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Indexing

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

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

Dear Colleagues,

I hope everyone had a fabulous summer. In May, many of us traveled to NCRA’s 45th Annual Educational Conference in Denver, Colorado. While the weather was ever changing with rain and snow, the conference provided a lot of great information.

We start this issue of the Journal of Registry Management (JRM) with an original manuscript from Paul Krebs, PhD, and coauthors examining the usefulness of cancer registry data for identifying current smokers. In our “How I Do It” section, Tracy Li, MPH, CTR, and colleagues present the systematic approach used by registrars in the Sutter Health Valley Area to quality control their registry data. In a special feature, the American Joint Committee on Cancer celebrates its 60th anniversary with an article by Frederick L. Greene, MD, FACS, and coauthors. Michele Webb, CTR, returns with her “Raising the Bar” section to remind us how to focus on opportunities instead of our limitations. We conclude the issue with a selection of poster content from this year’s NCRA conference.

A quick reminder that the JRM quiz is only available online through NCRA’s Center for Cancer Registry Education (CCRE). Here are the steps for purchasing a quiz:

1. Go to NCRA’s Center for Cancer Registry Education at [http://www.cancerregistryeducation.org/jrm-quizzes](http://www.cancerregistryeducation.org/jrm-quizzes)
2. Select a quiz to purchase and click “Add to Cart.” You may be prompted to login using your NCRA login.
3. Continue through the checkout process.
4. Once purchasing is complete, the quiz will load automatically into “My Learning Activities” for access at any time.

The last 2 pages of the JRM contains the call for papers and information for authors. Submissions of manuscripts or articles are accepted anytime. Content for our “How I Do It” section comes from readers who want to share their expertise and ideas on various topics. Throughout the year, people present at various state/regional educational conferences. Please consider converting those presentations into articles. Many certified tumor registrars (CTRs) would benefit from information on topics related to the 2018 changes.

Best regards,
Danette A. Clark, BS, RMA, AAS, CTR
JRMeditor@NCRA-USA.org
Utility of Using Cancer Registry Data to Identify Patients for Tobacco Treatment Trials

Paul Krebs, PhD; Erin Rogers, DrPH; Amanda Greenspan, MSc; Keith Goldfield, DrPH; Lei Lei, MA; Jamie S Ostroff, PhD; Bridgette E. Garrett, PhD; Behnoosh Momin, DrPH; S. Jane Henley, MSPH

Abstract: Background: Many tobacco-dependent cancer survivors continue to smoke after diagnosis and treatment. This study investigated the extent to which hospital-based cancer registries could be used to identify patients who smoke in order to offer them assistance in quitting. The concordance of tobacco use coded in the registry was compared with tobacco use as coded in the accompanying electronic health records (EHRs). Methods: We gathered data from 3 hospital-based cancer registries in New York City during June 2014 to December 2016. For each patient identified as a current combustible tobacco user in the cancer registries, we abstracted tobacco use data from their EHR to independently code and corroborate smoking status. We calculated the proportion of current smokers, former smokers, and never smokers as indicated in the EHR for the hospitals, cancer site, cancer stage, and sex. We used a logistic regression model to estimate the log odds of the registry-based smoking status correctly predicting the EHR-based smoking status. Results: Agreement in current smoking status between the registry-based smoking status and the EHR-based smoking status was 65%, 71%, and 90% at the 3 participating hospitals. Logistic regression results indicated that agreement in smoking status between the registry and the EHRs varied by hospital, cancer type, and stage, but not by age and sex. Conclusions: The utility of using tobacco use data in cancer registries for population-based tobacco treatment interventions is dependent on multiple factors, including accurate entry into EHR systems, updated data, and consistent smoking status definitions and registry coding protocols. Our study found that accuracy varied across the 3 hospitals and may not be able to inform interventions at these hospitals at this time. Several changes may be needed to improve the coding of tobacco use status in EHRs and registries.

Key words: cancer survivors, electronic health records, registries, smoking, tobacco use

Introduction

Tobacco use is the leading preventable cause of illness and death in the United States.1,2 Smoking cessation even after cancer diagnosis has many benefits, including improving efficacy of cancer treatments, reducing treatment- and cancer-related symptoms, and reducing the impact of other diseases.3,5 Cancer survivors who quit smoking experience lower risks of dying from their cancer or of developing subsequent cancers compared with those who continue to smoke.2 However, many cancer survivors continue to smoke, and promoting smoking cessation among cancer survivors is well-established as an indicator of quality cancer care.8

Beyond medical-legal requirements, electronic health records (EHRs) provide opportunities to enhance patient care, embed performance measures in clinical practice and facilitate clinical research through identification of patients who might benefit from and be eligible for behavioral and biomedical intervention trials. Identifying cohorts of at-risk patients and creating patient registries with linkage to patient contact information readily enables real-time targeting of evidence-based cancer prevention and control interventions.9 Databases for identifying at-risk populations and delivering population-based interventions include electronic patient registries (eg, cancer registries) and EHRs, which allow for real-time access to health data and patient contact information.9 The use of EHRs to guide and deliver population-based interventions, however, can be challenging because of the variety of EHR platforms as well as lack of interoperability, accuracy, and harmonization of patient data. For example, proactive tobacco use treatment approaches that identify current tobacco users and directly offer treatment for tobacco dependence have been shown to increase the use of tobacco use treatment and long-term abstinence in primary care and mental health populations.10,11 The use of registries and EHRs to guide and deliver population-based interventions can be challenging because of the variety of electronic platforms available, as well as inconsistency in registry or EHR implementation, even when using the same platform.

1 New York University School of Medicine, New York, New York. 2 Memorial Sloan Kettering Cancer Center, New York, New York. 3 Office on Smoking and Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, Georgia. 4 Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, Georgia.

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 provided through a supplemental award to grant number U48-DP001909-05 to the New York University, City University of New York Health Promotion & Prevention Research Center (U48 DP005008-02S3) from the National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention. Findings reported here are from Special Interest Project (SIP) 15-003: Proactive Care Coordination for Cancer Survivors Who Smoke.
The Health Information Technology for Economic and Clinical Health (HITECH) Act, the Patient Protection and Affordable Care Act (ACA), and the US Public Health Service have provided guidelines to systematically collect data on key clinical outcomes, with the ACA enabling financial incentives for health care providers to ask patients about tobacco use during clinical encounters and document patient responses in the EHR. For instance, HITECH has a recommended EHR outline for capturing tobacco use organized into 5 categories: history, assessment, plan (quit date/counseling), pharmacotherapy, and a follow-up plan. Since these categories are not mandatory fields in the recommended EHR outline and may be overlooked by providers, the frequency and quality of the data gathering are unknown. Some investigations have begun to examine the effect of variation in EHR platform use and patient outcomes. For example, Bae and colleagues reviewed the effects of using basic and advanced EHRs to document smoking status, delivery of smoking cessation counseling, and smoking cessation medication recommendations. They concluded that “more sophisticated EHRs are associated with better smoking cessation support by physicians.” Additionally, they recognized the need for an analysis of EHR platforms and functions and that future meaningful use incentive programs need explicit coding for documentation of tobacco use and follow ups.

While all states and the District of Columbia have central cancer registries (to which hospital-based cancer registries and other health care facilities send data on cancer diagnoses and related variables), tobacco use variables are not currently required by the North American Association of Central Cancer Registries to be collected. Some central cancer registries have continued to collect tobacco use variables, but not in a standardized format. A recent assessment of tobacco use data collected from 10 National Program of Cancer Registries (NPCR) registries funded for an enhanced data collection project concluded that “studies to evaluate the validity of specific tobacco-related variables and the ability of cancer registries to capture this information from the medical record are needed.” Addressing barriers for this identification and accurate documentation of tobacco use in the EHR is essential because proactive tobacco dependence treatment approaches that identify smokers and directly offer them cessation treatment for tobacco use have been shown to increase its use and long-term abstinence in primary care and mental health populations.

This study draws from the preliminary work done in preparation for a tobacco dependence treatment clinical trial, the aim of which was to assess the feasibility and effectiveness of using hospital cancer registry-based tobacco use status to identify and offer tobacco cessation treatment to smokers with a recent diagnosis of cancer. The sampling and recruitment plan called for use of hospital cancer registry data to identify a cohort of eligible tobacco-dependent cancer survivors. The current study has 2 primary aims: (1) to describe how the EHRs used at 3 large cancer care settings and corresponding cancer registries coded for tobacco use status, and (2) to compare and examine extent of agreement of tobacco use data coded in the cancer registries to that coded in the patient’s EHR.

Methods

Study Population

We worked with cancer registry programmers at 3 hospital-based cancer treatment settings in New York City (described below) to identify our study sample using cancer staging, administrative, and treatment date codes contained in the cancer registry. These study locations were chosen as they have affiliations with the primary project location (New York University Langone Health). The locations encompassed a National Cancer Institute-designated comprehensive cancer center (New York University Perlmutter Cancer Center), Bellevue Hospital (the flagship public hospital in New York City), and the VA New York Harbor, the Veterans Administration hospital encompassing Manhattan and Brooklyn. Each hospital system used different EHR systems and maintains their own independent cancer registry. Eligibility requirements were: (a) currently smoked a tobacco product in the past 30 days, (b) any cancer diagnosis of less than stage 3B in the previous 2 years (June 2014 to December 2016), and (c) no diagnosis of dementia. We used pathological staging codes as the primary source of staging data and used clinical staging codes when pathological staging was not available.

Tobacco Use Status from Cancer Registry

We identified tobacco users using an administrative code for tobacco status available in the registry. Each case in the cancer registry was categorized using New York state-mandated codes: (1) never used, (2) current cigarette smoker, (3) current cigar/pipe smoker, (4) current snuff/chew/smokeless tobacco user, (5) mixed use, (6) former smoker, or (7) unknown. We selected all patients with codes 2, 3, or 5 as representing patients currently using combustible forms of tobacco. Noncombustible tobacco use (chewing tobacco, snuff, or other smokeless tobacco) and former smoker were not a target of the cessation intervention and therefore were not included in the sampling plan. Use of electronic cigarettes also was not included.

Tobacco Use Abstraction from EHR

For each patient identified as a current combustible tobacco smoker in the cancer registries, we abstracted tobacco use data from their EHR to independently code smoking status. Each hospital EHR documented tobacco use differently (Table 1). The hospital that used the EPIC EHR system documented smoking status as a variable in the substance use history. This EHR platform enabled more granular fields to categorize patients as current every day smoker, current some day smoker, former smoker, heavy smoker, light smoker, never assessed, never smoker, passive smoke exposure – never smoker, smoker – current status unknown, and unknown if ever smoked. The VA and Bellevue clinics documented smoking status and history under social history in provider notes. While the VA creates tobacco use reminders that providers must complete every 6 months in the computerized patient record system (CPRS) EHR, these data are not able to be seen by provider-users of the EHR and are only available via a group data query. The Bellevue
system (Misys) has neither clinical reminders nor tobacco use history available as a provider-facing variable. For all clinics, we reviewed provider notes within each patient’s EHR to confirm that the listed smoking status was accurate and updated. The most recent smoking status was used to code patients as never, former, or current smokers. When no smoking history information could be found, patients were coded as never smokers, consistent with registry practice. For current and former smokers, we extracted years of smoking and the most recent cigarettes per day information, when available. When pack per day was used in a patient’s EHR instead of cigarettes per day, we calculated cigarettes per day based on a standard pack with 20 cigarettes. We also included date of quitting for former smokers.

Data Analysis

Descriptive statistics were calculated for each hospital to assess the number of current combustible tobacco users identified using the registry for all cancer patients diagnosed during 2014–2016, to determine the availability of detailed tobacco use data in the EHR for these patients, and to compare the coding of registry-based smoking status to that from the EHR. We calculated the proportion of current smokers, former smokers, and never smokers as indicated in the EHR for the hospitals, cancer site, cancer stage, and sex. We used a logistic regression model to estimate the log odds of the registry-based cigarette smoking status correctly predicting the EHR-based cigarette smoking status. The dependent variable in the model was an indicator of the prediction status; this indicator had a value of 1 if the smoking status in the EHR was current smoker and a value of 0 if the smoking status was either former smoker or never smoker. The model adjusted for hospital, cancer site, cancer stage, sex, and age. We did not conduct sensitivity analyses, as it was not feasible to check registry patients who did not have an indication of tobacco use against the EHRs. Analyses were conducted using R 3.4.3.\textsuperscript{19}

<table>
<thead>
<tr>
<th>Setting</th>
<th>EHR System</th>
<th>Tobacco Use Coding</th>
<th>Availability</th>
<th>Clinical reminder?</th>
</tr>
</thead>
<tbody>
<tr>
<td>New York University Langone Health</td>
<td>EPIC</td>
<td>• Current every day smoker&lt;br&gt;• Current some day smoker&lt;br&gt;• Former smoker&lt;br&gt;• Heavy smoker&lt;br&gt;• Light smoker&lt;br&gt;• Never assessed, never smoker&lt;br&gt;• Passive smoke exposure—never smoker&lt;br&gt;• Smoker—current status unknown&lt;br&gt;• Unknown if ever smoked&lt;br&gt;• Cigarettes per day</td>
<td>Variable. In Social History</td>
<td>Yes. On intake</td>
</tr>
<tr>
<td>Bellevue</td>
<td>Mysis</td>
<td>None</td>
<td>Provider notes only</td>
<td>No</td>
</tr>
<tr>
<td>VA New York Harbor</td>
<td>CPRS</td>
<td>• Never&lt;br&gt;• Former&lt;br&gt;• Current</td>
<td>Variable, not user-facing; provider notes</td>
<td>Yes. Every 6 months</td>
</tr>
</tbody>
</table>

HER, electronic health record.

Results

Current tobacco use (inclusive of cigarettes and cigar/pipe) at each of the 3 study locations using cancer registry data is reported in Table 2, and was 6.3% at NYU, 7.5% at Bellevue, and 19.1% at the VA.

As shown in Table 3, agreement in current cigarette smoking status between the registry-based smoking status and the EHR-based cigarette smoking status ranged from 65% at the VA to 71% at NYU and 90% at Bellevue. About 25% of patients identified by the NYU and VA cancer registries as current smokers were classified by their EHRs as former smokers. A small fraction (4% to 9%) of patients identified as current smokers in the cancer registries were classified as never smokers in the EHRs. The overall positive predictive value aggregating across clinics was 72.2% (95% CI, 70.9%–73.4%) (data not shown in table).

Logistic regression results indicated that agreement in cigarette smoking status between the registry and the EHR varied by hospital, cancer type, and stage, but not by age and sex (Table 4). Agreement in smoking status between the registry and the EHR was more likely at Bellevue than at NYU or the VA and among persons with endocrine (OR, 2.79; 95% CI, 1.15–6.23), genitourinary (OR, 1.99; 95% CI, 1.20–3.29), and hematologic malignancies (OR, 2.10; 95% CI, 1.04–4.25) compared to those with lung cancer, as well as for those with stage I cancer compared to stage 0 (OR, 1.96; 95% CI, 1.07–3.58). Age was not associated with agreement in current cigarette smoking status (OR, 1.01; 95% CI, 1.00–1.03). Classification accuracy did not differ by sex.

The Bellevue EHR had the least amount of data about cigarettes per day (32.1%) and years smoked (22.8%). NYU had data available for about half of their patients, while VA had cigarettes per day for 55% of patients, but we could not find years smoked for any of the registry-identified smokers.
Table 2. Current Tobacco Use Rates (Determined from Cancer Registry) among Cancer Patients who Met Study Eligibility Criteria from 2014–2016 in 3 New York City Hospitals and Availability of Detailed Data in EHR for Current Tobacco Users

<table>
<thead>
<tr>
<th>Setting</th>
<th>Patients n</th>
<th>Current Tobacco Users* n (%)</th>
<th>Data Available for Cigarettes/d n (%)</th>
<th>Data Available for Years Smoked n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>New York University Langone Health</td>
<td>11,679</td>
<td>739 (6.3)</td>
<td>422 (57.1)</td>
<td>358 (48.4)</td>
</tr>
<tr>
<td>Bellevue</td>
<td>1,461</td>
<td>109 (7.5)</td>
<td>35 (32.1)</td>
<td>27 (22.8)</td>
</tr>
<tr>
<td>VA New York Harbor</td>
<td>839</td>
<td>160 (19.1)</td>
<td>88 (55.0)</td>
<td>NA</td>
</tr>
</tbody>
</table>

HER, electronic health record; NA, not available.
* Includes cigarettes and other tobacco use.

Table 3. Smoking Status Abstracted from the EHR among Patients Identified as Current Cigarette Users Using Cancer Registry Data from 3 New York City Hospitals 2014–2016 by Select Characteristics

<table>
<thead>
<tr>
<th>Smoking Status in EHR</th>
<th>Smoker n =687</th>
<th>Former Smoker n =215</th>
<th>Never Smoker n =50</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NYU (n=696)</td>
<td>494 (71%)*</td>
<td>170 (24%)</td>
<td>32 (5%)</td>
</tr>
<tr>
<td>Bellevue (n=108)</td>
<td>97 (90%)*</td>
<td>7 (6%)</td>
<td>4 (4%)</td>
</tr>
<tr>
<td>VA (n= 148)</td>
<td>96 (65%)*</td>
<td>38 (26%)</td>
<td>14 (9%)</td>
</tr>
<tr>
<td>Cancer site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory/thoracic</td>
<td>84 (66%)</td>
<td>40 (31%)</td>
<td>4 (3%)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>21 (51%)</td>
<td>18 (44%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Breast</td>
<td>98 (77%)</td>
<td>27 (21%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Endocrine</td>
<td>49 (80%)</td>
<td>10 (16%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>102 (73%)</td>
<td>28 (20%)</td>
<td>9 (6%)</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>159 (75%)</td>
<td>45 (21%)</td>
<td>9 (4%)</td>
</tr>
<tr>
<td>Hematologic</td>
<td>68 (74%)</td>
<td>17 (18%)</td>
<td>7 (8%)</td>
</tr>
<tr>
<td>Neurologic</td>
<td>43 (68%)</td>
<td>12 (19%)</td>
<td>8 (13%)</td>
</tr>
<tr>
<td>Skin</td>
<td>52 (73%)</td>
<td>13 (18%)</td>
<td>6 (8%)</td>
</tr>
<tr>
<td>Other</td>
<td>11 (65%)</td>
<td>5 (29%)</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Cancer stage**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>43 (66%)</td>
<td>16 (25%)</td>
<td>6 (9%)</td>
</tr>
<tr>
<td>I</td>
<td>237 (76%)</td>
<td>62 (20%)</td>
<td>13 (4%)</td>
</tr>
<tr>
<td>II</td>
<td>140 (70%)</td>
<td>50 (25%)</td>
<td>9 (5%)</td>
</tr>
<tr>
<td>III</td>
<td>74 (73%)</td>
<td>25 (25%)</td>
<td>3 (3%)</td>
</tr>
<tr>
<td>IV</td>
<td>41 (63%)</td>
<td>19 (29%)</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>Unstaged</td>
<td>152 (73%)</td>
<td>43 (21%)</td>
<td>14 (7%)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>279 (76%)</td>
<td>78 (21%)</td>
<td>12 (3%)</td>
</tr>
<tr>
<td>Male</td>
<td>408 (70%)</td>
<td>137 (23%)</td>
<td>38 (7%)</td>
</tr>
</tbody>
</table>

EHR, electronic health record; NYU, New York University Langone Health; VA, VA New York Harbor.
* The percentage of patients identified as current smokers using cancer registry data and EHR (ie, agreement in current smoking status between the registry-based smoking status and the EHR-based smoking status).
** Based on stage recorded in the EHR; cancers may have progressed from time of initial registry coding.
This is the first study to compare smoking status recorded in hospital cancer registries with that recorded in EHRs. Using tobacco use data recorded in cancer registries could be a potential way to identify cancer survivors who smoked at the time of diagnosis. However, because information about tobacco use in cancer registries has not been routinely collected, questions remain about the quality, validity, and usefulness of these data.

We found that, while most patients classified as current smokers in the cancer registry were also classified as current smokers in the EHRs, about a quarter were classified as former smokers and a small fraction as never smokers. The largest discrepancies occurred when the registry categorizes patients as current smokers while the EHRs categorizes them as former smokers. Smoking status was abstracted from the EHR 6 to 24 months after it was recorded in the cancer registry, so it is possible that patients could have quit smoking during that interval. The discrepancies also could be due to differences in the way that the tobacco use questions were worded, differences in the way the patient responded to tobacco use questions, or differences in the way that responses were recorded.

Our study found that there was inconsistency in how tobacco use was recorded across 3 EHR systems. Only one EHR system (EPIC at NYU) included tobacco use as a user-facing variable; it also included the number of cigarettes smoked per day and the number of years smoked as variables. Thus, rates were highest for this information compared to Bellevue and the VA, which did not have variables for these details. The VA system prompts providers to assess tobacco use yearly, but does not allow users to see previous answers, and the Misys system at Bellevue had no tobacco prompts or standardized fields. In terms of agreement with registry data, agreement with current EHR information ranged from 65% to 90% for current cigarette use. Missing data rates for cigarettes per day and years smoked were high, as systems did not have standardized or required fields for these data points.

Examining the EHR systems suggests reasons for such variability. Even though Bellevue Mysis did not have tobacco use prompts, the agreement between EHR and registry data was highest at 90%. This could be attributable to the fact that tobacco use data is recorded only in clinical notes, which are able to be viewed by the registry. The lowest rate of agreement was at the VA, which prompts for and records tobacco use, but does not allow this information to be seen by EHR users, including registry abstractors. Thus, the registry can only record it if providers describe tobacco use in a clinical note. NYU’s EPIC build makes tobacco use

| Discussion |

This is the first study to compare smoking status recorded in hospital cancer registries with that recorded in EHRs. Using tobacco use data recorded in cancer registries could be a potential way to identify cancer survivors who smoked at the time of diagnosis. However, because information about tobacco use in cancer registries has not been routinely collected, questions remain about the quality, validity, and usefulness of these data.

We found that, while most patients classified as current smokers in the cancer registry were also classified as current smokers in the EHRs, about a quarter were classified as former smokers and a small fraction as never smokers. The largest discrepancies occurred when the registry categorizes patients as current smokers while the EHRs categorizes them as former smokers. Smoking status was abstracted from the EHR 6 to 24 months after it was recorded in the cancer registry, so it is possible that patients could have quit smoking during that interval. The discrepancies also could be due to differences in the way that the tobacco use questions were worded, differences in the way the patient responded to tobacco use questions, or differences in the way that responses were recorded.

Our study found that there was inconsistency in how tobacco use was recorded across 3 EHR systems. Only one EHR system (EPIC at NYU) included tobacco use as a user-facing variable; it also included the number of cigarettes smoked per day and the number of years smoked as variables. Thus, rates were highest for this information compared to Bellevue and the VA, which did not have variables for these details. The VA system prompts providers to assess tobacco use yearly, but does not allow users to see previous answers, and the Misys system at Bellevue had no tobacco prompts or standardized fields. In terms of agreement with registry data, agreement with current EHR information ranged from 65% to 90% for current cigarette use. Missing data rates for cigarettes per day and years smoked were high, as systems did not have standardized or required fields for these data points.

Examining the EHR systems suggests reasons for such variability. Even though Bellevue Mysis did not have tobacco use prompts, the agreement between EHR and registry data was highest at 90%. This could be attributable to the fact that tobacco use data is recorded only in clinical notes, which are able to be viewed by the registry. The lowest rate of agreement was at the VA, which prompts for and records tobacco use, but does not allow this information to be seen by EHR users, including registry abstractors. Thus, the registry can only record it if providers describe tobacco use in a clinical note. NYU’s EPIC build makes tobacco use...
data available, but abstractors prioritize oncology notes over the Social History/Smoking Status section, which is updated more frequently.

While this is the first study to compare EHR and cancer registry data, rates of recording smoking status in EHRs have been examined in previous studies, particularly in the lung cancer screening literature. A study of 4 lung cancer screening programs found that pack history and quit date could only be determined for 44% of those screened at 1 clinic and 44% at another, leading to considerable uncertainty about screening eligibility. Another study found that EHRs underreported pack years in 85% of cases, and the VA lung cancer screening demonstration project found inaccurate pack years in 39% of patients. Another recent study surveyed 200 patients and compared survey data to EHR data for determining eligibility for lung cancer screening found that only 70% had complete data for smoking status, years smoked, and pack years, rates which were on par or higher than our best results, found in NYU’s EPIC system.

In terms of limitations, we were not able to conduct a full sensitivity analysis. Our screening was for the purposes of enrollment for a smoking cessation clinical trial and we did not have resources to examine false negatives in the registry; that is, patients who were listed as non-tobacco users in the registry but who were categorized as current smokers in the EHRs. Such data would help to elucidate the quality of registry coding for tobacco use. Additionally, sample sizes, and thus, reliability of estimates, differed across clinics. Nevertheless, our data provides valuable insights for evaluating the utility of registry data and for suggesting improvements related to tobacco use.

A number of challenges exist in terms of ensuring accurate tobacco use coding and documentation in the EHR. First, no single health care provider or other staff may have sole workflow responsibility for entering tobacco use history. The format of questioning patients is not standardized across health systems, and variations in categorizing tobacco use are not well-defined, which may lead to inaccurate data collection. For instance, asking someone, “Are you a smoker?” rather than the recommended “Have you used any tobacco product in the past 30 days?” often resulted in a significantly different answer. Defining tobacco use behaviorally is essential, as it prevents misinterpretation about infrequent and light smoking and avoids stigmatizing terms (ie, “smoker”) which people are apt to deny. Moreover, misreporting of current smoking status may be attributable to the stigma associated with current smoking, particularly for cancer patients, making it even more important to ask smoking status questions in an empathic and nonambiguous manner. Second, the tobacco use categories and data entry fields are not standardized across EHR systems (eg, “smoker” vs “used tobacco product in past 30 days”), or do not exist as structured fields at all resulting in interoperability challenges. Third, delays from diagnosis to data coding into a registry has been noted as a barrier to using a EHR-linked tablet prior to a visit. Such a system could readily adopt the recommendations of the National Cancer Institute–American Association for Cancer Research (NCI-AACR) Cancer Patient Tobacco Use Assessment Task Force, which has developed a systematic tobacco screening protocol, the Cancer Patient Tobacco Use Questionnaire (C-TUQ). While intended for clinical trials, the structure of the questions provides essential data to inform a full range of tobacco-related trials and clinical services including brief cessation counseling (eg, Ask–Advise–Refer), population health interventions, and automated eligible casefinding and clinical reminders for lung cancer screening.

EHRs offer the functionality for systematically assessing and documenting tobacco use, yet, as demonstrated by this study, problems remain in implementing reminders within the systems, quality of how tobacco use is assessed by the health care team, availability of tobacco use data, and comprehensiveness of the tobacco use history. These limitations may hamper the ability of health systems to support tobacco cessation efforts via direct care by health care providers as well as through use of proactive, population-based tobacco cessation programs.

Strategies are underway to improve screening and recording of tobacco use in EHRs that would lead to increased accuracy and usability for population health interventions, namely modifying the tobacco use screening process, and improved technologies. Raz et al found that improving the tobacco use screen was minimally burdensome and increased the quality of data. Another method for improving the quality of tobacco use data could be to institute technology-enabled survey devices that link to EHRs where patients can complete patient reported outcomes and routine health update questions, including tobacco use history, prior to their appointments, thereby standardizing the questions and ensuring accurate data entry. While not widespread, some commercial systems are in place that allow patients to report data via tablet computer, and pilot studies have indicated acceptability on the part of patients and providers. Researchers have tried machine learning to search clinical notes with moderate success.

Because tobacco use data collected by cancer registries is dependent on the documentation of tobacco use in the medical record, the quality of these data may benefit from improving provider training in assessing and documenting tobacco use in the EHR. Providing patients with a rationale for asking about tobacco use and discussing current tobacco use in an empathic manner is likely to improve accurate patient reporting. Documentation of tobacco use should be improved by educating health care providers about the importance and utility of tobacco use data and implementing organizational policies that encourage documenting tobacco use.

Tobacco use data in cancer registries is typically recorded at the time of diagnosis, and may not accurately reflect changes in tobacco status over the course
of cancer treatment and survivorship. Our study results suggest registry-based tobacco use data does not appear to be sufficiently accurate at present to serve as a foundation for identifying eligible smokers for clinical trials and providing a referral to tobacco treatment services without greater attention to improving the quality of patient data capture. One must consider available resources and weigh the benefits of offering cessation services to the cohort of current smokers versus reaching patients who may have stopped smoking (former smokers) since inclusion in the registry. For studies that need real-time tobacco status, registry-based tobacco status data may not be sufficient. However, registry-based tobacco status may be useful in examining the association between tobacco use at time of diagnosis and cancer outcomes and in making decisions about survivorship care.16 Efforts are needed to improve the accuracy of tobacco use screening and data capture protocols in EHRs. Registrars could also increase attention to accuracy of tobacco use coding, which can better inform proactive methods for providing smokers with treatment for tobacco dependence.

References

Implementing a Systematic Quality Control Approach to Cancer Registry Data: A Quality Control Study on American Joint Committee on Cancer TNM Pathologic Staging for Cases with a Surgery Procedure Without Lymph Node Removal

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Abstract: Background: Both American Joint Committee on Cancer (AJCC) clinical and pathologic stage were required for cancer cases diagnosed from January 1, 2016 onward. This pathologic TNM stage quality control (QC) plan was developed at the end of 2017 when the certified tumor registrars (CTRs) found that they coded the pN category differently on surgical cases with no lymph node (LN) removal. Methods: Cancer registry data from 6 hospitals within the Sutter Health Valley Area (SHVA) were selected to review with the following search criteria: analytical cases with AJCC 7th edition, histology <9590/3 (excluding lymphoma) that were diagnosed between January 1, 2016 to December 31, 2017, with the surgical code ≥20 (code 20 is for tumor excision) with no LN removal. Four fields (pT, pN, pM, and p Stage) within each case were reviewed for accuracy. Accuracy rates before and after the QC action plan were compared. Results: Total of 1,473 cases were reviewed. The most common error was putting cN0 in the pN category, which then ultimately affected the pathologic stage group. Before the pathologic stage problem was identified, bladder site had the lowest accuracy rate (47.3%), followed by prostate (51.4%), kidney (56.8%), thyroid (60.6%), and other sites (66.7%), while the breast site had the highest accuracy rate (90%). An absolute increase of as high as 31.9% in coding accuracy rate was observed for prostate cancer (from 51.4% to 83.3%) after the corrective action. The overall accuracy rate was improved from 64.1% to 83.6%, resulting in an absolute improvement of 19.5% in this study. The improvement was statistically significant for all tumor sites as well as the overall rate ($P < .001$, except $P = .008$ for breast site). Conclusion: Registry teams are better prepared for rule changes by utilizing a rapid and systematic approach to quality control. In terms of immediate applications, this systematic approach will aid with effectively addressing the 2018 data changes and accreditation-specific requirements.

Introduction

Clean data is a cancer registry’s imperative. Strategist, data consultant, and thought leader Donato Diorio often is attributed with affirming, “Without a systematic way to start and keep data clean, bad data will happen.” In other words, cancer registry departments have the opportunity to guard against reporting bad data to stakeholders by implementing a systematic approach to confirming correct coding and mitigating human error. Linking this clean data theory to our current work, our cancer registry focused on national tumor registry rule changes.

In 2016, the Standard Setters implemented new changes requiring registrars to include clinical and pathological staging, when applicable. Standard Setters are comprised of experts from organizations such as the Surveillance, Epidemiology, and End Results Program, the National Cancer Institute, the Commission on Cancer, the American Joint Committee on Cancer (AJCC), and North American Association of Central Cancer Registries, among others. To support adherence to these rules, the specific guidelines were made available for the registry staff to review. At the time of these changes, professional cancer registrars were encouraged to attend education and training sessions provided by regional, state, or national programs to ensure that they became familiar with the AJCC staging changes. Additionally, there was an educational curriculum for registrars on these guidelines provided by the AJCC.\textsuperscript{2}

Unfortunately, this created a deficit for our registry due to the staffing and operational challenges of becoming a regionalized registry. Our focus at that time was on our routine quality control (QC) and quality assurance activities, including physician-led quality data reviews, peer review processes, and state reporting for accuracy, timeliness, and completeness. However, this type of visual editing has limitations on the number of cases and the data items being reviewed. In contrast, using a systematic way to QC registry data would allow the registry and leaders to focus on a specific topic for all cases in the selected fields. The addition of the systematic approach bloomed from a sense of continual improvement within the new regionalized team to ensure clean and accurate data for all cancer cases.

Background

Sutter Health is a not-for-profit health system in Northern California, headquartered in Sacramento. It includes physicians, hospitals, and other health care...
services in more than 100 Northern California cities and towns. Sutter Health, as a system, diagnoses approximately 17,000 new cancer cases per year. The system is divided into 2 operating units, designated by Valley and Bay Areas, due to the large geography of the different affiliate service locations. This article will focus on the work that our collective cancer registrars performed in the Sutter Health Valley Area (SHVA) operating unit, which contributes approximately 4,600 analytical cases a year to total system case volumes. Analytical cases are defined as having the initial diagnosis and/or the first course treatment or a decision not to treat at the reporting facility.

After completing a regionalization of geographically dispersed departments in 2017, the SHVA Cancer Registry leveraged this moment of integration to improve abstracting rates and accuracy of data collection, among other standardization activities. The integration combined cancer registry professionals from 6 hospitals under 1 management team. The additional synergy achieved with the integration allowed the cancer registry team to focus on a QC plan and improvement projects. This particular project was designed implementing Lean methodology, a zero-waste focus, and the Plan-Do-Study-Act (PDSA) model by Deming and Shewhart (Figure 1).

![Figure 1. Updated PDSA cycle. From the National Implementation Research Network, based on concepts from Deming and Shewhart.](image)

The planning phase for the QC program took into account national studies, aforementioned new abstracting rules, and accreditation requirements from the Commission on Cancer of the American College of Surgeons (ACS) to develop specific goals after defining the current and target state. Several QC projects were completed on different topics that emerged, but this article focuses on the pathologic stage in solid tumors. The pathologic TNM stage QC action plan was developed at the end of 2017 when the certified tumor registrars (CTRs) found they coded the pN category differently when there was no surgical removal of the lymph nodes in kidney surgical cases. Some coded the pN category as pNX with p Stage 99, while others used cN0 category differently when there was no surgical removal of the lymph nodes in kidney surgical cases. This variation alone was cause for concern and exploration. To establish the future state of what these cases should list and/or the first course treatment or a decision not to treat at the reporting facility.

The accuracy rates before and after the action plan was implemented were compared using Pearson’s $\chi^2$ test. Statistical analysis was performed using SAS 9.4.4

### Results

A total of eligible 1,473 cases were included in analysis. The study showed the most common error was putting cN0 in the pN category, which then ultimately affected the pathologic stage group. Table 1 displays the accuracy rates before and after the pathologic stage action plan was completed.

As we can see from Table 1, the bladder site has the lowest accuracy rate (47.3%). Entering pT-N-M information on bladder cases when they were not eligible for a pathologic stage (ie, transurethral resection of a bladder tumor, or TURBT) may contribute to this low accuracy rate. In contrast, the breast site has the highest accuracy rate (90%) before the pathologic stage problem was identified. It was statistically significantly higher than all other sites ($P < .001$). There was a high percentage (76%) of these breast cases that are ductal carcinoma in situ (DCIS) in this study, in which cN0 is a valid code for pN category. Also, the monthly Rapid Quality Reporting System (RQRS) data edit report and subsequent corrections on breast DCIS cases prior to the ACS submission could be another reason for the higher accuracy rate seen in the breast site. All ACS cancer programs are required to report on cases meeting certain criteria into RQRS, which is a reporting and quality improvement tool which provides real clinical time assessment of hospital level adherence to quality of cancer care measures.

In terms of data accuracy, Figure 2 displays an absolute improvement for this study ranging from 31.9% for prostate cancer (from 51.4% to 83.3%) to 4.5% for breast cancer (90.0% to 94.5%). The overall absolute improvement was 19.5%. Again, the lowest accuracy rate was observed for bladder cases and the highest was for breast cases. The
improvement was statistically significant for all tumor sites as well as the overall rate ($P < .001$ except $P = .008$ for the breast site).

**Discussion and Lessons Learned**

Even before the first planning processes began, it was essential that the management team fully understood their department motivators for implementing program changes. Using the diffusion theoretical framework, we assessed the cancer registry staff’s knowledge of how registry data is used by leadership and other stakeholders to improve health care services in the community. This assessment included a discussion that helped the management team discover the level of motivation within the greater team to make changes that would help impact and support the health needs of cancer patients. The leadership team discovered that most cancer registrars were not knowledgeable of how the cancer registry team could impact the patient experience. Subsequent interventions to help bridge this knowledge gap and motivate the team to engage in this QC project focused on sharing the cancer program’s strategic plan, cancer committee clinical studies, and business plans, each built using cancer registry data. We also shared our experiments and outcome metrics as they related to improving cancer services across our healthcare system. Each of these deliverables or products ultimately contributed to shaping patient care, safety, and outcomes. Once this foundation was created, we then introduced the vision behind the QC program. Focusing on impacting the patient experience contributed to the program’s success and sustainability.

Initially, the program’s action plan did not include a formalized education session or deliverable. After a cycle of PDSA in the fall of 2018 with new administrative leadership, the implementation team began to include educational materials, which gave a background for why the edit should be made. For example, materials were provided to address clinical staging versus pathological staging for each tumor site. This information was presented with Microsoft PowerPoint on a biweekly basis over teleconference to the regionalized cancer registry department. The CTRs then had a chance to refresh their knowledge on staging, exception rules on different sites, or other specific coding rules. The slide decks are available on an electronic shared drive for the team for later review and recall.

**Future Plans**

The internal impact of a systematic and rapid improvement cycle on data cleaning is as important as it is for external reporting sources. The utilization of this type of process improvement cycle will better position cancer registry teams for rapidly addressing any rule changes, completing edits for annual software changes, instilling a sense of purpose and urgency among staff, and provide a continual stream of educational topics for which leadership could develop and provide training seminars. In terms of immediate applications, this systematic approach will aid with effectively addressing data changes and accreditation-specific requirements.

With the extensive data changes issued in 2018, CTRs needed to be equipped with current knowledge to help
support the completion of case edits and subsequent abstracting. For cases diagnosed from January 1, 2018 onward, registrars were to use the AJCC 8th Edition and the Standards for Oncology Registry Entry (STORE) 2018 manual, entirely new manuals to digest and apply. Our study of implementing a systematic QC process will help the team to quickly identify educational needs, proactively complete a specific set of changes or edits, and posttest knowledge retention by generating the QC query a second time to ensure the target is met. Closing the loop by referring to the initial query will allow for leadership and staff to confirm consistent performance and provide periodic reports or analysis of the data before and after the intervention.

Furthermore, the importance of rapid and systematic approaches to clean data also lies in the resulting required reporting to our stakeholders—researchers, physicians, and health care providers—and others who use these data for positively improving patient outcomes. For example, the SHVA Cancer Registry prepared a specific QC plan for the various stakeholders and accreditation-based cancer committee membership throughout the Valley area, providing a systematic approach to completing the 2018 data changes. Although this plan was an accreditation-specific requirement, it presented an opportunity for a prospective advantage rather than a retrospective delay by utilizing our systematic approach to identify educational needs regarding major 2018 data changes, extent of disease (EOD), AJCC 8th Edition, and radiation treatment per the 2018 STORE Manual. As each registrar completes their 2018 edits, educational topics are quickly generated for the future QC action plans.

If clean data is the goal, cancer registry teams must be vigilant, persistent, and rapid in our efforts to achieve a patient-centric product.

**References**

In 2019, the American Joint Committee on Cancer (AJCC) celebrates a 60-year milestone of serving as the leading organization having as its sole mission the classification and staging of cancer. The AJCC was organized in 1959 as the American Joint Committee for Cancer Staging and End-Results Reporting (AJC). It is appropriate to commemorate and celebrate the founding of this multidisciplinary organization in the *Journal of Registry Management* in recognition of the strong collaboration that has been forged between the AJCC, the National Cancer Registrars Association (NCRA), cancer registrars working at Commission on Cancer (CoC)–accredited institutions as well as both National Cancer Institute–supported and state registries. The future strides in cancer staging depend on the strong collaboration of the AJCC and dedicated cancer registrars.

The first TNM cancer staging classification, which designated the terms *tumor* (*T*), *node* (*N*), and *metastasis* (*M*), was developed in the 1940s for breast cancer by a French surgeon, Pierre Denoix.¹ This clinical classification of cancer was pioneered before the organization of the AJC, the forerunner of the AJCC. The TNM system was developed as a common international language to facilitate the staging of neoplastic disease and to compare the results of therapy. The World Health Organization (WHO) played an important role in these early days, as did the International College of Radiology and the International Committee for Stage-Grouping in Cancer and for Presentation of the Results of Treatment of Cancer.² These organizations had a significant role in promoting the TNM system, which had as its primary objectives and guiding principles the provision of comparability of stage-grouping and of end results reporting compatible with the WHO rules.

In the 1950s, the Union for International Cancer Control (UICC) chose to formalize the TNM classification as the accepted means for cancer classification worldwide. On January 9, 1959, the AJC was organized as a result of a recommendation by the cancer committee of the American College of Radiology.² The American College of Radiology proposed the establishment of an American committee to evolve a system of staging and reporting cancer end results that would be acceptable to American physicians and that would continue the TNM format proposed by Denoix. There was a strong belief among the founding leadership that cancer classification, while embracing the TNM concepts, should also embrace the needs of American physicians and hospitals who were working in “cancer clinics” approved by the American College of Surgeons. This initiative represented the beginning of the accreditation process of the future CoC.³ It seemed wise, therefore, to develop an official body that could evaluate the recommendations of the UICC TNM committee so as to make suggestions or offer alternate classifications based on the TNM system, but were more suitable for use by North American physicians. In keeping with the concept that the fledgling AJC should be a coalition of organizations having cancer management as primary goals, the initial sponsoring organizations of this seminal organization were the American College of Surgeons, the American College of Radiology, the College of American Pathologists, the American College of Physicians, the American Cancer Society, and the National Cancer Institute.

The AJCC mission is to provide “worldwide leadership in the development, promotion, and maintenance of evidence-based systems for the classifications and management of cancer in collaboration with multidisciplinary organizations dedicated to cancer surveillance and to improving care.”⁴ The AJCC’s efforts are accomplishment by the assistance of many physicians and cancer registrars who volunteer their time to forward the growth of this evolving field. The AJCC’s worldwide effort in the development of a dynamic evidence-based classification system for cancer has been paramount in the formation of our only national cancer registry, the National Cancer Data Base (NCDB).⁵ Using the AJCC classification systems, cancer registries have collected and submitted data to the CoC and NCDB to be used for development of clinical guidelines, development of clinical trials and many other diverse areas of scientific inquiry.

The factors used in cancer staging have changed significantly over time. As a result, new AJCC manuals have been updated and published every 4 to 8 years (Table 1). According to the Cancer Registries Amendment Act, one of the purposes of cancer registries is to “identify cancer trends, pattern, and variation for directing cancer control intervention”.⁶ As stated by Dr. Oliver Beahrs, editor of the first AJCC staging manual (entitled *Classification and Staging of Cancer by Site*), “Proper classification and staging of cancer will allow the physician to determine treatment for the patient more appropriately, to evaluate results of management more reliably, and to compare statistics reported from various institutions more confidently.”⁷

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¹ Levine Cancer Institute, Charlotte, North Carolina.

² Address correspondence to Frederick L. Greene, MD, FACS, 128 Altondale Ave, Charlotte, NC 28207. Email: Frederick.Greene@atriumhealth.org.
The AJC developed a concept in which multidisciplinary task forces were created for each cancer site. These task forces or expert panels were assigned to review available outcomes data culled from existing rudimentary hospital registries and literature reports. This nascent approach has been the paradigm used by the AJCC expert panels and editorial boards of today. The power of the NCDB created in the late 1980s has proven to be a significant resource for modern approaches to updating the TNM system and inclusion of newer biological and molecular markers into cancer staging.

The AJCC has recognized that, while specific prognostic factors may not affect staging, they can affect outcomes when given targeted therapies. It is important to note that targeted therapies do not work the same way as standard therapies. Targets are specific genes that play some role in the development and growth of cancer. Targeted therapies attack the programming of abnormal cells while leaving the normal cells. The 8th edition of the AJCC Cancer Staging Manual has acknowledged the trend toward this individualized care and the value it adds to treatment outcome.

Throughout the ensuing decades, both the UICC and the modern AJCC have been partners in promoting and educating the international cancer community regarding the taxonomy of cancer staging and the importance of using both clinical and pathological staging to assess cancer outcomes. Through vigorous discussion and the dedicated work by many clinicians involved in cancer care in both organizations, promulgation of a worldwide TNM system was finally realized in 1987. Beginning in 1997 with the introduction of the 5th editions of both the UICC and AJCC print monographs, the 2 organizations have worked diligently to assure that each iteration of the TNM system is published in a synchronous fashion worldwide.

Over the last 60 years, the original concepts recognized by the founders of the AJC have metamorphosed into the principles of the AJCC that embrace not only the importance of anatomic staging, but have also now highlighted the critical significance of prognostic and predictive factors into the modern concepts of cancer treatment. Additionally, the critical role of cancer registrars has been recognized and highlighted by the AJCC. These dedicated professionals, especially those working in CoC-accredited institutions, have diligently collected, abstracted and transmitted data on cancer patients to the NCDB, allowing for the information gleaned to be used in all elements of AJCC cancer staging and patient treatment. For this reason, the current 8th edition of the AJCC Cancer Staging Manual has been dedicated to our cancer registrars.

Over the last 6 decades, working with cancer registrars, surveillance personnel, and literally hundreds of volunteer clinicians who serve on multiple expert panels, the AJCC has fine-tuned the cancer staging lexicon and has served as the primary promoter of education for the “language of cancer.” In recent years, the impact of the AJCC has been elevated by fruitful collaborations with other staging groups such as the International Federation of Gynecology and Obstetrics and the International Association for the Study of Lung Cancer representing gynecologic cancers and lung cancers, respectively.

As the current AJCC begins its 7th decade of work—strengthened by the inclusion of liaison members from the mainstream of cancer-related organizations (Table 2)—the opportunities to transform cancer staging from a purely anatomic basis to the essence of personalized cancer care are both daunting and exhilarating. The NCRA plays a major role in this transformation. The inclusion of artificial neural networks (machine learning), which lead to robust outcomes data culled from existing rudimentary hospital registries and literature reports. This nascent approach has been the paradigm used by the AJCC expert panels and editorial boards of today. The power of the NCDB created in the late 1980s has proven to be a significant resource for modern approaches to updating the TNM system and inclusion of newer biological and molecular markers into cancer staging.

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| Table 1. American Joint Committee on Cancer (AJCC) Cancer Staging Manuals and Effective Dates |
|---|---|
| **Edition** | **Year Published** |
| 1 | 1978 |
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| 3 | 1989 |
| 4 | 1993 |
| 5 | 1998 |
| 6 | 2003 |
| 7 | 2010 |
| 8 | 2018 |

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risk assessment tools in cancer care, and technical support systems that can translate the complexities of modern staging into understandable and useful instruments for both patients and clinicians alike are also important agenda items for the AJCC member organizations. There is little doubt that the solid foundation of collaboration developed and championed by the founders of the AJCC 60 years ago, and the partnership of the modern AJCC with the cancer registry community, will prove instrumental in meeting the significant challenges of cancer staging and cancer care going forward.

References
Raising the Bar

The Problem with Problems

Michele Webb, CTR

We have limits. In fact, we have an infinite number of limitations. You might be experiencing a process-related challenge, resource or funding limit, or new or constantly evolving standards. Or, you might feel as though others are working against you. Your back hurts, your child is sick, the boss does not listen, or the computer system is down (again)!

We also have opportunities. And, if we look at the world beyond limits, we have an endless supply of opportunities. There are always new sources of information, data to leverage, goals to accomplish, better or different ways to get the work done, or ideas to share that will inspire or trigger something great. Every cancer registrar can share something, give something, or make something better.

There are always limits and there are always opportunities. What we rehearse in our mind and focus on are the thoughts that shape our attitudes, actions, and responses to both. Have you ever considered how many times a week you think about or discuss the limits you are facing or the problems that you perceive as holding you back? Or, do you routinely look for ways to build up, encourage, and inspire your coworkers? Do you listen to them, support them, and find practical ways to help them meet a challenge or develop a new skill?

The problem with problems is that they always keep us from focusing on an opportunity or chance to contribute to something bigger than ourselves. Focusing on your opportunities does not mean that you will never have a problem. It means that you are far more likely to achieve a goal or to creatively manage your work so that it leads to monumental success, for everyone.

Yet, so many people miss out. Why? Because it is always easier to find a reason to focus on the limitation, to stay put in your career, to skip an opportunity, or to avoid taking a risk. In retrospect, it is easier to say “no” to a new opportunity than it is to say “yes” and lend our support or expertise. It’s hard to stand up for what is right and it’s easy to acquiesce. It’s hard to suggest an idea and risk it being rejected and easier to stay quiet and blame others for failure. It’s hard to follow the detailed and complex set of rules that drive our work and easy to take shortcuts and tell ourselves that it’s okay or that no one will notice. It’s hard to do what is right and easier to think that no one cares, or that our work does not matter. But it DOES matter!

We are living in a world that is filled with opportunity. In fact, cancer registrars today have more than an opportunity—we have an obligation. An obligation to spend our time becoming unrivaled subject-matter experts and serving our organizations in complete alignment with their mission and vision. To find ideas that matter and to share them. To push ourselves, and the people around us, to change, to be inspired and to grow. We should be demonstrating leadership, innovative thought, gratitude, and offering business and professional insights to those we serve, no matter how they respond to us.

Are these crazy times? Absolutely! But we know the drill. Cancer registrars are well acquainted with changes in data collection standards, delays in software upgrades, and clinical practices that frequently change. And that’s just part of our cancer registry history. We are the kings and queens of crazy times! There will always be changes, resource issues, and problems.

Stop thinking about how crazy or chaotic things are. Stop thinking about the collective set of changes, that change is being done “to you,” or “to you on purpose.” Instead, start thinking about what is really being asked of our profession and the underlying reason and goal for accomplishing something different. This is not a time to concede and go about your “business as usual.” If you let your brain slack, dulling your thoughts and retreating into the same or mediocre behaviors, you will fail. You will disappoint, numb out, and erase your dreams, accomplishments, and all that is good. This is the time to expect things to change. Your administrators, physicians, and coworkers are desperately looking for something exciting, something they can be passionate about, or something they can engage in. They are looking to recharge their energy and regain their passion for their work.

You get to make a choice. In fact, you get to make a choice every day. It’s not too late to choose fresh thinking over the doldrums. It’s not too late to choose action, or excellence, or stand ethically on what is right. It’s not too late to be innovative or optimistic. And it is never too late...
to change how you think, work, and interact with others. And the best part is that it only takes a moment—literally a second—to decide.

Before you finish reading this article, you will have the power to change everything in your world. You can do that by asking yourself these questions. Why not be great? Why not choose to focus on the opportunity instead of the limits? Why not discover why we change our data collection practices and approach them as an opportunity instead of railing against them? Why would you choose limited thinking by offering up weak or pathetic excuses that are not supportive of new or better therapies, or safe or more effective patient care? Why would you choose suboptimal data collection practices and reporting of information that does not ensure quality or support delivery of personalized care to cancer patients or their families?

None of us really knows exactly where we will end up in this journey. Some individuals have the vision and thought process to take us there. And some have the capacity to nurture and lead the rest, ensuring that no one is left behind. But that is only as good as we choose to reach out, stretch forward, and take hold of the opportunities despite the limitations.

What thoughts are you rehearsing in your mind? What is taking control of your actions and responses? What innovative ideas are you sharing that will inspire gratitude and excellence in your profession? As you finish reading this article, what are YOU going to do to change your thinking and world as you know it today? Consider yourself challenged to seek inspiration, to encourage and help others achieve greatness, and to choose opportunity over limitations.

Michele is a cancer registry speaker, author, and educator with 25 years’ experience in oncology health care. She is privileged to be part of the Cancer Registry and SCL Healthcare oncology service line in Colorado and Montana. Michele lives in Manteca, California with her 2 furbabies, Dolly and Cooper. She welcomes your feedback by email to michele@michelewebb.com.
A Collaboration between Oncology Analytics and a Multidisciplinary Genitourinary Cancer Team for Data Collection: A Comprehensive Community Cancer Program’s Perspective

Francheska Hayes, MPH, CTR\(^a\); Mildred Nunez Jones, BA, CTR\(^a\); Leslie Dillon\(^a\);
Nongnuch Taragittigul, RN, MSN, B.Ed, CCTN\(^a\)

Introduction
Northside Hospital Cancer Institute (NHCI) is a Commission on Cancer (CoC)–accredited Comprehensive Community Cancer Program with 3 acute care hospitals based out of Atlanta, Georgia, with an analytic volume of ≥10,000 cases. Northside Radiology Associates has 66 physicians contracted to provide radiology services across the system. Georgia Urology is the largest urology practice in Atlanta and the Southeast, with 45 urologists and 31 locations across the state.

The Axumin (fluciclovine F18) injection is indicated for positron emission tomography (PET) imaging in men with suspected prostate cancer recurrence based on prostate-specific antigen (PSA) levels following prior treatment. Because a majority of Axumin radiology exams in the state of Georgia are performed at NHCI, the Genitourinary Multidisciplinary Team (MDC) requested Oncology Analytics (OA) to create a registry for prostate cancer patients receiving Axumin radiology exams during 2017.

Purpose
- Capture initial treatment, radiology results, recurrence and/or progression of disease, subsequent therapy for the purposes of quality improvement and future research initiatives.
- Engage in collaboration with a large urology practice, a contracted radiology group and the Genitourinary MDC team to develop a comprehensive patient registry for data collection.
- Create opportunity for certified tumor registrars (CTRs) to collect data above what the CoC and state central registries require and demonstrate the value of OA beyond its traditional scope.

Methods
The methods are shown in Figures 1 and 2.

Discussion
- The Axumin registry proved to be a meaningful source for data collection for the MDC team.
- The collaboration of NHCI community cancer program with the physician practice demonstrated a successful initiative through the contributions of each organization.
- Scope of service of OA expanded beyond the traditional service area because knowledgeable staff were able to complete this work.
- Two posters presented at the 2018 Society of Nuclear Medicine and Molecular Imaging Conference based on the Axumin data abstracted by the CTR (Figure 3).
- Project provided increased understanding in research process at our facility for both physicians and CTR staff.

Lessons Learned
- Establishing an environment of trust upon project initiation is essential.
- Ensuring key stakeholders are in agreement of the long-term goals for the data collection is critical.
- Proactively planning for resource needs will streamline the abstraction process and ensure continuity among CTRs for the entire life span of the project.
- This database creation provided a springboard for larger clinical registry development and initiatives.

\(^a\)Northside Hospital Cancer Institute, Atlanta, Georgia.
Figure 1. Data Collection Steps

MDC team determined feasibility for data capture

Team agreed upon data points for capture (See Figure 2)

Software identified for this data collection

Data dictionary created for standardized data collection

Radiology generated reports identifying patients who received an Axumin Scan at NHCI

GA Urology provided the CTR access to their EMR for specific data collection

100 Patients abstracted; 45 minutes per abstract

Data Quality assessed and data clean up performed

Data Summary and Analysis provided to GU MDC team

Figure 2. Data Elements Collected

Patient Information
- Date of Birth
- Race/Ethnicity

Radiology Exams
- Date & type of exams
  - Bone Scan
  - CT Scan
  - MRI
  - PET/CT Scan
  - Other
- Exam results
- Date of Axumin Scan
- Axumin Scan results-location

Diagnosis
- Date of Diagnosis/Biopsy
- Primary & Secondary Gleason Grade
- Gleason Score
- PSA (Highest before & post Treatment)
- TNM Staging

Treatment
- Type of initial & subsequent treatment
  - Surgery
  - Radiation
  - Hormone
  - Chemotherapy
  - Other
- Change in treatment management & type
- Type of salvage local &/or distant therapy

Figure 3. Axumin Scan Studies

Utilization of F-18 Fluoride PET/CT for Initial Staging of Prostate Carcinoma
William Lively MD, James Weinstein MD, Hamilton Williams MD, and Vahan Kassabian MD
Northside Radiology Associates, GA, USA; Radiation Oncology of Atlanta, GA, USA; Georgia Urology, GA, USA

Probability of a Positive F-18 Fluoride Scan based on Level of PSA
William Lively MD, James Weinstein MD, Hamilton Williams MD, and Vahan Kassabian MD
Northside Radiology Associates, GA, USA; Radiation Oncology of Atlanta, GA, USA; Georgia Urology, GA, USA
A Collaborative Assessment and Community Outreach Intervention of HPV-Type Cancers in the Local Region Utilizing Cancer Registry Data

Susan VanLoon, RN, CTR, CCRP; Lisa Rosenberry, MS, MSW, LCSW, OSW-C; Monika Rivera, RHIT, CTR; Jackie Miller, RN, BSN, OCN*

Study Purpose

According to the Centers for Disease Control and Prevention (CDC), the HPV infection causes more than 33,700 cases of cancer in men and women every year in the United States. The HPV vaccine can prevent more than 90% of these cancers from developing by preventing HPV infections that cause HPV-associated cancers. In 2017, the CDC reported that only 49% of adolescents in the United States were up to date on the HPV vaccine.

Sex was collected for oropharynx cases. Data was sorted by site, postal code and county codes in our local communities based on the number of cancers reported by each participating Registry.

Our plan was to estimate the number of HPV-attributable analytic cancer cases in the local region collected by the Penn Medicine Virtua Cancer Program, Sidney Kimmel Cancer Center Wash Township, Lourdes Health System, and Cooper University Health Cancer Registries. Data from this project will be utilized to assess screening and educational needs in the local area communities for HPV associated cancers.

Data from this analysis was provided to the Community Outreach Coordinators to assist with targeted outreach efforts as follows:

• Develop targeted educational plan to increase awareness among health care professionals with ZIP codes noted to have higher HPV associated cancers
• Develop targeted plan to educate community, schools, etc about HPV-attributable cancers
• Develop targeted educational plan to increase awareness among nurses with ZIP codes noted to have higher HPV associated cancers (Figure 1)

Data Collection Activities and Findings

De-identified 2016 analytic Registry cases for cervix, vagina, vulva, penis, anus, rectum, oropharynx were included in this analysis from the above referenced American College of Surgeon Commission on Cancer approved Cancer Registry programs. At present, all of these registries do not collect whether HPV is present in the cancer tissue. CDC studies developed an algorithm that estimated the number of HPV associated cancers per year. Through the application of CDC’s formula, we were able to identify the number of HPV-attributable cancers limited to cellular types defined by the CDC including the additional data points of postal and county codes.

A total of 197 HPV-attributable cancers cases were identified. Although the numbers are small, there are opportunities in our local community to target educational efforts to increase HPV vaccine rates. The number of oropharynx cancers most likely caused by HPV is close to cervix. In our analysis, 82% of the oropharynx were male. The annual number of HPV positive oropharynx cancers is expected to surpass the annual number of cervical cancers by 2020. Data at the ZIP code level can be further analyzed to target health care professionals and schools for educational purposes to raise awareness.

Strategies Implemented for Improvement

We implemented a 3-pronged approach working through Burlington County Regional Chronic Disease Coalition to provide education to target health care professionals, educators, and parents of boys aged 11–21 years and girls aged 11–26 years who reside in the ZIP codes identified in this study. Education included that HPV may lead to several different types of cancer diagnoses that impact both males and females and that these diagnoses are occurring in their local community. Over 1,500 health care professionals, educators, and parents received education on the HPV vaccine and associated cancers in the targeted ZIP codes. This can be broken down as follows:

• 157 pediatricians and primary care physicians were sent educational materials and requested to partner in increasing the HPV vaccine rates
• 250 elementary schools and middle schools in the targeted counties were mailed CDC educational material on the HPV vaccine
• 40 health care professionals attended a continuing medical education/CNE educational program; 40.5% responded that after participating they planned to change their practice and 79.5% responded they would use the knowledge gained to educate their peers and patients

*Penn Medicine Virtua Cancer Program.
• 1,000 educational flyers were distributed within the community
• HPV educational information was posted on our Facebook page

**Did We Make a Difference?**

It may be too early to tell whether we have impacted vaccine rates in the targeted area and we may never know whether our educational campaign will impact vaccination rates. We have recently formed a partnership with a large pediatric practice to further enhance this effort. We plan to continue to educate the community and colleagues on the importance of the HPV vaccine in preventing cancer. In addition, we hope to expand outreach to include oral surgeons and dentists. Horizon NJ Health did share their vaccine rates with us. There was an overall increase in vaccine rates in both Burlington and Camden Counties from 2016–2017. In addition, the vaccine rates from January to September 2018 were above 2017 rates.

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**Bibliography**

6. Cooper University Health Cancer Registry, Karen Staller, CTR.
7. Sidney Kimmel Cancer Center, Peggy Wight, CTR.
8. Lourdes Health System, Stephanie Blassmann, CTR.

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**Figure 1. The Virtua System Market**

- **Burlington County**
- **Camden County**
- **Gloucester County**
Health Behaviors and Other Risk Factors in Early Onset Colorectal Cancer: A Collaboration Among Northside Hospital Cancer Institute, Centers for Disease Control and Prevention, and National Association of Chronic Disease Directors

Amy Waits, BS, CTR; Sheema Ahmed, CTR; Frank Bright, MS; Kate Canterbury, MPA; Mary Catherine Jones, MPH; Mildred Nunez Jones, BA, CTR; Kamilah Konrad, LMSW; Maurshanda Matthews, RHIT, CTR; Natasha McCoy, MPH; Marc Sonenshine, MD, MBA; Paulette Valliere, PhD; Julie Townsend, MS

Introduction

Northside Hospital Cancer Institute (NHCI), an American College of Surgeons Commission on Cancer (CoC)-accredited Comprehensive Community Cancer Center with 3 acute-care hospitals (Atlanta, Forsyth, and Cherokee) and analytic volume of >10,000 cases, was invited to participate in a joint project with the National Association of Chronic Disease Directors (NACDD) and the Centers for Disease Control and Prevention (CDC) because of rising early-onset colorectal cancer incidence rates.

Innovation

Although academic centers frequently have opportunities to work with public health organizations, the collaboration of the NHCI community cancer program with the CDC and NACDD has demonstrated a successful initiative through the unique contributions of each organization (Figure 1).

Purpose

- Demonstrate successful partnership between a private health care system and public health organizations
- Investigate health behaviors and risk factors in early-onset colorectal cancer patients
- Identify factors that both enable and hinder extended data collection beyond the scope of the traditional cancer abstract
- A total of 114 customized user-defined fields built into registry software (Figure 2)

Implementation

- Review of data performed in 2 electronic health record (EHR) systems: hospital and gastroenterology office
- Procedure followed for obtaining CTR access to physician office EHR
- Data definition of fields designed: date format, Y/N, checkbox, or text options
- 2016 colorectal cases identified
- Risk factor elements collected by CTRs for 440 colorectal cases
- Input of findings into user-defined fields of software for each case
- Initial 10-case quality assurance (QA) review for each abstractor with feedback and education provided
- Ongoing 10% QA review to ensure data completeness and accuracy
- Registry findings submitted to biostatistician for analysis (Figure 3)

Results

- Data collection determined to be sufficient for meaningful statistical analysis of risk factor trends by age, stage, distance to care
- Demonstrated the range of significant contributions a community cancer program makes to studies of public health trends
- Partnerships with public health entities can be replicated by other facilities using registry data and customized user-defined fields
- Expertise and skill set of the CTR is uniquely suited for custom projects, revealing immense potential for future requests
- Next step opportunity for improved patient outcomes through Genetics referrals

Funding for the Health Behaviors and Other Risk Factors in Early-Onset Colorectal Cancer project was provided by Grant or Cooperative Agreement Number 5NU38OT000225-05, sponsored by the Centers for Disease Control and Prevention, Division of Cancer Prevention and Control (CDC), and the National Association of Chronic Disease Directors (NACDD). This material was developed by Northside Hospital Cancer Institute, with assistance from CDC and NACDD. Authors acknowledge CDC and NACDD’s contribution to this publication. Its contents are solely the responsibility of the author(s) and do not necessarily reflect the views of the CDC, Department of Health and Human Services or NACDD.
Lessons Learned

Dedication to a project of large scope required project management coordinator and facility grant liaison, especially for grant time tracking. Learning curve for collaboration with legal/IRB and other organizations affected project timeline. Several data access challenges identified:

- Separate EHRs did not interface
- Inconsistent patient responses to social and/or family history on various documents
- Variation of data items (e.g., body mass index) arose between the 2 abstractors if recorded from different source documents
Overview

The Annual Report to the Nation on the Status of Cancer represents a collaborative effort from senior researchers at the American Cancer Society (ACS), Centers for Disease Control and Prevention (CDC), North American Association of Central Cancer Registries (NAACCR), and the National Cancer Institute (NCI) to produce current and comprehensive trends in cancer incidence and mortality. Our 21st report was spearheaded by NAACCR and will be published in the Journal of the National Cancer Institute this Spring. The purpose of this report is to communicate the most up-to-date and comprehensive trends in cancer incidence and mortality. Each year we also focus on a special topic. This year, our topic is cancer among young adults aged 20–49 years. This poster summarizes important highlights from the annual report and puts these findings into a larger epidemiological context.

Current Trends in National Cancer Incidence and Mortality

Overall, cancer death rates are decreasing in men, women, and children for all major racial and ethnic groups. This continues previously reported trends, as we have had 18 consecutive years of declining overall cancer mortality rates.

- In the past 5 years, cancer mortality rates decreased 1.8% annually among men; 1.4% annually for women.
- Mortality rates decreased for 10 of the 19 most common cancer sites for men, but increased for 6 cancers; most notably with increases in mortality for liver, oral cavity and pharynx, and nonmelanoma skin cancers among men (Figure 1).
- Mortality rates decreased for 13 of the 20 most common cancers among women, but increased for 5 cancer types; most notably with increases in liver and uterine cancers among women (Figure 1).

From 1999 to 2015, there was a decline in cancer incidence for men. For women, however, the rate of new cancers remained stable during the same time.

- In the past 5 years, cancer incidence rates decreased 2.1% annually for men, remaining stable for women.
- Incidence rates decreased for of 8 of the 17 most common cancers among men, but increased for 7 cancers and were stable for 2 cancers (Figure 2).
- Incidence rates decreased for 6 of the 18 most common cancers among women, but increased for 9 cancers and were stable for 3 cancers (Figure 2).

Several notable changes in trends were found:

- After decades of increasing incidence, thyroid cancer incidence rates have stabilized (Figure 2).
- Rapid declines in melanoma mortality were identified for the first time (Figure 1).

Cancer Among Patients aged 20–49 Years

Different patterns are seen in the 20–49 years age group (Figures 3 and 4). A main difference in cancer in this age group is that the burden is much higher for women than men. This is driven by cancers traditionally higher among women (breast, melanoma, and thyroid), female-specific cancers (uterine, cervical, and ovarian), and higher rates of lung and nonmalignant brain and central nervous system tumors among younger women than men. Additionally, incidence rates of in situ breast cancer among women and nonmalignant brain tumors among women and men are quite substantial (20.2, 17.6, and 9.5 per 100,000, respectively).

Personal Connection

Epidemiologic data are comprised of real people, and it is imperative that policymakers and clinicians are aware of the unique burden of cancer among younger women in order to make an impact on individual lives. This finding of breast cancer among younger women confirms what has been previously reported anecdotally and in smaller studies. This picture is of the mother (in wheelchair; Figure 5) of one of the authors of this report—one month before she died of breast cancer at age 49 in 1994. Years prior, this “Bosom Buddy” went to her doctor to get evaluated for a lump in her breast. She was sent home armed with only the message that breast texture changes with weight loss and that she was “too young” to have breast cancer. Although overall rates are lower among younger women, this report provides irrefutable evidence that cancer is still a significant burden for this age group.

Discussion

This year’s report found that incidence and mortality trends for most types of cancer continue earlier trends. Rates of new cases and deaths from lung, bladder, and larynx cancers continue to decrease as a result of long-term declines in tobacco smoking. In contrast, rates of new cases of cancers related to excess weight and physical inactivity—including uterine, postmenopausal breast, and colorectal (only in young adults)—have been increasing in recent decades.

The stabilization of thyroid cancer incidence may be due to changes in the diagnostic processes related to...
revisions in the American Thyroid Association management guidelines for small thyroid nodules rather than a decrease in cancer risk. The reason behind the decrease in melanoma mortality is unclear, but may be related to improvements in screening and early detection, which is often the case when incidence is rising but mortality is declining, as seen here.

The greater cancer burden among women than men was a significant finding. Some of the most frequent malignant and nonmalignant cancers that occur in this age group may be associated with considerable long-term and late effects related to the disease or its treatment. Access to timely and high-quality treatment and survivorship care is important to improve health outcomes and quality of life for younger adults diagnosed with cancer. And the high burden of breast cancer among younger women reinforces the importance of research tailored to this age group.

Reference
### Figure 2. Five-Year Incidence Trends, Average Annual Percent Change (AAPC)

<table>
<thead>
<tr>
<th>Site</th>
<th>Current trend</th>
<th>Rate ratio</th>
<th>Delay-adj. incidence rates</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5-year AAPC</td>
<td>Male/Female</td>
<td>Cases per 100,000</td>
</tr>
<tr>
<td>Prostate</td>
<td>-6.1% (-8.0 - 4.2)</td>
<td>1.4</td>
<td>71.4</td>
</tr>
<tr>
<td>Lung and bronchus</td>
<td>-2.6% (-2.8 - 2.5)</td>
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<td>45.9</td>
</tr>
<tr>
<td>Colon and rectum</td>
<td>-1.5% (-3.6 - 0.6)</td>
<td>9.0</td>
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</tr>
<tr>
<td>Urinary bladder</td>
<td>-0.9% (-1.1 - 0)</td>
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<td>27.9</td>
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<td>Melanoma of the skin</td>
<td>2.3% (2.0 - 2.5)</td>
<td>1.0</td>
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<tr>
<td>Non-Hodgkin lymphoma</td>
<td>-0.3% (-0.5 - 0.1)</td>
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<td>22.6</td>
</tr>
<tr>
<td>Kidney and renal pelvis</td>
<td>1.5% (1.1 - 1.9)</td>
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<td>18.9</td>
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<tr>
<td>Leukemia</td>
<td>0.7% (-0.3 - 1.6)</td>
<td>1.0</td>
<td>8.8</td>
</tr>
<tr>
<td>Oral cavity and pharynx</td>
<td>1.2% (1.0 - 1.5)</td>
<td>1.3</td>
<td>7.3</td>
</tr>
<tr>
<td>Pancreas</td>
<td>1.0% (1.0 - 1.1)</td>
<td>1.3</td>
<td>7.1</td>
</tr>
<tr>
<td>Liver and intrahepatic bile duct</td>
<td>2.7% (2.1 - 3.3)</td>
<td>1.3</td>
<td>7.4</td>
</tr>
<tr>
<td>Stomach</td>
<td>-0.6% (-1.0 - 0.3)</td>
<td>1.3</td>
<td>5.9</td>
</tr>
<tr>
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<tr>
<td>Esophagus</td>
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<tr>
<td>Brain and other nervous system</td>
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<td>1.4</td>
<td>8.8</td>
</tr>
<tr>
<td>Thyroid</td>
<td>1.9% (0.9 - 2.8)</td>
<td>1.4</td>
<td>8.8</td>
</tr>
<tr>
<td>Larynx</td>
<td>-2.3% (-2.5 - 2.2)</td>
<td>1.4</td>
<td>8.8</td>
</tr>
</tbody>
</table>

* Indicates the statistic (AAPC or rate) is statistically significant.

### Figure 3. Five-Year Mortality Trends, Average Annual Percent Change (AAPC), Ages 20–49 Years

<table>
<thead>
<tr>
<th>Site</th>
<th>Current trend</th>
<th>Delay-adj. incidence rates</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5-Year AAPC</td>
<td>Cases per 100,000</td>
</tr>
<tr>
<td>Breast</td>
<td>0.4% (0.2 - 0.7)</td>
<td>52.4</td>
</tr>
<tr>
<td>Lung and bronchus</td>
<td>-1.2% (-1.4 - 1.6)</td>
<td>34.8</td>
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<tr>
<td>Colon and rectum</td>
<td>-1.0% (1.6 - 0.5)</td>
<td>26.6</td>
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<tr>
<td>Corpus and uterus, NOS</td>
<td>1.2% (1.1 - 1.3)</td>
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<tr>
<td>Thyroid</td>
<td>1.0% (0.4 - 2.3)</td>
<td>17.2</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>1.7% (1.3 - 2.2)</td>
<td>16.1</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>-0.5% (-0.7 - 0.3)</td>
<td>11.6</td>
</tr>
<tr>
<td>Ovary</td>
<td>-1.5% (-1.6 - 1.4)</td>
<td>11.5</td>
</tr>
<tr>
<td>Kidney and renal pelvis</td>
<td>0.5% (0.2 - 0.9)</td>
<td>11.2</td>
</tr>
<tr>
<td>Leukemia</td>
<td>0.9% (0.7 - 1.1)</td>
<td>11.2</td>
</tr>
<tr>
<td>Pancreas</td>
<td>1.0% (0.9 - 1.1)</td>
<td>11.1</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>-0.8% (1.0 - 0.6)</td>
<td>11.1</td>
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<tr>
<td>Cervix uteri</td>
<td>0.5% (0.9 - 1.9)</td>
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</tr>
<tr>
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<td>0.7% (0.5 - 1.0)</td>
<td>7.7</td>
</tr>
<tr>
<td>Myeloma</td>
<td>1.4% (0.6 - 2.1)</td>
<td>6.5</td>
</tr>
<tr>
<td>Brain and other nervous system</td>
<td>-0.2% (-0.4 - 0.1)</td>
<td>5.8</td>
</tr>
<tr>
<td>Stomach</td>
<td>0.0% (0.6 - 0.5)</td>
<td>4.7</td>
</tr>
<tr>
<td>Liver and intrahepatic bile duct</td>
<td>3.8% (2.5 - 4.0)</td>
<td>4.4</td>
</tr>
</tbody>
</table>

* Indicates the statistic (AAPC or rate) is statistically significant.
Figure 4. Five-Year Incidence Trends, Average Annual Percent Change (AAPC), Ages 20–49 Years

<table>
<thead>
<tr>
<th>Site</th>
<th>Ages 20–29</th>
<th>Ages 30–39</th>
<th>Ages 40–49</th>
<th>Males</th>
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<tbody>
<tr>
<td>Colon and rectum</td>
<td>2.0</td>
<td>10.0*</td>
<td>8.3</td>
<td>4.4*</td>
</tr>
<tr>
<td>Testis</td>
<td>11.9*</td>
<td>13.1*</td>
<td>7.4</td>
<td>4.9*</td>
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<tr>
<td>Melanoma of the skin</td>
<td>2.0*</td>
<td>8.4</td>
<td>17.1</td>
<td>6.6*</td>
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<td>6.2</td>
<td>14.0</td>
<td>2.2*</td>
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<td>13.6</td>
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<td>2.1</td>
<td>18.0</td>
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<td>1.1*</td>
<td>8.6</td>
<td>1.4*</td>
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<td>4.3</td>
<td>6.0</td>
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<td>3.8</td>
<td>3.3</td>
<td>0.4*</td>
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<td>4.7</td>
<td>2.5*</td>
<td>14.2</td>
<td>3.3</td>
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</table>

* Indicates the statistic (AAPC or rate) is statistically significant.

Figure 5. Merrily Sherman (in wheelchair), 1945–1994
How Cancer Registry and Nurse Navigation Work Together to Improve Patient Care

Sarah R. Guzan, RHIT, CTR, BS; Lindsey Reed, BSN, RN, OCN, ONN-CG

Background
In the past, cancer registry and navigation functioned in silos and there was not a lot of communication among the teams. Previously, cancer registry had to track down where the patient received their treatment. This process is very arduous and involves some detective work, because they were guessing where treatment might have occurred based on patient’s address. Many patients these days do not have primary care physicians and this information is inconsistently documented in the patient’s medical record. Nurse navigators are very connected with patients and their treatment facilities and can be used as a resource for the cancer registry team. Complete treatment information for patients helps improve treatment options and future outcomes for all those facing cancer. Navigation also did not have an efficient way to identify patients and follow pathology reports.

Objective
To foster a relationship of teamwork between cancer registry and nurse navigation to improve efficiency, thus positively impacting patient care. Teambuilding events were set up to improve cross-collaboration between the teams. We focused on differing communication styles of those in the team and how to best communicate with one another.

Special software was also deployed: Patient ID. All pathology reports are reviewed by the software and positive cases are flagged. These positive cases are then reviewed by cancer registrars for accuracy and downloaded into cancer registry software, Metriq, as suspense cases. Positive cases are also sent to NavQue, a navigation tool, to notify the navigator of a new case. By identifying patients at this pivotal time, navigation can help impact the cancer patient’s journey at every step. This software has helped to improve efficiency for both registry and navigation.

Results
In 2018, there were 39,623 pathology reports reviewed by cancer registry for the 7 HCA facilities in the Kansas City market (Figure 1). Of those reports, there were 1,958, potential breast, colon, complex GI, and lung cancer patients identified. This resulted in 1,606 newly diagnosed navigated cancer patients (Figure 2). With an estimated analytic caseload of 3,100 for 2018, 50% of those patients have the potential of being helped through their cancer treatment by nurse navigators (Figure 3).

Conclusion
By working together as part of a team approach, patients benefit most by the collaboration of cancer registry and nurse navigation early in the cancer journey to offer integrated cancer services to patients from diagnosis through survivorship. This collaboration improves efficiency and allows more time to be spent on patient care and accurate data entry.

Figure 1. Pathology Reports Reviewed

39,623 Pathology Reports Reviewed

7 Kansas City Market Facilities
Figure 2. Cancer Patients Identified

1,958
Breast, Colon, Complex GI, & Lung Cancers IDENTIFIED

1,606
Newly Diagnosed NAVIGATED Cancer Patients

644
Breast*
215
Colon*
416
Complex GI*
376
Lung*

* Patients with multiple primary sites will appear in multiple site segmentation.

Figure 3. Estimated Potential Impact

In 2018

3,100
Estimated analytic caseload

50%
Potential Navigated patients
How do you Measure ACS–CoC Success?

Cheryl Sheridan, RHIT, CTR⁴

Background
Sarah Cannon is the global cancer institute of the Hospital Corporation of America (HCA). Collectively, our comprehensive patient-centric services ensure that we are fulfilling our mission to redefine cancer care around the world. Part of that mission is to ensure those facilities participating in the American College of Surgeons (ACS), Commission on Cancer (CoC), and NAPBC (National Accreditation Program for Breast Centers) are exceeding the standards set by ACS.

Method
HCA currently has 76 CoC-accredited facilities and 31 NAPBC facilities (Figure 1). The management of those accreditations are the responsibility of Sarah Cannon. We recently restructured the roles, responsibilities and structure of our cancer registry. A component of this new structure includes the hiring of 19 oncology data and accreditation managers (ODAMs) who service our 15 divisions of HCA. Our ODAMs have been provided a standardized toolkit for both CoC and NAPBC accreditation preparation and management.

Standardization Tools
Tools for standardization are shown in Figure 2.

Measures of Success
- Ability to compare timeliness of care and improved performance based on national guidelines
- Allocation of resources appropriately to new programs, new staff, gaps identified
- State of survey readiness ongoing
- Impactful, meaningful quality studies in all divisions
- Staffing maintained at high level in all divisions
- Centers of excellence and expansion possible

Results
This toolkit has provided the information needed to develop a facility scorecard. The facility scorecard provides leadership at Sarah Cannon the ability to understand the current status of each facility in the accreditation process, thus allowing any intervention or assistance that may be needed to address any issue identified.

Conclusion
This poster provides a review of this restructure, the role of the ODAM, the tools we have developed, and the scorecard used to measure our facilities to ensure accreditation success.

---

⁴ Sarah Cannon.
Address correspondence to Cheryl Sheridan, RHIT, CTR. Email: cheryl.sheridan@sarahcannon.com.
Figure 2. Standardization Tools

CoC Readiness Tool
Purpose: Tracking tool for tracking adherence to standards, tracking of goals and outcomes, and holding participants and leaders accountable

Program Activity Tracking Tool
Purpose: Tracks everything required for the CoC including membership, coordination for Cancer Committee Meetings, adherence to standards, and committee goals

Cancer Committee Agenda Items

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<tr>
<th>Cancer Committee Agenda Items</th>
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<th>1</th>
<th>2</th>
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<td>Analyze metrics that identify barriers to achievement of performance criteria</td>
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<tr>
<td>Develop a system to track the performance of the program</td>
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<tr>
<td>Establish performance targets for each program</td>
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<tr>
<td>Establish performance targets for each program</td>
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<td>Establish performance targets for each program</td>
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<td>Establish performance targets for each program</td>
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</table>

Cancer Committee Agenda/Minutes Template
Purpose: Quarterly tool to track each CoC standard and its incorporation into Cancer Committee Meetings
Strategic Implementation of a Shared Service Cancer Registry Model in a Large National Health Care System

Melissa A. Rinker, CTR

Why Shared Services

- High-volume routine transactions (Figure 1)
- Specialized skills
- Company-wide information

Benefits of shared services include:

- Promote quality through an improved leadership structure and functional specialization
- Improved turnaround time and productivity by focusing certified staff on tasks that require certified resources which will improve efficiency, job satisfaction, and total cost
- Cross-coverage across hospitals and divisions
- Focus noncertified staff on tasks such as meeting facilitation which is a large physician satisfier leading to improved physician engagement (tumor site-specific tumor boards, cancer committees and conferences)
- Decreased spend as we materially reduce contractors
- Turnover reduction by offering career ladders/promotional opportunities, flexible work hours, work from home options

Structure

ODAM responsibilities

- Q1–Q4 agenda template
- Prepare minutes
- Meet with chair/CLP
- Prepare deck
- Request reports based on agenda
- Attend meeting
- Lead, guide, interpret Commission on Cancer standards
- Pull, prepare, analyze data reports
- Survey ongoing readiness
- Support adherence to attendance
- Ongoing maintenance of SAR

RVP/aRVP facility leadership

- Champion accreditation vision
- Support attendance/engage physicians
- Escalate risks of noncompliance
- Service line update
- Sarah Cannon update

CC chair/CLP

- Attend meeting
- Engage in activities
- Participate
- Lead
- Communication
- Review data

Other members

- Attend meeting
- Provide departmental reports
- Provide ideas for quality studies/departmental goals based on identified issues

Navigation director/navigators

- Attend meeting
- Voice gaps in care
- Support survivorship for navigated patients
- Identify barriers of navigated patients

Facility/market

- Research accruals
- Service line leadership attendance
- Quality support
- Identify program goals
- Community needs assessment
- Physician accountability
- Survivorship process
- Nursing competency
- Genetics process
- Annual prevention and screening activity
- Distress/psychosocial assessment
- Annual CE event

Recommendations

- Standardized agenda and minutes template
- Facility lead support/Sarah Cannon ambassador
- Consider integrated network accreditation as appropriate
- Consider succession plan/term limits

Standardization Tools

Figure 2 shows tools for standardization.

Measures of Success

- Concurrent (3 months) abstracting, no backlogs
- State of survey readiness ongoing
- Data-driven, solution-seeking
- Impactful, meaningful quality studies in all divisions
- Staffing maintained at high level in all divisions
- Centers of excellence and expansion possible
- High levels of facility engagement
- Allocation of resources appropriately to new programs, new staff, gaps identified

*Sarah Cannon.

Address correspondence to Melissa A. Rinker, CTR. Email: melissa.rinker@sarahcannon.com.
Figure 1. Leveraging Scope and Scale

One of the world’s largest drug development/phase 1 programs

Utilizes the largest Patient access/ER system to diagnose cancer at earlier stages (8.4 million visits a year)

120,000+
Newly diagnosed cancer patients per year within the system

191 HCA Hospitals

1,000+
annual transplants the largest blood cancer transplant network

100+
CoC and/or NAPBC accreditations

200+
oncology-trained nurse navigators
the largest cancer navigation program in the US

Figure 2. Standardization Tools

CoC Readiness Tool
Purpose: Tracking tool for tracking adherence to standards, tracking of goals and outcomes, and holding participants and leaders accountable

Program Activity Tracking Tool
Purpose: Tracks everything required for the CoC including membership, coordination for Cancer Committee Meetings, adherence to standards, and committee goals

Cancer Committee Agenda Items Tool
Purpose: Quarterly tool to track each CoC standard and its incorporation into Cancer Committee Meetings

Cancer Committee Agenda/Minutes Template
Purpose: Quarterly tool to track each CoC standard and its incorporation into your Cancer Committee Meetings
Poster

Holden Comprehensive Cancer Center: Oncology Registry Quality Management System and Waste Reduction

Tania Viet; Alisha Loy; Zachary J. Pollock; Jennifer Pangburn; Cindy Kalvig; Amy Mattes; Katie Long; Gwen Durham

Description and Background

Gap and root cause analysis demonstrated an area of improvement through standardization of workflow, reduction of process waste, and development of a more robust quality management system for the Oncology Registry Program (Figure 1).

Aim

Reduce the burden on current staff, allow for setting clear individual and team goals, build strong team dynamics and assist in right sizing the staffing model to meet overall work demand.

Targets include:
- Standardize workflow for abstracts focusing on accurate & efficient data collection
- Reduce system wait by leveraging technology
- Reduce process waste
- Create system for corrective action planning
- Utilize current and future resources effectively and efficiently to track and meet standards.

Intervention

Using quality, lean and six sigma strategies analysis, improvement and system creation occurred. Current state process maps (Figure 2) captured variation in workflow. Individual assessments provided evaluation of use, demand, and daily work target creation. Morphing maps and a Bone diagram (Figure 3) assisted in working through creation and improvement processes. System waste was identified through process maps, standards review and institutional goals (Figure 4).

Measure

Gemba observations occurred to assist with identification of system waste and collection of cycle time data. Processes were mapped and baseline data collected to capture current state. A total quality management system was created that meets standards and institutional goals. Areas of focus included:
- Standardization of data collection entry
- Productivity and quality benchmarks created to meet institutional goals
- Quality summary provided utilizing individual performance scorecard, peer review methodology, and a department dashboard (Figure 5 and 6)
- Corrective action planning is utilized for identified improvement targets (Figure 7)

Conclusion and Results

- Workflow standardization and waste reduction lead to an average of 22 minutes per abstract in timesaving, with additional improvement upon implementation of leverage technology.
- Team members created department targets for productivity with guidance on daily demand.
- Department dashboard created and implemented in program evaluation, capturing key performance indicators with process, satisfaction and outcome measures.
- Quality performance summary created and implemented with targets for corrective action planning.
- System for corrective action resolution created and implemented.

References

Figure 1. Gap and Root Cause Analysis

Figure 2. Current State Process Map: Abstracting
Figure 3. Bone Diagram

Figure 4. Dashboard: Process Metrics

Figure 5. Individual Performance Score Card
Figure 6. Peer Review Quality Summary

Figure 7. Dashboard: Outcomes Metrics (Page 4 of 4)

<table>
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<th>Total Volume of Completed Abstracts</th>
<th>Quarterly CoC Peer Review</th>
<th>Department Performance Score Card</th>
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<td>Complete Totals by Month</td>
<td>Summary of Peer Review Findings</td>
<td>Department Average Defects by Category</td>
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<td>A: Abstracts: Accuracy of Data (CoC Section 6.4) 94.62%</td>
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<td>B: Collaborative Stage (CoC Section 9.9) 98.12%</td>
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<td>C: Followup: All B. Isolated Patients (CoC Sections 6.3 &amp; 5.4) 99.49%</td>
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<td>Last 5 Years toward Target (90% Reported)</td>
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<td>97.1%</td>
<td>98.9%</td>
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Quality Insiders: A Central Registry’s Quality Improvement Plan

Amy Cass, RHIA, BS, CTR\(^a\); Frances Krol, AAS, CTR\(^a\); Maryanne Burhenne, RN, BSN, CTR\(^a,b\); Harrine W. Katz, BS, CTR\(^a\); Adrian Botchway, CTR\(^a,b\); Antoinette M. Stroup, PhD\(^a,b,c\); Stephanie M. Hill, MPH, CTR\(^a,b\)

**Introduction**

The External Quality Improvement Team, established in 2018 at the New Jersey State Cancer Registry (NJSCR), reviews incoming data from hospital registrars on a regular basis to promote quality data and provide education to NJSCR staff and hospital registrars as needed.

Items to be included in these data quality audits are chosen based on:
- Common errors noted by staff during case consolidation
- Changes in data item coding rules
- Topics suggested during interaction with the registry community

In order to effectively communicate the audit results to hospital registrars and NJSCR staff, the “Quality Insiders” bulletin was created. The bulletin provides detailed, case-specific data errors to the individual hospitals included in the audit, along with appropriate data field references. The Quality Insiders bulletin complements NJSCR’s long-running, monthly electronic newsletter, “E-tips,” which is a more general educational article distributed to all NJ hospital registries. NJSCR staff receive both.

**Objectives**

1. Provide an overview of how central registries can execute an efficient and effective quality data review of incoming data from hospital registries.
2. Showcase a tool used by the NJSCR to reach out to registrars for educational purposes (Figure 1).
3. Reinforce the importance of an external data quality team in a central registry to educate hospital registry staff as well as internal staff.

**Methods**

**Step #1**

Decide on a data field(s) to audit and research supporting references.

**Step #2**

Choose a team member to lead the audit.

**Step #3**

Run a report(s) on hospital-level records in the central registry software system—consider Class of Case, Date of First Contact year.

**Step #4**

Determine the percentage of cases that will be audited based on the report results.

**Step #5**

Divide data among team members—export hospital-specific data to Excel and place on a secure, encrypted network drive to allow file sharing among reviewers.

**Step #6**

Review hospital-level coding transmitted to the central registry.

**Step #7**

Compare codes to documented text and electronic pathology reports, if available.

**Step #8**

Amend data fields in consolidated record and document reason for change in comments.

**Step #9**

Summarize findings and discuss any issues or questions that arose among workgroup members when audit is complete.

**Step #10**

Compile each team member’s summary of findings into one complete summary.

**Results**

- Reviewed 1,550 analytic bladder cancer cases diagnosed in 2016 submitted from 58 New Jersey hospital cancer registries.
- Each team member reviewed approximately 300 bladder cancer cases.
- The review focused on Grade and Site-Specific Factors (SSF) 1 (World Health Organization/International Society of Urologic Pathology [WHO/ISUP] Grade) (Figure 2; Table 1).

---

\(^a\) New Jersey State Cancer Registry, Cancer Epidemiology Services, New Jersey Department of Health, Trenton, New Jersey. \(^b\) New Jersey State Cancer Registry, Rutgers Cancer Institute of New Jersey, New Brunswick, New Jersey. \(^c\) Rutgers School of Public Health, Piscataway, New Jersey. Cancer Epidemiology Services, including the New Jersey State Cancer Registry, receives support from the National Program of Cancer Registries, Centers for Disease Control and Prevention under cooperative agreement NU56DP006279-02-00, the State of New Jersey, and the Rutgers Cancer Institute of New Jersey.
• A concerning number of incorrectly coded grades became apparent during the External QI team review. More than half (57%) of the bladder cases submitted from various facilities coded “Bladder Grade” incorrectly.
• In comparison, SSF1 (WHO/ISUP Grade) had a greater coding accuracy (94%).
• In conclusion, the interpretation of high grade vs low grade in the grade/differentiation field was coded incorrectly. Cancer registrars should review the appropriate standard-setting manuals to avoid coding errors.

Conclusion
• The External Quality Improvement Team projects and “Quality Insiders” bulletin provide a benefit in training cancer registrars on common coding errors.

• The External QI review process was also successfully applied to the following reviews: histology coding of thyroid malignancies, prostate cancer SSF12 (number of cores positive) and SSF 13 (number of cores examined), and unknown date of diagnosis.
• Positive feedback has been received from several hospital registrars regarding the External Quality Improvement Workgroup projects.
• Future reviews will assess the effectiveness of educational interventions provided to cancer registrars in improving the quality of coded data items.

Acknowledgements
We would like to thank our colleagues at the NJSCR as well as New Jersey hospital cancer registries.

<table>
<thead>
<tr>
<th>Table 1. Grade and SSF 1 (WHO/ISUP Grade)</th>
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<tr>
<td>Correct, n (%)</td>
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<tr>
<td>Bladder Cancer Grade</td>
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<tr>
<td>SSF 1 (WHO/ISUP Grade)</td>
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ISUP, International Society of Urologic Pathology; SSF, Site-Specific Factors; WHO, World Health Organization.
UTILITY OF USING CANCER REGISTRY DATA TO IDENTIFY PATIENTS FOR TOBACCO TREATMENT TRIALS

After reading this article and taking the quiz, the participants will be able to:
• Describe the factors contributing to tobacco use data for population-based tobacco treatment interventions
• Understand combustible and noncombustible forms of tobacco
• Describe the current smoking status between the registry-based smoking status and the electronic health record (EHR)-based smoking status

1. The eligibility requirements for the study population included:
   a) Currently smoked a tobacco product in the past 90 days
   b) Any cancer diagnosis of less than stage IV in the previous 2 years
   c) Pathological stage 3B
   d) No diagnosis of dementia

2. All are forms of combustible tobacco except:
   a) Snuff/chew/smokeless tobacco user
   b) Cigar/pipe
   c) Cigarette smoker
   d) Electronic cigarettes

3. Which EHR system documented smoking status as a variable in the substance use history?
   a) Mysis
   b) Epic
   c) NYU
   d) CPRS

4. According to Table 3, which hospital had the greatest agreement in “current” cigarette smoking status between the registry and EHR?
   a) NYU
   b) VA
   c) Bellevue
   d) Mysis

5. According to Table 3, about 25% of patients were identified as what type of smoker?
   a) Former
   b) Current smoker
   c) Never smoker
   d) Unknown smoker

6. Logistic results indicated agreement in smoking status between the registry and EHR varied by hospital, cancer type and stage. By which of the following did it NOT vary?
   a) Age and sex
   b) Age and race
   c) Age and ethnicity
   d) Age and income level

7. Where did the largest discrepancy occur between the cancer registry and EHR?
   a) Use of stigmatizing terms when asking tobacco use questions
   b) Patient response to tobacco-use questions
   c) Registry categorizing patients as current smokers and EHR categorizes them as former
   d) No defined field in the EHR for tobacco use

8. What 2 tobacco related questions resulted in 2 significantly different answers?
   a) Are you a smoker? vs Have you used any tobacco product in the past 30 days?
   b) Are you a smoker? vs Have you used any tobacco product in the past year?
   c) Are you a smoker? vs Are you a former smoker?
   d) Are you a smoker? vs Do you chew tobacco?

9. The study concluded registry-based tobacco status may be useful in examining the association between tobacco use at which time interval to aid cancer outcomes in making decisions about survivorship care?
   a) At the time of follow-up
   b) At the time of treatment
   c) At the time of diagnosis
   d) At the time of first contact

10. What single improvement at the provider level is considered the least burdensome?
   a) Patients updating their social/medical history via an EHR linked tablet prior to their visit.
   b) Standardized format for tobacco-related questions
   c) Implementation of a defined field in the EHR for the collection of tobacco use
   d) Provider prompts to assess tobacco use yearly
The *Journal of Registry Management*, official journal of the National Cancer Registrars Association (NCRA), announces a call for original manuscripts on registry methodology or research findings related to the 7 subjects listed below and related topics.

Topics:
1. Birth Defects Registries
2. Cancer Registries
   a. AJCC TNM Stage
   b. Cancer and Socioeconomic Status
   c. Cancer and Health Disparities
3. Trauma Registries
4. Recruitment, Training, and Retention
5. Public Relations
6. Quality Review
7. Registry Management

Contributed manuscripts are peer-reviewed prior to publication. Manuscripts of the following types may be submitted for publication:

1. **Methodology Articles** addressing topics of broad interest and appeal to the readership, including methodological aspects of registry organization and operation.
2. **Research articles** reporting findings of original, reviewed, data-based research.
3. **Primer** providing basic and comprehensive tutorials on relevant subjects.
4. **“How I Do It” Articles** describe tips, techniques, or procedures for an aspect of registry operations that the author does particularly well. The “How I Do It” feature in the *Journal* provides registrars with an informal forum for sharing strategies with colleagues in all types of registries.
5. **Opinion papers/editorials** including position papers, commentaries, essays, and interviews that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management.
6. **Bibliographies** which are specifically targeted and of significant interest will be considered.
7. **Letters to the Editor** are also invited.

Address all manuscripts to: Danette Clark, BS, RMA, AAS, CTR, Editor-in-Chief, *Journal of Registry Management*, (973) 971-5189, JRMEditor@ncra-usa.org.

Manuscript submission requirements are given in “Information for Authors” found near the back of each *Journal* and on the NCRA website at [http://www.ncra-usa.org/jrm](http://www.ncra-usa.org/jrm).
Journal of Registry Management

INFORMATION FOR AUTHORS

Journal of Registry Management (JRM), the official journal of the National Cancer Registrars Association, invites submission of original manuscripts on topics related to management of disease registries and the collection, management, and use of cancer, trauma, AIDS, and other disease registry data. Reprinting of previously published material will be considered for publication only when it is of special and immediate interest to the readership. JRM encourages authorship by Certified Tumor Registrars (CTRs); special value is placed on manuscripts with CTR collaboration and publication of articles or texts related to the registry profession. CTR continuing education (CE) credits are awarded; a published chapter or full textbook article equals 5 CE hours. Other published articles or documents equal CE hours. All correspondence and manuscripts should be addressed to the Danette Clark, BS, RMA, AAS, CTR, Editor-in-Chief at JREditor@ncra-usa.org or (973) 971-5189.

Manuscripts may be submitted for publication in the following categories: Articles addressing topics of broad interest and appeal to the readership, including Methodology papers about registry organization and operation; Research papers reporting findings of original, reviewed, data-based research; Primers providing tutorials on relevant subjects; and “How I Do It” papers are also solicited. Opinion papers/editorials including position papers, commentaries, and essays that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management; Letters to the Editor; and specifically-targeted Bibliographies of significant interest are invited.

The following guidelines are provided to assist prospective authors in preparing manuscripts for the Journal, and to facilitate technical processing of submissions. Failure to follow the guidelines may delay consideration of your manuscript. Authors who are unfamiliar with preparation and submission of manuscripts for publication are encouraged to contact the Editor for clarification or additional assistance.

Submission Requirements

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