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Letter from the Editor

Dear Colleagues,

I hope everyone is enjoying a wonderful and safe summer. Adapting to change has become part of the new "normal." This year, the annual NCRA conference will be presented on a virtual platform. The conference will be held on September 20–23. Visit **https://www.ncra-usa.org/Conference/2020-Virtual-Conference/2020-Virtual-Conference-Information** for more information.

The American College of Surgeons has provided a standards resource library and templates that are available in the PRQ (previously SAR). These provide guidance for the 2020 Standards.

I am very excited to announce that this issue of the *Journal of Registry Management* contains 5 original manuscripts, 1 article, and 5 National Program of Cancer Registries Success Stories posters.

We start with Adriana Koch, MPH, and coauthors, who discuss trace-back of death certificates in Argentina. Bozena M. Morawski, PhD, MPH, and colleagues discuss how data linkage can improve follow-up completeness. Richard Knowlton, MS, and associates provide an analysis of tobacco-associated cancers in Massachusetts from 2006–2015. Baozhen Qiao, PhD, leads a team that provides a comprehensive description of multiple primary cancers in the United States. Virginia Senkomago, PhD, and collaborators examine cancer statistics at the congressional district level in the United States.

In the "Raising the Bar" section, Michele Webb, CTR, covers what factors influence people to succeed. This issues also contains a special section made up of National Program of Cancer Registries (NPCR) Success Stories posters.

The NPCR began in 1992. Since that time, cancer registrars have diligently collected data to inform cancer control decisions across the nation. This edition of JRM contains just 5 poster presentations of Success Stories in 2019 from NPCR-funded programs illustrating the value of the work cancer registrars do.

The Georgia Comprehensive Cancer Registry highlighted differences in breast cancer disparities in racial and ethnic populations and suggested interventions that might be helpful in addressing these disparities.

The Mississippi Cancer Registry provided colorectal cancer incidence and mortality data to stakeholders that led to the development of an action plan for addressing disparities in the state.

The New York State Cancer Registry served as an honest broker for cancer data needed in a multi-center and multi-state study on cancer involving World Trade Center first responders.

The Tennessee Cancer Registry conducted a data quality review of histology documentation for Wilms tumor. Documentation was improved after collaboration with pathology and clinical partners at Vanderbilt University. Educational efforts are being instituted to sustain the progress made.

Finally, the Texas Cancer Registry participated in a multistate study linking data with birth records to show the elevated risk of cancer among children with birth defects. These results will be used to inform more in-depth studies.

The last 2 pages of the JRM contains the Call for Papers and Information for Authors. Submissions of manuscripts or articles are accepted at any time. The "How I Do It" section comes from readers that want to share their expertise and ideas on varying topics.

Regards,
Danette A. Clark, BS, RMA, AAS, CTR
JRMeditor@NCRA-USA.org

Original Article

Improving Data Validity at Population-Based Cancer Registry through Trace-Back of Death Certificates: A Concrete Experience in Argentina

Adriana Koch[a]; Maria Diumenjo[a]; Walter Laspada[a]; Isabelle Soerjomataram[b], Marion Piñeros[b]

Abstract: The validity of data provided by population-based cancer registries (PBCRs) is a key aspect in cancer surveillance. Tracing back cases initially reported by death certificate or death-certificate-notified (DCN) cases, improves data quality and has an especially significant impact on survival estimates. The present study performed in the Mendoza PBCR describes the trace-back procedure of cancer cases notified by death certificate for selected cancers (liver, lung, and stomach cancers) with the aim of reducing the percentage of cases diagnosed by death certificate only (DCO). The study was performed in 2018 using cancers diagnosed between 2006 and 2012 in the framework of a survival project (SURVCAN-3). Among the 822 cases that have been traced back, only 32.1% had an identified source of information. Of these, 70.3% had medical records available for review. Of the reviewed medical records, 86.9% of cancer diagnoses were confirmed. The DCN and DCO cases were much higher among older age groups. With the trace-back, the overall percentage of DCO was reduced from 23.8% to 19.9%. We conclude that DCN trace-back could improve data quality by reducing DCO diagnoses, which directly impacts survival estimates. Trace-back should be performed routinely and in a timely manner.

Key words: *data quality; death certificates; neoplasm; registries*

Background

Population-based cancer registries (PBCRs) are the key public health surveillance strategy to provide crucial indicators, including cancer incidence and survival data for planning and evaluating cancer control activities.[1-3] Therefore, it is important to provide high-quality data that is measured by 4 main aspects: comparability, validity, completeness, and timeliness.[4,5]

Validity, or accuracy of the data, refers to the proportion of cases that truly have the attribute or characteristic indicated.[4] It is mainly evaluated using the proportion of cancer cases that are microscopically verified (either using histological or cytological examination), and the proportion of cases for which the cancer diagnosis was based on death certificate only (DCO). In order to confirm a DCO case in the registry system, cases that were initially death-certificate notified (DCN) are scrutinized through a trace-back process.[4] This is done by tracing back the individual patient and reviewing the corresponding clinical records or other data sources and/or by contacting professionals in charge of the death certificate. Where no further information is found, cases will be designated as true DCO cases.

The validity of cause-of-death information in a death certificate may be questionable, especially among the older population. Even in the absence of errors, the information recorded for cancer cases is less precise as, based on topography, it misses salient data on cancer morphology.[5] In addition, the likelihood of dying at home increases with age among cancer patients,[6] posing more challenges to the quality of death certification. Furthermore, a high proportion of cases diagnosed through DCO pose important limitations in comparative survival studies, where they are normally excluded due to zero follow-up (survival) time, causing biased estimation of cancer survival.[7,8] As DCO cases are more common among poor prognosis cancers and among older adults, it has particular implications in survival estimates for this group of cases.[7]

We present a real-world experience of trace-back for 3 poor prognosis cancers (liver, lung, and stomach) in the PBCR of Mendoza in Argentina. The aim of this study is to provide an example of the implementation of the trace-back procedure in a PBCR that, incorporated as a routine, will improve the quality of data in the Mendoza PBCR.

Methods

Data Sources

The Mendoza PBCR covers the Mendoza province, with a population of 1.7 million inhabitants, and data are collected using mainly active data collection.[9] The PBCR receives data from 171 sources (77 health institutions, 88 laboratories and private practice, and 6 government programs).

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The authors alone are responsible for the views expressed in this article and they do not necessarily represent the decisions, policy, or views of the International Agency for Research on Cancer/World Health Organization. The trace-back procedure was funded through SURVCAN project, which is funded by the Tata Memorial Hospital, Mumbai, India and the International Agency for Research on Cancer. Funds for the trace-back of cases were provided by the regular budget of the Mendoza PBCR and SURVCAN-3 funding from the Tata Memorial Centre.

Within the framework of SURVCAN-3 survival project,[10] an international benchmarking cancer survival study, new cancer cases diagnosed between 2006 and 2012, followed-up for at least 2 years (up to December 2014) were submitted to the International Agency for Research on Cancer (IARC). Of the 33,785 cancer cases diagnosed in this period, 3,963 (11.7%) were initially recorded as DCO cases, most of which corresponded to DCN cases. Of the cancer cases submitted, 4,109 corresponded to liver (ICD-10: C22), lung (C34), and stomach (C16) cancer, with 891 cases (21.7%) for which the diagnoses were based on DCN.

A second review of these cases revealed that 9 neither corresponded to the selected cancers nor had the assigned basis of diagnosis. These were excluded from the study. Thus, a total of 882 liver, lung, and stomach cancer cases were traced back for this study.

Trace-Back Procedure

To trace back the information of the 882 DCN cases, 52 establishments and professionals who signed the death certificates were identified. For deaths that occurred within an institution (n = 445), authorization was obtained to review the corresponding clinical records. For deaths that occurred outside of an institution, mainly at home (n = 336), the professional who signed the certificate was identified, but only a few of them (11 physicians) could be interviewed. In most cases, the physician did not remember the case.

The trace-back activities were performed for 2 months in 2018 by 6 trained staff from the Mendoza PBCR. The data required in the cancer registry were retrieved, including incidence date, primary site, morphology, and stage of disease. The information was recorded in Excel and was analyzed with SPSS v.19 that allows a more efficient database management. The frequencies were calculated for categorical variables and the average for continuous variables.

Results

In 2006–2012, there were 4,109 new liver, lung, and stomach cancers, representing 12.2% of the cancers diagnosed in the PBCR of Mendoza. Incident cases (by age and sex) of liver, lung, and stomach cancer were more frequent among ages ≥65 years for both sexes. DCNs accounted for 882 cases, with the highest percentage found for liver cancer (30.9%) followed by lung (21.2%) and stomach (18%) cancer. DCN cases for liver and lung cancer were more frequent in males ≥65 years old, where they represented 81.2% and 82.1% (respectively), while DNC cases for stomach cancer were more frequent in females aged ≥65 years old, representing 86.2% (Table 1).

The process and results of the trace-back procedure are illustrated in Figure 1. Of 882 DCN cancers, the data source was identified in 283 cases (32.1%). Only in 199 (22.6%) could we review the clinical record, with a cancer diagnosis being confirmed in 173 cases. In 17 cases, the cancer diagnosis did not correspond to any of the 3 cancers of interest, nor was it a metastasis. As such, a new primary cancer site was assigned. Incomplete records where the specific cancer could not be confirmed after review (n = 19) were kept as DCO, while 7 other cases in which another disease was found were excluded from the registry database. Finally, in 84 cases, the institution was visited, but the corresponding clinical record could not be located.

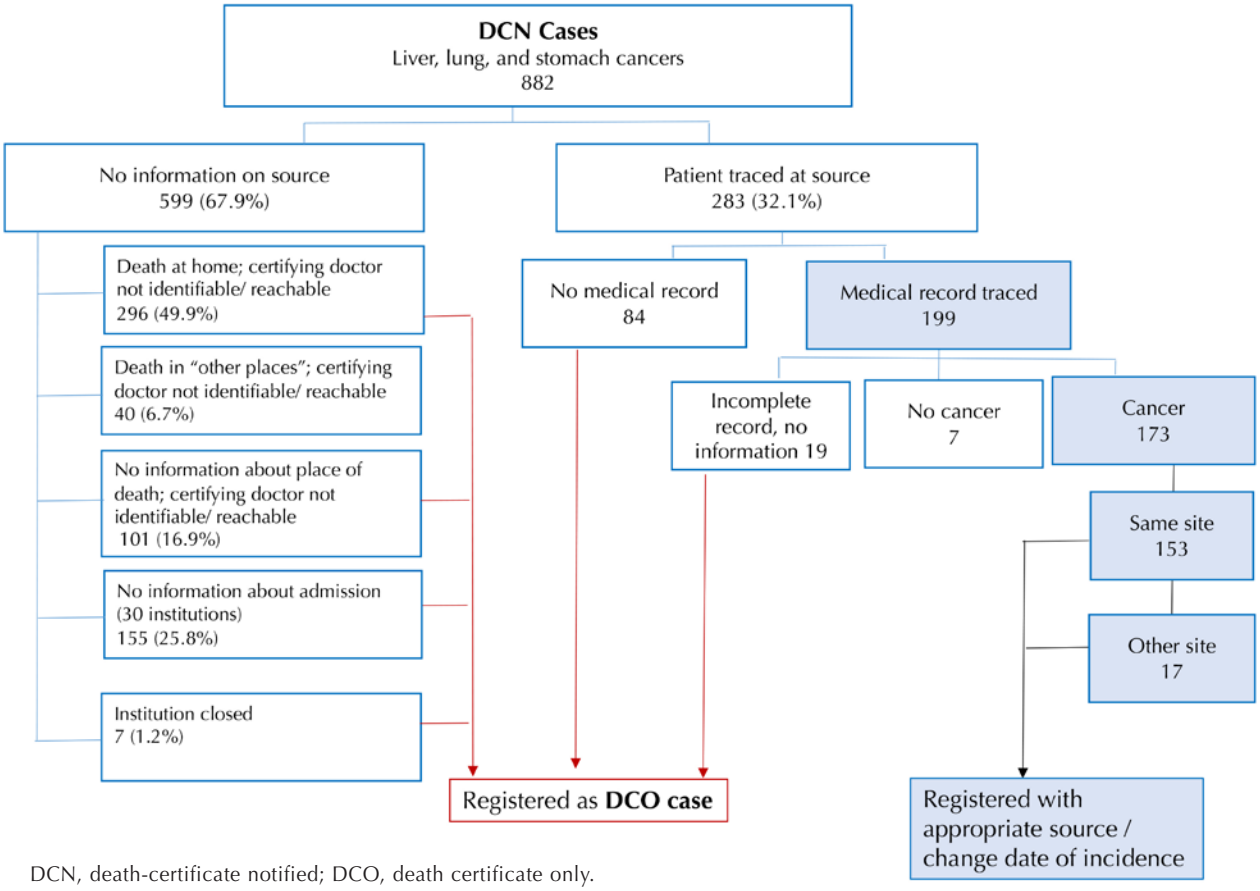
Table 2 shows the yearly availability of data for trace-back among DCN liver, stomach, and lung cancer cases in Mendoza. The difficulty in tracing clinical records varied with time of diagnosis: from 253 cases diagnosed in 2006–2007, 35 medical records (13.8%) were not available. Among the 263 cancer cases diagnosed in later years (2011–2012), only 15 medical records (5.7%) were not available. Of the 173 patients where cancer information was found in their clinical record, 93 (54%) corresponded to cases diagnosed in the last 3 years of the study period.

In 599 (67.9 %) DCN cancer cases, no further information was found after performing trace-back. Most of these cases corresponded to deaths at home (56%) or were missing information on the place of death (17%), and where the certifying doctor was not reachable or could not be identified. Notably, in 25.8% of the DCN cases, the institution

Table 1. Incident and Death-Certificate Notified (DCN) Cancer Cases (2006-2012): Percentages by Sex and Age Group, for Selected Cancer Sites (Mendoza, Argentina)

	Incident cases				*DCN cases*				
	n	Age group (%)			n	%	Age group (%)		
Cancer		<50 y	50–64 y	≥65 y			<50 y	50–64 y	≥65 y
Liver	553				171	30.9			
Males	340	5.9	32.0	62.1	101	29.7	2.0	16.8	81.2
Females	213	8.6	25.4	66.2	70	32.9	1.4	20.0	78.6
Lung	2,237				474	21.2			
Males	1,621	5.9	35.1	59.1	330	20.4	1.2	16.7	82.1
Females	616	7.3	34.9	58.5	144	23.4	0.6	4.6	25.1
Stomach	1,317				237	18.0			
Males	894	9.4	31.4	59.2	143	16.0	5.6	16.8	77.6
Females	423	12.5	28.3	59.5	94	22.2	0	13.8	86.2

Figure 1. Results of the Trace-Back of 3 Poor Prognosis Cancers Initially Notified by Death Certificate, Mendoza Population-Based Cancer Registry, Argentina



DCN, death-certificate notified; DCO, death certificate only.

Table 2. Annual Availability of Information Traced among Death-Certificate Notified (DCN) Cancer Cases: Percentages by Year for 3 Selected Cancers, in Mendoza, Argentina, 2006–2012

Information on source	*Total*	*2012*	*2011*	*2010*	*2009*	*2008*	*2007*	*2006*
	n	%	%	%	%	%	%	%
No information on source	599	67%	67%	66%	68%	66%	69%	71%
Patient traced at source								
No medical record available	84	7%	5%	10%	9%	9%	18%	10%
Incomplete medical record	19	2%	1%	2%	3%	4%	1%	3%
No cancer	7	1%	1%	0%	0%	2%	0%	1%
Cancer	173	25%	26%	21%	20%	18%	12%	15%
Total	882							

was known, but when visiting the institution (30 private and public institutions), there was no confirmation of the patient having been admitted.

When characterizing the DCN cases and grouping them into *unsuccessful trace-back* and *successful trace-back* (where patients were traced back in the source), no major differences were seen by type of cancer, sex, and age group, with most cases corresponding to lung cancer cases, males, and patients over 65 years old (Table 3).

Table 4 shows the proportion of DCN cases and definitive proportion of DCO after trace-back procedures for each of the 3 cancers. The best improvement was seen for stomach cancer: 18% DCN cases before trace-back was changed to 13.9% DCO after trace-back.

Discussion

In this study, we present an active method to improve PBCR data quality through trace-back and showed a success rate of 32% in tracing patients of 3 poor prognosis cancer cases notified through death certificate. We were able to review the corresponding clinical record and information in only 23% of the DCN cases. Most cases for which no

Table 3. Percentages of Main Characteristics of Successful and Unsuccessful Trace-Back of Death-Certificate Notified Cancer Cases (Selected Cancers), Mendoza Population-Based Cancer Registry, Argentina

	Unsuccessful (no information on source)			*Successful (patient traced at source)*	
	Death at home or "other place" (%)	No information place of death (%)	No information about admission (%)	No medical record (or incomplete) (%)	Cancer diagnosis (%)
Cancer type					
Liver	20.5	18.8	22.6	20.4	8.1
Lung	55.4	60.4	45.8	53.4	53.8
Stomach	24.1	20.8	31.6	26.2	26.6
Sex					
Male	65.8	70.3	58.1	69.9	65.9
Female	34.2	29.7	41.9	30.1	34.1
Age (y)					
<50	0.9	2.0	1.9	4.9	1.2
50–64	11.3	16.8	21.9	11.7	24.3
≥65	88.1	79.2	76.1	83.5	74.6

Table 4. Percentage of Selected Death-Certificate Notified (DCN) Cancers and after Trace-Back (Death Certificate Only; DCO), Mendoza Population-Based Cancer Registry, Argentina

Cancer	*DCN (%)*	*DCO (%)*
Liver	30.9	28.8
Lung	21.2	17.0
Stomach	18.0	13.9

information was found (n = 599) were patients who died at home and for whom the certifying doctor could not be identified or reached (56%). For those whose medical record could be examined (199), most (76.8%) had the same diagnoses as reported in the death certificate.

The cancer types included in our study (liver, lung, and stomach cancer) were poor-prognosis cancers that, in general, have a higher proportion of DCO compared to other types of cancer. For example, in the Mendoza PBCR, the proportion of DCO for breast, colon, and prostate cancers in 2008–2012 were 4.2%, 11.2% (both sexes combined), and 11.7%, respectively,[11] significantly lower than DCO percentages for those cancers in our study. Our results also showed that DCN and DCO cases were much higher among older age groups, confirming that patients with poor-prognosis cancers and older patients have a smaller probability of completing the diagnosis and treatment, and are therefore less likely to be registered through clinical or microscopic examination.[4,5] This finding is consistent with other low- and middle-income countries where disease awareness and access to diagnosis and treatment are low.[12]

Trace-back procedures are recommended in population-based cancer registries to improve data validity and quality[13]; nevertheless, in Latin America, many cancer registries have major constraints preventing them from performing it on a routine basis. This limits trace-back to the context of special studies such as ours. The current experience is not an exception: in the last years, the Mendoza PBCR had significantly reduced routine trace-back procedures given limited resources. This has resulted in higher percentages of DCO cases. Many registries that have access to mortality data, but do not routinely perform trace-back, are more likely to erroneously label DCN cases as DCO. Latin American PBCR data published in the international compendium, *Cancer Incidence in Five Continents*, have, with few exceptions, significantly higher DCO percentages compared to North America and other countries with available mortality statistics.[14] The reasons for the rather low success rate in our study are diverse and range from having a high percentage of deaths at home (where the practitioner could not be identified) to a long delay between diagnosis (2006–2012) and trace-back (2018).

An important proportion of the cancer deaths occurred at home, something that can be expected in the case of chronic diseases or cancer, where patients or relatives choose the place of death, but it may also reflect limited access to health care services.[14] Cancer patients who die at the hospital vary largely by setting and by type of cancer; they have been reported to represent between 26% to 35% of cases in the United Kingdom, 52% in the United States, 59% in Spain, and 74% in Canada. Patients diagnosed with hematological malignancies are also more likely to die in the hospital.[15,16] Nonhospital deaths will often miss information on main cause of death compared to hospital deaths,[16] and are associated with additional challenges to trace-back during identification, requiring contact with the certifying physician. This was clearly shown in the present study, where the main reason for an unsuccessful trace-back in our study was the difficulty in reaching the certifying doctor. Active follow-back through contact with patient relatives, as has been reported in another context,[17] was not considered

the given long delay between diagnoses and the study period, as well as confidentiality issues.

Although in poor-prognosis cancers, the doctor certifying the death might not necessarily be the treating physician, reaching out to treating oncologists as information sources (besides clinics and hospitals) is strongly recommended. The example of another Latin American country with a long history of data collection clearly illustrates this notion. The Cali Cancer Registry in Colombia reported a DCN proportion of 45% for stomach cancer; yet, the strong trace-back procedure, combined with periodic data collection of private physicians, successfully reduced it to a final DCO of 4%,[18] which is markedly better than the reduction observed in our study (from 18% to 13.9%). Based on the results obtained in this study, we also recommend reinforcing the training and awareness of the medical professional when completing the death certificate form, which has been shown to improve the quality of the information on the cause of death.[19,20] Moreover, as lung and liver are frequent metastatic sites, training of correct completion of cause of death information might have particular impact on the validity of information for these cancer sites.

We showed an inverse relationship between successful trace-back and amount of delay between diagnosis and trace back. The time elapsed between diagnosis and trace back largely impacted the availability of clinical records. This is especially the case in settings where electronic medical records are not yet in place, and where clinical records pertaining to deceased cases are stored in external locations or destroyed after a specified period. Indeed, in the present study, retrieval of clinical records of deceased patients had an additional cost for the cancer registry. Future improvement in electronic medical records could greatly improve the quality of the data in PBCR due to better capture and timely accessibility of the information, which would facilitate future trace-back procedures. Yet, even if computer systems were available, in many settings, they are weak and characterized by incompleteness, poor quality, and limited data utilization.[16] This clearly calls on the installation to perform more regular trace-back when possible. The present study highlights the importance of death certificates and their quality as source of information for cancer registries. In settings where they form an important source of data, trace-back procedures should routinely be performed when possible once a registry year is closed to ensure timeliness and also a higher success in trace-back and, ultimately, in PBCR data quality.

Although of limited success, active trace-back has led to additional retrieval of information for 180 cases, of which only 7 (4%) had no cancer. The overall reduction in the percentage of DCO cases for the 3 selected cancers, though small (from 23.8% to 19.9%), is important to improving data quality and survival estimates produced from this population-based data.

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Original Article

Impact of Linkage to the Social Security Administration on Follow-up Completeness and Cancer Relative Survival Estimates in 2 New SEER Registries: 2000–2016 Diagnosis Years

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Background: The Social Security Administration Service to Epidemiological Researchers (SSA-SER) can help central cancer registries meet the contractual follow-up requirements of the Surveillance, Epidemiology, and End Results (SEER) Program and improve survival estimate accuracy. We evaluated the impact of first-time SSA-SER linkage on follow-up rates and survival estimates for 2 SEER registries. Methods: In May 2019, cancer registries in Idaho (Cancer Data Registry of Idaho [CDRI]) and New York (New York State Cancer Registry [NYSCR]) used results from an SSA-SER linkage to update date of last contact and vital status for patients with a SEER-reportable tumor diagnosed during 2000–2016. We compared follow-up completeness through 2017 between pre-SSA-SER linkage and post-SSA-SER linkage data. Among individuals with a first primary tumor diagnosed during 2009–2015, we calculated 60-month age-standardized all sites and site-specific relative survival ratio (RSR) estimates via the presumed alive method using pre-SSA linkage data, and survival time calculated from last known date of contact using post-SSA linkage data. Results: SSA-SER linkage improved overall follow-up completeness from 79.0% to 97.4% and 55.7% to 92.6% for CDRI and NYSCR, respectively. Follow-up completeness improved most for laboratory-only reported tumors, in situ tumors, melanomas of the skin, prostate cancers, and benign and borderline brain and other central nervous system tumors. Post-SSA linkage RSRs were lower than pre-SSA presumed alive RSRs by an average –0.47% and –2.16% for Idaho and New York, respectively. Conclusions: SSA-SER linkage greatly and efficiently improved follow-up completeness for the 2 participating registries and revealed small difference in survival estimates by method. Use of the SSA-SER by all US registries would standardize and improve US survival estimates.

Key words: *follow-up completeness, population-based survival, presumed alive survival, relative survival, reported alive survival*

Introduction

Background

Determining vital status of cancer patients, part of a registry's patient follow-up process, is conducted to encourage best clinical practices and evaluate overall population-based survival and survival by key subpopulations.[1] Cancer registries conduct follow-up via 2 major methods, historically described as *active* or *passive*. The term *active follow-up* typically denotes activities that require contact with the patient, the patient's family, or the patient's clinical care team. Passive follow-up does not require such contact, but instead relies on other activities to ascertain vital status, such as linkage to state or national health care records, or state and national death certificate data.

Section 1106(d) of the Social Security Act authorizes the Social Security Administration (SSA) to act as a source of passive follow-up information for research that contributes to national health interests through the SSA Service to Epidemiological Researchers (SSA-SER).[2] Although SSA-SER data are not meant to provide a comprehensive view of all deaths in the United States,[3,4] these data are a timely source for consolidated national and subnational data, which provide assessments of vital status (alive, deceased, or unable to determine) and date of death. The SSA-SER provides data to researchers on a fee-for-service basis. Cancer registries participating in the National Cancer Institute (NCI)'s Surveillance, Epidemiology and End Results (SEER) Program, which covers approximately 36.7% of the US population across 21 registry jurisdictions,[5] have access to SSA-SER data, with the contractual and financial support of SEER.

In 2019, state population-based cancer registries for Idaho and New York participated in the SSA-SER linkage

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for the first time; these 2 new SEER registries were uniquely positioned to evaluate the impact of the SSA-SER linkage on follow-up and survival in their population-based data. The Cancer Data Registry of Idaho (CDRI) collects incidence and survival data on all cancer patients who reside in Idaho and any non-Idaho residents diagnosed with or treated for cancer in Idaho. The New York State Cancer Registry (NYSCR) collects incidence data on all New York State residents diagnosed with cancer and any non-New York State residents diagnosed with or treated for cancer in New York. NYSCR has not actively or passively collected survival data except by linking incidence data with state vital records and with the National Death Index (NDI) to ascertain deaths. CDRI and NYSCR have been population-based since 1971 and 1976, respectively. Both registries have been funded by the National Program of Cancer Registries (NPCR) since 1995 and by the NCI as part of the SEER Program since May 2018.

Rationale for Study

Resources such as the SSA-SER can assist registries with meeting SEER follow-up requirements and potentially improve survival estimate accuracy. Contractual standards for follow-up among SEER registries are that ≥90% of patients aged <65 years, ≥95% of patients aged ≥65 years with an invasive cancer diagnosis, and ≥90% of patients with an in situ diagnosis should have current follow-up (for this study, alive with date of last contact later than December 31, 2016, or deceased). This study assesses the impact of a first-time SSA-SER linkage on follow-up rates and population-based relative survival estimates among these 2 new SEER registries.

Methods

CDRI and NYSCR evaluated follow-up completeness among Idaho and New York residents diagnosed with a SEER-reportable first primary invasive cancer, including bladder in situ tumors, or a benign or borderline central nervous system (CNS) or other intracranial tumor during 2000–2016. We conducted survival analyses among individuals aged 15–99 years at diagnosis whose first primary tumor was diagnosed during 2009–2015.

In early 2019, registries created a North American Association of Central Cancer Registries (NAACCR) version 18 record layout flat file of their live database to serve as the basis for evaluating the change in follow-up and survival attributable to SSA-SER linkage. This file was generated with SEER data submission file parameters ("EXT-01") in the SEER Data Management System (SEER*DMS; Information Management Services, Inc), and included SEER-reportable cases for 2000–2017 diagnosis years.

Concurrent with the creation of the NAACCR version 18 data file, registry staff used the SSA Extract Report ("EXT-04") in SEER*DMS to generate a data file for submission to the SSA-SER linkage service. Patient-level records submitted to the SSA-SER linkage service met the following criteria: vital status recorded as alive in SEER*DMS; date of last contact was before January 1, 2019; patient had at least 1 SEER-reportable tumor; and patient had a valid and non-missing Social Security number (SSN), date of birth, and first and last name. Invalid SSNs were identified per the following criteria: SSN less than 9 digits; SSN beginning with "9"; SSN area number (first 3 digits) equal to "000" or "666", group number (middle 2 digits) equal to "00", or serial number (last 4 digits) equal to "0000". CDRI corrected invalid or missing SSNs via a LexisNexis batch process prior to creating the SSA extract file for submission to SSA-SER; NYSCR did not conduct this additional step. On behalf of the SEER registries, Information Management Services, Inc submitted SSA extract files that included SSN; first, last, and middle name; date of birth; and sex to the SSA's Office of Data Exchange, Policy Publications, and International Negotiations.

Registry SSA extract files sent to the SSA were linked to SSA follow-up data pulled on April 30, 2019. The SSA-SER returned vital status determinations for each patient's record with either (1) death information (the date of death and state where a claim was filed, or the state of residence at the time of death); (2) presumption that the individual is living, ie, there was sufficient information in SSA program records to support this determination; or (3) status unknown (SSA has neither a death record nor sufficient information to support a determination that the subject is alive). No information was returned for records that were unable to be verified. Registries used the SSA-SER linkage results to update date of last contact (NAACCR item 1750) and patient vital status (NAACCR item 1760) in the NAACCR version 18 file extracted in early 2019 for study purposes. SSA-SER linkage results provided date of death for deceased patients; for patients whose vital status was returned as alive by the SSA-SER, registries set the default date of last contact to March 1, 2019. Registries maintained a "pre-SSA" file—the NAACCR version 18 files reflecting registry follow-up efforts in the absence of the SSA-SER linkage; this pre-SSA file was used to create a post-SSA file, with updated vital status and date of last contact using results returned from SSA-SER.

We used SEER*Edits version 6.16.3 to evaluate follow-up completeness through 2017 among first primary cancer cases (sequence number central 00, 01, 60, or 61) diagnosed during 2000–2016. The proportion of patients that meet follow-up goals are those who are either deceased or who are alive with a follow-up date on or after January 1, 2017. Using the pre-SSA and post-SSA data sets, follow-up completeness was calculated for the overall cohort and the following subpopulations: *International Classification of Diseases for Oncology, 3rd Edition* (ICD-O-3) behavior code (invasive, in situ); age at diagnosis (<20, 20–64, or ≥65 years); age at time of SSA-SER linkage (<20, 20–64, or ≥65 years); sex (male or female); place of birth (United States, foreign, or unknown); ethnicity (Hispanic or non-Hispanic); race (White, Black, American Indian/Alaska Native, Asian/Pacific Islander, or unknown); reporting source (pathology only reports, or all other reporting sources); select primary site categories (melanoma of the skin, breast, prostate, colorectal, lymphomas, lung and bronchus, benign and borderline CNS and other intracranial tumors); US Department of Agriculture (USDA) tract-level rural-urban

commuting area (RUCA; urban commuting area, not an urban commuting area);[6] and census tract-level urban–rural indicator code (URIC; 100% population in urban area, ≥50–<100% population in urban area, >0–<50% population in urban area, or 0% population in urban area). Analyses of benign and borderline CNS and other intracranial tumors were conducted independently of the overall cohort, and not included in case totals.

To estimate the impact of SSA linkage on survival, we calculated the 60-month relative survival ratio (RSR) estimates in 2 ways: (1) the presumed alive method using pre-SSA-SER linkage data;[7] and (2) survival time calculated by using date of last contact available in post-SSA linkage data. We used estimates calculated from both methods to evaluate the difference in estimates between pre-SSA presumed alive and post-SSA observed survival.[8] For all survival analyses, we only included first primary cancers (sequence number central 00, 01, 60, or 61) diagnosed during 2009–2015; incident cases reported via death certificates or autopsy only and alive cases with no survival time were excluded. The survival study cutoff date was set to December 31, 2016 for both types of survival analyses; for presumed alive analyses, patients who were not known to be dead were censored as alive on December 31, 2016.

Using the methodology described in the 2019 Cancer in North America (CiNA) Survival Monograph, RSRs were calculated for all cancer sites combined and specific cancer sites, including benign and borderline CNS and other intracranial tumors.[9] Calculation of survival estimates was performed in SEER*Stat software version 8.3.6 (Information Management Services, Inc) using custom pre- and post-SSA linkage databases, which were based on the aforementioned pre-SSA and post-SSA data sets. The Ederer II method was used to calculate expected survival from age-, sex-, year-, geographic area–, race-, and socioeconomic status–matched life tables. Sixty-month relative survival was calculated via the actuarial method on monthly intervals.[9,10] RSRs were age-standardized using International Cancer Survival Standard age standards 1–3, depending on primary site.[9] Cases were censored when patients attained 100 years of age.

We also calculated the North American Cancer Survival Index (CSI) for all cancer sites combined to evaluate differences induced by SSA-SER linkage on a sex- and primary-site weighted estimate, which are typically more stable and comparable across jurisdiction. CSI is the weighted sum of age-standardized, site-specific RSRs, where weights are derived from the distribution of cases by sex and primary site diagnosed in North America during 2006–2008.[10,11] CSI estimates excluded benign and borderline CNS and other intracranial tumors. When age-standardized, site-specific RSRs were unable to be calculated in SEER*Stat, non-age-standardized RSRs and corresponding standard errors were used to calculate the CSI. RSR point estimates and 95% confidence intervals for RSRs were compared without being subjected to formal statistical evaluation.

The Idaho Department of Health and Welfare Research Determination Committee reviewed this protocol and determined that this study was not human subjects research.

Results

Among all SEER-reportable first primary cancers diagnosed during 2000–2016, about 54.3% and 50.5% were submitted to SSA-SER for linkage in Idaho and New York, respectively. The overall match return rate was 97.6% for CDRI and 96.6% for NYSCR. The detailed status of submission to SSA-SER and results of the SSA-SER linkage by demographic subpopulation are shown in Table 1. Characteristics of the population linked to SSA-SER, the distribution of linkage results, and the population not sent for linkage were overall similar in Idaho and New York. However, of the overall cohort, a slightly higher proportion was sent to SSA and had a vital status returned in Idaho than in New York (48.3% vs 44.6%). Conversely, a slightly higher percentage of the overall cohort was not sent to SSA-SER in New York than in Idaho (46.1% vs 45.5% due to being deceased or having a follow-up date after the study cut-off date, and 3.4% vs 0.3% due to having an invalid SSN or date of birth).

The distribution of age at diagnosis and age at time of SSA-SER linkage by SSA-SER disposition was similar across both registries. Patients who were aged ≥65 years at diagnosis had the best follow-up rates. A total of 31.6% (523,923/1,656,596) and 31.5% (33,935/107,431) of patients in New York and Idaho, respectively, were ≥65 years old at time of diagnosis and were not submitted to SSA-SER because they were deceased or had a follow-up date after the study cut-off date. SSA-SER linkage was most beneficial (ie, returned an updated vital status and date of last contact) for the age group of 20–64 years at diagnosis (57.3% or n = 460,442 in New York and 62.2% or n = 31,305 in Idaho) and ≥65 years at time of SSA-SER linkage (39.0% or n = 474,964 in New York and 42.1% or n = 33,716 in Idaho). Submission and linkage patterns were similar across jurisdictions by sex and ethnicity, although a larger proportion of Hispanic patients had ineligible SSN or date of birth in New York (7.3%) than in Idaho (3.3%); and a larger proportion of Hispanic patients in Idaho were linked with a vital status update (47.5%) than in New York (42.8%). A higher proportion of Hispanic patients were not submitted to SSA-SER due to ineligible date of birth or SSN than non-Hispanic patients (3.3% vs 0.2% in Idaho; 7.3% vs 3.0% in New York); vital status was unknown or no match was returned by SSA-SER for a higher proportion of Hispanic patients than non-Hispanic patients (10.7% vs 5.7% in Idaho; 9.3% vs 5.6% in New York).

In Idaho, vital status and date of last contact were updated for a higher proportion of patients with unknown race (78.9%) vs other racial groups (range, 43.8%–51.1%). In New York, a higher percentage of patients with unknown race were ineligible for linkage (24.8%) than other racial groups (range, 2.4%–8.5%). Similarly, vital status and date of last contact were updated in 57.5% (31,559) and 75.4% (339,577) of patients with an unknown country of birth via SSA-SER linkage in Idaho and New York, respectively. Relatively higher proportions of patients with a known country of birth (United States or foreign) were not submitted to SSA-SER because they were deceased or had a

Table 1. Results of SSA Linkage Among Persons Diagnosed with First Primary Tumor (Sequence Number Central 00, 01, 60, 61) during 2000–2016

Idaho						
	Sent to SSA			Not Sent to SSA		
	Vital status returned (dead/alive)	Unknown vital status	No return from SSA	Ineligible (eg, no SSN, DOB incomplete)	Died or follow-up after study cutoff date	Total
	n (%)	n (%)	n (%)	n (%)	n (%)	N
Overall	51,897 (48.3)	4,911 (4.6)	1,401 (1.3)	358 (0.3)	48,864 (45.5)	107,431
Age at diagnosis (y)						
<20	717 (48.3)	339 (22.8)	52 (3.5)	169 (11.4)	207 (14.0)	1,484
20–64	31,305 (62.2)	3,291 (6.5)	920 (1.8)	131 (0.3)	14,722 (29.2)	50,369
≥65	19,875 (35.8)	1,281 (2.3)	429 (0.8)	58 (0.1)	33,935 (61.1)	55,578
Age at time of SSA linkage (y)[a]						
<20	171 (24.1)	285 (40.1)	19 (2.7)	150 (21.1)	86 (12.1)	711
20–64	18,010 (67.4)	2,472 (9.3)	633 (2.4)	119 (0.5)	5,480 (20.5)	26,714
≥65	33,716 (42.1)	2,154 (2.7)	749 (0.9)	86 (0.1)	43,298 (54.1)	80,003
Sex[b]						
Male	26,028 (47.0)	1,433 (2.6)	604 (1.1)	171 (0.3)	27,106 (49.0)	55,342
Female	25,869 (49.7)	3,478 (6.7)	797 (1.5)	187 (0.4)	21,755 (41.8)	52,086
Ethnicity						
Non-Hispanic	50,014 (48.3)	4,663 (4.5)	1,227 (1.2)	227 (0.2)	47,338 (45.8)	103,469
Hispanic	1,883 (47.5)	248 (6.3)	174 (4.4)	131 (3.3)	1,526 (38.5)	3,962
Race						
White	50,188 (48.1)	4,699 (4.5)	1,339 (1.3)	316 (0.3)	47,798 (45.8)	104,340
Black	141 (51.1)	8 (2.9)	8 (2.9)	6 (2.2)	113 (40.9)	276
American Indian/ Alaska Native	423 (43.8)	62 (6.4)	11 (1.1)	1 (0.1)	468 (48.5)	965
Asian/Pacific Islander	330 (44.7)	59 (8.0)	14 (1.9)	12 (1.6)	323 (43.8)	738
Unknown	706 (78.9)	57 (6.4)	17 (1.9)	10 (1.1)	105 (11.7)	895
Country of birth						
United States	19,676 (39.0)	1,935 (3.8)	417 (0.8)	67 (0.1)	28,359 (56.2)	50,454
Foreign	662 (31.8)	101 (4.8)	64 (3.1)	71 (3.4)	1,187 (56.9)	2,085
Unknown	31,559 (57.5)	2,875 (5.2)	920 (1.7)	220 (0.4)	19,318 (35.2)	54,892

DOB, date of birth; SSA, Social Security Administration; SSN, Social Security number.

[a] N = 3 missing age at time of SSA linkage for Idaho.

[b] N = 3 unknown sex for Idaho; N = 165 unknown sex for New York.

follow-up after the study cut-off date (range, 51.3% –62.4%) in Idaho and New York.

Linkage with the SSA-SER improved overall follow-up completeness from 79.0% to 97.4% for Idaho and from 55.7% to 92.6% for New York. Improvement of follow-up completeness by different demographic, tumor, and diagnostic characteristics is shown in Table 2. Overall, New York saw larger follow-up improvements than Idaho for all groups evaluated. In Idaho, the largest increases in follow-up were noted among cases reported solely from pathology reports, and, relatedly, melanoma of the skin primary site category, with 60.7% and 53.1% absolute increases in follow-up completeness, respectively. A similar pattern was also noted in New York, with a 57.1% absolute increase in follow-up for melanomas of the skin. Additionally, there were large absolute increases in follow-up completeness for cancers of the breast and prostate of 52.6% and 53.9%, respectively, in New York. There was a larger increase in follow-up completeness among cases reported solely from pathology reports in New York (absolute increase of 47.2%) vs all other reporting sources (absolute increase of 36.7%), although the difference in increased follow-up completeness was larger in Idaho

Table 1 cont. Results of SSA Linkage Among Persons Diagnosed with First Primary Tumor (Sequence Number Central 00, 01, 60, 61) during 2000–2016

New York						
	Sent to SSA			Not Sent to SSA		
	Vital status returned (dead/alive)	Unknown vital status	No return from SSA	Ineligible (eg, no SSN, DOB incomplete)	Died or follow-up after study cutoff date	Total
	n (%)	n (%)	n (%)	n (%)	n (%)	N
Overall	739,261 (44.6)	68,813 (4.2)	28,087 (1.7)	56,096 (3.4)	764,339 (46.1)	1,656,596
Age at diagnosis (y)						
<20	6,359 (34.7)	2,463 (13.4)	675 (3.7)	6,114 (33.3)	2,737 (14.9)	18,348
20–64	460,442 (57.3)	50,819 (6.3)	19,664 (2.5)	34,657 (4.3)	237,679 (29.6)	803,261
≥65	272,460 (32.6)	15,531 (1.9)	7,748 (0.9)	15,325 (1.8)	523,923 (62.8)	834,987
Age at time of SSA linkage (y)[a]						
<20	906 (11.2)	1,671 (20.6)	237 (2.9)	4,141 (51.1)	1,147 (14.2)	8,102
20–64	263,391 (61.2)	38,187 (8.9)	13,528 (3.1)	25,806 (6.0)	89,795 (20.9)	430,707
≥65	474,964 (39.0)	28,955 (2.4)	14,322 (1.2)	26,149 (2.2)	673,397 (55.3)	1,217,787
Sex[b]						
Male	344,641 (43.0)	23,834 (3.0)	11,030 (1.4)	25,232 (3.2)	395,978 (49.5)	800,715
Female	394,549 (46.1)	44,969 (5.3)	17,051 (2.0)	30,855 (3.6)	368,292 (43.0)	855,716
Ethnicity						
Non-Hispanic	675,313 (44.8)	59,736 (4.0)	23,310 (1.6)	45,119 (3.0)	703,589 (46.7)	1,507,067
Hispanic	63,948 (42.8)	9.077 (6.1)	4,777 (3.2)	10,977 (7.3)	60,750 (40.6)	149,529
Race						
White	599,871 (45.2)	49,275 (3.7)	19,091 (1.4)	34,314 (2.6)	625,487 (47.1)	1,328,038
Black	96,573 (41.5)	9,658 (4.2)	5,060 (2.2)	10,214 (4.4)	111,383 (47.8)	232,888
American Indian/Alaska Native	1,118 (46.5)	145 (6.0)	36 (1.5)	58 (2.4)	1,045 (43.5)	2,402
Asian/Pacific Islander	30,439 (42.7)	7,690 (10.8)	2,373 (3.3)	6,051 (8.5)	24,706 (34.7)	71,259
Unknown	11,260 (51.2)	2,045 (9.3)	1,527 (6.9)	5,459 (24.8)	1,718 (7.8)	22,009
Country of birth						
United States	311,061 (33.1)	23,687 (2.5)	7,747 (0.8)	11,602 (1.2)	587,044 (62.4)	941,141
Foreign born	88,623 (33.4)	15,781 (6.0)	6,514 (2.5)	18,161 (6.9)	136,030 (51.3)	265,109
Unknown	339,577 (75.4)	29,345 (6.5)	13,826 (3.1)	26,333 (5.9)	41,265 (9.2)	450,346

DOB, date of birth; SSA, Social Security Administration; SSN, Social Security number.

[a] N = 3 missing age at time of SSA linkage for Idaho.

[b] N = 3 unknown sex for Idaho; N = 165 unknown sex for New York.

than in New York (44.8% vs 10.5% difference in increased follow-up between pathology reports and all other reports). There were larger absolute increases in follow-up completeness among in situ cases vs invasive cases for Idaho and New York; follow-up completeness increased by 34.3% and 58.7% among in situ cases, and 19.7% and 34.7% among invasive cases, in Idaho and New York, respectively.

In both jurisdictions, linkage with the SSA-SER yielded larger increases in follow-up completeness among patients aged <20 years and 20–64 years at diagnosis, relative to patients aged ≥65 years at diagnosis. In Idaho, there was an absolute 24.6% increase in follow-up among patients aged <20 years and 20–64 years at diagnosis vs an absolute 12.5% increase among patients aged ≥65 years. In New York, follow-up increased by 31.3% and 48.7% among patients aged <20 years and 20–64 years at diagnosis vs an absolute 25.8% increase among patients aged ≥65 years. In Idaho and New York, respectively, increases in follow-up completeness were 9.7% and 26.6% for US- and foreign-born patients, compared to 26.7% and 65.1% in patients with an unknown birthplace. Absolute increases in follow-up completeness were similar by race in Idaho and New York, apart from

Table 2. Proportion of Individuals Diagnosed with a Primary Tumor during 2000–2016 who Met SEER Follow-up Completeness Standards, Idaho and New York State

	Idaho					*New York*				
	N	Pre-SSA Linkage (%)	Post-SSA Linkage (%)	Absolute Increase (%)	Relative Increase (%)	N	Pre-SSA Linkage (%)	Post-SSA Linkage (%)	Absolute Increase (%)	Relative Increase (%)
Total	105,080	79.0	97.4	18.3	23.2	1,614,029	55.7	92.6	36.9	66.2
Behavior code (ICD-O-3)										
Invasive	95,425	81.6	97.6	16.0	19.7	1,468,221	58.3	93.0	34.7	59.5
In situ	9,659	60.1	94.4	34.3	57.1	145,808	29.8	88.5	58.7	197.0
Age at diagnosis (y)										
<20	1,392	60.3	84.9	24.6	40.7	16,342	27.4	58.7	31.3	114.2
20–64	49,035	71.5	96.2	24.6	34.5	779,272	40.7	89.4	48.7	119.7
≥65	54,653	86.2	98.7	12.5	14.5	818,415	70.5	96.3	25.8	36.6
Sex										
Male	54,502	77.6	98.0	20.4	26.3	786,174	58.4	94.0	35.6	61.0
Female	50,578	80.6	96.7	16.1	19.9	827,702	53.1	91.2	38.1	71.8
Birth Place										
United States	49,660	89.0	98.8	9.8	11.0	925,588	70.0	96.4	26.4	37.7
Foreign	2,044	88.8	95.4	6.6	7.4	258,540	60.2	87.6	27.4	45.5
Unknown	55,376	69.4	96.1	26.7	38.5	429,901	22.3	87.4	65.1	291.9
Ethnicity										
Non-Hispanic	101,265	79.0	97.5	18.5	23.4	1,469,942	56.1	93.2	37.1	66.1
Hispanic	3,815	78.7	94.5	15.8	20.1	144,087	51.7	86.8	35.1	67.8
Race										
White	102,078	79.5	97.4	17.9	22.5	1,296,486	56.5	93.8	37.3	66.0
Black	266	75.2	97.0	21.8	29.0	225,858	57.5	91.5	34.0	59.1
American Indian/ Alaska Native	940	80.2	96.7	16.5	20.6	2,331	55.5	92.2	36.7	66.1
Asian/Pacific Islander	721	83.8	95.0	11.2	13.4	68,640	46.2	81.9	35.7	77.2
Unknown	868	24.7	91.6	66.9	270.9	20,714	21.1	64.8	43.7	207.1
Reporting source										
Pathology only reports	5,767	31.2	91.9	60.7	194.6	37,522	33.0	80.2	47.2	143.0
All other reports	99,313	81.8	97.7	15.9	19.4	1,576,507	56.2	92.9	36.7	65.3

DOB, date of birth; ICD-O-3, International Classification of Diseases for Oncology, 3rd Edition; SEER, Surveillance, Epidemiology and End Results; SSA, Social Security Administration; SSN, Social Security number.

* N = 14 missing rural-urban commuting area or urban rural indicator code classification among Idaho cases, 3,349 among New York. 153 patients with other/or unknown sex in New York were not displayed in the sex category.

Relative increase was calculated as follows: (Post-SSA Linkage % – Pre-SSA Linkage %)/(Pre-SSA Linkage %) × 100

larger relative and absolute increases for cases with an unknown race. Increases in rates of follow-up in Idaho and New York were similar between males and females and between Hispanics and non-Hispanics.

Survival, as calculated using 60-month age-standardized RSRs among first primary tumors, was greater using the presumed alive method on pre-SSA linkage data vs when calculated from dates using post-SSA linkage data (Table 3). In Idaho, the pre-SSA-SER linkage all sites combined RSR was 68.2 (95% CI, 67.5–68.8; N = 42,005), and the post-SSA-SER linkage all sites combined RSR was 67.7 (95% CI, 67.1–68.4; N = 41,828). In New York, the pre-SSA-SER linkage all sites combined RSR was 68.2 (95% CI, 68.1–68.4; N = 615,249), and the post-SSA-SER linkage all sites combined RSR was 66.1 (95% CI, 65.9–66.2; N = 610,229). In Idaho, 177 (0.42%) patients that were included in survival estimates calculated using the presumed alive method were excluded from survival using calculated dates; in New York, 5,020

Table 2, cont. Proportion of Individuals Diagnosed with a Primary Tumor during 2000–2016 who Met SEER Follow-up Completeness Standards, Idaho and New York State

	Idaho					*New York*				
	N	Pre-SSA Linkage (%)	Post-SSA Linkage (%)	Absolute Increase (%)	Relative Increase (%)	N	Pre-SSA Linkage (%)	Post-SSA Linkage (%)	Absolute Increase (%)	Relative Increase (%)
Primary site category										
Melanoma of the skin	8,930	39.3	92.4	53.1	135.0	77,684	31.0	88.3	57.3	184.8
Breast	16,176	83.4	97.2	13.8	16.5	268,624	36.6	89.2	52.6	143.7
Prostate	16,598	70.9	97.9	27.0	38.1	232,863	39.1	93.0	53.9	137.9
Colorectal	8,965	83.9	98.1	14.1	16.8	158,429	61.2	93.6	32.4	52.9
Lymphomas	6,137	85.1	97.5	12.4	14.5	94,704	55.8	91.7	35.9	64.3
Lung and bronchus	10,656	97.5	99.8	2.3	2.3	177,749	89.0	98.2	9.2	10.3
Brain and other nervous system, benign and borderline	2,757	68.4	95.0	26.6	38.9	50,431	37.6	84.4	46.8	124.5
Rural urban commuting area, 2010 Census tract level										
Urban commuting Area	74,452	78.9	97.3	18.4	23.3	1,511,837	55.5	92.5	37.0	66.7
Not an urban commuting area	30,614	79.5	97.5	18.0	22.6	98,920	59.6	95.5	35.9	60.2
Urban rural indicator code, 2010 Census tract level										
100% population in urban area	34,022	82.1	97.8	15.7	19.1	1,220,621	55.8	92.0	36.2	64.9
≥50–<100% population in urban area	38,944	78.5	97.3	18.7	23.8	180,327	54.2	94.2	40.0	73.8
>0–<50% population in urban area	17,371	76.2	97.0	20.8	27.3	113,910	55.6	94.9	39.3	70.7
0% population in urban area	14,729	76.7	97.0	20.3	26.5	95,883	57.5	95.2	37.7	65.6

DOB, date of birth; ICD-O-3, International Classification of Diseases for Oncology, 3rd Edition; SEER, Surveillance, Epidemiology and End Results; SSA, Social Security Administration; SSN, Social Security number.

* N = 14 missing rural-urban commuting area or urban rural indicator code classification among Idaho cases, 3,349 among New York. 153 patients with other/or unknown sex in New York were not displayed in the sex category.

Relative increase was calculated as follows: (Post-SSA Linkage % – Pre-SSA Linkage %)/(Pre-SSA Linkage %) × 100

(0.82%) patients that were included in survival estimates calculated using the presumed alive method were excluded from survival using calculated dates. Patients included in presumed alive but not in survival calculated from follow-up dates were patients who were deemed "alive" but who had no follow-up time using dates.

Differences in pre- and post-SSA survival estimates were differentially impacted by this initial linkage to SSA-SER across jurisdictions. For Idaho, post-SSA linkage survival estimates were lower than pre-SSA presumed alive estimates by an average –0.47%, with particularly large differences for mesothelioma (–1.7%), cervix uteri (–1.3%), and CNS and other intracranial tumors (–1.3%). For New York, post-SSA linkage survival estimates were lower than pre-SSA presumed alive estimates by an average –2.16%, with particularly large differences for colon and rectum (–2.8%), larynx (–2.7%), liver and intrahepatic bile duct (–3.3%), oral cavity and pharynx (–2.5%), ovary (–2.5%), stomach (–4.7%), cervix uteri (-5.5%), and CNS and other intracranial tumors (–4.0%). Differences between pre- and post-SSA-SER linkage survival estimates using the age- and primary site-standardized North American CSI were smaller than pre- and post-estimates for non-age- and primary site-standardized all sites combined estimates. In Idaho, survival was 0.4% lower using the post-SSA linkage calculated dates method vs the pre-SSA linkage presumed alive method; in New York, survival was 1.8% lower using the post-SSA linkage calculated dates method vs the pre-SSA linkage presumed alive method.

Table 3. Sixty-Month Age-Standardized RSR Estimates among First Primary Tumors Diagnosed during 2009–2015, with Follow-up through December 2016

	Idaho					
	Pre-SSA linkage (presumed alive method)			Post-SSA linkage (from reported dates)		
	N	RSR	95% CI	N	RSR	95% CI
North American Cancer Survival Index	42,005	65.8	65.2–66.4	41,828	65.4	64.8–66.0
All sites combined	42,005	68.2	67.5–68.8	41,828	67.7	67.1–68.4
Site-specific estimates						
Oral cavity and pharynx	1,167	70.8	66.3–74.7	1,161	70.0	65.5–74.0
Esophagus	442	19.8	15.3–24.8	441	19.7[a]	15.3–24.6[a]
Stomach	469	28.6	23.9–33.6	468	28.2	23.4–33.1
Colon and rectum	3,464	63.9	61.6–66.1	3,446	63.5	61.2–65.7
Liver and intrahepatic bile duct	630	13.8[a]	10.5–17.6	630	13.1[a]	9.8–16.8[a]
Pancreas	1,151	8.9	6.9–11.3	1,150	8.7	6.7–11.1
Larynx	219	63.2[a]	54.9–70.3[a]	219	63.2[a]	54.9–70.3[a]
Lung and bronchus	4,426	21.1	19.4–22.8[a]	4,423	20.8	19.1–22.6
Melanoma of the skin	2,424	92.0	89.9–93.7	2,361	91.3	89.1–93.1
Breast, female	6,023	91.4	89.8–92.8	6,059	91.2	89.6–92.6
Cervix uteri	309	59.7	52.4–66.3	308	58.4	50.9–65.1
Corpus and uterus, NOS	1,384	76.4	71.8–80.4	1,380	75.9	71.2–79.9
Ovary	592	36.8	32.0–41.6	590	36.5	31.7–41.3
Prostate	6,581	94.8	93.3–96.0	6,544	94.6	94.9–97.3
Testis	336	97.3[a]	94.3–98.7[a]	334	97.2[a]	94.2–98.6[a]
Urinary bladder	1,878	82.3	79.4–84.8	1,875	81.9	79.0–84.5
Kidney and renal pelvis	1,440	73.3	69.3–76.9	1,438	73.0	68.9–76.6
Brain and other nervous system	619	27.6	23.9–31.5	617	26.3	22.5–30.2
Thyroid	1,547	95.1	91.8–97.0	1,541	94.8	91.5–96.8
Hodgkin lymphoma	254	89.9	84.7–93.4	253	89.6	84.4–93.1
Non-Hodgkin lymphoma	1,688	71.5	68.3–74.5	1,683	71.2	68.0–74.1
Myeloma	568	55.3	49.6–60.5	567	55.0	49.4–60.3
Leukemia	1,323	66.4	62.6–70.0	1,322	66.2	62.3–69.8
Mesothelioma	93	9.3[a]	3.5–18.8[a]	92	7.6[a]	2.4–17.0[a]
Brain and other ONS, benign and borderline	1,248	90.9	88.3–93.0	1,241	90.5	87.9–92.6

NOS, not otherwise specified; RSR, relative survival ratio.

Notes: Actuarial method. Ederer II method used for cumulative expected. Confidence interval: Log(-Log()) Transformation at 95%.

[a] Unable to estimate age-standardized estimates. Non-age-standardized RSRs provided.

Discussion

This study evaluated how SSA-SER linkage impacted follow-up completeness overall and by population demographics primary site category. We also compared differences in survival estimates across pre-SSA-SER and post-SSA-SER linked data calculated using the presumed alive and reported alive methods, respectively. With the exception of pediatric patients, Idaho met all SEER contractual standard follow-up goals after linkage to the SSA-SER. New York State met the contractual standard follow-up goal for patients aged ≥65 years, and almost met the goals for patients aged 20–64 years (89.4%) and for in-situ tumors (88.5%) after linkage to the SSA-SER. Even though there was a 31.3% absolute increase in the follow-up rate after linkage, the follow-up rate for pediatric patients was still well below the SEER standard. For both jurisdictions, the single SSA-SER linkage was associated with particularly large increases in follow-up completeness for tumors diagnosed in an outpatient setting, eg, melanomas of the skin and tumors only identified through pathology reports.

Table 3, cont. Sixty-Month Age-Standardized RSR Estimates among First Primary Tumors Diagnosed during 2009–2015, with Follow-up through December 2016

	New York					
	Pre-SSA linkage (presumed alive method)			Post-SSA linkage (from reported dates)		
	N	RSR	95% CI	N	RSR	95% CI
North American Cancer Survival Index	615,249	68.0	67.1–68.9	610,229	66.2	65.3–67.0
All sites combined	615,249	68.2	68.1–68.4	610,229	66.1	65.9–66.2
Site-specific estimates						
Oral cavity and pharynx	13,236	64.1	62.8–65.4	13,176	61.6	60.2–63.0
Esophagus	5,754	22.7	21.3–24.2	5,741	20.5	19.1–22.0
Stomach	10,905	41.2	40.0–42.4	10,782	36.5	35.2–37.7
Colon and rectum	50,663	66.1	65.5–66.7	50,157	63.3	62.7–63.9
Liver and intrahepatic bile duct	11,734	22.3	21.3–23.3	11,681	19.0	18.0–20.0
Pancreas	17,018	14.5	13.8–15.2	16,954	12.3	11.6–12.9
Larynx	4,440	63.4	61.2–65.5	4,434	60.7	58.4–62.9
Lung and bronchus	70,153	26.0	25.5–26.4	69,978	24.0	23.6–24.5
Melanoma of the skin	21,155	93.8	93.2–94.4	20,599	92.7	92.1–93.3
Breast, female	87,035	91.6	91.2–92.1	86,754	89.9	89.4–90.4
Cervix uteri	5,470	65.0	63.3–66.6	5,403	59.5	57.7–61.2
Corpus and uterus, NOS	23,251	78.4	77.4–79.3	23,082	76.1	75.1–77.0
Ovary	8,864	45.7	44.4–47.1	8,788	43.2	41.8–44.6
Prostate	92,205	97.5	97.1–97.8	91,549	96.8	96.5–97.1
Testis	3,686	94.6	91.9–96.4	3,623	94.0	91.3–95.9
Urinary bladder	26,978	82.1	81.3–82.8	26,628	80.7	79.9–81.5
Kidney and renal pelvis	19,418	76.4	75.4–77.4	19,150	74.8	73.7–75.8
Brain and other nervous system	7,493	33.2	32.1–34.3	7,427	29.2	28.1–30.4
Thyroid	24,584	97.8	97.4–98.2	24,137	97.6	97.1–98.0
Hodgkin lymphoma	4,067	86.6	85.2–87.8	4,035	85.6	84.0–87.0
Non-Hodgkin lymphoma	26,546	73.8	73.0–74.6	26,305	72.0	71.2–72.9
Myeloma	10,259	57.9	56.6–59.2	10,204	55.8	54.4–57.1
Leukemia	18,008	66.0	65.0–66.9	17,803	64.2	63.2–65.2
Mesothelioma	1,040	16.7	13.6–20.0	1,038	14.3	11.3–17.7
Brain and other ONS, benign and borderline	20,566	92.0	91.4–92.6	20,089	90.6	89.9–91.2

NOS, not otherwise specified; RSR, relative survival ratio.

Notes: Actuarial method. Ederer II method used for cumulative expected. Confidence interval: Log(-Log()) Transformation at 95%.

[a] Unable to estimate age-standardized estimates. Non-age-standardized RSRs provided.

Other subpopulations with particularly large increases in follow-up were patients with unknown birth country or unknown race, which could be related to both data quality among tumors reported through a single outpatient source or race, ethnicity, and patient residence at time of diagnosis. There were also particularly large increases in follow-up completeness among tumors of the breast and prostate in New York only.

This study demonstrated that differences in survival estimates calculated using the presumed alive method and the reported alive method after linkage with the SSA-SER were small for all sites combined and most primary cancer sites, even in instances when a registry does not attain follow-up completeness goals. Pre- and post-SSA-SER linkage rates were, however, more similar in Idaho (0.5% difference on average) than in New York (2.2% difference on average). The presumed alive method of calculating relative survival yielded consistently higher survival estimates, per expectation and as has been demonstrated elsewhere.[12,13] The 5 primary sites with the largest differences between

presumed alive and reported alive survival methods were cancers with low relative survival and/or cancers with higher incidence in non-White populations.[14,15] In Idaho, these primary sites were cervix uteri, CNS and other intracranial tumors, oral cavity and pharynx, mesothelioma, and liver and intrahepatic bile duct. In New York, these sites were cervix uteri, brain and other nervous system, stomach, liver and intrahepatic bile duct, and colon and rectum. Differences in survival for melanomas of the skin were also relatively large in Idaho, which could be attributable to the reporting type associated with these cancers (ie, pathology-only results).

The large average difference in survival estimates calculated by the presumed alive and reported alive methods in New York, as compared to Idaho, might, in part, be explained by the larger degree of ethnic diversity in New York relative to Idaho. Idaho patients included in this sample were 3.7% Hispanic and 2.9% non-White, and New York patients were 9.0% Hispanic and 20.1% non-White. As demonstrated in Pinheiro et al, non-Whites diagnosed with late-stage cancers were more likely to be lost to follow-up, accompanied with low survival.[13] This combination could contribute to presumed alive survival estimates being biased upward by artificially inflating survival time in jurisdictions or populations with relatively higher proportions of these patients. Loss to follow-up in non-Whites diagnosed with late-stage cancers has been attributed to lower death clearance linkage sensitivity (incorrect SSN, name misspellings, multiple last names, and first and last name swapping) and foreign returnees who die abroad and are not captured by state and national death clearance. Furthermore, relative survival estimates calculated with the presumed alive method vs the reported alive method increasingly diverge with decreasing follow-up completeness; that NYSCR's follow-up completeness was below SEER follow-up goals even after SSA-SER linkage may have also contributed to the average 2.0% difference in presumed and reported alive relative survival estimates.

A higher proportion of patients were ineligible for SSA linkage due to incomplete SSN or date of birth in New York (3.4%) than in Idaho (0.3%). This difference across registries is likely multifactorial, attributable in part to the LexisNexis linkage performed in Idaho prior to SSA-SER file preparation, and in part to the higher proportion of racial and ethnic subpopulations that are more likely to have invalid or absent SSNs in New York; eg, Hispanics and Asian Pacific Islanders.[14] There was also a higher proportion of patients that were <19 years of age at time of diagnosis in New York than Idaho and that were not submitted to SSA-SER for linkage due to missing SSN or date of birth. For tumors diagnosed among pediatric patients, follow-up rates were better among White patients, patients diagnosed with lymphoma/leukemia, and—even among pediatric patients—patients of younger age at diagnosis.[16,17]

Relatedly, there are potentially important limitations in using the SSA-SER to update follow-up information for specific populations. First, the SSA-SER linkage has a limited ability to increase follow-up completeness among patients <19 years of age at the time of follow-up. Although the SSA-SER linkage was helpful in increasing follow-up completeness among pediatric patients in Idaho and New York, it was not sufficient to allow these registries to achieve pediatric follow-up goals. Second, the SSA-SER will not provide data on individuals who do not have an eligible SSN; this includes certain nonresidents and resident aliens, their spouses, and dependents who are required to have a US Individual Taxpayer Identification Number (ITIN) but who are not eligible for an SSN—the same populations with higher rates of loss to follow-up given advanced disease. In the current data set, a small proportion of otherwise qualifying individuals without current follow-up information had ITINs.

Because Idaho used resources such as update records from hospitals accredited by the American College of Surgeons Commission on Cancer (CoC) to update the date of last contact for alive patients, and most Idaho cases are associated with CoC hospitals, Idaho very nearly achieved SEER goals for follow-up prior to the SSA-SER linkage, and only ascertained 4 new deaths occurring through the study cutoff via the SSA-SER linkage. Historically, CDRI performed active patient follow-up by sending annual letters to the physician responsible for ongoing care. This served as a reminder to physicians to continue to see the patient on a regular basis in order to monitor for disease recurrence/progression and quality of life. CDRI sent follow-up information gathered from physicians to Idaho hospitals that operated cancer registries, eliminating duplication of effort. Due to budget constraints, this activity was ceased in February 2009. Since that time, CDRI has ascertained deaths through linkages with state death files and the National Death Index. In Idaho, CoC hospitals needed to conduct their own follow-up, and CDRI mined update records from these hospitals to update the date of last contact for alive patients. Nonetheless, CDRI was unable to achieve SEER goals for patient follow-up through these practices. NYSCR did not utilize updated records from CoC hospitals for this purpose, which might be the main reason for the marked differences in pre-SSA linkage follow-up differences between the 2 registries (Table 2). This initial difference in follow-up rates was not equalized post-SSA linkage even though NYSCR's absolute increase in follow-up attributable to the SSA-SER linkage was twice that of Idaho's (36.9% vs 18.3%).

Although this study allowed for a very close estimate, we were not able to entirely isolate the impact of the SSA-SER linkage on our registry data. We evaluated changes to vital status and follow-up dates on a data set that was created at the time of SSA-SER submission, and not when the SSA-SER results were added to the database. Other changes could have been made to patient records as part of standard registry processes in the time from submission to SSA and when data were returned for linkage to the live database. We anticipate that this difference in time points (data set created at time of SSA-SER submission vs created prior to SSA-SER results added to the live database) represents a minimal difference in the impact of SSA-SER linkage on follow-up and survival estimates.

Another limitation of this study is the absence of a reference standard for relative survival estimates in the absence of 100% follow-up completeness; indeed, biases in presumed-alive and reported-alive estimates are directly related to reasons for loss to follow-up in the population of interest, and thus one method to calculate survival is the less biased option in one setting while being the more biased method in another. The largest contribution of the SSA-SER linkage was to increment survival time forward for reported alive survival. The linkage did not yield many additional deaths that had not previously been identified through state or national death clearance. Linkage to the SSA-SER did, however, identify numerous deaths beyond the follow-up period used for survival (2017 and 2018 deaths). As the cancer surveillance community considers how to increase timeliness of reporting, services such as the SSA-SER could provide valuable preliminary inference into "real-time" survival and mortality statistics. Further research to establish balance points between accuracy and timeliness could be valuable for the future of surveillance, as would identifying the most appropriate method of calculating survival for any given jurisdiction or population of interest.

Conclusions

SSA-SER linkage greatly and efficiently improved follow-up completeness for the 2 registries in this study. Differences in survival estimates calculated using the presumed alive method and the reported alive method after linkage with the SSA-SER were minimal for most cancer sites. Registry jurisdictions without set contractual follow-up standards (those exclusively funded by NPCR) may be less concerned with follow-up rates than those jurisdictions that are beholden to contractual follow-up standards. However, the SSA-SER linkage provides a standardized and efficient way to conduct follow-up for US registries and may prove particularly useful for registries with limited capacity to conduct multiple linkages. Although the ultimate utility of an SSA-SER linkage for any given registry depends on jurisdiction demographics and case distribution—and contractual follow-up requirements—the use of the SSA-SER by all US registries might standardize and improve US survival estimates.

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Original Article

Tobacco-Associated Cancer Incidence and Mortality in Massachusetts, 2006–2015

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Abstract: Objective: To describe the epidemiology of tobacco-associated cancers in Massachusetts from 2006–2015. Methods: Incident cases of tobacco-associated cancers diagnosed from 2006–2015 were provided by the Massachusetts Cancer Registry. Tobacco-associated cancers include lung, oral cavity, esophageal, laryngeal, pancreatic, cervical, liver, bladder, kidney, stomach, colorectal, and acute myeloid leukemia. Cancer deaths due to those cancers were provided by the Massachusetts Registry for Vital Records and Statistics. Joinpoint regression was used to assess trends in the rates and 95% confidence intervals were used to assess significant differences over the time period. Results: From 2006–2015, 42% of all cancer cases and 60% of all cancer deaths were due to a tobacco-associated cancer. Lung and colorectal cancers had the highest incidence (65.8 and 39.8 per 100,000, respectively) and mortality rates (44.6 and 13.6 per 100,000, respectively) of all the tobacco-associated cancers in Massachusetts. The incidence and mortality rates of lung, esophageal, laryngeal, and colorectal cancer decreased with statistical significance from 2006–2015. Non-Hispanic Whites and non-Hispanic Blacks had the highest incidence (203.9 and 189.2/100,000, respectively) and mortality rates (100.7 and 97.4/100,000, respectively) from tobacco-associated cancers, and these rates have decreased with statistical significance from 2006–2015. Conclusion: Tobacco cessation initiatives remain important even as the incidence and mortality rates of some tobacco-associated cancers have decreased in recent years. Understanding the distribution of these cancers by sex and race will provide public health officials with information on populations still affected by these cancers.

Key words: *cancer, epidemiology, population surveillance, tobacco*

Background

Tobacco-cessation initiatives have been an important public health priority in the United States for many years and, as a result, cigarette smoking has decreased significantly since the 1950s and 1960s.[1] However, the use of smokeless tobacco has been increasing among males since 2000.[2] Tobacco use is the leading preventable cause of cancer incidence and death in the United States.[3] Many cancers are thought to be caused by tobacco use, including lung, oral cavity, laryngeal, esophageal, pancreatic, cervical, liver, bladder, kidney, stomach, and colorectal cancer, as well as acute myeloid leukemia.[4] In addition to these multiple cancer sites, tobacco use is also associated with many chronic diseases, including cardiovascular and respiratory diseases.[5] Understanding the burden of tobacco-associated cancers in Massachusetts, a state with lower rates of smoking than the national median and mandatory health insurance coverage since 2006, will help elucidate the impact that tobacco-cessation programs have had and will highlight areas where further efforts are needed for cancer prevention.[6-8]

Methods

Incident invasive cancers in Massachusetts residents from 2006–2015 were provided by the Massachusetts Cancer Registry (MCR). Cancer deaths in Massachusetts residents from 2006–2015 were provided by the Massachusetts Registry for Vital Records and Statistics (MRVRS). Tobacco-associated cancers were defined as lung, oral cavity/pharynx, laryngeal, esophageal, pancreatic, cervical, liver, bladder (including in situ), kidney, stomach, colorectal, and acute myeloid leukemia. Please refer to the appendix for the ICD-O-3 (*International Classification of Diseases for Oncology*, 3rd ed) histology codes for cancer cases and the ICD-10 *(International Classification of Diseases, Tenth Revision)* codes for cancer deaths.

The MCR also collects information on tobacco history as a categorical variable (never used tobacco, current cigarette smoker, current cigar or pipe smoker, current snuff/cheek/smokeless tobacco user, current combination tobacco user, previous tobacco user and unknown). However, many cases are reported with an unknown tobacco history in the MCR despite its being a required field. Additionally, underreporting of previous tobacco use and overreporting of "never used tobacco" were found in an audit of MCR data.[9] Consequently, these statistics should be viewed with caution.

The numbers, incidence rates, mortality rates, and annual percent changes (APCs) were presented overall for all tobacco-associated cancers and each cancer separately

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by sex and race/ethnicity. The coefficient of variance (CV) was used to determine which APC rates to suppress as being unreliable. It was calculated by dividing the standard error by the mean age-adjusted incidence or mortality rate for each of the 5 years by and multiplying that by 100. According to the US Census, a CV less than 15% indicates high reliability and can be presented without caution, a CV between 15% and 30% indicates medium reliability and can be presented with care, and a CV over 30% indicates low reliability and can only be presented with extreme caution.[10] This paper presents only trends with a high or medium reliability.

Incidence and mortality rates are per 100,000 and are age-standardized to the 2000 United States Census population. The APC was calculated using the Joinpoint Regression Program.[11] Results were considered statistically significant if $P < .05$. All other statistical analyses were performed using SAS 9.3 (SAS Institute Inc., Cary, NY).[12] The 95% confidence intervals for incidence and mortality rates for the time period were compared for significant differences.

Results

Incidence Rates Overall

There were 369,752 cases of invasive cancer in Massachusetts residents from 2006–2015, of which 155,222 (42.0%) were cancers associated with tobacco use (Table 1). The incidence rate of all tobacco-associated cancers was 200.4/100,000 from 2006–2015, and decreased by 2.1% annually. The cancers with the highest incidence rates were lung (65.8), colorectal (39.8), and bladder (24.0). Cancers that had statistically significant annual decreases in the incidence rate included lung (–2.4%), esophageal (–3.2%), bladder (–2.5%), laryngeal (–2.6%), cervical (–1.6%), and colorectal cancers (–4.0%). The incidence rate of acute myeloid leukemia increased significantly by 2.7% annually from 2006–2013, but then decreased by 7.6% annually nonsignificantly from 2013–2015.

Incidence Rates by Sex

The incidence rate of tobacco-associated cancers in Massachusetts was 1.6 times higher among males than among females (257.1 vs 157.5/100,000, respectively) (Table 1). Both sexes saw significant annual decreases in the incidence rate of tobacco-associated cancers from 2006–2015 (males: –2.6%; females: –1.8%).

Among males, the cancers with the highest incidence rates included lung (73.1), colorectal (45.4), and bladder (41.7). While the incidence rate significantly decreased annually for lung (–3.4%), esophageal (–3.7%), bladder (–3.2%), laryngeal (–2.9%), and colorectal cancers (–4.5%) (Figure 1), there were no statistically significant increases.

Among females, the cancers with the highest incidence rates included lung (61.2), colorectal (35.4), and pancreatic (11.4). While the incidence rate decreased annually with statistical significance for lung (–1.6%), kidney (–0.9%), bladder (–2.3%), cervical (–1.6%) and colorectal cancers (–3.6%), there were no statistically significant increases.

Incidence Rates by Race/Ethnicity

For all tobacco-associated cancers combined, non-Hispanic Whites and non-Hispanic Blacks had the highest incidence rates (203.9 and 189.2 per 100,000, respectively) (Table 3). Among all race/ethnicities, lung cancer had the highest incidence rate, followed by colorectal cancer (Table 3). Non-Hispanic Whites had the highest incidence rate of lung cancer (68.5) while Hispanics had the lowest incidence rate of lung cancer (30.1). Non-Hispanic Blacks had the highest incidence rate of colorectal cancer (43.0) while non-Hispanic Asians the highest incidence rate of liver cancer (18.8) among the other race/ethnicity groups.

The incidence rate of all tobacco-associated cancers combined significantly decreased annually from 2006–2015 for non-Hispanic Whites (–1.9%), non-Hispanic Blacks (–2.7%), and non-Hispanic Asians (–2.8%). For Hispanics, it decreased significantly from 2009–2015 (–6.4%). For non-Hispanic Whites and non-Hispanic Blacks, the incidence rates of lung, and colorectal cancer significantly decreased annually. For non-Hispanic Asians, the incidence rate of liver and colorectal cancer significantly decreased annually (–5.5% and –5.6%) while for Hispanics, the incidence rates significantly decreased for kidney (–3.4%) and colorectal cancers (–5.7%) (Table 3).

Mortality Rates Overall

There were 129,170 deaths due to cancer in Massachusetts residents from 2006–2015, of which 77,198 (59.8%) deaths were caused by a cancer associated with tobacco use (Table 2). The mortality rate of all tobacco-associated cancers was 98.3 deaths per 100,000 from 2006–2015 and significantly decreased by 2.3% annually. The cancers with the highest mortality rates were lung (44.6), colorectal (13.6), and pancreatic (11.0). Cancers that had significant annual decreases in the mortality rate included lung (–3.3%), esophageal (–1.5%), kidney (–7.1% from 2006–2010), stomach (–2.1%), laryngeal (–4.2%), and colorectal cancer (–3.8%). The mortality rate of kidney cancer significantly increased by 3.0% annually from 2010–2015. The mortality rate of liver cancer significantly increased annually by 2.9% from 2006–2013, but then decreased by 6.5% annually from 2013–2015 without statistical significance.

Mortality Rates by Sex

The mortality rate of tobacco-associated cancers was 1.6 times higher among males than among females (127.5 vs 77.2/100,000, respectively) (Table 2). Both sexes saw an annual decrease in the mortality rate of tobacco-associated cancers from 2006–2015 (males: –2.9% and females: –2.0%).

Among males, the cancers with the highest mortality rates included lung (53.6), colorectal (16.3), and pancreatic (12.4). The mortality rate decreased with statistical significance annually for lung (–4.2%), esophageal (–1.3%), kidney (–9.6% from 2006–2010), bladder (–2.2%), laryngeal (–5.0%), stomach (–6.0% from 2006–2013), and colorectal cancer (–4.4%) (Figure 1). The mortality rate of kidney cancer significantly increased by 4.8% annually from 2010–2015. The mortality rate of liver cancer also significantly increased

Table 1. Total Cases and Age-Adjusted Incidence Rates† of Tobacco-Associated Cancers Overall and by Sex, Massachusetts, 2006-2015

Total	*Cases*	*Incidence Rate† (95% CI)*		*Years*	*APC*
All tobacco-associated	155,222	200.4	(199.4–201.4)	2006–2015	–2.1%*
Lung	50,792	65.8	(65.3–66.5)	2006–2015	–2.4%*
Colorectal	30,910	39.8	(39.3–40.2)	2006–2015	–4.0%*
Bladder	18,713	24.0	(23.7–24.4)	2006–2015	–2.5%*
Kidney	12,213	16.0	(15.7–16.3)	2006–2015	–0.4%
Pancreas	9,897	12.6	(12.4–12.9)	2006–2015	–0.5%
Oral cavity/Pharynx	9,134	11.6	(11.4–11.9)	2006–2015	0.8%
Liver	6,170	7.7	(7.5–7.9)	2006–2015	0.1%
Stomach	5,233	6.7	(6.5–6.9)	2006–2015	–1.2%
Esophagus	4,590	5.8	(5.7–6.0)	2006–2015	–3.2%*
Cervix (female only)	1,960	5.3	(5.1–5.5)	2006–2015	–1.6%*
Larynx	2,708	3.4	(3.3–3.6)	2006–2015	–2.6%*
Acute myeloid leukemia	2,901	3.9	(3.7–4.0)	2006–2013	2.7%*
				2013–2015	–7.6%
Males					
All tobacco-associated	87,104	257.1	(255.4,258.8)	2006–2015	–2.6%*
Lung	24,433	73.1	(72.3–74.1)	2006–2015	–3.4%*
Colorectal	15,299	45.4	(44.7–46.1)	2006–2015	–4.5%*
Bladder	13,661	41.7	(41.0–42.4)	2006–2015	–3.2%*
Kidney	7,741	22.3	(21.8–22.8)	2006–2015	–0.4%
Oral cavity/Pharynx	6,221	17.2	(16.8–17.7)	2006–2015	0.5%
Pancreas	4,762	14.1	(13.7–14.5)	2006–2015	–0.3%
Liver	4,580	12.7	(12.3–13.0)	2006–2015	–0.2%
Esophagus	3,568	10.2	(9.9–10.6)	2006–2015	–3.7%*
Stomach	3,214	9.6	(9.2–9.9)	2006–2015	–2.1%
Larynx	2,070	5.9	(5.6–6.1)	2006–2015	–2.9%*
Acute myeloid leukemia	1,555	4.7	(4.5–5.0)	2006–2011	3.8%
				2011–2015	–2.9%
Females					
All tobacco-associated	68,107	157.5	(156.3–158.7)	2006–2015	–1.8%*
Lung	26,354	61.2	(60.5–61.9)	2006–2015	–1.6%*
Colorectal	15,609	35.4	(34.8–35.9)	2006–2015	–3.6%*
Pancreas	5,135	11.4	(11.1–11.7)	2006–2015	–0.8%
Bladder	5,052	11.3	(11.0–11.7)	2006–2015	–2.3%*
Kidney	4,471	10.8	(10.4–11.1)	2006–2015	–0.9%*
Oral cavity/Pharynx	2,913	6.8	(6.6–7.1)	2006–2015	0.9%
Cervix	1,960	5.3	(5.1–5.5)	2006–2015	–1.6%*
Stomach	2,019	4.6	(4.4–4.8)	2006–2015	–0.1%
Liver	1,588	3.6	(3.4–3.8)	2006–2015	0.7%
Acute myeloid leukemia	1,346	3.3	(3.1–3.4)	2006–2015	0.5%
Esophagus	1,022	2.3	(2.2–2.5)	2006–2015	–1.9%
Larynx	638	1.5	(1.4–1.6)	2006–2015	–2.8%

APC, annual percent change.
* Statistically significant trend ($P < .05$).
† Per 100,000 and age adjusted to the 2000 US standard population. Numbers may not add up due to unknown sex. Data source: Massachusetts Cancer Registry.

Figure 1. Trends in the Incidence and Mortality Rates per 100,000 of Tobacco-Associated Cancers by Cancer Site and Sex in Massachusetts, 2006–2015

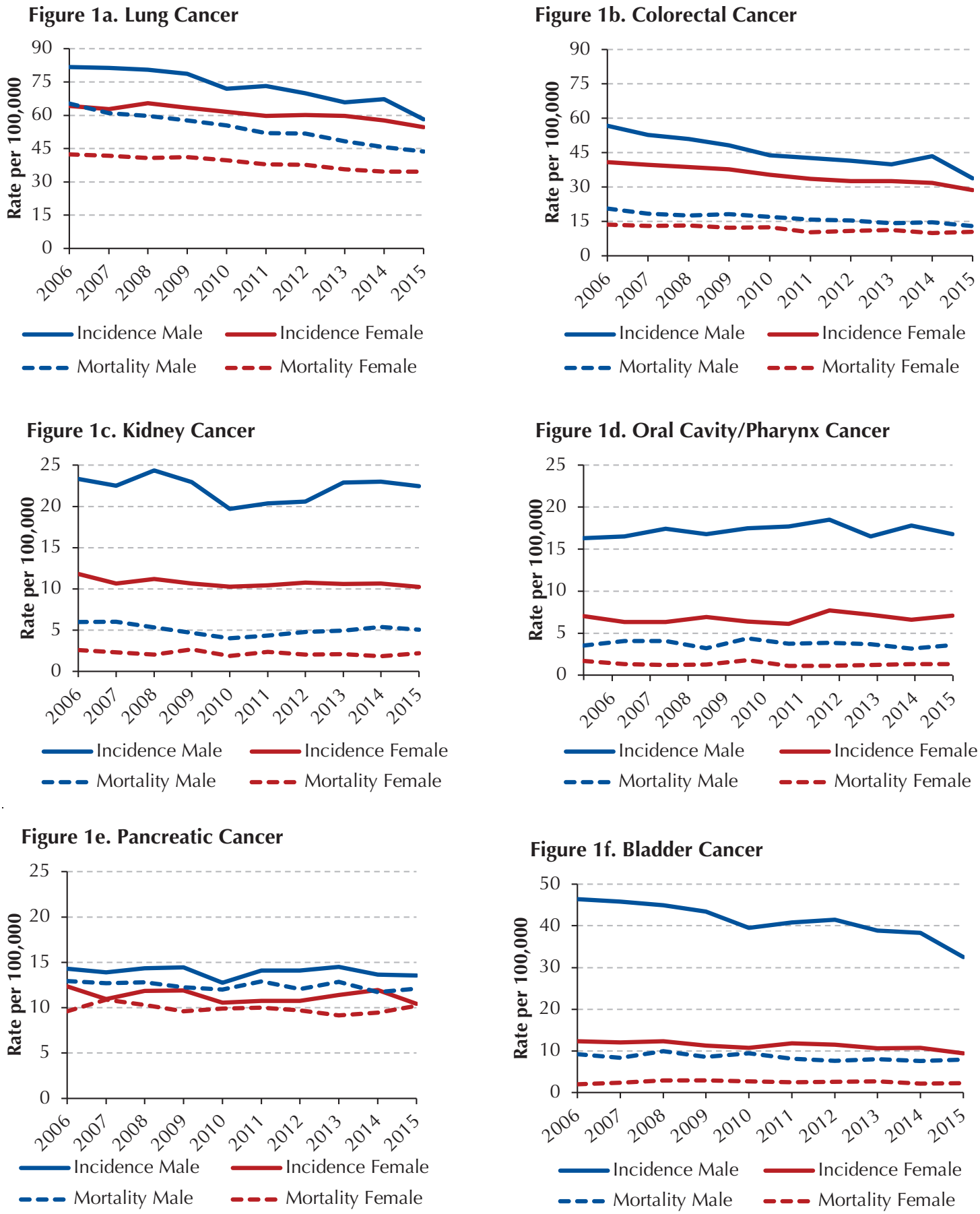


Figure 1, cont. Trends in the Incidence and Mortality Rates per 100,000 of Tobacco-Associated Cancers by Cancer Site and Sex in Massachusetts, 2006–2015

Figure 1g. Liver Cancer

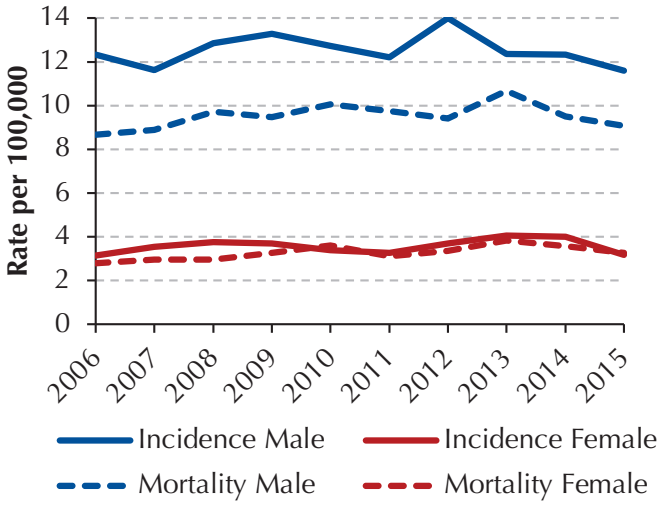


Figure 1h. Stomach Cancer

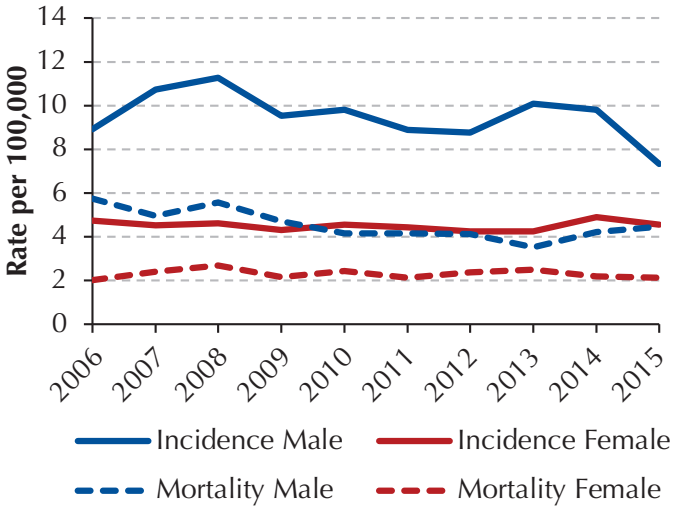


Figure 1i. Esophageal Cancer

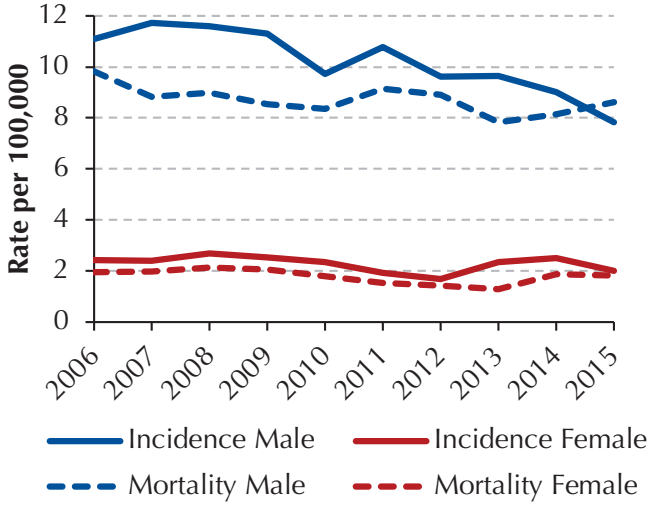


Figure 1j. Acute Myeloid Leukemia

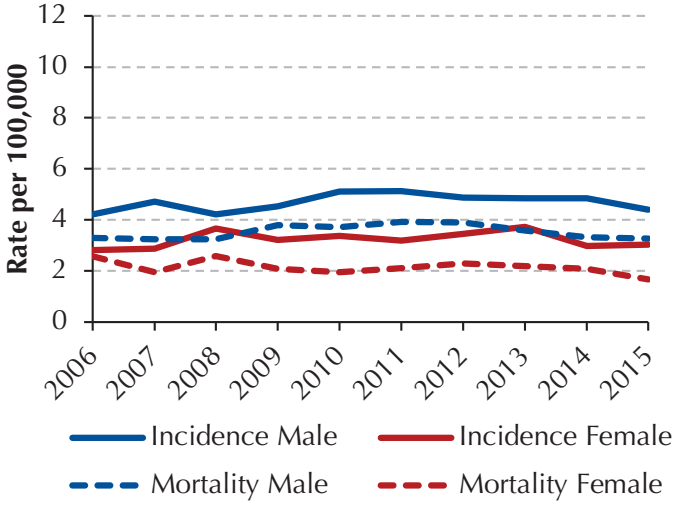


Figure 1k. Cervical Cancer

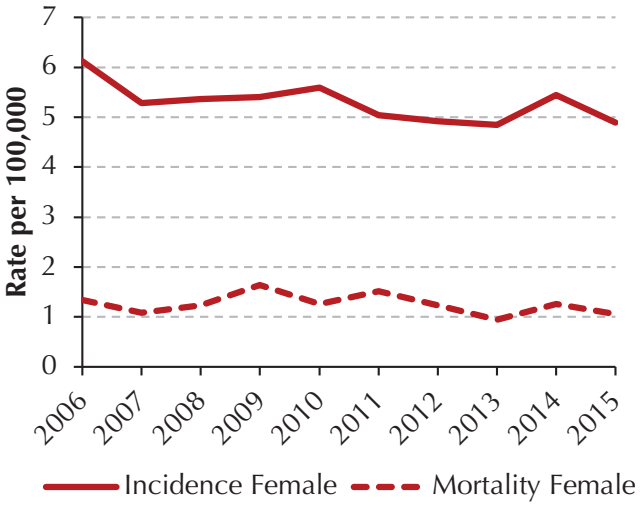
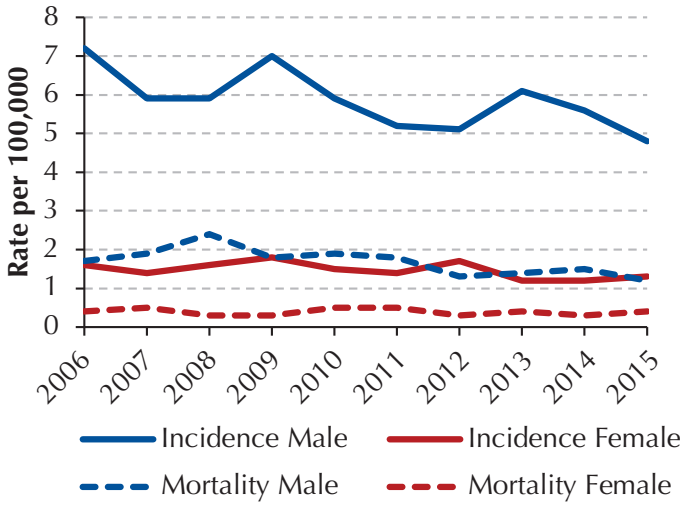


Figure 1l. Laryngeal Cancer



annually, by 2.1% from 2006–2013, but then it decreased without statistical significance by 6.5% from 2013–2015. The mortality rate of acute myeloid leukemia significantly increased by 4.5% from 2006–2011, but it significantly decreased by 4.9% from 2011–2015.

Among females, the cancers with the highest mortality rates included lung (38.4), colorectal (11.7), and pancreatic (9.9). While the mortality rate significantly decreased annually for lung (–2.5%) and colorectal cancers (–3.4%), it significantly increased annually by 2.4% for liver cancer.

Mortality Rates by Race/Ethnicity

The highest mortality rates for all tobacco-associated cancers occurred for non-Hispanic Whites (99.7) and non-Hispanic Blacks (96.4) from 2006–2015. Non-Hispanic Whites had the highest mortality rate of lung cancer (46.7) while Hispanics had the lowest mortality rate of lung cancer (17.3). Non-Hispanic Blacks had the highest mortality rate of colorectal cancer (16.1) while Hispanics had the lowest mortality rate of colorectal cancer (9.7). Non-Hispanic Asians had the highest mortality rate of liver cancer (12.7), significantly higher compared to the other race/ethnicities.

For all tobacco-associated cancers, the mortality rate significantly decreased annually from 2006–2015 for non-Hispanic Whites by –2.2% and for non-Hispanic Blacks by –4.5%. For non-Hispanic Whites and non-Hispanic Blacks, the mortality rates significantly decreased annually for lung (–3.1% and –4.7%, respectively) and colorectal cancer (–3.7% and –5.1%, respectively). Non-Hispanic Whites also saw a significant decrease in annual mortality rates of kidney cancer from 2006–2010 (–7.3%). The mortality rates for non-Hispanic Asians and Hispanics did not significantly change for any of the cancer sites (Table 3).

Tobacco Use History

The percentages of reported current and former smokers varied by cancer site (Table 4). The cancers with the highest proportion of current or former smokers included larynx (84.5%), lung (80.6%), esophageal (70.8%), and oral cavity (65.6%). The cancers with the highest proportion of never smokers included cervical (45.6%), colorectal (39.6%), and acute myeloid leukemia (39.5%). Again, these data should be interpreted with caution due to the large percentages of missing data. The cancers with the most missing data on tobacco use include liver (22.0%), bladder (21.0%), and pancreatic (19.9%). The cancers with the least missing data on tobacco use at diagnosis included larynx (7.8%), oral cavity (10.7%), esophageal (10.6%), and lung (12.0%).

Discussion

Many tobacco-associated cancer sites have seen decreasing incidence and mortality rates in Massachusetts from 2006–2015 with some variation by sex and race/ethnicity. These trends are consistent with what is seen in the United States during similar time periods.[13] A recent study of US data found that males have a 1.7 times higher incidence and mortality rate than females, while we found 1.6 times higher rates.[13] They also found larger annual percent changes for males than females, similar to the pattern observed in Massachusetts.[13] However, the overall rates in this study were slightly lower than the rates seen in the US from 2009–2013 (incidence rate, 193.1/100,000; mortality rate, 100.0/100,000).[14] Many of these cancer cases and deaths are preventable. A recent study looked at the proportion of cancer deaths attributable to cigarette smoking in 2014 for each state and found that in Massachusetts this was 28.1% (rank of 31).[15] While tobacco cessation may be part of the reason for these decreasing incidence and mortality rates, other risk factors for these cancers, such as alcohol and diet, or screening and treatment may have also changed over time and helped reduce the burden of these cancers.[16] Nonetheless, continuing to reduce tobacco use in Massachusetts can have a large impact on the tobacco-associated cancer incidence and mortality rates.

The prevalence of cigarette smoking has decreased among Massachusetts adults by 25% from 1986–2005 and in youths by 78% from 1995–2015.[7,8] Massachusetts has many programs in place to help with tobacco cessation through the Massachusetts Tobacco Cessation Program at the Massachusetts Department of Public Health.[16] These initiatives include youth programs, a smokers' hotline, tobacco sales laws, and smoke-free workplace laws. In addition to the prevention of tobacco-associated cancers through tobacco cessation programs, it is important to also utilize cancer screening for some tobacco-associated cancers. Current screening programs exist for lung cancer for those with a 30-pack-year smoking history, cervical cancer, and colorectal cancer.

This study is subject to a number of limitations. There may be underreporting of data in areas of Massachusetts close to neighboring states; however, Massachusetts has a reciprocal reporting agreement with 42 states that helps reduce this limitation. Due to the small number of cancer deaths and the small number of cases and deaths when examined by specific race/ethnicities, differences in the rates and trends may be due to chance and caution should be used when interpreting the findings with smaller numbers. While the MCR contains information on tobacco use collected at diagnosis, there is a large amount of missing data. The percentage of missing data gets smaller over time for all cancer sites (eg, lung cancer was 14.0% missing in 2006 and 6.6% missing in 2015). It appears that there is more missing data for cancers that have a weaker association with tobacco use. Lastly, the MCR does not contain any other information about risk factors for these cancers so we are not able to definitively determine the reasons for the trends seen with this data set alone.

In summary, while the decreasing incidence and mortality rates of tobacco-associated cancers are moving in the right direction, continuing to promote the importance of tobacco cessation is important for maintaining the health of Massachusetts residents. There are still nearly 15,000 cases of tobacco-associated cancers and 7,700 tobacco-associated cancer deaths occurring annually in Massachusetts. Promoting healthy behaviors and the use of cancer screening programs are important to help continue the decreasing trends for tobacco-associated cancers.

Table 2. Total Cases and Age-Adjusted Mortality Rates† of Tobacco-Associated Cancers Overall and by Sex, Massachusetts, 2006-2015

Total	*Deaths*	*Mortality Rate† (95% CI)*		*Years*	*APC*
All tobacco-associated	77,198	98.3	(97.6–99.0)	2006–2015	–2.3%*
Lung	34,638	44.6	(44.2–45.1)	2006–2015	–3.3%*
Colorectal	10,883	13.6	(13.4–13.9)	2006–2015	–3.8%*
Pancreas	8,704	11.0	(10.8–11.2)	2006–2015	–0.6%
Liver	4,807	6.1	(5.9–6.2)	2006–2013	2.9%*
				2013–2015	–6.5%
Esophagus	3,788	4.8	(4.7–5.0)	2006–2015	–1.5%*
Bladder	3,876	4.8	(4.7–5.0)	2006–2015	–1.3%
Kidney	2,715	3.4	(3.3–3.5)	2006–2010	–7.1%*
				2010–2015	3.0%*
Stomach	2,557	3.2	(3.1–3.4)	2006–2015	–2.1%*
Acute myeloid leukemia	2,061	2.7	(2.6–2.8)	2006–2015	–0.6%
Oral cavity/Pharynx	1,905	2.4	(2.3–2.5)	2006–2015	–1.2%
Cervix (female only)	515	1.3	(1.2–1.4)	2006–2015	–1.8%
Larynx	749	0.9	(0.9–1.0)	2006–2015	–4.2%*
Males					
All tobacco-associated	42,179	127.5	(126.2,128.7)	2006–2015	–2.9%*
Lung	17,610	53.6	(52.8–54.4)	2006–2015	–4.2%*
Colorectal	5,305	16.3	(15.8–16.7)	2006–2015	–4.4%*
Pancreas	4,133	12.4	(12.0–12.8)	2006–2015	–0.7%
Liver	3,334	9.5	(9.2–9.9)	2006–2013	2.1%*
				2013–2015	–6.5%
Esophagus	2,975	8.7	(8.4–9.0)	2006–2015	–1.3%*
Bladder	2,657	8.4	(8.1–8.8)	2006–2015	–2.2%*
Kidney	1,689	5.0	(4.78–5.3)	2006–2010	–9.6%*
				2010–2015	4.8%*
Stomach	1,479	4.5	(4.3–4.8)	2006–2013	–6.0%*
				2013–2015	10.9%
Oral cavity/Pharynx	1,289	3.7	(3.5–3.9)	2006–2015	–1.2%
Acute myeloid leukemia	1,138	3.5	(3.3–3.8)	2006–2011	4.5%*
				2011–2015	–4.9%*
Larynx	570	1.7	(1.5–1.8)	2006–2015	–5.0%*
Females					
All tobacco-associated	35,017	77.2	(76.4–78.0)	2006–2015	–2.0%*
Lung	17,027	38.4	(37.9–39.0)	2006–2015	–2.5%*
Colorectal	5,577	11.7	(11.3–12.0)	2006–2015	–3.4%*
Pancreas	4,571	9.9	(9.6–10.2)	2006–2015	–0.6%
Liver	1,473	3.3	(3.1–3.5)	2006–2015	2.4%*
Bladder	1,219	2.5	(2.3–2.6)	2006–2008	21.9%
				2008–2015	–3.5%
Stomach	1,078	2.3	(2.2–2.4)	2006–2015	–0.4%
Kidney	1,026	2.2	(2.1–2.3)	2006–2015	–2.2%
Acute myeloid leukemia	923	2.1	(2.0–2.3)	2006–2015	–2.4%
Esophagus	813	1.8	(1.7–1.9)	2006–2015	–2.6%
Oral cavity/Pharynx	616	1.3	(1.2–1.4)	2006–2015	–1.8%
Cervix	515	1.3	(1.2–1.4)	2006–2015	–1.8%
Larynx	179	0.4	(0.3–0.5)	2006–2015	–1.3%

APC, annual percent change.
* Statistically significant trend ($P < .05$).
† Per 100,000 and age adjusted to the 2000 US Standard population. Numbers may not add up due to unknown sex. Data source: Massachusetts Cancer Registry.

Figure 2. Trends in the Incidence and Mortality Rates per 100,000 of Tobacco-Associated Cancers by Cancer Site and Race/Ethnicity in Massachusetts, 2006–2015

Figure 2a. Lung Cancer Incidence

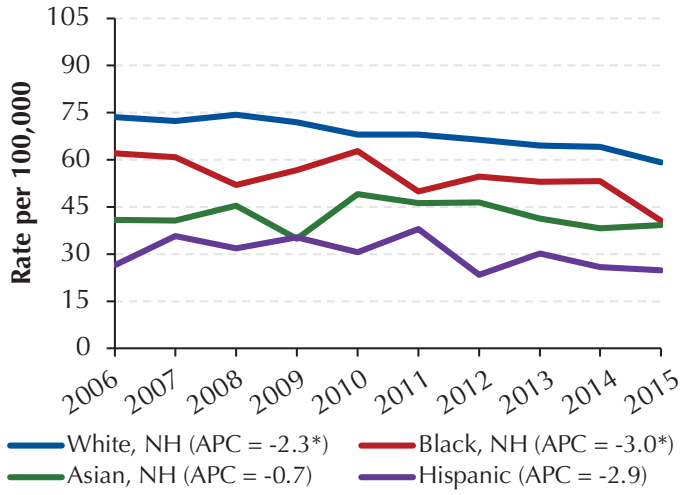


Figure 2a. Lung Cancer Mortality

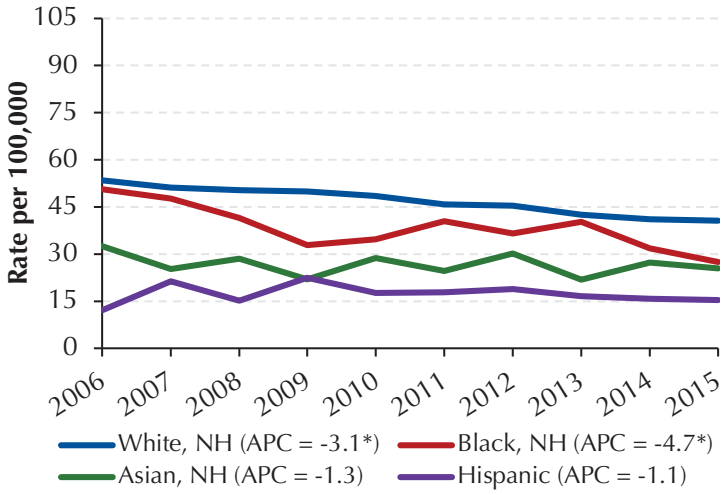


Figure 2b. Colorectal Cancer Incidence

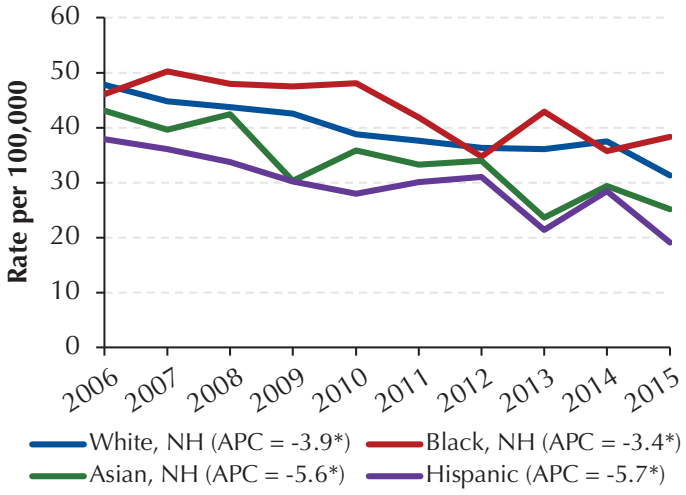


Figure 2b. Colorectal Cancer Mortality

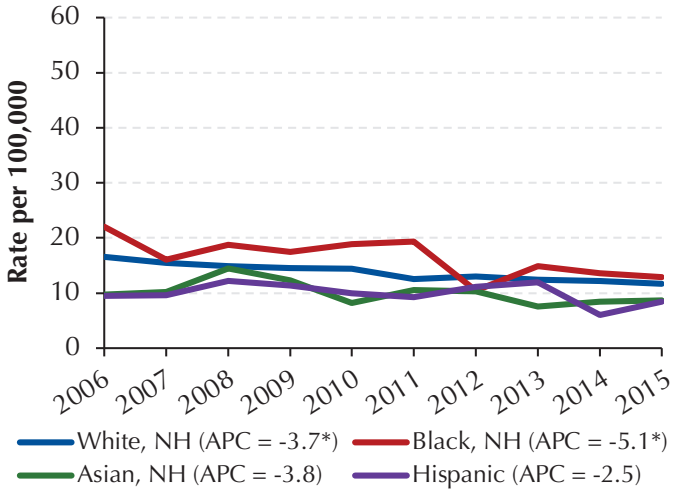


Figure 2c. Kidney Cancer Incidence

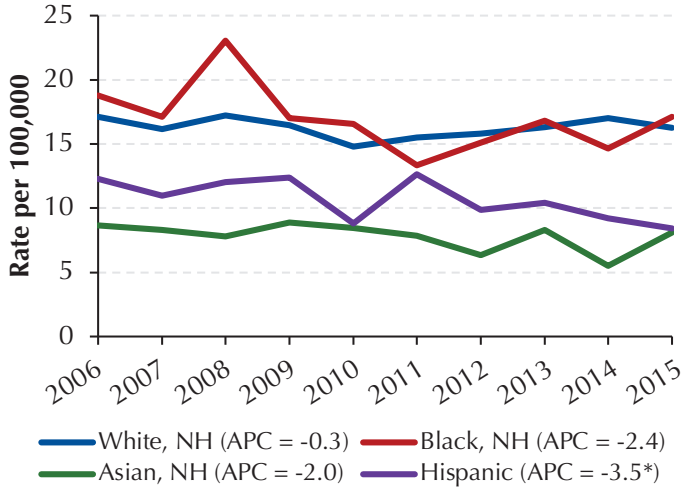
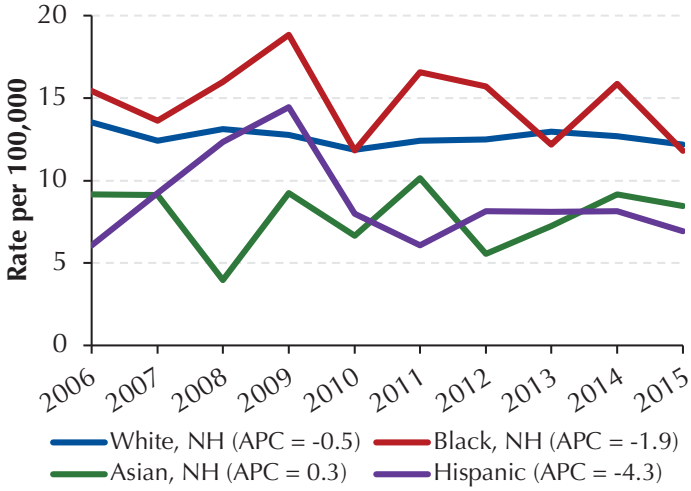


Figure 2d. Pancreatic Cancer Incidence



NH = non-Hispanic; APC = annual percent change; *p<0.05; data source: MCR and MRVRS

Figure 2, cont. Trends in the Incidence and Mortality Rates per 100,000 of Tobacco-Associated Cancers by Cancer Site and Race/Ethnicity in Massachusetts, 2006–2015

Figure 2e. Liver Cancer Incidence

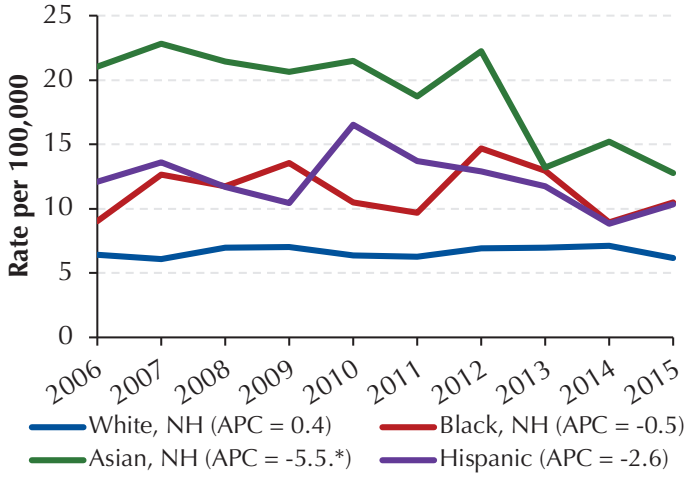


Figure 2f. Stomach Cancer Incidence

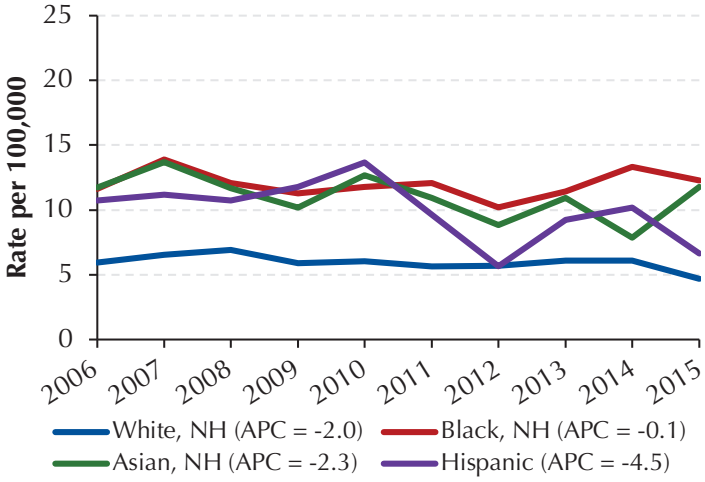


Figure 2g. Oral Cavity/Pharynx Cancer Incidence

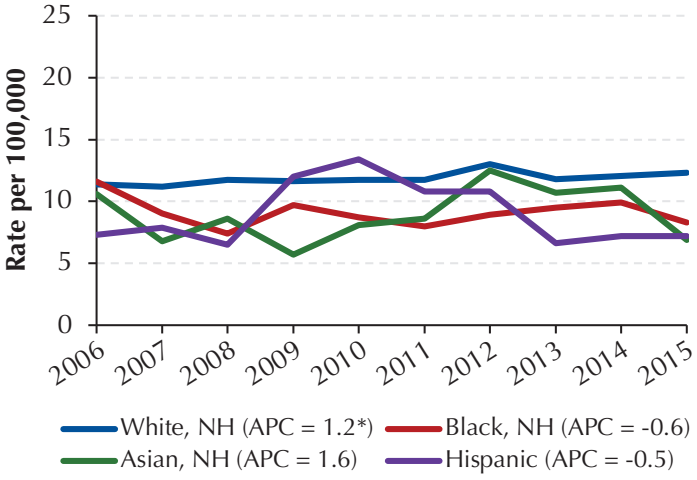
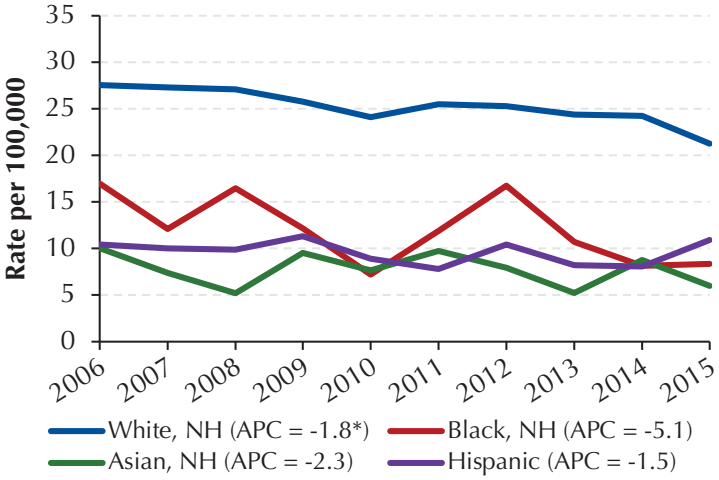


Figure 2h. Bladder Cancer Incidence



NH = non-Hispanic; APC = annual percent change; *p<0.05; data source: MCR and MRVRS

Table 3. Age-Standardized Incidence and Mortality Rates per 100,000 Tobacco-Associated Cancers by Race/Ethnicity in Massachusetts, 2006–2015

	Incidence					*Mortality*				
	Cases	**IR (95% CI)**		**Years**	**APC**	**Deaths**	**MR (95% CI)**		**Years**	**APC**
Non-Hispanic White										
All tobacco-associated	129,133	189.7	(188.7–190.8)	06–15	–1.9*	69,677	99.7	(99.0–100.5)	06–15	–2.2*
Lung	46,684	68.5	(67.9–69.2)	06–15	–2.3*	32,232	46.7	(46.2–47.2)	06–15	–3.1*
Colorectal	27,172	39.8	(39.4–40.3)	06–15	–3.9*	9,813	13.7	(13.4–14.0)	06–15	–3.7*
Kidney	10,746	16.3	(16.0–16.6)	06–15	–0.3	2,530	3.6	(3.4–3.7)	06–10	–7.3*
									10–15	3.2*
Oral cavity	10,522	15.4	(15.1–15.7)	06–15	0.1	1,690	2.4	(2.3–2.5)	06–15	–1.2
Pancreas	8,879	12.8	(12.5,13.1)	06–15	–0.5	7,928	11.3	(11.0–11.5)	06–15	–0.3
Bladder	8,100	11.6	(11.3–11.8)	06–15	–1.2*	3,705	5.1	(4.9–5.3)	06–15	–0.8
Liver	4,678	6.7	(6.5,6.9)	06–15	0.4	3,886	5.5	(5.4–5.7)	06–15	1.2
Esophagus	4,239	6.1	(6.0–6.3)	06–15	–2.6*	3,541	5.1	(4.9–5.3)	06–13	–2.3*
									13–15	6.5
Stomach	4,140	6.0	(5.8–6.2)	06–15	–2.0*	2,062	2.9	(2.8–3.0)	06–15	–3.1*
Cervix (female)	1,424	4.8	(4.6–5.0)	06–15	–1.8*	418	1.2	(1.1–1.3)	06–09	9.8
									09–15	–6.5*
AML	2,549	3.9	(3.8–4.1)	06–10	5.7*	1,872	2.8	(2.7–2.9)	06–15	–0.1
				10–15	–1.3*				06–15	–0.1
Non-Hispanic Black										
All tobacco-associated	6,511	183.9	(179.4–188.3)	06–15	–2.7*	3,179	96.4	(93.0–99.7)	06–15	–4.5*
Lung	1,863	54.3	(51.9–56.8)	06–15	–3.0*	1,227	37.6	(35.5–39.7)	06–15	–4.7*
Colorectal	1,534	43.0	(40.8–45.1)	06–15	–3.4*	530	16.1	(14.7–17.5)	06–15	–5.1*
Kidney	632	16.9	(15.5–18.2)	06–15	–2.4	93	2.7	(2.2–3.3)	06–15	–2.6
Pancreas	491	14.6	(13.3–15.9)	06–15	–1.9	396	12.4	(11.2–13.6)	06–15	–4.9*
Oral cavity	461	12.2	(11.0–13.3)	06–15	–2.0*	86	2.4	(1.9–3.0)	06–15	–4.9
Stomach	407	12.1	(11.0–13.3)	06–15	–0.1	188	6.0	(5.1–6.8)	06–15	–4.4*
Liver	449	11.5	(10.4–12.5)	06–15	–0.3	314	8.7	(7.7–9.6)	06–15	1.0
Cervix (female)	179	8.6	(7.3–9.8)	06–15	–2.5	47	2.3	(1.6–2.9)	06–15	–2.7
Bladder	214	6.8	(5.9–7.7)	06–15	–5.5	102	3.5	(2.8–4.1)	06–15	–7.9*
Esophagus	167	4.7	(4.0–5.4)	06–15	–6.5*	122	3.5	(2.9–4.1)	06–15	–6.8
AML	114	3.1	(2.5–3.6)	06–15	–3.8	74	2.3	(1.7–2.8)	06–15	–6.7
Non-Hispanic Asian										
All tobacco-associated	3,829	145.0	(140.4–149.6)	06–15	–2.8*	1,663	69.1	(65.8–72.4)	06–15	–1.5
Lung	1,050	42.9	(40.3–45.5)	06–15	–0.7	607	26.4	(24.3–28.5)	06–15	–1.3
Colorectal	880	33.0	(30.8–35.2)	06–15	–5.6*	236	9.8	(8.5–11.0)	06–15	–3.8
Liver	516	18.8	(17.1–20.4)	06–15	–5.5*	326	12.7	(11.3–14.0)	06–15	–2.7
Stomach	286	11.0	(9.7–12.3)	06–15	–2.3	121	4.8	(3.9–5.6)	06–13	–4.6
									13–15	29.2
Oral cavity	301	10.2	(9.0–11.3)	06–15	0.3	65	2.4	(1.8–2.9)	06–15	–1.6
Pancreas	196	8.0	(6.9–9.2)	06–15	0.3	147	6.3	(5.3–7.4)	06–15	3.3
Kidney	220	7.8	(6.7–8.8)	06–15	–2	26	1.1	(0.7–1.6)	06–15	–3.8
Cervix (female)	118	6.8	(5.6–8.0)	06–15	–1.9	–	–	–	–	–
Bladder	82	3.5	(2.7–4.2)	06–15	–6.8	21	1.0	(0.6–1.4)	06–15	–8.8
AML	102	3.3	(2.7–4.0)	06–15	0.4	46	1.8	(1.3–2.3)	06–15	–2.8
Esophagus	78	3.0	(2.3–3.6)	06–15	–4.5	52	2.3	(1.7–2.9)	06–15	–6.7

Table 3, cont. Age-Standardized Incidence and Mortality Rates per 100,000 Tobacco-Associated Cancers by Race/Ethnicity in Massachusetts, 2006–2015

	Incidence					*Mortality*				
	Cases	IR (95% CI)		Years	APC	Deaths	MR (95% CI)		Years	APC
Hispanic										
All tobacco-associated	4,209	126.0	(122.2–129.8)	06–09	3.1	1,735	57.5	(54.8–60.2)	06–09	9.7
				09–15	–6.4*				09–15	–4.1
Lung	887	30.1	(28.1–32.1)	06–15	–2.9	498	17.3	(15.7–18.8)	06–15	–1.1
Colorectal	954	28.7	(26.9–30.5)	06–15	–5.7*	277	9.7	(8.6–10.9)	06–15	–2.5
Liver	427	12.1	(11.0–13.3)	06–15	–2.6	262	7.8	(6.9–8.7)	06–15	3.1
Oral cavity	423	12.0	(10.8–13.1)	06–15	–3.0	57	2.0	(1.5–2.5)	06–15	1.7
Kidney	410	10.5	(9.5–11.5)	06–15	–3.4*	59	1.7	(1.3–2.1)	06–15	3.5
Stomach	327	9.7	(8.7–10.8)	06–15	–4.5	173	5.3	(4.5–6.1)	06–15	0.8
Pancreas	261	8.6	(7.6–9.7)	06–15	–4.3	213	7.1	(6.1–8.0)	06–15	–4.7
Cervix (female)	189	8.0	(6.9–9.2)	06–15	–4.9*	30	1.5	(1.0–2.0)	06–15	–5.1
Bladder	127	4.2	(3.4–4.9)	06–15	–1.9	43	1.7	(1.2–2.2)	06–15	–9.4
AML	117	3.0	(2.4–3.5)	06–15	–4.0	63	2.1	(1.6–2.6)	06–15	10.9
Esophagus	87	2.8	(2.2–3.4)	06–15	–13.1*	60	2.0	(1.5–2.5)	06–15	–3.0

AML, acute myeloid leukemia; APC, annual percent change; IR, incidence rate; MR, mortality rate.
* Statistically significant trend (P < .05).

Table 4. Tobacco Use at Diagnosis by Tobacco-Associated Cancer Site in Massachusetts, 2006–2015

	Never Tobacco User, No. (%)	*Current Tobacco User, No. (%)*	*Former Tobacco User, No. (%)*	*Missing Tobacco Information, No. (%)*
Lung	3,739 (7.4)	17,413 (34.3)	23,536 (46.3)	6,104 (12.0)
Oral Cavity/Pharynx	2,166 (23.7)	2,704 (29.6)	3,288 (36.0)	976 (10.7)
Esophagus	854 (18.6)	1,186 (25.8)	2,063 (45.0)	487 (10.6)
Kidney	4,354 (35.6)	2,107 (17.2)	3,812 (31.2)	1,940 (15.9)
Bladder	4,130 (22.1)	3,509 (18.8)	7,138 (38.1)	3,936 (21.0)
Liver	1,447 (23.5)	1,426 (23.1)	1,938 (31.4)	1,359 (22.0)
Pancreas	3,268 (33.0)	1,456 (14.7)	3,195 (32.3)	1,978 (19.9)
Stomach	1,821 (34.8)	820 (15.7)	1,848 (35.3)	744 (14.2)
Cervical	893 (45.6)	456 (23.3)	368 (18.8)	243 (12.4)
Colorectal	12,241 (39.6)	4,017 (13.0)	9,605 (31.1)	5,047 (16.3)
Larynx	211 (7.8)	1,286 (47.5)	1,001 (37.0)	210 (7.8)
Acute Myeloid Leukemia	1,145 (39.5)	362 (12.5)	922 (31.8)	472 (16.3)

Data source: Massachusetts Cancer Registry.

Acknowledgements

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Appendix. ICD Codes Used for This Report

Cancer Site/Type	*ICD-O-3**	*ICD-10***
Bronchus and lung	C34.0–C34.9 except 9050–9055, 9140, 9590–9992	C34
Cervix uteri	C53.0–C53.9 except 9050–9055, 9140, 9590–9992	C53
Colon/rectum	C18.0–C18.9, C19.9, C20.9, C26.0 except 9050–9055, 9140, 9590–9992	C18–C20, C26.0
Esophagus	C15.0–C15.9 except 9050–9055, 9140, 9590–9992	C15
Kidney and renal pelvis	C64.9, C65.9 except 9050–9055, 9140, 9590–9992	C64– C65
Larynx	C32.0–C32.9 except 9050–9055, 9140, 9590–9992	C32
Leukemia	C00.0–C80.9 (includes 9733, 9742, 9800–9801, 9805–9809, 9820, 9826, 9831–9836, 9840, 9860–9861, 9863, 9865–9867, 9869–9876, 9891, 9895–9898, 9910–9911, 9920, 9930–9931, 9940, 9945–9946, 9948, 9963–9964) C42.0, C42.1, C42.4 (includes 9811–9818, 9823, 9827, 9837)	C90.1, C91–C95
Liver and intrahepatic bile ducts	C22.0, C22.1 except 9050–9055, 9140, 9590–9992	C22
Oral cavity and pharynx	C00.0–C14.8 except 9050–9055, 9140, 9590–9992	C00–C14
Pancreas	C25.0–C25.9 except 9050–9055, 9140, 9590–9992	
Stomach	C16.0–C16.9 except 9050–9055, 9140, 9590–9992	C16
Urinary bladder (includes in situ)	C67.0–C67.9 except 9050–9055, 9140, 9590–9992	C67

* *International Classification of Diseases for Oncology, 3rd ed.* (includes codes added since publication) for incidence data.
** *International Classification of Diseases, Tenth Revision* (includes codes added since publication) for mortality data.

Original Article

Multiple Primary Cancers in the United States

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Abstract: Background and Objectives: The distribution of multiple primary cancers has been described previously using data from the Surveillance, Epidemiology, and End Results (SEER) Program. However, a complete picture regarding the distribution of multiple primary cancers in the United States is still lacking. The objective of the current study is to present a comprehensive description of multiple primary cancers in the United States. Materials and Methods: Invasive cancer cases (including in situ bladder cancers) diagnosed between 2001 and 2016 from 49 population-based state cancer registries in the United States were evaluated for this study. The sequence number central assigned to each tumor was used to determine whether a tumor was a first primary cancer or a subsequent multiple primary cancer. Tumors with a sequence number 00 or 01 were classified as the *first primary cancer*, while tumors with a sequence number 02 or above were classified as a *multiple primary cancer*. The percentage of multiple primary cancers was calculated by sex, age, race/ethnicity, cancer site, registry, and diagnosis year. In addition, the percentage of cancers diagnosed at a local stage among multiple primaries was compared with that among first primaries. Results: Overall, about 19.0% of cases were reported as multiple primary cancers; the percentage was higher among non-Hispanic Whites and among older patients. Bladder, melanoma of the skin, and lung cancers had the highest percentage of cases reported as multiple primaries. The percentage of multiple primary cancers also varied by registry and has been increasing over time. Cancers reported as multiple primaries were more likely to be diagnosed at a local stage than those reported as first primaries. Conclusions: Cancers registered as multiple primaries are common in the United States, showing an increasing trend over time and wide variation by race/ethnicity, age, cancer type, and registry. The findings have some practical implications for cancer registries that collect data and for researchers conducting investigations using information on multiple primary cancers.

Key words*:* *cancer registries, cancers in the United States, Cancer in North America (CiNA) data, multiple primary cancers*

Introduction

With increases in early diagnosis and advances in treatment, cancer survival has improved significantly.[1] However, with prolonged survival, cancer survivors face an increased risk of developing subsequent multiple primary cancers, with the risk varying by the type of first cancer diagnosis, age, genetic factors, environmental exposures, and treatments received.[2-6] Subsequent multiple primary cancers can develop in the same or different organ system as the first primary cancer.

All population-based state cancer registries in the United States define and code multiple primary cancers using the rules developed by the Surveillance, Epidemiology, and End Results (SEER) Program.[7,8] Whether a subsequent tumor should be abstracted as a new multiple primary cancer is determined by a set of factors including anatomic site, histologic type, laterality, behavior, and time interval between 2 diagnoses. It was estimated that among all invasive cancers reported in 2002 in 9 SEER registries, about 16% were registered as multiple primary cancers.[3] Using data on cancer cases diagnosed during 1995–2008 in 11 SEER registries, about 17.2% of cases among females and 15.8% of cases among males were identified as multiple primary cancers.[9] Multiple primary cancer is an important concept in cancer reporting; however, as far as we know, the literature on how multiple primary cancers are distributed among all newly reported cancers in the United States is relatively sparse. The objective of the current study is to present complete descriptive statistics of multiple primary cancers with respect to sex, age, race/ethnicity, registry, cancer site, and year of diagnosis, using the most recent data available for the United States.

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These data are based on the NAACCR December 2018 data submission. Support for cancer registries is provided by the state, province or territory in which the registry is located. In the United States, registries also participate in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program or the Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) or both. In Canada, all registries submit data to the Canadian Cancer Registry maintained by Statistics Canada.

Materials and Methods

Source of Data

Population-based state cancer registries in the United States submit their data to the North American Association of Central Cancer Registries (NAACCR) annually. The combined data are used to produce cancer incidence statistics for the United States.[10] In the current study, NAACCR's Cancer in North America (CiNA) Analytic File 1995–2016,[11] submitted in December 2018, was used. For this analysis, we only included data from 49 states (covering 98.9% of the US population) that met NAACCR's high-quality data standards. Invasive cancer cases (including in situ bladder cancers) diagnosed from 2012 to 2016 were our primary focus of interest for most evaluations. However, when the trend for multiple primary cancers was evaluated, cancer cases diagnosed back to 2001 were included. Cancer cases were grouped into 23 major cancer sites according to the SEER site recodes.[12] We categorized age at cancer diagnosis into the age-groups of ≤39, 40–49, 50–59, 60–69, 70–79, and ≥80 years, and race/ethnicity into the groups of non-Hispanic White, non-Hispanic Black, non-Hispanic other, and Hispanic.

Determination of Multiple Primary Cancers

The sequence number central assigned to each tumor was used to determine whether a tumor was a first primary cancer or a subsequent multiple primary cancer. The sequence number central is a standard NAACCR data item used to track the sequence of all reportable tumors over the lifetime of a person,[13] and a value of 00 indicates the person has only 1 primary cancer diagnosis; a value of 01 indicates the tumor is the first primary of 2 or more primary cancer diagnoses in a patient; a value of 02 indicates the tumor is the second primary of 2 or more primary cancer diagnoses in a patient, and so on. In this study, cancers diagnosed with sequence number 00 or 01 were classified as the *first primary cancer*, while cancers diagnosed with sequence number 02 or above were classified as a *multiple primary cancer*.

Data Analyses

Using data from 2012 to 2016, the percentage of multiple primary cancers was calculated by sex, age, race/ethnicity, registry, and cancer site. The trend in multiple primary cancers was examined by calculating the percentage of multiple primary cancers for individual diagnosis years from 2001 to 2016. In addition, the percentages of cancers diagnosed at a local stage, defined according to SEER summary stage derived from the Collaborative Staging System,[13] among multiple primaries was compared with that among the first primary for the selected cancer sites. All calculations were performed using the SEER*Stat version 8.3.6.[14]

Results

During 2012 to 2016, a total of 8,113,113 malignant cancer cases (including in situ bladder cancers) were reported to the 49 state cancer registries in the United States. Among these, 1,541,441 cases (19.0%) were reported as multiple primary cancers. Percentages of multiple primary cancers were similar among males (19.1%) and females (18.9%). Percentage of multiple primary cancers varied considerably by cancer site (Figure 1), with bladder (26.1%), melanoma of the skin (25.4%), and lung (24.2%) cancers having the highest percentage of tumors reported as multiple primaries, and testis (4.5%), cervix (7.4%), Hodgkin lymphoma (8.9%) having the lowest.

Figure 2 shows that the percentage of multiple primary cancers was positively associated with age at cancer diagnosis. Nearly 30.0% of all cancers diagnosed among people 80 years of age or older were multiple primaries, whereas, only about 4.6% were multiple primaries among people younger than 40 years. Figure 3 illustrates the percentage of cancers reported as multiple primaries among different race/ethnicity groups. The percentage of multiple primaries was the highest among non-Hispanic Whites (20.6%), followed by non-Hispanic Blacks (15.7%). The percentages of multiple primaries among non-Hispanic other and Hispanics were similar, each having about 13.0%. The percentage of cancers reported as multiple primaries also varied by registry (Figure 4), ranging from 12.2% to 22.9%, with a median of 19.0%. The percentage of cancers reported as multiple primaries has shown an increasing trend from 2001 to 2014; however, it remained relatively stable from 2014 to 2016 (Figure 5).

Table 1 shows the percentage of cancers diagnosed at a local stage by selected cancer sites and primary status (first primary vs multiple primary). For lung, oral cavity and pharynx, esophagus, pancreas, stomach, and liver cancers, tumors seemed more likely to be diagnosed at a local stage for the multiple primaries compared to the first primaries. On the other hand, for cervical cancer, the percentage of cases diagnosed at a local stage was slightly lower for the multiple primaries compared to the first primaries.

Discussion

This study described frequencies and patterns of multiple primary cancers using data reported to 49 state cancer registries in the United States. Overall, a significant proportion of newly diagnosed cancer cases were reported as multiple primary cancers. The percentage of multiple primary cancers varied by cancer site, age, race/ethnicity, and registry. For about half of cancer sites investigated in this study, tumors reported as multiple primaries seemed more likely to be diagnosed at a local stage than tumors reported as first primaries.

Our study found that about 19.0% of all cancer cases diagnosed during the most recent 5 years (2012–2016) in the United States were reported as multiple primary cancers. This number is slightly higher than reported previously using SEER data,[3,9] probably because these studies were based on older data, and multiple primary cancer diagnoses have been increasing over time.[9] The proportions of multiple primary cancers observed by registry in our study are much higher than those reported by Rosso et al (ranging from 0.4% to 12.9% by registry).[15] These differences are partly due to the different multiple primary cancer rules adopted by registries in European countries, which follow rules

Figure 1. Percentage of Cancers Reported as Multiple Primaries by Cancer Site, 2012–2016, 49 State Cancer Registries Combined

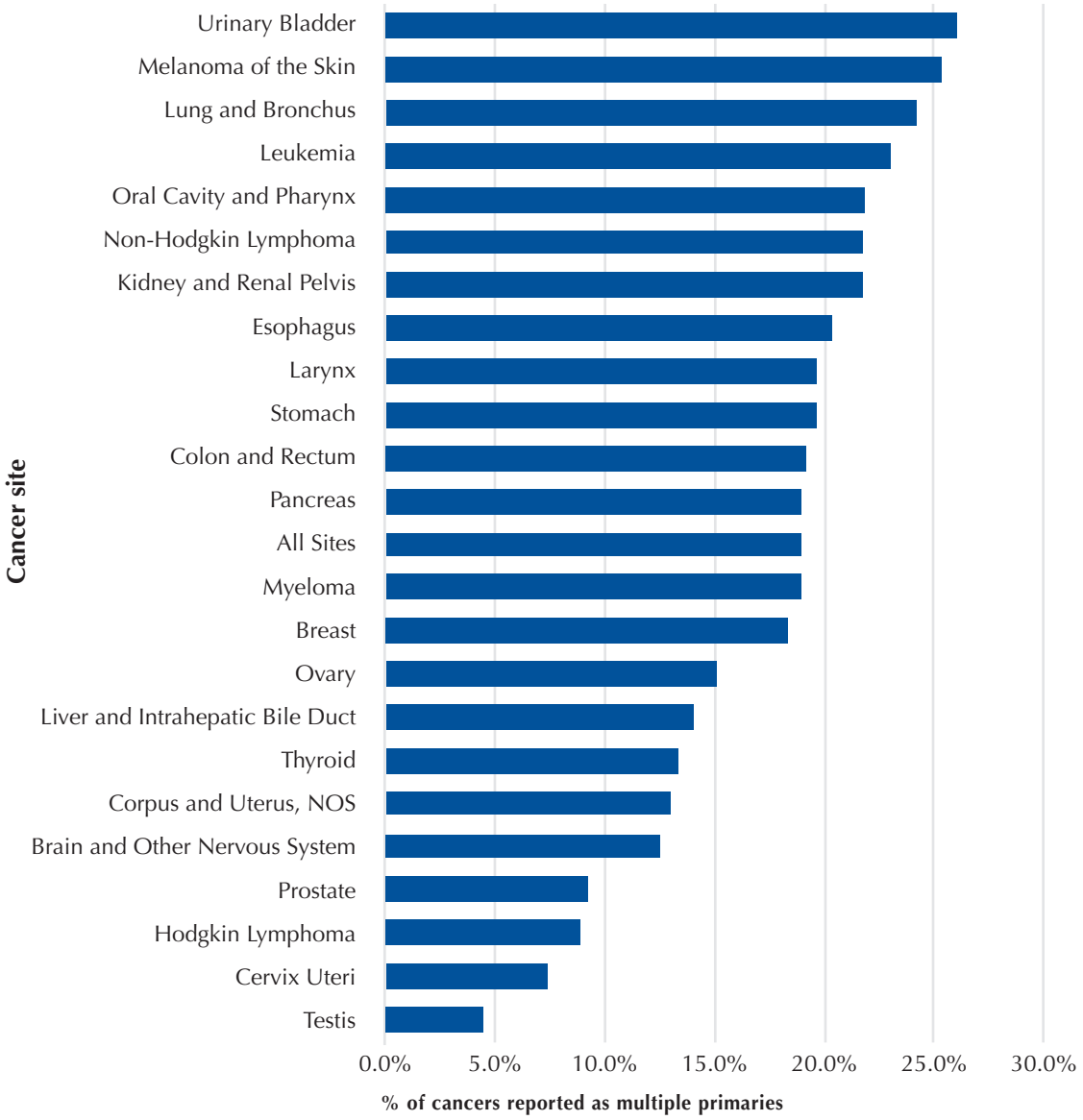

Figure 2. Percentage of Cancers Reported as Multiple Primaries by Age Group, All Cancer Sites Combined, 2012–2016, 49 State Cancer Registries Combined

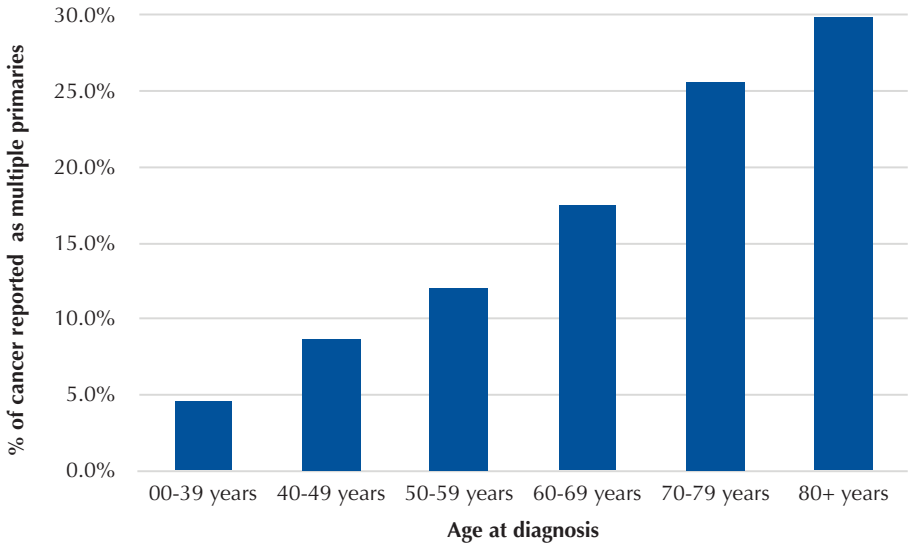

Figure 3. Percentage of Cancers Reported as Multiple Primaries by Race and Ethnicity, All Cancer Sites Combined, 2012–2016, 49 State Cancer Registries Combined

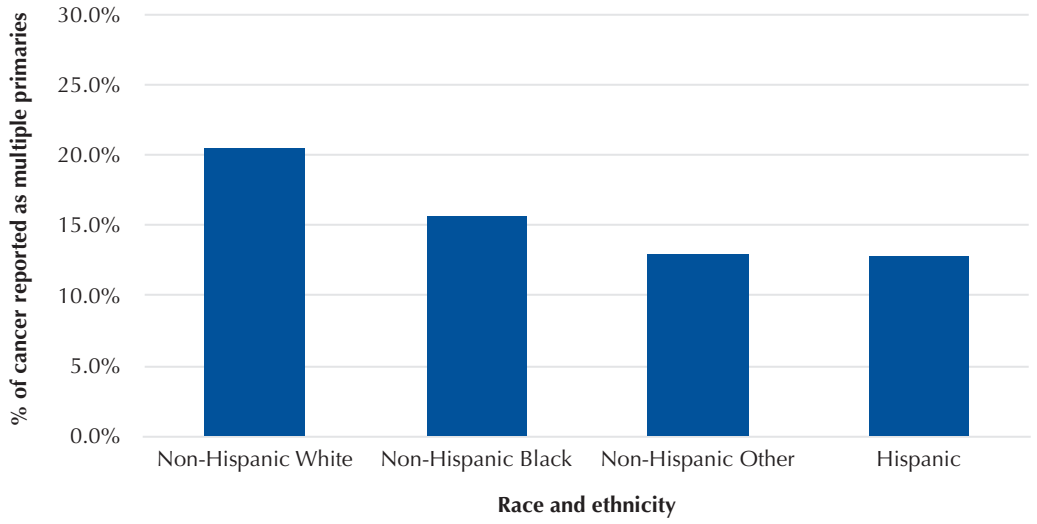

Figure 4. Percentage of Cancers Reported as Multiple Primaries by Registry, All Cancer Sites Combined, 2012–2016

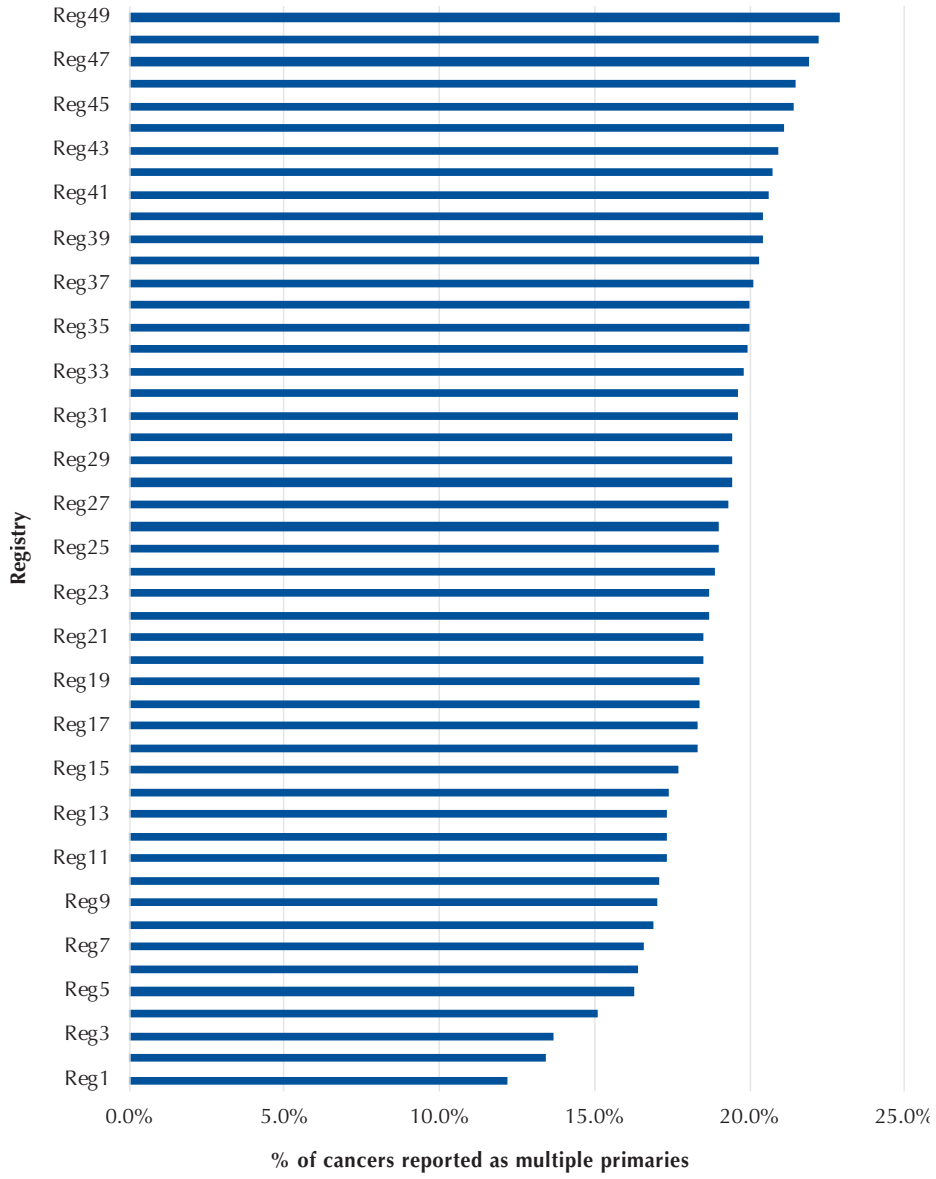

Figure 5. Percentage of Cancers Reported as Multiple Primaries by Year of Diagnosis, All Cancer Sites Combined, 49 State Cancer Registries Combined

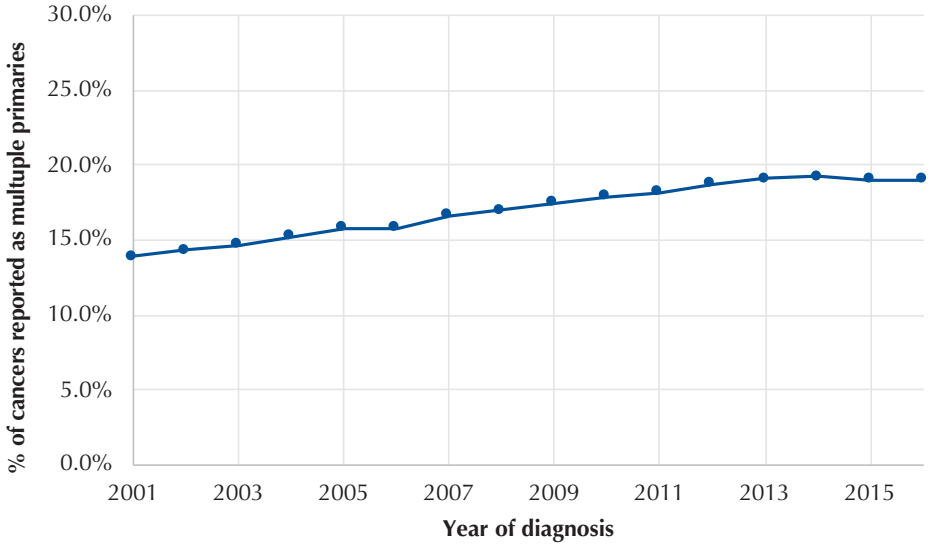

Table 1. Percentage of Cancer Diagnosed at a Local Stage by Cancer Site, First Primary vs Multiple Primary, 2012–2016, 49 State Cancer Registries Combined

Cancer Sites	*Percent of Cases Diagnosed at Local Stage among First Primaries (A)*	*Percent of Cases Diagnosed at Local Stage among Multiple Primaries (B)*	*Ratio (B/A)*
All sites	45.3	47.1	1.04
Oral cavity and pharynx	27.9	41.2	1.48
Esophagus	16.6	23.9	1.44
Stomach	27.7	34.6	1.25
Colon and rectum	36.5	42.4	1.16
Liver and intrahepatic bile duct	39.1	46.8	1.20
Pancreas	10.1	14.1	1.40
Larynx	51.0	57.5	1.13
Lung and bronchus	16.5	29.7	1.80
Melanoma of the skin	77.6	77.1	0.99
Breast	62.1	70.0	1.13
Cervix uteri	42.6	37.5	0.88
Corpus and uterus, not otherwise specified	66.2	62.6	0.95
Ovary	14.6	14.8	1.01
Prostate	74.0	76.2	1.03
Testis	68.0	68.7	1.01
Urinary bladder	83.8	83.9	1.00
Kidney and renal pelvis	64.3	69.1	1.07
Brain and other nervous system	76.1	78.3	1.03
Thyroid	68.4	67.5	0.99

developed by the International Association for Research on Cancer (IARC),[16] instead of SEER rules. In general, the SEER rules are less conservative and allow more multiple primary cancers to be reported compared to the IARC rules.[17,18]

In our study, bladder, melanoma of the skin, and lung were the top 3 cancer sites that had the highest percentages of tumors reported as multiple primaries. This might be partially explained by shared cancer risk factors and/or multiple primary cancer coding rules. Tobacco smoking is a major risk factor for both lung and bladder cancers. It is not uncommon for individuals with a history of tobacco use to develop multiple tobacco related cancers in their lifetime. As a result, multiple primary cancer diagnoses tend to be higher for tobacco-related cancer sites. [6] Excessive sun exposure is the major risk factor for melanoma of the skin, and patients with a first diagnosis of melanoma of the skin have a significantly higher risk of developing a subsequent melanoma. [2] Since the SEER multiple primary rules allow skin lesions occurring on different parts of the body to be coded as separate primary cancers, the percentage of multiple primary cancers for melanoma of the skin can be higher.

As expected, our study showed that multiple primary cancers were more likely to be reported among older age groups. With the increase in early diagnosis and better treatments, more patients are living longer after their first cancer diagnosis. As cancer survivors age, the risk of being diagnosed with subsequent new cancer primaries also increases. [3] The percentage of tumors reported as multiple primary cancers was higher among non-Hispanic Whites, compared to other racial and ethnic groups. This might be partially driven by the higher incidence rates of bladder cancer and melanoma of the skin among the non-Hispanic White population. In addition, overall cancer survival among non-Hispanic Whites tends to be better compared to other racial and ethnic groups, and longer survival time may also contribute to the higher percentage of multiple primary cancer diagnoses.

The current study showed that the percentage of tumors reported as multiple primary cancers varied considerably by registry. This variation might be due in part to the varying lengths of time registries have been in operation. In general, registries with longer operation times tended to have a higher proportion of multiple primary cancers than registries with shorter operation times.[15,19,20] In addition, lack of consistency in the assignment of sequence number and variations in the interpretation and application of the SEER multiple primary cancer rules across registries may have also affected the ascertainment of multiple primary cancers.[21]

This study found that the percentage of cancers registered as multiple primary cancers increased from 13.9% in 2001 to 19.0% in 2016, representing a 36.6% increase. This increasing trend is consistent with the trend observed previously based on SEER data.[9] However, we would not anticipate this trend to continue indefinitely. Brenner and Hakelinen stated that a true proportion of multiple primary cancers was likely to be reached after more than 40 years of a registry's operation.[17] The majority of cancer registries in the United States were established in the 1980s and 1990s. It will therefore be interesting to see what the trend will look like in another decade.

For about half of the cancer sites evaluated, tumors reported as multiple primary cancers were more likely to be diagnosed at an early stage than tumors reported as first primary cancers. This might be explained by the heightened medical surveillance of patients with a previous cancer diagnosis. Due to continued monitoring, subsequent tumors among cancer survivors are more likely to be caught at an early stage. This seems particularly true for cancers that by their nature are normally not easy to detect early, such as cancers of the lung, pancreas, and esophagus.

Traditionally, multiple primary cancers have been excluded from population-based survival analyses. However, this practice has come into question by several recent studies due to concerns of selection bias.[15,17,22] Our study has provided support for including multiple primary cancers in survival analyses. As shown, a significant proportion of cancer cases were reported as multiple primary cancers, and multiple primary cancers varied widely by cancer site, age, race/ethnicity, and registry. Therefore, if only first primary cancers are selected for survival analyses, it would mean that a significant proportion of cases would be excluded. In addition, this exclusion would be disproportionate across different cancer sites, age groups, race/ethnicity groups, and registries. All these factors are potential sources of selection bias, and consequently can affect the comparability of survival estimates.

One notable strength of our study is that it was based on data reported to 49 state cancer registries, covering almost 99% of the entire US population, therefore, the findings should be representative. However, our study also has some limitations. First, the statistics presented were solely descriptive. We did not intend to perform any formal tests to determine whether the differences between groups were statistical significance. Given the extremely large sample size of the study, any small differences would most likely be statistically significant. Secondly, our study defined and counted multiple primary cancers by tumor, instead of by patient. It was not intended to evaluate the proportion of individuals with multiple primary cancer diagnoses.

In conclusion, the current study describes frequencies and patterns of multiple primary cancers in the United States. The findings from the study have some practical implications for cancer registries that collect data and for researchers who intend to use multiple primary information for their studies.

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Original Article

Visualizing Cancer Incidence and Mortality Estimates by Congressional Districts, United States 2012–2016

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Abstract: Background: Cancer incidence and death rates in the United States are often published at the county or state-levels; examining cancer statistics at the congressional district (CD) level allows decision makers to better understand how cancer is impacting the specific populations they represent. Methods: Cancer incidence data were obtained from the Centers for Disease Control and Prevention's National Program of Cancer Registries and the National Cancer Institute's Surveillance, Epidemiology, and End Results Program. Mortality data were obtained from the National Center for Health Statistics. CD rates were estimated by assigning the county-level age-adjusted rates to the census block and weighting those by the block population proportion of the CD. Those weighted rates were then aggregated over the blocks within the CD to estimate the district rate. Incidence rate estimates for 406 CDs and death rate estimates for 436 CDs were reported according to the boundaries for the 115th Congress of the United States. Maps showing rate estimates for all cancers combined, lung/bronchus, colorectal, female breast, cervical, and prostate cancer are presented by sex and race/ethnicity. Results: The distribution of cancer incidence and death rates by CDs show similar patterns to those that have been observed at the county and state levels, with the highest cancer incidence and death rates observed in CDs in the South and Eastern regions. Conclusion: This examination of cancer rates at the CD-level provides data that can be used to inform cancer control strategies at the local and national levels. Displaying the data with the Data Visualizations tool makes it easily accessible to the public and decision makers.

Key words: *cancer, cancer incidence, cancer mortality, congressional district, small-area estimates*

Introduction

The United States Cancer Statistics (USCS) provides statistics on cancer, including information on cancer incidence from national registries and mortality from the National Vital Statistics System, for the entire US population. These statistics include cancer incidence data from Centers for Disease Control and Prevention (CDC)'s National Program of Cancer Registries (NPCR) and the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) Program, as well as mortality data from CDC's National Center for Health Statistics (NCHS). These data are essential for public health professionals, researchers, the medical community, and decision makers to monitor cancer trends, support critical research, identify and evaluate programmatic efforts, and allocate resources where they are most needed. The data can be used to inform decision makers about the effectiveness of interventions to reduce or prevent cancer occurrence. The numbers of new cancer cases and deaths in the United States are often published at the county or state levels.[1,2] Examining cancer statistics at the congressional district (CD) level provides decision makers with additional data to better understand how cancer is impacting the specific populations they represent.

Two previous studies have reported on cancer death rates by CD; however, these studies reported death rates from older periods (1990–2001 and 2002–2011), and did not include cancer incidence data.[3,4] In this paper, we present estimates of cancer incidence and mortality rates by CD for the 5-year period of 2012–2016. We also describe the Data Visualizations tool that houses the official US federal cancer data, US Cancer Statistics, including the estimates for cancer incidence and mortality by CDs.

Methods

We obtained cancer incidence data from US Cancer Statistics that includes both data from CDC's NPCR and the NCI's SEER Program.[5] Mortality data were obtained from the NCHS. Block-level population data came from the US Census Bureau's 2010 Census Summary File 1.[6]

There are 436 CDs for 50 states and the District of Columbia in the United States. We estimated cancer death rates and counts for 2012–2016 for the 436 CDs according to the boundaries for the 115th Congress of the United States. Similarly, cancer incidence rates and counts were estimated for 424 CDs. Incidence data are not included for Kansas (4 CDs) and Minnesota (8 CDs) because county-level incidence data were not reported to CDC. Illinois opted not to present

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CD-specific estimated incidence case counts and rates (18 CDs). Therefore, we reported estimated incidence rates and counts for 406 CDs in this paper and in the online Data Visualizations tool.

CDs were defined by census blocks according to census geography hierarchy.[7] The District of Columbia and 7 states (Alaska, Delaware, Montana, North Dakota, South Dakota, Vermont, and Wyoming) have a single CD that follows state or federal district boundaries. For these states that have only 1 CD, the same state rates and counts were used. For states that have multiple CDs, rates were estimated by assigning the county-level age-adjusted rates to the census block and weighting those by the block population proportion of the CD. Those weighted rates were then aggregated over the blocks within the CD to estimate the district rate. More specifically, the following steps were taken:

1. We obtained census block-level population counts by sex and race/ethnicity from the 2010 US Census Summary File 1.[6] We matched each census block to the assigned congressional district using the census Block Equivalency File downloaded from the census website.[8]
2. We calculated the age-adjusted county-level rates by sex and race/ethnicity using SEER*Stat software and merged with the block-level population counts by county.[9]
3. We calculated the cancer incidence and death rates for CDs as follows:

$$\mathbf{r_j} = \sum_{i=1}^{n} \left(\frac{p_{ij}}{p_j}\right) r_i$$

Where r_i is the age-adjusted cancer incidence/death rate for block i (estimated as the corresponding county incidence/death rate), p_{ij} is the population counts of block i within CD_j p_j is the total population count for CD_j, and n is the number of blocks within CD_j. This method has been used in a previous study.[4] To calculate counts for CDs, we first estimated counts by CDs within each county based on the proportion of the county population for each CD that intersect with the county, then we aggregated the counts from different counties that intersect with the CD. The district count n_j was defined as

$$\mathbf{n_j} = \sum_{k=1}^{m} \left(\frac{p_{kj}}{p_k}\right) n_k$$

Where n_k is the number of cases in county k, p_k is the population in county k, p_{kj} is the population of county k within district j, and m is the number of counties that intersect with CD_j. This gives the same estimates as weighting at the block level similar to the rate calculations above but is a more efficient calculation in terms of computing time. The district counts for both sexes combined were obtained by summing the male and female estimates.

Estimates were calculated by sex (both sexes, male, and female) and race/ethnicity (all races, non-Hispanic White, Black, and Hispanic). Block-level population data were not available by ethnicity for races other than White. As a result, the estimates for non-Hispanic Blacks could not be calculated; the Black race category includes both Hispanics and non-Hispanics.

Maps for incidence and mortality estimates for all cancers combined, and for 5 individual cancers (lung/bronchus, colorectal, female breast, cervical, and prostate) were constructed in ArcGIS (version 10.3). We chose to present data for these 5 individual cancers for which evidence-based prevention efforts (tobacco control and screening) are being implemented.[10,11] Estimates for cancer incidence and death rates by sex were displayed in quintiles on the maps to enable comparisons to previous studies.[3] Using quantile classification for choropleth maps has also been found to convey information to readers with great accuracy in comparison to other data classification methods.[12] Data are suppressed for cells with fewer than 16 estimated cases. Incidence data for Hispanics in Delaware, Kentucky, and Massachusetts were suppressed at the states' request.

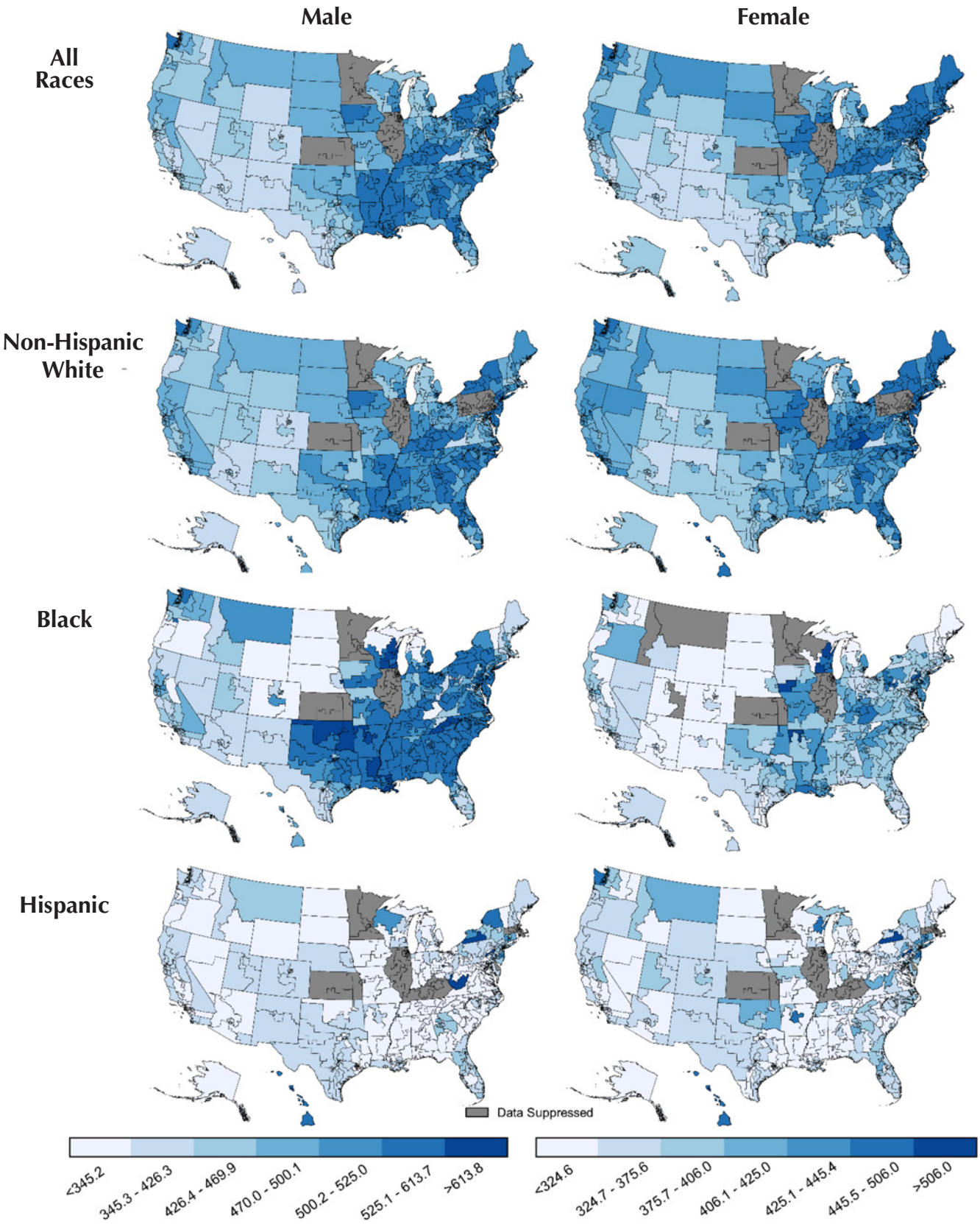
Results

Estimated Cancer Burden by Congressional Districts

Cancer incidence rates by congressional district. Estimates for overall cancer incidence rates by CD ranged from about 320 to 610 new cancer cases per 100,000 persons per year (Figure 1). In general, cancer incidence rate estimates were highest in CDs in the Southern and Eastern regions of the country. When examined by race, CD incidence rate estimates were lower for Hispanics compared to other races. Black men had higher incidence rate estimates (rates in highest quintile) compared to men of other races across CDs in the Southern and Eastern regions. Among women, Non-Hispanic White women had higher incidence rates (rates in the third and fourth highest quintiles) compared to women of other races across CDs.

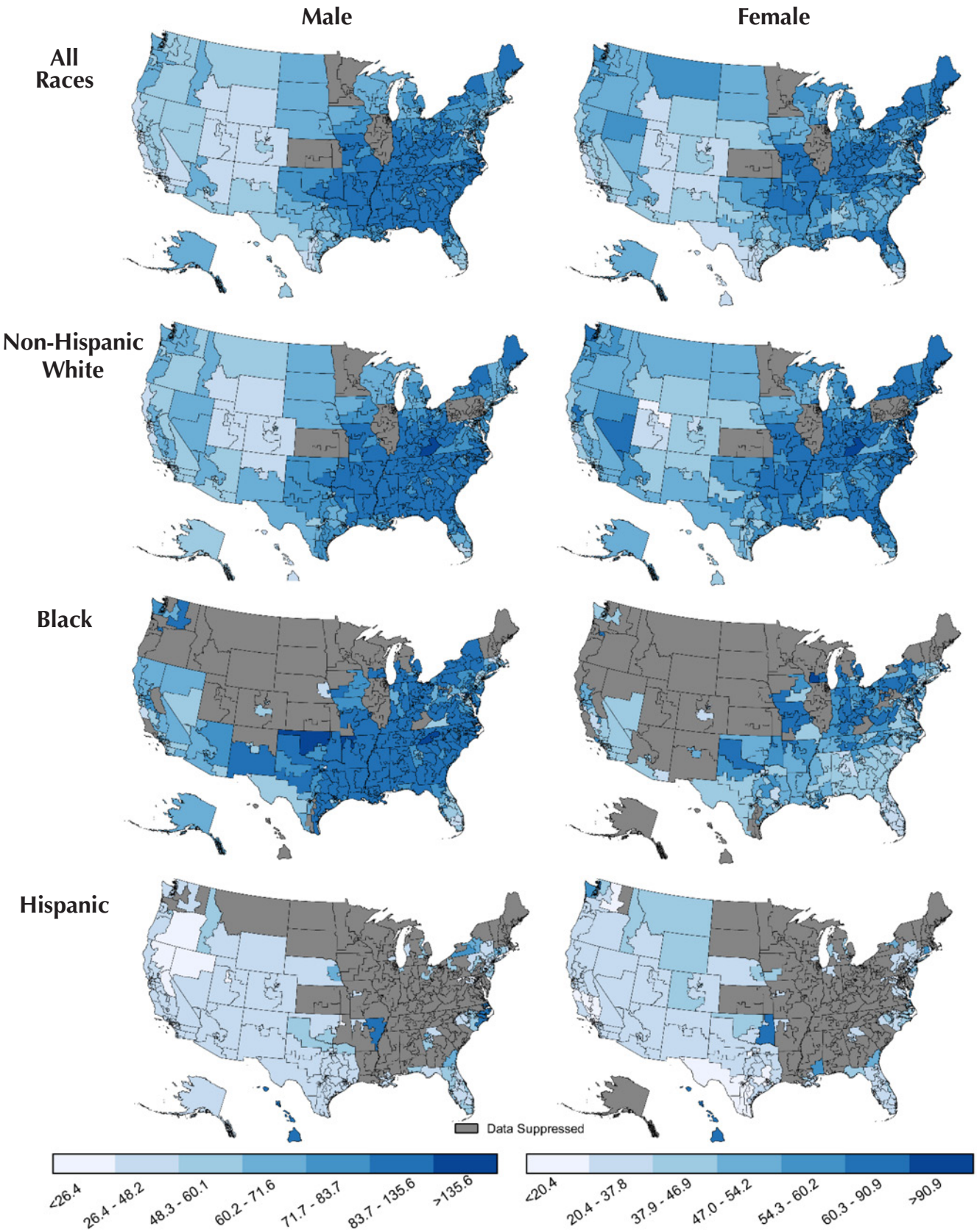
Incidence rate estimates for the 5 individual cancers by CD are shown in Figures 2 through 5. The distribution of lung cancer incidence rate estimates was similar to that of overall cancer incidence rate estimates. Among men, CDs in the Southern and Eastern part of the country had higher lung cancer incidence rate estimates, and Hispanic men had lower incidence estimates compared to men of other races. Among women, Non-Hispanic White women also appeared to have higher incidence rates compared to women of other races in CDs in the Southern and Eastern regions. The distribution of colorectal cancer incidence estimates was also similar to overall cancer incidence, with high incidence estimates seen in some Midwest states along with CDs in the South and East. The distribution of CDs with high incidence estimates for breast cancer appeared to differ by race; for non-Hispanic White women, CDs on the West and Northeast Coasts appeared to have higher incidence estimates. For Black women, CDs in the Appalachian region appeared to have higher incidence estimates for breast cancer. Cervical cancer incidence was higher in CDs for the South overall; among Black women, CDs in the Southeast had the highest rate estimates and among Hispanic women, CDs in the Southwest had the highest estimates. Prostate cancer incidence estimates showed a greater number of CDs with high incidence estimates for Black men in the Southern and Eastern regions compared to men of other races.

Figure 1. Overall Cancer Incidence Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 406 Congressional Districts (CDs) from 2012–2016



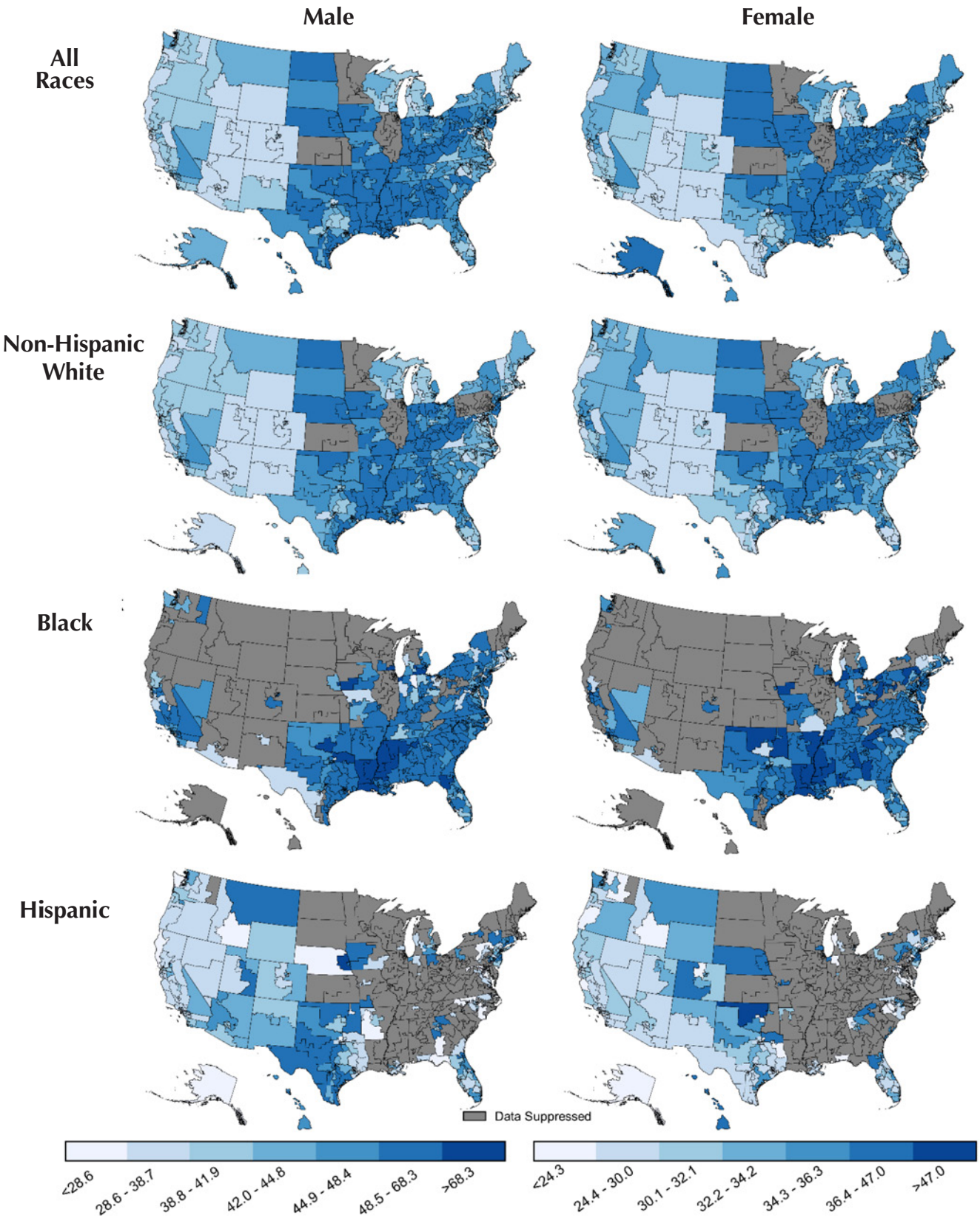
Data are not included for Kansas (4 CDs), Minnesota (8 CDs), and Illinois (18 CDs). Data were suppressed for CDs with cancer case counts below 16 (these areas are depicted in gray).

Figure 2. Lung Cancer Incidence Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 406 Congressional Districts (CDs) from 2012–2016



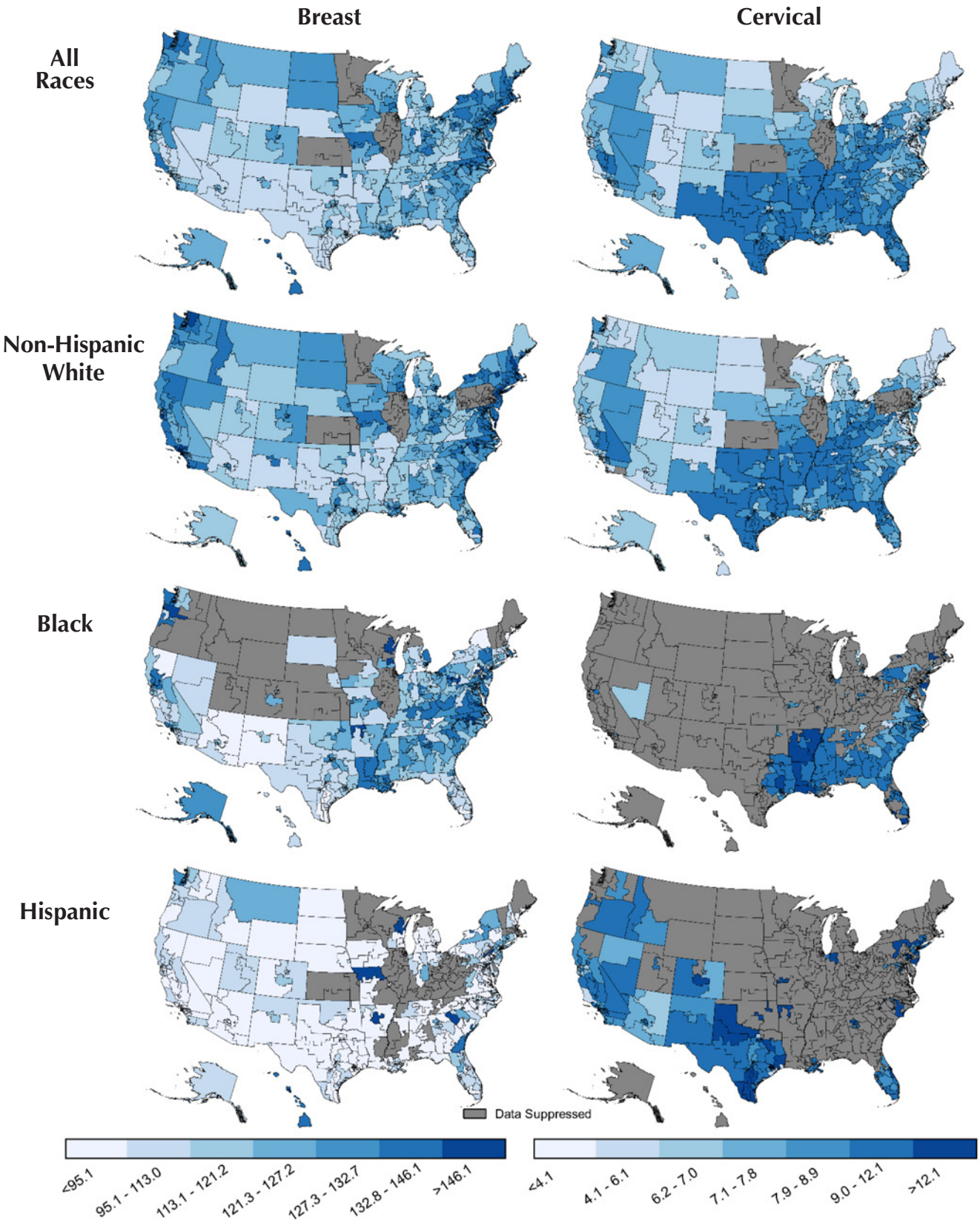
Data are not included for Kansas (4 CDs), Minnesota (8 CDs), and Illinois (18 CDs). Data were suppressed for CDs with cancer case counts below 16 (these areas are depicted in gray).

Figure 3. Colorectal Cancer Incidence Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 406 Congressional Districts (CDs) from 2012–2016



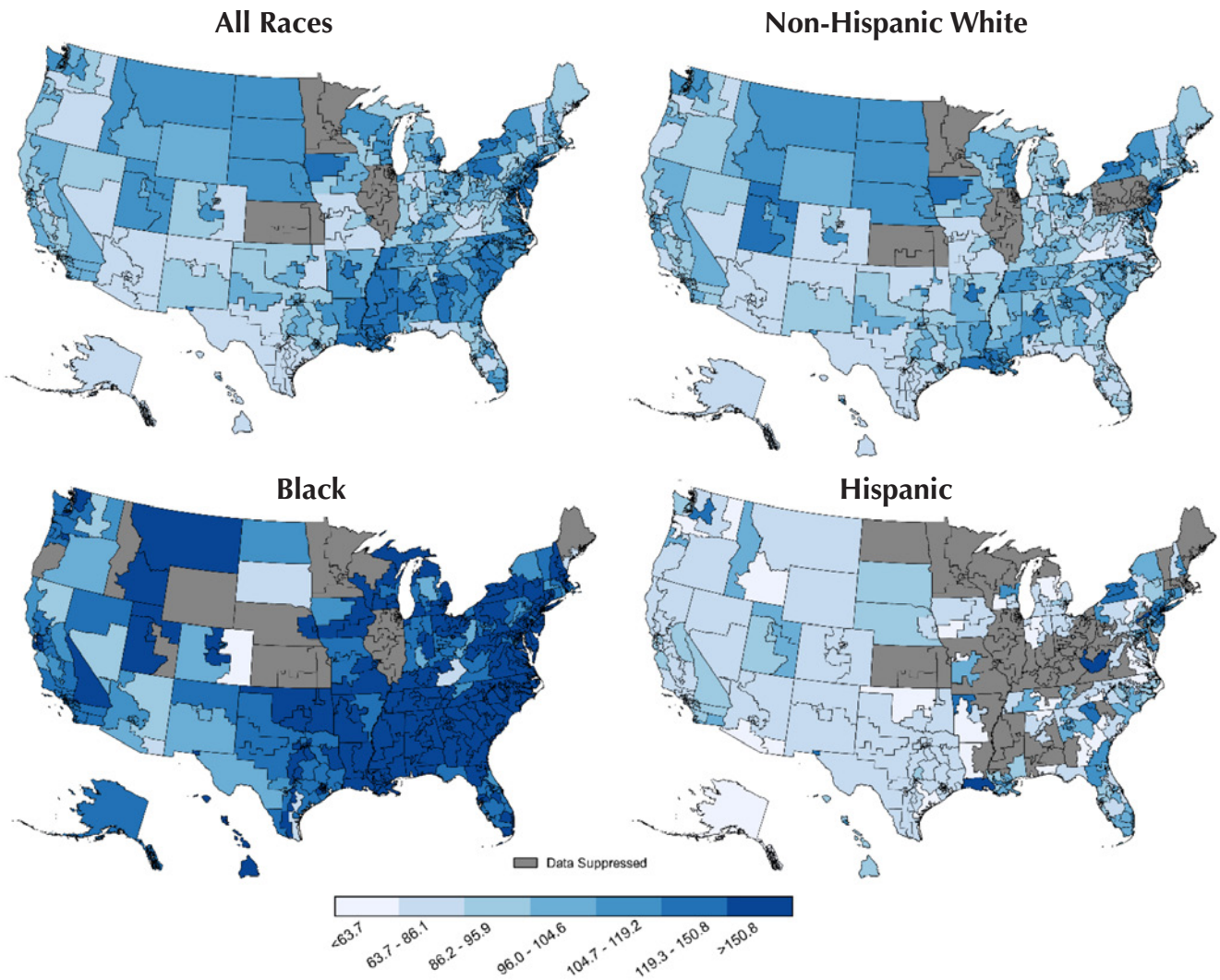
Data are not included for Kansas (4 CDs), Minnesota (8 CDs), and Illinois (18 CDs). Data were suppressed for CDs with cancer case counts below 16 (these areas are depicted in gray).

Figure 4. Breast Cancer and Cervical Cancer Incidence Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 406 Congressional Districts (CDs) from 2012–2016



Data are not included for Kansas (4 CDs), Minnesota (8 CDs), and Illinois (18 CDs). Data were suppressed for CDs with cancer case counts below 16 (these areas are depicted in gray).

Figure 5. Prostate Cancer Incidence Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 406 Congressional Districts (CDs) from 2012–2016



Data are not included for Kansas (4 CDs), Minnesota (8 CDs), and Illinois (18 CDs). Data were suppressed for CDs with cancer case counts below 16 (these areas are depicted in gray).

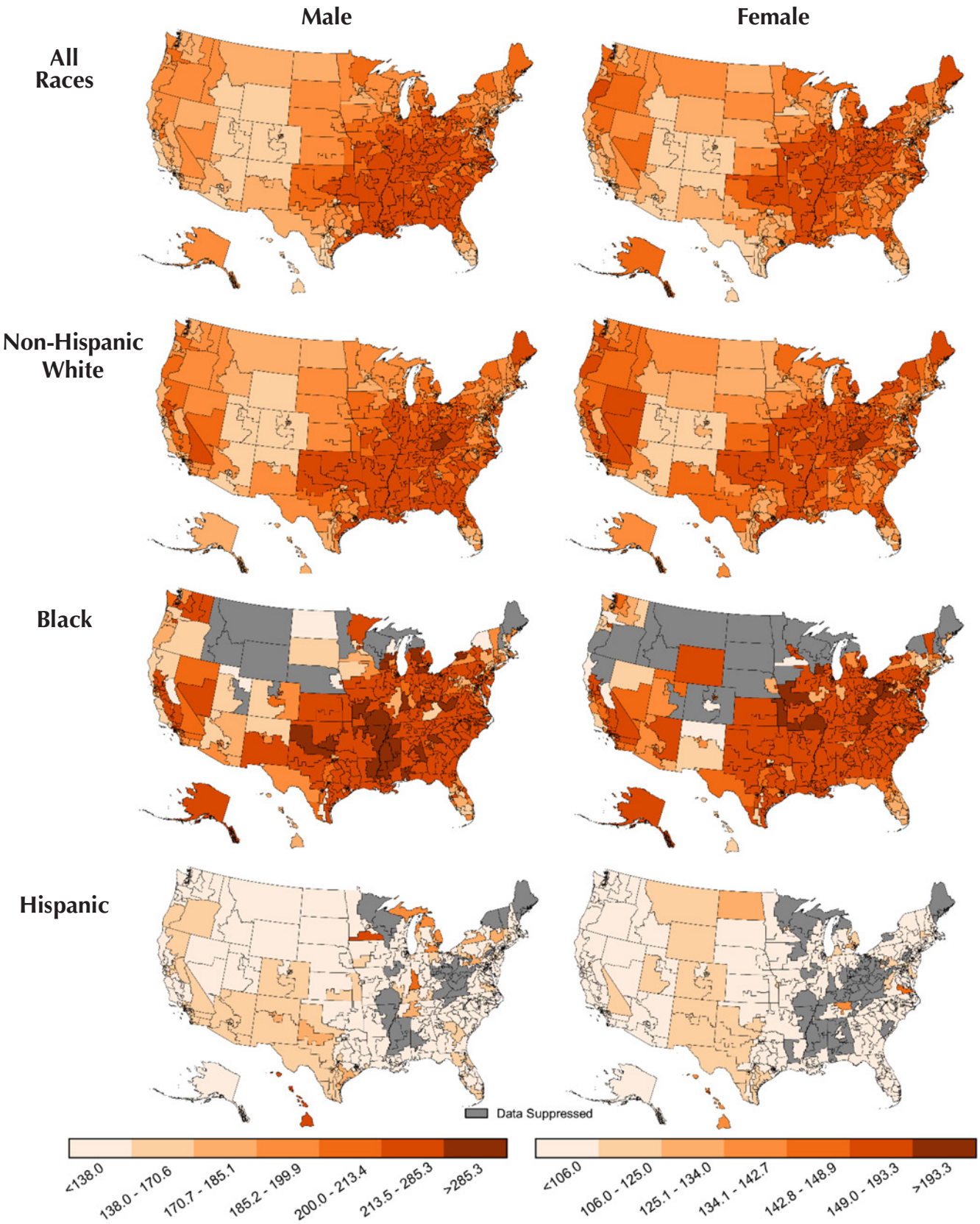
Cancer mortality rates by congressional district. The distribution of the overall cancer death rates by CD was similar to that of incidence rates, ranging from about 100 to 290 cancer deaths per 100,000 persons per year (Figure 6). Overall cancer mortality rates were highest in CDs in the Southern and Eastern regions of the country and were lower for Hispanics compared to other races. Mortality estimates were highest for Blacks compared to other races; both Black men and women had a greater number of CDs with high mortality rate estimates (rates in highest quintile) compared to other races.

Mortality rate estimates for the 5 individual cancers by CD are shown in Figures 7 through 10. When examined by race, for all cancers, Black men and women had higher mortality rates (rates in the highest quintile) in more CDs compared to men and women of other races. With the exception of prostate cancer, the distribution of cancer mortality rates by CD for the individual cancers was similar to that of overall cancer mortality with higher mortality rates seen in the Southern and Eastern regions of the country. Among non-Hispanic Whites, prostate cancer rates were highest in the CDs in the West, with lower rates in the Southeast.

Visualizing Cancer Burden Estimates by Congressional Districts

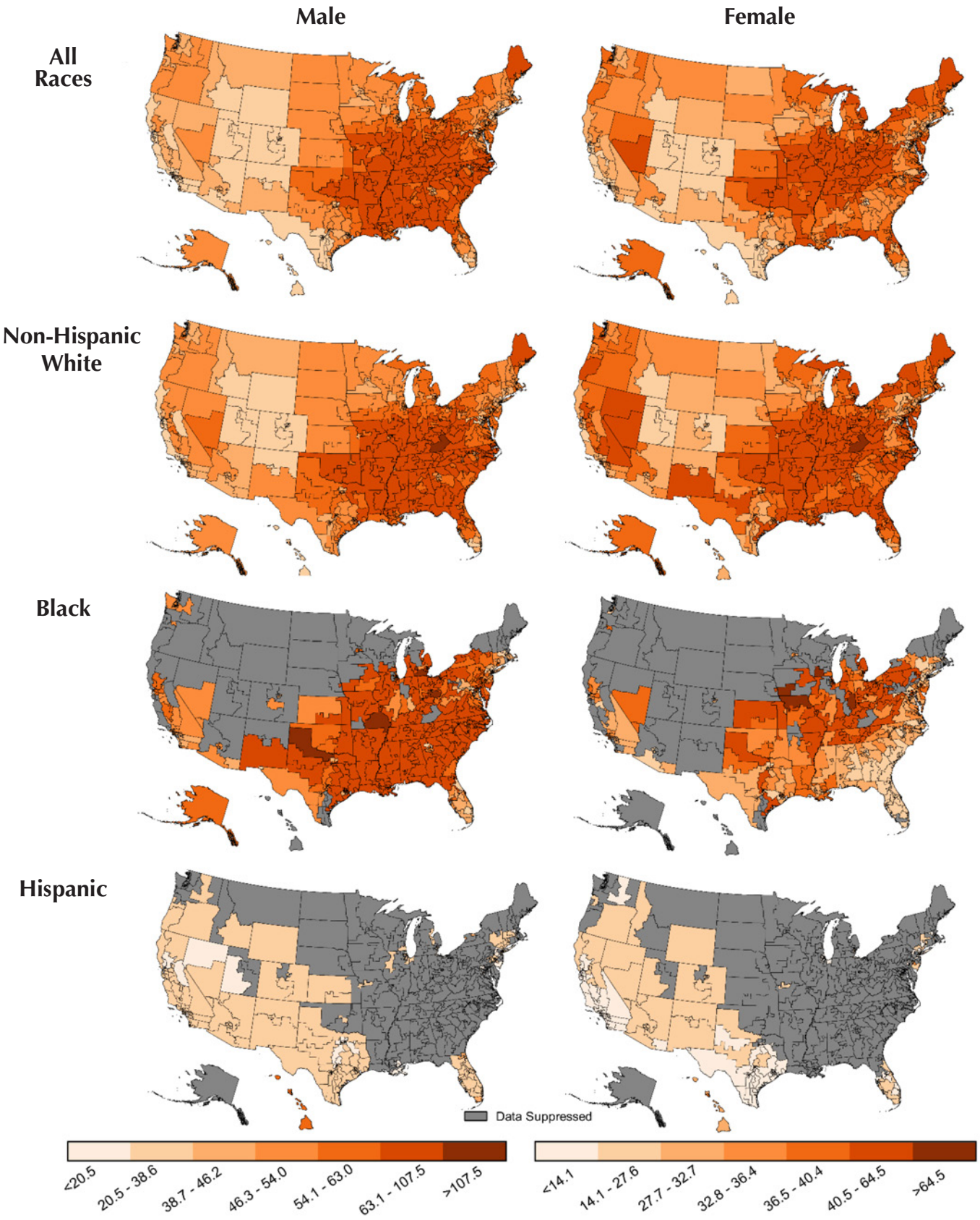
Cancer incidence and mortality estimates by congressional district are readily available to the public on the US Cancer Statistics Data Visualizations tool (**www.cdc.gov/cancer/dataviz**).[1] Estimates for overall cancer incidence and mortality, as well as those for the leading 20 cancer sites, are also easily accessible in the tool (Figure 11). Data graphics displayed in this tool include: (1) maps showing cancer incidence and mortality estimates for CDs in each state; (2) graphs ranking cancer incidence and mortality rates for leading cancer sites for each CD; (3) graphs ranking cancer incidence and mortality rates by sex and by race

Figure 6. Overall Cancer Death Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 436 Congressional Districts from 2012–2016



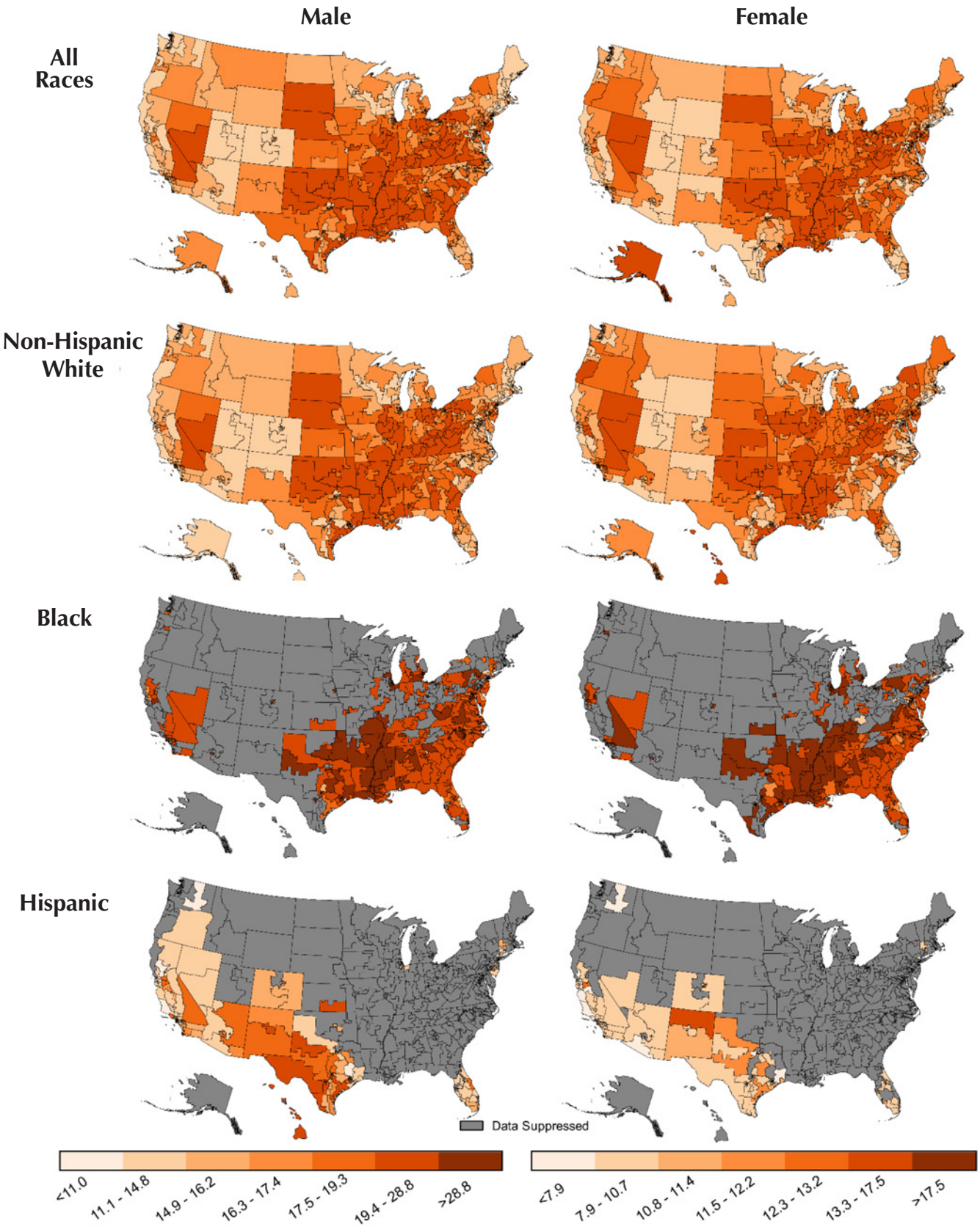
Data are suppressed for congressional districts with cancer case counts below 16 (these areas are depicted in gray).

Figure 7. Lung Cancer Death Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 436 Congressional Districts from 2012–2016



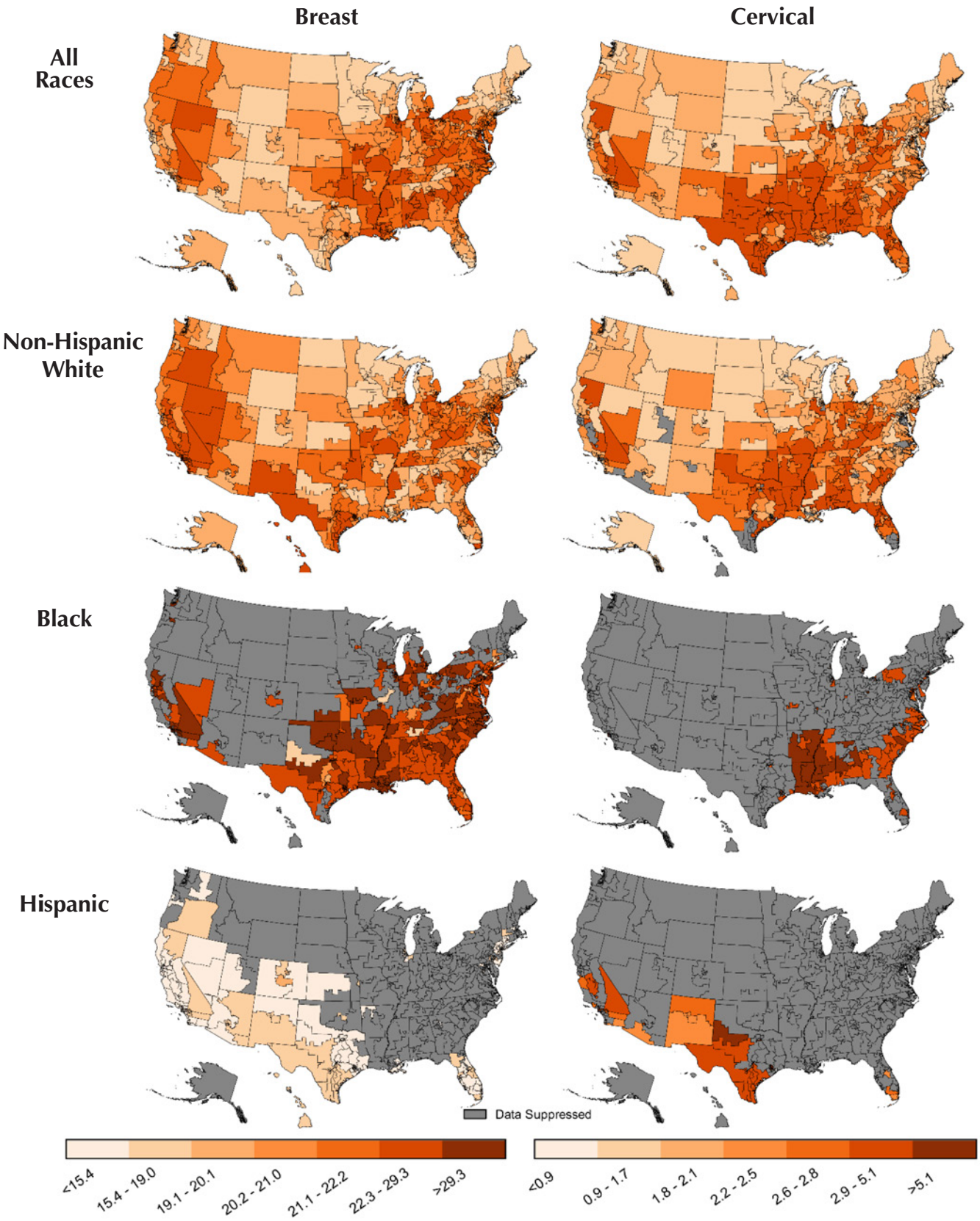
Data are suppressed for congressional districts with cancer case counts below 16 (these areas are depicted in gray).

Figure 8. Colorectal Cancer Death Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 436 Congressional Districts from 2012–2016



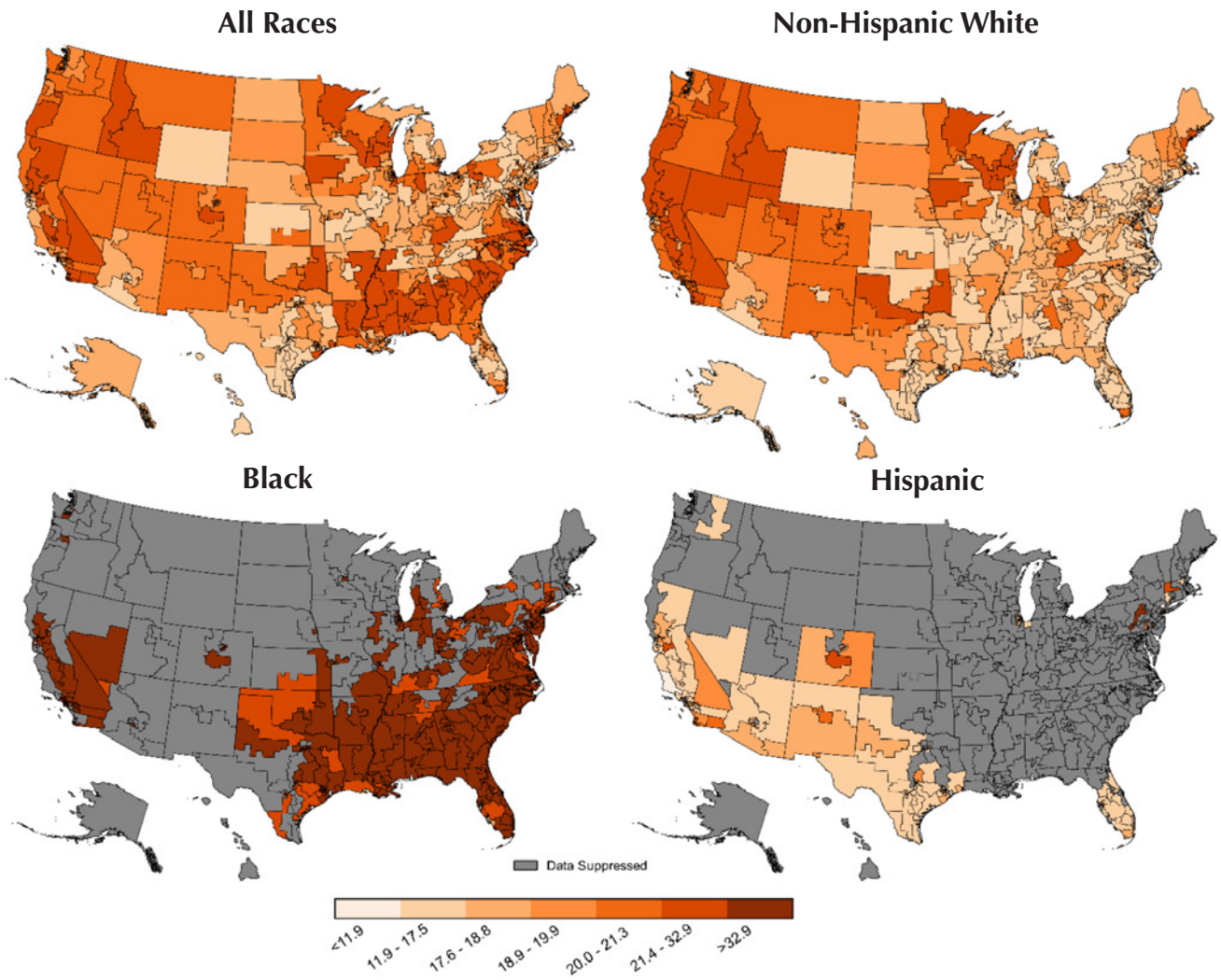
Data are suppressed for congressional districts with cancer case counts below 16 (these areas are depicted in gray).

Figure 9. Breast Cancer and Cervical Cancer Death Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 436 Congressional Districts from 2012–2016



Data are suppressed for congressional districts with cancer case counts below 16 (these areas are depicted in gray).

Figure 10. Prostate Cancer Death Rate Estimates (per 100,000) by Sex and Race/Ethnicity in 436 Congressional Districts from 2012–2016



Data are suppressed for congressional districts with cancer case counts below 16 (these areas are depicted in gray).

(non-Hispanic White, Black, and Hispanic) for each CD. The Data Visualizations tool also allows users to see the data used to generate the graphs and maps in table format by using the "Table" tab and to download data tables for cancer rates by CDs by using the "Export" tab.

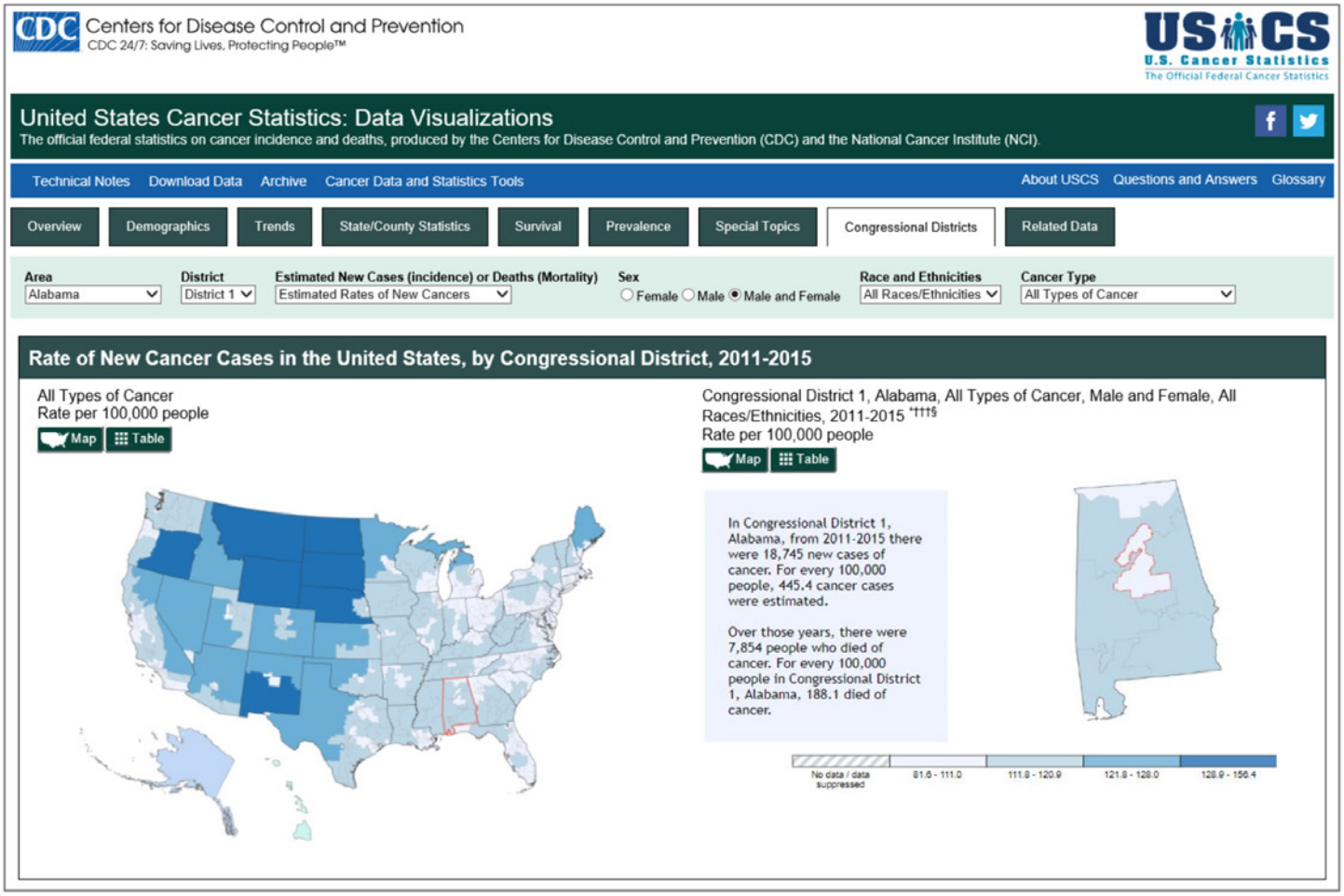
Discussion

The distribution of cancer incidence and death rates by CD showed similar patterns to those that have been observed at the county and state levels, with the highest cancer incidence and death rates observed in CDs in the Southern and Eastern regions of the country.[1] The patterns of cancer death rate estimates by CD from this analysis are similar to those found in previous studies conducted for the 1990–2001 and 2002–2011 periods.[3,4]

Overall, Hispanics had lower incidence and death rates and Blacks appeared to have a greater number of CDs with higher incidence and death rates. The distributions of lung and colorectal cancer incidence and mortality rates by CD were similar to those observed for overall cancer rates. The examination of breast, cervical, and prostate cancer incidence and death rates by CD highlighted differences in rate distributions by race/ethnicity. Graphics of these cancer rate estimates by CD, and other national cancer data are readily accessible to the public on the USCS Data Visualizations tool (**www.cdc.gov/cancer/dataviz**).[1]

Key strengths of this analysis are that it uses national cancer incidence data and provides an examination of both cancer incidence and death rates, including estimates for 5 individual cancer rates. Limitations of this analysis include the assumptions made that the population proportions from the 2010 US census used for weighting still apply to the study period (2012–2016) and rates at the block-level were similar to those at the county-level. This may underestimate or overestimate rates at the CD-level. Of note, most CD estimates were derived from whole county rate estimates. Only a small portion of CDs (65 of the 436; 15%) were composed of 2 or more counties, with county boundaries

Figure 11. Screenshot of US Cancer Statistics (USCS) Visualization Website that Enables the Public to View Cancer Incidence and Death Rate Estimates by State, County, and Congressional District



traversing adjacent CDs. Geocoding cases at the CD-level could address these limitations in the future. Lastly, race/ethnicity categories examined were limited based on available county-level data; we were unable to provide CD rate estimates for Asian-Pacific Islanders or American Indian/Alaskan Native people due to small case counts.

This examination of cancer rates at the CD-level provides data that can be used to inform cancer control strategies at the local and national levels. Displaying the data with the Data Visualizations tool makes it easily accessible to the public and decision makers.

Acknowledgments

We would like to thank the Geospatial Research, Analysis, and Services Program (GRASP) team at the Agency for Toxic Substances Disease Registry for their work in developing the US Cancer Statistics Data Visualizations tool, particularly Doug Day, Anil Kolli, and Lance Broeker.

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What Pushes You to Succeed?

Michele Webb, CTR

What pushes people to succeed? What drives a cancer registry student to nail the interview and land that first job? What pushes an experienced registrar to get a promotion in a management or a leadership role? Or, what is behind the cancer registrar who tirelessly mentors and helps others to succeed? Most hiring managers will tell you that they do not look at a candidate's grade point average, school location, or the speed by which they completed their degree. What they are looking for is *hunger*. Without this intangible trait, none of the other skills—such as initiative, good judgement, ability to learn, planning, or organization—matter.

As a department manager, this author has sat through many interviews looking for the candidate with that "spark" or a desire to prove something to themselves and others. These were the registrars who were hungry and eager to prove their abilities and drive on the job. I related well to these candidates because I saw a little of myself in them. I vividly remember sitting across the desk from a college counselor and being told that I would never amount to anything or be successful in life.

When you are handed information like this, you have a choice to make. You can listen to the feedback and let it become self-fulfilling, or you can use it to fuel your hunger and push you to succeed and prove the naysayers wrong. From my own personal experience, the satisfaction gained from proving them wrong and achieving some degree of professional success was well worth it.

When you are beginning your career as a cancer registrar, you will find many people ready to rush in and shower you with wisdom. Anyone who joined the profession before you will want to share their advice. From your first day and up to the moment you dance out of the building to retirement, you will receive a lot of valuable advice. But there is one thing you will need to take on this journey, from the first day until the last, and that is the concept of "hunger" versus "thirst."

We all approach our careers with either hunger or thirst. You will recognize a thirsty professional as someone who is driven by lust or envy. There are plenty of things to lust after: being a supervisor or manager, higher pay, a private office, status, benefits, or maybe just a sense of winning something. Wanting something for recognition, rather than the value of the work itself or the life it allows you to live, comes from being thirsty.

A hungry person fuels their own drive or push to succeed. They are passionate about their work and the organization they serve. They want to be employed by a certain organization because they want to be part of the vision and mission they embody. A hungry cancer registrar is someone who wants to continually improve their skills and contribution to cancer surveillance and the health care systems. They know that the process is a journey that will take time, patience and, quite frankly, a lot of hard work. Hungry cancer registrars are people who see and understand their potential and advocate for themselves in a selfless and intelligent manner.

Whether you are just starting out or have been around for a while, you will make mistakes. Thirsty registrars may get discouraged or frustrated by these mistakes, while a hungry registrar will analyze the steps they took before and after and learn from it. To succeed, you must face and own the consequences of your actions. If you do not, you will become desperate. Seth Godin said it so well: "Dig your well before you become thirsty."[1]

While we may not want to acknowledge it, we become desperate when we want to prove ourselves and are willing to do that by any means, even if it means crushing a colleague's spirit or behaving badly. When we crush anyone who comes between us and our dream, even if we are not prepared or ready to receive it, we are slipping into thirsty behavior.

Let us look at the definition of these terms.

Thirst: The act of seeking attention or approval, instead of doing things that will get people's attention or approval. Wanting instantaneous success as opposed to being ready to work for it; refusing to admit a misstep.[2]

Hunger: The act of making your wants known in a respectful way; willingly working toward a goal (and offering up your effort to others), instead of expecting success to fall into your lap; wanting something because it is the right fit, rather than because it sounds like what you're supposed to want.[3]

Merriam-Webster defines both words as "desire," but classifies thirst as an "ardent desire" and hunger as a "strong desire/craving."[4]

People who are thirsty are the ones who incessantly talk about the promotion that they are going to get or how the organization's leadership team knows who they are, or the power or status they will achieve. They will harass the people who already have the things they want. This behavior is the workplace equivalent of a junior high student who will not be quiet about how they want to be class president for the 6 months leading up to the election. Of course, sometimes that kid does win the election. Just like the person who does not stop tweeting and Facebooking about their employer ends up getting that cushy job. It happens—thirst occasionally works. But most of the time, it only alienates the very people you should be holding up or ingratiating yourself to.

Hunger is entirely different. It is getting the job done and handing in your productivity log without assuming you will get a raise or recognition for all your hard work. Hunger is reaching out to people and showing your appreciation, instead of taking it as a personal affront when they do not respond to your email right away. It is admitting fault and taking responsibility for your actions when you are in the wrong, as opposed to approaching mistakes with that wide-eyed Alice in Wonderland–esque expression and hiding behind excuses.

People, including cancer registrars, are either hungry or they are not. You cannot buy hunger, borrow it, tag along behind it, or steal it from a colleague. What you can do is look inward for hunger and tap into that fire in your belly and then fan the flame until it drives your behavior and actions to succeed in a caring and ethical manner.

When we are thirsty, we push down or dampen our hunger pangs. We choose the quick and easy way to get the job done, drawing attention to ourselves or climbing the ladder to the top, even if it means pushing our colleagues out of the way. Being thirsty is wanting instant gratification and expecting a gold star every time you do something right. Truth be told, all of us will, at some point, catch ourselves slipping into thirst. It is easy to fall into this trap and then get all puffed up about receiving compliments for something you may have done or expecting recognition for something you took from a colleague and claimed as your own.

The working world does not always accommodate thirsty behavior. And being hungry does not mean you should be okay with sitting behind the desk of a thankless job, because that is not how anyone should be treated. Hunger does mean that you will sit quietly at your desk, focus your strengths and energy on the tasks to be done, collaborate with others who can contribute their strengths in addition to yours, and then complete the work without expecting anything in return.

This kind of behavior can do 5 things to help you succeed at work and in life:

- Hunger eliminates failure as an option in both your personal and professional lives.
- Hunger drives you to seek continual improvement, not to settle for status quo.
- Hunger fuels solutions, not roadblocks.
- Hunger selflessly drives you to succeed, it does not seek power or recognition.
- Hunger opens your eyes to windows of opportunity.

Understanding these concepts is a life lesson that will come back to you repeatedly, both in good and bad ways. Knowing when to be hungry and how not to be thirsty is a short litmus test to consider when you are pursuing something you really want. You can look inward to decide how to persue that dream and know why you are chasing it. Occasionally you may find yourself feeling thirsty and wonder what is going to happen next in your career, or feeling down because you think the workplace no longer cares, but keep your responses in check. And, above all, stay hungry.

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New Insight: Tumor Characteristics and Breast Cancer Racial Disparities

Georgia Cancer Registry[a]: Rana Bayakly, BA, MPH

Summary

Recent studies using the Georgia Cancer Registry data expounded on the breast cancer mortality outcome race disparities in Atlanta. A study published in July 2019, analyzed breast cancer incidence data in Metro Atlanta area concluded that lower stage, hormonally responsive and luminal breast tumors were the primary drivers for disparity among African American women. A follow up study published in September 2019 further examined these characteristics, suggested that tumor heterogeneity, and treatment uptake maybe the drivers of racial disparities among women with hormone receptor positive (HR+) breast cancer diagnosed with stage I-IIIa. These 2 studies provided amenable intervention for cancer control professionals in Georgia.

Challenge

A study entitled "Black:white disparities in breast cancer mortality in the 50 largest cities in the United States, 2005-2014" was published in *Cancer Epidemiology* in July 2016. The study identified the city of Atlanta had the largest and significant difference in black/white breast cancer mortality disparities and that the disparity increased from 2005–2009 to 2010–2014. These findings generated many questions from cancer control professionals and stakeholders in the state of Georgia. Stakeholders and professional organizations such as Susan G. Komen Foundation, American Cancer Society, met several times with the Georgia Department of Public Health (DPH), Breast and Cervical Cancer Screening Program (BCCP) to further identify solutions and to partner with providers in the city of Atlanta to improve on mammography screenings for women of low socioeconomic status and women who were uninsured and underinsured.

DPH BCCP, Cancer Registry and the Behavioral Risk Factor Surveillance (BRFSS) epidemiologists provided data on breast cancer incidence, mortality, mammography screening and BCCP participants by racial distribution to various stakeholders.

Data from 2010–2014, showed that both Fulton and Dekalb counties, where the city of Atlanta is located, breast cancer incidence was higher for non-Hispanic white (NHW) women (Fulton=141.8/100,000; Dekalb=142.8/100,000) than NH black (NHB) women (Fulton=132.4/100,000; Dekalb=134.3/100,000), while breast cancer mortality was higher for NHB women (Fulton=36.1/100,000; Dekalb=30/100,000) than NHW women (Fulton=17.7/100,000; DeKalb=19.5/100,000). Mammography screening based on the 2014 GA-BRFSS for women 40 years and older in both Fulton (NHW=86%; NHB=84.5%) and DeKalb counties (NHW=85.6%; NHB=82.2%) were both higher than the state prevalence, as well as screening by race/ethnicity was similar for both NHW and NHB women. BCCP analysis showed that there were a higher proportion of NHB, and Hispanic women being screened through the program and were adherent to the United States Preventive Services Task Force (USPSTF) recommendations.

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Solution

DPH shared data with stakeholders: the American Cancer Society, Susan G. Komen Foundation, the Avon Comprehensive Breast Center at Grady, Emory Winship Cancer Institute, WellStar, Northside and Piedmont hospitals, Sisters by Choice, DeKalb and Fulton Public Health Districts and the Good Samaritan Health Center as well as faith-based communities. In addition, DPH/BCCP described their program, reach, outcomes and funding limitations in number of screening to be offered from both state and federal resources. As a result, the Greater-Atlanta Breast Cancer Task Force was established with a mission to bring awareness to the public that breast cancer disparity exists in Atlanta and to eliminate this disparity by bringing together a collaborative group to provide education, decrease barriers to access to care, provide access to quality mammography services and to establish effective navigation programs. Partners agreed to coordinate their efforts, share resources and improve referral practices and communication among them. Furthermore, Dr. McCullough from the Rollins School of Public Health received funding from Avon Foundation, the Cancer Prevention and Control Research program and the Winship Research Informatics, supported by the Winship Cancer Institute of Emory University, to conduct research on the possible causes of breast cancer disparities in Metropolitan Atlanta.

Dr. McCullough approached the Georgia Cancer Registry, to conduct her studies, Dr. McCullough received IRB approval from both the Georgia Department of Public

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Health and Emory University, Rollins School of Public Health. Both Dr. McCullough and the Georgia Cancer Registry Director agreed on using the federal definition for the city of Atlanta, during the analytic phase Dr. Kevin Ward was involved in providing technical guidance on the Georgia Cancer Registry data collection process. As a result, 2 studies were published in 2019 providing additional guidance on how to address breast cancer mortality disparities outcome. Various meetings are scheduled as a result of these recent publication to better address disparities by the Georgia Department of Public Health, Georgia Cancer Control Leadership team, Georgia Cancer Control Consortium and the Georgia Regional Cancer Coalitions.

Results

Results from the study entitled "Racial Disparities in Breast Cancer Outcomes in the Metropolitan Atlanta Area: New Insights and Approaches for Health Equity" showed that NHB women were more likely to be diagnosed at a younger age; with higher stage at the time of diagnosis (stage IV 9.4% vs 4.8%); higher grade (grade 3+); node positive; and triple-negative tumors than NHW women. NHB women are more likely to live in high-poverty neighborhood at the time of diagnosis. There was a consistent disparity in BC deaths between NHB women and NHW women, NHB women with ER+ disease had 2.49 times higher risk of dying of BC than NHW women. Within the strata of BC molecular subtype there was a consistent disparity indicating a more than twofold hazard of BC mortality among NHB patients diagnosed with luminal A Luminal B or HER2-overexpressing tumors. The smallest relative disparity was among women diagnosed with triple-negative BC (TNBC). NHB women living in the highest SES index had 2.67 times the hazard dying of BC when compared to their NHW counterparts while NHB women living in lowest SES index with no health insurance had less pronounced disparities (HR=1.56). The study concluded that effectively treating women with ER+ tumors substantially impacts race disparities in Metro-Atlanta area. This study also revealed that further understanding of the receipt of guideline-concordant, delay, and completion of BC treatment among NHB women and the biologic factors that may affect response to treatment and prognosis can help improve patient outcome.

While the second study entitled "Oncotype DX recurrence score implication for disparities in chemotherapy and breast cancer mortality in Georgia" focused on the Georgia women diagnosed with stage I-III. Study showed that NHB women were more likely to be diagnosed with high-risk recurrence score than NHW women, NHB women were more likely to receive chemotherapy if they had low-risk recurrence score but less likely to receive chemotherapy if they had high-risk recurrence score. Analysis showed that race disparity was most pronounced among the lowest-risk recurrence score group which constitute most of the breast carcinomas eligible for Oncotype DX recurrence testing. Based on Oncotype recommendations, women with low-risk recurrence score should not receive chemotherapy; the recommendation is to receive endocrine therapy. Therefore, the observed racial disparity in this subgroup may be driven by adherence to endocrine therapy, especially over the long term. Previous studies have reported that NHB women are more likely to report nonadherence and discontinuation of endocrine therapy compared to NHW women. Early discontinuation and nonadherence to adjuvant endocrine therapy were associated with adverse breast cancer outcomes. Thus, the authors concluded that further research into understanding the downstream factors such as receipt of guideline care, adherence to endocrine therapy, and treatment delay as important drivers of the disparity in these otherwise prognostic favorable tumors.

Sustaining Success

The director of the Georgia Cancer Registry shared 2 studies with the DPH cancer control leadership team (Comprehensive Cancer Control program and the BCCP program), as well as the 2 copresidents of the Georgia Cancer Control Consortium (GC3), the executive leadership of the Georgia Cancer Strategic Planning Committee and the co-chairs of the Diagnostic and Treatment subcommittee of the GC3. As a result, Dr. McCullough—primary author of these studies—was invited to present her findings and recommendations to the GC3 Steering Committee later this year. DPH cancer control leadership team discussed these articles and will further consult with the BCCP health care providers on how on implementing these findings within their practices.

Addressing the Burden of Colorectal Cancer in Mississippi

Mississippi Cancer Registry[a]: Deirdre Rogers, PhD, CTR

Summary

Mississippi has one of the highest incidence rates and the highest mortality rate from colorectal cancer in the United States. Additionally, Mississippi lags behind the nation in colorectal cancer screening. Because the data to show these issues exists, Mississippi was selected as one of six states to implement the National Association of Chronic Disease Directors (NACDD) State Engagement Model (StEM) to build on existing efforts in our state to address the high burden of colorectal cancer. An action plan was developed by stakeholders in Mississippi through these efforts during a meeting held on May 30, 2019.

Challenge

According to *United States Cancer Statistics*, Mississippi had the second highest rate of colorectal cancer incidence in the United States in 2016 and had the highest rate of deaths.[1] Though incidence rates have declined over time, mortality rates have remained relatively constant.[1] According to screening data from *State Cancer Profiles*, Mississippi had the fourth lowest rate among US states of colorectal cancer between the ages of 50 and 75 with 60.47% of Mississippians reporting being screened for colorectal cancer.[3] Also, according to State Cancer Profiles, Mississippi had the highest rate of late stage colorectal cancer diagnoses in adults ages 50 and older among US states in 2016.[4] Data from the Mississippi Cancer Registry cancer-rates.info website show that the rate of late state disease has not seen any decrease over time.[2] Statewide partners came together for an initiative to increase the screening rates for colorectal cancer to 70% by the year 2020 and colorectal cancer is a focus of the Mississippi Partnership for Comprehensive Cancer Control in its statewide cancer plan. However, Mississippi still lags behind the rest of the country in colorectal cancer statistics.

Solution

The Centers for Disease Control and Prevention partnered with the NACDD and Leavitt Partners, a health intelligence firm, to assist 6 states in their efforts to address colorectal cancer. Mississippi was selected based on the data showing the need to address colorectal cancer. Staff from the NACDD began the implementation of the State Engagement Model (StEM) with stakeholders from Mississippi. On May 30, 2019, they led a meeting of colorectal cancer stakeholders to develop a plan to address the need for increased colorectal cancer screening in Mississippi. The planning committee of Mississippi partners consisted of the Directors of the Mississippi Comprehensive Cancer Control Program, the Mississippi Breast and Cervical Early Detection Program, and the Mississippi Cancer Registry, as well as, a representative from the American Cancer Society. The meeting brought together stakeholders from public health, insurance, the state's only academic medical center, research, nonprofits, and medical providers. The goal of the meeting was to inform the stakeholders of the data and what activities have been carried out in the state and to develop an action plan with buy-in from the participants for implementation.

Results

There were 39 stakeholders in attendance at the meeting. The group heard the presentations on data and what had been done to date to address the need. Then, the group broke into 2 groups to create action plans around "Increasing Access to Screening Services" and "Provider Delivery and Screening." To increase access to screening services, the group decided to focus on developing a competitive application for the Centers for Disease Control and Prevention Colorectal Cancer Control Program (CRCCP) funding in 2020. Also, the group plans to engage 2 to 4 health systems and/or health insurance plans to increase screening. Additionally, the group plans to develop a Colorectal Cancer Roundtable in Mississippi to address the burden in the state. This group will lead efforts to engage public and private, self-insured employers to increase colorectal cancer screening in their employees. Before the meeting ended, the stakeholders present had to identify other stakeholders that need to be involved, and they had to write their name or organization's name next to the objectives that they would work on in this plan.

Sustaining Success

NACCD will continue to support the implementation efforts and provide technical assistance to this process throughout the first year. The Mississippi Colorectal Roundtable will be the group to sustain the effort once it is formed. To assist in efforts that are already in place, the planning committee is planning on applying for CRCCP funds when the new funding opportunity announcement is available. The Mississippi Cancer Registry, together with the Mississippi Office of Vital Statistics, will continue to collect the data to monitor the progress towards increasing screening and decreasing incidence and mortality from colorectal cancer in Mississippi.

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Cancer Among World Trade Center (WTC) Responders—A Collaboration of Three Principal Study Centers and the New York State Cancer Registry

New York Cancer Registry[a]: Maria J. Schymura; Amy R. Kahn ; Baozhen Qiao

Summary

In a multi-center, multi-state study to find and analyze associations between WTC exposures and cancer incidence, the New York State Cancer Registry (NYSCR) has the role of "honest broker." This brokerage entails creating a de-duplicated "finder file," coordinating linkages with 12 other central registries, and providing de-identified analytic data as well as epidemiologic and cancer-specific knowledge, to a multicenter study team.

Challenge

As a result of the attacks on the World Trade Center, the Centers for Disease Control and Prevention (CDC)'s National Institute for Occupational Safety and Health (NIOSH) has funded 3 separate major projects in New York City to follow individuals and identify health outcomes among persons who had exposures related to the attacks and their aftermath. The World Trade Center Health Registry, operated under the auspices of the New York City Department of Health and Mental Hygiene (WTCHR), the Fire Department of the City of New York (FDNY), and the General Responder Cohort (GRC) maintained by the General Responder Data Center of the Icahn School of Medicine at Mount Sinai had been identifying preliminary results based on cancer registry linkages and publishing independently for over a decade.

Although their cohorts were based on different personal and exposure characteristics, there was overlap among the 3 that had not been quantified, and that might have affected study outcomes. Although we (the NYSCR) had suggested early on that collaboration and de-duplication would improve the power to detect signals and to inform the results of their respective linkages, there were substantial data definition and institutional hurdles that kept the 3 projects from working together.

Solution

Three years ago, physician-epidemiologists and biostatisticians from the FDNY approached the other 2 study centers and the NYSCR with the concept of working together on a project to better understand cancer incidence rates among WTC responders. The NYSCR would participate as a full collaborator, adding their expertise in cancer epidemiology. The NYSCR would also act in the role of "honest broker," creating data sets that would be used to identify all incident cancers occurring among participants from any of the 3 study cohorts who met a common definition of "responder." In 2016, collaboration of the 4 parties resulted in a proposal that was accepted for funding by NIOSH ("Incidence, Latency, and Survival of Cancer Following World Trade Center Exposure." CDC/NIOSH U01 OH011315 AND U01 OH011932).

It would fall to the NYSCR to: (1) de-duplicate the combined cohort, using the best information available for a "finder file"; (2) coordinate linkages with 12 additional central registries, providing the "finder file" in a format consistent with each state's requirements and following each state's protocol for linkages; (3) standardize and consolidate the results of the linkages; 4) provide de-identified analytic files to the study team; and (5) collaborate in the interpretation of the results.

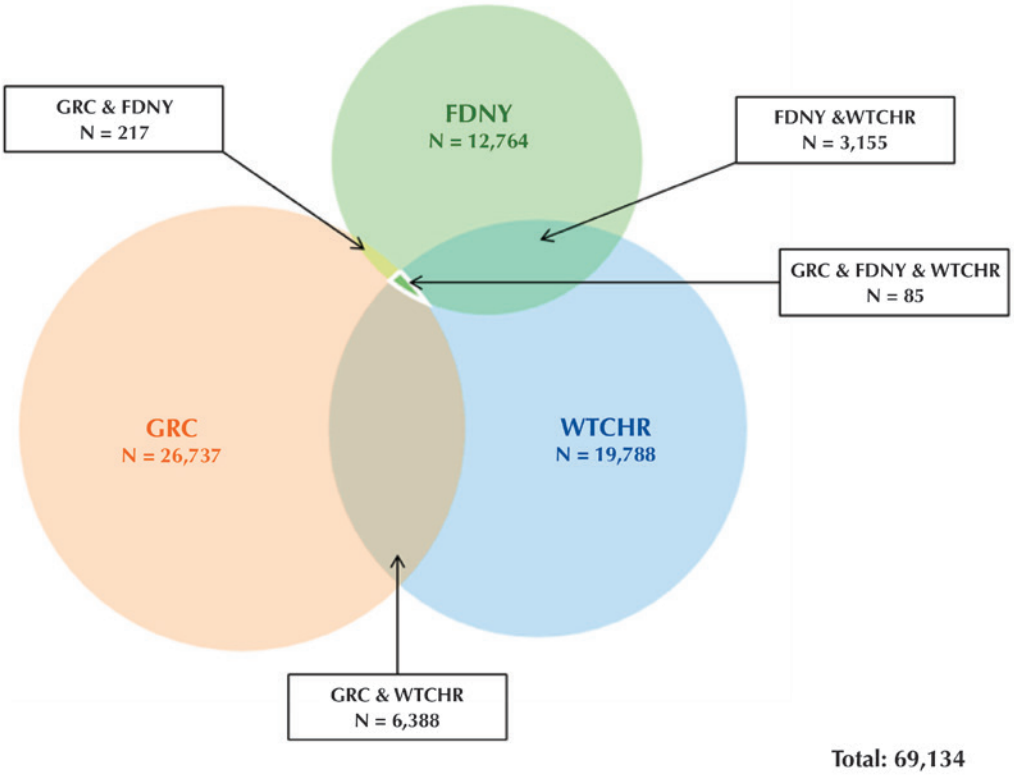
Results

The NYSCR received encrypted files from each of the cohort centers, totaling 79,062 records. We standardized the files and, using NPCR's LinkPlus software, we matched each standardized file to the other 2, identifying members of one-and-only-one cohort as well as identifying the overlapping cohort members. For each of the latter, we created a consolidated record, using the most complete information available (eg, known versus unknown social security numbers, and adding multiple addresses and phone numbers). The result was a finder file containing 69,143 records, 1 record for each member of any of the 3 cohorts (Figure 1). For each unique member, we assigned a study ID and a flag indicating the underlying cohort membership.

The 4 main collaborating groups held both in-person and conference call meetings to ensure that all parties agreed on definitions and methods. The 3 cohort centers arrived at a common set of exposure variables, and each was responsible for recoding their original data items to the agreed-upon codes and definitions. Because survival is one of the outcomes of interest, and each center independently identifies deaths through linkages to the National Death Index, it was important that decisions be based on common criteria. The NYSCR provided instruction to staff of all 3 centers on the use of the SAS algorithm, developed by NPCR participants, for maximizing the validity of NDI-identified matches.

[a] Address correspondence to Maria J. Schymura. Telephone: (518) 474-2255. Website: **https://www.health.ny.gov/statistics/diseases/cancer/**.

Figure 1.



The NYSCR provided frequencies of the residence states of the combined cohort members, and these numbers were used to identify the states to prioritize for cancer registry linkage. The FDNY study staff coordinated obtaining IRB approvals and data use agreements for each of 13 state cancer registries, a process that took between a few months and over 2 years, depending on the state. Once the approvals were in place, the NYSCR obtained file specifications from each of the other state cancer registries and sent each state an encrypted "finder file" based on these specifications. As of mid-September 2019, all match results from the 12 other central cancer registries have been received by the NYSCR.

Sustaining Success

As of early October 2019, preliminary data analyses are ongoing and at least 3 separate research questions have thus far been identified. The synergy resulting from this broad-based collaboration has been appreciated by all 3 cohort centers. Because the responders to 9/11 were predominantly young men, this consolidated cohort will be followed for many years. The NYSCR will continue to help track and analyze the cancer incidence and survival of the responders, using our unique perspective as the population-based cancer registry that includes the epicenter of the attacks on the World Trade Center.

Documentation of Wilms Tumor Histologic Presentation in a Statewide Cancer Registry: Importance to Prognostic Assessment

Tennessee Cancer Registry[a]: Martin Whiteside, DC, PhD, MSPH

Summary

Wilms tumor is the most common childhood kidney cancer in those that are less than 15 years of age and the fourth most common pediatric cancer overall. As a result, Wilms tumor is a major contributor to childhood morbidity in the United States, but thankfully, the overall 5-year survival rate for Wilms tumor patients is about 92%. Patient prognosis is profoundly affected by the histological presentation of the tumor, i.e. whether "favorable" or "unfavorable" histology. If the patient is reported to present without anaplasia or has focal anaplasia, this is designated as "favorable histology"; however, the presence of diffuse anaplasia is synonymous with "unfavorable histology". Histologic presentation is also an important tumor characteristic that drives the treatment decision-making process. As such, this information is critically important to capture during abstraction of patient medical records before submission to central cancer registries due to its importance in patient treatment and prognosis. Since no coded data items exist—including site-specific data items—that capture histologic presentation in the standard tumor abstract, this information could be provided in the tumor abstract text. However, this vital information is not provided in most abstracts submitted to the Tennessee (TN) Cancer Registry (TCR).

Challenge

All Wilms tumor cases, 130 total, within the TCR main cancer database diagnosed during the years 2004–2015 underwent quality control analysis. Dr. Whiteside, TCR Program Director, had to perform this analysis given the unavailability of cancer registrar staff that was dedicated to completing mandatory cancer registry operations. Firstly, all 130 cases were successfully evaluated by comparing the submitted histology code with the submitted text in the abstract. One incorrectly coded case was identified that should have been coded as a renal cell carcinoma and was excluded from the analysis.

Secondly, after reviewing the text fields for any mention of favorable/unfavorable histologic presentation, pathology reports were obtained from the reporting facilities to determine if histologic presentation was provided. This took significant time and effort and Dr. Whiteside had to perform this step, given that cancer registrar staff was not available to assist. Additional complexity associated with the acquisition of pathology reports involved ensuring that the pathology report principally associated with curative-intent surgery was obtained rather than ancillary reports prepared either before or after curative-intent surgery.

Thirdly, analysis revealed that some hospital-based cancer registrars may not include a detailed description of histologic presentation in the appropriate text field of the abstract. Thus, an additional challenge involves educating cancer registrars statewide about the importance of including enough text to document histologic presentation of Wilms tumor cases.

Solution

This project was made possible with the input of internal and external TCR stakeholders. TCR's program manager consulted with Dr. Whiteside on evaluating text fields in a standard cancer abstract. This included reviewing text fields for documentation of histology of the tumor and ancillary information about tumor histology, such as whether favorable or unfavorable histology was noted during examination of Wilms tumor surgical pathology specimens.

Indirectly, the American Cancer Society (ACS) provided significant assistance directing the completion of this quality assurance study. The ACS has webpages dedicated to presenting layperson-level information about Wilms tumor, including information about early detection, staging, potential provider questions, etc. One specific webpage entitled, "Survival Rates for Wilms Tumors" contains a table that details survival rates by stage at diagnosis stratified by histologic presentation; this table provided an understanding of the significance of histologic presentation to patient prognosis.

This study would not have been possible without the dedicated support and consultation received from staff members at the Vanderbilt University Medical Center (VUMC). Specifically, a pediatric general and thoracic surgeon—Dr. Harold N. Lovvorn, III—at VUMC provided significant assistance with study design. He provided the initial understanding of the relationship of tumor anaplasia to patient outcomes and how anaplasia related to the concept of favorable and unfavorable histologic presentation. Dr. Lovvorn has collaborated with TCR staff for many years performing research dedicated to a better understanding of childhood cancer, in particular childhood kidney cancers.

Lastly, the TN Tumor Oncology Data Analyst Association (TODAA), the main association in the state

[a] Telephone: (800) 547-3558. Website: **https://www.tn.gov/health/health-program-areas/tcr.html**.

supporting cancer registrars statewide, disseminated the results of this study. Leaders of TODAA learned that TCR staff were conducting this Wilms tumor quality assurance study and invited Dr. Whiteside to present the results at the annual TODAA educational conference on October 18, 2019. Most of the attendees at the TODAA conference are Certified Tumor Registrars that work for Commission-on-Cancer (CoC)- accredited hospitals, of which there are currently 30 CoC-accredited facilities in TN.

Results

There were a total of 130 Wilms tumor cases extracted from the TCR main cancer database (CRSPlus), of which 1 case was incorrectly coded, as previously mentioned, thus leaving 129 cases for evaluation. All cases evaluated were TN residents at the time of diagnosis. The sex, age, diagnosis stage and race distribution among the cases were as follows. There were 50 males (38.8% of cases) and 79 females (61.2% of cases), which is consistent with other studies that have demonstrated a slight excess in the number of female patients in this population. The median age of patients in this study was 3 years old, which is also consistent with prior published studies that observed the median age at 3.5 years of age. Most of the cases in this study (N = 57, 44.2% of all cases) were diagnosed at the localized stage, also consistent with other studies that have demonstrated approximately 40%–45% of all cases are diagnosed at the localized stage.[1] Black children accounted for 25.6% of all cases in this study. All cases were histologically confirmed at diagnosis.

During the next phase of the study, text documentation of histologic presentation was evaluated. In the state of TN, text is required for all abstracts to document treatment, primary site, histology, and other codes provided in the tumor abstract. Of the 129 cases evaluated, 62 (48.1%) had text documentation of histologic presentation specific to unfavorable/favorable status, whereas 67 cases (51.9%) lacked this documentation, though text may have been provided for other histologic characteristics. Statistics for text documentation of histologic presentation were stratified by facility, specifically for those facilities that diagnosed and/or treated greater than 10 cases during the study period, of which there were 4 facilities. The following percentages of text documentation of histologic presentation were observed for these facilities: 11.8%, 15.8%, 45.5% and 90.2%. Thus, 1 facility submitted 90.2% of Wilms tumor abstracts with text documentation of histologic presentation, whereas all other facilities only submitted a minority of Wilms tumor abstracts containing this vital information. However, when final pathology reports were obtained for all 129 patients, it was observed that all, except for 1, pathology report contained sufficient information to document histologic presentation.

The content provided in facility text submitted with a patient abstract was compared to the pathology report. For those cases containing text documentation of histologic presentation, there was a 100% match between the text submitted documenting histologic presentation and what was available in the pathology report. It's worth noting that not all patients with "unfavorable" histologic presentation had this information documented in the patient abstract text, which is essential given the seriousness of "unfavorable" histologic presentation and the importance of this to the treatment decision-making process. For all cases that had pathologic evidence of "unfavorable" histologic presentation, 66.0% were sufficiently documented in the text of the patient abstract. For all cases with pathologic evidence of "favorable" histologic presentation, 47.5% were sufficiently documented in the text of the patient abstract.

Sustaining Success

The information from this study was presented at the North American Association of Central Cancer Registries' Annual Conference in June 2019. In addition, leaders of the state's tumor registrar's association learned of this study and have invited Dr. Whiteside to speak at the annual educational conference on October 18, 2019. In attendance will be the tumor registrars representing most of the Commission-on-Cancer-accredited facilities in TN. Sustaining success will be to continue to highlight this information at the state's regional tumor registrar's meetings and encourage TCR educational staff to include information on Wilms tumor histologic presentation in phone and/or in-person training sessions with facility staff, when appropriate. Effectiveness of outreach efforts will be measured by noting that future abstracts contain text information documenting histologic presentation in a larger percentage of Wilms tumor patients.

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Multi-State, Population-Based Epidemiologic Study Identifies that Children with Birth Defects Have an Increased Risk of Certain Cancers

Texas Cancer Registry[a]: Keisha L. Musonda, MPH; Paige Miller-Gianturco, PhD, MPH

Summary

Although the causes of most major childhood cancers are unknown, research indicates cancer may be more frequent in children born with certain birth defects.[1-5] To better understand cancer risk among children, a team of researchers at Baylor College of Medicine partnered with multiple state cancer registries, birth defects registries, and vital registration systems to evaluate the associations of birth defects and childhood cancers. This multistate epidemiologic research study included data linkages with cancer incidence data, birth defects data, and birth records in Texas, Arkansas, Michigan, and North Carolina. For this study, the Texas Cancer Registry (TCR) included all records of children diagnosed with cancer at less than 18 years of age in the data linkages. Results showed an elevated risk of certain cancer types in children with chromosomal and nonchromosomal birth defects.

Challenge

Childhood cancers are rare. Of all new cancers diagnosed, less than 1% are among children.[6] There were 10,597 children under 15 years diagnosed with a new cancer in the United States in 2016,[7] and the TCR estimates that 1,242 children will be diagnosed in Texas in 2019. Although the occurrence of cancer in children is rare, it is the second most common cause of death among children.[6] The cause of most childhood cancers is unknown. However, being born with certain birth defects is a known risk factor. Nearly one in every 33 babies are born with birth defects in the United States each year.[8] Like childhood cancer, often the cause of birth defects is unknown.

Studies have shown that individuals born with certain birth defects are at increased risk of developing cancer during childhood or adolescence.[1-5] For example, being born with Down syndrome (trisomy 21) is associated with increased risk of developing leukemia.[3] Associations between childhood cancers and birth defects involving chromosomal abnormalities are better understood than those involving nonchromosomal defects, although the latter affect more children. Due to the rarity of both birth defects and childhood cancers, research on associations between specific birth defects and specific childhood cancers has been limited by insufficient numbers of cases.

Solution

A collaborative team of researchers at Baylor College of Medicine, in partnership with multiple state cancer registries, birth defects registries, and vital registration systems, set out to assess whether children with certain birth defects or those with more than one birth defect are more likely to develop specific childhood cancers. To achieve these aims, the researchers worked with multiple states, including Texas, Arkansas, Michigan, and North Carolina. The research was supported by the Cancer Prevention and Research Institute of Texas, National Cancer Institute, Arkansas Biosciences Institute, and Alex's Lemonade Stand Foundation. After researchers obtained the required approvals, including those from the Texas Department of State Health Services (DSHS) Institutional Review Board and Research Executive Steering Committee, the TCR collaborated with the DSHS Center for Health Statistics and DSHS Birth Defects Epidemiology and Surveillance Branch to link statewide data on cancer, births, and birth defects. Following the data linkages, the TCR provided de-identified linked data to the primary investigators at Baylor. Researchers then pooled the de-identified linked data from Texas with data from the other states. In total, the study examined data from over 10 million children under 18 years of age.

Results

A recent publication in the JAMA Oncology reports on the study's findings.[9] This study is thought to be the largest population-based study to date to examine associations between specific chromosomal and nonchromosomal birth defects and specific childhood cancers. Overall, researchers found an elevated risk of childhood cancer in children with birth defects. That means, children with chromosomal anomalies and nonchromosomal birth defects were more likely to be diagnosed with cancer during their childhood compared to children without birth defects. Compared to children without birth defects, children with chromosomal abnormalities were 11.6 times more likely to be diagnosed with any childhood cancer. Children with nonchromosomal birth defects were 2.5 times more likely to be diagnosed with any childhood cancer compared to those unaffected by birth defects.

[a]Telephone: (512) 776-3080. Website: **http://www.dshs.texas.gov/tcr/home.aspx**.

When evaluated individually rather than as a whole, all chromosomal anomalies and single-gene disorders (trisomy 13, 18, 21 and Turner syndrome; tuberous sclerosis and neurofibromatosis) were associated with an increased risk of cancer. For example, children with Down's Syndrome (trisomy 21) were 14.7 times more likely to be diagnosed with cancer that children without any birth defect, and children with neurofibromatosis were more than 54.0 times more likely.

Researchers also found that as the number of nonchromosomal birth defects increased, so did the risk for cancer before age 18. Children with two birth defects were 3.5 times more likely to be diagnosed with cancer than children without a birth defect. Children with four or more birth defects were even more likely to be diagnosed with childhood cancer; they were 5.9 times more likely to be diagnosed with cancer than those unaffected by birth defects.

In addition, this study evaluated whether there were associations between specific cancer types and specific birth defects. Researchers found strong associations between 40 specific birth defects and specific childhood cancers. Five of the associations were among chromosomal anomalies or single-gene disorders. Some of the strongest associations were between astrocytoma and non-rhabdomyosarcoma soft-tissue sarcoma among children with neurofibromatosis. The remaining 35 associations found in this study were among nonchromosomal birth defects. Strongest associations were found for biliary atresia and non-Hodgkin lymphoma (164.2 times more likely), and spina bifida without anencephaly non-rhabdomyosarcoma soft tissue sarcomas (75.6 times more likely).

Sustaining Success

Cancer registries play a vital role in collecting, maintaining, and disseminating high quality cancer data to support research designed to help reduce the burden of cancer. The TCR will continue to support DSHS IRB-approved epidemiologic cancer research including those involving data linkages among multiple programs like the current study. Through collaboration, the TCR will work with the DSHS Center for Health Statistics and DSHS Birth Defects Epidemiology and Surveillance Branch to develop robust datasets for researchers examining cancer etiology and outcomes. Based on insights achieved, researchers at the Baylor College of Medicine and their partner organizations plan to conduct additional studies on associations between birth defects and childhood cancer. The TCR will support researchers, like the ones responsible for this novel research, by facilitating new data linkages with the most current data available.

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Journal of Registry Management Continuing Education Quiz—SUMMER 2020

IMPROVING DATA VALIDITY AT POPULATION-BASED CANCER REGISTRY THOUGH TRACE-BACK OF DEATH CERTIFICATES: A CONCRETE EXPERIENCE IN ARGENTINA

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

- Describe the difference between DCN and death-certificate-only (DCO) cases in population-based cancer registries (PBCRs).
- Understand the reasoning for trace-back procedures in PBCRs.
- Describe the reasons for unsuccessful trace-back of DCN cases.

1. For PBCRs, what is the correct expansion of the acronym *DCN*?
   a) Death from cancer notice
   b) Determination of cancer notification
   c) Date of cancer notification
   d) Death certificate notification

2. Which cancer types were included in this trace-back study?
   a) Stomach, liver, and lung
   b) Lung, brain, and stomach
   c) Stomach, lung, and breas
   d) Lung, liver, and bone

3. Which of the following best describes the reduction of death-certificate-only (DCO) cases among the 3 cancers studied?
   a) From 32.1% to 23.8%
   b) From 23.8% to 19.9%
   c) From 70.3% to 23.8%
   d) From 32.1% to 19.9%

4. What is the reasoning given in the paper for DCO cases usually being excluded from comparative survival studies?
   a) They are excluded due to the inability to confirm the correct site of cancer diagnosis.
   b) They are excluded due to zero survival time, causing biased estimation of cancer survival.
   c) They are excluded due to the delay between the death cancer notification and inclusion in the registry.
   d) They are not excluded.

5. What is the reason(s) given for the greatest percentage (56%) of failure to trace-back DCN cases?
   a) Deaths at an institution where the medical records could not be located
   b) Deaths at home and the certifying doctor could not be identified or reached
   c) Deaths at home and the certifying doctor did not have record or memory of the patient
   d) Deaths at a hospice institution and the certifying doctor could not be identified or reached

6. What explanation was suggested for the relatively high percentage of DCN and DCO cancers in this study?
   a) DCN and DCO cases are much higher among older patients of lower socioeconomic status.
   b) DCN and DCO cases are much higher among poor-prognosis cancer regardless of age.
   c) DCN and DCO cases are much higher among higher-stage group cancers.
   d) DCN and DCO cases are much higher among older age groups and poor-prognosis cancers.

7. What was the major difference in unsuccessful trace-back and successful trace-back (Table 3)?
   a) Type of cancer
   b) Age group
   c) Sex
   d) There were no major differences.

8. Which cancer type reviewed in this study showed the greatest improvement from DCN to DCO cases (Table 4)?
   a) Liver
   b) Lung
   c) Stomach
   d) Brain

9. Based on this study, what was the success rate of tracing patients of the 3 poor-prognosis cancer cases notified through death certificate?
   a) 70%
   b) 23%
   c) 32%
   d) 19%

10. What are the recommendations that lead to a lower number of DCO and DCN cases for the Mendoza PBCR?
    a) A regular trace-back procedure, reinforcing training and awareness of the medical professional when completing the death certificate, and improvements in the electronic medical record.
    b) Increased Mendoza PBCR staff education on trace-back procedures, reinforcing training and awareness for medical professionals on completing the death certificate and improvements in the electronic medical record
    c) A regular trace-back procedure, increased Mendoza PBCR staff education, and concentration on poor-prognosis cancers
    d) A regular trace-back procedure, reinforcing training and awareness of the medical professional when completing the death certificate, and contact with patient family members

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National Cancer Registrars Association
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Danette A. Clark, BS, RMA, AAS, CTR | EDITOR-IN-CHIEF, *JRM*

The *Journal of Registry Management*, official journal of the National Cancer Registrars Association (NCRA), announces a call for original manuscripts on registry methodology or research findings related to the 7 subjects listed below and related topics.

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Address all manuscripts to: Danette Clark, BS, RMA, AAS, CTR, Editor-in-Chief, *Journal of Registry Management,* (973) 971-5189, JRMEditor@ncra-usa.org.

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Manuscripts may be submitted for publication in the following categories: **Articles** addressing topics of broad interest and appeal to the readership, including **Methodology papers** about registry organization and operation; **Research papers** reporting findings of original, reviewed, data-based research; **Primers** providing tutorials on relevant subjects; and **"How I Do It"** papers are also solicited. **Opinion papers/editorials** including position papers, commentaries, and essays that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management; **Letters to the Editor**; and specifically-targeted **Bibliographies** of significant interest are invited.

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Manuscripts. The terms manuscripts, articles, and papers are used synonymously herein. Email only submission of manuscripts is encouraged. If not feasible, submit the original manuscript and 4 copies to the Editor. Manuscripts should be double-spaced on white 8-1/2" x 11" paper, with margins of at least 1 inch. Use only letter-quality printers; poor quality copies will not be considered. Number the manuscript pages consecutively with the (first) title page as page one, followed by the abstract, text, references, and visuals. The accompanying cover letter should include the name, mailing address, email address, and telephone number of the corresponding author. For electronic submission, files should be IBM-compatible format in Corel WordPerfect™, Microsoft® Word for Windows®, or converted to ASCII code.

Manuscripts (Research Articles). Articles should follow the standard format for research reporting (Introduction, Methods, Results, Discussion, References), and the submission instructions outlined above. The introduction will normally include background information, and a rationale/justification as to why the subject matter is of interest. The discussion often includes a conclusion subsection. Comprehensive references are encouraged, as are an appropriate combination of tables and figures (graphs).

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