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

Letters from the Editors

Dear Colleagues,

This is a special edition of the *Journal of Registry Management (JRM)*, created in partnership with the North American Association of Central Cancer Registries (NAACCR). Our special guest editor, Recinda Sherman, PhD, CTR, has worked in cancer surveillance for over 20 years, and her role at NAACCR is to support the use of central cancer registry data, including the NAACCR Cancer in North America (CiNA) data sets. I sincerely hope you enjoy this special issue.

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

Dear Readers,

On behalf of the NAACCR Annual Conference Committee and NAACCR's Research and Data Use Steering Committee, I am delighted to present the inaugural NAACCR Annual Conference Special Edition of the *JRM*. I appreciated the guidance of the *JRM* editors as we worked to assemble this special edition. And I am particularly grateful to *JRM* for this collaboration, in the year 2020. This issue provided opportunities for NAACCR researchers to feature their cancer surveillance research in a year when so many personal and professional opportunities have been canceled.

I am pleased to present this special issue, which includes 9 original articles. The authors participated in the call for abstracts for the NAACCR Annual Conference and, after initial peer review, submissions accepted as oral presentations had the opportunity to submit their research in written form for consideration for inclusion in this special edition. The papers selected underwent a second peer review process by members of the NAACCR Research and Data Use Steering Committee. Accepted papers include a Canadian paper on survival by socioeconomic status and a Caribbean "How I Do It" paper on the status of population-based cancer registries in the Caribbean basin. The remaining papers are US-centric, and include 3 registry operations topics, including the utility of oncology practice claims in lieu of physician reporting, the impact of expanding pathology reporting, and remote facility audits by central registries. In addition, 4 research and data use topics are featured, including cancer incidence among Asian subtypes in Massachusetts, pediatric brain and central nervous system tumors in Kentucky, patterns of treatment and lymphoma survival, and cancer among the oldest old (which is the subject of the continuing education quiz).

This issue also presents the winning posters from the NAACCR's 2020 Virtual Conference poster session. Poster authors participated in the call for abstracts for the NAACCR Annual Conference and, after initial peer review, authors of submissions accepted as a poster had the opportunity to include their posters in an online session held in lieu of the in-person conference. All judging was conducted online, and the 5 posters that were selected for awards are featured in this issue. The 2 winning posters from the *Data Collection and Operations* category include the first-place poster about tools used to process incidence data in a NAACCR XML format. The second-place poster is this category is a presentation on a National Program of Cancer Registries data monitoring system. These posters are followed by the 3 winning posters from the *Data Use and Epidemiology* category. The first-place poster in this category is on risk factors for subsequent breast cancers among New York cancer survivors. The second-place poster is on non-Hodgkin lymphoma late effects by HIV status in adolescents and young adults, and the third-place poster, a submission from Germany, is on polygenic risk scores to determine screening intervals after negative colonoscopy.

It has been a privilege to coordinate with the *JRM* editors on the publication of a wide variety of central cancer registry–themed articles. Please note that the findings and conclusions in this report are those of the authors and do not necessarily represent the views of the NAACCR or the *JRM*.

Be well,
Recinda Sherman, PhD, CTR
Program Manager, Data Use & Research, NAACCR

Original Article

Comprehensive Cancer Survival by Neighborhood-Level Income in Ontario, Canada, 2006–2011

Ying Wang, MSc[a]; Naomi Schwartz, MPH[a]; Stephanie Young, MPH[a]; Julie Klein-Geltink, MHSc[a]; Rebecca Truscott, MHSc[a]

Abstract: Background: Cancer survival statistics can provide a means to assess the effectiveness of the cancer care system, including early detection strategies, the quality of clinical care, and disease management. Disparities in cancer survival (for instance, by neighborhood-level income) persist in Ontario, Canada despite the existence of a universal health care system. Lower income has been associated with an increased incidence of cancer and worsened survival. Purpose: This project aims to analyze and report on relative survival to provide a mechanism for understanding the level of equity within Ontario's cancer care system. Methods: Age-standardized relative survival ratios (ARSRs) by cancer type and age group were estimated for 229,934 Ontario adults aged 15–99 years diagnosed between 2006 and 2011 with 1 of 9 cancer types (stomach, colorectal, liver, lung, breast, cervical, ovarian, prostate, and leukemia) using a complete survival analysis. Using the Pohar-Perme estimator, the 1-, 3- and 5-year ARSRs with 95% confidence intervals were calculated by patients' neighborhood-level income quintile. Estimates were age-standardized using the International Cancer Survival Standard weights. Results: Fifty-four relative survival trend curves were developed covering 9 cancers by neighborhood-level income for Ontarians in 5 different age groups and all age groups combined. Disparities in cancer survival were observed between income groups and across age groups and different cancer types in Ontario. For most cancer types and age groups, survival was higher in higher income groups, but this trend was not consistently observed in adolescents and young adults aged 15–44 years. Conclusions: Disparities in cancer survival persist in Ontario across income groups. Relative survival was significantly higher for higher (Q4 or Q5) compared to lower (Q1 or Q2) neighborhood-level income populations for most cancer types and age groups. Adolescents and young adults with cancer are a small and unique group of patients in terms of the biology of their cancers and their cancer journey, thereby making the patterns of survival disparities observed in this age group more complicated to interpret. Further examination of factors contributing to these disparities is crucial to eliminate survival disparities, reduce premature deaths, and improve cancer survival in Ontario.

Key words: *income, net survival, socioeconomic status, survival disparities*

Introduction

Cancer survival statistics can provide a means to assess the effectiveness of the cancer care system, especially early detection strategies, and the quality of clinical care and disease management.[1] Cancer survival may also be used to make jurisdictional or temporal comparisons. Some studies have shown that that Canadians in lower socioeconomic status (SES) groups have an advantage in cancer survival compared to their American neighbors.[2-4] For example, one study suggested that there was no association between SES and survival for 12 of the 15 most common cancers in Toronto, Ontario between 1986–1990.[5] However, other studies have shown that disparities in cancer survival persist in Canada despite the existence of a universal health care system.[6-8] Lower income has been observed to be associated with increased incidence of cancer and worsened survival.[5,6] A large body of evidence shows that SES is an important predictor of health.[8-10]

SES is defined as the position of an individual on a social-economic scale that measures factors such as educational attainment, occupation, income, place of residence, wealth, and deprivation. It can be assessed at the individual or household level.[11] Cancer survival disparities between income groups may be influenced by different factors such as a patient's age, cancer type, access to the health system, access to or participation in screening, the disease stage at diagnosis, and the quality of treatment.[6] Differences in these factors across SES may affect survival outcomes for different income groups in Ontario, which suggests that further examination of these differences is warranted.[2,12,13]

The CONCORD-2 study is a global comparison of cancer survival led by the London School of Hygiene and Tropical Medicine. It is a worldwide population-based analysis that estimates net survival trends for 10 common cancers in 279 cancer registry populations in 67 countries around the world.[14-17] The present project aims to leverage the work that was done by the CONCORD-2 project, in

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This study was conducted with the support of Ontario Health (Cancer Care Ontario) through funding provided by the Ontario Ministry of Health and Long-Term Care. The opinions, results, view, and conclusions reported in this publication are those of the authors and do not necessarily reflect those of Ontario Health (Cancer Care Ontario). No endorsement by Ontario Health (Cancer Care Ontario) is intended or should be inferred.

which Ontario participated, in order to provide a more recent picture of differences in relative cancer survival in Ontario, by income.

In this study, population-based cancer survival was examined to calculate Ontarians' age-standardized relative survival ratios (ARSRs) by their neighborhood-level income quintile. The goal was to identify any income-related disparities in Ontario to help inform targeted strategies for populations at risk of poorer outcomes.

Methods

Study Cohort and Exclusion Criteria

The study cohort consisted of 229,934 incident cases (aged 15 to 99 years) of lung, colorectal, stomach, liver, breast, cervical, ovarian, or prostate cancer or leukemia diagnosed in Ontario between January 1, 2006 and December 31, 2011. These 9 cancer types were selected to align with the cancers included in the CONCORD-2 project; we excluded cases of acute lymphoblastic leukemia in children because this analysis was restricted to individuals aged 15 to 99 years. The cases were extracted from the Ontario Cancer Registry (OCR) and were followed up until December 31, 2011. During the follow-up period, 116,278 (50.6%) of the patients died. Relative survival ratios by income quintile were calculated for each cancer patient using age, sex, and income-specific Ontario life tables for the same time period as the years of diagnosis (2006–2011). Relative survival ratios by cancer type and age group were reported by years since diagnosis (1, 3, and 5 years).

Cancer types (Table 1) were defined using the third edition of the *International Classification of Disease for Oncology (ICD-O-3)* disease classification codes from the Surveillance, Epidemiology, and End Results Program (SEER) site recode.[18] All cases were identified using the OCR. The OCR is a computerized database containing information on all Ontario residents who have been diagnosed with invasive neoplasia (except basal cell and squamous cell skin cancers) since 1964. Several exclusion criteria were applied, and cases were excluded if they were death certificate only or autopsy only cases; had missing date of birth, date of death, or diagnosis date; or had an unknown sex or vital status information. Cases lost to follow up were assumed to be alive and all people with a qualifying cancer were included in the analyses, irrespective of whether it was their first, second, or a higher-order cancer (if a person had been diagnosed with multiple cancers). The cohort sample was restricted to individuals with cancer who had a valid postal code at the time of the cancer diagnosis. Among the 236,682 people in Ontario who were diagnosed with 1 of the 9 cancers, 229,934 (97.1%) patients had a known postal code and were included in further statistical analysis (Table 2).

Classification of Socioeconomic Status

As a proxy for patients' SES in this study, average household income quintiles at the neighborhood-level were derived from the patients' postal codes at diagnosis. Sociodemographic variables are not collected in the OCR; therefore, incident cases were linked by postal code to Canadian Census data in order to obtain neighborhood-level income data. The Postal Code Conversion File Plus (PCCF+) provides a linkage between the Canada Post Corporation 6-character postal code and Statistics Canada's standard geographic areas for which census data and other statistics such as the neighborhood-level income are produced.[19,20] PCCF+ version 6C was used to link information about the income of the patients' community of residence to the OCR patient cohort.[21] In the PCCF+, income quintiles are calculated by ranking all dissemination areas (DA), the smallest standard geographic area for which all census data are published, within each larger area (eg, census metropolitan

Table 1. Cancer Type Definition by ICD-O-3 Site Code

Cancer Site	*ICD-O-3 Site*	*ICD-O-3 Histology (Type)*	*Sex*
Stomach	C160-C169	All excluding 9050–9055, 9140, 9590–9992	Both
Colorectal	C180, C181, C182, C183, C184, C185, C186, C187, C188-C189, C260, C209	All excluding 9050–9055, 9140, 9590–9992	Both
Liver	C220, C221	All excluding 9050–9055, 9140, 9590–9992	Both
Lung	C340-C349	All excluding 9050–9055, 9140, 9590–9992	Both
Leukemia	C42.0, C42.1, C42.4	With histologies: 9733, 9742, 9800, 9801, 9870, 9805–9809, 9811–9818, 9823, 9826, 9827, 9837, 9835–9836, 9832–9834, 9940, 9840, 9861, 9820, 9865–9867, 9871–9874, 9895–9897, 9898, 9869, 9910–9911, 9920, 9891, 9860, 9863, 9875–9876, 9945–9946, 9930, 9931, 9831, 9948, 9963–9964	Both
Breast	C500–C509	All excluding 9050–9055, 9140, 9590–9992	Female
Cervix	C530–C539	All excluding 9050–9055, 9140, 9590–9992	Female
Ovary	C569	All excluding 9050–9055, 9140, 9590–9992	Female
Prostate	C619	All excluding 9050–9055, 9140, 9590–9992	Male

ICD-O-3, International Classification of Disease for Oncology, 3rd edition (2000). ICD-O-3 site/histology codes were based on the Surveillance, Epidemiology, and End Results (SEER) site recode definition (http://seer.cancer.gov/siterecode/). Cancer types in this manuscript are listed by the ICD-O-3 site code numerical order.

Table 2. Sample Size by Cancer Types and Age Groups							
Cancer Site	*Original Sample Size*	*After Quality Assurance (%)*	*Age 15–44 y (%)*	*Age 45–54 y (%)*	*Age 55–64 y (%)*	*Age 65–74 y (%)*	*Age 75–99 y (%)*
Stomach	7,314	7,131	365	792	1,362	1,821	2,791
		97.5%	5.1%	11.1%	19.1%	25.5%	39.1%
Colorectal	46,447	44,954	1,781	4,762	9,212	12,199	17,000
		96.8%	4.0%	10.6%	20.5%	27.1%	37.8%
Liver	4,997	4,787	168	694	1,264	1,227	1,434
		95.8%	3.5%	14.5%	26.4%	25.6%	30.0%
Lung	48,979	47,098	712	3,928	10,170	15,435	16,853
		96.2%	1.5%	8.3%	21.6%	32.8%	35.8%
Leukemia	11,332	10,822	1,092	1,221	2,059	2,649	3,801
		95.5%	10.1%	11.3%	19.0%	24.5%	35.1%
Breast	50,402	49,511	5,733	11,229	12,458	10,388	9,703
		98.2%	11.6%	22.7%	25.2%	21.0%	19.6%
Cervix	3,461	3,381	1,427	755	570	340	289
		97.7%	42.2%	22.3%	16.9%	10.1%	8.5%
Ovary	6,572	6,386	796	1,250	1,430	1,385	1,525
		97.2%	12.5%	19.6%	22.4%	21.7%	23.9%
Prostate	57,178	55,864	214	4,658	17,202	20,707	13,083
		97.7%	0.4%	8.3%	30.8%	37.1%	23.4%
Overall	236,682	229,934	12,288	29,289	55,727	66,151	66,479
		97.1%	5.3%	12.7%	24.2%	28.8%	28.9%

area)—by the average household-size adjusted measure of household income and then dividing the DAs into approximate fifths.[19-21] By linking the patients' 6-character postal codes with the standard census geographic areas and neighborhood income quintiles, the entire population cohort was categorized into 5 income quintiles (Q1 to Q5) based on their community median household income: Q1 represents the lowest income communities and Q5 represents the highest income communities.

Statistical Analyses

Net survival is a commonly used survival indicator for population-based cancer registry data and is useful for making international or temporal comparisons.[22] It is defined as the probability of surviving cancer after controlling for mortality from other causes of death. The relative survival ratio (RSR) is the ratio of the observed survival in the patient group to the expected survival of a comparable group from the general population and is a good approximation of net survival.[23,24] Cancer patient data used to calculate the observed survival are available in the OCR. Annual life tables by age, sex, and income quintile for 2006–2011 (developed by the Cancer Survival Group at the London School of Hygiene and Tropical Medicine and provided by the Canadian Partnership Against Cancer for the CONCORD-2 project) were used to calculate the background mortality rate of the general population in Ontario.[16,17]

We applied the Pohar-Perme estimator to perform the analyses, using the statistical analytic software, SAS 9.4, to calculate the ARSR with the corresponding 95% confidence intervals. The Pohar-Perme estimator takes an unbiased account of the fact that older patients are more likely than younger patients to die from causes other than cancer—ie, that the competing risks of death are higher for elderly cancer patients.[25] This method was embedded into a SAS macro program originally written by Dr. Paul Dickman of the Karolinska Institute, Stockholm, Sweden, the detailed methodology for which is described by Cronin and Feuer.[23,26] The International Cancer Survival Standard (ICSS) weights were applied (rather than Canadian Cancer Case Standard weights) so that the ARSR comparisons would be more comparable between countries and different cancer sites.

The ARSR was stratified by 5 different age groups (15–44 years, 45–54 years, 55–64 years, 65–74 years, and 75–99 years). The sample size for the 5 different age groups and for all ages combined (15–99 years) are reported in Table 2.

Relative survival disparity (Q5-Q1) is defined as the difference of the ARSR between the highest income quintile (Q5) and lowest quintile (Q1) at the same time point after the diagnosis. The value of the survival difference (Q5-Q1) of the ARSR could indicate the direction of the disparity: the higher the absolute value, the bigger the disparity; the lower the value, the smaller the disparity. A negative value means the lower income group has better survival.

Table 3. One-Year Age-Standardized Relative Survival Ratios (ARSRs) by Neighborhood-Level Income Quintile for Different Age Groups in Ontario, 2006–-2011**

Cancer sites	*Age*	*All (15-99)*		*15-44*		*45-54*		*55-64*		*65-74*		*75-99*	
	SES	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**
Stomach													
	All	53.0	52.5 - 53.4	62.6	60.5 - 64.6	63.2	61.8 - 64.5	58.6	57.5 - 59.7	53.4	52.4 - 54.3	41.5	40.7 - 42.3
	Q1	48.4	47.1 - 49.7	54.0	47.9 - 59.6	61.9	58.3 - 65.3	56.2	53.3 - 59.0	46.3	43.9 - 48.8	37.3	35.1 - 39.4
	Q2	53.0	51.7 - 54.3	70.6	64.6 - 75.8	63.9	60.1 - 67.6	54.5	51.7 - 57.2	54.0	51.6 - 56.3	42.0	39.9 - 44.1
	Q3	53.8	52.5 - 55.1	67.3	61.9 - 72.2	64.7	60.8 - 68.3	57.3	54.3 - 60.3	51.8	49.3 - 54.3	45.3	43.1 - 47.4
	Q4	53.7	52.3 - 55.0	50.6	43.9 - 56.8	58.6	54.7 - 62.4	59.9	57.2 - 62.5	60.1	57.5 - 62.6	41.0	38.8 - 43.2
	Q5	56.6	55.2 - 57.9	57.4	50.8 - 63.5	69.0	64.9 - 72.6	59.7	56.8 - 62.5	56.7	54.1 - 59.2	48.7	46.4 - 50.9
Colorectal													
	All	83.9	83.8 - 84.1	92.5	91.9 - 92.9	90.5	90.1 - 90.8	89.0	88.8 - 89.3	86.4	86.1 - 86.6	72.7	72.4 - 73.0
	Q1	81.0	80.6 - 81.5	94.1	92.6 - 95.3	85.6	84.3 - 86.8	84.2	83.2 - 85.0	83.1	82.3 - 83.9	71.5	70.6 - 72.4
	Q2	84.1	83.7 - 84.5	93.5	91.9 - 94.8	89.3	88.2 - 90.3	88.5	87.7 - 89.2	85.7	84.9 - 86.4	74.5	73.6 - 75.3
	Q3	84.8	84.4 - 85.2	90.1	88.4 - 91.5	88.8	87.7 - 89.8	89.8	89.0 - 90.5	87.7	87.0 - 88.4	74.9	74.0 - 75.8
	Q4	85.4	85.0 - 85.8	93.0	91.5 - 94.3	92.1	91.1 - 92.9	89.8	89.0 - 90.4	88.5	87.8 - 89.2	74.2	73.3 - 75.1
	Q5	86.5	86.1 - 86.9	90.4	88.6 - 91.9	91.4	90.5 - 92.3	91.1	90.4 - 91.7	88.7	88.0 - 89.4	77.6	76.7 - 78.4
Liver													
	All	45.7	45.1 - 46.3	59.0	55.9 -61.9	53.7	52.2 - 55.2	51.2	50.0 - 52.3	46.6	45.5 - 47.8	33.8	32.8 - 34.8
	Q1	40.8	39.4 - 42.3	39.2	32.3 - 46.1	45.3	42.3 - 48.3	47.9	45.2 - 50.5	43.9	41.0 - 46.8	30.8	28.3 - 33.3
	Q2	45.7	44.2 - 47.1	49.6	42.7 - 56.2	57.6	53.9 - 61.0	46.6	44.0 - 49.2	48.7	46.2 - 51.2	35.9	33.1 - 38.8
	Q3	43.4	41.8 - 45.0	59.1	50.4 - 66.8	51.5	47.6 - 55.3	45.5	42.6 - 48.3	43.3	40.2 - 46.4	34.6	31.7 - 37.5
	Q4	50.6	49.0 - 52.3	70.8	62.4 - 77.7	59.3	55.1 - 63.3	57.9	55.0 - 60.6	48.6	45.2 - 51.8	38.5	35.5 - 41.6
	Q5	48.9	47.2 - 50.6	42.8	31.6 - 53.5	56.2	51.3 - 60.8	56.8	53.8 - 59.7	50.2	47.0 - 53.3	39.9	36.9 - 42.9
Lung													
	All	43.1	42.9 - 43.3	61.2	59.7 - 62.6	49.1	48.5 - 49.8	46.7	46.3 - 47.1	43.5	43.2 - 43.8	32.9	32.6 - 33.2
	Q1	36.4	35.9 - 36.9	57.6	53.2 - 61.7	37.8	36.2 - 39.5	37.8	36.8 - 38.8	37.1	36.3 - 38.0	28.8	28.0 - 29.6
	Q2	39.8	39.2 - 40.3	56.3	52.0 - 60.3	42.1	40.3 - 43.9	43.6	42.5 - 44.7	39.3	38.4 - 40.2	32.3	31.5 - 33.1
	Q3	41.3	40.7 - 41.8	68.9	64.4 - 73.0	43.6	41.6 - 45.5	44.1	42.9 - 45.2	40.1	39.1 - 41.0	32.6	31.7 - 33.4
	Q4	42.0	41.4 - 42.6	54.1	49.4 - 58.5	47.3	45.2 - 49.4	45.4	44.2 - 46.6	43.1	42.2 - 44.0	33.1	32.2 - 33.9
	Q5	43.3	42.6 - 44.0	53.0	47.2 - 58.4	49.5	47.3 - 51.6	49.0	47.7 - 50.3	45.3	44.3 - 46.3	31.9	31.0 - 32.9
Leukemia													
	All	71.2	70.8 - 71.5	85.5	84.6 - 86.3	85.8	84.9 - 86.6	82.5	81.7 - 83.1	71.9	71.2 - 72.7	52.1	51.4 - 52.7
	Q1	68.8	68.0 - 69.7	84.6	82.5 - 86.5	83.0	80.8 - 85.0	79.4	77.6 - 81.1	69.3	67.5 - 71.0	50.4	48.8 - 51.9
	Q2	69.7	68.9 - 70.5	84.9	82.9 - 86.7	83.0	80.9 - 84.9	80.8	79.0 - 82.4	70.0	68.3 - 71.7	51.5	50.1 - 53.0
	Q3	71.4	70.7 - 72.2	85.7	83.6 - 87.5	89.1	87.4 - 90.6	85.4	83.8 - 86.8	70.0	68.3 - 71.6	51.1	49.5 - 52.7
	Q4	72.6	71.8 - 73.3	89.4	87.6 - 90.9	86.6	84.8 - 88.2	82.8	81.3 - 84.2	75.9	74.4 - 77.5	51.2	49.6 - 52.8
	Q5	73.0	72.2 - 73.7	82.5	80.3 - 84.5	86.4	84.6 - 88.0	83.3	81.9 - 84.7	73.9	72.4 - 75.4	55.9	54.4 - 57.5
Breast													
	All	96.0	95.9 - 96.1	98.5	98.4 - 98.6	98.2	98.1 - 98.3	97.7	97.5 - 97.8	97.1	96.9 - 97.2	92.0	91.7 - 92.3
	Q1	94.9	94.6 - 95.1	98.5	98.1 - 98.7	97.5	97.2 - 97.8	96.4	96.0 - 96.7	95.9	95.4 - 96.3	90.8	90.1 - 91.4
	Q2	95.5	95.3 - 95.7	97.8	97.4 - 98.1	98.1	97.8 - 98.3	97.3	96.9 - 97.5	96.8	96.4 - 97.2	91.2	90.6 - 91.8
	Q3	96.2	96.0 - 96.5	98.6	98.3 - 98.9	98.3	98.0 - 98.5	97.5	97.2 - 97.8	97.4	97.0 - 97.7	92.7	92.0 - 93.3
	Q4	96.2	96.0 - 96.4	98.6	98.3 - 98.9	98.2	98.0 - 98.4	98.4	98.1 - 98.6	96.9	96.5 - 97.2	92.4	91.7 - 93.0
	Q5	96.9	96.7 - 97.1	98.9	98.7 - 99.2	98.7	98.5 - 98.8	98.4	98.2 - 98.6	98.1	97.8 - 98.4	93.3	92.6 - 93.9
Cervix													
	All	77.4	76.5 - 78.4	97.0	96.6 - 97.3	89.7	88.8 - 90.6	86.2	85.0 - 87.3	77.4	75.5 - 79.2	60.8	58.3 - 63.2
	Q1	79.3	77.4 - 81.0	95.2	94.2 - 96.1	86.8	84.5 - 88.7	87.3	84.8 - 89.4	82.7	79.1 - 85.8	62.6	57.7 - 67.1
	Q2	78.8	76.7 - 80.7	96.8	95.8 - 97.5	89.7	87.6 - 91.4	85.8	82.9 - 88.2	84.3	80.2 - 87.6	59.0	53.6 - 64.1
	Q3	75.0	72.7 - 77.2	97.6	96.8 - 98.3	91.1	89.1 - 92.8	85.3	82.3 - 87.9	71.5	66.3 - 76.0	58.3	52.4 - 63.7
	Q4	73.2	70.9 - 75.4	97.3	96.4 - 98.0	88.7	86.3 - 90.8	88.8	86.0 - 91.1	69.8	65.0 - 74.1	52.1	46.2 - 57.7
	Q5	80.9	78.5 - 83.0	98.4	97.6 - 99.0	92.6	90.6 - 94.3	83.4	80.1 - 86.2	76.4	71.6 - 80.5	74.2	67.8 - 79.7
Ovary													
	All	72.5	72.1 - 73.0	93.9	93.2 - 94.6	89.6	88.9 - 90.3	83.6	82.8 - 84.4	76.0	75.0 - 76.9	48.1	47.0 - 49.1
	Q1	69.3	68.2 - 70.4	92.4	90.5 - 93.9	88.2	86.3 - 89.9	80.7	78.5 - 82.6	70.5	68.1 - 72.8	45.7	43.3 - 48.0
	Q2	70.4	69.4 - 71.5	94.3	92.7 - 95.5	87.2	85.4 - 88.8	79.9	77.8 - 81.8	75.1	72.9 - 77.2	45.6	43.3 - 47.8
	Q3	73.1	72.1 - 74.2	94.3	92.7 - 95.7	87.1	85.2 - 88.8	82.6	80.7 - 84.3	76.2	74.0 - 78.2	51.7	49.2 - 54.1
	Q4	74.7	73.7 - 75.7	93.7	92.0 - 95.1	90.9	89.4 - 92.2	87.6	86.0 - 89.0	78.4	76.3 - 80.3	49.5	47.1 - 51.9
	Q5	74.5	73.4 - 75.5	94.8	93.2 - 96.1	93.8	92.5 - 94.9	85.8	84.2 - 87.4	78.6	76.6 - 80.5	48.4	45.9 - 50.8
Prostate													
	All	97.7	97.6 - 97.7	*100.0	*	99.6	99.5 - 99.7	99.6	99.6 - 99.7	99.5	99.4 - 99.6	92.9	92.6 - 93.1
	Q1	96.6	96.3 - 96.8	*100.0	*	99.1	98.7 - 99.4	98.8	98.5 - 99.0	98.3	98.0 - 98.6	91.1	90.5 - 91.7
	Q2	97.1	96.9 - 97.3	*100.0	*	99.1	98.7 - 99.4	99.5	99.3 - 99.7	99.2	99.0 - 99.4	91.6	91.0 - 92.2
	Q3	97.4	97.2 - 97.6	*100.0	*	99.4	99.2 - 99.7	99.7	99.5 - 99.8	99.3	99.0 - 99.5	92.2	91.7 - 92.8
	Q4	98.4	98.3 - 98.6	*100.0	*	100.0	99.9 - 100.0	99.8	*	100.0	99.9-100.0	94.6	94.1 - 95.1
	Q5	98.4	98.3 - 98.6	*100.0	*	99.7	99.5 - 99.9	99.9	*	100.0	*	94.5	93.9 - 95.0

Income quintiles are calculated based on their community median household income: Q1 represents the poorest communities and Q5 represents the richest communities. ** International Cancer Survival Standard (ICSS) weights were applied to get the ARSRs. * No deaths were reported during this period.

Table 4. Three-Year Age-Standardized Relative Survival Ratios (ARSRs) by Neighborhood-Level Income Quintile for Different Age Groups in Ontario, 2006–2011**

Cancer Sites	*Age*	*All (15-99)*		*15-44*		*45-54*		*55-64*		*65-74*		*75-99*	
	SES	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**
Stomach													
	All	34.1	33.6 - 34.6	42.0	39.8 - 44.3	42.0	40.5 - 43.6	38.2	37.0 - 39.3	35.1	34.1 - 36.1	24.7	23.9 - 25.5
	Q1	29.2	27.9 - 30.6	43.0	36.7 - 49.1	34.9	31.1 - 38.7	36.0	33.0 - 39.0	23.7	21.4 - 26.1	23.8	21.7 - 26.0
	Q2	34.9	33.6 - 36.3	48.2	41.6 - 54.6	44.7	40.5 - 48.9	33.6	30.9 - 36.4	37.9	35.4 - 40.5	25.6	23.5 - 27.8
	Q3	34.0	32.6 - 35.4	55.6	49.7 - 61.2	41.2	37.0 - 45.3	33.1	30.0 - 36.3	35.7	33.0 - 38.4	24.9	22.8 - 27.0
	Q4	33.5	32.1 - 34.9	37.4	30.8 - 44.0	32.0	27.9 - 36.2	42.0	39.1 - 44.9	37.6	34.8 - 40.4	22.3	20.1 - 24.5
	Q5	34.5	33.1 - 36.0	25.8	19.8 - 32.3	45.7	41.2 - 50.1	36.3	33.2 - 39.3	33.9	31.2 - 36.7	31.3	28.8 - 33.8
Colorectal													
	All	72.0	71.8 - 72.2	78.4	77.5 - 79.3	77.8	77.3 - 78.4	77.0	76.6 - 77.4	75.6	75.2 - 76.0	60.5	60.1 - 60.9
	Q1	68.5	67.9 - 69.1	78.5	75.8 - 80.9	71.5	69.7 - 73.2	73.3	72.1 - 74.5	70.7	69.6 - 71.7	58.8	57.6 - 60.0
	Q2	71.0	70.4 - 71.5	77.8	75.1 - 80.3	73.8	72.1 - 75.4	76.0	74.8 - 77.0	74.8	73.8 - 75.8	60.4	59.2 - 61.5
	Q3	72.4	71.8 - 73.0	76.2	73.8 - 78.5	76.3	74.7 - 77.7	76.7	75.5 - 77.7	77.9	76.9 - 78.9	61.0	59.8 - 62.2
	Q4	74.2	73.7 - 74.8	77.8	75.2 - 80.1	80.0	78.5 - 81.4	78.3	77.3 - 79.3	78.2	77.2 - 79.1	63.8	62.6 - 65.0
	Q5	75.7	75.1 - 76.2	80.1	77.6 - 82.4	81.3	79.9 - 82.7	80.3	79.3 - 81.3	78.3	77.2 - 79.2	66.0	64.8 - 67.2
Liver													
	All	28.1	27.5 - 28.6	42.6	39.3 - 45.8	38.5	36.9 - 40.0	34.2	33.0 - 35.4	28.8	27.7 - 30.0	14.6	11.0 - 12.8
	Q1	21.7	20.4 - 23.0	19.2	13.3 - 25.9	31.6	28.6 - 34.6	29.7	27.1 - 32.4	22.4	19.8 - 25.2	11.1	9.2 - 13.2
	Q2	27.0	25.7 - 28.4	29.3	22.7 - 36.1	38.8	35.1 - 42.4	29.6	27.0 - 32.2	30.9	28.4 - 33.4	15.8	13.3 - 18.5
	Q3	26.4	24.9 - 28.0	41.2	32.2 - 49.9	32.8	29.1 - 36.7	30.9	28.1 - 33.8	28.9	25.8 - 32.1	14.2	11.8 - 16.9
	Q4	31.7	30.0 - 33.4	55.0	46.0 - 63.1	45.4	40.9 - 49.8	39.7	36.6 - 42.8	26.8	23.6 - 30.2	18.9	16.0 - 22.0
	Q5	33.1	31.4 - 34.9	41.0	29.7 - 51.9	47.7	42.7 - 52.6	41.6	38.5 - 44.8	33.9	30.6 - 37.2	17.8	15.2 - 20.5
Lung													
	All	24.0	23.8 - 24.2	40.3	38.7 - 41.9	27.0	26.4 - 27.6	26.4	26.0 - 26.7	24.5	24.2 - 24.8	16.6	16.3 - 16.8
	Q1	19.3	18.8 - 19.8	34.9	30.6 - 39.2	18.5	17.1 - 19.9	20.9	20.0 - 21.8	20.4	19.7 - 21.2	13.5	12.8 - 14.2
	Q2	20.8	20.3 - 21.4	34.9	30.6 - 39.1	23.1	21.5 - 24.7	22.1	21.1 - 23.1	21.7	20.9 - 22.5	14.6	13.9 - 15.3
	Q3	22.8	22.2 - 23.4	48.2	43.3 - 52.9	22.3	20.5 - 24.0	23.8	22.7 - 24.9	22.7	21.9 - 23.6	16.2	15.4 - 17.0
	Q4	22.0	21.4 - 22.6	32.1	27.6 - 36.6	22.1	20.3 - 24.0	24.4	23.2 - 25.5	23.2	22.3 - 24.1	16.5	15.7 - 17.3
	Q5	24.3	23.7 - 25.0	33.8	28.2 - 39.5	28.1	26.0 - 30.2	26.7	25.5 - 27.9	25.8	24.8 - 26.8	17.2	16.3 - 18.1
Leukemia													
	All	60.4	59.9 - 60.8	74.9	73.7 -76.0	75.7	74.6 - 76.7	72.4	71.6 - 73.3	60.3	59.4 - 61.1	41.0	40.2 - 41.8
	Q1	57.0	56.0 - 58.0	74.1	71.5 - 76.6	68.7	65.8 - 71.4	68.9	66.8 - 71.0	55.3	53.2 - 57.4	40.2	38.5 - 42.0
	Q2	59.5	58.6 - 60.5	71.9	69.3 - 74.3	71.2	68.5 - 73.7	70.3	68.2 - 72.3	63.8	61.8 - 65.6	39.0	37.3 - 40.7
	Q3	61.3	60.4 - 62.3	75.9	73.4 - 78.3	80.1	77.8 - 82.2	76.5	74.6 - 78.4	57.5	55.6 - 59.4	41.8	40.1 - 43.6
	Q4	61.1	60.2 - 62.1	79.9	77.6 - 82.1	78.0	75.7 - 80.1	71.3	69.4 - 73.2	63.0	61.0 - 64.8	39.7	38.0 - 41.5
	Q5	62.2	61.3 - 63.1	72.6	69.9 - 75.1	78.4	76.2 - 80.5	74.4	72.6 - 76.1	61.1	59.2 - 62.9	44.3	42.5 - 46.1
Breast													
	All	90.6	90.4 - 90.8	92.8	92.5 - 93.1	93.8	93.6 -94.0	93.5	93.3 - 93.7	93.3	93.1 - 93.6	83.6	83.2 - 84.1
	Q1	88.5	88.1 - 88.9	91.2	90.4 - 92.0	92.2	91.6 - 92.8	91.9	91.3 - 92.4	90.0	89.3 - 90.7	82.1	81.0 - 83.1
	Q2	89.6	89.2 - 90.0	92.8	92.0 - 93.5	92.7	92.1 - 93.2	92.0	91.5 - 92.5	92.7	92.1 - 93.3	82.6	81.6 - 83.6
	Q3	90.4	90.0 - 90.8	92.4	91.7 - 93.1	94.5	94.0 - 94.9	93.7	93.2 - 94.2	92.8	92.2 - 93.4	83.2	82.1 - 84.2
	Q4	90.8	90.4 - 91.2	93.6	93.0 - 94.2	93.9	93.4 - 94.3	94.2	93.8 - 94.7	93.9	93.3 - 94.5	83.1	82.0 - 84.1
	Q5	93.2	92.8 - 93.5	93.5	92.8 - 94.1	95.2	94.8 - 95.6	95.0	94.6 - 95.4	96.7	96.1 - 97.1	87.3	86.3 - 88.3
Cervix													
	All	61.4	60.3 - 62.6	90.7	90.0 - 91.3	78.2	76.9 - 79.5	72.5	70.8 - 74.1	58.8	56.3 - 61.2	41.3	38.5 - 44.1
	Q1	61.5	59.2 - 63.8	89.0	87.5 - 90.4	71.9	68.7 - 74.8	69.9	66.3 - 73.1	57.2	52.2 - 62.0	48.3	42.7 - 53.9
	Q2	60.9	58.3 - 63.3	88.1	86.3 - 89.7	75.5	72.5 - 78.2	75.0	71.3 - 78.4	62.4	56.3 - 67.9	35.5	29.8 - 41.3
	Q3	61.8	59.1 - 64.4	93.1	91.7 - 94.3	81.5	78.6 - 84.1	75.2	71.4 - 78.7	57.6	51.6 - 63.2	39.6	33.2 - 46.1
	Q4	60.1	57.5 - 62.6	91.9	90.3 - 93.2	79.8	76.6 - 82.7	73.2	69.2 - 76.8	59.2	53.7 - 64.3	34.7	28.7 - 40.9
	Q5	63.3	60.2 - 66.1	91.3	89.5 - 92.7	84.2	81.2 - 86.8	70.0	65.6 - 73.9	57.5	51.5 - 63.1	48.3	40.7 - 55.8
Ovary													
	All	50.6	50.0 - 51.2	85.8	84.7 - 86.9	71.9	70.7 - 73.0	59.4	58.2 - 60.6	50.2	49.0 - 51.4	26.7	25.6 - 27.7
	Q1	48.2	46.9 - 49.5	84.2	81.5 - 86.5	71.9	69.1 - 74.5	58.3	55.4 - 61.0	42.9	40.1 - 45.7	27.1	24.8 - 29.5
	Q2	48.5	47.3 - 49.8	84.2	81.6 - 86.5	67.2	64.6 - 69.8	59.4	56.7 - 62.1	48.8	46.0 - 51.5	23.3	21.1 - 25.5
	Q3	51.8	50.5 - 53.1	89.2	86.9 - 91.2	72.9	70.3 - 75.3	56.1	53.4 - 58.6	55.7	52.9 - 58.4	26.8	24.4 - 29.3
	Q4	52.1	50.8 - 53.3	87.4	85.0 - 89.5	72.1	69.6 - 74.5	62.1	59.6 - 64.5	48.9	46.1 - 51.6	30.4	27.9 - 33.0
	Q5	52.1	50.9 - 53.4	84.2	81.5 - 86.5	75.1	72.6 - 77.3	60.7	58.1 - 63.2	54.1	51.4 - 56.7	26.1	23.7 - 28.6
Prostate													
	All	95.0	94.8 - 95.1	95.1	93.5 - 96.3	98.6	98.4 - 98.8	98.7	98.5 - 98.8	98.6	98.4 - 98.8	86.9	86.4 - 87.3
	Q1	92.9	92.6 - 93.3	100.0	*	97.8	97.1 - 98.3	96.7	96.2 - 97.1	95.5	94.9 - 96.0	83.6	82.5 - 84.6
	Q2	94.1	93.7 - 94.5	94.0	89.2 - 96.8	97.7	97.1 - 98.2	98.6	98.3 - 98.9	98.2	97.8 - 98.6	85.1	84.2 - 86.0
	Q3	94.1	93.7 - 94.5	91.2	86.1 - 94.5	98.3	97.8 - 98.8	98.6	98.3 - 98.9	98.4	98.0 - 98.8	85.3	84.4 - 86.2
	Q4	96.3	96.0 - 96.6	98.7	96.4 - 99.7	99.5	99.1 - 99.8	98.6	98.3 - 98.9	99.6	99.2 - 99.9	89.3	88.4 - 90.2
	Q5	96.6	96.3 - 97.0	92.8	89.2 - 95.3	99.1	98.7 - 99.4	99.9	99.6 - 100.0	100.0	*	90.3	89.5 - 91.2

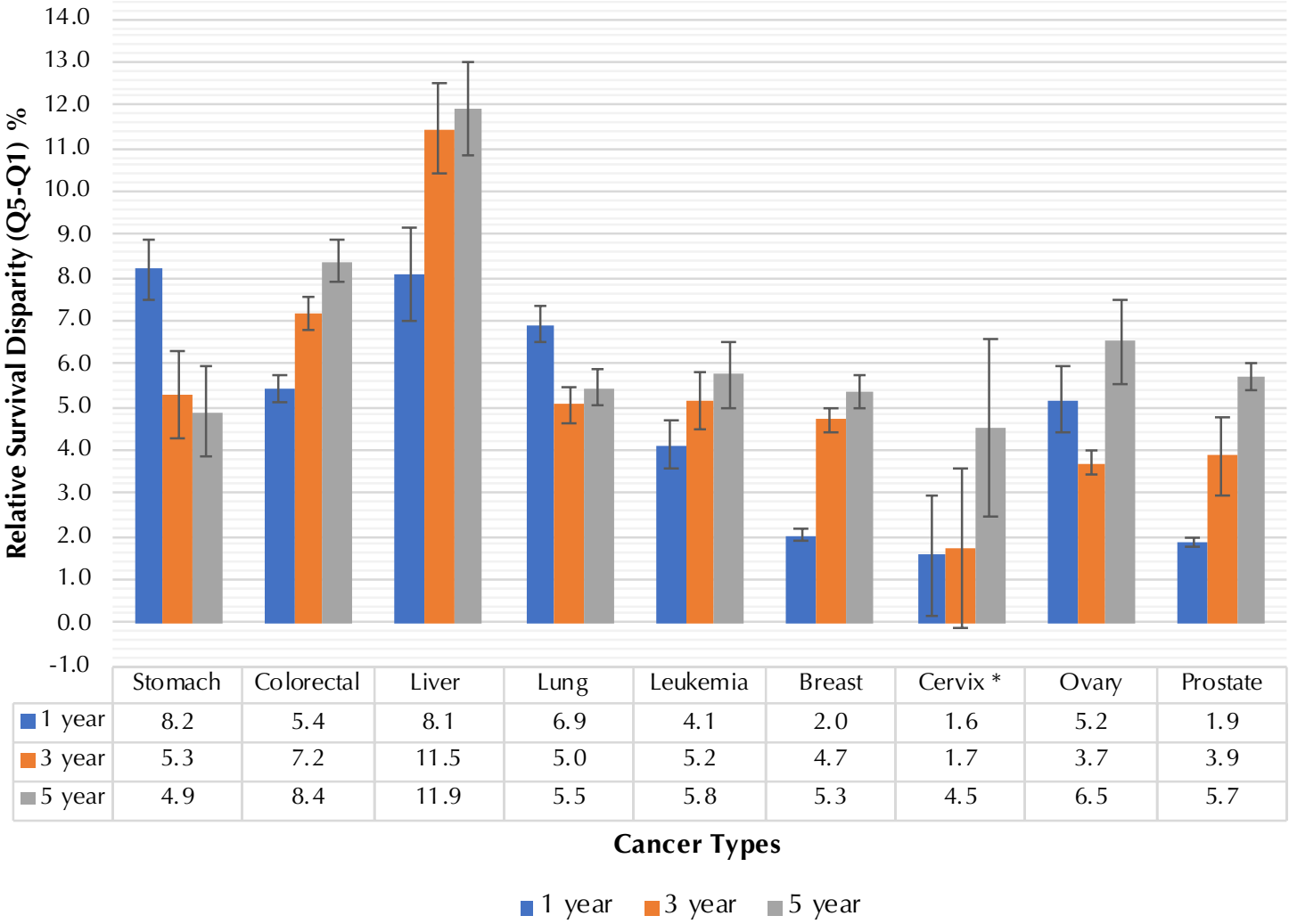
Income quintiles are calculated based on their community median household income: Q1 represents the poorest communities and Q5 represents the richest communities. ** International Cancer Survival Standard (ICSS) weights were applied to get the ARSRs. * No deaths were reported during this period.

Table 5. Five-Year Age-Standardized Relative Survival Ratios (ARSRs) by Neighborhood-Level Income Quintile for Different Age Groups in Ontario, 2006–2011**

Cancer Sites	*Age*	*All (15-99)*		*15-44*		*45-54*		*55-64*		*65-74*		*75-99*	
	SES	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**	**ARSR**	**95% CI**
Stomach													
	All	29.9	29.3 - 30.4	37.7	35.4 - 40.0	37.8	36.2 - 39.4	34.5	33.2 - 35.7	30.1	29.0 - 31.2	20.8	19.9 - 21.7
	Q1	26.1	24.7 - 27.5	40.7	34.2 - 47.1	33.4	29.6 - 37.3	30.9	27.7 - 34.1	20.5	18.1 - 23.0	21.3	19.0 - 23.8
	Q2	29.6	28.2 - 31.1	45.8	39.0 - 52.3	40.4	36.0 - 44.9	31.7	28.8 - 34.6	28.6	25.8 - 31.4	20.7	18.3 - 23.2
	Q3	29.0	27.6 - 30.5	48.2	41.9 - 54.2	35.1	30.7 - 39.6	31.3	28.0 - 34.5	30.4	27.6 - 33.3	18.8	16.6 - 21.2
	Q4	30.1	28.6 - 31.6	34.5	27.8 - 41.3	25.6	21.5 - 29.9	36.2	33.1 - 39.3	32.8	29.9 - 35.9	23.2	20.7 - 25.9
	Q5	31.0	29.4 - 32.6	25.2	19.2 - 31.7	39.8	35.2 - 44.4	33.8	30.7 - 37.0	30.9	27.9 - 33.9	26.5	23.7 - 29.5
Colorectal													
	All	66.0	65.8 - 66.3	72.2	71.2 - 73.2	71.5	70.9 - 72.1	70.3	69.8 - 70.8	69.7	69.2 - 70.1	55.2	54.7 - 55.7
	Q1	61.7	60.9 - 62.4	72.8	69.7 - 75.6	62.8	60.8 - 64.8	66.2	64.7 - 67.6	62.6	61.3 - 63.9	54.1	52.6 - 55.5
	Q2	64.7	64.0 - 65.4	73.7	70.6 - 76.5	68.1	66.2 - 69.9	69.3	68.0 - 70.6	68.1	66.8 - 69.4	54.1	52.7 - 55.6
	Q3	67.0	66.3 - 67.7	68.6	65.7 - 71.4	69.6	67.8 - 71.3	69.7	68.3 - 71.0	73.7	72.4 - 74.9	56.7	55.2 - 58.2
	Q4	68.1	67.4 - 68.8	71.6	68.6 - 74.3	73.3	71.5 - 75.0	71.0	69.7 - 72.2	71.5	70.3 - 72.8	59.4	57.9 - 60.9
	Q5	70.1	69.4 - 70.7	76.2	73.3 - 78.7	76.7	75.1 - 78.3	74.3	73.1 - 75.5	72.9	71.6 - 74.1	59.6	58.1 - 61.2
Liver													
	All	23.6	23.0 - 24.3	41.4	38.1 - 44.7	33.9	32.3 - 35.5	29.1	27.8 - 30.3	23.8	22.5- 25.0	10.7	9.7 - 11.7
	Q1	17.2	15.9 - 18.5	19.2	13.3 - 26.0	28.4	25.5 - 31.5	27.6	24.8 - 30.4	14.2	11.6 - 17.1	6.7	4.9 - 8.9
	Q2	21.5	20.1 - 22.9	26.8	20.3 - 33.7	34.6	30.9 - 38.4	23.6	20.9 - 26.5	26.3	23.6 - 29.0	8.3	6.1 - 11.0
	Q3	22.6	21.0 - 24.3	40.0	31.0 - 48.9	30.3	26.5 - 34.2	27.0	24.1 - 30.0	24.6	21.3 - 28.0	9.8	7.4 - 12.7
	Q4	26.3	24.6 - 28.0	53.8	44.7 - 62.1	42.5	37.9 - 47.1	33.4	30.2 - 36.7	19.6	16.4 - 23.0	14.0	11.1 - 17.3
	Q5	29.1	27.3 - 31.0	38.7	27.2 - 50.0	38.3	33.0 - 43.6	34.7	31.3 - 38.1	31.2	27.8 - 34.8	16.4	13.6 - 19.5
Lung													
	All	19.4	19.2 - 19.6	37.1	35.5 - 38.7	23.0	22.4 - 23.6	21.3	20.9 - 21.7	19.2	18.9 - 19.6	12.1	11.8 - 12.4
	Q1	14.6	14.1 - 15.1	29.5	25.4 - 33.8	15.6	14.2 - 16.9	15.5	14.6 - 16.4	15.3	14.6 - 16.1	9.1	8.5 - 9.8
	Q2	16.8	16.3 - 17.4	31.8	27.6 - 36.1	20.6	19.0 - 22.2	17.3	16.4 - 18.3	16.5	15.7 - 17.3	11.6	10.9 - 12.4
	Q3	18.7	18.1 - 19.3	42.9	37.8 - 47.9	18.5	16.8 - 20.2	20.1	19.1 - 21.2	17.9	17.0 - 18.8	12.6	11.8 - 13.5
	Q4	18.0	17.4 - 18.6	30.3	25.8 - 34.9	18.9	17.1 - 20.8	21.0	19.8 - 22.1	18.7	17.9 - 19.6	11.6	10.9 - 12.5
	Q5	20.0	19.4 - 20.7	33.9	28.3 - 39.6	24.0	21.9 - 26.1	22.4	21.2 - 23.6	20.9	19.9 - 21.9	12.4	11.5 - 13.3
Leukemia													
	All	55.5	55.0 - 56.0	72.0	70.8 - 73.2	71.6	70.4 - 72.8	66.9	65.9 - 67.9	55.7	54.7 - 56.7	35.6	34.6 - 36.5
	Q1	51.9	50.7 - 53.0	71.2	68.3 - 73.8	65.2	62.0 - 68.2	62.7	60.2 - 65.1	49.9	47.5 - 52.3	35.2	33.1 - 37.3
	Q2	53.6	52.5 - 54.7	71.1	68.5 - 73.6	68.0	65.0- 70.8	63.4	61.0 - 65.7	56.6	54.3 - 58.8	32.8	30.8 - 34.7
	Q3	56.7	55.6 - 57.8	73.5	70.8 - 76.0	74.5	71.8 - 77.1	71.3	69.0 - 73.5	53.8	51.7 - 56.0	36.7	34.6 - 38.8
	Q4	56.8	55.7 - 57.9	74.8	72.0 - 77.4	73.8	71.2 - 76.2	65.6	63.3 - 67.8	59.2	57.0 - 61.4	36.1	34.0 - 38.2
	Q5	57.7	56.6 - 58.7	69.3	66.4 - 72.0	74.7	72.1 - 77.1	70.6	68.5 - 72.5	58.0	55.8 - 60.1	37.2	35.0 - 39.4
Breast													
	All	86.2	85.9 - 86.4	87.8	87.4 - 88.2	90.4	90.1 - 90.7	90.3	90.0 - 90.6	90.2	89.8 - 90.6	76.7	76.1 - 77.4
	Q1	83.7	83.1 - 84.2	87.2	86.1 - 88.2	88.3	87.5 - 89.1	88.8	88.1 - 89.6	86.4	85.4 - 87.4	74.1	72.6 - 75.6
	Q2	85.1	84.5 - 85.6	86.7	85.6 - 87.7	88.7	87.9 - 89.4	88.1	87.3 - 88.8	90.1	89.2 - 90.9	75.8	74.4 - 77.2
	Q3	85.8	85.2 - 86.3	86.9	85.8 - 87.8	91.1	90.4 - 91.7	89.2	88.4 - 89.9	90.0	89.1 - 90.8	76.5	75.0 - 78.0
	Q4	86.8	86.3 - 87.3	88.0	87.1 - 88.9	90.3	89.7 - 90.9	91.8	91.2 - 92.4	90.9	90.0 - 91.7	77.0	75.5 - 78.5
	Q5	89.0	88.5 - 89.5	89.8	88.9 - 90.7	92.5	91.9 - 93.0	92.5	91.9 - 93.0	93.3	92.5 - 94.1	80.5	79.0 - 81.9
Cervix													
	All	55.3	54.0 - 56.6	87.6	86.7 - 88.4	72.8	71.2 - 74.3	65.2	63.2 - 67.1	54.0	51.2 - 56.7	33.8	30.7 - 37.0
	Q1	53.3	50.7 - 55.8	85.7	83.7 - 87.4	66.8	63.3 - 70.1	63.9	60.0 - 67.7	54.3	49.0 - 59.5	30.3	24.2 - 36.7
	Q2	52.2	49.1 - 55.2	85.8	83.7 - 87.7	67.1	63.4 - 70.5	63.3	58.6 - 67.6	53.9	46.8 - 60.6	27.5	21.0 - 34.7
	Q3	58.8	55.8 - 61.8	88.4	86.4 - 90.1	74.9	71.4 - 78.1	68.6	63.9 - 72.8	55.7	49.3 - 61.8	40.5	33.4 - 47.8
	Q4	56.0	53.1 - 58.8	87.9	85.8 - 89.6	74.8	71.0 - 78.2	67.0	62.4 - 71.3	53.7	47.6 - 59.5	34.0	27.5 - 40.9
	Q5	57.8	54.3 - 61.1	90.7	88.8 - 92.3	83.8	80.7 - 86.5	64.0	58.8 - 68.8	51.4	44.8 - 57.8	40.5	32.0 - 49.3
Ovary													
	All	41.2	40.6 - 41.9	79.0	77.6 - 80.4	63.4	62.1 - 64.7	49.7	48.4 - 51.0	36.7	35.3 - 38.1	20.7	19.6 - 21.9
	Q1	37.3	35.9 - 38.7	77.7	74.4 - 80.6	61.2	57.8 - 64.4	47.2	43.9 - 50.4	27.3	24.5 - 30.2	19.8	17.4 - 22.3
	Q2	38.2	36.9 - 39.6	77.9	74.6 - 80.8	59.6	56.6 - 62.5	48.6	45.5 - 51.7	33.7	30.7 - 36.8	16.1	13.9 - 18.5
	Q3	44.2	42.7 - 45.6	78.4	74.9 - 81.5	62.9	59.8 - 65.9	48.1	45.1 - 51.0	46.2	43.0 - 49.4	23.0	20.4 - 25.7
	Q4	42.4	41.0 - 43.8	80.4	77.1 - 83.2	68.1	65.3 - 70.8	52.6	49.8 - 55.3	33.7	30.6 - 36.8	23.3	20.7 - 26.2
	Q5	43.8	42.4 - 45.2	81.0	77.9 - 83.7	64.1	61.0 - 67.1	51.0	48.1 - 53.8	42.3	39.3 - 45.3	22.2	19.6 - 25.0
Prostate													
	All	94.0	93.7 - 94.2	94.4	92.6 - 95.8	98.1	97.8- 98.3	98.5	98.3 - 98.6	98.6	98.3 - 98.9	84.0	83.4 - 84.6
	Q1	91.0	90.5 - 91.5	100.0	*	97.3	96.4 - 98.0	95.9	95.3 - 96.5	94.1	93.4 - 94.9	78.9	77.5 - 80.3
	Q2	92.6	92.0 - 93.2	88.6	81.6 - 93.2	97.5	96.8 - 98.2	98.1	97.6 - 98.6	97.8	97.2 - 98.4	82.0	80.7 - 83.3
	Q3	93.5	92.9 - 94.0	91.6	86.4 - 95.0	97.4	96.6 - 98.1	97.9	97.4 - 98.3	99.4	98.9 - 99.9	82.9	81.6 - 84.2
	Q4	94.9	94.5 - 95.3	99.1	96.8 - 100.0	98.8	98.2 - 99.4	98.7	98.3 - 99.1	99.5	98.9 - 100.0	84.7	83.4 - 86.0
	Q5	96.7	96.2 - 97.1	92.7	88.9 - 95.3	98.6	98.1 - 99.1	100.0	99.8 - 100.0	100.0	*	90.2	89.0 - 91.4

Income quintiles are calculated based on their community median household income: Q1 represents the poorest communities and Q5 represents the richest communities. ** International Cancer Survival Standard (ICSS) weights were applied to get the ARSRs. * No deaths were reported during this period.

Figure 1. 1-, 3-, and 5-Year Relative Survival Disparity (Q5–Q1) for 9 Cancer Types in Ontario, 2006–2011



	Stomach	Colorectal	Liver	Lung	Leukemia	Breast	Cervix *	Ovary	Prostate
1 year	8.2	5.4	8.1	6.9	4.1	2.0	1.6	5.2	1.9
3 year	5.3	7.2	11.5	5.0	5.2	4.7	1.7	3.7	3.9
5 year	4.9	8.4	11.9	5.5	5.8	5.3	4.5	6.5	5.7

* Estimate is not statistically significant.
Source: Ontario Cancer Registry (Ontario Health| Cancer Care Ontario), 1964-2014. Patients' income quintile was classified by the Postal Code Conversion File Plus (PCCF+), version 6C is based on the 2011 Canadian Census of Population. Pohar-Perme method was used to estimate the net survival indicator ARSR. *Relative survival disparity* (Q5-Q1) is defined as the difference of the ARSR between the highest income quintile (Q5) and lowest quintiles (Q1) at the same time point after the diagnosis. Estimates were age-standardized using the International Cancer Survival Standard (ICSS) weights. Relative survival disparity between highest and lowest quintiles (Q5–Q1) and their 95% confidence intervals (as the vertical whiskers show) are reported for 9 different cancer types at 3 different postdiagnosis time points: 1 year, 3 years, and 5 years.

Results

We estimated 1-, 3-, and 5-year net survival for 9 cancers by age group and neighborhood-level income quintiles. The ARSRs with the 95% confidence intervals were reported in Tables 3, 4, and 5. Substantial age-related disparity was observed for net survival. Net survival decreased with increasing age for all cancer types.

The findings show that across neighborhood-level income quintiles, disparities exist in cancer survival in Ontario. Considerable variation in relative survival between cancer sites was seen across the different income groups of patients who were diagnosed from 2006 to 2011. Relative survival for all ages combined was significantly higher for higher (Q4 or Q5) compared to lower (Q1 or Q2) neighborhood-level income populations. After 5 years, the survival difference (Q5–Q1) between the highest (Q5) and the lowest (Q1) income quintiles for all ages combined were all positive (>0) for the following cancers: 11.9% for liver, 8.4% for colorectal, 6.5% for ovarian, 5.8% for leukemia, 5.7% for prostate, 5.5% for lung, 5.3% for breast, 4.9% for stomach, and 4.5% for cervical. With the exception of cervical cancer, these differences were statistically significant for all other cancers studied (liver, colorectal, ovarian, leukemia, prostate, lung, breast, and stomach).

When looking at the patterns of survival disparity across income quintiles, over time since diagnosis, the disparities generally increase by time since diagnosis for 7 cancers (liver, colorectal, leukemia, prostate, breast, cervical, and ovarian). These patterns of disparities in survival were similar across different time periods following diagnosis for different cancer types when all age groups were examined together (Figure 1). The reverse pattern was observed for stomach and lung cancer, with the disparities decreasing by time since diagnosis. One possible explanation may be that

Table 6. Relative Survival Disparity Trends of the Highest and Lowest Quintiles (Q5–Q1) by Time since Diagnosis for Different Age Groups

Cancer Site	All ages (15-99)				Age 15-44			
	1 year	3 year	5 year	Trend	1 year	3 year	5 year	Trend
Stomach	8.2	5.3	4.9		3.4	-17.1	-15.5	
Colorectal	5.4	7.2	8.4		-3.7	1.6	3.4	
Liver	8.1	11.5	11.9		3.5	21.8	19.4	
Lung	6.9	5.0	5.5		-4.6	-1.1	4.4	
Leukemia	4.1	5.2	5.8		-2.1	-1.5	-1.9	
Breast	2.0	4.7	5.3		0.5	2.3	2.6	
Cervix	1.6	1.7	4.5		3.2	2.2	5.0	
Ovary	5.2	3.9	6.5		2.4	0.0	3.3	
Prostate	1.9	3.7	5.7		-	-7.2	-7.3	

Cancer Site	Age 55-64				Age 65-74			
	1 year	3 year	5 year	Trend	1 year	3 year	5 year	Trend
Stomach	3.5	0.3	2.9		10.4	10.2	10.4	
Colorectal	7.0	7.0	8.2		5.6	7.6	10.3	
Liver	8.9	11.9	7.1		6.3	11.4	17.0	
Lung	11.2	5.8	6.9		8.2	5.4	5.6	
Leukemia	3.9	5.4	7.9		4.6	5.8	8.1	
Breast	2.1	3.2	3.6		2.3	6.7	6.9	
Cervix	-3.9	0.1	0.1		-6.4	0.2	-2.9	
Ovary	5.2	2.5	3.8		8.1	11.1	15.0	
Prostate	1.2	3.2	4.1		1.7	4.5	5.9	

The direction of change in trend is denoted using an upward-facing line or downward-facing line where the disparity or income-related inequality increased or decreased, respectively, between 2 follow-up time points after diagnosis.

these 2 types of cancer are both highly fatal and are typically diagnosed at a later stage in Ontario, making the overall survival poor for these cancers. However, more research is needed to better understand these findings.

When stratified by age groups, other than the adolescent and young adult age group (ages 15–44 years), survival was still consistently higher in higher neighborhood-level income groups compared to lower neighborhood-level income groups for most cancers, but this trend was not consistently observed in cervical and ovarian cancers. In the adolescent and young adult group (ages 15–44 years), liver, breast, and cervical cancers still had higher survival in the higher neighborhood-level income groups. For other cancer types, such as stomach, prostate, and leukemia, survival was lower in higher neighborhood-level income groups 5 years after diagnosis (Table 6).

Considering the survival patterns by cancer type, cervical cancer had the most complicated survival patterns. For example, for all ages combined and for younger females (ages 15–44 and 45–54 years), cervical cancer survival was higher for patients in higher income groups. However, in older females (ages 55–64, 65–74, and 75–99 years), different patterns emerged with the lowest or middle-income groups experiencing the highest survival rates (Tables 3, 4, and 5).

Discussion

Overall, the findings from our study contribute to the growing body of evidence indicating that disparities in cancer survival exist between high and low neighborhood-level income populations in Ontario.[6,8,27]

Currently, there are 3 organized cancer screening programs (colorectal, breast, and cervical) that exist in Ontario. For all ages combined, the disparity between income quintiles is smaller for 2 of the 3 cancers for which organized provincial screening programs exist (breast and cervical). This could potentially be highlighting the effectiveness of organized cancer screening in Ontario. Screening tends to result in diagnosis at an earlier stage, when treatment can be more effective.[28-31] Since the survival gap

widens over time for both breast and cervical cancer, it is evident that access to and participation in screening cannot be the only factor influencing survival differences between income groups. Colorectal cancer screening was only introduced as an organized screening program in Ontario in 2007, which may account for the larger disparities seen in this cancer type. Because the disparities in survival are much larger for cancers with no organized screening program than for screenable cancers, this suggests that screening, and therefore the earlier detection of cancer cases, have a substantial positive impact on cancer patient outcomes for these cancers. While conducting screening tests may not be a viable practice for nonscreenable cancers, it is important to identify cancer early to improve survival.

Differences in stage of cancer at diagnosis (which in some cases may be the result of early versus late cancer screening), treatment and patient factors may be influencing disparities in survival. Lower income groups have been shown to be more likely to have a higher incidence of late-stage, advanced cancers than higher income groups.[30,32,33] Therefore, independent of treatment interventions and access to care, lower neighborhood-level income groups may be more disadvantaged than higher income groups and experience worse survival at the time of diagnosis. Furthermore, differences in access to and the quality of treatment can cause further disparity in survival and widen the gap between income groups.[29,31,34]

The largest disparities exist for cancers that do not have a valid screening test, such as liver cancer. Regardless of the number of years since diagnosis, these disparities persist and generally widen with time since diagnosis.

These cancers are also ones that tend to be diagnosed at a late stage and have low survival in general.[29,32] Higher income groups may have better access to a family physician and/or be more likely to seek timely care than lower income groups, resulting in earlier diagnosis and treatment and, ultimately, better survival.[6,29] Lower income groups may wait longer, such as when they are already symptomatic, to seek care and may not have regular access to a family physician, delaying investigation of health concerns and subsequent treatment when needed.[8,9,28] This could result in a later stage at the time of diagnosis and delayed subsequent treatment, worsening their survival.

Disparities in modifiable factors by income. Additional factors beyond early detection and treatment may be impacting differences in cancer survival by income groups. Disparities in incidence and mortality rates from various cancers may reflect differences in the prevalence of modifiable risk factors, such as smoking, alcohol consumption, diet, obesity, physical inactivity, and health literacy, which are known to exist between high- and low-income groups.[35-38] Smoking after a cancer diagnosis is known to reduce the effectiveness of treatment and increase the risk of adverse effects and complications, thus negatively affecting survival outcomes.[10] Lower income groups are more likely to be smokers, may be less compliant with prescribed treatment regimens, and have more comorbidities.[9,29] Further, having multiple comorbidities can reduce treatment options and the effectiveness of cancer treatment.[9,26] Finally, in addition to modifiable risk factors, individual patient characteristics (such as genetics) may be important factors to consider when examining disparities in cancer outcomes and when considering interventions for at-risk groups.

One surprising finding of this study was that survival was much more unpredictable for all cancer types in the 15–44 years age group. Adolescents and young adults with cancer are a unique group in terms of both the biology of their cancers and the way they experience their cancer journey.[39] Cancers diagnosed in adolescents and young adults are relatively rare compared to cancers diagnosed in other age groups; this rarity may be impacting the variations observed in this population. A possible explanation might be that younger patients diagnosed with cancer have lower survival in general because the cancers are more advanced and aggressive than those diagnosed in their older counterparts.[34,39] More research is needed to understand the unique characteristics associated with this population in order to improve survival outcomes for adolescents and young adults.

Limitations

All cases included in this study were identified using the population-based OCR database. Its strengths include the large sample size, the ability to perform time-to-event analyses, and the generalizability of the findings. The limitations of using data from a passive cancer registry like the OCR include the lack of comprehensive data verification and incomplete data follow-up.[40] However, the OCR remains the most comprehensive and highest quality database for information on cancer in Ontario.

Compared to other classical methods used for the routine estimation of net survival from cancer-registry data, the Pohar-Perme net survival estimator is a robust and popular estimator and favorable to others such as Ederer II. However, it is prone to random variation when exact follow-up times are not available, or follow-up is incomplete, especially in long-term estimates (>5 years).[41] Additionally, cases lost to follow up are assumed to be alive in this study, which may increase the higher degree of unpredictability of the results for patients, especially in the adolescent and young adult group, and may affect the sensitivity of the results for age groups with a smaller sample size. However, the Pohar-Perme net survival estimator was the most appropriate method for this study, as it provides estimates of ARSR with up to 5 years of follow-up.

With this study representing the first comprehensive population-based study of cancer survival by neighborhood-level income in Ontario for the covered time span, there are some additional limitations to note. Data on survival for this study could only be analyzed up to 2011, given that the life tables by neighborhood income quintile were readily available only until 2011. Additionally, income quintiles were classified by neighborhood, rather than by individual income. While this methodology for calculating income is used as a proxy for individual or household income and this approach is consistent with previous cancer reports,[17,42] income quintile assignments may be misclassified and may not be generalizable at the individual-level.

This is particularly relevant for rural Canada, as the methodology for calculating income is less representative for rural communities than it is for urban communities.[43]

Although using income as a proxy for SES is a common practice, there are other components of socioeconomic status that were not controlled for or addressed in this study. Information on race and ethnicity is not available in the OCR, thus the analysis was not able to look at survival by these indicators, which have been shown to be associated with health disparities.[44] Nonetheless, there is evidence to suggest that neighborhood poverty or regional deprivation is an important component of SES affecting cancer survival outcomes.[45-47]

Due to changes made to the OCR in 2010, the stage of cancer at diagnosis is incomplete for most cases prior to 2010, which meant stage could not be included in this analysis. Another limitation of this study is that the number of cases in the 15–44 years age group was small for some income quintile subgroups, which likely affected the results for this age group due to high variability.

Lead-time bias might also be impacting the length of time of survival for cancers with organized screening programs such that early diagnosis of a disease may appear as though individuals are surviving longer.

A final limitation to consider is that the OCR changed its method of counting multiple primary incident cases starting with 2010 cases. Therefore, for the purposes of this study that spans from 2006 to 2011, we have selected only the cases that meet the International Association of Cancer Registries multiple primary rules (as used in the OCR prior to 2010) in order to remain consistent in our counting across years of diagnosis.[48] Inclusion of all primary cancers in survival estimates is important to consider because the number of people who develop a second cancer will continue to rise with ageing populations and overall improvements in survival due to advancements in science and treatments.[48,49] However, including all subsequent primaries should not affect survival estimates if all first cancers matching the selection criteria are used to produce site-specific survival estimates.

Conclusion

In this study, we found that disparities in survival exist between high and low neighborhood-level income populations with differences in patterns across cancer types and age groups. Disparities between income groups in Ontario may occur across the continuum of cancer care, which ultimately may affect cancer outcomes, including cancer survival. Further research looking at factors such as stage, disease biology, comorbidities, access to treatment, and quality of care and their impact on survival by income is needed to better understand these disparities and develop strategies to address the disparities in the outcomes of patients with cancer. Targeted policies and strategies aimed at improving equity in Ontario's cancer control system may reduce the number of potentially avoidable deaths and improve cancer survival for people diagnosed with stomach, colorectal, liver, lung, leukemia, breast, cervical, ovarian, and prostate cancer.

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Original Article

Can Oncology Practice Claims Data Replace Physician Reporting to State Cancer Registries?

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Abstract: Background: Recently, the Surveillance, Epidemiology, and End Results Program facilitated the linkage of claims data from oncology practices to cancer registry data. Since physician reporting places a burden on oncology practices and presents a challenge for cancer registries, the question arises as to whether claims data can replace physician reporting. Using data reported to the New York State Cancer Registry, we evaluated the information that would be lost if oncology practices were to cease reporting abstracted data to the registry. Methods: We identified cancer cases diagnosed in 2017 and reported by 3 oncology practices. We estimated the proportion of cases reported solely by these practices and examined characteristics of these cases compared to those reported by multiple sources. We used Match*Pro to link cases reported by the oncology practices to claims data and examined the availability of claims data for these cases. Results: The 3 oncology practices reported 3,224 malignant tumors diagnosed in 2017. Of these, 233 (7.2%) were reported solely by the practices. Cases reported by an oncology practice only tended to be older than those reported by multiple sources and were statistically significantly more likely to be non-Hispanic White and less likely to be a first reportable cancer, early stage, or receive treatment. Of the 233 sole report tumors, 5 (2.1%) were not captured in claims data. Conclusions: Most cancers reported by oncology practices were also reported by other sources or were included in claims data. However, relying on claims data for these cases would result in missing data items and a small number of unreported cancers. These results may help to optimize oncology practice reporting by informing reporting requirements to balance the need for complete data with the convenience of obtaining data through automated means.

Key words: *cancer reporting, insurance claims data, New York, physician practices, SEER Program*

Introduction

Each year, the New York State Cancer Registry (NYSCR) receives over 200,000 reports of invasive cancers, representing approximately 110,000 distinct tumors.[1] New cancer diagnoses are primarily reported by hospitals, but must also be reported by other facilities that diagnose or treat cancer patients, including pathology laboratories, physician offices, and ambulatory care centers.

Previous studies have clearly shown the value of augmenting cancer registry data with claims data.[2-18] The Surveillance, Epidemiology, and End Results (SEER)-Medicare data, which have been used in numerous research studies, are a prime example of this.[19-21] More recently, the SEER Program has facilitated the linkage of claims data from oncology practices to cancer registry data. The use of automated claims data may help to reduce the reporting burden on oncology practices, facilitate cancer registries' collection of timely data, and provide some additional information on cancer cases including comorbidities, diagnostic pathways, and detailed treatment data. However, the use of electronic claims data can also result in the loss of some information, either because a cancer is missing from the claims data or because some important variables are not included in the claims data or are incomplete.

Using claims data and data reported to the NYSCR by 3 oncology practices for cases diagnosed in 2017, we evaluated the information that would be lost if oncology practices were to cease reporting abstracted data to the registry. Goals of the study included examining the proportion of cases reported by oncology practices but no other sources, comparing characteristics of patients and tumors for cases reported by oncology practices only to those reported by multiple sources, and examining the availability of linked claims data for cases reported by oncology practices.

Methods

Study Population

Our study population included cancer cases diagnosed in 2017 and reported to the NYSCR by 3 oncology practices with claims data available. We retrieved data from the NYSCR SEER*DMS database and restricted cases based on the facility identification (ID), year of diagnosis, reportability of the diagnosis, and residence in New York State at the time of diagnosis. After exclusion of 53 records for cases reported more than once by an oncology practice, 3,224 tumors met the criteria for inclusion in our sample. We retrieved data for all reports of these 3,224 tumors, to

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examine whether each case was reported by an oncology practice only or by multiple sources. A total of 9,673 unique reports were received for the cancers of interest.

Covariate and Claims Data

We additionally retrieved data from SEER*DMS on characteristics of the cases of interest, including age at diagnosis (continuous), sex (female vs male), race/ethnicity (non-Hispanic White vs all other), marital status (single, married, divorced/separated, widowed, or other/unknown), sequence number (first cancer or subsequent primary), primary site, stage (in situ/local, regional/distant, or unknown), and receipt of treatment during initial therapy (yes or no/unknown for surgery, chemotherapy, radiation therapy, hormonal therapy, and immunotherapy). For each report of a tumor, we retrieved data on the type of record (North American Association of Central Cancer Registries [NAACCR] abstract, NAACCR modified, short health record [ie, an abbreviated abstract submitted by physician offices], HL-7 E-path, NAACCR casefinding, or death certificate).

Claims data for patients seen at oncology practices were electronically reported by Unlimited Technology Systems, LLC to Information Management Services, Inc (IMS) and uploaded to SEER*DMS. We retrieved information from SEER*DMS on patient name, date of birth, sex, Social Security number, address, diagnosis code, and primary site for each claim. We then retrieved full case abstracts in NAACCR 18 format for all cases reported by the 3 oncology practices in 2017 by uploading a file with the numeric portion of the display ID and the tumor record number to SEER*DMS and retrieving the consolidated data for these cases. We used Match*Pro Version 1.6.2 (IMS) to conduct probabilistic record linkages of the consolidated and claims data by first, middle, and last name, date of birth, Social Security number, street address, sex, and primary site, and we output the linkage results as a SAS data set to examine the availability of claims data for each case. We used this approach to retrieve and link the claims data to ensure that all relevant claims data were included and to maximize the percent of cases with a match in the claims data.

Statistical Analysis

We examined descriptive characteristics of all reports received for the cancers of interest, including the number of reports per tumor and the types of reports received. We then examined characteristics of each unique tumor. We calculated frequencies for each characteristic of interest overall and by number of reports (reported by practice only vs reported by multiple sources), and calculated *P* values for the association between each descriptive characteristic and number of reports using χ^2 tests. We also calculated the mean and standard deviation for age at diagnosis and examined differences in the mean value by number of reports using the *t* test. For individuals with more than 1 tumor diagnosed in 2017, individual-level characteristics (age, sex, and race/ethnicity) were reported at the person level, whereas tumor-level characteristics (first reportable cancer, stage, treatment, and primary site) were reported at the tumor level. Finally, we examined characteristics of the claims data reported for the cases of interest. All analyses were conducted using SAS version 9.4 (SAS Institute Inc).

Results

We received 9,673 total unique reports for 3,224 malignant tumors diagnosed in 2017 and reported by 3 oncology practices to the NYSCR. The majority of these cases were reported to the NYSCR 2 (29.5%) or 3 (34.3%) times, while 233 cases (7.2%) were reported by an oncology practice only and approximately 29% were reported by 4 or more sources (Table 1). Approximately two-thirds of the reports were NAACCR full case abstract records (66.8%), 14.6% were electronic pathology records, 11.1% were the result of NAACCR casefinding, 5.6% were death certificate reports, and approximately 2% were NAACCR modified or short health records.

The 3,224 malignant tumors diagnosed in 2017 included some instances where the same individual was diagnosed with 2 separate tumors. A total of 119 individuals had reports of 2 primary tumors (n=238 total), and the remaining 2,986 individuals had 1 tumor only, for a total of 3,105 individuals with a relevant cancer diagnosis in 2017. Of the 119 individuals with 2 separate tumors, 1 case had both tumors reported by an oncology practice only, 103 individuals had both tumors reported by multiple sources, and 15 individuals had 1 tumor reported by multiple sources and 1 reported by an oncology practice only. Comparing characteristics of individuals with tumors reported by an oncology practice only versus those with at least 1 tumor reported by multiple sources, the cases reported by an oncology practice only tended to be older (mean age of 69 vs 66 years; *P* = .001) and were more likely to be non-Hispanic

Table 1. Characteristics of 9,673 Reports Received for 3,224 Malignant Tumors Reported to the New York State Cancer Registry in 2017 by 3 Oncology Practices

Report characteristics	*n*	*%*
Number of reports received per tumor		
1	233	7.2
2	950	29.5
3	1,105	34.3
4	589	18.3
5	244	7.6
6 or more	103	3.2
Type of record		
NAACCR abstract	6,461	66.8
NAACCR modified	161	1.7
Short health record	28	0.3
HL-7 E-path	1,409	14.6
NAACCR casefinding	1,069	11.1
Death certificate	545	5.6

NAACCR, North American Association of Central Cancer Registries. Percentages may not sum to 100 due to rounding.

Table 2. Characteristics of 3,224 Malignant Tumors Reported to the New York State Cancer Registry in 2017 by 3 Oncology Practices

Characteristic	*Reported by practice only*	*Reported by multiple sources*	*P*†
Number of tumors*	233	2,991	
% of total	7.2	92.8	
Mean (SD) age in years	69 (15)	66 (13)	.001
Female, %	59.0	63.1	.23
Non-Hispanic White, %	92.6	87.6	.03
First reportable cancer, %	72.5	79.4	.01
Disease stage at diagnosis, %			
In situ/local	19.3	44.7	<.001
Regional/distant	66.1	52.5	
Unknown	14.6	2.9	
Received surgery‡, %	19.3	57.3	<.001
Received chemotherapy‡, %	24.9	44.6	<.001
Received radiation therapy‡, %	9.9	40.3	<.001
Received hormonal therapy‡, %	8.6	30.0	<.001
Received immunotherapy‡, %	6.4	15.1	<.001

Percentages may not sum to 100 due to rounding.

* Includes 119 individuals with two separate tumors reported in 2017; of these, one individual had both tumors reported by an oncology practice only, 103 individuals had both tumors reported by multiple sources, and 15 individuals had one tumor reported by multiple sources and one reported by an oncology practice only. For patient-level characteristics (age, sex, and race/ethnicity), frequencies are reported at the individual level (N = 3,105) instead of the tumor level and categorized based on report of any tumor by multiple sources.

† *P*-value from *t* test for age and $\chi 2$ test for categorical variables.

‡ Received during initial treatment.

White (92.6% vs 87.6%; *P* = .01). Examining characteristics of the 3,224 reported tumors, those that were reported by an oncology practice only were statistically significantly less likely to be a first reportable cancer (72.5% vs 79.4%; *P* = .01) or to receive treatment (*P* < .001 for receipt of surgery, chemotherapy, radiation therapy, hormonal therapy, and immunotherapy during initial treatment). Tumors reported by an oncology practice only were statistically significantly more likely to be regional/distant stage (66.1% vs 52.5%) or to have unknown stage (14.6% vs 2.9%; *P* < .001) (Table 2).

The primary site frequency distribution also differed for tumors reported by an oncology practice only versus those reported by multiple sources (Table 3). The most common cancer sites for tumors reported by both an oncology practice and 1 or more other sources were breast (33.5%), lung (17.1%), colorectal (8.4%), non-Hodgkin lymphoma (6.1%), leukemia (4.3%), and prostate (3.9%). In contrast, tumors reported by an oncology practice only were most likely to be coded as miscellaneous sites using the SEER site recode value of 37000 (38.2%), followed by leukemia (15.9%), non-Hodgkin lymphoma (10.3%), breast (6.9%), myeloma (5.6%), or colorectal (4.3%). Of the tumors coded as miscellaneous sites, the reported primary site was bone marrow (C421) for 94.4% of cases reported by an oncology practice only and 63.9% of cases reported by multiple sources, indicating that the majority of the miscellaneous tumors were hematopoietic cancers (results not shown). For miscellaneous site tumors reported by multiple sources, the next most commonly reported primary sites were C809 for an unknown primary site (19.6%) and C420 for blood (11.3%).

No relevant claims were recorded for 5 of the 233 tumors (2.1%) reported by an oncology practice only, indicating that these tumors would not be captured if oncology practices were to cease reporting abstracted data to the registry (results not shown). Of the 2,991 tumors reported by multiple sources, 113 were not included in the claims data (3.8%). However, we would expect these cases to still be reported if oncology practices were to cease reporting abstracted data to the registry, because of reporting by other facilities or sources.

Discussion

Our results indicate that a small proportion of tumors reported by oncology practices are not reported by other sources and would be lost if oncology practices were to cease reporting. In our sample, cancers reported by oncology practices only tended to differ from those reported by both an oncology practice and at least 1 other reporting source. Cancers reported by an oncology practice only were more advanced and less likely to be treated than the larger population of cases seen and reported by oncology practices. These results indicate that the omission of cancers seen and reported by oncology practices only would result in a slight bias in case characteristics. Although claims data are valuable and can provide data on some cancers reported by physician practices only, they do not capture all of these

Table 3. SEER Cancer Sites Most Frequently Reported by 1 vs Multiple Sources among 3,224 Malignant Tumors Reported to the New York State Cancer Registry in 2017 by 3 Oncology Practices

SEER site group and recode values	*n*	*%*
Reported by oncology practice only (N = 233)*		
Miscellaneous (37000)	89	38.2
Leukemia (35011–35043)	37	15.9
Non-Hodgkin lymphoma (33041–33042)	24	10.3
Breast (26000)	16	6.9
Myeloma (34000)	13	5.6
Colorectal (21041–21052)	10	4.3
Reported by multiple sources (N = 2,991)*		
Breast (26000)	1,003	33.5
Lung and bronchus (22030)	512	17.1
Colorectal (21041–21052)	251	8.4
Non-Hodgkin lymphoma (33041–33042)	183	6.1
Leukemia (35011–35043)	129	4.3
Prostate (28010)	116	3.9
Miscellaneous (37000)	97	3.2
Pancreas (21100)	94	3.1
Melanoma (25010)	64	2.1

* Cancer site groups with fewer than 10 cases or less than 2% of total cases are excluded from the table.

cases and also do not include all data that would be reported in a full record abstract. While automated reporting of electronic claims data has the potential to reduce the burden on oncology practices for reporting cases, it increases the work required by central cancer registries to identify and create a complete record for a case. This analysis suggests that additional work is needed to optimize automated reporting of cancer data, to ensure that information is not lost and to minimize the burden on central cancer registries.

To our knowledge, no prior studies have compared characteristics of cases reported to a central cancer registry by an oncology practice only to those reported by multiple sources. However, previous studies have examined the use of claims data for ascertainment of cancer diagnoses, particularly for cancers often diagnosed and treated outside of a hospital setting. A study of automated billing data from a large urology practice noted that some additional unreported prostate and bladder cancer cases could be identified by using claims data, but also noted that cases would be lost if the practice was no longer actively reporting.[22] Similarly, a study of hematologic malignancies identified additional cases in claims data that were not reported to a central cancer registry, with the highest proportion of unreported cases for chronic lymphocytic leukemia (CLL), and estimated that diagnostic accuracy in the claims data was 95% overall and 88% among cases without a match in the cancer registry data.[23] A third study reported that using Medicare data would increase the number of chronic myeloid leukemia (CML) cases reported to SEER registries by 10.7% and the number of bladder cancer cases by between 3.8 and 8.1%.[24] Two other studies assessed use of Medicare data to identify incident cases of common cancer types. Warren et al reported poor sensitivity of Medicare hospital and physician claims data to identify incident breast cancer cases reported to 1 of 5 SEER registries in 1992, as well as low positive predictive value for cases identified as having breast cancer based on Medicare claims data.[25] In contrast, Penberthy et al observed higher positive predictive values for identification of breast, prostate, and lung cancers in Medicare inpatient, outpatient, and physician data and noted the value of claims data in supplementing surveillance activities of state cancer registries.[26]

Other studies have assessed the benefits of augmenting central cancer registry data with automated claims data from physician practices. In a pilot project conducted in Florida, researchers observed that the addition of electronic claims data to registry data resulted in more accurate data on receipt of chemotherapy compared to what was reported to the registry, and that combining chemotherapy information from registry data and claims data was equivalent to the gold standard assessment using electronic health record data.[9] Other studies have similarly shown the benefit of claims data for improving registry data on receipt of cancer treatments including chemotherapy, hormone therapy, immunotherapy, and radiation therapy.[16,22,27-29]

These and other previous studies have demonstrated the benefits of using electronic claims data to augment cancer reporting, including identification of additional unreported cases, more rapid ascertainment of cases, and availability of additional data including more accurate treatment information. However, several limitations of electronic claims data hinder its use in place of cancer reporting by diagnosing and treating facilities. As noted in our study and in previous studies, some cancer cases are not captured in claims data and would not be reported using electronic claims data alone. Additional work is needed to characterize cases not captured in claims data, and whether these cases could be identified using other diagnosis codes such as those for palliative care. In addition, electronic claims data do not include several variables needed by central cancer registries, such as stage and tumor pathology, necessitating follow up of reported cases to obtain complete data. Further, electronic claims data may incorrectly identify cases or identify prevalent rather than incident cases, resulting in additional work by central cancer registries to determine whether a case is reportable. Although reliance on electronic reporting of claims data has the potential to decrease the reporting burden for physician practices, more work is needed to ensure that cases and key data elements are not lost and that the additional workload placed on central cancer registries is minimized.

Strengths of our analysis include the large number of cases included representing patients diagnosed with cancer at 3 oncology practices in 2017, and the availability of complete claims data for these practices. Further, the NYSCR has received gold-level certification since 1998 and routinely meets or exceeds all data standards for timeliness, completeness, and quality. However, there are also several

limitations of the analysis, including the focus on 1 year of data for 3 oncology practices, which may not be representative of other years, all regions of New York State, or other regions of the United States. In addition, we only examined cases that had already been reported to the NYSCR, and we were therefore unable to examine whether the claims data included previously unreported cases for these oncology practices. In addition, the claims data we retrieved from SEER*DMS included limited variables and may not reflect all information that is available in claims data and that could augment reported case data. Although there are limitations of the claims data, including the unavailability of claims for almost 4% of cases included in our analysis, there are also limitations of data reported by physician practices. Among the cases reported by an oncology practice only, 38.2% were coded with miscellaneous site and 14.6% with unknown stage, suggesting that there are deficiencies in the reports from some physician practices to central cancer registries. These limitations of the reported data may have contributed to the differences we observed between the cases reported by oncology practices only and those reported by multiple sources and should be considered when evaluating the benefits and limitations of automated claims data reporting.

In summary, our results indicate that although electronic claims data can identify the majority of cancer cases diagnosed or treated at oncology practices, including cases not reported by other sources, a small percentage of cases and several key data elements would be missed by relying on electronic claims data alone. We observed differences between cases reported by oncology practices only and those reported by multiple sources, indicating that the loss of some cases reported solely by physician practices may result in underreporting of certain types of cancer cases and bias in reported case characteristics. Although electronic claims data are valuable for casefinding, augmenting registry data, and research purposes, additional work is needed to optimize electronic claims data reporting before automated data can replace cancer reporting by physician practices and other facilities.

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Original Article

Cancer Incidence Rate Variations among the Chinese, South Asian, and Vietnamese in Massachusetts, 2011–2015

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Abstract: Objectives: To examine cancer incidence among the 3 Asian, non-Hispanic ethnicities with the highest frequency of cases (South Asian, Chinese, and Vietnamese). Methods: Age-adjusted incidence rates for all invasive cancers were calculated for South Asian (Indian, Pakistani), Chinese, and Vietnamese cancer cases reported to the Massachusetts Cancer Registry (MCR). Additionally, rates were calculated for the most frequent cancers among non-Hispanic Asians (prostate, colorectal, female breast, female thyroid, lung, and male liver). The 95% confidence intervals were calculated to determine statistical significance between the rates. Results: South Asian and Vietnamese females had significantly elevated rates of all invasive cancers compared to Chinese females, while Chinese and South Asian females had a significantly elevated breast cancer rate. Vietnamese males had a significantly elevated rate of all invasive cancers, liver cancer, and lung cancer compared to the other 2 groups. Due to the high rates of lung cancer among Vietnamese males, MCR current/previous smoking data were compared for all cancers. Among Vietnamese, Chinese, and South Asian male cancer cases, current/previous smoking percentages were 64%, 51%, and 35%, respectively. Conclusions: Our analyses showed a significant difference of rates for several cancers by specific Asian ethnicity within the broader Asian, non-Hispanic race category. Differences in tobacco use, maternal hepatitis B infection, and diet likely contribute to some of the differences. These data can aid in the development of prevention programs, such as smoking cessation and mammography screening that are culturally and linguistically specific within this large and diverse group.

Key words: *Asian ethnicity, Chinese peoples, South Asian peoples, Vietnamese peoples*

Background

According to the US Census definitions, *Asians* are people having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent.[1] Despite being part of the Asian continent, Arab people from the Middle East are, for the most part, counted as White non-Hispanics, as are Arabs from North Africa. According to the 2011–2015 American Community Survey of the US Census (ACS) estimates, Asian non-Hispanics constituted 5.9% of the general population in Massachusetts and 5.1% of the US population. The 2011–2015 ACS estimated that the Massachusetts Asian population was primarily Chinese (37%), South Asian (22%), Vietnamese (12%), Cambodian (8%), Korean (7%), Filipino (3%), and Japanese (2%).

Asians are routinely presented as 1 of the 4 main racial ethnic categories for cancer statistics released by the Massachusetts Cancer Registry (MCR). They are presented as Asian, non-Hispanic, though Asian Hispanics represented only 0.3% of the total Asian cases in the study period. In the MCR annual report for 2011–2015, non-Hispanic Asian males had the significantly lowest rate of all male cancer types combined with 312.4 (95% CI, 298.6–326.2) cases per 100,000 for the years 2011–2015 compared to 498.2 (95% CI, 494.5–501.8) for White non-Hispanics, 514.6 (95% CI, 498.4–530.7) for Black non-Hispanics, and 376.6 (95% CI, 362.0–391.1) for Hispanics. Non-Hispanic Asian females had the lowest rate, as well (307.2; 95% CI, 295.3–319.1), significantly lower than White non-Hispanics (464.5; 95% CI, 461.2–467.8) and Black non-Hispanics (399.1; 95% CI, 387.3–410.9), though not significantly lower than Hispanics (324.1; 95% CI, 315.9–338.0). Both non-Hispanic Asian males and females had lower rates for most individual cancers when compared to White and Black non-Hispanics and comparable rates to Hispanics, with the exception of liver cancer for both sexes.[2]

As described earlier, Asians are a very large and diverse group of people coming from an area thousands of miles from Japan to Pakistan and Mongolia to Indonesia. The language, diet, social norms, traditional healing practices, and religion of someone from India are very different than someone from China or Japan or the Philippines, yet they are grouped together under the auspices of Asian. A recent paper on Asian Americans and prostate cancer highlighted the differences among various Asian groups and showed the need for disaggregation of these data.[3] In order to better understand the diverse ethnic groups within the Asian category, this study examines in more detail the differences in cancer incidence between the 3 most populous Asian ethnic groups in Massachusetts: Chinese, South Asians (Indian and Pakistani), and Vietnamese.

Table 1 presents some demographic differences between South Asians, Chinese, and Vietnamese residents of Massachusetts.[4] The median income education levels are much higher among South Asians. The percentage of those American born is about equal among the 3 groups, while there are higher percentages of English speakers among South Asians. English is an official language in both Pakistan and India.

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Table 1. Characteristics of South Asian, Chinese, and Vietnamese People in Massachusetts, 2010–2014

	South Asian	*Chinese*	*Vietnamese*
Nativity			
Native born	30.9%	31.5%	32.5%
Naturalized	28.7%	36.0%	49.4%
Not a citizen	40.4%	32.5%	18.1%
Language			
English only	22.0%	17.7%	10.2%
English spoken well	56.7%	29.5%	38.6%
English spoken not well	21.3%	52.8%	61.2%
Poverty Level			
Individual poverty rate	6.1%	16.0%	16.7%
Family poverty rate	3.5%	9.9%	15.6%
Income			
Median household income	$113,566	$69,581	$56,895
Education			
Graduate degree	52.6%	34.2%	6.7%
Bachelor's degree	29.7%	23.1%	19.2%
High school diploma	11.5%	25.0%	43.0%
No high school diploma	6.2%	17.7%	31.1%

Source: 2010-2014 American Community Survey.

Methods

Incident invasive cancers in Massachusetts residents from 2011–2015 were provided by the MCR. Approximately 9% of non-Hispanic Asians were reported to the MCR from 2011–2015 with a specific ethnicity not otherwise specified (NOS). Since having a large number of NOS cases would lead to an underestimate of incidence rates for these ethnic groups, we recoded these cases based on the distribution of selected cancer types among cases with a specified ethnicity. For example, among Asian non-Hispanic males with a specified ethnicity, 48% of prostate cases were Chinese, 16% were South Asian (Indian or Pakistani), 9% were Vietnamese, and 27% were other. Prostate cancer cases among Asian NOS males were then recoded based on these distributions.

Once the NOS cases were recoded, analyses were limited to cancers with the highest frequencies among non-Hispanic Asians (all invasive, female breast, colorectal, liver, lung, thyroid, and prostate) in order to obtain statistically viable results. Even with this, rates were not calculated for cancers with fewer than 20 cases. Although the methodology for recoding Asian, NOS yielded estimated numbers for these groups, it is not a replacement for having actual numbers. Still, the importance of using the available data on Chinese, South Asians, and Vietnamese for these estimations in order to highlight the differences in incidence rates within the Asian, non-Hispanic category outweighed the limitations placed on the data analysis by the data quality.

While the population data for the Asian, non-Hispanic group as a whole and the total Massachusetts group came from US intercensal figures, the population estimates for the Chinese, Vietnamese, and South Asians were from the US Census 2011–2015 American Community Survey (ACS) estimates. As with the NOS reclassification methods, there are limitations to ACS data in terms of precision of the data resulting from smaller sample sizes. Incidence and mortality rates are per 100,000 and are age-standardized to the 2000 United States Census population. All statistical analyses were performed using SAS 9.3 (SAS Institute Inc).[5] We calculated 95% confidence intervals for incidence rates for the period and then examined the intervals for overlap to determine statistically significant differences (no overlap) or no significant differences (overlap). Rates were compared between South Asians, Chinese, and Vietnamese. These groups were then compared to all Asians and to all invasive cancer cases in Massachusetts, regardless of race/ethnicity.

Results

South Asian and Vietnamese females had significantly elevated rates of all invasive cancers compared to Chinese females, though significantly lower than all Massachusetts females. Additionally, the incidence rate for Vietnamese females was significantly elevated compared to all Asians. South Asian females had a breast cancer rate that was significantly elevated compared to all other Asian groups, but comparable to all Massachusetts females. Colorectal and lung cancer rates did not differ significantly within the Asian groups though only the rates among South Asian and Vietnamese females were significantly lower than all Massachusetts females. There were no significant differences in thyroid cancer between any of the groups, including all Massachusetts females (Table 2).

Vietnamese males had a significantly elevated rate of all invasive cancers compared to the other Asian groups, but significantly lower than all Massachusetts males. Like Vietnamese females, the incidence rates for males was significantly elevated compared to all Asians. While prostate and colorectal cancer rates were significantly lower than all Massachusetts males and comparable to all Asians, Chinese males did have a significantly elevated rate of prostate cancer compared to Vietnamese males. Compared to South Asian males, Chinese and Vietnamese males had significantly elevated rates of lung cancer. Vietnamese males in turn had a significantly elevated lung cancer rate compared to Chinese males. Vietnamese males also had a significantly elevated lung cancer rate compared to all Asian and Massachusetts males. The same was true for liver cancer with Vietnamese males having a significantly elevated rate compared to the other Asian groups and all Massachusetts males (Table 3).

Due to the high rates of lung cancer among Vietnamese males, tobacco use data among all cancers in the MCR were analyzed. Among Vietnamese, Chinese, and South Asian males, where there were significant lung cancer differences, the percentages of current or previous tobacco use were 64% (Vietnamese), 51% (Chinese), and 35% (South Asian). These percentages are likely an underestimate.[6]

Table 2. Age-Adjusted Cancer Incidence Rates (95% CI) among Specific Asian Ethnicities Compared to All Asians and All Massachusetts* Cases, Females, 2011–2015

Cancer	*South Asian (n = 484)*	*Chinese (n = 1,159)*	*Vietnamese (n = 324)*	*All Asian (n = 2,226)*	*All Massachusetts (n = 95,757)*
All invasive	324.9 (296.0–353.9)	270.1 (254.5–285.6)	369.7 (329.5–410.0)	309.1 (297.6–320.6)	450.9 (448.0–453.8)
Breast	126.5 (108.7–144.4)	77.2 (69.1–85.3)	83.3 (67.1–99.6)	91.1 (85.1–97.2)	137.6 (136.0–139.3)
Colorectal	20.4 (12.7–28.1)	27.6 (22.5–32.7)	22.0 (13.4–30.7)	28.7 (25.0–32.3)	33 (32.5–33.9)
Lung	NA	33.2 (27.5–38.8)	48.5 (29.8–67.1)	33.1 (29.1–37.2)	60.2 (59.1–61.2)
Thyroid	32.4 (24.4–40.5)	27.4 (22.6–32.2)	37.7 (27.2–48.1)	29.7 (26.4–33.0)	29.6 (28.7–30.4)

* *All Massachusetts* indicates all cancer cases in Massachusetts regardless of race/ethnicity. Rates are per 100,000 and were age adjusted to the 2000 US Standard Population. *NA* indicates fewer than 20 cases.

Table 3. Age-Adjusted Cancer Incidence Rates (95% CI) among Specific Asian Ethnicities Compared to All Asians and All Massachusetts* Cases, Males, 2011–2015

Cancer	*South Asian (n = 373)*	*Chinese (n = 1,000)*	*Vietnamese (n = 348)*	*All Asian (n = 2,777)*	*All Massachusetts (n = 87,884)*
All invasive	261.6 (235.0–288.1)	314.0 (294.6–333.5)	412.5 (369.2–455.8)	313.9 (300.8–326.9)	493.9 (490.6–497.3)
Prostate	62.6 (48.5–76.7)	68.5 (59.4–77.6)	42.9 (29.6–56.3)	57.3 (51.8–63.2)	106.3 (104.8–107.8)
Colorectal	20.6 (13.0–28.3)	32.8 (26.6–39.0)	52.4 (36.5–68.2)	32.4 (28.2–36.6)	41.8 (40.9–42.8)
Lung	32.3 (22.2–42.4)	62.3 (53.5–71.2)	106.4 (83.5–129.3)	57.9 (51.9–63.8)	69.3 (68.0–70.6)
Liver	NA	22.3 (17.3–27.3)	70.9 (53.2–88.5)	26.1 (22.4–29.8)	12.9 (12.4–13.4)

* *All Massachusetts* indicates all cancer cases in Massachusetts regardless of race/ethnicity. Rates are per 100,000 and were age adjusted to the 2000 US Standard Population. *NA* indicates fewer than 20 cases.

Conclusions

Our analyses showed a significant difference of rates for several cancers by specific Asian ethnicity within the broader Asian, non-Hispanic race category. The significantly lower rates for prostate and colorectal cancers among all Asian ethnicities compared to total rates found in this study has been previously described.[2] In the current study, there were some variations within Asian ethnic groups with Vietnamese males having a significantly lower prostate cancer incidence rate compared to Chinese males. Both groups, however, did not differ significantly from the prostate and colorectal rates for all non-Hispanic Asian males.

Breast cancer rates were highest among South Asian females, higher than what was reported nationally for 2008–2012.[7] Those national figures showed South Asian and Chinese with comparable breast cancer rates, but higher than Vietnamese females and lower than non-Hispanic white females. The current study found breast cancer rates among South Asian females to be significantly higher than the rate for all non-Hispanic Asian females and comparable to all Massachusetts cases. A 2010 study on breast cancer screening among South Asians suggested that the adoption of a western lifestyle may increase the risk of breast cancer among Asian immigrants.[8]

Vietnamese males had significantly elevated incidence rates of lung and liver cancer compared to all non-Hispanic Asian males and all Massachusetts males. These 2 cancers are the most common cancers in Vietnam among both males and females. The Vietnamese government has put tobacco control policies into place, resulting in a drop from 56% of all males smoking to 47% from 2002–2010.[9] Additionally, most newborns in Vietnam are immunized against hepatitis B to prevent future infections and cases of liver cancer.[9]

This study highlighted some of the ethnic differences in cancer incidence within the category of Asian, non-Hispanic in the Massachusetts Cancer Registry. While most of the cancers among non-Hispanic Asian ethnicities examined for this study did not differ significantly from all Asian, there were some notable differences in female breast cancer, lung, and liver cancer. These Asian groups differ not only in cancer rates, but also exhibit significant differences in income, education, and language, all of which can limit access to health care. Additionally, smoking data prevalence among adults (aged ≥18 years) from the 2016 National Survey on Drug Use and Health showed Vietnamese having higher percentages (16.3%) compared to South Asians and Chinese (both 7.6%).[10] The knowledge of all these differences can aid in the development of prevention programs, such as smoking cessation, mammography, and hepatitis B vaccination, that are culturally and linguistically specific within this large and diverse group.

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Original Article

Unintended Consequences of Expanding Electronic Pathology Reporting: The Inverse Relationship Between Data Completeness and Data Quality

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Abstract: Background: In 2016, the New Jersey State Cancer Registry (NJSCR) began expanding electronic laboratory reporting. As a result, the number of electronic pathology reports (EPRs) submitted to NJSCR increased markedly from 2015 to 2017. EPRs are more likely to contain incomplete or missing race than North American Association of Central Cancer Registry (NAACCR) abstracts from hospitals and physician offices. NJSCR staff conduct follow-back for additional information for laboratory-only cases, but response rates are poor, the process is lengthy, and laboratory reports often do not include physician information. Purpose: To assess the impact of increased EPR on the quality of race data. Methods: NJSCR data sets created 24 months after the end of the diagnosis year—with data that were more than 98% complete—were used to calculate the percent of EPR-only cases by primary site and the percent of cases with unknown race. We calculated the relative risk of unknown race by site, compared to all sites, and used Spearman's ρ to assess the correlation between EPR-only cases and unknown race. Results: While the percent of cases with unknown race was within the standards for NAACCR Gold Certification (3%), it varied by cancer site. Sites less likely to be reported by hospitals had higher rates of unknown race in the 24-month data set: prostate, leukemia, melanoma, bladder. After follow-back and death clearance activities, ≥36 months after the diagnosis year, the percent of cases with unknown race is reduced, although the impact varies by cancer site. Conclusion: Race-specific incidence rates for certain cancer types may be artificially depressed in the 24-month data set due to the unavailability of race for the increasing number of laboratory-only cases. While follow-back activities help to improve the collection of race data over time, these new values are not available until a revised data set is released. The higher proportion of unknown or other race in the 24-month data set impacts the accuracy of reporting the burden and trends of cancer by race. In addition, cases with unknown race may be ineligible for inclusion in cancer surveillance research studies.

Key words: *cancer reporting, completeness, electronic reporting, e-path, laboratory reporting, unknown race*

Introduction

A complete accounting of all incident cases of cancer is fundamental to the successful operation of a population-based cancer surveillance program.[1] Acute care hospitals have traditionally served as the primary means of case ascertainment and reporting of cancer to central registries. While hospitals remain the primary source of incident cases reported to central cancer registries, a growing trend toward cancer diagnosis and treatment services in nonhospital settings—particularly for skin, urologic, and some hematologic malignancies—means that laboratories, physician practices, and other outpatient facilities play an important role in supplementing diagnostic and treatment information and in identifying cancers that would otherwise go unreported.

Collecting detailed information that characterizes individual tumors, as well as the patients themselves, allows registries to analyze trends in cancer burden and outcomes by factors such as patient race and stage at diagnosis. These data provide the basis for understanding and assessing health disparities, the impacts of screening and early detection, treatment effectiveness, and survival. Data that include missing, unknown, or nonspecific values for key variables such as race cannot be included in stratified analyses. In some cases, the proportion of cases with unknown values may be great enough to significantly underestimate race-specific cancer incidence.

In this study, we aimed to assess the impact that increased electronic laboratory reporting (EPR) had on race-specific cancer incidence rates in New Jersey.

Methods

Data were obtained from the New Jersey State Cancer Registry (NJSCR), a population-based registry authorized under New Jersey state law to conduct cancer surveillance activities. Data were collected with support from the National Cancer Institute's (NCI's) Surveillance, Epidemiology, and End Results (SEER) program and the Centers for Disease

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Figure 1. Volume of Electronic Pathology Reports Sumitted to NJSCR by Year, 2015-2017

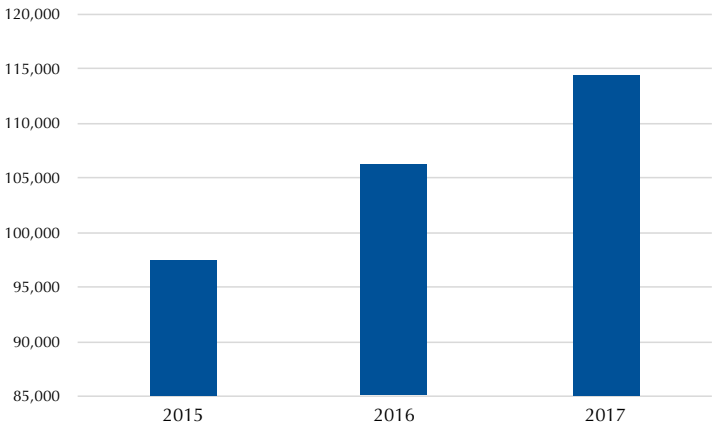


Figure 2. Cancer Types with Highest Percent of Cases from Electronic Pathology Only, 2015-2017

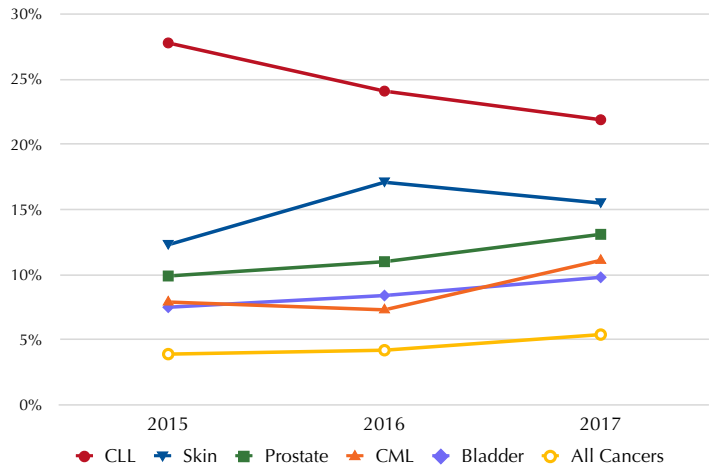


Figure 3. Percent of Incoming Records with Unknown or Other Race by Reporting Source, 2015-2017

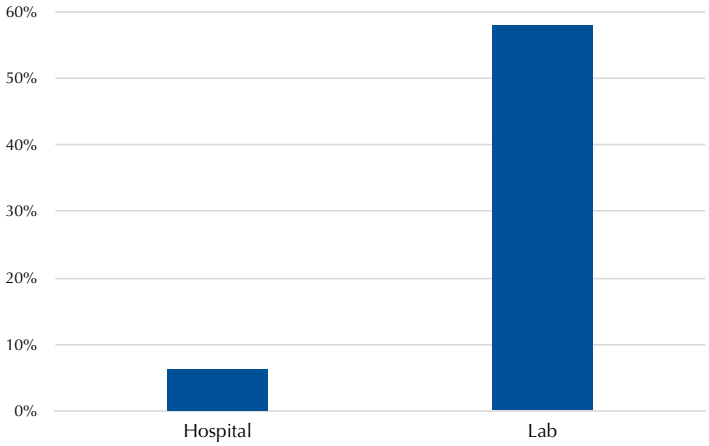
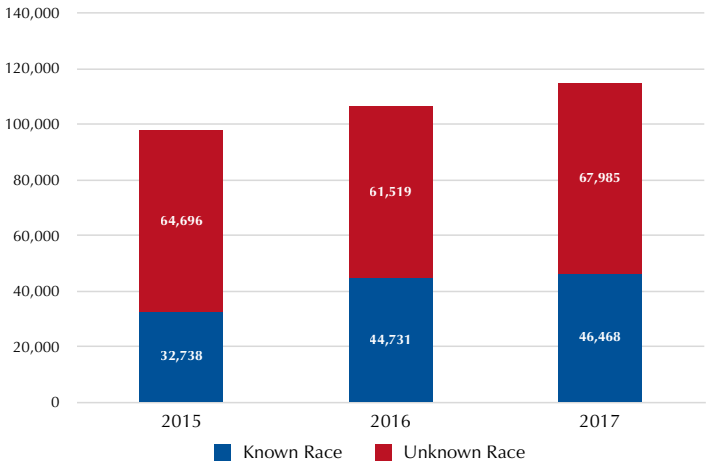


Figure 4. Electronic Pathology Reports Submitted to NJSCR with Known and Unknown Race by Year, 2015-2017



Control and Prevention (CDC) National Program of Cancer Registries (NPCR) and in accordance with standards set forth by the North American Association of Central Cancer Registries (NAACCR).[2] Both consolidated cases and source records reported to the NJSCR between 2015–2017 were analyzed by primary site, race, and reporting source. Spanish/Hispanic origin was not included in the analysis because there is no national standard for completeness of that variable, though the percent of cases with unknown Spanish/Hispanic origin tends to follow that of race.

For each cancer type, we calculated the percent of cases for which an electronic pathology report was the sole source of information reported to the registry, as well as the percent of cases for which no race was reported. We compared the percent of cases with unknown race for each cancer type to that of all cases to calculate relative risk (RR). The correlation between the proportion of laboratory-only cases and unknown race was measured using Spearman's ρ (r_s). All calculations were performed using MedCalc for Windows, version 19.4.1 (MedCalc Software), with significant correlations set at $P < .05$ ($\alpha = 0.05$).

Figure 5. Percent of Cases with Unknown Race for Cancer Types with Highest Proportion of Pathology Only, 2015-2017

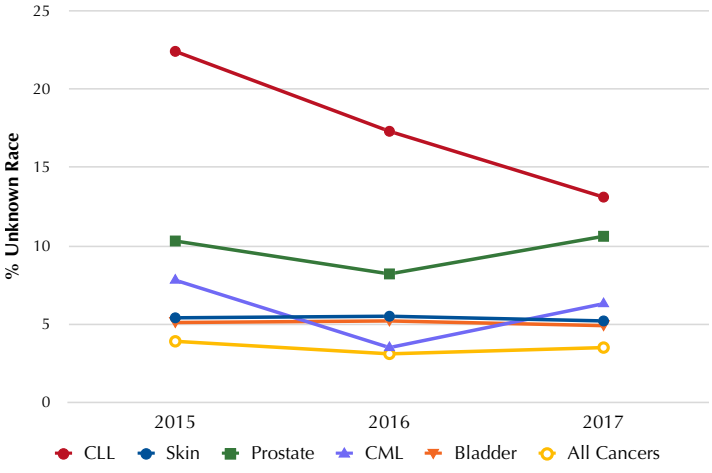


Table 1. Relative Risk (RR) of Cases with Unknown Race by Cancer Type Compared to All Cancers Combined, 2015–2017*

Cancer type (count)	*Laboratory only (%)*	*Unknown race (%)*	*RR*	*P Value (α = .05)†*
All Sites (155,183)	4.4	3.5%	1.00	--
Lip (113)	4.7	9.7	2.77	.0004
Tongue (1,157)	0.3	2.1	0.59	.0093
Salivary gland (437)	2.5	2.3	0.65	.1713
Floor of mouth (149)	2.4	3.4	0.96	.9182
Gum and other mouth (572)	1.7	1.7	0.50	.0263
Nasopharynx (162)	0.6	3.1	0.88	.7700
Tonsil (678)	0.6	1.2	0.34	.0019
Oropharynx (176)	0.6	2.3	0.65	.3792
Hypopharynx (166)	0.0	0.0	0.85	.0813
Other oral cavity and pharynx (67)	4.2	1.5	0.42	.3807
Esophagus (1,409)	0.3	0.5	0.34	<.0001
Stomach (2,543)	1.1	2.2	0.65	.0007
Small intestine (852)	1.8	3.4	0.97	.8658
Colon and rectum (12,900)	1.1	2.1	0.61	<.0001
Anus, anal canal, and anorectum (589)	1.8	2.0	0.58	.0571
Liver (2,115)	0.3	2.0	0.57	.0002
Intrahepatic bile duct (493)	0.2	1.0	0.89	.0053
Gallbladder (377)	0.5	1.6	0.45	.0509
Other biliary (626)	0.3	1.3	0.36	.0040
Pancreas (4,681)	0.3	0.7	0.21	<.0001
Retroperitoneum (91)	0.0	2.2	0.63	.5031
Peritoneum, omentum, and mesentery (119)	0.0	0.0	0.12	.1310
Other Digestive Organs (258)	0.8	0.8	0.22	.0320
Nose, nasal cavity, and middle ear (220)	0.9	2.7	0.78	.5308
Larynx (928)	0.5	1.3	0.37	.0005
Lung and bronchus (17,529)	0.2	0.5	0.16	<.0001
Pleura (5)	20.0	0.0	2.37	.5232
Trachea, mediastinum, and other respiratory organs (43)	0.0	2.3	0.66	.6769
Bones and joints (301)	1.0	2.0	0.57	.1616
Soft tissue including heart (1,049)	0.8	2.9	0.81	.2558
Skin excluding basal and squamous (7,612)	12.3	5.3	1.52	<.0001
Breast (23,312)	0.6	1.5	0.42	<.0001
Cervix uteri (1,153)	0.9	1.6	0.47	.0009
Corpus and uterus, NOS (5,769)	0.6	1.7	0.49	<.0001
Ovary (2,021)	0.2	1.4	0.41	<.0001
Vagina (104)	3.9	1.9	0.55	.3901
Vulva (518)	5.3	2.3	0.66	.1455
Other female genital organs (353)	0.8	1.7	0.48	.0733
Prostate (21,098)	11.4	9.7	2.77	<.0001

Table 1, cont. Relative Risk (RR) of Cases with Unknown Race by Cancer Type Compared to All Cancers Combined, 2015–2017*

Cancer type (count)	*Laboratory only (%)*	*Unknown race (%)*	*RR*	*P Value (α = .05)†*
Testis (754)	3.9	6.5	1.85	<.0001
Penis (121)	17.4	4.1	1.18	.7098
Other male genital organs (37)	9.5	8.1	2.30	.1305
Urinary bladder (7,474)	8.6	5.1	1.45	<.0001
Kidney and renal pelvis (5,206)	0.3	2.0	0.56	<.0001
Ureter (205)	1.3	0.0	0.07	.0586
Other urinary organs (149)	12.3	7.4	2.10	.0105
Eye and orbit (183)	1.5	5.5	1.56	.1505
Brain (1,854)	0.2	1.7	0.49	.0001
Cranial nerves other nervous system (107)	0.2	5.6	1.60	.2380
Thyroid (5,393)	0.7	3.5	1.01	.9034
Other endocrine including thymus (281)	0.3	2.5	0.71	.3583
Hodgkin, nodal (878)	0.4	3.1	0.88	.4856
Hodgkin, extranodal (18)	0.0	0.0	0.75	.8363
NHL, nodal (4,342)	1.6	2.0	0.56	<.0001
NHL, extranodal (2,545)	6.9	5.5	1.57	<.0001
Myeloma (2,430)	4.5	3.2	0.91	.4246
Acute lymphocytic leukemia (485)	1.6	3.1	0.88	.6185
Chronic lymphocytic leukemia (1,838)	24.6	17.5	4.99	<.0001
Other lymphocytic leukemia (149)	9.7	11.4	3.25	<.0001
Acute myeloid leukemia (1,340)	4.5	1.2	0.34	<.0001
Acute monocytic leukemia (80)	2.5	0.0	0.18	.2176
Chronic myeloid leukemia (573)	8.7	6.3	1.79	.0003
Other myeloid/monocytic leukemia (58)	5.1	1.7	0.49	.4732
Other acute leukemia (77)	0.0	1.3	0.37	.3169
Aleukemic, subleukemic, and NOS (145)	8.5	7.6	12.90	<.0001
Mesothelioma (357)	0.3	0.6	0.16	.0093
Kaposi sarcoma (104)	1.8	4.8	5.74	<.0001
Miscellaneous (5,255)	6.3	4.1	1.18	.0166

NHL, non-Hodgkin lymphoma; NOS, not otherwise specified.

* Relative Risk (RR) was calculated by comparing the proportion of unknown race for each cancer type relative to the proportion of unknown race for all cancer types combined.

† Although significance level was not adjusted for multiple comparisons, the risk of Type I errors was not felt to have any meaningful impact on the conclusions of this analysis.

Results

Between 2015 and 2017, 155,183 new invasive cases of cancer among New Jersey residents were reported to the NJSCR. The NJSCR received 318,137 EPRs during the same time frame; however, the number of EPRs submitted to NJSCR increased by 17.5% from 2015 to 2017 to nearly 115,000 reports (Figure 1). The percent of all New Jersey cancer cases with a laboratory as the sole reporting source (laboratory only) increased from 3.9% in 2015 to 4.2% in 2016 and to 5.4% in 2017. Some of the cancer types with the largest proportions of laboratory-only cases were chronic lymphocytic leukemia (24.6%); skin cancers, excluding basal and squamous cell carcinomas (12.3%); prostate cancers (11.4%); chronic myeloid leukemia (8.7%); and bladder cancers (8.6%) (Figure 2; Table 1).

EPRs were far less likely to contain the patient's race than hospital registry abstracts (42.0% vs 93.8%; Figure 3). While the percent of EPRs remained steady at approximately

60%, as the number of reports received increased, the number of reports without a documented race increased from 64,696 in 2015 to 67,985 in 2017, an increase of 5.1% (Figure 4).

The percent of all consolidated cases with an unknown race remained steady around 3%. Although there was no appreciable increase by cancer type, some cancers had higher proportions of unknown race compared to all cancers combined (Figure 5). Cancers with the highest proportion of laboratory-only cases also tended to have higher rates of unknown race: chronic lymphocytic leukemia (RR, 4.99; $P < .0001$), prostate, (RR, 2.77; $P < .0001$), chronic myeloid leukemia (RR, 1.79; $P = .0003$), skin (RR, 1.52; $P < .0001$), and bladder (RR, 1.45; $P < .0001$) (Table 1). We observed a statistically significant positive correlation between the percent of laboratory-only cases and the rate of unknown race ($r_s = 0.57$; $P < .0001$).

Discussion

National standards set forth by NAACCR, NCI, and CDC require cancer registries to meet strict criteria for quality, such as percent of cases with unknown race, in order to be considered fit for publication and use.[3-5] However, these standards are applied to all cases diagnosed in a given year. The result is that, while the aggregate data meet quality benchmarks (due in large part to the substantial effort of registry staff to conduct follow-back activities), data for a specific cancer site may fall below quality standards and, potentially, lead to downward bias in race-specific incidence rates.

This study revealed a statistically significant association between the proportion of cases with a laboratory as the only reporting source and the percent of cases with an unknown race. This is particularly problematic for cancers that are less likely to be treated in a hospital setting, such as certain urologic and skin malignancies and chronic leukemias. When data are used to calculate race-specific incidence rates, cases with an unknown race cannot be classified and are therefore excluded. Where the proportion of excluded cases is high enough, incidence rates may appear lower than the actual rate. This may lead to the false conclusion that incidence rates are declining for some cancer sites and among some racial groups, which could in turn lead to inaccurate assumptions about cancer burden, health disparities, and the effectiveness of screening and early detection programs. While rates of unknown race may improve over time as the data ages, researchers and other users of cancer registry data should be made aware of the proportion of unknown race in a given sample. This is particularly critical given nationwide efforts to increase early availability of cancer incidence data.

In addition to the effect on incidence rates, when the central cancer registry database is used as a source for patient recruitment into clinical trials and observational research studies, cases with no documented race may be excluded. Eligibility criteria for such studies, particularly those involving vulnerable populations, typically include race. A significant number of cases excluded from selection for missing race limits the pool of eligible candidates and may bias results, particularly for recruitment of individuals from more recent diagnosis years.

Population-based cancer registries across the country are expanding reporting from nonhospital sources in an effort to ensure complete capture of every new cancer case. Many of these new data sources, such as independent laboratories and medical billing claims, do not routinely include information on the patient's race. While registries may make every attempt to obtain complete information on cases reported by laboratories, the physician response rate is poor, the process is manual and labor-intensive, and many laboratory reports do not include the name of the ordering physician, leaving many cancer cases with incomplete information for key data items. Thus, an unintended consequence of expanding cancer reporting to increase completeness is a disproportionate decrease in the completeness of race-specific rates for certain cancer types. Calculated incidence rates for minority groups, for whom case counts tend to be smaller, would be especially impacted. It is likely that one would observe similar challenges with data stratified by other key variables, such as stage at diagnosis. Registries should explore alternative methods for obtaining demographic and other important data items through means that require less manual work, such as linkages with external databases.

The authors acknowledge the limitations of this study in that significance level was not adjusted for multiple comparisons. However, the risk of type I errors was not felt to have any meaningful impact on the conclusions of this analysis.

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Original Article

Informatics Methods and Infrastructure Needed to Study Factors Associated with High Incidence of Pediatric Brain and Central Nervous System Tumors in Kentucky

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Abstract: Pediatric brain and central nervous system tumors (PBCNSTs) are the most common solid tumors and are the leading cause of disease-related death in US children. PBCNST incidence rates in Kentucky are significantly higher than in the United States as a whole, and are even higher among Kentucky's Appalachian children. To understand and eventually eliminate such disparities, population-based research is needed to gain a thorough understanding of the epidemiology and etiology of the disease. This multi-institutional population-based retrospective cohort study is designed to identify factors associated with the high incidence of PBCNST in Kentucky, leveraging the infrastructure provided by the Kentucky Cancer Registry, its Virtual Tissue Repository (VTR), and the National Institutes of Health Gabriella Miller Kids First Data Resource Center (DRC). Spatiotemporal scan statistics have been used to explore geographic patterns of risk measured by standardized incidence ratios (SIRs) with 95% confidence intervals. The VTR is being used to collect biospecimens for the population-based cohort of PBCNST tissues that are being sequenced by Center for Data Driven Discovery in Biomedicine (D3b) at the Children's Hospital of Philadelphia (CHOP) with support from the Kids First DRC. After adjusting for demographic factors, we assess their potential relationship to environmental factors. We have identified regions in north-central and eastern Appalachian Kentucky where children experienced a significant increased risk of developing PBCNST from 1995–2017 (SIR, 1.48; 95% CI, 1.34–1.62). The VTR has been successful in the collection of a population-based cohort of 215 PBCNST specimens. Timely establishment of legal agreements for data sharing and tissue acquisition proved to be challenging which has been somewhat mitigated by the adoption of national agreement templates. Coronavirus disease 2019 (COVID-19) severely limited the generation of sequencing results due to laboratory shutdowns. However, tissue specimens processed before the shutdown indicated that punches were inferior to scrolls for generating enough quality material for DNA and RNA extraction. Informatics infrastructures that were developed have demonstrated the feasibility of our approach to generate and retrieve molecular results. Our study shows that population-based studies using historical tissue specimens are feasible and practical, but require significant investments in technical infrastructures.

Key words: *childhood cancer disparities, electronic pathology reporting, pediatric brain and central nervous system tumors, spatiotemporal scan statistics, virtual tissue repository*

Introduction

Approximately 15,000 children (aged 0–19 years) are diagnosed with cancer in the United States annually, compared with 1.7 million total new cancer cases diagnosed each year.[3] However, in spite of the relative rarity, cancer remains a leading cause of death in children and adolescents, second in rank only to motor vehicle crashes and other injuries.[4] Pediatric brain and central nervous system tumors (PBCNSTs) have recently surpassed leukemia as the leading cause of cancer death among children.[5] PBCNST incidence rates in Kentucky are significantly higher than in the United States as a whole, and are even higher among Kentucky's Appalachian children.[2,6] Our prior population-based study of all US childhood cancer cases from 2000–2011 has shown that the risk of developing PBCNST was 8% higher for Appalachian children compared to children residing outside of Appalachia.[7] The risk of developing a low-grade astrocytoma was 41% higher for Appalachian children for the years 2004–2011, suggesting that genomic risk factors may also play a role. It is widely recognized that genomic data are of increasing importance in the diagnosis, treatment, and outcomes of childhood cancer.[8-11] While population-based studies of childhood cancers remain limited overall, such disparities indicate that additional research is needed to gain a more thorough understanding of the factors that may be associated with geographic variations in the United States.[12] The maturation of informatics methods and infrastructures—such as spatiotemporal scan statistics, standardized electronic pathology (E-Path) reporting, and genomic data commons—provide new opportunities for central cancer registries to facilitate collaborative studies of the epidemiology and etiology of PBCNST.[13-16]

Here, we describe our approach to assessing the childhood cancer burden in Kentucky and the ensuing multi-institutional population-based retrospective cohort

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Figure 1. Age-Adjusted Pediatric Cancer Incidence Rates, 2007–2016[1,2]

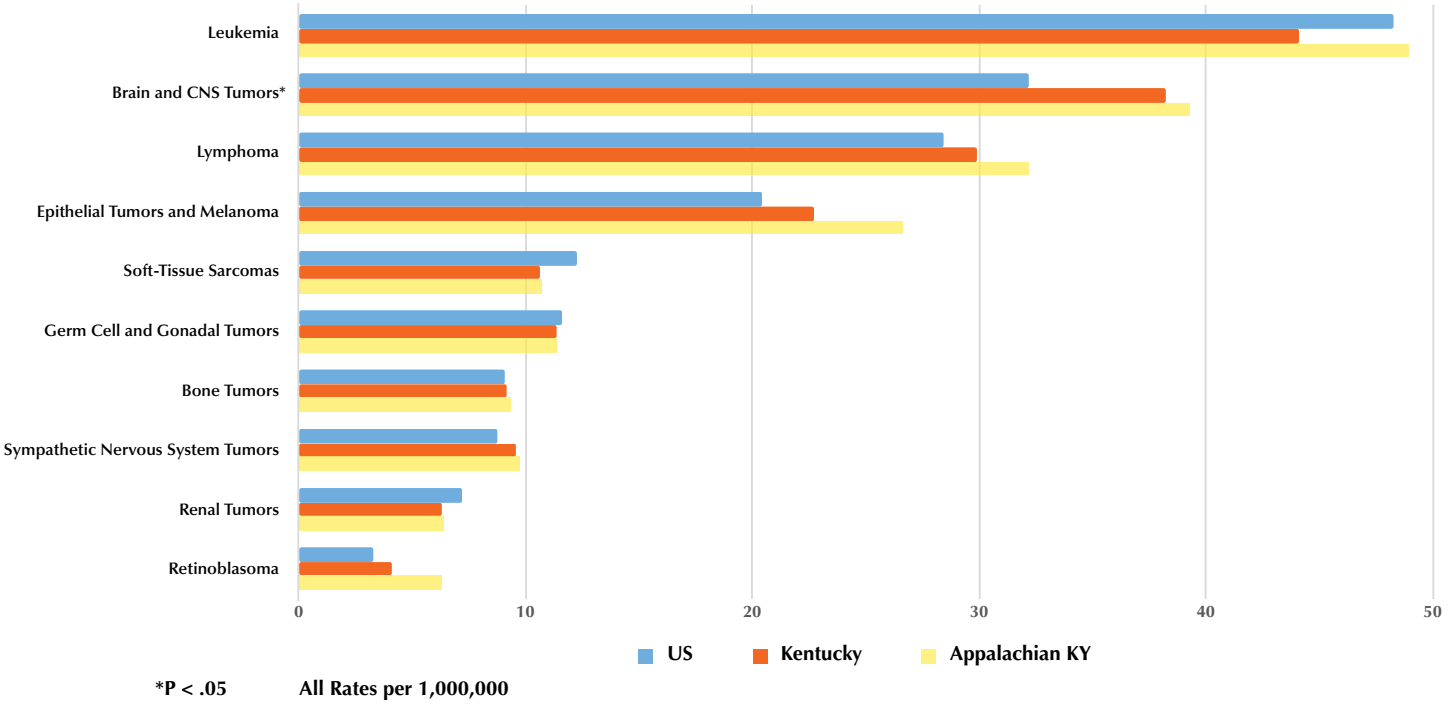
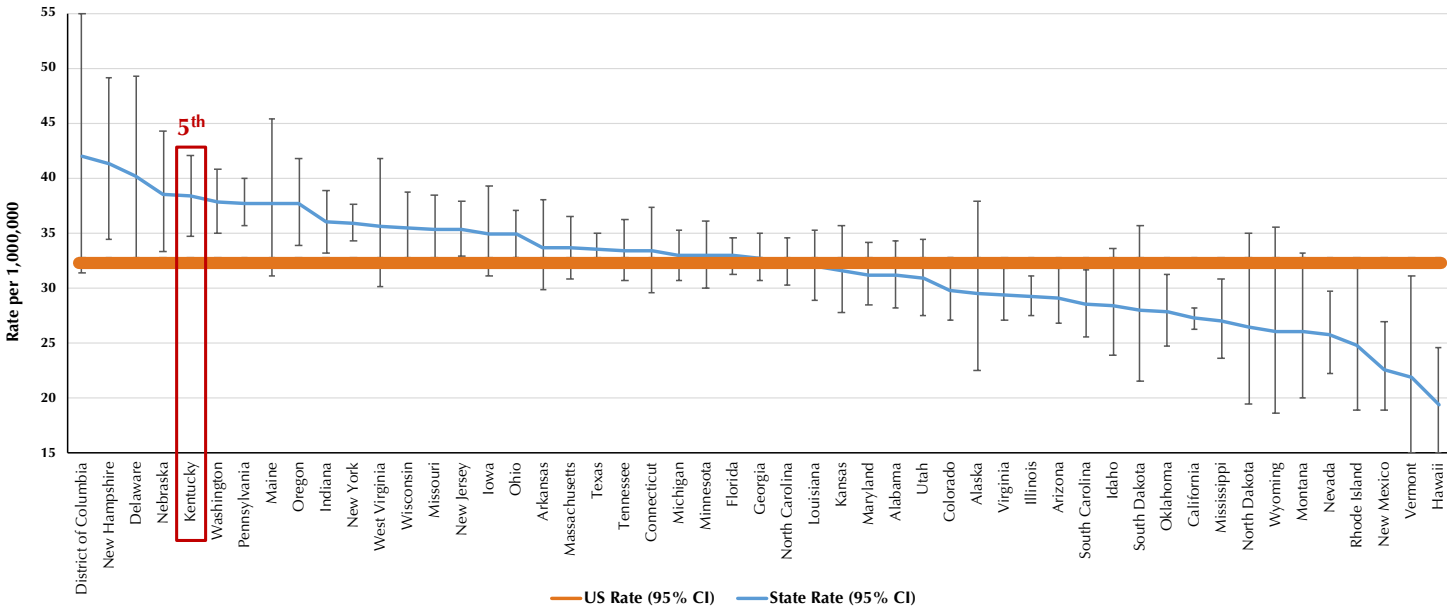


Figure 2. Age-Adjusted Childhood Brain and Central Nervous System (CNS) Tumor Incidence Rates Ranked by State, 2007–2016[2]



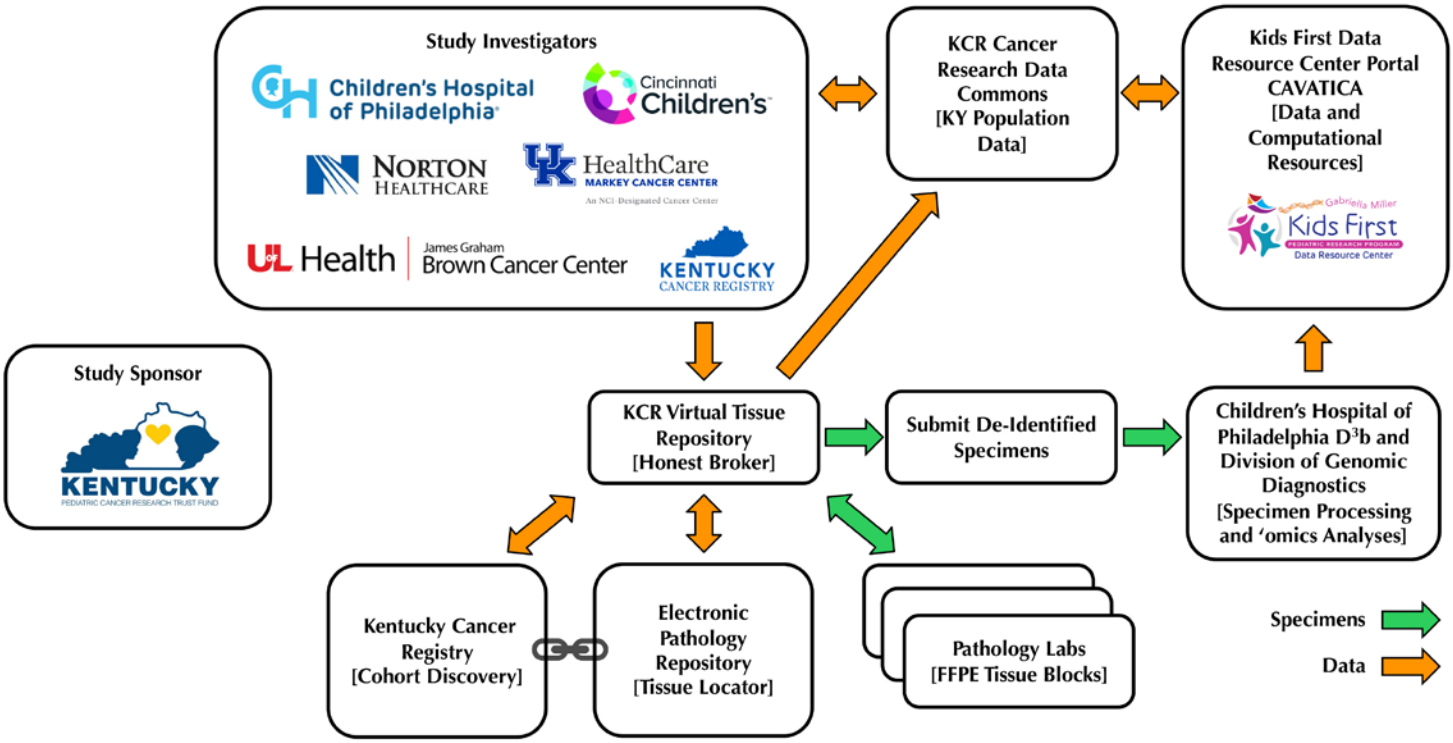
study of factors associated with the high incidence of PBCNSTs in Kentucky. The study leverages the infrastructures provided by the Kentucky Cancer Registry (KCR), its Virtual Tissue Repository (VTR), and the National Institutes of Health (NIH) Kids First Data Resource Center (DRC). Our specific aims are: (1) to identify potential environmental exposures associated with Kentucky's high rates; (2) to assess any population-specific mutations, mutational signatures, and genetic risk factors compared to other children; and (3) enhance informatics platforms for sustainable data sharing and collaboration with key national consortia in PBCNST.

Methods

Identifying the Burden of Childhood Cancer and Potential Disparities in the Kentucky Population

Publicly available incidence data from central cancer registries are routinely used to assess the childhood cancer burden in Kentucky compared to the US. Childhood cancer incidence rates from the latest United States Cancer Statistics

Figure 3. Data Flow Diagram



are readily available from the Centers for Disease Control and Prevention's (CDC's) Wide-ranging Online Data for Epidemiologic Research (WONDER) online database.[2] The WONDER cancer statistics interface supports querying state incidence data that are categorized into meaningful groups for childhood cancers. Groups are defined by the *International Classification of Childhood Cancer* (ICCC), third edition, using the *International Classification of Diseases for Oncology*, third edition (ICD-O-3) standardized coding for site and morphology.[17,18] Because Kentucky is known to have a high burden of cancer in the Appalachian region of the state, we also incorporated data from the latest submission year in WONDER (1995–2016 incidence data submitted in 2018) to calculate rates for Appalachian children in Kentucky.[1] It should be noted that childhood cancer incidence rates are typically calculated per 1,000,000 risk population, as opposed to rates per 100,000 used for all age incidence comparisons. Depending on the size of the population, relatively low numbers of incident cases may lead to unstable age-adjusted rates.[19] At least 10 years of data are needed to permit reliable comparisons of childhood cancers in Kentucky. A comparison of the age-adjusted rates for the 10 most frequently occurring ICCC groups, as shown in Figure 1, indicates that all Kentucky children and/or Appalachian Kentucky children had higher cancer incidence rates than all US children for 7 of the 10 groups for 2007–2016. Rates were significantly higher ($P < .05$) for brain and central nervous system (CNS) tumors. Brain and CNS tumors refer to "Group III. CNS and Miscellaneous Intracranial and Intraspinal Neoplasms" as defined by ICCC.

In addition, we used incidence data exported from WONDER to assess how Kentucky compares to all states. Figure 2 indicates that Kentucky children experienced the fifth highest rate of PBCNSTs during this period. Incorporating the 95% confidence intervals into the graphic in Figure 2 provides a visual cue that the state rate is significantly higher, when the state's lower CI does not overlap the US rate's upper CI. Kentucky, New Hampshire, Nebraska, Washington, Pennsylvania, Oregon, Indiana, New York, New Jersey, and Ohio all experience significantly higher rates compared to the overall US rate depicted by the solid horizonal line in Figure 2. The disparities in Kentucky revealed by these data provided evidence leading to the 2-year competitive award from the Kentucky Pediatric Cancer Research Trust Fund[20] to study factors associated with the high incidence rates of PBCNST in Kentucky. This study is being conducted with approval from the University of Kentucky Institutional Review Board (IRB).

Cohort Identification

Inclusion criteria for the overall study are all PBCNST cases reported to the KCR for patients aged 0 to 19 years who were diagnosed between 1995 and 2017 while residents of Kentucky. Only cases with an invasive (malignant) diagnosis and a surgical tumor resection were considered for genomic analysis. Biospecimen cases undergoing neoadjuvant therapy prior to specimen collection were excluded. In accordance with the IRB, the study investigators have obtained de-identified data sets from the KCR honest brokers, except for case geocode information necessary for the spatiotemporal analysis.

Spatiotemporal Analysis

The first aim is being accomplished using spatiotemporal scan statistics applied to geocoded incidence data

from KCR and environmental data from US Environmental Protection Agency.[21] Analyses have been performed using SaTScan, version 9.6.[22] SaTScan is a trademark of Martin Kulldorff. The SaTScan software was developed under the joint auspices of Martin Kulldorff, the National Cancer Institute (NCI), and Farzad Mostashari at the New York City Department of Health and Mental Hygiene. We have so far evaluated potential clusters of counties with high rates of PBCNST using data from 2 time periods, 1995–2017 and 2004–2017. The latter time period includes nonmalignant cases of PBCNST, which were not reported to KCR until 2004. The Poisson-based statistics allows for potential clusters of counties comprising up to 50% of Kentucky's population, and were adjusted for age and sex. These SaTScan analyses are helpful for characterizing the incidence of PBCNST above what would be expected under a hypothesis of random spatial distribution of rates over time. Confidence intervals for SIRs from SaTScan were estimated using the Vandenbroucke method.[23] Additional analyses will eventually include examination of environmental factors (air quality, land fill, watershed, radon, and proximity to hazardous waste, mining, and industrial sites) in relation to spatial and temporal clustering of high rates of PBCNST that we identify in this analysis.

Genomic Profiling using the KCR Virtual Tissue Repository

KCR established E-Path reporting from its first laboratory in 2004 and has expanded reporting to include over 55 pathology laboratories within and outside of the state. Population-based E-Path reporting has been accomplished by implementing reporting from all Kentucky hospital laboratories and all reference laboratories that evaluate a significant number of Kentucky resident cancer cases. Most laboratories report to KCR through the Transmed software application provided by Inspirata, Inc (formerly Artificial Intelligence in Medicine, Inc).[24] Support from the NCI's Surveillance, Epidemiology and End Results (SEER) Program was essential for establishing KCR's population-based E-Path reporting infrastructure.[25] In addition, approximately 2% of KCR E-Path reports are transmitted from national pathology laboratories with support from the Centers for Disease Control and Prevention (CDC) National Program of Registries–Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO) collaboration.[26] Improved surveillance of childhood cancer required targeted out-of-state installations of Transmed E-Path at Vanderbilt University Medical Center in Nashville, Tennessee and the Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio. These facilities see the largest number of Kentucky childhood cancer patients outside of the state.

KCR has developed database and software applications that support the use of E-Path data for statewide registry operations and for research. In addition to E-Path, KCR's electronic reporting data management system (ER-DMS) is designed to manage data from a variety of sources such as hospital electronic medical records and diagnostic radiology systems. E-Path records in the ER-DMS are stored in structures that closely resemble the health level seven (HL7) observation request and observational/result segments defined by the North American Association of Central Cancer Registries (NAACCR) E-Path reporting standards.[27] Within the ER-DMS, E-Path reports are linked to cancer cases from KCR's central registry database. KCR's population-based E-Path repository allows us to identify cohorts of cancer cases using detailed demographic, diagnostic, treatment, and outcome query parameters. Linked E-Path reports identify the pathology labs that reported the cases. Pathology labs retain the formalin fixed paraffin embedded (FFPE) tissue specimens that were used for cancer diagnoses for 10 years or more, thus allowing KCR to serve as a VTR with access to the historical specimens. KCR has established close working relationships and legal agreements that permit the acquisition of these materials from the pathology laboratories for IRB-approved research studies. Legal authority and operations of the KCR VTR have been previously described.[28]

Genomic tumor sequencing for this project is being performed at the Center for Data Driven Discovery in Biomedicine (D^3b) and Division of Genomic Diagnostics at the Children's Hospital of Philadelphia (CHOP) with support from the NIH Gabriella Miller Kids First DRC. In order to obtain and send material to CHOP for sequencing, KCR honest brokers begin with the cohort of patients known to have had a surgical tumor resection and review the associated E-Path reports to confirm the diagnosis. A small number of cases required requests for pathology reports from out-of-state hospital laboratories that do not report E-Path to KCR. VTR staff request each laboratory to confirm the existence of residual FFPE tissue blocks for their cases that meet the study inclusion criteria. Legal and financial agreements must be established with the laboratories for the tissues and diagnostic slides to be shipped to KCR. Eventually, prepared tissue specimens are sent to CHOP for DNA and RNA extraction and sequencing. Sequencing results are then loaded into the D^3b CAVATICA portal for data analysis or download by study biostatisticians. The KCR VTR is also responsible for returning the diagnostic slides back to the pathology laboratory of origin.

Informatics Data Sharing Infrastructure

The third study aim entails enhancing the KCR data sharing infrastructures to facilitate the integration of data with national PBCNST consortia. This work has primarily involved establishing data use agreements to permit the sharing of study data with the NIH Kids First DRC and accessing genomic data from cases contributed by other research groups such as the Children's Brain Tumor Tissue Consortium.[29] Study bioinformaticians use the CAVATICA platform to perform comparative analysis across multiple PBCNST datasets. KCR and D^3b established a secure protocol for uploading de-identified cancer abstracts as annotations to the genomic data for this study. KCR took advantage of the extensibility of the NAACCR Extensible Markup Language (XML) data exchange standard to send a customized NAACCR data set that preserved variables essential for the spatiotemporal analysis of this study, while fully protecting patient confidentiality.[30] A protocol for

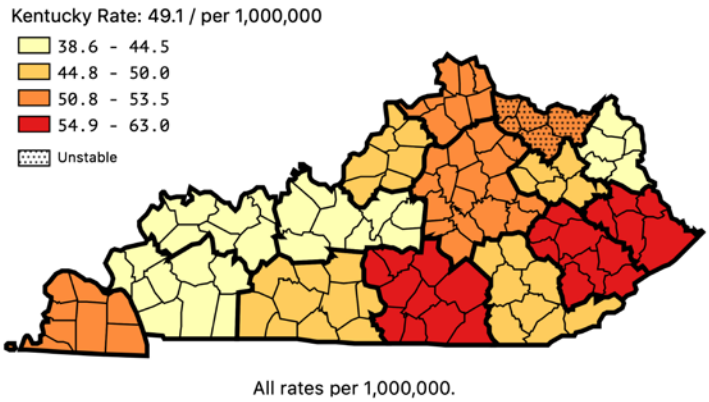
Table 1. Patient and Case Characteristics

	n	%
Sex		
Female	638	50.9
Male	615	49.1
Total	1,253	100.0
Race		
White	1,116	88.8
Black	107	8.5
Other	14	1.1
Unknown	16	1.3
Total	1,253	100.0
Age group (y)		
<5	332	26.2
5–9	304	24.0
10–14	305	24.0
15–19	328	25.8
Total	1,269	100.0
Behavior		
Benign	217	17.1
Borderline	143	11.3
Malignant	909	71.6
Total	1,269	100.0
Region		
Appalachian	364	28.7
Non-Appalachian	905	71.3
Total	1,269	100.0

Table 2. Subtypes of Pediatric Brain and Central Nervous System Tumors in Study Cohort

International Classification of Childhood Cancer subtype	*n*	%
Astrocytomas	507	40.0
Other specified intracranial and intraspinal neoplasms	326	25.7
Other gliomas	169	13.3
Intracranial and intraspinal embryonal tumors	154	12.1
Ependymomas and choroid plexus tumor	83	6.5
Unspecified intracranial and intraspinal neoplasms	30	2.4
Total	1,269	100.0

Figure 4. Distribution of Pediatric Brain and Central Nervous System Tumor Cases in Kentucky, 1995–2017[1]



securely downloading study data for integration into KCR's own Cancer Research Data Commons (CRDC) has also been established. The KCR CRDC is an expanded research data repository with data from the central registry, genomic data sources (including study data returned from D^{3}b), pathology reports, pathology images, and other 'omics data sets. Portals have been developed to permit investigators to view de-identified data and identify cohorts of cases needed for research. Figure 3 describes the data flows between the KCR, VTR, D^{3}b, and the Kids First DRC.

Results

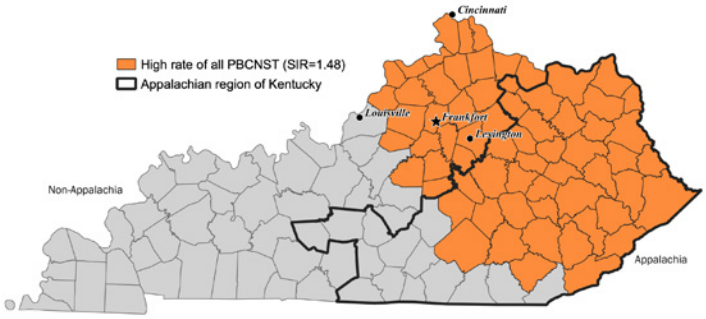
The coronavirus disease 2019 (COVID-19) pandemic interrupted progress in the final year of the study due to laboratory shutdowns beginning in March 2020. However, the methods previously described have proven successful and we anticipate completion of the project within a 1-year extension. Results to date follow.

A de-identified data set of 1,269 childhood brain and CNS cases diagnosed in 1,253 patients between 1995 and 2017 was successfully provided to study investigators by the KCR honest brokers. As shown in Table 1, the patients consist of nearly equal proportions of females (50.9%) and males (49.1%). The overwhelming majority of patients were White (88.8%), followed by Black (8.5%), other (1.1%), and unknown (1.3%). There was an even distribution of cases among the 5-year age groups. Most cases were diagnosed with malignant disease (71.6%), followed by a smaller proportion of benign and borderline cases (28.4%). The Appalachian region accounted for 28.7% of the cases while 71.3% occurred in non-Appalachian counties. Appalachia is home to 27.3% of Kentucky's childhood population. The majority of cases were astrocytomas (40.0%) followed by other specified neoplasms (25.7%), other gliomas (13.3%), embryonal tumors (12.1%), ependymomas and choroid plexus tumors (6.5%), and unspecified neoplasms (2.4%), shown in Table 2. Figure 4 highlights the age-adjusted cancer incidence rates represented by the entire cohort during the 1995–2017 period. Ordering rates by quartiles for groups of counties called Area Development Districts indicates that the highest rates tend to occur within central and southeastern regions of the state.

Spatiotemporal Scan Statistics

The spatiotemporal scan statistics have so far identified a significant high-rate cluster of PBCNSTs among Kentucky

Figure 5. Spatiotemporal Scan Reveals Cluster of High Rates for Pediatric Brain and Central Nervous System Tumors (PBCNSTs) for All Sites, including Benign, Borderline, and Invasive Lesions



counties for the 1995–2017 period. As shown in Figure 5, a large swath of north central and eastern Appalachian Kentucky had significantly higher rates of all PBCNSTs than expected (SIR, 1.48; 95% CI, 1.34–1.62), representing a nearly 50% increased risk for children residing in those counties during this period.

Biospecimen Procurement

The initial biospecimen cohort included 379 potential subject cases. Upon further work up and evaluation, 111 cases were excluded for several reasons shown in Table 3. The primary reasons for elimination were related to unavailable blocks (36.1%) or insufficient tissue quantity for sequencing (24.3%).

Viable specimens for the study were located at 11 individual pathology laboratories, 7 in Kentucky and 4 in adjacent states. All 11 labs have agreed to participate in the study. Nine have procured and shipped their tissue blocks and we are waiting on specimens from 2 remaining labs. Of the 268 eligible specimens, 215 have been sent to D^{3}b at CHOP for genomic processing.

Genomic Processing

Before the laboratory shutdown, CHOP had attempted a DNA and/or RNA extraction and library preparation for genomic sequencing on 163 of the 215 specimens. For DNA sequencing, 20 specimens have failed to meet minimal data quality measures. We have observed that specimens prepared using 2-mm punches were more likely to fail compared to specimens cut from the blocks as scrolls. To date, D^{3}b has completed DNA sequencing for 21 specimens. Five sequencing results have been made available for analysis in CAVATICA and/or download into the KCR CRDC.

Discussion

In addition to interruptions caused by the COVID-19 pandemic shutdowns, we encountered several significant challenges. Establishing data use agreements for specimen acquisition and data sharing was the most significant challenge, with some legal reviews requiring over 12 months of concerted effort. Negotiations with out-of-state laboratories were the most time consuming. Use of the Federal Demonstration Partnership Data Transfer and Data Use Agreement template has resulted in shorter turnaround times. Use of the Uniform Biological Material Transfer Agreement has also shown promise for shortening negotiations. As genomic processing began, we became aware that the material collected from some tissue blocks was insufficient, leading to changing our protocol from reliance on punches to scrolls, which increased the success rate. Data storage for the raw sequencing results was manageable at KCR, but required a significant investment in both hardware and information technology resources needed to maintain a secure data center with high throughput computational capacity.

Table 3. Cases Excluded from the Initial Biospecimen Cohort

Reason for case disqualification	*n (%)*
Tissue blocks unavailable	40 (36.1)
Tissue quantity insufficient for sequencing	27 (24.3)
Unable to obtain path report for evaluation	14 (12.6)
Diagnosis or other information miscoded	10 (9.0)
Patient received neoadjuvant therapy	9 (8.1)
Unable to contact out of state pathology laboratory	8 (7.2)
Biopsy only	3 (2.7)
Total	111 (100.0)

Despite the challenges, the methods and results presented here demonstrate the importance of informatics and registry infrastructures to empower research into PBCNST and other childhood cancers. Our study has shown how publicly available data from population-based registries can be used for assessing the childhood cancer burden that varies by geography and identifying possible disparities. To further elucidate the statewide childhood cancer burden, Kentucky published its first annual report of Childhood Cancer in Kentucky in 2019.[6] The Kentucky Cancer Consortium used these data when adding 6 new objectives related to childhood cancer survivors in the Kentucky Cancer Action Plan.[31] Publication of childhood cancer incidence data by additional state registries is needed to better understand geographical variations and disparities. As the interest in childhood cancer continues to gain momentum, population-based registry data will be necessary to support future evidence-based cancer prevention and control and research initiatives.

KCR's innovative use of E-Path as a VTR is also being tested in other states with support of the SEER Program. Significant investments in E-Path reporting infrastructures will be needed to establish population-based E-Path repositories in other states. As an alternative to expensive commercial E-Path products, biomedical informatics research in machine learning is making good progress towards the release of low-cost open source natural language processing applications that would be necessary to distinguish the cancer reports from all reports generated by anatomic pathology laboratories.[32-34] However,

screening and case identification is only one component of E-Path implementations. Secure and sustainable data transport mechanisms between pathology laboratories and central cancer registries are still needed. Once established, however, our results demonstrate that powerful population-based studies using historical tissue specimens are feasible and practical. To our knowledge, this represents the first population-based study of PBCNST genomic factors to be conducted.

The need for increased data sharing to support childhood cancer research is widely recognized.[37] Recent efforts such as the Childhood Cancer Data Initiative sponsored by the NCI cite a critical need to collect, analyze, and share data to address the burden of cancer in children, adolescents, and young adults.[38] Genomic data are of much greater research value when enhanced with clinical and outcome data, much of which is routinely collected in central cancer registries.[39,40] The Kids First DRC and participating consortia represent new opportunities to more broadly share PBNCST registry and genomic data in a secure computational environment. The rarity of childhood cancers and molecular subtypes requires additional data to advance our understanding of the etiology and risk factors associated with PBNCST and other childhood cancer types.[41] Our study demonstrates the vital role that central cancer registries can play in the generation of population-based genomic data sets for childhood cancer research. Furthermore, integrating study data into KCR's local CRDC, while simultaneously sharing data in the Kids First DRC, maximizes opportunities for researchers to leverage this unique and important resource.

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Original Article

Treatment Patterns and Survival in Older Adults with Diffuse Large B-cell Lymphoma: A Population-Based Study

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Abstract: Background and Objective: Diffuse large B-cell lymphoma (DLBCL) is the most common type of non-Hodgkin lymphoma, with a median age of diagnosis of 66 years. Anthracycline-containing regimens are the most common treatments, but toxicity concerns can limit their use in patients older than 80 years. Understanding treatment patterns and associated survival in adults older than 80 years (vs adults aged 65–80 years) can help determine effective management strategies in this population. We sought to describe the impact of age on treatment regimens used and associated survival in older adults with DLBCL. Methods: Data for 17,859 patients aged ≥65 years diagnosed with DLBCL from 2006 to 2017 were obtained from the California Cancer Registry. Detailed treatment information for each patient was extracted from treatment text fields. Multivariable logistic regression models examined characteristics associated with no treatment and multivariable Cox proportional hazards regression models examined the influence of treatment on overall survival and cancer specific survival. Results: Across both examined age groups (65–80 years and older than 80 years), the most common treatment was anthracycline-containing regimens followed by other drug combinations. For patients older than 80 years, fewer received anthracyclines (32.4%) and more received other drug combinations (17.6%) or had no treatment (13.1%) vs those aged 65–80 years (61.6% anthracyclines, 10.4% other combinations, 5% no treatment). Women were less likely to receive treatment, as were those who were older, had more comorbidities, received treatment at non–National Cancer Institute designated cancer centers, or were diagnosed more recently. For patients older than 80 years, anthracyclines and R-CVP conferred a survival advantage compared to other combinations. Conclusion: In this large, population-based group of older adults with DLBCL, patients older than 80 years were less likely to receive initial treatment and more likely to receive other drug combinations despite a survival advantage with more standard anthracycline and nonanthracycline regimen protocols.

Key words: *anthracycline, diffuse large B-cell lymphoma, patterns of care, population-based, systemic treatment*

Background

Diffuse large B-cell lymphoma (DLBCL) is the most common type of non-Hodgkin lymphoma (NHL),[1] with a median age of diagnosis of 66 years.[2] The incidence of DLBCL increases with age.[1] It is an aggressive form of NHL with a short life expectancy if left untreated, but with the standard anthracycline-containing regimen of rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisolone (R-CHOP), up to 70% of adults older than 60 years in clinical trials experienced a complete response.[3] R-CHOP is the recommended first-line treatment for most patients with DLBCL.[4]

Optimal management for adults older than 80 years with DLBCL is less clear. Patient comorbidities and concern about drug toxicities, especially cardiotoxicity[5] with anthracycline-containing regimens, can limit treatments in very old patients; more than a quarter of DLBCL patients aged 80 years and older do not receive chemotherapy.[6-9] A lower intensity or modified chemotherapeutic approach has been recommended for patients aged over 80 years.[10,11] However, studies have shown superior outcomes with standard anthracycline regimens.[3,6,9] Given the uncertainty of first-line systemic treatment for this age group and the age-related treatment disparities previously found, we sought to assess current usage of first-line systemic treatments and survival outcomes for adults older than 80 years compared to their younger counterparts (65 to 80 years) in a large population-based cohort.

Methods

Study Population

We identified patients with DLBCL from the California Cancer Registry (CCR). The CCR is a population-based cancer surveillance system that collects incidence reports on more than 160,000 new cases of cancer diagnosed annually

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in California. The CCR has collected data on tumor characteristics, treatment, and patient demographics for incident cancers diagnosed since 1988. Data are collected through a network of regional registries, which are also affiliated with the National Cancer Institute's (NCI's) Surveillance, Epidemiology and End Results (SEER) program.

We selected individual DLBCL patients using the World Health Organization International Classification of Diseases for Oncology, 3rd edition histology codes 9678, 9679, 9680, and 9684.[12] Patients aged 65 years and older and diagnosed from 2006 to 2017 were included in the analysis cohort.

Exclusions were those diagnosed at autopsy or death certificate only (n=43) or missing date of last contact (n = 177), resulting in a study population of 17,859.

Baseline Covariates

Patient characteristics collected in the CCR and used in the analysis include sex, race/ethnicity, neighborhood socioeconomic status (SES), health insurance type, rural/urban residence, age at diagnosis, diagnosis year, comorbidity score, initial treatment at an NCI-designated cancer center, stage at diagnosis, radiation treatment, and symptoms at diagnosis (B symptoms, pruritis).

Race/ethnicity was classified as non-Hispanic White, non-Hispanic Black, Hispanic, Asian/Pacific Islander, Native American, and other/unknown, based on the North American Association of Central Cancer Registries' Hispanic and Asian/Pacific Islander Identification Algorithm (NHAPIIA).[13] Neighborhood SES was assigned using an aggregate measure based on 2006 to 2010 American Community Survey data on education, occupation, unemployment, household income, poverty, rent, and home values of census tracts.[14]

Health insurance at diagnosis or initial treatment was categorized as private (HMO, PPO, fee for service, Veterans Affairs, Tricare, Medicare with supplement), public (Medicaid, Medicare with Medicaid eligibility, Medicare without supplement, county funded, Indian/public health service), uninsured, and unknown. Rural/urban residence was based on Medical Service Study Area designations[15] and on the 2010 US Census.

Patient comorbidities were assessed using the Charlson comorbidity index.[16,17] Categories of 0, 1, and 2 or more comorbidities are based on 16 medical conditions, excluding cancer diagnoses, reported in the Office of Statewide Health Planning and Development patient hospital discharge data linked to the CCR database.[17] Cardiac comorbidity was determined from the comorbidity index based on the presence of myocardial infarction, congestive heart failure, peripheral vascular disease, or cerebrovascular disease. Treatment at an NCI-designated cancer center was determined by reviewing all reporting facilities where a patient was treated. Stage at diagnosis was assigned using the American Joint Committee on Cancer staging system rules.[18]

First-Line Systemic Treatment Groups

First-line systemic treatment was defined as the initial systemic or oral chemotherapy or immunotherapy administered. This information was extracted from treatment text fields contained in the CCR data by a SAS-based text mining algorithm. This algorithm has been found to have a percent agreement with manual review ranging from 91.1% to 99.4%.[19]

The treatments identified in the text fields were grouped into the following categories (see Table 1 for acronym expansions):

- Anthracycline-containing regimens (R-CHOP, CHOP, R-EPOCH/EPOCH, mini-CHOP with/without R, other doxorubicin combinations)
- R-CEOP, R-CEPP, R-CNOP
- R-CVP
- R-ICE
- R-Bendamustine
- Methotrexate combinations
- Other combinations (combinations included 1 or more of the following: cyclophosphamide, etoposide, cytarabine, rituximab, prednisone, brentuximab, vincristine, temozolomide)

If treatment text fields were blank or noninformative, then treatment was categorized as *unknown*. Treatment was categorized as *no treatment* only when there was indication that none was given.

Outcomes

The primary outcomes of interest were no first-line receipt of systemic treatment, overall survival, and cancer-specific survival.

Statistical Analyses

We characterized baseline sociodemographic and clinical characteristics of DLBCL patients by age group, 65–80 years vs >80 years, using descriptive statistics (frequencies, percentages). We used multivariable logistic regression models to analyze sociodemographic and clinical associations with nonreceipt of systemic treatment for both age groups. Results are presented as adjusted odds ratios (ORs) and their associated 95% confidence intervals (CIs). We used multivariable Cox proportional hazards regression to evaluate overall survival and cancer-specific survival by treatment type for each age group, adjusting for variables likely to be associated with the receipt of treatment and survival (health insurance, diagnosis year, age, stage, race/ethnicity, neighborhood SES, comorbidity score, sex, rural/urban residence, treatment at NCI-designated cancer center, receipt of radiation, symptoms at diagnosis [B symptoms, pruritis], and age). Survival time was calculated as days from the date of diagnosis to the date of death from any cause for overall survival and to the date of death from cancer for cancer-specific survival or the date of last follow-up through November 2018. We assessed proportional hazards assumptions with tests based on Schoenfeld residuals and inspection of the survival curves (survival function vs survival time and log [–log] of the survival function versus the log of time) for all variables in the model. Results are presented as adjusted hazard ratios (HRs) and their associated 95% CIs. Analyses were conducted using SAS software version 9.4 (SAS Institute Inc).

Table 1. Regimen Acronym Definitions	
Anthracycline-containing regimens	
R-CHOP	rituximab, cyclophosphamide, doxorubicin hydrochloride (hydroxydaunorubicin), vincristine sulfate (Oncovin), prednisone
CHOP	cyclophosphamide, doxorubicin hydrochloride (hydroxydaunorubicin), vincristine sulfate (Oncovin), prednisone
R-EPOCH	rituximab, etoposide, prednisone, vincristine sulfate (Oncovin), cyclophosphamide, and doxorubicin hydrochloride (hydroxydaunorubicin)
EPOCH	etoposide, prednisone, vincristine sulfate (Oncovin), cyclophosphamide, and doxorubicin hydrochloride (hydroxydaunorubicin)
mini-CHOP with/without R	reduced dose of cyclophosphamide, doxorubicin hydrochloride (hydroxydaunorubicin), vincristine sulfate (Oncovin), prednisone with or without rituximab
Nonanthracycline regimens	
R-CEOP	rituximab, cyclophosphamide, etoposide, vincristine sulfate (Oncovin), prednisolone
R-CEPP	rituximab, cyclophosphamide, etoposide, procarbazine, prednisone
R-CNOP	rituximab, cyclophosphamide, mitoxantrone, vincristine sulfate (Oncovin), prednisone
R-CVP	rituximab, cyclophosphamide, vincristine sulfate (Oncovin), prednisone
R-ICE	rituximab, ifosfamide, carboplatin, etoposide
R-Bendamustine	rituximab, bendamustine

Table 2. Characteristics of DLBCL Patients by Age Group, 2006–2017, California (N = 17,859)		
	Age 65–80 years, % (n)	*Age > 80 years, % (n)*
Characteristics	**N = 11,912**	**N = 5,947**
Treatment*		
1. Anthracycline-containing regimens[a]	61.6 (7,332)	32.4 (1,924)
Nonanthracycline regimens		
2. R-CEOP/R-CEPP/R-CNOP	0.7 (83)	1.1 (68)
3. R-CVP	0.7 (83)	2.0 (116)
4. R-ICE	0.9 (105)	1.0 (62)
5. R-Bendamustine	1.0 (119)	2.5 (151)
6. Methotrexate combinations[b]	3.9 (461)	1.1 (65)
7. Other combinations[c]	10.4 (1,244)	17.6 (1,044)
8. No systemic treatment	5.0 (594)	13.1 (777)
9. Unknown	15.9 (1,891)	29.3 (1,740)
Year of diagnosis		
2006–2009	28.8 (3,436)	30.8 (1,829)
2010–2013	33.3 (3,969)	34.7 (2,066)
2014–2017	37.8 (4,507)	34.5 (2,052)
Radiation Treatment		
Yes	15.2 (1,811)	15.8 (938)
No	84.7 (10,088)	84.1 (5,001)
Unknown	0.1 (13)	0.1 (8)
Symptoms at diagnosis (B symptoms, pruritis)		
Yes	23.9 (2,848)	19.4 (1,156)
No	56.1 (6,686)	56.3 (3,346)
Unknown	20.0 (2,378)	24.3 (1,445)

Table 2, cont. Characteristics of DLBCL Patients by Age Group, 2006–2017, California (N = 17,859)		
	Age 65–80 years, % (n)	*Age > 80 years, % (n)*
Characteristics	**N = 11,912**	**N = 5,947**
Sex		
Female	46.4 (5,524)	50.5 (3,004)
Male	53.6 (6,388)	49.5 (2,943)
Stage at diagnosis		
Stage I	23.4 (2,786)	24.8 (1,474)
Stage II	17.5 (2,086)	18.5 (1,101)
Stage III	17.5 (2,083)	16.0 (951)
Stage IV	34.3 (4,080)	30.7 (1,826)
Unknown	7.4 (877)	10.0 (595)
Race/ethnicity		
Non-Hispanic White	60.8 (7,245)	67.5 (4,013)
Non-Hispanic Black	3.3 (397)	2.2 (129)
Hispanic	20.9 (2,494)	16.4 (975)
Asian/Pacific Islander	13.7 (1,633)	13.0 (776)
Native American	0.4 (53)	0.4 (22)
Other/Unknown	0.8 (90)	0.5 (32)
Neighborhood SES tertile		
1 Lowest	25.7 (3,061)	22.4 (1,335)
2	34.7 (4,139)	35.5 (2,112)
3 Highest	39.6 (4,712)	42.0 (2,500)
Rural/Urban location		
Rural	13.9 (1,651)	12.1 (717)
Urban	86.1 (10,261)	87.9 (5,230)
Charlson comorbidity score		
0	38.8 (4,627)	35.4 (2,103)
1	16.1 (1,915)	15.7 (931)
>1	24.1 (2,865)	30.5 (1,816)
Unknown	21.0 (2,505)	18.4 (1,097)
Health insurance[d]		
Private	54.6 (6,502)	50.5 (3,004)
Public	41.9 (4,994)	45.9 (2,727)
Uninsured	0.7 (84)	0.3 (19)
Unknown	2.8 (332)	3.3 (197)
Treatment at NCI-designated cancer center		
Yes	14.5 (1,730)	8.9 (530)
No	85.5 (10,182)	91.1 (5,417)

DLBCL, diffuse large B-cell lymphoma; NCI, National Cancer Institute; SES, socioeconomic status.
* See Table 1 for regimen acronym definitions.
[a] R-CHOP, CHOP, R-EPOCH/EPOCH, mini-CHOP with/without R, other doxorubicin combinations.
[b] Rituximab and temozolomide most common.
[c] Combinations included 1 or more of the following: cyclophosphamide, etoposide, cytarabine, rituximab, prednisone, brentuximab, vincristine, temozolomide.
[d] Private: HMO, PPO, fee for service, Veterans Affairs, Tricare, Medicare with supplement; Public: Medicaid, Medicare with Medicaid eligibility, Medicare without supplement, county funded, Indian/public health service.

Table 3. Systemic Treatment by Age Group and Presence of a Cardiac Comorbidity* among DLBCL Patients, 2006–2017, California (N = 17,859)

	Age 65–80 years, % (N)		*Age >80 years, % (N)*	
	18.6 (2,220)	**60.3 (7,187)**	**28.4 (1,687)**	**53.2 (3,163)**
Treatment**	Cardiac comorbidity	No cardiac comorbidity	Cardiac comorbidity	No cardiac comorbidity
1. Anthracycline Regimens[a]	49.7 (1,103)	64.8 (4,657)	25.1 (424)	35.7 (1,128)
Non-anthracycline regimens				
2. R-CEOP/R-CEPP/R-CNOP	1.3 (28)	0.5 (34)	1.2 (20)	1.3 (41)
3. R-CVP	1.1 (25)	0.6 (42)	1.8 (31)	2.0 (64)
4. R-ICE	1.1 (25)	0.9 (63)	1.8 (31)	1.3 (41)
5. R-Bendamustine	1.0 (23)	0.8 (54)	1.9 (32)	2.5 (79)
6. Methotrexate combinations[b]	5.0 (110)	4.0 (289)	1.0 (17)	1.2 (39)
7. Other combinations[c]	14.7 (327)	9.5 (684)	20.7 (350)	17.0 (537)
8. No systemic treatment	6.8 (151)	4.3 (307)	14.5 (245)	12.0 (378)
9. Unknown	19.3 (428)	14.7 (1,057)	33.0 (556)	27.1 (856)
	unknown cardiac comorbidity = 21.0 (2,505)		unknown cardiac comorbidity = 18.5 (1,097)	

DLBCL, diffuse large B-cell lymphoma.
* Includes myocardial infarction, congestive heart failure, peripheral vascular disease, or cerebrovascular disease.
**See Table 1 for regimen acronym definitions.
[a] R-CHOP, CHOP, R-EPOCH/EPOCH, mini-CHOP with/without R, other doxorubicin combinations.
[b] Rituximab and temozolomide most common.
[c] Combinations included 1 or more of the following: cyclophosphamide, etoposide, cytarabine, rituximab, prednisone, brentuximab, vincristine, temozolomide.

Table 4. Multivariable-Adjusted* Odds Ratio (OR) and 95% CI Estimates for Characteristics Associated with No Systemic Treatment among DLBCL Patients, 2006–2017, California**

	65–80 years	*>80 years*
Characteristic	**OR (95% CI)**	**OR (95% CI)**
Health insurance[a]		
Private	Reference	
Public	**1.32 (1.11–1.58)**	1.14 (0.96–1.35)
Uninsured	1.31 (0.46–3.70)	0.77 (0.16–3.71)
Unknown	**2.38 (1.44–3.91)**	1.62 (0.90–2.93)
Race/ethnicity		
Non-Hispanic White	Reference	
Non-Hispanic Black	0.93 (0.58–1.49)	0.91 (0.51–1.63)
Hispanic	0.90 (0.72–1.12)	0.98 (0.77–1.24)
Asian/Pacific Islander	0.99 (0.77–1.27)	**0.77 (0.59–1.00)**
Native American	1.09 (0.33–3.63)	2.21 (0.72–6.76)
Other/Unknown	2.13 (0.77–5.93)	0.62 (0.12–3.17)
Neighborhood SES tertile		
1 Lowest	**1.57 (1.25–1.97)**	1.22 (0.97–1.53)
2	**1.30 (1.05–1.60)**	1.19 (0.98–1.43)
3 Highest	Reference	

Table 4, cont. Multivariable-Adjusted* Odds Ratio (OR) and 95% CI Estimates for Characteristics Associated with No Systemic Treatment among DLBCL Patients, 2006–2017, California**

	65–80 years	*>80 years*
Characteristic	**OR (95% CI)**	**OR (95% CI)**
Charlson comorbidity score		
0	Reference	
1	1.20 (0.91–1.58)	1.08 (0.83–1.40)
>1	**1.88 (1.51–2.35)**	**1.60 (1.31–1.97)**
Unknown	**1.40 (1.10–1.78)**	1.19 (0.94–1.51)
Rural/urban location		
Rural	Reference	
Urban	1.21 (0.93–1.57)	1.30 (0.99–1.70)
Year of diagnosis		
2006–2009	Reference	
2010–2013	1.21 (0.97–1.51)	**1.29 (1.04–1.59)**
2014–2017	1.16 (0.92–1.46)	**1.39 (1.12–1.74)**
Treatment at NCI-designated cancer center		
Yes	Reference	
No	**2.36 (1.69–3.30)**	**2.63 (1.84–3.76)**
Symptoms at diagnosis (B symptoms, pruritis)		
No	Reference	
Yes	1.02 (0.82–1.28)	**0.78 (0.63–0.98)**
Unknown	**1.76 (1.43–2.17)**	**1.46 (1.19–1.78)**
Radiation treatment		
Yes	Reference	
No	**1.74 (1.32–2.30)**	1.23 (0.99–1.54)
Stage at diagnosis		
Stage I	Reference	
Stage II	**0.66 (0.51–0.87)**	**0.71 (0.56–0.91)**
Stage III	**0.43 (0.32–0.58)**	**0.54 (0.42–0.71)**
Stage IV	**0.71 (0.56–0.88)**	**0.68 (0.55–0.85)**
Unknown	1.35 (0.98–1.86)	1.28 (0.93–1.77)
Sex		
Male	Reference	
Female	1.09 (0.92–1.30)	**1.23 (1.05–1.45)**
Age (y)	**1.08 (1.06–1.10)**	**1.11 (1.08–1.13)**

DLBCL, diffuse large B-cell lymphoma; SES, socioeconomic status; NCI, National Cancer Institute.
* Adjusted for all variables in the table.
** Treatments classified via text mining algorithm; patients with unknown treatment were excluded from the analysis.
[a] Private: HMO, PPO, fee for service, Veterans Affairs, Tricare, Medicare with supplement; Public: Medicaid, Medicare with Medicaid eligibility, Medicare without supplement, county funded, Indian/public health service.
Bold type indicates statistically significant at $P < .05$ level.

Table 5. Multivariable-Adjusted* Hazard Ratio (HR) and 95% CI Estimates for Associations between Systemic Treatment Type and Survival among DLBCL Patients by Age Group, 2006–2017, California

	65–80 years		*>80 years*	
	Overall survival	**Cancer-specific survival**	**Overall survival**	**Cancer-specific survival**
Characteristic	**HR (95% CI)**	**HR (95% CI)**	**HR (95% CI)**	**HR (95% CI)**
Treatment[a]				
1. Anthracycline regimens[b]	**0.63 (0.58–0.68)**	**0.63 (0.56–0.71)**	**0.62 (0.57–0.68)**	**0.58 (0.50–0.66)**
Nonanthracycline regimens				
2. R-CEOP/R-CEPP/R-CNOP	0.80 (0.60–1.07)	0.74 (0.47–1.17)	**0.65 (0.47–0.89)**	0.74 (0.47–1.16)
3. R-CVP	1.09 (0.83–1.42)	0.95 (0.65–1.39)	**0.72 (0.57–0.91)**	**0.56 (0.39–0.82)**
4. R-ICE	1.13 (0.87–1.46)	1.26 (0.84–1.88)	**1.57 (1.19–2.07)**	**1.74 (1.19–2.55)**
5. R-Bendamustine	**1.41 (1.10–1.81)**	1.32 (0.87–2.01)	0.87 (0.71–1.08)	1.11 (0.82–1.50)
6. Methotrexate combinations[c]	**1.31 (1.12–1.52)**	**1.61 (1.31–1.97)**	**1.44 (1.06–1.95)**	1.54 (0.98–2.41)
7. Other combinations[d]	Reference			
8. No systemic treatment	**2.69 (2.38–3.03)**	**3.21 (2.71–3.81)**	**2.11 (1.90–2.34)**	**2.48 (2.13–2.88)**
9. Unknown	**1.48 (1.35–1.63)**	**1.69 (1.47–1.93)**	**1.72 (1.57–1.88)**	**2.02 (1.77–2.30)**
Radiation treatment				
Yes	Reference			
No	**1.23 (1.13–1.33)**	**1.15 (1.03–1.30)**	**1.45 (1.33–1.59)**	**1.55 (1.36–1.78)**
Health insurance[e]				
Private	Reference			
Public	**1.09 (1.03–1.15)**	1.04 (0.96–1.13)	0.98 (0.92–1.04)	0.93 (0.85–1.01)
Uninsured	**1.47 (1.08–2.00)**	**2.16 (1.48–3.14)**	0.91 (0.50–1.65)	0.54 (0.20–1.45)
Unknown	0.86 (0.73–1.03)	0.93 (0.72–1.19)	0.98 (0.82–1.17)	1.15 (0.89–1.48)
Race/ethnicity				
Non-Hispanic White	Reference			
Non-Hispanic Black	1.03 (0.90–1.19)	1.00 (0.82–1.23)	0.90 (0.73–1.11)	1.05 (0.79–1.40)
Hispanic	**1.08 (1.01–1.15)**	1.05 (0.96–1.16)	1.02 (0.94–1.12)	1.11 (0.98–1.26)
Asian/Pacific Islander	1.01 (0.93–1.09)	1.02 (0.92–1.14)	1.09 (0.99–1.19)	1.08 (0.95–1.23)
Native American	1.28 (0.87–1.88)	0.94 (0.47–1.89)	0.85 (0.50–1.44)	0.73 (0.36–1.47)
Other/Unknown	**0.32 (0.19–0.54)**	**0.17 (0.06–0.45)**	**0.23 (0.12–0.47)**	**0.12 (0.03–0.46)**
Neighborhood SES tertile				
1 Lowest	**1.25 (1.17–1.34)**	**1.24 (1.13–1.37)**	**1.13 (1.04–1.23)**	1.09 (0.97–1.24)
2	**1.15 (1.08–1.22)**	**1.16 (1.06–1.27)**	1.06 (0.99–1.14)	1.04 (0.94–1.15)
3 Highest	Reference			
Charlson comorbidity score				
0	Reference			
1	**1.34 (1.25–1.45)**	**1.27 (1.14–1.41)**	**1.34 (1.22–1.46)**	**1.28 (1.13–1.45)**
>1	**2.04 (1.92–2.18)**	**1.94 (1.77–2.12)**	**1.57 (1.46–1.69)**	**1.48 (1.34–1.65)**
Unknown	1.00 (0.91–1.09)	0.68 (0.59–0.77)	0.91 (0.82–1.00)	**0.64 (0.55–0.75)**
Symptoms at diagnosis (B symptoms, pruritis)				
No	Reference			
Yes	**1.32 (1.24–1.41)**	**1.47 (1.35–1.60)**	**1.32 (1.22–1.43)**	**1.48 (1.33–1.65)**
Unknown	1.02 (0.95–1.10)	1.04 (0.93–1.15)	0.94 (0.87–1.02)	0.92 (0.82–1.03)

Table 5, cont. Multivariable-Adjusted* Hazard Ratio (HR) and 95% CI Estimates for Associations between Systemic Treatment Type and Survival among DLBCL Patients by Age Group, 2006–2017, California

	65–80 years		*>80 years*	
	Overall survival	**Cancer-specific survival**	**Overall survival**	**Cancer-specific survival**
Characteristic	**HR (95% CI)**	**HR (95% CI)**	**HR (95% CI)**	**HR (95% CI)**
Rural/urban location				
Rural	Reference			
Urban	1.04 (0.97–1.12)	**1.13 (1.01–1.26)**	1.05 (0.95–1.15)	1.06 (0.92–1.22)
Year of diagnosis				
2006–2009	Reference			
2010–2013	**0.94 (0.88–1.00)**	**0.88 (0.81–0.96)**	**0.91 (0.85–0.98)**	0.94 (0.85–1.04)
2014–2017	1.04 (0.97–1.12)	**0.76 (0.68–0.84)**	1.08 (1.00–1.17)	0.95 (0.84–1.06)
Treatment at NCI-designated cancer center				
Yes	Reference			
No	**1.10 (1.02–1.19)**	1.11 (0.98–1.25)	**1.19 (1.06–1.34)**	**1.25 (1.05–1.49)**
Stage at diagnosis				
Stage I	Reference			
Stage II	**1.15 (1.05–1.26)**	**1.31 (1.14–1.50)**	**1.24 (1.12–1.36)**	**1.35 (1.17–1.56)**
Stage III	**1.33 (1.21–1.46)**	**1.70 (1.49–1.95)**	**1.31 (1.18–1.45)**	**1.50 (1.29–1.74)**
Stage IV	**1.86 (1.72–2.00)**	**2.43 (2.18–2.72)**	**1.61 (1.48–1.75)**	**1.89 (1.67–2.14)**
Unknown	**1.29 (1.15–1.45)**	**1.28 (1.06–1.53)**	1.09 (0.96–1.22)	1.00 (0.84–1.20)
Sex				
Male	Reference			
Female	0.96 (0.91–1.02)	0.97 (0.90–1.05)	**0.90 (0.85–0.95)**	0.95 (0.87–1.04)
Age (y)	**1.04 (1.03–1.04)**	**1.03 (1.02–1.04)**	**1.04 (1.04–1.05)**	**1.03 (1.02–1.04)**

DLBCL, diffuse large B-cell lymphoma; NCI, National Cancer Institute; SES, socioeconomic status.
* Model for each age group adjusted for all variables in the table.
[a] See Table 1 for regimen acronym definitions.
[b] R-CHOP, CHOP, R-EPOCH/EPOCH, mini-CHOP with/without R, other doxorubicin combinations.
[c] Rituximab and temozolomide most common.
[d] Combinations included one or more of the following: cyclophosphamide, etoposide, cytarabine, rituximab, prednisone, brentuximab, vincristine, temozolomide.
[e] Private: HMO, PPO, fee for service, Veterans Affairs, Tricare, Medicare with supplement; Public: Medicaid, Medicare with Medicaid eligibility, Medicare without supplement, county funded, Indian/public health service.
Bold type indicates statistically significant at $P < .05$ level.

Results

Demographic and clinical characteristics for the 17,859 patients in the study cohort are summarized in Table 2. Two-thirds of patients (11,912) were aged 65 to 80 years while one-third (5,947) were over 80 years old. More patients older than 80 years (vs ages 65 to 80 years) were female, non-Hispanic White, resided in the highest SES neighborhood, had comorbidities, and had public health insurance. More patients aged 65 to 80 years (vs >80 years) were treated at NCI-designated cancer centers and were Hispanic. The most common systemic treatment for both age groups was anthracycline-containing regimens. However, nearly twice as many patients aged 65 to 80 years received anthracycline regimens compared to those older than 80 years (61.6% and 32.4%, respectively). Among patients without cardiac comorbidities, a much higher percentage of those aged 65 to 80 years received anthracyclines compared to those older than 80 years (64.8% and 35.7%, respectively) (Table 3). A higher percentage of patients older than 80 years received other combinations (17.6%), no systemic treatment (13.1%), or unknown systemic treatment (29.3%) compared to patients aged 65 to 80 years (10.4% other combinations, 5.0% no treatment, 15.9% unknown).

Table 4 shows the results of the multivariable logistic regression analysis of factors associated with no systemic treatment use. For patients older than 80 years, characteristics associated with no systemic treatment included female sex, comorbidity index score >1 (vs 0), diagnosis in later years (vs 2006-2009), treatment at non-NCI-designated cancer centers (vs NCI-designated centers), and older age.

Asian/Pacific Islanders (vs non-Hispanic Whites), those with later stage disease (vs stage I), and those with symptoms at diagnosis were more likely to have systemic treatment. For patients aged 65 to 80 years, characteristics associated with no systemic treatment included public insurance (vs private), low neighborhood SES (vs high), comorbidity index score >1 (vs 0), treatment at non-NCI-designated cancer centers (vs NCI-designated centers), no radiation treatment, and increasing age. Increasing stage at diagnosis was associated with receipt of systemic treatment.

In multivariable Cox proportional hazards models by age (Table 5), patients older than 80 years experienced better overall survival and cancer-specific survival with anthracycline-containing regimens and R-CVP and worse survival with R-ICE compared to other combinations. Factors associated with a higher risk of death in this age group included nonreceipt of radiation treatment, increasing comorbidity score, having symptoms at diagnosis, treatment at non-NCI-designated cancer center, later stage of disease at diagnosis, and older age.

For patients aged 65 to 80 years, anthracycline-containing regimens were associated with better overall survival and cancer-specific survival while methotrexate combinations were associated with worse survival than other combinations (Table 5). Nonreceipt of radiation treatment, no insurance (vs private), residing in lower SES neighborhoods, increasing comorbidity score, having symptoms at diagnosis, treatment at non-NCI-designated cancer centers, later stage of disease at diagnosis, and older age were associated with a higher risk of death for patients 65 to 80 years old. Patients diagnosed 2010–2013 (vs 2006–2009) experienced a lower risk of death.

Given the large percentage of unknown treatment in both age groups, we undertook sensitivity analyses comparing the unknown treatment group to patients receiving anthracycline regimens, R-CEOP/R-CEPP/R-CNOP, R-CVP, or no systemic treatment and found that for patients older than 80 years, the unknown group had similar survival to the no treatment group. For patients aged 65 to 80 years, the unknown group had better survival than the no treatment group (Figures 1 and 2).

Figure 1. Kaplan–Meier Curves for Overall Survival in Diffuse Large B-Cell Lymphoma Patients Older Than 80 Years by Treatment Group

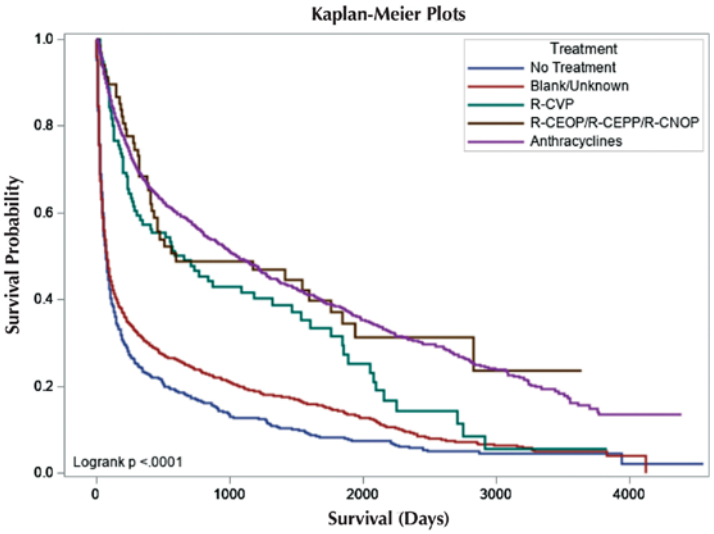
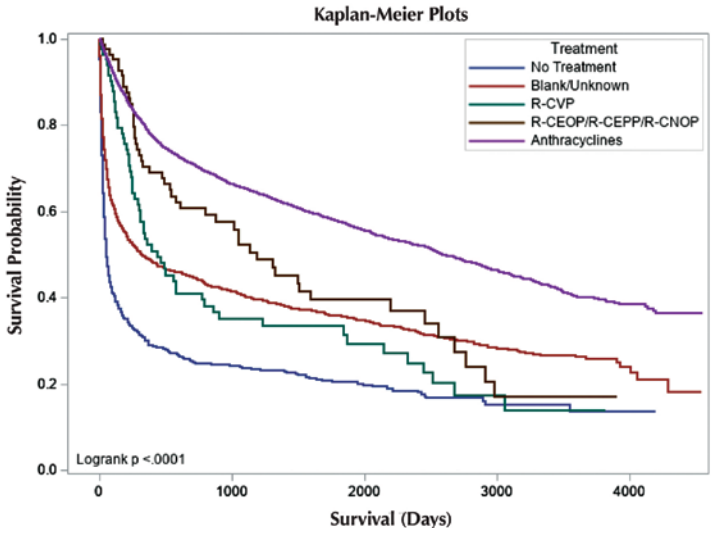


Figure 2. Kaplan–Meier Curves for Overall Survival in Diffuse Large B-Cell Lymphoma Patients Aged 65 to 80 Years by Treatment Group



Discussion

In this large population-based sample of over 17,000 older adult patients with DLBCL, patients older than 80 years were less likely than those aged 65–80 years to receive any initial systemic treatment and more likely to receive other drug combinations, consistent with previous studies demonstrating decreased use of standard regimen protocols in patients older than 80 years.[6,9] Sociodemographic and clinical factors, as well as treating facility, were associated with receiving systemic treatment in patients older than 80 years. Women, patients with greater comorbidity, and those diagnosed in later years (vs 2006-2009), treated at non-NCI-designated cancer centers, and of older age were less likely to receive systemic treatment. Asian/Pacific Islanders (vs non-Hispanic Whites), those with later stage disease (vs stage I), and patients with symptoms at diagnosis were more likely to have systemic treatment. Patients in both age groups experienced a survival advantage with anthracycline-containing regimens compared to other combinations. Overall, our study provides a snapshot of treatment patterns and outcomes in the older adult population of DLBCL patients.

National Comprehensive Cancer Network (NCCN) guidelines recommend anthracycline-containing regimens (R-CHOP, EPOCH) as first-line treatment for most patients with DLBCL.[4] In our study cohort, anthracycline-containing regimens were the most common treatment for both age groups, but about half as many patients older than 80 years received them compared to patients aged 65 to 80 years, regardless of whether patients had cardiac comorbidities. Other NCCN recommendations for patients older than 80 years with comorbidities include R-CEOP, R-CEPP, R-CNOP,

and R-CVP.[4] We saw modest uptake of these combinations in our study cohort. Instead, we saw a high percentage of other combinations or no treatment in patients older than 80 years both with and without cardiac comorbidities. However, both age groups experienced similar reductions in mortality with anthracyclines compared to other combinations. Additionally, for patients older than 80 years, R-CVP conferred better survival than other combinations. The survival benefit we observed among patients older than 80 years treated with R-CVP was similar to the survival benefit of anthracycline-containing regimens and confirms that this nonanthracycline combination can be a good alternative for patients too frail to tolerate anthracyclines, as seen in other studies showing the efficacy of nonanthracycline combinations in older adult patients.[6,20,21] For patients aged 65 to 80 years, R-CEOP/R-CEPP/R-CNOP, R-CVP, and R-ICE had no survival benefits compared to other combinations.

Several factors were associated with nonreceipt of systemic treatment in patients of both age groups. Those with more comorbidity were less likely to receive systemic treatment as has been described across different cancer sites.[22-25] Among older adults, the coexistence of cancer and chronic diseases is common, but evidence-based treatment strategies are lacking because older, more frail patients are often excluded from clinical trials.[26-28] Efforts are underway to improve treatment decision making in this population.[22] Patients treated at non-NCI-designated cancer centers (vs NCI-designated cancer centers)—the majority of patients (91%, >80 years; 85%, 65–80 years)—were over twice as likely to not receive systemic treatment, and for patients older than 80 years, there was a nearly 20% increased risk of death. This finding aligns with other studies that have noted better adherence to guideline-concordant care and increased survival for patients treated at NCI-designated cancer centers.[29,30] We observed that the proportion of patients receiving care at NCI-designated cancer centers decreased with age, suggesting that older patients may not be referred to these facilities[31] and highlighting the importance of understanding barriers to and increasing the proportion of patients receiving care at these facilities. Patients older than 80 years diagnosed in later years (2010–2017 vs 2006–2009) were 30% to 40% more likely to go without systemic treatment, a finding not observed among those aged 65 to 80 years. It is unclear why patients older than 80 years diagnosed in more recent years were less likely to receive systemic treatment, but this finding underscores the need for follow-up studies to monitor patterns of treatment uptake and outcomes in older patients.

Factors associated with more advanced disease, including diagnosis beyond stage I and B symptoms or pruritis, increased the likelihood of receiving treatment among patients older than 80 years. Additionally, we observed that Asian/Pacific Islander patients (vs non-Hispanic Whites) older than 80 years were more likely to receive systemic treatment. Previous studies have found increased treatment uptake and better survival among Asian/Pacific Islander cancer patients.[32-34]

Our findings that 13.1% of patients older than 80 years went without systemic treatment is likely an underestimate given our large percentage (29.3%) of unknown treatment for this age group. Prior studies have found that as many as 50% of patients older than 80 years go without chemoimmunotherapy.[9] Indeed, in sensitivity analyses, we observed that for patients older than 80 years, the unknown group had similar survival to the no treatment group, suggesting that many of those with unknown treatment did not receive it. It is possible that nonreceipt of systemic treatment is underreported in the text fields, resulting in blank or missing information, which we categorized as *unknown*. This might explain the large difference in unknown treatment between the age groups.

Our study has some limitations. First, we were only able to assess first-line treatment, without any information about dosing or number of chemoimmunotherapy cycles completed. The CCR does not collect information beyond first-line treatment nor does it collect specific drug doses patients receive. Second, we had a high percentage of unknown treatment, as described above. Third, we lack information that is important in treatment selection such as performance status and patient characteristics that may contraindicate certain treatments. However, our multivariable models adjusted for patient comorbidities, including cardiac comorbidities, and symptoms at diagnosis (B symptoms, pruritis), as well as factors found to be associated with access to care and/or survival including health insurance, rural/urban residence of patient, neighborhood SES, stage at diagnosis, radiation treatment, care at an NCI-designated cancer center, diagnosis year, sex, age, and race/ethnicity.[34-36] Fourth, approximately 20% of patients had unknown comorbidity score. This score is only available for patients who had an inpatient admission or encounter at the emergency department or ambulatory surgery center in the year prior to through 6 months following diagnosis.[17] Finally, our study lacked data on patient factors, such as cultural beliefs and perceptions about health care, that can impact decisions regarding commencement of treatment with chemoimmunotherapy. Despite these limitations, our study was able to describe population-wide systemic treatment use among older adult patients in a large ethnically and geographically diverse state, thus increasing the generalizability of our findings.

This real-world analysis describes patterns of care for older adult patients with DLBCL and adds to the body of literature showing treatment disparities by age. Many DLBCL patients older than 80 years go without systemic treatment despite anthracycline and nonanthracycline regimens conferring survival advantages compared to other drug combinations or no treatment. Although not all patients older than 80 years should receive systemic treatment, our study found that patients in this age group did benefit from standard regimen protocols. Given that forgoing treatment is associated with a very poor outcome, all patients should be counseled about their treatment options. In order to better guide management strategies in this age group, further research is warranted to better understand barriers to the use of effective treatments patients face and the treatment related toxicities they experience.

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Original Article

Remote Auditing of Reporting Facilities by the Central Registry: Challenging but Rewarding

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***Abstract*:** Objective: Discuss the experience of the New Jersey State Cancer Registry's (NJSCR's) transition to remote auditing of reporting facilities. Methods: We conducted remote audits from 2016–2019 for reporting years 2014–2017. Facilities were selected for audit if they (1) were <90% complete for the year; (2) had ≥10 electronic pathology records (HL7) without a corresponding hospital abstract; or (3) had not been audited in the past 5 years. HL7 records and disease index data were used to determine which cases were potentially unreported. Disease index data were linked to data from the NJSCR Surveillance, Epidemiology, and End Results Data Management System (SEER*DMS) via Match*Pro software. We describe the number of facilities audited and the number of unreported cases identified as a result of the audit process by reporting year and audit type. We also calculate the percent increase in cases reported by reporting year and describe salient challenges in the process. Results: During 4 years of data collection for the reporting years 2014–2017, 101 audits were completed and 10,546 cases were identified as unreported, representing a 7.1% increase in the number of reportable cases among those facilities audited. Challenges for the central registry involved organizing and reviewing large volumes of electronic data and Excel worksheets, and communications with facilities in the process of changing affiliations, personnel, or encryption policies. Conclusions: The new process has improved the audit experience for central registry staff and increased the capture of cases being reported to NJSCR. Facilities also made improvements to casefinding, reporting, and communications to the NJSCR.

Key words: *casefinding, disease index, HL7, New Jersey State Cancer Registry, remote auditing*

Introduction

The New Jersey State Cancer Registry (NJSCR) must fulfill a state-mandated mission (state law 8:57A-1.5 incorporated and referenced documents, New Jersey Administrative Code) to monitor trends in cancer incidence and mortality in New Jersey for more than 8.9 million residents.[1] To that end, NJSCR aims to audit each of the state's 63 acute care hospitals at least once every 5 years.

Initially, auditing required extensive statewide travel to facilities. Prior to electronic reporting, it was necessary to review paper pathology, autopsy and cytology reports, and chemotherapy and radiation logs, and, in some instances, create hard copies of reports or print reports from electronic sources to review in the office at a later time. On-site visits involved coordination with facility staff, finding work locations for 1 to 5 people, and, at times, requesting off-site (archived) records. With advances in technology, transitions to electronic medical records, and security protocols, audits eventually required workstations and information technology (IT) support for NJSCR staff at facilities. The off-site work was labor intensive, required travel with some overnight stays, and, for many years, involved 2 to 3 auditors working full-time and 2 to 4 more working part time, year-round.

To reduce cost, improve efficiency and timeliness of the auditing process, uncover missed cases, and utilize advancing technology, NJSCR transitioned from manual on-site facility auditing to electronic remote auditing, beginning in 2016 with the 2014 reporting year. Given the increasing amount of incoming data from 63 hospitals, this transition was viewed as an innovative way to expand the audit program and meet the demands of the process. Procedures were developed as described below.

Methods

A facility was considered for audit if it met at least 1 of 3 criteria:

1. A facility is below 90% expected completeness. *Expected completeness* is the number of cases from each reporting facility for the current reporting year divided by the expected number of cases. The number of expected cases is based on a weighted average of the past 5 years of submissions, lending greater weight to more recent years' data to compensate for fluctuating caseloads.

2. A facility has a total of 10 or more electronic pathology reports without a corresponding hospital abstract (applied from 2015 reporting year and forward).

3. A facility has not been audited in the past 5 years. This will verify reporting totals.

Due to staffing, competing programmatic priorities, and other limitations, it was not feasible to conduct audits of all facilities meeting any of the above criteria. Selection

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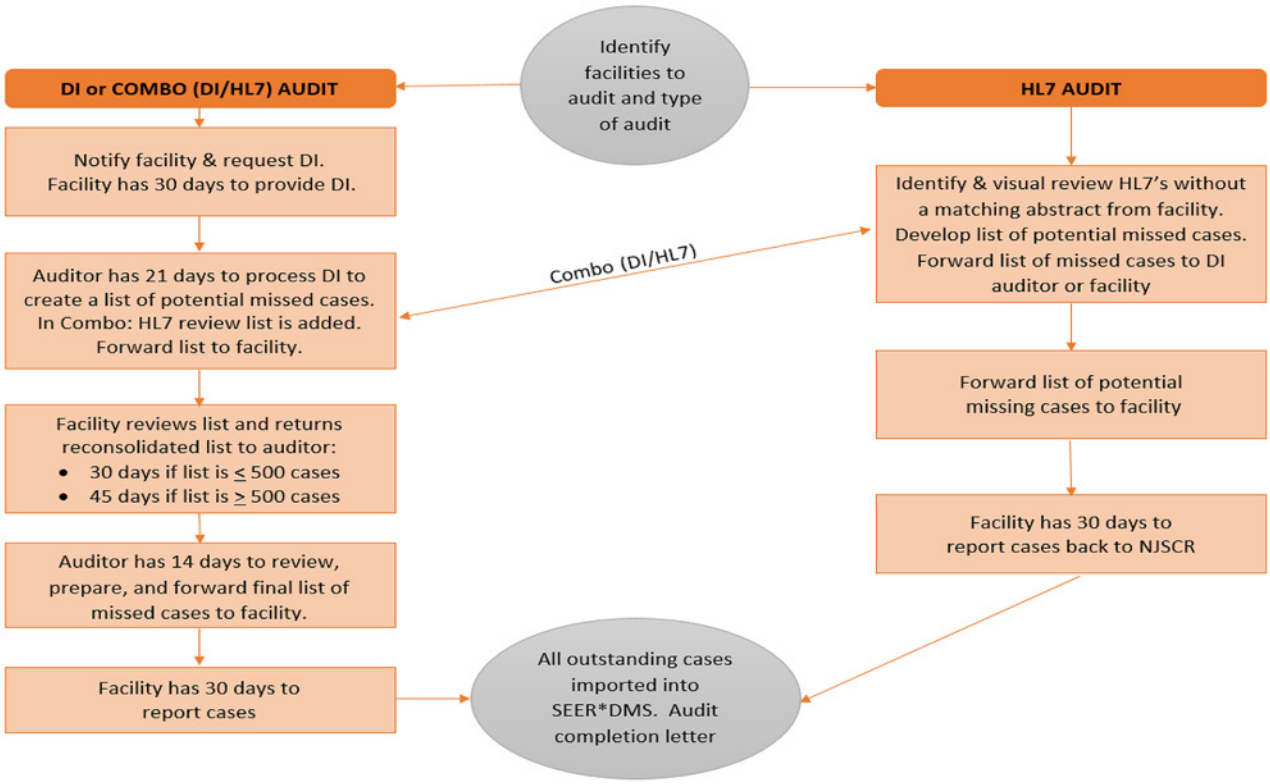
Cancer Epidemiology Services, including the New Jersey State Cancer Registry, receives support from the National Program of Cancer Registries, Centers for Disease Control and Prevention under cooperative agreement NU58DP006279-02-00, the State of New Jersey, the National Cancer Institute, and the Rutgers Cancer Institute of New Jersey.

Figure 1. The Steps by Audit Type and the Required Time Frames



DI, disease index; HLF, Health Level Seven; NJSCR, New Jersey State Cancer Registry; SEER*DMS, Surveillance, Epidemiology, and End Results Data Management System.

was therefore limited to the number of audits that could be conducted by available staff, with the first year serving as a pilot for testing and refining remote auditing procedures. As remote auditing procedures were improved, the registry's capacity to conduct audits was increased. In 2015, staff also expanded auditing to include not only disease indices, but also electronic pathology reports. Today, NJSCR conducts 1 of 3 types of audits: disease index (DI), electronic pathology report (Health Level Seven [HL7]), and combined (DI/HL7).

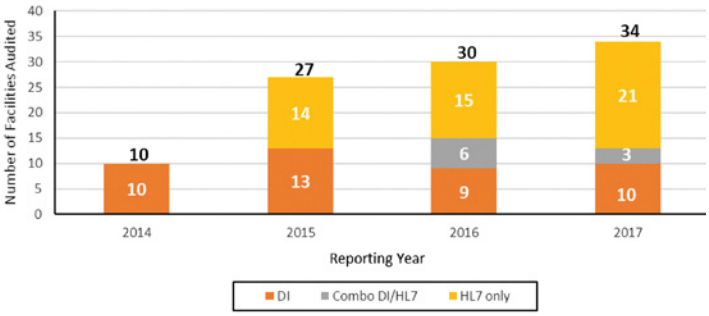
DIs[2] are maintained by facilities separately from medical records. Using codes from ICD-CM (*International Classification of Diseases, Clinical Modification*),[3] this data is generally used to classify disease, injuries, health encounters, and inpatient procedures for all inpatient and outpatient admissions. This data can be used for cancer surveillance. Casefinding lists are created and filtered for reportability based on codes from the *International Classification of Diseases, Tenth Revision, Clinical Modification* (ICD-10-CM).[4] A request is sent to a facility to submit an annual DI of reportable malignancies based on those codes for the audited year. NJSCR will then conduct probabilistic linkages for the selected facility comparing the DI report with data extracted from the Surveillance, Epidemiology, and End Results Data Management System (SEER*DMS) registry database using Match*Pro. A report is generated which identifies unreported cases for that facility and the resulting list is provided back to them for review and reconciliation. This type of audit must be conducted in facilities that do not transmit electronic pathology reports.

Electronic pathology reports[5] (HL7[6]) are used to transmit pathology reports of malignant and certain benign and borderline conditions electronically from laboratories to cancer registries. They include discrete, standardized, human-readable data items using a synoptic report associated with specific data identifiers and terminology codes. A central registry receiving electronic pathology reports from hospital-based laboratories may choose to use them as a reference for quality control for the hospital by performing comparisons between the pathology report data and the registry's data.[7] Several queries are run within NJSCR SEER*DMS to identify electronic pathology reports without a corresponding cancer registry abstract from the facility. After in-house manual screening, an Excel worksheet of potential missed cases is created and forwarded via encrypted email to the facility for review and reconciliation. Currently, 33 of 63 New Jersey hospitals submit electronic pathology reports.

The combined DI/HL7 audit consists of both DI and HL7 processes to create a more comprehensive list of unreported cases for the facility.

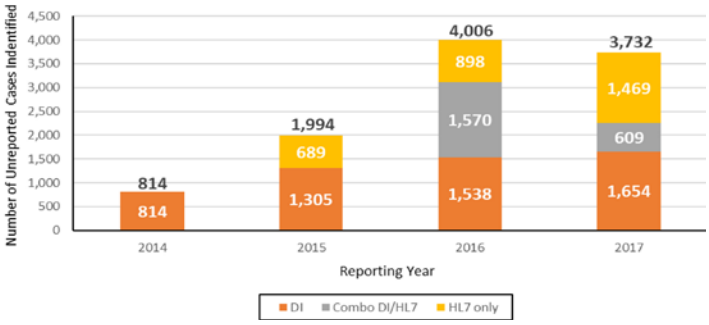
Figure 1 describes the audit process. Briefly, notifications and a request for a DI are sent to hospitals by NJSCR. If a hospital is selected for a HL7-only audit, then they are also notified of impending audit. After hospitals submit their DI data, NJSCR reviews the DI and conducts a Match*Pro

Figure 2. The Number of Facilities Audited by Year Increased as Additional Audit Types Evolved (HL7 and Combo DI/HL7)



DI, disease index; HLF, Health Level Seven.

Figure 3. The Significant Increase in the Number of Cases Identified by Year is Correlated to the Expansion on the Types of Audits Performed



DI, disease index; HLF, Health Level Seven.

linkage between the DI and a SEER*DMS extracted data set. NJSCR will visually review all DI and HL7 data for each hospital and generate an Excel spreadsheet of missing cases. Facilities have 30 days to conduct a review of missing cases and submit the appropriate records.

During the audit process, all correspondence and data exchanged between the health care facility and NJSCR must be transmitted using approved methods including encrypted email and secure file transfer protocols.

Results

Of the 63 facilities that currently report to NJSCR, we conducted remote audits of 10 facilities in 2016 (2014 reporting year), 27 facilities in 2017 (2015 reporting year), 30 facilities in 2018 (2016 reporting year), and 34 facilities in 2019 (2017 reporting year) (Figure 2). In total, 101 audits were conducted for 63 facilities over the 4-year period, as several facilities were audited more than once, mainly the HL7 type. Of note, the number of auditors increased over the 4 years. In 2016, DI audits for 2014 reporting year were performed by 1 auditor. In 2017, 2 additional auditors were added, 1 for DI and 1 to perform HL7 audits. A fourth auditor was added in 2018 to perform HL7 audits. The 2 DI auditors began to perform combined DI/HL7 audits in 2018.

Figure 3 describes the number of missed or unreported cases from reporting years 2014–2017. The total number of cases we identified by corresponding reporting year are: 814 (2014); 1,994 (2015); 4,006 (2016), and 3,732 (2017). For reporting years 2016 and 2017, when combined DI/HL7 audits were conducted, an additional 39% and 16% of unreported cases were identified, respectively. HL7-only audits accounted for 34.5% (2015), 22% (2016), and 39% (2017) of unreported cases. Including combined DI/HL7 audits, DI audits accounted for 65.5% (2015), 78.0% (2016), and 61.0% (2017) of unreported cases. For 2014, DI audits account for 100% of unreported cases. Increased audit staff and the subsequent increased number and type of audits conducted explain the increased number of audit cases identified in 2018/2019 (2016/2017 reporting years).

In summary, the 101 audits for the 4 years compared in this document revealed a total of 10,546 unreported cases. When compared to the 138,787 cases originally submitted by the audited facilities, the new total of 149,333 cases reveals that 7.1% of cases were missed by the reporting facility (Table 1). Current analysis of the facilities audited has revealed several reasons for missed cases including, but not limited to, expansion of services offered by the facility and outdated coding lists used by the facilities for case-finding. There are unique circumstances for each facility and each audit. A facility selected for audit due to the 5-year rule (not having been audited in the past 5 years) does not necessarily imply a shortage of cases. In fact, most would not have been eligible for an audit based on missing cases. Most missing cases are determined by DI and HL7 audits. Future analysis will be required to establish these values.

Discussion

Since 1978, state law has required that reportable cases be identified and reported to NJSCR. Using existing administrative data and the advanced technologies available with SEER*DMS, electronic pathology reporting and probabilistic matching software has efficiently and dramatically increased the number of facilities NJSCR is able to audit. Among the 63 facilities that had a total of 101 audits, 10,536 unreported cases were uncovered, representing a 7.1% increase for diagnosis years 2014–2017. Greater efficiency

Table 1. Cases Retrieved from Audited Facilities per Year, 2014–2017

	2014	*2015*	*2016*	*2017*	*4-Year Total*
Total cases submitted by facilities prior to audit	7,380	37,895	46,306	47,206	138,787
Total cases found in audit	814	1,994	4,006	3,732	10,546
Total cases submitted after audit	8,194	39,889	50,312	50,938	149,333
Percentage of cases retrieved from audited facilities	9.9%	5.0%	8.0%	7.3%	7.1%

was also evidenced by the reduction in staff hours needed to complete the audits. Prior to this process, NJSCR required 2 to 3 full-time auditors and 2 to 4 assistants year-round to conduct audits. The newly developed remote auditing process now requires 4 auditors working part time for 6 to 9 months of the year.

A variety of challenges manifested during the transition to remote auditing. It was necessary to learn and apply new software technology and to document the new process. Because all work involves visual review of electronic data, creating and organizing dozens of worksheets and reviewing an increasing volume of electronic path reports is the new standard. Interacting with changing and merging health care facility affiliations creates difficulties with confidential communications as encryption capabilities and polices are updated. There are IT issues with changing personnel and policies, as well as the outsourcing of cancer registry and IT personnel. Finally, adhering to the specific audit time frames developed to complete the audits within 4 months, can be affected by unexpected or temporary circumstances related to personnel changes or workload priorities facing auditors or facilities.

It was rewarding to develop remote auditing successfully. Auditing has been part of the work of NJSCR for decades, and it was a great success to produce more complete case counts for both health care facilities and NJSCR. There continue to be process improvements for all steps of auditing for NJSCR with increasing efficiency and teamwork. There were great improvements for facilities regarding casefinding and reporting, while communications regarding expectations and problems achieved greater understanding for all involved.

It can be expected that future opportunities for casefinding may become possible using Meaningful Use and claims data and other sources of electronic records that are being submitted to the central registry.[8] Meaningful Use was part of the American Reinvestment and Recovery Act (February 17, 2009), and provides for the electronic exchange of health information to improve quality of care.[9] The current Meaningful Use system does not meet cancer reporting requirements.[10] Another potential source to consider is the death clearance process. Because the timing for requesting case information from death clearance overlaps with the timing of performing remote audits, death clearance only (DCO) cases have been found in the DI audits.

Conclusion

Transitioning to remote health care facility auditing has successfully enhanced the awareness, support, involvement, and understanding necessary to capture and identify missing, reportable cases at both the hospital and central registry level. Future expectations for remote auditing at NJSCR include continuous process improvement, improved case capture, and expanded results analysis.

Acknowledgements

A special thank you to all our colleagues at the NJSCR as well as New Jersey hospital cancer registries.

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Original Article

Cancer Incidence in Older Adults in the United States: Characteristics, Specificity, and Completeness of the Data

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Abstract: Introduction: The number of cancer cases in the United States continues to grow as the number of older adults increases. Accurate, reliable and detailed incidence data are needed to respond effectively to the growing human costs of cancer in an aging population. The purpose of this study was to examine the characteristics of incident cases and evaluate the impact of death-certificate-only (DCO) cases on cancer incidence rates in older adults. Methods: Using data from 47 cancer registries and detailed population estimates from the Surveillance, Epidemiology and End Results (SEER) Program, we examined reporting sources, methods of diagnosis, tumor characteristics, and calculated age-specific incidence rates with and without DCO cases in adults aged 65 through ≥95 years, diagnosed 2011 through 2015, by sex and race/ethnicity. Results: The percentage of cases (all cancers combined) reported from a hospital decreased from 90.6% (ages 65–69 years) to 69.1% (ages ≥95 years) while the percentage of DCO cases increased from 1.1% to 19.6%. Excluding DCO cases, positive diagnostic confirmation decreased as age increased from 96.8% (ages 65–69 years) to 69.2% (ages ≥95 years). Compared to incidence rates that included DCO cases, rates in adults aged ≥95 years that excluded DCO cases were 41.5% lower in Black men with prostate cancer and 29.2% lower in Hispanic women with lung cancer. Discussion: Loss of reported tumor specificity with age is consistent with fewer hospital reports. However, the majority of cancers diagnosed in older patients, including those aged ≥95 years, were positively confirmed and were reported with known site, histology, and stage information. The high percentage of DCO cases among patients aged ≥85 years suggests the need to explore additional sources of follow-back to help possibly identify an earlier incidence report. Interstate data exchange following National Death Index linkages may help registries identify and remove erroneous DCO cases from their databases.

Key words: *Cancer in North America (CiNA); cancer incidence; cancer registries; case ascertainment; death certificate only; interstate data exchange; National Program of Cancer Registries; North American Association of Central Cancer Registries; older adults; Surveillance, Epidemiology, and End Results Program*

Introduction

In the United States, the total number of cancer incident cases has been increasing as the population of older adults grows.[1] Between 2000 and 2015, the largest increase (33%) in cancer-related deaths occurred among those aged ≥85 years.[2] While currently only 8% of all cancers are diagnosed in the oldest old,[3] the number of incident cases and cancer related deaths is likely to continue to increase as more adults reach ages at which the risk of being diagnosed with or dying from many types of cancer is highest. In 2030, 72.1 million adults will be aged ≥65 years in the United States, up from 40.2 million in 2010.[4] The number of cancer survivors is also expected to increase, particularly among older adults (aged ≥65 years).[5] To prepare to meet the need to diagnose, treat, and provide follow-up care to the growing number of older adult patients and survivors, researchers and health care planners and policy makers need accurate, reliable, and detailed cancer incidence, survival, and prevalence data.

The North American Association of Central Cancer Registries (NAACCR) annually certifies the quality and completeness of cancer incidence data collected and reported by member cancer registries.[6] One of the criteria used to evaluate the completeness of case ascertainment in a population-based registry is the percentage of death-certificate-only (DCO) cases.[7] DCO cases are incident cases that are reported solely on the basis of a death certificate. Registries with high quality incidence data have fewer than 5% (preferably <3%) DCO cases overall. A high percentage of DCO cases (eg, ≥5%) may suggest that the cancer registry is failing to identify and register all cancer patients at the time of their diagnoses and thereby potentially underreporting incident cases in the population.[8] However, a high percentage of DCO cases may also suggest that US registries are erroneously recording some DCO cases as incident cases and thereby overreporting incident cases. A linkage study conducted by the Florida Cancer Data System and the New

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York State Cancer Registry showed that some DCO cases in these 2 registries were reported as non-DCO incident cases in the other state's registry, raising the possibility that DCO incident cases were being overreported (ie, incorrectly reported as an incident case) in one state's registry, and double-counted as incident cases at the national level.[9]

We used data from cancer registries participating in the Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and the National Cancer Institute (NCI)'s Surveillance, Epidemiology and End Results (SEER) Program, and detailed population estimates released in 2017 by the SEER Program,[10] to examine the characteristics, specificity and completeness of cancer registry data, and evaluate the potential impact of DCO cases on cancer incidence rates for older adults.

Materials and Methods

We obtained a customized file from the December 2017 submission to NAACCR from 47 statewide cancer registries covering 95% of the US population, participating in the NPCR and the SEER Program.[11] The file included incidence data for diagnosis years 2000 through 2015 and denominator data for 21 age groups (0, 1–4…90–94, ≥95 years). The population data were produced by the Census Bureau's Population Estimation Program, in collaboration with the National Center for Health Statistics, and with support from the NCI.[10]

We included all invasive incident cases diagnosed in older adults (aged ≥65 years) and diagnosed between 2011 and 2015. In situ urinary bladder cancers were included in the file because these cases are considered invasive for the purpose of incidence reporting.[12] The following variables were selected for each incident case: age, sex, race/ethnicity, *International Classification of Diseases for Oncology*, 3rd edition (ICD-O-3) site and histology,[13] year of diagnosis, type of reporting source, sequence number central, method of diagnosis, and SEER Summary Stage. Characteristics of incident cases were categorized as follows:

- Type of reporting source
  - Hospital (inpatient, outpatient, clinic or surgery center)
  - Death certificate-only
  - Physician (office or private practice)
  - Treatment center and laboratory (radiation treatment, medical oncology center, laboratory)
  - Autopsy and nursing home
- Single primary only (sequence number central: 00)
- Method of diagnosis
  - Positive confirmation (microscopic, positive laboratory test, marker study)
  - Clinical and visual (including direct visualization and radiography)
  - Unknown method of diagnosis
- Specificity of diagnosis
  - Unknown site (C80.9)
  - Histology NOS (8000-8001)
  - Unknown stage
- SEER Summary Stage (in situ, local, regional, distant)

Race and ethnicity were used to construct 3 mutually exclusive racial/ethnic groups (Hispanic, non-Hispanic White [White], non-Hispanic Black [Black]). Persons with unknown or other race were included in the "all cases combined" group.

SEER*Stat[14] was used to calculate case counts and age-specific incidence rates, including 95% confidence limits. Rates per 100,000 population were age-standardized to the 2000 US standard population. We estimated the percentage of cases (all races and both sexes combined) by age (65–69 years, 70–74 years, 75–79 years, 80–84 years, 85–89 years, 90–94 years, and ≥95 years) and select characteristics of incident cases. Next, we examined the distribution of DCO cases by age and race/ethnicity. Lastly, we calculated age-specific incidence rates with and without DCO cases for cancers in the oldest old (ages ≥85 years) by sex and race/ethnicity. We selected cancers where there was a 5% minimum of cases in 2 or more of the 3 oldest age groups (85–89 years, 90–94 years, ≥95 years). We focused on the oldest old because the percentage of DCO cases was greater than 5% in each sex and racial/ethnic group after age 84 years (Figure 1). Because there was a lack of independence between rates calculated with and without DCO cases, there was no formal test to determine statistical differences between rates. Therefore, we noted differences in rates if the 95% CLs around the age-specific incidence rates with and without DCO cases did not overlap in at least 1 of the age groups.

Results

Table 1 shows select characteristics for all cancer cases combined in adults aged ≥65 years. As age at diagnosis increased, the percentage of cases reported by hospitals progressively decreased from 90.6% (ages 65–69 years) to 69.1% (ages ≥95 years) and by treatment centers and laboratories from 5.7% to 3.1%. As age increased, the percentage of DCO cases increased from 1.1% to 19.6%; by physicians, from 2.5% to 7.0%; and by autopsy and nursing home reports, from 0.1% to 1.2%. The percentage of DCO cases reported as a single primary only was over 95% in all age groups. As age increased, the percentage of cases (excluding DCO cases) with positive diagnostic confirmation decreased from 96.8% (65–69 years) to 69.2% (≥95 years), while the percentage of cases with a clinical and visual method of diagnosis increased from 2.3% to 23.3%; and from 0.8% to 7.1% for unknown method of diagnosis. In the absence of DCO cases, the percentage of cases with unknown site increased from 1.4% (65–69 years) to 6.7% (95+ years); from 1.6% to 20.6% for histology NOS; and from 6.0% to 28.5% for unknown stage. Excluding cases with unknown stage, the percentage of cases with local stage decreased from 50.5% to 41.4%, while the percentage of cases with distant stage increased from 25.0% to 34.0%. The percentage of in situ urinary bladder cancers increased from 2.1% to 4.2%.

Figure 1 shows the percentage of DCO incident cases for all cancers combined by sex, race/ethnicity, and age among adults aged ≥65 years. Black men had the highest percentage of DCO cases in all age groups, increasing from 1.7% (ages 65–69 years) to 25.5% (ages ≥95 years). The percentage of DCO cases was greater than 5% in all racial/ethnic groups among adults aged ≥85 years.

Figure 1. Percentage of Incident Cases Ascertained from Death Certicates Only for All Cancer Cases Combined by Sex, Race/Ethnicity, and Age among Adults Aged ≥65 Years (2011–2015)

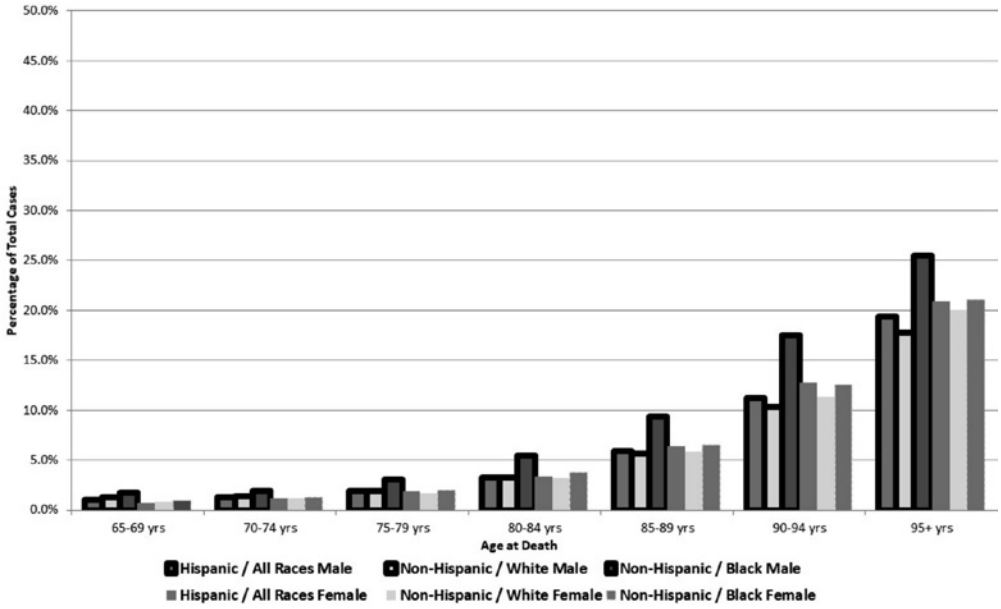
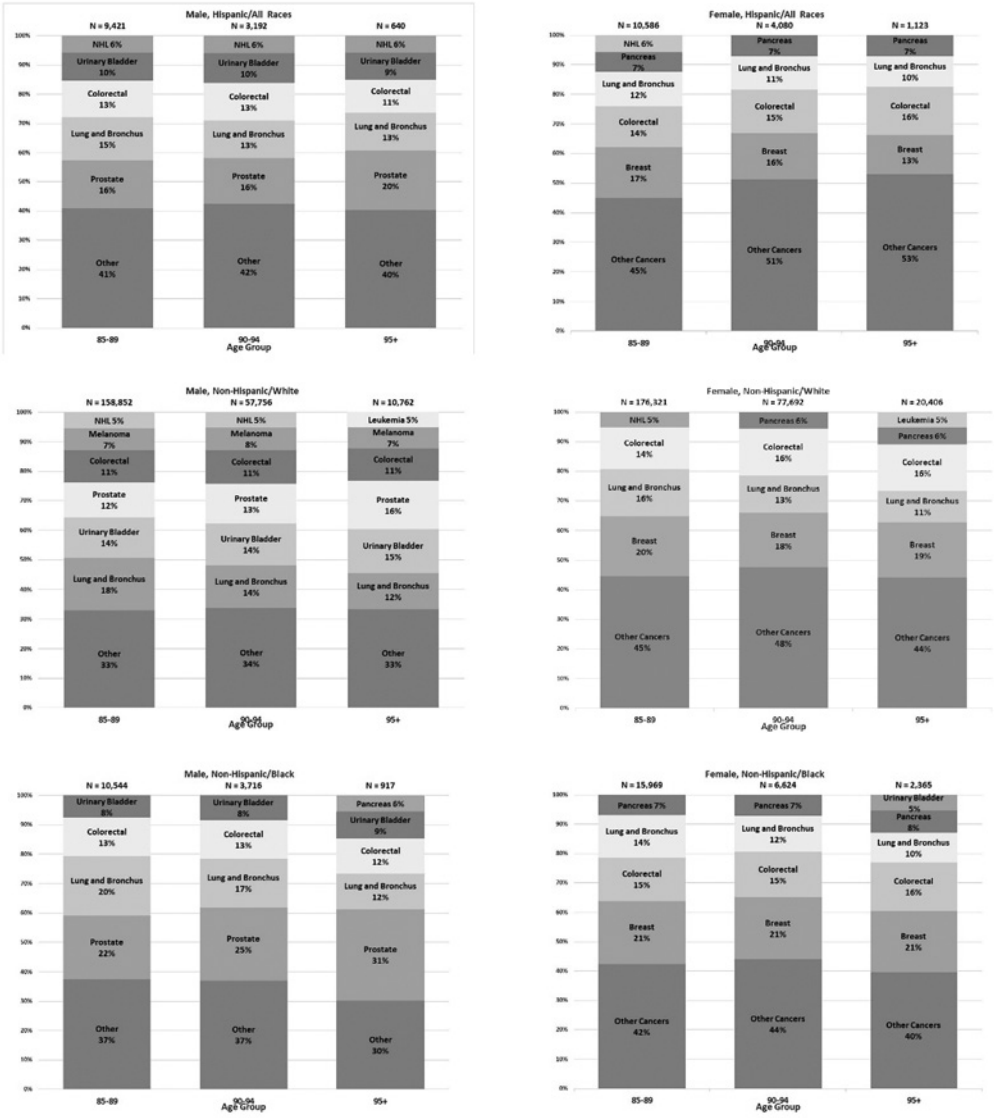


Table 1. Select Characteristics for All Cancer Cases Combined by Age among Adults Aged ≥65 Years (2011–2015)

	Age at diagnosis (y)						
	65–69	**70–74**	**75–79**	**80–84**	**85–89**	**90–94**	**≥95**
Type of reporting source (all cases)							
Number of DCO and non-DCO cases	1,078,687	936,430	766,146	593,552	381,693	153,060	36,213
Hospital	90.6%	90.0%	89.4%	88.3%	85.4%	78.9%	69.1%
DCO	1.1%	1.3%	1.9%	3.3%	5.9%	11.2%	19.6%
Physician	2.5%	2.7%	3.0%	3.4%	4.3%	5.6%	7.0%
Treatment center and laboratory	5.7%	5.8%	5.5%	4.7%	3.9%	3.5%	3.1%
Autopsy and nursing home	0.1%.	0.1%	0.2%	0.3%	0.5%	0.8%	1.2%
Sequence number of DCO cases							
Number of DCO cases	11,795	12,349	14,517	19,719	22,600	17,138	7,091
Single primary only	96.5%	96.3%	95.5%	95.7%	95.5%	95.7%	96.2%
Method, specificity, and stage at diagnosis (non-DCO cases)							
Number of non-DCO cases	1,066,892	924,081	751,629	573,833	359,093	135,922	29,122
Method of diagnosis							
Positive Confirmation	96.8%	96.1%	94.8%	91.9%	86.9%	78.8%	69.2%
Clinical and visual	2.3%	2.9%	4.0%	6.3%	10.3%	16.8%	23.3%
Unknown method of diagnosis	0.8%	1.0%	1.2%	1.8%	2.8%	4.7%	7.1%
Specificity of diagnosis							
Unknown site	1.4%	1.7%	2.1%	2.8%	3.9%	5.4%	6.7%
Histology NOS	1.6%	2.2%	3.0%	4.8%	8.0%	13.5%	20.6%
Unknown stage	6.0%	6.8%	8.2%	10.6%	14.3%	20.7%	28.5%
Stage at diagnosis[§]							
In situ (urinary bladder)	2.6%	3.1%	3.6%	4.1%	4.2%	4.2%	4.1%
Local	50.5%	48.3%	45.8%	42.8%	41.6%	41.4%	41.4%
Regional	21.9%	21.2%	21.0%	21.3%	21.0%	20.5%	20.5%
Distant	25.0%	27.4%	29.6%	31.9%	33.2%	33.9%	34.0%

DCO, death certificate only; NOS, not otherwise specified.
[§] Excluding cases with unknown stage.

Figure 2. Distribution of Cancer Types among Adults Aged ≥85 Years by Sex, Race/Ethnicity, and Age Group (2011–2015)



Selected cancers were those with a minimum 5% of cases in 2 or more of the 3 age groups (85–89 years, 90–94 years, ≥95 years).

Figure 2 shows the distribution of cancer cases by cancer site among adults aged ≥85 years by sex, race/ethnicity, and age. The most frequent cancers among men in all race/ethnicity groups included urinary bladder, colorectal, lung and bronchus (lung), and prostate. Cancers that were the most common among women included colorectal, lung and bronchus (lung), breast, and pancreatic.

Table 2 and Table 3 show age-specific incidence rates for the select cancers among adults aged ≥65 years with and without DCO cases by age and race/ethnicity, for men and women, respectively. Rates for all cancer sites combined peaked in Hispanic and White men in their late 80s and among Black men in their late 70s. Among women, overall cancer rates peaked in Hispanic and Black women in their late 80s and among White women in their early 80s. The peak age at incidence differed by cancer site. Incidence of prostate cancer and female breast cancer peaked in men in their late 60s and early 70s and among women in their 70s. Among men and women, the incidence of lung cancer peaked in the late 70s and early 80s, while the incidence for melanoma and non-Hodgkin lymphoma (NHL), and cancers of the colorectum and pancreas peaked in the 80s, and incidence of bladder cancer peaked in the late 80s and early 90s. Within cancers, the peak age at incidence rates varied somewhat by sex, and race and ethnicity. Lung cancer peaked among men somewhat later than among women, prostate cancer peaked among Black men earlier than among White and Hispanic men and female breast cancer peaked among White and Black women earlier than among Hispanic women.

Compared to site-specific incidence rates excluding DCO cases to those including DCO cases, rates in adults aged ≥95 years without DCO cases were 41.5% lower in Black men with prostate cancer (618.6 vs 361.9, respectively) and 29.2% lower in Hispanic women with lung cancer (126.7 vs 89.7, respectively). Rates excluding DCO cases were lower and ranged among women between 1.9% (White, ages 70–74 years, lung cancer) to 29.2% (Hispanic, ages ≥95

Table 2. Age-Specific Incidence Rates for the Most Common Cancers in Adults Aged ≥65 years With and Without Death-Certificate-Only (DCO) Cases by Race/Ethnicity for Males

Age (y)	65-69		70-74		75-79		80-84		85-89		90-94		≥95	
	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL
Male/Hispanic/All Races														
All Site	**1,500.9**	(1,486.1, 1,515.9)	**1,842.4**	(1,822.2, 1,862.7)	**2,117.1**	(2,091.0, 2,143.4)	**2,210.6**	(2,177.6, 2,243.9)	**2,237.2**	(2,192.2, 2,282.8)	**2,037.9**	(1,967.8, 2,109.8)	**1,576.4**	(1,456.6, 1,703.4)
	1,485.0	*(1,470.3, 1,499.9)*	***1,818.8***	*(1,798.7, 1,839.0)*	***2,076.3***	*(2,050.5, 2,102.3)*	***2,138.5***	*(2,106.1, 2,171.3)*	***2,104.4***	*(2,060.8, 2,148.7)*	***1,809.3***	*(1,743.3, 1,877.2)*	***1,270.9***	*(1,163.6, 1,385.5)*
							-3.3%		-5.9%		-11.2%		-19.4%	
Bladder	**64.4**	(61.4, 67.6)	**94.7**	(90.2, 99.4)	**145.2**	(138.4, 152.2)	**181.2**	(171.8, 190.9)	**215.4**	(201.6, 229.9)	**209.4**	(187.4, 233.3)	**164.7**	(124.8, 213.4)
	64.1	*(61.1, 67.3)*	***94.2***	*(89.7, 98.9)*	***144.4***	*(137.6, 151.4)*	***179.6***	*(170.3, 189.3)*	***211.6***	*(197.9, 225.9)*	***196.6***	*(175.3, 219.9)*	***150.3***	*(112.2, 197.1)*
Colorectal	**157.4**	(152.6, 162.3)	**188.5**	(182.1, 195.1)	**226.1**	(217.6, 234.8)	**265.1**	(253.8, 276.8)	**280.9**	(265.1, 297.4)	**261.1**	(236.4, 287.7)	**190.7**	(147.5, 242.7)
	156.1	*(151.3, 160.9)*	***186.4***	*(180.0, 192.9)*	***223.1***	*(214.7, 231.7)*	***259.9***	*(248.7, 271.5)*	***271.9***	*(256.4, 288.1)*	***241.3***	*(217.6, 266.9)*	***170.5***	*(129.8, 219.9)*
Lung	**147.5**	(142.8, 152.2)	**233.6**	(226.4, 240.9)	**301.1**	(291.3, 311.1)	**353.4**	(340.3, 366.9)	**332.7**	(315.5, 350.6)	**263.7**	(238.9, 290.4)	**202.3**	(157.7, 255.6)
	144.4	*(139.8, 149.0)*	***228.4***	*(221.3, 235.6)*	***293.1***	*(283.4, 303.0)*	***339.2***	*(326.43 52.5)*	***308.9***	*(292.4, 326.2*	***227.3***	*(204.3, 252.2)*	***164.7***	*(124.8, 213.4)*
Pancreas	**43.3**	(40.8, 45.9)	**65.1**	(61.4, 69.0)	**78.1**	(73.1, 83.3)	**91.8**	(85.2, 98.8)	**86.7**	(78.0, 96.0)	**88.7**	(74.6, 104.8)	**78.0**	(51.4, 113.5)
	42.1	*(39.7, 44.7)*	***63.6***	*(59.9, 67.5)*	***75.0***	*(70.1, 80.1)*	***84.7***	*(78.4, 91.4)*	***77.2***	*(69.0, 86.0)*	***73.4***	*(60.6, 88.1)*	***60.7***	*(37.6, 92.8)*
Prostate	**544.9**	(536.0, 554.0)	**575.3**	(61.4, 69.0)	**546.7**	(533.5, 560.2)	**412.6**	(398.4, 427.2)	**364.7**	(346.7, 383.5)	**320.5**	(293.1, 349.8)	**315.0**	(258.6, 380.0)
	544.0	*(535.1, 553.0)*	***572.9***	*(59.9, 67.5)*	***540.5***	*(527.3, 553.9)*	***396.5***	*(382.6, 410.8)*	***335.5***	*(318.3, 353.5)*	***252.2***	*(227.9, 278.3)*	***202.3***	*(157.7, 255.6)*
											-21.3%		-35.8%	
Melanoma	**15.6**	(14.1, 17.1)	**19.9**	(17.9, 22.1)	**28.3**	(25.3, 31.5)	**32.0**	(28.1, 36.2)	**43.9**	(37.8, 50.7)	**35.1**	(26.5, 45.7)	**46.2**	(26.4, 75.1)
	15.4	*(14.0, 17.0)*	***19.9***	*(17.9, 22.1)*	***27.9***	*(24.9, 31.0)*	***31.5***	*(27.6, 35.7)*	***42.7***	*(36.7, 49.5)*	***33.2***	*(24.8, 43.5)*	***34.7***	*(17.9, 60.6)*
NHL	**58.3**	(55.4, 61.3)	**82.9**	(78.7, 87.3)	**106.5**	(100.7, 112.6)	**120.4**	(112.8, 128.4)	**127.5**	(117.0, 138.8)	**120.0**	(103.5, 138.5)	**95.4**	(65.6, 133.9)
	57.7	*(54.9, 60.7)*	***82.4***	*(78.2, 86.8)*	***105.4***	*(99.6, 111.4)*	***119.1***	*(111.6, 127.1)*	***124.7***	*(114.2, 135.8)*	***114.3***	*(98.2, 132.3)*	***95.4***	*(65.6, 133.9)*
Male/Non-Hispanic/White														
All Sites	**1,910.6**	(1,905.2, 1,915.9)	**2,348.5**	(2,341.5, 2,355. 5)	**2,665.7**	(2,656.8, 2,674.5)	**2,820.9**	(2,810.1, 2,831.7)	**2,915.6**	(2,901.3, 2,929.9)	**2,662.0**	(2,640.4, 2,683.8)	**2,206.8**	(2,165.3, 2,248.9)
	1,885.7	*(1,880.4, 1,891.0)*	***2,315.9***	*(2,308.9, 2,322.8)*	***2,614.7***	*(2,606.0, 2,623.5)*	***2,729.8***	*(2,719.2, 2,740.5)*	***2,750.6***	*(2,736.7, 2,764.5)*	***2,387.2***	*(2,366.7, 2,407.9)*	***1,815.1***	*(1,777.5, 1,853.4)*
	-1.3%		-1.4%		-1.9%		-3.2%		-5.7%		-10.3%		-17.7%	
Bladder	**134.3**	(132.9, 135.8)	**205.3**	(203.2, 207.3)	**279.8**	(276.9, 282.7)	**349.0**	(345.2, 352.8)	**400.4**	(395.1, 405.8)	**380.8**	(372.6, 389.1)	**335.2**	(318.4, 352.7)
	133.7	*(132.3, 135.1)*	***204.4***	*(202.3, 206.5)*	***278.3***	*(275.5, 281.2)*	***345.4***	*(341.6, 349.2)*	***392.7***	*(387.5, 398.0)*	***366.5***	*(358.5, 374.7)*	***310.8***	*(294.6, 327.7)*
Colorectal	**142.5**	(141.0, 144.0)	**184.0**	(182.0, 186.0)	**233.7**	(231.1, 236.3)	**278.9**	(275.5, 282.3)	**316.2**	(311.5, 320.9)	**303.5**	(296.2, 310.9)	**244.5**	(230.1, 259.5)
	140.9	*(139.5, 142.4)*	***182.0***	*(180.1, 184.0)*	***230.7***	*(228.1, 233.4)*	***273.3***	*(269.9, 276.6)*	***305.7***	*(301.1, 310.4)*	***286.2***	*(279.1, 293.4)*	***214.2***	*(200.8, 228.3)*
									-3.3%		-5.7%		-12.4%	
Lung	**298.9**	(296.8, 301.0)	**430.8**	(427.8, 433.8)	**521.1**	(517.1, 525.0)	**550.2**	(545.4, 555.0)	**512.5**	(506.5, 518.5)	**378.3**	(370.1, 386.5)	**271.6**	(256.5, 287.5)
	290.3	*(288.2, 292.3)*	***419.0***	*(416.1, 422.0)*	***504.7***	*(500.9, 508.6)*	***524.7***	*(520.0, 529.4)*	***474.2***	*(468.5, 480.0)*	***328.0***	*(320.4, 335.7)*	***215.1***	*(201.6, 229.2)*
	-2.9%		-2.7%		-3.1%		-4.6%		-7.5%		-13.3%		-20.8%	
Pancreas	**56.0**	(55.1, 56.9)	**71.4**	(70.2, 72.6)	**88.2**	(86.6, 89.9)	**101.2**	(99.2, 103.3)	**109.0**	(106.2, 111.8)	**100.1**	(95.9, 104.4)	**100.1**	(78.0, 95.5)
	54.3	*(53.4, 55.2)*	***69.2***	*(68.0, 70.4)*	***84.9***	*(83.3, 86.5)*	***95.3***	*(93.3, 97.3)*	***97.5***	*(94.9, 100.1)*	***84.1***	*(80.3, 88.1)*	***84.1***	*(58.5, 73.8)*
					-3.8%		-5.8%		-10.6%		-15.9%		-15.9%	
Prostate	**582.4**	(579.4, 585.3)	**600.7**	(597.2, 604.2)	**513.6**	(509.7, 517.5)	**384.2**	(380.2, 388.2)	**345.9**	(341.0, 350.9)	**354.2**	(346.3, 362.2)	**366.6**	(349.0, 384.9)
	580.9	*(578.0, 583.8)*	***597.9***	*(594.4, 601.5)*	***507.6***	*(503.7, 511.5)*	***370.2***	*(366.3, 374.1)*	***310.5***	*(305.9, 315.2)*	***275.9***	*(268.9, 282.9)*	***240.4***	*(226.2, 255.3)*
							-3.6%		-10.2%		-22.1%		-34.4%	
Melanoma	**108.2**	(106.9, 109.5)	**137.0**	(135.4, 138.7)	**171.9**	(169.7, 174.2)	**199.0**	(196.1, 201.8)	**217.3**	(213.4, 221.2)	**205.1**	(199.1, 211.2)	**160.8**	(149.2, 173.1)
	107.8	*(106.6, 109.1)*	***136.6***	*(134.9, 138.3)*	***171.1***	*(168.9, 173.4)*	***197.6***	*(194.8, 200.5)*	***215.3***	*(211.5, 219.3)*	***201.6***	*(195.6, 207.6)*	***154.7***	*(143.3, 166.8)*
NHL	**76.0**	(74.9, 77.0)	**102.3**	(100.9, 103.8)	**129.2**	(127.3, 131.2)	**154.3**	(151.8, 156.8)	**158.7**	(155.4, 162.1)	**138.5**	(133.6, 143.6)	**95.9**	(87.0, 105.5)
	75.3	*(74.2, 76.3)*	***101.5***	*(100.1, 103.0)*	***127.7***	*(125.8, 129.6)*	***151.7***	*(149.2, 154.2)*	***154.0***	*(150.7, 157.4)*	***131.1***	*(126.3, 136.0)*	***87.5***	*(79.0, 96.7)*

Table 2, cont. Age-Specific Incidence Rates for the Most Common Cancers in Adults Aged ≥65 years With and Without Death-Certificate-Only (DCO) Cases by Race/Ethnicity for Males

Male/Non-Hispanic/Black

Age (y)	65-69		70-74		75-79		80-84		85-89		90-94		≥95	
	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL
All Sites	**2,378.9**	(2,361.4, 2,396.5)	**2,597.8**	(2,575.3, 2,620.5)	**2,662.0**	(2,634.1, 2,690.1)	**2,563.3**	(2,528.0, 2,598.9)	**2,556.3**	(2,507.7, 2,605.6)	**2,310.1**	(2,236.4, 2,385.6)	**1,984.8**	(1,858.4, 2,117.5)
	2,338.6	*(2,321.2, 2,356.1)*	***2,547.8***	*(2,525.5, 2,570.2)*	***2,581.0***	*(2,553.5, 2,608.7)*	***2,422.8***	*(2,388.5, 2,457.5)*	***2,316.3***	*(2,270.1, 2,363.2)*	***1,906.0***	*(1,839.2, 1,974.7)*	***1,478.3***	*(1,369.5, 1,593.4)*
	-1.7%		-1.9%		-3.0%		-5.5%		-9.4%		-17.5%		-25.5%	
Bladder	**72.8**	(69.8, 76.0)	**101.4**	(97.0, 105.9)	**130.6**	(124.5, 136.9)	**166.0**	(157.1, 175.3)	**194.4**	(181.2, 208.4)	**194.0**	(173.0, 216.7)	**187.4**	(146.9, 235.6)
	72.3	*(69.2, 75.4)*	***100.6***	*(96.2, 105.1)*	***128.8***	*(122.7, 135.1)*	***161.6***	*(152.8, 170.7)*	***188.9***	*(175.8, 202.6)*	***180.3***	*(160.1, 202.3)*	***169.4***	*(131.0, 215.5)*
Colorectal	**198.6**	(193.6, 203.7)	**234.5**	(227.8, 241.4)	**283.0**	(273.9, 292.3)	**317.6**	(305.2, 330.3)	**333.6**	(316.2, 351.7)	**303.4**	(277.1, 331.5)	**238.7**	(19,2.7, 292.4)
	195.3	*(190.3, 200.4)*	***231.1***	*(224.4, 237.9)*	***276.0***	*(267.1, 285.2)*	***307.3***	*(295.1, 319.8)*	***319.5***	*(302.5, 337.3)*	***277.9***	*(252.7, 304.9)*	***205.3***	*(162.8, 255.6)*
Lung	**366.6**	(359.7, 373.5)	**487.5**	(477.7, 497.3)	**550.6**	(538.0, 563.5)	**557.9**	(541.5, 574.7)	**519.3**	(497.5, 541.8)	**382.9**	(353.3, 414.4)	**256.7**	(208.8,312.2)
	355.3	*(348.6, 362.2)*	***473.2***	*(463.6, 482.9)*	***531.1***	*(518.7, 543.8)*	***523.0***	*(507.2, 539.3)*	***474.7***	*(453.9, 496.2)*	***326.4***	*(299.1, 355.5)*	***192.5***	*(151.4, 241.3)*
							-6.2%		-8.6%		-14.8%		-25.0%	
Pancreas	**65.5**	(62.6, 68.5)	**83.0**	(79.1, 87.2)	**97.6**	(92.3, 103.1)	**108.5**	(101.4, 116.1)	**115.6**	(105.5, 126.5)	**102.6**	(87.5, 119.5)	**123.2**	(90.8, 163.4)
	62.7	*(59.8, 65.6)*	***79.2***	*(75.3, 83.3)*	***92.1***	*(87.0, 97.4)*	***100.5***	*(93.6, 107.8)*	***99.6***	*(90.2, 109.8)*	***77.1***	*(64.1, 91.9)*	***105.2***	*(75.5, 142.8)*
Prostate	**1,010.1**	(998.7, 1,021.7)	**957.4**	(943.8, 971.2)	**789.8**	(774.6, 805.2)	**569.2**	(552.7, 586.2)	**552.0**	(529.6, 575.2)	**574.4**	(538.0, 612.7)	**618.6**	(543.0, 701.8)
	1,004.9	*(993.5, 1,016.3)*	***947.3***	*(933.8, 961.0)*	***768.9***	*(754.0, 784.1)*	***530.3***	*(514.3, 546.6)*	***461.8***	*(441.3, 483.1)*	***399.1***	*(368.8, 431.2)*	***361.9***	*(304.6, 426.8)*
							-6.8%		-16.3%		-30.5%		-41.5%	
Melanoma	**3.8**	(3.1, 4.6)	**4.5**	(3.6, 5.6)	**6.4**	(5.1, 7.9)	**9.4**	(7.4, 11.8)	**5.6**	(3.5 8.4)	**6.8**	(538.0, 612.7)	**10.3**	(2.8, 26.3)
	3.7	*(3.1, 4.5)*	***4.4***	*(3.5, 5.5)*	***6.2***	*(4.9, 7.7)*	***9.3***	*(7.3, 11.7)*	***4.8***	*(3.0, 7.5)*	***6.8***	*(368.8, 431.2)*	***10.3***	*(2.8, 26.3)*
NHL	**49.9**	(47.4, 52.5)	**57.3**	(54.0, 60.7)	**70.5**	(66.0, 75.2)	**76.7**	(70.7, 83.1)	**72.7**	(64.7, 81.4)	**54.7**	(43.9, 67.4)	**61.6**	(39.5, 91.7)
	49.3	*(46.8, 51.9)*	***56.5***	*(53.2, 59.9)*	***69.6***	*(65.1,74.3)*	***74.2***	*(68.3, 80.4)*	***69.1***	*(61.3, 77.6)*	***51.0***	*(40.5 63.3)*	***53.9***	*(33.4, 82.4)*

Rates were standardized to the 2000 US standard population. Italicized rates do not include DCO cases. Bolded rates, highlighted in grey, indicate peak age at incidence in a given sex, site, and race/ethnic group. Percentage differences between rates are shown where the 95% confidence limit (CL) of rates with and without DCO cases did not overlap. NHL, non-Hodgkin lymphona.

Table 3. Age-Specific Incidence Rates for the Most Common Cancers in Adults Aged ≥65 years With and Without Death-Certificate-Only (DCO) Cases by Race/Ethnicity for Females

Female/Hispanic/All Races														
Age (y)	65-69		70-74		75-79		80-84		85-89		90-94		≥95	
	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL
All Sites	**1,056.1**	(1,044.6, 1,067.6)	**1,219.4**	(1,204.9, 1,234.1)	**1,374.8**	(1,357.0, 1,392.9)	**1,468.0**	(1,446.2, 1,490.1)	**1,493.3**	(1,465.0, 1,522.0)	**1,342.1**	(1,301.2, 1,383.9)	**1,123.1**	(1,058.3, 1,190.7)
	1,048.0	*(1,036.6, 1,059.5)*	***1,205.3***	*(1,190.9, 1,219.9)*	***1,348.6***	*(1,330.9, 1,366.5)*	***1,417.9***	*(1,396.4, 1,439.6)*	***1,398.2***	*(1,370.8, 1,426.0)*	***1,171.0***	*(1,132.9, 1,210.1)*	***888.0***	*(830.6, 948.4)*
							-3.4%		-6.4%		-12.7%		-20.9%	
Bladder	**16.4**	(15.0, 17.9)	**23.8**	(21.8, 26.0)	**31.9**	(29.2, 34.7)	**45.4**	(41.7, 49.5)	**48.0**	(43.0, 53.3)	**47.0**	(39.6, 55.4)	**43.0**	(30.1, 59.6)
	16.3	*(14.9, 17.8)*	***23.8***	*(21.8, 25.9)*	***31.6***	*(29.0, 34.5)*	***44.5***	*(40.8, 48.5)*	***46.1***	*(41.3, 51.4)*	***42.8***	*(35.7, 50.8)*	***38.3***	*(26.2, 54.0)*
Colorectal	**95.3**	(91.9, 98.8)	**115.0**	(110.6, 119.5)	**142.0**	(136.3, 147.8)	**180.8**	(173.2, 188.7)	**206.8**	(196.3, 217.7)	**197.0**	(181.6, 213.5)	**181.7**	(154.0, 213.0)
	94.9	*(91.5, 98.4)*	***114.4***	*(109.9, 118.9)*	***140.1***	*(134.5, 146.0)*	***177.8***	*(170.3, 185.6)*	***199.0***	*(188.8, 209.7)*	***179.3***	*(164.5, 195.0)*	***156.6***	*(130.9, 185.8)*
Breast	**320.1**	(313.8, 326.4)	**318.1**	(310.7, 325.6)	**320.8**	(312.2, 329.6)	**284.0**	(274.4, 293.8)	**255.0**	(243.4, 267.1)	**209.2**	(193.3, 226.1)	**143.5**	(118.9, 171.6)
	319.0	*(312.7, 325.4)*	***316.6***	*(309.3, 324.1)*	***317.9***	*(309.3, 326.6)*	***279.4***	*(269.9, 289.1)*	***246.2***	*(234.7, 258.0)*	***191.8***	*(176.5, 208.0)*	***112.4***	*(90.8, 137.5)*
Lung	**98.1**	(94.6, 101.6)	**141.0**	(136.1, 146.0)	**168.0**	(161.8, 174.4)	**183.7**	(176.0, 191.6)	**174.9**	(165.3, 184.9)	**152.0**	(138.4, 166.5)	**126.7**	(103.8, 153.3)
	96.6	*(93.2, 100.2)*	***138.4***	*(133.5, 143.4)*	***163.5***	*(157.4, 169.8)*	***174.2***	*(166.7, 181.9)*	***159.3***	*(150.1, 168.8)*	***122.4***	*(110.2, 135.5)*	***89.7***	*(70.5, 112.4)*
											-19.5%		-29.2%	
Pancreas	**34.6**	(32.5, 36.7)	**49.6**	(46.7, 52.6)	**69.3**	(65.4, 73.5)	**76.9**	(72.0, 82.1)	**100.0**	(92.8, 107.7)	**95.7**	(85.0, 107.4)	**84.9**	(66.3, 107.1)
	34.0	*(32.0, 36.1)*	***48.5***	*(45.6, 51.5)*	***66.7***	*(62.8, 70.8)*	***72.5***	*(67.7, 77.5)*	***89.7***	*(82.9, 97.0)*	***76.3***	*(66.8, 86.8)*	***65.8***	*(49.5, 85.6)*
Melanoma	**11.4**	(10.2, 12.6)	**12.0**	(10.6, 13.5)	**14.6**	(12.8, 16.5)	**19.1**	(16.7, 21.8)	**19.2**	(16.1, 22.7)	**15.8**	(11.6, 20.9)	**14.3**	(7.4, 25.1)
	11.4	*(10.2, 12.6)*	***11.9***	*(10.5, 13.4)*	***14.5***	*(12.7, 16.5)*	***18.8***	*(16.4, 21.5)*	***18.5***	*(15.5, 21.9)*	***15.5***	*(11.4, 20.6)*	***14.3***	*(7.4, 25.1)*
NHL	**50.0**	(47.5, 52.5)	**62.5**	(59.2, 65.9)	**84.1**	(79.8, 88.7)	**86.6**	(81.4, 92.1)	**85.2**	(78.5, 92.3)	**62.8**	(54.2, 72.4)	**50.2**	(36.2, 67.9)
	49.6	*(47.2, 52.2)*	***62.1***	*(58.8, 65.4)*	***83.7***	*(79.3, 88.2)*	***85.1***	*(79.9, 90.5)*	***83.1***	*(76.5, 90.1)*	***57.9***	*(49.7, 67.1)*	***44.2***	*(31.1, 61.0)*
Female/Non-Hispanic/White														
All Sites	**1,400.5**	(1,396.1, 1,404.9)	**1,669.5**	(1,663.9, 1,675.0)	**1,875.2**	(1,868.5, 1,881.9)	**1,925.2**	(1,917.7, 1,932.8)	**1,889.6**	(1,880.8, 1,898.4)	**1,616.0**	(1,604.6, 1,627.4)	**1,269.5**	(1,252.2, 1,287.1)
	1,389.6	*(1,385.2, 1,393.9)*	***1,650.1***	*(1,644.6, 1,655.6)*	***1,842.8***	*(1,836.2, 1,849.5)*	***1,863.6***	*(1,856.2, 1,871.0)*	***1,778.7***	*(1,770.2, 1,787.3)*	***1,432.5***	*(1,421.9, 1,443.3)*	***1,015.0***	*(999.5, 1,030.7)*
	-0.8%		-1.2%		-1.7%		-3.2%		-5.9%		-11.4%		-20.0%	
Bladder	**35.0**	(34.3, 35.7)	**48.5**	(47.6, 49.5)	**62.6**	(61.4, 63.9)	**75.1**	(73.6, 76.6)	**83.1**	(81.3, 85.0)	**76.9**	(74.4, 79.4)	**63.0**	(58.9, 67.3)
	34.8	*(34.2, 35.5)*	***48.4***	*(47.4, 49.3)*	***62.2***	*(61.0, 63.4)*	***73.9***	*(72.4, 75.4)*	***80.8***	*(79.0, 82.7)*	***72.5***	*(70.1, 74.9)*	***55.7***	*(51.9, 59.8)*
Colorectal	**98.0**	(96.8, 99.2)	**133.5**	(131.9, 135.0)	**182.8**	(180.7, 184.9)	**230.1**	(227.5, 232.7)	**267.4**	(264.1, 270.8)	**254.4**	(249.9, 259.0)	**207.8**	(200.3, 215.6)
	97.4	*(96.2, 98.5)*	***132.3***	*(130.8, 133.9)*	***180.9***	*(178.8, 183.0)*	***225.6***	*(223.0, 228.2)*	***258.3***	*(255.0, 261.6)*	***233.8***	*(229.5, 238.1)*	***176.6***	*(169.7, 183.7)*
									-3.4%		-8.1%		-15.0%	
Breast	**442.4**	(439.9, 444.9)	**476.5**	(473.6, 479.5)	**474.9**	(471.6, 478.3)	**428.8**	(425.3, 432.4)	**382.7**	(378.7, 386.7)	**297.2**	(292.3, 302.1)	**241.6**	(233.4, 249.9)
	441.0	*(438.5, 443.5)*	***474.2***	*(471.2, 477.1)*	***471.6***	*(468.3, 475.0)*	***422.9***	*(419.4, 426.5)*	***370.7***	*(366.8, 374.6)*	***272.6***	*(268.0, 277.4)*	***198.6***	*(191.2, 206.2)*
									-3.1%		-8.3%		-17.8%	
Lung	**239.7**	(237.9, 241.5)	**339.4**	(336.9, 341.9)	**389.5**	(386.4, 392.6)	**368.6**	(365.3, 371.9)	**299.3**	(295.8, 302.8)	**204.2**	(200.2, 208.3)	**140.6**	(134.5, 147.0)
	236.1	*(234.3, 237.9)*	***332.8***	*(330.3, 335.3)*	***378.7***	*(375.7, 381.7)*	***350.5***	*(347.3, 353.7)*	***272.9***	*(269.5, 276.2)*	***169.8***	*(166.1, 173.5)*	***105.0***	*(99.6, 110.5)*
			-1.9%		-2.8%		-4.9%		-8.8%		-16.8%		-25.4%	
Pancreas	**38.6**	(37.8, 39.3)	**52.8**	(51.8, 53.8)	**67.7**	(66.4, 69.0)	**82.1**	(80.6, 83.7)	**93.5**	(91.6, 95.5)	**91.5**	(88.8, 94.2)	**78.7**	(74.1, 83.5)
	37.8	*(37.1, 38.6)*	***51.3***	*(50.3, 52.3)*	***65.1***	*(63.9, 66.4)*	***76.1***	*(74.6, 77.6)*	***82.5***	*(80.7, 84.4)*	***73.7***	*(71.2, 76.1)*	***56.7***	*(52.8, 60.8)*
							-7.4%		-11.8%		-19.5%		-28.0%	
Melanoma	**50.5**	(49.7, 51.4)	**54.7**	(53.7, 55.7)	**61.6**	(60.4, 62.8)	**66.3**	(64.9, 67.7)	**68.3**	(66.6, 70.0)	**59.9**	(57.7, 62.1)	**51.5**	(47.8, 55.5)
	50.4	*(49.6, 51.3)*	***54.5***	*(53.5, 55.5)*	***61.4***	*(60.2, 62.6)*	***65.9***	*(64.5, 67.3)*	***67.3***	*(65.7, 69.0)*	***58.2***	*(56.0, 60.4)*	***48.5***	*(44.9, 52.3)*
NHL	**54.3**	(53.4, 55.1)	**72.3**	(71.2, 73.5)	**88.3**	(86.9, 89.8)	**99.1**	(97.4, 100.8)	**97.2**	(95.2, 99.2)	**80.7**	(78.2, 83.3)	**54.4**	(50.6, 58.5)
	54.0	*(53.1, 54.9)*	***71.9***	*(70.8, 73.1)*	***87.4***	*(86.0, 88.9)*	***97.4***	*(95.7, 99.1)*	***94.0***	*(92.1, 96.0)*	***75.8***	*(73.4, 78.3)*	***47.9***	*(44.4, 51.7)*

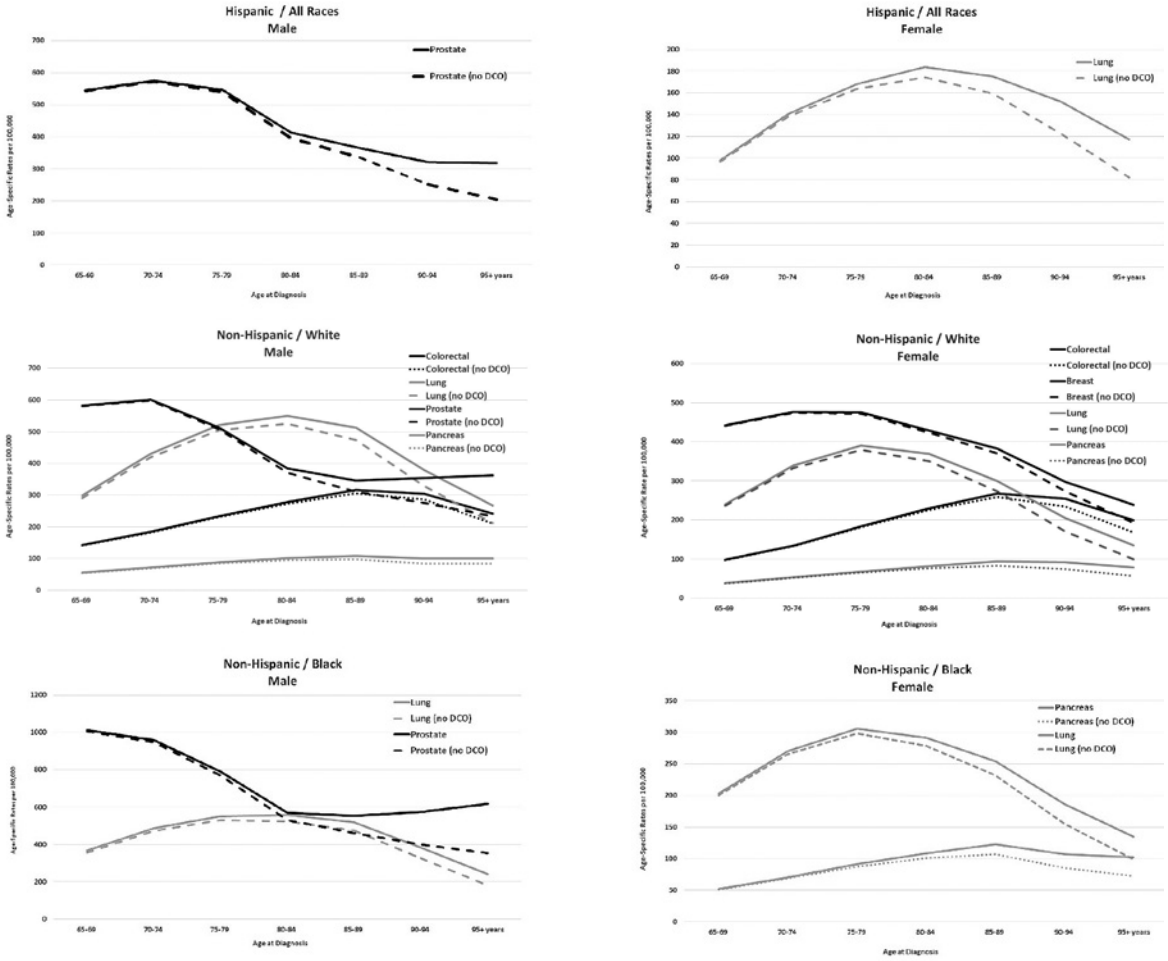
Table 3, cont. Age-Specific Incidence Rates for the Most Common Cancers in Adults Aged ≥65 years With and Without Death-Certificate-Only (DCO) Cases by Race/Ethnicity for Females

Female/Non-Hispanic/Black

Age (y)	65-69		70-74		75-79		80-84		85-89		90-94		≥95	
	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL	Rate	95% CL
All Sites	**1,362.9**	(1,351.3, 1,374.7)	**1,559.9**	(1,545.1, 1,574.7)	**1,711.1**	(1,693.1, 1,729.2)	**1,737.7**	(1,716.2, 1,759.4)	**1,760.8**	(1,733.6, 1,788.3)	**1,507.7**	(1,471.6, 1,544.4)	**1,346.4**	(1,292.7, 1,401.8)
	1,350.4	*(1,338.8, 1,362.1)*	***1,539.1***	*(1,524.5, 1,553.9)*	***1,676.3***	*(1,658.5, 1,694.3)*	***1,672.3***	*(1,651.2, 1,693.6)*	***1,645.6***	*(1,619.3, 1,672.2)*	***1,319.0***	*(1,285.3, 1,353.4)*	***1,063.5***	*(1,015.8, 1,112.8)*
							-3.8%		-6.5%		-12.5%		-21.0%	
Bladder	**22.5**	(21.0, 24.0)	**32.6**	(30.5, 34.8)	**43.4**	(40.6, 46.4)	**57.1**	(53.3, 61.2)	**64.2**	(59.1, 69.6)	**64.6**	(57.3, 72.6)	**73.3**	(59.9, 88.8)
	22.4	*(21.0, 24.0)*	***32.4***	*(30.3, 34.6)*	***42.9***	*(40.1, 45.9)*	***55.9***	*(52.1, 59.9)*	***62.1***	*(57.1, 67.4)*	***61.2***	*(54.1, 69.0)*	***59.2***	*(47.2, 73.3)*
Colorectal	**133.9**	(130.3, 137.6)	**158.5**	(153.8, 163.2)	**193.1**	(187.1, 199.2)	**223.7**	(216.1, 231.6)	**260.0**	(249.6, 270.7)	**231.5**	(217.5, 246.2)	**227.7**	(203.6, 254.0)
	133.1	*(129.5, 136.8)*	***156.6***	*(152.0, 161.4)*	***190.2***	*(184.3, 196.3)*	***218.1***	*(210.5, 225.9)*	***247.8***	*(237.6, 258.2)*	***211.9***	*(198.5, 226.0)*	***191.8***	*(169.6, 216.0)*
Breast	**405.9**	(399.5, 412.3)	**427.4**	(419.7, 435.2)	**425.0**	(416.0, 434.0)	**384.1**	(374.0, 394.4)	**377.0**	(364.5, 389.8)	**320.0**	(303.5, 337.2)	**282.7**	(255.7, 311.8)
	404.3	*(398.0, 410.7)*	***425.1***	*(417.4, 432.8)*	***421.7***	*(412.8, 430.8)*	***377.3***	*(367.3, 387.5)*	***362.7***	*(350.4, 375.3)*	***292.5***	*(276.7, 308.9)*	***240.4***	*(215.6, 267.3)*
Lung	**203.7**	(199.2, 208.2)	**270.6**	(264.5, 276.9)	**305.8**	(298.2, 313.5)	**291.7**	(282.9, 300.7)	**253.9**	(243.7, 264.5)	**186.2**	(173.6, 199.4)	**142.4**	(123.4, 163.5)
	200.4	*(196.0, 205.0)*	***266.0***	*(259.9, 272.1)*	***298.3***	*(290.8, 305.9)*	***278.7***	*(270.1, 287.4)*	***232.1***	*(222.3, 242.2)*	***155.5***	*(144.0, 167.6)*	***107.9***	*(91.5, 126.4)*
									-8.6%		-16.5%			
Pancreas	**52.0**	(49.8, 54.4)	**70.6**	(67.5, 73.8)	**91.3**	(87.1, 95.5)	**108.3**	(103.0, 113.9)	**122.4**	(115.3, 129.8)	**107.0**	(97.5, 117.1)	**100.8**	(85.0, 118.8)
	50.7	*(48.5, 53.0)*	***69.0***	*(66.0, 72.2)*	***87.1***	*(83.1, 91.3)*	***101.1***	*(96.0, 106.4)*	***107.3***	*(100.7, 114.2)*	***85.6***	*(77.1, 94.7)*	***73.3***	*(59.9, 88.8)*
									-12.3%		-20.0%			
Melanoma	**2.7**	(2.2, 3.3)	**3.4**	(2.7, 4.1)	**4.4**	(3.5, 5.4)	**6.4**	(5.2, 7.9)	**6.9**	(5.3, 8.9)	**5.2**	(3.3, 7.9)	**4.9**	(2.0, 10.2)
	2.7	*(2.2, 3.3)*	***3.2***	*(2.6, 4.0)*	***4.3***	*(3.4, 5.3)*	***6.0***	*(4.8, 7.4)*	***6.7***	*(5.1, 8.6)*	***5.0***	*(3.1, 7.6)*	***4.9***	*(2.0, 10.2)*
NHL	**38.3**	(36.3, 40.3)	**41.2**	(38.8, 43.6)	**51.0**	(47.9, 54.2)	**54.1**	(50.3, 58.0)	**51.8**	(47.2, 56.7)	**40.5**	(34.8, 46.9)	**34.5**	(25.6, 45.7)
	38.1	*(36.1, 40.1)*	***40.9***	*(38.5, 43.3)*	***50.1***	*(47.1, 53.3)*	***52.9***	*(49.2, 56.8)*	***50.5***	*(46.0, 55.3)*	***37.8***	*(32.3, 44.0)*	***33.8***	*(25.0, 44.9)*

Rates were standardized to the 2000 US standard population. Italicized rates do not include DCO cases. Bolded rates, highlighted in grey, indicate peak age at incidence in a given sex, site, and race/ethnic group. Percentage differences between rates are shown where the 95% confidence limit (CL) of rates with and without DCO cases did not overlap. NHL, non-Hodgkin lymphona.

Figure 3. Age-Specific Incidence Rates for Selected Cancers among Adults Aged ≥65 Years, With and Without Death-Certificate-Only Cases, by Sex and Race/Ethnicity (2011–2015)



years, lung cancer), and among men between 2.7% (White, ages 70–74 years, lung cancer) to 41.5% (Black, ages ≥95 years, prostate cancer). Cancer rates not reduced by the removal of DCO cases included urinary bladder, melanoma, and NHL.

Figure 3 shows age-specific incidence rates for cancers in adults aged ≥65 years where the 95% confidence limits of rates with and without DCO cases did not overlap in at least 1 of the age groups, by sex and race. The removal of DCO cases did not change the peak age at incidence in men or women although their removal did result in steeper declines in age-specific incidence rates for several common cancers, including lung, colorectal, and prostate cancers among men and colorectal, breast, lung, and pancreatic cancers among women. Among White and Black men, prostate cancer incidence rates, including DCO cases, increased a second time in men in their 90s, while rates without DCO cases continued to decline with age.

Discussion

Our study documents a loss of reported tumor specificity with age. However, the majority of cancers diagnosed in older adults had a positive diagnostic confirmation and were reported with specific site, histology, and stage information. At the same time, the increasing percentage of DCO cases among the oldest old (aged ≥85 years) may suggest the need to explore additional sources of follow-back to help possibly identify an earlier incidence report. Interstate data exchange following National Death Index linkages may help registries identify and remove erroneous DCO cases from their databases.

As the percentage of cancer cases reported by hospitals, treatment centers, and laboratories decreased with age, there was an increase in the percentage of cases reported by physicians, autopsy and nursing home reports, and death certificates. As age increased, there was a decline in the percentage of cases reported with positive diagnostic confirmation and tumor specificity (site, histology, and stage). At the same time, there was an increase in the percentage of cases with a clinical diagnosis or diagnosed by direct visualization. And as others have reported, there was an increase in the percentage of cases reported with distant or unknown stage with increasing age.[15,16] Older adults have not been recommended by the US Preventive Services Task Force to undergo routine screening for breast, cervical, and colorectal cancer past certain ages, thus limiting the opportunity for early detection of these cancers at advanced ages.[17-20] In addition, older cancer patients may have undergone fewer and less intrusive diagnostic procedures, perhaps because

they had comorbidities, were frail, or were otherwise poor candidates for treatment.[16,21-23] However, it should be noted that less than 10% of cancers diagnosed in older patients were reported with unknown method of diagnosis, and the majority of cancer cases diagnosed, even in the oldest age group (aged ≥95 years), had a positive diagnostic confirmation (69%) and were reported with specific site (93.3%), histology (79.4%), and stage (71.5%). The finding that the majority of older cancer patients, including the oldest old, had detailed and specific tumor information, necessary for effective, evidenced-based treatment, may help explain why population-based cancer survival in the United States has been reported to be among the highest worldwide.[24]

Age-specific incidence rates for all cancer sites combined are reported to peak between the ages of 80–84 years for women and 85–89 years in men, and then decline.[3,10,25] Our study reported that peak incidence for all cancer sites combined occurred somewhat earlier among Black men (75–79 years) compared to Hispanic and White men (85–89 years), and somewhat later among Black women (85–89 years) compared to Hispanic and White women (80–84 years). In addition, prostate cancer incidence rates were higher and peaked somewhat earlier in Black men (65–69 years) compared to White and Hispanic men (70–74 years); and female breast cancer incidence rates were lower and peaked somewhat later in Hispanic women (75–79 years) compared to Black and White women (70–74 years). Because screening advances the age at which a cancer is diagnosed, it is not surprising that the peak age at incidence for prostate and female breast cancers occurred somewhat earlier compared to the other common cancers of older adults. As colorectal cancer is a screen-detectable cancer, screening has had the effect of reducing incidence rates overall because it often finds precancerous polyps that can be removed before they become incident cases.[26]

For the most part, age-specific incidence patterns including DCO cases were similar to those without DCO cases. Rates without DCO cases tended to decline more steeply with age for all sites combined and for cancers of the colorectum, lung, pancreas, prostate, and female breast. Of particular note was prostate cancer. After an initial decline, rates which included DCO cases increased for a second time among White and Black men in their 90s, while rates excluding DCO cases continued to decline with age into the oldest age groups. There were no differences in age-specific rates with and without DCO cases for urinary bladder, melanoma, and NHL. Deaths from melanoma and NHL may be underreported based on DCO cases because histologic information, needed to code these causes of death, was not recorded on death certificates.

The large percentage of DCO cases among the oldest old may limit the utility of incidence data in this age group. Cancer registries may want to examine the reporting sources used to identify incident cases in this age group, particularly those cases reported solely by death certificates. All US cancer registries follow similar procedures for the reporting of DCO cases.[27] The higher percentage of DCO cases among the oldest cancer patients suggests possible underreporting, particularly for Black men who had the largest percentage of DCO cases. While a cancer can be diagnosed at the time of a patient's death, this occurrence, even among the oldest old, should be somewhat uncommon in the US population. First, most patients present to a health care provider with signs and symptoms of their cancer prior to their death. Second, cancer is a reportable disease in all states,[6] thus encounters with health care providers should result in an incident report being sent to the statewide cancer registry. And third, most US cancer registries have been in operation for several decades, and prevalent cases (cases diagnosed before the registry began operation) should no longer be reported as DCO cases, as can happen in the early years of operation in a start-up cancer registry.[28] However, prostate DCO cases may pose a particular challenge for some registries: 20-year survival following a diagnosis of prostate cancer is reported to be high (≥80%) for patients diagnosed in calendar years just before many NPCR-funded cancer registries became fully operational,[6,29] and because prostate cancer deaths may be subject to attribution bias.[30] Furthermore, as fewer cancer cases diagnosed in the oldest patients were reported by hospitals and without diagnostic confirmation, the accuracy of the cause-of-death listed on the death certificate may be less reliable; a study assessing the concordance between cancer-specific cause of death and primary cancer site at diagnosis showed significant differences by cancer type and certifier type.[31,32] Nonphysician coroners had lower accuracy rates compared with physicians.

A higher percentage of DCO cases may also suggest that registries are possibly overreporting incident cases. Over 95% of DCO cases in our analysis were reported as a single primary (ie, the death certificate was the only report of cancer for that person). As shown by Wohler,[9] a DCO case may result if a cancer patient, diagnosed and registered with the cancer registry in one state, moves to a different state, dies of cancer, and is registered as a DCO case in the death state's cancer registry. Because SEER and NPCR do not require their registries to submit personal identifiers to their respective federal programs, it is not possible for the programs to identify cancer patients who are registered in 2 or more registries. However, there is a way for cancer registries to identify these cases. Cancer registries routinely link their incidence data to the National Death Index to update vital status among patients who leave the state after their diagnosis. If the registry initiating the National Death Index linkage shared relevant information with death state registries, the death state registry can identify and remove erroneous DCO cases from their databases. The exchange of information has been facilitated by the NAACCR National Interstate Data Exchange Agreement.

There are strengths and limitations that should be kept in mind when interpreting the findings and conclusions of this study. This large, population-based study was nationally representative of the US population, and was able to look at the burden of cancer in older adults by race and ethnicity. However, because cancer registries do not routinely collect information on comorbidities or insurance status, we were unable to explore possible reasons for why some older adults did not have diagnostically confirmed cancers or why their cancers were diagnosed at a later stage compared to other older adults.

In conclusion, the surveillance data are greatly enriched by having detailed incidence data for the oldest old. These data will enable health care professionals to prepare for the growing number of adults with cancer. However, the high percentage of DCO cases among patients aged ≥85 years may suggest the need to explore additional sources of follow-back.

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How I Do It

Cancer Registration in the Caribbean

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Abstract: The Caribbean region faces a growing burden due to cancer. Urgent action needs to be taken to monitor this disease and inform measures required for prevention and control. Cancer surveillance, supported by the implementation of population-based cancer registries (PBCRs), is an important component of cancer prevention and control strategies. Yet, the ability of some Caribbean countries to implement infrastructure needed for sustainable, high-quality PBCRs remains a challenge given limitations in resources and competing health priorities. While some Caribbean cancer registries have been successful in contributing high-quality cancer data in support of national cancer control and prevention efforts, this represents coverage of only a small percentage of the Caribbean population, and these data have limited generalizability to other countries in the region. The International Agency for Research on Cancer (IARC) Caribbean Cancer Registry Hub (**http://caribbeancrh.carpha.org**) is performing an important role in providing technical support, capacity building, advocacy, and research needed for strengthening cancer registration in the region. The Caribbean Hub engages high-level political and technical stakeholders, and shares appropriate and relevant resources and expertise to help health care and public health professionals and policymakers understand the importance of data generated from PBCRs for cancer control planning and monitoring. Through the provision of technical support for the implementation or strengthening of PBCRs in the region, the Caribbean Hub will support efforts being made by Caribbean countries to establish high-quality PBCRs. The Hub will continue to facilitate capacity building through training workshops and other similar activities as well as support training opportunities for cancer registries throughout the region. Research initiatives will continue to be conducted and supported by the Caribbean Hub to identify priorities and to monitor and evaluate cancer control strategies in the region. Through the work of the IARC Caribbean Cancer Registry Hub, Caribbean countries are better equipped to overcome challenges faced and strengthen cancer surveillance nationally and regionally. This is an important step towards mitigating the cancer burden and improving cancer prevention and control measures in the Caribbean.

Key words: *cancer registration, Caribbean, Caribbean Public Health Agency, Global Initiative for Cancer Registry Development, International Agency for Research on Cancer Caribbean Cancer Registry Hub*

Introduction

The Caribbean region consists of independent countries and overseas territories of varying population sizes, political structures, and levels of economic development. The region is located within the Caribbean basin, southeast of the Gulf of Mexico and North America, east of Central America and north of South America. The region also includes Bermuda in the North Atlantic Ocean and 3 mainland countries; namely, Guyana and Suriname in South America and Belize in Central America.[1-3]

Mortality data available for the region show that the Caribbean has the highest burden of deaths from noncommunicable diseases (NCDs) in the Americas.[4] Having long undergone the epidemiologic transition from predominately infectious diseases to chronic diseases, NCDs are currently the leading causes of death in the region.[4-6] Among all NCDs, cancer is the second-leading cause of death, representing a significant regional public health threat.[7,8] Based on global estimates, annual cancer incidence and mortality in the Caribbean is expected to increase by 55.2% (n = 111,933 to 173,751) and 67.4% (n = 63,075 to 105,608), respectively, between 2018 and 2040.[9] This increase in cancer burden is expected to soon result in an unmanageable economic burden in the region, both in terms of productivity losses and national health care costs.[10]

This growing cancer burden among Caribbean populations can be partially attributed to changes in lifestyle factors, including an increasingly western pattern of diet, high levels of obesity, physical inactivity, and tobacco smoking.[7] This coincides with the rapid economic growth and standard of living improvements within the region.[7] Elevated cancer incidence and mortality rates have been increasingly occurring in sites such as female breast cancer, lung cancer, and colorectal cancer, which have been associated with documented lifestyle-related risk factors.[7,9] Other risk factors such as heritability and infectious agents have also contributed to the cancer burden in this region. Prostate cancer, which exhibits one of the highest effects of heritability of any of the major cancers, is a leading cause of incidence and mortality among Caribbean men.[7,9,11-16] Cancers related to infectious agents, such as cervical, liver, and stomach cancers, also contribute considerably to the regional burden, despite cervical cancer being a mostly preventable cancer through screening and vaccination.[7,9] Recent analysis of

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regional cancer mortality data indicates prostate and lung cancers accounted for the highest mortality rates in men, while breast and cervical cancers were the leading causes of cancer deaths in women.[7] Notable variations in cancer mortality across the Caribbean region were noted between 2003–2013 (analysis done using most recent 5 years of available data), with the lowest age-standardized mortality rates found in Turks and Caicos Islands (46.1 per 100,000) and the highest found in St. Kitts and Nevis (139.3 per 100,000).[7]

The Caribbean Ministries of Health have recognized cancer as a major public health challenge and have established important frameworks and targets for reducing the burden of this disease. The 2007 Declaration of Port of Spain was the first political commitment to place focus on reducing morbidity and mortality from NCDs in the region.[17,18] The World Health Organization's (WHO's) Action Plan on NCDs[19] and the WHO's NCD Global Monitoring Framework targets (eg, 25% reduction in premature death from cancer and other priority NCDs)[20] provide the foundation for tracking and evaluating progress in mitigating the burden from all NCDs, including cancer. This is also supported by targets outlined in the United Nations (UN) Sustainable Development Goals (eg, one-third reduction in NCD mortality by 2035).[21] The latest phase of the Caribbean Cooperation in Health Initiative (CCH IV), which unites the region for improvements to health, shares the objectives of these frameworks.[22] The ability of the Caribbean to track and assess progress in the reduction of its cancer burden is pivotal in evaluating the region's progress in reaching the relevant global targets.

The utility of tracking cancer trends in this region to reduce the burden of this disease is undisputable. Unfortunately, the lack of reliable, high-quality data on cancer incidence and related risk factors has limited the ability of Caribbean stakeholders to monitor these important trends and understand the full extent of the problem. The paucity of reliable data also negatively impacts the allocation of adequate resources to mitigate the cancer burden.[8] Ultimately, this has stymied the ability of relevant stakeholders to track their respective country's progress in meeting agreed targets for reducing NCDs and, more specifically, cancers.

Population-based cancer registries (PBCRs) are an effective method of providing high-quality information on cancer incidence rates, required as the basis for planning and monitoring of population-wide cancer prevention and control programs. Data from high-quality PBCRs can be used to quantify the cancer burden in defined populations, monitor changes in cancer incidence and survival at the population level, evaluate the impact of cancer control activities in populations, provide data to support evidence-based decision-making, and define priorities in cancer prevention, treatment, and care.[23-25] National mortality surveillance systems and accurate, timely population data are also critical sources of information that support and complement the work of PBCRs.[25] PBCRs serve as an invaluable resource for health care and public health planning and policy-making and, as such, the implementation and strengthening of sustainable cancer registries has become a focus for many Caribbean countries.

While there has been some progress made toward improving cancer registration in the region, including the development of sustainable PBCRs, several challenges have limited the implementation of these initiatives. National policies and legislation to support cancer registration data flow are sometimes lacking and, where it exists, there are difficulties with enforcing legislation. Due to multiple competing priorities, adequate funding and a well-trained work force to support cancer registration are not always available. Data security and confidentiality concerns, persons who go abroad for cancer care, as well as issues related to the quality and storage of medical records and death certificates can compromise access to complete information by cancer registries.

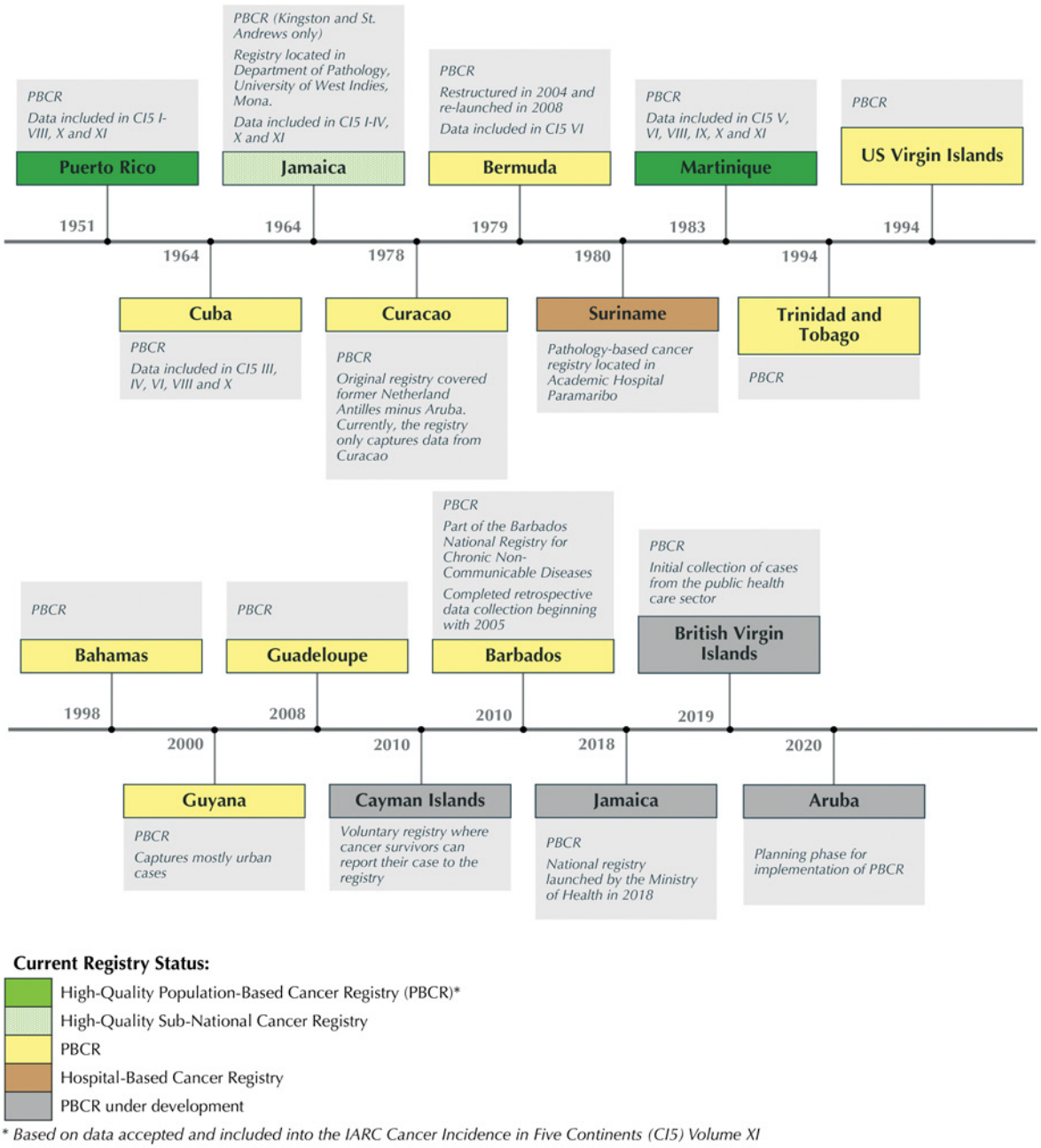
This paper will provide an overview of cancer registration activities in the Caribbean, including challenges faced and plans for strengthening cancer registration in the countries of the region. A growing recognition of the increasing burden of chronic diseases regionally and the need for stronger surveillance systems to track this disease have been driving factors in cancer registration efforts in the region to date. Current work to strengthen cancer registration in the Caribbean is coordinated by the recently established International Agency for Research on Cancer (IARC) Caribbean Cancer Registry Hub.[26]

Timeline of Caribbean Cancer Registries

The Caribbean has a noteworthy history of both hospital-based registries and PBCRs spanning almost 7 decades (Figure 1).[8,27-33] The first cancer registry in this region was established in the 1950s, and cancer registration activities peaked during the 1970s, alongside growing regional and worldwide recognition of the emergence of cancer as a public health problem and the importance of cancer registries in tracking cancer outcomes.[28-34] However, responding to infectious diseases remained the main priority for the region during this period, which limited the resources available for the implementation and sustainability of cancer registries.

Beginning in the 1990s, several additional cancer registries were established in the countries of the region, coinciding with activities aimed at mitigating the burden from cancer and other NCDs, as a consequence of the epidemiological transition and shift in public health priorities in the Caribbean. More recently, the region has initiated activities with the intention of incorporating international concepts and lessons learned to strengthen capacity and improve registration. For example, in 2010, the former Caribbean Epidemiology Centre (CAREC/PAHO/WHO) (the functions of CAREC are now included in the Caribbean Public Health Agency)[35] in collaboration with the Pan American Health Organization (PAHO/WHO) and IARC conducted an international cancer registration course in the Caribbean. The course introduced cancer registration, demonstrated the utility of IARC's CanReg[36] software and delivered training in the use of CanReg4. Participants included representatives from the Bahamas, Barbados, Cayman Islands, Guyana, Jamaica, and Trinidad and Tobago. This workshop gave impetus for the establishment of a cancer registry at

Figure 1. Timeline of Establishment of Caribbean Cancer Registries



Cornwall Regional Hospital in Jamaica, which later was expanded into the Jamaica National Cancer Registry.

Despite the long history of cancer registration within the Caribbean, however, cancer data from only 3 Caribbean PBCRs (Martinique, Puerto Rico, and a portion of Jamaica) were accepted into the most recent IARC publication *Cancer in Five Continents* (*Volume XI*).[37] Inclusion of registry data into this publication required the submission of a minimum of 3 consecutive years of high-quality data. The IARC GLOBOCAN data series[9] generates model-based estimates for cancer incidence, mortality, and prevalence for 185 countries worldwide based on available mortality and cancer incidence data. In this series, contemporary year estimates are available for 13 Caribbean countries that have been calculated based on cancer incidence data available from only a few countries in the region.

Establishing a Mechanism to Support and Sustain Cancer Registration in the Caribbean

The long history of PBRCs and the high-level of political commitment to NCDs, as well as collaborative approaches to tackling common problems, support and facilitate regional initiatives to strengthen cancer registration in the Caribbean.[17,22]

Caribbean Community Heads of Government held the first summit in the world that focused on the need to take action to mitigate the growing burden of NCDs in the region.[38] This resulted in the 2007 Port of Spain Declaration "Uniting to Stop the Epidemic of Chronic NCDS" which focused on policy implementation, intersectoral collaboration, and collective action.[17,38] This summit was also the impetus for the subsequent UN Political Declaration on

the Prevention and Control of NCDs and the WHO Global Action Plan for the Prevention and Control of NCDs 2013–2020.[38]

The Caribbean Cooperation in Health Initiative (CCH IV) is another example of regional approaches to addressing common health challenges. This strategy provides a framework for Caribbean Community members to achieve advancements in health through joint action.[22] Established political will and a readiness for collaborative approaches contributed to the successful operationalization of an IARC regional cancer registry Hub in the Caribbean.

The recent global focus on NCDs and the need for the provision of data in support of national cancer control and for the tracking of progress towards global targets led to the implementation of the IARC's Global Initiative for Cancer Registry Development (GICR), launched in 2011.[39-41] The GICR, with a focus on countries with limited resources for cancer surveillance systems, is a partnership-based approach that aims to assist in improving the capacity for PBCRs with the key goal of developing high-quality cancer data in 50 countries by 2025.[41] This change is envisioned to be primarily delivered through a network of 6 IARC regional cancer registry Hubs, which have been established in partnership with several international and regional organizations.[41]

The Caribbean Public Health Agency (CARPHA) became the home to the IARC Caribbean Cancer Registry Hub (Caribbean Hub) in 2015.[26] CARPHA was selected to host the Caribbean Hub due to the following attributes: its leadership in public health in the region; its international standing for expertise in epidemiology; its high-quality surveillance systems for infectious diseases, mortality and risk factors for NCDs; its research; its history of collaboration with international organizations; and its capacity to deliver technical assistance required for supporting cancer registration priorities for the region.

The US National Cancer Institute (NCI), US Centers for Disease Control and Prevention (CDC), the North American Association of Central Cancer Registries (NAACCR), and PAHO work collaboratively with IARC and CARPHA to serve as the Steering Committee for the Caribbean Hub, with the role of guiding and planning activities for strengthening regional cancer registration. They assist in the implementation of the Hub within the Caribbean region by providing direct and in-kind support, including limited funding, as well as technical expertise for strategic cancer registry-related activities. After several years of planning and public health assessments, the Caribbean Hub was formally launched in June 2018 during the Meeting of Caribbean Chief Medical Officers of Health.[42] It now serves as the point of contact for the Caribbean registry community.

An important role of the IARC cancer registry hubs is establishing regional networks and collaborating with regional partners as a means of further expanding technical expertise to support the strengthening of cancer registration in the region. To this end, the PBCR in Martinique is now an IARC GICR Collaborating Centre and provides technical and financial resources to strengthen cancer registration in the region.[43] Discussions are also underway with other high-quality PBCRs in the region to serve in a similar capacity.

Overcoming Challenges for Cancer Registration in the Caribbean

Despite having a political environment that supports advancements in cancer registration in the Caribbean region, several challenges exist that have limited the establishment and operation of sustainable, high-quality PBCRs that could cover a larger percentage of the Caribbean population. Ongoing activities and initiatives are actively addressing these challenges and will be described below. The IARC Caribbean Cancer Registry Hub is working with regional and international partners to overcome these challenges and strengthen PBCRs in the Caribbean, through advocacy, targeted technical support, training, and research-capacity building.[40]

Due to finite national resources and many other important competing priorities, a major challenge faced by Caribbean countries is placing a focus on cancer registration. National policies and legislation to support reporting of cancer are sometimes lacking and, where they exist, there are often difficulties with their legal enforcement, particularly in small island states. Implementing policies to make cancer a notifiable disease often facilitates increased access to information by a cancer registry; however, cancer is not a reportable disease in many Caribbean countries. Legislation to support mandatory reporting of cancer cases may assist in making information on cancer cases more accessible and available to Caribbean cancer registries.

Government funding for cancer registration is often insufficient.[44] Economic studies on cancer registry operations in the United States, Kenya, and Barbados have shown that labor costs accounted for the largest expense,[45-47] followed by infrastructure (eg, computers), travel, training, and other materials.[45,46] Research on the cost of cancer registration has important implications for Caribbean countries with ongoing registries as well as those countries currently in the planning stages.

The lack of an adequate workforce to support cancer registries is a common challenge for cancer registries worldwide and in the Caribbean alike. The ability to recruit, train, and retain qualified personnel remains a challenge.[44] Trained, qualified technical personnel are needed to improve casefinding, data abstraction, quality control, quality-assurance checks, and data analysis.[25] Ideally, such personnel should have some knowledge of local oncology and health care systems, as well as training in public health, epidemiology, and information technology.[25]

Multiple data sources are required for collecting cancer registry data, including medical records from hospitals and doctors' offices, reports from pathology or cytology laboratories, and other statistical records such as death certificates.[25] In several Caribbean countries, medical records are completed with varying degrees of accuracy. Inefficient archiving practices, and lack of access to or incomplete death certification present challenges that often compromise data abstraction procedures and ultimately the quality and timeliness of cancer data.[48]

Physicians, both in the private and public sectors, are often reluctant to report on cancer cases, due to concerns about patient confidentiality. Lack of confidence in data security also creates a challenge for accessing information by cancer registries. Building relationships with physicians and providing routine feedback may encourage improved reporting.[25] The implementation of policies at cancer registries that ensure data security and patient confidentiality is also essential.

In many Caribbean countries, deficiencies in cancer-related health services leads to patients receiving diagnostic and treatment services in other countries. This provides additional challenges for cancer registries, as there is currently limited or no sharing of case data between countries and, as such, registries are unable to capture complete data for their populations.

Research is critical for the identification of priorities and for evaluating the effectiveness of cancer control initiatives, nationally, and regionally. [44,49] Despite high-level support for research and substantial research efforts within the region, there is still a need for strengthening health research capacity at all levels within cancer registries and Ministries of Health.[44]

Advocacy

Advocacy is a core function of the Caribbean Hub. Through high-level stakeholder engagement, as well as meetings of Ministers of Health and Chief Medical Officers, the Caribbean Hub aims to educate stakeholders to raise the profile of cancer registration and its potential benefits for cancer control nationally and regionally. Information, education and communication materials, intended to be shared with a wide audience, including technical stakeholders, civil society, media, and the general public, have also been developed and are available on the Caribbean Hub website.[26]

Although some progress has been made with the development and implementation of NCD plans or national cancer plans[44], the development and enforcement of national policies to support cancer registration are not common in Caribbean countries. The Caribbean Hub has advocated for and supported work towards establishing a legal basis that supports national cancer registry operations in countries in the region. Through the provision of technical guidance, and sharing relevant documentation and regional lessons learned, the Hub supports countries in the development and implementation of legislation to make cancer a reportable disease.

Advocacy is also key to help governments understand budgetary requirements for the implementation and functioning of a national cancer registry. Stable and sustainable funding sources are necessary to support the core functions of a PBCR.[25] Countries with ongoing registries should assess yearly costs to ensure maximum productivity and for future budget planning. Additionally, research-related grants could be explored by Caribbean cancer registries to further enable use of cancer registry data for cancer control planning and serve as potential external supplementary funding sources for registry expenses.

Targeted Technical Support

Through targeted technical support, the Caribbean Hub and its partners provide guidance on implementing and strengthening PBCRs. The Hub conducts evaluations of the quality of existing cancer registry data sets, provides on-site and remote information technology (IT) support, and develops and makes available materials to support the standardization of recommended cancer registry procedures within the region. Ongoing technical support is being provided to Barbados, Bermuda, Jamaica, Guyana, and Trinidad and Tobago for strengthening their national PBCRs, and to Antigua and Barbuda, Aruba, the Bahamas, the British Virgin Islands, Cayman Islands, and Curacao for the establishment of PBCRs. The Caribbean Hub is also assisting other countries, including Belize, Grenada, Haiti, St. Kitts and Nevis, and Suriname, who have expressed a desire to establish PBCRs and are in various stages of development (Table 1).

As part of the collection of high-quality data, a standardized approach to cancer registration is needed to ensure use of best practices and allow for comparison with other countries. To address this challenge, a standard operating procedures manual for cancer registration was developed by the Hub for use in the Caribbean.[50] Standard procedures were detailed for casefinding, data abstracting, coding, data entry, and secure storage of data, including electronic and paper files. The manual incorporates guidelines from IARC as well as from similar manuals from other GICR regions (including the Sub-Saharan African region and the Izmir region) and procedures used in North America. An iterative process was utilized for developing the manual involving inputs from regional partners, Caribbean stakeholders, and regional cancer registry experts. The manual, which is available on the Hub's website, was finalized and distributed in April 2018.[26]

The fact that many cancer patients travel to other countries for diagnostic and treatment services has been noted as an additional challenge for cancer registries, particularly as there is currently limited or no sharing of case data between countries. To improve data completeness for the Caribbean region, the Caribbean Hub has been working with NAACCR[51] to facilitate cancer data exchange between US central state cancer registries and Caribbean cancer registries.

Several small-island states in the region have attempted to or have a desire to establish independent cancer registries; however, progress has been limited due to insufficient resources for implementing and sustaining such registries. Some of these countries belong to the Organization of Eastern Caribbean States (OECS), an 11-member state grouping with established political and economic ties and a history of joint approaches in health.[52] The Caribbean Hub has been working with the OECS Health Unit to develop a plan for a subregional virtual cancer registry as an innovative and cost-effective solution. The concept is well suited for areas with small and geographically distant populations that share a need for local and regional data.[52] If successful, this concept could be adopted by other subregions of the Caribbean.

Table 1. Summary of Technical Support and Training Provided by the International Agency for Research on Cancer (IARC) Caribbean Cancer Registry Hub, January 2015–July 2020

	Site Assessment[a]	*Data Quality Assessment*[b]	*CanReg5 Assistance*[c]	*Training*
Activities to strengthen National PBCRs				
Barbados	√		√	√
Bermuda			√	√
Jamaica	√		√	√
Guyana	√	√	√	√
Trinidad and Tobago	√	√	√	√
Activities to support the establishment of National PBCRs				
Anguilla				√
Antigua and Barbuda			√	
Aruba	√		√	√
Bahamas	√		√	√
Belize				√
British Virgin Islands	√		√	√
Cayman Islands			√	√
Curacao			√	
Grenada				√
Haiti				√

PBRC, population-based cancer registry.

[a] The Caribbean Hub provides external assessments of existing cancer registry activities via site visits to document the status of cancer registration and identify opportunities for improvement. Meetings are held with key persons in each country to assess political and cultural barriers to data collection, reinforce the importance of timely, and accurate cancer incidence data, review registry operations, and to respond to technical questions. Following the site visit subsequent meetings are held to review and discuss the findings and recommendations from the assessment with local officials and stakeholders. A plan of action to improve cancer registration is developed and progress with implementation tracked.

[b] Data generated by cancer registries can only be useful if the data are of high quality. As noted previously, there are only 3 PBCRs within the region that are of high quality. As a means of assisting cancer registries in the improvement of data quality, statistical assessments of existing cancer registry data sets are completed by the Caribbean Hub. Registry datasets were evaluated for validity, timeliness, completeness, and comparability.[63,64] Following the assessment, meetings were held with each country team to review the results and recommendations were made for strengthening data quality within the registries.

[c] CanReg5 is an IARC-developed and supported software application specifically designed for use to capture and analyse cancer incidence data in cancer registries in lower- and middle-income countries worldwide.[36] The Caribbean Hub has provided technical support in customization, operationalizing and use of CanReg5 to several cancer registries.

Training

The lack of an adequately trained workforce has been a limiting factor in the successful implementation of many cancer registry initiatives in the Caribbean. To address this challenge, training and continuous education on various aspects of cancer registration has been delivered via targeted workshops. To date, 4 Hub-sponsored workshops have focused on the following topics: basics of cancer registration procedures (2016); the use of registry data management software (CanReg5[36], 2016); statistical software for registry analysis (SEER*Stat[53], 2018); and standardization and assessment of cancer registry data (2018). Information delivered during these workshops included material on fundamentals of cancer surveillance, use of cancer registry data for cancer control planning, basic cancer epidemiology, hands-on training for CanReg5 and SEER*Stat, cancer coding, and evaluation and assessment of collected registry data. Collectively, these workshops have provided training to 49 registry personnel from over 13 Caribbean countries (Table 1).

GICR regional trainers are part of a network of experts built by IARC's GICRNet to support capacity building within their respective regions.[54] In the Caribbean, 5 GICR regional trainers are available for key areas of cancer registration, including coding and staging, data quality, and data analysis.[54] Each trainer has access to standardized reference material and to IARC's experts and other regional trainers. Regional trainers serve as faculty in training workshops, assist with assessments, and contribute to the development of educational materials.

Several relevant online training courses are available to Caribbean registries. The NAACCR "Cancer Registry & Surveillance Webinar Series,"[55] which reviews site-specific coding and staging instructions, has been made available to registry personnel from 4 Caribbean cancer registries through funding by the Caribbean Hub. In addition, NAACCR offers a free training series, "Understanding Central Cancer Registries," which is available on its website.[56]

Research-Capacity Building

The Caribbean Hub recognizes the importance of research in monitoring and evaluating cancer control activities.[44,49] As such, the Caribbean Hub has conducted research and has supported Caribbean cancer registries in the development and completion of research initiatives. The Hub published 2 peer-review manuscripts on cancer mortality in the Caribbean[6,7] and contributed to publications on cancer in small-island states.[44,49] The Caribbean Hub has presented on work completed at the 2017 CARPHA Health Research Conference, the 2017 and 2018 NAACCR Annual Conferences, and the 2018 Annual Scientific Conference of the International Association of Cancer Registries (IACR).[57-60] In 2019, the Hub collaborated with the Bermuda National Tumour Registry, the Guyana National Cancer Registry, and the OECS Health Unit to develop and submit abstracts to the NAACCR/IACR Combined Conference 2019. These were accepted and presented as oral presentations during the conference.[61] Abstracts were also submitted and accepted to the 2020 CARPHA Health Research Conference and the 2020 NAACCR Annual Conference; however, these conferences were impacted by the COVID-19 pandemic.

The Caribbean Hub will continue to conduct research as well as collaborate with and build capacity in Caribbean cancer registries to support the conduct of research to inform public health actions for cancer prevention and control.

Conclusions

The Caribbean region faces a growing burden due to cancer. The region needs to take urgent action to monitor this disease and inform needed cancer prevention and control measures. Cancer surveillance, including baseline quantification of cancer, is an important component required for guiding cancer prevention and control actions. The ability of some Caribbean countries to implement infrastructure needed for sustainable, high-quality PBCRs remains a challenge, given limitations in resources and competing health priorities. While some Caribbean cancer registries have been successful in contributing high-quality cancer data in support of national cancer control and prevention efforts, this represents coverage of only a small percentage of the Caribbean population.

The IARC Caribbean Cancer Registry Hub has been performing an important role in providing advocacy, targeted technical support, training, and research capacity building which is needed for strengthening cancer registration in the region. The Hub will continue to engage high-level political and technical stakeholders and share appropriate resources and expertise, to help policymakers and health care professionals understand the importance of high-quality cancer data for supporting cancer control planning. Through the provision of technical support, the Caribbean Hub will continue to support efforts made by Caribbean countries to establish high-quality PBCRs. The Hub will continue to facilitate capacity building through the provision of training opportunities for cancer registries throughout the region. Research initiatives will be conducted and supported by the Caribbean Hub to identify priorities and monitor and evaluate cancer-control strategies in the region.

Cancer surveillance systems and efforts to strengthen these systems remain critical, even as we recognize the impact of the COVID-19 pandemic on cancer care, treatment, and registration.[62] The Caribbean Hub will continue its efforts to support implementation and strengthening of PBCRs in the region, while embracing the new ways of working necessitated by the need to control spread of the new virus.

Through the work of the Hub, Caribbean countries are better equipped to strengthen cancer surveillance. This is an important step towards reducing the cancer burden and improving cancer prevention and control, nationally and in the region.

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First Place Poster, Data Collection and Operations: National Center for Chronic Disease Prevention and Health Promotion

Using Python and SAS to Efficiently Process Cancer Incidence Data in NAACCR XML Format

Tongyang Liu[a]; Xing Dong[a]; Yuan Ren[a]; Kevin Zhang[a]; Olga Galin[a]; Reda Wilson[b]

Introduction

- The Centers for Disease Control and Prevention's (CDC's) National Program of Cancer Registries (NPCR) represents ~97% of the US population.
- Since its inception, NPCR Cancer Surveillance System (CSS) used the North American Association of Central Cancer Registries (NAACCR) flat file format for data submission.
- Custom XML data exchange standard Version 1.0 approved in 2015.
  - NPCR CSS 2019 utilized Version 1.4.
- NAACCR XML data structure challenges with data processing.
  - SAS XML mapper slow and inefficient, even for small XML data.
  - Large data files, some approaching 35 GB, especially burdensome.
- Efficient and convenient XML data processing is critical.

This poster presents 2 solutions to process XML data efficiently—SAS and Python.

Data

A test XML data provided by a state is used as the foundation to create a series of testing data sets, with sizes range from 1 GB to 30 GB, and cases from 152495 to 4574850.

Methods

We have tested and evaluated a variety of tools and technologies. This presentation will focus on two methods—SAS and Python.

- *SAS/Data Step:* This method treats XML data as an ACSII format and parses it as a text file. By leveraging PROC FORMAT, the method can dynamically restrict data items (based on NAACCR V18 dictionary) to those required by the NPCR call for data in order to avoid the burden for reading through all NAACCR data items.
- *Python:* Python is an open source programming language and has vibrant community that provides robust as well as free data processing and analytical packages. We tested Xml.etree.ElementTreepackage in Python to parse the XML data. A lookup table was also used to limit data items to the NPCR required items. A memory reclamation technique was deployed in Python code to control the memory usage by Python application.

Materials

- *Hardware:* A Windows virtual server, 1 Intel Xeon E5-2650v3 CPU (4 cores), 16 GB Memory
- *Software:* SAS 9.4, Python 3.7

Results

As shown in Table 1:

- The maximum central processing unit (CPU) usage of SAS and Python at different system parameter setup was 25% regardless of the setup and data sizes.
- SAS offers limited capabilities of CPU customization and multithreading in system options, which only applies to PROC SORT and SQL at the data step. The SAS program developed doesn't rely heavily on SORTING so that the gain from SAS multithreading is minimum. Therefore, all SAS tests as well as Python programs were run in single thread mode.

As shown in Figure 1:

- For all test data sizes, SAS managed to use 21 MB memory constantly.
- For Python with Xml.etree.ElementTreepackage, the memory usage increases linearly with data size. For example, on average processing 1 GB XML data used 34 MB memory, 15 GB for 217 MB memory, and 30 GB for 413 MB memory.

As shown in Figure 2:

- Both SAS and Python runtime increases linearly with the increase of XML data sizes, whereas SAS's runtime increases more dramatically than Python's.
- The runtime differences are striking when data size gets relatively large. For instance, for 15 GB and 30 GB XML data, SAS used 34 and 72 minutes, while Python used 22 and 44 minutes, respectively.

Discussion

- The single thread operations of SAS and Python limit CPU usage to 25%, which could hinder efficiency in processing NPCR XML data when files get larger over time. Multithreading in SAS and Python may help on

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this. However, the resources needed to program and maintain multithreading in SAS and Python could be very demanding. We have explored the concurrent processing of SAS with parallel jobs on subdivided XML data. The results are very promising, but it needs states' involvement in subdividing XML data.

- Figure 1 summarizes the memory usage by SAS and Python when running different sizes of XML data. Contrary to low memory usage in SAS, Python memory usage increases linearly with data size. Earlier tests of Python without memory reclamation procedure resulted in Python monopolizing all memory for a 30 GB XML data. However, the memory usage of Python became manageable with memory reclamation procedure.
- Figure 2 demonstrates the runtime performance of SAS and Python when parsing XML data.
- Regardless of data sizes, Python ran 30% to 40% faster than SAS. However, Python does use more memory than SAS. The memory usage restriction implemented by SAS itself may become a limiting factor on SAS performance.
- If we can boost SAS memory and CPU usage, the SAS performance might be improved. SAS concurrent processing could be a good candidate.
- SAS programs for parsing NAACCR XML data could be more adaptable since SAS is widely used in cancer registries. Python, however, may require registries more time and resources to implement, even though it provides free, powerful, efficient, and versatile ways in processing XML data.

Conclusions

- Python performed 30% to 40% faster than SAS.
  - SAS and Python parse XML data reasonably efficiently.
- Python requires more memory than SAS.
  - A 30 GB XML dataset requires 413 MB memory with memory reclamation technique.
  - Reasonable for most servers, even workstations.
- Possible parsing performance issue with XML data size >30 GB.
  - Especially evident in SAS.
  - Further evaluation needed to study SAS concurrent processing.
- Python module used in NPCR-CSS data processing.
  - Valuable tool for QC data processing.

Table 1. Comparisons of SAS and Python CPU Usage for Parsing NAACCR XML Data

Parameter combinations	*SAS w/CPUCOUNT=MAX multithreading*	*SAS w/ multithreading*	*SAS w/ default*	*Python*
CPU Usage	25%	25%	25%	25%

Figure 1. Comparisons of SAS and Python memory usage for parsing NAACCR XML Data

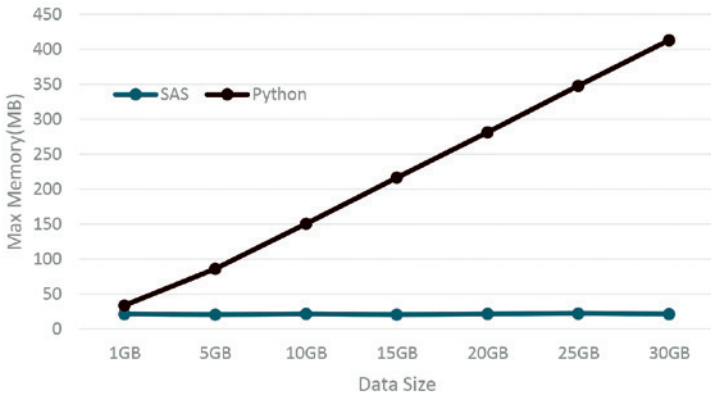
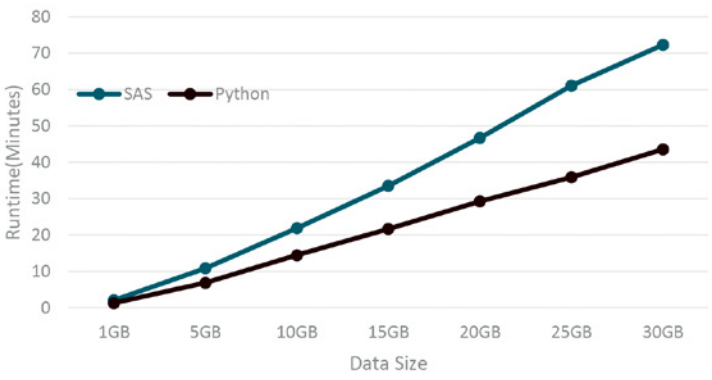


Figure 2. Comparisons of Runtime Performance of SAS and Python for Parsing NAACCR XML Data



Second Place Poster, Data Collection and Operations: National Center for Chronic Disease Prevention and Health Promotion

Modernizing an Online Data Monitoring System for the CDC's National Program of Cancer Registries

Kevin Zhang[a]; Shailendra Bhavsar[a]; Yuan Ren[a]; Jon Stanger[a]; Jing Guo[a]; Reda Wilson[b]; Manxia Wu[b]; Mary Elizabeth O'Neil[b]

Introduction

- Rapid and effective data monitoring is critical for cancer surveillance systems.
- Centers for Disease Control and Prevention's (CDC's) National Program of Cancer Registries (NPCR) modernizing an online tracking system (Monitoring Dashboard or MDB).
- Monitors program activities, data submission and processing, and data quality control.
- Building on the current NPCR Cancer Surveillance System (CSS).
- Provides data visualization tools.
- Allows CDC staff (and eventually NPCR awardees) to monitor program activities.
- Enhances transparency and communications.
- Quality cancer data is critical for cancer research and for cancer prevention and control at the national, state, and local levels.
- CDC's NPCR has played an important role in building a national cancer data ecosystem that provides quality cancer surveillance data for cancer control and prevention missions.

Purpose

This presentation illustrates the design of a secure and modernized online tracking system that facilitates NPCR program monitoring and management. This modernization effort aims to enhance the existing CSS by providing a secure web portal for CDC and state users to monitor and track data submission activities and address data quality and other related issues for effective program administration.

Methods

Data visualization and secure data driven query building are the key components of the MDB's modernization (Figure 1). By applying the National Institute of Standards and Technology (NIST) standards for security and .NET technologies, the system follows the industry best practice in enterprise software development. The Integrated Project Management approach for project management, requirement gathering , documentation , design, and deployment as well as quality control is also being followed to ensure the efficiency of the system development process. Sample data are used in this presentation for illustration purposes only.

Results

- Role-based menu items and features for CDC and registry users
- Interactive dashboards for enhanced data visualization (Figure 2)
- Flexible querying system to allow users to customize their search
- Modernized functionality and look and feel of MDB site

Discussion

- Responsive design allows adjustment to different devices (phones, tablets, laptops).
- Provides export ability in Microsoft Excel or Adobe PDF formats.
- Utilizes security best practices for password policies.
- Uses inbuilt .NET Cryptographic libraries to create random salts and hashed passwords.
- Leverages C# libraries ensuring compliance with NIST security standards.
- Applies scanning software to discover and address security vulnerabilities.
- Ensures Section 508 compliance.

Conclusions

- Visually displays major programmatic components.
  - Dashboards modules using tables, infographics, and maps.
- CDC staff can track awardee activities.
  - Interstate data exchange
  - Program Evaluation Instrument
- State users can generate reports
  - Frequency counts
  - Data trends
- Enhancements expected to improve NPCR program management and contribute to overall improvement in efficiency and accuracy.

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This project is funded by the CDC and managed by ICF (contract 75D30119C05228). The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Figure 1. Methods

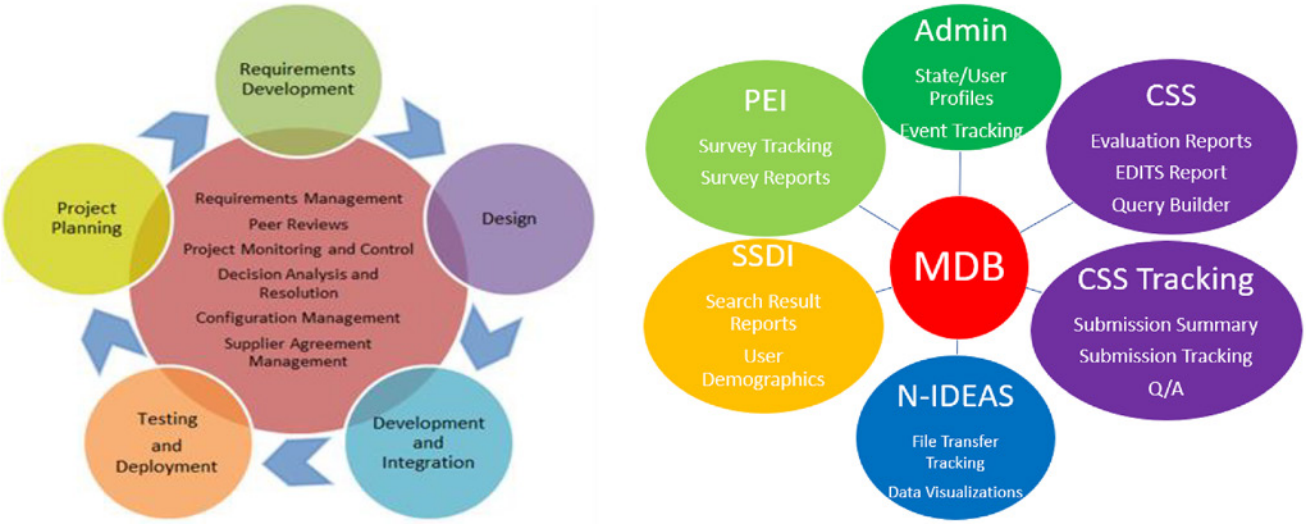


Figure 2. Dashboards Modules Using Tables, Infographics, and Maps

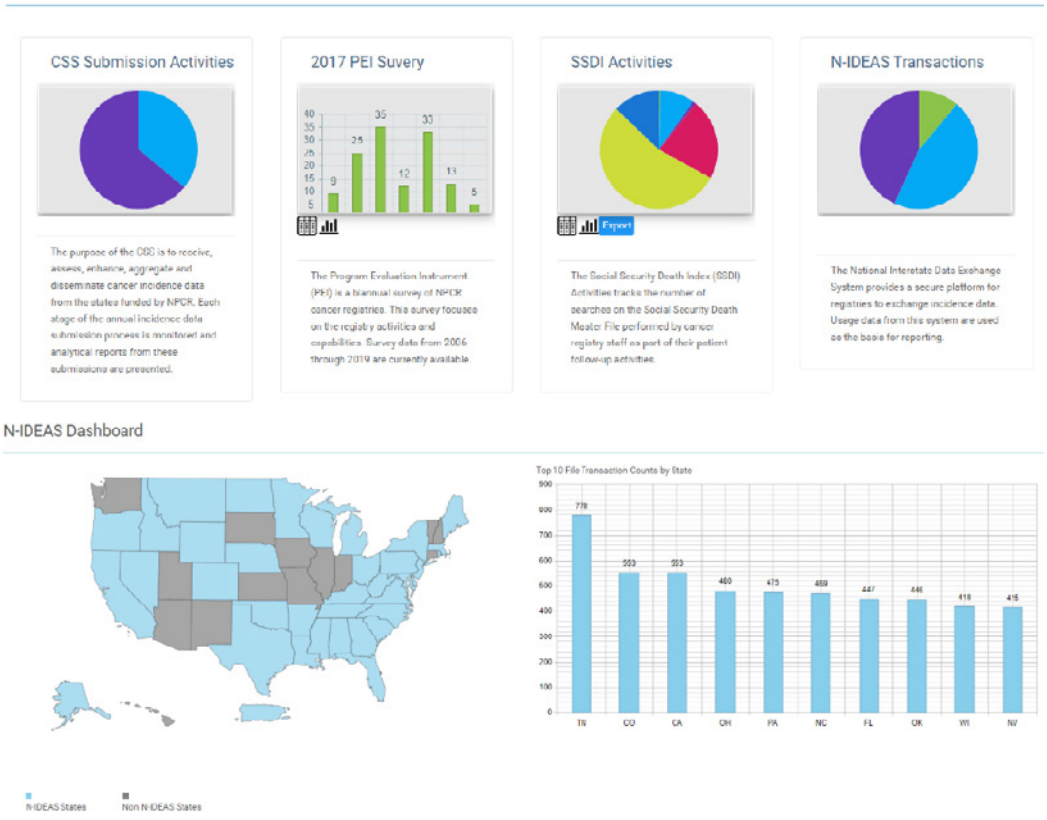
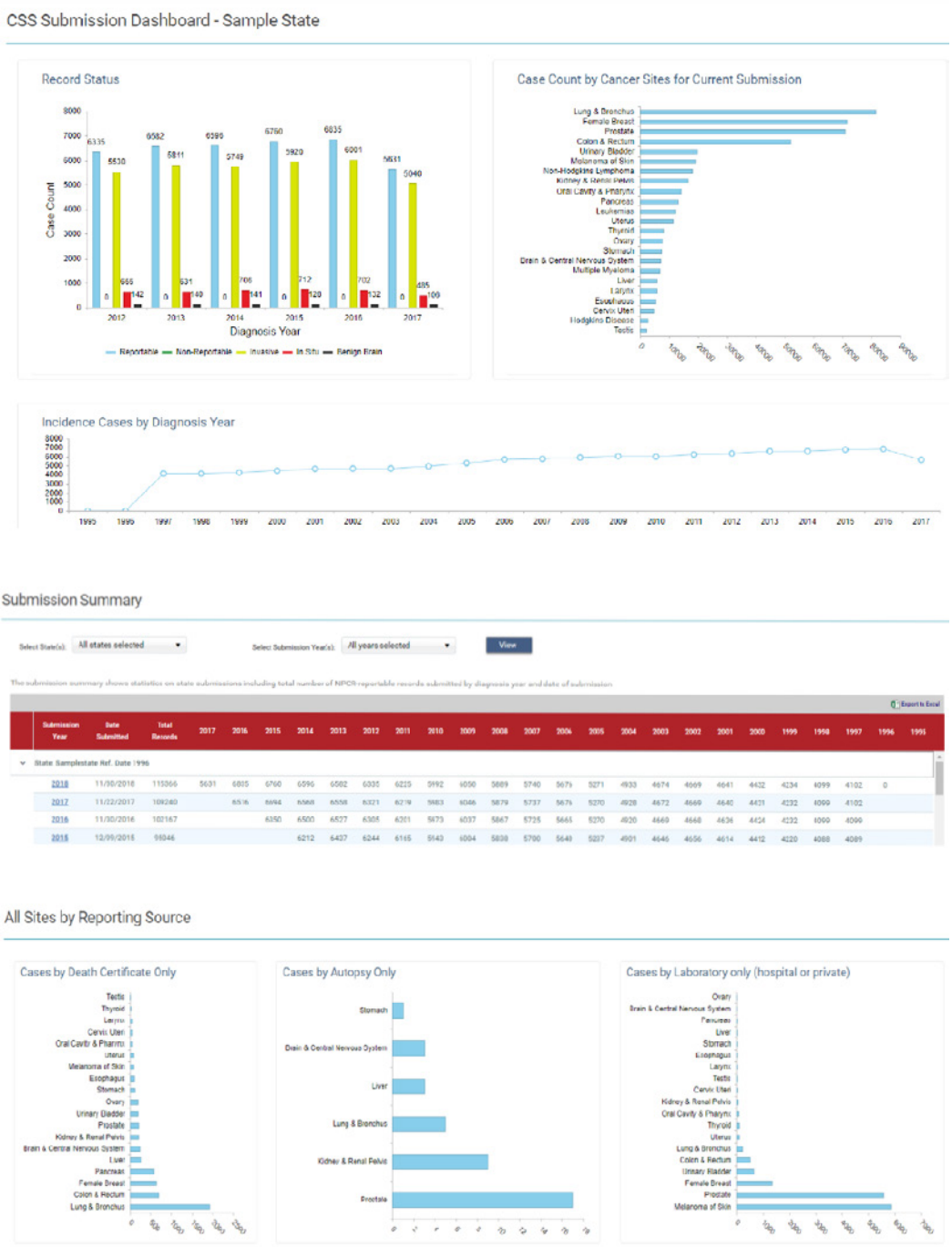


Figure 2, cont. Dashboards Modules Using Tables, Infographics, and Maps



Identifying Risk Factors Associated with Subsequent Breast Cancer Diagnosis among Breast Cancer Survivors in New York State

Baozhen Qiao[a]; Maria J. Schymura[a]; April A. Austin[a]; Amy R. Kahn[a]

Introduction

Background

Women with a history of breast cancer have an increased risk of developing subsequent breast cancers. Factors associated with the risk have been evaluated using the public use data from the National Cancer Institute's (NCI's) Surveillance, Epidemiology, and End Results Program (SEER). However, due to lack of critical data elements such as granular treatment information, findings could be potentially biased.

Objectives

The purpose of this study is to identify the risk factors that are associated with the development of subsequent breast cancers among female breast cancer survivors by examining demographic and tumor characteristics as well as the treatment received for the first cancer.

Materials and Methods

Data Source

Female invasive breast cancer cases reported to the New York State Cancer Registry (NYSCR) were used for this study.

Index Case Selection

In order to have a meaningful and relatively homogeneous cohort to follow up and study, index cases were defined and selected using the following criteria:

- Breast cancer was diagnosed during 2004–2007, and the breast cancer was the first cancer diagnosis for an individual
- Breast cancer was not ascertained through death certificate or autopsy only
- Patient's age at diagnosis was younger than 80 years
- Breast cancer was diagnosed at a local stage and the patient had received breast-conserving surgery
- Patient survived at least 2 months after this initial breast cancer diagnosis

Identification of Subsequent Breast Cancer

Women with an index breast cancer diagnosis were followed for 10 years to identify any subsequent breast cancer diagnoses.

Data Analysis

- The index cases were characterized by the following demographic and tumor characteristics, and first-course treatment received: age, race/ethnicity, census tract poverty level, grade, histologic type, estrogen receptor (ER) status, progesterone receptor (PR) status, year of diagnosis, radiation therapy, chemotherapy, and hormone therapy. The detailed categories for each factor are shown in Table 1.
- Percentages of index patients who developed a subsequent breast cancer were calculated by specified category for each factor.
- For patients with a subsequent breast cancer, the time interval between the index and the subsequent breast cancers was categorized into 1 of 3 groups (2 months to 1 year, 1–5 years, or 5–10 years). Frequency distribution of time interval by each factor was calculated.
- To evaluate the associations of these factors with the risk of developing a subsequent breast cancer, univariate and multivariate subdistribution hazard regression analyses were performed. Only factors with an overall $P < .15$ in the univariate analysis were included in the multivariate model.
- For factors showing significant effects on the occurrence of subsequent breast cancer, cumulative incidence functions (CIF) were generated and are illustrated.

Results

- A total of 17,391 female breast cancer patients met the selection criteria and were included in the study as index cases. Among them, 757 (4.4%) developed a subsequent breast cancer within 10 years after the initial breast cancer diagnosis.
- Among women who developed a subsequent breast cancer, 63.0% were contralateral to the first breast cancer. About 5.0% of the subsequent breast cancers were diagnosed within 1 year after the first cancer diagnosis, 28.7% between 1 and 5 years, and 66.3% between 5 and 10 years.
- Women with an initial breast cancer diagnosed before age 40 were more likely to develop a subsequent breast cancer (7.7%) than women with an initial breast cancer diagnosed at older ages (4.3%, 3.9%, 4.6%, and 4.0%

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among 40–49, 50–59, 60–69, and 70–79 years of age, respectively). The percentage of women developing a subsequent breast cancer was also relatively higher among non-Hispanic Blacks (5.5%), those with an initial ER negative breast cancer (5.8%) and those not treated with hormone therapy (4.8%) (Table 1).

- Multivariate subdistribution regression analysis showed that age at first breast cancer diagnosis, ER status, and receipt of hormone therapy were significantly associated with the risk of developing subsequent breast cancer, with younger women having an increased risk, and women with an ER positive tumor or receiving hormone therapy for the first cancer having a decreased risk (Table 1).
- Cumulative incidence functions of developing a subsequent breast cancer among breast cancer survivors by age group, ER, and hormone therapy status are illustrated in Figure 1.

Strengths and Limitations

Strengths

One notable strength of the current study is that we were able to include demographic, tumor, and treatment information in the risk evaluations.

Limitations

- We could not determine whether patients who moved out of state after their initial breast cancer diagnosis developed a second breast cancer, therefore, the overall subsequent breast cancer risk reported in this study may be slightly underestimated. The underestimation could potentially differ slightly by age, race, and ethnicity.
- We could not rule out that some breast cancer recurrences may have been misclassified as subsequent primary cancers.
- The effect of HER2 status could not be evaluated because cancer registries in the United States did not routinely collect HER2 information for cancer cases diagnosed before 2010.
- Hormone therapy is indicated for ER positive breast cancer; thus, ER and hormone therapy status are not independent factors.
- The breast cancer survivors were only followed for up to 10 years, and the long-term effects of these factors on the risk of subsequent breast cancer need to be further evaluated.

Conclusions

Understanding the unique subsequent cancer risk among specific breast cancer survivors could help improve medical surveillance and result in earlier stage at diagnosis of subsequent cancers. Diligent monitoring for women treated with breast-conserving surgery is needed, particularly for women who are diagnosed at a younger age, who have an ER negative tumor, and/or do not receive hormone therapy.

Table 1. Percentage of Index Female Breast Cancer Patients Who Have Developed a Subsequent Breast Cancer within 10 Years after the Initial Diagnosis by Demographic/Tumor Characteristics and Treatment Status, and Results of Univariate and Multivariate Subdistribution Hazard Regression Analyses

		Number of index patients	Index patients who developed a subsequent breast cancer		Time interval between index breast cancer diagnosis and subsequent breast cancer diagnosis						Univariate subdistribution hazard regression analysis		Multivariate subdistribution hazard regression analysis[2]	
			Count	%	2 months–1 year		1–5 years		5–10 years		Crude sHR	*P* value	Adjusted sHR	*P* value
					Count	%	Count	%	Count	%				
Total		17,391	757	4.4	38	5.0	217	28.7	502	66.3				
Age	≤39	735	57	7.7	3	5.3	18	31.6	36	63.2	Ref		Ref	
	40–49	3,354	144	4.3	4	2.8	41	28.5	99	68.8	**0.54**	**.0001**	**0.57**	**.0004**
	50–59	4,724	186	3.9	10	5.4	45	24.2	131	70.4	**0.50**	**<.0001**	**0.53**	**<.0001**
	60–69	4,790	219	4.6	13	5.9	67	30.6	139	63.5	**0.58**	**.0003**	**0.63**	**.0022**
	70–79	3,788	151	4.0	8	5.3	46	30.5	97	64.2	**0.51**	**<.0001**	**0.54**	**.0001**
Race/ethnicity[1]	Non-Hispanic White	13,463	572	4.3	32	5.6	163	28.5	377	65.9	Ref		Ref	
	Non-Hispanic Black	1,877	104	5.5	6	5.8	27	26.0	71	68.3	**1.31**	**.01**	1.18	.14
	Non-Hispanic API	637	22	3.5	0	0.0	3	13.6	19	86.4	0.81	.31	0.73	.15
	Hispanics	1,361	59	4.3	0	0.0	24	40.7	35	59.3	1.02	.90	0.95	.69
Poverty level	0% – <5%	5,692	240	4.2	16	6.7	67	27.9	157	65.4	Ref			
	5% – <10%	4,817	208	4.3	9	4.3	67	32.2	132	63.5	1.03	.80	-	-
	10% – <20%	4,154	177	4.3	9	5.1	43	24.3	125	70.6	1.01	.93	-	-
	20% – 100%	2,698	131	4.9	4	3.1	40	30.5	87	66.4	1.16	.18	-	-
Grade	Well differentiated	3,688	155	4.2	11	7.1	42	27.1	102	65.8	Ref			
	Moderately differentiated	7,198	325	4.5	17	5.2	85	26.2	223	68.6	1.08	.45	-	-
	Poorly Differentiated/undifferentiated	5,170	217	4.2	3	1.4	70	32.3	144	66.4	1.00	1.00	-	-
	Unknown	1,335	60	4.5	7	11.7	20	33.3	33	55.0	1.07	.64	-	-
Histologic type	Infiltrating duct carcinoma, NOS	11,927	509	4.3	19	3.7	138	27.1	352	69.2	Ref			
	Lobular carcinoma, NOS	1,212	49	4.0	5	10.2	14	28.6	30	61.2	0.95	.73	-	-
	Infiltrating duct/lobular/or other Types mixed	2,481	109	4.4	8	7.3	29	26.6	72	66.1	1.03	.77	-	-
	All other types combined	1,771	90	5.1	6	6.7	36	40.0	48	53.3	1.20	.12	-	-
ER status	Negative	2,945	170	5.8	2	1.2	65	38.2	103	60.6	Ref		Ref	
	Positive	12,478	501	4.0	30	6.0	126	25.2	345	68.9	**0.69**	**<.0001**	**0.73**	**.02**
	Borderline/unknown	1,968	86	4.4	6	7.0	26	30.2	54	62.8	**0.75**	**.03**	1.07	.84
PR status	Negative	4,611	229	5.0	6	2.6	73	31.9	150	65.5	Ref		Ref	
	Positive	10,509	435	4.1	26	6.0	113	26.0	296	68.1	**0.83**	**.02**	1.10	.44
	Borderline/unknown	2,271	93	4.1	6	6.5	31	33.3	56	60.2	0.82	.11	0.74	.30
Year of diagnosis	2004	4,258	183	4.3	10	5.5	56	30.6	117	63.9	Ref			
	2005	4,257	178	4.2	7	3.9	51	28.7	120	67.4	0.97	.77	-	-
	2006	4,545	209	4.6	7	3.4	67	32.1	135	64.6	1.07	.51	-	-
	2007	4,331	187	4.3	14	7.5	43	23.0	130	69.5	1.00	.98	-	-
Radiation	No radiation	3,381	160	4.7	7	4.4	48	30.0	105	65.6	Ref		Ref	
	Radiation given	12,886	538	4.2	31	5.8	150	27.9	357	66.4	0.88	.14	0.96	.64
	Unknown	1,124	59	5.3	0	0.0	19	32.2	40	67.8	1.11	.49	1.08	.61
Chemotherapy	No chemotherapy	11,616	512	4.4	32	6.3	140	27.3	340	66.4	Ref			
	Chemotherapy given	4,850	205	4.2	5	2.4	63	30.7	137	66.8	0.96	.61	-	-
	Unknown	925	40	4.3	1	2.5	14	35.0	25	62.5	0.98	.91	-	-
Hormone therapy	No hormone therapy	10,020	478	4.8	22	4.6	145	30.3	311	65.1	Ref		Ref	
	Hormone therapy given	6,559	235	3.6	16	6.8	54	23.0	165	70.20	**0.75**	**.0002**	**0.83**	**.04**
	Unknown	812	44	5.4	0	0.0	18	40.9	26	59.1	1.14	.40	1.22	.22

API, Asian/Pacific Islander; ER, estrogen receptors; NOS, not otherwise specified; PR, progesterone receptors.

[1] Fifty-three patients with unknown race/ethnicity were excluded from the regression analyses.

[2] Only variables with an overall P value < .15 in the univariate analysis were included in the multivariate analysis

A hyphen (-) indicates that the variable was not in the model.

Figure 1. Cumulative Incidence Function (CIF) of Developing a Subsequent Breast Cancer among Breast Cancer Survivors by Age at the First Cancer Diagnosis (A), ER status (B), and hormone treatment status (C)

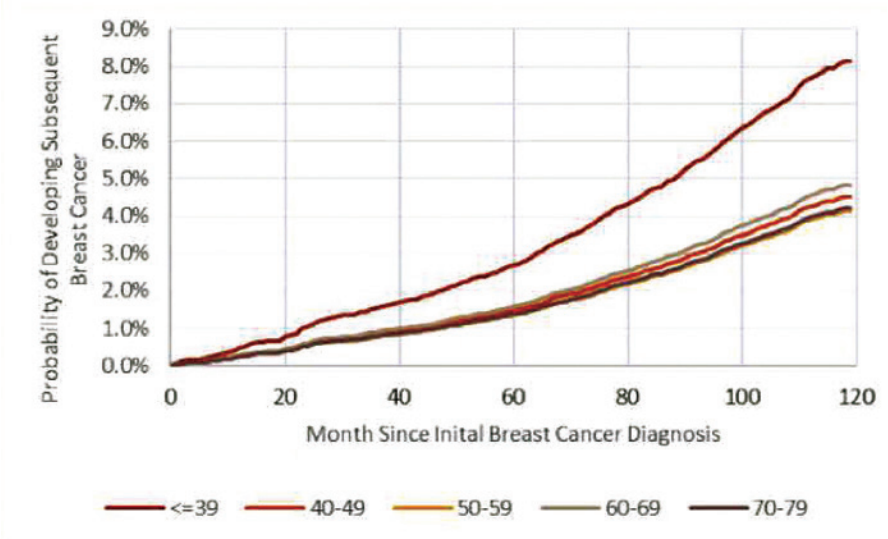

Figure 1A

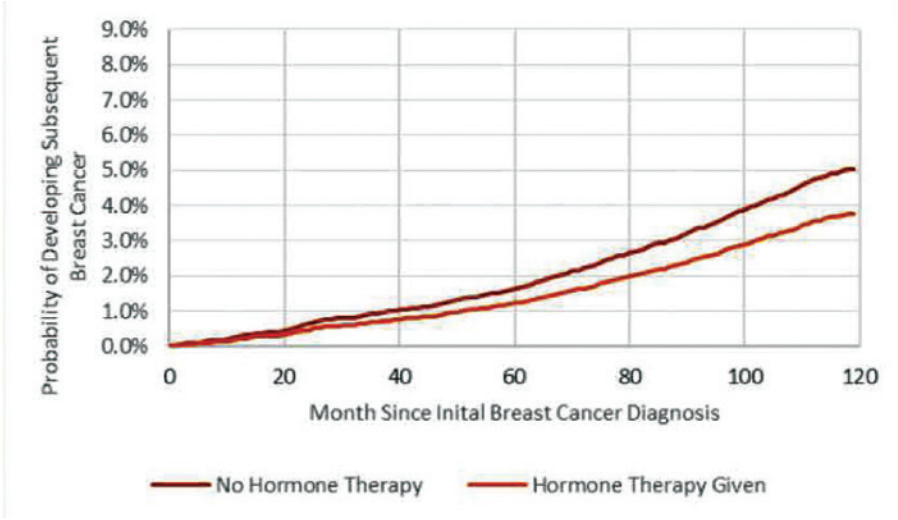

Figure 1B

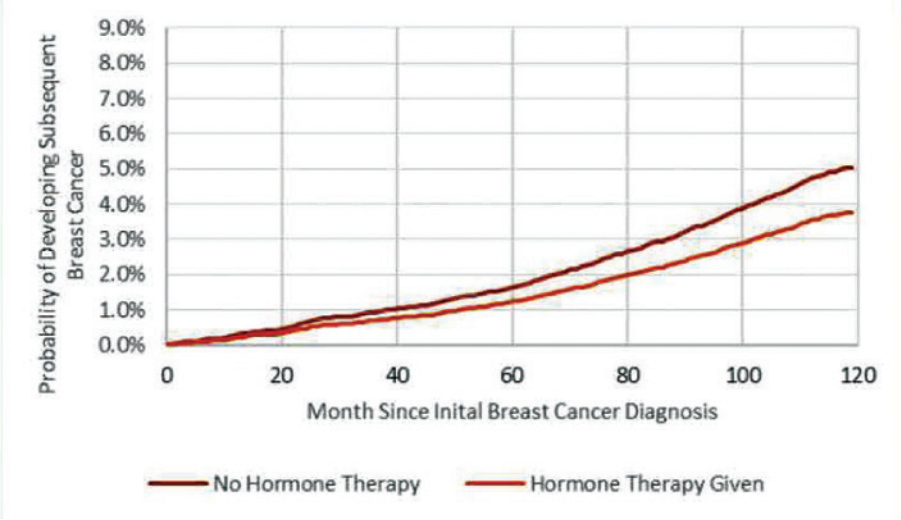

Figure 1C

Second Place Poster, Data Use and Epidemiology: UC Davis Center for Healthcare Policy and Research

Late Effects following Non-Hodgkin Lymphoma in HIV-Uninfected and HIV-Infected Adolescents and Young Adults: A Population-Based Study

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Introduction

- In the United States, non-Hodgkin lymphoma (NHL) is the 4th and 5th leading cause of cancer deaths in patients aged 20–39 and <20 years, respectively.
- Advances in NHL treatment (chemotherapy, radiation and hematopoietic stem cell transplant [HSCT]) has led to high cure rates: 5-year survival approaches 80% in young adults.
- In HIV-infected patients, NHL survival improved dramatically after the introduction of antiretroviral therapy in 1996, but survival is still worse than that in HIV-uninfected survivors.
- Unfortunately, treatment is associated with a lifelong risk of severe late effects, such endocrine and cardiovascular diseases, as well as second cancers.
- To date, little is known about the incidence of late effects of NHL in adolescents and young adults (AYAs) aged 15–39 years.

Methods

- We used data from the California Cancer Registry (CCR) linked to hospitalization data from the Office of Statewide Health and Planning and Development (OSHPD). Eligible patients were AYAs diagnoses with a primary NHL during 1996–2012 (Figure 1).
- We estimated the cumulative incidence of each late effect up to 10 years after diagnosis accounting for death as competing risk.
- We used multivariable Cox proportional-hazards models to examine whether the occurrence of late effects were associated with sociodemographic and clinical factors.

Patient Characteristics

Patient characteristics are shown in Table 1.

Results

- The most common NHL subtype was diffuse large B-cell lymphoma in both HIV-infected (52%) and HIV-infected patients (42%).
- HIV-uninfected patients were more likely to have private insurance and receive radiation and a HSCT than HIV-infected patients. In contrast, HIV-infected survivors were more likely to be diagnosed at advanced stage and live in lower socioeconomic neighborhoods (nSES) compared with HIV-uninfected survivors (Table 1).
- The most frequent late effects at 10 years were: endocrine (18.5%), cardiovascular (11.7%), and respiratory (5.0%) diseases, followed by second cancer (2.6%). The incidence of all late effects was higher among HIV-infected compared with HIV-uninfected survivors (Figure 2).
- In multivariable models, HIV-uninfected patients, AYAs with public/no insurance, residents in lower SES neighborhoods and recipients of a HSCT had a higher risk of most late effects (Figure 3).
- Among HIV-uninfected patients, those of Hispanic or black race/ethnicity had nearly twice the risk of renal disease than white patients, whereas HIV-infected survivors, had nearly six-fold higher risk of renal disease than white patients (Table 2).

Conclusions

- The most frequent late effects after NHL treatment were endocrine, cardiovascular, and respiratory diseases, followed by second cancer.
- We identified higher risk of late effects among HIV-infected patients, AYAs with public/no insurance, recipients of a HSCT, and residents in lower SES neighborhoods.
- Our findings of substantial incidence of late effects among NHL AYA survivors emphasize the need for long-term survivorship care in order to reduced morbidity and mortality in these patients.

[a]Division of Hematology/Oncology, University of California, Davis, Sacramento, California. [b]St. Jude Children's Research Hospital, Memphis, Tennessee.

Figure 1. Study Cohort, Non-Hodgkin Lymphoma (NHL), California, 1996–2012

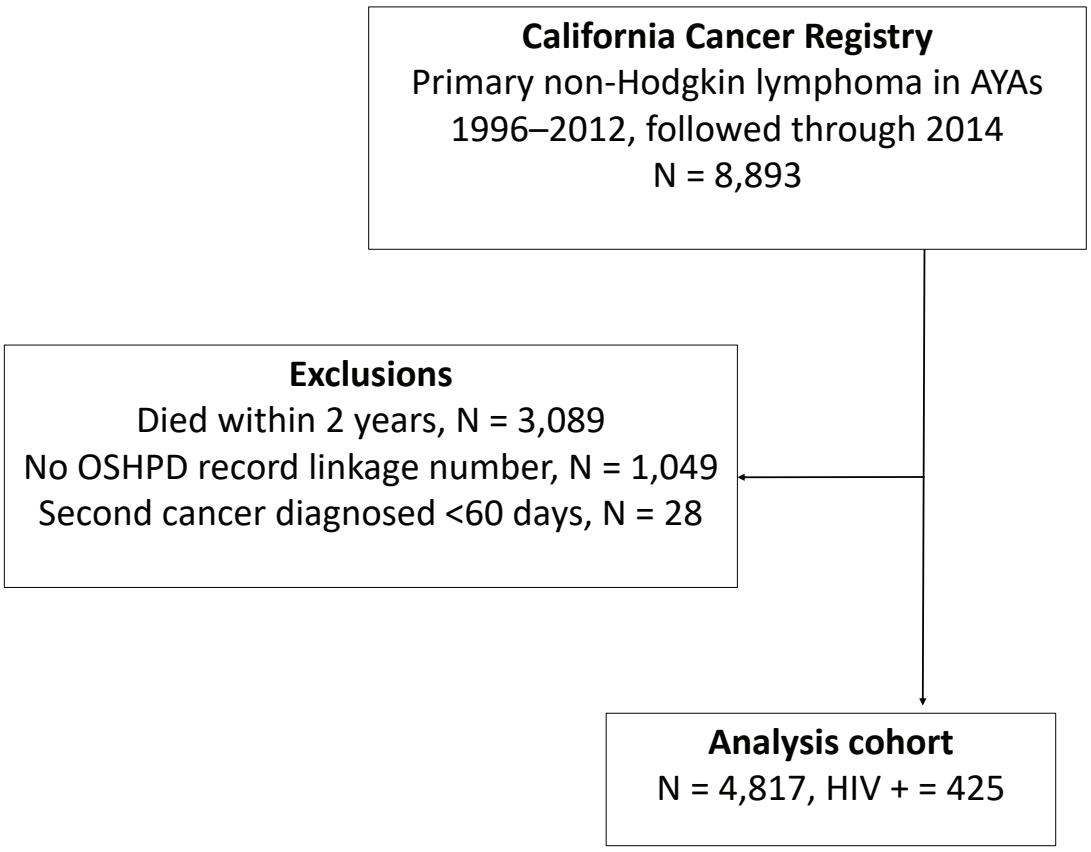

Table 1. Characteristics of Non-Hodgkin Lymphoma Survivors, California, 1996-2012

	HIV-uninfected (N = 4,392)		*HIV-infected (N = 425)*	
Characteristics	**n**	**%**	**n**	**%**
Race/ethnicity				
Non-Hispanic Whites	2,285	52.0	201	47.3
Hispanics	1,156	26.3	132	31.1
Stage at diagnosis				
Localized/regional	2,417	55.0	208	48.9
Advanced	1,638	37.3	203	47.8
Health insurance				
Private	3,186	72.5	197	46.4
Hematopoietic stem cell transplant				
Yes	584	13.3	23	5.5
Radiation				
Yes	1,274	29.0	75	17.6
Neighborhood socioeconomic status				
Lower (quintiles 1–3)	2,270	51.7	286	67.3

Figure 2. Cumulative Incidence of Late Effects after Non-Hodgkin Lymphoma (NHL), by HIV Status, California, 1996–2012

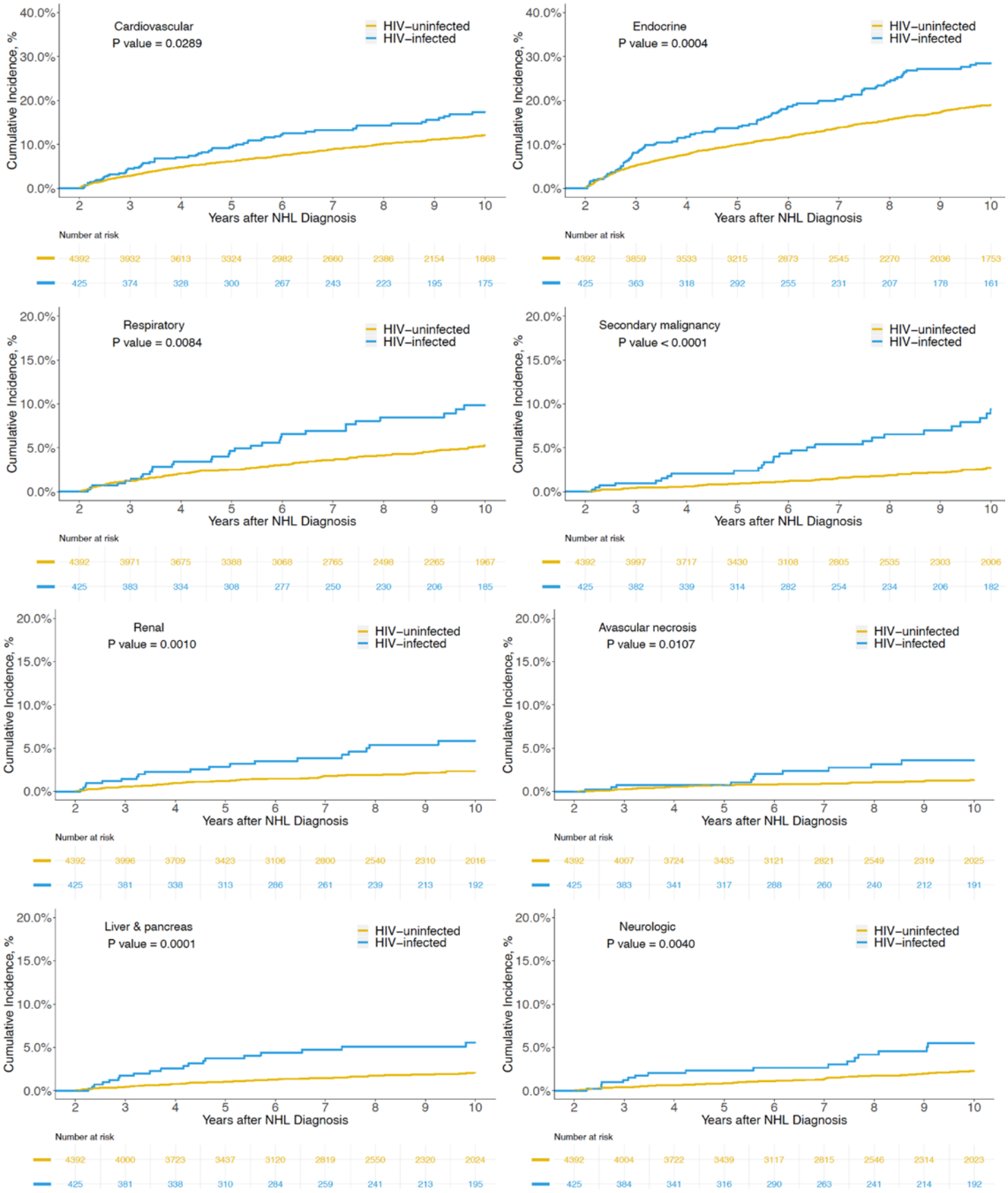

Figure 3. Associations of Late Effects† with (A) Public or None Insurance, (B) Lower Neighborhood Socioeconomic Status, and (C) Receipt of Hematopoietic Stem Cell Transplant

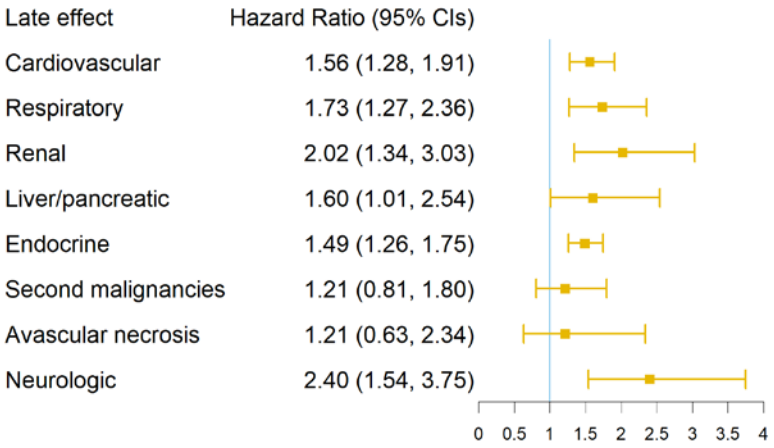

Figure 3A

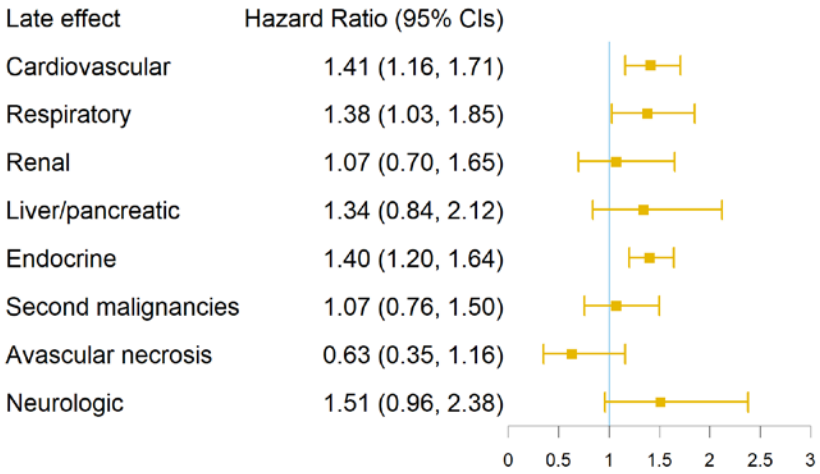

Figure 3B

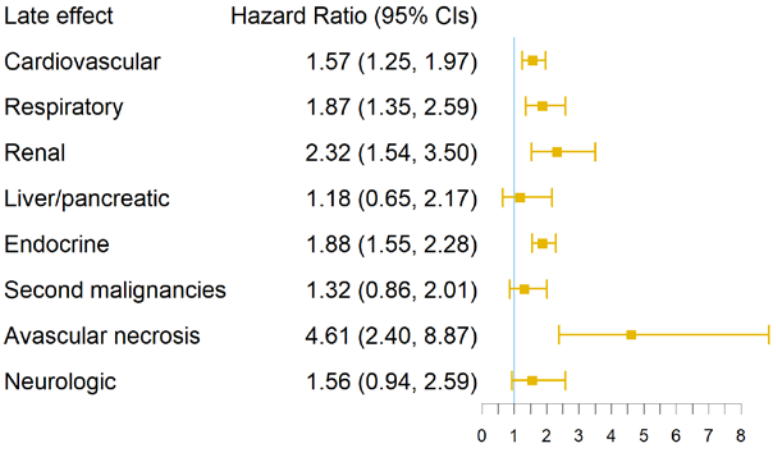

Figure 3C

† Adjusted for age at diagnosis, sex, nSES, health insurance, NHL subtype, and year of diagnosis. Stratified by stage at diagnosis and initial treatment. * Refers to Hispanic, non-Hispanic (NH) Black, NH Asian/Pacific Islander (PI), or other/unknown.

Table 2. Associations of Renal Disease with Race/Ethnicity	
Race/ethnicity	*Hazard ratio (95% CI)†*
HIV-uninfected	
NH White	Reference
NH Black	1.91 (1.02–3.57)
Hispanic	1.73 (1.11–2.71)
NH Asian/PI	0.94 (0.48–1.85)
HIV-infected	
NH White	Reference
Other*	5.64 (1.88, 16.90)

† Adjusted for age at diagnosis, sex, nSES, health insurance, NHL subtype, and year of diagnosis. Stratified by stage at diagnosis and initial treatment. * Refers to Hispanic, non-Hispanic (NH) Black, NH Asian/Pacific Islander (PI), or other/unknown.

Use of Polygenic Risk Scores to Select Screening Intervals after Negative Findings from Colonoscopy

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Background

- Polygenic risk scores (PRS) have been suggested for defining personalized starting ages for colorectal cancer (CRC) screening, but the potential role of PRS in defining the length of screening intervals after a negative colonoscopy is unclear.
- In this study, we aimed to evaluate CRC risk according to PRS and time since last negative colonoscopy.

Methods

- We collected data from 3,827 cases and 2,641 CRC-free controls in a population-based case-control study in Germany.
- We constructed a polygenic risk scoring system, based on 90 single nucleotide polymorphisms, associated with risk of CRC in people of European descent.
- Participants were classified as having low, medium, or high genetic risk according to tertiles of PRSs among controls.
- Logistic regression models were used to assess CRC risk according to PRS and time since last negative colonoscopy.

Results

- When using participants without colonoscopy in the respective PRS groups as the reference, a negative colonoscopy was significantly associated with low CRC risk for time windows within and beyond 10 years after negative colonoscopy in all PRS groups (Table 1).
- Compared to individuals without colonoscopy in the low PRS category, a much lower risk of CRC was observed for people within 10 years after negative colonoscopy. Beyond 10 years, significantly lower risk only persisted for the low and medium PRS groups, but not for the high PRS group (Table 1).
- While significantly low CRC risks sustained only up to 5 years after negative colonoscopy in medium and high PRS groups of people recruited during 2003–2008, such low risks persisted across more than 10 years after negative colonoscopy in medium PRS group and up to 10 years in high PRS group of people recruited during 2009–2016 (Figure 1, Panels A and B).
- Very low risks of distal CRC were seen within 10 years after a negative colonoscopy and even beyond 10 years for all PRS groups, whereas significantly lower risks of proximal CRC were observed for up to 5 years only after a negative colonoscopy among people with high PRS and for up to 10 years after a negative colonoscopy only among those with low or medium PRS (Figure 1, Panels C and D).

Conclusion and Discussion

- Our study suggests the recommended 10-year screening interval for colonoscopy may not need to be shortened among people with high PRSs, but could potentially be prolonged for people with low and medium PRS.
- Across time periods, low CRC risk after negative colonoscopy uniformly persisted longer for people recruited during 2009–2016 than those recruited during 2003–2008, suggesting a sustained improvement in colonoscopy quality in Germany since the introduction of screening colonoscopy in 2002.
- The persisting low risk of distal CRC across more than 10 years after negative colonoscopy irrespective of PRS suggests the possibility of prolonging screening intervals for flexible sigmoidoscopy beyond the guideline-recommended 5 years.

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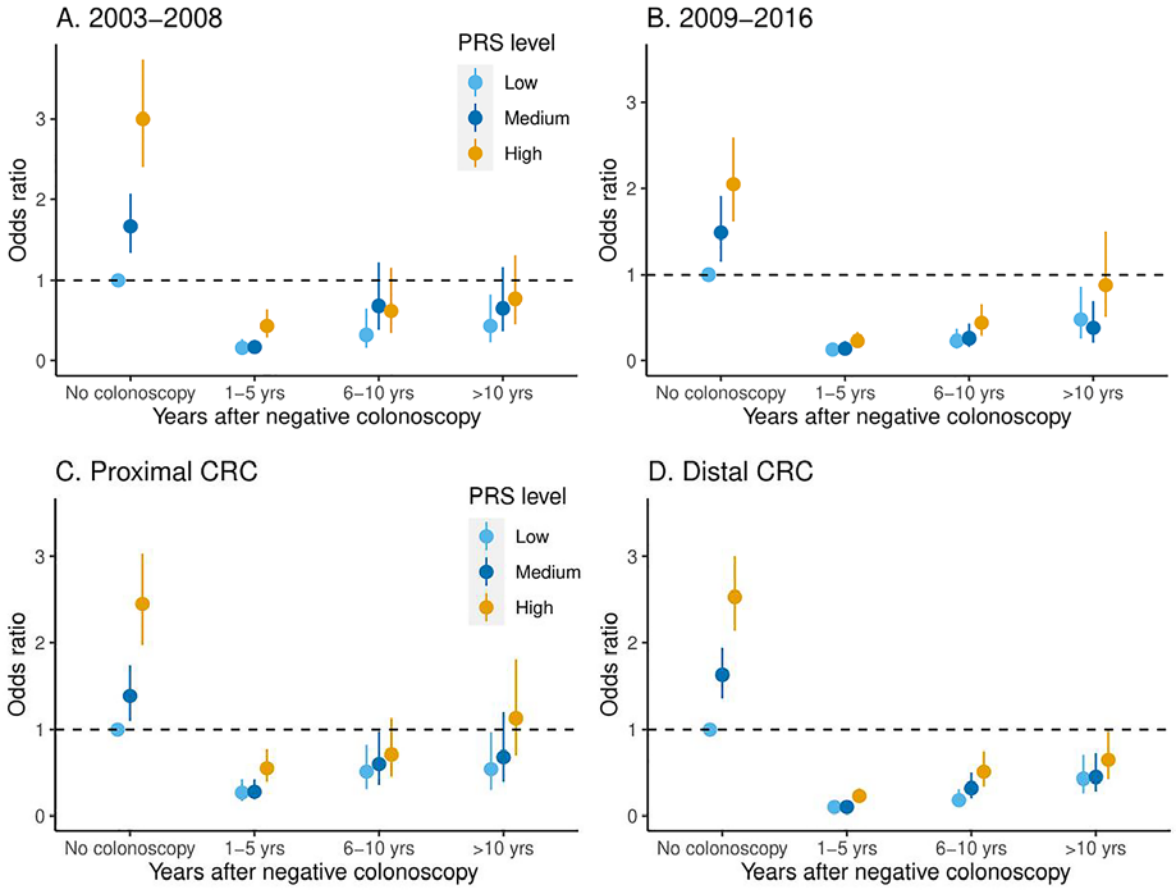
These findings have been published in: Guo F, Weigl K, Carr PR, et al. *Clin Gastroenterol Hepatol*. 2020;18(12):2742-2751.e7. doi:10.1016/j.cgh.2020.04.077

Table 1. Results

PRS level	Time since last negative colonoscopy	Cases	Controls	Odds ratio (95% confidence interval)[a]	
				People without colonoscopy within PRS group as reference	Low PRS group without colonoscopy as reference
Low	No colonoscopy	682	490	Reference	Reference
	1-5 years	48	242	**0.15 (0.11-0.21)**	**0.15 (0.11-0.21)**
	6-10 years	41	105	**0.27 (0.18-0.40)**	**0.27 (0.18-0.40)**
	>10 years	40	61	**0.44 (0.29-0.68)**	**0.44 (0.29-0.68)**
Medium	No colonoscopy	993	462	Reference	**1.57 (1.33-1.85)**
	1-5 years	57	257	**0.10 (0.07-0.14)**	**0.16 (0.11-0.22)**
	6-10 years	50	92	**0.27 (0.18-0.39)**	**0.41 (0.28-0.60)**
	>10 years	46	60	**0.33 (0.22-0.50)**	**0.51 (0.34-0.77)**
High	No colonoscopy	1617	467	Reference	**2.52 (2.15-2.95)**
	1-5 years	111	248	**0.13 (0.10-0.17)**	**0.32 (0.25-0.42)**
	6-10 years	74	94	**0.23 (0.17-0.33)**	**0.58 (0.41-0.81)**
	>10 years	68	63	**0.35 (0.24-0.51)**	0.85 (0.58-1.23)

a Adjusted for age, sex, education, body mass index, participation in a health check-up, family history of colorectal cancer, smoking, ever regular use of nonsteroidal anti-inflammatory drugs, and ever regular use of hormone replacement therapy.

Figure 1. Risk of Colorectal Cancer (CRC) by Polygenic Risk Score (PRS) Level



Journal of Registry Management Continuing Education Quiz—FALL 2020

THE QUIZ IS DERIVED FROM THE JRM ARTICLE, *CANCER INCIDENCE IN OLDER ADULTS IN THE UNITED STATES: CHARACTERISTICS, SPECIFICITY AND COMPLETENESS OF THE DATA* BY HANNAH WEIR, PHD AND CO-AUTHORS.

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

- Describe general patterns of cancer burden among the oldest age-groups in the US.
- Understand why detailed age-categories for the oldest age-groups is important to inform cancer control planning for an aging population.
- Understand cancer data collection issues relevant to the oldest age-groups.

1. What reporting source reports the highest number of incident cases to population-based cancer registries for patients aged ≥65 years?
   a) Pathology laboratories
   b) Death certificate only (DCO)
   c) Radiology facilities
   d) Hospitals

2. What reporting source reports the second highest number of incident cases among patients aged ≥85 years?
   a) Pathology laboratories
   b) DCO
   c) Radiology facilities
   d) Hospitals

3. What combination of racial group, ethnic group, and sex has reported the most DCO cases?
   a) Hispanic men and women (combined)
   b) White non-Hispanic women
   c) Black non-Hispanic men
   d) Black non-Hispanic women

4. Incidence for all cancers combined peaks at age 85–89 for all men.
   a) True
   b) False

5. Peak incidence for breast cancers among women, regardless of race and sex, is largely driven by:
   a) Screening rates
   b) Workplace exposures
   c) Artifact of the data
   d) Genetics

6. Prostate cancer is the most commonly diagnosed cancer among all men aged ≥85 years.
   a) True
   d) False

7. Breast cancer is the most commonly diagnosed cancer among all women aged ≥85 years.
   a) True
   d) False

8. By what age did the percentage of DCO cases exceed 5% (all sites combined) for all racial/ethnic groups and both sexes?
   a) 65–69 years
   b) 75–79 years
   c) 85–89 years
   d) ≥95 years

9. Removing DCO cases from reporting statistics lowers cancer rates evenly among all age groups.
   a) True
   d) False

10. After removing DCO cases, are the majority of incident cases diagnosed in patients aged ≥85 years diagnostically confirmed?
    a) True
    d) False

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National Cancer Registrars Association
CALL FOR PAPERS

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.

Topics:

1. **Birth Defects Registries**
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   a. **AJCC TNM Stage**
   b. **Cancer and Socioeconomic Status**
   c. **Cancer and Health Disparities**
3. **Trauma Registries**
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Contributed manuscripts are peer-reviewed prior to publication. Manuscripts of the following types may be submitted for publication:

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

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

Manuscript submission requirements are given in "Information for Authors" found near the back of each *Journal* and on the NCRA website at **http://www.ncra-usa.org/jrm**.

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2. Hanks GE, Myers CE, Scardino PT. Cancer of the prostate. In: DeVita VT, Hellman S, Rosenberg SA. *Cancer: Principles and Practice of Oncology*. 4th ed. Philadelphia, PA: J.B. Lippincott Co.; 1993:1073–1113.

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