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Original Article

Economic Assessment of Central Cancer Registry Operations. Part I: Methods and Conceptual Framework

Sujha Subramanian, PhD[a]; Jeremy Green, BA[a]; Florence Tangka, PhD[b]; Hannah Weir, PhD[b]; Frances Michaud, CTR[b]; Donatus Ekwueme, PhD[b]

Abstract: In this article, we report on the development of methods and a framework to guide the economic evaluation of central cancer registry operations. We used both quantitative and qualitative information collected from central cancer registries funded by the National Program of Cancer Registries to develop the framework. Several factors were identified that can influence the cost 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 advanced activities performed. A range of state-level and central cancer registry-level factors may influence the cost and cost-effectiveness of registries. These findings will inform planned future economic data collection and cost and cost-effectiveness analyses of central cancer registries.

Key words: *cancer registry, cost, economics*

Introduction

Cancer is the second leading cause of death among Americans. In the United States, 1,240,046 people were diagnosed with cancer in 2002, and 557,264 died as a result of their cancers.[1] The economic impact of cancer is also high, with health care expenditures and lost productivity from illness and death in 2006 estimated at $206 billion.[2] Targeted cancer control interventions and policies are needed to reduce the burden of cancer.

The US Congress passed the Cancer Registries Amendment Act in 1992, authorizing the Centers for Disease Control and Prevention (CDC) to establish the National Program of Cancer Registries (NPCR) to help collect complete, timely, and accurate data on newly diagnosed cancer cases. NPCR-funded cancer registries are required to collect and report information on all state residents diagnosed or treated with *in situ* or invasive cancer, including residents who are diagnosed and treated outside their state of residence. NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, the Republic of Palau, and the Virgin Islands. The remaining five states are supported by funding from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. In addition, SEER operates metropolitan area cancer registries within several NPCR-funded states. Together, the NPCR and SEER collect data for the entire US population.

State registries collect data on type of cancer, stage of diagnosis, location of cancer, first course of treatment, and date and cause of death. This information enables health agencies to report on cancer trends, assess the impact of cancer prevention and control efforts, conduct research, and respond to reports of suspected increases in cancer occurrence. These data are also critical for assessing progress toward goals of cancer prevention and control, including those established by *Healthy People 2010.*

To date, no comprehensive study has analyzed the true cost of the NPCR at either the national program level or the state-based central cancer registries level. A previous study used federal funding sources to analyze state variations in the average cost per case reported by NPCR registries.[3] However, this approach is likely to result in underestimates of the true costs[4] because other sources of funding, including the state government and the SEER program, were not included. In addition, in-kind contributions to the programs were not assessed. The objective of the present study is to develop methods and a framework to guide the economic evaluation of central cancer registry operations. Using this framework, activity-based costs[5] will be obtained from all registry-funding sources, followed by a systematic cost and cost-effectiveness analysis of central registry operations. A comprehensive economic evaluation will provide the CDC and the registries with better tools for improving efficiency and making resource allocation decisions that meet program priorities.

Such an analysis requires a thorough understanding of factors that influence the total economic cost of reporting a cancer case and the cost-effectiveness of central cancer registries. Central cancer registries perform a large number of functions including aspects of core surveillance, activities related to the collection and reporting of incidence data (eg, casefinding and development of the registry database)

"Economic Assessment of Central Cancer Registry Operations. Part I: Methods and Conceptual Framework"

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The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

and advanced surveillance, activities related to enhancing surveillance data for research (eg, geocoding of cases for latitude and longitude), and linking to the National Death Index and other records for follow-up. Central cancer registries can differ in the types of advanced activities that they perform, how the facilities report data to them, and other operating characteristics.[6] These differences between the registries influence the total cost of registry operations and the cost per reported case. Therefore, before initiating any economic comparisons among the central cancer registries, it is essential to identify factors that have the potential to affect both the cost and cost-effectiveness of registry operations. These factors will form the foundation of the conceptual framework for comparative cost and cost-effectiveness analysis of registry operations.

Methods

To develop the methodological approach and framework, we used both quantitative and qualitative information from central cancer registries funded by the NPCR. In 2004, we made site visits to 4 central cancer registries to understand the data-collection infrastructure, the types of activities performed, and the type of information that should be collected to enable the cost assessment tool to quantify the cost of registry operations. The 4 registries were hand selected to ensure organizational and geographical diversity that would be representative of NPCR-funded central registries nationally. As reported in Table 1, the registries selected included those that were administered by heath departments and those that were private organizations. The registries were also diverse in their funding sources, regional location, size of area served, presence of rural areas, and volume of cases, in order to ensure generalizability to all NPCR programs.

Prior to initiating the site visits, we developed a detailed protocol and interview guide to ensure the collection of standardized information during each of the 4 site visits. The site visit protocol explained the purpose of the project and the site visit, while the interview guide requested specific information. We asked registries to provide details about resources used to perform central registry operations including staffing, contracts, and in-kind contributions. We also requested information on specific issues related to the feasibility of obtaining reliable cost estimates for all registry activities, the ability to separate the costs of core and advanced activities, and the identification of an appropriate methodology to distribute overhead costs. Finally, we interviewed registry staff representing the key functions of management, data collection and analysis, accounting, and fiscal management.

Detailed transcripts of the interviews conducted during each site visit were compiled. To analyze the qualitative data collected during the site visits, we systematically compared the responses by all 4 registries to each question on the interview guide. Qualitative information on each question was then compiled to gain a better understanding of the similarities and differences between the 4 registries in terms of staffing, contracts, in-kind contributions, allocation of overhead costs, and additional resource requirements. We also obtained organizational charts and budgets from the registries, and analyzed the budgets to identify the type and magnitude of costs that the registries expected to incur. Budgeted items were grouped into several specific categories including: staffing, travel, equipment and supplies, contracts, and other costs. To protect the identity of the 4 registries, we will refer to them as Registry A, B, C, or D throughout this article.

To supplement the site visits, we analyzed data from 45 registries for the years 2003 and 2004. The data set included all the NPCR-funded central cancer registries except for non-state-based cancer registries in the District of Columbia, Puerto Rico, the Republic of Palau, and the Virgin Islands. We analyzed registry data on all NPCR-funded activities, obtained through the Annual Program Evaluation Instrument (APEI), to further understand the registry infrastructure and activities. The registries provided information on staffing, policies and procedures, legislation, computer infrastructure, number of reporting sources, data coding, audits, use of registry data, data items and format, and advanced activities. Since 1996, all NPCR registries have completed the APEI annually for the CDC. Registries complete the APEI through a Web-based interface, and responses to key questions are retained from year to year to permit longitudinal comparisons. Built-in validation checks are provided to eliminate non-responses, to improve the validity of responses, and to minimize and eliminate potential errors.[7]

Table 1. Characteristics of Registries Selected for Site Visit

	Registry A	Registry B	Registry C	Registry D
Organizational structure	*Private organization—hospital association*	*Private organization—university*	*State health department*	*State health department*
Funding				
NPCR funding	X	X	X	X
SEER funding		X		
State funding	X	X	X	X
Other funding	X	X		
Region	Western	Southern	Northeastern	Northeastern
Size of area served	Large	Medium	Medium	Small
Presence of rural areas	Low	Medium	High	Low
Volume of cases	Low	Medium	High	Medium

Table 2. Summary of Budget Categories for Registries Who Participated in the Site Visits							
Budget Category	Registry A	Registry B	Registry C	Registry D	Average Dollars Expended	95% CI* Lower Bound	95% CI* Upper Bound
Staffing (personnel and fringe benefits)	72.3%	72.5%	67.5%	91.9%	$281,335	$170,305	$392,364
Travel	6.8%	5.5%	6.4%	2.3%	$19,923	$8,053	$31,793
Equipment & supplies	13.0%	2.7%	4.6%	0.7%	$7,375	$0	$14,938
Contractual	0.0%	12.0%	16.0%	1.6%	$36,572	$0	$75,336
Other**	8.0%	7.2%	5.6%	3.4%	$22,704	$9,657	$35,751

*CI = confidence interval.
**Other costs can include cost of software purchase, technical support, and office rent.
Source: Analysis of central cancer registry budgets

Using information reported in the APEI, we determined the number and types of sources that report cancer cases to the registries. We identified the number of hospitals and other reporting sources and the proportion of these sources reporting electronically. In addition, we noted the number of hospitals that are certified by the American College of Surgeons (ACoS) Commission on Cancer (CoC). The CoC establishes standards for 1,435 Commission-accredited cancer programs and evaluates and accredits these programs. Because of the accreditation received from ACoS, the CoC-certified facilities are presumed to provide high quality data to the central cancer registries. We were able to calculate the percent of registries performing advanced activities and report the type of advanced activities performed.

The CDC evaluates cancer registry data based on timeliness, completeness, and accuracy, following the criteria established by the North American Association of Central Cancer Registries (NAACCR)—a professional organization that develops and promotes uniform data standards for cancer registration, certifies population-based registries, and promotes the use of cancer surveillance data. Descriptive statistics were produced to identify specific problems in achieving completeness—the criterion generally most difficult to achieve. We identified the percent of registries encountering problems with staffing, software, hardware, and data exchanges. The SAS statistical package[8] was used to generate a variety of statistics for all of the measures mentioned above, including mean, range, 25th and 75th percentiles, and upper and lower bounds for 95% confidence intervals.

Using the information learned from the 4 site visits and the APEI analysis, we identified a set of factors that could affect either registry operating costs or registry effectiveness. *Cost* is defined as the value of all resources required for registry operations, regardless of funding source. A registry is considered "effective" if it meets the US Cancer Statistics publication criteria. Publication criteria are demonstrated through case ascertainment of ≥90% with ≤5% of cases being ascertained by death certificate only, ≤5% of cases missing race, ≤3% of cases missing sex and age, and ≥97% of cases passing a set of single-field and inter-field computerized edits. Advanced activities performed by a registry, such as dissemination of findings from the analysis of registry data, can result in increased effectiveness. The factors were classified as central cancer registry-level factors and state-level factors. *Central cancer registry-level factors* include factors specifically related to the operation, structure, or other specific characteristics of the registry. *State-level factors* are independent of the central registry operations and beyond the immediate control of the central registry; yet these factors play a critical role in the future cost-effectiveness comparisons of central registries.

Results

Findings from Site Visits

The NPCR registries varied in both their data-collection processes and their reporting formats. At Registry A, a centralized registry, both the registry and its reporting hospitals used the same software package allowing for relatively easy electronic data transfers. Registry B was decentralized and maintained 8 regional offices in addition to its central location. Approximately one-quarter of all hospitals in the state reported cases directly through their own hospital-based cancer registries, and central registry staff collected cases directly from the remaining hospitals and other reporting facilities. The regional registries and the central registry used the same software and exchanged data electronically. Registry C operated as a single, centralized registry in which approximately 80% of all the cases were reported by CoC-certified facilities, and nearly all of the reporting was completed electronically. Registry D was also centralized, and almost 100% of the cases were reported electronically.

All of the registries performed the core activities of management, training, database management, case ascertainment, death certificate clearance, quality assurance and improvement, analytic file development, report generation, case sharing, and meeting reporting required by the CDC and the NAACCR. The registries also carried out a wide variety of advanced activities. Registry A performed geocoding and survival analysis, Registry B participated in patterns-of-care studies and outcomes research, Registry C had implemented automated casefinding processes and record linkages, and Registry D conducted several special studies and developed geographic information systems.

Table 2 provides a summary of the budget information supplied by the registries. Staffing—including both personnel and fringe benefits—is the largest budget category at each of these 4 registries, ranging from 67.5% at Registry C to 91.9% at Registry D. Other high-cost categories include travel,

Table 3. Number and Types (Percent) of Sources Reporting to Central Cancer Registries in 2004					
Statistic	Number of Hospitals Reporting	% Hospitals Reporting Electronically	% Hospitals CoC Approved	Number of Other Reporting Sources*	% Other Sources Reporting Electronically
Mean	108	77%	31%	64	31%
Range	9–519	22%–100%	0%–78%	0–667	0%–100%
25th percentile	47	57%	17%	8	1%
75th percentile	131	100%	38%	59	44%
95% Confidence Interval:					
Lower bound	80	70%	25%	28	21%
Upper bound	136	84%	37%	100	41%

* Other sources include pathology facilities, laboratories, and physician offices.
Source: Analysis of 2004 APEI data

contracts, and other costs. A large proportion of the contractual and other costs involve resources expended on licensing database software and purchasing information technology services. Some registries reported software purchases under "other" costs while others reported these expenses under "contracts." Based on the type of software and the number of site licenses purchased, the cost ranged from zero to $30,000. Even when the software is free (eg, the CDC's Registry Plus™ package), the registry might incur costs associated with technical support for installing, maintaining, and upgrading the software and hardware systems.

Findings from the APEI Analysis

Table 3 shows the number and type of facilities reporting to 45 central cancer registries in 2004. The number of hospitals reporting cancer data to an individual registry averaged 108, with 77% reporting electronically. About one-third of these hospitals were CoC-certified. Overall, pathology facilities, laboratories, and physician's offices made up a smaller proportion of the reporting sources; the average number reporting to an individual registry was 64, with 31% reporting electronically. The ranges and percentiles in Table 2 indicate a large variation among the registries in terms of the number and types of facilities reporting.

Table 4 lists the types of advanced activities performed by the registries in 2003 and 2004. Nearly all of the registries linked their registry records with other databases such as state vital statistics. About one-half of the registries geocoded cases, and a similar number received encrypted data. A smaller proportion performed automated casefinding and survival analysis. Overall, the proportion of registries reporting specific advanced activities increased between 2003 and 2004.

Table 5 shows the percent of registries that reported specific problems in achieving completeness in data submissions in 2003 and 2004. In both years, staffing was most frequently cited as the problem in achieving completeness. More than one-half of the registries reported staffing problems at the central registry and more than 70% indicated staffing problems at the reporting facilities. Other problems frequently mentioned were related to software and hardware.

Table 4. Listing of Advanced Activities Performed by Registries		
	2003	2004
Automatic casefinding:	%	%
Pathology reports	23	26
Master disease index	21	28
Other source	33	41
Receive encrypted data	52	57
Geocode cases	46	54
Survival analysis	25	22
National Death Index (NDI)		
Link to NDI	25	28
Resolve matches	23	24
Link to records for follow-up etc.:		
State vital statistics	92	100
Dept. of Motor Vehicles	15	15
Medicare	10	13
Medicaid	10	13
Managed care orgs.	10	9

Source: Analysis of 2003 and 2004 APEI data

Table 5. Problems Reported by Registries in Achieving Completeness in Data Submissions		
Source of Reported Problem	Percent (%) of Registries Encountering Problem	
	2003	2004
Staffing shortages	56	54
Qualified staffing shortages	52	54
Software problems	21	26
Hardware problems	10	9
State data exchange problems	27	28
Reporting facility staff problems	73	78

Source: Analysis of 2003 and 2004 APEI data

Conceptual Framework for Economic Analysis

Based on the site visits and the APEI analysis, we identified several types of factors that could influence the cost and effectiveness of a registry. Table 6 groups these factors into those affecting the central-registry level versus the state level. Factors affecting the central cancer registry-level include the organizational structure, reporting formats, data-collection process, database-management software, work mix between core and advanced activities, reporting requirement to certify or fund organizations, type of funding received (NPCR, SEER, and state), and data-exchange caseload with neighboring central registries. Factors influencing the state level include the volume of cases, the number of abstracts versus incidence cases, the proportion of death-certificate-only cases, the size of the area served, the presence of rural areas, the number of certified tumor registrars in hospital-based registries, the availability of trained personnel, the local cost of living, and the quality of reporting facilities (based on CoC certification and number of certified tumor registrars available). Most of these factors could affect both the cost and the effectiveness of registries.

Figure 1 represents a framework for guiding the economic analysis of cancer registries. Registry- and state-level factors have an impact on both the cost and the effectiveness of the registries, so they must be included in performing comparisons across the registries. The state-level factors are generally beyond the control of the central registry. For instance, the volume of the cancer cases and the cost-of-living differentials are exogenous factors that cannot be directly influenced by the central registry. These factors, though, are potential confounders when comparing the cost and effectiveness of registries, and need to be controlled for in any comparative assessment. Many central registry-level factors, such as choice of database management software or data-collection process, can be modified by the registry management; therefore, these factors could be targeted to improve the cost-effectiveness of registry operations.

The effectiveness measures adopted should capture the benefits of both the core and advanced activities. As seen in the APEI analysis, registries often devote a significant proportion of their resources to advanced activities, and effectiveness measures need to acknowledge the resulting benefits. It is also important to estimate the expenses using activity-based costing, because this level of detail is required to understand the impact of state- and central registry-level factors. For example, the volume of cases is likely to have an impact on core activities such as casefinding, but will not necessarily affect the resources expended for advanced activities such as survival analysis.

Table 6. Central Cancer Registry and State-level Factors That Impact Program Cost and Effectiveness

	Impacts Program Cost	Impacts Registry Effectiveness
CENTRAL CANCER REGISTRY-LEVEL FACTORS		
Organizational structure (operated by state health department or private organization)	X	X
Reporting formats (paper, web-based, other electronic linkages, or diskettes)	X	X
Data-collection process (percent of data abstracted directly from hospitals)	X	X
Database management software	X	X
Work mix (core versus advanced activities)	X	X
Reporting requirements to certification/funding organizations	X	X
Type and level of funding (NPCR*, SEER*, state)	X	X
Data exchanged caseload and reporting nonresident cases	X	X
STATE-LEVEL FACTORS		
Volume of cases	X	
Number of abstracts versus incidence cases	X	
Proportion of death certificate-only cases	X	X
Size of area served	X	X
Presence of rural areas	X	X
Number of CTRs* in hospital-based registries	X	X
Availability of trained personnel	X	X
Cost of living in geographic location	X	
Quality of facility reporting and presence of hospital-based registries	X	X

*NPCR = National Program of Cancer Registries; SEER = Surveillance, Epidemiology, and End Results Program; CTR = certified tumor registrar.
Source: Analysis of qualitative and quantitative data

Discussion

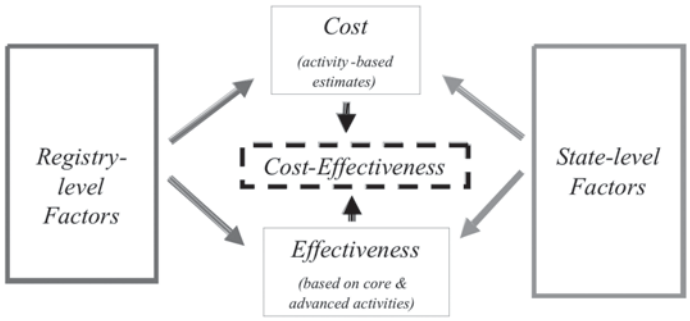
The findings from the site visits and the APEI analysis clearly highlight numerous differences among the central cancer registries, pointing to a wide range of factors at the cancer registry and the state levels that can affect the cost and effectiveness of registry operations. This study has outlined a comprehensive set of factors, based on qualitative and quantitative research, that need to be considered in any comparative assessment of cancer registries. A few of these factors were identified in previous assessments,[3,7] but this research substantially expands the types of factors that

may be involved. Future economic evaluations of cancer registries should carefully assess the impact of these factors. Failure to thoroughly account for underlying differences could result in misleading conclusions about the cost and effectiveness of registries.

In the next phase of our economic evaluation of central cancer registries, we will develop econometric models to assess the direction and the magnitude of the impact of these factors on both the cost and effectiveness of the cancer registries. The information gathered on the core and advanced activities, and the list of potential factors, will also be used to develop a comprehensive cost data-collection tool. The cost information collected with this tool will provide a standardized database that can be used to determine the costs of performing core and advanced activities. The database will be used to perform a comprehensive analysis of the cost of cancer registry operations and to evaluate the impact of state- and central registry-level factors on registry costs. Per capita costs at the state population level, as well as per capita costs for cancer cases, will be estimated. The impact of type of funding source and level of funding will be performed. The analysis will include in-kind contributions and other indirect costs as a percent of state funding to indicate support for the cancer reporting. This will help to indicate states with supportive infrastructures such as VA hospital participation. Differences between state-run and contractor-run registries will be controlled for, as will NAACCR accreditation records. A migration factor will be included for states with large seasonal migratory patterns. The percent of automated reporting and research funding will also be accounted for in the analysis. These characteristics may impact the efficiency of the registries and will help control for the inherent differences. In addition, since the list of factors affecting registry operations is not expected to be static, we will continue to identify issues that should be considered. For example, the movement toward electronic reporting will generate additional factors, including the level of connectivity in the system and the interoperability of software.

Cost considerations of public health programs are becoming increasingly important, and economic evaluations are being undertaken more frequently. Information from this study will help the CDC, other sponsors, and the registries to understand the resources required to run the central registries, to understand the efficiency of the registries, and to learn how to allocate resources to enhance the functioning of the registries. Such information will also be useful to other researchers in their economic analysis of cancer registries. We have attempted to present comprehensive methods and a framework for analyzing central cancer registry operations using both qualitative and quantitative methodology. Although the 4 pilot site visit registries were selected to be representative of all registries, the results may not be generalizable across all NPCR programs. Future data collection will include all NPCR-funded registries and data collection over several years to provide stable estimates of the cost of registry operations.

Figure 1. Framework for the economic evaluation of cancer registries



The complex nature of registry operations and the range of underlying differences among the registries mandate a comprehensive and systematic approach to economic assessment. A well-planned and thorough economic analysis can identify potential approaches for better use of scarce resources and enhance the efficiency of cancer registries in performing their vital roles. Results from the pilot test of the cost assessment tool will be presented separately in Part II of this manuscript series.

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Original Article

Revising the Multiple Primary and Histology Coding Rules

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Abstract: The National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program worked in close collaboration with representatives and experts in the field of cancer to review and revise the multiple primary and histology (MP/H) coding rules used by cancer registrars for standardized abstracting and coding of cancer surveillance data in the United States and Canada. This article examines the development of the 2007 cancer site-specific MP/H coding rules for 8 site-specific cancer sites/site groups. It also investigates the impact the rules have on registrars to make multiple primary decisions and to more accurately code tumor histology. Data presented in this article show that the new rules clarify and standardize the determination of the number of primaries. In addition, the rules make it easier for registrars to correctly assign histology codes, which more accurately represent specific histologic types and subtypes for complex, mixed, and combined tumors.

Key words: *beta test, histology, multiple primary, SEER, site-specific*

Introduction

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) collects and publishes cancer incidence, survival, and mortality data from approximately 26% of the US population. The program places a major emphasis on data quality, providing national and international leadership to the cancer surveillance community in the areas of data collection, quality improvement, and education and training. The multiple primary and histology (MP/H) coding rules have been in existence for over 25 years and have been used by cancer registrars to determine the number of primary tumors to abstract and to assign histology codes for cancer cases. SEER recognized that the rules were no longer effective for registrars and that standardized coding at the data collection level was needed.

Between 2000 and 2004, various SEER data quality assessment audits, such as reabstracting studies, case identification (casefinding) audits, and data reliability studies, were performed, which either directly or indirectly tested the MP/H coding rules. These studies and audits repeatedly revealed inconsistencies in coding that demonstrated problems with the rules. For example, a case with diffuse bilateral lung nodules might be one, two, or more primaries; or squamous cell carcinoma, NOS might be coded as nonkeratonizing squamous. These problems were exacerbated by increasingly complex diagnosis, pathology reports with more descriptors and histologic types, and non-standard use of nomenclature by pathologists.

The MP/H Coding Rules Project is Phase I of a SEER-sponsored collaborative effort to review and revise the long-established MP/H coding rules. Future phases will focus on hematopoietic diseases, gynecological, and other malignancies, as needs are identified. The purpose of revising the MP/H rules was to promote consistency by improving the instructions used by registrars to make multiple primary decisions and code histology.

Methods

In July 2002, a working group was formed to discuss plans to address the problems identified and associated with the historic MP/H coding rules. The working group formally expanded into the MP/H Task Force in January 2003. SEER took the lead on the project. The diverse MP/H Task Force consisted of 11 subcommittees (8 cancer site committees, a general instructions committee, an editing committee, and an education and training committee). The committee membership consisted of 15 state and central cancer registry representatives including 12 SEER regions, the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR), the American Joint Committee on Cancer (AJCC), the American College of Surgeons Commission on Cancer (ACoS CoC), the National Cancer Registrars Association (NCRA), the North American Association of Central Cancer Registries (NAACCR), and Canadian Cancer Registry, Statistics Canada. The MP/H Task Force reviewed the SEER Inquiry System (SINQ) **(http://seer.cancer.gov/seerinquiry/)** and findings from various SEER quality assessments performed during the years 2000 through 2004, to further identify problems using the MP/H rules. Physician guidance by specialty pathologists and clinicians was an integral part of the review and revision process. Regular consultation with the editors of the World Health Organization (WHO) International Classification of Diseases for Oncology,

"Revising the Multiple Primary and Histology Coding Rules"

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Third Edition, (ICD-O-3) helped to clarify ICD-O-3 coding rules and to ensure that the new rules accurately reflected the ICD-O-3 intent and purpose. The Clinical Advisory Panels of the CoC acted as consultants and disease experts and provided clinician advice for the overall process. The standard reference for the rules was the series of WHO Classification of Tumours, **http://www.iarc.fr/WHO-Bluebooks/.**

The MP/H Task Force recommended that the MP/H coding rules be site-specific, clearly defined, and prioritized. It was further recommended that the timing rule be revised and made site-specific. NAACCR later reinforced the necessity for the work that was already in progress by the MP/H Task Force by reporting and highlighting the MP/H problems found. In May 2003, NAACCR published "A Review of the Definition for Multiple Primary Cancers in the United States" taken from workshop proceedings in December 2002.[1] This report highlighted problems associated with the interpretation and general use of the multiple primary rules and listed specific recommendations and comments that proposed reviewing, clarifying, and possibly revising the rules. In December of 2003, the "Report to the NAACCR Board, Creation of a Record Consolidation Test File" also confirmed variability of the interpretation and application of the MP/H rules among US central cancer registries.[2]

Procedures and Responsibilities to Develop the Rules

Over the course of 3 years, the MP/H Task Force held meetings twice a month via videoconference/teleconference. The Task Force made decisions about rules development, classification of disease, and histologic types. SEER provided leadership to the project by chairing the task force, overseeing rules development, providing technical expertise, and providing historical reference through the use of the SEER database to help make rule decisions.

A major criterion in the development of the rules was that they must be site-specific. There are significant differences in the types of histology and in multiple primary decisions across different cancer sites. It was impossible to write generic coding rules when each cancer site has its own individual issues. Eight site-specific cancer sites/site groups were selected based on their high rate of occurrence in the population and/or because of their potential for high risk of human error in coding data. Breast, colon, and lung were selected because they, along with prostate, represent 60% of all cancer cases and because they are high risk for coding error. Site-specific rules were not written for prostate because there are no major problems coding histology or determining single versus multiple primaries for this site. Head and neck, melanoma, kidney, urinary (renal pelvis/ureter/bladder), and malignant brain and central nervous system tumors were also selected based on high risk. Another set of rules was developed for solid malignant tumors that occur in primary sites not covered by the site-specific rules.

The development of the new rules involved several steps. The cancer site subcommittees were appointed by the MP/H Task Force membership to draft the first copy of the new MP/H rules. The draft was reviewed and revised by the Task Force several times until approved. There were multiple rule revisions during this process. SEER staff performed an additional review and revision and pre-tested the rules. Further revisions to the rules were made based on the pre-test comments and results.

Each set of rules was written in 3 formats: flowchart, matrix, and text. The 3 formats are designed for different learning styles among users. Ensuring the consistency between the 3 rule formats was an important and labor-intensive task performed by SEER.

Beta Tests

Once the rules were drafted, the functionality and usability of the new MP/H rules were beta tested with a series of well established, Web-based reliability studies—one for each of the 8 cancer sites and one for the other sites. SEER conducted the beta tests by first calling for cases, administering the tests, and identifying opportunities to improve the rules. The test cases were actual de-identified medical records. The MP/H Task Force selected the cases for use in beta tests and reviewed the test cases and rules before testing. Study participants were registrars from hospital and central registries, state and federal programs, the CoC, NCRA, and Canadian registries. SEER oversaw the analysis and review process for beta testing and again revised the rules based on the test results.

Formal Review

Final beta test results were reported to the Implementation Oversight Board (IOB) ad hoc team and 2 NAACCR committees: the Registry Operations Committee (ROC) and the Uniform Data Standards Committee (UDSC).

The Central Brain Tumor Registry of the United States (CBTRUS) provided expertise in the review and testing of the malignant brain and central nervous system rules. The malignant brain rules were also reviewed by the AJCC Brain Tumor site team and by a physician member of ROC's Benign Brain Tumor Committee which developed rules for reporting and abstracting benign brain tumors.

The Canadian Cancer Registry, Statistics Canada provided provincial representation on the MP/H Task Force. They independently abstracted a wide variety of cancer cases and evaluated the expected impact of the new rules on cancer surveillance efforts in Canada.

The CoC Quality Integration Committee—a group of professional organizations whose membership consists of surgeons representing the ACoS—reviewed and approved the final rules. Seven CoC Clinical Advisory Group Panels **(http://www.facs.org/cancer/coc/qualityinteg.html#disease)** reviewed the rules for their respective cancer sites.

When the rules were complete, one of the final review and improvement steps started with the statistical review. A statistical committee from the National Cancer Institute's Division of Cancer Control and Population Science, and the Division of Cancer Epidemiology and Genetics, as well as Emory University, was formed to analyze the proposed rules for their impact on cancer incidence rates and for any change in histology. The statisticians reviewed site-specific MP/H tables prepared by SEER, comparing old and new rules in numeric order.

They evaluated the effect of the rule change, where possible. The tables provided a side-by-side comparison of the old rules to the new rules along with any expected change or impact resulting from each rule.

The statisticians also reviewed "timing" in the new rules. Timing was previously 2 months for all cancer sites. "Timing" represents the length of time between tumor diagnoses, and is used to determine whether a new tumor is a recurrence or a new primary. The SEER database was used to assess the impact on incidence when reviewing the timing changes. Under the new rules, timing increased for all sites except melanoma, which remained the same: 2 months.

Reliability Study and Reabstracting Field Studies

In early 2006, SEER and other North American cancer surveillance partners (CoC, NAACCR, NCRA, Canadian Cancer Registries) conducted field studies to evaluate the usability and impact of the rules and their adaptation within registry operations by implementing extensive testing. Testing consisted of a Web-based reliability study and 2 reabstracting field studies. Participants used abbreviated abstracts instead of full cancer reporting abstracts.

There was no training for participants prior to the reliability study. There were 10 cases per cancer site/site group, except for kidney which had 8 cases. Participants were required to complete a minimum of 2 cancer sites (18-20 cases). A total of 304 people participated in the study. After the completion of the study, five 4-hour meetings were held for review and reconciliation of the findings.

The 2 reabstracting field studies were central registry-based and hospital-based. Five central registries—Georgia Cancer Registry, Kentucky Cancer Registry, Utah Cancer Registry, Northern California Cancer Center (NCCC), and the New Mexico Tumor Registry—participated in the study. One to 2 hospitals within the 5 regions participated in the hospital-based component of the field study. Twenty central registrars and 8 hospital registrars used the revised rules to make multiple primary decisions and recode histology on 10–20 recent cancer cases for each of the 8 cancer sites and other sites in the registry databases. This yielded approximately 90–160 cases per registry in both studies. Each hospital provided 5–6 recent cancer cases for each of the 8 cancer sites and other sites, yielding a total of approximately 45–50 total cases per participating hospital. Five new data items were included in these studies to aide in central registry record consolidation to identify cases where multiple tumors are abstracted as a single primary, and to identify cases accessioned based on ambiguous terminology. After the reabstracting field studies were completed, two 2-hour meetings were scheduled to review the study findings with the central registry and hospital participants. SEER identified opportunities for improvement on the rules, and they were further refined.

Self-reported data on the usefulness of the rules was obtained through an exit questionnaire completed by the participants of the Web-based reliability study and the reabstracting studies. The usefulness and clarity of the instructions, terms and definitions, charts, tables, and anatomical drawings within the rules were the variables examined.

Results

After each beta test, an analysis review process took place with the site-specific cancer subcommittee. All participant answers were examined and cross-referenced to rules applied. Frequency distributions showing the number and percent of respondent answers matching the expected answers were calculated (Table 1). Based on the participants' answers, the MP/H Task Force decided whether to revise, add, or delete a rule.

The statistical reviewers documented findings where rules changed and attempted to evaluate the impact where possible (Tables 2 and 3). The timing rule, which was previously 2 months, was changed for all sites but melanoma (Table 4). The timing for abstracting a new primary for breast was changed from 2 months to 5 years. The SEER database has 565,304 cases of breast cancer. Only 2,006, or 0.35%, recurred between 2 months and 5 years (same histology, same breast). The timing rule for coding a new primary for kidney was changed from 2 months to 3 years. The total number of kidney cases in the SEER database is 54,555. There are no cases of multiple tumors of the same histology in the ipsilateral kidney occurring during the 3–36 month interval. The new timing rule for colon is one year. The total number of colon cases in the SEER database is 248,519. The number of second tumors, same histology and same segment of colon, within one year is 61 which is 0.02%. The new timing rule for lung is 3 years. Of the 393,911 lung cases, only .04% had a recurrence in the same lung with the same histology between 2 months and 3 years. The new timing rule for urinary is 3 years. For renal pelvis and ureter there are only 2 cases of recurrence in the same site, same histology within a 3-year period. There are no changes in the

Table 1. Frequency Report for Colon—All Registries, All Cases

Case: 2004001		
Data Item: Is this a multiple primary?		
Answer	*# Participants*	*% Participants*
blank	1	0.72%
Yes	130	93.53%
No	8	5.75%
Total	139	100%
Data Item: Histologic Type ICD-O-3		
Answer	*# Participants*	*% Participants*
8140	135	97.12%
8221	4	2.88%
Total	139	100%
Data Item: Histologic Type ICD-O-3 (2nd Primary)		
Answer	*# Participants*	*% Participants*
blank	9	6.47%
8140	127	91.37%
8221	3	2.16%
Total	139	100%

*The shaded rows are the expected answers.

Table 2. Sample of Comparison of Old and New Multiple Primary Rules			
Breast C500-C509 (excludes lymphoma and leukemia—M-9590–9989 and Kaposi sarcoma M9140)			
Rule	**New Rule**	**Old Rule**	**Change**
MULTIPLE TUMORS Multiple tumors may be a single primary or multiple primaries. ***Note 1:*** Tumors not described as metastases ***Note 2:*** Includes combinations of in situ and invasive			
M5	Tumors diagnosed **more than five (5) years apart** are multiple primaries.	**Several rules applicable and all would be multiple primaries except for exceptions to rule 5:** **Rule 5:** If a tumor with the same histology is identified in the same site at least *two months* after the initial/original diagnosis (metachronous), this is a separate primary. **Exception 1: This is a single primary only when the physician documents that the initial/original tumor gave rise to the later tumor.**	Old rules: 2 months. New rules: 5 years. For multiple tumors more than 5 years apart: Under new rules these are always multiples; under old rules, these are multiple primaries unless a physician states one is a recurrence or metastases.

timing rule for melanoma. Neither timing nor laterality is used to determine multiple primaries for malignant intracranial and CNS tumors.

During the 2006 reabstracting field studies, participants reported abstracting 3–4 cases before feeling comfortable using the new rules. Participants overwhelmingly (80% from the reliability study and 100% of the respondents from the reabstracting studies) found that the histology charts and tables helped clarify general versus specific terms, and when to use combination and mixed histology codes, among other items. They also found the equivalent terms and definitions useful in understanding and applying the rules.

The Web-based reliability study was designed to test the registrar's ability to read and apply the rules in a consistent manner. To test the rules more stringently, the participants were given no training. The majority of the 304 participants found the new rules and instructions more beneficial than the long-established rules. The frequency distribution results of the two reabstracting studies showed

Table 3. Sample of Comparison of Old and New Histology Coding Rules			
Renal Pelvis, Ureter, Bladder, and Other Urinary C659, C669, C670–C679, C680–C689 (excludes lymphoma and leukemia—M-9590–9989)			
Rule	**New Rule**	**Old Rule**	**Change**
SINGLE TUMOR			
H1	Code the ***histology documented by the physician when there is no tumor specimen*** or the *pathology report is not available.* ***Note 1:*** Priority for using documents to code the histology • *From reports or notes in the medical record that document or reference pathologic or cytologic findings* • *From mention of type of cancer in the medical record* ***Note 2:*** Code the specific histology when documented. ***Note 3:*** Code the histology to cancer /malignant neoplasm (8000), or carcinoma (8010) as stated by the physician when nothing more specific is documented.	Coding Instructions 1. If there is no tumor specimen, code the histology described by the medical practitioner.	Priority order for using documents to code histology established by new rules. New rules add, if the pathology report is not available. No effect on database, documents presumed current practice.
H2	Code the histology from the metastatic site when there is **no pathology/cytology specimen from the primary site.** ***Note:*** Code the behavior /3.	Coding Instructions 4. Cases reported to SEER cannot have a metastatic (/6) behavior code. If the only pathology specimen is from a metastatic site, ***code the appropriate histology code and the malignant behavior code /3.*** The primary site and its metastatic site(s) have the same basic histology.	No change

that the histology and site differences for hospitals and for central registries were similar. Of the central registry participants, 89% gave the expected histology answer and 90% chose the accurate number of primary sites. Of the hospital participants, 83% had the expected histology answer and 88% chose the accurate number of primary sites.

Based on the findings in the reliability and the two reabstracting studies, final revisions were made to the rules, and a number of training issues were identified and documented.

Training on the New Rules

Registrar training is an important component of successfully implementing the new rules. The SEER Program, in cooperation with NPCR, initiated the education process in September 2005 by establishing a Train the Trainers workshop to prepare approximately 100 registrar educators representing 48 states, Canada, Puerto Rico, and Palau, to introduce the new rules in their respective regions. The education process continued when the trainers returned in August of 2006 for a second, more in-depth, training workshop. In September 2006, the trainers began educating registrars on the new rules at autumn association meetings and workshops. Over 7,000 registrars have been trained and the number is growing.

Online training sessions for each cancer site began October 2006 and continued through April 2007. These online Webcast sessions are virtual conferences to allow registrars to view and hear presentations on the new MP/H coding rules. The live Webcasts were opened to a selected group of participants. The sessions were recorded and made available for anyone to access at any time from the SEER Web site **(http://www.seer.cancer.gov).** Instructional Web modules were also created and made available on the SEER Web site. The online Webcast training sessions and the Web modules are training options for registrars who cannot attend an in-person workshop or for anyone needing a refresher.

Further training on the MP/H rules will be done by NCRA, SEER, and NAACCR at the fall 2007 association meetings.

Discussion and Conclusion

The development of the 2007 site-specific MP/H coding rules was a huge undertaking accomplished by cancer data collection organizations working collaboratively. The creation of each set of site-specific rules involved a physician specialist, the MP/H Task Force, and as many ad hoc professionals as were needed. Consultants and specialty physicians worked to review concepts. The use of certain codes and code definitions were also reviewed by the editors of the ICD-O-3. This is the first time in the history of data collection that the same MP/H coding rules will be used by everyone in the United States and Canada.

Table 4. The Effect the Change in Timing Rules Will Have on Incidence

Tumors occurring in same site with same histology as the original tumor*

Site	Timing	# of Cases	Recurrence	
			#	%
Breast	2 mos.–60 mos.	565,304	2,006	0.35%
Kidney	2 mos.–36 mos.	54,555	0	0
Colon	2 mos.–12 mos.	248,519	61	0.02%
Lung	2 mos.–36 mos.	393,911	162	0.04%
Bladder**	2 mos.–36 mos.	127,107	387	0.30%
Renal Pelvis and Ureter	2 mos.–36 mos.	12,124	2	0

*SEER*Stat database-Incidence SEER 9 (1973–2002)

** The rule for papillary transitional cell will not change; it is always a single primary.

- Head and Neck was not presented in this table due to sheer volume. The timing rule for coding a new primary for head and neck was changed from 2 months to 5 years.

The SEER database was an important resource used to obtain data on multiple primaries and histologic types for the cancer sites. Containing 30 years of data, the database confirmed the most frequent histology and patterns of multiple primaries for select cancer sites. The SEER database also added validity to the timing rule changes in the new MP/H rules.

Another historical achievement in developing the rules was consideration of the user's learning style. The new rules are available in 3 formats and registrars choose according to their preference. During testing and training on the rules, approximately one-third of registrars preferred flowchart, one-third preferred matrix, and one-third preferred text.

Across medical specialties and subspecialties, variability in medical terminology and nomenclature has presented new challenges for disease classification and coding systems. Pathologists, radiologists, clinicians, and registrars may each interpret and apply vague and ambiguous terminology somewhat differently, depending on the context and use of the terminology and nomenclature. The revised rules will aid registrars in making multiple primary decisions and coding histology. The 2006 reliability and the 2 reabstracting field studies helped to further refine implementation processes in registry operations, informatics, and statistical reporting of cancer incidence.

The new MP/H coding rules were implemented on January 1, 2007. The rules are available on the SEER Web site and are incorporated into the 2007 SEER Program Coding and Staging Manual. Phase II of the rules development process, which is in progress, will focus on hematopoietic malignancies and will repeat the "review-and-revise" methods of Phase I.

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Original Article

Staffing a Cancer Registry in a Commission on Cancer (CoC) Approvals Program

Mary Marshall, CTR and Nora McMurrey, BA

Abstract: Kootenai Medical Center directed its cancer registry to evaluate the cancer registrar's duties and formulate a time study that would serve as the basis for future staffing of their CoC-approved registry. The cancer registry gathered information from 29 other registries for the purpose of identifying problem areas and comparing tasks performed by the registrar to their caseloads. The ultimate goal was to provide quality data that would, in turn, benefit the patient as well as the facility.

Key words: *cases, Commission on Cancer (CoC), full-time employee (FTE), staffing, task category*

Introduction

As more pharmaceutical therapies and new technologies emerge in the treatment of cancer, one has to wonder: "How do you meet the growing demand for care and provide accurate medical information?"

Kootenai Medical Center (KMC) has always provided excellent patient care. Since the opening of its first cancer clinic in 1987, the North Idaho Cancer Center (NICC), the facility has remained committed to its patients. In fact, the first published Annual Report[1] proudly stated KMC's intention in just 3 words: compassion, gratitude, and hope.

In 1987, the KMC/NICC Cancer Registry accessioned (entered into their registry database) 370 new cases. One full-time employee (FTE) collected the information and probably never imagined that by the year 2005, the registry would accession 898 new cases.

KMC/NICC grew along with the complex developments in cancer care. An onsite pharmacy was built in the clinic, a research department emerged, advances in radiation treatment—such as IMRT—were implemented, and more staff was hired, including several medical oncologists, another radiation oncologist, a nurse practitioner, a director, and an additional cancer registrar.

Even with all these amazing changes, it was clear that KMC/NICC would have to do more to meet their patients' needs. In 2003, a temporary satellite clinic was opened in a neighboring county. In 2006, the decision was made to begin new construction and keep the satellite clinic open permanently. A second satellite clinic is now being planned in a neighboring city.

KMC/NICC has always believed in the importance of accurately collecting and reporting data. The medical facility takes pride in its recognition as a CoC-approved cancer program.[2] Every 3 years KMC/NICC voluntarily undergoes a rigorous audit to evaluate a series of standards set by the CoC.

In 2006, NICC directed its cancer registry to evaluate the cancer registry duties,[3] including compiling historical and current information from 29 other CoC-approved registries, and formulating a time study that would serve as a guideline for hiring cancer registrars and running the optimal cancer registry.

Methods

Setting the Stage

The first item of business was to identify areas of concern.

1. The data should not be compromised because of an understaffed registry. With the opening of satellite clinics, data were needed to know what changes to expect in the registry.
2. The tasks performed in the registry needed to be identified and optimum staffing needed to be reviewed, not just in the number of employees needed, but also in how to effectively divide the work and determine job descriptions.

A questionnaire (Figure 1) and task tracking table (Figure 2) were developed and sent to 4 cancer registries within the Northwest. The registries agreed to document time spent in their registries and to participate in the study. The study would conclude with the enlistment of 25 other registries to provide historical data used to validate a comparison of the 5 northern (including KMC/NICC) registries' data to caseloads and FTEs of the 25 other CoC registries.

Figure 1. KMC/NICC cancer registry time study survey questions

1. Who coordinates the CoC Approval Program in your facility?
2. Who coordinates the cancer conferences in your facility?
3. Who maintains case follow-up in your facility?
4. Who does the cancer registry staff report to? (Office Manager, Radiation, Supervisor, Facility Director, Physician, etc.)
5. Does your registry have a supervisor/coordinator? If you have no supervisor/coordinator, do registrars coordinate and operate the registry splitting the work between them?
6. What tasks do you perform that you feel should not be the duties of the cancer registry?
7. Is there a difference between the role of the cancer registrar and cancer registry coordinator? (If yes, please explain.)
8. Is the estimate of 1 case per hour still appropriate for your abstracting average?
9. Are you given adequate time for continuing education and maintaining and/or learning new information?
10. List 3 problem areas in the registry that you would like to see changed and if applicable your ideas to change them.
11. List 3 procedures your registry does that could be of benefit to other registries

"Staffing a Cancer Registry in a Commission on Cancer (CoC) Approvals Program"

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Figure 2. KMC/NICC tracking table

ACTIVITY	DAILY—1 WK (Tracking)					MO HRS	YR HRS	COMMENT
Ex. Abstracting	**5**	**6**	**8**	**7**	**5**	**124**	**N/A**	
Ex. NCDB Call for Data	**x**	**x**	**x**	**x**	**x**	**1**	**12**	
Abstracting								
Pulling Charts								
Pulling Path Reports								
Pulling New Pt Consults								
Preparing Monthly Patient Case List								
Case Finding from the Hospital Disease Index List								
Maintaining Non-Reportable Index								
Cancer Conference Preparation								
Cancer Conference Meeting								
Maintaining Cancer Conference Records								
Didactic Speakers								
Cancer Committee Preparation								
Cancer Committee Meeting								
Maintaining Cancer Committee Records								
Other Meetings								
NCDB Call for Data								
CoC Special Studies								
Other Studies								
Data Requests								
Placement of Staging Forms								
Annual Reports and/or Newsletter								
Physician Staging Audit								
Registrar Completeness Audit								
Maintaining Procedure Manual								
Staff Training								
Staff Continued Education								
Maintaining CoC Standards								
SARS								
Follow-up thru Medical Record								
Follow-up Letters								
Follow-up Phone Calls								
Maintaining Follow-up Records								
Computer Activities								
Creating Documents								
Other Registry Operations								
Research Activities								
Outreach Activities								
Physician Related Tasks and/or Meetings								
State Reporting								
Other Reports								
Other:								
Other:								
Other:								

The Process Begins

The first step towards realizing the goal was to review the comments from the questionnaire completed by the 5 northern registrars on the coordination and performance of tasks and responsibilities.

Deciphering the Data

As a result of the abundance of data provided by area registrars, it was immediately clear there would be no easy formula to answer the survey questions. The following suggestions on analyzing variables were solicited from a mathematician and other cancer registrars:

1. Patterns in data were used to make comparisons; facility size, case history, current cases, CoC-approved facilities, tasks performed, along with registrar comments.
2. Data were compared with the American Cancer Society annual survival statistics[4] to look for follow-up percentages.
3. All data results would then be based on an average for specific results.
4. All variables were taken into consideration.
5. The time spent abstracting was evaluated.
6. Facilities' levels of collection capabilities—electronic, paper, and various software applications—were considered.
7. The use of some spurious data was limited or omitted.
8. The majority of the information was compiled from the 5 northern registries and, while accurate in reporting, due to the many variables, this information would be generalized with caution. The data were intended for internal use by KMC/NICC and not intended as a statistical report.

Figure 3. Averaged case/staffing history for 30 registries

Accessioned Cases	FTE*	Accessioned Cases	FTE
250	1	1200	2.5
471	1	1200	4.5
588	2	1325	3
850	2.5	1500	4.5
903	1.5	1750	4
920	2.5	2000	6
1000	3	2100	7.5

*FTE—Full-time employee

Results

The following is a compilation of the responses received from the 5 northern registries:

1. A cancer registrar coordinates the CoC Approval Program standards.
2. A cancer registrar or a designated cancer conference coordinator coordinates Cancer Conference.
3. A cancer registrar or a designated employee maintains follow-up.
4. Most cancer registries have no cancer registry coordinator/manager; all registrars equally perform the tasks.
5. All respondents agreed that they have adequate time for continuing education and maintaining and/or learning new information.

Figure 4. Description of time study task categories—the building blocks of a CoC-accredited cancer registry

ABSTRACTING	FOLLOW-UP	CANCER CONFERENCE	CANCER COMMITTEE
• Abstracts • Pulling charts • Pull path reports • Pulls new patient admits and/or consults • Maintains a casefinding list & suspense list • Prepares a hospital disease index list • Identifies and maintains non-reportable records • Placement of staging forms	• Maintains follow-up information through patient medical records • Patient letters • Patient phone calls • Physician/and or facility phone calls/letters	• Organizes patient cases for conference presentation • Schedules meetings and speakers • Maintains Cancer Conference records to meet CoC Program Standards • Promotes Cancer Conference	• Organizes the agenda • Schedules meetings • Maintains information to comply with CoC Program Standards • Assists in the annual report or newsletter if applicable • Promotes Cancer Committee
CoC Standards	**Education**	**Data Reporting**	**Registry Operations**
• Coordinates the facility compliance with CoC Program Standards (Survey preparation) • Maintains Survey Application Record, National Cancer Data Base Records & Audit records • Maintains the Policy & Procedure Manual	• Staff training and continued education.	• Organizes and compiles registry data for release to research departments, physicians, and other health care related agencies • Provides data for all requests; studies, out-reach, research activities, state reporting, etc.	• Creates registry documents • Attends meetings • Updates and maintains computer applications • Answers telephones • Completes misc. registry tasks.
Non-productive hours			
Vacations (annual 40 hours), sick leave, down time, unrelated meetings, etc.			

Figure 5. Monthly hours summary for 5 northern registries

TASK CATEGORY BY HOURS	FACILITY #1 500+ New Cases/ 3900+ Follow-Up 160 Hours 1 FTE	FACILITY #2 600+ New Cases/ 4100+ Follow-Up 240 Hours 1.5 FTE	FACILITY #3 900+ New Cases/ 9000+ Follow-Up 320 Hours 2 FTE	FACILITY #4 1100+ New Cases/ 16,600+ Follow-Up 400 Hours 2.5 FTE	FACILITY #5 2100+ New Cases/ 37,000+ Follow-Up 1200 Hours 7.5 FTE
Abstracts	59.6	92	134	292	520
Follow-Up	13	40	51	34	160
Cancer Conference	11.1	41	35	44	128
Cancer Committee	3	10.75	6.5	4	9
CoC Standards	13.3	21.7	20	33	7.3
Education	3.5	5.25	9.6	7.3	31
Data Reporting	8.3	12	23	18	16
Registry Operations	7.7	3.2	17	46.1	14
Non-Productive Hours	5.8	5.8	11.6	14.5	43.5
Total Hours	125.3	231.7	307.7	492.6	951.5

- Non-productive hours include vacation (annual 40 hours), sick leave, and miscellaneous down time
- Facility #5 is a merging clinic (numbers were estimated between facilities)
- Hours were averaged to calculate task category percentages

Problem areas identified from the information provided by area registries are:

1. Pay scale doesn't match the task/responsibility level.[5]
2. The medical industry doesn't understand what the cancer registry does.
3. All the necessary information isn't available in the electronic record; ie, staging form and other facility physician notes.
4. Some cancer registries perform other facility tasks not related to the cancer registry.
5. There are fewer advancement opportunities when a registrar's duties are lumped together.
6. All abstractors that collect data are not certified.
7. Facilities wait too long to add staff.

Although pay scale was identified as a problem area, it was not the subject of this study.

Patterns Emerge

The first pattern to emerge from the 5 northern registries was similarities in the size of each registry compared to staffing numbers. The similarity continued with the reporting from the 25 outside registries. Registries ranged in the number of new cases accessioned from 250 to 2100 annually. These registries were staffed anywhere from 1 FTE to 7.5 FTEs. Figure 3 illustrates a sampling from the 30 participating registries.

The majority of the registries felt they were understaffed. The registries most comfortable with their staffing needs averaged 1 FTE per 300 annual cases. However, the ratio of 1 FTE per 300 cases only became apparent in the study once their annual cases topped 800. One FTE per 400 cases was sufficient up to 800 cases. Of course, the reference date of the registry and follow-up number influence the number of cases.

The second pattern to develop was the clear description of duties performed in a CoC-approved cancer registry. Figure 4 shows the time spent in each area broken into 9 categories. The time spent (total hours) was averaged from all 5 northern facilities and is shown in Figure 5.

The information also revealed that at least 60% of a registry's current year cases become next year's follow-up. There is no way to calculate total expected follow-up cases in relation to annual cases accessioned because of the volume of past cases being updated. The fact that registries collect data on benign brain tumors in addition to invasive cancers affects the number of follow-up cases. The older the registry reference date, the more cases there are in follow-up. Also, not all registries keep a historical record of their annual follow-up cases. There are too many variables to determine an exact follow-up rate. The American Cancer Society data for 2005 published a table estimating 1,372,910 new cancer cases and 570,280 deaths.[4] That would leave 58% eligible for follow-up in 2005. The Central Data Registry of Idaho estimated that 73% of 2005 Idaho resident cases (invasive, *in situ,* and benign brain and other CNS) were eligible to be followed 1 year after diagnosis.[6] The information is not a direct comparison, but implies that as annual cases accessioned increase, so will the follow-up numbers. This is an established and understood occurrence. A minimum of 60% of annual cases can be expected to be carried over to the next year, adding to the follow-up database.

Working the Data

To substantiate our data, historical case and staffing information compiled from 25 other CoC registries compared favorably with the 5 original facilities (as seen in Figure 6). Comparisons made of the number of new cases accessioned, follow-up cases, and number of employees provided an average total. Job requirements and the amount of time spent in each category had previously been determined.

Totals clearly showed workloads were excessive for some registries. The facilities outside of the 100% range were not able to meet the workload demands with their cur-

Figure 6. Rising task category percentages

Summary of All Participating Registries

TASK CATEGORY	400 New Cases 3500+ Follow-Up	400+ New Cases 9000+ Follow-Up	800+ New Cases 14,000+ Follow-Up
Abstracts	45%	45%	51%
Follow-Up	13%	15%	17%
Cancer Conference	10%	11%	12%
Cancer Committee	3%	3%	3%
CoC Standards	11%	11%	12%
Education	3%	3%	3%
Reporting	5%	7%	7%
Registry Operations	6%	6%	7%
Non-productive Hours	4%	4%	4%
Total	100%	105%	116%

- Annual case and follow-up percentages rounded off to the nearest number
- Follow-up percentages will continue to increase even if new case numbers remain the same
- Task categories that stayed constant even with caseload increases: cancer committee duties, education, and non-productive hours

rent staff. Of special interest were the 3 task categories that remained constant even with caseload increases.

Cancer Committee is a regular activity that should be a well organized and operating function becoming more streamlined over time. As long as CoC standard requirements remain static, it stands to reason that coordinating this committee will not increase with caseload.

Education should be a continuing effort. The need for additional education and training to stay current in cancer registry operations will remain the same.

Non-productive hours remain consistent with facility policies and procedures. These hours are not likely to change except for extenuating circumstances. Most facilities include a 40-hour annual vacation benefit.

Based on the combined averages from all registry study participants, a new guideline (Figure 7) was formulated to suggest Task Category Percentages for a CoC-approved Cancer Registry accessioning 400 annual cases.

The historical and current case information from the participating registries created the staffing table (Figure 8) for a CoC-approved cancer registry. The table accommodates for the varying facility management styles and increasing number of follow-up cases.

Discussion

The KMC/NICC time study data suggests that the staffing table can be a useful tool for the cancer registry manager as an accurate and flexible method to evaluate staffing requirements. The table offers a realistic approach in consideration of the needs of each individual facility.

Some limitations to this study were identified. Of most importance, there was no exact measurement for time spent abstracting. Abstracting has too many variables to project an accurate block of time, such as one abstract per hour. All facilities collect the required informational fields, but many have additional fields due to research and/or individual facility needs. Second, facilities had different levels of collection capabilities: electronic, paper, and various software applications. Third, some respondents indicated confusion in their replies providing spurious data which limited the use of their information or omission from the study.

Figure 7. Suggested task category percentages

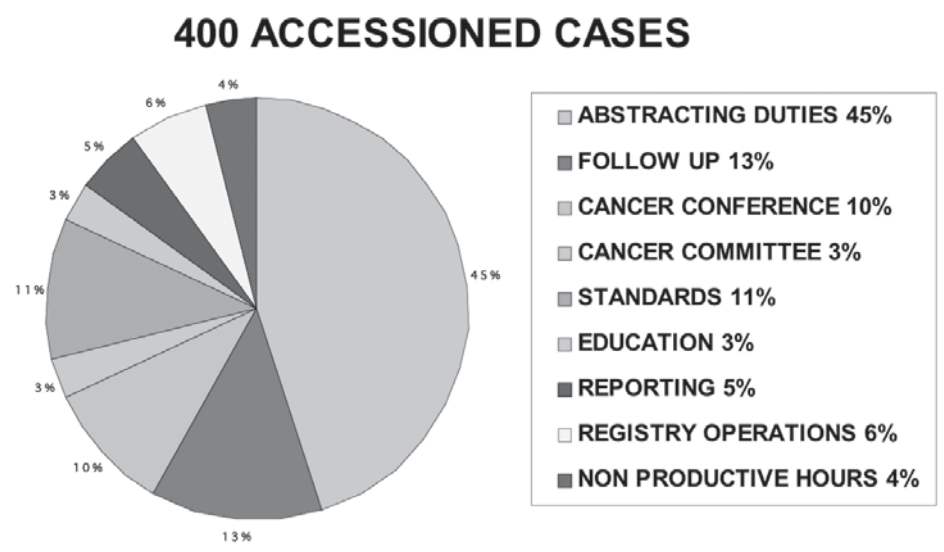

Figure 8. Flexible staffing table for CoC-approved registries

FTEs	1	1	1.5	1.5	2	2	2.5	3	3.5	4	5	6
New Cases	0–300	400	500	600	700	800	900	1000	1100	1200	1500	1800

- Only 1 FTE is needed for the first 400 new cases
- 1 additional FTE should be added at 800 new cases
- Continues to increase by 1 FTE for every 300 new cases

Finally, the data in this study is limited to the information provided by participating registries. Some registry responses were not included or were restricted due to "guesstimates." The use of this data should be generalized with caution and used with discretion. A statistician did not develop this study.

The purpose of this study was to study CoC-approved facilities and review staffing patterns to formulate a recommendation for staffing a CoC cancer registry. Registry duties were also evaluated and separated into task categories. The information supplied by additional registries identified the following managerial concepts:

- The implementation of a cancer registry coordinator or manager. The cancer registry has evolved into an entity of its own as complex as the disease it serves. There is a constant flow of new and additional information with many variables that need to be managed and followed.
- The cancer registry's duties and responsibilities can be divided into categories. The categories can then be combined and/or delegated individually providing a flexible management style suitable to each individual facility.
- In determining staffing positions as they apply to the categories, one should consider the potential for advancement.
- Hire Certified Tumor Registrars (CTRs). This protects and guarantees the accuracy of the data. This practice yields the best results for cancer patients.
- Promote and provide cancer registry education. Help medical professionals and other allied staff to understand what the cancer registry does and how the data can be used.
- The cancer registry is not the medical records department or clerical office staff; it has an identity of its own. Registries performing other facility duties may compromise accuracy.
- Hire additional staff before the registry is in distress. Years of documentation provides excellent criteria upon which to base future expectations.

Today's cancer registry is a sophisticated mechanism in the forefront of cancer diagnosis and treatment. It is an integral part of the multidisciplinary team approach to improving the quality of cancer care.

Conclusion

The focus of this undertaking was to successfully establish staffing guidelines and to formulate optimum management practices ensuring an efficient and accurate cancer registry. The concern was about providing quality information that would in turn benefit KMC/NICC patients.

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- Saint Alphonsus Regional Medical Center, Boise, Idaho
- St. Joseph Regional Medical Center, Lewiston, Idaho
- St. Luke's Regional Medical Center & Mountain States Tumor Institute, Boise and Twin Falls, Idaho

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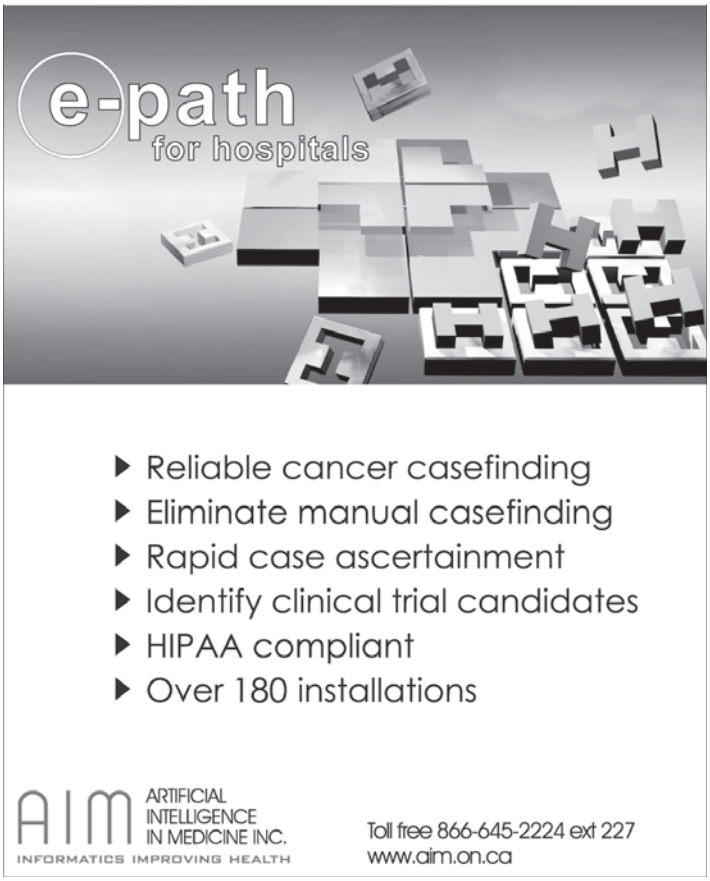

Original Article

Evaluating the Timeliness and Completeness of a Web-based Reporting and Communication System of the New York State Congenital Malformations Registry

Ying Wang, PhD[a,b]; Zhen Tao, PhD[a]; Philip K. Cross, BS[a]; Syni-An Hwang, PhD[a,b]

Abstract: This study found that the implementation of the Web-based reporting and communication system has resulted in more timely submission of cases to the New York State Congenital Malformations Registry (CMR) and promoted effective communication between the CMR and reporting hospitals. There was a nearly 50% reduction in median days used for reporting by the electronic, Web-based reporting system when compared to the manual, paper-based reporting system. The percent of unspecified diagnoses for 3 selected birth defect categories examined was significantly decreased for cases submitted though the Web-based reporting system. A significant improvement in the completion rate was found for some data fields of cases submitted through the Web-based system, such as child's first name, medical record number, and birth hospital information. However, the completion rates for some data fields, such as birth plurality and mother's name, were significantly decreased for cases submitted through the Web-based system. Stratified analyses showed that the decreases resulted from using the batch file upload method of reporting. CMR staff will continue to work with hospitals using the Web-based batch file upload utility to improve the completeness and timeliness of reporting.

Key words: *case reporting, completeness, congenital malformations registry, timeliness, Web-based*

Introduction

Since the beginning of the 21st century, Web-based event reporting systems have been developed and implemented by researchers in the academic and medical environment around the world to facilitate the efficient collection of information from multiple, geographically-dispersed organizations.[1–11] In order to improve the completeness and usefulness of public health surveillance and the timeliness of reporting and response to outbreak of disease, the Centers for Disease Control and Prevention has worked with states and local health departments since 2000 to develop and implement Internet-based disease reporting systems. As of April 2005, a total of 27 states were using a secure, Internet-based system for entry of notifiable disease reports.[12] Recently, the Indiana Birth Defects Registry and the Virginia Congenital Anomalies Reporting and Education System started to receive hospital reports through Web-based tracking and database systems.[13] In addition, some state birth defects surveillance programs such as New Jersey and Washington are currently developing Web-based birth defects reporting systems.[13]

The Congenital Malformations Registry (CMR), which was established and began operations in late 1982, is one of the largest statewide, population-based birth defects registries in the nation. Using the passive method of reporting with an active follow-up case tracking system,[13] the CMR annually receives birth defects reports for more than 10,000 children of New York State residents, which comprise approximately 4% of all live births. Over the past several years, CMR staff have developed a Web-based case reporting, data management, and communication system for the statewide birth defects registry in New York State using New York State Department of Health's (NYSDOH) Health Provide Network (HPN).[14] The HPN is an Internet-based communications infrastructure that provides highly secure and efficient exchange of reporting, surveillance, statistical, and general information with its public health and health provider partners, using the powerful Internet Secure Sockets Layer (SSL) encryption technology. As early as 2002, 5 hospitals started to submit cases using the CMR's newly developed Web-based data entry utility (the only online application developed at that time). By January 2006, the CMR had converted all 163 reporting hospitals statewide from a manual, paper-based reporting system to the electronic, Web-based case reporting, data management, and communication system. This innovative system provides a platform-independent environment for data submission, retrieval and analysis, and communication, and offers a cost-effective solution for participating hospitals and requires minimal technical assistance from CMR staff. The objectives of this study were to evaluate the completeness of submitted case information and timeliness of reporting to the CMR using the new Web-based system, and to evaluate the effectiveness of the Web-based communication and query system, when compared to the previous manual, paper-based system.

"Evaluating the Timeliness and Completeness of a Web-based Reporting and Communication System of the New York State Congenital Malformations Registry"

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Methods

Case reporting systems. For the manual, paper-based reporting system that had been in use since 1983, staff of the reporting hospitals completed a standard report form for each child and then mailed the completed form to the CMR. CMR staff manually entered the reports into a computerized database system. The Web-based case reporting system as described elsewhere[14] provides 2 options for the hospital users: a manual online data entry of individual reports or a data file upload of batch reports. The online data entry function allows users to submit reports using a fully customized online data entry form. The file upload utility enables hospitals to send, at regular intervals, batch files containing cases collected via their own information technology system to the CMR Web server through the data submission process.

Case selection. Children 2 years of age or younger, born or reside in New York State, diagnosed with major birth defects, discharged between 2002 and 2006, and reported to the CMR through the manual, paper-based reporting system or the electronic, Web-based reporting system, were selected for the study. Cases submitted as a result of CMR staff's onsite and offsite audits and the cases with an invalid discharge date or CMR receiving date were excluded from the analysis. Some hospitals used the Web-based reporting system to submit their overdue cases immediately after the implementation of this new system. These cases were also removed from the analysis. Cases submitted to the CMR using either the manual, paper-based reporting or the electronic, Web-based reporting system were identified using a report-type variable stored in the CMR's relational database. In addition, information on cases submitted to the CMR using the 2 different methods of the Web-based reporting, online data entry and batch file upload, was also stored in the database and used for a comparison analysis.

Timelines. The timeliness of reporting was defined as the interval between the hospital discharge date and the CMR receiving date. The number of days in each time interval was calculated for each case. The median days used for reporting by hospitals were calculated by discharge year for the 2 reporting systems: manual, paper-based reporting and electronic, Web-based reporting. Moreover, the median days used for reporting were also calculated by discharge year for the 2 electronic Web-based reporting methods: online data entry and batch file upload.

Completeness. The completeness of submitted case information was measured by calculating the completion rate of specific data fields for submitted reports. The selected data fields included child's name, child's medical record number, birth plurality, birth hospital information, mother's name, and mother's social security number. If the entry for a data field was invalid or blank for an individual case, it was then treated as incomplete. The percent completion of these selected data fields was calculated for the 2 reporting systems, as well as for the 2 methods of the Web-based reporting.

Accuracy. The Web-based online query/communication tools allow CMR staff to immediately communicate via the Web browser with an institution if a case report lacks information or has an unspecified diagnosis. The user-friendly application facilitates the reporting and allows for the submitting of additional information by hospital staff. To evaluate the effectiveness of this query/communication system in comparison to the paper-based system which relied on mailings to the hospitals, the accuracy of diagnoses reported to the CMR was examined by calculating the percent of unspecified diagnoses of selected birth defect categories of cases submitted using the 2 systems. Three birth defect categories were selected for the analysis: 1) other specified anomalies of heart (the British Pediatric Association [BPA] codes[15]: 746.8xx and 746.9xx with unspecified codes, 746.880, 746.900, and 746.990); 2) other specified anomalies of pulmonary artery (BPA codes: 747.3xx with unspecified codes, 747.380 and 747.390); and 3) other obstructive defects of renal pelvis/ureter (BPA codes: 753.2xx with unspecified codes, 753.290). The last 2 digits of the 6-digit BPA codes (referred to as "xx" here) are sub-categories for each BPA category and were all included in the analysis. For each selected birth defect category, the percent of unspecified diagnoses was calculated using the number of cases with unspecified BPA codes divided by the total number of cases in the category. Stratified analysis by the 2 Web-based methods of reporting was not performed since they used the same Web-based query/communication applications.

Statistical analysis. Summary statistics, simple and stratified, were generated using the SAS software package.[16] Two-sample *t*-test was used to test for significant differences between the percentages of completed data fields.

Results

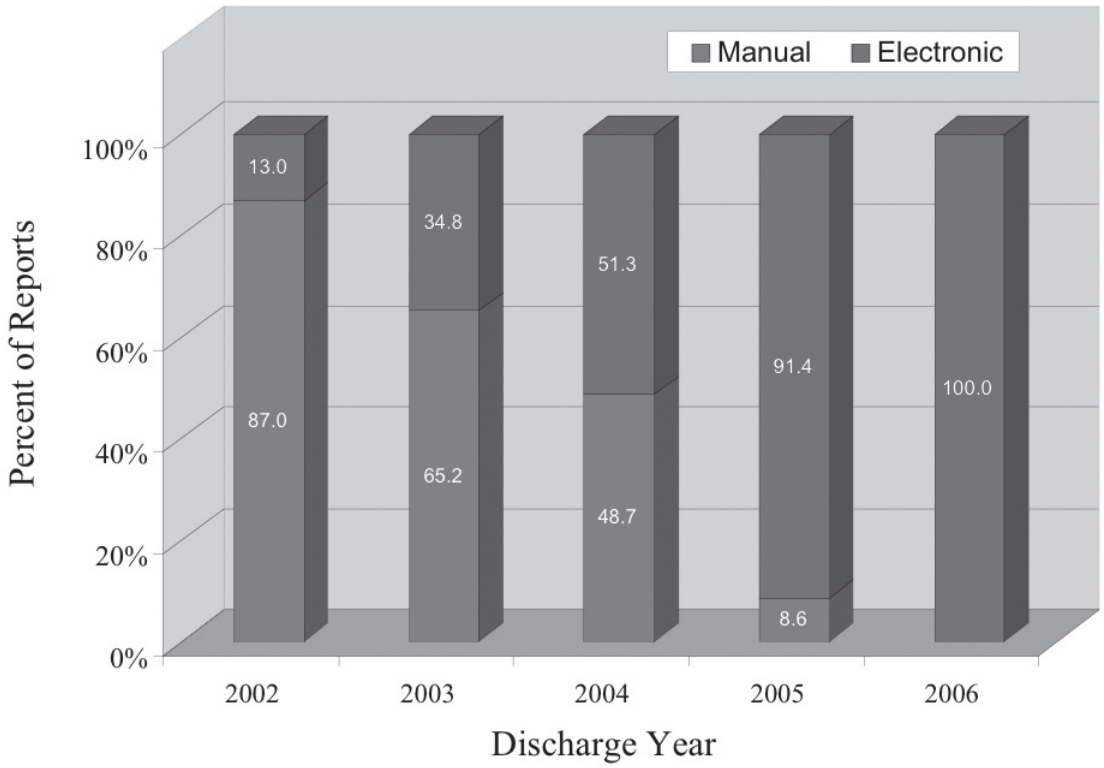
A total of 47,232 cases, submitted by reporting hospitals through the manual, paper-based reporting (44%) or the electronic, Web-based reporting system (56%), were selected for the study (discharge years: 2002–2006). The calculated percentages of reports submitted by hospitals using the 2 reporting systems for discharge years 2002–2006 are shown in Figure 1. In 2002, the cases reported to the CMR through the Web-based reporting system consisted of only about 13% of all cases. The percentage increased drastically in 2005 (91%) and in 2006 (100%).

Timeliness of Reporting

Figure 2A shows the median days—the interval between the discharge date and the CMR receiving date—used for reporting by hospitals during the discharge years 2002–2006, through the 2 reporting systems. Overall, the median days (31 days) used for reporting by the Web-based reporting system was significantly less than that (59 days) used by the manual paper-based reporting system. The median days used for reporting by hospitals through manual, paper-based reporting system was the highest in 2004. When checking the individual records, it was found that several hospitals delayed their manual reporting of cases to the CMR substantially in 2004.

Figure 2B shows the median days used for Web-based reporting by hospitals during the discharge years 2002–2006. The median days (14 days) used for reporting by the online data entry method were significantly less than the median days (53 days) used by the batch file upload method for all the discharge years, 2002–2006.

Figure 1. The percent of reports submitted by hospitals using the 2 reporting systems: manual, paper-based reporting vs. electronic, Web-based reporting, for the discharge years 2002–2006



Completeness of Case Information

Figure 3 shows the completion rates of selected data fields for cases submitted by hospitals using the 2 reporting systems (Figure 3A) or using the 2 Web-based methods of reporting (Figure 3B). As shown in Figure 3A, there was a significant improvement in the completion rate for the data fields of reports submitted through the Web-based reporting system such as child's first name (increased from 66.2% to 90.4%), medical record number (increased from 99.1% to 99.6%), and the hospital of birth information (increased from 62.8% to 99.3%). However, the completion rates were significantly decreased for data fields such as birth plurality (from 88.6% to 67.8%), mother's first name (95.7% to 89.3%), and mother's last name (96.2% to 87.7%) on reports submitted through the Web-based reporting system.

As can be seen in Figure 3B, stratified analyses by the Web-based reporting methods showed that the decreases in completion rates resulted from hospitals using the batch file upload method of reporting. Except for the child's name fields, the completion rates of all other data fields examined were significantly lower for cases submitted by hospitals using the Web-based batch file upload method for reporting when compared to using online data entry for reporting. It was found that the biggest decreases in completion rate were in the birth plurality (84.5% to 43.2%) and mother's first name (96.4% to 74.9%) data fields, when comparing the batch file upload method to the online data entry method.

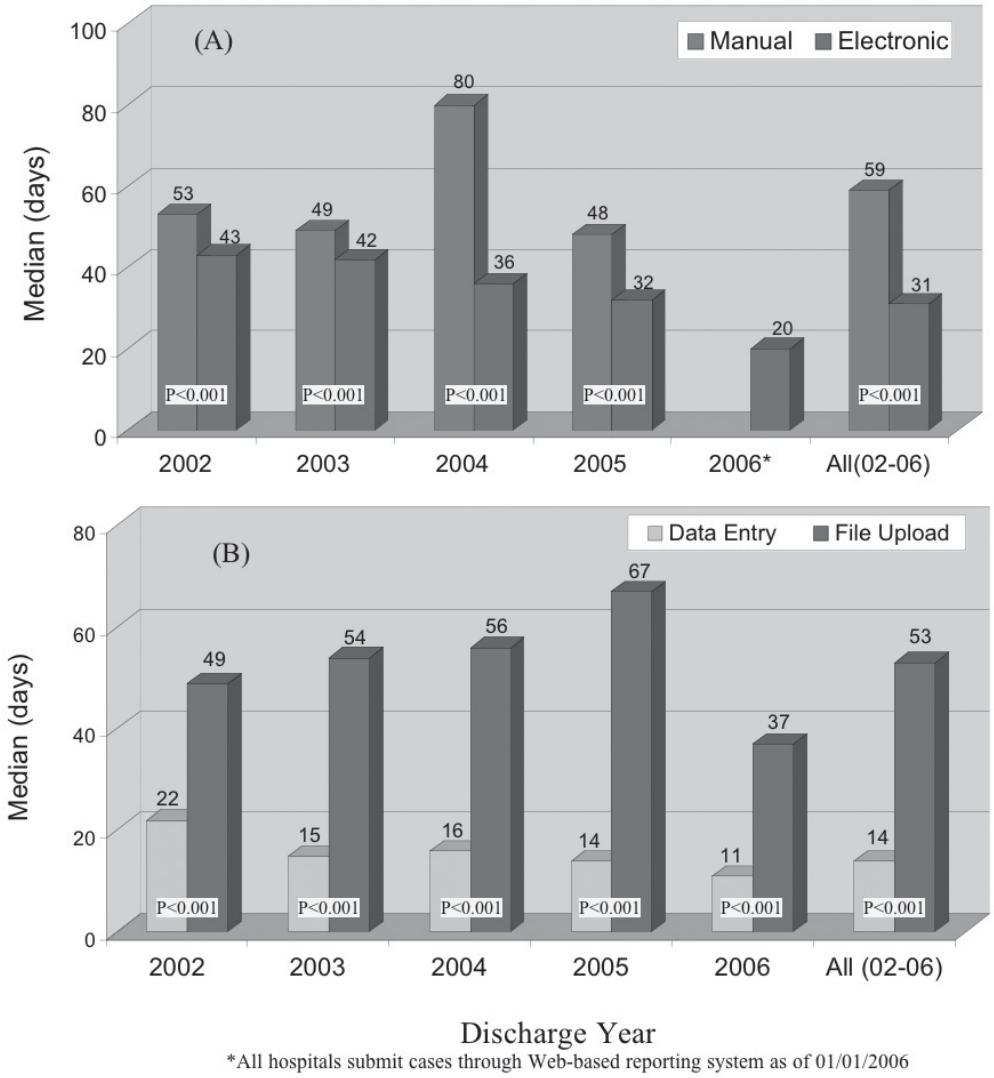
Accuracy of Diagnoses

Figure 4 compares the percent of cases with unspecified diagnoses for the selected birth defect categories, other specified anomalies of heart, other specified pulmonary artery, and other obstructive defects of renal pelvis and ureter for the 2 reporting methods. For all 3 birth defect categories examined, the percentage was significantly decreased for cases submitted though the electronic, Web-based reporting system when compared to the manual, paper-based reporting system. The biggest difference was observed for the category "other obstructive defects of renal pelvis and ureter:" 12.7% vs. 3.4%.

Discussion

In the past decade, the Internet has become a powerful and effective tool for disease surveillance, information retrieval, and exchange and communication. Studies have shown that Web-based electronic reporting has improved the timeliness and completeness of disease surveillance data.[8,12,17–25] The implementation of a flexible and user interactive Web-based system by the New York State CMR has promoted an increase in the number of reports submitted by hospitals using this new system (Internal report, data not shown). This has resulted in better compliance and more timely submission of birth defects cases. The findings from the current study show that there was a nearly 50% reduction in the median days used for reporting by the electronic, Web-based reporting system when compared to the manual, paper-based reporting system.

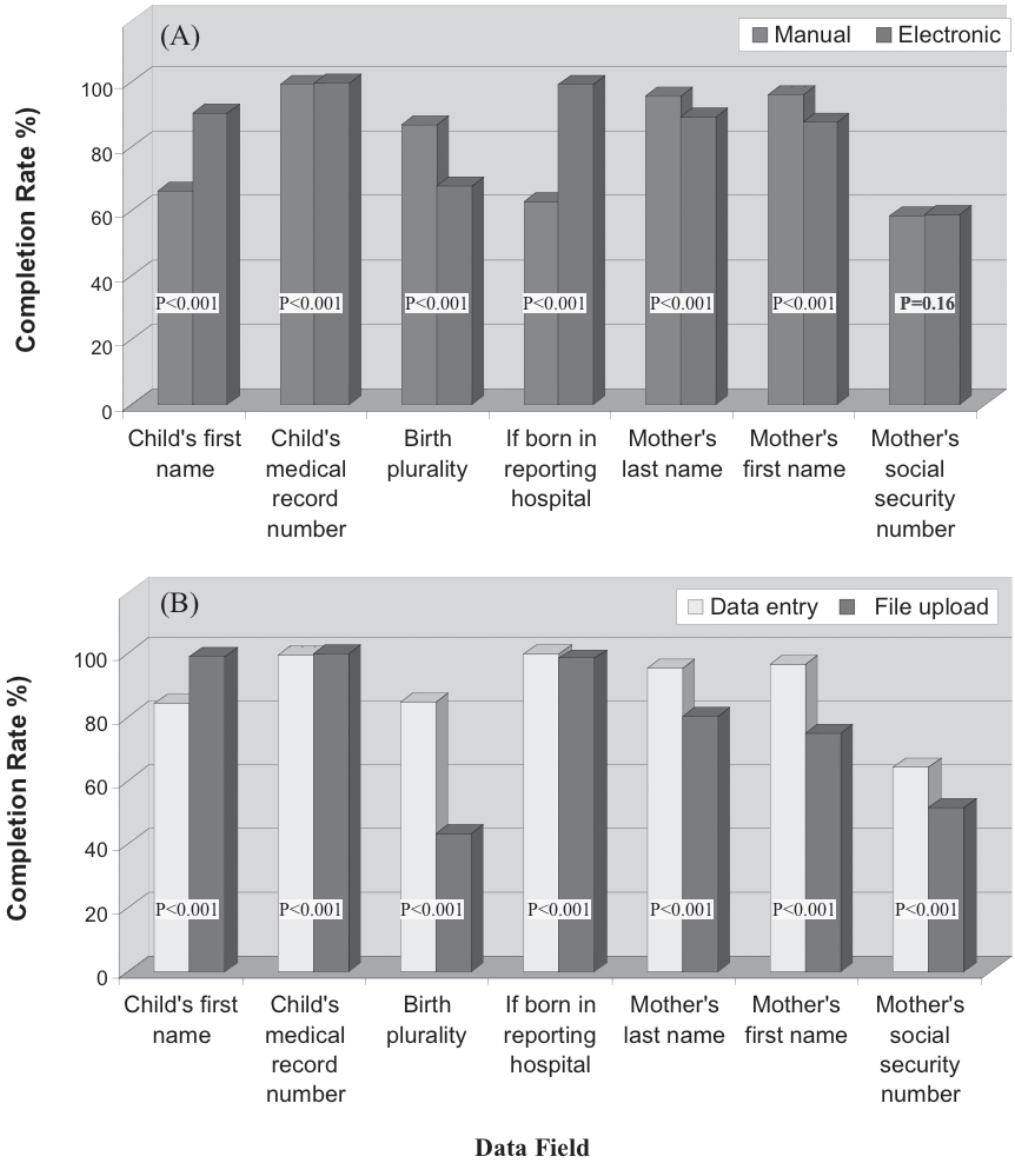
Figure 2. The median days used for reporting by hospitals (2002–2006). (A) Manual, paper-based reporting vs. electronic, Web-based reporting; (B) Two electronic, Web-based reporting methods: online data entry vs. batch file upload



For the two Web-based reporting methods, the median days used for reporting by hospitals using the batch file upload method was more than 3 times that used for reporting by the online data entry method. Although the set-up of the file upload utility was challenging and required data preparation using a specific data format and file type for transferring data to the CMR, the use of this method for reporting is relatively easy and more efficient when compared to online data entry. Using the file upload method, the users can submit a batch file containing tens, hundreds, or thousands of records at one time with one single command (one click of the submit function button). The online data entry method requires the user to complete the form for each case, which can be time consuming when dealing with a large dataset. Our findings show that a few hospitals that used the file upload method were delinquent in reporting to the CMR with large time intervals (4–6 months) between uploads. On the other hand, most reporting hospitals that used online data entry method routinely and promptly submitted their cases to the CMR and thus, resulted in short time intervals between the discharge date and the CMR receiving date. CMR staff will continue to monitor the reporting status of hospitals and contact hospitals with long delays in reporting to improve timeliness.

The current study found mixed results for the completion rates of the selected data fields for cases submitted by hospitals using the Web-based system. There was a significant improvement in the completion rate for the data fields child's first name, medical record number, and hospital of birth information. While the completion rates for the data fields birth plurality and mother's name were significantly decreased. Stratified analyses by the 2 Web-based reporting methods showed that the decrease resulted from using the batch file upload method of reporting. This might be because that the CMR's Web-based reporting system allows missing values for these data fields. Thus, some users might purposely remove the information of these data fields when preparing data for batch file upload. The CMR's Web-based reporting system, especially the automated batch file upload utility, provided a powerful tool with great potential for improving the timeliness and completeness of case reporting. However, it could not replace users' responsibility to submit

Figure 3. The completion rate (%) of selected data fields for reports submitted by hospitals (2002–2006). (A) Manual, paper-based vs. electronic, Web-based reporting; (B) Two electronic, Web-based reporting methods: online data entry vs. batch file upload

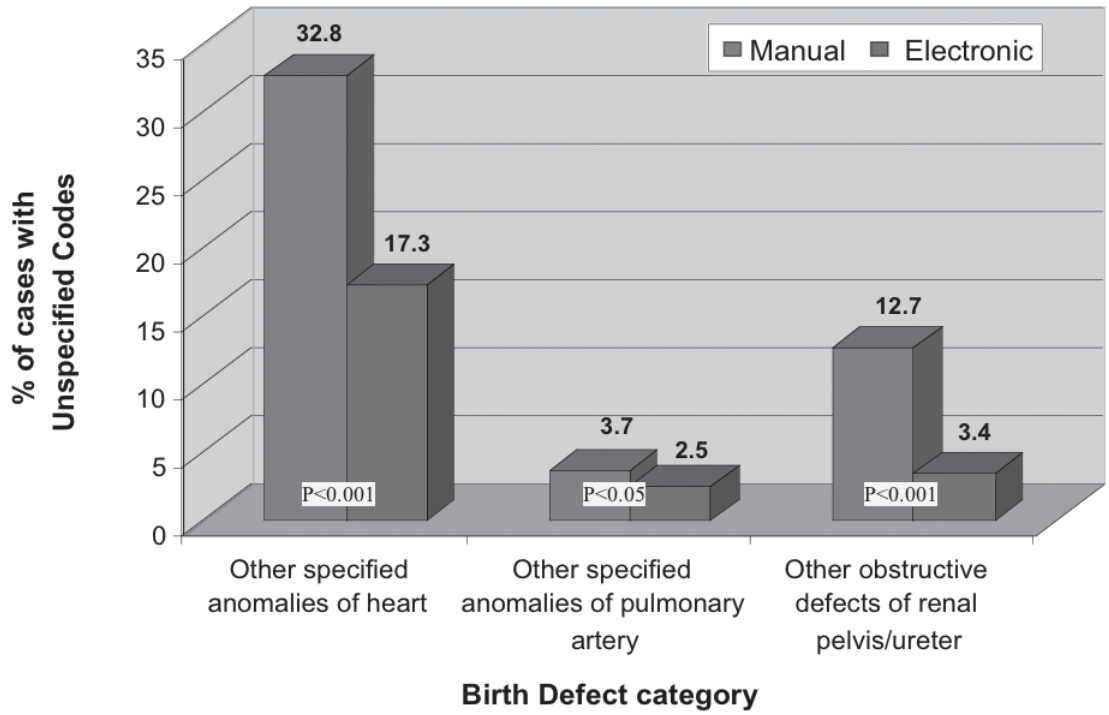


case reports with good quality of data. CMR staff are working with hospitals that submitted reports with low completion rates for selected fields to improve the data quality.

The implementation of the Web-based system allows CMR staff to review and perform quality assurance on every report submitted, including the specificity of the diagnoses, before adding it to the database system. This innovative system also enables CMR staff to communicate with reporting hospitals faster and more effectively about submitted cases. Utilization of the system's Web-based, online query/communication tools dramatically increased the number of responses from the hospitals, decreased the turnaround time for updating case information, and, therefore, improved the data quality of the CMR. As shown from the findings of the current study, the percent of cases with unspecified diagnoses for each of the 3 birth defect categories examined was significantly decreased for cases submitted though the Web-based system when compared to the paper-based system. This finding indicates the effectiveness of CMR's Web-based, online query/communication system.

In conclusion, the implementation of the Web-based reporting and communication system has resulted in the more timely submission of cases to the CMR and promoted effective communication between the CMR and reporting hospitals. This has resulted in an increased completeness of data fields such as child's first name, medical record number, and the hospital of birth information and has improved the specificity of diagnoses of some birth defect categories such as, other specified anomalies of heart, other specified pulmonary artery, and other obstructive defects of renal pelvis and ureter. CMR staff will continue to work with hospitals using the Web-based batch file upload utility to improve the completeness and timeliness of reporting.

Figure 4. The percent of cases with unspecified codes for the selected birth defect categories by reporting system: manual, paper-based reporting vs. electronic, Web-based reporting (2002–2006)



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Original Article

Colorectal Cancer Incidence and Mortality in Northeastern Pennsylvania

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Abstract: **Background:** Colorectal cancer (CRC) is the fourth most common non-skin cancer and the second leading cause of cancer death in the United States. Both incidence of and mortality from CRC are believed to be unusually high in Northeast Pennsylvania. **Objective:** We sought to document current and recent rates of CRC incidence and mortality in this community, to compare these rates to representative US data, and to identify differences in the clinical characteristics of the disease where they exist. **Methods:** Using data from a regional cancer registry, the Pennsylvania Cancer Registry, and the SEER program, we calculated age-adjusted and age-specific incidence and mortality rates, standardized incidence, and mortality ratios, and examined the distribution of stage at the time of diagnosis for Lackawanna County Pennsylvania. **Results:** In Lackawanna County between 1985–2003, both standardized incidence (SIR) and standardized mortality ratios (SMR) for CRC were significantly elevated. For the period 1985–1994, SMRs were greater than the corresponding SIRs. However, since 1995, the SMRs were similar in magnitude to the SIRs. For 2000–2003, the SMR was 1.29 (95% Confidence Interval [CI], 1.15–1.45); the SIR for this same period was 1.31 (95% CI, 1.22–1.41). Age-adjusted incidence rates were significantly higher than SEER program rates for the entire period 1985 through 2003 and showed a trend of decreasing incidence comparable to the trend in SEER rates. Age-adjusted mortality showed a similar pattern compared to US mortality rates. A significantly smaller proportion of incident cases were diagnosed at the local stage in Lackawanna County than at SEER program sites. **Conclusions:** These data document that both incidence and mortality rates for CRC in Northeast Pennsylvania are higher than corresponding US rates. These patterns have been present since at least 1985. The distribution of stage at the time of diagnosis suggests that CRC screening rates could be substantially increased. Making CRC awareness and screening a priority for this community may be the most effective interventions to decrease CRC mortality rates in the near term.

Key words: *colorectal cancer, epidemiology, incidence, mortality, time trends*

Introduction

Historical evidence suggests that mortality due to colorectal cancer (CRC) among white men and women in Northeast Pennsylvania is among the highest in the United States.[1] The Northeastern United States in general has relatively high mortality rates from CRC, the second leading cause of cancer death in the United States, although the reasons for the high rates are not well understood. Residents' concern about the unusually high CRC incidence rates in some neighborhoods of Northeast Pennsylvania prompted the Pennsylvania Health Department to target a number of counties in the region for investigation in the mid 1990's. More recently, we reexamined this issue in current data. Understanding the reasons for high CRC mortality in Northeast Pennsylvania may provide clues to the reasons for high CRC mortality in the entire Northeastern United States.

The incidence of CRC in the United States, as documented in the SEER registries, has been decreasing since 1985.[2] Likewise, US CRC mortality has been decreasing since 1978.[2] These decreases have occurred in both blacks and whites, but the decreases have been greater in whites than blacks. The reasons for improvements in incidence and mortality are uncertain, but it has been suggested that increased screening and polyp removal, prevention of progression of polyps to invasive cancers, and changes in dietary and exercise habits may have contributed to the decreased incidence. Detection of a greater proportion of invasive cancers at early stages and the introduction of new surgical techniques and adjuvant chemotherapy may have also contributed to the improvements in mortality.[3] Five-year survival rates for CRC are 90% for local tumors, 68% for regional tumors, and 9.8% for distant tumors.[2] Although CRC screening may be the most important factor contributing to these improvements in mortality, it is underutilized and is used substantially less than screening for other cancers.

This study examines data from Lackawanna County Pennsylvania, where the CRC mortality rate is in the top tenth percentile of US counties, and seeks to identify the cause of this high mortality. Specifically, we aim first to document recent trends in incidence and mortality rates and to compare them with corresponding rates for the United States. We aim further to determine whether the high CRC mortality is accounted for by high CRC incidence or whether the excess may be due to other factors, for example differences in detection, diagnosis, treatment, or survival.

"Colorectal Cancer Incidence and Mortality in Northeastern Pennsylvania"

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Materials and Methods

Lackawanna County is one of 6 counties in Northeast Pennsylvania (PA) served by Northeast Regional Cancer Institute (NRCI) for cancer surveillance, epidemiology, and control. In 2000, the population of Lackawanna County was 213,295, comprised of 47.2% male, 19.5% aged 65 years and over, with 83% living in urban areas.[4] Compared to the population of PA, Lackawanna County is older, has a lower income, and is less racially diverse. According to the 2000 US census, the median age in Lackawanna County was 40.3 years (vs. 38 years in PA); the median income $34,438 (vs. $40,106 in PA); 96.7% of the population was white, and 1.3% was black (vs. 85.4% white and 10% black in PA).

The number of invasive cases diagnosed at each stage (localized, regional, distant, and unstaged) and the number of deaths due to CRC were obtained for each age group and sex and each year between 1985 and 2003 from the statewide Pennsylvania Cancer Registry (PCA). The PCA was started in 1982, and had full year data for the entire state as of 1985. It is North American Association of Central Cancer Registries (NAACCR) "gold certified" for meeting the highest standards of complete, accurate, and timely data. *In situ* cancers were excluded from analysis. Because the population of Lackawanna County is greater than 96% white, our analysis examines national and county data for whites only.

All primary tumor sites of the colon and rectum were selected for incidence and mortality data based on the second edition of International Classification of Diseases for Oncology (ICD-O-2) codes C180–C189, C199, and C209. These codes correspond to the cecum, appendix, ascending colon, hepatic flexure, transverse colon, splenic flexure, descending colon, sigmoid colon, recto-sigmoid junction, and rectum.

Newly diagnosed CRC cases occurring in the United States from 1985 to 2003 were identified from the National Cancer Institute's Surveillance Epidemiology, and End Results (SEER) program, the most authoritative source for this information. SEER cancer incidence and associated population data for this period were sampled in 9 geographic areas (Atlanta, Connecticut, Detroit, Hawaii, Iowa, New Mexico, San Francisco-Oakland, Seattle-Puget Sound, and Utah).[5,6] Information regarding CRC deaths in the United States was also obtained directly from the SEER program.[7] Selection was made on the basis that the underlying cause of death was one of the primary tumor sites of the colon and rectum, which was noted above and coded in the field UCR 282. Incidence rates were computed by year of diagnosis, and mortality rates were computed by year of death.

Age-specific and age-adjusted incidence and mortality rates are expressed per 100,000 persons in the population. Age-adjustment was by the direct method with standardization to the 2000 US Standard Million Population.[8] Population denominators used for Lackawanna County cancer incidence and mortality rates were the census figures (1990 or 2000) closest to the respective years for which the rates are calculated. Thus, population estimates of year 1990 were used to calculate rates for 1985–1994, and year 2000 estimates were used to calculate the rates for 1995–2003. Population denominators for SEER 9 region cancer incidence rates are county-level population data summed across participating geographic areas. Denominators for US cancer death rates are county-level population data summed across all of the counties for the entire United States.[9] Poisson regression was used to test for differences between Lackawanna County and the SEER 9 regions and the United States in incidence and mortality rates, respectively. A stepwise backward selection procedure was used, beginning with variables for age, sex, year, geographic location, and first order interaction terms. Joinpoint regression was used to test for changing trends over successive years, that is, whether at any point(s) in time the slope significantly increases or decreases.[10]

Indirect standardization was used to calculate Standardized Incidence Ratios (SIR) and Standardized Mortality Ratios (SMR) for CRC in Lackawanna County in intervals using the SEER 9 incidence rates and US CRC mortality rates, respectively, as the reference.[2] SIR and SMR are computed in order to compare the relative excess in incidence and mortality in Lackawanna County. An SMR greater than the SIR implies that mortality is higher than would be accounted for by excess incidence alone. Ninety-five percent exact confidence intervals were calculated assuming a Poisson process.[11] Potential differences in the distributions of stage of disease at diagnosis were examined by computing odds ratios using maximum-likelihood logistic regression estimates on grouped data while controlling for age and sex.

Annual United States and Pennsylvania CRC screening examination statistics were obtained from the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Survey System (BRFSS).[12] The BRFSS is an ongoing system of telephone surveys conducted by state health departments in cooperation with the CDC, and designed to collect risk factor information and to monitor intervention efforts over time. Questions from the 1999 survey selected for analysis asked whether the respondent had ever had a fecal occult blood test (FOBT), the time since the last FOBT, whether the respondent had ever undergone a sigmoidoscopic or colonoscopic exam, and the time since the last examination. The BRFSS core survey component in 1993, 1995, and 1997 asked whether the respondent had a digital rectal exam or a proctoscopic exam and the time since these most recent examinations.

Screening behavior rates reported in the BRFSS were compared between Lackawanna County and the United States by analyzing contingency tables using Fisher's Exact test, with significance level at $p<0.05$. STATA 9.0[13] and Joinpoint 3.0[10] were used for statistical analyses.

Results

SIRs for CRC in Lackawanna County by sex and time period are shown in Table 1. The SIRs for both sexes combined in 1985–1989, 1990–1994, 1995–1999, and 2000–2003 were 1.28 (95% CI, 1.21–1.35), 1.28 (95% CI, 1.21–1.36), 1.27 (95% CI, 1.20–1.35), and 1.31 (95% CI, 1.22–1.41), respectively. Sex-specific SIRs were similar. Age-adjusted CRC

Table 1. Standardized Mortality Ratios (SMR) and Standardized Incidence Ratios (SIR) by Sex and Years of Death/Diagnosis, Lackawanna County, Pennsylvania

		Mortality Ratios		Incidence Ratios	
Sex	Period**	SMR*	(95% Confidence Interval)	SIR‡	(95% Confidence Interval)
Male	1985–1989	1.48	(1.30, 1.67)	1.39	(1.28, 1.50)
	1990–1994	1.64	(1.45, 1.85)	1.37	(1.25, 1.49)
	1995–1999	1.17	(1.00, 1.36)	1.38	(1.27, 1.50)
	2000–2003	1.40	(1.19–1.64)	1.33	(1.20–1.47)
Female	1985–1989	1.22	(1.08, 1.39)	1.21	(1.12, 1.31)
	1990–1994	1.37	(1.21, 1.55)	1.24	(1.14, 1.35)
	1995–1999	1.27	(1.11, 1.45)	1.20	(1.10, 1.30)
	2000–2003	1.24	(1.06–1.45)	1.32	(1.20–1.45)
Total	1985–1989	1.32	(1.21, 1.44)	1.28	(1.21, 1.35)
	1990–1994	1.47	(1.35, 1.60)	1.28	(1.21, 1.36)
	1995–1999	1.21	(1.10, 1.34)	1.27	(1.20, 1.35)
	2000–2003	1.29	(1.15–1.45)	1.31	(1.22–1.41)

*SMR calculated using US colorectal cancer mortality rates as the reference
‡SIR calculated using SEER 9 colorectal cancer incidence rates as the reference
**Years of Death (SMR) and Years of Diagnosis (SIR).

incidence for 1985–2003 for Lackawanna County and the SEER 9 regions are shown in Figure 1. Compared with the SEER regions, incidence was consistently higher in Lackawanna County, with an average of 16.9 more cases diagnosed per year per 100,000 (paired t statistic = -13.172, p<.0001). US CRC incidence rates, as reflected in the SEER 9 regions, decreased by an average 1.5 % per year between 1985 and 2003, from 67.2 to 49.0 cases per 100,000 per year. During the same period, incidence rates in Lackawanna County decreased by 1.7% per year from, 97.2 to 70.0 cases per 100,000 per year. The difference between the SEER regions and Lackawanna County secular trends was not statistically significant as indicated by the region by time interaction term (p=.397). Similar incidence trends were observed for men and women in Lackawanna County (p for sex by time interaction =0.5).

Figure 1. Age-adjusted colorectal cancer incidence rates with 95% confidence intervals among Whites

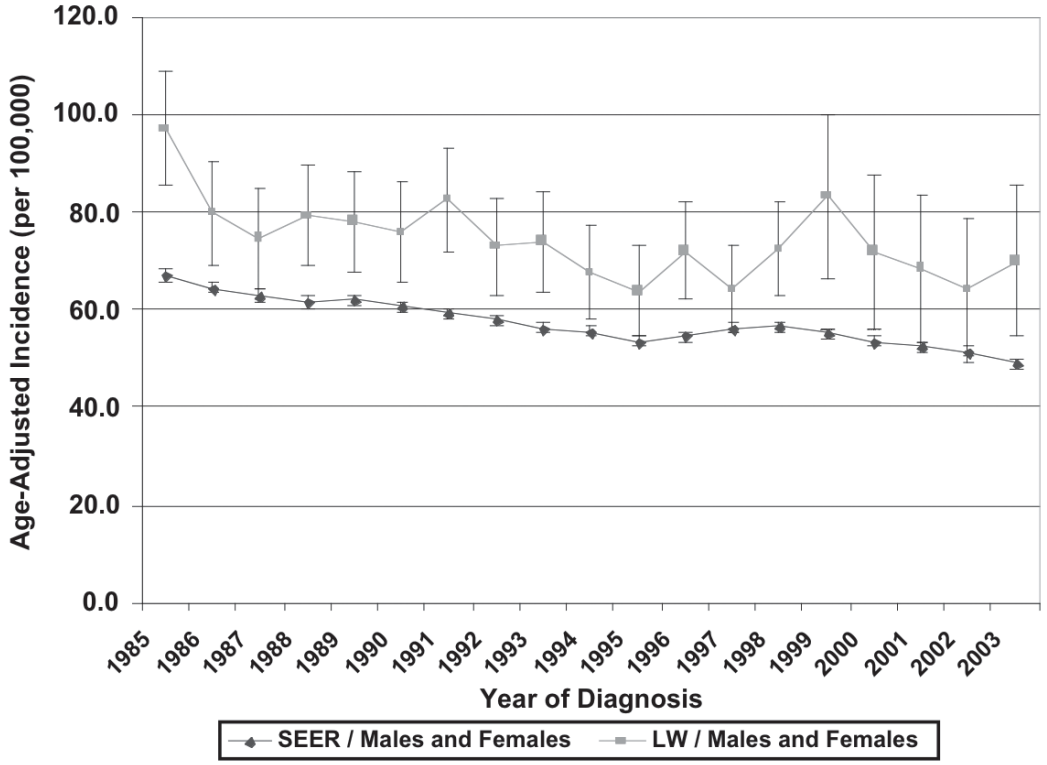


Figure 2. Age-specific colorectal cancer incidence and mortality rates for Lackawanna County, PA, 9 SEER regions (incidence) and the United States (mortality) in years 2000–2003

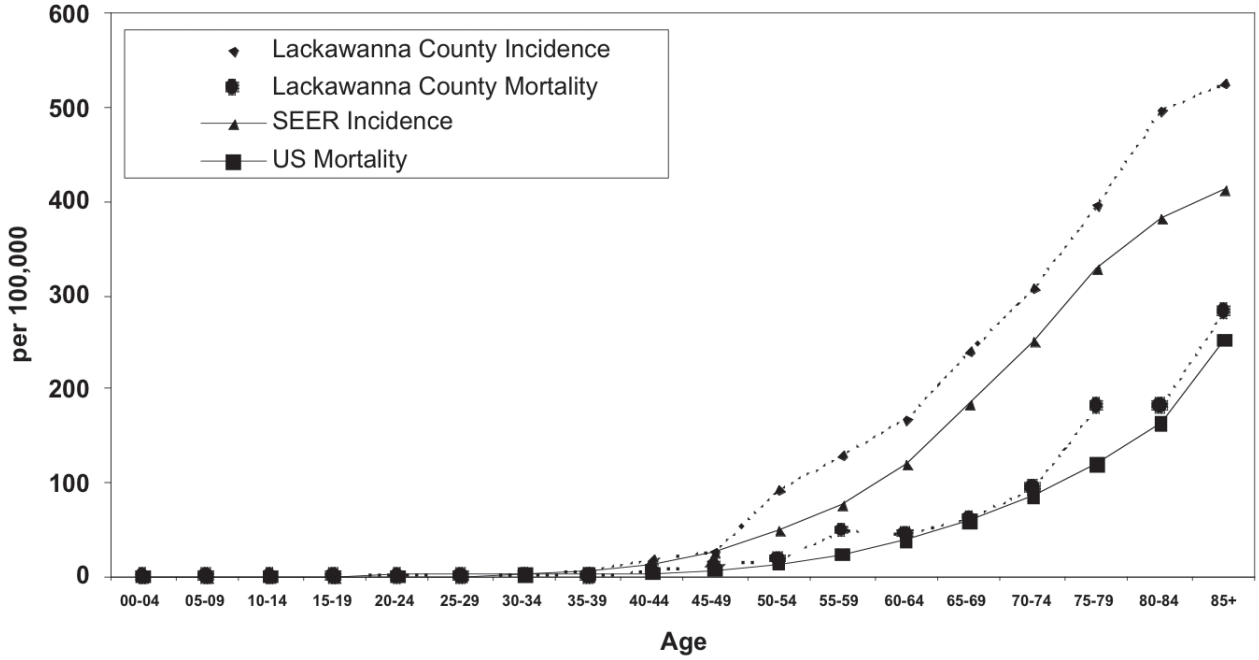
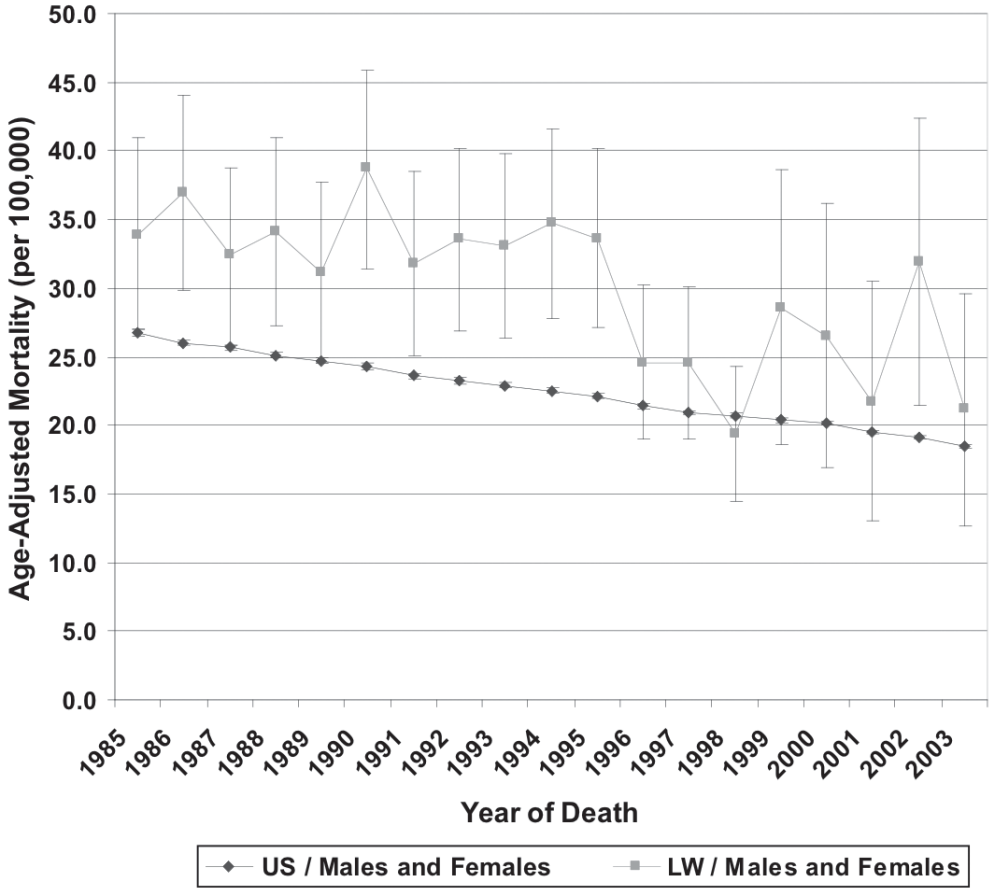


Figure 3. Age-adjusted colorectal cancer mortality rates with 95% confidence intervals



Age-specific incidence in 5-year age categories for the years 2000–2003 are shown in Figure 2. Incidence rates were higher in Lackawanna County in all age groups over 40 years. Similar patterns were seen for both men and women and in earlier 5-year time periods (data not shown).

SMRs and 95% CI for CRC in Lackawanna County for successive 5-year periods are shown in Table 1. For 1985–1989, 1990–1994, 1995–1999, and 2000–2003, SMRs for both sexes combined were 1.32 (95% CI, 1.21–1.44), 1.47 (95% CI, 1.35–1.60), 1.21 (95% CI, 1.10–1.34), and 1.29 (95% CI, 1.15–1.45), respectively. Sex-specific SMRs were similar. Age-adjusted CRC mortality rates for the entire period 1985-2003 for Lackawanna County and the United States are shown in Figure 3. In general, CRC mortality was higher in Lackawanna County than the United States. The age-adjusted CRC mortality rates in Lackawanna County exceeded those of the United States by an average of 7.6 deaths per 100,000 per year (paired t statistic = -8.02, p<.0001). During this period, the US CRC mortality rate decreased by an average of 1.9% per year.

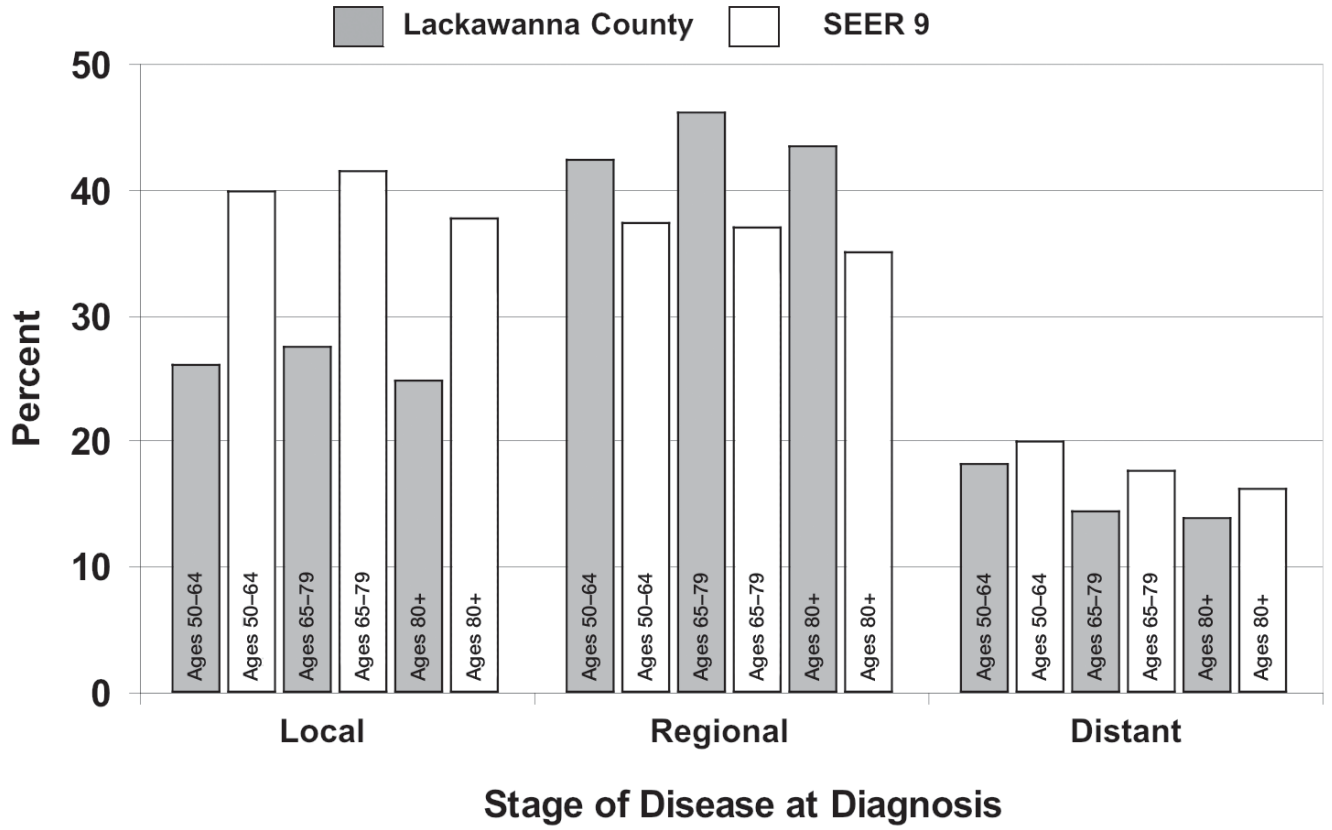
The rate of decline in CRC mortality in Lackawanna County was not significantly different from the change in the US rates. The p-value for the region by time interaction term in the Poisson regression model was 0.13. Similar trends were observed for both men and women. Joinpoint regression failed to find a significant change in the slope of the mortality rate curve in Lackawanna County from 1985 through 2003.

Age-specific mortality rates for 2000–2003 for Lackawanna County and the United States are shown in Figure 2. Overall, CRC mortality rates increased with age. For most age categories, mortality was higher in Lackawanna County. The effect of age in Lackawanna County was not statistically significantly different than the effect of age in the United States (p=0.236). Similar patterns were seen for men and women and for earlier 5-year time periods (data not shown).

Because SMRs were greater than SIRs in Lackawanna, implying that incidence alone may not account for the high mortality, we examined the distribution of stage at diagnosis of invasive CRC cases and compared cases diagnosed between 1990 and 2003 in Lackawanna County with the SEER 9 regions according to age. These are shown in Figure 4. Compared to SEER data, the proportions of Lackawanna County cases diagnosed at the localized and distant stages were lower; the corresponding odds ratios (OR) were 0.54 (95% CI, 0.50–0.59) and 0.82 (95% CI, 0.72–0.91), respectively. The proportion diagnosed at the regional stage was higher in Lackawanna County (OR=1.41; 95% CI, 1.31–1.52).

In 1999, the prevalence of FOBT screening during the prior year among white adults aged 50 years and older in Lackawanna County was 25.9 (95% CI, 8.3–43.6), and it was 24.1 (95% CI, 21.8–26.4) in the remainder of Pennsylvania. The corresponding percentage in the United States was 20.6 (95% CI, 20.1–21.2).[14] The proportions of adults over 50 reporting a sigmoidoscopy or colonoscopy examination during the previous 5-years were 26.9 (95% CI, 8.7–45.1)

Figure 4. Distribution of stage at diagnosis according to age in Lackawanna County, PA and 9 SEER regions, 1990–2003. Unstaged CRC cancers, included in the denominator for percentage calculations, are not shown.



and 29.9 (95% CI, 27.5–32.4) in Lackawanna County and the remainder of Pennsylvania, respectively. The corresponding percentage in the United States overall was 33.6 (95% CI, 33.0–34.2).[14] When data from earlier periods (1993, 1995, and 1997) were examined, no statistically significant differences by region were identified for any CRC screening method.

Discussion

This study confirms and describes the trend over 19 years of excess incidence of CRC in Lackawanna County in Northeast Pennsylvania. The excess is evident in both sexes and across adult age groups. CRC mortality was also found to be in excess across sex and age groups. Although changes over time in age-adjusted incidence and mortality rates among Lackawanna County adults generally parallel US trends (but at higher levels), the excess in mortality, at least prior to 1995, appears to be proportionally greater. We therefore examined available data on stage at diagnosis to determine whether other features of these cases may have contributed to the excess mortality. Excess incidence appears to account to a great extent for the excess mortality observed, however the underlying cause for this higher incidence is not clear. In addition, diagnosis at a later stage of disease may also contribute to the excess CRC mortality. The higher proportions of men and women in Northeast Pennsylvania diagnosed at regional stage of disease likely contributes to the excess mortality and raises questions about the adequacy of screening in this population.

Effective screening tests for CRC have been available for some time, but are underutilized, and screening for this disease lags far behind screening for other cancers in the United States. Findings from BRFSS indicate that in 1999, only 44% of US adults aged 50 years or older had ever had a sigmoidoscopy or colonoscopy for screening or diagnostic purposes, and only 34% of respondents had either of these screening tests in the previous 5 years—the recommended time interval.[14] For FOBT using a home kit, 40% of respondents aged 50 years or older reported ever having this test, and only 21% reported having had the test in the previous year. Only 44% of adults aged 50 and older had had at least one of these screening tests within the recommended interval (1 year for FOBT or 5 years for lower endoscopy).[14] In July 2001, Medicare began reimbursing for screening colonoscopy for participants at average risk. As such, lack of insurance coverage should not be a barrier to screening in an older population.

Although the prevalence of FOBT use was significantly higher and colonoscopy was significantly lower in Pennsylvania than the US average, BRFSS data for Lackawanna County were too limited to allow us to document disparities in screening rates for this county. The estimated prevalence figures for these 2 screening tests in Lackawanna County were more extreme than the figures for Pennsylvania (higher FOBT and lower sigmoidoscopy/colonoscopy), however these differences were not statistically significant, possibly because of small numbers of observations, which are reflected in the wide CIs for the estimates of screening prevalence in the county. Additional data will be needed to definitively determine whether important differences exist in screening between Lackawanna County and the United States. Still, the available data suggest that CRC screening in this county is different from the reported practice in the United States. Our findings on stage at diagnosis are compatible with this hypothesis and suggest a need to increase awareness of CRC and promote regular screening in this community.

Early detection is particularly important because advancements in treatment, such as improvements in chemotherapy, do not appear to be responsible for the observed decrease in mortality nationally. A previous study found little relationship in the SEER populations between the temporal trend of increasing 5-year survival and changes in mortality rates.[15] Improvement in survival in that study was attributed to earlier diagnosis rather than to more effective treatment. We note also that annual age-adjusted CRC incidence rates for the SEER 9 regions are highly correlated with age-adjusted CRC mortality rates. This suggests that fewer advanced stage cases, rather than improved treatment, accounts for the decreasing trend in CRC deaths observed nationally. If stage-specific survival is not improving substantially, then early detection through increased screening is all the more important, particularly in regions with excess burden such as Northeast Pennsylvania.

In these analyses, the incidence data were of high quality and unlikely to introduce any important biases. The SEER program is designed to provide complete ascertainment of all invasive cancer cases and is the authoritative source of information on cancer incidence and survival in the United States. The SEER program is the only comprehensive source of population-based information in the United States that includes stage of cancer at the time of diagnosis and patient survival data.[16] The other major source of US CRC incidence data is the publication "United States Cancer Statistics," which does not contain information on stage at diagnosis. CRC incidence in the United States as reported in "United States Cancer Statistics: 2003 Incidence and Mortality" was similar to SEER rates for 2000–2003.[17] The data for Lackawanna County were obtained from the PCR, a "gold standard" registry. Between 1996–1999, 0.2% of all incident cancers in this registry were ascertained by death certificate only; the corresponding figure for CRC was 0.1%.

Because the cause-of-death data were derived from information reported by the certifying physicians on death certificates filed in state vital statistics offices and consolidated into the national database, they are subject to the usual errors and uncertainties in such data. However, CRC mortality rates for the entire United States the SEER regions are quite similar suggesting that under ascertainment of CRC deaths is not a large problem. In addition, there is no evidence that CRC mortality data are collected differently in Pennsylvania than the other states. The small volume of BRFSS data available at the county level is another limitation of this study. As a result our estimates of CRC screening prevalence in Lackawanna County are imprecise. Further, we had no data on CRC risk factors, so we could not study potential causes of the high incidence of this cancer.

One encouraging sign in these data is that age-adjusted CRC incidence and mortality rates in Lackawanna County have been slowly declining although they remain nearly 30% higher than the US rate. Further since 1995, the excess in CRC mortality in this community has come in line with the observed excess in incidence. Although the overall trends in incidence and mortality are encouraging, the reason(s) for the consistently higher CRC incidence in Northeast Pennsylvania are not known. Further study of this issue is clearly warranted. It should be noted however, that even if one or more modifiable risk factors that accounted for the excess incidence in this community were clearly identified and could be changed, it would take years or decades before incidence would decrease to the US average. On the other hand, data on CRC screening available at the state and national level and data on stage at diagnosis available locally suggest that there is ample room to enhance the early detection of this serious disease. Improvements in screening can be expected to yield a rapid increase in the proportion of cases diagnosed at the localized stage, resulting in a decrease in mortality rates. Increasing awareness of CRC and improving screening rates in Northeast Pennsylvania may be the most effective approach to reducing cancer deaths in this community in the short term.

In summary, data from state and regional cancer registries have been used to document high incidence and mortality rates and relatively advanced stage at diagnosis for CRC in Northeast Pennsylvania. The results of this study, documenting these important cancer disparities, are being shared with both medical practitioners and the general population in the community. We believe that an increased awareness of CRC and improved utilization of currently available screening tests will result in reductions in deaths from this common cancer.

Acknowledgement

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Don't Settle for Less

Michele Webb, CTR

Do you know the origin of the phrase "raising the bar?" It's a metaphoric phrase used as an expression to convey the idea of gradually setting the accepted minimum standards higher in order to reach a level of excellence.

"Raising the bar" came into use with the track and field sports of high jumping and pole-vaulting where athletes run and jump to propel their bodies over obstacles. For each subsequent round, the bar which establishes the vertical height of the obstacle is raised, making the event progressively challenging. The athlete displaying the greatest skill and stamina and who clears the highest bar, or series of bars, wins the event.

When we apply this phrase to cancer registry, *raising the bar* generally pertains to setting ever higher expectations of *quality, productivity,* or *service.* Our expectations come from two sources. First, those imposed upon us by others who judge our performance. And second, those internally imposed as a method of self-improvement. Ideally both work in tandem to bring about greater levels of achievement not seen in the context of previous measures of excellence.

Let me tell you about Carol and Linda, two cancer registrars in suburban cities. They attended a presentation by Mike, a cancer registrar in a neighboring city, at a state association meeting. Mike presented a new and unique technique for collaborating with physicians to complete AJCC staging on newly-accessioned cases. His stats were phenomenal; his methodology concise and easy to implement. He offered to demonstrate his program to anyone interested in coming to visit his facility to see it in action.

Soon after, Carol and Linda scheduled a visit to Mike's facility. They were eager to learn all the "ins and outs" of his program. Both planned to quickly implement a similar program at each of their facilities and noted that they would benefit from a shared visit. They would also be able to provide ongoing support for each other afterwards.

Mike did not let them down. Not only did his staging methods exceed their expectations, but his vision for cancer registry operations, staffing, performance, and productivity was also exemplary. Carol and Linda took copious notes and "ooh'd" and "aah'd" over everything Mike shared. They were in awe of Mike and his team's accomplishments. Although a bit embarrassed by what he considered "the norm," he extended a sincere invitation to mentor and help each of them.

Later they marveled at the level of quality, productivity, and service they had observed. Mike's program was deserving of his peer's respect and admiration. They believed that every cancer registrar could easily implement his program in order to achieve even higher levels of quality and service. Mike's level of performance demonstrated where hard work and dedication could carry a cancer registrar.

Everyone should have the opportunity to learn from someone like Mike. Each of us should be determined to operate with high and ever-increasing levels of quality, productivity, and excellence while serving the greater effort to manage, and ultimately, eradicate cancer.

Whether you have observed a program like Mike's, or have learned a new technique from a mentor, you should create a mental image of these moments to keep with you always. These images can serve as a prod when you begin to "settle" in life. When tempted to slide the bar down a little bit rather than leave it high, or stretch to reach a new level of achievement, bring these images to mind. Sometimes stretching to reach the bar is not so fun, and you might want the bar to come to you instead of stretching to meet it. Leaving the bar where it is, or even lowering it a bit, might be more comfortable at that moment in time, but it will never lead to a comfortable or optimal life.

If you would like to live an extraordinary life, filled with all the successful moments and opportunities only the best cancer registrars achieve, you will need to imbed two basic principles into every thought and action:

1. **Hard work.** It may be a given, but it's worth repeating. If you want the level of success that allows you to create your own little "heaven on earth" you had better be willing to work hard. Working hard means sometimes having to do unpleasant things when you would *rather be doing something else.* It means making sure that the people in your organization know that you'll not only work extra hours when called upon, but you'll do it willingly, happily, and with an eye toward a bigger goal. It means that, when called upon, you will make each of them feel as though you expected to be asked, not as though it is a disservice. *It means getting out of your comfort zone and making things happen, not waiting for them to happen.*
2. **Smart work.** Hard work is commendable. But if it's ineffective work, it will still be unsuccessful work no matter how much effort you put in to it. For example: if Carol works for several weeks to create an elaborate tracking system to monitor incomplete cases, when her software system provides the tools to do this automatically via an easily-customized report, Carol would be working ineffectively not smartly. Far too often cancer registrars spend countless hours of valuable time creating com-

plex, unnecessary processes rather than using the tools or resources already available to them. Whether it is fear of the unknown, loss of control, stubbornness, lack of vision, fear of change, or resistance to doing something different, you can see a Carol just about everywhere you look. Except, of course, in Mike's facility where everyone works smart and people like Carol would not carry on without change!

Perhaps adding "bells and whistles" to your cancer registry program is not the most effective use of your time and resources right now. Let's face it, data quality, productivity, and timeliness is worth a lot. All I am saying is that if you could have all of that *and* the very best quality, productivity, and services, then you would be foolish not to plan your work and then work your plan. It's all about *not* "settling for anything less than everything!"

"I ain't settling for just getting by
I've had enough so so for the rest of my life
Tired of shooting too low, so raise the bar high
Just enough ain't enough this time
I ain't settling for anything less than everything…"
—Excerpt from the lyrics for "Settlin" by Sugarland

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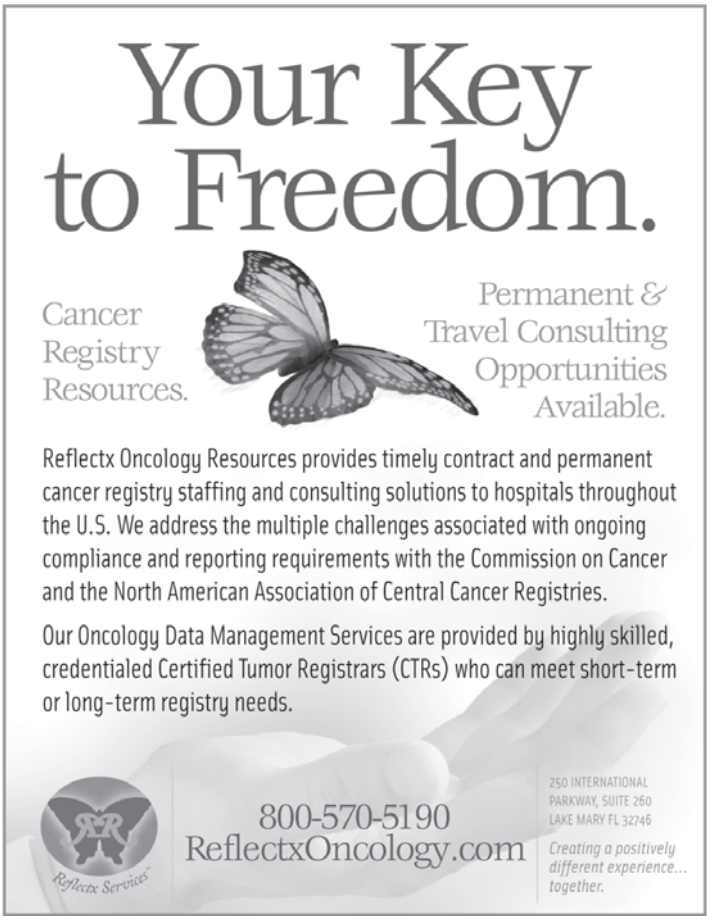

Data Directions

Seijeoung Kim, PhD and Faith G. Davis, PhD

Incarcerated individuals present multiple health concerns due to increased risks in behavioral, socioeconomic, and environmental factors. However, they are often excluded from national surveys. Infectious diseases among the incarcerated population have been traditionally perceived as threats not only to the health of the inmates but also to the health of the public. Chronic illnesses are recently beginning to receive attention as an emerging burden in this population. The National Commission for Correctional Health Care (NCCHC), which provides a voluntary accreditation of correctional health services, recommends evidence-based standards and consistent surveillance and follow-up of chronic illnesses for the incarcerated population.[1] Standardized surveillance systems in this setting, for both infectious and chronic conditions, are still a work in progress. Here we present 4 articles reflecting surveillance of different infectious and chronic conditions in this population to raise several critical issues and to encourage further discussion on the topic.

Dean H, Lansky A, Fleming P. HIV surveillance methods for the incarcerated population. *AIDS Educ Prev.* 2002;14(Suppl B):65–74.

Comment: This article describes the use of the HIV/AIDS Reporting System (HARS) and the Supplement to HIV and AIDS Surveillance (SHAS) in correctional facilities. HARS and SHAS are the 2 surveillance systems through which state departments report HIV/AIDS cases to the Centers for Disease Control and Prevention (CDC). The HARS includes information on the facility where each case is diagnosed. Individuals whose HIV status is first diagnosed in jails and prisons are reported as 'correctional facility' cases. Utilizing SHAS, supplemental information is collected from a subset of cases from HARS. However, very few interviews have been conducted with incarcerated individuals. The authors describe that HIV/AIDS cases from correctional facilities are more likely to be male, black, younger, and injection drug users at the time of diagnosis. They found that higher drug related risks were reported among incarcerated HIV cases than among non-incarcerated cases. The authors conclude that SHAS data may not represent all incarcerated individuals with HIV infection, and call for more complete and better quality data collection methods in correctional settings.

Osher F, Steadman H, Barr H. A best practice approach to community reentry from jails for inmates with co-occurring disorders: The APIC model. *Crime & Delinquency.* 2003;49(1):79–96.

Comment: This article discusses the importance of discharge planning and service linkages between jail and the community for mentally ill inmates. Over 11 million individuals are incarcerated in jails every year. An estimated 700,000 inmates have serious mental illness and over 70% are substance users. The authors argue that while discharge planning for these mentally ill inmates is an essential element of mental health, mentally ill inmates are actually less likely to benefit from discharge planning. The short length of stay and unpredictable release schedule make assessment and service planning challenging for jail inmates. When inmates with mental health problems return to the community without transition planning and linkages to community based services, these individuals (a high proportion of them experience multiple co-occurring conditions, such as substance abuse, homelessness, and poverty) would be more likely to be exposed to the high-risk environment for repeated psychiatric episodes and re-incarceration. The APIC model consists of assessing, planning, identifying, and coordinating steps, and has been evaluated to be effective. The authors conclude that if any mental health program is to be effective, collaborations between jail and community mental health and substance treatment systems are essential. Jails provide unique opportunities to screen and provide interventions to those who might not receive care in the community.

Vonga S, Fiorea A, Haightc D, et al. Vaccination in the county jail as a strategy to reach high risk adults during a community-based hepatitis A outbreak among methamphetamine drug users. *Vaccine.* 2005;23(8):1021–1028.

Comment: This article demonstrates the effectiveness of a vaccination program in a county jail controlling a hepatitis A outbreak in the community. Polk County, Florida, experienced an unusual increase in the incidence of hepatitis A in 2001. The incidence rates have been about 7.3 per 100,000 between 1991 and 2000, but in 2001, the rate reached up to 30.9 per 100,000. In Polk County, 48% of hepatitis A patients were drug users and 80% had a history of recent incarceration, and nationally, 5% of cases recorded in the National Notifiable Diseases Surveillance System were injection drug users. The Advisory Committee on Immunization Practices (ACIP) recommends that substance users be vaccinated for hepatitis A. However, illicit drug users are generally a hard-to-reach population, which makes it quite a challenge for health departments to identify and implement vaccination programs for this group. During the outbreak in Polk County, the authors implemented an alternative strategy where a seroprevalence survey was conducted and hepatitis A vaccination was provided in the County Jail. The total number

of individuals vaccinated in the jail was over 70% of all people vaccinated through the county health department. The intervention was able to reduce the rate of hepatitis A in the community to the baseline level within a year.

Clark B, Grossman E, White M, Goldenson J, Tulsky J. Diabetes care in the San Francisco County Jail. *Am J Pub Health.* 2006;96(9):1571–1574.

Comment: The authors argue that chronic illness has become an important part of correctional health care, but chronic care management in jails is challenging because of the nature of correctional settings. Data on adherence to national guidelines in this population is limited. Without adequate data, the ability to measure the quality of care provided and the patient's adherence to care regimens is limited. The article reports that immediate-term quality indicators (finger-stick glucose measure, blood pressure check at intake, diabetic diet, and assessment within 30 days) showed higher adherence rates than the longer-term indicators (HgA1C check, fasting lipid measure, and aspirin use when appropriate). The adherence rate for the longer-term indicators significantly increased when the analysis included only those who stayed in jail more than 30 days). The authors discuss that because inmates do not have control over their medication, mealtimes, and activities, diabetes management is difficult in jail settings. It is also true that because of this restricted daily schedule, however, patients and care providers may better monitor the progress and adhere to the care guidelines.

We reviewed 4 conveniently selected articles to explore the usefulness of surveillance systems in correctional settings. Dean et al note that despite the well known increased risks of HIV infection and transmission in this population, there remain significant challenges in collecting high quality data in this transient and difficult-to-access population. Osher et al stress that in the context of mental health care, the purpose of developing surveillance systems in correctional settings is not to create separate and isolated systems that work only within jails and prisons, but to link, integrate, and streamline screening, data collection, interventions, and follow-up as part of the public health systems. Such integrated surveillance systems would help ensure continuity of care and minimize unnecessary repeat screening or testing. Effective data and service linkages may help design cost-effective alternative interventions to incarceration.[2–4] Vonga et al actually demonstrate that a jail-based surveillance and intervention program can be an effective strategy to control a community-based infectious disease. Clark et al also note that inmates often do not have a stable primary care provider and are affected by co-occurring chronic conditions, thus they may be disproportionately left undiagnosed. Clinics in jails may help identify these undiagnosed patients and provide care at an earlier stage of disease. Utilizing the intake process to screen for unknown conditions among incoming inmates may be a logical place to help reduce multiple disparities in underserved populations. Finally, Clark et al demonstrate that the structured jail environment may provide a unique moment for improving health, in this case diabetes, in this underserved population that often does not have access to quality care.

Together these articles suggest that the link between health care in jails and public health systems needs to be highlighted. The majority of inmates return to their communities after a short stay in jail. Increased risks among this population could easily be diffused to the general public. On the other hand, effective surveillance systems in jail settings would be a useful tool in controlling health problems in the community, particularly by targeting high-risk groups. While the need for improvement in health care quality and continuity in jails and prisons are apparent, establishing comprehensive screening and follow-up systems is not an easy task. Surveillance systems should be able to facilitate information flow in a transient, hard-to-follow population, which is key to a successful monitoring program. The ability to effectively screen and follow-up this specific high-risk population is essential to reducing overall health risks in the general population.

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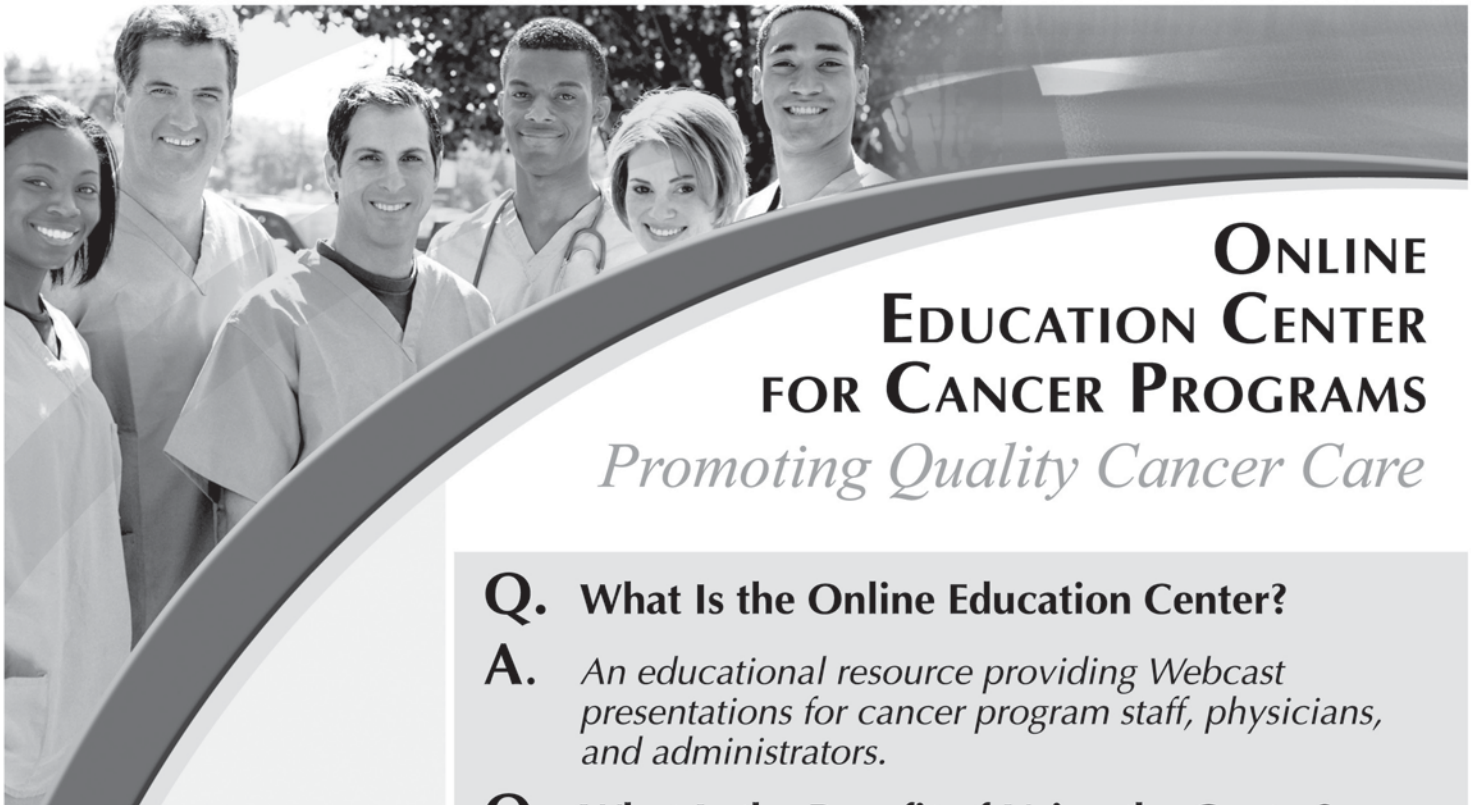

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It's Time for an International CTR Exam… and Other Thoughts

April Fritz, RHIT, CTR

This summer I had the opportunity to meet 2 extraordinary CTRs. Now, it's true that all CTRs are special people, but I really admire these 2 and others who have gone to exceptional lengths to become CTRs. I met Asif Mehmood, CTR and Hye-Young Shim, CTR when they were attending the summer school on cancer registration at the International Agency for Cancer Research in Lyon, France. Asif is a native of Pakistan who is working in the National Cancer Registry of Saudi Arabia. Hye-Young works for the national cancer registry in Jung-Gu, Republic of Korea. Both have made the effort to study for and pass the US version of the Certification Examination for Tumor Registrars (CTR exam).

According to NCRA records, there are 61 CTRs who live outside of the United States (see Table 1). Over 70% are Canadians; the others are in the Middle East, Asia, Central America, and Ireland. All of these folks are to be commended for becoming CTRs, especially those whose native language is not English, like the CTRs in French Canada. I have also spoken to registrars in Greece, Singapore, Australia, England, and Africa who are interested in formal recognition as cancer data professionals.

We know that becoming a CTR is an accomplishment regardless of where you live, but consider the following:

- The US CTR exam tests on the American College of Surgeons Commission on Cancer (CoC) standards, US abstracting and coding rules, US staging systems (Collaborative Stage), and US cancer data, most of which non-US registrars will never need in their daily work.
- The CTR exam is administered only in English, using English language reference books.
- The CTR exam costs as much as 2 months salary in some countries.
- The continuing education for a CTR is much more difficult when you do not have access to registrar association workshops and other avenues to obtain CEs.
- With the implementation of further formal education requirements for eligibility to take the CTR exam, it will be even tougher for non-US registrars to become certified.

To become a CTR when you live outside of the United States requires sacrifice (both financial and time) as well as tremendous dedication to the field.

In my opinion, it's time that the National Cancer Registrars Association (NCRA) moves forward with an international certification exam for cancer registry professionals. More than 3 years ago, I was part of a task force to develop a plan for NCRA to offer an international CTR credential. After more than a year of conference calls, the task force presented a complete business plan to the Council on Certification, which took it to the NCRA Board of Directors, which sent it back to another NCRA group called the Specialty Model Task Force (SMTF) to rework using the Canadian model. As I understand it, a Canadian candidate for the CTR exam would have to pass the US version of the exam with all of its US rules and standards, *as well as* a Canadian module. I think it's a waste of time—and a deterrent to future international CTRs—to have to learn US rules and standards that aren't relevant to the registrars' activities in their native country. The SMTF has been working on specialty modules but, as of this writing, has yet to present its final recommendations to the Council on Certification and the NCRA Board—and even then it's only a development proposal, not the exam itself. Meanwhile, there is increasing interest—and pressure—in other countries to develop nation-specific cancer registration proficiency tests without the involvement of the world's premier cancer registry professional association, NCRA. That would truly be a shame, but if NCRA's glacially-slow pace continues, that may indeed be the reality. If the concern is funding, there are a variety of international agencies and federal programs that could contribute the necessary funding to develop the exam.

Asif Mehmood, CTR (Saudi Arabia) and Hye-Young Shim, CTR (Republic of Korea)

Why couldn't there be a 2-part CTR exam for all registry professionals? Many parts of the job and knowledge base are the same regardless of where you live and work. The first part of the exam could cover basic knowledge of oncology (spread of cancer), terminology, anatomy, morphology, statistics, quality control, and database management. The second part of the exam could cover information such as COC standards in the United States, NAACCR standards in the United States

Table 1. International CTRs by Country	
Canada	43
Saudi Arabia	8
South Korea	5
Costa Rica	1
Ireland	1
Israel	1
Republic of Korea	1
United Arab Emirates	1
Total	**61**

and Canada, rules for counting multiple primaries (United States vs. international), and unique staging systems (like CS), that are used in a specific country. If that country follows SEER rules (as many do), that information could be tested in the second part of the exam. The successful candidate (who would have to pass both parts) would therefore demonstrate an understanding of the cancer disease process, which is the foundation for our profession, as well as an understanding of national standards.

We know there will be a shortage of registrars in this country in the next few years based on the findings of last year's NCRA-sponsored Workforce Analysis Study of the Cancer Registry Field, the retirements of colleagues all around us, and the changes in the education requirements for eligibility to take the exam. Let's not compound that by failing to meet the needs of registrars outside of the United States, whose professional recognition levels are even lower than what we perceive in this country.

Feedback on ICD-9-CM Casefinding Article

Thank you all for your responses to my piece in the last issue of the *Journal of Registry Management* regarding the revised ICD-9-CM casefinding codes for the hematopoietic diseases. I had some feedback and clarifications from the National Center for Health Statistics (NCHS) that are important to share with you.

First, while I pointed out that the Federal Register announcement that contains the new ICD-9-CM codes is published by the Centers for Medicare and Medicaid Services (CMS), it is actually the National Center for Health Statistics that is fully responsible for developing and revising the new diagnosis codes that are implemented each year. My apologies for not making that clear.

Second, I stated that the term "cervical intraepithelial neoplasia" had been added to 233.1 as a synonym and that the various grades of CIN are not distinguished. To clarify, CIN III (potentially reportable) is coded as 233.1; the lower grades (not reportable) CIN I and CIN II are coded as 622.11 and 622.12, respectively. NCHS may need to add the phrase "grade III" to the newly-added words "cervical intraepithelial neoplasia" to avoid confusion and miscoding of lower CIN grades in 233.1.

Third, I indicated that code 238.7 is no longer in effect, which is true for *encoding* new cases. When an existing code is expanded in ICD-9-CM, it is correct that the old code is no longer valid, but the old code does remain a valid subcategory for statistical purposes. If codes in 5-digit categories are collapsed for reporting, the older 4- or 3-digit subcategories may still be used in some tabulations. This is a fine, but important distinction, and I am grateful to NCHS for pointing this out.

We have asked NCHS to investigate the correct coding of *malignant* GIST cases arising in solid organs. Their logic was that "GIST not otherwise specified" is a borderline tumor in ICD-O-3, so it defaults to the very generic 238.1, neoplasm of uncertain behavior of connective and other soft tissue. Benign GIST defaults to 215.5, benign neoplasm of connective tissue of abdomen, and therefore malignant GIST would default to malignant neoplasm of connective and soft tissue of abdomen. Stay tuned.

Finally, there are more new cancer casefinding codes on the horizon. ICD-9-CM is updated each October, so it is only a few more months until the next round of updates. There are several new codes for specific types of lymphomas (which are really needed) and a new malignant ascites code, as well as some other revisions for VIN and VAIN, all of which will become effective October 1, 2007. The proposed new codes are already posted on the NCHS Web site if you want to take an advance look. NCHS is working hard to resolve the coding discrepancies between ICD-9-CM and ICD-O-3.

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The opinions in this column are those of the author. She can be reached for comments and feedback at: april@afritz.org.

CORRECT ANSWERS FOR SUMMER 2007

Journal of Registry Management **Continuing Education Quiz**

Changes in ICD-9-CM Casefinding Codes for Reportable Neoplasms

*(correct answers in **bold**)*

1. ICD-9-CM coding changes for health information (medical record) diagnoses were published by the:
   a) American Joint Committee on Cancer;
   b) World Health Organization;
   c) Centers for Medicare and Medicaid Services;
   d) Commission on Cancer.

2. There is a trend toward greater specificity of codes, with important changes in the coding of many clinical conditions, particularly:
   a) ill-defined and unknown primary sites;
   b) brain and central nervous system primaries;
   c) endocrine disorders;
   d) hematopoietic diseases and other blood disorders.

3. Refractory anemias are now recognized as:
   a) neoplasms of uncertain behavior;
   b) generic diseases of blood and blood-forming organs;
   c) a non-specific category without its own code;
   d) none of the above.

4. Considering the added clarity for refractory anemias and cytopenias, registrars using the facility diagnosis index for casefinding:
   a) need to sift carefully through many non-reportable diagnoses in 284 and 285 to find the reportable cases;
   b) screen charts for myelofibrosis cases;
   c) carefully distinguish myelofibrosis from primary or idiopathic myelofibrosis;
   d) both b and c above.

5. In the cancer registry database, malignant gastrointestinal stromal tumors of the stomach or small intestine should be coded to:
   a) connective and other soft tissue;
   b) the involved organ;
   c) overlapping lesion of stomach and small intestine;
   d) none of the above.

6. Cervical intraepithelial glandular neoplasia has been added as a synonym for cervix carcinoma *in situ*.
   a) true
   b) false

7. Table 2, *Comprehensive ICD-9-CM Casefinding List for Reportable Tumors,* is effective for encounters and discharges beginning:
   a) January 1, 2004;
   b) January 1, 2007;
   c) October 1, 2006;
   d) October 1, 2007.

8. Cases with codes listed in Table 3, *Supplementary ICD-9-CM Codes to Screen for Cancer Cases Not Identified by Other Codes:*
   a) should be screened immediately;
   b) should be screened as registry time allows;
   c) are neoplasm-related secondary conditions for which there should also be a primary diagnosis of a reportable neoplasm;
   d) both b and c above.

9. Table 4, *Errata #2 to Abstracting and Coding Guide for the Hematopoietic Diseases:*
   a) is a SEER publication;
   b) is effective beginning January 1, 2007;
   c) states that refractory anemia with excess blasts in transformation is an obsolete term and should be correctly coded to acute myelogenous leukemia;
   d) states that code 289.83 Myelofibrosis (NOS) should be deleted.

10. The author recommends joining the discussion group at:
    a) Match.com;
    b) http://health.groups.yahoo.com/group/NCRAMember;
    c) Wikipedia.com;
    d) Ask.com.

Journal of Registry Management Continuing Education Quiz—FALL 2007

REVISING THE MULTIPLE PRIMARY AND HISTOLOGY CODING RULES

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:

- Describe the development of the 2007 multiple primary and histology (MP/H) coding rules
- List the 8 site-specific cancer sites/site groups addressed by the revised MP/H rules and the timing specifications for each
- Code multiple primaries/histologies more accurately

1. Data quality assessment audits of the MP/H coding rules, which have been in use for over 25 years, revealed:
   a) consistent coding that demonstrated the clarity of the rules
   b) inconsistent coding that demonstrated problems with the rules
   c) non-standard use of nomenclature by pathologists compounding coding problems
   d) both b and c above

2. The purpose of revising the MP/H rules was to promote consistency by improving the instructions used by registrars to make multiple primary decisions and code histology.
   a) true
   b) false

3. The MP/H Task Force consisted of a diverse group led by:
   a) National Cancer Registrars Association (NCRA)
   b) American Joint Committee on Cancer (AJCC)
   c) Surveillance, Epidemiology, and End Results (SEER)
   d) National Program of Cancer Registries (NPCR)

4. The MP/H Task Force recommended that the MP/H coding rules be site-specific, clearly defined, prioritized, and that the timing rule should be:
   a) the same for all sites
   b) site specific
   c) eliminated
   d) none of the above

5. The 8 site-specific cancer sites/site groups were selected based on:
   a) their rate of occurrence in the population
   b) the potential for errors in coding
   c) both a and b above
   d) none of the above

6. The new MP/H rules underwent pre-testing and numerous revisions ("review-and-revise" methods) prior to being released.
   a) true
   b) false

7. To accommodate different learning styles among users, the MP/H rules were:
   a) standardized into a single format
   b) set up as fishbone diagrams
   c) made available in 3 formats: flowchart, text, or matrix
   d) charted as histograms

8. According to Table 1, *Frequency Report for Colon—All Registries, All Cases,* beta test participants were least likely to agree on which of the 3 data items?
   a) Data Item: Is this a multiple primary?
   b) Data Item: Histologic Type ICD-O-3
   c) Data Item: Histologic Type ICD-O-3 (2nd Primary)

9. According to Table 4, *The Effect the Change in Timing Rules Will Have on Incidence,* the timing rule for abstracting a new primary for bladder was changed from 2 months to 3 years for all histologies.
   a) true
   b) false

10. Phase II of the MP/H rules development process will focus on:
    a) malignant brain and central nervous system tumors
    b) prostate malignancies
    c) neuroendocrine tumors
    d) hematopoietic malignancies

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