

**Open Access:** Full open access to this and thousands of other papers at http://www.la-press.com.

# CancerInformatics

Supplementary Issue: Computational Advances in Cancer Informatics (B)

# Conducting Retrospective Ontological Clinical Trials in ICD-9-CM in the Age of ICD-10-CM

Neeta K. Venepalli<sup>1,†</sup>, Ardaman Shergill<sup>1,†</sup>, Parvaneh Dorestani<sup>2</sup> and Andrew D. Boyd<sup>2–5</sup>

<sup>1</sup>Department of Medicine, Section of Hematology/Oncology, University of Illinois at Chicago, Chicago, IL, USA. <sup>2</sup>Departments of Biomedical and Health Information Sciences, University of Illinois at Chicago, Chicago, IL, USA. <sup>3</sup>Institute for Translational Health Informatics, University of Illinois at Chicago, Chicago, IL, USA. <sup>4</sup>Department of Strategic Initiatives, University of Illinois Hospital and Health Science System, Chicago, IL, USA. <sup>5</sup>Department of Medicine, University of Illinois at Chicago, Chicago, IL, USA. <sup>†</sup>Both authors contributed equally to the manuscript.

## ABSTRACT

**OBJECTIVE:** To quantify the impact of International Classification of Disease 10th Revision Clinical Modification (ICD-10-CM) transition in cancer clinical trials by comparing coding accuracy and data discontinuity in backward ICD-10-CM to ICD-9-CM mapping via two tools, and to develop a standard ICD-9-CM and ICD-10-CM bridging methodology for retrospective analyses.

**BACKGROUND:** While the transition to ICD-10-CM has been delayed until October 2015, its impact on cancer-related studies utilizing ICD-9-CM diagnoses has been inadequately explored.

MATERIALS AND METHODS: Three high impact journals with broad national and international readerships were reviewed for cancer-related studies utilizing ICD-9-CM diagnoses codes in study design, methods, or results. Forward ICD-9-CM to ICD-10-CM mapping was performing using a translational methodology with the Motif web portal ICD-9-CM conversion tool. Backward mapping from ICD-10-CM to ICD-9-CM was performed using both Centers for Medicare and Medicaid Services (CMS) general equivalence mappings (GEMs) files and the Motif web portal tool. Generated ICD-9-CM codes were compared with the original ICD-9-CM codes to assess data accuracy and discontinuity.

RESULTS: While both methods yielded additional ICD-9-CM codes, the CMS GEMs method provided incomplete coverage with 16 of the original ICD-9-CM codes missing, whereas the Motif web portal method provided complete coverage. Of these 16 codes, 12 ICD-9-CM codes were present in 2010 Illinois Medicaid data, and accounted for 0.52% of patient encounters and 0.35% of total Medicaid reimbursements. Extraneous ICD-9-CM codes from both methods (Centers for Medicare and Medicaid Services general equivalent mapping [CMS GEMs, n = 161; Motif web portal, n = 246]) in excess of original ICD-9-CM codes accounted for 2.1% and 2.3% of total patient encounters and 3.4% and 4.1% of total Medicaid reimbursements from the 2010 Illinois Medicare database.

**DISCUSSION:** Longitudinal data analyses post-ICD-10-CM transition will require backward ICD-10-CM to ICD-9-CM coding, and data comparison for accuracy. Researchers must be aware that all methods for backward coding are not comparable in yielding original ICD-9-CM codes.

**CONCLUSIONS:** The mandated delay is an opportunity for organizations to better understand areas of financial risk with regards to data management via backward coding. Our methodology is relevant for all healthcare-related coding data, and can be replicated by organizations as a strategy to mitigate financial risk.

KEYWORDS: cancer research, ICD-9-CM, cancer informatics infrastructure, clinical trials

SUPPLEMENT: Computational Advances in Cancer Informatics (B)

CITATION: Venepalli et al. Conducting Retrospective Ontological Clinical Trials in ICD-9-CM in the Age of ICD-10-CM. Cancer Informatics 2014:13(S3) 81–88 doi: 10.4137/CIN.S14032.

RECEIVED: May 19, 2014. RESUBMITTED: June 30, 2014. ACCEPTED FOR PUBLICATION: July 1, 2014.

ACADEMIC EDITOR: JT Efird, Editor in Chief

TYPE: Review

FUNDING: Authors disclose no funding sources

COMPETING INTERESTS: AB has received speaking fees from Epic Corporation, outside the submitted work.

**COPYRIGHT:** © the authors, publisher and licensee Libertas Academica Limited. This is an open-access article distributed under the terms of the Creative Commons CC-BY-NC 3.0 License.

CORRESPONDENCE: nkv@uic.edu; boyda@uic.edu

This paper was subject to independent, expert peer review by a minimum of two blind peer reviewers. All editorial decisions were made by the independent academic editor. All authors have provided signed confirmation of their compliance with ethical and legal obligations including (but not limited to) use of any copyrighted material, compliance with ICMJE authorship and competing interests disclosure guidelines and, where applicable, compliance with legal and ethical guidelines on human and animal research participants. Provenance: the authors were invited to submit this paper.

CANCER INFORMATICS 2014:13(S3)



#### Introduction

The United States was originally scheduled to transition from the International Classification of Disease 9th Revision Clinical Modification (ICD-9-CM) to ICD-10-CM on October 1, 2014. However on April 1, 2014, the Protecting Access to Medicare Act of 2014 was enacted with delay in ICD-10-CM implementation until October 1, 2015.<sup>2</sup> In 2012, Centers for Medicare and Medicaid Services (CMS) estimated that a 1-year delay in ICD-10-CM implementation could cost \$306 million<sup>3</sup>; a more recent estimate by the American Health Information Management Association estimated an additional \$1 billion to \$6.6 billion in excess of already incurred costs.4 The vast majority of these costs are estimated to arise from financing ICD-10-CM implementation including technology upgrades, biller and coder training, and clinical documentation enhancement. However, less attention has been paid to post-implementation costs of, and management strategies for, data accuracy within longitudinal databases spanning both ICD-9-CM and ICD-10-CM.

While ICD-10-CM has greater specificity and promises to be more effective at comprehensive public health data reporting, ICD-10 implementation in other countries has resulted in considerable disruption in data reporting with demonstrable impact on relative risk estimates for death<sup>5</sup> and reported differences in comorbidity coding within 5 years of transition.6 While the original intent for ICD codes was for global standardization of epidemiological reporting to the World Health Organization (WHO), ICD-9-CM codes are widely utilized in the US for billing and reimbursement purposes, in addition to measuring safety and quality of medical care, designing delivery symptoms and setting healthcare policy, resource utilization, performance measures, healthcare research and clinical trials, and public health reporting. Given that coded data is essential for public health disease tracking, epidemiological healthcare research, cancer registries, clinical trials, healthcare utilization patterns and resource allocation, and payer reimbursements, the impact of discontinuity in data reporting has significant financial impact. Data collection spanning October 2015 will require both forward (ICD-9-CM to ICD-10-CM) and backward (ICD-10-CM to ICD-9-CM) coding to ensure data congruency. Currently, there is a dearth of published literature on the sensitivity and specificity of backward coding methods, and no standard ICD-9-CM and ICD-10-CM bridging methodology for accurate coding in longitudinal data analyses.

The CMS has created a reference bidirectional GEM code translation system which is widely utilized and publically available. CMS GEMs files provide forward and backward translations in a numerical and tabular format<sup>7,8</sup> without further information about ambiguous or complex code mappings. The Translational Health Informatics group at the University of Illinois at Chicago (UIC) has developed an unbiased network modeling methodology (Motif web portal ICD-9-CM conversion tool, or Motif web portal

tool at http://www.lussierlab.org/transition-to-ICD10CM) to visually map ICD-9-CM and ICD-10-CM code conversions, and quantitatively predict problematic ICD-9-CM to ICD-10-CM bidirectional mappings.<sup>9</sup>

Per prior work, 36% of ICD-9-CM to ICD-10-CM translations are associated with complex mappings, and 1% of ICD-9-CM codes have no corresponding ICD-10-CM codes. Despite prior work suggesting hematology—oncology would be the least impacted medical specialty based on a lower ICD-10-CM to ICD-9-CM code ratio, and smaller frequency of complex mappings, recently published data showed forward mapping of commonly utilized ICD-9-CM hematology—oncology diagnoses within an academic cancer center's database, and Illinois Medicaid database resulted in information loss affecting upwards of \$500,000, and 6% of total billing costs. 10

The objective of our study was to quantify the impact of ICD-10-CM transition in cancer clinical trials by comparing coding accuracy and data discontinuity with backward ICD-10-CM to ICD-9-CM mapping via two tools, and to develop a standard ICD-9-CM and ICD-10-CM bridging methodology for use in longitudinal data analyses.

## Methods

**Data collection.** The research project was approved by the University of Illinois Institutional Review Board 2012–0773. ICD-9-CM diagnosis codes were collected from three high impact medical journals, and utilization data from an Illinois Medicaid dataset.

Identification of articles utilizing ICD-9-CM diagnoses. Three high impact medical journals with broad national and international readerships were selected by the authors for analysis, including the New England Journal of Medicine (NEJM), Journal of Clinical Oncology (JCO), and Blood. All published articles between January 1, 2013 and December 31, 2013 were reviewed manually and independently by two University of Illinois hematology-oncology physicians for utilization of ICD-9-CM diagnoses codes in study design, methods, or results (Fig. 1). Upon final review, only cancer-related studies based in the United States utilizing ICD-9-CM codes were included. While SEER-Medicaid, SEER-Medicare, and Veterans Administration databases (only those which confirmed usage of ICD-9-CM) were included, publications utilizing WHO ICD9, WHO ICD10, ICD-O, National Death Index, and SEER were not included because ICD-9-CM codes were not utilized. Review articles, editorials, correspondence, commentaries, and grand rounds were also excluded. In cases of disagreement or confusion regarding ICD-9-CM usage, corresponding authors of the publication were contacted via email for confirmation. Two contact attempts were made within 4 weeks, and articles without responses were excluded. For articles confirmed to utilize ICD-9-CM codes, all ICD-9-CM diagnoses and the numbers of associated patients were recorded (Table 1).

ICD-9-CM to ICD-10-CM forward coding. Each ICD-9-CM code was mapped forward to its associated



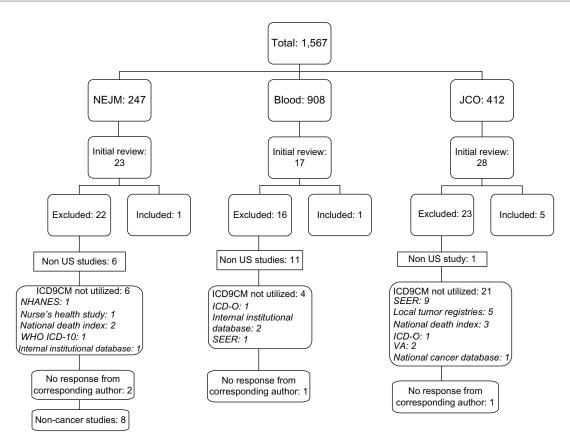


Figure 1. Selection of articles utilizing ICD-9-CM codes within study design, methods, and/or results.

Abbreviations: ICD-0, International Classification of Diseases for Oncology; JCO, Journal of Clinical Oncology; NEJM, The New England Journal of Medicine; NHANES, National Health and Nutrition Examination Survey; SEER, surveillance epidemiology, and end results program; VA, US Department of Veterans Affairs; WHO, World Health Organization.

ICD-10-CM code(s) via the Motif web portal tool (version 1.2) per previously described methodology<sup>9</sup> (Table 1).

ICD-10-CM gap analysis. The generated list of ICD-10-CM codes was again reviewed by two hematology—oncology physicians to confirm clinical relevance to the original article. A gap analysis was conducted by comparing generated ICD-10-CM codes to a complete listing of all 2014 ICD-10-CM codes (http://www.icd10data.com) to identify clinically relevant ICD-10-CM codes missing from the initial generated list. This step was necessary as 1% of all ICD-10-CM codes do not have any associated mapping, and to be representative of how a researcher would view ICD-10-CM data. Missing ICD-10-CM codes which were categorized as relevant and important for the study were added to the initial generated ICD-10-CM list to create a comprehensive ICD-10-CM list.

ICD-10-CM to ICD-9-CM backward coding and comprehensive analysis. The comprehensive list of ICD-10-CM codes (generated and additional relevant codes) was coded backward to ICD-9-CM through two methods, including the Motif web portal tool (v1.2)<sup>9</sup> and publically available existing CMS GEMs files (http://www.cms.gov/Medicare/Coding/ICD10/2014-ICD-10-CM-and-GEMs.html).

To assess data fidelity and identify the method with the highest backward coding accuracy, original ICD-9-CM codes

from the seven final articles were compared to the generated ICD-9-CM codes from the Motif web portal method and the CMS GEM method.

Cost analysis. Original ICD-9-CM codes that were missing from the final lists generated by both backward coding methods were categorized as "lost in translation." Additional ICD-9-CM codes generated by both methods were categorized as "extraneous." An Illinois Medicaid database was assessed for the presence of ICD-9-CM codes that were lost in the final translation back to ICD-9-CM per previously described methodology.<sup>9,10</sup> Illinois Medicaid data consisted of reimbursement data and associated ICD-9-CM diagnosis codes for calendar year 2010 for all patients assigned to a UIC primary care physician as of April 2011. In total, Illinois Medicaid 2010 data consist of 1,466,581 patient encounters, 299 institutions, 38,644 patients, and \$382 million in Medicaid reimbursements. For "lost" and "extraneous" ICD-9-CM codes, associated reimbursements and patient visits were tallied to provide an estimate of potential financial risk associated with ICD-9-CM transition with regards to longitudinal data analysis.

# Results

**Identification of articles utilizing ICD-9-CM diagnoses.** In total, 1,567 original articles were reviewed from the



Table 1. Final articles and ICD-9-CM codes, with cancer-specific and Klabunde-specific categories.

ARTICLE	JOURNAL	ICD-9-CM DATABASE	N (PTS)	N (PTS) ICD-9-CM CODES (N)	CANCER-SPECIFIC ICD-9-CM CODES (N)	CANCER-SPECIFIC KLABUNDE SPECIFIC ICD-9-CM CODES (N)	ICD-10-CM CODES (N)	KLABUNDE SPECIFIC ICD-10-CM ADDITIONAL ICD-10-CM ICD-9-CM CODES (N) CODES (N)
6	NEJM	5 data sources with information about Medicare fee-for-service beneficiaries: The carrier file The hospital Outpatient file The centers of medicare and medicaid Services Beneficiary summary file The medicare physician identification and eligibility registry file The national provider identifier file information	n/a	12	12	0	<del>4</del>	2
20	900	SEER-Medicare linked database	25983	164	27	0	664	480
21	OOF	California Cancer Registry – Medicaid enrollment files New York State Cancer Registry – Medicare and Medicaid enrollment files California SEER-Medicare database	62100	253	7	167	1395	1142
22	900	SEER-Medicare database	16085	275	28	167	1486	1211
23	OOF	VA Central cancer registry Centralized VA data system	2022	256	10	167	1382	1126
24	JCO	SEER-Medicare Texas cancer registry-medicare linked database	9535	112	6	0	410	298
25	Blood	Institutional lymphoma database Social Security Administration Database	1334	6	6	0	100	91

Abbreviations: ICD-9-CM, The International Classification of Diseases, 9th Revision, Clinical Modification; ICD-10-CM, The International Classification of Diseases, 10th Revision, Clinical Modification; JCO, Journal of Clinical Oncology; and end results program; VA: US Department of Veterans Affairs.



NEJM (247), Blood (908), and JCO (412). Initially, 68 articles were identified as utilizing administrative databases. Of these, 18 were excluded due to being non-US-based studies with the use of country-specific ICD codes; eight were excluded due to being non-cancer related; four were excluded due to lack of email response from corresponding authors; 31 were excluded due to utilization of other diagnoses codes or administrative databases. Seven articles were included in the final evaluation (Fig. 1).

In total, 412 discrete ICD-9-CM codes were identified from all seven articles (Table 1), of which 245 ICD-9-CM codes were associated with the Klabunde comorbidity classification. The Klabunde comorbidity index incorporates diagnostic and procedure data contained within Medicare physician claims to incorporate comorbidities recorded on both inpatient and outpatient claims, and is based on Charlson comorbidity conditions. A total of 54 ICD-9-CM codes were associated with malignancy: prostate (2), secondary neoplasm of lymph nodes (8), secondary neoplasm of bone and bone marrow (1), colo-rectal-anal (15), breast (11), trachea and lung (7), and lymphoma (10).

ICD-9-CM to ICD-10-CM forward coding. In total, 412 ICD-9-CM codes mapped forward to 1437 ICD-10-CM codes; six of these ICD-9-CM parent codes did not map forward to any ICD-10-CM codes. Parent codes are ICD-CM codes that do not map forward to ICD-10-CM, but are still utilized for diagnoses, reimbursement, and clinical research.

ICD-10-CM gap analysis. Given that 1% of ICD-10-CM codes are without associated mappings, we felt it necessary to compare the generated ICD-10-CM codes with a manual review of the comprehensive 2014 ICD-10-CM CMS GEMs diagnoses list. This step is necessary for retrospective research utilizing ICD-9-CM and ICD-10-CM codes. Upon manual review of the complete ICD-10-CM CMS GEMs diagnoses list, an additional 441 ICD-10-CM codes were found to be clinically relevant to the initial articles. These additional 441 ICD-10-CM codes were not identified during forward mapping from the original ICD-9-CM codes. In total, 1,864 discrete ICD-10-CM codes were included in comprehensive ICD-10-CM list.

ICD-10-CM to ICD-9-CM backward coding, and comprehensive analysis. Mapping backward from 1864 ICD-10-CM codes via both the CMS GEMS and Motif web portal methods resulted in a higher number of ICD-9-CM codes than the original list of 406 ICD-9-CM (excluding parent codes). While the Motif web portal method yielded 652 ICD-9-CM codes including 406 original ICD-9-CM codes, the CMS GEMS method yielded 551 ICD-9-CM codes including 390 of the original 406 ICD-9-CM codes. The 16 original codes missing from the CMS-GEMS backward map method are listed in Table 2; none were cancer related, and 12 codes were associated with the Klabunde comorbidity index. The Motif web portal tool demonstrated higher sensitivity for identifying initial ICD-9-CM codes in comparison to the CMS-GEMs method ( $\rho$  < 0.0001 using Wilcoxon

matched pairs); the Motif web portal tool sensitivity was 0.985 and specificity was 0.983, compared to CMS GEMs sensitivity 0.947 and specificity of 0.989, respectively (Fig. 2).

Cost analysis. The 16 ICD-9-CM codes that were "lost in translation" during backward coding from ICD-10-CM via CMS GEMs method to ICD-9-CM accounted for 3.9% of the original 412 ICD-9-CM codes from all seven articles. Of these 16 codes, 12 were present in the Medicaid data. Medicaid reimbursements associated with the 12 ICD-9-CM codes accounted for a total of 7,489 patient encounters and a cost of \$1,134,999 million, or 0.52% of total patient encounters and 0.35% of total Medicaid reimbursements from the 2010 Illinois Medicare database (Table 2).

"Extraneous" ICD-9-CM codes generated by the Motif web portal method (n = 246) accounted for a total of 32,989 patient encounters, and \$13,498,800 in Medicaid Reimbursements. "Extraneous" ICD-9-CM codes generated by the CMS GEMs method (n = 161) accounted for a total of 30,560 patient encounters, and \$11,396,400 in Medicaid Reimbursements. In total, extraneous ICD-9-CM codes from both methods (CMS GEMs, n = 161; Motif web portal, n = 246) in excess of original ICD-9-CM codes accounted for 30,560 and 32,989 or 2.1% and 2.3% of total patient encounters and \$11,395,000 and \$13,498,000 or 3.4% and 4.1% of total Medicaid reimbursements from the 2010 Illinois Medicare database. Dollar amounts are rounded to 5 significant digits.

# Discussion

Immediate impact upon longitudinal data analyses. While the majority of ICD-10-CM transition has revolved around implementation challenges, little discussion has been devoted to the impact of coded data discontinuity for clinical trials and cancer registries, public health disease tracking, epidemiological healthcare research, healthcare utilization patterns and resource allocation, and payer reimbursements. Based on international experiences with ICD-10 transition,<sup>5,6</sup> we anticipate substantial challenges with backward coding from ICD-10-CM to ICD-9-CM for databases spanning the ICD-10-CM transition, and ensuring the backward codes are consistent and inclusive of the initial ICD-9-CM codes utilized in administrative databases. Based on our evaluation of seven cancer-related studies, we present a specific bridging methodology and analytic tools which can replicated for retrospective longitudinal data analyses to ensure data fidelity between original ICD-9-CM, ICD-10-CM codes, and generated ICD-9-CM via backward coding. We confirm the necessity for a manual review of ICD-10-CM codes after the initial forward coding is completed to ensure a comprehensive and relevant ICD-10-CM list is being utilized, based on our findings that manual review yielded an additional 23% of clinically relevant ICD-10-CM codes absent with forward coding alone. Finally, we show significant differences in backward coding methodology in yielding original ICD-9-CM codes



Table 2. ICD-9-CM codes lost in backward translation, and associated fiancial information.

ICD-9-CM	ARTICLES*	PATIENT VISITS (N)	ILLINOIS MEDICAID REIMBURSEMENTS (\$)
250.02 type II diabetes mellitus [non-insulin dependent type] [NIDDM type] [adult-onset type] or unspecified type, uncontrolled, without mention of complication	24*	5685	626537.36
250.03 type I diabetes mellitus [juvenile type], uncontrolled, without mention of complication	20–24*	1250	165326.91
250.21 Diabetes mellitus, type I [insulin dependent type] [IDDM] [juvenile type] with hyperosmolarity, not stated as uncontrolled	20–24*	28	36558.56
290.12 Presenile dementia with delusional features	21–23*		
410.00 Acute myocardial infarction, of anterolateral wall, episode of care unspecified	20–24*	3	201.1
410.2 Acute myocardial infarction, of inferolateral wall, episode of care unspecified	20–24*	2	3600
410.30 Acute myocardial infarction, of inferoposterior wall, episode of care unspecified	20–24*		
410.50 Acute myocardial infarction, of other lateral wall, episode of care unspecified	20–24*	1	120
410.70 Acute myocardial infarction, subendocardial infarction, episode of care unspecified	20–24*	52	9125.5
410.90 Acute myocardial infarction, unspecified site, episode of care unspecified	20–24*	67	11972.5
413.0 Angina decubitus	20,24	6	1034.05
414.00 Coronary atherosclerosis of unspecified type of vessel, native or graft	24	380	270232.66
425.7 Nutritional and metabolic cardiomyopathy	24		
433.30 Occlusion and stenosis of multiple and bilateral precerebral arteries, without mention of cerebral infarction	20–23*	13	4773
482.30 Pneumonia due to Streptococcus, unspecified	20	2	5517
532.71 Chronic duodenal ulcer without mention of hemorrhage or perforation, with obstruction	21–23		
Total:		7,489	\$1,134,998.64

Note: \*included in Klabunde comorbidity

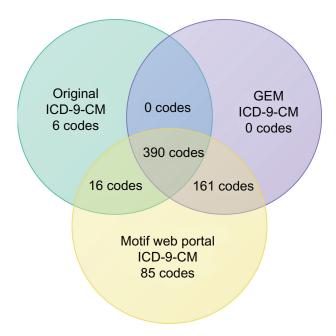
with greater sensitivity and full coverage with the Motif web portal method compared to the CMS GEMs files method. The 16 missing ICD-9-CM codes accounted for a substantial potential financial impact of greater than \$1 million, while extraneous ICD-9-CM codes accounted for greater than \$24 million in the 2010 Illinois Medicaid database, highlighting significant financial risk of data and diagnoses discontinuity with impact on reimbursements and business analytic forecasting.

International experience with ICD-10 transition provides some insight and limited guidance into the types of challenges we may face in the US with ICD-10-CM transition. In a Swiss analysis evaluating comorbidity indices scoring for three hospitals between 1999 to 2003 following ICD-10 introduction, sensitivity estimates improved by greater than 5% to a sensitivity of 43% over 5 years, suggesting that improved data accuracy was related to a coding "learning curve". A Canadian publication evaluated 32 medical conditions with ICD-10 diagnoses within 4,008 charts, and subsequently recoded the medical conditions to ICD-9-CM for data comparison;

researchers found that ICD-10 data had lower sensitivity for 7 of 32 conditions assessed relative to ICD-9-CM data, and that validity differed between coding versions with sensitivity varying between 9% and 80%. A publication assessing the impact of ICD-9 to ICD-10 transition on relative risk estimates found sensitivity as low as 26%, and reported that inconsistencies in mortality outcomes as classified by ICD-9 and ICD-10 could bias and substantially impact relative risk estimates. S

However, the majority of these data utilized dual coding rather than backward coding as a means for comparison. There are little published data reporting on the impact of backward coding for longitudinal databases. A recent US-based publication assessed the impact of Medicare payments to hospitals utilizing 2009 Medicare data, through converting ICD-9-CM diagnoses to ICD-10, and converting ICD-10 via CMS GEMs to ICD-9-CM. The study found that backward mapping resulted in change in diagnoses for 3.66% of patients with moderate financial impact with decreases in up to 0.46% of payment distributions to all hospitals. <sup>14</sup> This is consistent





**Figure 2.** Venn diagram of original ICD-9-CM and backward generated ICD-9-CM codes. The sensitivity of CMS GEMs method was 0.946 and specificity was 0.989. The sensitivity of the Motif web portal tool was 0.985 and specificity was 0.983.

with our findings with regards to the substantive impact for "missing" ICD-9-CM codes, impacting more than 7,000 patient encounters and more than \$1 million in 2010 Illinois Medicaid reimbursements (0.3% of all bills and 0.5% of all visits). This highlights the importance of supplementing the initial ICD-10-CM codes generated by forward coding with a manual review of a comprehensive ICD-10-CM diagnoses list; given that 1% of ICD-10-CM codes will not have associated ICD-9-CM codes, the potential for data loss is greater without this additional step. Additionally, our study reports a significant number of "extraneous" ICD-9-CM codes with backward coding; extraneous ICD-9-CM codes are potential data confounders with substantial financial impact, affecting 4.4% of total patient encounters (>60,000 patient encounters) and 7.6% of total Medicaid reimbursements (>\$24 million) in the 2010 Illinois Medicaid dataset. There is likely greater financial risk associated with backward coding than has previously been reported. Missing or extraneous diagnoses may present as reimbursement differences and significantly impact future practice financial analyses, business forecasting, and resource allocation. Missing diagnoses are more likely to result in decreased reimbursements, while extraneous codes may result in resource misallocation. A reliable methodology for backward coding may mitigate financial risk by identifying areas of data discrepancy and anticipating financial impact.

Notably, our study demonstrated significant differences in data quality through backward coding via two methods, the Motif web portal and CMS GEMs. Both results yielded more ICD-9-CM codes than the original list, but the Motif web portal method successfully yielded all of the

initial 412 codes (missing six parent codes), whereas the CMS GEMs method missed 16 of the original 412 codes. Twelve of these 16 codes were relevant for the Klabunde comorbidity classification, demonstrating the potential risk for information loss for comorbidity indices and impact on incorrect scoring. A substantive body of health services research and clinical trials research focuses on specific comorbidities, and comorbid illness is of significant concern for patients with cancer. Widely utilized comorbidity measures include the Charlson index, the Klabunde index (incorporating both inpatient and outpatient diagnoses and procedure codes from Medicare data), the Adult comorbidity Evaluation 27<sup>15</sup>; disease-specific comorbidity measures are also frequently utilized, and most have been adapted for use with ICD-9-CM administrative databases.<sup>16</sup> It will be necessary to devise new ICD-10-CM coding algorithms for defining comorbidities to improve data accuracy, similar to the Canadian experience. 17,18

Long-term challenges with longitudinal data analyses. Backward coding will be most relevant in the first few years when ICD-9-CM data are still being utilized within clinical research, disease tracking, hospital reimbursements, and practice utilization and resource forecasting. In addition to the implications for clinical research as detailed above, from an organizational financial health and private sector perspective, it is vital to understand comparative data trends from a quarterly to an annual perspective. Without careful attention to data fidelity between ICD-9-CM diagnoses prior to October 1 2015, and ICD-10-CM diagnoses on and after October 1 2015, it is likely that organizations will be at significant financial risk with regards to forecasting resource utilization, understanding differences in reimbursements, and predicting future revenue cycle management. Given that ICD-CM-10 transition has been delayed until at least October 2015, and that ICD-11-CM transition will likely occur within a few years of WHO ICD-11 presentation in 2017, it is even more essential that equivalent comparative data is being utilized for financial decision-making.

Limitations and future directions. Limitations of our study include our manual review of initial articles, our use of one forward mapping methodology, our use of a Medicaid dataset, and lack of real-world financial forecasting examples taking into account missing and extraneous diagnoses resulting from backward coding. While manual review was accurate and detailed, development of programming for automated review and quality control would increase our method's applicability toward larger literature reviews, epidemiological trends, and for use in private practices. Based on prior work, we chose to proceed with forward mapping utilizing the Motif web portal methodology rather than the CMS GEMs method; repeating the analysis with the CMS GEMs method may have shown more potential areas of data discontinuity. Medicaid dataset was characterized by a high volume of primary care and pediatrics-related diagnoses; use of a Medicare dataset would likely have yielded a more thorough financial analysis



with likely more associated visits and billing costs. Based on prior international experience, current reimbursement practices, and business analytic models, we are concerned about substantial financial risk ensuing from missed and extraneous diagnoses but are unable to parse out the relative financial risk from each grouping. Precise financial risk modeling would be helpful to further quantify financial impact.

#### Conclusion

In conclusion, there are significant implications for data discontinuity during the ICD-10-CM transition that has not been adequately explored. The mandated delay is an opportunity for organizations to better understand areas of financial risk with regards to data management via backward coding. Based on our evaluation of seven cancer-related studies, we present a broadly applicable ICD-9-CM and ICD-10-CM bridging methodology. These analytic tools can be replicated by organizations and clinical researchers for retrospective longitudinal data analyses to ensure data fidelity between present ICD-9-CM codes, associated ICD-10-CM codes, and the backward mapping of those ICD-10-CM codes to ICD-9-CM codes. We confirm the necessity for a manual review of ICD-10-CM codes after the initial forward coding is completed to ensure a comprehensive and relevant ICD-10-CM list is being utilized. Finally, we show significant differences in backward coding methodology in yielding original ICD-9-CM codes with greater sensitivity and full coverage with the Motif web portal method compared to the CMS GEMs files method. Despite our focus on cancer-related journals, our methodology is widely applicable and relevant for all healthcarerelated coding data, and can be replicated by organizations as a strategy to mitigate financial risk.

# **Author Contributions**

Conceived the concepts: NKV, ADB, AS, PD. Analyzed the data: NKV, ADB, AS, PD. Wrote the first draft of the manuscript: NKV, ADB, AS, PD. Contributed to the writing of the manuscript: NKV, ADB, AS, PD. Agree with manuscript results and conclusions: NKV, ADB, AS, PD. Jointly developed the structure and arguments for the paper: NKV, ADB, AS, PD. Made critical revisions and approved final version: NKV, ADB, AS, PD. All authors reviewed and approved of the final manuscript.

## **REFERENCES**

Office of the Secretary HHS. Administrative simplification: adoption of a standard for a unique health plan identifier; addition to the National Provider Identifier requirements; and a change to the compliance date for the International Classification of Diseases, 10th Edition (ICD-10-CM and ICD-10-PCS) medical data code sets. Final rule. Fed Regist 2012;77:54663-720.

- Official CMS Industry Resources for the ICD-10 Transition. 2014. Available at http://www.cms.gov/Medicare/Coding/ICD10/index.html?redirect=/icd10. Accessed May 18, 2014.
- Carlson J, Conn J, Robeznieks A. Bruised by ICD-10 delay, healthcare execs huddle over what to do next. Mod Healthc. 2014;44:8–9.
- Behavioral Healthcare. ICD-10: The Good, the Bad, and the Advice. Behavioral Healthcare. May 15, 2014.
- Richardson DB. The impact on relative risk estimates of inconsistencies between ICD-9 and ICD-10. Occup Environ Med. 2006;63:734–40.
- Januel JM, Luthi JC, Quan H, et al. Improved accuracy of co-morbidity coding over time after the introduction of ICD-10 administrative data. BMC Health Serv Res. 2011:11:194.
- Centers for Medicare and Medicaid Services. ICD-10-CM/PCS: An Introduction. Washington, DC; 2010. Available at http://www.cms.gov/ICD10/downloads/ ICD-10Overview.pdf
- Rihanek T, DeVault K. Converting data to ICD-10 with GEMs: reference mapping tools will aid in system transition. *J AHIMA*. 2012;83:42–3.
- Boyd AD, Li JJ, Burton MD, et al. The discriminatory cost of ICD-10-CM transition between clinical specialties: metrics, case study, and mitigating tools. J Am Med Inform Assoc. 2013;20:708–17.
- Venepalli NK, Qamruzzaman Y, Li JJ, Lussier YA, Boyd AD. Identifying clinically disruptive international classification of diseases 10th revision clinical modification conversions to mitigate financial costs using an online tool. J Oncol Pract. 2014;10:97–103.
- Klabunde CN, Potosky AL, Legler JM, Warren JL. Development of a comorbidity index using physician claims data. J Clin Epidemiol. 2000;53:1258–67.
- Group Health Research Institute. Example of Effects of ICD-9 to ICD-10 Conversion on Research: Charlson/Klabunde Score Calculation. Group Health Research Institute. Available at http://www.grouphealthresearch.org/capabilities/it/ posters/2011/11-icd9-to-icd10-conversion.pdf. Accessed May 29, 2014.
- Quan H, Li B, Saunders LD, et al. Assessing validity of ICD-9-CM and ICD-10 administrative data in recording clinical conditions in a unique dually coded database. *Health Serv Res.* 2008;43:1424–41.
- Mills RE, Butler RR, McCullough EC, Bao MZ, Averill RF. Impact of the transition to ICD-10 on Medicare inpatient hospital payments. *Medicare Medicard Res Rev.* 2011;2:E1–13.
- Geraci JM, Escalante CP, Freeman JL, Goodwin JS. Comorbid disease and cancer: the need for more relevant conceptual models in health services research. J Clin Oncol. 2005;23:7399–404.
- Deyo RA, Cherkin DC, Ciol MA. Adapting a clinical comorbidity index for use with ICD-9-CM administrative databases. J Clin Epidemiol. 1992;45:613-9.
- So L, Evans D, Quan H. ICD-10 coding algorithms for defining comorbidities of acute myocardial infarction. BMC Health Serv Res. 2006;6:161.
- Quan H, Sundararajan V, Halfon P, et al. Coding algorithms for defining comorbidities in ICD-9-CM and ICD-10 administrative data. *Med Care*. 2005;43:1130–9.
- Mitchell JM. Urologists' use of intensity-modulated radiation therapy for prostate cancer. N Engl J Med. 2013;369:1629–37.
- Snyder CF, Frick KD, Herbert RJ, et al. Quality of care for comorbid conditions during the transition to survivorship: differences between cancer survivors and noncancer controls. J Clin Oncol. 2013;31:1140–8.
- Mack JW, Chen K, Boscoe FP, et al. Underuse of hospice care by Medicaidinsured patients with stage IV lung cancer in New York and California. *J Clin Oncol.* 2013;31:2569–79.
- Hershman DL, Wright JD, Lim E, Buono DL, Tsai WY, Neugut AI. Contraindicated use of bevacizumab and toxicity in elderly patients with cancer. J Clin Oncol. 2013;31:3592–9.
- Zullig LL, Carpenter WR, Provenzale D, Weinberger M, Reeve BB, Jackson GL.
   Examining potential colorectal cancer care disparities in the Veterans Affairs health care system. J Clin Oncol. 2013;31:3579–84.
- Chavez-MacGregor M, Zhang N, Buchholz TA, et al. Trastuzumabrelated cardiotoxicity among older patients with breast cancer. J Clin Oncol. 2013;31:4222–8.
- Tan D, Horning SJ, Hoppe RT, et al. Improvements in observed and relative survival in follicular grade 1–2 lymphoma during 4 decades: the Stanford University experience. *Blood*. 2013;122:981–7.