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Comparison of SEER Treatment Data With Medicare Claims

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Background: The population-based Surveillance, Epidemiology, and End Results (SEER) registries collect information on first-course treatment, including surgery, chemotherapy, radiation therapy, and hormone therapy. However, the SEER program does not release data on chemotherapy or hormone therapy due to uncertainties regarding data completeness. Activities are ongoing to investigate the opportunity to supplement SEER treatment data with other data sources.

Methods: Using the linked SEER-Medicare data, we examined the validity of the SEER data to identify receipt of chemotherapy and radiation therapy among those aged 65 and older diagnosed from 2000 to 2006 with bladder, female breast, colorectal, lung, ovarian, pancreas, or prostate cancer and hormone therapy among men diagnosed with prostate cancer at age 65 or older. Treatment collected by SEER was compared with treatment as determined by Medicare

claims, using Medicare claims as the gold standard. The κ , sensitivity, specificity, positive predictive values, and negative predictive values were calculated for the receipt of each treatment modality.

Results: The overall sensitivity of SEER data to identify chemotherapy, radiation, and hormone therapy receipt was moderate (68%, 80%, and 69%, respectively) and varied by cancer site, stage, and patient characteristics. The overall positive predictive value was high (>85%) for all treatment types and cancer sites except chemotherapy for prostate cancer.

Conclusions: SEER data should not generally be used for comparisons of treated and untreated individuals or to estimate the proportion of treated individuals in the population. Augmenting SEER data with other data sources will provide the most accurate treatment information.

Key Words: SEER, Medicare, treatment, validation, chemotherapy (*Med Care* 2016;54: e55–e64)

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The Surveillance, Epidemiology, and End Results (SEER) program, sponsored by the National Cancer Institute (NCI), is a system of population-based cancer registries that currently covers approximately 28% of the US population from geographically defined areas. In addition to reporting national cancer statistics on incidence and survival, the SEER registries serve as a platform for studies of cancer-related care and health disparities. As such there is considerable interest in treatment information for individuals diagnosed with cancer captured in the population-based registries. The SEER registries routinely collect data on the first course of cancer treatment including information on surgery, radiation therapy (RT), chemotherapy (CT), and hormone therapy (HT). Information on surgery and RT is reported in the publically available SEER dataset, although several studies have reported underascertainment of RT on the SEER data.^{1,2} NCI does not make data on CT and HT publically available due to concerns about the completeness of the information.

Persons in the SEER data who are Medicare eligible have been matched to their Medicare claims to create the linked SEER-Medicare data. The SEER-Medicare data include longitudinal claims, allowing for the identification of cancer treatments from Medicare claims for cancer patients appearing in the SEER data.³ Prior validation studies have shown that Medicare claims can accurately identify persons

receiving RT^{1,4,5} and CT.^{6–10} Several studies have used Medicare claims to identify individuals who received HT^{11–13} although these claims have not been validated.

Activities are ongoing at NCI to further investigate the opportunity and benefit of using claims to supplement treatment data. The linkage of the SEER and Medicare data offers the opportunity to validate treatment reported on the SEER data, using Medicare claims as the gold standard. As an initial step, this analysis will evaluate the completeness and validity of SEER treatment data. We compared treatment data from SEER with Medicare claims for (1) CT among individuals diagnosed with bladder, female breast, colorectal, lung, ovarian, pancreas, and prostate cancer; (2) RT among individuals diagnosed with these cancers except ovarian; and (3) HT among individuals diagnosed with prostate cancer. The concordance of treatment between the 2 data sources was estimated across a number of covariates including cancer site, stage, sex, age, race/ethnicity, geographic location, and year of diagnosis. The sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV) of SEER treatment variables were also estimated across the same covariates using Medicare claims as the gold standard.

METHODS

Data Sources

The SEER-Medicare data used for this study included cases reported from 17 SEER cancer registries, with the exception of Alaska Natives. To augment available public use of SEER data, we were able to access internal NCI data that included information about CT and HT administration collected by the SEER registries. This internal information and publically available information on RT was used for comparison to Medicare treatment information.

Individuals in the SEER data have been matched to Medicare's master enrollment file maintained by the Centers for Medicare and Medicaid Services (CMS).¹⁴ For persons reported to a SEER registry who were aged 65 or older, 94% have been linked to Medicare and their Medicare claims have been extracted.^{15–17} For this analysis, we included claims from inpatient hospitalizations (MEDPAR), outpatient facilities, physician claims, or durable medical equipment (DME). These files include claims for CT, RT, and injected HT for each beneficiary with fee-for-service coverage.¹⁷ All Medicare claims include codes that indicate the type of services performed. Services are reported using the International Classification of Diseases, Ninth Revision (ICD-9), Healthcare Common Procedure Coding System (HCPCS), and National Drug Codes (NDCs). In general, oral agents for CT are covered by Medicare Part D and so could not be captured in this analysis. However, oral chemotherapeutic agents that are equivalent to those intravenously administered, such as capecitabine, are covered as a part of Medicare Part B and could be identified in our study.

Study Sample

We identified 433,415 individuals in the SEER-Medicare data who were diagnosed with bladder, female breast,

colorectal, lung, ovary, pancreas, or prostate cancer from 2000 to 2006 for analysis. For inclusion in our study, individuals had to be at least 65 years of age at diagnosis, have continuous Part A, B, and fee-for-service coverage and not be enrolled in a Health Maintenance Organization during that year, and only have 1 cancer according to SEER data. These criteria were implemented to ensure complete Medicare claims for all individuals and so that any treatment identified using claims would be attributed to the correct cancer. In addition, those diagnosed on autopsy or death certificate (n=9276) or without a known month of diagnosis (n=4984) were excluded. A small number of individuals were part of the Patterns of Care (POC) studies performed by the SEER registries which involve obtaining more detailed information about CT and HT verified by the treating physician. These individuals were excluded as we were interested in the routine collection of SEER data (n=2671).¹⁸

Identification of Treatment

Treatment information was identified independently from the SEER data and from Medicare claims. SEER collects information on the first course of therapy. As individuals initiate therapy at different times postdiagnosis, cancer registrars update treatment information as it becomes available. For analysis, SEER treatment data for CT, RT, and HT were classified as received, not received, or unknown.

Treatment information for CT, RT, and HT was identified from Medicare claims data by reviewing the MEDPAR, outpatient, physician, and DME claims for 12 months after diagnosis. The first of the month and year of diagnosis reported by SEER registries was used as the diagnosis date. An individual was considered to have received CT, RT, or HT if at least 1 Medicare claim included a code for each specific treatment and to not have received treatment if no claims for the specific treatments were found. Thus, no individual had an unknown treatment status from the Medicare data. Codes used to identify treatment are listed in Table (Supplemental Digital Content 1, <http://links.lww.com/MLR/A665>, which lists codes).

Comparison of SEER and Medicare Treatment Data

Sensitivity, specificity, PPV, and NPV and their 95% confidence intervals were calculated to quantify the validity of SEER data to identify treatment receipt using Medicare claims as the gold standard. Although we calculated sensitivity, specificity, PPV, and NPV, we focused our analyses on sensitivity and PPV with the other measures reported in the Supplemental Tables (Supplemental Digital Content 2–4, <http://links.lww.com/MLR/A666>, <http://links.lww.com/MLR/A667>, <http://links.lww.com/MLR/A668>, which shows additional statistics).¹⁹ The analysis was performed separately for each treatment and by patient characteristics such as cancer site, stage, sex, age, race/ethnicity, geographic location, and year of diagnosis from the SEER data. As SEER does not define a fixed interval for the collection of treatment information, the overall sensitivity and PPV were also evaluated using a 4- and 8-month postdiagnosis Medicare claims window to provide a comparison to the 12-month

claims window length. Concordance between the 2 data sources was quantified with the κ statistic and the percent agreement which was defined as the proportion of individuals with the same reported treatment receipt from SEER and Medicare data (ie, the number of individuals where SEER data and Medicare claims agree about treatment receipt/total number of individuals with treatment recorded in SEER). Neither of these quantities assumes a gold standard but the κ statistic does account for agreement occurring by chance alone.

RESULTS

Our analysis included a total of 433,415 individuals diagnosed with the selected cancers. Twenty-seven percent of individuals were diagnosed with prostate cancer followed by lung (24%), female breast (18%), and colorectal (18%) (Table 1). The remaining individuals were diagnosed with bladder, pancreatic, or ovarian cancer (7%, 5%, and 2%, respectively). The majority of individuals were diagnosed at localized or regional stage except for individuals with cancer of the lung, pancreas, or ovary who were primarily diagnosed with distant stage disease. Our study included individuals who were predominantly non-Hispanic whites (82%) and diagnosed at ages 65–79 years.

CT

A total of 415,341 individuals were included in the comparison of CT after excluding 4.2% with unknown CT status from SEER. For all cancers combined, there was a high level of agreement between the Medicare claims and the SEER data (90%, Fig. 1), attributable to the fact that most individuals did not receive CT. The majority of discordant findings were individuals identified as receiving CT using Medicare claims but not receiving CT using SEER data.

The sensitivity of SEER data to identify individuals who received CT was 68% overall and varied by patient and tumor characteristics (Table 2). The sensitivity of SEER data was highest for ovarian cancer and lowest for bladder and prostate cancers (84%, 22%, and 7%, respectively). In addition, the sensitivity decreased with age for all cancers combined, specifically 74% for individuals aged 65–69 compared with 47% for those aged 85 and older. The sensitivity was low for detecting CT in individuals diagnosed with in situ or localized disease. In addition, there was some variation in sensitivity by registry (range, 60%–78%). The sensitivity, however, did not vary greatly based on year of diagnosis (data not shown), sex, or race with the exception of individuals with unknown race.

The poor results for prostate cancer did not, however, greatly affect the overall results because so few men receive CT as first-course therapy. Specifically, among men with all cancer sites combined, the sensitivity was 62.3% and modestly increased to 66.3% when prostate cancer was excluded. Finally, we further investigated potential misclassification of men with prostate cancer who had a claim for CT administration that may have been used for delivery of HT. We considered additional CT administration claims found on the same day as HT but the number of men with these additional

codes was small and hence their impact on the overall results would be minimal.

Overall the PPV was high indicating that among those identified in the SEER data as receiving CT, the vast majority also had Medicare claims for CT (Table 2). The κ statistics showed a moderate level of agreement overall and also followed a similar pattern to sensitivity and PPV. The specificity (range, 93%–100%) and NPV (range, 80%–99% excluding bladder) were high across all characteristics (Table, Supplemental Digital Content 2, <http://links.lww.com/MLR/A666>, which shows additional statistics for CT). Finally, as an addition to the sensitivity analysis we evaluated the individuals excluded because of unknown CT in SEER data and found them to have similar rate of CT as those with known CT status (72% vs. 76%, respectively).

RT

Overall 2.8% of individuals had unknown RT status reported in the SEER data, thus 412,350 patients were available for comparison. The overall agreement between Medicare claims and the SEER data for identifying RT was high (91%, Fig. 1). The majority of discordant findings were individuals identified as receiving RT using Medicare claims but were not identified using SEER data (7.4%).

The sensitivity of SEER data to identify individuals who received RT was 80% overall and varied by patient and tumor characteristics (Table 3). The sensitivity of SEER data was highest for prostate cancer (85%), lowest for bladder (54%), and ranged between 66% and 80% for the remaining cancer sites. The sensitivity decreased by year of diagnosis (data not shown, range, 82%–78%) and increasing age (range, 81%–65%). The sensitivity did not vary greatly by stage or race with the exception of low sensitivity of individuals in the unstaged or unknown race categories.

For all cancer sites combined, the PPV of RT on the SEER data was 95%. Although there was some variation in PPV by patient and tumor characteristics, the PPV was high for all cancer sites. The overall κ statistics were moderate to strong and followed a similar pattern as sensitivity and PPV. In addition, the overall specificity and NPV were high. The specificity overall was 97% and ranged between 94% and 100% by characteristic and the NPV was 89% overall and ranged from 82% to 96% (Table, Supplemental Digital Content 3, <http://links.lww.com/MLR/A667>, which shows additional statistics for RT). For all cancer sites combined, 73% of those with unknown RT in the SEER data did not have claims, ranging from 90% for colorectal cancer to 60% for breast cancer.

HT

A total of 115,724 men with prostate cancer were in the study cohort and 111,466 had known HT status recorded in the SEER data and were included in the analysis of HT. The overall agreement between SEER and Medicare was 81% (Fig. 1).

The sensitivity of the SEER data to identify HT was 69% and followed a similar pattern to CT. Specifically, the sensitivity was lower for localized/regional stage or unknown stage disease and decreased with increasing age

TABLE 1. Characteristics of 433,415 Individuals Diagnosed With Selected Cancers and Included in Analysis by Cancer Site

	N (%)						
	Bladder N = 29,259 (6.8%)	Female Breast N = 78,609 (18.1%)	Colorectal N = 77,242 (17.8%)	Lung N = 103,640 (23.9%)	Ovary N = 8920 (2.1%)	Pancreas N = 20,021 (4.6%)	Prostate N = 115,724 (26.7%)
Stage at diagnosis*							
In situ	0 (0)	11,901 (15.1)	3890 (5.0)	54 (0.1)	16 (0.2)	49 (0.2)	23 (0.02)
Localized	21,339 (72.9)	42,548 (54.1)	29,486 (38.2)	17,129 (16.5)	815 (9.1)	1740 (8.7)	—
Regional	5768 (19.7)	17,389 (22.1)	25,279 (32.7)	24,774 (23.9)	542 (6.1)	4963 (24.8)	—
Localized/regional†							105,132 (90.8)
Distant	1134 (3.9)	4832 (6.1)	14,047 (18.2)	53,442 (51.6)	6612 (74.1)	10,086 (50.4)	5710 (4.9)
Unstaged	1018 (3.5)	1939 (2.5)	4540 (5.9)	8241 (8.0)	935 (10.5)	3183 (15.9)	4859 (4.2)
Sex							
Male	20,867 (71.3)	—	34,417 (44.6)	54,016 (52.1)	—	8605 (43.0)	115,724 (100)
Female	8392 (28.7)	78,609 (100)	42,825 (55.4)	49,624 (47.9)	8920 (100)	11,416 (57.0)	—
Age at diagnosis (y)							
65–69	5123 (17.5)	19,488 (24.8)	14,105 (18.3)	23,078 (22.3)	1784 (20.0)	3564 (17.8)	33,991 (29.4)
70–74	6317 (21.6)	18,417 (23.4)	15,739 (20.4)	26,271 (25.3)	1881 (21.1)	4260 (21.3)	32,720 (28.3)
75–79	6840 (23.4)	17,844 (22.7)	17,098 (22.1)	25,642 (24.7)	2010 (22.5)	4628 (23.1)	26,111 (22.6)
80–84	5810 (19.9)	12,988 (16.5)	15,336 (19.9)	17,593 (17.0)	1726 (19.3)	3913 (19.5)	14,681 (12.7)
85+	5169 (17.7)	9872 (12.6)	14,964 (19.4)	11,056 (10.7)	1519 (17.0)	3656 (18.3)	8221 (7.1)
Race/ethnicity							
NH white	25,955 (88.7)	66,530 (84.6)	62,922 (81.5)	86,889 (83.8)	7569 (84.9)	15,816 (79.0)	89,213 (77.1)
NH black	1171 (4.0)	5489 (7.0)	6329 (8.2)	8371 (8.1)	537 (6.0)	1936 (9.7)	11,536 (10.0)
Hispanic	1011 (3.5)	3414 (4.3)	3972 (5.1)	3985 (3.8)	494 (5.5)	1209 (6.0)	7100 (6.1)
NH AI/AN	29 (0.1)	170 (0.2)	163 (0.2)	289 (0.3)	37 (0.4)	73 (0.4)	266 (0.2)
NH API	730 (2.5)	2609 (3.3)	3483 (4.5)	3959 (3.8)	268 (3.0)	964 (4.8)	4296 (3.7)
NH other/unknown	363 (1.2)	397 (0.5)	373 (0.5)	147 (0.1)	15 (0.2)	23 (0.1)	3313 (2.9)
Year of diagnosis							
2000	3754 (12.8)	10,625 (13.5)	11,015 (14.3)	13,957 (13.5)	1367 (15.3)	2607 (13.0)	15,626 (13.5)
2001	3894 (13.3)	11,596 (14.8)	11,337 (14.7)	14,460 (14.0)	1310 (14.7)	2701 (13.5)	16,711 (14.4)
2002	4116 (14.1)	11,707 (14.9)	11,729 (15.2)	15,034 (14.5)	1118 (12.5)	2916 (14.6)	17,814 (15.4)
2003	3949 (13.5)	11,421 (14.5)	11,608 (15.0)	15,648 (15.1)	1310 (14.7)	2966 (14.8)	16,731 (14.5)
2004	4677 (16.0)	11,085 (14.1)	11,232 (14.5)	15,412 (14.9)	1289 (14.5)	2967 (14.8)	16,835 (14.5)
2005	4424 (15.1)	11,050 (14.1)	10,152 (13.1)	14,436 (13.9)	1229 (13.8)	2822 (14.1)	15,566 (13.5)
2006	4445 (15.2)	11,125 (14.2)	10,169 (13.2)	14,693 (14.2)	1297 (14.5)	3042 (15.2)	16,441 (14.2)
Reporting source‡							
Inpatient	27,795 (95.0)	76,584 (97.4)	74,907 (97.0)	98,951 (95.5)	8555 (95.9)	18,487 (92.3)	94,636 (81.8)
RT or Med Onc Center	—	51 (0.1)	—	48 (0.0)	—	—	299 (0.3)
Laboratory only	545 (1.9)	607 (0.8)	600 (0.8)	312 (0.3)	27 (0.3)	56 (0.3)	8085 (7.0)
Physician's office	812 (2.8)	1188 (1.5)	1603 (2.1)	3967 (3.8)	295 (3.3)	1341 (6.7)	12,426 (10.7)
Nursing	17 (0.1)	62 (0.1)	93 (0.1)	285 (0.3)	39 (0.4)	111 (0.6)	89 (0.1)
Other	83 (0.3)	117 (0.1)	27 (0.0)	77 (0.1)	—	18 (0.1)	189 (0.2)

*SEER historic stage A.

†Prostate cancer is categorized as in situ, localized/regional, or distant. All other cancer sites have localized and regional as separate categories.

‡Reporting source is from the Medicare data. Inpatient, hospital inpatient; RT or Med Onc Center, Radiation Treatment Centers or Medical Oncology Centers; Physician's office, Physician's Office/Private Medical Practitioner; Nursing, Nursing/Convalescent/Hospice; Other, Other Hospital Outpatient Units/Surgery Centers.

— indicates cell counts were suppressed if <16 individuals; AI/AN, American Indian/Alaskan Native; API, Asian/Pacific Islander; NH, non-Hispanic.

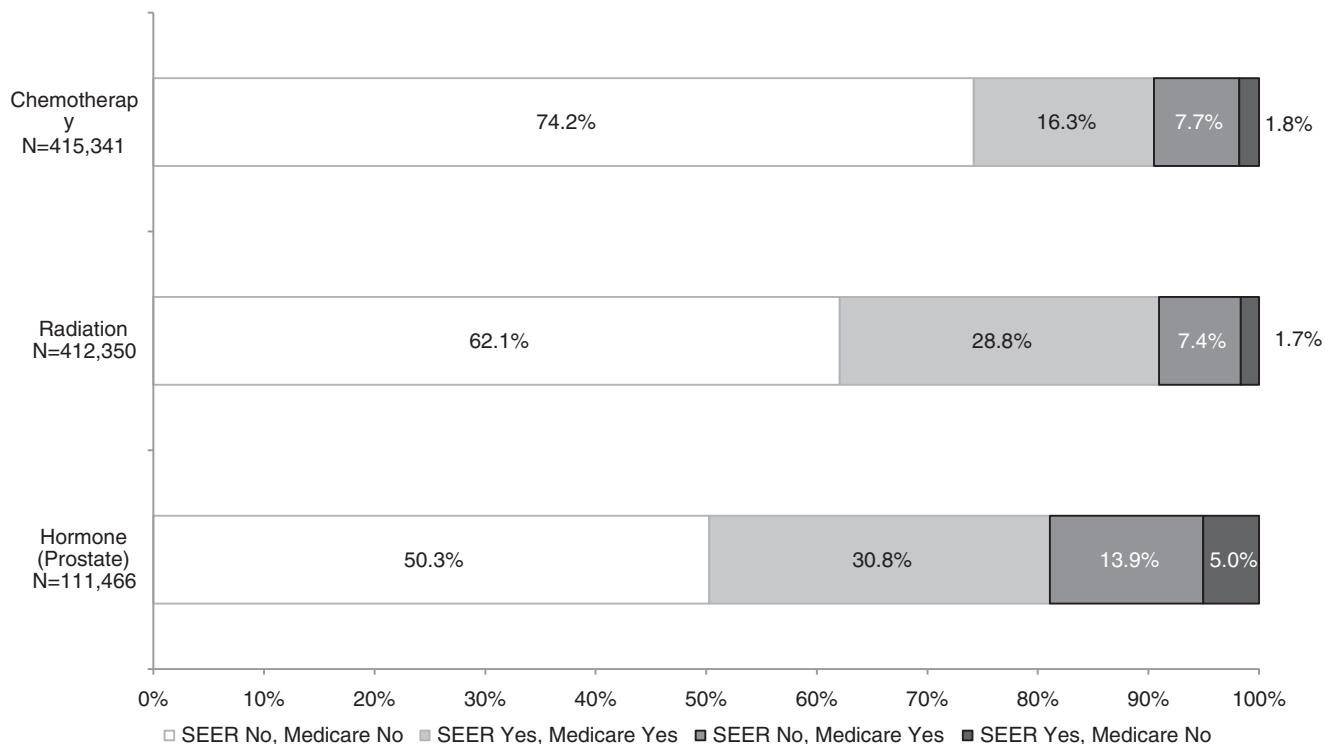


FIGURE 1. Agreement between chemotherapy, radiation, and hormone therapy collected by SEER and treatment identified using Medicare claims^a. ^aA 12-month postdiagnosis window was used to identify treatment using Medicare claims (gold standard). SEER indicates Surveillance, Epidemiology, and End Results.

(Table 4). The sensitivity did not vary much by race with the exception of unknown race and, finally, the sensitivity varied by registry (range, 47%–76%).

The overall PPV was 86% and did not vary substantially by characteristic. American Indian/Alaska Natives and those with distant-stage disease had lower PPVs (66% and 75%, respectively). The overall κ showed a low level of agreement. Similar to CT and RT, the specificity was high except for distant stage; however, the NPV was only 78% overall (Table, Supplemental Digital Content 4, <http://links.lww.com/MLR/A668>, which shows additional statistics for HT). The NPV was lower for individuals with distant (61%) or unstaged (66%) cancers compared with local/regional stage (79%) or for older patients (87% for age 65–69 vs. 62% for age 85+). The NPV did not vary substantially by race or registry.

DISCUSSION

In order for the treatment data recorded by the SEER registries to be useful to assess how patients are treated, the information must have good sensitivity and PPV. We found that the overall utility of the SEER data to identify cancer treatment was limited. The sensitivity of the SEER data varied by treatment type, cancer site, stage, age at diagnosis, and registry. For CT and HT, the sensitivity was low, whereas the sensitivity was better for reporting of RT. We investigated whether SEER data may be appropriate for use among specific site/stage strata. However, for the cancer sites

included in this analysis the sensitivity was <90% for all stages and treatment types (See Table, Supplemental Digital Content 5, <http://links.lww.com/MLR/A672> which shows sensitivity and PPV by cancer site and stage). These results indicate that using SEER data to assess treatment will miss a number of patients who have been treated, resulting in misclassification and inaccurate estimates of the proportion of individuals treated.

Although the sensitivity was poor, the PPV was high among all treatment types and did not vary greatly by cancer site or characteristic with the exception of CT for prostate cancer. As within many site/stage strata SEER reliably identified individuals who truly received treatment, SEER treatment data may have a limited role in research projects to identify a cohort of treated individuals within these strata (See Table, Supplemental Digital Content 5, <http://links.lww.com/MLR/A672> which shows sensitivity and PPV by cancer site and stage). SEER data, however, will not capture all individuals who received treatment.

This is the first study to compare CT reported in the SEER data with Medicare claims. Prior studies from 2 SEER registries compared CT data collected by medical records to registry data for women of all ages with breast cancer. These earlier studies had similar rates of concordance as the current study.^{7,20} As treatment is more often received in settings outside of the hospital system, either a physician’s office or an outpatient clinic, identification of treatment is difficult and may be a major contributing factor to the low capture of CT

TABLE 2. Sensitivity and PPV of SEER Data to Identify Chemotherapy Receipt and κ Statistics by Patient and Tumor Characteristics*

	SEER No, Medicare No	SEER Yes, Medicare Yes	SEER No, Medicare Yes	SEER Yes, Medicare No	Sensitivity (95% CI) [†]	PPV (95% CI) [‡]	κ (95% CI)
Overall							
12 mo window	308,119	67,681	32,184	7357	67.8 (67.5, 68.1)	90.2 (90.0, 90.4)	71.5 (71.3, 71.8)
8 mo window	310,664	67,234	29,639	7804	69.4 (69.1, 69.7)	89.6 (89.4, 89.8)	72.7 (72.4, 72.9)
4 mo window	314,771	65,103	25,532	9935	71.8 (71.5, 72.1)	86.8 (86.5, 87.0)	73.3 (73.1, 73.6)
Cancer site							
Bladder	16,760	2468	8,848	293	21.8 (21.0, 22.6)	89.4 (88.2, 90.5)	23.0 (22.1, 23.9)
Female Breast	58,972	10,330	4726	996	68.6 (67.9, 69.4)	91.2 (90.7, 91.7)	73.8 (73.2, 74.4)
Colorectal	50,646	14,909	5967	1413	71.4 (70.8, 72.0)	91.3 (90.9, 91.8)	73.5 (72.9, 74.1)
Lung	57,068	30,030	7446	3562	80.1 (79.7, 80.5)	89.4 (89.1, 89.7)	75.8 (75.3, 76.2)
Ovary	3109	4285	790	239	84.4 (83.4, 85.4)	94.7 (94.1, 95.4)	75.2 (73.8, 76.6)
Pancreas	11,402	5442	1608	522	77.2 (76.2, 78.2)	91.2 (90.5, 92.0)	75.2 (74.2, 76.2)
Prostate	110,162	217	2799	332	7.2 (6.3, 8.1)	39.5 (35.4, 43.6)	11.4 (10.0, 12.9)
Stage at diagnosis [‡]							
In situ	15,137	26	218	49	10.7 (6.8, 14.5)	34.7 (23.9, 45.4)	15.7 (10.2, 21.2)
Localized	86,334	8915	12,271	1165	42.1 (41.4, 42.7)	88.4 (87.8, 89.1)	50.8 (50.2, 51.5)
Localized/ regional [§]	101,176	105	2029	242	4.9 (4.0, 5.8)	30.3 (25.4, 35.1)	7.9 (6.4, 9.4)
Regional	37,467	26,267	8492	2118	75.6 (75.1, 76.0)	92.5 (92.2, 92.8)	71.0 (70.5, 71.5)
Distant	49,518	30,743	7704	3535	80.0 (79.6, 80.4)	89.7 (89.4, 90.0)	74.4 (74.0, 74.9)
Unstaged	18,487	1625	1470	248	52.5 (50.7, 54.3)	86.8 (85.2, 88.3)	61.3 (59.6, 62.9)
Sex							
Female	131,627	39,592	15,190	3404	72.3 (71.9, 72.6)	92.1 (91.8, 92.3)	74.5 (74.2, 74.9)
Male	176,492	28,089	16,994	3953	62.3 (61.9, 62.8)	87.7 (87.3, 88.0)	67.4 (67.0, 67.8)
Age at diagnosis (y)							
65–69	65,372	21,811	7874	2153	73.5 (73.0, 74.0)	91.0 (90.7, 91.4)	74.3 (73.8, 74.8)
70–74	70,775	20,113	8521	1906	70.2 (69.7, 70.8)	91.3 (91.0, 91.7)	72.7 (72.2, 73.2)
75–79	70,378	15,836	7937	1661	66.6 (66.0, 67.2)	90.5 (90.1, 90.9)	70.5 (70.0, 71.1)
80–84	55,058	7569	5190	1062	59.3 (58.5, 60.2)	87.7 (87.0, 88.4)	65.6 (64.9, 66.4)
85+	46,536	2352	2662	575	46.9 (45.5, 48.3)	80.4 (78.9, 81.8)	56.1 (54.8, 57.5)
Race/ethnicity							
NH white	250,536	56,576	26,730	5710	67.9 (67.6, 68.2)	90.8 (90.6, 91.1)	71.8 (71.5, 72.1)
NH black	25,896	4,881	2215	826	68.8 (67.7, 69.9)	85.5 (84.6, 86.4)	70.8 (69.8, 71.8)
Hispanic	15,281	3225	1620	405	66.6 (65.2, 67.9)	88.8 (87.8, 89.9)	70.1 (68.8, 71.3)
NH AI/AN	747	188	58	19	76.4 (71.1, 81.7)	90.8 (86.9, 94.8)	78.1 (73.5, 82.8)
NH API	11,510	2736	1307	379	67.7 (66.2, 69.1)	87.8 (86.7, 89.0)	69.8 (68.4, 71.1)
NH other/ unknown	4149	75	254	18	22.8 (18.3, 27.3)	80.6 (72.6, 88.7)	33.4 (27.6, 39.2)
Registry							
A					78.2 (77.3, 79.1)	90.9 (90.3, 91.6)	78.4 (77.6, 79.2)
B					65.6 (64.5, 66.7)	90.1 (89.4, 90.9)	70.0 (69.0, 70.9)
C					78.6 (77.7, 79.6)	92.5 (91.8, 93.2)	80.9 (80.1, 81.7)
D					62.8 (60.8, 64.9)	88.8 (87.2, 90.4)	67.9 (66.1, 69.8)
E					65.5 (64.4, 66.5)	91.8 (91.1, 92.5)	70.4 (69.4, 71.4)
F					70.8 (69.8, 71.8)	88.8 (88.0, 89.6)	73.3 (72.4, 74.2)
G					64.7 (64.2, 65.2)	88.3 (87.9, 88.7)	68.5 (68.0, 69.0)
H					62.8 (62.1, 63.5)	92.2 (91.7, 92.6)	67.8 (67.1, 68.5)
I					66.0 (64.4, 67.6)	91.6 (90.5, 92.7)	70.3 (68.9, 71.8)
J					60.1 (58.0, 62.3)	91.6 (90.1, 93.1)	68.0 (66.1, 70.0)
K					77.7 (76.6, 78.8)	89.7 (88.8, 90.6)	78.9 (77.9, 79.9)
L					70.8 (68.4, 73.3)	88.4 (86.4, 90.3)	73.2 (71.0, 75.4)

*A 12-month postdiagnosis window was used to identify treatment using Medicare claims (gold standard) unless otherwise specified.

[†]95% CIs computed using normal approximation.

[‡]SEER historic stage A.

[§]Prostate cancer is categorized as in situ, localized/regional, or distant. All other cancer sites have localized and regional as separate categories.

^{||}Sample sizes omitted to preserve anonymity of the registries. Data from registries in California were combined (Greater California, Los Angeles, and San Jose-Monterey) and data from registries in Georgia were combined (Atlanta and Rural Georgia).

AI/AN indicates American Indian/Alaskan Native; API, Asian/Pacific Islander; CI, confidence interval; NH, non-Hispanic; PPV, positive predictive value; SEER, Surveillance, Epidemiology, and End Results.

TABLE 3. Sensitivity and PPV of SEER Data to Identify Radiation Therapy and κ Statistics by Patient and Tumor Characteristics*

	SEER No, Medicare No	SEER Yes, Medicare Yes	SEER No, Medicare Yes	SEER Yes, Medicare No	Sensitivity (95% CI) [†]	PPV (95% CI) [†]	κ (95% CI)
Overall							
12 mo window	256,031	118,949	30,529	6841	79.6 (79.4, 79.8)	94.6 (94.4, 94.7)	79.7 (79.5, 79.9)
8 mo window	260,499	116,358	26,061	9432	81.7 (81.5, 81.9)	92.5 (92.4, 92.6)	80.4 (80.2, 80.6)
4 mo window	267,798	101,995	18,762	23,795	84.5 (84.3, 84.7)	81.1 (80.9, 81.3)	75.4 (75.2, 75.6)
Cancer site							
Bladder	25,809	1492	1283	106	53.8 (51.9, 55.6)	93.4 (92.1, 94.6)	65.8 (64.2, 67.5)
Female breast	36,076	31,232	8026	808	79.6 (79.2, 80.0)	97.5 (97.3, 97.6)	76.9 (76.5, 77.4)
Colorectal	65,932	5962	3036	393	66.3 (65.3, 67.2)	93.8 (93.2, 94.4)	75.2 (74.4, 76.0)
Lung	56,114	32,666	9396	2039	77.7 (77.3, 78.1)	94.1 (93.9, 94.4)	76.0 (75.6, 76.4)
Pancreas	15,897	2447	1042	100	70.1 (68.6, 71.7)	96.1 (95.3, 96.8)	77.7 (76.5, 78.9)
Prostate	56,203	45,150	7746	3395	85.4 (85.1, 85.7)	93.0 (92.8, 93.2)	80.0 (79.7, 80.4)
Stage at diagnosis [‡]							
In situ	9945	4451	1039	103	81.1 (80.0, 82.1)	97.7 (97.3, 98.2)	83.3 (82.3, 84.2)
Localized	77,219	24,449	6975	824	77.8 (77.3, 78.3)	96.7 (96.5, 97.0)	81.5 (81.1, 81.9)
Localized/ regional [§]	48,928	43,733	6648	3174	86.8 (86.5, 87.1)	93.2 (93.0, 93.5)	80.8 (80.4, 81.2)
Regional	45,632	22,272	6901	1148	76.3 (75.9, 76.8)	95.1 (94.8, 95.4)	76.7 (76.3, 77.2)
Distant	56,203	22,364	7177	1397	75.7 (75.2, 76.2)	94.1 (93.8, 94.4)	77.0 (76.5, 77.4)
Unstaged	18,104	1680	1789	195	48.4 (46.8, 50.1)	89.6 (88.2, 91.0)	58.2 (56.6, 59.8)
Sex							
Female	117,289	51,088	15,423	1441	76.8 (76.5, 77.1)	97.3 (97.1, 97.4)	79.3 (79.0, 79.6)
Male	138,742	67,861	15,106	5400	81.8 (81.5, 82.1)	92.6 (92.4, 92.8)	80.0 (79.8, 80.3)
Age at diagnosis (y)							
65–69	51,784	34,082	7957	2599	81.1 (80.7, 81.4)	92.9 (92.7, 93.2)	77.4 (77.0, 77.8)
70–74	54,250	36,246	8120	2091	81.7 (81.3, 82.1)	94.5 (94.3, 94.8)	79.1 (78.8, 79.5)
75–79	57,258	29,372	7368	1383	79.9 (79.5, 80.4)	95.5 (95.3, 95.7)	80.0 (79.6, 80.4)
80–84	49,431	14,035	4304	575	76.5 (75.9, 77.1)	96.1 (95.7, 96.4)	80.6 (80.1, 81.1)
85+	43,308	5214	2780	193	65.2 (64.2, 66.3)	96.4 (95.9, 96.9)	74.6 (73.8, 75.5)
Race/ethnicity							
NH white	208,152	98,707	24,742	5066	80.0 (79.7, 80.2)	95.1 (95.0, 95.2)	80.3 (80.1, 80.5)
NH black	20,913	9410	2598	1052	78.4 (77.6, 79.1)	89.9 (89.4, 90.5)	75.8 (75.1, 76.5)
Hispanic	12,988	5465	1528	385	78.1 (77.2, 79.1)	93.4 (92.8, 94.1)	78.3 (77.4, 79.2)
NH AI/AN	630	250	70	22	78.1 (73.6, 82.7)	91.9 (88.7, 95.2)	77.7 (73.4, 82.0)
NH API	9907	4585	1092	282	80.8 (79.7, 81.8)	94.2 (93.5, 94.9)	80.5 (79.6, 81.5)
NH other/ unknown	3441	532	499	34	51.6 (48.5, 54.7)	94.0 (92.0, 96.0)	60.2 (57.2, 63.1)
Registry							
A					82.6 (81.9, 83.2)	93.4 (92.9, 93.9)	80.4 (79.7, 81.1)
B					74.0 (73.2, 74.8)	95.9 (95.5, 96.3)	75.5 (74.7, 76.2)
C					85.9 (85.2, 86.6)	96.0 (95.6, 96.5)	86.7 (86.0, 87.3)
D					68.4 (66.8, 70.0)	93.7 (92.7, 94.7)	71.0 (69.5, 72.5)
E					72.8 (72.0, 73.6)	95.4 (95.0, 95.9)	73.0 (72.2, 73.7)
F					82.9 (82.3, 83.6)	95.3 (94.9, 95.6)	82.3 (81.7, 83.0)
G					79.2 (78.8, 79.6)	94.0 (93.7, 94.2)	79.7 (79.4, 80.1)
H					78.6 (78.1, 79.1)	95.2 (94.9, 95.5)	78.9 (78.5, 79.4)
I					82.2 (81.1, 83.2)	94.9 (94.2, 95.5)	81.2 (80.2, 82.3)
J					82.5 (81.3, 83.8)	95.4 (94.7, 96.2)	83.3 (82.2, 84.4)
K					86.9 (86.2, 87.7)	92.1 (91.5, 92.7)	83.8 (83.1, 84.5)
L					82.6 (81.1, 84.2)	93.2 (92.1, 94.3)	79.5 (77.9, 81.1)

*A 12-month postdiagnosis window was used to identify treatment using Medicare claims (gold standard) unless otherwise specified.

[†]95% CIs computed using normal approximation.

[‡]SEER historic stage A.

[§]Prostate cancer is categorized as in situ, localized/regional, or distant. All other cancer sites have localized and regional as separate categories.

^{||}Sample sizes omitted to preserve anonymity of the registries. Data from registries in California were combined (Greater California, Los Angeles, and San Jose-Monterey) and data from registries in Georgia were combined (Atlanta and Rural Georgia).

AI/AN indicates American Indian/Alaskan Native; API, Asian/Pacific Islander; CI, confidence interval; NH, non-Hispanic; PPV, positive predictive value; SEER, Surveillance, Epidemiology, and End Results.

in the SEER data. For example, the low sensitivity of CT for bladder cancer is likely explained by more patients being treated primarily in the physician office. Other challenges include a trend away from intravenous CT drugs to oral CT

and identification of prescription drug use is difficult for cancer registrars to find.

Among men with prostate cancer, the sensitivity of CT was poor, even among men with distant-stage disease

(13.6% vs. 4.9% for localized/regional stage). These findings could be influenced by the challenges of distinguishing men who received CT, HT, or both using Medicare claims. Among men with prostate cancer included in this analysis who received CT according to Medicare claims, 67% also had a claim for HT within the same year. For these men, we cannot definitively determine if all claims were related to administration of HT or if some were for CT. A recent study compared CT and HT data compiled by the Cancer Research Network's (CRN) Virtual Data Warehouse, which included encounter, claims, and electronic medical record data, to gold standard tumor registry data abstracted from medical charts.²¹ The PPV for identifying CT

for prostate cancer was only 6%, similar to our current findings. These results reflect the fact that registry data is limited to the first course of therapy and the difficulty in distinguishing CT and HT using claims for prostate cancer. In contrast to poor reporting of CT in the CRN data, the authors found that among men with prostate cancer identified as receiving HT in the CRN data, 92% also had HT captured in the tumor registry data. The success in identifying HT from the CRN claims data compared with Medicare claims may be due to availability of pharmacy information in the CRN data.

We found moderate sensitivity and agreement between SEER data and Medicare claims for receipt of RT. In pre-

TABLE 4. Sensitivity and PPV of the SEER Data to Identify Hormone Therapy and κ Statistics by Patient and Tumor Characteristics Among Men With Prostate Cancer*

	SEER No, Medicare No	SEER Yes, Medicare Yes	SEER No, Medicare Yes	SEER Yes, Medicare No	Sensitivity (95% CI) [†]	PPV (95% CI) [‡]	κ (95% CI)
Overall							
12 mo window	56,022	34,379	15,451	5614	69.0 (68.6, 69.4)	86.0 (85.6, 86.3)	61.0 (60.6, 61.5)
8 mo window	56,723	33,955	14,750	6038	69.7 (69.3, 70.1)	84.9 (84.6, 85.3)	61.3 (60.8, 61.8)
4 mo window	57,867	32,516	13,606	7477	70.5 (70.1, 70.9)	81.3 (80.9, 81.7)	60.2 (59.8, 60.7)
Stage at diagnosis [‡]							
In situ	—	—	—	—	—	—	—
Localized/regional	52,831	30,748	13,673	4470	69.2 (68.8, 69.6)	87.3 (87.0, 87.7)	62.9 (62.4, 63.4)
Distant	1104	2796	720	937	79.5 (78.2, 80.9)	74.9 (73.5, 76.3)	34.4 (31.8, 36.9)
Unstaged	2073	827	1058	207	43.9 (41.6, 46.1)	80.0 (77.5, 82.4)	36.2 (33.6, 38.8)
Age at diagnosis (y)							
65–69	20,780	7566	3090	1499	71.0 (70.1, 71.9)	83.5 (82.7, 84.2)	66.9 (66.0, 67.8)
70–74	16,401	9943	3719	1542	72.8 (72.0, 73.5)	86.6 (86.0, 87.2)	65.4 (64.6, 66.3)
75–79	10,703	9126	4033	1283	69.4 (68.6, 70.1)	87.7 (87.0, 88.3)	58.1 (57.1, 59.0)
80–84	5209	5147	2838	808	64.5 (63.4, 65.5)	86.4 (85.6, 87.3)	49.0 (47.6, 50.4)
85+	2929	2597	1771	482	59.5 (58.0, 60.9)	84.3 (83.1, 85.6)	43.5 (41.7, 45.4)
Race/ethnicity							
NH white	44,009	26,430	11,397	3899	69.9 (69.4, 70.3)	87.1 (86.8, 87.5)	63.1 (62.5, 63.6)
NH black	5333	3361	1496	937	69.2 (67.9, 70.5)	78.2 (77.0, 79.4)	55.0 (53.4, 56.5)
Hispanic	3166	2187	1160	436	65.3 (63.7, 67.0)	83.4 (82.0, 84.8)	53.7 (51.7, 55.6)
NH AI/AN	131	66	31	34	68.0 (58.8, 77.3)	66.0 (56.7, 75.3)	47.1 (36.1, 58.1)
NH API	1856	1523	607	220	71.5 (69.6, 73.4)	87.4 (85.8, 88.9)	60.8 (58.4, 63.1)
NH other/unknown	1527	812	760	88	51.7 (49.2, 54.1)	90.2 (88.3, 92.2)	46.5 (43.7, 49.3)
Registry [§]							
A					72.4 (70.7, 74.0)	82.8 (81.3, 84.2)	59.9 (57.9, 61.8)
B					70.8 (69.4, 72.1)	87.5 (86.4, 88.6)	60.7 (59.0, 62.3)
C					71.6 (70.1, 73.2)	89.5 (88.4, 90.7)	64.5 (62.8, 66.3)
D					47.4 (44.4, 50.4)	72.7 (69.4, 76.0)	42.4 (39.1, 45.8)
E					67.0 (65.4, 68.6)	84.5 (83.1, 85.8)	55.4 (53.5, 57.3)
F					60.9 (59.4, 62.5)	86.9 (85.6, 88.2)	57.8 (56.2, 59.5)
G					70.6 (69.9, 71.4)	84.8 (84.2, 85.5)	63.0 (62.1, 63.8)
H					70.2 (69.3, 71.1)	87.9 (87.2, 88.6)	55.2 (54.0, 56.4)
I					50.9 (48.0, 53.9)	81.1 (78.1, 84.0)	51.4 (48.3, 54.5)
J					70.8 (68.5, 73.1)	88.3 (86.5, 90.1)	68.9 (66.6, 71.2)
K					72.9 (71.2, 74.7)	87.0 (85.5, 88.5)	69.8 (68.0, 71.6)
L					75.6 (72.8, 78.4)	86.8 (84.4, 89.2)	61.3 (57.5, 65.0)

*A 12-month postdiagnosis window was used to identify treatment using Medicare claims (gold standard) unless otherwise specified.

[†]95% CIs computed using normal approximation.

[‡]SEER historic stage A.

[§]Sample sizes omitted to preserve anonymity of the registries. Data from registries in California were combined (Greater California, Los Angeles, and San Jose-Monterey) and data from registries in Georgia were combined (Atlanta and Rural Georgia).

— indicates cell counts were suppressed if <16 individuals and statistics were not calculated due to at least 1 cell size <5; AI/AN, American Indian/Alaskan Native; API, Asian/Pacific Islander; CI, confidence interval; NH, non-Hispanic; PPV, positive predictive value; SEER, Surveillance, Epidemiology, and End Results.

vious comparisons of reported RT use between SEER and Medicare data, breast, endometrial, lung, prostate, and rectal cancer had strong agreement when comparing RT use for individuals diagnosed between 1991 and 1996.⁴ A more recent study compared receipt of RT as reported in the SEER data for individuals diagnosed with breast cancer aged 20 to 79 and diagnosed between 2005 and 2007 with self-reported treatment information obtained through patient survey.² This analysis found overall agreement of 83%, and 21% of individuals who self-reported receiving RT were recorded as not receiving RT in the SEER data. Underascertainment of RT was higher in women under the age of 65 who would not be eligible for Medicare. We also found more underreporting of RT in the SEER data, about 21%, which is consistent with the more recent study.^{1,2,5} The poorer performance with more recent diagnoses could be due to the increasing difficulty for registries to collect treatment information delivered in the outpatient setting. Underascertainment of RT may also result if individuals receive surgical treatment in a large cancer center but receive RT in a community setting.

There are several limitations to this study. One caveat is the potential for underreporting of treatment by both Medicare claims and the SEER data. Underreporting of treatment in the Medicare claims would result from individuals receiving care outside of the Medicare system, such as from the Veterans Health Administration, or if individuals are still working and have employer-sponsored insurance. Whereas, underreporting of treatment in the SEER data may be caused by care not captured by the registry, such as prescription drugs or outpatient treatment, or individuals leaving the registry catchment area for treatment. The sensitivity among those over the age of 85 is lower which may be due to these individuals leaving home while receiving treatment. In addition, the sensitivity varied by registry. This may be due to differences in how the data are collected at the registry and the proportion of patients receiving inpatient treatment.

Apparent differences in the reporting of treatment between the SEER and Medicare data may be caused by misalignment of the treatment window captured by SEER and Medicare files. In this evaluation, a 12-month postdiagnosis window was used to identify claims from Medicare. This timeframe was chosen as it aligned with guidelines from the SEER Program Coding and Staging Manual followed by SEER registrars stating that in the absence of additional documentation the first course of therapy ends after 1 year postdiagnosis.²² However, SEER is only capturing first-course treatment, whereas Medicare claims would also capture secondary treatment due to an inability of individuals to tolerate the initial treatment or failure of the initial treatment to produce the desired outcome. The overall sensitivity of the SEER data increased and the PPV decreased using a shorter window postdiagnosis to identify claims but these differences were modest (Tables 2–4).

In addition, there may have been some missed opportunity for the SEER registries to capture treatment. We reviewed the claims for individuals identified as having received treatment in Medicare but not in the SEER data to determine the number of encounters the individual had with the health

care system. The number of encounters was quantified by the number of days in the first year postdiagnosis a claim for treatment was found. Thirty-two percent of individuals with any claims for CT and 55% of those with any claims for RT had at least 10 encounters. As most of the reporting was from inpatient claims (Table 1) this may imply that SEER may have missed the opportunity to capture treatment information. Finally, treatment status for individuals in managed care systems may be more easily identified by the registries as there is a unified record of incident cancer and treatment but only individuals with fee-for-service were included in this analysis.

Registries' ability to capture accurate treatment information is becoming more difficult over time because of trends in cancer treatment and also privacy concerns. Although the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule includes provisions to allow mandated cancer reporting without patient consent for public health surveillance and research, it does create confusion on the disclosure of protected health information by health care providers.²³ A survey of North American Association of Central Cancer Registries (NAACCR) found that two thirds of registries cited HIPAA as interfering with nonresearch operations. Among those, 75% reported that HIPAA was identified as the reason for either ceased case reporting from at least 1 source, prevented case finding or auditing, or interfered with collection of follow-up data.²⁴

Although there are significant limitations found with the SEER treatment data, there are several possible uses. For example, researchers used SEER treatment data to select a cohort of treated individuals.²⁵ Furthermore, SEER treatment data could be improved by correcting the bias using the POC data, as done in the study by Mariotto et al,²⁶ and also by potentially augmenting SEER treatment data using other larger scale data sources. Linkages between the SEER data and data sources such as the CRN, state-employee data, electronic medical records, and insurance billing claims data, such as Medicare, may provide an opportunity to enhance the quality of treatment data for individuals with cancer and possibly provide an opportunity to estimate rates of treatment receipt in the population. For example, data from CRN's Virtual Data Warehouse have been shown to reliably identify CT as treatment for breast,^{21,27} colorectal,²¹ lung,²¹ and ovarian²⁸ cancer. Additional benefits to these data are that they include pharmacy data, individuals under 65 years of age, and those receiving treatment in HMOs.

In conclusion, caution should be taken when using treatment information from the SEER data. As the sensitivity of SEER data to identify treatment was consistently low, these data cannot be used to accurately describe the proportion of individuals in the population who received treatment. In addition, comparisons between individuals who received and did not receive treatment based on the SEER data would be biased. In contrast, the PPV was high for most cancer sites suggesting that SEER treatment data could be used reliably to identify a cohort of individuals with cancer who received treatment. RT data are currently available in the public-use SEER research data file. CT and HT data are not publically available but approval may be granted upon special data request to the SEER program. Our findings can inform investigators about potential uses of the CT and HT

data, albeit limited. Finally, NCI is currently investigating linkages to the SEER data, such as Medicare data, that could be used to supplement SEER treatment information leading to more accurate and complete information about treatment for individuals with cancer.

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