



# Journal of Registry Management

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**DISTAL BILE DUCT**

Primary Tumor

Clinical Definitions  Pathologic Definitions

- TX Primary tumor cannot be assessed
- T0 No evidence of primary tumor
- Tis Carcinoma *in situ*: (intraductal tumor)
- T1 Tumor confined to the bile duct histologically
- T2 Tumor invades beyond the wall of the bile duct
- T3 Tumor invades the gallbladder, pancreas, duodenum or other adjacent organs without involvement of the celiac axis, or the superior mesenteric artery
- T4 Tumor involves the celiac axis, or the superior mesenteric artery

Tumor Size:   cm  mm

Laterality:  Left  Right  Bilateral  N/A

**DISTAL BILE DUCT**

Regional Lymph Nodes

Clinical Definitions  Pathologic Definitions

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- N0 No regional lymph node metastasis
- N1 Regional lymph node metastasis present

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*Contents*

**Commentary**

Quality of Care: The Role of Disease Registries.....133  
*Sreenivas P. Veeranki, MD, MPH; Billy Brooks; Susan Bolick, MSPH, CTR; Mary Robichaux; Timothy Aldrich, PhD, MPH*

**Original Articles**

Comparisons of Directly Coded SEER Summary Stage 2000 and Collaborative Staging Derived SEER Summary Stage 2000.....137  
*Xiao-Cheng Wu, MD, MPH; Qingzhao Yu, PhD; Patricia A. Andrews, MPH; Praveen Ranganath, MD, MPH; Baozhen Qiao, PhD; Umed Ajani, MD, MPH; Brad Wohler, MS; Zhenzhen Zhang, MD, MPH*

Impact of Automated Data Collection from Urology Offices: Improving Incidence and Treatment Reporting in Urologic Cancers.....141  
*Lynne T. Penberthy, MD, MPH; Donna McClish, PhD; Pamela Agovino, MPH*

Towards the Use of a Census Tract Poverty Indicator Variable in Cancer Surveillance .....148  
*Francis P. Boscoe, PhD*

Economic Assessment of Central Cancer Registry Operations, Part III: Results from 5 Programs .....152  
*Florence Tangka, PhD; Sujha Subramanian, PhD; Maggie Cole Beebe, PhD; Diana Trebino, BA; Frances Michaud, CTR*

Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking.....156  
*Shilpa Jain, MD, MPH; Norma Kanarek, MPH, PhD; Robert J. Arceci, MD, PhD*

**Features and Other Journal Departments**

Experiencing Change: The Users' Perspective (CSv2).....163  
*Cynthia Boudreaux, LPN, CTR*

Epi Reviews: Data Directions.....164  
*Faith G. Davis, PhD*

Raising the Bar: Speaking Your Customer's Language .....165  
*Michele Webb, CTR*

Cancer Forum: Combining Community and Experience—Getting Started.....166  
*Asa Carter, CTR; Vicki Chiappetta, RHIA, CTR; Anna Delev, CTR; Debbie Etheridge, CTR; Donna Gress, RHIT, CTR; Lisa Landvoigt, CTR*

Fall 2010 Continuing Education Quiz Answers.....168  
*Deborah C. Roberson, MSM, CTR; Denise Harrison, BS, CTR*

Winter 2010 Continuing Education Quiz.....169  
*Deborah C. Roberson, MSM, CTR; Denise Harrison, BS, CTR*

Index .....171

Information for Authors .....Inside back cover

Call for Papers .....Back cover

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## Quality of Care: The Role of Disease Registries

Sreenivas P. Veeranki, MD, MPH<sup>a</sup>; Billy Brooks<sup>a</sup>; Susan Bolick, MSPH, CTR<sup>b</sup>; Mary Robichaux<sup>c</sup>; Timothy Aldrich, PhD, MPH<sup>a</sup>

### Introduction

The origin of cancer registries was to create clinical surveys and perform patient follow-up, the objective being to bring surgical patients back to the doctor periodically to identify recurrences. Over the past 60 years, cancer registries have continued to compile patient care data and perform patient follow-up. However, over the past decade, emphasis has been placed on the direct involvement of the cancer registry in monitoring quality of care.<sup>1</sup> In contrast, stroke registries monitor the quality of care for patients, but do not follow them periodically to identify recurrences. The biology of these diseases is an intricate part of the different roles played by both types of registries, yet each has a page to take from the other's book. This article examines the manner in which these registries operate to improve the quality of patient care.

### Cancer Registries and Quality of Care

Hospital-based cancer registries collect information about the first course as well as total treatment in many cases. The precision of the data description has been expanded over the years from the general, mainly consisting of type of treatment administered, to the detailed measures of the treatment, eg, total dosage, duration of the treatment, and combinations of a multiple-chemotherapy regime. Many cancer registries also monitor disease-related intervals as the patient's time-to-recurrence and survival. However, the degree of completeness of these sorts of post hoc determinations has been sometimes regarded as suspect by clinicians who wish to perform a thorough evaluation of a specific clinical regime.

According to the American College of Surgeons (ACS) Commission on Cancer (CoC), hospital cancer committees are responsible for meeting the CoC standards for the Quality Improvement Plan for accreditation of their cancer programs.<sup>2,3</sup> Annually, 2 quality studies are required for most cancer programs, 1 of which is based on cancer registry data,<sup>1</sup> and these studies can include structure, process, or outcome variables. Programs are then rated at survey for their compliance of the standards based on complete documentation of the design, conduct, implementation, and evaluation of the studies.

Hospital registries submit their data annually to the National Cancer Data Base (NCDB).<sup>4</sup> NCDB special studies designed to improve patient care are conducted with

select approved facilities meeting specific study criteria. If requested to participate, cancer programs must fulfill Standard 3.8 for accreditation.<sup>5</sup> Records are pulled and enhanced data related to the care and its outcome are collected. In some programs, this sort of enhanced data is collected prospectively, rather than retrospectively. Many of the country's most prestigious registries have this capacity, yet most community hospitals have too few staff or resources. Special studies are a favorite task assigned to medical students or residents, so that they perform the arduous page-by-page search for specific clinical details.

Central cancer registries often compile the hospital-recorded treatment data, yet it is quite rare for these data to be used for service planning. Incomplete data is the main impediment to such use, with suspicions that complete courses of treatment are not known. Cancer patients may refuse prescribed treatment, develop toxicity, or have their treatment plan interrupted or stopped. Patients may go to other facilities for a portion of their care, which is not recorded by the reporting hospital. In fact, this specific limitation underpins the hospital's designation of class of cases,<sup>6,7</sup> reflecting the degree to which their facility is the care provider. In many hospitals, the improvements in patient care are measures to improve medical documentation, along with clinical staging and history taking, rather than truly assessing the patient's therapeutic experience.

Central cancer registries often direct their quality of care to screening considerations, of which stage-at-diagnosis is a splendid guide to understand disparities in a population. Even the prestigious Surveillance, Epidemiology, and End Results (SEER) registries develop a study protocol when they evaluate a therapy. The recent Centers for Disease Control and Prevention (CDC) National Program for Cancer Registries (NPCR) Patterns of Care studies, in collaboration with the worldwide CONCORD study, are examples of how cancer registries managed an evaluation of quality of care.<sup>8</sup> This is yet again a case of "enhanced" data collection ("enhanced" meaning that unusual variables are collected, cases are required to meet specific criteria, and the interval of collection is short). Some proponents have urged central and hospital registries to collect minimal data (to advantage case-finding for directed studies) and cease the detailed collection of data items that are essentially never used. Given the fiscal times we face, and the reality of how these treatment

*"Quality of Care: The Role of Disease Registries"*

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data items are used, this approach may be regarded as prudent and cost-effective. Considering the 2010 mandate, registrars need to collect an additional 55 data items related to Collaborative Stage Data Collection System Version 2 (CSv2),<sup>9</sup> and the 7th edition of Cancer Staging Manual of American Joint Committee on Cancer (AJCC),<sup>10</sup> which imposes more burden on the overworked, understaffed registries. However, instructions have been disseminated that if the factor is not documented in the record, no extra effort is necessary to acquire it. Will this ambiguity of inclusion of incomplete data improve quality of care?

Attempts at compiling cancer therapy data are resisted by the nature of caregiving. Clinical courses are usually long, around several months duration for the first course. Also, as mentioned before, patients frequently receive parts of their care as outpatients, and may do so at facilities far from the registry responsible for recording the treatment data. Such time inefficiencies underpin the protracted time delay found with compiling cancer data; now at its shortest interval, but still commonly 16 to 18 months. No wonder the former ACS strategy of Patient Care Evaluations (PCEs) was cross-sectional when an assessment of quality is desired, prompt attention is needed.<sup>11</sup> This is a signal distinction from stroke registries, whose primary justification is monitoring quality of care.

### Stroke Registries and Quality of Care

Metrics of quality of care for a stroke patient are radically different from that of a cancer patient. It is not uncommon for a cancer surgery to be delayed for several days to a few weeks, but, with stroke patients, care is delivered within minutes or hours. In fact, the conventional 3-hour critical window in receiving tissue plasminogen activator (tPA) is illustrative of this rapid time-to-care perspective.<sup>12,13</sup> The biology of a cerebrovascular event is such that death, if it is to occur, will usually do so rapidly. If death does not occur quickly following a stroke, then it is likely not to occur during the hospitalization at all. Hospital-based stroke registries collect data at a frantic pace compared to cancer registries. Some of the stroke registry data items require face-to-face interviews to obtain patient or family recall of clinical details. Many stroke registry variables are time periods, measured in minutes, eg, time of arrival at the emergency room (ER), time of onset of symptoms, time to the hospital, time to see a doctor, time to computerized tomography (CAT) scan.<sup>14</sup> Such precise time measurements are facilitated in most stroke centers by patient documents being stamped with a mechanical date/time when clinical procedures are conducted.

Hospital stroke registries complete their abstract of a case's clinical course very proximally to the patient's discharge, preferably within 2 days. As mentioned before, stroke registries do not perform follow-up, which is collecting data following discharge. Hospital stroke registry orientation is wholly with the hospitalization, and their quality improvement is focused on the hospital experience. The extent of their documentation relative to post-discharge care is the recording of directives given to the patient by their physician just before discharge.

The Joint Commission, formerly the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), has established performance criteria that are necessary for a facility to satisfy in order to maintain their accreditation.<sup>15</sup> What would such an authoritative requirement pose for hospitals for cancer care, eg, documentation of staging and details of treatment?

Central stroke registries are not population-based, but hospital-based, focusing on time-dependent metrics and quality of care.<sup>16</sup> In addition, the reporting of hospital stroke registries to central stroke registries takes only a few days, and never longer than a month. Central stroke registries also provide data management training for their hospital partners, a shared practice with cancer registries.

The focal issues with centralized stroke registries become the aggregate metrics of care reported by contrasting hospital size or geographic and demographic traits. Central stroke registries provide feedback to their member registries about their performance on the quality measures (usually quarterly) and they promote strategies for improvement of declining operations, either for the clinical protocols, nursing care, or medical services. This close involvement of the central stroke registry with hospital performance is a sharp contrast with the relationship in cancer registries. Central cancer registries report the number of missing codes or unknown designations, but do not become closely involved with their hospital partners by trying to remedy the clinical performance, rather concentrating solely on the data collection accuracy.

A concluding operational consideration for hospital-based stroke and cancer registries is their pattern of forming a collaborative organization with proximal facilities. In cancer programs, this cooperation may include shared tumor boards and visiting physicians from remote clinic operations. The fiscal solution is usually with initial treatment and care, and returning the patient to their local providers for adjuvant and follow-up care. With stroke registries, the "drip-and-ship" philosophy may be viewed as similar. Mid-size hospitals may have a "strokologist" who is trained in acute stroke care and is able to differentiate the type of stroke and administer tPA. The strokologist may be a physician assistant or nurse; the imperative being that rapid clinical action is evident for stroke, distinctive from cancer. However, the scarcity of specialty physicians residing in rural areas is always evident.<sup>17,18</sup> The need for follow-up evaluation by these specialists is common to the both disease processes, but many more oncologists are present in the United States than are stroke neurologists. Stroke centers that operate a telemedicine program (eg, direct patient visualization for treatment determination) are few and far between, with the cost being high and the on-call demands crushing.<sup>18</sup> Cancer has an advantage here in that waiting until the next day or week to see a patient rarely poses clinical impact. Yet, the 2 disease programs share a strategy to utilize mid-level professionals for efficiency and cost savings.

Stroke registries are just beginning to become involved with epidemiologic research studies.<sup>19-24</sup> Clinical research has been in place for many years with stroke, yet not in a

routine, small-project manner as with cancer. The periodic conduct of quality of care assessments and the compiling of data from proximal facilities for a regional population are the strategies that stroke programs should take from cancer.<sup>25</sup> It is also one process that the accrediting organizations for stroke and the funding for cancer registries from federal agencies should be considered a requirement.<sup>18</sup> Adding an aspect of research orientation to stroke programs, as with cancer, will stimulate the staff performance and elevate their proficiency. The benefit for the populations served is patent. Stroke programs should also operate public education initiatives for promoting signs and symptoms recognition, similar to what cancer programs did in the 1970s (“the warning signs of cancer”). Cancer programs should assist here with cooperative education.

### Conclusions

Both cancer and stroke registries have lessons to learn from one another. Simply put, stroke registries need to conduct follow-up. Vastly different quality of life outcomes accrue depending on the post-discharge course of stroke patients. Also, central stroke registries need to begin to collect public health oriented data items, eg, county-of-residence and household median income (some do at this time, but many do not). Cancer registries need to streamline their data collection (reduce the variables collected) and make the data collection more concomitant with the clinical course. When epidemiologists or genetic researchers wish to identify cancer patients rapidly, the cancer registries have the capacity to perform rapid case ascertainment. This timing for data needs to become the standard of data collection in cancer registries, eg, completed by the discharge, not trailing out for months and across facilities. Such involvement of the cancer registrars with clinical protocols would follow the spirit of the tumor board but it would generalize for all cases, not only the difficult ones and those selected for didactic value.

Certainly the diversity of disease manifestations differs between these leading morbidities and so does the complexity of treatments. Cancer manifests in 40 to 70 varieties while stroke really has only 4 or 5 manifestations. Yet, the objectives are in common: improving the quality of care, delivering it rapidly, and saving lives. Cancer registries need to adopt some of the acute perspectives from stroke registries (eg, how long the patient waited before receiving care and the reasons for delay). Likewise, stroke registries need to shift their focus beyond simple life or death to embrace the much broader issue of quality-of-life after the disease event. Central cancer registries need to benefit from the central stroke registries’ data swiftness, eg, the online reporting, when data is available in weeks. Electronic reporting for cancer registries is achievable.

Both of these disease registries have an audience of intermediate providers. For cancer, they are the diagnostic providers, primary care physicians and screening professionals. The partnership aims to improve early detection of the disease, and to generalize access to high-quality care for all of the population served. However, for stroke registries, the intermediate providers are emergency medical services

(EMS) staff. The quality of symptoms information collected and forwarded to the treating hospital greatly impacts the potential for quality care. Both types of disease registries should involve these partners with their education programs, and make specific efforts to train the staff for coordination/linkage with the therapeutic course. For example, identification of geographic areas that are weak on a particular service criterion (eg, tardy diagnosis, reduced access to care) is the intercept with these prehospital partners.

Operation of hospital programs is similar for size considerations with both disease registries. Institutions that see less than 150 or so cases per year (by disease) may be too small to make the operation of a facility-specific clinical program or data system cost-effective. It often falls to the central disease registry to provide support for data collection (for completeness of case ascertainment) to these smaller hospitals. For both registries, the national performance expectations include assurance that data is included from such small facilities in the central database (these small hospitals are where many poor and rural cases “stop” rather than reaching state-of-the-art centers). Both of the central disease registries provide this assistance to smaller hospitals with batch processing cycles, eg, quarterly or annually. Hospitals with 200 to 500 cases per year are at the cusp for operating a disease-specific program. Such small programs generally have a single registrar with a highly motivated physician. Hospitals that see 500 specific-disease cases annually are the start of the continuum for centers, where multiple data-oriented staff may be present and program administration becomes a distinct operation. Additionally, both disease programs have accreditation standards that these larger institutions strive to achieve as well as comprehensive program designations for facilities doing basic research and having community outreach programs.

It is likely that both of these registries have benefits that could be developed from trauma registries or birth defect registries (the other main audiences of this journal). The professionals of these other registries benefit enormously with the experience from cancer registrars organizations, both state and national. It would appear that federal interests would be advanced by communication between registries as stroke care, like cancer care, often transcends state lines for the information exchange to be valuable.

However, the greatest benefits that these writers see for these diverse registries are cross-training and system linkage. With the advent of electronic medical records, it should only be the disease-unique variables that need registrar abstraction, and that should include some direct patient or family interaction. This “ask the customers” idea resides at the heart of improving care, specifically by learning the expectations and experiences of the client. Follow-up should be a universal activity of registries, whatever the frequency or duration. The accrued quality of care for chronic disease processes is not limited to the initial outcome, but also includes the life that patients return to when they leave the facilities.

Central stroke registries are few at the time of this writing, perhaps a dozen nationally, and the majority of them are voluntary programs without federal funds. This pattern is reminiscent of the rise with cancer registries. Also

similar to the 2 disease data systems is the gradual emergence of legislative support for the data-collection procedures. It should not be overlooked that the emergence of cardiac data systems is in the offing. Such systematic surveillance for the nation's 3 leading causes of death would be propitious; the 3 information systems should synergize procedures and practices for optimizing efficiency and quality of care. The concomitant population value is evident, particularly with the shared risk factors for these diseases, and the common prevention measures to be promoted to the general public.

### Addendum

As we prepared to submit this article, we learned that the Coalition of Stroke Coordinators in Tennessee has been awarded funding from the state to hold an educational workshop now scheduled for March 25, 2011. The workshop, called the "Stroke University," will be in Nashville, Tennessee. This connection between a state health program and a registrars organization is reminiscent of how state cancer registrars organizations benefited in the mid-1990's when the National Program of Cancer Registries promoted ties between statewide registries and hospital registrar education. This is one example of how stroke registrars are following the precedent of cancer registrars in becoming a professional community. If your hospital has a stroke registry, and your stroke program coordinator would be interested in information about the Stroke University, please have him or her email Billy Brooks at [brooks1@goldmail.etsu.edu](mailto:brooks1@goldmail.etsu.edu) for more information.

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# Comparisons of Directly Coded SEER Summary Stage 2000 and Collaborative Staging Derived SEER Summary Stage 2000

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**Abstract:** This study assessed comparability of the directly coded Summary Stage 2000 and the Collaborative Stage (CS) Derived Summary Stage 2000 (SS2000) using 2001–2004 data from 40 population-based cancer registries in the United States that met the high quality criteria. The likelihood ratio test was employed to determine whether stage differences between 2003 (pre-CS) and 2004 (CS) were attributable to 2001–2004 linear trends, decreases in percentage of unknown stage cases, or both. Statistically significant differences in stage distribution between 2003 and 2004 were observed for 30 out of the 34 cancer sites. For 4 cancer sites, the differences were attributable to 2001–2004 linear trends of stage distribution. For 8 cancer sites, the differences were attributable to decreases in percentage of unknown stage cases alone or in combination with the temporal trends of stage distribution. For the remaining 18 cancer sites, either (1) no linear trends of stage distribution were identified or (2) the combination of the decline in cases with unknown stage plus linear trends did not explain the stage differences between 2003 and 2004. By comparing the SS2000 and CS manuals, we found differences in coding definitions for direct extension and/or lymph node involvement for all cancer sites except cancers of the breast, cervix, and cranial nervous and other nervous system. Evidence showed that the stage differences between 2003 and 2004 may be attributable in part to the implementation of the CS System for some cancer sites.

**Key words:** cancer registry, cancer stage, collaborative stage, summary stage, stage comparability

## Introduction

Collaborative Staging (CS) is a coding system implemented in the United States and Canada for staging cancer cases diagnosed in 2004 and after. Historically, there were 2 main staging systems: American Joint Committee on Cancer's Tumor Node Metastasis (AJCC TNM) staging system and Surveillance, Epidemiology, and End Results (SEER) Summary Stage System.<sup>1,2</sup> The AJCC TNM stage is used primarily by clinicians who need clinically relevant information for planning treatments and evaluating outcomes. The SEER Summary Stage (SEER SS) is used mostly by epidemiologists who require consolidated information to determine stage variations by sociodemographics, monitor stage trends, and evaluate the effectiveness of intervention programs for early detection. In order to meet the needs of both clinicians and epidemiologists, tumor registrars had to abstract and stage cancer cases using both the staging systems. To eliminate duplicate efforts in staging cancer cases, the CS system was developed.<sup>3</sup> With the CS codes, AJCC TNM and SEER SS can be derived automatically using specific computer algorithms. The directly coded Summary Stage (SS2000) refers to the Summary Stage that was coded based on the SEER Summary Stage 2000 manual, and the Collaborative Stage derived Summary Stage 2000 (CSdSS2000) refers to the Summary Stage that was derived from CS codes.

Although the CS system has been in place for a few years, questions about the comparability of the SS2000 and CSdSS2000 remain unanswered. To address the issue, the Data Use and Research Committee of the North American Association of Central Cancer Registries (NAACCR) formed a work group. This report summarizes findings of the work group's research and provides recommendations for data users.

## Methods

### Data source

The 2001–2004 data for 40 cancer registries were obtained from the NAACCR (December 2007 submission). The 40 registries that participated in the National Program of Cancer Registries of the Centers for Disease Control and Prevention and/or the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute included: Alabama, Alaska, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Texas, Utah, Washington, West Virginia, and Wyoming. Data from these states met the NAACCR standards for high-quality incidence data.<sup>4</sup>

*"Comparisons of Directly Coded SEER Summary Stage 2000 and Collaborative Staging Derived SEER Summary Stage 2000"*

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.

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Only invasive cancers were included in this study. Cancer sites were grouped according to the SEER site recodes.<sup>5</sup> Pleural cancer, multiple myeloma, and leukemia were excluded due to either a small number of cases or the systemic nature of the diseases.

### Statistical analysis

The likelihood ratio test was employed in data analysis.<sup>6-8</sup> Because of the absence of double-coded stage data, which would have provided a more accurate picture of comparability, pre-CS (2001–2003) and CS (2004) stage data were compared directly. To determine the impact of coincidental temporal stage trends on the comparability assessment, 2001–2004 linear trends of stage distribution were examined first by cancer site. If the observed stage distribution of 2004 cases did not differ statistically significantly from the expected distribution based on the linear trends, the differences in stage distribution between 2003 and 2004 would be attributable to the temporal linear trends. In other words, the SS2000 and CSdSS2000 stages were comparable.

If the stage distribution of 2004 cases differed significantly from the expected after adjusting for the percentage of unknown stage cases, the impact of the percentage of unknown stage cases was examined in addition to the 2001–2004 linear trends. If the observed stage distribution of 2004 cases did not differ from the expected, the differences were assumed to be attributable to decreases in the percentage

of unknown stage cases alone or in combination with the 2001–2004 linear trends. If temporal linear trends, decreases in percentage of unknown stage cases, or a combination of these did not explain the variations in stage distributions between 2003 and 2004, it is possible that other factors such as changes in coding instructions explain the observed patterns. The level of significance was 0.05 for all tests.

As a final step, the SS2000 Manual and the Version One of the CS Manual for all study cancer sites were compared to determine whether changes in coding definitions of direct extension and/or lymph node involvement might contribute to variations in stage distributions between 2003 and 2004.

## Results

### Findings from the likelihood ratio tests

Most of the cancer sites (30 of 34) had significant differences in stage distribution between 2003 and 2004, although some differences were relatively small. Cancer sites were categorized into 5 groups based on the results of likelihood ratio tests and findings from comparisons of the coding definitions in the SS2000 and CS staging manuals (Table 1).

The first group included cancers of the bones and joints, intrahepatic bile duct, and penis as well as non-Hodgkin lymphoma. For these cancers, stage distributions were not significantly different between 2003 and 2004. The second group was comprised of cancers of the other

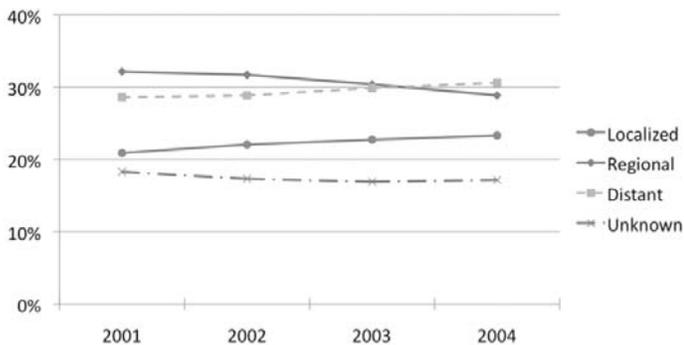
**Table 1. Attributable factors for changes in stage distribution between 2003 and 2004.**

Significant differences absent	Significant stage differences present			
	Attributable to 2001–2004 linear trends	Attributable to decrease in % of unknown stage cases in 2004 and/or to 2001–2004 linear trends	Others <sup>6</sup>	
Linear trend present			Linear trend absent	
Bones and joints <sup>2</sup>	Other non-epithelial skin <sup>2</sup>	Brain <sup>2</sup>	Bladder <sup>2</sup>	Anus, anal canal and anorectum <sup>2</sup>
Intrahepatic bile duct <sup>2</sup>	Pancreas <sup>2</sup>	Breast <sup>1</sup>	Cervix <sup>1</sup>	Cranial nerves and other nervous system <sup>1</sup>
Non-Hodgkin lymphoma <sup>2</sup>	Stomach <sup>2</sup>	Corpus and uterus, NOS <sup>2</sup>	Colon excl. rectum <sup>2</sup>	Eye and orbit <sup>2</sup>
Penis <sup>3</sup>	Thyroid <sup>2,5</sup>	Esophagus <sup>2</sup>	Kidney and renal pelvis <sup>2</sup>	Gallbladder <sup>2,3</sup>
		Liver <sup>2</sup>	Larynx <sup>2</sup>	Hodgkin lymphoma <sup>2</sup>
		Prostate <sup>2</sup>	Lung and bronchus <sup>2</sup>	Small intestine <sup>2</sup>
		Soft tissue includ. heart <sup>2</sup>	Melanoma of the skin <sup>2</sup>	Vagina <sup>2</sup>
		Testis <sup>2</sup>	Oral cavity and pharynx <sup>2,3,4</sup>	
			Ovary <sup>2</sup>	
			Rectum and recto. junction <sup>2</sup>	
			Vulva <sup>2,3</sup>	

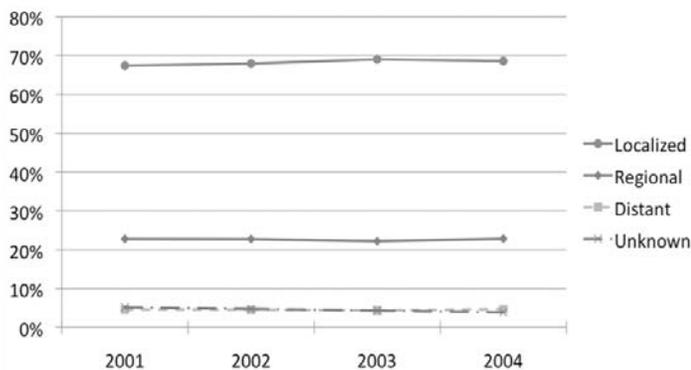
1. Coding definitions for direct extension and lymph node involvement in the SS2000 manual are the same as those in the CS manual.
2. CS manual includes additional sites/subsites to define extension and/or lymph node involvement. It is assumed that fewer cases will be staged unknown.
3. Some extension sites a/o lymph nodes are coded to different stages in the 2 manuals.
4. Site was subdivided in CS, with separate coding schemas for each subsite.
5. Some extension sites a/o lymph nodes are coded to different stages in the SS2000 and CS v1 manual, but to the same stage in the CSv2 manual.
6. Decreases in % of unknown stage cases in 2004 and/or 2001–2004 linear trends can't explain all stage differences between 2003 and 2004. Other factors such as changes of coding instructions and/or human error may be involved.

non-epithelial skin, pancreas, stomach, and thyroid. For these cancer sites, the significant differences in stage distributions between 2003 and 2004 were attributable to the 2001–2004 linear trends of stage distribution (see examples in Figures 1 and 2).

**Figure 1. Stage distribution by year of diagnosis (stomach).**

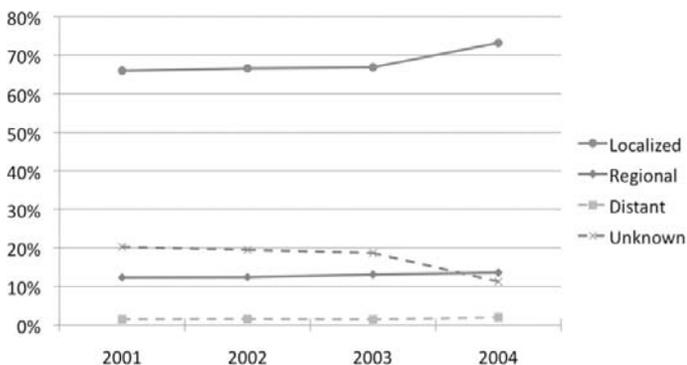


**Figure 2. Stage distribution by year of diagnosis (thyroid).**



The third group included cancers of the brain, breast, corpus/uterus, esophagus, liver, prostate, soft tissue including heart, and testis. For these 8 cancer sites, the differences in stage distributions between 2003 and 2004 were attributable to decreases in percentages of unknown stage cases from 2003 to 2004 alone or in combination with the 2001–2004 temporal linear trends of stage distribution (see an example in Figure 3).

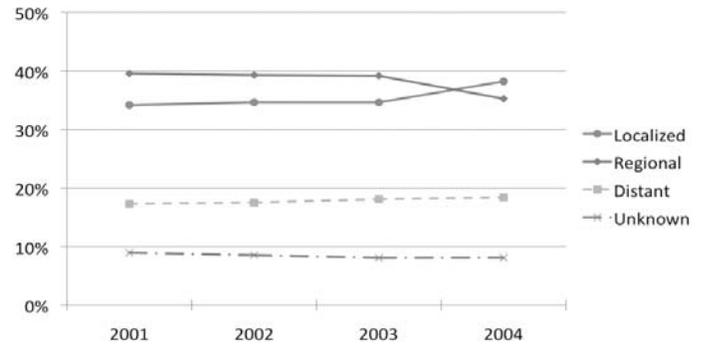
**Figure 3. Stage distribution by year of diagnosis (brain).**



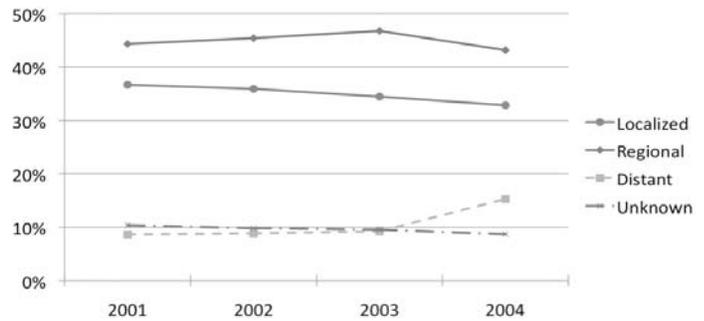
For cancers of the bladder, cervix, colon, kidney, larynx, lung, melanoma of the skin, oral cavity/pharynx, ovary, rectum, and vulva, linear trends in stage distributions were identified, but the differences in stage distribution between

2003 and 2004 could not be explained by the trends, decreases in percentage of unknown stage, or both (Figures 4 and 5).

**Figure 4. Stage distribution by year of diagnosis (colon).**



**Figure 5. Stage distribution by year of diagnosis (oral cavity and pharynx).**



For Hodgkin lymphoma and cancers of the anus, anal canal and anorectum, cranial nerves and other nervous system, eye and orbit, gallbladder, small intestine, and vagina, there were no linear trends in stage distributions from 2001 through 2004.

*Comparison of the Coding Instructions in SS2000 and the CS-Derived SS2000*

Cancer sites were grouped into 5 categories based on the findings from comparisons of the SS2000 and CS staging manuals (Table 1). CS introduced differences in coding definitions of direct extension and/or lymph node involvement for all sites except cancers of the breast, cervix, and cranial nerves and other nervous system.

The major difference in the coding instructions was the addition of anatomic sites or subsites in the CS manual to define direct extension and/or lymph node involvement. For example, direct extension to the non-peritonealized pericolic tissues is used to define localized stage of colon cancer in the CS manual but is not included in the SS2000 manual. Circulating cells in the nasal cavity, nasopharynx, or posterior pharynx are distant disease for brain tumor in the CS manual but are not listed in the SS2000 manual.

In some cases, extension to certain anatomical sites changed the stage decision in Collaborative Staging. For example, nasopharynx cancer with lymph node extension to the posterior cervical (spinal accessory) is a regional disease in the SS2000 manual but distant in the CS manual. Similarly, cancer of the tonsil/oropharyngeal with direct extension to the retropharynx is a regional disease in the SS2000 manual but distant in the CS manual. Gallbladder cancer with direct extension to colon or stomach is a distant disease in the SS2000 manual but regional in the CS manual. Vulvar cancer with direct extension to the bladder mucosa, upper urethral mucosa, or fixed to the pubic bone is a distant disease in the SS2000 manual but regional in the

CS manual. Vulvar cancer with microscopic/macroscopic peritoneal implants beyond the pelvis, including on the liver, is a regional disease in the SS2000 but distant in the CS manual. Thyroid cancer with direct extension to the submandibular (submaxillary), submental, or mandibular is a distant disease in the SS2000 manual but regional in the CS manual.

## Discussion

Significant differences in stage distribution between 2003 and 2004 were observed for 30 out of the 34 cancer sites in this study. For 4 cancer sites, the differences were attributable to 2001–2004 linear trends of stage distribution. For 8 cancer sites, the differences were attributable to decreases in percentage of unknown stage cases alone or in combination with the temporal trends of stage distribution. For the remaining 18 cancer sites, either (1) no linear, temporal trends for stage distribution were identified or (2) the combination of the decline in cases with unknown stage plus linear trends did not explain the stage differences between 2003 and 2004.

By comparing the SS2000 and CS manuals, we found that the CS coding definitions are more detailed in listing anatomic structures for either direct extension and/or lymph node involvement than those in the SS2000 manual. We believe that the clearer guidelines in the CS manual make it easier for tumor registrars to make uniform coding decisions, but we were uncertain exactly how changes in coding definitions affected stage distributions. As noted above, for thyroid cancer, we found a switch from distant stage in the SS2000 manual to regional in the CS manual. But its impact on stage distribution between 2003 and 2004 was too small to be observed. The likelihood ratio test showed that the differences in stage distribution between 2003 and 2004 for thyroid cancer were consistent with 2001–2004 linear trends. Although changes in coding definitions from the SS2000 to the CS occurred for the majority cancer sites, not all these changes showed significant impact on stage distributions.

Nevertheless, when changes in coding definitions from the SS2000 to CS were consistent with variations in stage distribution between 2003 and 2004 cases, it is legitimate to speculate that the changes indeed affected stage coding. For example, colon cancers with the direct extension to the nonperitonealized pericolic tissues are coded as localized disease in the CS manual. In the SS2000 manual, however, the pericolic tissues are not used to define direct extension and colon cancers with direct extension to these tissues could have been coded to localized, regional or unknown stage. The sudden increase in percentage of the localized colon cancer cases and the decrease in the regional cases from 2003 to 2004 support this speculation.

The observed differences in stage distributions between 2003 and 2004 cases in this study are consistent with those reported by the New York Cancer Registry, except for changes in percentage of unknown stage cases.<sup>8</sup> The New York report was based on 2004–2006 data on breast, cervical, colorectal, prostate, and oral cavity and pharynx cancer cases, which were coded with both SS2000 and CS systems simultaneously. It is not clear why the New York data did not show decreases in percentage of unknown stage cases from SS2000 to CSdSS2000.

Several limitations of this study should be noted. First, because of the absence of double-coded stage data using both the SS2000 and CS manuals, we were not able to assess agreement rates of the 2 staging systems with Kappa statistic method. Second, the impact of changes in coding definitions of direct extension and/or lymph node involvement on stage

distributions could not be quantified. Third, not all changes in stage distribution from 2003 to 2004 could be explained. Some may be attributable to coding errors. Fourth, although numerous variations in stage distribution between 2003 and 2004 cases are statistically significant, some may not have significant meaning in practice. Fifth, we only compared SS2000 manual with the Version One of the CS manual; the latter was used for 2004 cases. Some mapping issues may have been corrected in the Version Two of the CS manual. For example, thyroid cancer with direct extension to the submandibular (submaxillary), submental, or mandibular is a distant disease in the SS2000 manual but regional in the CS manual, Version One. In the CS manual, Version Two, these cases of thyroid cancer are considered distant disease, which is consistent with the SS2000 manual.

Because changes in coding instructions for staging cancer cases may confound real changes in stage distribution over time, researchers must evaluate impacts of stage revisions on their findings when analyzing stage data that encompass both pre-CS and CS cases. Stage incomparability may need to be included in the limitation of reports.

In the future, revisions in staging system, whether for SEER Summary Stage or for AJCC TNM stage, may continue due to changes in clinical knowledge and practice such as diagnostic imaging and biopsy techniques as well as new tumor markers. Comparability issues should be considered prior to the implementation of new or revised coding systems. Double-coded stage data using the old and new or revised systems should be included as part of implementation process.

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# Impact of Automated Data Collection from Urology Offices: Improving Incidence and Treatment Reporting in Urologic Cancers

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**Abstract:** **Background:** Urologic cancers represent a substantial proportion of the total cancer burden, yet the true burden of these cancers is unknown due to gaps in current cancer surveillance systems. Prostate and bladder cancers in particular may be underreported due to increased availability of outpatient care. Thus, there is a critical need to develop systems to completely and accurately capture longitudinal data to understand the true patterns of care and outcomes for these cancers. **Methods:** We determined the accuracy and impact of automated software to capture and process billing data to supplement reporting of cancers diagnosed and treated in a large community urology practice. From these data, we estimated numbers of unreported cancers for an actively reporting and for a non-reporting practice and the associated impact for a central cancer registry. **Results:** The software automatically processed billing data representing 26,133 visits for 15,495 patients in the 3.5-month study period. Of these, 2,275 patients had a cancer diagnosis and 87.2% of these matched with a central registry case. The estimated annual number of prostate and bladder cancers remaining unreported from this practice was 158. If the practice were not actively reporting, the unreported cases were estimated at 1,111, representing an increase of 12% to the registry. Treatments added from billing varied by treatment type with the largest proportion of added treatments for biologic response modifiers (BRMs) (127%–166%) and chemotherapy (22%). **Conclusion:** Automated processing of billing data from community urology practices offers an opportunity to enhance capture of missing prostate and bladder cancer surveillance data with minimal effort to a urology practice. **Impact:** Broader implementation of automated reporting could have a major impact nationally considering the more than 12,000 practicing urologists listed as members of the American Urological Association.

**Key words:** cancer surveillance, prostate cancer, bladder cancer, automation

## Background

Urologic cancers represent a substantial proportion of the morbidity burden of cancer. The largest proportions of urologic cancers are prostate and bladder, with 263,260 incident cases in 2009 in the US.<sup>1</sup> The economic burden associated with these 2 cancers is high, estimated at up to \$8 billion annually.<sup>2-7</sup> Prostate and bladder cancers also represent a substantial mortality burden, with prostate cancer anticipated to account for more than 27,000 deaths and bladder cancer, an additional 14,000 deaths per year in the US.<sup>1</sup>

Current surveillance information on cancer is based primarily on hospital reporting. Therefore, as the diagnosis and treatment of cancer moves to outpatient-based specialty clinics, capturing information on the incidence, treatment and outcomes becomes increasingly difficult. Unlike many other cancers, where there is likely to be an inpatient

admission resulting in reporting from a hospital cancer registry, the diagnosis and treatment of prostate and bladder cancer often occur only in the outpatient setting. The trend for community urology practices to increasingly provide comprehensive services, including radiation, chemotherapy and surgical pathology services, further reduces the likelihood of complete reporting.

Additional challenges in the collection of surveillance information on these 2 urologic cancers are related to the lack of consensus regarding optimal treatment.<sup>9-23</sup> For example, the optimal use of active surveillance (watchful waiting) for prostate cancer remains an issue, with reduced life expectancy for patients undergoing active surveillance based on observational studies using SEER (Surveillance, Epidemiology and End Results Program) data.<sup>24</sup> However, the underreporting of systemic therapy from these data may result in potentially inaccurate measures of the true survival

*"Impact of Automated Data Collection from Urology Offices: Improving Incidence and Treatment Reporting in Urologic Cancers"*

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IRB and HIPAA compliance: Institutional Review Board approval was obtained under a waiver of informed consent from the Virginia Department of Health and from Virginia Commonwealth University. A HIPAA waiver of informed consent was obtained from the VCU HIPAA privacy office. A determination that this research was exempt from IRB approval was obtained from the New Jersey Department of Health and Senior Services.

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benefit of treatment over active surveillance.<sup>24-37</sup> Similarly, the high risk of recurrence and second primary for bladder cancer requires significant amounts of outpatient surveillance and follow-up.<sup>10,15,28</sup> Yet, the information needed to determine optimal treatment and follow-up are largely lacking. These examples demonstrate the critical need to develop systems to completely and accurately capture longitudinal data on both these cancers. Without complete data on treatment and associated outcomes, understanding differences in outcomes as they relate to differing patterns of care is impossible.<sup>29-31</sup>

This manuscript presents the results of a study evaluating automated surveillance software for use in community urology practices. The software automatically screens and processes standardized electronic billing data and reports urologic cancers and their treatment to the central cancer registry.

## Methods

The purpose of the project was to determine the accuracy and impact of automated capture and processing of billing data to supplement reporting of cancers diagnosed and treated in a community urology practice.

### *Automated Software*

The software uses submitted billing data in a standardized format (HIPAA 837 Professional). The billing uses codified data elements that represent diagnosis (ICD-9 codes) and detailed information on treatment (HCPCS: Healthcare Common Procedure Coding System). The latter have been demonstrated to have high validity, sensitivity, and specificity.<sup>32-39</sup> The software screens the billing data for cancer diagnoses and treatments. From these data, it creates and populates a Microsoft SQL Server database and tables specific to demographics, diagnosis (including probable dates of diagnosis based on first occurrence in billing), comorbidity, and specific treatment tables for each of the categories of treatment, including surgery, chemotherapy, radiation therapy, hormonal therapy, and biologic response modifiers (BRMs) or immunotherapy. The software then combines data from the tables to automatically generate a North American Association of Central Cancer Registries (NAACCR) record to send to the central cancer registry on a scheduled interval.

### *Description of the Participating Urology Practice*

The participating urology practice was a large and independent general urologic practice with 35 urologists and 3 nurse practitioners in 13 locations. The practice has performed active case reporting to the central registry since October 2006.

### *Study Design*

We captured and processed all billing data for the 3.5-month period of May 1, 2008 to Aug 15, 2008. The data represented both incident and prevalent cancers as well as non-cancer diagnoses. This sample was used to estimate the number of cancers and treatment unreported to the central cancer registry. Certified tumor registrars performed a validation study on a sample of 200 prostate and bladder cancers (as the most commonly unreported cancers) to

verify diagnosis and treatment using the practice electronic medical record (see description of validation sample below). The results of the validation study were used to calculate estimates of missed cancers from reporting and non-reporting urology practices.

### *Case Definition*

We counted even a single occurrence on billing of a particular ICD-9 code as a case whether or not treatment was included for that patient. This sensitive definition was used to optimize the validation space by capturing the maximum number of cases and treatments identified for this pilot study.

### *Match with the Central Cancer Registry*

The urology billing data were matched by personnel at the New Jersey State Cancer Registry (NJSCR) against all years of registry data and the pathology report datatore (electronic pathology reporting system). Cases were matched initially on combinations of name, date of birth, gender, and address using a routine probabilistic match algorithm—AutoMatch Record Linkage software, Version 4.1.<sup>40</sup> Patients with a billing-reported cancer also identified as having a registry-reported cancer were then matched on cancer site using the 2-digit ICD-O Topography cancer site code to maximize the match rate. Treatment data in the registry were compared with the treatment data captured from the billing data for matched patients based on FORDS (Facility Oncology Registry Data Standards), the generic treatment reporting system used by cancer registries. The data for cases that were not matched to the NJSCR were used, along with validation information, to provide an estimate of the number of unreported cancer cases.

### *Validation*

In order to determine the accuracy of billing-reported cancers, we performed a validation study focusing on bladder and prostate cancer patients as these represented the most commonly reported urologic cancers. For each of the 2 cancer sites, a sample of 100 cancers was randomly selected, stratified by whether the billing data indicated treatment (yes/no) and whether there had been a bill for an inpatient hospitalization (yes/no). Validation was performed by certified cancer registrars who independently abstracted information from the practice electronic health record (EHR) to confirm the date of diagnosis, diagnosis, and accuracy of billing-reported treatment. In addition, they recorded any inpatient hospitalizations indicated in the EHR. The latter served as an indicator of whether that patient was likely to be reported to the central registry, as we assumed if the EHR indicated an inpatient hospitalization, the patient would be reported from that facility. This was used for subsequent estimates of missed cancers from non-reporting practices. Date of diagnosis from the validation sample was used in estimating the incidence rate and in determining follow-up information available for prevalent cancers.

### *Analysis*

Estimating unreported cases. The validation data were utilized to adjust our estimate of missed or unreported

cases to account for false positive cases. Using the results from the validation sample, we “corrected” the number of unmatched cases to estimate the under reporting of prostate and bladder cancers to the central registry. From the corrected numbers, we estimated the potential added value in automated capture of unreported cases.

We estimated the number of potential missing cancer cases as follows: The number of cases reported on billing was adjusted by the false positive (FP) rate reported from the validation sample for each cancer site. We subtracted the number of cases already reported to the registry to obtain the total number of cases added by the billing data. Because the data are cross sectional, we also used the information on diagnosis date from the validation sample to adjust for prevalent disease to arrive at the number of incident cases identified by billing in the 3.5-month billing period (May 1, 2008–August 15, 2008). This was done by multiplying by the percent of incident cases for prostate and bladder cancer from the validation study (defined as cases with a diagnosis date after November 1, 2007). Additionally, to estimate an annualized number based on the 3.5 months, we multiplied the result by 12/3.5.

$$\{ \# \text{ billing cases} * (1 - \text{FPR}) - \# \text{ reported to registry} \} * \% \text{ incident} * 12/3.5$$

Because the participating practice was performing active case reporting, we also estimated the number of potential missing cases for a similarly sized non-reporting practice, as this may have a substantially greater impact on unreported numbers of urologic cancers. The principal difference in the calculation is that we removed any cases that had the opportunity to be reported from a hospital registry based on an inpatient admission to that hospital. The inpatient admission rate was derived from data captured independently from the practice EHR for the validation sample. For this calculation, we assumed (conservatively) that all cancers with an inpatient admission would be reported from that

facility. Thus, our new estimate would be  $\{ \# \text{ billing cases} * (1 - \text{FPR}) - \# \text{ reported to registry} * \text{hospitalization rate} \} * \% \text{ incident} * 12/3.5$

**Estimating unreported treatments.** We were interested in estimating the ability of billing data to augment both initial treatment as well as ongoing treatment and treatment of recurrences. For this analysis, we defined 3 cohorts of patients from the registry-matched sample based on date of diagnosis in the registry. As patients may still be undergoing active therapy during the 6 months after diagnosis, we defined the initial treatment cohort as billing-identified cases matched to NJSCR cases with a registry diagnosis date on or after November 1, 2007. For the cohort of patients diagnosed between January 1, 2007 and October 31, 2007, we could not be sure whether the treatment was initial course of therapy or treatment of recurrent disease or of a second primary (for bladder). We therefore evaluated these cases separately as the “possible initial treatment” cohort. We also presented data separately for the third treatment cohort defined as treatment reported in patients diagnosed prior to January 1, 2007. Treatment in these patients was considered indicative of possible recurrence or second, concordant primary (“subsequent treatment” cohort).

## Results

### Automated Processing of Billing

The automated software captured and processed 26,133 visits for 15,495 patients in the 3.5-month study period representing an average of 7,466 visits per month. Of these, 14.7% of patients (N=2,275) had a diagnosis of cancer. (Table 1)

The distribution of cancers identified through the billing data is provided in Table 1. The 2,275 unique patients represented 2,360 distinct cancer diagnoses from billing during the study interval. The 3 most common cancers were prostate (67.2%), bladder (20.7%) and kidney (8.3% – data

**Table 1. Distribution of urology patients by cancer site and treatment category in 3.5 months of billing data from a general urology practice.**

Two Digit ICD-O Code	Cancer Site or Grouping	#Cancers Identified from Billing by Site	Percent Distribution by Cancer Site	#Cancers Matched to the NJSCR	Percent Matched	Number Patients with Chemo Rx	Number Patients with Hormonal Rx	Number Patients with Immune Rx (BRM)	Number Patients with Radiation Rx	Number Patients with Surgery
61	Prostate	1587	67.20%	1425	89.8	0	288	0	35	69
67	Bladder	489	20.70%	419	85.7	14	0	81	0	128
60, 62, 64–66, 68	Other urologic cancers	269	11.40%	201	75.6	2	0	0	0	22
18–20, 26, 54, 56, 74	Other Solid Tumors	15	0.60%	11	73.3	0	0	0	0	0
<b>Total</b>	<b>All Cancers</b>	2360		2056	87.2	16	288	81	35	219

not shown). Because of the higher likelihood of underreporting, we focused on prostate and bladder for subsequent analyses. Other urologic cancers represented 11.4% of the cancers identified from billing and other solid tumors representing 0.6% of cases. The non-urologic cancers identified from the billing data included ovary, colon and rectum, uterus, and other endocrine cancers.

Table 1 also provides the distribution of patients who received chemotherapy, hormonal therapy, radiation, and surgery by cancer site. The automated capture of billing data identified 623 patients receiving 1,256 treatments for the 2,345 urologic cancer cases identified during the study interval.

### Matching with the Central Cancer Registry

**Matched cases.** The overall match rate with the NJSCR by patient and 2-digit ICD-O code was 87.2%. The match rate by cancer site/group is provided in Table 1.

<b>Table 2. Percent added treatment from billing by diagnosis date and treatment cohort for prostate and bladder cancers.</b>			
<i>“Initial Rx” Cohort diagnosed &gt; Nov 1, 2007 (N=338)</i>			
Treatment Category	Rx Reported to NJSCR	Billing Added Rx	% added by billing
Hormonal therapy	45	10	22.2
Chemotherapy	20	2	10.0
Biologic Response Modifier (BRM)	11	18	163.6
Radiation	94	1	1.1
Surgery	209	6	2.9
<i>“Possible Initial Rx” Cohort diagnosed Jan 1–Oct 31, 2007 (N=308)</i>			
Treatment Category	Rx Reported to NJSCR	Billing Added Rx	% added by billing
Hormonal therapy	44	10	22.7
Chemotherapy	7	2	28.6
Biologic Response Modifier (BRM)	11	14	127.3
Radiation	106	0	0.0
Surgery	195	0	0.0

**Matched treatment.** Because a cancer case may be reported to the registry without complete treatment information, we examined the treatment added from billing according to reporting (match) status to the central registry as initial, possible initial, or subsequent treatment. The top portion of Table 2 provides the number of unreported treatments for the 338 prostate and bladder cases in the “initial treatment” cohort. These treatments are likely to represent missed initial course of therapy. The percent of added treatment by category ranges from 1% for radiation to 163.6% for BRM. For the 308 patients diagnosed between January 1, 2007 and October 31 2007 (“possible initial treatment” cohort), the proportion of cases for whom additional treatment was added through the billing data ranged from none for radiation and surgery to 127.3% added information

for BRM therapy. For the “subsequent treatment” cohort of patients with a registry diagnosis date before January 1, 2007, and for whom the registry had no subsequent treatment information (data not shown), 177 of 947 (19%) prostate patients and 57 of 223 (26%) bladder cancer patients had billing reported treatment likely indicating either treatment of recurrence or of a second, concordant primary cancers.

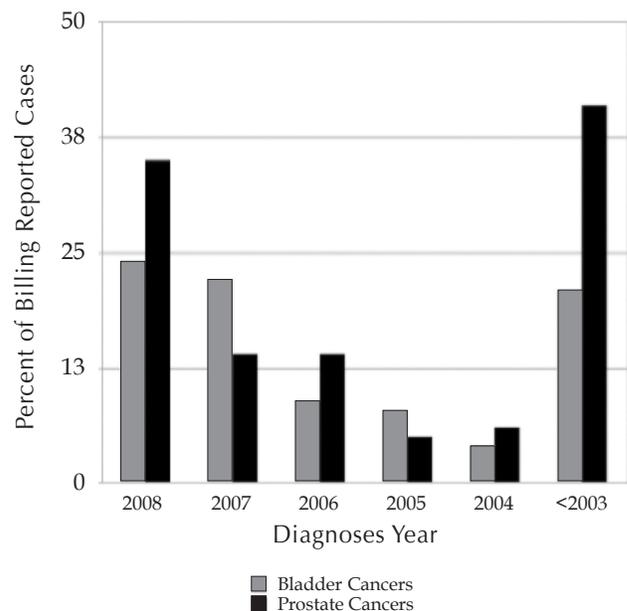
### Validation Study Results

We validated 196 of the 200 patients selected for the validation sample who had 107 bladder cancers and 105 prostate cancers. These represented 6.6% of prostate cancers and 20.9% of bladder cancers captured from the 3.5 months of billing data. There were 10 cases in which the medical record validation did not confirm the billing diagnosis (9 bladder and 1 prostate). Of the FPs, 8 were noncancers and 2 were cancers with incorrect cancer site. Both cases with incorrect site (adenocarcinoma of unknown origin and renal cell) were reported on billing as bladder cancers. Of the 7 remaining non-cancer FPs for bladder cancer, 5 had chronic bladder inflammation, 1 had amyloidosis, and an additional tumor was a transitional cell neoplasm of low malignant potential, thus not reportable. Overall, these 9 cases represented a FP rate of 8.6% for bladder cancer. There was a single false positive for prostate cancer: a “High Grade Prostatic Intraepithelial Neoplasia,” representing a FP rate for prostate cancer of <1% (0.9%).

Among validated cases, the proportion of “incident” cases based on the practice EMR was 33% for bladder and 23% for prostate (see Table 3).

The validation of 152 treatments for the 196 patients in the validation sample resulted in an accuracy rate of 99.3%. The 1 FP was a single occurrence of hormonal therapy for a prostate cancer patient not identified in the medical record as received during the study period.

**Figure 1. Frequency distribution(%) of prostate and bladder cancers by diagnosis year among validate**



### Using Automated Data Capture for Follow-up Reporting

There were 1,297 patients matched with the central registry and diagnosed prior to January 1, 2007. We defined these as prevalent cancers. Few (<2%), had recurrence or other follow-up information indicated in the central registry. We used the distribution of diagnosis year for the validation cases as shown in Figure 1 to represent the distribution of prevalent cases for whom billing data might provide automated follow-up information. Thus, follow-up was automatically provided by billing information on the 67% of bladder cancers and 76% of prostate cancer patients for whom registries often have limited follow-up information, including those diagnosed more than 5 years prior to the study interval.

### Estimating the Potential Impact From Automated Reporting in Urology Practices

In order to estimate the potential impact of ongoing automated reporting, we calculated the annual number of potential missed prostate and bladder cases from this practice. A summary of the numbers used for calculating these estimates and the estimated unreported case numbers are provided in Table 3.

Table 3. Estimating number of potential missed prostate and bladder cancer cases in a reporting and non-reporting urology practice.		
Validation Study		
	Bladder	Prostate
False Positive Rate	8.6%	0.9%
% Incidence	33%	23%
% No Inpatient Admission	48.5%	65.1%
Annual Number of Potential Missed Cases		
	Bladder	Prostate
Reporting Practice	41	117
Non-reporting Practice	264	847
# cases per non-reporting urologist	8	24

We identified 1,587 prostate cancers during the 3.5-month study interval, which, after adjusting for FP rates, incidence and the reporting period would result in an additional 117 unreported incident prostate cases added from billing at this practice annually. The number was calculated as follows:

$$([1587 * 0.99] - 1425) * 0.23 * (12 / 3.5) = 117$$

Similarly, for bladder we estimate that 41 additional incident cases would be reported annually.

$$([498 * 0.914] - 419) * 0.33 * (12 / 3.5) = 41$$

Using this conservative adjustment factor, information would be provided on a minimum of 158 missed incident cases per year for prostate and bladder from a practice that is actively reporting.

While substantial, the potential benefit of using claims data for capturing additional cancers calculated above underestimates the benefit from non-reporting practices.

Therefore, we estimated the number of missed cancers for a similarly sized non-reporting practice. We used the proportion of patients from the validation sample with a hospital admission (65.1% of prostate and 48.5% of bladder cancer patients) to adjust for cases likely reported from a hospital registry. As described in the analysis section, and shown in summary in Table 3, we estimated the number of potential prostate and bladder cancer cases that would be found through the billing from a non-reporting practice as

$$\text{Prostate: } ([1587 * 0.99] - [1425 * 0.349]) * 0.23 * 12 / 3.5 = 847$$

$$\text{Bladder: } ([489 * 0.914] - [419 * 0.515]) * 0.33 * 12 / 3.5 = 264$$

Thus, for a nonreporting practice the size of the study practice, automated processing of billing data might provide an additional 1,111 prostate and bladder cancers to a central cancer registry annually. Dividing by the number of urologists in the participating practice, an estimate of the number of annual cases that might be missed per non-reporting urologist are 8 bladder and 24 prostate cases.

## Discussion

Automated capture of cancer cases and their treatment from urology practice billing data provides an opportunity to efficiently report critical missing data on urologic cancers likely to be unreported to a central cancer registry. Automated processing of billing also has the potential to supplement cancer treatment and follow-up for which data may be incomplete. In this study, we found that nearly 13% of cancers were not reported to the cancer registry, even with active reporting on the part of the practice. Thus, using billing data to supplement case identification/reporting and treatment reporting demonstrated a substantial impact on the numbers of cancers and treatments with high accuracy. The cancers captured through billing represent both incident and prevalent cases in this cross-sectional study. However, once established as an ongoing reporting tool, the capture of incident cases and associated subsequent treatment will be a higher proportion of reported information, as newly diagnosed cases would be identified with the initial visit to the practice.

The overall impact of implementing automated processing of billing data could be substantial as described above. Even from the single large practice in this study, additional cancers captured through billing would represent a nearly 2% increase in the numbers of prostate and bladder cancers that could be reported annually to the NJSCR (158 / [1822 bladder + 7363 prostate cancers]).<sup>41</sup> Data collection from urology practices that don't report cases to a registry would likely provide a much higher yield. Again, using the study practice as an example, a similarly sized nonreporting practice could represent an additional 12% of prostate and bladder cancer cases reported annually to the NJSCR.

The potential impact could be significant nationally. The American Urological Association has approximately 12,000 members practicing in the US, with 27% of members specializing in oncology and 61% in general urology practices. Of the latter, nearly all provide some cancer treatment including brachytherapy as well as other treatment for cancer patients.<sup>42-43</sup> Focusing on urology practices for automated capture of cancer surveillance information may

significantly enhance both incident case and treatment reporting of urologic cancers. If each of these 12,000 urologists had even the 12% underreporting rate estimated from the general urology practice participating in this study, this could represent as many as 4.5 bladder and prostate cancer cases per year per urologist or up to 54,000 additional cancers annually.

### Treatment Reporting

Treatment captured through automated reporting of billing data may be otherwise missed because they are provided at the physician's office. In particular, immunotherapy (BRM) representing 46.4% of the treatments for bladder cancers and hormonal therapy representing 22.6% of the treatments for prostate cancers were the 2 categories of therapy that were most likely to be unreported. The capture of these data would provide an important component to understanding patterns of care and providing the ability to perform comparative effectiveness of treatments for these common cancers.

### Automated Follow-up

The utility of the billing data to provide follow-up status on a large percentage of patients with urologic cancers is another important benefit. Based on the distribution of diagnosis year for the validation sample, the ongoing automated data collection is likely to provide longitudinal follow-up information while requiring minimal effort from urology staff or central registries. The addition of follow-up information would permit registries to calculate time to recurrence and provide information on treatment of recurrence. Both represent critical information gaps in our understanding of outcomes in urologic cancer survivors. Automatically collecting this information through billing may represent a cost-efficient mechanism to complete a significant component of that information gap.

### Limitations

Because we chose to use the most sensitive definition of a cancer case—using any mention of a diagnosis code for cancer as a “cancer”—the FP rate in this pilot was higher than optimal. Simple modifications of the algorithm requiring more than 1 diagnosis over time or requiring an associated cancer-specific therapy could decrease the sensitivity in the short term. Ongoing longitudinal data collection is likely to minimize this decrease in sensitivity. Further evaluation of the ability of these data to distinguish second primary from recurrent disease needs to be performed.

### Conclusion

Focusing on urology practices for automated capture of cancer surveillance information may provide significant enhancement to both incident reporting and treatment reporting of urologic cancers. Further study will be required to assess the potential impact on reporting through implementation of automated reporting on a larger scale or in other geographic locations.

The increased completeness of data captured through automated reporting is likely to reduce bias in reporting and provide a more complete picture of the patterns of care and outcomes associated with these 2 important cancers, while simultaneously reducing the burden on practices to report these cases and follow up to the central cancer registries.

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# Towards the Use of a Census Tract Poverty Indicator Variable in Cancer Surveillance

Francis P. Boscoe, PhD<sup>a</sup>

**Abstract:** Incidence rates for many cancer sites are strongly correlated with area measures of socioeconomic conditions such as poverty rate. Analyzing such measures at the county scale produces misleading results by masking enormous within-county variations. The census tract is a more suitable scale for assessing the relationship between cancer and socioeconomics. The North American Association of Central Cancer Registries (NAACCR) developed a census tract-level poverty indicator variable which was included as an optional item in its 2010 Call for Data. This variable does not allow the identification of individual census tracts as long as the county of diagnosis is not known. It is expected that this data item will be made available to researchers in future releases of the CINA Deluxe file.

**Key words:** call for data, census tract, disclosure risk, poverty

## Introduction

The North American Association of Central Cancer Registries (NAACCR) included an optional census tract-level poverty indicator variable in its 2010 Call for Data. The purpose of this data item is to provide a measure of local socioeconomic conditions for each cancer case that can be made available to researchers. The socioeconomic environment directly influences cancer rates and can confound other etiologic studies of cancer. This relationship has been well established, though attention has largely been limited to the more common sites of cancer. The monograph by Singh et al,<sup>1</sup> for example, was limited to all cancers combined and 6 individual cancer sites (lung, colorectal, prostate, female breast, cervical, and melanoma). As the relationship between socioeconomic status and cancer is dynamic and can vary by geographic location, it requires ongoing surveillance and study-specific measurement. Lung cancer, for example, was historically associated with higher socioeconomic status but since the 1980s has been associated with lower socioeconomic status,<sup>2</sup> but this relationship varies by race, ethnicity, and geography.

Most cancer epidemiology studies avail themselves of county-level measures of socioeconomic status, as these are relatively easily obtained.<sup>3-5</sup> While well-intentioned, the coarseness of this scale can result in biased findings. One only need consider any large urban county to see the problems inherent in using a county-level variable—assigning identical codes to each of the millions of people living in each of the hundreds or thousands of neighborhoods in Los Angeles County, Manhattan, or Miami-Dade County is obviously flawed. In general, using large and heterogeneous geographic areas for analysis obscures important relationships, sometimes even to the point of reversing the apparent direction of association.<sup>6</sup>

Census tracts, in contrast, are a useful scale at which to identify social gradients in health.<sup>7-10</sup> A census tract is formally defined as a small, relatively permanent statistical

subdivision of a county with an optimum size of 4000 people and designed to be relatively homogeneous with respect to population characteristics, economic status, and living conditions.<sup>11</sup> In urban settings, it roughly equates to a neighborhood. As an ecologic unit, census tracts still pose potential inferential problems, but their size and homogeneity make these issues far more manageable.

There are many ways of measuring socioeconomic status, including measures of poverty, education, income, substandard housing, or indexes that combine multiple variables. Of these, poverty rate has been found to be singularly effective, both for its simplicity and ability to capture variations in the health of populations.<sup>1,12</sup> A tract-level poverty rate is properly viewed not as a proxy for an individual's poverty status, but rather as a useful measure of environmental context.

The NAACCR poverty indicator variable assigns each cancer case to 1 of 5 poverty rate categories: less than 5%, 5% to less than 10%, 10% to less than 20%, 20% and above, and undefined. (The latter category applies to rare instances of census tracts with populations but no sampled households, as in some university campuses or prisons, or census tracts with no population at the time of the decennial census but with residents before or after, as with large urban renewal projects. Because this category adds no useful information about local socioeconomic conditions, it would be omitted from any data file made available by NAACCR to researchers.) A SAS program available on the NAACCR Web site allows registrars to assign this code to their own cases.<sup>13</sup> This data element can thus be derived and transmitted without the need to also transmit census tract, which is of concern to some state cancer registries because of potential disclosure risk.

This paper describes how this variable will be useful to researchers and demonstrates how it does not present a disclosure risk, so long as the county of diagnosis is not made available simultaneously.

*"Towards the Use of a Census Tract Poverty Indicator Variable in Cancer Surveillance"*

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## Methods and Materials

There were 2 methodological objectives: first, to illustrate how the census tract poverty rate indicator variable highlights substantial differences in cancer risk by cancer site, and second, to assess the potential for disclosure risk. To meet the first objective, the census tract poverty rate indicator variable was assigned to all cancer cases among white non-Hispanics diagnosed between 2003 and 2007 in New York State (n=382,285). White non-Hispanics were selected to minimize confounding by race and ethnicity. Census tracts were available for over 99% of the cases, with the remaining values imputed using a previously published method.<sup>14</sup> Age-adjusted rates standardized to the 2000 US population were calculated by site and poverty category for each site and site grouping listed in the SEER (Surveillance, Epidemiology and End Results Program) ICD-O3 Site Recode table.<sup>15</sup> The rate ratio of living in the highest-poverty category (poverty rate of 20% or higher) to the lowest-poverty category (less than 5%) was calculated for each site. The process was then repeated at the county level. As New York only has a single county with a poverty rate below 5% (Putnam), the cut point for the lowest-poverty category was relaxed to 6% to allow the inclusion of 3 additional counties (Nassau, Suffolk, and Saratoga). There were 3 counties above 20% poverty (Bronx, Brooklyn, and Manhattan).

The potential for disclosure risk was measured by cross-tabulating states (including the District of Columbia), counties, census tracts, and their associated poverty indicator values to determine the number of instances where the census tract of an individual case could be identified. This is well-illustrated through the example of St. Lawrence County, New York, a sparsely populated rural county bordering Canada. St. Lawrence County contains 1 tract with a poverty rate below 5%, 1 that is between 5 and 10%, 1 that is undefined because of an absence of households, and 25 others with poverty rates over 10%. The combination of county and poverty rate can thus potentially identify 3 distinct census tracts, 2 of which would potentially be available to researchers.

## Results

Table 1 lists age-adjusted incidence rate ratios and 95% confidence intervals between the highest-poverty and lowest-poverty census tracts for non-Hispanic whites for numerous cancer sites. The table includes all of the most common cancer sites along with several selected subsites and rare sites with unusually high or low values, listed in order by SEER ICD-O3 Site Recode. The table reveals that the number of sites and subsites elevated among residents of the highest-poverty census tracts is twice that of the lowest-poverty census tracts. This is counterbalanced by the fact that several of the most common sites (specifically, prostate, female breast, and melanoma) have higher rates among residents of the lowest-poverty census tracts. For all cancers combined, rates are just 4% higher among residents of the highest-poverty census tracts. When these tract-level results are compared with county-level results, major differences are evident among several the most common sites (Table 2).

**Table 1. Age-adjusted cancer incidence rate ratios for the most common cancer sites and other selected sites, highest-poverty census tracts to lowest-poverty census tracts, New York State, white non-Hispanics, 2003–2007.**

<i>Site</i>	<i>Rate Ratio (95% CI)</i>
All invasive malignant tumors	1.04 (1.02–1.05)
Oral cavity and pharynx	1.41 (1.29–1.52)
Oral cavity	1.20 (1.08–1.33)
Pharynx	1.89 (1.63–2.18)
Esophagus	1.19 (1.06–1.33)
Stomach	1.58 (1.45–1.72)
Colorectal	1.24 (1.19–1.28)
Anus, anal canal and anorectum	2.10 (1.73–2.51)
Liver and IBD	1.62 (1.46–1.80)
Pancreas	1.05 (0.98–1.13)
Larynx	1.77 (1.56–2.01)
Lung and bronchus	1.26 (1.22–1.30)
Melanoma of the skin	0.56 (0.52–0.61)
Female breast	0.90 (0.87–0.93)
Cervix uteri	1.79 (1.55–2.04)
Corpus uterus and NOS	1.17 (1.09–1.25)
Ovary	1.08 (0.98–1.19)
Vagina	1.64 (0.95–2.58)
Prostate	0.78 (0.76–0.81)
Testis	0.94 (0.80–1.08)
Penis	1.73 (1.01–2.65)
Urinary bladder	0.89 (0.84–0.94)
Kidney and renal pelvis	1.09 (1.02–1.16)
Ureter	0.74 (0.51–1.00)
Other urinary organs	0.51 (0.23–0.86)
Brain and other nervous system	1.06 (0.95–1.17)
Cranial nerves/other nervous system	1.55 (1.09–2.13)
Thyroid	0.88 (0.81–0.96)
Hodgkin lymphoma	1.06 (0.91–1.22)
Non-Hodgkin lymphomas	0.95 (0.89–1.00)
Multiple myeloma	1.04 (0.93–1.16)
Leukemia	1.04 (0.97–1.11)
Mesothelioma	0.75 (0.54–0.77)
Kaposi sarcoma	4.18 (2.99–5.88)
Miscellaneous	1.26 (1.19–1.33)

**Table 2. Age-adjusted cancer incidence rate ratios for selected sites, census-tract-derived versus county-derived, New York State, white non-Hispanics, 2003–2007.**

Site	Census tract-derived rate ratio (95% CI)	County-derived rate ratio (95% CI)
Oral cavity and pharynx	1.41 (1.29–1.52)	0.88 (0.81–0.95)
Colorectal	1.24 (1.19–1.28)	0.92 (0.89–0.95)
Lung and bronchus	1.26 (1.22–1.30)	0.79 (0.77–0.82)
Melanoma of the skin	0.56 (0.52–0.61)	0.84 (0.80–0.89)
Prostate	0.78 (0.76–0.81)	0.71 (0.69–0.74)

Specifically, the positive associations between poverty rate and oral, colorectal, and lung cancers are all reversed.

The disclosure-risk analysis reveals 1833 census tracts (2.8% of the nationwide total) that would be identifiable in combination with knowledge of county. This includes 205 census tracts which are coterminous with counties; if these are excluded, then the number is 1,628 (2.5%). Given that census tracts are roughly equal in population, this implies that the fraction of cancer cases with an identifiable census tract would also be around 2.5%. However, this subset of census tracts includes many with younger populations at lower risk for cancer, such as universities, Indian reservations, and military bases (2 of the unique tracts in St. Lawrence County describe university campuses). Thus, the total fraction of cancer cases impacted nationally is likely well below 2.5%; in New York State, it is under 0.3%. There are no census tracts that would be identifiable in combination with knowledge of state. Every state has at least 2 census tracts in each of the poverty rate categories.

### Discussion

Cancer sites with rates that are elevated among patients residing in census tracts with the highest poverty rates include many associated with smoking (head and neck, stomach, colorectal, liver, lung, female reproductive sites),<sup>16</sup> alcohol consumption (head and neck, colorectal, liver),<sup>17</sup> and sexually transmitted viruses (cervix, head and neck, anogenital, Kaposi's sarcoma).<sup>18</sup> However, not all such sites show statistically significant elevations or even elevations, as with bladder cancer, which is associated with smoking but also with independent occupational and lifestyle factors.<sup>19</sup> Sites that are elevated among residents of the lowest-poverty census are less easy to summarize in terms of shared risk factors, but tend to be characterized by extremely high relative survival, as with breast, thyroid, prostate, and melanoma,<sup>20</sup> suggesting a role of better access to health care for this group. The association between the

cranial nerves/other nervous system category and poverty has not been widely identified in the literature, if at all.

But rather than attempt to interpret each of these findings, the main point is simply to illustrate that there are strong associations between socioeconomic status and cancer that exist for many cancer sites, and these are often uncontrolled for or insufficiently controlled for in analyses. When analyzed at the county scale, these relationships can be highly distorted, even reversing the direction of association, as seen for several sites in Table 2. This is a direct consequence of the severe misclassification of poverty that occurs when areas as large and diverse as Manhattan and Brooklyn and the 2 counties comprising Long Island are each classified with a single poverty value. Manhattan, in particular, is counted in the highest-poverty category even though it includes neighborhoods among the wealthiest in the world.

The proposed mechanism for making this data available to researchers is through the CINA (Cancer in North America) Deluxe Analytic File.<sup>21</sup> This file consists of data from 1995 onward from registries which met specific quality standards for each year of data included. To gain access to this file, researchers must submit an application to NAACCR which goes through a review and approval process. Individual registries then grant access to their own data on a project-specific basis. Based on past experience, a large majority of eligible registries consent to most projects. In the case of the census tract poverty indicator, initial participation may be below average because of inadequate geocoding, but a recent analysis by Singh et al finds such states to be in the minority.<sup>22</sup> Geocoding has become dramatically easier and less expensive in recent years, and more and more states are geocoding their cases on a routine basis.<sup>23</sup>

Restricting the simultaneous availability of county and the census tract poverty indicator on this file will minimize disclosure risk by making it impossible to identify the exact census tract for any cancer case. While Howe et al have proposed an acceptable threshold up to 5% record uniqueness in public-use data files,<sup>24</sup> in practice there is little tolerance for any record uniqueness when small geographic units are involved.

Census tract poverty indicator values assigned to 2004–2008 cases will be based on poverty rates from the 2000 census, but in future years will be based on an exact temporal match. Beginning in the winter of 2010–2011, the US Census Bureau's American Community Survey will begin annual releases of poverty rates by census tract averaged over a 5-year period which will correspond with the most recent 5 years of cancer data. This means that analysis of 2005–2009 cancer data will make use of poverty rates for 2005–2009, and so on. This added temporal precision will make this data item even more useful.

In summary, the census tract poverty indicator variable being introduced in the NAACCR's 2010 Call for Data has the promise of becoming a standard item in the cancer epidemiologist's tool kit, promising a better understanding of the relationship between local socioeconomic conditions and cancer incidence and mortality. Moreover, it will permit better control of confounding in etiologic studies generally.

The application provided here using New York State data was intended as a quick and coarse demonstration of its utility. Future researchers will be able to enhance these results through the inclusion of additional registries, race and ethnic groups, confounding variables, and time periods.

### Acknowledgments

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# Economic Assessment of Central Cancer Registry Operations, Part III: Results from 5 Programs

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**Abstract:** In this article, we report results from the cost analysis of 5 central cancer registries funded by the National Program of Cancer Registries (NPCR). To estimate the true economic costs of operating a cancer registry, we used a cost-assessment tool (CAT) to collect data on all registry activities, not just those funded by the NPCR. Data were collected on actual, rather than budgeted, expenditures, including personnel, consultants, information technology (IT) support, and other factors influencing costs. Factors that can affect registry costs include the amount of consolidation from abstract to incident cases, the method of data reporting, the number of edits that must be performed manually versus electronically, and the amount of interstate data exchange required of a registry. Expenditures were allocated to specific surveillance and data enhancement and analysis activities. Our study confirmed that cost per case varies across registry activities. The cost of surveillance activities per case ranges from \$24.79 to \$95.78 while the cost of data enhancement and analysis registry activities per reported cancer case ranges from \$2.91 to \$9.32. Total cost per reported cancer case also varies, ranging from \$30 to slightly more than \$100, with a median of \$45.84. Further research using data from all NPCR-funded registries is required to assess reasons for this variation. Information gained from such an assessment will improve efficiency in registry operations and provide data to better quantify the funding requirements for expanding registry activities.

**Key words:** economics, cost, cancer registry

## Introduction

Cancer causes more deaths among the nonelderly than any other disease, and 1 in every 4 deaths in the United States is caused by cancer. In 2006, 1,370,095 people were diagnosed with invasive cancer in the United States, and 559,880 people died as a result of their cancers.<sup>1</sup> The burden of cancer is also economic: Direct health care expenditures and lost productivity were estimated at \$219 billion in 2007.<sup>2</sup>

In 1992, the Centers for Disease Control and Prevention (CDC) established the National Program of Cancer Registries (NPCR) to collect complete, timely, and accurate population-based cancer incidence data. Currently, NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the Pacific Island Jurisdictions. NPCR-funded cancer registries are required to collect and report information on all state residents diagnosed or treated with in situ or invasive cancer. The data provided by these NPCR-funded registries and by the registries funded by the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program provide national data to assess cancer trends, evaluate the impact of cancer prevention and control efforts, conduct research, and guide response to suspected increases in cancer occurrence.

During fiscal year 2009, NPCR received approximately \$46 million in a Congressional appropriation to help support cancer registries. Although NPCR has received Congressional funding since 1994, no comprehensive study of the economic costs incurred by the NPCR has been conducted. One previous study analyzed state variations

in average cost per case reported by NPCR registries using federal funding sources, but that study did not include other sources of funding.<sup>3</sup> Consequently, the true cost of operating cancer registries is unknown. One of the strategic priorities of NPCR is to collect cost data and conduct economic analysis and evaluation of the program. A comprehensive economic assessment of the costs and cost-effectiveness of the registry operations will provide both CDC and the registries with better tools to improve efficiency and make resource allocation decisions meeting program priorities.<sup>4</sup> CDC initiated an economic analysis in 2005 to estimate the costs of cancer registry operations, evaluate factors affecting costs, identify costs of surveillance and data enhancement and analysis activities, assess the registries' cost-effectiveness, and develop a resource allocation tool.

In Part I of the Economic Assessment of Cancer Registry Operations, we presented methods and a framework to guide the economic evaluation of central cancer registry operations.<sup>5</sup> We used both quantitative and qualitative information collected from central cancer registries funded by the NPCR to develop the framework. Several factors were identified that can influence the costs of registry operations: size of the geographic area served, quality of the hospital-based registries, setting of the registry, local cost of living, presence of rural areas, years in operation, volume of cases, complexity of out-of-state case ascertainment, extent of consolidation of records to cases, and types of data enhancement and analysis activities performed. In addition, we reported that both costs and cost-effectiveness of registries may be influenced by a range of factors at the state level and at each central cancer registry.

*"Economic Assessment of Central Cancer Registry Operations, Part III: Results from 5 Programs"*

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In Part II, we described the development and testing of the Cost Assessment Tool (CAT) that is being used to collect data from NPCR-funded cancer registries.<sup>6</sup> Incorporating findings from 4 site visits (these 4 central cancer registries were not included in the pilot data collection reported in this study) with well-established methods for collecting cost data for health care program evaluation, we developed a Microsoft Excel-based tool.<sup>7</sup> The CAT consisted of several modules designed to collect data to estimate costs for the program, rather than for a specific funder. To estimate the true economic costs of operating a central cancer registry, we collected data on in-kind contributions (both labor and non-labor) and on direct financial support. We found that most registries were able to provide detailed data needed to assign costs to specific activities performed by the registries. Registries faced challenges that included lack of continuity due to staff turnover and complicated structures of decentralized programs that require data collection from multiple entities.

The objective of the present study is to report on the analysis of the economic data collected from 5 NPCR-funded programs that were among those involved in pilot testing the CAT. These data provide preliminary information on the distribution and types of costs incurred by central cancer registries. Since this study only reports results from 5 selected registries, the generalizability of these findings will be assessed in the near future using cost data collected from all NPCR-funded registries as part of the ongoing comprehensive economic evaluation of the NPCR.

## Methods

The CAT includes questionnaires, definitions, and automated data checks based on well-established methods for collecting cost data for health care program evaluation.<sup>8</sup> The CAT was designed to collect information for all registry activities, not just those related to or funded by the NPCR. This comprehensive approach allowed us to measure the true costs associated with operating a registry.<sup>9</sup> The objective of the CAT is to collect activity-based cost data.<sup>10</sup> Data were collected for fiscal year 2005 (July 1, 2004 to June 30, 2005). The cost data reported here are from 5 registries from which we collected data during the pilot testing of the CAT. We have previously reported information on all registries involved in the pilot testing.<sup>6</sup> These pilot study registries were selected by using a systematic approach to ensure diversity of organizational structure, geographic location, and size and to be representative of NPCR-funded central cancer registries nationally. All 5 registries have been in operation for more than 10 years and therefore the focus of this study was to determine ongoing costs rather than start-up costs.

The information collected by the CAT consists of a set of standardized cost data elements developed to ensure the collection of consistent and complete information on annual expenditures; in-kind contributions; personnel activities and expenditures; consultant expenditures; costs associated with hardware, IT support, software, and other materials; administrative costs; and factors affecting costs and effectiveness. These data items are minimally necessary to evaluate the cost-effectiveness of the central cancer registries.

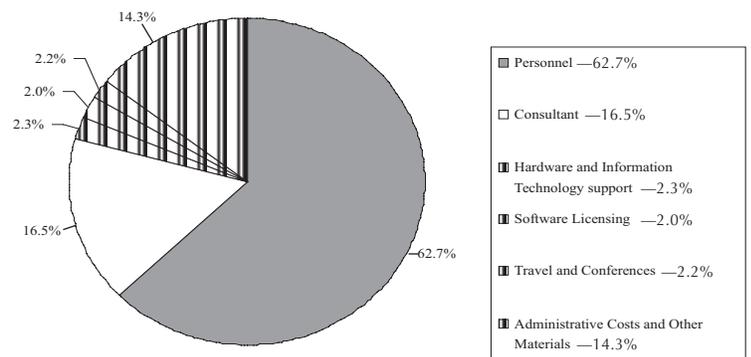
Registries were given a detailed user's guide that provided instructions and definitions for reporting the required data. In the CAT, registries reported resources spent and costs associated with each surveillance and data enhancement and analysis activity performed. Using this information, we allocated program costs to NPCR surveillance and data enhancement and analysis activities. Surveillance activities include management, training for registry staff, training provided by registry staff, IT support, data collection/abstraction, database management, case ascertainment, death certificate clearance, administration, quality assurance and improvement, developing analytic files, analyzing data/reports, electronic case reporting, sharing cases, automated case finding, and fulfillment of reporting requirements (listed as "CDC/NAACCR reporting requirements" in Figure 4) to CDC and North American Association Central Cancer Registries (NAACCR). Data enhancement and analysis activities include geocoding cancer case, linking with state/national data, implementing a cancer inquiry response system, research studies and advanced analysis using registry data, publication of research studies using registry data, and active follow-up.

Detailed assessment of these activity-based costs was performed, and summary statistics were generated for costs associated with each NPCR activity. We report the costs associated with surveillance activities and data enhancement and analysis activities separately. Total costs and costs for the individual surveillance activities and data enhancement and analysis activities, as applicable, are compared among the registries. We developed histograms to compare the distribution of costs across the activities for each registry. We also generated cost per case reported by dividing the total or activity-based costs by the total number of cancer cases reported. For values summarized across the 5 cancer registries, we report the median to take into account variation across the registries. Although fiscal year 2005 was used for costs, cancer cases diagnosed during 2003 were used to calculate cost per case reported to reflect the 2-year delay in processing and reporting cancer cases.

## Results

Figure 1 shows the distribution of registry costs across budget categories.

**Figure 1. Distribution of costs for 5 NPCR\*-funded pilot cancer registries by budget category as reported using the cost-assessment tool.**

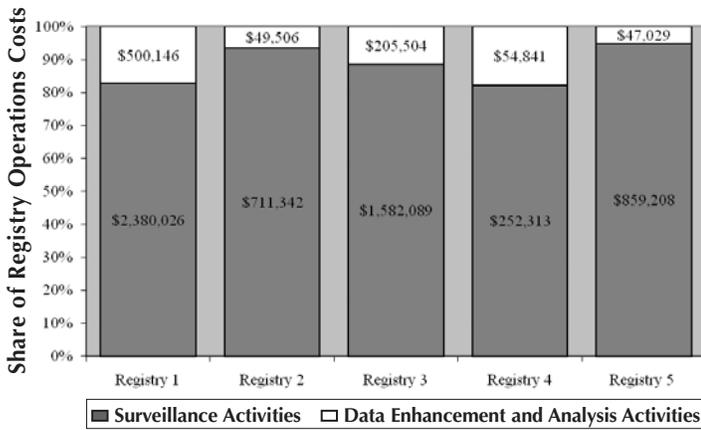


Source: Centers for Disease Control and Prevention and RTI International  
\*National Program of Cancer Registries

Analysis of registry cost data averaged over the 5 pilot registries shows that 62.7% of total registry costs is allocated to personnel, 16.5% to consultants, and 2.3% to hardware and IT support. Two percent of registry expenditures are allocated to software licensing costs, 2.2% to travel and conferences, and 14.3% to administrative costs and other materials.

Figure 2 presents total registry costs and the distribution of costs between surveillance and data enhancement and analysis activities for each of the 5 pilot registries.

**Figure 2. Distribution of costs for 5 NPCR\*-funded pilot cancer registries' surveillance activities and data enhancement and analysis activities as reported using the cost-assessment tool.**



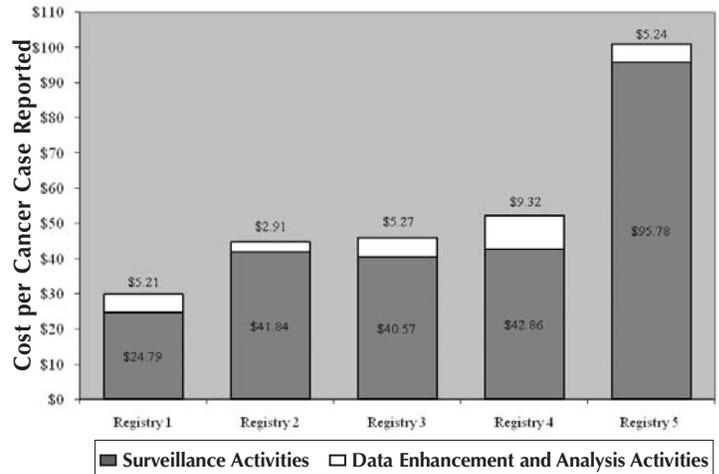
Source: Centers for Disease Control and Prevention and RTI International  
\*National Program of Cancer Registries

This figure presents both the dollar amount expended by each registry and the percentage distribution of surveillance and data enhancement and analysis activities. Registry costs vary widely, as does the portion spent on surveillance vs data enhancement and analysis activities (Figure 2). Total spending among the 5 registries ranges from \$307,154 to \$2,880,172 with a median of \$906,237. Median spending on surveillance

activities across the 5 pilot registries is \$859,208 with a range of \$252,313 to \$2,380,026. Surveillance activities represent a median of 88.5% of total registry costs and range from 82.1% to 94.8% of registry costs. Median spending for data enhancement and analysis activities is \$54,841 with a range of \$47,029 to \$500,146. Data enhancement and analysis activities represent a median of 11.5% of total registry costs and range from 5.2% to 17.9% of all registry costs.

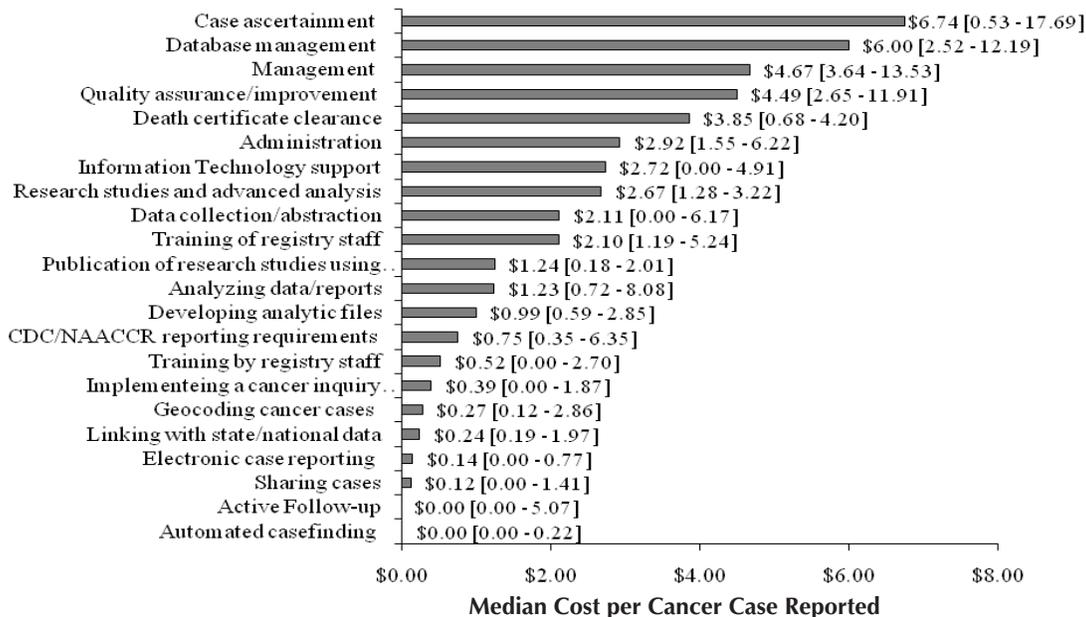
Figure 3 displays the distribution of costs per cancer case reported for surveillance and data enhancement and analysis activities for each of the 5 pilot registries. The cost of surveillance activities per case reported ranges from \$24.79 to \$95.78. The cost of data enhancement and analysis registry activities per cancer case reported ranges from \$2.91 to \$9.32. Total cost per cancer case reported varies, ranging from \$30 to just over \$100.

**Figure 3. Cost per cancer case for surveillance activities and data enhancement and analysis activities as reported by 5 NPCR\*-funded pilot cancer registries using the cost-assessment tool.**



Source: Centers for Disease Control and Prevention and RTI International  
\*NPCR, National Program of Cancer Registries

**Figure 4. Median cost per cancer case by registry activity for surveillance and selected data enhancement and analysis activities as reported by 5 NPCR\*-funded pilot cancer registries by using the cost-assessment tool.**



Source: Centers for Disease Control and Prevention and RTI International  
\*NPCR, National Program of Cancer Registries

The median cost of each surveillance and selected data enhancement and analysis activities per cancer case reported is shown in Figure 4. The most expensive activities were case ascertainment, database management, program management, and quality assurance and improvement, which incurred the median costs of \$6.74, \$6.00, \$4.67, and \$4.49, respectively. The range of these costs varied widely among the registries.

## Discussion

Personnel costs are by far the largest budget category. Although the percentage distribution varies, the majority of total costs are spent on surveillance registry activities across all 5 registries; data enhancement and analysis activities represent a smaller share. Similarly, the cost per cancer case reported varies greatly among registries, with surveillance activities representing most of the cost.

This pilot provided an in-depth look at the true costs of operating a cancer registry, but the study has limitations. First, as is characteristic of pilot studies, our sample is small (only 5 registries were able to report all data). Although the pilot registries were chosen systematically to be representative of central cancer registries nationwide, the findings from this study may not be generalizable to all registries. A second limitation arises because registries report data retrospectively, and the potential for recall error makes the reliability of retrospective data uncertain. Reliability is a particular concern when measuring the amount of time registry personnel spend on various activities. A third issue arises from the regional diversity of registries. This study utilizes raw data, which may account for some portion of the differences in costs among registries. We plan to adjust future data by using the Consumer Price Index to eliminate regional variation in costs. Fourth, costs by activity may vary annually, and annual variability limits the value of 1 year of data. Finally, when calculating cost per cancer case reported, we used cancer cases diagnosed in 2003 due to a lag in reporting cancer cases, along with fiscal year 2005 cost data.

Several of these noted limitations are being addressed in ongoing work. We have recently begun to collect 3 years of cost data (program years 2009, 2010, and 2011) from NPCR-funded registries in 45 states and the District of Columbia. Based on findings from the pilot study, the CAT is now Web-based to minimize the burden to registries. Analyzing data from all 46 NPCR-funded registries will allow us to better understand the sources of variation in registry costs and clarify the generalizability of the findings from the present 5-registry study. Three years of data will

identify annual variation in activity-based costs and permit us to study factors affecting costs and effectiveness of registry operations. Variability in the costs across registries could be due to several reasons, including the size of area served by the registry, total number of cases processed, and the use of electronic reporting. Adjusting this raw data for regional cost differences will further isolate factors affecting registry costs. Outcomes from this ongoing work, which build on the findings presented here, will provide information and tools that allow both CDC and registries to improve efficiency and meet program priorities through better resource allocation decisions.

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# Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking

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**Abstract:** **Objective:** We determined the frequency of deaths associated with histiocytosis in the United States (US) for which incidence data are lacking and could be potentially important in understanding outcomes for patients with these disorders. **Methods:** National death data collected by the US Vital Statistics Reporting System and aggregated using [wonder.cdc.gov](http://wonder.cdc.gov) were analyzed for underlying cause of death due to malignant histiocytosis (MH), Langerhans cell histiocytosis (LCH) and Letterer-Siwe disease (LS, a form of LCH) for 3 periods: 1979–1988, 1989–1998, and 1999–2006. To capture histiocytosis, International Classification of Diseases (ICD)-9 codes 202.3, 202.5, and 277.8 and ICD-10 codes C96.1, C96.0, and D76.0–76.1 were used. Deaths were calculated for US residents stratified according to sex, race, region, and age. Other listed contributing causes of death with a histiocytosis diagnosis were also examined. **Results:** A total of 2,416 deaths primarily due to histiocytosis as underlying cause occurred between 1979 and 2006. On comparison of the underlying and contributory cause for the period 1999–2006, histiocytosis mentioned on the death certificate as a contributory cause (N=562) occurs nearly as often as does underlying cause alone (N=648). The age-adjusted (year 2000) death rate was highest for MH (2.62 deaths per 10 million, 95% CI: 2.40–2.83) and for LCH and LS disease (2.17, 95% CI: 1.98–2.36) during the period 1979–1988. Death rates of each type of histiocytosis dropped significantly from 1979 to 1988 to 1999–2006 (p-value <0.0001). Distribution of the conditions showed the majority of deaths were due to LCH and LS (67%) across all time periods. LCH/LS was significantly more common in persons younger than 5 years of age irrespective of gender (p-value <0.0001) whereas death rates from MH were significantly greater in ages >54 years (p-value <0.0001). There were more MH deaths among males than females whereas no gender differences were seen for LCH/LS. **Conclusions/Discussion:** Death due to histiocytosis or histiocytosis-related causes is a rare event that is trackable in the US by person, place and time characteristics. However, a population-based, disease incidence registry has begun to accurately ascertain incidence cases, which will facilitate study of these conditions.

**Key words:** Histiocytosis, Langerhans cell histiocytosis, Malignant histiocytosis, Hand-Schüller-Christian disease, Letterer-Siwe disease, mortality, disease registries, United States

## Introduction

Langerhans cell histiocytosis (LCH), formerly known as histiocytosis X, is a rare proliferative disorder characterized by accumulation of clonal, functionally and phenotypically immature, CD1a+ Langerhans cells along with immunoreactive cell types, including eosinophils (giving rise to the term eosinophilic granuloma), neutrophils, macrophages and lymphocytes.<sup>1–4</sup> Organ involvement by LCH may vary from localized, single-system disease, which has an excellent prognosis, to multisystem disease with target organ dysfunction, which is associated with a significantly poorer outcome.<sup>3,5–8</sup> A definitive diagnosis is made based on the characteristic pathological and immunohistochemical findings from an involved tissue biopsy.<sup>2</sup>

The etiology and pathogenesis of LCH remain largely unknown.<sup>1,2</sup> There have been no definitive associations of LCH in terms of associated viruses, seasonal variation, geographic clustering or racial clustering,<sup>9–14</sup> making a conventional infectious etiology unlikely. No conclusive association has been identified to date with any environmental toxin<sup>9,10</sup> with the exception of cigarette smoking

associated with the development of isolated pulmonary disease.<sup>15</sup> A genetic predisposition is suggested by the high concordance observed in identical twins, presentation at an earlier age, and the report of some instances of familial clustering of LCH.<sup>16</sup> Through retrospective reviews of the literature and data obtained from registries, a higher association than would be expected by chance has been observed for LCH with various malignancies,<sup>17,18</sup> including acute lymphoblastic leukemia (ALL, especially T-lineage), acute myelogenous leukemia (AML), myelodysplastic syndrome (MDS), Hodgkin lymphoma, non-Hodgkin lymphoma as well as a variety of solid tumors. When LCH occurs in patients with leukemia, it is usually observed following treatment for ALL, while AML has more frequently been reported following treatment for LCH, possibly as a secondary AML as a consequence of LCH-directed treatment. The LCH dendritic cells have also been shown to have decreased telomere lengths, similar to that observed in various preneoplastic and some neoplastic disorders such as MDS.<sup>19</sup> Other investigators have reported the presence of characteristic mutations in the BRAF1 gene in about half of

*"Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking"*

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cases studied, strongly pointing toward a genetic etiology for those cases of LCH.<sup>20</sup> Mortality for single system and multisystem LCH without risk organ involvement (liver, lungs, hematopoietic system, spleen) is <10%, whereas risk organ involvement and dysfunction along with a poor response to initial treatment has been reported to be as high as 80%.<sup>7</sup>

In 1987, the Histiocyte Society grouped these disorders into 3 major classes.<sup>21</sup> Class I, termed LCH, included diseases that had been referred to historically as eosinophilic granuloma, Hand-Schüller-Christian disease, and Letterer-Siwe (LS) disease. Class II was termed non-LCH, with the major disorders being infection associated and inherited forms of hemophagocytic lymphohistiocytoses, but also including Rosai-Dorfman disease and Erdheim-Chester disease. Class III, termed malignant histiocytosis (MH), included disorders such as monocytic leukemia, true histiocytic lymphoma and the very rare malignant tumors of dendritic cells and macrophages. Based on further understanding of the pathogenesis of these disorders, a more recent classification schema is based on the type of cell believed to be primarily involved in the disease process: 1) dendritic cell-related, 2) macrophage related, and 3) malignant disorders of the mononuclear phagocytic system.<sup>22</sup>

To date, the annual incidence of LCH in the general population has been reported to be between 2 to 9 cases per million people based on several studies conducted outside the United States (US).<sup>13,23-26</sup> Males are more frequently diagnosed than females (male to female ratio: 1.2-2:1).<sup>14,23,25</sup> Most cases of LCH have been reported in children under the age of 15 years, with variable incidence figures ranging from 2.2 to 9 cases per million per year, and a peak incidence between 1 and 3 years of age.<sup>23,25,27-29</sup> However, it is evident that this disease can occur at any age<sup>24</sup> and has been reported to occur in adults as well. It is probably under-reported and under-diagnosed in both children and adults because of the varied clinical presentation and multi-specialty involvement in patient care. Thus, the true incidence of the disease may be higher than reported.

The aims of this study were to estimate the overall and age- and gender-specific death rates of histiocytic disorders in the US from 1979-2006, as well as to assess their distribution by US region and population race.

## Methods

Deaths associated with histiocytosis occurring in the US in 1979-1988, 1989-1998, and 1999-2006 were obtained from the US Vital Statistics Reporting System (Centers for Disease Control and Prevention).<sup>24,30-32</sup> Compilation of numbers, rates, and confidence intervals was accomplished at [wonder.cdc.gov](http://wonder.cdc.gov). Histiocytosis was categorized as either: 1) MH, or 2) LS Disease and LCH. We combined LS with LCH as both are classified as LCH. Underlying cause of death due to MH or LS/LCH was determined according to the International Classification of Diseases (ICD)-9<sup>33</sup> codes 202.3, and 202.5 and 277.8 respectively for the period 1979-1998.<sup>34</sup> CDC (Centers for Disease Control and Prevention) WONDER (Wide-Ranging Online Data for Epidemiologic Research) does not provide ICD-9 codes to the second

decimal place, which means that some non-histiocytosis disorders may have been included in the aggregation of Langerhans cell histiocytosis through the use of 277.8 rather than 277.89, which replaced the older 4-digit code in 2004.<sup>31,32,34</sup> Underlying cause of death information for years 1999-2006<sup>34,35</sup> was obtained and coded under ICD version 10<sup>27</sup> codes: C96.0, and C96.1 and D76.0. We examined histiocytosis as a contributory cause of death, which was reported in the 1999-2004 and 2005-2006 multiple cause of death [wonder.cdc.gov](http://wonder.cdc.gov) database by the National Center for Health Statistics (NCHS).<sup>31,32</sup> Up to 20 contributory causes of death may be reported on Part II of the death certificate.<sup>36</sup>

Age-adjusted (year 2000 standard) death rates were calculated by sex, race, region, age, and calendar year strata using CDC WONDER.<sup>37</sup> Most confidence intervals (95%) were obtained through [wonder.cdc.gov](http://wonder.cdc.gov).<sup>30-32</sup> When they were not provided, they were calculated using the NCHS recommended formula.<sup>37</sup> NCHS denotes rates unreliable when the number of deaths is fewer than 20. Initial age groups were determined by NCHS and reported in 11 categories (<1, 1-4, 5-14, 15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, and 85+ years). After examining the 11 age-specific histiocytosis rates, we further aggregated the groups into <5, 5-54, and 55+ years of age. This grouping was based on the observation that the youngest and the oldest individuals had the highest death rates that statistically exceeded those between ages 5-54 years. Two deaths were excluded from age-adjusted rates because age was reported as unknown. Race was reported on the death certificate according to NCHS conventions and categorized as whites, blacks, Asians (includes Pacific Islanders), and other (American Indians, Native Americans, Hawaiian, Samoan, and Guamanian). Hispanic origin has been reported on death certificates since 1978 by some states and during the period 1997-2006 all states have added this information to the death certificate.<sup>37</sup> While data completeness improved during the period of 1997-2006, complete ethnicity reporting is lacking over the entire period. Thus, we did not report ethnicity in this analysis. NCHS geographical definitions of Northeast, Midwest, South and West US provided at [wonder.cdc.gov](http://wonder.cdc.gov) were used to characterize region.

We examined histiocytosis as a contributory cause of death by age (<1, 1-4, 5-54, and 55-84 years) in the period 1999-2006 from data available in the online database.<sup>31,32</sup> Contributory causes of death associated with histiocytosis were aggregated using the NCHS 113 major cause of death categories.

We performed chi-square tests to examine the independence of population characteristics, the signed rank sum to test for trend, and Spearman's correlation for similar but nonmonotonic patterns between MH and LCH by age.<sup>38</sup> We considered a p-value of 0.05 or less to be statistically significant and thus show 95% confidence intervals (CI).

## Results

Death due to histiocytosis in the US is a rare event. In the 28-year period studied, deaths due to histiocytosis as a primary, underlying cause of death numbered 2,416 or about 82 deaths per year (Table 1).

**Table 1. Distribution of histiocytosis as underlying cause of death by selected characteristics: United States, 1979–2006.**

Characteristics	<i>Malignant Histiocytosis</i>				<i>Langerhans Cell Histiocytosis and Letterer-Siwe Disease</i>				p Value
	1979–1988	1989–1998	1999–2006	1979–2006	1979–1988	1989–1998	1999–2006	1979–2006	
TOTAL	588	143	62	793	512	525	586	1623	
<b>Sex</b>				ns**				ns**	ns***
Male	341 (58.0)	83 (58.0)	42 (67.7)	466 (58.8)	264 (51.6)	262 (49.9)	326 (55.6)	852 (52.5)	
Female	247 (42.0)	60 (42.0)	20 (33.3)	327 (41.2)	248 (48.4)	263 (50.1)	260 (44.4)	771 (47.5)	
<b>Race</b>				ns**				ns**	ns**
Whites	501 (85.2)	118 (82.5)	52 (83.9)	671 (84.6)	429 (83.8)	436 (83.0)	467 (79.7)	1332 (82.1)	
Blacks	66 (11.2)	18 (12.6)	8 (12.9)	92 (11.6)	68 (13.3)	63 (12.0)	83 (14.2)	214 (13.2)	
Other Races	21 (3.6)	7 (4.9)	2 (3.2)	30 (3.8)	15 (2.9)	26 (5.0)	36 (6.1)	77 (4.7)	
<b>Region*</b>				ns**				ns**	p=0.02
Northeast	121 (20.6)	28 (19.6)	7 (11.3)	156 (19.7)	100 (19.5)	72 (13.7)	95 (16.2)	267 (16.5)	
Midwest	152 (25.9)	40 (28.0)	21 (33.9)	213 (26.9)	124 (24.2)	140 (26.7)	134 (22.9)	398 (24.5)	
South	178 (30.3)	39 (27.3)	23 (37.1)	240 (30.3)	187 (36.5)	181 (34.5)	219 (37.4)	587 (36.2)	
West	137 (23.3)	36 (25.2)	11 (17.7)	184 (23.2)	101 (19.7)	132 (25.1)	138 (23.5)	371 (22.9)	
<b>Age</b>				p<0.0001				p<0.0001	p<0.0001
Under 1 year	11 (1.9)	4 (2.8)	6 (9.7)	21 (2.6)	89 (17.4)	105 (20.0)	100 (17.1)	294 (18.1)	
1–4 years	23 (3.9)	11 (7.7)	6 (9.7)	40 (5.0)	129 (25.2)	142 (27.0)	124 (21.2)	395 (24.3)	
5–9 years	11 (1.9)	2 (1.4)	1 (1.6)	14 (1.8)	20 (3.9)	27 (5.1)	10 (1.7)	57 (3.5)	
10–14 years	21 (3.6)	3 (2.1)	0 (0)	24 (3.0)	14 (2.7)	6 (1.1)	24 (4.1)	44 (2.7)	
15–24 years	43 (7.3)	7 (4.9)	2 (3.2)	52 (6.6)	27 (5.3)	21 (4.0)	40 (6.8)	88 (5.4)	
25–34 years	45 (7.7)	10 (7.0)	3 (4.8)	58 (7.3)	31 (6.1)	24 (4.6)	29 (4.9)	84 (5.2)	
35–44 years	49 (8.3)	13 (9.1)	6 (9.7)	68 (8.6)	37 (7.2)	40 (7.6)	38 (6.5)	115 (7.1)	
45–54 years	57 (9.7)	7 (4.9)	4 (6.5)	68 (8.6)	32 (6.3)	35 (6.7)	53 (9.0)	120 (7.4)	
55–64 years	115 (19.6)	18 (12.6)	7 (11.3)	140 (17.7)	45 (8.8)	36 (6.9)	69 (11.8)	150 (9.2)	
65–74 years	116 (19.7)	35 (24.5)	11 (17.7)	162 (20.4)	48 (9.4)	43 (8.2)	50 (8.5)	141 (8.7)	
75–84 years	79 (13.4)	27 (18.9)	11 (17.7)	117 (14.8)	31 (6.1)	31 (5.9)	36 (6.1)	98 (6.0)	
85+ years	18 (3.1)	6 (4.2)	5 (8.1)	29 (3.7)	9 (1.8)	14 (2.7)	13 (2.2)	36 (2.2)	
Unstated	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.2)	0 (0)	1 (0.1)	

\*Northeast region includes CT, ME, MA, NH, NJ, NY, PA, RI, and VT; Midwest region includes IL, IN, IA, KS, MI, MN, MO, NE, ND, OH, SD, and WI; South region includes AL, AR, DE, DC, FL, GA, KY, LA, MD, MS, NC, OK, SC, TN, TX, VA, and WV; and West region includes AK, AZ, CA, CO, HI, ID, MT, NV, NM, OR, UT, WA, and WY. \*\*Chi-square tests independence of time periods and individual characteristics. \*\*\*Chi-square tests independence of all MH and all LCH/LS and individual characteristics.

The distribution of deaths from the 3 conditions showed the majority to be LCH with 1593 (66%), and the remainder being LS with 30 (1%) and MH with 793 (33%). We examined additional person, place and time characteristics of histiocytosis as underlying cause of death in the US (Table 1). Beyond age, the examination of independence of time period from gender, race, and region showed no statistical significance within either the MH or the LCH/LS groups (Table 1). However, age was significant, with increased numbers of deaths in the oldest (55+ years) and youngest (age <5 years) persons by disease (p-value <0.0001) in each of the disease groups (Table 1).

Person characteristics of race and gender did not differ between the 2 histiocytosis disease groups. Region (p-value = 0.02) and age (p-value <0.0001) differed significantly between the MH and LCH/LS. Over all time periods, there were more deaths from MH as compared to LCH/LS in the Northeast US (19.7% vs 16.5%; chi-square df=1 = 3.83, p-value = 0.05), while there were more deaths from LCH/LS deaths in the South US (36.2% vs 30.3%; chi-square df=1 = 195.4, p-value <0.0001). Over all time periods, there were more MH deaths in ages older than 55 years (56.6% vs 26.1%; chi-square df=1 = 212.0, p-value <0.0001) while more deaths from LCH/LS were observed in ages 0-4 (42.4% vs 7.6%; chi-square df=1 = 683.9, p-value <0.0001) (Table 1). This finding is illustrated in Figure 1.

**Figure 1. Histiocytosis death rates by age and diagnostic groups, United States, 1979–2006.**

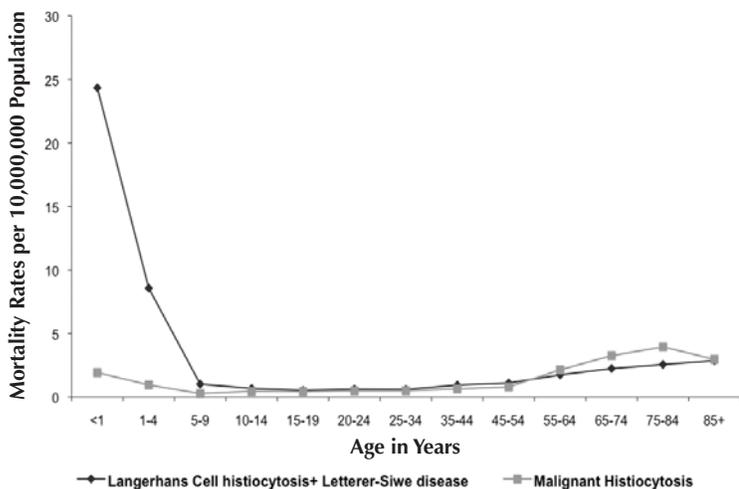


Table 1 shows the number of deaths occurring in each time period for MH and LCH/LS. MH has a decreasing number of annual deaths per period: 1979–1988 showed an average number of deaths per year of 58.8 (95% CI: 43.8–73.8), in 1989–1998 of 14.3 deaths per year (95% CI: 6.9–21.7), and in 1999–2006 of 7.8 deaths per year (95% CI: 2.3–13.3). Average annual number of deaths for LCH/LS was essentially the same for the first 2 periods at 51.2 (95% CI: 37.2–65.2) and 52.5 (95% CI: 38.1–66.7) deaths per year.

In contrast, deaths from LCH/LS for 1999–2006 were higher at 73.3 (95% CI: 56.5–90.1) deaths per year. The observed pattern of death rates was similar for MH and LCH/LS when age-adjusted death rates were compared (Table 2) across the 3 time periods.

For MH, there was a significant decrease in age-adjusted death rates from 2.62 (95% CI: 2.40–2.83) in 1979–1988 to 0.55 (95% CI: 0.46–0.64) in 1989–1998, and further to 0.27 (95% CI: 0.21–0.34) in 1999–2006. For LCH/LS, the age-adjusted death rates were similar in the first 2 time periods: 2.17 (95% CI: 1.98–2.36) and 1.96 (95% CI: 1.79–2.13), 1979–1988 and 1989–1998, but significantly lower in the most recent time period, 1999–2006 (1.45 [95% CI: 1.29–1.60]).

Table 2 displays death rates by age groups (<5 years, 5–54 years and 55+ years) and gender for MH and LCH/LS as an underlying cause of death. A significant decline in age-specific death rates from MH occurred from one time period to the next among both males and females. However, males had significantly higher number of MH deaths than females during every time period as seen in Table 2. Among males, a significant decrease in MH death rates was observed for ages 5–54 years from the period of 1979–1988 (1.75 [95% CI: 1.47–2.04]) to the period of 1989–1998 (0.28 [95% CI: 0.18–0.40]) and ages 55 years and older across all 3 time periods: 8.34 (95% CI: 7.11–9.56) to 2.08 (95% CI: 1.54–2.75) and to 0.98 (95% CI: 0.61–1.48). A significant decrease

**Table 2. Distribution of histiocytosis as underlying cause of death across age groups in males and females, 1979–1988, 1989–1998, and 1999–2006.**

	<i>Malignant Histiocytosis (MH) §</i>			<i>Langerhans Cell Histiocytosis-Letterer-Siwe (LCH-LS) §</i>		
	<i>Number</i>			<i>Number</i>		
	<i>Age-Specific Rate* (95% Confidence Interval)</i>			<i>Age-Specific Rate* (95% Confidence Interval)</i>		
	<i>Age-Adjusted Rate* [95% Confidence Interval]</i>			<i>Age-Adjusted Rate* [95% Confidence Interval]</i>		
	1979–1988	1989–1998	1999–2006	1979–1988	1989–1998	1999–2006
<b>Males</b>	<b>341</b>	<b>83</b>	<b>42</b>	<b>264</b>	<b>262</b>	<b>187</b>
	<b>3.39 [3.02-3.77]</b>	<b>0.72 [0.57-0.89]</b>	<b>0.40 [0.29-0.54]</b>	<b>2.34 [2.04-2.63]</b>	<b>2.03 [1.78-2.28]</b>	<b>1.64 [1.40-1.87]</b>
<5 years	16 1.79 (1.02-2.91)	8 0.80 (0.35–1.59)	10 1.24 (0.59–2.28)	109 12.21 (9.91–14.50)	115 11.57 (8.45–13.68)	100 12.39 (1.00–14.82)
5-54 years	147 1.75(1.47-2.04)	26 0.28 (0.18–0.40)	10 0.12 (0.06–0.22)	85 1.01 (0.81–1.25)	83 0.88 (0.70–1.09)	54 0.65 (0.49–0.85)
>55 years	178 8.34(7.11-9.56)	49 2.08 (1.54–2.75)	22 0.98 (0.61–1.48)	70 3.28 (2.56–4.14)	64 2.72 (2.09–3.47)	33 1.47 (1.01–2.06)
<b>Females</b>	<b>247</b>	<b>60</b>	<b>20</b>	<b>248</b>	<b>263</b>	<b>147</b>
	<b>2.02 [1.76-2.27]</b>	<b>0.42 [0.32-0.54]</b>	<b>0.16 [0.10-0.25]</b>	<b>2.07 [1.81-2.33]</b>	<b>1.91 [1.68-2.15]</b>	<b>1.25 [1.05-1.46]</b>
<5 years	18 2.11 (1.25-3.34)	7 0.74 (0.30–1.52)	2 0.26 (0.03–0.94)	109 12.79 (10.39–15.19)	132 13.91 (11.54–16.29)	58 7.52 (5.71–9.72)
5-54 years	79 0.94 (0.75-1.17)	16 0.17 (0.10–0.28)	6 0.07 (0.03–0.16)	76 0.91 (0.71–1.13)	70 0.75 (0.58–0.95)	49 0.60 (0.44–0.79)
55+ years	150 5.33 (4.48-6.18)	37 1.20 (0.85–1.65)	12 0.98 (0.22–0.75)	63 2.24 (1.72–2.86)	60 1.95 (1.49–2.51)	40 1.42 (1.02–1.94)
<b>Total</b>	<b>588</b>	<b>143</b>	<b>62</b>	<b>512</b>	<b>525</b>	<b>334</b>
	<b>2.62 [2.40-2.83]</b>	<b>0.55 [0.46-0.64]</b>	<b>0.27 [0.21-0.34]</b>	<b>2.17 [1.98-2.36]</b>	<b>1.96 [1.79-2.13]</b>	<b>1.45 [1.29-1.60]</b>

§Chi-square calculated for time and age (MH: chi-square=2.24, LCH: chi-square=3.09, df=2) were not significant and for time and disease (chi-square=276, df=2), p<0.0001. \*Per 10 million.

in death rates from MH occurred amongst females only in ages 55 years and older across the 3 time periods: 5.33 (95% CI: 4.48–6.18) to 1.20 (95% CI: 0.85–1.65) and more recently to 0.98 (95% CI: 0.22–0.75).

The age-adjusted LCH/LS death rates for females and males were lower in 1999–2006 than 1979–1998: in females, 1.25 (95% CI: 1.05–1.46) vs 2.07 (95% CI: 1.81–2.33), and in males, 1.64 (95% CI: 1.40–1.87) vs 2.34 (95% CI: 2.04–2.63) (Table 2). A significant decline in age-specific LCH/LS death rates occurred in males for ages 55 years and older in 1999–2006 (1.47 [95% CI: 1.01–2.06]) as compared to 1979–1988 (3.28 [95% CI: 2.56–4.14]) and 1989–1998 (2.72 [95% CI: 2.09–3.47]) and similarly a significant decline was observed among females ages less than 5 years of age in 1999–2006 (7.52 [95% CI: 5.71–9.72]) as compared to 1979–1988 (12.79 [95% CI: 10.39–15.19]) and 1989–1998 (13.91 [95% CI: 11.54–16.29]). Declines in LCH/LS death rates appeared to occur among males overall, but did not reach statistical significance. Unlike MH, in which death rates in males were

significantly greater when compared to females over the periods studied, LCH/LS death rates did not differ significantly between males and females in each time period.

The age-adjusted MH death rate (2.62 [95% CI: 2.40–2.83]) was statistically higher than the death rate for LCH/LS (2.17 [95% CI: 1.98–2.36]) during 1979–1988. In contrast, the age-adjusted MH death rate was statistically less than the death rate for LCH/LS in the subsequent 1989–1998 (0.55 [95% CI: 0.46–0.64] vs 1.96 [95% CI: 1.79–2.13]) and was even lower in 1999–2006 (0.27 [95% CI: 0.21–0.34] vs 1.45 [95% CI: 1.29–1.60]) time periods. This pattern of MH relative to LCH/LS is seen across all time periods in both males and females except in 1979–1988, when age-adjusted death rates among females was comparable between MH and LCH/LS.

Age-adjusted 1999–2006 death rates for any histiocytosis as a contributory cause of death are presented in Table 3. On comparison of deaths from any histiocytosis listed as underlying or contributory cause for the period 1999–2006,

**Table 3. Histiocytosis\* as a contributory cause of death by underlying cause of death and age groups: United States, 1999–2006.**

<i>Underlying Causes of Death</i>	<i>All Ages #(%)</i>	<i>1–5 year #(%)</i>	<i>5–54 years #(%)</i>	<i>&gt;54 years #(%)</i>
Deaths	562(100)	207(100)	177(100)	178(100)
Rate (95% CI)**	2.4 (2.2–2.6)	13.1 (11.3–14.9)	1.1 (0.9–12.3)	3.5 (3.0–4.0)
<b>A00-B99</b> Certain infectious diseases and parasitic diseases	20(4)	9(4)	9(5)	2(1)
<b>C00-D48</b> Neoplasms	103(18)	14(7)	28(16)	61(34)
<b>D50-D89</b> Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism	346(62)	167(81)	106(60)	73(41)
<b>E00-E88</b> Endocrine, nutritional and metabolic disorders	4(1)	—	2(1)	2(1)
<b>F01-F99</b> Mental and behavioral disorders	1(<1)	—	1(1)	—
<b>G00-G98</b> Diseases of the nervous system	7(1)	3(1)	3(2)	1(1)
<b>H00-H57</b> Diseases of the eye and adnexa	—	—	—	—
<b>H60-H93</b> Diseases of ear and mastoid	—	—	—	—
<b>I00-I99</b> Diseases of the circulatory system	39(7)	4(2)	13(7)	22(12)
<b>J00-J98</b> Diseases of the respiratory system	23(4)	—	10(6)	13(7)
<b>K00-K92</b> Diseases of the digestive system	10(2)	5(2)	2(1)	3(2)
<b>L00-L98</b> Diseases of the skin and subcutaneous tissue	—	—	—	—
<b>M00-M98</b> Diseases of the musculoskeletal system	4(1)	3(1)	1(1)	—
<b>N00-N98</b> Diseases of the genitourinary system	1(<1)	—	—	1(1)
<b>O00-O99</b> Pregnancy, childbirth and the puerperium	—	—	—	—
<b>P00-P96</b> Certain conditions originating in the perinatal period	2(<1)	2(1)	—	—
<b>Q00-Q99</b> Congenital malformations, deformations and chromosomal abnormalities	—	—	—	—
<b>R00-R99</b> Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	—	—	—	—
<b>V01-Y89</b> External causes of morbidity and mortality	2(<1)	—	2(1)	—

\*Histiocytosis includes malignant and Langerhans cell histiocytosis, and Letterer-Siwe disease. \*\*Rate (per 10,000,000) for all ages is age-adjusted (year 2000); all other rates are crude, ie, age-specific. Note percentages may not total 100% due to rounding.

it was observed that histiocytosis mentioned on the death certificate as a contributory cause (N=562) occurred nearly as often as an underlying cause alone (N=648). Notation of any histiocytosis as a contributory cause was associated with a death rate of 2.4 deaths (95% CI, 2.2-2.6) per 10 million (Table 3), which is comparable in magnitude to the histiocytosis death rate as an underlying cause [1.82 deaths 99% CI, 1.65-1.99]).

Contributory causes of death when any histiocytosis is listed as underlying cause of death is presented in Table 3 for 1999-2006. For all ages, diseases of the blood and blood forming organs and certain disorders involving immune dysfunction predominated (62%) and as age increased (81%, 60%, and 41% for age groups <5, 5-54 and 55+) (chi-square, df=2 = 63.9, p-value <0.0001). Cardiovascular diseases were the next most common contributory cause and increased with age from 7% to 34% from youngest to oldest age group (chi-square, df=2 = 16.2, p-value <0.001). Respiratory diseases, on the other hand, were more commonly seen exclusively in individuals older than 5 years (chi-square, df=1 = 13.9, p-value <0.001). Neoplasms made up 18% of contributory deaths overall and were more common in the 55+ age group (chi-square, df=1 = 44.2, p-value <0.0001).

## Discussion

This article presents for the first time the overall death rates from histiocytosis using population-based US death data. The death rates associated with these disorders appear to be low (0.27-1.45 per 10 million) from the most recent reporting period (1999-2006) with the higher death rate associated with LCH/LS. There were more males than females who died from MH; this finding was not observed for LCH/LS. Most deaths from histiocytosis occurred under 5 years of age and in individuals 55 years of age and older. Regional differences between the distribution of MH and LCH/LS showed an excess in US South region for LCH/LS and more MH deaths in Northeast supporting a potential geography-related etiology or regional coding preferences or reporting conventions.

The observed decline in MH death rates over 27 years supports the hypothesis that there is improved understanding, diagnosis, and treatment of patients for this group of disorders; in particular, these changes may reflect the recognition that many of these cases actually represent anaplastic large cell lymphoma (ALCL).<sup>39</sup> Death rates from LCH/LS did not differ significantly until recently (1999-2006), a time when ICD coding changed from ICD-9 to ICD-10, weakening diagnosis specificity in the available online death data. These temporal trends suggest that, though physicians may be well aware of the diagnostic entity LCH/LS, our observations in cause of death reporting demonstrate an evolving coding convention in the Internet presentation National Vital Statistics System surveillance data.<sup>1,2</sup>

Since histiocytosis cases in this study were collected from a national mortality registry, information may reflect contributions from many medical specialties, thus reducing selection or recruitment biases. Nevertheless, there are limitations associated with the information obtained from the

death certificate collection system which aggregates deaths according to the underlying cause defined as "...the disease or injury which initiated the train of morbid events leading directly or indirectly to death...."<sup>35</sup> This definition excludes other causes of death listed on the death certificate, possibly missing the total contribution of any given cause of death. In this study we have reported both underlying deaths associated with histiocytosis and contributory deaths available for 1999-2006. With this limitation in mind, future reports of histiocytosis deaths could be reported as "histiocytosis-related deaths" to capture any deaths with histiocytosis reported on the death certificate and to follow the convention used for "diabetes-related" deaths.<sup>3</sup>

As of January 2010, the North American Association of Central Cancer Registries (NAACCR) made LCH reportable as LCH NOS (not otherwise specified) with ICD-O code as 9751/3 with change in behavior coding from benign to malignant.<sup>41</sup> This relatively recent addition to cancer coding had been delayed in part because of significant controversy over the etiology and type of disorder LCH represented, ie, malignant or an immune dysregulation syndrome. Current registry reporting (NCI [National Cancer Institute]-funded SEER [Surveillance, Epidemiology and End Results Program] and CDC-funded state registries) now includes MH and the new category of ALCL neoplasms.<sup>41</sup> Thus, this new national registry effort for the US begins with standard cancer registry inclusions of these diseases that can now be used to report the incidence of these rare conditions (<http://www.naacccr.org/>) as a group and their component conditions such as Letterer-Siwe disease.<sup>42</sup> With the advent of this more complete and representative data collection future source for histiocytosis incidence, additional prognostic information is also gained: date of diagnosis, first course of treatment, and (when known) date of death.<sup>40</sup>

Without disease duration, it is not possible to conclude from the death records what the incidence of these histiocytic disorders was during the time periods studied. Nevertheless, the results we have presented reveal potentially important trends and differences in some characteristics of those individuals who died from these histiocytic disorders. With the addition of recently improved incidence reporting of these disorders by state cancer registries (<http://www.cdc.gov/cancer/npcr/about.htm>) and the existing SEER registries (<http://seer.cancer.gov/registries/>), an opportunity is presented where we may learn more about a cohort of newly diagnosed individuals with a rare condition that benefits from the larger numbers accrued at the national level. The national US cancer registries (American College of Surgeons,<sup>41</sup> NAACCR,<sup>42</sup> SEER,<sup>45</sup> and the National Cancer Registries Program<sup>40</sup>) have begun including MH and LCH in their case collections, making incidence tracking possible. Nevertheless, more reports of histiocytosis may be found under other categorizations such as "reticuloendothelial neoplasms." Thus, increased attention paid to reporting histiocytic conditions will begin to inform us of the total incidence of this class of conditions. Moreover, as our molecular understanding of current disease classifications increases, additional demands will be made on registries to capture characteristics beyond the usual morphology and histology markers, especially for those classifications that are evolving. This study of mortality is just the first step in quantifying the health issue of histiocytosis for the US.

## Acknowledgement

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## Experiencing Change: The Users' Perspective (CSv2)

Cynthia Boudreaux, LPN, CTR

As we reach a crossroads in the profession of cancer registration, we have to stay focused on the bottom line. What is the bottom line? It is accurate and consistent data reporting.

So, one must then ask the pressing question, "How do we assure accuracy and consistency with so many changes?" Can we reasonably ask this of ourselves with so many errata hitting our front door?

There are no easy answers to these burning questions, but we do have some tactics to ease the burden of change. Cancer registrars from across the country were surveyed this past fall and asked to give feedback on their CSv2 experience. The results of the survey were not surprising. We have been challenged in the registry profession and, as usual, the registry profession has risen to the challenge. More than 67% of the respondents have been in the registry field for 11 years or more. This speaks to the overall commitment to the profession.

While we all dance to the beat of different standard setters, one thing is constant: our continuous efforts to produce the highest quality data possible.

When asked specific questions on the use and understanding of CSv2 coding instructions and schemas, the responses were also consistent. Many are struggling with understanding which data elements need to be collected and, more importantly, where to find the information. A great resource for finding information on site-specific factors and general instructions is through the newly established CAnswer Forum. The link can be found at <http://www.cancerstaging.org>. One might also want to routinely check the CSv2 Web site for updates and helpful hints. The CSv2 Web site lists the recommendations and requirements from each standard-setting organization.

If you have not entered the world of dual monitors, this would be as good a time as any to join the ranks. Dual monitors are a relatively inexpensive way to increase your productivity. Everyone is charged with looking at more than one software application in order to complete an abstract. Whether it is the abstracting software and the electronic medical record or the CSv2 manual and inputting data into the abstract, there must be 2 applications open. Dual monitors ease the process of data entry when more than 1 application can be open and available to you simultaneously.

Implementation of CSv2 has been challenging for all involved. It is extremely important that everyone stay familiar with the changes and errata being published. How does one accomplish this task of staying updated? There are multiple venues to do so, including the CSv2 Web site. The Commission on Cancer (CoC) distributes a monthly newsletter called the *CoC Flash*. This newsletter is sent out electronically through a monthly email blast.

The North American Association of Central Cancer Registries (NAACCR) distributes information through the NAACCR Listserv. This is also an email blast sent out to all the membership.

Finally, we can stay tuned-in through our professional organization, the National Cancer Registrars Association (NCRA). NCRA will periodically send emails to its membership to keep them informed of important news, in addition to publishing *The Connection*, the organization's official newsletter.

Any of these media are an efficient and effective means of keeping oneself informed.

Beyond implementation is the reality of recording the coding information for the purpose of completing an abstract. What if the information is not available? What if I simply do not know where the information is located? What if I do not know if a specific test is being offered or performed at the facility?

All of these questions are valid. We must be proactive, not reactive, in our quest for data collection and data coding. Ask the physician leaders in the facility to assist with uncovering the answers to the previously asked questions. If the information is not available, there are specific instructions, per CSv2 schema, on how to address the proper coding of that field. If the information is unfamiliar to you, it is vital to do some homework in locating the document, if it exists, or eliminating the item if it is not performed at the facility. In order to make some of these determinations, you must ask others who are part of your leadership team. This will not be a canned response, but will ultimately differ from facility to facility. This is truly where the challenge arises. It may be necessary to document through policy and procedures how specific items or data fields are handled in the facility. Doing so may offer consistency in coding, and can give references years from now on how and why specific items were coded in a certain way.

Processes may also need to be developed by the facility and its external partners to complete some data fields. It is not unreasonable to ask the medical oncology practice to submit the consult note on mutually treated patients to the cancer registry for completion of the abstract. Formalizing relationships between these parties can help in bridging gaps in data collection.

Many survey respondents shared additional comments. The most consistent comment was that of "too much on my plate." Unfortunately, the reality of the situation is that it can not be avoided. In order to report current practices in cancer care, along with maintaining accuracy of data collection, all changes have to coincide. The relationship between CSv2, American Joint Committee on Cancer (AJCC) staging, and College of American Pathologists (CAP) protocols forced the revision of all coding manuals. While it is definitely not an easy transition for anyone involved, it is absolutely necessary in order to keep pace with the advancement of the science of cancer care. Gone are the days where HER2 is not listed as a required NAACCR data element. The focus of the AJCC work groups was to look to the future and avoid the issue of missed opportunities in the research arena. The updated version of CSv2 will be available to the vendors by the end of the year. The updates include corrections to coding structures within specific schemas, clarification on site-specific factors, and a shift to uniformity among all schemas.

The user feedback elicited from the survey helped identify areas that need immediate work, and also priorities for the future.

We did note that 96.4% of users did find Part I, Section II of the coding instructions very helpful.

Also, an average of 90% of users found the manual easy to use for both coding instructions and schemas. We were excited to hear this. As a result of the survey, we better understand the areas where clarifications and enhancements are necessary. The survey results also provided a better understanding of areas where education is key to providing clarity to the existing version of the manual in order to meet our goal of consistent and accurate data collection.

While the challenge is great, there is no doubt that the registry community will meet it head-on. In this author's opinion, there is no other profession where the persons involved are as dedicated to a purpose; accurately recording information that will have a real impact on the lives of cancer patients. We all have valid reasons to be frustrated, but as I hear the frustrations, I also hear the resounding voice of reason and resolution. Thus is the quest of the registrar against the disease we record. Cancer may be a forever changing disease, but we are a resilient species. We will prevail!

## Data Directions

Faith G. Davis, PhD

Survival data are valuable health outcome measures providing complementary information to the more readily available public health surveillance measures (incidence and mortality rates) that are used in many settings, including evaluation of screening, diagnostic and treatment programs. Survival data support hypothesis generation by identifying disparities that require further elucidation and are also used to evaluate the effectiveness of individual, institutional and population-based programmatic and intervention efforts. Given the widespread use of survival measures, it is important that they are readily available and accurate so that programmatic and policy decisions are based on the best available evidence. Since 1973, the cancer research community in the United States has been fortunate to have survival data available on a subset of the population through the Surveillance, Epidemiology, and End Results (SEER) program. There is now an effort to make these data more widely available on a larger subset of the US population through the National Program of Cancer Registries.

A paper published in the Fall 2010 *Journal of Registry Management*<sup>1</sup> was a provocative example of how to use modeling of existing data to understand the accuracy of survival statistics under different data completeness scenarios. The results have implications for data collection priorities for the North American Association of Central Cancer Registries (NAACCR) member registries that are moving towards providing survival data and may also point to cost effective ways to generate survival data within the international surveillance community for which survival data is less readily available. There may also be protocol implications for the research community conducting observational cohort studies with survival as an endpoint.

To very simply cap the highlights of the results from this detailed effort using simulated datasets, results show that as the proportion of lost to follow-up increase in a dataset, the mortality rates decline and/or the mortality outcome of the group appears artifactually better. They also show that as the number of deaths missing in a dataset increases, the mortality rates decline and similarly the mortality rate appears artificially better. These shifts in rates reflect known information biases that have driven surveillance systems to try to achieve high data collection standards for both follow-up contacts and deaths recording. What is striking is that with a large magnitude of lost to follow-up for cancer outcomes (20%) about 70% of cancer sites showed a very modest 1%-2% decrease in 5-year survival rates. Of note

is that those cancer sites at the extremes of prognosis, high or low, had marginal impact by these increases in lost to follow-up. In contrast, proportional missing death information had a larger impact on survival rates. At 10% missing deaths the increase in observed survival was 5% or greater for about 50% of cancer sites. Cancer sites with low survival were affected the most. The authors conclude that when death ascertainment is high, there are only minor differences in survival estimates with complete follow-up and non-follow-up of live patients. In contrast, having complete information on deaths is quite important in obtaining accurate survival estimates. This result is important as cancer registries do rely on record linkage processes to obtain death information, making the accuracy of those datasets being linked to increasingly important. The author promotes NAACCR guidelines for linkages with the 2 major national death databases (the National Death Index and the Social Security Death Index) in an effort to standardize death ascertainment.

It is a pleasure to see this carefully conducted methodological work coming from within the NAACCR programs. For external users of the survival data generated, it will be important to understand the methods utilized within the different programs in order to interpret comparisons appropriately. The authors do note that complete follow-up of younger populations and complete death information on increasingly mobile populations are challenges to the data veracity. Given the emphasis on health inequities in the United States which rely on the surveillance system to identify and monitor progress in these inequities, it would also be useful to understand how factors such as race, income, and geography may impact the quality of the data used to generate those relevant survival statistics.

It is my hope that registries will further explore these issues in their data estimation while following the recommendations to utilize standard methods that will help make the survival rate data comparable from region to region. Just as important will be the impact of these results on the international registry community as they generate more regional survival data, and on the accuracy and interpretation of survival data being generated from cohort studies.

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## Raising the Bar: Speaking Your Customer's Language

Michele Webb, CTR

Not too far from my house is a local donut shop called Scott's Donuts. A wonderful family owns the business and they are always so warm, friendly, and ready to offer a free cup of coffee or a donut hole with sprinkles to "top off" your order. I learned one day that no one in their family is actually named Scott. They picked the name for their shop from a baby book a number of years ago. I guess they closed their eyes, opened a page and pointed at a name and painted it on the sign. They laughed when they told me I was the only customer that had ever asked that question. Here's the best part: Since that day, we have developed a wonderful business relationship that has given me at least an extra 10 pounds! Oh, did I forget to say they have THE BEST donuts ever? But, I digress...

Imagine one morning I were to walk into the shop and ask for a "cake NOS" donut to go. Or, what if I wanted to order my favorite donut, a maple-glazed cruller. I could walk in the door and ask Lilly for "a twisted, ring-shaped, fried pastry made of choux pastry with a light airy texture, topped with a delicate, but generous, amount of maple icing." Huh? I can only imagine what their response might be.

Okay, goofy examples, I suppose, but there is a fundamental lesson for cancer registrars here. If you do not speak in your customer's language, you will lose them before you've even begun. As a cancer registrar, you have the corner on the language market for what applies to our business. We often speak in "code" using acronyms and shortcuts, or use incredibly detailed descriptions that no one else understands or wants to hear.

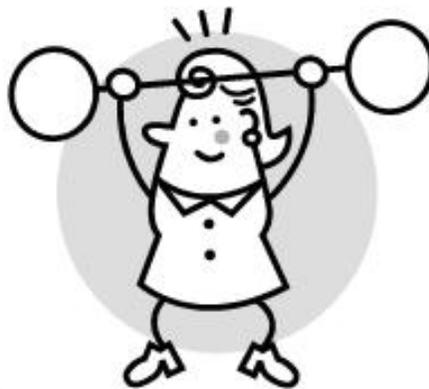
Many reading this article are already speaking the language of their customers—at least, I hope they are. But for some, the challenge of communicating in a language that is easily understood and well received is a daily effort. Perhaps you are intimidated by your customers or are reluctant to try something new. So, here's a secret: If you want to learn to speak another language, listen to it being spoken. For example, if you want to learn how to order a French cruller in French, go to France.

Communicating with physicians, administrators and peers is no different. You need to know what they want and you need to use *their* language to communicate with them. Listen, and I mean *really listen*, to how they talk with one another. Then, when you communicate with them in their language and they reject your thoughts or plans without so much as a blink of the eye, do not be hurt, offended or put off. It simply means that a piece of information was missing, or the delivery was not "coded" in such a way that it elicited a response.

The important point I want to make is that you need to address whatever it is that is important to your customers and do it quickly and clearly. If all else fails and you seem to be losing ground because of a communication issue, you can quietly approach them and ask them what they want to know about cancer registry performance. Ask *them* what is important, how often they want to hear it, and how best to communicate with them. Be willing to accept what they say and to follow through using their language. Your willingness to listen to their needs and to speak in their language is a powerful tool that will take you far in business and personal success.

Finally, whenever you are rethinking how to communicate with your customers set aside your pride and feelings. Recognize that they are not sitting at their meticulously organized desk, with hands folded in front of them, waiting to hear from their cancer registrar. Remember that their schedules are as hectic, or more, than yours. So, catch their attention. Make it worth their while. And give them something positive to remember.

*Michele is an independent consultant, speaker and trainer and provides cancer registry services through her Web sites at [www.RegistryMindset.com](http://www.RegistryMindset.com) and [www.CancerRegistryTraining.com](http://www.CancerRegistryTraining.com). Your feedback is welcomed by email at [michele@michelewebb.com](mailto:michele@michelewebb.com).*



## Cancer Forum: Combining Community and Experience—Getting Started

Asa Carter, CTR; Vicki Chiappetta, RHIA, CTR; Anna Delev, CTR; Debbie Etheridge, CTR; Donna Gress, RHIT, CTR; Lisa Landvogt, CTR

In the fall of 2010, the Commission on Cancer (CoC) officially launched the new CAAnswer Forum to replace the Inquiry and Response (I&R) System.

The CAAnswer Forum is a Web-based and robust virtual bulletin board accessible to all cancer care professionals. The new format allows specific forums for discussion on all relevant topics such as American Joint Committee on Cancer (AJCC) TNM Staging, CoC Cancer Program Standards, Collaborative Stage (CS), Facility Oncology Registry Data Standards (FORDS), and National Cancer Data Base (NCDB) Quality Tools.

There are multiple reasons for changing to a bulletin board system. First, an online bulletin board will foster the development of a community of cancer care experts who are performing registry operations within cancer programs every day, and who have a wealth of practical experience to share. Second, this new interactive system allows for real-time responses to questions from experts who can serve as mentors to their peers. Finally, the I&R System was antiquated in both software and process, creating delays in responding to a person who submitted a question.

Using CAAnswer Forum, the cancer care community can post questions to a variety of forums, as well as answer questions that others have posted, thus becoming a source of information that is available 24 hours per day, 7 days per week. The exception to the community-based response process is the questions submitted to the CS forum. CS questions will be answered by the Collaborative Staging Technical Advisory Panel (CTAP). This panel consists of members from the CSv2 mapping team (who wrote the code structures for the schemas) and the CSv2 education and training team (responsible for writing the webinars and training the trainers). The team also includes many registrars from within the registry community.

While the I&R System has been retired and is no longer accepting new questions, the I&R data base continues to be available in a read-only format as many questions and answers remain relevant to program operation and data collection.

If you have not taken the opportunity to register for the new CAAnswer Forum, log on now at <http://cancerbulletin.facs.org/forums> and let's get started!

### Registration Tips

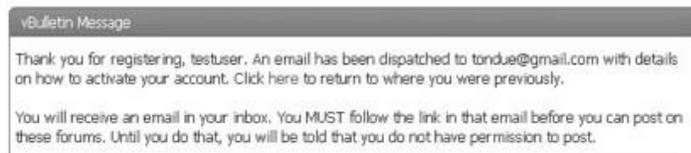
To become part of CAAnswer Forum, you must register and become a member (user) in the new system. Registration is a 2-step process.

#### Step 1

Starting from the home page, click the "Register" button located at the top right corner of the page.



The registration page will open and you will be prompted to fill in all the required information. Click on "Complete Registration" at the bottom of the page and the following message will appear:



#### Step 2 (required for full participation in CAAnswer Forum)

At this time, please check your email as CAAnswer Forum will send a message to the email address you provided. This email instructs you to click the link provided to fully activate your account. Click the link just below "To complete your registration, please visit this URL." Missing this step will result in an incomplete registration and provide only limited access to the CAAnswer Forum. You will not be able to participate in either posting or responding to questions.

Once you have successfully activated your account, registration is complete. You are now free to move about the new CAAnswer Forum.

### Resource Section

After successfully logging in, please review the Resources section, located on the left side of the screen.

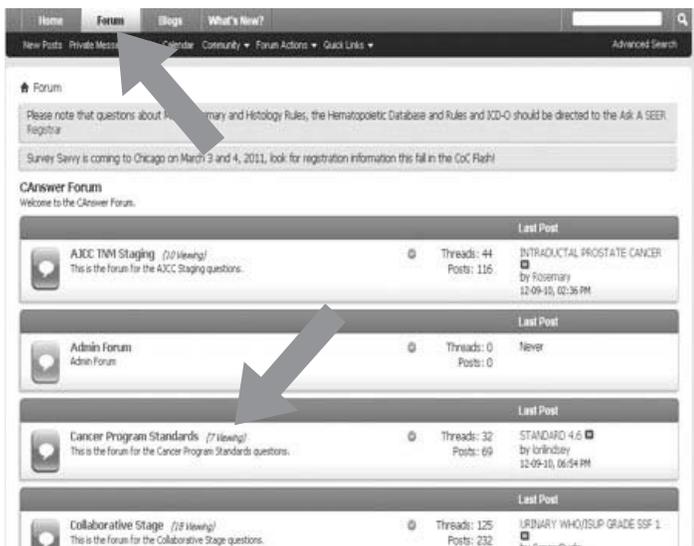


The Resources section provides information about the forum categories. For example, click on "AJCC TNM Staging" and you will find a list of frequently asked questions, related articles, and a link to the current staging manual.

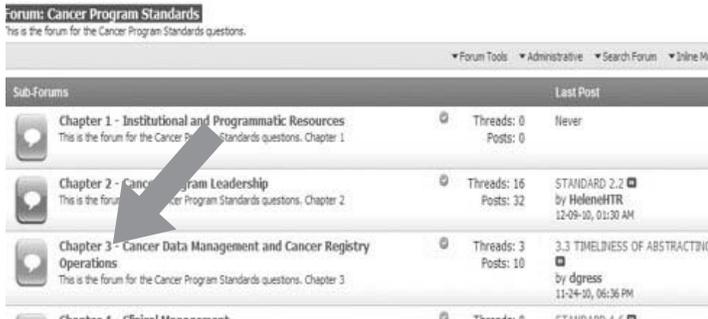
The Resources section is where the I&R Archives is located. Before posting a new question to a forum, you may want to search the I&R Archives for your answer.

### Post a New Thread (submit a question)

To post a question, you must first click on the “Forum” button at the top of the page. A drop down list of categories will appear. Select the best category for your question. For example, if your question pertains to meeting a standard, click on “Cancer Program Standards.”



A page will open to select a sub-forum to further categorize your question. Click on the appropriate sub-forum. For example, if your question is about abstracting timeliness (which is standard 3.3 in the Cancer Data Management and Cancer Registry chapter), click on “Chapter 3.”



Then, click on “Post a New Thread” and a box will open. Enter your question and click “Submit New Thread” at the bottom of the page.

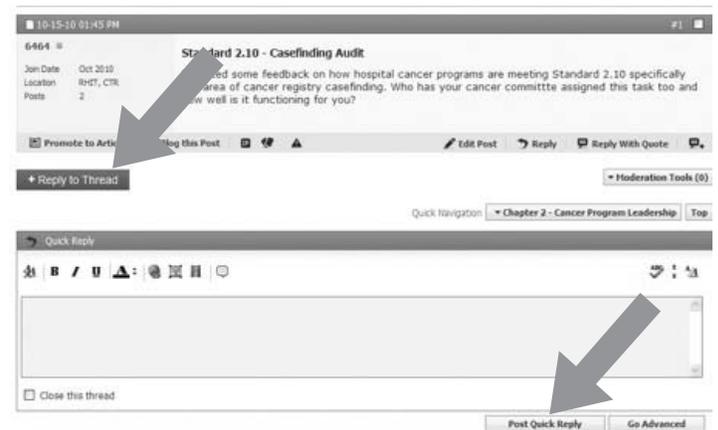


### Reply to a Thread (answer a question)

Locate the question you want to answer in the sub-forum.



Open the question and click on “Reply to Thread.” Type in the answer and click on “Post Quick Reply” at the bottom on the page



Now that you are a member of the CAnswer Forum, and have had a brief introduction to submitting a question and answering a question, take this opportunity to navigate the new system and discover the many functions available in the CAnswer Forum.

We look forward to your participation and encourage you to continue accessing the CAnswer Forum. The Commission on Cancer (CoC) will continue to provide information on the CAnswer Forum. Watch for upcoming CoC Flash articles.

For further follow-up on this article, please contact Debbie Etheridge, CTR, Cancer Program Specialist at [detheridge@facs.org](mailto:detheridge@facs.org) or (312) 202-5291.

## CORRECT ANSWERS FOR FALL 2010

### JOURNAL OF REGISTRY MANAGEMENT CONTINUING EDUCATION QUIZ

#### COLLABORATIVE STAGE DATA COLLECTION SYSTEM, VERSION 2: AN INTRODUCTION TO SITE-SPECIFIC FACTORS: A NEW FOCUS OF ABSTRACTING

- Which of the following statements is FALSE?
  - The changes in the seventh edition AJCC *Cancer Staging Manual* were evidence-based
  - The changes in the seventh edition AJCC *Cancer Staging Manual* were based on the analysis of hundreds or thousands of cases
  - The T, N, and M in the form of the stage group remain an important prognostic factor and an important component of personalized medicine for treatment decisions
  - The Collaborative Stage Data Collection System (CSv2) is based on SEER Summary Staging**
- Part I of CSv2 is divided into two sections. Section 1 includes the general CS rules plus the rules for the individual data items. Section 2 includes which of the following?
  - information about site-specific issues, such as the lymph node data items for head and neck and breast
  - clarification of problem areas
  - detailed information on lab values, tumor markers, and other site-specific factors
  - all of the above**
- Reasons cited for TNM staging not meeting the needs of clinicians and patients include all of the following, except:
  - a desire for a more generalized approach to medicine**
  - anatomic staging by itself was not sufficient to predict individual outcomes for some types of cancer
  - additional information was needed to plan more personalized treatments
  - additional diagnostic methods and alternative ways of estimating the patient's prognosis have been developed that for some primary cancers are more useful than anatomic staging
- A prognostic factor is one
  - that helps estimate the patient's outcome, whether that is recurrence or overall survival**
  - which predicts whether the patient will respond to a particular drug or type of treatment
  - both a and b above
  - none of the above
- Estrogen and progesterone receptor status is an important predictor of whether the patient will respond to
  - hormone therapy**
  - chemotherapy
  - radiation therapy
  - combination therapy
- Overexpression of HER2 receptors
  - is both a prognostic and predictive factor for breast cancer
  - indicates that the tumor may grow more aggressively and recur sooner
  - both a and b above**
  - none of the above
- All of the following statements about the circumferential resection margin (CRM) are correct, except the CRM:
  - is the width of the surgical margin at the deepest part of the tumor in areas of the large intestine or rectum without, or only partially covered by serosa
  - is the distance to the proximal and distal margins of the colon specimen**
  - may be referred to as the mesenteric margin in areas such as the transverse colon, where serosa completely surrounds the bowel
  - is the most important predictor of local recurrence for rectal cancers
- Most tumor markers and lab values are not needed for deriving T, N, M, or stage group, but provide the clinician with important information about the cancer.
  - true**
  - false
- Which of the following statements is correct?
  - KRAS is an oncogene and a prognostic site-specific factor in colorectal cancer
  - Stage IV colorectal patients should be tested for KRAS if any chemotherapeutic agent is being considered
  - The presence of 18q LOH is an adverse prognostic factor and may predict resistance to fluorouracil-based chemotherapy**
  - 18q Loss of Heterozygosity (LOH) is a colorectal predictive factor that, when present, results in tumor suppression
- All of the following descriptions of tumor markers are correct, except:
  - AFP and hCG measured before treatment are used to assess the histology of testicular tumors
  - Many tumor markers are non-specific but have value in monitoring for possible recurrence of known cancer
  - Individuals who acquire a mutated form of the JAK-2 gene are more susceptible to develop a myeloproliferative disorder (MPD)
  - CA-125 is specific to ovarian or primary peritoneal cancers and is useful as a screening test for these two cancers**

**COMPARISONS OF DIRECTLY CODED SEER SUMMARY STAGE 2000 AND COLLABORATIVE STAGING DERIVED SEER SUMMARY STAGE 2000**

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

**After reading this article and taking the quiz, the participants will be able to:**

- Compare and contrast the 3 main staging systems
- Identify problems associated with the comparability of the SEER Summary Stage 2000 (SS2000) and Collaborative Stage derived Summary Stage 2000 (CSdSS2000)
- Explain how differences in coding definitions for direct extension and/or lymph node involvement may contribute to certain stage differences between 2003 and 2004

1. The staging system(s) used primarily by clinicians for planning treatments and evaluating outcomes is/are:
  - a) Collaborative Staging (CS)
  - b) American Joint Committee on Cancer's Tumor Node Metastasis (AJCC TNM)
  - c) Surveillance, Epidemiology, and End Results (SEER) Summary Stage System
  - d) all of the above
2. SEER Summary Stage is used
  - a) mostly by epidemiologists
  - b) to monitor stage trends
  - c) to evaluate the effectiveness of intervention programs for early detection
  - d) all of the above
3. The Collaborative Stage derived Summary Stage 2000 (CSdSS2000) refers to the Summary Stage that was directly coded based on the SEER Summary Stage 2000 manual.
  - a) true
  - b) false
4. The data used in this study include:
  - a) 2001–2004 data from 400 cancer registries
  - b) invasive and in situ cancers
  - c) data from states that met the NAACCR standards for high-quality incidence data
  - d) systemic diseases such as multiple myeloma and leukemia
5. Most of the cancer sites (30 out of 34) had significant differences in stage distribution between 2003 and 2004.
  - a) true
  - b) false
6. According to Table 1, *Attributable factors for changes in stage distribution between 2003 and 2004*, the following sites had significant stage differences attributable to 2001–2004 linear trends:
  - a) pancreas, stomach, thyroid, and other non-epithelial skin
  - b) bladder, cervix, colon, kidney, and renal pelvis
  - c) anorectum, cranial nerves, Hodgkin lymphoma, and vagina
  - d) brain, breast, liver, and prostate
7. For colon cancers, direct extension to the nonperitonealized pericolic tissues is
  - a) coded as localized disease in the CS manual
  - b) used to define direct extension in the SS2000 manual
  - c) appropriately coded to distant disease in the SS2000 manual
  - d) all of the above
8. The observed differences in stage distributions between 2003 and 2004 cases in this study are inconsistent with those reported by the New York Cancer Registry.
  - a) true
  - b) false
9. Limitations of this study include
  - a) SS2000 manual was compared only with the Version Two of the CS manual
  - b) all changes in stage distribution from 2003 to 2004 could be explained by coding errors
  - c) the impact of changes in coding definitions of direct extension and/or lymph node involvement on stage distributions could not be quantified
  - d) double-coded stage data allowed assessment of agreement rates of the 2 staging systems using the Kappa statistic method
10. In the future, revisions in staging systems
  - a) are unlikely to continue
  - b) may reflect changes in clinical knowledge and practice
  - c) should be implemented prior to consideration of comparability issues
  - d) should avoid double-coded stage data



# Journal of Registry Management

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## Multiple Author Index—Vol. 37 (2010)

### A

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**Schneiderman, Chris P.**

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**Schoellhorn K. Janine**

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**T****Tajahmad, Akram**

Dastgiri S, Kalankesh LR, Heidarzadeh M, Tajahmad A, Rezaian E. A New Registry of Congenital Anomalies in Iran. Spring;37(1):27–29.

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**Tao, Zhen**

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**Trebino, Diana**

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## V

### **Veeranki, Sreenivas P.**

Veeranki SP, Brooks B, Bolick S, Robichaux M, Aldrich T. Quality of Care: The Role of Disease Registries. Winter;37(4):133–136.

## W

### **Watkins, Sharon M.**

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### **Webb, Michelle A.**

Webb MA. Raising The Bar: Justifying Registry Operations. Spring;37(1):35–36.

Webb MA. Raising The Bar: Act Like You Belong. Summer;37(2):75–76.

Webb MA. Raising the Bar: Speaking Your Customer's Language. Winter;37(4):165.

### **Webster, Pamela**

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Wu X, Yu Q, Andrews PA, Ranganath P, Qiao B, Ajani U, Wohler B, Zhang Z. Comparisons of Directly Coded SEER Summary Stage 2000 and Collaborative Staging Derived SEER Summary Stage 2000. Winter;37(4):137–140.

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Wu X, Yu Q, Andrews PA, Ranganath P, Qiao B, Ajani U, Wohler B, Zhang Z. Comparisons of Directly Coded SEER Summary Stage 2000 and Collaborative Staging Derived SEER Summary Stage 2000. Winter;37(4):137–140.

## Y

### **Yin, Daixin**

Johnson CJ, Weir HK, Yin D, Niu X. The Impact of Patient Follow-up on Population-based Survival Rates. Fall;37(3):86–103.

## Yu, Qingzhao

Wu X, Yu Q, Andrews PA, Ranganath P, Qiao B, Ajani U, Wohler B, Zhang Z. Comparisons of Directly Coded SEER Summary Stage 2000 and Collaborative Staging Derived SEER Summary Stage 2000. Winter;37(4):137–140.

## Z

### **Zhang, Zhenzhen**

Wu X, Yu Q, Andrews PA, Ranganath P, Qiao B, Ajani U, Wohler B, Zhang Z. Comparisons of Directly Coded SEER Summary Stage 2000 and Collaborative Staging Derived SEER Summary Stage 2000. Winter;37(4):137–140.

## Key Word Index—Vol. 37 (2010)

## A

### **Abstracting**

Fritz A. Collaborative Stage Data Collection System, Version 2: An Introduction to Site-Specific Factors: A New Focus of Abstracting. Fall;37(3):122–124.

Roberson DC, Harrison D. Fall 2010 Continuing Education Quiz. Fall;37(3):127.

Roberson DC, Harrison D. Fall 2010 Continuing Education Quiz Answers. Winter;37(4):168.

### **Accuracy**

Roberson DC, Harrison D. Winter 2009 Continuing Education Quiz Answers. Spring;37(1):37.

### **Adobe Reader**

Fritz A. In My Opinion: Adobe Reader Tools for CSv2 and the Heme Coding Manual. Summer;37(2):71–74.

### **AI/AN**

Hoopes MJ, Taulii M, Weiser TM, Brucker R, Becker TM. Including Self-Reported Race to Improve Cancer Surveillance Data for American Indians and Alaska Natives in Washington State. Summer;37(2):43–48.

### **Alaska**

Schoellhorn KJ, Collins S. Evaluation of Passive Surveillance for NTD-affected Births in Alaska: a Case Verification Study, Birth Years 1996–2007. Spring;37(1):4–9.

### **Alaska Native**

Hoopes MJ, Taulii M, Weiser TM, Brucker R, Becker TM. Including Self-Reported Race to Improve Cancer Surveillance Data for American Indians and Alaska Natives in Washington State. Summer;37(2):43–48.

### **American Indian**

Hoopes MJ, Taulii M, Weiser TM, Brucker R, Becker TM. Including Self-Reported Race to Improve Cancer Surveillance Data for American Indians and Alaska Natives in Washington State. Summer;37(2):43–48.

### **Analytic**

Phillips JL. New Class of Case Definitions Implemented by the American College of Surgeons in 2010. Fall;37(3):83–85.

## **Automation**

Penberthy LT, McClish D, Agovino P. Impact of Automated Data Collection from Urology Offices—Improving Incidence and Treatment Reporting in Urologic Cancers. Winter;37(4):141–147.

## **B**

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### **Birth Certificates**

Luquetti DV, Koifman RJ. Validity and Reliability of the Brazilian Birth Certificate for Reporting Birth Defects. Fall;37(3):112–120.

### **Birth Defects**

Dastgiri S, Kalankesh LR, Heidarzadeh M, Tajahmad A, Rezaian E. A New Registry of Congenital Anomalies in Iran. Spring;37(1):27–29.

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Schneiderman CP, Davis FG. Epi Reviews: Data Directions. Spring;37(1):30.

Schoellhorn KJ, Collins S. Evaluation of Passive Surveillance for NTD-affected Births in Alaska: a Case Verification Study, Birth Years 1996–2007. Spring;37(1):4–9.

Birth Defects Surveillance

Wang Y, Le LH, Wang X, Tao Z, Druschel CD, Cross P, Hwang S. Development of Web-Based Geocoding Applications for the Population-Based Birth Defects Surveillance System in New York State. Spring;37(1):16–21.

Wang Y, O'Leary LA, Rickard RS, Mason CA. Geocoding Capacity of Birth Defects Surveillance Programs: Results from the National Birth Defects Prevention Network Geocoding Survey. Spring;37(1):22–26.

### **Bladder Cancer**

Penberthy LT, McClish D, Agovino P. Impact of Automated Data Collection from Urology Offices—Improving Incidence and Treatment Reporting in Urologic Cancers. Winter;37(4):141–147.

## **C**

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### **Call for Data**

Boscoe FP. Towards the Use of a Census Tract Poverty Indicator Variable in Cancer Surveillance. Winter;37(4):148–151.

### **Cancer**

Hoopes MJ, Taualii M, Weiser TM, Brucker R, Becker TM. Including Self-Reported Race to Improve Cancer Surveillance Data for American Indians and Alaska Natives in Washington State. Summer;37(2):43–48.

Polednak AP, Phillips CE. Obtaining Data on Comorbid Diabetes among Patients in a US Population-based Tumor Registry. Summer;37(2):57–64.

Roberson DC, Harrison D. Summer 2010 Continuing Education Quiz. Summer;37(2):57–64.

Roberson DC, Harrison D. Summer 2010 Continuing Education Quiz Answers. Fall;37(3):126.

Webster P, Rousseau D, Maranda R. A Report on Rhode Island's Efforts to Ameliorate the CTR Shortage. Fall;37(3):104–106.

### **Cancer Data Reporting**

Celaya M, Riddle BL, Cherala SS, Armenti KR, Rees JR. Reliability of Rapid Reporting of Cancers in New Hampshire. Fall;37(3):107–111.

### **Cancer Forum**

Carter A, Chiappetta V, Deleva A, Etheridge D, Gress D, Landvogt L. Cancer Forum: Combining Community and Experience—Getting Started. Winter;37(4):166–167.

### **Cancer Registries**

Celaya M, Riddle BL, Cherala SS, Armenti KR, Rees JR. Reliability of Rapid Reporting of Cancers in New Hampshire. Fall;37(3):107–111.

Polednak AP, Phillips CE. Obtaining Data on Comorbid Diabetes among Patients in a US Population-based Tumor Registry. Summer;37(2):57–64.

Roberson DC, Harrison D. Summer 2010 Continuing Education Quiz. Summer;37(2):57–64.

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### **Cancer Registry**

Johnson CJ, Weir HK, Yin D, Niu X. The Impact of Patient Follow-up on Population-based Survival Rates. Fall;37(3):86–103.

Roberson DC, Harrison D. Winter 2010 Continuing Education Quiz. Winter;37(4):169.

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### **Cancer Stage**

Roberson DC, Harrison D. Winter 2010 Continuing Education Quiz. Winter;37(4):169.

Wu X, Yu Q, Andrews PA, Ranganath P, Qiao B, Ajani U, Wohler B, Zhang Z. Comparisons of Directly Coded SEER Summary Stage 2000 and Collaborative Staging Derived SEER Summary Stage 2000. Winter;37(4):137–140.

### **Cancer Surveillance**

Celaya M, Riddle BL, Cherala SS, Armenti KR, Rees JR. Reliability of Rapid Reporting of Cancers in New Hampshire. Fall;37(3):107–111.

Penberthy LT, McClish D, Agovino P. Impact of Automated Data Collection from Urology Offices—Improving Incidence and Treatment Reporting in Urologic Cancers. Winter;37(4):141–147.

### **CAP Cancer Checklists**

Roberson DC, Harrison D. Winter 2009 Continuing Education Quiz Answers. Spring;37(1):37.

### **Census Tract**

Boscoe FP. Towards the Use of a Census Tract Poverty Indicator Variable in Cancer Surveillance. Winter;37(4):148–151.

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## **Change**

Boudreaux C. Experiencing Change: The Users' Perspective (CSv2). *Winter*;37(4):163.

## **Class of Case**

Phillips JL. New Class of Case Definitions Implemented by the American College of Surgeons in 2010. *Fall*;37(3):83–85.

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Carter A, Chiappetta V, Deleva A, Etheridge D, Gress D, Landvogt L. The Inquiry and Response System: Standard 4.6—Understanding Compliance and Commendation. *Spring*;37(1):31–32.

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Boudreaux C. Experiencing Change: The Users' Perspective (CSv2). *Winter*;37(4):163.

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Polednak AP, Phillips CE. Obtaining Data on Comorbid Diabetes among Patients in a US Population-based Tumor Registry. *Summer*;37(2):57–64.

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## **Compliance**

Dearmon, B. How I Do It: Implementing Measures to Improve Cancer Program Practice Profile Reports (CP3R) Compliance Rates for Breast, Colon, and Rectal Cancers. *Summer*;37(2):65–66.

## **Congenital Anomalies**

Dastgiri S, Kalankesh LR, Heidarzadeh M, Tajahmad A, Rezaian E. A New Registry of Congenital Anomalies in Iran. *Spring*;37(1):27–29.

## **Congenital Malformations**

Roberson DC, Harrison D. Spring 2010 Continuing Education Quiz. *Spring*;37(1):38.

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## **Congenital Malformations Registry**

Wang Y, Le LH, Wang X, Tao Z, Druschel CD, Cross P, Hwang S. Development of Web-Based Geocoding Applications for the Population-Based Birth Defects Surveillance System in New York State. *Spring*;37(1):16–21.

## **Cost**

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## **CP3R**

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## **D**

### **Database**

Roberson DC, Harrison D. Spring 2010 Continuing Education Quiz. *Spring*;37(1):38.

Roberson DC, Harrison D. Summer 2010 Continuing Education Quiz Answers. *Summer*;37(2):77.

Salemi JL, Hauser KW, Tanner JP, Sampat D, Correia JA, Watkins SM, Kirby RS. Developing a Database Management System to Support Birth Defects Surveillance in Florida. *Spring*;37(1):10–15.

### **Database Management System**

Schneiderman CP, Davis FG. Epi Reviews: Data Directions. *Spring*;37(1):30.

### **Data Quality**

Celaya M, Riddle BL, Cherala SS, Armenti KR, Rees JR. Reliability of Rapid Reporting of Cancers in New Hampshire. *Fall*;37(3):107–111.

### **Diabetes Mellitus**

Polednak AP, Phillips CE. Obtaining Data on Comorbid Diabetes among Patients in a US Population-based Tumor Registry. *Summer*;37(2):57–64.

Roberson DC, Harrison D. Summer 2010 Continuing Education Quiz. *Summer*;37(2):57–64.

Roberson DC, Harrison D. Summer 2010 Continuing Education Quiz Answers. *Fall*;37(3):126.

### **Disclosure Risk**

Boscoe FP. Towards the Use of a Census Tract Poverty Indicator Variable in Cancer Surveillance. *Winter*;37(4):148–151.

### **Disease Registries**

Jain S, Kanarek N, Arceci RJ. Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking. *Winter*;37(4):156–162.

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## **E**

### **Economics**

Tangka F, Subramanian S, Beebe MC, Trebino D, Michaud F. Economic Assessment of Central Cancer Registry Operations, Part III: Results from 5 Programs. *Winter*;37(4):152–155.

## **Electronic Transmission**

Roberson DC, Harrison D. Winter 2009 Continuing Education Quiz Answers. Spring;37(1):37.

## **Epidemiology**

Dastgiri S, Kalankesh LR, Heidarzadeh M, Tajahmad A, Rezaian E. A New Registry of Congenital Anomalies in Iran. Spring;37(1):27–29.

## **F**

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### **Florida**

Roberson DC, Harrison D. Spring 2010 Continuing Education Quiz. Spring;37(1):38.

Roberson DC, Harrison D. Summer 2010 Continuing Education Quiz Answers. Summer;37(2):77.

Salemi JL, Hauser KW, Tanner JP, Sampat D, Correia JA, Watkins SM, Kirby RS. Developing a Database Management System to Support Birth Defects Surveillance in Florida. Spring;37(1):10–15.

### **Follow-Up**

Johnson CJ, Weir HK, Yin D, Niu X. The Impact of Patient Follow-up on Population-based Survival Rates. Fall;37(3):86–103.

### **FORDS**

Phillips JL. New Class of Case Definitions Implemented by the American College of Surgeons in 2010. Fall;37(3):83–85.

## **G**

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### **Geocoding**

Lin G, Gray J, Qu M. Improving Geocoding Outcomes for the Nebraska Cancer Registry: Learning from Proven Practices. Summer;37(2):49–56.

Wang Y, Le LH, Wang X, Tao Z, Druschel CD, Cross P, Hwang S. Development of Web-Based Geocoding Applications for the Population-Based Birth Defects Surveillance System in New York State. Spring;37(1):16–21.

Wang Y, O'Leary LA, Rickard RS, Mason CA. Geocoding Capacity of Birth Defects Surveillance Programs: Results from the National Birth Defects Prevention Network Geocoding Survey. Spring;37(1):22–26.

## **H**

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### **Hand-Schuller-Christian Disease**

Jain S, Kanarek N, Arceci RJ. Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking. Winter;37(4):156–162.

### **Hematopoietic Neoplasms Coding Manual**

Fritz A. In My Opinion: Adobe Reader Tools for CSV2 and the Heme Coding Manual. Summer;37(2):71–74.

### **Histiocytosis**

Jain S, Kanarek N, Arceci RJ. Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking. Winter;37(4):156–162.

## **I**

---

### **Incidence**

Hoopes MJ, Tauallii M, Weiser TM, Brucker R, Becker TM. Including Self-Reported Race to Improve Cancer Surveillance Data for American Indians and Alaska Natives in Washington State. Summer;37(2):43–48.

## **Information Systems**

Luquetti DV, Koifman RJ. Validity and Reliability of the Brazilian Birth Certificate for Reporting Birth Defects. Fall;37(3):112–120.

## **Inquiry & Response System**

Carter A, Chiappetta V, Deleva A, Etheridge D, Gress D, Landvogt L. The Inquiry and Response System: Standard 4.6—Understanding Compliance and Commendation. Spring;37(1):31–32.

Carter A, Chiappetta V, Deleva A, Etheridge D, Gress D, Landvogt L. The Inquiry and Response System: Knowledge Is Power—Chapter 7: Cancer Program Standards, 2009 Revised Edition. Summer;37(2):69–70.

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## **Iran**

Dastgiri S, Kalankesh LR, Heidarzadeh M, Tajahmad A, Rezaian E. A New Registry of Congenital Anomalies in Iran. Spring;37(1):27–29.

## **L**

---

### **Langerhans Cell Histiocytosis**

Jain S, Kanarek N, Arceci RJ. Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking. Winter;37(4):156–162.

### **Letterer-Siwe Disease**

Jain S, Kanarek N, Arceci RJ. Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking. Winter;37(4):156–162.

## **M**

---

### **Malignant Histiocytosis**

Jain S, Kanarek N, Arceci RJ. Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking. Winter;37(4):156–162.

### **Maternal Residential Address**

Wang Y, O'Leary LA, Rickard RS, Mason CA. Geocoding Capacity of Birth Defects Surveillance Programs: Results from the National Birth Defects Prevention Network Geocoding Survey. Spring;37(1):22–26.

### **Misclassification**

Hoopes MJ, Tauallii M, Weiser TM, Brucker R, Becker TM. Including Self-Reported Race to Improve Cancer Surveillance Data for American Indians and Alaska Natives in Washington State. Summer;37(2):43–48.

### **Modeling**

Davis FG. Epi Reviews: Data Directions. Winter;37(4):164.

### **Mortality**

Jain S, Kanarek N, Arceci RJ. Analysis of Histiocytosis Deaths in the US and Recommendations for Incidence Tracking. Winter;37(4):156–162.

## **N**

---

### **National Accreditation Program for Breast Centers**

Burgin C. NAPBC Accreditation Gains National Attention. Fall;37(3):121.

### **Neural Tube Defects**

Schoellhorn KJ, Collins S. Evaluation of Passive Surveillance for NTD-affected Births in Alaska: a Case Verification Study, Birth Years 1996–2007. Spring;37(1):4–9.

### **New York State**

Wang Y, Le LH, Wang X, Tao Z, Druschel CD, Cross P, Hwang S. Development of Web-Based Geocoding Applications for the Population-Based Birth Defects Surveillance System in New York State. Spring;37(1):16–21.

## **P**

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### **Passive Surveillance**

Schoellhorn KJ, Collins S. Evaluation of Passive Surveillance for NTD-affected Births in Alaska: a Case Verification Study, Birth Years 1996–2007. Spring;37(1):4–9.

### **Positive Predictive Value (PPV)**

Schoellhorn KJ, Collins S. Evaluation of Passive Surveillance for NTD-affected Births in Alaska: a Case Verification Study, Birth Years 1996–2007. Spring;37(1):4–9.

### **Poverty**

Boscoe FP. Towards the Use of a Census Tract Poverty Indicator Variable in Cancer Surveillance. Winter;37(4):148–151.

### **Pregnancy Registry**

Schneiderman CP, Davis FG. Epi Reviews: Data Directions. Spring;37(1):30.

### **Professional Improvement**

Webb MA. Raising the Bar: Act Like You Belong. Summer;37(2):75–76.  
Webb MA. Raising the Bar: Speaking Your Customer's Language. Winter;37(4):165.

### **Prostate Cancer**

Penberthy LT, McClish D, Agovino P. Impact of Automated Data Collection from Urology Offices—Improving Incidence and Treatment Reporting in Urologic Cancers. Winter;37(4):141–147.

## **Q**

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### **Quality of Care**

Veeranki SP, Brooks B, Bolick S, Robichaux M, Aldrich T. Quality of Care: The Role of Disease Registries. Winter;37(4):133–136.

## **R**

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### **Record Linkage**

Lin G, Gray J, Qu M. Improving Geocoding Outcomes for the Nebraska Cancer Registry: Learning from Proven Practices. Summer;37(2):49–56.

### **Registrar**

Webster P, Rousseau D, Maranda R. A Report on Rhode Island's Efforts to Ameliorate the CTR Shortage. Fall;37(3):104–106.

### **Registry**

Dastgiri S, Kalankesh LR, Heidarzadeh M, Tajahmad A, Rezaian E. A New Registry of Congenital Anomalies in Iran. Spring;37(1):27–29.

### **Registry Justification**

Webb MA. Raising the Bar: Justifying Registry Operations. Spring;37(1):35–36.

### **Registry Management**

Roberson DC, Harrison D. Spring 2010 Continuing Education Quiz. Spring;37(1):38.  
Roberson DC, Harrison D. Summer 2010 Continuing Education Quiz Answers. Summer;37(2):77.  
Salemi JL, Hauser KW, Tanner JP, Sampat D, Correia JA, Watkins SM, Kirby RS. Developing a Database Management System to Support Birth Defects Surveillance in Florida. Spring;37(1):10–15.

### **Reliability**

Luquetti DV, Koifman RJ. Validity and Reliability of the Brazilian Birth Certificate for Reporting Birth Defects. Fall;37(3):112–120.

## **S**

---

### **Shortage**

Webster P, Rousseau D, Maranda R. A Report on Rhode Island's Efforts to Ameliorate the CTR Shortage. Fall;37(3):104–106.

### **Site-Specific Factors**

Fritz A. Collaborative Stage Data Collection System, Version 2: An Introduction to Site-Specific Factors: A New Focus of Abstracting. Fall;37(3):122–124.  
Roberson DC, Harrison D. Fall 2010 Continuing Education Quiz. Fall;37(3):127.  
Roberson DC, Harrison D. Fall 2010 Continuing Education Quiz Answers. Winter;37(4):168.

### **Spatial Analysis**

Lin G, Gray J, Qu M. Improving Geocoding Outcomes for the Nebraska Cancer Registry: Learning from Proven Practices. Summer;37(2):49–56.

### **Staffing**

Merrill D. How I Do It: Training and Retaining Staff in the Cancer Registry. Summer; 38(2):67–68.

### **Stage Comparability**

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### **Timeliness**

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## **U**

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### **United States**

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## **V**

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### **Validity**

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## **Title Index—Vol. 37 (2010)**

## **A**

---

### **A New Registry of Congenital Anomalies in Iran**

Dastgiri S, Kalankesh LR, Heidarzadeh M, Tajahmad A, Rezaian E. A New Registry of Congenital Anomalies in Iran. Spring;37(1):27–29.

### **A Report on Rhode Island's Efforts to Ameliorate the CTR Shortage**

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## **D**

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### **Experiencing Change: The Users' Perspective (CSv2)**

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## F

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### **Fall 2010 Continuing Education Quiz**

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### **Fall 2010 Continuing Education Quiz Answers**

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## G

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## H

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### **How I Do It: Training and Retaining Staff in the Cancer Registry**

Merrill D. How I Do It: Training and Retaining Staff in the Cancer Registry. Summer; 38(2):67–68.

## I

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### **Impact of Automated Data Collection from Urology Offices—Improving Incidence and Treatment Reporting in Urologic Cancers**

Penberthy LT, McClish D, Agovino P. Impact of Automated Data

Collection from Urology Offices—Improving Incidence and Treatment Reporting in Urologic Cancers. Winter;37(4):141–147.

### **Improving Geocoding Outcomes for the Nebraska Cancer Registry: Learning from Proven Practices**

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### **In My Opinion: The 411 on 988**

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### **In My Opinion: Adobe Reader Tools for CSV2 and the Heme Coding Manual**

Fritz A. In My Opinion: Adobe Reader Tools for CSV2 and the Heme Coding Manual. Summer;37(2):71–74.

### **Including Self-Reported Race to Improve Cancer Surveillance Data for American Indians and Alaska Natives in Washington State.**

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## N

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### **NAPBC Accreditation Gains National Attention**

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### **New Applications and Methodologies for Birth Defects Surveillance Programs**

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### **New Class of Case Definitions Implemented by the American College of Surgeons in 2010**

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## O

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### **Obtaining Data on Comorbid Diabetes among Patients in a US Population-based Tumor Registry**

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## Q

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### **Quality of Care: The Role of Disease Registries**

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## R

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### **Raising the Bar: Justifying Registry Operations**

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**S**

***Spring 2010 Continuing Education Quiz***

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***Summer 2010 Continuing Education Quiz***

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***Summer 2010 Continuing Education Quiz Answers***

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**T**

***The Impact of Patient Follow-up on Population-based Survival Rates***

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***The Inquiry and Response System: Knowledge Is Power—Chapter 7: Cancer Program Standards, 2009 Revised Edition***

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**V**

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**W**

***Winter 2009 Continuing Education Quiz Answers***

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