NCRA has revised its popular study guide to reflect the changes to the 2018 exam. The guide begins with a review of the Core Knowledge required of all cancer registrars, including the principles of oncology and the body’s systems. The main sections are organized by the new 2018 Domains of Practice and contain basic information on these areas, including a general overview and additional resources to aid in your studying. There are five case studies that include answers and rationales. NCRA member price: $85; non-member price: $105.

LIVE! CTR Exam Prep Online Workshop
The NCRA CTR Exam Prep Online Workshop has been updated to reflect the 2018 changes to the exam. The series consists of nine, 90-minute live webinars on critical exam topics. The first webinar begins January 30, 2018. Workshop member price: $365; non-member price: $485. Individual webinars can be purchased separately. Member price: $45; non-member price: $60.

Online CTR Exam Practice Test
NCRA offers a 125-question online CTR Exam Practice Test through its Center for Cancer Registry Education (CCRE). The Practice Test is designed to provide candidates a tool to assess understanding and determine where further study is needed.

Pricing options: One-time access: NCRA member: $65; non-member: $105. Unlimited access for 60 days: NCRA member: $180; non-member: $220

Archived CTR Exam Prep Webinars
The nine webinars from the 2017 Online CTR Exam Prep Workshop have been archived and are available on NCRA’s Center for Cancer Registry Education. (The updated 2018 archived webinars will be posted in early spring 2018.) These webinars address critical exam topics. Each archived webinar is $25 for NCRA members; $40 for non-members.

Sharpen Your Skills with NCRA’s Online Case Studies
NCRA has produced 15 online cancer case studies to provide opportunities for registrars to practice assigning AJCC TNM Stage and coding SEER Summary Stage. It is a great study tool for those taking the CTR Exam. The correct answers and corresponding rationales are provided upon the completion of each case. NCRA member price: $30; non-member price: $60.

In-Person CTR Exam Prep Workshop: Hands-On Strategies for the Open-Book Section
Sunday, May 20, 2018
Sheraton New Orleans Hotel
New Orleans, LA
The NCRA intensive review for the open-book portion of the CTR exam is a must for exam candidates who want to make the most out of their time in the exam. Offered as a pre-conference event, NCRA has designed this one-day workshop focused exclusively on abstracting scenarios that make up the open-book portion of the CTR exam. Faculty will provide a thorough review of resources and offer hands-on case studies in a simulated exam environment.

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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.
Letter from the Editor

Dear Colleagues,

Greetings! I hope you had a great summer. We had another excellent annual education conference this year in New Orleans, Louisiana. There were a variety of education opportunities available for attendees including education on the 2018 changes. Plus, there was always an opportunity to meet new people.

The food was exceptional. My mouth is watering right now just thinking about the jambalaya, benignets, and gumbo. I’m still working out at the gym to reduce the extra pounds I gained from all of the great food. Congratulations to all the new CTRs! The new CTRs who attended the NCRA awards luncheon are featured in the picture below. Be sure to get involved with your state, regional, and national organization.

I was humbled to be nominated and receive the Volunteer Excellence Award this year at the NCRA awards luncheon. I work with so many of you, and it is my pleasure to share and have an opportunity to use my gifts and even learn about gifts that I did not know that I have. The work that I do with NCRA and the Journal of Registry Management is a blessing to me. I would also like to congratulate Ebony Johnson, who received the inaugural April Fritz Outstanding New Professional Award, and Melanie Rogan, who received the Distinguished Member Award. Congratulations to the both of you for a job well done!

I would like to address something with you, and I say this to you with love. During the NCRA annual conference, a few colleagues stated that some of their team members did not attend NCRA because their company did not pay for them to attend. Please listen to me carefully: It is YOUR responsibility to ensure that you maintain your CTR education, continuing education hours, and know all of the 2018 changes. If your company will not pay for you to attend NCRA, then negotiate and ask for support to attend one of your state or regional conferences. If you are not successful with this option, then you must save your own money and pay for your own travel-related expenses and negotiate time off as education days. In addition, use your networking and research skills. For example, you can share the cost of a room with another colleague; research the total cost for you to attend your state, regional, or national conference and set aside a certain amount of money from each paycheck for this expense; research the cost of flights (including local cities and airports near you); carpool (especially if the conference is within a reasonable driving distance); and pack you own snacks and drinks or plan to shop for these items when you arrive at the conference location. If you cannot support yourself financially to attend the national conference every year, make plans to attend every 2 years. If you save $100.00 per month for 2 years, you can make this happen! We are all accountable for our own thoughts, words, and actions, so stop complaining, stop making excuses, and turn this lemonde into lemoncello!

In this journal issue we have 2 original manuscripts. The first manuscript is from Maggie Cole-Beebe, PhD, and colleagues who evaluated the costs associated with operating a central cancer registry. The second manuscript is from Anthony P. Polednak, PhD, who analyzed incidence trends with HPV and oropharyngeal carcinoma in the elderly population.

In addition to the original manuscripts, we are excited to highlight all of the excellent poster abstracts presented at the NCRA conference this year so that you can see all of the great work from our colleagues. We have 10 poster presentations being highlighted. Finally, we have a How I Do It article from Wilson Apollo on understanding the various radiation therapy techniques and how they impact what is coded for radiation therapy. This is a great read with all of the new radiation therapy modality codes introduced with the 2018 changes.

Respectfully,

Vonetta L. Williams, PhD, MPH, CTR
Editor-in-Chief, Journal of Registry Management
National Cancer Registrars Association
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New CTRs, NCRA 2018 Annual Education Conference, New Orleans, Louisiana
Abstract: The Centers for Disease Control and Prevention initiated an economic analysis of the National Program of Cancer Registries (NPCR) in 2005 to estimate the true economic costs of operating a cancer registry, identify costs associated with registry activities, and evaluate the factors that may affect the efficiency of registry operations. We developed a Web-based NPCR cost assessment tool (NPCR-CAT) to collect activity-based cost data from all 48 NPCR registries. We collected data on registry funding, actual expenditures, and factors that may affect the efficiency of operating a central cancer registry. Key lessons learned during data collection and analysis include the importance of working closely with registry staff and balancing the need for standardized data elements with an understanding of individual registry characteristics. Our findings and lessons can be adapted to develop costing tools for other surveillance systems and cancer control programs, both domestically and internationally.

Key words: activity-based costing, cancer registry, cost data collection

Background

In the United States, more than 1.5 million invasive cancers were diagnosed in 2012, and more than 582,000 people died because of their cancers.1 State-based central cancer registry programs provide critical cancer incidence data to inform the development, implementation, and evaluation of state-based cancer control programs.

Congress established the National Program of Cancer Registries (NPCR) in 1992 through the Cancer Registries Amendment Act (Public Law 102-515), finding that the cancer burden varies by geographic location and that prevention and early detection efforts are best addressed locally by state health departments.2 These state-based cancer registries monitor cancer trends over time; determine cancer patterns in various populations; guide planning and evaluation of cancer control programs (ie, determine whether prevention, screening, and treatment efforts are making a difference); help set priorities for allocating health resources; advance clinical, epidemiological, and health services research; and provide information for a national database of cancer incidence.3

Although the first NPCR registries began receiving funding in 1994, prior to 2005, no data were being systematically reported on how registries were allocating resources to perform registry operations. Information was needed to inform cost-control efforts and to provide decision-makers in state legislatures with information about the resources needed to support registry activities. A previous study examined the federal costs of operating cancer registries but did not address the additional resources (eg, state funds) on which most registries rely.4

An economic analysis of NPCR was initiated in 2005 to examine all the resources used and activities performed by the registries. The goals of the economic analysis were to estimate the value of all the resources used in operating a cancer registry, identify costs associated with specific registry activities, and evaluate the factors that may affect the efficiency of registry operations. Initial steps in the economic analysis included conducting site visits to a subset of NPCR registries, developing and piloting a Microsoft Excel–based cost data collection tool, and analyzing preliminary data.5–7 Following these initial steps, the Centers for Disease Control and Prevention (CDC) undertook a comprehensive economic analysis of the entire NPCR, which entailed collecting data from all 48 NPCR registries.

In this article, we describe the methodology used to perform the comprehensive economic analysis of the NPCR and the Web-based tool that was developed to facilitate cost data collection. We also present high-level summary results that complement results published elsewhere.8,9 The data-collection process presented here can inform future efforts to collect data on cost and resource use to further critically evaluate central cancer registry operations. This approach can be adapted for analyses of other noncommunicable disease registries (eg, heart disease and stroke). Additionally, the Web-based tool provides a validated platform to further enhance cost data collection. To guide future research, we also summarize how these data can inform implementation processes to improve efficiency in registry operations and serve as an information tool for budgeting purposes.

**Notes:**
- RTI International, Waltham, Massachusetts.
- Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, Atlanta, Georgia.
- Partners HealthCare, Boston, Massachusetts.

Address correspondence to Maggie Cole Beebe, PhD, RTI International, 307 Waverly Oaks Road Suite 101, Waltham, MA 02452. Telephone: (781) 434-1728. Fax: (781) 434-1701. Email: mbeebe@rti.org.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention. Support was provided to RTI by the Centers for Disease Control and Prevention (Contract No. 200200827958, Task order 020).
Figure 1. Data Collection, Cleaning, and Analysis Process

Data collection: Registries report via NPCR-CAT

Analysis

Data checks

Automated validation

Manual validation

Final submission: Registries approve data submission

Data cleaning

Sum cost of each registry activity across all budget categories

Sum costs that did not have any associated registry activity

Prorate across all registry activities

Calculate cost per case

Break out costs by registry characteristics

Report results

NPCR-CAT, National Program of Cancer Registries cost assessment tool.

Methods

We developed a Web-based NPCR cost assessment tool (NPCR-CAT) to collect activity-based cost data from the 48 NPCR-funded registries. Using the NPCR-CAT, all NPCR registries reported data for fiscal years (FY) 2009, 2010, and 2011. Prior to developing the tool, we conducted site visits at 4 registries to understand the data collection infrastructure, the types of activities performed, and other factors that needed to be assessed.5 We pilot-tested a Microsoft Excel-based version of the tool at 5 registries reporting cost data for FY 2005.6,7

We considered well-established methods of collecting cost data for program evaluation, such as the ingredient approach when developing the tool.10-12 Using a programmatic perspective, registries reported data via the NPCR-CAT on registry funding (including in-kind contributions), expenditures, and factors that may affect the efficiency of operating a central cancer registry, including the number of cancer cases reported.

We identified several elements that can affect registry efficiency. These include case volume, geographic region where registry resides, quality of registry data reported to the registry, case consolidation effort, data editing requirements, and the type of database management software used.9 Registry structure (public health department, health department with a contractor, or bona fide agent—often a university) was relevant to our data-collection approach. To obtain a comprehensive picture and collect accurate data from registries composed of a health department with a contractor or their designee, we collected data from both the health department and the contractor or the designee. The NPCR-CAT was designed to link the data reported by each entity for those registries where the registry structure included a contractor or bona fide agent. This approach yielded data that were consistent between each entity.

Significant variation exists within a single registry in advanced registry activities performed and costs from year to year. In addition, because case reporting may be delayed, the number of cases reported in the NPCR-CAT did not match the cost-reporting period. We collected 3 rounds of NPCR-CAT data to smooth our estimates of registry costs and cost per case reported.

Figure 1 describes the data collection and analysis process. The process began with registries reporting data via the NPCR-CAT, followed by data validation. Once data were validated by the CDC and RTI and reviewed and approved by the registries, the data were cleaned to prepare for analysis. Finally, once analyzed, the data were disseminated through a variety of outlets (data analysis is discussed in the Results section and data dissemination is included in the Discussion section).

The 48 NPCR registries include 40 NPCR funded by the CDC only, 7 funded by the CDC and the National Cancer Institute (NCI)’s Surveillance Epidemiology and End Results (SEER) program, and 1 Pacific Regional Central Cancer Registry. Based on input from registry experts and our preliminary data analysis, we excluded the 7 registries that receive both CDC and NCI funding from our analyses because of the potential for differences in registry operations. Finally, the Pacific Regional Central Cancer Registry was awarded its first cooperative agreement in 2007 and therefore was not fully operational during the data collection period. We also excluded this registry to avoid any distortions in cost-per-case calculations due to the low volume of cases reported during this period. We used the same data set of 40 registries over 3 years in all analyses, including those presented below and previously published elsewhere.5,9

Data Collection

Data were collected across the following budget categories: labor; consultant and contract expenditures; software licensing; computer hardware, travel and training; and administrative or overhead expenses. Registries provided data on all funding sources (NPCR funds, other federal funds, and nonfederal funds) as well as on actual, rather than budgeted, expenditures. Registry staff members were asked to allocate expenditures (including employee time) to various program activities.

Registries were able to allocate expenditures at a percentage level if desired. When expenses reported for a
budget category were not allocated to individual registry activities, we prorated the expense across activities based on aggregate allocations reported for other budget categories.

To ensure that data were standardized across the registries, registry directors, data managers, and other registry staff responsible for reporting NPCR-CAT data were provided training, a user's guide with detailed definitions of each activity, and ongoing technical assistance to address any questions about data collection and reporting. Definitions of registry activities were refined based on the first 2 years of data collection in consultation with the CDC and the registries. For example, data reported during the first year indicated that the quality assurance activity was too broadly defined. To address this issue, we collaborated with a few of the registries that volunteered based on their knowledge to break out the activity into more narrow activities such as visual editing, consolidation, and auditing. We discovered the importance of working closely with the registry staff who are engaged in the activities that support cancer data collection. For data collection years 2 and 3, this activity was subset into 6 activities (see Table 1 for an example of subset quality assurance activities). Note that we prorated the quality assurance activity from the first year of data collection across the subset of activities to allow comparison with years 2 and 3. As a check, the combined quality assurance values from years 2 and 3 are similar to the year 1 values.

Data Validation

We used both manual and automated data validation methods. We performed a series of data checks to ensure the accuracy of the data reported by registries. Automated data validation was developed and implemented directly in the NPCR-CAT. Those checks that were automated within the NPCR-CAT prevented final submission of the data until the following conditions were met: (1) the difference between reported funding and total expenditure was limited ±5%, and (2) reported time spent on activities was required to sum to 100% for each registry employee. As noted above, in cases where a registry had a major contractor, both the registry and contractor were required to submit data via the NPCR-CAT. To facilitate the aggregation of registry and contractor data and to avoid duplication, reported funding for both the contractor and registry were linked. First the registry reported the amount of funds allocated to the contractor. These fields were replicated and could not be changed in the contractor's tool.

We manually validated the data by comparing reported NPCR funding with funding amounts in CDC records. Comparisons between the registry-reported number of cancer cases and both CDC case reported records and US Cancer Statistics (USCS) cancer cases served as guidelines but were not expected to match exactly (registries may report additional cases not required by the CDC or USCS, such as cases from neighboring states). Registries were required to correct data errors as necessary prior to finalizing data for analysis. Each registry was required to review and approve summaries of the validated data following each round of data collection.

We were able to collect data from all 48 NPCR registries. All registries’ final data submissions for each data collection year met our rigorous standards: 30% of registries were able to allocate 100% of reported funding, 47.5% were able to allocate 98% to 99%, and 22.5% were able to allocate 95% to 97%.

Data Cleaning and Analysis

Following data validation, we cleaned the NPCR-CAT data to prepare for activity-based cost analysis. We first allocated costs to specific registry activities by summing the cost of each registry activity across all budget categories (eg, personnel costs were allocated across activities based on the reported percentage time spent on each activity). As noted above, we added together expenditures that did not have any associated registry activity and prorated across all registry activities.

As a first step, data reported via the NPCR-CAT were processed in SAS and output to Microsoft Excel. The validated data were then aggregated to the level of a single observation per registry per year. The aggregated data was imported to Stata for further analysis. We conducted initial analyses using a variety of statistical tests (eg, testing means and standard deviations to determine the distribution of the data) and generating several basic statistics (including summary statistics and correlations) to further assess the robustness of the data. Regression analyses have been reported previously.9 Summary results are presented below.

Results

Figure 2 presents average registry expenditures across 5 budget categories for the 40 registries: labor; consultants; computers, travel, and training; software licensing; and administrative. Most funding resources were allocated to labor (72%), followed by administrative expenditures (13%), consultants (8%), computers, travel, and training (6%), and software licensing (1%). As discussed above, registries reported expenses for each budget category and allocated the expenses to specific registry activities whenever possible (and prorated when not allocated). As an example, when reporting expenses related to software licensing, a registry might allocate that expense to data cleaning and analysis. For all budget categories other than labor, expenses were directly allocated by percentage of the expense associated with each activity. For labor expenses, data were reported at the staff level and percentage time spent on each activity were reported. We then determined the expense associated with each activity at the staff level by multiplying the staff salary and fringe expenses by the percentage reported for each activity.

We present the percentage of registry resources allocated by registry activity in Table 1. The values reported are unweighted means across the 3 years. On average, the largest share of registry resources (12.5%) was allocated to data collection and abstraction activities. Management and administration were allocated 9.5% and 7.4% of registry resources, respectively. Data analysis and report generation represents 5.9% of registry resources, on average,
whereas IT (information technology) support activities accounted for 5.6%. The case ascertainment and database management activities were each allocated 4.7% of registry resources, whereas death certificate clearance received 4.5% of resources on average. Training of registry staff was allocated 4.2% of registry expenditures, on average. Three of the quality assurance activities were among the top 12 in terms of resource allocation: consolidating records (4.0%), visual editing (3.7%), and tracking completeness and timeliness (1.6%). The remaining registry activities account for 31.8% of registry resources, each less than 1.5% individually: training of others by registry staff; case sharing; geocoding of cancer cases; electronic case reporting and data encryption; CDC reporting requirements; automatic case finding using electronic linkage; quality assurance: computer editing; quality assurance: tracking data flow; quality assurance: auditing; record linkage to other statewide or national databases; implementation of a cancer inquiry response system; research studies and advanced analysis using registry data; active follow-up; and publication of research studies using registry data.

We previously analyzed costs by various characteristics, including registry type, volume of incident cases, region, and by core and advanced activities. Examples of core activities include registry management and administration, database management, and quality assurance. Advanced registry activities include active follow-up and implementing a cancer inquiry response system. We measured case consolidation effort by subtracting the ratio of incident cases reported to the number of records received from one. We found that higher levels of effort would require greater registry resources. Similarly, increased data editing requirements (measured by the proportion of records passing automated edits and the number of records submitted electronically) require additional registry resources, resulting in an increase in the cost per case reported. Registries used a variety of database management software suites that we classified into 3 categories: CDC software, proprietary software, and in-house software (developed and maintained by the registry). We found differences in resource needs related to the type of database management software used. In contrast to proprietary software, which generally comes with outside technical IT support, in-house software required additional registry resources.

Using expenditures from all budget categories, we calculated the 3-year average cost per case for the 40 registries, both overall and by registry activity. Table 2 presents
Use of the Cost Data by Key Stakeholders

The largest consumers of the data and findings from this evaluation are the CDC and the NPCR registries. Table 3 identifies these stakeholders and provides examples of how each could use these data and findings. As part of this evaluation, we developed a data repository for the CDC as well as a registry data tool. In addition to these tools, both the CDC and the registries could use the data and findings as well as a registry data tool. In addition to these tools, both the CDC and the National Cancer Institute and the Pacific Regional Central Cancer Registry.

CDC Use of NPCR Cost Data. The CDC data repository contains registry-level data collected by the NPCR-CAT and consists of a set of standardized data elements. This information consists of annual expenditures and in-kind contributions; personnel activities and expenditures; consultant expenditures; costs associated with hardware, IT support, software, and other materials; administrative costs; and other factors affecting cost, effectiveness, and data collection. The data repository is a workbook that contains a tab with protected source data, a data dictionary, and a series of tabs with pivot tables. A user guide was developed to accompany the data repository and provides definitions of each registry activity as well as instructions for conducting analysis with the pivot tables.

In addition to the data repository, the data have been used to derive estimates of the cost of specific registry activities and to assess differences across registries related to cost per case by individual activities. This analysis identified reasons for these differences and the potentially modifiable factors that may lead to additional efficiencies in registry operations. Further analysis could examine fixed versus variable costs and the magnitude of economies of scale related to pooling registry activities at the regional or national level. These data could be used to identify best practices in terms of cost-effective registry operations at

<table>
<thead>
<tr>
<th>Table 2. Three-Year Mean Cost per Case for Core and Advanced Registry Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total (Range)</strong></td>
</tr>
<tr>
<td>$60.77 (ranging from $15.96 to $233.48)</td>
</tr>
</tbody>
</table>

Source: Three rounds of National Program of Cancer Registries (NPCR) registry cost data (fiscal years 2009, 2010, 2011) for 40 cancer registries funded by the Centers for Disease Control and Prevention (CDC’s NPCR only. Analysis excludes 7 cancer registries that receive funding from both the CDC and the National Cancer Institute and the Pacific Regional Central Cancer Registry.

Table 3. Current and Potential Uses for National Program of Cancer Registries (NPCR) Registry Cost Data

<table>
<thead>
<tr>
<th>Who is using NPCR registry cost data?</th>
<th>How have NPCR registry cost data been used?</th>
<th>What are potential uses for NPCR registry cost data?</th>
</tr>
</thead>
</table>
| Centers for Disease Control and Prevention (CDC) | • Data repository: analysis of 3 years of cost data for all 48 NPCR registries.  
• Derive estimates of the cost of specific cancer registry activities.  
• Assess reasons for differences across cancer registries in terms of cost by activity to identify reasons for these differences; modifiable factors can lead to further efficiencies in registry management.  
• Generate estimates of certified tumor registrar salaries. | • Identify best practices (cost-effective processes) at specific registries that can be adopted more widely.  
• Compare IT (information technology) costs across registries using different categories of database management software (in-house software, CDC software suite, proprietary software).  
• Use evidence-based cost estimates to provide information about the resources needed to support NPCR activities.  
• Understand fixed vs variable costs and magnitude of economies of scale related to pooling registry activities at the regional or national level. |
| Registries | • CDC registry funding applications (subsequent grant years).  
• State funding applications to defend continued support for registry activities.  
• Develop business plans.  
• Assess how efficiently they operate.  
• Support quality improvement efforts. | • Registry data tool: analysis of 3 years of cost data, including projections of changes in registry staffing mix.  
• Assess resources allocated to specific registry activities to assess potential changes to enhance efficiencies. |

Discussion

The largest consumers of the data and findings from this evaluation are the CDC and the NPCR registries. Table 3 identifies these stakeholders and provides examples of how each could use these data and findings. As part of this evaluation, we developed a data repository for the CDC as well as a registry data tool. In addition to these tools, both the CDC and the registries could use the data and findings from this evaluation for a variety of purposes.
specific registries that may be adopted more widely. The data on registry personnel (labor costs) has allowed for the generation of certified tumor registrar (CTR) estimated salaries. Finally, as noted above, data from this evaluation could be used to examine the cost of IT support activities across registries using different categories of database management software (proprietary, CDC software, or in-house software).

Registry Use of NPCR Cost Data. A registry-specific data tool was developed for each NPCR registry. Like the CDC data repository, each data tool consists of a set of standardized data elements reported via the NPCR-CAT, including annual expenditures and in-kind contributions; personnel activities and expenditures; consultant expenditures; costs associated with hardware, IT support, software, and other materials; administrative costs; and other factors affecting cost, effectiveness, and data collection. Each workbook contains individual data reported by the registry and summary data reported by all NPCR registries.

Along with a data dictionary, each workbook includes a tab with protected source data and a series of tabs with pivot tables in addition to the individual data reported by the registry during the last round of data collection. An additional tab allows the registry to calculate the impact of any changes to staffing information. A user guide accompanies the tool and provides general information on the data in the tool, detailed descriptions of each registry activity, instructions for using the tool to analyze changes in staffing, a data dictionary, and instructions for creating and manipulating pivot tables.

Some registries have used the data from this evaluation when preparing funding applications for CDC cooperative agreements for subsequent funding years as well as to support state funding applications. Registries have also used the data to develop business plans, assess how efficiently they operate, and support quality improvement efforts. The data from this evaluation could also be used to assess potential changes in registry operations by examining allocation of resources to specific registry activities with a focus on enhancing operational efficiencies.

Lessons Learned, Limitations, and Future Work

In addition to a rich data set with many uses, this evaluation has yielded important lessons learned during the data collection and analysis process. Key lessons learned include the importance of working closely with the registry staff who are engaged in the activities that support registry operations and balancing the need for standardized data elements with an understanding of individual registry characteristics. Without support from various stakeholders, most importantly the registries, the quality of data collected would have been much lower.

Collaboration with central cancer registry staff and cancer registration experts were invaluable for this project. First, we provided individualized technical support to the registries as needed. Second, we consulted registry and other CDC staff for their expertise on the activities related to collecting and reporting data on cancer incidence and on the factors that may affect registry operations. Through these relationships we gained understanding of issues that, once resolved, yielded higher quality, more standardized data. For example, we found that many registries had challenges with accessing requested data related to funding and expenditures information. This suggested there was a common disconnect between the registry operations and financial teams. Registries indicated that improvements in this connection (born out of necessity for data collection purposes) benefited both teams, particularly when gathering data for subsequent funding applications.

The importance of clarity when defining registry activities became evident during the first round of data collection. Working with some of the registries, we were able to refine our definitions of registry activities. For example, as noted above, we realized that “quality assurance” was too broad an activity, and the registries helped in separating this activity into more precise activities. We also found in the data analysis process that “linking records” should be classified as a core rather than advanced activity. These improvements would not have been possible without the expertise provided by registry staff.

Further improvements to the NPCR-CAT, described above, related to the integration of data reporting by registries and their contractors. Additionally, we added additional fields related to data sharing with out-of-state registries because such agreements required a notable portion of registry resources. These advances highlighted the importance of balance between individual registry characteristics and maintaining standardized, high-quality data.

While this effort has advanced prior methods for collecting activity-based cost data and has yielded a rich data set with many uses, the study is not without limitations. Because the focus of the study was NPCR-funded registries, we did not collect data from registries solely funded by SEER. Further because of incomplete information about registries jointly funded by NPCR and SEER, we have excluded those registries from our analysis. Future work to collect data from all registries would yield even more valuable data. There are likely additional lessons to be learned by comparing NPCR-funded registries with those funded jointly by NPCR and SEER and those solely funded by SEER.

We hope our findings and lessons learned can inform future data collection efforts both domestically and internationally. This approach can be adapted to develop costing tools for other surveillance systems and cancer-control programs. To date we have disseminated our findings through presentations, publications, and data tools. Results from the economic evaluation of the NPCR have been presented both nationally, including the North American Association of Central Cancer Registries Annual Conference, and internationally, including the Union for International Cancer Control World Cancer Congress and the International Association of Cancer Registries Annual Conference. Work is in progress to adapt the NPCR-CAT for use in low- and middle-income countries to identify resource needs and issues related to the development of cancer registries in these countries.
References


Anthony P. Polednak, PhD

Abstract: Background: For squamous cell carcinoma (SCC) of the base of tongue and palatine tonsil, the oropharyngeal sites most strongly associated with human papillomavirus (HPV), increasing age-standardized incidence rates (ASIRs) (2002–2012) have been reported for elderly US men but not women. These findings were based on data from Surveillance, Epidemiology, and End Results (SEER) registries, covering 28% of the US population. Methods: Trends in ASIRs (2001–2014) at ages ≥65 years for base of tongue–palatine tonsil SCC were analyzed using a SEER research database, along with a US Cancer Statistics (USCS) research database with registries covering 48 states (98% of the US population). Annual percent change in ASIR was estimated using joinpoint regression. Results: Using either SEER or USCS, ASIRs for ages ≥65 years increased after the late 2000s for women, whereas men showed a larger and more continuous increase during 2001–2014. Increases were evident for the age subgroups 65–74 and 75–84 years, but the trend for women aged 75–84 years was clearer using USCS vs SEER. For 2003–2014, the 38 states in USCS that were certified by the North American Association of Central Cancer Registries showed increases for women and men that were similar to those using all 48 USCS states or SEER. Conclusions: Continued surveillance is needed, along with studies on HPV markers in tumor tissues for large samples of elderly oropharyngeal SCC patients. Findings support the need for expanding resources for diagnosis, treatment and clinical trials for the growing numbers of elderly oropharyngeal SCC patients.

Key words: elderly, human papillomavirus, oropharyngeal carcinomas, squamous cell carcinomas.

Introduction

In the United States, temporal increases in age-standardized incidence rates (ASIRs) and age-specific rates for invasive squamous cell carcinomas (SCC) of oropharynx at selected anatomical sites regarded as associated with human papillomavirus (HPV, primarily type 16) have been largely limited to middle-age white men.1,3 Using data from the US National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Program, however, the ASIR at ages ≥65 years for oropharyngeal SCC (OPSCC) sites associated with HPV increased (2002–2012) for men but not women.4 This finding largely reflected increases in white men for base of tongue–lingual tonsil SCC (BTSCC) and palatine tonsillar SCC (TSCC) combined.4 These oropharyngeal sites had the highest reported prevalence of HPV (70% and 82%) detected in tumor tissues of samples of patients from selected US cancer registries.5,6

SEER has provided high-quality incidence data from 18 registries (SEER-18) since 2000, covering about 28% of the US population (http://www.seer.cancer.gov), not entirely representative of the total US population.7 A recent Annual Report to the Nation on the Status of Cancer used data from 41 US registries (together covering 89% of the US population) certified for data quality and completeness by the North American Association of Central Cancer Registries (NAACCR).8 ASIRs were not provided for the elderly, however, and oral cavity–pharynx cancers were combined.9

The present study analyzed trends (2001–2014) in ASIRs for BTSCC-TSCC at ages ≥65 years using an updated SEER database10 and a US Cancer Statistics (USCS) database with data from registries funded by SEER and/or the Centers for Disease Control and Prevention’s National Program of Cancer Registries (NPCR).11

Methods

The Databases Used

This study used deidentified public-use research databases, requiring signed data-use agreements.10,11 USCS suppressed any output based on fewer than 16 cases, and did not allow listing of individual cases.11 International Classification of Diseases for Oncology Third Edition (ICD-O-3) codes were used to select SCC (morphology codes M8050–8084) for base of tongue, defined as sites C019 (base of tongue, not otherwise specified) and C024 (lingual tonsil) combined, and for palatine tonsil (C090–099). SEERStat software (at the default setting) selected only cancers coded as malignant (ie, ICD-O-3 behavior code 3).10,11

USCS had omitted all cases ascertained by death certificate only or autopsy alone, and included diagnoses in 2001–2014.11 For the SEER-18 database (2000–2014), this study omitted data for 2000, along with death-certificate-only and autopsy cases.

From the USCS database, this study selected the 48 states (excluding Mississippi, Nevada, and the District of Columbia), together covering 98% of the US population, that met USCS data quality criteria for every year (2001–2014). These criteria involved low proportions for death certificate only, missing data (age, sex, and race), and failure to pass single- and multiple-field computerized edits.11 USCS has discontinued (as unnecessary) the use of a criterion for

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estimated case completeness based on incidence/mortality rate ratio for all cancers combined.\textsuperscript{12}

Certification by NAACCR, which requires estimated completeness of more than 95\% (“gold”) or more than 90\% (“silver”), for the 2 states with the largest total populations among all US states was attained by year of diagnosis 2002 (Texas) and by 2003 (California).\textsuperscript{13} In order to include both of these states (also having racially and ethnically diverse populations) and to increase the representativeness (vs the entire US population), a separate analysis was done selecting only those 38 states that were NAACCR-certified for every year in 2003–2014. Of all 456 data cells (38 states × 12 years), 27 involved NAACCR certification at the silver level and 429 at the gold level, based on data in detailed tables provided by NAACCR.\textsuperscript{13}

For each database, separate variables for race and Hispanic ethnicity/Spanish surname were used to classify cancer cases into groups, including non-Hispanic white, Hispanic white, non-Hispanic black (excluding a small numbers of Hispanics with a relatively lower BTSCC–TSCC rate), and non-Hispanic Asian–Pacific Islander.

Statistical Methods

ASIRs per 100,000 for ages ≥65 years were standardized to the age distribution of the 2000 US population (in 5-year age categories from 65–69 through 80–84 years, plus ≥85 years). These ASIRs, and their 95\% standard errors (SEs) and confidence intervals (CIs) were obtained using SEER\textsuperscript{⁎}Stat software.\textsuperscript{10,11}

SEER\textsuperscript{⁎}Stat\textsuperscript{10,11} was also used to create output files with all annual ASIRs and their SEs, which were imported into a joinpoint regression program, for statistical analyses of changes in the magnitude and/or direction of the trend (as in national surveillance reports).\textsuperscript{2,3,9,14} The point in time (calendar year of diagnosis) when any change in the trend occurs is called a “joinpoint,” which connects 2 adjacent line segments; thus, 1 joinpoint involves 2 line segments. A statistical algorithm determines the optimal number (and location in time) of change(s) in the trend. SEER Joinpoint Regression Program Version 4.0.1 (January 2013) was used for log-linear regression analysis, with the natural logarithms of the rates. Using the specifications of the program, the maximum number of joinpoints (for 2001–2014) was 2.

With joinpoint regression, the rates are assumed to increase or decrease (exponentially) by a constant percentage per year, and the slope (“m”) of the regression line (y=\text{e}^{mx+c}) is used to estimate the annual percent change (APC) in incidence rate within each segment (time period).\textsuperscript{15} The APC, with 95\% CI and P value (using a permutations test),\textsuperscript{15} was obtained for each line segment. For complex trends with a joinpoint, the average APC\textsuperscript{c} (ie, for the last 10 years, in this report) was tabulated. Any APC or average APC with a 95\% CI not including zero may be regarded as statistically significant.

A previous report on incidence trends (2000–2012, using SEER alone) for OPSCC at ages ≥65 years used the ASIR for ages ≥80 years (80–84 years and ≥85 years combined) as the oldest subgroup for analysis. For the present study, trends in ASIRs were examined for age subgroups 65–74 years and 75–84 years. For ages ≥85 years (the upper age category),\textsuperscript{10,11} ASIRs could not be obtained. In the SEER database\textsuperscript{10} (although not in USCS),\textsuperscript{11} numbers of cancers (but not rates) could be generated within the broad age category of ≥85 years. Also, accurate population estimates by age subgroup within ≥85 years (needed for calculating the ASIR) are lacking for calendar years between the decennial censuses in 2000 and 2010.\textsuperscript{16} Joinpoint regression was not done for trends in the crude rate for ages ≥85 years, because temporal changes could reflect changes in the age distribution of the population.

Statistical adjustment of trends for delayed reporting was not done; adjustment was available in 1 database\textsuperscript{10} and only for all oral cavity–pharynx sites combined (with little impact reported on trends).\textsuperscript{14}

Results

Trends for All Elderly Women vs Men: 2001–2014

Using the SEER database,\textsuperscript{10} for women, the ASIR per 100,000 was higher in 2014 vs 2001, but CIs overlapped. A joinpoint occurred in 2009, with a negative APC (P = .080) for 2001–2009 and a positive APC (P = .002) for 2009–2014 (not shown); the average APC for the last 10 years was statistically significantly positive (Table 1). Annual ASIRs for women fluctuated using SEER, but CIs were wider vs those using USCS. Using the USCS database,\textsuperscript{11} women showed no clear trend in the ASIR during the early mid-2000s, followed by an increase (Figure 1A), but there was no joinpoint. For elderly men, ASIRs were slightly higher using SEER vs USCS in most years, and 95\% CIs did not overlap only for all years combined (2001–2014) (Table 1). For men, a continuous increase over time was evident using either database (Figure 1B), with APCs close to 5\% and rates for 2014 almost twice those for 2001 (Table 1).


For non-Hispanic whites, using SEER, ASIRs for elderly women increased, with a joinpoint (ie, in 2009) vs none using USCS; for men, the APC was about 5\% using either database, and rates for 2014 were almost twice those for 2001 (Table 1).

For non-Hispanic blacks, ASIRs for women had wider CIs in SEER vs USCS, but APCs were not statistically significantly different from zero using either database (Table 1). For non-Hispanic black men, the APC was positive, but not statistically significant using either database (Table 1); P values were .058 (using SEER) and .118 (using USCS) (not shown).

The ASIR for non-Hispanic black men was slightly higher vs non-Hispanic white men in 2001, but statistically significantly higher for non-Hispanic white vs black patients in 2014 (Table 1, Figure 2). Annual rates during 2001–2014 for non-Hispanic black men showed greater fluctuation using SEER vs USCS (Figure 2).

For Hispanic whites (not shown), the limited number of cancers for women (n = 158) in SEER precluded analysis; using USCS, for women and men, the annual ASIRs had...
wide CIs, and an increase for men was not statistically significant (APC, 1.6%; 95% CI, -0.2% to 3.4%; \( P = .083 \)). For cancers in non-Hispanic Asian-Pacific Islanders (n = 427 in SEER vs 635 in USCS), small numbers of cancers for at least 1 year of diagnosis (suppressed in USCS, and fewer than 10 in SEER) for each sex precluded analysis of trends in ASIRs.

**Trends by Age Subgroups ≥65 Years for Women and Men: 2001–2014**

For ages 65–74 years, ASIRs were similar using SEER vs USCS, and APCs were statistically significantly positive for women and (albeit higher) for men (Table 2). For ages 75–84 years, the trend for women using SEER was complex (2 joinpoints and 3 line segments; not tabulated), reflecting an apparent decline from the early to middle 2000s followed by an increase (Figure 3A), but the CIs on annual rates were wide, and the average APC for the last 10 years was positive (Table 2). Using the (larger) USCS database, however, ASIRs for women aged 75–84 years had narrower CIs (relative to those using SEER) (Table 2) and the increase was roughly continuous after the mid-2000s (Figure 3A). The trends for women for the 2 age groups (Figure 3A) were similar to those for women in all ages combined (Figure 1A).

**Table 1. Age-Standardized Incidence Rates per 100,000 per Year for Ages ≥65 Years for Base of Tongue and Palatine Tonsil Carcinomas: SEER vs USCS Database, 2001–2014**

<table>
<thead>
<tr>
<th>Sex</th>
<th>Database</th>
<th>2001 Rate (95% CI)</th>
<th>2014 Rate (95% CI)</th>
<th>2001–2014 Rate (95% CI)</th>
<th>n</th>
<th>APC (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>SEER</td>
<td>3.9 (3.4–4.5)</td>
<td>4.6 (4.1–5.1)</td>
<td>3.9 (3.7–4.0)</td>
<td>3,056</td>
<td>2.1 (0.9–3.4)</td>
</tr>
<tr>
<td>Women</td>
<td>USCS</td>
<td>3.5 (3.3–3.8)</td>
<td>4.4 (4.1–4.6)</td>
<td>3.9 (3.8–4.0)</td>
<td>11,737</td>
<td>1.7 (1.3–2.1)</td>
</tr>
<tr>
<td>Men</td>
<td>SEER</td>
<td>11.7 (10.6–12.8)</td>
<td>21.9 (20.6–23.2)</td>
<td>16.0 (15.7–16.4)</td>
<td>9,962</td>
<td>4.6 (4.0–5.2)</td>
</tr>
<tr>
<td>Men</td>
<td>USCS</td>
<td>11.1 (10.6–11.7)</td>
<td>20.3 (19.7–20.9)</td>
<td>15.4 (15.2–15.5)</td>
<td>36,741</td>
<td>4.9 (4.5–5.3)</td>
</tr>
<tr>
<td>Non-Hispanic whites only</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>SEER</td>
<td>4.4 (3.7–5.1)</td>
<td>5.4 (4.8–6.2)</td>
<td>4.5 (4.3–4.6)</td>
<td>2,538</td>
<td>2.6 (0.5–4.7)</td>
</tr>
<tr>
<td>Women</td>
<td>USCS</td>
<td>3.7 (3.4–4.0)</td>
<td>4.9 (4.6–5.3)</td>
<td>4.2 (4.1–4.3)</td>
<td>10,203</td>
<td>2.2 (1.6–2.9)</td>
</tr>
<tr>
<td>Men</td>
<td>SEER</td>
<td>12.6 (11.3–13.9)</td>
<td>25.2 (23.6–26.9)</td>
<td>17.8 (17.4–18.2)</td>
<td>8,157</td>
<td>4.6 (4.7–6.0)</td>
</tr>
<tr>
<td>Men</td>
<td>USCS</td>
<td>11.2 (10.6–11.8)</td>
<td>22.1 (21.4–22.9)</td>
<td>16.1 (16.0–16.3)</td>
<td>31,407</td>
<td>4.9 (4.5–5.3)</td>
</tr>
<tr>
<td>Non-Hispanic blacks only</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>SEER</td>
<td>3.1 (1.7–5.2)</td>
<td>4.0 (2.6–6.0)</td>
<td>3.1 (2.7–3.6)</td>
<td>223</td>
<td>1.9 (–1.2, 5.1)</td>
</tr>
<tr>
<td>Women</td>
<td>USCS</td>
<td>3.0 (2.3–4.0)</td>
<td>2.8 (2.1–3.5)</td>
<td>3.0 (2.8–3.2)</td>
<td>806</td>
<td>–0.9 (–2.4, 0.6)</td>
</tr>
<tr>
<td>Men</td>
<td>SEER</td>
<td>14.5 (10.4–19.6)</td>
<td>17.5 (13.7–22.1)</td>
<td>16.4 (15.3–17.6)</td>
<td>812</td>
<td>1.2 (–0.4, 2.8)</td>
</tr>
<tr>
<td>Men</td>
<td>USCS</td>
<td>13.9 (11.8–16.3)</td>
<td>14.9 (13.0–16.9)</td>
<td>14.7 (14.2–15.3)</td>
<td>2,748</td>
<td>1.2 (–0.0, 2.4)</td>
</tr>
</tbody>
</table>

APC, annual percent change in rate; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics (see text).

* Using joinpoint regression, the trend was complex; the average APC for the last 10 years is tabulated (see text). \(^{b}\) CI does not include zero.

**Figure 1. Trends in Age-Standardized Incidence Rates at Ages ≥65 Years for Women (A) and Men (B) for Base of Tongue and Palatine Tonsil Carcinomas Combined: Surveillance, Epidemiology, and End Results Program (SEER) vs United States Cancer Statistics (USCS)**

A. Women

![Graph A](image1)

B. Men

![Graph B](image2)
For men aged 65–74 years and 75–84 years, ASIRs tended to be slightly higher using SEER vs USCS (Figure 3B), although CIs overlapped except for 2001–2014 for men aged 75–84 years (Table 2). APCs were similar and statistically significantly positive (Table 2) and the trends in annual ASIRs for each of these 2 age groups were similar using either database (Figure 3B).

For ages ≥85 years (data not shown), as explained in the Methods section, ASIRs were not available and joinpoint regression was not done. Numbers of cancers were limited in SEER for all years combined (2001–2014; 433 men and 314 women). Using USCS, with 1,553 cancers in men and 1,068 in women diagnosed in 2001–2014, the crude rate increased from 5.6 (95% CI, 4.4–7.1; n = 70) in 2001 to 8.6 (95% CI, 7.4–10.0; n = 178) in 2014 for men; for women, annual rates showed no clear trend.

Table 2. Age-Standardized Incidence Rates per 100,000 per Year for 2 Age Subgroups within Ages ≥65 Years for Base of Tongue and Palatine Tonsil Carcinomas: SEER vs USCS Database, 2001–2014

<table>
<thead>
<tr>
<th>Sex</th>
<th>Database</th>
<th>2001</th>
<th>Rate (95% CI)</th>
<th>2014</th>
<th>Rate (95% CI)</th>
<th>2001–2014</th>
<th>Rate (95% CI)</th>
<th>n</th>
<th>APC (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages 65–74 Years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>SEER</td>
<td>4.0 (3.3–4.9)</td>
<td></td>
<td>5.2 (4.5–6.0)</td>
<td></td>
<td>4.4 (4.2–4.6)</td>
<td>1,765</td>
<td></td>
<td>1.7 (0.7–2.7)</td>
</tr>
<tr>
<td>Women</td>
<td>USCS</td>
<td>3.9 (3.5–4.3)</td>
<td></td>
<td>5.0 (4.6–5.4)</td>
<td></td>
<td>4.2 (4.3–4.6)</td>
<td>6,877</td>
<td></td>
<td>1.8 (1.2–2.4)</td>
</tr>
<tr>
<td>Men</td>
<td>SEER</td>
<td>13.8 (12.2–15.4)</td>
<td></td>
<td>27.3 (25.5–29.2)</td>
<td></td>
<td>19.9 (19.4–20.4)</td>
<td>6,938</td>
<td></td>
<td>4.2 (4.1–5.6)</td>
</tr>
<tr>
<td>Men</td>
<td>USCS</td>
<td>13.7 (12.9–14.5)</td>
<td></td>
<td>25.6 (24.7–26.5)</td>
<td></td>
<td>19.3 (19.1–19.5)</td>
<td>25,867</td>
<td></td>
<td>4.2 (4.7–5.7)</td>
</tr>
<tr>
<td>Ages 75–84 Years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>SEER</td>
<td>4.2 (3.4–5.3)</td>
<td></td>
<td>4.4 (3.5–5.4)</td>
<td></td>
<td>3.6 (3.4–3.8)</td>
<td>977</td>
<td></td>
<td>3.2 (0.1–6.4)</td>
</tr>
<tr>
<td>Women</td>
<td>USCS</td>
<td>3.4 (3.0–3.9)</td>
<td></td>
<td>4.2 (3.8–4.7)</td>
<td></td>
<td>3.6 (3.5–3.8)</td>
<td>3,972</td>
<td></td>
<td>1.6 (0.9–2.2)</td>
</tr>
<tr>
<td>Men</td>
<td>SEER</td>
<td>10.3 (8.6–12.2)</td>
<td></td>
<td>18.1 (16.0–20.3)</td>
<td></td>
<td>13.5 (12.9–14.0)</td>
<td>2,591</td>
<td></td>
<td>4.2 (2.9–5.5)</td>
</tr>
<tr>
<td>Men</td>
<td>USCS</td>
<td>9.2 (8.3–10.1)</td>
<td></td>
<td>16.5 (15.5–17.6)</td>
<td></td>
<td>12.6 (12.3–12.8)</td>
<td>9,321</td>
<td></td>
<td>4.5 (3.7–5.3)</td>
</tr>
</tbody>
</table>

APC, annual percent change in rate; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics (see text).

Using joinpoint regression, the trend was complex; the average APC for the last 10 years is tabulated (see text).

CI does not include zero.
Trends for NAACCR-Certified States, All USCS-Certified States, and SEER: 2003–2014

The 38 states NAACCR certified for every year of diagnosis from 2003–2014 accounted for 83% of all BTSCC–TSCC cases in ages ≥65 years in the 48 states in USCS for this period; the rates and APCs were higher in men than women, but differed little using the 38 NAACCR-certified states vs using all 48 USCS-certified states (Table 3). Using SEER, for women, a joinpoint in 2009 occurred, with a statistically significant average APC for the last 10 years; for men, SEER rates were slightly higher (vs USCS) but APCs were similar (about 5%) (Table 3).

Discussion

Comparison of Trends in ASIRs Using the Different Databases

Using SEER data for 2001–2014, increases in ASIRs for BTSCC–TSCC were evident for elderly women as well as men (Table 1, Figure 1), whereas an increase for elderly men but not women was previously reported using SEER data for 2002–2012.4 The difference reflects the impact of recent increases (2009–2014) for elderly women in SEER (Figure 1A).

Trends were generally consistent using SEER vs USCS. Using the larger USCS database, however, narrower CIs on annual ASIRs (vs using SEER) apparently clarified the trends for all women and non-Hispanic black women (Table 1), non-Hispanic black men (Figure 2), and all women aged 75–84 years (Table 2, Figure 3).

For the 38 states in USCS-certified states that were also certified by NAACCR for years of diagnosis 2003–2014, annual ASIRs and APCs (2003–2014) for ages ≥65 years were similar to those for all 48 USCS-certified states combined (and SEER) (Table 3). This supports the utility of the larger USCS-certified database for analysis of recent trends in incidence rates, at least for the cancer sites studied.

Interpretation of Surveillance Data on Trends in ASIRs

A previous study detailed the “strong circumstantial support” for the role of the epidemic of oral HPV infection in explaining the rising incidence of OPSCC at ages ≥65 years in SEER data for 2002–2012.4 In samples of OPSCC patients (diagnosed in the 1990s to mid-2000s) from selected US cancer registries, oncogenic HPV types in tumor tissues were reported as about 60%–65% at age ≥70 years5 or ≥65 years,6 vs about 75% for younger ages.5,6 Data were not reported for elderly patients by sex and/or racial–ethnic group, and total samples for minorities were limited (eg, with 71 or 74 non-Hispanic black OPSCC of all ages).5,6 Larger OPSCC samples appear to be needed from expanding registry-based tumor biospecimen resources,7 including historical data on HPV prevalence in archived tissues.

Of potential relevance to future surveillance is SEER’s attempt to collect a data item, not included in the SEER research database,10 on any clinical testing done for HPV DNA in tumor tissues, for selected oropharyngeal cancer sites diagnosed since 2010.18 A SEER “patterns of care” study found that only 14% of a sample of 335 OPSCC patients diagnosed in 2009 had been tested clinically for HPV,19 although such testing may be increasing.18 HPV-positive (vs HPV-negative) OPSCC patients tend to have better prognosis and this has led to changes in the latest revision of a staging system used by clinicians,20 potentially affecting decisions about testing for HPV markers in tumor tissues of patients.

Study Limitations

The registry databases lacked data items10,11 on other risk factors for OPSCC, including history of tobacco or alcohol use. Trends in the prevalence of these risk factors in the population have impacted trends in OPSCC. Also, tonsillectomy, which removes most palatine tonsillar tissue, has been declining in prevalence in the US population and has been associated with reduced risk of tonsillar but not base of tongue cancers.21 In Sweden, linkages of national hospital and cancer registry databases showed increasing TSCC incidence rates independent of declines in tonsillectomy rates; this suggested a role for HPV.21 In an analysis (not shown) of trends in ASIRs at ages ≥65 years using the USCS database,11 for BTSCC alone (ie, not affected by trends

Table 3. Age-Standardized Incidence Rates per 100,000 per Year for Ages ≥65 Years for Base of Tongue and Palatine Tonsil Carcinomas for 38 NAACCR-Certified States in USCS,11 All USCS-Certified States,11 and SEER Alone10 2003–2014

<table>
<thead>
<tr>
<th></th>
<th>Database</th>
<th>2003 Rate (95% CI)</th>
<th>2014 Rate (95% CI)</th>
<th>2003–2014 Rate (95% CI)</th>
<th>2003–2014 n</th>
<th>APC (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>USCS-38a</td>
<td>3.6 (3.3–3.9)</td>
<td>4.4 (4.2–4.7)</td>
<td>4.0 (3.9–4.0)</td>
<td>8,489</td>
<td>2.3 (1.7–2.8)</td>
</tr>
<tr>
<td>Women</td>
<td>USCS-Allb</td>
<td>3.6 (3.3–3.8)</td>
<td>4.4 (4.1–4.6)</td>
<td>3.9 (3.9–4.0)</td>
<td>10,299</td>
<td>2.0 (1.5–2.5)</td>
</tr>
<tr>
<td>Women</td>
<td>SEER</td>
<td>3.7 (3.2–4.3)</td>
<td>4.6 (4.1–5.1)</td>
<td>3.9 (3.7–4.0)</td>
<td>2,651</td>
<td>2.2 (0.6–3.8)</td>
</tr>
<tr>
<td>Men</td>
<td>USCS-38a</td>
<td>12.5 (11.9–13.2)</td>
<td>20.9 (20.2–21.6)</td>
<td>16.2 (16.0–16.4)</td>
<td>27,665</td>
<td>5.0 (4.4–5.6)</td>
</tr>
<tr>
<td>Men</td>
<td>USCS-Allb</td>
<td>12.3 (11.7–12.9)</td>
<td>20.3 (19.7–20.9)</td>
<td>16.0 (15.8–16.1)</td>
<td>33,389</td>
<td>5.1 (4.5–5.6)</td>
</tr>
<tr>
<td>Men</td>
<td>SEER</td>
<td>13.1 (12.0–14.3)</td>
<td>21.9 (20.6–23.2)</td>
<td>16.6 (16.3–17.0)</td>
<td>9,036</td>
<td>4.7 (3.9–5.5)</td>
</tr>
</tbody>
</table>

APC, annual percent change in rate; NAACCR, North American Association of Central Cancer Registries; SEER, Surveillance, Epidemiology, and End Results Program; USCS, United States Cancer Statistics (see text).

aIncludes 38 states (see text). bIncludes 48 states (see Table 1 and text). cUsing joinpoint regression, the trend was complex; the average APC for the last 10 years is tabulated (see text). dCI does not include zero.
in palate tonsillectomy). APCs were statistically significantly positive but larger for men than women.

Other study limitations include some misclassification of racial-ethnic group with the various resources (eg, hospital records and surname–birthplace algorithms) used by cancer registries; also, denominator data used for cancer rates are from national censuses that involve self-reported race and ethnicity.22

In addition, ICD-O-3 codes for anatomical site and histologic type in SEER and USCS databases are subject to miscoding in central cancer registries, but also misclassification in pathology reports representing “usual US practice” of pathologists in the community.23 Imprecise codes (eg, NOS codes for topography) in registries may need to be routinely reviewed. For example, a review of pathology reports for a sample of cases coded as tongue NOS (C029) in 1 SEER registry found that a substantial proportion could be recoded to a more specific site (mainly oral tongue, C023), and a small proportion to base of tongue.24 Independent review of coding by anatomical site using an expert pathologist or panel, however, was not included.24 Pathology review may be useful, a shown for assessing the certainty of palatine tonsilar (vs other oropharyngeal) origin of tumors coded as TSCC in a tumor registry in Denmark.25

In the United States, suggestions for collaboration among cancer registries include use of computerized “natural language processing” of pathology reports, in an attempt to reduce the extent of missing data and miscoding during data abstraction in the registries.23 Development of registry-based collections of digital images of pathological specimens, for potential use in pathology practices and in cancer surveillance research, also has been recommended.23

**Conclusions**

Increasing ASIRs for BTSCC–TSCC in the US elderly population were generally consistent using SEER vs USCS research databases, and included both subgroups 65–74 and 75–84 years. For surveillance of age subgroups within ≥85 years, however, other databases are needed, along with more accurate intercensus US population estimates, especially in view of projected population growth.16

The APCs/AAPCs for BTSCC–TSCC at ages ≥65 years (Table 1) should be used to project rates and numbers of cases for only a few calendar years16 beyond 2014. Continued surveillance using population-based registries is needed, including the growing elderly minority populations. Studies using expanded biospecimen resources are needed on HPV markers in tumor tissues, to aid in explaining the increases in ASIRs.

HPV vaccination of youths has been associated with reduction in risk of oral HPV infection among young adults in a US survey, although the impact was limited by low vaccination coverage (especially in males).27 Introduced in the United States in 2006 for girls and 2011 for boys and recommended at age 11–12 years, HPV vaccination coverage among adolescents has been increasing, although remaining much lower than that for other common infectious diseases.28 This could result in reductions in future OPSCC incidence rates, as vaccinated youths eventually reach older ages with substantial OPSCC risk,3,6 but not for several decades for the population aged ≥65 years.

The present findings, however, support the need for planning diagnostic and treatment resources for increasing numbers of elderly OPSCC patients with head and neck cancers in the aging US population.29 There is also a need for expansion of clinical trials of treatments for OPSCC in elderly patients, who tend to have lower survival rates vs younger patients.4

**References**


Can Technology Help Us Find Patients? Identifying Patients for Cancer Registry with the Use of a Software Product

Cheryl Sheridan, RHIT, CTR

Objective
Create a standardized method using technology (software) to identify cancer patients at the point of diagnosis (in this case – pathology report) for potential case finding for cancer registry.

Background
Upon an internal review, cancer registrars were spending up to 20% of their time identifying cancer patients (Figure 1). That time was spent manually reviewing pathology reports. Then, manually entering that case into the cancer registry database. Which is time consuming, delayed, and not standardized.

Method
In collaboration with both Sarah Cannon information technology (IT) and a partnered vendor, the patient identification (PT ID) software was designed to analyze content from electronic medical record (EMR) pathology reports.

Efficiencies
It is estimated that it would require 11,963 hours to read the total pathology reports reviewed by PT ID in the first quarter of 2018. Utilizing PT ID, the estimated hours are 822. Hours saved by using PT ID is 11,141 between January 1, 2018 and March 31, 2018 (Figure 2).

Results
During the first quarter of 2018, the PT ID tool reviewed 239,262 pathology reports. The pathology reports predicted as having cancer and reviewed by cancer registrars totaled 56,696. The breast, colon, complex gastrointestinal, and lung cancer patients identified for navigation totaled 12,291 patients (Figure 3).

Conclusion
Timely access to navigators is of utmost importance to cancer patients. The use of PT ID to identify positive cancer patients at the point of diagnosis; creates a standardized method for navigators to receive patients. Utilizing technology to help identify patients allows for advancement to concurrent abstracting (Figure 4).

This content was originally presented as a poster at the National Cancer Registrars Association’s 44th Annual Educational Conference, May 20–23, 2018, New Orleans, Louisiana.

Sarah Cannon, the Cancer Institute of HCA.
Address correspondence to Cheryl Sheridan, RHIT, CTR. Email: cheryl.sheridan@sarahcannon.com
Figure 3. Results

- 239,262 Pathology Reports Reviewed by Patient ID NLP Model
- 56,696 Pathology Reports Predicted as Having Cancer; Reviewed by Cancer Registrars
- 23,231 Identified Cancer Patients (All Cancers)
- 12,291 Breast, Colon, Complex GI, Lung Cancer Patients Identified for Navigation
- 3,925 Newly Diagnosed, Navigated Cancer Patients

Figure 4. Downstream Impact on Navigators

- Navigators no longer have to “mine” procedural areas to ID patients
- New relationships with physicians are being formed due to patient ID
- Improved timeliness of care for patients
An Innovative Response to Achieving Commission on Cancer Standard 3.3 Survivorship Care Plans

Ebony Johnson, CTR; Mildred Jones, BA, CTR; Donna Meyer, BSN, MS; Kate Canterbury, MPA; Patty Huggins, BS, CTR; Nora Flowers, CTR; Clarice Schuyler, WHNP-BC, RNC-OB, C-MC; Carol Del Campo, RN, BSN, OCN

Commission on Cancer Standard

Northside Hospital Cancer Institute (NHCI) is an American College of Surgeons Commission on Cancer (CoC)-accredited facility with an annual volume of more than 9,000 newly diagnosed cases.

CoC Standard 3.3 requires that cancer programs develop and implement a process to monitor the dissemination of survivorship care plans (SCPs), which are comprised of a comprehensive care summary of their first course of therapy (Figure 1) and a follow-up plan (Figure 2).

Methods

A certified tumor registrar (CTR) position, dedicated to survivorship, was created and has evolved into a specialized treatment summary registrar. This individual creates treatment summaries from abstracted cancer registry data; collaborates with providers and practice staff members to ensure accuracy; and transmits each summary to the oncology care team for ultimate delivery to the patient (Figure 3).

The Collaborative Survivorship Team includes:

- Treatment summary CTR
- Registry software vendor
- CTR abstractors
- Physician office practices
- Survivorship coordinator
- Nurse practitioners
- Physician Assistants
- Nurses
- NHCI information technology (IT)

Innovation

The Survivorship Program Coordinator, along with the cancer registry team, used today’s software technology to create a streamlined approach to the development and dissemination of SCPs. In 2016, Northside collaborated with their registry vendor to create custom, automated templates that translate aggregated patient data from the abstract to a patient/provider-friendly document that includes all required elements per guidelines from American Society of Clinical Oncology (ASCO).

Implementation

Currently, priority populations for generation and delivery of SCPs are breast, melanoma, and gynecological cancer patients. Maintaining a high level of quality was cornerstone to this process. After a case is fully abstracted, which includes all data pertaining to the patient’s diagnosis and treatment, the treatment summary CTR completes a quality assurance check. Then, the CTR generates the treatment summary and transmits to designated practice contact. At that point, the practice prepares the treatment summary and follow-up plan for patient delivery.

Once the provider or nurse has completed the survivorship visit with the patient delivering an SCP, the visit date is then communicated to the CTR. The cancer registry serves as the repository for all treatment summary related-data that is required for reporting by the CoC. A dashboard is created quarterly for the Survivorship Oversight Committee and reported annually to Cancer Committee.

Results

With this system in place, NHCI exceeded the goal in 2016 by delivering more than 25% of survivorship care plans to eligible patients. For 2017, we met the goal of 50% and are on track to deliver 50% again in 2018 (Figure 4).

Lessons Learned

- Development of a plan to satisfy Survivorship Care Plan Standard 3.3 required a collaborative, multidisciplinary approach.
- The cancer registry team is well suited to assist the clinical team in the delivery of SCPs due to automation and comprehensiveness of data collected.
- NHCI continues to experience challenges with treatment summary delivery in a large community-based system across multiple cancer sites.

Acknowledgements

We would like to acknowledge the assistance of the Northside Hospital Cancer Institute and the Northside Oncology Analytics and Quality Team.
Poster

Validation of the American Joint Committee on Cancer (AJCC) Cancer Staging Eighth Edition for Prostate Cancer: A Registry Database Review

Honghong Huang a; Mei Ying Ng a; Saajida Begum Binte Syed Aneesur Rahman a; Weber Kam On Lau a

Introduction

• The eighth edition (2018) of the American Joint Committee on Cancer (AJCC) cancer staging for prostate cancer revised the T category criteria and incorporated grade grouping and preoperative prostate-specific antigen (PSA) (Table 1).
• To date, limited survival data to suggest that the eighth edition is applicable to an Asian population.

Materials and Methods

• Retrospectively reviewed all 977 clinically staged prostate cancer patients with radical prostatectomy performed at our hospital from 2000–2014.
• A total of 904 patients included in the analysis after excluding 72 patients with missing data and 1 patient in Stage IVB (eighth edition) due to n = 1.
• Kaplan–Meier analysis performed in SPSS version 23 and concordance index calculated for sixth and eighth editions in R 3.3.1.

Results

• Results are shown in Tables 2 and 3 and Figures 1 and 2.
• 2-year BCR-free survivals: 92.9%, 94.2%, 89.1%, 76.3%, 74.5%, and 59.6% in stage I, IIA, IIB, IIC, IIIA and IIIB, respectively, according to the eighth edition (P < .001) compared with 87.8% and 62.6% in stage II and III, respectively, according to the sixth edition (P < .001).

Limitations

• Short follow-up period post radical prostatectomy (median ± IQR: 2.0 ± 3.8 years).
• Small sample size, especially for stage I and IV cases.
• Hospital-based cancer registry data may not be representative of population in Singapore.

Table 1. Comparisons between the Sixth and Eighth Editions of The American Joint Committee on Cancer (AJCC) Cancer Staging for Prostate Cancer

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>T1a</td>
<td>cT1a-c, cT2a</td>
<td>N0 M0 &lt;10 ng/mL</td>
<td>cT1a-c, cT2a</td>
</tr>
<tr>
<td>T1b</td>
<td>Any</td>
<td>N0 M0 &lt;10 ng/mL</td>
<td>Any</td>
</tr>
<tr>
<td>T1c</td>
<td>cT2b-c</td>
<td>N0 M0 &lt;20 ng/mL</td>
<td>cT2b-c</td>
</tr>
<tr>
<td>T1</td>
<td>T1-2</td>
<td>N0 M0 &lt;20 ng/mL</td>
<td>T1-2</td>
</tr>
<tr>
<td>T1c</td>
<td>T1-2</td>
<td>N0 M0 &lt;20 ng/mL</td>
<td>T1-2</td>
</tr>
<tr>
<td>T2</td>
<td>T1-2</td>
<td>N0 M0 &lt;20 ng/mL</td>
<td>T1-2</td>
</tr>
<tr>
<td>T2</td>
<td>T1-2</td>
<td>N0 M0 &lt;20 ng/mL</td>
<td>T1-2</td>
</tr>
<tr>
<td>T3</td>
<td>T1-2</td>
<td>N0 M0 &lt;20 ng/mL</td>
<td>T1-2</td>
</tr>
<tr>
<td>T4</td>
<td>T1-2</td>
<td>N0 M0 &lt;20 ng/mL</td>
<td>T1-2</td>
</tr>
</tbody>
</table>

Conclusion

• Modifications in the eighth TNM classification show a significant improvement in survival stratifications over the sixth edition in our Asian cohort.

This content was originally presented as a poster at the National Cancer Registrars Association’s 44th Annual Educational Conference, May 20–23, 2018, New Orleans, Louisiana.

a Singapore General Hospital, Outram Road, Singapore.

Address correspondence to Honghong Huang. Email: huang.hong.hong@sgh.com.sg.

This project received funding from the SingHealth Endowment Fund, Teaching Fund and NMRC /TA/0005/2012.
Table 2. Stage Groups According to Sixth and Eighth Editions

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number (%)</td>
<td>Number (%)</td>
</tr>
<tr>
<td>I</td>
<td>0 (0)</td>
<td>276 (30.5)</td>
</tr>
<tr>
<td>II</td>
<td>863 (95.5)</td>
<td>102 (11.3)</td>
</tr>
<tr>
<td></td>
<td>IIA</td>
<td>IIA</td>
</tr>
<tr>
<td></td>
<td>IIB</td>
<td>IIB</td>
</tr>
<tr>
<td></td>
<td>IIIC</td>
<td>IIIC</td>
</tr>
<tr>
<td>III</td>
<td>36 (4.0)</td>
<td>74 (8.2)</td>
</tr>
<tr>
<td></td>
<td>IIIA</td>
<td>IIIA</td>
</tr>
<tr>
<td></td>
<td>IIIB</td>
<td>IIIB</td>
</tr>
<tr>
<td></td>
<td>IIIC</td>
<td>IIIC</td>
</tr>
<tr>
<td>IV</td>
<td>5 (0.6)</td>
<td>IVA</td>
</tr>
</tbody>
</table>

Table 3. Concordance Index for Sixth and Eighth Editions of The American Joint Committee on Cancer (AJCC) Cancer Staging for Prostate Cancer

<table>
<thead>
<tr>
<th>AJCC Edition</th>
<th>Concordance Index</th>
<th>95% CI</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>6th</td>
<td>0.600</td>
<td>0.547–0.653</td>
<td>.01224</td>
</tr>
<tr>
<td>8th</td>
<td>0.655</td>
<td>0.604–0.707</td>
<td></td>
</tr>
</tbody>
</table>

Figure 1. Biochemical Recurrence (BCR)–Free Survival According to Sixth Edition

Figure 2. Biochemical Recurrence (BCR)–Free Survival According to Eighth Edition
American Joint Committee on Cancer (AJCC) Cancer Staging Eighth Edition: Prognostic vs Anatomic Path Stage Group for Breast Cancer

Bal Sidhu, Lorette Bowers, Gail Noonan, Patricia Murison, Grace Liu, Ketsia Ly, Joanne Turner, Kim Vriends, Christine St-Pierre

Background
• Anatomic and prognostic stages categorize patients and help facilitate whether to give systemic therapy and also predict future outcomes
• Anatomic stage uses tumor nodes metastases (TNM) information, while prognostic stage takes into account TNM plus prognostic factors (PFs)
• Effective 2018 diagnosis in American Joint Committee on Cancer (AJCC) eighth edition, certain PFs will now be used to calculate a prognostic stage for both clinical and pathological classification
• With the addition of the PFs, the prognostic stage that is derived may be different than what is derived for anatomic stage

Objectives
• Describe the difference between anatomic and prognostic stage group for breast cancer
• Identify the breast PFs and their impact on path stage subgroups
• Recognize the important role of certified tumor registrars (CTRs) in collection of prognostic factors

Methods
• The Data Quality Management Committee of the Canadian Council of Cancer Registries (CCCR) gathered 42 AJCC seventh edition staged breast cases from the Canadian Cancer Registry, across 7 Canadian provincial registries
• Assigned prognostic stage as per tables in the revised AJCC eighth edition breast chapter by applying prognostic factors
• Compared the anatomic path stage with the prognostic path stage (Figure 1)

Results
• Of 42 cases reviewed, 31 cases (74%) resulted in different prognostic path stage than anatomic stage
• 11 cases (26%) remained the same
• 6 cases (14%) up-staged (all had Her2, ER, PR=Neg)
• 25 cases (60%) down-staged (15/25 cases moved by more than 2 categories) (all had ER, PR=Pos) (Figure 2)

Cancer Tumor Registrar’s Role
• AJCC seventh edition cases: in registry software, the breast prognostic factors collected are independent and do not affect anatomic path stage subgroup
• AJCC eighth edition: the breast prognostic factors collected will be used to assign the prognostic path stage group
• CTRs will need to ensure completeness and accuracy of PFs in the registry software, since PFs will affect the prognostic path stage subgroup

Conclusion
• Prognostic stage group will be the standard for reporting for breast cancer
• Prognostic factors have direct impact on the prognostic stage group for breast cancer
• CTRs play a vital role in ensuring that prognostic factors are entered correctly in registry software so that an accurate prognostic path stage subgroup is assigned
**Figure 1. Anatomic Stage vs Prognostic Path Stage for a 2015 Diagnosis Case**

<table>
<thead>
<tr>
<th>ANATOMIC</th>
<th>PROGNOSTIC</th>
<th>AJCC 8th Ed</th>
</tr>
</thead>
<tbody>
<tr>
<td>T - Tumour size/extent</td>
<td>T - Tumour size/extent</td>
<td>T4b, N1a, M0</td>
</tr>
<tr>
<td>N - Regionally lymph nodes</td>
<td>N - Regional lymph nodes</td>
<td>Grade = 2</td>
</tr>
<tr>
<td>M - presence/absence of distant metastases</td>
<td>M - presence/absence of distant metastases</td>
<td>Her2 = Neg</td>
</tr>
<tr>
<td>Path Stage = IIIB</td>
<td>Prognostic Factors</td>
<td>ER = Pos</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PR = Pos</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OncotypeDx*</td>
</tr>
<tr>
<td>* Applicable only for T1-2, N0, M0 ER Pos, Her2 Neg cohort</td>
<td>Path Stage = IIIA</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 2. Results**

<table>
<thead>
<tr>
<th>Path Stage Group</th>
<th>AJCC 8th Edition Prognostic Path Stage SubGroup</th>
<th># of Breast Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>AJCC 7th Ed Anatomic Path Stage SubGroup</td>
<td>IA</td>
<td>IB</td>
</tr>
<tr>
<td>IA</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>IB</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>IIA</td>
<td>4*</td>
<td>1</td>
</tr>
<tr>
<td>IIB</td>
<td>2*</td>
<td>5*</td>
</tr>
<tr>
<td>IIIA</td>
<td>2*</td>
<td>1*</td>
</tr>
<tr>
<td>IIIB</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>IIIC</td>
<td>1*</td>
<td>2</td>
</tr>
<tr>
<td>Grand Total</td>
<td>12</td>
<td>12</td>
</tr>
</tbody>
</table>

Cases downstaged

*Cases downstaged by 2 or more substage groups

Cases upstaged by 1 substage group
Introduction
The New Jersey State Cancer Registry (NJSCR)’s certified tumor registrar (CTR) Exam Readiness Guide was developed for individuals seeking certification to better navigate exam registration and preparation. Utilizing NCRA’s CTR exam tools to start, NJSCR created a mini-guide to include:
• Exam content
• Exam day tips
• Study materials
• Required references
• Eligibility requirements
• Application instructions

Purpose
The guide consolidates resources and provides a keen snapshot of all necessary components of the CTR exam so that trainees can successfully register and prepare for certification testing.

The CTR Exam Readiness Guide serves as a quick reference or “How-To-Guide” for eligible test takers.

Methods
NJSCR identified a need to integrate a process in preparation and application for the CTR exam. A 3-page guide was created comprising key elements to streamline access to available information from multiple sources (Figure 1). The guide also accounts for content changes and highlights new segments to promote awareness.

The CTR Exam Readiness Guide was then distributed among staff, students, and several external candidates to evaluate usefulness.

Discussion
Though relatively new, CTR Exam Readiness Guide feedback has been positive. Next steps in expanding accessibility include distribution through:
• NJSCR student visits
• NJSCR website
• Oncology Registrar’s Association of New Jersey (ORANJ) publications

Through these channels, additional data collection on usefulness and efficacy will support its existence or demonstrate a need for improvement. Long-term goals aim to improve exam pass rates for the New Jersey region and increase the availability of qualified CTRs.

Result
Since May of 2017, the CTR Exam Readiness Guide has been used by 3 internal CTR candidates along with a number of external registrars as a convenient guide from study preparation through exam day.

This guide was recently introduced as a resource during our in-house student clinical rotations (American Health Information Management Association and Rowan College at Burlington County Cancer Registry Management Program students) and distributed at Pierce College’s Cancer Registry Seminar of Health Information Management and Allied Health students and alumni.

Conclusion
The CTR Exam Readiness Guide is a pragmatic tool in navigating exam registration and preparation. The guide benefits those new to oncology data collection needing appropriate resources and even those currently in the field looking to improve upon their registry skills.

Overall, the CTR Exam Readiness Guide is a convenient tool to improve education through better access to verified resources, increase awareness of exam content, and provide a comprehensive overview of registry functions.

Acknowledgements
The NJSCR would like to thank the cancer registry students and others who have used the guide and provided their feedback for its improvement. We would also like to acknowledge the many organizations whose educational tools and CTR exam resources serve as the foundation for this guide, including the National Cancer Registrars Association, the National Cancer Institute Surveillance, Epidemiology and End Results program, the American College of Surgeons Commission on Cancer, and the North American Association of Central Cancer Registries.

This content was originally presented as a poster at the National Cancer Registrars Association’s 44th Annual Educational Conference, May 20–23, 2018, New Orleans, Louisiana.

Cancer Epidemiology Services, including the New Jersey State Cancer Registry, receives support from the Surveillance, Epidemiology, and End Results Program of the National Cancer Institute under contract HHSN 2612013000211 and control No. N01PC-2013-000221, the National Program of Cancer Registries, Centers for Disease Control and Prevention under cooperative agreement 6NU58DP006279-01-01, the State of New Jersey, and the Rutgers Cancer Institute of New Jersey.
Figure 1. The Certified Tumor Registrar Exam Readiness Guide from the New Jersey State Cancer Registry

**Read**

& **Complete**

provide short step-by-step directions to quickly orient individuals and streamline the application process.

**Know**

displays test format while ensuring the most recent version of exam content through biannual updates.

**Bring**

lists required references along with rules & regulations associated with each.

**Prepare**

presents all verified study tools allowing students to choose what educational product best meets their needs.

**Study**

introduces NEW exam content and directs focus to specialty topics or areas of significance.

**Remember**

highlights exam day strategies and specifics commonly overlooked.
Improving Accuracy: Coding Type of Reporting Source at the New Jersey State Cancer Registry

Frances Krol, AAS, CTR; Harrine Katz, BS, CTR; Maureen Romero, RHIA, CTR; Suzanne Schwartz, MS, CTR; Karen Pawlish, ScD, MPH; Stephanie M. Hill, MPH, CTR; Antoinette M. Stroup, PhD

Introduction

Who
The New Jersey State Cancer Registry (NJSCR) identified an opportunity to evaluate, correct, and improve the coding accuracy of the data item Type of Reporting Source.

What
Type of Reporting Source (TRS)
- Identifies the source documents that provided the best information when abstracting the case.
- Utilized and required by the following:
  - National Program of Cancer Registries (Centers for Disease Control and Prevention) and Surveillance, Epidemiology, and End Results (SEER) Program (National Cancer Institute)
  - NJSCR staff
  - New Jersey Cancer Epidemiology Services
  - Researchers
- Measures nonhospital case reporting.
- Monitors trends in reporting source over time.

Why
To improve coding accuracy

When
Project Start Date: January 2017
Project End Date: May 2017

Type of Reporting Source
A vital tool for demonstrating the variety of facility types diagnosing and treating cancer in today’s health care landscape.

Methods

How
- Step #1: Reviewed baseline data to define quality parameters.
- Step #2: Contacted standard setters to clarify coding rules.
- Step #3: Created auto-coding algorithm to differentiate between independent and hospital pathology labs.
- Step #4: Explored practices used by other state registries to successfully code this field.
- Step #5: External Training Measures:
  - Trained hospital registrars on enhanced coding definitions via our electronic newsletter (E-Tips).
- Step #6: Internal Training Measures:
  - Established supplemental in-house coding guidelines.
  - Conducted training, data review, and retraining.
  - Trained in large and small group settings, as well as 1:1 sessions.
  - Added TRS to checklist of data fields reviewed monthly.

Results
Results are shown in Figure 1.

Data Reviewed
- Nursing home, hospice, autopsy, and death certificate only cases were excluded due to the small sample size.
- Baseline data showed a high accuracy rate (X%) for hospital-reported cases (TRS = XX); and, therefore, excluded from further analysis.
- Cases coded to pathology lab (PL), surgery center (SC), oncology center (OC), or physician office (PO) had a high number of cases coded inaccurately.

Pre-Training Data Review: January 2017
- Accuracy rate ranged between 7%–71% for nonhospital reporting source types.

Post-Training Data Review: April 2017
- Accuracy for all nonhospital records improved from 35% to 40%.
- SC and PO coding improved.
- PL and OC decreased in TRS coding accuracy.
- Additional training was held in small group and 1:1 settings.
Post-Training Data Review: May 2017

- Accuracy increased from 40% to 65%.
- PL, SC, and OC coding improved.
- PO accuracy decreased.

Conclusions

Findings

- Routine quality assurance review is necessary for sustained improvement.
- Training in multiple formats is recommended to meet the needs of trainees.
- Interpreting coding guidelines, ambiguity of coding rules, and frequent restructuring of health care organizations are factors that contribute to incorrect coding of this data field.

Outcomes

- Achieved approximately 30% increase in internal coding accuracy over a period of 5 months.
- Added Type of Reporting Source to list of data fields reviewed during monthly quality review.
- Developed SQL report for data analysis that can be modified for use in other data field quality improvement projects.

Future Plans

- Update NJCSR Program Manual with specific coding guidelines for Type of Reporting Source.
- Monitor accuracy through monthly quality reviews.
- Explore additional software autocoding algorithms to improve accuracy without manual review.
- Apply this QI methodology to improve coding accuracy of other data fields.

Acknowledgements

We thank IMS Data Management software for their help.

Resources

1. SEER Program Coding and Staging Manual 2016

Figure 1. Type of Reporting Source: New Jersey State Cancer Registry Coding Accuracy Data Review Results
Improving Completeness of Treatment Documentation through Resubmission of Data in New Jersey

Stephanie M. Hill, MPH, CTR a,b; Jamal D. Johnson, BS, CTR a,b; Hannah Montemurno, CTR a,b; Adrian Botchway, CTR a,b; Heather Stabinsky, MS Ed, CTR a,b; Mireille Lemieux, MSc, CTR a,b; Antoinette M. Stroup, PhD a,b,c

Background and Purpose
The New Jersey State Cancer Registry (NJSCR) requires cases be submitted within 6 months of diagnosis. While the Commission on Cancer (CoC) no longer requires hospitals to abstract cases within 6 months of date of first contact, the CoC is encouraging hospitals to abstract in a timelier fashion for the Rapid Quality Reporting System (RQRS). The increase in timely reporting of cases from hospitals may result in incomplete treatment reported to the central registry if treatment begins after case submission. The primary objective of this study was to assess the impact on the completeness of the central registry’s documentation of treatment and other information by resubmission of the North American Association of Central Cancer Registries (NAACCR)-modified records 15 months after diagnosis. It also allowed NJSCR to assess its capacity to absorb these additional tasks into the consolidation workflow and to identify areas where automated consolidation algorithms may reduce staff time required for these updates (eg, manual review tasks).

Methods
- Approximately 24,000 cases from the NJSCR database met the eligibility criteria:
  - Diagnosed from January 1, 2014 to December 31, 2014
  - Adult age (≥20 years old at diagnosis)
  - Invasive behavior
  - Primary site: lung, breast, prostate, colon and rectum
- Sample of cancer cases selected from 7 CoC-accredited hospitals (1 facility was unable to participate, resulting in 6 participating facilities)
- SEER*DMS used to link NAACCR-modified records to existing cases
- Manual and automated consolidation used to update cases with additional information form NAACCR-modified records
- Analyzed updates (manual and automated) from 15-month resubmission data for:
  - Treatment
  - Recurrence status
  - Other key data items
  - Nonrelevant data items

Discussion
Resubmission of cancer registry cases by the hospital to the central registry 15 months after diagnosis could have a marked impact on the completeness of treatment documentation at the central registry, particularly for certain sites and treatment types. Given that a substantial portion of patients are receiving adjuvant therapies more than 6 months after diagnosis and after submission to the central registry, resubmission of cases is crucial to ensuring the central registry has an accurate record of the first course of treatment for every patient. However, under current SEER*DMS auto-consolidation rules, these resubmitted files result in an unmanageable number of manual tasks. Future work should focus on creating auto-consolidation rules that allow treatment field values of “none” or “unknown” to be automatically overwritten when a NAACCR-modified record is submitted with specific, known treatment field values. NJSCR has also begun to work with hospital registry software vendors to define parameters for NAACCR-modified records in order to reduce the number of records resubmitted with updates only to non-relevant data items. Exploring non-traditional data sources, such as medical claims data, will also enhance the NJSCR’s ability to collect complete and accurate treatment information.

Results
The 6 participating facilities originally submitted 5,530 NAACCR abstract records meeting the study criteria. The 15-month resubmission files contained a total of 3,692 (67%) records and resulted in 1,032 manual consolidation tasks within the NJSCR database. There was substantial variation among reporting facilities in the percent of resubmitted cases that generated manual review tasks (17%–40%) (Figure 1).
Of those cases receiving treatment, 12.8% had updates to treatment information based on the resubmitted data. Breast cancer cases had the highest proportion of updates to treatment (15.8%), with the greatest impact on radiation therapy documentation (16.1%). Also of note was chemotherapy for colon cancer, with 12.4% of cases updated. Prostate cancer cases received the fewest updates to treatment information (1.0%) (Figure 2). The majority of treatment updates were from “none” or “unknown” to a known value.

Analysis of treatment dates demonstrated a considerable proportion of treatment beginning more than 6 months after diagnosis. Hormone therapy (30.6%) and radiation therapy (26.2%) were the most likely to begin more than 6 months after diagnosis, while chemotherapy was only 2.9% (Figure 3).

Acknowledgements

We would like to thank our colleagues at the NJSCR and especially the hospital cancer registrars who resubmitted data for this study.
Creating Efficiency: Automating Cancer Conference Data Collection for a Hospital-Based Networked Cancer Registry

Mary Fleming, CTR, MSOL

Introduction
At Hartford Healthcare, there are a total of 76 cancer conferences per month between 5 facilities. Tracking, gathering and reporting out of the required data elements for cancer conferences is labor intensive and time-consuming. Each cancer registry in the Hartford Healthcare Network performed this task differently causing inconsistent data element collection. Disparate collection tools and output for reporting contributed to the extensive work hours spent in developing a report out for cancer committee.

The cancer registry needed to find a collection tool that would:
- Make it more efficient
- Make it user friendly
- Make it consistent
- Reduce the time spent in collection, analysis and output

Materials and Methods
REDCap (Research Electronic Data Capture) is a Web-based software program that allows the user to custom design databases, forms, and reports. Often used for research studies, its flexibility allowed for creation of 2 databases:
1. Cancer Conference Attendance
2. Cancer Conference Data Element Collection
   And 1 form—the Cancer Conference Worksheet Form.
   The project required 5 phases:
   - Determine the exact data elements that the Network wanted to collect and design a recording worksheet
   - Design 2 databases: 1 to collect multidisciplinary conference attendance and another to collect the discussion elements
   - Test both databases
   - Train users on the process
   - Launch the process and monitor for problems

Results
Timeline
- July 2016—designed the mockup of the collection form
- September 2016—both databases were designed
- October–December 2016—testing and training
- January 2017—go live

Examples of worksheet and Web-based database forms are shown in Figures 1 and 2.

Reports
For required reporting to the cancer committee of cancer conference activity, REDCap can produce on-demand reports that you can design to make all of the calculations for you. Examples of these reports are shown in Figure 3.

Discussion
There are 2 options for recording cancer conference discussion elements into the Cancer Conference Database. Conference coordinators have the option of using a paper worksheet to note-take then enter the data when it is convenient. If a laptop is available, the data can be entered into the Web-based form during the conference in real time. Review of the standard sign-in sheet allows the coordinator to enter the attendance elements into the Conference Attendance Database. Facilities with a large number of cancer conferences require an automated system of data collection to capture the required Commission on Cancer (CoC) cancer conference elements.

Conclusion
Data that once took 1-2 working days to collect, compile, and analyze each month now takes minutes; at a minimum, a savings of 96 hours per year.

Acknowledgement
Thank you to Stephen Wilcox, System Analyst, who provided technical expertise in database design for this project.

References
3. REDCap at projectredcap.org.
Figure 1. Example Worksheet

MULTIDISCIPLINARY CANCER CONFERENCE CASE NOTES WORKSHEET

Facility: ____________________ Name of Conference: ____________________ Conference Date: ____________

Patient Name: __________________________ (PRINT) DOB: __________________________

Case Type: ____________ Presenting Physician: __________________________

Size: ____________________ Date of Dx: ____________________ Date: ____________________

PHYSICIAN STAGING (omits ANY staging discussed in conference)

Clinical Stage: T ____________ N ____________ M ____________ (tumor) (lymph nodes) (metastatic disease)

Pathologic Stage: T ____________ N ____________ M ____________ (tumor) (lymph nodes) (metastatic disease)

DISCUSSION - Please check off all that apply:

Clinical Trials YES NO N/A

Genetic Testing YES NO N/A

National Guidelines YES NO N/A

Palliative Care YES NO N/A

Provincial Care YES NO N/A

Rehab Service YES NO N/A

RECOMMENDATIONS:

Referred: (if referred out of HHC, what facility and why?)

Figure 2. Example Web-Based Database Forms

Figure 3. Percent of Treatment Started More Than 6 Months after Diagnosis

Hartford HealthCare

HHCCI CANCER HEALTHCARE

Conference Attendance

Friday, February 23, 2018

1/1/2017 – 12/31/2017

HM


Breast

46

98%

97%

100%

98%

99%

97%

99%

97%

97%

GI

21

95%

95%

100%

94%

99%

95%

96%

95%

96%

GYN

38

79%

80%

100%

87%

89%

89%

90%

89%

90%

HNS

1

100%

77%

100%

100%

100%

77%

100%

100%

100%

NURSE

9

95%

95%

100%

95%

95%

95%

100%

95%

100%

Therapists

25

99%

98%

100%

98%

98%

98%

100%

98%

100%

Totals

200

92%

91%

100%

95%

95%

94%

100%

95%

99%

Cancer Registry Conferences: 1/1/2017 – 12/31/2017

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% Conf: 95% 38% 33% 19%
**Hospital Inpatient Discharge Data Helps Improve the Comorbidity and Insurance Information in Cancer Registry’s Data**

Yong Yi, PhD; Meichin Hsieh, PhD, CTR; Xiao-cheng Wu, MD, MPH, CTR

**Introduction**

Although comorbidity and insurance information are included in the standard data elements for cancer registries in the United States, the quality and completion of these data elements are uncertain. In response to the Surveillance, Epidemiology, and End Results (SEER) Program Task Order Request for Proposal (TORFP) SEER RRSS 2016-05, the Louisiana Tumor Registry (LTR) submits this proposal to join the team effort to overcome such shortcomings, by exploring alternatives to improve SEER data to expand the utility of the data for cancer research in general.

The Louisiana Hospital Inpatient Discharge Data (HIDD) covers 74% of hospital beds. LTR has established the Data Use and Confidentiality Agreement (DUCA) with the Louisiana State Department of Health and Hospitals (DHH) in 2011 to receive HIDD file annually without a fee. LTR will like to explore the quality and usefulness of HIDD to supplement the comorbidity and insurance information in registry’s database.

**Objectives**

- Assess the quality and completeness of comorbidity and insurance data in cancer registries by comparing corresponding data from HIDD.
- Identify types of missing comorbidities and insurance data in the registry data.
- Determine root causes of missing data by cancer registries.

**Methods and Materials**

First, we select cases from liver and intrahepatic bile duct, pancreatic, stomach cancers, and myeloma in the LTR database. Then, these were matched with HIDD encounters by patient name, date of birth, and Social Security number, using LINK-PLUS 3.0. We used information on gender, race, and parish of residence as references for decision making in the manual review of possible matched cases.

For comorbidity, we included any admissions within the 12-month window prior to the diagnosis. There was a 30-day cushion in between to exclude any complications incurred by the cancer diagnosis and treatment. The comorbid conditions we collected were based on Charlson Index, which has been proved to significantly affect cancer survival prospect. Each case might have none to multiple comorbid conditions. Same conditions appeared multiple times for one patient were counted only once.

Insurance information in HIDD was extracted from any admissions within the 6-month window right after the diagnosis, which is the typical cancer diagnosis and treatment period.

We compared the comorbidity and insurance information found in HIDD with that documented in registry’s database and summarized the level of improvement.

The process is illustrated in the flowchart (Figure 1). HIDD we received was from 2008–2014. Because of settings of the windows, we selected cancer cases diagnosed between 2009 and 2013.

**Results**

A total of 3,021 cancer patients were found to be admitted to hospitals within the 1-year window prior to their cancer diagnosis. After being combined with HIDD, the number of comorbid conditions increased from 2,282 to 4,544. The HIDD doubled the number of comorbid conditions for these patients (Figure 2).

A total of 5,091 cancer patients were found to be admitted into hospitals within the 6-month window right after their cancer diagnosis. Half of the no insurance and 90% of unknown insurance patients had insurance information identified through HIDD (Figure 3).

**Discussion**

- Generally, abstractions concentrate on the period from the cancer diagnosis to the first-course treatment, in which documented comorbidities are more likely treatment-related. Other comorbid conditions might be neglected.
- The full picture of a patient’s comorbidity requires searching all the medical records not only for a longer period but also in all the facilities the patient visited. This is not feasible during the abstraction.
- In addition, cancer registries also have problems collecting comorbidities from physician offices, which may affect the completeness of comorbidity and insurance.
• With the more and more extensive data exchanges among health care agencies, extracting useful information in the exchanged data from various sources can be a cost-effective alternative for collecting the information.

Conclusions
Because of the inadequate resource to collect complete information on comorbidities and insurance, HIDD might be a regular and cost-effective data source to improve the quality and completeness of the comorbidity and insurance data.

Figure 1. Process Flowchart for the Study

Figure 2. The comparison of original comorbidity in registry’s database and the combined information with Hospital Inpatient Discharge Data (HIDD)

Figure 3. The distribution of insurance at diagnosis. Left: Registry’s database only; Right: Registry’s database + Hospital Inpatient Discharge Data (HIDD)
American Joint Committee on Cancer (AJCC) Eighth Edition Oncotype Dx for Assigning Prognostic Stage Group for T1-T2 N0M0, ER+, HER2– Breast Cancers (Standard 4.7/4.8)

Danillie Clark, RMA, AAS, CTR; Danette Clark, BS, RMA, AAS, CTR

Study
• Review of 2016 breast cases that are stage group T1-T2 N0 M0, ER+, HER2–
• 186 cases met the criteria for the study

Benchmark
• National Comprehensive Cancer Network (NCCN): Breast
• American Joint Committee on Cancer (AJCC eighth edition)

References
• Springer Link: Oncotype DX breast cancer recurrence score can be predicted with a novel nomogram using clinicopathologic data; Breast Cancer Research and Treatment May 2017, Volume 163, Issue 1, pp 51-61
• Multigene assays: Implications for breast cancer staging, Journal of Surgical Oncology 2017;115-663664
• Prognostic Indicators Incorporated Into Breast Cancer Guidelines; ONCAler 2017 NANETS Symposiums, Wayne Kuznar

Data
• 2016 Primary Site Table: 463 breast cases
  ○ 186 (40%) cases met the requirements:
    ○ Stage group T1-T2 N0 M0, ER+, HER2–
    ○ Data was separated by stage, ER+ and HER2– to ensure only cases that met the above criteria were included.
• Number of patients who received:
  - Chemotherapy: 9
  - Radiation Therapy: 72
  - Hormone: 105

Results
53 (28%) Oncotype DX was performed
14 (8%) MammaPrint was performed
16 (9%) Myriad Myrisk Genetic Testing
90 (48%) with no multigene testing
13 (7%) documented pt refused
186 (100%) Total Cases

Results Summary
• Less than a third of cases are being tested for Oncotype DX
• Physicians are using a variety of different tests—Myriad Myrisk, MammaPrint
• The majority of cases are not receiving any documented genomic testing

Related Factors
Who will absorb the cost associated with testing if insurance does not cover? Patients may not be able to pay out of pocket.

Recommendation
Cancer Committee needs to determine:
1. Cost associated with testing.
2. Determine why Oncotype DX is not being routinely ordered—physician preference, using another test.
3. How to educate physicians on the new staging system
4. Develop a process that is health system–wide.

Outcome
Cancer committee determined patients should be made aware that insurance may not cover the cost of testing. Prior authorization is recommended if there is concern for out-of-pocket expenses. The financial counselor should be consulted. Some physicians prefer other types of testing. System-wide education on eighth edition staging should be developed to ensure consistency across the health system.
How I Do It

Online Adaptive Radiation Therapy

Wilson Apollo, MS, CTR, RTT

Computed tomography (CT)-guided online adaptive radiotherapy? Magnetic resonance (MR)-guided online adaptive radiotherapy? These are terms that will be part of the vocabulary of certified tumor registrars (CTRs) as we begin to adapt to the new changes incorporated into the upcoming revised 2018 Standards for Oncology Registry Entry (STORE) manual. We had a glimpse of these changes recently in the North American Association of Central Cancer Registries (NAACCR) webinars that were presented in May 2018, and I alluded to these changes as well during my presentation at the National Cancer Registrars Association (NCRA) conference in New Orleans, May 2018.

Among the changes are a list of new radiation therapy modality codes and a separate set of external beam radiation planning technique codes, both of which place a greater burden on the cancer registry profession to understand more fully what goes into the planning stages in the delivery of external beam radiation therapy (EBRT). Until we are provided with a very clear and concise treatment summary that contains all the radiation therapy (RT) items we are required to code, as CTRs, we need to educate ourselves on the actual RT techniques and modalities used in the clinical setting to more accurately interpret the RT information we are provided, and to more precisely code the treatment delivered to patients. The delivery of EBRT is rather complex, and involves sophisticated dosimetry, medical knowledge, and radiation physics. In this article, I will give a brief summary of key components of EBRT production and delivery, with an eye on some key new RT items we are expected to capture and code.

To understand online adaptive RT, we need to have a basic grasp of what exactly is meant by EBRT, how it is generated, and what equipment is used to deliver this modality. To put it simply, EBRT refers to the delivery of ionizing radiation, in the form of photons or gamma rays, that is produced outside the body, directed as multiple radiation beams at the target within the body. It typically involves the use of a linear accelerator (linac), around since the 1950s, with the advent of the cobalt teletherapy unit. These units work similarly, despite the numerous models on the market. A linac accelerates a stream of electrons at speeds approaching the speed of light and directs it against a tungsten target. Tungsten is used because of its high melting point (6,192°F). The violent collision that results, known as Bremsstrahlung radiation, produces photons that are then directed at the patient. A linac can be programmed to produce a range of photon and electron energies, in the megavoltage (MV/MeV) range. If the RT prescription states the use of a 6 MV photon beam, it means that the maximum energy produced is 6 MV. The photon beam is comprised of a range of photon energies up to a maximum of 6 MV, in this example. On the head of the gantry where the collision occurs are collimator leaves. These metallic leaves can open and close to create a shape that conforms to the target volume within the patient.

A second method of delivering EBRT is cobalt-60 teletherapy units. In principle, they work similarly to a conventional linac, but they emit gamma radiation through the process of radioactive decay. These units, such as the Gamma Knife®, are equipped with a cobalt-60 radioactive source safely shielded when the unit is not in operation. When in the treatment mode, the radioactive source is removed from its shielded housing, allowing the gamma rays to be directed to the target within the patient. A cobalt-60 source decays into a more stable state of nickel-60 by emitting an electron (which is absorbed by the shielding, preventing it from contributing to dose to the patient) and 2 gamma rays of 1.17 MV and 1.33 MV, giving the beam an average energy of 1.25 MV, a perfectly suitable beam energy for treating tumors that are not deeply seated in the body (ie, head and neck or brain lesions, benign or malignant). Gamma rays are basically photons. This is important to code the radiation therapy modality correctly.

The success of an RT plan depends heavily on the process of target delineation and the precision of the delivery system used. Target delineation refers to the process of identifying the target volume (tumor), adjacent structures, and/or organs at risk (OARs), and the contouring of these volumes with dose constraints. Photon beams directed at the patient will pass through and exit through healthy tissue as it deposits the prescribed dose to the tumor or tumor bed. This is an unavoidable consequence of EBRT. The best we can do is to try to minimize dose to healthy tissues as we deliver therapeutic doses to the tumor. In addition, organs of the body have different dose tolerances, with some body tissues known to be keenly sensitive to radiation while others are highly tolerant of RT. If a target volume is in the vicinity of radiosensitive structures or OARs, we need to more precisely identify these structures to ensure they are not needlessly irradiated. The radiosensitivity of certain structures makes it challenging to deliver a curative dose to certain organs. But to achieve this level of precision, we rely on imaging technology to identify the target volume and surrounding critical structures. Radiation therapists are challenged daily, as they, too, must adapt to rapidly changing technology to deliver precise doses of radiation to their patients.
The following are steps involved when a patient is referred to a radiation oncologist for consultation or treatment (keeping in mind that they are rather limited in scope):

1. **Patient is referred for a radiation oncology consult.**
2. **Radiation oncology determines the best type of treatment for the patient considering the patient’s stage of disease, age, medical history, comorbidities and potential outcome.**
3. **Patient then undergoes a CT-based simulation, where it is determined how best to position the patient in the treatment couch for daily treatments and what immobilization device to use, if any.** Primarily, images of the area to be irradiated are obtained and later converted into 3D rendering for the radiation oncologist and dosimetrist to work on. The critical step of target delineation is performed here. The gross tumor volume (GTV) and OARs are contoured and dose constraints are placed on these to ensure that the treatment will deliver the planned dose to the target volume while sparing healthy tissue. Beam energy, number of beams, and the direction and weight of each beam are all determined in this step. Dose-volume histograms (DVHs) are generated to give a graphic representation of the dose any critical structure will receive during the treatment.
4. **Treatment is then initiated, traditionally once a day for several weeks, excluding weekends.**
5. **As part of the quality assurance required for RT treatments, imaging is obtained during the duration of treatment, typically daily, and compared to the original plan generated during the simulation process.** It is critical to determine that the treatment is still targeting the contoured volume as originally planned. This step is the driving force behind the newer technologies entering the market for the delivery of EBRT, and the focus of this article.

There was a time in the evolution of radiation therapy that patients treated with EBRT would get a couple of radiographs (*orthogonal pairs*, namely, 2 images taken 90° apart) once a week and have that image compared with the original plan. Radiographs primarily capture bony anatomy and do a poor job in capturing soft tissue anatomy, which comprises most tumors. The rationale behind this approach was that if you could ensure that the bony anatomy at the time of treatment matched the bony anatomy on the original plan, the soft tissues in question would be in the same location, as well. So, if the patient’s position on the treatment couch was off on that day, you would make adjustments (*shifts*) along various planes to match the bony anatomy as seen on the original plan relative to the target volume.

Today, imaging is performed daily prior to the administration of any dose and the imaging technology is more robust. We now have image-guided radiation therapy (IGRT) and cone-beam CT imaging. Daily imaging allows for quick adjustments to ensure that the radiation beam is still hitting the target and missing healthy tissues as planned during the simulation process. Imaging can also occur while the patient is being irradiated, and the treatment unit can be programmed to turn the beam off if the target volume falls outside the set parameters.

Consider the following scenarios:

1. **Will a shift(s) correct this?**

![Original plan](Image 307x270 to 579x379) ![On day 1 of treatment](Image 303x598 to 590x698)

While the schematic is simplistic in nature, it helps to illustrate that, if the anatomy remains constant during treatment, then shifts (patient repositioning on the treatment couch) will ensure adequate coverage of the GTV as planned. Organs do move between treatment sessions (*interfraction motion*) and, indeed, they move during the actual treatment (*intrafraction motion*). IGRT can adequately address these deviations. The premise of this approach is that the human anatomy is static.

It is important to note that IGRT is extremely useful in repositioning the patient so that the target volume is in the radiation field. However, with IGRT, the original simulation plan is still being used and is not modified during this process.

Consider the following scenario.

2. **Will shifts correct this?**

![Original plan](Image 307x270 to 579x379) ![On day 10 of treatment](Image 303x598 to 590x698)

The patient can certainly be repositioned on the treatment couch so that the GTV is within the irradiated field, but no matter how the patient is shifted (repositioned), the original shape of the irradiation field is simply too large to cover the now shrunken GTV. As a result, all healthy tissue around the GTV is now being irradiated to the same planned dose as the original target volume. In addition, now a significant volume of an OAR is within the irradiated field, which was not the case at the time of the simulation process.

The lesson learned is that the human anatomy is dynamic and changes constantly. A patient can potentially lose or gain weight during therapy, thereby changing the volumes around the GTV. The tumor itself can undergo deformation (volume and shape changes). If the original plan is not adapted (*reoptimized*) to these changes, then we can potentially be irradiating an excessive volume of...
healthy tissue, thereby increasing the risk of toxicities. We may also be inadvertently underdosing the target volume, compromising tumor control.

What if we can reoptimize the original plan to target the changed GTV during the actual treatment?

Enter online adaptive radiation therapy (ART). Online ART addresses the temporal changes that occur in the tumor volume and adjacent structures, accounting for any changes to the patient’s anatomy, ensuring a more precise targeting of the tumor. It is heavily dependent on IGRT, as it is critically important to accurately delineate the target volume and record any changes that may occur over the course of treatment.

It is a very complex process, but the latest linacs and teletherapy units on the market are equipped with the technology to perform the complex calculations required to reoptimize a treatment plan while the patient is still on the treatment couch (online ART). It also requires a substantive team effort as the radiation oncologist, medical physicist, dosimetrist/treatment planner all need to collaborate in real time and on site to get the new plan completed. The entire process, from the time the patient is brought into the treatment room to the time the treatment is administered, can take up to 1.5 hours.

Today, there are 2 primary approaches to obtain the required images for reoptimization. The oldest and most prevalent technology used is CT based on-board imaging (OBI) or cone-beam CT. A more recent entry into the market in 2017 is the magnetic resonance imaging (MRI)-based linac and MRI-based teletherapy unit (with 3 cobalt-60 sources), MRIdian® by ViewRay. These units use an actual MRI to obtain the images of the target volume and OARs while the patient is being irradiated. Proponents of this technology maintain that the images of soft tissue obtained are superior to those obtained by cone-beam CT technology.

How does this technology fit into the new RT codes we have to apply in 2018 and going forward? It is important for CTRs to understand that ART is performed using EBRT technology. What this means is that the radiation treatment modality code we use for ART, whether it is CT-based or MRI-based, is 02: external beam, photons. This code is also used when a teletherapy cobalt-based unit is used. In both clinical scenarios, the therapeutic photons are generated outside the patient’s body, one by artificial means (linac) and the other through radioactive decay (teletherapy unit, cobalt-60).

As per the external beam radiation planning technique codes, there are 2 new codes that specifically address adaptive radiotherapy. Use code 09 for CT-guided online ART. Code 10 should be used for MRI-guided online ART.

We also should be aware that there is such a thing as offline ART, and codes 09 and 10 should not be applied to this planning technique according to the new rules. Offline ART refers to a plan reoptimization after a patient has left the treatment couch. For example, after a certain number of fractions, it is noted that the GTV and OARs show significant deformation when compared to the original plan. The decision is then made to reoptimize the plan before the patient comes in for the next treatment, offline. In this scenario, all the replanning, reoptimization is taking place between treatment sessions, without the patient waiting on the treatment couch.

The new RT codes will result in the collection of RT data that will be very valuable, and it has addressed several shortcomings from the old set of codes. But the numerous additions to the RT items in the upcoming STORE manual that we now must code and collect poses a challenge to the profession to remain informed and have a deeper understanding on the multiple tools and techniques at the disposal of a radiation oncologist. If CTRs are to rise to the challenge and continue to gather accurate data that can be used, the profession needs to respond to these challenges by making a concerted effort to create more targeted learning opportunities for its members. I hope that this article is a step in the right direction.
Journal of Registry Management Continuing Education Quiz—SUMMER 2018

OROPHARYNGEAL CARCINOMAS STRONGLY ASSOCIATED WITH HUMAN PAPILLOMAVIRUS: INCIDENCE TRENDS IN THE ELDERLY US POPULATION USING SEER VS US CANCER STATISTICS DATABASES

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:
- Identify the oropharyngeal sites most closely related to human papillomavirus (HPV)–associated squamous cell carcinomas
- Compare and contrast trends in age-standardized incidence rates (ASIRs) of oropharyngeal squamous cell carcinomas using Surveillance, Epidemiology, and End Results (SEER) Program and United States Cancer Statistics (USCS) data
- Discuss the impact of HPV vaccination on projected future incidence rates of HPV-associated oropharyngeal cancers

1. The oropharyngeal sites most strongly associated with human papillomavirus (HPV) include:

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<th>base of tongue</th>
<th>vallecula</th>
<th>palatine tonsil</th>
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2. According to the article, increases in squamous cell carcinomas of the base of tongue and palatine tonsil were evident for age subgroups:
   a) 35 to 44
   b) 45 to 54
   c) 55 to 64
   d) 65 to 74

3. Increases in HPV-related squamous cell carcinomas of the oropharynx have been largely limited to:
   a) sexually active young adults
   b) middle-aged white men
   c) same-sex partners
   d) elderly Asian women

4. According to Table 1, Age-Standardized Incidence Rates per 100,000 per Year for Age ≥65 Years for Base of Tongue and Palatine Tonsil Carcinomas: SEER vs USCS Database, 2001-2014, the annual percent change (APC) for all racial ethnic groups was greatest for:
   a) women based on the SEER database
   b) women based on the USCS database
   c) men based on the SEER database
   d) men based on the USCS database

5. Using either the SEER or USCS database, men showed:
   a) a continuous decrease in ASIRs over time
   b) a continuous increase in ASIRs over time
   c) rates for 2014 that were half those of 2001
   d) rates for 2001 that were twice those of 2014

6. According to Figure 1, Trends in Age-Standardized Incidence Rates at Ages ≥65 Years for Women and Men for Base of Tongue and Palatine Tonsil Carcinomas Combined: Surveillance, Epidemiology, and End Results Program (SEER) vs United States Cancer Statistics (USCS), in 2014:
   a) women had higher ASIRs than men
   b) men had higher ASIRs than women
   c) ASIRs were higher for both men and women using USCS data
   d) women's ASIRs doubled between 2001 and 2014

7. When looking at trends for elderly women and men by racial–ethnic group between 2001–2014:
   a) non-Hispanic white elderly women increased by about 5% using either database
   b) the ASIR for non-Hispanic white men was significantly higher than non-Hispanic black men in 2014
   c) annual rates during 2001–2014 for non-Hispanic black men showed less fluctuation using SEER vs USCS
   d) Hispanic white women represented a large proportion in the SEER analysis

8. HPV-positive oropharyngeal cancers tend to have a better prognosis than those that are HPV-negative.
   a) True
   b) False

9. HPV vaccination of youth:

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<th>has reduced the risk of oral HPV infection</th>
<th>is recommended for both boys and girls</th>
<th>should occur no earlier than age 13 to 14</th>
<th>is higher than for other infectious diseases</th>
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10. According to the authors, elderly patients with oropharyngeal squamous cell carcinomas
    a) experience higher survival rates than younger patients
    b) should be excluded from clinical trials
    c) are showing decreases in incidence rates
    d) need further studies based on HPV markers

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. Download the article, complete the quiz and claim CE credit all online.
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Instructions: Mark your answers clearly by filling in the correct answer, like this ■ not like this □. Passing score of 70% entitles one (1) CE clock hour per quiz.

Please use black ballpoint pen.

1 A □ B □ C □ D ☐
2 A □ B □ C □ D ☐
3 A □ B □ C □ D ☐
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10 A □ B □ C □ D ☐

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Journal of Registry Management 2018 Volume 45 Number 2 95
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Vonetta L. Williams, PhD, MPH, CTR | EDITOR-IN-CHIEF, JRM

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