



Journal of Registry Management

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The web index is a cumulative index of all *JRM* articles ever published.

International CTR Exam

As co-chair of the Specialty Model Task Force, which replaced the Council on Certification's former International Exam committee, I would like to respond to the comments April Fritz made in her recent column (*JRM*, Fall 2007, p. 111-112).

An article presenting an update on the activities of the Task Force has been published in the Winter 2008 issue of *The Connection*. It explains what the Task Force has been doing and where the project is along its proposed timeline. Briefly, Phase I of the project is completed. This involved drafting a Procedure Manual for other countries or specialty organizations to use when developing a certifying examination module based on their own needs. Phase II will be starting soon. This will involve a 'Beta testing' of the manual by Canadian volunteers to see if the procedures recommended in the Manual can be of use in developing a Canadian-specific examination. If so, the Manual will be available to others who need to use it. Of course, some problems may arise during the test period, and solving them will aid in modifying the Manual.

In November, I attended the annual conference of the National Organization for Competency Assurance. This is an organization to which most certifying boards, such as our Council on Certification, belong. I also attended the

conference in 2006. Both times I made a point of sitting in on all presentations concerning international exam development, and of discussing NCRA's situation with presenters.

The NCRA Board and the Council on Certification recognize the achievement and sacrifices that registrars from other countries make in becoming a CTR. However, the financial issues in developing an international program are enormous. In fact, I made a point of writing down two comments made by presenters who had gone through the process of developing an international exam: One said, it is an "amazingly expensive process." Another agreed, stating, if you are not careful, the process has the "possibility of bankrupting your organization." Comments like these, from people who know, certainly gives one pause. The NCRA Board and the Council are trying to solve the issue of international certification in the most financially responsible way.

No solution ever satisfies everyone. However, we hope that this project—which is being funded by NCRA—will prove acceptable to the majority.

Sincerely,
Amy Fremgen, PhD, CTR
Administrator, Council on Certification
November 2007

Comparison of Registrar Collaborative Staging and Physician AJCC Staging Using Data Submitted to the National Cancer Data Base

Jerri Linn Phillips, MA, CTR^a; Donna M. Gress, RHIT, CTR^b

Abstract: Background. Over one million cancer cases diagnosed in 2004 were submitted to the National Cancer Data Base (NCDB) with facility registrar staging using the Collaborative Staging (CS) system, and physician coded clinical and pathologic T, N, M and stage group entered. No major comparisons of the two approaches have been published since CS was adopted in 2004. The purpose of this study was to compare the two in routine NCDB data submissions from cancer programs approved by the American College of Surgeons Commission on Cancer. Methods. Physician-assigned, American Joint Committee on Cancer (AJCC) stage groups was compared to CS-derived AJCC stage groups for completeness and consistency. Completeness was evaluated separately based on whether or not the standard site-stage registry edit required the case to be AJCC-staged. Analysis of consistency was limited to cases requiring staging. Consistency was evaluated separately for cases with complete pathologic physician staging (known pT, known pN, known M) or pure clinical physician staging (no known pT, no known pN, not pM1), due to differences in the staging rules for the two approaches. Staging differences were examined to determine the strengths and weakness of the two approaches. Results. Registrar CS staging was minimally more complete than physician AJCC staging; both were most complete for cases required to be staged by the site-stage edit. Seventy-eight percent of cases with required staging, regardless of clinical or pathologic status, had identical stage groups assigned by the two approaches. Aside from differences in rules for assigning stage group, the principle differences identified involved unknown vs. known stage group assignment. Conclusions. Physicians were less likely to assign a stage where stage may not have been seen as clinically useful, or when the formula for computing the stage group involved items other than T, N, and M. Registrars were apparently less able to derive a stage when the exact terminology necessary for staging was not in the patient record. Comparison of the two will help achieve the best results. It is recommended that any presentation of data based on physician staging using AJCC or registrar CS-derived AJCC stage should identify the approach used until studies of the analytic effect of these differences can be conducted.

Key words: AJCC, Collaborative Stage, NCDB, stage

Introduction

The National Cancer Data Base (NCDB) collects reports on cancer cases that are diagnosed or provided at least part of first course treatment by facilities with a cancer program approved by the Commission on Cancer (CoC) of the American College of Surgeons. All input and derived Collaborative Stage (CS) items¹ became required CoC items in 2004 when CS was first implemented in the United States and Canada. The CoC also required managing physicians to record American Joint Committee on Cancer (AJCC) T, N, M, and stage group information,² as part of its efforts to assure treatment quality. This paper describes a comparison of registrar CS staging and physician staging using the traditional AJCC staging form for cancers diagnosed in 2004. The comparison of the two approaches reveals strengths and weaknesses of each.

Methods

Sample

The analysis was based on over one million deduplicated cases diagnosed in 2004 and reported to NCDB by the close of the 2004 submission period (September 1, 2006). The cases, representing approximately 75% of all cancers diagnosed in the United States in 2004, were submitted by 1,368 CoC-approved programs in 49 states, the District of Columbia, and Puerto Rico. CoC-approved programs are surveyed once every 3 years, and must meet specified structure and process standards.³ Among these standards were the requirements that the managing physician stages at least 90% of analytic cases, that the program's registry collects all items specified in the *Facility Oncology Registry Data Standards (FORDS) Manual*,⁴ and that the registry's routine submissions to NCDB meet high data quality edit standards.

"Comparison of Registrar Collaborative Staging and Physician AJCC Staging Using Data Submitted to the National Cancer Data Base"

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The NCDB was established in 1989 as a joint project of the American College of Surgeons and the American Cancer Society.

Coding Instruments

The characteristic AJCC staging form identifies site-and-histology specific criteria for coding clinical and/or pathologic T (tumor), N (regional node involvement), and M (metastases) from which clinical and/or pathologic stage groups are compiled. The criteria by which the individual T, N, and M are assigned by physicians can be quite complicated, often involving simultaneous reference to more than one information source within the patient record. The instructions and item definitions were designed for use by experienced clinicians. Cases in this study were staged according to the sixth edition of the *AJCC Staging Manual*.²

CS was created for use by registrars. The site-and-histology specific items are recorded in discrete input items, rarely requiring simultaneous reference to multiple reports in the patient record. From those input items, AJCC T, N, M, and stage group, as well as 1977 and 2000 Surveillance, Epidemiology, and End Results (SEER) Summary Stage values,^{5,6} are derived by computer algorithm. The computer program can be incorporated in facility and central registry software. An update to CS, which corrected several computation errors in the earlier version, was introduced in mid-2005 (version 01.02.xx), and was the version applied to derive AJCC values for 91% of the cases in this study. Analysis of the consistency of staging was limited to cases with CS Version Latest coded 01.02.xx, but the completeness analysis was based on all versions.

AJCC *chapters* describe staging rules for groups of sites and subsites having particular histopathologic growth characteristics. CS rules are grouped in *schema* that have similar computational characteristics for deriving AJCC and SEER Summary Stage values. The terms *chapter* (for the AJCC manual) and *scheme* (for CS) are used in this analysis to identify the applicable grouping used.

The rules for computation of stage group differ between AJCC and CS. For AJCC, a clinical stage uses all information gathered about the tumor prior to treatment. Pathologic stage is based on "evidence acquired before treatment, supplemented or modified by the additional evidence acquired during and from surgery, particularly from pathologic examination."² cTcNcM is used to derived clinical stage. pTpN and an M are used to derive pathologic stage (where M is either positive pM or a known cM). CS derives a "combined stage" based on the best information available. CS "Eval" items record the clinical or pathologic source of information used.

Coders

Soon after CoC required approved programs to stage all sites with defined AJCC staging, it required physicians to assign and initial AJCC stage for 90% of analytic cases, to begin with 1995 cases:⁷ "Medical chart documentation... contains the American Joint Committee on Cancer stage assigned and initialed by the physician."⁸ CoC rules for cancer program approval in 2004 required that the *managing physician* stage 90% of cases diagnosed or provided with first course treatment at the facility, and record that information in a systematic location in the patient record.

Registrars were familiar with many of the concepts of staging when CS was developed. In addition, registrars in SEER regions and some other states had been performing SEER Extent of Disease (EOD) staging prior to 2004.⁹ Because CS was modeled after EOD, the adoption of CS probably was not as great a change for those registrars. A concerted national training effort provided in-person and web-based training for registrars.

Registrar CS and physician AJCC staging were not performed entirely independently. Many registrars routinely check physician staging, either for internal accuracy or against CS-derived staging. In addition, CoC standards require that a physician review 10% of facility registry cases for accuracy, wherein CS may be among the contents reviewed.

Analysis

The issues of most immediate interest to CoC and its constituents revolve around the completeness of staging using each of the two systems and their consistency. Data analysis was limited to comparison of the data contained in routine submissions to NCDB. No review of hospital patient records was attempted, nor was information available to consider the timing of staging with respect to the planning for patient treatment.

AJCC does not define stage groups for all site-histology combinations. For example, leukemia and brain primaries have no staging defined, nor is there staging defined for liposarcoma arising in the breast. The 6th edition of the *AJCC Staging Manual* provides a list of histologies at the end of each chapter. However, some histologies that develop in the respective organ, and for which the staging procedure is applicable, are not included in those lists. Consequently, the standard site-stage consistency edit used by facility and central registries¹⁰ categorizes site-histology combinations as (1) those that are required to be staged, (2) those that cannot be staged, and (3) those for which staging is permitted but not required (optional staging). The principle combinations with optional staging are the unlisted carcinomas for AJCC chapters that apply to carcinomas, the unlisted sarcomas for the soft tissue and bone chapters, and the unlisted germ cell tumors for the testis chapter. The analysis reported here distinguishes among cases for which AJCC staging is required, optional, or not defined.

Completeness of CS input items was evaluated as the percent of cases with known values for schemes that have defined values assigned for the respective item. Completeness of physician T, N, and M AJCC component staging was calculated separately for clinical and pathologic items. Completeness of staging is based on the derived AJCC stage group for CS, and on the presence of either a known pathologic stage group or a known clinical stage group for physician AJCC staging.

Accuracy was not directly measured. *Consistency* (or agreement) between the two approaches was reviewed separately for cases that were pathologically staged and those that could only be clinically staged according to AJCC rules. Pathologic staging, for AJCC, applies when pT, pN, and either clinical or pathologic M are known. For this group, there should be no unknown AJCC physician

assigned stages. Clinically-only staged cases are, for this analysis, limited to cases where pT and pN are *not* known, and pM is *not* positive. By this selection, all cases with an unknown AJCC stage should be grouped with the clinical stage subsample. Lymphoid cancers have no T, N, and M defined, and are examined separately.

Results

Eighty-five percent (862,351) of the 1,017,763 cases were of the type that must be staged, 2% (23,746) were optionally stageable, and 13% (130,837) have no AJCC staging defined. *Completeness* of stage assignment was marginally better (3–4%) across all sites combined for CS-derived AJCC stage group than for physician-assigned AJCC stage (Table 1). Both were substantially greater for those types of cases for which AJCC staging is required than for cases that may be optionally staged according to the standard site-stage edit. The remainder of the physician AJCC analysis is limited to cases with required staging, so that discrepancies are not solely based on facility choices regarding the staging of optional cases.

AJCC Category	Physician AJCC Stage	Registrar CS-derived Stage
Required	87%	91%
Optional	51%	54%
No AJCC Stage Group Defined*	N.A.	N.A.

*Includes 829 cases with a T, N, and M defined but no defined stage group.

N.A. = Not applicable. CS cannot calculate an AJCC stage where no AJCC stage group is defined.

Completeness

Completeness of registrar CS staging and physician AJCC staging both varied by AJCC chapter (Table 2), and neither approach was consistently more complete. For example, while the two approaches were nearly identical for breast cancer staging completeness, pharyngeal cancer staging was more completely performed by physicians and liver cancer staging was more complete for registrars.

Physician clinical AJCC staging completeness. Both the completeness and appropriateness of physician AJCC staging are more sensitively determined in the context of patient treatment. Clinical staging should be possible for most cancer patients. Only patients who undergo surgical exploration due to undiagnosed symptoms, and who are initially diagnosed and treated during that surgery, can reasonably be expected to have no clinical workup. Among patients who had no surgery or whose surgery followed initial diagnosis by at least one day, a known cT (not X or blank) was reported to NCDB for 53%, cN for 49%, and cM for 55%. It is possible, of course, to have cN and cM values that are clinically determined even though primary site surgery was performed. A known cN was reported for 41% of the patients diagnosed on the same day they had surgery, with 53% for cM.

Table 2. Completeness of Physician and Registrar Staging by AJCC Chapter*

AJCC Chapter	Number of Cases	Known Physician AJCC Stage	Known CS-derived Stage
3—Lip and Oral Cavity	8,630	90%	87%
4—Pharynx	11,868	91%	79%
5—Larynx	10,262	91%	93%
6—Nasal Cavity and Paranasal Sinuses	1,181	84%	93%
7—Major Salivary Glands	2,429	88%	90%
8—Thyroid	21,071	86%	91%
9—Esophagus	11,532	78%	81%
10—Stomach	13,398	80%	85%
11—Small Intestine	1,492	83%	86%
12—Colon and Rectum	100,813	90%	93%
13—Anal Canal	3,691	85%	72%
14—Liver	10,510	70%	77%
15—Gallbladder	2,209	85%	91%
16—Extrahepatic Bile Ducts	2,227	65%	74%
17—Ampulla of Vater	1,375	81%	85%
18—Exocrine Pancreas	20,834	82%	88%
19—Lung	136,116	88%	92%
20—Pleural Mesothelioma	1,863	72%	79%
21—Bone	1,922	70%	60%
22—Soft Tissue Sarcoma	5,934	73%	61%
23—Carcinoma of the Skin	2,353	72%	68%
24—Melanoma of the Skin	32,265	84%	85%
25—Breast	160,184	93%	94%
26—Vulva	4,750	86%	90%
27—Vagina	995	85%	92%
28—Cervix Uteri	12,767	89%	89%
29—Corpus Uteri	22,189	90%	94%
30—Ovary	14,208	89%	93%
31—Fallopian Tube	545	90%	96%
32—Gestational Trophoblastic Tumor	103	82%	95%
33—Penis	884	84%	92%
34—Prostate	119,796	89%	92%
35—Testis	5,633	88%	90%
36—Kidney	26,739	88%	91%
37—Renal Pelvis and Ureter	3,954	84%	92%
38—Urinary Bladder	39,740	88%	94%
39—Urethra	491	78%	89%
43—Malignant Melanoma of the Uvea	1,028	77%	86%
48—Lymphoid Neoplasms	44,370	83%	93%

*Limited to histologies required to be staged and AJCC chapters that have a defined stage group. Physician AJCC staging completeness is the percent of cases assigned a known clinical or pathologic stage group. Registrar CS staging completeness is the percent of cases with a known stage group derived by the CS algorithm

Physician pathologic AJCC staging completeness. To obtain a pathologic T, surgery of the primary site is necessary for most AJCC chapters. Eighty percent of patients treated with primary site surgery had a known pT assigned. To obtain a pathologic N, pathologic examination of at least one regional lymph node is required; 88% of cases by that definition had a known pN assigned. However, one fifth of the cases with no pathologic regional lymph node evaluation were submitted with a “known” pN. Diagnosis of pM1 requires either a biopsy or surgical resection of a metastatic site. Of the patients reported with pM1, 83% had no distant site surgery. Nearly half (44%) of the cases with no distant site surgery were reported to have a known pM, most of those pM0.

Registrar CS staging completeness. With the exception of the item “CS Tumor Size,” 80% or more of cases with codes defined for the respective CS item had known CS input values assigned (Table 3). For most input items, completeness did not vary much based on whether or not the standard edit for AJCC site-stage requires staging. However, only about half as many “Eval” items were known for cases lacking AJCC staging schemes. Among the cancers with limited tumor size values recorded is prostate cancer, which is frequently evaluated with a transurethral resection of the prostate (TURP), for which only 12% had a known tumor size (Table 4).

Table 3. CS Input Item Completeness by AJCC Staging Requirements*

Item	Required	Optional	Unstageable	Total
CS Tumor Size	62%	62%	65%	63%
CS Extension	93%	84%	94%	93%
CS TS/Ext Eval	97%	94%	42%	93%
Number Regional LN Examined	98%	96%	91%	97%
Number Regional LN Positive	98%	96%	91%	97%
CS Lymph Nodes	90%	82%	82%	89%
CS Regional Nodes Eval	95%	89%	74%	94%
CS Mets at Diagnosis	95%	90%	90%	94%
CS Mets Eval	91%	90%	40%	87%
CS Site-Specific Factor 1	84%	64%	49%	80%
CS Site-Specific Factor 2	84%	64%	49%	80%
CS Site-Specific Factor 3	88%	77%	89%	88%
CS Site-Specific Factor 4	93%	66%	97%	93%
CS Site-Specific Factor 5	97%	78%	98%	97%
CS Site-Specific Factor 6	97%	78%	98%	97%

*Limited to schema with defined responses for the respective CS item.

Table 4. CS Input Item Completeness for the Most Frequent Schemes*

Item	Breast	Colon	Lung	Prostate
CS Tumor Size	88%	78%	71%	12%
CS Extension	88%	93%	88%	97%
CS TS/Ext Eval	99%	98%	96%	98%
Number Regional LN Examined	99%	99%	97%	98%
Number Regional LN Positive	99%	99%	97%	98%
CS Lymph Nodes	94%	93%	86%	93%
CS Mets at Diagnosis	96%	96%	94%	95%
CS Mets Eval	97%	96%	95%	96%
CS Site-Specific Factor 1	93%	70%	N.A.	88%
CS Site-Specific Factor 2	93%	N.A.	N.A.	93%
CS Site-Specific Factor 3	100%	N.A.	N.A.	100%
CS Site-Specific Factor 4	100%	N.A.	N.A.	98%
CS Site-Specific Factor 5	100%	N.A.	N.A.	97%
CS Site-Specific Factor 6	100%	N.A.	N.A.	97%

*N.A. = Not Applicable. Lung cancer has no site-specific factors defined, and the colon scheme uses only one (carcinoembryonic antigen). Site-specific factors whose completeness rounds to 100% are shown as 100%.

Consistency

Pathologic stage consistency. There were 392,707 cases eligible for the pathologic analysis. The small intestine, breast, vagina, prostate, and kidney AJCC chapters had over 90% agreement between physician pathologic AJCC stage and the derived CS stage group. The percent distributions of stage and substage groups were very similar for the two approaches for these chapters (Figure 1), and the distribution of cases identically staged by the two approaches very nearly mirrors the separate distributions of the individual approaches. For both approaches, nearly all cases are staged into substage groups (for example, IIA, IIB) with very few cases assigned to the corresponding broad groups (II, III).

For the majority of AJCC chapters, there was between 70 and 90% agreement for pathologic cases. For the chapters in this range, there is slightly more use of broad stage groups and accordingly less use of substages for both approaches, but not always for the same cases, resulting in the lower exact agreement between the two approaches. The ovary is an example, with 82% agreement (Figure 2).

The bone, soft tissue and testis chapters had less than 70% agreement between the two approaches. Soft tissue sarcoma registrar CS staging is characterized by more unknown stages, and the physicians assigned more broad stage groups (Figure 3).

Figure 1. Breast pathologic stage group: percent stage distribution by approach (90.1% identical, N = 107,497)

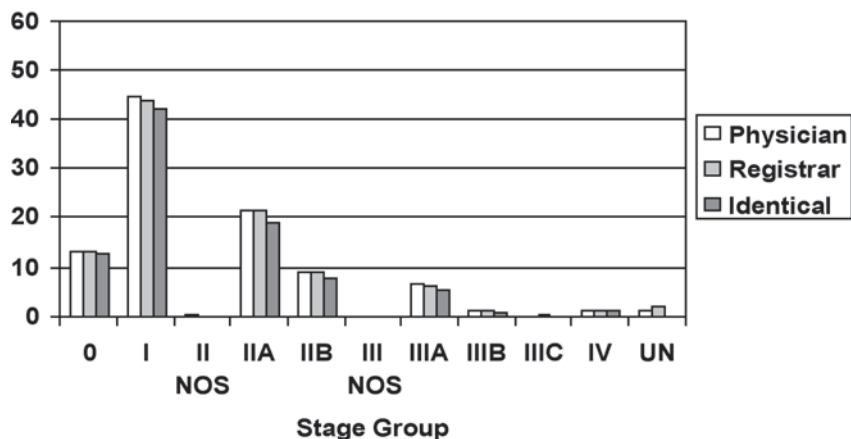


Figure 2. Ovary pathologic stage group: percent stage distribution by approach (81.6% identical, N = 4,508)

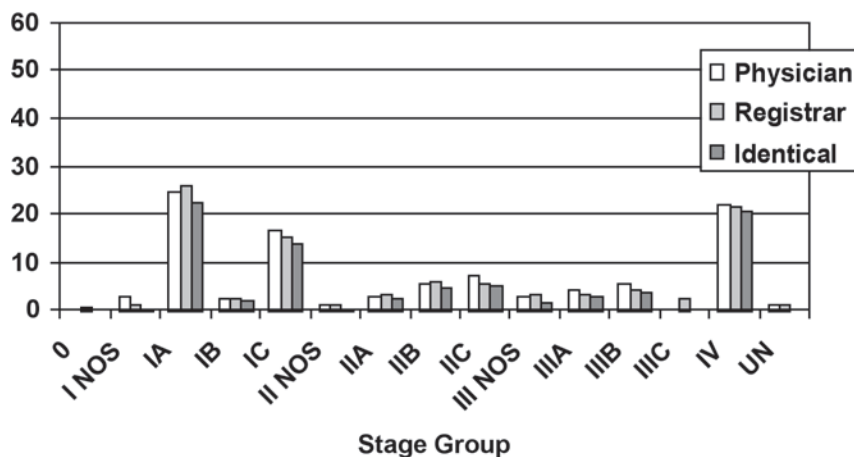
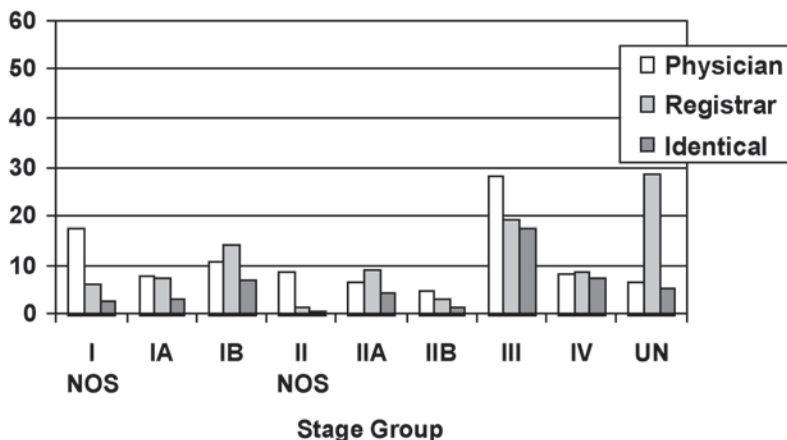


Figure 3. Soft tissue sarcoma pathologic stage group: percent stage distribution by approach (51.1% identical, N = 2,180)



Clinical stage consistency. The clinical stage group comparison was based on 340,332 cases. Overall agreement between physician AJCC stage group and registrar CS derived stage group was about 10% lower for the clinical stage groups than for pathologic. The three examples shown here are selected to illustrate the types of problems uncovered by the discrepancies. More lung cancer cases

were assigned a known stage by registrars using CS than by physicians, especially for cases in CS-derived stage group IV (Figure 4). Notably fewer physicians staged cervical cancer to Stage 0 than registrars (Figure 5), with more physicians than registrars leaving the case unknown. Registrars, using CS, assigned more thyroid cases to Stage I and had fewer cases with an unknown stage than physicians (Figure 6).

Figure 4. Lung clinical stage group: percent stage distribution by approach (79.1% identical, N = 83,099)

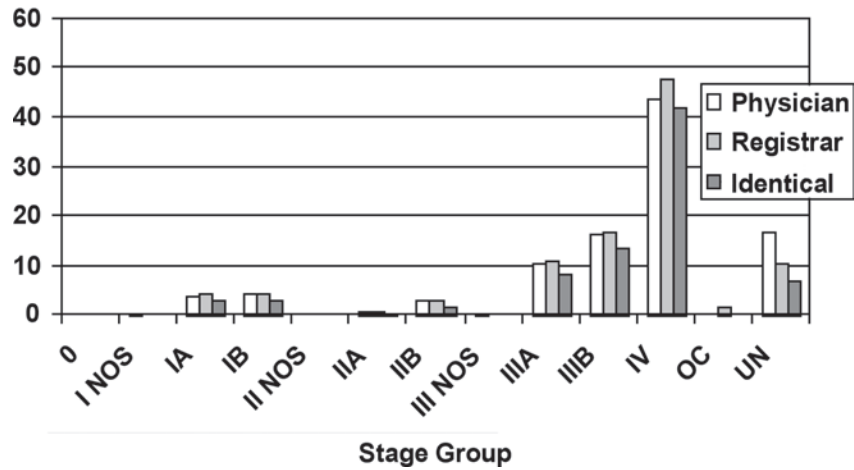


Figure 5. Cervix uteri clinical stage group: percent stage distribution* by approach (67.4% identical, N = 1,162)

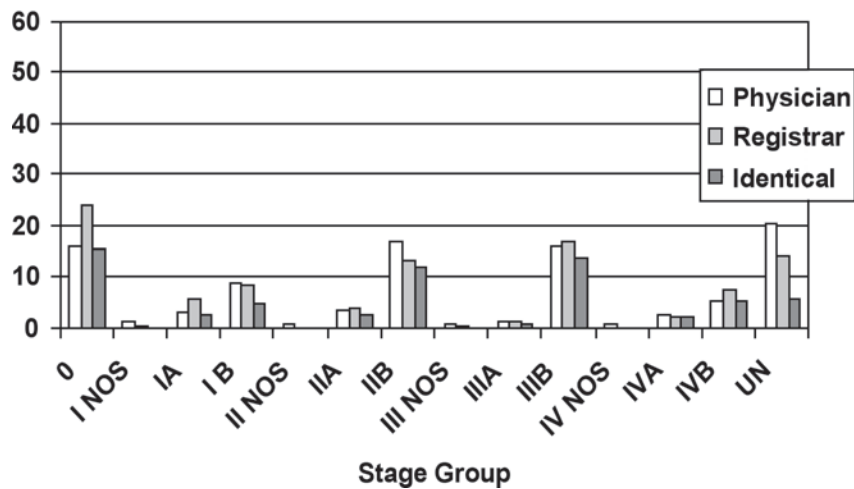


Figure 6. Thyroid clinical stage group: percent stage distribution by approach (53.5% identical, N = 3,558)

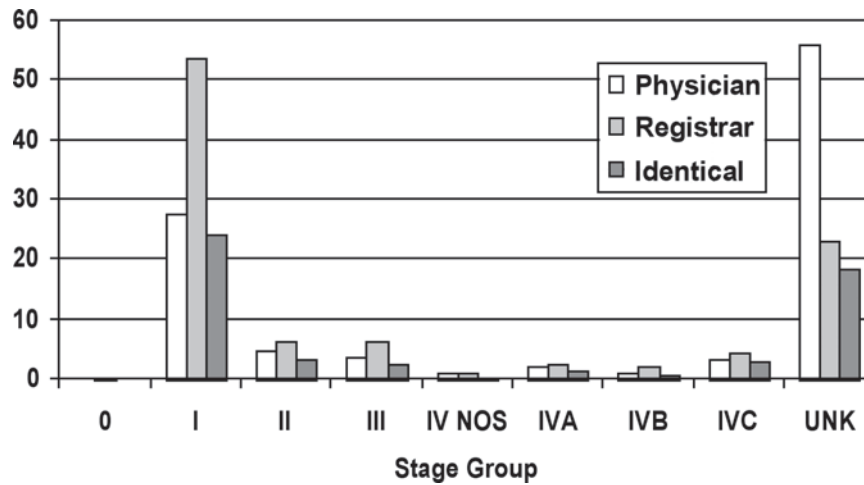
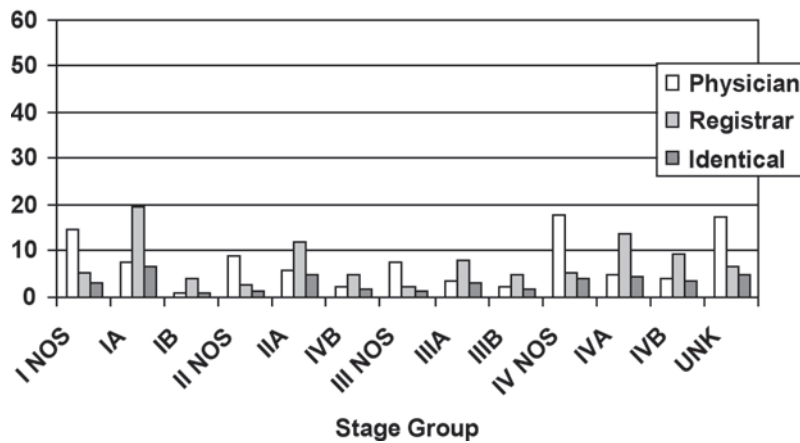


Figure 7. All lymphoid neoplasms: percent stage distribution by approach (44.0% identical, N = 40,648)



Lymphoid consistency. Lymphoid cancers were analyzed separately from solid tumors, and a combined AJCC stage group was compared to CS. That is, for the AJCC stage, the pathologic stage was used for the comparison if it was known; otherwise the clinical stage was used. Registrars using CS assigned substage groups A and B more frequently than did physicians, and the physicians used more broad stages and left more cases with unknown stage (Figure 7).

Site Specific Factor (SSF) 1 (lymphoma associated with HIV-AIDS) was unknown for 38% of the CS cases. The A and B substages are defined by the presence or absence of systemic symptoms. SSF 2 (systemic symptoms at diagnosis) was unknown for 20% of the CS cases. The International Prognostic Index (IPI),¹¹ included in the AJCC staging form for lymphoid cancers and recorded in CS as SSF 3, was unknown for 80% of the advanced non-Hodgkin cases for which it was designed, as recorded by CS.

A final dimension of staging for lymphoid neoplasms involves the S (spleen) and E (extralymphatic) suffixes. Those are recorded in separate "Descriptor" fields in the registry record, and are derived as part of the stage group by CS, based on CS Extension. Table 5 shows the variability between the two approaches in recording this information. The two approaches were in agreement for only 52% of the cases (the cases in the diagonal of the table are in agreement). Of the 27,156 cases, the descriptor code indicated involved neither the spleen nor extralymphatic tissue, CS identified 10% as involving one or both. Conversely, of the 18,818 cases identified in CS as not involving either tissue, nearly the same proportion (9%) was identified in the AJCC descriptors as involving one or both.

Discussion

Completeness

The findings of this study indicate the relative completeness of the two approaches is complex.

Registrar CS staging completeness. As the soft tissue example illustrates, when registrars are unable to locate or interpret the information needed for staging, CS can be less completely staged than physician staging. The soft tissue sarcoma chapter uses the distinction between deep and superficial tissue involvement to determine whether a cancer is Stage II or III. Incomplete staging can occur when some of the necessary information is kept in physician offices away from the facility, or when the terminology used in CS descriptions is not met by similar terms in the patient record. Both problems can be resolved largely by developing good communications between physicians and registrars.

The soft tissue data suggest that registrars may have difficulty interpreting the anatomical terms used in reports when the terms "deep" or "superficial" are not explicitly mentioned. The Collaborative Staging Steering Committee is writing guidelines to help code these concepts. It is likely that when more registrars have mastered the allied health coursework required beginning in 2008 for Certified Tumor Registrar (CTR) credentialing,¹² they will be better prepared to interpret the anatomic terms, and to ask more pertinent questions when the record is not clear.

Of note, the A and B subcategories of Stage I and II for soft tissue were not originally printed in the *AJCC Staging Manual*, but were added with later addenda. Stages IA and IB are distinguished by tumor size. Stages IIA and IIB are distinguished by tumor size and the depth the involved tissue. The CS algorithm makes the distinction between A and B substages.

Physician AJCC staging completeness. The consistency comparison indicated two types of situations for which physician AJCC stage was assigned less frequently. The first, illustrated by the clinical comparisons of lung and cervix staging, appears to occur when the physician sees limited clinical value in staging, especially if it is hypothesized that the physician actually was filling in the form weeks after

Table 5. Lymphoid Neoplasms: Spleen (S) and Extralymphatic (E) Involvement

CS	Descriptors				Unknown
	Neither	E	S	E and S	
Neither	14,795	1302	231	164	2,326
E	2,320	2,727	24	57	448
S	281	8	295	8	56
E and S	151	20	29	67	24
Unknown	9,609	2,132	297	1,610	3,131

the workup that provided the staging information. To the extent that completeness of clinical staging revolves around delayed completion of the staging form, resolution would likely include a mechanism to obtain staging information immediately following patient workup and/or surgery.

The second situation, illustrated by thyroid and lymphoid cancers, involved physician failure to use the information available in the patient record when assigning stage. The AJCC staging scheme for thyroid cancer makes use of the histologic type of cancer and patient age to differentiate between Stage I and Stages II and IV. Registrar CS staging identified more patients as Stage I, while physician AJCC staging assigned more cases as unknown. The Lymphoid Ann Arbor staging adapted by AJCC makes use of systemic symptoms and involvement of the spleen or extralymphatic regions, and—for the IPI—serum levels of lactate dehydrogenase, age at diagnosis, and performance status (as measured with the Eastern Cooperative Oncology Group Performance Status Scale).¹³ It is possible that physicians who fail to make use of the information, even though the registrar finds it in the patient record, may be staging based solely on a pathology report, rather than taking into account the entire patient workup. This problem, too, may be resolved if staging is implemented as an integral part of comprehensive patient workup.

The CS algorithm implements combined staging in which both pathologic and clinical elements contribute to the derivation of AJCC stage group. That approach reflects the assumption that many or most physicians routinely use mixed staging.¹⁴ The analysis of pathologic T, N, and M assignment based on reported surgery and, for pM, presence of positively-confirmed metastases, appears to support this assumption. Although a known pT nearly always has the appropriate surgical action recorded that supports it, one fifth of pN reported as known are not backed by recorded pathologic evaluation of regional nodes. For most of those cases, known values for cT were not reported (data not shown), so no stage can be assigned if AJCC rules are strictly followed.

For twice as many cases (44%) as for pN, a known cM was reported as if it were pathologic (pM). If both pT and pN are known, the known cM can and should be used to derive a pathologic stage when pM is not positive for metastases. It is not clear from the data whether the coding of clinical components as pathologic is due to physician action, or the manner in which physician documentation is entered into the registry by the registrar. Both authors have heard several registrars say that they were taught “if the stage is pathologic, record the components as pT, pN, and pM,” in effect putting the cart before the horse.

Consistency

Because of their differences in rules for using clinical and pathologic information to derive stage group, registrar CS and physician AJCC staging can be expected to yield different results under some circumstances. Allowing those differences to operate, and comparing at the substage level, the two approaches still agreed on 78% of stage group assignments for cases requiring AJCC staging. The differences that were noted when specifically pathologic or

specifically clinical stages were compared primarily affected known versus unknown codes, with much less frequent disagreement between known codes. The most remarkable coding difference observed dealt with recording of spleen and extralymphatic involvement for lymphoid neoplasms.

Conclusions

It has been noted that the registrars and physicians do not operate in isolation. Any facility-level effort to resolve differences in staging prior to submission of the data to NCDB certainly contributed to the overall agreement observed. The authors recommend that registrars continue to monitor differences in stage assignment and work with the physicians involved to resolve them, with particular attention to information that may have been available to either the physician or the registrar, but not both. This process will be most beneficial if action is taken by cancer programs to assure optimal availability of the necessary information on a consistent and timely basis. The AJCC is making efforts to inform physicians of the data that registrars need to collect, and the importance of recording it. Registrars, on the other hand, are likely to benefit from continued training in how to record staging concepts and experience with the CS approach.

The purpose of this review was to compare registrar CS and physician AJCC stage assignment. It does not address the potential impact on analysis if one approach is adopted in preference to the other, especially given the different rules for computing stage group. At least until such reviews have been completed, when data are presented using either CS or AJCC staging, the approach should be clearly identified for readers.

References

1. *Collaborative Staging Manual and Coding Instructions*, version 01.03.00. Collaborative Staging Task Force of the American Joint Committee on Cancer. Jointly published by American Joint Committee on Cancer (Chicago, IL) and U.S. Department of Health and Human Services (Bethesda, MD). NIH Publication Number 04-5496.
2. *AJCC Cancer Staging Manual*, Sixth Edition. New York: Springer; 2002.
3. *Cancer Program Standards*, 2004. Chicago: American College of Surgeons; 2003.
4. *Facility Oncology Registry Data Standards Revised for 2007*. Chicago: American College of Surgeons; 2002.
5. *Summary Stage Guide*. SEER Program, U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health; 1977.
6. Young JL Jr, Roffers SD, Ries LAG, Fritz AG, Hurlbut AA (eds). *SEER Summary Staging Manual—2000: Codes and Coding Instructions*, NIH Pub. No. 01-4969. Bethesda, MD: National Cancer Institute; 2001.
7. *News from the Commission on Cancer*. 1994;(5)1:4.
8. *Standards of the Commission on Cancer, Volume I: Cancer Program Standards*. Chicago: American College of Surgeons; 1995, page 19.
9. *SEER Extent of Disease—1988: Codes and Coding Instructions*, Third Edition. National Cancer Institute, U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health; 1998.
10. The North American Association of Central Cancer Registries. *NACR111 Edit Logic Report*. Available at: http://www.naacr.org/index.asp?Col_SectionKey=7&Col_ContentID=136. Accessed February 2008.
11. [No authors listed.] A predictive model for aggressive non-Hodgkin's lymphoma. The International Non-Hodgkin's Lymphoma Prognostic Factors Project. *N Engl J Med*. 1993;329:987-994.
12. National Cancer Registrars Association. Council on Certification eligibility requirements. Available at: <http://www.ctrexam.org/eligibility/index.htm>. Accessed February 2008.
13. Oken MM, Creech RH, Tormey DC, Horton J, Davis TE, McFadden ET, Carbone, PP. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol*. 1982;5:649-655.
14. Edge S. *Collaborative Staging System*. Presentation to the AJCC Prognostic Factors in Cancer Conference, Washington, DC, April 2006.

National Trauma Registry for Children Project: A National Hospital Survey

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Abstract: Background. Injury is the leading cause of death and major disability in children. Individual hospital trauma registries exist at trauma centers and are often aggregated at the state level. Currently, there are no centralized statistics available that are nationally representative of pediatric trauma, especially with regard to the number of children treated in smaller community hospitals or the extent to which children are treated at non-trauma centers, which account for almost 75% of all facilities. Data from both trauma centers and non-trauma centers regarding the extent to which they see and treat pediatric trauma patients, how they collect data on such patients and how those data are used is crucial to obtaining accurate national estimates on pediatric trauma. **Methods.** We surveyed knowledgeable personnel from a nationally-representative random sample of trauma and non-trauma facilities of all sizes to obtain information on their pediatric trauma patients. Two surveys were developed, full and abbreviated, and included questions about the size and trauma status of the hospital, the number of pediatric trauma patients treated, whether a trauma registry existed, the inclusion and exclusion criteria for the registry, where and how data were collected, and what incentives would encourage hospitals to submit their data to a national pediatric trauma registry. **Results.** A total of 690 hospitals, or 81.9% of the target, responded to either the full or abbreviated survey; 249 (36%) completed the full survey and 441 (64%) completed the abbreviated survey. Respondents to the abbreviated survey were smaller and less likely to be trauma centers than respondents to the full survey. Over 95% of the respondents to the abbreviated survey collect data on demographic variables and more than 80% collect information on clinical variables, Glasgow Coma Scale (GCS) score, and type and mechanism of injury. They expressed willingness to have their data included in a National Trauma Registry for Children but would require additional resources to be able to do so. **Conclusion.** The information that trauma centers as well as smaller and/or non-trauma hospitals could provide on pediatric injury is essential to fully understanding the extent and nature of pediatric trauma in this country. This survey highlights the need to have these smaller, non-trauma centers included in a nationally-representative pediatric trauma database and also the efforts that would be required to get valid data submitted from such facilities.

Key words: injury statistics, National Trauma Registry for Children, pediatric trauma, trauma center

Introduction

For the last 50–60 years, injury has been the primary cause of mortality and morbidity for America's children between the ages of 1–19 years. In 2003, the most recent year for which summary statistics are available, there were 21,423 injury-related fatalities among individuals 1–21 years.¹ Furthermore, the overall fatality rate has remained fairly constant since 1999.* In 2001, approximately 11,387,056 injuries in individuals 1–21 years of age were cared for in emergency departments.¹ That same year, there were approximately 228,000 children hospitalized for injury-related diagnoses.¹

Most injuries can be prevented through targeted programs and policies, however, effective program and policy development rely on access to valid and reliable data. Independent trauma registries exist in many states, however,

there is no standardized, centralized database that adequately collects comprehensive data entry points representing pediatric trauma throughout the United States. In an effort to develop a national information system that would provide data to improve the system of care provided to injured children, the Emergency Medical Services for Children (EMSC) Program**, provided funds to design a National Trauma Registry for Children (NTRC). One important aspect of this project was to accurately determine the types and availability of data currently collected by hospitals treating pediatric trauma; another important aspect was to determine what incentives could be provided to hospitals for the voluntary submission of case records. We designed and administered a survey to a random sample of acute care hospitals in the United States to address these issues.

*"National Trauma Registry for Children Project:
A National Hospital Survey"*

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*Rate comparisons prior to 1999 are difficult due to comparability issues between ICD-9 and ICD-10, especially for deaths previously attributed to falls.³

**EMSC is within the Maternal Child Health Bureau, Division of Health Services, United States Department of Health and Human Services

Methods

Statistical Sample

We designed a statistical sample of hospitals representative of each census region in the country, the types of hospital (designated trauma center versus non-designated trauma centers; dedicated children's hospitals versus non-children's hospitals) and size. Our sampling frame included all general and surgical hospitals listed in the American Hospital Association's (AHA) database. We then used census division groupings for our first level of stratification (New England, Middle Atlantic, East North Central, West North Central, South Atlantic, East South Central, West South Central, Mountain, Pacific, and Associated Areas (American Samoa, Guam, Mariana Islands, Puerto Rico, and the Virgin Islands). All 50 states, plus Washington, DC and the 5 associated islands were included.

Hospitals within each census division were stratified by size (small = 6–49 beds, medium = 50–199 beds, and large = >200 beds) and sorted within each stratum by trauma level designation (yes or no). The sample was systematically selected within each frame using a random start. Because of the small number of dedicated pediatric hospitals and the large volume of children treated in these hospitals, we included all dedicated pediatric hospitals in the final sample to ensure adequate representation of pediatric patients.

The final sample consisted of 886 hospitals and was based on a conservative population proportion estimate of 0.5 and an error bound of 0.03. Because a stratified sampling design increases the precision of the estimate and ensures that the population is properly represented, we were able to reduce the sample by 5%, resulting in a target sample size of 842 hospitals. The sample size was then inflated to adjust for an expected response rate of 60%, resulting in a final sample size of 1,404 hospitals.

Survey

Two surveys were developed: a full survey and an abbreviated survey. The full survey included questions about a hospital's size, trauma level designation, and the volume of pediatric trauma patients treated annually. Additionally, a series of focused trauma registry questions were incorporated and included:

1. Existence of a hospital trauma registry
2. Inclusion and/ or exclusion criteria for the registry
3. Description of how registry data were collected
4. Description of how data were used, audited, and stored
5. Incentives that would encourage data submission to a national trauma registry

The abbreviated survey was developed after initial contact with several of the smaller sample hospitals indicated concern about the ability to answer questions due to the low volume of pediatric trauma seen in those institutions. This shorter survey included questions about the existence of a hospital trauma center, whether and how facilities treated pediatric patients or transferred those patients to other facilities, whether and what types of data were collected on pediatric patients, and incentives to encourage data submission to a national trauma registry.

From January 2003 through July 2005, University of Pittsburgh staff attempted to identify and contact a knowledgeable informant at each hospital for a telephone interview. The interviewer requested to speak with the person most knowledgeable about the volume and composition of pediatric patients treated. The type of informant varied but was typically the trauma coordinator, program manager, or registrar. For smaller hospitals, the emergency room manager or nurse generally provided the information. Members of the Society of Trauma Nurses facilitated identification of a knowledgeable informant. Each hospital contact was given the option of responding to the questionnaire immediately over the telephone, completing the questionnaire online, or submitting a completed paper version via facsimile.

Results

Hospital Characteristics

A total of 677 hospitals in 39 states responded to the survey, or 80.4% of our target sample. The response rate of the targeted sample varied by census region, from 0% of the Associated Islands to 100% for the New England, Mid-Atlantic, and South-Atlantic regions. We received responses for approximately 67% of the children's and almost 90% of the adult-targeted hospitals.

Of the hospitals responding, 236 (35%) answered the full survey and 441 (65%) answered the abbreviated survey. Four (2%) of the 236 full survey responses and 246 (66%) of the 441 abbreviated survey responses were incomplete. More than 2/3 of the incomplete surveys were from facilities in the South Atlantic region. As shown in Table 1, 56% of the hospitals with less than 50 beds completed the survey. However, only 22% of the largest hospitals—those with bed sizes over 200—completed the abbreviated survey.

Table 1. Bed Size Comparison among Respondents and Non-Respondents to the Abbreviated Survey

Bed Size	Response		Non-Response		Total
	Number	Percent	Number	Percent	
<50	56	56.0	44	44.0	100
50–199	113	50.7	110	49.3	223
200+	26	22.0	92	78.0	118

The self-reported bed size of the hospitals that completed the abbreviated survey was compared to those that completed the full survey in Table 2. As expected, hospital personnel who completed the abbreviated survey were from statistically significantly smaller facilities than those completing the full survey. Only 9% (n=15) of the respondents to the abbreviated survey were at designated trauma centers while almost 70% (n=160) of the respondents to the full survey were from designated trauma centers.

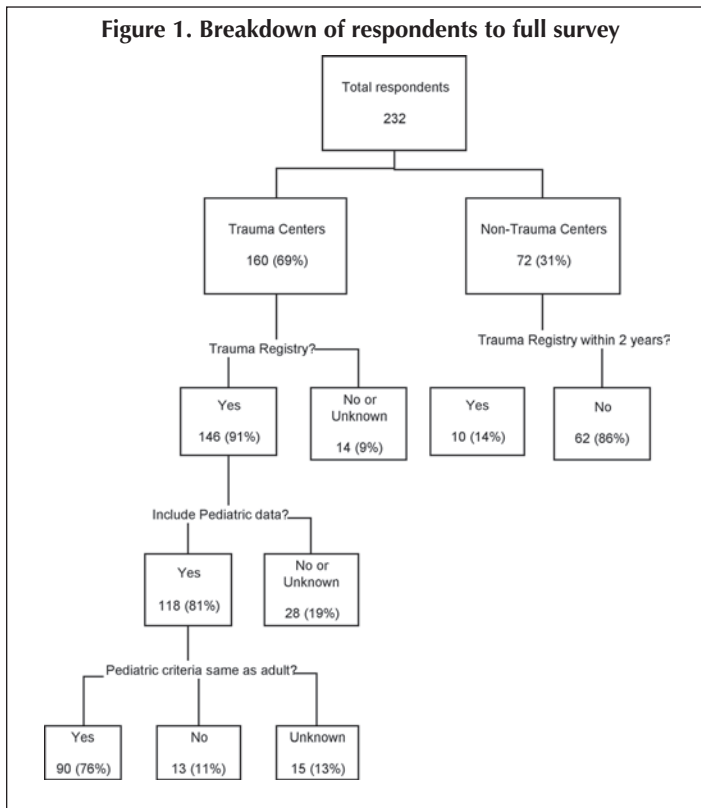
Trauma Centers

Hospitals with trauma level designation reported anywhere from under 100 to over 100,000 admissions per year, highlighting the extremely wide range of services

Table 2. Self-Reported Bed Size among Respondents to the Full and Abbreviated Surveys

Bed Size	Full Survey		Abbreviated Survey	
	Number	Percent	Number	Percent
<50	43	18.5	106	54.4
50–199	54	23.3	89	45.6
200+	135	58.2	0	0.0
Total	232	100.0	195	100.0

offered by such facilities. Figure 1 indicates that 69% of full survey respondents reported that their institution was a designated trauma center, and 91% of these maintain a hospital trauma registry. Of the 146 hospitals that currently have trauma registries, pediatric data are included in 81% (118). Hospital trauma registry inclusion and/or exclusion criteria are the same for children and adults in 76% of those registries that include children. Only 25% of the trauma centers surveyed indicated that they submitted their data to a national trauma registry, although many of the respondents did not know this information.



Fifteen trauma centers responded to the abbreviated survey. All 15 indicated that they treat and transfer pediatric patients. For 13 of the 15 facilities (87%), the closest trauma center was more than 20 miles away. Nine of the facilities (60%) indicated that they collect data on pediatric patients.

Trauma registry data were used for various purposes by the hospitals. Approximately 90% of respondents indicated that quality assurance, improvement, and trauma center designation were the most common uses for trauma

registry. Additional uses for registry data were injury surveillance and prevention, system performance assessment, and patient care outcomes. Facilities also use data for policy and clinical guideline development and for research and development.

Non-Trauma Centers

More than 90% of respondents to the abbreviated survey were non-trauma centers. Almost half of the non-trauma centers reported that their facilities had more than 50 acute care beds, although they were not able to easily translate that into trauma cases seen. Among the respondents, 94% stated that they treat pediatric patients. However, only 60% of the non-trauma centers indicated that their facilities collect and record clinical data on children that they transfer. The primary method of data collection was using hard copy forms; only 28% of respondents recorded clinical data in a computerized format. Table 3 shows the variables most commonly collected by the transferring facilities. Over 95% of the facilities collect data on demographic variables and more than 80% collect information on clinical variables, Glasgow Coma Scale (GCS) score, and type and mechanism of injury. Revised Trauma Scale (RTS) score was collected sporadically, by only 23% of responding facilities. Only 14% of non-trauma centers plan to develop a hospital trauma registry within the next two years.

Table 3. Abbreviated Survey Report of Variables Collected on Transferred Pediatric Patients

Variable Type	Percent
Demographic (age, race, sex, date of birth)	98.0
Clinical (pulse rate, unassisted respiratory rate, systolic blood pressure)	89.7
Glasgow Coma Scale (GCS) score	87.6
Revised Trauma Scale (RTS) score	23.7
Type of injury	88.1
Mechanism of injury	84.5

Nearly all (88%) indicated that they transfer pediatric patients to another facility. The primary means of transport were helicopter (46%), ambulance (24%), or a combination of both (11%). As shown in Table 4, 83% of the facilities transported their pediatric patients to a trauma center that was further than 10 miles away from their facility. Close to 40% of the facilities reported the nearest trauma center to which children could be transferred was more than 50 miles away.

Table 4. Abbreviated Survey Reports of Distance to Nearest Trauma Center to Transfer Pediatric Trauma Patients

Distance To Nearest Trauma Center	Percent
<5 miles	7.7
5–10 miles	8.2
11–20 miles	13.8
20–50 miles	30.8
50+ miles	39.5

Table 5 shows the top five incentives reported by respondents to the full and abbreviated survey. Respondents had several incentives in common, although the top incentives named were little to no cost for participation and money, for the full and abbreviated surveys respectively, indicating the vast disparity in resources available to each of these types of facilities.

Table 5. Comparison of Top Five Incentives to Contribute Data to an NTRC by Full and Abbreviated Survey Respondents

<i>Full Survey Respondents</i>	<i>Abbreviated Survey Respondents</i>
Little to no cost for participation/software	Money
No additional manpower or excessive time	Manpower/Training
Easy data submission	Ease of Use
Electronic and web based data submission	Computer resources (hardware & software)
Access to data	Use of data for benchmarking

Discussion

Despite intensive efforts to reach a knowledgeable informant at each hospital, we had difficulty both identifying the appropriate person and obtaining the requested information regarding hospital practices. This was due mainly to the environment which we were calling; busy hospital personnel simply could not set aside the time to respond to even an abbreviated questionnaire. However, many small hospitals did not have or could not identify a knowledgeable respondent, which may be another indicator of the lack of attention to pediatric data at these institutions. We reached over 80% of our targeted population and received complete responses to nearly all of the full surveys but only approximately one-third of the abbreviated surveys.

Interestingly, the hospitals that were more likely to have incomplete surveys were from the South Atlantic region, covering Delaware, Washington DC, Maryland, Virginia, West Virginia, Georgia, Florida, and North and South Carolina. Because we assigned interviewers to particular regions, this could reflect a bias in the interviewing; it could also reflect a regional reluctance to share such information with us or regional work and staffing practices that limited the amount of time employees were able to spend answering our survey.

Because of the efforts to reach small hospitals and non-trauma centers, this survey provides valuable information that cannot be found elsewhere. While some surveys on trauma centers have been conducted either locally or nationally,²⁻⁴ little research exists on hospitals that are not trauma centers, especially in regard to pediatric patients. Our results are similar to those found by MacKenzie et al,² indicating that non-trauma centers are generally smaller than trauma centers.

Nearly all of the non-trauma centers in our survey are seeing and treating children initially, though most transfer trauma cases to larger trauma centers. Valuable initial phys-

ologic data from these hospitals are not being included or represented in the continuum of care for pediatric trauma patients. This finding highlights the importance of these non-trauma hospitals in the overall care of pediatric trauma cases and emphasizes that such small facilities should be represented in the NTRC. They already collect some basic data on pediatric patients but would need to expand data collection and information systems to contribute to a national surveillance system (Table 3).

The two existing national trauma registries—the National Trauma Data Bank® (NTDB) and the National Pediatric Trauma Registry (NPTR)—depend upon voluntary submissions. As captured in our survey, even larger trauma center respondents did not indicate that their facilities were voluntarily submitting data. Even more problematic is that many of the facilities treating children are small, non-trauma centers without existing trauma registries. Such facilities do not have the time, computer hardware, or, in some instances, electronically-formatted records necessary to voluntarily submit their data to these repositories.

The small hospitals expressed willingness to have their data included in the NTRC but would require additional resources to be able to do so. As shown in Table 5, while respondents to the full survey would be willing to submit data if it did not place an undue burden on already busy personnel, respondents to the abbreviated survey would require more resources to contribute their data. The small hospitals do not have the trained personnel and computer resources that such data collection and reporting would require. As indicated by the higher proportion of incomplete abbreviated surveys, personnel at smaller hospitals either lack the knowledge or have extremely limited time to adequately respond to data requests. Because the volume per hospital is relatively small, one option may be to have trained personnel visit and abstract the data on sampled hospitals. The inclusion of these facilities into a national sample is essential to generate accurate estimates on pediatric trauma and to enhance research capabilities. To be included, however, the number of variables reported would need to be significantly fewer than at the larger facilities.

Future Recommendations

To date, there is no mandate for submission of pediatric trauma data to a national data repository. Federal or state funding with mandatory reporting requirements may be necessary to obtain pediatric trauma data from all types of facilities. Ultimately, the success of a nationally-representative pediatric trauma database, such as the NTRC, is dependent upon the quality of data collected. A representative sample must include both larger trauma centers and smaller, local hospitals because information from all facilities is essential to fully understanding the extent and nature of pediatric trauma in this country. This survey highlights the need to include all types of facilities in the NTRC and also the efforts that would be required to get valid data submitted from such institutions.


Acknowledgement

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References

1. Prevention CfDca. Web-based Injury Statistics Query and Reporting System (WISQARS). National Center for Injury Prevention and Control, Centers for Disease Control and Prevention; 2003.
2. MacKenzie EJ, Hoyt DB, Sacra JC, et al. National inventory of hospital trauma centers. *JAMA*. 2003;289(12):1515-1522.
3. Anderson RN, Miniño AM, Hoyert DL, Rosenberg HM. Comparability of cause of death between ICD-9 and ICD-10: preliminary estimates. *Natl Vital Stat Rep*. 2001;49(2):1-32.
4. Mann NC, MacKenzie E, Teitelbaum SD, Wright D, Anderson C. Trauma system structure and viability in the current healthcare environment: a state-by-state assessment. *J Trauma*. 2005;58(1):136-147.
5. Reilly JJ, Chin B, Berkowitz J, Weedon J, Avitable M. Use of a state-wide administrative database in assessing a regional trauma system: the New York City experience. *J Am Coll Surg*. 2004;198(4):509-518.



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Education and Training Series from the National Program of Cancer Registries

Linda Mulvihill, RHIT, CTR

Abstract: This article discusses the purpose of the National Program of Cancer Registries' Education Training Series, the methods used to assess the educational needs of registry personnel, and the establishment of subject priorities. The materials can be modified for many types of media presentations and the intended audience. The modules provide training and education for the beginner and incidence reporters, as well as advanced abstracting training or review materials for certified tumor registrars (CTRs) at both hospital cancer programs and central cancer registries. The extensive review process included CTRs, physicians, and other subject matter experts, and has resulted in training materials of the highest quality to promote data accuracy and consistency.

Key words: capacity, education, modules, review, training

Education and Training Series from the National Program of Cancer Registries

Citing the need for a national program of cancer registries that would provide the local, state, regional, and national cancer incidence data required for national and state health planning, the U.S. Congress established the National Program of Cancer Registries (NPCR) through Public Law (PL) 102-515, the Cancer Registries Amendment Act in 1992.^{1,2}

PL 102-515 authorized the Centers for Disease Control and Prevention (CDC) to provide funds to states and territories to:

1. Improve existing cancer registries
2. Plan and implement registries where they did not exist
3. Help develop model legislation and regulation for states to enhance the viability of registry operations
4. Set standards for data completeness, timeliness, and quality
5. **Provide training for registry personnel**
6. Help establish a computerized reporting and data processing system

Introduction

Ongoing education and training is essential to the NPCR core mission of enabling the collection and use of complete, timely, and high-quality surveillance data at the national, state, and local levels. The NPCR educational objectives include: (1) providing resources, through sponsorship of training opportunities, development of materials, and funding of registries, for participation in educational sessions; (2) building the capacity of NPCR registries to provide education within their community of reporting facilities; (3) monitoring the educational infrastructure for gaps in access to education; and (4) searching for methods

and technology that will provide improved access to education for the entire cancer surveillance community. NPCR partnered with the North American Association of Central Cancer Registries (NAACCR) from 2001 to 2006 to provide educational and training activities (Table 1).

Several national organizations offer educational conferences and workshops for registry professionals. For example, the American College of Surgeons Commission on Cancer (CoC) has an Online Education Center that provides fee-based Web sessions and Collaborative Staging (CS) sessions. The CS sessions are free of charge and were developed with funding from the CoC; American Joint Committee on Cancer; and the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. SEER offers excellent free-of-charge Web-based learning opportunities, especially for those new to the cancer registry field. Professional organizations such as the NAACCR and the National Cancer Registrars Association (NCRA) offer fee-based Webinars, classroom learning opportunities, and annual education conferences.

While there are many excellent educational programs available, NPCR's goal is to build educational capacity and "local expertise" within each state/central registry. In addition to the Public Law authorization to provide training for registry personnel, the 2007 NPCR Program Standards require each program or NPCR-funded central cancer registry (CCR) to designate an education coordinator or trainer. The education coordinator/trainer must be a certified tumor registrar (CTR). NPCR Train-the-Trainer conferences and the educational materials support states in their efforts to build their educational infrastructure to provide education to reporters, registrars, and central registry staff, and to provide them with day-to-day support as well.

"Education and Training Series from the National Program of Cancer Registries"

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Table 1. NPCR-sponsored Training and Educational Activities and Resources, 2001 through 2006

<i>Activities and Resources</i>	<i>Description</i>
NPCR East Institute: Central Registry Operations NPCR West Institute: Central Registry Operations	Four-day basic training for CCR staff
CD1 Case Ascertainment CD2 Principles of Abstracting CD3 Data Edits and EDITS CD4 Coding and Visual Editing CD5 Follow-up: Active and Passive CD6 Audits: Casefinding & Reabstracting CD7 Coding Race and Ethnicity CD8 Statistics	Set of interactive CD-ROMs covering basic registry operations
Cancer Surveillance Institute	Four-day workshop and small group projects. Topics include core functions of surveillance, uses of data, epidemiology, special populations, and responsibilities of a public health cancer epidemiologist.
Train-the-Trainer Sessions	Three workshops, each consisting of a 1-day training session on various Registry Plus products, followed by 3 to 3.5 days of training on cancer data collection, registry operations, and management.
Web Conferences	Four live, Web-based conferences. The format of the sessions included didactic (PowerPoint) presentations followed by hands-on exercises and a discussion of answers supported by detailed rationale and references.

Methods

Recognizing that ongoing education is essential to NPCR's core mission, in October 2006 NPCR contracted Science Applications International Corporation (SAIC) which, in turn, subcontracted with A. Fritz and Associates to develop educational materials and assist in the first annual Train-the-Trainer Conference. The project is referred to as the National Program of Cancer Registries Education and Training Series (NETS). The first step in the development of educational materials was an Educational Needs Assessment Report (ENAR) to identify gaps in training related to collection of cancer data and to cancer registry operations. CCRs were divided into national regions to identify regional training needs (Table 2). A conference call was conducted with each region, and a survey was sent to gather data for the ENAR. Each region identified current educational efforts among their cancer registries;

areas perceived to be lacking in educational materials; and potential subjects. The regions also discussed the preferred media and methods for education and training. Many states provided source materials, particularly medical records, pathology reports, and other medical documents.

The ENAR provided a list of educational subjects, and each subject was rated based upon the frequency of requests from regions. The regional rating of subject material was used to develop a priority list, and from this list, the subject matter for 12 educational modules was determined. Another goal of NPCR educational materials is to promote data accuracy and consistency. To ensure that the materials would meet this goal, a series of review steps was established. In addition to expert review of the subject matter, CDC requires that all informational products authored by CDC staff members or published by CDC and released for public use go through an extensive CDC review or "clearance process."

Table 2. Education Regions

<i>Region I</i>	<i>Region II</i>	<i>Region III</i>	<i>Region IV</i>	<i>Region V</i>
Maine	Delaware	Kentucky	Illinois	Montana
New Hampshire	Maryland	Tennessee	Wisconsin	Wyoming
Vermont	Virginia	Alabama	Missouri	Colorado
Massachusetts	West Virginia	Mississippi	Minnesota	Idaho
Rhode Island	District of Columbia	Louisiana	North Dakota	Arizona
New York	North Carolina	Arkansas	South Dakota	Alaska
New Jersey	South Carolina	Texas	Nebraska	Washington
Pennsylvania	Georgia	Oklahoma	Kansas	Oregon
	Florida		Ohio	Nevada
	Puerto Rico		Indiana	California
			Michigan	

The purpose is to ensure that materials are of the highest quality and are scientifically sound, technically accurate, and useful to the intended audience. Part of the process includes checking facts and copyright permissions. NETS Module 5, *Head and Neck Malignancies*, was also reviewed by CDC's Oral Health Program. Module 8, *Lung Malignancies*, was also reviewed by CDC's Office of Smoking and Health. As the developers completed each module, a draft was sent to NPCR. The review steps for each of these modules are listed below:

1. Subject matter review by CTRs on staff at NPCR.
2. Subject matter review by CTRs on staff at three to five state/central registries.
3. All comments from all reviewers summarized and returned to the developers.
4. Module(s) updated by the developers to include all corrections/changes identified by reviewers.
5. Updated modules reviewed by CTRs on staff at NPCR.
6. Advanced abstracting modules sent for additional review by a physician on staff at NPCR.
7. Physician comments/corrections added to the modules.
8. Module(s) submitted to the CDC Clearance System for review by several experts.
9. Suggested changes noted during the clearance process added to each module by a CTR at NPCR.
10. Modules forwarded to the CDC's Web development staff, where each one is again reviewed as part of the preparation to post on the NPCR Web site.

Results

Subsequent steps in the NPCR Education and Training Series plan, based upon a summary of the regional calls and the results of the needs assessment, included:

- Development of 12 education modules (see Table 3)
- Annual Train-the-Trainer conference in Atlanta, Georgia
- Preferred media for education

The priority list of the most requested subjects was given to the developers. Training materials for the death clearance process were requested by three of the five regions, advanced abstracting by four of the five regions, case consolidation by four of five regions, and a beginner module for reporters by three of five regions. All regions voiced the importance of quality control.

A framework was established for an annual Train-the-Trainer conference in Atlanta, Georgia, designed to assist state trainers in discerning educational needs within their geographic region, developing materials for adult learners, providing a networking forum, and encouraging regional cooperation. The first meeting, which was held in August 2007, was very well received by the state trainers. The group consisted of well-seasoned trainers from some states and some novice trainers from others. Work groups for different activities were composed of those with a mix of experience, with the intent that the novice trainers could learn from the seasoned trainers.

The regions agreed that the preferred media or method of delivering education is the traditional, classroom, in-person meeting, but all agreed that it is necessary to provide education and training in a variety of formats (such as Web conferences) to facilitate training for data reporters who cannot travel to a workshop. PowerPoint presentations are adaptable from in-person meetings to videoconferencing and teleconferencing. In an effort to make the materials versatile for all media, nine of the modules are PowerPoint presentations, complete with speaker's notes, instructions for the speaker, and case exercises with answer sheets that include the rationale for the correct answer. Module 3, *Quality Control of Data in the Central Cancer Registry*, as the name implies, is a training module for central registry staff. Module 4, *Validating Data with Text*, includes the importance of text, how to record text, and what text to record. It is useful to both central registry staff and reporters.

Table 3. Complete List of NETS Modules

<i>Module</i>	<i>Title</i>	<i>Audience</i>
Module 1	Building a Quality Presentation	Training for the Trainer
Module 2	Beginner Module for Reporters	Abstracting for the Beginner
Module 3	Quality Control of Data in the Central Cancer Registry	Training for Central Registry Staff
Module 4	Validating Data with Text	Central Registry and Hospital Staff
Module 5	Head and Neck Malignancies	Central Registry and Hospital Staff
Module 6	Gynecological Malignancies	Central Registry and Hospital Staff
Module 7	Colorectal Malignancies	Central Registry and Hospital Staff
Module 8	Lung Malignancies	Central Registry and Hospital Staff
Module 9	Breast Malignancies	Central Registry and Hospital Staff
Module 10	Prostate, Testicular, and Bladder Malignancies	Central Registry and Hospital Staff
Module 11	Uses of Cancer Registry Data	Central Registry and Hospital Staff
Module 12	Death Clearance Process for Central Cancer Registries	Training for Central Registry Staff

Discussion

In addition to being easily modified to the media of choice by each state, the trainer may modify the length and complexity of each module to meet the audience's needs. Two of the modules are self-directed (Module 1, which is for trainers, and Module 2, which is for beginners), and one will be an interactive, Web-based module (Module 12, *Death Clearance Process for Central Cancer Registries*). Module 12 has been delayed until the publication of the *Death Clearance Manual* by NAACCR in mid-2008. The module will be modified at that time to reflect the minimum requirements for the death clearance process published in the manual to promote consistency in the process across all state registries. Modules 3 and 4 will be presented to CCR staff during an NPCR Track at the 2008 NCRA meeting in Minneapolis, MN. Modules 5 through 10 are advanced abstracting modules for registrars and central registry staff.

A decision was also made to defer the development of a training module on record consolidation until a consensus is reached by standards-setting organizations on the best practices for this activity. The extensive external and internal reviews required by CDC have delayed the project, while greatly adding to its educational value. The NETS modules may be limited by the inexperience and/or teaching style of the individual trainer. However, practice should build confidence that will in turn form the foundation for the educational infrastructure within each CCR. The annual Train-the-Trainer conferences will provide the state trainers with an opportunity to network and share their expertise and ideas that, it is hoped, will lead to collaboration to provide educational activities in regions rather than having each state work alone (see Table 3 for a complete list of the NETS modules).

Conclusions

The NPCR Education and Training Series' (NETS) modules and annual Train-the-Trainer conferences will enable NPCR to meet core functions of providing education and training while supporting the states' education and training endeavors. NETS supports Public Law 102-515 and the NPCR Program Standards. The selection of subject and media presentation was the collective effort of all of our states. The modules can be reformatted for Web-based training. Many states contributed numerous hours of review time to this project and/or de-identified medical records and other educational materials. The materials have gone through extensive review processes to enable state trainers to have the best information available to promote accurate, consistent data reporting. The modules will be available at no cost on the NPCR Web site in 2008. It is the intent of NPCR that the modules be used by state trainers and be available to anyone who is providing educational activities for cancer reporting.

NPCR extends a special thank-you to the CTRs in state registries who contributed to the success of this project.

Acknowledgement

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References

1. Public Law 102-515. *Cancer Registries Amendment Act* 1992. Available at: <http://www.cdc.gov/cancer/npcr/npcrpdfs/publaw.pdf>. Accessed February 2008.
2. Centers for Disease Control and Prevention. State cancer registries: status of authorizing legislation and enabling regulations—United States, October 1993. *MMWR Morb Mortal Wkly Rep* 1994;43(4):71, 74-75.

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

Linking with Birth Certificate Data to Improve Patient Follow-up in Central Cancer Registries

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Abstract: Maintaining and improving patient follow-up is a challenging task faced by many population-based cancer registries. In order to examine the effectiveness of birth certificate data as a passive follow-up source, the authors conducted a linkage between selected patients from a large central cancer registry and data from recent birth certificate files. Out of 149,372 female California cancer patients less than or equal to 65 years of age who were diagnosed between 1988 and 2005, 6,514 (4%) were successfully matched to maternal birth certificate data. Compared to patients who did not match, those matched patients were more likely to be from sub-groups that are generally more difficult to follow-up, for instance, patients who were <35 years at diagnosis (56.9% vs. 12.3%), or patients of Hispanic ethnicity (30.3% vs. 21.8%). The differences were statistically significant (p value of Chi-square test <0.01). Because the registry has already used extensive data sources to collect follow-up information, this linkage obtained updated date of follow-up for about 288 patients (4% of the total matched). The majority (94.8%) of these updates occurred among patients <35 years at diagnosis. This study indicates that linking with maternal data from birth certificate is an effective way for population-based cancer registries to update date of follow-up, especially for younger patients.

Key words: birth certificate data, California, passive follow-up, population-based registry, record linkage

Introduction

Population-based cancer survival studies are an important component of cancer surveillance, and require accurate and timely follow-up information on cancer patients to determine vital status. The proportion of cases with recent follow-up confirming current vital status (usually referred to as follow-up rate) is often used as a quality indicator for central cancer registries.¹ As survival times increase, the lifetime follow-up of cancer patients is becoming an increasing challenge to population-based cancer registries, many of which are constantly in search of new data sources to improve patient follow-up.

Central cancer registries may use active and passive methods to conduct patient follow-up. Active follow-up refers to the process of contacting the patient, family member, a physician, treatment facility, or other source to obtain more recent patient information, while passive follow-up refers to the process of obtaining updated patient information through record linkage with various administrative data sources. Studies of these two methods indicate they are similarly effective for updating the most essential follow-up data items, i.e., vital status and follow-up date.^{2,3} Passive follow-up requires less staff time and therefore is generally more cost-effective than active follow-up, but has its own limitations as some population sub-groups (such as minority and childhood/young adult cancer survivors) are not well-represented in commonly-used sources such as voter registration, Department of Motor Vehicles, or Medicare databases.

Birth certificate data of children have been linked to cancer registry data for research on childhood cancer patients.^{4,5} However, birth certificates also contain maternal and/or paternal personal identification information that

could be used to ascertain vital status of the parents who have a history of cancer. This use of maternal and/or paternal data from the birth certificate has not been reported, and could be useful in obtaining updated information on the hard-to-find younger and minority cancer patients. The authors linked maternal data from birth certificate with female patients from a central cancer registry and evaluated the effectiveness of the linkage by asking three questions: (1) How many female cancer patients in the (California Cancer Registry (CCR) database could be matched to maternal data on birth certificates?; (2) Of the patients that matched, how many provided more recent follow-up date than that already obtained in the CCR database from other sources?; and (3) Of the patients that obtained a more updated follow-up date, how many changed from a not-current follow-up date to a current follow-up date by the Surveillance, Epidemiology, and End Results (SEER) Program definition, and thus contributed to improvement of follow-up rate?

Methods

The CCR, a population-based registry, is a participant of the National Cancer Institute's SEER Program, which is considered the standard for quality among cancer registries around the world. The authors identified female cancer patients reported to the CCR as of August, 2006 who were aged 65 years or younger at diagnosis, not known to be deceased, with a follow-up date between 1988 and 2005 ($n=180,483$). Patients who were diagnosed with *in situ* cervical cancer only ($n=31,111$) were excluded because SEER does not require follow-up for *in situ* cervical cancer, which is no longer reportable after year 1994. A total of 149,372 patients were included in this linkage study.

"Linking with Birth Certificate Data to Improve Patient Follow-up in Central Cancer Registries"

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Birth certificate data obtained from California Department of Public Health (CDPH) were the confidential version of the Birth Statistical Master Files for years 1997 to 2005, consisting of a total of 4,267,706 birth records reported to CDPH during these years. Birth Statistical Master Files have the following variables: date of birth of child, Social Security Number (SSN) of mother and father, date of birth of mother and father, race of mother and father, ethnicity of mother and father, first name and birth surname of mother, and last name of father. Because the father's first name was not available, male patients were not linked with the birth certificate file.

Deterministic and probabilistic matching algorithms were performed using Integrity® software to match female cancer patients in the CCR database to maternal data from the birth certificate files. A sequential algorithm with seven-passes was used with the following variables as matching variables (see Figure 1): SSN, year of birth, month of birth, day of birth, first name, last name or maiden name, address at diagnosis, and address from birth certificate. Records that were not classified as matches in any pass went on to the subsequent pass until all seven were completed. The first three passes use a deterministic method which classifies records as matches when all the matching variables from the two files matched exactly. Pass four to pass seven uses a probabilistic method, which gives each matching variable comparison a matching score based on the degree of agreement and also takes into account frequency of the particular values of each matching variable.

CCR patients included in the linkage were first categorized as matched (found in the birth certificate database) and unmatched (not found in the birth certificate database). Matched patients were further classified into two sub-groups: updated (birth certificate provided updated follow-up information) and not updated (birth certificate data did not provide any updated information), by comparing child birth date on the birth certificate and the date of follow-up from CCR before the linkage. Finally, the authors examined how many patients in the updated group changed their follow-up date from "not-current" to "current" by applying the SEER definition, which defines a current follow-up date as a date not more than 22 months prior to data extraction. For this study (data from the CCR August 2006 data extraction), October 1, 2004 was the cut-off date to classify follow-up date as current or not-current. Therefore, only patients whose follow-up date was updated from a date prior to October 1, 2004 to a date after that had their status changed from "not current" to "current."

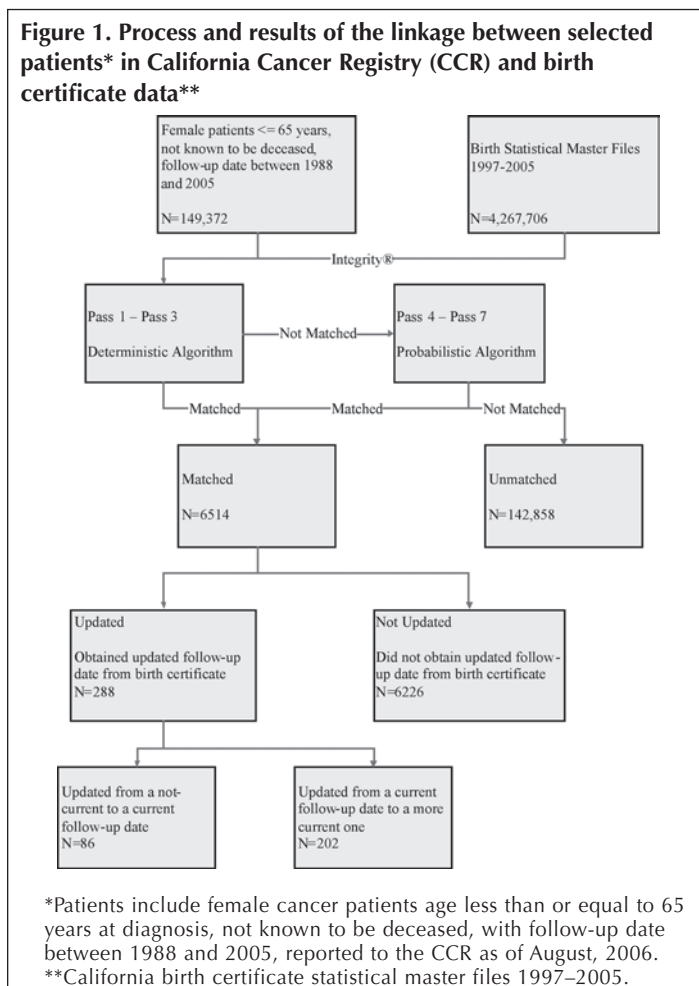
To evaluate which patient characteristics were associated with having their registry records matched and updated using birth certificate data, the authors compared both the matched and unmatched patients, and the updated and not updated patients using the Chi-square test. The updated records were examined to determine how many additional months of follow-up were added, and how the updated year of follow-up was distributed. In addition, number and percentage of patient with current follow-up date (by SEER definition) were calculated. Percentage of patients with current date of follow-up, often referred to as follow-up rate, was calculated using an adaptation of the SEER method⁶ for all patients in the study. In the SEER method, the denominator of follow-up rate calculation is the sum of deceased patients and all living patients, and the numerator is deceased patients and living patients who had a current date of follow-up. Because only living patients were included in the study, follow-up rate was calculated slightly differently in this study, with all the living patients in the denominator and living patients who had a current date of follow-up in the numerator. All data manipulation and statistical analyses were performed in SAS 9.1.3 (Cary, NC) for Windows.

Results

As shown in Figure 1, among the 149,372 female cancer patients included in the linkage, 6,514 (4%) were matched to maternal data on birth certificates (matched patients). Of these matched patients, an updated follow-up date was obtained from birth certificate for 288 patients (updated patients), out of which 86 patients were updated from a not-current follow-up date to a current one according to the adapted SEER definition.

Characteristics of patients in the matched and unmatched, and updated and not updated groups are shown in Table 1. Matched patients were much younger (median age 33 years vs. 50 years) than unmatched patients, more likely to be of Hispanic ethnicity, and more likely to be diagnosed in more recent years. Among matched patients, registry records were updated most frequently among younger patients <35

Figure 1. Process and results of the linkage between selected patients* in California Cancer Registry (CCR) and birth certificate data**



years, with 23.6% of all updated records occurring among the youngest age group (<20 years) compared to 5.1% of the not updated group. The updated group also contained a larger proportion of patients diagnosed with non-invasive cancers compared to the not updated group. The differences observed between matched and unmatched patients and between updated and not updated patients were all statistically significant (p value of Chi-square test <.0001, not shown in Table 1).

Among the 288 patients in the updated group, follow-up time was extended up to 12 months for 66%, to 13-60 months for 32%, and to over 60 months for 2% of the patients, and more than 72% of these updated patients were matched to a birth certificate record of year 2005 (Figure 2). The number and percentage of patients with current follow-up date before and after the linkage are shown in Table 2. The follow-up rate increased slightly for patients who were 0-19 years (64.3% to 64.7%), 20-34 years (70.0% to 70.4%) at diagnosis, and for patients of Hispanic ethnicity (73.6% to 73.7%). These follow-

up rates for living patients only were much lower than what were expected using the standard SEER method, because deceased patients were not included in the denominator and the numerator of the follow-up rate calculation.

Discussion

This linkage of central cancer registry data with birth certificate data successfully matched about 4% (n=6,514) of female cancer patients in the CCR database who were <66 years at diagnosis and were not ascertained as deceased by the registry. If birth certificate data were the sole passive follow-up source (other than death certificate data used for death clearance), they would potentially provide an updated date of follow-up for the majority of those matched patients. In reality, because the CCR uses multiple administrative databases for passive follow-up (including the Department of Motor Vehicles, California Voter Registration, Social Security Administration, Social Security Death Master File, Center

Table 1. Characteristics of Patients* in California Cancer Registry (CCR) Database By Matching Status with Birth Certificate Data**

	<i>All Patients included in Linkage</i>				<i>All Matched Patients</i>			
	Unmatched¹ (n=142,858)		Matched² (n=6,514)		Not updated³ (n=6,226)		Updated⁴ (n=288)	
	N	%	N	%	N	%	N	%
Age at diagnosis (years)								
0-19	5,485	3.8	384	5.9	316	5.1	68	23.6
20-34	12,092	8.5	3,323	51.0	3,118	50.1	205	71.2
35-44	28,659	20.1	2,465	37.8	2,451	39.4	14	4.9
45-54	48,351	33.9	334	5.1	333	5.3	1	0.4
55-65	48,271	33.8	8	0.1	8	0.1	0	0
Race/Ethnicity								
Non-Hispanic white	80,818	56.6	3,322	51.0	3,180	51.1	142	49.3
Non-Hispanic black	9,479	6.6	301	4.6	289	4.6	12	4.2
Hispanic	31,163	21.8	1,975	30.3	1,887	30.3	88	30.6
Asian/Pacific Islander	16,075	11.3	741	11.4	716	11.5	25	8.7
American Indian	77	0.1	5	0.1	5	0.1	0	0
Unknown	5,246	3.7	170	2.6	149	2.4	21	7.3
Tumor Behavior								
Non-invasive	23,983	16.8	1,043	16.0	979	15.7	64	22.2
Invasive	118,875	83.2	5,471	84.0	5,247	84.3	224	77.8
Year of Diagnosis								
1988-1990	17,566	12.3	305	4.7	273	4.4	32	11.1
1991-1993	18,941	13.3	445	6.8	414	6.7	31	10.8
1994-1996	21,099	14.8	665	10.2	615	9.9	50	17.4
1997-1999	24,747	17.3	1,044	16.0	978	15.7	66	22.9
2000-2002	28,506	20.0	1,691	26.0	1,625	26.1	66	22.9
2003-2005	31,999	22.4	2,364	36.3	2,321	37.3	43	14.9

*Patients include female cancer patients age less than or equal to 65 years at diagnosis, not known to be deceased, with follow-up date between 1988 and 2005, reported to the CCR as of August, 2006.

**California birth certificate statistical master files 1997-2005.

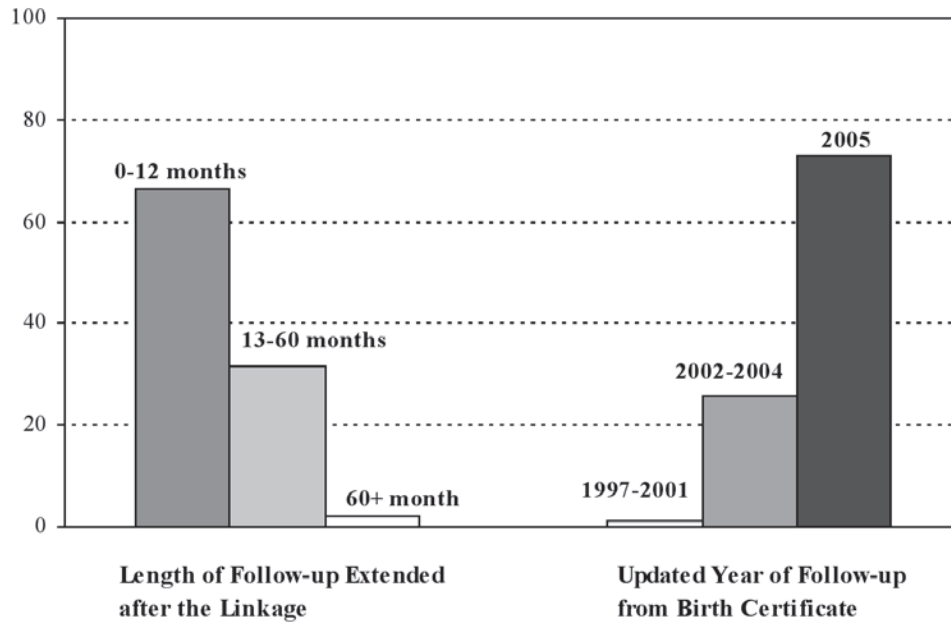
¹Patients in the CCR database who did not match with birth certificate data.

²Patients in the CCR database who matched with birth certificate data.

³Patients in the CCR database who matched with birth certificate data but did not obtain updated date of follow-up.

⁴Patients in the CCR database who matched with birth certificate data and obtained updated date of follow-up.

Figure 2. Patients* in California Cancer Registry (CCR) who matched with and obtained updated date of follow-up from birth certificate data (N=288)**



*Patients include female cancer patients age less than or equal to 65 years at diagnosis, not known to be deceased, with follow-up date between 1988 and 2005, reported to the CCR as of August, 2006.

**California birth certificate statistical master files 1997-2005.

for Medicare and Medicaid Services, National Change of Address, National Death Index, and State Hospital Discharge Data)⁷ in addition to a variety of active follow-up procedures, the majority of patients matched using birth certificates already had current follow-up dates obtained from other sources. Therefore, the final yield of the linkage was more current follow-up dates for approximately 4% (n=288) of the total matched patients. For cancer registries that use fewer data sources in passive and active follow-up, the percentage of patients who obtained updated follow-up from birth certificate data could certainly be higher.

Although a relatively small proportion of cases were updated through this birth certificate linkage, the linkage was differentially more effective for matching and updating young adult and childhood cancer survivors than older patients. These younger patients are typically more mobile than their older counterparts and are often not found in the usual administrative databases, resulting in lower current follow-up rates than for older age groups. In this linkage, nearly 24% of the updated patients were childhood cancer patients <20 years at diagnosis. As childhood cancer survival rates continue to increase (current five-year survival rates are over 70% for childhood cancers overall⁸), there will be a growing need for better sources of follow-up data for this demographic sub-group.⁹ Results from this linkage suggest that maternal data from birth certificates are useful for updating date of follow-up for female childhood cancer patients. Similarly, follow-up on some minority cancer patients can be hard to obtain. This linkage with birth certificates was successful in slightly increasing the updated follow-up on Hispanic cancer patients in California.

From the point of view of researchers conducting survival studies, any update on date of follow-up is welcomed as any extended follow-up time will contribute to the calculation of survival time and will increase the reliability of survival estimates. From the registry operation point of view, however, registries want follow-up date not only to be updated but also to be updated beyond a certain date, ie, beyond the cut-off date defined as current follow-up date. This is especially relevant for SEER registries that are required to meet certain standards on patients' follow-up rates. In this study, improvement on patients' follow-up rate after the linkage seemed rather small because the rate is based only upon being "current" (updated within the past 22 months) or "not current" (last update was over 22 months past). For study patients whose follow-up date was already within the current range before the linkage, updates from the birth certificate did not have any impact on their status. However, in a future data extract, the few added months of follow-up may keep that patient within the "current" timeframe and thus contribute to a sustained improvement in follow-up rates. For example, one patient whose follow-up date was December 12, 2004, obtained an updated follow-up date of September 20, 2005 from the linkage; follow-up status of this patient in August 2006 data extraction was current before and after the linkage. As data extraction date moved from August 2006 to November 2006, the cut-off date for current follow-up moved from October 1, 2004 to January 1, 2005, making this patient's follow-up date before the linkage not current. The updated follow-up date, which still fell in the new current range, helped to maintain the current follow-up rate in this data extraction.

Table 2. Patients* with Current Follow-up and Follow-up Rate in California Cancer Registry (CCR) Database Before and After Matching with Birth Certificate Data*****

	<i>Before the Linkage</i>			<i>After the Linkage</i>	
	Total Number of Patients in the Study	Patients with Current Follow-up	Follow-up Rate (%)	Patients with Current Follow-up	Follow-up Rate (%)
Total	149,372	122,113	81.8	122,199	81.8
Age at diagnosis (years)					
0–19	5,869	3,773	64.3	3,796	64.7
20–34	15,415	10,794	70.0	10,855	70.4
35–44	31,124	24,522	78.8	24,524	78.8
45–54	48,685	40,937	84.1	40,937	84.1
55–65	48,279	42,087	87.2	42,087	87.2
Race/Ethnicity					
Non-Hispanic white	84,140	72,700	86.4	72,739	86.4
Non-Hispanic black	9,780	8,692	88.9	8,693	88.9
Hispanic	33,138	24,404	73.6	24,433	73.7
Asian/Pacific Islander	16,816	13,340	79.3	13,352	79.4
American Indian	82	68	82.9	68	82.9
Unknown	5,416	2,909	53.7	2,914	53.8
Tumor Behavior					
Non-invasive	24,193	20,006	82.7	20,026	82.8
Invasive	125,179	102,107	81.6	102,173	81.6
Year of Diagnosis					
1988–1990	17,871	13,151	73.6	13,161	73.6
1991–1993	19,386	14,588	75.3	14,601	75.3
1994–1996	21,764	16,851	77.4	16,866	77.5
1997–1999	25,791	20,724	80.4	20,744	80.4
2000–2002	30,197	24,900	82.5	24,915	82.5
2003–2005	34,363	31,899	92.8	31,912	92.9

*Patients include female cancer patients age less than or equal to 65 years at diagnosis, not known to be deceased, with follow-up date between 1988 and 2005, reported to the CCR as of August, 2006.

**Follow-up rate was calculated using a method adapted from the SEER method, which is calculated as the percentage of living patients that have a current date of follow-up (within the 22 months prior to data extraction) among all living patients.

***California birth certificate statistical master files 1997–2005.

Although the yields from birth certificate linkages may be relatively small, for most states this data source is readily accessible either free of charge or at minimal cost. In the United States, electronic birth certificate data files are created and maintained by the State Health Departments. In the majority of states, central cancer registries already have well-established relationships with their State Health Departments and receive administrative data files like State death certificate files, Medicare eligibility files, and hospital discharge files. Therefore, it is feasible for central cancer registries to request and obtain birth certificate data as a passive follow-up source. In addition, timeliness of birth certificate files is generally very good. For example, in California, the time when individuals are recorded on the data file and the availability of the data files is around

six to twelve months for birth certificate data, shorter than many other administrative files used in passive follow-up linkages. Timeliness of passive follow-up source file is of particular importance for registries that are striving to meet certain goals in patient follow-up rate.

The exclusion of male patients due to the absence of paternal first name on the birth certificate is currently a limitation of this linkage. In the future, the addition of sufficient personal identifiers may make it possible to link male patients with birth certificate data and thus extend the usefulness of this data source.

In summary, findings from this study indicate that linking with birth certificate files is a cost-effective way for central cancer registries to improve date of follow-up on female patients, and is particularly useful for the follow-

up of hard-to-find younger and minority cancer patients. Although the amount of improvement on follow-up date and follow-up rate depends on follow-up sources already used by the registry, the accessibility and timeliness of birth certificate data make it a very good addition to central cancer registries' existing passive follow-up data sources.

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References

1. Havener L (ed). *Standards for Cancer Registries Volume III: Standards for Completeness, Quality, Analysis, and Management of Data*. Springfield (IL): North American Association of Central Cancer Registries; October 2004, 180 pp.
2. Shannon HS, Jamieson E, Walsh C, Julia JA, Fair Me, Buffet A. Comparison of individual follow-up and computerized record linkage using the Canadian Mortality Database. *Can J Public Health*. 1989;80(1):54-57.
3. Kato I, Toniolo P, Koenig LK, Kahn A, Schymura M, Zeleniuch-Jacquotte. A comparison of active and cancer registry-based follow-up for breast cancer in a prospective cohort study. *Am J Epi*. 1999;149(4):372-378.
4. Reynolds P, Urayama KY, Von Behren J, Feusner J. Birth characteristics and hepatoblastoma risk in young children. *Cancer*. 2004 Mar 1;100(5):1070-1076.
5. Emerson JC, Malone KE, Daling JR, Starzyk P. Childhood brain tumor risk in relation to birth characteristics. *J Clin Epi*. 1991;44(11):1159-1166.

6. *November 2006 Data Submission Requirements and Guidelines*. SEER Program Technical Memorandum 09-08-06. Available at: <http://seer.cancer.gov/tools/SEER2006.instructions.pdf>. Accessed February 2008.
7. Laurent A, McDavid K, Yin D, Allen M, O'Connor L. An investigation of the methodology and feasibility of passive follow-up for central registries. *J Reg Mgmt*. 2005;32(3):104-112.
8. Ries LAG, Smith MA, Gurney JG, Linet M, Tamra T, Young JL, Bunin GR (eds). *Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975-1995*, National Cancer Institute, SEER Program. NIH Pub. No. 99-4649. Bethesda, MD; 1999.
9. Skinner R, Wallace WH, Levitt GA. UK Children's Cancer Study Group Late Effects Group. Long-term follow-up of people who have survived cancer during childhood. *Lancet. Oncol*. 2006 Jun;7(6):489-498.

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Studying Patterns of Care: An Evaluation of a Project Using CDC-NPCR Data

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Abstract: This report describes an evaluation of a 2002–2005 study of patterns of care (PoC) received by cancer patients in seven US States, conducted by the Centers for Disease Control and Prevention’s National Program of Cancer Registries (CDC-NPCR). Representatives from the Centers for Disease Control and Prevention (CDC) and all seven states who participated in the PoC Study helped design and implement the study evaluation, which was conducted during regular cycles of documentation, discussion, and decision-making throughout the course of the PoC Study. As the PoC Study and its evaluation developed, a variety of research and project management processes became the foci of ongoing evaluation cycles. The evaluation team first identified key areas of concern that it divided into two broad categories: (1) *operational efficiency concerns*, which included issues such as human resources, the pace of data collection, and the cost of accessing primary data sources, and (2) *data quality concerns*, which included issues such as data completeness, case triage and potential bias, and the extent to which construct validity was achieved. The study team then identified nine main lessons, each corresponding to one of the two identified key areas of concern. The lessons learned included: (1) study management needs to be flexible; (2) the independence of study personnel from normal registry operations is preferred; (3) more study personnel should be hired (but for shorter periods of time) in order to prevent discontinuities that could delay the study; (4) careful consideration needs to be given to the costs associated with accessing primary records; (5) early in study planning, investigators need to evaluate multiple data sources before selecting those most appropriate for data collection; (6) the completeness and accuracy of study data should be evaluated regularly throughout the study; (7) significant challenges encountered were compensated by a robust study design; (8) the relative cost effectiveness of this approach was demonstrated in studying determinants and consequences of naturally-occurring patterns of care across diverse populations; and (9) some limitations of the treatment data requiring ongoing improvement efforts.

Key words: breast cancer, cancer treatment patterns, colon cancer, lessons learned, patterns of care, prostate cancer

Introduction

The potential for large-scale, population-based studies of patterns of cancer care in the United States has been strengthened by the availability of high quality incidence data collected by the Centers for Disease Control and Prevention’s National Program of Cancer Registries (NPCR)—a national cancer data surveillance system that has evolved over the past 12 years.¹ Population-based studies can make valuable contributions to the national cancer surveillance, in part by supplementing clinical trials and institution-based studies of cancer treatment through examination of differences in conformity to clinical guidelines across geographic areas. Thus, between 2002 and 2005, public health investigators from the Centers for Disease Control and Prevention (CDC) and seven state cancer regis-

tries designed and implemented the first NPCR patterns of care (PoC) study.^{2,3} The study included an evaluation of the effectiveness of the research and project management processes used to conduct the study.

Recent papers stemming from a variety of cancer-related projects have suggested that systematic evaluations of the research and project management processes used in these projects may prove useful in guiding future research efforts.^{4–10} Systematically examining the lessons learned in completed projects and incorporating them in the design and implementation of subsequent related studies can lead to more refined future projects. We believe that the evaluation of the PoC Study described in this report will be useful in the conduct of similar retrospective studies, by illustrating the problems we faced in conducting a complex study

“Studying Patterns of Care: An Evaluation of a Project Using CDC-NPCR Data”

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across multiple locations and the collaborative solutions we devised to address those problems.

In 2000, the Institute of Medicine recommended that NPCR data be used to: (1) assess the quality of cancer data collected by registries and the quality of cancer care received by patients in the United States, and (2) evaluate variations in adherence to established standards of care.¹¹ In response to this recommendation, between 2002 and 2005, investigators from the CDC and seven state cancer registries participating in the CDC-funded NPCR, conducted the first PoC Study using NPCR data.^{2,3} The main study objectives of the 3-year retrospective study were to: (1) assess the data quality and completeness of stage and treatment data routinely collected by NPCR cancer registries, (2) determine the extent to which patients are receiving guidelines-based, stage-specific treatments for localized female breast cancer^{12,13} and for Stage III colon cancer (with regional lymph nodes metastasis),¹⁴ (3) identify factors related to the receipt of treatment for localized breast and Stage III colon cancer, in compliance with established guidelines, and (4) describe the treatment patterns for localized prostate cancer (for which there are no well-established treatment guidelines).

An overview of the project, including highlights of the study methodology, the sampling plan, and characteristics of the 6,777 subjects, is presented elsewhere, along with a discussion of the advantages and disadvantages of using state cancer registry data to assess the quality of cancer care.² Members of the PoC Study team reabstracted detailed clinical data on cancer treatment, as well as salient patient and tumor characteristics, from hospital and non-hospital records over approximately an 18-month period, and assessed the extent to which key variables were associated with disparities in the receipt of recommended treatments for breast and colon cancers; they also collected data regarding the types of localized prostate treatments received by patients. In addition, the study team compared a subset of variables from these reabstracted clinical data (obtained directly from medical records) with the same subset of variables originally abstracted and reported to the state cancer registries for each case.

Strategies for accessing archived records were built into the study methodology; this effort represented one part of our plan for accessing all study patients' medical records (both hospital and physician office charts). Because the PoC Study started in 2002 (about 5 years after the diagnosis year of 1997), we expected that some records would be archived and thus not easily accessible. While retrieval of all archived records would be preferred, we expected that in some cases this retrieval might not be feasible. To address this issue, we built in an over-sampling (by 20%) in the calculation of sample size, as described previously.² Although this over-sampling could compensate, at least in part, for our inability to access some archived records, it could also result in bias. At the same time, the seven registries vigorously pursued the off-site, stored (ie, archived) records whenever possible (even at a charge), to minimize the chances of having a biased sample.

Evaluation of the research and project management processes used in the PoC Study described in this paper

has helped CDC to develop the infrastructure and capacity within NPCR to conduct more refined PoC studies (and other advanced surveillance research) based on the lessons learned. The PoC investigators also sought to further expand knowledge regarding successful PoC projects' methodologies by studying insights provided by numerous past cancer patient care investigations, for example, case series using hospital- and clinic-based data, patient care evaluation (PCE) studies by the American College of Surgeons (ACoS) and others, randomized clinical trials, and population-based PoC Study collaborations among state cancer registries, the ACoS, and the American Cancer Society.¹⁵

Methods for the Evaluation

The seven state registries in California, Colorado, Illinois, Louisiana, New York, Rhode Island, and South Carolina were selected to participate in the NPCR PoC Study because of their demonstrated ability to successfully complete such a study. All of the registries selected met standards established by the NPCR for having high quality incidence data¹ and had certification by the North American Association of Central Cancer Registries (NAACCR), which recognizes state registries for their ability to produce complete, accurate, and timely data.¹⁶ All of the registries selected had submitted applications/study proposals that provided strong evidence of their abilities and resources to successfully conduct and complete the project (eg, a work plan describing activities to meet the project goals and objectives demonstrating the capability to abstract the required number of cases; a personnel plan describing the team members' roles in carrying out the objectives of the project, including the planned percent of effort for team members; a timeline that adequately demonstrates appropriate distribution of project activities over the 3-year study period; letters of support from collaborating partners that provide evidence of an active collaboration and commitment to work as full partners). Some of the registries selected for participation documented considerable past experience in conducting special studies such as the PoC Study, while others documented past preparation activities and resulting organizational readiness to begin successful participation in the PoC Study.

One of the strengths of NPCR is the wealth of state-based experience from which it can draw, and CDC took full advantage of this expertise by encouraging the participation of staff with diverse backgrounds in the design and conduct of the evaluation of the PoC Study. Thus, the PoC evaluation had guidance from central registry managers, veteran registrars with considerable experience in the conduct and management of research projects, and epidemiologists; among the epidemiologists were three physicians and an oncology nurse who provided valuable clinical insight. This clinical expertise was especially important, for example, when assessing the advantages and limitations of data abstracted from non-hospital sources and when analyzing cancer staging issues related to the collected data.

A CDC epidemiologist in the Division of Cancer Prevention and Control and a CDC-contracted project manager provided oversight for the project and for conduct

of the evaluation cycles. Throughout the PoC Study, these two study leaders coordinated activities to encourage the large study group to identify various research and project management processes with potential issues/problems, to be subjected to evaluation cycles, resulting in the identification and resolution of concerns and, ultimately, “lessons learned” to guide the design and efficiency of future CDC-NPCR–sponsored special studies. The PoC Study evaluation, like other tasks performed by the study investigators during the project, used a multi-state, multi-disciplinary team approach, with the principal representatives engaged from each of the participating registries and from the CDC.

Our main objectives in conducting the evaluation cycles were to identify potential or existing problems in our research and project management processes as early as possible, to determine the best possible solution for each problem, and to take corrective actions in a timely manner. As described elsewhere,² the PoC Study was carried out in conjunction with phase 2 of the international CONCORD Study, which is focused on elucidating international differences in survival and on enabling direct comparisons of cancer survival rates within and between countries. Given the survival focus of the CONCORD Study, the PoC Study had to use the 1997 diagnosis year, so that calculation of 5-year survival rates for the CONCORD Study could be made. The 1997 diagnosis year proved to be a challenging limitation for the PoC Study because of the frequent problem with accessing archived records. To address this problem, we used iterative problem solving. Because we had to assemble 5–7-year-old data from various sources (both hospital and non-hospital) across seven states within a relatively short data collection period, we had to work extremely hard to ensure the uniformity of data needed to facilitate the comparisons we intended to make.

Throughout the conduct of the study, a variety of issues/problems stemming from research and project management processes employed in the study emerged and became foci of the evaluation process. Once identified, issues/problems were defined as clearly as possible and then subjected to the documentation-discussion-decision cycle. Different issues assumed higher priority at different phases of the study. For example, access to medical records was an early focus of data collection, thus requiring our close attention at that time, while construct validity of analytical variables was an ongoing focus in the data analysis and interpretation phases of the study.

Research and Project Management Processes Evaluated

We evaluated research and project management processes throughout the various stages of the study, generally outlined here:

- **Stage 1 – Addressing IRB, HIPAA issues and designing protocols and instruments:** The PoC Study was reviewed at the CDC and state registry levels; it was examined by eight independent Institutional Review Boards (IRBs), each of which had slightly different issues with the study protocols and instruments. Health Insurance Portability and Accountability Act (HIPAA) regulations were also addressed independently at the national (CDC), jurisdictional (state), and institutional levels, which resulted in sometimes conflicting interpretations about the release

of data to other entities and jurisdictions for research purposes. Protocols and data collection instruments were designed not only to meet the needs of the seven central registries engaged in data collection, but also to address IRB demands and the widely varying interpretation of HIPAA regulations.

- **Stage 2 – Training abstractors:** Abstractors from the seven registries were assembled for in-depth “initial” training (to assure uniformity of abstracting); delays in data collection (largely attributable to local HIPAA interpretations, the archiving – and destruction – of paper records, and just too few data collection staff) inevitably led to the challenge of staff attrition, which in turn was met with uniform “interim” training for both new and experienced abstractors and the evaluation of the quality of data abstraction.
- **Stage 3 – Evaluating “early” data:** During a short pilot study, we tested the first data collected for consistency in abstracting and coding across the seven states. Significant data collection issues were identified and addressed in this phase.
- **Stage 4 – Editing data:** Initial edits of a semi-complete, cross-state data set revealed continuing differences among registries, especially in the completeness of particular data fields. Considerable effort was expended at the national and local levels to address problems with omitted data. The process was iterative and intensely collaborative. Partners especially benefited from one another’s expertise and feedback during this phase.
- **Stage 5 – Evaluating “mature” data:** This phase was a natural extension of Phase 4, during which we identified remaining problems with completeness and comparability of the semifinal data, and we tested main variables for construct validity.
- **Stage 6 – Managing analysis and writing:** Analysis and writing teams were organized and coordinated during an in-person investigator meeting, telephone conferences, and through email exchanges. Like the Phases 4 and 5 processes, the Phase 6 process was iterative and intensely collaborative. As analytical tables were constructed, they were circulated among all researchers for comments and suggestions. Analyses were “built” step by step in this way.

Communications

Frequent and regular forms of communication among all the research team members were essential to the success of the evaluation cycles. The CDC investigators coordinated this communications effort among all the investigators and study personnel from all seven state registries and the CDC investigators, to move the various issues/problems through the evaluation cycles, in order to document, discuss, and make decisions regarding a variety of issues. Examples of the forms of communication used regularly by the PoC Study Group are briefly described here.

Teleconference calls

Multiple types of teleconferences were used throughout the course of the study, and the work resulting from these conferences provided the issues/problems that were evaluated in the regular cycles of documentation, discussion, and

decision-making. Splitting the large number of needed teleconferences into different types of conference calls, based on specific project functions, served two purposes. This strategy served to encourage project personnel vital to certain topics to participate on those particular calls while also freeing them from participation on teleconferences less relevant to their assigned activities and expertise; also, the strategy allowed abstractors and project coordinators to focus conference call discussions on topics relevant to the pressing work in progress at particular times. Monthly conference calls of the study's Scientific Advisory Group (SAG) were attended by the co-investigators at the states and from CDC. SAG calls dealt with global, high-level project methodology and analytic issues. Abstractor/Coding Committee calls dealt with in-the-field data collection issues and data quality concerns across the states; lead abstractors and project coordinators in each state were the main participants on these conference calls. Written records of the various conference calls, which were available for review by all investigators and main study personnel, as well as subsequent email discussions, helped move the evaluation cycles from discussion, through decision-making, to action.

In-person meetings

At the beginning of the project, CDC investigators hosted a face-to-face meeting of the principal investigators from all seven states and CDC, during which they sought to reach a consensus on some elements of the study before the collaborators went back to their respective states to draft and share with the collaborator group their assigned protocol sections. At the same time, CDC investigators also hosted a face-to-face abstractor training meeting that used a "train-the-trainer" model. Principal investigators also met as a group for intensive, half-day sessions to participate in evaluation cycles addressing identified concerns, which led to changes, such as modifications of study protocols. As the final data set was being organized, representatives from the state registries and CDC met for two days, during which they developed a PoC Study manuscript master plan and the rules of publications and initiated writing groups to work on various manuscripts.

PoC Study presentations

During the course of the study, more than 15 presentations on various scientific aspects of the PoC Study were presented by the study investigators at national and academic meetings. These podium talks and posters highlighted selected study-related topics, including an interim analyses of data, and resulted in valuable feedback from the audiences that helped us think through ideas to stimulate fresh thinking at that time and for future related projects.

In summary, as problems and issues related to various research and project management processes were evaluated at different points in the study, the analysis and discussion of data completeness, quality, and utility led to an informed understanding of the determinants—and the consequences—of the many challenges encountered in PoC studies. Key concerns emerged from these ongoing dialogues among the NPCR state and CDC co-investigators.

Results

Emergence of Concerns

As the study and its evaluation of issues developed, key concerns surfaced. The concerns were divided broadly into two categories: *operational efficiency concerns* and *data quality concerns*.

Operational Efficiency Concerns

Evaluation team members identified three operational issues, or sets of issues, that affected the conduct of the PoC Study: human resource issues, the pace of data collection, and the cost of accessing primary data sources.

Human resource issues. Throughout the course of the study, it became increasingly obvious that many study registries did not have sufficient local-level staff fully trained and dedicated specifically to the project. In addition, costs associated with accessing archived records proved to be greater than originally estimated. Expected costs and work time estimates had been based in large part on registries' past hospital-based cost experiences; in contrast, our PoC data collection settings proved to be diverse, that is, data collection activities were conducted in many kinds of non-hospital settings, in addition to hospital settings.

Two additional issues contributed to the underestimation of costs. First, as mentioned earlier, because we conducted the study in conjunction with the international CONCORD Study, we had to use an older diagnosis year than we might have chosen otherwise.² Secondly, because the initial start-up period of this first PoC Study lasted longer than anticipated, data collection started comparatively early in a few registries, while other registries had more preparatory work to accomplish before data collection could begin. Thus, for many registries, substantial resources planned for use early in the project were not used in accordance with the original timetable. This led to challenging questions such as: over what specific period of time could study personnel be assured that their salaries would be funded through the PoC project (since substantial delays had been encountered in year 1) and how much study funding could be carried over from year to year. Exacerbating the difficulties associated with accessing archived records, HIPAA regulations became operative during the course of the study. As a result, PoC staff had to familiarize themselves with the new regulations before many health care facilities would grant them access to medical records for the PoC Study. Furthermore, the manner in which PoC staff members were placed within participating central registries—either integrated into normal registry operations or organized as independent teams—emerged as an issue. We found that the integrated approach, which was used in most of the seven registries for this project, led to job-related stress because staff members often had to meet competing deadlines.

The pace of data collection. The second issue related to difficulties in accessing data was that the pace of data collection was slower than we had anticipated. As a result of unexpected delays, some PoC staff members left employment before the study was finished, which necessitated the hiring and training of new staff. This development, in turn,

resulted in some identified inefficiencies and inconsistencies in data collection, which required additional time and effort to correct within each data collection team.

The high cost of accessing primary data sources. The third issue, the high cost of accessing primary data sources, was never satisfactorily resolved over the course of the study and affected many decisions about data collection (eg, decisions about on-site abstraction versus copying medical records; staff size; and strategies for the actual data collection effort). As noted previously, accessing archived medical records was a major challenge in the PoC Study, leading to both delays in completing the study and to increased study costs.

Data Quality Concerns

In part because of the unexpectedly high cost of accessing archived data, the data collected for the PoC Study were not as complete as we would have liked. The costlier the access, the less likely one will achieve completeness goals. NPCR staff kept close tabs on how many cases had been completed in each of the states over time, paying particular attention to regularly discussed benchmarks for data collection. Discussions about the challenges of accessing data led to fruitful discussions about case *triage*, in which cost was the primary criterion in determining what data needed to be collected, and the lack of any potential bias was the secondary criterion. In any case, as the data collection deadline neared, the PoC team realized that it did not have the resources to collect all potentially accessible data; at this point, the discussion shifted to issues of data bias, data validity, and the statistical power that the data provided.

After the data collection phase was completed and the team began focusing on preliminary data analyses, team members noted that the data supported some of the relationships expected among variables but did not support other relationships—or at least not to the same extent. Thus, *construct validity*—addressing the extent to which associations found between given variables and patterns of care agreed with previous scientific findings—became a focus of analysis. The team actively discussed why examination of some variables seemed to allow demonstration of expected associations with patterns of care while others did not; through this process, we developed some understanding of the adequacy of particular sources of data for describing and explaining patterns of care, their determinants, and their consequences. This *preliminary* evaluation of essential variables preceded their use in hypothesis testing.

Conclusions/Lessons Learned

After carefully considering the study concerns raised, members of the study evaluation team reached a consensus on the following nine “lessons learned.” The first four related to operational efficiency, the next two to data quality, the following two to the general approach to the study, and the final one to data limitations. Some lessons learned have already led to methodological improvements in the subsequent NPCR PoC Study undertaken at the completion of the project discussed in this paper. In addition to having the potential to improve future PoC

projects, we believe that the lessons will be useful in planning and operating other special studies involving the implementation of complex research and project management processes. Each of the nine main lessons learned was steeped in multiple cycles of documentation, discussion, and decision-making, and emerged from a strong consensus among team members with multidisciplinary backgrounds and diverse experience.

Operational Efficiency

Lesson 1: Flexible study management is useful in overcoming barriers to accessing data and in minimizing delays in data collection. Management flexibility in the PoC Study was enhanced by gathering the entire team regularly using well-structured conference calls and by drawing on multidisciplinary expertise networked within the study partners.

Lesson 2: Projects such as this PoC Study should use independent study teams rather than teams integrated with normal cancer registry staff, so that team members are not distracted by the strain of competing deadlines. Building independent management into study teams also reduces strains on central registry managers. In addition, training and management costs can be reduced by ensuring that all members of the study staff use standardized registry variables, nomenclature, and data collection techniques.

Lesson 3: Discontinuities of staffing (and associated inefficiencies) may be avoided by hiring more staff for a shorter period of time. Given the plethora of barriers to accessing data, careful timing in the hiring and training of study personnel is essential to the cost-efficiency of operations. Small but diverse pilot studies may be useful in determining staffing needs. In some cases, shortening the data collection period may also help minimize problems with accessing data.

Lesson 4: Because of the cost of accessing primary records is a central consideration in the design of PoC studies, study managers should assess the merits of alternative data sources carefully before selecting particular sources to use in their study. Requiring additional data in mandatory cancer case reports would lessen the need for researchers to access more costly data sources.” Although the development of electronic medical records archives should reduce the cost of retrieving archived data, few such archives are currently available. Studying cases diagnosed more recently than the cases assessed in this PoC Study would also reduce study costs, especially costs related to accessing archived data.

Lessons Learned: Data Quality

Lesson 5: The quality of data in a study may be optimized by evaluating alternative data sources before selecting the ones to use in a study. Data from primary sources are much costlier to access than central registry data because primary data sources are not developed or maintained with the standards or oversight characteristic of central cancer registries. Variations in the accessibility and quality of primary data sources within and across jurisdictions complicates study planning and necessitates commitment

of additional human resources to address unexpected problems as they arise.

Lesson 6: Evaluating data completeness and accuracy throughout the course of a complex study like this PoC project helps improve its efficiency. Minor adjustments to which all study participants have agreed are easier to implement than major adjustments that are unanticipated. By evaluating the protocols and the data completeness and accuracy of study data at each stage of the study, from sample design through tests of construct validity, study members were better able to understand evaluation results throughout the course of the study. This continuous data evaluation was especially helpful in identifying potential biases in study data.

Lessons Learned: General Approach

Lesson 7: Despite the significant barriers encountered in the PoC Study, its general design proved to be robust. Although we had to deal with problems associated with accessing archived data, efficient problem-solving yielded satisfactory completeness with a minimum of bias. Tests of construct validity have been quite positive.

Lesson 8: For the most part, the PoC Study's use of central registry cancer treatment data was a relatively inexpensive way to study the determinants and consequences of naturally-occurring patterns of cancer care across diverse populations.

Lessons Learned: Limitations of the Data

Lesson 9: Thus far, the PoC Study data have been found to have several limitations. Most importantly, perhaps, chemotherapy seems to have been underreported, and the resources at our disposal did not permit us to the extent to which those data were underreported. In a similar vein, limited resources and a lack of organizational readiness to conduct a study involving more than seven registries limited the generalizability of study results. Although the Surveillance Epidemiology and End Results (SEER) Program, which is experienced in conducting population-based patterns of care studies, is also limited geographically, it has addressed a potential lack of generalizability of study results by selecting study populations that are *reasonably* representative of the United States as a whole. This is a strategy that the NPCR may also be able to use in conducting large collaborative studies across its many central registries. Furthermore, it may be possible to include all NPCR registries, perhaps even *all* NPCR and SEER registries, in some future PoC studies that would, thus, reduce the number of cases needed from the various population groups. In any case, NPCR's first PoC Study serves as *more* than a methodological pilot because the PoC Study sample is *reasonably* distributed by geographic region, by level of urbanization, by socioeconomic status, and by race.

Discussion

Several characteristics of the PoC Study were especially challenging, and future PoC studies will likely face similar challenges until a standardized electronic medical

record is widely adopted in North America and elsewhere. Without this new technology, researchers conducting retrospective studies of PoC for cancers must organize the identification, retrieval, abstracting, and coding of medical records from disparate sources so that the data collected are as uniform as possible. The completeness of study data will vary no matter what sampling frame is employed. Older records, however, are especially difficult to access because they are commonly archived, then eventually destroyed as the likelihood of their re-use declines. Nonetheless, PoC studies may be forced to use archived records in order to achieve the statistical power necessary to produce significant results. By using archived records, the NPCR's first PoC Study was able to access data on a sufficient number of cancer cases in all seven jurisdictions covered, although not without all participants experiencing severe strains on their existing resources.

Accessing the archived records turned out to be only one of many challenges in creating a usable assemblage of data collected originally at different times, in different places, for different purposes. The participating central registries in the study quickly learned that problem-solving across several jurisdictions (in our situation, seven states) is much more complex than problem-solving in one jurisdiction. The data collection problems encountered by participants in a multi-jurisdictional study such as this PoC Study will likely vary from site to site, and unfortunately, an ideal solution for one problem in one jurisdiction might create additional problems in other jurisdictions, thus necessitating complex, collaborative problem-solving. The need for multi-jurisdictional problem-solving is relevant now and will continue to be relevant in the future, because PoC-type studies require data of uniform completeness and quality across comparative strata in order to accurately identify and explain *differences* in patterns of care.

Through the conduct and evaluation of the first CDC-NPCR PoC Study described in this paper, NPCR has laid the foundation to ensure that we learn lessons from both the successes/strengths and the challenges/weaknesses identified while using chosen PoC research approaches and then refine PoC Study methodologies and study questions posed in subsequent studies, based on both study findings and lessons learned. Two long-term goals of special studies using NPCR data are to: (1) conduct focused studies that yield results that can provide data to help improve aspects of care to cancer patients, and (2) continue to determine how the work of NPCR and other national data surveillance systems can be complementary² in improving the quality of cancer care.

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References

1. Centers for Disease Control and Prevention. National Program of Cancer Registries (NPCR). Available at: <http://www.cdc.gov/cancer/npcr/>. Accessed October 3, 2007.
2. Alley LG, Chen VW, Wike JM, et al. CDC-NPCR's breast, colon, and prostate cancer data quality and patterns of care study: overview and methodology. *J Reg Mgmt*. 2007;34(4):148-157.
3. McDavid K, Schymura MJ, Armstrong L, et al. Rationale and design of the National Program of Cancer Registries' breast, colon, and prostate cancer patterns of care study. *Cancer Causes Control*. 2004;15:1057-1066.
4. Van Duyn MAS, Reuben SH, Macario E. Special populations networks: themes and lessons learned. *CANCER Suppl*. 2006;107(8):1945-1954.
5. Marcus AC, Heimendinger J, Berman E, et al. A case study in dissemination: lessons learned from a pilot study involving the National Cancer Institute's Cancer Information Service. *J Health Commun*. 2005;10 Suppl(1):219-233.
6. Kiger H. Outreach to multiethnic, multicultural, and multilingual women for breast cancer and cervical cancer education and screening: a model using professional and volunteer staffing. *Fam Community Health*. 2003;26(4):307-318.
7. Viadro CI, Farris RP, Will JC. The WISEWOMAN projects: lessons learned from three states. *J Womens Health*. 2004;13(5):529-538.
8. Fleisher L, Woodworth M, Morra M, et al. Balancing research and service: the experience of the Cancer Information Service. *Prev Med*. 1998;27:S84-S92.
9. Goodwin PJ, Leszcz M, Quirt G, et al. Lessons learned from enrollment in the BEST study: a multicenter, randomized trial of group psychosocial support in metastatic breast cancer. *J Clin Epidemiol*. 2000;53(1):47-55.
10. Plumb M, Price W, Kavanaugh-Lynch MH. Funding community-based participatory research: lessons learned. *J Interprofessional Care*. 2004;18(4):428-439.
11. Hewitt M, Simone JV, eds. *Enhancing Data Systems to Improve the Quality of Cancer Care*. Washington, DC: National Academy Press; 2000.
12. Anonymous. Treatment of early-stage breast cancer. *JAMA*. 1991;265(3):391-395.
13. National Institutes of Health. Clinical alert from the National Cancer Institute. *Breast Cancer Research & Treatment*. 1988;12:3-5.
14. National Institutes of Health. NIH Consensus Conference: adjuvant therapy for patients with colon and rectal cancer. *JAMA*. 1990;264:1444-1450.
15. Wingo PA, Luke E, O'Brien K, et al. Population-based patterns of care studies: collaboration among state cancer registries, The American College of Surgeons, and The American Cancer Society. *J Reg Mgmt*. 2001;28(1):5-16.
16. North American Association of Central Cancer Registries. Registry Certification. Available at: http://www.naacrr.org/index.asp?Col_SectionKey=11&Col_ContentID=54. Accessed October 3, 2007.

This manuscript was written on behalf of the Patterns of Care (PoC1) Study Group. This group is composed of investigators involved in the study, both from the Centers for Disease Control and Prevention (CDC) and from the seven study registries, all of whom are associated with the CDC-funded National Program of Cancer Registries.

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What can ERS do for you?

Perception vs. Reality

Michele Webb, CTR

Improving the perception others have of you and cancer registrars everywhere is a hot topic in many circles today, as it should be. Far too many registrars are inadequately compensated and not recognized or valued for their service or expertise. Not too long ago NCRA changed the certification pathway where a 2-year degree will be required before sitting for the exam in the year 2010. Independent studies have demonstrated that a degree requirement helps to elevate the standing of a profession or job category within its peer and administrative groups. There is, however, more that you can do to elevate professional recognition and support.

Creating and managing your professional image is important. If you are not managing your image, then others are. People constantly observe your behavior and form opinions about your competence, character, and commitment. A wise cancer registrar will add his/her own voice to frame others opinions about who they are and what they can accomplish.

You can go to your local bookstore and find plenty of books telling you how to “dress for success,” control your body language, or talk like a corporate giant. But, keeping on top of your personal traits is only part of the big picture. You also belong to social identity groups—healthcare, oncology, health information, and cancer registry—and each group brings its own stereotyping from the people you work with—especially in today’s diverse workplace. You can fire up your laptop computer and sit at the table with the “big boys,” but how do you manage their perceptions of you?

Begin by asking yourself: What is your professional image? It is the set of qualities and characteristics that represent the perceptions about your competence and character as judged by your coworkers, fellow registrars, physicians, and administrators.

Then, you should understand the difference between your *desired* professional image and others *perceived* image of you. It is important to distinguish between the image you *want* others to have of you and the image that you *think* people may have of you. Most people want to be regarded as technically competent, socially adjusted, of strong character and integrity, ethical, and, of course, committed to their work and organization. Surveys have shown, however, that the most favorably regarded traits are trustworthiness, caring, humility, and capability.

Now, ask yourself: What do I want others to say about me when I am not in the room? Whatever this description might be, it is your *desired* professional image. Next, ask yourself a second question: What am I concerned that others might say about me when I am not in the room? The

answer to this question defines your *undesired* professional image.

You will never know exactly what anyone thinks about you or how he or she describes you when you are not in the room. And, you can make some assumptions

about your current professional image based on your interactions with others in the workplace. People will often give you direct feedback about your personality that will tell you what they think about your level of competence, character, and commitment. You can draw from the indirect signals about your image from the work assignments, referrals, or recommendations made by others. Take these direct, and indirect, messages and put them together to form your *perceived* professional image. This is your best guess of how you *think* others perceive you.

How do you manage those perceptions? You do this by observing non-verbal behaviors, verbal cues, and demonstrative acts (job performance, annual reviews). You can also improve upon others perceptions of you by enhancing your social perception. This is done by strategically presenting yourself in a manner that communicates the meaning of your work and its significance with your social identities. Present yourself to your coworkers, fellow registrars, physicians, and administrators as a vital and important member of the group. For example, you would probably not walk into your cancer committee and begin talking about the benefits of waxing, or not waxing, your surfboard. You can imagine what might happen to your perception ratings if you did this! Instead, use your words, actions and data to collaborate and support the cancer committee goals and directions while strategically placing the cancer registry in a position to provide the data and support of this effort. Do this and watch your “approval ratings” climb!

Here’s the best part! By successfully managing your image and the impressions you make on others, you can generate a number of personal and professional benefits including: career advancement, client satisfaction (administrators, physicians), better work relationships (trust and collaboration), group cohesiveness (local, regional, state, and national), a more pleasant work environment, and a fulfilling job experience.



When you manage your own image, you are also managing it for registrars worldwide! It is through individual and collaborative effort that recognition, support, and value of your profession comes about. Compensation and other job perks are a natural result of image management. When you unselfishly build your credibility, and that of your profession, in an authentic and sincere manner, you will be valued and believed by others and reap the benefits for yourself, your team, your organization, and your profession.

What are the steps cancer registrars should take in order to manage their professional image?

1. Identify your "ideal" state of being. What are the core competencies and character traits you want people to associate with you? Which of your social identities do you want to emphasize and incorporate into the workplace? Which would you rather minimize?
2. Assess your current image, culture, and audience. What are the expectations for professionalism within your social identity group and organization? How do others currently perceive you?
3. Conduct a cost-benefit analysis for changing your image. Do you care about others perceptions of you? Are you capable of changing your image? Are the benefits worth the costs (cognitive, psychological, emotional, and physical)?
4. Use effective communication techniques to manage impressions for changing your image. Balance building your credibility with maintaining sincerity and authenticity.
5. Lastly, manage the effort you invest in this process. Routinely monitor others perceptions of you and your own behavior. On a daily basis, strategically demonstrate by your words, actions, and data management methods your alignment with your organization and profession. Become preoccupied with proving your worth and integrity.


You *can* create a positive professional image, change others perceptions of you, and turn any situation into a positive reality. Effectively managing your image and the

perceptions of your peer group is a hallmark of a cancer registry professional. Each of you has the capability to "rock your world" for your personal benefit and for cancer registrars worldwide!

Michele is the Cancer Registry Manager at Saddleback Memorial Medical Center in Laguna Hills, CA, and an independent consultant and speaker. Send your comments to michele@michelewebb.com.

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The Inquiry and Response System: Understanding the Multiple Primary and Histology Coding Rules

Carol Hahn Johnson, BS, CTR and Margaret (Peggy) Adamo, RHIT, CTR

The new Multiple Primary and Histology (MP/H) Coding Rules became effective for cases diagnosed on or after January 1, 2007. There are nine sets of MP/H rules, eight of which cover specific sites or site groups:

1. Head and neck
2. Brain and CNS
3. Melanoma
4. Kidney
5. Urinary, including bladder
6. Breast
7. Colon
8. Lung
9. Other sites

The rules and a recently released set of clarifications can be downloaded from the Surveillance, Epidemiology, and End Results (SEER) Program Web site at <http://www.seer.cancer.gov/tools/mphrules/download.html>. Abstracting and coding cases using the new rules does generate questions. The most common problem is not following the hierarchical order of the rules. Many of these questions have been submitted to the Commission on Cancer (CoC) Inquiry and Response (I&R) System. Listed below is a sampling of some of the most common I&R questions and answers pertaining to the MP/H rules. See the I&R Web site for a complete listing <http://web.facs.org/coc/default.htm>.

Urinary

Question: How do we code bladder tumors when the histology is identified as *in situ* papillary and flat transitional cell carcinoma? The urologist and pathologist stated it was a Tis. If we code the histology as papillary transitional cell carcinoma (8130) and the stage as Tis, an edit appears saying this is not a correct histology/stage combination.

Answer: Override the edit. See the *TNM Supplement, 3rd Edition*, p 68: "In case of multifocal tumors of urinary bladder with Ta and Tis tumors, Tis should be classified." Stage these tumors as Tis.

Use rule H4 to code the histology and appearance as documented in the pathology report, papillary transitional cell carcinoma (8130/2).

Question: Diagnosis of transitional cell carcinoma of the ureter 8/06 and was treated with surgery. The patient is now diagnosed with transitional cell carcinoma of the bladder, not called metastatic. According to MP/H rules, is this one primary recurrent to the bladder or two primaries?

Answer: This is a single primary. See rule M8.

Lung

Question: In 2/05 a patient had a right upper lobe lobectomy. Pathology: three nodules, well differentiated adenocarcinoma with non-mucinous bronchoalveolar features, as well as papillary features, coded 8255. In 4/07, the patient had a biopsy of a left lower lobe nodule. Pathology: well differentiated adenocarcinoma. The lesion was treated with radiofrequency ablation. Is the left lower lobe nodule a new primary according to the MP/H rules?

Answer: Bronchoalveolar and papillary are both specific types of adenocarcinoma (see Chart 1). The first tumors were completely resected so the pathologist had enough tissue to make a specific diagnosis. The 2007 nodule in the left lower lobe was biopsied. It is not unusual to get a less-specific diagnosis such as adenocarcinoma when there is little tissue to examine. Use the multiple tumor module rule M12. This is a single primary/recurrence.

Question: Diagnosis in 2003 of adenocarcinoma in the upper lobes of both lungs. The cancer was unresectable; the patient received chemotherapy and achieved a partial response. All of the serial CT scans noted the right upper lobe nodule. A 5/07 PET scan continued to show activity in the right upper lung. The patient had a right upper lobectomy in 6/07. The pathology was non-small cell carcinoma. Is this a new primary?

Answer: The patient had continuing disease in the right lung through 5/07 (activity on PET scan). The resection was 6/07. Since the patient was never disease free, this is disease progression/etc; not a new primary.

Breast

Question: A breast cancer patient had a tumor with ductal carcinoma at the 9:00 position, and another tumor with lobular carcinoma in the same breast at the 3:00 position. Does rule M12 apply since this is two separate tumors and not a "mixed" histology?

Answer: Use the rules in hierarchical order. Start with the multiple primary module and stop at H10. This is a single primary.

Question: How do you code infiltrating duct carcinoma of the breast with predominant mucinous features and focal micropapillary features?

Answer: Use rule H17 and code duct and any other carcinoma 8523/3.

Question: A patient had breast cancer, metaplastic carcinoma (8575/3) 3 cm. close margin. Separate DCIS, solid, cribriform, and micropapillary. Is this a single primary? What is the correct histology code?

Answer: Because metaplastic carcinoma is not a duct or intraductal type, use rule M12 and abstract as two primaries. Using rule H14, the first primary is metaplastic carcinoma 8475/3. Using rule H6 code the DCIS, solid, cribriform, and micropapillary as 8523/3.

Question: For a DCIS with lobular extension, solid and cribriforming, focal comedo features, what is the histology code?

Answer: Use rule H4 and code to comedocarcinoma (8501/2) if all lesions are *in situ*.

Other Sites

Question: Pathology report stated, "salivary gland, parapharyngeal space mass–noninvasive carcinoma arising in mixed tumor (carcinoma ex pleomorphic adenoma)." What is the histology code?

Answer: Occasionally, an overt carcinoma will arise in a pleomorphic adenoma (pleomorphic adenoma used to be called "mixed tumor" because histologically it appears to be a mixture of epithelial and stromal cells). Using the histology rules, you determine that there is a carcinoma arising within a benign tumor; the diagnosis is "carcinoma ex pleomorphic adenoma" which means, "carcinoma arising in a mixed tumor." Use the other sites histology coding rule H2 and code the histology to carcinoma *in situ* 8010/2.

Question: A prostate path report had the histology as a mixed ductal and acinar adenocarcinoma. What code is used?

Answer: Use histology code 8255, adenocarcinoma combined with other types of carcinoma.

Question: What is the histology for a uterine primary with the final diagnosis of carcinosarcoma with a component of high-grade uterine papillary serous carcinoma?

Answer: The carcinosarcomas are mixed tumors, often having many different components. Code to carcinosarcoma, NOS. Use rule H11.

Question: 2007 path report states papillary serous carcinoma for an ovarian primary. Is it coded 8461 or 8323 per Multiple Primary and Histology Coding Rules?

Answer: Use rule H11. Code the single histology, papillary serous carcinoma of the ovary to 8323.

Summary

Specific questions on the MP/H Coding Rules should be submitted to the I&R System at <http://web.facs.org/coc/default.htm>. This allows tracking of the particular sites that are receiving the most questions to determine future educational needs. It also serves as a resource to cancer registrars across the country who utilize the I&R System.

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To 'Errata' is Human

April Fritz, RHIT, CTR

As I was thinking about what to write for this issue, I was notified that yet another errata has been issued for one of our standard references. As usual, I have mixed feelings about this, because doing the page replacement thing is a pain in the acetabulum. However, having been on the development side of some of these references, I can understand the need to publish periodic updates and errata. Things change over time, such as the Commission on Cancer's requirements for physician staging. Furthermore, despite the best efforts of the development team—including alpha- and beta-testing of rules, databases, algorithms, formats, and guidelines, as well as proofing and reproofing of text, tables, and everything else—once a new reference is out and implemented, somebody always seems to find a significant typo or an outlier that doesn't fit the published document and must be inserted. It's human nature to err. One of my favorite signs says "Pobody's nerfect!"

Regardless of what these documents are called—errata, clarifications, updates, addenda, or just plain fixes—they are important supplements to your references and the changes need to be made to avoid future errors in the collection or interpretation of data.

So what can you do about errata, other than grit your teeth and *just do it*? The first thing is to stay as current as possible with updates. Make the errata changes as soon as you find out about them. There are three major sources that notify the registry community of updates via email bulletins. In my opinion, the best advice is to subscribe to all of them—after all, electrons are free!

1. The *CoC Flash* is a monthly newsletter distributed electronically by the American College of Surgeons Commission on Cancer (CoC) on the last workday of the month. In addition to CoC news and activities, the *CoC Flash* also announces new publications and products from other registry standards setters, such as NAACCR, NCRA, AJCC, and Collaborative Staging. The *CoC Flash* is not just for hospital-based registrars or registrars in CoC-approved cancer programs—central registry staffers need to be aware of changes that affect hospital reporting activities. To subscribe, send an email message with your name, address, phone number, and email address to coc@facs.org.
2. The **NAACCR Listserv** is an information dissemination tool that sends out emails to subscribers on an as-needed or as-requested basis. You don't have to be a central registry person to receive this information—hospital registrars need to be aware of changing central registry standards that affect case reportability. NAACCR members can subscribe by going to <http://www.naacr.org/membership/index.asp>. If you're not a member of NAACCR, you request to be added to the NAACCR courtesy Listserv. Email Monica Thornton at mthornton@naacr.org, and be sure to include your name, facility, state, and email address.

3. The National Cancer Registrars Association (NCRA) sends the *NCRA: Update* to its members periodically to remind them of NCRA events such as the annual meeting, continuing education submission deadlines, and new products and services, as well as changes in registry operations procedures like the publication of new manuals. You must be an NCRA member (and have a working email address) to receive *NCRA: Update*, but then you're probably a member if you're reading this article! NCRA also sends out occasional information to CTRs who may or may not be members. Interested individuals can request to be on NCRA's mailing list by sending an email request to NCRA at info@ncra-usa.org with their full name, email address, and mailing address.

And one more thing—make sure that you have "unblocked" your email or put these organizations on an "acceptable" list in your messaging software so that you actually do receive their communications!

Okay, now that you know you're going to stay up to date on errata, what might you have missed? I've included a table in this article that lists all of the updates/clarifications/errata/addenda that I could find for our standard references and where to obtain them. Please note that this list does not include new versions of references, such as the publication of version 1.04 of the Collaborative Staging manual last October. The list includes only supplementary documents to update publications that have not been reprinted or republished on the Web. In addition, if you have a specific question, you should check the CoC's Inquiry and Response (I&R) System (<http://web.facs.org/coc/default.htm>), which has been recently upgraded, and the SEER Inquiry System (SINQ) (<http://www.seer.cancer.gov/sinq>) for answers.

The 2008–2009 CTR Examination Eligibility Requirements

On a completely unrelated topic, while the fireworks were going off to celebrate the New Year of 2008, a big change came over the eligibility requirements to take the CTR exam. The new requirements have been publicized for a couple of years, but a number of future registrars have been caught "betwixt and between." The following comments are for soon-to-be CTRs and for the supervisors of registrars who anticipate taking the exam within the next 2–3 years.

According to the NCRA Council on Certification's Web site (<http://www.ctrexam.org>), a candidate for the 2008 CTR exam must have at least two semesters/three quarters of college-level anatomy and physiology (A&P) in addition to the previously required two years, full-time (24 months or 3,900 hours) or equivalent experience in the Cancer Registry field to apply for the exam under Route 1. Route 1—two years of work experience—has been the

most common eligibility route for the exam, but it will be eliminated in 2010. The problem is with those working registrars who were eligible but didn't take (or didn't pass) the exam by September 2007 and haven't taken the now-required courses in A&P. By the time you read this, it will be too late to apply for the March exam, and it is unlikely that it would be possible to complete the required two semesters of A&P before the July 31, 2008 deadline for the September 2008 exam unless you are already taking the required classes. Then, for the next exam in 2009, the educational requirements to apply through Route 1 increase again, to completion of 12 credit hours of college education that includes two semesters/three quarters of A&P, one semester of medical science/biology, and a college-level course in Medical Terminology. All this means that a new registrar with no previous college had to start taking classes in the Spring of 2008 in order to complete the educational requirements to take the exam in 2009, while working full time to accrue the job hours to meet the application criteria. That's a pretty heavy load for anyone.

I have been asked by a number of new registrars where A&P classes can be taken to meet the 2008 requirements. One source is your local community college, but I've been told that the A&P classes at many brick-and-mortar colleges have a prerequisite of a medical science or biology course. That creates a catch-22 situation: if you take the biology before the two semesters of A&P, you won't be eligible for the September 2008 exam *or* the March 2009 exam, but at least you'll meet the 2009 exam eligibility requirements, assuming that you've also taken medical terminology. Alternatively, many of the cancer information management (CIM) formal education programs approved by NCRA offer online anatomy and/or physiology courses. It's hard to tell what the prerequisites are from the Web sites I visited, but you can make inquiries of those CIM programs to find out.

A Google search for "anatomy and physiology class online" yielded about 173,000 sites, most of them pretty vague or not what I was looking for. I found everything from

A&P classes for physical education students to continuing education courses for allied health professionals to some really questionable "schools." The point I want to make is that if you are planning to take online classes to meet the eligibility requirements for the CTR exam, be very careful about your choice of schools. ***Make sure that the courses you take are college-level courses*** that are potentially transferable to an accredited college for course credit. Many of the online sites I checked were not *college-level* courses, or were not offered by accredited institutions, or were not of sufficient length (quarters or semesters) to meet NCRA's requirements. Some professional organizations offer online A&P courses but they are not accredited as college-level courses. Similarly, there are brick-and-mortar and online "career colleges" and technical schools that are not regionally accredited academic institutions. In addition, the few that listed their course fees were extremely expensive compared to community college fees.

The educational path for a CTR has become more challenging, especially for those caught in the midst of the evolving requirements. If you have any questions about your potential eligibility, you should contact the NCRA Council on Certification as early as possible to determine whether your educational plan meets the requirements to take the exam at the time you want to take it. You can download the question form from <http://www.ctrexam.org/eligibility/index.htm> under "Eligibility Review Requests." Be aware that it may take several weeks for a response, but when the answer comes, it will be official, not just something someone heard somewhere about the exam. When you apply to take the CTR exam, you are required to provide transcripts of your classes and the examination company *will* review them. Avoid being disappointed that you are not eligible when you are mentally – if not educationally – prepared to take the exam.

April Fritz, RHIT, CTR is CEO of A. Fritz and Associates in Reno, NV. The opinions in this column are hers. She can be reached for comments and feedback at april@afritz.org.

Updates/Clarifications/Errata for Registry Standard References	
STAGING AND CODING	Implementation Date*
<p>International Classification of Diseases for Oncology, Third Edition 5-22-2001 Set #1 seer.cancer.gov/icd-o-3/errata.d05222001.pdf 5-06-2003 Set #2 seer.cancer.gov/icd-o-3/errata.d05062003.pdf</p>	2001–
<p>AJCC Cancer Staging Manual, Sixth Edition Coding Updates and Clarifications <i>replacements for 9 pages in the big manual</i> www.springer.com/west/home/medicine/oncology/cancer+staging?SGWID=4-40654-12-148156-0&teaserId=61512&CENTER_ID=148194 [this is one long, continuous URL, or go to www.cancerstaging.net and click on Coding Updates and Clarifications near the top of the right column]</p>	2003–
<p>SEER Summary Staging Manual 2000 06-14-2001 Errata seer.cancer.gov/tools/ssm/errata.d06142001.pdf 08-20-2002 Errata seer.cancer.gov/tools/ssm/errata_08202002.pdf</p> <p>Note: These errata are for the first printing (July 2001, red cover) of SSSM2000. The corrections were incorporated into the second printing (January 2006, red and blue cover).</p>	2001–2003
DATA COLLECTION	
<p>FORDS: Revised for 2007 12-03-2007 <i>Revisions due to changes in physician staging requirement</i> 1. www.facs.org/cancer/coc/sectionone_0108_ncdb_112607.pdf 2. www.facs.org/cancer/coc/stageofdisease_0108_ncdb_112607.pdf 3. www.facs.org/cancer/coc/appendixc_0108_ncdb_112607.pdf 7-26-2007 Pages updated during 2007 <i>Summary of changes:</i> www.facs.org/cancer/coc/fords/2007/summarychangesupdate.pdf <i>Replacement pages:</i> www.facs.org/cancer/coc/fords/2007/correctedupdate2007a.pdf <i>Revised page 99G:</i> www.facs.org/cancer/coc/fords/2007/revisedpage99G.pdf</p>	2007–
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<p>Cancer Program Standards 2004 Revised Edition (Volume I) 01-01-2008 Standards Update 2008 www.facs.org/cancer/coc/standardsupdate2008.pdf</p>	2006–
<p>NAACCR Data Standards and Data Dictionary (Volume II), version 11.2 June 2007 Errata 1 (Pages 181–186) www.naacr.org/filesystem/pdf/Version%2011.2%20Data%20Standards%20and%20Data%20Dictionary%20Chapter%20X%20Revision%20Pages%20181-186-June%202007.pdf [one long URL] December 2007 Errata 2 (Standard Status Table) www.naacr.org/filesystem/pdf/Standards%20Vol%20II%20Chapter%20VIII%20Required%20Status%20Table_Revised%20December%202007.pdf [one long URL]</p>	

* effective with cases diagnosed on or after January 1 of the initial stated year and ending with cases diagnosed on December 31 of the closing year

CORRECT ANSWERS FOR WINTER 2007

Journal of Registry Management Continuing Education Quiz

Use of Free-text Documentation for Research Involving Imaging and Scoping Procedures in Lung Cancer in the Sacramento Region of the California Cancer Registry

(correct answers in **bold**)

- Abstracted free-text documentation:
 - is an important part of recording a patient's medical history
 - is used to explain and supplement coded data, and to record information deemed important and useful
 - has yet to be added as a permanent feature of the data management system software
 - all of the above**
- According to Table 1, *Patients and Percent of Patients Who Had at Least One Imaging and Scoping Procedure by Stage of Diagnosis, Sacramento Region, 1994–2004*, what percent of patients in this cohort had at least one imaging and scoping procedure?
 - 98.9%
 - 98.7%
 - 98.4%
 - 98.1%**
- According to Table 1, *Patients and Percent of Patients Who Had at Least One Imaging and Scoping Procedure by Stage of Diagnosis, Sacramento Region, 1994–2004*, what was the most used imaging procedure?
 - CXR
 - CT**
 - MRI
 - PET
- According to Figure 1, *Trends in the use of imaging and scoping procedures as a percentage of total cases reports with any imaging and scoping procedures done, by year of diagnosis, Sacramento Region, 1994–2004*:
 - mediastinoscopy, MRI and CT remained relatively stable over the study period
 - PET increased
 - CXR and bronchoscopy decreased
 - all of the above**
- Some of the problems encountered in constructing the database for this study included:
 - failure of CTRs to use standardized abbreviations for imaging procedures and lack of standardized abbreviations for scoping procedures
 - free-text documentation of a procedure found in other text fields
 - lack of a standard format for free-text documentation, resulting in excessive wordiness
 - all of the above**
- According to Table 2, *Imaging and Scoping Procedures, Keywords and Synonyms, and Text Field Placement, Sacramento Region, 1994–2004*, the percentages of PET scans documented in the Scopes and Remarks fields, respectively were:
 - 6.7% and 14.4%
 - 78.9% and 6.7%
 - 4.7% and 11.5%**
 - 83.8% and 4.7%
- The proposed recommendations of this study:
 - are based on methods that could decrease errors
 - reduce the need for quality assurance
 - facilitate the more efficient use of CTRs' time
 - all of the above**
- Data entry into coded fields for imaging and scoping procedures would:
 - initially cost less to program as compared to free-text documentation
 - increase data accessibility for researchers**
 - increase ambiguity
 - make documentation more difficult and less efficient for the CTR
- Computerized standard text templates:
 - cannot be modified to represent variations
 - can increase errors since information is entered in a structured manner
 - make computerized retrieval of data more challenging
 - should incorporate standard abbreviations for procedures and results**
- The use of standard text formats:
 - requires more rigorous initial and ongoing training
 - reduces errors to a lesser extent than the use of structured coded data fields
 - both of the above**
 - neither of the above

Journal of Registry Management Continuing Education Quiz—SPRING 2008

COMPARISON OF REGISTRAR COLLABORATIVE STAGING AND PHYSICIAN AJCC STAGING USING DATA SUBMITTED TO THE NATIONAL CANCER DATA BASE

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

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

- Compare the strengths and weaknesses of the two approaches to staging: physician AJCC staging and registrar Collaborative Staging (CS)
- Identify common problems that result in an unknown stage
- Discuss CoC requirements regarding CS and AJCC staging

1. The current criteria by which individual T, N, and M are assigned by physicians:
 - a) rarely require simultaneous reference to multiple reports in the patient record
 - b) employ instructions and item definitions designed for use by laypersons
 - c) can be complicated
 - d) are referenced in the fifth edition of the *AJCC Staging Manual*
2. Registrars use CS to record site- and histology-specific items as discrete input items that employ a computer algorithm to derive:
 - a) AJCC T, N, M, and stage group
 - b) 1977 SEER Summary Stage
 - c) 2000 SEER Summary Stage
 - d) all of the above
3. The CoC required all approved programs to:
 - a) have physicians assign and initial AJCC stage for 95% of analytic cases
 - b) record AJCC staging information anywhere in the patient record
 - c) record staging information in a systematic location in the patient record
 - d) have the admitting physician stage analytic cases
4. According to the article, *Table 1: Percent of Cases with a Known Stage Group by Approach* and *Table 2: Completeness of Physician and Registrar Staging by AJCC Chapter*, completeness of stage assignment is:
 - a) better across all sites combined for CS-derived stage group
 - b) better for physician-assigned AJCC stage
 - c) nearly identical for both AJCC staging and CS for sites such as pharynx and liver
 - d) greater for cases where AJCC staging is optional
5. According to AJCC rules:
 - a) clinical stage is derived from cT cN cM, and uses all information gathered about the tumor prior to treatment
 - b) pathologic stage is derived from pT pN and either cM or pM, and is based on evidence acquired before treatment, plus additional evidence acquired during and from surgery and pathologic examination
 - c) the rules for computation of stage group differ between AJCC and CS
 - d) all of the above
6. The standard site-stage consistency edit used by facility and central registries categorizes site-histology combinations as:
 - a) those that are required to be staged
 - b) those that cannot be staged
 - c) those for which staging is permitted but not required (optional staging)
 - d) all of the above
7. Pathologic stage consistency between physician AJCC stage and the derived CS stage group was greatest for which of the following AJCC chapters?
 - a) small intestine, breast, vagina, prostate, and kidney
 - b) the majority of AJCC chapters
 - c) bone, soft tissue, and testis
 - d) none of the above
8. In the analysis of lymphoid consistency:
 - a) lymphoid cancers were analyzed together with solid tumors
 - b) registrars assigned substage groups A and B more frequently than physicians
 - c) registrars left more cases with unknown stage than physicians
 - d) none of the above
9. Incomplete staging can occur when:
 - a) registrars do not have access to information kept in physician offices
 - b) the physician sees limited clinical value in staging
 - c) the physician fails to use the information available in the medical record when assigning stage
 - d) all of the above
10. Registrar CS and physician AJCC staging can be expected to yield different results because of differences in rules for using clinical and pathologic information to derive stage group.
 - a) true
 - b) false

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