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Validation of a Questionnaire for Measuring Patient Views on Their Willingness to Participate in Registries: Experience with Joint Replacement Recipients

Amanda L. Terry, PhD^a; Paul Stolee, PhD^b; Bert M. Chesworth, PhD^c;
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Abstract: The study objective was to develop a valid and reliable questionnaire to measure patients' views about health information privacy, and their willingness to participate in patient registries. Our demonstration sample included patients undergoing hip or knee joint replacements. Participants completed a self-administered mailed questionnaire. Construct validity, internal consistency, and test-retest reliability were assessed using correlation coefficients, Cronbach's alpha, and intraclass correlation coefficients, respectively. Two scales were identified: the Concern Scale and the Registry Scale. Construct validity was supported by the correlation between the Concern Scale and the Registry Scale ($r = -.63, p < .01$), confirming that respondents who were less concerned about privacy were more willing to participate in patient registries. Cronbach's alpha values for the two scales showed excellent internal consistency (.95 for Concern & .80 for Registry). Intraclass correlation coefficients were .81 for the Concern Scale and .83 for the Registry Scale.

Key words: health information privacy, psychometrics, registry, reliability, questionnaire development, validity

Introduction

The health information environment in most industrialized countries is complex and swiftly changing.^{1,2} Uncertainties about properly implementing new legislation intended for the protection of personal health information are apparent.^{3,4} Researchers are concerned about the potential negative effect on health research should access to data become more restricted.⁵ For instance, the quality of any analysis could suffer through a potential loss of sample size and the introduction of selection bias. This type of bias is a serious issue in epidemiologic research as it can make conclusions and generalizations from research invalid.⁶

Patient registries are becoming an increasingly popular research and health care tool; they are a unique source of data for health researchers.⁷ Province-wide surgical registries have recently begun to develop in Canada, for example the Surgical Wait List Registry in the Province of Saskatchewan. This type of registry represents an advanced application of information technology to enhance patient care. The Swedish Total Hip Replacement Register, created in 1979, has led to quality improvements in total hip replacement surgery, resulting in a decrease in revision surgery to 8%–9% as of the year 2000.⁸ In comparison, the proportion of hip replacement revisions in Canada captured by the Canadian Joint Replacement Registry for the fiscal year 2002–2003 was 13%.⁹ While the capability of registries to collect, store and link

personal health information is an important advantage, it can also pose greater risks to personal health information privacy.¹⁰ Potential breaches of health information privacy raise serious concerns for individuals.

Despite these concerns, little is known about the health information privacy views of individuals in general,^{7,11} and few quantitative studies about these views exist.^{12–15} Further, the factors that influence patients to give consent for the use of their personal health information are not clear.^{16–18} We identified 3 studies that examined the characteristics of individuals agreeing to participate in patient registries, none of which pertained to total hip and knee recipients.^{19–21} Attitude scales are often developed specifically for particular studies.²² Our literature search did not identify an instrument developed to measure concerns about health information privacy and willingness to participate in registries in joint replacement recipients.

We wanted to explore the views of these patients because of the development of a total hip and knee joint replacement registry in the Province of Ontario, and possible restrictions on the use of these registry data for research. We therefore set out to better understand the health information privacy views of joint replacement patients and their willingness to participate in patient registries. In this paper, we report on the development of a questionnaire used for this purpose.

"Validation of a Questionnaire for Measuring Patient Views on Their Willingness to Participate in Registries: Experience with Joint Replacement Recipients"

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The study objective was to develop a valid and reliable questionnaire to measure patients' views about health information privacy, and their willingness to participate in patient registries. Further, test-retest reliability was assessed since the questionnaire was also intended to measure patients' views over time, prior to their joint replacement surgery, and after their surgery.

Methods

The study population included joint replacement patients treated at London Health Sciences Centre, a tertiary care teaching hospital with a capacity of 744 beds in London, Ontario, Canada. Patients were eligible if they satisfied the study inclusion criteria: 1.) 50 years of age or older, 2.) had received or was eligible for a hip or knee arthroplasty at London Health Sciences Centre as of March/April 2004, 3.) was not an emergency or non-elective procedure, and 4.) was a Canadian resident. Including only patients who were 50 years of age and older ensured that the majority of individuals sampled would be undergoing joint replacement surgery due to degenerative conditions, such as osteoarthritis. Because the questionnaire was intended for pre- and post-operative evaluation, 2 groups of patients were sampled: those who were scheduled for surgery and those who had already had their surgery. Previously treated patients were listed in a billing database that permitted simple random sampling. Pre-surgery patients were sampled from a chronological list ordered by the date they were deemed eligible for surgery. To ensure that the sample was spread uniformly across the range of time that they had been waiting for surgery, a systematic random sample with a random start was employed.

As a first step in developing the questionnaire, we reviewed key documents pertaining to health information privacy.^{1,23-29} "Health information privacy refers to an individual's claim to control the circumstances in which personally identifiable health information is collected, used, and disclosed."²⁷ Accordingly, we then created questionnaire items that were related to the concepts of health information collection, use, disclosure, and identifiability. In addition, Willison's (1999) elements of personal health information protection, including stakeholders, levels of identifiability, and governance, informed development of the questionnaire items.³⁰ In addition, we developed questions related to willingness to participate in patient registries. This resulted in a questionnaire with 4 parts: Part A—Concern Scale, Part B—Registry Scale, Part C—demographic information, and Part D—joint replacement expectations and satisfaction.

Part A (Concern Scale) of the questionnaire was conceptualized within 4 domains—health information privacy, consent, governance, and registries—and measures privacy views with 47 items, each with 5-point, Likert-type response categories. Responses are summed for all items in the scale. The potential range in scores is 47 (low concern) to 235 (high concern). The health information privacy domain contained 2 general questions about the importance of health information privacy. The consent domain contained 6 questions pertaining to aspects of consent and personal control over uses of information, and 2 questions about acceptable per-

sonal health information uses and users. Because we believed responses to the latter 2 questions may have been different based on whether individuals were identifiable or not, we repeated the questions but changed the wording on the basis of the identifiability of the personal health information. A further question asked specifically about the use of grouped health care information to assess health system functioning and patient care. Within the governance domain we sought to identify the importance of laws and rules to protect personal health information with three questions. The remainder of the questions in this section dealt with health information and patient registries. Part B of the questionnaire (Registry Scale) posed 8, hypothetical "yes" or "no" consent scenarios about joining a patient registry. The responses are summed for all items, with total scores ranging from 0 (less willing to participate in a patient registry) to 8 (more willing to participate in a patient registry). We developed consent scenarios since we wanted to measure willingness to participate in patient registries and we thought that the specific context surrounding this consent decision might influence responses, for example, whether or not the registry was funded by private industry. Please see Appendix A for the questionnaire items. Additional questions in Part C of the questionnaire tapped respondent demographic information. The tested version of the questionnaire contained a satisfaction scale and expectation questions (Part D) that have been previously validated in the patient group of interest.^{31,32}

Study participants completed the questionnaire using a self-administered survey, mail-in procedure. The questionnaire was administered using a modified version of the method outlined by Dillman.³³ In order to assess test-retest reliability a second questionnaire was sent to participants 2 weeks after they returned the first questionnaire. A strong correlation between the scores from the first and second administration was expected.³⁴ Therefore, to detect a correlation of .80 or better, setting $p_0 = .60$, as a more moderate correlation, with a 5% significance level for a 2-tailed test to be conservative, and with 80% power, 52 subjects were required using the method of Kraemer and Thieman.³⁵ Response rates of 75% or greater have generally been achieved for mail surveys using a modified Dillman method,³³ therefore we adjusted the sample size upward and the questionnaire was administered to 68 potential study participants. The study received approval from The University of Western Ontario's Research Ethics Board.

To assess face validity, the questionnaire was sent to a group of experts that included orthopaedic surgeons, arthritis researchers, a patient advocate, a lawyer, and an ethicist. Responses were received from an arthritis researcher, patient advocate, and lawyer, with one respondent remaining anonymous. Face validity was also addressed in a focus group of 7 joint replacement recipients from the orthopaedic practice of one of the authors (R.B.). The expert and patient groups were asked to evaluate the clarity of instructions and objectives of the questionnaire, and the ease of completion, order, and flow of the questions. Questionnaire responses of the focus group participants were assessed for completeness. The questionnaire was revised based on input from the 2 groups.

Table 1. Participant Characteristics

Characteristic N=51	n	%*
Sex		
Men	22	43
Women	29	57
Age (yr)		
50–60	6	12
61–70	14	27
71–80	27	53
>80	4	8
No Response	0	0
Education		
Less than Grade Nine	9	18
Secondary School Without Graduation Certificate	4	8
Secondary School With Graduation Certificate	8	16
Trades Certificate or Diploma	3	6
College Without Certificate or Diploma	4	8
College With Certificate or Diploma	6	12
University Without Degree	3	6
University With Degree	14	28
No Response	0	0
Employment		
Employed	6	12
Retired	34	67
Other (e.g. looking for work)	5	10
Multiple Response	6	12
No Response	0	0
Surgery Status		
Pre-Surgery	24	47
Post-Surgery	27	53

* Percentages may not add to 100% due to rounding

A matrix was used to assess the content validity of the Concern Scale to ensure there was reasonable coverage of each domain of interest.³⁴ To assess construct validity, we evaluated the relationship between scores for the Concern Scale and the Registry Scale. Specifically, we hypothesized that respondents who were less concerned about personal health information privacy (Concern Scale) would be more willing to participate in patient registries (Registry Scale), and that the magnitude of this association would be large ($r = .5$ or greater).³⁶ Criterion validity could not be assessed because there is no comparable scale or “gold standard” with which to compare the questionnaire.

Internal consistency was evaluated using Cronbach’s alpha coefficient for the Concern Scale and the Registry Scale.^{34,37} Because the questionnaire was going to be used to measure patient views over time, test-retest reliability was determined with the intraclass correlation coefficient and a 2-week time period between repeat administrations of the questionnaire.³⁴

Results

The response rate was 51/68 (75%) of all eligible participants for the first administration. The second administration yielded a response of 39/51 or 77% (17 subjects either declined to participate or did not respond to the initial mailing, and were not sent a second questionnaire), for a cumulative response rate of 39/68 or 57%. All results presented (with the exception of the test-retest analysis) are based on data collected in the first administration.

Respondent characteristics are outlined in Table 1. Forty-three percent were men. The greatest modal age group was 71 to 80 years of age. Educational attainment was bimodal, with nearly one-fifth having less than Grade 9 and over one-quarter having a university degree. The majority of participants were retired. Respondents to the second survey administration did not differ significantly from non-respondents in terms of sex, age, and surgery status. Responders to the retest were more likely to have higher education levels and to be retired.

Table 2. Concern and Registry Scale Scores and Psychometric Data

	Mean (N=51)	SD (N=51)	Minimum— Maximum Values (N=51)	Cronbach's Alpha (N=51)	Intraclass Correlation Coefficient (N=39)	Intercorrelation Concern and Registry Scale (N=51)
Concern Scale	146.6	24.8	82–202	.95	.81	-.63**
Registry Scale	4.4	2.3	0–8	.80	.83	

** Significant at .01 level

The results of the reliability and validity analyses for the Concern and Registry Scales are outlined in Table 2. Based on a review of internal consistency scores for the original questionnaire, 2 items were removed from the Concern Scale and 4 items were removed from the Registry Scale (see note at bottom of Appendix A for details). This increased Cronbach's alpha values from .94 to .95 for the Concern Scale and from .75 to .80 for the Registry Scale. Maximum values of Cronbach's alpha are 1.0. Our results suggest that our questions are tapping the same underlying construct. Intraclass correlation coefficient scores to measure test-retest reliability were .81 for the Concern Scale and .83 for the Registry Scale. These values indicate that the scales are tapping the same underlying construct over time.

Review of input received from expert reviewers and focus group participants in the context of the analyses facilitated item clarification, rewording, and improvements in the order of questions within the questionnaire. Constructing a content validity matrix ensured the inclusion of appropriate items. The correlation coefficient between the revised versions of the Concern Scale and the Registry Scale ($r = -.63, p < .01$) supported our initial hypothesis that respondents who were less concerned about personal health information privacy would be more willing to participate in patient registries.

Discussion

In this study, the measurement properties of a questionnaire for measuring joint replacement recipients' views toward personal health information privacy, and their willingness to participate in patient registries were assessed. We studied separate representative samples of pre- and post-surgery joint replacement recipients because this method could be efficiently completed with smaller samples over a shorter period of time. A longitudinal design in which the same patients were measured pre- and post-surgery would require a larger sample size to account for cancelled and postponed surgeries.

The Concern and Registry Scales had satisfactory overall internal consistency and strong test-retest reliability.³⁴ In our assessment of construct validity, the correlation found between the Concern Scale and the Registry Scale supported our original hypothesis that respondents who were less concerned about personal health information privacy would be more willing to participate in patient registries. Study participants had strong and consistent views about privacy, consent, and registries. Respondents may have core beliefs both about privacy, and the decisions they would like to make regarding the uses of their

personal health information, such as joining a patient registry. Joint replacement is an effective treatment and recipients are routinely satisfied with their outcomes; therefore, they may have certain attitudes toward health information privacy and registry participation that may not hold true for other patient populations.^{38,39} This limits the generalizability of our findings.

In conclusion, we tested the reliability and validity of a questionnaire that examined the privacy attitudes and willingness to participate in patient registries among joint replacement recipients. This study included a specific patient population, which limits the application of this questionnaire to uses with total joint replacement recipients. However, we have produced a questionnaire with satisfactory reliability and validity that can be tested in future research with other patient groups that are likely candidates for inclusion in patient registries. The next stage of our research is to administer this questionnaire to a larger sample of joint replacement recipients in order to assess their views regarding health information privacy and participation in patient registries.

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Appendix A. Concern and Registry Scales

Concern Scale

Questionnaire Item*†‡§

1. Personal health information privacy is important to me.
2. I am concerned about the privacy of my personal health information.
3. Being able to view or get copies of the medical charts that contain my personal health information is important to me.
4. I need to be asked for my permission if my personal health information will be accessed or used.
5. Being able to correct errors in my medical chart is important to me.
6. I should be told how the privacy of my personal health information is protected.
7. It is important that I can ask to have my information from a computer database erased or deleted at any time.
8. My personal health information should only be accessed or used by the group or organization I gave my permission to.
9. The following individuals or organizations should be able to use my personal health information, if I could be identified: a) administrators (health care), b) drug companies, c) employers (if you were working), d) government insurers, e) insurance companies, f) lawyers, g) medical device manufacturers, h) medical doctors, i) medical students, j) provincial and federal health agencies, k) university health researchers.
10. The following individuals or organizations should be able to use my personal health information, if I could not be identified: a) administrators (health care), b) drug companies, c) employers (if you were working), d) government insurers, e) insurance companies, f) lawyers, g) medical device manufacturers, h) medical doctors, i) medical students, j) provincial and federal health agencies, k) university health researchers.
11. The following uses of my personal health information should be allowed, if I could be identified: a) education, b) health care administration, c) insurance purposes, d) research.
12. The following uses of my personal health information should be allowed, if I could not be identified: a) education, b) health care administration, c) insurance purposes, d) research.
13. Your personal health information can be grouped with similar information from other people. By looking at a group rather than individuals, this information can be used for different purposes. It is important that grouped personal health information be used to: a) assess the operation of the health care system, b) assess patient care.
14. It is important to me that the public has a say in decisions about how personal health information is accessed and handled.
15. Laws about the collection, use, and sharing of personal health information should be created by government.
16. I worry that without strict guidelines and rules for organizations and individuals dealing with personal health information, my information will not be safe.
17. I would be comfortable joining a registry if I knew the registry followed generally accepted rules and guidelines for personal health information.
18. It is acceptable for my personal health information to remain in patient registry forever, even after I die.
19. It is important to me to be given the choice (yes or no) to have my information included in a government sponsored patient registry (eg, the Ontario Joint Replacement Registry).
20. My permission would be needed for the Ontario Joint Replacement Registry to share my personal health information with other researchers.

* Response options = Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree

† Scale score is the sum of responses to all items

‡ Items 9 to 13, 17, and 18 were reverse coded; numbered questions reflect the final version of the scales. Deleted items include those originally numbered on the Concern Scale #20 (Clear that decision could be made to join Ontario Joint Replacement Registry), #21a (Want to be asked again to join the Ontario Joint Replacement Registry if a different surgeon performed second surgery); #21b (Want to be asked again to join the Ontario Joint Replacement Registry if the same surgeon performed second surgery)

§ Two of the questionnaire items had greater than 10% missing values. We reworded these questions in an attempt to increase clarity in future applications.

Registry Scale

Questionnaire Item*†‡

1. If you had an illness or condition that you wouldn't want to tell anyone about, would you agree to have your personal health information included in a registry for that illness or condition?
2. Would you agree to have your personal health information included in a registry if the registry was supported by private industry, for example by a company that makes drugs or medical equipment? Your information would not be accessible to this company.
3. Would you be willing to join a registry if you knew your information would be shared with private industry, for example insurance companies?
4. Would you be willing to join a registry if you knew your information would be shared with private industry, for example private research firms?
5. Would you be willing to join a registry if you knew your information would be shared with private industry, for example a company that makes drugs or medical equipment?
6. Would you be willing to join a registry if you knew that the registry would combine your personal health information with your information from other health databases (for example, a hospital patient database)?
7. Would you be willing to join a registry if you knew the registry would combine your personal health information with your information from other non-health databases?
8. There are reasons that would prevent me from joining a registry.

*Response options = Yes/No

Scale score is the sum of affirmative responses

† Item 8 was reverse coded

‡ Numbered questions reflect the final version of the scales. Deleted items include those originally numbered on the Registry Scale #2 (More likely to agree to join a registry if information in registry would benefit others), #3 (More likely to join a registry if had previously joined a different registry), #4 (More likely to join a registry if there were a financial reward for doing so), and #9 (Join registry if PHI would not be combined with any other information and only used by the registry itself).



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A Picture of Prevention: Adding Geocodes to a Trauma Registry—Methods and Applications

Mark Markarian, MD, MSPH^a; Charles C. Branas, PhD^b; Elizabeth Snavelly, BA^c;
Deborah Kuhls, MD^a; Jay Coates, DO^a; John Fildes, MD^a

Abstract: Background: As populations grow and new demographic subsets establish themselves, so to does the need to better serve these communities. Trauma systems and emergency responders have used geo-depiction models to better isolate and identify the areas they serve. Such mapping allows for better identification of patient injury distribution, opportunity for specific injury prevention, and further development of trauma management. Methods: Separate data sets including individual addresses, intersections, and general locations were converted to data points and subsequently mapped, either by manual entry or initial conversion to geocodes. Results: Data sets were depicted in demographic maps. Conclusion: Geocodes serve as useful tools in mapping demographics served by specific trauma systems and provide a convenient method of communicating information on regional and national levels.

Key words: Federal Information Processing Standards (FIPS) codes, geocodes, Geographic Information System (GIS), trauma registry

Introduction

A trauma registry is a disease-based data file that is rich in information regarding patient demographics, physiologic changes, diagnoses, and severity of illness. Trauma registries also include geographically referenced data elements. They involve various levels of geographic aggregation such as states, counties, ZIP codes, and addresses. These can be converted to geocodes that describe location in terms of latitude and longitude. Geocodes are then utilized to spatially describe trauma registry data by conversion into a graphical format such as mapping. This is a powerful tool that allows individual trauma centers to analyze patient flow, patient location at time of injury, and injury patterns, and that provides an opportunity for injury prevention programs and trauma system development.

As population demographics change and steadily grow, trauma systems face the responsibility of recognizing the changing needs of the community they serve, and adjust or augment resources accordingly. Such organization is critical in our immediate region of Southern Nevada. Serving a steadfastly growing population, our trauma system has utilized a spectrum of care that includes sending out emergency responders, working closely with trauma registry personnel, and utilizing county Geographic Information System (GIS) analysts to better identify demographics served and those in need of further attention by utilizing geo-depiction models.

The objective of this paper is to describe a method used to add injury location and home location to the trauma registry data file. In addition, it will show maps depicting patient and system issues. A hierarchy of geographic infor-

mation exists; patients in a trauma registry can be grouped by individual countries, states, or provinces. Increased resolution would include grouping patients by county or city. Within a city, individual zip codes, Federal Information Processing Standards (FIPS) codes, and district lines could be used to group patients geographically. Adding latitude and longitude provides the highest level of resolution for geographic grouping. Adding geocodes to the trauma registry file means that each patient file would contain the latitude and longitude in degrees, minutes, and seconds for their injury location and their home location.

A number of terms will be mentioned in this article. Geocodes, as mentioned earlier, refers to a hierarchy of information that includes zip codes and FIPS codes, converted into latitude and longitude, to be used for mapping illustrations. Many definitions of GIS have been suggested over the years, such as “a container of maps in digital form,” “a computerized tool for solving geographic problems,” and “a tool for performing operations on geographic data that are too tedious or expensive or inaccurate if performed by hand.”¹ The United States Geological Survey defines GIS as a computer system capable of assembling, storing, manipulating, and displaying geographically referenced information, ie, data identified according to their locations. Practitioners also define GIS as including the procedures, operating personnel, and spatial data that go into the system. Trauma registry is defined as a disease-specific data collection composed of a file of uniform data elements that describe the injury event, demographics, pre-hospital information, diagnosis, care, outcomes, and costs of treatment for injured patients.² FIPS codes are a standardized

“A Picture of Prevention: Adding Geocodes to a Trauma Registry—Methods and Applications”

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set of numeric or alphabetic codes issued by the National Institute of Standards and Technology (NIST) to ensure uniform identification of geographic entities through all federal government agencies. The entities covered include: states and statistically equivalent entities, counties and statistically equivalent entities, named populated and related location entities (such as, places and county subdivisions), and American Indian and Alaska Native areas.³

Methods

Home addresses and injury locations were obtained from emergency medical service (EMS) run records. Two custom data fields were created for longitude and latitude. District lines were also obtained and utilized by fire department personnel, tracked on run reports.

Trauma registry personnel initially located addresses on local county maps and corresponding latitude and longitude coordinates were manually entered into a database utilizing BusinessMAP Pro. The following data points were used with the prefix H and S, applied to latitude and longitude, corresponding to *Home* and injury *Scene* information, respectively—HLAT, HLONG, SLAT, and SLONG. Data points utilized positive or negative, 10-digit integer fields, separated by periods, corresponding to degrees, minutes, and seconds. For example, University Medical Center is located at 115.10.30. x 036.09.30.

Information was then transferred to the Clark County GIS office for conversion into geocodes and subsequent mapping. Databases were managed using Microsoft Excel 2000, and addresses were converted to geocodes by utilizing

the Environmental Systems Research Institute (ESRI) application ArcInfo 9.0. ArcGIS 9.0 was utilized for mapping.

Three different types of information were processed –transport time, type of injury, and location. Location was either converted to geocodes or manually entered. Two other forms of data—intersections and general locations such as mile markers—were then processed. General locations and highway mile markers were also manually entered and mapped. Overall, approximately 85% of records were converted utilizing geocodes. Approximately 10%–15% of geocodes were not obtained secondary to invalid addresses from EMS records, misspellings, and other miscellaneous errors.

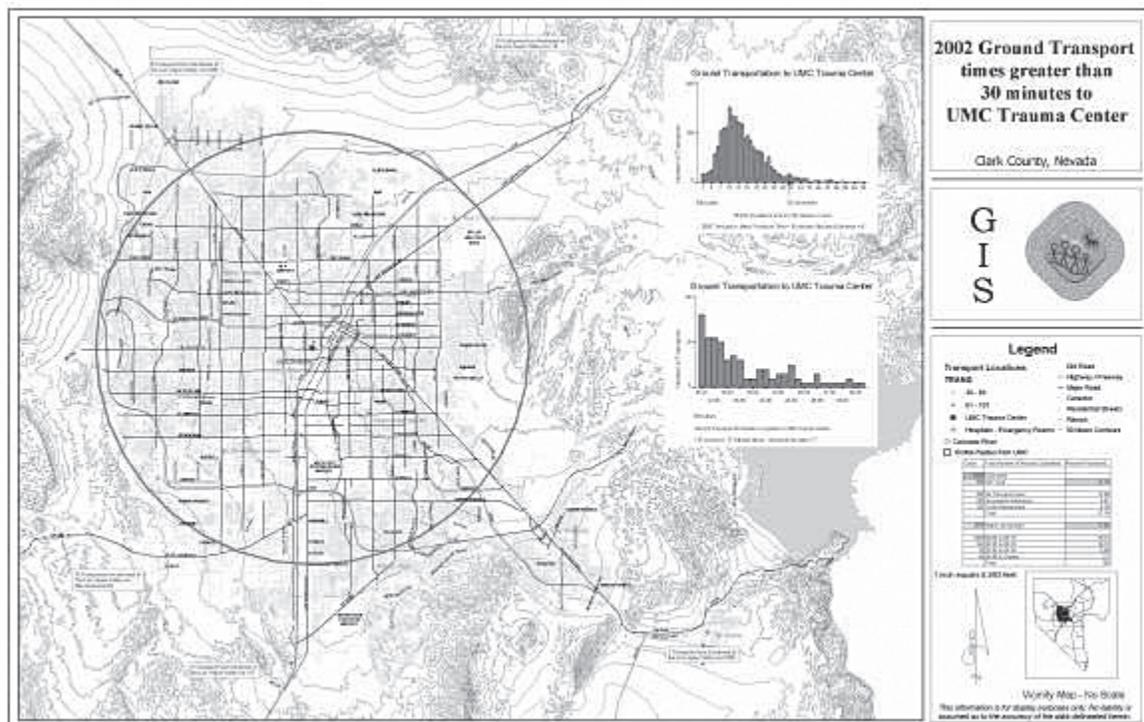
Results

A number of maps were obtained that represent compilations of different data entered and processed by personnel at the trauma registry and GIS offices. Below is a sample map that depicts ground transport times greater than 30 minutes to the trauma center.

Discussion

Trauma care involves the continuum of public health and prevention, pre-hospital care, resuscitation, surgery, critical care, convalescent care, rehabilitation, and final outcome. Geocodes can be applied and utilized for targeted interventions at each component of this continuum, from injury prevention to outcomes measurement.⁴ Although 10%–15% of geocodes were not obtained in our study due to incomplete information on EMS run records, this will change with the widespread use of National Emergency Medical Services Information Systems (NEMSIS) compliant

Sample Map That Depicts Ground Transport Times Greater Than 30 Minutes to the Trauma Center



databases by pre-hospital personnel. Considerable time will be saved utilizing NEMESIS and we can also expect a higher yield of geocode conversions once this newer convention is established among EMS personnel. This convention stresses the utility of different pieces of information on EMS run records that would be used in geocodes conversion.

Geocodes have been useful with a number of applications. We have used injury location to locate patients with ground transportation times less than (or greater than) 30 minutes, pedestrians struck by cars at specific intersections, gun-shot wounds, stab wounds, and traumas involving kids of car-seat age.

Geocodes have also been utilized to look at home location of patients. Applying geocodes coordinates lends itself to targeted interventions, for example, home addresses were obtained for kids of car-seat age (who were secured in car seats at the time of trauma); car seats were subsequently donated to local church or civic centers.

Another geocodes application involved the Department of Transportation, which utilized data to located dangerous intersections and took steps to improve road conditions. Highway fatality rates were also monitored using GIS.⁵

Future applications could include better characterizing after-school injuries by looking at a demographic such as children of kindergarten and elementary age involved in accidents in afternoon hours, approximately 2:00–4:00 PM. Other applications involve impact analysis of demographic gaps—information can be gathered to elucidate geographic areas of concern (or gaps) that need better access to emergency care, eg, either a heli-pad or a new trauma center.

Geocoding and mapping facilitate trauma centers to better aggregate data at the local, state, and national levels. This can only serve to improve trauma systems, allow us to locate areas that may be underserved, and subsequently help shape public policy to provide trauma centers the opportunity to better compare outcomes with a standardized tool that may be used regionally and nationally. Such information can be used to justify institutional and financial support of needed personnel and capital expenditures.

Another consideration involves patient privacy and Health Insurance Portability and Accountability Act (HIPAA) concerns. We recognize that geocodes may be so specific that they may serve as a “unique patient identifier” and disclose valuable patient information, such as home location, which may in turn compromise HIPAA regulations. An approach to dealing with this issue would be to put latitude and longitude points into increasingly larger levels of geographic aggregation (ie, block groups, census tracts, and ZIP codes) and then to instead map these aggregates to de-identify patients and preserve confidentiality.

Conclusion

The purpose of this article is to describe a methodology used to add latitude and longitude to patient records in a trauma registry. This output was used to create maps, which depict a variety of trauma center activities and trauma system functions. The use of GIS in individual hospitals, or

state and regional trauma registries, is a powerful method for analyzing acute care and system planning.

Adding GIS technology to our trauma registry has only served to facilitate patient care, and we look forward to customizing this new tool for future endeavors involving the entire spectrum of the trauma system.

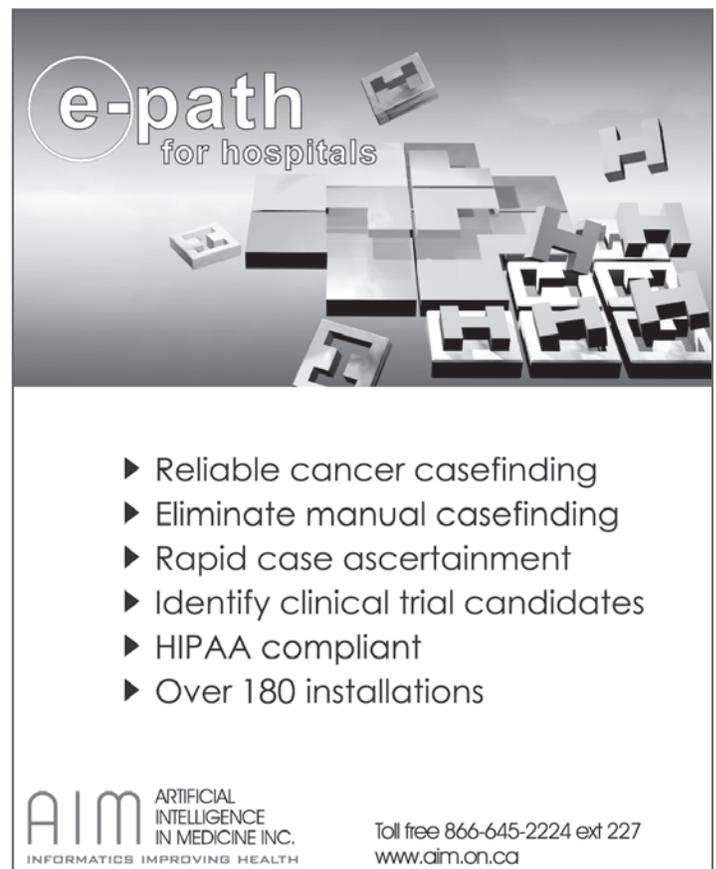
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- Rose Broderick, GIS analyst at Clark County, Nevada GIS Management Office

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Development of a Web-based Case Reporting, Management, and Communication System for the Statewide Birth Defects Registry in New York

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Abstract: A Web-based reporting, data management, and communication system has been successfully developed by the staff of the New York Congenital Malformations Registry (CMR) and implemented with the collaborative efforts of CMR staff and the medical records personnel of the reporting hospitals in New York. By January 2006, the CMR has converted all reporting hospitals statewide from a manual, paper-based reporting system to the Web-based system. This new system provides a platform-independent environment for data submission, retrieval and analysis and offers a secure, cost-effective solution for participating hospitals. An authorized user can submit/edit data and view, update, or query case information dynamically from the CMR's database using any personal computer equipped with an Internet browser from any geographic area throughout the state. This innovative system enables CMR staff to review and perform quality assurance on every report submitted and to communicate with the hospitals online with regards to submitted reports.

Key words: case reporting, communication, congenital malformations registry, data management, Web-based

Introduction

The Congenital Malformations Registry (CMR) of the New York State Department of Health (NYSDOH) is one of the largest statewide, population-based birth defects registries in the nation. Since 1982, over 180 hospitals in New York have participated in a mandatory process of reporting children who are born or reside in New York and are diagnosed before the age of 2 years with reportable birth defects. Using the passive method of reporting with an active follow-up case tracking system,¹ the CMR annually receives birth defects reports for more than 10,000 children of New York state residents, which comprise 4% of all live births.

From 1982 to 1998, the only method available to report birth defect cases to the CMR was a paper-based reporting system, ie, the use of a standard report card that needed to be filled out by hospital staff for each child and then mailed to the CMR. CMR staff, then, manually entered the reports into a computerized database system. This reporting process had several disadvantages such as data entry errors due to the illegibility of the handwritten report cards and delays in receiving reports. Moreover, filling in the cards by hand or a typewriter and then submitting the reports to the CMR had been perceived as an extra burden on the reporting hospitals.

In 1998, in an attempt to reduce this reporting burden and to improve the completeness and timeliness of the reporting, CMR staff worked with hospitals' medical records personnel and software vendors to promote electronic

reporting through the New York Statewide Planning and Research Cooperative System (SPARCS). This system was used because New York hospitals were already required to submit hospital discharge data through SPARCS. From 1998 to 2005, 27 hospitals reported cases to the CMR through SPARCS. However, the reports submitted by these hospitals comprised only about 10% of the total cases reported to the CMR. Problems CMR staff encountered in implementing the SPARCS reporting system were mainly limited to the programming difficulties and resources needed to create a new data processing system.² Moreover, after evaluating the data quality of the reports submitted by hospitals using SPARCS, it was found that some information required by the CMR such as narrative diagnoses and birth and maternal variables was missing in as many as one-third of the reports (CMR unpublished data).

Since the beginning of the 21st century, Web-based event reporting systems have been developed and implemented by researchers in academic and medical environments around the world to facilitate the efficient collection of information from multiple geographically-dispersed organizations.³⁻¹³ In order to improve the completeness and usefulness of public health surveillance and the timeliness of reporting and response to outbreak of disease, the Centers for Disease Control and Prevention has worked with states and local health departments since 2000 to develop and implement Internet-based disease reporting systems. As of April 2005, a total of 27 states were using a secure, Internet-based sys-

"Development of a Web-based Case Reporting, Management, and Communication System for the Statewide Birth Defects Registry in New York"

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tem for entry of notifiable disease reports.¹⁴ Recently, the Virginia Congenital Anomalies Reporting and Education System started to receive hospital reports through the Virginia Infant Screening and Infant Tracking Program, a Web-based tracking and database system.¹ In addition, some state birth defects surveillance programs such as New Jersey and Washington are currently developing Web-based birth defects reporting systems.¹

In late 1990's, the NYSDOH developed an Internet-based communications infrastructure—the Health Provider Network (HPN)—to provide highly secure and efficient exchange of reporting, surveillance, statistical, and general information with its public health and health provider partners, using the powerful Internet Secure Sockets Layer (SSL) encryption technology. Since 2001, CMR staff has been exploring the possibility of reporting hospitals submitting cases to the CMR using NYSDOH's HPN system. The objective of this project was to develop an interactive Web-based case reporting, data management, and communication system using NYSDOH's HPN to facilitate effective data collection and review processes to improve the accuracy, completeness, timeliness, and quality of the birth defects registry data.

Methods

System architecture: The system architecture includes several high-performance servers including the Web server, the application server, and the database server. The Web server controls users' access and directs inputs and requests from users' browsers to the Web application server which

hosts the CMR's Web applications. The application server provides the user interface and accepts data submitted by an authorized user. The database server enables the users to store and retrieve registry information. The CMR data is stored in a relational database system residing on the database server.

System security: The security system consists of security protocols that limit access to the servers, firewall facilities that enforce access control policies between networks, and authentication procedures ensuring that only authorized users can access the services and the services/application screens for which they are authorized. This system ensures information confidentiality, integrity, and availability. That is, the information submitted by the reporting hospitals is not accessed by an unauthorized person, is protected from unauthorized modification, and is available when needed by the authorized users.

Web applications: The CMR's Web applications with rich user interfaces were developed using Web development tools, including JAVA, PERL, and Dreamweaver. Structured Query Language (SQL) was used in the Web application programs for authorized users to view, update, or query case information dynamically from the CMR's database using a regular Web browser.

SAS/IntrNet,¹⁵ the newly-developed software that functions as Web services and runs on top of the CMR server, was used to develop Web applications for users to search and retrieve hospital's data submitted online, generate real-time reports, and perform simple statistical analysis using the CMR's databases.

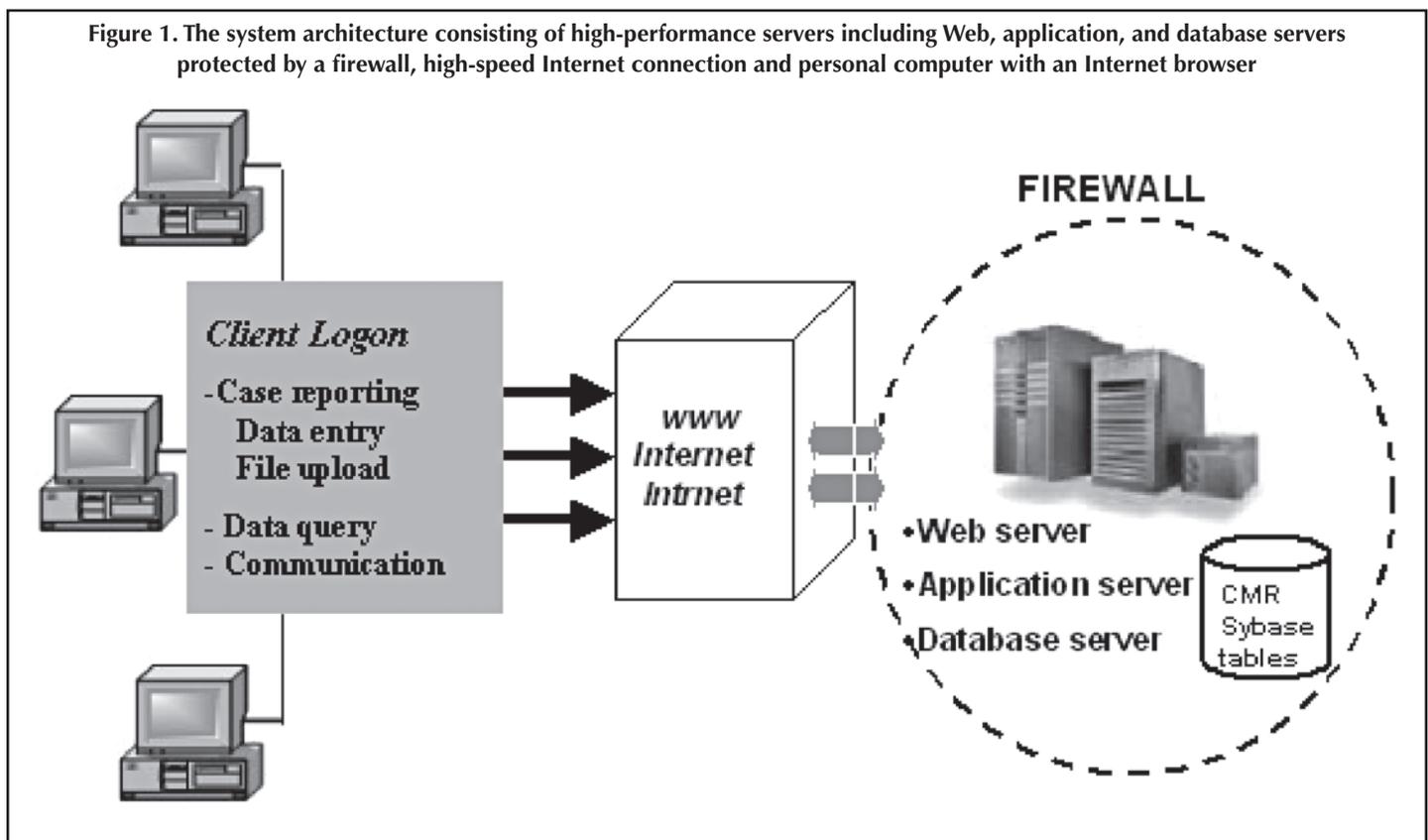
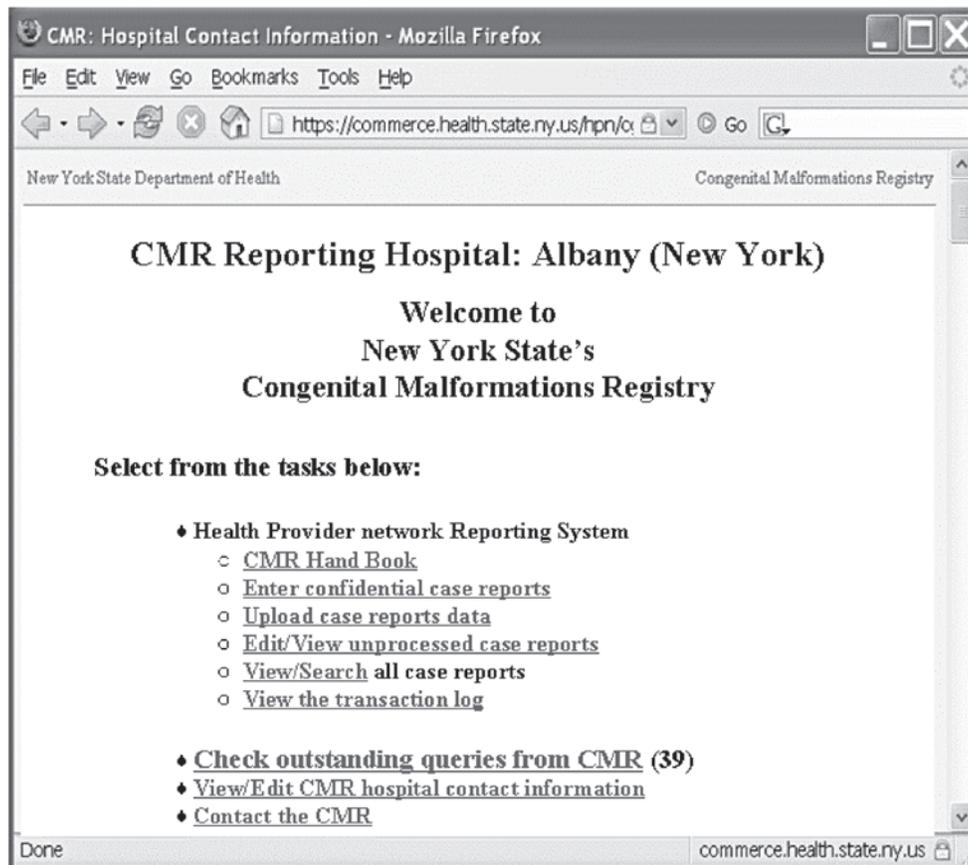


Figure 2. The Web-based applications of the New York CMR: data reporting, data management, and communication system—the main menu



Results

Over the past several years (2002–2005), a Web-based case reporting, data management, and communication system for the statewide birth defects registry in New York has been developed and implemented using NYSDOH's HPN. In 2002, 5 hospitals started to submit cases using our newly developed, Web-based data entry utility (the only online application developed then). By January 2006, 100% of all 164 reporting hospitals submitted reports to the CMR through this Web-based reporting system. The system architecture is shown in Figure 1. An authorized user, such as NYSDOH staff or hospital medical records personnel, can submit/edit data and view, update, or query case information dynamically from the CMR's database using any personal computer equipped with just an Internet browser from any geographic area. Figure 2 shows the CMR's Web-based applications, the main menu, including data reporting, data management, and communication between CMR staff and hospital users. In addition, an online handbook prepared by CMR staff was added to the main menu to provide hospitals and physicians with complete information for submitting case reports to the CMR.

Case Reporting

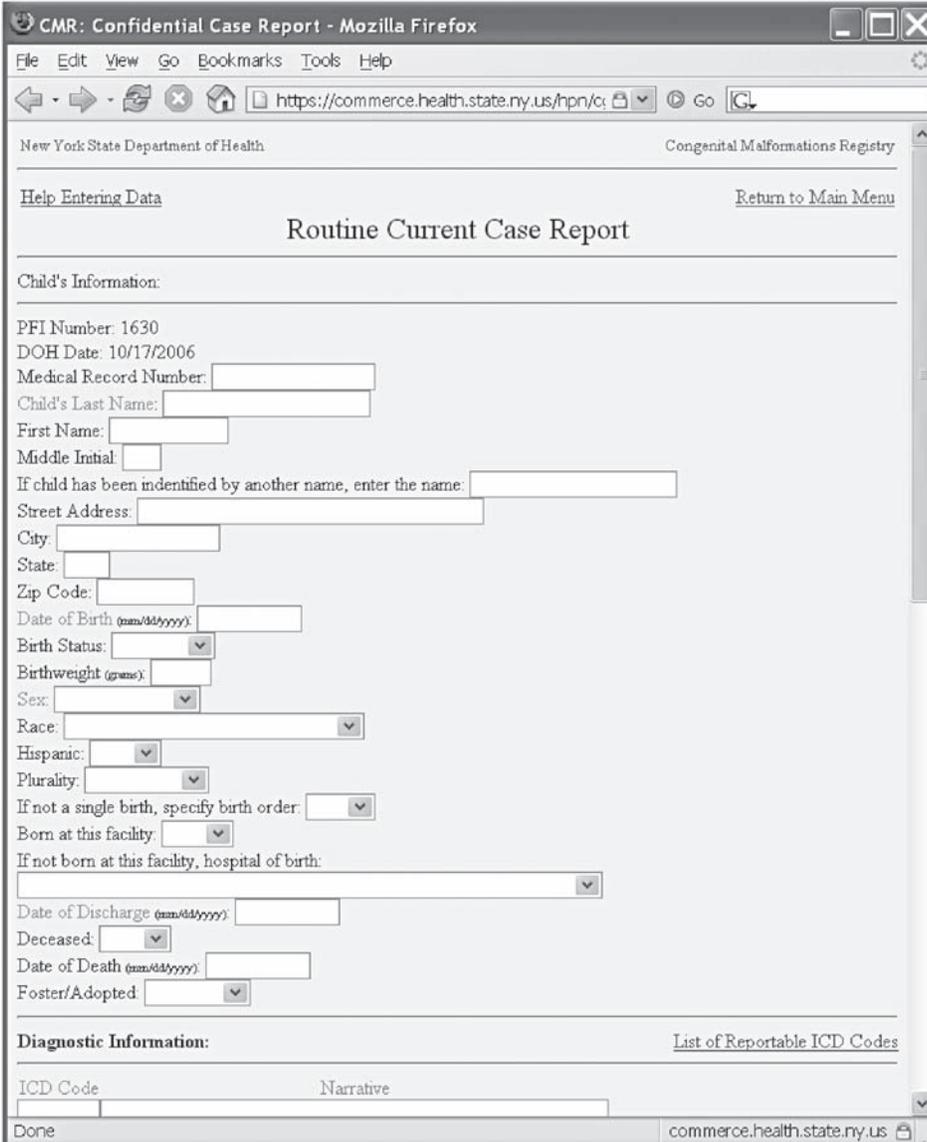
The Web-based case reporting utility provides 2 options for the users: manual online data entry of individual reports or data file upload of a batch of reports (Figure 2). The manual online data entry function allows users to submit reports

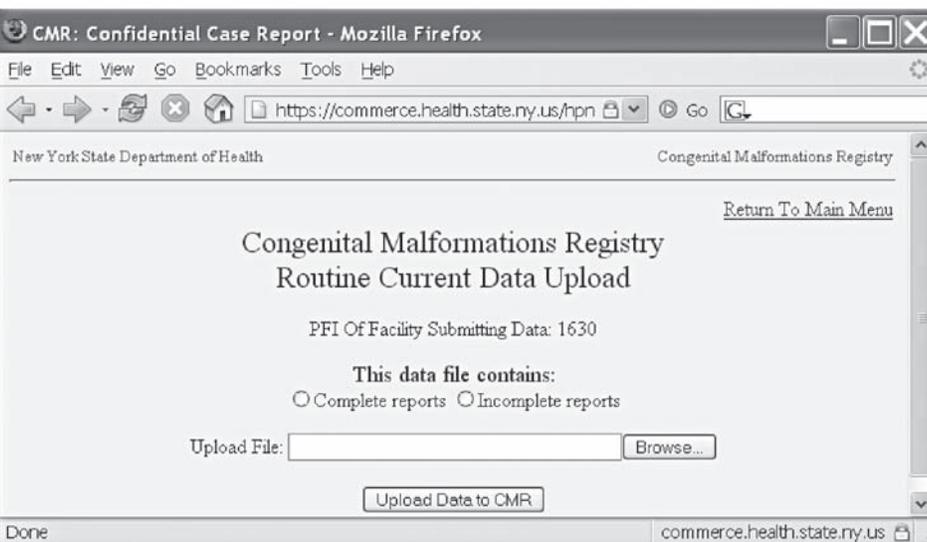
using a fully customized online data entry form (Figure 3A). An online help system was built into the data entry form to assist users in entering the data fields correctly, for instance, using appropriate data type and range.

Data validation functions were also built into the data entry form for validating the values entered by the users. The data validation rules ensure that the required fields are entered and a user's input conforms to a certain standard for each selected data field such as data type and range. Data is verified as it is entered into the system and is not accepted or forwarded to the next field until it is correct. To avoid data entry errors, drop-down lists were built-in for certain fields to allow users to select values instead of typing.

The file upload utility allows hospitals to send, at regular intervals, batch files containing cases collected via their own information technology (IT) system to the CMR Web server through the data submission process. The user's IT department needs to be involved in data preparation according to a specific required data file format and file type for transferring data to the CMR. Either complete or incomplete data may be uploaded to the CMR server (Figure 3B). The records with missing or incomplete diagnosis and narratives are defined as incomplete reports. The hospital users need to view these incomplete reports and add the appropriate narratives manually using CMR's online editing facility: the "Edit/View Unprocessed Case Reports" function on the main menu (Figure 2).

Figure 3. The Web-based case reporting system of the New York CMR: (A) a screen shot of the manual data entry form, using a Web browser (note: not all fields in the data entry form are shown here) and (B) a screen shot of data entry form for file upload

(A) 

(B) 

Data Management

Extended editing capabilities were developed for both CMR staff and users of reporting hospitals to check completeness and correctness of the entered/uploaded records stored in the database table. Staff from reporting hospitals can search, view, and edit the reports submitted by their own hospitals (Figure 2). In addition, the users can also view the transaction history of each case reported for their specific hospital using a function button built into the data management system.

Data management utilities were developed specifically for CMR staff to routinely check the quality of the submitted reports. For instance, if the required information for a reported case is missing or there is an error in the entered fields, then an update indicator will be set to "No" by clicking one of the function buttons. The system update function, new reports retrieval and update, enables CMR staff to routinely retrieve unprocessed (new) reports with complete case information and add them to the CMR's database tables. Each added report is checked against existing reports using the auto-match function and duplicate reports are removed.

Communication

Web-based communication utilities were developed for CMR staff and hospital users to communicate online via the Web browser or e-mail. These innovative functions allow CMR staff to notify an institution immediately if a specific case report has an unspecified diagnosis or lacks information, and allows for submission of this additional information. As shown on the main menu in Figure 2, the function button "Check outstanding queries from CMR" is in a relatively large font in order to catch the user's attention. The number in the parenthesis indicates the total number of outstanding queries. If a user clicks the link, a list of the reports that need additional information will appear in a new screen (Figure 4A). A CMR information request form is linked to each report so that the user is able to review the information of the original case report and then respond to the questions right on the query form (Figure 4B). The majority of queries that are sent to hospitals are requesting specificity for narratives that are too general to clearly identify a malformation or requesting chromosome study results or karyotype to confirm chromosomal anomalies.

The users can also view and update their own facility's contact information by using the "View/Edit CMR hospital contact information" function as shown on the main menu (Figure 2). Moreover, secure contacts between hospitals and the CMR were made available by simply clicking a function button on the main menu, "Contact the CMR," which connects to the CMR's group e-mail system.

Report Monitoring

The developed online SAS/IntrNet applications empower the users to search and retrieve hospital submitted cases, generate real-time reports, and perform simple statistical analysis using the CMR's database. For instance,

the users can select a reporting hospital and discharge years of interest and then generate a real-time report table which lists the number of cases by discharge year and month (Figure 5). By reviewing this report, CMR staff is able to see if the hospital has been submitting an appropriate number of cases routinely or if the hospital stopped or skipped reporting for certain months or years. On the other hand, hospital users can query, view the cases, and generate a report using the data submitted by their own facilities.

Discussion

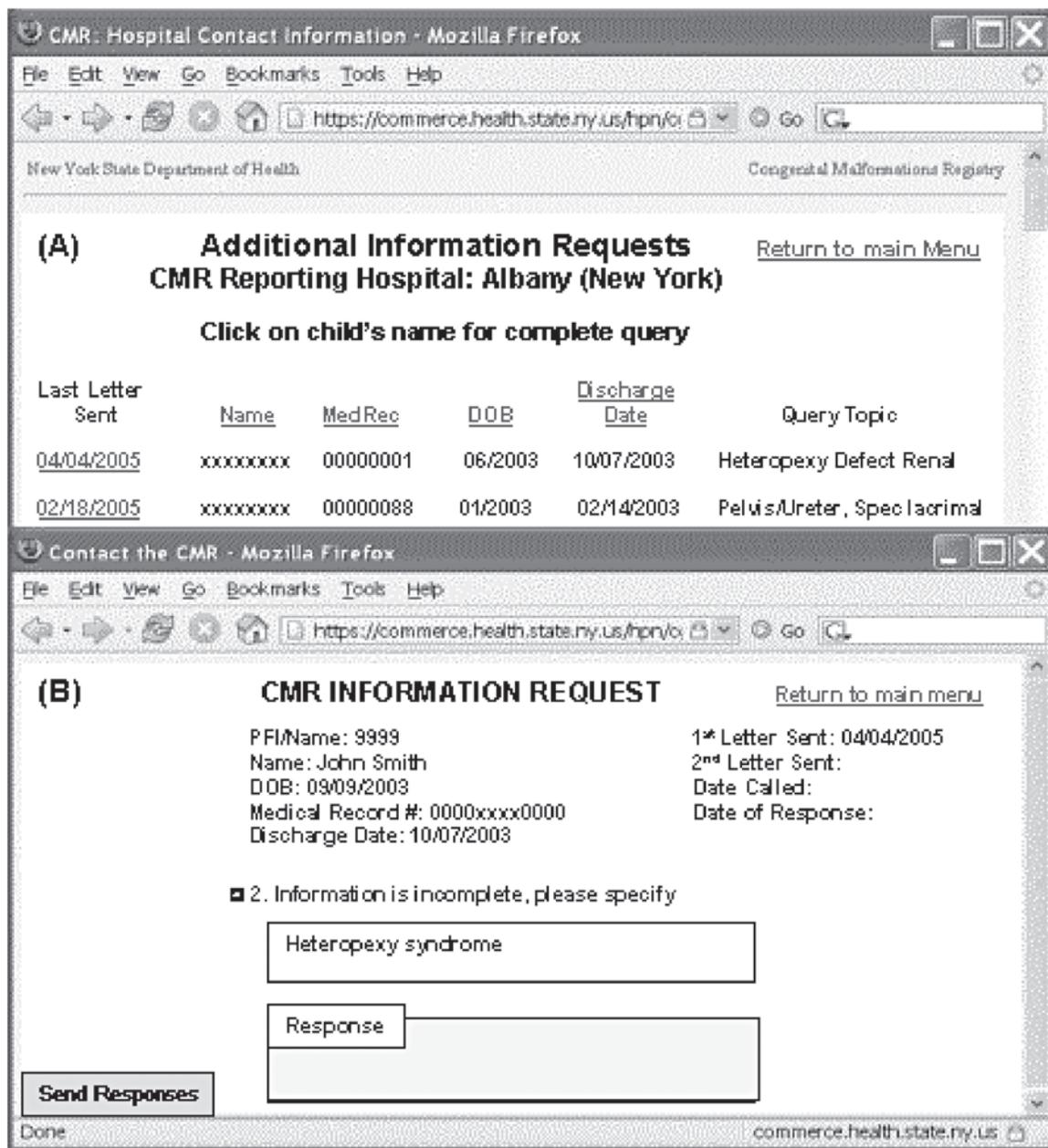
An in-house Web-based reporting, data management, and communication system has been successfully developed by CMR staff and implemented with the collaborative efforts of CMR staff and medical records personnel of reporting hospitals in New York. This system provides a platform-independent environment for data submission, retrieval, and analysis and offers a cost-effective solution for participating hospitals. The online data entry and file upload capabilities transform the user's computer into an efficient workstation to submit data rapidly and accurately without the need for additional, special hardware and with minimum technical assistance from CMR staff. Moreover, the structured data entry and file upload applications permit validity checks for data quality, prompting the user for complete case information and, thus, improving the completeness and accuracy of the data.

In the past decade, the Internet has become a powerful and effective tool for disease surveillance, information retrieval and exchange, and communication. Studies have shown that Web-based electronic reporting has improved the timeliness and completeness of disease surveillance data.^{11,14,16-20} The implementation of a flexible and user-interactive, Web-based reporting system in New York has promoted an increase in the number of reports submitted by hospitals using this new system. This has resulted in better compliance and more timely submission of birth defects cases. CMR staff is currently evaluating the impact of the implementation of the Web-based system on the timeliness, completeness, and effectiveness of case reporting to the CMR.

The implementation of this Web-based system allows CMR staff to review and perform quality assurance on every report submitted before adding it to the database. This innovative system also enables CMR staff to communicate with reporting hospitals faster and more effectively about the submitted cases. Utilization of the system's online query/communication tools dramatically increased the number of responses from the hospitals, decreased the turn around time for updating case information, and, therefore, improved the data quality of the CMR. An investigation with quantitative analysis of the effects of the online Web-based communication on improving the data quality of the CMR is underway.

The SAS/IntrNet tools built into the Web-based system have made the monitoring of hospitals' case reporting more effective and much easier. Based on the computer-generated

Figure 4. The Web-based applications of the New York CMR: online communication (information query and response) between CMR staff and the hospital users. (A) A list of the reports that need additional information; (B) CMR information request and hospital response form

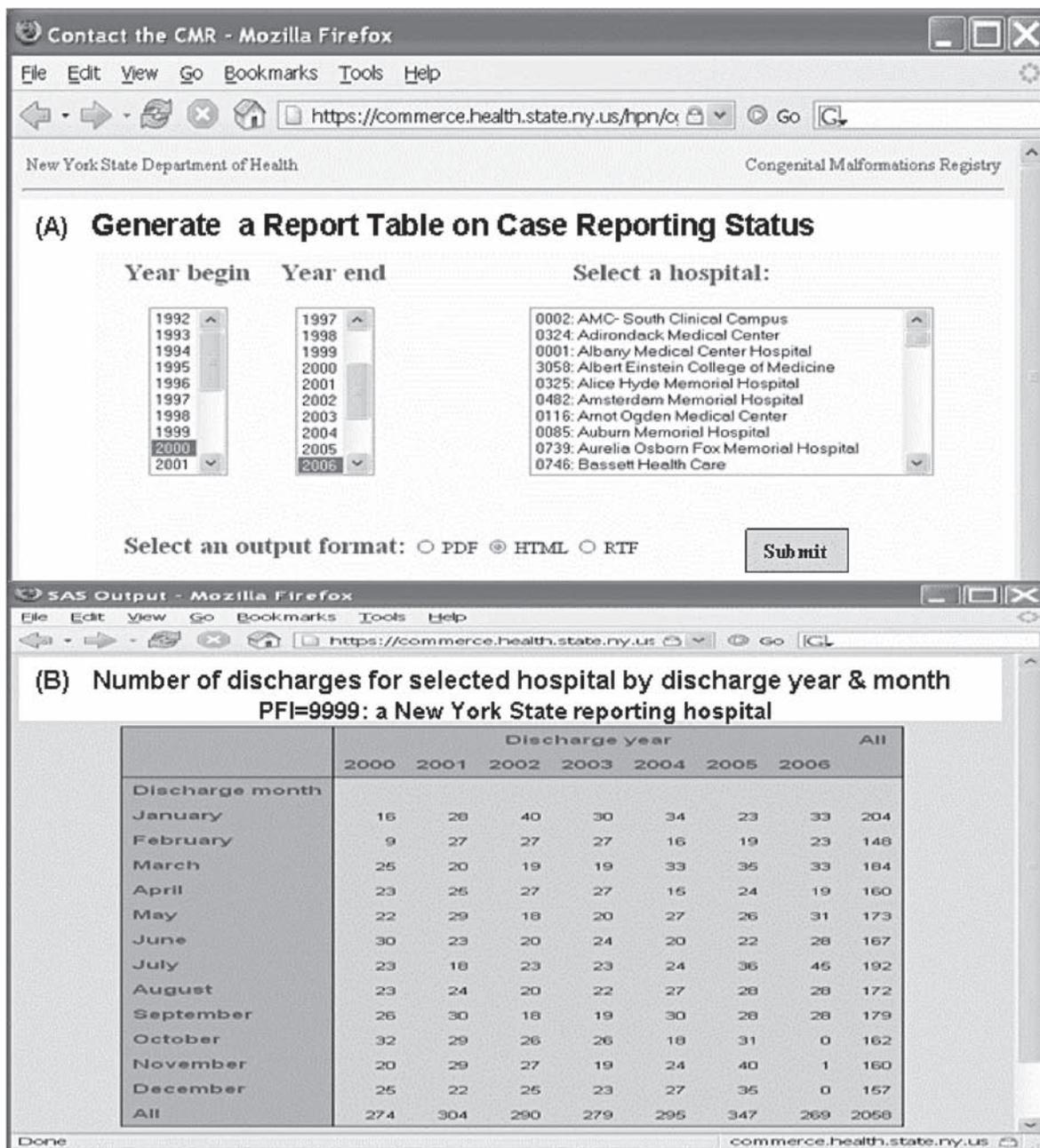


reports, CMR staff are able to check the status of reporting and identify and contact the hospitals with low reporting rates. CMR staff are currently developing new applications to improve and expand the system and verify and improve data quality.

It should be noted that, although the use of Web-based applications has many benefits and advantages, there are some drawbacks. For instance, although it occurs infrequently, server or network downtime due to technical problems cannot be avoided and sometimes interrupts the routine operation of the system. Moreover, the file upload utility on the CMR's Web-based reporting system requires a data file to be prepared in a fixed data format. If a user tries to upload a

dataset containing field(s) with a format that is incompatible with the required one, the upload process will be interrupted and the Internet browser will generate error messages that rarely identify the specific cause. CMR staff have worked on modifying the file upload program to make it more flexible in handling data in as many different formats as possible. In addition, the built-in data validation functions in the online data entry application check the data type and range of specific data fields and, thus, greatly reduces data entry errors. However, this online reporting system is not error-proof. CMR staff are currently developing Web-based data quality assurance and quality control applications as ongoing efforts to improve the data quality of the registry.

Figure 5. The Web-based applications of the New York CMR: an SAS/IntrNet application. (A) Report generating form for selecting hospitals and discharge years; (B) A real-time report table which lists the number of cases by discharge year and month for a selected hospital



In conclusion, the Web-based reporting system provides a platform-independent environment for data submission, retrieval, and analysis and offers a secure, cost-effective solution for participating hospitals. An authorized user can submit/edit data and view, update, or query case information dynamically from the CMR's database using any personal computer equipped with an Internet browser from any geographic area throughout the state. Moreover, this innovative system enables CMR staff to review and perform quality assurance on every report submitted and to communicate with the hospitals online with regards to submitted reports.

Acknowledgment

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How-to and Why: Managing Tumor Board Images— A Comparison Between Picasa™ and ThumbNailer

Richard H. Siderits, MD, FCAP^a; Stacy L. Yates, CTR^b; Wilfredo C. Causing, MD^a; Janusz J. Godyn, MD, FCAP^{a,b}

Abstract: One of the most challenging and potentially time consuming aspects of weekly Tumor Board presentations is managing the many images that can accumulate on your computer. This is especially true if the images are kept for future inclusion in a “look-back” type of case presentation. We have identified and compared 2 software programs that facilitate image management for the oncology registrar. The programs are quick to learn, easy to use, inexpensive, and reliable. It is possible to conveniently manage large image collections with many sub-folders using Picasa™, while ThumbNailer is used to create a multi-page, indexed online Web-page version of the image archive. This paper describes the step-by-step process for configuring and running each of these programs and compares the relative advantages and disadvantages of both.

Key words: Picasa, ThumbNailer, tumor board

In a previous publication we described the “Tumor Board Toolbox” which permitted the coordination of online educational materials for weekly Tumor Board presentations.¹ We have been using this approach, with success, for more than 3 years and have acquired over 2000 Tumor-board related (macroscopic organ and histologic) images. Each week we add new images from our presentation cases to the archive. It became clear fairly early on that we would need to have a way to conveniently manage increasingly large collections of teaching images. These images were not only used inside of the weekly PowerPoint® presentations, but also kept separately for use as a global archive of Tumor Board images. Having them available in one archive permits us to use the images in different ways, eg, to collect images for comparison of tumors in a given organ system, to create sub-collections for residency training programs, or to have the images available in a searchable format for “look-back” case presentations.

To accomplish these capabilities we have identified 2 different programs. The first is a shareware program called “ThumbNailer” offered by the Smaller Animals, Inc. software company.² The second is the freely downloadable program Picasa 2™ available from Google, Inc.³ Both programs will automatically import all images from a file folder and both will create an Internet-ready set of Web pages that show thumbnail sized versions of the images. The user clicks on the small image to see the same image at full resolution. There is no need to learn HTML coding or to manage the Web-page version of the image collection in any special manner.

So what are the differences between these 2 programs? ThumbNailer can recreate the folder structure that the images are stored under. That means the parent folder and the sub-folders of images that it contains. For example if you

have images in a folder on your computer called “Tumor Board Images” and the images are divided between 2 sub-folders called “Macroscopic images” and another folder called “Histology images” then the ThumbNailer program can recreate the subfolders in the Web-page version so that you can click on either collection of subfolder images (Macroscopic or Histologic) in order to view the images in the selected folder. The other difference between the 2 programs is that the ThumbNailer program can create multiple Web pages as an output for the online version, whereas Picasa can only generate one Web page with all of the images listed on that one page. This is not the best approach if your image collection has more than 500 images.

So, why use the Picasa program? The advantage of Picasa is that it is very easy to keep track of images in sub-folders because you can see them in the Picasa program. It is also very easy to batch rename an entire directory of images with a case number or add text for searching for specific images in the entire collection. The “Timeline” function in Picasa also makes it easy to find images by date-added. This shows a graphic representation of a timeline for all folders in the image collection. The program can also automatically scan for any new images in the Tumor Board image folders or anywhere on your computer. The Picasa program allows you to crop and enhance images as well as add explanatory text. As a matter of fact, it can be used to save the Web-page version of the images in a slide show format that can be used as a weekly Tumor Board presentation instead of using PowerPoint®.

In the following paragraphs we outline the procedure for our weekly archive update. However, there are several variations in using this approach that could well suit your institution. We begin by gathering images from several sources to be used in each Tumor Board presentation. Some

“How-to and Why: Managing Tumor Board Images—A Comparison Between Picasa™ and ThumbNailer”

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Figure 1. ThumbNailer main configuration page showing input and output directory

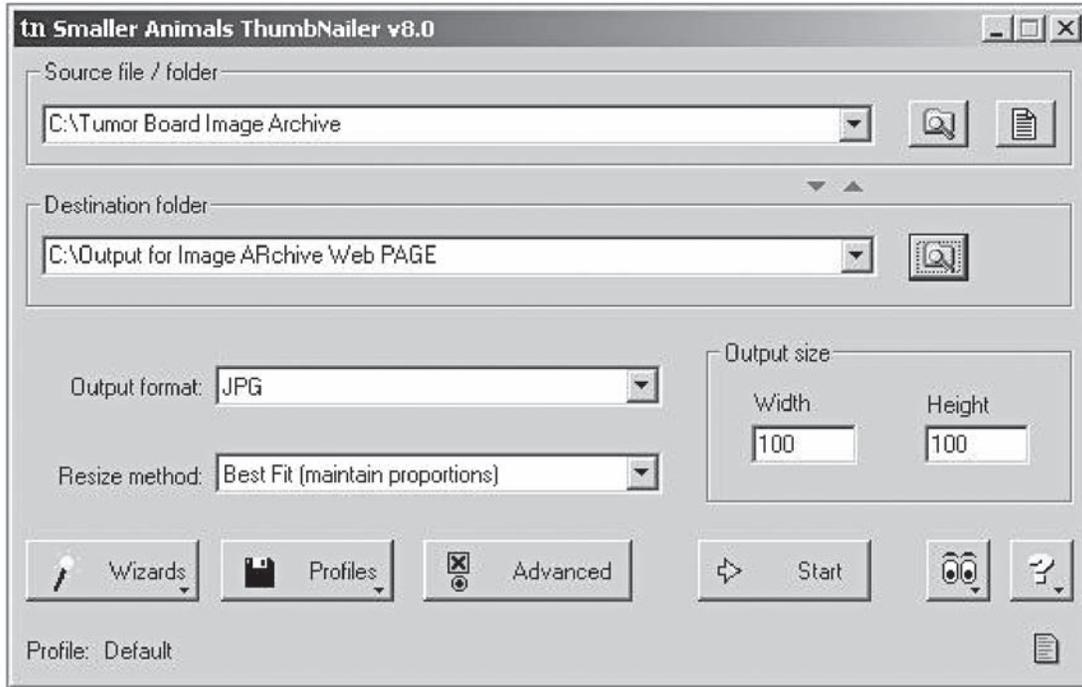


Figure 2. Picasa 2 showing images and folders



of the images come from the surgical, pathology-grossing table using a hand held digital camera or the digital camera on the pathologist's microscope. Others come from diagnostic imaging and include x-rays, CT scans, bone scans, PET images, and ultrasound studies. Still more images include charts, graphs, or schematics used to illustrate a point during a presentation. These may be scanned into the computer from reference texts using a flatbed scanner or obtained using Internet resources with image "saves."

Next we empty the camera chips or transfer saved images into a file folder on the computer. The folder is generally named with the date of the presentation and exists as a subfolder in our "Tumor Board" parent folder. The images are then batch named using Picasa with the date of the presentation (since there are several different cases in each presentation). This allows the program to automatically sort the images by date of the presentation according to the filename. We then review the images and crop them as needed or add explanatory text as a caption. Once the images have been renamed and are in their own folder, ThumbNailer can automatically create a multi-page, online image archive which not only separates the individual folders of Tumor Board images but also combines the new folder with all previous folders of all previous presentations. In short, either program can be assigned an input directory corresponding to the folders where the grouped images are kept, and an output directory for the Web-page version that is accessible over the hospital Intranet or from outside the hospital over the Internet.³ ThumbNailer can make this even more convenient by setting the auto-run preference to automatically generate a new

image archive at a specific time each week. Since the program can save a profile of preferences, any changes in the format or file structure are automatically incorporated into the new archive without having to start from scratch.

For our system, the preferences for the Web page are automatically saved and subsequently loaded when the program starts. The ThumbNailer program automatically creates an indexed html set of Web pages that are sent to the directory that our Tumor Board Toolbox uses to reference the image archive.

A comparison of the strengths and weaknesses of each program are listed below.

Picasa 2: Strengths and weaknesses

- 1) Can write folders of images directly to Web page version
- 2) Is ideal for small collections of images
- 3) Can be used *as* weekly Tumor Board presentations instead of PowerPoint®
- 4) Has timeline view to see images by date
- 5) Features convenient naming, batch renaming, and deletion
- 6) Can tag images with key words for searching
- 7) Feature cropping and image enhancement
- 8) Can create CD with viewing software on CD
- 9) Weaknesses include single page Web output format with no direct image editing in program. However, it is possible to open the image in your favorite image editor from inside Picasa by right clicking on the image and selecting "Open with" then choosing your favorite image editor. This will allow you to add text to the image as well as image annotation (circles and arrows).

Figure 3. Timeline view of image folders in Picasa 2

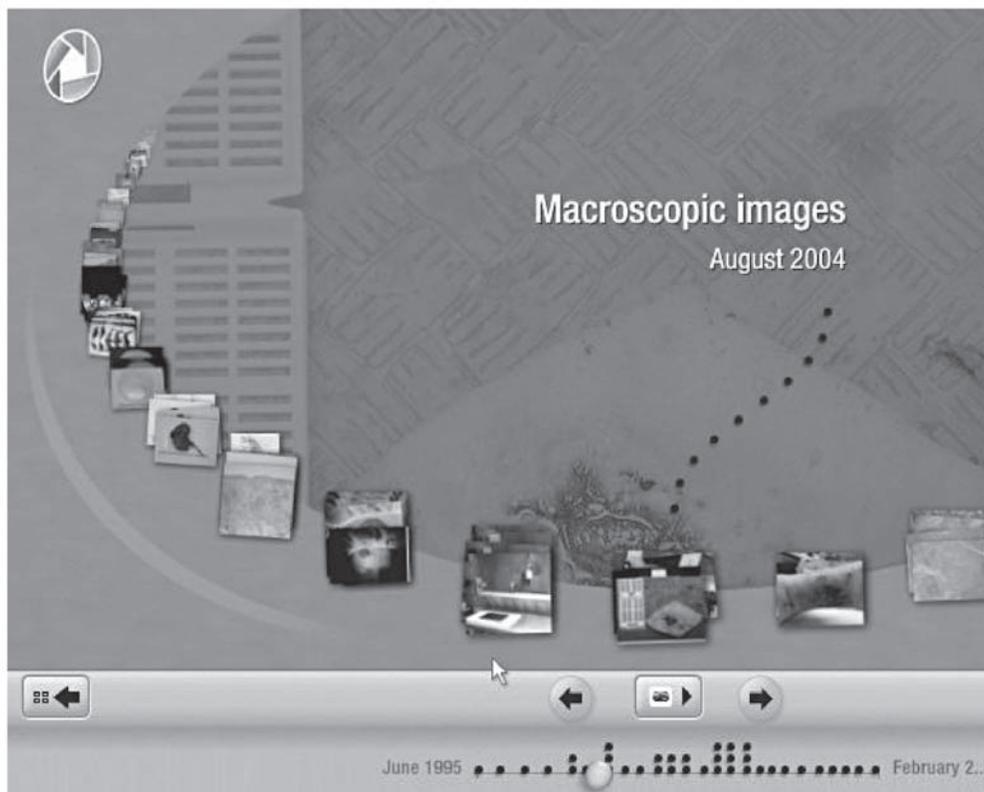
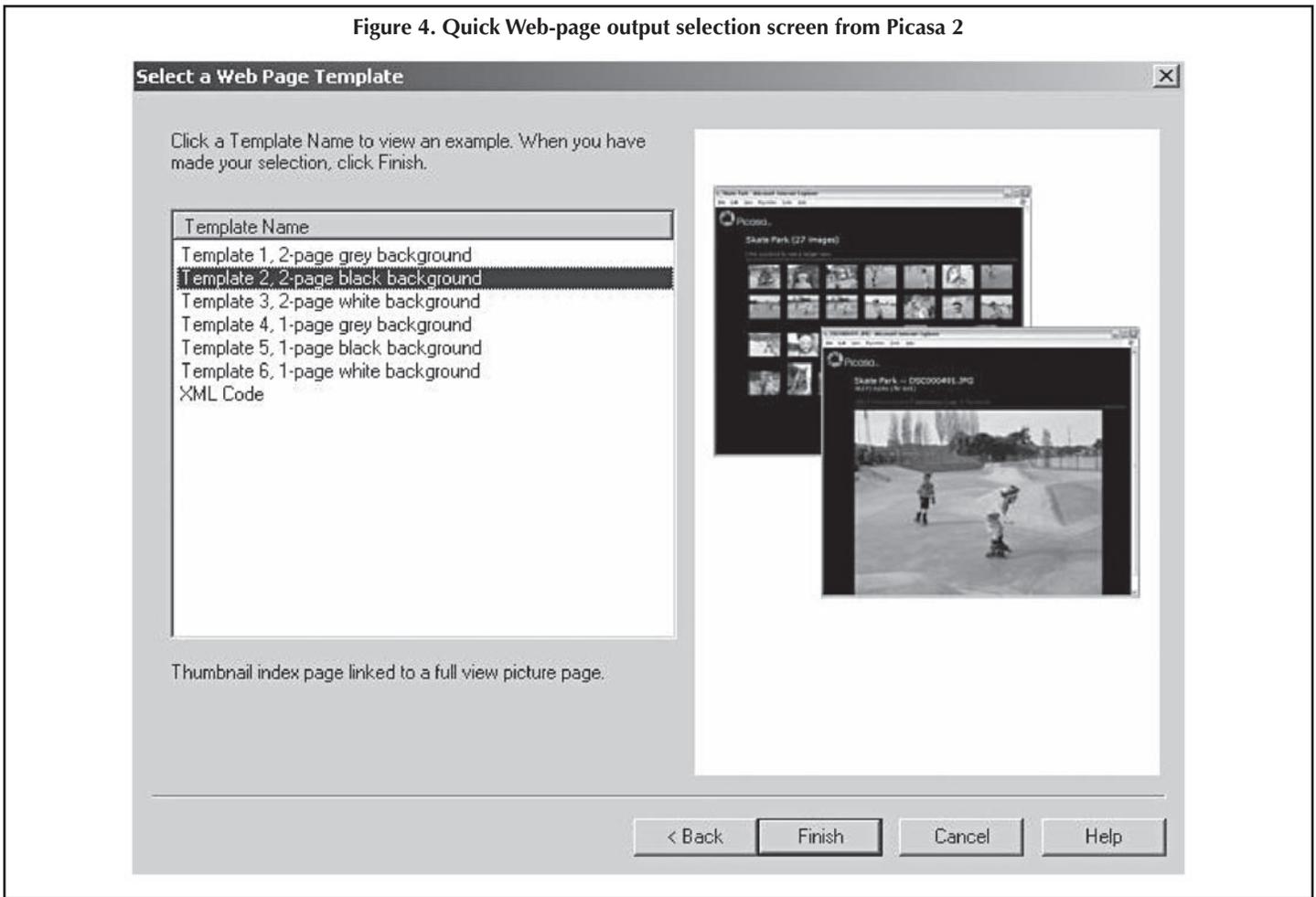


Figure 4. Quick Web-page output selection screen from Picasa 2



ThumbNailer version 8.0: Strengths and weaknesses

- 1) Can be set to run automatically at a given time each day or week
- 2) Is good for very large collections of images (500–2000)
- 3) Supports multiple Web page output format
- 4) Supports customizable number of rows and columns of images per page
- 5) Features automatic [next-previous and first-last] buttons for navigating
- 6) Recreates subdirectories so image folders can remain separate on computer
- 7) Features very flexible html formatting for personalizing the online image archive
- 8) Weaknesses include no image viewer and no direct image editor in program

Discussion

Managing the many images that can accumulate in association with a weekly Tumor Board conference can be challenging and time consuming. It's easy to let folders in your computer or on our hospital system fill up with images and to forget what they were named or where they were put. It can be inconvenient to keep up with naming the images so that they can be recognized easily when you need to find them for a "look-back" case. Using image archiving or an image management software program is a good solution.

There are many image programs available today and they range in price from absolutely free to hundreds of dollars. We have compared 2 programs that can help conveniently manage images for a Tumor Board program.

Both Picasa and ThumbNailer are quick to learn, easy to use, inexpensive (or free), and do what they are designed to do reliably and reproducibly. Each has specific advantages although neither has significant disadvantages. We have used both programs and have found that together they can provide for most any image management need, including the creation of year-end CD image collections.

It is possible to conveniently manage large image collections with many sub-folders using Picasa, while using ThumbNailer to create a multi-page, indexed online Web-page version of the image archive running automatically once a week.

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The Cancer Legal Resource Center—A Place for Cancer Patients, Health Care Providers, and Others Coping with Cancer

Herman R. Menck, Editor

The *Journal of Registry Management (JRM)* met with Barbara Schwerin, Esq, founder of the Cancer Legal Resource Center (CLRC) to increase registrar's knowledge regarding the legal needs of cancer patients. The CLRC is a joint program of the Disability Rights Legal Center and Loyola Law School in Los Angeles, California. It was established in 1997 and has become a thriving national program providing information, education, resources, and referrals on a national level. The Editor was inspired by the intent and outreach of the program.

JRM: Why was the CLRC started?

Schwerin: While there was medical and psychosocial support for people with cancer, there was no place for them to turn for cancer-related legal issues. We first conducted a needs assessment, contacting many cancer organizations in the Los Angeles area, including UCLA, John Wayne Cancer Institute, City of Hope, Norris Cancer Center, and the American Cancer Society. The health care providers were uniformly enthusiastic. We also conducted a survey with The Wellness Community, West Los Angeles and confirmed that patients were also looking for a resource. We designed the model with input from the community, working on the supposition that if the community had a hand in designing the CLRC, the community would use the CLRC. It was based on an education model, not a litigation model.

JRM: What types of cancer-related legal issues arise?

Schwerin: The CLRC works with people with numerous issues. The top 3 categories for cancer-related legal issues are:

1. Employment
 - a. A person is recently diagnosed and needs information on working with their employer while they go through treatment;
 - b. A person starts receiving negative employment evaluations after disclosing their medical condition;
 - c. Someone has lost their job and requests information on what options, if any, are available for them; and
 - d. A person is going back into the work force and needs information on what they need to disclose, or not disclose.
2. Health Insurance
 - a. Getting health insurance and keeping it
 - b. Navigating through managed care
3. Government Benefits

JRM: What other issues arise?

Schwerin: Other cancer-related legal issues that come up regularly are:

1. Estate Planning Issues
 - a. Advance Directives, powers of attorney
 - b. Wills and trusts
2. Family Law Issues
3. Financial Assistance/Consumer Issues
4. Immigration
5. Real Estate
6. Landlord/Tenant
7. Disability Insurance/Life Insurance

JRM: What is the relative call volume?

Schwerin: Since its inception, the following breakdown of percentage of calls for certain issues has remained relatively constant:

Employment	14%
Government Benefits/Disability	12%
Health Insurance	
Navigating through Managed Care	10%
Getting and Keeping Health Insurance	11%
Immigration	4%
Estate Planning Issues	6%
Failure to Diagnosis/Delayed Diagnosis	6%
Financial Concerns	15%
Other	32%

JRM: What does the CLRC do?

Schwerin: The CLRC has a 3-pronged approach. First, there is the Telephone Assistance Line which received 3107 calls in 2004 and 3165 calls in 2005. The Telephone Assistance Line is staffed primarily by advanced law school students under the supervision of CLRC staff attorneys. There are approximately 12-15 students per semester. It is a unique, 2-tiered educational model using a clinical externship program for the law students. The students educate the callers about different laws, and at the same time are themselves educated about the laws and the dynamics of people facing life crises.

Second, the CLRC is very active in the cancer community. This provides for face-to-face contact in different venues. In 2005, the CLRC presented 65 substantive legal programs at cancer support groups, conferences, and continuing education programs for health care providers, reaching over 1500 people. Over 7300 additional people were reached through 45 other activities in the cancer community, including health fairs, Komen Race for the Cure, the Leukemia and Lymphoma Society Light the Society, and American Cancer Society activities.

So far in 2006, the CLRC has received over 3000 calls to its Telephone Assistance Line, conducted 89 substantive legal trainings reaching over 1500 people, and participated in 74 other activities in the cancer community, reaching almost 13000 people.

Finally, the CLRC relies upon its Pro Bono Panel of attorneys and other professionals. The CLRC does not represent anyone or provide any legal advice. However, sometimes callers to the CLRC need more information. The Pro Bono panel does this, helping with drafting wills, contacting insurance companies, and working with callers so they can negotiate with their employers. The attorneys on the Pro Bono Panel have various areas of specialty and are located throughout the United States.

JRM: Where do the calls come from?

Schwerin: Although initially a local program, over the years the CLRC has received a large percentage of its calls from outside of California. In 2002, 45% of the calls to the Telephone Assistance Line were outside California, in 2003, 50% were from outside California, 2004 had 60% of its calls from outside California, and in 2005, the CLRC received 57% of its calls from outside of California.

JRM: How are the calls handled?

Schwerin: Advanced law school students are the "front door" to the program and handle the calls to the CLRC's Telephone Assistance Line. All of the calls are supervised by

CLRC staff attorneys. Resources are provided to the callers, along with information on the relevant laws. The CLRC does not provide legal advice, but can provide valuable information to meet the caller's needs. When appropriate, the caller is referred to an attorney on the CLRC's Pro Bono Panel.

JRM: What are the goals of the CLRC?

Schwerin: The CLRC strives to foster an informed patient and caregiver base through education and support. This knowledge hopefully leads to an empowerment model so that a person can advocate for him/herself or a loved one.

For health care providers and other professionals, the goals are for them to understand and be sensitive to the legal rights of cancer patients and the issues they face, identify cancer-related legal issues facing specific clients, and learn what help is available, so that they can assist their patients by guiding them through the system or referring them to the CLRC.

For assistance or more information, please contact:

Cancer Legal Resource Center
919 Albany St.
Los Angeles, CA 90015
919 Albany St., Los Angeles, CA 90015-1211
telephone: (213) 736.1455
toll-free #: (866) THE-CLRC
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Changes in ICD-9-CM Casefinding Codes for Reportable Neoplasms

April Fritz, RHIT, CTR

Last year at a fall meeting, I picked up a list of new ICD-9-CM codes that took effect for Fiscal Year 2007 reimbursement. When I couldn't find that list, I asked for help from members of the NCRAMember Yahoo! Groups online discussion group. I was pleased with the response—I received 3 different lists from various parts of the country. Thank you to the registrars who responded and otherwise sent comments. (If you haven't joined the discussion group, I recommend it! Go to YahooGroups.com and search for "NCRAMember.") Those lists, plus the original one that I eventually found in the wrong folder, indicate that many organizations and state central registries try hard to stay on top of coding changes in the health information department. Unfortunately, none of the 4 documents were complete. This column is an attempt to provide some discussion of the changes and a comprehensive list of the new and existing codes for the registry community—hopefully in time for end-of-year casefinding.

The ICD-9-CM coding changes for health information (medical record) diagnoses were published by the Centers for Medicare and Medicaid Services (CMS) last year and became effective for healthcare encounters and discharges October 1, 2006 and after. More than 200 diagnosis codes were added; overall, there were more than 340 code changes. In a trend toward greater specificity of codes, there were important changes in the coding of many clinical conditions. In particular, the coding of hematopoietic diseases and other blood disorders was substantially changed. The former code 238.7—neoplasm of uncertain behavior of other lymphatic and hematopoietic tissues—has been greatly expanded, and many reportable blood diseases previously coded in non-specific categories have been assigned their own codes.

Of greatest importance are the refractory anemias and cytopenias, which had been mixed in with various types of anemia. These diseases have been moved from 284.9 and 285.0 (unspecified aplastic anemia and sideroblastic anemia, respectively) to specific, expanded, 5-digit codes under 238.7. This means that the refractory anemias are now recognized as neoplasms of uncertain behavior rather than generic diseases of blood and blood-forming organs—a significant step in reconciling the malignant behavior codes that these diseases carry in ICD-O-3 with the way they have been coded in the *International Classification of Diseases*. In my opinion, this is a very good step forward. Table 1 shows the new codes, the former codes for these diseases, the corresponding ICD-O-3 morphology codes, and my comments about the changes.

The added clarity for the refractory anemias and refractory cytopenias will help registrars who use the facility diagnosis index for casefinding, because they will no longer have

to sift through many non-reportable diagnoses in 284 and 285 to find the reportable cases. However, it will still be necessary to screen charts for myelofibrosis cases. Although myelofibrosis was given its own ICD-9-CM code (289.83) to distinguish it from primary or idiopathic myelofibrosis (238.76, in the hematopoietic malignancy section), all cases in code 289.83 should be reviewed, since it is possible that a coder might have coded a reportable case to myelofibrosis, NOS.

Another clarification has been published regarding GIST (gastrointestinal stromal tumors). An exclusion note has been added to the codes for malignant neoplasm of stomach and malignant neoplasm of small intestine saying that malignant stromal tumor of either of these organs should be coded to 171.5, malignant neoplasm of connective tissue and other soft tissue. It is good that GIST has been recognized as a distinct entity somewhere in ICD-9-CM; however, a registrar would code *malignant* GIST of the stomach or small intestine to the involved organ, rather than to soft tissue, since the tumor arises in the muscular layer of the organ rather than in the surrounding soft tissues. Borderline stromal tumor of the digestive system has been added to 238.1, neoplasm of uncertain behavior of connective and other soft tissue.

If a registry is accessioning carcinoma *in situ* of cervix as a reportable-by-agreement diagnosis, it is important to note that cervical intraepithelial glandular neoplasia (CIN) has been added as a synonym of 233.1 cervix carcinoma *in situ*. This will require a little extra screening also, since the various grades of CIN are not distinguished. There is yet another new code—795.06—that should be reviewed for “cytologic evidence of malignancy without histologic confirmation”—in other words, a positive Pap smear without tissue.

Because of the discrepancies in various reportable lists that exist around the country, a comprehensive list is needed. Table 2 shows the codes that must be screened for reportable diagnoses effective with October 1, 2006 encounters and discharges. This list has also been posted on the Surveillance, Epidemiology, and End Results (SEER) Program Web site at http://training.seer.cancer.gov/module_icdo3/icd_o_3_lists.html. If you request a computer printout of the cancer diagnoses from your facility's diagnosis index as a casefinding mechanism, give this list to your information technology (IT) person. Make sure the IT department knows to *add* the new codes and *delete* the previous codes so you won't have to screen through frequently used codes that no longer contain reportable diagnoses. Also, check that the casefinding programs supplied in your registry software apply these changes as soon as possible.

While we are on the subject of screening for reportable cases, several new codes have been added to ICD-9-CM that would be useful for screening for possible cancer cases, assuming that the registrar has the time to review cases with these codes. Screening for these codes also assumes that a case would not have more readily identifiable diagnosis or procedure codes such as a primary reportable neoplasm in the 140 to 209 range. Table 3 lists various diagnosis and procedure codes that *should* be screened as time allows.

And of course, changes in the ICD-9-CM hematopoietic diseases codes also necessitate an update of the case-finding codes in SEER's Abstracting and Coding Guide for the Hematopoietic Diseases. Table 4 is an errata (the second) to the "red heme book." This list has also been posted on the SEER Web site at <http://seer.cancer.gov/tools/codingmanuals/>.

Space in this issue does not permit discussion and listing of a series of new procedure codes that are often used for cancer treatment. If you are interested in using these codes for screening reportable cancer cases, please contact me directly.

April Fritz, RHIT, CTR
CEO, A. Fritz and Associates, Reno, NV

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

Resources

1. "Know the October 2006 ICD-9-CM Changes: Part 1 Diagnosis Codes" in *Advance for Health Information Professionals*, October 9, 2006, pages 12-14.
2. "ICD-9-CM Changes Make a Big Impact" in *Advance for Health Information Professionals*, October 9, 2006, pages 28-33.
3. *Abstracting and Coding Guide for the Hematopoietic Diseases*, SEER Program, National Cancer Institute. NIH Publication 03-5146, reprinted September 2003.
4. *ICD-9-CM Tabular List of Diseases Addenda Effective October 1, 2006 (FY07)*. Available at: http://www.cdc.gov/nchs/datawh/ftp/ftp9/icdtab_addenda07.pdf. Accessed April 10, 2007.
5. *International Classification of Diseases for Oncology, Third Edition*, Fritz AG, et al., World Health Organization, 2000.
6. ICD-9-CM reportable lists shared by registrars on NCRAMember discussion list (<http://health.groups.yahoo.com/group/NCRAMember>)

Table 1. New ICD-9 Heme Codes, Old ICD-9 Codes, and Corresponding ICD-O-3 Morphology Codes

From: ICD-9-CM TABULAR LIST OF DISEASES ADDENDA
Effective October 1, 2006 (FY07)
(my comments in italics)

238.7	Other lymphatic and hematopoietic tissues <i>(This code ceases to exist. All terms moved to new codes.)</i>
Delete	Disease: <ul style="list-style-type: none"> lymphoproliferative (chronic) NOS <i>(moved to 238.79)</i> myeloproliferative (chronic) NOS <i>(moved to 238.79)</i> Idiopathic thrombocytopenia <i>(moved to 238.71)</i> Megakaryocytic myelofibrosis <i>(moved to 238.79)</i> Myelodysplastic syndrome <i>(moved to 238.75)</i> Myelofibrosis with myeloid metaplasia <i>(moved to 238.76)</i> Panmyelosis (acute) <i>(moved to 238.79)</i> Refractory anemia <i>(moved to 238.72)</i>
Add	Excludes: acute myelogenous leukemia (205.0)
Add	chronic myelomonocytic leukemia (205.1)
Revise	myelofibrosis (289.83) <i>(code change)</i>

New code	238.71 Essential thrombocythemia <i>(was 238.7; 9962/3)</i> <ul style="list-style-type: none"> Essential hemorrhagic thrombocythemia Essential thrombocytosis Idiopathic (hemorrhagic) thrombocythemia Primary thrombocytosis
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New code	238.72 Low grade myelodysplastic syndrome lesions <ul style="list-style-type: none"> Refractory anemia (RA) <i>(was 284.9; 9980/3)</i> Refractory anemia with ringed sideroblasts (RARS) <i>(was 285.0; 9982/3)</i> Refractory cytopenia with multilineage dysplasia (RCMD) <i>(was 238.7; 9985/3)</i> Refractory cytopenia with multilineage dysplasia and ringed sideroblasts (RCMD-RS) <i>(was 238.7; 9985/3)</i>
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New code	238.73 High grade myelodysplastic syndrome lesions <ul style="list-style-type: none"> Refractory anemia with excess blasts-1 (RAEB-1) <i>(was 285.0; 9983/3)</i> Refractory anemia with excess blasts-2 (RAEB-2) <i>(was 285.0; 9983/3)</i>
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New code	238.74 Myelodysplastic syndrome with 5q deletion <i>(was 238.7; 9986/3)</i> <ul style="list-style-type: none"> 5q minus syndrome NOS Excludes: constitutional 5q deletion (758.39) <i>(not reportable)</i> high grade myelodysplastic syndrome with 5q deletion (238.73)
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Table 1. New ICD-9 Heme Codes, Old ICD-9 Codes, and Corresponding ICD-O-3 Morphology Codes (continued)

From: ICD-9-CM TABULAR LIST OF DISEASES ADDENDA

Effective October 1, 2006 (FY07)

(my comments in italics)

New code 238.75 Myelodysplastic syndrome, unspecified *(was 238.7; 9985/3, 9989/3)*

New code 238.76 Myelofibrosis with myeloid metaplasia *(was 238.7; 9961/3)*

Agnogenic myeloid metaplasia

Idiopathic myelofibrosis (chronic)

Myelosclerosis with myeloid metaplasia

Primary myelofibrosis

Excludes: myelofibrosis NOS (289.83)

myelophthistic anemia (284.2) *(not reportable)*

myelophthisis (284.2) *(not reportable)*

secondary myelofibrosis (289.83)

New code 238.79 Other lymphatic and hematopoietic tissues

Lymphoproliferative disease (chronic) NOS *(was 238.7; 9970/1)*

Megakaryocytic myelosclerosis *(was 238.7; 9961/3)*

Myeloproliferative disease (chronic) NOS *(was 238.7; 9960/3)*

Panmyelosis (acute) *(was 238.7; 9931/3)*

284.9 Aplastic anemia, unspecified *(not reportable)*

Revise Excludes: refractory anemia (238.72) *(Refractory anemias should no longer be coded in 284.9)*

285 Other and unspecified anemias *(not reportable)*

285.0 Sideroblastic anemia

Revise Excludes: refractory sideroblastic anemia (238.72) *(Refractory anemias should no longer be coded in 284.9)*

New code 289.83 Myelofibrosis

Myelofibrosis NOS

Secondary myelofibrosis

Code first the underlying disorder, such as:

malignant neoplasm of breast (174.0–174.9, 175.0–175.9)

Excludes: idiopathic myelofibrosis (238.76)

leukoerythroblastic anemia (284.2) *(not reportable)*

myelofibrosis with myeloid metaplasia (238.76)

myelophthistic anemia (284.2) *(not reportable)*

myelophthisis (284.2) *(not reportable)*

primary myelofibrosis (238.76)

289.89 Other specified diseases of blood and blood-forming organs

Delete ~~Myelofibrosis~~ *(moved to 289.83)*

Table 2. Comprehensive ICD-9-CM Casefinding List for Reportable Tumors (Effective Date: 10/1/2006)

140.0–208.9	Malignant neoplasms
225.0–225.9	Benign neoplasm of brain and spinal cord neoplasm
227.3–227.4	Benign neoplasm of pituitary gland, pineal body, and other intracranial endocrine-related structures
230.0–234.9	Carcinoma <i>in situ</i>
237.0–237.9	Neoplasm of uncertain behavior [borderline] of endocrine glands and nervous system
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmacytoma (9731/3)
238.6	Extramedullary plasmacytoma (9734/3)
238.71*	Essential thrombocythemia (9962/3)
238.72*	Low grade myelodysplastic syndrome lesions (includes 9980/3, 9982/3, 9985/3)
238.73*	High grade myelodysplastic syndrome lesions (includes 9983/3)
238.74*	Myelodysplastic syndrome with 5q deletion (9986/3)
238.75*	Myelodysplastic syndrome, unspecified (9985/3)
238.76*	Myelofibrosis with myeloid metaplasia (9961/3)
238.79*	Other lymphatic and hematopoietic tissues (includes 9960/3, 9961/3, 9970/1, 9931/3)
273.2	Gamma heavy chain disease (9762/3); Franklin's disease (9762/3)
273.3	Waldenstrom's macroglobulinemia (9761/3)
288.3	Hypereosinophilic syndrome (9964/3)
289.83*	Myelofibrosis (NOS) (9961/3)
795.06*	Papanicolaou smear of cervix with cytologic evidence of malignancy (<i>without histologic confirmation</i>) (<i>positive Pap smear</i>)
V10.0–V10.9	Personal history of malignancy (<i>review these for recurrences, subsequent primaries, and/or subsequent treatment</i>)
* New code effective 10/1/2006	
Effective with 10/1/2006 discharges, screening for malignancies is no longer required for the following codes:	
238.7	This code is no longer in effect.
284.9	Aplastic anemia, unspecified
285.0	Sideroblastic anemia
289.89	Other specified diseases of blood and blood-forming organs

Table 3. Supplementary ICD-9-CM Codes to Screen for Cancer Cases Not Identified by Other Codes (Effective Date: 10/1/2006)

NOTE:	Cases with these codes should be screened only as registry time allows. These are neoplasm-related secondary conditions for which there should also be a primary diagnosis of a reportable neoplasm.
042	AIDS (<i>This is not a malignancy code; this is for AIDS itself. Coders are instructed to add codes for AIDS-associated malignancies. Screen 042 for 'history of' cancers that might not be coded as active cancers.</i>)
210.0–229.9	Benign neoplasms (<i>screen for incorrectly coded malignancies or reportable-by-agreement tumors</i>)
235.0–236.9	Neoplasms of uncertain behavior (<i>screen for reportable-by-agreement tumors</i>)
238.0–238.9	Neoplasms of uncertain behavior (<i>screen for reportable-by-agreement tumors</i>)
239.0–239.9	Neoplasms of unspecified behavior (<i>screen for incorrectly coded malignancies or reportable-by-agreement tumors</i>)
273.9	Unspecified disorder of plasma protein metabolism (<i>screen for potential 273.3 miscodes</i>)
338.3	Neoplasm related pain (acute) (chronic) (<i>new code</i>) Cancer associated pain Pain due to malignancy (primary) (secondary) Tumor associated pain
528.01	Mucositis due to antineoplastic therapy (<i>new code</i>)
790.93	Elevated prostate specific antigen [PSA]
795.8	Abnormal tumor markers (<i>new sub-category</i>) Elevated tumor associated antigens [TAA] Elevated tumor specific antigens [TSA] Excludes: elevated prostate specific antigen [PSA] (790.93)
795.81	Elevated carcinoembryonic antigen [CEA] (<i>new code</i>)
795.82	Elevated cancer antigen 125 [CA 125] (<i>new code</i>)
795.89	Other abnormal tumor markers (<i>new code</i>)
E879.2	Adverse effect of radiation therapy
E930.7	Adverse effect of antineoplastic therapy
E933.1	Adverse effect of immunosuppressive drugs
V07.3	Other prophylactic chemotherapy (<i>screen carefully for miscoded malignancies</i>)
V07.8	Other specified prophylactic measure
V58.0	Encounter or admission for radiotherapy
V58.11	Encounter for antineoplastic chemotherapy
V58.12	Encounter for antineoplastic immunotherapy
V66.1	Convalescence following radiotherapy
V66.2	Convalescence following chemotherapy
V67.1	Radiation therapy follow-up
V67.2	Chemotherapy follow-up
V76.0–V76.9	Special screening for malignant neoplasm
V86.0	Estrogen receptor positive status [ER+] (<i>new code</i>)
V86.1	Estrogen receptor negative status [ER-] (<i>new code</i>)

Table 4. Errata #2 to Abstracting and Coding Guide for the Hematopoietic Diseases (NIH publication 03-5146) Errata effective date: October 1, 2006

The following changes should be made to the ICD-9-CM casefinding code line for these diagnoses:

Page	Diagnosis	Change ICD-9-CM code to
23	Acute panmyelosis with myelofibrosis	238.79 Other lymphatic and hematopoietic tissues
30	Chronic myeloproliferative disease	238.79 Other lymphatic and hematopoietic tissues
31	Myelosclerosis with myeloid metaplasia	238.76 Myelofibrosis with myeloid metaplasia
31	Myelosclerosis with myeloid metaplasia	289.83 Myelofibrosis
32	Essential thrombocythemia	238.71 Essential thrombocythemia
38	Refractory anemia	238.72 Low grade myelodysplastic syndrome lesions
39	Refractory anemia with sideroblasts	238.72 Low grade myelodysplastic syndrome lesions
40	Refractory anemia with excess blasts	238.73 High grade myelodysplastic syndrome lesions
41	Refractory anemia with excess blasts in transformation [obs]*	238.73 High grade myelodysplastic syndrome lesions
42	Refractory cytopenia with multilineage dysplasia	238.72 Low grade myelodysplastic syndrome lesions
43	Myelodysplastic syndrome with 5q- syndrome	238.74 Myelodysplastic syndrome with 5q deletion
44	Therapy-related myelodysplastic syndrome	238.72 Low grade myelodysplastic syndrome lesions
46	Myelodysplastic syndrome, NOS	238.75 Myelodysplastic syndrome, unspecified

Page 36—ICD-9-CM CASEFINDING CODES FOR REFRACTORY ANEMIAS

Add the following statement to this page:

Effective with 10/1/2006 encounters and discharges, ICD-9-CM codes 284.9 and 285.0 are **not** to be used for coding refractory anemias. Refractory anemias are now coded 238.72 through 238.75.

Page 53—INDEX TO ICD-9-CM CODES USED IN THIS GUIDE

Delete the following codes and references:

- 238.7 Neoplasm of uncertain behavior of other lymphatic and hematopoietic tissues, 23, 30, 31, 32, 42, 43, 44, 46
- 284.9 Aplastic anemia, unspecified, 39
- 285.0 Sideroblastic anemia, 39, 40, 41
- 289.8 Other specified diseases of blood and blood-forming organs, 31

Add the following codes and references:

- 238.71 Essential thrombocythemia, 32
- 238.72 Low grade myelodysplastic syndrome lesions, 38, 39, 42, 44
- 238.73 High grade myelodysplastic syndrome lesions, 40, 41
- 238.74 Myelodysplastic syndrome with 5q deletion, 43
- 238.75 Myelodysplastic syndrome, unspecified, 46
- 238.76 Myelofibrosis with myeloid metaplasia, 31
- 238.79 Other lymphatic and hematopoietic tissues, 23, 30
- 289.83 Myelofibrosis (NOS), 31

* Note: this is an obsolete diagnostic term. The condition should be correctly coded to 205.0 acute myelogenous leukemia.

Errata issued April 15, 2007. Prepared by April Fritz, RHIT, CTR.

Is Your Cancer Registry Profitable?

Michele A. Webb, CTR

When was the last time you reviewed the profitability of your cancer registry? Last week? Last month? Last year? Have you even considered doing this? Before you can begin to review your profitability you will need to familiarize yourself with 3 basic terms—entrepreneurs, business, and mindsets—and then put these terms into context with your cancer registry.

First, you should know what an entrepreneur is and does. An *entrepreneur* is a person who undertakes and operates an enterprise or venture and assumes some accountability for the inherent risks. Simply put, an entrepreneur is someone who creates a system to offer products or services in order to obtain a profit. Successful entrepreneurs have strong beliefs about their market or industry and are willing to accept high levels of personal and professional risk to pursue the opportunities available to them.

Second, *business* has been defined as the social science of managing people in order to organize and maintain collective productivity geared to accomplishing a set of specific, creative, and productive goals, usually for the purpose of generating a profit.

If your organization is classified as a nonprofit, the term *business* still applies. The distinction between “for profit” and “nonprofit” is simply that a nonprofit organization may accept, hold, and provide services, or other things of value, instead of cash. Nonprofits can even legally and ethically trade at a profit. However, the extent to which they can generate income, or how they may use those profits, may be restricted. If you work for a nonprofit you only need to read the annual financial reports to see how the bottom line, or profitability, contributes to its overall success.

The last term to understand is mindset. A *mindset* can be defined as a set of assumptions, methods, or facts held by individual(s) or groups, which are established to create a powerful incentive to adopt or accept specific behaviors, choices, or tools. Mindset may also be called *groupthink*, or *paradigm*.

To recap, let’s take these concepts and put them in context with the cancer registry.

Successful and motivated cancer registrars are entrepreneurs who undertake and operate their business while assuming some accountability for its inherent risks, failures, and successes. And, just in case it has been a while since you have been to a high-spirited cancer registry association meeting, there is no shortage of strong beliefs about the market or industry in which we work!

As cancer registrars, we also manage and organize people, from all business and health care specialties, to maintain a collective productivity geared to accomplish a specific set of goals and requirements unique to our organization or industry and their respective quality programs and services.

Cancer registrars hold a common mindset and operate under the same assumptions, methods, and guidelines. As health care professionals we strive to create, adopt, and accept similar behaviors, standards, and tools. By taking advantage of the resources and mentoring programs available you will be able to effectively manage your business and establish the goals and requirements necessary to be profitable.

While some cancer registrars have adopted these basic concepts, one piece of the equation is typically missing and that is *profitability*. It is true that most cancer registries are not in the business of cash exchange for their products or services. But, regardless of where your funding comes from, the cancer registry is still a business enterprise. So,

it is vitally important to develop the entrepreneurial skills and mindset by which to market and grow the business. This is important in order to measure its profitability and to secure your business and professional success.

So, what is the cancer registry equivalent to cash flow? Simple. It is the *use of the products and services* you provide. What are these products and services? It all begins with the collection of data followed by how effectively you *use and market* that data. You can quantify the resources and time required to do this in terms of dollars and cents. So, your “cash register” should be ringing up “sales” every day! This concept should not be confused with the notion that cancer registries make a financial profit from the cancer patient. Nothing is further from the truth! However, we are in the legitimate and ethical business of providing *products and services* that enable health care organizations to meet the needs of cancer patients.

Your business will be diversified when you routinely create reports or respond to requests for cancer registry data; when you coordinate Tumor Board/Cancer Conference, Cancer Committee, or other program activities; or when you collect non-reportable data items in order to provide your organization with strategic marketing information, etc. Diversification, or providing a wide variety of products and services, is the key to ensuring long-term success for the cancer registry. It also demonstrates the cancer registry’s use and value to your health care organization. Diversification also determines the profitability of the cancer registry and demonstrates the capabilities and professional credibility of its staff.



Once you understand these basic concepts, you will be ready to begin reviewing the profitability of your cancer registry. Here are some questions to ask:

- Do you generally manage your business by “flying blind” and hoping for the best, or are you proactive, accountable, and visibly motivated?
- Does your cancer registry provide services or products that support your organizations goals, value, and mission?
- Are the products and services provided by your cancer registry valuable enough to offset the overhead expenses of keeping your business in operation?
- How much revenue, or use, of your products and services do you, or can you, generate?
- Do you routinely evaluate, develop, and market new or enhanced products and services to your organization in order to remain profitable?
- Do you know who your cancer registry competitors are? Do you work to market and provide your products and services more efficiently and with higher quality?
- Do you prepare a written plan for your cancer registry to incorporate your thoughts, ideas, standards, and industry-specific needs with your organization’s needs?
- How will you distribute and market this plan within your organization?
- What is keeping you, or the cancer registry, from meeting its goals and objectives?
- What step did you take today, this week, or this month, towards making your cancer registry profitable?

Your first review may be difficult, but don’t be discouraged, it is well worth the exercise. Consider using the information you gather as the basis for your business and marketing plans. Whatever you do, keep moving forward and do not give up. Take the opportunity to take your cancer registry to the next level of service, performance, and productivity.

I encourage you to take immediate action to “raise the bar!” Be accountable for implementing innovative management techniques that will secure your future within your organization’s business. Be prepared to engage in continual learning and ongoing implementation of valuable business

practices and appropriately apply them to your niche market. Continually review your cancer registry’s profitability. Once you begin this exciting journey you will be amazed and rewarded with the professional credibility and recognition that you and your cancer registry deserve.

Michele is the Cancer Registry Manager at Saddleback Memorial Medical Center in Laguna Hills, CA and is an independent consultant and speaker. You can reach her by e-mail at: michele@michelewebb.com.

Cancer Registrar Dallas/Fort Worth, Texas

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The Inquiry and Response System: Expert Physician and Curator Support

Nancy Etzold, CTR

The Commission on Cancer (CoC) utilizes the Inquiry & Response (I&R) System to identify opportunities for improvement related to cancer registry data and *Cancer Program Standards*. Multiple submissions of a specific question or a continued “theme” identify areas for improvement. The I&R System has been influential in the development, clarification, and revision of the *Cancer Programs Standards*, new or updated policies and procedures, expanded documentation, clearer communications, increased education, and training resources. This article will focus specifically on the process for utilizing expert and curator resources when answering I & R questions.

Background

The I & R Team is composed of cancer program technical staff who meet weekly to review the questions submitted and determine consensus answers. The technical staff includes certified tumor registrars and also has access to a team of physicians and curators who provide additional support.

The I & R Team uses specific criteria to designate when a question is to be sent to a physician or curator:

- The initial question was submitted by a physician.
- The question is beyond the I & R Team’s technical expertise and requires an expert curator or physician response.
- The question relates to a topic that is outside of the CoC’s area of responsibility, for example, *SEER’s 2007 Multiple Primary and Histology Coding Rules* or the ICD-O 3.
- The question requires review by another committee or professional group.

Physician Curators

All I & R questions submitted by a physician are answered by a physician. Currently, over 50 physicians provide technical expert support to the I & R System. The multidisciplinary spectrum of cancer care is represented by organizations including, but not limited to, the American Joint Committee on Cancer (AJCC), the American College of Surgeons, the Society of Surgical Oncology, the College of American Pathologists, the American Society of Clinical Oncology, and the American Society for Therapeutic Radiology and Oncology.

AJCC

Questions specific to AJCC Staging are sent to one of the 15 AJCC taskforce chairs. These physicians have site-specific expertise and are nationally renowned experts in their fields.

The 2007 Multiple Primary and Histology Coding Rules Curator

An inter-organizational group sponsored by SEER produced the *2007 Multiple Primary and Histology Coding Rules* for assigning histology where more than one histology appears in the patient record and for determining whether one or multiple case reports apply. With the implementation of these rules (cases diagnosed on or after 1/1/2007), the I & R System received an increased number of questions related to this topic. To assure quality and consistency, the I & R Team answers these questions then forwards them to a technical staff member at SEER for review and approval. These questions are then posted on the Web.

The Collaborative Staging Steering Committee

The Collaborative Staging (CS) Steering Committee oversees the continuing technical support of the CS data as well as the computer algorithm that derives the AJCC and Summary Stages. This group meets bi-monthly via conference call, and the group addresses issues related to the data items, as well as clarifications to notes, tables, and instructions. The most recent change to CS (01.03.xx) was distributed in the fall of 2006. CoC did not identify a date by which the new version had to be implemented and required conversions made except to specify that they must have been completed in time for the upcoming Call for Data. See <http://www.cancerstaging.org/cstage/cocspecCS010300.doc> for the CoC instructions. Please be advised that some states may have more stringent rules.

Clarification

Recent questions submitted to the I & R database that have been answered by the CS Steering Committee include:

CS Tumor Size: The size ranges have been expanded to include the description of “less than, greater than, and between.” These codes allow more flexibility to code the

tumor size when a vague description is provided. For an incisional needle biopsy, code tumor size as 999 in the absence of a clinical size. Code the size if no residual tumor is found on resection.

CS Lymph Nodes for Breast: New information has been added to Part I to assist in defining the terms used in the breast schema. Additional description of terms have been added for isolated tumor cells, hemotoxyn & eosin stains, immunohistochemistry, molecular study-reverse transcriptase/polymerase chain reaction, and micrometastasis. A table has been added to assist registrars in the relationship between coding CS Lymph Nodes, SSF 3 (number of positive axillary nodes), SSF 4 (IHC), and SSF 5 (molecular studies).

Prostate SSF 5 and SSF 6: Additional instructions have been added when only a single Gleason's number is given and it is not defined as a Gleason's pattern or score. If the number is ≤ 5 , code as the primary pattern and code the score as 999. If the number is ≥ 5 , codes as the score and code the pattern as 099.

We encourage all cancer professionals to submit questions to the I&R. These inquiries benefit other constituents and provide important feedback to the CoC and AJCC. To review the I&R database or to submit a question, please log on to: <http://web.facs.org/coc/default.htm>.

If you have specific issues or clarifications that you would like us to address, please contact Nancy Etzold at: Netzold@facs.org.

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5. **Public Relations**

The *Journal of Registry Management*, official journal of the National Cancer Registrars Association (NCRA), announces a call for original manuscripts on registry methodology or research findings related to the above 5 subjects, and related topics. Contributed manuscripts are peer-reviewed prior to publication.

Manuscripts of the following types may be submitted for publication:

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

Address all manuscripts to: Reda J. Wilson, MPH, RHIT, CTR, Editor-in-Chief, *Journal of Registry Management*, (770) 488-3245, dfo8@cdc.gov.

Manuscript submission requirements are given in “Information for Authors” found on the inside back cover of each *Journal* and on the NCRA Web site at <http://www.ncra-usa.org>.

CORRECT ANSWERS FOR SPRING 2007

Journal of Registry Management Continuing Education Quiz

Trends in Testicular Cancer Incidence in Massachusetts

(correct answers in **bold**)

- Although testicular cancer is rare:
 - it is the most-frequently-diagnosed cancer in males aged 20–44 years;
 - since 1973, the incidence rate has increased at least 50% in the United States;
 - the age-adjusted incidence rate is about 5 times higher in the white population than in the black population;
 - all of the above.**
- Germ cell tumors (GCT) constitute:
 - 25% of all testicular cancers;
 - 50% of all testicular cancers;
 - 75% of all testicular cancers;
 - 95% of all testicular cancers.**
- Studies have shown that the incidence of testicular cancer is higher in:
 - lower socioeconomic groups and in non-industrialized countries;
 - upper socioeconomic groups and in industrialized countries;**
 - upper socioeconomic groups and in non-industrialized countries;
 - lower socioeconomic groups and in industrialized countries.
- The etiology of testicular cancer is well understood.
 - true
 - false**
- In Figure 1, *Age Adjusted Incidence Rates of Testicular Cancer by Histology in Massachusetts, 1982–2002*:
 - the points represent the values of the incidence rates;
 - the lines show the linear approximation of the trend from 1982–2002;
 - both a and b;**
 - neither a nor b.
- The increase in seminoma is statistically significant in Massachusetts and contributes strongly to the overall increase in testicular cancer.
 - true**
 - false
- Table 5, *Percent of Testicular Cancer Cases by First Course of Treatment, Stage, and Histology in Massachusetts, 1995–2002*, reveals that:
 - most of the seminomas diagnosed between 1995 and 2002 were detected early;
 - non-seminomas were more equally divided between detection at early and advanced stages;
 - both a and b;**
 - neither a nor b.
- The most important finding of this study is the clear diverging patterns of testicular cancer incidence by histologic type in Massachusetts.
 - true**
 - false
- According to the article:
 - seminoma is known to respond well to hormone therapy;
 - seminoma is known to respond well to chemotherapy;
 - seminoma is known to respond well to radiation therapy;**
 - none of the above.
- The limitations of this study include:
 - the reliability of the findings is dependent on the completeness of reporting of testicular cancer to the MCR;
 - there could be misclassification of seminomas and non-seminomas over time;
 - a full age-period-cohort model cannot be fit due to the “non-identifiable problem” induced by the linear dependency among age, period, and cohort: $\text{Period} = \text{Age} + \text{Cohort}$;
 - all of the above.**

CHANGES IN ICD-9-CM CASEFINDING CODES FOR REPORTABLE NEOPLASMS

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:

- Cite examples of lymphatic and hematopoietic diseases which were previously coded in non-specific categories, but now have assigned codes of their own
- Discuss the difference between how GIST is coded according to ICD-9-CM and how a registrar would code malignant GIST
- Communicate the importance of updating a facility's diagnosis index to reflect changes in ICD-9-CM

1. ICD-9-CM coding changes for health information (medical record) diagnoses were published by the:
 - a) American Joint Committee on Cancer;
 - b) World Health Organization;
 - c) Centers for Medicare and Medicaid Services;
 - d) Commission on Cancer.
2. There is a trend toward greater specificity of codes, with important changes in the coding of many clinical conditions, particularly:
 - a) ill-defined and unknown primary sites;
 - b) brain and central nervous system primaries;
 - c) endocrine disorders;
 - d) hematopoietic diseases and other blood disorders.
3. Refractory anemias are now recognized as:
 - a) neoplasms of uncertain behavior;
 - b) generic diseases of blood and blood-forming organs;
 - c) a non-specific category without its own code;
 - d) none of the above.
4. Considering the added clarity for refractory anemias and cytopenias, registrars using the facility diagnosis index for casefinding:
 - a) need to sift carefully through many non-reportable diagnoses in 284 and 285 to find the reportable cases;
 - b) screen charts for myelofibrosis cases;
 - c) carefully distinguish myelofibrosis from primary or idiopathic myelofibrosis;
 - d) both b and c.
5. In the cancer registry database, malignant gastrointestinal stromal tumors of the stomach or small intestine should be coded to:
 - a) connective and other soft tissue;
 - b) the involved organ;
 - c) overlapping lesion of stomach and small intestine;
 - d) none of the above.
6. Cervical intraepithelial glandular neoplasia has been added as a synonym for cervix carcinoma *in situ*.
 - a) true
 - b) false
7. Table 2, *Comprehensive ICD-9-CM Casefinding List for Reportable Tumors*, is effective for encounters and discharges beginning:
 - a) January 1, 2004;
 - b) January 1, 2007;
 - c) October 1, 2006;
 - d) October 1, 2007.
8. Cases with codes listed in Table 3, *Supplementary ICD-9-CM Codes to Screen for Cancer Cases Not Identified by Other Codes*:
 - a) should be screened immediately;
 - b) should be screened as registry time allows;
 - c) are neoplasm-related secondary conditions for which there should also be a primary diagnosis of a reportable neoplasm;
 - d) both b and c above.
9. Table 4, *Errata #2 to Abstracting and Coding Guide for the Hematopoietic Diseases*:
 - a) is a SEER publication;
 - b) is effective beginning January 1, 2007;
 - c) states that refractory anemia with excess blasts in transformation is an obsolete term and should be correctly coded to acute myelogenous leukemia;
 - d) states that code 289.83 Myelofibrosis (NOS) should be deleted.
10. The author recommends joining the discussion group at:
 - a) Match.com;
 - b) <http://health.groups.yahoo.com/group/NCRAMember>;
 - c) Wikipedia.com;
 - d) Ask.com.

This JRM CE Quiz can be completed online at www.creducationcenter.org!

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1. LeMaster PL, Connell CM. Health education interventions among Native Americans: A review and analysis. *Health Education Quarterly*. 1995;21(4):521–38.
2. Hanks GE, Myers CE, Scardino PT. Cancer of the Prostate. In: DeVita VT, Hellman S, Rosenberg SA. *Cancer: Principles and Practice of Oncology*, 4th ed. Philadelphia, PA: J.B. Lippincott Co.; 1993:1073–1113.

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