2012. The increase in BB brain tumor incidence rates was parallel to the trend of nonmicroscopically confirmed (from 4.8 per 100,000 to 7.6 per 100,000; APC = 4.9) cases or no surgery BB brain tumor cases (from 5.5 per 100,000 to 8.2 per 100,000; APC = 4.8), respectively. The incidence rates of BB brain tumors reported from hospitals also increased significantly over time (APC = 2.4). No significant changes were found for the incidence rates of BB brain tumors with microscopic confirmation, surgery, or reported from nonhospital facilities. In contrast, incidence rates of malignant brain tumors slightly decreased from 6.8 per 100,000 in 2004 to 6.3 per 100,000 in 2012 (APC = −0.9). There was no significant change for malignant brain tumors with surgery. Malignant tumor cases with nonmicroscopic confirmation, microscopic confirmation, or no surgery decreased over time.

The percentage of BB brain tumor cases without microscopic confirmation or with no surgery varied by registry (from 34.4% to 60.1% and from 37.0% to 61.6 %, respectively). Registries with a higher percentage of nonmicroscopically confirmed or no surgery BB brain tumor cases had higher BB brain tumor incidence rates (Figure 2).

BB brain tumor age-adjusted incidence rates were significantly \(P < .001\) correlated with the proportion of cases without microscopic confirmation \((\rho = 0.622)\), and the proportion of cases with no surgery \((\rho = 0.591)\). In contrast, malignant brain tumor incidence rates were not associated with any of these clinical factors (Table 5).

**Discussion**

This study showed that about half of BB brain tumors were not microscopically confirmed or treated with surgery. The majority of those cases were diagnosed radiographically with no pathology report. BB brain tumor patients were more likely to be diagnosed or treated at outpatient clinics or physician offices. Since many tumor registries routinely conduct casefinding through pathology reporting, those cases diagnosed in radiology centers potentially may be underreported or experience a delay in reporting through routine casefinding.

The incidence rate of BB brain tumor varies by registry in the United States and is significantly associated with the percentage of no surgery or nonmicroscopically confirmed cases. Registries with a small proportion of no-surgery or nonmicroscopically confirmed BB brain tumor cases may have underreporting problems. Thus, the differences in casefinding strategies may have contributed to the wide variation of BB brain tumor incidence rates from registries across the United States.\(^{5-7}\) The increasing incidence rate of BB brain tumors from 2004–2012 corresponded with the increase in the reporting of cases without microscopic confirmation or surgery during this period. It suggests that improvement in capturing more clinically diagnosed BB brain tumor cases may contribute to the increase in the trends.
A study of intracranial meningiomas in North Europe, 1968–1997 indicated that cases detected through radiography without microscopic examination were possibly underreported. One study in the United Kingdom suggested that cancer registries may improve case ascertainment by screening neuroradiology data. A study conducted by Larjavaara, et al found that only about two-thirds of meningiomas were reported to the Finnish Cancer Registry, and underreporting was more prominent among patients over 80 years old and those diagnosed only radiographically (27% for elders and 29% for those without histologic confirmation were reported). The meningioma cases not reported to the Finnish Cancer Registry could be found in the neurosurgical clinic or hospital discharge databases. The same study also noted underdiagnoses issues for meningiomas, especially among the elderly (Larjavaara’s study). Huang’s

### Table 2. Case Counts and Incidence Rates\(^a\) of Benign and Borderline and Malignant Brain Tumors, 47 US Population-Based Cancer Registries Combined, NAACCR 2004–2012

<table>
<thead>
<tr>
<th>47 US Registries Combined</th>
<th>Benign &amp; Borderline</th>
<th>Malignant</th>
<th>Total</th>
<th>Benign vs Malignant Rate Ratio and 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Counts</td>
<td>%</td>
<td>Rate</td>
<td>Counts</td>
</tr>
<tr>
<td>Overall</td>
<td>385,469</td>
<td>100</td>
<td>14.2</td>
<td>178,729</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 20 (children)</td>
<td>15,064</td>
<td>3.9</td>
<td>2.1</td>
<td>23,544</td>
</tr>
<tr>
<td>20–64 (adults)</td>
<td>219,161</td>
<td>56.9</td>
<td>13.5</td>
<td>91,738</td>
</tr>
<tr>
<td>65+ (senior adults)</td>
<td>151,244</td>
<td>39.2</td>
<td>45.4</td>
<td>63,447</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>136,564</td>
<td>35.4</td>
<td>10.9</td>
<td>98,887</td>
</tr>
<tr>
<td>Female</td>
<td>248,905</td>
<td>64.6</td>
<td>17.2</td>
<td>79,842</td>
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<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whites</td>
<td>313,346</td>
<td>81.3</td>
<td>13.9</td>
<td>158,391</td>
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<tr>
<td>Blacks</td>
<td>48,715</td>
<td>12.6</td>
<td>16.2</td>
<td>13,030</td>
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<tr>
<td>American Indian/Alaska Native</td>
<td>2,394</td>
<td>0.6</td>
<td>9.6</td>
<td>908</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>14,020</td>
<td>3.6</td>
<td>11.4</td>
<td>4,672</td>
</tr>
<tr>
<td>Cancer location</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Meninges</td>
<td>205,105</td>
<td>53.2</td>
<td>7.5</td>
<td>3,524</td>
</tr>
<tr>
<td>Brain</td>
<td>34,571</td>
<td>9.0</td>
<td>1.3</td>
<td>164,924</td>
</tr>
<tr>
<td>Spinal cord and other CNS</td>
<td>52,111</td>
<td>13.5</td>
<td>1.9</td>
<td>7,957</td>
</tr>
<tr>
<td>CNS endocrine</td>
<td>93,682</td>
<td>24.3</td>
<td>3.5</td>
<td>2,324</td>
</tr>
<tr>
<td>Diagnostic confirmation(^b)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Microscopic confirmation</td>
<td>195,148</td>
<td>50.6</td>
<td>7.2</td>
<td>154,939</td>
</tr>
<tr>
<td>Without microscopic confirmation</td>
<td>185,459</td>
<td>48.1</td>
<td>6.9</td>
<td>20,446</td>
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<tr>
<td>Unknown</td>
<td>4,862</td>
<td>1.3</td>
<td>0.2</td>
<td>3,344</td>
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<tr>
<td>Surgery(^c)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No surgery</td>
<td>203,721</td>
<td>52.9</td>
<td>7.5</td>
<td>54,772</td>
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<tr>
<td>Surgery</td>
<td>174,299</td>
<td>45.2</td>
<td>6.4</td>
<td>120,655</td>
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<td>Unknown</td>
<td>7,449</td>
<td>1.9</td>
<td>0.3</td>
<td>3,302</td>
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<tr>
<td>Type of Reporting Sourced</td>
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<td></td>
<td></td>
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<tr>
<td>Hospital</td>
<td>377,783</td>
<td>98</td>
<td>14</td>
<td>172,485</td>
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<tr>
<td>Nonhospital</td>
<td>7,686</td>
<td>2</td>
<td>0.3</td>
<td>6,244</td>
</tr>
</tbody>
</table>

CNS, central nervous system; NAACCR, North American Association of Central Cancer Registries.

\(^a\) Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1130) standard.

\(^b\) Microscopically confirmed includes positive histology, positive cytology, and positive microscopic confirmation, method not specified.

\(^c\) Surgery included codes 10 to 90.

\(^d\) Hospital includes hospital inpatient/outpatient or clinic, radiation treatment or medical oncology center, and other hospital outpatient units/surgery centers.

\(*\) The rate ratio indicates that the rate for benign/borderline brain tumor is significantly different than the rate for malignant (P < .05).
Table 3. Distribution of Primary Brain Tumor Cases without Microscopic Confirmation, 47 US Population-Based Cancer Registries Combined, NAACCR 2004-2012

<table>
<thead>
<tr>
<th></th>
<th>Benign &amp; Borderline</th>
<th>Malignant</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>%</td>
</tr>
<tr>
<td>Cases without microscopic confirmation</td>
<td>185,459</td>
<td>100</td>
</tr>
<tr>
<td>Positive laboratory test/marker study</td>
<td>324</td>
<td>0.2</td>
</tr>
<tr>
<td>Direct visualization</td>
<td>917</td>
<td>0.5</td>
</tr>
<tr>
<td>Radiography</td>
<td>180,174</td>
<td>97.2</td>
</tr>
<tr>
<td>Clinical diagnosis only</td>
<td>4,044</td>
<td>2.2</td>
</tr>
</tbody>
</table>

NAACCR, North American Association of Central Cancer Registries.

Table 4. Trend of Incidence Rate\(^a\) of Primary Brain Tumors, 47 US Population-Based Cancer Registries Combined, NAACCR 2004–2012

<table>
<thead>
<tr>
<th></th>
<th>PC</th>
<th>APC</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign and borderline brain tumors</td>
<td>24.3</td>
<td>2.3*</td>
<td>11.8</td>
<td>13.3</td>
<td>13.8</td>
<td>14.1</td>
<td>14.7</td>
<td>15.5</td>
<td>15</td>
<td>14.9</td>
<td>14.7</td>
</tr>
<tr>
<td>Diagnostic confirmation(^b)</td>
<td>Without microscopic confirmation</td>
<td>57.7</td>
<td>4.9*</td>
<td>4.8</td>
<td>5.9</td>
<td>6.4</td>
<td>6.7</td>
<td>7.1</td>
<td>7.8</td>
<td>7.6</td>
<td>7.6</td>
</tr>
<tr>
<td></td>
<td>Microscopic confirmation</td>
<td>1.8</td>
<td>0.05</td>
<td>6.8</td>
<td>7.3</td>
<td>7.3</td>
<td>7.3</td>
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<td>7.5</td>
<td>7.2</td>
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<td></td>
<td>Unknown</td>
<td>–17.6</td>
<td>–1.8</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Surgery(^c)</td>
<td>No surgery</td>
<td>51</td>
<td>4.8*</td>
<td>5.5</td>
<td>6.4</td>
<td>6.9</td>
<td>7.3</td>
<td>7.8</td>
<td>8.6</td>
<td>8.4</td>
<td>8.2</td>
</tr>
<tr>
<td></td>
<td>Surgery</td>
<td>3.6</td>
<td>0.23</td>
<td>6.1</td>
<td>6.5</td>
<td>6.4</td>
<td>6.4</td>
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<td>6.7</td>
<td>6.4</td>
<td>6.3</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>–42.7</td>
<td>–13.6</td>
<td>0.3</td>
<td>0.4</td>
<td>0.5</td>
<td>0.4</td>
<td>0.3</td>
<td>0.2</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Type of Reporting Sourced</td>
<td>Hospital</td>
<td>24.9</td>
<td>2.4*</td>
<td>11.6</td>
<td>13.1</td>
<td>13.6</td>
<td>13.6</td>
<td>14.3</td>
<td>15.1</td>
<td>14.8</td>
<td>14.8</td>
</tr>
<tr>
<td></td>
<td>Nonhospital</td>
<td>–9.5</td>
<td>–3.05</td>
<td>0.2</td>
<td>0.2</td>
<td>0.3</td>
<td>0.5</td>
<td>0.5</td>
<td>0.4</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Malignant brain tumors</td>
<td>–7.1</td>
<td>–0.9*</td>
<td>6.8</td>
<td>6.8</td>
<td>6.7</td>
<td>6.8</td>
<td>6.7</td>
<td>6.7</td>
<td>6.5</td>
<td>6.4</td>
<td>6.3</td>
</tr>
<tr>
<td>Diagnostic confirmation(^b)</td>
<td>Without microscopic confirmation</td>
<td>–15.1</td>
<td>–1.8*</td>
<td>0.8</td>
<td>0.8</td>
<td>0.8</td>
<td>0.8</td>
<td>0.8</td>
<td>0.8</td>
<td>0.7</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td>Microscopic confirmation</td>
<td>–5.2</td>
<td>–0.7*</td>
<td>5.8</td>
<td>5.9</td>
<td>5.8</td>
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APC, annual percent change; NAACCR, North American Association of Central Cancer Registries; PC, percent change.

\(^a\) Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups—Census P25-1130) standard.

\(^b\) Microscopically confirmed includes positive histology, positive cytology, and positive microscopic confirmation, method not specified.

\(^c\) Surgery included codes 10 to 90.

\(^d\) Hospital includes hospital inpatient/outpatient or clinic, radiation treatment or medical oncology center, and other hospital outpatient units/surgery centers.

\(^*\) Annual percentage change (APC) statistically significant from 0.
Figure 2. Incidence Rates of BB Brain Tumors and Proportion of BB Brain Tumors with No Surgery or Nonmicroscopic Confirmation by Registry, NAACCR 2004–2012

BB, benign/borderline; NAACCR, North American Association of Central Cancer Registries.

a Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups—Census P25-1130) standard.
b Primary brain tumors with ICD-O-3 behavior codes 0 benign and 1/borderline.
c Percent with no surgery = no surgery/ (no surgery + surgery + unknown) at individual registry level.
d Percent without microscopic confirmation = nonmicroscopic confirmation/ (nonmicroscopic confirmation + microscopic confirmation + unknown) at individual registry level.

Table 5. Pearson Correlation Coefficients for Primary Brain Tumor Incidence Rate with Clinical Factors, 47 US Population-Based Cancer Registries, NAACCR 2004–2012

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<th>Malignant Brain Tumor Incidence Rate b</th>
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<tr>
<td>% reporting from hospital e</td>
<td>-0.048</td>
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NAACCR, North American Association of Central Cancer Registries.
a Age-adjusted benign brain tumor incidence rate at individual registry level.
b Age-adjusted malignant brain tumor incidence rate at individual registry level.
c Percent without microscopic confirmation = nonmicroscopic confirmation/ (nonmicroscopic confirmation + microscopic confirmation + unknown) at individual registry level.
d Percent with no surgery = no surgery/ (no surgery + surgery + unknown) at individual registry level.
e Percent reporting from hospital = hospital reporting/ (hospital reporting + nonhospital reporting) at individual registry level.

presentation during 2011 NAACCR’s annual conference revealed that the proportion of microscopically confirmed cases, surgery cases, and older population are inversely correlated with the rates for benign and borderline brain tumors.11

Electronic reporting of data has been addressed by many groups. One institution reported an 18% increase in the reporting of nonmalignant brain tumors through the use of electronic capture of radiology reports.12 One British study found that overall availability of data was 80% in 1995–2000 and 95% in 2000–2005 when electronic notes were introduced.13 More recently, the experience of the Louisiana Tumor Registry (LTR)14 showed that a linkage of registry data with hospital inpatient discharge data (HIDD) is a cost-effective way to improve the reporting of BB brain tumors; their linkage with 2011 HIDD identified 13% of missed BB brain tumor cases. Among the missing reported cases, over 77% were not microscopically confirmed. In rechecking for potentially missed cases, the LTR noticed that many clinical diagnoses identified by the HIDD linkages could also be found by reviewing hospital disease indexes, rather than relying solely on pathology reports. Reviewing disease indexes is, therefore, especially important for facilities that do not submit cases to the HIDD.

Delays in reporting and late ascertainment are known issues influencing registry completeness, especially for more recent data collection years.15-17 This problem may be even more likely to occur in the reporting of BB brain tumors, where reporting comes from nonhospital-based sources and clinical diagnoses. McCarthy’s study analyzed the 1997–2008 data from 11 population-based state registries and found that the age-adjusted incidence rate significantly increased from 1997 to 2002, increased at a faster rate from 2002 to 2005, and showed no change from 2005 to 2008. Our study showed that the age-adjusted incidence rate of BB brain tumors significantly increased from 2004 to 2009,
and no significant changes were observed over the time period 2009–2012. The rapid increase in the BB brain tumor incidence rate from 2004 to 2009 in this study and from 2002 to 2005 in McCarthy’s study suggested that the Benign Brain Tumors Cancer Registries Amendment Act (Public Law 107-26) had a profound impact on the reporting of BB brain tumors in the United States. Reporting delays may have influenced the age-adjusted incidence rate and the trend from 2009-2012 in this study and from 2005 to 2008 in McCarthy’s study. The incidence rate of BB brain tumors was relatively constant during these time periods, which probably also suggests the stabilization in reporting.

Over 86% of the primary malignant brain tumors cases received surgery or had microscopic confirmation, indicating that casefinding may be less of a challenge as routine casefinding protocols include the review of pathology reports. This study also found that the variation in malignant brain tumor incidence rates by registry was relatively small, suggesting consistency in the reporting of malignant brain tumors across the states.

Prior to the early 2000s, the incidence rate of all primary malignant brain tumors increased in the United States and was partly attributable to the introduction of computerized tomography scans, magnetic resonance imaging, and stereotactic brain biopsies. The broad use of these modalities may have reduced the underdiagnoses of primary brain tumors and improved diagnostic accuracy. A previous study showed that the age-adjusted incidence rate of malignant brain tumors was declining after the early 2000s. This study further confirmed their findings: age-adjusted incidence rate of primary malignant brain tumors decreased from 2004 to 2012. We believe this is attributable to the reduction in those cases documented as having no surgery or without microscopic confirmation while cases receiving surgery remained level, and those microscopically confirmed decreased only slightly over time. The cases without microscopic confirmation or surgery may have been considered malignant brain tumors in the past; however, due to improved clinical and radiographic technology, they could now be diagnosed as nonmalignant. Coding rules and tumor classification changes for primary brain and CNS tumors may have also influenced case ascertainment and data collection, thus impacting the incidence rates for all brain tumors. It may be possible that the incidence rate of malignant brain tumor has been “truly” declining during this time period.

In summary, as registries adopt new collection techniques aimed at capturing clinically diagnosed BB brain tumor cases from different data sources, such as neurosurgical clinics, radiology centers, hospital disease indexes, and linkage with hospital discharge data, a true assessment of the incidence of BB brain tumors will emerge.

Acknowledgements

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Improving Vital Status Data Using Text Searches

Lindsey M. Hutchison, MS, CTR; Francis P. Boscoe, PhD

Abstract: Objective: To identify missed deaths in the New York State Cancer Registry database and correct the vital status code. Methods: The SEER*DMS SQL data search feature was used to identify cases which were potentially miscoded based on key words in the pathology and remarks text section of the abstract and the vital status coded. Results: The SEER*DMS SQL data search feature allowed for miscoded vital status cases to be easily identified and corrected in our database. Conclusions: Improving the quality of the data being used for analysis, despite the quantity of changes being made, will in time generate more accurate survival statistics for the state of New York.

Introduction

Vital status is among the most fundamental data items collected by central cancer registries, as it is needed for calculating survival statistics. While vital status is generally very accurate, deaths can be missed when death certificates are not issued in a timely manner; when patients die outside the country; or when information necessary for linkage, such as name, date of birth, and Social Security number, is missing or incorrect. Here we show how text fields were used to identify some of these missed deaths in the New York State Cancer Registry (NYSCR).

The NYSCR has a number of cases where there is not a confirmed death record for the patient, yet it is possible that these patients have expired. After converting our database from a homegrown system to SEER*DMS, we improved our ability to perform text searches of the records in our database. Using the SEER*DMS Structured Query Language (SQL) data search feature, it was possible to identify cases where the text stated that the patient was expired, even when the NYSCR did not have a confirmed death record for the patient. Identifying these patients allows the NYSCR to reduce the number of incorrect vital statuses.

A similar technique was previously used by the NYSCR to identify cases that were diagnosed outside of New York, but had New York listed as their state of diagnosis.

Methods

We identified all records in the NYSCR database with a vital status code of alive and text containing the terms autopsy, patient expired, or patient died, along with various abbreviations of these. We also included text containing “SSDI” (an abbreviation of Social Security Death Index), as sometimes hospital registrars will include a phrase such as “exp per SSDI.” The terms died and deceased were also considered, but found to more commonly refer to patients’ relatives rather than the patients themselves. We restricted the search to cases with a year of last contact on or before 2013, since cases later than this have not yet been matched to New York State vital records.

The search was limited to the pathology and remarks text sections of cases submitted after 1996, when the NYSCR began receiving text. The search was limited to the pathology and remarks text sections of cases submitted after 1996, when the NYSCR began receiving text. The pathology text section was the usual source of documentation that an autopsy had been performed, which is a clear sign that the patient is deceased. The pathology section also occasionally contained a phrase such as patient expired. The remarks text field was the most common field that contained comments about the patient being found in the SSDI or referencing vital status. Noting that the patient had an autopsy, or family declining an autopsy, was also sometimes included in the remarks text section.

Using the SEER*DMS SQL data search feature, the following data search was performed:

```sql
SELECT distinct patient.display_id, patient.name_first, patient.name_last, record_id, record.textRemarks from record, patient
WHERE (record.textRemarks ilike '%AUTOPSY%'
OR record.text_dx_proc_path ilike '%AUTOPSY%'
OR record.textRemarks ilike '%PATIENT EXPIRED%'
OR record.textRemarks ilike '%PAT EXPIRED%'
OR record.textRemarks ilike '%PT EXPIRED%'
OR record.textRemarks ilike '%PATIENT EXPIRED%'
OR record.textRemarks ilike '%SSDI%'
OR record.textRemarks ilike '%PATIENT DIED%'
OR record.textRemarks ilike '%PAT DIED%'
OR record.textRemarks ilike '%PT DIED%'
OR record.textRemarks ilike '%P DIED%'
OR record.text_dx_proc_path ilike '%PATIENT EXPIRED%'
OR record.text_dx_proc_path ilike '%PAT EXPIRED%'
OR record.text_dx_proc_path ilike '%PT EXPIRED%'
OR record.text_dx_proc_path ilike '%P EXPIRED%'
AND patient.vital_status = 1
AND record.pat_id = patient.pat_id
AND patient.date_of_last_contact_yyyy <= 2013
```
The above code was written in PostgreSQL used by SEER*DMS, but would only require minor modifications to work with other types of SQL.

After running the SQL data search, the identified cases were manually reviewed to check the text of the record to verify that the vital status of the case should be changed.

**Results**

The SEER*DMS SQL query generated over 500 cases to be reviewed. After reviewing the text of these cases, 86% were determined to be expired and their vital status was changed from one (alive) to zero (dead). Five certified tumor registrars (CTRs) were able to complete the review in a morning.

**Discussion**

In an effort to clean up vital status of patients that the NYSCR believes could be expired but are coded as alive, a SEER*DMS SQL data search was performed. Once cases were identified that contained a key word that implied that the patient was expired, but their vital status was coded as alive, the cases were manually reviewed.

The majority of these cases were determined to be coded incorrectly based on text, and the vital status code for the consolidated record was changed to reflect that the patient was expired. This procedure reduced the number of incorrectly coded vital statuses in our database, and in turn reduced inflation of survival rates in New York State. There was a need to manually review these cases, instead of making a mass change for the cases identified through the SQL query, as some of the wording was ambiguous. An example was the phrase not found in SSDI when there was not any other text supporting that the patient expired. Of course, linking directly to SSDI is a more direct and efficient option that is available to registries.

**Conclusion**

Utilizing the SEER*DMS SQL data search function, the NYSCR was able to change the vital status of over 400 cases, helping to reduce the number of cases in the NYSCR database marked as alive when the patient is actually expired. While this is a very small percentage of cases changed in the NYSCR database, and by itself will not have a significant change on our survival statistics, this procedure improves the quality of data in the NYSCR database and is worthwhile to perform as small improvements over time lead to larger changes in the quality and accuracy of data. The cumulative effect of many small steps such as this helps ensure accurate survival statistics for New York.

The data search has been saved, and will be run periodically to update vital status in our database. Other cancer registries should be able to perform similar searches, even if they are not using SEER*DMS.

**References**

**Journal of Registry Management** Continuing Education Quiz—WINTER 2016

**ARE BENIGN AND BORDERLINE BRAIN TUMORS UNDERREPORTED?**

Quiz Instructions: The multiple choice or true/false quiz below is provided as an alternative method of earning CE credit hours. Refer to the article for the ONE best answer to each question. The questions are based solely on the content of the article. Answer the questions and send the original quiz answer sheet and fee to the NCRA Executive Office before the processing date listed on the answer sheet. Quizzes may not be retaken nor can NCRA staff respond to questions regarding answers. Allow 4–6 weeks for processing following the submission deadline to receive return notification of your completion of the CE process. The CE hour will be dated when it is submitted for grading; that date will determine the CE cycle year.

After reading this article and taking the quiz, the participants will be able to:
- Assess variations of benign and borderline brain tumor incidence rates by registry and incidence rate trends
- Identify factors that are associated with the reporting of benign and borderline brain tumors
- Discuss approaches to improve case ascertainment and reporting of benign and borderline brain tumors

1. Compared to malignant brain tumors, benign and borderline brain tumors:
   a) are more likely to be diagnosed microscopically
   b) significantly decreased in incidence from 2004 to 2012
   c) have been reportable since 2007
   d) are less likely to be treated surgically

2. According to this study, incidence rates of benign and borderline brain tumors are:
   a) lower than those for malignant brain tumors
   b) consistent across all US registries
   c) reflective of improved case ascertainment
   d) increasing due to biological trends

3. Benign and borderline brain tumors:
   a) frequently invade adjacent tissues
   b) may cause life-threatening health problems
   c) metastasize to other parts of the body
   d) are underreported by US cancer registries

4. Many central registries routinely conduct casefinding at:
   a) radiography centers
   b) hospitals
   c) clinics
   d) physician offices

5. Data for this study included:
   a) information from 50 US state-based cancer registries
   b) benign, borderline, and malignant brain tumors
   c) death certificate only and autopsy cases
   d) ICD-O-3 behavior codes 0, 1, 2, and 3

6. For the purposes of this study, which of the following reporting sources were included in the nonhospital category?
   a) Radiology clinic
   b) Outpatient clinic
   c) Nursing home/hospice
   d) Medical oncology center

7. According to Table 2, Case Counts and Incidence Rates of Benign and Borderline and Malignant Brain Tumors, 47 US Population-Based Cancer Registries Combined, NAACCR 2004–2012, incidence rates for benign and borderline tumors were higher in:
   a) senior adults, compared to adults
   b) males, compared to females
   c) whites, compared to blacks
   d) nonhospital, compared to hospital reporting source

8. This study showed most benign and borderline brain tumors were:
   a) microscopically confirmed
   b) diagnosed radiographically
   c) treated surgically
   d) diagnosed in a hospital

9. Compared to benign and borderline brain tumors, casefinding for primary malignant brain tumors is less challenging because:
   - they tend to be surgically treated
   - pathology reports are routinely reviewed
   - of the availability of stereotactic brain biopsies
   - their incidence rates are stable
   
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<td>d) Outpatient</td>
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10. Improving the capture of clinically diagnosed benign and borderline brain tumors can be accomplished using data sources such as:
   - hospital disease indices
   - neurosurgical clinics
   - pathology reports
   - radiology centers
   
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The JRM Quiz and answers are now available through NCRA’s Center for Cancer Registry Education (CCRE). For your convenience, the JRM article and quiz can be accessed online at [www.CancerRegistryEducation.org/jrm-quizzes](http://www.CancerRegistryEducation.org/jrm-quizzes). Download the article, complete the quiz and claim CE credit all online.
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1 A B C D
2 A B C D
3 A B C D
4 A B C D
5 A B C D
6 A B C D
7 A B C D
8 A B C D
9 A B C D
10 A B C D

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National Cancer Registrars Association
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Vonetta L. Williams, PhD, MPH, CTR | EDITOR-IN-CHIEF, JRM

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