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CORRECTION NOTICE

In the Fall 2018 issue, for the article, “Case-Completeness of Nonmalignant Central Nervous System Tumors in the Canadian Cancer Registry, 2011–2015” by Dianne Zakaria et al, affiliations were omitted for the following 2 authors in the printed version:

• Prithwish De, PhD: Cancer Care Ontario, Toronto, Ontario, Canada.

• Faith Davis, PhD: School of Public Health, University of Alberta, Edmonton, Alberta, Canada.

We apologize for this omission.
Indexing

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

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

Dear Colleagues,

As I mentioned in the fall 2018 issue, my term as editor-in-chief officially ends on May 31, 2019 and I will transition to editor emeritus on June 1. I would like to take this opportunity to thank all of you for your support and feedback, and for reading our journal. I’m officially passing the baton to Danette Clark who will be transitioning from associate editor to editor-in-chief on June 1. Danette is contributing a letter as well.

We are publishing some correspondence in this issue: a commentary from Jason L. Salemi, PhD, MPH, describing the terminology and use of the words multivariable and multiple from a statistical perspective. We are aware of the importance of terminology in the cancer registry field. The same applies to research and methodology, and is helpful to know when you are reading manuscripts published in JRM and other peer-reviewed journals.

Respectfully,
Vonetta L. Williams, PhD, MPH, CTR

Greetings,

As associate editor, I have been preparing for this transition and can’t believe it’s almost here. Vonetta has provided me with phenomenal training and I am ready to assume the challenge of editor-in-chief. I am very excited and will ensure that JRM will continue to publish quality manuscripts and articles.

Here is a quick summary of myself. I manage the Commission on Cancer Accreditation at 5 hospitals for Atlantic Health System in New Jersey and oversee the cancer registries at those hospitals. My degrees and certifications are Bachelor of Science, Associates Applied Science, Registered Medical Assistant, and Certified Tumor Registrar. I am the Council of Certification Administrator and serve on several committees for NCRA. I also play the piano and cello.

This journal issue contains a variety of great material. We start with 3 original manuscripts: Honghong Huang, MD, CTR, and colleagues provide a case study on automating the renal cell carcinoma registry in Singapore; Rebecca Ehrenkranz, MPH, and coauthors write about pancreatic and breast cancer tumor size data collection; and Yan Yuan, PhD, and collaborators review the under-reporting of nonmalignant brain tumors in Canada. We also have 3 articles in the How I Do It section. We start with Azimeh Danesh Shahraki, PhD, and team evaluating the usefulness of an electronic Web-based registry system. Barbara J. Dearmon, BS, CTR, takes us to Peru to explore the 2018 International Association of Cancer Registries Conference. The final article is provided by Vicki Hawhee, MEd, CTR, and JRM Editor-in-Chief, Vonetta L. Williams, PhD, MPH, CTR, provide a great registry resource guide for new and seasoned registrars that includes a chart with description and URLs. Also included in this edition is the 2018 index. I want to thank our quiz writing team of Deborah C. Roberson, MSM, CTR, and Denise Harrison, BS, CTR. They spend a lot of time preparing the quizzes for each edition.

Starting with the spring 2019 edition, the JRM quiz will be offered only in an electronic format, available on the NCRA website (more information to come).

Hope to see you at NCRA’s 45th Annual Educational Conference in Denver, Colorado in May.

Best Regards,
Danette A. Clark, BS, RMA, AAS, CTR
Letter to the Editor Concerning Terminology Used to Describe Statistical Models with Multiple Independent Variables

Jason L. Salemi, PhD, MPH*

In a recent publication in *Epidemiology*, I noticed the use of the phrase “multivariate regressions” in the abstract, “multiple logistic regression” and “multiple linear regression” in the statistical analysis section, and “multivariate” in the titles of 4 tables to refer to statistical models that appeared to have a single dependent variable (eg, a binary indicator of gestational diabetes for logistic models) and multiple independent variables (the primary exposure, bisphenol A, and potential confounders). In epidemiology and clinical research, it is common and appropriate to use different terms with the same underlying meaning interchangeably—mediator and intervening variable, external validity and generalizability, prevalence-incidence bias and Neyman bias—with choice often dictated by conventions in one’s discipline, training institutions, workplace, or by journal requirements. One of the most common methodological elements of many published research articles is the need to describe statistical models (eg, linear, logistic, Poisson, proportional hazards) with more than 1 regressor/predictor. Although other terms are used, the 2 most frequent to date, multivariate and multivariable (the latter which actually redirects to the former in the online Merriam-Webster dictionary), continue to evoke ongoing disagreement and commentary. Despite their similar definitions, 2 commentaries in 2013 argued that the interchangeable use of these terms was not a matter of semantics and that a clear distinction should be made and implemented consistently in the literature. A specific argument was made, first by Hidalgo and Goodman, in favor of the term multivariable, primarily because multivariate regression could be confused with its more accurate description of statistical models in which multiple regressands/outcomes are modeled jointly. This convention has been adopted by some journals, including *JAMA*, who request in their author instructions that submissions “identify regression models with more than 1 independent variable as multivariable and regression models with more than 1 dependent variable as multivariate.” However, as pointed out in a recent statistical commentary, confusion persists with use of the term multivariable. Technically, a multivariate model has more than 1 variable; therefore, a regression model with 1 regressand (dependent variable) and 1 regressor (independent variable or predictor), which has more than 1 variable, could also be referred to as multivariable. The same problem exists with a third term, multiple (eg, multiple linear regression), that is also commonly used to describe models with 1 regressand and multiple regressors. Unfortunately, the commentary offers no alternative solution to the recommendations of Hidalgo and Goodman.

I propose a slight revision to current terminology that would clarify the description specifically of common statistical models with 1 dependent variable and more than 1 predictor. Instead of stating, “A multivariable logistic regression model was used to generate adjusted odds ratios...”, one could better clarify the description of the model by stating, “A multipredictor logistic regression model was used to generate adjusted odds ratios...” The key difference is that multivariable (or even multivariate or multiple) fails to make a distinction between dependent and independent variables, whereas multipredictor specifically identifies a model that incorporates more than 1 independent variable. Furthermore, predictor is a commonly accepted term for independent variables in a regression model, and the term multipredictor regression model will likely be more acceptable in prose than other too lengthy or too confusing alternatives such as multi-independent variable regression model or multiregressor regression model.

In many scientific journals, there remains substantial variability in the ways in which statistical regression models with 1 dependent variable and more than 1 independent variable are described. Despite leading to commentaries highlighting conflicting, incorrect, or nonspecific terminology, this variation reflects a looseness in the peer review and editorial process. It may also reflect a lack of belief that the widespread uptake of newer, more accurate terms such as multipredictor will be challenging, or that the problem being addressed is too minor. However, the models in question arguably constitute the most common types of statistical models currently reported in the epidemiological and clinical research literature; therefore, pursuit of improved means of communicating overarching statistical approaches seems justified. Adoption of revised terminology also has broader application, as illustrated in Figure 1. The figure uses a linear model as an example. The use of single-predictor vs multipredictor to describe the number of independent variables in a statistical model, instead of their less-specific alternatives, could also be extended to distinguish between actual multivariate models that have more than 1 dependent variable.

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* Baylor College of Medicine, Houston, Texas.

Address correspondence to Jason L. Salemi, PhD, MPH, Department of Family and Community Medicine, Baylor College of Medicine, 3701 Kirby Dr., Suite 600 (MS: BCM4700), Houston, TX 77098. Telephone: (713) 798-4698. Fax: (713)798-7940. Email: Jason.Salemi@bcm.edu.
Figure 1. Proposed Terminology to Distinguish between Linear Regression Models with Different Numbers of Independent Variables (Regressors) and Dependent Variables (Regressands)

References
Automating the Renal Cell Carcinoma Registry in Singapore: A Case Study on the Integration of the Research Electronic Data Capture System with the Enterprise Data Warehouse

Honghong Huang, MD, CTR, Mei Ying Ng, BSc; Jun Tian Wu, BEng, MPH; Jeffrey Chern Hui Fong; Saajida Begum, BSc; Anita; Sean Shao Wei Lam, PhD; John Shyi Peng Yuen, PhD, MRCS, FAMS; Tsung Wen Chong, MBBS, FRCS, FAMS; Henry Sun Sien Ho, MRCS, MMed, FAMS; Lay Guat Ng, FRCS, MMed, FAMS; Lui Shiong Lee, MBBS, MRCS, MMED; Weber Kam On Lau, MBBS, FRCS, FAMS

Abstract: The renal cell carcinoma registry (RCCR) at the Singapore General Hospital was established in the 1980s. In 2012, the registry transited to a partially automated system using Research Electronic Data Capture (REDCap) and Oracle Business Intelligence Enterprise Edition (OBIEE), which is a platform for retrieval of electronic data from the Electronic Health Intelligence System (eHIntS). A committee was formed of experts from the department of urology and the health services research center, as well as an information technology (IT) team to evaluate the efficacy of the partially automated system. In the 5 years after the new system was implemented, 1,751 cases were recorded in the RCCR. The casefinding completeness increased by 1.9%, the data accuracy rate was 97%, and the efficiency increased by 12%. Strengths of the new system after partial automation were: (1) secure access to the registry via the hospital Web, (2) direct access to REDCap via the electronic medical records system, (3) automated and timely data extraction, and (4) visual presentation of data. On the other hand, we also encountered several challenges in the process of automating the registry, including limited IT support, limited expertise in matching data variables from RCCR and eHIntS, and limited availability and accessibility of eHIntS information for import into REDCap. In summary, despite these challenges, partial automation was achieved with the REDCap/OBIEE system, enhancing efficiency, data security, and data quality.

Key words: automation, computerization, electronic medical records (EMRs), health services research, renal cell carcinoma registry

Introduction

The department of urology at Singapore General Hospital (SGH) established the Renal Cell Carcinoma Registry (RCCR) in the 1980s. SGH is the largest hospital within the regional health care cluster in Singapore, the Singapore Health Services (SingHealth), with nearly 1,800 beds and staff strength of approximately 10,000, with an inpatient volume exceeding 80,000 in 2016.

The RCCR collected data on histologically proven renal cell carcinoma (RCC) patients or patients who were treated for clinically metastatic RCC but without histology confirmation by biopsy or surgery. It had evolved from a research database to a hospital-based registry through the following efforts: (1) setting a predefined purpose for the RCCR, (2) creating a prespecified data collection form, (3) follow-up of patient cancer and survival outcomes, and (4) statistical use. It had served as a critical and valuable source of information for clinical audit, research publications, clinical trials, and collaborations with international researchers. However, the RCCR had relied on manual abstraction of data for the past 30 years. Due to increased demand for RCCR data over time, especially since the adoption of international standards in 2008 in casefinding, data coding, data quality, and data analysis, the registry was unable to meet the needs of its requestors in data completeness and timeliness. Therefore, automation of the RCCR was essential to improve data quality, reduce health care costs, and increase efficiency through record linkages such as the hospital’s electronic medical record (EMR) system. Studies showed that automated data extraction from record linkages such as primary care EMRs for monitoring treatment patterns and complications and implementation of guidelines was safe, feasible, and cost-effective.

In 2012, the hospital conducted pilot studies on the development of research databases on Research Electronic Data Capture (REDCap), a Web-based data capture tool that supported clinical and translational research. REDCap served as a research repository, capturing institutional review board–approved research studies. REDCap had the ability to pull demographic data from EMRs via context switch, a mechanism that linked REDCap and EMRs.

Some of the desirable characteristics of the REDCap system included easy scalability hospital-wide, rapid deployment capabilities, cost-effectiveness, ease of setup, ability to meet the needs of researchers in a hospital-wide survey of clinician scientists and other researchers, and sustainability with a globally active consortium of users made up of established academic medicine centers, universities hospitals, and health care providers.

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* Singapore General Hospital, Singapore. ** Singapore Health Services, Singapore. *** Integrated Health Information Systems, Singapore.
Address correspondence to Honghong Huang, MD, CTR. Email: huang.hong.hong@sgh.com.sg.
Oracle Business Intelligence Enterprise Edition (OBIEE), a business-intelligence tool, was used by SingHealth for data visualization and interaction with the enterprise data warehouse. This provided a common application for end users to produce enterprise reports and data analysis through its Web interface. OBIEE functioned primarily as the visualization tool for the SingHealth Enterprise analytics platform, Electronic Health Intelligence Systems (eHIntS). eHIntS integrated data from various source applications in the health care setting (eg, EMRs, pharmacy, laboratory information system, operating theater management, and outpatient administrative system) into a single enterprise data warehouse to provide a common, secure, and standardized platform for data analysis and decision support.

Our aim was to investigate the efficacy of the REDCap/OBIEE system and highlight the strengths of this new system and challenges in automation of the RCCR.

Methods
The prespecified RCC data collection form (Figure 1)—which collected information such as demographics, diagnostic information, treatment, and follow-up data—was modified to leverage the capabilities of REDCap. For example, branching logic and calculated fields were used in the data collection form to improve data consistency and efficiency of data collection.

Approval to retrieve eHIntS reports was obtained from the institution’s senior management. The automated reports were created on the OBIEE interface and results were generated on demand. We identified RCC patients through 4 pathways: surgical procedure codes, SNOMED (Systematized Nomenclature of Medicine) international T codes, ICD-10-AM codes, and RCC drugs.

Surgical Procedure Codes:
The majority of the RCC patients were surgically treated with either partial or radical nephrectomies. Based on 5 surgical procedure codes for nephrectomy (SG005K, SG710K, SG804K, SG720K, and SG721K) used at SGH, the information technology (IT) team retrieved patient demographic information and operation details from eHIntS.

SNOMED International Codes
A list of SNOMED (Systematized Nomenclature of Medicine) international T codes (Table 1) and the laboratory marker mnemonic, HT.CA (meaning histologically confirmed carcinoma), were used to identify all histologically diagnosed RCC patients at SGH, including patients with nephrectomies and patients with renal biopsies who were not surgically treated. Histological information retrieved via OBIEE was then cross-checked against the list of patients generated from the 5 surgical procedure codes mentioned above to avoid missing nephrectomy cases due to coding errors.

ICD-10-AM Codes
ICD-10-AM refers to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification. ICD-10-AM code C64 was used to identify RCC patients who were diagnosed at SGH.
by computed tomography and magnetic resonance imaging scans, or were discharged from SGH with RCC.

RCC Drugs

A list of drugs (Table 2) was used to identify potentially eligible RCC patients and the drug information from eHIntS was then processed using R 3.3.1 to obtain information for data variables related to drug usage in RCCR.8

Preoperative and postoperative laboratory results were retrieved from eHIntS based on information from 3 subject areas in OBIEE: operating theater perioperatively, diagnosis, and laboratory general subject (Figure 2).

The manually-captured RCCR data in Excel and eHIntS data consisting of demographics, diagnostics information, laboratory results, operation details, mortality outcomes, and drug information were compiled in R, with records matched by the national registry identification card (NRIC) number and/or date of operation. Lastly, the compiled data was imported into REDCap.

Urologists at the institution also notified the registry of eligible RCC cases by adding these cases into REDCap via EMRs. To import data from EMRs into REDCap, a system modification based on a context switch9 was developed to establish the computing process of storing and restoring state of a central processing unit (CPU) to enable multiple processes to share a single CPU. Context switch essentially refers to the switching of the CPU from one process or thread to another, making multitasking possible. The context switch was developed on the .NET framework to link certain variables from EMRs with REDCap so that data captured under those variables could be pulled seamlessly into REDCap. While logged into Sunrise Clinical Manager, a platform holding electronic medical records, urologists would be able to insert patient demographics (NRIC number, patient name, date of birth, sex, and race) into REDCap.

A committee was formed consisting of experts from the department of urology and the health services research center, as well as an IT team to evaluate the efficacy of the REDCap/OBIEE system based on timeliness of case accession, efficiency, completeness of casefinding, and accuracy of automated data capture.

Results

Timeliness of Case Accession

After the transition to REDCap along with the utilization of OBIEE in 2012, 1,751 cases were recorded in the RCCR. The interval between the date of diagnosis and when the case was available in the registry for utilization was as short as 1 day, typical of an enterprise data-warehouse framework. In contrast, before the new process, case accession was done at the point of data abstraction, which was within 6 months of date of first contact, in line with the Commission on Cancer’s Cancer Program Standards 2009 Revised Edition (Standard 3.3). Hence, automation using the SingHealth enterprise applications (eHIntS, OBIEE, and REDCap) enhanced timeliness in data availability.

Efficiency of Casefinding

The traditional manual casefinding sources included:
- Positive histopathology notification
- Genitourinary tumor board meeting
- Urophathological meeting
- Patients’ case notes from the clinic

Table 1. SNOMED (Systematized Nomenclature of Medicine) International T Codes Used to Identify Histologically Proven Renal Cell Carcinoma Patients

<table>
<thead>
<tr>
<th>T Code</th>
<th>Description of T Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>T46600</td>
<td>Renal artery</td>
</tr>
<tr>
<td>T46680</td>
<td>Kidney, capillary</td>
</tr>
<tr>
<td>T48740</td>
<td>Renal veins</td>
</tr>
<tr>
<td>T70004</td>
<td>Renal cyst aspirate</td>
</tr>
<tr>
<td>T700061</td>
<td>Smear from renal</td>
</tr>
<tr>
<td>T70014</td>
<td>Renal cyst aspirate right</td>
</tr>
<tr>
<td>T70024</td>
<td>Renal cyst aspirate left</td>
</tr>
<tr>
<td>T71000</td>
<td>Kidney</td>
</tr>
<tr>
<td>T7100A</td>
<td>Kidney, transplanted</td>
</tr>
<tr>
<td>T71010</td>
<td>Kidney right</td>
</tr>
<tr>
<td>T71020</td>
<td>Kidney left</td>
</tr>
<tr>
<td>T71030</td>
<td>Kidney biopsy</td>
</tr>
<tr>
<td>T71030</td>
<td>Renal biopsy</td>
</tr>
<tr>
<td>T71040</td>
<td>Kidney, interstitial tissue</td>
</tr>
<tr>
<td>T71050</td>
<td>Kidney, cortex</td>
</tr>
<tr>
<td>T71065</td>
<td>Kidney, corticomedullary junction</td>
</tr>
<tr>
<td>T71070</td>
<td>Kidney, medulla</td>
</tr>
<tr>
<td>T71120</td>
<td>Renal Papilla</td>
</tr>
<tr>
<td>T71800</td>
<td>Kidneys, both</td>
</tr>
</tbody>
</table>

Table 2. Drugs Used to Identify Potentially Eligible Renal Cell Carcinoma Patients

<table>
<thead>
<tr>
<th>Drug</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afinitor/Everolimus</td>
</tr>
<tr>
<td>Aldesleukin/IL-2/Interleukin-2/Proleukin</td>
</tr>
<tr>
<td>Avastin/Bevacizumab/SAM-Bevacizumab</td>
</tr>
<tr>
<td>Axitinib/Inlyta</td>
</tr>
<tr>
<td>Cabometyx/Cabozantinib</td>
</tr>
<tr>
<td>Lenvatinib/Lenvima</td>
</tr>
<tr>
<td>Nexavar/Sorafenib</td>
</tr>
<tr>
<td>Tosylate</td>
</tr>
<tr>
<td>Nivolumab/Opdivo</td>
</tr>
<tr>
<td>Pazopanib/Votrient/SAM-Pazopanib</td>
</tr>
<tr>
<td>Sunitinib/Sutent/SAM-Sunitinib</td>
</tr>
<tr>
<td>Temsirolimus/Torisel</td>
</tr>
<tr>
<td>Pembrolizumab/Keytruda</td>
</tr>
<tr>
<td>Interferon Alfa2b/Alpha Interferon/Intron-A</td>
</tr>
</tbody>
</table>

context switch was developed on the .NET framework to link certain variables from EMRs with REDCap so that data captured under those variables could be pulled seamlessly into REDCap. While logged into Sunrise Clinical Manager, a platform holding electronic medical records, urologists would be able to insert patient demographics (NRIC number, patient name, date of birth, sex, and race) into REDCap.

A committee was formed consisting of experts from the department of urology and the health services research center, as well as an IT team to evaluate the efficacy of the REDCap/OBIEE system based on timeliness of case accession, efficiency, completeness of casefinding, and accuracy of automated data capture.

Results

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After the transition to REDCap along with the utilization of OBIEE in 2012, 1,751 cases were recorded in the RCCR. The interval between the date of diagnosis and when the case was available in the registry for utilization was as short as 1 day, typical of an enterprise data-warehouse framework. In contrast, before the new process, case accession was done at the point of data abstraction, which was within 6 months of date of first contact, in line with the Commission on Cancer’s Cancer Program Standards 2009 Revised Edition (Standard 3.3). Hence, automation using the SingHealth enterprise applications (eHIntS, OBIEE, and REDCap) enhanced timeliness in data availability.

Efficiency of Casefinding

The traditional manual casefinding sources included:
- Positive histopathology notification
- Genitourinary tumor board meeting
- Urophathological meeting
- Patients’ case notes from the clinic
Identification of eligible RCC cases diagnosed and/or treated from 2015 to 2016 took 1,014 hours. The REDCap/OBIEE system used 4 pathways for casefinding: surgical procedure codes, SNOMED international codes, ICD-10-AM codes, and RCC drugs. The 4 pathways replaced the first 6 traditional casefinding sources in the list above and led to a reduction of 119 hours (12%) after considering the time spent on the REDCap/OBIEE system development, case processing, and data verification.

Completeness of Casefinding

A comparison of the efficacy of casefinding of eligible RCC cases diagnosed and/or treated at SGH from 2015 to 2016 between manual casefinding and the REDCap/OBIEE system showed that 348 cases were identified by manual casefinding whereas the REDCap/OBIEE system identified 355 cases. There were 335 cases that were common to both systems; 13 cases and 20 cases were identified exclusively by manual casefinding and the REDCap/OBIEE system respectively. The completeness rates were 94.5% [348/ (335+13+20)] and 96.5% [355/ (335+13+20)] for the manual RCCR and REDCap/OBIEE system respectively. Thus, the new system provided 1.9% more completeness in casefinding.

Validation of Automated Data

The cancer registrars reabstracted and recoded patient identification and cancer identification information for cases diagnosed and/or treated at SGH from 2015 to 2016 and compared the data against that retrieved from eHIntS via OBIEE. Demographics and date of nephrectomy specimen received from eHIntS were 100% correct (Table 3). However, the accuracy rate for primary sites was 82% due to inaccurate coding of source documents. The average accuracy rate was 97% for patient identification and cancer identification information. The preoperative and postoperative laboratory results reports, which included full blood count, liver function, and renal function tests, were found to be 100% accurate, providing test values according to the specified timeframes.

Discussion

REDCap provided secure access to the RCCR with authenticated login, and the audit trails allowed users to track data changes. The Web-based application enabled simultaneous data entry by different users and provided the potential for data linkages. Direct access to REDCap via EMRs enabled urologists to add new RCC cases directly to the registry, increasing the completeness and timeliness in casefinding. Various codes, namely surgical procedure codes, SNOMED international codes, and ICD-10-AM codes, as well as a list of RCC drugs, were used to identify eligible RCC patients. Patient’s NRIC number was the primary key to link a patient’s record from eHIntS to the registry for automated extraction. Automation eliminated the issue of typing errors in coding and recording by
registrars, improving data accuracy. The OBIEE dashboards enabled users to perform self-service data visualization and management in an intuitive manner. Users could perform data analysis and data mining tasks from simple count of measures to more complex statistical calculations and represent the data graphically.

We encountered several challenges in the process of automating the registry. While the cost incurred for IT support was not an issue, as the project was fully sponsored by the institution as a showcase project, there was a practical limit to the extent of IT support that could be offered to the registry team, as substantial IT resources were required for tasks such as linkages set-up, business rules definition, and report generation.

Registry expertise was needed to identify variables of interest in eHIntS and then map them to the data variables in the RCCR data collection form. As data was stored across thousands of tables in eHIntS, considerable effort was required to identify relevant information and aggregate the variables without the aid of registry-friendly data dictionaries. Manual screening of histological information was necessary to determine if the patient had multiple primary sites as each primary site would require a separate record in REDCap according to SNOMED International T codes.

In summary, partial automation was achieved with the REDCap/OBIEE system and 26.3% of data variables in the registry could be automatically extracted from eHIntS. Full automation was not possible at this stage either due to limited availability of information in eHIntS (eg, Eastern Cooperative Oncology Group score and Clavien–Dindo classification of surgical complications) or storage of information in an unstructured format that rendered it inaccessible.

The RCCR and eHIntS had been created independently without any linkages, leading to enormous multiplied documentation. We showed that the integrated framework comprising RCCR, eHIntS, REDCap, and OBIEE enabled data from eHIntS to be reused for the RCCR, reducing data manual collection time and increased data quality in terms of timeliness, completeness, and accuracy. Well-defined data variables in eHIntS could be identified and automatically extracted for import to REDCap, achieving partial automation of the RCCR and greatly enhancing efficiency and security. The next phase of this current project would be the extraction of useful information from unstructured data in eHIntS with text mining.

Acknowledgements

We appreciate the Department of Urology at SGH for its continuous support to the Urological Cancer Registry, Mr. Christopher John Lalonde for generating the reports from eHIntS, and Ms. Sing Yi Chia for her administrative assistance.

References

Quality Assessment of Tumor Size Data Collection for Pancreatic and Breast Cancer in SEER

Rebecca Ehrenkranz, MPH; Clara Lam, PhD; Valentina I. Petkov, MD, MPH; David Dilts, PhD, MBA; Steven Cheng, PhD, MBA; Amy Solis, BS; Serban Negoita, MD DrPH

Abstract: Background and Objectives: In 2017, the Surveillance, Epidemiology, and End Results (SEER) program piloted a reactive quality audit plan (r-QAP) to analyze Collaborative Stage (CS) tumor size in breast and pancreatic cancer. Preevaluation objectives were to establish procedures and analytic scope for SEER quality audits, cutoffs for data completeness/accuracy, and key decision checkpoints. Methods: Tumor size data between 2004–2014 were selected from SEER registries for pancreatic and breast cancers, and initially assessed by site and registry for completeness. Further exploration was undertaken via cross tabulation in SEER with the American Joint Committee on Cancer (AJCC) 6th edition derived T data item to evaluate discrepancies between these closely related variables. Results: For both cancer sites, completeness improved between 2004 and 2014, with the proportion of known tumor size values increasing from 60.6% to 79.2% in pancreatic cancer and from 94.0% to 95.9% in breast cancer. Tumor size plausibility categories were established wherein any tumor over 100 mm for pancreatic cancer or over 200 mm for breast cancer were considered highly unlikely. Only 2% of pancreas tumors and 0.1% of breast tumors were implausibly large per site-specific cutoffs. Less than 2% of all tumor size values were potentially discrepant in cross-tabulation with AJCC 6th edition derived T for each site. Conclusions: Most tumor size values appear to fall within acceptable ranges based on r-QAP activities, and implausibly large tumor size values are rare. Different natural histories and clinical presentation for pancreatic and breast cancer illustrate the need for site-specific cutoffs. Our results indicate that there are no major quality issues in the SEER research database for the CS tumor size data item in either pancreatic or breast cancer.

Key words: breast; quality audit; pancreas; Surveillance, Epidemiology, and End Results Program; tumor size

Introduction

Tumor size is a crucial variable across many cancers when establishing diagnosis, staging, and prognosis. This variable also helps determine which treatment options are appropriate and may predict patient survival. Thus, it is critical to collect this variable accurately in surveillance systems to analyze cancer trends and outcomes.

The National Cancer Institute (NCI)’s Surveillance, Epidemiology, and End Results (SEER) Program database provides detailed information on tumor characteristics for cancers diagnosed in approximately 44% of the US population, including data directly pertaining to TNM staging. The American Joint Committee on Cancer Tumor-Node-Metastasis (AJCC-TNM) system describes the cancer at time of diagnosis—from local tumor size (T), to nodal involvement (N), to metastasis (M), to other body sites. TNM staging supports clinical decision-making and enables researchers to describe the anatomical extent of cancer at the time of diagnosis and to stratify groups of patients for clinical trials or surveillance studies. SEER has utilized the Collaborative Stage Data Collection System (CS) since 2004 as a standardized means of data collection, and within CS, the AJCC T equivalent is determined by the CS tumor size and the CS tumor extension fields. Given the importance of capturing high-quality data for tumor size, NCI-SEER initiated a pilot reactive quality assessment plan (r-QAP) to systematically assess and evaluate data quality for the CS tumor size variable in breast and pancreatic cancer. The r-QAP is a retrospective data monitoring process designed to find potential inconsistencies and triggers in the data that could be targeted for corrective actions.

Explicit goals of the r-QAP are to assess the magnitude of latent error in each site, determine the research utilization and importance of selected variables, define characteristics of the data quality trigger, and standardize reproducible outlier detection methodology.

This study describes the r-QAP methodology and tested the r-QAP approach to analyze the quality of the tumor size variable in SEER data from 2004–2014. The scope included assessing potential effect on related variables, the feasibility of addressing any underlying issues, and implications for treatment guidelines and prognostic predictions.

Methods

Study Design

Pancreatic and breast cancer cases were defined via CS v0204 schemas for the years 2004–2014 from the SEER 20 registries database (November 2016 submission) using SEER*Stat version 8.3.4. The following population-based
Pancreas and breast were chosen as sites for the pilot project to represent tumors with and without screening availability, as well as to better understand SEER data quality for cancers with very different natural histories. Quality indicators to support preevaluation efforts were established based on literature review and institutional knowledge; preliminary cutoffs were established against which SEER data could be compared. The literature review was conducted for each site, focusing on the epidemiology and natural history of each cancer, as well as determining if any preexisting benchmarks have been created for this data item by other standard-setting organizations. Institutional knowledge was documented to codify the decision-making history within SEER for tumor size.

National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology were reviewed for each site to provide a clinical, up-to-date context of the role of tumor size in treatment and cancer management decisions at the physician level.8 Per NCCN guidelines for tumor size in pancreatic cancer, the main T considerations are whether the tumor is less than or greater than 20 mm, and whether the tumor remains limited to the pancreas. T should be obtained from gross measurement of the largest tumor dimension, but NCCN notes that relatively few patients with pancreatic cancer undergo pancreatic resection.9 Clinical tumor size in pancreatic cancer is a determinant of whether a patient can undergo surgery, and a main prognostic factor for survival. Per NCCN guidelines for tumor size in breast cancer, the T component is based mainly on the size of the invasive component of the cancer, and the maximum size is used as an estimate of disease volume. T designations are based solely on tumor size through the T3 category and designated per extension to other structures for the T4 category. Similar to pancreatic cancer, clinical tumor size in breast cancer is considered a key prognostic factor for survival and risk of recurrence and may help determine a patient’s eligibility for surgery.10

Specific triggers for tumor size were defined to include very large tumor size given the anatomic structure of the organ, discrepancies between tumor size and the AJCC-derived T variable, or a high proportion of missing data. QAP procedures were documented and refined in consultation with experts both internal and external to NCI-SEER. The Derived AJCC T (6th edition) variable was identified as a data item that could be affected by inconsistencies or errors with tumor size, and as such was selected so tumor size could be cross-referenced. Derived AJCC T is a numeric representation for the AJCC 6th edition T descriptor (from TNM staging), and is derived from CS coded fields via the CS algorithm.11 To further explore tumor size, cross-tabulations were completed for tumor size and AJCC-derived T, with the following goals: to create and test a means of categorizing and comparing data in a preevaluation, to assess tumor size in the context of a closely related variable, and to gain insight into data quality by looking for discrepancies. Cross-tabulations were also intended to identify any discrepancies that may merit further exploration beyond the initial QAP assessment. AJCC categories and definitions for each site were referenced to identify inconsistencies. The smallest tumor size values (≤20 mm) were divided into even smaller distributions to identify at a more granular level where inconsistencies exist. Of note, the algorithm that derives AJCC-derived T prioritizes tumor extension over tumor size. While this weakens the direct relationship presented in cross-tabulation because extension was not directly considered, it was considered biologically implausible for tumors ≤20 mm to have invasive extension warranting T4 status.

Data Analysis

Completeness of the data item was assessed for both sites by year and by registry, with completeness being defined as the proportion of known tumor size for each case out of all cases meeting inclusion criteria. Two data runs were completed: 1 including all reporting sources, and 1 excluding death certificate only (DCO) and autopsy as primary reporting sources. Next, the biological plausibility of reported tumor size was evaluated. Biologic plausibility was determined according to how large the tumor is relative to the size of the organ. A conservative approach was used to define biologically implausible tumors to ensure that the distribution of tumor size across all SEER data was captured. AJCC staging categories for T were used as guidelines in the initial distribution breakdown, with tumors over 100 mm (pancreas) and 200 mm (breast) considered biologically implausible.12 Tumor sizes categorized as biologically implausible were flagged as likely to be incorrect and thus eligible for follow-up action. Also assessed was the distribution of biologically implausible tumor sizes by registry. A cross-tabulation of CS tumor size with derived AJCC T was completed to gain insight into the consistency of the data by examining discrepancies in expected relationships. This provides another means through which to flag data for further consideration.

Outlier Detection

As the r-QAP is designed as a data validation activity, it can be utilized to assess data for completeness, consistency, and accuracy. Part of the validation process entails determining what entails an outlier for a given characteristic of the data item under review—in this case, completeness of tumor size values in pancreatic and breast cancer.
Outlier detection procedures followed the data quality standards used in the SEER Box Plot Outlier Tool: initially, 95% Wilson’s confidence intervals were calculated for each registry’s proportion of complete tumor size values. The Wilson’s confidence interval was used because its coverage probability (the proportion of the time that the interval contains the value of interest) is closer to the nominal value even for smaller sample sizes and proportions. Then the first (25th percentile) and third (75th percentile) quartiles were calculated and the interquartile range (IQR) was determined. Lower fences were established via calculating the 25th percentile – (1.5 × IQR), and upper fences were established via calculating the 75th percentile + (1.5 × IQR). A registry would be considered an outlier if its confidence intervals fell entirely outside the range established by the upper and lower fences. If a registry’s confidence intervals partly overlapped with one of the fences or entirely encompassed the fences, one would not be able to designate that registry an outlier, because the true value may fall within the range set by the fences.

Results

For pancreas, there were no discrepancies in the T1 or T2 categories for small tumors. Once a tumor extends beyond the pancreas (T3 and T4), that clinical finding takes precedence over tumor size (Table 1). Therefore, a T3 or T4 finding could fall into any tumor size category and still be correct. However, the 656 T4 values under 20 mm are highly unlikely to have extended into the celiac axis or superior mesenteric artery (the requirement for a T4 designation) based on their small size. Similarly, it would be highly unlikely that a tumor of >100 mm would fail to extend beyond the pancreas, as is noted in 319 patients (Table 1).

For breast, there was only 1 tumor size value coded as T1 that did not match the AJCC T1 requirement that only tumors ≤20 mm can fall under T1, and only 3 tumor size values that did not match the AJCC T2 requirement that a tumor must be >20 mm to fall under T2 (Table 2). Similarly, there were 473 tumors between 21 and 50 mm in the T3

Benchmarking for proportion of complete tumor size values in pancreatic cancer

<table>
<thead>
<tr>
<th>25th percentile</th>
<th>75th percentile</th>
<th>IQR</th>
<th>Lower Fence</th>
<th>Upper Fence</th>
</tr>
</thead>
<tbody>
<tr>
<td>67.4%</td>
<td>72.8%</td>
<td>5.4%</td>
<td>59.4%</td>
<td>80.8%</td>
</tr>
</tbody>
</table>

Completeness in pancreatic cancer by year and registry (anonymized); vertical bars represent proportion of completeness for each registry alongside 95% CIs; horizontal lines represent lower and upper fence benchmarks (±1.5 IQR)

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column, which is discrepant because AJCC rules that all T3 breast tumors must be >50 mm. The 2,550 tumors ≤20 mm may technically be accurate, as a tumor of any size with direct extension to the chest wall or skin is automatically considered T4 based on extension. Therefore, while it cannot be stated that this subset of values is inaccurate, it is still considered an implausible relationship.

Discussion
The r-QAP pilot project helped define the steps in a preevaluation data quality effort that can be standardized and applied to reviews of other variables. Our results demonstrate that tumor size completeness greatly improves over time, especially for pancreatic cancer. For both sites, only a very small proportion of tumors are coded with implausibly large values. When considering completeness by site, both sites were deemed to have an acceptably low level of missing data, especially given outlier detection and site-specific considerations. Of note, an outlier in this context does not directly indicate that a registry is producing incorrect data or falling short of a SEER quality requirement. Instead, if a registry is found to be an outlier, that may simply mean that the registry has a significantly different population than other registries (for example, a registry may have a much higher proportion of older patients in its catchment area). SEER would then follow up with this registry to better understand their population and data collection practices for quality assurance and documentation purposes. It is important to note how cutoffs for acceptable levels of missing data vary greatly by site: the levels of completeness seen in breast cancer may not be possible to capture for pancreas due to the biologic realities of that disease. This indicates that for new quality assessments, SEER cannot plausibly implement 1 benchmark for all sites or all data items.

Only a small proportion for each site has an improbable tumor size. With that in mind, there must still be a threshold for intervention and further quality assessment. Given the volume and intricacy of surveillance data SEER receives, it would not be feasible to dedicate the resources to tracking down each individual implausible measurement. Additionally, it is crucial to consider the quality assessment in the broad context of how a variable is used for research. Thus, the role of a QAP is to determine which errors affect research outcomes, and to provide enough information to suggest a direction for resource allocation.

Strengths of this research include improved completeness for each site with each passing year, and standardizing the steps used by the SEER program to detect outliers and ensure data quality. While the proportion of cases with missing tumor size was at least ~20% in all years reported, this was likely due to the natural history of this cancer. Given that most pancreatic cancer has metastasized by the time of diagnosis, in many cases, there may be no surgery performed and extensive local invasion by the time of diagnosis. The hypothesis that the natural history of pancreatic cancer drives the proportion of unknown tumor size measurements was supported by the finding that there are zero pancreatic tumors of unknown size in

**Table 1. Pancreas Tumor Size and AJCC 6th Edition—Derived T Cross Tabulation**

<table>
<thead>
<tr>
<th>Tumor Size (mm)</th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
<th>Row Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1–5</td>
<td>184</td>
<td>0</td>
<td>53</td>
<td>28</td>
<td>265</td>
</tr>
<tr>
<td>6–10</td>
<td>443</td>
<td>0</td>
<td>156</td>
<td>46</td>
<td>645</td>
</tr>
<tr>
<td>11–20</td>
<td>3,137</td>
<td>0</td>
<td>2,522</td>
<td>582</td>
<td>6,624</td>
</tr>
<tr>
<td>21–40</td>
<td>0</td>
<td>12,122</td>
<td>16,728</td>
<td>6,115</td>
<td>34,965</td>
</tr>
<tr>
<td>41–100</td>
<td>0</td>
<td>7,850</td>
<td>12,154</td>
<td>7,405</td>
<td>27,409</td>
</tr>
<tr>
<td>≥101</td>
<td>0</td>
<td>319</td>
<td>525</td>
<td>341</td>
<td>1,185</td>
</tr>
</tbody>
</table>

AJCC, American Joint Committee on Cancer. Less than 2% of 70,710 tumor size values were potentially discrepant with the derived T variable.

**Table 2. Breast Tumor Size and AJCC 6th Edition—Derived T Cross Tabulation**

<table>
<thead>
<tr>
<th>Tumor Size (mm)</th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
<th>Row Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1–5</td>
<td>46,709</td>
<td>0</td>
<td>13</td>
<td>164</td>
<td>46,886</td>
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<tr>
<td>6–10</td>
<td>103,986</td>
<td>3</td>
<td>23</td>
<td>414</td>
<td>104,426</td>
</tr>
<tr>
<td>11–20</td>
<td>207,499</td>
<td>0</td>
<td>58</td>
<td>1,972</td>
<td>209,529</td>
</tr>
<tr>
<td>21–50</td>
<td>177,448</td>
<td>473</td>
<td>8,527</td>
<td>186,449</td>
<td></td>
</tr>
<tr>
<td>51–100</td>
<td>0</td>
<td>30,877</td>
<td>8,129</td>
<td>39,006</td>
<td></td>
</tr>
<tr>
<td>101–150</td>
<td>0</td>
<td>2,269</td>
<td>2,104</td>
<td>4,373</td>
<td></td>
</tr>
<tr>
<td>151–200</td>
<td>0</td>
<td>333</td>
<td>404</td>
<td>737</td>
<td></td>
</tr>
<tr>
<td>≥201</td>
<td>0</td>
<td>316</td>
<td>194</td>
<td>510</td>
<td></td>
</tr>
</tbody>
</table>

AJCC, American Joint Committee on Cancer. Less than 1% of 591,916 tumor size values were potentially discrepant with the derived T variable.
Stage I pancreatic cancer. However, 52.9% of tumors are of unknown size in stage IV pancreatic cancer. In contrast to pancreatic cancer, for breast cancer, completeness was over 90% in all years reported, with 93.2% of cases reported with tumor size data in 2004 rising to 95.2% by 2014 (Figure 2). These results may reflect the implementation of screening programs for breast cancer, as well as widespread public awareness, insofar as both of these factors lead to detection of tumors prior to metastatic spread. By detecting breast tumors at earlier stages, it is more likely that patients will present with less extensive local invasion and undergo resection, based on which a tumor size value can be recorded. Per the outlier strategy delineated above, no registries were considered outliers for either cancer (Figures 1 and 2). In pancreatic cancer, registries F, L, and M, all overlap the fence either partly or completely. Thus, it remains possible that the true value for each of those registries falls within the benchmark range.

Limitations of this research include that using only data available through SEER*Stat does not permit further claims regarding the accuracy of tumor size measurements. Cross-tabulations indicate relatively minor inconsistencies in the data, add a level of nuance to understanding the relationship of CS tumor size to other related variables, and further delineate which cases would be worthy of additional review. A limitation specific to the cross tab for pancreas is that derived T is based on the CS tumor size when CS extension is coded 100, 150, 200, or 300, which may have entirely precluded any discrepancies from being found in the T1 and T2 categories. In order to assess accuracy thoroughly, pathology reports from SEER*Data Management System would need to be evaluated, followed by a manual review of highly discrepant cases while using a random sample of plausible tumor sizes as a comparison group. To warrant that level of resource-intensive audit, the analysis of SEER*Stat data would need to uncover significant outliers in the data for completeness and consistency. Per the results of the r-QAP, there are no registry outliers and so few cases in each site that seem to be discrepant that this pilot project did not meet the criteria to progress to a full evaluation.

This assessment does provide insight into where issues may lie and some sense of the prevalence of those issues. To address potential challenges, a key goal of the r-QAP process is to establish a quality improvement plan that will address 1 or more of the following: additional training for registrars, revision of coding rules or instructions, edit flags in SEER*Data Management System and/or SEER*Abstracting tool, or reexamination of the process of data item collection. Due to this assessment, SEER is planning to implement the edit flags component of a corrective action plan, which will consist of flags for large tumor sizes. Thus, if a tumor size value deemed implausibly large is entered into the tumor size data item, that entry would be flagged for internal review at the registry level. Additionally, it may be possible that some tumor size entries are incorrect due to mistakes converting centimeters to millimeters. Another quality measure in the process of implementation is to create a dropdown menu for the tumor size field, such that the measurement could be entered as written and the unit of measurement merely selected. These changes serve to reduce the potential for error in recording tumor size across all registries, which will boost confidence in SEER data and demonstrate reproducible data quality metrics to the registrar and research communities alike.

## Conclusions

Our results suggest that there are no major errors in the CS tumor size variable for breast and pancreas in terms of completeness, biological plausibility, or in cross-tabulation with AJCC-derived T. The r-QAP underscores the complexity and necessity of developing quality metrics and provides an initial template for doing so. Additionally, this assessment indicates the necessity for considering each variable in its site-specific context. Through this process, it is possible to gain a broad understanding of a variable, its clinical context, and determine if there are red flags in SEER data. Methods and calculations for determining outliers can be utilized in the future by SEER as well as by the research community at large.

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11. NAACCR item #2940: derived AJCC-6 T. National Cancer Institute’s Surveillance, Epidemiology, and End Results Program website. https://staging.seer.cancer.gov/naaccr/item/cs/02.05.50/2940/?version=/tnm/home/1.4/.


**Abstract:** Nonmalignant brain tumors are underreported by an estimated 60% in Canadian cancer registries. One explanation is that radiology facilities or their databases may not be adequately included in the cancer reporting infrastructure. A multidisciplinary stakeholder team met for 1 day, followed by teleconferences, to discuss the evidence for the importance of incorporating radiology diagnoses in brain tumor reports. A role for the neuroradiologist was delineated in brain tumor diagnosis and in ensuring that radiology report information is available to support cancer case ascertainment in the cancer surveillance system. It was noted that brain tumors identified through imaging are clinically managed depending on the diagnosis and prognosis of the disease, and that patient radiology reports become a part of a larger administrative information system. The proportion of nonmalignant brain tumors diagnosed using histology is lower in the United States (49.3%) than in Canada (59%), suggesting that a higher proportion of cases with nonhistologic (likely radiology) diagnosis are captured by the US system (eg, tumors of the sellar region, cranial and spinal tumors, and tumors of the meninges). Finding a way to use existing electronic radiology reports to identify nonmalignant brain tumors needs to be prioritized. This will require access to electronic radiology reports, as manual reporting is impractical. Once access is achieved, an electronic flag to identify new cases through a natural language processing algorithm could be pursued. As radiologists and cancer registrars become more familiar with each other’s mandates and workflow demands, innovative and collaborative solutions to improve case ascertainment for brain and other cancers are likely to emerge.

**Key words:** algorithm solution, electronic access, natural language processing, radiology reports, tumors

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**Introduction**

Brain and other central nervous system (CNS) tumors account for only approximately 2% of primary cancer diagnoses among Canadians annually.\(^1\) However, these tumors cause a strain on the health care system that is disproportionate to their incidence.\(^2\) Due to the anatomical location of these tumors, the associated clinical and public health burden is not limited to those classified as malignant. Recognizing this, including diagnoses of nonmalignant brain and other CNS tumors in comprehensive surveillance efforts for brain tumors has been mandated. For example, the Canadian House of Commons passed legislation (MB-235) in 2007 for the “creation of uniform national standards for all malignant and benign brain tumors.”\(^3\)

Provincial cancer registries are mandated to collect population-based data on cancer incidence, and aim to maintain high-quality databases so that patterns of disease generated from these data reflect all reportable cases within a jurisdiction. However, accuracy and completeness of cancer registry data is assessed using criteria developed by the North American Association of Central Cancer Registries (NAACCR), which only takes into account certain tumor sites and behaviors when calculating completeness, omitting nonmalignant tumors.\(^4\) Therefore, provincial registries are able to meet the criteria for NAACCR certification while missing a large proportion of reportable brain tumor diagnoses. As a result, there is uncertainty regarding the extent to which nonmalignant brain tumors are missing from cancer registry data in Canada. Further, barriers to efficient capture of nonmalignant tumors in provincial registries designed to collect data on malignancies have not been clearly outlined or addressed.

A report by the Public Health Agency of Canada (PHAC) highlighted a potential barrier to nonmalignant CNS tumor registration related to the method of diagnosis for these tumors, which is predominantly through radiology.\(^5\) In this report, PHAC suggested that radiology facilities may not have been sufficiently integrated into the...
reporting infrastructure.\(^5\) A subsequent report compared the brain tumor cases captured in the Canadian Cancer Registry (CCR) during 2006 to 2010 to the number of expected cases based on incident rates from the Central Brain Tumor Registry of the United States (CBTRUS).\(^6\) At that time, it found that Canada registered only 33% of expected nonmalignant brain cases. The Ontario Cancer Registry was the least complete in capturing nonmalignant brain tumors, while the Manitoba Cancer Registry was the most complete, capturing 73% of expected cases. Efforts are being made in Canada to fill these gaps. For example, in some provinces, hospital discharge records are now being used to supplement casefinding, which has significantly improved completeness of nonmalignant brain tumors.\(^2\)

The Brain Tumour Foundation of Canada (BTFC) has made the establishment of a Canadian brain tumor registry a priority, with supporting funds from both Brain Canada and the BTFC. During an inaugural meeting of affiliates of the registry in June 2017, the missing of radiologically diagnosed brain and other CNS tumors in Canadian cancer registries was determined to be a priority. The team decided to explore this further and identify potential solutions by inviting experts to a workshop aimed at gaining insight into the pathways to brain tumor diagnosis and registration, with a focus on the role of radiology.

**Methods**

**Meeting Organization and Agenda**

To review the current status of under-registration of nonmalignant brain tumors and radiological diagnosis in Canada and to discuss the role of radiology in current reporting infrastructure, we organized a meeting titled, “Capturing Radiology Diagnoses of Primary Brain Tumours” on April 24, 2018 in Edmonton, Alberta. Participants examined the issue through a series of presentations, including a surveillance data review, a review of neuroradiology diagnosis of brain tumor and its data flow in Alberta, the neuropathology diagnosis of brain tumor and its synergy with neuroradiology, and an example of available software that captures brain tumors by processing pathology and radiology reports. Group discussions followed, focusing on the current use of radiology data across provinces and challenges associated with incorporating brain tumor diagnoses from radiology reports.

**Data Analysis**

Surveillance data on the diagnostic methods associated with brain tumor diagnosis were compared for Canada (CCR data release 2015, version 1) and the United States (Table 6 of the 2016 CBTRUS statistical report) to better understand the contribution of radiology in brain tumor registration.\(^7,8\) Canadian data were limited to malignant tumors.

**Discussion Synthesis and Proposed Solutions**

All presentations and discussions were recorded, and detailed notes were taken throughout the meeting and used to develop a draft of the discussion synthesis, which was then circulated for review by the attending cancer registrars, physicians, and epidemiologists. Meeting participants proposed solutions based on the information shared during the meeting. The proposed solutions were developed into a set of recommendations during follow-up discussions among the coauthors.

**Results**

Participants brought their experience and expertise to this discussion as the following 6 questions were explored.

What is the Current Status of Brain Tumor Diagnosis by Radiology Alone?

Neuroradiology has a critical role in the diagnosis and management of brain tumors.\(^9\) Imaging procedures such as computed tomography (CT) and magnetic resonance imaging (MRI) are the most common clinical investigations used for the initial evaluation and characterization of suspected brain tumors.\(^9,10\) The field of neuroimaging is rapidly expanding beyond traditional anatomical examinations to identifying nuanced functional, metabolic, and cellular-level abnormalities. In the future, multimodality imaging techniques such as magnetic resonance/positron emission topography (PET) may enable radiologists to make fairly accurate diagnoses of histological tumor types, grade brain tumors, and identify structural and physiological changes to brain parenchyma.\(^11,12\) In light of recent changes to brain tumor classification by the World Health Organization,\(^13\) which now incorporates both histology and molecular parameters, there has been an increased interest around the role of biology-driven MRI techniques for noninvasive exploration of the association between neuroimaging findings and molecular level tissue aberrations.\(^9,12\)

Patient-related demographic and clinical factors—including age, sex, clinical history, anatomical location, tumor spread, calcifications, and contrast enhancement—guide the radiological diagnosis of brain tumors. For example, glioblastoma, a highly aggressive brain tumor, is characterized by presentation in old age, midline crossing, and ring enhancement. Imaging findings supplemented by relevant clinical history help the radiologist reach the most probable diagnosis from a list of differentials. Neuroimaging findings are also being analyzed in relation to genetic mutations. For example, MRI findings of high contrast enhancing/necrotic volume and increased perfusion are being associated with epidermal growth factor receptor amplification, which is a feature of glioblastoma tumors.\(^7\)

Neuroradiology also plays a key role in clinical care, treatment protocol decisions, and evaluation of tumor progression. For example, the radiological diagnostic work up of grade III astrocytoma is supplemented by histological and molecular marker assessments to determine tissue diagnosis and help direct treatment planning. Nonmalignant tumors such as some meningioma can be typically followed-up for years on neuroimaging without undergoing biopsy and active treatment. These “wait and watch” tumor diagnoses are more likely to be missed by the cancer registries, leading to delayed reporting or under-reporting of these tumors.
How Does Radiology Reporting Affect Brain Tumor Surveillance Information?

In the United States, approximately a third of all registered brain tumors were malignant and two-thirds were nonmalignant during 2009–2013. The proportion of malignant tumors identified through histology was similar in Canada during 2004–2015 to that of the United States (Table 1) and this proportion was also similar across Canadian provinces (Table 2). This suggests that the impact of a radiology diagnosis on case ascertainment may be mild, although the proportions of radiological confirmation of malignant brain tumors varied from 4.4% in Ontario to 20.5% in Manitoba (Table 2), raising concern about the comparability of data on malignant tumors across provinces. It should also be noted that radiology diagnosis still plays a significant part in the diagnosis of certain subtypes of malignant brain tumors both in the United States and Canada: the CCR data showed that 16.7% of unclassified and 47.0% of glioma (not otherwise specified) malignant tumors were diagnosed radiologically during 2004–2015.

With respect to nonmalignant tumors, the proportion of tumors diagnosed by histology and radiology were similar (49.3% and 47.8%, respectively) in US data (Table 1). The proportion diagnosed by radiology varied by tumor type. For example, 96.3% of tumors of the sellar region were confirmed using a nonhistological diagnosis. Other subtypes of brain tumors likely to be diagnosed without histological confirmation include tumors of cranial and spinal nerves (83.9%) and tumors of meninges (66.4%). Further, the proportion of nonmalignant brain tumors diagnosed using histology is lower in the United States (49.3%) compared to Canada (59%) (Table 1).

Assuming confirmation methods for nonmalignant brain tumors in the United States are similar to those used in Canada, this comparison suggests that Canada is missing nonmalignant cases, especially those diagnosed by radiology. In the United States, electronic capture of radiology reports for casefinding has been shown to improve case entertainment for CNS neoplasms compared to traditional methods (pathology reports and hospital discharge lists).

How Do Radiology Report Results Move from Clinical to Administrative Databases?

Multiple information systems are involved in the creation, transmission, storage, and distribution of neuro-radiology reports. Using Alberta as an example, the process is initiated when a neuroimaging referral containing patient information and brief clinical indication enters the Radiology Information System (RIS) database, which houses imaging requests and the final text reports. When a patient undergoes the requested radiological procedure, the resulting image is transmitted to the picture archiving and communication system and is then analyzed by a radiologist, who has available patient clinical information and previous imaging results in the system for review. The radiologist dictates an unstructured medical record that relays key imaging findings with an initial diagnosis. The dictated text report is then sent to the RIS database for storage and is further distributed to several electronic health record systems, including a provincial text result repository and physician electronic medical records database. However,

<table>
<thead>
<tr>
<th>Diagnostic Confirmation</th>
<th>Malignant Tumors</th>
<th>Nonmalignant Tumors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Histology (%)</td>
<td>85.5</td>
<td>83.8*</td>
</tr>
<tr>
<td>Radiology (%)</td>
<td>9.8</td>
<td>7.3</td>
</tr>
<tr>
<td>All other (%)</td>
<td>5.1</td>
<td>8.9</td>
</tr>
</tbody>
</table>

* Defined as histology and cytology.
US data is cited from the CBTRUS Statistical Report 2016. The summary of malignant tumours is based on the analysis of Canada Cancer Registry data available to the study authors (see Table 2 for details). The summary of nonmalignant tumors in Canada is based on Shaw’s analysis (unpublished).

Table 2. Method of Diagnosis of Malignant Brain Tumors in 4 Canadian Provinces (2004–2015)

<table>
<thead>
<tr>
<th>Province</th>
<th>Microscopic Confirmation n (%)</th>
<th>Radiological Confirmation n (%)</th>
<th>Other* n (%)</th>
<th>Unknown n (%)</th>
<th>Total n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta</td>
<td>2,600 (83.9)</td>
<td>475 (15.3)</td>
<td>25 (0.8)</td>
<td>0 (0)</td>
<td>3,100</td>
</tr>
<tr>
<td>British Columbia</td>
<td>3,650 (84.4)</td>
<td>305 (7.1)</td>
<td>370 (8.6)</td>
<td>0 (0)</td>
<td>4,325</td>
</tr>
<tr>
<td>Manitoba</td>
<td>885 (79.0)</td>
<td>230 (20.5)</td>
<td>5 (0.5)</td>
<td>0 (0)</td>
<td>1,120</td>
</tr>
<tr>
<td>Ontario</td>
<td>11,265 (84.0)</td>
<td>590 (4.4)</td>
<td>215 (1.6)</td>
<td>1,340 (10.0)</td>
<td>13,410</td>
</tr>
<tr>
<td>Total</td>
<td>18,400 (83.8)</td>
<td>1,600 (7.3)</td>
<td>615 (2.8)</td>
<td>1,340 (6.1)</td>
<td>21,955</td>
</tr>
</tbody>
</table>

Note: Quebec data is only available up to 2010 and thus is not included in the table. Numbers are randomly rounded in accordance with Statistics Canada requirements.
*Other category includes death certificate, clinically confirmed, surgically confirmed, autopsy, and positive lab marker.


### Where is the Gap between the Clinical Practice and Cancer Registration?

For a patient and clinician, the pathway to clinical care is most important, but for surveillance researchers and stakeholders, the completeness and accuracy of cancer registration is also important. Patients cared for by oncologists are routinely being registered, since oncologists are part of the cancer care system (Table 3). The question arises as to what happens when a radiologically diagnosed patient is not immediately seen by a surgeon or an oncologist. If new patients do not require this attention, confidence in surveillance data decreases. If repeated MRIs establish a diagnosis and a patient requires surgical or oncological care at a later date, the cancer registry information will be delayed and the level of accuracy is uncertain. If repeated MRIs indicate neither surgical intervention nor oncological care, the potential for that case to be missed in the surveillance system increases. This may help explain why information on malignant brain tumors appears to be complete and the information on nonmalignant tumors is incomplete. As discussed above, underreporting varies by province and tumor subtype. Therefore, policymakers and researchers using these data need to be cautious with data interpretation.

### How May Software Applications Be Used to Process Radiology Reports?

Natural language processing is increasingly being used to read pathology reports for case identification. Different solutions are being explored in different registries. For example, Manitoba, and Newfoundland and Labrador use Artificial Intelligence in Medicine Inc (AIM) and some institutions in Quebec use the Système d’Arhivage des Données en Oncologie (SARDO) to process pathology reports. Both of these software packages are used to identify cancer cases for cancer surveillance purposes.

Recently, AIM developed an imaging interpreter software that uses natural language processing and artificial intelligence to detect reportable lesions in the central nervous system. This imaging interpreter software processes the unstructured narrative radiological reports of MRI and PET scans of the brain and CT scans of the head, selects relevant reports to be forwarded to the cancer registry or other authorized department, and provides coding assistance for registrars.

The AIM software processes the unstructured reports in several stages. The first stage uses text analysis and context determination to identify concepts such as cancer terms based on terminology and specific terms from the International Classification of Diseases for Oncology, third edition (ICD-O-3), such as metastatic or mention of history. It assigns every report a yes/no value for each of the 4 categories: primary tumor, previously known, metastatic, and past history of cancer. In the second stage, a logic module is applied to all reports using these category values previously assigned to determine 1 of 5 classes: negative, negative but has...
Cancer registries choose different classes depending on the output desired. When all 4 classes are included from history to positive, sensitivity and specificity are excellent (typically 98% to 99%). When the system has to differentiate between classes (eg, metastatic and history), the accuracy declines. Users are provided with tables showing the confidence levels reached by class.

**What is the Cancer Registry’s Legal Responsibility and Approach in Case Ascertainment?**

All provincial health authorities in Canada operate a centralized cancer registry that is responsible for collecting and managing data for residents diagnosed with cancer in the province under provincial law. Although the House of Commons passed legislation (MB-235) to mandate the collection of all malignant and nonmalignant brain tumors, cancer registration is a provincial responsibility governed by provincial legislation. A summary of relevant legislations in the 5 participating provinces is provided in Table 4. There are noticeable differences in these legislative acts, which have contributed to differences in cancer registration practices. While none of these acts specifically mandates the role of radiologists or the use of radiology reports, the general reporting requirement by health care professionals subsumes this specialty.

**Discussion**

The information provided highlights the importance of including radiology diagnosis data in the pathway to brain tumor registration. CBTRUS reports a significant increase in incidence of radiographically confirmed nonmalignant brain tumors from 2004 to 2009, which was believed to be due to improvement in collection of nonmalignant cases in general, as well as improved collection of radiographically diagnosed cases specifically. Similar to our findings in Canada, variations in benign and borderline brain tumors were found when comparing the 47 US population-based cancer registries, which were believed to be largely attributable to differences in casefinding strategies between the different registries.

Primary brain tumor subtype categories with a high proportion of malignant cases typically have a high proportion of histologic confirmations and low proportion of radiology confirmations at diagnosis (Tables 1 and 2). In contrast, primarily nonmalignant histology types are less likely to be histologically confirmed and more likely to have other forms of diagnostic confirmations (Table 1). These categories of nonmalignant tumors, such as tumors of the sellar region, tumors of cranial and spinal nerves, and tumors of meninges, are at considerable risk of being underreported if radiology results are not in the cancer registration pathway.

Our review of provincial legislation indicates that, while the language regarding responsibility of reporting is general, there is a role for the neuroradiology professionals in ensuring that reportable conditions identified through radiology are reported to a cancer registry. Each province needs to clarify whether this is a direct or indirect role. Given the advances in radiology diagnosis (particularly for brain tumors), it is important to recognize that provincial legislation allows creating new options for case reporting as relevant to today’s clinical practice.

Artificial intelligence solutions for analyzing radiology reports need to be considered in the context of busy, high-volume radiology practices where identifying a rare brain tumor is like looking for a needle in a haystack. Any manual approach would put a significant burden on individual radiologists/clinics and cancer registry systems. These diagnoses also may involve repeat imaging and may be inconclusive, making data extraction more complex. As general systems for electronic radiology reports exist, building new information solutions (electronic or manual) to address cancer case ascertainment may be feasible with collaboration between the cancer registry community and the radiology community. An electronic approach could be developed within provincial health information/surveillance systems. While unstructured radiology reports make information extraction difficult, natural language processing solutions are beginning to emerge.

In the long term, it might be helpful to explore adopting a form of synoptic reporting for radiology reports, which has been shown to help the flow of clinical information and increase the overall completeness for case capturing in pathology reporting. However, the advantages would need to clearly outweigh the staff burden of doing so in such a high-volume environment, and the structure of the synoptic report should not require radiologists to oversimplify descriptions of complex cases to the point they become less accurate.

With the passing of MB-235, provincial cancer registries are undertaking the added responsibility for the collection of all primary brain tumors in the cancer registry system without additional resources. Radiologists, by extension, have a role in reporting nonmalignant (as well as malignant) brain tumors and cancer registries have the freedom to create options for high-quality reporting processes for these tumors. Doing this effectively will dramatically improve the surveillance information on nonmalignant brain tumors, but it could also improve the completeness of case registration for other types of malignant tumors. Some potential solutions for better using radiologists and radiology reports at the provincial level were discussed:

- **British Columbia**: Engage all clinical staff at hospitals, diagnostic and laboratory departments, and other diagnostic facilities, to update, educate, and advise compliance with registry guidelines regarding reportable cases (as per CCR). Update coding and abstracting guidelines and associated reference material to match national and international standards; work with tumor registrars to ensure understanding of and adherence to the updated guidelines. Create and improve algorithms to capture cases from radiology and other reports based on brain terminology, while collaborating with information management and information technology department(s) to flag appropriate radiology reports for the registry.
Alberta: Explore the opportunity to search radiology reports to find a solution for notifying the cancer registry of brain tumors found on imaging.

Manitoba: Engage the radiology community; discuss their understanding of the provincial legislation and work to find a solution for notifying the cancer registry of nonmalignant brain tumors found on imaging.

Ontario: Conduct a quality control/proof-of-concept study in 1 institution having high-volume neuroimaging as a starting point for understanding the magnitude of issues and opportunities. Incidentally, develop physician champions during this process.

Quebec: Varied. Each hospital registry will try a strategy and compare the effectiveness of different approaches, in addition to ongoing efforts to develop SARDO so it can process imaging reports and report cancer cases to the registers.

Conclusion and Recommendations

Radiologically diagnosed nonmalignant brain tumors are disproportionally underreported in Canada. Registries need to adopt new casefinding strategies to capture clinically diagnosed cases from a range of data sources, including radiology information. This review highlights that cancer registries are free to modify case reporting strategies within the context of their provincial law in order to ensure high-quality cancer surveillance. It also becomes clear that an electronic solution is likely, given that manual review of radiology reports is impractical.

Finding a way to use existing electronic radiology reports to identify nonmalignant brain tumors should be prioritized in the near future, as using some form of electronic text search or natural language processing approach seems readily doable. Specific solutions will vary by province, but must involve cancer registry access to radiology reports and ways to use the information in electronic radiology reports. Another question to explore for the longer term would be to find out whether synoptic reporting in radiology, as being used in pathology reporting, would seem readily doable. Specific solutions will vary by province, but must involve cancer registry access to radiology information. This review highlights that cancer registries are free to modify case reporting strategies within the context of their provincial law in order to ensure high-quality cancer surveillance. It also becomes clear that an electronic solution is likely, given that manual review of radiology reports is impractical.

As radiologists and cancer registrars become more familiar with each other’s mandates and workflow demands, innovative and collaborative solutions to improve case ascertainment for brain and other cancers are likely to emerge.

Acknowledgements

Special thanks to Sheila Fukumura at CancerCare Manitoba for her helpful input, and Erin Hamilton for her assistance in meeting planning. We are also grateful to Dr. Marie Christine Guiot, Dr. Jay Easaw, Cindy Nikiforuk, Gail Noonan, Prithwish De, Lorette Bowers, and Tracy Jones for their participation and contributions to the discussion. Lastly, we would like to thank the staff at Brain Canada and Brain Tumour Foundation of Canada for their generous support.

References

How I Do It

The Evaluation of a Web-Based Stroke Quality Registry System

Azimeh Danesh Shahraki, PhD a,b; Mojdeh Ghabaee, MD c; Leila Shahmoradi, PhD a,c; Reza Safdari, PhD a; Jaleh Shoshtarian Malak, PhD c

Abstract: Quality registry systems are very useful and have many benefits for clinical experts. Assessing the user experience while working with such a system is one of the most important steps in their development. An evaluation of the quality of the user experience allows designers to improve the system’s usability and efficiency. Various usability engineering approaches may be used to analyze and improve the functionality of a Web-based registry system. User experience questionnaires (UEQs) are a reliable and validated tool that have been used to evaluate many systems. The UEQ questionnaire can be linked to the system and users can evaluate the system online. Thus, the gathering of questionnaire data can be a continuous process, allowing for ongoing analysis of the quality of the user experience, leading to a more user-friendly system. Our research focused on the evaluation phase of registry system development and indicated how we can evaluate the quality of the user experience of a registry system. In this paper, a Web-based stroke quality registry system was evaluated through a usability assessment methodology with a UEQ. The results may be applicable to other registry systems.

Key words: evaluation, stroke, quality registry system, user experience assessment questionnaire, usability engineering

Introduction

The evaluated system is a Web-based stroke quality registry with guideline-based diagnosis for intravenous thrombolysis monitoring (www.iranstroke.ir). The system was developed through primary studies on other similar systems and experts surveys. Stroke is one of the main causes of long-term disability and the second-leading cause of death in Eastern Mediterranean countries. This system records detailed medical information for stroke patients. The patient’s information is adjusted in 13 tabs, including patient information, early assessment, past medical history, drug history, laboratory data, imaging, eligibility, diagnosis, medication, discharge, discharge drugs, drug base, and guide (including important guidelines for the user). The system (in its present form; Figure 1) was established on April 16, 2017 and is funded by the Research Center of Neurological Disease at the Tehran University of Medical Sciences.

Usability Engineering and User Experience

Identifying the needs of users is very effective and necessary to improve the user experience when working with the system. There are several ways to apply usability engineering, and the principles of this subject have been thoroughly investigated. In order to evaluate the usability of the system, the user experience is evaluated and ranked in terms of efficiency, attractiveness, and user satisfaction when working with the system. It has been recognized that improving usability is not always enough. In addition to usability, users’ perceptions before, during, and after using the system are considered part of the user experience. This includes users’ assumptions and expectations, as well as their emotional bond to the product (in this case, the Web-based registration system). The process of evaluating the user experience is intended to identify possible sources of misunderstanding, thereby allowing developers to optimize the product for the user group.

Methods

User Experience Test

To evaluate the user experience of the Web-based stroke quality registry system, a User Experience Questionnaire (UEQ) was administered. In addition to the classical evaluation of the user experience via UEQ, additional evaluation with data entry was completed. The target group consisted of users who have experience with similar Web-based systems and who can understand the requirements and guidelines for the system.
of 10 neurology experts from the Research Center for Neurological Disease at the Tehran University of Medical Sciences in Tehran, Iran.

The Practiced Questionnaire

In addition to interval assessments of the system during the development phase (which included several sessions with neurology experts), the first phase of system evaluation (May 2017) was data entry for 60 patients to test the system’s functionality. During the data-entry process (through November 2017), functional or presentation problems were identified and fixed. The second phase of system evaluation (September–November 2017) was the user experience evaluation with a paper UEQ questionnaire distributed in parallel with the first phase.

Users who participated in the questionnaire (neurology experts) were asked to rank 26 items regarding their personal impressions of the portal on a 7-point Likert scale (Figure 2). Ten neurology experts answer all of the questions on the UEQ. Some of them asked their students for feedback on the data entry phase before filling out the questionnaire with them. The process of using the system and filling out the questionnaires took about 3 months.

Of the 26 items in the questionnaire, 6 important criteria were evaluated. These criteria were attractiveness, awareness, trust, efficiency, stimulation, and innovation. Each criterion was ranked on a 7-point scale, and the numerical value was interpreted from −3 (most inverted) to +3 (most positive), including 0 (neutral). From these values, we calculated an average for each criterion. 5

Results

The evaluation of the UEQ for the Web-based clinical information system was based on 10 completed

<table>
<thead>
<tr>
<th>Table 1. Statistics for UEQ Questionnaire Items</th>
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<tbody>
<tr>
<td><strong>Item</strong></td>
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</table>
questionnaires. For the analysis, an Excel worksheet provided by Laugwitz, Held, and Schrepp M9 was used. The UEQ does not produce an overall score for the user experience. Because of the construction of the questionnaire, an overall score is meaningless, since this value cannot be interpreted properly. The values for the single items are listed to allow you to detect outliers in the evaluations. If an item shows large deviations from the evaluations of other items of the same scale, this can be a hint that the item is misinterpreted (for example, because of a special context in your evaluation) by a higher number of participants.9

Values between -0.8 and 0.8 represent a neutral evaluation of the corresponding scale. Values above 0.8 represent a positive evaluation, while values below -0.8 represent a negative evaluation. The range of the scales is between -3 (horribly bad) and +3 (extremely good). However, in real applications, only values in a restricted range are generally observed. Thus, even a good value of +1.5 for a scale appears less positive than it really is, from the purely visual standpoint of a scale ranging from -3 to +3. For this reason, this sheet contains 2 variants for the figure that depict the scale means. It may be preferred to use the figure with the reduced scale (-2 to +2) when communicating the results to persons with limited knowledge on interpreting this type of data, or in situations where a detailed explanation is not proved on building mean values.9

For the Web-based clinical information system, the statistics of the UEQ questionnaire are shown in Table 1. UEQ values vary between 1.725 and 2.175 (Figures 3 and 4, Tables 2 and 3). According to the results, it can be said that the system has a high level of user satisfaction in all 6 criteria.

The measured scale means are set in relation to existing values from a benchmark data set. This data set contains data from 9,905 persons from 246 studies concerning different products like business software, webpages, online stores, and social networks.9

The comparison of the results for the evaluated product with the benchmark data allows conclusions about the relative quality of the evaluated product compared to other products. The result of system evaluation comparison with previous studies (Table 4, Figure 5) shows that the system is in the range of the 10% best results.

The 5% confidence intervals for the scale means and the means of the single items are shown in Table 5. The confidence interval is a measure of the precision of the estimation of the mean. The smaller the confidence interval, the higher the precision of the estimation and the more trustworthy the

<table>
<thead>
<tr>
<th>Table 2. System Evaluation Results: UEQ Scales</th>
</tr>
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<tbody>
<tr>
<td>Attractiveness 1.98</td>
</tr>
<tr>
<td>Perspicuity 2.175</td>
</tr>
<tr>
<td>Efficiency 1.95</td>
</tr>
<tr>
<td>Dependability 1.975</td>
</tr>
<tr>
<td>Stimulation 1.80</td>
</tr>
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<td>Novelty 1.725</td>
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<table>
<thead>
<tr>
<th>Table 3. The System Evaluation Results: Pragmatic and Hedonic Qualities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attractiveness 1.98</td>
</tr>
<tr>
<td>Pragmatic Qualities 2.03</td>
</tr>
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<td>Hedonic Qualities 1.76</td>
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<table>
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<tr>
<th>Table 4. Comparison with Previous Studies</th>
</tr>
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<tbody>
<tr>
<td>Scale</td>
</tr>
<tr>
<td>Attractiveness</td>
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<td>Perspicuity</td>
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results. The width of the confidence interval depends on the amount of available data and on how consistently the users judged the evaluated product. The more consistent their opinion, the smaller the confidence interval.

**Conclusion**

The system was used by the product owner for 7 months and possible defects were corrected over time and during data entry for 60 patients. In order to evaluate the system’s usability, a 26-item user experience questionnaire was used, covering various aspects of user experiences, including attractiveness, clarity, reliability, authenticity, and motivation. The UEQ questionnaire had high reliability and validity, containing premade Excel files and an automatic evaluation mechanism. In addition to facilitating the analysis and application of tools, the data analysis was an efficient and accurate method for analyzing user experience of software products. This questionnaire has been used extensively in human–computer interaction research and can be considered a complementary component to other quantitative and qualitative assessment methods that will accurately identify the weaknesses and strengths of the system. By comparing the obtained results, the data analysis of the questionnaire and the 246 previous studies that used the UEQ questionnaire for evaluation showed that the results of the system are in the range of 10% of the best results.

In the future, user experience studies should be evaluated online in several steps over different time periods. The user experience should be analyzed when working with the system in order for the results of the analysis to be judged correctly.

**References**

How I Do it

International Association of Cancer Registries
Conference Review 2018: Arequipa, Peru

Barbara J. Dearmon, BS, CTR

Introduction

The International Association of Cancer Registries (IACR) was founded in 1966 as a professional society dedicated to fostering the aims and activities of cancer registries worldwide. It is primarily for population-based registries, which collect information on the incidence and outcome of cancer in defined population groups (usually the inhabitants of a city, region, or country). For each new cancer case, registries record details on demographics, cancer identification, treatment, staging, and follow-up. Cancer incidence reporting is mandatory to population-based registries in Latin America and other countries. International registries use data linkages from vital records, citizen identifications, and other resources for cancer reporting. The North American Association of Central Cancer Registries (NAACCR) has aided with standardizing cancer registration in the Caribbean through the IACR regional hub to help establish operational procedures for collecting cancer incidence. IACR provides training and education to health professionals working in population-based registries in Latin America.

Methods

There is no international certified tumor registrar (CTR) credentialing. The data collection is performed by researchers, physicians, pathologists, and nurses and reported to incidence-based population registries. In some countries, data is collected manually. CanReg5 is a software for collecting required core data items for reporting cancer incidence. This software is provided free of charge to IACR members. International registries do not have American College of Surgeons Commission on Cancer-accredited programs or the National Accreditation of Breast Programs for monitoring quality measures and data completeness. Registries in Latin America and the Caribbean, as well as other registries, encounter some of the same challenges seen in US hospital-based cancer registries, with data being fragmented, barriers preventing access to data, and a need for additional training. International registries use the International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3) for coding primary site and histology, as well as the American Joint Commission on Cancer (AJCC) Cancer Staging Manual and pediatric cancer staging guidelines, and have standards for collecting multiple primary tumors. Data reporting is required from hospitals and mandated in these countries to track trends and morbidity rates.

IACR Poster Presentations

I was honored and privileged to be invited to attend this year’s Annual IACR 40th Scientific Conference held November 13–15, 2018 in Arequipa, Peru (known as the White City), representing the National Cancer Registrars Association (NCRA) as their immediate past president (Figure 1). I shared my journey on LinkedIn. The posting received 1,425 views, 49 likes, and 9 comments. The meeting
brought back memories of my first international meeting hosted by the Florida Tumor Registrars Association (FTRA; now known as FCRA) in the early 90s in Miami, Florida, held in conjunction with the Inter-American Congress on Cancer. The program theme this year was “Cancer Registration: from Data Generation to Decision Making.” There were several keynote speakers from around the world, and more than 128 abstract submissions, with oral and poster presentations. Health professionals, students, and researchers interested in cancer surveillance or registry operations submitted posters (Figure 2).

NCRA participated in the poster presentation with theme 4: challenges (and solutions) to cancer registration at IACR. The poster was entitled “A Role Delineation Study of the Cancer Registry Profession.” The study results and analyses were reviewed by the Council on Certification and subject-matter experts in 2017, examining our current skills, knowledge, and practices in the cancer registry profession. The study was conducted in 2017 and based on the results of the examination content in 2018. The coauthors were Michael Hechter, NCRA Director of Certification, and Kimberly Watson, CTR, Administrator of NCRA Council on Certification. The executive summary may be viewed at: http://www.ncra-usa.org/Portals/68/PDFs/NCRARoleDelineationStudy2017-ExecutiveSummary.pdf.

The poster presentation was educational and showed how cancer reporting is used in cancer control planning, implementing programs to reduce morbidity and mortality rates. The poster presentations included, but were not limited to, background on data collection derived from population based-registries, time frame, key points, methods, results, references, tables, charts, and conclusions. Below are some titles from poster presentations:

- Inequities in cancer survival in Manizales, Colombia: a population-based study
- Improving mortality data accuracy through cancer registration the cervix uteri case
- Screening history of women 60 years and older diagnosed in the Netherlands
- Proposal: National Electronic Registry of Cancer in Peru
- Cancer Registration: from data generation to decision-making
- Myeloproliferative neoplasms-incidence, prevalence and survival across Europe
- International comparison of ovarian cancer survival in young women, by histologic subtype (CONCORD-3)

Approximately 150 to 200 participants were in attendance representing Latin America, which covers 33 countries, including the Caribbean Islands. Health care professionals were able to exchange information and network with cancer registry colleagues from the Netherlands, Russia, France, Belgium, South Africa, Nigeria, Canada, Thailand, Malaysia, and the United States. IACR members traveled great distances to be educated on current trends related to cancer surveillance in population-based registries. Dr. Luis E. Medina Fernandez, the director of the Arequipa Population Cancer Registry (host of the meeting and keynote speaker), discussed the incidence of cancer in Peru, as well as causes, risk factors, and prevention interventions to reduce cancer.

**Plenary and Keynote Speaker Topics**

Topics of interest presented at the IACR conference included:
• 2018 Clemmesen Lecture covering cancer incidence in 5 continents, which focused on development of cancer registration in Latin America and the cooperation with South European countries and reviewed 3 case studies
• Global strategies and the challenge of treatment in low- and middle-income settings
• Social disparities on breast cancer in the low- and middle-income Colombian population in Cali, Columbia to include educating citizens, access to health care, later stages, lifestyle, social characteristics, and disparities
• Cancer prevention in the Caribbean and South America: how many can be prevented in France and reduce an individual’s risk of cancer, with discussion on the effects of tobacco, dietary habits, and ethanol
• Descriptive epidemiologic studies using registry data and using statistical models to estimate the burden of cancer
• Puerto Rico Central Cancer Registry: the transformation of an epidemiologic cancer surveillance system
• Global strategies in cancer control from data to implementation
• Using registry data for clinical decision making
• Use of population-based cancer registry data and cancer control planning
• Cancer registries role in improving cancer control: the Colombian experience

Data Comparison

Members of IACR have access to data visualization cancer facts and tools on the burden of cancer in selected countries or regions, or globally by primary site via the Global Cancer Observatory (GLOBOCAN) database. This database provides estimates on incidence, mortality, and prevalence on 36 specific cancer types and sites, covering 185 countries or territories worldwide in 2018. The data from GLOBOCAN is available through collaboration with population-based cancer registries from IACR as well as the World Health Organization (WHO). This information is publicly available online. In the United States, health professionals can use resources from the American Cancer Society (ACS), the Surveillance, Epidemiology, and End Results (SEER) Program, the National Cancer Institute (NCI), the Centers for Disease Control and Prevention (CDC), and other programs to obtain data on cancer incidence and mortality rates in North America. According to ACS, cancer is considered a leading cause of death worldwide. In 2012, India, China, and other East and Central Asian countries accounted for nearly half of the world’s new cancer cases and deaths (http://canceratlas.cancer.org/the-burden/). Latin America and the Caribbean represented 7.8% of the total estimated new cancer cases in 2012. The most common cancer sites diagnosed in Arequipa include breast, prostate, cervix, stomach, lung, and lymphoma. Some recent cancer statistics from GLOBOCAN and ACS are presented in Figures 3 through 5 and Tables 1 through 3.
Conclusion

Cancer registration is important to assess the burden of cancer nationally and internationally, which aids in the development of cancer control plans and in gaining financial support to implement interventions. Cancer registrars and registries will continue to play a vital role in cancer research. Quality cancer data is essential for monitoring patterns, trends, and mortality rates, and identifying priorities in public health. An international CTR certification would be beneficial to population-based registries to complement current educational training provided through IACR to enhance quality of data collection. Attending the IACR meeting is a great opportunity for cancer registry professionals to learn about cancer surveillance abroad.

I would like to thank Lori Swain, NCRA’s executive director, and Michael Hechter, NCRA’s director of certification for preparing me for the presentation and creating the poster to present at IACR.

The 2019 IACR conference will be held in Vancouver, Canada, June 10–12, in partnership with the North American Association of Cancer Registries. For more information, please visit www.iacr.com/fr/.

References

How I Do It


Vickie Hawhee, MEd, CTR; Vonetta L. Williams, PhD, MPH, CTR

Introduction
The Registry Resources Guide for Cancer Registrars was first published in this journal in 2015, presented as a list of current resources that registry personnel could use. The list has become longer since then, with many new resources being added in 2018, a year with many changes. Trying to keep up with all the new resources can be daunting for a new certified tumor registrar (CTR) as well as the seasoned professional. This list of resources is not meant to be comprehensive, but rather should serve as a foundation for all things cancer registry.

Methods
The Registry Resources Guide was initially developed to aid new employees when training and with setting up their computer for ease of access to all references. The guide was then expanded to aid employees outside of the cancer registry who work directly with the data, helping those employees understand what we report, how we report it, and why.

Results
The Registry Resources Guide is divided into the following resource categories:

- American College of Surgeons, Commission on Cancer (CoC)
- American Joint Committee on Cancer (AJCC)
- Surveillance, Epidemiology, and End Results (SEER) Program
- World Health Organization (WHO)
- North American Association of Central Cancer Registries (NAACCR)
- Physician and Facility Information
- National Treatment Guidelines
- Chemotherapy/Systemic Drug and Regimen Information
- Follow-up/Outcome
- National Organizations
- Education and Training
- Other Resources

Conclusion
In summary, the Registry Resources Guide should be useful and beneficial to new and current cancer registrars; further development of this guide can incorporate your specific state standards along with any other resources that you use on a regular basis that were not included.

Contact
Vicki Hawhee, MEd, CTR, is the quality control/education specialist for Moffitt Cancer Center in Tampa, Florida. She can be contacted at Vicki.Hawhee@Moffitt.org with any questions.

<table>
<thead>
<tr>
<th>Registry Resources Guide for Cancer Registrars</th>
<th>Description</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>STORE: Standards for Oncology Registry Entry (cases diagnosed beginning 01/01/2018)</td>
<td><a href="https://www.facs.org/quality-programs/cancer/ncdb/registrymanuals/cocmathanuals">https://www.facs.org/quality-programs/cancer/ncdb/registrymanuals/cocmathanuals</a></td>
<td>Manual used for abstracting cases diagnosed 01/01/2018 and forward, including new radiation data items</td>
</tr>
<tr>
<td>FORDS—Facility Oncology Registry Data Standards (used for cases diagnosed from 01/01/2003–12/31/2017)</td>
<td><a href="https://www.facs.org/quality-programs/cancer/ncdb/registrymanuals/cocmathanuals/fordsmanual">https://www.facs.org/quality-programs/cancer/ncdb/registrymanuals/cocmathanuals/fordsmanual</a></td>
<td>Manual used for abstracting cases diagnosed 2003–2017</td>
</tr>
<tr>
<td>Cancer Program Standards</td>
<td><a href="https://www.facs.org/quality%20programs/cancer/coc/standards">https://www.facs.org/quality%20programs/cancer/coc/standards</a></td>
<td>Downloadable copy of the standards required for CoC facilities.</td>
</tr>
<tr>
<td>CAnswer Forum</td>
<td><a href="http://cancerbulletin.facs.org/forums/">http://cancerbulletin.facs.org/forums/</a></td>
<td>Virtual bulletin board for CoC questions including AJCC, TNM staging, STORE, NCDB, CoC standards, etc</td>
</tr>
<tr>
<td>CoC Data Links</td>
<td><a href="https://www.facs.org/quality%20programs/cancer/ncdb">https://www.facs.org/quality%20programs/cancer/ncdb</a></td>
<td>National Cancer Database</td>
</tr>
<tr>
<td>Name of Resource</td>
<td>Website</td>
<td>Description</td>
</tr>
<tr>
<td>------------------</td>
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<td>--------------</td>
</tr>
<tr>
<td><strong>American Joint Committee on Cancer (AJCC)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AJCC Registrar Education</td>
<td><a href="https://cancerstaging.org/CSE/Registrar/Pages/default.aspx">https://cancerstaging.org/CSE/Registrar/Pages/default.aspx</a></td>
<td>Self-guided education</td>
</tr>
<tr>
<td>AJCC Curriculum for Registrars (7th Edition)</td>
<td><a href="https://cancerstaging.org/CSE/Registrar/Pages/AJCC-Curriculum.aspx">https://cancerstaging.org/CSE/Registrar/Pages/AJCC-Curriculum.aspx</a></td>
<td>Self-guided education based on 7th edition; great introduction into staging concepts</td>
</tr>
<tr>
<td>AJCC Disease Site Webinars (7th edition)</td>
<td><a href="https://cancerstaging.org/CSE/Registrar/Pages/Disease-Site-Webinars.aspx">https://cancerstaging.org/CSE/Registrar/Pages/Disease-Site-Webinars.aspx</a></td>
<td>Site-specific webinars for melanoma, lung, breast, prostate, and colorectal cases</td>
</tr>
<tr>
<td>AJCC Past Editions</td>
<td><a href="https://cancerstaging.org/references-tools/deskreferences/Pages/default.aspx">https://cancerstaging.org/references-tools/deskreferences/Pages/default.aspx</a></td>
<td>Past editions of the AJCC staging manual available online</td>
</tr>
<tr>
<td>AJCC channel on YouTube</td>
<td><a href="https://www.youtube.com/user/AJCCancer">https://www.youtube.com/user/AJCCancer</a></td>
<td>Various videos 3–9 minutes long giving instruction in staging.</td>
</tr>
<tr>
<td>AJCC 8th edition Staging form Supplement</td>
<td><a href="https://cancerstaging.org/references-tools/deskreferences/Pages/Cancer-Staging-Forms.aspx">https://cancerstaging.org/references-tools/deskreferences/Pages/Cancer-Staging-Forms.aspx</a></td>
<td>104 printable staging forms for each staging system</td>
</tr>
<tr>
<td><strong>Surveillance, Epidemiology and End Results (SEER) Program</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SEER (Surveillance, Epidemiology, and End Results Program)</td>
<td><a href="http://seer.cancer.gov/registrars">http://seer.cancer.gov/registrars</a></td>
<td>NCI SEER provides information, education, and training</td>
</tr>
<tr>
<td>SEER Registrar Staging Assistant (RSA)</td>
<td><a href="https://seer.cancer.gov/tools/staging/rsa.html">https://seer.cancer.gov/tools/staging/rsa.html</a></td>
<td>Provides information for EOD, SS2018, SSDIs, and grade</td>
</tr>
<tr>
<td>SEER Summary Staging Manual 2018 (cases diagnosed 01/01/2018 forward)</td>
<td><a href="http://seer.cancer.gov/tools/ssm/">http://seer.cancer.gov/tools/ssm/</a></td>
<td>Most basic way of summarizing how far a cancer has spread</td>
</tr>
<tr>
<td>Hematopoietic and Lymphoid Neoplasm Database</td>
<td><a href="http://seer.cancer.gov/seertools/hemelymph/">http://seer.cancer.gov/seertools/hemelymph/</a></td>
<td>Information for primary site and histology codes for hematopoietic and lymphoid neoplasms</td>
</tr>
<tr>
<td>SEER RX</td>
<td><a href="http://seer.cancer.gov/seertools/seerrx/">http://seer.cancer.gov/seertools/seerrx/</a></td>
<td>Interactive antineoplastic drugs database</td>
</tr>
</tbody>
</table>
### Registry Resources Guide for Cancer Registrars, cont.

<table>
<thead>
<tr>
<th>Name of Resource</th>
<th>Website</th>
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<th>Comments</th>
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<tbody>
<tr>
<td><strong>Surveillance, Epidemiology and End Results (SEER) Program</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>SEER Educate</td>
<td><a href="https://educate.fhcrc.org">https://educate.fhcrc.org</a></td>
<td>Comprehensive training program for cancer registry</td>
<td>Will need to sign up, free training</td>
</tr>
<tr>
<td><strong>World Health Organization (WHO)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>International Classification of Diseases for Oncology, Third Edition (ICDO-3)</td>
<td><a href="http://apps.who.int/iris/bitstream/handle/10665/96612/9789241548496_eng.pdf?sequence=1">http://apps.who.int/iris/bitstream/handle/10665/96612/9789241548496_eng.pdf?sequence=1</a></td>
<td></td>
<td>PDF available for download</td>
</tr>
<tr>
<td>ICD-O-3 updates for histology codes beginning 01/01/2018</td>
<td><a href="https://www.naaccr.org/implementation-guidelines/#ICDO3">https://www.naaccr.org/implementation-guidelines/#ICDO3</a></td>
<td>Must consult the update list first for new histology code/name prior to looking for the histology code in ICD-O-3. This will all be incorporated into the next version of ICD-O</td>
<td>List can be downloaded in histology number order or alphabetical order</td>
</tr>
<tr>
<td><strong>NAACCR (North American Association of Central Cancer Registries)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSDI Manual (Site Specific Data Items)</td>
<td><a href="https://apps.naaccr.org/ssdi/list/">https://apps.naaccr.org/ssdi/list/</a></td>
<td>Manual for coding SSDIs for cases diagnosed 01/01/2018 and later</td>
<td>Note also included as a download are Appendix A (schema list) and Appendix B (comparison chart of old SSFs to new SSDIs)</td>
</tr>
<tr>
<td>Recommended Abbreviations for Abstractors</td>
<td><a href="http://datadictionary.naaccr.org/?c=17">http://datadictionary.naaccr.org/?c=17</a></td>
<td>List of acceptable abbreviations to be used in text documentation for the abstract</td>
<td></td>
</tr>
<tr>
<td><strong>Physician and Facility Information</strong></td>
<td></td>
<td></td>
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<tr>
<td>NPI (National Provider Identifier)</td>
<td><a href="https://npiregistry.cms.hhs.gov/">https://npiregistry.cms.hhs.gov/</a></td>
<td>Unique Identifier number for providers/facilities</td>
<td>Can obtain address/phone/fax information for providers</td>
</tr>
<tr>
<td>Facility Identification Number (FIN) List</td>
<td><a href="https://datalinks.facs.org/CPM/ACSHosp.cfm">https://datalinks.facs.org/CPM/ACSHosp.cfm</a></td>
<td>ACOS listing of facilities in the Cancer Program Database</td>
<td></td>
</tr>
<tr>
<td><strong>National Treatment Guidelines</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National Comprehensive Cancer Network (NCCN)</td>
<td><a href="http://www.nccn.org/">http://www.nccn.org/</a></td>
<td>Treatment guidelines for cancer by site</td>
<td>You will need to register to get the health care provider recommendations (patient information can be obtained without a sign in)</td>
</tr>
<tr>
<td><strong>Chemotherapy/Systemic Drug and Regimen Information</strong></td>
<td></td>
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</table>
### Registry Resources Guide for Cancer Registrars, cont.

<table>
<thead>
<tr>
<th>Name of Resource</th>
<th>Website</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>National Treatment Guidelines</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MacMillan Cancer Support</td>
<td><a href="http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/">http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/</a>...</td>
<td>Helpful site for chemotherapy regimens</td>
<td></td>
</tr>
<tr>
<td>National Cancer Institute</td>
<td><a href="http://www.cancer.gov/about-cancer/treatment/clinical-trials/search/">http://www.cancer.gov/about-cancer/treatment/clinical-trials/search/</a>...</td>
<td>Information about clinical trials</td>
<td></td>
</tr>
<tr>
<td>NIH information on clinical trials</td>
<td><a href="https://clinicaltrials.gov/">https://clinicaltrials.gov/</a></td>
<td>Get descriptions of clinical trials and agents being used</td>
<td></td>
</tr>
<tr>
<td><strong>Follow-up/Outcome</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Online obituaries</td>
<td><a href="http://www.tributes.com/">http://www.tributes.com/</a></td>
<td>Search for obituary by patient name/state</td>
<td></td>
</tr>
<tr>
<td>Ancestry.com</td>
<td><a href="https://search.ancestry.com/search/obit/">https://search.ancestry.com/search/obit/</a></td>
<td>Search for obituary by patient name/birth year/birth location</td>
<td></td>
</tr>
<tr>
<td>CDC – SSDI (social security death index)</td>
<td><a href="https://www.npcrcss.org/ssdi/login.cfm">https://www.npcrcss.org/ssdi/login.cfm</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>National Organizations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SNOMED</td>
<td><a href="http://www.ihtsdo.org/snomed-ct">http://www.ihtsdo.org/snomed-ct</a></td>
<td>Global language of health care</td>
<td></td>
</tr>
<tr>
<td>NAACCR (North American Association of Central Cancer Registries)</td>
<td><a href="http://www.naaccr.org/">http://www.naaccr.org/</a></td>
<td>Professional organization that promotes uniform data standards</td>
<td>Provides education and training</td>
</tr>
<tr>
<td>NCRA (National Cancer Registrar's Association)</td>
<td><a href="http://www.ncra-usa.org">http://www.ncra-usa.org</a></td>
<td>Nonprofit organization for cancer registry professionals</td>
<td></td>
</tr>
<tr>
<td>National Cancer Institutes (NCI)</td>
<td><a href="http://www.cancer.gov/">http://www.cancer.gov/</a></td>
<td>Nation’s leader in cancer research</td>
<td>Information about cancer types and current research</td>
</tr>
<tr>
<td>National Program of Cancer Registries (NPCR)</td>
<td><a href="http://www.cdc.gov/cancer/npcr/">http://www.cdc.gov/cancer/npcr/</a></td>
<td>Database/statistics collected from cancer registries by the CDC</td>
<td></td>
</tr>
<tr>
<td>Cyber Cancer Registry</td>
<td><a href="https://www.cdc.gov/cancer/npcr/training/ccr.htm">https://www.cdc.gov/cancer/npcr/training/ccr.htm</a></td>
<td>The Cyber Registry is an interactive tool developed with the National Program of Cancer Registries (NPCR) to prepare people for a career in the cancer registry field. By working through the exercises and quizzes, you will gain practical experience in the functions of a cancer registrar in both hospitals and central registries.</td>
<td></td>
</tr>
<tr>
<td><strong>Education and Training</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Center for Cancer Registry Education (CCRE)</td>
<td><a href="http://www.cancerregistryeducation.org/">http://www.cancerregistryeducation.org/</a></td>
<td>Education/training programs</td>
<td></td>
</tr>
<tr>
<td>CTR Exam prep</td>
<td><a href="http://www.cancerregistryeducation.org/ctr-prep">http://www.cancerregistryeducation.org/ctr-prep</a></td>
<td>On line practice tests and webinars for the CTR</td>
<td>Currently $25–$365</td>
</tr>
<tr>
<td>CDC – NPCR Training</td>
<td><a href="http://www.cdc.gov/cancer/npcr/training/">http://www.cdc.gov/cancer/npcr/training/</a></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Registry Resources Guide for Cancer Registrars, cont.

<table>
<thead>
<tr>
<th>Name of Resource</th>
<th>Website</th>
<th>Description</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education and Training</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NAACCR CTR Prep</td>
<td><a href="https://www.naaccr.org/ctr-exam-preparation-review/">https://www.naaccr.org/ctr-exam-preparation-review/</a></td>
<td></td>
<td>Currently $195</td>
</tr>
<tr>
<td>CTR Exam</td>
<td><a href="http://www.ctexam.org">http://www.ctexam.org</a></td>
<td></td>
<td>Currently $315 for members, $415 for nonmembers</td>
</tr>
<tr>
<td><strong>Other Resources</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCRA Informational Abstracts</td>
<td><a href="http://www.cancerregistryeducation.org/rr">http://www.cancerregistryeducation.org/rr</a></td>
<td>Sample abstracts by primary site provide information on important resources and an outline to follow when determining what text to include</td>
<td>Free for download</td>
</tr>
<tr>
<td>3D Body Maps</td>
<td><a href="http://www.healthline.com/human-body-maps/">http://www.healthline.com/human-body-maps/</a></td>
<td></td>
<td>Anatomy and physiology</td>
</tr>
<tr>
<td>American Cancer Society – Cancer Glossary</td>
<td><a href="http://www.cancer.org/cancer/cancerglossary/index">http://www.cancer.org/cancer/cancerglossary/index</a></td>
<td>Alphabetic listing of terms related to cancer</td>
<td>Medical terminology</td>
</tr>
<tr>
<td>Medscape Oncology</td>
<td><a href="http://www.medscape.com/oncology">http://www.medscape.com/oncology</a></td>
<td>Information about diseases, drugs, oncology news</td>
<td>Use the search box to find topics</td>
</tr>
<tr>
<td>ICD – 10</td>
<td><a href="http://apps.who.int/classifications/icd10/browse/2010/en">http://apps.who.int/classifications/icd10/browse/2010/en</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CTR Exam Resources</td>
<td><a href="http://www.ctexam.org/resources/">http://www.ctexam.org/resources/</a></td>
<td>References required for the CTR exam</td>
<td>Lists those resources you should use to study as well as those you are required to bring for the open book portion of the exam</td>
</tr>
<tr>
<td>Radiology Assistant</td>
<td><a href="http://www.radiologyassistant.nl/en/p42023a885587e/welcome-to-the-radiology-assistant.html">http://www.radiologyassistant.nl/en/p42023a885587e/welcome-to-the-radiology-assistant.html</a></td>
<td>Great site showing nodal stations and other anatomy</td>
<td></td>
</tr>
<tr>
<td>Pelvic surgery atlas</td>
<td><a href="http://www.atlasofpelvicsurgery.com/home.html">http://www.atlasofpelvicsurgery.com/home.html</a></td>
<td>Describes various pelvic surgeries</td>
<td></td>
</tr>
</tbody>
</table>
1. According to the authors, the hospital-based registry evolved from a research database through which of the following efforts?

- Setting a predefined purpose for the registry
- Collaborating with international researchers
- Following patient cancer and survival outcomes
- Creating a prespecified data collection form

   a) Y Y Y N  
   b) Y Y N Y  
   c) Y N Y Y  
   d) N Y Y Y  

2. The Renal Cell Carcinoma Registry (RCCR) excluded data on patients who:
   a) were clinically diagnosed with locoregional disease
   b) had clinical diagnoses and metastatic disease
   c) had histologic confirmation of metastatic disease
   d) had biopsy-proven disease without surgery

3. Desirable characteristics of Research Electronic Data Capture (REDCap) include:
   a) scalability limited to the kidney clinic
   b) slow and deliberate deployment capabilities
   c) cost-effectiveness and easy setup
   d) use restricted to in-house clinicians

4. Automation of the RCCR was essential in order to:

<table>
<thead>
<tr>
<th>increase efficiency</th>
<th>improve data quality</th>
<th>eliminate record linkages</th>
<th>reduce health care costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>b) Y</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>c) Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>d) N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

5. The application chosen to allow for enterprise reports and data analysis was:
   a) Research Electronic Data Capture (REDCap)
   b) Electronic Health Intelligence Systems (eHIntS)
   c) Oracle Business Intelligence Enterprise Edition (OBIEE)
   d) Systematized Nomenclature of Medicine (SNOMED)

6. According to Table 3, Validation of Automated Data, which of the following items failed to achieve a 100% accuracy rate?
   a) Primary site
   b) Date of birth
   c) Sex
   d) Name

<table>
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<th>ICD-10-CM codes</th>
<th>surgical procedure codes</th>
<th>RCC drugs</th>
<th>laboratory results</th>
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<td>c) N</td>
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<td>d) N</td>
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</table>

7. Renal Cell Carcinoma (RCC) patients were identified through

   a) ICD-10-CM codes
   b) surgical procedure codes
   c) RCC drugs
   d) laboratory results

   a) Y Y N N
   b) Y Y N N
   c) N N Y Y
   d) N Y Y N

8. Automation resulted in an interval between date of diagnosis and data availability for utilization as short as:
   a) 6 months
   b) 6 weeks
   c) 30 days
   d) 1 day

9. The REDCap/OBIEE system utilized 4 pathways for casefinding, including:
   a) inpatient discharge summary
   b) SNOMED international codes
   c) uropathological meetings
   d) abnormal radiology notifications

10. The integrated framework comprising RCCR, eHIntS, REDCap and OBIEE reduced:
     a) data quality
     b) completeness
     c) timeliness of data collection
     d) data manual collection times

The JRM Quiz and answers are now available through NCRA’s Center for Cancer Registry Education (CCRE). For your convenience, the JRM article and quiz can be accessed online at [www.CancerRegistryEducation.org/jrm-quizzes](http://www.CancerRegistryEducation.org/jrm-quizzes). Download the article, complete the quiz and claim CE credit all online.
Instructions: Mark your answers clearly by filling in the correct answer, like this ■ not like this □. Passing score of 70% entitles one (1) CE clock hour per quiz.

Please use black ballpoint pen.

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Submit the original quiz answer sheet only! No photocopies will be accepted.

This original quiz answer sheet will not be graded, no CE credit will be awarded, and the processing fee will be forfeited unless postmarked by:

June 30, 2021

Quiz Identification Number: 4504

JRM Quiz Article:

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Reviewer acknowledgement: JRM gratefully acknowledges the individuals who have served as manuscript reviewers or have otherwise assisted in the review process during the past year. Their wise counsel and contributions to the Journal have been most valued.

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**Acute Stroke Care Quality Surveillance**

**Acute Stroke Registry Planning**

**Administrative Claims Data**

**Aged**

**AJCC Cancer Staging**

**Automation**

B

**Bilateral Mastectomy**

**Birth Defects Surveillance**

**Brain Tumor**

**Breast**

**Breast Cancer Surgery**

C

**Canadian Cancer Registry**

**Cancer**

**Cancer Registry**


**Eckstrand A, Shack L, Pham TM, Davis F. The Impact of Hospital Discharge Linkage on Case Ascertainment of Brain Tumors in the Alberta Cancer Registry, 2010–2015. Fall;45(3):109-116.**

**Cancer Surveillance**

**Care Quality Measures**

**Case Ascertainment**

**Case-Completeness**

**Central Nervous System Tumors**
Colorectal Cancer

Contralateral Prophylactic Mastectomy

Completeness

Computerization

Cost Data Collection

Core Data Set

Double Mastectomy

Elderly

Electronic Access

Electronic Medical Records (EMRs)

Epidemiology

Emergency Care Quality

Esophageal Atresia

Health Services Research

High-Grade Dysplasia

Hospital Discharge

Human Papillomavirus

ICD-9-CM Diagnostic Codes

In Situ

International Agency for Research on Cancer
Mammography

Medical Records

Multiple Primary Rules

N

Natural Language Processing Algorithm Solution

Nonmalignant

Obstructive Genito-Urinary Defects

Oral Cavity Cancer

Oropharyngeal Carcinomas

P

Pancreas

Population Surveillance

Preventive Mastectomy

Q

Quality Audit

Radiology Reports

Record Linkage

Registry/Registries

Registry Data Elements

Registry Development

Registry Establishment

Renal Cell Carcinoma Registry

Reporting
Screening Compliance

SEER

SEER Database

Squamous Cell Carcinomas

Tumor Size

Validation Study

Stroke

Surveillance, Epidemiology, and End Results (SEER) Program

Tumors
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Winter 2018 Continuing Education Quiz
National Cancer Registrars Association

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Vonetta L. Williams, PhD, MPH, CTR | EDITOR-IN-CHIEF, JRM

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Topics:
1. Birth Defects Registries
2. Cancer Registries
   a. AJCC TNM Stage
   b. Cancer and Socioeconomic Status
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Contributed manuscripts are peer-reviewed prior to publication.

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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.
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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: Vonetta L. Williams, PhD, MPH, CTR, Editor-in-Chief, Journal of Registry Management, (813) 745-1783, JRMEditor@ncra-usa.org.

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Journal of Registry Management

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